

EPF's response on the European Pillar for Social Rights

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Contents

1. Introduction	3
1.1 What is the European Pillar for Social rights?	3
1.2 Why is it of interest for patients?	4
1.3 Methodology for the EPF response	4
2. Responses to the consultation	4
2.1 On the social situation and EU social "acquis"	4
2.2 On the future of work and welfare systems	7
2.3 On the European Pillar of Social Rights	9
2.4 Detailed comments by domain	12
2.4.1 Skills, education and life-long learning	13
2.4.2 Secure professional transitions	14
2.4.3 Gender equality and work-life balance	15
2.4.4 Equal opportunities	17
2.4.5 Health and safety at work	18
2.4.6 Social dialogue and involvement of workers	19
2.4.7 Integrated social benefits and services	20
2.4.8 Health care and sickness benefits	22
2.4.9 Disability benefits	24
2.4.10 Long-term care	25
2.4.11 Childcare	26

1. Introduction

1.1 WHAT IS THE EUROPEAN PILLAR FOR SOCIAL RIGHTS?

On March 2016 the European Commission launched a consultation on a first outline for a European Pillar of Social Rights. The purpose of the Pillar is to express a number of essential principles to support well-functioning and fairer labour markets and welfare systems in the European Union. While Member States are primarily competent to define their employment and social policy, the EU has a supporting role in these areas defined by the treaty on the functioning of the European Union in Title X “Social Policy”, and by the Charter of fundamental rights of the European Union.

At this stage the future legal status of the Pillar or potential change to legislation that it could imply has not been defined. The Commission will consult with the Parliament and the Council to define the appropriate legislative instruments.

The Pillar is first developed for member states belonging to the “Eurozone”¹ but will allow other EU Member States to join voluntarily. Once established, the ambition is that the Pillar should become a reference framework to evaluate the employment and social performance of Member States.

There are 3 main heading for the pillars:

- **Equal opportunities and access to the labour market**
- **Fair working conditions**, with a balance of rights and obligations between employers and workers
- **Adequate and sustainable protection** including access to high quality essential services such as childcare, healthcare and long term care to ensure dignified living

The full outline of the principles proposed is available in [this document](#).

The public consultation aims at:

- Assessing the EU acquis² in the social domain – whether it is still fit for purpose
- Reflecting on new trends in work patterns and societies due to the impact of demographic trends new technologies and other factors
- Identifying good practices from social innovation
- Discussing the scope and content of the Social pillar

¹Belgium, Germany, Ireland, Greece, Spain, France, Italy, Cyprus, Luxembourg, Malta, The Netherlands, Austria, Portugal, Slovenia, Slovakia, Finland, Estonia, Latvia, Lithuania

² The notion of social “acquis” refers to the body of social rules that exist in the EU legal order today. It includes existing treaties, directives and regulations. For more information, see this document: <http://ec.europa.eu/social/BlobServlet?docId=15292&langId=en>

1.2 WHY IS IT OF INTEREST FOR PATIENTS?

The consultation is of interest for patients and their organisations as it provides an opportunity to raise awareness of the need to support patients' inclusion in the workplace. In addition, the consultation also encompasses topics like access to healthcare and social services and long term care which are essential to patients.

This is a high level, cross cutting initiative therefore by participating, EPF can advocate for patients' rights in healthcare, social services and other domains, and to highlight the importance of applying the principle of health in all policies in this initiative.

1.3 METHODOLOGY FOR THE EPF RESPONSE

EPF's draft response is based on our previous work, including [our response to the chronic diseases reflection process](#), our [position statement on equal treatment of patients in education and the workplace](#), and [EPF's definition of access to healthcare](#). It is also based on a preliminary discussion held with the EPF Policy Advisory Group in July 2016.

EPF held a round of consultation with our members in order to develop our response in September and October, and finalised it with the aim to submit it in early December. The response will be made public on EPF website.

2. Responses to the consultation

2.1 ON THE SOCIAL SITUATION AND EU SOCIAL "ACQUIS"

1. What do you see as most pressing employment and social priorities? (2000 Characters maximum)

From EPF's perspective, focusing on the needs of patients with chronic and long term conditions, a **first pressing social priority is universal, equitable access to high quality healthcare**. Inequalities persist both in terms of access to healthcare and quality of care, within and between Member States. Data collected by patients' organisations show that there are disparities in access to healthcare and treatment that affect patients' quality of life, health outcomes and ability to remain in employment.³

Another priority is the **development of supportive working environments** for patients. 1 in 4 people of working age are estimated to live with long standing health problems that

³ See sources cited on p10 of EPF response to the consultation on chronic diseases <http://www.eu-patient.eu/globalassets/policy/chronic-disease/epf-chronic-diseases-consultation-response-2012.pdf>

restrict their daily activities.⁴ The participation of people with chronic conditions in the job market in the EU has been described by the Eurofound as “problematic”.⁵ They may face stigma or discrimination at work at various stages (during interview, after revealing a diagnosis, after a sick leave) which prevents them from entering/remaining in the labour market. Chronic conditions can be complex, can cause functional limitations and may require change and flexibility in the workplace. Patients’ rights are unclear and employers or managers are often untrained to face such situations. Ensuring that workplaces offer support for patients is crucial to achieve EU 2020’s goal of “smart, sustainable and inclusive growth”.

