**Equal treatment for patients in education and employment**

Tackling discrimination in education and in the workplace

**CONFIDENTIAL DRAFT for member consultation**

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# Introduction

## FOREWORD FOR EPF MEMBERS

The European Patients’ Forum has been committed to combating discrimination on the ground of illness and to addressing health inequalities from the perspective of patients since its beginnings. Non-discrimination is one of our core principles.

In July 2013, we held the EMPATHY seminar with young patients, which confirmed that discrimination in education and employment are priorities.[[1]](#footnote-1)

We adopted non-discrimination as one **strategic goal** of our strategic plan 2014-2020 after consultation with our membership and a vote at our Annual General Meeting 2013.[[2]](#footnote-2)

**Non-discrimination**

To promote the development of EU and national policies that tackle discrimination faced by patients

in health and social care as well as in domains like education and employment.

This position paper is the second in our series of positions on discrimination. In 2014, EPF addressed discrimination in healthcare through our position statement healthcare for all.[[3]](#footnote-3)

The objectives of this position statement are:

* To **gather perspectives** of patients organisations on key issues and good practices in education and in employment for the equal treatment of patients
* To **raise awareness** amongst decision makers on issues that patients with chronic and/or long-term conditions face in education and in the workplace
* To become a **tool to engage important stakeholders** including employers, educational institutions, health professionals, and appropriate ministries, to take actions with patient organisations to break down the barriers that patients encounter in education and on the labour market
* **To make recommendations** from the patients’ perspective to ensure decision makers at EU level take actions towards patient-friendly education and workplaces.

## WHAT IS DISCRIMINATION?

**Discrimination can be direct:** within EU law, direct discrimination occurs when one person is treated less favourably than another is, has been, or would be treated in a comparable situation, based on a particular characteristic they hold[[4]](#footnote-4).

**It can also be indirect**: when an apparently neutral provision, criterion, or practice would put one person at a particular disadvantage compared with other persons.

EPF also combats **stigma**: stigma occurs when “certain differences (or imagined differences) are labelled or pointed out” and given negative associations. Stigma is not a legal concept, unlike discrimination.

## Fact and figures: why should decision makers act?

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1. According to Eurofound’s Third European Quality of Life Survey 2001–2012, about **28% of Europeans report having a chronic (longstanding) physical or mental health problem, illness or disability**, though with much variation depending on member states.[[5]](#footnote-5)
2. **1 in 4 people of working age** (15 to 64) are estimated to live with long standing health problems that restrict their daily activities. The majority of these health problems come directly from chronic diseases.[[6]](#footnote-6)

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1. Various sources show that the participation of people with chronic and long standing conditions in the job market is problematic in the EU[[7]](#footnote-7).
2. While the **proportion of young people (children, adolescents, and young adults) with chronic diseases** is difficult to quantify[[8]](#footnote-8), surveys carried out in France, Switzerland and Canada estimate that 10% of adolescents have chronic conditions.[[9]](#footnote-9) The World Health Organisation also estimates it could be as high as **15%**[[10]](#footnote-10).

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1. According to Eurofound, “Young people with health problems or disabilities in the EU have difficulty accessing employment. The limited information available on this group points to very low employment rates and increasing numbers taking up disability and other benefits, either directly from school or early in their working lives.”[[11]](#footnote-11)

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1. About **350 million working days are lost** in the European Union each year due to health-related problems[[12]](#footnote-12).

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1. Direct patient evidence also indicates that this is a fundamental issue for patients. In the EPF project EMPATHY “Europe meets Young Patient”, funded under the Youth in Action Programme, young patients identified discrimination and stigma in education and the workplace as important issues that they face, regardless of their nationalities or conditions.

Integration of patients with chronic conditions into the job market is a key issue, starting from a young age. It is also a widespread issue. To realise the goals of Europe 2020 for inclusive growth, it is essential to address the barriers and obstacles that patients face in education, accessing jobs, staying employed, and returning to work.[[13]](#footnote-13)

## HOW IS Discrimination addressed in EU legislation?

### Treaties and Conventions

Article 19 of the Treaty on the Functioning of the European Union provides the legal basis to take action to combat discrimination on six grounds (sex, racial or ethnic origin, religion or belief, disability, age, or sexual orientation).The Charter of Fundamental Rights of the European Union prohibits discrimination on these six grounds and nationality (Article 21).

At international level, The UN Convention on the Rights of Persons with Disabilities (UNCPRD) sets the right to education and to work and employment for people with disabilities in articles 24 and 27.[[14]](#footnote-14) The UNCPRD was ratified by the EU in 2010. In 1985, The International Labour Organisation also issued the Convention concerning Vocational Rehabilitation and Employment (Disabled Persons). However, neither text mentions chronic diseases explicitly.

### Policy framework

To combat direct and indirect discriminations, the EU has adopted a legislative framework to implement the principle of equal treatment between persons. The principle of equal treatment requires that all people have the right to receive the same treatment and will not be discriminated against.

In particular, the Council Directive 2000/78/EC of 27 November 2000 establishes a general framework for equal treatment in employment and occupation, and addresses discrimination on grounds of disability.[[15]](#footnote-15)

The EU programme “Rights, Equality and Citizenship 2014-2020” aims at promoting non-discrimination through funding various types of activities, including training activities and research.[[16]](#footnote-16) The EU Programme for Employment and Social Innovation (EaSI) also aims at improving working conditions in the EU.[[17]](#footnote-17)

Various EU policies aim at promoting the inclusion of persons with disabilities. However, given the variety of definitions of disability applied in Member States, it is not always clear whether this also includes all patients with chronic and long-term conditions, creating a policy gap.

