

# **EPHA Position FRA Annual report 2012 and FRA Strategic Objectives 2013-2017**

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**EPHA Position Paper – October, 2013**





## EPHA Position

# FRA Annual report 2012 and FRA Strategic Objectives 2013-2017

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The *European Public Health Alliance (EPHA)* is the European Platform **bringing together public health** organisations representing health professionals, patients groups, health promotion and disease specific NGOs, academic groupings and other health associations. Our membership includes representatives at international, European, national, regional and local level.

EPHA's mission is **to protect and promote public health in Europe**. EPHA brings together organisations across the public health community, to share learning and information and to bring a public health perspective to European decision-making. We help build capacity in civil society participation across Europe in the health field, and work to empower the public health community in ensuring that the health of European citizens is protected and promoted by decision-makers. **Our aim is to ensure health is at the heart of European policy and legislation.**

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## Table of Content

<b>1 EXECUTIVE SUMMARY .....</b>	<b>4</b>
1.1 SUMMARY .....	4
1.2 RECOMMENDATIONS .....	4
<b>EPHA POSITION - FRA ANNUAL REPORT 2012 AND FRA STRATEGIC OBJECTIVES 2013-2017 .....</b>	<b>5</b>
<b>2 INTRODUCTION - THE EUROPEAN UNION AGENCY FOR FUNDAMENTAL RIGHTS (FRA) .....</b>	<b>5</b>
2.1 THE FRA MANDATE – THE MULTI-ANNUAL FRAMEWORK (2013-2017) .....	5
2.2 THE FUNDAMENTAL RIGHTS PLATFORM (FRP) .....	5
2.3 EPHA'S COMMITMENTS TO THE PROTECTION AND PROMOTION OF FUNDAMENTAL RIGHTS.....	6
2.3.1 <i>Various activities aiming at reducing health inequalities</i> .....	6
2.3.2 <i>The European Charter for Health Equity</i> .....	6
<b>3 FRA ANNUAL REPORT: 'FUNDAMENTAL RIGHTS: CHALLENGES AND ACHIEVEMENTS IN 2012'</b>	<b>8</b>
<b>4 FRA STRATEGIC PLAN 2013-2017.....</b>	<b>8</b>
4.1 STRATEGIC PRIORITIES .....	8
4.2 THEMATIC PRIORITIES .....	8
<b>5 THE RELEVANCE OF THE FRA DOCUMENTS FOR THE PUBLIC HEALTH COMMUNITY .....</b>	<b>8</b>
5.1 SOCIAL RIGHTS PROTECTION AND THE FRA MANDATE.....	8
5.1.1 <i>Social Rights in Europe</i> .....	8
5.1.2 <i>The relevance of Social Rights for the FRA</i> .....	9
5.2 STRATEGIC PRIORITIES .....	9
5.2.1 <i>Enhancing FRA's contribution to legal and policy processes at EU level</i> .....	9
5.2.2 <i>Enhancing FRA's contribution processes at national level</i> .....	10
5.2.3 <i>Identifying trends over time and measuring progress in Member States</i> .....	11
5.2.4 <i>Developing timely and targeted responses to fundamental rights emergencies</i> .....	12
5.3 THEMATIC OBJECTIVES AND SPECIFIC AREAS OF THE FRA ANNUAL REPORT 2012 .....	13
5.3.1 <i>Information society and, in particular, respect for private life and protection of personal data</i> ..	13
5.3.2 <i>Roma Integration</i> .....	13
5.3.3 <i>Rights of the child</i> .....	16
5.3.4 <i>Discrimination based on sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of national minority, property, birth, disability, age or sexual orientation</i> .....	16
5.3.5 <i>Immigration and integration of migrants, visa and border control and asylum</i> .....	17
<b>6 CONCLUSIONS .....</b>	<b>17</b>

# 1 Executive summary

## 1.1 Summary

The **Fundamental Rights Agency (FRA)**, as an independent EU Agency monitors the promotion of Fundamental Rights proclaimed in **the Charter of the Fundamental Rights of the European Union**. The Agency disseminates objective, reliable and comparable data on the situation of fundamental rights in all EU countries within the scope of EU law. Due to its unique position FRA could make sure within its mandate that European political decision and legal acts **comply with basic Fundamental Rights criteria**.

EPHA takes this opportunity to highlight **general elements in the FRA working documents** pointing out the specific links between Social Rights protection and the FRA mandate, Fundamental Rights and the Europe 2020 strategy, the Universal Access to healthcare as a Fundamental Right and reforming health systems under financial pressure. EPHA expresses its opinion on the **FRA's specific priorities** as well as on **some parts of the Annual report 2012** which are especially relevant for the public health community.

## 1.2 Recommendations

- FRA could underline the importance of **widening its mandate** in all of its working areas so that it **include Social Rights** and should demonstrate by evidences the need **for more social protection**, presenting the legal possibilities for Member states **to enhance the protection of social rights of their citizens by international commitments**.
- In line with **the European Charter for Health Equity**, the FRA should promote **adequate social protection systems as a basic right for all persons** living in Europe and adopt, implement and enforce **evidence-based measures** targeted to poorer individuals, families and communities.
- In times of crisis, investments in health systems should continue, and the Fundamental Rights Agency should provide decision makers with the scientific evidence suggesting that **significant reductions in healthcare budgets risk creating new inefficiencies, undermining access to and quality of care, and damaging health outcomes** which can compromise **basic EU principles and Fundamental Rights standards**
- Since FRA's mandate covers **discrimination based on disability**, **appropriate indicators** are needed in FRA's future research and data collection activity to raise awareness of such invisible groups as **COPD patients**, which belong to **both the public health and disability community**
- There is a strong link between the **economic crisis** and **Fundamental Rights emergencies** and the **criminalisation of homeless people** clearly demonstrates the danger that the **economic crisis** may turn into **Fundamental Rights emergency situations**.
- By capitalising on its expertise in linking sociological issues with legal frameworks, the FRA can make a major contribution to ensuring that **existing health inequalities will not be aggravated** in an increasingly digitalised world.
- In its Roma related activities, the FRA should focus and rely on successful practices as the European network of **Roma health mediators**, **the civil shadow report on the implementation of the National Roma Integration Strategies (NRIS)** or the **training of Roma EU health advocates**.
- The FRA shall take into consideration good examples aiming at tackling **children's malnutrition**.
- The public health community **clearly demands the right to provide healthcare** – in accordance with medical ethics – **to all patients, regardless of their social status or ethnic origin**.
- The FRA should enhance collaboration for data **collection on migrant demographic and health data**. For example, **the Clandestino-project**<sup>1</sup> found a lot of variability in data qualifying across Europe. The public health community finds worth towards **standardized data collection and sharing**.

