

Associations between cohort study participation and self-reported health and well-being

The Northern Finland Birth Cohort 1966 Study

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Abstract

Aim: The aim of this study was to explore whether active participation in a longitudinal birth cohort study is associated with study participants' health behaviour and well-being. **Methods:** The subjects of this study were part of the Northern Finland Birth Cohort 1966 (NFBC1966). The follow-up data were collected through clinical examinations and questionnaires when the cohort members were 1, 14, 31 and 46 years old. In this study, cohort participation activity was divided into three categories: active (those participating in the 14-year, 31-year and 46-year studies); semi-active (those participating the 14-year and 46-year studies but in 31-year study only through a postal survey or clinical trials; and least active (those participating only in the 14-year and 46-year studies). **Results:** The total number of study participants who participated in the 46-year follow-up on both the survey and clinical trials was 6,392, of which 66.5% ($n = 4,268$) participated actively in the cohort study. A total of 67.6% were female ($p < 0.001$). Of the participants, 23.7% ($n = 1,519$) were semi-active, and 9.5% ($n = 605$) were the least active. Women who participated least actively experienced statistically significantly more depressive symptoms and poorer health, were more dissatisfied with their lives and had more addiction problems. In men, there was not a statistically significant association between participation activity and these well-being variables other than addiction problems and mental health. **Conclusions:** The findings indicate that participation activity is associated with better self-reported

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health and well-being, especially among women. With this knowledge, people can be encouraged to participate in longitudinal health research and, at the same time, may improve their own health and quality of life.

Keywords: *Participation activity, longitudinal study, well-being, self-reported health, cohort study, health behaviour*

What is already known on this topic

- Self-reported health is a good predictor of an individual's future health status.
- The medical information obtained, the sense of loyalty and the feeling of belonging are the main motives for participating in the cohort studies.

What this study adds

- This is the first study that investigates associations between cohort participation activity and well-being in NFBC 1966
- Cohort research should not be an intervention, but is it nonetheless?

How this study might affect research, practice and/or policy

- Emphasizing the benefits of participation, participation activity may be increased.

Introduction

It has long been recognised that health and diseases are not evenly distributed across the population [1].

Previous studies have shown how age, gender, marital status, education, occupation and/or residential area are related to differences in health status and health behaviours. Recognising the differences among population groups is a prerequisite for successful health promotion work [2]. Human well-being consists of health, material well-being and social relations. Active participation in society, such as participation in volunteering, research, political activities or other social activities, can also contribute to well-being [3–6].

Self-reported health is one indicator of a person's well-being [7]. It is an individual's interpretation of the health and illness they experience in daily life. The experience is based on available knowledge, past experience and social and cultural norms; for example, different cultures may have different health ideals. Studies have shown that self-reported health is a good predictor of an individual's future health status [8–9]. This has increased interest in measuring self-reported health. The life expectancy of older people is most strongly influenced by self-reported health, dependence on other people and social networks. Experiencing health, symptoms and various sensations are important determinants of an individual's mental well-being. [7–8].

Garbarski (2016) developed a model in which she described the formation of self-reported health and the effect of various factors on each other. According to the model (Figure 1), the factors are divided into physical, psychological, social and environmental factors. The boundaries are not always clear, and different health factors often overlap and determine self-reported health in different ways depending on the individual [9]. Factors related to **physical health** are medical diagnoses, medications, level of functioning, various symptoms and health behaviour, such as alcohol use and exercise [10,11–14]. **The psychological factors** that underlie self-reported health are mental health, positive or negative attitude, cognitive abilities and motivation. **Social and environmental factors** underlying self-reported health are socio-economic status, social relations, trust in loved ones and communities, society, culture and living environment [10]. Studies

have shown how those in a lower socio-economic position assess their general self-reported health status as poorer than those in a higher socio-economic position [15–18]. Low socio-economic status and environmental factors such as culture and living environment are associated with poorer self-reported health in various ways [16]. Self-reported health can be impaired, for example, by stress caused by economic scarcity or because health services are perceived as difficult to access. Correspondingly, a stable economic situation increases the sense of security and controllability of life, which contributes to improving self-reported health [6,11,16].