# Discrimination and stigma in education

## At school and university

As the EPF EMPATHY seminar with young patients has highlighted, patients’ integration into the workplace is also linked to education. Young people with chronic diseases can face various obstacles within the educational system. The effect of chronic conditions is not only medical; it may affect a patients’ academic performance, their emotional and physical development, and relationships with their peers. It may cause anxiety and stress, cognitive impairments (sometimes also as a side effect of medication), fatigue, pain, and restlessness.[[18]](#footnote-18) These issues are often overlooked by staff in educational institutions (from school to university).[[19]](#footnote-19)

The first issue that was raised at the EMPATHY seminar is that patients may miss courses because of their disease, medical appointments, or treatment. School attendance is often an issue for young patients with chronic diseases and this is not always understood by the school/university staff. Absences can depend of the severity of the disease and in many chronic conditions, symptoms are fluctuating. Attendance may affect students’ ability to pass a course, which can place patients with chronic diseases at a disadvantage. In addition, patients may be affected by side effects of treatment. They may also experience psychological issues as a result of living with and managing their condition. When the illness is invisible or changing, patients may sometimes experience stigma and may even be accused of exploiting their conditions by their peers or even staff.[[20]](#footnote-20)Patient organisations have also highlighted that in some cases, the staff refuses to help: this is the case for young patients with food allergies (see quote), or with young patients with diabetes that need help with insulin injections[[21]](#footnote-21).

 “*Sometimes students with severe food allergy are refused to be treated with adrenaline. The use of adrenaline is needed to save lives. Teachers do not want to have the responsibility to do something wrong, but this is of course more dangerous for allergic people.*

*Our members try to overcome this situation with education meetings at schools where they train teachers to use correctly adrenaline injectors and use them when needed*”

Patient representative, allergies

In order to be able to follow their curricula at school, or later on at university, patients’ may need adaptations to their timetable and studies that are not always available. They may need adaptations for exam timetables for the same reasons. They sometimes also need adaptation to exam conditions (e.g. access to the bathroom, possibility to bring food during an exam). However, they can face rigid administrative rules and miscomprehension from teachers and examiners..

Because of issues of treatment availability or costs in some countries, and lack of clear information about cross-border healthcare, some young patients may be prevented from benefiting from the EU exchange programme ERASMUS.

Young patients have highlighted that structural discrimination and stigma can affect their academic success, their professional orientation, their future ability to obtain a job, as well as their future income. Research also shows that poor health can be a predicator for decreased educational attainment, but that this can be mitigated with appropriate support.[[22]](#footnote-22)

## Transition towards Employment

Young people with chronic and/or long-term conditions face specific difficulties in accessing employment, yet they are rarely targeted in active inclusions policies, or in policies aimed at promoting youth employment at EU or national level. They may also be absent from statistics, as employment statistics do not account for health status.[[23]](#footnote-23)

**Good practice:** The European Multiple Sclerosis Platform is leading a project called “Believe and Achieve” which establishes partnerships with European businesses to provide young people with MS opportunities to work in a supportive environment. The project launched offers for 17 paid internships in various EU countries.

<http://www.emsp.org/projects/believe-and-achieve>

Unemployment from a young age is known to have long lasting effects. Patients with chronic diseases are more likely to leave education early or with low qualifications.[[24]](#footnote-24)In addition, young patients may scale down their ambitions or career goals, or change path all together as a result of their conditions.

Young patients in the EMPATHY seminar also explained that growing up and learning to manage a chronic condition, sometimes from a young age, may also help young people to develop important qualities such as resilience and the ability to take on responsibilities.

# Discrimination, stigma and other barriers patients face in the workplace

## Difficulties finding a job / interview stage

Patients can face discrimination during interviews if they disclose their condition. They may also be discriminated against through mandatory medical examinations. For example, at the EMPATHY seminar a patient with HIV explained that he could not practice his profession due to the need for a certificate that medical examiners refused to provide. Rules preventing patients from accessing certain jobs are not always medically justified. Healthcare professionals may also have a protective attitude, as another patient highlighted at the seminar. She explained that she was perfectly capable of performing a job that her doctor had originally advised against. Young patients may also face stigma from society from the misconception that they are unable to work because of a chronic condition, when they may be fully able to work, sometimes with only minor adjustments. Conditions may affect individual patients differently and may have different degrees of severity.

*“Having a chronic condition is not out of the norm”*

Patient representative, Multiple Sclerosis

## working with A CHRONIC CONDITION

While some patients cannot continue their professional activity due to their health condition, many patients with chronic diseases continue working or wish to do so. With adequate support they can work, resulting in a hugely improved quality of life that minimises the negative financial impact of chronic illness and the risk of social exclusion.

For example, a study carried out with unemployed COPD patients indicated that they had

a more severe disease, lower quality of life and health status, more exacerbations, higher incidence of co-morbidities (including anxiety and depression) and a greater use of healthcare services. [[25]](#footnote-25) This makes the case for prevention, including measures to slow progression of the disease and policies to keep patients in employment.

For patients, the value of staying at work goes beyond providing financial stabilities - it contributes to social inclusion and well-being.