Patients’ organisations often note a correlation between patients’ ability to remain at work and access to healthcare. **Early diagnosis and intervention** are crucial to ensure that adequate care and compensation are provided to patients as early as possible, to prevent the increase of their vulnerability in regards to employment access and retention. To maximise economic productivity and minimise the economic and social impact on patients and families, EU social legislation must be consistently implemented and access to rapid diagnosis and treatment must be available to all patients.

2. How can we account for different employment and social situations across Europe? (2000 Characters maximum)

The existence of health inequalities in the EU as well as their socio-economic consequences are well documented. While there is a good body of research on health inequalities, it tends to focus on health determinants and prevention. Further indicators on access to healthcare services and support for chronic and long-term disease management are needed in order to truly reflect and ultimately improve the situation of vulnerable groups such as patients. More and better indicators focusing on groups vulnerable to health inequalities would also be essential to measure progress towards universal health coverage. In 2015, EPF developed a definition of access to healthcare from the patients’ perspective as patients with chronic diseases are more often in contact with the healthcare system and have specific experience of access barriers and health inequalities. The definition we adopted looks at five dimensions: adequacy, appropriateness, accessibility, availability and affordability. We also provided recommendations towards developing indicators on access to healthcare that capture the patients’ experience more accurately than existing indicators currently do. This work is available publicly on our website.⁶ We believe that such a definition and indicators

⁴ http://ec.europa.eu/health/social_determinants/docs/final_full_ecorys_web.pdf, p94-95

⁵ <http://www.eurofound.europa.eu/observatories/eurwork/comparative-information/employment-opportunities-for-people-with-chronic-diseases>

⁶ http://www.eu-patient.eu/globalassets/policy/access/epf_position_defining_and_measuring_access_010316.pdf

defined with patients' input are crucial in order to identify issues accurately, and implement the appropriate policy responses to tackle access barriers.

Patients diagnosed with chronic diseases may be vulnerable to socio-economic difficulties. A key issue when it comes to employment is the disparities both in terms of rights and practices in managing chronic conditions at work and supporting patients who cannot work. Gathering knowledge at EU level is essential in order to scale up good practices and successful policy measures across Member States.

3. Is the EU "acquis" (legislation and initiatives so far in the social area; click [here](#) for a summary prepared by the EU Commission) up to date and do you see scope for further EU action? (2000 Characters maximum)

From our perspective, there are several gaps in the EU acquis. The first one relates to **equal treatment in the workplace**. In most member states, patients with chronic conditions may be protected from discrimination on the ground of disability, yet different definitions of disabilities are applied across EU countries' functioning assessment systems. As a result, some patients are not adequately supported if their condition does not fit in the definition. EPF recommends that EU and Member States' legislation on equal treatment in workplaces and in other areas of life (healthcare, insurances) should prohibit discrimination based on ground of health status/chronic conditions.

When it comes to **termination of employment**, there are also gaps. Patients and carers who can no longer stay in employment due to deteriorating health conditions suffer the additional burden of losing their job without any financial compensation or social support. This leads to serious mental, financial and physical hardships.

As regards social security coordination, the Regulation on the coordination of social security systems and the Directive on **patients' rights in cross border healthcare**, if implemented well, could serve to reinforce a healthy society and tackle inequalities. However, in our experience there are challenges related to providing information to patients and citizens, and ensuring Member States work towards removing barriers to access cross border-healthcare. EPF has held conferences with the patient community to gather feedback on the implementation of the Directive and made recommendations on the changes needed in this area which are available [here](#).

The **European Semester** is also cited as part of the EU social acquis. We welcome the increasing number of country reports and recommendations that take into account access to healthcare and its consequences on the health of the workforce and ultimately the economy. However stronger recommendations could be made for Member States that invest too little in access to health and social support for people affected by chronic conditions and their carers.

2.2 ON THE FUTURE OF WORK AND WELFARE SYSTEMS

4. What trends would you see as most transformative? [Please select at most three from the list below] between 1 and 3 choices

- Demographic trends (e.g. ageing, migration)
- Changes in family structures
- New skills requirements
- Technological change
- Increasing global competition
- Participation of women in the labour market
- New ways of work
- Inequalities
- Other

Other Please specify:

5. What would be the main risks and opportunities linked to such trends? 2000 character(s) maximum

From the perspective of patients, **health inequalities** are an important trend that affect the health workforce, the economy, social cohesion, well-being and healthcare sustainability. Current risks related to health inequalities arise from the cost they carry for the healthcare system, human cost for the patient, and ultimately to society as a whole, as a healthy workforce is important for a productive economy. The economic cost of health inequalities could be as high as 20% of the costs of healthcare and 15% of the total costs of social security benefits.⁷ It is estimated that about 350 million working days are lost in the European Union each year due to health-related problems.⁸ Coordinated actions to reduce health inequalities represent a key opportunity for the future of work and welfare systems.

Demographic change is also a transformative trend. As the general population ages, the number of patients with chronic diseases will inevitably grow. Though some chronic diseases are to some extent preventable, many including neurodegenerative, genetic or rare diseases are not. This trend requires adaptation in our welfare systems, changes in healthcare including a more person centred, integrated, holistic approach to care, and patient empowerment strategies. It also requires changes in the workplace in order to ensure patients with chronic conditions can remain at work longer.

