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Recommendations for design and analysis of health examination surveys under selective non-participation

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Abstract

Background: The decreasing participation rates and selective non-participation peril the representativeness of health examination surveys (HESs).
Methods: Finnish HESs conducted in 1972-2012 are used to demonstrate that survey participation rates can be enhanced with well-planned recruitment procedures and auxiliary information about survey non-participants can be used to reduce selection bias.
Results: Experiments incorporated to pilot surveys and experience from previously conducted surveys lead to practical improvements. For example, SMS reminders were taken as a routine procedure to the Finnish HESs after testing their effect on a pilot study and finding them as a cost-effective way to increase participation rate especially among younger age groups. Auxiliary information about survey non-participants can be obtained from many sources: sampling frames, previous measurements in longitudinal setting, re-contacts and non-response questionnaires, and record linkage to administrative data sources. These data can be used in statistical modelling to adjust the population level estimates for the selection bias. Information on the characteristics of non-participants also helps to improve targeting the recruitment in the future.
Conclusion: All methods discussed and recommended are relatively easy to incorporate to any national HES in Europe except the record linkage of survey data from administrative data sources. This is not feasible in all European countries because of non-existence of registries, lack of an identifier needed for record linkage, or national data protection legislation which restricts the data use.

Keywords: missing data, study design, registers, record linkage, public health, non-participation

1 Introduction

Informed decisions on the health policy require up-to-date knowledge on the health of the population. In many countries, an important instrument for obtaining this knowledge has been health examination surveys (HESs). The usefulness of a HES, and surveys in general, is based on a fundamental statistical result that regardless the size of the population, a random sample is sufficient to obtain unbiased estimates of the population statistics.

Unfortunately, it is practically impossible in public health monitoring and research to obtain survey data that are truly representative for the population. There is a lot of evidence that even if the invited sample is a representative random sample, the actual participants differ from the population with respect to their health [1–11], health behaviours [10, 12–14] and socio-demographic status [14–16]. Due to these differences, health indicators estimated from the participants only are likely to suffer from selection bias. For example, recent results indicate that the true prevalence of smoking in Finland may be five percentage points higher than the prevalence based on the participants only [10].

Although most researchers in epidemiology are aware of the possibility of selective non-participation, it is relatively common to see results reported without any attempt to assess or correct the selection bias. In addition to bias in point estimates, the uncertainty of the estimates is underestimated if the participants are falsely assumed to represent the whole population. Selective participation may cause bias not only in estimated population statistics but also in estimated regression coefficients [17].

The extent of selection bias is limited by but not determined by the participation rate [18]. Although decreasing participation rates do not necessarily imply higher selection bias, they increase the potential bias the selective participation may cause. If the participation rates were over 90%, only strong selection could significantly bias the population statistics estimated from the participants alone.

Selective non-participation should be taken into account in the design and analysis of a HES. We use the term 'design' broadly to mean the decisions made during the planning and preparation phase of the survey. By analysis we mean actions made after the data have been collected. Here we discuss actions for survey design and analysis which could help to reduce the selection bias.

2 Methods

Our recommendations are based on lessons learned in the project "Non-participation in health examination surveys" (NoPaHES, `http://www.ehes.info/nopahes/`) carried out in 2013–2017. The project aimed to find ways to carry out reliable public health research despite the decreasing participation rates in HESs.

Our data consist of FINRISK surveys 1972–2012 [19], cross-sectional national HES with total of 99,259 invitees, and Health 2000 survey with 10,000 invitees together with its re-measurement survey Health 2011 [20]. The following data from administrative registries were linked to the HES datasets:

- date and cause of death,
- dates and diagnoses of hospitalizations,
- dates and diagnoses of cancers,
- education and socio-economic status,

- purchase of medicines by The Anatomical Therapeutic Chemical (ATC) Classification System codes,
- entitlement to specifically reimbursed medications due to specific chronic conditions,
- sickness absences and work disability pensions, and
- geographical coordinates of the place of residence and the examination centres.

The data include events both before and after the health examination and have been linked both to participants and non-participants, which allows the comparison of the characteristics of these groups in detail. The linking is based on unique personal identification code that is systematically used in all administrative registers in Finland and included in survey samples as well.

Statistical methods, especially multiple imputation and survival analysis, were used to gain understanding on the differences between participants and non-participants and to reduce selection bias.

3 Results

We present our results in the form of five recommendations that are illustrated in Figure 1. Each recommendation is placed at the phase of the survey process when it is implemented.