For employers, the benefits of hiring and retaining employees that have chronic conditions are also multiple: it shows the employer values diversity and inclusion, which are part of a well-functioning company. It ensures that the company matches its customer base and also ensures retention of skilled staff while sparing additional costs of recruitment and training new staff. Inclusive hiring policies show the company is taking responsibility for its impact on society (corporate social responsibility-CSR). According to the European Commission, CSR is beneficial for companies, as well as for societies.[[26]](#footnote-26)

**Did you know?** In most Member States, patients are only protected by law on the ground of disability; therefore a key debate is whether their condition fits the definition of disability.

However, in several Member States (Finland, France, Belgium, and Netherlands) anti-discrimination laws also protect from discrimination on the ground of health status/ chronic diseases.\*

\* Isabelle Chopin, Thien Uyen Do “Developing Anti-Discrimination law in the European Union” October 2012, pp11-13

In the workplace, patients may face stigma and discriminatory attitudes from employers or colleagues such as inappropriate disclosure of their condition, lack of support when returning to work after sick leave, or even difficulties after a long-term absence (e.g. some patients are “side-lined”).[[27]](#footnote-27) The Eurofound study on employment opportunities for people with chronic conditions shows that they may have more difficulties obtaining training opportunities and promotion.[[28]](#footnote-28)

There is little awareness of the difficulties that working patients may encounter: combining health issues with professional preoccupations and schedules can be very challenging. For example, patients may need to take medical appointments during working hours. This can be worsened by symptoms such as pain, tiredness, or anxiety. Experiential knowledge shows that patients will first sacrifice their leisure, social, and resting time to deal with health issues, which can lead to isolation and worsening of their health condition.[[29]](#footnote-29)

In addition, discrimination in other areas of life can affect patients’ ability to work: for example, patients with COPD encounter discrimination in air transport as they need to travel with their oxygen, which can be a barrier to joining some professions for which travel is needed. Patients with diabetes face discrimination and barriers in obtaining driving licenses, which also affect their ability to work.[[30]](#footnote-30)

Cases of negative experiences in the workplace have been flagged in relation to cancer in France, for example.[[31]](#footnote-31) Evidence provided by patient organisations indicates this can be an issue across chronic and long-term conditions in the EU.

Some example of data available in various diseases areas show that:

Multiple Sclerosis: A survey by EMSP showed that 65 percent of young people that responded to the survey where employed or doing voluntary work but approximately 8 out of 10 people stop working within 15 years of the onset of the disease.[[32]](#footnote-32)

Diabetes: The French Federation of Diabetes Patients (AFD) carried out a survey that showed a person living with diabetes is 4 times more likely to be excluded from their working environment due to their condition.[[33]](#footnote-33)

Chronic pain and neurological conditions: Current evidence shows that only 4 in 10 people with chronic pain say they receive enough support from their employers to manage their job, and that chronic pain results in more than 500 million sick days in Europe, costing the European economy >€34 billion.[[34]](#footnote-34) In addition, people with epilepsy are more than twice as likely to be unemployed as the general population.[[35]](#footnote-35)

### disclosing the illness

Disclosing the illness is often a sensitive issue for patients as there is a stigma attached to chronic conditions. There is usually a lack of awareness of the ability of patients to continue to work safely. Illnesses may also sometimes be considered as a private matter both by patients or their employers.

At the same time, disclosing the condition to the employer may open the rights of patients to accommodation and appropriate adjustments: ***The Council Directive 2000/78/EC of 27 November 2000* *establishing a general framework for equal treatment in employment and occupation*** creates a general framework for combating discrimination on the grounds of religion or belief, disability, age, or sexual orientation regarding employment and occupation, putting the principle of equal treatment into effect in the Member States. **Article 5** of the Directive specifies that employers shall take appropriate measures where needed in a particular case, to enable a person with a disability to have access to, participate in, advance in employment, or to undergo training.[[36]](#footnote-36)

**Good practice:** In Belgium, the Flemish government works with an integration protocol (‘integratieprotocol’). In this document, the staff member describes the disability/chronic illness in his own words. Only things that are relevant in the workplace are discussed. Additionally the integration protocol specifies the exact needs of the employee to work in the best conditions, such as the measures and arrangements that must lead to successful employment.

<http://www.bestuurszaken.be/integratieprotocol>

A key shortcoming of the Directive is that it does not harmonize definitions of disability, which can vary between Member States and be more or less inclusive. This creates ambiguity as to whether the Directive applies to patients with chronic diseases. Furthermore, a European Court of Justice case law *Chacon Navas v Eurest Colectividades SA* specified that people with sickness are not covered by the Directive.[[37]](#footnote-37) Nevertheless, if the chronic condition is considered as disability by the Member State, or if the Member State has further provisions compared to the Directive, patients may have the right to accommodation and adjustments. For this reason, EPF strongly believes that forbidding discrimination on health status or chronic condition and promoting equal treatment of patients with chronic/long term conditions is a key solution to overcome this issue of definition.

**Good practice:** The UK government provides an online platform FitForWork with advice for GPs, employees and employers, containing information about health at work including workplace adjustments, as well as a helpline: <http://support.fitforwork.org/app/home/type/employee>

In Austria, a website Fit2Work has also been put in place to provide advice for employees and employers:
<http://www.fit2work.at/home/>

Data from a study carried out with Multiple Sclerosis patients in Australia indicates that disclosing can be beneficial to career progression.[[38]](#footnote-38) However, patient groups indicate a preference for disclosure to remain voluntary and non-compulsory due to the risk of discrimination and as part of patients’ right to privacy. Patients should be protected from undue disclosure of data about their health status to their employers.

