

# Awareness and beliefs about cancer and barriers to healthcare seeking in the general population

PhD dissertation

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# PREFACE

*I did not know that if you experience a change in bowel habits that lasts more than 3 weeks – then you should see your doctor (Female, 52 years old).*

*For several months, the bleeding occurred on and off, but it was only a bit – it has gotten slightly worse during the past months – I listened to a radio broadcast and then realized that it could be a sign of bowel cancer (Female, 69 years old).*

*Since I have not been able to link my cancer with "HARMLESS" discomfort like fatigue, discomfort with satiety, hot flushes, I think that a campaign on early detection of this cancer should focus on many of the various "HARMLESS" kinds of discomfort that may co-occur, so that "we – the affected" would have been able, perhaps earlier, to do something (Male, 56 years old).*

These are three retrospective reflections stated by newly diagnosed cancer patients in the questionnaire study 'Patient delay in colon and rectal cancer patients'. The study was part of my master thesis in Public Health Science. As the title implies, the study was on patient delay or patient interval as it is better referred. In line with others (1-3), this study showed that about 25% of the cancer patients reported having experienced cancer-related symptoms for about three months before seeking care and found that the patient's cognitive and emotional symptom perception influenced the duration of the patient interval (4).

I was subsequently given the opportunity to do a PhD project; assessing cancer awareness, beliefs about cancer and anticipated barriers to healthcare seeking among the general population. The underlying assumption for this PhD project was that low cancer awareness, negative beliefs about cancer and anticipated

barriers to healthcare seeking are likely to contribute to a longer patient interval, decreasing the chance that the cancer is found at an early stage and ultimately decreasing the chance of survival. And though I was fully aware that healthcare seeking is not a straightforward process and that no magic bullet exists in explaining neither the patient interval nor the differences we see in cancer survival across countries and within our own country (which will be elucidated in Chapter 1), I was curious to have a closer look at some of the factors that may affect healthcare seeking and ultimately survival.

Hence, in this thesis, I assess awareness and beliefs about cancer and anticipated barriers to healthcare seeking in the general population and whether there are differences between two largely comparable countries and between socio-economic groups in Denmark.

The PhD thesis is based on the following four papers:

- I Hvidberg L, Pedersen AF, Wulff CN, Carlsen AH, Vedsted P. Measurement properties of the Danish version of the Awareness and Beliefs about Cancer (ABC) measure. (Resubmitted to BMC Medical Research Methodology).
- II Hvidberg L, Lagerlund M, Pedersen AF, Hajdarevic S, Tishelman C, Vedsted P. Awareness of cancer symptoms and anticipated patient interval for healthcare seeking. A comparative study of Denmark and Sweden. *Acta Oncol* 2016;55(7):917-924.
- III Hvidberg L, Wulff CN, Pedersen AF, Vedsted P. Barriers to healthcare seeking, beliefs about cancer and the role of socio-economic position. A Danish population-based study. *Prev Med* 2015;71:107-113.
- IV Hvidberg L, Pedersen AF, Wulff CN, Vedsted P. Cancer awareness and socio-economic position: results from a population-based study in Denmark. *BMC Cancer* 2014;14:581.

In addition, contributions to the following papers were made:

- V Wulff CN, Pedersen AF, Hvidberg L, Vedsted P. Befolkningens viden og forestillinger om kræft [In Danish]. *Ugeskr Læger* 2011;3;173(40):2493-2496.
- VI Simon AE, Forbes LJ, Boniface D, Warburton F, Brain KE, Dessaix A, Donnelly M, Haynes K, Hvidberg L, Lagerlund M, Petermann L, Tishelman C, Vedsted P, Vigmostad MN, Wardle J, Ramirez AJ, ICBP Module 2 Working Group. An international measure of awareness and beliefs about cancer: development and testing of the ABC. *BMJ Open* 2012;18;2(6).
- VII Forbes LJ, Simon AE, Warburton F, Boniface D, Brain KE, Dessaix A, Donnelly C, Haynes K, Hvidberg L, Lagerlund M, Lockwood G, Tishelman C, Vedsted P, Vigmostad MN, Ramirez AJ, Wardle J, ICBP Module 2 Working Group. Differences in cancer awareness and beliefs between Australia, Canada, Denmark, Norway, Sweden and the UK (the International Cancer Benchmarking Partnership): do they contribute to differences in cancer survival? *Br J Cancer* 2013;5;108(2):292-300.
- VIII Lagerlund M, Hvidberg L, Hajdarevic S, Pedersen AF, Runesdotter S, Vedsted P, Tishelman C. Awareness of risk factors for cancer: a comparative study of Sweden and Denmark. *BMC Public Health* 2015;23;15.
- IX Hajdarevic S, Hvidberg L, Lin Y, Donnelly C, Gavin A, Lagerlund M, Pedersen AF, Rasmussen BH, Runesdotter S, Vedsted P, Tishelman C. Awareness of sunburn in childhood, use of sunbeds and change of moles in Denmark, Northern Ireland, Norway and Sweden. *Eur J Public Health* 2016;26(1):29-35.
- X Pedersen AF, Forbes L, Brain KE, Hvidberg L, Wulff CN, Lagerlund M, et al. Negative cancer beliefs, recognition of cancer symptoms and anticipated time to help-seeking: an international cancer benchmarking partnership (ICBP) study. (Submitted to *BMC Cancer*).

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ABBREVIATIONS

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ABC	Awareness and Beliefs about Cancer
CAM	Cancer Awareness Measure
CATI	Computer-assisted telephone interviewing
CFA	Confirmatory factor analysis
CFI	Comparative Fit Index
CI	Confidence interval
CRN	Civil registration number
CRS	Civil Registration System
CVI	Content validity index
DCR	Danish Cancer Registry
EFA	Explorative factor analysis
EUROCARE	European Cancer Registry based study on survival and care of cancer patients
GDP	Gross Domestic Product
GLM	Generalised linear models
GNI	Gross National Income
GP	General practitioner
HCP	Healthcare provider
HPV	Human papillomavirus
ICBP	International Cancer Benchmarking Partnership
ICC	Intraclass correlation coefficient
iFOBT	Immunochemical faecal occult blood test
ISCED	International Standard Classification of Education
NAEDI	National Awareness and Early Diagnosis Initiative
OECD	Organisation for Economic Co-operation and Development
PPV	Positive predictive value
PR	Prevalence ratio
RMSEA	Root mean square error of approximation
SEP	Socio-economic position
SPAR	Swedish Population and Address Register
TLI	Tucker-Lewis Index
TNM	Tumour, Nodes, Metastasis
UK	United Kingdom

# CHAPTER 1

## BACKGROUND

This chapter will introduce the general background of the thesis and the underlying assumption for studying awareness and beliefs about cancer and barriers to healthcare seeking in a general population. The hypotheses and aims of the thesis are presented at the end of this chapter.

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## CANCER EPIDEMIOLOGY

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Cancer is a major public health burden and the burden will continue to increase in the foreseeable future due to population growth and an ageing population (5). Estimates from the GLOBOCAN database show that in 2012, there were 254 new cancer cases for every 100,000 persons in Europe, and the corresponding age-standardised mortality rate in Europe was 113 per 100,000 persons, all numbers excluding non-melanoma skin cancer. The cancer incidence was highest in Denmark with an estimated 338 men and women per 100,000 being diagnosed with cancer in 2012 and with a mortality rate (125 per 100,000 persons/year) also being above the European average (6). In Denmark, colorectal, breast, lung and prostate cancer are the four most common incident cancer types overall (7).

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## CANCER RISK FACTORS AND SYMPTOMS

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Cancers arising in different parts of the body often have very different causes. Still, in large part, cancer is associated with risks from lifestyle, environmental and biological factors (8). The single most important modifiable cause of cancer in developed countries is tobacco smoking, which is estimated to account for up to 30% of all new cancer cases (9). There is a growing recognition that other lifestyle factors including physical inactivity, high alcohol consumption and poor diet contribute to an increased cancer risk. Still, there is some controversy over the role diet plays and more evidence is needed on which dietary components are carcinogenic (8). Environmental exposures include ionizing radiation from, for example, radioactive materials, x-rays and radon. Finally, biological causes of cancers include, among others, older age and genetic susceptibility (8,10). Some of these risk factors are modifiable, others are non-modifiable; and it has been estimated that at least one third of all cancer cases are preventable and that another one third can be cured given early diagnosis and effective treatment (10-12). Awareness about the modifiable risk factors is an important prerequisite for engaging in preventive actions intended to reduce cancer risk, albeit it cannot stand alone (13,14). Furthermore, awareness about both modifiable and non-modifiable risk factors is important for understanding personal risk, which can facilitate healthcare seeking (14,15).

However, whether the Danish population is aware of the cancer risks from lifestyle, environmental and biological factors has never been explored in a large-scale study among the general population.

Another aspect deserving further study is whether the general Danish population is aware of the signs and symptoms of the most common cancers, since the majority of cancer cases are found through symptomatic presentation in general practice (16). In Danish 'signs and symptoms' are often denoted symptoms, which will also be the case in this thesis. In medicine, however, a 'sign' is defined as an objective (e.g. rectal bleeding) and a 'symptom' as a subjective (e.g. pain and tiredness) indication of a health problem (17). The challenge for the population as well as for the general practitioner (GP) is, however, that even alarm symptoms of cancer are, in fact, more often due to benign diseases than to a health problem or an underlying cancer (18,19). This was also evident in a recent systematic review on positive predictive values (PPV) of alarm symptoms for colorectal, breast and lung cancer in general practice. PPVs of 5-8% were reported for rectal bleeding, change in bowel habits, hemoptysis and a mass, whereas symptoms such as weight loss and abdominal pain had PPVs below 2%, depending on age and gender (18). The PPVs of these symptoms are even lower among people who have not presented the symptoms to the GP (20), which suggests that to some extent people are able to identify which symptoms warrant GP attention (16). However, we do not know whether the awareness that some symptoms may be indicative of cancer differ among groups in the Danish population and this has to be systematically explored. This information is even more interesting in light of the fact that Denmark has a relatively low cancer survival rate compared with other countries and because there are large variations in survival between different groups within the country; an issue to which I will now turn to.

CANCER SURVIVAL ACROSS AND WITHIN COUNTRIES

Survival from cancer has generally improved worldwide, but a strong and consistent finding is that substantial differences in cancer survival still exist between countries. Several large international comparisons of cancer survival have been published in the past two decades, among them the studies under EUROCARE (21) CONCORD (22) and the International Cancer Benchmarking Partnership (ICBP) (23). The latter study compares survival estimates between Australia (New South Wales, Victoria), Canada (Alberta, British Columbia Manitoba, Ontario), Norway, Sweden (Uppsala-Örebro and Stockholm Gotland health regions), Denmark and the United Kingdom (UK) (England, Northern Ireland and Wales), which are all high-income countries with universal access to healthcare and high-quality cancer registration. For an overview, see Table 1.1.

Table 1.1: Economy, healthcare system indicators and completeness of cancer registration in the ICBP countries

	Australia	Canada	UK	Norway	Sweden	Denmark
<b>GNI per capita (Atlas method)<sup>a</sup> (24)</b>	\$60,070	\$47,500	\$43,340	\$93,820	\$57,810	\$58,590
<b>Life expectancy at birth (2013) (25)</b>	83	82	81	82	82	80
<b>Percentage of GDP spent on healthcare (2014) (25)</b>	9.4%	10.4%	9.1%	9.7%	11.9%	10.8%
<b>Number of practicing physicians per 1,000 population (2012/13) (26)</b>	3.4	2.5	3.6	4.3	4.0	2.8
<b>Gatekeeping (26)</b>	Yes	Yes	Yes	Yes	No	Yes
<b>Out-of-pocket costs for seeing a GP (26)</b>	About 15% of GP visits lead to out-of-pocket cost <sup>b</sup>	None	None	About \$15 per visit (capped at \$220)	\$10-30 per visit (capped at \$120)	None
<b>Completeness of the cancer registry<sup>c</sup></b>	~ 97% (27)	90-95% (28)	96-97 (29,30)	98-99% (31)	~ 96% (32)	>95% (33,34)

<sup>a</sup> Method used by World Bank to classify countries in low, middle and high-income categories (>\$12,476).

<sup>b</sup> GP visits are subsidized at 100% of the Medicare Benefits Schedule (MBS) by the Australian Government, but GPs can choose to charge above the MBS fee, which results in out-of-pocket costs for the patient (average \$20).

<sup>c</sup> Different methods are used to estimate completeness.

Notes: GNI: Gross National Income, GDP: Gross Domestic Product

However, despite these countries being largely comparable, significant differences in both 1-year and 5-year relative survival are observed (Figure 1.1). In general, British and Danish cancer patients experience poorer cancer survival rates than cancer patients in the other countries. For example, the 5-year relative survival of patients diagnosed with breast, colorectal and lung cancer during 2005-2007 was 89%, 63% and 16% in Sweden compared with 82%, 56% and 11% in Denmark, respectively (23).

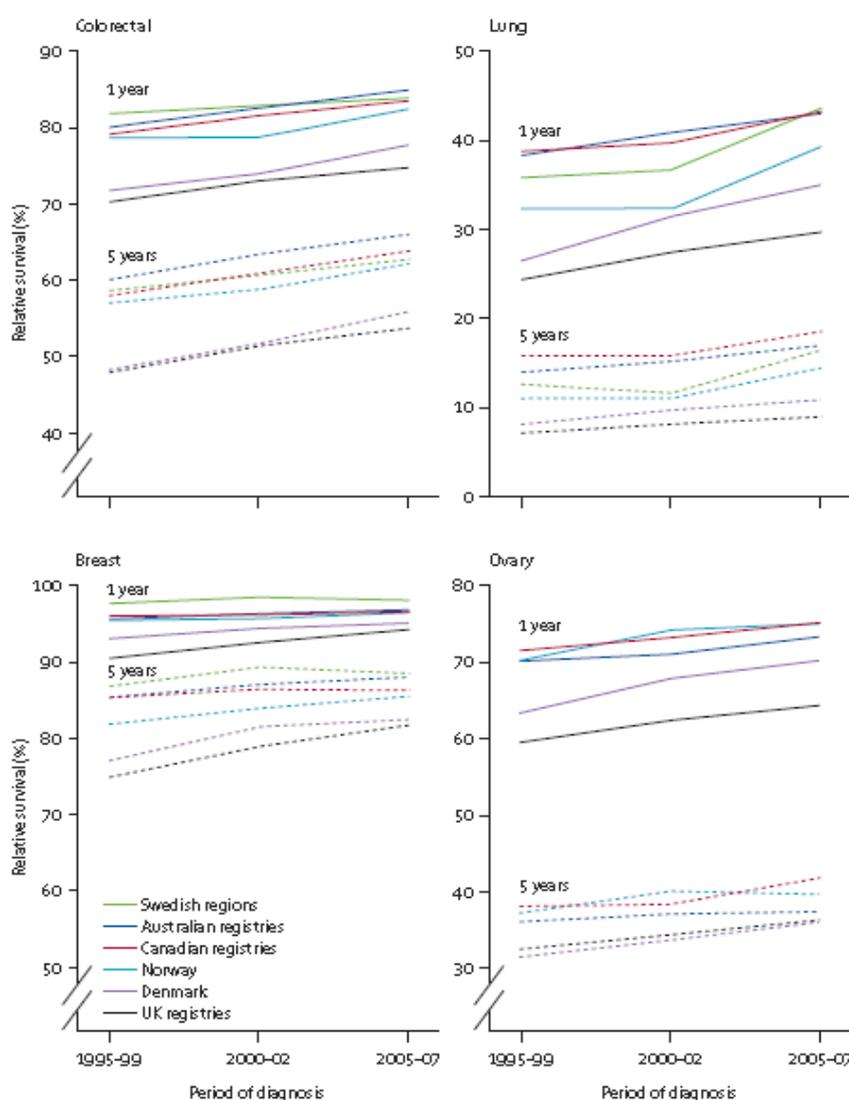


Figure 1.1: Trends in age-standardised 1-year and 5-year relative survival for adults diagnosed with colorectal, lung, breast or ovarian cancer in 1995-99, 2000-02 (cohort approach) and 2005-07 (period approach) by cancer and country. Ovarian cancer data were not available for Sweden (23).

It is noteworthy that these two Scandinavian welfare states have so divergent cancer survival rates, and possible explanations for this difference will be discussed in the next section. Furthermore, even within Denmark, where all residents have free access to the majority of healthcare services (26), there are differences in cancer survival between groups with different socio-economic positions (SEP) (35). Hence, a Danish population register-based study found that the relative 5-year survival for all cancers together was 50% among women with basic or high-school education compared with 62% for women with higher education. The magnitude of the differences varied by cancer site; still, non-negligible differences were found for most cancer sites using disposable income, work affiliation, housing tenure and dwelling size as the SEP indicators (35). SEP can be defined as ‘the social and economic factors that influence what positions individuals or groups hold within the structure of a society’ (36). It is a broad concept that cannot be measured directly (36,37); but gender, marital status, educational level, occupation and income are often used as SEP indicators. SEP indicators are often related, but in most cases they capture different aspects of SEP and the specific manner in which the different SEP indicators exert their influence may vary across the outcomes of a study (36,37).

