

EPF Briefing: Tackling discrimination and promoting equal treatment for patients with chronic diseases

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Background

Principles of **equal treatment** and **non-discrimination** are deeply rooted in international, EU and Member States legislation. Most EU countries have provisions against discrimination in their constitutions or/and law. Equality and protection of fundamental rights have also been recognized as general principles of EU law.

Discrimination can be *direct*: within EU law it is considered direct discrimination occurs where one person is treated less favourably than another is, has been or would be treated in a comparable situation.

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

To combat these forms of discrimination, the EU has adopted a legislative framework to implement the principle of **equal treatment between persons**.¹ The principle of equal treatment requires that all people have the right to receive the same treatment, and will not be discriminated against.²

A **grounds** of discrimination means the reason why a person is treated less favourably. Legislation to prohibit discrimination often cites legal grounds for which discrimination is prohibited.

Discrimination is different from health inequalities and barriers in access to healthcare but there is often a correlation: when health systems fail to meet the needs of a vulnerable group, this may be considered as an indirect form of discrimination.³ It is sometimes referred to as structural discrimination.⁴ In addition, discriminations along with other factors (e.g. social factors, ethnicity, and geographical localisation) contribute to placing groups of people at systematic disadvantage with respect to their health status.⁵

The European Patients' Forum's commitment to tackling discrimination

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

We also adopted non-discrimination as a specific strategic goal for 2014-2020 in our Annual General Meeting: "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."⁶

Our performance indicators for this goal are as follow:

¹ http://europa.eu/legislation_summaries/human_rights/fundamental_rights_within_european_union/em0008_en.htm

² <http://www.eurofound.europa.eu/areas/industrialrelations/dictionary/definitions/equaltreatment.htm>

³ The differences and relations between barriers to healthcare and discrimination are further discussed in http://fra.europa.eu/sites/default/files/inequalities-discrimination-healthcare_en.pdf p47

⁴ <http://fra.europa.eu/en/news/2012/combating-inequalities-and-multiple-discrimination-access-healthcare>

⁵ http://fra.europa.eu/sites/default/files/inequalities-discrimination-healthcare_en.pdf , p14

⁶ <http://www.eu-patient.eu/Documents/Library/Strategic%20Planning/EPF%20Strategic%20Plan%202014-2020%20Final.pdf>

- EPF is successful in gathering evidence and raising awareness of how people, especially youngsters, with chronic conditions can be discriminated against, e.g. at school, university, labour market, etc., as a result of their disease.
- EPF is successful in establishing partnerships within European Commission's Directorates-General and EU Parliament's committees in charge of non-discrimination legislation as well as employment, education, youth, and social policies.
- EPF is successful in promoting the recognition of health status/ chronic disease as a specific ground of discrimination and paving the way for the inclusion of chronic disease within the scope of non-discrimination legislation at EU and national level.

EPF already worked toward the first performance indicator through the EMPATHY conference in July 2013 where young patients discussed discrimination they encountered in education and on the employment market. Our work in promoting older patients' rights and gender equity in healthcare, and in promoting health equity also links with the first performance indicator.⁷

EPF also combats **stigma**: stigma occurs when "certain differences (or imagined differences) are labelled or pointed out" and given negative associations.⁸ Stigma is not a legal concept, unlike discrimination. EPF is watching carefully the growing consumerist approach to health and increased focus on "well-being" as there is a risk of stigmatisation with this approach. Indeed, consumerism combined with the idea that lifestyle factors can cause various chronic diseases, is shifting discussions towards "individual responsibility" over one's health. Many chronic diseases however do not result from lifestyle factors. In the medium to longer term and under the current economic circumstances, there is a risk that patients may increasingly be stigmatised for having a disease.

Objectives of this paper

The aim of this briefing paper is to summarize the research and knowledge gathered by the European Patients' Forum to this date on discrimination that patients with chronic or/and long-term conditions encounter in the European Union. It is based on relevant literature, comments received from EPF membership through various consultations, as well as events and projects. The objectives are:

- To inform patient organisations of current non-discrimination policies at EU level
- To make a first mapping of discrimination encountered by patients
- To foster internal discussions with EPF membership
- To discuss priorities for our future work in the area of discrimination

⁷ See EPF website policy sections on ageing and older patients and health inequalities: www.eu-patient.eu
<http://www.eu-patient.eu/News/News-Archive/Health-and-the-life-continuum-from-a-gender-perspective/>

⁸ WHO Europe: Stigma, an international briefing paper" NHS health Scotland, 2008, p5
http://ec.europa.eu/health/mental_health/eu_compass/reports_studies/stigma_paper.pdf

1 EU policy to tackle discrimination

1.1 TREATY AND CONVENTIONS

Article 19 of the Treaty on the Functioning of the European Union⁹ provides for 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 Union¹⁰ prohibits discrimination on these six grounds and nationality (Article 21). It also establishes the right of access to healthcare (Article 35).