### rights of patients at work

Ensuring that workplace environments offer adequate support and adjustment for patients with chronic conditions, so that they can remain healthy and employed, is crucial to achieve EU 2020’s goal of “smart, sustainable and inclusive growth”. It is essential to support both people with chronic diseases and older people to stay employed for longer periods of time. This has multiple benefits for the employee and for the employer who is able to retain staff, and also for the economy. Such a strategy could also contribute to tackling the issue of the shrinking population size of working-age adults as a result of demographic change.

*“We get a lot of questions of people who are looking for information about what opportunities they have. It is a gut feeling that patients aren’t informed as well as they should be.”* -Patient representative

The lack of clear structure and rights encountered by patients in various situations could be considered as indirect structural forms of discrimination. For example, it is unclear whether patients with chronic and long-term conditions are protected when they risk losing their job due to repeated or long-term absence[[39]](#footnote-39). Patients’ rights regarding workplace adjustments and accommodation are not always clear or responding to the needs of patients, and they are not always well-implemented across the European Union.

Adapted systems and protective legislation are not always in place to allow patients with chronic diseases to remain in the workplace under acceptable conditions. When these systems and laws do exist, they are usually under-used; employers and the population at large tend not to be aware of their existence.[[40]](#footnote-40) Actions to raise awareness within companies or trade unions and for the general public could contribute significantly to tacking this problem.[[41]](#footnote-41)

A critical situation is when patients are diagnosed as being terminally ill. A recent campaign in the UK called “Dying to work” uncovered that terminally ill patients are inadequately protected by legislation in this situation. As a result, patients have to undergo stressful human resource procedures, financial difficulties, and anxiety resulting from the loss of employment.[[42]](#footnote-42)

Some diseases are progressive, therefore the need for adjustments needs to be reassessed continuously. This is the case with conditions like Alzheimer’s diseases.

### employers and colleagues

Patients often face low levels of awareness from their employers on managing chronic conditions. Employers are often misinformed regarding the abilities of patients to continue working, resulting in stigma. They may have concerns about costs, productivity, and absences. Because of negative perceptions, patients may not mention they have a disease or may not ask for the necessary adaptations.

“*People with MS often have difficulties due to the fluctuating nature of the condition and employers wanting certainty (even though there is no such thing!) without preparing the business to effectively manage absence.”*

Patient representative, Multiple Sclerosis

In the workplace, patients may face stigma and discriminatory attitudes from employers or colleagues such as undue disclosure of their condition, lack of support to go back to work after a sick leave, or even difficulties after a long-term absence (e.g. some patients are “side-lined”).[[43]](#footnote-43)

The Eurofound study on employment opportunities for people with chronic conditions also shows that they may have more difficulties obtaining training opportunities and promotion.[[44]](#footnote-44)

### SICK leave and return to work

**Good practice:** The UK has established a new policy around return to work, with a fit note instead of a sick note and guidance for all stakeholders’ concerned (patients, managers, healthcare professionals). The aim is to allow doctors to advise on returning to work, and to propose phased return to work or adjustments that could be necessary. The Health and Safety Executive has also published guides on how to facilitate return to work. \*

\*<http://www.hse.gov.uk/sicknessabsence/>

According to a report by The Economist, chronic conditions are among the main reasons why employees take sick leave.[[45]](#footnote-45)

Provisions for sick leave vary across Member States, with different degrees of burden on State, employers and employees to bear the cost. The Economist report suggests that some systems are deterring absenteeism[[46]](#footnote-46) and encouraging presenteeism[[47]](#footnote-47), which can have a negative impact as it may inadvertently encourage “complacency in tackling work related causes of ill-health” and pose more risk of injury.[[48]](#footnote-48)

Returning to work after a sick leave has also been flagged as an important issue by patient organisations, and was also documented as a key issue by the OECD.[[49]](#footnote-49)

In 2014 in France, the Cancer League indicated that 2 years after diagnosis, 1 in 3 people lose or quit their job, mostly due to discrimination and stigma or simply due to a lack of return to work policies.[[50]](#footnote-50)

Having a sound return to work procedure is essential for employees after a long-term absence, helping to prevent prolonged sick leaves, lower job quality, or even long-term unemployment for the employees with chronic and long-term conditions.

### Relation between appropriate healthcare access and patients’ ability TO REMAIN at work

Patients’ organisations often note than in their experience, there is a correlation between patients’ ability to remain at work and appropriate access to healthcare. For example, early diagnosis is often highlighted as key to ensure patients can remain at work longer.

Patient empowerment and self-management skills may also be useful to patients in the context of managing their conditions in the workplace. According to the EMPATHIE study, “An empowered patient has control over the management of their condition in daily life. They take action to improve the quality of their life and have the necessary knowledge, skills, attitudes and self-awareness to adjust their behaviour and to work in partnership with others where necessary, to achieve optimal well-being. “[[51]](#footnote-51)

*“Early diagnosis of dementia and early access to treatment and support would be a beneficial factor for people with dementia to remain in their job for as long as possible”*

Patient representative, Alzheimers’ disease and Dementia

Self-management has been defined by Fit For Work Europe as: “an individual’s ability to manage the symptoms, treatment, physical, social and psychological consequences of living with a chronic condition”. A study conducted by Fit for Work on patients with musculoskeletal conditions has shown that patients often utilise self-management strategies but are not always supported by other stakeholders (line managers, colleagues, healthcare professionals).[[52]](#footnote-52)

## patients who cannot work/ need to retire early due to their conditions

Some patients cannot work as a result of their illness or/and the secondary effects of their treatment. They should be appropriately supported, including financially. Patients may also retire early as a result of their condition.

