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# **Use of complementary and alternative medicine among Norwegian cancer patients**



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## List of Abbreviations

CAM	Complementary and alternative medicine
FM	Folk medicine
NAFKAM	The National Research Center in Complementary and Alternative Medicine
OTC	Over the counter
CRN	Cancer Registry of Norway
CHD	Coronary heart disease (cardiac infarction or angina pectoris)
I-CAM-Q	International CAM questionnaire
T1	The first Tromsø study (1974)
T4	The fourth Tromsø study (1994–1995)
T5	The fifth Tromsø study (2001–2002)
T6	The sixth Tromsø study (2007–2008)
Q1	Questionnaire used in the Cancer Registry of Norway's study
Q2	The first questionnaire used in T5
Q3	The second questionnaire used in T5
Q4	The first questionnaire used in T6
Q5	The second questionnaire used in T6



## **List of publications**

### **Paper I**

Kristoffersen AE, Fønnebø V, Norheim AJ: “*Use of complementary and alternative medicine among patients: Classification criteria determine level of use*”. J Altern Complement Med. 2008 Oct;14(8):911-9.

### **Paper II**

Kristoffersen AE, Fønnebø V, Norheim AJ: “*Do cancer patients with a poor prognosis use complementary and alternative medicine more often than others?*” J Altern Complement Med. 2009 Jan;15(1):35–40.

### **Paper III**

Kristoffersen AE, Norheim AJ, Fønnebø V: “*Any difference? Use of a CAM provider among cancer patients, coronary heart disease (CHD) patients and individuals with no cancer/CHD.*” BMC Complement Altern Med. 2012 Jan 12;12:1.

### **Paper IV**

Kristoffersen AE, Norheim AJ, Fønnebø V: “*Complementary and Alternative Medicine Use among Norwegian Cancer Survivors: Gender-Specific Prevalence and Associations for Use.*” Evid Based Complement Alternat Med. 2013 In press.

## Definitions

### Complementary and alternative medicine (CAM)

Many different definitions of CAM treatment have been provided, and the definitions vary widely between countries and organizations. In this thesis I apply the definition used in §2 in the Norwegian law about alternative treatment, *Lov om alternativ behandling mv (2003–06–27–64)*, as all the studies included in this thesis are conducted in Norway:

"Med alternativ behandling menes helserelatert behandling som utøves utenfor helsetjenesten, og som ikke utøves av helsepersonell. Behandling som utøves i helsetjenesten eller av autorisert helsepersonell, omfattes likevel av begrepet alternativ behandling når det brukes metoder som i all vesentlighet anvendes utenfor helsetjenesten" [1].

"Alternative treatment is understood to mean health-related treatment which is practiced outside the established health services and which is not practiced by authorized health personnel. However, treatment practiced within the scope of the established health services or by authorized health personnel is also covered by the term alternative treatment when the methods employed essentially are used outside the established health services" [2].

The definition of CAM applied in this thesis includes folk medicine (FM), which is commonly used in the northern part of Norway. Examples of FM in northern Norway are faith healing, herbs, blood stemming and clairvoyance. When it is necessary to distinguish between FM and other types of CAM modalities' the terms FM and modern CAM are used.

### Cancer

The term cancer refers to malignant tumors and stems from the Greek word for crab. It originally described advanced breast cancer with a central node with arms or "claws" into surrounding tissue. Cancer is characterized by disturbances in cell division, cell differentiation and tissue organization [3].

In this thesis I have not limited the studies to specific cancer sites; all cancer cases registered in the Cancer Registry of Norway (CRN) are included.

## 1. Introduction

Despite the fact that there were only 4–5 medical doctors practicing in Norway in the 17<sup>th</sup> century, the first legislative decree regulating quackery came in 1619, giving educated and authorized Medici exclusive rights to treat internal diseases. At the same time the church was active in performing witch trials, forcing the people to hide their traditional medicine practices. Despite the legislative decree and the witch trials, people continued using the lay doctors as authorized medical doctors were rare [4].

In 1836, a system of district physicians was established in Norway. The first district physicians were given responsibility for enormous areas and would therefore rarely get in close contact with the people. When the districts were divided into smaller units, the physicians came closer to the local people, but treatment was expensive, causing most people to continue to use lay doctors [5]. Though this could cause conflict between the lay doctors and the medical doctors, there also existed a tolerance and even collaboration between individuals within the two systems [4]. Today, FM no longer exists as a separate medical system. However, some of the methods are still in use, also by modern CAM providers.

The introduction of modern CAM modalities in Norway started with homeopathy and acupuncture around 1860. Today numerous CAM modalities are practiced and many people use CAM as part of their cancer care even though the law continues to limit laymen's right to treat serious illnesses.

The first known study describing CAM use in Norway was conducted by the Norwegian Gallup Institute (now TNS Gallup Norway) in 1949, where 14% of the respondents reported to have visited “what we normally call a quack doctor (chiropractor, natural doctor, wise

woman or man, etc.)”. Almost half of the respondents reported to believe in the effectiveness of such treatment. The study is referred to by Bruusgaard and Efskind in 1977 [6].

The first known Norwegian study regarding the use of CAM in cancer treatments was conducted in Alta, which is located in the northern part of Norway, in 1975. The study found that 42% of the respondents, more men (47%) than women (36%), had contacted a traditional healer, and that most of them (79%) experienced good results from the treatment. Most respondents stated they would use such treatment if they had a serious illness (69%) or if they were terminally ill, suffering, for example, from cancer (77%) [7].

On the basis of the Alta study, a new, national study was conducted in 1977. The study found that 84% of the respondents believed that certain illnesses could be healed by herbs, homeopathy, or spiritual/religious healing, while one out of five (19%) had used such treatment themselves. More than half of the respondents (63%) reported they would use such treatment if they were terminally ill. No major differences in gender or age were found, only regional differences: While spiritual and religious healing were the modalities mostly used in the northern part of Norway, herbal medicine and homeopathy were the most commonly used practices in the rest of the country. Furthermore, low family income was associated with the use of, and belief in, religious healing, while higher education was associated with little faith in most CAM modalities, especially religious healing [6].

Several studies of CAM use in the general Norwegian population have subsequently been conducted, investigating both general use of CAM and use of a CAM provider. The first studies were part of the health surveys performed by Statistics Norway, investigating people’s use of a CAM provider (chiropractor, homeopath and other provider) during the 14 days prior to responding to the survey [8]. Reported use was 0.4% in 1975 [4, 8, 9]. In 1985

the study was repeated, finding that 1.6% had seen a CAM provider during the previous 14 days, where the definition of CAM provider had been expanded to include acupuncturist, reflexologist and natural healer [9, 10]. Ten years later, in 1995, 13% of the people surveyed were found to have seen a CAM provider during the preceding 12 months [11]. Similar use was found in 1997 [4] when one third of the respondents in addition reported to have *ever used* a CAM provider [4, 12]. In Sweden and Denmark, a higher proportion of respondents reported to have seen a CAM provider both in the preceding 12 months and sometime previously [12]. The most recent study on CAM use in the general population was conducted in November 2012 by NAFKAM reporting overall use of CAM and use of a CAM provider to be 45.3% and 36.6% over the last 12 months [13].

In addition to these studies drawn from a national sample, regional studies have been conducted in Nord-Trøndelag (HUNT) and in Tromsø (the Tromsø cohort study). In Nord-Trøndelag, visits to a CAM provider were studied in 1997 and 2008. These studies found the proportion of respondents reporting to have used a CAM provider during the preceding 12 months to be 9.4% in 1997 and 12.6% in 2008 [14]. In Tromsø the use of CAM was studied in the fourth (T4), fifth (T5), and sixth (T6) studies conducted in 1994/95, 2001/02 and 2007/08, respectively. The results from T5 and T6 are presented in the appendix in Papers III and IV.

Prevalence of CAM use among *cancer patients* was furthermore described in 1979, where 57% of the cancer patients at Fredrikstad Central Hospital reported to have used “natural remedies”. Most of them had used ash extract, which was highly popular at the time. Patients who had used natural remedies only once or twice were not classified as users. More women (65%) than men (50%) had used natural remedies [15]. Furthermore, positive remedy effects

were reported by 21% of the users. Use of a CAM provider (“para-medical personnel”) was reported by 13% of the respondents, of whom 5% had seen a natural doctor, 7% a homeopath and 1% an acupuncturist. Similar prevalence of use was reported among men and women [15].

Few studies can be found internationally describing CAM use among cancer patients in the 1970s. One exception is a paper from 1977 describing use of unproven cancer remedies in pediatric outpatients. They found that 8.7% (n=6) of the studied population had tried unproven drugs, diets, or miscellaneous treatments [16].

In 1998, the first systematic review describing prevalence of CAM use among cancer patients internationally, found that the average prevalence of overall CAM use across all adults studied was 31.4% in the period 1977 to 1998, with results varying from 7–64% [17].

In the 1990s a series of surveys describing CAM use among Norwegian cancer patients was initiated at the University Hospital of North Norway [18-22]. These mapped the attitudes towards [18], opinions about [21], and reasons for CAM use [22], resulting in the doctoral thesis of Terje Risberg [23], which described CAM use among Norwegian cancer patients. He found that 20% of the participating cancer patients used one or more types of CAM [19], and that the estimated cumulative likelihood of being a user of CAM during the five year follow-up period was 45% [20]. Among the users of CAM, he found a greater proportion of patients with distant metastases and patients receiving palliative treatment [19].

CAM use among cancer patients was also studied in HUNT 2 and T4 in 1994–1997. In the HUNT 2 study, 16.1% of the cancer patients were found to have visited a CAM provider over the previous 12 months [24], which was a little more than what was found in T4. In

HUNT 2 the likelihood of consulting a CAM provider was associated with a university degree, low perceived global health, and recent health complaints [24].

The surveys reporting CAM use among Norwegian cancer patients up to 2004 were performed in a period where CAM providers could not legally treat cancer patients. In 2004 a new law regulating alternative treatment was implemented. This law allows CAM providers to treat people with serious diseases and disorders when the treatment takes place in cooperation with or in consultation with the patient's physician. The law stipulates that CAM providers can also treat people with serious diseases or disorders if the sole purpose is to alleviate or moderate symptoms or consequences of the disease, or side effects of a given treatment. Treatment where the purpose is to strengthen the body's immune system or its ability to heal itself is also further allowed [2, 25]. The passing of the law necessitated new studies in the field.

Worldwide, many studies have presented data on CAM use among cancer patients over the years. A systematic review presenting studies on CAM use in Australia, New Zealand, North America, Canada and Europe found that 49% of cancer patients used CAM; this amount ranged from 38–60% in studies conducted after 1999 [26].

The wide range in self-reported use both nationally and internationally could be due to differences in the definition of a CAM user [17, 27] and/or differences in the timeframes investigated [20]. The need for a standardized method to report CAM use is essential if comparisons of studies between cultures and periods of time are to be made reliable [17, 28]. This need for standardized ways to report CAM use, coupled with the need for an overview of CAM use among Norwegian cancer patients, led to the aim of this thesis.



## **2. Aim of this thesis**

The aim of this thesis is to explore the use of CAM among Norwegian patients with a previous cancer diagnosis. To achieve this, four studies were conducted (Papers I–IV), each with its own specific aim:

1. To present a six-level model for classifying patients' reported exposure to CAM.
2. To explore whether reported use of CAM in cancer survivors is associated with diagnostic survival prognosis.
3. To (1) examine how CAM use in cancer patients differs from people with a previous CHD diagnosis and people with no cancer or CHD diagnosis in an unselected general population and (2), investigate the use of a CAM provider among individuals with a previous cancer diagnosis.
4. To (1) describe prevalence of CAM use in individuals with a previous cancer diagnosis, and (2) to investigate whether men and women differ with regard to socio demographical and health related factors associated with CAM use.

### **3. Material and methods**

#### **3.1 Studied population**

To ensure a valid outcome of a study, the studied population is of great importance. To avoid selection bias, the studied population needs to reflect the population we want to describe.

The best way to ensure this is to study the whole population or a random sample. Self-selection of respondents might result in a studied population with a special interest for the studied topic. Such selection can also occur when the response rate in a study is low. Three populations were used in the studies in this thesis, one sample drawn directly from the Cancer Registry of Norway (the CRN study), one based on respondents that participated in the fifth Tromsø study (T5) and one based on cancer patients that participated in the sixth Tromsø study (T6).

#### **3.2 The Cancer Registry of Norway's study of poor prognosis (the CRN study)**

In Papers I and II the included participants were cancer patients aged 20 years or older who were registered in the CRN and who were diagnosed with cancer between January 1986 and December 1997.

All patients who survived more than 5 years after diagnosis with less than 20% expected 5-year survival at the time of diagnosis were included (n=286). In addition, a random sample of all patients with a 40–60% expected 5-year survival rate at the time of diagnosis (n=599) were included. The random selection was done by sorting all patients who met the inclusion criteria (n=2716) by their personal identification number, after which the first 600 were

selected. Since the last two digits in the ID number are random, this generates a random sample. After selection of the sample, one informant was found to no longer be alive. The final sample was thus made up of 599 patients. The 885 cancer patients from the two prognosis groups were treated at 108 different hospital departments. These departments were asked to confirm the diagnosis and forward the questionnaire to the patients. 735 questionnaires were forwarded from the hospitals to the patients, of which 400 were completed and returned by mail. Three questionnaires were excluded due to missing ID number or because they were filled in by relatives, leaving us with 397 questionnaires used in the study.

It is important to note that the CRN includes all cancer patients in Norway regardless of treatment choice, place of residence, age, gender, or other socio-demographic variables.

### **3.2.1 The Tromsø study series (T1–T6)**

The Tromsø study series started in 1974, and was initiated due to the high mortality rate of patients with cardiovascular diseases in Norway, where men in particular were affected. In the mid-1970s, 20% of Norwegian men died from cardiac infarction before the age of 75. The situation in northern Norway was even worse [29].

The survey was organized as repeated health surveys of large proportions of the population, based on the official population registry. Health screenings and self-administrated questionnaires were used to collect information. The purpose was primarily to determine the reasons for the high mortality from cardiac infarction and to develop methods for preventing cardiac infarction and stroke. As the Tromsø cohort study developed further, other disease groups were included, such as rheumatic, neurological and psychiatric disorders, skin

diseases, diseases of the stomach/bowel, cancer, and osteoporosis. The use of health services was included as an item from the fourth study (T4), including questions about CAM use.

A total of 40051 unique individuals have participated in the six studies (Table 1), of whom 15157 have participated three times or more [30].

**Table 1. Participants in the Tromsø cohort study**

Year of survey	Name of survey	Number of participants <sup>1</sup>	Age group
1974	<u>Tromsø 1</u> (T1)	6595 men	20-49
1979-80	<u>Tromsø 2</u> (T2)	16621 men and women	20-54
1986-87	<u>Tromsø 3</u> (T3)	21826 men and women	12-67
1994-95	<u>Tromsø 4</u> (T4)	27158 men and women	25-97
2001-02	<u>Tromsø 5</u> (T5)	8130 men and women	30-89
2007-08	<u>Tromsø 6</u> (T6)	12984 men and women	30-87

### **The fifth Tromsø study (T5)**

T5 was carried out in 2001-2002 with a total of 8130 men and women aged 30–89 years participating. Two groups of individuals were invited. The largest group consisted of 6185 men and women attending the extended special study in T4 and who were still residing in Tromsø. A smaller, random group of 1916 men and women was included as part of a nationwide health survey of people aged 30, 40, 45, 60 or 75 years [31]. In addition, 29 people were included as they met uninvited to the health screening and fulfilled the inclusion criteria. 8040 of the 8130 included participants had given informed consent at the time the data presented in Paper III was analyzed.

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<sup>1</sup> The number of respondents who have provided consensus varies over time and can therefore result in different numbers of participants at different points of time.

### **The sixth Tromsø study (T6)**

T6 was carried out in 2007–2008 and was the first Tromsø study after the new law regulating CAM providers' right to treat serious diseases and disorders was implemented in Norway.

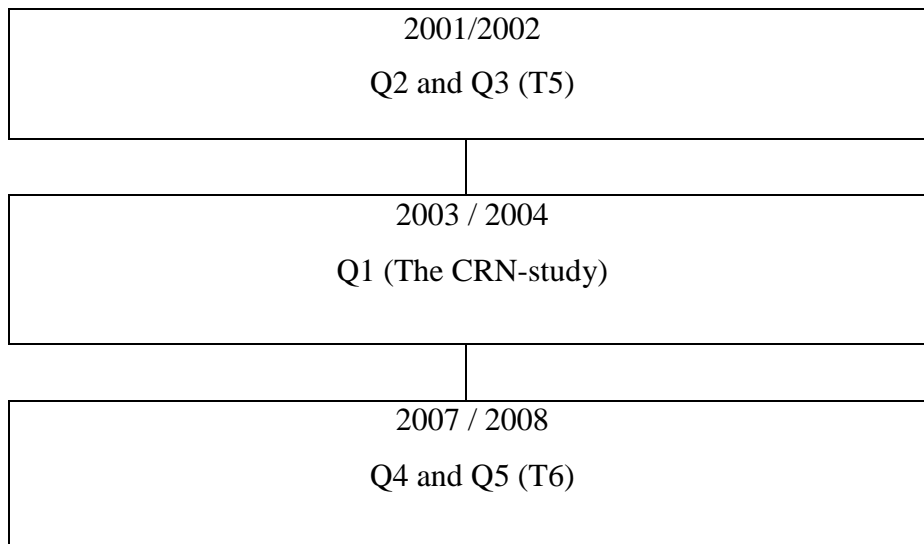
19762 individuals were invited from four different groups:

1. All participants attending the extended special study in T4 and who were still residing in Tromsø
2. All citizens of Tromsø aged 40–42 and 60–87.
3. A 40% random sample of citizens of Tromsø aged 43–59
4. A 10% random sample of citizens of Tromsø aged 30–39

The response rate (65.7%) was lower than in previous Tromsø studies. Of those who completed the questionnaire, the response rate was higher for women (68.4%) than men (62.9%) [32]. The study thus consisted of 12984 respondents, of whom 12982 had given informed consent at the time the data presented in Paper IV was analyzed. Eight hundred respondents were registered with a cancer diagnosis in the CRN of whom 630 answered the three questions concerning CAM use and included in the analyses.

### **3.2.2 Chronology of the questionnaires used in the thesis**

Data for the papers in this thesis are collected over a period of seven years, between 2001 and 2008, as described in figure 1 below.



**Figure 1. Chronology of the questionnaires in this thesis**

### **3.3 Study design**

In order to study CAM use among cancer patients, we have chosen an epidemiological approach.

Common epidemiological approaches are case-control, cross-sectional, and cohort studies, all observational in nature. In addition, some epidemiological studies are interventional.

*Case-control studies* are used to compare patients who have a disease or outcome of interest (cases) with patients who do not have the disease or outcome (controls). Both groups are retrospectively studied to compare how frequently the exposure to a risk factor is present in each group. This is done to determine the relationship between the risk factor and the disease. Case-control studies are observational because no intervention is attempted and no attempt is made to alter the course of the disease. The goal is to determine exposure to the risk factor of interest from each of the two groups of individuals: Cases and controls [33, 34]. The main disadvantage with case-control studies is that suitable controls can be difficult to find, and that the studies are done retrospectively with possible risk of recall bias [33].

*Cross-sectional studies* measure the prevalence of disease(s) and are often called prevalence studies. In a cross-sectional study the measurements of exposure and outcome are made at the same time. This makes it difficult to assess the reasons for associations. Data from cross-sectional studies are helpful in assessing the health-care needs in a population. Data from repeated cross-sectional surveys using independent random samples with standardized definitions and survey methods provide useful indications for trends. Valid surveys need well-designed questionnaires and an appropriate sample of sufficient size, in addition to a high response rate [34].

*Cohort studies* are used to identify the incidence and natural history of a disease by following two or more groups from exposure to outcome. If the former group has a higher or lower frequency of an outcome than the exposed group, an association between the exposure and the outcome is evident. The study can be done prospectively or retrospectively. Cohort studies enable us to calculate incidence rates and relative risk [35].

In the studies presented in this thesis several observational techniques were used. The CRN study (Papers I and II), T5 (Paper III) and T6 (Paper IV) as single studies are typical cross sectional studies. T5 and T6 are additionally part of a longitudinal cohort study. All the studies measure self-reported use of CAM, collected through five different questionnaires (Table 2). Q1 was sent and returned by mail, Q2 was enclosed in the mailed invitation to the T5 participants and returned personally to a nurse offering help if the questionnaire was insufficiently filled in. Q3 was handed out directly to the participants as they attended the health screening where they delivered Q2, and was completed either onsite or at home and returned by mail. Q4 and Q5 were administered in the same manner as Q2 and Q3.

**Table 2. Overview of studies, questionnaires and papers presented in this thesis**

<b>Name of study</b>	<b>Questionnaires used</b>	<b>Presented in paper</b>	<b>Displayed in</b>
CRN study	Q1	I and II	Appendix 1C
T5	Q2 and Q3	III	Appendices 2C-E
T6	Q4 and Q5	IV	Appendices 3D-E

The questions were mostly closed-ended with several linguistic answer options to choose from. There were two exceptions: One open-ended question in Q1 that was optional for the respondents to respond to, and a ratio scale in Q5 with numbers only.

In contrast to participant observation, we were unable to directly observe the CAM use among cancer patients, only data based on *self-reported* use from a retrospective perspective was collected. There are some possible sources of errors in this method that will be discussed under *bias considerations*.

### **3.3.1 Questionnaires**

Questionnaires are commonly used in surveys. Both self-administrated questionnaires answered anonymously and questionnaires administered by an interviewer are common. The possibilities to reach people in their own homes and in a large geographical area with limited recourses, are two advantages of self-administrated questionnaires mailed to the respondents. The possibility to answer anonymously increases the chance for valid answers, especially when sensitive topics are addressed. It has been challenging to collect responses to surveys on CAM use among cancer patients in Norway as providers treating cancer patients did this illegally up to 2004. Self-administrated questionnaires answered anonymously might therefore have been an appropriate tool for researching CAM use by cancer patients prior to



2004. Self-administrated questionnaires answered anonymously was used in the CRN study, the only study in this thesis where CAM use and cancer was clearly connected in the questionnaire.

A challenge when questionnaires are developed is to find the right wording for the questions to ensure a reliable answer from the respondents. Furthermore, the reply options have a considerable influence on how people answer the questions. Thus, both the wording and the reply options constitute a potential challenge when the results are compared to findings in other studies.

We found, for example, that 47.1% of the respondents reported poor health in T5 (Paper III) while only 9% reported poor health in T6 (Paper IV). The differences were not likely to be found in people's experience of their own health, but rather in how the reply options were formulated. While T5 had four categories (excellent, good, not good, and bad) T6 included a fifth category (neither good nor bad), where 38% of the answers could be found. Another example of how different wordings can give different results is the question concerning use of a CAM provider in Q2 (T5) and Q4 (T6). While Q2 asked for visits to a CAM provider without defining a CAM provider further, Q4 presented examples of CAM providers in the question. This could possibly explain the lower missing rate for the CAM provider question in Q5 (8%, n=1045) when compared to Q4 (15.9%, n=1280), as the question is clearer.

Different wordings make it difficult to compare findings between different points in time as the change in reported CAM use might be due to the difference in the wording and not actual CAM use.

With a personally administered questionnaire, as opposed to a self-administrated questionnaire, there is a possibility to clarify questions for the respondent where questions

are unclear or misunderstood. This option was nevertheless offered in Q2 and Q4 where a trained nurse received the questionnaire offering help if needed.

Unlike qualitative methods like personal and focus group interviews, self-administrated questionnaires might fail to give information that could be of importance to the respondent, because it is not covered by the questionnaire. Qualitative methods could give a better understanding of why cancer patients use CAM and how they use it [36]. However, the purpose of this thesis was to describe the prevalence and association of CAM use among Norwegian cancer patients. Thus, in order to cover this aim, I found self-administrated questionnaires to be most suitable.

### **3.3.2 Development of the questionnaires**

The first step in designing a questionnaire is to have a clear purpose of the study. The topic and the type of information you want to collect must be clear to keep the questionnaire focused. The questions must measure what they intend to measure, and the wording must be easy to understand and suitable for comparison with other studies. Most questionnaires also include socio-demographical questions such as gender, age, marital status, occupation, income, education, etc., that describe the characteristics of the participants. These demographics are often used as confounding variables during analysis. Other non-demographical questions can also be included to provide confounding variables. The length of the questionnaire must be long enough to collect the information needed, and short enough to keep the respondent focused when completing the questionnaire [37].

Once the intention is clear and the questions formulated, it is necessary to address the answer alternatives. Open-ended and closed-ended questions might be used. Open-ended questions allow the respondent to answer the question in his or her own words. Such information may

be more complete and accurate than information obtained with a more restricted question format. However, if the respondent does not accurately understand what is being asked, the researchers might end up with an answer that does not provide the information needed. Another drawback with open-ended questions is that summarizing data can be difficult. The researcher must decide how to classify different answers, which increases the risk of misclassifications [37].

A restricted question with clear alternatives for the answer is another possibility, where alternatives are provided in a logical order [37]. This can be illustrated by one of the questions from Q5:

How do you in general consider your own health to be?

- Very bad
- Bad
- Neither good nor bad
- Good
- Excellent

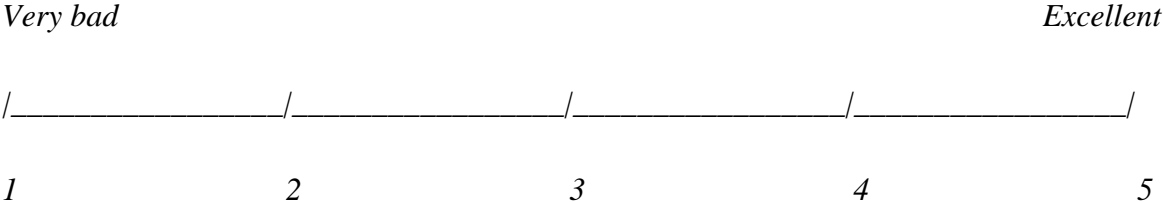
This type of question could also be set up with numbers rating from 1–5 after each question, indicating that the answers go from very bad health (1) to excellent health (5) in an ordinal scale.

This example also illustrates another issue that must be considered: The “middle alternative” (neither good nor bad) does not force people to decide whether or not their health is mostly good or mostly bad. 10–20% of respondents tend to choose the middle alternative when this

option is offered in a forced choice attitude item [38]. In Q5 as many as 37.6% of the cancer survivors chose this option.

Another issue that must be addressed is the possibility of offering a “Don’t know” (DK) alternative. Before including this, it is important to determine whether the respondent can identify with one of the given options or not [38]. In questions where the respondent has an option, the DK question could preferably be left out to ensure that the respondent tries to give an answer that is useful for the study. The questionnaires used in this thesis only occasionally include DK options.

An alternative to boxes or numbers to tick off after or before the question, is the use of visual scales. Such scales can be provided with or without numbers and labels, and the scale can vary from few (for example 1-5) to many (1-100), labeled or not, or a combination of both. The scales can be placed horizontally or vertically:



Scales with specific numbers and labels connected to the numbers often work like a question with closed answers. An open line, on the other hand, allows the respondent to mark the line exactly where he or she feels he/she belongs independently of linguistic interpretation. When coding a scale with no numbers, a marker with values can be placed over the line later to show what “value” the respondent has ticked off.

In T6, self-reported health was measured both with a closed-ended question as mentioned above, and with a vertical rating scale numbered 0–100. The closed-ended question was used

in Q4, which was completed by the respondents before the health screening, including also the question regarding visits to a CAM provider. The rating scale was placed in Q5, which respondents completed after the health screening together with the use of OTC products and CAM techniques questions.

The reported proportion of CAM users in relation to self-reported health might have been somewhat different if the scale had been used instead of the closed-ended questions. When the two health questions were compared by transforming values from the scale into equally numeric-sized categories (0–20: Very bad, 21–40: Bad, 41–60: Neither good nor bad, 61–80: Good, 81–100: Excellent), the respondents were found to, in general, illustrate their health with a number on the scale placing them in a better category than the category they picked themselves, as illustrated in table 3 below.

**Table 3. Self-reported health in T6: Scale responses compared to category responses.**

		Scale response transformed into categories				
		0-20 (very bad)	21-40 (bad)	41-60 (neither good nor bad)	61-80 (good)	81-100 (excellent)
How do you in general consider your own health to be?	Very bad	2	8	3	0	1
	Bad	9	80	112	52	4
	Neither good nor bad	6	89	438	686	150
	Good	2	20	132	1222	1485
	Excellent	1	2	6	116	778

This raises a methodological concern as the respondents' self-reported health might have been reported to be better if the health scale had been used rather than the close-ended question.

The differences can thus be due to the nature of the measurement, as discussed above, or due to the fact that the scale was placed in the second questionnaire, which was filled in after the health screening. This is because the health screening results might have adjusted the respondents' impression of their own health.

One open-ended question was placed in Q1, asking for further information about issues experienced as meaningful in coping with cancer. Very few respondents (20 out of 400) answered the question and the question has not been analyzed.

When a questionnaire is fully developed, a pilot study testing the questionnaire might be useful. Q1 was tested in a pilot study with a test-retest and an interview after the questionnaires were filled in: Identical questionnaires were sent twice (two weeks apart) to five cancer survivors outside the study, while the interview was conducted with two of the test-persons. No major discrepancies were found between the first and the second completion of the questionnaire or between the interview and the questionnaire.

### **Development of the questionnaires used in this thesis**

This thesis is based on five different questionnaires (Table 2). Q1, used in Paper I and II, was fully developed by me and is described in Paper II. Q2 and Q3 used in Paper III, and Q4 and Q5 used in Paper IV, were developed as a cooperation project where the aim was to organize a joint collection of data to be used by several research groups [39].

## **4. Summary of study results**

### **4.1 Paper I: Use of complementary and alternative medicine among patients:**

#### **Classification criteria determine level of use**

**Background:** Self-reported use of CAM among cancer patients varies widely between studies, possibly because the studies' definitions of CAM-users are not comparable. This makes it difficult to compare study results. The aim of this study was to develop a model to classify patients' use of CAM according to intensity of use.

**Methods:** A six-level model for reporting CAM use among cancer patients was developed. The levels included more than three visits to a CAM provider (level 1), one to three visits (level 2), use of OTC products/CAM techniques (level 3), use of diet (level 4), use of exercise (level 5) and use of prayer (level 6) as treatment in a cumulative manner according to involvement of use.

**Results:** By applying the model to responses given by Norwegian cancer patients, we found only 11.1% reporting CAM use when CAM was defined as four or more visits to a CAM provider. This proportion increased to 72.3% in the same patient group when the use of OTC products/CAM techniques, special diets, and physical exercise were also included as CAM use.

**Conclusion:** We recommend that future studies of CAM use among cancer patients clarify the intensity level of CAM use on which the report is based.

## **4.2 Paper II: Do cancer patients with a poor prognosis use complementary and alternative medicine more often than others?**

**Background:** One circumstance under which cancer patients use CAM is when their cancer cannot be cured by conventional therapy. The aim of this study was to explore whether use of CAM is associated with survival prognosis in long-term survivors of cancer.

**Methods:** Two groups of cancer patients who were alive 5 years or more after diagnosis were included in the study: Those with less than 20% expected five-year survival at the time of their diagnosis, and those with a similar 40–60% expected survival rate. 735 patients received a four-page postal questionnaire about CAM use, of which 397 were returned by mail (response rate=54%).

**Results:** The results are reported at five levels of CAM use (levels 1–5 in the model presented in Paper I). The poor prognosis group reported CAM use more often than the better prognosis group, however only significantly higher at CAM level 2 (use of a CAM provider,  $p=0.021$ ) and in use of self-support/CAM techniques ( $p<0.001$ ). In terms of the patients' use of OTC products and diet as treatment, no significant differences were found between the groups.

**Conclusion:** This study supports the suggestion that the use of a CAM provider and the use of self-support/CAM techniques might be associated with poor survival prognosis at the time of diagnosis.



### **4.3 Paper III: Any difference? Use of a CAM provider among cancer patients, coronary heart disease (CHD) patients and individuals with no cancer/no CHD**

**Background:** Although use of CAM among cancer patients has been described, prevalence of use has not commonly been compared to other disease groups in a true population sample where CAM use or cancer is not the main focus. The aim of this study was to examine whether the use of a CAM provider among cancer patients differs from CHD patients and individuals with no cancer/no CHD.

**Methods:** We performed a study using data from the T5 study to compare use of a CAM provider among cancer survivors to CHD survivors and people without a history of cancer/CHD.

**Results:** Of 331 patients with a cancer diagnosis, 7.9% reported having seen a CAM provider within the last 12 months. This did not differ significantly from neither the CHD group (6.4%,  $p=0.402$ ) nor the no-cancer group (9.5%,  $p=0.325$ ).

**Conclusion:** According to this study, the proportion of cancer patients seeing a CAM provider was not statistically significantly different from patients with CHD or individuals without cancer or CHD.

#### **4.4 Paper IV: CAM use among Norwegian cancer survivors. Gender specific prevalence and associations for use**

**Background:** The predictors for CAM use in whole populations and among female cancer survivors are described in the literature. Predictors for CAM use among male cancer survivors are still insufficiently studied. The associations for CAM use is only occasionally differentiated by gender in populations where both male and female cancer survivors occur. The aim of this study was to describe prevalence of CAM use among individuals with a previous cancer diagnosis and to investigate gender differences with regard to factors associated with use.

**Methods:** A total of 12982 men and women aged 30 to 87 in the county of Tromsø, Norway, filled in a questionnaire developed specifically for the T6 study with questions on life style and health issues. 800 of these had a previous cancer diagnosis, of whom 630 answered three questions concerning CAM: Use of a CAM provider, use of CAM techniques, and use of OTC products within the last 12 months.

**Results:** A total of 33.8% of all cancer survivors reported CAM use, 39.4% of the women and 27.9% of the men ( $p < 0.01$ ). The relationship between the demographic variables and being a CAM user differed significantly between men and women with regard to age ( $p = 0.03$ ), education ( $p = 0.04$ ), and income ( $p < 0.01$ ). Female CAM users were more likely to have a university degree than the non-users, while male CAM users were more likely to have a lower income than the non-users.

**Conclusion:** According to this study prevalence and associations for CAM use differs significantly between women and men with cancer.

## **5. General discussion**

In the studies included in this thesis I have found that CAM use among cancer patients is common, and more so among women than men. Furthermore, I developed a model to clarify degree of CAM involvement that enables comparison of CAM use across cultures. Lastly, I found the associations for CAM use are different among men and women.

### **5.1 Bias considerations**

In order to study CAM use among Norwegian cancer patients, quantitative research methods was used with five different self-administrated questionnaires. Using the collected responses based on linguistic phrases, we investigated what people report to have done in the past or at present and categorized their experience into numbers suitable for statistical analyses. In some cases the respondents categorized their experience into a numbers themselves, and thus there is a risk that different people categorized the same experience into different categories/numbers, as illustrated in Table 3. The use of qualitative research methods might have given more detailed information about the respondents and reduced the risk for misclassification dependent on different categorizations from experience to categories/numbers. The chosen research method, on the other hand, strengthened the ability for generalizability of the findings. To determine the validity of the studies included in this thesis, internal validity, external validity and generalizability is considered [40].

#### **5.1.1 Internal validity**

Internal validity can be classified into three categories: Confounding, selection bias, and information bias [40].

## **Confounding**

When a presumed causal relationship between two variables is fully or partly caused by a third factor, we call this confounding variables [41]. This is an important issue in observational studies [40] as the differences between the two groups could be due to other variables than the studied ones. Paper IV has, in accordance with the general literature [19, 27, 42-44], shown that the female gender and younger age are associated with being a cancer patient and at the same time a user of CAM. These two variables can therefore be seen as possible confounding variables when studying the association between being a cancer patient and CAM use. As shown in Paper II and elsewhere in the literature [45], poor survival prognosis could also possible be a confounding variable for CAM use in cancer treatments. When confounding variables were suspected in the studies presented in this thesis, analyses adjusted for, or stratified by, these factors were presented.

