

**“The challenges of chronic diseases and patients’ rights  
in the framework of EU healthcare sustainability”**

**9th European Patients’ Rights Day**

**Press Kit**

**May 12th 2015  
9:15 - 13:30**

Room A1E2  
European Parliament, ASP, Bruxelles



***Brief Description of the  
9th edition of the  
European Patients' Rights Day***

Active Citizenship Network (ACN) has decided to dedicate the 9<sup>th</sup> celebration of the European Patients' Rights Day 2015, launched by ACN in 2003, to the sustainability of healthcare systems focusing on what concerns chronic diseases.

The focus will be on different but complementary main aspects such as the responsibility of different actors involved in sustainable healthcare systems and the role of prevention and innovation.

### **The responsibility of different actors in the sustainability of healthcare systems**

Starting from an empowered patient, the main topic of last European Patients' Rights Day 2014, we need to reflect on the role and the responsibilities of other actors involved in healthcare systems, in a context where there is a high risk that indirect costs for patients and informal carers become unsustainable.

We are talking about costs that are often unsustainable and have as much weight as the disease itself on the quality of people lives. As a consequence, treatment and dignity for chronic patients are no longer a right, but a privilege for few lucky ones. All these considerations cannot be done at a national dimension anymore, but a wider perspective at European level is needed, as chronic patients may suffer same issues and face same challenges even if they do not live in the same place. We believe these are very relevant aspects to reflect on, as informal carers play a fundamental role in the assistance and taking care of chronic patients also from an economic point of view.

### **The role of prevention and innovation in sustainable healthcare systems**

What we need to look for are more effective and smarter approaches to the prevention and treatment of chronic diseases and to the preservation of "life with dignity" for patients. To find new approaches and change what is wrong, it is fundamental to reflect on how and to what extent the right to the observance of quality standards can be respected, in a context of cuts and financial constraints. This also leads us to another aspect that has been a key preoccupation of the informal meeting of the 28 European Health Ministers held on 22 and 23 September 2014 during the Italian Presidency of the Council of the European Union: *if there is a real danger for quality of healthcare to not be guaranteed to patients, what would be the*

*“innovative approaches” to make the healthcare sector more sustainable?* This is a concern highlighted also in the 2015 European Commission's Annual Growth Survey. It is true that many EU countries already have recommendations to reform their health systems to make them more efficient and sustainable, but this is not enough. So, it is not only how much money is spent, but also how it is spent that determines a Country's health status. This is in line with the new Health Commissioner Andriukaitis said in the concluding remarks of the Council of Ministers of Health on 1 December 2014 in Brussels. According to him *“health sector is a contributor to growth”* and *“innovation is crucial to guarantee patient safety and quality of care”*.

The debate will be focused on the role and the responsibility of each involved actor in the healthcare sector to make it sustainable and efficient, to create a shared understanding of sustainability, an integrated approach which consists of a balance of economic development, social equity and quality of care.

We hope, the conference can help to identify concrete strategies to strengthen citizen participation to define efficient, equitable and sustainable European health systems that improve population health outcomes.

For further information: <http://www.activecitizenship.net/primopiano/170-9th-european-patients-rights-day.html>

***The Origins of the European  
Patients' Rights Day***

In 2002, Active Citizenship Network together with a group of European citizens organizations<sup>1</sup> established a European Charter of Patients' Rights, which includes the following 14 rights: the right to preventive measures; access care; information; consent; free choice; privacy and confidentiality; respect of patients' time; observance of quality standards; safety; innovation; avoidance of unnecessary suffering and pain; personalized treatment; to complain; to receive compensation. All these rights, based on the *Charter of Fundamental Rights* of the European Union (art. 35), are crucial in matter of European citizens and healthcare services.

The majority of these rights are also embodied within the Council conclusions on Common values and principles in EU Health Systems adopted in June 2006.

Recently, the EU Directive 2011/24/EU on the application of patients' rights in cross-border healthcare officially recognizes the "right to free choice"<sup>2</sup> and the "right to information"<sup>3</sup> included in the European Charter of Patients' Rights.

Article 6 § 1 of the Directive establishes that "Member States shall ensure that the national contact points consult with patient associations, healthcare providers and health insurance agencies", recognizing and enhancing also the ultimate principle of the European Charter of Patients' Rights, namely the "right to participate in policy-making in the health area".