Sometimes, patients may also need a career change to a less physically demanding or stressful job but support is not always available to achieve this.

The focus should be placed on what the patient can still do, whether at work or in other areas of life. A process is not always in place in workplaces to assess with the patient when they will no longer be able to work in some progressive diseases.

Patients’ health status and their difficulties to remain at work may also affect the working situation of their informal carers. Caring may lead to difficulties balancing paid work with care responsibilities. Carers may also give up on work due to their caring activities, or may lose their job.

Patients (and carers) who can no longer work need appropriate financial support. However depending on the country and the condition of the patients, they are not always entitled to disability benefits.

*“When you have a better day and people see you walking on the street they say “well, it appears she’s healthy enough to take a walk, but not to work…”. That hurts, even after 10 times, even after 100 times. What people can’t see is the condition you’re in at home, how you need to rest after every effort you make, how many pills you have to take to get there. The worst thing is that you can’t see pain from the outside”.*

-Belgian patient with chronic pain, in “Brain, mind and pain, the book of evidence”<http://issuu.com/efna/docs/book-of-evidence-issuu/1?e=13518211/11530120>,

## occupational and work related diseases

Long-term and chronic conditions are sometimes caused by work itself. When work is the main cause of a condition, it is classified as an occupational disease (e.g. some substances present or manipulated at work can cause allergies, respiratory diseases, cancer). When work is one of several factors causing an illness, it is classified as work-related disease. In this case, the EU and Member States have specific policies in place, called occupational health and safety policies.

EPF responded in 2013 to the European Commission’s consultation on the next health and safety at work strategy. We provided recommendations on addressing the needs of patients with chronic conditions through occupational health and safety policies: <http://www.eu-patient.eu/globalassets/policy/anti-discrimmination/epf-response-osh-2013.pdf>. We particularly emphasised that low awareness and action as regards chronic diseases and the workplace needs to be addressed in the new occupational health and safety at work strategy.

# Patient organisations’ initiatives and role

Many patients’ organisations have taken action to advocate for the rights of patients at the workplace and to support patients in this area. Examples of the diverse initiatives carried out by EPF are as follows:

**Awareness raising and advocacy**

In July 2013, Alzheimer Europe, the European Multiple Sclerosis Platform, and the European Parkinson Diseases’ Association co-organised the **panel discussion “The Challenges of Neurodegenerative Diseases in the Workplace: what can be done at EU level?”** at the European Parliament.[[53]](#footnote-53)

The European Federation for Allergies and Airways Diseases Patients Associations organised a **workshop on COPD at work**. The outcomes of the workshop showed that with adequate support from employers, patients can continue working. It also demonstrated the need to work across disease areas, as high quality care, development of self-care,: and measures to empower patients can contribute to their ability to remain at work.[[54]](#footnote-54)

The European Federation of Neurological Associations has published a **book of evidence** which contains several patients’ testimonies on work, as well as good practices. EFNA has also launched a **call to action.**

The organisation the ALLIANCE Scotland launched a **campaign to promote employability** of people with long-term conditions, called“**My skills, my strengths, my work**”. This campaign aims to change the perceptions of employees with chronic conditions, particulary amongst employers.

**Initiating projects and research**

The European Multiple Sclerosis Platform also launched a **European Pact for Employment campaign**, directed at businesses, to encourage their commitment to providing sustainable employment for people with MS.[[55]](#footnote-55)

In 2013, GAMIAN-Europe conducted **a survey on mental illnesses at work**, which was presented in the European Parliament in a meeting focusing on mental health and societal integration.[[56]](#footnote-56)

**Participating in policy making**

The Flemish Patients Platform (VPP) is part of the ‘Gebruikersoverleg Handicap, Chronische Ziekte en Arbeid’. This organ reunites different user-organisations concerning a disability or? a chronic disease and work. In addition, it also represents the voice of the user in several policy bodies in Flanders, such as the Diversity Commity (Committee? “Commissie” in Flemish)of the SERV .This body is currently working on a list of actions that must be executed the next few years to achieve a more inclusive labour market (including education and the transition to a job).

**What role for patients’ organisations?** Patient organisations can play a key role in finding and implementing solutions, as illustrated above, and need to be meaningfully involved in making equal treatment at work and in education a reality. However, this requires resources (staff and financial) that patient organisations do not always have available, and also the support and willingness to involve patients on the part of stakeholders and decision makers at EU and national level. Patients’ organisations consider equal treatment in education and the workplace as a collective societal responsibility. Therefore, while they can help, universities, relevant ministries, employers, and trade unions also have an essential role to play in seeking solutions and keeping patients well informed.