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<sup>1</sup> <http://research.icmpd.org/1244.html>

# EPHA Position - FRA Annual report 2012 and FRA Strategic Objectives 2013-2017

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## 2 Introduction - The European Union Agency for Fundamental Rights (FRA)

The FRA was set up by the founding [Council Regulation \(EC\) No 168/2007](#) as an independent EU Agency to monitor the promotion of Fundamental Rights proclaimed in the Charter of the Fundamental Rights of the European Union. The FRA, based in Vienna, disseminates objective, reliable and comparable data on the situation of fundamental rights in all EU countries within the scope of EU law. It works closely with other bodies and institutions at national and European level. The Agency aims to give EU institutions and EU countries assistance and expertise relating to fundamental rights when they implement EU law. The FRA provides the EU Institutions and Member States with independent, evidence-based advice on fundamental rights. The Agency plans its research on the basis of annual work programmes and within the thematic areas listed in its Multiannual Frameworks.



### 2.1 The FRA mandate – the Multi-annual Framework (2013-2017)

The FRA has mandate to cover thematic areas which are determined through a five-year Multi-annual Framework (2013-2017). On 11 March 2013, the Justice and Home Affairs Council of the European Union, on proposal of the European Commission and after consulting the European Parliament, adopted the agency's current Multi-annual Framework. The Framework is implemented in complementary to the work of other EU bodies, the Council of Europe and other international organisations involved in the field of human rights. The [current Multi-annual Framework 2013-2017](#)<sup>2</sup> will expire on 31st December 2017 and will be replaced by a new Council Decision. The Agency's mandate covers the following nine areas:

1. access to justice;
2. victims of crime, including compensation to victims;
3. information society and, in particular, respect for private life and protection of personal data;
4. Roma integration (new);
5. judicial cooperation, except in criminal matters (new);
6. rights of the child;
7. discrimination based on sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation (new);
8. immigration and integration of migrants, visa and border control and asylum;
9. racism, xenophobia and related intolerance.

### 2.2 The Fundamental Rights Platform (FRP)

Based on article 11 TEU which states that “the institutions shall maintain an open, transparent and regular dialogue with representative associations and civil society”, the Fundamental Rights Platform (FRP) meeting is the flagship event of the FRA. The meeting brings together participants of the Fundamental Rights Platform (FRP) – the agency's network for cooperation with over 300 civil society organisations working on a variety of fundamental rights issues across the European Union at European, national or local level. It allows information exchange and the pooling of knowledge, thereby maintaining an

<sup>2</sup> <http://fra.europa.eu/en/about-fra/what-we-do/areas-of-work>

open, transparent and regular dialogue between FRA and civil society organisations, and among civil society organisations themselves. The FRA gives an opportunity for FRP participants to provide feedback and suggestions to **FRA's Annual Work Programme and Annual report**.

### 2.3 EPHA's commitments to the protection and promotion of fundamental rights

EPHA became a **recognised partner organisation of FRA and FRP participant organisation in 2012**. EPHA's successful application was based on proven record of working for **the protection and promotion of fundamental rights**.

#### 2.3.1 Various activities aiming at reducing health inequalities

It is well recognised that differences in health status at a population level are closely linked to **social determinants of health**<sup>3</sup>. **Social and environmental determinants of health** are the conditions in which people are born, grow up, live, work and age. They will affect their opportunities to be healthy, their risks to develop illnesses or suffer injuries and their life expectancy.

**Health inequalities** - the unfair but avoidable differences in health status across different socio-economic groups in society - usually result from the uneven distribution of social and environmental determinants; the differential access to resources such as education, employment, housing, health services; different levels of participation in society and different levels of control over life.

Although the issue of **Health Inequalities** is currently on the agenda of the European Commission, the European Parliament, and the World Health Organization, increasing economic and political pressures put even more burden on socially deprived, most vulnerable and under-served population groups. All health gains achieved in the recent decades are thus at risk.<sup>4</sup>

All across Europe, within and between countries, health inequalities persist and grow. Therefore, in order to reduce those EPHA has engaged in many activities (advocacy and policy-making) for the protection and **promotion of fundamental rights to reduce those health inequalities**: in the field of children; Roma minorities; disables and patients' rights; violence against women (European Women's Lobby campaign supporter); right to water and sanitation (European Citizens' Initiative), and to clean and safe environments; sexual and reproductive health and rights.

EPHA was an official and active partner to the End Poverty Campaign (EAPN) in a framework of the 2010 EU Year against Poverty and Social Exclusion. EPHA regularly participates in the **EU Platform against Poverty and Social Exclusion** as well as the **EU Platform for Roma Integration**. EPHA also participated twice with an observer status in the work of the Council of Europe on the **child-friendly healthcare services**.

In 2012, **the EPHA Annual Conference (Restructuring health systems: How to promote health in times of austerity?)**<sup>5</sup> was dedicated to the issue of the impact of austerity measures on health systems and services in the EU, the consequences of the crisis on population health, inequalities and social justice.

#### 2.3.2 The European Charter for Health Equity

In 2010, EPHA developed and ever since has been promoting the **European Charter for Health Equity**<sup>6</sup> – an inspirational, bottom-up and cross-sectoral document intended **to keep the issue of health equity high on the political and human rights agenda's**. The Charter reaffirms the commitment to the values of well-being, solidarity, social justice, promotion of fundamental human rights and gender equity. Furthermore, it

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<sup>3</sup> COM 14848/09.