The European Union has ratified the United Nations Convention on the Rights of People with Disabilities¹¹ in January 2012. The EU institutions will now have to endorse the values of the Convention in all policies under their competence. The 27 Member States have signed it, and 16 have ratified it.

1.2 POLICY FRAMEWORK

Several actions have been taken by the European Union to combat discrimination. Under the existing European Community legal framework¹², discrimination is prohibited:

- On the grounds of religion or belief, disability, age and sexual orientation in the field of employment;
- On the grounds of gender, in the field of employment, access to of supply good and services
- On the grounds of race/ethnicity, in the fields of employment, social protection (including social security and healthcare); social advantages, education and access to and supply of goods and other services which are available to public, including housing.

The legislation states that people who have been discriminated against should have access to judicial or administrative remedies. Member States also have to put in place independent equalities bodies to support victims of discrimination in their legal proceedings, and to publish studies on discriminations.

On 2 July 2008, the European Commission adopted a proposal for a new directive on discrimination beyond the workplace, which sets a framework for prohibition of discrimination on the grounds of religion of belief, disability, age or sexual orientation outside the field of employment.¹³ The proposal applies both to public and private bodies, in relation to social protection (including social security and healthcare); social advantages, education and access to and supply of goods and other services which are available to public, including housing. But the debate in the Council is still on-going and this piece of legislation requires unanimity among Member States to be adopted.

⁹ <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2008:115:0047:0199:en:PDF>

¹⁰ <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2010:083:0389:0403:en:PDF>

¹¹ <http://www.un.org/disabilities/convention/conventionfull.shtml>

¹² http://ec.europa.eu/justice/discrimination/law/index_en.htm

¹³ <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:52008PC0426:EN:HTML>

The EU has also put in place a European Disability Strategy and a Disability Action Plan to promote the active inclusion and full participation of people with disability in society.¹⁴

The EU Programme for Employment and Social Solidarity (PROGRESS) has funded projects that responded to the objective of tackling discrimination from 2007 to 2013 with an overall budget of 743 million euros.¹⁵ Its successor for 2014-2020 is the EU Programme for Employment and Social Innovation (EaSI).

1.3 PATIENTS AND THE EU EQUAL TREATMENT LEGISLATION

A key question for patients is whether or not they are in the scope of EU legislation on discrimination. This currently depends on the definition used by their Member State's law for disability, as the concept of disability does not have a common definition at EU level. These vary from very restrictive definitions in which only a group of "truly disabled people" (according to definitions of social security law) is protected, to definitions where patients can be included if they have an "impairment" which is considered to have an impact important enough on their life, to yet a broader definition (used in Ireland) in which patients can always be included. Inclusion or exclusion within this concept also depends on the patient's type of disease.

EPF believes that patients with chronic and/or long term conditions should be protected from discrimination on the ground of health status. Such provisions already exist in the legislation of some Member States and need to be replicated across the EU and at EU level.¹⁶

1.4 THE EU FUNDAMENTAL RIGHTS AGENCY (FRA)

The [EU Fundamental Rights Agency](http://fra.europa.eu) is an advisory body set up in 2007 that contributes to the application of the Charter by collecting evidence and carrying out research about the situation and on the protection of the fundamental rights of people living within the EU. The Agency also make s evidence-based recommendations to policy-makers. The Agency has carried out important research in the field of discrimination related to healthcare:

- Multiple discrimination in healthcare: The FRA explored how multiple discrimination (i.e. discrimination on more than one ground) is addressed legally. It also focused on experiences of healthcare users and on the views of healthcare professionals on this issue, especially for people of different gender, age, disability and ethnic origin who experience discrimination and multiple discrimination. It found respondents had experienced unequal or unfair treatment in relation to access to and quality of healthcare, discusses a number of barriers they face and points to possible improvements.¹⁷
- Migrants in an illegal situation: the FRA also examined the issues that migrants in illegal situation face as regards access to healthcare within the EU.¹⁸

