

# Roadmap towards inclusion of vulnerable groups' perspective within patients' organisations

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## 1. Introduction

### 1.1 WHY THIS ROADMAP?

This roadmap is a tool to contribute towards EPF's strategic goals and core values as outlined in our strategic plan 2014-2020<sup>1</sup>:

#### **Goal 5: Sustainable Patient Organisations**

To support the development, growth and capacity building of inclusive, effective and sustainable representative patient organisations and to foster cooperation and synergies between them.

And in particular working towards the performance indicator: "EPF is successful in strengthening inclusiveness, representativeness, and accountability of European and national patient organisations".

#### **Goal 6: Non Discrimination**

To promote the development of EU and national policies that tackle discrimination faced by patients in health and social care as well as in domains like education and employment.

Inclusiveness is also a core value of EPF. We strive to ensure that our work reflects the needs of all patients and their informal carers including those who are under-represented. In 2013 EPF published a position on the rights and needs of older patients, a group with vulnerability to health inequalities.<sup>2</sup> In 2014 EPF adopted the position paper "healthcare for all" where we adopted key principles and recommendations for decision makers, to ensure that the principle of equal treatment in healthcare becomes a reality for all patients, and tackle discrimination in healthcare.<sup>3</sup>

This roadmap was developed as part of a reflection process on how patients' organisations can ensure they are inclusive and represent the views of all patients with chronic and long term conditions. It defines actions that EPF needs to take in order to improve its inclusiveness and to establish meaningful cooperation with organisations representing groups that are vulnerable to health inequalities at EU level. It also provides our members with suggestions of possible actions they could integrate into their work, where relevant to them, in order to advocate for inclusiveness and universal access to high quality healthcare.

### 1.2 GROUPS VULNERABLE TO HEALTH INEQUALITIES AND DISCRIMINATION IN ACCESS TO HEALTHCARE AND EU ACTIONS

At EU level, meeting the needs of vulnerable or underserved groups is an important focus in several initiatives and communications:

<sup>1</sup> <http://www.eu-patient.eu/globalassets/library/strategic-planning/epf-strategic-plan-2014-2020-final.pdf>

<sup>2</sup> [http://www.eu-patient.eu/globalassets/policy/ageing/epf\\_position-paper\\_older-patients\\_jan14.pdf](http://www.eu-patient.eu/globalassets/policy/ageing/epf_position-paper_older-patients_jan14.pdf)

<sup>3</sup> [http://www.eu-patient.eu/globalassets/policy/anti-discrimination/epf-position-discrimination-jan2015\\_final.pdf](http://www.eu-patient.eu/globalassets/policy/anti-discrimination/epf-position-discrimination-jan2015_final.pdf)

- In the European Commission’s communication “Solidarity in health” of 2009, vulnerable groups were already one of the issues identified for action. The Commission acknowledged that “Addressing health inequalities effectively requires policies which include both actions to address the gradient in health across the whole of society as well as actions which are specifically targeted to vulnerable groups”, citing people in poverty, disadvantaged migrant and ethnic minority groups, people with disabilities, elderly people or children living in poverty as target groups.<sup>4</sup> In its report on health inequalities published in 2013 the European Commission flagged actions it had taken to address health inequalities for the Roma, undocumented migrants, early intervention in childhood, and older people.<sup>5</sup>
- The European Parliament’s motion for a resolution on health inequalities in the EU, adopted in 2011 called on the European Commission and member states to “ focus on the needs of vulnerable groups, including disadvantaged migrant groups and people belonging to ethnic minorities, children and adolescents, people with disabilities, with a special focus on mental illness, patients diagnosed with chronic diseases or conditions, older people, people living in poverty, and people affected by alcoholism and drug addiction”.<sup>6</sup>
- The Council has also noted that vulnerable and socially excluded groups are facing worse health outcomes, and that they are facing a worse impact from the economic crisis. The Council committed to take actions focusing on vulnerable groups to reduce health gaps.<sup>7</sup>

This roadmap addresses 5 groups that are vulnerable to health inequalities or discrimination (the LGBTI people, undocumented migrants, the Roma people, homeless people and disabled people) and also looks at cross cutting actions.

### 1.3 METHODOLOGY

This roadmap was developed with the input of a group of volunteers within the EPF membership that set up a task force on inclusion of vulnerable groups’ perspective within patients’ organisations. The task force held monthly teleconferences with representatives from various organisations working with vulnerable groups in order to explore areas where working collaboratively would bring synergies. The roadmap was then approved by the EPF board.

