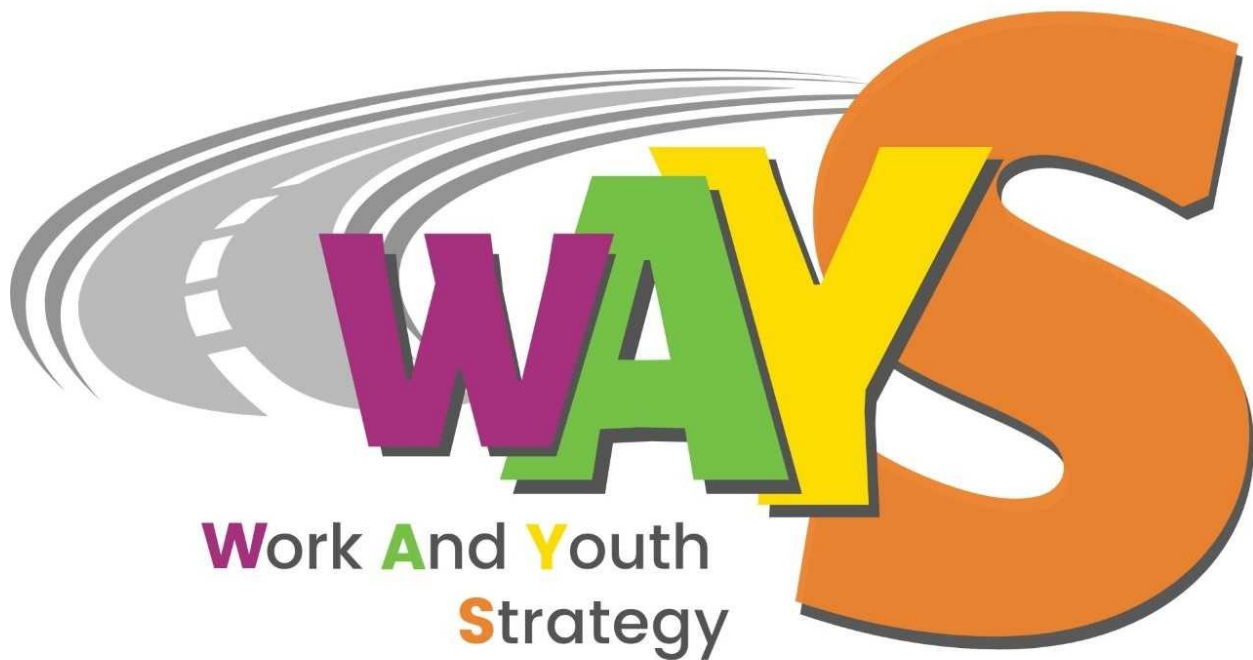




# Work And Youth Strategy

SURVEY REPORT 2020



# Contents

About us .....	3
About EPF.....	3
About EPF Youth Group .....	3
Special acknowledgements.....	3
Message from the Youth Group Presidents.....	4
Executive Summary.....	5
Introduction .....	6
Background and Objectives .....	6
Methodology.....	6
Survey results.....	7
Basic characteristics of respondents.....	7
Patient profiles of respondents .....	8
Employment profiles of respondents .....	8
Finding a job – easy or difficult? .....	9
Support in finding employment.....	11
The role of employers .....	12
Issues at the workplace.....	14
What measures can be taken?.....	15
Patients’ Rights .....	16
Analysis of results .....	17
Limitations .....	17
Key findings.....	19
Recommendations .....	20
We encourage training for managers and employers to engage in better dialogue with young employees living with chronic conditions.....	20
We call for flexible working policies .....	20
We call for more home and remote working opportunities if feasible by profession .....	20

# About us

## About EPF

[The European Patients' Forum](#) (EPF) is an umbrella organisation that works with patients' groups in public health and health advocacy across Europe. Our members represent specific chronic disease groups at EU level or are national coalitions of patients.



## About EPF Youth Group

The EPF Youth Group (YG) consists of young patient representatives aged between 15-29 years old, who have different chronic conditions and come from all over Europe. The EPF Youth Group plays an important role in implementing the EPF Youth Strategy and engaging in youth projects to share first-hand experiences, and raise awareness about the challenges young patients face in their daily lives.



## Special acknowledgements

The EPF Youth Group would like to thank the [CHRODIS+](#) project partners in Work Package 8 for their contribution to the development of the questionnaire in the WAYS project.

The following EPF Youth Group members have contributed significantly to the survey development, analysis and the writing of the report: Andreas Christodoulou, Borislava Ananieva, Ivett Jakab, Lembe Kullamaa, Louise Piersman, Magdalena Dörögrip, Martin Mastrotto, Sally Hatton, Jana Popova and Yolita Pavlova.

We would like to give special thanks to several EPF Secretariat colleagues for their helpful reviews and comments: Elena Balestra, Emily Bowles, Katie Gallagher and Lyudmil Ninov.

**Written by** EPF Youth Group 2019-2020  
**Together with** EPF Secretariat

**Contact:** [youthgroup@eu-patient.eu](mailto:youthgroup@eu-patient.eu)

# Message from the Youth Group Presidents

**Our mission is to improve young patients' lives!**

As EPF Youth Group, we raise awareness about the challenges young patients face in their daily lives and advocate for the development of policies to overcome them. Employment was one of the first topics that we recognised as essential for young patients. We started with our first initiative on employment back in 2016 when we participated at the European Youth Event in Strasbourg. We held a workshop together with young patients' representatives from the European Multiple Sclerosis Platform (EMSP) about the topic "Young Patients: Ready, Brilliant and Able to Work!"

At this event we tackled the physical and emotional symptoms of chronic conditions, together with social stigma and attitudes, which create significant barriers for young patients in the job market. With the appropriate support, young patients, like all enthusiastic young people, can be assets for employers, therefore it is essential to overcome such barriers.