¹⁴ http://ec.europa.eu/justice/discrimination/disabilities/disability-strategy/index_en.htm and

¹⁵ <http://ec.europa.eu/social/main.jsp?catId=327>

¹⁶ Isabelle Chopin, Thien Uyen Do "Developing Anti-Discrimination law in the European Union" October 2012, pp11-13 http://www.migpolgroup.com/wp_mpg/wp-content/uploads/2013/07/Developing-Anti-Discrimination-Law-in-Europe-2012-EN-.pdf

¹⁷ European Union Agency for Fundamental Rights "Inequalities and multiple discrimination in access to and quality of healthcare", March 2013 <http://fra.europa.eu/en/publication/2013/inequalities-discrimination-healthcare>

¹⁸ European Union Agency for Fundamental Rights "Migrants in an irregular situation: access to healthcare in 10 European Union Member States" October 2011 <http://fra.europa.eu/en/publication/2012/migrants-irregular-situation-access-healthcare-10-european-union-member-states>

2 Patients with chronic diseases and discrimination

While it is unclear whether patients are in the scope of EU legal provisions on discrimination, evidence shows that patients with chronic and/or long term condition do face stigma or discrimination because of their conditions.

2.1 HEALTHCARE

Legal protection against discrimination in healthcare is uneven across Europe, as a mapping study has shown.¹⁹ In most EU countries there is at least a general principle of equal treatment. Some countries have specific anti-discrimination legislation for social protection and social benefits (including healthcare), sometimes covering only some of the grounds for discrimination. Other countries only have general provisions in their penal codes or in their constitutions.

However in practice various groups of patients may face discrimination and/or stigma in healthcare. You can find an overview below.

2.1.1 DISABILITY

Disabled patients can face discriminatory attitude by healthcare providers, which can lead to exclusion from the provision of some treatments (e.g. to prolong life, problems in access to sexual and reproductive health, denial of adequate treatment for people who live in institutions). Fear can lead to less detailed examination, adherence issues and lesser use or avoidance of health services. Disabled people also face access-related barriers which can sometimes be perceived as indirect discrimination. This includes problems to access healthcare facilities, lack of adequate and targeted information, and difficulties in communicating with healthcare providers.²⁰

2.1.2 AGE

Age may also be a factor of discrimination. Upper age limits can be used to restrict access to treatments such as kidney dialysis, heart bypass operations, cardiac rehabilitation programmes and knee replacements.²¹ People over a certain age may be excluded from clinical trials (which leads to less evidence of effectiveness of interventions in older people), or may sometimes not be referred to surgery even when there is no positive evidence that they would not benefit from it. Evidence suggests there may be age discrimination in access to prevention and rehabilitation. For example there are age limits for free medical screening (e.g. breast cancer) that may not always be justified scientifically. Sometimes healthcare professionals also base their decision regarding an intervention on perception of which group will benefit the most from it, to the detriment of older patients.²² Reports and empirical evidence from patients' organisations also suggest there are deficits in treatment due to stigma and negative perception of old age: e.g. for depression, there is sometimes an assumption that it is a natural part of ageing. There is also a risk of discrimination or stigma as regards the ability of older people to give consent in healthcare.

When health policies and healthcare systems do not respond to the specific needs of younger and older patients, it can also be perceived as indirect discrimination. Some specific needs of older

¹⁹ McColgan, A, J Niessen, and F Palmer. "Comparative Analysis on National Measures to Combat Discrimination outside Employment and Occupation." December 2006.

²⁰ European Policy Evaluation Consortium (EPEC), "Study on discrimination on the grounds of religion and belief, age, disability, and sexual orientation outside of employment", 13 June 2008.

²¹ *ibid*

²² *ibid*

patients are inadequately addressed (e.g. issues of malnutrition, co-morbidities). For more information on discrimination and older patients please also see the section dedicated to this issue in the EPF position paper on the rights and needs of older patients.²³

Younger patients also face issues in healthcare such as lack of adequate skillset from healthcare professionals which results in these patients' not being involved in decision making, lack of adequate support and information targeted at this audience. In addition the needs of young patients transitioning towards adult care are not always addressed efficiently.²⁴

2.1.3 GENDER

According to the Value+ project "Women and men are different in regards to their biological make-up (sex). **Gender** is not related to biology; it refers to cultural issues: men and women's different roles and responsibilities in society, their access to and control over resources, including information, and their decision-making power."²⁵

There are significant differences in how men and women are affected by chronic diseases, i.e. in term of prevalence, degree of severity of the disease, symptoms- biological differences and gender aspects. Gender differences have a direct impact on the health behaviour, risk exposure, social factors, and also on needs and access to care of women and men. Men are more likely to die, at all ages, of all the causes of death recorded by Eurostat. Women live longer, are more likely to suffer illness and disability in later life. Governments and health systems do not always recognize or address these differences.