## **Selection Bias**

The best way to avoid selection bias is to invite the entire background population to participate, as was done with the poor prognosis group in the CRN study referred to in Papers I and II. When this is not possible, a random sample is a good way to ensure that the studied population reflects the background population, as done in T5, T6 [46, 47], and in the “better prognosis group” in the CRN study.

A common source of selection bias is self-selection. Self-referral of subjects is ordinarily considered a threat to validity because the reasons for self-referral may be associated with the outcome of the study [48]. None of the populations used in the studies in this thesis are based on self-selection.

Low response rate is also a challenge to the validity of the findings. Papers I and II are based on a study with only a 54.4% response rate. This is a challenge to the generalizability of the findings. The clear purpose of the study might have led to an overrepresentation of CAM users among the respondents. This is suspected because the reported use of CAM was higher among the respondents answering the questionnaire *before* the reminder, compared to those responding *after* the reminder was sent out. The respondents did not differ from the non-responders with regard to age and gender.

The response rate in T5 and T6 was 77.6% and 65.7%, respectively. The high response rate in these two studies strengthens the validity of our findings, though the non-responders could have qualities that differ from those found in the studied population. The non-responders were found to be younger and the proportion of men tended to be higher than among those that responded. Non-responders also tended to be unmarried: In T6, 59% of the respondents were married while only 41% of the non-responders were married. This was found in all age groups [46]. However, we found no differences in CAM use between married and unmarried respondents. Information about age and gender distribution is described at the official T6 website [32].

### **Information bias**

When the groups to be compared in a population have been identified, information about them must be collected and used in the analysis. Bias in estimating an effect or exposure can be caused by measurement errors in the needed information. Such bias is often called information bias [40].

There are two types of information bias: Differential and non-differential. Non-differential errors produce findings that are too high or too low in approximately equal amounts in the

studied groups. Differential bias occurs when one group is more likely to over- or under estimate compared to the other groups [49]. In Q2 (Paper III), “CAM provider” was not defined. This could have led to a misclassification of certain types of treatment as CAM and placed a non-CAM user in the CAM user category. This is not likely to be differential between the groups compared. Also, self-reported cancer was shown to not always coordinate with cancer registered in the CRN (Paper III), causing a potential risk for being misclassified as a cancer patient. To avoid misclassification concerning cancer, self-reported cancer was controlled towards the CRN in Paper III. In Papers I, II and IV the CRN was used as the only source.

Information bias can also occur when the recall time is long, and is referred to as recall bias. When CAM use is reported internationally the terms “ever used”, “used since diagnosis”, “used the last 12 months”, and “current use” have been seen [50]. In T5 and T6, CAM use within the last 12 months was applied in accordance with Quant et al.’s suggestion [50]. In the CRN study, on the other hand, use since diagnosis was measured in a population who had been diagnosed at least five years previously. This can cause severe challenges regarding recall, but I believe this was reduced by the provided check-list for the respondents. The fact that the cancer diagnoses in both groups were severe also makes it less likely to be differential between groups.

The ability to remember a former illness can also influence potential recall bias. This is a possible reason for the 47 respondents in T5 presented in Paper III, who ticked “no” for cancer despite a cancer diagnosis in the CRN.

Differential recall is a potential source of misclassification when two groups with different backgrounds are compared. A person with a health problem might be more likely to

remember health related issues in a more accurate way than people without a health problem [49, 51]. This possible differential recall can occur when CAM use among cancer patients is compared to CAM use in a healthy population, as in Paper III. I believe though, that this might have been reduced by the rather short recall time (12 months) concerning use of CAM.

Another possible source of information bias is that the new role as a research participant can create a change in the participants' attitude. This change can be grouped into the following three categories: The cooperative attitude, the defensive or apprehensive attitude, and the negative attitude [52]. In voluntary studies a positive or defensive attitude is most common. The cooperative attitude is characterized as a strong desire to please the researcher; to perform well with a desire to be positively evaluated by others [37].

One example of this could be if the survey is performed by an oncologist and the cancer patient feels uncomfortable about having contacted a CAM provider, and therefore denies this in the survey. Or the opposite can occur: The patient might feel that CAM treatment should be part of standard cancer care and may therefore add extra CAM treatments to the survey to express their support for CAM. Perhaps have the treatments already been used, but not within the time frame asked for. These two scenarios can lead to over- or under estimation of CAM use, but are not likely to be differential between groups in the papers in this thesis. However, when the purpose of the study is not clear to the respondent (e.g., CAM use in cancer treatment), as in T5 and T6, or full anonymity is secured, as in The CRN-study, this less likely to be a problem.

### **5.1.2 External validity and generalizability**

*External validity* refers to when the results found in a sample represent the situation in the population the sample has been extracted from. *Generalizability* expresses whether results

found in one population can be true for other populations. In this thesis I studied CAM use in different cancer populations. The question is whether these studies reflect CAM use in other cancer populations than the ones studied here.

In the CRN survey, one of the studied groups was the whole population of “cancer survivors with poor survival prognosis at the time of diagnosis” which strengthens the generalizability of the findings. The finding of higher use of CAM in the poor prognosis group is in addition in accordance with findings in other studies [53]. The level of CAM use among Norwegian cancer patients is not necessarily transferable to other countries as the legislation concerning CAM use varies widely between countries [54]. The prevalence of CAM use in T5 and T6 is, however, in accordance with findings in other parts of Norway [24], and the population of Tromsø reflects the population of Norway, though somewhat younger [55].

## **5.2 Reliability**

*Reliability* is the ability of a measure to produce the same or highly similar results on repeated administrations. The reliability of a questionnaire relates to the consistency of responses across retesting with the same or equivalent instrument [37].

Repeated testing is the oldest and most conceptual way to establish the reliability of a questionnaire [37]. The time between the tests must be short enough to ensure that the underlying condition is unaltered and long enough to ensure that the respondents do not remember their first answer(s). The test–retest was used to determine the reliability of Q1, which was used in Papers I and II. No major discrepancies were found between the first and second administrations of the questionnaire, strengthening the reliability of the questionnaire.



The Tromsø study was developed as a cohort study that used experience from former parts of the cohort study to ensure reliability of the questions. However, the questionnaires used in T5 and T6 have not been tested as though they were a single study, which constitutes a potential reliability risk.

### **5.3 Gender differences**

Gender differences in health issues is not a new topic. “Women suffer – men die” [56] discusses a variety of gender-specific health issues. Men less often use primary health care or report to have a health problem when compared with women, and do not fall as easily out of work [56]. This can be associated with findings of lower CAM use among men than women in Papers I–IV. There are both biological and sociological explanation models of why women and men behave differently.

Medhus claims that the testosterone and the estrogen hormone affect the fetus in a way that creates a male brain and a female brain while still in the womb. He claims among other things that boys are more focused on technical things than girls [57]. While Medhus explains the differences purely with hormones, Nielsen and Rudberg claim that boys and girls are treated differently from early childhood, which creates typical gender specific behavior [58]. West and Zimmerman argue for a more complex relation between social and physical features. Their "doing gender" refers to performing complex societal activities of perception, interaction, and micro politics in order to define certain activities and pursuits as masculine or feminine [59].

Medhus’ characterization of men as being technical can shed light on the lower use of CAM among men with cancer found in Papers I-IV. If the average man is more technically

focused, he might be more likely to see the body as a technical instrument that needs to be fixed if it is broken. This kind of treatment might be easier to find within conventional health care than in most CAM modalities.

West and Zimmerman's [59] explanation of activities being masculine or feminine might have an influence, as health complaints and CAM use might possibly be seen as feminine and therefore avoided by men. This theory correlates with Christie who claims that the patient's role is more like a traditional female role than a male role [60]. These studies, along with Baketeig's study [56] referred to above, can explain the lower use of CAM among men in Papers I- IV.

The reason for the discrepancy concerning use of health services like CAM might be explained by the fact that men often have a wife who cares for them if they do not feel well. Women, on the other hand, often lack this caregiver even though they live in a relationship with men and therefore need to share their concerns other places [60]. Furthermore, if health care can be categorized as a feminine rather than a masculine activity this is also reflected in the colored press. Health problems and CAM use are more often addressed in magazines for women than for men, and mass media is pointed out as one of the sources of information for women with breast cancer in a recent systematic review [61]. This again leads to a higher exposure for women than men, which can explain the more active use of CAM among women.

When associations for CAM use were addressed, we found in some cases that men using CAM tended to be more similar to women using CAM than the male non-users of CAM (i.e., income and education, Paper IV). When it came to age and self-reported health, women using CAM tended to be younger and with better self-reported health than men using CAM.

This might indicate that men, contrary to women [62], use CAM as a specific treatment for their disease more than for prevention and well-being. This is supported by the findings showing that men with metastatic cancer are more likely to use CAM than men with no metastatic cancer [63].

The gender aspect is also relevant in regards to cancer sites. While breast cancer is the most common cancer site among women, prostate cancer is most common among men [64]. A study of men with prostate cancer indicated that they prefer to avoid disclosure about their illness due to a low need for support and a wish to sustain a normal life without being stigmatized by others [65]. These findings are supported by Harrison who found that men shared their concern with mainly one person while women shared it in a wide circle of family, friends, and their partner [66]. A man with prostate cancer reported that the reason he would not share this information with a friend who thought he was going to get prostate cancer: *“It’s none of his damn business”* [65]. As CAM is not offered within conventional health-care in Norway, many patients receive information about CAM use by talking to others. If men are more reluctant to discuss their cancer with others than women are, they are also likely to receive less information about CAM modalities for cancer. This, in addition to the less expressed need for support, might partly explain the lower use of CAM among men found in Papers I-IV.

#### **5.4 Use of a model for reporting CAM use**

A model has in principle the same function as a theory. While a theory provides a simplified picture of reality in words, a model uses a graphical representation. Like a theory, a model

consists of two main components: Concepts and relationships between concepts; it is a schematic presentation of terms and theories.

*One or more terms*

+The relationship between the terms

=A model

As with theories, models classify and abstract the information to make it easier to distinguish between the important and unimportant information. In social science it is common to distinguish between three different models:

*Descriptive models* describe a relationship or a phenomenon—how factors relate. *Models to understand and explain a phenomenon* provide an understanding and explanation. *Normative models* provide advice about how to act [67].

The main advantage of models is that they simplify and make the data more easily accessible. The main limitations are that there will always be data that do not fit into the model and the richness of the data may disappear. The model described in Paper I was developed for two purposes:

1. To be able to compare studies across cultures.
2. To categorize involvement of CAM use.

Developing a model for reporting CAM use in a population was necessary in order to compare studies across cultures as the definition of a CAM user varied widely [17]. As described in Paper I, some models were already in use. What was needed was a simple model that published studies could fit into; a model that could work across cultures and also measured the CAM involvement. From my point of view, as a CAM provider, it seemed

essential to differentiate between CAM modalities that included a CAM provider and those that were performed by the patients themselves without the guidance of a professional provider. This differentiation is important, as many studies describe the patient's experience and effect of CAM use. It was also essential to differentiate between CAM and life-style changes like exercise and dietary changes that are also recommended by conventional health care providers. Prayer was important to both include and exclude as there is no common agreement on whether or not to classify prayer as CAM. From my point of view, prayer is not to be classified as CAM, as discussed in Paper I. Since many studies already include prayer in their definition of CAM, prayer was placed in the outer circle of the model, easy both to include and exclude. The model can be seen as both descriptive and normative as the model both describes what a CAM user can be and suggests how CAM use should be reported in future studies.

Four years after the model was published, it has been referred to by several publications on CAM use [50, 68-74] and used as a model to present data on CAM use at least once [68]. The model has also served as a basis for a new questionnaire (I-CAM-Q) [50].

## **6. Conclusion**

### **6.1 What does this thesis add?**

I developed a six-level model for classifying patients' exposure to CAM that enables studies to be comparable across cultures. When studies were placed in the model and compared with other studies presenting data at the same level, the reported use of CAM among cancer patients was found to be more similar across cultures than first expected.

Cancer survivors in Norway do not differ significantly from people with CHD with regard to prevalence of CAM use. Cancer patients with a poor prognosis seem to be more frequent users of some CAM modalities than patients with a better prognosis.

Associations for CAM use differ statistically significantly between men and women. Female CAM users are younger, better educated and have a higher income than non-users. Male CAM users do not differ significantly from their non-user counterparts except in terms of income, where they, contrary to women, tend to have lower income than male non-users.

### **6.2 Future reseach**

Studies following patients over time, starting at the first diagnosis of cancer, are still missing in this important research area. This could provide more knowledge about CAM use among all cancer patients, not only retrospectively among the survivors with potential recall bias. We also need qualitative studies to better understand the mechanisms behind the choice of using CAM, with a special focus on gender-specific and other socio-demographic factors.

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## **8. Papers I-IV**

**Paper I:** Use of complementary and alternative medicine among patients: Classification criteria determine level of use

**Paper II:** Do cancer patients with a poor prognosis use complementary and alternative medicine more often than others?

**Paper III:** Any difference? Use of a CAM provider among cancer patients, coronary heart disease (CHD) patients and individuals with no cancer/ CHD

**Paper IV:** Complementary and Alternative Medicine Use among Norwegian Cancer Survivors: Gender-Specific Prevalence and Associations for Use

## **9. Appendices**

### **9.1 Appendix 1: The Cancer Registry of Norway (CRN)-study**

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Appendix 1-B: Information sent to the patients

Appendix 1-C: Questionnaire used in the CRN-study

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### **9.3 Appendix 3: The sixth Tromsø study (T6)**

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# Paper I



# Use of Complementary and Alternative Medicine Among Patients: Classification Criteria Determine Level of Use

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 and Arne Johan Norheim, M.D., Ph.D.

## Abstract

**Background and objectives:** Self-reported use of complementary and alternative medicine (CAM) among patients varies widely between studies, possibly because the definition of a CAM user is not comparable. This makes it difficult to compare studies. The aim of this study is to present a six-level model for classifying patients' reported exposure to CAM. Prayer, physical exercise, special diets, over-the-counter products/CAM techniques, and personal visits to a CAM practitioner are successively removed from the model in a reductive fashion.

**Methods:** By applying the model to responses given by Norwegian patients with cancer, we found that 72% use CAM if the user was defined to include all types of CAM. This proportion was reduced successively to only 11% in the same patient group when a CAM user was defined as a user visiting a CAM practitioner four or more times. When considering a sample of 10 recently published studies of CAM use among patients with breast cancer, we found 98% use when the CAM user was defined to include all sorts of CAM. This proportion was reduced successively to only 20% when a CAM user was defined as a user of a CAM practitioner.

**Conclusions:** We recommend future surveys of CAM use to report at more than one level and to clarify which intensity level of CAM use the report is based on.

## Introduction

Prevalence of self-reported use of complementary and alternative medicine (CAM) among patient groups is difficult to interpret when no standardized way of reporting CAM use has been established. Among patients with cancer, self-reported use of CAM varies between 7%<sup>1</sup> and 98%.<sup>2</sup> Possible reasons for this wide range in reported use could be differences in the definition of a CAM user<sup>3,4</sup> and/or differences in timeframe of the use.<sup>5</sup> Some studies report all possible nonconventional health activities including prayer and exercise as CAM use,<sup>6–10</sup> others limit it to visits to a CAM therapist or use of CAM techniques, over-the-counter (OTC) products, and dietary changes,<sup>5</sup> while some limit the reported use of CAM to be only CAM treatment given by a therapist.<sup>11,12</sup> It is also likely that self-reported use varies dependent on whether the question addresses use of specific CAM methods connected with cancer disease or CAM use

in general. These possible methodological differences necessitate a clarification of the criteria used when classifying a person as a CAM user. A more standard series of questions and definitions to generate comparable data has been proposed,<sup>3</sup> but a comprehensive model for reporting "CAM use in patients" is still lacking.

CAM is mostly defined as something it is not: "A broad set of health care practices that are not part of that country's own tradition and are not integrated into the dominant health care system";<sup>13</sup> "[a] group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine";<sup>14</sup> and "a diverse group of health-related therapies and disciplines which are not considered to be a part of mainstream medical care."<sup>15</sup>

Several researchers and institutions have suggested ways of categorizing CAM users. Some classify according to the nature of the treatment,<sup>14</sup> others classify from the general ac-

ceptance of the treatment<sup>15</sup> or from the provider giving the treatment,<sup>12</sup> and others again from the commitment of use.<sup>16</sup>

Harris and Rees<sup>17</sup> suggest three categories of CAM use: visiting a practitioner, use of OTC products, and a combination of both. Among the studies included in their review, none supplied information on all of the three categories. Implementation of these three categories is claimed to improve comparability between studies. A subsequent study of CAM use among patients with cancer in Wales with the same first author adds “use of CAM techniques” to the previously suggested categories without a further discussion of a comprehensive model.<sup>18</sup>

The National Center for Complementary and Alternative Medicine (NCCAM) in the United States<sup>14</sup> classifies CAM practices into four domains: mind–body medicine, biologically based practices, manipulative and body-based practices, and energy medicine. The advantage of the NCCAM model is that a reader will clearly understand which groups of therapies are most commonly used. The major limitation is that the model does not attempt to classify users with regard to overall exposure to CAM treatments. Adding the number of treatments used will not necessarily give a meaningful description of the patient’s total exposure to CAM.

The British House of Lords<sup>15</sup> classifies CAM into three groups: *Group 1: professionally organized alternative therapies*: acupuncture, chiropractic, herbal, homeopathy, osteopathy. *Group 2: complementary therapies*: Alexander technique, aromatherapy, Bach and other flower remedies, body work therapies, including massage—counseling stress therapy, hypnotherapy, meditation, reflexology, shiatsu, healing, Maharishi Ayurvedic medicine, nutritional medicine, and yoga. *Group 3: alternative disciplines*. *3a*: long-established and traditional systems of health care: anthroposophic medicine, Ayurvedic medicine, Chinese herbal medicine, Eastern medicine, naturopathy, Traditional Chinese Medicine. *3b*: *Other alternative disciplines*: crystal therapy, dowsing, iridology, kinesiography, radionics. The Select Committee gives this explanation for the three groups: Group 1 includes the most organized professions; Group 2 contains those therapies that most clearly complement conventional medicine, while Group 3 contains therapies that cannot be supported unless convincing research evidence can be produced.

The Ontario Cancer Institute’s Guide to Alternative Therapies<sup>19</sup> suggests classification schemes based on the nature of the CAM intervention and not on the patient using them. Other studies have used questionnaires that include varying CAM treatment modalities without defining overall exposure to CAM in any specific manner.<sup>7,20</sup>

Shmueli and Shuval<sup>12</sup> suggest that the relationship between conventional and complementary medicine should be taken into account when classifying a patient as a CAM user. They examine three aspects of the relationship: (1) whether only CAM or both conventional and CAM therapies are used for the same problem; (2) whether or not the CAM provider is a medical doctor, and (3) whether or not the referral to the CAM practitioner was made by the attending physician. In their study, they focus on CAM as provided by a CAM practitioner and do not include as “users” persons who used herbs or other products as self-medication without consultation with any practitioner.

Balneaves et al.<sup>16</sup> suggest taking into account the patient’s commitment to CAM use based on (1) the number of thera-

pies used, (2) the frequency of use, (3) the effort, and (4) the cost associated with use. They also report prevalence of use in three different categories based on a liberal, a conservative, and a very conservative definition of a CAM user. A *liberal definition* includes use of alternative medical systems, vitamins and mineral supplements, herbal/plant products, pharmacological/biological supplements, dietary therapies/changes, physical/movement therapies, energy therapies, psychologic/expressive therapies, spiritual therapies, and miscellaneous therapies. The *conservative definition* excludes complementary therapies that are available within the Canadian health care system or are considered a lifestyle choice. The *most conservative definition* includes only those therapies that are part of a large alternative health care system with a paradigm distinct from allopathic medicine such as homeopathy, etc.

What still seems to be missing internationally is a simple model that can classify an individual’s total exposure level to CAM, and at the same time gives room for cultural differences, making studies comparable across cultures. The aim of this study is therefore to present a six-level model for classifying patients’ reported exposure to CAM.

## Methods

### Constructing the model

From a CAM practitioner’s point of view, many of the existing classification systems seem illogical. The individual’s total exposure to CAM treatment(s) has rarely been addressed, and activities that also would be recommended within conventional medicine can be found included in the CAM use definition.

As a start, we distinguish between patients who have consulted a CAM practitioner (two levels of exposure) from patients who only have practiced self-treatment. This identified levels 1–3 of the model. Since several researchers classify activities as diet, exercise, and prayer as CAM, the model needed to accommodate these activities to be comparable to already published studies. Level 4 (diet) and level 5 (exercise) were therefore added to the model. The model with these five levels was presented at several research conferences in Norway, England, and in the United States and was also discussed with CAM researchers and practitioners as well as medical doctors. Arguments for including prayer in the model and leaving it out were put forward and discussed. Through these discussions, we realized that many researchers consider both prayer and healing as one common spiritual CAM category. From our point of view, these are distinctly different activities. To allow the separation of these two, we added CAM level 6 (prayer) to the model.

### Testing the model

To test the usefulness of the proposed model, we applied it to a recent Norwegian study on CAM use among cancer survivors (unpublished). Data on prayer were not collected in that study, and it is therefore only possible to demonstrate the first five levels of the model. The patients were all long-term survivors of cancer despite an expected 5-year survival less than 60% at the time of diagnosis. Patient information was extracted from the Norwegian Cancer Registry. A 40-item, 4-page multiple-choice postal questionnaire on use of

- CAM 6:** All CAM use including prayer
- CAM 5:** Use of a CAM provider, OTC-products, CAM techniques, special diets or exercise
- CAM 4:** Use of a CAM provider, OTC-products, CAM techniques or special diets
- CAM 3:** Use of CAM provider, OTC-products or CAM techniques
- CAM 2:** Seen a CAM practitioner at least once
- CAM 1:** Seen a CAM practitioner at least 4 times

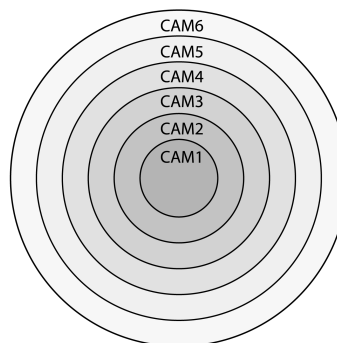


FIG. 1. Accumulative model of complementary and alternative medicine (CAM) level 1–6. OTC, over-the-counter.

CAM was filled in and returned by 400 of 735 included patients (response rate 54%) who received the questionnaire, 56% of the patients were women. Mean patient age was 68, ranging from 32 to 99. Mean time from diagnosis was 10.6 years, ranging from 7 to 17 years. The questionnaire included questions about use of CAM providers, use of dietary supplements, practice of self-support, change in diet, and physical activity. It also included sociodemographic variables such as age, educational level, place of residence, and population size of place of residence.

The model was also tested by applying it to recent publications on CAM use among patients with breast cancer. Publications were selected using the MEDLINE® database, with the following search terms: “Breast cancer” in title AND “Complementary Ther\*” as a MeSH term. This search yielded 121 published studies. We chose the 10 most recent studies with at least 100 patients that describe prevalence of

CAM use after the breast cancer diagnosis was established. Each publication was carefully scrutinized with the purpose of determining at which level CAM use was reported.

**Results**

*Model*

A six-level model describing extent of exposure to CAM use in patients was developed. Six cutoff points were identified that would represent widely accepted levels of exposure to CAM. The model is shown in a generic form in Figure 1.

**CAM level 6.** When classifying individuals as level 6 CAM users, all reported CAM use is included. Use can include visit(s) to a CAM provider, dietary supplements, self-help CAM techniques, dietary changes, exercise, prayer, or a com-

TABLE 1. SPECIFIC COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM) MODALITIES INCLUDED AT EVERY CAM USE LEVEL IN THE NORWEGIAN STUDY OF CAM USE IN CANCER SURVIVORS

<i>CAM user type</i>	<i>Measurement in Norwegian study</i>
CAM level 6	No data collected
CAM level 5	Persons with at least one treatment encounter in one or more of the following areas: acupuncture, homeopathy, reflexology, healing, natural therapy, massage/aromatherapy, stay at alternative cancer clinic, other kinds of treatment given outside the national health care system, individually adapted herbal cure subscribed by a vitamin and mineral therapist and in addition individuals who have used a self-defined cure made of herbs and vitamin supplements, other supplements and/or participated in self-support groups, done relaxation exercise on their own, done meditation regularly, done positive visualization or partaken in other forms of self-support or changed their diet radically or totally or indicated in the questionnaire that “Physical activity is important to me.”
CAM level 4	All CAM users defined at level 5 except individuals who reported no other CAM use than “Physical activity is important to me.”
CAM level 3	All CAM users defined at level 4 except individuals who reported no other CAM use than radical changes in their diet.
CAM level 2	Persons with at least one treatment encounter in one or more of the following areas: acupuncture, homeopathy, reflexology, healing, natural therapy, massage/aromatherapy, stay at alternative cancer clinic, other kinds of treatment given outside the national health care system, individually adapted herbal cure prescribed by a vitamin and mineral therapist.
CAM level 1	Persons with at least four treatment encounters in one or more of the areas described at level 2.

bination of all. This level has been used when defining CAM users in previous studies.<sup>7-10,16</sup>

**CAM level 5.** Classifying individuals as level 5 CAM users excludes those who only have used prayer as a CAM "treatment." This level otherwise includes all the other possible CAM modalities identified at level 6.

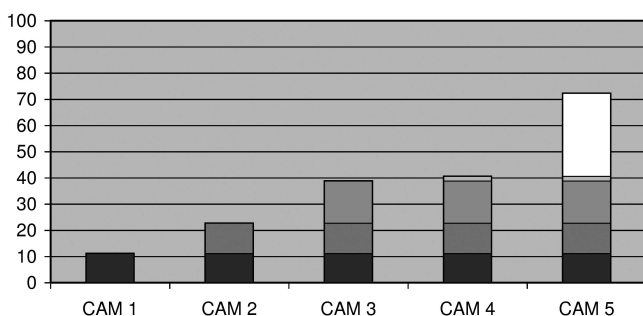
**CAM level 4.** Classifying individuals as level 4 CAM users excludes those who only have used exercise or prayer as a CAM "treatment," but retains those with dietary changes, users of OTC products, self-help CAM techniques, and users who have seen a CAM practitioner. This level has been used when defining CAM users in previous studies<sup>5,21-24</sup>

**CAM level 3.** Classifying individuals as level 3 CAM users limits CAM users to those who have used OTC products or self-help CAM techniques that do not require a personal encounter, as well as all users who have seen a CAM practitioner. This level has been used when defining CAM users in previous studies.<sup>25,26</sup> Yoga, meditation, visualization, *qi gong*, and *t'ai chi* are examples of techniques included in this category.

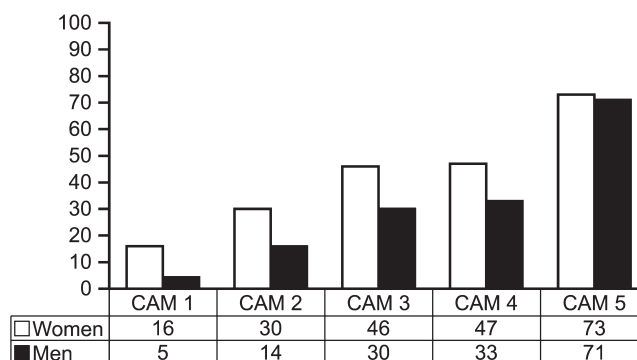
**CAM level 2.** Classifying individuals as level 2 CAM users limits CAM users to only those who have visited a CAM practitioner one or more times. Level 2 CAM use is similar to Harris' "CAM use involving a personal encounter with a CAM practitioner"<sup>17</sup> and has also been used when defining CAM users in previous studies.<sup>11,12,23,24</sup>

**CAM level 1.** Finally, classifying individuals as level 1 CAM users requires that the person has seen a CAM practitioner at least four times. Frequent use is suggested as a marker for commitment in use.<sup>16</sup>

All CAM level 1 users are included in levels 2-6, all CAM level 2 users are included in levels 3-6, all CAM level 3 users are included in levels 4-6, all CAM level 4 users are included in levels 5-6 and finally, all CAM level 5 users are included in CAM level 6. Identification of users of the CAM treatment added from levels 1 to 2 can be achieved by subtracting CAM level 1 users from CAM level 2 users. The same approach can be applied if identification of users of added treatment at any level needs to be isolated.



**FIG. 2.** Self-reported use of complementary and alternative medicine (CAM) dependent on level of CAM use.



**FIG. 3.** Self-reported complementary and alternative medicine (CAM) use among men and women dependent on level of use.

The presented model does not specify beforehand which specific treatment modalities to include when establishing each level. This is deliberately done to accommodate cultural differences with regard to what treatments are considered as CAM in each specific environment. Researchers reporting CAM use using this model should, however, specify which practitioners, supplements, techniques, diet programs, physical activity programs, and prayer activity programs they include from their own culture/setting when defining a level.

#### Variation of Self-Reported CAM Use According to the Six-Level Model

In the Norwegian study on CAM use among cancer survivors, data on prayer were not collected, and it is therefore only possible to demonstrate the first five levels of the model. By applying the model described above to the responses given by the patients in the Norwegian study (Table 1), we found large differences in reported prevalence of use dependent on which level of reporting that was chosen. The reported use of CAM varied from 11% at level 1 to 72% at level 5 (Fig. 2). Among women, the use of CAM varied between 15% and 76% while CAM use among men varied from 5% to 71% (Fig. 3). The gender differences in use of CAM are highly significant when reported at CAM level 1, where more than three times as many women than men reported CAM use ( $p = 0.001$ ). At level 5, on the other hand, we did not find statistically significant differences in CAM use between men and women. The ratio here was close to 1 ( $p = 0.614$ ). In this particular study, the question concerning physical activity was not as stringent as suggested in the model. This might give a higher number of CAM 5 users than what we would have seen if the question was formulated more like that suggested in the model.

Among the recently published studies of CAM use among patients with breast cancer, one study reports CAM use at level 2,<sup>27</sup> two studies report at level 3,<sup>28,29</sup> six studies report at level 4,<sup>30-35</sup> and the last study reports at level 5.<sup>2</sup> The level 2 study reports 20% use,<sup>27</sup> the level 3 studies report 33%<sup>28</sup> and 62%<sup>29</sup> use (weighted mean 56%), the level 4 studies vary from 20%<sup>30</sup> to 69%<sup>35</sup> use (weighted mean 47%), while the level 5 study reports 98%<sup>2</sup> use (Table 2, Fig. 4).

By applying our model to these studies, it was thus possible to partly account for the extremely wide variation in reported CAM use. Residual variation within each level will

TABLE 2. REPORTED USE OF COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM) AMONG PATIENTS WITH BREAST CANCER (BC) DEPENDENT ON LEVEL OF USE

Authors (year of publ.)	Sample (country)	Method	Type of treatments	Prevalence	Comment	CAM level
Gray et al. 2003 <sup>27</sup>	731 Canadian patients diagnosed with BC 23–36 months prior to contact about the study	Postal questionnaire	CAM service from chiropractors, naturopaths, homeopaths, massage therapists, acupuncturists, and practitioners of Chinese medicine.	20%	To help in dealing with their BC	2
Damkier al. 2007 <sup>28</sup>	498 Danish BC patients	Not mentioned	Vitamins and minerals, natural medicine and dietary supplements, acupuncture, dietary support, reflexology, massage, other treatment, healing, music therapy (T), biopathy, kinesiology, hypnosis, iris analysis, aromatherapy.	33%		3
Buettner 2006 <sup>29</sup>	2022 BC survivors diagnosed in 1998–2003	Postal questionnaire	Reflexology, spiritual healing, yoga, energy healing, acupuncture, massage, chiropractic, high-dose vitamins, herbs, homeopathy, other CAM T.	62%	Used during the previous 2 years After diagnosis	3
Yap et al. 2004 <sup>30</sup>	290 Canadian postmenopausal BC patients treated with tamoxifen after surgery	Self-administered questionnaire	15 categories of treatments: natural health practices, herbal T, dietary T, vitamins, minerals, from earth and sea, energy life force T, movement T, physical T, psychological T, to and from the body, oxygen therapies, drugs, immune boosters.	20%		4
Nagel et al. 2004 <sup>31</sup>	263 German BC patients 3 years postdiagnosis	Postal questionnaire	Vitamins (high dose), mistletoe, ozone therapy, selenium T, diets (cancer specific), thymus preparations, others.	36%	After diagnosis	4
Ahn et al. 2004 <sup>32</sup>	178 Korean BC patients undergoing chemotherapy	Personal question of use	Herbs, diets, mushrooms, and others.	37%	Use during chemotherapy period	4
Rakovitch 2005 <sup>33</sup>	251 BC patients	Self-administered survey	Macrobiotic diet, vitamin T, minerals, low-fat/vegetarian diets, soy products, homeopathy, herbal medicine, shark cartilage, naturopathy, meditation/relaxation, guided imagery/visualization, hypnosis, biofeedback, faith and spiritual healing, massage therapy, acupuncture, reflexology, yoga, <i>t'ai chi</i> .	43%	Use of CAM as part of treatment	4
Henderson et al. 2004 <sup>34</sup>	588 Post BC patients	Telephone survey	Relaxation/meditation, herbs, spiritual healing, vitamins/nutrient T, massage/manipulation, imagery, chiropractor, naturopathy, support group, lifestyle diet, immune T, acupuncture, energy healing, biofeedback, hypnosis.	66%	Past 12 months	4
Matthews et al. 2007 <sup>35</sup>	115 BC survivors	Telephone interviews	Vitamins or supplement (ex low doses of common vitamins, minerals and multivitamins), herbs or medical herbal teas, relaxation techniques, natural	69%	Current CAM use	4

(continued)

TABLE 2. REPORTED USE OF COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM) AMONG PATIENTS WITH BREAST CANCER (BC) DEPENDENT ON LEVEL OF USE (CONT'D)

<i>AAuthors (year of publ.)</i>	<i>Sample (country)</i>	<i>Method</i>	<i>Type of treatments</i>	<i>Prevalence</i>	<i>Comment</i>	<i>CAM level</i>
Cui et al. 2004 <sup>2</sup>	Newly diagnosed women with BC in Shanghai, China	Face-to-face interviews	anticancer remedies, diet changes (outside standard biomedical guidelines), body work. Traditional Chinese Medicine, supplements, physical exercises, and support groups.	98%	Continually using at least one form of CAM therapy for at least 1 month after diagnosis	5

T, therapy/therapies.



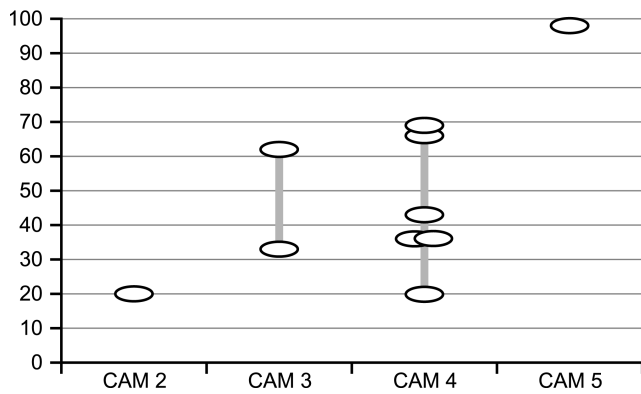


FIG. 4. Complementary and alternative medicine (CAM) use among patients with breast cancer depending on level of use.

of course be expected, given that the studies come from several continents and in addition differ somewhat with regard to the number of specific treatments explored.

### Discussion

Use of a model will always imply limitations. Different countries and cultures have different traditions with regard to complementary and/or alternative medicine. The suggested model can generally accommodate these local variations because the locally used modalities themselves are fairly easy to place in the indicated generic categories of the model.

One major potential limitation is how to relate to traditional folk medicine. Several indigenous populations are reluctant to classify their traditional treatment as CAM. However, in the development of this model we have assumed traditional folk medicine to be a part of broadly defined CAM use, although the World Health Organization distinguishes between the two.<sup>13</sup>

There will, however, be a few treatment modalities that do not readily fit any category, and also some modalities that could possibly fit into more than one category. Treatment support by telephone/mail and the self-practice of CAM techniques with a personal encounter are two examples that might fit into more than one category. We suggest these to be placed in the category that includes a treatment provider (CAM 1–2).