⁷ 8 JP Mackenbach et al., "Economic costs of health inequalities in the European Union", J Epidemiol Community Health 2011;65: 412-419.

⁸ <https://osha.europa.eu/en/tools-and-publications/publications/magazine/4>

Technological change presents important opportunities to support the management of chronic conditions, but is often driven by technology or profit motives rather than users' needs in healthcare. In order to avoid waste in this area, the European Union should ensure end users including patients are meaningfully involved in the development of technology related to health.

6. Are there policies, institutions or firm practices – existing or emerging – which you would recommend as references? 2000 character(s) maximum

There are various schemes and good practices implemented in EU Member States in the area of supporting patients with chronic diseases at the workplace:

In Ireland, welfare schemes allow employers to get grants towards the costs of adapting the workplace or buying equipment, to retain employees that acquire an illness or a disability, or provide trainings to employees to maintain good working relationships with colleagues with disabilities, as well as financial incentives to employ people with disabilities.⁹

Finland offers all employees with long-term illnesses an opportunity to work part-time.

¹⁰

The UK government provides an online platform, FitForWork to advise GPs, employees and employers, with information about health at work including workplace adjustments, as well as a helpline.¹¹ The UK has established a new policy around return to work, with a fit note instead of a sick note and guidance for stakeholders concerned (patients, managers, healthcare professionals). The aim is to propose phased return to work or adjustments that could be necessary.

In Austria, a website Fit2Work has also been put in place to provide advice for employees and employers.¹²

For good practices within firms, one example is the German car manufacturer BMW which employed a research team to collect information from a group of employees on all the pains they experienced on the job, and suggestions on how conditions might be improved to reduce or eliminate these. Through small changes e.g. adjustable worktables, the project had an important impact, with less sick leave, and financial benefit for the company through increased productivity.¹³

⁹ <http://www.welfare.ie/en/Pages/Supports-for-People-with-Disabilities.aspx>

¹⁰ <http://www.brainmindpain.eu/wp-content/uploads/2016/11/BMP-WrittenDeclaration-SCREEN.pdf>

¹¹ <http://support.fitforwork.org/app/home/type/employee>

¹² <http://www.fit2work.at/home/>

¹³ <http://www.brainmindpain.eu/wp-content/uploads/2016/11/BMP-WrittenDeclaration-SCREEN.pdf>

The European Multiple Sclerosis Platform led the “Believe and Achieve” project which established 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.¹⁴

As regards new technology and health, EPF has highlighted various innovations that have been developed with patients’ organisations in the field of eHealth in our position paper on eHealth, including the MyDystonia application.¹⁵

2.3 ON THE EUROPEAN PILLAR OF SOCIAL RIGHTS

7. Do you agree with the approach outlined [here](#) for the establishment of a European Pillar of Social Rights?

- I strongly agree
- I agree
- I disagree
- I strongly disagree

Please specify:

While we agree with the general approach outlined we disagree with the idea that it should only apply to the Eurozone countries in the first place. The latest country reports of the European Semester have shown that in the area of healthcare, the countries most in need of actions to improve universal health coverage for example are often outside of the Eurozone.¹⁶

Once the principles are adopted it is critical to define appropriate means in order to support their implementation, and indicators to monitor the process and ensure accountability of Member States.

From the patients’ perspective it is crucial that the Pillar of Social Rights also focuses prominently on access to healthcare. It is a basic human right and one of the fundamental principles of European health systems. Healthcare should be accessible to every person who needs it, not only those who can pay; regrettably this is not a reality for all in the EU. Issues in access to healthcare have a socio-economic impact for patients with chronic conditions and their families, including in terms of accessing and retaining employment, which in turn can affect their financial situation and can lead to social exclusion. Health inequalities and barriers to access also have consequences on the economy and society as a whole, as they

¹⁴ <http://www.emsp.org/projects/believe-and-achieve>

¹⁵ *To add once available*

¹⁶ http://ec.europa.eu/europe2020/making-it-happen/country-specific-recommendations/index_en.htm

impact the health of the workforce. As a result, these can affect productivity, spending on sick leave and can also lead to more premature mortality.

The Pillar should also be linked to international charters in the social area, such as the United Nations Convention on the Rights of Persons with Disabilities ratified by the EU. No reference is made of the United Nations sustainable development goals for health which are global goals to which the European Union should contribute. The goals set clear targets for 2030 such as achieving universal health coverage. Experience from our membership shows that universal health coverage is not yet a reality for many patients in the EU, in terms of the population covered, the services covered, or the co-payments required.

8. Do you agree with the scope of the Pillar, domains and principles proposed here? (there is space for more detailed comments later

	<u>I strongly agree</u>	I agree	I Disagree	I strongly disagree
1. Skills, education and life-long Learning				
2. Flexible and secure labour Contracts				
3. Secure professional transitions				
4. Active support for employment				
5. Gender equality and work-life Balance				
6. Equal opportunities				
7. Conditions of employment				
8. Wages				
9. Health and safety at work				
10. Social dialogue and involvement of workers				
11. Integrated social benefits and Services				
12. Health care and sickness Benefits				
13. Pensions				
14. Unemployment benefits				
15. Minimum income				
16. Disability benefits				
17. Long-term care				
18. Childcare				
19. Housing				
20. Access to essential services				

Are there aspects which are not adequately expressed or covered so far?