The reinforcement of these rights will become effective only with the cooperation and commitment of all healthcare stakeholders in every EU country, where patients must be considered as partners in the health policy, sharing with the institutions and professionals the responsibility of finding the balance between patients' interests and the sustainability of healthcare systems. It is thus essential to increase awareness

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<sup>1</sup> Apovita (Portugal); Cittadinanzattiva/Tribunale per i diritti del malato (Italy); Confederacion de Consumidores y Usuarios (Spain); Danish Consumer Council (Denmark); Deutsche Gesellschaft fur Versicherte und Patienten e. V. (DGVPV) (Germany); Fédération Belge contre le Cancer (Belgium); International Neurotrauma Research Organization (Austria); KE.P.K.A. (Greece); Nederlandse Patienten Consumenten Federatie (NPCF) (the Netherlands); The Patients Association (United Kingdom); Vereniging Samenwerkende Ouderen Patientenorganisaties (VSOP) (the Netherlands); Irish Patients Association Ltd (Ireland). For further information: [http://www.activecitizenship.net/images/patientsrights/fr\\_english.pdf](http://www.activecitizenship.net/images/patientsrights/fr_english.pdf)

<sup>2</sup> "Everyone has the right freely to choose among different treatments and suppliers on the basis of adequate information".

<sup>3</sup> "Everyone has the right to access all information regarding their health status, health services and their use and all that scientific research and technological innovation provides".

regarding the importance of patients' rights and everyone's responsibilities in guaranteeing their respect.

We believe that celebrating a *European Patients' Rights Day* every year, the same day, in all the EU Member States would greatly contribute to this goal. It is a common occasion to inform, discuss and take commitments to improve patients' rights in Europe and in each Member State.

For this reason Active Citizenship Network, together with citizens' and patients' organizations throughout Europe, have taken the initiative to organize for the last eight consecutive years the European Patients' Rights Day.

### **What has been done**

- April 18<sup>th</sup>, 2007, the 1<sup>st</sup> European Patients' Rights Day: at the European Parliament, Brussels.
- 2008, the 2<sup>nd</sup> European Patients' Rights Day, contemporaneously celebrated in 26 countries: *The challenge that patients' rights represent for the European Union and the national healthcare systems.*
- 2009, the 3<sup>rd</sup> European Patients' Rights Day: 34 citizen and patient organizations setting up over 80 events in 24 European countries.
- 2010, the 4<sup>th</sup> European Patients' Rights Day: in more than 100 European cities, citizens' and patients' organizations set up their own events to inform, discuss and take actions in improving patients' rights in Europe.
- 2011, the 5<sup>th</sup> European Patients' Rights' Day in Brussels at the European Economic Social Committee. Presentation of the assessment "*Report on the EU Patients' Charter*" and a collection of good practices for "*Engaging citizens and patients in Health policy*". Establishment of "*The Best Practice on civic participation award*" and a discussion of the new *Directive 2011/24/EU on patients' rights in cross-border healthcare.*
- 2012, the 6<sup>th</sup> European Patients' Rights Day in Brussels: "*Active Ageing citizens at the center of EU health policy*".
- 2013, the 7<sup>th</sup> European Patients' Rights Day in Brussels: dedicated to the final principle of the European Charter of Patients' Rights.

- 2014, the 8<sup>th</sup> European Patients' Rights Day in Brussels at the European Economic Social Committee: *“The role of citizens' organizations in the empowerment of patients with chronic diseases”*.

For further information: <http://www.activecitizenship.net/patients-rights/projects/155-european-patients-rights-days-what-has-been-done.html>

***Make it official!***

***Why should the European  
Patients' Rights Day be  
Institutionalized?***

- 1) Across Europe, the sustainability of healthcare systems is a common good to be safeguarded. We are worried about how to find this goal, without the involvement of citizens, patients and their associations, with the consequence that the protection of patients' rights could not be taken into consideration. Indeed, the economic crisis has a direct impact on healthcare access, especially for the vulnerable population, which are exposed to social exclusion, increased private costs or giving up altogether medical care.  
**Faced with this scenario, the institutionalization of the European Patients' Rights Day could represent an effective message of the European Institutions' commitment that any action towards a sustainable healthcare system should be done by putting patients' rights at the forefront.**
- 2) EU Institutions and Member States are addressing the challenge of patient safety. **We believe that the patient safety is also closely related to the patients' awareness of their rights.** The reinforcement of patients' rights will become effective only with the cooperation and commitment of all healthcare stakeholders at the EU level and in every EU country. It is thus essential to increase awareness regarding the importance of patients' rights and everyone's responsibilities in guaranteeing their respect. **To contribute to this goal, the EU Parliament could welcome and recognize the value of the European Patients' Rights Day,** and so, to invite the EU Commission and Member States to support the citizens' and patients' organizations throughout Europe in celebrating, every year on the same date, the European Patients' Rights Day at the local, national and EU level.
- 3) Each European Day is a bearer of rich stories and experiences, with a message towards the future. The institutionalization of a European Patients' Rights Day (not particularly related with a specific diseases, age, gender etc.), unites and recognizes the daily activities of thousands of organizations and hundreds of citizens, volunteers and professionals deeply involved to improve the quality of patients' life and the protection of their rights. **The institutionalization of the European Patients' Rights Day enforces this civic activism as an essential resource for the health systems in each country.**
- 4) The European Patients' Rights Day has been celebrated for nine years, an initiative created by civic associations and already included in the European political agenda. So, **the request to institutionalize the European Patients' Rights Day, does not mean to create it, but rather to officially recognize it by the European Institution. In doing so, the European Institutions would show**

