

# Cancer alarm symptoms and healthcare-seeking behaviour in the general population

PhD Thesis

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## Abbreviations

CI:	Confidence interval
CPR:	Civil registration number
CRS:	Civil registration system
CT:	Computed tomographies
GP:	General practitioner
OR:	Odds ratio
SES:	Socioeconomic status

## List of papers

This PhD thesis is based on the following three papers which will be referred to by their roman numerals:

- I **Prevalence of cancer alarm symptoms: a population-based cross-sectional study.** Svendsen RP, Stovring H, Hansen BL, Kragstrup J, Sondergaard J, Jarbol DE. *Scand J Prim Health Care* 2010;28:132-137.
- II **Associations between reporting of cancer alarm symptoms and socioeconomic and demographic determinants: a population-based, cross-sectional study.** Svendsen RP, Paulsen MS, Larsen PV, Hansen BL, Stovring H, Jarbol DE, Sondergaard J. *BMC Public Health* 2012;12:686. Svendsen RP, Paulsen MS, Larsen PV,
- III **Associations between health care seeking and socioeconomic and demographic determinants among people reporting alarm symptoms of cancer: a population-based cross-sectional study.** Svendsen RP, Jarbol DE, Larsen PV, Stovring H, Hansen BL, Soendergaard J. *Fam Pract* 2013;30:655-665.

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# 1 Background

## 1.1 Cancer epidemiology

Cancer is a leading cause of death worldwide, accounting for 7.6 million deaths (around 13% of all deaths) in 2008.<sup>1</sup> Survival of cancer has improved in Europe through the past years, but substantial differences still exist within and between countries. Through many years cancer incidence has been increasing in Denmark and today approximately 37,000 patients are diagnosed with cancer every year.<sup>2</sup> For men, colorectal, prostate, lung, and urinary tract cancer account for most new cases, whereas breast, colorectal, and lung cancer are the most common cancer forms among women.<sup>2</sup> Since 2000, cancer has been the most frequent cause of death in Denmark, accounting for 30% of all deaths,<sup>3</sup> and despite major efforts to improve outcomes, Denmark (and the UK) have persistently lower survival rates after diagnosis than the other European countries.<sup>4;5</sup> Whilst there are several reasons for this, diagnostic delays and later stage at diagnosis are likely to be contributory factors for Danish cancer patients' lower survival rates.<sup>6</sup>

Early detection of cancer may be one key factor in improving the outcomes for cancer patients,<sup>6;7</sup> and it seems reasonable to assume that some cancers may be diagnosed at an earlier stage and deaths may be avoided every year, if medical help was sought immediately after patients notice alarm symptoms. Therefore, national initiative programmes have been launched in many countries with the intention of achieving earlier presentation of symptoms and earlier diagnosis through more effective diagnostic routes, for example the English National Awareness and Early Diagnosis Initiative (NAEDI)<sup>8</sup> and by the Danish Cancer Society.<sup>9</sup>

Most investigators define the time that elapses from recognition of symptoms until the first contact with a medical provider as patient delay.<sup>10</sup> It has been shown that patient and primary care delays contributed to substantial parts of the total diagnostic delay among patients with different cancer types<sup>11;12</sup> and many studies have indeed attempted to analyse factors associated with delayed early presentation. It has proved difficult, though, to compare results from the different studies as there is little consistency in the definition and measurement of key time points and intervals.<sup>13</sup> Some researchers divide the patient delay into even smaller time points,<sup>14</sup> and various cut-off points have been defined as delay/no delay in different studies.<sup>15;16</sup> To establish consensus for future research of different 'delayed' time intervals in the diagnostic routes, a consensus working group developed the 'Aarhus Statement'.<sup>17</sup> This diagnostic pathway is popularly divided into three main intervals: The *patient interval* (from recognition of symptom until first presentation to

a clinical doctor, most often a GP), the *doctor interval* (from first presentation until referral is initiated by the GP), and the *system interval* (from referral, over diagnosis, until initiation of treatment).<sup>18</sup>

Long time intervals were found in Danish studies among cancer patients diagnosed in 2003 and 2004-2005.<sup>18;19</sup> The Danish government (Danish Health and Medicines Authority) launched Cancer Plan II in 2005 to improve Danish cancer outcomes. This recommended that the time interval for the standard patient's ideal pathway (from a symptom suspicious of cancer was presented to the general practitioner (GP) until diagnosis and finally treatment) should be minimised. In other words: shortening waiting times and accelerating the diagnostic process. Multidisciplinary cancer groups were established, ensuring standardised cancer pathways, and in April 2008 the first cancer pathways were initiated for head and neck cancer, breast cancer, colorectal cancer, and lung cancer. In January 2009, the remaining cancer pathways were introduced for all other cancer forms.<sup>20</sup>

## 1.2 Danish healthcare system, the general practitioner as gatekeeper

Denmark has a tax-financed health care system with free access to medical advice and treatment in general practices and hospitals. All GPs in Denmark are independent contractors with the public health service (through the regional health authorities) and are remunerated on a mixed fee for service and capitation basis.<sup>6</sup> All Danish citizens are eligible to be listed with a GP and approximately 98% choose to be.<sup>21</sup> The GPs act as gatekeepers, i.e. being the first point of contact, e.g. when the patient presents with a symptom to the GP she makes the decision whether and when to refer the patient for further diagnostic investigations. The GPs have the opportunity to refer patients to most office-based specialists, as well as to inpatient and outpatient hospital care through a structured referral system. Only a small number of patients are referred to further diagnostic investigations directly from other points of entry, for instance the emergency departments, ophthalmologists, dermatologists, or from ear-nose-and-throat doctors. For certain symptoms it may be appropriate for a GP to wait and see if the symptom resolves; others require urgent assessment by a specialist.

## 1.3 What is a symptom?

The WONCA Dictionary of General/Family Practice defines symptoms as 'any subjective evidence of a health problem as perceived by the patient'.<sup>22</sup> This definition implies that symptoms are the

result of an interpretation process, where sensations are transformed into signs of ill-health.<sup>23</sup> In different studies a distinction between subjective health complaints, 'symptoms' and objectively verifiable 'signs' (e.g. blood in the urine or lump in the breast) is made. Signs are often seen as reliable markers of disease, whereas symptoms often refer to subjective complaints.<sup>23</sup> In this thesis self-reported symptoms gathered from the general population are analysed. People have not necessarily seen a doctor, and their possible sensations/experiences are therefore denoted as 'symptoms'. Further, in Danish both symptoms and signs are most often called 'symptoms'. It has to be remembered that surveys of symptom prevalence in the general population and in primary care reflect a variety of interpretations of sensations, which are not necessarily equivalent to expressions of underlying disease.

## 1.4 What is an alarm symptom?

Alarm symptoms are characteristic and distinctive features in the clinical presentation considered to predict serious, often malignant, diseases.<sup>24</sup> These specific symptoms are defined in national cancer referral guidelines<sup>25;26</sup> and serve as quick access to fast-track hospital referrals. That is, when an alarm symptom is presented to a GP, she has to decide whether the cancer suspicion is sufficiently strong to refer the patient to the hospital for further standardised investigations, and whether the patient has to be seen already within a few days.

Beyond the well-defined alarm symptoms in the cancer referral guidelines, some early symptoms shown to be related to cancer diseases are quite unspecific and actually quite common among cancer patients. Approximately 50% of the symptoms that newly diagnosed cancer patients presented with prior to diagnosis were non-specific.<sup>27</sup> This knowledge gave rise to a recommendation in the Danish Cancer Plan III, 2010, that regional diagnostic centres should be developed so that GPs may refer patients with suspected cancer although they have no cancer alarm symptoms.<sup>28</sup>

## 1.5 Symptom experience

It is well known that a wide range of symptoms are experienced every day in the general population and that many people manage these symptom experiences without consulting the healthcare system.<sup>29;30</sup> A community perspective is important when researching the epidemiology of cancer alarm symptoms, but only few studies on alarm symptoms of cancer among the general population have been made.<sup>30-34</sup> By providing prevalences of symptoms in the general population

and person characteristics of the people who have experienced these symptoms efficient symptom-based models for predicting serious disease – for instance which symptoms should be included in the national cancer referral guidelines - could be developed.

Symptom prevalences of cancer alarm symptoms and person characteristics associated with symptom reporting have never been estimated among the general population in Denmark. In other countries different population-based studies found that younger people were more likely to report symptoms<sup>31;35;36</sup> and women were more likely to report symptoms than men.<sup>37</sup> McAteer et al. (2011) found that several symptoms in the public were very common and that factors independently associated with the prevalence of symptoms varied considerably. Age and employment status were most commonly associated with the prevalence of different symptoms. Gender, marital status, level of social support, household income, and smoking status were associated with fewer symptoms. Level of education, housing tenure, and ethnicity were not associated with any symptoms. A Swedish study among middle-aged women found that being non-employed increased the odds of a high level of common symptoms,<sup>38</sup> and a Norwegian study found that those who reported low education reported more symptoms.<sup>39</sup>

The hypothesis for the present Study was that the prevalence of cancer alarm symptoms in the general population would be high and that different person characteristics would be associated with experiencing these alarm symptoms. With the knowledge of previous studies' results we wanted to test whether their findings concerning person characteristics also applied to our study population. Intuitively, we hypothesised that older subjects were more likely to report symptoms than younger subjects and that women were more likely to report symptoms than men. Moreover, the hypothesis was that high socioeconomic status (SES) (measured by education, income, or labour market affiliation) was negatively associated with symptom reporting.

## 1.6 Healthcare-seeking

Healthcare-seeking among cancer patients – and among numerous other patient groups - has been studied for many years. Already in the 1930s, Pack and Gallo defined 'undue patient delay' arbitrarily as 'three months or more elapsed time between discovery of symptoms and a visit to a physician',<sup>40</sup> and as a recent study has shown that the patient interval accounts for a substantial part of cancer patients' pre-hospital time interval,<sup>12</sup> it is obviously still important to obtain a deeper insight into the patients' decisions in relation to healthcare-seeking; the reasons why patients present, when they do, and with the symptoms they do.

An enhanced understanding of healthcare-seeking behaviours may assist health care professionals in identifying patients who are at risk of delayed help seeking and may help development of health campaigns targeting these patients. If longer patient intervals do impact on prognosis<sup>41</sup> and survival, which intuitively appears to be obvious, even though it has only been shown for breast cancer,<sup>42</sup> such campaigns, if they work well, could save a significant number of lives. The challenge lies in achieving a suitable balance, which targets the appropriate population without creating undue fear and overburdening primary care services with patients seeking reassurance. Before developing help-seeking interventions, it is, however, important to estimate the healthcare-seeking behaviour among people from the general population who have experienced cancer alarm symptoms and to analyse person characteristics associated with healthcare-seeking behaviour.

Evidence shows that many people delay help-seeking for self-discovered cancer alarm symptoms<sup>43-47</sup> and several studies have tried to analyse different factors associated with healthcare-seeking. What factors trigger healthcare-seeking; what factors are barriers in healthcare-seeking? These studies provide important insights into the complex process of recognising cancer symptoms as abnormal, attributing symptoms to cancer, assessing the seriousness of the condition, and seeking medical assessment for men and women with cancer symptoms.<sup>48</sup> Some studies have focused on the decision to consult a doctor and on the variables influencing this decision using different health belief models.<sup>49;50</sup>

In a review of qualitative research on the help-seeking experiences of adult patients with cancer, from first onset of symptoms to first medical consultation, Smith et al. (2005) found that key concepts were recognition and interpretation of symptoms, and fear. Fear manifested itself as a fear of embarrassment (the feeling that symptoms were trivial or that symptoms affected a sensitive body area), or a fear of cancer (pain, suffering, and death), or both. Further, they found that the patient's gender and the sanctioning of help-seeking were important factors in prompt consultation. The sanctioning of help-seeking, for example by the media or by friends and family, legitimised help-seeking and allowed patients to lessen their fear of being labelled as time-wasters. Not recognising a symptom as suspicious was one of the most common reasons given by cancer patients for delayed help-seeking.<sup>51</sup> Similar results were found in other systematic reviews.<sup>52-54</sup> Ramos et al. concluded that some of the main triggers for consulting were changes in symptoms or the persistence of symptoms that were initially thought to be unimportant; suspecting that one had cancer; and in the case of men discussing it with a closely related female, were the main triggers in medical consultation, when symptoms of colorectal cancer were present.<sup>55</sup>

Among demographic factors, older age has been found to be associated with longer patient delay among cancer patients.<sup>41;52;56;57</sup> Macleod et al. (2009) also found demographic factors (age,

gender) to be associated with delay in presentation of symptoms, but the results varied between different cancer types. Moreover, they found that there was evidence of longer delay with ambiguous/vague rather than classical (e.g. lump) symptoms<sup>52;58</sup> and shorter delay for severe symptoms such as pain or bleeding.<sup>44</sup>

A review on healthcare-seeking of breast cancer patients found that older age, the nature of the breast symptom, not disclosing the symptom to someone close, negative attitudes towards the GP and fears about cancer treatment were risk factors for delay.<sup>43</sup> A review on healthcare-seeking for colorectal cancer symptoms found that age and gender had no impact on presentation times, whereas fear of cancer and non-recognition of seriousness were predictors of increased delay.<sup>53</sup>

Studies concerning factors associated with healthcare-seeking for experienced cancer alarm symptoms among the general population are sparse, even though it seems important when encouraging people to seek health care promptly. A small Australian study (2008) found that only a minor proportion of the subjects, sampled from the general population, with rectal bleeding had consulted a doctor for it.<sup>31</sup> Similar results were found in a UK study (Crosland et al.)<sup>36</sup> and a US study (Talley et al.).<sup>35</sup> Crosland further documented that perceived seriousness of the symptoms seemed to be an important factor in deciding whether to seek medical advice. In contrast, another Australian community-based study (2012) found that the majority of subjects who had experienced rectal bleeding sought medical help; men were more likely to seek help, and the main reason for seeking medical advice was the thought that the symptom was serious. Moreover, they showed that perceived seriousness was associated with faster healthcare-seeking.<sup>15</sup> In a study on symptoms of colorectal cancer, Courtney et al. concluded that only one in five subjects had ever consulted a doctor when having experienced alarm symptoms and men were more likely to consult than women.<sup>15</sup>

## **1.7 Socioeconomic differences in healthcare-seeking**

A strong and consistent finding of epidemiological research is that there are health differences among socioeconomic groups. This concerns both cancer patients and patients with other severe diseases. Large differences in disease risk have repeatedly been observed in relation to socioeconomic indicators, such as educational level, occupational class and household income.<sup>59;60</sup> For example, people with low SES have higher rates of uncontrolled blood pressure<sup>61</sup> and higher rates of morbidity and mortality from cardiovascular diseases.<sup>62</sup> Likewise, lower SES is most often associated with higher cancer mortality,<sup>63;64</sup> and some variations may be attributable to socioeconomic differences in smoking, excessive alcohol consumption, and access to health care<sup>15</sup> – and thereby a higher rate of comorbidity.

An association between low SES and lower cancer survival was reported in the UK by Coleman et al. (2004),<sup>65</sup> and a review from 2006 found that an association between SES and cancer survival continued to be demonstrated.<sup>66</sup> Similar associations were reported for the incidence, detection, treatment and outcome for a variety of cancer types.<sup>67</sup>

Despite the fact that all Danish citizens have free and equal access to the majority of health services, socioeconomic disparities persist among Danish cancer patients, both with respect to cancer incidence and cancer survival.<sup>68</sup> For most cancer types investigated, higher incidence rates were found amongst patients from lower social groups, but reverse results were found for breast cancer, prostate cancer and malignant melanoma. Survival rates were most often higher among patients from higher social groups.

Beyond the demonstrated associations between healthcare-seeking and demographic factors (gender, age), clinical factors (the symptom), and psychosocial factors (e.g. fears, embarrassment, awareness, interpretation of symptoms), as described in the previous section, Macleod et al. found in their review on delay and symptomatic cancers that socioeconomic differences in healthcare-seeking were observed in cancer patients with regard to the patient interval. The results varied with cancer type – lower SES was associated with increased delay for patients presenting with symptoms of upper gastrointestinal cancer and by men with prostate cancer. However, there were no overall relationship between SES and delay for colorectal cancer, gynaecological cancer, or lung cancer. Similarly, although lower educational attainment was associated with greater delay for patients with breast and colorectal cancers, it was not related to presentation for any of the urological, gynaecological cancers, or for lung cancers.<sup>44</sup> Among Danish cancer patients, Hansen et al. (2008) found that the only socioeconomic factor associated with delayed healthcare-seeking was employment status; retired female patients experienced shorter delays than employed female patients.<sup>11</sup> Although a very good study, due to relatively low statistical power the existence of moderate strength associations between socioeconomic factors and delay cannot be excluded.

Only very few studies concerning healthcare-seeking for cancer alarm symptoms and socioeconomic differences have been conducted among people from the general population. A study by Talley et al. could not identify any socioeconomic factors associated with healthcare-seeking in a US Caucasian population from Minnesota<sup>35</sup> Similarly, no relationship between socioeconomic status and help-seeking behaviour was identified by Simon et al. in relation to other cancer-related symptoms.<sup>69</sup> Courtney et al. showed that persons experiencing changes in bowel habits with a lower household income were more likely to having ever sought medical advice compared to persons with higher household income.<sup>15</sup> In line with this, van Osch et al. found that if



people had experienced some listed symptoms of cancer, those with low educational level were more likely to perform timely healthcare-seeking than those with high educational level.<sup>49</sup>

In the general population it has been demonstrated that demographic and socioeconomic inequality exists with regard to cancer knowledge and cancer awareness,<sup>70-74</sup> and people from lower SES groups are more likely to cite fear of cancer as a deterrent to seeking medical advice.<sup>71</sup> In the US, the general population's information seeking about cancer was predicted by higher education,<sup>75</sup> and in the UK, a study on associations between SES and cancer fatalism found that low SES was associated with higher fear of reporting symptoms of cancer and that low SES respondents were less positive about the value of early detection than those in higher SES groups.<sup>76</sup>

Gathering the different aspects found in other studies that high SES is positively associated with cancer awareness, cancer knowledge, and cancer information seeking in combination with that low SES is associated with fear of reporting symptoms of cancer the hypothesis for the present studies was that high SES, that is, people with higher education, with an affiliation to the labour market, and with higher income are more likely to seek health care and do it earlier when having experienced alarm symptoms of cancer.

All in all, the hypotheses for this thesis were that cancer alarm symptoms among the general population are common; that demographic and socioeconomic person characteristics are associated with symptom reporting; and that demographic and socioeconomic person characteristics are associated with healthcare-seeking behaviour for people in the general population who have experienced alarm symptoms of cancer.

## 2 Objectives of the thesis

The overall purpose of the thesis was to estimate the prevalence of alarm symptoms of four common cancer types and subsequent healthcare-seeking among people in the general population. The specific objectives in the three studies were:

- I to determine the prevalence of alarm symptoms of common cancers in the general population (Study I)
- II in a population-based cross-sectional design to investigate possible associations between socioeconomic and demographic determinants and self-reporting of frequent cancer alarm symptoms (Study II)
- III in a population-based cross-sectional design to analyse associations between healthcare-seeking behaviour and socioeconomic and demographic factors among persons reporting cancer alarm symptoms (Study III)

### **3 Material and methods**

In this chapter the sampling procedure and the development of the questionnaire are described. Furthermore, a description of the data sources, questionnaire data and socioeconomic data are presented together with a description of the methods used in the studies.

#### **3.1 Setting and design**

The study was conducted among 20,000 adult Danish citizens all living in the former County of Funen, Denmark, in April 2007. It was designed as a cross-sectional questionnaire survey and register study based on an age- and gender-stratified random sample of the general population. In addition, register data from Statistics Denmark<sup>77</sup> were used.<sup>78</sup>

#### **3.2 Data sources**

##### **The Danish Civil Registration System**

All Danish citizens with a permanent residence in Denmark are registered with the Danish Civil Registration System (CRS) and assigned a unique personal identification (CPR) number. For each individual the CRS contains information on name, gender, date of birth, citizenship. Further, the system is continuously updated with regard to each individual's vital status, place of residence, and marital status. The CPR number assigned to each individual can be used in all national registers and enables accurate linkage between all of them.<sup>79;80</sup>

##### **The questionnaire**

The idea for these studies was developed by Associate Professor, GP Bjarne Lühr Hansen, PhD, and by Associate Professor, Statistician, Henrik Støvring, PhD, and they designed it together with Professor, GP, Jakob Kragstrup, DMedSci, PhD. Professor Jill Cockburn, PhD (University of Newcastle, Australia) participated in meetings in Denmark as an expert on health behaviour research. The heading of the questionnaire was: 'Signs of cancer'. The purpose of the questionnaire was in general to elucidate the prevalence of symptom experiences of some cancer types in the general population, to elucidate whether subjects sought health care when having

experienced an alarm symptom of cancer, and to analyse barriers and triggers to healthcare-seeking. The questionnaire concerned symptoms of four types of cancer: breast, lung, urinary tract, and colorectal cancer. As no validated questionnaire was identified after a thorough literature search, ad hoc questions were formulated based on the literature and on previously used questions within the research area. Items concerning beliefs about healthcare-seeking were formulated based on inspiration from items from Jill Cockburn's paper: Construction and validation of a questionnaire to measure the health beliefs of general practice patients. *Fam Pract* 1987; 4(2):108-116.

Items were phrased to be readily understandable, so that persons regardless of literacy skills would be able to answer without difficulty and within a short time. For each cancer form there was a question on whether the person had had a specific symptom strongly related to that particular cancer, e.g. 'Felt a lump in your breast?' 'Coughed for more than 6 weeks?' 'Seen blood in the urine?' or 'Seen blood in the stool?' within the preceding 12 months. They were further asked: 'Do you have, or have you had, a cancer disease?' Answers to each question could be ticked as a 'yes' or a 'no'.

Subjects reporting at least one of the four symptoms were then asked to choose one and only one of their symptoms to be their 'personal symptom'. If they had experienced more than one symptom, they could freely choose between them. For this 'personal symptom' they were to answer a series of questions concerning subsequent healthcare-seeking: 'Did you consult your GP regarding your personal symptom?' (yes/no) and a question on patient interval: 'How long did it take from noticing your personal symptom until consulting your GP?' ('<1 month', '1-3 months', '3-6 months', '>6 months', and 'did not consult my GP'). All subjects were asked: 'Do you have, or have you had, a cancer disease?' (yes/no) (Appendices 1 and 2).

The first part of the questionnaire concerning the prevalence of symptom experience was pilot tested. Prior to the pilot testing, the questionnaire was discussed by an expert panel, a group of researchers with different academic background, to assess face validity and content validity – was the questionnaire measuring, what it was supposed to measure? Then among the target population a field-test was carried out on 200 subjects aged 40 years and older, with the objective of testing the questionnaire and its feasibility, and of assessing its reliability by test-retest, i.e. are the answers to the questions stable over time, do people give the same answers twice? The test was made with a two-week interval and showed acceptable agreement. Then a qualitative pilot test was conducted. A total of 10 people, six women and four men, aged 47-82 years accepted to be interviewed to test content validity, comprehensibility, acceptability and feasibility of the questionnaire.<sup>81</sup> The pilot-testing only led to minor changes in terms of language and

comprehension and the removal of questions on testes cancer and skin cancer to focus on the four large cancer forms. No further validation procedures were performed.

### **Socioeconomic and demographic registers**

From Statistics Denmark<sup>77</sup>, a governmental institution collecting information electronically provided by administrative registers of different governmental agencies, information on each person about a number of socioeconomic and demographic variables was obtained. Data on highest attained education were obtained from the Population's Education Register,<sup>82</sup> income was obtained from the Income Statistics Register,<sup>83</sup> and labour market affiliation was obtained from Register-based Labour Force Statistics.<sup>84</sup> Data in these registers primarily come from administrative registers such as the tax and customs register and educational institutions and are updated annually. Beyond socioeconomic data, information on cohabitation status from Register of Family and Income statistics was also obtained, as this demographic factor was hypothesised to be important, when reporting cancer alarm symptoms.

## **3.3 Sampling procedure**

### **Study I**

The sample of 20,000 people aged 20 years or older was randomly selected from the Danish Civil Registration System, stratified by gender and age, half of them women and half of them men, so that for each gender only 1000 subjects under the age of 40 years were included. The persons drawn to participate received in April 2007 the questionnaire by mail. A postage paid envelope and covering letter containing information on the study were enclosed with each questionnaire.

Telephone numbers were also provided so that the person could get in touch with the investigators, if further clarification was needed. The questionnaire was to be returned within one week. A reminder was sent two weeks later to those who had not yet returned their questionnaire. Data from the questionnaires were entered into the database by three secretaries, who were not involved in the data analyses. The response status was registered in the database as 'immediate respondents', 'late respondents' (i.e. after a reminder), and 'non-respondents'.

### **Studies II and III**

For Studies II and III the total sample (respondents and non-respondents) was linked with the registers in Statistics Denmark.

### 3.4 Outcome variables

In Study I weighted prevalence estimates of reporting alarm symptoms of cancer were calculated.

In Study II the following outcomes were calculated: 1) reporting of any cancer alarm symptom, and 2) reporting of each of the four cancer alarm symptoms separately.

In Study III the following outcomes were calculated: 1) healthcare-seeking for cancer alarm symptoms, and 2) patient interval (dichotomised into: 'consulted within 1 month from noticing my personal symptom' and 'consulted after at least 1 month from noticing my personal symptom'). Both healthcare-seeking and patient interval were further calculated for each symptom separately.

### 3.5 Independent variables

In all three studies the demographic variables age and gender were used to estimate the hypothesised contrasts between the different age categories and genders. Age was categorised into the following categories: 20-39 years; 40-59 years; 60-79 years; and 80+ years.

#### Studies II and III

From the questionnaire self-reported health-related data (having a cancer diagnosis) were gathered.

Register data were retrieved for the year preceding the questionnaire (index year 2006), although to account for annual variation in income the average income for the preceding 5 years was calculated. In order to compare the sample with the Danish general population and for calculating weighted estimates, data on gender, age, education, and labour market affiliation for the entire Danish population aged 20 years and older were retrieved as well for the year 2006. With regard to income this variable was gathered for the preceding 5 years, as was done for the study sample.

For each individual the highest attained educational level was extracted from the Population's Education Register. This register is based on administrative data from all educational institutions and has an eight-digit code for each individual's highest attained educational level. Education was categorised according to the highest attained educational level: <10 years (primary and lower

secondary school), 10–12 years (vocational education and upper secondary school), >12 years (short, medium and long-term higher education).<sup>61;85;86</sup> This categorisation was chosen so as to reflect the organisation of the Danish educational system.

Gross income was retrieved for each person from the Income Statistics Register, comprising all income liable to general taxation (wages and salaries, all types of benefits and pensions). Income was categorised according to the 5-year average income as low income (1st quartile), middle income (2nd and 3rd quartile), and high income (4th quartile).<sup>87</sup>

Labour market affiliation was extracted from Register-based Labour Force Statistics, which categorises the individuals according to their main source of income each year. The variable was categorised into three groups: working, student (employed or enrolled in an educational programme); pensioners (early retirement pension and old-age pension); out of the labour market (receiving disability pension, social security, and being unemployed).<sup>61</sup>

Cohabitation status was extracted from Register of Family and Income statistics. It was categorised as living with a partner (married/ cohabiting) or single (divorced, widowed or never married).<sup>61</sup>

## 3.6 Statistical analyses

### Study I

Prevalence estimates of each cancer alarm symptom in the population within the preceding 12 months stratified by gender and age as well as number of cancer alarm symptoms experienced within the preceding 12 months were calculated. Estimates were reported as percentages (%) with 95% exact confidence intervals (CIs), based on the binominal distribution for the proportion of respondents reporting the particular symptom. The effect of age was initially explored by dividing people into five-year age categories. As results indicated that symptom estimates were homogeneous across the 5-year age categories, it was decided to merge them into 20-year age categories to allow reliable estimation of contrasts between age groups.

A 'yes' response to one of the listed symptoms was considered a positive response. The answer 'no' and not answering an item were considered negative responses. Estimates of questionnaire return status were reported with percentages (%) and 95% exact CIs. Since the age and gender composition of the source population was known,<sup>88</sup> estimates for symptom prevalence, questionnaire returning status, and number of alarm symptoms experienced, across age and gender, were obtained by simple weighting with inverse sampling probabilities.<sup>89</sup> For these

analyses the gender and age distribution of the former County of Funen was used, since participants were sampled from this population.

### **Study II**

Prevalence estimates of reporting one or more alarm symptoms of cancer and prevalence estimates of reporting each specific alarm symptom of cancer in the sample within the preceding year were calculated. Estimates were reported as percentages (%) with 95%

CI based on binominal distributions. Logistic regression models were used to calculate unadjusted and adjusted odds ratios (ORs) with 95% CI for the association between each covariate and reporting of cancer alarm symptoms. The covariates considered were: gender, age, education, income, labour market affiliation, cohabitation status,<sup>87</sup> and having a cancer diagnosis. Multiple logistic regression models were used in the adjusted analyses. Adjustments were made for gender, age, and having a cancer diagnosis.<sup>90;91</sup> All estimates for symptom prevalences were weighted according to the gender and age distribution of the total Danish population to account for the stratified sampling procedure.

### **Study III**

Prevalence estimates of healthcare-seeking behaviour concerning any alarm symptom and for each separate alarm symptom of cancer were calculated. All prevalence estimates were weighted according to the general Danish population's age and gender distribution to account for the stratified sampling procedure. Logistic regression models were used to calculate unadjusted and adjusted ORs with 95% CI for the associations between each covariate and healthcare-seeking and patient interval, respectively. The covariates considered for each outcome were gender, age, education, income, labour market affiliation, cohabitation status and having a cancer diagnosis. In adjusted analyses, (multiple logistic regression) adjustments were made for gender, age, and having a cancer diagnosis.

