

Healthcare for all

Tackling discrimination in healthcare

EPF Position Statement

19/12/2014



1 Introduction

1.1 INTRODUCTION

In EPF's vision, the fundamental goal of healthcare is to support every citizen in achieving the best possible health outcome and quality of life and to enable them to take their rightful place in society.

Patients have a fundamental right to health. The WHO defined the right to health as an inclusive right, that gives entitlements among which figure the availability and access to quality services, goods and facilities, without discrimination.¹ The Charter of Fundamental Rights of the EU states that "Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices" (article 35) and prohibits discrimination (article 21).² The European Union has also ratified the *United Nations Convention on the Rights of People with Disabilities* in January 2012, and article 25 of the Convention states that "persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability".³

Yet there is important evidence both from research and from feedback of patient organisations that **patients face various forms of discrimination in the European Union**, because of their health status and/or other grounds.

Furthermore, **patients are not always protected by non-discrimination legislation** within the European Union, depending on the grounds⁴ on which they are discriminated and on the Member States where the act of discrimination occurs, and of their disease:

- Some countries protect from discrimination on the grounds of health status,
- Other countries protect patients under the grounds of disability, but disability has no common EU definition, and inclusiveness of the definition of Member States varies.
- Overall protection in the area of healthcare varies, not all Member States have detailed legislation for this area, and at EU level.

Promoting 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 is one of EPF's strategic goals⁵. EPF will also publish a position paper on discrimination of patients with chronic diseases in the workplace and in education in 2015.



EPF believes in ensuring patients' rights for all regardless of health status, age, sex, ethnic origin, political belief, religious conviction, marital status, economic status, sexual orientation, gender identity or any other factor that could lead to discrimination. This is part of the core values of the European Patients' Forum as defined by our Strategic Plan 2014-2020.

¹ http://www.who.int/hhr/activities/Right_to_Health_factsheet31.pdf

² <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2010:083:0389:0403:en:PDF>

³ <http://www.un.org/disabilities/convention/conventionfull.shtml>

⁴ 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.

⁵ <http://www.eu-patient.eu/globalassets/library/strategic-planning/epf-strategic-plan-2014-2020-final.pdf>

While there are existing principles and laws on discrimination, we believe further steps need to be taken to truly tackle discrimination and stigma in the EU and to apply the right to health for all, without discrimination.

1.2 WHAT DO WE CONSIDER AS DISCRIMINATION?

In this paper, EPF considers both direct and indirect forms of discrimination. **Direct discrimination** happens when one person is treated less favourably than another is, has been or would be treated in a comparable situation.

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

In addition, we also believe that **structural forms of discrimination**, when health systems fail to meet the needs of a vulnerable group, also need to be identified and tackled.

Discrimination can be unintentional. However, if it is not addressed and if the system that allows it is not changed, it becomes deliberate.

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

1.3 WHY SHOULD DECISION MAKERS ACT?

Discrimination is against the common values of the European Union as defined in the Charter of Fundamental Rights and to the overarching values of universality, access to good quality care, equity, and solidarity that the Council committed to in the Council Conclusions on Common values and principles in European Union Health Systems of 2006.

Stigma and discrimination may result in patients or groups avoiding contact with the healthcare system which can potentially cause **worse health outcomes** as a result of delaying diagnosis and/or treatment, and lower health literacy. This has negative impacts both for individual patients' health and quality of life, and for the sustainability of healthcare systems.

In addition, discrimination can contribute importantly to **health inequalities** as they can lead to placing groups of people at systematic disadvantage with respect to their health status.



Healthcare is a particular area, as patients depend upon having timely access to quality healthcare. In addition, **health is constantly cited as one of the highest values** by European citizens and people's health influence many economic outcomes (productivity, labour supply, human capital and public spending)⁶. Health status is also a determinant for social inclusion/exclusion. Therefore we believe that **ensuring healthcare is an area free of discrimination should be one key focus of non-discrimination policies**.