We believe that empowerment of people in the EU in relation to their health and social rights is an important aspect that is not addressed here. Empowerment is “a multi-dimensional process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important.”¹⁷ Collective empowerment is “a process through which individuals and communities are able to express their needs, present their concerns, devise strategies for involvement in decision-making, and take political, social, and cultural action to meet those needs.”¹⁸

Key work has been developed these last few years in relation to patient empowerment notably through the EMPATHiE study¹⁹, and on health literacy, a concept that encompasses literacy skills but also the capacity to use information and effectively navigate the health system.²⁰

In the context of the rights and principles addressed in this consultation we believe that information and awareness of rights, as well as facilitating access to these rights would be essential to implement the social rights pillar in the EU, and to ensure engagement of citizens.

In the area of healthcare, health literate, empowered patients have been shown to have better health outcome, less hospitalization, and to make less costly treatment choices. Patient empowerment is in our assessment a vital element in the future sustainability of European healthcare systems, to enable them to cope with the challenges posed by organisational and structural reforms, increasing prevalence of chronic conditions, and the impact of innovative technologies.

To raise awareness about empowerment and to identify key actions towards patient empowerment in the EU, EPF has developed a charter for patient empowerment which provides key principles and a roadmap for an EU patient empowerment strategy available on our website.²¹

¹⁷ Joint Action on Patient Safety and Quality of Care (PaSQ,) adapted from Luttrell et al. 2009 and the Duque project (www.duque.eu)

¹⁸ http://www.eu-patient.eu/globalassets/campaign-patient-empowerment/briefing_paperpatient-empowerment_final_external.pdf, p5

¹⁹ <http://www.eu-patient.eu/whatwedo/Projects/EMPATHiE/>

²⁰ For more information on EPF’s work on health literacy please see: <http://www.eu-patient.eu/whatwedo/Policy/Health-Literacy/>

²¹ <http://www.eu-patient.eu/campaign/PatientsprescribE/>

9. What domains and principles would be most important as part of a renewed convergence for the euro area? (Please select maximum 5)

1. Skills, education and life-long learning	11. Integrated social benefits and services
2. Flexible and secure labour contracts	12. <u>Health care and sickness benefits</u>
3. Secure professional transitions	13. Pensions
4. Active support for employment	14. Unemployment benefits
5. Gender equality and work-life balance	15. Minimum income
6. <u>Equal opportunities</u>	16. <u>Disability benefits</u>
7. Conditions of employment	17. Long-term care
8. Wages	18. Childcare
9. <u>Health and safety at work</u>	19. Housing
10. Social dialogue and involvement of workers	20. Access to essential services

2.4 DETAILED COMMENTS BY DOMAIN

If you wish to provide detailed comments on any of the domains, please select one or more from the list below and fill the table(s) and comment box(es) underneath. (A detailed description of the domains and principles is available [here](#))

- Skills, education and life-long learning
- Flexible and secure labour contracts
- Secure professional transitions
- Active support for employment
- Gender equality and work-life balance
- Equal opportunities
- Conditions of employment
- Wages
- Health and safety at work
- Social dialogue and involvement of workers
- Integrated social benefits and services
- Health care and sickness benefits
- Pensions

- Unemployment benefits
- Minimum income
- Disability benefits
- Long-term care
- Childcare
- Housing
- Access to essential services

2.4.1 SKILLS, EDUCATION AND LIFE-LONG LEARNING

Challenges identified and actions proposed by the European Commission: The challenges identified in this area include issues of basic literacy, equal access to education regardless of economic means, and need for more up-skilling and lifelong learning due to demographic ageing.

The principle proposed as a solution is that all person should have access to high quality education throughout the life course, with a particular emphasis on low skilled young people and workers.

	I strongly agree	I agree	I disagree	I strongly disagree
Do you agree with the challenges described?		X		
Is the principle addressing these challenges in the right way?	X			
Should the EU act to put in reality this principle?	X			

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle? (2000 characters max)

EPF suggests that the EU should also focus on equal treatment in education for vulnerable groups. Young patients with chronic and long-term conditions can face obstacles within the educational system which can affect their future employment prospects. The effect of chronic conditions is not only medical; it may affect academic performance, emotional and physical development, and relationships with peers (e.g. stigmatisation).²² It may cause anxiety and stress, cognitive impairments, fatigue, pain, and restlessness. It may lead to

²² 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

absences that affect academic success. People with chronic conditions are more likely to leave education early or with low qualifications.²³

In order to encourage equal treatment of young patients in education, we believe that the EU has a key role to play in collecting and scaling up good practices that are beneficial for their inclusion and equal treatment in education, to facilitate their entry, full inclusion and retention in the workforce. Member States should take actions to improve training of staff in relation to students with chronic conditions, establish and implement appropriate rights to accommodation or adjustments for these students.

