

# Nonparticipation in a Danish cohort study of long-term sickness absence

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**Aim:** The aim of the present study was to identify predictors of nonparticipation in a Danish cohort of individuals on long-term sickness absence with a nonparticipation rate of 53.6%.

**Methods:** Data from Danish public registers were linked to all 2414 individuals initially recruited to the cohort. Information regarding social- and health-related characteristics was retrieved. Adjusted logistic regression was carried out to examine differences between participants and nonparticipants as well as to identify predictors of nonparticipation.

**Results:** Nonparticipation was associated with being male, relatively young, having a vocational secondary education, and having a low income, whereas a recent somatic disease treated in hospital was a predictor for participation. Having had a psychiatric disorder in the past was generally a barrier for participation, while a recent psychiatric disorder was a positive factor for participation.

**Conclusion:** Individuals with low socioeconomic status and individuals with prior psychiatric disorders were less willing to participate in this cohort study of long-term sickness absence.

**Keywords:** mental disorders, nonparticipation, nonresponse, sickness absence

## Introduction

It is common for some eligible participants to refuse to participate in the recruitment phase of a study. Nonparticipation is a problem for all epidemiological studies as it is widely accepted that participants and nonparticipants may differ in many ways.<sup>1</sup> Nonparticipation has not been previously analyzed in regards to studies of long-term sickness absence (>8 weeks). This may be because such studies are typically affected by incomplete coverage. In 2004–2005, we carried out a study of psychiatric disorders in a large Danish cohort of individuals on long-term sickness absence.<sup>2</sup> Initially, all individuals on long-term sickness absence in the source population were chosen for study. The cohort was, however, influenced by nonparticipation, since 53.6% of the sick-listed population chose not to participate. The numerous public registers in Denmark, which hold information on all citizens, provided a unique opportunity to examine nonparticipation in this study.

If nonresponse occurs randomly, it will not affect the validity of a study, since the characteristics of individuals under observation will not be systematically different from those not participating. However, if there are unique characteristics among nonparticipants, the remaining sample may differ from the original sample. Findings from empirical studies have consistently shown that participants in epidemiological studies are more often from higher socioeconomic strata. Other characteristics may

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be associated with participation depending on the topic of research and the nature of the source population.<sup>3-8</sup> Nonparticipation is, therefore, considered a major threat to the external and internal validity of a study.<sup>9-11</sup> Nevertheless, selection problems have received little attention in the research of long-term sickness absence. The aim of the present study was to compare the social- and health-related characteristics of participants and nonparticipants and to identify predictors of nonparticipation – in particular, the impact of psychiatric disorders.

## Materials and methods

### Study setting and sample

This study included six municipalities in the Western part of Denmark with approximately 120,000 inhabitants. Recruitment took place from August 30, 2004 through August 29, 2005. On a weekly basis, information regarding sick-listed individuals was reported from the local job centers to the research project. Individuals on long-term sickness absence, defined as continuous sickness absence of more than 8 weeks, were eligible for inclusion in the study. Individuals with a prior period of long-term sickness absence within the study period, under 18 years of age on the day when the sickness absence period exceeded eight weeks, or unable to understand the Danish language were excluded. In total, 2414 individuals were eligible for participation in this cohort study. They received a questionnaire and were invited to participate in a psychiatric examination. Of these, 1121 (46.4%) agreed to participate and gave informed consent.

### Data collection procedures

All participants and nonparticipants were linked to public registers using their Danish personal identification numbers. This identification number is provided by the Danish Centralized Civil Register, which contains information about every person who is or has been a Danish inhabitant since 1968, and which is updated daily.<sup>12</sup> Nine individuals (one respondent and eight nonrespondents) were excluded, since their personal identification number did not match any data in the registers.