P-values < 0.05 were considered statistically significant in Studies II and III. All statistical analyses were carried out using STATA 12 (STATA Corp, College Station, TX, USA)

### **Missing data**

In Studies I and II, if respondents had completed at least one question on symptom experience, but had not answered the remaining questions on symptom experiences, the missing answer was regarded as the answer 'no'.



In Study III only complete data sets were included, in other words: subjects who had reported a personal symptom *and* had answered the subsequent question on healthcare-seeking. Seven subjects had answered that they did not consult their GP at the question on time to healthcare-seeking (patient interval), even though they had answered 'yes' to the healthcare-seeking question. It was decided to use the answers given unaltered (Figure 1).

With respect to missings from register data in Studies II and III, these were not included in the analyses.

### **3.7 Ethical considerations**

According to the Act on a Biomedical Research Ethics Committee System the project was not a biomedical research project and therefore did not need the ethics committee's approval, journal number 2011-41-6709. The study was approved by the Danish Data Protection Agency.

An alarm symptom is by definition a feature that could potentially be a sign of cancer, therefore confronting people with questions dealing with cancer alarm symptoms may cause anxiety. To minimise undue anxiety, an information letter was provided, and the respondents were encouraged to contact the researchers by phone if they needed clarification or had any further questions. The respondents were informed that their responses were confidential.

## 4 Results

This chapter gives an overview of the study population and of the most important results found in the three studies.

### 4.1 Participants

A total of 20,000 subjects aged 20 years or older were invited to participate in the study; half of them women, half of them men. Only 1000 subjects aged 20-39 years were invited for each gender. Of the 20,000 subjects identified, 144 (0.7%) were not eligible because they were either dead or could not be reached (wrong address). Of the 19,856 subjects eligible, 96 were not interested in participating; 36 subjects could not participate because they were suffering from dementia or they had language problems. In total 13,777 subjects of the 19,856 eligible returned the questionnaire, yielding an overall response rate of 69.4%. The 13,777 respondents were included in the study (Figure 1). The mean age of respondents was 57.9 years, 47.4% of the respondents were male, 52.6% female (Table 1.1).

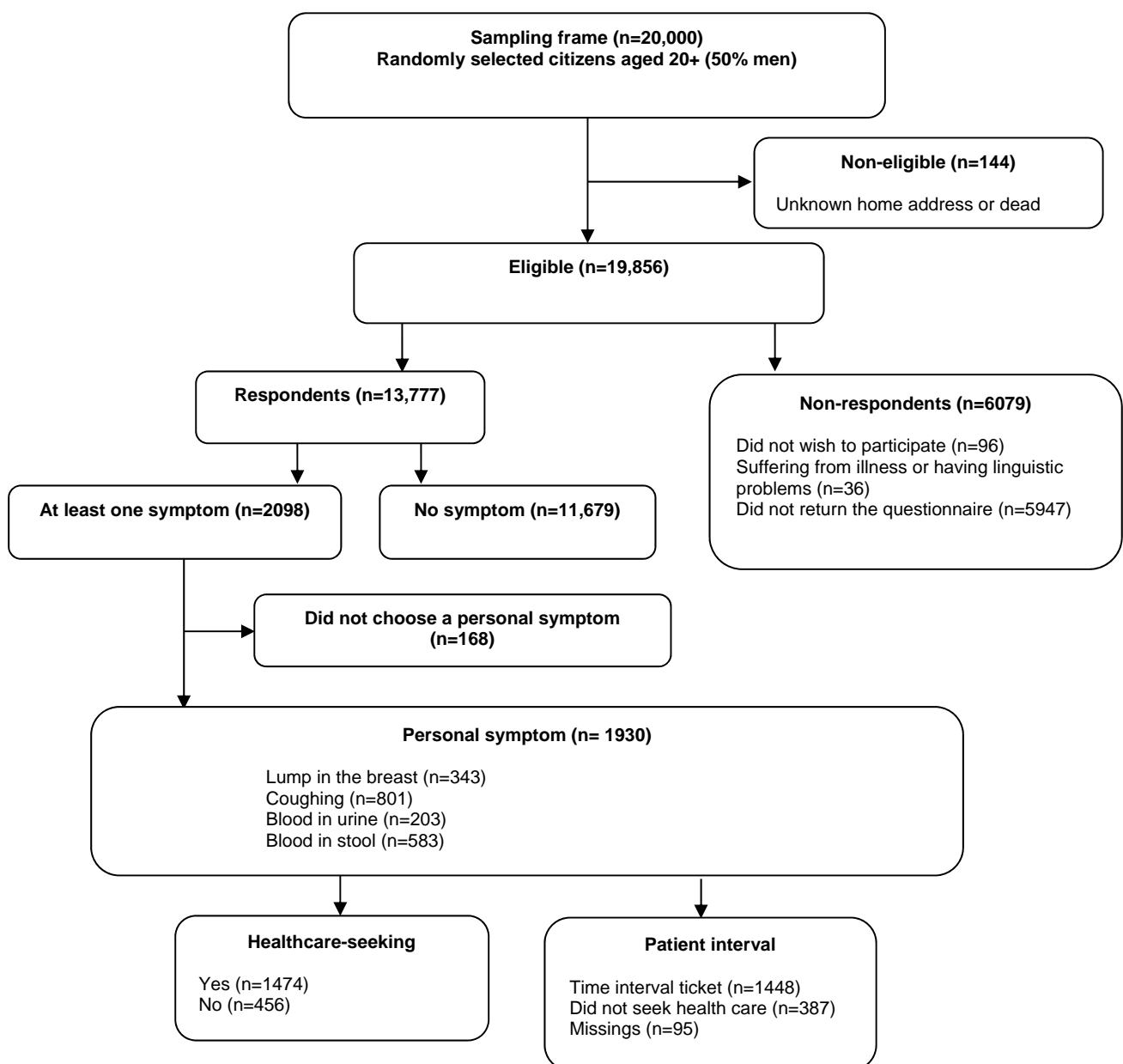
For Study III, subjects who had experienced a cancer alarm symptom were to choose only one symptom to be their 'personal symptom' (n=2098). Some 168 subjects did not fill in this item and were excluded for analyses. A total of 1930 subjects filled in the question *and* completed the question on healthcare-seeking, and 1448 subjects answered the question on patient interval (Figure 1).

Table 1.1 summarises the characteristics of respondents, non-respondents and the total Danish population aged 20+. In the group of respondents compared to the non-respondents more people were women, more people were aged 60-79 years, fewer people were represented in the youngest and oldest age groups, and more people lived with a partner. SES among the respondents was higher than among the non-respondents, i.e. the respondents had a higher level of education, they had a higher income, and more people were affiliated to the labour market.

### 4.2 Study I: Prevalence of cancer alarm symptoms

Overall, 3.3% (95% CI 2.9-3.7) of respondents (n=411) reported a lump in their breast, 6.5% (95% CI 6.1-7.5) (n=940) reported coughing for more than six weeks, 2.2% (95% CI 1.9-2.5) (n=307) reported blood in the urine, and 5.7% (95% CI 5.2-6.3) (n=713) reported blood in the stool. Prevalence estimates of cancer alarm symptoms were slightly different in different gender and age groups. The frequency of a lump in the breast decreased with age for women, and the frequency of seeing blood in the stools decreased with age for both men and women (Table 1.2).

**Figure 1. Study flowchart**



Overall, 13.8% of the subjects and 15.3% (95% CI 14.3-16.3) of the women vs 12.7% (11.6-13.7) of the men reported having experienced one cancer alarm symptom within the preceding year (Table 1.3). A total of 15.7% (95% CI 14.9-16.4) reported having experienced at least one cancer alarm symptom (Table 1.4)

**Table 1.1 Respondents, non-respondents , and the Danish population aged 20+ characteristics**

	Respondents		Non-respondents		Danish population
	n=13,777		n=6223		n=4,110,110
	n	%	N	%	%
<b>Gender</b>					
Men	6533	47.4	3467	55.7	48.9
Women	7244	52.6	2756	44.3	51.1
<b>Age, years</b>					
20-39	1105	8.0	730	11.7	33.8
40-59	6403	46.5	2836	45.6	37.1
60-79	5357	38.9	1877	30.2	23.7
80-99	912	6.6	780	12.5	5.5
<b>Educational level</b>					
Low	4136	30.0	2376	38.2	29.1
Medium	5588	41.8	2197	35.3	41.1
High	3631	27.2	1055	17.0	23.3
Missing	422	3.1	595	9.6	6.6
<b>Income level</b>					
Low	3444	25	2380	38.3	28.7
Medium	6888	50	2747	44.4	50.1
High	3444	25	1090	17.5	20.5
Missing	1	0	6	.1	0.7
<b>Labour market affiliation</b>					
Working, student	7989	58.0	3060	49.2	62.1
Pensioners	4414	32.0	1982	31.9	21.4
Out of labour market	1105	8.0	953	15.3	13.1
Missing	269	2.0	228	3.7	3.5
<b>Cohabitation status</b>					
Living alone	3760	27.3	2845	45.7	-
Cohabiting / married	10,013	72.7	3370	54.2	-
Missing	4	0.0	8	.1	-
<b>Cancer diagnosis</b>					
No	12,531	91.0	-	-	-
Yes	1246	9.0	-	-	-

**Table 1.2 Age- and gender-specific one-year prevalences of each cancer alarm symptom.**

Age, years	Felt a lump in your breast				Coughed for more than six weeks				
	Women		Men		Women		Men		
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	
20-39	42	7.0 (5.1 - 9.3)	4	0.8 (2.2 - 2.0)	36	6.0 (4.2 - 8.2)	24	4.8 (3.1 - 7.0)	5.4 (4.2 - 6.9)
40-59	223	6.6 (5.8 - 7.5)	36	1.2 (8.1 - 6)	251	7.4 (6.6 - 8.4)	190	6.3 (5.4 - 7.2)	6.9 (6.3 - 7.6)
60-79	68	2.5 (1.9 - 3.1)	21	0.8 (.5 - 1.2)	216	7.9 (6.9 - 9.0)	183	7.0 (6.0 - 8.0)	7.5 (6.8 - 8.2)
80-99	12	2.3 (1.2 - 3.9)	5	1.3 (.4 - 3.0)	25	4.7 (3.1 - 6.9)	15	3.9 (2.2 - 6.4)	4.4 (3.2 - 5.9)
<b>Total both genders*</b>									<b>3.3 (2.9 to 3.7)</b>

Note: Figures are percentages (95% CI) unless stated otherwise

\*Weighted estimate (Funen)

**Table 1.2 continued**

Age, years	Seen blood in your urine				Seen blood in your stools				
	Women		Men		Women		Men		
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	
20-39	17	2.8 (1.7 - 4.5)	4	0.8 (2.2 - 2.0)	44	7.3 (5.4 - 9.7)	44	8.8 (6.4 - 11.6)	8.0 (6.5 - 9.7)
40-59	74	2.2 (1.7 - 2.7)	46	1.5 (1.1 - 2.0)	173	5.1 (4.4 - 5.9)	234	7.7 (6. - 8.7)	6.3 (5.7 - 6.9)
60-79	56	2.1 (1.6 - 2.7)	86	3.3 (2.6 - 4.0)	81	3.0 (2.4 - 3.7)	115	4.4 (3.6 - 5.2)	3.6 (3.2 - 4.2)
80-99	11	2.2 (1.0 - 3.7)	13	3.4 (1.8 - 5.7)	13	2.5 (1.3 - 4.2)	9	2.3 (1.1 - 4.4)	2.4 (1.6 - 3.6)
<b>Total both genders*</b>									<b>2.2 (1.9 to 2.5)</b>

Note: Figures are percentages (95% CI) unless stated otherwise

\*Weighted estimate (Funen)

**Table 1.3. Age- and gender-specific description of how many cancer alarm symptoms people have reported within the preceding year**

Age, years	Gender	n	Have not experienced any symptoms		Have experienced one symptom		Have experienced two symptoms		Have experienced three or more symptoms		Have experienced at least one symptom	
			n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)
20-39	Women	604	484	80.1 (76.8 to 88.6)	102	16.9 (14.1 to 20.1)	17	2.8 (1.8 to 4.5)	1	0.2 (0.0 to 1.2)	120	19.9 (16.9 to 23.2)
	Men	501	430	85.9 (82.5 to 88.6)	66	13.2 (10.5 to 16.4)	5	1.0 (0.4 to 2.4)	0	0.0 (0 to 0.7)***	71	14.2 (11.4 to 17.5)
40-59	Women	3379	2742	81.1 (79.8 to 82.5)	562	16.6 (15.4 to 17.9)	66	2.0 (1.5 to 2.5)	9	0.3 (0.1 to 0.5)	637	18.9 (17.6 to 20.2)
	Men	3024	2571	85.0 (83.7 to 86.2)	408	13.5 (12.3 to 14.6)	39	1.3 (0.9 to 1.8)	6	0.2 (0.1 to 0.4)	453	15.0 (13.8 to 16.3)
60-79	Women	2733	2354	86.1 (84.8 to 87.4)	341	12.5 (11.3 to 13.8)	34	1.2 (0.9 to 1.7)	4	0.1 (0.1 to 0.4)	379	13.9 (12.6 to 15.2)
	Men	2624	2277	86.8 (85.4 to 88.0)	293	11.2 (10.0 to 12.4)	50	1.9 (1.4 to 2.5)	4	0.2 (0.1 to 0.4)	347	13.2 (12.0 to 14.6)
80-99	Women	528	474	89.8 (86.9 to 92.1)	47	8.9 (6.8 to 11.7)	7	1.3 (0.6 to 2.8)	0	0.0 (0 to 0.7)***	54	10.2 (7.9 to 13.1)
	Men	384	347	90.4 (86.9 to 92.4)	33	8.6 (6.2 to 11.8)	3	0.8 (0.3 to 2.4)	1	0.3 (0.0 to 1.8)	37	9.6 (7.1 to 13.0)
<b>Total</b>	Women	7244	6054	83.6 (82.7 to 84.4)	1052	14.5 (13.7 to 15.4)	124	1.7 (1.4 to 2.0)	14	0.2 (0.1 to 0.3)	1190	16.4 (15.6 to 17.3)
	Men	6533	5625	86.1 (85.2 to 86.9)	800	12.2 (11.5 to 13.0)	97	1.5 (1.2 to 1.8)	11	0.2 (0.1 to 0.3)	908	13.9 (13.1 to 14.8)
<b>Total Weighted*</b>	Women			82.9 (81.8 to 83.9)		15.3 (14.3 to 16.3)		2.0 (1.5 to 2.4)		0.2 (0.1 to 0.3)		17.1 (16.1 to 18.2)
	Men			86.1 (85.0 to 87.1)		12.7 (11.6 to 13.7)		1.4 (1.1 to 1.7)		0.1 (0.1 to 0.2)		13.9 (12.9 to 15.0)
<b>Total Weighted**</b>	Women			82.8 (81.9 to 83.7)		15.1 (14.2 to 15.9)		2.0 (1.7 to 2.3)		0.2 (0.1 to 0.3)		17.2 (16.3 to 18.1)
	Men			86.0 (85.1 to 86.9)		12.5 (11.6 to 13.3)		1.4 (1.1 to 1.7)		0.1 (0.1 to 0.3)		14.0 (13.1 to 14.9)
<b>Total Weighted*</b>	Both			84.3 (83.6 to 85.1)		13.8 (13.1 to 14.6)		1.7 (1.4 to 2.0)		0.2 (0.1 to 0.3)		15.7 (14.9 to 16.4)
	Both			84.3 (83.6 to 84.9)		13.9 (13.3 to 14.5)		1.7 (1.5 to 1.9)		0.2 (0.1 to 0.2)		15.7 (15.1 to 16.4)

Note: Figures are percentages (95% CI) unless stated otherwise.

\*Weighted estimate (Former county of Funen)

\*\* Weighted estimate (Denmark)

\*\*\* one-sided anova

**Table 1.4 Age- and gender-specific data on questionnaire response status**

Age group, years	Gender	Response status								
		Immediate respondents		Late respondents		Total respondents				
		Total n	n	n	n	Total respondents	Non-respondents			
20-39	Women	898	417	46.4 (43.1 to 49.8)	186	20.7 (18.1 to 23.5)	603	67.1 (64.0 to 70.2)	295	32.9 (29.8 to 36.0)
	Men	896	319	35.6 (32.5 to 38.8)	183	20.4 (17.8 to 23.2)	502	56.0 (52.7 to 59.3)	394	44.0 (40.7 to 47.3)
40-59	Women	4425	2661	60.1 (58.7 to 61.6)	718	16.2 (15.2 to 17.3)	3379	76.4 (75.1 to 77.6)	1046	23.6 (22.4 to 24.9)
	Men	4772	2135	44.7 (43.3 to 46.2)	889	18.6 (17.5 to 19.7)	3024	63.4 (62.0 to 64.7)	1748	36.6 (35.3 to 38.0)
60-79	Women	3576	2036	56.9 (55.3 to 58.6)	697	19.5 (18.2 to 20.8)	2733	76.4 (75.0 to 77.8)	843	23.6 (22.2 to 25.0)
	Men	3628	1890	52.1 (50.5 to 53.7)	734	20.2 (18.9 to 21.6)	2624	72.3 (70.8 to 73.8)	1004	27.7 (26.2 to 29.2)
80-99	Women	1027	302	29.4 (26.6 to 32.6)	226	22.0 (19.5 to 24.7)	528	51.4 (48.3 to 54.5)	499	48.6 (45.5 to 51.7)
	Men	634	260	41.0 (37.2 to 45.0)	124	19.6 (16.5 to 22.9)	384	60.6 (56.6 to 64.4)	250	39.4 (35.6 to 43.4)
<b>Total</b>	Women	9926	5416	54.6 (53.6 to 55.5)	1827	18.4 (17.6 to 19.2)	7243	73.0 (72.1 to 73.8)	2683	27.0 (26.2 to 27.9)
	Men	9930	4604	46.4 (45.4 to 47.4)	1930	19.4 (18.7 to 20.2)	6534	65.8 (64.9 to 66.7)	3396	34.2 (33.3 to 35.2)
<b>Total*</b>	Women			52.8 (51.6 to 54.0)		18.9 (18.0 to 19.9)		71.7 (70.6 to 72.8)		28.3 (27.2 to 29.4)
	Men			43.8 (42.6 to 45.0)		19.7 (18.7 to 20.7)		63.5 (62.2 to 64.7)		36.5 (35.3 to 37.8)
<b>Total*</b>	Both			48.4 (47.6 to 49.3)		19.3 (18.6 to 20.0)		67.7 (66.9 to 68.5)		32.3 (31.5 to 33.1)
	Both			15.8 (14.9 to 16.7)		15.4 (14.0 to 16.9)		15.7 (14.9 to 16.4)		-

Note: Figures are percentages (95 % CI) unless stated otherwise



## **4.3 Study II: Associations between reporting of cancer alarm symptoms and socioeconomic and demographic determinants**

### **Reporting at least one cancer alarm symptoms (adjusted analyses)**

Women were more likely to report at least one cancer alarm symptom, as were subjects out of the labour market, and subjects having a cancer diagnosis. Those aged 60–79, those aged 80–99, and those living with a partner were less likely to report at least one cancer alarm symptom than those in the reference groups. Education and income showed no statistically significant association with reporting at least one cancer alarm symptom (Table 2.1).

### **Reporting each specific cancer alarm symptom (prevalence and adjusted analyses)**

Table 2.2 shows the prevalences of person characteristics by each cancer alarm symptom reported. Table 2.3 shows the results of the odds ratios for reporting each cancer alarm symptom. Women were more likely than men to report a lump in the breast and to report coughing, but were less likely to report blood in the stool. Subjects aged 60–79 years were more likely to report coughing. Subjects with older age were less likely to report a lump in the breast and to report blood in the stool than the reference groups.

Subjects with high educational level were less likely to report coughing than those with a low educational level. Those with a high income were less likely to report coughing than those with low income, and those out of the labour market were more likely to report coughing and to report blood in the stools than the reference groups.

Those living with a partner were less likely to report coughing and seeing blood in the urine than those living alone, and finally, those having a cancer diagnosis were more likely to report a lump in their breast, seeing blood in their urine, or seeing blood in the stools.

No statistically significant associations could be identified for the remaining variables analysed (Table 2.3).

Table 2.1 Reporting at least one cancer alarm symptom within the preceding year. Prevalence, crude, and adjusted odds ratios

	At least one symptom					
	yes, n=2 098		OR		OR	
	n	% (95 % CI)	Crude	95 % CI	adjusted*	95 % CI
<b>Gender</b>						
Men	908	43.3 (41.1 to 45.4)	1		1	
Women	1190	56.7 (54.6 to 58.8)	1.22**	1.11 to 1.34	1.19**	1.09 to 1.31
<b>Age, years</b>						
20-39	191	9.1 (7.9 to 10.3)	1		1	
40-59	1090	52.0 (49.8 to 54.1)	0.98	0.83 to 1.16	0.96	0.81 to 1.14
60-79	726	34.6 (32.6 to 36.6)	0.75**	0.63 to 0.89	0.71**	0.60 to 0.85
80-99	91	4.3 (3.5 to 5.2)	0.53**	0.41 to 0.69	0.48**	0.37 to 0.63
<b>Educational level</b>						
Low	634	30.9 (28.9 to 32.9)	1		1	
Medium	852	41.5 (39.3 to 43.6)	0.99	0.88 to 1.11	0.94	0.84 to 1.06
High	568	27.7 (25.7 to 29.6)	1.02	0.91 to 1.16	0.95	0.83 to 1.08
<b>Income level</b>						
Low	496	23.6 (21.8 to 25.5)	1		1	
Medium	1081	51.5 (49.4 to 53.7)	1.11	0.99 to 1.24	0.98	0.87 to 1.11
High	521	24.8 (23.0 to 26.7)	1.06	0.93 to 1.21	0.95	0.82 to 1.10
<b>Labour market affiliation</b>						
Working, student	1249	61.0 (58.9 to 63.1)	1		1	
Pensioners	544	26.6 (24.7 to 28.5)	0.76**	0.68 to 0.85	0.93	0.78 to 1.10
Out of labour market	254	12.4 (11.0 to 13.8)	1.61**	1.38 to 1.88	1.59**	1.36 to 1.86
<b>Cohabitation status</b>						
Living alone	618	29.5 (27.5 to 31.4)	1		1	
Cohabiting / married	1480	70.5 (68.6 to 72.5)	0.88**	0.80 to 0.98	0.84**	0.76 to 0.93
<b>Cancer diagnosis</b>						
No	1841	87.8 (86.3 to 89.2)	1		1	
Yes	257	12.2 (10.8 to 13.7)	1.51**	1.30 to 1.75	1.63**	1.40 to 1.89

Note: Figures are odds ratios with 95% CIs.

\*adjusted for gender, age, having a cancer diagnosis

\*\*P<0.05

**Table 2.2 Prevalence of demographic and socioeconomic participant characteristics by reporting of each cancer alarm symptom within the preceding year**

	Total		Felt a lump in your breast		Coughed for more than six weeks		Seen blood in your urine		Seen blood in your stool	
	n=13,777		yes, n=411		yes, n=940		yes, n=307		yes, n=713	
	n		n		n		n		n	
<b>Gender</b>										
Men	6533	47.4	66	16.1 (12.5 to 19.6)	412	43.8 (40.7 to 47.1)	149	48.5 (42.9 to 54.1)	402	56.4 (52.7 to 60.0)
Women	7244	52.6	345	83.9 (80.4 to 87.5)	528	56.2 (53.0 to 59.3)	158	51.5 (45.9 to 57.1)	311	43.6 (39.9 to 47.3)
<b>Age, years</b>										
20-39	1105	8.0	46	11.2 (8.3 to 14.4)	60	6.4 (4.8 to 8.0)	21	6.8 (4.0 to 9.7)	88	12.3 (9.9 to 14.8)
40-59	6403	46.5	259	63.0 (58.1 to 67.7)	441	46.9 (43.7 to 50.1)	120	39.1 (33.6 to 44.6)	407	57.1 (53.4 to 60.7)
60-79	5357	38.9	89	21.7 (17.8 to 26.0)	399	42.4 (39.3 to 45.6)	142	46.3 (40.7 to 51.8)	196	27.5 (24.2 to 30.8)
80-99	912	6.6	17	4.1 (2.4 to 6.5)	40	4.3 (3.0 to 5.5)	24	7.8 (4.8 to 10.8)	22	3.1 (1.8 to 4.4)
<b>Educational level</b>										
Low	4136	31.0	120	29.7 (25.3 to 34.4)	329	36.1 (33.0 to 39.2)	93	31.4 (26.1 to 36.7)	186	26.5 (23.3 to 29.8)
Medium	5588	41.8	152	37.6 (32.9 to 42.5)	381	41.8 (38.6 to 45.0)	133	44.9 (39.3 to 50.6)	290	41.4 (37.7 to 45.0)
High	3631	27.2	132	32.7 (28.1 to 37.5)	202	22.1 (19.5 to 24.8)	70	23.6 (18.8 to 28.5)	225	32.1 (28.6 to 35.6)
<b>Income level</b>										
Low	3444	25	86	20.9 (17.1 to 25.2)	261	27.8 (24.9 to 30.6)	87	28.3 (23.3 to 33.4)	148	20.8 (17.8 to 23.7)
Medium	6888	50	226	55.0 (50.0 to 59.9)	480	51.1 (47.9 to 54.3)	152	49.5 (43.9 to 55.1)	357	50.1 (46.4 to 53.7)
High	3444	25	99	24.1 (20.0 to 28.5)	199	21.2 (18.6 to 23.8)	68	22.1 (17.5 to 26.8)	208	29.2 (25.8 to 32.5)
<b>Labour market aff.</b>										
Working, student	7989	59.1	283	70.6 (66.1 to 75.0)	481	52.7 (49.5 to 56.0)	157	52.0 (46.3 to 57.6)	472	67.7 (64.2 to 71.2)
Pensioners	4414	32.7	69	17.2 (13.6 to 21.3)	289	31.7 (28.7 to 34.7)	119	39.4 (33.9 to 44.9)	137	19.7 (16.7 to 22.6)
Out of labour market	1105	8.2	49	12.2 (9.0 to 15.4)	142	15.6 (13.2 to 17.9)	26	8.6 (5.4 to 11.8)	88	12.6 (10.2 to 15.1)
<b>Cohabitation status</b>										
Living alone	3760	27.3	121	29.4 (25.1 to 34.1)	302	32.1 (29.1 to 35.1)	102	33.2 (27.9 to 38.5)	190	26.6 (23.4 to 29.9)
Cohabiting / married	10,013	72.7	290	70.6 (65.9 to 74.9)	638	67.9 (64.9 to 70.9)	205	66.8 (61.5 to 72.1)	523	73.4 (70.1 to 76.6)
<b>Cancer diagnosis</b>										
No	12,531	91.0	331	80.5 (76.4 to 84.3)	842	89.6 (87.6 to 91.5)	257	83.7 (79.6 to 87.9)	632	88.6 (86.3 to 91.0)
Yes	1246	9.0	80	19.5 (15.7 to 23.6)	98	10.4 (8.5 to 12.4)	50	16.3 (12.1 to 20.4)	81	11.4 (9.0 to 13.7)

Figures are percentages unless stated otherwise (95% CI)

**Table 2.3 Crude and adjusted odds ratios for reporting each cancer alarm symptom**

	Felt a lump in your breast			Coughed for more than six weeks			Seen blood in your urine			Seen blood in your stool		
	Crude	95% CI	Adjusted*	95% CI	Crude	95% CI	Adjusted*	95% CI	Crude	95% CI	Adjusted*	95% CI
<b>Gender</b>												
Men	1		1		1		1		1		1	
Women	4.90**	3.76 to 6.39	4.63**	3.54 to 6.04	1.17	1.02 to 1.33	1.17**	1.02 to 1.34	0.96	0.76 to 1.20	0.93	0.74 to 1.17
<b>Age, years</b>												
20-39	1		1		1		1		1		1	
40-59	0.97	0.70 to 1.34	0.91	0.66 to 1.26	1.29	0.98 to 1.70	1.28	0.97 to 1.69	0.99	0.62 to 1.57	0.95	0.59 to 1.51
60-79	0.39**	0.27 to 0.56	0.34**	0.23 to 0.49	1.40**	1.06 to 1.85	1.39**	1.05 to 1.84	1.41	0.88 to 2.23	1.29	0.81 to 2.05
80-99	0.44**	0.25 to 0.77	0.33**	0.18 to 0.58	0.80	0.53 to 1.20	0.77	0.51 to 1.17	1.40	0.77 to 2.52	1.22	0.67 to 2.22
<b>Education level</b>												
Low	1		1		1		1		1		1	
Medium	0.94	0.73 to 1.19	0.88	0.69 to 1.14	0.85**	0.73 to 0.99	0.86	0.73 to 1.00	1.06	0.81 to 1.39	1.14	0.87 to 1.50
High	1.26	0.98 to 1.62	1.06	0.82 to 1.38	0.68**	0.57 to 0.82	0.69**	0.57 to 0.83	0.85	0.62 to 1.17	0.94	0.68 to 1.30
<b>Income level</b>												
Low	1		1		1		1		1		1	
Medium	1.32**	1.03 to 1.70	1.05	0.80 to 1.38	0.91	0.78 to 1.07	0.86	0.73 to 1.02	0.87	0.67 to 1.14	0.96	0.73 to 1.28
High	1.16	0.86 to 1.55	1.28	0.92 to 1.78	0.75**	0.62 to 0.91	0.71**	0.57 to 0.88	0.78	0.56 to 1.07	0.89	0.62 to 1.28
<b>Labour market aff.</b>												
Working, student	1		1		1		1		1		1	
Pensioners	0.43**	0.33 to 0.56	0.66	0.42 to 1.03	1.09	0.94 to 1.27	1.06	0.85 to 1.33	1.38**	1.08 to 1.76	1.05	0.72 to 1.52
Out of labour market	1.26	0.93 to 1.72	1.10	0.80 to 1.52	2.30**	1.89 to 2.81	2.10**	1.72 to 2.57	1.02	0.79 to 1.83	1.30	0.88 to 1.93
<b>Cohabit. status</b>												
Living alone	1		1		1		1		1		1	
Cohabiting/ married	0.90	0.72 to 1.11	0.91	0.72 to 1.14	0.78**	0.68 to 0.90	0.74**	0.64 to 0.86	0.75**	0.59 to 0.95	0.77**	0.60 to 0.98
<b>Cancer diagnosis</b>												
No	1		1		1		1		1		1	
Yes	2.53**	1.97 to 3.25	2.73**	2.14 to 3.55	1.19	0.95 to 1.47	1.17	0.94 to 1.46	2.00**	1.47 to 2.72	1.90**	1.39 to 2.60

Figures are odds ratios with 95% CIs  
 \*adjusted for gender, age, having a cancer diagnosis  
 \*\*P<0.05

## **4.4 Study III: Associations between healthcare-seeking and socioeconomic and demographic determinants**

### **Prevalence of healthcare-seeking (any symptom)**

The mean age of respondents reporting a personal alarm symptom (n=1930) of cancer was 55 years, and 57% were women. A total of 26.1% (weighted estimate) reported that they did not seek health care when having experienced a cancer alarm symptom (Table 3.1).

