

# Labour participation of the chronically ill

## A profile sketch

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**Background:** To improve our understanding of the problematic labour market position of people with a chronic disease, this paper describes the participation rates of several subgroups of the chronically ill in the Netherlands, as well as the aspects by which the working chronically ill differ from those who are fully work-disabled and from those who are not working for other reasons. **Methods:** Data for this study are derived from the Panel of Patients with Chronic Diseases, a nationwide study in the Netherlands. The results discussed here relate to data collected in 1998 from a representative sample of 1266 people aged 15–64 with various chronic somatic diseases. The factors taken into account include medical diagnosis, disease duration, episodic occurrence and frequency of symptoms, pain, fatigue, functional disabilities with respect to motor control, somatic autonomy and cognitive autonomy, as well as the covariates gender, age and education. **Conclusion:** Labour market position is primarily related to health problems that can be considered common consequences of a chronic illness, while no independent effect of specific disease diagnosis was observed. In comparison with fully work-disabled people, those who are employed experience less pain and fatigue and encounter fewer problems in motor control and cognitive functioning (besides being younger and more highly educated). The main factor besides gender, age and education, distinguishing employed from non-employed involves problems with motor control.

**Keywords:** chronically ill, employment status, the Netherlands

Having a chronic disease often negatively affects the capacity to participate in gainful employment. A poor health condition, however, does not necessarily imply exclusion from the labour market. Yet, the chronically ill seem to have more difficulties in finding and keeping a job.<sup>1–3</sup> In various studies, the participation rates of chronically ill people are found to be much lower than those of healthy people.<sup>4–6</sup> This situation is increasingly regarded as undesirable, not only in the Netherlands, but in other western countries as well.<sup>7–11</sup>

Previous studies on this topic have focused on single diseases (e.g. multiple sclerosis,<sup>5</sup> asthma,<sup>12</sup> arthritis,<sup>6</sup> epilepsy,<sup>13</sup> diabetes,<sup>14</sup> or musculo-skeletal conditions<sup>15</sup>), or have used a subjective self-report measure of having a chronic disease or ill-health.<sup>8,9,16</sup> In contrast, this study includes a variety of chronic somatic diseases, which were objectively diagnosed by a medical practitioner. Consequently, a comprehensive impression of the labour market position of the chronically ill in general can be given. This paper describes the participation rates among the chronically ill for several subgroups, as well as some job characteristics. To put the observed rates in perspective, they are compared with reference data for the general Netherlands' population as published by Statistics Netherlands.<sup>17</sup>

A question of interest is whether labour participation is a problem for the chronically ill in general, or if it is more pressing for some chronic diseases than for others. Gaining insight into this matter, may be helpful to determine whether generic or disease-specific policy measures are required to improve labour market prospects of the chronically ill, and which factors require attention in reintegration policy. To identify the factors which affect the labour market position of the chronically ill, the following research question was formulated:

- Which factors distinguish the chronically ill who are working from the ones who are not working?

As reintegration policy in the Netherlands is aimed in particular at people who are officially work-disabled, this study will make a further distinction between people who do not participate because they are fully work-disabled and those who are otherwise non-employed. The latter include housewives/men, unemployed and early-retired persons.

With respect to general characteristics of a chronic disease, several factors emerge from the literature that may affect the ability to function in paid labour. These include disease duration, the episodic nature and frequency of symptoms, pain, fatigue, and functional disabilities. Since episodic attacks of symptoms are likely to disrupt daily routines<sup>2</sup> and cause uncertainty,<sup>18</sup> it was expected that such attacks would be reported less frequently by the employed than by the work-disabled or non-employed. Similarly, pain, fatigue and functional disabilities can interfere with labour market participation.<sup>19–22</sup> It was, therefore, expected that on average employed people

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would experience less pain and fatigue, and fewer problems with somatic autonomy, motor control, and cognitive autonomy.<sup>15,23</sup>

Besides general health problems, chronically ill people may endure work-interfering impairments and disabilities that are typical of a given disease while not present in others. As it is hardly feasible to define and measure all disease-specific health problems, diagnosis will be included as a proxy variable. If a given disease has specific symptoms that interfere with labour participation besides the general symptoms mentioned above, this will be reflected as an independent effect of the diagnosis variable.