The Danish Psychiatric Central Register and the Danish National Patient Registry<sup>13</sup> provided information regarding psychiatric and somatic diseases that led to admission to a hospital or visits to emergency rooms and outpatient clinics. Psychiatric and somatic diseases in sick-listed individuals were defined according to the International Classification of Diseases, Tenth Revision (ICD-10).<sup>14</sup>

The following demographic and socio-economic covariates were available from Statistics Denmark:<sup>15</sup> sex, age, municipality, children living at home, civil status, homeowner, education, employment, weekly working hours, and annual gross income in DKK (100 DKK  $\approx$  12 GBP). Employment was categorized as high skills/managers, self-employed, basic skilled workers (eg, white-collar worker, artisan, farming, shipping), unskilled worker (eg, blue-collar worker, cleaning operative, refuse collector), and without a job (eg, unemployed, student, sickness benefit, leave of absence). Municipality was categorized as urban (municipalities with  $\geq$ 50,000 inhabitants) and rural (municipalities with  $<$ 50,000 inhabitants). Other covariates were categorized according to Table 1. Once a year, Statistics Denmark assesses socioeconomic and demographic factors. In this study, registration prior to the index absence period was used.

The Register of Medicinal Products Statistics<sup>16</sup> provided information on redeemed prescriptions on psychoactive drugs (ATC codes N03, N05A, N05B, N05C, N06A and N06B), which were defined as redemption of at least one type of these drugs during the study period.

The Danish National Labour Market Authority's DREAM database<sup>17</sup> provided information about economic compensation for unemployment, sickness absence, and other kinds of economic assistance. Data were dichotomized as receiving public benefits or not.

The study was approved by the Danish Data Protection Agency. Statistics Denmark<sup>15</sup> prepared the dataset by linking information from all databases using each individual's personal identification number. This number was then removed from the dataset before the data was transferred to the researchers.

### Statistical analysis

Nonparticipation was defined as nonresponse to the baseline questionnaire that was sent out with an invitation to participate in the study. When considered predictors of nonparticipation, psychiatric and somatic diseases and psychoactive drugs were defined at two points in time: (1) during a period of 1 year before the first day of the index sickness absence period; and (2) the first 8 weeks of the index sickness absence period, which was the period required for inclusion in the study. In addition, psychiatric diagnoses from admission to a hospital, emergency room, and outpatient clinic were also monitored from 1 to 5 years before the index sickness absence period.

**Table 1** Nonparticipation according to demographics characteristics in the year before sickness absence

Variable	Level	N	Participation %	OR <sub>crude</sub> (CI)	OR <sub>adj.</sub> <sup>a</sup> (CI)
Sex	Female	1293	49	1	1
	Male	1112	43	1.3 (1.1–1.5)	1.2 (1.0–1.5)*
Age	>50	775	50	1	1
	40–50	753	47	1.1 (1.0–1.4)	1.2 (1.0–1.5)
	18–40	877	43	1.3 (1.1–1.6)	1.3 (1.0–1.6)*
Municipality	Rural	1243	48	1	1
	Urban	1162	45	1.1 (1.0–1.3)	1.1 (1.0–1.3)
Children living at home	Yes	1043	49	1	1
	No	1362	45	1.2 (1.0–1.4)	1.2 (1.0–1.4)
Civil status	Married/cohabiting	1750	48	1	1
	Single	655	43	1.2 (1.0–1.5)*	1.0 (0.8–1.2)
Homeowner	Yes	1734	48	1	1
	No	671	42	1.3 (1.1–1.6)	1.3 (1.0–1.6)*
Education	Higher education	394	54	1	1
	High school	110	47	1.3 (0.8–2.0)	1.1 (0.7–1.6)
	Vocational school	1034	45	1.4 (1.1–1.8)	1.3 (1.0–1.7)*
	Primary school	867	46	1.4 (1.1–1.4)	1.3 (0.9–1.5)
Employment	High skills/managers	425	51	1	1
	Self-employed	176	39	1.6 (1.1–2.3)	1.5 (0.9–2.3)
	Basic skilled worker	959	50	1.1 (0.8–1.3)	0.9 (0.7–1.2)
	Unskilled worker	527	43	1.4 (1.1–1.8)	1.2 (0.9–1.6)
	Without a job	318	41	1.5 (1.1–2.1)	1.2 (0.8–1.7)
Weekly working hours	≥30 hours	1964	48	1	1
	<30 hours	129	42	1.3 (0.9–1.8)	1.2 (0.8–1.8)
Annually gross income	Unemployed	312	40	1.4 (1.1–1.7)	1.3 (1.0–1.7)
	≥300.000 DKK	452	50	1	1
	250.000–299.999 DKK	456	49	1.0 (0.8–1.4)	1.1 (0.8–1.4)
	200.000–249.999 DKK	645	49	1.0 (0.8–1.3)	1.1 (0.8–1.4)
Social transfer income	<200.000 DKK	852	42	1.4 (1.1–1.7)	1.3 (1.0–1.7)*
	No	285	47	1	1
	Yes	2120	47	1.0 (0.8–1.3)	1.0 (0.7–1.2)