### 1.4 KEY PRINCIPLES FOR COOPERATION

While developing the roadmap, several important principles that should underpin the patient community’s work in this area emerged from the discussion.

<sup>4</sup> <http://eur-lex.europa.eu/legal-content/EN/TXT/?qid=1396946539740&uri=CELEX:52009DC0567>

<sup>5</sup> [http://ec.europa.eu/health/social\\_determinants/docs/report\\_healthinequalities\\_swd\\_2013\\_328\\_en.pdf](http://ec.europa.eu/health/social_determinants/docs/report_healthinequalities_swd_2013_328_en.pdf)

<sup>6</sup> <http://www.europarl.europa.eu/sides/getDoc.do?type=REPORT&reference=A7-2011-0032&language=EN>

<sup>7</sup> Council conclusions on closing health gaps within the EU through concerted action to promote healthy lifestyle behaviours, December 2011

[http://www.consilium.europa.eu/uedocs/cms\\_data/docs/pressdata/en/lisa/126524.pdf](http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lisa/126524.pdf)

**A Cross cutting issue for patients with chronic and long term conditions:** Vulnerability is an issue across chronic and long term conditions, patients may be vulnerable due to the impact of their condition, and belonging to another vulnerable group may result in increased barriers to access quality healthcare that corresponds to their needs.

**Active inclusiveness:** Proactive action is necessary in order to make the principle of inclusiveness a reality.

**Complementarity and cooperation:** It is important to involve vulnerable groups in advocacy regarding their own health and building cooperation, the aim of this roadmap is to ensure cooperation in areas where joining forces with other non-governmental organisations could bring synergies and result in universal access to healthcare for all patients in the EU.

**Involvement at all levels:** Like for meaningful patients' involvement<sup>8</sup>, involving vulnerable groups means involving them at all level, in research, in policies, and in designing healthcare. Healthcare cannot be patient-centred if it does not meet the needs of all.

**Sharing of good practices by patient organisations:** Many patients' organisations are already developing activities in partnership with other associations or groups in order to promote inclusiveness and to advocate for universal access. Sharing publications or information about these activities amongst the patient community is important in order to scale them up, and foster more cooperation.

**Tackling multiple discrimination and stigma in healthcare:** While establishing the recommendations, the task force paid particular attention to addressing cross cutting forms of discrimination or health inequalities, as people who belong to several vulnerable groups encounter more barriers in access to healthcare.

## 1.5 HOW TO USE THIS ROADMAP

This roadmap was developed for patients' organisations. The aim is to raise awareness and foster reflection and action on inclusiveness in the patient movement, and ensuring patients' organisations advocate for the rights and specific needs of all groups of patients in an inclusive way within the EU.

**Please note that the group identified are not in any particular order of priority.**

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<sup>8</sup> Meaningful patient involvement is a concept developed in the Value + project: [http://www.eu-patient.eu/globalassets/projects/valueplus/doc\\_epf\\_policyrec.pdf](http://www.eu-patient.eu/globalassets/projects/valueplus/doc_epf_policyrec.pdf)

## 2. Undocumented Migrants

Undocumented migrants<sup>9</sup> are individuals who are not nationals of an EU Member State and are present in an EU Member State without a valid visa or residence permit.<sup>10</sup> Undocumented migrants typically enter the EU through a regular channel but lose their status, although the number of entries by irregular means has increased due to the absence of safe and regular channels for people to come to Europe. There are no reliable up-to-date statistics on the number of undocumented migrants in the EU. Between approximately 2 and 4 million undocumented migrants were estimated to be in the EU in 2008 ([www.http://irregular-migration.net/](http://irregular-migration.net/)). This figure is bound to have increased with the recent rise in the new arrivals, many of whom will not obtain asylum. They face often social disadvantage, exclusion and discrimination.

## 3. Key issues in healthcare

When accessing healthcare, undocumented migrants face several barriers:

- **Legal entitlements:** For people without residence status, the right to access healthcare is not always protected by the law, since legal entitlements often give them access only to emergency or essential care.<sup>11</sup> Very often the scope of their rights under national law is left to the judgment of healthcare providers or institutions, which can lead to a narrower interpretation.
- **Practical barriers:** Even when the right to access healthcare is established under national law, undocumented migrants can face other barriers. For instance, they may have to comply with burdensome administrative requirements, or may have to pay for treatments or procedures out of pocket. The complexity of the rules determining their rights, and their variation from country to country, and even from region to region, can lead to confusion and misapplication of the law, so that they may be wrongly turned away. According to the EU FRA, very often there is not continuity of care for undocumented migrants, because they cannot access primary health services and because much of the care they do receive is informal so that medical records are not kept.<sup>12</sup>

