

Preferences for prevention programs against chronic disease: does expected cause of death matter?

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Foreward

The most common response I have encountered after telling people that my master's thesis examined the question of people's preferences over the manner of their death was some variant of "I want to die in bed at the age of ninety-five, shot by a jealous husband," or its Norwegian equivalent "I want to die at the age of ninety-five, skiing in the forest." So, it was not surprising that designing a survey to elicit this information was quite a challenge—one that I would never have accomplished without the advice and support of several individuals.

My heartfelt thanks go to my primary supervisor, Ivar Sønbo Kristiansen, for his enthusiastic support at all stages of this project, and to my co-supervisors, Dorte Gyrd-Hansen and Jan Abel Olsen, for their insightful comments and suggestions, particularly with regard to survey design. Kjartan Sælensminde's critique of an early version of the survey during my internship at the Directorate of Health and Social Affairs helped me to define the issues more carefully. Michael Robinson of Mount Holyoke College (USA) provided important statistical advice. Lastly, I must thank my family and friends in the United States who have been so understanding of my desire to study and live in Norway.

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Abbreviations and Acronyms

ATP III	Adult Treatment Panel III
CEA	Cost effectiveness analysis
CUA	Cost utility analysis
CVD	Cardiovascular disease
NCEP	National Cholesterol Education Program
NHLBI	National Health, Lung, and Blood Institute
NIL	Named disease / individual perspective / life-style intervention
NIP	Named disease / individual perspective / pharmaceutical intervention
NSL	Named disease / societal perspective / life-style intervention
NSP	Named disease / societal perspective / pharmaceutical intervention
QALY	Quality adjusted life-year
UIL	Unnamed disease / individual perspective / life-style intervention
UIP	Unnamed disease / individual perspective / pharmaceutical intervention
USL	Unnamed disease / societal perspective / life-style intervention
USP	Unnamed disease / societal perspective / pharmaceutical intervention

Abstract

Western countries devote significant resources to prevention of chronic illnesses, particularly cardiovascular disease (CVD). Consequently, life expectancy increases but deaths from other causes, such as cancer, also rise. Preferences for additional longevity later in life may be sensitive to expected cause of death, but this factor is typically ignored in economic evaluations of chronic disease prevention programs. We use current Norwegian mortality data to estimate life expectancy gains and changed distributions of cause of death associated with CVD and cancer prevention programs. For realistic levels of risk reduction, prevention programs against CVD and cancer increase longevity by 6 and 4 months, respectively. We survey a random sample of 2700 Norwegians, ages 40–67, to examine preferences for prevention programs against CVD and cancer when individuals are informed about expected increases in life expectancy and resulting changes in the distribution of cause of death in the population. The survey is randomized for named vs. unnamed disease (CVD/cancer vs. Condition X/Y), medical vs. life-style interventions, and individual vs. societal perspective. A pilot study improved the design of the final survey. Results show little evidence that a desire for an “easy” death influenced respondents’ willingness to participate in a CVD prevention program; respondents accepted the offer of both CVD and cancer prevention at similar rates of 61%. Participation decisions were influenced by framing: more were willing to accept intervention if the disease was named and if treatment involved life-style changes rather than pharmaceutical treatment. Willingness-to-pay for prevention was low, with only 26% of the full sample agreeing to pay 150 NOK per month for CVD prevention, and 28% willing to pay for cancer prevention.

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1. Introduction

In the health care sector, decisions about how best to allocate limited resources increasingly rely on economic analysis—usually cost effectiveness analysis (CEA) or cost utility analysis (CUA)—to weigh the costs of a treatment or health intervention against its benefits, measured in, for example, life-years or quality-adjusted life-years (QALYs) gained. There is a broad literature critiquing this methodology with excellent summary discussions in Brazier et al. (2007); Drummond et al. (2005); Dolan and Olsen (2002); and Nord (1999). Issues range from the validity of underlying utility assumptions (mutual utility independence between quantity and quality of life, constant proportional time trade-off, risk neutrality with respect to life years, and additive separability) to equity issues implied by the assumption that a “life-year is a life-year” or “a QALY is a QALY,” to concerns about the role of process utility (see Brouwer et al, 2005). On the basis of these criticisms, policy makers routinely consider such concerns as minimizing societal differences in health, age of patient, potential for improved health, previous treatment received, responsibility for health condition, etc.

Largely ignored in these discussions is the difficult issue of people’s preferences over the manner of their death. Anecdotal evidence suggests that people prefer an “easy” death—one that is sudden and relatively pain free—to death from a disease that is prolonged, painful and potentially debilitating. A recent review by Hales et al. (2008) of research on the definition and conceptualization of the quality of death and dying supports the idea that most consider a “good” death to be relatively free of pain and suffering. Although studies about end-of-life decision-making have begun to challenge the assumption that extending life by whatever means is always desirable (see SUPPORT study, (1995)), there have been few attempts to measure preferences with regard to interventions that offer benefits in terms of a lower mortality rate and increased life expectancy for one condition, but ultimately result

in an increased risk of death from other, possibly less “desirable” diseases¹. To some extent this may be a problem of insufficient information; perhaps individuals would accurately value the “less desirable death” if informed of its possibility. However, it is also possible that this scenario violates time independence assumptions or represents an example of the role of process utility. In any of these cases, it is important to have an understanding of preferences over the manner of death.

This issue is particularly relevant given the predominance in Western societies of chronic disease as a cause of mortality. James F. Fries (2005) describes these diseases and what he calls “the compression of mortality” using a multiple-risk-factors, universal-susceptibility model in which diseases have onset early in life, follow a progression which is determined by a variety of risk factors, and ultimately reach a symptomatic threshold at which point the disease can be diagnosed. Individuals differ with respect to their rates of progression through the disease so that those individuals with low risk and slow progression may remain below the symptomatic threshold and die “disease-free” of other causes while those with high risk and rapid progression will die of the disease. Treatment can slow the rate of progression and may result in postponement of the disease, i.e. reaching the symptomatic threshold at a later time, or prevention of the disease, i.e. slowing progression so that the threshold is never reached. Interventions to treat a given disease or to reduce the risk factors associated with it also slow progression relative to other chronic diseases; an individual treated for cardiovascular disease may avoid a death by heart attack and prolong life enough to die of cancer or develop dementia instead.

¹ Studies that address these issues often do so as a side point while investigating other questions. In order to evaluate the procedural invariance of the TTO method, Anne Spencer (2003) conducted an unconventional TTO survey in which respondents compare a period of ill health with a longer period with a lower quality of life. Her results indicate a seeming willingness to trade longevity for quality of life. F. Reed Johnson, et al (1998) used tradeoff questions related to health-state attributes, longevity and cost as a frame for testing a stated-preference

Additionally, significant emphasis is placed on programs aimed at reducing cardiovascular disease. In the United States, the Adult Treatment Panel III (ATP III) of the National Heart, Lung and Blood Institute's National Cholesterol Education Program (NCEP) has issued treatment guidelines for cholesterol management, which include both therapeutic lifestyle changes and statin therapy (Grundy, et. al. 2004). In conjunction with "National Cholesterol Education Month," the NCEP encouraged all adults to "have their cholesterol measured, know their cholesterol numbers and their risk for heart disease, and follow a heart-healthy lifestyle to lower their risk and keep it down," and provided a packet of web-based materials to help individuals make necessary lifestyle changes (NHLBI, 2007). In Norway, which has one of the highest and rapidly growing sales of statins among European countries (Rønning, 2008), twelve governmental ministries are participating in a five-year initiative to promote healthier diets with the aim of reducing chronic diseases such as CVD, type-2 diabetes, and individual forms of cancer (Ministry of Health and Care Services, 2007).

This study investigates preferences among Norwegians, aged 40-67, for preventative intervention against cardiovascular disease and cancer given the knowledge that increased life expectancy and reduced numbers of death among patients treated for a given disease will be balanced by greater numbers of deaths from other causes, e.g. successful treatment of cardiovascular disease will result in more deaths from cancer and other causes. We decided for ethical reasons to pursue this indirect method of determining preferences over manner of death rather than posing the question directly. Our primary hypothesis is that, when provided with information about changes in life expectancy and distribution of deaths, fewer individuals will accept preventative interventions against CVD than against cancer, a result that would be consistent with a preference for an "easy" death over a

“hard” one. We also hypothesize that individuals’ willingness to participate in prevention programs will be affected by whether: (1) the offered intervention entails a pharmaceutical regime or lifestyle changes, (2) the description of a disease includes name, e.g. cardiovascular disease or cancer, and symptoms or only symptoms, and (3) the respondents are asked to consider the program from an individual or societal perspective. The scenario used in the study was developed from a model of life expectancy in Norway in which changes in the numbers of deaths from different causes can be estimated by varying the effectiveness of the prevention programs.

