RESEARCH REPORT

Total and cause specific mortality among participants and non-participants of population based health surveys: a comprehensive follow up of 54 372 Finnish men and women

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J Epidemiol Community Health 2005;**59**:310–315. doi: 10.1136/jech.2004.024349

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Accepted for publication 6 September 2004

Study objective: To assess total and cause specific mortality among participants and non-participants of large population based health surveys.
Design: A prospective follow up study. Baseline surveys were conducted in 1972, 1977, 1982, 1987, and 1992. Study end points were overall, cardiovascular, cancer and violent mortality, and deaths related to smoking and alcohol. Study cohorts were followed up until the end of 2000 through computerised record linkage. All analyses were adjusted for age.
Setting: Finland.
Participants: Participants and non-participants of five population based risk factor surveys. The samples included 54 372 men and women aged 25 to 64 years at baseline.
Main results: The average participation rate was 81.7% among men and 87% among women. At eight year follow up, the non-participating men had twice and non-participating women 2.5-fold higher overall mortality than the participating men and women. Non-participants had also significantly higher cause specific mortality, except cancer and smoking related mortality among women. Relative differences in mortality were largest in violent and alcohol related deaths. Non-participants had considerably higher overall mortality than smoking participants, and their mortality was threefold compared with non-smoking participants.
Conclusions: Observed differences in mortality show that health behaviour and health status substantially differ between non-participants and participants. Low participation rate may considerably bias the results of population based health surveys.

Health and risk factor monitoring is important for healthcare planning and evaluation, and as a tool for medical research. For some health indicators, such as mortality, monitoring may be based on existing registers. However, data on many health related factors, such as health behaviour, the levels of various risk factors, and health status of the people, can be obtained only by conducting special surveys. Because it is not possible to examine all subjects in large populations, sample surveys are often used to estimate the levels of these factors in the target population.[1] To obtain reliable results, the sample should be (a) representative for the target population, (b) the sampled people should participate in the survey, (c) methods and instruments used in the survey measurements should be valid, and (d) the sample should be sufficiently large.

In large population based surveys, the participation rate is never 100%. The participation is also not a random phenomenon. Thus, non-response is a problem for at least two reasons. Firstly, a low participation rate reduces the number of study observations, which reduces statistical power and the precision of survey estimates. Secondly, and a more serious problem is that non-response can lead to bias when participants and non-participants differ systematically with respect to survey indicators.[2]

It has been shown in many studies that the participants differ from non-participants in various aspects, such as socioeconomic status, health behaviour, health status, and use of health services.[3–10] Participation rate may also vary between different time periods, areas, and age groups, which affects comparability between population groups and areas, and analyses of secular trends.[7 11 12] Therefore, the possible bias caused by self selection may be a serious concern, and a sufficiently high participation rate is essential for reliable results. However, the participation rates in published studies, as well as the opinions of researchers about the acceptable level of non-participation vary considerably.[13 14] Only a few studies, conducted mostly in comparatively small local communities or occupational settings, have been able to assess the long term disease outcome among non-participants.[5 10 15–17]

In this study we have had a unique opportunity to follow up a random sample of nearly 55 000 people representing the general population and having comprehensive mortality data. We compare total and cause specific mortality among participants and non-participants of large population based chronic disease risk factor surveys in Finland. In addition, mortality difference between participants and non-participants was quantified by comparing the mortality of non-participants with non-smoking and smoking participants.

METHODS

Study population

The study population consists of participants and non-participants of five cross sectional population surveys carried out in Finland in 1972, 1977, 1982, 1987, and 1992 for the assessment of the levels of chronic disease risk factors.[12] In each survey, an independent random sample was drawn from the population register, which includes all people living permanently in Finland. Institutionalised people were not included in the sampling frame. The name, address, date of

Table 1 Sample size, number of participants and participation rate by sex, study year, and area

	Men			Women		
Area and year	Sample size	Number of participants	Particpation rate (%)	Sample size	Number of participants	Participation rate (%)
Eastern Finland						
1972	6714	5816	86.6	6721	6054	90.1
1977	6768	5898	87.2	6927	6257	90.3
1982	3853	3013	78.2	3587	3030	84.5
1987	2972	2354	79.2	2973	2546	85.6
1992	1978	1425	72.0	1985	1633	82.3
South western Finland						
1982	1965	1602	81.5	1979	1702	86.0
1987	989	755	76.3	997	824	82.7
1992	994	749	75.4	995	832	83.6
Southern Finland						
1992	993	675	68.0	982	737	75.1

birth, and personal identification number of the sampled persons were obtained from the register.