<sup>9</sup> (also called migrants in an irregular situation)

<sup>10</sup> As defined by the European Union Agency for Fundamental Rights [http://fra.europa.eu/sites/default/files/fra\\_uploads/1848-FRA-Factsheet-fundamental-rights-irregular-migrants\\_EN.pdf](http://fra.europa.eu/sites/default/files/fra_uploads/1848-FRA-Factsheet-fundamental-rights-irregular-migrants_EN.pdf)

<sup>11</sup> FRA, "Migrants in an irregular situation: access to healthcare in 10 European Union member states" (2011), [https://fra.europa.eu/sites/default/files/fra\\_uploads/1925-FRA-2011-fundamental-rights-for-irregular-migrants-healthcare\\_EN.pdf](https://fra.europa.eu/sites/default/files/fra_uploads/1925-FRA-2011-fundamental-rights-for-irregular-migrants-healthcare_EN.pdf); Medecins du Monde, "Legal Report on Access to Healthcare in 12 Countries" (2014), <https://mdmeuroblog.files.wordpress.com/2014/05/mdm-legal-report-on-access-to-healthcare-in-12-countries-3rd-june-20151.pdf>; PICUM, "The Sexual and Reproductive Health Rights of Undocumented Migrants: Narrowing the Gap between their Rights and the Reality in the EU," (2016), [http://picum.org/picum.org/uploads/publication/Sexual%20and%20Reproductive%20Health%20Rights\\_EN\\_FI\\_NAL.pdf](http://picum.org/picum.org/uploads/publication/Sexual%20and%20Reproductive%20Health%20Rights_EN_FI_NAL.pdf).

<sup>12</sup> European Union Agency for Fundamental Rights "Migrants in an irregular situation:

- **The absence of firewall between immigration control and provisions of services:** Healthcare administrators sometimes have a duty to report undocumented migrants to immigration authorities, or to share information about their patients' migration status with immigration authorities. This is an important deterrent to seeking healthcare.

There are some good practices in the European Union: for example, local or regional authorities sometimes grant more rights to migrants than what is provided at national level.<sup>13</sup>

Undocumented migrants can also belong to other groups vulnerable to discrimination or stigma in healthcare, leading to some combination of issues:

- **Mental health:** Undocumented migrants can sometimes face traumatic experiences, as part of their migration journey, as well as in their country of residence, which lead to or worsen mental health conditions.
- **Young undocumented migrants** face particular problems when transitioning to adult age. Although they are sometimes entitled to care as children, this often stops abruptly when they reach the age of majority.
- **Chronic diseases:** According to a survey by Médecins du Monde, one-third of the undocumented migrants that come for a consultation report they are suffering from one or more chronic conditions.<sup>14</sup> While in some countries undocumented migrants have access to primary care, in a majority of EU countries they have access only when their chronic conditions lead to an acute event. Access to medicines is also an important issue, as undocumented migrants may often have to pay out of pocket.<sup>15</sup>
- In addition, **the status of undocumented migrants** has an important impact on many areas of a person's life, severely limiting their mobility and opportunities in a variety of areas (education, work etc...), which in turn can negatively impact the physical and mental health and wellbeing of the person.

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access to healthcare in 10 European Union Member States", 2011

[http://fra.europa.eu/sites/default/files/fra\\_uploads/1771-FRA-2011-fundamental-rights-for-irregular-migrants-healthcare\\_EN.pdf](http://fra.europa.eu/sites/default/files/fra_uploads/1771-FRA-2011-fundamental-rights-for-irregular-migrants-healthcare_EN.pdf)

<sup>13</sup> PICUM Policy Brief, October 2014 "Access to Health Care for Undocumented Migrants in Europe: The Key Role of Local and Regional Authorities"

<sup>14</sup> European Observatory on Access to Healthcare of Médecins du Monde (2009), Access to healthcare for undocumented migrants in 11 European countries, p. 11 [Their most recent observatory report is available here: <https://mdmeuroblog.files.wordpress.com/2014/05/mdm-intl-obs-2015-report-en.pdf>. And a new one should be out this fall.]