Indirect discrimination of patients based on gender occurs in the research field: There is an increasing recognition in research of the impact of gender on health though initially only biological differences were studied. Traditionally the research community has been reluctant to involve women in clinical trials. Clinical research only recently started to implement gender balance in trials, in recognition of the fact that men and women metabolise and react to medicines differently. Discrimination occurs in the content of the project (e.g. the subjects studied), and in the process (e.g. lack of disaggregated data, absence of women's perspective).²⁶

Discrimination also appears in the management of patients' health and chronic or long term conditions: While both women and men have unmet medical needs, it is for distinctive reasons: e.g. women are usually more likely than men to be constrained by barriers to access, such as the cost of medical care, time and geographical distance, while men are more likely to declare other reasons such as: could not take time', 'fear', 'wait-and-see strategies', 'didn't know any good specialist or doctor'.²⁷ Less favourable treatment because of gender occurs for various reasons: one key problem is gender labelling of a disease, which can have devastating consequences for secondary prevention as it can lead to delaying diagnosis and treatment. Two well-known examples are cardiovascular diseases and osteoporosis. Cardiovascular diseases are usually labelled by the public and professionals as men's diseases, when it is also very present among women, who face difficulties to access diagnosis and treatment as a result. They may have different symptoms but most research is

²³ <http://www.eu-patient.eu/whatwedo/Policy/Ageing/>

²⁴ EMPATHY project conference: <http://www.eu-patient.eu/whatwedo/Projects/EPF-led-EU-Projects/EMPATHY/>

²⁵ This simple definition of gender was developed by the European Institute for Women's Health (EIWH) and the European Men's Health Forum (EMF) as part of the project Value+: <http://www.eu-patient.eu/Documents/Projects/Valueplus/Value+%20Toolkit.pdf>

²⁶ ENGENDER project, "policy brief 5 : gender imbalance in health research" <http://eurohealth.ie/wp-content/uploads/2012/02/PB5-Draft.pdf>

²⁷ Access to healthcare and long term care: Equal for men and Women? (European commission, October 2009)

<http://bookshop.europa.eu/en/access-to-healthcare-and-long-term-care-pbKE3110298/>

conducted with male participants. Osteoporosis is labelled as a woman's disease but it is estimated 1 in 5 men will develop the condition and many are misdiagnosed.²⁸ One striking example of gender stereotype occurs in combination with mental health: Women are more likely to be diagnosed with depression and be prescribed mood altering psychotropic drugs than men with identical symptoms. The European Commission also reported that most comprehensive screening programmes are targeting women's health (in particular sexual and reproductive) and women's specific cancers.²⁹

2.1.4 MENTAL HEALTH

There is evidence that patients with mental health conditions can face stigma and discrimination by administrative and healthcare staff. Physical problems may be too quickly attributed to psychological factors; in particular a diagnosis of a mental illness or learning disability can overshadow other issues.³⁰ Evidence shows that sometimes patients are even denied adequate examination because their mental health diagnosis overshadows physical health issues.³¹ Patients may encounter difficulties when they are on waiting lists for a treatment or surgery (e.g. in Poland people with Schizophrenia are placed at the end of the list).³² Attitude of staff and healthcare providers can lead to avoidance of healthcare system and non-adherence, which in turn may have negative consequences for patients' health. Patients with mental health conditions are also affected by barriers in access such as lack of targeted information and communication issues with healthcare professionals.