In 1972 and 1977, a simple random sample of the population was drawn in the provinces of Kuopio and North Karelia in eastern Finland. In 1982 Turku-Loimaa region from south western Finland and in 1992 Helsinki-Vantaa area from southern Finland were included in the surveys. Since 1982 the sampling was done according to the WHO MONICA (multinational monitoring of trends and determinants in cardiovascular disease) protocol.[14] In each survey year the sample included people aged 25–64 years and the samples were stratified so that at least 250 subjects of each sex and each 10 year age group were chosen in each area. The total sample size of the five surveys was 54 453 men and women, of whom 45 902 (84.3%) participated. Eighty subjects, who died between the sampling and the actual survey were excluded from the analyses and 3232 subjects who were selected to more than one sample were included only in their first survey cohort. The surveys were conducted according the ethical rules of the National Public Health Institute and the investigations were carried out in accordance with the Declaration of Helsinki.

In every survey year the study protocol consisted of a self administered questionnaire, including data on health behaviour (such as smoking) and other health related data, anthropometric and blood pressure measurements, and laboratory tests. An invitation letter and the questionnaire were sent to the sampled persons two to four weeks before the survey. In the letter, the recipient was advised to fill in the questionnaire at home and bring it at a given time to the survey site. If the invitee did not appear to the survey site, they were contacted by phone to provide a new survey time. The study subjects were not paid for participation.

Follow up

The study cohorts were followed up until the end of year 2000 through computerised record linkage. Mortality data were obtained from the National Mortality Register and were linked to the study cohort data using the personal identification number assigned to every resident in Finland. The data covered all deaths in Finland and the deaths of Finnish citizens abroad. Thus, the mortality data were practically complete. During the follow up of 1 000 258 person years 10 395 people died.

The *International Classification of Diseases, Injuries and Causes of Death (ICD)*, eighth revision was used from 1969 to 1986, the ninth revision from 1987 to 1995, and the 10th revision was adopted at the beginning of 1996. ICD codes 410–414 and I20–I25 were classified as coronary heart disease deaths, codes 430–438 and I60–I69 as stroke deaths, codes 410–414, 430–438, I20–I25, and I60–I69 as cardiovascular disease deaths, codes 140–239 and C00–C97 as cancer deaths, and codes 800–999 and S00–T98 as violent deaths (including suicides, ICD codes E95 and X60–X84). Mortality from lung cancer (ICD codes 162 and C34) and chronic obstructive pulmonary disease (ICD codes 491–492 and J41–J44) were considered as smoking related deaths. Alcohol related deaths included injuries, diseases, and poisonings, where alcohol was either the main or contributing cause for the death (ICD-8 codes 291, 303, 5710, 577, and E860; ICD-9 codes 291, 303, 3575, 4255, 5353, 5710–5713, 5770D–5770F, 5771C–5771D, and E851; ICD-10 codes F10.0, F10.1–9, G312, G621, G721, I426, K292, K70, K860, O354, and X45).

Statistics

Mortality of non-participants, compared with the participants, was assessed using Cox proportional hazard models.

Table 2 Hazard ratios* (HR) and 95% confidence intervals (CI) for total and cause specific mortality by sex

	Men			Women		
Cause of death	HR	95% CI	Number of deaths	HR	95% CI	Number of deaths
Total	2.06	1.87 to 2.27	2261	2.56	2.19 to 3.00	866
CVD	1.89	1.62 to 2.19	1030	2.63	1.97 to 3.51	267
Stroke	1.68	1.12 to 2.52	153	1.91	1.07 to 3.42	81
CHD	1.92	1.63 to 2.26	877	2.94	2.11 to 4.11	186
Cancer	1.54	1.22 to 1.95	453	1.22	0.87 to 1.71	293
Suicides	1.71	0.96 to 3.03	54	5.07	1.76 to 14.6	14
Tobacco †	1.97	1.43 to 2.70	232	1.46	0.49 to 4.35	22
Alcohol ‡	3.10	2.37 to 4.04	236	4.33	2.10 to 8.94	31

CVD, cardiovascular disease; CHD, coronary heart disease. *Non-participants compared with participants, eight year follow up, adjusted for age, area, and study year. †Deaths caused by lung cancer and chronic obstructive pulmonary disease. ‡Alcohol related diseases, injuries, and poisonings.