<sup>4</sup> <http://www.epha.org/a/4318>

<sup>5</sup> <http://www.epha.org/a/5080>

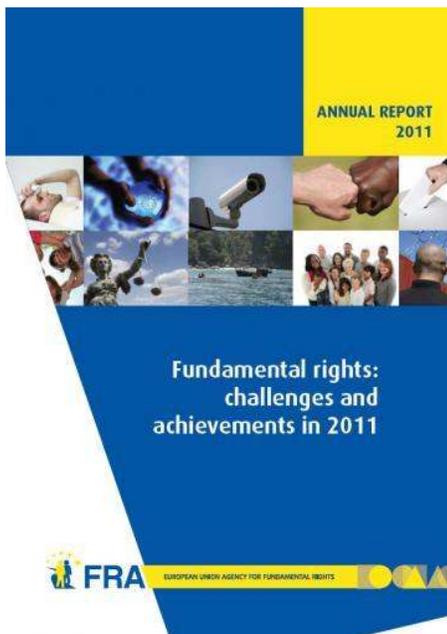
<sup>6</sup> <http://www.epha.org/spip.php?article4368>



reaffirms the commitment to the principle enunciated in the constitution of the WHO that the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being.

**The purpose** of the Charter is to call for action from the civil society to all relevant stakeholders and in particular decision makers, relevant governmental and civil society partner organisations, and other regulatory bodies, to protecting and promoting people’s health by acting on health inequalities between and within countries in Europe.

### 3 FRA Annual report: ‘Fundamental rights: challenges and achievements in 2012



On the 18th of June 2013, the European Union Agency for Fundamental Rights (FRA) published its **annual report** on challenges and achievements in the field of fundamental rights in 2012. The annual report provides in-depth evidence and analysis of fundamental rights developments in the European Union, its Member States and Croatia. **It looks at fundamental rights related developments** in

- asylum, immigration and integration;
- border control and visa policy;
- information society and data protection;
- the rights of the child and protection of children;
- equality and non discrimination;
- racism and ethnic discrimination;
- participation of EU citizens in the Union’s democratic functioning;
- access to efficient and independent justice; and
- rights of crime victims.

**This annual report focuses on how European values are being tested and what must be done to protect fundamental rights in this period of crisis.** It also considers the impact on the rule of law, as well as what some EU Member States are doing to ensure trust in their justice systems.

#### Examples of issues in this year’s report include:

- **The impact of budget cuts on education, healthcare and social services for vulnerable groups, such as children;**
- **Roma** continue to face discrimination and social exclusion, with many living in deep poverty and lacking access to healthcare and decent housing;<sup>7</sup>
- **The EU is driving forward efforts to reform the EU’s data protection framework, the most far-reaching reform of EU data protection laws in 20 years;**<sup>8</sup>
- **As 2012 was Year of Active Ageing the EU also focused on the challenges and obstacles facing older people, including those with disabilities.**<sup>9</sup>

<sup>7</sup> <http://fra.europa.eu/en/press-release/2012/widespread-roma-exclusion-persists-find-new-surveys>

<sup>8</sup> <http://fra.europa.eu/en/opinion/2012/fra-opinion-proposed-eu-data-protection-reform-package>

<sup>9</sup> <http://fra.europa.eu/en/press-release/2013/eu-agency-fundamental-rights-fra-presents-its-annual-report>

## 4 FRA Strategic Plan 2013-2017

After the expiry of the last FRA strategic document (**FRA Mission and Strategic Objectives 2007-2012**<sup>10</sup>), the FRA is about adopting its **new Strategic Plan for the 2013-2017**. The FRA's Executive/Management Board in finalising the Strategic Plan 2013-2017 end of September 2013. As a registered partner civil society organisation, EPHA takes the opportunity to highlight the following elements in respect of the mentioned elements of the draft strategy.

### 4.1 Strategic priorities

FRA's strategic objectives for the period 2013 – 2017 are based on the results achieved by the Agency so far and the challenges that lie ahead. Importantly, the strategic priorities take into account the outcomes of the external evaluation that in 2012 has reviewed progress and achievements during the first five years of operations of the Agency. Those strategic priorities are:

1. Enhancing FRA's contribution to legal and policy **processes at EU level**
2. Enhancing FRA's contribution **processes at national level**
3. Identifying **trends** over time and **measuring progress** in Member States
4. Developing timely and targeted responses to **fundamental rights emergencies**

### 4.2 Thematic priorities

These are the thematic areas of the agency's work which are determined through the new five-year Multi-annual Framework. They indicate the main fundamental rights issues and external developments foreseen in this period. Based on this, the thematic objectives, main activities and expected results for 2013-2017 are identified by the Agency.

## 5 The relevance of the FRA documents for the public health community

EPHA takes this opportunity to highlight elements which are **especially relevant for the public health community**.

### 5.1 Social Rights protection and the FRA mandate

FRA could underline the importance of **widening its mandate** in all of its working areas - including the FRA strategic priorities and annual reports – and should demonstrate by evidences the need **for more social protection**, presenting the legal possibilities of Member states **to enhance the protection of social rights of their citizens by international commitments**.

#### 5.1.1 Social Rights in Europe

In the Human Rights evolution process, Europe played a leading role in developing the second generation of Human Rights, the so-called **Social Rights**. Providing citizens with appropriate social protection is a common element in the constitutional traditions of different European countries. **The Council of Europe (CoE)** contributed to this development by elaborating common European standards, such as **the European Social Charter (ESC)** which sets out rights and freedoms and establishes a supervisory mechanism guaranteeing their respect by the States Parties. Following its revision, the 1996 revised European Social Charter, which came into force in 1999, is gradually replacing the initial 1961 treaty.