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#### POSSIBLE EXPLANATIONS FOR DIFFERENCES IN CANCER SURVIVAL

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Disparities in cancer survival rates between different countries and socio-economic groups have been remarkably persistent and several studies have sought to explain these disparities, pointing to four likely categories of factors: 1) differences in quality of cancer registry data, 2) patients’ characteristics such as prevalence of comorbidity, 3) factors related to the healthcare system, e.g., access to optimal treatment and 4) differences in cancer stage at diagnosis (23,38,39). Of particular interest to the present thesis is differences in cancer stages at diagnosis. Hence, differences at this point give a stronger indication of underlying causes like differences in awareness and beliefs about cancer and barriers to healthcare seeking (23,40). In relation to cancer stage, studies from the ICBP show that for breast cancer, 22% of the Danish women had advanced disease (i.e. Tumour, Nodes, Metastasis (TNM) stage III or IV) compared with

8% in Sweden (41). A more adverse stage distribution has also been found for lung, colon, rectal and ovarian cancer patients in Denmark compared with Sweden (42-44). Within Denmark, socio-economic disparities in survival can be explained partly by socio-economic differences in stage for some cancers (45,46), but not for others (45,47).

## THE PATIENT INTERVAL

A number of theoretical models have been developed to describe the cancer pathway from the first notion of a bodily change to diagnosis and treatment initiation (48-51). One of the most influential models is the Andersen's General Model of Total Patient Delay (51), which was refined and conceptualised by Walter et al. (Figure 1.2) (48).

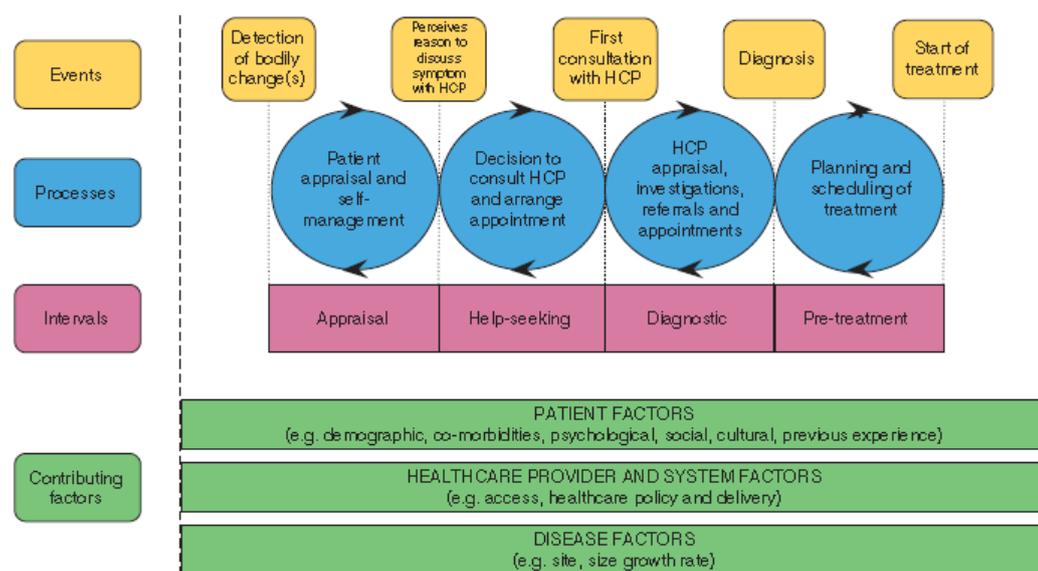


Figure 1.2: Contributing factors, processes, events and time intervals in the route from noticing a bodily change until start of treatment. HCP: Healthcare provider (48).

This model outlines processes and events along the cancer pathway and identifies contributing factors that can influence the four most important overlapping time intervals (appraisal, help-seeking, diagnostic and pre-treatment) (48). Among these intervals, the most important intervals for this

thesis are the appraisal interval (i.e. the time from noticing a bodily change to perceiving a reason to discuss it with a healthcare professional) and the help-seeking interval (i.e. the time from perceiving a reason to discuss the symptom with a healthcare professional to the first consultation) (48), collectively referred to as the patient interval (49).

There is no gold standard for measuring the patient interval. 'The Aarhus Statement' includes several recommendations for definitions and proposals for methodological considerations with a view to furthering consensus (49). It is expected that the first comparable estimates of how patient intervals compare between countries will be published soon (52), and it will be interesting to see whether the differences in stage distribution and cancer survival between Denmark and Sweden translate into differences in patient interval as well. Within countries, a series of studies on the association between several SEP indicators and the patient interval have been conducted (53-56), but contrary to the results on SEP and cancer survival, there has been no strong conclusive evidence underpinning this association. It is, however, generally agreed that the patient interval accounts for a substantial proportion of the total interval (51,53,57). This may be due to the complexity of the process of symptom interpretation and decision-making in healthcare seeking for potential cancer symptoms and to the influence exerted by contextual, psychological and physical factors (15,51,58). At the core of the present thesis are the more psychological factors.

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## AWARENESS, BELIEFS AND BARRIERS

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Awareness can be defined as the ability to know or to be conscious of something based on information or experience (59). Cancer awareness seems to be of particular importance during the appraisal interval where the individual is trying to determine the cause and significance of the symptom (60,61). In an extensive review on factors influencing the patient interval, Macleod et al. (54) found that symptom awareness, e.g. not recognising the seriousness of a symptom, was the most important risk factor for a long patient interval across all cancer sites. A similar result was found in a qualitative synthesis of 32

international papers, which also found that no awareness of risk was a key theme for a long patient interval (15).

Beliefs, in this thesis, are mind states of where a person thinks that something exists or is true. Negative beliefs about cancer, sometimes manifested as cancer fatalism, i.e. 'the belief that death is inevitable when cancer is present' (62), has been identified as a risk factor for longer patient intervals and as a factor that may mediate the association between cancer awareness and patient intervals (61,63,64). Leventhal's 'fear and danger control framework' (65) may be useful for explaining the effect of cancer beliefs on healthcare seeking. The first response, fear control, is elicited if the individual feels that the threat cannot be controlled. This response is likely to be more prominent among persons with negative beliefs about cancer (e.g. the person believes that a cancer diagnosis is a death sentence); and fear control processes such as ignoring symptoms will result in postponement of healthcare seeking. In contrast, fear will manifest in danger control such as fast healthcare seeking if a perception of a high threat is accompanied by beliefs that the person is able to deal with it. If beliefs about early detection of cancer are positive, the person is more likely to seek healthcare.

Barriers to healthcare seeking when experiencing a possible symptom of cancer are commonly classified as practical (e.g. being too busy), service-related (e.g. communication problems with the GP) or emotional (e.g. embarrassment, worry and fear) (40,66). The barriers play an important role especially in the time period from perceiving that there is a reason to discuss the symptom with a healthcare professional to the first consultation (i.e. help-seeking interval) (60). In a study of 625 newly diagnosed lung, breast and colorectal cancer patients, patients with a patient interval of more than three months reported that this was partly because they had been too busy to seek healthcare (3). In the qualitative synthesis, 26 studies reported that fear was a major barrier to healthcare seeking. In particular, fear of cancer and fear of embarrassment in terms of being stigmatised as a hypochondriac or a 'time-waster' were important factors for a longer patient interval (15). Yet, it is generally agreed that the association between fear and healthcare seeking depends on the cause of the fear, its

intensity and, as outlined above, the belief that action will reduce the threat (61,65,67).

In Denmark and the UK, recent years have seen a stronger policy focus on the effect of low cancer awareness, negative beliefs about cancer and barriers to healthcare seeking and on the contribution of these factors to the duration of the patient interval, the chance of cancer being found at an early stage and, ultimately, the chance of survival (40,68,69).

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### POLICY INITIATIVES

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In Denmark, three National Cancer Plans have been carried out and a fourth plan was issued in August 2016 (70). The third national cancer plan from 2010 addressed five main issues: 1) cancer prevention and health promotion, 2) early detection of cancer, 3) rehabilitation and follow-up of cancer, 4) palliative care and 5) user involvement (69). Awareness of cancer was a central theme in relation to the issue of early detection and the plan highlighted the need for tailored awareness campaigns. However, it was also recognised that little is known about awareness in the Danish population (69).

The UK has undertaken a number of initiatives to attain earlier presentation of cancer and improved cancer survival (40,68). In November 2008, the National Awareness and Early Diagnosis Initiative (NAEDI) was launched in a collaboration between the UK Department of Health and Cancer Research UK to coordinate activities and generate research that promotes earlier diagnosis of cancer. In this connection, the NAEDI pathway was developed (40), and recently an updated version of the NAEDI pathway was published (71). This updated NAEDI pathway is shown in Figure 1.3. The Figure does not capture the entire multifactorial and complex nature of the pathway, but illustrates some of the determinants, among other the determinants (awareness, beliefs and barriers) explored in this thesis.

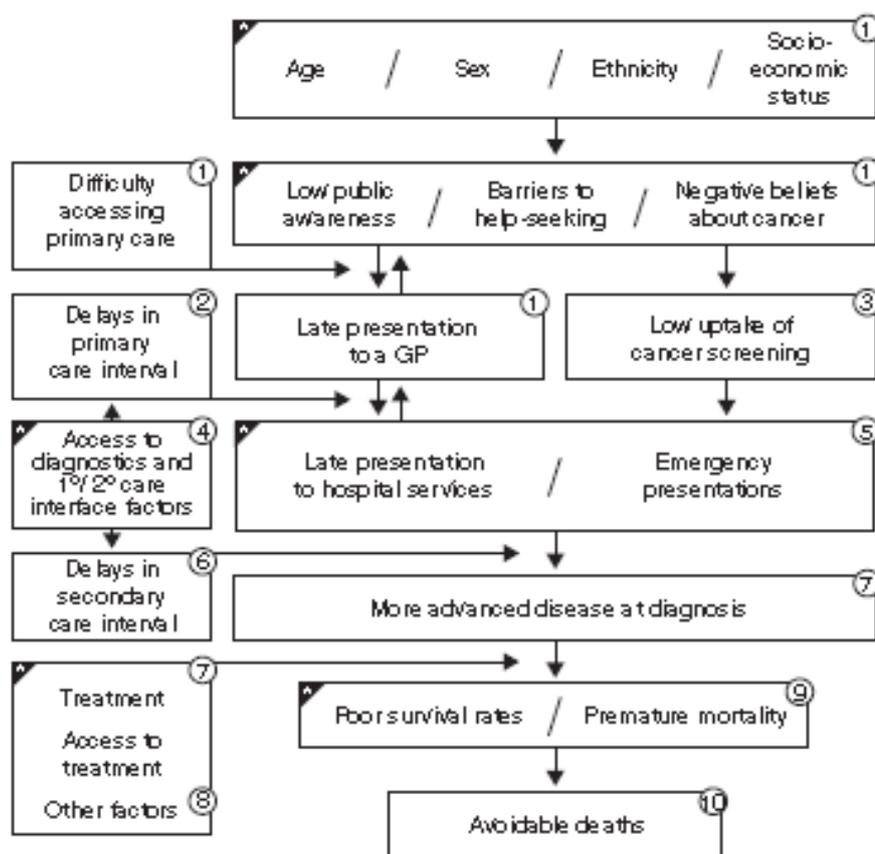


Figure 1.3: Updated NAEDI pathway (71).

The ICBP, consisting of five modules, was initiated as part of the NAEDI framework (68). Module 1 provides the epidemiological estimates of cancer staging and survival as highlighted in the section on cancer survival across countries, whereas modules 2-5 explore possible reasons for differences in survival between the participating countries. Module 2 explores awareness and beliefs about cancer and barriers to healthcare seeking among the general population in the different countries; and for this purpose the Awareness and Beliefs about Cancer (ABC) measure was developed.

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## THE AWARENESS AND BELIEFS ABOUT CANCER MEASURE

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The ABC measure is a further development of the Cancer Awareness Measure (CAM) developed as part of the NAEDI to assess the general population's awareness of cancer symptoms and risk factors, length of anticipated patient interval when experiencing a possible symptom of cancer and anticipated barriers to healthcare seeking (72).

A paper from 2015 collated data from surveys using the CAM, showing that people with low SEP recognised significantly fewer cancer symptoms and were more likely to endorse emotional barriers to healthcare seeking than people with high SEP (73). Similar associations may be found in Denmark, but the studies in this thesis are the first to explore this association in a Danish context.

Further, as shown above, beliefs about cancer are also relevant to early detection of cancer, and the ABC measure has therefore been extended to include items on beliefs about cancer and screening for cancer. These items have mainly been adapted from items used in other population-based surveys and from studies on cancer beliefs, screening uptake and healthcare seeking (74-76).

The measurement aim of the ABC measure is first and foremost to be able to differentiate between countries and socio-economic groups in terms of awareness, beliefs and barriers. Thus, the measure is not based on a particular theoretical model, but it is guided by different theoretical models outlining the factors that influence the processes of healthcare seeking and that may have application as a potential source of differences across and within countries.

The ABC measure has undergone validation in England and it has shown to have acceptable content validity and test-retest reliability (77). It has been translated into Canadian French, Swedish, Norwegian and Danish; and as noted by Simon and colleagues, the measurement properties of the ABC measure need to be tested in every country where it is used (77).

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## AIMS

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The overall aims of this thesis are to examine awareness and beliefs about cancer and barriers to healthcare seeking in the Danish general adult population and to examine whether there are differences in these factors between two comparable countries (Denmark and Sweden) and between socio-economic groups within Denmark.

In light of the lower survival rates in Denmark than in Sweden, it is hypothesised that the Danish population sample will show lower symptom awareness and longer anticipated patient intervals than the Swedish sample. Further, given the lower survival rates among people with lower SEP, we hypothesise that people with lower SEP will have lower cancer awareness, more negative beliefs and anticipate more barriers to healthcare seeking compared to people with higher SEP.

We use the internationally developed ABC measure, and the specific aims of the four studies are:

- (1) To appraise the translation process and measurement properties of the Danish version of the ABC measure (Paper I).
- (2) To compare awareness of symptoms of cancer and anticipated patient interval between a Danish and Swedish population sample (Paper II).
- (3) To assess awareness and beliefs about cancer and anticipated barriers to healthcare seeking in a sample of the Danish population and to analyse the association with SEP (Paper III and IV).



# CHAPTER 2

## METHODS

This chapter outlines the process of developing and translating the ABC measure, and it describes the register-based data sources, the data collection procedures and the study populations. The chapter ends with a description of the analyses used in each study.

The four papers in this thesis are all based on the ABC measure. Table 2.1 gives an overview of the study design, the study population, as well as the exposures and outcomes of the papers.

Table 2.1: Characteristics of Paper I-IV

	Paper I	Paper II	Paper III	Paper IV
Design	Cross-sectional validation study	Cross-sectional study	Cross-sectional study	Cross-sectional study
Study population	Eight persons for pilot-test. Three known groups. Ten academic researchers. 123 test-retest participants. 3,000 respondents of the Danish ABC survey.	3,000 respondents of the Danish ABC survey. 3,070 respondents of the Swedish ABC survey.	3,000 respondents of the Danish ABC survey.	3,000 respondents of the Danish ABC survey.
Exposures		Country: Denmark/Sweden	SEP indicators: Age <sup>1</sup> Gender <sup>1</sup> Marital status <sup>1</sup> Ethnicity <sup>1</sup> Education <sup>1</sup> Occupation <sup>1</sup> Household income <sup>1</sup> Cancer diagnosis <sup>2</sup> Close relatives with cancer <sup>3</sup> Self-rated health <sup>3</sup>	SEP indicators: Age <sup>1</sup> Gender <sup>1</sup> Marital status <sup>1</sup> Ethnicity <sup>1</sup> Education <sup>1</sup> Occupation <sup>1</sup> Household income <sup>1</sup> Cancer diagnosis <sup>2</sup> Close relatives with cancer <sup>3</sup> Self-rated health <sup>3</sup>
Outcomes	Data quality. Content validity. Construct validity. Test-retest reliability.	Lack of awareness of three cancer symptoms. Longer anticipated interval for three symptoms.	Anticipated barriers to healthcare seeking. Beliefs about cancer.	Lack of awareness of: cancer symptoms, cancer risk factors, growing risk of cancer with age and 5-year survival from cancer

<sup>1</sup> Source: Statistics Denmark (78).

<sup>2</sup> Source: The Danish Cancer Registry (33).

<sup>3</sup> Source: The Danish ABC measure (Appendix I).

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**THE AWARENESS AND BELIEFS ABOUT CANCER (ABC) MEASURE**

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**Development of the English version of the ABC measure**

The ABC measure was developed as part of the ICBP Module 2. The English version of the ABC measure was developed in the period from March 2010 to May 2011. The ABC measure is generic, yet is focused mainly on colorectal, breast, lung and ovarian cancer; and it was designed to be administered by telephone interview. The measure was developed using an iterative process of evaluating and adapting, among other, to inputs from each ICBP country.

Many of the items in the ABC measure were adopted from the CAM which has undergone validation in England and has shown to reliably assess cancer awareness (72). Some minor modifications were made to some of these items and their introductions. New items on beliefs about cancer and screening for cancer were adapted mainly from previous measures (74-76) and some items were generated specifically for the ABC measure.

The first version of the English ABC measure was created once agreement with the items had been reached in each ICBP country. This version was assessed by academic researchers with expertise in the area, pilot-tested in a small sample of the target population and then went through a test-retest process in the English setting (77). Following evaluation and adaption, the English ABC measure was translated into Australian English, Canadian English, Canadian French, Norwegian, Swedish and Danish.