An additional aspect to consider here is the possible distorting effect of a person's sociodemographic background. After all, sociodemographic characteristics have been found to be related both to labour market opportunities<sup>8,25</sup> and to health status.<sup>9,10,25–27</sup> In the analyses, the background variables of gender, age and educational level will therefore be included as covariates.

## DATA AND METHODS

### *Data and study population*

Data were derived from the Panel of Patients with Chronic Diseases (PPCD), a nationwide study in the Netherlands, which covered the period 1998–2000. From the files of a random sample of 56 general practices, 2992 potential respondents of 15 years and older, who were diagnosed as having a chronic somatic disease, were recruited and agreed to participate in the panel. In the Netherlands, practically all inhabitants ( $n=15,620,000$ <sup>17</sup>) are registered at a general practice (7093 practitioners, on average 2212 patients per practitioner<sup>28</sup>). Pre-analysis of respondents and non-respondents revealed that the two groups did not differ with respect to diagnosis, illness duration, comorbidity, or health status as reported by the general practitioner.<sup>29</sup> A total of 2487 respondents (83%) returned the first questionnaire of April 1998. The sample of 56 practices appeared to differ slightly from the total population of practices with respect to urbanization level and region of their place of residence. In order to bring the distribution of the sample in accordance with that of the population, a weighting factor was applied, so that the findings below can be considered representative of the Netherlands' population of chronically ill.

Twice a year, participants fill out extensive postal questionnaires. The findings in this study are based on the first two rounds of data collected in 1998. For the purpose of this study, only respondents belonging to the potential working population (that is, people aged between 15 and 64 years,<sup>30</sup>  $n=1481$ ) were included. Of these, a total of 1351 returned the second questionnaire, which contains crucial information on the labour market position (91.2%; weighted numbers). Because some data were missing for the question about having a paid job and the number of working hours, 1266 respondents could be classified as either employed, fully work-disabled or non-employed.

Data published by Statistics Netherlands<sup>17</sup> have been used as reference data with regard to labour participation of the general population.

### *Concepts and operationalization*

In accordance with the definition of Statistics Netherlands,<sup>30</sup> labour market participation is defined as having a paid job for at least twelve hours per week. In the sample, 571 respondents met this definition. Classification of the fully work-disabled was based on whether benefit was received for 80–100% disablement in accordance with the Netherlands Disability Act ( $n=237$ ). The remaining group of individuals not participating in the labour market ( $n=458$ ) consisted of people who were unemployed, had retired early, kept house, or were enrolled in education. They are referred to as the non-employed.

The background variables included in this study are gender, age, and educational level. Bearing in mind that most individuals under the age of 24 are still enrolled in education, and that after the age of 45 people start leaving the labour force for early retirement, age was classified into three categories: 15–24, 25–44, 45–64. Educational level reflected the highest level of education ever completed and was divided into five categories: primary education; lower secondary and lower vocational education; intermediate secondary and intermediate vocational education; higher vocational education and university. The coding of these background variables matches that used by Statistics Netherlands, so comparison with their reference data for the general population is possible. Disease diagnosis has been classified according to the official codes of the International Classification of Primary Care (ICPC).<sup>31</sup> In the case of comorbidity, the disease first diagnosed was used as the index disease.<sup>32</sup> In the following analyses several ICPC categories have been merged, resulting in a classification of eight diagnostic categories. Several rare diseases have been combined in the category of 'other diseases'. Duration since diagnosis was classified into five categories to distinguish short-term (1–2, 3–5 years); mid-term (6–10 years); and long-term (11–20, >20 years) disease experience. Respondents were asked whether their disease was characterized by an episodic occurrence of symptoms and, if so, how regularly these attacks occurred. In addition, two items measuring pain and fatigue levels as perceived by the respondent were used. Response categories ranged from 'not at all' through 'to some extent' to 'to a large extent'. Functional disabilities were assessed by a shortened version of the Sickness Impact Profile.<sup>33</sup> In this study, three scales of the SIP68 considered relevant for labour market participation were included: somatic autonomy (17 items); motor control (12 items); and cognitive autonomy and communication (11 items). A large proportion of respondents reported no disabilities on these scales, so the variables were dichotomized (no disabilities versus one or more disabilities). In order to compare the impact of disabilities among the chronically ill with reference data for the general population, the long-term indicator for physical disabilities that is employed in the General Health Survey of Statistics