The outcome of the workshop was amazing! We were approached by other young patients who wanted to share their story, so the idea for WAYS

came up. WAYS aims to gather the opinions of young patients across the EU, to voice their struggles, but also their successes when it comes to employment. With these results we will make a valuable contribution towards fostering self-awareness and self-esteem in young people that are looking for employment across Europe.

WAYS has become a strategic project of the Youth Group, the first in its kind, with three Youth Group presidents, several alumni and current Youth Group members leaving their marks on its development. As a team, we would like to express our gratitude and thanks to all the brave young people that took part in our survey. Without them our efforts would be fruitless.

**Andreas Christodoulou**

President of the EPF Youth Group (2017-2019)

**Borislava Ananieva**

President of the EPF Youth Group (2019-2020)

**Ivett Jakab**

President of the EPF Youth Group (2020-2021)



# Executive Summary

## The special situation of young patients with chronic conditions

Finding employment can be challenging for any young person, even more so if they live with a chronic condition which affects their everyday life, educational opportunities and ability to find and keep a job.

The European Patients' Forum Youth Group's Work And Youth Strategy (WAYS) project aims to provide useful insights into the experience of young patients in the field of employment.

## WAYS Survey and Objectives

An online survey was launched in December 2018 and shared broadly on EPF and EPF Youth Group platforms to form recommendations on the bases of employment-related real-life experiences from young patients.

## Key highlights

- 44% of those interviewed felt that finding a job was 'Difficult' or 'Very Difficult'
- 35% of respondents said that they would not want to disclose an 'invisible' condition under any circumstances
- 21% of young people identified prejudice against their chronic condition as a barrier to finding employment
- 81% of respondents were not aware of employment support registries available in their country of residence
- Only 5% of young people identified their wider community (outside of family and friends), as supporting them in finding employment

- Young patients reported a general perception from employers that they won't be as effective as other employees with a comparable level of education and experience, without a chronic condition.

## Recommendations

- 1. We encourage training for managers and employers to engage in better dialogue with young employees living with chronic conditions.** They should seek to understand their individual condition and circumstances, and to identify and implement together the support and adjustment they need. This should be led at all times by the experiences and expertise of the young person and not the expectations of the employer.
- 2. We call for flexible working policies such as adjusted work hours,** and opportunity to manage workload around appointments, to be applied to young employees with complex medical needs as they currently are for other circumstances, for example, childcare arrangements.
- 3. There should be greater opportunities for home and remote working made available** to young people living with a chronic condition, so that they can make a valuable contribution to the employment market without the rigorous demands of travelling to work and working within environments not adjusted to their needs.

# Introduction

## Background and Objectives

The EPF Youth Group decided to focus on the topic of employment during its Spring Meeting in 2018. We believe it is crucial to assess young patients' needs and to provide better understanding to all kind of stigma faced by young people with chronic conditions today. We believe that equal access to working opportunities and working in a tolerant environment is an essential human right ([United Nations Convention on the rights of people with disabilities \(2008\), Art 27](#)) and helps young patients' integration and inclusion in society. The main purpose of the conducted survey was to examine whether patients with chronic conditions have equal access to job opportunities and whether they have ever experienced intolerant attitudes in the working place due to their health condition.

The results of the research provided evidence on the experience of young patients in the job market. Such evidence can support stronger evidence-based advocacy and may lead to greater impact.

## Areas of focus

The survey focused on the employment status, experience in finding a job, remaining in employment, the role of institutions and support groups in the process, disclosure of chronic condition, difficulties and good practices.

## Methodology

We designed an online survey which was validated by a panel of [CHRODIS+](#) Joint Action experts from the fields of employment, patient advocacy, sociology and employment law. CHRODIS+ is a three-year project (2017-2020) funded by the European Commission and partner organisations to support member states by stepping up together and sharing best practices to alleviate the burden of chronic diseases. CHRODIS+ has a work package dedicated to Employment & Chronic diseases, with whom the EPF Youth Group collaborated in the framework of the WAYS project. The questionnaire was disseminated by email to young patients, Summer Training Course for Young Patient Advocates ([STYPA](#)) graduates, EPF membership, EPF's monthly newsletter subscribers, through the Youth Group's social media channels and the Youth Group members' organisations on European and national level. The questionnaire consisted of 37 questions with open-ended and multiple-choice answers. The online survey was released in December 2018 and ran for more than two months, allowing enough time for young patients to complete it. All recorded information was handled confidentially and will not be shared with a third party in line with the EU General Data Protection Regulation (GDPR).

The data collected in the questionnaire was stored in a protected file to ensure confidentiality and anonymity.

# Survey results

## Basic characteristics of respondents

Overall, 62 full answers were submitted and analysed. The profile of the respondents was heterogeneous when it came to their demographics. Female respondents were more prevalent in the survey (73%) and males were only round one third of all (27%) (Table 1).

The survey succeeded to gather insights from different age groups about their attitudes towards employment. The majority (76%) were in their twenties or thirties (mean: 26 years; range: 17-47 years) – appropriate age to start their career development or consider combining education and employment. There were some respondents (37%) just about to graduate school who already started thinking about employment. 19% was aged 30+ years who provided us with more experienced point of view (Table 1).