**The translation process from the English to the Danish ABC measure**

The aim of the translation process was to achieve a Danish version of the ABC measure that was conceptually rather than literally equivalent to the English ABC measure. To achieve this aim, we used a standardised forward and backward translation and pilot-tested the Danish version (79). The translation process is shown in Figure 2.1.

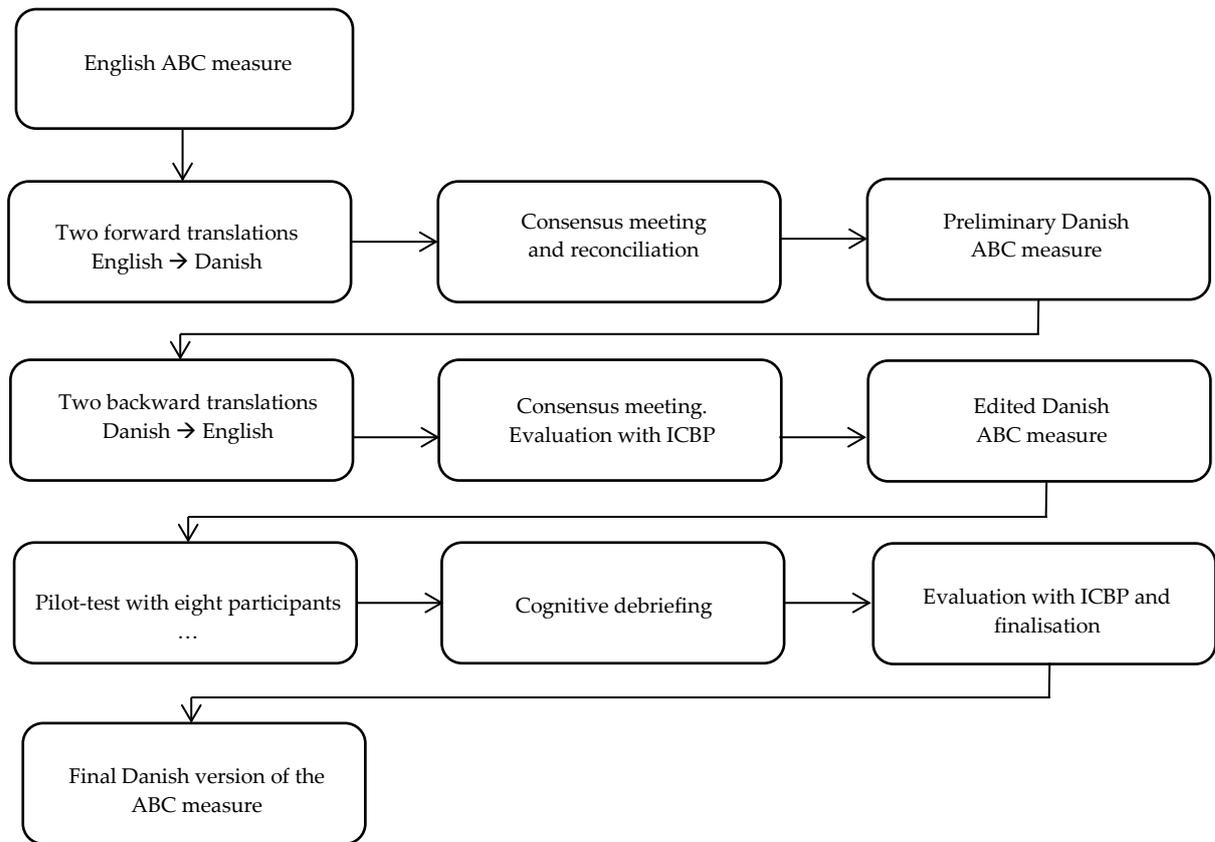


Figure 2.1. The translation process from the English ABC measure to the Danish ABC measure

The forward translations were made independently by two Danish translators, both fluent in English. A consensus meeting was held where one reconciled forward preliminary version of the ABC measure was established and a forward translation report was compiled. This reconciled version was translated back into English by two native English-speakers who were fluent in Danish. Both translators were blinded to the original English version. Discrepancies were discussed at a consensus meeting and a back translation report was compiled. After evaluation with the ICBP Module 2 team, an edited version of the Danish ABC measure was reconciled. This version was pilot-tested among eight men and women aged 43-77 years using face-to-face interviews. The main purpose of the pilot-test was to investigate whether the ABC measure was accepted and understood by the participants. Methods such as think-aloud and probing were used and the length of the interviews was approximately one hour. The pilot-

test took place at the Department of Orthopaedic Surgery (foot/ankle and spine sectors) at Aarhus University Hospital and the results of the pilot-test were gathered in a cognitive debriefing report. After revisions, which particularly concerned shortening of the introductory texts and explanations of some terms (e.g. processed meat), the Danish version of the ABC measure was finalised (Appendix I). Briefly, the final Danish ABC measure included the following sections:

**Introduction:** Included the purpose of the survey, information on the expected duration of the telephone interview (i.e. 20-25 minutes), the voluntary nature of the survey and a confidentiality statement.

**Awareness of cancer symptoms** (1 recall item and 11 recognition items): The recall item (open-ended format) was asked before asking the closed questions on recognition of symptoms; and answers were recorded exactly as they were stated. The 11 symptoms, which are all possible cancer symptoms, had a yes/no response option.

**Anticipated patient interval for healthcare seeking** (4 items): By using a hypothetical scenario, the items assessed how long it would take one to go to the doctor from the first time of noticing a symptom that could be indicative of each of the four target cancers. Response options were not stated, but were categorised into predefined time intervals: I would go as soon as I noticed; I would go up to 1 week, over 1 up to 2 weeks, over 2 up to 3 weeks, over 3 up to 4 weeks, more than a month after I noticed; I would not contact my doctor; I would go to another healthcare professional. These four items were asked in between the recall and the recognition of cancer symptoms to minimize the risk that the anticipated patient interval was affected by the symptoms stated in the recognition format.

**Anticipated barriers for healthcare seeking** (4 items): Items examined whether these barriers (e.g. worry about wasting the doctor's time) could put one off going to the doctor when experiencing a symptom that might be serious. Response options were: yes often, yes sometimes, and no.

**Beliefs about cancer** (6 items): These items focused on beliefs about cancer outcomes and early detection. Three items were positively framed (e.g. these

days, many people with cancer can expect to continue with their normal activities and responsibilities) and three were negatively framed (e.g. a diagnosis of cancer is a death sentence). Answers were given on a four-point Likert response scale: strongly disagree, tend to disagree, tend to agree and strongly agree.

**Beliefs about breast cancer screening** (3 items for women only): These items focused on beliefs about worry and of the purpose of screening for breast cancer. The four-point Likert scale was used.

**Beliefs about bowel cancer screening** (3 items): Here the beliefs were asked in relation to bowel cancer and both men and women were asked how much they agreed or disagreed with each item using the four-point Likert scale.

**Awareness of 5-year survival** (4 items): Assessed awareness about the chances of survival of the four target cancers (i.e. how many out of 10 people diagnosed would survive for five years). The respondents should state a number between 0-10.

**Awareness of risk factors for cancer** (1 item specifically on awareness of growing risk of cancer with age and 13 recognition items): The first explicitly assessed awareness that the risk of cancer increases with age, and four possible response options were given: 30-year-olds, 50-year-olds, 70-year-olds, people of any age are equally likely to be diagnosed with cancer. Awareness of 13 current risk factors was measured. The above-mentioned four-point Likert scale was used.

For all the described sections, 'don't know' and 'don't want to answer' were not offered as specific response options, but they were recorded and accepted as an answer. In addition, randomisation of the order of the questions in each section was used to minimize order-effect bias (80).

Lastly, the ABC measure included questions on whether respondents themselves or someone close to them had ever been diagnosed with cancer, their self-rated health, access to a doctor, smoking behaviour, screening behaviour (men and women  $\geq 50$  years only) and SEP indicators (e.g. educational level and marital status). As will be described in the next section, it was possible to link

data from the ABC measure to individual data on several register-based SEP indicators in Denmark. However, as this approach was not done in any other ICBP country, the questions on SEP at the end of the ABC measure were required to allow comparison with the other ICBP countries.

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## REGISTER-BASED DATA SOURCES

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

The Danish Civil Registration System (CRS) is a register established in 1968 containing individual-level information on all persons with permanent residence in Denmark (81). A ten-digit Civil Personal Register (CPR) number is assigned to all persons registered in the CRS; and along with the CPR number, the CRS also contains information on variables such as date and place of birth, full name and address, and continuously updated information on whether a person is alive and resident in Denmark (82). Ongoing use and validation of the CRS ensure high quality of the information recorded (81).

The CRS has been a key tool for this thesis as it was used to identify the study base, to obtain phone number(s) of possible participants and to link data on numerous SEP indicators from Statistics Denmark to survey data.

### **The Swedish Population and Address Register**

The Swedish Population and Address Register (SPAR) was created in 1976. It is a separate register under the Swedish Population Register. SPAR comprises name and address of all residents living in Sweden and is updated on every weekday (83). The SPAR was used to identify the Swedish study base.

### **Statistics Denmark**

Statistics Denmark gathers information from numerous public administrative registers (78). Researchers can work on encrypted data from these registers on the server of Statistics Denmark. Statistics Denmark provided data on age, gender, marital status, ethnicity, educational level, occupation and household income.

### The Danish Cancer Registry

The Danish Cancer Registry (DCR) is a population-based registry with systematic data collection on Danish cancer patients since 1943 (33). It keeps information on all incident cancers together with stage of cancer, date of diagnosis and date and cause of death. The validity of the DCR is ensured through computerised data checks and manual quality control routines (34). A study from 1997 found that data in the registry were 95-97% complete (33), and the completeness of registration is expected to be even higher now (34). The DCR was used to identify persons who had been registered with a cancer diagnosis within the past ten years (i.e. December 31, 2000-2010).

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### SAMPLE SIZE CALCULATION

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Results from a population-based UK study using the CAM (66) formed the basis for the sample size calculation for the ICBP Module 2. The calculation was based on differences in proportions between low and high socioeconomic groups (based on occupational position) (see Table 2.2).

Table 2.2: Estimated sample size for two-sample comparison of proportions with a power of 0.9 at alpha equal to .05

	Low SEP	High SEP	Number needed in each group to demonstrate a difference
Awareness of a lump or swelling	93%	97%	671
Awareness of persistent cough or hoarseness	64%	74%	468
Agreeing that embarrassment could put them off going to the doctor	26%	16%	367

With 90% power at the 0.05 significance level, a sample size of 671 respondents would be sufficient to demonstrate significant awareness differences of this magnitude. This number was multiplied in order to, e.g., stratify by

socioeconomic group (low-middle-high) in each ICBP country. Thus, all countries of the ICBP Module 2 agreed to include a total sample size of minimum 2,000 respondents aged 50 years and older. Furthermore, Denmark and Sweden agreed to include a younger group, i.e. 1,000 respondents aged 30-49 years. This was chosen because though the risk of cancer increases with age, 152 men out of 100,000 and 283 women out of 100,000 aged 30-49 years are diagnosed with cancer in Denmark every year (all sites but non-melanoma skin cancer) (84). Moreover, assessing awareness of risk factors for cancer in this age group is particular important in relation to cancer prevention.

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## DATA COLLECTION PROCEDURE

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### **Danish ABC survey (Paper I-IV)**

A study base of 20,000 persons aged 30-49 years and 40,000 persons aged  $\geq 50$  years who were alive and residents in Denmark were randomly drawn from the CRS. For each person, information was obtained on the following variables: CPR number, gender, age, full name (first, middle, and last) and full address (municipality, road, and house number). By using the full name and address, a Danish market research and consulting firm (NN Markedsdata) identified landline and/or mobile phone number of all persons in the study base, apart from persons marked with a research protection status (i.e. publicly recorded rejection to be contacted in connection with statistical and scientific surveys (85)).

Immediately before data collection, a requested update from the CRS was received. The update identified persons with a newly established research protection status and persons who had emigrated from Denmark or had passed away.

Data were collected using computer-assisted telephone interviewing (CATI) of the Danish ABC measure. Interviews were conducted by the research company Ipsos MORI (86) who conducted the interviews in each ICBP country and had native-speaking interviewers from each country. All interviewers completed a rigorous and structured training programme with emphasis on obtaining

consent, consistency in interviews, uniformity between interviewers and handling participants' concerns. In addition, ongoing supervision was performed to facilitate a consistent data quality (87). Ipsos MORI conducted the interviews between 31 May and 4 July, 2011. Each person was called up to seven times at different weekdays and times of the day, and an average interview lasted approximately 20 minutes. Interviews were not performed if the person was unable to speak or understand Danish.

### **Swedish ABC survey (Paper II)**

In Sweden, 8,000 persons 30-49 years of age and 15,000 persons aged 50 and over comprised the study base and were selected from SPAR (83). The sample of 23,000 persons was drawn from the Uppsala-Örebro and Stockholm-Gotland healthcare regions (county of Stockholm, Uppsala, Södermanland, Gotland, Värmland, Örebro, Västmanland, Dalarna and Gävleborg), which is 45% of the Swedish population of 9.5 million in 2011 (88). Names and/or addresses as listed in SPAR were supplemented with landline and/or mobile phone numbers by a national market research and consulting firm (Infodata).

The data collection was identical to that of the Danish ABC survey described above; however, Ipsos MORI conducted interviews of the Swedish version of the ABC measure from 15 August to 30 September, 2011.

### **Test-retest (Paper I)**

For test-retest, the Danish ABC measure was completed twice with an interval of two to three weeks in the period from March to June 2012. This interval was believed to be sufficiently long for the respondents not being able to precisely recall their previous responses, and so short that it would be unlikely that the respondents' cancer awareness, beliefs and barriers would have changed. The telephone interviews for the test-retest were carried out by two student workers who went through a small training programme and several pilot-interviews to attain consistency across interviews and interviewers.

**Known group comparison (Paper I)**

Due to difficulties in recruiting participants to the known group comparison and because we did not want the data from the known group comparison to be affected by a Danish cancer awareness campaign that was carried out March-April 2013 (89), the data were collected in two rounds from November 2012 to March 2013 and from November 2013 to January 2014. The interviews were carried out by three student workers of whom two had also conducted the interviews for the test-retest.

**Content validity assessment (Paper I)**

The content validity assessment was performed in November 2014. Here academic researchers having expertise in creating and validating measurements and in cancer and public health research were invited per mail to go through the measure and to evaluate its contents in terms of whether items adequately reflected and comprehensively represented the constructs intended to be measured.

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## STUDY POPULATIONS

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### **The Danish population sample (Paper I-IV)**

Among the study base of 60,000 persons aged  $\geq 30$  years, 6,570 (11.0%) persons were registered with research protection. Of the remaining 53,430 persons, NN Marketsdata was able to identify the landline and/or mobile phone number of 47,121 persons (88.2%). Of these, the update from the CRS identified seven persons with a newly established research protection status, 11 persons who had emigrated from Denmark and 37 persons who had passed away. Thus, 47,066 persons were eligible to be contacted to answer the ABC measure. However, not all these persons were approached. Ipsos MORI conducted interviews for the Danish ABC measure until the target recruitment of 3,000 respondents was achieved. To achieve this target, 11,297 persons were approached. Of these, 1,664 persons (14.7%) were not reached due to technical annulment (e.g. unobtainable number), 1,431 persons (12.7%) could not be contacted after seven attempts and 33 persons (0.3%) were unable to speak or understand Danish. Hence, 8,169 persons were eligible and successfully contacted, of whom 5,169 refused or did not complete the interview, resulting in a total of 3,000 respondents completing the full interview of the ABC measure. The overall response rate was calculated as 36.7% by dividing the number of completed interviews ( $n=3,000$ ) with the number of eligible persons successfully contacted ( $n=8,169$ ). Figure 2.2 is a flowchart showing the recruitment process.