2. Methodology

2.1 Model of distribution of deaths from different causes

To obtain estimates of the distribution of deaths by different causes, we created a simple model based on detailed Norwegian life expectancy and mortality data from 2002. The mortality data provided cause-specific numbers of deaths by sex and one-year age groups, classified according to the European short-list. We focused on three causes of deaths, which, for the most part, could be calculated directly from the 2002 mortality data²: (1) Coronary heart disease [total of Deaths from Ischemic heart diseases (I20-I25), Cerebrovascular diseases (I60-I69) and one half of Other heart disease (I30-I33, I39-I52)³], (2) Malignant cancers [deaths from malignant neoplasm (C00-C97)], (3) Other deaths [Total deaths less sum of (1) & (2)].

Total mortality risk and mortality risks for each of the three categories listed above were computed by one-year age groups by dividing number of deaths in an age group by the population for that age group for 2002. For the age groups “under 5” and “over 100”, numbers of deaths were available only for the whole group so the individual one-year mortality rates were assumed to be the average rate for the age group. Beginning with a population of 100 000, and using the mortality risks from the 2002 data, annual total deaths and deaths in each of the three categories were calculated and summed to arrive at the distribution of deaths for the population. These totals formed the basis for the distribution of deaths by different causes without preventative interventions. The distribution of deaths with a cardiovascular prevention program in place was then computed by multiplying the relative risk of

² Classifications are in accordance with ICD-10.

³ Including half of the deaths in the category “Other heart disease” is a way of capturing deaths that are likely attributable to CVD but appear elsewhere in the death statistics.

heart disease for each age group by a relative risk-reduction factor, and re-calculating the model, assuming that relative risk for other causes of death remained the same. We chose to use a risk-reduction factor of 30% based on empirical evidence on the effectiveness of treatment of coronary heart disease with statins (Grundy, et. al. 2004). A similar procedure was followed to obtain the distribution of deaths when a cancer prevention intervention was substituted for the cardiovascular intervention. In both cases, intervention was assumed to have begun at age 50. Results are in Table 1.

Table 1. Estimated distribution of deaths and life expectancy per 100 000 individuals

	Baseline Totals	With CVD intervention	With Cancer intervention
Cause of Death			
Cardiovascular Disease	34 205	27 072	37 044
Cancer	23 613	25 072	17 384
Other Deaths	42 182	47 856	45 572
Life Expectancy (in years)	78.7	79.2	79.0

2.2 Survey description

Using the results from the mortality model, we developed a survey to examine preferences for prevention programs for cardiovascular disease and cancer when information about disease symptoms, average increases in life expectancy, and changes in the distribution of deaths from different causes is provided. The survey was randomized for: (1) named vs. unnamed disease, e.g. CVD and cancer vs. Conditions X and Y—to determine if preferences might be influenced by fears associated with the name rather than the symptoms of a disease, (2) individual vs. societal perspective—to determine if preferences differ when participation is offered to the individual or as a program for the general population, and (3) pharmaceutical

vs. life-style interventions—to determine if preferences differ based on the type of prevention treatment offered. We tested the survey design in a pilot study with 15 respondents. Following suggestions, we added a survey version that excluded the information on changes in the distribution of causes of death, and revised the format of questions about willingness-to-pay for prevention. We were also able to refine possible responses to questions about reasons for various choices.

The final survey was structured as follows: After an initial description of the two diseases (CVD/Condition X and cancer/Condition Y) and a numeric and graphical presentation of the current distribution of deaths per 1000 individuals, respondents were asked to imagine that a life-long prevention program (pharmaceutical or life-style) existed for one of the diseases⁴, given a description of the intervention and resulting average increase in life expectancy, and provided with numerical information and a bar graph comparing the current distribution of deaths with what would occur with the prevention program. Respondents were then asked if they would participate in (individual perspective) or favor government provision of (societal perspective) the prevention program. A positive response led to a further question about whether they would be willing to pay 150 NOK⁵ (approximately \$30 at \$1=5.12 NOK) per month to participate (or pay 150 NOK per month in extra taxes for a societal program), while a negative or uncertain response led to a question in which respondents could check reasons for not choosing to participate. The procedure was repeated for the second disease. Individuals who were willing to participate in both prevention programs were then asked which one they would choose if it were possible only to select one. A follow-up question asked respondents to check reasons for their choice. All participants were asked whether

⁴ The order of presentation was varied so that half of respondents were asked first about CVD prevention and the others about cancer prevention.

⁵ 150 NOK reflects the average monthly cost of a one-year supply of statins and two annual medical examinations to monitor cardiovascular health. We applied the same cost to all offered interventions (pharmaceutical, life-style, CVD and cancer) in order to minimize the complexity of the survey.

they or an immediate family member had ever been diagnosed with CVD or cancer. The survey concluded with three questions to gauge numeracy.⁶

With full randomization, there were eight versions of the survey, which can be described using the initials N (named), U (unnamed), I (individual perspective), S (societal perspective), P (pharmaceutical intervention), and L (life-style intervention): NIP, NIL, NSP, NSL, UIP, UIL, USP, USL.⁷ We included an additional version, “Short” (named disease, individual perspective, pharmaceutical intervention), in which only information about disease symptoms and average increase in life expectancy was provided, with no mention of the distribution of deaths, so that we could test whether knowledge of the changed distribution of deaths affected preferences. A native-speaker translated the surveys into Norwegian.

The survey was conducted via the internet by TNS Gallup during the period March 27 – April 2, 2008. To achieve a random set of sub-samples representative of the Norwegian population aged 40 – 67, TNS Gallup used the following procedure: Based on a requested sample size of 2700 individuals and an expected response rate of 60%, 4509 respondents from among the TNS Gallup access panel of 35,000 pre-recruited individuals were invited to participate. Respondents were distributed randomly across the different survey versions, with net response rates of approximately 60% for all survey versions.

⁶ Numeracy tests are frequently used to confirm individuals’ ability to understand risk information presented in percentage terms. While we do not use percentages in the survey, we felt that the numeracy questions would be, nonetheless, a useful gauge of whether individuals possessed the analytical ability needed to answer a rather demanding survey.

⁷ The “named disease, individual perspective, pharmaceutical intervention” (NIP) version of the survey is provided in Appendix 1. A complete set of surveys is available upon request.

3. Results

3.1 Descriptive results

In total, 2712 individuals responded to the survey. Descriptive statistics for gender, age, income, level of education, region of residence, experience with CVD and cancer, and numeracy are grouped by survey version and presented in Table 2.

Table 2. Descriptive statistics of respondents by survey version

Variable	Named Disease				Unnamed Disease				Short	Total
	Individual Perspective		Societal Perspective		Individual Perspective		Societal Perspective			
	Pharaceuti al	Life-Style	Pharaceuti al	Life-Style	Pharaceuti al	Life-Style	Pharaceuti al	Life-Style		
	NIP	NIL	NSP	NSL	UIP	UIL	USP	USL		
Number	279	354	296	302	304	303	289	276	309	2712
Gender: % female	52.3	48.0	50.0	49.3	50.3	49.5	47.1	47.8	53.1	49.7
Age, median in years	52	53	53	52	53	52	53	53	51	52
Age, 10%, 90% percentiles.	(42, 63)	(42, 63)	(43, 64)	(43, 64)	(43, 63)	(42, 63)	(42, 63)	(42, 63)	(41, 63)	(42, 63)
Marital Status, % cohabitating	77.8	79.4	74.7	79.8	79.9	78.9	78.9	75.4	75.7	77.8
Household Income, median in 1,000 NOK	600-799	600-799	400-599	600-799	600-799	400-599	600-799	600-799	400-599	600-799
Household income, 10%, 90% percentiles	200-300, 800-999	200-300, 800-999	200-300, 800-999	200-300, 800-999	200-300, 1000-1199	200-300, 1000-1199	200-300, 800-999	200-300, 800-999	200-300, 800-999	200-300, 800-999
Education % at										
Elementary	11.8	9.9	7.4	9.3	7.2	9.2	8.3	7.2	7.4	8.7
High School	29.4	28.2	38.2	31.5	30.6	28.1	32.9	39.1	32.7	32.2
Trade School	31.9	33.6	26.4	32.1	30.9	31.4	30.8	28.6	33.7	31.1
University (1-4 yrs)	16.8	18.4	12.2	15.2	16.1	18.8	13.5	13.4	13.9	15.4
University (4+ yrs)	10.0	9.9	15.9	11.9	15.1	12.5	14.5	11.6	12.3	12.6
Region										
Oslo/Akershus	24.1	21.5	23.3	21.2	22.7	21.1	22.8	22.5	21.7	22.3
Rest Østland	25.5	27.4	28.4	26.2	28.9	30	26.3	29	29.8	27.8
Sør-/Vestland	27.7	30.2	28.7	31.1	30.9	29.7	32.5	30.8	30.7	30.3
Tr.lag/Nord-Norge	22.7	20.9	19.6	21.5	18.4	19.1	18.3	17.8	17.8	19.6
CVD: self or immediate family, %yes	58.8	56.5	56.8	58.9	54.3	60.1	58.5	55.4	59.9	57.7
Cancer: self or immediate family, % yes	58.4	52.8	63.5	59.6	57.9	56.4	61.9	60.5	57	58.5
Numerate (3 correct answers, %)	70.6	74.6	76.7	75.8	71.7	69.3	73.7	74.3	75.4	73.6