**Social Rights are especially relevant for the public health community**. The ESC guarantees **in Article 11<sup>11</sup> the right to protection of health saying that** with a view to ensuring the effective exercise of the right

<sup>10</sup> [http://fra.europa.eu/sites/default/files/fra\\_uploads/459-FRA-mission-strategic-objectives\\_en.pdf](http://fra.europa.eu/sites/default/files/fra_uploads/459-FRA-mission-strategic-objectives_en.pdf)

<sup>11</sup> <http://conventions.coe.int/Treaty/Commun/QueVoulezVous.asp?NT=035&CL=ENG>

to protection of health, the Contracting Parties undertake, either directly or in co operation with public or private organisations, to take appropriate measures designed inter alia:

1. to remove as far as possible **the causes of ill health**;
2. to provide advisory and educational facilities for the **promotion of health** and the encouragement of **individual responsibility** in matters of health;
3. to **prevent** as far as possible **epidemic, endemic and other diseases**.

There are other rights therein, which are relevant for public health such as **the right of children and young persons to protection (article 7), the right to social security (article 12) or the right of the family to social, legal and economic protection**

As regards **the enforcement of the ESC, the European Committee of Social Rights (ECSR)**<sup>12</sup> has been set up as **an independent quasi judicial body** which interprets the rights enshrined in the European Social Charter in a legally binding manner. The case law of the ECSR contribute to the legal protection of individuals since the relevant areas – following the ECS’s structure – reflect the FRA’s working areas. The ECSR’s case law cover:

- **Roma rights**
- **Children's rights**
- **Rights of persons with disabilities**
- **Equality between women and men**
- **Migrants' rights**
- **Right to education**
- **Right to health**

### **5.1.2 The relevance of Social Rights for the FRA**

Before making specific remarks, EPHA would like to underline the importance of the inclusion of Social Rights into the **FRA’s mandate**. In order to monitor the full range of Fundamental rights, the FRA’s work should not limit its activities only to the first generation of Human Rights; **the inclusion of all generations of Human Rights** - including Social Rights – into FRA’s mandate in the future is a must.

Another point is the significance of the adoption of **Social Rights related international legal instruments by the Member States in order to improve the enforcement of social rights and the level of protection of social rights of individuals**. Although a total of 43 States have ratified the Charter (either the 1961 Charter or revised version) **the additional protocol of the European Social Charter Providing for a System of Collective Complaints** has been signed only by 13 states<sup>13</sup>. This means that a wide range of European citizens are simply excluded from the ECSR’s protection based indirectly on their nationality which is not acceptable since it will widen the already **existing inequalities** in Europe.

## **5.2 Strategic priorities**

### **5.2.1 Enhancing FRA’s contribution to legal and policy processes at EU level**

FRA, as the EU’s par excellence Fundamental Rights body, is in a position to fulfil its mandate to collect, record and analyse relevant, objective, reliable and comparable information and data relating to fundamental rights issues in the European Union and its member states. Due to its unique position FRA could make sure within its mandate that political decision and legal acts at European level **comply with basic Fundamental Rights criteria**.

<sup>12</sup> [http://www.coe.int/t/dghl/monitoring/socialcharter/ecsr/ecsrdefault\\_EN.asp](http://www.coe.int/t/dghl/monitoring/socialcharter/ecsr/ecsrdefault_EN.asp)

<sup>13</sup> <http://conventions.coe.int/Treaty/Commun/ChercheSig.asp?NT=158&CM=8&DF=&CL=ENG>

### 5.2.1.1 Fundamental Rights and the Europe 2020 strategy – who watch the watches?

The Europe 2020 Strategy was launched in 2010 to promote **‘smart, sustainable and inclusive growth**. In order to reach the goals of the Europe 2020 Strategy, the Commission has acknowledged that **better economic governance and closer monitoring of member states’ economic, fiscal and social policy** is required<sup>14</sup>

EPHA highlights the analysis of the FRA which stated that in the first quarter of 2013, around 11% of the active population was unemployed and in some member states youth unemployment had reached over 50%.<sup>15</sup> Moreover, since the financial crisis struck in 2007, the EU has launched a series of initiatives to address the economic recessions affecting its member states. These have included both **short-term rescue funds** and **austerity measures**, and **long-term restructuring of the economic governance framework**. In the former category, the ‘bail-outs’ provided to Ireland, Greece and Portugal have been agreed between economic and finance representatives from the European Commission, the International Monetary Fund (IMF) and the European Central Bank (ECB), and comprise a number of interventions into national different national systems – including the health systems.

As FRA properly pointed out, the close association of the European Commission and European Central Bank with key decisions at the national level related to the economic crisis may **further undermine trust and support for the institutions and the Union**. These will inevitably trickle down to the agencies and bodies of the Union. The role and actions of independent bodies of the Union **may therefore come under greater scrutiny**.<sup>16</sup>

In time of economic crisis and Fundamental Rights emergency, it is crucial that all measures having huge impact on the European society be **fully in line with Fundamental Rights commitments**. The FRA should make sure that the necessary Fundamental Rights checks and balances are embed into the European processes in order to **avoid that the economic crisis turn into Fundamental Rights crisis**.

### 5.2.2 Enhancing FRA’s contribution processes at national level

#### 5.2.2.1 Universal Access to healthcare as a Fundamental Right

The **Charter of Fundamental Rights of the European Union**<sup>17</sup> lists the rights that the EU Institutions and member states must respect when they develop and implement EU law and policy. The Charter **Article 31**<sup>18</sup> on health lays down 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. A high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities.

However, the absence of **Fundamental Rights Impact Assessments** of the austerity measures being implemented across Europe is a real problem. Ensuring Fundamental Rights is a key element of reforming national systems. It should include the provision of evidence, tools and support to the formulation of policy and regulation so that the actions support Fundamental Rights standards. None of the countries currently implementing austerity measures have systematically evaluated their Fundamental Rights impact.

Thus, the public health community urges the Fundamental Rights Agency to remind European decision makers their Fundamental Rights commitments in order to **ensure the right to health** for all regardless of socioeconomic status, geographic location or ethnic origin.