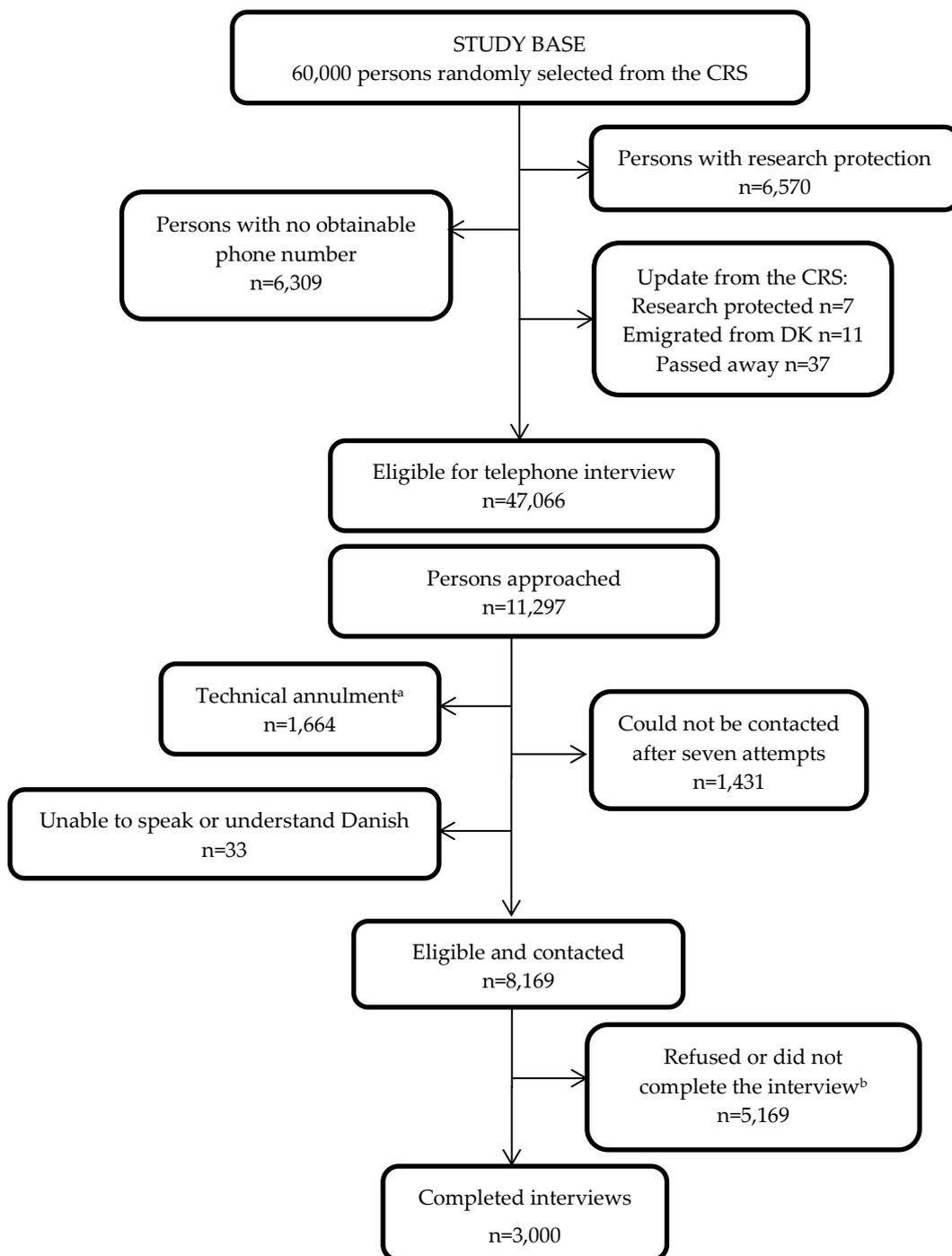


Figure 2.2. Flowchart of recruitment for the Danish sample.

<sup>a</sup> Includes unobtainable number; business/fax number; wrong and barred number.

<sup>b</sup> Includes persons who refused before receiving information about the study; refused after receiving information about the study; asked to be called back, but could not be contacted again; stated that he/she did not want to speak to the interviewer; another stated that the person eligible for the study was not available during data collection period; stated that he/she was not in the age group anyway and stopped the interview.

Table 2.3 is not included in any of the papers, but has been included here in the method to show the SEP characteristics of the study base, respondents and the various groups of non-participants. In this table, the 5,169 persons who declined or did not complete the interview are divided into two groups: a group of 3,106 persons who declined before being given information about the study and 2,063 persons who declined after they had been introduced to the study. The differences between the groups will be discussed in the section on selection bias, Chapter 7.

Table 2.3. SEP characteristics of the study base, non-participants and respondents

SEP indicators	Study base	Research protection	No phone number	Technical annul.	Could not be contacted	Refused before study information	Refused after study information	Respondents
<b>N</b>	60,000	6,577	6,309	1,664	1,431	3,106	2,063	3,000
<b>Gender</b>								
<i>Female</i>	51.6	50.5	51.3	49.3	53.0	48.7	54.1	55.3
<i>Male</i>	48.5	49.5	48.7	50.7	47.0	51.3	45.9	44.7
<b>Age</b>								
<i>30-49</i>	33.3	57.7	36.2	50.8	47.6	30.7	24.4	33.3
<i>50-69</i>	46.2	33.2	43.5	40.1	42.1	43.5	42.9	50.3
<i>≥ 70</i>	20.5	9.1	20.4	9.1	10.3	25.9	32.7	16.3
<i>Mean age</i>	56.7	48.5	56.1	50.6	51.4	58.8	61.7	55.9
<b>Marital status</b>								
<i>Married/cohabit.</i>	67.5	60.7	45.4	69.5	68.6	72.2	67.3	76.8
<i>Living alone</i>	32.5	39.3	54.6	30.5	31.4	27.8	32.7	23.2
<b>Ethnicity</b>								
<i>Ethnic Danes</i>	92.2	92.1	84.8	87.8	90.2	93.3	93.5	95.9
<i>Immigrant/Descendants</i>	7.8	7.9	15.2	12.2	9.1	6.7	6.5	4.1
<b>Education</b>								
<i>High</i>	22.5	20.8	19.0	26.8	26.3	19.7	17.9	32.3
<i>Middle</i>	47.1	49.3	43.3	50.7	50.2	47.0	44.0	46.2
<i>Low</i>	30.4	29.9	37.7	22.5	23.5	33.2	38.1	21.5
<b>Occupation</b>								
<i>Labour force</i>	56.5	65.2	48.6	70.5	70.0	54.0	44.9	62.6
<i>Outside</i>	11.2	18.5	19.4	12.7	10.8	8.7	9.6	8.1
<i>Retired</i>	32.3	16.3	32.0	16.7	19.3	37.2	45.5	29.3
<b>Household income</b>								
<i>High</i>	20.0	13.1	15.5	18.8	22.3	19.7	16.8	25.2
<i>Middle</i>	60.0	64.3	53.6	62.5	61.6	59.6	59.9	63.6
<i>Low</i>	20.0	22.6	30.9	18.6	16.1	20.7	23.3	11.2
<b>Cancer (10 years)</b>								
<i>Yes</i>	7.7	5.8	7.4	5.7	6.9	7.5	9.5	8.6
<i>No</i>	92.3	94.2	92.6	94.4	93.2	92.5	90.6	91.4

**The Swedish population sample (Paper II)**

Among the 23,000 persons  $\geq 30$  years of age randomly selected from the SPAR, Infodata was able to obtain a phone number for 19,042 persons (82.8%), who were eligible to be contacted by Ipsos MORI.

In total, 12,750 persons were approached, but it was not possible to get hold of 1,113 persons (8.7%) due to technical annulment and another 3,414 persons (26.8%) were not reached after having been called on seven occasions at different weekdays and times. Lastly, 102 persons (0.8%) were unable to speak or understand Swedish. In total, 8,121 persons were eligible for inclusion and were successfully contacted and 3,070 persons completed the Swedish ABC measure; hence, the response was 37.8%. A detailed flowchart of the Swedish population sample is shown in Figure 2.3.

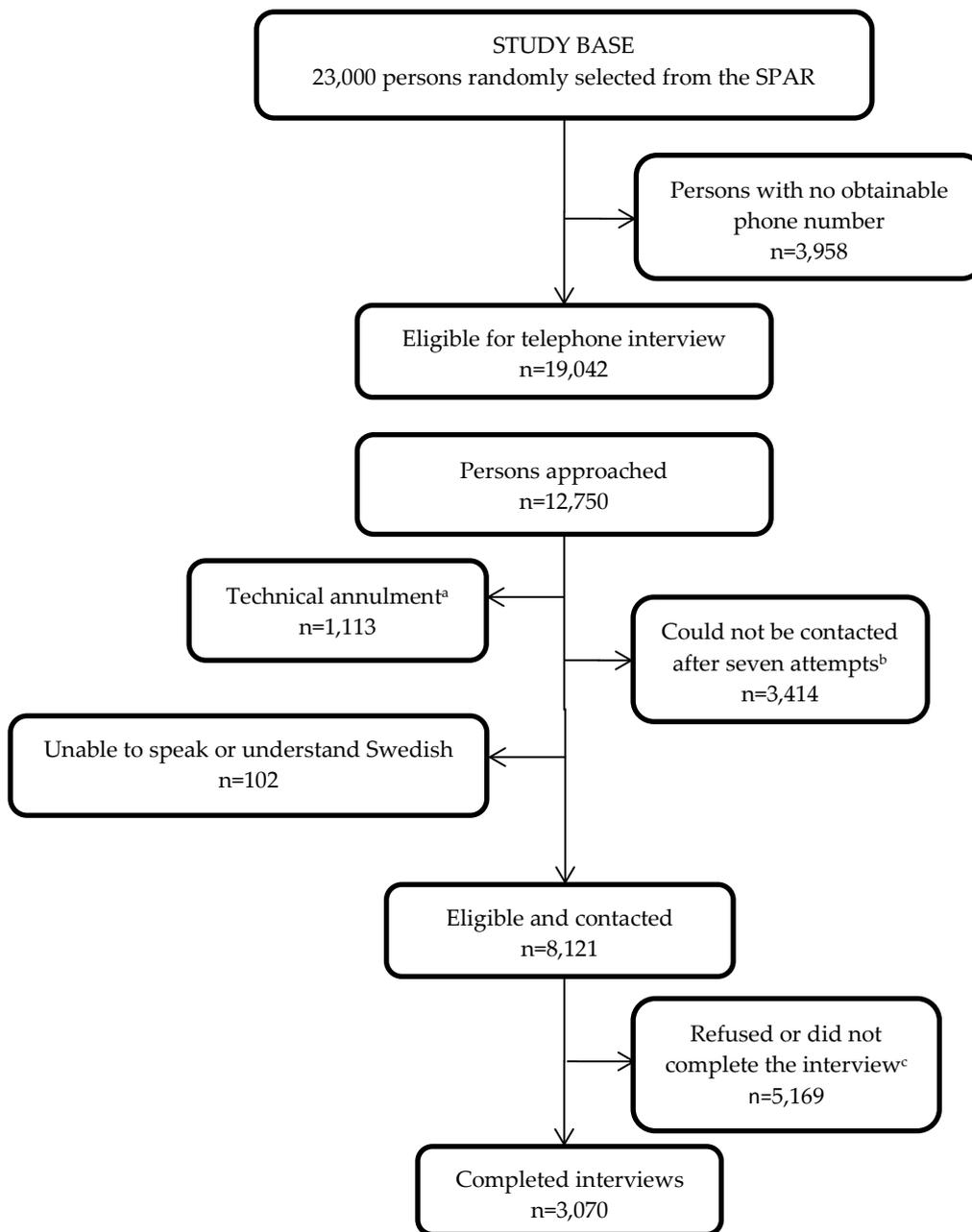


Figure 2.3. Flowchart of recruitment for the Swedish sample.

<sup>a</sup> Includes unobtainable number; business/fax number; wrong and barred number.

<sup>b</sup> Includes persons could not be contacted after seven attempts; the persons answering the phone did not want to speak to the interviewer; another stated that the person eligible for the study was not available during the data collection period.

<sup>c</sup> Includes persons who refused before receiving information about the study; refused after receiving information about the study; asked to be called back at a later date, but could not be contacted again; stated that he/she was not in the age group anyway and stopped the interview.

**Participants for test-retest (Paper I)**

For the test-retest, persons aged 30-40 years and 60-70 years were included. Persons older than 70 years were not included, because we wanted to reduce the risk of cognitive impairment, which could affect stability over time. The persons for the test-retest were randomly selected among those who were eligible for being contacted to answer the Danish ABC measure, but who had not been approached. In total, 362 persons were approached for participation and 138 persons (38.1%) participated on both occasions. A transition question was included, and respondents who thought that their awareness and beliefs about cancer had changed since the test interview were excluded (n=15); hence, 123 persons were included for the test-retest. The flowchart for the test-retest is presented in Paper I, Chapter 3.

**Groups for known-group comparison (Paper I)**

Three groups were included for the known-group comparison: 1) Blue-collar workers at Building Service at Aarhus University; 2) academics at departments at Aarhus University 3) GPs and doctors at the Department of Oncology at Aarhus University Hospital. Following authorization from a senior member of each department, an email was sent to employees who were asked to write back if they agreed to participate. Subsequently, a day and time was scheduled where they were called to answer the ABC measure. In total, 56 persons were included: 16 blue-collar workers from the Building Service, 21 academics from departments at Aarhus University and 19 GPs and oncologist.

**Researchers for content validity assessment (Paper I)**

In total, 10 academic researchers from the Research Unit for General Practice, Aarhus were invited to participate and all agreed.

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## EXPOSURE VARIABLES

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### **Paper II**

Country, i.e. Denmark and Sweden, was used as the exposure variable.

### **Paper III and IV**

The exposure variables used in Paper III and IV were gender, age, marital status, ethnicity, educational level, occupation, OECD-modified disposable household income, cancer diagnosis within the past 10 years, close relative(s) with cancer and self-rated health. The categorisation of the SEP indicators will now be explained.

Gender was categorised as male and female. Age was categorised into the following age groups: '30-49 years', '50-69 years', and '≥70 years'. Marital status was categorised as 'married/cohabiting' and 'living alone' as per 1 January 2011. Ethnicity was categorised as 'ethnic Danes' and 'immigrants/descendants', based on country of origin and citizenship (90) as per 1 January 2011. Educational level was categorised according to the International Standard Classification of Education (ISCED) developed by UNESCO as 'low: ≤10 years', 'middle: >10≤15 years', and 'high: >15 years' (91) as per 1 January 2011. Occupation was categorised into 'in the labour force' (i.e. employed and students), 'outside the labour force (i.e. unemployed, early retirement pensioner, disability retirement pensioner, personal leave or sick leave, and retired), and 'voluntarily retired person' (i.e. special pension or old-age pensioner) on the basis of the main affiliation in year 2010. For household income, the OECD-modified disposable household income was used where the household's total disposable income is divided by equivalent size to take account of the size and composition of the household. The first adult in the household is assigned a weight of 1, each additional adult the weight of 0.5 and each child (≤ 14 years) a weight of 0.3 (92,93). Income was divided into quintiles based on the distribution of household income for the study base and categorised into three groups: 20% with the lowest income (≤16,536 £/year), 60% with a middle income (>16,536 ≤ 33,095 £/year) and 20% with the highest income (>33,095 £/year); the

income was calculated based on a 3-year average for the years 2008-2010. Data on the above-mentioned variables were all retrieved from Statistics Denmark (78).

Cancer diagnosis within the past 10 years was categorised into yes and no based on information from the DCR (33). Close relative(s) with cancer was categorised into yes and no. Self-rated health was categorised into good and fair/poor. Data on the latter two exposure variables were obtained from the Danish ABC measure.

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## OUTCOME VARIABLES

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### **Paper II**

#### *Lack of awareness*

Responses of 'no' and 'don't know' were combined to indicate lack of awareness of the following three symptoms of cancer: unexplained lump or swelling, unexplained bleeding and persistent cough or hoarseness.

#### *Longer anticipated patient interval*

For any breast changes and rectal bleeding, a longer anticipated patient interval was defined as an interval of > 2 weeks (i.e. the response categories: over 2 up to 3 weeks, over 3 up to 4 weeks, more than a month, and I would not contact my doctor); and for a persistent cough, a long anticipated interval was defined as > 3 weeks.

### **Paper III**

#### *Anticipated barriers to healthcare seeking*

The response options 'yes, often' and 'yes, sometimes' that the particular barrier in question could put them off going to the doctor were combined to indicate an anticipated barrier to healthcare seeking.

### *Beliefs about cancer*

For the six beliefs about cancer (three positively and three negatively framed), response options were categorised as strongly agree/tend to agree and strongly disagree/tend to disagree, and the outcomes were agreement with each belief.

## **Paper IV**

### *Awareness of less than nine symptoms of cancer symptoms*

A total score was generated by summarising responses to the 11 possible cancer symptoms (no/don't know: 0 points; yes: 1 point) which resulted in a possible range of 0-11. By using the median split, awareness of cancer symptoms was categorised into low (<9 symptoms) and high ( $\geq 9$  symptoms) awareness.

### *Awareness of less than nine risk factors for cancer*

Awareness of risk factors for cancer was computed using the same method (strongly disagree/tend to disagree/don't know: 0 points; tend to agree/strongly agree: 1 point) which gave a possible range of 0-13. Low awareness was defined as awareness of < 9 risk factors and a high awareness as awareness of  $\geq 9$  risk factors.

### *Lack of awareness of growing risk of cancer with age*

The answer '70-year-olds' was coded as correct, while all other answers were coded as incorrect and used as the outcome.

### *Lack of awareness of 5-year survival of cancer*

Awareness of 5-year survival from breast, bowel, lung and ovarian cancer was dichotomised into correct estimation and lack of awareness (underestimation and overestimation) by using information on these numbers from the Danish Health Authority and the Danish Cancer Society. The following answers were coded as correct: Breast (8-9), bowel (4-5), ovarian (3-4) and lung (1-2) (94,95).

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## STATISTICAL ANALYSES

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### **Paper I**

Data quality was assessed in terms of discriminative ability and percentage of respondents answering 'don't know' or 'don't want to answer' for each item. Content validity was evaluated based on content validity indexes, using ratings of item relevance and construct comprehensiveness from the ten academic researchers. Construct validity was determined by a confirmative factor analysis (CFA) and explorative factor analysis (EFA) using the Danish survey data; and to assess the goodness of fit, the following three indices were used: The comparative fit index (CFI), the Tucker-Lewis Index (TLI) and the root mean square error of approximation (RMSEA) (96). Also, construct validity was assessed by testing predefined hypotheses about expected differences between the three groups included for known-group comparison. Differences in proportions between the groups were assessed using Fisher's exact test. Lastly, the test-retest reliability was assessed using unweighted Cohen's Kappa (97) for nominal items, quadratic weighted Kappa for ordinal items and the intraclass correlation coefficient (ICC<sub>2,1</sub> (98)) for the total number of symptoms and risk factors recognised. The CFA and EFA were conducted using Mplus version 7.4 (99), and all other statistical analyses were performed using Stata version 13.1.