Treatments that are performed by a treatment provider without personal contact, such as distant healing, can also be difficult to classify. In some cases the healer can provide distant healing daily over a long period of time, even though the contact between the patient and the therapist is limited to one telephone call. We suggest this to be classified as treatment including a personal encounter (CAM 1–2) and that the number of treatments is counted as the number of treatments the treatment provider has carried out. Self-treatment based on information in books, the Internet, and friends should be placed in the category not including a treatment provider (CAM 3–6).

The borderline between religious healing and prayer can be vague. Many researchers therefore combine the two in the

same question when asking about CAM use. We suggest that religious healing is classified as CAM level 1–2 (seeing a provider) when the provider of this healing is considered a person with special “gifts” and at CAM level 6 when prayer is conducted by the user him/herself or by a priest /church community with no special “gifts.”

Some patients increase the amount of healthy food in their diet and exercise more as a result of their current disease without changing to a totally new recommended dietary system. We do not recommend these changes to be considered CAM use.

Other challenges to consider are within what timeframe the use is reported. Some studies report “ever use,” others “since diagnosis,” “current use,” “used within the last 3 or 12 months,” or within the last 14 days. One study reports “use that was helpful to their recovery.”

We recommend reporting CAM use “Since diagnosis” when a definite diagnosis has been established, and within the last year in other circumstances to optimize the comparability between studies.

### Implications of the Model

CAM level 1 is a category that is not commonly seen in published studies to date. We think it is important to distinguish a comprehensive course of CAM treatment involving personal encounters from just a casual visit or solely self-administered CAM use. It is important to identify this group because they are the ones choosing an alternative or complementary comprehensive treatment regimen to treat their condition over a potentially important period of time. The patients seeing a provider from one to three times probably represent patients trying a CAM modality without completing a comprehensive series of treatments. The cutoff point of four or more visits is of course partly arbitrary in nature, but does represent a longer treatment trajectory. This cutoff point has also been used in at least one study that has attempted to distinguish at this dimension.<sup>36</sup>

Using CAM level 2 as an identification of CAM users follows international recommendations to delineate CAM users going to CAM providers from a broader definition of CAM use, where use of OTC products could be the only CAM use reported.<sup>17</sup> The individuals in this category who do not simultaneously fulfill the CAM level 1 criterion might represent those individuals only trying out alternative therapy but not deciding to continue with a full treatment plan. We think the CAM level 3 definition of a CAM user represents what people broadly define as a possible CAM user. CAM levels 4 and 5 can be useful if the focus of a study is to include individuals using dietary change and exercise involvement in the definition of a CAM user. These individuals are thus distinguished from individuals with “normal” attention to diet and “routine” self-care.<sup>4</sup> These are elements that have been advocated in the conventional health care system for a long time and are considered “lifestyle-oriented” therapies. As seen in the Norwegian study, the proportion of “CAM users” increases substantially when exercise (CAM level 5) is considered CAM. Interestingly, most patients who make major changes in their diet have already utilized CAM at levels 1–3. Identifying CAM users at CAM level 6 is useful in order to be able to compare studies that have included prayer as CAM treatment.<sup>7,16</sup>

To report CAM use on various levels as suggested in the model might serve several purposes. A medical doctor needs to be informed about the number of patients receiving CAM treatment to consider whether he or she needs to make an effort to ensure that CAM therapy does not interact negatively with ongoing conventional treatment. We believe that this will be in the interest of the patient.<sup>20</sup> Use of only OTC products and/or CAM techniques without a provider (the difference between CAM 2 and CAM 3 level use) might require extra awareness from the doctor since there is no CAM provider who is monitoring the treatment. If many patients are CAM users at levels 1–2, the medical doctor and alternative treatment practitioner can ideally enter into a dialogue and, if possible, coordinate and/or integrate their treatment efforts.

Since health authorities have an overall regulatory responsibility, they will need information on the proportion of users who are CAM 1–2 users if they consider integrating provision of CAM treatment with conventional care.

For researchers, the suggested model is useful for a more valid and reliable comparison of prevalence of CAM use between populations and studies. The model can accommodate cultural differences concerning what treatments are considered CAM at different levels. It also presents a meaningful exposure variable in determining effectiveness of CAM use.

We realize that this model has potential for extension and that further discussions around a model for classifying patients as CAM users is required.

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## Paper II



## Do Cancer Patients with a Poor Prognosis Use Complementary and Alternative Medicine More Often than Others?

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 and Arne J. Norheim, M.D., Ph.D.

### Abstract

**Introduction:** One reason for patients with cancer to use complementary and alternative medicine (CAM) is that their cancer cannot be cured by conventional therapy. The aim of the present study is to explore whether use of CAM is associated with survival prognosis in long-term survivors of cancer.

**Materials and methods:** Cancer patients who were alive 5 years or more after diagnosis were chosen to participate in the study, one group with less than 20% and another group with 40%–60% expected five-year survival at the time of diagnosis. A total of 735 patients received a four-page postal questionnaire about CAM use; 397 questionnaires were returned (response rate = 54%).

**Results:** The results are reported at five levels of CAM use. The poor prognosis group reported CAM use more often than the better prognosis group; however, only significantly higher at CAM level 2 (use of a CAM provider) ( $p = 0.021$ ) and in use of self-support/CAM techniques ( $p < 0.001$ ). Use of over-the-counter (OTC) dietary supplements and use of diet as treatment were not significantly different between the groups.

**Discussion:** This study supports the suggestion that use of a CAM therapist and use of self-support/CAM techniques might be associated with less hope of cure given by the physician.

### Introduction

Although self-reported use of complementary and alternative medicine (CAM) among cancer patients is increasing,<sup>1,2</sup> studies report substantial differences in level of use, ranging from 7%<sup>3</sup> to 95%.<sup>4</sup> This wide range in self-reported use could be due to differences in the definition of a CAM user<sup>5,6</sup> and/or differences in timeframe of CAM use.<sup>7</sup>

Younger, highly educated women are the most frequent users of CAM among cancer patients.<sup>8–10</sup> Frequent use is also reported among patients with symptoms related to their cancer, patients receiving only palliative treatment, patients with metastatic disease, and patients diagnosed with cancer more than 3 months previously.<sup>11</sup>

Other researchers report that use of or interest in CAM among cancer patients is predicted by younger age, progressive cancer, active coping behavior,<sup>12</sup> and time after diagnosis.<sup>7</sup> Likelihood of death occurring from the cancer is both associated<sup>13,14</sup> and not associated<sup>15</sup> with CAM use.

The use of CAM among cancer survivors with a poor survival prognosis at diagnosis is still insufficiently studied, and

a comparison of CAM use among survivors who had a poor prognosis compared to survivors with a better prognosis at the time of diagnosis has, to our knowledge, not been performed. The aim of the present study was therefore to explore whether reported use of CAM in cancer survivors is associated with diagnostic survival prognosis.

### Materials and Methods

#### Materials

Cancer patients were extracted from the Norwegian Cancer Registry. All patients had been diagnosed with cancer between 1 January 1986 and 31 December 1997 and were older than 15 years of age at the time of first diagnosis, and more than 20 years old at the time of the study. Two groups with different survival prognosis at the time of diagnosis according to a previous classification model<sup>16</sup> were selected.

**Poor prognosis group.** All 286 patients with less than 20% expected 5-year survival at time of diagnosis were included (31.4% with colon cancer, 10.2% with breast cancer, 7.4% with

tracheal cancer). Of the patients in this group, 64.9% were women and the mean age was 65.3 years. Mean time from diagnosis was 10.1 years.

**Better prognosis group.** A random sample of 599 of 2,716 patients with 40%–60% expected 5-year survival at the time of diagnosis were included (35.2% with rectal cancer, 17.6% with stomach cancer, 10.9% with cervical cancer). Of the patients in this group, 51.9% were women and the mean age was 69.1 years. Mean time from diagnosis was 10.8 years.

In September 2003 a request was sent to the 144 hospital departments where the patients were diagnosed. The departments were asked to confirm the diagnosis and forward a numerically coded questionnaire to the patient; 108 departments (response rate 75%) agreed.

Questionnaires were forwarded to 735 patients. 400 questionnaires were returned directly to the researchers, 82 of them after a reminder. Three questionnaires were excluded from the study because of death, dementia, or absence of the identification number. The material thus consists of 397 cancer patients; 114 in the poor prognosis group and 283 in the better prognosis group. This is a response rate of 54.4% to the questionnaires actually sent out by the hospital departments (Fig. 1). Patients in the better prognosis group were significantly older than those in the poor prognosis group ( $p = 0.024$ ), and

the better prognosis group also included fewer women than the poor prognosis group ( $p = 0.019$ ) (Table 1).

#### Methods

The information from the patients was collected through a 40-item 4-page multiple-choice postal questionnaire developed on the basis of the self-developed questionnaire used in a previous Norwegian study.<sup>17</sup> The validation process included discussions and feedback from more than five Norwegian CAM providers and pilot testing on more than five cancer patients who had used CAM treatment in connection with their cancer. The questionnaire included questions about use of CAM providers, use of dietary supplements, practice of self-support, and change in diet and physical activity. It also included sociodemographic variables like age, educational level, place of residence, and population size of place of residence. We have in a previous report presented a cumulative 6-level model for classifying cancer patients' use of CAM, the NAFKAM model<sup>18</sup>:

- CAM 6: All CAM use including prayer
- CAM 5: Use of a CAM provider or OTC-products or CAM techniques such as yoga, meditation etc. or special diets or exercise

All cancer patients who had survived at least 5 years after diagnosis with less than 20 % expected five-year survival at the time of diagnosis.	All cancer patients who had survived at least 5 years after diagnosis with 40 - 60 % expected five-year survival at the time of diagnosis.
286 patients found in the Cancer Registry that met the inclusion criteria. All patients were included in the study	2716 patients found in the Cancer Registry that met the inclusion criteria. A random sample of 599 patients was included in the study.
<b>September 2003</b>	
Questionnaire and invitation letter was sent from the Cancer Registry of Norway to 144 different hospital departments responsible for the patients included in the study.	
<b>October 2003 through May 2004</b>	
108 hospital departments (response rate 75 %) agreed to forward the questionnaire to 735 patients.	
<b>October 2003 through March 2005</b>	
400 completed questionnaires were returned to the researchers at the University of Tromsø after the main sending and a reminder. Response rate 54.4 %	
Three questionnaires were excluded from the study due to missing ID-number or not filled in by the patient him/herself	
114 cancer patients with less than 20 % expected five- year survival	283 cancer patients with 40 - 60 % expected five-year survival.

FIG. 1. The process of selecting the patients. ID, identification.



TABLE 1. SOCIODEMOGRAPHIC CHARACTERISTICS OF THE STUDY PARTICIPANTS

	Poor expected survival % (n = 114)	Better expected survival % (n = 283)	p-value
Sex			
Men	35.1 (40)	48.1 (136)	
Women	64.9 (74)	51.9 (147)	0.019
Age			
31–50 years	14.9 (17)	5.7 (16)	
51–70 years	47.8 (55)	45.7 (129)	
71 years or more	36.5 (42)	48.9 (138)	0.004
Years of education			
Less than 8 years	23.9 (27)	24.9 (70)	
8–9 years	9.7 (11)	17.4 (49)	
10–12 years	39.8 (45)	40.2 (113)	
13–16 years	17.7 (20)	10.3 (29)	
More than 16 years	8.8 (10)	7.1 (20)	0.218
Mean time from diagnosis (years)	10.1	10.8	0.113

- CAM 4: Use of a CAM provider or OTC-products or CAM techniques or special diets
- CAM 3: Use of CAM provider or OTC-products or CAM techniques
- CAM 2: Seen a CAM provider at least once
- CAM 1: Seen a CAM provider at least 4 times.

The exact CAM modalities included in this study at every level have been presented elsewhere.<sup>18</sup> In this article the use of CAM will be reported only at the first five levels of the NAFKAM model because we did not collect data on prayer.

*Statistical analysis*

A descriptive presentation of the data is given. Comparison of CAM use dependent on survival prognosis was done within CAM level 1–5 using the Pearson chi-square test. The two prognosis groups differed with regard to mean age and proportion of males. Age- and sex-adjusted analyses were done using logistic regression with use/non-use as the outcome binary variable. All analyses were done with the use of SPSS 11.0 for Windows (2003). The Data inspectorate has

been notified about the study and The Regional Ethics Committee has recommended it.

**Results**

In this section use of a CAM provider and CAM use without a CAM provider are presented separately. Subsequently CAM use is presented following the five levels of the NAFKAM model listed above.

*Use of a CAM provider*

More than 10% of the survivors using a CAM provider (13.3% in the poor prognosis group, 11.1% in the better prognosis group) were already in CAM treatment at the time of cancer diagnosis. One third of the survivors in the poor prognosis group had seen a CAM provider at least once after they were diagnosed with cancer. This is almost twice as many as in the better prognosis group (33.3% versus 18.4%,  $p = 0.021$ ) (Table 2). While 77.8% ( $n = 21$ ) of those consulting a CAM provider in the poor prognosis group had received more than three consultations, 58.8% ( $n = 30$ ) in the better prognosis group reported the same ( $p = 0.094$ ).

TABLE 2. SELF-REPORTED USE OF COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM) AT FIVE DIFFERENT LEVELS AMONG LONG-TERM CANCER SURVIVORS IN TWO DIFFERENT PROGNOSIS GROUPS

	n = 397	Poor prognosis n = 114	Better prognosis n = 283	p-value	Age and sex adjusted p-value
Use of CAM at level 1	11.1%	17.5%	8.50%	0.009	0.069
Use of CAM at level 2	22.7%	33.3%	18.4%	0.001	0.021
Use of CAM at level 3	38.8%	48.2%	35.0%	0.014	0.087
Use of CAM at level 4	40.6%	48.2%	37.5%	0.048	0.213
Use of CAM at level 5	72.3%	71.1%	72.8%	0.726	0.521
Use of OTC products	14.9%	18.4%	13.4%	0.206	0.362
Use of self-support/CAM techniques	19.9%	33.3%	14.5%	<0.001	<0.001
Use of diet as treatment	6.7%	7.1%	6.5%	0.841	0.878

OTC, over-the-counter.

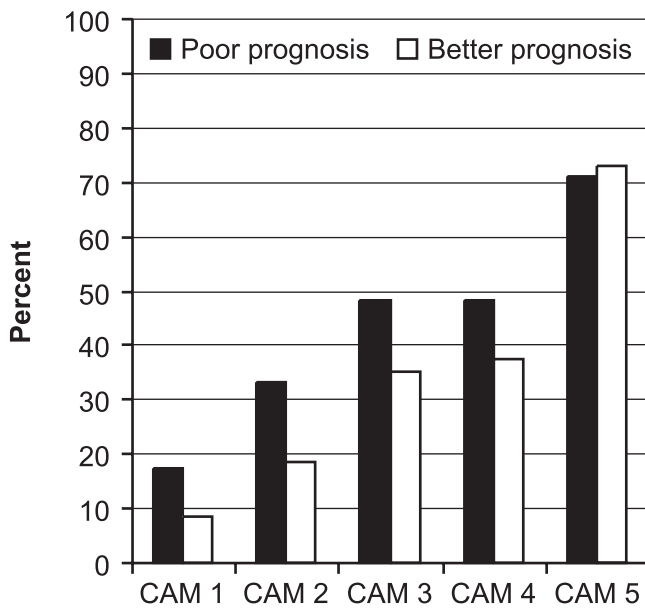


FIG. 2. Use of complementary and alternative medicine (CAM) among long-term cancer survivors.

About half of all the survivors who had seen a provider had seen him/her within the first 6 months after diagnosis. Three out of four who had seen a provider claimed a positive or very positive effect of the treatment. These results were similar in both groups.

Whereas 66.7% of the poor prognosis group had seen the CAM provider alongside the conventional treatment, 53.1% of the better prognosis group had done the same ( $p = 0.021$ , adjusted). Only four survivors, two in each group, reported use of CAM therapy instead of conventional treatment.

#### CAM use without a provider

Use of dietary supplements above RDA doses was reported by 18.4% ( $n = 21$ ) in the poor prognosis group and 13.4% ( $n = 38$ ) in the better prognosis group. These differences were not statistically significant.

Reported use of CAM techniques/self-support was 33.3% ( $n = 38$ ) in the poor prognosis group and 14.5% ( $n = 41$ ) in the better prognosis group ( $p \leq 0.001$ ). This difference was only present in the survivors who also saw a CAM provider.

Approximately 7% of the patients in the two groups reported use of diet as treatment (made big differences or completely changed their diet).

#### Use of CAM according to the NAFKAM cumulative model

The use of CAM therapy in our study can be classified according to levels 1–5 in the NAFKAM model. Self-reported use of CAM in the *total patient group* increased from 11.1% when reported at CAM level 1 to 22.7% at CAM level 2, 38.8% at CAM level 3, 40.6% at CAM level 4, and 72.3% at CAM level 5 (Fig. 2, Table 2).

At levels 1–4, we found a statistically significantly higher use in the poor prognosis group compared to the better prognosis group, a difference varying from 9–14.9 percentage points. When adjusting for age and sex, we found

that the difference between the two prognosis groups maintained statistically significant at CAM level 2 ( $p = 0.021$ ) (Table 2).

#### Discussion

This study indicates that cancer survivors who had a poor prognosis tended to visit a CAM provider to a higher degree than survivors with a better prognosis at the time of diagnosis. The poor prognosis group also seems to be more engaged in use of self-support/CAM techniques.

#### Bias considerations

**Election bias.** The Cancer Registry of Norway includes all cancer patients diagnosed in Norway since 1952. On the one hand, the selected cancer patients for this study represent our target group. The response rate (54.4%), on the other hand, will influence the generalizability of our findings.

The response rate is, however, probably somewhat underestimated. Some of the participating hospitals did not confirm dispatching all questionnaires to previous patients. In addition the actual number of questionnaires reaching survivors could have been lower due to relocation or death of the patient without the hospital's informing the researchers. The study population could therefore be lower than 735, resulting in a possible higher response rate.

The responders did not differ from non-responders with regard to age and sex. They could, however, have a higher use of CAM than non-responders. This is suspected because the reported use of CAM is higher at CAM levels 1, 2, and 4 in the responders that answered the questionnaire *before* the reminder compared to those responding after the reminder. This would, however, not influence between-group comparisons.

**Information bias.** The present study has two main sources of potential information bias: (1) failure of the questionnaire to include items that would be crucial in determining what CAM treatment the patient actually has used and (2) failure of describing the treatments in a manner that makes the patient response valid.

The questionnaire was developed in cooperation with experienced CAM providers and cancer survivors with CAM treatment experience. We are therefore confident that no major treatment option was left out. Whether the patients actually described in a correct manner what they had done is difficult to assess. Because of ethical considerations (full anonymity was required) it was not deemed suitable to perform qualitative interviews to validate the responses. We did, however, administer the questionnaire twice (2 weeks apart) to five cancer survivors outside the study who have used CAM treatments in connection with their cancer, and we then performed an interview with each of them. No major discrepancies were found between the two questionnaires and the interview descriptions of CAM use by these control responders.

The fact that the questionnaire was returned anonymously to independent researchers at the university and not to the patient's doctor probably ensures high validity of the responses regarding use of CAM. Recalling treatment details up to 17 years after diagnosis in mainly elderly participants

might, on the other hand, reduce accuracy in the reporting. Again, this would apply to both prognosis groups.

**Other studies.** Our result of 40.6% CAM level 4 use is similar to a previous Norwegian study reporting at level 4. This study reports 45% use among cancer patients within the first 5 years after diagnosis.<sup>7</sup>

A study in the South Thames NHS region in England among breast cancer patients reported 30.7% use of CAM among patients who have survived more than 4 years since diagnosis.<sup>19</sup> Their definition of CAM is similar to our CAM level 2, and their results are close to our reported level 2 CAM use according to the presented model.

Some 39.4% of breast cancer patients diagnosed in 1994 or 1995 in an Ontario, Canada, report visiting at least one CAM provider (CAM level 2), and 66.7% of the respondents indicated using some form of CAM (provider or product, CAM level 4).<sup>20</sup> These numbers are higher than those in our study. The difference might be due to our inclusion of both sexes and the fact that the mean age in our study is 10 years higher. Both younger age and female gender are shown to indicate high use of CAM.

Our findings of a higher use of CAM providers among cancer survivors with a poor prognosis is in accordance with previous findings of more frequent use of CAM if patients have been given less hope of cure by their physicians.<sup>21,22</sup> Furthermore, our study supports the finding that CAM users are more likely to have nodal or distinct metastasis than non-CAM users,<sup>23</sup> as well as a greater fear of dying from their cancer than the non-users.<sup>13,14</sup>

## Conclusions

This study supports the suggestion that use of a CAM therapist and self-support/CAM techniques might be associated with a poor survival prognosis at the time of diagnosis. The variation both in total CAM use and the variation in CAM use between groups dependent on reported level of use according to the NAFKAM model, underlines the need to report CAM use on more than one level of use. We emphasize that the present data are based on cancer survivors only.

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## Disclosure Statement

No competing financial interests exist.

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# Paper III



RESEARCH ARTICLE

Open Access

# Any difference? Use of a CAM provider among cancer patients, coronary heart disease (CHD) patients and individuals with no cancer/CHD

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## Abstract

**Background:** Although use of complementary and alternative medicine (CAM) among cancer patients has been described previously, prevalence of use has not commonly been compared to other disease groups in a true population sample where CAM use or cancer is not the main focus. The aims of the present study are to (1) examine how CAM use in cancer patients differs from people with a previous CHD diagnosis and people with no cancer or CHD diagnosis in an unselected general population and (2), investigate the use of a CAM provider among individuals with a previous cancer diagnosis.

**Methods:** A total of 8040 men and women aged 29 to 87 in the city of Tromsø, Norway filled in a questionnaire developed specifically for the Tromsø V study with questions on life style and health issues. Visits to a CAM provider within the last 12 months and information on cancer, heart attack and angina pectoris (heart cramp) were among the questions. 1449 respondents were excluded from the analyses.

**Results:** Among the 6591 analysed respondents 331 had a prior cancer diagnosis, of whom 7.9% reported to have seen a CAM provider within the last 12 months. This did not differ significantly from neither the CHD group (6.4%,  $p = 0.402$ ) nor the no cancer/CHD group (9.5%,  $p = 0.325$ ).

**Conclusion:** According to this study, the proportion of cancer patients seeing a CAM provider was not statistically significantly different from patients with CHD or individuals without cancer or CHD.

## Background

Cancer patients' self-reported use of complementary and alternative medicine (CAM) is increasing, [1-3] although studies report substantial differences in the level of use, ranging from 7 [4] to 91% [5]. Younger, highly educated women are the most frequent users [6-8]. Frequent use is also reported among patients with symptoms and symptom progression related to their cancer [9-13].

CAM treatment is mostly offered outside the national health care service in Norway and paid out-of-pocket by the patients. Prior to 2004 only physicians and dentists could legally treat cancer patients [14]. The proportion of cancer patients reporting CAM use in Norway varies between 11.1 and 72% [15,16] depending on how CAM is defined [15]. When defined as "at least one visit to a

CAM provider during the previous 12 months" the variation narrows down to 16.1% [16] to 22.7% [15].

CAM use among cancer patients has rarely been reported in an unselected general population sample, and even more rarely been compared to use among other patient groups in this type of sample [17].

Coronary heart disease (CHD) and cancer constituted 58% of all deaths in Norway in 2009 [18], and are the two most common causes of death. In planning, administering and monitoring health care provisions, knowledge about the choices and health care-related behaviours made by these patient groups is important, particularly the choices and behaviours related to treatments outside the national health care service.

The magnitude of use of conventional health care in CHD patients is well known. Few studies have, however, examined CAM use in these patients, most of them in highly selected population subgroups. Substantial

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differences in the proportion of users ranging from 12%-85% [19-21] have been reported.

As with patients with other chronic diseases, CHD patients are likely to use CAM to manage their condition, increase their quality of life, and prevent recurrence of disease [22,23]. So far, there are no comparable data regarding use of CAM among Norwegian CHD patients.

This wide range of reported CAM use in both cancer and CHD patients may be due to several factors; differences in the definition of a CAM user [15,24,25], whether CAM is used for general health purposes or for illness-specific reasons [20,23], the time frame of reported use [26] and differing legislation [27] regulating CAM provisions and funding. The differences might also be due to lack of population-based data on CAM use in these two patient groups.

The aims of the present study are therefore to (1) examine how CAM use in cancer patients differs from people with a previous CHD diagnosis and people with no cancer or CHD diagnosis in an unselected general population and (2), investigate the use of a CAM provider among individuals with a previous cancer diagnosis.

## Methods

The Tromsø Study series (I-VI) are prospective studies in the municipality of Tromsø, Northern Norway. The design includes repeated population health surveys to which total birth cohorts and random samples are invited. This paper is based on data from the Tromsø V study conducted in 2002.

A total of 10353 men and women were invited to participate in this study. This included individuals participating in the extended fourth survey in 1994-1995 (Tromsø IV) [28]. In addition, all inhabitants who turned 30, 40, 45, 60 or 75 during 2001 were invited to participate. As 2313 did not attend, the study included 8040 subjects, 4565 women and 3475 men, aged between 29 and 87 (response rate 77.6%).

The Tromsø studies have been linked electronically to the Cancer Registry of Norway (CRN) enabling the identification of cancer patients by two methods; through self-reporting of cancer in the survey and through registration in the CRN. Registration of cancer has been mandatory by law since 1952, and the registry is therefore considered virtually complete.

A total of 1280 participants had not answered the question regarding visits to a CAM provider and were therefore excluded from the current analysis. Further, 169 persons were excluded due to the following two reasons: They had experienced both cancer *and* CHD, or they had reported having cancer without this being registered in the CRN (Figure 1). The analysis of visits to a CAM provider in cancer and CHD patients thus included 6591 respondents.

The letter of invitation contained a questionnaire developed specifically for the Tromsø study. Individuals who attended the survey by undergoing a health screening and answering the first questionnaire received subsequently a *second* questionnaire that they were asked to complete and return by mail.

The two questionnaires included questions on general state of health, diseases suffered by the respondent or their family, muscle pain and physical discomfort, food habits, alcohol consumption, smoking habits, physical activity in leisure time, level of education, use of medicine and use of health services including a CAM provider [29].

The question regarding visits to a CAM provider was not directly related to any specific disease condition. The questions concerning CAM and CHD were included in the first questionnaire completed before the health screening, while the question concerning cancer was placed in the second questionnaire returned by mail after the health screening.

A CAM user in this study is defined as a respondent who checked one or more visits on the question: *How many visits have you made during the past year to an alternative medical provider?* A "no CAM user" is a respondent who checked for *no visits*. This question was one item in a list including 12 other non-CAM health care providers (for example general practitioner (GP), psychologist, psychiatrist, emergency room physician, home nurse, physiotherapist, chiropractor, dentist etc.).

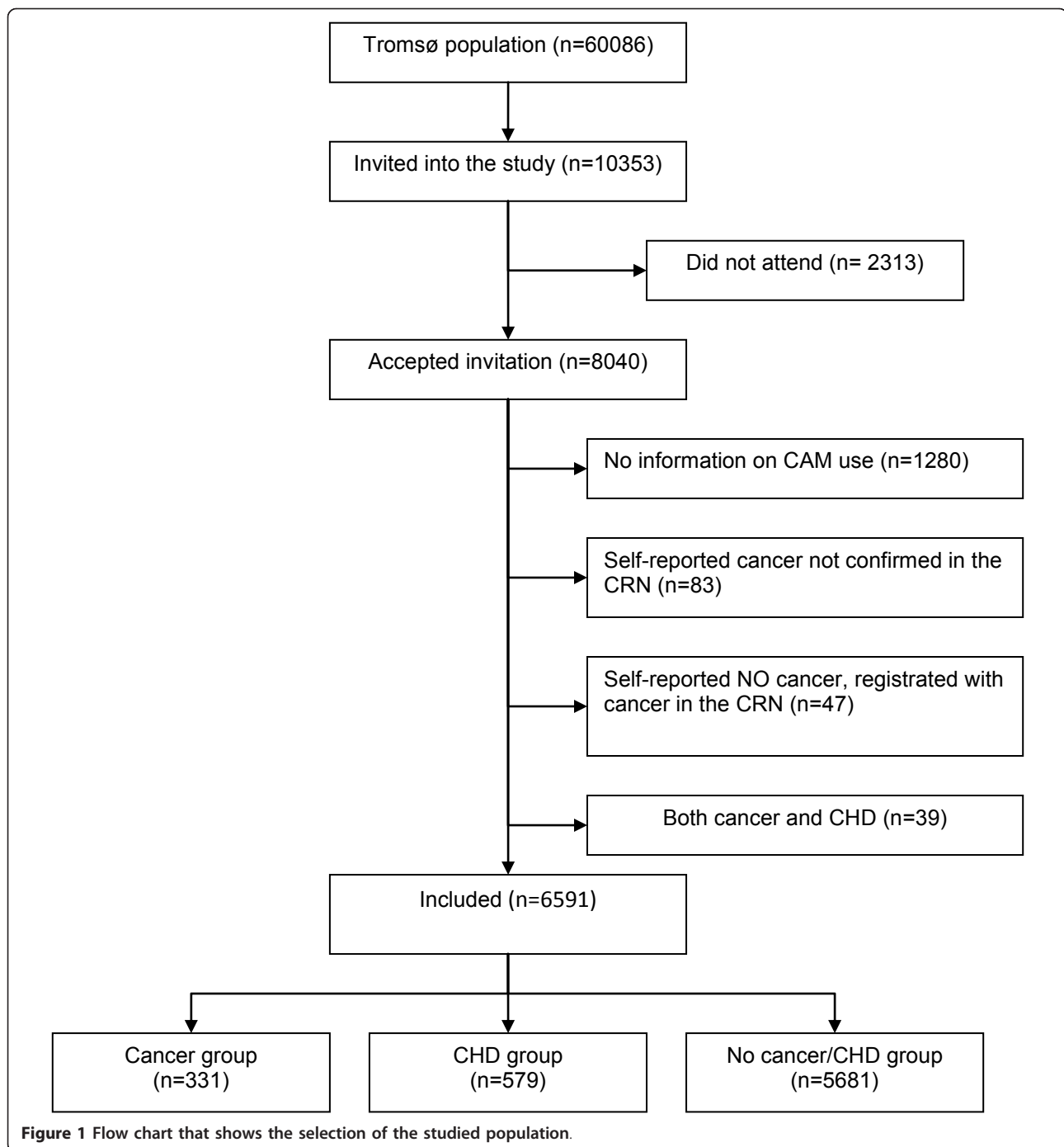
In Norway, an alternative medical provider is commonly understood by the public as a practitioner providing CAM both as alternative and complementary treatment. A CAM provider offers therapies that are not commonly offered within the public health care service and are paid out-of-pocket by the patients themselves.

CAM use was compared between three groups:

1. The cancer group (n = 331)
2. The CHD group (n = 579)
3. The no cancer/CHD group (n = 5681)

The cancer group consisted of informants who had checked *Yes* for: *Have you ever had, or do you have cancer?* and were registered with a cancer diagnosis in the CRN. Informants were also included in this group if they had left the question unanswered (due to deliberate choice or failing to return the second questionnaire) but were registered with a cancer diagnosis in the CRN. Informants in this group were also required to have checked *No* or have a missing value for both: *Do you have, or have you had a heart attack AND Do you have, or have you had angina pectoris (heart cramp)?* The members of this group are referred to as "cancer patients" even though the time of their clinical cancer





disease may have been several years ago and/or they considered themselves to be healed from their cancer.

The CHD group consisted of respondents who had checked *Yes* for: *Do you have, or have you had a heart attack OR Do you have, or have you had angina pectoris (heart cramp)?* and who were not included in the cancer group.

The no cancer/CHD group consisted of respondents who had checked *No* or had a missing value for: *Have*

*you ever had, or do you have cancer?*, and were *not* registered with cancer in the CRN nor were included in the CHD group.

The primary endpoint in this study was reported visits to a CAM provider over the previous 12 months in the cancer group compared to the CHD group and the no cancer/CHD group. The secondary endpoint was visits to a CAM provider over the previous 12 months within the cancer group.

With a statistical power of 80% and using an alpha of 0.05 we were able to report as statistically significant differences in reported use of approximately 6.5 percentage points between the two smallest groups.

The endpoints were analyzed using chi-square tests and logistic regression in SPSS Windows (version 17.0, SPSS Inc., Chicago, IL). When the compared groups differed significantly from each other in terms of baseline characteristics with possible influence on CAM use, the comparison between groups are also reported with adjusted p-values.

The data inspectorate has been notified about the study and the regional ethics committee has recommended it.

## Results

### Basic characteristics of the studied participants

The cancer group consisted mainly of women, the CHD group mainly of men, while the no cancer/CHD group was gender-balanced. Individuals in the no cancer/CHD group were higher educated than the cancer group and the CHD group. The no cancer/CHD group had the best self-reported health, the CHD group the poorest (Table 1).

Mean time from first diagnosis was 9.6 years (median = 6.6), ranging from 0 to 41 years in the cancer group, and 9.6 years (median = 8) in the CHD group ranging from 0 to 54.

### Use of a CAM provider in the cancer group compared to the CHD group

26 participants (7.9%) in the cancer group and 37 participants (6.4%) in the CHD group had visited a CAM provider within the last 12 months ( $p = 0.402$ , Figure 2).

The insignificant difference between the two groups remains when adjusted for gender, age, self-reported health and education.

### Use of a CAM provider in the cancer group compared to the no cancer/CHD group

593 participants (9.5%) in the no cancer/CHD group and 26 participants in the cancer group (7.9%) had seen a CAM provider the last 12 months ( $p = 0.325$ , Figure 2). 16 participants (4.8%) in the cancer group and 270

(4.3%) in the no cancer/CHD group had seen their provider more than three times ( $p = 0.209$ ).

### Use of a CAM provider within the cancer group

Among the 26 patients (7.9%) in the cancer group that had visited a CAM provider in the previous 12 months, 10 patients had seen their provider one to three times while 16 patients had visited a provider more than three times.

A higher proportion of women compared to men tended to have visited a CAM provider, 21 women (10.6%) versus five men (3.8%) ( $p = 0.025$ ). Of these, both men and women were most likely to have visited a provider more than three times.

Nine patients (11.5%) with metastases and 15 patients (7.5%) with no metastases at first diagnosis had visited a CAM provider in the previous 12 months ( $p = 0.287$ ). Eight patients (10.8%) with metastases and eight patients without metastases (3.7%) had visited a CAM provider more than three times.

16 patients (8.3%) with at least five years since first diagnosis were just as likely to have visited a CAM provider as patients with one to five years since last diagnosis (9 patients, 8.3%). Only one person with less than one year since last diagnosis had visited a CAM provider within the last 12 months (2.9%).