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<sup>14</sup> [Communication from the Commission: Europe 2020](#)

<sup>15</sup> draft FRA Strategic Plan 2013-2017, page 14

<sup>16</sup> draft FRA Strategic Plan 2013-2017, page 14

<sup>17</sup> <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2010:083:0389:0403:en:PDF>

<sup>18</sup> <http://www.jusline.eu/index.php?cpid=f92f99b766343e040d46fcd6b03d3ee8&lawid=30&paid=32>

The FRA shall call for **national and regional public health systems** built on universality, access to good quality care, equity, and solidarity - in line with the legally binding Charter of Fundamental Rights - rather than systems based on a commercial rationale or on pay for performance. **Our vision is equal access** for all to national immunisation schemes, primary care, paediatric care, and for all pregnant women to have equal access to pre- and postnatal care.

Our request is for a coherent EU public health policy for the prevention, early diagnosis, treatment and management of chronic non-communicable diseases and infectious diseases which fully respects the individuals right to health. We encourage the **FRA to make full use of its role as coordinator** of best practices and **source** of objective, reliable and comparable **data** on the situation of fundamental rights in all EU countries **to protect health systems and social protection mechanism during these times of crisis**.

### 5.2.3 Identifying trends over time and measuring progress in Member States

The austerity measures being implemented across Europe in all fields of social protection have a negative impact on EU health systems. Since **national health systems aim to reduce the gap in health inequalities** their restriction affect the Fundamental Rights situation of European citizens.

#### 5.2.3.1 Reforming health systems under financial pressure

For most EU governments, health is typically **the largest area of government expenditure** (around 19.9% of the public budget<sup>19</sup> after social protection and it is one of the main areas of public expenditure projected to come under additional pressure as a result of demographic ageing, increases in chronic diseases, and the widening gap of health inequalities. Therefore, health and social affairs ministries have an important role to play in demonstrating **the link between sustainability and investment in health** and social protection.

According to the OECD Health at a Glance Report, “Governments, under pressure to protect funding for acute care, are cutting other expenditures such as **public health and prevention programmes**.”<sup>20</sup> In 2010, the expenditure was **3.2% less than in the previous** year. This means that on average, only 3% of a shrinking health budget was allocated to prevention and public health programmes in areas such as immunisation, smoking, alcohol consumption, nutrition and physical activity across the EU. The underlying causes of the **'healthcare crisis'** – increasing incidence of non-communicable diseases, an ageing population, rising health disparities, etc. – have received **very little attention**.

In times of crisis, investments in health systems should continue, the Fundamental Rights Agency should provide decision makers with the scientific evidence suggesting that **significant reductions in healthcare budgets risk creating new inefficiencies, undermining access to and quality of care, and damaging health outcomes** which can compromise **basic EU principles and Fundamental Rights standards**.<sup>21</sup>

#### 5.2.3.2 Covering specific vulnerable communities – the example of COPD community

The FRA has two communication tasks according to its mandate: communicating **evidence-based advice** by disseminating the results of its work, and **awareness raising**. The FRA Annual Activity report already includes a wider range of indicators for each project and an in depth account of all yearly activities. To develop appropriate indicators for specific target groups, such as **Chronic Obstructive Pulmonary Disease (COPD)** patients, is crucial to respect the often forgotten and neglected Fundamental Rights of persons affected by such a disease.

COPD is a serious respiratory disease that **affects up to 10% of the European adult population**, an estimated 64 million people worldwide and is estimated to be the **third leading cause of death by 2020**<sup>22</sup> COPD affects up to 10% of the European population. Every hour, 250 people die because of COPD. 300

<sup>19</sup> [General government expenditure statistics](#). Data from April 2012, most recent data: Further Eurostat information.

<sup>20</sup> [Health at a Glance: Europe 2012](#) - The Organisation for Economic Co-operation and Development (OECD)

<sup>21</sup> Martin McKee et al. [Health policy responses to the financial crisis in Europe](#). WHO Policy Paper

<sup>22</sup> Murray & Lopez, 1996

000 deaths in Europe happen each year because of COPD. That is the equivalent of 3 Hiroshima atomic bombs.

**COPD** causes wheezing, provokes breathlessness, damages the tiny air sacs at the tips of the airways and the airways themselves. This makes it hard to move air in and out of the lungs. COPD is characterised by the fact that it is **a long-term condition** that is **not curable**. While the disease progression can be stopped, once they are diagnosed, COPD patients have to learn how to live with the disease **for the rest of their lives**. Patients with COPD often accommodate to their symptoms, which makes it difficult for health professionals to assess the impact of the condition on their daily lives. However, it is estimated that 80% of COPD patients are unable to maintain their previous lifestyle while simple life-adaptation measures could be completed in this direction<sup>23</sup>.

Due to muscular aches, breathing difficulties and in some cases, the eventual need of an oxygen bottle, COPD patients face the same challenges as **other disabled people** as regards **mobility, transport and accessibility to the built environment**. Thus, since the FRA's mandate covers **discrimination based on disability, appropriate indicators** are needed in FRA's future research and data collection activity to raise awareness of such invisible groups, which belong to **both the public health and disability community**.

#### 5.2.4 Developing timely and targeted responses to fundamental rights emergencies

There is a strong link between the **economic crisis** and **Fundamental Rights emergencies**. The criminalisation of homeless people which happened in Hungary clearly demonstrates the danger that the **economic crisis** may turn into **Fundamental Rights emergency situations**.

##### 5.2.4.1 Criminalisation of homelessness as a Fundamental Rights emergency

###### 5.2.4.1.1 Economic crisis and homelessness

Facts and figures show the impact of the **economic crisis on the population health** in Europe. The current recession has made the situation worse, as redundancies and house repossessions are on the rise. At the same time, public spending is being cut across the EU. Frontline services need to protect people's right to have a roof over their head.<sup>24</sup>

**Homelessness has a profound effect** on the lives of hundreds of thousands, perhaps millions of people living in the EU. Homelessness is the extreme form of housing deprivation<sup>25</sup>. Decent housing is an important **social and environmental determinant of health**. High housing costs have indirect negative health outcomes as it dangerously limits families spending for other basic needs. According to a 2011 report inadequate housing accounts for around 100 000 deaths per year in the WHO European region.<sup>26</sup> There is a range of **factors**, which may lead to people to become homeless: **health and homelessness** have a relationship of both cause and effect: and illness (such as mental illness, substance abuse or illness leading to loss of employment) may be among the trigger factors that lead to homelessness.