Netherlands<sup>17</sup> was used, i.e. the one developed by the Organisation of Economic Cooperation and Development (OECD-indicator).

#### Analysis

The labour participation rate among the chronically ill was assessed by dividing the number of working chronically ill by the total number of chronically ill in the sample. To generate profiles of the employed, the fully work-disabled and the non-employed, the distribution of the independent variables among the three groups was compared. The chi-square statistic was used to test differences between the groups. The significant differences between groups 1 and 2, 1 and 3, and 2 and 3 are indicated in the tables by *a*, *b* and *c* respectively. In addition to studying the univariate effects of the independent variables, multivariate logistic regression analysis was performed. Logistic regression facilitates the identification of the probability of falling into either of two categories. In this way, a multivariate characterization of the groups can be attained. Only the variables found to have a significant effect through the bivariate analyses were included. By opting for a forward stepwise method, the most important predictors were selected. Separate analyses were performed to identify the predictors of being employed versus work-disabled and of being employed versus non-employed.

## RESULTS

Of the chronically ill in the Netherlands, 45% are engaged in paid labour. Participation rates (*table 1*) for men are higher than those for women, smaller for persons older than 45 years than for the 25–44 year-olds, and higher with increasing educational level. As the physical disabilities are more serious, participation rates also appear to be lower.

Basically, the reference data for the general population reflect similar patterns. Yet, in comparison to the chronically ill, the proportion of employed people among the general population is significantly higher. This is the case for practically all subgroups studied here: within each category of social background or disability level the chronically ill are in a relatively disadvantaged position with respect to labour participation. In other words, besides disabilities there are additional factors leading to a disadvantaged position for the chronically ill.

Almost 80% of the working chronically ill have stable labour contracts, 8% have temporary jobs and 12% are self-employed. This is similar to the situation for the general population. More than half of the employed chronically ill (59.6%) work full-time. In comparison with the proportion working full-time in the general population (71.1%), this proportion is significantly smaller ( $p < 0.001$ ).

Notwithstanding the relatively low participation rate among chronically ill, a number of people with a chronic disease are regularly employed. We will now deal with the question in what respects employed chronically ill people differ from the work-disabled and from the non-employed chronically ill, respectively.

To start with the background variables, *table 2* shows that, compared to the employed group, women are only over-represented in the non-employed group, and not in the work-disabled group. In addition, the employed were significantly younger than the work-disabled and the non-employed, and their educational level was significantly higher.

The results in *table 3* show whether differentiation in labour market position can be attributed to disease characteristics and/or consequences of the disease. When comparing the employed with the fully work-disabled, a significant effect was observed for disease diagnosis, episodic occurrence and frequency of symptoms, pain, fatigue and functional disabilities owing to somatic problems, motor control problems and cognitive problems. Among the work-disabled, the proportion of people with a cardiovascular disease or locomotor disease was considerably higher, whereas the proportion of

**Table 1** Net labour market participation rate (working  $\geq 12$  hours per week) in the population of chronically ill versus general Netherlands population (in %; 95%-confidence intervals in brackets)