## Discussion

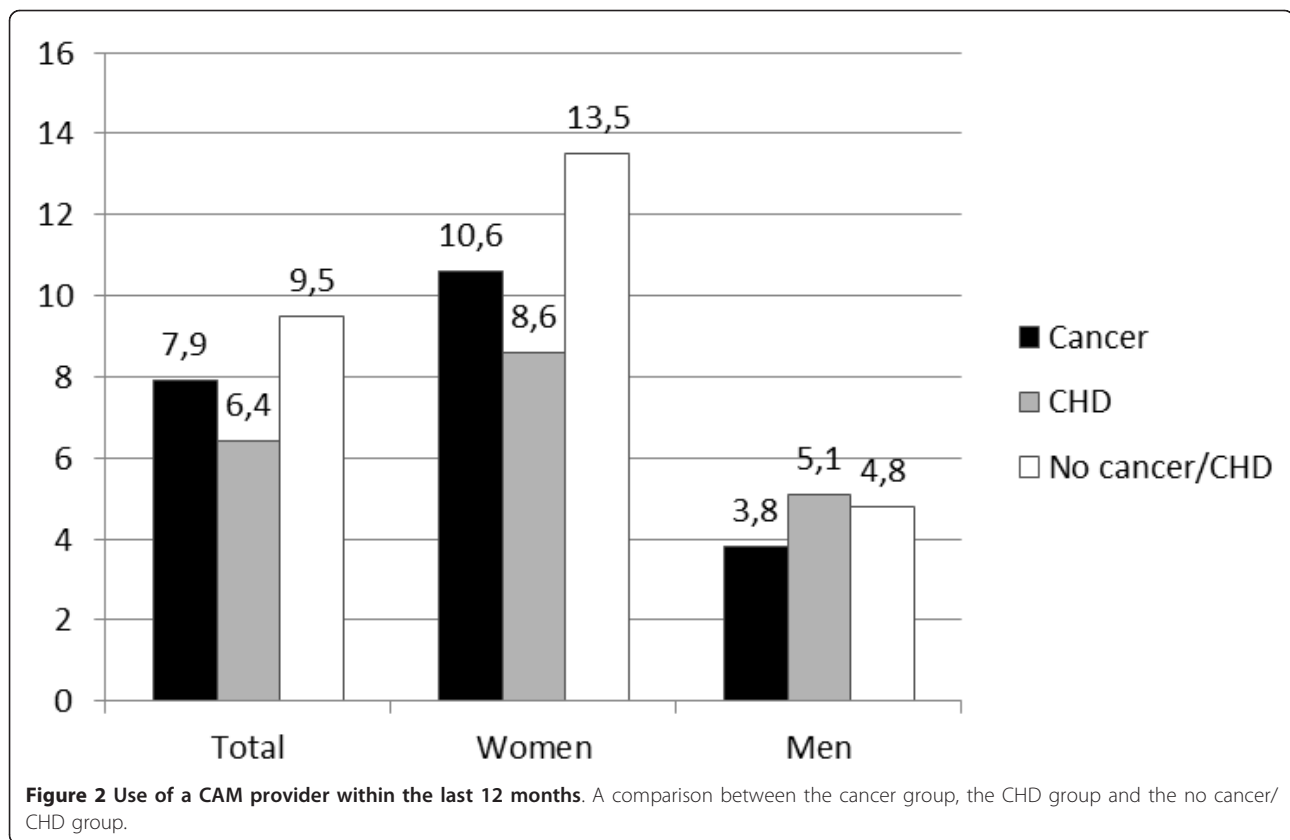
This study shows no significant difference in visits to a CAM provider between population-based patients with a prior cancer or CHD diagnosis, and also no statistically significant difference in visits to a CAM provider between patients with a prior cancer diagnosis and individuals without cancer or CHD when adjusted for possible confounding factors. The findings can be seen as contra intuitive, but are therefore possibly even more important.

### Bias considerations

The high response rate in this study ensures a representative sample of the population. There was a mismatch between self-reported cancer and the registrations in the CRN regarding 130 participants. They had either identified themselves as having had cancer without a

**Table 1 Basic characteristics of studied participants**

	Cancer (n = 331)	CHD (n = 579)	No cancer/CHD (n = 5681)
Mean age, years (range)	66.6 (30-84)	68.9 (39-85)	57.12 (29-87)
Median age	67	69.5	60
Percentage of women	60.1%	36.1	55.0%
Years of education (mean)	9.9	9.1	11.2
Self-reported poor health	47.1	61.6%	32.8%
Living with a spouse/partner	68.1%	68.9%	73.2%



confirmed diagnosis in the CRN ( $n = 83$ ), or identified themselves as having had no cancer with a confirmed diagnosis in the CRN ( $n = 47$ ). Possible reasons for this may be (1) that the diagnosis had been uncertain and therefore not confirmed in the CRN, (2) the respondent had ticked off incorrectly in the questionnaire, (3) did not remember their diagnosis as cancer or (4) forgot about their previous cancer while filling in the questionnaire.

The exclusion of patients denying actively a cancer diagnosis despite a CRN registration can be seen as controversial. None of these reported using CAM. If we had included them in the cancer group, the proportion using CAM in this group would therefore have been slightly lower, while the differences would remain statistically insignificant. It might also be controversial to include patients with missing values on the CHD variable in the cancer group when excluding patients with both cancer and CHD. The number of cancer patients with a missing value on the CHD variables was seven, and none of these reported to be CAM users. Excluding them in the cancer group would only minimally have changed our estimates, and none of the differences would reach statistical significance.

The questionnaire asked for the number of visits to a CAM provider without *defining* a CAM provider. This

could constitute an over- or underreporting of visits depending on how each participant defined a CAM provider. However, since the question regarding visits to a CAM provider was listed among a number of other health care providers, the separation between a CAM provider and a conventional health care provider should have been clear. There is no study in Norway on how the public defines a CAM provider, but the most commonly used CAM providers are massage therapists, acupuncturists, reflexologists, spiritual healers and homeopaths [30]. A chiropractor is in Norway licensed by the government as a regulated profession within conventional health care, and is not seen or classified as a CAM provider. There is no study in Norway on how the public defines a CAM provider, but this possible misclassification is not likely to be differential. The 12-month recall period concerning use of a CAM provider might also result in inaccuracies with regard to number of visits.

The onset of cancer or CHD might have occurred several years ago and the patient might therefore have given an inaccurate answer concerning whether or not they have had the disease.

The potential misclassifications in this study are likely to be non-differential and the results from this sample are therefore a conservative estimate of any population differences between groups.

The possible information bias generated when participants are fully aware of the purpose of the study (CAM use in cancer and CHD) was low in this study as this was the purpose of this paper but not in any way the main purpose of the Tromsø V study.

#### **Other studies**

##### ***CAM use in CHD populations***

We have not succeeded in finding other studies reporting use of a “CAM provider” among patients with CHD and are therefore unable to present a direct comparison. However, a British study reporting use of “any alternative or complementary therapies/medicines” reported findings similar to ours (9.2%) [21]. The similar and rather low CAM use in both studies might be due to the fact that patients in neither study were given a definition of CAM or a pre-prepared list of CAM treatments that might have added to the recall and produced a higher rate of CAM use [31]. The British study had a wider definition of CAM but was, on the other hand, administrated by a nurse in a hospital setting which might have made some patients reluctant to disclose CAM use.

##### ***CAM use in cancer patients***

Comparison of our results with other studies in cancer was also difficult since the variation in time frame of use, purpose of use, time since diagnosis, definitions of a CAM provider and the population studied, strongly influence the results. We have therefore chosen to compare our study to a limited selection of other studies with focus on equality and comparability.

Breast cancer patients in England [32] and Canada [33] had visited a CAM provider more often than women with cancer in our study. This might be explained by the fact that women with breast cancer are generally more likely to be CAM users than patients with cancer at other sites [34]. Since our study consisted of all cancer sites, this might hamper the comparison. These differences might also be explained by the limitation of CAM use within the last 12 months in our study, while long-term use of CAM was included in the Canadian study.

A Norwegian study of CAM use in cancer patients with a poor survival prognosis at the time of first diagnosis, found that 22.7% had seen a CAM provider at least once after their diagnosis. They also found that the reported use increased to 40.6% when CAM techniques and over the counter (OTC) products were included [15]. The rather higher use in that study might be due to the longer time frame (since diagnosis) and the poor prognosis [35].

##### ***Comparative studies***

Our results are supported by lack of significant differences in use of a CAM provider between different

disease groups in a Canadian study. They compared CAM use in patients with inflammatory bowel disease (IBD), arthritis and a group with mixed chronic diseases where a minority were cancer patients [36]. The substantially higher self-reported use in the Canadian study (38.1%) might be due to the different nature of the diseases studied and the different availability of adequate curative and/or palliative treatment within the health care system. The fact that our study is a population-based and not a study limited to patients with the condition under study or to CAM use in general, might also explain some of the differences.

Similar use of a CAM provider in a cancer and a no cancer group was found in a US study conducted in 2002 [37]. Their study was like ours mainly based on long-term cancer survivors which might explain the similarities between the two groups. They found, however, that reported CAM use was higher in the cancer group when non-prayer CAM services, products, and practices were included.

It is not unlikely that the similar use of a CAM provider in the cancer group and the no cancer/CHD group in our study partly could be due to the strict legislation that regulated the CAM field at the time of the study; only physicians and dentists were allowed to treat cancer patients. It is therefore possible that the reported use was, at least partly, connected to other health problems than treating the cancer.

Cancer patients in our study visited a CAM provider less frequently than cancer patients in the USA [17]. Contrary to our results, the US-study found that cancer patients were more likely to use a CAM provider than the general population and individuals with chronic serious diseases, including CHD [17]. The higher use might be due to different definitions of a CAM provider and the legal restrictions on CAM treatment of cancer in Norway [38].

Cancer patients in our study also used a CAM provider less than Norwegian cancer patients in a similar study conducted in Nord-Trøndelag, Central Norway in 1995-1997 (HUNT) [16](8.2% versus 16.1%). They found, contrary to us, that cancer patients were more likely to have seen a CAM provider than the total population. Possible reasons for the higher use might be that the availability of CAM providers is higher in their area. And possibly more important, in the HUNT study they listed several commonly used CAM providers as a reminder for the patients in the questionnaire. This might have improved the recall and made it easier to understand what the researchers were asking for [31,39]. They also included chiropractors in their definition of a CAM provider which is specifically excluded in our study as they are licensed health care personnel in Norway; if visits to a chiropractor were included in our

analyses, the use of a CAM provider would increase to 10.9% in the cancer group.

The rather low use of a CAM provider in all groups compared to studies from other countries shows how important it is to do domestic, locally-based studies. The observed low use might be due to cost differences in Norway. While most treatments offered within the public health care service are free of charge, most CAM treatments are paid out-of-pocket.

### Interpretation

This is the first population-based study that to our knowledge reports use of a CAM provider in CHD patients and is therefore a door-opener to the field. In research regarding use of CAM in cancer patients, it is important to make comparisons with other relevant chronic disease groups. The differences and similarities found might contribute to a better understanding of the needs of the different groups. In addition, our study can inspire further research in the field.

Knowledge of CAM use in different patient groups is important for the conventional medical community. It is therefore important that they ask their patients about CAM use as negative interactions between conventional and CAM treatments can occur. The number of CAM users are likely to be higher than what was found here if OTC products and self-help techniques were included in the study [26].

Our study contributes to the information needed for health care providers and politicians to make knowledge-based decisions concerning CAM use. Our results differ from those from other countries, supporting the importance of locally performed surveys. However, this possible interpretation must be drawn with caution, as worldwide experience and knowledge give a broader perspective for creating guidelines and political priorities.

Studies like ours contribute to a broader knowledge base regarding cancer patients' attitudes to, and experience with, use of a CAM provider. This is needed to balance the impressions from random magazine reports and/or prejudiced points of view obtained from strong believers or opponents of CAM. The assumed widespread use of CAM among cancer patients is not documented in our results.

### Conclusions

The proportion of cancer patients in the Tromsø V study that visited a CAM provider was not statistically significantly different from patients with CHD or individuals without cancer or CHD. These findings are in accordance with some studies and contrary to others. Most other studies report a higher use of a CAM provider than we found in our study.

This study indicates that locally based contextual surveys are necessary to make scientific and political decisions from a knowledge-based point of view.

### Abbreviations

CAM: Complementary and alternative medicine; CHD: Coronary heart disease; CRN: Cancer registry of Norway; I-CAM-Q: International questionnaire to measure use of complementary and alternative medicine; NAFKAM: National research center in complementary and alternative medicine; OTC: Over the counter.

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### Authors' contributions

AEK conceived the study, performed the initial and final analyses and drafted the manuscript. AJN helped draft the manuscript and reviewed subsequent versions. VF conceived the study together with AEK, helped draft the manuscript, and reviewed subsequent versions. All authors read and approved the final manuscript.

### Competing interests

The authors declare that they have no competing interests.

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# Paper IV





## Research Article

# Complementary and Alternative Medicine Use among Norwegian Cancer Survivors: Gender-Specific Prevalence and Associations for Use

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The associations for CAM use are only occasionally differentiated by gender in populations where both male and female cancer survivors occur. The aim of this study is to describe the prevalence of CAM use in individuals with a previous cancer diagnosis and to investigate gender differences regard to factors associated with use. A total of 12982 men and women filled in a questionnaire with questions about life style and health issues. Eight hundred of those had a previous cancer diagnosis of whom 630 answered three questions concerning CAM use in the last 12 months. A total of 33.8% of all cancer survivors reported CAM use, 39.4% of the women and 27.9% of the men ( $P < 0.01$ ). The relationship between the demographic variables and being a CAM user differed significantly between men and women with regard to age ( $P = 0.03$ ), education ( $P = 0.04$ ), and income ( $P < 0.01$ ). Female CAM users were more likely to have a university degree than the nonusers, while male CAM users were more likely to have a lower income than the nonusers. According to this study, prevalence and factors associated with CAM use differ significantly between male and female survivors of cancer.

## 1. Introduction

Although self-reported use of complementary and alternative medicine (CAM) among cancer patients is increasing [1–4], studies report substantial difference in the level of use ranging from 7% [5] to 95% [6]. This wide range in self-reported use could be due to differences in the definition of a CAM user [7, 8] and/or differences in the time frame of the use [9].

Younger, highly educated women have been described as the most frequent users of CAM [4, 8, 10–12]. Frequent use has also been reported among patients with symptoms related to their cancer, patients receiving only palliative treatment, patients with metastatic disease, and patients diagnosed with cancer more than three months previously [13].

Others again report that use of, or interest in, CAM is predicted by younger age, progressive cancer, and active coping behaviour [14]. CAM use related to time after diagnosis has also been studied [9]. Likelihood of death occurring from the cancer has been reported to be both associated [15, 16] and not

associated [17, 18] with CAM use. Likelihood of consulting a CAM provider has been associated with a university degree, low-perceived global health, and recent health complaints [19].

The predictors for CAM use in whole populations and among female cancer survivors have been described, while predictors for CAM use in male cancer survivors are still insufficiently studied in all cancer categories except prostate [20]. The reported reasons for CAM use have been only occasionally differentiated by gender in populations where both male and female cancer survivors occur [21, 22].

Since women with cancer are documented to use different kinds of CAM than men [21, 23] and that other patient groups are found to have gender-specific correlations for use [22, 24, 25], it is important also to investigate if the factors associated with CAM use in cancer are gender specific.

The aim of this study is (1) to describe prevalence of CAM use in individuals with a previous cancer diagnosis and (2) to investigate whether men and women differ with regard

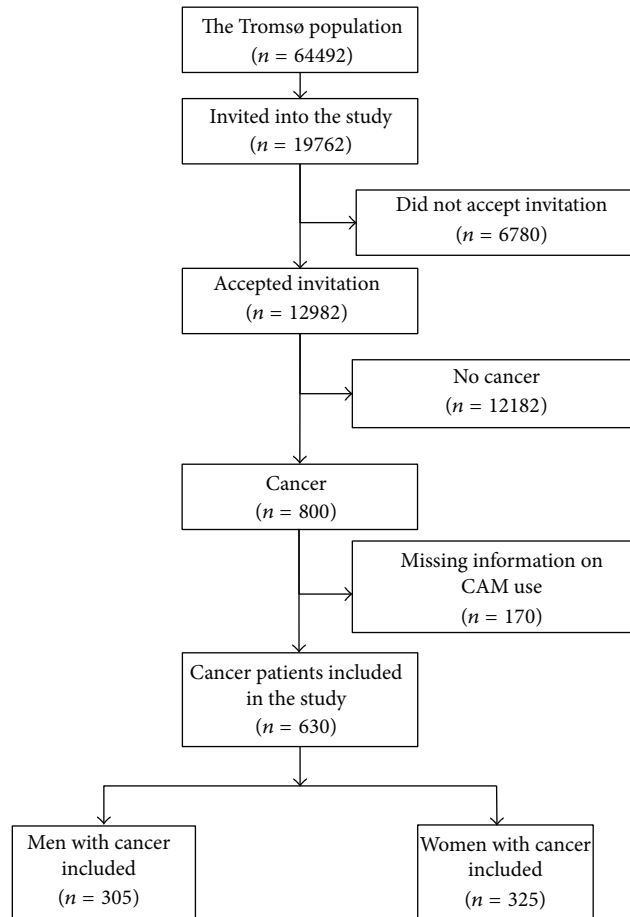


FIGURE 1: Flow chart that shows the selection of the studied population.

to sociodemographical and health-related factors associated with CAM use.

## 2. Materials and Methods

The Tromsø Cohort Study series are a single-centred prospective and population-based health surveys of the adult inhabitants of the municipality of Tromsø, Northern Norway [26]. The population of Tromsø reflects the distribution of gender, educational level, and average income in Norway overall, but the population is somewhat younger [27]. The design includes repeated population health surveys to which total birth cohorts and random samples are invited. The Tromsø Cohort study collects information on a wide range of health-related issues, using questionnaires and health screenings. Use of CAM is collected through two different questionnaires.

This paper is based on data from the sixth Tromsø study conducted in 2007/2008, including 12982 participants, 6053 men and 6929 women aged between 30 and 87 years old (response rate is 65.7%, 62.9% of the men and 68.4% of the women). Eight hundred of these participants have had

cancer prior to the survey according to the Cancer Registry of Norway. Sixty-five men and 105 women failed to answer all the three questions concerning CAM use and were excluded from the analyses. This leaves us with 630 informants who responded to all three questions about CAM use, constituting the studied population (Figure 1).

The letter of invitation contained a short questionnaire developed specifically for the sixth Tromsø study including use of a CAM provider. Individuals who attended the survey by answering the first questionnaire and undergoing a health screening, received subsequently a *second, more detailed*, questionnaire which they were asked to complete onsite or at home and return by mail. The questions concerning use of OTC products and self-techniques were placed in this *second* questionnaire.

The two questionnaires included questions on general state of health, diseases suffered by the respondent or their family, muscle pain and physical discomfort, food habits, alcohol consumption, smoking habits, physical activity in leisure time, level of education, use of medicine, and use of health services including CAM. The questions regarding CAM use were not related to any specific disease condition.

TABLE 1: Basic characteristics of the studied participants.

	Cancer patients ( <i>n</i> = 630)	Women with cancer ( <i>n</i> = 325)	Men with cancer ( <i>n</i> = 305)
Percentage women	51.6		
Mean age	65.9	66.5	66.3
Median age (range)	66 (30–87)	66 (30–87)	67 (36–86)
Living with a spouse/partner %	70.2	56.8	84.4
University degree %	32.6	28.3	37.2
Self-reported good health %	53.0	53.1	53.0
Self-reported poor health %	9.0	8.4	9.6
More than 400 000 NOK (70 000\$/54 000€) in house hold income last year %	47.5	38.9	55.8
Less than 125 000 NOK (21 500\$/16 400€) in house hold income last year %.	3.5	5.7	1.4
Seen a general practitioner last year %	89.6	90.7	88.4
Mean time since diagnosis (years)	10.6	12.0	9.4

TABLE 2: Gender-specific CAM use in the last 12 months.

	Total ( <i>n</i> = 630) %	Women ( <i>n</i> = 325) %	Men ( <i>n</i> = 305) %	<i>P</i> value
Have you during the last 12 months seen an alternative provider (homeopath, acupuncturist, foot zone therapist, herbal medicine practitioner, laying on of hands practitioner, healer, clairvoyant, etc.)?	( <i>n</i> = 79) 12.5	( <i>n</i> = 51) 15.7	( <i>n</i> = 28) 9.2	0.01
In the last 12 months have you used herbal or “natural” medicine?	( <i>n</i> = 155) 24.6	( <i>n</i> = 93) 28.6	( <i>n</i> = 62) 20.3	0.02
In the last 12 months have you used meditation, yoga, qi gong, or Tai Chi as a self-treatment?	( <i>n</i> = 29) 4.6	( <i>n</i> = 23) 7.1	( <i>n</i> = 6) 2.0	<0.01
Over all CAM use	( <i>n</i> = 213) 33.8	( <i>n</i> = 128) 39.4	( <i>n</i> = 85) 27.9	<0.01

Study participants were classified as “CAM-users” by checking Yes for one or more of the three questions concerning visits to a CAM provider, use of CAM over-the-counter products (OTC), and CAM techniques (displayed in Table 2). Accordingly, a participant who checked No for all the three specific CAM-questions was classified as a nonuser.

Informants who had seen a chiropractor were not defined as CAM users in this study as chiropractors are regulated health care personnel in Norway. This also applies to informants who had used cod liver oil, fish oil capsules, Omega-3, or ordinary vitamins/mineral supplements as these supplements are commonly used in the Norwegian population.

In Norway, an alternative medical provider is commonly understood as a practitioner providing CAM both as an alternative to and complementary to conventional treatment. A CAM provider offers therapies that are not commonly offered within the public health care service and are paid out-of-pocket by the patients themselves.

With a statistical power of 80% and using an alpha of 0.05, we were able to report a statistically significant within-gender differences in reported use of approximately 10 percentage

points when cross tabulating use with other dichotomous variables.

Associations for CAM use in men and women were analysed using chi-square tests in SPSS Windows (version 19.0, SPSS Inc., Chicago, IL), one variable at a time. Interaction between women and men concerning associations was investigated by testing homogeneity of the odds ratio in a multivariate analysis.

The data inspectorate has been notified about the study, and the regional ethics committee has recommended it. The participants have given their informed written consent.

### 3. Results

**3.1. Basic Characteristics of the Studied Participants.** The studied population (*n* = 630) consisted of 325 women and 305 men. Most cancer sites were represented, though breast cancer dominated among women (37.8%) and prostate cancer (34.8%) among men. Mean time since diagnosis was 10.6 years, 12 years in women and 9.4 years in men. Only 30 participants (ten women and 20 men) were less than 12

months after diagnosis. Most of the men (84.4%) and half of the women (56.8%) were living with a spouse/partner, and more than half of the participants reported good or excellent health (53%). Mean self-reported health was 73.7, ranging from 5 to 100 on a 100 point scale where 100 was the best imaginable health. Very few reported poor health (9%) despite a cancer diagnosis and a median age of 66 (Table 1).

**3.2. Prevalence of CAM Use in the Cancer Patients.** A total of 33.8% of all cancer survivors reported CAM use, 39.4% of the women and 27.9% of the men ( $P < 0.01$ ). OTC products were most often used, used by 29% of the women and 20% of the men. A CAM provider was seen by 13% of the population, 16% of the women and 9% of the men. CAM techniques were least used, 7% of the women and only 2% of the men (Table 2).

There were no significant differences in CAM use according to time since diagnosis and self-reported health, neither among men nor women.

Nonresponders could be included in the analysis by including informants answering “yes” to at least one of the three questions concerning CAM in the *CAM group* and all the patients with no or missing response to all the three questions were included in the *no CAM group*. The prevalence of CAM use would then have been 30.5% ( $n = 244$ ), 35.3% among women ( $n = 152$ ) and 24.9% among men ( $n = 92$ ).

The cancer patients did not differ significantly from the group without cancer when the use of a CAM provider, CAM techniques, and OTC products were analysed separately. When the three CAM modalities were analysed together (CAM level 3 [23]), men with cancer were significantly more likely to be CAM users than men without cancer (27.9% versus 22.1%,  $P = 0.02$ ).

**3.3. Factors Associated with CAM Use in Cancer Patients.** There were no overall significant differences between users and nonusers of CAM in relation to age, education, income, self-reported health, time since diagnosis, or metastasis at first diagnosis. We found that CAM users were significantly more likely to be women ( $P = 0.002$ ) and more likely to have breast cancer ( $P = 0.02$ ).

The relationship between the demographic variables and being a CAM user differed significantly between men and women with regard to age ( $P = 0.03$ ), education ( $P = 0.04$ ), and income ( $P < 0.01$ ) (Table 3). It was, therefore, necessary to present data stratified by gender.

When analysed separately, we found that university education ( $P < 0.01$ ) and breast cancer ( $P < 0.01$ ) was significantly associated with CAM use in women. We found no significant associations for age, income, or self-reported health in women (Tables 3 and 4). As breast cancer was significantly associated with CAM, the same analysis was conducted without breast cancer with the same result, however, no longer at a significant statistical level.

When the three CAM modalities CAM provider (Table 5), OTC products (Table 6), and CAM techniques (Table 7) were analysed separately, we found that university education and younger age was associated with the use of

CAM techniques and university education to be associated with the use of OTC products in women.

Among men, we found that lower income was significantly associated with CAM use ( $P = 0.016$ ). University education, age (Table 3), and self-reported health (Table 4) were not significantly associated with CAM use in men, though older age seemed to be a tendency ( $P = 0.072$ , Table 3). As prostate cancer was the most common cancer site among men, the same analyses was conducted without prostate cancer with the same result to ensure that the associations found were associated with men in general and not with prostate cancer in particular.

When the three CAM modalities CAM provider (Table 5), OTC products (Table 6), and CAM techniques (Table 7) were analysed separately, we did not find age, income, or university education to be associated with use at a significant level. A tendency was, on the other hand, found for older age ( $P = 0.065$ ) and lower family income ( $P = 0.085$ ) in the use of OTC products in men.

When analysing interaction in CAM use between men and women, we found significant interactions in overall CAM use concerning age, university education, and family income (Table 3). We did not find significant interaction concerning the use of neither a CAM provider nor CAM techniques. In the use of OTC products, on the other hand, we found significant interactions concerning age and university education in men and women (Table 6).

## 4. Discussion

This study has shown that women were more likely to have used CAM than men and that the associations for CAM use differ between men and women.

**4.1. Bias.** The cancer registry of Norway includes all patients diagnosed with cancer in Norway since 1952. This should ensure that the selected cancer patients for this study represent our target group. The response rate (65.7%), on the other hand, could influence the generalizability of our findings. The generalizability will also be influenced by the 170 respondents that were excluded from the study as they did not answer all the three questions concerning CAM. This might have led to an overestimated CAM use as respondents with missing answers might have been more likely to not have used CAM [28]. These patients did, on the other hand, not differ significantly from the informants answering all three CAM questions concerning gender, age, or income.

The 12-month recall period concerning CAM use might likewise result in inaccuracies with regard to use. This factor should be equally distributed among women and men.

One of the three CAM questions asked for the use of herbal or “natural” medicine without defining this further. This could constitute an over- or underreporting of such use depending on how each participant defined their use and could also be differential between gender as men and women might define this in a different way.

It is also important to be aware of the fact that 37.8% of the women had breast cancer and 34.8% of the men had

TABLE 3: Overall CAM use. Socio demographic characteristics of users and nonusers.

	CAM users		Nonusers of CAM		P value	CAM users		Nonusers of CAM		P value	Interaction
	Women (n = 128*)		Women (n = 197*)			Men (n = 85*)		Men (n = 220*)			women/men
	(n)	%	(n)	%		(n)	%	(n)	%		P value
Age											
30–66 years	(75)	58.6	(102)	51.8	0.228	(32)	37.6	(108)	49.1	0.072	<b>0.032</b>
67–87 years	(53)	41.4	(95)	48.2		(53)	62.4	(112)	50.9		
Education											
Primary/secondary school	(80)	63.5	(148)	77.1	0.008	(54)	64.3	(135)	62.2	0.738	<b>0.041</b>
University education	(46)	36.5	(44)	22.9		(30)	35.7	(82)	37.8		
Family income											
Low to medium	(61)	47.7	(110)	55.8	0.149	(45)	52.9	(83)	37.7	0.016	<b>0.006</b>
Medium to high	(67)	52.3	(87)	44.2		(40)	47.1	(137)	62.3		
Living with a spouse/partner											
Yes	(74)	61.2	(106)	54.1	0.217	(69)	82.1	(185)	85.3	0.505	<b>0.211</b>
No	(47)	38.8	(90)	45.9		(15)	17.9	(32)	14.7		

\* Due to missing response on one or more variables, the analysed numbers do not always add up to the total number.

prostate cancer. One could, therefore, think that the gender-specific associations were connected to these cancer sites rather than gender itself, but this is shown to be unlikely as separate analyses excluding these two cancer sites were conducted with the same results, however, no longer at a statistical significant level.

**4.2. Prevalence.** Many studies report the use of CAM in cancer patients, but the studied population, time frame in use, and definition of CAM varies widely. We have, therefore, chosen to compare our study to a limited selection of other studies with focus on comparability.

A former Tromsø study conducted in 2001/2002, the fifth Tromsø study, found lower use of a CAM provider in the last 12 months than what we found six years later, 10.6% in women and 3.8% in men [29]. The reason for this is likely to be the strict legislation that regulated the CAM field at the time of the fifth study; only physicians and dentists were allowed to treat cancer patients. When the sixth Tromsø study was conducted in 2007/2008, this legislation had been considerably moderated. Also the preprepared list exemplifying CAM providers in the sixth study might have increased reported CAM use as this might have improved the recall and clarified what to consider as CAM.

A Norwegian study, reporting CAM use in cancer patients with a poor survival prognosis at the time of first diagnosis, found that 22.7% had seen a CAM provider at least once after first diagnosis [28], 30% of the women and 14% of the men [23]. The reported use increased to 38.8% [28], 46% among women and 30% among men [23], when CAM techniques and OTC products were included. The somewhat higher use in that study might be due to the longer time frame of use (since diagnosis, at least 5 years) and the poorer prognosis in the studied population.

Cancer patients in the county of Nord-Trøndelag, Central Norway were found to use a CAM provider to a larger degree than found in our study [19]. They found, contrary to us, that cancer patients were more likely to have seen a CAM provider than the total population. The difference in use might be due to a wider definition of a CAM provider in their study. Mao et al. found that 40% of all cancer survivors in a national sample in the US had used CAM within the last 12 months. They also found, contrary to us, that the cancer survivors were more frequent users than the total population. They found 45% CAM use in women and 33% CAM use in men [30]. The somewhat higher prevalence of use in their study might be due to their wider definition of CAM [23]. Average CAM use of 40% was also found in a systematic review presenting data from 152 studies in 18 countries representing more than 65 000 cancer patients. When limited to Europe, 34% CAM use was found which is very close to our findings. This study did not, however, provide gender-specific prevalence of use [31].

A large community-based national registry study in USA found that 33% of men with prostate cancer had used some sort of CAM. This is somewhat higher than what we found in men with cancer in our study and might be due to the specific cancer site. The US study also had a wider definition of CAM than what we had, but limited, on the other hand, the use to the last 6 months compared to our 12 months [32]. The use of CAM in Canadian men with prostate cancer was found to be 29.8% and was closer to our findings [33].

Our findings of CAM use in women were somewhat lower than what was found in recent studies in Europe, USA, and Australia [3, 17, 34–38], though some studies also found less use of CAM than what we found [39–41]. When less use was found, the CAM use was limited to a CAM provider [42] or to a newly diagnosed breast cancer patients [40]. The wide range of 16.5% to 87.9% reported use is partly due to the

TABLE 4: Overall CAM use. Health-related characteristics of users and nonusers.

	CAM users		Nonusers of CAM		P-value	CAM users		Nonusers of CAM		P-value	Interaction
	Women		Women			Men		Men			women/men
	(n = 128*)	(n = 197*)	(n)	(n)		(n = 85*)	(n = 220*)	(n)	(n)		P-value
	(n)	%	(n)	%		(n)	%	(n)	%		
Self-reported health											
Medium to good health	(114)	90.5	(181)	92.3	0.554	(74)	88.1	(199)	91.3	0.399	<b>0.852</b>
Poor health	(12)	9.5	(15)	7.7		(10)	11.9	(19)	8.7		
Time since diagnosis											
Less than one year	(5)	3.9	(5)	2.5	0.819	(3)	3.5	(17)	7.7	0.479	<b>0.737</b>
1–5 years	(33)	25.8	(46)	23.4		(34)	40	(74)	33.6		
5–10 years	(35)	27.3	(60)	30.5		(22)	25.9	(56)	25.5		
More than 10 years	(55)	43	(86)	43.7		(26)	30.6	(73)	33.2		
Cancer localization											
Breast	(57)	44.5	(66)	33.5	0.193						
Cervix uteri	(4)	3.1	(13)	6.6							
Other parts of uterus	(4)	3.1	(14)	7.1							
Ovary	(10)	7.8	(7)	3.6							
Prostate						(35)	41.2	(71)	32.3	0.439	
Testis						(3)	3.5	(17)	7.7		
Colon	(9)	7.0	(14)	7.1		(4)	4.7	(18)	8.2		
Bladder	(2)	1.6	(8)	4.1		(7)	8.2	(15)	6.8		
Rectum and anus	(4)	3.1	(4)	2.0		(5)	5.9	(10)	4.5		
Trachea, bronchus, and lung	(1)	0.8	(4)	2.0		(4)	4.7	(6)	2.7		
Lymphoid	(7)	5.5	(9)	4.6		(4)	4.7	(17)	7.7		
Kidney	(0)	0	(1)	0.5		(1)	1.2	(10)	4.5		
All other cancer sites	(30)	23.4	(57)	28.9		(22)	25.9	(56)	25.5		
Breast cancer											
Breast	(57)	44.5	(66)	33.5	0.045						
Other sites	(71)	55.5	(131)	66.5		(85)	100	(220)	100		
Prostate cancer											
Prostate						(35)	41.2	(71)	32.3	0.143	
Other sites	(128)	100	(197)	100		(50)	58.8	(149)	67.7		
Metastases											
Metastases at first diagnosis	(27)	21.1	(54)	27.4	0.415	(12)	14.1	(37)	16.8	0.487	<b>0.953</b>
No metastases	(73)	57	(106)	53.8		(49)	57.6	(110)	50		
Unknown	(28)	21.9	(37)	18.8		(24)	28.2	(73)	33.2		

\* Due to missing response on one or more variables, the analysed numbers do not always add up to the total number.

different ways of collecting data on CAM use (open questions and preprepared lists, different time frame of use, and current use to life time use) and different levels of use (level 2 to 6 in the NAFKAM model [23]). There were also differences with regard to the populations studied, varying from newly diagnosed breast cancer patients undergoing conventional treatment to national samples of women diagnosed with cancer. When these factors were taken into consideration, we still found a somewhat higher proportion of CAM users in most studies, especially American, Canadian, and Australian

studies. This might be due to a more established tradition with integrated complementary cancer care compared to Norway and that most of these studies reported use in breast cancer patients only.

The proportion of cancer patients using CAM in this study does not differ much from what was found in other studies when the comparison is restricted to comparable parameters. This shows how important it is to ensure comparability when studies are compared [23, 43]. It is important to define clearly with examples how to define a CAM provider

TABLE 5: CAM provider. Basic characteristics of users and nonusers.

	CAM provider		No CAM provider		<i>P</i> -value	CAM provider		No CAM provider		<i>P</i> -value	Interaction women/men <i>P</i> -value
	Women ( <i>n</i> = 51*)		Women ( <i>n</i> = 274*)			Men ( <i>n</i> = 28*)		Men ( <i>n</i> = 273*)			
	( <i>n</i> )	%	( <i>n</i> )	%		( <i>n</i> )	%	( <i>n</i> )	%		
<b>Age</b>											
30–66 years	(28)	54.9	(149)	54.4	0.945	(12)	42.9	(128)	46.2	0.734	0.757
67–87 years	(23)	45.1	(125)	45.6		(16)	57.1	(149)	53.8		
<b>Education</b>											
Primary/secondary school	(38)	76	(190)	70.9	0.462	(16)	57.1	(173)	63.4	0.516	0.335
University education	(12)	24	(78)	29.1		(12)	42.9	(100)	36.6		
<b>Family income</b>											
Low to medium	(27)	52.9	(144)	52.6	0.960	(14)	50	(114)	41.2	0.366	0.497
Medium to high	(24)	47.1	(130)	47.4		(14)	50	(163)	58.8		

\* Due to missing response on one or more variables, the analysed numbers do not always add up to the total number.

TABLE 6: OTC products. Basic characteristics of users and nonusers.

	OTC products		No OTC products		<i>P</i> -value	OTC products		No OTC products		<i>P</i> -value	Interaction women/men <i>P</i> -value
	Women ( <i>n</i> = 93*)		Women ( <i>n</i> = 232*)			Men ( <i>n</i> = 62*)		Men ( <i>n</i> = 243*)			
	( <i>n</i> )	%	( <i>n</i> )	%		( <i>n</i> )	%	( <i>n</i> )	%		
<b>Age</b>											
30–66 years	(55)	59.1	(122)	52.6	0.284	(22)	35.5	(118)	48.6	0.065	0.036
67–87 years	(38)	40.9	(110)	47.4		(40)	64.5	(125)	51.4		
<b>Education</b>											
Primary/secondary school	(56)	61.5	(172)	75.8	0.011	(42)	68.9	(147)	61.3	0.273	0.014
University education	(35)	38.5	(55)	24.2		(19)	31.1	(93)	38.8		
<b>Family income</b>											
Low to medium	(47)	50.5	(124)	53.4	0.635	(32)	51.9	(96)	39.5	0.085	0.108
Medium to high	(46)	49.5	(108)	46.6		(30)	48.4	(147)	60.5		

\* Due to missing response on one or more variables, the analysed numbers do not always add up to the total number.

