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§)	71%
2007	11,953	North Karelia, Kuopio region, Turku + surrounding communities, Helsinki-Vantaa, Oulu region, Lapland$	25-74	67%
2012	9,905	North Karelia, Kuopio region, Turku + surrounding communities, Helsinki-Vantaa, Oulu region	25-74	65%

FINRISKI

* 25-74 y. in North Karelia, Helsinki-Vantaa, § 25-74 y. in North Karelia, Helsinki-Vantaa, Lapland, $ Lapland only questionnaire

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	%
Participation, at least one part	**702**	**70,2**	**512**	**51,2**	**632**	**63,2**
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
Refused / no show / no appointment	**201**	**20,1**	**299**	**29,9**	**226**	**22,6**
Not contacted	**84**	**8,4**	**144**	**14,4**	**134**	**13,4**
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
Moved / abroad	**13**	**1,3**	**45**	**4,5**	**8**	**0,8**
Total	**1000**	**100**	**1000**	**100**	**1000**	**100**

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)

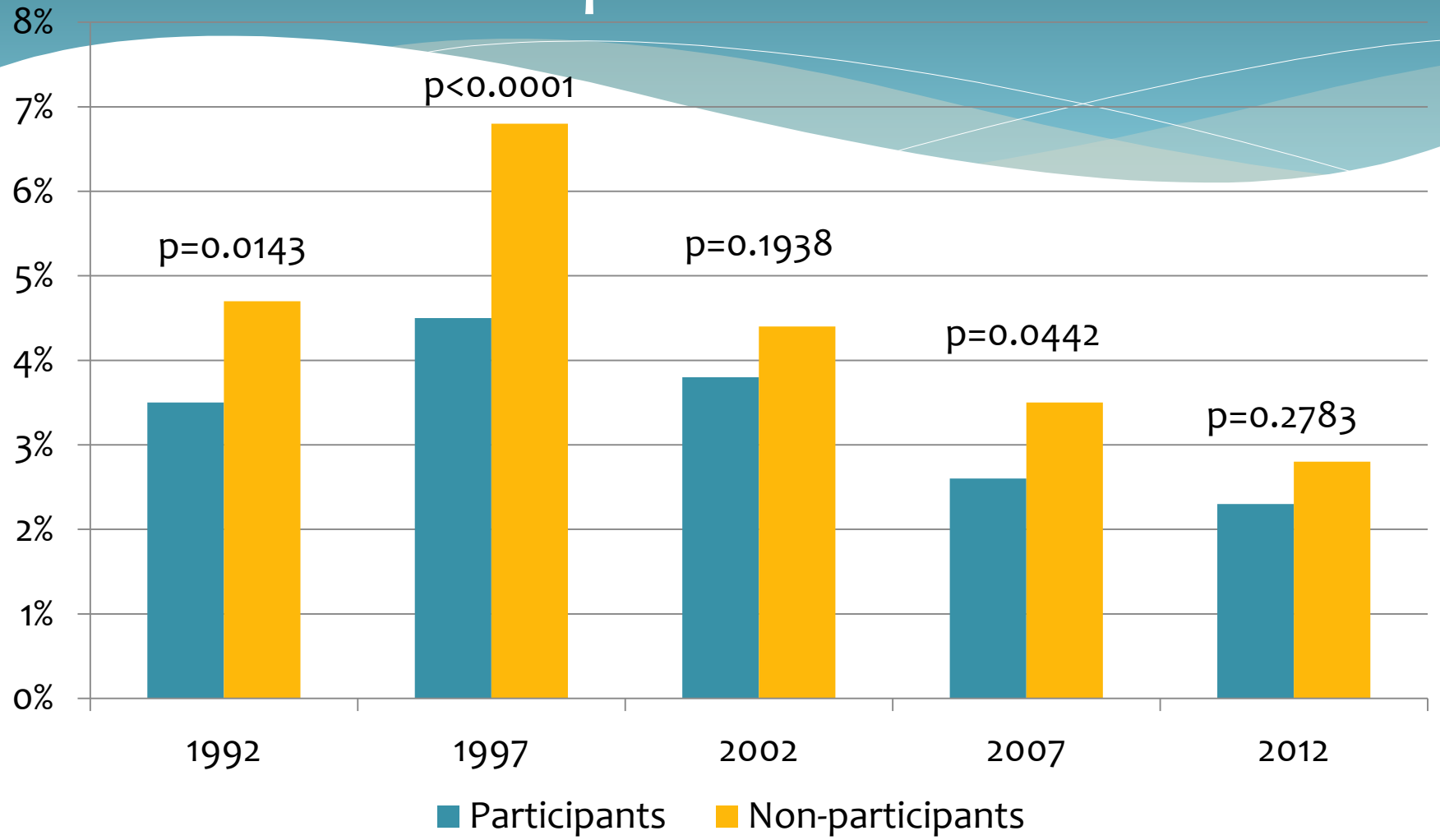
28-years follow-up	Cause of death	Men		Women	
		HR	95% CI	HR	95% CI
	All causes	2.06	1.87,2.27	2.56	2.19,3.00
	CVD	1.89	1.62,2.19	2.63	1.97,3.51
	Cancer	1.54	1.22,1.95	1.22	0.87,1,71
	Tobacco related	1.97	1.43,2.70	1.46	0.49,4.35
	Alcohol related	3.10	2.37,4.04	4.33	2.10,8.94