### **Healthcare-seeking for any symptom (adjusted analyses)**

The adjusted analyses showed that women; subjects aged  $\geq 40$ ; subjects living with a partner, and subjects having a cancer diagnosis were more likely to seek health care, whereas those with a medium educational level were less likely to do so compared to the reference groups. No statistically significant associations could be identified for the remaining variables analysed (Table 3.1).

### **Prevalence of healthcare-seeking (for each specific symptom)**

A total of 21% did not seek health care when having felt a lump in the breast; 30.5% did not seek health care when having coughed for more than six weeks; 14.4% did not seek health care when having seen blood in the urine; 22.5% did not seek health care when having seen blood in their stool. All weighted estimates (Table 3.2).

### **Healthcare-seeking for each specific symptom (adjusted analyses)**

When analysing each symptom separately, Table 3.2 showed that women were more likely to seek health care when having felt a lump in the breast or having coughed. Subjects aged 40–59 years were more likely to seek health care when having felt a lump in the breast, while subjects aged 40–59 or 60–79 years were more likely to seek health care than those aged 20–39 years when having seen blood in their stool.

Those with a medium educational level were less likely to seek health care for having seen blood in the urine. Those living with a partner were more likely to seek health care for coughing,

and finally concerning blood in the stool: those having a cancer diagnosis were more likely to seek health care

No statistically significant associations could be identified for income/labour market affiliation and healthcare-seeking, and no statistically significant associations could be identified for the remaining variables analysed (Table 3.2).

#### **Patient interval for any symptom (prevalence and adjusted analyses)**

Among those who had answered the question on patient interval (n=1448), a total of 801 subjects (54.8%, weighted estimate) waited for at least 1 month to seek health care. Women were more likely to seek health care within 1 month, whereas subjects out of the labour market were more likely to wait for at least 1 month. No statistically significant associations could be identified for the remaining variables analysed (Table 3.3).

#### **Patient interval for any specific symptoms (adjusted analyses)**

Analysing each symptom separately showed that women were more likely than men to seek health care within 1 month when having felt a lump in the breast or having coughed. With regard to age, subjects aged 40–59 years were more likely to seek health care within one month when having felt a lump in the breast. Subjects living with a partner were more likely to wait for at least 1 month when having reported blood in stools.

Educational level, income level, and labour market affiliation showed no statistically significant association with the patient interval, nor did having a cancer diagnosis (Table 3.4).

## **4.5 Missing register data**

### **Respondents**

Of the 13,777 respondents 3.1% (n=422) had no educational level registered; 0% (n=1) had no income level registered; 1.3% (n=269) had no affiliation to the labour market registered; 0.0% (n=4) had no cohabitation status registered (Table 1.1).

### **Total Danish population**

A total of 6.6% (n=269,483) had no information with respect to educational level; 0.7% (n=30,184) had missing income; 3.5% (n=142,795) had missing labour market affiliation (Table 1.1).

**Table 3.1: Descriptive participant characteristics together with weighted prevalences, crude and adjusted odds ratios for not seeking health care**

	Participants not seeking medical help						
	Total sample	Healthcare-seeking	Weighted prevalence	Crude		Adjusted*	
	n	%	%	OR	95 % CI	OR	95 % CI
<b>Total</b>	1930	23.6	26.1				
<b>Gender</b>							
Men	837	30.5	32.3	1		1	
Women	1093	18.4	21.9	0.51**	0.42 to 0.64	0.52**	0.42 to 0.64
<b>Age, years</b>							
20-39	187	33.7	33.7	1		1	
40-59	1031	24.4	24.1	0.64**	0.46 to 0.89	0.63**	0.45 to 0.89
60-79	641	20.9	20.8	0.52**	0.36 to 0.74	0.52**	0.36 to 0.75
80-99	71	9.9	9.8	0.22**	0.09 to 0.50	0.28**	0.12 to 0.65
<b>Education</b>							
Low	561	20.3	21.7	1		1	
Medium	787	29.2	32.6	1.62**	1.25 to 2.09	1.40**	1.07 to 1.81
High	541	19.8	21.9	0.97	0.72 to 1.30	0.84	0.62 to 1.14
<b>Income</b>							
Low	422	22.0	27.6	1		1	
Medium	1018	23.1	24.8	1.06	0.81 to 1.39	0.98	0.73 to 1.31
High	490	26.1	27.5	1.25	0.92 to 1.70	0.96	0.69 to 1.35
<b>Labour market aff.</b>							
Working, student	1192	24.5	28.0	1		1	
Pensioners	459	17.6	17.6	0.63**	0.48 to 0.82	0.84	0.56 to 1.27
Out of labour market	232	24.1	25.1	0.93	0.67 to 1.29	1.09	0.78 to 1.53
<b>Cohabitation status</b>							
Single	554	26.6	29.8	1		1	
Cohabiting / married	1376	22.5	24.6	0.81	0.65 to 1.02	0.72**	0.57 to 0.91
<b>Cancer diagnosis</b>							
No	1700	25.5	27.9	1		1	
Yes	230	10.0	9.4	0.33**	0.21 to 0.51	0.41**	0.26 to 0.64

\*adjusted for gender, age, having a cancer diagnosis

\*\*P<0.05

**Table 3.2: Weighted prevalence estimates and crude and adjusted odds ratios of healthcare-seeking for each symptom**

	Felt a lump in the breast										Coughed for more than 6 weeks											
	Healthcare-seeking					Healthcare-seeking					Healthcare-seeking					Healthcare-seeking						
	n=	yes %	Weighted %	Crude OR	95% CI	Adjusted OR*	95% CI	n=	yes %	Weighted %	Crude OR	95% CI	Adjusted OR*	95% CI	n=	yes %	Weighted %	Crude OR	95% CI	Adjusted OR*	95% CI	
<b>Total</b>	343	89.5	89.0					801	70.4	69.5					727	69.1	68.3	1	1.22 to 4.38	1.86	0.97 to 3.58	
<b>Gender</b>																						
Men	49	77.6	83.0	1		1		355	63.9	63.9	1		1									
Women	294	91.5	85.9	3.11**	1.42 to 6.94	3.27**	1.42 to 7.51	446	75.6	73.6	1.74**	1.28 to 2.37	1.70**	1.25 to 2.32								
<b>Age, years</b>																						
20-39	42	76.2	76.2	1		1		54	64.8	64.8	1		1									
40-59	222	92.8	92.9	4.02**	1.68 to 9.64	4.05**	4.65 to 9.94	387	65.9	66.2	1.05	0.58 to 1.90	1.04	0.57 to 1.89								
60-79	66	84.8	85.0	1.75	0.66 to 4.65	4.86	0.65 to 5.36	330	75.5	75.6	1.67	0.90 to 3.08	1.63	0.88 to 3.03								
80-99	13	100	100.0	....	....	....	.....	30	83.3	83.4	2.71	0.89 to 8.24	2.16	0.69 to 6.72								
<b>Educational level</b>																						
Low	94	91.5	87.3	1		1		275	71.6	72.5	1		1									
Medium	125	84.0	76.8	0.49	0.21 to 1.16	0.55	0.22 to 1.36	321	66.0	64.3	0.77	0.54 to 1.09	0.83	0.58 to 1.419								
High	118	93.2	93.5	1.28	0.46 to 3.55	1.27	0.43 to 3.72	184	75.0	72.1	1.19	0.78 to 1.82	1.32	0.85 to 2.03								
<b>Income level</b>																						
Low	63	82.5	73.9	1		1		206	72.3	71.8	1		1									
Medium	195	91.8	88.9	2.37**	1.03 to 5.41	1.83	0.73 to 4.56	420	69.8	68.8	0.88	0.61 to 1.28	1.01	0.69 to 1.49								
High	85	89.4	91.0	1.79	0.69 to 4.61	1.32	0.44 to 3.96	175	69.7	68.4	0.88	0.56 to 1.37	1.25	0.78 to 2.01								
<b>Labour market affiliation</b>																						
Working, student	247	91.5	87.0	1		1		429	66.7	66.5	1		1									
Pensioners	50	88.0	88.1	0.69	0.26 to 1.79	0.37	0.72 to 1.93	231	76.6	76.7	1.64**	1.14 to 2.36	1.04	0.60 to 1.80								
Out of labour market	38	81.6	74.8	0.41	0.16 to 1.05	0.41	0.15 to 1.10	120	74.2	74.3	1.44	0.91 to 2.26	1.27	0.79 to 2.02								
<b>Cohabitation status</b>																						
Single	99	85.9	81.1	1		1		247	66.0	65.2	1		1									
Cohabiting/ married	244	91.0	87.5	1.66	0.81 to 3.40	1.64	0.78 to 3.45	554	72.4	74.4	1.35	0.98 to 1.86	1.44**	1.04 to 2.01								
<b>Cancer diagnosis</b>																						
No	274	88.3	84.0	1		1		727	69.1	68.3	1		1									
Yes	69	94.2	94.5	2.15	0.73 to 6.30	1.92	0.61 to 6.01	74	83.8	94.5	2.32**	1.22 to 4.38	1.86	0.97 to 3.58								

\*adjusted for gender, age, and having a cancer diagnosis  
 \*\* P<0.05



Table 3.2 continued

	Seen blood in urine Healthcare-seeking						Seen blood in stool Healthcare-seeking														
	yes		Weighted		Crude OR	95% CI	Adjusted		95% CI		n	yes		Weighted		Crude OR	95% CI	Adjusted		95% CI	
	n	%	%	%			OR*	OR*	%	%		OR*	OR*	%	%			OR*	OR*		%
<b>Total</b>	203	91.1	85.6							583	71.7	67.5									
<b>Gender</b>																					
Men	92	88.0	84.5	1	1	1	1	341	69.2	65.8	1	1	1	1	1	1	1	1	1	1	
Women	111	93.7	91.4	2.02	0.75 to 5.43	2.82	0.89 to 8.87	242	75.2	69.8	1.35	0.93 to 1.96	1.32	0.90 to 1.93							
<b>Age, years</b>																					
20-39	16	81.3	81.2	1	1	1	1	75	58.7	58.7	1	1	1	1	1	1	1	1	1	1	
40-59	81	92.6	92.7	2.88	0.64 to 13.00	4.24	0.85 to 21.13	341	71.3	71.4	1.75**	1.04 to 2.93	1.70**	1.01 to 2.87							
60-79	92	91.3	91.4	2.42	0.57 to 10.33	4.51	0.84 to 24.11	153	77.1	77.2	2.38**	1.31 to 4.30	2.13**	1.16 to 3.89							
80-99	14	92.9	93.1	3.00	0.27 to 32.75	5.38	0.41 to 69.99	14	92.9	92.6	9.16**	1.14 to 73.70	5.87	0.70 to 48.98							
<b>Educational level</b>																					
Low	59	96.6	97.0	1	1	1	1	133	80.5	75.4	1	1	1	1	1	1	1	1	1	1	
Medium	85	83.5	79.6	0.18**	0.39 to 81.53	0.20**	0.04 to 0.94	256	66.0	61.8	0.47**	0.29 to 0.78	0.60	0.36 to 1.00							
High	52	96.2	96.7	0.88	0.12 to 6.46	0.86	0.12 to 6.45	187	72.7	70.0	0.65	0.38 to 1.11	0.83	0.48 to 1.45							
<b>Income level</b>																					
Low	51	94.1	87.2	1	1	1	1	102	78.4	66.6	1	1	1	1	1	1	1	1	1	1	
Medium	106	91.5	93.3	0.67	0.17 to 2.60	0.53	0.13 to 2.18	297	72.1	69.0	0.71	0.42 to 1.21	0.67	0.37 to 1.19							
High	45	87.0	80.4	0.42	0.10 to 1.77	0.33	0.06 to 1.70	184	67.4	65.6	0.57**	0.32 to 1.00	0.56	0.29 to 1.08							
<b>Labour market affiliation</b>																					
Working, student	110	90.9	87.3	1	1	1	1	406	68.0	64.3	1	1	1	1	1	1	1	1	1	1	
Pensioners	77	92.2	92.3	1.18	0.41 to 3.40	1.33	0.28 to 6.33	101	85.1	85.0	2.70**	1.50 to 4.86	2.23	1.00 to 4.99							
Out of labour market	11	81.8	86.6	0.45	0.09 to 2.38	0.31	0.52 to 1.80	63	74.6	73.9	1.38	0.76 to 2.53	1.24	0.66 to 2.31							
<b>Cohabitation status</b>																					
Single	59	91.5	87.2	1	1	1	1	149	71.1	62.6	1	1	1	1	1	1	1	1	1	1	
Cohabiting / married	144	91.0	90.0	0.93	0.32 to 2.74	1.04	0.29 to 3.69	434	71.9	69.3	1.04	0.69 to 1.57	1.15	0.75 to 1.76							
<b>Cancer diagnosis</b>																					
No	175	90.9	88.3	1	1	1	1	524	69.5	65.5	1	1	1	1	1	1	1	1	1	1	
Yes	28	92.9	93.5	1.31	0.28 to 6.03	1.12	0.23 to 5.53	59	91.5	92.4	4.75**	1.86 to 12.09	3.83**	1.49 to 9.90							

\*adjusted for gender, age, and having a cancer diagnosis.

\*\*P<0.05

**Table 3.3: Patient interval  $\geq 1$  month for any personal symptom. Weighted prevalences, crude, and adjusted odds ratios.**

	Any personal symptom						
	Total sample	Patient interval $\geq 1$ month	Weighted prevalence	Crude		Adjusted*	
	n	Yes %	%	OR	95 % CI	OR	95 % CI
<b>Total</b>	1448	55.3	54.8				
<b>Gender</b>							
Men	574	63.9	60.8	1		1	
Women	874	50.3	51.2	0.60**	0.48 to 0.74	0.60**	0.48 to 0.74
<b>Age, years</b>							
20-39	125	53.6	53.6	1		1	
40-59	767	56.3	56.1	1.12	0.76 to 1.63	1.11	0.76 to 1.63
60-79	496	55.4	55.5	1.09	0.73 to 1.61	1.04	0.69 to 1.55
80-99	60	43.3	43.2	0.66	0.36 to 1.23	0.68	0.36 to 1.29
<b>Educational level</b>							
Low	438	56.6	55.8	1		1	
Medium	548	55.3	53.8	0.95	0.74 to 1.22	0.90	0.69 to 1.16
High	427	54.3	55.6	0.91	0.70 to 1.19	0.88	0.67 to 1.16
<b>Income level</b>							
Low	324	54.0	53.4	1		1	
Medium	771	55.0	55.4	1.04	0.80 to 1.35	0.98	0.74 to 1.28
High	353	57.2	54.7	1.14	0.84 to 1.54	0.93	0.67 to 1.29
<b>Labour market affiliation</b>							
Working, student	877	55.1	53.4	1		1	
Pensioners	365	52.9	52.8	0.92	0.72 to 1.17	0.98	0.66 to 1.44
Out of labour market	174	63.2	65.4	1.40**	1.00 to 1.96	1.46**	1.04 to 2.06
<b>Cohabiting status</b>							
Single	394	52.0	51.0	1		1	
Cohabiting / married	1054	56.5	56.2	1.20	0.95 to 1.51	1.09	0.86 to 1.39
<b>Cancer diagnosis</b>							
No	1248	56.0	55.7	1		1	
Yes	200	51.0	47.4	0.82	0.61 to 1.10	0.91	0.67 to 1.25

\*adjusted for gender, age, having a cancer diagnosis

\*\*P<0.05

**Table 3.4 Weighted prevalence estimates and crude and adjusted odds ratios of patient interval for each symptom**

	Felt a lump in the breast										Coughed for more than 6 weeks										
	Patient interval $\geq 1$ month					Patient interval $\geq 1$ month					Patient interval $\geq 1$ month					Patient interval $\geq 1$ month					
	Yes n	Weighted %	OR	Crude 95% CI	Adjusted* 95% CI	Yes n	Weighted %	OR	Crude 95% CI	Adjusted* 95% CI	Yes n	Weighted %	OR	Crude 95% CI	Adjusted* 95% CI	Yes n	Weighted %	OR	Crude 95% CI	Adjusted* 95% CI	
<b>Total</b>	303	39.9				559	71.4				62	72.0				497	72.0				
<b>Gender</b>																					
Men	36	72.2	1			225	79.1	1			62	66.1	1			497	72.0	1			
Women	267	35.6	0.21**	0.10 to 0.46	0.22**	334	66.2	0.52**	0.35 to 0.77	0.51**	66	69.5	1	0.76	0.43 to 1.33	0.83	0.46 to 1.49				
<b>Age, years</b>																					
20-39	32	56.3	1			36	61.1	1			62	66.1	1			497	72.0	1			
40-59	204	35.3	0.43**	0.20 to 0.90	0.41**	254	74.4	1.85	0.89 to 3.83	1.95	66	69.5	1	0.76	0.43 to 1.33	0.83	0.46 to 1.49				
60-79	54	50.0	0.78	0.32 to 1.87	0.60	246	70.3	1.51	0.73 to 3.11	1.55	66	69.5	1	0.76	0.43 to 1.33	0.83	0.46 to 1.49				
80-99	13	30.8	0.35	0.09 to 1.36	0.26	23	65.2	1.19	0.40 to 3.54	1.41	66	69.5	1	0.76	0.43 to 1.33	0.83	0.46 to 1.49				
<b>Educational level</b>																					
Low	85	49.1	1			193	70.5	1			62	66.1	1			497	72.0	1			
Medium	103	36.9	0.66	0.37 to 1.18	0.63	209	71.8	1.07	0.69 to 1.64	1.02	66	69.5	1	0.76	0.43 to 1.33	0.83	0.46 to 1.49				
High	109	37.6	0.68	0.38 to 1.21	0.69	140	71.4	1.05	0.65 to 1.69	1.01	66	69.5	1	0.76	0.43 to 1.33	0.83	0.46 to 1.49				
<b>Income level</b>																					
Low	52	51.9	1			144	66.0	1			62	66.1	1			497	72.0	1			
Medium	175	37.7	0.56	0.30 to 1.05	0.63	295	72.5	1.36	0.89 to 2.09	1.32	66	69.5	1	0.76	0.43 to 1.33	0.83	0.46 to 1.49				
High	76	36.8	0.54	0.26 to 1.11	0.55	120	75.0	1.54	0.90 to 2.65	1.21	66	69.5	1	0.76	0.43 to 1.33	0.83	0.46 to 1.49				
<b>Labour market affiliation</b>																					
Working	224	38.4	1			286	72.0	1			62	66.1	1			497	72.0	1			
Pensioners	43	51.2	1.68	0.87 to 3.24	2.46	172	69.2	0.87	0.58 to 1.32	0.96	66	69.5	1	0.76	0.43 to 1.33	0.83	0.46 to 1.49				
Out of labour market	30	40.0	1.07	0.49 to 2.33	0.91	89	74.2	1.11	0.65 to 1.91	1.13	66	69.5	1	0.76	0.43 to 1.33	0.83	0.46 to 1.49				
<b>Cohabitation status</b>																					
Single	82	37.8	1			163	70.6	1			62	66.1	1			497	72.0	1			
Cohabiting / married	221	40.7	1.13	0.67 to 1.90	1.18	396	71.7	1.06	0.71 to 1.58	0.98	66	69.5	1	0.76	0.43 to 1.33	0.83	0.46 to 1.49				
<b>Cancer diagnosis</b>																					
No	239	38.9	1			497	72.0	1			62	66.1	1			497	72.0	1			
Yes	64	43.8	1.22	0.70 to 2.13	1.34	62	66.1	0.76	0.43 to 1.33	0.83	66	69.5	1	0.76	0.43 to 1.33	0.83	0.46 to 1.49				

\*adjusted for gender, age, having a cancer diagnosis  
\*\*P<0.05

Table 3.4 continued

	Seen blood in urine						Seen blood in stool					
	Patient interval $\geq 1$ month						Patient interval $\geq 1$ month					
	Yes n	Weighted %	OR	Crude 95% CI	Adjusted* 95% CI	n	Yes %	Weighted %	OR	Crude 95% CI	Adjusted* 95% CI	
<b>Total</b>	175	25.1	23.0			411	57.7	57.4				
<b>Gender</b>												
Men	78	29.5	29.5	1	1	235	57.0	56.2	1	1	1	
Women	97	21.6	19.6	1.51	0.76 to 3.00	176	58.5	59.9	0.94	0.63 to 1.40	1.07	
<b>Age, years</b>												
20-39	13	15.4	15.4	1	1	44	56.8	56.8	1	1	1	
40-59	70	28.6	28.6	0.45	0.09 to 2.24	239	63.2	63.2	0.77	0.40 to 1.47	1.32	
60-79	81	23.5	23.2	0.59	0.12 to 2.91	115	49.6	49.5	1.34	0.67 to 2.70	0.76	
80-99	11	27.3	26.9	0.48	0.07 to 3.61	13	30.8	30.5	2.96	0.79 to 11.1	0.37	
<b>Educational level</b>												
Low	53	30.2	26.5	1	1	107	52.3	56.6	1	1	1	
Medium	69	21.7	19.6	1.56	0.69 to 3.53	167	59.9	53.9	0.74	0.45 to 1.20	1.24	
High	47	25.5	27.0	1.26	0.52 to 3.04	131	60.3	62.6	0.72	0.43 to 1.21	1.21	
<b>Income level</b>												
Low	48	25.0	22.3	1	1	80	51.3	56.1	1	1	1	
Medium	90	23.3	21.3	1.10	0.48 to 2.48	211	58.3	57.8	0.75	0.45 to 1.26	1.12	
High	37	29.7	29.5	0.79	0.30 to 2.06	120	60.8	58.0	0.68	0.38 to 1.20	1.13	
<b>Labour market affiliation</b>												
Working	95	23.2	18.4	1	1	272	62.1	58.5	1	1	1	
Pensioners	66	27.3	27.0	0.80	0.39 to 1.65	84	40.5	40.5	2.41**	1.46 to 3.98	0.45	
Out of labour market	9	33.2	53.3	0.60	0.14 to 2.61	46	63.0	68.2	0.96	0.50 to 1.84	0.97	
<b>Cohabitation status</b>												
Single	49	24.5	24.6	1	1	100	47.0	46.3	1	1	1	
Cohabiting / married	126	25.4	22.1	0.95	0.44 to 2.05	311	61.1	60.8	0.56**	0.36 to 0.89	1.69**	
<b>Cancer diagnosis</b>												
No	153	24.2	22.4	1	1	359	58.8	59.0	1	1	1	
Yes	22	31.8	27.1	0.68	0.26 to 1.80	52	50.0	43.7	1.43	0.80 to 2.55	0.86	

\*adjusted for gender, age, having a cancer diagnosis  
\*\*P<0.05

## 5 Discussion

This chapter comprises discussion of the methods and of the results.

### 5.1 Main findings

In Study I a high prevalence of alarm symptoms for breast, lung, urinary tract, and colorectal cancer in the general population was found. Within the preceding year approximately 15% of the population reported having experienced at least one cancer alarm symptom.

Study II showed that socioeconomic and demographic factors were statistically significantly associated with reporting of common cancer alarm symptoms. Women were more likely to report at least one cancer alarm symptom, as were subjects out of the labour market, and subjects with a cancer diagnosis. Those with older age and those living with a partner were less likely to report at least one cancer alarm symptom. Education and income showed no association.

Study III found that socioeconomic and demographic factors were statistically significantly associated with healthcare-seeking among subjects reporting cancer alarm symptoms. When examining the four symptoms together, approximately three out of four subjects sought health care when noticing an alarm symptom. However, approximately 50% waited for at least 1 month. Demographic factors such as female gender, increasing age, living with a partner and having a cancer diagnosis were positively associated with seeking health care. Among socioeconomic factors, medium educational level was negatively associated with healthcare-seeking. Women were more likely than men to seek health care within 1 month. Subjects out of the labour market were more likely than those in the labour market to wait for at least one month.

### 5.2 Methodological considerations

#### Study design

The study was designed as a cross-sectional questionnaire survey and a register-based study, which provided an opportunity to analyse the cancer alarm symptom prevalence in the general population, the proportion of healthcare-seeking and the patient interval among those who had experienced alarm symptoms of cancer. Further, it provided an opportunity to determine possible factors associated with symptom experience and healthcare-seeking behaviour. A strength of this

study was the high participation rate at approximately 70% and the large sample size, which ensured a high statistical precision of our estimates on symptom prevalence with narrow CIs.

Another strength of this study was that it was a 'real-life' study, meaning that real symptom experiences and healthcare-seeking experiences were reported, which is in contrast to other studies where hypothetical scenarios are studied. Cross-sectional studies are limited, though, by allowing only measurement of exposure and outcome variables at a certain point in time, and the cross-sectional design does not allow for the study of causality. On the other hand, a cross-sectional questionnaire survey is a convenient and reliable way to obtain symptom-related information from the general population. There are other ways to collect information on symptom experiences in the general population. It could be as a field study where a researcher follows the persons included in the study every day or as a prospective cohort study, with people writing the symptoms into a diary whenever they appear. A prospective registration of symptoms would require a very large sample and a long study period to obtain enough information, with the risk of dropouts in the long study period.

The symptom prevalences found in a prospective registration of symptoms may be influenced due to subjects may be even more aware of bodily sensations in the study period than they probably would have been if they were not included in the study. By using a prospective symptom registration a predefined list of symptoms which could introduce recall, meaning that reading the list of symptoms will make people remember symptoms, that they actually had not paid attention to when the symptom was present, would be eliminated. One could argue that this was actually a truer picture of symptom prevalences in the general population. However, in the interpretation of these results one should remember that people would probably register symptoms that they would not have paid attention outside this study

A limitation of the present studies is a reliance on self-reported recall with no objective verification of the symptom episode and time taken to consult. It is possible that recall bias may have affected some answers given, as respondents were asked to report on circumstances that had occurred up to one year previously. Therefore, the symptom prevalences in this thesis may be underestimated due to recall bias. Older people, who are more likely to have symptoms, were less likely to report symptoms than younger people, which could be due to a higher degree of recall bias among the older subjects. Alternatively it could be a result of older people accepting a higher degree of symptoms and then simply attribute it to ageing. Symptom prevalence in this thesis may further be underestimated, since symptoms turning out to be harmless may quickly be forgotten. And some people may have sought health care, but as the symptom may have been found harmless by the GP, these persons may have forgotten all about the healthcare-seeking, leading to an underestimation.

In this study a time frame of one year for symptom experience was chosen, increasing the likelihood of getting enough symptom experiences to obtain statistically precise estimates. It may, however, be quite difficult to remember exactly what symptoms one has experienced say 8 or 13 months ago. Future studies should probably shorten the time interval for reporting symptoms to limit recall bias, but should then increase sample size to achieve similar precision.

The symptom prevalence and healthcare-seeking behaviour may be overestimated as a group of the respondents - those who had experienced symptoms and had consulted for a symptom - were more willing to participate - the most motivated people. On the other hand, the prevalence estimates of cancer alarm symptoms may be underestimated due to patients who were already dead or very ill with a cancer disease could not participate.

Selection bias was reduced by randomly selecting participants by means of the Danish Civil Registration System.

When comparing the respondents and non-respondents according to demographic factors, more women were represented among the respondents, more people were aged 60-79 years, fewer people were represented in the youngest and oldest age groups, and more people lived with a partner. Therefore, non-response bias may have influenced the results. As women in many studies have been found to report more symptoms than men, the symptom prevalence reported in this thesis may be overestimated due to the larger proportion of women among respondents. Further, as one of the cancer alarm symptoms was rather gender-specific (lump in the breast), the symptom prevalence may be overestimated. The over-representation of women may have influenced the healthcare-seeking behaviour. However, as conflicting findings are found in different studies according to gender differences in healthcare-seeking behaviour, it is difficult to comment on the direction in which the results were affected by this.

People with high SES were overrepresented among the respondents. This may have led to an underestimation of the symptom prevalences, since several studies about symptom experiences in the general population have documented that people with low SES report more symptoms.<sup>37-39</sup> However, as Studies II and III considered associations between SES and symptom reporting/healthcare-seeking behaviour, we believe the effect of non-response has only influenced the results to a minor degree.

We did not perform statistical tests to compare respondents and non-respondents because the large sample size itself, which is a strength of this study, would make any small difference statistically significant.