There is also a strong need to raise awareness about chronic conditions at school and university for both staff and students.²⁴ The World Health Organisation (WHO), recommended to put in place initiatives for children to provide them with opportunities to learn about health, especially at school, and to provide opportunities for lifelong learning and for adults with limited skills in order to contribute to health literacy.²⁵

2.4.2 SECURE PROFESSIONAL TRANSITIONS

Challenges identified and actions proposed by the European Commission: The challenges perceived by the Commission are more diverse working lives with multiple jobs, need for up-skilling and the fact that some social protections entitlements cannot be easily transferred, and can become disincentive to re-starting work.

Principles proposed by the Commission to facilitate transition. is that every job seeker should have access to personalised help to find a job, and to be encouraged to train or up-skill. In addition, portability of social entitlements and training should be ensured.

	I strongly agree	agree	I disagree	I strongly disagree
Do you agree with the challenges described?		X		
Are the principles addressing these challenges in the right way?		X		
Should the EU act to put in reality the principles?		X		

²³ <http://www.eurofound.europa.eu/observatories/eurwork/comparative-information/employment-opportunities-forpeople-with-chronic-diseases>

²⁴ See also our recommendations on equal treatment of patients in education: http://www.eu-patient.eu/globalassets/policy/anti-discrimination/epf-position-paper_equal-treatment-in-education-and-employment.pdf

²⁵ See chapter 8 of “Health literacy, the solid facts”, World Health Organisation, 2013, pp35-39 http://www.euro.who.int/_data/assets/pdf_file/0008/190655/e96854.pdf

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle? (2000 characters max)

For our constituency, professional transition can be a challenge. Many patients with chronic conditions can continue to work, though some may need accommodations.

There is considerable variation in the effect of chronic conditions on employment in different Member States. There are examples of good practice which could be applied EU-wide.

The Eurofound agency found that there is often a quick transition towards inactivity for workers with chronic illnesses, while transition from unemployment to employment is qualified as “particularly complicated” for this group.²⁶ Key solutions our members have highlighted include clearer rights in the workplace to ask for reasonable accommodations, better processes, awareness-raising and training of managers and employers, and financial incentives for employers.

Appropriate support and policies for prevention, reasonable accommodations, and return to work after a period of inactivity due to illness or unadapted workplace need to be implemented, building on existing good practices and combined with legal protection from discrimination on the basis of health status (see our previous comment in question 3). More research in this area is needed in the EU and good practices should be evaluated with the participation of relevant stakeholders, including patients.

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, regional and local level. The EU could compare the diverse sick leave models applied in Member States and their impact on patients’ health outcome and careers. EU funds should also be used to support employers in adapting their workplace for people with specific health and functioning needs.

2.4.3 GENDER EQUALITY AND WORK-LIFE BALANCE

Challenges identified and actions proposed by the European Commission: This section is highlighting gender inequalities at work, and pointing out that lack of appropriate support, leave or care arrangements often puts women in the role of primary caregivers for children or other dependent members of the family. Some workers (self-employed or part-time) may not have access to family-related support measures. But there is also opportunity for more flexible work arrangements with technology.

²⁶ <http://www.eurofound.europa.eu/sites/default/files/ef1459en.pdf>, p19

Principles proposed include encouraging more gender equality at work and in the use of leave arrangements for people with caring responsibilities. In agreement between employers and workers, flexible working arrangements including in the area of working time shall be made available and encouraged, taking into account both workers and employers' needs.

	I strongly agree	agree	I disagree	I strongly disagree
Do you agree with the challenges described?		X		
Are the principles addressing these challenges in the right way?		X		
Should the EU act to put in reality these principles?	X			

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle? (2000 characters max)

As regards conciliating family and working life, family **carers** (in most cases, close family members, but this role can also be taken on by friends, neighbours) play a key role in supporting patients with chronic and long term conditions but may face difficulties at school or remaining in paid employment as a result. 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. The situation of informal carers needs to be assessed across the EU and recognition should be given for their work. Member States should provide them with adequate support, including financially, and with training.

Most of the problems encountered by people with chronic, long term diseases at work are equally applicable to their carers. The role of carers is absolutely crucial and must be duly recognised: for example, the healthcare and the state of health of a person with rare diseases depends on his or her carer. Labour inclusion of carers of people with chronic diseases must be addressed. Specific problems faced by carers (such as absenteeism when having to accompany the sick person to appointments, check-ups, tests, treatment and medical and complementary interventions) have to be taken into consideration. To give carers an equal opportunity to participate in the economy and society, they need adapted and flexible labour conditions.

A carer's leave should be put in place, accompanied by flexible work conditions, decent and non-discriminatory remuneration and social protection.

2.4.4 EQUAL OPPORTUNITIES

Challenges identified and actions proposed by the European Commission: While discrimination on the basis of sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation is prohibited in the EU, various groups are still facing discriminatory practices and low awareness of non-discrimination principles amongst employers. People subject to discriminations also have low awareness of their rights.

The principle proposed is that “Labour market participation of under-represented groups shall be enhanced, ensuring equal treatment in all areas, including by raising awareness and addressing discrimination.”