*“Patients and carers must be equal partners in finding solutions alongside the employers who are rather motivated by productivity and competitiveness”-* Patient representative

# Supporting equal treatment of patients in education and in the workplace: Recommendations

In order to establish equal treatment in education and at the workplace for patients with chronic diseases, EPF believes that various actors from the health, education, and employment sectors need to be involved in implementing an equal treatment strategy. This includes decision makers at EU and national level as well as the EU OSHA and other agencies responsible for occupational health and safety, associations of employers, associations that are active in the field of education, healthcare professionals, and trade unions. While the main responsibilities for employment and education are at national level, we strongly believe the EU has an important role to play in encouraging action and ensuring good practices are shared.

## ESTABLISHING APPROPRIATE Rights and legislation for patients with chronic diseases

1. EPF recommends that **EU[[57]](#footnote-57) and Member States’ legislation on equal treatment in workplaces** should also prohibit discrimination based on health status/chronic conditions
2. The EU and Member States should also provide for clear **rights to adjustments and accommodations in education and at work,** and take initiative to encourage implementation of these rights
3. While **access to a profession** may need to be restricted for some conditions, limitations need to be justified and restricted to what is necessary. Healthcare professionals should be objective in assessing a patient’s ability to fully or partially perform a job. Lists that exclude patients with some conditions from entering a profession, where they exist, need to be reviewed by decision makers with the involvement of all parties, including patient organisations.
4. The impact of various **sick leave** organisations and legislation needs to be further studied, including impact on the patients, their health outcomes, and consequences on their career.
5. **Patients facing discrimination** should have access to mediation, complaint and redress mechanisms at national level, and appropriate independent support structure to seek reparation.
6. Member States should ensure that **terminally ill patients** are adequately protected by legislation, and ensure that employers provide reasonable adjustments for terminally ill patients to be supported in remaining at work.
7. Patients who cannot work as a result of their health status should have the right to financial support. Financial incentives are also an important policy option to explore to encourage employment of patients with chronic diseases.
8. Appropriate legislation also needs to be in place to support **carers** and allow them to benefit from their right to work. Appropriate respite should be granted, as well as flexible solutions for carers’ leave.

## Information, training and awareness raising

**In education:**

1. **Communication within the educational institutions**: Staff in educational institutions should be appropriately trained to support young patients with chronic diseases. The direction should ensure, with the consent of the students and their parents, that professors and other staff members (school nurse, etc…) are appropriately informed about the condition and its consequences, as well as necessary adaptations.
2. Staff in charge of the implementation of the **ERASMUS programme** should be able to provide appropriate support and direct patients with chronic diseases to appropriate contact points to ensure they have access to quality treatment and care abroad. They should collaborate with National Contact Points for cross-border healthcare, when appropriate.
3. **Ministries of education** could provide an online webpage for advice on equal treatment of students with chronic conditions, designed for students and for staff or institutions. They could also develop and disseminate guidelines. Such information and guidelines should be developed in consultation with appropriate stakeholders, including patient organisations.
4. While patients’ organisations can play a role in supporting young patients in their **transition** from education to employment, it is essential that education authorities such as universities and employment services also engage in this area.

**At work:**

1. **Actions and campaign to raise awareness at EU and national level,** within educational institutions, companies, trade unions and for the public, could contribute significantly to tackling stigma faced by patients with chronic diseases. It is also important to inform workers, employers, and human resources managers about existing rules and rights.
2. **Appropriate ministries or authorities should make policies available to employees and managers** regarding chronic and long-term conditions at work.
3. The EU should encourage Member States to provide **one stop shop websites** to inform employees with chronic and long-term conditions and employers about the rights of patients at work, and also resources to support their implementation.

## Creating supportive Patient-friendly environments for patients

**Patient-friendly educational institutions:**

1. Educational institutions should be **proactive in offering support** to young patients, pointing them towards the right points of contact and providing information on their website. Patients may need more than occasional accommodations and should receive continuous support, reviewed after an appropriate period of time involving the young student.
2. **Management of absences in class and exams:** Young patients with chronic diseases and long-term conditions should be supported in case they need to be absent. Schools and teachers should work out flexible solutions to ensure that young patients can take exams at a later date if medically necessary, or if measures are needed to enable the student to take the exam in good conditions. Appropriate arrangements should be discussed and agreed upon with the young person and the staff overseeing the exam should also be duly informed (e.g. to allow student to take their food, to allow extra time if justified).
3. Schools and educational institutions should be provided **adequate resources** in order to offer appropriate in-house medical and psychological support to students with chronic conditions.

**Patient-friendly workplaces:**

1. Workplace environments should be encouraging of **disclosure,** whichrequires employers and managers to be open and know that they may need outside help/expertise. It also requires a fully-functional absence-management procedure, audit and evaluation of illness/absence management policies, and staff properly trained to support colleagues who have a health condition.
2. Appropriate support and policies for workplace adjustment, accommodations, and **return to work** need to be implemented, building on existing good practices. More research in this area is needed and good practices should be evaluated with the participation of relevant stakeholders, including patients.
3. If patients cannot continue to work in their current job because of their health status but are willing to **reconvert**, policies and structure aiming at supporting them should be put in place at national level.
4. EU and Member States **occupational health and safety at work strategies** and policies should widen their scope to support patients with chronic conditions at work (whether the condition is caused by work or not).
5. **Case reviews** or discussions involving the employer (involving the human resources department), the employee, and external advisors (medical, insurance, health and safety officers…) would be crucial for patients who may need to retire early or quit work due to their condition.
6. Employers, whether from the public or private sectors, have a key role to play in implementing measures towards making the workplace patient-friendly and raising awareness of the benefits of these actions for the employers and employees: they should be encouraged to become **diversity and inclusion champions** by national or European institutions.