### Quality of data sources, the questionnaire

As no validated questionnaire existed suiting all our research questions, a new questionnaire was developed. A general weakness of questionnaire-based studies is that the respondents may understand or interpret the items differently than intended. In order to minimise this source of bias, a qualitative and a quantitative pilot study were conducted concerning the items on symptom prevalence and health care seeking, and accordingly adjustments in items and formulations were made prior to the final questionnaire. The response rate was sought improved by mailing the questionnaire to each subject and providing them with a pre-paid return envelope.<sup>92</sup> A limitation of this study was that the full version of the questionnaire was not validated. Therefore it was chosen to study the questions that we regarded as being most valid – the questions that were pilot tested.

A more comprehensive validation process of the entire questionnaire would have been desirable. In the development of the questionnaire the suggested items should have been reviewed by health professionals with research experience and afterwards by people from the target group. A qualitative approach with interviews with these people should ensure the content validity. The results from the interviews should have been transcribed and interpreted by the researchers, and next the proposed questionnaire should have been shown to those who were interviewed, asking them to review it for acceptability, comprehensiveness, relevance of items, clarity of wording, and ambiguity of items.

After the development, a comprehensive pilot test of the questionnaire should have been performed - first a small pilot test among a new representable group of the target population to identify and solve potential problems such as difficult phrasing of the questions and responses, or problems relating to the layout or flow in the questionnaire. They should be asked to complete the provisional questionnaire and then be debriefed using a pre-structured interview to identify potential problems and other important issues that should be covered.

Secondly, the adjusted questionnaire should be field-tested, with the objective to determine and confirm acceptability, validity, and general applicability. For this test a larger group, representative of the full range of the target population, should have been invited to participate. And as with the pilot test, the questionnaire should be followed by a debriefing interview. Problems such as the extent of missing data, problems with wording of response options to a question, problems understanding the structure of the questionnaire, and exhaustions (if the questionnaire was too long) could be identified.<sup>93</sup>

In order to claim content validity the design and development of the questionnaire should have followed this rigorously defined development process. Further, one has to ensure that the entire range of relevant issues has been covered, and that items included in the questionnaire are relevant. Face validity concerns the critical review of the questionnaire, after it has been



constructed, and checks whether the questionnaire appears to clearly and unambiguously cover the intended topics.

There is no 'gold-standard' to compare the results with. The prevalence estimates were solely based on self-reported symptom experiences and neither on clinical examinations nor clinical journals, which could probably have validated or determined the appropriateness of symptom reporting. It was not an aim of this thesis to validate the appropriateness of symptom reporting. The aim was solely to elucidate subjective experiences of symptoms – a bodily sensation that people had experienced, without the interpretation of the symptom given by either GP or patient. Further, it is unknown what subjects have answered, when ticking 'yes' in the question on for instance blood in stool. Was it rectal bleeding, blood in the stool, or was it actually blood on the toilet paper that people had experienced? This may have led to overestimation of the symptom prevalence for at least blood in the stool. By asking people if they had coughed for more than 6 weeks within the preceding 12 months, it is unclear whether they should have coughed for 6 weeks constantly to qualify for a 'yes'-answer – or whether they could have coughed on and off during the preceding year, amounting to 6 weeks in total. This may have led to bias with overestimation of prevalence. In Danish guidelines for lung cancer pathways it is recommended that cough lasting for 4-6 weeks consecutively in non-smoking patients should be referred for diagnostic interventions immediately.<sup>94</sup> Therefore, a time frame of 6 weeks was chosen in this study.

The front page of the questionnaire had the title: 'Signs of cancer'. This may have affected the way people interpreted the questions, meaning that some people may have had the symptom asked for – but as they may never have had a cancer diagnosis – they may have decided to answer 'no', leading to an underestimation of the symptom prevalence.

The healthcare-seeking behaviour and the patient interval could have been validated by means of a medical record review. It would, however, require an enormous amount of time with almost 14,000 respondents. Another way to address this could have been through register data from Statistics Denmark on GP contacts. However, the register data do not address the *causes* for consultations. In this study it was decided to stick to the self-reported symptom experienced and the self-reported healthcare-seeking behaviour. Some respondents may have stated that they sought medical help for an alarming symptom experienced, although this was not the real case, because they found it to be the most culturally 'correct' or 'accepted' answer, leading to overestimation of healthcare-seeking.<sup>95</sup>

In Study III, subjects were to choose one and only one symptom, and healthcare-seeking was determined from this single symptom. It may have affected the results for healthcare-seeking as the subjects may have chosen the symptom they found most important, for instance the

symptom they sought health care for. This may have led to overestimation of the healthcare-seeking behaviour. It seems of minor magnitude, though, as only few people reported more than one symptom within the preceding year.

In the analyses the patient interval was dichotomised into 'within 1 month' and 'after at least 1 month', as a time frame of one month was found to be long enough to allow the patients to make an interpretation of their symptom and yet be able to get an appointment with their GP. Other studies have defined the length of patient delay in another way, e.g. as consulting after 3 months, after one week, and after 4 weeks, respectively.<sup>15;34;36;45;49</sup> It is difficult to define what the most appropriate patient interval is, but as time to diagnosis seems to have an impact on cancer mortality,<sup>96</sup> intuitively, the shorter time frame the better when aiming to achieve earlier diagnoses.

Data from the questionnaire were chosen as the source of information on whether or not people had already had a cancer disease. This information was needed, as it seemed obvious that former experiences with a cancer disease would affect the awareness of symptoms and the subsequent healthcare-seeking. As no question on which cancer form they had had or when it was diagnosed was asked, it is impossible to comment on whether the symptom experienced was a result of the cancer diagnosis they already had. Information on cancer diagnosis could have been gathered from Statistics Denmark, but as with symptom reporting, the aim was to study self-reported data and the person's own interpretation, and we believe that having a cancer disease interfere so much with people's lives that the validity of asking people about it would be high.

The four symptoms: lump in breast, cough during 6 weeks, blood in urine, and blood in stool were chosen because they are all symptoms indicating a potential underlying malignant disease. However, they are all also symptoms of benign causes such as fibroadenomatosis, common cold or flu, urological infections or lithiasis, and haemorrhoids. The symptoms do not necessarily cause pain or interfere with functioning; consequently they may not trigger healthcare-seeking.

The same symptom will by some people be regarded as harmless,<sup>51</sup> others will perhaps regard it as being too serious to ignore.<sup>36</sup> These considerations or interpretations about the symptom will probably lead people to a decision about consulting or not consulting. Some will wait to see if it clears up on its own; some will discuss it with relatives;<sup>55</sup> others will probably deny it; some will seek health care for a second opinion. The persistence of a symptom may also influence the way people interpret it differently.<sup>55</sup> The key issue seems not always to be the symptom itself. The decision to consult a general practitioner is based on a complex mix of physical, psychological and social factors.<sup>97;98</sup>

Surveys of symptom prevalence in the general population and in primary care reflect a variety of interpretations of sensations, which are not necessarily equivalent to expressions of underlying disease. These issues could not be addressed with the items on which this thesis

focused. Future studies should address this, as it seems very important in the decision-making of consulting. Further studies should also remember that reporting of symptoms may not be consistent with what people have really experienced.

### **Quality of data sources, register data.**

A main strength in Studies II and III is the use of socioeconomic register data solely, obtained from Statistics Denmark. These data are collected and updated annually from different administrative registers (tax-, labour market-, educational- and social registers) and thus considered to be of generally high quality, leading to an overall low probability of misclassification.<sup>77;99</sup> A decision on which socioeconomic variables should be explored was made and educational level, income and labour market affiliation, all considered being important measures for SES together with cohabitation status were chosen.<sup>100;101</sup>

Generation of the variable 'highest attained education' is based on the educational institutions' administrative data.<sup>82;102</sup> Misclassification of subjects as having a higher education than was actually the case is unlikely, but a few work-related skills may not be registered in the education register and these individuals may be misclassified.

The income variable in Statistics Denmark is based on tax information.<sup>83;103</sup> In the studies the variable income included the person's own gross income only, and no other sources were included such as partner's salary or allowances of any kind. This may have misclassified some people. Those who have a low gross income, but who rely on the partner's income may be misclassified into low income, whereas those who have a high income themselves but live together with a partner with a low income may be misclassified into a high income level. Information on the preceding 5 years was obtained to account for annual variation, and the mean income was calculated for the values given. A few people were registered with a negative income, which may have been people who were owners of their own company. These people were nonetheless included in the analyses.

Labour market affiliation is based on tax information in Statistics Denmark and is therefore assumed to be highly valid.<sup>84;104</sup> A person is categorised according to his or her main income source each year. However, if a person has received sickness benefits or maternity pay most of the year, these persons will be classified as being unemployed, although in fact in employment. Misclassification in the other categories (working and pensioners) is unlikely.

With regard to cohabitation status persons were classified as cohabiting if they had the same residential address and were adults living together with no family relation.<sup>105</sup> This means that a married couple not living together was classified as being single. An alternative approach could be to use registered partnerships only as 'cohabiting', but as many couples in Denmark live together

without being married or registered, the approach chosen will likely have misclassified fewer people.

## 5.3 Discussion of statistics

### Analyses

By using a cross-sectional study design, estimates of prevalence (what fraction of the population has the particular characteristics looked for?) can be calculated; in this case: alarm symptoms of cancer, healthcare-seeking, and patient interval. Associations can also be calculated, that is, what is the correlation between an “exposure” (person characteristics) and an “outcome” (symptom, healthcare-seeking, and patient interval)? As binary outcomes were used in Studies II and III, logistic regression models were used.

### Confounders

Confounding is a result of mixing effects between the exposure and an unknown or unaccounted confounding factor, which leads to masking or distortion of the true relationship between exposure and outcome. A confounder is a factor associated with the exposure (but not a consequence of it) and with the outcome. Confounding factors were controlled for using multiple logistic regression models. As confounding factors, gender, age, and having a cancer diagnosis were selected a priori, as it was hypothesised that these factors would be associated with both the exposure and the outcome. Although we were able to control for these factors as potential confounders in the analyses, it should be kept in mind that it is only possible to control for confounders, if information on them is obtained and they are measured properly. Other unmeasured variables or residual confounding should be considered as alternative explanations for the findings. In the models used for Studies II and III the effects of different socioeconomic variables were analysed separately, as the socioeconomic variables were expected to be collinear and causally associated.

### Not measured, potentially influential variables.

Comorbidity could be interesting to include, as comorbidity may give rise to more symptoms<sup>30</sup> and it may influence the way people interpret their bodily sensations. If people already have some chronic diseases, one would assume that they tend to be more aware of symptoms. This could lead to a higher prevalence of symptom reporting. Contrarily, if people are used to having many symptoms they may not be able to distinguish new symptoms from already known symptoms,

leading to an underestimation of symptom prevalence – or they may attribute the new symptoms to their chronic disease. Moreover, comorbidity may affect healthcare-seeking. First of all, it could lead to a higher proportion of healthcare-seeking, as patients are already familiar with seeing their GP. Secondly, the patient interval may be affected, as patients wait to present the symptoms to the GP when they consult for something else - their chronic disease. Comorbidity was not included in this study, but it could be included when designing future research on symptom prevalences and healthcare-seeking behaviour, as long as comorbidity is defined and measured in the same setting as the rest of the study.

Lifestyle factors such as smoking status could also be interesting to include when analysing associations between symptom reporting and SES, as in populations with lower social status for instance, smoking is more prevalent. And smoking is known to cause ill health. Unfortunately smoking status was not included in our questionnaire. This would be relevant to assess in future research of symptom experiences and healthcare-seeking, especially when examining symptoms and diseases significantly affected by smoking.

Even though we may be missing the confounders described above, we did have the variables that we were interested in analysing. We believe that the analyses of the associations between SES and symptoms and healthcare-seeking are valid.

### **Missing values**

Some considerations were made about missing values in the questionnaire, and it was decided that missing answers in the symptom prevalence section should count as a 'no', if subjects had also answered other questions about symptom experiences. This may have led to underestimation of the symptom prevalence.

Concerning the items for healthcare-seeking subjects were only included, if they had chosen a personal cancer alarm symptom and had answered the question on whether they had consulted a GP for it. This led to a few more missings and may have overestimated the proportion of people who had sought health care by excluding potential non-consulters. A total of 10 subjects had answered 'no' to healthcare-seeking, even though they had answered the question on patient interval. This may have underestimated the healthcare-seeking estimates, as it seemed that these subjects actually had consulted a GP for it; and it may have overestimated the proportion of subjects who consulted within one month.

There were a few missing values in the socioeconomic register data. The maximum percentage of missing values was 3.1% (Table 2.1). No sensitivity analyses were performed, because only a few percentages were missing.

## Generalisability

The population-based approach, the large sample and the high response rate make the results generalisable to the Danish population due to the demographic and socioeconomic similarities between the respondents and the entire Danish population aged 20+. The 480,000 inhabitants of the County of Funen, from where the sample was randomly selected, effectively comprise a representative 9% sample of the total Danish population, and the cancer incidence of Funen is similar to that of Denmark as a whole. All prevalence estimates were weighted according to the gender- and age-distribution of the population of Funen (Study I) and of the Danish population (Studies II and III), suggesting that the prevalence estimates are fairly generalisable to the total Danish population. To compare the two different weights, the symptom prevalences in Table 1.1 have been calculated for both weights. The differences in the prevalence estimates were very small, making all the weighted results from Study I generalisable to the Danish population. Further, as associations between health and socioeconomic status seem to be rather universal, it is reasonable to assume that the results are generalisable to other Western countries with similar healthcare systems and morbidity patterns.

Smith et al.<sup>51</sup> found that healthcare-seeking experiences among cancer patients including several cancer forms were very similar across cancer forms. As alarm symptoms of four common cancer types exhibiting easily detectable symptoms, e.g. a lump or bleeding, were included, it seems reasonable to assume that the results to a large degree are generalisable to other groups of cancers with similar distinct onset of symptoms.

## 5.4 Discussion of the results and comparisons with other studies

### Study I

In Study I the prevalence of alarm symptoms of cancer was estimated. Previous studies have focused on the prevalence of several symptoms present in the general population,<sup>15;30;31;34-36;38;39;45;95;106;107</sup> but this study is the first large, epidemiological study which provides precise prevalence estimates of alarm symptoms of breast, lung, urinary tract, and colorectal cancer in a general population setting.

### Cough for more than 6 weeks

A total of 6.5% (n=940) reported coughing for more than 6 weeks in the present study. European and US studies about the prevalence of cough have been performed as questionnaire surveys in general population settings.<sup>30;32;108</sup> Questions are, however, posed very differently between this and other studies and time frames and gender-age distributions are very differently defined. The studies do, however, confirm our result that coughing in the general population is very common. For instance McAteer et al. found that 17.8% of adults had experienced cough within the past 2 weeks. Their prevalence is much higher than in the present study, probably because benign self-limiting causes such as a simple cold or flu are included in their study as well. Hannay et al.<sup>32</sup> found in 1978 a prevalence of cough during the past 2 weeks of 15%. They included children in the analyses, which may have contributed to the much higher prevalence. Further, it should be kept in mind that Hannay's study was conducted almost 40 years ago. Interpretations of symptoms may have changed a lot since then, because diagnostic and treatment strategies have changed.

Some researchers have defined cough lasting for more than 8 weeks as 'chronic cough',<sup>108</sup> whereas others have defined it as cough lasting for 3 weeks.<sup>109</sup> By gathering information during a whole year for the present study the risk of seasonal variation in coughing was eliminated.

### Blood in the stool

In contrast to other population-based studies, the present study found that only 5.7% had experienced blood in the stool in the preceding year. Rectal bleeding within the past year was reported by 14–20% in UK surveys (n=842-1749), but new onset of bleeding within the past year was reported by only 2.2%.<sup>36;106;107</sup> An Australian population-based study from 2009 (n=338) found that 18.3% reported blood in the stools within the previous 12 months, and it was similar among men and women.<sup>31</sup> The differences found between the studies can be due to the way questions were posed. Only blood in the stool was asked for in our study, whereas some of the other studies asked about rectal bleeding. They may have included subjects who had discovered blood on the toilet paper as well. Further, the difference between the studies can be caused by different age distributions in the samples compared. In the present study, very old people were included – a group known to report symptoms less often than younger people. There may be some inattention to or acceptance of certain symptoms in the older part of the population. With increasing age people are more likely to have experienced symptoms before and thus through experiences perceive these symptoms less alarming over time. Further, it is possible that younger people are more aware of symptoms when they interfere with the demands of everyday life such as studies, career and children, in contrast to older people without the same demands, thus resulting in the differences in reported symptom experiences.

### **Lump in the breast and blood in the urine**

A total of 3.3% of respondents (n=411) reported a lump in their breast and 2.2% (n=307) reported blood in the urine. No other prevalence studies based on a sample from the general population reporting these symptoms have been found through literature searching.

### **Study II**

In Study II possible associations between reporting of cancer alarm symptoms and socioeconomic and demographic determinants were calculated.

As hypothesised, the present study found that women were more likely to report at least one cancer alarm symptom than men. This was in line with other studies, which also found female gender to be associated with more symptom reporting.<sup>30;31;37-39</sup> One possible explanation could be that women have a higher bodily awareness, they pay more attention to bodily sensations, they may recognise more symptoms, and as a consequence report symptoms more often than men.<sup>49;110</sup> Another explanation could be that women may have higher morbidity and therefore may be more familiar with recognising symptoms. In conflict with this, Talley et al. found that men were more likely to report rectal bleeding than women.<sup>35</sup> The conflicting findings regarding the association between gender and symptom experiences may indicate that gender differences may not be the same for different symptoms. This may suggest that researchers in the future should not pool all the symptoms together to analyse gender differences.

In contrast to what was hypothesised, older-aged people were less likely to report at least one cancer alarm symptom than the younger people in the present study. This result was confirmed by other studies of symptoms in the general population,<sup>30;31;36;111</sup> which could be due to the interpretation of symptoms by elderly people. Elderly people, who are more likely to experience symptoms qua increasing morbidity, may not consider the symptoms to be serious, they normalise it, and therefore they do not necessarily report it. For instance Hickey (1988) reported that elderly people have more symptoms than younger people, but when they consult doctors they tend to report fewer symptoms.<sup>112</sup> Younger people may in general have a lower threshold for reporting symptoms than older people. Contrarily, Kroenke found that older age was positively associated with symptom reporting,<sup>37</sup> probably reflecting that they studied life time prevalences of symptoms.

Studies have shown that having a close experience with a cancer diagnosis is associated with greater awareness of cancer symptoms.<sup>90;91</sup> In line with this, subjects with a cancer diagnosis were found to be more likely to report symptoms, which could be explained by a higher level of morbidity and/or by greater awareness of cancer symptoms in this group of people.



In the present study it was found that those living with a partner were less likely to report at least one cancer alarm symptom, which was in contrast to what was hypothesised. McAteer et al. found that the mean number of symptom experiences was positively associated with marital status,<sup>30</sup> but they included several symptoms, whereas this study only assessed a few cancer alarm symptoms. Kroenke, on the other hand, found that marital status had no consistent effect on symptom prevalence.<sup>37</sup> They included many other symptoms, though, and examined lifetime prevalences. Marital status was not examined alone in our study, as many people in Denmark live together without being married. Instead cohabitation status was examined, as we wanted to study whether living together with a partner was associated with symptom reporting and healthcare-seeking behaviour. Living together gives the opportunity to discuss the symptom noticed with a close relative. This may have led to a common decision that the symptom was not important, and therefore it was not reported.

Education and income showed no association with symptom reporting in this study. Kjeldsberg et al. found that the highest mean number of symptoms was reported by people with a low educational level.<sup>39</sup> They used the same categorisation for low educational level as was done in this study, but they primarily investigated the number of musculoskeletal symptoms and non-musculoskeletal symptoms such as chest pain, eczema and sleep problems within the past 30 days, none of the symptoms that were included in this study. In line with our study, McAteer et al. found no association between symptom reporting and education/household income, after adjusting for other person characteristics.<sup>30</sup>

Subjects out of the labour market were more likely to report at least one cancer alarm symptom, which could be explained by a higher degree of morbidity in this group of people. A number of studies confirm that working people are healthier than non-working people.<sup>113;114</sup> These results were confirmed by Kroenke, who found that low SES, measured by occupational status, had a low but consistent effect on symptom prevalence. Those with low SES were more likely to report a large amount of the symptoms investigated, including menstrual and gastrointestinal complaints.<sup>37</sup> Likewise Kjeldsberg et al. and Krantz et al. found that unemployed people reported more symptoms.<sup>38;39</sup>

Women and those with a cancer diagnosis were more likely to report having felt a lump in the breast. To a large extent this may be due to the fact that lumps in the breast are predominantly a gender-specific condition, and because people with a cancer diagnosis pay more attention to bodily sensations. Furthermore, the cancer diagnosis reported could be breast cancer, thereby giving the higher odds. Those aged 60+ years were less likely to report a lump in the breast. These findings are consistent with others studies, indicating that older people notice or report fewer

symptoms.<sup>30;112</sup> Another explanation is that benign conditions in the breast such as fibroadenomatosis are found more often among younger women.

Regarding coughing, subjects with high education and income level were less likely to report it, and those out of the labour market were more likely to report coughing. This might be explained by differences in causal factors such as tobacco smoking.<sup>115</sup> Future studies on symptom reporting in a population should include data on lifestyle parameters such as tobacco use, alcohol consumption and diet.

Those living with a partner were less likely to report having seen blood in the urine. This could be due to people having discussed the symptom with their partner, interpreted it to be harmless, and then having forgotten about it.

Those out of the labour market and those with a cancer diagnosis were more likely to report having seen blood in the stool. It is known that in general persons out of the labour market have a higher level of morbidity<sup>116</sup> and consequently this phenomenon may also contribute to more symptoms. Women and those aged 40+ were less likely to report having seen blood in the stool. We have no qualified explanation as to why women report blood in the stools less often. An assumption is that the lower odds for older people compared to the youngest age group are seen because older people to a higher degree accept having different symptoms more frequently – and therefore report symptoms less often.

### Study III

In the third study possible associations between reporting of cancer alarm symptoms and healthcare-seeking and the patient interval were calculated.

#### Healthcare-seeking

When examining the four symptoms together, it was found that 74% sought health care, when having experienced an alarm symptom of cancer. In accordance with this, Simon et al. found in a study from 2010 that 75% of their sample sought health care for symptoms they themselves thought might be symptoms of cancer.<sup>69</sup> Unfortunately, the researchers did not ask what kind of symptoms, the subjects had experienced.

When examining the symptoms separately, in the present study feeling a lump in the breast was the symptom with the highest rate of healthcare-seeking, 89%, which could be explained by the fact that a lump in the breast is a well-known cancer-related symptom.<sup>117;118</sup> Further, a total of 67% sought health care when having noticed blood in the stool. Crosland found that only 41% sought health care after having noticed rectal bleeding. But in their study a distinction was made

between seeing blood on the toilet paper and blood mixed with stools,<sup>36</sup> which may explain some of the differences. Eslick found that 69% of respondents experiencing rectal bleeding had not presented to their physician in the previous year.<sup>31</sup> Reasons given for not consulting for rectal bleeding were the beliefs that the symptom was not serious or would clear up by itself.<sup>45</sup>

No other studies on healthcare-seeking among the general population for persistent cough or blood in the urine were identified.

As hypothesised, this study found that women were more likely to seek health care than men when having experienced an alarm symptom of cancer. It may partly be due to the fact that one of the symptoms in our study was predominantly gender-specific (lump in the breast) and that the majority sought health care for this particular symptom. When analysing the symptoms separately, women sought health care more often than men only for feeling a lump in the breast and for coughing. Courtney et al. found that men were more likely to seek medical advice for rectal bleeding.<sup>15</sup> This finding is inconsistent with previous literature which has indicated that men are less likely to present for medical care across a wide trajectory of health issues.<sup>119;120</sup> Others have found no gender differences in healthcare-seeking for rectal bleeding.<sup>31;45</sup> These findings may indicate that gender is not that important a factor for healthcare-seeking for symptoms in general as first believed. Gender differences in healthcare-seeking may be related to the particular symptom in question.

When examining the symptoms together, increasing age was positively associated with healthcare-seeking. The effect of age may partly be explained by the association between higher knowledge of cancer symptoms and age.<sup>71</sup> When examining the symptoms separately, the only significant result across all age groups was found regarding blood in the stool. For this symptom increasing age was positively associated with healthcare-seeking, and similar results were found by Crosland and Jones.<sup>36</sup>

Subjects living with a partner were more likely to seek health care than singles. The same tendency was found when analysing the symptoms separately, although it was not statistically significant. This might reflect an increased knowledge of cancer symptoms among married/cohabiting couples.<sup>71</sup> The possibility of discussing a symptom with a partner may also encourage healthcare-seeking. No other studies on the association between seeking health care for cancer symptoms and marital status were identified.

Subjects with a cancer diagnosis were more likely to seek health care. These people may have a higher level of morbidity and/or an increased fear of a relapse of their disease or of a new cancer, and therefore they have an increased attention to bodily sensations and symptoms. A limitation to our variable: 'having a cancer diagnosis' is that some of the people with a cancer diagnosis might report a symptom experience, which occurred prior to their cancer diagnosis.

Thus, the variable “having a cancer diagnosis” as a personal characteristic associated with future symptom experiences might be misleading. A few people may have been misclassified in this manner, and this may have led to a minor underestimating of the associations found between person characteristics and healthcare-seeking/patient interval in the adjusted multiple logistic regression analyses, as ‘having a cancer diagnosis’ was used as a confounder.

When examining the four symptoms together, the only association found between healthcare-seeking and socioeconomic factors was that subjects with a medium educational level were less likely to seek health care compared to subjects with a low educational level. This could be explained by an overall higher usage of primary healthcare services in lower educated people.<sup>121</sup> No other studies on socioeconomic factors and healthcare-seeking among the general population reporting cancer alarm symptoms were identified.

It seems clear that many other factors are associated with healthcare-seeking beyond those factors examined in this study, such as duration and frequency of the symptom, and indeed the interpretation of the symptom are important factors.

### **Patient interval**

In line with a previous study<sup>122</sup> our study found that approximately 44% of the subjects who sought health care waited for at least 1 month, when having noticed a lump in the breast. In a small study among lung cancer patients, Corner et al. found that all subjects waited for 3 months or longer to seek health care when having noticed a symptom which could indicate a lung cancer.<sup>46</sup> In their study several symptoms of lung cancer such as shortness of breath, persistent cough and tiredness were included. The patients may have attributed their symptoms to everyday causes, ageing, and comorbidity, rather than interpreting them as indicative of ill health. In the present study, the majority of subjects coughing for >6 weeks waited for at least one month before seeking health care. This could indicate that persistent cough may not be interpreted as a cancer alarm symptom in the general population.

Van Osch et al. discriminated, in a study on healthcare-seeking for hypothetically experienced symptoms, between urgent symptoms, i.e. blood in stool, blood in urine, and a lump and prolonged symptoms such as a nagging cough. They found that 75% of their sample performed appropriate healthcare-seeking (defined as within one week for urgent symptoms and within 4 weeks for prolonged symptoms), when having experienced blood in stool.<sup>49</sup> By calling it ‘a nagging cough’ the researchers may have measured on the disturbance in daily living. Other community-based studies have indicated that in case of persons over 40 years, approximately one-third either fail to seek or delay (>3 months) seeking medical advice for rectal bleeding.<sup>34;45</sup> A US

study found that 86% of respondents reporting rectal bleeding had failed to seek medical care within the previous year.<sup>35</sup> Courtney et al. found that 67% of subjects who had experienced rectal bleeding had consulted a doctor for it within 2 weeks.<sup>15</sup> This result may be biased to recall, as the respondents were asked about symptoms within the previous 5 years. Courtney, Cockburn and Byles found that persons perceiving their symptoms as serious were more likely to seek medical help at an earlier time point. This suggests that perception of seriousness is an important factor for medical consultation and it contributes to earlier presentation time.

A study has shown that women have higher knowledge of cancer symptoms, pay more attention to symptoms and are more likely to seek timely health care than men.<sup>49</sup> Likewise, the present study found that women were more likely to seek health care within 1 month than men.

There have been conflicting findings concerning age and patient interval. Older age is found to be associated with long patient intervals among breast cancer patients.<sup>52</sup> Among the general population, Van Osch et al. found that older respondents reported more timely healthcare-seeking for cancer alarm symptoms than respondents in the younger age groups.<sup>49</sup> Others found no association.<sup>122</sup> This study found that subjects aged 40–59 years were more likely to seek health care within 1 month when having felt a lump in the breast compared with the younger age group. One reason could be that people in this age group are more aware of the higher cancer risk involved in feeling a lump in the breast.

Hypotheses on socioeconomic differences in patient interval among people with cancer alarm symptoms were also tested. When analysing the symptoms together, the only statistically significant result was that subjects out of the labour market were more likely to wait for at least 1 month before seeking health care when having noticed an alarm symptom. Surprisingly, no consistent patterns were found between SES and patient interval, when analysing the symptoms separately. One explanation for the lack of pattern may be that people in Denmark have free and equal access to primary health care. Another explanation may be that not only physical sensations but also psychological, cultural and other aspects influence the interpretations of symptoms and the subsequent actions, including healthcare-seeking.

Our results suggest that demographic factors are associated with the patient interval when studying cancer alarm symptoms and that SES is not. Beyond demographic factors the literature indicates that perception of seriousness is important for deciding to seek medical advice and it may contribute to earlier presentation time.

## 6 Conclusion

With a symptom prevalence of approximately 15%, a conclusion can be made that alarm symptoms of cancer are common in the general population. Factors such as gender, age, and having a cancer diagnosis are associated with reporting of symptoms. Among socioeconomic factors only labour market affiliation is found to be associated with symptom reporting.