	I strongly agree	agree	I disagree	I strongly disagree
Do you agree with the challenges described?		X		
Is the principle addressing these challenges in the right way?	X			
Should the EU act to put in reality this principle?	X			

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle? (2000 characters max)

EPF calls on the Commission and Member States to look at equal treatment for all groups that face stigma, discrimination and exclusion in the workplace and in education, including but not limited to the groups mentioned in the Treaty. Patients can face discrimination during interviews. They may be discriminated against through mandatory medical examinations. Rules preventing patients from accessing certain jobs are not always medically justified. There is a misconception that they may be unable to work, when they may be, sometimes with only minor adjustments. Patients may face 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 being side-lined after a long-term absence. They can have more difficulties in accessing trainings and promotions.²⁷

From EPF’s perspectives, to implement this principle several actions need to be taken by the EU:

²⁷ <http://www.eurofound.europa.eu/sites/default/files/ef1459en.pdf>

Ensuring appropriate rights and legislation are in place to prohibit discrimination related to health conditions and to put in place clear rights for reasonable accommodations. Patient friendly processes should also be put in place in workplaces to manage return to work and case reviews.

Raising awareness towards employers and employees about the challenges faced by people with chronic conditions and functioning limitations so their specific needs are fully accepted by fellow employees.

Informing employees, employers, and human resources managers about existing rules and rights: Actions and campaigns to raise awareness at EU and national level of difficulties faced by patients and existing policies to support both employees and managers, within companies, trade unions and for the public, to tackle stigma faced by patients.

EPF has developed a position statement on equal treatment in the workplace with further recommendations that are relevant for this question, available on our website.²⁸

2.4.5 HEALTH AND SAFETY AT WORK

Challenges identified by the European Commission: New challenges for health and safety at work have emerged in light of less stable employment relationships, new working patterns and an ageing workforce. protection against occupational injuries and ill-health should be ensured for all workers, irrespective of the form of employment reintegration and rehabilitation efforts should be reinforced with more involvement of the employers for re-training or workplace adaptation.

The principle proposed by the European Commission is that *“An adequate level of protection from all risks that may arise at work, with due support for implementation, notable in micro and small enterprises, shall be ensured. “*

	I strongly agree	agree	I disagree	I strongly disagree
Do you agree with the challenges described?	X			
Is the principle addressing these challenges in the right way?		X		
Should the EU act to put in reality this principle?	X			

²⁸ Health literacy, the solid facts”, World Health Organisation, 2013, p44
http://www.euro.who.int/__data/assets/pdf_file/0008/190655/e96854.pdf

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle? (2000 characters max)

In the area of **protection of health and safety at work**, EPF believes that EU and Member States strategies should widen their scope of occupational health and safety strategies beyond occupational and work related diseases, to help tackle the difficulties that patients with chronic conditions face at work and implement health literacy at work.²⁹

An accessible workplace and assistive technology can allow a person with a chronic disease to perform their job without difficulty. Making minor adjustments to a workplace can benefit an employee and employer. Not all workplace adjustments are costly. Flexible working hours, a resting area, workstation redesign or other adjustments can actually be cost effective by retaining and integrating valued staff.

The WHO stressed that interventions to improve health literacy at the workplace “have been shown to help prevent accidents, lower the risk of industrial or occupational diseases, improve lifestyle choices and reduce the risk of non-communicable diseases”.³⁰ The WHO also stresses that such interventions usually have a good return on investment for employers. Good practices have been put in place in companies in this area – they need to be collected, evaluated, and scaled up where possible.

The mental health of all employed people must be safeguarded. Both the workplace and education system must ban mental and psychological harassment that often lead these employees and students with chronic conditions to abandon employment and school, and greatly affect their self-confidence and well-being.

It is important to include health and safety in other surroundings such as schools for instance. These environments should be safe and friendly to enable people with chronic conditions to follow the same educational pathways as other citizens free of disease or disabling conditions. This investment in health and safety at school is expected to positively impact access to employment to people with chronic and disabling diseases.

2.4.6 SOCIAL DIALOGUE AND INVOLVEMENT OF WORKERS

Challenges identified and actions proposed by the European Commission: The importance of a well-functioning of social dialogue is highlighted, but challenges like new forms of work

²⁹ See also our input to the European Commission consultation on a new EU occupational safety and health policy framework of 2013:

<http://www.eu-patient.eu/globalassets/policy/anti-discrimination/epf-response-osh-2013.pdf>

and decrease of representativeness of social partnership are acknowledged, and make consultation and information of workers more complex.

Principles proposed: Social partners shall be consulted in the design and implementation of employment and social policies. Information and consultation should be possible for all workers.

	I strongly agree	agree	I disagree	I strongly disagree
Do you agree with the challenges described?		X		
Is the principle addressing these challenges in the right way?		X		
Should the EU act to put in reality this principle?		X		

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle? (2000 characters max) While EPF does not have specific expertise as regards social dialogue, EPF believes that patient and/or patient organisations have an essential role to play in developing and implementing initiatives to promote and improve health and safety at work at all levels (EU, national, regional, local and also in the workplace). Involving meaningfully social partners and stakeholders from the development stage will help ensure ownership of the policies and initiatives developed under the social rights Pillar.

2.4.7 INTEGRATED SOCIAL BENEFITS AND SERVICES

Challenges identified and actions proposed by the European Commission: The multiplicity of benefits make it difficult for people to access the support they need, the European Commission identifies that alignment between social benefits, active support and social services is needed to solve this.