[Insert Figure 1 here.](#)

There is a lack of qualitative research on the motives of people participating in longitudinal population-based cohort studies, but a sense of usefulness and altruism are two of the reasons why people participate in cohort studies [19]. Mein et al. (2012) indicated that the main motives for and experiences of participation were the personal benefit that participants perceived, especially the information and care received during medical examinations and the sense of loyalty and membership associated with being part of the cohort study. Dahlin-Ivanoff et al. (2019) studied older adults' experiences of participating in a population-based cohort study. The study showed that the most important factors for participation were health benefits, such as detecting early signs of disease, and that research gives people a lot of free health information. Promoting the well-being of others was also a very important factor in participation [20].

To the best of our knowledge, the association between active participation in a research programme with health behaviour and health status has not been studied in the Northern Finland Birth Cohort 1966 (NFBC 1966). In general, little research has been done on this matter, but, for example, Nohr et al. studied the Danish National Birth Cohort and low participation rates and found that the active study participants were somewhat healthier in comparison to those who did not participate in all the data collection phases, but not statistically significantly [21]. In contrast, a number of studies have examined participatory activity from different perspectives. For example, several studies have examined the participation of older people in physical activities or, for example, volunteering [22–23]. Also, there have been studies on the participation of young people in sport and exercise, but the participation activity of middle-aged people in relation to

health behaviours and health has not been studied to any degree. In any case, these studies focus more on short-term activity and are not longitudinal studies [23–24].

The purpose of this study was to explore whether active participation in the longitudinal birth cohort study is associated with individual's self-reported health and well-being. We also examined the association between active participation in the cohort study and well-being-related issues of the participants, such as depression and anxiety symptoms, mental health problems, addiction problems and life satisfaction. Our aim was to study how cohort participation activity is independently associated with self-reported health and well-being.

Materials and methods

Participants

The subjects of this study were part of the NFBC1966. Initially, the cohort study included mothers whose expected delivery date was 1966 in the provinces of Oulu and Lapland ($N = 12,058$ born alive, which contained 96% of all births in the area during 1966) [25]. After pregnancy, the follow-up data were collected through clinical examinations and questionnaires when the cohort members were 1, 14, 31 and 46 years old. In the 46-year follow-up study, the questionnaires consisted of self-reported information about lifestyle, health, socio-economic factors and use of healthcare services [26]. The Northern Ostrobothnia Ethical Committee (94/2011) approved the 46-year follow-up study. Cohort members provided informed consent for the use of their data [27].

Measures

In this study, cohort participation activity was divided into three categories: active, semi-active and least active. Active means that the participant participated in all aspects/follow-ups of the study in each age group (14-year, 31-year, and 46-year studies). Semi-active means that participants participated in a 14-year study and 46-year study, but in the 31-year study, only through postal survey or clinical trials. The least active means that the participants participated in the 14-year study and 46-year studies, but they did not participate in 31-year study at all. Thus, the inactivity was determined through the 31-year study. Inactivity was determined by the fact that the subjects received the questionnaires and an invitation to the clinical examination but decided not to participate in them.

Individuals whose address information was not available or who had died were excluded from the data.

As confounding factors, we used the following data from the 46-year study: education, work history and marital status. In the socio-economic variables, the Marital/cohabiting variable consisted of 'Married and Cohabiting and Registered couples', and the Divorced/separated variable consisted of 'Divorced and Widowed'. In the work history variable, Always employed consisted of the 'At work and Entrepreneur' option. More employed consisted of 'Student, Maternity/paternity leave and Childcare' options and More unemployed consisted of 'Unemployed', 'Retired', 'I run my own household' and 'What else' options.

Self-reported health data were obtained through the answers to the question: 'How would you estimate your current state of health?' The answer options consisted of 'Very good', 'Good', 'Moderate', 'Poor' and 'Very Poor'. Life satisfaction was assessed by the question: 'How satisfied are you with your current situation in life in general?'. The answer options were 'Very satisfied', 'Somewhat satisfied', 'Somewhat dissatisfied', 'Very dissatisfied' and 'Cannot say'.