	PPCD 1998 N=1481		Reference data: general population 1997 <sup>a</sup>
All	45.1	(42.6–47.6)	60.1
Gender			
Male	53.4	(49.2–57.5)	73.0
Female	38.7	(35.0–42.2)	46.8
Age (years)			
15–24	39.1	(27.6–50.6)	40.8
25–44	62.9	(58.2–67.4)	74.7
45–64	35.9	(32.5–39.9)	50.3
Educational level			
Primary	15.3	(8.8–21.7)	27.6
Lower secondary + vocational	37.4	(33.3–41.5)	41.5
Intermediate secondary + vocational	57.8	(52.5–63.0)	63.1
Higher vocational	57.4	(49.8–65.0)	69.2
University	75.4	(64.3–86.6)	84.8
Physical disabilities <sup>b</sup>			
No physical disabilities	62.2	(58.3–66.1)	73.0
Some physical disabilities	41.4	(35.9–47.0)	58.0
Serious physical disabilities	29.2	(22.2–36.0)	44.0
Complete physical disabilities	21.3	(14.8–30.0)	28.0

PPCD: Panel of Patients with Chronic Diseases

a: Based on data from Statistics Netherlands<sup>34</sup> and data on Internet site www.cbs.nl

b: Students excluded

**Table 2** Comparison of background characteristics of employed, fully work-disabled, and not-employed people with a chronic disease (%)

	Employed n=571 <i>a</i>	Fully work-disabled n=237 <i>b</i>	Not-employed n=458 <i>c</i>	Significance
Gender				
Male	51.5	45.1	32.6	<i>b, c</i>
Female	48.5	54.9	67.4	
Age (years)				
15–24	4.7	0.8	8.7	<i>a, b, c</i>
25–44	46.8	20.3	23.8	
45–64	48.7	78.9	67.5	
Educational level				
Primary	3.3	15.1	15.1	<i>a, b</i>
Lower secondary + vocational	35.9	56.0	47.7	
Intermediate secondary + vocational	35.9	14.7	25.7	
Higher vocational	17.0	11.9	9.6	
University	7.8	2.3	1.8	

The indication *a* in the last column of the table denotes that the distribution in column *a* differs significantly from the distribution in column *b*, *b* indicates that *a* differs from *c*, and *c* indicates that *b* differs from *c* ( $p < 0.01$ ).

**Table 3** Comparison of disease characteristics of employed, fully work-disabled, and not-employed people with a chronic disease (%)

	Employed <i>a</i>	Fully work-disabled <i>b</i>	Not-employed <i>c</i>	Significance
Disease				
Cardiovascular disease	5.3	10.6	9.4	<i>a</i>
Chronic nonspecific lung diseases	21.2	13.6	17.9	
Locomotor disease	11.9	23.7	14.4	
Cancer	4.4	3.8	6.6	
Diabetes mellitus	10.2	8.9	11.6	
Neurological disease	8.2	10.2	9.6	
Digestive disorder	3.7	3.8	3.1	
Other	35.2	25.4	27.5	
Duration since onset of disease (years)				
1–2	17.1	9.2	18.2	<i>c</i>
3–5	23.0	18.0	24.4	
6–10	24.9	29.4	27.3	
11–20	23.4	29.8	21.7	
≥21	11.6	13.6	8.3	
Episodic occurrence of symptoms				
No	45.0	38.2	47.7	<i>a, c</i>
Daily—several times a week	14.4	32.0	13.5	
Once a week—several times a month	15.4	13.6	10.8	
Once a month—several times a year	19.5	12.0	18.6	
Once a year	5.8	4.2	5.4	
Pain				
Not at all	57.1	23.7	48.0	<i>a, b, c</i>
To some extent	33.0	37.3	35.3	
To a major extent	9.9	39.0	16.7	
Fatigue				
Not at all	31.3	7.6	26.3	<i>a, c</i>
To some extent	51.7	44.1	50.2	
To a major extent	17.0	48.3	23.5	
Functional disabilities				
Having somatic problems	10.5	29.4	10.3	<i>a, c</i>
Having motor control problems	23.1	70.0	36.0	<i>a, b, c</i>
Having cognitive problems	17.3	41.1	19.9	<i>a, c</i>

