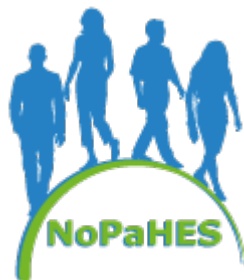


# What can be learned about survey non-response through record linkage? Examples from health examination surveys

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# Background

- \* Participation rates have been declining in all kinds of surveys over the past decades, also in Finland
- \* Previous studies have shown that survey non-participants differ from participants on socio-economic status but also in their health status



# 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
- \* In longitudinal surveys, information from previous round(s)

# NoPaHES Project

- \* Non-Participation in Health Examination Surveys (NoPaHES) project, 2013-2017
- \* Joint collaboration of National Institute for Health and Welfare and University of Jyväskylä
- \* Funding from the Academy of Finland

# NoPaHES materials - surveys

- \* HESs conducted by THL (former KTL) between 1972-2012
  - \* FINRISK surveys:
    - \* 1972, 1977, 1982, 1987, 1992, 1997, 2002, 2007, 2012
  - \* Mini-Finland survey, Health 2000 and Health 2011  
Migrant Health and Wellbeing Survey (Maamu)
    - \* 2010-2012

# FINRISK surveys

Survey year	Eligible sample size	Areas	Age group (years)	Participation rate
1972	13,500	North Karelia, Kuopio region	25-59	88%
1977	13,699	North Karelia, Kuopio region	30-64	89%
1982	11,359	North Karelia, Kuopio region, Turku + surrounding communities	25-64	82%
1987	7,932	North Karelia, Kuopio region, Turku + surrounding communities	25-64	82%
1992	7,927	North Karelia, Kuopio region, Turku + surrounding communities, Helsinki-Vantaa	25-64	76%
1997	11,500	North Karelia, Kuopio region, Turku + surrounding communities, Helsinki-Vantaa, Oulu region	25-64 (-74*)	73%
2002	13,437	North Karelia, Kuopio region, Turku + surrounding communities, Helsinki-Vantaa, Oulu region, Lapland	25-64 (-74 <sup>§</sup> )	71%
2007	11,953	North Karelia, Kuopio region, Turku + surrounding communities, Helsinki-Vantaa, Oulu region, Lapland <sup>§</sup>	25-74	67%
2012	9,905	North Karelia, Kuopio region, Turku + surrounding communities, Helsinki-Vantaa, Oulu region	25-74	65%

# Mini-Finland, Health 2000/2011 surveys

	Mini-Finland	Health 2000	Health 2011
Survey year	1978-1980	2000	2011-2012
Covered age group	30+ years	18-29 years, only questionnaire 30+ years, full	18+ years
Sample size	8 000	10 000	10 859
Participation rate	90%	18-29 years: 90% 30+ years: 93%	18-29 years: 52% 30+ years: 73%

# Maamu-survey - sample

- \* Random sample from the National Population Register
- \* 3 000 persons, 1 000 persons / ethnic group
- \* 6 cities: Helsinki, Espoo, Vantaa, Turku, Tampere, Vaasa
- \* Selection criteria
  - \* Age 18–64-years
  - \* country of birth: Somalia, Iraq/Iran, Russia/Soviet Union
  - \* mother tongue: Kurdish (sorani), Russian/Finnish
  - \* minimum one year residence in Finland
- \* Comparable information for the Finnish overall population from the Health 2011 Survey (same age range and same cities)



# Maamu-survey – participation rates

	Russian		Somali		Kurdish	
	N	%	N	%	N	%
<b>Participation, at least one part</b>	<b>702</b>	<b>70,2</b>	<b>512</b>	<b>51,2</b>	<b>632</b>	<b>63,2</b>
Health examination + full interview	466	46,6	317	31,7	480	48,0
Health examination + short interview	1	0,1	42	4,2	26	2,6
Only interview	79	7,9	34	3,4	28	2,8
Only health examination	1	0,1	19	1,9	14	1,4
Only short interview	155	15,5	101	10,1	81	8,1
<b>Refused / no show / no appointment</b>	<b>201</b>	<b>20,1</b>	<b>299</b>	<b>29,9</b>	<b>226</b>	<b>22,6</b>
<b>Not contacted</b>	<b>84</b>	<b>8,4</b>	<b>144</b>	<b>14,4</b>	<b>134</b>	<b>13,4</b>
Wrong address	22	2,2	38	3,8	54	5,4
Tried home visit 5 times	62	6,2	106	10,6	80	8,0
<b>Moved / abroad</b>	<b>13</b>	<b>1,3</b>	<b>45</b>	<b>4,5</b>	<b>8</b>	<b>0,8</b>
<b>Total</b>	<b>1000</b>	<b>100</b>	<b>1000</b>	<b>100</b>	<b>1000</b>	<b>100</b>

# NoPaHES materials – administrative registers

HES data (entire samples) will be linked to administrative registers

- \* **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
- \* **Ministry of Employment and the Economy:** working status unemployment information