Anxiety and depressive symptoms were defined by Hopkins Symptom Checklist-25 (HSCL-25) in a 46-year postal questionnaire. HSCL-25 is a 25-item shortened version of the original 90-item questionnaire designed by Derogatis and colleagues [28] and has been found to be a valid instrument in Finnish [28]. HSCL-25 includes both depression and anxiety subscales. In this study, the mean score of ≥ 1.55 on the HSCL-25 depression and anxiety subscale was used as a cut-off point to define depression and anxiety [30,31]. Using those subscales, the subject assessed the presence and intensity of depressive and anxiety symptoms over the previous week. The answers were scored on a scale from 1 (not bothered) to 4 (extremely bothered). The HSCL subscale score is the sum of items divided by the number of items answered. A cut-off point of 1.54/1.55 or over was used as an indicator of depression and anxiety.

Statistical analyses

Categorical variables are presented as numbers and percentage of proportions and were tested by the chi-square test. Logistic regression analyses were used to estimate the association between active participation and different self-reported health and well-being. The following variables were used in the adjusted multivariate model: education, work history and marital status. The statistical analyses were conducted using the R software package version 4.0.2 (<https://cran.rstudio.com>).

Results

The total number of study participants who had participated in 46-year follow-up in NFBC1966 on both the survey and clinical trials was 6,392. All 4,268 (66.5%) participated actively (67.6% were female ($p < 0.001$)). Of the participants, 1,519 (23.7%) were semi-active, and 605 (9.5%) were the least active. Table I shows how demographic factors were distributed in the study population according to the participation activity. Regardless of participation activity, secondary education was the main level of education in both men and women. About 15% of men and 10% of the women in the least active group had attended primary school, and just over 18% of them had been more unemployed both in men and women. Of the least active, 17.1% of the men and 10.5% of the women were unmarried. In the least active category, for both men and women, about 12% were divorced.

[Insert Table 1 here.](#)

Table II shows that 66.1% of those who actively participated in the cohort studies reported that their self-reported health was either very good or good, while the same figure was 56.4% for the least active. Of the active and least active participants, 3.5% and 5.1% reported poor or very poor health, respectively, while 90.1% of the active people and 88% of the least active people were satisfied with their lives. Among active participants, 13% reported mental health issues, while 16.5% in the least active group reported them. In addition, 2.3% of active participants suffered from substance abuse problems, while 7.0% of the least active participants suffered from these problems. Alcohol was the main substance in these problems.

[Insert table 2 here.](#)

The unadjusted binary regression analyses showed that the low participation activity in the NFBC 1966 at the age of 46 was associated with poor self-reported health in women ($OR = 2.69$, 95% CI [1.56, 4.43], $p <$

0.001), but not in men ($OR = 1.01$, 95% CI [0.53, 1.94]). In women, the association between low participation and poor self-reported health remained statistically significant even though socio-economic factors and marital status were adjusted from the model ($OR = 1.92$, 95% CI [1.06, 3.35], $p < 0.026$). Figure 2 shows how self-reported health was associated in men and women.

[Insert figure 2 here.](#)

The unadjusted binary regression analyses also revealed that the low participation activity in the cohort study at the age of 46 was associated with the experience of dissatisfaction with life situation among women ($OR = 1.78$, 95% CI [1.21, 2.54], $p < 0.002$). The association remained even though the socio-economic factors and marital status were adjusted from the model ($OR = 1.45$, 95% CI [0.96, 2.13], $p < 0.065$), but it was no longer statistically significant. In men, there was no association between low participation activity and experience of dissatisfaction with life situation ($OR = 1.11$, 95% CI [0.75, 1.61], $p > 0.578$).