3.1 Learn from previous surveys

Knowledge on the extent and the characteristics of non-participation can be obtained from two main sources: in general level from surveys that aim to find factors explaining non-participation and specifically from previous similar surveys. Although the results on the factors affecting non-participation may not be directly generalizable to the survey to be planned, they can be used as proxy to devise plausible scenarios and hypotheses.

National HESs and other surveys are in some countries conducted periodically, e.g. every five years or so, and the design and implementation are similar between the years. The relative differences in the participation between demographic groups often remain stable even if the overall participation rate decreases. For instance, in all FINRISK surveys in 1972–2012, the participation rate is higher for the oldest age group than for the youngest age group. Age-period-cohort analysis provides more information on the demographic structure of non-participation over the time [21].

In longitudinal surveys, previous measurements are a rich source of individual level information that can be used to study the attrition. As an example, the full sample

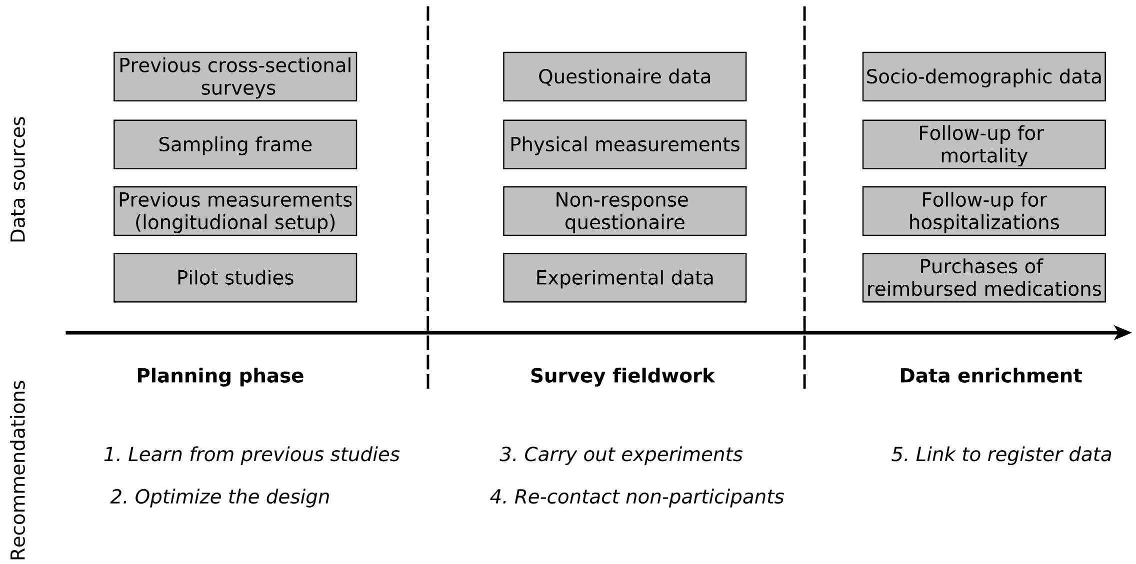

Figure 1: Recommendations for the different phases of the research and the key sources of information.

of the Health 2000 survey were invited for re-measurements 11 years later in Health 2011 survey (excluding dead, refused and emigrated sample members), thus some of the non-participants of the Health 2000 survey did participate in 2011. The participation rate in Health 2000 survey was exceptionally high, 93%, but dropped to 73% in Health 2011 survey. If not treated appropriately, the difference in the participation rates may cause bias when the change in the population level health indicators is estimated. Majority of non-participants in 2011 had participated in 2000 and their health examination and questionnaire data were available as predictors in a weighting or multiple imputation model [20]. The results showed that using multiple imputation and data from previous measurements improved the point estimates substantially for selected indicators (disability pension, hospitalizations and drug reimbursements) by removing almost all non-response bias.

3.2 Optimize the design for your objectives

Surveys should be designed so that the actual sample of participants is optimal for the study objectives [22]. Sometimes this implies that the invited sample will not represent the population of interest. The researchers may want to oversample subgroups that have a low participation rate or have special importance. For instance, in Health 2000 survey, the sampling probabilities were doubled for individuals who were at least 80 years old [20, 23] to ensure that a sufficient number of participants is obtained for this group. In the Migrant Health and Wellbeing Study, Maamu, [24] different sampling probabilities were utilized to ensure that the number of participants was sufficient for comparisons of immigrant groups, for which the population sizes varies considerably in different cities and country of origin. Oversampling could be applied also to young men who often have a low participation rate. In the analysis, inverse probability weighting [25, 26] can be used to account for both unequal sampling probabilities and non-participation.