Randomization of individuals across the different survey versions appears to have been successful and relatively representative of the Norwegian population. The survey sample was 49.7% female compared to 49.2% female in the Norwegian population for the relevant age group. The age distribution for the sample population was 36.5% age 40-49, 38.6% age 50-59, and 24.8% age 60-67. The corresponding distribution for the Norwegian population is 40.3% age 40-49, 36.1% age 50-59, and 23.6% age 60-67. In the sample population, 28% had at least one year of college education compared to 27% of the Norwegian population in the relevant age group. All data analysis was performed using SPSS 16.0 for Mac.

Tables 3 and 4 and Charts 1 and 2 summarize the responses to the questions about whether individuals would participate in (or support provision of) free prevention programs against CVD and cancer, respectively. Mean support was 61.9% for the CVD prevention program and 61.7% for cancer prevention although support varied significantly across the different versions of the survey. For CVD prevention, support ranged from 46% in the USP version to 78% in the NIL version. Support for the cancer intervention ranged from 42% in the UIP version to 77% in the NIL version. 14% of respondents declined participation in the CVD prevention program while 25% were uncertain. For the offered cancer intervention, 14% declined and 26% were uncertain. Contrary to our hypothesis, there is no significant difference in individual responses with respect to CVD vs. cancer interventions.

Table 3. CVD intervention by survey version

	Yes	No	Uncertain	Total
Version	%	%	%	n
NIP	55.6	17.6	26.9	279
NIL	78.0	6.5	15.5	354
NSP	59.8	11.1	29.1	296
NSL	72.8	7.6	19.5	302
UIP	46.4	23.7	29.9	304
UIL	68.0	11.2	20.8	303
USP	45.7	24.6	29.8	289
USL	52.5	12.7	34.8	276
Short	64.7	12.3	23.0	309
Total	60.9	13.9	25.1	2712

Table 4. Cancer intervention support by survey version

	Yes	No	Uncertain	Total
Version	%	%	%	n
NIP	57.0	17.9	25.1	279
NIL	76.6	5.4	18.1	354
NSP	64.2	8.1	27.7	296
NSL	76.5	7.3	16.2	302
UIP	42.4	24.7	32.9	304
UIL	65.7	13.2	21.1	303
USP	48.1	21.8	30.1	289
USL	51.8	14.5	33.7	276
Short	59.9	12.6	27.5	309
Total	60.7	13.7	25.6	2712

Chart 1. Support for CVD intervention by survey version

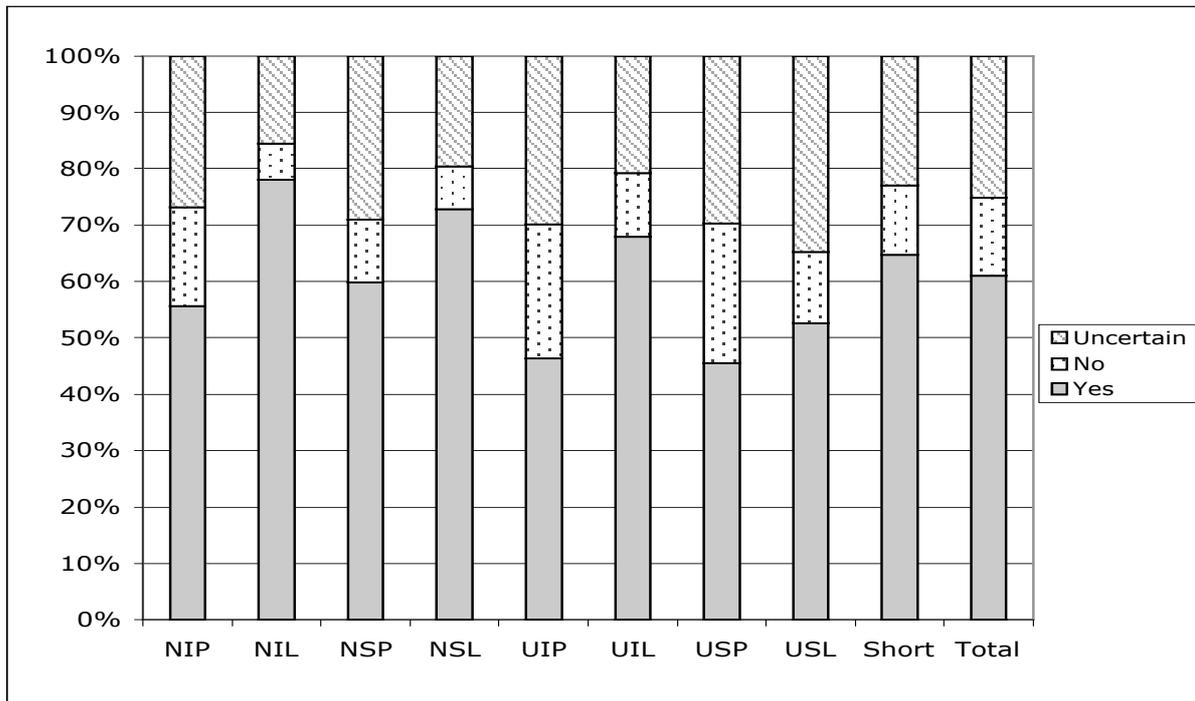
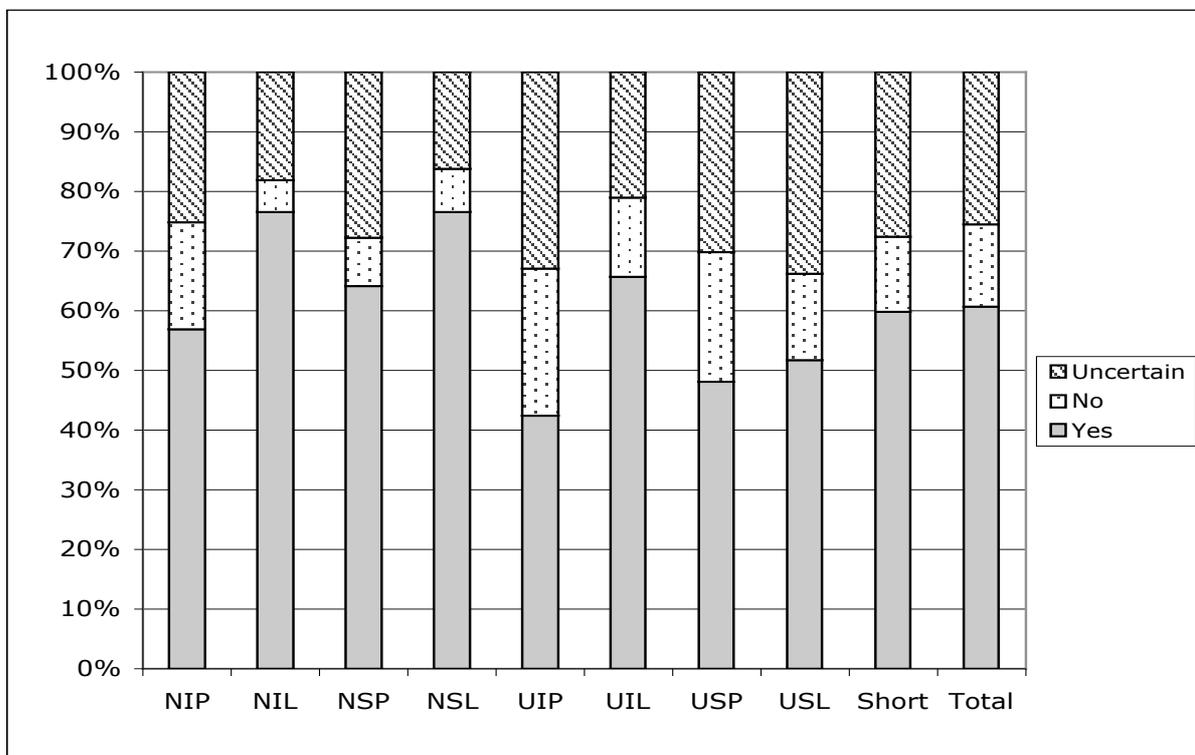


Chart 2. Support for cancer intervention by survey version



Individuals who responded “yes” to questions concerning support for free CVD and/or cancer prevention programs were further asked whether they would be willing to pay 150 NOK (approximately \$30) per month in either personal payments or extra taxes to participate in or support the program. The responses are summarized in Tables 5 and 6 and Charts 3 and 4.