### **Paper II-IV**

Multivariable analyses using a generalised linear model (GLM) for the binomial family were carried out, and estimates were reported as prevalence ratios (PRs) with 95% confidence intervals (CIs) (100). For all three papers, data were analysed using Stata 13.1, and an unadjusted model was presented followed by multivariable analysis adjusting for possible confounders (see the individual papers for further detail).

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## ETHICS AND APPROVALS

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The study was approved by the Danish Data Protection Agency (J. no.2011-41-6237) and the Danish Health Authority. In accordance with the Central Denmark Region Committees on Biomedical Research Ethics, the study needed no further approval (Report no. 128/2010).

However, asking people questions about possible cancer symptoms and cancer beliefs may cause anxiety and distress. Hence, an agreement was made with the Danish Cancer Society that respondents were offered contact details so that if at any point during the telephone interview they had concerns or questions regarding cancer they were informed that they could contact the Danish Cancer Society. Also, in the introduction to the telephone interview, respondents were informed that all information would be treated in the strictest confidence and that their responses would not be passed onto their GP.

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## STUDY DESIGN

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A cross-sectional study design was applied in all the studies. This design is limited by allowing measurement of exposure and outcome variables only at one single point in time and the design cannot be used for determining the causal direction of the observed associations (101). However, the cross-sectional design was very efficient for obtaining information on awareness and beliefs about cancer and about barriers to healthcare seeking within a short time period and at a relatively low cost. This design was also appropriate for exploring several possible exposure-outcome associations across Denmark and Sweden and across socio-economic groups within Denmark.

It was not ideal that the data used for the content validity assessment, the known-group comparison and the test-retest were collected after the Danish ABC survey because this barred us from making any alterations to the Danish ABC measure before using it within the large population sample. Nevertheless, the systematic evaluation of the measurement properties of the Danish version of the ABC measure provided useful knowledge that will be used in this discussion of the methods as well as in the discussion of the results, the conclusion and the suggestions for future research.

### **Computer-assisted telephone interviews**

The ABC measure was designed to be used for computer-assisted telephone interviews (CATI) and this raised some methodological issues. Firstly, response rates have been declining over the past decades and surveys using telephone interviewing have been particularly affected by this decline (102). This decline may likely be attributed to the growth in telemarketing (103); and public debates on violation of privacy and confidentiality are likely to have worsened the situation even more (104). We had many fruitful discussions within the Danish ICBP Module 2 Group about collecting data using telephone interviews and would have preferred to send an introductory letter to potential respondents and informing them that they would be approached by telephone and invited to participate within a certain time period. This approach has shown to increase response rates (105). However, consistency in the manner in which data were

obtained was very important, and we therefore deselected that approach as it could not be used in all the participating ICBP countries (77).

Secondly, in order for the results to be reliable and valid, telephone interviewing requires that respondents comprehend a verbally presented item while reflecting on their verbal response on a rating scale (103). This requires several cognitive skills; and in relation to the more comprehensive statements on beliefs about cancer in particular, it was a disadvantage that the respondents could not see the statements themselves and could not reflect on the answers in private. Thirdly, interviewing by telephone may lead to social desirability bias and to underrepresentation of particular groups, which will be discussed in the sections on information and selection bias, respectively.

However, CATI was chosen over face-to-face interviews as well as web-based and paper-and-pencil versions of the ABC measure for several reasons. Firstly, it was a practical way to collect data across diverse geographic areas in the ICBP countries and it was less costly than face-to-face interviews (106), which is the method of choice for studies in this research area (66,73,107). Secondly, in contrast to web-based and paper-and-pencil questionnaires, respondents were not able to look up the answers at the internet or correspond with friends and family while answering. Thirdly, it facilitated data collection by randomising the order of items, by ensuring skip patterns were accurately followed and that only valid responses were provided.

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#### SELECTION BIAS

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By using the Danish CRS, we were able to obtain individual-level information on all the various groups of non-participants (Table 2.3 in the Methods, page 38). This is the first study in this research area which has data for all non-participants. The significance of selection bias will be discussed in relation to these groups below.

The first risk of selection bias appeared because about 10% of the study base had a publicly registered protection from being contacted for research purposes (108). In Denmark, the number of 'researcher protected persons rose from 24 in

1999 to 591,694 in 2006, because it became possible to obtain 'research protection' simply by ticking a box on a vacate form in these years. About 750,000 persons had a research protection status at the time of the Danish ABC survey (108). As can be seen from Table 2.3, persons with a research protection status were significantly younger than the study base. This was expected because younger persons are residentially more mobile than elderly people and the younger persons may intentionally or unintentionally have ticked the box on the vacate form (108). Thus, the exclusion of persons who had disclaimed any contact for research purposes is related to the exposure variable 'age', among others. However, as these persons were excluded for reasons we believe are not closely related to the outcome it merely affect the prevalence estimates and not the estimation of PRs.

The second risk of selection bias occurred in relation to data collection since this was performed using telephone interviews. Hence, persons with unavailable landline or mobile phone number, persons who were not reached due to technical annulment and persons who could not be contacted after seven attempts did not participate. These groups differed from the study base in certain ways, e.g. persons with an unavailable phone number were more often living alone, immigrant/descendants, had a lower-level education and a low household income. Again, it is anticipated that this dropout is mainly associated with the exposure as no information about the study was given at the time of this exclusion. Thus, the prevalence estimates may be affected by this selection, but it is unlikely that the PRs are affected.

Lastly, among those who were eligible and successfully contacted, a modest response rate of 36.7% was achieved. Of the 5,169 persons who declined to participate, 60% (n=3,106) declined before they had received any information about the study and even before it was confirmed that the person contacted was, indeed, eligible for study participation. However, the other 2,063 persons (40%) declined after they had received information about the study, some of them having answered part of the Danish ABC measure. These 2,063 persons are of particular interest because this non-response is evidently associated with exposure levels of, among other, educational level, occupation and household

income; and this non-response may be associated with the outcomes of interest. The majority of the 2,063 persons whom declined after they had received information about the study stated that they were just not interested (64%), did not have the time (10%), the survey took too long (5%) and it would be upsetting to take part because they had personal experience of cancer (5%); and a few persons stated that they did not know anything about cancer (2%). It is difficult to know what the underlying mechanism is for 'not being interested', but if the underlying mechanism is low awareness and negative beliefs about cancer then it has caused an underestimation of the social gradient found in cancer awareness and negative beliefs about cancer. However, this remains conjecture and we do believe that the population-based approach helped us reach a good representativeness of the study base. It is, however, very likely that the estimated prevalence of awareness of cancer symptoms and risk factors and of the negative beliefs about cancer is underestimated given the strongly graded relationship between SEP and these factors and the underrepresentation of people with a low educational level and low household income.

It is anticipated that similar selection mechanisms are present for the Swedish sample, and a similar response rate was also obtained in the two countries.

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#### INFORMATION BIAS

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The data used in the studies are obtained from the Danish registers (Statistics Denmark and the DCR) and the ABC measure. The risk of information bias from these two sources will be discussed in the following sections.

##### *Statistics Denmark and the DCR*

Data on SEP indicators were obtained from registers at Statistics Denmark. The DCR was used to identify persons who had received a cancer diagnosis within the past 10 years. Both the validity and the completeness of the registers at Statistics Denmark and the DCR are considered to be high, and the risk of systematic errors is estimated to be low (33,34,109,110). However, data from Statistic Denmark are extracted from already existing administrative registers and the reasons for 'missing' are unknown (111). Due to the fact that Statistics

Denmark and the DCR are only updated annually (109,110) and that the Danish ABC survey took place from May to July 2011 some misclassification of marital status, occupational status and income may have occurred in Paper III and Paper IV. However, the proportion of respondents with misclassification on SEP indicators is expected to be low and the advantages of using register-based information on SEP indicators outweigh the disadvantages. Thus, an advantage of using register-based information on SEP indicators is that data collection on SEP exposures are collected independently of the research questions and the outcomes of interest, which reduces the risk of differential misclassification (101). Thus, any misclassifications of SEP indicators are likely to bias the results towards the null.

#### *The ABC measure*

Paper I showed that the Danish ABC measure was accepted and understood by the target group and that test–retest reliability was moderate to substantial for most items, which limits some sources of information bias. However, evaluation of the data quality also showed some problems, which could result in misclassification.

The three main issues of information bias are related to the omission of a midpoint response in the ABC measure and to the outcomes ‘anticipated patient interval for healthcare seeking’ (Paper II) and ‘awareness of cancer symptoms’ (Paper II and IV).

The assessment of the data quality in Paper I showed that the number of respondents answering ‘don’t know’ to the items was non-acceptable for about every third of the items in the Danish ABC measure. This may partly be explained by the omission of a scale midpoint as respondents may have answered ‘don’t know’ when they felt that the other response options did not fit their answers. However, omitting a scale midpoint may also have forced some respondents to take side (e.g. agree or disagree), even where they may not have had such a preference (79), which would result in inaccurate measurement and misclassification.

To minimise potential social desirability bias, the questions on anticipated interval for healthcare seeking were asked in the beginning of the ABC measure and prompted response options of time intervals were not provided (112). However, the introduction had already set the context of early detection and cancer and the risk of social desirability bias in relation to these items should therefore be acknowledged. The tendency to give a socially desirable response in relation to health behaviour is well documented and so is the tendency for respondents to provide more socially desirable responses in interviews (face-to-face and telephone) than in self-administered questionnaires (113). It has also been acknowledged that culture is important in classifying behaviours as desirable or not (106). However, there appears to be no studies signifying that either Danish or Swedish citizens should give more socially desirable answers in relation to healthcare seeking for potential cancer symptoms. Moreover, the same data collection method was used in both countries, and all interviewers from both Denmark and Sweden completed the same structured training programme to minimise social desirability bias, among others. Therefore, if social desirability is an issue for the outcome of anticipated patient interval, it is most likely non-differential for the comparison between Denmark and Sweden. Another issue related to the anticipated patient interval outcomes is the hypothetical nature of these questions, which will be discussed in detail in the next chapter.

In Paper II and Paper IV, differences in awareness of cancer symptoms between Denmark and Sweden and between SEP groups were examined using a prompted recognition format. However, data on awareness of cancer symptoms were also assessed using an unprompted recall format. The two formats have been shown to produce very different estimates of awareness of cancer symptoms (66,107). Neither of the two formats is perfect and both have biases. Recall involves re-accessing experience or information from the past and is limited by retrieval of memory and the perseverance of the recall, and hence may underestimate awareness (107). In contrast, recognition may overestimate awareness because it elicits guessing (107,114) and respondents guessing correctly may be misclassified as having awareness of the symptom. The strength of agreement between test and retest assessed in Paper I for awareness

of cancer symptoms was categorised as 'poor', 'slight' and 'fair' for several of the eleven items, indicating that some degree of guessing may have occurred. However, this prompted format was used in the two studies because this process better reflects 'real life situations', where the symptom itself may act as a prompt after which it is recognised as potentially serious or not. Other studies have shown that the recall and recognition formats have similar correlates (66,107,115), and it is anticipated that a potentially incorrect classification of awareness is the same in the compared groups.

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### CONFOUNDING

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Gender, age, marital status, educational level, experience of cancer (Paper II-IV), ethnicity and self-rated health (Paper III-IV) were selected as confounding factors *a priori* and were adjusted for in the statistical models. However, the results could still be affected by residual confounding due to improper categorisation and unknown or unaccounted for confounding (101), and this is important to take into consideration in the interpretation of the results of the studies. Possibly unaccounted confounders for Paper II-IV could be smoking status and comorbidity.

Smoking is more prevalent among lower socio-economic groups than among higher socio-economic groups (116) and in Denmark than in Sweden (117). Also, smokers have been found to be more likely to hold negative beliefs about cancer than never smokers or former smokers (118). As a consequence, we may have overestimated the true association between e.g. low educational level and the negative belief that 'I would not want to know if I had cancer'. Yet, additional analyses showed that adjusting for smoking status (current, former or never) did not significantly alter the estimates presented in Paper III.

In Paper III and IV, we could have adjusted for comorbidity by extracting data from the Danish National Patient Registry (119). Low SEP is positively associated with comorbidity (120) and comorbidity gives rise to a higher frequency of symptoms (121) and comorbidity may affect the interpretation of

the symptoms, the beliefs about cancer and the anticipated barriers to healthcare seeking.

Lastly, in the validation paper (Paper I), we tested differences in cancer and barriers to healthcare seeking between different groups regarding educational level or medical proficiency. However, the groups differed on other indicators too; and as no adjustments were made, it cannot be excluded that residual confounding might be present.

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#### STATISTICAL ANALYSES

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In Paper I, the Kappa coefficient was computed using quadratic weighting for the ordinal items. However, calculation of the weighted Kappa ignored that the response scales were, in fact, ordinal. The rationale for using the weighted Kappa was that disagreement between adjacent categories was considered more reliable than disagreement between more distant categories and by using the weighted Kappa it was possible to make this division in the assessment of test-retest reliability.

In Paper II-IV, associations were estimated using GLM. This method was used because it provides PR estimates in cross-sectional studies which can be interpreted as relative risk (100). This method was preferred over logistic regression as odds ratios would have overestimated the associations as the prevalence of the outcome measures was generally high (100). The 95% confidence interval was chosen to indicate statistical significance. However, especially in Paper III and IV, a large number of significance tests was performed which increases the risk of type 1 error (101). For example, 10 independent tests were performed for the outcome 'awareness of risk factors for cancer', and the chance of at least one test being significant was no longer 0.05, but 0.40. Multiple testing corrections have been developed to solve this problem (e.g. Bonferroni correction (122)). However, sometimes a correction for multiple testing creates more problems than it solves, e.g. Bonferroni correction implies that a given test should be interpreted differently depending on the number of other tests (123). It may therefore be more appropriate simply to interpret the results in light of this limitation. For these reasons, we did not perform multiple

testing corrections in the papers. A similar line of argument lay at the root of our decision not to attempt to correct for any selection bias by using weights.

Lastly, all outcomes in Paper II-IV were dichotomised. For example, the anticipated patient interval for healthcare seeking for rectal bleeding was categorised as  $\leq 2$  weeks and  $> 2$  weeks. The anticipated patient interval was not analysed as a continuous variable as the increases in time intervals were unequal, making it an ordinal rather than an interval scale. Also awareness of symptoms and risk factors were dichotomised as neither were within the normal distribution ranges. Using the median split procedure to dichotomise awareness can come across as arbitrary and sensitivity analyses were therefore performed, which showed that the results were robust using different cut-off for low and high awareness.

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#### EXTERNAL VALIDITY

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The Danish study base of 60,000 persons was randomly selected from the Danish CRS and the only exclusion criteria were that the persons selected should be living in Denmark and be  $\geq 30$  years. We were able to contact both mobile and landline phone numbers. This was particularly important for achieving representativeness within the age group of 30-49-year-olds of whom 41% were not registered with a landline phone number. Thus, using this approach, we were able to target a selection of the Danish population that we believe closely resembles the entire population in terms of a number of SEP indicators. However, the generalisability of our findings may be affected by the various selections described under 'Selection bias' and to the fact that compared with the study base the respondents were more often females, younger, cohabiting, had higher educational level, were in the labour force, had higher household income and were of Danish origin. Hence, the prevalence estimates of especially awareness of symptoms and risk factors and of the negative beliefs about cancer in this thesis may underestimate the true prevalences in the general Danish population aged 30 years and older. We may also have underestimated the social gradient in cancer awareness and beliefs if the underlying reasons for 'not being interested' were related to having low cancer awareness and more

negative cancer beliefs, but we generally believe that the associations found in the studies apply to the Danish background population.

It is, however, important to note that there have been some large campaigns about symptoms of cancer and the importance of early detection since data was collected (89,124) and the prevalence estimates of awareness of cancer symptoms and the anticipated patient interval may have changed accordingly. Also, the campaigns may have affected the PRs depending on whether or not the information has accrued equally among the socio-economic groups (125).

In Sweden, the study base was 23,000 persons from the Uppsala-Örebro and Stockholm-Gotland healthcare regions. These two regions include a variety of large and medium-sized cities and rural areas. However, the average levels of education are higher than in the country as a whole (126). In addition, people with low SEP were also underrepresented among the Swedish respondents, and again this may have resulted in an overestimation of the awareness of the cancer symptoms studied in Paper II compared with the 'true prevalence of awareness' in Sweden. We are inclined to believe that the estimates of the associations between Denmark and Sweden have not been considerably affected given that the selection mechanisms are similar in the two countries.



# CHAPTER 8

## DISCUSSION OF RESULTS

This chapter discusses the main results of the four individual papers. The results are discussed in relation to the aim of each paper and in relation to the results of other studies.

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PAPER I

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**Measurement properties of the Danish version of the Awareness and Beliefs about Cancer (ABC) measure**

Like a similar study on the English ABC measure (77), we found that the Danish ABC measure was accepted and understood by the target group and that the items comprehensively represented each construct (e.g. awareness of cancer symptoms). The ABC measure also discriminated well between non-medical academics and medical academics, a finding that is consistent with the known-groups comparisons in the generic and cancer-specific versions of the CAM (72,112,127-129). However, the Danish ABC measure did not discriminate well between the blue-collar workers and non-medical academics. It was surprising that 80% of the blue-collar workers were aware that unexplained bleeding could be a warning sign for cancer compared to only 60% of the academics, as earlier studies have found that people with higher SEP are more aware of this symptom compared to people with lower SEP (66,112). There were more women among the academics (48%) than among the blue-collar workers (37%), but since earlier studies have found that women are more aware of an unexplained bleeding than men (66,74,112,130), our finding cannot be explained by the difference in gender between the two groups.

