

# Non-response in a nationwide follow-up postal survey in Finland: a register-based mortality analysis of respondents and non-respondents of the Health and Social Support (HeSSup) Study

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**To cite:** Suominen S, Koskenvuo K, Sillanmäki L, *et al.* Non-response in a nationwide follow-up postal survey in Finland: a register-based mortality analysis of respondents and non-respondents of the Health and Social Support (HeSSup) Study. *BMJ Open* 2012;**2**:e000657. doi:10.1136/bmjopen-2011-000657

► Prepublication history for this paper is available online. To view these files please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2011-000657>).

Received 25 November 2011  
Accepted 31 January 2012

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## ABSTRACT

**Objective:** To examine difference in mortality between postal survey non-respondents and respondents.

**Design:** A prospective cohort study with baseline survey in 1998 and comprehensive linkage to national mortality registers until 2005, the Health and Social Support study.

**Setting:** A population-based postal survey of the working-aged population in Finland in 1998.

**Participants:** The original random sample comprised 64 797 working-aged individuals in Finland (20–24, 30–34, 40–44, 50–54 years of age; 32 059 women and 32 716 men), yielding 25 898 (40.0%) responses in the baseline postal survey in 1998.

**Primary outcome measure:** Registry-based primary causes of death encoded with the International Classification of Diseases (ICD-10).

**Results:** In women, HR for total mortality was 1.75 (95% CI 1.40 to 2.19) times higher among the non-respondents compared with the respondents. In men, non-response was associated with a 1.41-fold (1.21–1.65) excess risk of total mortality. Non-response associated in certain age groups with deaths due to diseases in women and with deaths due to external causes in men. The most prominent excess mortality was seen for total mortality for both genders and for mortality due to external causes among men.

**Conclusions:** Postal surveys result in slight underestimation of illness prevalence.

## INTRODUCTION

Response rates in health-related postal surveys are declining in the Western world. In the Nordic countries, the situation has been somewhat better compared with the rest of Europe and the USA, but recently even there, declining trends have been observed.<sup>1 2</sup> Previous studies have suggested that women,

## ARTICLE SUMMARY

### Article focus

- Women and individuals from upper social strata tend to participate more actively in postal health surveys.
- What this exactly means in terms of health selection among respondents is unclear.
- Postal health surveys are believed to produce underestimates of illness prevalence.

### Key messages

- Total mortality was consistently and for women in the age group  $\geq 50$  years and for men in the age groups  $\geq 40$  years significantly higher among non-respondents compared with respondents during a 7-year follow-up among a total Finnish nationwide sample in working age comprising almost 65 000 individuals.
- The excess mortality observed was 1.5–2 fold. Among men, it was explained by external causes, whereas among women, it was due to diseases and was statistically significant only in the age group 50–54 years.
- Postal surveys result in slight underestimation of illness prevalence.

### Strengths and limitations of the study

- The linkage to mortality data was successful for virtually all individuals of the original sample comprising nearly 65 000 individuals. The sample size secures the reliability of the conclusions drawn. Furthermore, the registry data on mortality in Finland can be considered as reliable. To the best of the authors' knowledge, a corresponding study based on an as large a sample as in this study has not previously been carried out.
- Some inaccuracy concerning the final diagnosis of death is possible. A further study limitation is that data of socioeconomic status or educational level of non-respondents were not available, and hence, adjustments of the statistical analyses for these variables were not possible.

older persons and persons from upper social strata tend to participate more actively in health surveys compared with the rest.<sup>3–11</sup> However, not all studies have consistently supported these observations.<sup>10 12 13</sup> Furthermore, recent studies have extended analysis of non-response beyond demographic variables showing lower rate of hospital admissions,<sup>2</sup> mortality and maternal smoking during pregnancy among the participants as compared with non-participants.<sup>14 15</sup>

Studies on causes for non-participation to health surveys have revealed incorrect address or incorrect delivery by post to contribute to some of the dropout.<sup>5 8 16</sup> The non-respondents themselves have reported various kinds of reasons for their behaviour, such as gaining no benefit for participation,<sup>5 16</sup> no interest in the topic,<sup>7 8 16 17</sup> feeling of intrusion of privacy,<sup>8</sup> lack of time,<sup>7 8 17</sup> forgetfulness<sup>8</sup> and present illness.<sup>17</sup> Surveys including questions on issues perceived as intimate have often decreased participation rates.<sup>18</sup> It has also been speculated that late respondents might resemble more the non-participants<sup>5 17 19</sup> but to date decisive evidence for this pattern is lacking.<sup>20</sup> In the follow-up studies, participation has been explored according to the number of rounds the individual has taken part in<sup>14</sup> and more occasions of non-response found to be positively associated with subsequent mortality rates. On the whole, health selection among participants might decrease the generalisability of prevalence estimates, but this effect is until now not satisfactorily described.<sup>21</sup> However, even in the case of health selection, the results related to the strength of association between the variables studied need not necessarily be biased.<sup>15 21</sup>