<sup>15</sup> European Union Agency for Fundamental Rights "Migrants in an irregular situation: access to healthcare in 10 European Union Member States", 2011

[http://fra.europa.eu/sites/default/files/fra\\_uploads/1771-FRA-2011-fundamental-rights-for-irregular-migrants-healthcare\\_EN.pdf](http://fra.europa.eu/sites/default/files/fra_uploads/1771-FRA-2011-fundamental-rights-for-irregular-migrants-healthcare_EN.pdf)



As regards the cost of providing undocumented migrants with access to healthcare, a report using economic models with hypertension and prenatal care as case studies indicates that providing preventive rather than emergency care would be cost saving for healthcare systems.<sup>16</sup>

### 3.1 RECOMMENDATIONS FOR ACTIONS BY PATIENT ORGANISATIONS

#### 3.1.1 ACTION TO BE TAKEN BY EPF

objective	Actions	By when?
Promoting the right of undocumented migrants to full access to healthcare, contributing to give visibility to the barriers they face legally and in practice.	Involve PICUM in EPF campaign 2017 on universal health coverage to raise awareness about this issue & good practices at local level	2017
	Providing information and disseminate publications to EPF members on undocumented migrants and the issues they face as regards their right to health	ongoing
	Provide where possible country specific information to EPF national members regarding issues related to healthcare entitlement for undocumented migrants	ongoing
Raise awareness on the barriers young undocumented migrants face when coming of age	Include the issue in the youth group recommendations on transition to adult care, to raise awareness and make appropriate recommendation, in consultation with PICUM	2017

#### 3.1.2 AREAS FOR ACTIONS BY PATIENTS' ORGANISATIONS

Who?	What could you do?
National organisations	Monitor rights to access to healthcare for undocumented migrants and raise awareness of issues and good practices
	Build relations with organisations advocating for undocumented migrants' rights
Members working in the field of mental health	Research the link between mental health and undocumented migrants' status
	Advocate for undocumented migrants' right to access mental health support and care
members working with older patients or patients who live with disabilities	Monitor and facilitate access to healthcare for older patients who are undocumented migrants, or for undocumented migrants with disabilities, and raise awareness about specific issues and good practices

<sup>16</sup> European Union Agency for Fundamental Rights " Cost of exclusion from healthcare The case of migrants in an irregular situation", 2015 [http://fra.europa.eu/sites/default/files/fra\\_uploads/fra-2015-cost-healthcare\\_en.pdf](http://fra.europa.eu/sites/default/files/fra_uploads/fra-2015-cost-healthcare_en.pdf)

## 4. LGBTI people

### 4.1 KEY ISSUES IN ACCESS TO HEALTHCARE

LGBTI is the acronym for Lesbians, Gay, Bisexual, Trans and Intersex. The type of discrimination and stigma they face in healthcare is not always blatant but sometimes subtler, it is essentially lack of access to appropriate, inclusive, patient centred healthcare.

Issues LGBTI people can face in healthcare include:

- Undue curiosity from healthcare professionals, lack of **respect for privacy** and practices or procedures which put people in a position where they have to disclose their LGBTI status either against their wishes or in order to benefit from the same rights and services as non-LGBTI people.
- **Denial of service** like access to sexual and reproductive health services or mental health services. Lack of specific tailored prevention of sexually transmitted infections towards trans people and men who have sex with men.
- **Next of kin:** Lack of recognition of same sex partners and their children (resulting in no visitation rights, or right around consent).
- **Mental health** issues are also important amongst LGBTI people due to minority stress and discriminatory practices within the health sector (e.g. conversion therapies, pathologisation of patients' sexual orientation or gender identity, etc.)
- **Multiple discrimination** for example of young or older LGBTI people, or of those pertaining to a minority ethnic background.
- Being subjected to **moral or value judgements** and disrespectful comments or behaviours including overt or covert discrimination and devaluation.
- Lack of access to **trans specific care** and affordable treatment for transgender people
- Issues around lack of **informed consent** for the treatment of intersex children, which may include heavy interventions.

### 4.2 RESOURCES ON RIGHT TO HEALTH OF LGBTI PEOPLE

In the EU, discrimination on the grounds of sexual orientation or gender is prohibited by the Charter of fundamental rights.<sup>17</sup> There is no EU level legal protection against discrimination on the ground of sexual orientation since the Equal treatment EU directive proposed by the EC in 2008 has not been adopted yet. Trans people are partly protected by the 2004 directive on equality between women in men in access to goods and services, which is interpreted as covering the ground of gender reassignment. There is so far no protection on the ground of sex characteristics (intersex) in any area.