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

FINRISKI

Jousilahti et al. JECH 2005

Changes over time in % of hospital periods



FINRISKI

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	

FINRISKI

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

NoPaHES

Correcting smoking trends for non-participation

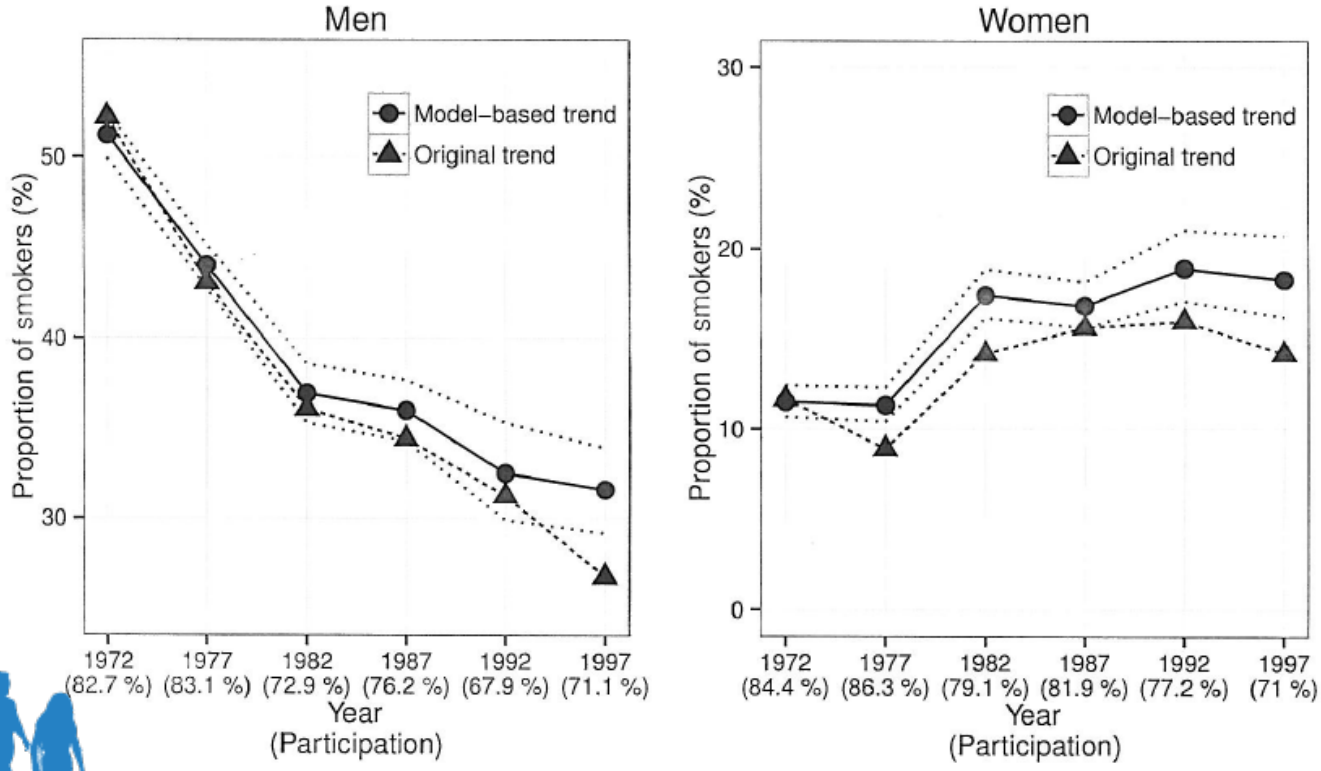


Figure : *Trends of smoking prevalence for Northern Karelia.*

NoPaHES

FINRISKI

Kopra J et al. Stat 2015

Kopra J presentation, BaNoCoSS 2015, Session 12 on Tuesday 25 August 2015

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

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* NoPaHES group
* http://www.ehes.info/nopahes/index.htm