We found that the 'beliefs about cancer' subscale measured two constructs. Thus, it seems that the positive and negative beliefs about cancer are not two poles on a unidimensional scale. Earlier studies (131,132) have used the Burns' Cancer Beliefs Scales (133) to assess beliefs about cancer. The Burns' Cancer Belief Scales ask respondents to select between opposing terms (e.g. certain death vs. being cured and optimism vs. pessimism) each placed at opposite ends of a seven-point Likert scale (133). However, using such scales may distort the picture if the positive and negative beliefs people have about cancer cannot be seen as mutually excluding each other. This issue will be addressed further in the discussion of Paper III. Also, because the subscale 'beliefs about cancer' was not unidimensional, the use of a sum-score based upon the six items on beliefs about cancer is not appropriate for analysing the data (79). In Paper IV, we used sum-scores to evaluate awareness of cancer symptoms and awareness of cancer

risk factors. This analysis was supported by the EFA and the ICCs, which found that these subscales were unidimensional and reliable.

Test-retest reliability was moderate to substantial for most items in the Danish ABC measure, but two items on the subscale 'awareness of cancer symptom' had poor (change in the appearance of a mole,  $k=-0.01$ ) and slight (unexplained lump or swelling,  $k=0.20$ ) kappa coefficients. This was despite high observed agreements of 98% for a change in the appearance of a mole and 90% for an unexplained lump or swelling. This apparent paradox has been highlighted by Feinstein and Cicchetti (134) proposing it to be explained by a high sensitivity of the Kappa statistic to the distribution of the marginal totals, also known as the prevalence bias (79). Hence, the prevalence of the response 'yes' was very high for these two items at both time points and the symptoms should not be omitted from the subscale 'awareness of cancer symptom' due to their importance for face validity (77,79).

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## PAPER II

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### **Awareness of cancer symptoms and anticipated patient interval for healthcare seeking. A comparative study of Denmark and Sweden.**

In Paper II, we focused on the three common cancers (breast, colorectal and lung) and tested the hypotheses that the awareness of cancer symptoms is higher and the anticipated patient intervals are shorter among the Swedish respondents than among the Danish respondents. Yet, contrary to what we expected, we found that the Swedish respondents were more likely to lack awareness of an unexplained lump or swelling and persistent cough or hoarseness as potential cancer symptoms and more likely to have longer anticipated patient intervals (>2 weeks) for any breast changes and rectal bleeding. However, the absolute differences were small and it was reassuring that the majority of the respondents (>90%) in both countries anticipated seeking healthcare within 2 weeks after noticing any breast changes or rectal bleeding and that most respondents would go to their doctor as soon as they noticed these two symptoms.

Other studies exploring anticipated patient intervals in population samples have found a similar proportion of people who report that they would wait less than 2 weeks for these symptoms (66,135). One study conducted by Quaipe et al. (135) used the ICBP Module 2 data from the three UK jurisdictions (England, Wales and Northern Ireland) restricted to respondents'  $\geq 50$  years and found that 92% and 93% of the UK respondents anticipated going to their doctor within 2 weeks after noticing any breast changes and rectal bleeding, respectively. Hence, the anticipated patient intervals seem not to vary much between these countries.

It has been questioned whether intentions to seek help translate into actual healthcare seeking behaviour (136). Actual healthcare seeking behaviour among the general population was recently estimated in a large Danish nationwide study (137). In this study, approximately 65% of persons who had noticed rectal bleeding within the past 4 weeks reported that they had not contacted their GP (137). Thus, it seems unlikely that anticipated healthcare seeking will map onto actual healthcare seeking behaviour. However, the approach used in the present study was a pragmatic one that allowed us to explore intentions of healthcare seeking in two countries where differences in survival for breast, colorectal and lung cancer are relatively large (23,68).

Persistent cough or hoarseness was recognised as a warning sign of cancer by 76% of the Danish respondents compared with 65% of the Swedish respondents. In the UK sample, this symptom was recognised by 70% (135). The underlying reasons for these differences in symptom awareness are unknown, but the finding that the Danish respondents had higher awareness of symptoms of cancer than the Swedish respondents is not confined to the symptoms examined in this paper. Hence, additional analyses have shown that the Danish respondents are more aware than Swedish respondents of 10 out of the 11 symptoms examined. In contrast, the Swedish respondents are more aware than the Danish respondents of 10 out of the 13 risk factors studied in the ABC measure (138).

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PAPER III

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**Barriers to healthcare seeking, beliefs about cancer and the role of socio-economic position. A Danish population-based study**

Like the anticipated patient interval, we assessed the barriers to healthcare seeking using a hypothetical scenario. We found that approximately every fourth respondent reported that being too busy could put them off going to the doctor when experiencing a potentially serious symptom. Interestingly, in the Danish study on *actual* healthcare seeking, a much similar response was found for this barrier (139). Hence, among the approximately 65% of the respondents who had not contacted their GP with rectal bleeding, 26% reported that the reason was that they had been too busy (139). Competing demands and priorities may explain this finding; and because people in the labour force were much more likely to endorse this barrier in this study and others (66,73,140), it is possible that the competing priority is, indeed, work. Prioritising work over one's own health has also been found to be a delaying factor in the literature on patient interval among cancer patients (3,15,141). Greater flexibility in how people access primary care may lessen this barrier to healthcare seeking. There are, however, often conflicting objectives (142) as for example in relation to extended opening hours in general practice (143). In the General Practice Patient Survey it was found that among the 20% of respondents who found that current opening hours were inconvenient, the majority (74%) stated that Saturday opening would make it easier for them to access general practice. Those who worked full time were more likely to report that improved access at Saturday would help (144). However, while this may indicate that such flexibility may reduce the barrier that being too busy could put them off going to the doctor, when experiencing a symptom that might be serious, it could have implications for continuity of care and availability at other times (142,143), which could potentially reinforce the social inequality that we seek to alleviate.

Another highly endorsed barrier among the general Danish population was worry about what the doctor might find. This barrier was endorsed by every fourth respondents and again a similar response was found in the Danish study on actual healthcare seeking, where 21% of those who had not contacted their

GP with rectal bleeding stated that they had not done so because they were worried what the doctor might find (139).

In this study, 15% also expressed worry about wasting the doctor's time as a possible barrier to healthcare seeking. The endorsement of this barrier is lower than found among respondents in the UK (34% among respondents aged  $\geq 50$  years (145)); but similar to the proportion (17%) that did not seek healthcare for rectal bleeding in the Danish study (139). Worry about wasting the doctor's time may both be related to self-identity (e.g. fear of being labelled a 'time-waster' (15)) and to the norms that govern the medical consultation (146,147), and it is reasonable to believe that the two are interrelated. Beyond having the potential to increase the patient interval (15), such a barrier might also affect the diagnostic interval (Figure 1.2, page 17) (48). For instance, if people do not communicate the complexity of their symptoms, because they feel they must hurry in order not to use too much consultation time (148). This is particularly disquieting seen in the light of that people reporting fair or poor health were more likely to endorse this barrier.

As noted in the discussion of Paper I, the EFA on the 'beliefs about cancer' subscale revealed two independent constructs rather than a bipolar unidimensional one. This is very well reflected in the proportion agreeing that cancer can often be cured and that a diagnosis of cancer is a death sentence. Hence, 87.6% of the respondents agreed that cancer can often be cured; yet, at the same time, 28.5% agreed that a diagnosis of cancer is a death sentence. These apparently contradictory results have also been found in the UK sample which was part of the ICBP Module 2 (149). However, interpreting the results in light of the dual-processing theory (150), these results are neither unexpected nor contradictory. The dual-processing theory distinguishes between two processes: Type 1 which has been characterised as fast, non-analytic and intuitive and type 2 which denotes a slow, analytic and reflective reasoning (150,151). In the context of the present study, the beliefs that cancer is a death sentence could be a type 1 response and the beliefs that cancer can often be cured could be a type 2 response. Interestingly, a qualitative study on the balance of positive and negative beliefs also found that the first response of cancer identified fear or

death, but this first response was followed by a reflective reasoning that cancer can be curable in almost all interviews. As expressed by one of the participants in the qualitative study: *"I see it as a killer, although I'm heartened by the fact that the rate of cure is increasing"* (152). Hence, the inclusion of both positive and negative beliefs in the ABC measure is essential in order to access beliefs about cancer in a general population, which was one of the aims of this study. Another aim was to analyse the association of such beliefs with SEP. The analysis of this association showed that respondents with a low educational level and those with a low household income were more likely to hold negative beliefs about cancer than those with a high educational level and a high household income. As suggested by others (153), life experiences of people with lower SEP can engender negative beliefs about cancer. This may, among other, be explained by the fact that people with lower SEP are more likely to experience fatal cancers such as cancer of the lung and pancreas, whereas less aggressive cancers such as breast and prostate cancer are more common among higher socio-economic groups (35). Breaking the vicious circle is not likely to be easy, but addressing these negative beliefs may lead to earlier detection of cancer, especially in the lower socio-economic groups.

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#### PAPER IV

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##### **Cancer awareness and socio-economic position: results from a population-based study in Denmark.**

In this study, we found that people with lower educational level and lower household income were more likely to have a lower awareness of cancer symptoms and cancer risk factors than people with higher educational level and higher household income, and the association proved robust at different cut-offs for awareness. These results confirm findings from earlier studies (130,154,155). One possible explanation for the consistent associations between educational level and household income and cancer awareness may lie in the ability to obtain, process and understand health information, i.e. health literacy (153,156). A Danish study (157) found that low health literacy skills for understanding health information were associated with low education level and low income

(157), and a UK study specifically found that individuals with low health literacy had lower symptom awareness (158).

A rather surprising result was the lack of awareness of the growing risk of cancer with age among the respondent in general and among respondents with low educational level and low household income in particular. In total, 42% responded that people of any age are equally likely to be diagnosed with cancer, and merely a quarter of the respondents were aware that 70-year olds were at a greater risk of developing cancer than younger people. According to the 'availability heuristic', the probability of an event is judged by how easily examples of that event come to mind rather than by identifying all the alternatives and calculating the real probabilities (159). The media are undoubtedly a source to cancer information and the media might focus on younger people who have cancer and hence these examples may be more *available*, maybe in particular to people with lower SEP.

# CHAPTER 9

## MAIN CONCLUSIONS

This chapter presents the main conclusions drawn from the included papers.

In **Paper I**, we found that the Danish ABC measure was understandable and acceptable and had adequate reliability and validity when used in the general Danish population. However, the data quality was unacceptable because of the high proportion of 'don't know' responses. Moreover, the measure had some difficulties in discriminating between educational groups, and the subscale 'beliefs about cancer' was two-dimensional.

In **Paper II** it was somewhat surprising that the highest awareness of an unexplained lump or swelling and persistent cough or hoarseness was found in the Danish sample which also had shorter anticipated patient intervals for breast changes and rectal bleeding than the Swedish sample. However, the absolute differences were small, and it is fairly unlikely that the anticipated patient intervals can be used as a proxy for actual healthcare seeking behaviour.

**Paper III** assessed anticipated barriers to healthcare seeking and beliefs about cancer in the Danish population sample. Worrying about what the doctor might find and being too busy to make time to go to the doctor were endorsed by every fourth respondent as anticipated barriers when experiencing a potentially serious symptom. The former barrier was significantly more likely to be endorsed by persons with a low-level education, whereas persons with a high-level education were significantly more likely to endorse the latter. People reporting fair or poor health were more likely to worry about wasting the doctor's time than people reporting good health. Seen in the light of the healthcare seeking literature, the anticipated barriers assessed here are likely to reasonably well reflect actual barriers people experience when they are faced with a possible cancer symptom. The overall proportion of respondents who agreed with the positive beliefs about cancer was high (e.g. that cancer can often be cured); fewer agreed with the negative beliefs about cancer (e.g. that a diagnosis of cancer is a death sentence) and both constructs are important in an effort to obtain a nuanced assessment of beliefs about cancer. Having a low educational level and a low household income were strongly associated with the negative beliefs about cancer.

In **Paper IV**, we found large variations in awareness for the 11 symptoms, the 13 risk factors and for the awareness of 5-year survival for bowel, breast, ovarian, and lung cancer. Also, we found socio-economic differences with a lower awareness of symptoms and risk factors among people with a low educational level and a low household income and the findings were robust when different cut-offs for low awareness were used. No clear socio-economic differences were found for awareness of 5-year survival from four mentioned cancers.

The underlying assumption for this PhD project was that low cancer awareness, negative beliefs about cancer and anticipated barriers to healthcare seeking are likely to contribute to a longer patient interval, decreasing the chance that the cancer is found at an early stage and ultimately decreasing the chance of survival. The studies in this thesis were, however, not designed to answer whether differences in these determinants can help explain the differences in survival between Denmark and Sweden and between socio-economic groups within Denmark. Therefore, I will evade from answering this question, especially, given the complexity of the cancer pathway described in the very first chapter of this thesis. Yet, this thesis has drawn attention to some of the determinants that can affect the patient interval and possibly also other intervals in the cancer pathway and it has highlighted differences and similarities between Denmark and Sweden and between socio-economic groups in Denmark.



# CHAPTER 10

## PERSPECTIVES AND FUTURE RESEARCH

It was encouraging to see that the majority of the respondents anticipated a short patient interval for potential cancer symptoms and that there was near-universal agreement that going to the doctor quickly increases chances of surviving, which may indicate that initiatives regarding healthcare seeking for potential cancer symptoms will fall on fertile ground. The findings of this thesis also indicate that such initiatives should not merely focus on cancer awareness, which has been the main focus of policy and national campaigns (69,89,124). They should also react to the common barriers anticipated by the general population and to the negative beliefs about cancer which, given the two-dimensionality of the construct, may not necessarily be achieved by increasing the positive beliefs about cancer. Moreover, it is important that if an intervention is being planned, monitoring of effect should be included (160).

A systematic review of interventions to promote cancer awareness and early presentation found limited evidence that they increase cancer awareness in the long-term and that they promote early symptomatic presentation (160). However, there is now some evidence that recent English Be Clear on Cancer campaigns have been able to raise awareness and to promote earlier stage at diagnosis (161-163), yet; they have not been able to reduce barriers to healthcare seeking (161) and different approaches may be needed to achieve this. The impact of such national campaigns has also raised concerns about adding to GP workload, over-investigation, increasing treatment delay for other diseases (164-166). Such adverse outcomes should be considered and further explored in future research.

Another and very different area for future research is to link individual respondents' ABC responses to future screening behaviour and cancer diagnoses in a prospective research design. The year 2014 saw the introduction of national screening for colorectal cancer using immunochemical faecal occult blood test (iFOBT) in Denmark; and over a 4-year period (2014-2017), all Danish citizens aged 50-74 years are invited to take part in the screening programme (167). The ABC survey data were collected in 2011 and a total of 1,773 men and women 50-74 years of age participated. We have a unique possibility to link ABC survey data to participation in colorectal cancer screening, while adjusting

for possible confounders such as the SEP indicators from Statistics Denmark. The strength of this particular study would be the use of screening uptake from registries, the use of individual-level measures of SEP and the separation in time between exposure and outcome.

Lastly, this thesis raised a series of methodological issues related to administering the Danish ABC measure by telephone interviews. Therefore, if the measure is utilised in future research it may be considered collecting data using a web-based version of the ABC measure. This has shown to be feasible in a large Danish study on symptom experience and healthcare seeking (168). A web-based survey would still enable randomisation of the order of items, ensure that skip patterns were accurately followed, and it would give respondents the possibility to reflect on the answers in private. However, this approach would also enable the respondents to seek information by reading, consulting the internet and conferring with friends and family. The impact of this should be carefully considered, but like the discussion of the use of recognition of symptoms as opposed to recall of symptoms, this approach would resemble a 'real life situation', as the internet, friends and family are often consulted when persons experience symptoms (15,169).



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# ENGLISH SUMMARY

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## BACKGROUND AND AIMS

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Survival from cancer has generally improved worldwide, but considerable differences in cancer survival remain between countries and within countries among different socio-economic groups. The causes of these differences are multifactorial and complex. However, recent years have seen a strong focus on differences in awareness and beliefs about cancer and barriers to healthcare seeking as possible contributors to the duration of the patient interval (i.e. time from first symptom to first consultation), the chance of cancer being found at an early stage and, ultimately, the chance of survival.

As part of the of the International Cancer Benchmarking Partnership (ICBP), the Awareness and Beliefs about Cancer (ABC) measure was developed to be able to differentiate between countries and socio-economic groups in terms of awareness, beliefs and barriers.

This thesis used the internationally developed ABC measure, and the specific aims of the four studies were:

- (1) To appraise the translation process and measurement properties of the Danish version of the ABC measure (Paper I).
- (2) To compare awareness of symptoms of cancer and anticipated patient intervals between a Danish and Swedish population sample (Paper II).
- (3) To assess awareness and beliefs about cancer and anticipated barriers to healthcare seeking in a sample of the Danish population and to analyse the association with socio-economic position (SEP) (Paper III and IV).