When it comes to education, there was an equal distribution of education level amongst the audience. The level of education was in accordance with the age of the respondents. The largest group was represented by young people

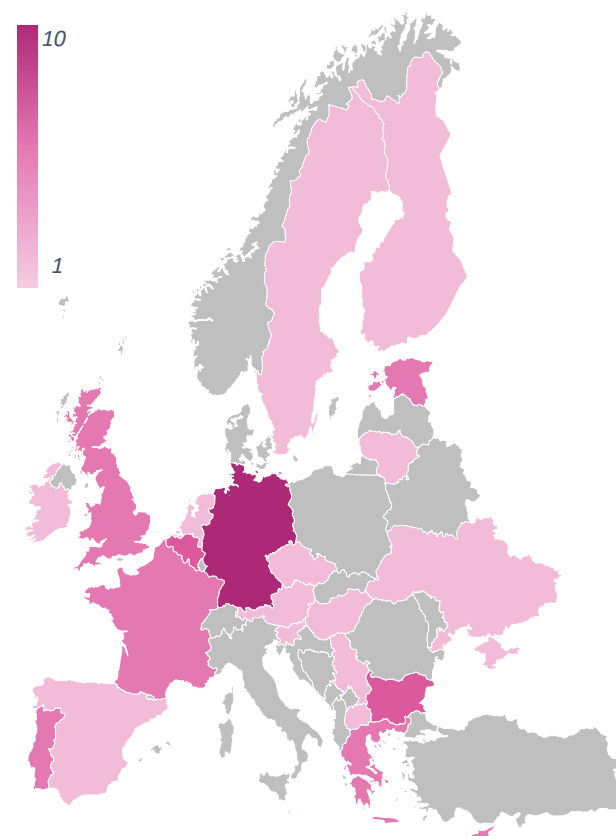
<b>Sex</b>	Female	<b>73%</b>
	Male	<b>27%</b>
<b>Age</b>	17-18 years	<b>5%</b>
	19-24 years	<b>37%</b>
	25-30 years	<b>39%</b>
	30+ years	<b>19%</b>
<b>Education (finished)</b>	Primary	<b>3%</b>
	Secondary/Upper-secondary	<b>33%</b>
	Vocational	<b>3%</b>
	Bachelor	<b>25%</b>
	Master	<b>31%</b>
	Doctoral	<b>5%</b>

Table 1: Basic demographics of respondents (n=62)

with secondary education as their highest level of education attained at the time of the survey. Two thirds of respondents (56%) had higher education, while 5% of them had a doctoral degree.

People from 21 countries all over Europe took part in the survey. Most of the respondents were living in Western Europe, but all European regions were represented. Germany was the most represented country, followed by Bulgaria, Belgium and Portugal (Figure 1).

Figure 1: Country of residence of respondents (n=62, in absolute values)





## Patient profiles of respondents

Several characteristics of the respondents were defined in the survey. One of these was the connection of the patients with patient organisations and their general involvement with the patient community issues. Around half (55%) of the respondents were affiliated with one or more patient organisations and 6% were stand-alone patient representatives (Table 2). To sum up, 61% of the respondents were advocating for patients’ needs and wellbeing in their own countries or at a European level.

**Sixty-one percent (61 %) of the participants were actively advocating for patients besides being patients themselves**

More than two thirds of the respondents (77%) considered their condition “invisible”, which gives them the opportunity to choose between disclosing it or not at their workplace or while looking for a job (Table 2).

**More than two-thirds (77%) of respondents considered their condition as ‘invisible’**

The survey also sought to identify whether respondents had received treatment outside of their country of residence. This is important as constant travel to another country for treatment

<b>Patient profile</b>	Patient	39%
	Patient and stand-alone patient representative	6%
	Patient affiliated with patient organisation(s)	55%
<b>Visibility of condition</b>	Visible	23%
	Invisible	77%
<b>Treatment location</b>	Country of residence	85%
	Other country	15%

Table 2: Patient profiles of respondents (n=62, in %)

could potentially mean missing more time from work and education. Overall, this was not the case with the respondents, As the majority (85%) receive treatment in the country where they currently live (Table 2).

## Employment profiles of respondents

The survey gathered insights on the patient perception of the employment climate in their country of residence. Thus, it was very important that both currently employed and unemployed patients (with prevalence of the employed – 61%) completed the questionnaire. Of all unemployed respondents, 80% reported not actively searching for a job for several reasons: ongoing education, maternity leave or being

**Sixty-one percent (61%) of respondents were employed at the time of completing the survey**

discouraged. These reasons are further detailed in the ‘Analysis of results’ section (page 14).

The survey focused further on the employed patients and gathered insights about their work position. It appears that around half of the respondents (45%) were employed at entry level positions and one third of the respondents occupied middle or higher-level management

<b>Employment status</b>	Employed	61%
	Unemployed	39%
<b>Searching for work (if unemployed)</b>	Yes	20%
	No	80%
<b>Position level (if employed)</b>	Entry	45%
	Middle management	26%
	Management	5%
	Other	24%

Table 3: Employment profiles of respondents (n=62, in %)

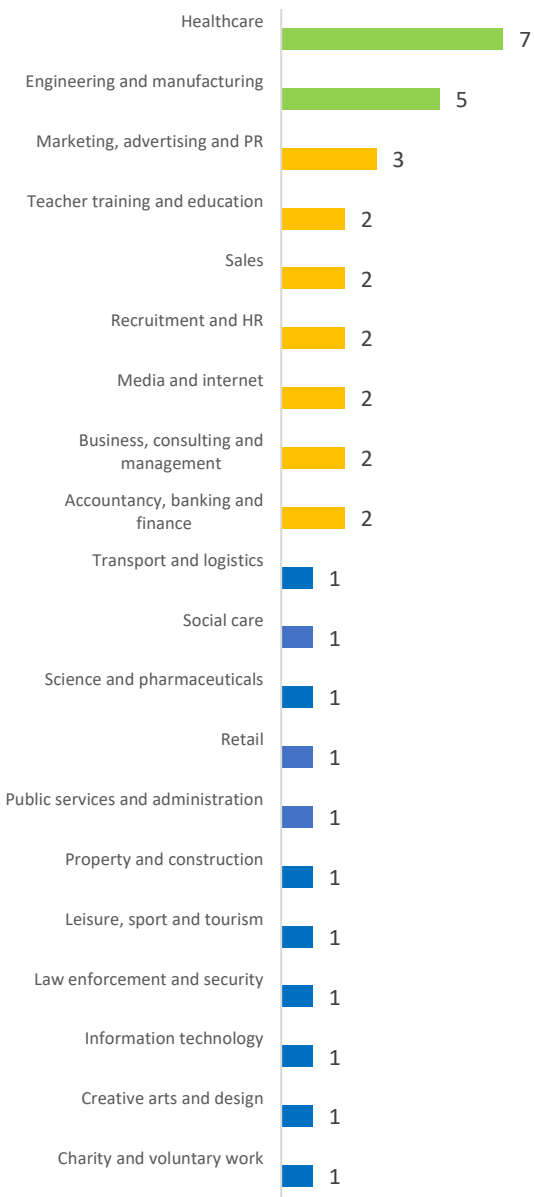
positions (31%) (Table 3).