**their support to civil societies' initiative, a message which is relevant nowadays as there is a growing gap between the EU Institutions and the citizens.**

- 5) The European Patients' Rights Day was established on 18 April 2007 at the European Parliament and is celebrated every year at the local, national and European level. The reason of its birth, is the need to highlight a number of patients' rights that must be recognised and respected in every place and nation all around Europe. These rights are drafted in the European Charter of Patients' Rights, written in 2002 by civic and patient associations from 12 European countries. The European Charter of Patients' Rights states 14 patients' rights that together aim to guarantee a "high level of human health protection" (Article 35 of the Charter of fundamental rights of the European Union) and to assure the high quality of services provided by the various national health services in Europe. The 14 rights are an embodiment of fundamental rights and, as such, they must be recognized and respected in every country. They are correlated with duties and responsibilities that both citizens and healthcare stakeholders have to assume. The Charter applies to all individuals, recognizing the fact that differences, such as age, gender, religion, socio-economic status etc., may influence individual healthcare needs. For all the previous reasons, **the institutionalization of the European Patients' Rights Day has an implicit message linked to the commitment of the European Institutions in order to effectively apply the principles and rights established of the European Charter of Patients' Rights.**
- 6) Talking about the officially recognized European Days, if the previous European Parliament at the end of its mandate established the European Ice-cream Day (on 5 July 2012), **the current European Parliament could be remembered for having established one year after its inauguration the European Patients' Rights Day.** From our point of view, this is one more reason to embrace this initiative, of which the European branch of Cittadinanzattiva, Active Citizenship Network, is proud to have promoted since 2007 through the involvement of many associations and the management of events at the local, national and European level.

***Time for Action:  
Our Demands to Institutionalize  
the European Patients' Rights  
Day***

The following three actions have already been initiated:

- 1) With the new European Parliament and European Commission, we have started a dialogue to raise awareness on institutionalizing the European Patients' Rights Day. The fact that this year the Day is hosted by the Presidents of two parliamentary groups shows a relevant signs of awareness of which we would like to thank them.
- 2) We have organized the celebration for the European Patients' Rights Day 2015 inside the European Parliament, in order to close the gap between those who send the message aimed at institutionalizing the Day and those who receive this message in the hope that they make it their own.
- 3) We have created awareness across Europe among civic and patient associations to support this initiative. And the fact that in a short time we have received the endorsement from hundreds of them all over Europe, even outside the European Union, makes us believe that this is a plural request and a common goal.

In occasion of the 9th edition of the European Patients' Rights Day, Active Citizenship Network launches the following three initiatives:

**1) Constitution of the MEPs interest group called "European Patients' Rights and Cross-Border Healthcare", with the aim to:**

- Make the European Parliament acknowledge on the European Patients' Rights Day in order to officially recognize and institutionalize it.
- Actively support the celebrations of the European Patients' Rights Day and collaborate with civic and patient associations at the national and European level.
- Strengthen the protection of patients' rights in the European legislation, starting from the adoption of the European Charter of Patients' Rights, which has become a reference point for discussion on the issues of health at the European level, as well as an essential milestone for further European charters (i.e. the European Cancer Patient's Bill of Rights, European Charter of the Rights of Citizens over 65 with Chronic Pain, etc.).
- Promote initiatives that encourage and ensure among the EU countries the respect of the primary and secondary European legislation focused on the patients' safety and the protection of their rights. It could be done with the involvement of civic and patient association, starting from the

Directive 2011/24/EU on patients' rights in cross-border healthcare (which is included in the title for the first time the patients' rights) and the most recent "Draft Report on safer healthcare in Europe: improving patient safety and fighting antimicrobial resistance (2014/2207(INI))",<sup>4</sup> approved unanimously on 16 April 2015 by the Committee on the Environment, Public Health and Food Safety.

- Establish the European Year of Patients' Rights during its mandate, hopefully in 2017.

