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

Tackling patients’ discrimination in education and in the workplace

**CONFIDENTIAL DRAFT for member consultation**

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# Introduction

## FOREWORD FOR EPF MEMBERS

EPF is taking position on discrimination in education and the workplace as part of our strategic goals:

**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.

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

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 which 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 which 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 where one person is treated less favourably than another is, has been or would be treated in a comparable situation.

**It can also be indirect**: where an apparently neutral provision, criterion or practice would put one person at a particular disadvantage compared with other persons, unless that provision, criterion or practice is objectively justified by a legitimate aim and the means of achieving that aim are appropriate and necessary.

To combat these forms of discrimination, 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.

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.[[2]](#footnote-2)
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. Overall the major cause for this appears to be chronic diseases.[[3]](#footnote-3)

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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[[4]](#footnote-4)

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1. While the **proportion of young people (children, adolescents, and young adults) with chronic diseases** is difficult to quantify[[5]](#footnote-5), surveys carried out in France, Switzerland and Canada estimate that 10% of adolescents have chronic conditions.[[6]](#footnote-6) The World Health Organisation also estimates it could be as high as **15%**.[[7]](#footnote-7)

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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.”[[8]](#footnote-8)

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1. About **350 million working days are lost** in the European Union each year due to health-related problems[[9]](#footnote-9)

Integration of patients with chronic conditions in 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.[[10]](#footnote-10)

## HOW Are patients protected from DISCRIMINATION BY the EU?

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 sets the right to education and to work and employment for people with disabilities in its articles 24 and 27.[[11]](#footnote-11)The International Labour Organisation also issued in 1985 the Convention concerning Vocational Rehabilitation and Employment (Disabled Persons). However both texts don’t mention chronic diseases explicitly.

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.[[12]](#footnote-12) The EU Programme for Employment and Social Innovation (EaSI) also aims at improving working conditions in the EU.[[13]](#footnote-13)

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 issues 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 relationship with their peers. It may cause anxiety and stress, cognitive impairments (sometimes also as a side effect of medication), fatigue, pain, and restlessness.[[14]](#footnote-14) These issues are often overlooked by staff in educational institutions (from school to university).[[15]](#footnote-15)

The first issue which 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.[[16]](#footnote-16)

In order to be able to follow their curricula whether 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 miscomprehension from teachers and examiners and rigid administrative rules.

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 discriminations and stigma can affect their academic success, their professional orientation, and 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.[[17]](#footnote-17)

**Questions to EPF Members**

1. Does this reflect your experience/ the experience of young patients in your country or disease area?
2. Do you have positive examples or good practice to share regarding support schemes for young patients at school or university?

## Transition towards Employment

Young people with chronic and/or long-term conditions face specific difficulties in accessing employment yet they are very often not 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.[[18]](#footnote-18)

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.[[19]](#footnote-19)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 have 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 ability to take on responsibilities.

**Question to EPF members**

1. Who should be in charge of supporting young patients in their transition, e.g. organising workshops and events and publishing supporting tools? Patient organisations, employers, ministries of education, universities, other?
2. What key recommendations should we make to decision makers and stakeholders at EU and/or national level to ease the transition of young patients between education and employment?

# 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 examination. 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 that don’t allow patients to access 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 able to perform a job which her doctor had originally advised against. They also may face stigma from society from the misconception that they are unable to work because they have a chronic condition whereas patients may be able to work, sometimes with minor adjustments. Conditions may affect individual patients differently and may have different degrees of severity.

**Questions to EPF members:**

1. What political or legal incentives need to be established to encourage employment of people with chronic diseases: quotas/legislation/compensation schemes for employers/ campaigns to raise awareness/other?

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

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”).[[20]](#footnote-20) The Eurofound study on employment opportunities for people with chronic conditions shows that they may have more difficulties obtaining training opportunities and promotion.[[21]](#footnote-21)

There is little awareness of the difficulties patients that remain at work 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.[[22]](#footnote-22)

Cases of negative experiences in the workplace have been flagged in relation to cancer in France, for example.[[23]](#footnote-23) Experiences from patient organisations indicate this can be an issue across chronic and long-term conditions in the EU.

### disclosing the illness

**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

Disclosing the illness is often a key 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 as regards 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, or advance in employment, or to undergo training.[[24]](#footnote-24)

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.[[25]](#footnote-25)

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.

**Question to EPF members:**

1. In your view, what would be needed to ensure that patients can disclose their conditions safely?
2. The European Network for Workplace Health Adaptation (ENWHP) recommends that a line manager organise a discussion and a case review with the employee, sometimes involving external advice (medical, insurance), to finally adopt a commonly agreed action plan. [[26]](#footnote-26) Do you believe this would be helpful? Are you aware of such existing processes?

### rights of patients at work

Ensuring that workplace environments offer adequate support and adjustment for patients with chronic conditions so that they can stay at work in good condition is crucial to achieve EU 2020’s goal of “smart, sustainable and inclusive growth”. It is essential to support 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 raised by the shrinking size of population of working age as a result of demographic change.