**Notes:** <sup>a</sup>Adjusted for all variables in the table and for somatic and psychiatric diseases and use of psychoactive drugs in the year before the sickness absence period; \* $P < 0.05$ .

**Abbreviations:** CI, confidence interval; OR, odds ratio.

Predictors of nonparticipation were estimated using logistic regression analyses. In the first analysis, crude odds ratios were estimated for all covariates listed in Tables 1 and 2. This was followed by an adjusted analysis in which all variables were mutually adjusted. In an earlier version, we carried out the adjusted analysis in two steps. First, we adjusted for all variables except somatic and psychiatric diseases and use of psychoactive drugs, which were then added in a final model to examine any independent association between diseases and nonparticipation. Because the results of the two models were almost identical, we decided to present only the fully adjusted model.

In order to examine the impact of psychiatric diseases on nonparticipation, we identified whether an individual had been affected by a psychiatric disorder prior to the index sickness absence. Psychiatric diseases were identified for two separate periods of time: (1) in the year before the index

sickness absence period; and (2) in the preceding 1–5 years before (not including the first year). This led to the following four categories: (1) no psychiatric disease, representing individuals with neither a psychiatric disease in the year before nor 1–5 years before the index sickness absence; (2) psychiatric disease in the past, representing individuals with a psychiatric disease 1–5 years before sickness absence but not in the year before; (3) recent psychiatric disease, representing individuals with psychiatric disease in the year before sickness absence but not in the preceding 1–5 years; and (4) psychiatric disease, both recent and in the past, representing individuals with a psychiatric disease in both periods. Logistic regression was applied to compare the risk of nonparticipation in these categories with “no psychiatric disease.” We controlled for confounders as described above.

All point estimates are presented with 95% confidence intervals (95% CI) and a  $P$ -value (two-sided)  $< 0.05$  was

**Table 2** Nonparticipation according to diseases in the year before sickness absence and during the 8 weeks of sickness absence

Variable	Level	1 year before sickness absence				The 8-week sickness absence period			
		N	Participation %	OR <sub>crude</sub> (CI)	OR <sub>adj</sub> <sup>a</sup> (CI)	N	Participation %	OR <sub>crude</sub> (CI)	OR <sub>adj</sub> <sup>b</sup> (CI)
Somatic disease	No	1610	45	1	1	1887	47	1	1
	Yes	795	51	0.8 (0.7–0.9)	0.8 (0.7–1.0)*	518	46	1.0 (0.8–1.2)	1.0 (0.8–1.2)
Psychiatric disease	No	2355	48	1	1	2344	49	1	1
	Yes	50	47	0.9 (0.5–1.7)	0.8 (0.5–1.5)	61	47	0.9 (0.5–1.5)	0.8 (0.5–1.3)
Psychoactive drugs	No	1817	46	1	1	1790	46	1	1
	Yes	588	49	0.9 (0.7–1.0)	0.9 (0.7–1.1)	615	49	0.9 (0.7–1.0)	0.9 (0.8–1.1)

**Notes:** <sup>a</sup>Adjusted for all variables in Table 1 and for somatic and psychiatric diseases and use of psychoactive drugs in the year before the sickness absence period; <sup>b</sup>adjusted for all variables in Table 1 and for somatic and psychiatric diseases and use of psychoactive drugs in the 8-week sickness absence period; \* $P < 0.05$ .

**Abbreviations:** CI, confidence interval; OR, odds ratio.

considered statistically significant. We used STATA 11.0 IC (Stata Corp, College Station, TX) for all statistical analyses.

## Results

### Predictors for nonparticipation

The overall nonparticipation rate in the present study was 53.4% (95% CI: 51.4–55.4). The lowest participation was found among self-employed and the highest was among individuals with higher education (Table 1).