A non-response analysis of the postal survey of the population-based Health and Social Support study—which achieved a relatively modest (40%) response rate<sup>9</sup>—replicated previous findings on the differences in demographic characteristics between respondents and non-respondents. The aim of the present study was to extend these analyses to explore whether survey non-respondents differ from the respondents in terms of mortality (all-cause, disease mortality, mortality for external causes).

## MATERIALS AND METHODS

The study is based on the complete sample (N=64 797) of the Health and Social Support prospective mail survey initiated in 1998. The concurrent joint Ethics Committee of the University of Turku and the Turku University Central Hospital considered approval not necessary for a normal cohort study, but all participants were requested to sign a consent form containing information about the study and to grant permission to allow subsequent studies with the same data set and possibility to link with national health registries. The sample represented the concurrent age groups of 20–24, 30–34, 40–44 and 50–54 years in Finland.<sup>9</sup> However, by purpose, the Swedish speaking Finns (5% of the general population) as well as the Turku region were slightly over-represented. Of the 64 797 persons,

22 could not be included in the present study since the follow-up had to be set to begin from the first death among respondents which was 22 September 1998. Certain cases of deaths among non-respondents had occurred already earlier and potentially before sending out the initial questionnaire. Totally 25 898 satisfactory responses were returned. In 2007, the survey material was by means of a unique social security number linked to Statistics Finland data on mortality between the years 1998 and 2005. Totally 1174 cases of deaths among 25 290 observations that could be linked with registry data were identified. Moreover, mortality data of non-respondents from the same time period was likewise as for respondents obtained from Statistics Finland and further analysed by age group and gender.

The outcome variable was primary causes of death encoded with the International Classification of Diseases (ICD-10). Mortality for external causes (S00–Y98) and disease mortality (A00–R99) were examined separately. The differences in mortality between non-respondents and respondents were analysed separately for women and men using Cox proportional hazards regression. The analyses were carried out by the research group. HRs with 95% CIs for mortality (total, external causes, disease) of non-respondents versus respondents according to age (1998) were reported. Cox proportional hazard assumptions were tested by visual examination of log-minus-log plots showing parallelism among the selected strata variable (responding status). The statistical analysis was performed by the SAS® software V.9.2 for Windows.

## RESULTS

Between the years 1998 and 2005, 1174 individuals belonging to the complete sample died (table 1). Of the deaths, 70% occurred in men.

Total mortality was higher for non-respondent women in age group 50–54 years and for non-respondent men in age group 40–44 and 50–54 years and for each gender with all age groups combined. In analyses combining women and men, excess total mortality associated with non-response was observed in age groups 40–44 and 50–54 years when age groups were examined separately as well as when all observations were combined (table 2). Non-respondent men had a higher mortality for external causes in age groups 30–34 and 40–44 years and with all age groups combined. In analyses with genders combined, this was seen in age groups 30–34 and 40–44 years and when all observations were combined. In women, no statistically significant differences in mortality for external causes were detected (table 3). Non-respondent women showed significantly higher disease-related mortality in age group 50–54 years as well as when all age groups were combined. The same held true for both genders when age groups 40–44 and 50–54 years were examined separately as well as when all observations were

**Table 1** Demographics of respondents and non-respondents and number of deaths during follow-up from 1998 to 2005 (N and %)