**Almost half of the patients (45%) occupied entry level positions**

Moreover 24% could not see themselves in any of these categories.

Figure 2: Employment sector (n=38, in absolute numbers)



The survey also gathered information about the sectors of occupation. When we have a look at the sectors where the respondents were

occupied, we can see that there was quite a variety (please refer to exhaustive list of sectors and the number of patients that were occupied in them, according to patients' self-report during the survey in Figure 2).

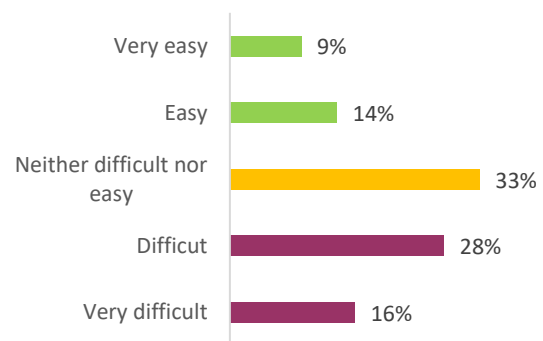
### Finding a job – easy or difficult?

In the next part we will introduce some key findings about the process of finding a job, based on patients' personal experiences.

**Nearly half of patients (44%) experienced finding a job to be difficult**

Almost half (44%) said that finding a job was "difficult" or "very difficult" and have a negative attitude about their chances of find a job, while 33% were neutral on the matter. Only 23% said that it was easy (Figure 3).

Figure 3: What is your experience with finding a job? (n=43, in %)

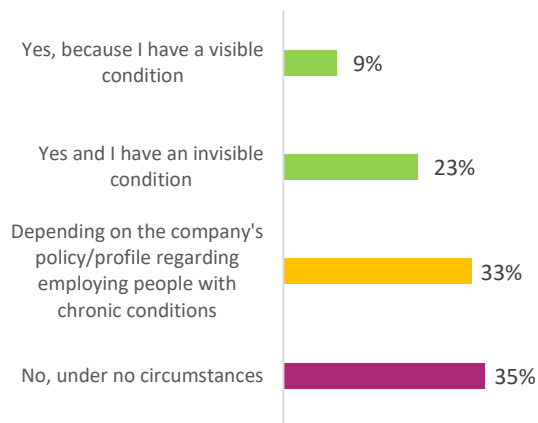


As the interview is one of the key factors of finding a job, the disclosure of chronic condition before the interview becomes a very important choice for patients. Those having a visible condition have less of a choice, 9% said they disclose their condition because of this. One third (35%) said they would not disclose under any circumstances their invisible condition (Figure 4).

**Thirty-five percent (35%) would not disclose their invisible condition before a job interview**

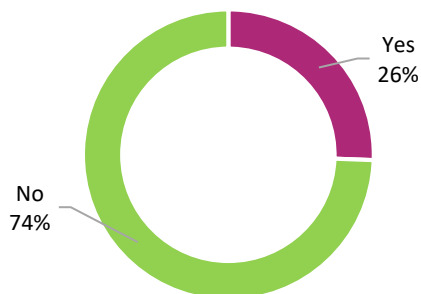
A third of respondents (33%) would consider the company's profile/policy regarding people with chronic conditions before taking the decision to disclose their condition.

Figure 4: Do you usually disclose your chronic condition before going to an interview? (n=43, in %)



Furthermore, 26% of all respondents said they felt that they have been invited to interviews with the aim to satisfy certain diversity quota/national government standards.

Figure 5: Have you experienced being invited to interviews with the aim to satisfy certain diversity quota/national government standards? (n=43, in %)



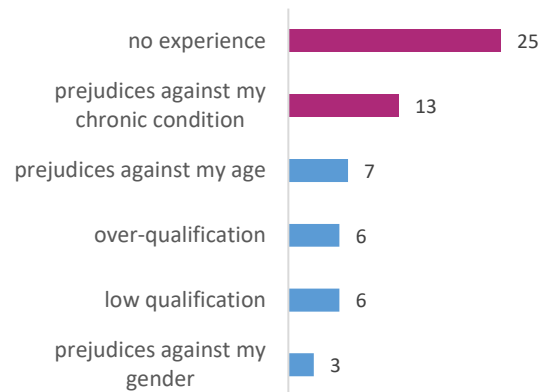
**Twenty-six percent (26%) believed they have been invited to a job interview just to satisfy a diversity quota**

When asked what it is which is difficult about finding a job, almost half of young patients (40%) felt difficulties in finding employment were due to lack of experience (Figure 6).

This aligns with the insight that young age could contribute to the struggle with employment.

**Forty percent (40%) of patients consider the lack of experience to be a reason for difficulties when finding a job in the past**

Figure 6: Reasons for struggling finding a job in the past (multiple, n=60, in absolute numbers)



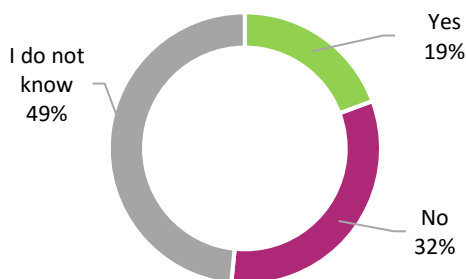
However, being a patient was also an important factor for some. 21% mentioned prejudices against their chronic condition as a reason for struggles. This was the second most frequently mentioned reason after lack of experience, which explains why some young patients would not disclose their chronic condition before a job interview. If we dive deep into other possible factors that influence why it is difficult for

patients to find a job, we should also consider the institutional framework and its role. The insights we gathered are presented in the next section.