# Linking administrative 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

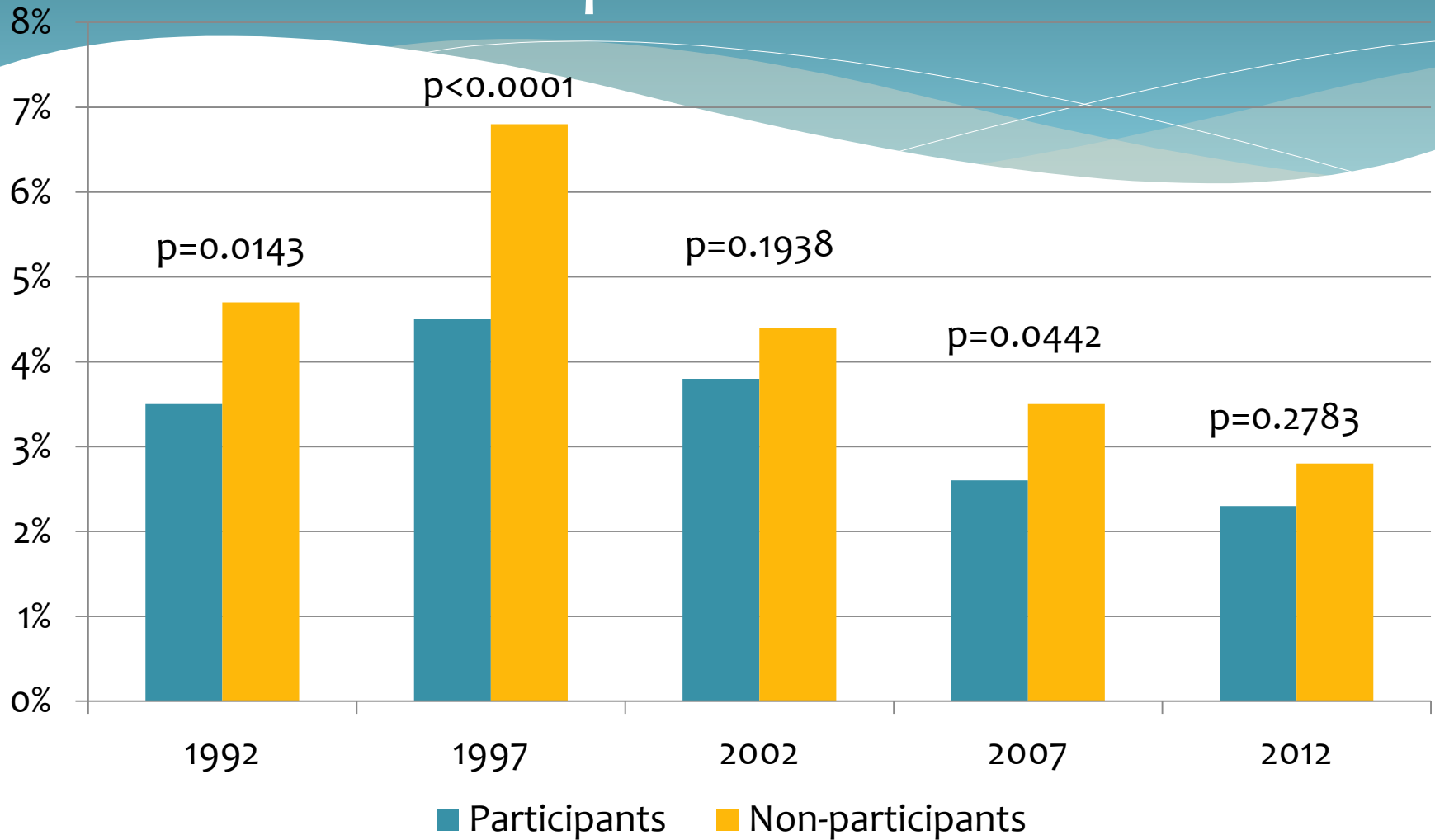
# Selected results

# Excess mortality of non-participants in FINRISK Study (25-64 years at baseline)

28-years follow-up	Cause of death	Men		Women	
		HR	95% CI	HR	95% CI
	All causes	2.06	1.87,2.27	2.56	2.19,3.00
CVD	1.89	1.62,2.19	2.63	1.97,3.51	
Cancer	1.54	1.22,1.95	1.22	0.87,1.71	
Tobacco related	1.97	1.43,2.70	1.46	0.49,4.35	
Alcohol related	3.10	2.37,4.04	4.33	2.10,8.94	

2-years follow-up	Cause of death	Men		Women	
		HR	95% CI	HR	95% CI
	All causes	2.43	2.01,2.90	3.38	2.50,4.56
CVD	2.31	1.77,3.01	2.19	1.16,4.13	
Cancer	2.50	1.65,3.81	2.37	1.35,4.17	