Table 5. Willingness to pay 150 NOK for CVD prevention by survey version, as % of those accepting treatment

Version	Yes	No	Uncertain	Total
	%	%	%	n
NIP	42.6	25.2	32.3	155
NIL	42.0	26.8	31.2	276
NSP	49.2	20.3	30.5	177
NSL	36.8	34.5	28.6	220
UIP	41.8	32.6	25.5	141
UIL	36.4	30.6	33.0	206
USP	46.2	25.8	28.0	132
USL	44.1	28.3	27.6	145
Short	45.0	26.0	29.0	200
Total	42.3	27.9	29.8	1652

Table 6. Willingness to pay 150 NOK for cancer prevention by survey version, as % of those accepting treatment

Version	Yes	No	Uncertain	Total
	%	%	%	n
NIP	41.5	29.6	28.9	159
NIL	45.4	25.8	28.8	271
NSP	56.3	18.9	24.7	190
NSL	45.5	29.0	25.5	231
UIP	41.1	34.1	24.8	129
UIL	40.7	30.2	29.1	199
USP	46.8	26.6	26.6	139
USL	46.2	27.3	26.6	143
Short	49.7	21.1	29.2	185
Total	46.1	26.7	27.3	1646

Chart 3. Willingness to pay 150 NOK for CVD prevention by survey version

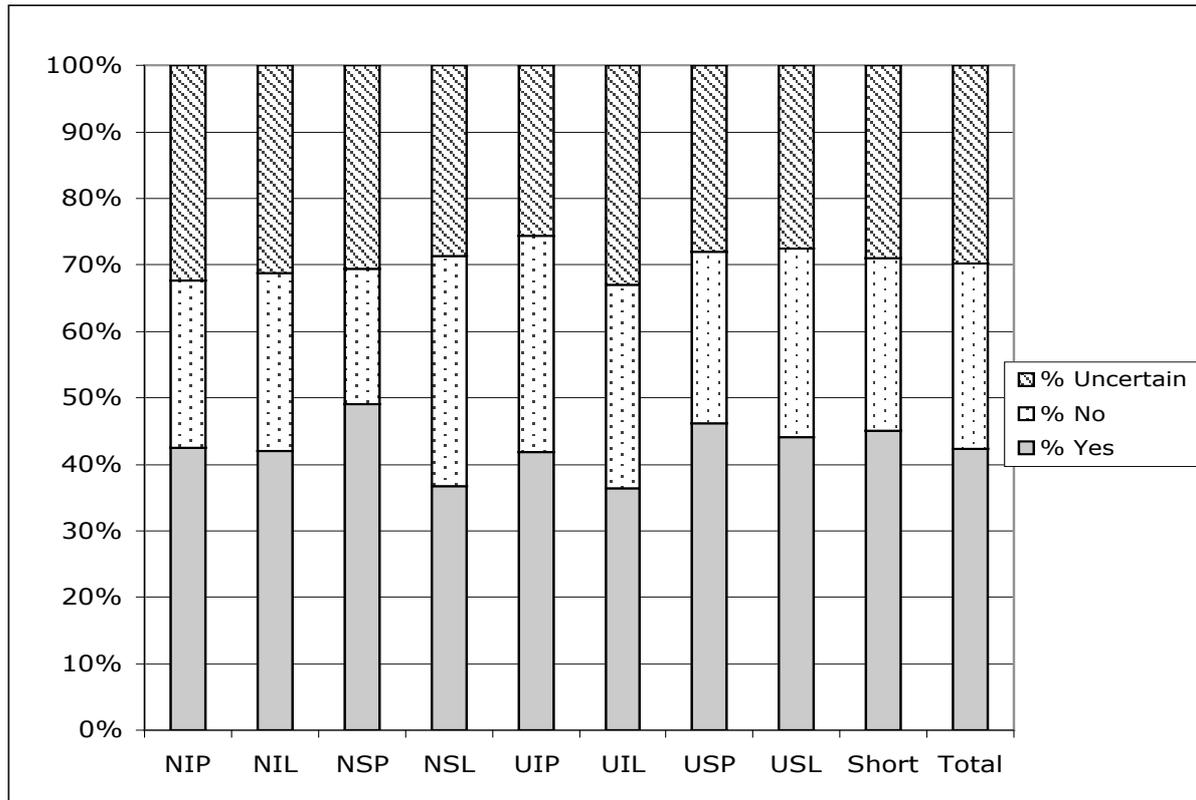
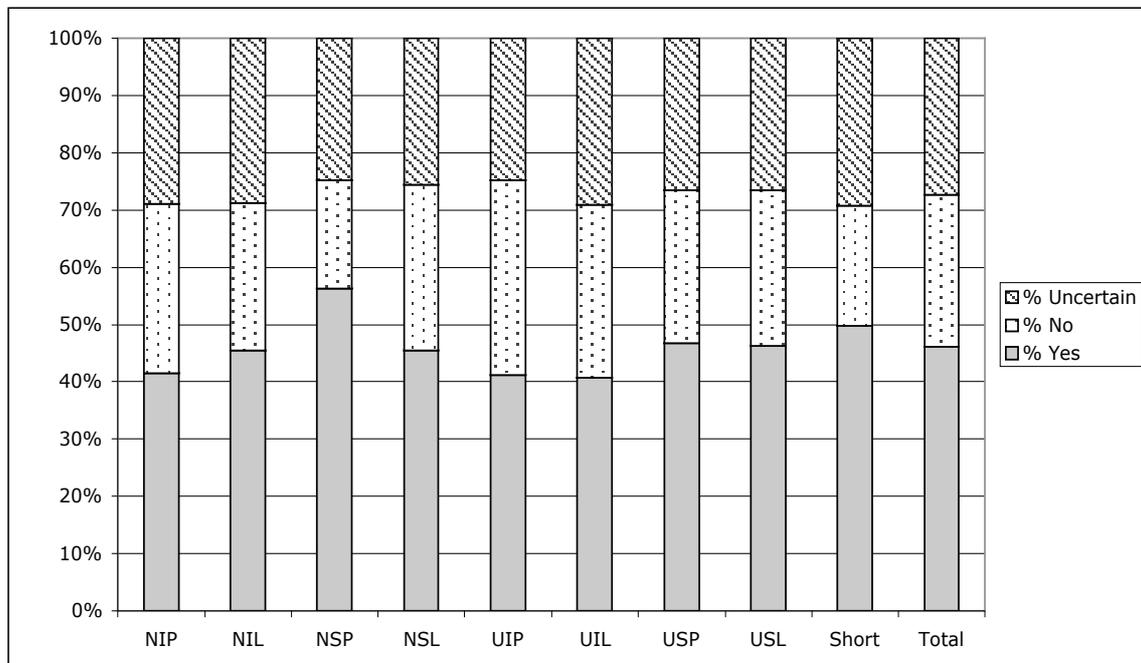


Chart 4. Willingness to pay 150 NOK for cancer prevention by survey version



Among the 1652 individuals who supported the CVD intervention, 42% were willing to pay 150 NOK per month for the program, 28% declined, and 30% were uncertain. For cancer prevention, the “yes”, “no” and “uncertain” responses were 46%, 27%, and 27%, respectively, for the 1646 individuals who were willing to participate in a free program. Assuming that individuals who declined or were uncertain about participation in the prevention program would not have been willing to pay for it, only 26% of the entire survey population expressed a willingness to pay 150 NOK per month for CVD prevention, with 28% willing to pay that amount for cancer prevention. There was relatively little variation in willingness-to-pay responses across survey versions.

