

Session: Missing data in health examination surveys

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Non-Participation in Health Examination Surveys (NoPaHES)

- A project funded by the Academy of Finland for 2013 – 2017
- A joint initiative of the National Institute for Health and Welfare (THL) and University of Jyväskylä
- Aims of the project:
 - to increase knowledge about the characteristics of the non-participants
 - to increase knowledge about the effect of recruitment methods on participation rates
 - to learn about the effect of non-participation on the survey results
 - to develop methods for controlling non-participation bias in the results

NoPaHES group

- THL
 - Kari Kuulasmaa, Hanna Tolonen, Katja Borodulin, Tommi Härkönen, Pekka Jousilahti, Anne Juolevi, Jukka Kontto, Päivikki Koponen, Seppo Koskinen, Satu Männistö, Markku Peltonen, Jaakko Reinikainen, Harri Rissanen, Perttu Saarsalmi, Erkki Vartiainen
- University of Jyväskylä
 - Juha Karvanen, Juho Kopra, Elli Hirvonen

<http://www.ehes.info/nopahes>

Selective non-participation in health surveys and available auxiliary information for non-participation adjustment

Hanna Tolonen for the NoPaHES Project

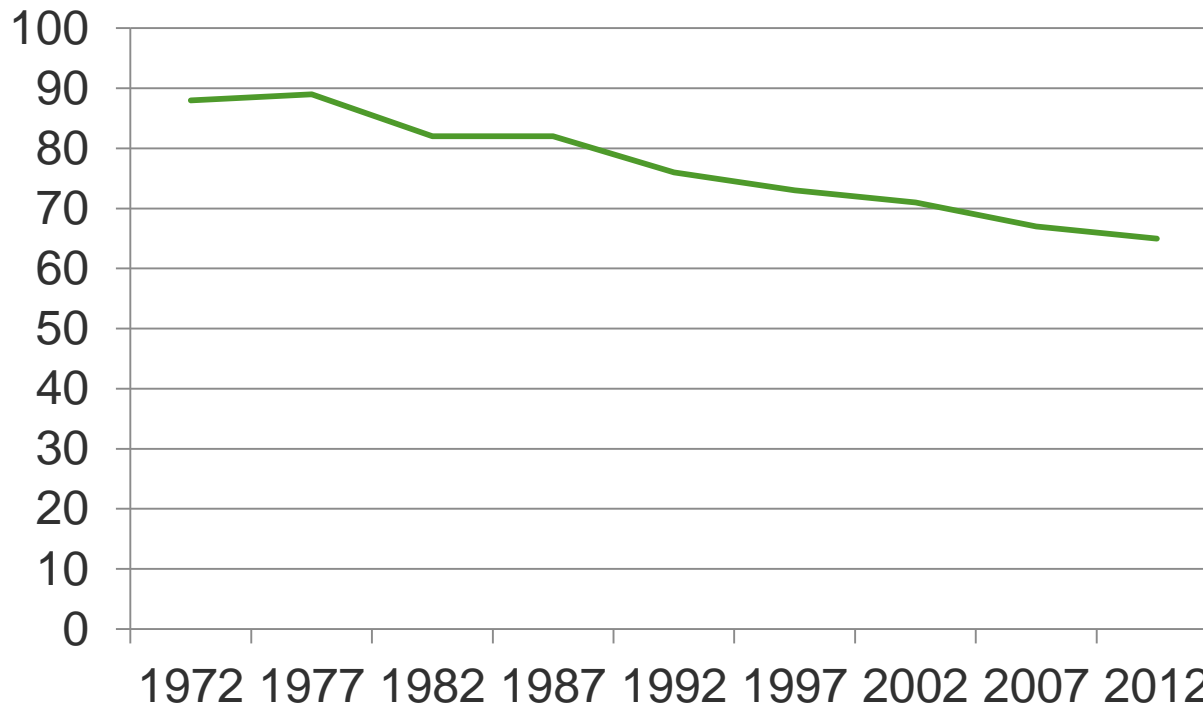


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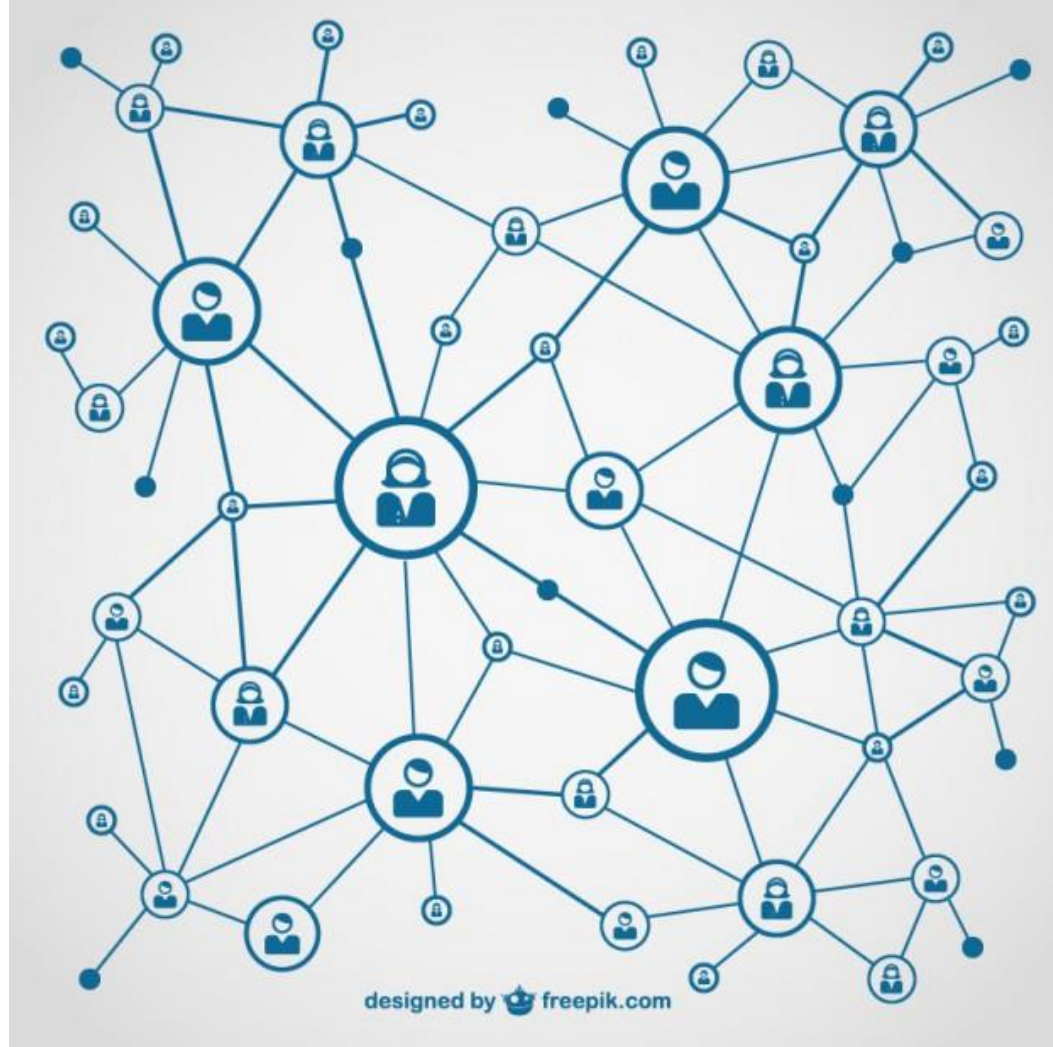


Background

- Participation rates have been declining in all kinds of surveys over the past decades, also in Finland