TABLE 7: CAM techniques. Basic characteristics of users and nonusers.

	CAM techniques		No CAM techniques		<i>P</i> -value	CAM techniques		No CAM techniques		<i>P</i> -value	Interaction women/men <i>P</i> -value
	Women ( <i>n</i> = 23*)		Women ( <i>n</i> = 302*)			Men ( <i>n</i> = 6*)		Men ( <i>n</i> = 299*)			
	( <i>n</i> )	%	( <i>n</i> )	%		( <i>n</i> )	%	( <i>n</i> )	%		
<b>Age</b>											
30–66 years	(20)	87	(157)	52	0.001	(4)	66.7	(136)	45.5	0.419	0.550
67–87 years	(3)	13	(145)	48		(2)	33.3	(163)	54.5		
<b>Education</b>											
Primary/secondary school	(10)	43.5	(218)	73.9	0.002	(2)	33.3	(187)	63.4	0.200	0.987
University education	(13)	56.5	(77)	26.1		(4)	66.7	(108)	36.6		
<b>Family income</b>											
Low to medium	(9)	39.1	(162)	53.6	0.179	(1)	16.7	(127)	42.5	0.407	0.625
Medium to high	(14)	60.9	(140)	46.4		(5)	83.3	(172)	57.5		

\* Due to missing response on one or more variables, the analysed numbers do not always add up to the total number.

and to use a standard questionnaire like the I-CAM-Q [44]. It is also important to clarify which level of CAM use was investigated and to report CAM use at more than one level as discussed in the NAFKAM cumulative model of reporting CAM use [23].

**4.3. Associations.** Our findings of CAM use associated with female gender and breast cancer are in accordance with findings in other studies [10, 45–48]. The reasons for higher CAM use in women might be explained by the fact that women use health services in general to a larger degree than men [49]. The increased use in breast cancer patients might be due to a high number of survivors suffering from severe side effects from conventional treatment and a somewhat younger cancer population more likely to feel their cancer as a threat to future plans [10] and care for children.

Different associations for CAM use in men and women concerning age and university education were also found in a recent Norwegian study [19]. Many find like us that female CAM users are more likely to have university education than nonusers. Women with university education might be more aware of CAM and more able to find relevant information about CAM. Young age [42, 50–52] and higher income [50, 51] have often been associated with CAM use in women. This was also found in our study, however not at a significant level. The reason for this might be that we have a strong tradition for the use of traditional healers among the elderly in Northern Norway and that these healers are classified as CAM providers in this study.

Our finding of lower income in male CAM users compared to nonusers is not in accordance with findings in other studies [33, 53–56]. The reason for this might be due to that more CAM users than nonusers have reached the age of 67 and as a consequence of this are likely to be retired from work.

We found no association between education and CAM use in men. This is in accordance with several other studies [33, 56, 57]. Boon suggests that CAM use is no longer a phenomenon restricted to a unique segment of the population that is highly educated and enjoys a high family income [33]. This seems valid for our male CAM users. The lack of differences in educational level is not in accordance with what we found in women using CAM. The discrepancy between men and women in our study might be due to a general higher educational level among men.

The tendency towards older age in overall CAM use and OTC products in men in our study is not found in other studies that we are aware of. Some studies found no associations between age and CAM use [57, 58], other found male CAM users to be younger than the nonusers [54, 56]. Inclusion of both traditional healers commonly used by elderly people and modern CAM providers used by the younger generations might explain the lack of significant age differences in our study.

The findings of different associations for CAM use in men and women are important both for researchers and in clinical practice as the general impression of CAM users seems to be based on studies where the CAM users are dominated by women. This could give an incorrect impression of male CAM users.

## 5. Conclusion

According to this study, prevalence and associations (age, education, and income) for CAM use differ significantly between male and female survivors of cancer. This underlines the importance of gender-specific analyses in future research.

## Conflict of Interests

The authors declare that they have no competing interests.

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Appendix 1:  
The Cancer Registry of Norway (CRN)-Study



Appendix 1-A:  
Information letters to the hospitals





**Krefregisteret**  
 Institutt for populasjonsbasert kreftforskning



Tromsø/Oslo 27.10.2003

Kjære kollega

I følge flere publikasjoner av overlege dr. med. Terje Risberg ved kreftavdelingen, Universitetssykehuset i Nord-Norge (UNN), oppsøker omlag 45 % av alle kreftpasienter alternativmedisinsk behandling en eller flere ganger i løpet av sin kreftsykdom (Risberg et.al.1998).

Nasjonalt forskningscenter innen komplementær og alternativ medisin (NAFKAM) har i samarbeid med Krefregisteret igangsatt en undersøkelse om bruk av alternativ medisin blant to grupper kreftpasienter identifisert i Krefregisteret. Faktisk bruk av alternativ medisin skal kartlegges hos pasienter som har overlevd 5 år eller mer etter påvist kreft. I studien vil disse deles i to grupper. En hovedgruppe bestående av kreftpasienter med en utgangspåprognose på mindre enn 20 % sjans for 5 års overlevelse, og en kontrollgruppe med en utgangspåprognose på 40-60 % sjans for 5 års overlevelse etter påvist kreft. Alle pasientene som er trukket ut til å delta i studien er i live per dags dato. Et eksemplar av forskningsprotokollen kan hvis ønskelig fåes ved henvendelse til NAFKAM (nafkam@fagmed.uit.no).

Krefregisteret presiserer at henvendelser til pasienter skal gå gjennom behandlende lege. Vi vil derfor be dere om å videresende den/de vedlagte konvolutt(ene) (et åpent prøve-eksemplar ligger vedlagt) bestående av et følgebrev, et firesiders spørreskjema og en ferdig frankert svarkonvolutt til de av pasientene i vår utvalgsgruppe som tilhører ditt sykehus. Samtidig vil vi be dere stemple utsendelseskonvolutt med ditt sykehus' stempel. Når spørreskjemaene er sendt ut til pasientene, ber vi dere returnere vedlagte svarsending til oss med opplysninger om når skjemaene er sendt ut. Det gir oss oversikt over hvilke pasienter som har fått skjemaet og når de har mottatt det. Det må være helt sikkert at pasienten er informert om sin kreftsykdom.

Studien er tilrådd av etisk komité og personidentifiserbare opplysninger om pasienten vil kun foreligge i Krefregisteret. NAFKAM vil kun arbeide med ikke-personidentifiserbare data.

Vi håper på deres positive bidrag til denne viktige studien og at dere videresender dette så snart som mulig. Vi imøteser deres svar på vår henvendelse.

Med vennlig hilsen

Frøydis Langmark  
 Direktør  
 Krefregisteret

Vinjar Fønnebo  
 Professor dr. med.  
 Universitetet i Tromsø



**Krefregisteret**  
Institutt for populasjonsbasert kreftforskning



## **BEKREFTELSE**

↑ Vi har per \_\_\_\_\_ (dato) videresendt samtlige skjema som vi fikk tilsendt

↑ Vi har per \_\_\_\_\_ (dato) videresendt skjemaene vi fikk tilsendt med unntak av

konvoluttnummer:.....

.....

**Signatur**.....

**Sykehusets stempel**.....

Svarsendingen fakses, mailes eller sendes i posten til:

**NAFKAM, Universitetet i Tromsø, Breivika, 9037 Tromsø**  
**Tlf. 77 64 66 50, Fax 77 64 6866, e-mail [nafkam@fagmed.uit.no](mailto:nafkam@fagmed.uit.no)**





Krefregisteret  
Institutt for populasjonsbasert kreftforskning



Tromsø/Oslo 21.10.2004

Kjære kollega!

Først vil vi benytte anledningen til å takke for at avdelingen i fjor høst sendte ut brev til pasientene som var trukket ut til deltagelse i undersøkelsen om bruk av alternativ medisin blant to grupper kreftpasienter identifisert i Krefregisteret. Faktisk bruk av alternativ medisin kartlegges hos pasienter som har overlevd 5 år eller mer etter påvist kreft. Et eksemplar av forskningsprotokollen kan hvis ønskelig fåes ved henvendelse til Nasjonalt forskningssenter innen komplementær og alternativ medisin (NAFKAM) ([nafkam@fagmed.uit.no](mailto:nafkam@fagmed.uit.no)) ved universitetet i Tromsø. Etter første utsendelse har vi fått svar fra 43% av pasientene. Vi har fått mange positive tilbakemeldinger fra de som svarte. Det var fra etisk komité gitt tillatelse til å sende ut én gjentatt henvendelse til de pasientene som ikke svarte på første henvendelse. På grunn av at responsraten er såvidt lav at det svekker utsagnskraften i undersøkelsen, vil vi gjerne gjøre en ny henvendelse til pasientene, slik at undersøkelsen blir så representativ som mulig. Alle pasienter som vi nå gjør henvendelse om er i live per dags dato.

Krefregisteret presiserer at henvendelser til pasienter skal gå gjennom behandlende lege. Vi vil derfor be dere om å videresende den/de vedlagte konvolutt(ene) (et åpent prøve-eksemplar ligger vedlagt) bestående av et følgebrev, et firesiders spørreskjema og en ferdig frankert svarkonvolutt til de av pasientene i vår utvalgsgruppe som tilhører ditt sykehus. Samtidig vil vi be dere stemple utsendelseskonvolutt med ditt sykehus' stempel. Når spørreskjemaene er sendt ut til pasientene, ber vi dere returnere vedlagte svarsending til oss med opplysninger om når skjemaene er sendt ut. Det gir oss oversikt over hvilke pasienter som har fått skjemaet og når de har mottatt det. Vi presiserte sist at det måtte være helt sikkert at pasienten var informert om sin kreftsykdom. I et par tilfeller fikk vi tilbakemelding om at pasientenes antatte kreftsykdom var en feildiagnose. Vi er meget takknemlige for de tilbakemeldingene. Det burde, på bakgrunn av dette, ikke være nødvendig med en ny gjennomgang av pasientenes journaler, og vi antar at brevene kan sendes ut direkte.

Studien er tilrådd av etisk komité og personidentifiserbare opplysninger om pasienten vil kun foreligge i Krefregisteret. NAFKAM vil kun arbeide med ikke-personidentifiserbare data.

Vi håper på deres positive bidrag til denne viktige studien og at dere videresender dette så snart som mulig. Vi imøteser deres svar på vår henvendelse.

Med vennlig hilsen

Frøydis Langmark  
Direktør  
Krefregisteret

Vinjar Fønnebo  
Professor dr. med.  
Universitetet i Tromsø



**Kreftregisteret**  
Institutt for populasjonsbasert kreftforskning



## **BEKREFTELSE**

↑ Vi har per \_\_\_\_\_ (dato) videresendt samtlige skjema som vi fikk tilsendt

↑ Vi har per \_\_\_\_\_ (dato) videresendt skjemaene vi fikk tilsendt med unntak av

konvoluttnummer:.....

.....

**Signatur**.....

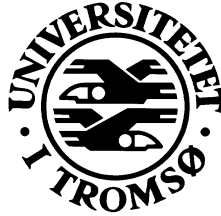
**Sykehusets stempel**.....

Svarsendingen fakses, mailes eller sendes i posten til:

**NAFKAM, Universitetet i Tromsø, Breivika, 9037 Tromsø**  
**Tlf. 77 64 66 50, Fax 77 64 6866, e-mail [nafkam@fagmed.uit.no](mailto:nafkam@fagmed.uit.no)**

Appendix 1-B:  
Information sent to the patients





Tromsø, 27.10.03

Forespørsel om å delta i forskningsprosjekt

## **LIVSTIL FØR OG ETTER KREFTDIAGNOSE**

Dette skjemaet sendes til deg fra din behandlingsinstitusjon/lege – forskningsledelsen har kun kjennskap til nummeret på vedlagte spørreskjema. Nummeret er kun for å kunne sjekke at skjemaet er videresendt til deg. Kreftregisteret registrerer årlig rundt 20 000 nye tilfeller av kreft. Alle krefttilfeller, både alvorlige og mindre alvorlige skal meldes inn og registreres i Kreftregisteret. Her finnes derfor alt fra ondartede hudlidelser med meget gode utsikter til helbredelse, til mer alvorlige kreftformer.

Det er kjent at mennesker som får kreft tidvis oppsøker behandling og gjennomfører livsstilsendringer som går utover det det norske helsevesenet normalt tilbyr. Hensikten med denne studien er å kartlegge hvor stor andel av kreftpasientene som rent faktisk gjør dette. Hvis du ønsker å delta i denne studien, vil vi be deg svare på det vedlagte spørreskjemaet og returnere det til oss i den ferdig frankerte svarkonvolutt. Det vil ta cirka 10 minutter å svare på spørreskjemaet. Svarene dine kan hjelpe oss til å få en bedre forståelse av i hvilken grad personer med kreft endrer livsstil og benytter seg av behandlingsformer tilbudt utenfor det etablerte helsevesenet, og hvilken nytte de selv opplever å ha hatt av slik behandling. Hvis du ikke ønsker å delta i studien trenger du ikke å foreta deg noen ting.

Det gis ingen godtgjørelse for deltakelse i denne studien.

Kun forskningsleder og forskningsmedarbeider vil ha tilgang til skjemaene. Når studien er avsluttet vil skjemanummeret bli slettet og dataene vil ikke lenger kunne kobles til enkeltpersoner. Opplysninger i eventuelle rapporter vil heller ikke kunne tilbakeføres til enkeltpersoner.

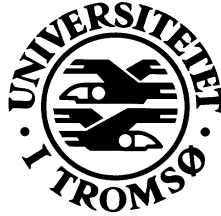
Deltakelse i studien er frivillig. Dersom du ikke ønsker å delta i studien trenger du ingen begrunnelse for det og det får ingen konsekvenser for deg om du ikke samtykker i å delta.

Samtykke til å delta i studien gir du ved å fylle ut det vedlagte spørreskjemaet og returnere det i den ferdig frankerte svarkonvolutt som ligger vedlagt. **Undersøkelsen består kun av dette ene spørreskjemaet.**

Med vennlig hilsen

Vinjar Fønnebo, prosjektleder  
Professor dr.med.

Hvis du har spørsmål om prosjektet, er du velkommen til å ringe eller skrive til prosjektmedarbeider, stipendiat Agnete Egilsdatter Kristoffersen eller prosjektleder, professor Vinjar Fønnebo, telefon 77646650.



Tromsø, 25.10.04

Forespørsel om å delta i forskningsprosjekt

## LIVSTIL FØR OG ETTER KREFTDIAGNOSE

Dette skjemaet sendes til deg fra din behandlingsinstitusjon. Kreftregisteret registrerer årlig rundt 20 000 nye tilfeller av kreft. Alle krefttilfeller, både alvorlige og mindre alvorlige skal meldes inn og registreres i Kreftregisteret. Her finnes derfor alt fra ondartede hudlidelser med meget gode utsikter til helbredelse, til mer alvorlige kreftformer.

Det er kjent at mennesker som får kreft tidvis oppsøker behandling og gjennomfører livsstilsendringer som går utover hva det norske helsevesenet normalt tilbyr. Hensikten med denne studien er å kartlegge hvor stor andel av kreftpasientene som rent faktisk gjør dette. Hvis du ønsker å delta i denne studien, vil vi be deg svare på det vedlagte spørreskjemaet og returnere det til oss i den ferdig frankerte svarkonvolutt. Det vil ta cirka 10 minutter å svare på spørreskjemaet. Svarene dine kan hjelpe oss til å få en bedre forståelse av i hvilken grad personer med kreft endrer livsstil og benytter seg av behandlingsformer tilbudt utenfor det etablerte helsevesenet, og hvilken nytte de selv opplever å ha hatt av slik behandling. Dersom du ikke ønsker å delta vil det være til stor hjelp at du legger svarskjemaet utfyllt i svarkonvolutt og returnerer det slik at vi unngår å eventuelt etterlyse svar.

Du kan ha fått denne henvendelsen en gang tidligere. Når vi velger å sende den ut på nytt til de som ikke har svart/ikke har mottatt skjemaet i første utsendelse, skyldes det at svarresponsen på den første utsendelsen var så vidt lav (43 % svarrespons) at vi vanskelig kan trekke noen konklusjoner på bakgrunn av det materialet vi nå sitter på. Vi vil derfor spørre deg på nytt om du kunne tenke deg å delta i denne spørreundersøkelsen. Vi vil likevel presisere at det selvfølgelig er frivillig å delta og at dersom du fortsatt ikke ønsker å delta i studien trenger du ingen begrunnelse for det og det får ingen konsekvenser for deg om du ikke samtykker i å delta.

Det gis ingen godtgjørelse for deltakelse i denne studien.

Forskningsledelsen har bare kjennskap til nummeret på vedlagte spørreskjema og dette er kun for å sjekke at brevet er sendt til deg. Kun forskningsleder og forskningsmedarbeider vil ha tilgang til skjemaene. Når studien er avsluttet vil skjemanummeret bli slettet. Opplysninger i eventuelle rapporter vil heller ikke kunne tilbakeføres til enkeltpersoner.

Samtykke til å delta i studien gir du ved å fylle ut det vedlagte spørreskjemaet og returnere det i den ferdig frankerte svarkonvolutt som ligger vedlagt. **Undersøkelsen består kun av dette ene spørreskjemaet.**

Med vennlig hilsen

Vinjar Fønnebø, prosjektleder  
Professor dr.med.

Hvis du har spørsmål om prosjektet, er du velkommen til å ringe eller skrive til prosjektmedarbeider, stipendiat Agnete Egilsdatter Kristoffersen eller prosjektleder, professor Vinjar Fønnebø, telefon 77646650

**DET MEDISINSKE FAKULTET**

Nasjonalt forskningssenter innen komplementær og alternativ medisin  
Universitetet i Tromsø, N-9037 Tromsø, telefon 77 64 66 50, telefaks 77 64 68 66

Appendix 1-C:  
Questionnaire used in the CRN-study







## Spørreundersøkelse Livsstil før og etter kreftdiagnose

Mennesker som får påvist kreft oppsøker tidvis behandling og gjør livstilsendringer som går utover det norske sykehus normalt tilbyr. Hensikten med denne studien er å kartlegge hvor stor andel av pasienter med kreftdiagnose som rent faktisk gjør dette. Hvis du ønsker å delta i denne studien, vil vi be deg svare på dette spørreskjemaet og returnere det til oss i den ferdig frankerte svarkonvolutten. Det tar cirka 10 minutter å svare på skjemaet. Det er ingen krav om at alle spørsmål besvares.

Med vennlig hilsen

*Vinjar Fønnebo*  
Vinjar Fønnebo

Nasjonalt forskningssenter innen  
komplementær og alternativ medisin

### Bakgrunnsinformasjon om deg:

- 1) Er du  Mann  
 Kvinne
- 2) Hvilket år er du født? 19\_\_\_\_\_
- 3) Hva er din sivilstand i dag?
  - Enslig
  - Gift / samboende / registrert partner
  - Skilt / separert
  - Enke / enkemann
- 4) Hva er din høyeste fullførte utdanning?
  - Mindre enn 7-årig folkeskole
  - 7-årig folkeskole
  - Ungdomsskole / Realskole
  - Videregående skole / Gymnas / yrkesfaglig utdanning
  - Høyskole / Universitet inntil 4 år
  - Høyskole / Universitet mer enn 4 år
- 5) Da du fikk påvist kreft første gang, bodde du da (sett ett eller flere kryss):
  - Alene
  - Sammen med ektefelle/samboer
  - Sammen med egne barn
  - Sammen med andre slektninger
  - På institusjon
  - Annen boform.....
- 6) Hva var din sivilstand da du fikk kreft?
  - Enslig
  - Gift / samboende / registrert partner
  - Skilt / separert
  - Enke / enkemann
- 7) Hvor bodde du da kreften ble påvist?
  - På Østlandet
  - På Sørlandet
  - På Vestlandet
  - I Trøndelag
  - I Nord-Norge
  - I utlandet, angi land:



## Bakgrunnsinformasjon fortsetter:

### 8) Hvor mange innbyggere har stedet / byen der du bodde da du fikk kreft?

- Færre enn 500 innbyggere
- 500-1 999 innbyggere
- 2000-19 999 innbyggere
- 20 000-99 999 innbyggere
- 100 000 innbyggere eller mer

### 9) Hvordan bodde du da kreften ble påvist?

- På gård
- I enebolig
- I tomannsbolig / rekkehus
- I blokk / bygård
- På hybel
- På institusjon
- Annen boform:

.....

### 10) Da kreften ble påvist var du da:

- i inntektsgivende arbeid
- hjemmeværende
- arbeidssøkende
- student / skoleelev
- pensjonist
- uføretrygdet / på attføring
- annet:

.....

## Familiebakgrunn:

### 11) Hva er/var din fars høyeste fullførte utdanning?

- Mindre enn 7-årig folkeskole
- 7-årig folkeskole
- Ungdomsskole / Realskole
- Videregående skole / Gymnas / yrkesfaglig utdanning
- Høyskole / Universitet inntil 4 år
- Høyskole / Universitet mer enn 4 år
- Vet ikke

### 12) Hva er/var din mors høyeste fullførte utdanning?

- Mindre enn 7-årig folkeskole
- 7-årig folkeskole
- Ungdomsskole / Realskole
- Videregående skole / Gymnas / yrkesfaglig utdanning
- Høyskole / Universitet inntil 4 år
- Høyskole / Universitet mer enn 4 år
- Vet ikke

### 13) Hva er/var din ektefelle/samboers / partners høyeste fullførte utdanning?

- Mindre enn 7-årig folkeskole
- 7-årig folkeskole
- Ungdomsskole / Realskole
- Videregående skole / Gymnas / yrkesfaglig utdanning
- Høyskole / Universitet inntil 4 år
- Høyskole / Universitet mer enn 4 år
- Vet ikke
- Har ikke / har ikke hatt ektefelle / samboer / partner

### 14) Hvor bodde familien din det meste av tiden da du vokste opp?

- På Østlandet
- På Sørlandet
- På Vestlandet
- I Trøndelag
- I Nord-Norge
- I utlandet, angi land:

.....

- Jeg flyttet hele barndommen (gå til spørsmål 17)

### 15) Hvor mange innbyggere hadde stedet/byen der du vokste opp?

- Færre enn 500 innbyggere
- 500-1 999 innbyggere
- 2000-19 999 innbyggere
- 20 000-99 999 innbyggere
- 100 000 innbyggere eller mer

### 16) Hvordan bodde familien din hovedsakelig da du vokste opp?

- På gård
- I enebolig
- I tomannsbolig / rekkehus
- I blokk / bygård
- Annen boform:

.....

## Bruk av komplementær- og alternativ behandling:

17) Har du mottatt en eller flere av følgende behandlinger i tiden etter at du fikk kreft (sett ett etter flere kryss)?

**JA, følgende behandling(er):**

- Akupunktur
- Homøopati
- Soneterapi
- Healing
- Naturterapi
- Massasje / aromaterapi
- Samtale med psykolog, psykiater, gestaltterapeut el.
- Religiøs helbreder som har bedt / lest for deg
- Opphold på alternativ kreftklinikk
- Annen behandling gitt **utenfor** det etablerte helsevesenet:

.....

**NEI,**

- har vurdert denne type behandling men ikke tatt i bruk
- har aldri vurdert slik behandling

Hvis NEI – gå til spørsmål 22

18) Hvis JA, hvor mange konsultasjoner har du hatt i alt?

- 1-3
- 4-8
- 9 eller fler

19) På hvilket tidspunkt startet du denne behandlingen?

- Jeg var allerede i gang med behandling da kreften ble påvist
- 0-6 måneder etter påvist kreft
- 7-12 måneder etter påvist kreft
- 13-24 måneder etter påvist kreft
- Mer enn 2 år etter påvist kreft

20) Ble behandlingen benyttet:

- parallelt med behandling på sykehus / hos lege?
- etter at behandlingen på sykehuset / hos legen var avsluttet?
- i stedet for behandling på sykehus / hos lege?

21) Hvordan opplevde du denne behandlingen?

- Den har hatt svært positiv effekt
- Den har hatt litt positiv effekt
- Den har ikke hatt effekt
- Den har hatt litt negativ effekt
- Den har hatt svært negativ effekt
  
- Vet ikke

## Kosthold:

22) Hvordan er kostholdet ditt i dag?

- Jeg spiser som før kreften ble påvist
- Jeg har endret kostholdet noe
- Jeg har endret kostholdet mye
- Jeg har lagt kostholdet helt om

23) Har du i forbindelse med sykdommen tatt spesielle kosttilskudd / vitamintilskudd?

**JA,** (sett kryss for det du har tatt, ett eller flere kryss):

- vanlige vitamin- og mineraltabletter
- egendefinert kur av urter og kosttilskudd
- kur spesialtilpasset av kostveileder eller vitamin- og mineralterapeut

**Ferdig kur:**

- Nitterkuren
- Andre ferdigkurer, hvilke:

.....

- Annet.....

**NEI,**

- har vurdert dette, men ikke tatt i bruk
- har aldri vurdert dette

## Hjelp til selvhjelp:

### 24) Har du i tiden etter kreftdiagnosen

(sett ett eller flere kryss):

- deltatt i selvhjelpsgrupper?
  - drevet avspenningsøvelser på egenhånd?
  - meditert jevnlig?
  - drevet med positiv "visualisering"?
  - annen form for selvhjelp / egenerapi?
- Spesifiser:

.....

- Har ikke drevet bevisst egenerapi

### 25) Hvordan vurderer du din nåværende helsetilstand?

- Svært god
- God
- Middels
- Dårlig
- Svært dårlig

### 26) Hvis du føler det er noe som har vært særlig betydningsfullt i din takling av kreften som ikke er fanget opp av dette spørreskjemaet, formulerer du dette med dine egne ord på et eget ark og legger det ved spørreskjemaet.

## Mestring:

Utsagnene nedenfor handler om hvordan du opplever og mestrer de plagene / problemene du har hatt. Sett ett kryss i den ruten som passer best slik du opplever deg selv:

	Helt enig	Nokså enig	Både og	Nokså uenig	Svært uenig
27) Jeg sier i fra når jeg er sint eller trist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28) Jeg snakker gjerne med noen utvalgte mennesker når det røyner på	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29) Å gjøre nye ting er ofte vanskelig for meg	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30) Jeg går aktivt inn for å finne en løsning på problemene mine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31) Fysisk aktivitet er viktig for meg	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32) Jeg prøver å glemme plagene mine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33) Jeg legger problemene mine bak meg ved å konsentrere meg om noe annet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34) Jeg tror det kan komme noe positivt ut av problemene / plagene mine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35) Jeg har god tro på at plagene mine vil bli bedre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36) Jeg arbeider mye for å holde plagene / problemene på avstand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37) Jeg føler langt på vei at jeg har gitt opp	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38) Jeg trekker meg tilbake fra andre når jeg har det vanskelig	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39) Det betyr mer for meg hvordan jeg selv opplever min egen helse, enn hva fagpersonene rundt meg måtte mene	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Takk for at du svarte på spørreskjemaet!**



Appendix 2:  
The Fifth Tromsø Study (T5)



Appendix 2-A:  
Information leaflet Tromsø V





**Welcome to the fifth round  
of the Tromsø Study!**

*-a collaboration between:*



**Department of Community Medicine,  
University of Tromsø**  
tlf: 77 64 48 16 (kl. 9 - 11) Tromsøsus@stn.uft.no



**National Health Screening Service**  
tlf: 22 34 21 00 (kl. 9 - 15) post@shus.no

*You will find more information about the health survey on  
the homepage of the National Health Screening Service*

[www.shus.no](http://www.shus.no)

**Take the chance!**

**INVITATION TO  
A HEALTH STUDY**

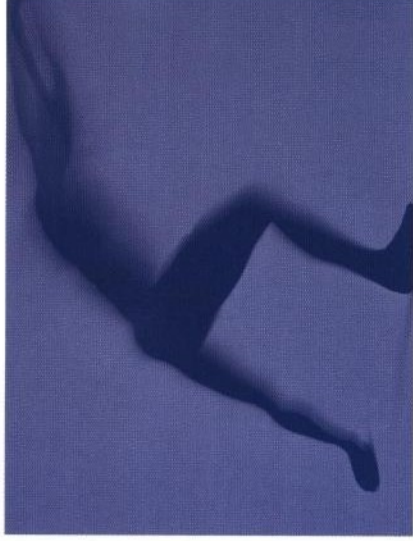
## Would you like to participate in the fifth survey of the Tromsø study?

### Why a new round of the Tromsø study?

Large health studies were conducted in Tromsø in 1974, 1979-80, 1986-87, and 1994-95. These surveys have given us important knowledge concerning cardiovascular epidemiology and other serious diseases, such as cancer.

The main purpose of another

Tromsø study is to monitor any changes in the health of the population since last survey. We will analyze the information we have about a person, both personal data and results from analysis of frozen blood, and see if there are relationships to diseases that occur. This way we learn more on how cardiovascular diseases, cancer and other major diseases develop and how they can be prevented.



### Why are we asking you to participate?

We ask everyone who participated in the Special Study in the Tromsø study in 1994-95 and a selection of others older than 29 years.



### **Where are you going to meet?**

The survey will for the vast majority take place in Elizabeth Center in Tromsø. For some of the outer places in the municipality, the survey will take place locally. Those concerned are notified in this letter.

On the front page of the questionnaire that you receive with this letter are the opening hours for the health survey and when you have to attend the survey. If you cannot attend at that time, you are welcome any another time during the opening hours of the survey. There is no need to tell us about this — just show up when we are open.

### **What does the study include?**

The Tromsø study is first and foremost a research project. Through following up as many as possible from the study of 1994-95, we gain valuable information of health and disease in the population of Tromsø.

Participants' general health status will be examined with regard to certain diseases and risk conditions. If you have a high risk of developing cardiovascular diseases you will be notified of this.

On the day of the examination you will be guided through the survey and there will be an opportunity to ask questions. Your height, weight and waist circumference is measured, as well as blood pressure, and a blood sample is taken. Your lung capacity is determined, in addition to simple tests of vision and strength. Tests to determine osteoporosis is also conducted.

The blood sample may later be analyzed for fatty substances, blood sugar, indicators of infections, diet, hormones, liver- and kidney function, and bone markers.

Everyone who participated in the Special Study in 1994-95 is also offered to take part in another Special Study. This study provides information on the heart and the main arteries in neck and abdomen, and offers a more detailed analysis on tendency of osteoporosis.

This survey is also located at the Elisabeth-center in Tromsø. A time will be scheduled for you and information is provided upon arrival.

### **The Questionnaires**

With this letter a questionnaire is attached. We kindly ask you to complete this form at home and bring it on the day of the examination.

If you are unsure of how to answer a question, leave it blank. You will be aided at the examination.

Everyone who participates in the study will be given an additional questionnaire of other factors which might affect your health. The questionnaire is to be completed at home and sent to the National Health Screening Service in the enclosed envelope.

### **Future analysis of blood**

The blood which is frozen will be used for medical research only, in order to find factors influencing disease. In most cases this means that data from people with a disease is compared to data from those without it. The comparison is done on already collected data and the new analysis from the frozen blood.

We might want to analyze parts of the DNA from the frozen blood cells. Because DNA is important for the regulating and development in human being, we need knowledge on DNA to understand why diseases evolve. Analysis of this kind are only conducted after the Data Inspectorate has given a permission and if The Regional Committee for Research Ethics has no objections to the analysis.

## We need your consent

When you attend the study, you will be asked to sign a consent form where you agree to the following six points:

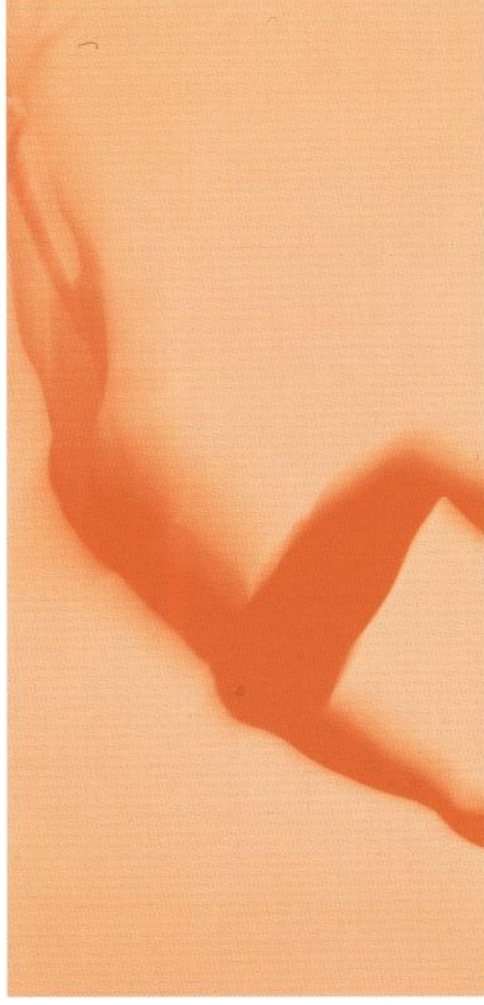
- That we may contact you with recommendations of follow ups, treatment or prevention of disease.
- That we may ask you to participate in similar studies in the future.
- That we may use the results for medical research.
- That the results, after legal approval from the Data Inspectorate, may be linked with information about you in other registries, to be used for research purposes. This might be registries including information on health, pension and disease, and also data on income, education and occupation, in addition to information from previous health studies in Tromsø. Examples of such registries are the Cancer Registry, the Cause of Death registry and population censuses. In these cases your name and social security number are removed when data is analyzed.
- That the blood sample may be stored and used for medical research. All use of this sample will only take place after approval from the Data Inspectorate and if The Regional Committees for Research Ethics has no objections.
- That the blood sample may also be used for analysis of DNA.

*Even if you approve to this now, you are entitled to change your opinion later and also ask to have your profile deleted from the registry. You may also decline to consent to one or more of the points above. The Data Inspectorate has given consent to this fifth survey of the Tromsø Study, and the Regional Committee for Research Ethics has no objections. We keep your results confidential and safe. Everyone employed in the Tromsø Study has signed a confidentiality agreement.*

## When will you receive your results?

About four weeks after you participated in the study you will receive a letter wherein your recorded values for cholesterol, blood pressure and blood sugar are stated. You will also receive more information on the different risk factors.

People who are found to be at particularly high risk of developing cardiovascular diseases and diabetes will be recommended to seek further examination from their own doctor.



Appendix 2-B:  
Declaration of consent Tromsø V



## SAMTYKKEERKLÆRING

Sammen med forespørselen om deltaking i undersøkelsen, ble jeg informert om undersøkelsen. Jeg har lest/blitt forklart det informasjonen.

Jeg samtykker i at (stryk det/de avsnitt du reserverer deg mot)

1. jeg kan bli kontaktet med anbefaling om oppfølging, behandling eller for å forebygge sykdom.
2. jeg kan bli bedt om å delta i lignende undersøkelser i framtida.
3. resultatene mine kan brukes i medisinsk forskning.
4. resultatene mine (etter godkjenning fra Datatilsynet) kan settes sammen med opplysninger om meg i andre registre til bruk i forskning. Det kan være registre om helse, trygd og sykdom. Det kan også være registre om inntekt, utdanning og yrke, samt opplysninger fra de tidligere helseundersøkelser i Tromsø. Eksempler på slike registre er Kreftregisteret, Dødsårsaksregisteret og folketellingene. I disse tilfellene blir navnet og personnummeret mitt fjernet når dataene blir analysert.
5. blodprøven min kan lagres og brukes i medisinsk forskning. All bruk av denne prøven vil bare skje etter godkjenning fra Datatilsynet og dersom den regional komité for medisinsk forskningsetikk ikke har innvendinger.
6. blodprøven også kan brukes til analyse av arvestoff.