# Changes over time in % of hospital periods



# Logistic regression about non-participation

		Odds ratio	95% CI
Hospitalized during the survey period	Yes	1.50	1.31,1.65
	No	1.00	
Sex	Men	1.58	1.51,1.65
	Women	1.00	
Age group	25-34	1.00	
	35-44	0.74	0.70,0.79
	45-54	0.61	0.57,0.65
	55-65	0.50	0.47,0.53
Survey year	1992	0.49	0.45,0.52
	1997	0.61	0.57,0.66
	2002	0.68	0.64,0.73
	2007	0.84	0.78,0.90
	2012	1.00	

# Causes of hospitalization

- \* Non-participants have more hospitalizations with diagnoses on
  - \* Mental health
  - \* Pregnancies, giving birth and pregnancy/birth related diagnoses (women)
  - \* Alcohol related diseases
  - \* Injuries, accidents, and other external causes (men)
- \* Non-participants have worse health and more health problems than participants





# Correcting smoking trends for non-participation

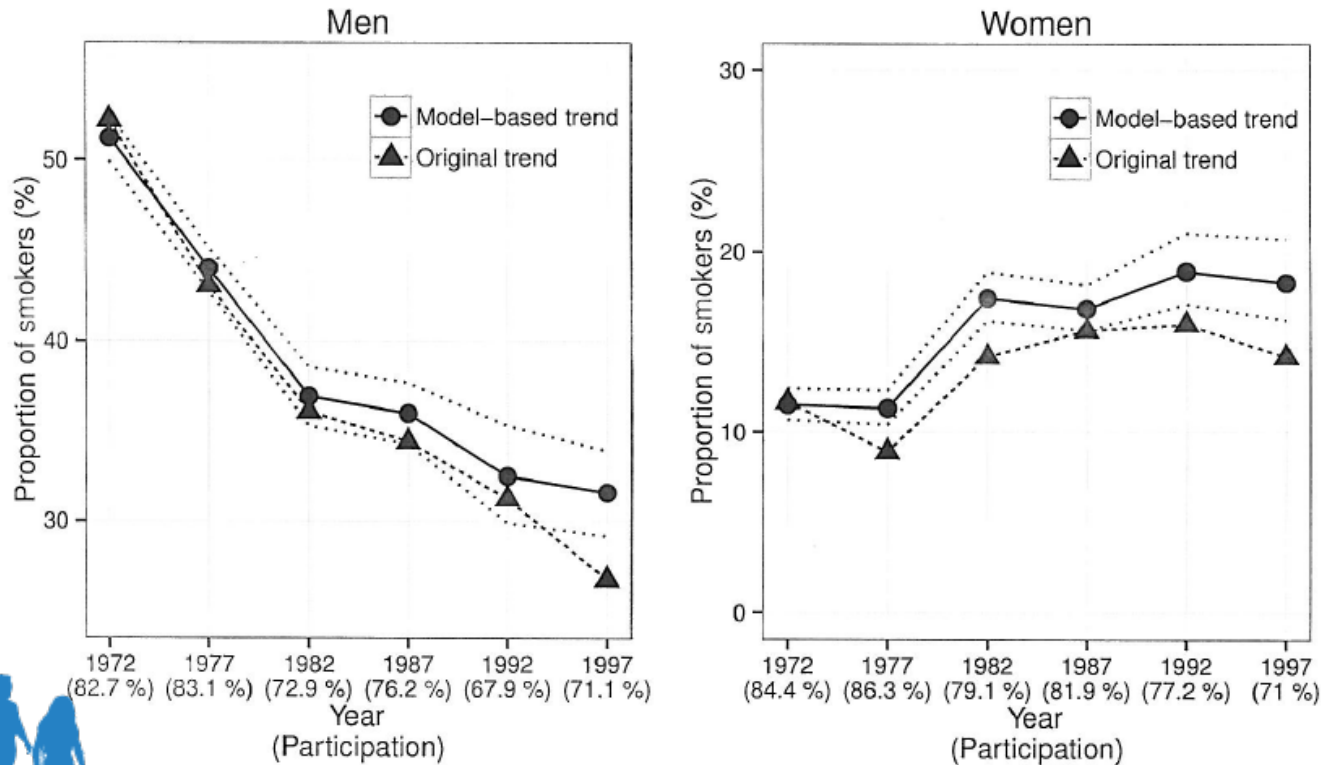
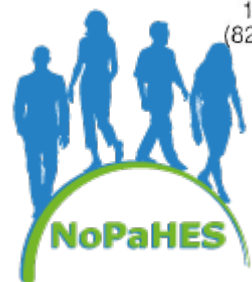


Figure : Trends of smoking prevalence for Northern Karelia.



# Conclusions

- \* Linking health surveys to administrative registers will
  - \* increase our knowledge about survey non-participants
  - \* help us to adjust population based estimates for non-participation
- \* Use of administrative data and statistical adjustment methods does not remove the non-participation bias



# Acknowledgement

- \* Funding from the Academy of Finland (no. 266251)
- \* NoPaHES group
- \* <http://www.ehes.info/nopahes/index.htm>