## Support in finding employment

In the next part of the survey we asked the respondents if there was a national register to help them find employment. 32% of respondents said that there was no such option based on their knowledge (Figure 7).

Figure 7: Does your country have a national register for patient with chronic conditions and their preferences and availabilities for employment? (n=62, in %)

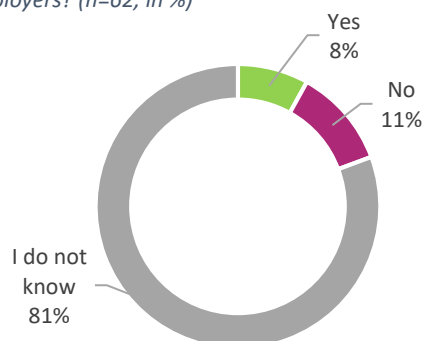


Such registers aim to connect patients and employers and allow the patients to find the most appropriate job for them, but most of the respondents (81%) would not take advantage of such as they didn't know about it or there wasn't any in their countries.

**Eighty-one percent (81%) didn't know or didn't have a national register for patients with chronic conditions**

Furthermore, 81% of the asked didn't not know whether the register was accessible for the employers in their country (Figure 8).

Figure 8: Is this register accessible to employers? (n=62, in %)

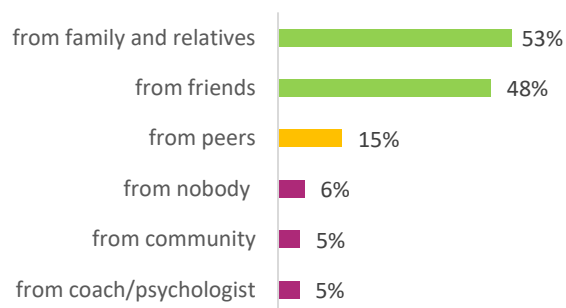


When it comes to sources of help it seems that young patients found support mostly in their close circle (53% stated family and relatives; 48% stated friends). It is interesting to note that only 5% of participants shared that their community supported young patients on the labour market (Figure 9).

**Young patients stated they found support mostly in their close circle (family, friends and relatives)**

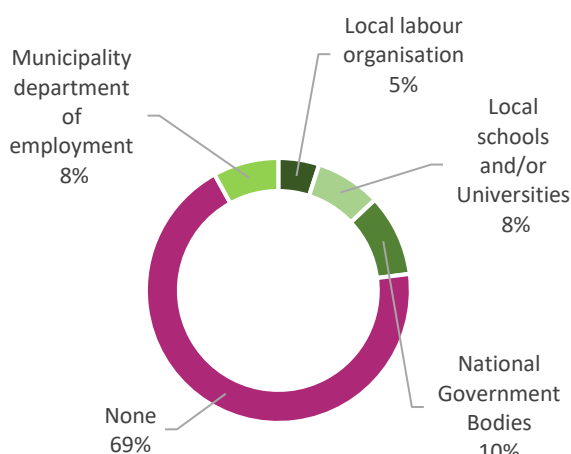
In addition, 6% of respondents felt that nobody was supporting them. Thus, we may conclude that young patients felt that the society in general was not creating an enabling environment for young patients that want to be active citizens and ensure their economic independence.

Figure 9: Are you supported and encouraged by somebody in looking for a job (multiple, n=82, in %)



If we dive deeper into the role of national institutions in helping young patients on the labour market, most of the participants did not mention them as supporting parties when finding a job. Responding to the question 69% replied that there was no institution that helped them. (Figure 10)

Figure 10: Is there any institution that supported you/helped you when looking for a job? (n=39, in %)



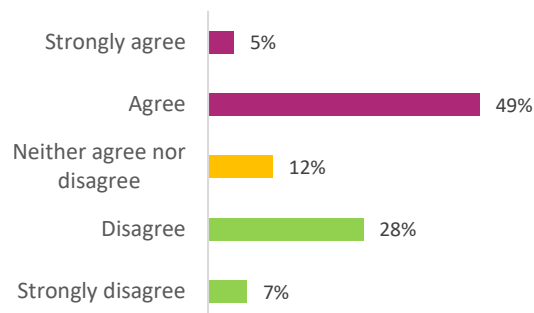
30% said that either national government bodies (10%), municipality department of employment (8%), local schools and/or universities (8%) or local labour organisation (5%) supported them in finding employment.

**Sixty-nine percent (69%) shared there was no institution that helped/supported them when looking for a job**

If we look at the wider picture and check the attitudes of the society, we will see that young patients involved in the study seemed to feel generally misunderstood when it comes to job opportunities. When directly asked 54% (23 people) agree that there are general attitudes that prevent them to work, while only 35% disagree (Figure 11).

**Fifty-four percent (54%) felt there is a misunderstanding from society which is preventing them to work**

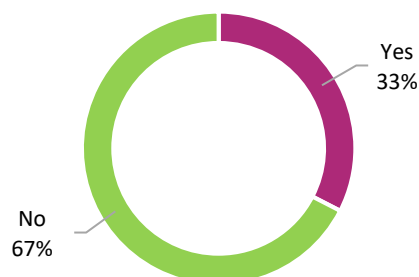
Figure 11: I am encountering misunderstandings from society which is preventing me to work (n=43, in %)



## The role of employers

Sixty-seven percent (67%) of participants reported they have not encountered any inaccurate perceptions about their abilities by employers. Still, there are some patients that admit to encountering inaccurate beliefs when it comes to their work abilities. (Figure 12).