Table 3 Hazard ratios* (HR) and 95% confidence intervals (CI) for total and cause specific mortality by sex and the length of follow up

	Men			Women		
Length of follow up and cause of death	HR	95% CI	Number of deaths	HR	95% CI	Number of deaths
Total mortality						
2 years	2.43	2.04 to 2.90	626	3.38	2.50 to 4.56	211
4 years	2.29	2.00 to 2.63	1087	3.08	2.48 to 3.84	405
6 years	2.13	1.91 to 2.39	1650	2.79	2.32 to 3.45	619
8 years	2.06	1.87 to 2.27	2261	2.56	2.19 to 3.00	866
28 years†	1.66	1.56 to 1.77	6638	1.84	1.68 to 2.01	3757
CVD mortality						
2 years	2.31	1.77 to 3.01	292	2.19	1.16 to 4.13	62
4 years	2.14	1.74 to 2.63	504	2.67	1.74 to 4.09	120
6 years	2.00	1.68 to 2.37	743	2.67	1.90 to 3.75	189
8 years	1.89	1.62 to 2.19	1030	2.63	1.97 to 3.51	267
28 years†	1.55	1.40 to 1.71	2899	1.81	1.56 to 2.11	1401
Cancer mortality						
2 years	2.50	1.65 to 3.81	111	2.37	1.35 to 4.17	69
4 years	2.01	1.43 to 2.81	193	1.77	1.14 to 2.74	135
6 years	1.63	1.24 to 2.16	317	1.45	1.00 to 2.09	215
8 years	1.54	1.22 to 1.95	453	1.22	0.87 to 1.71	293
28 years†	1.27	1.09 to 1.47	1433	1.18	0.98 to 1.44	1052
Violent mortality						
2 years	2.04	1.37 to 3.04	126	4.57	2.02 to 10.4	25
4 years	2.13	1.57 to 2.90	205	4.00	2.24 to 7.14	51
6 years	2.18	1.67 to 2.81	293	4.07	2.49 to 6.64	71
8 years	2.28	1.83 to 2.86	380	3.57	2.31 to 5.52	93
28 years†	1.85	1.57 to 2.17	816	2.25	1.64 to 3.07	237

CVD, cardiovascular disease. *Non-participants compared with participants, adjusted for age, area, and study year. †Maximum follow up time, all cohorts are followed up until the end of year 2000.

The models were adjusted for age, area, and study year. In the main analyses, each cohort was followed up for eight years. In addition, to assess the time dependency of the hazard ratios, analyses with two, four, six, eight, and a maximum of 28 years of follow up were conducted. To characterise the excess mortality among non-participants, mortality between non-smoking participants, smoking participants, and non-participants was compared. The statistical analyses were performed using SAS statistical software.

RESULTS

Participation rates were 81.7% in men and 87% in women (table 1).

Participation rate increased with age being 79% and 85.1% in the age group 25 to 44 years, and 85.3% and 89% in the age group 45 to 64 years, in men and women, respectively.

Mortality (adjusted for age, area, and study year, eight year follow up) among non-participating men was twice and among non-participating women two and half times as high as among participating men and women (table 2). The hazard ratios were 1.89 and 2.63 for cardiovascular disease mortality, 1.54 and 1.22 (non-significant) for cancer mortality, 2.29 and 3.57 for violent mortality, 1.97 and 1.46 (non-significant) for smoking related mortality, and 3.10 and 4.33 for alcohol related mortality, among men and women, respectively. Among women, the hazard ratio for suicidal death was 5.07, and nearly half of the suicides occurred among the non-participants.

In two year follow up the hazard ratio for total mortality was 2.43 in men and 3.38 in women (table 3). The hazard ratio decreased gradually when the length of follow up was extended, being 2.06 and 2.56 in eight year, and 1.66 and 1.84 in a maximum of 28 year follow up, in men and women, respectively. Similar gradual decrease in hazard ratio was also seen in cardiovascular disease mortality among men but not among women. In cancer mortality the decrease in hazard

Table 4 Hazard ratios* (HR) and 95% confidence intervals (CI) for total and cause specific mortality by sex and age group

	Men			Women		
Age group and cause of death	HR	95% CI	Number of deaths	HR	95% CI	Number of deaths
Total mortality						
25–44	2.18	1.79 to 2.66	483	3.02	2.12 to 4.32	152
45–64	2.03	1.81 to 2.27	1778	2.44	2.05 to 2.92	714
CVD mortality						
25–44	1.84	1.21 to 2.81	125	2.15	0.80 to 5.76	27
45–64	1.93	1.64 to 2.27	905	2.67	1.97 to 3.60	240
Cancer mortality						
25–44	1.29	0.69 to 2.41	60	2.20	0.99 to 4.90	36
45–64	1.60	1.24 to 2.06	393	1.13	0.78 to 1.64	257
Violent mortality						
25–44	2.34	1.75 to 3.12	213	3.50	1.90 to 6.45	47
45–64	2.33	1.65 to 3.28	167	3.91	2.09 to 7.31	46

CVD, cardiovascular disease. *Non-participants compared with participants, eight year follow up, adjusted for age, area, and study year. Interaction between age and participation: Men; total mortality p=0.455, CVD mortality p=0.415, cancer mortality p=0.931, violent mortality, p=0.563. Women; total mortality p=0.321, CVD mortality p=0.846, cancer mortality p=0.290, violent mortality 0.712.