2.1.5 SEXUAL ORIENTATION

Patients can face discriminatory attitudes in healthcare depending on their sexual orientation, e.g. labelling of their orientation as a 'sickness' in some countries, and refusal by staff within health care systems to provide help with medical services. One particular issue for the LGBT³³ people is the denial of right of partner to visit, to have next of kin status, take medical decision, and have access to psychological support.³⁴ The lack of understanding of their specific health needs can also be perceived as an indirect discrimination. The World Medical Association adopted in October 2013 a statement on natural variations of human sexuality which condemns discrimination and stigmatisation, and stresses that "direct and indirect discrimination, stigmatisation, peer rejection, and bullying continue to have a serious impact upon the psychological and physical health of people with a homosexual or bisexual orientation. These negative experiences lead to higher prevalence rates of depression, anxiety disorders, substance misuse, and suicidal ideations and attempts".³⁵ The Standing Committee of European Doctors also endorsed this statement.³⁶

²⁸ Value + Toolkit <http://www.eu-patient.eu/Documents/Projects/Valueplus/Value+%20Toolkit.pdf>

²⁹ ibid

³⁰ European Commission, Quality in and equality of access to healthcare services (European Communities, 2008)

³¹ Samele C, Seymour L, Morris B, Cohen A and Emerson E (2006) A Formal Investigation into Health Inequalities Experienced by People with Learning Difficulties and People with Mental Health Problems. Area Studies Report." London: Disability Rights Commission. 86-88

³² European Commission, Quality in and equality of access to healthcare services (European Communities, 2008)

³³ The LGBT acronym stands for lesbian gay bisexual and transsexual people

³⁴ European Policy Evaluation Consortium (EPEC), "Study on discrimination on the grounds of religion and belief, age, disability, and sexual orientation outside of employment", 13 June 2008.

³⁵ World Medical Association Statement on Natural Variations of Human Sexuality, October 2013 <http://www.wma.net/en/30publications/10policies/s13/>

³⁶ CPME Statement on Natural, Non-pathological Variations of Human Sexuality, November 2013 http://cpme.dyndns.org:591/adopted/2013/CPME_AD_Brd_23112013_136_Final_EN.Non-pathological.variations.human.sexuality.pdf

2.1.6 RELIGIOUS BELIEF

Discrimination occurs on the grounds of religious belief in healthcare because of a lack of understanding or flexibility as regards specific needs or preferences due to religious practice (e.g. dietary needs).³⁷ There is also a lack of targeted prevention campaigns and public health messages towards certain religious group e.g. when the content of a health message contravenes with a religious belief or practice. This could be considered as indirect “structural” discrimination.

2.1.7 DISEASE

Discrimination may also occur on the grounds of a specific condition. This is for example the case of patients with HIV who may face discriminatory attitudes or stigma, including in the provision of healthcare services.³⁸

2.1.8 ETHNICITY

Ethnicity can also be a ground for discrimination in healthcare: The interview conducted in the FRA project on multiple discrimination provides evidence that healthcare professionals may have discriminatory attitude or stigmatise patients due to their ethnic background.³⁹

2.1.9 VULNERABLE GROUPS

Certain groups of patients are particularly vulnerable to discrimination in healthcare. This includes for example undocumented migrants and Roma people.

Migrants in an irregular situation are often only granted access to emergency care. They are often treated informally and therefore they do not benefit from the continuity of care required in the management of a chronic condition. As they often are not covered by health insurance or social security systems, they may have to pay care out of pocket and receive no reimbursement. They may also face indirect discrimination by healthcare staff due to lack of awareness about migrants’ entitlements. There is also lack of clarity as regards the possibility for healthcare providers to refrain from reporting information about migrants to immigration authorities.⁴⁰ These direct or indirect discriminations all affect migrants’ access to healthcare, and may infringe on their right to health.

Roma people are another minority group vulnerable to discrimination according to the FRA. It is estimated that 15 percent of them are affected by a disability of chronic condition.⁴¹ According to the EU-MIDIS survey they perceive they are discriminated against by healthcare personnel in various countries.⁴² They may face issues such as refusal of assistance, segregation in health care facilities, and difficulties to access emergency care due to their ethnicity or status. Some countries refuse to give Roma legal status or certificates.⁴³

³⁷ European Policy Evaluation Consortium (EPEC), “Study on discrimination on the grounds of religion and belief, age, disability, and sexual orientation outside of employment”, 13 June 2008.