The indication *a* in the last column of the table denotes that the distribution in column *a* differs significantly from the distribution in column *b*, *b* indicates that *a* differs from *c*, and *c* indicates that *b* differs from *c* ( $p < 0.01$ ).

patients with chronic nonspecific lung diseases was significantly lower than among the employed. People whose disease fell into the 'other diseases' category were overrepresented in the employed group. The proportion experiencing episodic occurrence of disease symptoms was significantly higher among the work-disabled than among the employed; furthermore, their symptoms occurred more frequently. Among the work-disabled people, the proportion experiencing more pain and more fatigue was higher than among the working chronically ill. Also, the proportion of people experiencing problems in motor control, cognitive functioning and, to a lesser extent, in somatic autonomy appeared to be significantly higher within the work-disabled group than within the working group.

When comparing the employed with the non-employed, the data show a significant effect for pain and motor control problems. In comparison with the non-employed, the proportion of employed people suffering from some or extreme pain or having problems with motor control was significantly lower.

Multivariate logistic regression analyses were performed to ascertain the relative importance of the significant independent variables discussed above. Only variables that were found to have a significant bivariate effect were included in the analyses. The results in the first column of *table 4* show that the status of being employed versus work-disabled is significantly predicted by younger age, higher educational level, less pain, less fatigue, less problems with motor control and less cognitive problems. When the effect of these predictors is taken into account, the independent effects of disease diagnosis, episodic

occurrence of symptoms, and problems with somatic autonomy found previously are no longer observed. In accounting for employment versus non-employment (second column), being male, middle aged, higher educated and not experiencing motor control problems are significant predictors. When controlling for these factors, type of disease diagnosis and pain no longer add to the explanation of being employed or not.

## DISCUSSION

In this study, the labour participation of the chronically ill was examined. We have seen that in 1998 45% of the chronically ill in the Netherlands were involved in paid labour. This proportion is significantly lower than the 60% that is reported for the general Dutch population, indicating that the chronically ill share a relatively disadvantaged position on the labour market. When controlling for the impact of physical disabilities, the participation rates among the chronically ill still lag behind those among the general population with comparable physical disabilities. Apparently, there are additional factors affecting the labour market opportunities of the chronically ill.

By sketching a profile of the working chronically ill as opposed to the non-working, this study has contributed to the specification of the factors associated positively or negatively with labour participation. The further distinction between the fully work-disabled and otherwise inactive people – among which there are many people who are not oriented towards the labour market – proved to be a useful one, adding to a better understanding of the

**Table 4** Logistic regression predicting work-disablement versus employment (column 1) and not-employment versus employment (column 2) among the chronically ill

Work-disabled vs employed		Not-employed vs employed	
	B-coefficient		B-coefficient
Age (years)		Gender	
15–24 (ref.category)	0.00	Male (ref.category)	0.00
25–44	-1.05	Female	-1.02 **
45–64	-1.93 *	Age (years)	
Educational level		15–24 (ref.category)	0.00
Primary	-2.73 **	25–44	1.17 **
Lower secondary + vocational	-1.65 **	45–64	0.04
Intermediate secondary + vocational	-0.47	Educational level	
Higher vocational	-1.10	Primary	-2.78 **
University (ref.category)	0.00	Lower secondary + vocational	-1.52 **
Pain		Intermediate secondary + vocational	-1.04
Not at all (ref.category)	0.00	Higher vocational	-0.79
To some extent	-0.53	University (ref.category)	0.00
To a major extent	-1.04 **	Motor control problems	-0.49 **
Fatigue			
Not at all (ref.category)	0.00		
To some extent	-0.59		
To a major extent	-1.11 **		
Motor control problems	-1.51 **		
Cognitive problems	-0.54 *		

\*  $p < 0.05$ ; \*\*  $p < 0.01$

problem of labour market exclusion, and the factors that should be addressed to promote labour reintegration.