Table III shows that a statistically significant association between mental health problems and low participation activity occurred only in men ($OR = 1.61$, 95% CI [1.12, 2.27], $p = 0.008$), but after adjusting for socio-economic factors and marital status, there was no longer an association. Depression symptoms also occurred statistically significantly in the least active women after adjustment ($OR = 1.41$, 95% CI [1.06, 1.86], $p = 0.017$) but not in men. The association with anxiety symptoms did not occur in either men or women. The association between addiction problems and low participation activity in the study occurred in both men and women statistically significantly, also after adjustment: men ($OR = 1.81$, 95% CI [1.09, 2.93], $p = 0.014$) and women ($OR = 2.61$, 95% CI [1.17, 5.44]).

[Insert Table 3 here.](#)

Discussion

The purpose of this study was to investigate how participation activity in the cohort study was associated with participants' self-reported health and well-being. Based on data from The NFBC 1966 study, the main findings were that women who participated less actively in the cohort study experienced statistically significantly more depressive symptoms and poorer health, were more dissatisfied with their lives and had

more addiction problems than men. In men, there was a statistically significant association between low participation activity and mental health problems and addiction problems.

According to previous studies, women are generally more actively involved in research [32]. Also, in this study, the participation rate of women was higher. Overall, participation in the NFBC 1966 study was quite high, but 9.5% of participants did not participate in the 31-year study, either completely or at least partially. The probable reason is that people in their thirties usually have small children and career development at work is important, so they have less time to be involved in this kind of research. Also, they are young and usually healthy, so health does not yet seem to be so important. Health issues begin to be considered important at a later age, and therefore participants do return to studies because they can gain relevant information about their own health through clinical trials in these kinds of studies. Studies have also shown that altruism is one reason that people participate in studies [24]. This is also likely to be affected by an increase in age. Social factors and the remaining legacy seem more significant than at a young age. As people get older, they may start to think more about the future of next generations and participating in research may help them. One explanation for the lower participation rate, especially in men, could be that in this study, almost 30% of the least active men were unmarried or divorced. Studies have shown that unmarried or divorced men are more easily excluded from society and, as a result, participate less in research [33].

As this study shows, active participation in this cohort study had a positive association with well-being, especially in women. These results can be used to promote and encourage people to participate in longitudinal studies. This is important because the participation rates in these kinds of studies have been declining for many years [34,35]. This is also important because when society conducts such extensive and expensive research, it is essential to motivate people to participate.

Strengths and limitations

The strengths of the study were its extensive research data, which were based on a representative and unselected large birth cohort with high response rates. The longitudinal data were collected from the three research points over a 46-year time period after the mothers' pregnancy. The collected data provided a good

picture of the health and well-being of the cohort participants. However, our study has some limitations. All the information was based on self-reported questionnaires, which may have caused some variability in answers.

Conclusions

The findings indicate that participation activity is associated with good self-reported health and well-being, especially among women. Why activity appears to affect women's well-being more than men's has not been investigated in this connection, and this should be explored in future studies. Also, questions about the association between active participation and morbidity will require further investigation. However, with this knowledge, people can be encouraged to participate in longitudinal research and, at the same time, may improve their own health and quality of life.

Declaration of conflicting interests

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Table I. Distribution of education, work history and marital status by participation activity to the Cohort study.

	Men			Women		
	Active <i>n</i> = 1,896 (65.8)	Semi-active <i>n</i> = 658 (22.8)	Least active <i>n</i> = 329 (11.4)	Active <i>n</i> = 2,372 (67.6)	Semi-active <i>n</i> = 861 (24.5)	Least active <i>n</i> = 276 (7.9)
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
Education						
Tertiary (>12 years)	423 (22.8)	67 (10.5)	74 (23.2)	664 (29.0)	336 (40.7)	75 (28.3)
Secondary(10–12 years)	1,258 (67.9)	342 (62.9)	197 (59.9)	1,494 (65.4)	448 (54.4)	164 (61.9)
Basic (<10 years)	172 (9.3)	170 (26.6)	48 (15.1)	128 (5.6)	40 (4.8)	26 (9.9)
Work history						
Always employed	1,674 (88.7)	568 (87.3)	257 (79.8)	2,056 (87.6)	762 (88.0)	215 (79.3)
More employed	18 (0.91)	10 (1.5)	5 (1.2)	69 (2.9)	20 (2.4)	6 (2.2)
More unemployed	196 (10.4)	73 (11.2)	60 (18.6)	222 (9.1)	74 (8.6)	50 (18.5)
Marital status						
Married/cohabiting	1,490 (79.1)	519 (79.3)	231 (70.4)	1,830 (77.4)	664 (77.4)	212 (76.8)
Unmarried	236 (12.5)	80 (12.2)	56 (17.1)	252 (10.7)	84 (9.8)	29 (10.5)
Divorced/separated	158 (8.4)	56 (8.6)	41 (12.5)	280 (11.8)	110 (12.8)	35 (12.7)