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## METHODS

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This thesis comprises four papers. In all four papers a cross-sectional study design was applied and each paper used the Danish version of the ABC measure. Data was collected using telephone interviews among 3000 people  $\geq 30$  years in Denmark between 31 May and 4 July, 2011.

Paper I was also based on data from a forward and backward translation, a pilot-test among eight participants, content validity indexes from ten academic researchers, known group comparison analyses including 56 persons and a test-

retest among 123 person, whom completed the Danish ABC measure twice with an interval of 2-3 weeks. In Paper II, we used data from 3,070 Swedish respondents answering the Swedish version of ABC measure. Data on socio-economic position was obtained from registers for Paper III and IV.

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## RESULTS

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In **Paper I**, we found that the Danish ABC measure was conceptually equivalent to the English ABC measure. The data quality in relation to the number of respondents answering 'don't know' was non-acceptable (>3%) for about every third of the items. Content validity indexes showed that items adequately represented the constructs and factor analysis showed that all subscales except 'beliefs about cancer' were unidimensional. The ABC measure discriminated well between non-medical academics and medical academics, but not between educational groups. Test-retest reliability was moderate to substantial for most items.

Contrary to what we expected, in **Paper II** we found that the Swedish respondents were significantly less likely to be aware that an unexplained lump or swelling and persistent cough or hoarseness could be potential cancer symptoms than the Danish respondents. Also the Swedish respondents were more likely to have longer anticipated patient intervals (>2 weeks) for any breast changes and rectal bleeding than the Danish respondents, however, the absolute differences were small and the majority of all respondents anticipated a short patient interval.

We found that approximately every fourth of the Danish respondents reported that being too busy and worry about what the doctor might find could put them off going to the doctor when experiencing a potentially serious symptom. The former barrier was significantly more likely to be endorsed by persons with a high-level education, whereas persons with a low-level education were significantly more likely to endorse the latter. Further, in **Paper III**, agreement with the positive beliefs about cancer was high, while fewer agreed with the negative beliefs about cancer and having a low educational level and a low household income were only associated with the negative beliefs about cancer.

In **Paper IV**, we found a lower awareness of symptoms and risk factors among people with a low educational level and a low household income. No clear socio-economic differences were found for awareness of 5-year survival.

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#### CONCLUSIONS AND PERSPECTIVES

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Overall, the Danish ABC measure was understandable and acceptable and had adequate reliability and validity when used among the general Danish population. We found that respondents, overall, had intentions to and positive beliefs about seeking **care** promptly after noticing a potential cancer symptom. However, we also found that respondents endorsed positive and negative beliefs about cancer simultaneously and having a low educational level and a low household income were associated with having negative beliefs about cancer. Also these SEP indicators were associated with lower awareness of cancer symptoms and risk factors, which could potentially affect the patient interval. Interventions that aim to facilitate healthcare seeking for potential cancer symptoms should consider these findings and evaluation of such interventions should be prioritized.

# DANSK RESUME

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## BAGGRUND OG FORMÅL

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Kræftoverlevelsen er generelt steget i hele verden, men der findes stadig betydelige forskelle i kræftoverlevelsen mellem normalt sammenlignelige lande samt mellem socioøkonomiske grupper inden for hvert land. Årsagen til disse forskelle er multifaktoriel og kompleks, men i de senere år har der været stor fokus på, at viden og forestillinger om kræft samt barrierer for lægesøgning kan påvirke tiden fra første symptom til lægesøgning (kaldet 'patientintervallet'), hvilket kan have indflydelse på sygdomsstadie på diagnosetidspunktet og dermed kræftoverlevelsen.

Som en del af *the International Cancer Benchmarking Partnership* (ICBP) er *Awareness and Beliefs about Cancer* måleredskabet (ABC) blevet udviklet med henblik på måling og sammenligning af viden, forestillinger og barrierer mellem landes populationer og socioøkonomiske grupper. Med afsæt heri var formålene med dette ph.d.-studie:

- 1) At beskrive oversættelsen af ABC måleredskabet fra engelsk til dansk samt vurdere datakvaliteten, reliabiliteten og validiteten af det danske ABC måleredskab (artikel I).
- 2) At undersøge om der er forskelle i kendskabet til symptomer på kræft og forventet patientinterval mellem danske og svenske respondenter (artikel II).
- 3) At beskrive kendskabet til kræft (symptomer, risikofaktorer, overlevelse), forestillinger om kræft og forventede barrierer for lægesøgning, samt undersøge sammenhænge med en række socioøkonomiske karakteristika hos danske respondenter (artikel III og IV).

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## METODE

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Denne afhandling indeholder fire artikler. Fælles for de fire artikler er, at alle anvender et tværsnitsdesign og bygger på data indsamlet ved hjælp af den danske version af ABC måleredskabet. Data blev indsamlet blandt 3000

personer  $\geq 30$  år i Danmark ved hjælp af telefoninterviews i perioden fra 31. maj til 4. juli 2011.

Artikel I er derudover baseret på data fra oversættelsen (frem- og tilbageoversættelse), en pilottest blandt otte deltagere, indholdsvaliditetsindeks baseret på bedømmelser fra 10 forskere, 'known group'-sammenligning med 56 deltagere og en test-retest blandt 123 deltagere, der besvarede den danske version af ABC-måleredskabet med 2-3 ugers mellemrum. I artikel II blev data fra 3,070 respondenter, der havde besvaret den svenske version af ABC-måleredskabet, inkluderet. Data vedr. socioøkonomisk position blev indhentet fra registre til artikel 3 og 4.

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## RESULTATER

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I **artikel I** fandt vi, at den danske version af ABC-måleredskabet svarer begrebsmæssigt til den engelske version af ABC-måleredskabet. Datakvaliteten i forhold til antallet af respondenter, der svarede 'ved ikke', var uacceptabel ( $> 3\%$ ) for omkring hvert tredje item. Indholdsvaliditeten var god. I forhold til begrebsvaliditet viste faktoranalysen, at alle subskalaer undtagen 'forestillinger om kræft' var unidimensional. ABC-måleredskabet var i stand til at skelne mellem ikke-medicinske akademikere og medicinske akademikere. Test-retest-reliabiliteten var moderat til betydelig for de fleste items.

I modsætning til hvad vi forventede, fandt vi i **artikel II**, at de svenske respondenter var signifikant mindre tilbøjelige til at genkende at en uforklarlig knude eller hævelse og længerevarende hoste eller hæshed kunne være tegn på kræft samt signifikant mere tilbøjelige til at have et længere forventet patientinterval ( $> 2$  uger) for symptomerne forandringer i brystet og blødning fra endetarmen end de danske respondenter. De absolutte forskelle var dog små.

Hos de danske respondenter fandt vi, at cirka hver fjerde angav, at 'have for travlt til at tage sig tid til at gå til læge' og 'bekymring for, hvad lægen måske ville finde' kunne få dem til at udsætte lægesøgningen ved oplevelsen af et muligt alvorligt symptom. Den førstnævnte barrier blev i højere grad angivet af personer med en lang uddannelse, mens personer med en kort uddannelse i højere grad angav 'bekymring for, hvad lægen måske ville finde' som en mulig

barriere. Endvidere fandt vi i **artikel III**, at respondenterne generelt var enige i de positive forestillinger om kræft, mens færre respondenter var enige i de negative forestillinger om kræft. Personer med en kort uddannelse og personer med en lav indkomst var i højere grad enige i de negative forestillinger om kræft.

I **artikel IV** fandt vi, at personer med kort uddannelse og personer med en lav indkomst havde et mindre kendskab til symptomer og risikofaktorer for kræft. Der blev ikke fundet nogen klar sammenhæng mellem socioøkonomisk position og kendskabet til 5-års-overlevelse.

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#### KONKLUSION OG PERSPEKTIVERING

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Denne afhandling viser, at den danske version af ABC-måleredskabet var forståelig og acceptabel samt havde tilstrækkelig reliabilitet og validitet, når den blev anvendt i den almene danske befolkning. Vi fandt, at respondenterne generelt havde intention om og positive forestillinger om at gå til lægen hurtigst muligt efter at have bemærket et symptom på kræft. Samtidig fandt vi, at respondenterne besad umiddelbart modstridende positive og negative forestillinger om kræft, og at personer med kort uddannelse og personer med en lav indkomst i højere grad var enige i de negative forestillinger om kræft. Ligeledes var disse socioøkonomiske indikatorer associeret med et mindre kendskab til symptomer og risikofaktorer for kræft, hvilket potentielt kan have betydning for patientintervallet. Interventioner der har til formål at fremme lægesøgning for potentielle symptomer på kræft bør overveje disse resultater, og ligeledes bør evaluering af sådanne interventioner prioriteres.

# APPENDIX I

## THE DANISH ABC MEASURE

## Spørgeskema om viden og forestillinger om kræft

### Dansk spørgeskema

OPRINDELSESLAND GENERERES AUTOMATISK AF CATI SCRIPT

#### INTRODUKTION

Godmorgen/goddag/godaften, mit navn er <<(INDSÆT)>>, og jeg ringer på vegne af Sundhedsstyrelsen og Aarhus Universitet.

**NÆVNES KUN, HVIS DU BLIVER SPURGT:** Forskningsenheden for Almen Praksis ved Aarhus Universitet.

#### SPØRG ALLE

#### ENKELTKODE

QSR1. Jeg vil gerne tale med [INDSÆT NAVN FRA LISTEN]

01 Ja, det er mig

02 Ja, lige et øjeblik

**LÆS INTRODUKTIONEN IGEN FØR DU FORTSÆTTER**

03 Nej – er ikke til stede for øjeblikket

**SKRIV NED OG AFTAL AT RINGE TILBAGE SENERE**

04 Nej – ønsker ikke at deltage

**TAK OG AFSLUT SAMTALEN**

#### INFORMATION

Jeg arbejder for det uafhængige analyseinstitut Ipsos MORI. Vi er på vegne af Sundhedsstyrelsen og Aarhus Universitet i gang med en undersøgelse af danskernes kendskab til og forestillinger om kræft og vil gerne invitere dig til at deltage.

Undersøgelsen er landsdækkende, men foregår derudover også i syv andre lande. Vi henvender os til personer på 30 år og derover og du er tilfældigt udtrukket til at deltage.

**NÆVNES KUN, HVIS DU BLIVER SPURGT:** De deltagende lande er England, Nordirland, Wales, Australien, Canada, Norge, Sverige og Danmark.

**NÆVNES FOR ALLE:** Resultaterne af undersøgelsen skal bruges til at få mere viden om folks syn på kræft i forskellige lande og til at forbedre informationen om kræft til befolkningen. Resultaterne af undersøgelsen skal samtidig bruges til at hjælpe læger med tidligere at kunne stille en kræftdiagnose.

Hvis du siger ja til at deltage, vil det tage cirka 20-25 minutter at svare på de spørgsmål jeg om lidt vil stille dig.

## FORTROLIGHED OG ANONYMITET

Projektet er godkendt af Datatilsynet ([NÆVNES KUN, HVIS DU BLIVER SPURGT: journalnummer: 2010-54-1016](#)) og dine kontaktoplysninger har projektet modtaget fra Sundhedsstyrelsen.

Alle de oplysninger, du giver os, bliver behandlet strengt fortroligt, og din identitet bliver ikke givet videre til andre. Oplysningerne vil ikke blive videregivet til din egen læge.

[NÆVNES KUN, HVIS DU BLIVER SPURGT](#): Ipsos MORI er medlem af en forening ved navn Market Research Society [Foreningen af Analyseinstitutter] og dine personoplysninger bliver opbevaret i henhold til den britiske persondatalov. Hvis resultaterne af undersøgelsen bliver offentliggjort, kan oplysningerne ikke henføres til dig som person.

## UNDERSØGELSENS FRIVILLIGE KARAKTER

Det er frivilligt at deltage i undersøgelsen og du kan altid springe fra uden at fortælle hvorfor. Det er også i orden at springe over enkelte spørgsmål undervejs.

## [SPØRG ALLE](#)

## [ENKELTKODE](#)

QS4. Nu hvor du har fået de indledende oplysninger, vil jeg høre, om du siger ja til at deltage i undersøgelsen?

01 Ja

[FORTSÆT](#)

02 Nej – har ikke tid lige nu

[LAV EN AFTALE OM AT RINGE TILBAGE](#)

03 Nej – ønsker ikke at deltage

[GÅ TIL QS5](#)

# Ipsos MORI

SPØRG ALLE DER SIGER 'NEJ' TIL QS4

FLERE KODER

ACCEPTER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"

SPØRG FORSIGTIGT UDEN AT INSISTERE PÅ ET SVAR. LÆS IKKE DETTE OP

QS5. Det er naturligvis helt i orden, at du siger nej, men vil du fortælle mig, hvorfor du ikke ønsker at blive interviewet, bare så vi kan få en idé om, hvorfor folk ikke ønsker at deltage?

- 01 Det ville være ubehageligt/følelsesmæssigt svært for mig at deltage
- 02 Jeg har ikke tid
- 03 Undersøgelsen tager for lang tid
- 04 Jeg deltager ikke i interviewundersøgelser
- 05 Jeg er ikke interesseret
- 06 Jeg ved ikke noget om kræft
- 07 Jeg har personlige erfaringer med kræft, så jeg ville føle mig oprevet over at deltage
- 08 Andet

AFSLUT UNDERSØGELSEN

TILBYD RESPONDENTER, SOM PÅ ET ELLER ANDET TIDSPUNKT VIRKER MEGET KEDE AF DET, ELLER SOM ER BEKYMREDE ELLER HAR SPØRGSMÅL OM KRÆFT, AT AFSLUTTE INTERVIEWET OG TILBYD DEM KONTAKTINFORMATIONER EFTER BEHOV:

Kræftens Bekæmpelses gratis telefonrådgivning: Tlf. 80 30 10 30. Åben: Hverdage 9.00-21.00, lørdag og søndag 12.00-17.00, helligdage lukket.

## **BAGGRUNDSINFORMATION 1**

Først vil jeg gerne have lov at spørge dig om...

SPØRG ALLE

ENKELTKODE

ACCEPTER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET" ELLER "VED IKKE"

Q3. Har du eller nære venner eller familiemedlemmer nogensinde fået diagnosen kræft?

**HVIS JA, SÅ SPØRG AFKLARENDE:** Må jeg spørge, er det dig selv, nogen der står dig nær eller både dig selv og nogen, der står dig nær?

- 01 Ja, mig selv
- 02 Ja, nogen der står mig nær
- 03 Ja, både mig selv og nogen der står mig nær
- 04 Ja, men jeg vil foretrække ikke at fortælle, hvem det er
- 05 Nej

## Spørgeskema om viden og forestillinger om kræft (ABC)

### Interview spørgeskema

#### VIDEN OM KRÆFT

De følgende spørgsmål handler om dit kendskab til og dine forestillinger om kræft; det er ikke en vurdering af din personlige risiko for at få kræft. Det er ikke en test. Vi er interesserede i dine tanker og forestillinger, så vi vil gerne have, at du svarer så ærligt, som du kan.

**NÆVNES KUN, HVIS DU BLIVER SPURGT:** Jeg beklager, at jeg ikke kan svare på detaljerede spørgsmål i løbet af interviewet, men vi kan gå tilbage til disse efter interviewet er afsluttet, hvis du har lyst. Jeg kan dog ikke gå tilbage for at ændre svar, du allerede har givet.

#### TEGN OG SYMPTOMER

SPØRG ALLE

SKRIV IND

**ACCEPTER "VED IKKE" ELLER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"**

Q4. Der er mange tegn og symptomer på kræft. Vær venlig at nævne så mange som du kan komme i tanke om.

**NÆVNES KUN, HVIS DU BLIVER SPURGT:** Jeg vil bede dig om, at tænke på alle forskellige former for kræft.

**NOTÉR ALLE DE TEGN OG SYMPTOMER, SOM RESPONDENTEN NÆVNER, NØJAGTIGT SOM DE BLIVER SAGT OG BLIV VED MED AT SPØRGE INDTIL RESPONDENTEN IKKE KAN KOMME I TANKE OM FLERE TEGN OG SYMPTOMER:**

Kan du komme i tanke om flere?

- 01 .....
- 02 .....
- 03 .....
- 04 .....
- 05 .....
- 06 .....
- 07 .....
- 08 .....
- 09 .....
- 10 .....

## FORVENTET FORSINKELSE I LÆGESØGNING

### SPØRG ALLE

ENKELTKODE FOR HVER DEL. SKIFT MELLEML RÆKKEFØLGEN AF SPØRGSMÅL Q5-Q8

### ACCEPTER "VED IKKE" ELLER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"

De næste spørgsmål handler om at gå til læge. Jeg vil nu læse en liste med tegn og symptomer op for dig. For hvert enkelt af dem, vil jeg bede dig fortælle mig, hvor lang tid der ville gå, før du ville gå til læge, efter at du havde bemærket symptomet første gang.

Q5. Længerevarende hoste?

**NÆVNES KUN, HVIS DU BLIVER SPURGT:** Med længerevarende mener jeg, at det har varet et stykke tid.

Q6. Blødning fra endetarmen?

### SPØRG KUN KVINDER

Q7. Forandringer i brystet?

### SPØRG ALLE

Q8. Oppustethed?

**NÆVNES KUN, HVIS DU BLIVER SPURGT:** Med oppustethed mener jeg, at din mave er oppustet på en måde, du ikke er vant til.