The sampling probabilities could be inversely proportional to the expected participation probability. This kind of stratification or quota sampling will make sure that there is a sufficient number of individuals in all subgroups of interest. In the analysis, the sampling weights are then proportional to the expected participation probabilities and the analysis weights that take into account both sampling and non-participation are constant if the model for non-participation is correct.

Sampling does not solely solve the fundamental problem of selection bias because the participants and the non-participants may still differ with respect to a variable of interest. The benefits of optimized sampling are realized when used together with statistical modelling. The modelling adjusts for the unequal sampling probabilities and the assumed missing data mechanism. Optimized sampling makes sure that the parameters of interest can be estimated as precisely as possible under the given constrains on the total sample size. Mechanistic use of the overall participation rate as an indicator of the quality of the survey is not advisable if an optimized design has been applied because oversampling in population subgroups with low participation rates decreases the overall participation rate.

Complicated study designs provide challenge for communication and documentation. Textual descriptions often miss important details. In the NoPaHES project, we used graphical models to visualize study design and the assumptions on the missing data mechanism together with the assumed causal model [10, 20, 27, 28].

3.3 Carry out experiments to improve the implementation

Implementation of a HES covers practical arrangements such as the invitation letter and other means of participant recruitment, the schedule of the health examinations and the questionnaire layout. Factors that increase the response probability in surveys have been studied extensively in the framework of questionnaire surveys [29] and many of these findings are directly applicable also in HESs. For instance, it is evident that the invitation letter must be informative and easy to understand and the length of the questionnaire may not appear too extensive. In addition to these factors common to surveys in general, HESs have unique features that arise from the fact that the participants are required to travel to the examination site.

As a general recommendation, we suggest conducting experiments to find practices that may increase the participation rate. These experiments can be carried out in a pilot survey or as a part of the actual HESs. The invitees are randomly divided into the experimental group(s) and the control group which, for instance, receive differently formulated invitation letters. As always in experiments, randomization is crucial and must be based on computer generated random numbers. The response variable for experiment is the participation. If the participation rate is higher for experimental group than the control group and the difference is large enough to compensate the potential increase in the costs, the new practice may be applied for everyone in the next survey.

In the FINRISK 2012 pilot called The Kuusamo Health Examination Survey [30], an experiment on the use of SMS reminders to increase HES participation was carried out. Although the sample size for the experiment was small and the availability of mobile phone numbers was far from perfect, the impact of SMS reminders was concluded to be positive and cost-efficient. As a consequence, SMS reminders were taken in use in FINRISK 2012 survey and many studies conducted after that.

3.4 Re-contact non-participants

In many studies, several contact attempts are made to reach invitees and even the non-participants can be contacted again if they have not explicitly declined further contacts. Re-contacts are different from reminders where invitees are reminded about their health examination appointment or asked to schedule a new appointment. Re-contacts are planned to obtain as much information as possible from non-participants and therefore questionnaires are more extensive than traditional non-respondent questionnaires. In postal and telephone surveys, differences between early respondents, late respondents and non-respondents have been studied under various setups, e.g. [31–35]. These studies suggest that early respondents and late respondents differ from each other but in general late respondents cannot be directly used as a proxy for non-respondents.

Re-contact data were collected in FINRISK 2007 and 2012 surveys where the main survey questionnaire was re-sent to non-participants. Although the response rates for the re-contact were very low, 13% and 14%, respectively, the re-contact data turned out to be useful in reducing selection bias [10, 36]. It was found that when adjusted for age and sex, the re-contacted respondents tend to resemble the non-participants with respect to their mortality and hospitalizations. This surprising observation inspired a specialized multiple imputation approach. The approach was applied to estimate the prevalence of daily smoking and heavy alcohol usage in FINRISK 2007 and 2012 surveys [10, 36]. For daily smoking, the mean prevalence estimates from the proposed approach were about five percentage points higher than those estimated from participants only. For the prevalence of heavy alcohol usage, the differences were about two percentage points.

A questionnaire sent to re-contacted non-participants should contain the key questions that can be used as proxies for the actual measurements and are also asked of individuals participating in the health examination part of the survey. For example, it makes sense to ask for self-reported height and weight even though they are measured in the health examination. These data can be used to build a statistical model for the measured values as a function of self-reported values. This model serves as an imputation model for the measured values that are missing.