##  COOPERATION ACROSS policy areas: health/education and employment

1. To effectively raise awareness and tackle the issue of stigma and discrimination in education and at work, the **involvement of various stakeholders from the health, education and employment sectors is needed**.
2. **Active inclusions [[58]](#footnote-58)** and **youth employment policies and programmes[[59]](#footnote-59)** at EU and national level should explicitly target the unmet needs of young patients with chronic and long -term conditions.
3. The **EU OSHA[[60]](#footnote-60)** and similar agencies in Member States should collaborate with patients’ organisations to develop information and resources for persons with chronic and long-term conditions regarding health and safety at work.
4. More cooperation between EU Member States is needed to exchange **information on good practices** in the area of education and employment of people with chronic diseases.
5. **Healthcare professionals** have a key role to play in taking into account outcomes that are important for patients, such as school and exam attendance or ability to work, into their dialogue with patients. Similarly, researchers should take into account these aspects in clinical trials, and ability to work should be accepted as a valid clinical outcome.
6. Policies and initiatives aiming at ensuring equal treatment in education and in employment should **involve patients and their organisations** in order to ensure they meet patients’ needs.

# Conclusion

A cultural shift is needed to address the barriers that patients face in education and in the workplace. To reach the goals of Europe 2020, both educational institutions and workplaces need to become more supportive environments. This is also essential to improving quality of life for patients with chronic conditions, who are an important share of the population. With a concerted action from stakeholders, driven by political incentives at EU and national level, we strongly believe it is possible to put in place measures to ensure patients are better supported and are encouraged to seek support when they need it ,in education and in the workplace,.

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| http://www.mentorfoundation.org/uploads/pictures/Flag-of-Europe-150.png | This draft position paperarises from the EPF 2015 Work Programme, which has received funding under an operating grant from the European Union’s Health Programme (2014-2020).. The content of this draft position paperrepresents the views of the author only and is his/her sole responsibility; it cannot be considered to reflect the views of the European Commission and/or the Consumers, Health and Food Executive Agency or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains. |

1. EMPATHY project page: http://www.eu-patient.eu/whatwedo/Projects/EPF-led-EU-Projects/EMPATHY/ [↑](#footnote-ref-1)
2. http://www.eu-patient.eu/globalassets/library/strategic-planning/epf-strategic-plan-2014-2020-final.pdf [↑](#footnote-ref-2)
3. http://www.eu-patient.eu/globalassets/policy/anti-discrimmination/epf-position-discrimination-jan2015\_final.pdf [↑](#footnote-ref-3)
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5. http://www.eurofound.europa.eu/observatories/eurwork/comparative-information/employment-opportunities-for-people-with-chronic-diseases [↑](#footnote-ref-5)
6. <http://ec.europa.eu/health/social_determinants/docs/final_full_ecorys_web.pdf>, p94-95 [↑](#footnote-ref-6)
7. http://www.eurofound.europa.eu/observatories/eurwork/comparative-information/employment-opportunities-for-people-with-chronic-diseases [↑](#footnote-ref-7)
8. A variety of definitions of chronic conditions are used, sometimes statistics are also merged with disabilities, or there is not a specific focus on this age group. [↑](#footnote-ref-8)
9. The adolescent with a chronic condition. Part I: developmental issues J-C Suris, P-A Michaud, R Viner *Arch Dis Child* 2004 89: p 938 [↑](#footnote-ref-9)
10. The adolescent with a chronic condition : epidemiology, developmental issues and health care provision, P-A. Michaud, J.C. Suris and R. Viner. World Health Organization 2007. [↑](#footnote-ref-10)
11. <http://www.astri.nl/media/uploads/files/EF1226EN6.pdf>, p1 [↑](#footnote-ref-11)
12. https://osha.europa.eu/en/publications/magazine/4/ [↑](#footnote-ref-12)
13. http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:2020:FIN:EN:PDF [↑](#footnote-ref-13)
14. http://www.un.org/disabilities/convention/conventionfull.shtml [↑](#footnote-ref-14)
15. http://eur-lex.europa.eu/legal-content/en/TXT/?uri=CELEX:32000L0078 [↑](#footnote-ref-15)
16. More information on objectives and activities: http://ec.europa.eu/justice/grants1/programmes-2014-2020/rec/index\_en.htm [↑](#footnote-ref-16)
17. More information: http://ec.europa.eu/social/main.jsp?catId=1081 [↑](#footnote-ref-17)
18. J-C Suris, P-A Michaud, R Viner “The adolescent with a chronic condition. Part I:

developmental issues” Arch Dis Child 2004;89:938–942 [↑](#footnote-ref-18)
19. idem [↑](#footnote-ref-19)
20. idem [↑](#footnote-ref-20)
21. See this example of a boy who was refused in a school due to his condition: <http://www.diabetes.co.uk/news/2012/Sep/boy-with-diabetes-denied-admission-to-primary-school-92907071.html> [↑](#footnote-ref-21)
22. The adolescent with a chronic condition : epidemiology, developmental issues and