More provisions can be found in international texts on the right to health of LGBTI people including:

- The Yogyakarta principles<sup>18</sup>

<sup>17</sup> <http://fra.europa.eu/en/charterpedia/article/21-non-discrimination>

<sup>18</sup> <http://www.yogyakartaprinciples.org/>

- UN General comment n°14 of the Committee on Economic, Social and Cultural rights (2000)<sup>19</sup>
- UN comment n°20 (gender identity) of the Committee on Economic, Social and Cultural rights<sup>20</sup>
- PAHO resolution on LGBT health disparities (Oct. 2013)<sup>21</sup>

### 4.3 RECOMMENDATIONS FOR ACTIONS

#### 4.3.1 ACTION TO BE TAKEN BY EPF

Objective	Actions	By when?
Improve awareness and training of healthcare professionals	Supporting dissemination of good practices in training on competence for LGBTI health	ongoing
Raise awareness about issues around informed consent of intersex children and of their parents (including objective information)	<ul style="list-style-type: none"> <li>• Include this issue in our work on informed consent</li> <li>• Explore possibility to do a joint statement e.g. on the intersex awareness day in October</li> </ul>	2017  2017 or 2018
Raise awareness about health issues of LGBTI young people, with a focus on mental health	Facilitate contact between youth organisations in this field and the EPF youth group	2017

#### 4.3.2 AREAS FOR ACTIONS BY PATIENTS' ORGANISATIONS

Who?	What can you do?
National organisations	Raise awareness about rights and needs of LGBTI patients e.g. when advocating for patient-centred care
Mental health organisations	<ul style="list-style-type: none"> <li>• Raise awareness on mental health in the LGBTI community e.g. by doing common statements with LGBT organisations on awareness days etc....</li> <li>• Participate in research related to LGBTI mental health or impact of discrimination on mental health</li> </ul>
All	Refer to and mention relevant international texts on LGBTI right to health where relevant to contribute to awareness of these rights

<sup>19</sup> [http://www.nesri.org/sites/default/files/Right\\_to\\_health\\_Comment\\_14.pdf](http://www.nesri.org/sites/default/files/Right_to_health_Comment_14.pdf)

<sup>20</sup> <http://www.refworld.org/docid/4a60961f2.html>

<sup>21</sup> [http://www.paho.org/hq/index.php?option=com\\_docman&task=doc\\_download&gid=23145&Itemid=270&language=en](http://www.paho.org/hq/index.php?option=com_docman&task=doc_download&gid=23145&Itemid=270&language=en)

## 5. The Roma

### 5.1 KEY ISSUES

One of the most universally disadvantaged communities living in Europe is the Roma. The great majority of the estimated 10-12 million Roma population is found at the very bottom of the socio-economic spectrum: they suffer worse health than the other populations in the countries due to their higher exposure to the range of unfavourable factors that influence health.

The main issue that they face:

- They are impacted by a **combination of factors** such as poor nutrition, poor living conditions, difficult physical work, inadequate environment, and insufficient education.
- According to the European Commission's report on the health status of the Roma population in Europe, disadvantaged Roma in Europe suffer a greater exposure to **wider risks of ill health**, have poorer access to preventive healthcare services and suffer poorer health outcomes than the general population.<sup>22</sup>
- **Discrimination and an unregulated civil status** (including a lack of personal documents, such as birth certificates and insurance) make it particularly difficult for Roma to access health services.
- Groups working with Roma Communities have identified a number of barriers to accessing health services among the Roma, namely a **lack of knowledge** on disease prevention, a lack of knowledge about their health service rights and difficulties of physically accessing services.
- Roma are also more affected from more **communicable and chronic diseases** than the majority population, and often live in secluded areas where they have no access to healthcare.<sup>23</sup>

### 5.2 CURRENT POLICIES AT EU LEVEL

Several initiatives have been taken at EU level to improve Roma's living conditions and well-being which can also be used for health advocacy:

- The **Council Directive 2000/43/EC** of 29 June 2000 implements the principle of equal treatment between persons irrespective of racial or ethnic origin.<sup>24</sup> The objective of this legislation is to combat discrimination on the grounds of racial or ethnic origin. The Commission launched infringement procedures against the Czech Republic, Slovakia and most recently Hungary on the basis of EU equal treatment legislation.