.....  
Sted og dato

.....  
Underskrift





## Appendix 2-C:

First questionnaire for subjects aged <70 years

Tromsø V



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# Health survey

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## Personal Invitation

Don't write here

5.3 (Municipality)

(County)

(Country)

└

9.3 (Business)

9.4 (Occupation)

14.7 (Mark)

## 1. YOUR OWN HEALTH

### 1.1 What is your current state of health? (Tick one only)

Poor  1      Not so good  2      Good  3      Very good  4

### 1.2 Do you have, or have you had?:

	Yes	No	Age first time
Asthma.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
Hay fever .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
Chronic bronchitis/emphysema .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
Diabetes .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
Osteoporosis .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
Fibromyalgia/chronic pain syndrome .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
Psychological problems for which you have sought help .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
A heart attack .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
Angina pectoris (heart cramp) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
Cerebral stroke/brain haemorrhage .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>

1.3 Have you noticed attacks of sudden changes in your pulse or heart rhythm in the last year? ..... Yes  No

1.4 Do you get pain or discomfort in the chest when: Walking up hills, stairs or walking fast on level ground? Yes  No

### 1.5 If you get such pain, do you usually:

Stop?  1      Slow down?  2      Carry on at the same pace?  3

1.6 If you stop, does the pain disappear within 10 minutes? ..... Yes  No

1.7 Can such pain occur even if you are at rest?..... Yes  No

## 2. MUSCULAR AND SKELETAL COMPLAINTS

### 2.1 Have you suffered from pain and/or stiffness in muscles and joints during the last 4 weeks?

(Give duration only if you have had problems)

	No complaint			Duration	
	Some complaint	Severe complaint	Up to 2 weeks	2 weeks or more	
Neck/shoulders .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Arms, hands .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Upper part of your back...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lumbar region .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hips, legs, feet .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other places .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

1      2      3      1      2

### 2.2 Have you ever had:

	Yes	No	Age last time
Fracture in the wrist/forearm .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
Hip fracture?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>

## 3. OTHER COMPLAINTS

### 3.1 Below is a list of various problems. Have you experienced any of this during the last week (including today)?

(Tick once for each complaint)

	No complaint	Little complaint	Pretty much	Very much
Sudden fear without reason .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Felt afraid or anxious .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Faintness or dizziness .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Felt tense or upset .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tend to blame yourself .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sleeping problems .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Depressed, sad .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling of being useless, worthless .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling that everything is a struggle .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling of hopelessness with regard to the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

1      2      3      4

## 4. USE OF HEALTH SERVICES

### 4.1 How many times in the last 12 months have you been to/used: (Tick once for each line)

	None	1-3 times	4 or more
General practitioner (GP) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical officer at work .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologist or psychiatrist (private or out-patient clinic) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other specialist (private or out-patient clinic) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emergency GP (private or public) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospital admission .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home nursing care .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapist .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chiropractor .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dentist .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Alternative practitioner .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## 5. CHILDHOOD/YOUTH AND AFFILIATION

5.1 How long altogether have you lived in the county?   year (Put 0 if less than half a year)

5.2 How long altogether have you lived in the municipality?   year (Put 0 if less than half a year)

### 5.3 Where did you live most of the time before the age of 16? (Tick one option and specify)

Same municipality ....  1

Another municipality in the county .....  2      Which one: \_\_\_\_\_

Another county in Norway  3      Which one: \_\_\_\_\_

Outside Norway .....  4      Country:: \_\_\_\_\_

### 5.4 Have you moved within the last five years?

No  1      Yes, one time  2      Yes, more than once  3

## 6. BODY WEIGHT

6.1 Estimate your body weight when you were 25 years old:     kg

## 7. FOOD AND BEVERAGES

### 7.1 How often do you usually eat these foods? (Tick once per line)

	Rarely /never	1-3 times /month	1-3 times /week	4-6 times /week	1-2 times /day	3 times or more /day
Fruit, berries .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cheese (all types).....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Potatoes .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Boiled vegetables .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fresh vegetables/salad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fatty fish (e.g. salmon, trout, mackerel, herring)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	1	2	3	4	5	6

### 7.2 What type of fat do you usually use? (Tick once per line)

	Don't use	Butter	Hard margarine	Soft/light margarine	Oils	Other
On bread .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
For cooking .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	1	2	3	4	5	6

### 7.3 Do you use the following dietary supplements:

	Yes, daily	Sometimes	No
Cod liver oil, fish oil capsules .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vitamins and/or mineral supplements?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### 7.4 How much of the following do you usually drink? (Tick once per line)

	Rarely /never	1-6 glasses /week	1 glass /day	2-3 glasses /day	4 glasses or more /day
Full milk, full-fat curdled milk, yoghurt .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Semi-skimmed milk, semi-skimmed curdled milk, low-fat yoghurt .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Skimmed milk, skimmed curdled milk .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Extra semi-skimmed milk .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Juice .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Water .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mineral water (e.g. Farris, Ramløsa etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cola-containing soft drink .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other soda/soft drink .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	1	2	3	4	5

### 7.5 Do you usually drink soft drink: with sugar 1 without sugar 2

### 7.6 How many cups of coffee and tea do you drink daily? Number of cups (Put 0 for the types you don't drink daily)

Filtered coffee .....	<input type="text"/>
Boiled coffee/coarsely ground coffee for brewing .....	<input type="text"/>
Other type of coffee .....	<input type="text"/>
Tea .....	<input type="text"/>

### 7.7 Approximately how often have you during the last year consumed alcohol? (Do not count low-alcohol and alcohol-free beer)

Never consumed alcohol	Have not consumed alcohol last year	A few times last year	About 1 time a month
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2-3 times per month	About 1 time a week	2-3 times a week	4-7 times a week
<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8

To those who have consumed the last year:

### 7.8 When you drink alcohol, how many glasses or drinks do you normally drink? number

### 7.9 Approximately how many times during the last year have you consumed alcohol equivalent to 5 glasses or drinks within 24 hours? Number of times

### 7.10 When you drink, do you normally drink: (Tick one or more)

Beer	Wine	Spirits
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## 8. SMOKING

### 8.1 How many hours a day do you normally spend in smoke-filled rooms? Number of total hours

### 8.2 Did any of the adults smoke at home while you were growing up? Yes No

### 8.3 Do you currently, or did you previously live together with a daily smoker after your 20<sup>th</sup> birthday? Yes, now Yes, previously Never

### 8.4 Do you/did you smoke daily? If NEVER: Go to question 9 : (EDUCATION AND WORK)

### 8.5 If you smoke daily now, do you smoke: Yes No

Cigarettes?.....

Cigars/cigarillos?.....

A pipe?.....

### 8.6 If you previously smoked daily, how long is it since you quit? Number of years

### 8.7 If you currently smoke, or have smoked previously:

How many cigarettes do you or did you normally smoke per day? Number of cigarettes

How old were you when you began daily smoking? Age in years

How many years in all have you smoked daily? Number of years

## 9. EDUCATION AND WORK

### 9.1 How many years of education have you completed? Number of years (Include all the years you have attended school or studied)

### 9.2 Do you currently have paid work?

Yes, full-time  1 Yes, part-time  2 No  3 T

### 9.3 Describe the activity at the workplace where you had paid work for the longest period in the last 12 months. (e.g. Accountancy firm, school, paediatric department, carpentry workshop, garage, bank, grocery store, etc.)

Business: \_\_\_\_\_

If retired, enter the former business and occupation. Also applies to 9.4

### 9.4 Which occupation/title have or had you at this workplace? (e.g. Secretary, teacher, industrial worker, nurse, carpenter, manager, salesman, driver, etc.)

Occupation: \_\_\_\_\_

### 9.5 In your main occupation, do you work as self-employed, as an employee or family member without regular salary?

Self-employed  Employee  Family member

### 9.6 Do you believe that you are in danger of losing your current work or income within the next two years? Yes No

### 9.7 Do you receive any of the following benefits? Yes No

Sickness benefit (are on sick leave) .....

Old age pension, early retirement (AFP) or survivor pension .....

Rehabilitation/reintegration benefit .....

Disability pension (full or partial) .....

Unemployment benefits during unemployment .....

Social welfare benefits .....

Transition benefit for single parents .....

## 10. EXERCISE AND PHYSICAL ACTIVITY

### 10.1 How has your physical activity in leisure time been during this last year?

Think of a weekly average for the year.

Time spent going to work is count as leisure time. Answer both questions.

	Hours per week			
	None	Less than 1	1-2	3 or more
Light activity (not sweating/out of breath).....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hard physical activity (sweating/out of breath).....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	1	2	3	4

### 10.2 Describe exercise and physical exertion in your leisure time. If your activity varies much e.g. between summer and winter, then give an average. The question refers only to the last year. (Tick the most appropriate box)

Reading, watching TV or other sedentary activity? .....  1

Walking, cycling or other forms of exercise at least 4 hours a week? .....  2  
(Include walking or cycling to work, Sunday walk/stroll, etc.)

Participation in recreational sports, heavy gardening, etc.? .....  3  
(Note: duration of activity at least 4 hours a week)

Participation in hard training or sports competitions, regularly several times a week? .....  4

## 11. FAMILY AND FRIENDS

### 11.1 Do you live with: Spouse/partner?.....

Yes  No

### 11.2 How many good friends do you have?

Count the ones you can talk confidentially with and who can give you help when you need it. Do not count people you live with, but do include other relatives.

Number of friends

### 11.3 How much interest do people show for what you do? (Tick only once)

Great interest  1    Some interest  2    Little interest  3    No interest  4    Uncertain  5

### 11.4 How many associations, sport clubs, groups, religious communities or similar do you take part in? (Write 0 if none)

Number

### 11.5 Do you feel that you can influence what happening in your local community where you live? (Tick only once)

Yes, a lot  1    Yes, some  2    Yes, a little  3    No  4    Never tried  5

## 12. ILLNESS IN THE FAMILY

### 12.1 Have one or more of your parents or siblings had a heart attack (heart wound) or angina pectoris (heart cramp)?

Yes  No  Don't know

### 12.2 Tick for the relatives who have or have had any of the illnesses: (Tick for each line)

	Mother	Father	Brother	Sister	Child	None of these
Cerebral stroke or brain haemorrhage .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Heart attack before age of 60 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Asthma.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cancer .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diabetes .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### 12.3 If any relatives have diabetes, at what age did they get diabetes (if for e.g. many siblings, consider the one who got it earliest in life):

Don't know, not applicable	Mother's age	Father's age	Brother's age	Sister's age	Child's age
<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

## 13. USE OF MEDICINES

With medicines, we mean drugs purchased at pharmacies. Supplements and vitamins are not considered here.

### 13.1 Do you use:

	Now	Previously, but not now	Never used
Blood pressure lowering drugs .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cholesterol-lowering drugs .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### 13.2 How often have you during the last 4 weeks used the following medicines? (Tick once for each line)

	Not used in the last 4 weeks	Less than every week	Every week but not daily	Daily
Painkillers non-prescription ....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Painkillers on prescription .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sleeping pills .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tranquillizers .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Antidepressants .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other prescription medicines ...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	1	2	3	4

### 13.3 For those medicines you have checked in points 13.1 and 13.2, and that you've used during the last 4 weeks:

State the name and the reason that you are taking/have taken these (disease or symptom):

(Tick for each duration you have used the medicine)

Name of the medicine: (one name per line)	Reason for use of the medicine	How long have you used the medicine	
		Up to 1 year	1 year or more
		<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>

If there is not enough space here, you may continue on a separate sheet that you attach

## 14. THE REST OF THE FORM IS TO BE ANSWERED BY WOMEN ONLY

### 14.1 How old were you when you started menstruating?

Age in years

### 14.2 If you no longer menstruating, how old were you when you stopped menstruating?

Age in years

### 14.3 Are you pregnant at the moment?

Yes  No  Uncertain  Above fertile age

### 14.4 How many children have you given birth to?

Number of children

### 14.5 Do you use, or have you ever used? (Tick once for each line)

	Now	Before, but not now	Never
Oral contraceptive pills/mini pill/contraceptive injection .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hormonal intrauterine device (IUD) (not ordinary IUD) ..	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Estrogen (tablets or patches) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Estrogen (cream or suppositories)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### 14.6 If you use/have used prescription estrogen:

How long have you used it? Number of years

### 14.7 If you use contraceptive pills, mini pill, contraceptive injection, hormonal IUD or estrogen, what brand do you use?

Appendix 2-D:

First questionnaire for subjects aged >70 years

Tromsø V





T

# Health survey

## Personal invitation

Do not write here:

E13 (Municipality)

(County)

(Country)

E15 (Mark)

T

## E1. YOUR OWN HEALTH

What is your current state of health? (Tick only once)

Poor  1      Not so good  2      Good  3      Very good  4

Do you have, or have you had?:

	T		Age first time	
	Yes	No		
Asthma.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>
Chronic bronchitis/emphysema.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>
Diabetes .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>
Osteoporosis .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>
Fibromyalgia/chronic pain syndrome .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>
Psychological problems for which you have sought help .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>
A heart attack .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>
Angina pectoris (heart cramp) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>
Cerebral stroke/brain haemorrhage .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>

Do you get pain or discomfort in the chest when: Yes No

Walking up hills, stairs, or walking fast on level ground?

If you get such pain, do you usually:

Stop?  1      Slow down?  2      Carry on at the same pace?  3

If you stop, does the pain disappear within 10 minutes? ..... Yes No

Can such pain occur even if you are at rest?.... Yes No

## E2. ILLNESS IN THE FAMILY

Have one or more of your parents or siblings had: T

A heart attack (heart wounds) or angina pectoris (heart cramp) ..... Yes No Don't know

Tick for the relatives who have or have had any of the illnesses: (Tick for each line)

	Mother	Father	Brother	Sister	Child	None of these
Cerebral stroke or brain haemorrhage ...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Heart attack before age of 60 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Asthma .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cancer .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diabetes .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If any relatives have diabetes, at what age did they get diabetes (if for e.g. many siblings, consider the one who got it earliest in life)

Don't know, not applicable       Mother's age        Father's age        Brother's age        Sister's age        Child's age

## E3. COMPLAINTS

Below is a list of various problems.

Have you experienced any of this during the last week (including today)?

(Tick once for each line)

	No complaint	Little complaint	Pretty much	Very much
Sudden fear without reason .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Felt afraid or anxious .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Faintness or dizziness .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Felt tense or upset .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tend to blame yourself .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sleeping problems.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Depressed, sad .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling of being useless, worthless ..	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling that everything is a struggle	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling of hopelessness with regard to the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	1	2	3	4

## E4. TEETH, MUSCLE AND SKELETON

How many teeth have you lost/extracted? Number of teeth (disregard milk-teeth and wisdom teeth)

Have you been bothered by pain and/or stiffness in muscles and joints during the last 4 weeks?

	No complaint	Little complaint	Severe complaint
Neck / shoulders .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Arms, hands.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Upper part of the back .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lumbar regions .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hips, legs, feet .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other places.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Have you ever had:

	Yes	No	Age last time
Fracture in wrist/forearm? .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
Hip fracture?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>

Have you fallen down during the last year? (Tick once only)

No  1      Yes, 1-2 times  2      Yes, more than 2 times  3

## E5. EXERCISE AND PHYSICAL ACTIVITY

How has your physical activity been during this last year?

Think of a weekly average for the year. Answer both questions.

	Hours per week			
	None	Less than 1	1-2	3 or more
Light activity (not sweating/out of breath).....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hard physical activity (sweating/out of breath).....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	1	2	3	4

## E6. BODY WEIGHT

Estimate your body weight when you were 25 years old:     kg.

## E7. EDUCATION

How many years of education have you completed? *Number of years*

(include all the years you have attended school or studied)

## E8. FOOD AND BEVERAGES

How often do you usually eat these foods? (Tick once for each line)

	Rarely /never	1-3 times /month	1-3 times /week	4-6 times /week	1-2 times /day	3 times or more /day
Fruit, berries .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cheese (all types) ...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Potatoes .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Boiled vegetables ..	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fresh vegetables/salad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fat fish (e.g. salmon, trout, mackerel, herring)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	1	2	3	4	5	6

Do you use dietary supplements: Yes, daily Sometimes No

Cod liver oil, fish oil capsules .....

Vitamins and/or mineral supplements ...

How much of the following do you usually drink? (Tick once for each line)

	Rarely /never	1-6 glasses /week	1 glass /day	2-3 glasses /day	4 glasses or more /day
Full milk, full-fat curdled milk, yoghurt .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Semi-skimmed milk, semi-skimmed curdled milk, low-fat yoghurt .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Skimmed milk, skimmed curdled milk .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Extra semi-skimmed milk ....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Juice .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Water .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Soft drink, mineral water .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	1	2	3	4	5

How many cups of coffee and tea do you drink daily? (Put 0 for the types you do not drink daily)

Filtered coffee .....   T

Boiled coffee/coarsely ground coffee for brewing ....

Other type of coffee .....

Tea .....

Approximately, how often have you during the last year consumed alcohol? (Do not count low-alcohol and alcohol-free beer)

Never consumed alcohol <input type="checkbox"/> 1	Have not consumed alcohol last year <input type="checkbox"/> 2	A few times last year <input type="checkbox"/> 3	About 1 time a month <input type="checkbox"/> 4
2-3 times per month <input type="checkbox"/> 5	About 1 time a week <input type="checkbox"/> 6	2-3 times a week <input type="checkbox"/> 7	4-7 times a week <input type="checkbox"/> 8

To those who have consumed the last year:

When you drink alcohol, how many glasses or drinks do you normally drink? *Number*

Approximately how many times during the last year have you consumed alcohol equivalent to 5 glasses or drinks within 24 hours? *Number of times*

## E9. SMOKING

How many hours a day do you normally spend in smoke-filled rooms? *Number of total hours*

Did any of the adults smoke at home while you were growing up? ..... Yes  No

Do you currently, or did you previously live together with a daily smoker after your 20<sup>th</sup> birthday? Yes  No

Do you/did you smoke daily? ..... Yes, now  Yes, previously  Never

If you have NEVER smoked daily; Go to question E11 (BODILY FUNCTIONS AND SAFETY)

If you smoke daily now, do you smoke: Yes No

Cigarettes?.....

Cigars/cigarillos? .....

A pipe?.....

If you previously smoked daily, how long is it since you quit? *Number of years*

If you currently smoke, or have smoked previously:

How many cigarettes do you or did you normally smoke per day? *Number of cigarettes*

How old were you when you began daily smoking? *Age in years*

How many years in all have you smoked daily? *Number of years*

## E10. BODILY FUNCTIONS AND SAFETY

Would you feel safe by walking alone in the evening in the area where you live?

Yes  A little unsafe  Very unsafe

When it comes to mobility, sight and hearing, can you: (Tick once for each line)

	Without problems	With some problems	With great problems	No
Take a 5 minute walk in fairly high pace? .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Read ordinary text in newspaper, if necessary with glasses? .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hear what is said in a normal conversation? .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	1	2	3	4

Do you because of chronic health problems have difficulties with: (Tick once for each line) No difficulties Some difficulties Great difficulties

Move around in your home? .....

Get out of your home by yourself? .....

Participate in organization or other leisure time activities? .....

Use public transport? .....

Perform necessary daily shopping? .....

## E11. USE OF HEALTH SERVICES

### How many times in the last 12 months

have you been to/used:

(Tick once for each line)

	None	1-3 times	4 or more
A general practitioner (GP) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialist (private or out-patient clinic) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emergency GP (private or public).....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospital admission .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home nursing care .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapist .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chiropractor .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Municipal home care .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dentist .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Alternative practitioner .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Are you confident that you will receive health care and home assistance if you need it?

YES	NO	Don't know
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

## E12. FAMILY AND FRIENDS

Do you live: At home?  1 In an institution/shared apartment?  2

Do you live with:

	YES	NO
Spouse/ partner?.....	<input type="checkbox"/>	<input type="checkbox"/>
Other people? .....	<input type="checkbox"/>	<input type="checkbox"/>

How many good friends do you have?

Count the ones you can talk confidentially with and who can give you help when you need it. Do not count people you live with, but do include your children and other relatives.....

Number of friends

How much interest do people show for what you do?

(Tick only once)

Great interest	Some interest	Little interest	No interest	Uncertain
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

How many associations, sport clubs, groups, religious communities, or similar do you take part in? (write 0 if none)

Number

## E13. CHILDHOOD/YOUTH AND AFFILIATION

How long altogether have you lived in the county?   years

How long altogether have you lived in the municipality?   years

Where did you live most of the time before the age of 16? (Tick one option and specify)

Same municipality.....  1

Another municipality in the county.....  2 Which one: \_\_\_\_\_

Another county in Norway  3 Which one: \_\_\_\_\_

Outside Norway .....  4 Country: \_\_\_\_\_

Have you moved during the last five years?

No	Yes, once	Yes, more than once
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

## E14. USE OF MEDICINES

With medicines, we mean drugs purchased at pharmacies. Supplements and vitamins are not considered here

Do you use?

(Tick once for each line)

	Now	previously, but not now	Never used
Blood pressure lowering drugs .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cholesterol-lowering drugs .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drugs for osteoporosis .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Insulin.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tablets for diabetes .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How often have you during the last 4 weeks used the following medicines?

(Tick once for each line)

	Not used in the last 4 weeks	Less than every week	Every week, but not daily	Daily
Painkillers non-prescription.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Painkillers on prescription .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sleeping pills.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tranquillizers .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Antidepressants .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other prescription medicines ....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

State the name of the medicines you are using now and the reason you are taking the medicines (disease or symptom):

(Tick for each duration you have used the medicine)

How long have you used the medicine

Name of the medicine: (one name per line):	Reason for use of the medicine:	How long have you used the medicine	
		Up to 1 year	One year or more
		<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>

If there is not enough space here, you may continue on a separate sheet that you attach.

## E15. THE REST OF THE FORM IS TO BE ANSWERED BY WOMEN ONLY

How old were you when you started menstruating? Age in years

How old were you when you stopped menstruating? Age in years

How many children have you given birth to? Number of children

Do you use, or have you ever used estrogen? Total number of years

	Never	Previously	Now	
Tablets or patches .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
Cream or suppositories .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>

If you use estrogen, which brand you use now?

Have you ever used contraceptives pills? .....  Yes  No

Appendix 2-E:  
Second questionnaire Tromsø V



Label

## Additional questions to the health survey in Troms and Finnmark 2001-2002

The main aim of the Tromsø Study is to improve our knowledge about cardiovascular diseases in order to aid prevention. The study is also intended to improve our knowledge of cancer and other general conditions, such as allergies, muscle pains and mental conditions. We would therefore like you to answer some questions about factors that may be relevant for your risk of getting these and other illnesses. This form is part of the Health Survey, which has been approved by the Norwegian Data Inspectorate and the Regional Board of Research Ethics. The answers will only be used for research purposes and will be treated strictly confidential.

### T1. NEIGHBORHOOD AND HOME

**1.1 In which municipality did you live at the age of 1 year?**  
(If you have not lived in Norway, state country of residence instead of the municipality)

**1.2 What type of house do you live in? (Tick only once)**

- Detached house/villa.....  1  
 Farm .....  2  
 Flat/apartment .....  3  
 Terraced/semi-detached house .....  4  
 Institution/care home .....  5  
 Other .....  6

**1.3 How big is your house?**    m<sup>2</sup> (gross)

**1.4 Are you bothered by: (Tick once for each line)**

- |   | No complaint             | Little complaint         | Severe complaint         |
|---|--------------------------|--------------------------|--------------------------|
| Moisture, drought or coldness in your home        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Other forms of bad indoor climate                 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Traffic noise (cars or aircraft)                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Other noise (industrial, construction, etc.)      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Neighbour noise                                   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Drinking water quality                            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Air pollution from traffic                        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Air pollution from wood/oil heating, factory etc. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

**1.5 What home language did your grandparents have?**  
(Tick for one or more alternatives)

- |                       | Norwegian                | Sami                     | Kven/<br>Finnish         | Other<br>language        |
|-----------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Mother's mother ...   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Mother's father ..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Father's mother ...   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Father's father ..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

The information you give us may later be linked with information from other public health registers in accordance with the rules laid down by the Data Inspectorate and the Regional Board of Research Ethics.

If you are unsure about what to answer, tick the box that you feel fits best.

The completed form should be sent to us in the enclosed prepaid envelope. Thank you in advance for helping us.

Yours sincerely

Department of Community Medicine  
University of Tromsø

National Health  
Screening Service

If you do not wish to answer the questionnaire, tick the box below and return the form. Then you will not receive reminders.

I do not wish to answer the questionnaire

Date of completion:

Day Month Year T

### T1. NEIGHBORHOOD AND HOME (cont.)

**1.6 What do you consider yourself as?**  
(Tick for one or more alternatives)

- Norwegian  Sami  Kven/  
Finnish  Other

**1.7 Do you feel that you have enough good friends?** Yes  No

**1.8 How often do you normally take part in organised gatherings, e.g. sewing circles, sports clubs, political meetings or other associations?**  
(Tick only once)

- Never, or just a few times a year .....  1  
 1-3 times a month .....  2  
 Approximately once a week .....  3  
 More than once a week .....  4

### T2. PAID AND UNPAID WORK

**2.1 If you have paid or unpaid work, how would you describe your work? (Tick only once)**

- Mostly sedentary work?  
(e.g. office work, mounting) .....  1  
 Work that requires a lot of walking?  
(e.g. shop assistant, light industrial work, teaching)  2  
 Work that requires a lot of walking and lifting?  
(e.g. Postman, nursing, construction) .....  3  
 Heavy manual labour?  
(e.g. forestry, heavy farm-work, heavy construction) .....  4

**2.2 Can you decide yourself how your work (paid or unpaid) should be organised? (Tick only once)**

- No, not at all .....  1  
 To a small extent .....  2  
 Yes, to a large extent .....  3  
 Yes, I decide myself .....  4

**2.3 Are you on call, do you work shifts or nights?** Yes  No

### T3. TOBACCO

#### 3.1 Do you smoke?

Yes, daily  1    Yes, sometimes  2    No, never  3

If "Yes, sometimes"

#### What do you smoke?

Cigarettes     Pipe     Cigar/cigarillos

#### 3.2 Have you used or do you use snuff daily?

Yes, now     Yes, previously     Never

If YES:

How many years altogether have you used snuff?   years

### T4. ALCOHOL

#### 4.1 Are you a teetotaler?.....

Yes  No

#### 4.2 How many times a month do you normally drink alcohol?.....

*(Do not count low-alcohol beer. Put 0 if less than once a month)*

Number of times

#### 4.3 How many glasses of beer, wine or spirits do you normally drink in a fortnight?

*(Do not count low-alcohol beer. Put 0 if you do not drink alcohol)*

Beer      Wine      Spirits

#### 4.4 For approximately how many years has your alcohol consumption been at the same level you described above?

years

#### 4.5 Have you, in one or more periods in the last 5 years consumed so much alcohol that it has inhibited your work or social life?

Yes, at work  1    Yes, socially  2    Yes, both at work and social life  3    No, never  4

### T5. FOOD AND DIETARY SUPPLEMENTS

#### 5.1 Do you usually eat breakfast every day?...

Yes  No

#### 5.2 How many times a week do you eat a warm dinner?.....

times

#### 5.3 How important is it for you to have a healthy diet?

Very  1    Somewhat  2    Little  3    Not  4

#### 5.4 Do you use the following dietary supplements?

Yes, daily    sometimes    No

Iron tablets .....

Calcium tablets or bonemeal .....

Vitamin D supplements .....

Cod liver oil .....

### T6. BODY WEIGHT

#### 6.1 Do you currently try to change your body weight?

No  1    Yes, I try to gain weight  2    Yes, I try to lose weight  3

#### 6.2 What weight would you be satisfied with (your "ideal weight")?.....

kg

### T7. ILLNESSES AND INJURIES

#### 7.1 Have you ever had:

*Tick once for each question. Also give the age at the time. If you have had the condition several times, how old were you the last time*

	Yes	No	Age last time
Severe injury requiring hospital admission .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> years
Ankle fracture .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> years
Peptic ulcer .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> years
Peptic ulcer surgery .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> years
Neck surgery .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> years
Prostate surgery .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> years

#### 7.2 Do you have, or have you ever had: *(Tick once for each question)*

	Yes	No
Cancer .....	<input type="checkbox"/>	<input type="checkbox"/>
Psoriasis.....	<input type="checkbox"/>	<input type="checkbox"/>
Thyroid disease .....	<input type="checkbox"/>	<input type="checkbox"/>
Glaucoma .....	<input type="checkbox"/>	<input type="checkbox"/>
Cataract .....	<input type="checkbox"/>	<input type="checkbox"/>
Osteoarthritis (arthrosis).....	<input type="checkbox"/>	<input type="checkbox"/>
Bent fingers .....	<input type="checkbox"/>	<input type="checkbox"/>
Skin contractions in your palms .....	<input type="checkbox"/>	<input type="checkbox"/>
Kidney stone .....	<input type="checkbox"/>	<input type="checkbox"/>
Appendectomy.....	<input type="checkbox"/>	<input type="checkbox"/>
Hernia surgery .....	<input type="checkbox"/>	<input type="checkbox"/>
Surgery/treatment for urine incontinence ....	<input type="checkbox"/>	<input type="checkbox"/>
Epilepsy.....	<input type="checkbox"/>	<input type="checkbox"/>
Poliomyelitis (polio) .....	<input type="checkbox"/>	<input type="checkbox"/>
Parkinson's disease.....	<input type="checkbox"/>	<input type="checkbox"/>
Migraine.....	<input type="checkbox"/>	<input type="checkbox"/>
Leg ulcer .....	<input type="checkbox"/>	<input type="checkbox"/>

#### Allergy and hypersensitivity:

	Yes	No
Atopic eczema (e.g. childhood eczema)	<input type="checkbox"/>	<input type="checkbox"/>
Hand eczema.....	<input type="checkbox"/>	<input type="checkbox"/>
Food allergy .....	<input type="checkbox"/>	<input type="checkbox"/>
Other hypersensitivity (not allergy).....	<input type="checkbox"/>	<input type="checkbox"/>

#### 7.3 Have you had common cold, influenza, gastroenteritis, etc. during the last 14 days?

Yes  No

#### 7.4 Have you during the last 3 weeks had common cold, influenza, bronchitis, pneumonia, sinusitis, or other respiratory infection?.....

Yes  No

#### 7.5 Have you ever had bronchitis or pneumonia?.....

Yes  No

#### 7.6 Have you during the last 2 years had bronchitis or pneumonia? *(Tick only once)*

No  1    1-2 times  2    More than 2 times  3



## T8. SYMPTOMS

**8.1 Have you in the last two weeks felt:**  
(Tick once for each question)

	No	A Little	A lot	Very much
Nervous or worried .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bothered by anxiety.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Confident and calm .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Irritable.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Happy and optimistic .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Down/depressed .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lonely.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	1	2	3	4

**8.2 Do you cough about daily for periods of the year?** Yes  No

If YES:

**Is your cough productive?** ..... Yes  No

**Have you had this kind of cough for as long as 3 months in each of the last two years?**..... Yes  No

**8.3 Have you had episodes with wheezing in the chest?**  Yes  No

If YES:

**Has this occurred:** (Tick once for each question) Yes  No

At night .....

In connection with respiratory infections .....

In connection with physical exertion .....

In connection with very cold weather .....

**8.4 Do you get pain in the calf while walking** ..... Yes  No

If YES:

**How long can you go before you notice the pain?**.....    meter

**8.5 Do you get short-winded in the following situations?**  
(Tick once for each question)

While walking fast on level ground or slight up hills ..... Yes  No

While walking calmly on level ground .....

While washing or dressing yourself .....

While resting .....

**8.6 Do you have to stop because of short-windedness while walking in your own pace on level ground?...** Yes  No

**8.7 Have you during the last year suffered from pain and/or stiffness in muscles and joints that have lasted continuously for at least 3 months?** ..... Yes  No

If YES:

**Has the complaint reduced your leisure time activity?** ..... Yes  No

**For how long has the complaint endured in total?**

approx.   years and   months

**Has the complaint reduced your ability to work during the last year?** (Also applies to domestic workers and pensioners) (Tick once)

No/insignificantly  1 To some extent  2 Significantly reduced  3 Do not know  4

**Have you been on sick leave due to these complaints during the last year?** ..... Yes  No  Do not work

## T8. SYMPTOMS (continue)

**8.8 How often do you suffer from sleeplessness?**  
(Tick only once)

Never, or just a few times a year .....  1

1-3 times a month .....  2

Approximately once a week .....  3

More than once a week .....  4

**8.9 If you suffer from sleeplessness monthly or more frequently, what time of the year does it affect you most?**

No particular time of the year .....  1

Especially during the polar night .....  2

Especially during the midnight sun season .....  3

Especially in spring and autumn .....  4

**8.10 Have you in the last year suffered from sleeplessness to the extent that it has affected your ability to work ?** ..... Yes  No

**8.11 Do you usually sleep during the day?**..... Yes  No

**8.12 How often do you suffer from urinary incontinence?**

Never .....  1

Not more than once a month .....  2

Two or more times a month .....  3

Once a week or more .....  4

**8.13 Are you able to walk down 10 steps without holding on to something (e.g. a handrail) ...** Yes  No

**8.14 Do you use glasses?**..... Yes  No

**8.15 Do you use a hearing aid?**..... Yes  No

**8.16 How is your memory?**  
(Tick once for each question)

Do you forget what you just have heard or read?..... Yes  No

Do you forget where you have placed things?..... Yes  No

Is it more difficult to remember now than earlier?.. Yes  No

Do you more often write memos now than earlier? Yes  No

If "YES" on one of these questions;  
**Is this a problem in your daily life?**..... Yes  No

## T9. MEDICINES

**9.1 Do you use, or have you used any of the following medicines:**

	Now	Previously, but not now	Age when used 1 <sup>st</sup> time	Never used
Drugs for osteoporosis.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> years	<input type="checkbox"/>
Tablets for diabetes .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> years	<input type="checkbox"/>
Drugs for hypothyroidism (thyroxine) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> years	<input type="checkbox"/>

**9.2 Do you use any medicines which you take as injections?** ..... Yes  No

If YES:

**Give the name of the medicines (for injection):** T

(one name per line)

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**T10. ILLNESS IN THE FAMILY**

**10.1 Tick for the relatives who have or have ever had any of the diseases: (Tick for each line)**

	Mother	Father	Brother	Sister	Child	None of these
Heart attack (heart wound)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Angina pectoris (heart cramp)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
High blood pressure .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Aneurysm.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gastric/duodenal ulcer ....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hip fracture .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychological problems ..	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Allergy .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Osteoarthritis (arthrosis) ..	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dementia .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**10.2 How many siblings and children do you have?**

Number	Brothers	Sisters	Children
	<input type="text"/>	<input type="text"/>	<input type="text"/>

**10.3 Do you usually do extra caring work because of illness etc. in your close family?**

Yes, daily/almost daily	Yes, sometimes	No
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

**10.4 Do you/your family receive home aid or home nursing care?.....**

Yes  No

**10.5 Is your mother alive? .....**

Yes  No  Age at death  years

**10.6 Is your father alive? .....**

Yes  No  Age at death  years

**T11. MOBILE TELEPHONE**

**11.1 Do you have (own, rent, etc.) a mobile telephone?**

Yes, always  1 Yes, sometimes  2 No  3

If Yes:

**What do you use your mobile telephone for, and how often do you use it? (Tick once for each line)**

	Number of times per day				
	30 or more	10-29	2-9	1 or less	Never
Conversations..	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Text messaging	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12345

**T12. THE REST IS TO BE ANSWERED BY WOMEN ONLY**

**12.1 If you have given birth, fill in each child's birth year and how many months you breastfed after delivery.**

(If you did not breastfeed, write 0)

Child:	Birth year:	Number of months breastfed:
1 <sup>st</sup> child	<input type="text"/>	<input type="text"/>
2 <sup>nd</sup> child	<input type="text"/>	<input type="text"/>
3 <sup>rd</sup> child	<input type="text"/>	<input type="text"/>
4 <sup>th</sup> child	<input type="text"/>	<input type="text"/>
5 <sup>th</sup> child	<input type="text"/>	<input type="text"/>
6 <sup>th</sup> child	<input type="text"/>	<input type="text"/>

(If more children, use additional sheet)

**T12. THE REST IS TO BE ANSWERED BY WOMEN ONLY**

**12.2 If you still have menstruate or are pregnant: What date did your last menstruation start?**

Day   Month   Year

**12.3 If you no longer menstruate; why did your periods stop? (Tick once)**

It stopped by itself .....  1  
 Uterus surgery .....  2  
 Surgically removed both ovaries .....  3  
 Other reason (e.g. radiation, chemotherapy) ...  4

**12.4 Do you use or have you used prescribed estrogen (tablets or patches)?.....**

Yes  No

If YES: How old were you when you started taking estrogen? .....  years

If you stopped using estrogen, How old were you when you stopped taking estrogen?.....  years

**12.5 Do you use or have you used oral contraceptive pills?.....**

Yes  No

If YES: How old were you when you started taking the pill?.....  years

How many years in total have you taken the pills?....  Number of years

If you have given birth: How many years did you take the pill before your first delivery?...  Number of years

If you stopped taking the pill: How old were you when you stopped?....  years

**12.6 Apart from pregnancy and after giving birth, have you ever stopped having menstruation for 6 months or more?**

Yes  No

If YES: How many times?.....  times

**12.7 How is your current menstruation status?**

I have not had menstruation in the last year  1  
 I have regular menstruation .....  2  
 I have irregular menstruation .....  3

**12.8 When you were 25-29 years old, how many days usually passed between the start of two periods?**

Minimum  days Maximum  days Do not know

The periods were of approximately equal length every time?..... Yes  No

How many days did a typical menstrual bleeding period last?...  days

**Thank you for the help! Remember to mail the form today!**

Appendix 3:  
The Sixth Tromsø Study (T6)



Appendix 3-A:  
Information to participants in Tromsø VI



## Den 6. Tromsøundersøkelsen er i gang!

Vi spør deg om du vil delta i den sjette Tromsøundersøkelsen. Den varer i om lag ett år med oppstart oktober 2007. Vedlagt finner du en informasjonsbrosjyre hvor du kan lese om hva Tromsøundersøkelsen går ut på.