Table 5 Hazard ratios* (HR) and 95% confidence intervals (CI) for total and cause specific mortality by sex

	Smoking participants		Non-participants	
	HR	95% CI	HR	95% CI
Total mortality				
Men	2.21	2.00 to 2.43	3.01	2.69 to 3.37
Women	1.84	1.50 to 2.26	2.80	2.38 to 3.29
CVD mortality				
Men	2.14	1.86 to 2.47	2.70	2.28 to 3.20
Women	2.22	1.52 to 3.24	2.89	2.16 to 3.88
Cancer mortality				
Men	2.67	2.16 to 3.31	2.48	1.87 to 3.24
Women	1.26	0.87 to 1.82	1.26	0.90 to 1.77
Violent mortality				
Men	2.22	1.72 to 2.85	3.50	2.66 to 4.59
Women	3.16	1.84 to 5.40	4.88	3.03 to 7.88
Smoking related mortality				
Men	6.66	4.63 to 9.58	1.96	0.63 to 6.14
Women	3.53	1.28 to 9.71	1.96	0.63 to 6.14
Alcohol related mortality				
Men	2.60	1.84 to 3.68	5.03	3.78 to 7.06
Women	4.67	1.79 to 12.2	6.88	2.97 to 15.9

CVD, cardiovascular disease. *Compared with the non-smoking participants, eight year follow up, adjusted for age, area, and study year.

ratios occurred mainly during the first six years of follow up and in violent mortality only after the eight years of follow up.

Among men, the hazard ratios (non-participants compared to participants) for total, cardiovascular disease and violent mortality were similar both in the age group 25 to 44 and 45 to 64 years (table 4). For cancer mortality, a statistically significant difference was found only in the older age group. Among women, the hazard ratio for total mortality was higher among the younger age group, and a similar tendency was seen in cancer mortality. However, the interactions between age and participation status were not significant at 0.05 level for any of the causes of death.

In both sexes, total mortality was about twice as high among smoking participants, and about three times higher among non-participants than among non-smoking participants (table 5). Mortality of smoking participants, compared with non-smoking participants, was significantly higher from all analysed causes, except cancer deaths among women, In both sexes, mortality of non-participants exceeded that of smoking participants in cardiovascular disease, violent and alcohol related mortality.

Key points

- Non-participating men had twice and non-participating women had 2.5 times higher overall mortality than the participating men and women
- Also cause specific mortality was higher among non-participants and relative mortality differences were largest in violent and alcohol related deaths
- Non-participants had considerably higher overall mortality than smoking participants, and their mortality was threefold compared with non-smoking participants
- Differences in mortality show that health behaviour and health status substantially differ between people who participate and who do not participate in health surveys
- Low participation rate may considerably bias the results of population based health surveys

In eastern Finland, where the survey was conducted every five years since 1972, the participation rate decreased between 1972 and 1992 from 86.6% to 72% among men and from 90.1% to 82.3% among women. During the same time period in the same area hazard ratio (adjusted for age, eight year follow up, non-participants compared with participants) for total mortality increased gradually from 1.61 to 2.77 in men and from 2.57 to 3.18 in women (data not shown).

DISCUSSION

Mortality among the non-participants was more than twice as high as among the participants. Relative difference was larger among women than among men, but in both sexes the mortality ratio was fairly independent of age. The difference between participants and non-participants was particularly large in violent and alcohol related deaths. Mortality difference between the groups diminished when the follow up period was extended, but remained significant even in the maximum of 28 year follow up. The excess mortality among non-participants is characterised by the finding that their mortality was considerably higher than among smoking participants, and about three times as high as among non-smoking participants.

Characteristics of non-participants can be studied using secondary sources of information, such as hospital, taxation, and population registers. If the sampling is based on population register data, basic demographic data, such as age, sex, and area of residence of non-participants, are usually available from the sampling frame. Previous studies have shown, that the participation in population surveys is related to age, sex, socioeconomic status, and health status at baseline, and that the health related behaviour differs considerably between participants and non-participants.[5 6 11 12 18] Participation rate is usually lower, compared with the other

Policy implications

- The effect of participation rate needs to be considered, when the results of health surveys are interpreted
- To reduce the selection bias, data collection strategies that maximise the participation rate should be used

groups, among young men, people with low educational level and socioeconomic status, heavy smokers and alcohol drinkers, and people with psychiatric and some other chronic illnesses.