###### 5.2.4.1.2 Constitutional stigma on homeless people in Hungary

Hungary was hit very hard by the **economic crisis**. Hungary received 25.1 billion US\$ bailout from the EU in 2008. Public health decreased from almost €4 billion to €1.2 billion- with a 40% cut in the pharmaceutical sub-budget and sickness benefits significantly decreased from 2009 to 2010 due to the Semmelweis Plan introduced as of 1 August 2009.<sup>27</sup>

In Spring 2013, the amendment of the Hungarian Constitution prohibited street homelessness. The amendment allows municipalities to ban homeless people from public spaces which will not only create further legal and social conflicts, but will worsen the situation of thousands of homeless people in Hungary.

<sup>23</sup> <http://copd.about.com/od/livingwithcop1/a/Copd-And-Work.htm>

<sup>24</sup> <http://www.who.org/spip.php?article5192>

<sup>25</sup> <http://www.who.org/spip.php?article5549>

<sup>26</sup> WHO report Environmental burden of disease associated with inadequate housing. Methods for quantifying health impacts of selected housing risks in the WHO European Region, 2011

<sup>27</sup> <http://www.who.org/spip.php?article5192>

**Homeless persons should** not be deprived of their basic rights to liberty, or to privacy, personal security and protection of the family, only because they are poor and need shelter. Robust evidences developed by the FRA should influence Member States so that they amend the anti-homeless legislation and to adopt a national housing strategy, which will take into account the needs and views of the homeless and those inadequately housed, in conformity with **international human rights obligations**.

**The criminalisation of homelessness is completely out of context** and contrary to the European values and Fundamental Rights commitments of EU Member states. Criminalising homeless people is not the answer. Criminalisation measures are cruel and ineffective, since they aim to remove the visible aspect of homelessness from public view, rather than offering any real solution. Therefore, the Fundamental Rights Agency strategic priorities should **reflect these developments** in order to make sure that every EU member states behaviour in a way which **is not contrary to Fundamental Rights commitments** they are bound with.

### 5.3 Thematic objectives and specific areas of the FRA Annual report 2012

#### 5.3.1 Information society and, in particular, respect for private life and protection of personal data

The FRA is in a unique position to emphasise the importance of fundamental rights in **an information society context**, which will become all the more important as more Europeans are able to access the Internet and engage in exchanges that involve the transfer of confidential personal data such as health data in the context of **e-Health / m-Health**.

FRA recognises the clear need for a harmonised set of data protection regulations and the danger attached to the current patchwork of legislation across member states. This is particularly concerning in the area of health, where the most sensitive personal data is increasingly transferred between member states in digitalised and non-ICT forms. Given the vast **differences in literacy** between already proficient and emerging ICT users (e.g., members of vulnerable groups including the elderly, disabled, migrants and ethnic minorities such as the Roma) it will be particularly important to ensure that everybody's privacy and data are protected. Members of disadvantaged groups tend to be particularly volatile to phishing, identity theft and other abuses (such as involuntary disclosure of health status) as they are less familiar or even unfamiliar with online processes, etiquette and formats.

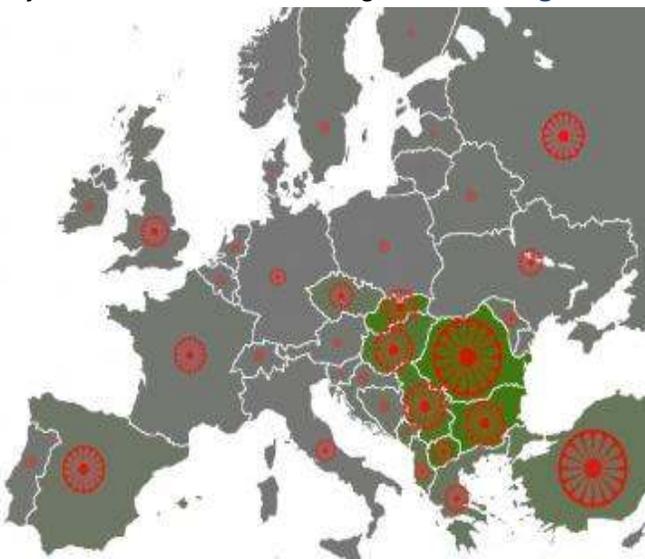
Another core concern is the availability of data for research. Whilst the protection of personal data is vital, public health outcomes depend upon the availability of data for research purposes and a sound framework for the correct use of such data. FRA is in a position to raise this issue and ensure that European research is nurtured and guided by comprehensive data protection reforms.

By capitalising on its expertise in linking sociological issues with legal frameworks, the FRA can make a major contribution to ensuring that **existing health inequalities will not be aggravated** in an increasingly

digitalised world. It can help ensuring that the rights of non-traditional ICT users, as well as of individuals unable to / less inclined to depend on ICT, are upheld, and that their data is protected. Such an inclusive approach would also make a potentially important impact for public health.

#### 5.3.2 Roma Integration

One of **the most universally disadvantaged** communities living in Europe is the **Roma population**. The great majority of the Roma population is found at the very bottom of the socio-economic spectrum. It is



generally accepted that the Roma suffer **worse health** than the other populations in the countries where they live due to their higher exposure to the range of unfavourable factors that influence health<sup>28</sup>. **Poverty, inadequate education and lower social integration** result in **poor health** outcomes. Moreover, discrimination and unregulated civil status (including lack of personal documents, birth certificates, insurance) make it particularly difficult for Roma to **access health services**. Due to the multiplicity of their discrimination and social exclusion, the inequalities faced by the Roma population highlights the cause for combating the social determinants of health across the board.