### Hvor og når

Undersøkelsen vil foregå ved den gamle husmorskolen, Gamle Breivang.

### Åpningstidene for Tromsøundersøkelsen er:

Mandag og torsdag: 10.30-13.30 og 14.30-18.00

Tirsdag og onsdag: 08.30-11.30 og 12.30-16.00

Fredag: 08.30-11.30 og 12.30-14.00

Vi holder stengt i juleuken (uke 52) 2007, påskeuken (uke 12), samt hele juli 2008.

Du har fått tildelt fremmøtetid:

Adressen er: Breivangveien 23, 9010 Tromsø

Kan du ikke komme på dette tidspunktet er du velkommen når som helst i åpningstiden vår. Du behøver ikke gi beskjed om du skulle komme til en annen tid.

### Buss

Følgende buss kan brukes:

**Fra Sentrum (Wi-To) og Giæverbukta:** Rute 24. Stoppested: Dramsveien

**Fra Sentrum (Wi-To):** Rute 20 og 24. Stoppested: Dramsveien

Rute 27,32 og 42. Stoppested: Stakkevollveien.

### Kart

Kart som viser hvor Tromsøundersøkelsen foregår, finnes på baksida av dette arket.



## Forberedelser til undersøkelsen

Av hensyn til måling av blodtrykk bør du ha på klær som ikke strammer på armer og bein. Ha gjerne et kortermet plagg innerst.

Du vil bli intervjuet om hvilke legemidler du har brukt regelmessig de siste fire ukene. Navn på legemidler du bruker fast kan besvares i det vedlagte spørreskjemaet. Intervjuet vil foregå på en skjermet plass.

Du vil bli spurt om hva du har brukt av smertestillende midler det siste døgnet. Et utvalg vil bli spurt om bruk av antibiotika (penicillin og lignende legemidler) det siste døgnet. Det vil bli spurt om navnet på legemiddelet og hvor mye du har brukt.

**Kvinnene** vil få spørsmål om menstruasjon og eventuell bruk av hormoner som påvirker menstruasjonen.

Ta gjerne med deg legemidlene du bruker ved frammøte til undersøkelsen.

**Du finner mer informasjon om undersøkelsen i vedlagte brosjyre.**

Med vennlig hilsen

Tromsøundersøkelsen



Appendix 3-B:  
Information leaflet Tromsø VI



## Vil du være med i den 6. Tromsøundersøkelsen?

- » viktig forskning
- » undersøkelse av egen helse
- » forebygging av helseproblemer



## Hva er Tromsøundersøkelsen?

Tromsøundersøkelsen er et stort forskningsprosjekt. Opplysninger som samles inn skal brukes til å gi oss kunnskap som kan bedre menneskers helse.

Den første Tromsøundersøkelsen ble gjennomført allerede i 1974, og dette er den sjettede i rekken. Et viktig mål med undersøkelsen er å få kunnskap om hvorfor noen blir syke mens andre beholder god helse gjennom livet.

### Visste du at ..?

Den som deltar på Tromsøundersøkelsen får også en enkel undersøkelse av sin egen helse.

## Hva forskes det på i Tromsøundersøkelsen?

Tromsøundersøkelsen gjennomføres først og fremst for å kunne øke kunnskapen om de store folkehelseproblemene og forhold som påvirker disse, blant annet:

- » Hjerte- og karsykdommer
- » Lungesykdommer (f.eks. KOLS)
- » Diabetes
- » Stoffskiftesykdommer
- » Kreftsykdommer
- » Psykiske plager
- » Demens
- » Muskel- og skjelettplager

Undersøkelsen vil også bli benyttet til forskning om bruk og effekter av legemidler, trivsel, livskvalitet, livsstil, døgnrytme, smerter, sosial ulikhet, fysisk aktivitet, kosthold, bruk av helsetjenester og alternativ behandling. Det vil også bli undersøkt om miljøgifter kan påvises i blodet og om disse innvirker på helsa.

Videre vil det bli gjort forskning på kvinnesykdommer, sykdommer i fordøyelsesorganer, allergi, nyrer og urinveier, nervesystemet, sanseorganer og hud. Det vil også bli forsket på arbeidsuførhet

som følge av disse sykdommene eller tilstandene. En del av prosjektene vil spesielt undersøke samspillet mellom arv, miljø, sykdom og helse. Til slike prosjekter vil det bli hentet ut DNA (arvestoff) fra blodprøvene.

Det er allerede planlagt mange forskningsprosjekter som skal benytte data fra Tromsøundersøkelsen. Du vil finne en liste over disse på vår internettside:

<http://www.tromso6.no>

## Vil du delta?

Ved å delta på Tromsøundersøkelsen er du med på å bidra til forskning om hvordan sykdom kan forebygges og behandles, hva som fremmer god helse, og hva som er årsak til helseproblemer.

## Hvorfor spør vi deg?

Alle som møtte til spesialundersøkelsene i Tromsøundersøkelsen i 1994 og 2001, og et tilfeldig uttrukket utvalg av personer som er over 30 år og som er innbyggere i Tromsø kommune, blir spurt om å delta.

## Alle er viktige!

Hver deltaker er like viktig, enten du er ung eller gammel, frisk eller syk. Det har vært stort fram møte til de tidligere Tromsøundersøkelsene. Godt oppmøte er viktig for gode forskningsresultater. Det er en styrke for forskningen at de som har vært med i tidligere Tromsøundersøkelser møter fram på nytt.

## Frivillig

Det er frivillig å delta. Det vil ikke få noen konsekvenser for deg dersom du ikke deltar eller velger å trekke deg fra undersøkelsen på et senere tidspunkt. Du må ikke gi noen begrunnelse dersom du ønsker å trekke deg fra undersøkelsen.

## Visste du at ..?

Du kan delta på Tromsøundersøkelsen selv om det er deler av undersøkelsen du ikke ønsker å være med på.

## Din helse

Cirka fire uker etter undersøkelsen vil du få et brev med resultatene fra målinger av kolesterol og blodtrykk. Dersom det er nødvendig, vil du bli anbefalt å ta kontakt med din fastlege. Det blir ikke gitt rutinemessig tilbakemelding om resultater av andre blodprøver eller målinger.

Dersom resultatet av prøvene viser at det er nødvendig med oppfølging av lege eller henvisning til spesialist, vil du bli orientert om det. Ved behov for henvisning til spesialist, vi vil sørge for at slik henvisning blir sendt.

Du kan reservere deg mot å få vite resultatene av prøvene dine. Men hvis et prøveresultat er slik at det er nødvendig med rask legebehandling, vil du uansett bli kontaktet.

Tromsøundersøkelsen er gratis. Trenger du videre undersøkelse / oppfølging av fastlegen eller i spesialisthelsetjenesten, betaler du vanlig egenandel.

## Slik foregår undersøkelsen

Sammen med dette informasjonsskrivet ligger det et ark med praktiske opplysninger og beskjed om hvor og når du kan møte fram. Her står også

åpningstidene for undersøkelsen. Hvis du vil delta og den foreslåtte tiden ikke passer, kan du komme en annen dag. Du trenger ikke melde fra om dette på forhånd.

## Unngå før undersøkelsen

For at resultatene skal bli mest mulig korrekt, er det en fordel om du avstår fra alkohol og smertestillende medisiner 12 timer før undersøkelsen.

## Påkledning

Vekt og høyde, liv- og hoftevidde måles med lett påkledning, men uten sko. For at det skal gå raskt å måle blodtrykk, er det en fordel om du har plagg som ikke strammer over armen og benet. Ha gjerne et kortermet plagg innerst.

## Spørreskjema

Sammen med denne brosjyren har du fått et spørreskjema som du skal fylle ut og ta med til undersøkelsen. Hvis du er i tvil om hvordan du skal svare på et eller flere av spørsmålene, lar du det stå åpent. Personalet på undersøkelsen hjelper deg da med utfyllingen om du ønsker det.

Utfylte svar i spørreskjema er like viktig for forskningen som resultater fra blodprøver og undersøkelser.



## Regelmessig bruk av legemidler

Ved frammøte til undersøkelsen vil du bli intervjuet om hva slags legemidler du har brukt regelmessig de siste fire ukene, og om noen av de legemidlene du har brukt siste 24 timer. Navn på legemidler du bruker fast kan besvares i skjemaet på forhånd. Ta gjerne med deg legemidlene du bruker ved frammøte til undersøkelsen.

## Undersøkelser

Når du møter fram, vil kvalifisert helsepersonell veilede deg gjennom undersøkelsen og svare på spørsmål. Du vil bli intervjuet og få utlevert et nytt spørreskjema med en frankert svarkonvolutt. Spørreskjemaet kan også besvares mens du er tilstede på undersøkelsen, og du vil kunne få hjelp underveis. Hver enkelt undersøkelse varer bare noen minutter. Totalt vil undersøkelsen vare cirka en time.

De måler høyde, vekt, hoftevidde og livvidde, de måler blodtrykket og tar blodprøve av deg. I tillegg vil følgende undersøkelser bli gjort:

- » Beintetthetsmåling (måling av beinmasse) i den ene armen med svake røntgenstråler. Målingene brukes til å undersøke risiko for beinskjørhet og brudd.
- » Bakterieprøve fra nese og hals fra om lag halvparten av deltagerne, for å se etter gule stafylokokker, en bakterie som normalt finnes på hud og slimhinner hos mennesker, men som i enkelte tilfeller kan forårsake alvorlige infeksjoner. Prøven gjøres med fuktet vattpensel.
- » Smertefølsomhet som måler hvordan kroppen reagerer på smerte. Du blir bedt om å holde hånden i isvann i opptil 1 minutt. Underveis registreres blodtrykk og du angir hvor mye smerte du kjenner. Du kan ta hånden ut av vannet før tiden er ute hvis det blir for ubehagelig.
- » Hårprøve. Vi vil be om å få noen hårstrå for å undersøke forekomsten av spormetaller som kvikksølv.

- » Fysisk aktivitet og kosthold. Vi planlegger at utvalgte deltakere vil bli bedt om å registrere fysisk aktivitet (aktivitetsmålere som skrittellere og lignende) og kosthold i en periode.



## Blodprøver

Blodet fordeles på fem glass, men til sammen utgjør det ikke mer enn 45 milliliter, som er mindre enn en tidel av det en blodgiver gir. For de aller fleste vil det være tilstrekkelig med ett stikk. Disse analysene blir gjort:

- » Måling av kolesterol og andre fettstoffer, blodsukker, blodlegemer, stoffskifteprøver, hormoner, markører for betennelsesreaksjoner, allergi, mage- og tarmfunksjon, lever- og nyrefunksjon samt muskel- og beinmarkører.
- » DNA (arvestoff) vil bli lagret til bruk i forskningsprosjekter som er omtalt i denne brosjyren og som kartlegger sammenhengen mellom arv og miljø, sykdom og helse. DNA vil ikke bli brukt til andre formål enn forskning.
- » Miljøgifter, blant annet sporstoffer, spormetaller og organiske stoffer. Forekomsten i blodet skal sammenlignes med tilsvarende målinger i andre befolkninger. Forskere vil studere om miljøgifter kan påvirke helsa vår.

## Spesialundersøkelsen

Når første del av Tromsøundersøkelsen er gjennomført, kan du bli forespurt om å delta i en eller flere deler av Spesialundersøkelsen noen uker senere. Over halvparten vil bli spurt om dette. Hele Spesialundersøkelsen vil vare cirka en time, og

varigheten vil være avhengig av hvor mange deler du blir spurt om å være med på. Ved oppmøte til Spesialundersøkelsen vil det bli tatt ny blodprøve som skal brukes til samme formål som beskrevet for første del av undersøkelsen. Deler av blodprøven blir frosset ned for senere bruk i forskning som er beskrevet i denne brosjyren.

## Hvilke undersøkelser gjøres i Spesialundersøkelsen?

- » Ultralyd av blodårene (arteriene) på halsen. Undersøkelsen gjøres for å se etter forkalkninger og innsnevring av årene. Undersøkelsen kartlegger også blodforsyningen til hjernen.
- » Ultralyd av hjertet gjøres for å undersøke hjertets form og funksjon.
- » Måling av beintetthet i rygg/hofte og kroppens fettmengde. Målingene brukes til å undersøke risiko for beinskjørhet og brudd, og for studier om sammenhengen mellom kroppsfett, beinmasse og brudd.
- » Fotografering av øyebunn. Fotografiet vil vise tilstanden for blodkarene i øyet som også sier noe om blodkarene i kroppen. Ved øyestasjonen tas fotografi av øyebunnen din. Deltagerne får en øyedråpe i hvert øye en tid før fotografering for at pupillene skal utvide seg. Dette kan svi noe og synet kan forbigående bli noe uklart. Effekten går gradvis over, og etter en time er den borte. I tillegg vil det gjøres en enkel synstest som du vil få svar på umiddelbart.
- » Tester av hukommelse gjøres ved hjelp av enkle spørsmål og omfatter også evne til gjenkjenning av ord og grad av fingerbevegelse.
- » EKG og blodtrykk. EKG er en registrering av hjerterytmen som også kan gi informasjon om hjertesykdom. Ved registrering festes ledninger til kroppen. Blodtrykket måles både på overarmen og ved ankelen.

- » Pusteprobe. Dette er en enkel undersøkelse av lungefunksjonen. Du skal puste så hardt du klarer gjennom et munnstykke. Hvor mye luft som blåses ut pr. sekund, er et mål på lungefunksjonen din.
- » Ny bakterieprøve fra nese og hals. Prøven utføres på samme måte som i første del av undersøkelsen.
- » Urinprøve. Du vil bli bedt om å avlevere urinprøver fra de tre siste dagene før spesialundersøkelsen. Du gis alt nødvendig utstyr. Urinen blir lagret til bruk i forskning som er beskrevet i denne brosjyren.

For å sikre høy kvalitet på forskningsdata ønsker vi å undersøke et lite utvalg som møter til undersøkelsen to ganger med cirka en ukes mellomrom. De som er aktuelle vil bli forespurt om dette ved frammøte.

## Nye prosjekter

Noen deltakere vil i ettertid bli spurt om å delta i videre undersøkelser. Hvis dette gjelder deg, vil du få en forespørsel i posten. Du er ikke forpliktet til å delta selv om du har deltatt i andre deler av Tromsøundersøkelsen. Omtale av alle delprosjektene finner du på nettsiden vår:

<http://www.tromso6.no>

## Forsikring og finansiering

Deltakere i Tromsøundersøkelsen er forsikret gjennom Norsk Pasientskadeerstatning.

Tromsøundersøkelsen er finansiert av Universitetet i Tromsø, Helse Nord HF samt ulike forskningsfond.



## Etikk, personvern og sikkerhet

Du kan være trygg på at informasjon som gis til Tromsøundersøkelsen vil bli behandlet med respekt for personvern og privatliv, og i samsvar med lover og forskrifter. Alle medarbeidere som jobber med undersøkelsen har taushetsplikt. Opplysningene som samles inn vil bare bli brukt til godkjente forskningsformål.

Alle opplysninger om deltakere vil bli lagret på datamaskin. Navn og personnummer blir fjernet og erstattet med en kode. Kodenummeret oppbevares separat og kun noen få, autoriserte medarbeidere har tilgang til denne.

Den enkelte forsker får ikke tilgang til opplysninger som gjør det mulig å identifisere enkeltpersoner. Hver enkelt deltaker har en rett til å vite hvilke opplysninger som er lagret om en selv.

For alle prosjekter kreves det at prosjektlederen tilhører en kompetent forskningsinstitusjon.

Tromsøundersøkelsen har konsesjon fra Datatilsynet og er godkjent av Regional komité for medisinsk forskningsetikk, Nord-Norge.

### Sammenstilling med andre registre

Opplysninger om deg fra den sjette Tromsøundersøkelsen kan bli knyttet sammen med opplysninger fra tidligere Tromsøundersøkelser. For enkelte prosjekter kan det være aktuelt å sammenstille opplysninger om deg med opplysninger fra barn, søsken, foreldre og besteforeldre hvis disse har deltatt i Tromsøundersøkelsen.

For spesielle forskningsprosjekter kan det være aktuelt å sammenstille informasjon fra Tromsøundersøkelsen med nasjonale helseregistre som Reseptregisteret, Medisinsk fødselsregister, Kreftregisteret, Norsk pasientregister og Dødsårsaksregisteret, og andre nasjonale registre over sykdommer som det forskes på i Tromsøundersøkelsen.

I tillegg kan det være aktuelt å innhente helseopplysninger fra primær- og spesialisthelsetjenesten til bruk i forskning på sykdommer og helseproblemer som er nevnt i denne brosjyren, for

eksempel hjerte-karsykdom, diabetes og beinbrudd. I slike tilfeller innhentes nytt samtykke, eller annen type godkjenning (dispensasjon fra taushetsplikten).

Informasjon fra Tromsøundersøkelsen kan også bli sammenstilt med registre ved Statistisk sentralbyrå, for eksempel om miljø, befolkning, utdanning, inntekt, offentlige ytelser, yrkesdeltakelse og andre forhold som kan ha betydning for helsa.

Slike sammenstillinger krever noen ganger forhåndsgodkjenning av offentlige instanser, for eksempel Regional komité for medisinsk forskningsetikk, Datatilsynet eller NAV.

### Bruk av innsamlede data i framtiden

Data fra Tromsøundersøkelsen vil kun bli brukt til forskning og vil ikke kunne brukes til andre formål.

Opplysninger og prøver som du gir, blir oppbevart på ubestemt tid til bruk i forskning til formål som nevnt i denne brosjyren. I noen tilfeller kan det bli aktuelt å gjøre analyser av blodprøver ved forskningsinstitusjoner i utlandet. Hvis dette gjøres, vil det skje i en slik form at våre utenlandske samarbeidspartnere ikke kan knytte prøvene opp mot deg som person.

Hva som er aktuelle problemstillinger i medisinsk forskning forandrer seg hele tiden. I framtiden kan data bli brukt i forskningsprosjekter som i dag ikke er planlagt, forutsatt at det er i samsvar med gjeldende lover og forskrifter. For alle slike nye prosjekter kreves det at prosjektet er godkjent av Regional komité for medisinsk forskningsetikk og Datatilsynet.

Tromsøundersøkelsen informerer om nye forskningsprosjekter på: <http://www.tromso6.no> Her kan du også lese om forskningsresultatene fra Tromsøundersøkelsen. Forskningsresultater vil ellers bli publisert i internasjonale og nasjonale tidsskrifter, på faglige konferanser og møter. Det vil ikke være mulig å identifisere enkeltpersoner når forskningsresultatene offentliggjøres.



## Samtykke

Hvis du vil delta i den sjette Tromsøundersøkelsen, må du gi skriftlig samtykke til dette. Personalet på Tromsøundersøkelsen vil kunne gi mer informasjon om undersøkelsen, og kan svare deg dersom du har spørsmål i forbindelse med samtykket.

Det er viktig å vite at selv om du sier ja til dette nå, kan du senere ombestemme deg. Du kan når som helst etter undersøkelsen trekke ditt samtykke tilbake. Allerede innsamlede data blir lagret videre, men kan ikke lenger knyttes til deg som person, og dine data vil ikke bli brukt i nye forskningsprosjekter. Du kan be om at blodprøven din blir ødelagt.

Hvis du vil trekke tilbake ditt samtykke, henvend deg til:

[Tromsøundersøkelsen, Inst. for samfunnsmedisin](#)  
[Universitetet i Tromsø](#)

9037 Tromsø

telefon: 77 64 48 16

telefaks: 77 64 48 31

e-post: [tromsous@ism.uit.no](mailto:tromsous@ism.uit.no)

internett: [www.tromso6.no](http://www.tromso6.no)

Hvis vi i framtiden ønsker å forske på nye spørsmål som ikke er beskrevet i denne brosjyren, kan det bli nødvendig å be deg om et nytt samtykke.

## Vil du delta?

Følgende tekst er en kopi av dokumentet du blir bedt om å signere når du møter fram til undersøkelsen:

### **Samtykke til bruk av helseopplysninger i forskning - den 6. Tromsøundersøkelsen**

I brosjyren jeg har fått tilsendt, har jeg lest om undersøkelsens innhold og formål, og jeg har hatt mulighet til å stille spørsmål. Jeg samtykker herved i å delta i undersøkelsen [dato/signatur].





# Tromsø-undersøkelsen

Tromsøundersøkelsen  
Institutt for samfunnsmedisin, Universitetet i Tromsø  
9037 TROMSØ

**telefon:** 77 64 48 16

**telefaks:** 77 64 48 31

**epost:** [tromsous@ism.uit.no](mailto:tromsous@ism.uit.no)

**internett:** [www.tromso6.no](http://www.tromso6.no)



Appendix 3-C:  
Declaration of consent Tromsø VI

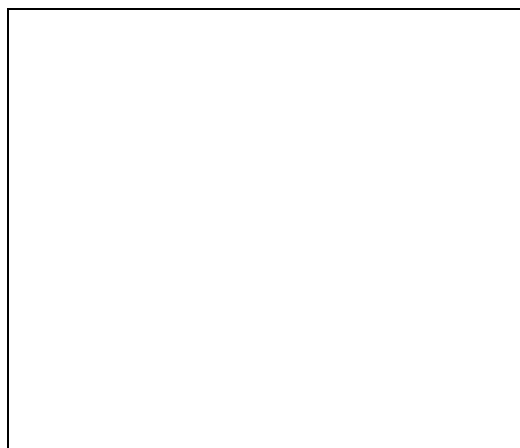




## **Samtykke til bruk av helseopplysninger i forskning, den 6. Tromsøundersøkelsen**

I brosjyren jeg har fått tilsendt, har jeg lest om undersøkelsens innhold og formål, og jeg har hatt mulighet til å stille spørsmål. Jeg samtykker herved i å delta i undersøkelsen.

Dato: \_\_\_\_\_ Signatur: \_\_\_\_\_





Appendix 3-D:  
First questionnaire Tromsø VI







# The Tromsø Study

The form will be read electronically. Please use a blue or black pen  
You can not use comas, use upper-case letters.

2007 - 2008 Confidential

## HEALTH AND DISEASES

1 How do you in general consider your own health to be?

- Very good  
 Good  
 Neither good nor bad  
 Bad  
 Very bad

2 How is your health compared to others in your age?

- Much better  
 A little better  
 About the same  
 A little worse  
 Much worse

3 Do you have, or have you had?

	Yes	No	Age first time
A heart attack .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Angina pectoris ( <i>heart cramp</i> ) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Cerebral stroke/brain hemorrhage..	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Atrial fibrillation .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
High blood pressure .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Osteoporosis .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Asthma .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Chronic bronchitis/Emphysema/COPD ....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Diabetes .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Psychological problems ( <i>for which you have sought help</i> )	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Hypothyroidism .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Kidney disease, <i>not including urinary tract infection (UTI)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Migraine .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

4 Do you have persistent or constantly recurring pain that has lasted for 3 months or more?

- Yes  No

5 How often have you suffered from sleeplessness during the last 12 months?

- Never, or just a few times  
 1-3 times a month  
 Approximately once a week  
 More that once a week

6 Below you find a list of various problems.

Have you experienced any of this during the last week (including today)? (Tick once for each complaint)

	No complaint	Little complaint	Pretty much	Very much
Sudden fear without reason	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Felt afraid or anxious .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Faintness or dizziness .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Felt tense or upset .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tend to blame yourself .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sleeping problems .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Depressed, sad .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling of being useless, worthless .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling that everything is a struggle	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling of hopelessness with regard to the future .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## USE OF HEALTH SERVICES

7 Have you during the last 12 months visited:

If YES; how many times?

	Yes	No	No. of times
General practitioner (GP) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Psychiatrist/psychologist .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Medical specialist outside hospital ( <i>other than general practitioner/psychiatrist</i> )	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Physiotherapist .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Chiropractor .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Alternative practitioner ( <i>homeopath, acupuncturist, foot zone therapist, herbal medicine practitioner, laying on hands practitioner, healer, clairvoyant, etc.</i> )	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Dentist/dental service .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

8 Have you during the last 12 months been to a hospital?

	Yes	No	No. of times
Admitted to a hospital .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Had consultation in a hospital without admission;			
At psychiatric out-patient clinic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
At another out-patient clinic .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

9 Have you undergone any surgery during the last 3 years?

- Yes  No

## USE OF MEDICINES

10 Do you currently use, or have you used some of the following medicines? (Tick once for each line)

	Never used			Age first time
	Now	Earlier		
Blood pressure lowering drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Cholesterol lowering drugs ...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Drugs for heart disease .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Diuretics .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Drugs for osteoporosis .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Insulin .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Tablets for diabetes .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
The drugs for hypothyroidism				
Thyroxine/levaxin .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

11 How often have you during the last 4 weeks used the following medicines? (Tick once for each line)

	Not used in the last 4 weeks	Less than every week	Every week, but not daily	Daily
	Painkillers on prescription .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Painkillers non-prescription .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sleeping pills .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tranquillizers .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Antidepressants .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12 State the name of all medicines -both those on prescription and non-prescription drugs- you have used regularly during the last 4 weeks. Do not include vitamins, minerals, herbs, natural remedies, other nutritional supplements, etc.

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If there is not enough space for all medicines, continue on a separate sheet.

When attending you will be asked whether you have used antibiotics or painkillers the last 24 hours. If you have, you will be asked to provide the name of the drug, strength, dose and time of use.

## FAMILY AND FRIENDS

13 Who do you live with? (Tick for each question and give the number)

	Yes	No	Number
Spouse/partner .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Other people older than 18 years..	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
People younger than 18 years .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

14 Tick for the relatives who have or have had

	Parents	Children	Siblings
A heart attack .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A heart attack before age of 60	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Angina pectoris ( <i>heart cramp</i> ) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cerebral stroke/brain haemorrhage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Osteoporosis .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gastric/duodenal ulcers .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Asthma .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diabetes .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dementia .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychological problems .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Substance abuse .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15 Do you have enough friends who can give you help when you need it?

Yes  No

16 Do you have enough friends whom you can talk confidentially with?

Yes  No

17 How often do you normally take part in organised gatherings, e.g. sport clubs, political meetings, religious or other associations?

Never, or just a few times a year

1-2 times a month

Approximately once a week

More than once a week

## WORK, SOCIAL SECURITY AND INCOME

18 What is the highest level of education you have completed? (Tick once)

Primary/secondary school, modern secondary school

Technical school, vocational school, 1-2 years senior high school

High school diploma

College/university less than 4 years

College/university 4 years or more

19 What is your main activity? (Tick once)

Full time work  Housekeeping

Part time work  Retired/benefit recipient

Unemployed  Student/military service

20 Do you receive any of the following benefits?

- Old-age, early retirement or survivor pension
- Sickness benefit (on sick leave)
- Rehabilitation benefit
- Full disability pension
- Partial disability pension
- Unemployment benefits
- Transition benefit for single parents
- Social welfare benefits

21 What was the household's total taxable income last year? Include income from work, pensions, benefits and similar

- Less than 125 000 NOK
- 125 000-200 000 NOK
- 201 000-300 000 NOK
- 301 000-400 000 NOK
- 401 000-550 000 NOK
- 551 000-700 000 NOK
- 701 000 -850 000 NOK
- More than 850 000 NOK

22 Do you work outdoor at least 25% of the time, or in cold buildings (e.g. storehouse/industry buildings)?

- Yes
- No

## PHYSICAL ACTIVITY

23 If you have paid or unpaid work, which statement describes your work best?

- Mostly sedentary work  
*(e.g. office work, mounting)*
- Work that requires a lot of walking  
*(e.g. shop assistant, light industrial work, teaching)*
- Work that requires a lot of walking and lifting  
*(e.g. postman, nursing, construction)*
- Heavy manual labour

24 Describe your exercise and physical exertion in leisure time. If your activity varies much, e.g. between summer and winter, then give an average. The question refers only to the last year. (Tick the most appropriate box)

- Reading, watching TV, or other sedentary activity.
- Walking, cycling, or other forms of exercise at least 4 hours a week *(include walking or cycling to work, Sunday-walk/stroll, etc.)*
- Participation in recreational sports, heavy gardening, etc. *(note: duration of activity at least 4 hours a week)*
- Participation in hard training or sports competitions, regularly several times a week.

25 How often do you exercise?(With exercise we mean for example walking, skiing, swimming or training/sports)

- Never
- Less than once a week
- Once a week
- 2-3 times a week
- Approximately every day

26 How hard do you exercise on average?

- Easy- do not become short-winded or sweaty
- You become short-winded and sweaty
- Hard- you become exhausted

27 For how long time do you exercise every time on average?

- Less than 15 minutes
- 15-29 minutes
- 30-60 minutes
- More than 1 hour

## ALCOHOL AND TOBACCO

28 How often do you drink alcohol?

- Never
- Monthly or less frequently
- 2-4 times a month
- 2-3 times a week
- 4 or more times a week

29 How many units of alcohol (a beer, a glass of wine or a drink) do you usually drink when you drink alcohol?

- 1-2
- 3-4
- 5-6
- 7-9
- 10 or more

30 How often do you drink 6 units of alcohol or more in one occasion?

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

31 Do you smoke sometimes, but not daily?

- Yes
- No

32 Do you/did you smoke daily?

- Yes, now
- Yes, previously
- Never

33 If you previously smoked daily, how long is it since you quit?

Number of years

34 If you currently smoke, or have smoked previously: How many cigarettes do you or did you usually smoke per day?

Number of cigarettes

35 How old were you when you began daily smoking?

Age in years

36 How many years in all have you smoked daily?

Number of years

37 Do you use or have you used snuff or chewing tobacco?

- No, never
- Yes, previously
- Yes, sometimes
- Yes, daily

## DIET

38 Do you usually eat breakfast every day?

Yes  No

39 How many units of fruit or vegetables do you eat on average per day? (units means for example a fruit, a cup of juice, potatoes, vegetables)

Number of units   +

40 How many times a week do you eat warm dinner?

Number

41 How often do you usually eat these foods? (Tick once for each line)

	0-1 times/ mth	2-3 times/ mth	1-3 times/ week	4-6 times/ week	1-2 times/ day
Potatoes .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pasta/rice .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Meat (not processed) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Processed meat (sausages, hamburger, etc.) ...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fruits, vegetables, berries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lean fish .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fatty fish (e.g. salmon, trout, mackerel, herring, halibut, redfish)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

42 How much do you usually drink the following? (Tick once for each line)

	Rarely/ never	1-6 glasses /week	1 glass /day	2-3 glasses /day	4 or more glasses /day
Milk, curdled milk, yoghurt .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Juice .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Soft drinks with sugar .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

43 How many cups of coffee and tea do you drink daily? (Put 0 for the types you do not drink daily)

	Number of cups
Filtered coffee .....	<input type="text"/> <input type="text"/>
Boiled coffee (coarsely ground coffee for brewing)	<input type="text"/> <input type="text"/>
Other types of coffee .....	<input type="text"/> <input type="text"/>
Tea .....	<input type="text"/> <input type="text"/>

44 How often do you usually eat cod liver and roe? (i.e. "mølje")

Rarely/never  1-3 times/year  4-6 times/year  
 7-12 times/year  More than 12 times/year

45 Do you use the following nutritional supplements?

	Daily	Sometimes	No
+ Cod liver oil or fish oil capsules .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Omega 3 capsules (fish oil, seal oil) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Calcium tablets .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## QUESTIONS FOR WOMEN

46 Are you pregnant at the moment?

Yes  No  Uncertain

47 How many children have you given birth to?

Number   +

48 If you have given birth, fill in for each child: birth year, birth weight and months of breastfeeding (Fill in the best you can)

Child	Birth year	Birth weight in grams	Months of breastfeeding
1	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>
2	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>
3	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>
4	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>
5	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>
6	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>

49 Have you during pregnancy had high blood pressure?

Yes  No

50 If yes, during which pregnancy?

The first  Second or later

51 Have you during pregnancy had proteinuria?

Yes  No

52 If yes, during which pregnancy?

The first  Second or later

53 Were any of your children delivered prematurely (a month or more before the due date) because of preeclampsia?

Yes  No

54 If yes, which child?

1st child 2nd child 3rd child 4th child 5th child 6th child

55 How old were you when you started menstruating?

Age   +

56 Do you currently use any prescribed drug influencing the menstruation?

Oral contraceptives, hormonal  
intrauterine or similar .....

Yes  No

Hormone treatment for  
menopausal problems .....

Yes  No

When attending you will get supplementary questions about menstruation and any use of hormones. Write down on a sheet of paper the names of all the hormones you have used and bring it with you. You will also be asked whether your menstruation have ceased and possibly when and why.

Appendix 3-E:  
Second questionnaire Tromsø VI





# Tromsø

- part of The Tromsø Study



## FILL OUT THE FORM IN THIS WAY:

The form would be read by machine, it is therefore important that you tick appropriately:

Correct

Wrong

Wrong

If you tick the wrong box, correct by filling the box like this

Write the numbers clearly *1 2 3 4 5 6 7 8 9 0*

7	4
---	---

 Correct

7	4
---	---

 Wrong

Use only black or blue pen, do not use pencil or felt tip pen



# 1. DESCRIPTION OF YOUR HEALTH STATUS

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today:

1.6 To allow you to show us how good or bad your state of health is we have made a scale (almost like a thermometer) where the best state of health you can imagine is marked 100 and the worst 0. We ask you to show your state of health by drawing a line from the box below to the point on the scale that best fits your state of health.

## 1.01 Mobility

- I have no problems in walking about
- I have some problems in walking about
- I am confined to bed

## 1.02 Self-care

- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

## 1.03 Usual activities (e.g. work, study, housework, family or leisure activities)

- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

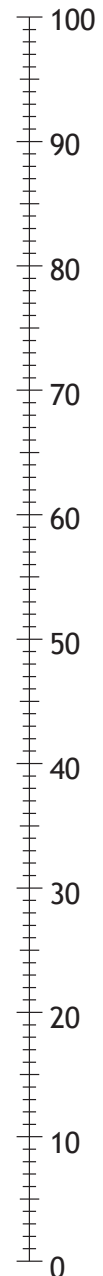
## 1.04 Pain and discomfort

- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

## 1.05 Anxiety and depression

- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed

Best imaginable health state



Your own health state today

Worst imaginable health state

## 2. CHILDHOOD/YOUTH AND AFFILIATION

2.01 **Where did you live at the age of 1 year?**

- In Tromsø (with present municipal borders)
- In Troms, but not Tromsø
- In Finnmark
- In Nordland
- Another place in Norway
- Abroad

2.02 **How was your family's financial situation during your childhood?**

- Very good
- Good
- Difficult
- Very difficult

2.03 **What is the importance of religion in your life?**

- Very important
- Somewhat important
- Not important

2.07 **What was/is the highest completed education for your parents and your spouse/partner?**  
(Tick once for each column)

	Mother	Father	Spouse/ partner
7-10 years primary/secondary school, modern secondary school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Technical school, vocational school, 1-2 years senior high school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
High school diploma .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
College or university (less than 4 years) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
College or university (4 years or more) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2.04 **What do you consider yourself as? (Tick for one or more alternatives)**

- Norwegian
- Sami
- Kven/Finnish
- Another

2.05 **How many siblings and children do you have/have you had?**

Number of siblings .....