The observed difference in mortality between participants and non-participants is caused by differences either in genetic and ethnic, environmental or behavioural factors, or differences in health status at baseline. In our study, practically all of the sampled people were of the same ethnic origin. We can assume that most of the differences in mortality are attributable to differences in health behaviour during the whole course of life, or health status at baseline. Our data suggest clearly, in accordance with some previous surveys, that health behaviour differs considerably between participants and non-participants. A difference in health status and existing disease at baseline also seems to be evident. Differences in education and socioeconomic status, and their relation to working and living conditions, may also have contributed to the unequal mortality among participants and non-participants.

Smoking is a fairly specific cause for lung cancer and chronic obstructive pulmonary disease. Both diseases are 10–15 times more common among smokers than among non-smokers.[19] Thus, the aetiological fraction of smoking in the development of these diseases is about 80%–90%. In our study, mortality from causes related to smoking was about two times higher among non-participating than among participating men. We can estimate that also the prevalence of smoking among non-participants was about twice as high as among the participants. Among women, smoking related deaths were rare and the difference between groups was less evident.

The association of alcohol drinking with health and mortality is more complex than that of smoking. Moderate alcohol consumption is most probably not unhealthy, and it may even prevent cardiovascular disease.[20–22] Extensive alcohol consumption and binge drinking, however, is surely hazardous for health.[23 24] It contributes to the development of a large number of diseases, increases the risk of injuries, and causes serious social problems. In our data, alcohol related mortality of non-participants, compared with participants, was three times more common in men and more than four times more common in women. Even though the specificity and aetiological fraction of alcohol in the development of these diseases and injuries vary, unhealthy and socially hazardous alcohol drinking is common among those who do not participate in population surveys.

Relative difference between participants and non-participants in cancer mortality, among women particularly, was smaller than the difference in total mortality. However, the difference was larger, about 2.5 times, when the length of follow up was only two years. This suggests that people with prevalent cancer are not motivated to participate in the surveys because of their health status and otherwise frequent contacts to health services because of the disease. Among men participation status was associated with cancer mortality particularly in the older age group whereas among women the association was stronger in the younger age group. Age and sex differences in hazard ratios may be explained by the differences in types of cancer and their relations to age, health behaviour, and socioeconomic status. Common cancer forms in men, such as lung and stomach cancers develop usually in old age and are related to smoking, alcohol drinking, and low socioeconomic status.[25] Breast and some genital cancers, which are common among women, are fairly common already at middle age and more common among women in high than in low social class.[26]

In eastern Finland, participation rate decreased gradually, from 87% to 72% in men and from 90% to 82% in women between 1972 and 1992. In the same time period relative mortality difference between participants and non-participants increased. This may show increased health related polarisation of the society over time. The polarisation may be attributable to deterioration of health conditions among non-participants, or improvement among participants. We know that many health related factors, such as smoking, blood pressure, and serum cholesterol concentrations, as well as perceived health, improved noticeably between 1972 and 1992 among the participants.[12] However, we know also that even among participants socioeconomic differences in some health behaviours have increased. Both smoking and the prevalence of obesity are increasing among people with low education, particularly among women.[27 28] It has also been shown, that the mortality gap between socioeconomic groups is not narrowing in Finland.[29]

The practical implications of non-participation depend on the study outcome. Even if the participation rate is fairly high, the results can be seriously biased, if the non-participants differ considerably from participants and the outcome is rare. As an example, in our study cohorts, the average participation rate of women was very high, 87%. However, because suicidal deaths were about five times more common among the non-participants than among the participants, nearly half of the suicides occurred among the non-participants. Psychiatric diseases, depression in particular, are important risk factors for suicide, and they are also closely related to the participation activity.[30 31] If the study aims to estimate the prevalence of depressive symptoms and other psychiatric conditions, the participation rate should be high and tracing of non-participants active. In addition to psychiatric conditions, cognitive disorders, functional capacity and substance misuse are areas, where the possible effect of selection bias on the results needs to be carefully assessed.[18 32–34] In these conditions, sample surveys alone may not provide reliable estimates, and the data should be complemented from other sources of information.

In conclusion, low participation rate may considerably bias the results of population based health surveys. Our results show that health behaviour, such as smoking and alcohol drinking as well as health status at baseline, differ considerably between non-participants and participants. To reduce the selection bias, data collection strategies that maximise the participation rate should be used.

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Funding: none.

Conflicts of interest: none declared.

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