The results showed that the presence of pain, fatigue, problems with motor control or with cognitive functioning are significant factors distinguishing working chronically ill from the work-disabled. The disabling effects of these factors are in agreement with previous studies.<sup>18,19,22,34-37</sup> However, these studies usually addressed specific diseases and focused on one particular complaint, because it was symptomatic for the disease under study. From this study it has been learned that these complaints and disease consequences affect all persons with a chronic disease, irrespective of their specific disease.

Moreover, the multivariate analyses revealed that besides these health factors no additional independent effect of disease diagnosis can be observed. The probability of being employed can be explained entirely by such common complaints as pain, fatigue and functional disabilities, and the diagnosis, or rather the unique consequences of a given disease, do not add to the identification of factors which limit the capacity to function in the labour market.

This also implies that policy measures to stimulate labour participation should not only focus on particular diseases. Instead, a generic approach, which applies to the total group of people with any kind of chronic disease, is justified. As such, these findings support the Netherlands policy objective of developing generic measures. Moreover, the fact that functional disabilities and the disabling effect of pain and fatigue are found to be important impeding factors reinforces a policy of introducing adjustments at the workplace.<sup>11,38,39</sup> Previous research has shown, however, that this intervention is not yet put into practice very often.<sup>40</sup>

A possible limitation of this study is the use of single item ratings to measure pain and fatigue. It should be stressed that we specifically aimed to obtain intensity ratings. To measure pain intensity, a single-item verbal rating scale has been found to be a valid and reliable instrument, which has the advantage that it can be easily completed in a written survey.<sup>41-43</sup> The same holds for the assessment of fatigue. Moreover, the results of this study are in line with previous studies, which sustains the reliability of the single-items used here.

Another limitation is the cross-sectional design of the study. Consequently, we can only observe in what respects the condition of working and non-working chronically ill differ at the time of the survey. Strictly speaking, this implies that one cannot really conclude that the observed determinants affect labour participation in general. One can merely say that they interfere with labour market re-entry. To verify whether the same factors as observed here are also related to the decision to leave paid employment, a longitudinal approach is more appropriate. This would provide an even more solid ground for developing policy measures, as prevention of job discontinuation appears to be more effective than enhancing work resumption.<sup>44</sup> Moreover, longitudinal

studies enable one to examine the effectiveness of work adjustments and its potential to avoid work disability among the chronically ill.

The results of this study apply to the situation in the Netherlands. In comparison to other European countries, the Netherlands have a relatively favourable disability arrangement, in which the work-disabled are entitled to disability pension for longer periods of time.<sup>44</sup> This may have consequences for the composition of the non-working group, because in other European countries this also comprises many long-term work-disabled. As a result, the health effects observed here may be less pronounced when replicating this study in other countries. Yet, as the impact of a chronic illness is not likely to vary between countries, the health factors that appear to thwart labour participation in the Netherlands, are likely to apply to the chronically ill in other countries as well.

Efforts to stimulate labour participation of the chronically ill can be counteracted by the fact that chronically ill often have to deal with discriminating preconceptions among employers.<sup>45,46</sup> This calls for additional measures to establish societal awareness that a chronic disease neither automatically nor completely undermines the capacity to work.

Moreover, reintegration measures in the Netherlands are directed at people who are officially work-disabled, thus leaving out the chronically ill who are non-employed for other reasons. However, our findings show that among the non-working chronically ill there are relatively more people with mobility problems than among the employed. Thus, the group of non-employed probably also consists, in part, of individuals whose illness is a reason for being out of work. Policy measures should therefore be extended and not focus exclusively on those who meet the criteria of labour-disability.

On the other hand, however, one should recognize that there is always a number of chronically ill, for whom labour participation is no longer feasible because of their illness,<sup>47,48</sup> and who cannot be helped by work adjustments or other integration policies. For them, the scope of policy measures should be extended to other crucial aspects of social position and participation.

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