Participation rate in FINRISK Study from 1972-2012



DATA

Health survey data

- HESs conducted by THL (former KTL) between 1972-2012
 - Series of cross-sectional FINRISK surveys among adults (25+):
 - 1972, 1977, 1982, 1987, 1992, 1997, 2002, 2007, 2012
 - Participation rates were above 90% in 1970's and around 60% in 2012
 - Mini-Finland survey in 1978-1980
 - Age group 30+, participation rate 90%
 - Health 2000 and Health 2011
 - In 2000: Examination for 30+, participation rate 93%
 - In 2011: Examination for 29+, participation rate 59%
 - Migrant Health and Wellbeing Survey (Maamu) in 2010-2012
 - Age group 18-64 years
 - Russian origin: 70%
 - Somali: 51%
 - Kurdish: 63%

Information sources about non-participants

- Sampling frame
 - Dependent on sampling frame, often at least sex, age, area
 - Possibly also other socio-demographic information such as education, marital status, country of birth, nationality and/or mother tongue
- Special efforts during the recruitment
 - Short non-response questionnaire
 - Information from proxy respondents
- Record linkage to the administrative registers
- Comparison on participants with entire target population
- In health examination surveys, comparison of participants with physical measurements with those having only questionnaire information (non-response questionnaire)
- In longitudinal surveys, information from previous round(s)

Register data

- **National hospital discharge register:** dates and diagnoses of hospitalizations and outpatient visits
- **Birth register and register of induced abortions**
- **Causes of death register:** dates and causes of death
- **Registers of the Social Insurance Institution:** entitlement and purchase of specifically reimbursed medications, sickness allowance, pensions, for Maamu and Health 2000/2011 Studies also information of several social benefits
- **Cancer register:** date and diagnoses of cancers
- **Population Register Centre:** geographic information on the place of residence and the examination centres, mother tongue, for Maamu Study also information on household members
- **Statistics Finland registers:** socio-economic information

Linking administrative register data to health survey data

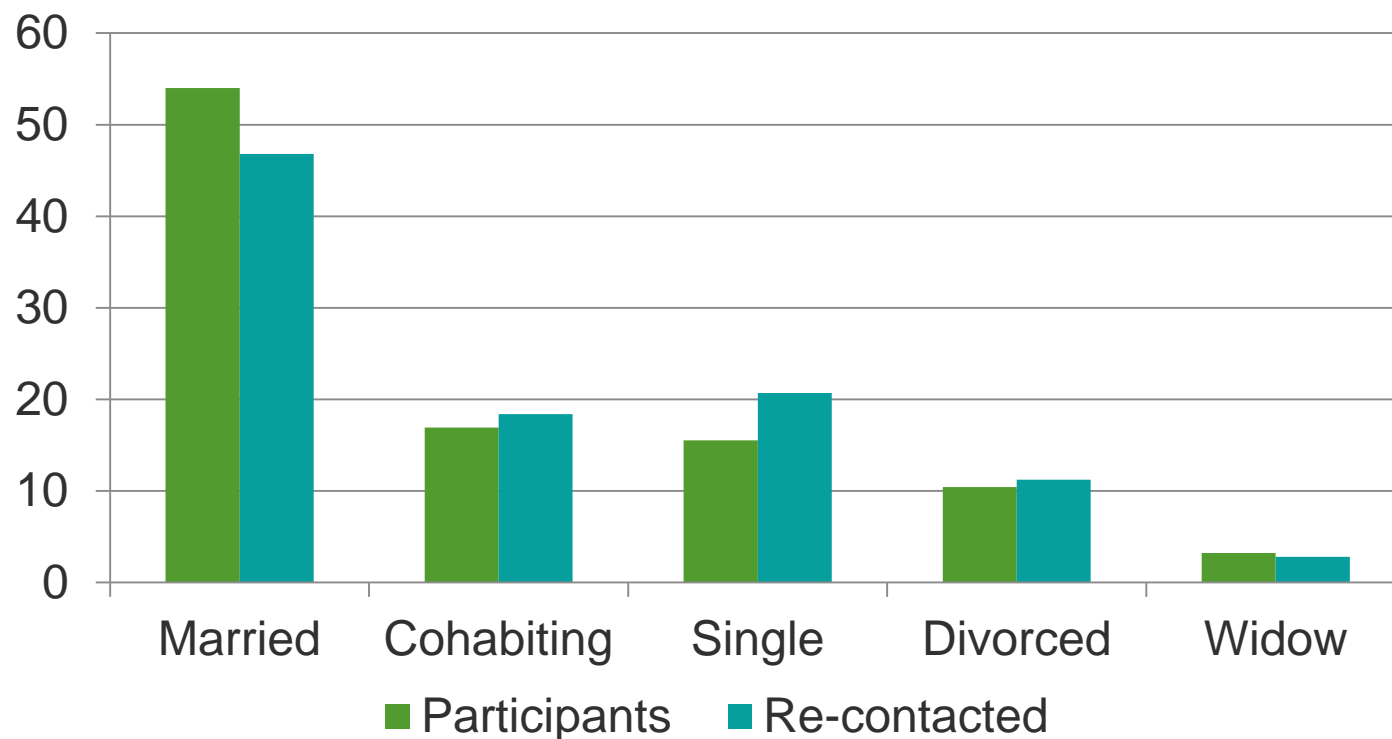
- Linkage is done using the personal identification code, a unique code given to everyone living in Finland
- From survey participants, written informed consent since 1997 (Helsinki Declaration)
- For each administrative register, a special permit has to be applied from the register owner



