Equal treatment for patients in education and employment

Tackling discrimination in education and in the workplace

1 Contents

2 Introduction

2.1 FOREWORD

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. 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.[1]

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.[2]

The objectives of this position statement are:

- To **raise awareness** amongst decision makers on challenges 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 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.

2.2 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[3].

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.

Multiple discrimination is relevant in the area of employment (i.e. when a person is discriminated on multiple grounds).

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[1] http://www.eu-patient.eu/globalassets/library/strategic-planning/epf-strategic-plan-2014-2020-final.pdf

[2] http://www.eu-patient.eu/globalassets/policy/anti-discrimmination/epf-position-discrimination-jan2015_final.pdf

[3] For more information please see the Handbook on European non-discrimination law of the Fundamental Right Agency, the European Court of Human Rights and Council of Europe, pp21-31
http://fra.europa.eu/sites/default/files/fra_uploads/1510-FRA-CASE-LAW-HANDBOOK_EN.pdf

EPF also combats **stigma**: stigma occurs when “certain differences (or imagined differences) are labelled or pointed out” and given negative associations.

Various EU policies aim at promoting at tackling discrimination and addressing inclusion of people with disabilities (see annex 1 page 20). However, given the variety of definitions of disability applied in Member States, it is not always clear whether this includes all patients with chronic and long-term conditions, creating a policy gap.

2.3 FACT AND FIGURES: WHY SHOULD DECISION MAKERS ACT?

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.[4]
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.[5] The participation of people with chronic and long standing conditions in the job market is problematic in the EU. [6]
3. While the **proportion of young people (children, adolescents, and young adults) with chronic diseases** is difficult to quantify[7], surveys carried out in France, Switzerland and Canada estimate that 10% of adolescents have chronic conditions.[8] The World Health Organisation also estimates it could be as high as **15%**.[9]
4. 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.”[10]
5. About **350 million working days are lost** in the European Union each year due to health-related problems. [11]
6. Direct patient evidence clearly indicates that this is a fundamental challenge for patients. In the EPF project EMPATHY “Europe Meets Young Patients”, funded under the Youth in Action Programme, young patients identified discrimination and stigma in education and the workplace as important obstacles they face, regardless of their nationalities or conditions.[12]

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[4] http://www.eurofound.europa.eu/observatories/eurwork/comparative-information/employment-opportunities-for-people-with-chronic-diseases

[5] http://ec.europa.eu/health/social_determinants/docs/final_full_ecorys_web.pdf, p94-95

[6] http://www.eurofound.europa.eu/observatories/eurwork/comparative-information/employment-opportunities-for-people-with-chronic-diseases

[7] 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.

[8] 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

[9] 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.

[10] http://www.astri.nl/media/uploads/files/EF1226EN6.pdf, p1

[11] https://osha.europa.eu/en/publications/magazine/4/

[12] http://www.eu-patient.eu/whatwedo/Projects/EMPATHY/

Integration of patients with chronic conditions into the job market is a widespread issue, starting from a young age. 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]

3 Discrimination and stigma in education

3.1 AT SCHOOL AND UNIVERSITY

As the EPF EMPATHY seminar with young patients highlighted, integration into the workplace is linked to education. Young patients with chronic and long-term conditions can face obstacles within the educational system. The effect of chronic conditions is not only medical; it may affect academic performance, emotional and physical development, and relationships with peers. It may cause anxiety and stress, cognitive impairments, fatigue, pain, and restlessness.[14] These problems are often overlooked by staff in educational institutions from school to university.[15]

> *"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

Patients may miss courses because of their disease, medical appointments, or treatment. 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 them at a disadvantage. In addition, patients may be affected by side effects of treatments and experience psychological problems as a result of living with and managing their condition. When the illness is invisible or changing, patients may experience stigma and be accused of exploiting their conditions by their peers or even staff.[16] Patient organisations have highlighted that in some cases, the staff refuses to help: this can be the case for young patients with food allergies (see quote), or with young patients with diabetes that need help with insulin injections[17]. In addition, in the field of mental health, school can be a root cause or contribute to the development of a condition; therefore early prevention (including secondary and tertiary) is important.