	Respondents		Non-respondents		Total	
	N	%	N	%	N	%
Gender						
Women	14 922	59.0	17 137	43.4	32 059	49.5
Men	10 368	41.0	22 348	56.6	32 716	50.5
Total	25 290	100.0	39 485	100.0	64 775	100.0
Age in 1998 (years)						
20–24	6783	26.8	9405	23.8	16 188	25.0
30–34	5981	23.7	10267	26.0	16 248	25.1
40–44	6073	24.0	10198	25.8	16 271	25.1
50–54	6453	25.5	9615	24.4	16 068	24.8
Total	25 290	100.0	39485	100.0	64 775	100.0
Number of deaths by gender						
In women	110	0.7	240	1.4	350	1.1
In men	218	2.1	606	2.7	824	2.5
Total	328	1.3	846	2.1	1174	1.8
Number of deaths by age in 1998 (years)						
20–24	21	0.3	47	0.5	68	0.4
30–34	38	0.6	105	1.0	143	0.8
40–44	85	1.4	252	2.5	337	2.1
50–54	184	2.9	442	4.6	626	3.9
Total	328	1.3	846	2.1	1174	1.8
Number of deaths from external causes						
In women	26	0.2	48	0.3	74	0.2
In men	55	0.5	217	1.0	272	0.8
Total	81	0.3	265	0.7	346	0.5
Number of deaths from external causes by age in 1998 (years)						
20–24	10	<0.1	32	<0.1	42	<0.1
30–34	16	<0.1	66	0.2	82	0.1
40–44	22	<0.1	90	0.2	112	0.2
50–54	33	0.1	77	0.2	110	0.2
Total	81	0.3	265	0.7	346	0.5
Number of deaths due to diseases						
In women	84	0.6	192	1.1	276	0.9
In men	163	1.6	389	1.7	552	1.7
Total	247	1.0	581	1.5	828	1.3
Number of deaths due to diseases by age in 1998 (years)						
20–24	11	<0.1	15	<0.1	26	<0.1
30–34	22	<0.1	39	<0.1	61	<0.1
40–44	63	0.2	162	0.4	225	0.3
50–54	151	0.6	365	0.9	516	0.8
Total	247	1.0	581	1.5	828	1.3

combined. On the other hand, in separate analyses for men, non-respondents showed a slightly increased disease mortality compared with respondents only when all age groups were combined (table 4).

## DISCUSSION

In this large population-based epidemiological study, comparison of mortality of non-respondents with respondents showed, as expected, consistently higher

**Table 2** HRs for total mortality of non-respondents versus respondents and the 95% CIs according to gender and age at the beginning of the follow-up in 1998

Non-respondents versus respondents (= 1.00)	Age in 1998, 20–24 years	Age in 1998, 30–34 years	Age in 1998, 40–44 years	Age in 1998, 50–54 years	Total age or age and gender adjusted
Women	1.00 (0.34 to 2.97)	1.45 (0.77 to 2.73)	1.40 (0.93 to 2.10)	<b>2.17 (1.58 to 2.98)</b>	<b>1.75 (1.40 to 2.19)</b>
Men	1.28 (0.70 to 2.34)	1.41 (0.89 to 2.24)	<b>1.71 (1.25 to 2.35)</b>	<b>1.31 (1.07 to 1.61)</b>	<b>1.41 (1.21 to 1.65)</b>
Total gender or age and gender adjusted	1.21 (0.71 to 2.04)	1.42 (0.98 to 2.07)	<b>1.59 (1.24 to 2.04)</b>	<b>1.54 (1.29 to 1.83)</b>	<b>1.52 (1.34 to 1.73)</b>

Statistically significant associations are in bold.

**Table 3** HRs for deaths due to external causes in non-respondents versus respondents and the 95% CIs according to gender and age at the beginning of the follow-up in 1998

<b>Non-respondents versus respondents (= 1.00)</b>	<b>Age in 1998, 20–24 years</b>	<b>Age in 1998, 30–34 years</b>	<b>Age in 1998, 40–44 years</b>	<b>Age in 1998, 50–54 years</b>	<b>Total age or age and gender adjusted</b>
Women	4.65 (0.52 to 41.62)	1.94 (0.68 to 5.49)	1.38 (0.58 to 3.28)	1.18 (0.57 to 2.45)	1.50 (0.93 to 2.42)
Men	1.36 (0.64 to 2.88)	<b>2.04 (1.07 to 3.90)</b>	<b>2.42 (1.37 to 4.28)</b>	1.62 (0.99 to 2.67)	<b>1.87 (1.39 to 2.52)</b>
Total gender or age and gender adjusted	1.61 (0.78 to 3.30)	<b>2.01 (1.16 to 3.49)</b>	<b>2.07 (1.30 to 3.31)</b>	1.47 (0.98 to 2.22)	<b>1.78 (1.39 to 2.29)</b>

Statistically significant associations are in bold.

mortality rates among the former group. The differences between non-respondents and respondents were 1.5–2 fold and of quite similar magnitude for both genders although with varying causes. Among women, the greatest statistically significant differences were seen in disease mortality in the oldest age group of initially 50–54 years of age. The greatest significant differences for men were caused by external causes of death and involved age groups 30–34 and 40–44 years. However, it is worth to notice that an increase of total mortality of the magnitude seen in this study implies approximately 300 extra deaths among non-respondents during the follow-up of 7 years.