Unadjusted odds ratios showed that nonparticipation was associated with being male, relatively young, single, not a house owner, with a vocational secondary education or primary school background, being self-employed, an unskilled worker or unemployed, and having a low income. When all variables were mutually adjusted, nonparticipation remained related to being male, relatively young, not a house owner, with a vocational education, and with a low income.

Individuals with somatic disease leading to hospital contact during the year before the sickness absence period participated to a significantly higher degree than individuals without somatic disease (Table 2). No difference in participation related to somatic disease was found for the eight weeks of the sickness absence period. Individuals with a psychiatric disease or using psychoactive drugs generally participated more often than other individuals at both periods of time. In contrast, individuals with a psychiatric disease 0–5 years before the index sickness period generally participated less than individuals without a psychiatric disease (OR: 1.2; 95% CI: 0.8–1.8) (results not shown).

### Psychiatric disease and risk of nonparticipation

Individuals with prior psychiatric disease 1–5 years before sickness absence, but not <1 year before, had twice the rate of nonparticipation compared to individuals with no disease

at any of these points in time (Table 3). When adjustment for all other variables was carried out, this association was reduced only marginally. It is worth mentioning that individuals with psychiatric disease in both periods had a lower risk of nonparticipation than individuals with no disease at any point in time. No excess risk of nonparticipation was found among individuals with a psychiatric disease in the year before sickness absence.

## Discussion

### Nonparticipants

We found that nonparticipation was more common in those with no or short education or with low income. Furthermore, nonparticipants were younger and more often male than female. These characteristics have also been associated with greater levels of nonparticipation in previous studies, as participation rates are typically markedly higher among individuals with higher education and income<sup>3–8,18–22</sup> and among employed individuals.<sup>5,6,19–23</sup> Furthermore, women tend to participate more frequently in studies than men.<sup>3,5,7,18,22</sup> Previous findings regarding age are inconsistent: some studies have documented that elderly people are

**Table 3** Risk of nonparticipation according to recent and past psychiatric disease

Variable	N	OR <sub>crude</sub> (CI)	OR <sub>adj</sub> <sup>a</sup> (CI)
No psychiatric disease	2294	1	1
Psychiatric disease in the past	52	2.0 (1.1–3.6)	1.8 (1.0–3.3)
Recent psychiatric disease	34	1.1 (0.5–2.5)	1.1 (0.5–2.4)
Psychiatric disease, both recent and in the past	25	0.7 (0.4–1.4)	0.7 (0.3–1.4)

**Notes:** <sup>a</sup>Adjusted for all variables in Table 1 and for somatic disease and use of psychoactive drugs in the year before the sickness absence period. No psychiatric disease: no psychiatric disease in the year before sickness absence or in the preceding 1–5 years. Psychiatric disease in the past: psychiatric disease 1–5 years before sickness absence, but not in the year before. Recent psychiatric disease: psychiatric disease in the year before sickness absence, but not in the preceding 1–5 years. Psychiatric disease, both recent and in the past: psychiatric disease in both periods.

more likely to participate,<sup>3,4,18,22</sup> while other studies have found higher participation rates among relatively young individuals.<sup>7,23</sup>

## Prior psychiatric disease – a strong predictor of nonparticipation

The strongest predictor of nonparticipation was found to be individuals who had a psychiatric disease in the past. These individuals were significantly less likely to participate than individuals with a psychiatric disease at the time of the study. This is consistent with a review that found that potential participants in epidemiologic studies are generally more likely to take part in studies that are concerned with an issue of particular relevance to their lives.<sup>5</sup> Since mental disorders were the primary focus of the present study, participation may pose a particular challenge for individuals with prior psychiatric disease. A mental disorder often creates a difficult emotional period; participation in the original study could remind patients of their prior condition, which may result in refusal to participate.