3.5 Link to register data

Administrative registries are potential sources of auxiliary data, for instance, on hospitalizations, medication and socio-economic status. This information can be used to reduce selection bias. Depending on the national legislation and the availability of personal identifiers, register data can be linked both to participants and non-participants or only to participants who have given an informed consent. If register data cannot be linked to non-participants, population statistics aggregated by age and sex, and preferable also by other variables, may provide a benchmark for the analysis of non-participation [37].

The register linking must be planned as a part of the HES because it requires an informed consent from the participants and the acceptance by the ethics committee. Ideally, the whole process of register linking, including the schedule and the budget, is planned in advance.

Individual level register data can be divided into historical data, current status data and follow-up data. Historical data refer to events before the survey, the dates and diagnoses of hospitalizations being a typical example. Current status data refer, for instance, to the marital status and the level of education at the time of the survey. These may naturally change during the course of life. Follow-up data refer to events after the survey. These data typically include the dates and diagnoses of hospitalizations and deaths.

The timing of the register linking is important due to the nature of available information in different time points. Historical data and current status data can usually be obtained soon after the sample has been selected and informed consents have been collected but the possible updating delays of the registers must be taken into account. Useful follow-up data for the analysis of the non-participation bias are available only years after the survey, not right after the survey when they would be the most valuable.

Register data linked to the invited sample can be used to compare participants and non-participants, and to reduce selection bias. As an example of the former, it was found in FINRISK 2007 survey that the age and sex standardized mortality in the five-year follow-up was over two times higher for the non-participants than for the participants [10]. Reducing selection bias often requires advanced statistical modelling. For example, Bayesian modelling was used in [38] to reduce selection bias when estimating the prevalence of smoking. The key idea was to learn about the smoking prevalence of non-participants indirectly via hospitalizations and deaths due to lung cancer and chronic obstructive pulmonary disease during the follow-up. Starting from the year 1977, the Bayesian mean estimates were systematically higher than the mean estimates from the participants only and for many years the difference was higher than four percentage points.

4 Discussion

We have presented countermeasures for the selection bias due to non-participation. The main idea behind these countermeasures is maximising participation as well as gathering auxiliary information on non-participants. The key sources for this information are the sampling frame, additional data collection rounds and previous measurements (in a longitudinal setup), and administrative registers. We also recommend regular experimentation in the study implementation for finding ways to prevent the decline of the participation rates. These elements could be described by Generic Statistical Business Process Model (GSBPM, https://statswiki.unece.org/display/GSBPM/), which is used worldwide to define a set of business processes needed to produce official statistics. Our recommendations can contribute to four of the eight phases of the GSBPM: Specify needs, Design, Collect, and Process data.

Obtaining as much auxiliary information as possible through sampling frames would be helpful not only for non-response adjustment but also for planning of the sub-group targeted recruitment methods. Whenever possible, linkage of the sampling frame to several administrative registers should be considered before actual sample selection.

Non-participation is a threat that must be addressed in the design, implementation and analysis of a HES. Based on our experience, we emphasize the importance of the design. After the survey has been completed, it may be difficult or even impossible to follow the recommended actions if they have not been planned beforehand and required parts implemented during the fieldwork.

Out of the five recommendations we have made here, the register linkage is the most challenging to implement. There are three prerequisites for it: 1) High quality administrative registries exist. 2) There is an identifier that can be used to merge the survey data and the register data. 3) Legislation allows data linkage. All European countries have at least some administrative health registers either regionally or nationally. A bigger problem is the lack of personal identifiers which could be used for data linkage. Nordic countries as well as increasing number of other European countries have a personal identification code or health/social insurance code which is systematically used in administrative health registers and could, in theory, be used for data linkage. Even when registers and personal identification code exists, national data protection legislation may prevent the data linkage, i.e. use of register data together with survey data. It is still unclear how the new General Data Protection Regulation (GDPR) by the European Union, effective since 25 May 2018, changes the situation even in those countries where all three prerequisites are currently fulfilled. The results with the FINRISK data demonstrate the benefits of a record-linkage infrastructure in addressing bias in non-participation.

The four other recommendations can be implemented more widely. Although access to register data would be useful also with these recommendations, it is not a requirement for their implementation. For instance, we have used registry-based follow-up data to check assumptions on re-contact respondents and non-participants but this is not an absolute requirement. Non-participation can be studied also indirectly by comparing the demographics of the participants with population statistics.

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Conflicts of interest
None declared.

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Key-points

- Selection bias due to non-participation perils the representativeness of health examination surveys.
- Selection bias can be reduced if it is taken into account already in the study design.
- We present five practical recommendations for designing a HES from the perspective of preventing and reducing selection bias.

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