Postal surveys are frequently used in population-based health research. The impact of health selection on the results has been studied but not very extensively. An affirmative view on the potential demographic difference between respondents and non-respondents is still lacking. According to the previous findings,<sup>3 8 9</sup> respondents tend to be somewhat healthier and report a more favourable health behaviour compared with non-respondents. However, the bias caused by this was limited and applied mainly to health problems or risk behaviours that generally are not eagerly communicated to others, such as mental problems or binge drinking. From the previous studies, it is also known that women as well as those well off in the society tend to participate more actively in health-related survey research on the whole. Hence, this might result in underestimation of the prevalence of health problems common among men as well as individuals from lower social strata. Results from a previous non-response analysis of the initial phase of this study supports this view.<sup>9</sup> Women as well as individuals with high level of education were somewhat over-represented among respondents but no clear health-related selection could be shown. According to

our present results, 7 years later, the potential health-related selection can be further clarified. In Finland, mortality for external causes is intimately associated with alcohol consumption and alcoholism.<sup>22</sup> As could be expected, we could see a significantly higher mortality for external causes among male non-respondents as compared with the respondents.

Moreover, in previous studies,<sup>23</sup> it has also been pointed out that non-respondents are not necessarily a homogenic group but can differ internally, for example, depending on the wave of the survey in which they have taken part. Also the correspondence between late respondents and total non-respondents has been questioned.<sup>20</sup>

Given the health selection related to postal surveys, it has to be kept in mind that population studies usually do not focus solely on prevalence estimates anymore but more or less on potential risk or protective factors of certain health problems. From the previous research,<sup>21</sup> there are indications that even if prevalence estimates are not accurate, the associations between the variables studies are not necessarily biased.

**Strengths and limitations of the study**

A major strength of this study is that the linkage to mortality data was successful for virtually all individuals of the original sample. Furthermore, the registry data on mortality in Finland could be considered as quite reliable. All deaths with suspicion of an external cause and in the age groups studied are investigated by autopsy.

The large sample size secures that the conclusions drawn from the statistical analyses are reliable and cannot have been caused by random effects. To the best of our knowledge, a corresponding study based on as large a sample as in this study has previously not been carried out.

**Table 4** HRs for disease mortality of non-respondents versus respondents and the 95% CIs according to gender and age at the beginning of the follow-up in 1998

<b>Non-respondents versus respondents (= 1.00)</b>	<b>Age in 1998, 20–24 years</b>	<b>Age in 1998, 30–34 years</b>	<b>Age in 1998, 40–44 years</b>	<b>Age in 1998, 50–54 years</b>	<b>Total age or age and gender adjusted</b>
Women	0.39 (0.08 to 1.92)	1.21 (0.54 to 2.69)	1.41 (0.88 to 2.23)	<b>2.46 (1.73 to 3.52)</b>	<b>1.83 (1.41 to 2.36)</b>
Men	1.13 (0.40 to 3.18)	0.83 (0.42 to 1.66)	1.43 (0.98 to 2.09)	1.25 (1.00 to 1.57)	<b>1.25 (1.04 to 1.51)</b>
Total gender or age and gender adjusted	0.81 (0.37 to 1.80)	0.98 (0.58 to 1.67)	<b>1.42 (1.06 to 1.90)</b>	<b>1.55 (1.28 to 1.88)</b>	<b>1.43 (1.23 to 1.66)</b>

Statistically significant associations are in bold.



Some inaccuracy concerning the final diagnosis of death is possible. Another study limitation is that data of socioeconomic status or educational level of non-respondents were not available, and hence, adjustments of the statistical analyses for these variables were not possible.

## Conclusions

Total mortality was consistently 1.5–2 fold and for women in the age group  $\geq 50$  years and for men in the age group  $\geq 40$  years significantly higher for the non-respondents of a nationwide mail survey compared with the respondents. For women, this was mostly due to disease mortality in age group 50–54 years but for men due to mortality for external causes in age groups 30–34 and 40–44 years. The most prominent excess mortality was seen for total mortality for both genders and for mortality due to external causes among men. Selection by health, especially mental health in men, can cause bias in health-related population surveys. However, this applies to prevalence estimates and does not necessarily jeopardise results from studies on risk and protective factors.

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**Funding** The study was supported by the Academy of Finland (three different decisions on funding).

**Competing interests** None.

**Ethics approval** Ethics approval was provided by the concurrent joint Ethics Committee of the University of Turku and the Turku University Central Hospital.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data sharing statement** At this point, we are not willing to share data based on a totally open principle. However, naturally we are willing to collaborate with other researchers based on plans approved by our research group.

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