2) **Online petition:** open to citizens and patients across Europe.

3) **Civic mobilization:** in 2016, for the 10th anniversary, the European Patients' Rights Day will be celebrated at the national level at least in 20 countries, both inside and outside the European Union, with the direct involvement of civic and patient associations. Below there is a list of the countries where the initiatives will be organized:

- 1) Austria
- 2) Belgium
- 3) Bulgaria
- 4) Cyprus
- 5) Croatia
- 6) Denmark
- 7) Estonia
- 8) France
- 9) Germany
- 10) Kosovo
- 11) Ireland
- 12) Iceland
- 13) Italy
- 14) Macedonia
- 15) Malta
- 16) Lithuania
- 17) Netherlands
- 18) Poland
- 19) Slovakia
- 20) Spain
- 21) Switzerland
- 22) Ukraine

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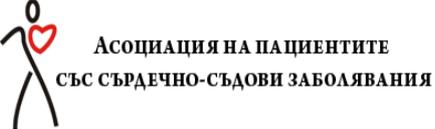
<sup>4</sup> Rapporteur Piernicola Pedicini, speaker at the European Patients' Rights Day 2015. This Report, in which its included the institutionalization of the European Patients' Rights Day among other proposals, will be voted during the EU Parliament plenary session on 18-21 May.

***Civic and patient organizations  
that support the  
European Patients' Rights Day***

Below is a list of the first 70 organizations which have given us their support for the institutionalization:

	ASSOCIATION	DIRECTOR	COUNTRY	LOGO
1.	Lower Austrian Patient and Nursing Advocacy (NÖ Patienten- und Pflegeanwaltschaft)	Dr. Bachinger	Austria	NÖ Patienten- und Pflegeanwaltschaft 
2.	The European Huntington Association	Bea De Schepper	Belgium	
3.	Natural & Integrative Health and Wellness (Under Voor Natuurlijke & Integrale Gezondheid en Welzijn)	Frans Copers	Belgium	
4.	Users League of Health Services (Ligue des Usagers des Services de Santé)	Fabrizio Cantelli	Belgium	

5.	Naturopathica	Ludo Letor	Belgium	
6.	Bulgarian Association for Patients Defence (Българска Асоциация за Закрила на Пациентите )	Plamen Taushanov	Bulgaria	
7.	Patients' Organizations With you (Пациентски организации Заедно с теб)	Penka Georgeva	Bulgaria	ПАЦИЕНТСКИ ОРГАНИЗАЦИИ Заедно с теб
8.	Institute Innovations (Институт по иновации)	Penka Georgeva	Bulgaria	 INNOVATIONS INSTITUTE
9.	Association of Reproductive Health, Pregnancy and Childcare "Smile" (Пациентска асоциация за репродуктивно здраве "Усмихни се")	Penka Georgeva	Bulgaria	 Асоциация за репродуктивно здраве, бременност и грижа за децата "Усмихни се"

10.	<p>Alliance of Transplanted and Operated ATO "Future for All"</p> <p>(Алианс на трансплантите и оперираните АТО "Бъдеще за всички")</p>	Penka Georgeva	Bulgaria	
11.	<p>Association of Patients with Cardiovascular Diseases</p> <p>(Асоциация на пациентите със сърдечно-съдови заболявания)</p>	Penka Georgeva	Bulgaria	
12.	<p>Center for Hope Foundation</p> <p>(Фондация "Център за надежда")</p>	Silvi Gavrilov	Bulgaria	
13.	<p>Heart Association</p> <p>(Асоциация "Сърце")</p>	Silvi Gavrilov	Bulgaria	
14.	Bulgarian Haemophilia	Silvi Gavrilov	Bulgaria	

	Association (Българска Асоциация по хемофилия)			
15.	Open Interaction Association (Фондация Отворено общуване)	Silvi Gavrilov	Bulgaria	 OPEN INTERACTION ASSOCIATION
16.	Bulgarian Union of Transplanted (Съюз на трансплантите в България)	Silvi Gavrilov	Bulgaria	
17.	Croatian Association for the Promotion of Patients' Rights (Hrvatska udruga za promicanje prava pacijenata)	Đula Rušinović-Sunara	Croatia	

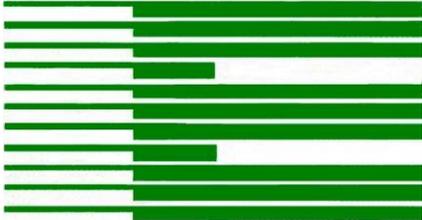
18.	Cyprus League Against Rheumatism	Persefoni Markidou	Cyprus	
19.	The Cyprus Association of Cancer Patients and Friends  (Παγκύπριος Σύνδεσμος Καρκίνοπαθών και Φίλων)	Nicolas Philippou	Cyprus	
20.	Danmarks Psoriasis Association  (Danmarks Psoriasis Forening)	Julie Emilie Petersen	Denmark	
21.	Estonian Cancer Society  (Eesti vähiliit)	Maie Egipt	Estonia	