health care provision, P-A. Michaud, J.C. Suris and R. Viner. World Health Organization 2007, p5 [↑](#footnote-ref-22)
23. http://www.eurofound.europa.eu/observatories/eurwork/comparative-information/employment-opportunities-for-people-with-chronic-diseases [↑](#footnote-ref-23)
24. idem [↑](#footnote-ref-24)
25. Miguel Román Rodríguez et al. “The Real World Burden of COPD: A cross-sectional retrospective analysis on employed and ‘not in paid employment’ patients in Europe” in Journal of Health and Productivity [JHP] Volume 7, Number 1, Produced in Nov 2013 <http://www.ihpm.org/pdf/jhp_V7_N1_2014.pdf> [↑](#footnote-ref-25)
26. http://ec.europa.eu/growth/industry/corporate-social-responsibility/index\_en.htm [↑](#footnote-ref-26)
27. Observatoire du CISS sur les droits des maladies rapport annuel de santé info droit 2011 [↑](#footnote-ref-27)
28. <http://www.eurofound.europa.eu/observatories/eurwork/comparative-information/employment-opportunities-for-people-with-chronic-diseases> [↑](#footnote-ref-28)
29. Source: [im]Patients,Chroniques & Associés’ white paper “vivre comme les autres” 2nd edition 2011, p17-18, available at http://www.afh.asso.fr/IMG/pdf/2ndeedit\_livre-blanc\_vivre\_comme\_les\_autres\_2011.pdf [↑](#footnote-ref-29)
30. IDF Europe survey on diabetes and driving license : https://www.idf.org/sites/default/files/DL\_report\_220910.pdf [↑](#footnote-ref-30)
31. http://www.lemonde.fr/sante/article/2014/04/17/avoir-un-cancer-n-est-pas-une-faute-grave\_4402835\_1651302.html [↑](#footnote-ref-31)
32. http://www.emsp.org/projects/paving-the-path-to-participation [↑](#footnote-ref-32)
33. See further data at: <http://newsroom.idf-europe.org/index.php?option=com_content&view=article&id=168:france-fighting-discrimination-at-the-workplace&catid=9:news-from-europe&Itemid=109> [↑](#footnote-ref-33)
34. These examples and further data can be found at <http://issuu.com/efna/docs/book-of-evidence-issuu/1?e=13518211/11530120>, p 12 [↑](#footnote-ref-34)
35. idem [↑](#footnote-ref-35)
36. http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex:32000L0078 [↑](#footnote-ref-36)
37. http://curia.europa.eu/juris/liste.jsf?language=en&num=C-13/05 [↑](#footnote-ref-37)
38. http://msj.sagepub.com/content/20/7/871.abstract [↑](#footnote-ref-38)
39. Observatoire du CISS sur les droits des maladies rapport annuel de santé info droit 2011 [↑](#footnote-ref-39)
40. For example that is the situation in France. Source: [im]Patients,Chroniques & Associés’ white paper “vivre comme les autres” 2nd edition 2011, p17-18, available at http://www.afh.asso.fr/IMG/pdf/2ndeedit\_livre-blanc\_vivre\_comme\_les\_autres\_2011.pdf [↑](#footnote-ref-40)
41. The white paper “ vivre comme les autres” indicates that through local actions, these negative perceptions can be significantly modified. Source: [im]Patients,Chroniques & Associés’ white paper “vivre comme les autres” 2nd edition 2011, p18, available at <http://www.afh.asso.fr/IMG/pdf/2ndeedit_livre-blanc_vivre_comme_les_autres_2011.pdf> [↑](#footnote-ref-41)
42. Campaign  « Dying to work » led by the Trade Union Congress in the UK : <http://www.dyingtowork.co.uk/> [↑](#footnote-ref-42)
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44. <http://www.eurofound.europa.eu/observatories/eurwork/comparative-information/employment-opportunities-for-people-with-chronic-diseases> [↑](#footnote-ref-44)
45. <http://www.economistinsights.com/sites/default/files/Out%20of%20office_WEB.pdf>, P5 [↑](#footnote-ref-45)
46. Absenteeism means the practice of being frequently absent from work [↑](#footnote-ref-46)
47. Presenteeism in this context means staying at work in spite of illness or injury, resulting in loss of productivity [↑](#footnote-ref-47)
48. http://www.economistinsights.com/sites/default/files/Out%20of%20office\_WEB.pdf, p7 [↑](#footnote-ref-48)
49. http://www.eurofound.europa.eu/observatories/eurwork/comparative-information/employment-opportunities-for-people-with-chronic-diseases [↑](#footnote-ref-49)
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52. <http://www.fitforworkeurope.eu/REPORT%20-%20Self-management%20of%20chronic%20musculoskeletal%20disorders%2009%202014.pdf>, p4-8 [↑](#footnote-ref-52)
53. Event report available at: http://www.emsp.org/attachments/article/198/Neurodegenerative%20diseases%20event\_final%20report.pdf [↑](#footnote-ref-53)
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56. http://gamian.eu/wp-content/uploads/2014/11/Arteel\_19-11-2014-Mental-Illness-and-Workplace.pdf [↑](#footnote-ref-56)
57. http://eur-lex.europa.eu/legal-content/EN/NOT/?uri=CELEX:32000L0078 [↑](#footnote-ref-57)
58. http://ec.europa.eu/social/main.jsp?catId=1137&langId=en [↑](#footnote-ref-58)
59. http://ec.europa.eu/social/main.jsp?catId=1036 [↑](#footnote-ref-59)
60. <https://osha.europa.eu/en> [↑](#footnote-ref-60)