<sup>22</sup> European Commission (2014). *Roma Health Report – Health Status of the Roma Population*. Available at: [http://ec.europa.eu/health/social\\_determinants/docs/2014\\_roma\\_health\\_report\\_en.pdf](http://ec.europa.eu/health/social_determinants/docs/2014_roma_health_report_en.pdf)

<sup>24</sup> Council Directive 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin, <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:32000L0043:en:HTML>

- The Council adopted **Conclusions on Roma integration** on May<sup>25</sup> and June<sup>26</sup> 2011. Most recently, at its 9-10 December 2013 meeting, the Council of the European Union adopted unanimously the **Council recommendations on effective Roma integration measures in the Member States**<sup>27</sup>.
- In the EU Framework for national Roma integration strategies<sup>28</sup>, all Member States are expected to present to the European Commission a **strategy for Roma inclusion** or sets of policy measures within their social inclusion policies for improving the situation of Roma people on a yearly basis. For this purpose, they set up national contact points<sup>29</sup>. The European Commission (DG JUST)<sup>30</sup> assesses these strategies and publishes its conclusions.<sup>31</sup>
- Member States have to adopt **national Roma strategies**. The 4 core elements of the strategies are housing, education, employment and healthcare, including discrimination. That includes a shadow reporting process where patient organisations can in the future fill an on-line reporting tool where they can give direct input to the Commission about the situation of Roma integration, including access to healthcare. The framework encompasses a yearly conference called the European Roma Platform (29-30 November 2016) and a Roma Summit every 3 years (the next will take place in 2017)
- **Country Specific Recommendations (CSRs)** of the European Semester can also address Roma integration although the economic governance policy is changing and CSRs are expected to be shorter and more specific.
- EU funding is available through **structural funds** but the use of the funds is decided at national level. Under the 2014-2020 financial period of the EU, the following financial instruments are relevant for Roma communities:
  - European Social Fund (ESF)<sup>32</sup>
  - European Regional Development Fund (ERDF)<sup>33</sup>
  - European Agricultural Fund for Rural Development (EAFRD)<sup>34</sup>
  - European Maritime and Fisheries Fund (EMFF)<sup>35</sup>

### 5.3 RESOURCES ON ROMA AND HEALTH

Key resources available on Roma health at EU level include:

<sup>25</sup> An EU Framework for National Roma Integration Strategies up to 2020 - Council Conclusions, <http://register.consilium.europa.eu/doc/srv?l=EN&t=PDF&gc=true&sc=false&f=ST%2010658%202011%20INIT>

<sup>26</sup> European Council 23/24 June 2011 Conclusions, [http://ec.europa.eu/commission\\_2010-2014/president/news/speeches-statements/pdf/20110624\\_1\\_en.pdf](http://ec.europa.eu/commission_2010-2014/president/news/speeches-statements/pdf/20110624_1_en.pdf)

<sup>27</sup> [http://www.consilium.europa.eu/uedocs/cms\\_data/docs/pressdata/en/lisa/139979.pdf](http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lisa/139979.pdf)

<sup>28</sup> An EU Framework for National Roma Integration Strategies up to 2020, <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2011:0173:FIN:EN:PDF>

<sup>29</sup> National Contact Points for the implementation of national Roma integration strategies, [http://ec.europa.eu/justice/discrimination/files/roma\\_nationalcontactpoints\\_en.pdf](http://ec.europa.eu/justice/discrimination/files/roma_nationalcontactpoints_en.pdf)

<sup>30</sup> Directorate-General for justice and consumers

<sup>31</sup> DG SANTE is involved, but with limited resources to input in the process

<sup>32</sup> <http://ec.europa.eu/esf/home.jsp?langId=en>

<sup>33</sup> [http://ec.europa.eu/regional\\_policy/thefunds/regional/index\\_en.cfm](http://ec.europa.eu/regional_policy/thefunds/regional/index_en.cfm)

<sup>34</sup> [http://ec.europa.eu/agriculture/cap-funding/index\\_en.htm](http://ec.europa.eu/agriculture/cap-funding/index_en.htm)

<sup>35</sup> [http://ec.europa.eu/fisheries/reform/emff/index\\_en.htm](http://ec.europa.eu/fisheries/reform/emff/index_en.htm)

- The European Public Health Alliance’s position on Roma health in Europe from 2014<sup>36</sup>
- A joint pro-Roma civil society contribution to the public consultation on access to health services in the EU coordinated by EPHA<sup>37</sup>
- The EU fundamental rights agency is monitoring discrimination faced by the Roma community and application of their fundamental rights (including the right to health) <sup>38</sup>
- The Report on the health status of the Roma population in the EU and monitoring data collection in the area of Roma health in the Member States published in 2014<sup>39</sup>
- AGE Platform and ERIO joint position on voicing the experience of older Roma<sup>40</sup>