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[13] http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:2020:FIN:EN:PDF

[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

[15] idem

[16] idem

[17] 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

To follow their curricula, patients' may need adaptations to their timetable and studies that are not always available. This encompasses adjusting exam conditions (e.g. access to the bathroom, food during an exam) and schedules. However, young patients can face rigid administrative rules and miscomprehension from teachers and examiners.

Because 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, and their future income. Research also shows that poor health can be a predicator for decreased educational attainment, but this can be mitigated with appropriate support.[18]

3.2 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 inclusion or youth employment policies. They may be absent from employment statistics as well, as they do not account for health status.[19]

Unemployment from a young age is known to have long lasting effects. Patients are more likely to leave education early or with low qualifications.[20] In addition, young patients may scale down their ambitions or career goals, or change paths all together as a result of their condition.

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

Young patients in the EMPATHY seminar 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.

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[18] 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

[19] http://www.eurofound.europa.eu/observatories/eurwork/comparative-information/employment-opportunities-for-people-with-chronic-diseases

[20] idem

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

4.1 DIFFICULTIES FINDING A JOB / INTERVIEW STAGE

> *"Having a chronic condition is not out of the norm"*
> Patient representative, Multiple Sclerosis

Patients can face discrimination during interviews if they disclose their condition. They may 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 as he needed 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, and young patients can also face stigma from society. There is a misconception that they may be unable to work, when they may be, sometimes with only minor adjustments. Conditions can affect individual patients differently and have different degrees of severity.

4.2 WORKING WITH A CHRONIC CONDITION

While some patients cannot continue their professional activity due to their health condition, many 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. One example is that unemployment can contribute to mental health conditions: the longer unemployment lasts, the more difficult it is for patients with mental health conditions to go back to work. This illustrates that for patients, the value of staying at work goes beyond providing financial stability - it contributes to social inclusion, well-being, and even to recovery in some diseases areas.

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

For employers, the benefits of hiring and retaining employees with chronic conditions are 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, while retaining skilled staff and sparing additional costs of recruitment and training. Inclusive hiring policies show the company is taking responsibility for its impact on society. According to the European Commission, Corporate Social Responsibility is beneficial for companies, as well as for societies.[21]

In the workplace, 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 disclose 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

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").[22] The Eurofound study on employment opportunities for people with chronic conditions shows that they may have more difficulties obtaining training opportunities and promotion.[23]

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/

Combining a health condition with professional responsibilities can be challenging. For example, patients may need to take medical appointments during working hours or work with 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, which can lead to isolation and worsening of their condition.[24]

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 must travel with their oxygen, which can be a barrier to joining professions that require travel. Patients with diabetes face discrimination and barriers in obtaining driving licenses, which also affect their ability to work.[25]

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[21] http://ec.europa.eu/growth/industry/corporate-social-responsibility/index_en.htm

[22] Observatoire du CISS sur les droits des maladies rapport annuel de santé info droit 2011

[23] http://www.eurofound.europa.eu/observatories/eurwork/comparative-information/employment-opportunities-for-people-with-chronic-diseases

[24] 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

[25] IDF Europe survey on diabetes and driving license : https://www.idf.org/sites/default/files/DL_report_220910.pdf

There are data available across diseases and across Member States on the specific difficulties, stigma, and discrimination that patients can face at the workplace:

- 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.[26]
- 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.[27]
- 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.[28] In addition, people with epilepsy are more than twice as likely to be unemployed as the general population.[29]
- Rare Diseases: In EURORDIS Care Survey to 12000 patients from 23 countries (2002-2008) - 1/3 of the respondents reported that a patient in their family had to reduce or stop professional activities due to the disease; an additional 1/3 reported that one member in the family had to reduce or stop professional activities to take care of a relative with a rare diseases.[30] In the ENSERio Study performed in Spain (2009) - patients mentioned that they generally need support for educational/professional activities (39%); patients reported they feel discriminated in education (30%) and in labour market (32%) either when searching for a job (17%) or in their current job (15%). [31]
- Mental health: People with mild to moderate disorders, such as anxiety or depression, are twice as likely to be unemployed. They also run a much higher risk of living in poverty and social marginalisation. Mild to moderate mental health problems will affect one fifth of the working age population.[32]
- Cancer: Survivors are at higher risk of unemployment (data exist particularly in breast cancer, gastrointestinal cancers, and cancer of the female reproductive organs), for multiple causes including discrimination.[33] Various sources indicate that even with legislation in place,