Table II. Distribution of association between participation activity and well-being.

	Active <i>n</i> = 4,268 (66.5%)		Semi-active <i>n</i> = 1,519 (23.7%)		Least active <i>n</i> = 605 (9.5%)		<i>p</i> -value
	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)	
Gender							
Male	1,896	(65.8)	658	(22.8)	329	(11.4)	<0.001
Female	2,372	(67.6)	861	(24.5)	276	(7.9)	
Self-reported health							
Very good	532	(12.6)	206	(13.7.)	67	(11.2)	<0.001
Good	2,266	(53.5)	868	(57.6)	271	(45.2)	
Moderate	1,288	(30.4.)	373	(24.8)	231	(38.5)	
Bad	129	(3.0)	49	(3.3)	26	(4.3)	
Very bad	20	(0.5)	10	(0.7)	5	(0.8)	
Satisfaction with life							
Very satisfied	885	(20.9)	334	(22.2)	108	(18.1)	<0.001
Somewhat satisfied	2,937	(69.2)	1,040	(69.0)	406	(67.9)	
Somewhat dissatisfied	346	(8.2)	94	(6.2)	61	(10.2)	
Very dissatisfied	49	(1.2)	26	(1.7)	14	(2.3)	
Cannot say	27	(0.6)	13	(0.9)	9	(1.5)	
Mental illness	553	(13.0)	228	(15.1)	99	(16.5)	0.019
Mental illness, psychosis	49	(1.2)	18	(1.2)	14	(2.3)	0.050
Depression	451	(10.6)	183	(12.2)	76	(12.7)	0.127
Other mental illness	157	(3.7)	65	(4.3)	35	(5.9)	0.038
Addiction problems	97	(2.3)	42	(2.8)	42	(7.0)	<0.001
Alcohol problem	90	(2.1)	41	(2.7)	40	(6.7)	<0.001
Other substance abuse problem	20	(0.5)	7	(0.59)	7	(1.2)	0.084

Table III. Association between the Cohort study participation activity and self-reported health, life satisfaction, depression symptoms, anxiety, addiction and mental health problems.