Respondents answering either “no” or “uncertain” to the offer of prevention programs were asked to explain their choice by selecting all relevant options from a list possible explanations. Results for refusal to participate in CVD and cancer prevention are provided in Table 7 and Table 8, respectively. Possible explanations differed somewhat across survey versions. All respondents could indicate that they thought the program was of no value, that they did not want to increase the number of deaths for the other disease or from other causes, or that they did not want to experience (or expose others to) side effects. Other possible responses included: not wanting to extend life (Individual versions), not wanting to take medication (Pharmaceutical versions), not wanting to change life-style (Life-style versions), not wanting to pay more taxes (Societal versions) and not believing taxes should be spent on the programs (Societal versions). Reasons selected least often were “taxes shouldn’t be used for this purpose” [CVD: 13%, Cancer: 12%], “don’t want to pay more taxes” [CVD: 13%, Cancer: 14%] and “the program has no value” [CVD: 19%, Cancer: 20%]. Average frequencies for other reasons ranged from 26% [CVD: “don’t want to change life-style”] to 40% [Cancer: “don’t want to extend life”], with most grouped around 33%.

Table 7. Reasons for not accepting offered CVD prevention as % of respondents by survey version

Reasons	NIP %	NIL %	NSP %	NSL %	UIP %	UIL %	USP %	USL %	Total* %
Not valuable	12.1	14.1	19.3	29.3	13.5	13.4	29.3	19.1	18.8
Don't want to increase cancer deaths	38.7	26.9	38.7	47.6	23.3	18.6	28.0	35.1	31.5
Don't want to increase other deaths	27.4	25.6	41.2	36.6	31.9	20.6	37.6	44.3	33.9
Don't want (to expose others to) side effects	42.7	21.8	44.5	22.0	37.4	24.7	45.9	29.8	35.4
Don't want to extend life by 6 months	36.3	29.5			39.9	30.9			35.3
Don't like to take medicine	29.0				37.4				33.8
Don't want to change life style		29.5				23.7			26.3
Don't think taxes should be used for this			11.8	14.6			12.7	13.0	12.9
Don't want higher taxes			11.8	17.1			7.6	18.3	13.1
Total Number of Cases (n)	124	78	119	82	163	97	157	131	951

*Percent selecting option relative to total number presented with option. "Short" version cases excluded.

Table 8. Reasons for not accepting offered cancer prevention as % of respondents by survey version

Reasons	NIP %	NIL %	NSP %	NSL %	UIP %	UIL %	USP %	USL %	Total* %
Not valuable	12.9	15.4	21.0	30.5	16.0	12.4	26.8	20.6	19.6
Don't want to increase CVD deaths	30.6	24.4	30.3	28.0	28.2	19.6	23.6	32.8	27.7
Don't want to increase other deaths	30.6	26.9	32.8	35.4	30.1	18.6	37.6	44.3	33.0
Don't want (to expose others to) side effects	46.0	26.9	45.4	23.2	39.3	25.8	45.2	32.1	37.5
Don't want to extend life by 4 months	41.1	34.6			47.9	36.1			39.6
Don't like to take medicine	25.8				34.4				29.8
Don't want to change life style		26.9				30.9			27.3
Don't think taxes should be used for this			8.4	12.2			14.0	11.5	12.4
Don't want higher taxes			13.4	15.9			7.6	18.3	14.1
Total Number of Cases (n)	120	83	106	71	175	104	150	133	942

*Percent selecting option relative to total number presented with option. "Short" version cases excluded.

Although a systematic presentation of all of the explanatory responses is beyond the scope of this paper, several results can be highlighted. The pattern of responses was similar for decisions to decline CVD vs. cancer prevention with two exceptions: “I don’t want to extend life” was mentioned more frequently as a reason for refusing cancer vs. CVD prevention, and “I don’t want to increase cancer deaths” was mentioned more often as a reason for refusing CVD intervention than was the comparable “I don’t want to increase CVD deaths” as a reason for refusing cancer intervention. There was also variation in the frequency of responses across survey groups. Most notably, “I don’t want to (expose others to) side effects” and “I don’t want to extend life” were selected more often on “pharmaceutical” than “life-style”

versions as reasons to refuse both CVD and cancer prevention. “Don’t want to increase cancer deaths (deaths from Condition Y)” appeared more frequently as a reason for declining CVD intervention for “named” vs. “unnamed” survey versions although this was not the case for “I don’t want to increase CVD deaths (deaths from Condition X)” and refusal to accept cancer intervention.

The 1471 individuals who were willing to participate in (or support) both the CVD and cancer prevention programs were asked to choose between the programs. Results are provided in Table 9.

Table 9. Preference for CVD vs. Cancer intervention by survey version

	CVD prevention	Cancer prevention	Equally valuable	Don't Know	Total
Version	%	%	%	%	n
NIP	13.0	17.4	68.1	1.4	138
NIL	16.8	25.0	56.6	1.6	256
NSP	9.8	16.0	71.8	2.5	163
NSL	9.9	25.2	62.9	2.0	202
UIP	20.8	14.2	57.5	7.5	120
UIL	20.3	12.3	61.5	5.9	187
USP	19.6	10.7	66.1	3.6	112
USL	18.3	18.3	54.8	8.7	126
Short	6.0	18.0	76.0	0.0	167
Total	14.6	18.4	63.7	3.3	1471

A large majority, 63.7%, indicated that they thought both programs were equally valuable. Cancer prevention was chosen by 18.4% and CVD prevention by 14.6%, while 3.3% were uncertain about which program they would choose. The results also varied by survey version with cancer prevention preferred when the disease was named and CVD prevention preferred among respondents who answered the “unnamed” version. Individuals who expressed a preference for one of the

prevention programs were asked to check answers to explain their reasoning. Among the 270 respondents who preferred the cancer prevention program, reasons selected were: “It is worse to die of cancer than CVD” (44%), “Cancer is a more serious disease than CVD” (41%), “I have a family history of cancer” (20%), and “I don’t think I will get CVD” (10%). Responses among the 215 individuals who preferred CVD prevention were: “There is a larger increase in life expectancy” (51%), “There are more cases of CVD than cancer” (40%), “I have a family history of CVD” (26%), “It is worse to die of CVD than cancer” (7%), and “I don’t think I will get cancer” (6%).

3.2 “Short” survey version

The “short” version of the survey posed identical questions to the “named disease, individual perspective, pharmaceutical intervention” version but removed all references to changes in the distribution of causes of death resulting from prevention programs. Chi-squared tests indicated that there were no significant differences in patterns of answers between the two versions with regard to willingness to accept cancer prevention treatment, willingness-to-pay for either CVD or cancer prevention, or the head-to-head choice between the CVD and cancer prevention programs. Responses patterns were different with regard to willingness to accept CVD treatment, with fewer respondents agreeing to participate when information about changes in the distribution of causes of death was provided, but the result was not strongly significant ($p = .058$).

3.3 Multinomial logistic regressions

We performed multinomial logistic regressions to gain insight into the determinants of willingness to accept CVD and cancer intervention, of willingness to pay for treatment among those who said they would accept the interventions, and of the choice between CVD and cancer intervention. Cases in which respondents answered the “short” survey version were not included in the regressions because they received less information about the effects of intervention than other respondents. All regressions used “yes” as the reference category. Odds ratios for “no” responses are presented below. Full regression results, including odds ratios for “uncertain” responses, are reported in Tables 10, 11, 12 and 13.

Willingness to participate in a CVD prevention program was explained by whether the disease was “named” or “unnamed”, the type of treatment offered, and whether the respondent had direct experience with CVD and was numerate. The odds of refusing CVD prevention were 2.2 ($p < .001$, CI: 1.7 - 2.8) times greater than the odds of accepting treatment when the respondent answered a survey with “unnamed” diseases; 2.7 ($p < .001$, CI: 2.1 – 3.5) times greater when offered drug treatment rather than life-style intervention; 1.5 ($p = .001$, CI: 1.2 – 1.9) times greater if there was no personal experience with CVD; and 1.4 ($p = .024$, CI: 1.05 – 1.9) times greater if the respondent was numerate (defined as answering all three numeracy questions correctly).

For explaining willingness to participate in the cancer intervention, only the type of treatment offered and whether the disease was “named” or “unnamed” were significant. The odds of refusing participation were 2.6 ($p < .001$, CI: 2.1 – 3.4) times greater than the odds of accepting when the diseases were “unnamed” in the survey, and 2.4 ($p < .001$, CI: 1.9 – 3.1) times higher when a pharmaceutical

intervention was offered. Numeracy increased the odds of refusing the intervention, but was not significant at the 95% level ($p = .076$).