As FRA points out, despite efforts at national, European and international level to advance Roma integration, many Roma still face **deep poverty, profound social exclusion, barriers to exercising fundamental rights, and discrimination**, which often means limited access to quality education, jobs and services, low income levels, sub-standard housing conditions, **poor health** and lower life expectancy.<sup>29</sup>

**Access to and utilisation of health care services** is vital to good and equitable health. Without health care, many opportunities for health interventions (both prevention and treatment) are lost. The provision of equitable, universal access to health care services- regardless of the ability to pay- should be a priority to reduce health inequities among deprived communities. Groups working with Roma Communities have identified **a number of barriers** to accessing health service among the Roma, namely a lack of knowledge on disease prevention, a lack of knowledge about their health service rights and a lack of physical access to services. Many Roma are thought not to be registered with a general practitioner, which may result from a lack of documents, but also a reluctance on the part of health service providers to accept Roma patients. Furthermore, their access to health services may be influenced to a certain extent by their beliefs and cultural norms as it has been shown that Roma communities tend to access services for severe problems only, as hospitalisation is sometimes perceived as a sign of death.<sup>30</sup>

FRA should focus and rely in its activities on such successful practices as the European network of **Roma health mediators**, **the civil shadow report on the implementation of the National Roma Integration Strategies (NRIS)** or the **training of Roma EU health advocates**.

### 5.3.2.1 Roma health mediators

In the past 10 years, in the course of different Roma integration programmes – appearing in several projects and in different forms and with a variety of names -a new function or rather a professional role has emerged: that of the **Roma mediator**. They are experts of equal opportunity, who in the course of mediation between Roma communities and various institutions facilitate the availability of public services – mainly those of education, health care and labour market – for the Roma, by creating interaction between and providing information for the parties and by treating conflicts effectively on the basis of involving active participation of affected parties. Practice indicates that intercultural mediators have an eminent role in creating a more effective communication and in aiding availability of public services of the minority groups.<sup>31</sup>

Roma Mediators also played a key role in the programme entitled **‘A Good Start’ (2010-2012)**, carried out by the Roma Education Fund in **Macedonia, Hungary, Slovakia and Romania** with the support of the Regional Directorate of the European Commission.

According to the **ROMED** – the joint Council of Europe - EU programme for Roma mediators, there are several differences among particular countries concerning the needs and circumstances of the Roma communities, the terminology in use and also how much the work of intercultural mediators is exploited, and what qualification people who are trained to fulfil these tasks originally had. Immigrant Roma mean new challenges<sup>32</sup>

<sup>28</sup> Health and Economic Development in South Eastern Europe

<sup>29</sup> draft FRA Strategic Plan 2013-2017, page 23

<sup>30</sup> Health and Economic Development in South-Eastern Europe.

<sup>31</sup> Éva Deák, Intercultural Mediator – the birth of a new profession? The forms and role of the intercultural mediator function in the social integration of Romas during the past few years

<sup>32</sup> <http://www.coe-romed.org/>

The Council of Europe High Level Meeting on Roma on 20 October 2010 adopted the “**The Strasbourg Declaration on Roma**” which lays down that “(46) agree to set up a European Training Programme for **Roma Mediators** with the aim to streamline, codify and consolidate the existing training programmes for and about **Mediators for Roma**, through the most effective use of existing Council of Europe resources, standards, methodology, networks and infrastructure, notably the European Youth Centres in Strasbourg and Budapest, in close co operation with national and local authorities;”<sup>33</sup>

The European Commission assessed the national Roma strategies and published its conclusions “National Roma Integration Strategies: a first step in the implementation of the EU Framework” in which it underlined that Several Member States have already put in place or are considering programmes **involving qualified Roma as mediators** for improving access to healthcare. These are very welcome initiatives. However, such measures **need to be supplemented by other actions** to have a significant impact on the **health gap between Roma and the rest of the population**.<sup>34</sup>

In the past decade a significant amount of knowledge has piled up about the operation of Roma intermediaries - the intercultural mediators - working in various fields (especially in the key-fields of Roma integration: education, health care, employment, residence) and about the intercourse between social groups, between different cultures, about results and successes in understanding and conflict management. In order to have a comparative assessment of the project results and impact analysis it would be worthwhile for **FRA to carry out concise scientific research and creating a unified system the basis of the research for assessing and measuring mediatory work on**.

### 5.3.2.2 Civil shadow report on the implementation of the National Roma Integration Strategies (NRIS)

In 2012, the Decade Secretariat and the Open Society Foundations supported the creation of civil society monitoring reports on the implementation of NRIS and Decade of Roma Inclusion National Action Plans in eight countries (**Albania, Bulgaria, Czech Republic, Hungary, Macedonia, Romania, Slovakia, Spain**). In addition, the Decade Secretariat made a template public in order to encourage additional civil society actors to monitor the implementation of NRIS and Decade Action Plans.

In the reports, civil society coalitions supplement or **present alternative information** to Decade Progress Reports submitted by Participating Governments in the Decade of Roma Inclusion and to any reports submitted by State parties to the European Commission on implementation of their NRIS. These reports are not meant to substitute for monitoring and quantitative evaluation by State authorities but to channel **local knowledge into national and European policy processes** and reflect on the **quality and outcomes of government measures**. As these are the first reports of this sort, they also evaluate the quality of the NRIS. In some cases, the reports address **social impacts of policies** as well. The reports provide **additional data to official ones, proxy data** where there is not official data or **alternative interpretation** of published data.<sup>35</sup>

### 5.3.2.3 Roma EU health advocates

With the support of the OSI Roma Health Project (Open Society Institute), EPHA launched **a two-year programme (2012 - 2014)** to **train and mentor three Roma health EU advocates** in order to develop their professional skills with a practical and European orientation, and develop contacts and cooperation with the most important European actors. The following skills and knowledge will be developed:

- Developing an **advocacy strategy** on an EU Roma Health Strategy
- **Understanding the EU decision making process**, with a focus on health actors within the EU institutions, as well as within the broader European scene

<sup>33</sup> <https://wcd.coe.int/ViewDoc.jsp?id=1691607>

<sup>34</sup> <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2012:0226:FIN:EN:PDF>

<sup>35</sup> [www.romadecade.org/civilsocietymonitoring](http://www.romadecade.org/civilsocietymonitoring)

- **Building alliances** with various organizations operating in the social and field sectors.
- **Developing policy/advocacy messages** targeting the EU institutions and particularly decision makers that would have an impact on Roma Health. Here again, the identification of the decision makers is an integral part of the programme.<sup>36</sup>

An example of this mentoring programme the Roma health advocates contributed to **the EPHA press release** published on the **International Romany day** in 2013.<sup>37</sup>

### 5.3.3 Rights of the child

From a public health perspective, we believe the currently ongoing economic crisis has uncovered the levels and areas where **children's rights lack implementation and protection**. Child poverty and social exclusion, ethnic and sexual orientation, as well as gender-based discrimination threaten full achievement of children's right to health by **undermining inequality-free access to healthcare, medicines**. But most importantly, such **essential determinants of health** as affordable, accessible and adequate nutrition, housing, childcare, water and sanitation, quality and safe environment, freedom from maternal and social deprivation.