Self-reported health		Good or very good <i>n</i> (%)	Poor or moderately poor <i>n</i> (%)	<i>OR</i> (unadjusted)	<i>OR</i> (adjusted for all)
Men	Active	1,215 (94.6)	70 (5.4)	-	-
	Semi-active	454 (94.2)	28 (5.8)	1.07 (0.67–1.66, <i>p</i> =0.767)	0.99 (0.60–1.59, <i>p</i> =0.965)
	Least active	189 (94.5)	11 (5.5)	1.01 (0.50–1.87, <i>p</i> =0.976)	0.74 (0.34–1.48, <i>p</i> =0.425)
Women	Active	1,583 (95.2)	79 (4.8)	-	-
	Semiactive	620 (95.2)	31 (4.8)	1.00 (0.65–1.52, <i>p</i> =0.993)	1.00 (0.62–1.57, <i>p</i> =0.996)
	Least active	149 (88.2)	20 (11.8)	2.69 (1.56–4.43, <i>p</i> <0.001)	1.92 (1.06–3.35, <i>p</i> =0.026)
Life satisfaction		Good or very good	Poor or moderate poor		
Men	Active	1,677 (89.7)	193 (10.3)	-	-
	Semi-active	582 (90.4)	62 (9.6)	0.93 (0.68–1.24, <i>p</i> =0.615)	0.90 (0.65–1.23, <i>p</i> =0.517)
	Least active	281 (88.6)	36 (11.4)	1.11 (0.75–1.61, <i>p</i> =0.578)	0.83 (0.54–1.23, <i>p</i> =0.363)
Women	Active	2,145 (91.4)	202 (8.6)	-	-
	Semi-active	792 (93.2)	58 (6.8)	0.78 (0.57–1.05, <i>p</i> =0.104)	0.80 (0.58–1.09, <i>p</i> =0.173)
	Least active	233 (85.7)	39 (14.3)	1.78 (1.21–2.54, <i>p</i> =0.002)	1.45 (0.96–2.13, <i>p</i> =0.065)
Mental health		No	Yes		
Men	Active	1,726 (91.0)	170 (9.0)	-	-
	Semi-active	583 (88.6)	75 (11.4)	1.31 (0.98–1.73, <i>p</i> =0.069)	1.30 (0.95–1.76, <i>p</i> =0.095)
	Least active	284 (86.3)	45 (13.7)	1.61 (1.12–2.27, <i>p</i> =0.008)	1.16 (0.78–1.70, <i>p</i> =0.446)
Women	Active	1,989 (83.9)	383 (16.1)	-	-
	Semi-active	708 (82.2)	153 (17.8)	1.12 (0.91–1.38, <i>p</i> =0.273)	1.14 (0.92–1.41, <i>p</i> =0.243)
	Least active	222 (80.4)	54 (19.6)	1.26 (0.91–1.72, <i>p</i> =0.148)	1.03 (0.72–1.43, <i>p</i> =0.883)
Depression symptoms		-1.54**	1.55+**		
Men	Active	1,450 (78.8)	391 (21.2)	-	-
	Semi-active	499 (78.2)	139 (21.8)	1.03 (0.83–1.28, <i>p</i> =0.771)	1.03 (0.82–1.30, <i>p</i> =0.783)
	Least active	254 (79.1)	67 (20.9)	0.98 (0.73–1.30, <i>p</i> =0.882)	0.79 (0.58–1.08, <i>p</i> =0.147)
Women	Active	1,730 (75.5)	562 (24.5)	-	-
	Semi-active	617 (74.0)	217 (26.0)	1.08 (0.90–1.30, <i>p</i> =0.391)	1.09 (0.90–1.31, <i>p</i> =0.363)
	Least active	175 (66.3)	89 (33.7)	1.57 (1.19–2.05, <i>p</i> =0.001)	1.41 (1.06–1.86, <i>p</i> =0.017)
Anxiety		-1.54**	1.55+**		
Men	Active	1,622 (87.4)	234 (12.6)	-	-
	Semi-active	548 (86.3)	87 (13.7)	1.10 (0.84–1.43, <i>p</i> =0.478)	1.09 (0.83–1.43, <i>p</i> =0.525)
	Least active	267 (83.4)	53 (16.6)	1.38 (0.99–1.89, <i>p</i> =0.054)	1.21 (0.86–1.69, <i>p</i> =0.267)
Women	Active	1,909 (83.5)	376 (16.5)	-	-
	Semi-active	680 (82.5)	144 (17.5)	1.08 (0.87–1.33, <i>p</i> =0.501)	1.09 (0.88–1.34, <i>p</i> =0.447)
	Least active	214 (80.8)	51 (19.2)	1.21 (0.87–1.66, <i>p</i> =0.250)	1.07 (0.76–1.48, <i>p</i> =0.704)
Addiction problems		No	Yes		
Men	Active	1,826 (96.3)	70 (3.7)	-	-
	Semi-active	629 (95.6)	29 (4.4)	1.20 (0.76–1.85, <i>p</i> =0.413)	1.11 (0.68–1.76, <i>p</i> =0.667)
	Least active	298 (90.6)	31 (9.4)	2.71 (1.73–4.18, <i>p</i> <0.001)	1.81 (1.09–2.93, <i>p</i> =0.018)
Women	Active	2,345 (98.9)	27 (1.1)	-	-
	Semi-active	848 (98.5)	13 (1.5)	1.33 (0.66–2.54, <i>p</i> =0.400)	1.63 (0.79–3.20, <i>p</i> =0.169)
	Least active	265 (96.0)	11 (4.0)	3.61 (1.70–7.16, <i>p</i> <0.001)	2.61 (1.17–5.44, <i>p</i> =0.014)

* Adjusted for education, work history and marital status using binary logistic regression analysis by gender.