⁶ Investing in health http://ec.europa.eu/health/strategy/docs/swd_investing_in_health.pdf

2 Patients and discrimination in healthcare

Discrimination may 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. Patients with rare diseases also face access barriers which could be considered as structural discrimination, as often no care pathway is developed for these diseases as there is a low prevalence. Patients without diagnosis or in search of a diagnosis also face important difficulties in healthcare. Patients with chronic diseases also face a general form of stigma or blame for their condition, particularly when it is considered preventable or caused by lifestyle factors. As a result they are sometimes represented as “burden on the system”.

Patients with mental health conditions are severely affected by discrimination in various areas of life, including healthcare. The stigma they face hampers their quality of life and the opportunity to accomplish their role as citizens. This often results in loss of opportunities in several areas: academic, employment, access to housing, emotional, etc.

In healthcare, the lack of information available to the public about mental health conditions results in delaying request for medical help by the affected person due to the fear and the shame of being rejected and misunderstood. This adds to delays in accessing adequate support. These factors affect all aspects of life, day to day. A project led by Mental Health Europe and funded under the Community Action Programme to combat discrimination 2001-2006 further highlighted the issues faced by people with mental health conditions in healthcare and provided recommendations and best practices.⁷

Patients with disabilities can face discriminatory attitude by healthcare providers, which can lead to exclusion from the provision of specific treatments (e.g. to prolong life, problems in access to sexual and reproductive health, denial of adequate treatment for people who live in institutions).⁸ Disabled people also face problems with access healthcare facilities, lack of adequate and targeted information, and difficulties in communicating with healthcare providers. The later point is also a key issue for patients with learning disabilities.

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 etc. People over a certain age are often excluded from clinical trials. Age discrimination also occurs in access to prevention and rehabilitation. There is also a risk of discrimination or stigma as regards the ability of older people to give consent in healthcare. Reports 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.

Younger patients also face structural issues in healthcare. For example, healthcare professionals lack the adequate skillset and as a consequence, young patients are not involved in decision making. There is no adequate support and information targeted at this audience. In addition, the needs of young patients transitioning towards adult care are not always addressed efficiently and they may face a decrease in support when they transition to adult care.

⁷ <http://old.mhe-sme.org/our-projects/past-projects/harassment-and-discrimination.html>

⁸ 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.

For more detailed information we refer you to *EPF position on the rights and needs of older patients*⁹ and the report of the *Empathy seminar for young patients*¹⁰.

Gender is another significant factor of indirect discrimination, as there are differences in how men and women are affected by chronic diseases, i.e. in term of prevalence, degree of severity of the disease, symptoms. 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 and 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: Clinical research only recently started to implement gender balance in trials, to take into account the fact that men and women metabolise and react to medicines differently.

Discrimination based on gender also appears in the management of patients' health and chronic or long term conditions: one key problem is "gender labelling" of a disease, which can have devastating consequences including delaying diagnosis and treatment. Two well-known examples are cardiovascular diseases and osteoporosis.¹¹ Another 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.¹²

Patients can face discriminatory attitudes in healthcare depending on their **sexual orientation**, e.g. labelling of their orientation as a 'sickness', and staff within health care systems who refuse to provide help with medical services.¹³ Their partners may be denied the right to visit, to have next of kin status, take medical decision, or have access to psychological support. There is also indirect discrimination, as this group faces lack of understanding of their specific health needs and lack of targeted information. According to the World Medical Associations, the negative experience this group face in healthcare "lead to higher prevalence rates of depression, anxiety disorders, substance misuse, and suicidal ideations and attempts".¹⁴

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 practices (e.g. dietary needs).¹⁵ There is also a lack of targeted prevention campaigns and public health messages towards certain religious groups e.g. when the content of a health message contravenes with a religious belief or practice.