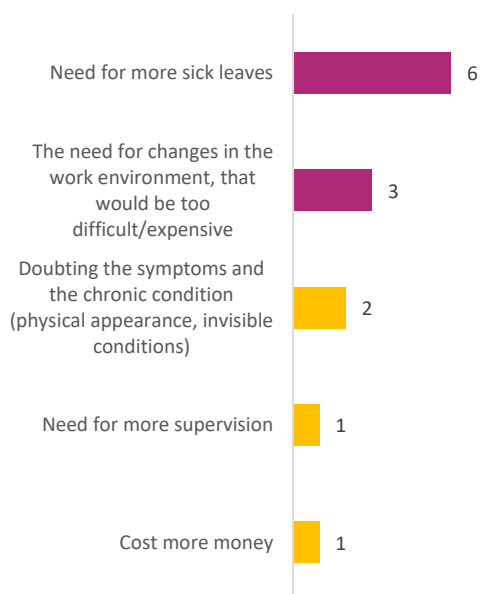
Figure 12: Do you encounter any inaccurate perceptions about your abilities by employers? (n=43, in %)



**One third of the respondents considered that employers misjudge their abilities to work**

Furthermore, we asked those, who reported inaccurate perceptions towards them, to define the perceptions and the most common (shared by almost half of those who answered, n=6) was the expectation that they would need more sick leaves (Figure 13).

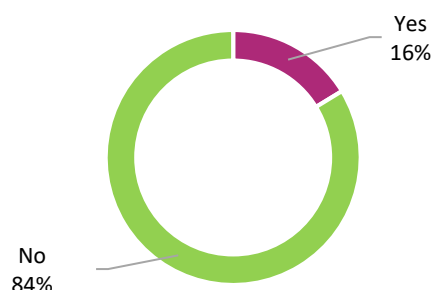
Figure 13: What inaccurate perceptions have you encountered in particular? (n=13, in absolute numbers)



We measured not only potential misperceptions towards young patients, but also whether some misperceptions could lead to discriminative practices towards them. To the question “Have you ever been downgraded to a lower position because of your condition?” most of the respondents (84%) answered negatively (Figure 14).

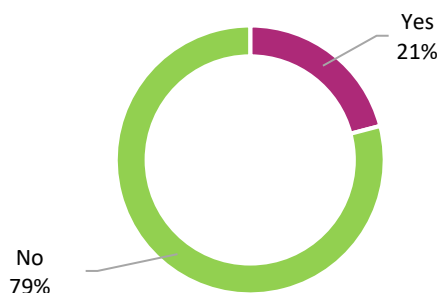
**Eighty-four percent (84%) shared not being downgraded to a lower position because of their chronic condition**

Figure 14: Have you ever been downgraded to a lower position that required no special background or skills, because of your condition? (n=43, in %)



Similar results were shown when asked whether they had ever missed a promotion because of their condition. To this question 79% answered “No”. On the other hand, 21% shared that they had such experience (Figure 15).

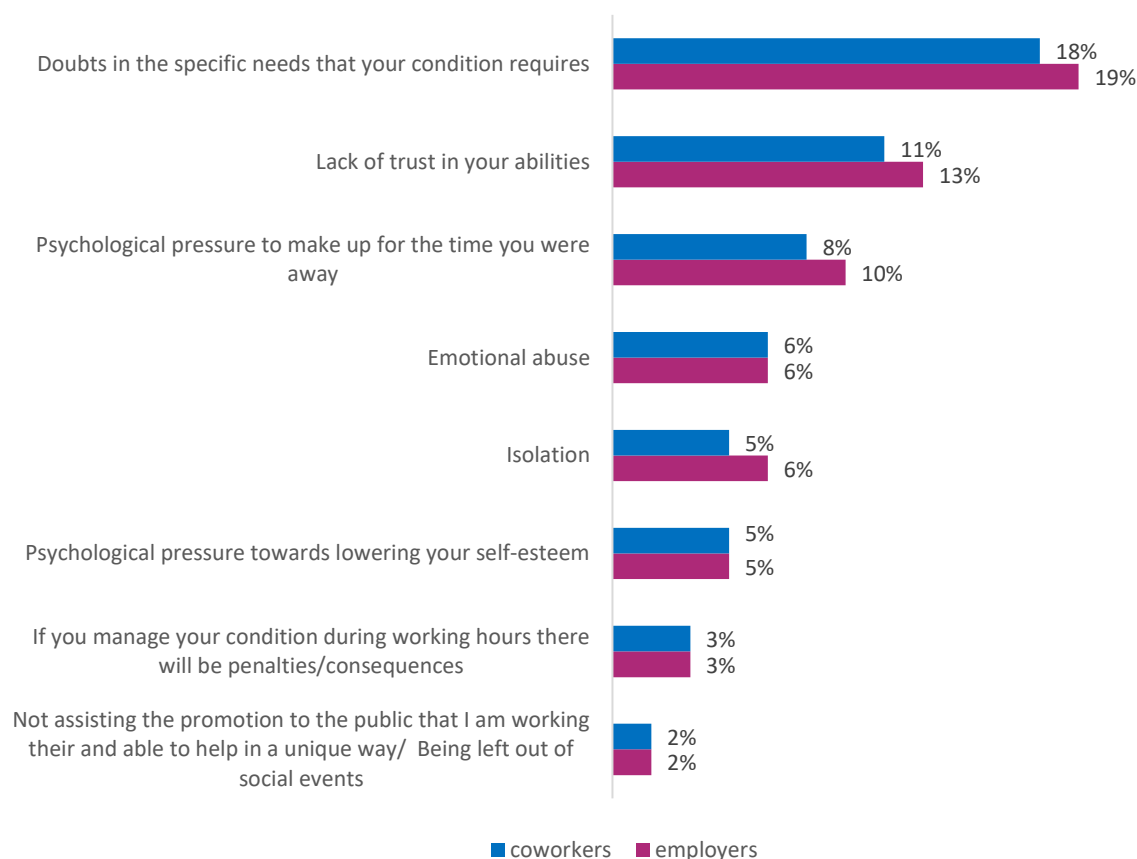
Figure 15: Have you ever missed a promotion that required no special background or skills, because of your condition? (n=43, in %)



To explore their reactions, we focused on these cases and asked how they responded to such discrimination. They had different approaches from not taking action at all (n=2) through sharing with friends and family (n=1) to taking action and signalling to human resources (n=4).