Approximately three out of four subjects seek health care when noticing an alarm symptom of cancer. However, approximately 50% wait for at least 1 month. Demographic factors such as gender, age, cohabitation status, and having a cancer diagnosis are associated with seeking health care, but, among socioeconomic factors, only educational level is associated with healthcare-seeking. Women are more likely than men to seek health care within 1 month. Subjects out of the labour market are less likely than those in the labour market to seek health care within 1 month.

## 7 Implications

Early diagnosis and prompt treatment are generally presumed to be a key to a better prognosis of most illnesses. To improve early diagnosis it is important to gain knowledge about which symptoms, groups of symptoms, and related factors leading to healthcare-seeking.

In the general population knowledge and awareness of cancer warning signs are an important stipulation for adequate performance of early self-detection. Previous studies have shown significant deficiencies in public knowledge levels of cancer symptoms<sup>49;70;72;123;124</sup>, though, and similar results have been found with regard to awareness of cancer warning signs.<sup>70;71;74;125</sup> Further, it has been demonstrated in hypothetical situations that recognition of cancer warning symptoms is associated with faster intended help-seeking for potential symptoms of cancer<sup>49;118</sup> and that men had less knowledge and were less likely to seek medical help.<sup>49</sup> Therefore, it may be important to improve these different aspects to promote timely healthcare-seeking.

The symptoms included in this thesis are all alarm symptoms of cancer, which people are nowadays recommended to react upon. It may be an issue that only half of the people sought health care within one month for symptoms potentially indicating cancer diseases as found in this thesis, a problem that may require public health actions. Future research should address this issue. Does it really matter that some people have a longer patient interval than one month when experiencing alarm symptoms of cancer? Will it only introduce lead time bias or will it actually improve cancer survival rates if people seek medical help faster? Education about the seriousness of symptoms and the need for early medical advice may be required, enabling people to recognise symptoms and to react appropriately. But improving knowledge may not automatically lead to improved health seeking-behaviour when an actual episode of illness is taking place, as many other factors are important in decision-making for healthcare-seeking.

Future exploration of the barriers to healthcare-seeking for cancer alarm symptoms and addressing such behaviours in public awareness campaigns may assist in improving overall consultation rates. Our study results suggest the need for targeting of specific sub-groups in future public health messages, encouraging prompt medical advice seeking. Importantly, patient delay in seeking medical advice is a modifiable factor that must be addressed, if the burden of illness associated with cancer is to be reduced. Interventions within the primary health care setting could be an important starting point to obtain this. For instance, it is reasonable to assume that where health care providers have previously raised the issue of cancer alarm symptoms, patients may subsequently feel freer to seek health care and feel more open about discussing potential symptoms and realise the importance of discussing symptoms.

Probably GPs should be encouraged to contact certain patients at increased risk of developing cancer diseases, i.e. patients with a family history of cancer diseases and with a health threatening lifestyle, such as cigarette smoking and alcohol overconsumption. It would be those people with demographic and socioeconomic characteristics as found in this thesis, who experience alarm symptoms of cancer, but who do not consult their GP for it. Thereby the group of people who may not have noticed the symptom, ignored it, or forgotten all about it could be reached. This may, on the other hand, introduce the chance of contacting healthy people who may then feel that they are sick and introduce the risk of iatrogenic harm by over-investigating healthy people.

In Denmark, all GPs must now apply diagnosis codes and/ or symptom codes in the electronic health record systems for patients with chronic diseases after every single consultation, and IT tools are continuously developed to support GPs in making decisions about the treatment of their patients with chronic diseases. Likewise, IT tools could perhaps be developed to ensure that patients at risk of developing cancer diseases were continuously asked whether they had experienced any symptoms suspicious of cancer.

However, as cancer alarm symptoms in the public are common, as demonstrated in this study, and if all people were to present their symptoms to their GP, many people might become unduly distressed and anxious about having cancer.<sup>126</sup> Subsequently investigations may lead to iatrogenic harm by over-investigation of people turning out to be healthy. Furthermore, encouraging prompt symptom presentation and increasing consultation rates might have a significant impact on the primary care workload and flood hospital clinics.

Cancer pathways are designed to assist the GP in identifying patients in whom the risk of cancer is high enough to warrant urgent investigation. A useful figure to use in setting a threshold level for who should seek medical advice and who should be referred for further diagnostic investigations is the positive predictive value (PPV), but no matter how specific the cancer alarm symptoms are, the PPVs will be low and several patients should be seen in primary care to find the ones having cancer. Studies have demonstrated that from primary care settings the PPVs of cough<sup>127</sup> and of rectal bleeding<sup>128</sup> for cancer disease are very low – often below 5% - and that the PPV of rectal bleeding in the general population is significantly lower (0.1%),<sup>128</sup> as many people experiencing rectal bleeding do not consult their GP for it. Gathering study results on symptom reporting from different settings (general population and general practice), Hamilton and Sharp presented in a paper that in a community of 2000 people, approximately 280-380 will have experienced rectal bleeding within the past year; 14-30 people report it to their GP and only one will have cancer.<sup>129;130</sup> So maybe it is time to look for other symptoms or combinations of symptoms combined with lifestyle factors and genetics to improve the chances of finding the cancer patients.



Our study can be used to calculate the symptom's positive predictive value for cancer in the general population and in primary care by linkage to the Danish Cancer Registry. This would provide important knowledge that should be included in national guidelines on cancer diseases for specifying when and for which symptom people should seek health care and which symptoms should be referred immediately for further diagnostic investigations. Data from primary care can now be extracted from the Danish General Practice Database which may in the future provide new opportunities to calculate the PPV in an easy and inexpensive way. But first the data validity of the database should be ensured.

Ensuring GPs' access to referring directly to further diagnostics test such as computed tomographies (CTs) in contrast to referring to a specialist – who then decides whether to refer to the CT – seems more effective in reducing unnecessary waiting times in the diagnostic pathway.<sup>131</sup>

Last but not least, it is important to bear in mind that every time a novel intervention is being planned, monitoring of effect should be included.

Rikke Pilsgaard Svendsen, June 2014.

## 8 Summary in English

**Background:** Through many years cancer incidence has been increasing in Denmark, and today approximately 37,000 patients are diagnosed with cancer every year. Since 2000, cancer has been the most frequent cause of death in Denmark, and despite major efforts to improve outcomes, Denmark has persistently lower survival rates than other European countries. Early detection of cancer may be one key factor in improving the outcomes of cancer patients, and it seems reasonable to assume that some cancers may be diagnosed at an earlier stage, if medical help is sought immediately after patients noticing alarm symptoms, which could be related to a cancer disease. Therefore, national initiative programmes have been launched with the objective to achieve earlier presentation of alarm symptoms. These symptoms are characteristic and distinctive features in the clinical presentation and are considered to predict serious, often malignant diseases. They are defined in national cancer referral guidelines and serve as quick access to the fast-track hospital referrals. Knowledge about the prevalence of cancer alarm symptoms among the general population and subsequent healthcare-seeking is, however, very sparse. It is known that demographic and socioeconomic factors are associated with healthcare-seeking among cancer patients. Therefore the hypothesis was that demographic and socioeconomic factors would be associated with symptom reporting and with healthcare-seeking among the general population experiencing cancer alarm symptoms.

**Aims:** Among people from the general population:

- I. to determine the prevalence of alarm symptoms of common cancers in the general population (Study I)
- II. in a population-based cross-sectional design to investigate possible associations between socioeconomic and demographic determinants and self-reporting of frequent cancer alarm symptoms (Study II)
- III. in a population-based cross-sectional design to analyse associations between healthcare-seeking behaviour and socioeconomic and demographic factors among persons reporting cancer alarm symptoms (Study III)

**Methods:** A cross-sectional questionnaire and register study formed the basis for the Study, conducted among 20,000 adult Danish citizens living in the former County of Funen, Denmark, in April 2007. The study population was an age- and gender-stratified random sample of the general population aged 20 years or older, randomly selected by means of their Danish civil registration

(CPR) number. The purpose of the questionnaire was to elucidate the prevalence of symptom experiences of some cancer types in the general population and to elucidate whether subjects sought health care when having experienced a cancer alarm symptom. The questionnaire concerned symptoms of four types of cancer: breast, lung, urinary tract, and colorectal cancer. By linking each person's CPR number to Danish national registers, socioeconomic data were obtained on highest attained educational level, income, labour market affiliation, and cohabitation status. Possible associations between demographic and socioeconomic factors with the three main outcomes: reporting of cancer alarm symptoms, healthcare-seeking, and patient interval, were calculated.

**Results:** With a response rate of 69%, approximately 15% reported having experienced at least one alarm symptom within the preceding year. Women, subjects out of the labour market, and subjects with a cancer diagnosis were more likely to report at least one cancer alarm symptom. Subjects with older age and subjects living with a partner were less likely to report at least one symptom.

A total of 26.1% of all subjects reported that they did not seek health care when having experienced an alarm symptom. Of those who did seek health care, approximately 50% waited at least one month. Women, those aged  $\geq 40$ , those living with a partner, and those having a cancer diagnosis were more likely to seek health care, whereas those with a medium educational level were less likely to do so. Further, women were more likely to seek health care within one month, whereas those out of the labour market were more likely to wait at least one month.

**Conclusions:** Cancer alarm symptoms are common in the general population, and demographic factors such as gender, age and having a cancer diagnosis are associated with reporting of symptoms and with healthcare-seeking for cancer alarm symptoms. No consistent associations were found with regard to socioeconomics.

## 9 Dansk resume (Summary in Danish)

**Baggrund:** Cancerincidensen har igennem de seneste mange år i Danmark været stigende, og på nuværende tidspunkt bliver der hvert år diagnosticeret ca. 37.000 nye cancertilfælde. Siden år 2000 har cancer været den hyppigste dødsårsag i Danmark, og på trods af stor indsats for at forbedre statistikkerne har Danmark stadig en ringere canceroverlevelse end andre europæiske lande. Tidlig opsporing af canceren synes at være en vigtig faktor for at bedre overlevelsen for cancerpatienter, og det virker rimeligt at antage, at nogle cancertilfælde vil blive diagnosticeret på et lavere stadie, hvis patienterne søgte egen læge, så snart de opdagede et alarmsymptom, som kunne være tegn på en cancersygdom. Derfor er der i mange lande iværksat nationale handlingsplaner med det formål at få folk til at søge egen læge hurtigere, hvis de har oplevet alarmsymptomer på kræft. Disse symptomer er særegne ved, at de i klinikken anses for at prædiktere alvorlige - ofte maligne - lidelser. De er beskrevet i nationale, kliniske retningslinjer og udløser et kræftpakkeforløb. Viden om forekomsten af cancer-alarmsymptomer blandt befolkningen og den efterfølgende lægesøgning herfor er dog mangelfuld. Man ved, at demografiske og socioøkonomiske faktorer er associeret med lægesøgning blandt cancerpatienter. Derfor var hypotesen, at demografiske og socioøkonomiske faktorer ville være associeret med angivelsen af at have oplevet et alarmsymptom på cancer og med lægesøgningsadfærden blandt personer i befolkningen, som havde oplevet et cancer-alarmsymptom.

**Formål:** Blandt personer fra befolkningen:

- I. At estimere forekomsten af cancer-alarmsymptomer inden for det seneste år (Studie I)
- II. At beregne mulige associationer mellem socioøkonomiske og demografiske determinanter og angivelsen af at have oplevet et cancer-alarmsymptom (Studie II)
- III. At beregne mulige associationer mellem socioøkonomiske og demografiske determinanter og lægesøgningsadfærd blandt personer, der har angivet en cancer-alarmsymptom (Studie III)

**Metode:** Et tværsnits-, spørgeskema- og registerstudie dannede grundlag for Studiet, som blev foretaget blandt 20.000 voksne, danske borgere, som var bosat i det tidligere Fyns Amt i april 2007. Studiepopulationen var en alders- og kønsstratificeret stikprøve fra baggrundsbefolkningen i alderen 20 år og derover, som blev tilfældigt udvalgt ved hjælp af deres danske CPR-nummer. Formålet med spørgeskemaet var at belyse prævalensen af alarmsymptomer på fire cancerformer:

bryst-, lunge-, urinvejs- og colorektal cancer. Ved at koble CPR-numrene til nationale registre blev der indhentet data om højest fuldførte uddannelse, indkomst, tilknytning til arbejdsmarkedet og samlivsstatus. Mulige associationer mellem demografiske og socioøkonomiske faktorer og de tre hovedoutcomes, angivelsen af et canceralarmsymptom, lægesøgning og patientintervallet, blev beregnet.

**Resultater:** Med en responsrate på 69 %, angav ca. 15 % at have oplevet mindst ét canceralarmsymptom inden for det seneste år. Kvinder, personer uden tilknytning til arbejdsmarkedet og personer med en cancerdiagnose angav i højere grad at have oplevet mindst ét canceralarmsymptom. Personer i de højere aldersgrupper og de, som boede sammen med en partner, angav i lavere grad mindst ét symptom.

26,1 % angav, at de ikke søgte læge efter at have oplevet et alarmsymptom. Blandt dem, der søgte læge, ventede ca. 50 % i mindst en måned. Kvinder, personer som var 40 og derover, personer som boede med en partner, og personer, som angav at have en cancerdiagnose, var mere tilbøjelige til at søge læge, hvorimod personer med et middel uddannelsesnivea i lavere grad gjorde det. Dertil var kvinderne mere tilbøjelige til at søge læge inden for en måned, hvorimod personer uden tilknytning til arbejdsmarkedet, var mere tilbøjelige til at vente i mindst en måned.

**Konklusion:** Cancer-alarmsymptomer er almindelige i befolkningen, og demografiske faktorer såsom køn, alder og det at have en cancerdiagnose er associeret med at angive symptomer og med lægesøgning for cancer-alarmsymptomer. Med hensyn til socioøkonomi blev der ikke fundet nogen konsistente associationer.

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## 11 The Papers

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### 11.1 Paper I ORIGINAL ARTICLE

## Prevalence of cancer alarm symptoms: A population-based cross-sectional study

RIKKE PILSGAARD SVENDSEN, HENRIK STØVRING, BJARNE LÜHR HANSEN, JAKOB KRAGSTRUP, JENS SØNDERGAARD & DORTE EJG JARBØL

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#### Abstract

**Objective.** To estimate the prevalence of alarm symptoms for breast, colorectal, urinary tract, and lung cancer in the general population. **Design.** Cross-sectional questionnaire survey. **Setting.** The former County of Funen, Denmark, with 480 000 inhabitants. **Participants.** A total of 13 777 randomly selected persons aged 20 years and older. **Main outcome measures.** Prevalence estimates of having experienced cancer alarm symptoms during the past 12 months: a lump in the breast, blood in bowel movements, blood in urine, or coughing for more than six weeks. The number of alarm symptoms experienced within the past 12 months was also calculated. **Results.** With a response rate of 69%, 3.3% of responders (95% CI 2.9% to 3.7%) reported a lump in their breast, 5.7% (5.2% to 6.3%) reported blood in bowel movements, 2.2% (1.9% to 2.5%) reported blood in urine, and 6.5% (6.1% to 7.5%) reported coughing for more than six weeks within the past 12 months. Overall, 15.3% (95% confidence interval 14.3% to 16.3%) of the females and 12.7% (11.6% to 13.7%) of the males reported having experienced at least one cancer alarm symptom within the past 12 months. **Conclusion.** Alarm symptoms of breast, colorectal, urinary tract, and lung cancer are common in the general population and approximately 15% of the population have experienced at least one of these cancer alarm symptom within the past 12 months.

**Key Words:** *Breast cancer, colorectal cancer, cross-sectional survey, health surveys, lung cancer, signs and symptoms, urinary tract cancer*

In order to reduce cancer mortality and morbidity, health care systems have primarily focused on prevention and treatment strategies [1,2]. However, in recent years focus has also been on reducing the time span from when a person experiences a symptom that could potentially be caused by cancer, until the diagnosis has been made [3,4]. One approach has been that patients presenting with cancer alarm symptoms should promptly be referred for clinical investigations [1,2] and many campaigns aim to encourage people to contact their general practitioner immediately when experiencing alarm symptoms [5]. Furthermore, in many countries alarm symptoms give access to the fast track cancer diagnostic pathways [1]. Studies have been made with general practice patients [6]. It is the general practitioner who decides which patients warrant referral, but little is known about the prevalence of cancer alarm symptoms in the population.

If alarm symptoms are frequent in the general population, the positive predictive values for cancer alarm symptoms would be low and many healthy people might become unduly worried about having cancer and be investigated for cancer [7]. Hence, prevalence estimates of cancer alarm symptoms are important. Can we actually base our referral guidelines on alarm symptoms of cancer? For most general practitioners the prevalence of alarm symptoms of cancer will be tacit knowledge. We therefore aimed to determine the prevalence of cancer alarm symptoms of common cancers in the general population.

#### Material and methods

##### *Study design*

A cross-sectional questionnaire survey based on an age- and gender-stratified random sample of the general population.

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Alarm symptoms of cancer are used as quick access to the fast-track cancer diagnostic pathways. The prevalence of cancer alarm symptoms in the general population is largely unknown.

- Prevalence of alarm symptoms of breast, colorectal, urinary tract, and lung cancer in the general population within the past 12 months are high.
- Approximately 15% of the population have experienced at least one of these cancer alarm symptom within the past 12 months.

### Setting

The former County of Funen, Denmark, with 480 000 inhabitants, comprising 9% of the total Danish population [8]. All Danish citizens are registered in the civil registration with a unique personal identification number, used in all national registers and enabling accurate linkage between all of them [9].

### Sampling

The survey comprised a questionnaire sent to a sample of 20 000 people aged 20 years or older. The sample was randomly selected from the Danish Civil Registration Number register, stratified by gender and age, half of them women and half of them men, so that for each gender only 1000 subjects under the age of 40 years were included. A postage paid envelope and a covering letter containing information on the study were enclosed with each questionnaire. Telephone numbers were provided so that the subject could get in touch with the investigators if further clarification was needed. The questionnaire was to be returned within one week. A reminder was sent two weeks later to those who had not yet returned their questionnaire.

### The questionnaire

The questionnaire concerned four types of cancer: breast, colorectal, urinary tract, and lung cancer. For each cancer type, there was one question on whether the person had experienced a symptom presumed to be highly related to that particular cancer. These four cancers were chosen because they were the most common cancer forms in Denmark [10] and because their symptoms are well described in the literature [11–14].

Items were phrased to be readily understandable so that persons regardless of literacy skills would be able to answer, without difficulty and within a short time. Subjects were asked whether

they within the past 12 months had: “Felt a lump in your breast?”, “Seen blood in your bowel movements?”, “Seen blood in your urine?”, or “Coughed for more than six weeks?” Questionnaire response status was registered in the database as “immediate responder”, “late responder” (i.e. after a reminder), and “non-responder”.

The questionnaire was field tested before use. As a first step, 10 subjects were interviewed regarding their understanding of the questions. Then the questionnaire was completed twice by 200 subjects aged 40 years and older, with the objective of analysing how the questionnaire was perceived by recipients and to test its reproducibility. The testing led to minor changes, namely removing of two questions on testes cancer.

### Statistical analysis

Prevalence estimates of each cancer alarm symptom in the population within the past 12 months stratified by gender and age as well as number of cancer alarm symptoms experienced within the past 12 months were reported. Estimates were reported as percentages (%) with 95% confidence intervals, based on the binominal distribution for the proportion of responders reporting the particular symptom. The effect of age was initially explored by dividing people into five-year age categories, but as results indicated estimates to be homogeneous within 20-year age categories, we present results only in 20-year age categories.

A “yes” response to one of the listed symptoms was considered a positive response. The answer “no” and not answering an item were considered negative responses. Estimates of questionnaire returning status were reported with percentages (%) and 95% confidence intervals.

Since the age and gender composition of the source population is known [8], estimates for overall symptom prevalence, questionnaire returning status, and number of alarm symptoms experienced, across age and gender, were obtained by simple weighting with inverse sampling probabilities [15]. Data were analysed using STATA 10.0 software.

### Ethical considerations

According to the Scientific Ethics Committee for the County of Funen, the Biomedical Research Ethics Committee System Act does not apply to this project. The study was approved by the Danish Data Protection Agency.

An alarm symptom is by definition a feature that could potentially be a sign of cancer. Confronting people with questions dealing with cancer alarm

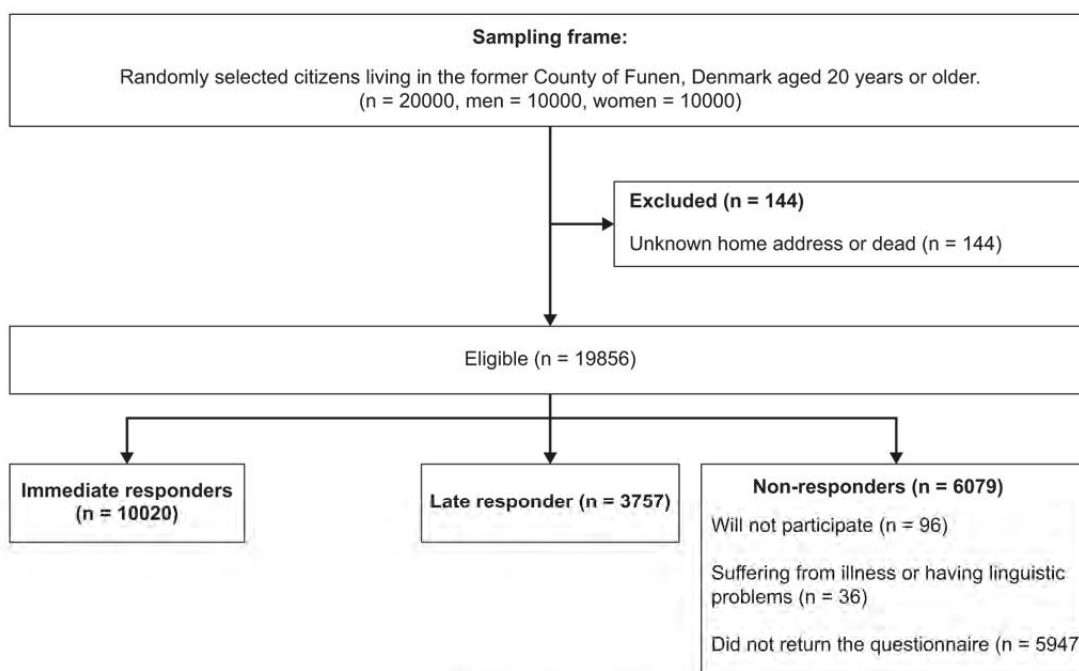


Figure 1. Study sample.

symptoms may cause anxiety [7]. To minimize undue anxiety, we provided an information letter, and the respondents were encouraged to contact us by phone if they needed clarification or had any further questions. The respondents were informed that their responses were confidential.

## Results

### Participants/descriptive data

Of the 20 000 subjects identified, 144 (0.7%) were not eligible because they were either dead or could not be reached (wrong address). Of the 19 856 subjects eligible, 36 subjects could not participate because they were suffering from dementia or had language problems. In total 13 777 subjects (of the 18 856 subjects eligible) returned the questionnaire, yielding an overall response rate of 69.4% (47.4% male and 52.6% female) (Figure 1). Overall, 3.3% of respondents ( $n = 411$ ) reported a lump in their breast, 5.7% ( $n = 713$ ) reported blood in bowel movements, 2.2% ( $n = 307$ ) reported blood in urine, and 6.5% ( $n = 940$ ) reported coughing for more than six weeks within the past 12 months.

Table I shows that prevalence estimates of cancer alarm symptoms were slightly different when stratified by gender and age. Frequency of a lump in the breast decreased with age for women and frequency of seeing blood in the stools decreased with age for both men and women.

Overall, 15.3% (95% confidence interval 14.3% to 16.3%) of the females and 12.7% (11.6% to 13.7%) of the males reported having experienced at least one cancer alarm symptom within the past 12 months (Table II).

### Questionnaire response status

Of the 13 777 responders, 10 020 subjects (72.8%) returned the questionnaire after the first mail-out (immediate responders) and 3757 subjects (27.3%) returned it after the second mail-out (late responders). Males had a tendency to respond later, as 46.0% of immediate responders were males, while 51.4% of late responders and 55.9% of non-responders were males. No age gradient was observed with regard to response status.

Response status (immediate or late responder) showed no significant association with reports of a cancer alarm symptom within the past 12 months (15.8% vs. 15.4%).

## Discussion

### Summary and main findings

We found a high prevalence of alarm symptoms for breast, colorectal, urinary tract, and lung cancer. Within the past 12 months 12.7% men and 15.3% women reported having experienced at least one alarm symptom.

Table 1. Age- and sex-specific prevalences of cancer alarm symptoms.

Age group (years)	Felt a lump in your breast? One-year prevalence			Seen blood in your stools? One-year prevalence			Seen blood in your urine? One year prevalence			Coughed for more than six weeks? One year prevalence		
	Women	Men	Total, weighted	Women	Men	Total, weighted	Women	Men	Total, weighted	Women	Men	Total, weighted
	n	n	n	n	n	n	n	n	n	n	n	n
20-39	42	4	0.8 (2.2-2.0)	44	44	8.8 (6.4-11.6)	44	17	2.8 (1.7-4.5)	36	24	4.8 (3.1-7.0)
40-59	223	36	1.2 (8-1.6)	173	234	7.7 (6-8.7)	46	74	2.2 (1.7-2.7)	251	190	6.3 (5.4-7.2)
60-79	68	21	0.8 (5-1.2)	81	115	4.4 (3.6-5.2)	3.6 (3.2-4.2)	56	2.1 (1.6-2.7)	216	183	7.0 (6.0-8.0)
80-99	12	2.3	1.2-3.9	13	9	2.3 (1.1-4.4)	2.4 (1.6-3.6)	11	2.2 (1.0 to 3.7)	23	15	3.9 (2.2-6.4)
Total, both gender weighted			3.3 (2.9-3.7)			5.7 (5.2-6.3)			3.3 (2.9 - 3.7)			6.5 (6.1-7.5)

Note: Figures are percentages (95% CI) unless stated otherwise.

*Limitations and strengths*

This study aimed to describe the prevalence of alarm symptoms of the four most prevalent cancer forms: breast, colorectal, urinary tract, and lung cancer. It is likely that the overall prevalence of all cancer alarm symptoms is considerably higher.

Selection bias was reduced by randomly selecting participants by means of the Danish Civil Registration Number system. The large sample ensured a high statistical precision of our estimates, supported by the high overall participation rate of 69.4%. As late responders essentially had the same prevalence as immediate responders, we believe that non-responders can reasonably be expected to also have a similar prevalence. The estimate of cancer alarm symptoms may represent minimum prevalences, as patients who are already dead or very ill with a cancer disease cannot participate. Further, our re-scoring of the missing values to the response category "no" would tend to underestimate the cancer alarm symptom prevalence.

The questionnaire's topic was: "Signs of Cancer", which may have influenced the way people interpreted the questions, meaning that some people may have noticed the symptoms described but as they had never had cancer they answered "no" to the questions, confirming an underestimate of symptom prevalence.

Asking people retrospectively about symptoms may have induced recall bias. However, this was probably rather limited, as we had restricted the time span to 12 months. Further, recall bias would probably lead to underestimation of the prevalence of alarm symptoms, as a symptom showing up to be harmless is likely to be quickly forgotten and some people cannot remember symptoms that they experienced a long time ago.

The population-based approach, the large sample and the high response rate make our results generalizable to the Danish population due to the demographic similarity between the County of Funen and the rest of Denmark. Indeed, the 480 000 inhabitants of the county effectively comprise a representative 9% sample of the total Danish population [8], and the cancer incidence of Funen is similar to that of Denmark as a whole [16]. Furthermore, we believe that our results are generalizable to other Western countries with similar health care systems and morbidity patterns.

*Comparison with existing literature*

Previous studies have focused on alarm symptoms of cancer in the general population [17], but our study is the first large, epidemiological study which provides precise estimates of alarm symptoms of breast, colorectal, urinary tract, and lung cancer in a general population. We have not found other studies on breast and lung cancer symptoms in an unselected population.





Table II. Sex- and age-specific description of how many alarm symptoms of cancer the sample have experienced within the last year.

Age group (years)	Gender	n		Have not experienced any symptoms	Have experienced one symptom		Have experienced two symptoms		Have experienced three or more symptoms	
				n	n	n	n	n	n	
20–39	Women	603	483	80.1 (76.7–83.2)	102	16.9 (14.0–20.2)	17	2.8 (1.7–4.5)	1	0.2 (0.0–0.9)
	Men	502	431	85.9 (82.5–88.8)	66	13.1 (10.3–16.4)	5	1.0 (0.3–2.3)	0	0 (0–0.7)*
40–59	Women	3379	2742	81.1 (79.8–82.5)	562	16.6 (15.4–17.9)	66	2.0 (1.5–2.5)	9	0.3 (0.1–0.5)
	Men	3024	2571	85.0 (83.7–86.3)	408	13.5 (12.3–14.8)	39	1.3 (0.9–1.8)	6	0.2 (0.1–0.4)
60–79	Women	2733	2354	86.1 (84.8–87.4)	341	12.5 (11.3–13.8)	34	1.3 (0.9–1.7)	4	0.1 (0.0–0.4)
	Men	2624	2277	86.8 (85.4–88.0)	293	11.2 (10.0–12.4)	50	1.9 (1.4–2.5)	4	0.2 (0.0–0.4)
80–99	Women	528	474	89.8 (86.9–92.2)	47	8.9 (6.6–11.7)	7	1.3 (0.5–2.7)	0	0 (0–0.7)*
	Men	384	347	90.4 (87.0–93.1)	33	8.6 (6.0–11.9)	3	0.8 (0.2–2.3)	1	0.3 (0.0–1.4)
Total	Women	7243	5912	83.6 (82.7–84.4)	1052	14.8 (14.0–15.7)	124	1.7 (1.4–2.1)	14	0.2 (0.1–0.3)
	Men	6534	5489	86.1 (85.2–86.9)	800	12.5 (11.7–13.3)	97	1.5 (1.2–1.8)	9	0.2 (0.1–0.3)
Total weighted	Women			82.6 (81.5–83.6)		15.3 (14.3–16.3)		2.0 (1.5–2.4)		0.2 (0.1–0.3)
	Men			85.8 (84.7–86.9)		12.7 (11.6–13.7)		1.4 (1.1–1.7)		0.1 (0.1–0.2)
Total, weighted estimate	Both genders			84.3 (83.6–85.1)		13.8 (13.1–14.6)		1.7 (1.4–2.0)		1.6 (0.1–0.3)

Notes: Figures are percentages (95% CI) unless stated otherwise. \*One-sided ANOVA.