³⁸ <http://www.ncbi.nlm.nih.gov/pubmed/12816317>

³⁹ European Union Agency for Fundamental Rights “Inequalities and multiple discrimination in access to and quality of healthcare”, March 2013 http://fra.europa.eu/sites/default/files/inequalities-discrimination-healthcare_en.pdf

⁴⁰ “Health and the Roma Community, comparative analysis of the situation in Bulgaria, Czech Republic, Greece, Portugal, Romania, Slovakia and Spain” http://ec.europa.eu/justice/discrimination/files/roma_health_en.pdf

⁴¹ EU- MIDIS (European Union Minorities and Discrimination Survey) – December 2009

⁴² EU Fundamental Rights Agency “The situation of Roma EU citizens moving to and settling in other EU Member States” – November 2009

⁴³ *ibid*

They also face indirect discrimination through failure to meet their specific health needs: for example there is an absence of targeted information and communication. There is also a lack of health facilities in Roma neighbourhoods.⁴⁴

2.1.10 MULTIPLE DISCRIMINATION

Multiple discrimination occurs when discrimination happens on more than one ground or at the intersection of two grounds of discrimination. Although data are often lacking on these types of discrimination, and individuals generally perceive they are discriminated on a single ground, several groups were identified as vulnerable: older people belonging to ethnic minorities, young people with learning disabilities, and women in ethnic minorities.⁴⁵

2.2 FINANCE

In the EU, it is a widespread practice to propose less advantageous conditions for certain financial services to patients with chronic diseases. This occurs for example in the provision of private health insurance, life insurance, home insurance and travel insurance.

These practices are considered as legal. In the EU private insurers can choose who is eligible for cover, and to set the level of premiums according to their assessment of the risk the person represents. Their business logic is based on setting higher premiums for (or excluding) higher risk individuals (“pre-existing conditions”). Therefore, private insurers are likely to discriminate in favour of those who are young, healthy and likely to use less health services, and against those who are likely to need more services. Further, private insurers can exclude specific conditions thus shifting these on to the public system.

2.2.1 PRIVATE HEALTH INSURANCE

Private health insurance does not play a major role in most European countries, but rather a complementary⁴⁶ and supplementary⁴⁷ role. Common barriers for patients’ access to these services include age, and certain chronic diseases categorised as “pre-existing conditions”. In Italy chronic and recurrent diseases as well as mental illnesses are part of the conditions usually excluded from individual insurance policies. In the UK and in Portugal long term chronic diseases are on the list of conditions usually excluded from voluntary health cover (moratorium underwriting. If declared in the UK it is usually possible to find a cover (but with higher premium, time limit, or/and up to a certain amount). In Denmark, for-profit health insurance schemes do not cover pre-existing illnesses and chronic illnesses. People with chronic illness cannot subscribe to non-profit (“mutual”) private health insurance either. In Spain “individuals with chronic diseases are excluded from private health insurance, as are those suffering from alcoholism, diabetes and AIDS, among others”. In the Czech Republic, the substitutive cover for foreigners can exclude services linked to some chronic conditions, notably mental illness. A few countries forbid this practice however (Ireland, Belgium, and France).⁴⁸

⁴⁴ “Health and the Roma Community, comparative analysis of the situation in Bulgaria, Czech Republic, Greece, Portugal, Romania, Slovakia and Spain” http://ec.europa.eu/justice/discrimination/files/roma_health_en.pdf

⁴⁵ European Union Agency for Fundamental Rights “Inequalities and multiple discrimination in access to and quality of healthcare”, March 2013 http://fra.europa.eu/sites/default/files/inequalities-discrimination-healthcare_en.pdf

⁴⁶ Complementary private health insurance provides coverage for services excluded or not fully covered by statutory health insurance.

⁴⁷ Supplementary private health insurance usually covers the same range of services as statutory health insurance. Its main purpose is to increase the choices of provider, fasten access, propose a larger choice of conditions for treatment (single room etc...)

⁴⁸ Mossialos, E, S Thomson, and al. Voluntary health insurance in the European Union. World Health Organisation, 2004.

2.2.2 OTHER FINANCIAL SERVICES

Potential discrimination in other financial services for patients with chronic diseases include difficulties to access loan insurance, life-insurance, request for supplementary medical examination and difficulties to access travel insurance. Sometimes these services are available at extra cost for patients. As regards loan and mortgages, patients may face indirect discrimination (e.g. they may be asked to arrange for insurance in connection with the loan).⁴⁹

While these types of different treatment are accepted as necessary for insurance, methods of risk calculations also raise ethical questions. Whether it is fair and reasonable to exclude conditions or ask for higher premiums needs to be reflected upon, and some research studies question the efficiency of these practices from a public policy perspective.⁵⁰ Some countries like Ireland have taken measures to put in place community rating, which prohibits restriction because of medical grounds by insurers (a practice called medical underwriting).