**Examples of 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/>

The lack of clear structure and rights in various situations encountered by patients with chronic diseases 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[[27]](#footnote-27). 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.[[28]](#footnote-28) Actions to raise awareness within companies or trade unions and for the public could contribute significantly to tacking this problem.[[29]](#footnote-29)

**Questions to EPF members**

1. In your experience, is information on the rights of patients to be protected from discrimination and to adjustments easy to access in your country/disease area?
2. What kind of adjustments may be necessary/ provided in your disease area?
3. Are employers and employee usually aware of these rights?
4. Are these rights well implemented?

### 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.

**Good practice:** The organisation the Alliance Scotland launched a campaign to promote employability of people with long-term conditions, “My skills, my strengths, my work”, which aims to change perceptions of employers: http://www.alliance-scotland.org.uk/what-we-do/projects/my-skills-my-strengths-my-right-to-work/

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”).[[30]](#footnote-30)

The Eurofound study on employment opportunities for people with chronic conditions also shows that they may have more difficulties obtaining training opportunities and promotion.[[31]](#footnote-31)

**Questions to EPF members**

1. In your country, do employers have a management policy to tackle discrimination against patients with chronic disease at work?
2. If not, how should these policies be developed (EU or national level)?
3. What more can be done to support patients (e.g. organising workshops, providing resources…) and who can be involved in supporting them?

### SICK leave and return to work

According to a report by The Economist, chronic conditions are among the main reasons why employees take sick leave.[[32]](#footnote-32)

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 and encouraging presenteeism 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.[[33]](#footnote-33)

**Good practice example:** 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 professional). The aim is to allow doctors to advise on return to work, and 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/

Return 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.[[34]](#footnote-34)

In 2014 in France, the Cancer League indicated that 2 years after diagnosis, one in 3 people loses or quits their job, mostly due to discrimination and stigma or simply lack of return to work policies.[[35]](#footnote-35)

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.

**Question to EPF members:**

1. Are there issues around sick leave and return to work in your country/ disease area?
2. Are patients adequately supported? If not, what needs to change?

### 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. “[[36]](#footnote-36)

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).[[37]](#footnote-37)

## 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 the 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.

**Questions to EPF members**

1. Do you have comments regarding stigma attached to patients who cannot work?
2. Do you have comments regarding early retirement due to chronic conditions?
3. What measures would you recommend to better support these groups of patients?

## 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. When work is one of several factors causing the illness among other causes, 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 key 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> .

# Patients’ stories & Patient organisations’ initiatives

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.[[38]](#footnote-38)

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, and development of self-care and measures to empower patients can contribute to their ability to remain at work.[[39]](#footnote-39)

The European Multiple Sclerosis Platform also launched a European Pact for Employment, directed at businesses, to encourage their commitment to provide sustainable employment for people with MS.[[40]](#footnote-40)

GAMIAN-Europe conducted a survey in 2013 on mental illnesses at work, which was presented in the European Parliament in a meeting focusing on mental health and societal integration.[[41]](#footnote-41)

**Question to EPF members:**

1. **Has your organisation (or members) done an initiative in relation to this topic?** Please share with us by providing a link (event report/project/survey/other) and a short paragraph describing the initiative which we will include in the position paper.
2. **You can also share a relevant patients’ quote**, which we can use within this paper
3. What do you think **the role of patients’ organisations** can be in relation to supporting patients in education? And in the workplace? (E.g. developing resources, workshops etc…) What type of support would organisations need to achieve this?

# 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, association of employers, associations that are active in the field of education, and healthcare professionals.

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

1. EPF recommends that **EU[[42]](#footnote-42) 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 sometimes 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.

## 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.

**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 available policies 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 resources to support their implementation.

## Creating supportive Patient-friendly environments for patients

**In education:**

1. Educational institutions should be **proactive in offering support** to young patients, pointing them towards the right point of contact, and providing information on their website. Patients may need more than punctual 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. School and teachers should work out a flexible solution to ensure they can take exams at a later date if their health conditions do not allow them to participate in an exam, 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 staff overseeing the exam should 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.

**At Work:**

1. 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.
2. 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.
3. 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).

## 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, **involvement of various stakeholders from the health, education and employment sectors are needed**.
2. **Active inclusions [[43]](#footnote-43)** and **youth employment policies and programmes[[44]](#footnote-44)** at EU and national level should explicitly target the unmet needs of young patients with chronic and long -term conditions.
3. The **EU OSHA[[45]](#footnote-45)** 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, in their dialogue with patients. Similarly, researchers should take into account these aspects in clinical trials.
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.

**Question to EPF members on final recommendations:**

1. Are you in contact with actors from the education field, or employers? What could help establish a dialogue between the patient community and this sector?
2. How do you think the EU can contribute to improvements in education and at work for patients with chronic diseases?
3. Do you agree with the above recommendations?
4. Do you have further recommendations?