⁹ http://www.eu-patient.eu/Documents/Policy/Ageing/EPF_Position-paper_Older-patients_Jan14.pdf

¹⁰ http://www.eu-patient.eu/Documents/Projects/EMPATHY/EMPATHY_Project-Report_2014.pdf

¹¹ Value + Toolkit <http://www.eu-patient.eu/Documents/Projects/Valueplus/Value+%20Toolkit.pdf>, p77

¹² http://www.who.int/mental_health/prevention/genderwomen/en/

¹³ European Union Agency for Fundamental Rights "Homophobia and Discrimination on Grounds of Sexual Orientation and Gender Identity in the EU Member States Part II – The Social Situation", 2009 http://fra.europa.eu/sites/default/files/fra_uploads/397-FRA_hdgso_report_part2_en.pdf

¹⁴ World Medical Association Statement on Natural Variations of Human Sexuality, October 2013 <http://www.wma.net/en/30publications/10policies/s13/>

¹⁵ 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.

Ethnicity can also be a ground for discrimination in healthcare: healthcare professionals may have discriminatory attitudes or stigmatise patients due to their ethnic background.¹⁶

Patients belonging to **linguistic minorities** in some countries can also face unavailability of some healthcare services in their language, which is a form of structural discrimination.

Roma people are a group vulnerable to discrimination. It is estimated that 15 percent of them are affected by a disability or chronic condition.¹⁷ According to the EU-MIDIS survey, they perceive they are discriminated against by healthcare personnel in various countries.¹⁸ They may face issues such as refusal to assist them, segregation in health care facilities, and difficulties to access emergency care due to their ethnicity or status. 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.

Migrants (including both documented and undocumented migrants) face discrimination. **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 insurances 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 as there can be 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.¹⁹

Major **Health determinants** can also trigger discrimination in healthcare. According to the World Health Organisation the determinants of health include:

- the social and economic environment,
- the physical environment, and
- the person's individual characteristics and behaviours.²⁰

Major determinants of health were identified by the WHO including social gradient, social exclusion, food, employment, addiction.²¹

For example obesity, alcoholism, homelessness, and drug dependency are cited by our members as factors that can lead to discriminatory behaviours towards patients within the healthcare system.

Among the determinants related to social and economic environment, EPF members cited the example of geographical localisation. Issues such as "medical desert", which are areas where there

¹⁶ 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

¹⁷ "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
EU- MIDIS (European Union Minorities and Discrimination Survey) – December 2009

¹⁸ EU- MIDIS (European Union Minorities and Discrimination Survey) – December 2009

¹⁹ 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

²⁰ <http://www.who.int/hia/evidence/doh/en/>

²¹ Further information is available in "Social Determinants of Health: the solid facts" 2nd edition, edited by Richard Wilkinson and Michael Marmot
http://www.euro.who.int/_data/assets/pdf_file/0005/98438/e81384.pdf

is a lack of healthcare professionals, when not actively addressed, are a form of discrimination for patients living in such areas.²² Patients from small or isolated countries or regions may also face specific difficulties. According to patients' groups' feedback, **low socio-economic status** is also an important element that leads to patients being discriminated by healthcare services.

Discrimination may also happen on **multiple grounds**, that is to say across two or more of the grounds mentioned above.²³



While this list is non-exhaustive, it shows the need for further actions to ensure the principle of equal treatment is truly implemented in healthcare in the European Union.

3 Key principles and recommendations for patients' equal treatment in healthcare

To tackle discrimination in healthcare and ensure that the principle of equal treatment becomes a reality for all patients, EPF calls on Member States and the EU to support the following rights and implement our recommendations.

3.1 THE RIGHT OF ACCESS AND EQUAL TREATMENT IN HEALTHCARE FOR ALL

EPF strongly believes that the **right to equal treatment in healthcare** regardless of health status, age, sex, ethnic origin, political belief, religious conviction, marital status, economic status, sexual orientation, gender identity, and nationality needs to be better implemented in the European Union. It encompasses the **right for all to access healthcare**. For patients, access to healthcare means its availability and affordability. It also means access to care services from primary prevention to chronic diseases management, not just emergency care. It should include access to innovative treatments when they bring significant added value for the patients compared to older treatments. Healthcare should also be sustainable. Healthcare needs to shift from a disease based approach to a patient centred approach. Many structural forms of discrimination and unmet needs of vulnerable groups arise from a "one-size-fits-all" approach. A change towards a genuinely **patient-centred healthcare** is part of the solution. In 2015 EPF will adopt a position paper on access to healthcare from the patients' perspective.