When Buntinx carried out a systematic review of published reports in 1997 on the diagnostic value of macroscopic haematuria he could not find a single population-based study or primary care study [18]. We have not been able to identify any reports on macroscopic haematuria in the general population published since then.

In contrast to other population-based studies, we found that only 5.7% had experienced blood in their bowel movements in the past 12 months. Rectal bleeding within the past year was reported by 14–19% in UK surveys, but new onset of bleeding within the past year was reported by only 2.2% [19–21]. Another recently published, Australian population-based study (n = 440) found that 18.3% (95% CI 14.3 to 22.9) reported blood in the stools within the previous 12 months and it was similar among men and women [22].

#### Implications of the study

In this population-based study we found a high prevalence of all four cancer alarm symptoms across all ages and for both genders. By looking at four different cancer forms we found that many people had actually noticed at least one alarm symptom within the past 12 months. If all these patients should follow the fast-track recommendations for cancer alarm symptoms and undergo further clinical investigations [1], the health care systems may not have the capacity to examine all of them in a timely fashion – and those with a real need for fast-track diagnostic pathways may not benefit [23]. Furthermore, many patients may be unnecessarily bothered and worried about having cancer.

GPs face an important diagnostic challenge and cannot rely solely on one alarm symptom. In order to decide who should be referred promptly for further diagnostic investigations and who could undergo watchful waiting, the GP should include knowledge on symptom complexes, patient characteristics, and patients' narratives [24].

#### Conclusion

Alarm symptoms of breast, colorectal, urinary tract, and lung cancer are common in the general population and approximately 15% of the population have experienced at least one of these cancer alarm symptom within the past 12 months.

#### Acknowledgements

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#### Contributors

BLH and HS had the original idea for the overall study and they designed it together with JK. The plan of analysis for this sub-study was developed by RPS in collaboration with HS, JK, JS, and DEJ, who all participated in the extraction of data and interpretation of results. RPS drafted the manuscript and conducted all statistical analyses under the supervision of HS, JK, JS, and DEJ. All authors contributed to the final version. RPS is the guarantor.

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## Competing interests

None declared.

## Ethical approval

According to the Scientific Ethics Committee for the County of Funen, the Biomedical Research Ethics Committee System Act does not apply to this project. The study was approved by the Danish Data Protection Agency.

## Data

All authors, external and internal, had full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

## Data sharing

No additional data available.

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## RESEARCH ARTICLE

## Open Access

# Associations between reporting of cancer alarm symptoms and socioeconomic and demographic determinants: a population-based, cross-sectional study

Rikke Pilsgaard Svendsen<sup>1\*</sup>, Maja Skov Paulsen<sup>1</sup>, Pia Veldt Larsen<sup>1</sup>, Bjarne Lühr Hansen<sup>1</sup>, Henrik Støvring<sup>2</sup>, Dorte Ejg Jarbøl<sup>1</sup> and Jens Søndergaard<sup>1</sup>

## Abstract

**Background:** Reporting of symptoms which may signal cancer is the first step in the diagnostic pathway of cancer diseases. Cancer alarm symptoms are common in the general population. Public awareness and knowledge of cancer symptoms are sparse, however, and many people do not seek medical help when having possible cancer symptoms. As social inequality is associated with cancer knowledge, cancer awareness, and information-seeking, our hypothesis is that social inequality may also exist in the general population with respect to reporting of cancer alarm symptoms. The aim of this study was to investigate possible associations between socioeconomic and demographic determinants and reporting of common cancer alarm symptoms.

**Methods:** A cross-sectional questionnaire survey was performed based on a stratified sample of the Danish general population. A total of 13 777 randomly selected persons aged 20 years and older participated. Our main outcome measures were weighted prevalence estimates of self-reporting one of the following cancer alarm symptoms during the preceding 12 months: a lump in the breast, coughing for more than 6 weeks, seen blood in urine, or seen blood in stool. Logistic regression models were used to calculate unadjusted and adjusted odds ratios with 95% confidence intervals for the associations between each covariate and reporting of cancer alarm symptoms.

**Results:** A total of 2 098 (15.7%) of the participants reported one or more cancer alarm symptoms within the preceding 12 months.

Women, subjects out of the workforce, and subjects with a cancer diagnosis had statistically significantly higher odds of reporting one or more cancer alarm symptoms. Subjects with older age and subjects living with a partner had lower odds of reporting one or more cancer alarm symptoms. When analysing the four alarm symptoms of cancer separately most tendencies persisted.

**Conclusions:** Socioeconomic and demographic determinants are associated with self-reporting of common cancer alarm symptoms.

**Keywords:** Breast cancer, Colorectal cancer, Cross-sectional survey, Lung cancer, Socioeconomic factors, Signs and symptoms, Urinary tract cancer

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## Background

Reporting of symptoms which may signal cancer is the first step in the diagnostic pathway of cancer diseases [1]. Some cancer symptoms are quite unspecific while others are more characteristic and distinctive – so-called cancer ‘alarm symptoms’.

Cancer alarm symptoms are common in the general population [2]. In a Danish population-based study a total of 15% reported having experienced at least one of four common cancer alarm symptoms [3], and 18% of the Australian population reported blood in the stools during a 12-month period [4]. However, public awareness and knowledge of cancer symptoms are sparse and many people do not seek medical help when experiencing cancer symptoms. Hence, increasing focus is on raising awareness in the population of early symptoms of cancer in order to increase the ability to notice and report alarm symptoms [5-8].

Socioeconomic inequalities in health are ubiquitous and relations between socioeconomic status and morbidity and mortality seem to persist for numerous diseases, including many cancers [9]. Further, social disparities are significantly associated with different information-seeking behaviours among cancer patients [10].

In Denmark, the majority of health services are free of charge. Still, socioeconomic differences persist for cancer incidence, time from experiencing a symptom until seeking medical help, and cancer survival [11]. As social inequality is associated with cancer knowledge, cancer awareness, and information-seeking, our hypothesis is that social inequality also exists with respect to reporting of cancer alarm symptoms.

The aim of this study was, in a population-based cross-sectional design, to investigate possible associations between socioeconomic and demographic determinants and self-reporting of frequent cancer alarm symptoms.

## Methods

### Study design

A cross-sectional questionnaire survey based on a stratified sample of the general population was conducted in April 2007 in the former County of Funen, Denmark, with approx. 480 000 inhabitants, comprising 9% of the total Danish population [12]. All Danish citizens are registered with the Danish Civil Registration System with a unique personal identification number, used in all national registers and enabling accurate linkage between all of them [13].

### Sampling

The survey comprised a questionnaire sent out to a sample of 20 000 people aged 20 years or older. The sample was randomly selected from the Danish Civil Registration

System, stratified on gender and age, half of them women and half of them men, so that for each gender, only 1000 subjects under the age of 40 years were included. Further details of the survey are described elsewhere [3].

### Data sources and measurements

#### *The questionnaire*

The questionnaire concerned four types of cancer: breast, lung, urinary tract, and colorectal cancer. These four cancers were chosen because they are the most common cancer forms in Denmark [14] and because their symptoms are well described in the literature [15-18]. For each cancer type there was a question on whether the person had a specific symptom highly related to that particular cancer. Subjects were asked whether they within the preceding 12 months had: “Felt a lump in your breast?”, “Coughed for more than 6 weeks?”, “Seen blood in your urine?”, or “Seen blood in your stool?” They were further asked: “Do you have, or have you had, a cancer disease”? Answers to each question could be checked as a “yes” or a “no”. All symptoms reported in this paper are thus self-reported.

Before the questionnaire was sent out, it was tested: First 10 subjects were interviewed on its comprehensibility. Then the questionnaire was filled in twice by 200 subjects aged 40 years and older, with the objective of analysing how the questionnaire was perceived by recipients and to assess its reproducibility. The assessment led to minor changes.

#### **Outcome variables**

A “yes” response to one of the listed symptoms was considered a positive response. The answer “no” and not answering an item were considered negative responses.

#### **Statistics Denmark and socioeconomic and demographic variables**

All socioeconomic and demographic factors were collected by data linkage to Statistics Denmark using a person unique civil registration number. Statistics Denmark is a governmental institution collecting information electronically provided by administrative registers of different governmental agencies [19]. We obtained information for each subject about a number of socioeconomic variables: educational level, income level and labour market affiliation. Furthermore, we obtained information on cohabitation status, as we believed this demographic factor to be important, when reporting cancer alarm symptoms. Information was retrieved for the year preceding the questionnaire (2006). To account for annual variation in income we calculated the average income for the preceding 5 years.

In order to compare our sample with the Danish general population and for calculating weighted estimates we retrieved data on sex, age, education, income and employment for the entire Danish population aged 20 years and older for the year 2006.

Education was categorised according to the highest attained educational level: < 10 years (primary and lower secondary school), 10–12 years (vocational education and upper secondary school), >12 years (short, medium and long-term higher education) [20-23]. We obtained gross income, comprising all income liable to general taxation (wages and salaries, all types of benefits and pensions) for each person. Income was categorised according to the 5-year average income as low income (1<sup>st</sup> quartile), middle income (2<sup>nd</sup> and 3<sup>rd</sup> quartile), and high income (4<sup>th</sup> quartile) [24]. Labour market affiliation was categorised into three groups: working; pensioners (early retirement pension and old-age pension); out of the workforce (receiving disability pension, social security, and being unemployed). Cohabitation status was categorised as living with a partner (married/cohabitating) or single (divorced, widowed or never married) [23].

#### Statistical analysis

Prevalence estimates of reporting one or more alarm symptoms of cancer and prevalence estimates of reporting each specific alarm symptom of cancer in the population within the preceding 12 months were calculated. Estimates were reported as percentages (%) with 95%

exact confidence intervals (CIs), based on binominal distributions.

“Logistic regression models were used to calculate unadjusted and adjusted odds ratios (ORs) with 95% CIs for the association between each covariate and reporting of cancer alarm symptoms. The covariates considered were: sex, age, education, income, affiliation to the labour market, cohabitation status [24], and having a cancer diagnosis. In the adjusted analyses adjustments were made for the a priori selected possible confounders: sex, age and having a cancer diagnosis [25,26]”.

All estimates for symptom prevalences were weighted according to the total Danish population to account for the stratified sampling procedure.

#### Ethical considerations

According to the Act on a Biomedical Research Ethics Committee System the project was not a biomedical research project and therefore did not need the ethics committee's approval, journal number 2011-41-6709. The study was approved by the Danish Data Protection Agency.

#### Results

##### Description of participants

Of the 20 000 subject identified, 144 subjects (0.7%) were not eligible because they were either dead or could not be reached (Figure 1). Of the 19 856 eligible, 36 (0.2%) subjects could not participate because they were suffering from dementia or had language problems. Overall 13 777 subjects returned the questionnaire yielding a response

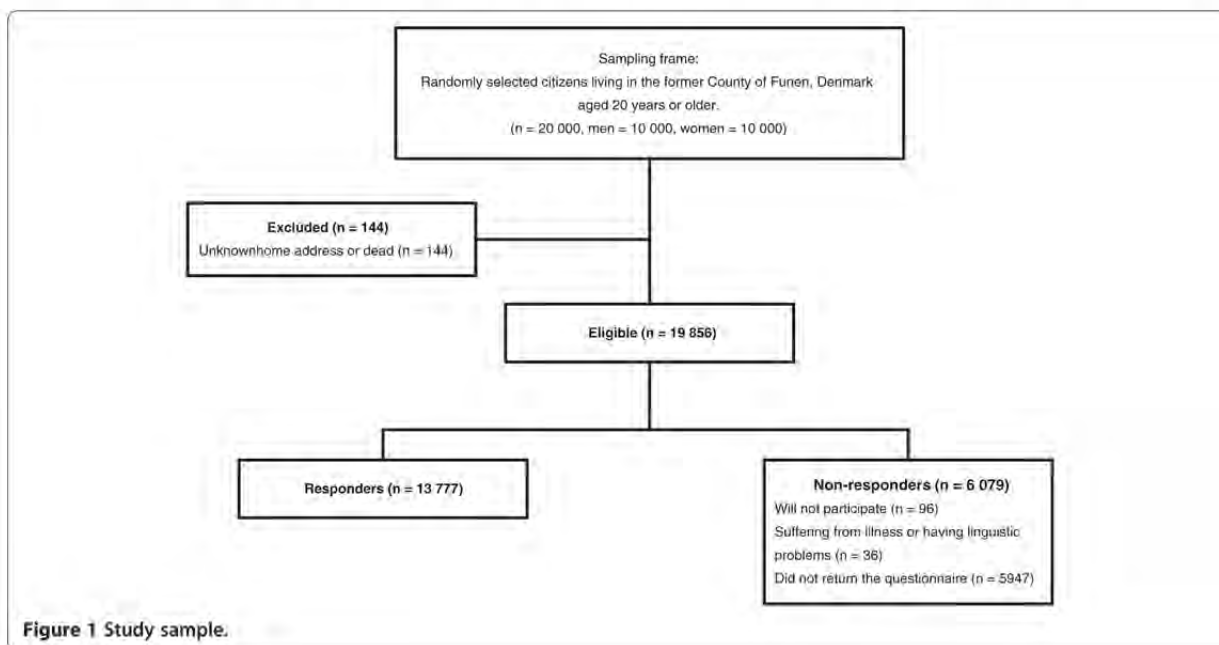


Figure 1 Study sample.

**Table 1 Descriptive data on study population and the Danish population**

		Total study population n = 13 777		Weighted total study population n = 13 777	Danish population n = 4 110 111
		n	% (95% CI)	% (95% CI)	%
<b>Sex</b>	Men	6 533	47.4 (46.6 to 48.3)	45.8 (45.0 to 46.7)	48.9
	Women	7 244	52.6 (51.7 to 53.4)	54.2 (53.3 to 55.0)	51.1
<b>Age, years</b>	20-39	1 105	8.0 (7.6 to 8.5)	29.0 (28.2 to 29.8)	33.8
	40-59	6 403	46.5 (45.6 to 47.3)	35.9 (35.1 to 36.7)	37.1
	60-79	5 357	38.9 (38.1 to 39.7)	30.0 (29.2 to 30.8)	23.7
	80-99	912	6.6 (6.2 to 7.0)	5.1 (4.8 to 5.5)	5.5
<b>Educational level</b>	Low	4 136	31.0 (30.2 to 31.8)	26.6 (25.8 to 27.3)	31.2
	Medium	5 588	41.8 (41.0 to 42.7)	43.4 (42.6 to 44.3)	43.9
	High	3 631	27.2 (26.4 to 27.9)	28.9 (28.1 to 29.7)	24.9
<b>Income level</b>	Low	3 444	25 (24.3 to 25.7)	26.6 (25.8 to 27.3)	31.1
	Medium	6 888	50 (49.2 to 50.8)	50.7 (49.8 to 51.5)	49.1
	High	3 444	25 (24.3 to 25.7)	22.7 (22.0 to 23.5)	19.8
<b>Labour market affiliation</b>	Working	7 989	59.1 (58.3 to 60.0)	66.4 (65.6 to 67.2)	64.3
	Pensioners	4 414	32.7 (31.9 to 33.5)	25.3 (24.6 to 26.1)	22.2
	Out of workforce	1 105	8.2 (7.7 to 8.6)	8.3 (7.8 to 8.7)	13.5
<b>Cohabiting status</b>	Single	3 760	27.3 (26.6 to 28.0)	29.4 (28.6 to 30.1)	-
	Cohabitant / married	10 013	72.7 (72.0 to 73.4)	70.6 (69.9 to 71.4)	-
<b>Cancer diagnosis</b>	No	12 531	91.0 (90.5 to 91.4)	92.6 (92.1 to 93.0)	-
	Yes	1 246	9.0 (8.6 to 9.5)	7.4 (7.0 to 7.9)	-

rate of 69.4% (Figure 1). Table 1 shows the descriptive data of the participants (weighted and unweighted) and of the entire Danish population aged 20+.

#### Socioeconomic and demographic participant characteristics and reporting of one or more cancer alarm symptoms

Weighted prevalence estimates of reporting of one or more cancer alarm symptoms within the preceding 12 months together with crude and adjusted odds ratios for associations between symptom reporting and socioeconomic and demographic characteristics are presented in Table 2.

A total of 2 098 participants (15.7%) reported one or more cancer alarm symptoms within the preceding 12 months. The mean age of respondents who reported one or more cancer alarm symptoms was 49.7 years and 59.3% were women (all weighted estimates).

The adjusted analyses showed that women had statistically significantly higher odds of reporting a symptom of cancer, as did subjects out of the workforce, and subjects with a cancer diagnosis. Those aged 60–79, those aged 80–99, and those living with a partner, had statistically significantly lower odds of reporting alarm symptoms. Education and income were not statistically significantly

associated with reporting of one or more cancer alarm symptoms.

#### Socioeconomic and demographic participant characteristics and prevalence of reporting each specific cancer alarm symptom

Weighted prevalence estimates of reporting each specific alarm symptom of cancer within the preceding 12 months and socioeconomic and demographic characteristics are presented in Table 3.

A total of 411 subjects (3.3%) had felt a lump in the breast; 940 subjects (6.5%) had coughed for more than 6 weeks; 307 subjects (2.1%) reported having seen blood in the urine, and 713 subjects (5.8%) reported having seen blood in the stool within the preceding 12 months (weighted prevalences).

Crude and adjusted odds ratios of associations between reporting a specific alarm symptom within the preceding 12 months and socioeconomic and demographic participant characteristics are presented in Table 4. Only results from the adjusted analyses are presented in the manuscript.

#### Gender

Women had statistically significantly higher odds than men of reporting a lump in the breast and of reporting

**Table 2 Weighted prevalence estimates and Crude and adjusted odds ratios of reporting one or more cancer symptoms**

		Participants reporting of one or more symptoms					
		n = 2 098	weighted prevalence% (95% CI)	OR (crude)	95% CI	OR (adjusted)*	95% CI
<b>Sex</b>	Men	908	40.7 (38.6 to 47.7)	1		1	
	Women	1 190	59.3 (57.2 to 61.4)	<b>1.22</b>	1.11 to 1.34	<b>1.19</b>	1.09 to 1.31
<b>Age, years</b>	20-39	191	31.9 (29.8 to 33.9)	1		1	
	40-59	1 090	39.0 (36.9 to 41.1)	0.98	0.83 to 1.16	0.96	0.81 to 1.14
	60-79	726	25.9 (24.0 to 27.8)	<b>0.75</b>	0.63 to 0.89	<b>0.71</b>	0.60 to 0.85
	80-99	91	3.3 (2.5 to 4.0)	<b>0.53</b>	0.41 to 0.69	<b>0.48</b>	0.37 to 0.63
<b>Educational level</b>	Low	634	27.7 (26.9 to 28.6)	1		1	
	Medium	852	42.7 (40.6 to 44.9)	0.99	0.88 to 1.11	0.94	0.84 to 1.06
	High	568	30.0 (28.0 to 32.0)	1.02	0.91 to 1.16	0.95	0.83 to 1.08
<b>Income level</b>	Low	496	26.7 (24.8 to 28.6)	1		1	
	Medium	1 081	51.7 (49.6 to 53.9)	1.11	0.99 to 1.24	0.98	0.87 to 1.11
	High	521	21.6 (19.8 to 23.3)	1.06	0.93 to 1.21	0.95	0.82 to 1.10
<b>Labour market affiliation</b>	Working	1 249	68.5 (66.4 to 70.5)	1		1	
	Pensioners	544	19.9 (18.2 to 21.7)	<b>0.76</b>	0.68 to 0.85	0.93	0.78 to 1.10
	Out of workforce	254	11.6 (10.2 to 13.0)	<b>1.61</b>	1.38 to 1.88	<b>1.59</b>	1.36 to 1.86
<b>Cohabiting status</b>	Single	618	30.4 (28.4 to 32.4)	1		1	
	Cohabitant / married	1 480	69.6 (67.6 to 71.6)	<b>0.88</b>	0.80 to 0.98	<b>0.84</b>	0.76 to 0.93
<b>Cancer diagnosis</b>	No	1 841	90.2 (88.9 to 91.5)	1		1	
	Yes	257	9.8 (8.5 to 11.1)	<b>1.51</b>	1.30 to 1.75	<b>1.63</b>	1.40 to 1.89

(\*adjusted for sex, age and having a cancer diagnosis.) Highlighted figures are statistically significant (p < 0.05).

coughing for more than 6 weeks, but had statistically significantly lower odds of reporting blood in the stool.

#### Age

Subjects aged 60–79 years had statistically significantly higher odds of reporting coughing. Subjects with older age had statistically significantly lower odds of reporting a lump in the breast and of reporting blood in the stool within the preceding 12 months.

#### Education

Subjects with high educational level had statistically significantly lower odds of reporting coughing for more than 6 weeks within the preceding 12 months than those with a low educational level.

#### Income

Analyses showed a tendency towards subjects with increasing income having lower odds of reporting alarm symptoms (apart from having felt a lump in the breast) than those with low income. Results were only statistically significant for reporting coughing for more than 6 weeks within the preceding 12 months.

#### Labour market affiliation

Those out of the workforce were statistically significantly associated with reporting coughing for more than 6 weeks and reporting blood in the stools within the preceding 12 months.

#### Cohabiting status

For all four cancer alarm symptoms there was a tendency towards lower odds of symptom reporting for those living with a partner than for those being single. Results were statistically significant with respect to coughing and seeing blood in the urine.

#### Having cancer

For all four cancer alarm symptoms there was a tendency towards higher odds of reporting cancer alarm symptoms for subjects with a cancer diagnosis. Results were not statistically significant of reporting coughing for more than 6 weeks.

#### Discussion

In this large population-based survey socioeconomic and demographic factors were associated with reporting of common cancer alarm symptoms. Some 15.7% of the

**Table 3 Weighted prevalence estimates of participant characteristics by reporting a specific cancer symptom within the preceding 12 months**

		Weighted prevalences							
		Felt a lump in the breast yes, n = 411		Coughed for more than six weeks yes, n = 940		Seen blood in urine yes, n = 307		Seen blood on stools yes, n = 713	
		n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)
<b>Sex</b>	Men	66	13.4 (10.2 to 16.6)	412	43.1 (39.8 to 46.4)	149	42.7 (40.0 to 48.5)	402	54.4 (50.9 to 58.0)
	Women	345	86.6 (83.4 to 89.8)	528	56.8 (53.6 to 60.2)	158	57.3 (51.5 to 63.0)	311	45.6 (42.0 to 49.1)
<b>Age, years</b>	20-39	46	36.5 (32.0 to 41.1)	60	23.7 (20.9 to 26.6)	21	25.1 (20.0 to 30.1)	88	39.1 (35.7 to 42.6)
	40-59	259	45.1 (40.4 to 49.8)	441	38.2 (35.0 to 41.5)	120	31.4 (26.0 to 36.8)	407	39.6 (36.2 to 43.1)
	60-79	89	15.4 (12.0 to 18.8)	399	34.6 (31.4 to 37.8)	142	37.2 (31.5 to 42.8)	196	19.1 (16.3 to 21.9)
	80-99	17	2.9 (1.3 to 4.5)	40	3.5 (2.2 to 4.7)	24	6.3 (3.4 to 9.1)	22	2.1 (1.1 to 3.2)
<b>Educational level</b>	Low	120	25.5 (21.4 to 29.7)	329	34.2 (31.0 to 37.4)	93	27.3 (22.0 to 32.6)	186	22.2 (19.2 to 25.2)
	Medium	152	40.5 (35.8 to 45.2)	381	42.7 (39.3 to 46.0)	133	49.9 (43.8 to 55.8)	290	42.6 (39.1 to 46.2)
	High	132	34.0 (29.5 to 38.5)	202	23.2 (20.3 to 26.0)	70	22.9 (17.9 to 27.9)	225	35.2 (31.8 to 38.6)
<b>Income level</b>	Low	86	26.1 (21.9 to 30.2)	261	28.2 (25.2 to 31.2)	87	32.1 (26.7 to 37.6)	148	26.2 (23.1 to 29.4)
	Medium	226	53.6 (48.9 to 58.3)	480	52.4 (49.1 to 55.8)	152	47.3 (41.4 to 53.1)	357	49.7 (46.1 to 53.3)
	High	99	20.3 (16.5 to 24.1)	199	19.4 (16.8 to 22.1)	68	20.6 (15.9 to 25.3)	208	24.1 (21.0 to 27.1)
<b>Labour market affiliation</b>	Working	283	76.0 (72.0 to 80.1)	481	60.0 (56.7 to 63.3)	157	60.6 (54.8 to 66.3)	472	74.6 (71.4 to 77.7)
	Pensioners	69	12.2 (9.0 to 15.3)	289	25.7 (22.8 to 28.7)	119	31.6 (26.1 to 37.0)	137	13.7 (11.3 to 16.2)
	Out of workforce	49	11.8 (8.7 to 14.8)	142	14.2 (11.9 to 16.6)	26	7.8 (4.7 to 11.0)	88	11.7 (9.4 to 14.0)
<b>Cohabitation status</b>	Single	121	30.3 (26.0 to 34.6)	302	32.7 (29.5 to 35.8)	102	37.9 (32.2 to 43.6)	190	25.8 (22.7 to 28.9)
	Cohabitant / married	290	69.7 (65.4 to 74.0)	638	67.3 (64.2 to 70.4)	205	62.1 (56.4 to 67.8)	523	74.2 (71.1 to 77.3)
<b>Cancer diagnosis</b>	No	331	85.5 (82.1 to 88.8)	842	91.5 (89.6 to 93.4)	257	85.0 (80.9 to 89.2)	632	91.1 (89.0 to 93.1)
	Yes	80	14.5 (11.2 to 17.9)	98	8.5 (6.6 to 10.4)	50	15.0 (10.8 to 19.1)	81	8.9 (6.9 to 11.0)

participants reported having experienced one or more cancer alarm symptoms within the preceding 12 months.

Women, subjects out of the workforce, and subjects with a cancer diagnosis had statistically significantly higher odds of reporting one or more cancer alarm symptoms. Subjects with older age and subjects living with a partner had statistically significantly lower odds of reporting one or more cancer alarm symptoms. When analysing each cancer alarm symptom separately, most tendencies persisted.

#### Strengths and limitations

Because no validated measure suited our purposes, the use of an ad hoc developed questionnaire was necessary. Although a validated measure is preferable, using ad hoc, but relevant items meant that we could limit the number of items, thus, we believe, improving the response rate. Our symptom prevalences may be underestimated due to recall bias, since symptoms turning out to be harmless may probably soon be forgotten. However, we found no indication that this phenomenon was pertinent to socioeconomic status

and therefore it is unlikely to have influenced our socioeconomic analyses.

The results in this paper reflect self-report and as we did not perform any clinical examinations we cannot determine the appropriateness of reporting symptoms.

Selection bias was reduced by randomly selecting participants by means of the Danish Civil Registration System. The large sample ensured a high statistical precision of our estimates with narrow confidence intervals, supported by the high participation rate.

Late responders had essentially the same prevalence of symptom reporting as immediate responders. Therefore we believe that non-responders can reasonably be expected to have a similar prevalence as well [3].