Table 10. Multinomial logistic regression results.
Dependent variable: Willingness to accept CVD prevention treatment

	Odds-ratio	Sig.	95% Confidence Interval: Odds-ratio	
			Lower bound	Upper bound
Refused participation				
Unnamed disease	2.182	< 0.001	1.696	2.807
Drug intervention	2.734	< 0.001	2.119	3.529
No CVD history	1.499	0.001	1.169	1.923
Numerate	1.410	0.024	1.047	1.898
Uncertain				
Unnamed disease	1.592	< 0.001	1.307	1.938
Drug intervention	1.725	< 0.001	1.417	2.101
No CVD history	1.203	0.071	0.984	1.470
Numerate	0.937	0.562	0.753	1.167

Reference category for dependent variable is: Accepted participation

Reference categories for independent variables are: named disease, life-style intervention, CVD history, innumerate

Table 11. Multinomial logistic regression results.
Dependent variable: Willingness to accept cancer prevention treatment

	Odds-ratio	Sig.	95% Confidence Interval: Odds-ratio	
			Lower bound	Upper bound
Refused participation				
Unnamed disease	2.638	< 0.001	2.052	3.392
Drug intervention	2.377	< 0.001	1.852	3.050
Numerate	1.299	0.076	0.973	1.735
Uncertain				
Unnamed disease	1.796	< 0.001	1.482	2.177
Drug intervention	1.708	< 0.001	1.409	2.070
Numerate	0.875	0.217	0.707	1.082

Reference category for dependent variable is: Accepted participation

Reference categories for independent variables are: named disease, life-style intervention, innumerate

We tested a variety of variables in an attempt to explain willingness-to-pay for the prevention programs, but only found a significant explanatory relationship for willingness-to-pay for cancer prevention, for which income, personal experience

with the disease and survey perspective were important. Lacking a continuous income variable and needing to guarantee sufficient numbers of respondents at each income level, we created three income categories “below median” (< 600,000 kroner), “median” (600,000-799,000 kroner), and “above median” (>799,999 kroner). The odds of refusing to pay 150 kroner per month for the cancer prevention program were 1.6 ($p = .007$, CI: 1.1 – 2.2) times greater than the odds of being willing to pay for the lowest income group relative to the highest, 1.6 ($p < .001$, CI: 1.3 – 2.1) times higher for those without personal experience with cancer, and 1.4 ($p = .014$, CI: 1.1 – 1.8) times greater when the individual was considering paying to participate in the program (individual perspective) rather than paying higher taxes for societal provision. The odds ratio for the median income group relative to the highest group was also greater than one, but not significant.

Table 12. Multinomial logistic regression results. Dependent variable: Willingness to pay 150 NOK/month for Cancer prevention treatment

	Odds-ratio	Sig.	95% Confidence Interval: Odds-ratio	
			Lower bound	Upper bound
Unwilling to pay				
Below median Y	1.568	0.007	1.130	2.174
Median Y	1.270	0.194	0.886	1.820
No Cancer history	1.629	< 0.001	1.254	2.115
Individual Perspective	1.385	0.140	1.069	1.795
Uncertain				
Below median Y	1.763	0.001	1.258	2.469
Median Y	1.493	0.033	1.034	2.156
No Cancer history	1.466	0.005	1.125	1.909
Individual Perspective	1.384	0.015	1.066	1.796

Reference category for dependent variable is: Willing to pay
Reference categories for independent variables are: above median income, cancer history, societal perspective

The final regression explains the choice of preferred prevention program with the response “both programs are equally valuable” serving as the reference category. Cases in which individuals chose “don’t know” were omitted from the regression. The odds of selecting CVD prevention were 1.6 ($p = .008$, CI: 1.1 – 2.3)

times greater than the odds of selecting “both programs are equally valuable” when the respondent had personal experience with CVD, 1.6 ($p = .004$, CI: 1.2 – 2.2) times greater when the disease was “unnamed”, and 0.61 ($p = .003$, CI: 0.44 - 0.84) times less when the respondent had personal experience with cancer. The odds of selecting cancer prevention were 1.5 ($p = .008$, CI: 1.1 – 2.1) times greater than saying the programs were equally valuable when a life-style intervention was offered rather than a pharmaceutical intervention, 0.68 ($p = .014$, CI: 0.49 – 0.92) times lower when the disease was “unnamed”, and 0.60 ($p = .001$, CI: 0.45 – 0.82) times lower when the respondent had personal experience with CVD. Personal history with cancer increased the odds ratio but was not significant at the 95% level ($p = .082$).

Table 13. Multinomial logistic regression results. Dependent variable: Choice between prevention programs

	Odds-ratio	Sig.	95% Confidence Interval: Odds-ratio	
			Lower bound	Upper bound
Prefer CVD program				
CVD History	1.617	0.008	1.134	2.307
Cancer History	0.609	0.003	0.440	0.842
Unnamed disease	1.611	0.004	1.165	2.226
Life-style intervention	1.158	0.382	0.833	1.610
Prefer Cancer program				
CVD history	0.603	0.001	0.446	0.815
Cancer history	1.319	0.082	0.966	1.802
Unnamed disease	0.673	0.014	0.490	0.924
Life-style intervention	1.528	0.008	1.115	2.093

Reference category for dependent variable is: Both interventions are equally valuable
Reference categories for independent variables are: no CVD history, no cancer history, named disease, drug intervention

4. Discussion and conclusion

Our primary goal in conducting this study was to determine whether information about increases in life expectancy and changes in the distribution of causes of death resulting from CDV and cancer prevention programs would influence willingness to accept preventative treatment against these diseases. We hypothesized that if individuals have a preference for an “easy” death, they would be less likely to accept preventative treatment for CVD vs. cancer. Our results provided little evidence that this is the case. Respondents accepted the offers of prevention programs against CVD and cancer at similar rates of approximately 61%. When asked to choose between the two programs, a majority indicated that they thought the programs were of equal value, and although slightly more of the remainder preferred cancer prevention, the difference was not statistically significant. Neither was there a strongly significant difference in the responses of individuals answering the “short” survey version, in which there was no mention of changes in the distribution of causes of death, compared to the otherwise identical “named, individual, pharmaceutical” survey version.

We did find evidence that individuals are sensitive to the way in which questions are framed. Respondents were more likely to accept preventative treatment that involved life-style changes rather than pharmaceutical intervention (Odds ratio: CVD = 2.7, Cancer = 2.4). They were also more likely to accept treatment when the disease was named in addition to being described (Odds ratio: CVD = 2.2, Cancer = 2.6). This result is consistent with more thorough studies of the affects of naming (Sackett and Torrance, 1978; Llewelyn-Thomas et al., 1984) and with the theory of affect heuristics, which suggests that strong emotional response to a word can alter judgment (Finucane, 2000). Cancer, in particular, is a term that often carries strongly negative associations that can be far worse than the reality of the disease (Sontag, 1990). Whether surveys involved an individual or societal perspective had little

effect on responses, although we found slightly more willingness to pay for cancer prevention when the question was framed a societal rather than individual perspective.

While a large majority of respondents were willing to participate in both CVD and cancer prevention programs, relatively few were willing to pay 150 kroner per month, which reflects a low estimate of the cost of the CVD pharmaceutical intervention, to do so. For CVD prevention, 42% of those agreeing to participate (26% of all survey respondents) were willing to pay, while for the cancer prevention program 46% of those accepting treatment (28% of all respondents) were willing to pay. It is interesting to note that the minimum value of an extra life-year implied by these figures is quite low. For CVD treatment, given an average six-month extension in life expectancy and assuming that individuals would participate in the program for an average of 30 years, the implied undiscounted value of an extra life-year is 108,000 NOK (approximately \$21,600 at \$1=5.12 NOK). For cancer treatment, which yields an average four-month increase in life expectancy with an average of 20 years of participation, the implied undiscounted value of an extra life-year is also 108,000 NOK. If the stream of payments and benefits are discounted at a rate of 4%, the value of an extra life-year is 64,735 NOK (approximately \$12,950) under the CVD prevention program and 76,250 NOK (approximately \$15,250).

Our study has several limitations that reflect our attempt to design a survey that focused attention on differences in changes in the distribution of causes of death resulting from the two prevention programs without overburdening respondents with a variety of other information. The need to provide balance in the cognitive demands of the survey is supported by the fact that, even with simplifications, in some instances survey answers varied according to whether respondents were “numerate” or not. Descriptions of the diseases were therefore quite brief and generic, particularly for cancer. While it is not unreasonable to describe a general pattern of symptoms, disease progression and life expectancy for CVD, the same is

likely not true for cancer, where experiences vary widely depending on which type of cancer one considers. Similarly, the prevention programs presented were identical across diseases, with the pharmaceutical intervention described as requiring daily medication and extra annual doctor visits, and the life-style intervention described as requiring changes in diet and significant increases in exercise. It is possible, that, confronted with the difficult task of assessing the differences in life expectancy and varying patterns of distributions of causes of death, respondents focused instead on the similarities between the prevention programs.