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[26] http://www.emsp.org/projects/paving-the-path-to-participation

[27] 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

[28] These examples and further data can be found at http://issuu.com/efna/docs/book-of-evidence-issuu/1?e=13518211/11530120, p 12

[29] idem

[30] EURORDIS. The Voice of 12 000 Patients. Experiences and expectations of rare disease patients on diagnosis and care in Europe. Paris: EURORDIS; 2009- http://www.eurordis.org/IMG/pdf/voice_12000_patients/EURORDISCARE_FULLBOOKr.pdf

[31] FEDER - Federación Española de Enfermedades Raras. Study on the Situation of Social-sanitary Needs of People with Rare Diseases in Spain – ENSERio. 2009. https://www.enfermedades-raras.org/images/stories/documentos/Estudio_ENSERio.pdf

[32] http://www.oecd.org/els/health-systems/Focus-on-Health-Making-Mental-Health-Count.pdf

[33] Cancer Survivors and Unemployment: A Meta-analysis and Meta-regression Angela G. E. M. de Boer; Taina Taskila; Anneli Ojajärvi; Frank J. H. van Dijk; Jos H. A. M. Verbeek, JAMA 2009 301: 753-762. http://jama.jamanetwork.com/article.aspx?articleid=183387#ref-jcr90000-7

patients face obstacles in practice.[34] Workplace was integrated in the Council of Europe report "Towards optimum breast cancer services across Europe".[35]

- In the Netherlands: A study carried out in partnership between patient and disability associations showed that many patients are still facing barrier to work including lack of appropriate work and discrimination or lack of support.[36]
- Lupus: Lupus Europe carried out a survey in 2010 which showed the substantial burden of lupus on patients' careers: 69 percent of respondents reported lupus affected their career. While 53 percent of respondents were still employed, after a few years of diagnosis many patients leave the workforce. [37]

4.2.1 DISCLOSING THE ILLNESS

> *"If you reveal that you have had a mental health issue in the past you can lose out of the possibility to get the job. If you reveal it at the workplace it still all too often happens that you lose your job. Despite the fact that evidence shows that having a diverse workforce is of great benefit for a company!"*
> Mental Health Europe

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

Data from a study carried out with Multiple Sclerosis patients in Australia indicates that disclosing can be beneficial to career progression.[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.

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*** combats 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.[39]

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[34] http://cancerworld.org/pdf/3146_pagina_56-61_patientvoice.pdf
http://www.lemonde.fr/societe/article/2014/04/17/le-retour-au-travail-apres-un-cancer-reste-souvent-problematique_4402828_3224.html

[35] http://www.assembly.coe.int/nw/xml/XRef/X2H-Xref-ViewPDF.asp?FileID=21051&lang=en

[36] https://iederin.nl/nieuws/17680/arbeidsdeelname-van-mensen-met-een-beperking-onnodig-laag/

[37] http://www.ncbi.nlm.nih.gov/pubmed/24049101

[38] http://msj.sagepub.com/content/20/7/871.abstract

[39] http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex:32000L0078

A key shortcoming of the Directive is that it does not harmonize definitions of disability, which can 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.[40] Nevertheless, if the chronic condition is considered as disability by the Member State 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: 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

4.2.2 RIGHTS OF PATIENTS AT WORK

> *"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

Ensuring that workplace environments offer adequate support and adjustment for patients with chronic conditions is crucial to achieve EU 2020's goal of "smart, sustainable and inclusive growth". Supporting people with chronic diseases to stay employed could have multiple benefits for the employee, for the employer who is able to retain staff, and for the economy. This strategy could contribute to tackling the shrinking population size of working-age adults as a result of demographic change.