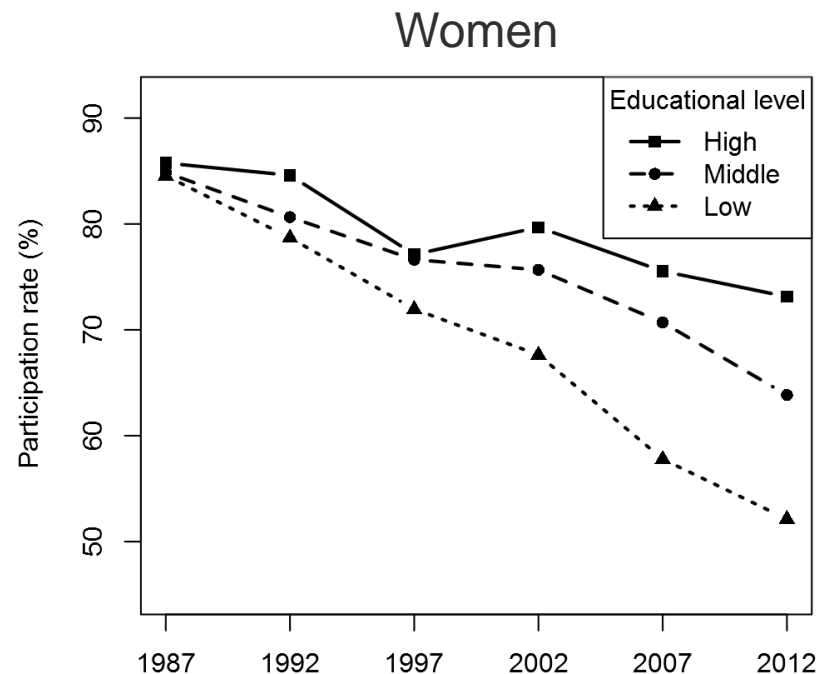
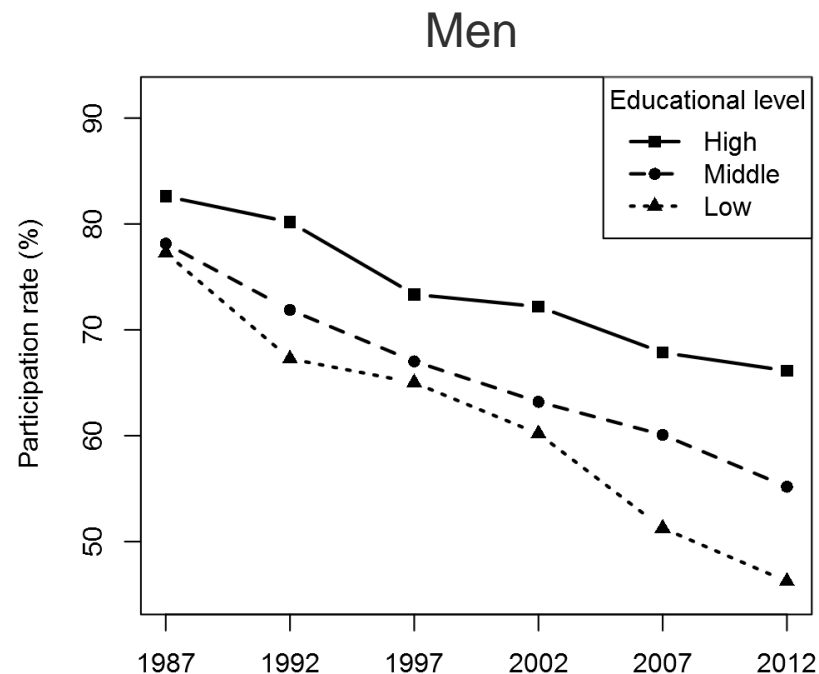
PROFILES OF NON-PARTICIPANTS IN FINLAND