²² See the example of the medical desert in France, described in the paper " Démographie médicale: repartition des médecins sur le territoire: Enjeux pour l'accès au soins et la sécurité des usagers » by the Collectif Interassociatif sur la Santé

http://www.leciss.org/sites/default/files/101117_DOSSIER_DesertsMedicaux_Cahier1.pdf

²³ 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>

RECOMMENDATIONS:

1. EPF calls on the European Institutions and Member States to work toward adopting the **proposal for a directive on discrimination** beyond the workplace of 2 July 2008. This directive should explicitly apply to the area of healthcare services.
2. We call on Member States and the EU to put in place **a right to assistance for seriously ill undocumented migrants** who cannot have access to care in their country of origin, as they currently stand unprotected by EU law.²⁴
3. At the conference “health in Europe, making it fairer”, former health Commissioner Tonio Borg demonstrated **leadership in this area**. We encourage the European Commission and the EU to step up actions to raise awareness of discrimination in the area of healthcare and of good practices that exist to tackle it.
4. We call on the new Health Commissioner to take actions on **key demands** expressed by Non-Governmental Organisations before the hearing of the Commissioner.²⁵
5. The European Union and Member States should implement **principles of patient-centred healthcare**²⁶, and research and implement models of care and of healthcare governance that correspond to these principles.

3.2 THE RIGHT TO BE PROTECTED FROM DISCRIMINATION ON HEALTH STATUS

EPF believes that patients with chronic and/or long term conditions should be protected from discrimination on the grounds of health status.

RECOMMENDATIONS:

1. Provisions already exist in the legislation of some Member States and need to be replicated across the EU and at EU level in **antidiscrimination law**.
2. We encourage the EU and national government to **combat misconception and risk of stigmatisation** in their policies and communications related to chronic diseases: Though some chronic diseases are to some extent preventable, many diseases are not (e.g. neurodegenerative or genetic diseases), and diseases influenced by lifestyle factors arise from multiple factors which the patient may not have control over.

²⁴ Doctor of the World report on [access to healthcare in Europe in times of crisis and rising xenophobia](http://www.eu-patient.eu/Documents/Campaign-2014-EU-Elections/Demands_EU-NGOs_Health-Commissioner.pdf)

²⁵ http://www.eu-patient.eu/Documents/Campaign-2014-EU-Elections/Demands_EU-NGOs_Health-Commissioner.pdf

²⁶ See the definition of the International Alliance of Patients' Organizations <http://www.patientsorganizations.org/declaration>

3.3 THE RIGHT TO RESPECT AND TO DIGNITY IN HEALTHCARE FACILITIES

EPF believes that every patient has the right to be treated with respect and dignity by healthcare staff and health professionals. Yet as illustrated in section 2, many patients experience stigma due to staff behaviour in healthcare facilities. However, EPF also recognizes the strong role that healthcare professionals and their organisations are playing in the fight against discrimination. Ensuring that patients are treated with dignity and respect when coming in contact with the healthcare system is a principle of the Tallinn Charter²⁷.

RECOMMENDATIONS:

1. We believe **healthcare professionals' actions** to promote non-discrimination and ensure access to healthcare by vulnerable groups should be adequately supported and when relevant, resourced including by the EU and Member States.²⁸
2. Non-discrimination principles and understanding of ageing, disability, and cultural differences should be part of healthcare staff and **healthcare professionals' education or training**.
3. **Guidelines and good practices** in integrating fundamental rights in the education of healthcare professionals. [The OSCE guidelines for human rights education for health professionals](#) which also list several resource materials should be evaluated and shared at EU level to encourage their implementation on a wider scale.
4. Healthcare professionals and healthcare staff should be trained to use appropriate, non stigmatising terminology when communicating with patients.