The lack of clear structure and rights encountered by patients in various situations could be considered an indirect structural form of discrimination. For example, it is unclear whether they are protected when they risk losing their job due to repeated or long-term absence[41]. Patients' rights regarding the workplace are not always clear, do not respond to the needs of patients, and 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.[42] Actions to raise

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[40] http://curia.europa.eu/juris/liste.jsf?language=en&num=C-13/05

[41] Observatoire du CISS sur les droits des maladies rapport annuel de santé info droit 2011

[42] 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

awareness within companies or trade unions and for the general public could contribute significantly to tackling this problem.[43]

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.[44]

4.2.3 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.[45] Provisions for sick leave vary across Member States, with different degrees of burden on State, employers, and employees to bear the cost. The report suggests that some systems are deterring absenteeism[46] and encouraging presenteeism[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]

Returning to work after a sick leave has also been flagged as important by patient organisations, and it was documented by the OECD.[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]

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. Flexible solutions like part-time sick leave[51] implemented in Sweden, have been flagged as beneficial by patient organisations.

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/

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[43] 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

[44] Campaign « Dying to work » led by the Trade Union Congress in the UK : http://www.dyingtowork.co.uk/

[45] http://www.economistinsights.com/sites/default/files/Out%20of%20office_WEB.pdf, P5

[46] Absenteeism means the practice of being frequently absent from work

[47] Presenteeism in this context means staying at work in spite of illness or injury, resulting in loss of productivity

[48] http://www.economistinsights.com/sites/default/files/Out%20of%20office_WEB.pdf , p7

[49] http://www.eurofound.europa.eu/observatories/eurwork/comparative-information/employment-opportunities-for-people-with-chronic-diseases

[50] http://www.lemonde.fr/societe/article/2014/04/17/le-retour-au-travail-apres-un-cancer-reste-souvent-problematique_4402828_3224.html

[51] With part-time sick leave patients can work part of the time while still being on sick leave.

4.2.4 RELATION BETWEEN APPROPRIATE HEALTHCARE ACCESS AND PATIENTS' ABILITY TO REMAIN AT WORK

> *"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

Patients' organisations often note a correlation between patients' ability to remain at work and appropriate access to healthcare. Early diagnosis is highlighted as crucial to ensure patients can remain at work longer.

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. [52] The study postulates that improved management of COPD (both through healthcare policies and workplace adjustments) could allow patients to remain at work longer.

Patient empowerment and self-management skills may 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. "[53] A study conducted by Fit for Work on patients with musculoskeletal conditions has shown that patients often utilise self-management[54] strategies but are not always supported by other stakeholders (line managers, colleagues, healthcare professionals).[55]

4.3 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 retire early as a result of their condition and need appropriate financial support. However depending on the country and the condition of the patients, they are not always entitled to disability benefits. Sometimes, patients may need a career change to a less physically demanding or stressful job but support is not always available to achieve this.

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[52] 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

[53] http://ec.europa.eu/health/patient_safety/docs/empathie_frep_en.pdf, p6

[54] 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".

[55] http://www.fitforworkeurope.eu/REPORT%20-%20Self-management%20of%20chronic%20musculoskeletal%20disorders%2009%202014.pdf, p4-8

The focus should be placed on what the patient can still do, whether at work or in other areas of life. When patients have a progressive disease, in many instances there is no process in place in workplaces to assess, with the patient, when they will no longer be able to work.

> *"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".*
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> -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,

4.4 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 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.[56]

4.5 PATIENTS' FAMILIES AND CARERS

For patients with various chronic diseases, for example the rare disease community, parents, grand-parents, siblings, partners, and other family members face huge challenges in regards to school, employment and other daily life areas. Patients' health status and their difficulties to remain at work may affect the working situation of their family carers. Caring may lead to difficulties balancing paid

> *MP has so many medical appointments, and therapy sessions each week that I had to stop working. I have only 4 hours free to come back home, do the cleaning, cook, go to supermarket, deal with the infinite bureaucratic processes that we have to deal with to get a special school, special social wealth assistance and ask for national families budget support. Then, I pick him up again, come back home and accompany him in all the exercises his therapist has given him. I go to bed exhausted and I don't get a lot of help at home. I'm an architect, I loved my work and I miss it a lot! At this moment, it is impossible for me to find a job»*
> Sandra, mother of MP, 3 years old, living with Congenital Disorder of Glycosylation, Spain (provided by EURORDIS)

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[56] http://www.eu-patient.eu/globalassets/policy/anti-discrimmination/epf-response-osh-2013.pdf.

work with care responsibilities. Carers may give up on work due to their caring activities, or may lose their job, and may need support (including financial).