Socio-demographic profiles of non-participants – marital status

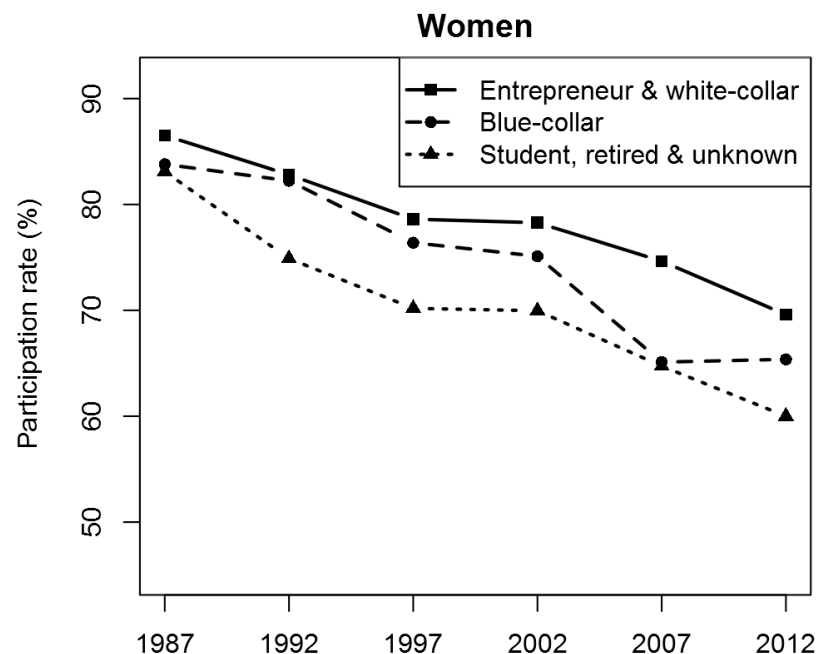
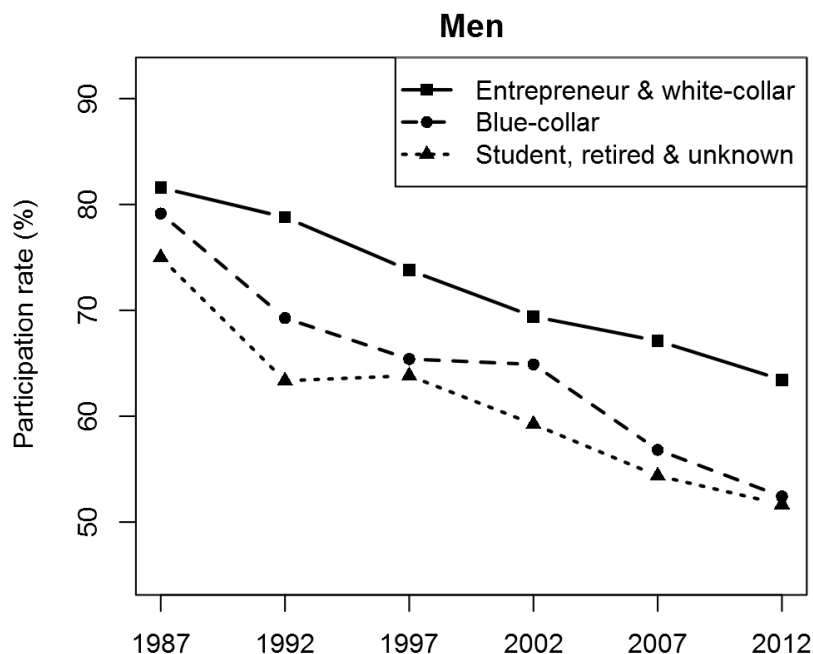
- Marital status, proportion among participants and re-contacted (non-participant questionnaire)