Other studies have found that healthy individuals are more likely to participate<sup>24</sup> and that psychiatric disease<sup>3,8,18,19,25</sup> and use of psychoactive drugs are associated with nonparticipation.<sup>7,26</sup> Previous studies examining psychopathology and nonparticipation have not categorized psychiatric diseases as actual and prior, but found that individuals with psychiatric disease generally participated less actively than those without psychiatric disease.<sup>3,8,18,19,25</sup> In the present study, we observed the same tendency when comparing individuals with any mental disease in the full 5-year period before sickness absence with those without. Thus, consistent findings show that individuals with a history of psychiatric disease participate less frequently in research studies than those without a disease. Nonparticipation among eligible individuals with psychiatric disease may be affected by symptoms from their disorder, such as phobia, passivity, and an antisocial personality.<sup>19,25</sup>

## Participation rate

In the present study, the participation rate was 46.4%. Similar studies involving postal questionnaires to collect information from individuals on long-term sickness absence have shown response rates between 69% and 81%.<sup>27,28</sup> Our questionnaires were sent from a psychiatric department, which may have influenced the participation rate in a negative manner. Psychiatry remains connected with taboo and stigma, and individuals are often not inclined to take part in studies which do not concern them;<sup>5</sup> for example, some eligible

participants indicated they were absent from work due to a somatic disease.

To increase the participation rate in this type of research, face-to-face recruitment may be an option. A personal interview carried out by a social worker at the job center may help the sick-listed individuals to provide necessary information, but this method is also more time-consuming. Alternatively, questionnaires could be handed to the sick-listed individuals after consultation at the job center.

Nonparticipation is influenced by individuals who cannot be located, who refuse to participate, and who are incapable due to mortality or morbidity. Psychopathology has been found to be associated with all three types of attrition.<sup>18,25</sup> In our study, we posted a questionnaire to each participant's newly stated address shortly after the eligible subject had been sick-listed. Thus, the likelihood of nonparticipation related to mortality or failure to locate was small. Nonparticipation due to morbidity was plausible, since individuals in the study were all sick-listed. Additionally, nonparticipation due to refusal was plausible, since the psychiatric topic may be controversial.

## Strengths and limitations

This is the first report examining nonparticipation in studies of long-term sickness absence. In the present study, all individuals from the original study were identified from registers and included in the analyses, except for nine individuals. We included a wide range of information from national registers to describe both participants and non-participants. The information was reported to registers before the sickness absence period and was not affected by whether the individuals chose to participate in the study. Furthermore, all analyses have been adjusted for potential confounders.

Our study has some limitations. Information regarding psychiatric diagnoses came from hospitals, where they were given to patients upon admission, or when visiting emergency rooms and outpatient clinics. In Denmark, only a small number of individuals with psychiatric disorders are seen in hospitals since individuals with minor psychiatric disorders are treated by a general practitioner or in private practice by a specialist in psychiatry. Thus, it is very likely that individuals registered with a mental disorder in this study are more severely ill than the average psychiatric patient. According to the World Health Organization, 24% of all individuals contacting their general practitioner suffer from mental disorders,<sup>29</sup> and previous findings indicate that nearly half of individuals on long-term sickness absence have an unrecognized mental disorder.<sup>2</sup>

Additionally, according to the present study, the number of people taking psychoactive drugs is ten times higher than the number of those with a psychiatric disease. This may all contribute to underestimation of psychiatric disease in the present study. We did not differentiate between types of psychiatric disease or severity since subgroups would have been too small. Somatic disease was also based on hospital records and may have been affected by underestimation. While we clearly admit that we only have identified severe illness, this may also be seen as a benefit; individuals more prone to participate in a study may also be more prone to contact their general practitioner with symptoms of minor psychiatric disorders, while non-participants with the same symptoms may stay undiagnosed more often. This could lead to an incorrect association between participation and disease. Restricting the definition of psychiatric disease to the most severe diagnoses will limit this problem.

Our results are of interest to studies examining individuals with long-term sickness absence in other Western European countries with the same level of social welfare as in Denmark. The results cannot be generalized to low-income countries or to countries in which sick-listed individuals do not receive sickness benefits.

## Conclusion

Individuals with low socioeconomic status were less willing to participate in this Danish study of long-term sickness absence; the same was true for individuals with previous mental disease. These findings are important when planning studies to examine long-term sickness absence. Since individuals most reluctant to participate may also be those to benefit most from intervention to help regain full work capacity, specific strategies to include these individuals are justified.

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## Disclosure

The authors report no conflicts of interest in this work.

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