#### Generalisability

Our sample is fairly representative of the Danish population according to the distribution of sex and socioeconomic factors. We calculated weighted prevalence estimates according to the Danish population. Further, as associations between health and socioeconomic status seem to be rather universal [9], it is reasonable to



**Table 4 Unadjusted and adjusted odds ratios of reporting a specific cancer symptom within the preceding 12 months by participant characteristics**

	Felt a lump in the breast			Coughed for more than six weeks			Seen blood in urine			Seen blood in stool						
	Crude	95% CI	Adjusted*	Crude	95% CI	Adjusted*	Crude	95% CI	Adjusted*	Crude	95% CI	Adjusted*				
<b>Sex</b>	1		1	1		1	1		1	1		1				
male																
Female	<b>4.90</b>	3.76 to 6.39	<b>4.63</b>	3.54 to 6.04	<b>1.17</b>	1.02 to 1.33	<b>1.17</b>	1.02 to 1.34	0.96	0.76 to 1.20	0.93	0.74 to 1.17	<b>0.68</b>	0.59 to 0.80	<b>0.66</b>	0.57 to 0.77
<b>Age, years</b>	1		1		1		1		1		1		1		1	
20-39																
40-59	0.97	0.70 to 1.34	0.91	0.66 to 1.26	1.29	0.98 to 1.70	1.28	0.97 to 1.69	0.99	0.62 to 1.57	0.95	0.59 to 1.51	<b>0.78</b>	0.62 to 1.00	<b>0.76</b>	0.60 to 0.96
60-79	<b>0.39</b>	0.27 to 0.56	<b>0.34</b>	0.23 to 0.49	<b>1.40</b>	1.06 to 1.85	<b>1.39</b>	1.05 to 1.84	1.41	0.88 to 2.23	1.29	0.81 to 2.05	<b>0.44</b>	0.34 to 0.57	<b>0.40</b>	0.31 to 0.53
80-99	<b>0.44</b>	0.25 to 0.77	<b>0.33</b>	0.18 to 0.58	0.80	0.53 to 1.20	0.77	0.51 to 1.17	1.40	0.77 to 2.52	1.22	0.67 to 2.22	<b>0.29</b>	0.18 to 0.46	<b>0.26</b>	0.16 to 0.42
<b>Educational level</b>	1		1		1		1		1		1		1		1	
Low																
Medium	0.94	0.73 to 1.19	0.88	0.69 to 1.14	<b>0.85</b>	0.73 to 0.99	0.86	0.73 to 1.00	1.06	0.81 to 1.39	1.14	0.87 to 1.50	1.16	0.96 to 1.40	0.96	0.79 to 1.16
High	1.26	0.98 to 1.62	1.06	0.82 to 1.38	<b>0.68</b>	0.57 to 0.82	<b>0.69</b>	0.57 to 0.83	0.85	0.62 to 1.17	0.94	0.68 to 1.30	<b>1.40</b>	1.15 to 1.71	1.14	0.93 to 1.40
<b>Income level</b>	1		1		1		1		1		1		1		1	
Low																
Medium	<b>1.32</b>	1.03 to 1.70	1.05	0.80 to 1.38	0.91	0.78 to 1.07	0.86	0.73 to 1.02	0.87	0.67 to 1.14	0.96	0.73 to 1.28	<b>1.22</b>	1.00 to 1.48	0.95	0.77 to 1.69
High	1.16	0.86 to 1.55	1.28	0.92 to 1.78	<b>0.75</b>	0.62 to 0.91	<b>0.71</b>	0.57 to 0.88	0.78	0.56 to 1.07	0.89	0.62 to 1.28	<b>1.43</b>	1.15 to 1.79	0.93	0.73 to 1.19
<b>Labour market affiliation</b>	1		1		1		1		1		1		1		1	
Working																
Pensioners	<b>0.43</b>	0.33 to 0.56	0.66	0.42 to 1.03	1.09	0.94 to 1.27	1.06	0.85 to 1.33	<b>1.38</b>	1.08 to 1.76	1.05	0.72 to 1.52	<b>0.51</b>	0.42 to 0.62	0.80	0.60 to 1.08
Out of workforce	1.26	0.93 to 1.72	1.10	0.80 to 1.52	<b>2.30</b>	1.89 to 2.81	<b>2.10</b>	1.72 to 2.57	1.02	0.79 to 1.83	1.30	0.88 to 1.93	<b>1.38</b>	1.09 to 1.75	<b>1.51</b>	1.18 to 1.91
<b>Cohabit status</b>	1		1		1		1		1		1		1		1	
Single																
Cohabitant / married	0.90	0.72 to 1.11	0.91	0.72 to 1.14	<b>0.78</b>	0.68 to 0.90	<b>0.74</b>	0.64 to 0.86	<b>0.75</b>	0.59 to 0.95	<b>0.77</b>	0.60 to 0.98	1.04	0.87 to 1.23	0.93	0.78 to 1.11
<b>Cancer diagnosis</b>	1		1		1		1		1		1		1		1	
No																
Yes	<b>2.53</b>	1.97 to 3.25	<b>2.73</b>	2.14 to 3.55	1.19	0.95 to 1.47	1.17	0.94 to 1.46	<b>2.00</b>	1.47 to 2.72	<b>1.90</b>	1.39 to 2.60	<b>1.31</b>	1.03 to 1.66	<b>1.68</b>	1.31 to 2.14

(\*adjusted for sex, age and having a cancer diagnosis.) Highlighted figures are statistically significant (p < 0.05).

assume that that our results are generalisable to other Western countries.

#### Comparison with existing literature

A Scottish community-based study from 1978 analysed symptom reporting and socioeconomic factors [27]. Our results cannot be compared directly, as the studies included different symptoms and had different time intervals for symptom reporting. We found different prevalence estimates for symptom reporting, which could be explained by the different time frames for symptom reporting and by the fact that children were not included in our study. For instance, we found a lower prevalence estimate for the total group with regard to coughing (6.5 vs. 15%). One reason could be that the Scottish study asked for coughing within a 2-week period only, thus including more people suffering from a simple cold.

Other studies also found that female sex were associated with more symptoms reporting [28-30]. One possible explanation could be that women have a higher bodily awareness, they pay more attention to bodily sensations, and as a consequence report symptoms more often than men [31]. Another explanation could be that women may have higher morbidity and therefore may be more familiar with recognising symptoms.

Subjects with older age had statistically significantly lower odds of reporting one or more cancer alarm symptom. The same result was found in other studies [30,32] which could be due to the interpretation of symptoms by elderly people. Elderly people, who are more likely to experience symptoms qua increasing morbidity, may not consider the symptoms to be serious, they normalise it, and therefore not necessary to report. For instance Hickey (1988) reported that elderly people have more symptoms than younger people, but when they consult doctors they tend to report fewer symptoms [33].

In line with McAteer et al. we found that those out of the workforce had significantly higher odds of reporting one or more symptoms [30]. This result may reflect a higher morbidity among this group of people [9].

A Scottish study has shown that living alone was associated with increased time before lung cancer patients consulted their doctor about symptoms [34]. Our hypothesis was that people living with a partner would report symptoms more often than singles [30], simply because they can discuss the symptom with their partner, and thereby remember the symptom. We found that subjects living alone had higher odds of reporting cancer alarm symptoms than subjects living with a partner. This pinpoints the issue that symptom registration may be a mixture of actual symptom experience and symptom interpretation.

Studies have shown that having a close experience with a cancer diagnosis is associated with greater awareness of cancer symptoms [25,26]. Likewise, we found that subjects with a cancer diagnosis had statistically significantly higher odds of reporting symptoms, which could be explained by a higher level of morbidity and by greater awareness of cancer symptoms in this group of people.

Women and those with a cancer diagnosis had statistically significantly higher odds of reporting having felt a lump in the breast. To a large extent this may be due to the fact that lumps in the breast being predominantly a gender-specific condition and because people with a cancer diagnosis pay more attention to bodily sensations. Furthermore the cancer diagnosis reported could be breast cancer, thereby giving the higher odds. Age above 60 years was statistically significantly associated with lower odds of reporting a lump in the breast. This findings are consistent with others studies indication that older people notice or report fewer symptoms [30,33]. Another explanation is that benign conditions in the breast such as fibro adenomas are found more often among younger women.

We found that subjects with high educational and income level had statistically significantly lower odds of reporting coughing for more than 6 weeks in adjusted analyses. Furthermore, we found that those out of the workforce had statistically significantly higher odds of reporting coughing. This might be explained by differences in causal factors such as tobacco smoking [35]. Future studies on symptom reporting in a population should include data on life-style parameters like tobacco use, alcohol consumption and diet.

Those living with a partner had statistically lower odds of reporting having seen blood in the urine. This could be due to the fact that people had discussed the symptom with their partner, interpreted it to be harmless, and then have forgotten about it.

Those out of the workforce and those with a cancer diagnosis had statistically higher odds of reporting having seen blood in the stool. It is well known that in general persons out of the workforce have a higher level of morbidity [36] and consequently this phenomenon may also contribute to more symptoms. Further, having a cancer diagnosis will make you more concerned about symptoms and bodily sensations. Women and subjects aged 40+ had statistically lower odds of reporting having seen blood in the stool. We have no qualified explanation as to why women report blood on the stools less often but we assume that the lower odds for older people are seen because they accept having different symptoms frequently – and therefore report symptoms less often.

### Implications of the study

The finding that socioeconomic and demographic determinants are associated with reporting of cancer alarm symptoms in this population-based study may help healthcare systems target preventive campaigns. However, in order to tailor campaigns these should be preceded by studies on associations between cancer alarm symptoms and healthcare consulting behaviour. Future studies should also address the impact of other factors on symptom reporting such as comorbidity, previous diseases, cancer in the respondent's network etc.

### Conclusions

Socioeconomic and demographic determinants are associated with reporting of common cancer alarm symptoms.

### Ethical approval

According to the Scientific Ethics Committee for the County of Funen, the Biomedical Research Ethics Committee System Act does not apply to this project. The study was approved by the Danish Data Protection Agency.

### Competing interests

The authors declare that they have no competing interests.

### Authors' contributions

BLH and HS had the original idea for the overall study. The plan of analysis for this sub-study was developed by RPS in collaboration with MSP, PVL, JS, and DEJ, who all participated in the extraction of data and interpretation of results. RPS drafted the manuscript and conducted all statistical analyses under the supervision of MSP, PVL, JS, and DEJ. All authors contributed to the final version. RPS is the guarantor.

### Data

All authors, external and internal, had full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

### Data sharing

No additional data available.

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## Associations between health care seeking and socioeconomic and demographic determinants among people reporting alarm symptoms of cancer: a population-based cross-sectional study

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**Background.** Late diagnosis of cancer may partly be explained by the fact that some patients do not seek health care promptly when experiencing an alarm symptom. Socioeconomic and demographic differences exist concerning knowledge and awareness of cancer alarm symptoms in the general population and socioeconomic differences are found in cancer incidence and survival. We therefore hypothesise that socioeconomic and demographic differences in health care-seeking behaviour are present among people with alarm symptoms.

**Objectives.** To analyse associations between health care seeking and socioeconomic and demographic factors among people reporting cancer alarm symptoms.

**Methods.** A questionnaire survey comprising 20 000 people aged >20 from the Danish population. The questionnaire concerned alarm symptoms of common cancers and subsequent health care seeking. Data on socioeconomic factors were obtained from Statistics Denmark. Main outcomes: health care seeking and patient interval.

**Results.** A total of 26.1% of all subjects reported that they did not seek health care when having experienced an alarm symptom. Women—subjects aged >40, subjects living with a partner and subjects having a cancer diagnosis—were more likely to seek health care, whereas medium educational level was negatively associated with health care seeking. Further, women were more likely to seek health care within 1 month, whereas subjects out of the workforce were less likely to do so.

**Conclusions.** Approximately three out of four subjects sought health care when having experienced an alarm symptom but 50% waited for at least 1 month. Some demographic factors were found to be associated with health care-seeking behaviour and the patient interval, whereas no consistent associations were found with regard to socioeconomics.

**Keywords.** Cross-sectional survey, demographic factors, family practice, health care-seeking behaviour, signs and symptoms, socioeconomic factors.

### Introduction

Early symptoms of cancer are well described in the literature. Some early cancer symptoms are quite unspecific, while others are more characteristic and distinctive—so-called ‘alarm symptoms’. Alarm symptoms are features in the clinical presentation considered to predict serious, often malignant, diseases.<sup>1</sup>

Cancer alarm symptoms are common in the general population<sup>2</sup> and socioeconomic and demographic

differences are present among people reporting alarm symptoms.<sup>3</sup> Previous studies have shown inequality in the general population concerning cancer knowledge, cancer awareness and awareness of lifestyle risk factors related to cancer.<sup>4,5</sup>

In comparison with many other countries, Denmark has poor cancer survival rates.<sup>6</sup> One reason for this may be late diagnosis, although considerable efforts have been put into facilitating more effective diagnostic pathways in order to reduce the diagnostic delay.

Late diagnosis may to some extent be explained by patients not seeking medical help immediately after experiencing an alarm symptom. This phenomenon is described as the 'patient delay' or 'patient interval' and accounts for the time from the first symptom is noticed by the patient until he/she seeks medical advice.<sup>7</sup> The patient interval accounts for a substantial part of cancer patients' pre-hospital time interval.<sup>8</sup> It is reasonable to assume that some cancers may be diagnosed at an earlier stage if medical help was sought immediately after noticing alarm symptoms. Hence, it is important to obtain a deeper insight into the patients' decisions in relation to health care seeking.

The Danish health care system is tax financed, giving all Danish citizens free and equal access to the majority of health services. Still socioeconomic disparities persist among Danish cancer patients, both with respect to patient delay,<sup>9</sup> cancer incidence and survival.<sup>10</sup>

Our hypothesis is that socioeconomic and demographic differences in health care-seeking behaviour exist among people who have experienced an alarm symptom. The aim of this study was therefore, in a population-based cross-sectional design, to analyse associations between health care-seeking behaviour and socioeconomic and demographic factors among persons reporting cancer alarm symptoms.

## Methods

### Study design

A cross-sectional questionnaire survey based on a stratified sample of the general population was conducted in April 2007 in the former County of Funen, Denmark, comprising 9% of the Danish population. The population of Funen is generally regarded as being representative of Denmark, e.g. with respect to rural as well as urban patients.

### Sampling

The survey comprised 20000 people aged >20. The sample was randomly selected using the Danish Civil Registration System (CRS) stratified on gender, ensuring that half of the included were women and half of them men. We stratified the sample with respect to age, so that only 1000 subjects of each gender were under the age of 40 and the remaining subjects were at least 40 years. Further details are described elsewhere.<sup>2</sup>

### Data sources and measurements

The questionnaire concerned breast, lung, urinary tract and colorectal cancer. These four cancers were chosen because they are the most common cancer forms in Denmark and their symptoms are well described in the literature. For each cancer form there was a question on whether the person had had a specific symptom strongly related to that particular cancer, e.g. 'Felt a lump in

your breast?' 'Coughed for >6 weeks?' 'Seen blood in the urine?' or 'Seen blood in the stool?' within the preceding 12 months. When the study was conducted in 2007, the Danish National Board of Health had not yet implemented standardised referral guidelines for cancer, and no public health campaigns concerning cancer alarm symptoms were initiated in the years preceding the data collection. Today the four alarm symptoms are included in the current fast-track referral guidelines.<sup>11</sup> The subjects also had to report whether they had a cancer diagnosis. Subjects reporting at least one of the four symptoms were asked to choose one of their symptoms to be their 'personal symptom' and to answer two questions concerning health care seeking: 'Did you consult your GP regarding your personal symptom?' (Yes/No), 'How long did it take from noticing your personal symptom until consulting your GP?' ('<1 month', '1–3 months', '3–6 months', '>6 months' and 'did not consult my GP').

The two outcome variables were (i) health care seeking (Yes/No) and (ii) patient interval (dichotomised into: 'consulted within 1 month from noticing my personal symptom' and 'consulted after at least 1 month from noticing my personal symptom').

The questionnaire was based on a thorough literature search and clinical experience. A qualitative pilot test was conducted. Then a test–retest was carried out on 200 subjects aged >40 with the objective of analysing how the questionnaire was perceived by recipients and to assess its reproducibility.

All Danish citizens are registered with the Danish CRS with a unique personal identification number enabling accurate linkage between national registers. Socioeconomic and demographic factors were collected through data linkage to Statistics Denmark using the civil registration number. For each subject we obtained information on the following socioeconomic variables: education, income and labour market affiliation. Further, we obtained information on cohabitation status. Information was retrieved for the year preceding the questionnaire (2006). To level out annual variation in income, we calculated the average income for the preceding 5 years. Education was categorised according to the length of highest attained educational level: <10 years (primary and lower secondary school), 10–12 years (vocational education and upper secondary school) and >12 years (short-, medium- and long-term higher education). This categorisation was selected because it reflects the organisation of the Danish educational system. We obtained gross income comprising all income liable to general taxation. Income was categorised as low, middle and high income.<sup>12</sup> Labour market affiliations were categorised into three groups: (i) working, (ii) pensioners and (iii) out of the workforce. Cohabitation status was categorised into: cohabiting/married or single. Further details about the socioeconomic variables are given in Svendsen *et al.*<sup>3</sup>

### Statistical analysis

Prevalence estimates of health care-seeking behaviour concerning any alarm symptom and for each separate alarm symptom of cancer were calculated with 95% exact confidence intervals (CIs), based on binomial distributions. All prevalence estimates were weighted according to the general Danish population's age and gender distribution to account for the stratified sampling procedure.

Logistic regression models were used to calculate unadjusted and adjusted odds ratios (ORs) with 95% CIs for the associations between each covariate and health care seeking and patient interval, respectively. The covariates considered for each outcome were gender, age, education, income, labour market affiliation, cohabitation status<sup>12</sup> and having a cancer diagnosis. In adjusted analyses, adjustments were made for the *a priori* selected possible confounders: gender, age and having a cancer diagnosis.<sup>4,13</sup>

## Results

### Description of participants

Overall 13777 subjects returned the questionnaire, yielding a response rate of 69.4%, and 1930 subjects reported a personal alarm symptom (Fig. 1).

### Health care seeking (any symptom)

The mean age of respondents reporting a personal alarm symptom of cancer was 55 years, and 57% were women. A total of 26.1% of all subjects reported that they did not seek health care when having experienced an alarm symptom. The adjusted analyses showed that women—subjects aged >40, subjects living with a partner and subjects having a cancer diagnosis—were more likely to seek health care, whereas medium educational level was negatively associated with health care seeking (Table 1).

### Health care seeking (specific symptoms)

Analysing each symptom separately showed that women were more likely to seek health care when having felt a lump in the breast or having coughed for >6 weeks. Subjects aged 40–59 years were more likely to seek health care when having felt a lump in the breast, while subjects aged 40–59 or 60–79 years were more likely to seek health care than those aged 20–39 years when having seen blood in their stool. Medium educational level was negatively associated with health care seeking for subjects having seen blood in the urine. Those living with a partner were more likely to seek health care when having coughed for >6 weeks, and having a cancer diagnosis was positively associated with health care seeking when having seen blood in the stool (Table 2).

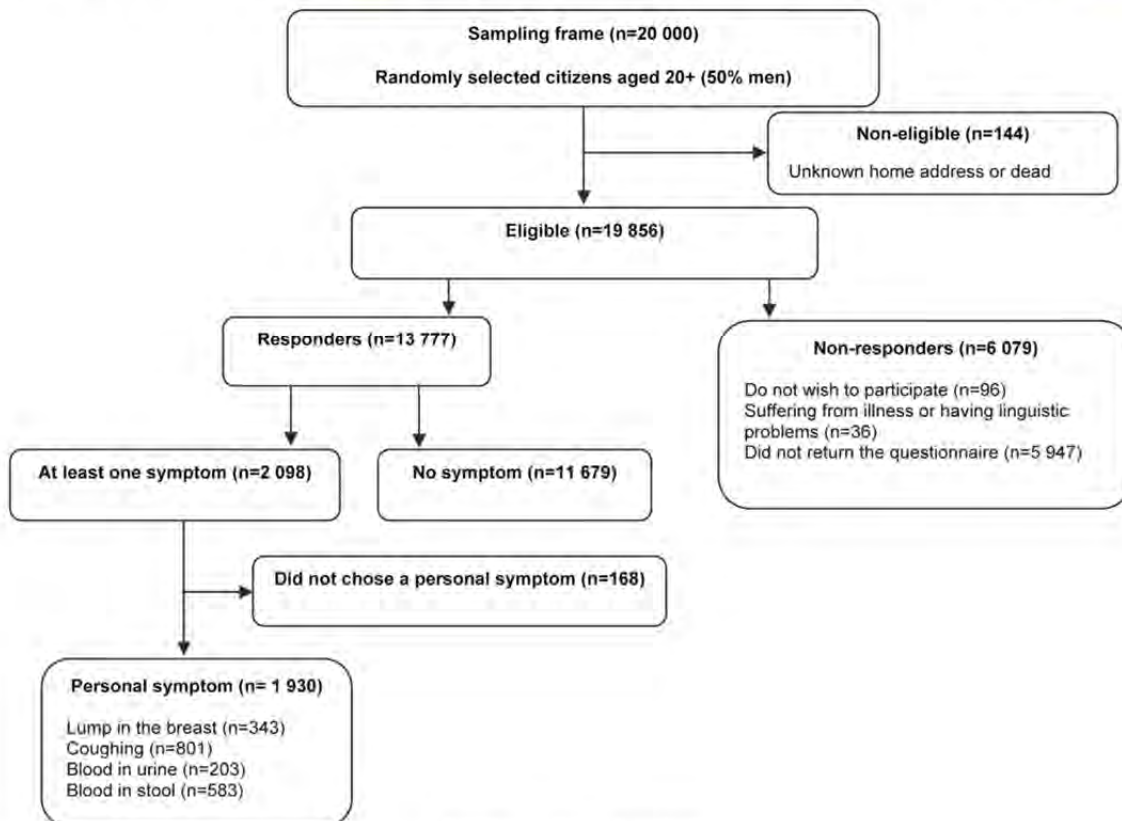


FIGURE 1 Study flowchart

TABLE 1 Descriptive participant characteristics together with weighted prevalences and crude and adjusted ORs for health care seeking (any symptom)

	Health care seeking						
	Total sample (n)	Yes (%)	Weighted prevalence (%)	Crude OR	95% CI	Adjusted OR*	95% CI
Total	1930	76.4	73.9				
Gender							
Men	837	69.5	67.7	1		1	
Women	1093	81.6	78.1	<b>1.94</b>	1.57–2.40	<b>1.94</b>	1.56–2.40
Age, years							
20–39	187	66.3	66.3	1		1	
40–59	1031	75.6	75.9	<b>1.57</b>	1.12–2.20	<b>1.58</b>	1.12–2.22
60–79	641	79.1	79.2	<b>1.92</b>	1.34–2.75	<b>1.93</b>	1.33–2.78
80–99	71	90.1	90.2	<b>4.65</b>	2.01–10.73	<b>3.64</b>	1.54–8.56
Educational level							
Low	561	79.7	78.3	1		1	
Medium	787	70.8	67.4	<b>0.62</b>	0.48–0.80	<b>0.72</b>	0.55–0.94
High	541	80.2	78.1	1.03	0.77–1.39	1.19	0.88–1.61
Income level							
Low	422	78.0	72.4	1		1	
Medium	1018	76.9	75.2	0.94	0.72–1.24	1.02	0.76–1.35
High	490	73.9	72.5	0.80	0.59–1.09	1.04	0.74–1.46
Labour market affiliation							
Working	1192	74.5	72.0	1		1	
Pensioners	459	82.4	82.4	<b>1.60</b>	1.22–2.10	1.19	0.79–1.80
Out of workforce	232	75.9	74.9	1.08	0.78–1.49	0.92	0.65–1.29
Cohabitation status							
Single	554	73.6	70.2	1		1	
Cohabiting/ married	1376	77.5	75.4	1.23	0.98–1.54	<b>1.40</b>	1.10–1.77
Cancer diagnosis							
No	1700	74.5	72.1	1		1	
Yes	230	90.0	90.6	<b>3.08</b>	1.97–4.80	<b>2.45</b>	1.55–3.85

The values given in bold are statistically significant ( $P < 0.05$ ).

\*Adjusted for gender, age and having a cancer diagnosis.

### Patient interval (any symptom)

Among those who sought health care, a total of 801 subjects (55.3%) waited for at least 1 month to seek health care. Women were more likely to seek health care within 1 month, whereas subjects out of the workforce were more likely to wait for at least 1 month (Table 3).

### Patient interval (specific symptoms)

Analysing the symptoms separately showed that women were more likely to seek health care within 1 month when having noticed a lump in the breast or having coughed for >6 weeks.

Subjects aged 40–59 years were more likely to seek health care within 1 month when having noticed a lump in the breast and subjects living with a partner were more likely to seek health care after at least 1 month when having seen blood in the stool (Table 4).

## Discussion

We analysed possible associations between socioeconomic and demographic factors and health care seeking among subjects reporting cancer alarm symptoms. The results reflect self-reporting of four predefined alarm symptoms of cancer and registration of how often the symptoms were presented to the GP. When examining all four symptoms together, we found that approximately three out of four subjects sought health care when noticing an alarm symptom. However, ~50% waited for at least 1 month.

Demographic factors such as female gender, increasing age, living with a partner and having a cancer diagnosis were positively associated with seeking health care. Among socioeconomic factors, only medium educational level was negatively associated with health care seeking. Women were more likely to seek health care within 1 month, whereas subjects out of the workforce were less likely to.



TABLE 2 Weighted prevalence estimates and crude and adjusted ORs of health care seeking (specific symptoms)

	Coughed for >6 weeks													
	Felt a lump in the breast					Health care seeking								
	<i>n</i>	Yes (%)	Weighted (%)	Crude OR	95% CI	Adjusted OR*	95% CI	<i>n</i>	Yes (%)	Weighted (%)	Crude OR	95% CI	Adjusted OR*	95% CI
Total	343	89.5	89.0				801	70.4	69.5					
Gender														
Male	49	77.6	83.0	1		1	355	63.9	63.9		1		1	
Female	294	91.5	85.9	<b>3.11</b>	1.42–6.94	<b>3.27</b>	446	75.6	73.6		<b>1.74</b>	1.28–2.37	<b>1.70</b>	1.25–2.32
Age, years														
20–39	42	76.2	76.2	1		1	54	64.8	64.8		1		1	
40–59	222	92.8	92.9	<b>4.02</b>	1.68–9.64	<b>4.05</b>	387	65.9	66.2		1.05	0.58–1.90	1.04	0.57–1.89
60–79	66	84.8	85.0	1.75	0.66–4.65	4.86	330	75.5	75.6		1.67	0.90–3.08	1.63	0.88–3.03
80–99	13	100	100.0	–	–	–	30	83.3	83.4		2.71	0.89–8.24	2.16	0.69–6.72
Educational level														
Low	94	91.5	87.3	1		1	275	71.6	72.5		1		1	
Medium	125	84.0	76.8	0.49	0.21–1.16	0.55	321	66.0	64.3		0.77	0.54–1.09	0.83	0.58–1.419
High	118	93.2	93.5	1.28	0.46–3.55	1.27	184	75.0	72.1		1.19	0.78–1.82	1.32	0.85–2.03
Income level														
Low	63	82.5	73.9	1		1	206	72.3	71.8		1		1	
Medium	195	91.8	88.9	<b>2.37</b>	1.03–5.41	1.83	420	69.8	68.8		0.88	0.61–1.28	1.01	0.69–1.49
High	85	89.4	91.0	1.79	0.69–4.61	1.32	175	69.7	68.4		0.88	0.56–1.37	1.25	0.78–2.01
Labour market affiliation														
Working	247	91.5	87.0	1		1	429	66.7	66.5		1		1	
Pensioners	50	88.0	88.1	0.69	0.26–1.79	0.37	231	76.6	76.7		<b>1.64</b>	1.14–2.36	1.04	0.60–1.80
Out of workforce	38	81.6	74.8	0.41	0.16–1.05	0.41	120	74.2	74.3		1.44	0.91–2.26	1.27	0.79–2.02
Cohabitation status														
Single	99	85.9	81.1	1		1	247	66.0	65.2		1		1	
Cohabiting/ married	244	91.0	87.5	1.66	0.81–3.40	1.64	554	72.4	74.4		1.35	0.98–1.86	<b>1.44</b>	1.04–2.01
Cancer diagnosis														
No	274	88.3	84.0	1		1	727	69.1	68.3		1		1	
Yes	69	94.2	94.5	2.15	0.73–6.30	1.92	74	83.8	94.5		<b>2.32</b>	1.22–4.38	1.86	0.97–3.58

TABLE 2 Continued

	Seen blood in urine						Seen blood in stool					
	Health care seeking						Health care seeking					
	n	Yes (%)	Weighted (%)	Crude OR	95% CI	Adjusted OR* 95% CI	n	Yes (%)	Weighted (%)	Crude OR	95% CI	Adjusted OR* 95% CI
Total	203	91.1	85.6				583	71.7	67.5			
Gender												
Male	92	88.0	84.5	1		1	341	69.2	65.8	1		1
Female	111	93.7	91.4	2.02	0.75–5.43	2.82	242	75.2	69.8	1.35	0.93–1.96	1.32
Age, years												
20–39	16	81.3	81.2	1		1	75	58.7	58.7	1		1
40–59	81	92.6	92.7	2.88	0.64–13.00	4.24	341	71.3	71.4	<b>1.75</b>	1.04–2.93	<b>1.70</b>
60–79	92	91.3	91.4	2.42	0.57–10.33	4.51	153	77.1	77.2	<b>2.38</b>	1.31–4.30	<b>2.13</b>
80–99	14	92.9	93.1	3.00	0.27–32.75	5.38	14	92.9	92.6	<b>9.16</b>	1.14–73.70	5.87
Educational level												
Low	59	96.6	97.0	1		1	133	80.5	75.4	1		1
Medium	85	83.5	79.6	<b>0.18</b>	0.39–81.53	<b>0.20</b>	256	66.0	61.8	<b>0.47</b>	0.29–0.78	0.60
High	52	96.2	96.7	0.88	0.12–6.46	0.86	187	72.7	70.0	0.65	0.38–1.11	0.83
Income level												
Low	51	94.1	87.2	1		1	102	78.4	66.6	1		1
Medium	106	91.5	93.3	0.67	0.17–2.60	0.53	297	72.1	69.0	0.71	0.42–1.21	0.67
High	45	87.0	80.4	0.42	0.10–1.77	0.33	184	67.4	65.6	<b>0.57</b>	0.32–1.00	0.56
Labour market affiliation												
Working	110	90.9	87.3	1		1	406	68.0	64.3	1		1
Pensioners	77	92.2	92.3	1.18	0.41–3.40	1.33	101	85.1	85.0	<b>2.70</b>	1.50–4.86	2.23
Out of workforce	11	81.8	86.6	0.45	0.09–2.38	0.31	63	74.6	73.9	1.38	0.76–2.53	1.24
Cohabitation status												
Single	59	91.5	87.2	1		1	149	71.1	62.6	1		1
Cohabiting/ married	144	91.0	90.0	0.93	0.32–2.74	1.04	434	71.9	69.3	1.04	0.69–1.57	1.15
Cancer diagnosis												
No	175	90.9	88.3	1		1	524	69.5	65.5	1		1
Yes	28	92.9	93.5	1.31	0.28–6.03	1.12	59	91.5	92.4	<b>4.75</b>	1.86–12.09	<b>3.83</b>

The values given in bold are statistically significant ( $P < 0.05$ ).