Socio-demographic profiles of non-participants – education



Occupational status / Socio-economic position



Mother tongue/ethnic origin



- In FINRISK 2012 data, OR for non-participation

Language	Men	Women
Finnish	Ref.	Ref.
Swedish	1.47 (1.17,1.84)	1.06 (0.82,1.38)
Foreign	2.00 (1.68,2.40)	1.67 (1.40,1.99)

- 65 different registered mother tongues in the sample
- Material available in Finnish, Swedish and English

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Urbanization and non-participation

- In FINRISK survey in 2012, OR for non-participation

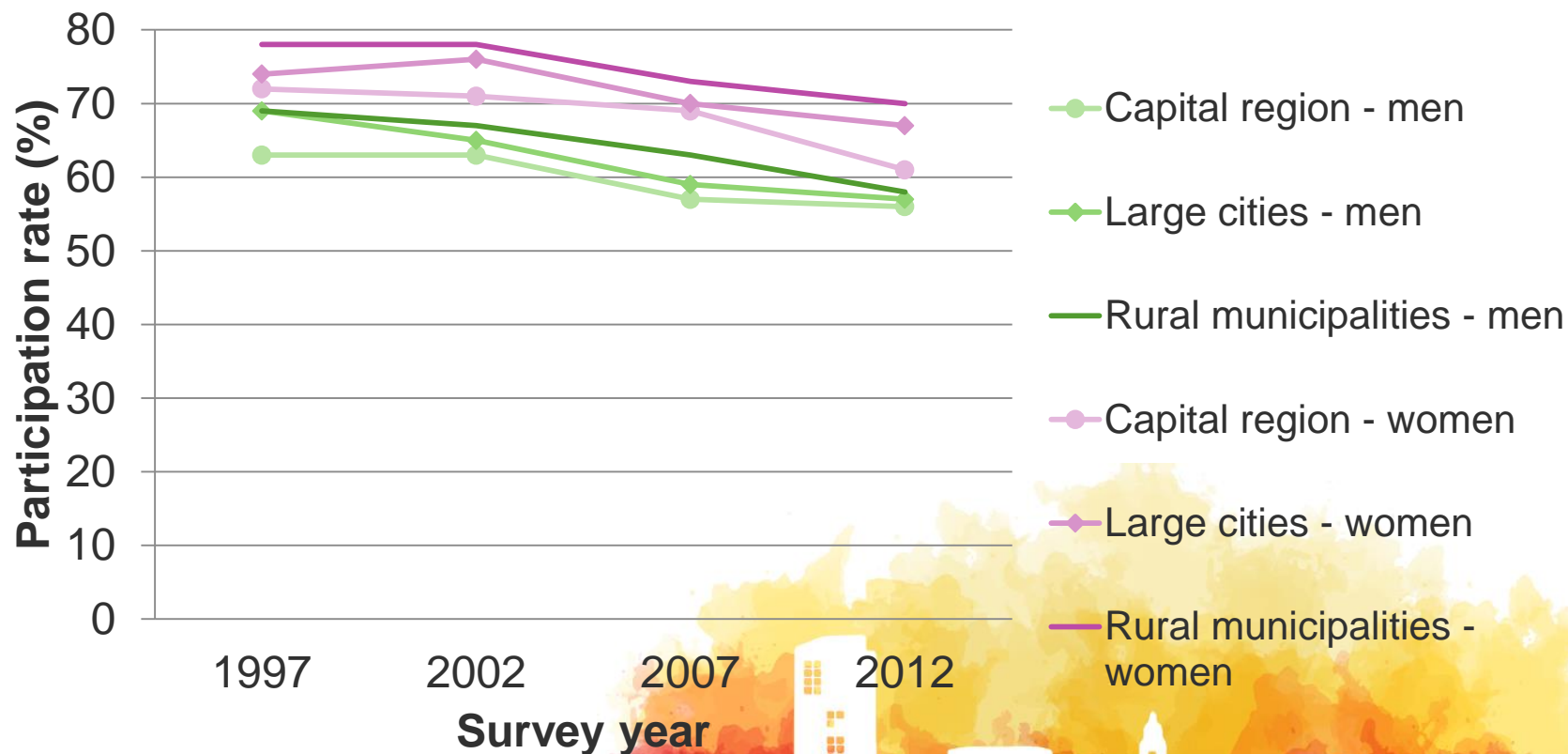
	Men	Women
Capital region	1.28 (1.18,1.40)	1.41 (1.29,1.54)
Other large cities	1.11 (1.03,1.19)	1.19 (1.10,1.28)
Rural municipalities	Ref.	Ref.