The principle proposed is that:” Social protection benefits and services shall be integrated to the extent possible in order to strengthen the consistency and effectiveness of these measures and support social and labour market integration.”

	I strongly agree	agree	I disagree	I strongly disagree
Do you agree with the challenges described?	X			
Is the principle addressing these	X			

challenges in the right way?				
Should the EU act to put in reality this principle?	X			

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle? (2000 characters max)

Patients and their carers often face difficulties in accessing essential social benefits and social services. These are crucial to improve patients' care, well-being and autonomy. They are not always available in all Member States, may not function well or respond to the needs of patients. Patients indicate that improved information about social services and benefits is strongly needed.

A key barrier is the lack of integration between social and health services, as the two sectors often work in silo and are not communicating. The result of organisational and financial fragmentation is that patients need to spend significant time and energy navigating the system just to know the support they are entitled to and how these services can be accessed.

Patients may be vulnerable to financial difficulties or poverty due to the impact of their illness on their ability to work. Alongside improvements in access and retention of employment, social benefits are a crucial part of the equation to prevent economic vulnerability of patients.

Employees with specific needs due to their state of health must not lose out on social benefits necessary for their conditions when taking up a job.

The EU should encourage countries to invest in providing quality social services and benefits through the European Semester process. Patients should be supported to have a decent standard of living when they cannot work or can only work part time due to their conditions.

Integrated health and social care should become the norm, to improve the quality of care provided to patients, their quality of life, and efficiency gains for the system via the maximisation of resources and optimisation of care pathways.

The EU should also encourage, notably through provision of research funding, innovation in a wider sense, encompassing "low tech" social, process and systems innovation in the area of social services and for more effective linking of health and social services.

2.4.8 HEALTH CARE AND SICKNESS BENEFITS

Challenges identified and actions proposed by the European Commission (full text):

“Population ageing and the high costs of treatments are putting increased pressure on the financial sustainability of health systems and the ability to provide adequate healthcare for all. High cost of treatment relative to income, or too long waiting periods have been shown to be key determinants in the inability to access medical care. Ensuring universal access to high quality care while guaranteeing the financial sustainability of health systems, encouraging the cost-effective provision of care, and encouraging health promotion and disease prevention requires increased efforts in improving the resilience, efficiency and effectiveness of health systems, and can improve the ability of healthcare systems to cope with the challenges. Providing universal access to healthcare and addressing health inequalities will reinforce social cohesion and improve economic outcomes.

Arrangements for sickness benefits and/or paid sick leave vary considerably in what concerns waiting days, duration, replacement levels and control mechanisms. Securing an adequate minimum replacement level of sickness benefits and encouraging rehabilitation and reintegration while, simultaneously, maintaining the financial sustainability of such schemes remains a challenge.”

The principles proposed are that:

- *Everyone shall have timely access to good quality preventive and curative health care, and the need for healthcare shall not lead to poverty or financial strain.*
- *Healthcare systems shall encourage the cost-effective provision of care, while strengthening health promotion and disease prevention, in order to improve the resilience of healthcare systems and their financial sustainability.*
- *All workers, regardless of contract type, shall be ensured adequately paid sick leave during periods of illness; the participation of the self-employed in insurance schemes shall be encouraged. Effective reintegration and rehabilitation for a quick return to work shall be encouraged.*

	I strongly agree	agree	I disagree	I strongly disagree
Do you agree with the challenges described?		X		
Are the principles addressing these challenges in the right way?		X		
Should the EU act to put in reality these principles?	X			

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle? (2000 characters max)

The draft pillar has neglected to address the challenge of the increasing prevalence of chronic diseases linked with demographic ageing. This requires actions beyond prevention as provision of care also needs to adapt. Though some chronic diseases are to some extent preventable, many are not. For diseases that are preventable, multiple factors come into play that patients cannot always control. Patient centred healthcare models need to be applied as they are increasingly proven to be more cost effective and to increase patient satisfaction and to improve clinical outcomes. The benefits of these models are seen in terms of reducing avoidable hospitalisations, more effectively allocated healthcare resources, better quality care throughout the “patient journey,” and better informed, motivated and empowered patients. Interventions such as peer support can be highly cost effective and help to keep conditions stable and reduce hospitalisation. Such intervention promoting self-management could reduce healthcare expenditure by 7%.³¹

Experience of patients show that universal access to healthcare is not yet a reality in the EU and should be a priority. In order to achieve it, we believe the EU and Member States should:

- Provide quality of care across the EU: to achieve this, health system performance assessments should be carried out involving patients, who as end users of healthcare services have an essential role to play in defining what quality of care is
- Commit to sustainable investment in health: Insufficient or inadequate investment in health is an issue in many EU countries, which often translates in health inequalities and poorer health outcomes for the population
- Encourage affordability of healthcare products and services for patients
- Implementing access to a holistic range of health and social services for patients according to their needs
- End discrimination and stigma that various groups in the population face when it comes to access and provisions of healthcare: Universal health coverage means that all the people in the EU should have access to healthcare³²

³¹ [The Business Case for People Powered Health. Nesta, London,UK; 2013

³² For more information: http://www.eu-patient.eu/globalassets/policy/anti-discrimination/epf-position-discrimination-jan2015_final.pdf

2.4.9 DISABILITY BENEFITS

Challenges identified and actions proposed by the European Commission: The Commission acknowledges the increased risk of poverty and exclusion as a result of disability, and that the design of disability benefits can sometimes be a disincentive to work.