#### 5.3.3.1 A Grassroots Method to Help Eradicate Child Hunger in the Most Deprived Regions of Hungary

Child hunger is an essential symptom of child poverty which hit especially hard vulnerable groups, such as **Roma children**. Experience shew in Hungary that the failure of Roma children in school is not related to their background but due to their **malnutrition**. According to some estimations and date, half of the children in Hungary live in poverty. Therefore, the **"No Child Should Go Hungry"** Foundation ("Minden gyerek lakjon jól" foundation) in Hungary which was founded in 2009 to support children in the most deprived regions of Hungary, provided mini-farms to over 28,000 families to date and another planned 30,000. The basic principle of the Foundation is that financial public aid is not always as effective as we might think, since it assumes that people in need will buy essential goods, which is not always the case. Simply donating money is not always enough: we need to teach people how they can best manage themselves. That is why it is more effective **to give material goods**, such as **grain and live animals**, as they can more directly improve the nutrition levels of the whole family. In 2011-2012, the foundation has reached out to 27,732 families in 504 municipalities. According to the estimations, it had a positive impact on approximately 75,000 children in Hungary. The foundation is funded by private donations and receives no state support.<sup>38</sup>

It is important to give back to poor people their **human dignity** and show them that they can do things **for themselves. Priority should be given to improving people's situations by involving them in the process**. The FRA shall take into consideration such good examples which aim tackling children's malnutrition which can be a good example for other countries / vulnerable groups facing extreme poverty.

#### 5.3.4 Discrimination based on sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of national minority, property, birth, disability, age or sexual orientation

EPHA finds necessary to highlight here the FRA finding that there is an implicit recognition in Europe 2020 that some groups may be **more vulnerable** to the transition than others such as the poor, the low skilled, the disabled, the old, those with migrant background and the Roma.<sup>39</sup> EPHA would like to specify other vulnerable groups such as **children, chronic disease and other patient groups** (such as **COPD patients**).

<sup>36</sup> <http://www.eph.org/spip.php?article4997>

<sup>37</sup> <http://www.eph.org/spip.php?article5682>

<sup>38</sup> <http://www.eph.org/spip.php?article5617>

<sup>39</sup> draft FRA Strategic Plan 2013-2017, page 14

In this regard, the importance of **access to healthcare** should be emphasised as **a very specific form of discrimination**. 2012 has been marked by a **social and economic crisis** that has generated austerity measures which are having an impact on social protection schemes, including **healthcare services**. We have noticed a rise in xenophobic acts and regulations in Greece and in other European countries.

Whilst all levels of the population must cope with increasing poverty, we are witnessing a significant increase in xenophobic actions and declarations against migrants, who have become the scapegoats of a situation which is making them even more vulnerable. A significant number of Member States have raised out-of pocket expenditure for patients. In Greece, the entire public health system is under enormous pressure due to austerity measures.

Therefore, the public health community **clearly demand the right to provide healthcare** – in accordance with medical ethics – **to all patients, regardless of their social status or ethnic origin**. FRA should make sure within its mandate that national public health systems are built on solidarity, equality and equity, open to all those living in the EU, rather than systems based on a profit rationale. We ask for a Fundamental Rights friendly, coherent EU public health policy for the prevention and treatment of infectious diseases. We demand equal access for all to national immunisation schemes and to paediatric care. We demand that all pregnant women have equal access to pre and post natal care.<sup>40</sup>

### 5.3.5 Immigration and integration of migrants, visa and border control and asylum

While the general population is facing increasing poverty, populist political parties are taking advantage of the situation by laying the responsibility on destitute migrants, as easy scapegoats. Rising unemployment and poverty across Europe have generated extreme right statements stigmatising migrants. Spain has legally restricted access to care for undocumented migrants. Another effect of the increase in poverty is a rise in **internal migration**. EU citizens who are destitute and have no health coverage are considered in the same way as **undocumented migrants** from outside the EU if they need medical care. Thus, the public health community demand **full protection in Europe** for seriously ill migrants who cannot access adequate healthcare in their country of origin.<sup>41</sup>

In this regard, the FRA should enhance collaboration for data collection on migrant demographic and health data. For example, **the Clandestino-project**<sup>42</sup> found a lot of variability in data qualifying across Europe. The public health community finds worth towards **standardized data collection and sharing**.

## 6 Conclusions

The FRA, as the EU's Fundamental Rights body par excellence, is in a position to fulfil its mandate to collect, record and analyse relevant, objective, reliable and comparable information and data relating to fundamental rights issues in the **European Union** and its **member states**. Due to its unique position FRA could make sure within its mandate that political decision and legal acts at European level **comply with basic Fundamental Rights criteria**.

In time of economic crisis, it is crucial that all measures having huge impact on the European society be **fully in line with Fundamental Rights standards**. The FRA should make sure that the necessary Fundamental Rights checks and balances are embed into the European processes in order to **avoid that the economic crisis turn into Fundamental Rights crisis**.

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<sup>40</sup> <http://www.mdm-international.org/spip.php?article1205>

<sup>41</sup> <http://www.mdm-international.org/spip.php?article1205>

<sup>42</sup> <http://research.icmpd.org/1244.html>