## 5.4 RECOMMENDATIONS FOR ACTIONS

### 5.4.1 ACTIONS TO BE TAKEN BY EPF

Objective	Actions	By when?
Advocacy for sustainable Roma health mediators’ programmes	Include this recommendation in EPF 2017 campaign	December 2017
To advocate for collection of data on Roma health and access to healthcare	<ul style="list-style-type: none"> <li>• To include in EPF recommendations on Health System Performance Assessment</li> <li>• To inform membership about DG JUST shadow reporting tool once it is available</li> </ul>	ongoing
European Semester and Country specific recommendations	To call for recommendations on improving access to healthcare for the process of the European Semester to coordinate with the Ministry of Finance and Ministry of Health for the Roma health specific European Semester documents	2017

### 5.4.2 AREAS FOR ACTIONS BY PATIENTS’ ORGANISATIONS

Who?	What can you do?
National organisations	<ul style="list-style-type: none"> <li>• Advocate for sustainable Roma health mediator programmes in your country</li> </ul>

<sup>36</sup> <http://epha.org/epha-position-roma-health-in-europe/>

<sup>37</sup> <http://epha.org/joint-pro-roma-civil-society-contribution-to-the-public-consultation-on-access-to-health-services-in-the-eu/>

<sup>38</sup> <http://fra.europa.eu/en/theme/roma>

<sup>39</sup> [http://ec.europa.eu/health/social\\_determinants/docs/2014\\_roma\\_health\\_report\\_en.pdf](http://ec.europa.eu/health/social_determinants/docs/2014_roma_health_report_en.pdf)

<sup>40</sup> [http://age-platform.eu/images/stories/EN/position\\_paper\\_age\\_erio\\_oct2011\\_final.pdf](http://age-platform.eu/images/stories/EN/position_paper_age_erio_oct2011_final.pdf)

	<ul style="list-style-type: none"> <li>• Call for data collection on Roma health if lacking in your country</li> <li>• Make contact with the national Roma contact point in your country</li> </ul>
All types of patient organisations	To provide information you may have on health inequalities/ barriers to access faced by Roma in the future tool for reporting to be set up by the European Commission (DG JUST)

## 6. Homelessness

Homelessness means the absence of home in the physical, legal, social sense.<sup>41</sup> It is estimated in the EU that 410.000 people are homeless in any given night. It affects all Member States but only half of them have targeted homeless strategies.

### 6.1 KEY ISSUES IN HEALTHCARE

Homeless people face extreme health inequalities:

- **Premature mortality** is an important issue.
- **Multimorbidity** caused by a mix of public health, mental and physical health issues, diseases they commonly face include hepatitis, depression, cardiovascular diseases.
- **Dental health** is also a key issue.
- Cross cutting inequalities and discrimination related to **disability**.
- Homeless people make a **higher use of ambulatory and emergency healthcare services**.
- They tend to overstay in hospital, and can be **inadequately discharged** or changed from service to service, which can lead homeless people to distrust healthcare services.
- **Non-compliance** to treatment is an important issue, treatment received is often not adequate to their needs.
- They sometimes have no choice as regards some aspects of their **lifestyle** (e.g. nutrition).

Overall, homeless people tend to face important barriers to access to healthcare.

### 6.2 RESOURCES ON HOMELESS PEOPLE AND HEALTH

Further resources regarding homeless people’s access to healthcare and health inequalities can be found on the page of FEANTSA working group on health.<sup>42</sup> The organisation has also identified various good practices in the EU, such as the “Find and Treat programme in the UK” which aims at

<sup>41</sup> See FEANTSA’s FAQ on what is homelessness here for more information: <http://www.feantsa.org/en/about-us/faq>

<sup>42</sup> <http://feantsa.org/spip.php?article385&lang=en>

diagnosing and treating tuberculosis, and involves peer workers who have experienced homelessness amongst the multidisciplinary team.<sup>43</sup>

## 6.3 RECOMMENDATIONS FOR ACTIONS

### 6.3.1 ACTIONS TO BE TAKEN BY EPF

Objective	Actions	By when?
To work with FEANTSA to disseminate existing, identified good practices on access to care for homeless people and training for healthcare professionals	<ul style="list-style-type: none"> <li>• Include issues related to health inequalities and homelessness in the recommendations of the 2017 EPF access campaign</li> <li>• To discuss in the EPF blog in 2017</li> </ul>	2017
To take into account homeless people’s challenges when working on patient empowerment, eHealth, adherence and multimorbidity	To include in 2016 eHealth position paper, and in relevant work on other themes mentioned	ongoing