Another simplification in our survey was in the choice of method used to describe gains in life expectancy resulting from prevention programs. We presented the information as average number of life-years gained. Although such information is accurate, it provides no information about the expected distribution of gains across a population. In the case of CVD, for example, a prevention program yielding an average increased life expectancy of six months would only be expected to benefit the one-third of the population at risk for CVD, implying an eighteen-month gain in life expectancy for this group and no benefit for the remaining two-thirds. Gyrð-Hansen and Kristiansen (2007) found that expected utility from gains in life expectancy is significantly decreased if the gain is less than six months and significantly increased if the probability of gains exceeds 0.083. If this is the case, providing information about the distribution of life expectancy gains might actually have increased willingness to participate in prevention programs.

A final simplification in our study is that it did not include any mention of dementia—a chronic disease that individuals are often quite anxious to avoid. Initially, we intended to include dementia in our analysis of the distribution of causes of death and provide information about the increased numbers of people who would die of dementia as a result of extending life through prevention programs against CVD or cancer. This was not possible, however, because dementia is rarely reported as a primary cause of death. We also considered calculating the additional

number of years that individuals were likely to spend in a demented state given current estimates of the age-specific prevalence of dementia (ranging from 12.2% for ages 80-84 to 32.5% for ages 95+ [Knapp, Prince, et. al. (2007)]), but decided that respondents might be unable to easily incorporate this additional information when deciding whether to support the intervention programs. To the extent that individuals have a preference for not living in a demented state, there might have been less support for the CVD prevention program.

In retrospect, we note that we may have forgone the opportunity to obtain better information about preferences regarding the potential trade-off between more life-years and a less preferred manner of death by allowing respondents who expressed willingness to support both CVD and cancer prevention to answer “equally valuable” when asked to choose between the two. Only one-third of respondents selected one of the programs, with slightly more preferring cancer prevention. Greater extension of life expectancy was a popular explanation for those who preferred the CVD program, while believing that it was worse to die of cancer than CVD was mentioned frequently among those who chose cancer prevention. It would have been instructive to have had the opinions of the other two-thirds of respondents, had they been forced to make a choice.

Our study has examined the influence that information about changes in life expectancy and the distribution of causes of death has on preferences for CVD and cancer prevention programs. While our results provided little support for our hypothesis that such information would reduce demand for CVD prevention, they did confirm previous findings that the framing of an issue plays an important role in individual responses. Continued investigation into the best ways of presenting cognitively challenging information is needed in order to further explore preferences over the manner of death. If society continues to actively promote CVD prevention, our study provides evidence that focusing on life-style changes may be most productive in terms of individuals’ willingness to participate.

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Appendix 1. Survey – NIP version

In Norway, as in most Western countries, life expectancy has increased over the last 100 years. In earlier times, people died at younger ages of infectious diseases such as pneumonia and tuberculosis. Now, most people live longer lives and die of chronic diseases that develop over time and which usually are diagnosed after the age of 50. Prevention programs exist that may postpone the development of a particular chronic disease. Such measures will allow a slightly longer life, but may ultimately lead to death from another disease. This survey is being undertaken to gain a better understanding of attitudes about prevention of two chronic health conditions that many people face in later life. Please read the following descriptions and respond as carefully as possible to the questions.

Cardiovascular disease

Individuals with cardiovascular disease may experience shortness-of-breath and mild to severe chest pains in connection with physical activity. Approximately half of patients die suddenly. The large majority of deaths from cardiovascular disease (almost 9 of 10) occur after the age of 70.

Cancer

Individuals with cancer may experience loss of appetite, significant unintended weight loss, fatigue, nausea, and pain. Approximately half of patients are cured, but the others die after 2-3 years with increasingly severe symptoms, including increasing pain. Most deaths (6 in 10) from cancer occur after the age of 70.

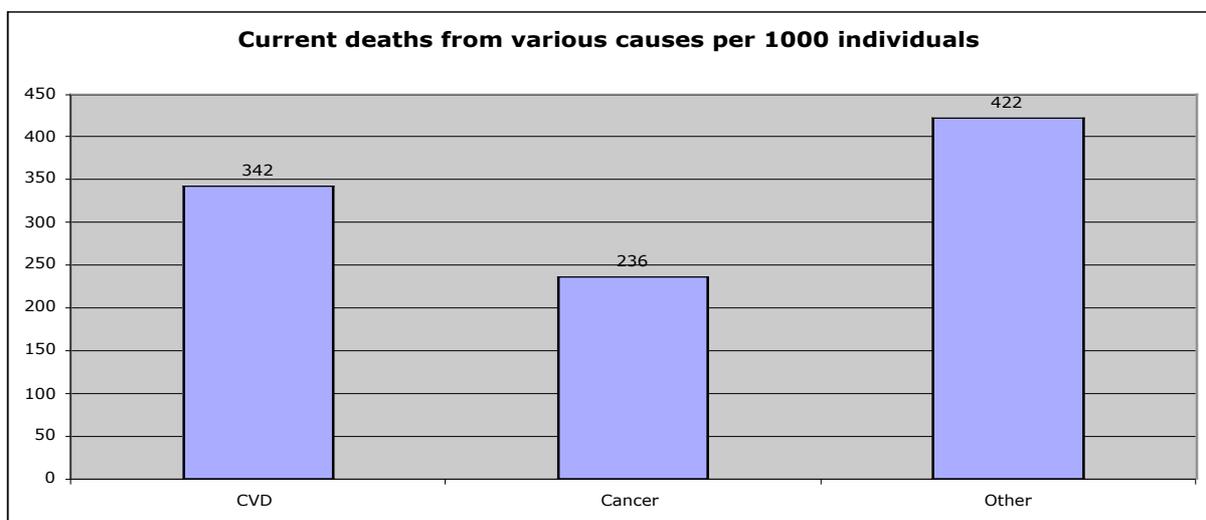
Currently in Norway, out of every 1000 individuals approximately:

342 will die of cardiovascular disease

236 will die of cancer

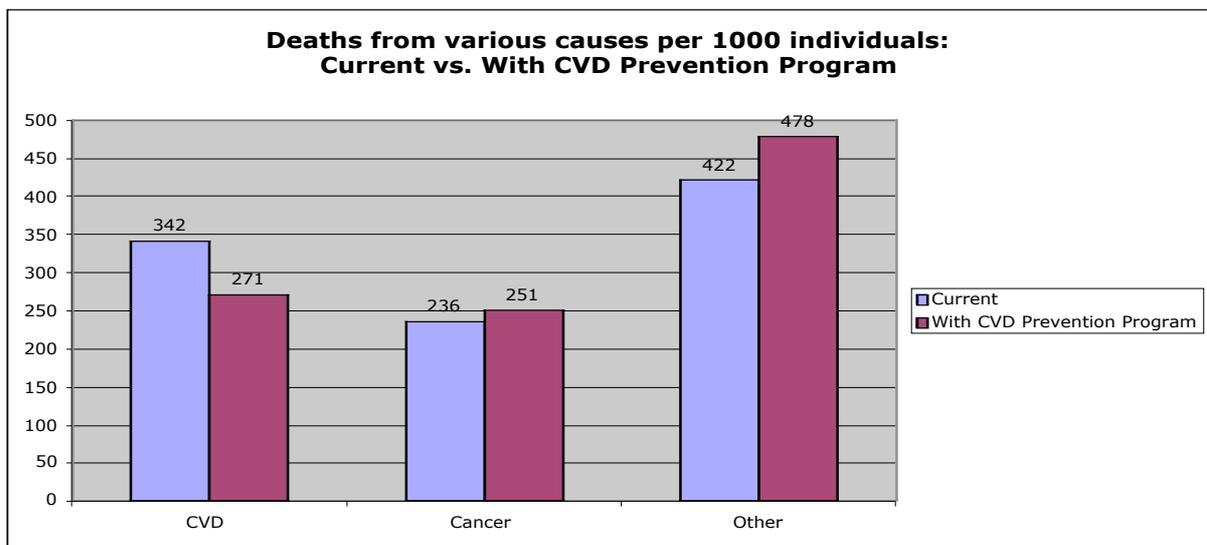
422 will die of other causes.

Here is a graph showing that information.



Suppose the health authorities are considering implementing a new disease prevention program against cardiovascular disease. The program would require that individuals take daily medication and make annual visits to the doctor for the rest of their lives. This prevention program extends life by an average of approximately six months and may have minor side effects. As a result of this program, out of 1000 individuals, 71 fewer people will die of cardiovascular disease, but 15 more people will die of cancer, and 56 more people will die of other causes.

Here is a graph comparing the number of deaths from various causes without a prevention program (the current situation) and with the prevention program against cardiovascular disease. The blue bars show the current situation. The red bars show the number of deaths if the program were implemented.