**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 when they need it in education and in the workplace, and are encouraged to seek support.

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| http://www.mentorfoundation.org/uploads/pictures/Flag-of-Europe-150.png | This position paperarises from the EPF 2015 Work Programme, which has received funding from the European Union, in the framework of the Health Programme. Disclaimer: The content of this briefingreflects only the author’s views and the Executive Agency is not responsible for any use that may be made of the information contained therein. |

1. EMPATHY project page: http://www.eu-patient.eu/whatwedo/Projects/EPF-led-EU-Projects/EMPATHY/ [↑](#footnote-ref-1)
2. http://www.eurofound.europa.eu/observatories/eurwork/comparative-information/employment-opportunities-for-people-with-chronic-diseases [↑](#footnote-ref-2)
3. <http://ec.europa.eu/health/social_determinants/docs/final_full_ecorys_web.pdf>, p94-95 [↑](#footnote-ref-3)
4. http://www.eurofound.europa.eu/observatories/eurwork/comparative-information/employment-opportunities-for-people-with-chronic-diseases [↑](#footnote-ref-4)
5. 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-5)
6. 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-6)
7. 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-7)
8. <http://www.astri.nl/media/uploads/files/EF1226EN6.pdf>, p1 [↑](#footnote-ref-8)
9. https://osha.europa.eu/en/publications/magazine/4/ [↑](#footnote-ref-9)
10. http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:2020:FIN:EN:PDF [↑](#footnote-ref-10)
11. http://www.un.org/disabilities/convention/conventionfull.shtml [↑](#footnote-ref-11)
12. More information on objectives and activities: http://ec.europa.eu/justice/grants1/programmes-2014-2020/rec/index\_en.htm [↑](#footnote-ref-12)
13. More information: http://ec.europa.eu/social/main.jsp?catId=1081 [↑](#footnote-ref-13)
14. 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-14)
15. idem [↑](#footnote-ref-15)
16. idem [↑](#footnote-ref-16)
17. 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-17)
18. http://www.eurofound.europa.eu/observatories/eurwork/comparative-information/employment-opportunities-for-people-with-chronic-diseases [↑](#footnote-ref-18)
19. idem [↑](#footnote-ref-19)
20. Observatoire du CISS sur les droits des maladies rapport annuel de santé info droit 2011 [↑](#footnote-ref-20)
21. <http://www.eurofound.europa.eu/observatories/eurwork/comparative-information/employment-opportunities-for-people-with-chronic-diseases> [↑](#footnote-ref-21)
22. 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-22)
23. http://www.lemonde.fr/sante/article/2014/04/17/avoir-un-cancer-n-est-pas-une-faute-grave\_4402835\_1651302.html [↑](#footnote-ref-23)
24. http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex:32000L0078 [↑](#footnote-ref-24)
25. http://curia.europa.eu/juris/liste.jsf?language=en&num=C-13/05 [↑](#footnote-ref-25)
26. <http://www.enwhp.org/uploads/media/ENWHP_Guide_PH_Work_final.pdf> p 16-19 [↑](#footnote-ref-26)
27. Observatoire du CISS sur les droits des maladies rapport annuel de santé info droit 2011 [↑](#footnote-ref-27)
28. 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-28)
29. 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-29)
30. Observatoire du CISS sur les droits des maladies rapport annuel de santé info droit 2011 [↑](#footnote-ref-30)
31. <http://www.eurofound.europa.eu/observatories/eurwork/comparative-information/employment-opportunities-for-people-with-chronic-diseases> [↑](#footnote-ref-31)
32. <http://www.economistinsights.com/sites/default/files/Out%20of%20office_WEB.pdf>, P5 [↑](#footnote-ref-32)
33. http://www.economistinsights.com/sites/default/files/Out%20of%20office\_WEB.pdf, p7 [↑](#footnote-ref-33)
34. http://www.eurofound.europa.eu/observatories/eurwork/comparative-information/employment-opportunities-for-people-with-chronic-diseases [↑](#footnote-ref-34)
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37. <http://www.fitforworkeurope.eu/REPORT%20-%20Self-management%20of%20chronic%20musculoskeletal%20disorders%2009%202014.pdf>, p4-8 [↑](#footnote-ref-37)
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40. http://www.emsp.org/attachments/article/299/EMSP\_PACT.pdf [↑](#footnote-ref-40)
41. http://gamian.eu/wp-content/uploads/2014/11/Arteel\_19-11-2014-Mental-Illness-and-Workplace.pdf [↑](#footnote-ref-41)
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43. http://ec.europa.eu/social/main.jsp?catId=1137&langId=en [↑](#footnote-ref-43)
44. http://ec.europa.eu/social/main.jsp?catId=1036 [↑](#footnote-ref-44)
45. <https://osha.europa.eu/en> [↑](#footnote-ref-45)