## HVIS SVARET ER 'VILLE IKKE GÅ TIL LÆGE', SÅ SPØRG AFKLARENDE OM GRUNDEN DERTIL

- 01 Op til 1 uge
- 02 Over 1 og op til 2 uger
- 03 Over 2 og op til 3 uger
- 04 Over 3 og op til 4 uger
- 05 Mere end en måned
- 06 Jeg ville gå til læge, så snart jeg bemærkede det
- 07 Jeg ville ikke gå til læge
- 08 BLANKT FELT
- 09 BLANKT FELT
- 10 BLANKT FELT
- 11 BLANKT FELT
- 12 Jeg ville kontakte andet sundhedspersonale

Nu vil jeg nævne nogle symptomer, som kan være tegn på kræft, men som ikke behøver at være det. Jeg vil gerne have, at du for hvert enkelt symptom fortæller mig, om du tror, at det kan være et tegn på kræft.

## SPØRG ALLE

ENKELTKODE FOR HVER DEL. SKIFT MELLEM RÆKKEFØLGEN AF SPØRGSMÅL Q9-Q19

ACCEPTER "VED IKKE" ELLER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"

Q9-Q19. Tror du [INDSÆT TEGN/SYMPTOM] kan være et tegn på kræft?

NÆVNES KUN, HVIS DU BLIVER SPURGT: Med længerevarende mener jeg, at det har varet 3-6 uger.

NÆVNES KUN, HVIS DU BLIVER SPURGT: Med uforklarlig mener jeg, at det ikke skyldes en sygdom eller en skade, som du allerede kender til.

Q9. en uforklarlig knude eller hævelse

Q10. længerevarende, uforklarlige smerter

Q11. at bløde, uden at man kender årsagen

Q12. længerevarende hoste eller hæshed

Q13. ændringer i afførings- eller vandladningsmønster

Q14. længerevarende besvær med at synke

Q15. en ændring i den måde, et modermærke ser ud på

Q16. et sår, der ikke heler

Q17. uforklarlige svedeture om natten

Q18. uforklarligt vægttab

Q19. uforklarlig træthed

01 Ja

02 Nej

## SELVVURDERET HELBRED, ADGANG TIL LÆGEN OG RYGEADFÆRD

Nu vil jeg gerne stille dig et par spørgsmål om dig selv.

SPØRG ALLE

ENKELTKODE. LÆS OP

ACCEPTER "VED IKKE" ELLER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"

SKIFT MELLEM RÆKKEFØLGEN AF SVARMULIGHEDERNE FOR 50% AF RESPONDENTERNE

Q20. Hvordan synes du dit helbred er alt i alt ...?

- 01 Meget godt
- 02 Godt
- 03 Nogenlunde
- 04 Dårligt
- 05 Meget dårligt

SPØRG ALLE

ENKELTKODE. LÆS OP

ACCEPTER "VED IKKE" ELLER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"

SKIFT MELLEM RÆKKEFØLGEN AF SVARMULIGHEDERNE FOR 50% AF RESPONDENTERNE

Q21. Hvor let eller svært er det for dig at komme i kontakt med en læge, hvis du har et symptom, du tror, kunne være alvorligt?

- 01 Meget svært
- 02 Ret svært
- 03 Ret let
- 04 Meget let

SPØRG ALLE

ENKELTKODE

ACCEPTER "VED IKKE" ELLER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"

Q22. Ryger du på nuværende tidspunkt cigaretter, inklusiv hjemmerullede, pipe eller cigar?

- 01 Ja
- 02 Nej

# Ipsos MORI

SPØRG ALLE DER SIGER 'NEJ' TIL Q22

ENKELTKODE

ACCEPTER "VED IKKE" ELLER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"

Q23. Har du på noget tidspunkt røget cigaretter, inklusiv hjemmerullede, pibe eller cigar?

- 01 Ja
- 02 Nej

## ADGANG TIL DIN LÆGE: TIDLIG SYMPTOMPRÆSENTATION

Nogle mennesker venter med at gå til læge, selvom de har et symptom, som de tror, kan være alvorlig. Her er nogle af de forklaringer, folk giver som begrundelse for at vente. Kan du sige, om nogle af disse grunde kunne få dig til at vente med at gå til læge?

For hver af de begrundelser, jeg læser op, vil jeg bede dig svare enten 'Ja, ofte', 'Ja, nogle gange' eller 'Nej'.

### SPØRG ALLE

ENKELTKODE FOR HVER DEL. SKIFT MELLEMLÆG RÆKKEFØLGEN AF SPØRGSMÅL Q24-Q27

HVIS RESPONDENTEN BEDER OM DET, SÅ LÆS SVARMULIGHEDERNE OP IGEN  
ACCEPTER "VED IKKE" ELLER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"

Q24. Det ville være pinligt for mig

Q25. Jeg ville være bekymret for at spilde lægens tid

Q26. Jeg ville være bekymret for, hvad lægen måske ville finde

Q27. Jeg har for travlt til at tage mig tid til at gå til læge

- 01 Ja, ofte
- 02 Ja, nogle gange
- 03 Nej

## ALMINDELIGE FORESTILLINGER OM KRÆFT OG FORESTILLINGER OM TIDLIG SYMPTOMPRÆSENTATION OG TIDLIG DIAGNOSTIK AF KRÆFT

Nu læser jeg nogle udsagn om kræft op for dig, som man sommetider hører om kræft. Kan du for hvert udsagn fortælle mig, hvor enig eller uenig du er?

SPØRG ALLE

ENKELTKODE FOR HVER DEL. SKIFT MELLEM RÆKKEFØLGEN AF SPØRGSMÅL Q28-Q32

ACCEPTER "VED IKKE" ELLER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"

HVIS RESPONDENTEN SIGER ENIG/UENIG: Er det meget eller delvist enig/uenig?

Q28. Mange mennesker med kræft kan i dag forvente at fortsætte med deres normale gøremål og forpligtelser.

Q29. De fleste former for kræftbehandling er værre end selve kræftsygdommen.

Q30. Jeg ville IKKE ønske at vide det, hvis jeg havde kræft.

Q31. Kræft kan ofte helbredes.

Q32. Chancerne for at overleve øges, hvis man går til lægen hurtigst muligt efter, at man har bemærket et symptom på kræft.

- 01 Meget uenig
- 02 Delvist uenig
- 03 Delvist enig
- 04 Meget enig

SPØRG ALLE

ENKELTKODE

ACCEPTER "VED IKKE" ELLER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"

Q33. Nogle mennesker tror, at en kræftdiagnose er en dødsdom. Hvor enig eller uenig er du i, at en kræftdiagnose er en dødsdom?

HVIS RESPONDENTEN SIGER ENIG/UENIG: Er det meget eller delvist enig/uenig?

- 01 Meget uenig
- 02 Delvist uenig
- 03 Delvist enig
- 04 Meget enig

## SPØRG ALLE

ANGIV MED ET TAL (FRA 0-10) VED HVERT SPØRGSMÅL. SKIFT MELLE  
RÆKKEFØLGEN AF SPØRGSMÅL Q34-Q37

ACCEPTER "VED IKKE" ELLER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"

Nu vil jeg bede dig tænke på forskellige former for kræft og chancerne for overlevelse.

Q34. Hvor mange ud af 10 personer, som får konstateret tarmkræft, tror du, vil være i live 5 år senere?

Q35. Hvor mange ud af 10 personer, som får konstateret brystkræft, tror du, vil være i live 5 år senere?

Q36. Hvor mange ud af 10 personer, som får konstateret kræft i æggestokkene, tror du, vil være i live 5 år senere?

Q37. Hvor mange ud af 10 personer, som får konstateret lungekræft, tror du, vil være i live 5 år senere?

01      Skriv antal personer her .....

## RISIKO

Og nu vil jeg bede dig tænke på befolkningen i almindelighed

## SPØRG ALLE

ENKELTKODE. LÆS OP

ACCEPTER "VED IKKE" ELLER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"

Q38. Hvilken af følgende grupper – om nogen – tror du har størst sandsynlighed for at få konstateret kræft inden for det næste år?

01      30-årige

02      50-årige

03      70-årige

04      Alle har lige stor sandsynlighed for at få konstateret kræft uanset alder.

## Modul 1 Kræftscreening – adfærd og forestillinger

### ADFÆRD I FORBINDELSE MED KRÆFTSCREENING

DENNE SEKTION ER KUN FOR PERSONER  $\geq 50$  ÅR

De næste spørgsmål handler om screeningsprogrammer for kræft. I sådanne programmer inviteres alle i en bestemt aldersgruppe til en undersøgelse af om de måtte have tarm- eller brystkræft.

Først vil jeg gerne vide, om du har deltaget i screening.

SPØRG ALLE KVINDER  $\geq 50$  ÅR

ENKELTKODE

ACCEPTER "VED IKKE", "ØNSKER IKKE AT BESVARE SPØRGSMALET" ELLER "IKKE RELEVANT"

QM1. Er du blevet screenet for brystkræft, også ofte kaldet mammografiscreening, indenfor de sidste 5 år?

- 01 Ja
- 02 Nej

SPØRG ALLE  $\geq 50$  ÅR

ENKELTKODE

ACCEPTER "VED IKKE", "ØNSKER IKKE AT BESVARE SPØRGSMALET" ELLER "IKKE RELEVANT"

**NÆVNES KUN, HVIS DU BLIVER SPURGT:** Ved screening for tarmkræft bliver man undersøgt for blod i afføringen. I Danmark påbegyndes screeningsprogrammet for tarmkræft først i år 2014 for personer i alderen 50-74 år. Indtil nu har screening for tarmkræft kun været udført som teststudier i de tidligere Vejle og Københavns amter i år 2005-6.

QM2. Er du blevet screenet for tarmkræft indenfor de sidste 5 år?

- 01 Ja
- 02 Nej

## FORESTILLINGER OM KRÆFTSCREENING (SPØRG ALLE)

SPØRG ALLE KVINDER ≥30 ÅR

ENKELTKODE FOR HVER DEL. SKIFT MELLEML RÆKKEFØLGEN AF SPØRGSMÅL QM3-QM5

ACCEPTER "VED IKKE" ELLER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"

De følgende udsagn handler om screening for brystkræft. Kan du for hvert udsagn fortælle mig, hvor enig eller uenig du er?

**HVIS RESPONDENTEN SIGER ENIG/UENIG:** Er det meget eller delvist enig/uenig?

QM3. Jeg ville være så bekymret for, hvad der måske ville blive fundet ved screening for brystkræft, at jeg ville foretrække ikke at deltage.

QM4. Screening for brystkræft er kun nødvendig, hvis jeg har symptomer

QM5. Screening for brystkræft kan mindske min risiko for at dø af brystkræft

- 01 Meget uenig
- 02 Delvist uenig
- 03 Delvist enig
- 04 Meget enig

Nu læser jeg nogle udsagn op for dig om screening for tarmkræft. Kan du for hvert udsagn fortælle mig, hvor enig eller uenig du er?

SPØRG ALLE ≥30 ÅR

ENKELTKODE FOR HVER DEL. SKIFT MELLEML RÆKKEFØLGEN AF SPØRGSMÅL QM6-QM8

ACCEPTER "VED IKKE" ELLER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"

**HVIS RESPONDENTEN SIGER ENIG/UENIG:** Er det meget eller delvist enig/uenig?

QM6. Jeg ville være så bekymret for, hvad der måske ville blive fundet ved screening for tarmkræft, at jeg ville foretrække ikke at deltage.

QM7. Screening for tarmkræft er kun nødvendig, hvis jeg har symptomer.

QM8. Screening for tarmkræft kan mindske min risiko for at dø af tarmkræft.

- 01 Meget uenig
- 02 Delvist uenig
- 03 Delvist enig
- 04 Meget enig

## **Modul 2 Viden om risikofaktorer for kræft**

Nu remser jeg noget op, som måske, måske ikke øger din generelle risiko for at få kræft.

For det jeg nævner, kan du fortælle mig, hvor enig eller uenig du er i, at det kan øge din risiko for at få kræft?

SPØRG ALLE

ENKELTKODE FOR HVER DEL. SKIFT MELLEM RÆKKEFØLGEN AF SPØRGSMÅL QN1-QN13

ACCEPTER "VED IKKE" ELLER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"

HVIS RESPONDENTEN SIGER ENIG/UENIG: Er det meget eller delvist enig/uenig?

QN1. Rygning?

QN2. At være udsat for passiv rygning?

QN3. At drikke mere end 1 genstand om dagen. En genstand svarer til 4 cl spiritus, en almindelig øl eller et lille glas vin?

QN4. At spise mindre end 5 stykker frugt og grønt om dagen?

QN5. At spise rødt eller forarbejdet kød én eller flere gange om dagen?

NÆVNES KUN, HVIS DU BLIVER SPURGT: Med forarbejdet kød mener jeg kød, som er røget, saltet eller kemisk konserveret.

QN6. At være svært overvægtig?

NÆVNES KUN, HVIS DU BLIVER SPURGT: Med svært overvægtig mener jeg en BMI  $\geq$  30.

QN7. At blive solskoldet mere end én gang som barn?

QN8. At være over 70 år?

QN9. At have en nær slægtning, som har kræft?

QN10. At være smittet med HPV, human papilloma virus?

QN11. Ikke at være særlig fysisk aktiv?

QN12. At gå i solarium?

QN13. At være udsat for radioaktiv stråling fra for eksempel radioaktivt materiale, røntgen eller radon?

- 01 Meget uenig
- 02 Delvist uenig
- 03 Delvist enig
- 04 Meget enig
- 05 Ved ikke (GÆLDER KUN FOR QN10)

## BAGGRUNDSINFORMATION 2

Afslutningsvist vil jeg gerne stille dig nogle spørgsmål om dig selv, som kan hjælpe os med at analysere resultaterne af undersøgelsen.

SPØRG ALLE

ENKELTKODE

ACCEPTER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"

Q39. I hvilket land er du født?

01 Danmark

02 Andet land (angiv hvilket) .....

SPØRG ALLE DER SIGER 'ANDET' TIL Q39

SKRIV IND

ACCEPTER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"

Q39o. Hvilket andet land er der tale om?

SPØRG ALLE

ENKELTKODE

ACCEPTER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"

Q40. Hvad er dit modersmål?

01 Dansk

02 Andet modersmål (angiv hvilket) .....

**NÆVNES KUN, HVIS DU BLIVER SPURGT:** Med modersmål mener jeg, det sprog du som barn har lært at tale i dit hjem.

SPØRG ALLE DER SIGER 'ANDET' TIL Q40

SKRIV IND

ACCEPTER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"

Q40o. Hvilket andet modersmål er der tale om?

SPØRG ALLE

ENKELTKODE

ACCEPTER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"

Q40. Hvilket sprog taler I mest derhjemme?

- 01 Dansk
- 02 Andet sprog (angiv hvilket) .....

SPØRG ALLE DER SIGER 'ANDET' TIL Q41

SKRIV IND

ACCEPTER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"

Q40o. Hvilket andet sprog er der tale om?

SPØRG ALLE

ENKELTKODE. LÆS OP

ACCEPTER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"

Q41. Hvad er den højeste uddannelse, du har gennemført?

- 01 Folkeskole 1.-6. klassetrin
- 02 Folkeskole 7.-9./10. klassetrin
- 03 Gymnasial (stx, hhx, htx, hf og studenterkursus) eller erhvervsfaglig uddannelse (erhvervsuddannelser inkl. eux, de maritime uddannelser og Egu)
- 04 Gymnasial suppleringskursus m.fl.
- 05 Universitetsbacheloruddannelse, professionsbacheloruddannelse mv., erhvervsakademiuddannelse mv. eller kandidatuddannelse.
- 06 Ph.d. - Forskeruddannelse
- 07 Anden uddannelse (angiv hvilken) .....

SPØRG ALLE DER SIGER 'ANDET' TIL Q41

SKRIV IND

ACCEPTER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET"

Q41o. Hvilken anden uddannelse er der tale om?

SPØRG ALLE

ENKELTKODE. LÆS OP

ACCEPTER "ØNSKER IKKE AT BESVARE SPØRGSMÅLET" ELLER "VED IKKE"

Q5a. Hvilken af følgende udsagn passer bedst på din nuværende ægteskabelige status?

- 01 Gift eller i et registreret partnerskab
- 02 Bor sammen med min partner
- 03 Enlig, dvs. ikke tidligere gift og bor ikke sammen med en partner
- 04 Skilt eller separeret og bor ikke sammen med en anden partner
- 05 Enke(mand) og bor ikke sammen med en anden partner

## EFTER AT INTERVIEWET ER AFSLUTTET

Det var slut på undersøgelsen, mange tak fordi du ville være med.

## TIL RESPONDENTER, SOM GERNE VIL HAVE YDERLIGERE INFORMATION OM UNDERSØGELSEN:

Du er velkommen til at kontakte projektgruppen på tlf. 89 42 62 41. Du er også velkommen til at besøge hjemmesiden [www.au.dk/ABC](http://www.au.dk/ABC), hvor du vil kunne læse mere om undersøgelsen.

## TAK RESPONDENTEN OG AFSLUT

Jeg siger tak for hjælpen på vegne af Ipsos MORI.

Hvis du har spørgsmål til undersøgelsen eller vores firma, kan jeg give dig telefonnummeret på firmaet eller gratisnummeret til Market Research Society [Foreningen af Analyseinstitutter].

## OPLYS VED BEHOV

Firma tlf. nr. – 0131 561 4603

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INTERVIEWERE: MRS KAN KUN BEKRÆFTE, AT VI ER ET SERIØST ANALYSEINSTITUT.