1. Would you participate in the prevention program if offered the opportunity free of charge?

- Yes (go to question #2)
- No (go to question #3)
- Uncertain (go to question #3)

2. Would you be willing to pay NOK 150 per month to participate in this prevention program?

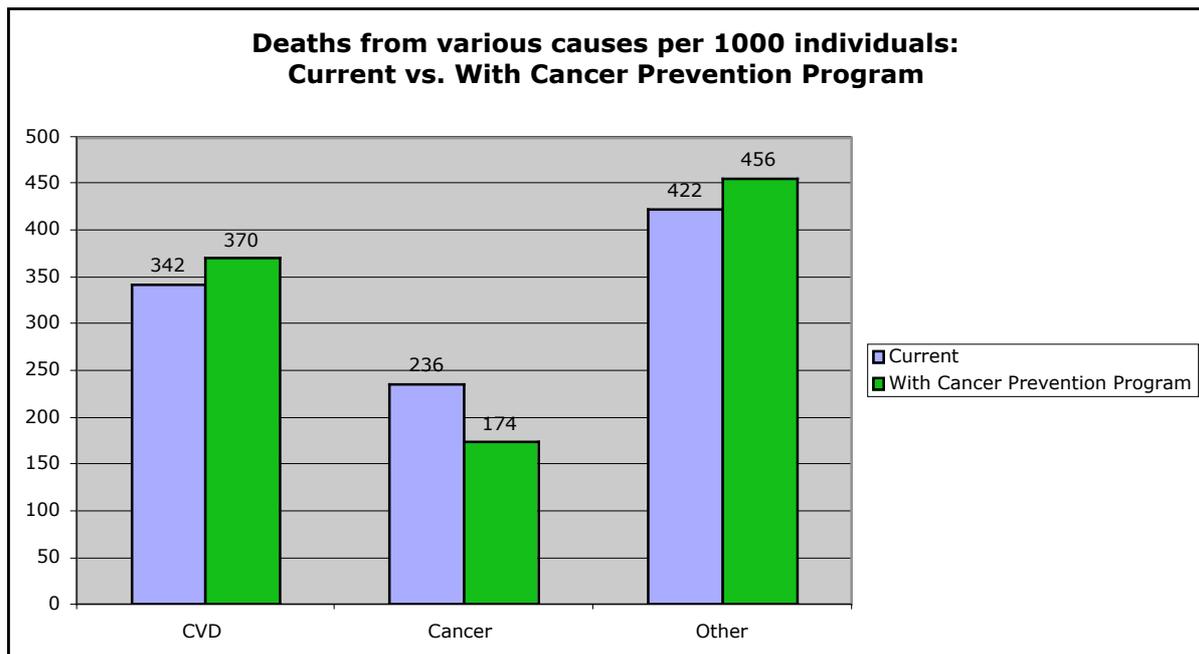
- Yes
- No
- Uncertain

3. Why were you not willing to participate in the prevention program against cardiovascular disease? (select as many as applicable)

- I don't think the prevention program is of sufficient value
- I don't like to take medications
- I don't want to experience side effects
- I do not want to increase my life by 6 months in my old age
- I would rather not increase the number of deaths from cancer
- I would rather not increase the number of deaths from other causes

Suppose instead that there is a general, lifelong prevention program against cancer. This prevention program requires that individuals take daily medication and make annual visits to the doctor for the rest of their lives. The prevention program would extend life by an average of approximately 4 months and may have minor side effects. As a result of this prevention program, 62 fewer people will die of cancer, but 28 more people will die of cardiovascular disease, and 34 more will die of other causes.

Here is a graph comparing the number of deaths from various causes without a prevention program (the current situation) and with the prevention program against cancer. The blue bars show the current situation. The green bars show the number of deaths if the program were implemented.



4. Would you participate in the prevention program if offered the opportunity free of charge?

- Yes [If yes: go to #5]
- No [If no/uncertain: Go to question #6]
- Uncertain

5. Would you be willing to pay NOK 150 per month in additional taxes to participate in this prevention program?

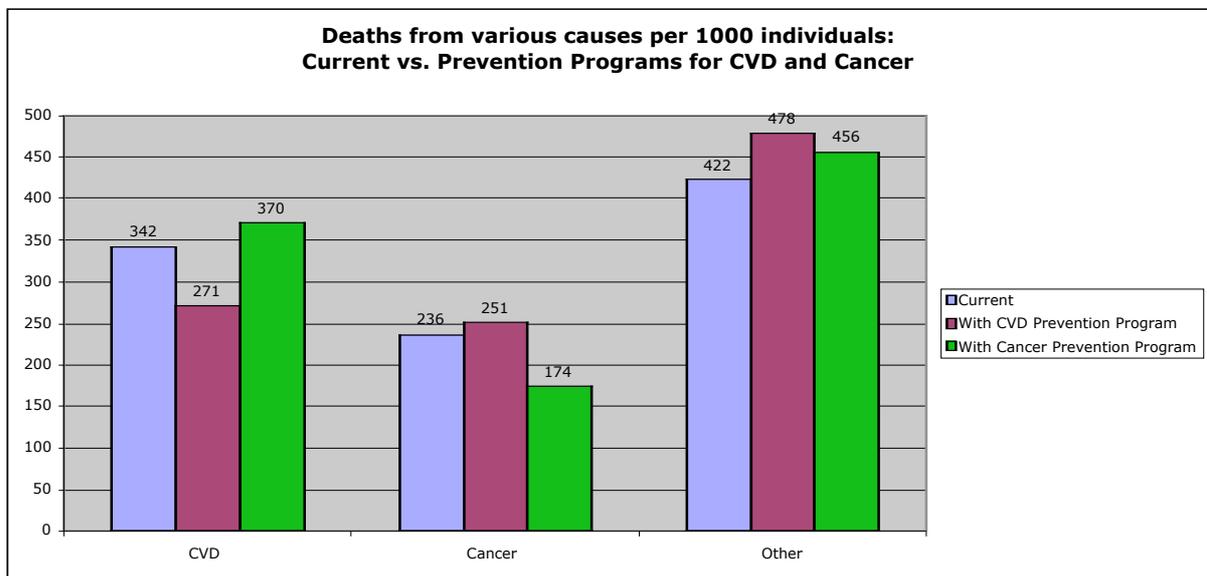
- Yes
- No
- Uncertain

[If 1 & 4 both are yes: go to #7, otherwise go to #9]

6. Why were you not willing to participate in the prevention program against cancer?

- I don't think the prevention program is of sufficient value
- I don't like to take medication
- I don't want to experience side effects
- I don't want to extend my life by four months in my old age
- I would rather not increase the number of cardiovascular deaths
- I would rather not increase the number of other deaths

Here is a graph showing both the current number of deaths from various causes and the different numbers of deaths from various causes that would occur under each of the two prevention programs. The blue bars show the current situation, the red bars show the situation with prevention program against cardiovascular disease, and the green bars show the situation with the prevention program against cancer.



7. Suppose you had to choose between the prevention program against cardiovascular disease and the prevention program against cancer, in which prevention program would you participate? You can imagine that they have identical costs.

- Prevention program against cardiovascular disease
- Prevention program against cancer
- They are equally valuable
- Uncertain

8. [a. IF ANSWER TO #7 = cardiovascular disease] Why do you prefer the prevention program against cardiovascular disease to the cancer prevention program? (check as many as applicable)

- There are more cases of cardiovascular disease than cancer
- The cardiovascular disease prevention offers a greater gain in life expectancy
- It would be worse to die from cardiovascular disease than from cancer
- I have a family history of cardiovascular disease
- I don't believe that I will get cancer

[b. IF ANSWER TO #7 = cancer] Why do you prefer the prevention program against cancer to the cardiovascular prevention program? (check as many as applicable)

Cancer is a more serious disease than cardiovascular disease

It would be worse to die from cancer than cardiovascular disease

I have a family history of cancer

I don't believe that I will get cardiovascular disease

9. Have you or any close relative (parent, child, sibling, spouse) been diagnosed with or treated for cardiovascular disease (heart disease)?

Yes

No

Uncertain

10. Have you or any close relative (parent, child, sibling, spouse) been diagnosed with or treated for any form of cancer?

Yes

No

Uncertain

11. Imagine that you toss a krone in the air. How many times on average do you think it will land on "krone" if the coin is tossed 1000 times? ____ times out of 1000

12. If the probability that you get a disease is 10%, how many people can expect to get the disease of 100? _____ people out of 100

13. Imagine that you are buying a sweater that is reduced by 25% from the original price of 400 kroner. How much do you have to pay for the sweater

100 kroner

250 kroner

300 kroner

400 kroner

500 kroner

Thank you for your participation!