## Issues at the workplace

Figure 16: Issues at the work place by employers and coworkers (multiple, n=76, in %)



There are also specific problems that some young patients said to be experiencing in their work environment. The answers are similar: this indicates that there were general misconceptions in the workplace that affected equally the colleagues and employer's relationship to the young person. There were 3 key issues that came both from employers and colleagues that were most frequently mentioned by patients – doubts in the specific needs that the condition requires, lack of trust in patient's abilities, and psychological pressure for the patient to make up for the time they were away (Figure 16).

**Three misperceptions of employers and co-workers towards the respondents were most frequently mentioned: (1) doubts in the specific needs that the condition requires, (2) lack of trust in patient's abilities, and (3) psychological pressure for the patient to make up for the time they were away**

## What measures can be taken?

After we uncovered the complicated situation of patients on the labour market (the issue with finding a job, the sources of support, misperception from society, employers and employees and the concrete issues they face in the workplace) we gathered insights into what are the actual working measures that could help patients. Respondents supported mostly 3 measures:—trainings for management level to handle better employees with specific needs (37%, n=23), flexible working hours (32%, n=20), home office/ home based working opportunities (29%, n=18). These are perceived as positive measures, which can increase the employment among patients with chronic conditions (Figure 17).

**The top 3 measures that young patients believed could be helpful for them – trainings for management level to handle better employees with specific needs (37%), flexible working hours (32%), home office/ homebased working opportunities (29%)**

Figure 17: Helpful measures to find a job (multiple, n=120, in %)





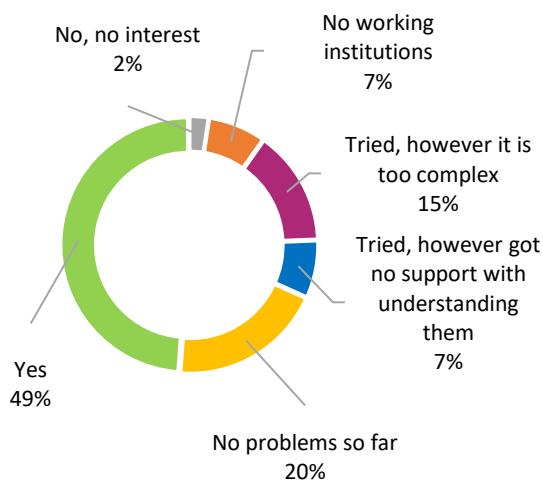
## Patients' Rights

A key part of the issue of discrimination is the awareness of the patient community about their rights. The results are very optimistic: 49% of the respondents shared they knew their rights at the working place (Figure 18).

**Around half (49%) of the respondents shared they knew their rights at the working place**

The high percentage could be attributed to the fact that 55% of the audience was affiliated to patient organisations and involved in patient advocacy.

Figure 18: Do you know your rights at the working places as an employee with chronic condition? (n=41, in %)

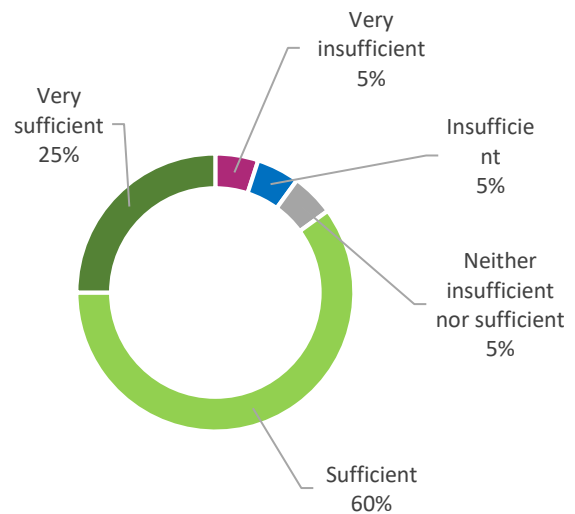


Furthermore 20% shared they had no problems so far. However, we need to highlight that 22% of respondents tried to inform themselves but failed to do so, as it was too complex or got no support (Figure 18).

**Twenty-two percent (22%) reported trying to inform themselves about their rights at the working place and failing**

Patient organisations have a significant role in helping patients feel more prepared to face the employment world by knowing their rights as both a patient and an employee, but still there are some that need to be further helped to feel more confident. This finding is supported by the fact that 10% of the participants evaluate their knowledge of rights at the workplace as "insufficient" and "very insufficient" (Figure 19).

Figure 19: How do you evaluate your knowledge in terms of your rights? (n=20, in %)



# Analysis of results

Almost two thirds of all respondents were employed which corresponds to the prevalence of people with high education (Bachelor, Masters or Doctoral). This finding suggests that young patients that succeed to finishing higher education tend to find employment. Most of the respondents were still students. It has several implications on job opportunities for the target audience. The patients may be currently focusing on receiving higher education or they may be looking for a job position offered for people without higher education. If they aimed to finish higher education while also looking for a job, they may need to find a way to coordinate it with their university commitments.

We must further highlight that 80% of the unemployed respondents were not actively searching for a job for several reasons. Additional qualitative responses revealed that some were dedicating themselves to family and education (14 people were focused on education and 1 person was on maternity leave). 3 people shared struggling for too long with the limited job opportunities for part-time job or for a patient, so they discouraged themselves.

As the result showed, young patients didn't get help from different institutions. This means that although some institutions exist, they were not experienced as useful by the respondents. One explanation could be that young patients simply do not look for help from institutions. Furthermore, there could be differences when it comes the respondents' national context.