5 Patient organisations' initiatives

Many patients' organisations have taken action to advocate for the rights of patients at the workplace. Examples of various initiatives by EPF members are listed below. They show the important role patient organisations can have in advocating against stigma, in carrying out research to better identify the obstacles and solutions, and in taking concrete initiatives.

Awareness raising and advocacy:
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 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.[57] 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.[58]These examples provide further details on specific challenges in various diseases area.

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, particularly amongst employers. Other campaigns have been carried out by patient organisations, for example "Make LUPUS Work"[59], and Mental Health Europe's campaign "Tried and Trusted" around employment of young people with mental health conditions and published a video on individual placement and support.[60]

Gathering information
In 2013, GAMIAN-Europe conducted a survey on mental illnesses at work.[61] The European Federation of Neurological Associations has published a book of evidence which contains several patients' testimonies on work, as well as good practices.[62] The Collectif Interassociatif Sur la Santé (CISS) publishes a report every year analysing the inquiries received on their helpline. Several

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[57] http://www.efanet.org/wp-content/documents/EFANewsletterCOPDWorkshop2.pdf

[58] Event report available at:
http://www.emsp.org/attachments/article/198/Neurodegenerative%20diseases%20event_final%20report.pdf

[59] Lupus Europe put in place a campaign in 2012 Make LUPUS Work! To raise awareness of consequences of Lupus on patients' careers.

[60] https://employmentforyouth.wordprVess.com/ . The campaign promotes individual placement and support for people with mental health problems. A video was produced to explain this concept and show its implementation:
https://www.youtube.com/watch?v=wTGDDGJT-M4

[61] http://gamian.eu/wp-content/uploads/2014/11/Arteel_19-11-2014-Mental-Illness-and-Workplace.pdf

[62] "Brain, mind and pain, the book of evidence"http://issuu.com/efna/docs/book-of-evidence-issuu/1?e=13518211/11530120,

chapters provide information on the situation in the workplace of patients with chronic diseases and people with disabilities in France.[63]

Initiating projects and research

The European Multiple Sclerosis Platform launched a **European Pact for Employment campaign**, directed at businesses, to encourage their commitment to providing sustainable employment for people with MS.[64]

The association FEDER for rare diseases (Spain) put in place the educational program “Go to the school with FEDERITO” to promote the inclusion of children living with rare diseases. It consists of making a didactic playful activity with teachers and students in kindergarden and Primary Education, based on a children's story "The Story of FEDERITO”, with teaching materials to raise awareness of families.

The Italian federation of rare diseases put in place the project "Fantasia" Restaurant in Venice: it is designed to give dignity to people with disabilities, contributing to their working integration and professional training. It gives patients a place to socialise and a testing laboratory to try new experiences. The goal is to provide job placement to patients, promote a working culture that integrate people affected by rare diseases.[65]

Participating in policy making

The Flemish Patients Platform (VPP) is part of the ‘Gebruikersoverleg Handicap, Chronische Ziekte en Arbeid’. It reunites different user-organisations active on work and chronic diseases/disabilities. It represents the voice of the user in several policy bodies in Flanders, such as the diversity committee of the SERV. This body is currently working on a list of actions that must be executed in the next few years to achieve a more inclusive labour market, including education and transition to a job.

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

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.