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Urbanization and non-participation



Health behaviours (smoking, alcohol)

- Based on results from FINRISK morbidity and mortality follow-up
 - Smoking related causes (lung cancer and COPD)
 - Alcohol related causes (e.g. alcoholic liver disease, toxic effect of alcohol, alcoholic poisoning)
 - Excess mortality on 10-years follow-up
 - Smoking related: Men HR=2.43 (1.92,3.08)
women HR=2.87 (1.81,4.56)
 - Alcohol related: Men HR=2.81 (2.01,3.93)
women HR=5.81 (2.77,12.18)
 - More hospitalization around time of the survey
 - Smoking related: Men OR=2.3 (1.0,5.0),
women OR=NA
 - Alcohol related: Men OR=3.9 (2.7,5.9),
women OR=6.9 (2.7,19.7)



Health behaviours (smoking, alcohol) cont.

- Based on results from FINRISK 2007 survey re-contact (i.e. non-participants) questionnaire

	Participants	Re-contacted
Smoking	21.8% (20.5,23.0)	33.4 (28.2,38.6)
Heavy alcohol use	5.2 (4.6,5.9)	6.4 (3.7,9.1)





Health profiles

- Based on results from morbidity and mortality follow-up
 - Excess mortality on 10-years follow-up

Outcome	Men	Women
Mental health	3.39 (2.19,5.39)	4.38 (2.01,9.57)
CVD	2.29 (2.05,2.56)	2.88 (2.38,3.49)
Cancer	1.63 (1.40,1.90)	1.51 (1.23,1.84)
Injuries	2.21 (1.84,2.66)	3.30 (2.35,4.62)
Suicides	1.88 (1.33,2.65)	3.30 (1.76,6.17)

- Results indicate that non-participants have more health problems than participants
 - In 1-year follow-up, among women, HR for cancer was 5.05 (most of the cases were breast cancer)

Conclusions

- Non-participation in health examination surveys is selective (MNAR).
- Linking health surveys to administrative registers will
 - increase our knowledge about survey non-participants
 - help us to adjust population based estimates for non-participation
- Auxiliary information can be used to estimate the non-participation bias through statistical methods such as multiple-imputation and Bayesian modeling.

The big question is...

... how much these observed differences between survey participants and non-participants effect of outcomes of interest

Thank you!

<http://www.ehes.info/nopahes>

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