Number of children .....

2.06 **Is your mother alive?**

- Yes       No

If NO: her age when she died .....

**Is your father alive?**

- Yes       No

If NO: his age when he died .....

### 3. WELL BEING AND LIVING CONDITIONS

**3.01** Below are three statements about satisfaction with life as a whole. Then there are two statements about views on your own health. Show how you agree or disagree with each of the statements by ticking in the box for the number you think fits best for you. (tick once for each statement)

	Completely disagree	1	2	3	4	5	6	7	Completely agree
In most ways my life is close to my ideal .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
My life conditions are excellent .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
I am satisfied with my life .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
I have a positive view of my future health .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
By living healthy, I can prevent serious diseases	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

**3.02** Below are four statements concerning your current job conditions, or if you are not working now, the last job you had. (Tick once for each statement)

	Completely disagree	1	2	3	4	5	6	7	Completely agree
My work is tiring, physically or mentally .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
I have sufficient influence on when and how my work should be done .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
I am being bullied or harassed at work .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
I am being treated fairly at work .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

**3.03** I consider my occupation to have the following social status in the society (if you are not currently employed, think about your latest occupation)

- Very high status
- Fairly high status
- Medium status
- Fairly low status
- Very low status

**3.04** Have you over a long period experienced any of the following? (Tick one or more for each line)

	No	Yes, as a child	Yes, as adult	Yes, last year
Been tormented, or threatened with violence .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Been beaten, kicked at or victim of other types of violence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Someone in your close family have used alcohol or drugs in such a way that it has caused you worry .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you have experienced anything of the above, how much are you affected by that now?

- Not affected       Affected to some extent       Affected to a large extent

## 4. ILLNESS AND WORRIES

4.01 **Have you during the last month experienced any illness or injury?**

Yes       No

If YES: have you during the same period?  
(Tick once for each line)

	Yes	No
Been to a general practitioner .....	<input type="checkbox"/>	<input type="checkbox"/>
Been to a medical specialist .....	<input type="checkbox"/>	<input type="checkbox"/>
Been to emergency department .....	<input type="checkbox"/>	<input type="checkbox"/>
Been admitted to a hospital .....	<input type="checkbox"/>	<input type="checkbox"/>
Been to an alternative practitioner (chiropractor, homeopath or similar) .....	<input type="checkbox"/>	<input type="checkbox"/>

4.02 **Have you noticed sudden changes in your pulse or heart rhythm in the last year?**

Yes       No

4.03 **Do you become breathless in the following situations? (tick once for each question)**

	Yes	No
When you walk rapidly on level ground or up a moderate slope .....	<input type="checkbox"/>	<input type="checkbox"/>
When you walk calmly on level ground .....	<input type="checkbox"/>	<input type="checkbox"/>
While you are washing or dressing .....	<input type="checkbox"/>	<input type="checkbox"/>
At rest .....	<input type="checkbox"/>	<input type="checkbox"/>

4.04 **Do you cough about daily for some periods of the year?**

Yes       No

If YES: Is the cough usually productive?

Yes       No

Have you had this kind of cough for as long as 3 months in each of the last two years?

Yes       No

4.05 **How often do you suffer from sleeplessness? (tick once)**

Never, or just a few times a year  
 1-3 times a month  
 Approximately once a week  
 More than once a week

If you suffer from sleeplessness monthly or more often, what time of the year does it affect you most? (Put one or more ticks)

No particular time  
 Polar night time  
 Midnight sun time  
 Spring and autumn

4.06 **Have you had difficulty sleeping during the past couple of weeks?**

Not at all  
 No more than usual  
 Rather more than usual  
 Much more than usual

4.07 **Have you during the last two weeks felt unhappy and depressed?**

Not at all  
 No more than usual  
 Rather more than usual  
 Much more than usual

4.08 **Have you during the last two weeks felt unable to cope with your difficulties?**

Not at all  
 No more than usual  
 Rather more than usual  
 Much more than usual

4.09 **Below, please answer a few questions about your memory: (tick once for each question)**

	Yes	No
Do you think that your memory has declined? .....	<input type="checkbox"/>	<input type="checkbox"/>
Do you often forget where you have placed your things? .....	<input type="checkbox"/>	<input type="checkbox"/>
Do you have difficulties finding common words in a conversation? .....	<input type="checkbox"/>	<input type="checkbox"/>
Have you problems performing daily tasks you used to master? .....	<input type="checkbox"/>	<input type="checkbox"/>
Have you been examined for memory problems? .....	<input type="checkbox"/>	<input type="checkbox"/>

If YES to at least one of the first four questions above: Is this a problem in your daily life?

Yes       No

4.10 Have you during the last last year suffered from pain and/or stiffness in muscles or joints in your neck/shoulders lasting for at least 3 consecutive months?  
(tick once for each line)

	No complaint	Little complaint	Severe complaint
Neck, shoulders .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Arms, hands.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Upper part of the back...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The lumbar region.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hips, leg, feet.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other places.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4.11 Have you suffered from pain and/or stiffness in muscles or joints during the last 4 weeks? (tick once for each line)

	No complaint	Little complaint	Severe complaint
Neck, shoulders .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Arms, hands .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Upper part of the back ...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The lumbar region .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hips, leg, feet.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other places .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4.12 Have you ever had:

	Yes	No	Age last time
Fracture in the wrist/forearm? .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Hip fracture? .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

4.13 Have you been diagnosed with arthrosis by a physician?

Yes  No

4.14 Do you have or have you ever had some of the following:

	Never	Some	Much
Nickel allergy .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pollen allergy .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other allergies .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4.15 Have you ever experienced infertility for more than 1 year?

Yes  No

If Yes: was it due to:

	Yes	No	Do not know
A condition concerning you?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A condition concerning your partner?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4.16 To which degree have you had the following complaints during the last 12 months?

	Never	Some	Much
Nausea .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Heartburn/regurgitation....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diarrhoea.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constipation.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Alternating diarrhoea and constipation.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bloated stomach.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Abdominal pain.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4.17 If you have had abdominal pain or discomfort during the last year:

	Yes	No
Was it located in your upper stomach?.....	<input type="checkbox"/>	<input type="checkbox"/>
Were you bothered as often as once a week or more during the last 3 months?.....	<input type="checkbox"/>	<input type="checkbox"/>
Do you feel symptoms relief after bowel movement?.....	<input type="checkbox"/>	<input type="checkbox"/>
Are the symptoms related to more frequent or rare bowel movements than normally? .....	<input type="checkbox"/>	<input type="checkbox"/>
Are the symptoms related to more loose or hard stool than normally?.....	<input type="checkbox"/>	<input type="checkbox"/>
Do the symptoms appear after a meal? ...	<input type="checkbox"/>	<input type="checkbox"/>

4.18 Have you ever had:

	Yes	No	Age last time
Gastric ulcer .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Duodenal ulcer .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Ulcer surgery .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

4.19 For women: Have you ever had a miscarriage?

Yes  No  Do not know  
If Yes: number of times .....

4.20 For men: Have your partner ever had a miscarriage?

Yes  No  Do not know  
If Yes: number of times .....

4.21 Is your diet gluten-free?

Yes  No  Do not know

4.22 Have you been diagnosed with Dermatitis Herpetiformis (DH)?

Yes  No  Do not know

4.23 Have you been diagnosed with coeliac disease, based on a biopsy from your intestine taken in a gastroscopy examination?  
 Yes     No     Do not know

4.24 Do you have your natural teeth?  
 Yes     No

4.25 How many amalgam tooth fillings do you have/have you had?  
 0     1-5     6-10     10+

4.26 Have you been suffering from headache the last year?  
 Yes     No

If No: go to section 5, food habits

4.27 What kind of headache are you suffering from?  
 Migraine     Other headache

4.28 How many days per month do you suffer from headache?  
 Less than one day  
 1-6 days  
 7-14 days  
 More than 14 days

4.29 Is the headache attacks usually:  
 (tick once for each line)

	Yes	No
Pounding/pulsatory pain .....	<input type="checkbox"/>	<input type="checkbox"/>
Pressing/tightening pain .....	<input type="checkbox"/>	<input type="checkbox"/>
Unilateral pain ( <i>right or left</i> ) .....	<input type="checkbox"/>	<input type="checkbox"/>

4.30 What is the normal intensity of your headache attacks?  
 Mild (*do not hinder normal activity*)  
 Moderate (*decrease normal activity*)  
 Strong (*block normal activity*)

4.31 What is the normal duration of the headache attacks?  
 Less than 4 hours  
 4 hours - 1 day  
 1-3 days  
 More than 3 days

4.32 If you suffer from headache, when during the year does it affect you most? (tick one or more)  
 No particular time  
 Polar night time  
 Midnight sun time  
 Spring and/or Autumn

4.33 Before or during the headache, do you have a temporary:

	Yes	No
Visual disturbances? ( <i>flickering, blurred vision, flashes of light</i> ).....	<input type="checkbox"/>	<input type="checkbox"/>
Unilateral numbness in your face or hand? .....	<input type="checkbox"/>	<input type="checkbox"/>
Aggravated pain by moderate physical activity? .....	<input type="checkbox"/>	<input type="checkbox"/>
Nausea and/or vomiting? .....	<input type="checkbox"/>	<input type="checkbox"/>

4.34 Describe how many days you have been away from work or school during the last month due to headache?  
 Number of days.....

## 5. FOOD HABITS

5.01 How often do you usually eat the following? (tick once for each line)

	0-1 times per month	2-3 times per month	1-3 times per week	More than 3 times per week
Fresh water fish ( <i>not farmed</i> ) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Salt water fish ( <i>not farmed</i> ) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Farmed fish ( <i>salmon, trout, char</i> ) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tuna fish ( <i>fresh or canned</i> ) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fish bread spread .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mussels, shells .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The brown content in crabs .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Whale or seal meat .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pluck (liver/kidney/heart) from reindeer or elk/moose..	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pluck (liver/kidney/heart) from ptarmigan/grouse .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5.02 How many times during the year do/did you usually eat the following? (number of times)

	In adulthood	In childhood
Mølje (cod or pollack meat, liver, and roe)( <i>Number of times per year</i> )	_	_
Sea gull's egg ( <i>Number of eggs per year</i> ) .....	_	_
Reindeer meat ( <i>Number of times per year</i> ) .....	_	_
Local mushroom and wild berries ( <i>blueberries/lingonberries/cloudberries</i> ) ( <i>Number of times per year</i> ) .....	_ _	_ _

5.03 How many times per month do you eat  
canned (tinned) foods (from metal boxes)?

Number .....

5.04 Do you take vitamins and/or mineral  
supplements?

Yes, daily     Sometimes     Never

5.05 How often do you eat?

	Never	1-3 times per month	1-3 times per week	4-6 times per week	1-2 times per day	3 times per day or more
Dark chocolate .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Light chocolate/milk chocolate ...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chocolate cake .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other sweets .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5.06 If you eat chocolate, how much do you usually eat each time?

Compared with the size of a Kvikk-Lunsj sjokolade (*a chocolate brand in the market*) and describe how much do you eat in relation to it.

$\frac{1}{4}$       $\frac{1}{2}$      1     1  $\frac{1}{2}$      2     More than 2

5.07 How often do you drink  
cocoa/hot chocolate?

Never	1-3 times per month	1-3 times per week	4-6 times per week	1-2 times per day	3 times per day or more
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## 6. ALCOHOL

6.01 How often have you in the last year:

	Never	Less than monthly	Monthly	Weekly	Daily or almost daily
Not been able to stop drinking alcohol when you have started? .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Failed to do what was normally expected of you because of drinking? .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Needed a drink in the morning to get yourself going after a heavy drinking session? .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Had feeling of guilt or remorse after drinking? .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not been unable to remember what happened the night before because of your drinking?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Never	Yes, but not in the last year	Yes, during the last year
6.02 Have you or someone else been injured because of your drinking? .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has a relative, friend, physician, or other health care workers been concerned about your drinking or suggested you to cut down? .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## 7. WEIGHT

<p>7.01 Have you involuntary lost weight during the <u>last 6 months</u>?</p> <p><input type="checkbox"/> Yes      <input type="checkbox"/> No</p> <p>If Yes: how many kilograms? ..... <input style="width: 50px;" type="text"/></p>	<p>7.03 Are you satisfied with your present body weight?</p> <p><input type="checkbox"/> Yes      <input type="checkbox"/> No</p>
<p>7.02 Estimate your body weight when you were 25 years old:</p> <p>Number of kilograms ..... <input style="width: 50px;" type="text"/></p>	<p>7.04 What weight would you be satisfied with (your "ideal" weight)?</p> <p>Number of kilograms ..... <input style="width: 50px;" type="text"/></p>

## 8. SOLVENTS

<p>8.01 How many hours per week, do you do the following <u>leisure- or professional activities</u>:</p> <p>Automobile repair/paint, ceramic work, painting/varnishing/solvents, hair dressing, glazier, electrician. (Put 0 if you do not engage in such leisure or professional activities)</p> <p>Number of hours per week on average: <input style="width: 50px;" type="text"/></p>	<p>8.02 Do you use hair color preparations</p> <p><input type="checkbox"/> Yes      <input type="checkbox"/> No</p> <p>If Yes: How many times per year?.. <input style="width: 50px;" type="text"/></p>
---	---



## 9. USE OF HEALTH SERVICES

9.01 Have you ever experienced that diseases have been insufficiently examined or treated, and this had a serious consequence?

- Yes, this has happened to me  
 Yes, this has happened to a close relative  
*(child, parents, spouse)*  
 No

If Yes, was it caused by?  
 (tick once or more):

- general practitioner  
 emergency medical doctor  
 private practising specialist  
 hospital doctor  
 other health personnel  
 alternative practitioner  
 more than one person due to deficient routines and interaction

9.02 Have you ever felt persuaded to accept an examination or treatment that you did not want?

- Yes  No

If Yes, do you think this has had unfortunate consequences for your health?

- Yes  No

9.03 Have you ever complained about a treatment you have received?

- Have never had a reason for complaining  
 Have considered complaining, but did not do  
 Have complained verbally  
 Have complained in writing

9.04 How long have you had your current general practitioner/other physician?

- Less than 6 months  
 6 to 12 months  
 12 to 24 months  
 More than 2 years

9.05 At the last visit to your GP, did you have a hard time to understand what the doctor(s) told you? Answer on a scale from 0 to 10, where 0 = they were difficult to understand and 10 = they were always easy to understand

- 0 1 2 3 4 5 6 7 8 9 10

9.06 How would you rate the treatment or counselling, you got at your last visit to your GP? Answer on a scale from 0 to 10, where 0 = worst treatment or counselling, and 10 = best treatment or counselling

- 0 1 2 3 4 5 6 7 8 9 10

9.07 During the last 12 months, how much of a problem, if any, was it to get a referral to special examinations (as x-ray, etc.) or to a specialist health care (private practising specialist or at hospital)?

- Not relevant  
 No problem  
 Some problem  
 Major problem

9.08 During the last 12 months, how much of a problem, if any, was it to get a referral to physiotherapist, chiropractor, etc.?

- Not relevant  
 No problem  
 Some problem  
 Major problem

9.09 Altogether, how much of a problem, if any, was it to get a referral to specialist health care?

- Not relevant  
 Very difficult  
 Some difficulties  
 Easy  
 Very easy



9.10 During the last 12 months, have you been examined or treated by the specialist health care?

Yes       No

If Yes, did you have a difficult time to understand what the doctor(s) told you? Answer on a scale from 0 to 10, where 0 = they were difficult to understand and 10 = they were always easy to understand

0 1 2 3 4 5 6 7 8 9 10

9.11 How would you rate the treatment or counselling you got at your last visit to a specialist? Answer on a scale from 0 to 10, where 0 = worst treatment or counselling, and 10 = best treatment or counselling

0 1 2 3 4 5 6 7 8 9 10



9.12 Have you ever, previous to the year 2002, had an operation at a hospital or a specialist clinic?

Yes       No

9.13 Have you, during the last 12 months, used herbal or natural medicine?

Yes       No

9.14 Have you, during the last 12 months, used meditation, yoga, qi gong or thai chi as self-treatment?

Yes       No



## 10. USE OF ANTIBIOTICS

10.01 **Have you used antibiotics during the last 12 months?** (all penicillin-like medicine in the form of tablets, syrups or injections)

Yes       No       Do not remember

If YES: What did you get the treatment for?

Have you taken many antibiotic treatments, tick for each treatment.

	Treatment 1	Treatment 2	Treatment 3	Treatment 4	Treatment 5	Treatment 6
--	----------------	----------------	----------------	----------------	----------------	----------------

- |   |                          |                          |                          |                          |                          |                          |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| • Urinary tract infection ( <i>bladder infection, cystitis</i> ) .....                          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Respiratory tract infection ( <i>ear, sinus, throat or lung infection, bronchitis</i> ) ..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Other .....   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Treatment duration: number of days .....

--	--	--	--	--	--	--

How did you acquire the antibiotics for treatment?

Have you acquired many treatments, tick for each one.

With prescription from a physician/dentist .....

	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

Without contacting a physician/without prescription:

- |   |                          |                          |                          |                          |                          |                          |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| • Purchase from a pharmacy abroad .....         | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Purchase over the internet .....              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Remnants from earlier treatment at home ..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • From family/friends .....                     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Other ways .....                              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

10.02 **Do you presently have antibiotics at home?**

Yes       No

If YES: is this after an agreement with your physician for treatment of chronic or frequently recurring disease?

Yes       No

If No: how did you acquire this antibiotic? (Multiple ticks are possible)

- Purchased from a pharmacy abroad ...
- Purchased over the internet .....
- Remnants from earlier treatment .....
- From family/friends .....
- Other ways .....

10.03 **Would you consider using antibiotics without consulting your physician?**

Yes       No

If YES: which conditions would you treat in such situation? (multiple ticks are possible)

- Common cold .....
- Cough .....
- Bronchitis .....
- Sore throat .....
- Sinusitis .....
- Fever .....
- Influenza .....
- Ear infection .....
- Diarrhoea .....
- Urinary tract infection .....
- Other infections .....

## 11. YOUR CIRCADIAN RHYTHM

We will ask you some questions about your sleeping habits

11.01 Have you worked in a shift work schedule during the last 3 months?

Yes  No

11.02 Number of days per week which you cannot freely choose when you sleep (e.g. work days)?

0 1 2 3 4 5 6 7

Then I go to bed at .....

I get ready to fall asleep at .....

Number of minutes I need to fall asleep .....

I wake up at .....

With help of:  Alarm clock  External stimulus (*noise, family members etc.*)  By myself

Number of minutes I need to get up .....

11.03 Number of days per week which you can freely choose when you sleep (e.g. free days or holidays)

0 1 2 3 4 5 6 7

Then I go to bed at .....

I get ready to fall asleep at .....

Number of minutes I need to fall asleep .....

I wake up at .....

With help of:  Alarm clock  External stimulus (*noise, family members etc.*)  By myself

Number of minutes I need to get up .....

## 12. SKIN AND DERMATOLOGY

12.01 How often do you usually take a shower or a bath? (tick once)

- 2 or more times daily
- 1 time daily
- 4-6 times per week
- 2-3 times per week
- Once a week
- Less than once a week

12.02 How often do you usually wash your hands with soap daily? (tick once)

- 0 times
- 1-5 times
- 6-10 times
- 11-20 times
- More than 20 times

12.03 Have you ever taken any antibiotics (penicillin and penicillin-like medicines) because of a skin disease, for example infected eczema, acne, non-healing leg ulcers, recurrent abscess?

- Yes       No

If Yes: How many times in average per year did you take antibiotics during the period you were most affected (tick once)

- 1-2       3-4       More than 4 times

12.04 Have you or have you ever had the following skin disorders? (tick once for each line)

- |   | Yes                      | No                       |
|---|--------------------------|--------------------------|
| Psoriasis .....   | <input type="checkbox"/> | <input type="checkbox"/> |
| Atopic eczema (children's eczema)....                   | <input type="checkbox"/> | <input type="checkbox"/> |
| Recurrent hand eczema .....                             | <input type="checkbox"/> | <input type="checkbox"/> |
| Recurrent pimples/spots for several months .....        | <input type="checkbox"/> | <input type="checkbox"/> |
| Leg or foot ulcer that did not heal for 3-4 weeks ..... | <input type="checkbox"/> | <input type="checkbox"/> |

If YES on the question concerning leg and/or foot ulcer, do you have any leg ulcer today?

- Yes       No

12.05 Have you often or always any of the following complaints? (tick once for each line)

- |   | Yes                      | No                       |
|---|--------------------------|--------------------------|
| Swelling in the ankles or legs, particularly in the evenings .....                                    | <input type="checkbox"/> | <input type="checkbox"/> |
| Varicose veins .....  | <input type="checkbox"/> | <input type="checkbox"/> |
| Eczema (red, itchy rash) on your legs .....   | <input type="checkbox"/> | <input type="checkbox"/> |
| Leg pain that is getting worse when you are walking and is relieved when you are standing still ..... | <input type="checkbox"/> | <input type="checkbox"/> |

12.06 Have you ever had the following diagnoses by a physician? (tick once for each line)

- |                     | Yes                      | No                       |
|---------------------|--------------------------|--------------------------|
| Psoriasis .....     | <input type="checkbox"/> | <input type="checkbox"/> |
| Atopic eczema ..... | <input type="checkbox"/> | <input type="checkbox"/> |
| Rosacea .....       | <input type="checkbox"/> | <input type="checkbox"/> |

12.07 Have you recurring large acne/abscesses that are tender/painful and often form scars in the following places? (tick once for each line)

- |                                | Yes                      | No                       |
|--------------------------------|--------------------------|--------------------------|
| Armpits .....                  | <input type="checkbox"/> | <input type="checkbox"/> |
| Under the breasts .....        | <input type="checkbox"/> | <input type="checkbox"/> |
| Stomach groove/the navel ..... | <input type="checkbox"/> | <input type="checkbox"/> |
| Around the genitalia .....     | <input type="checkbox"/> | <input type="checkbox"/> |
| Around the anus .....          | <input type="checkbox"/> | <input type="checkbox"/> |
| The groin .....                | <input type="checkbox"/> | <input type="checkbox"/> |

If Yes: Have you ever visited a physician because of abscesses?

- Yes       No

If Yes, did you get any of the following treatments? (tick once for each line)

- |   | Yes                      | No                       |
|---|--------------------------|--------------------------|
| Antibiotic ointment .....                                   | <input type="checkbox"/> | <input type="checkbox"/> |
| Antibiotic tablets .....                                    | <input type="checkbox"/> | <input type="checkbox"/> |
| Surgical drainage .....                                     | <input type="checkbox"/> | <input type="checkbox"/> |
| A larger surgical intervention including skin removal ..... | <input type="checkbox"/> | <input type="checkbox"/> |
| Surgical laser treatment .....                              | <input type="checkbox"/> | <input type="checkbox"/> |

# Follow-up questions



## INFORMATION TO FOLLOW-UP QUESTIONS

The following pages with questions should not be answered by everybody. If you have answered yes to one or more of questions below, we ask you to move on to the follow-up questions on the topic or topics you have answered yes to. The first four topics are from the first questionnaire and the last question is from this form.

We have for the sake of simplicity highlighted topics with different colours so that you will find the questions that applies to you.

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If you answered YES to that you have: long-term or recurrent pain that has lasted for 3 months or more, please answer the questions on page 19 and 20. The margin is marked with green.

---

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If you answered YES to that you have undergone any surgery during the last 3 years, please answer the questions on page 21 and 22. The margin is marked with purple.

---

---

If you answered YES to that you're working outdoors at least 25% of the time, or in facilities with low temperature, such as warehouse/industrial halls, please answer the questions on page 23. The margin is marked with red.

---

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If you answered YES to that you have used non-prescription pain relievers, please answer questions on page 24. The margin is marked with orange.

---

---

If you answered YES to that you have or have ever had skin problems (such as psoriasis, atopic eczema, non-healing leg or foot ulcers, recurrent hand eczema, acne or abscesses), please answer the questions on page 25. The margin is marked with yellow.

---

If you have answered **NO** to these five questions, you are finished with your answers. The questionnaire is to be returned in the reply envelope you were given at the survey site. The postage is already paid.

Should you wish to give us written feedback on either the questionnaire or The Tromsø Study in general, you are welcome to that on page 26.

Do you have any questions, please contact us by phone or by e-mail. You can find the contact information on the back of the form. **THANK YOU** for taking the time to the survey and to answer our questions.

## 13. FOLLOW-UP QUESTIONS ON PAIN

You answered in the first questionnaire that you have protracted or constantly recurrent pain that has lasted for 3 months or more. Here, we ask you to describe the pain a little closer.

13.01 **How long have you had this pain?**

Number of years   months

13.02 **How often do you have this pain?**

- Every day  Once a month or more  
 Once a week or more  Less than once a month

13.03 **Where does it hurt?** (Tick for all locations where you have protracted or constantly recurrent pain)

- |   |   |
|---|---|
| <input type="checkbox"/> Head/face                    | <input type="checkbox"/> Thigh/knee/leg                 |
| <input type="checkbox"/> Jaw/temporo-mandibular joint | <input type="checkbox"/> Ankle/foot                     |
| <input type="checkbox"/> Neck                         | <input type="checkbox"/> Chest/breast                   |
| <input type="checkbox"/> Back                         | <input type="checkbox"/> Stomach                        |
| <input type="checkbox"/> Shoulder                     | <input type="checkbox"/> Genitalia /reproductive organs |
| <input type="checkbox"/> Arm/elbow                    | <input type="checkbox"/> Skin                           |
| <input type="checkbox"/> Hand                         | <input type="checkbox"/> Other location                 |
| <input type="checkbox"/> Hip                          |   |

13.04 **What do you believe is the cause of the pain?** (Tick for all known causes)

- |  |  |
|--|--|
| <input type="checkbox"/> Accident /acute injury                      | <input type="checkbox"/> Fibromyalgia                            |
| <input type="checkbox"/> Long-term stress                            | <input type="checkbox"/> Angina pectoris                         |
| <input type="checkbox"/> Surgical intervention/operation             | <input type="checkbox"/> Poor blood circulation                  |
| <input type="checkbox"/> Herniated disk ( <i>prolapse</i> ) /lumbago | <input type="checkbox"/> Cancer                                  |
| <input type="checkbox"/> Whiplash                                    | <input type="checkbox"/> Nerve damage/neuropathy                 |
| <input type="checkbox"/> Migraine/headache                           | <input type="checkbox"/> Infection                               |
| <input type="checkbox"/> Osteoarthritis                              | <input type="checkbox"/> Herpes zoster                           |
| <input type="checkbox"/> Rheumatoid arthritis                        | <input type="checkbox"/> Another cause ( <i>describe below</i> ) |
| <input type="checkbox"/> Bechterews syndrome                         | <input type="checkbox"/> Don't know                              |

Describe the other cause:

.....

13.05 **Which kind of treatment have you received for the pain?** (Tick for all types of pain treatments you have received)

- |   |  |
|---|--|
| <input type="checkbox"/> No treatment                         | <input type="checkbox"/> Psycho-educative/relaxation training/ psychotherapy                                       |
| <input type="checkbox"/> Analgesic medications/painkillers    | <input type="checkbox"/> Acupuncture   |
| <input type="checkbox"/> Physiotherapy/chiropractic treatment | <input type="checkbox"/> Complimentary and alternative medicine ( <i>homeopathy, healing, aromatherapy, etc.</i> ) |
| <input type="checkbox"/> Treatment at a pain clinic           | <input type="checkbox"/> Other treatment   |
| <input type="checkbox"/> Surgery                              |  |



13.06 On a scale of 0 to 10, where 0 corresponds to no pain and 10 corresponds to the worst possible pain you can imagine:

How strong would you say that the pain usually is? .....  
No pain 0 1 2 3 4 5 6 7 8 9 10 Worst imaginable pain

How strong is the pain when it is in its strongest Intense? .....  
No pain 0 1 2 3 4 5 6 7 8 9 10 Worst imaginable pain

To what degree does the pain interfere with your sleep? .....  
No effect 0 1 2 3 4 5 6 7 8 9 10 Impossible to sleep

To what degree does the pain interfere with performing common activities at home and at work? .....  
No effect 0 1 2 3 4 5 6 7 8 9 10 Can not do anything

## 14. FOLLOW-UP QUESTIONS ON SURGERY

In the first questionnaire you answered that you have undergone an operation during the last 3 years.

14.01 **How many times have you undergone surgery during the last 3 years?**

Number .....

Below, please describe the operation. If you have undergone several operations during the last 3 years, these questions concern the last surgery you underwent.

14.02 **Where in your body did you have surgery?**  
(If you were operated simultaneously in several places in the body, tick more than once)

Surgery in the head/neck/back

- Head/face .....
- Neck/throat .....
- Back .....

Surgery in the chest

- Heart .....
- Lungs .....
- Breasts .....
- Another surgery in the chest region .....

Surgery in the stomach/pelvis

- Stomach/intestines .....
- Inguinal hernia .....
- Urinary tract/reproductive organs .....
- Gall bladder/biliary tract .....
- Another surgery in the stomach/pelvis .....

Surgery in the hip/legs

- Hip/thigh .....
- Knee/leg .....
- Ankle/foot .....
- Amputation .....

Surgery in the shoulder and arm

- Shoulder/overarm .....
- Elbow/underarm .....
- Hand .....
- Amputation .....

14.03 **Reason for the surgery:**

- Acute illness/trauma .....
- Planned non-cosmetic operation .....
- Planned cosmetic operation .....

14.04 **Where did you have the surgery?**

- The hospital in Tromsø .....
- The hospital in Harstad .....
- Other public hospital .....
- Private clinic .....

14.05 **How long time is it since you had surgery?**

Number of years .....  Months .....

14.06 **Do you have reduced sensitivity in an area near the surgical scar?**

- Yes       No

14.07 **Are you hypersensitive to touch, heat or cold in an area near the surgical scar?**

- Yes       No

14.08 **Does slight touch from clothes, showering or similar cause discomfort/pain?**

- Yes       No

14.09 **If you had pain at the site of surgery before you had surgery, do you have the same type of pain now?**

- Yes       No



14.10

**The pain at the site of surgery:** Answer on a scale from 0 to 10, where 0=no pain and 10=worst pain you can imagine

	No pain	0	1	2	3	4	5	6	7	8	9	10	Worst imaginable pain
How strong pain did you have at the site of surgery <u>before</u> you had surgery		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

	No pain	0	1	2	3	4	5	6	7	8	9	10	Worst imaginable pain
How strong pain do you normally have at the site of surgery now .....		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

	No pain	0	1	2	3	4	5	6	7	8	9	10	Worst imaginable pain
How strong pain do you normally have at the site of surgery when it is most intense .....		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	



## 15. FOLLOW-UP QUESTIONS ABOUT WORK IN COLD ENVIRONMENT

In the first questionnaire you answered yes to that you work in cold environments. Here are some follow-up questions that we hope you will answer.

15.01 Do you feel cold at work?

- Yes, often
- Yes, sometimes
- No, never

15.05 Have you had itching and/or rash in relation to cold exposure?

- Yes       No

15.02 For how long have you been exposed to cold air below 0°C during the last winter?

Leisure/hobbies (hours/week) .....

Work (hours/week) .....

Outdoors, with suitable clothing (hours/week) .....

Outdoors, without suitable clothing (hours/week) .....

Indoors, with no heating (hours/week) .....

In cold, with wet clothing (hours/week) .....

Contact with cold objects/tools (hours/week) .....

15.06 Have you during the last 12 months had an accident where cold has been involved, and which required medical treatment?

	Yes	No
At work .....	<input type="checkbox"/>	<input type="checkbox"/>
In leisure time .....	<input type="checkbox"/>	<input type="checkbox"/>

15.07 Do you experience any of the following symptoms while you are in a cold environment? If so, at what temperature do the symptoms occur?

	Yes	No	Under °C
Breathing problems .....	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 50px;" type="text"/>
Wheezy breathing .....	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 50px;" type="text"/>
Mucus secretion from lungs .....	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 50px;" type="text"/>
Chest pain .....	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 50px;" type="text"/>
Disturbance in heart rhythm .....	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 50px;" type="text"/>
Impaired blood circulation in hands/feet .....	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 50px;" type="text"/>
Visual disturbance (short term/transient) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 50px;" type="text"/>
Migraine (short term/transient) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 50px;" type="text"/>
Fingers turning white (short term/transient) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 50px;" type="text"/>
Fingers turning blue-red (short term/transient) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 50px;" type="text"/>

15.03 What ambient temperature prevents you from:

	Under °C
Working outdoors .....	<input style="width: 50px;" type="text"/>
Training outdoors .....	<input style="width: 50px;" type="text"/>
Performing other activities outdoors .....	<input style="width: 50px;" type="text"/>

15.04 Have you during the last 12 months had a frostbite with blisters, sores or skin injury?

- Yes       No

If Yes, how many times?.....

15.08 How does cold environments and cold-related symptoms influence your performance?

	Decrease	No effect	Improve
Concentration .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Memory .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Finger sensitivity (feeling) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Finger dexterity (motor) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Control of movement (for example tremor) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Heavy physical work .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Long-lasting physical work .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## 16. USE OF NON-PRESCRIPTION PAINKILLERS

In the first questionnaire you answered that you had used non-prescription painkillers (analgesics) in the last 4 weeks. Here are some follow-up questions we hope you will answer.

### 16.01 What types of non-prescription painkillers have you used?

**Paracetamol:** (*Pamol, Panodil, Paracet, Paracetamol, Pinex*)

- Not used
- Less than every week
- Every week, but not daily
- daily

How much do you usually take daily when you use these medicines? (number of tablets, suppositories) .....

**Acetylsalicylates:** (*Aspirin, Dispril, Globoid*)

- Not used
- Less than every week
- Every week, but not daily
- Daily

How much do you usually take daily when you use these medicines? (number of tablets) .....

**Ibuprofen:** (*Ibuprofen, Ibuprofen, Ibuprofen, Ibuprofen*)

- Not used
- Less than every week
- Every week, but not daily
- Daily

How much do you usually take daily when you use these medicines? (number of tablets, suppositories) .....

**Naproxen:** (*Ledox, Naproxen*)

- Not used
- Less than every week
- Every week, but not daily
- Daily

How much do you usually take daily when you use these medicines? (number of tablets) .....

**Phenazone with caffeine:** (*Antineuralgica, Fanalgin, Fenazon-koffein, Fenazon-koffein sterke*)

- Not used
- Less than every week
- Every week, but not daily
- daily

How much do you usually take daily when you use these medicines? (number of tablets) .....

### 16.02 For which complaints do you use non-prescription painkillers? (multiple ticks are possible)

- Headache
- Menstrual discomfort
- Migraine
- Back pain
- Muscle/joint pain
- Tooth pain
- Other

### 16.03 Do you think you have experienced side effects of some of the medicines? (tick once for each line)

	Yes	No
Paracetamol .....	<input type="checkbox"/>	<input type="checkbox"/>
Acetylsalicylates .....	<input type="checkbox"/>	<input type="checkbox"/>
Ibuprofen .....	<input type="checkbox"/>	<input type="checkbox"/>
Naproxen .....	<input type="checkbox"/>	<input type="checkbox"/>
Phenazone with caffeine .....	<input type="checkbox"/>	<input type="checkbox"/>

### 16.04 Where do you usually purchase painkillers?

- Pharmacy
- Grocery
- Petrol stations
- Abroad
- Internet

### 16.05 Do you combine the treatment with the use of painkillers on prescription?

- Yes
- No





**Thank you for your help**







The Tromsø Study

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