### 6.3.2 AREAS FOR ACTIONS BY PATIENTS’ ORGANISATIONS

Who?	What can you do?
National organisations	Meet with organisations dealing with homeless health in order to identify specific issues related to homeless people’s health and access to healthcare in the country
Disease specific organisations	For diseases that are widespread amongst homeless people (e.g. cardiovascular diseases, mental health issues), establish cooperation with organisations active in the area of homelessness to ensure needs are taken into account

<sup>43</sup>

[http://www.feantsa.org/spip.php?action=acceder\\_document&arg=2526&cle=90903f42c7b00a961790878f30f354e769cd8a25&file=pdf%2Fpress\\_release\\_tb.pdf](http://www.feantsa.org/spip.php?action=acceder_document&arg=2526&cle=90903f42c7b00a961790878f30f354e769cd8a25&file=pdf%2Fpress_release_tb.pdf)



## 7. Disability

### 7.1 KEY ISSUES

People with disabilities encounter key obstacles in accessing healthcare:

- Lack of **accessibility to healthcare facilities** and health information which takes into account people’s possible impairments (e.g. cognitive, physical etc.).
- Issues with healthcare providers around **respect of dignity**, lack of flexibility.
- Specific services are not always provided (i.e. multidisciplinary care in some countries) or covered by the healthcare system in the required measure: e.g. rehabilitation programmes, mobility and continence support devices etc.
- In many cases the specific care or treatment needed by the disabled patient might not be available locally, which forces the patient to travel, resulting in an extra financial burden
- There is a **shortage of healthcare professionals adequately trained** on medical issues faced by people with disabilities (e.g. brain injuries, Spina Bifida).
- At the same time, many healthcare professionals lack **knowledge on human rights** and particularly rights of persons with disabilities.
- Care is not always provided with the **adequate informed consent procedure** e.g. for people with intellectual disabilities resulting in treatment that is not adapted to the need of the person.
- There is a tendency to **over-emphasise physical disability** resulting in a failure to recognise certain conditions as resulting in disabilities and consequently a failure to provide appropriate services and support for all people with disabilities (e.g. including people with dementia).

Overall key issues arise from the lack of person centred healthcare services.

As for other groups mentioned in the roadmap, there can be a combination of factors and grounds such as age or gender that can lead to specific forms of discrimination or specific barriers when combined with disability.

### 7.2 RECOMMENDATIONS FOR ACTIONS

#### 7.2.1 ACTIONS TO BE TAKEN BY EPF

Objective	Actions	By when?
Exchanging information at EU level on actions as regard healthcare between patients’ and disability organisations	Meeting with EDF secretariat including EU members with an expertise in the area of disability	2017
Take into account issues around stigmatisation of people with disability in our work on discrimination,	Integrate in future relevant positions	ongoing

consent, training of healthcare professionals and access to information		
Take into account the UNCRPD to promote and protect the rights of people with disabilities (e.g. article 25_ Right to health Article 9 Accessibility-including medical care/ eHealth)	Integrate in future relevant positions	ongoing
Raise awareness of the definition of "Discrimination on the basis of disability" in the UNCRPD in order to ensure that the rights of all groups with disabilities are recognised and promoted.	Integrate in future relevant positions or advocacy activities	ongoing

### 7.2.2 AREAS FOR ACTIONS BY PATIENTS' ORGANISATIONS

Who?	What can you do?
National organisations	Meet with organisations dealing with disability and /or health in order to identify specific issues related to disabled people's health and access to healthcare
Disease specific organisations	For diseases/conditions that are widespread amongst certain groups - (e.g. dementia in the elderly), establish cooperation with organisations active in the area of disability to ensure needs are taken into account

## 8. Cross cutting actions

### 8.1 FOR EPF

Objective	Actions	By when?
To follow up on the progress of implementation of actions proposed for EPF within the roadmap	<ul style="list-style-type: none"> <li>Develop a progress report</li> </ul>	2018

To involve NGOs as partners during the EPF campaign on universal access to healthcare to ensure vulnerable groups' needs and rights, as well as potential barriers they face are taken into account	<ul style="list-style-type: none"> <li>Determine appropriate form of involvement with partners (event invitation, joint statement, blog etc...)</li> </ul>	2017
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## 8.2 SUGGESTIONS OF ACTIONS FOR MEMBERS:

All members	Share your actions (and actions of your members at national level) addressing rights and needs of vulnerable or underserved groups with EPF in order to share ideas for activities and good practices across patients' organisations in the EU	In 2017
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- Etienne Cuhe, European Parliament officer, European Disability Forum (EDF)
- Vera Bonvalot, executive committee member and chair of EDF health group, European Disability Forum

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<sup>44</sup> <http://www.togetherforbetterhealth.eu/>



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