** The Symptom Check-List (SCL-25) is used here to assess a person's depression symptoms and anxiety: -1.54 means there are no depression symptoms and/or anxiety, and $1.55+$ means that there are some depression symptoms and/or anxiety.

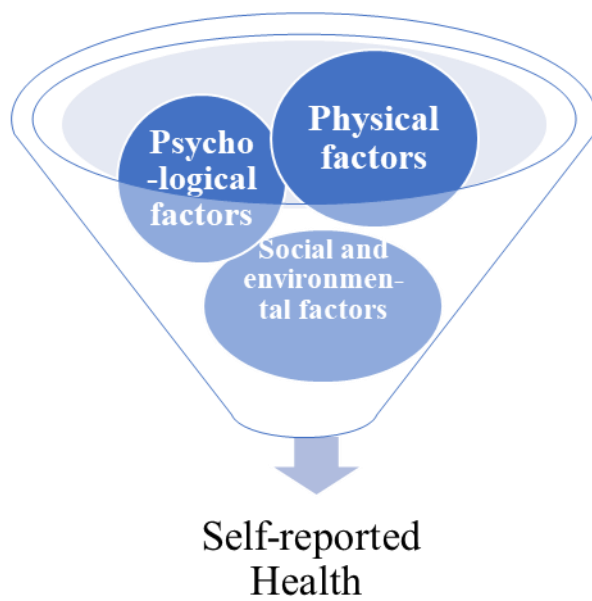


Figure 1. Factors affecting self-reported health. Adapted from Garbarski's (2016) model.

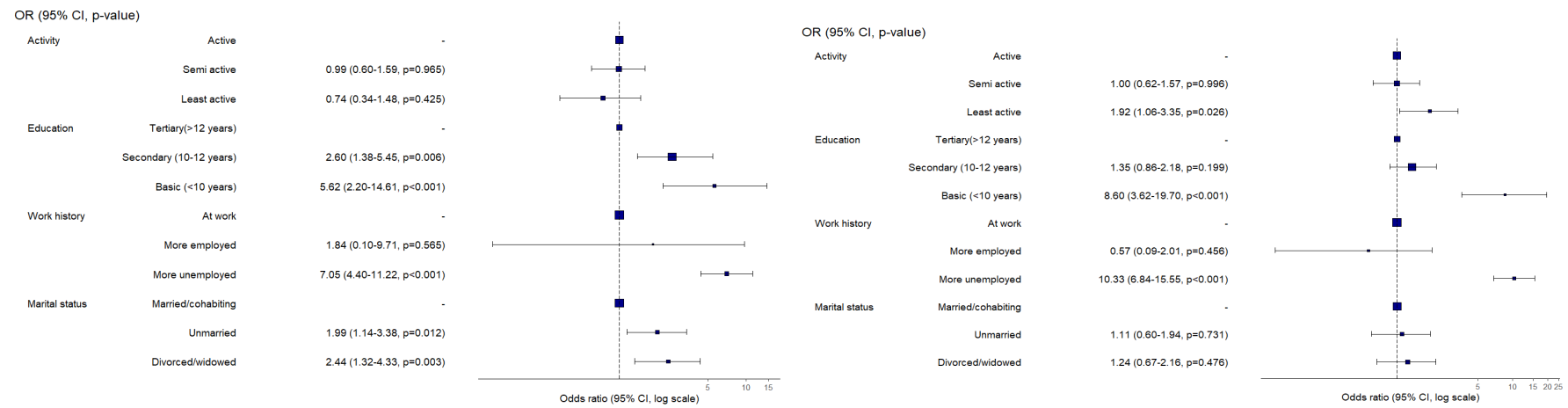


Figure 2. How self-reported health is associated with participation activity, education, work history and marital status in men (left image) and women (right image).