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[63] See Chapter 3 and 5 http://www.leciss.org/sites/default/files/Observatoire-CISS-2014-BD.pdf
[64] http://www.emsp.org/attachments/article/299/EMSP_PACT.pdf
[65] http://www.rare-diseases.eu/wp-content/uploads/2014/05/0605_Renza_Barbon_GALLUPPI.pdf

6.1 ESTABLISHING APPROPRIATE RIGHTS AND LEGISLATION FOR PATIENTS WITH CHRONIC DISEASES

1. EPF recommends that **EU and Member States' legislation on equal treatment in workplaces** should prohibit discrimination based on health status/chronic conditions. [66]
2. EPF recommends improving Member States **disability assessment systems**, to ensure there are no gaps in integration of chronic diseases that cause disabilities. Functionality/incapacity should be properly assessed and supported with adequate compensation measures.
3. The EU and Member States should provide for clear **rights to adjustments and accommodations in education and at work,** and encourage implementation of these rights.
4. While **access to a profession** may need to be restricted for some conditions, limitations need to be justified and proportionate.
5. The impact of various **sick leave** models of organisations [67] and legislation needs to be further studied, including impact on the patients, their health outcomes, and their career.
6. **Patients facing discrimination** should have access to mediation, complaint and redress mechanisms at national level, and independent support structure to seek compensation.
7. Member States should ensure that **terminally ill patients** are adequately protected by legislation, and ensure that employers provide reasonable adjustments to these patients.
8. Patients who cannot work as a result of their health status should have the right **to financial support.** Financial incentives are an important policy option to encourage employment of patients with chronic diseases.
9. Appropriate legislation is needed to support **carers** and ensure they benefit from their right to work. Appropriate respite should be granted, as well as flexible solutions for carers' leave.

6.2 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 (whether for physical or mental health conditions). The direction should ensure, with the consent of the students and their parents, that staff members are appropriately informed about the condition, its consequences, and 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** should provide an online webpage for advice on equal treatment of students with chronic conditions, designed for students and for staff or institutions.

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[66] http://eur-lex.europa.eu/legal-content/EN/NOT/?uri=CELEX:32000L0078

[67] How benefits to cover sick leave are organised vary vastly across Europe, and different proportion of the costs are supported by employers, employees, and governments.
http://www.economistinsights.com/sites/default/files/Out%20of%20office_WEB.pdf

At work:

1. **Actions and campaign to raise awareness at EU and national level of difficulties faced by patients and existing policies to support both employees and manager,** within companies, trade unions and for the public, could contribute significantly to tackling stigma faced by patients with chronic diseases. It is important to inform workers, employers, and human resources managers about existing rules and rights.
2. The EU should encourage Member States to provide **one stop shop websites** to inform employers and employees with chronic conditions about the rights of patients at work.

6.3 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. Patients should receive continuous support, reviewed after an appropriate period of time involving the young student. This should include management of absences and special needs in exams, when needed.
2. 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**. It requires employers and managers to be open and know that they may need outside expertise. It requires a functional absence-management procedure, audit and evaluation of absence management policies, and staff properly trained to support colleagues who have a health condition.
2. Appropriate support and policies for prevention, workplace adjustment, accommodations, and **return to work** need to be implemented, building on existing good practices. More research in this area is needed in the EU 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 **have a professional reorientation**, 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, 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. The EU and member states should encourage them to become **diversity and inclusion champions**.

6.4 COOPERATION ACROSS POLICY AREAS: HEALTH/EDUCATION AND EMPLOYMENT

1. To effectively raise awareness and tackle 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** [68] and **youth employment policies and programmes**[69] at EU and national level should explicitly target the unmet needs of young patients with chronic and long -term conditions.
3. The **EU OSHA**[70] 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 aiming at ensuring equal treatment in education and in employment should **involve patients and their organisations** in order to ensure they meet patients' needs. Patient organisations are actively promoting equal treatment at school and at work and combating stigma, as shown in part 5. But to do so effectively, they need appropriate resources to support their project, including funding, and willingness of decision makers and institutions to involve them. With appropriate support, successful initiatives put in place by patient organisations could be replicated and scaled up.

7 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 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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[68] http://ec.europa.eu/social/main.jsp?catId=1137&langId=en
[69] http://ec.europa.eu/social/main.jsp?catId=1036
[70] https://osha.europa.eu/en

8 Annex I How is discrimination addressed in EU legislation?

8.1 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. 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.

8.2 POLICY FRAMEWORK

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

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. In addition, the EU Programme for Employment and Social Innovation (EaSI) aims at improving working conditions in the EU.

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