3.4 THE RIGHT TO INFORMATION AND SUPPORT

In order to tackle discrimination, EPF believes that adequate information is a key cornerstone to support patients. This first means the right to have access to health information that is of high quality and that meets the diverse needs of patients needs to be put in place and implemented. Patients should also be informed about their rights and where to find adequate support or existing mechanisms for redress when they are victims of discrimination.

RECOMMENDATIONS:

1. EPF calls on the European Union to put in place an **action plan on health literacy**, with a focus on ensuring patients have access to high quality information. Civil society organisations must represent groups that are vulnerable to discrimination, to ensure that health literacy **interventions are tailored** to reach them.²⁹

²⁷ http://www.euro.who.int/__data/assets/pdf_file/0008/88613/E91438.pdf

²⁸ Example of such actions include the adoption by the World Medical Association of a Statement [on natural variation of human sexuality](#), or actions by NGOs such as the Doctor of the World (see the [report on access to healthcare in Europe in times of crisis and rising xenophobia](#))

²⁹ For more detailed recommendations, please consult our position on information to patients: <http://www.eu-patient.eu/whatwedo/Policy/Information-to-Patients/>

2. The EU and Member States should work with civil society organisations to ensure patients have access to **quality information about their rights as patients** and about existing **rights and mechanisms when they face stigma and/or discrimination** in healthcare facilities.
3. **Equality bodies**³⁰, who play a key role in informing citizens about their rights, should be independent and appropriately resourced and have a platform to consult non-governmental organisations.

3.5 THE RIGHT FOR VULNERABLE GROUPS TO PARTICIPATE IN NON-DISCRIMINATION POLICIES

To put in place effective non-discrimination policies, several actors need to work together. First and foremost, organisations representing vulnerable groups should be meaningfully involved in defining these policies. We commend the work of the EU Fundamental Rights Agency in involving various vulnerable groups in research.

RECOMMENDATIONS:

1. EPF recommends that at EU level and within Member States, departments with responsibilities for tackling discrimination and departments with responsibilities for health **work commonly** on this issues, not in silos, involving civil society organisations of both areas.
2. We recommend involving patients in **advisory bodies** on discrimination.
3. We recommend that the **Fundamental Rights Agency** continues to monitor the situation in this area. We recommend that the European Commission take actions to ensure that the Agency's opinions are implemented by Member States. We also recommend that the agency takes into account in its research grounds for discrimination such as health status, which are not explicitly mentioned by the treaties but are nonetheless factors of discrimination.
4. **Patients should be involved in research related to discrimination in healthcare**, in accordance with the findings of the project Value + which showed the added value of involving patients in health related projects and defined an approach for meaningful patient involvement.³¹
5. We recommend the EU put in place a joint action or common initiative to ensure **exchange of good practices between Member States on measures to tackle discrimination and health inequalities** in healthcare services (whether legislative measures or other policy initiatives), and that promote access to quality healthcare and information for groups of patients that are vulnerable to discrimination. The joint initiative should also look at best practices in collecting data and monitoring discrimination in healthcare. It should be carried out with meaningful involvement of civil society organisations representing vulnerable groups including patients.

³⁰ Bodies set up to act independently in promoting equal treatment of all persons without discrimination on the grounds of religion or belief, disability, age or sexual orientation

³¹ <http://www.eu-patient.eu/whatwedo/Projects/EPF-led-EU-Projects/ValuePlus/>

4 Conclusions

The European Patients' Forum is strongly committed to realise its vision that all patients with chronic and/or lifelong conditions in the EU have access to high quality, patient-centred equitable health and social care. This implies that healthcare should be free of discrimination, and that it should be respectful of and responsive to the diversity of patients in the European Union. We encourage more engagement from the EU on this theme.



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