\*Adjusted for gender, age and having a cancer diagnosis.

TABLE 3 Weighted prevalences and crude and adjusted ORs for the patient interval  $\geq 1$  month (any symptom)

	Patient interval $\geq 1$ month						
	Total sample (n)	Patient interval $\geq 1$ month (%)	Weighted prevalence (%)	Crude OR	95% CI	Adjusted OR*	95% CI
Total	1448	55.3	54.8				
Gender							
Men	574	63.9	60.8	1		1	
Women	874	50.3	51.2	<b>0.60</b>	0.48–0.74	<b>0.60</b>	0.48–0.74
Age, years							
20–39	125	53.6	53.6	1		1	
40–59	767	56.3	56.1	1.12	0.76–1.63	1.11	0.76–1.63
60–79	496	55.4	55.5	1.09	0.73–1.61	1.04	0.69–1.55
80–99	60	43.3	43.2	0.66	0.36–1.23	0.68	0.36–1.29
Educational level							
Low	438	56.6	55.8	1		1	
Medium	548	55.3	53.8	0.95	0.74–1.22	0.90	0.69–1.16
High	427	54.3	55.6	0.91	0.70–1.19	0.88	0.67–1.16
Income level							
Low	324	54.0	53.4	1		1	
Medium	771	55.0	55.4	1.04	0.80–1.35	0.98	0.74–1.28
High	353	57.2	54.7	1.14	0.84–1.54	0.93	0.67–1.29
Labour market affiliation							
Working	877	55.1	53.4	1		1	
Pensioners	365	52.9	52.8	0.92	0.72–1.17	0.98	0.66–1.44
Out of workforce	174	63.2	65.4	<b>1.40</b>	1.00–1.96	<b>1.46</b>	1.04–2.06
Cohabitation status							
Single	394	52.0	51.0	1		1	
Cohabiting/ married	1054	56.5	56.2	1.20	0.95–1.51	1.09	0.86–1.39
Cancer diagnosis							
No	1248	56.0	55.7	1		1	
Yes	200	51.0	47.4	0.82	0.61–1.10	0.91	0.67–1.25

The values given in bold are statistically significant ( $P < 0.05$ ).

\*Adjusted for gender, age and having a cancer diagnosis.

### Strengths and limitations

Selection bias was reduced by randomly selecting participants by means of the Danish CRS. No differences between respondents and non-respondents were observed in terms of age, but women were slightly more represented among respondents. Late respondents had similar prevalences of symptom reporting,<sup>2</sup> health care seeking and patient interval as immediate respondents.

The symptom prevalences may be underestimated due to recall bias, since symptoms turning out to be harmless may soon be forgotten. However, this phenomenon is probably not pertinent to a specific socioeconomic status and therefore unlikely to have influenced the estimated effects of socioeconomic factors. The subjects included in this study were to choose only one symptom to be their personal symptom, even if they had noticed more than one. They may have chosen the symptom they experienced as the most serious, i.e. the one they sought health care for, if any, which could lead to overestimation of health care seeking. However,

since only few reported more than one symptom,<sup>2</sup> the possible overestimation will be of minor magnitude.

### Generalisability

Smith *et al.*<sup>14</sup> found that health care-seeking experiences among cancer patients including several cancer forms were very similar across cancer forms. As we included alarm symptoms of four common cancer types exhibiting easily detectable symptoms, e.g. a lump or bleeding, we find it reasonable to assume that our results to a large degree are generalisable to other groups of cancers with similar onset of symptoms or symptoms that the public is aware of. The associations between socioeconomics and health care seeking can probably be generalised to other western countries with similar health care systems.

### Comparison with existing literature

As expected, we found that women were more likely to seek health care than men when having experienced

TABLE 4 Descriptive participant characteristics together with weighted prevalences and crude and adjusted ORs for the patient interval  $\geq 1$  month (each symptom)

	Coughed for >6 weeks													
	Felt a lump in the breast					Patient interval $\geq 1$ month								
	<i>n</i>	Yes (%)	Weighted (%)	Crude OR	95% CI	Adjusted OR*	95% CI	<i>n</i>	Yes (%)	Weighted (%)	Crude OR	95% CI	Adjusted OR*	95% CI
Total	303	39.9	44.2	1		1		559	71.4	69.2	1		1	
Gender														
Male	36	72.2	65.5	1		1		225	79.1	73.8	1		1	
Female	267	35.6	41.4	<b>0.21</b>	0.10–0.46	<b>0.22</b>	0.10–0.48	334	66.2	66.3	<b>0.52</b>	0.35–0.77	<b>0.51</b>	0.35–0.76
Age, years														
20–39	32	56.3	56.2	1		1		36	61.1	61.1	1		1	
40–59	204	35.3	35.0	<b>0.43</b>	0.20–0.90	<b>0.41</b>	0.19–0.90	254	74.4	74.2	1.85	0.89–3.83	1.95	0.93–4.08
60–79	54	50.0	49.8	0.78	0.32–1.87	0.60	0.24–1.53	246	70.3	70.0	1.51	0.73–3.11	1.55	0.74–3.23
80–99	13	30.8	30.6	0.35	0.09–1.36	0.26	0.06–1.11	23	65.2	65.1	1.19	0.40–3.54	1.41	0.45–4.40
Educational level														
Low	85	49.1	45.7	1		1		193	70.5	67.4	1		1	
Medium	103	36.9	45.4	0.66	0.37–1.18	0.63	0.34–1.19	209	71.8	71.1	1.07	0.69–1.64	1.02	0.66–1.59
High	109	37.6	42.6	0.68	0.38–1.21	0.69	0.37–1.30	140	71.4	68.9	1.05	0.65–1.69	1.01	0.62–1.64
Income level														
Low	52	51.9	52.9	1		1		144	66.0	63.8	1		1	
Medium	175	37.7	43.0	0.56	0.30–1.05	0.63	0.31–1.27	295	72.5	71.7	1.36	0.89–2.09	1.32	0.85–2.06
High	76	36.8	38.6	0.54	0.26–1.11	0.55	0.24–1.24	120	75.0	69.4	1.54	0.90–2.65	1.21	0.69–2.14
Labour market affiliation														
Working	224	38.4	44.6	1		1		286	72.0	67.6	1		1	
Pensioners	43	51.2	50.8	1.68	0.87–3.24	2.46	0.72–8.42	172	69.2	69.0	0.87	0.58–1.32	0.96	0.52–1.76
Out of workforce	30	40.0	37.7	1.07	0.49–2.33	0.91	0.39–2.09	89	74.2	76.7	1.11	0.65–1.91	1.13	0.65–1.98
Cohabitation status														
Single	82	37.8	44.3	1		1		163	70.6	67.8	1		1	
Cohabiting/ married	221	40.7	44.1	1.13	0.67–1.90	1.18	0.68–2.06	396	71.7	69.9	1.06	0.71–1.58	0.98	0.65–1.48
Cancer diagnosis														
No	239	38.9	44.8	1		1		497	72.0	69.5	1		1	
Yes	64	43.8	41.2	1.22	0.70–2.13	1.34	0.72–2.49	62	66.1	66.0	0.76	0.43–1.33	0.83	0.46–1.49

TABLE 4 Continued

	Seen blood in urine										Seen blood in stool									
	Patient interval $\geq 1$ month										Patient interval $\geq 1$ month									
	#	Yes (%)	Weighted %	Crude OR	95% CI	Adjusted OR*	95% CI	n	Yes (%)	Weighted %	Crude OR	95% CI	Adjusted OR*	95% CI						
Total	175	25.1	23.0				411	57.7	57.4											
Gender																				
Male	78	29.5	29.5	1		1	235	57.0	56.2	1		1								
Female	97	21.6	19.6	1.51	0.76–3.00	0.62	176	58.5	59.9	0.94	0.63–1.40	1.07	0.72–1.60							
Age, years																				
20–39	13	15.4	15.4	1		1	44	56.8	56.8	1		1								
40–59	70	28.6	28.6	0.45	0.09–2.24	1.90	239	63.2	63.2	0.77	0.40–1.47	1.32	0.68–2.53							
60–79	81	23.5	23.2	0.59	0.12–2.91	0.86	115	49.6	49.5	1.34	0.67–2.70	0.76	0.38–1.55							
80–99	11	27.3	26.9	0.48	0.07–3.61	0.64	13	30.8	30.5	2.96	0.79–11.1	0.37	0.09–1.41							
Educational level																				
Low	53	30.2	26.5	1		1	107	52.3	56.6	1		1								
Medium	69	21.7	19.6	1.56	0.69–3.53	0.65	167	59.9	53.9	0.74	0.45–1.20	1.24	0.75–2.05							
High	47	25.5	27.0	1.26	0.52–3.04	0.82	131	60.3	62.6	0.72	0.43–1.21	1.21	0.71–2.08							
Income level																				
Low	48	25.0	22.3	1		1	80	51.3	56.1	1		1								
Medium	90	23.3	21.3	1.10	0.48–2.48	0.80	211	58.3	57.8	0.75	0.45–1.26	1.12	0.64–1.93							
High	37	29.7	29.5	0.79	0.30–2.06	0.90	120	60.8	58.0	0.68	0.38–1.20	1.13	0.59–2.17							
Labour market affiliation																				
Working	95	23.2	18.4	1		1	272	62.1	58.5	1		1								
Pensioners	66	27.3	27.0	0.80	0.39–1.65	2.03	84	40.5	40.5	<b>2.41</b>	1.46–3.98	0.45	0.20–1.01							
Out of workforce	9	33.2	53.3	0.60	0.14–2.61	2.22	46	63.0	68.2	0.96	0.50–1.84	0.97	0.53–1.99							
Cohabitation status																				
Single	49	24.5	24.6	1		1	100	47.0	46.3	1		1								
Cohabiting/ married	126	25.4	22.1	0.95	0.44–2.05	0.96	311	61.1	60.8	<b>0.56</b>	0.36–0.89	<b>1.69</b>	1.36–2.71							
Cancer diagnosis																				
No	153	24.2	22.4	1		1	359	58.8	59.0	1		1								
Yes	22	31.8	27.1	0.68	0.26–1.80	1.72	52	50.0	43.7	1.43	0.80–2.55	0.86	0.46–1.59							

The values given in bold are statistically significant ( $P < 0.05$ ).

\*Adjusted for gender, age and having a cancer diagnosis.

an alarm symptom of cancer. This may partly be due to the fact that one of the symptoms in our study was predominantly gender specific (lump in the breast) and that the majority sought health care for this particular symptom. When analysing the symptoms separately we found that women sought health care more often than men only for feeling a lump in the breast and for coughing. Feeling a lump in the breast was the symptom with the highest rate of health care seeking. This could be explained by the fact that a lump in the breast is a well-known cancer-related symptom.<sup>15</sup>

In the present study, a total of 67% sought health care when having noticed blood in the stool. Crosland and Jones<sup>16</sup> found that only 41% sought health care after having noticed rectal bleeding. In their study a distinction was made between seeing blood on the toilet paper and blood mixed with stools. This may explain some of the difference from our results.

Increasing age was associated with health care seeking among people reporting having seen blood in the stool, and similar results were found by Crosland and Jones. The effect of age may partly be explained by the association between higher knowledge of cancer symptoms and age.<sup>17</sup> Subjects living with a partner were more likely to seek health care than singles. The same tendency was found when analysing the symptoms separately, although it was not statistically significant. This might reflect an increased knowledge of cancer symptoms among married couples.<sup>17</sup> The possibility of discussing a symptom with a partner may also encourage health care seeking. We have not been able to identify other studies on the association between seeking health care for cancer symptoms and marital status.

When examining the four symptoms together, the only association found between health care seeking and socioeconomic factors was that subjects with a medium educational level were less likely to seek health care compared with subjects with a low educational level. We have not identified other studies on socioeconomic factors and health care seeking among the general population reporting alarm symptoms. Van Osch *et al.*<sup>18</sup> in a hypothetical setting studied help-seeking for different symptoms, ranging from mild, self-limiting symptoms to alarm symptoms. They found that educational level was negatively related to medical help-seeking among the general population,<sup>18</sup> which could be explained by an overall higher usage of primary health care services in lower educated people.<sup>19</sup> In our study we did not find that subjects with a high educational level had a different health care-seeking behaviour compared with subjects with a low educational level. One explanation for this difference may be that the analyses of Van Osch *et al.*<sup>18</sup> assumed a linear effect of education and thus treated education as a continuous variable, while we treat education as a categorical variable. Our results suggest that the effect of education may be non-linear.

Finally, subjects with a cancer diagnosis were more likely to seek health care. These people may have an increased fear of a relapse or of a new cancer and therefore they have an increased attention to bodily sensations and symptoms. Or maybe the cancer diagnosis in question was a diagnosis they got after presenting their 'personal symptom' to their GP.

Other studies have shown that women have higher knowledge of cancer symptoms, pay more attention to symptoms and are more likely to seek timely health care than men.<sup>18</sup> Likewise, we found that women were more likely to seek health care within 1 month than men. In line with a previous study,<sup>20</sup> ~44% of the subjects (who sought health care) waited for at least 1 month, when having noticed a lump in the breast.

In a small study among lung cancer patients, Corner *et al.*<sup>21</sup> found that all subjects waited for 3 months or longer to seek health care. They included several symptoms of lung cancer such as shortness of breath, persistent cough and tiredness. Apparently, the patients attributed their symptoms to everyday causes, ageing and comorbidity, rather than interpreting them as indicative of ill health.<sup>21</sup> In the present study, the majority of subjects coughing for >6 weeks waited for >1 month before seeking health care. This could indicate that persistent coughing may not be interpreted as an alarm symptom in the general population.

There have been conflicting findings concerning age and patient interval. Older age is found to be associated with long patient intervals among breast cancer patients.<sup>22</sup> Others found no association.<sup>20</sup> We found that subjects aged 40–59 years were more likely to seek health care within 1 month when having felt a lump in the breast compared with the younger age group. One reason could be that people in this age group are more aware of the higher cancer risk involved in feeling a lump in the breast.

We also tested hypotheses on socioeconomic differences in patient interval among people with alarm symptoms. Surprisingly, no consistent patterns were found. Subjects out of the workforce were more likely to wait for at least 1 month before seeking health care when having noticed an alarm symptom. One explanation for the lack of pattern may be that people in Denmark have free and equal access to primary health care. Another explanation may be that not only physical sensations but also psychological, cultural and other aspects influence the interpretations of symptoms and the subsequent actions, including health care seeking.

## Conclusions

Approximately three out of four subjects sought health care when having noticed an alarm symptom but 50% waited for at least 1 month. Some demographic factors

were found to be associated with health care seeking and the patient interval, whereas no consistent associations were found with regard to socioeconomics.

### Implications

Our results suggest that campaigns encouraging people to seek health care promptly upon noticing a cancer alarm symptom should be tailored to specific gender and age groups, rather than to specific socioeconomic groups. Health care professionals should be aware of possible reasons for the patient interval in seeking health care and find new ways to address these barriers. To explore why some differences in patient intervals persist, future studies may focus on people's interpretation of symptoms, recognition of symptom seriousness and anxiety related to health care seeking.

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### Declaration

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Ethical approval: According to the Scientific Ethics Committee for the County of Funen, the Biomedical Research Ethics Committee System Act does not apply to this project. The study was approved by the Danish Data Protection Agency, journal number 212-41-1160.

Conflict of interest: none.

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## 12 Appendices

### Appendix 1 Questionnaire in English

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## Signs of cancer

**A study of signs of cancer  
in the Danish population**

### **Important:**

The questionnaire should be filled in within 1 week and returned in the enclosed postage paid envelope. Your answers will be treated strictly confidentially, and when the study is completed the questionnaire will be destroyed.



## How to fill in the questionnaire

Please read this before you start.

The questions in the questionnaire should be completed by the person whose name appears on the envelope. You have been randomly selected to fill in our questionnaire.

**It is important for the study that all questions are answered, even if some may seem like repetitions.**

For each question please place a tick in the box that most closely matches your answer. If you make the wrong selection, you can simply cross out the wrong answer and place a new tick.

**Example:**

1. You get sick more easily than other	totally agree	partly agree	partly agree	totally agree
	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Please return the questionnaire in the enclosed postage paid envelope.**

1. Have you **at some point in your life** had any of the following symptoms?  
(You may tick more than one answer).

	Yes	No
A lump in your breast	<input type="checkbox"/>	<input type="checkbox"/>
Discovered that you could squeeze fluid or blood out of your nipple	<input type="checkbox"/>	<input type="checkbox"/>
Discovered that there was nipple discharge or bleeding by itself	<input type="checkbox"/>	<input type="checkbox"/>
Pain in your breast gland	<input type="checkbox"/>	<input type="checkbox"/>
Coughed up blood	<input type="checkbox"/>	<input type="checkbox"/>
Coughed for more than 6 weeks	<input type="checkbox"/>	<input type="checkbox"/>
Discovered blood in your urine	<input type="checkbox"/>	<input type="checkbox"/>
Change in the number of bowel movements (at least a doubling) that lasted for more than 4 weeks	<input type="checkbox"/>	<input type="checkbox"/>
Changes in the firmness of the stool (from solid to loose or vice versa) that lasted for more than 4 weeks	<input type="checkbox"/>	<input type="checkbox"/>
Pain in your stomach for more than 4 weeks	<input type="checkbox"/>	<input type="checkbox"/>
Blood in your stool	<input type="checkbox"/>	<input type="checkbox"/>
Blood on toilet paper after defecation	<input type="checkbox"/>	<input type="checkbox"/>
Blood in the toilet bowl after defecation	<input type="checkbox"/>	<input type="checkbox"/>
Black and shiny stool	<input type="checkbox"/>	<input type="checkbox"/>
Been so tired that you could not cope with everyday life	<input type="checkbox"/>	<input type="checkbox"/>
Lost more than 2 kg without making an effort	<input type="checkbox"/>	<input type="checkbox"/>

---

2. Have you within the **preceding year** had one of the following symptoms?  
(You may tick more than one answer).

	Yes	No
Felt a lump in your breast	<input type="checkbox"/>	<input type="checkbox"/>
Coughed for more than 6 weeks	<input type="checkbox"/>	<input type="checkbox"/>
Seen blood in your urine	<input type="checkbox"/>	<input type="checkbox"/>
Seen blood in your stool	<input type="checkbox"/>	<input type="checkbox"/>

3. Choose **one and only one** of the symptoms listed in question 2. The symptom you choose we will designate '**Your personal symptom**'.

Which symptom – **Your personal symptom** – do you choose? (tick one and only one, and only if you have had the symptom within the preceding year)

- Felt a lump in your breast
- Coughed for more than 6 weeks
- Seen blood in your urine
- Seen blood in your stool
- I have not had any of the listed symptoms in the past year  (if none go to question 14)
- 

Question 4-13 concerns **your personal symptom** (the symptom you chose in question 3)

---

4. How many times in your life have you experienced **your personal symptom**?

- It was the first time
- From 1-10 times
- More than 10 times

5. When did you discover **your personal symptom** for the first time in your life?

- Less than 1 month ago
- Between 1 and 3 months ago
- Between 3 and 6 months ago
- Between 6 and 12 months ago
- Between 1 and 5 years ago
- More than 5 years ago

6. Did you talk to your doctor about **your personal symptom**? Yes  No

*If yes, what was the reason for consulting your doctor (you may tick more than one answer)?*

I was afraid that it was cancer

I was afraid that it was something serious

It did not go away

I wanted to know what it was

An acquaintance asked me to consult a doctor

Other, please specify: \_\_\_\_\_

*If no, what was the reason for not consulting your doctor (you may tick more than one answer)?*

I didn't think that it could be cancer

It was not that dangerous

I knew what it was

It went away

Other, please specify: \_\_\_\_\_

7. How long did it take from noticing **your personal symptom** until you consulted your GP?

Less than 1 month

1-3 months

3-6 months

More than 6 months

Did not consult my GP

---

The next questions should describe your perception of **your personal symptom** (*that you chose in question 3*).

---

	totally agree	partly agree	partly agree	totally agree
8. <i>I was afraid that it could be a sign of cancer</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. <i>It caused great concerns</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. <i>It seriously affected my everyday life</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. <i>It was not more serious than any other symptoms, I have had</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. <i>I was afraid that it could lead to serious health problems</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. <i>My doctor knows what's best for me when I have such a symptom</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

---

**The following questions concern all kinds of cancer**

---

14. *Do you have, or have you had, a cancer disease?* Yes  No

*If yes, which kind?*

Breast cancer   
Lung cancer   
Colorectal cancer   
Bladder cancer   
Other, please specify: \_\_\_\_\_

	totally agree	partly agree	partly agree	totally agree
15. <i>Every time you get sick, you are afraid, that it is cancer</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. <i>You are more likely to get cancer than others</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. <i>You are often afraid that you will get cancer</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. <i>Doctors know what is best for you, if you were to get cancer</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. <i>Doctors can cure most cancers</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. <i>Doctors can help you if you were to get cancer</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. <i>Has anyone in your immediate family (father, mother, sisters, brothers, or children) died from cancer?</i>	Yes <input type="checkbox"/> No <input type="checkbox"/>			

22. *Has anyone in your immediate family (father, mother, sisters, brothers, or children) survived cancer?*

Yes  No

Thank you very much for your reply. The questionnaire should be returned in the enclosed postage paid envelope.

Kind regards  
Bjarne Lühr Hansen  
General practitioner

**Institut for Sundhedstjenesteforskning  
Syddansk Universitet  
Telf. 65 50 30 32**

*Praktiserende læge og lektor Bjarne Lühr Hansen*

## **Tegn på kræft**

**En undersøgelse af tegn på kræft  
i den danske befolkning**

**Vigtigt:**

**Spørgeskemaet bedes udfyldt i løbet af 1 uge og returneret i vedlagte frankerede svarkuvert.  
Din besvarelse behandles strengt fortroligt og når undersøgelsen er afsluttet vil  
spørgeskemaet blive tilintetgjort.**

## Sådan udfylder du spørgeskemaet

Læs venligst dette inden du går i gang.

Spørgsmålene i spørgeskemaet bedes besvaret af den person, hvis navn er anført på kuverten. Det er helt tilfældigt, at netop du bliver bedt om at udfylde vores spørgeskema.

**Det er vigtigt for undersøgelsen at alle spørgsmålene besvares, også selvom enkelte kan virke som gentagelser.**

De fleste spørgsmål besvares ved, at sætte et kryds ud for det svar, som du synes passer bedst. Hvis du laver forkert afkrydsning, kan du blot strege det forkerte ud og sætte et nyt kryds.

### Eksempel:

1. Du bliver lettere syg end andre
- |           |             |                          |                          |                          |                          |  |  |
|-----------|-------------|--------------------------|--------------------------|--------------------------|--------------------------|--|--|
| helt enig | delvis enig | delvis uenig             | helt uenig               |                          |                          |  |  |
|           | X           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |  |  |

**Spørgeskemaet bedes returneret i vedlagte frankerede svarkuvert.**



1. Har du på **et eller andet tidspunkt i dit liv** haft et eller flere af følgende symptomer?  
(Du må gerne sætte flere kryds).

	Ja	Nej
En knude i dit bryst	<input type="checkbox"/>	<input type="checkbox"/>
Opdaget at du kunne presse væske eller blod ud af brystvorten	<input type="checkbox"/>	<input type="checkbox"/>
Opdaget at det af sig selv blødte eller væskede fra brystvorten	<input type="checkbox"/>	<input type="checkbox"/>
Smerter i din brystkirtel	<input type="checkbox"/>	<input type="checkbox"/>
Hostet blod op	<input type="checkbox"/>	<input type="checkbox"/>
Hostet i mere end 6 uger	<input type="checkbox"/>	<input type="checkbox"/>
Opdaget blod i din urin	<input type="checkbox"/>	<input type="checkbox"/>
Ændring i antal afføringer (mindst en fordobling) og som varede mere end 4 uger	<input type="checkbox"/>	<input type="checkbox"/>
Ændring i fastheden af afføringen (fra fast til løs eller omvendt) og som varede mere end 4 uger	<input type="checkbox"/>	<input type="checkbox"/>
Ondt i maven i mere end 4 uger	<input type="checkbox"/>	<input type="checkbox"/>
Blod i din afføring	<input type="checkbox"/>	<input type="checkbox"/>
Blod på toiletpapir efter afføring	<input type="checkbox"/>	<input type="checkbox"/>
Blod i toiletkummen efter afføring	<input type="checkbox"/>	<input type="checkbox"/>
Sort og glinsende afføring	<input type="checkbox"/>	<input type="checkbox"/>
Været så træt, at du ikke kunne klare din hverdag	<input type="checkbox"/>	<input type="checkbox"/>
Tabt dig mere end 2 kg uden at du gjorde noget for det	<input type="checkbox"/>	<input type="checkbox"/>

---

2. Har du inden for **det sidste år** haft et af følgende symptomer?  
(Du må gerne sætte flere kryds)

	Ja	Nej
Følt en knude i dit bryst	<input type="checkbox"/>	<input type="checkbox"/>
Hostet i mere end 6 uger	<input type="checkbox"/>	<input type="checkbox"/>
Opdaget blod i din urin	<input type="checkbox"/>	<input type="checkbox"/>
Set blod i din afføring	<input type="checkbox"/>	<input type="checkbox"/>

3. Vælg **et og kun et** af de nævnte symptomer fra spørgsmål 2. Det symptom du vælger, vil jeg kalde for "**dit personlige symptom**".

Hvilket symptom – **dit personlige symptom** - vælger du?(sæt et og kun et kryds og kun hvis du har haft symptomet inden for det sidste år)

- Følt en knude i dit bryst
- Hostet i mere end 6 uger
- Opdaget blod i din urin
- Set blod i din afføring
- Jeg har ikke haft nogle af de nævnte symptomer det sidste år  (hvis ingen, spring frem til spørgsmål 14)
- 

Spørgsmål 4-13 handler om **Dit personlige symptom** (det symptom du valgte i spørgsmål 3)

---

4. Hvor mange gange har du oplevet **Dit personlige symptom** i løbet af dit liv?

- Det var første gang
- Fra 1-10 gange
- Mere end 10 gange

5. Hvornår opdagede du **Dit personlige symptom** for første gang i dit liv?:

- For mindre end 1 måned siden
- For mellem 1 og 3 måneder siden
- For mellem 3 og 6 måneder siden
- For mellem 6 og 12 måneder siden
- For mellem 1 og 5 år siden
- For mere end 5 år siden

6. Har du talt med din læge om **Dit personlige symptom**? Ja  Nej

**Hvis ja**, hvad var så årsagen til, at du søgte læge (du må gerne sætte flere kryds)?

Jeg var bange for, at det var kræft

Jeg var bange for, at det var noget alvorligt

Det gik ikke væk

Jeg ville gerne vide, hvad det var

En bekendt bad mig om at søge læge

Andet, skriv hvad: \_\_\_\_\_

**Hvis nej**, hvad var så årsagen til, at du ikke har søgt læge (du må gerne sætte flere kryds)?

Jeg mente ikke, det kunne være kræft

Det var ikke så farligt

Jeg vidste, hvad det var for noget

Det gik væk

Andet, skriv hvad: \_\_\_\_\_

7. Hvor lang tid gik der fra du opdagede **Dit personlige symptom** og til du søgte læge?

mindre end 1 måned

1-3 måneder

3-6 måneder

over 6 måneder

har ikke søgt læge

---

De næste spørgsmål skal beskrive din opfattelse af **Dit personlige symptom** (som du valgte i spørgsmål 3).

---

	helt enig	delvis enig	delvis uenig	helt uenig
8. <i>Jeg var bange for, at det kunne være tegn på kræft</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. <i>Det gav anledning til store bekymringer</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. <i>Det påvirkede min hverdag væsentligt</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. <i>Det var ikke mere alvorligt end andre symptomer, jeg har haft</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. <i>Jeg var bange for at det kunne føre til alvorlige helbredsproblemer</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. <i>Min læge ved, hvad der er bedst for mig, når jeg har sådan et symptom</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

---

**De følgende spørgsmål handler om alle mulige kræftsygdomme.**

---

14. Har du eller har du haft en kræftsygdom? Ja  Nej

**hvis ja, hvilke slags?**

Brystkræft   
Lungekræft   
Kræft i endetarm eller tyktarm   
Blærekræft   
Andre, skriv hvilke: \_\_\_\_\_

- |  | helt enig                   | delvis enig                  | delvis uenig             | helt uenig               |
|--|-----------------------------|------------------------------|--------------------------|--------------------------|
| 15. Hver gang du bliver syg, er du bange for, at det er kræft  | <input type="checkbox"/>    | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> |
| 16. Du er mere udsat for at få kræft end andre   | <input type="checkbox"/>    | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> |
| 17. Du er tit bange for, at du skal få kræft   | <input type="checkbox"/>    | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> |
| 18. Læger ved, hvad der er bedst for dig, hvis du skulle få kræft                                      | <input type="checkbox"/>    | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> |
| 19. Læger kan helbrede de fleste former for kræft.   | <input type="checkbox"/>    | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> |
| 20. Læger kan hjælpe dig, hvis du skulle få kræft.   | <input type="checkbox"/>    | <input type="checkbox"/>     | <input type="checkbox"/> | <input type="checkbox"/> |
| 21. Er der nogen i din nærmeste familie (far, mor, søstre, brødre eller børn) der er døde af kræft?    | Ja <input type="checkbox"/> | Nej <input type="checkbox"/> |                          |                          |
| 22. Er der nogen i din nærmeste familie (far, mor, søstre, brødre eller børn) der har overlevet kræft? | Ja <input type="checkbox"/> | Nej <input type="checkbox"/> |                          |                          |

Mange tak for dine svar. Spørgeskemaet bedes sendt retur i vedlagte frankerede svarkuvert.

Med venlig hilsen  
Praktiserende læge  
Bjarne Lühr Hansen