Young patients faced discrimination at the working place. The issues were connected to the general expectation that they won't be as effective as employees without chronic conditions with a comparable education and skills, which could be very discouraging for the young patients. There was also an expectation

that the young person would be absent too often due to the condition, which will again prevent them to work as effectively as they could. Still when it comes to serious cases of discrimination, the results of the survey are rather optimistic for the patient's community in Europe.

Additionally, the results showed young patients wished for a more flexible working environment if feasible by the profession. Implementing "working from home" and flexible working hours are changes that a company/organisation could easily implement to support patients in being more productive, at ease and efficient in their workspace. They show signs of being very easy to apply, thanks to the new communication technologies for connection with a home office or cloud base services for sharing information. The trainings for management could be conducted with the involvement from labour institutions to ensure a regular training for management. Patient organisations could also help in the process to provide the patient perspective to all employers that would be interested in supporting their various workforce needs.

## Limitations

The sample size of the survey is small and does not necessarily give a complete overview of all the difficulties young patients in Europe face in employment. A large-scale research project is needed to sufficiently cover all the countries. There was also no exclusion criterion employed regarding the age of respondents, anyone considering themselves 'young patients' were included in the research. It is important to underline that as the sample was not controlled, there were no predefined quotas to ensure a balanced sample on key demographics such as

gender, age, location, education level and employment status.

Even though the study is missing the perspective of patients from several European countries, all European regions are represented in the survey. This finding indicates that the Youth Group should work more on reaching and building better ties with unrepresented countries and marginalized groups such as migrants/vulnerable populations in order to increase its representativeness in Europe regarding the collective needs and expectations of young patients.

When it comes to the respondents' profiles, only a third of them were patients not working as a patient representative and/or with a patient organisation. This is likely due to the recruitment strategy of the survey, as the main channel for the Youth Group when distributing the survey was through patient organisations. Additionally, working or volunteering in the NGO sectors suggests higher interest in the topic of patients' rights such as to take part in a survey that tackles patient-related issues. As these patients tend to be more informed on their rights and more active in general, this might induce a selection bias.

# Key findings

**1** Young people living with a chronic condition can be in an especially difficult situation at the beginning of their careers because their long-term illness might have affected their ability to benefit fully from regular education (long hospital stays, general issues with health preventing them), besides their lack of working experience.

**2** A significant amount of young patients would not disclose their condition before a job interview, in the fear of negative discrimination. There is however a notable difference in patients having a visible condition with less of a choice of disclosure.

**3** Many of the respondents have already experienced negative attitude towards them at the job market and their previous workplaces, such as:

- a) Doubts in the specific needs that the condition requires,
- b) Lack of trust in the patients' professional abilities,
- c) Psychological pressure on the patient to make up for the time he/she was away (for example, on sick leave).

Altogether, there might be a general stereotype that young patients can't be reliable employees, because they have special needs.

**4** Just like conditions and people, everyone's situation is special. But there are general measures that can be taken to ensure more inclusive workplaces for chronically ill patients and anyone with special needs:

- a) Trainings for employers to handle people with special needs,
- b) Flexible working hours and home-based working options (if the type of the work permits),
- c) Institutional support (e.g. financial benefits for employers who employ special needs people) with proper information given to both sides.

One might say young people with chronic conditions have special needs; but in reality, our needs are just like everyone else's: living a full life on the best quality as possible and being a useful part of society through leading a meaningful life. We just might need a little more support for that from society and our close environment. We hope our report, the challenges and potential solutions assessed may bring us a closer to that goal.

# Recommendations

## **We encourage training for managers and employers to engage in better dialogue with young employees living with chronic conditions.**

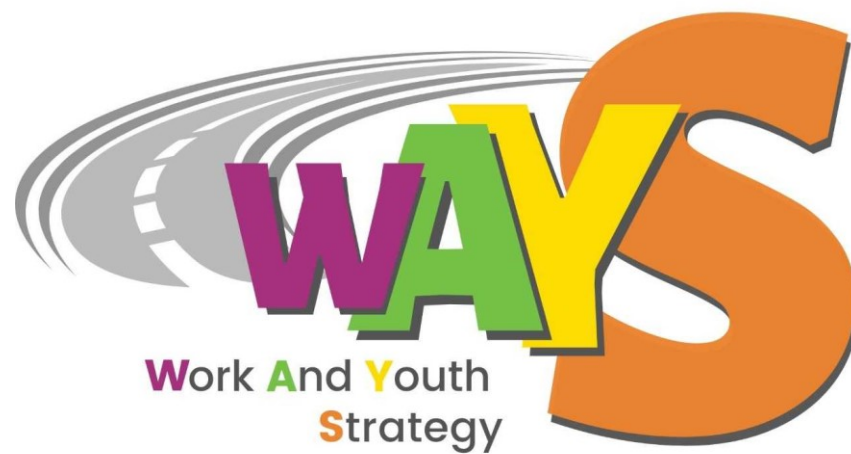
Managers and employers should seek to understand their individual condition and circumstances, and to identify and implement together the support and adjustment they need. This should be led at all times by the experiences and expertise of the young person and not the expectations of the employer.

## **We call for flexible working policies**

We call for flexible working policies such as adjusted work hours, and opportunity to manage workload around appointments, to be applied to young employees with complex medical needs just as they should be applied for other circumstances, for example, childcare arrangements.

## **We call for more home and remote working opportunities if feasible by profession**

There should be greater opportunities for home and remote working made available to young people living with a chronic condition, so that they can make a valuable contribution to the employment market without the rigorous demands of travelling to work and working within environments not adjusted to their needs.



European Patients' Forum  
Chaussée d'Etterbeek 180  
1040 Brussels

+32 2 280 23 34

[info@eu-patient.eu](mailto:info@eu-patient.eu)



EPF Youth Group  
Chaussée d'Etterbeek 180  
1040 Brussels

[youthgroup@eu-patient.eu](mailto:youthgroup@eu-patient.eu)