2.3 EDUCATION

The seminar organised as part of the EMPATHY project showed, through direct testimonies of young patients who participated in the event, that they face indirect discrimination during their education. Patients may miss courses because of their disease, medical appointments or treatment. They may need adaptations for exam timetables for the same reasons. They sometimes need adaptation to exam conditions (e.g. access to the bathroom, possibility to bring food during an exam) but may face miscomprehension from teachers and examiners and rigid administrative rules. Because of issues around 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 highlighted that these discriminations affect their academic success, their professional orientation, and their future ability to obtain a job, as well as their future income.

2.4 WORKPLACE

Patients can face discrimination during interviews if they disclose their condition. They may also be discriminated through mandatory medical examination (e.g. a patient with HIV explained he could not practice his profession due to the need for a certificate a medical examiners refused to provide), and through rules forbidding them to access certain jobs that are not always medically justified (e.g. restrictions on patients with HIV, and “black list” of jobs people with diabetes cannot access).⁵¹ They also may face misperception and stigma from society that they are unable to work because they have a chronic condition.

In the workplace patients may face stigma and discriminatory attitudes from employers or colleagues such as undue disclosure of a condition, and lack of support to go back to work after a sick leave, or even difficulties after a long-term absence (e.g. sidelining of the employee).⁵²

Thomson, Sarah, and Elias Mossialos. Private health Insurance in the European Union. Final report prepared for the European Commission, LSE Health and Social Care, 2009.

⁴⁹ Civic Consulting. “Civic consulting country reports.” 2010. ec.europa.eu/social/BlobServlet?docId=5600&langId=en. CIVIC consulting. “CIVIC consulting report.” 2010. <http://ec.europa.eu/social/BlobServlet?docId=5599&langId=en>.

⁵⁰ Guy Thomas “Some novel perspectives on risk classification” *The Geneva Papers on Risk and Insurance - Issues and Practice*, 2007, vol. 32, issue 1, pages 105-132

⁵¹ EMPATHY project conference: <http://www.eu-patient.eu/whatwedo/Projects/EPF-led-EU-Projects/EMPATHY/>

⁵² Observatoire du CISS sur les droits des maladies rapport annuel de santé info droit 2011

The lack of clear structure and rights in various situations encountered by patients with chronic diseases could be considered as indirect structural forms of discrimination. For example it is unclear whether patients with chronic and long-term conditions are protected when they risk losing their job due to repeated or long-term absence⁵³. Rights of patients as regards workplace adjustments and accommodation are not always clear or responding to the needs of patients, and they are not always well-implemented.

Adapted systems and protective legislation are not always in place to allow patients with chronic diseases to remain in the workplace with acceptable conditions. Where they exist they are usually under-used; employers and the population at large tend not to be aware of their existence.⁵⁴ Actions to raise awareness within companies or trade unions and for the public could contribute significantly to tackling this problem.⁵⁵

2.5 DISCRIMINATION BASED ON GENETIC DATA

The health and genetic data of patients with chronic diseases are increasingly shared including through electronic systems, for various purposes including advancing public health and research. In this context there is a potential risk that genetic or health data may cause discrimination in the future (e.g. disclosure of a condition to an employer without the patient's consent etc...).

3 The way forward for EPF: Discussion section

Below are some discussion questions for EPF memberships, to ensure we map accurately the situation of patients with chronic and/or long term conditions as regards discrimination.

They also aim at assessing members' priorities for EPF's future work in this area.

1. Do you agree with the assessment of EPF as to areas of discrimination? Are there important types of discrimination faced by patients that we overlooked?
2. Do discriminations mentioned in this paper occur in your disease area/country?
3. Has your organisation held events or published materials as regards discrimination of patients?
4. Are you aware of mechanisms for complaint, redress and support for patients facing discrimination (e.g. in your Member State)? If yes can you explain how they work?
5. Which form(s) of discrimination you perceive are happening the most in your disease area/country?

EPF members are welcome to send comments and material from their own work related to the above questions to laurene.souchet@eu-patient.eu. As this is a reflection process, there is no formal deadline but feedback received will build into EPF's positions on this topic.

⁵³ Observatoire du CISS sur les droits des maladies rapport annuel de santé info droit 2011

⁵⁴ 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

⁵⁵ 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



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