The principle proposed as a solution is that persons with disabilities shall be ensured enabling services and basic income security that allows them a decent standard of living. The conditions of benefit receipt shall not create barriers to employment.

	I strongly agree	agree	I disagree	I strongly disagree
Do you agree with the challenges described?		X		
Is the principle addressing these challenges in the right way?		X		
Should the EU act to put in reality this principle?	X			

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle? (2000 characters max)

One of the challenges of disability benefits which is not mentioned by the European Commission is the lack of an EU framework and tools for the assessment of functionality. Chronic and long term conditions can lead to disability, yet depending of the definitions used in Member States, patients' entitlement to disability benefits vary widely. EPF recommends the development of a framework and tools to support Member States improving their functionality assessment systems, established with consultation of patients' organisations, to ensure there are no gaps in the integration of chronic diseases that generate disabilities. These systems need to be flexible and comprehensive enough to take into account the global social disability of complex and debilitating diseases, which may not only generate physical and cognitive impairments but can also be highly socially disabling, due to the complexity of both the disease and the care pathway.

Functionality/incapacity should be properly assessed and supported with adequate compensation measures.

Additionally, the access to disability benefits shall not create barriers to employment and employees with specific needs due to their state of health should not lose out on social benefits necessary for their conditions when taking up a job.

2.4.10 LONG-TERM CARE

Challenges identified and actions proposed by the European Commission: Due to demographic change and other societal changes, demand for long term care is increasing, and family carers are often left to fill the gap. Home based care is under-developed. Improving access to long term care while ensuring sustainability is seen as the main objective.

Principles:

- *Access to quality and affordable long-term care services, including home-based care, provided by adequately qualified professionals shall be ensured*
- *The provision and financing of long-term care services shall be strengthened and improved in order to ensure access to adequate care in a financially sustainable way.*

	I strongly agree	agree	I disagree	I strongly disagree
Do you agree with the challenges described?	X			
Is the principle addressing these challenges in the right way?		X		
Should the EU act to put in reality this principle?	X			

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle? (2000 characters max)

While the role of family carers is acknowledged in the outline of the pillars, the principles proposed do not address the need to put in place more support for them. Long-term care could benefit from an official recognition of carers who often need respite care themselves. We refer to our response point 2.4.3 for actions that need to be taken in this area. While it is important to develop professional home based care and long term care, it is equally important to recognise the family carer role in care provision and support them in undertaking this role.

Although physical or intellectual impairments often require long-term care, other less disabling health conditions can also require long-term care. Access to employment should not deprive those in need from requiring and accessing long-term care support.

In order to fulfil the principles proposed in a patient centred way, Member States should ensure patients have access to health and social care solutions that meet their needs and preference. In particular, older patients who wish to remain at home should have access to home care solutions and support. Easily accessible and affordable care homes should be an integral part of the community rather than large scale institutions.

In order to ensure quality in long term care, it is important to implement key rights of older people, including right to autonomy and to dignity. A key instrument which could be leveraged in this area is the European Charter of rights and responsibilities of older people in need of long-term care and assistance.³³ The EU and Member States should support and assess implementation of this charter. Since 2011, EPF has participated in the innovation partnership on active and healthy ageing, and carried out several activities with our members to gather knowledge on the needs of older patients. These specific needs, which we developed further in our position paper on rights and needs of older patients also need to be addressed in the provision of long term care.³⁴

2.4.11 CHILDCARE

Challenges identified and actions proposed by the European Commission: Access to childcare is important both for children’s development and work-life balance, but there are issues of availability and affordability

Principles:

- *Access to quality and affordable childcare services, provided by adequately qualified professionals, shall be ensured for all children.*
- *b. Measures shall be taken at an early stage and preventive approaches should be adopted to address child poverty, including specific measures to encourage attendance of children with disadvantages backgrounds.*

	I strongly agree	Agree	I disagree	I strongly disagree
Do you agree with the challenges described?		X		
Is the principle addressing these challenges in the right way?	X			
Should the EU act to put in reality this principle?	X			

³³ http://www.age-platform.eu/images/stories/22204_AGE_charte_europeenne_EN_v4.pdf

³⁴ http://www.eu-patient.eu/globalassets/policy/ageing/epf_position-paper_older-patients_jan14.pdf

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle? (2000 characters max)

For children with chronic conditions, access to childcare can be problematic. Specialised childcare facilities are dearly lacking and the staff in mainstream child care facilities are not always trained or in sufficient number to adequately meet the specificities of these children. Parents of children with chronic conditions are often left with no other solutions than stopping to work to care for their child. Therefore, in applying the principle proposed, we believe the European Commission and Member States should also take into account the needs of young children with chronic conditions and their right to access childcare services that are appropriate, affordable with opening hours that are flexible to take into account parents' working hours. We believe that good practices in this field need to be collected and disseminated.

It is important to have a long-term vision that does not stop at childcare but includes education, training and entry into the labour force.



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