22.	Estonian Patient Advocacy Association	Elvis Veidrik	Estonia	 Eesti Patsientide Esindusühing
23.	European Public Health Alliance	Sascha Marschang	Europe	 epha european public health alliance
24.	European Medical Association	Vincenzo Costigliola	Europe	
25.	European Shiatsu Federation	Eugenio Airaghi	Europe	
26.	European Federation of Nurses Associations	Paul De Raeve	Europe	
27.	European Confederation of Care-Home Organization	Alberto De Santis	Europe	

28.	European Network of Fibromyalgia Associations	Pam Stewart	Europe	
29.	European Patient Forum	Nicola Bedlington	Europe	
30.	European Region of the WCPT	David Gorria	Europe	
31.	European Federation of Neurological Associations	Audrey Craven	Europe	
32.	Myeloma Patients Europe	Ananda Plate	Europe	

33.	Europa Uomo	Ken Mastris	Europe	
34.	European Federation of Crohn's and Ulcerative Colitis Associations	Luisa Avedano	Europe	
35.	Pain Alliance Europe	Cristina Fernández	Europe	
36.	Federation of European Psoriasis Associations	Celia Marín	Europe	
37.	Inter-association on health (Collectif Interassociatif Sur la Santé)	Marc Paris	France	

38.	[im]Patients, Chroniques & Associés	Muriel Londres	France	
39.	Bürger Initiative e Gesundheit e.V.	Wofram-Arnim Candidus	Germany	
40.	Evropaiki Ekfrasi	Rodoula Derzekou	Greece	
41.	Dutch patientorganist ation congintal heart defects  (Patientenvere niging aangeboren hartafwijkingen)	Eugene van Galen	Holland	
42.	Foundation Against Cancer  (The Stichting tegen Kanker)	Nele Van den Cruyce	Holland	 Stichting tegen Kanker <i>Stichting van openbaar nut</i> Fondation contre le Cancer <i>Fondation d'utilité publique</i>

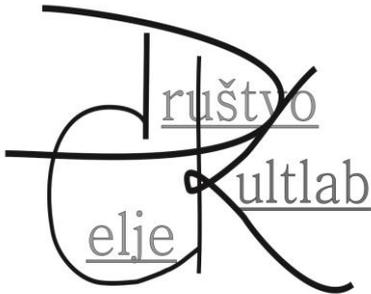
43.	Haemochromatosis Patient Association (Hemokromatózisos Betegek Egyesülete)	Maria Ábele	Hungary	 <p>Hemokromatózisos Betegek Egyesülete</p>
44.	Associazione Nazionale Strutture Terza Età (National Association of Senior Citizens Facilities)	Alberto De Santis	Italy	 <p>ASSOCIAZIONE NAZIONALE STRUTTURE TERZA ETÀ</p>
45.	Movimento Europeo (European Movement)	Pier Virgilio Dastoli	Italy	 <p><b>Consiglio Italiano del Movimento Europeo</b></p>

46.	Tribunale dei Diritti del malato	Tonino Aceti	Italy	
47.	National Coalition of Associations for Patients suffering Chronic Diseases (Coordinamento Nazionale delle Associazioni dei malati Cronici)	Tonino Aceti	Italy	
48.	Professional Health Association (Asociacioni Shëndetësor Profesional)	Adem Bytyqi	Kosovo	
49.	Patients' Rights Association (Shoqata e të Drejtave të Pacientëve)	Besim Kodra,	Kosovo	

50.	Pacientu Ombuds	Santa Japeniņa	Latvia	
51.	<p>Council Of Representatives Of Patients' Organizations Of Lithuania</p> <p>(Lietuvos Pacientų Organizacijų Atstovų Taryba)</p>	Vida Augustiniene	Lithuania	
52.	Studorium	Neda Milevska	Macedonia	
53.	Malta Health Network	Gertrude Buttigieg	Malta	
54.	Europa Donna Malta	Gertrude Abela	Malta	

55.	Arka Foundation (Fondazzjoni Arka)	Emanuel Curmi	Malta	 FONDAZZJONI ARKA
56.	Malta Food Bank Foundation	Irene Schembri	Malta	
57.	No Pain Foundation	Silvana Fanalista	Malta	 NO PAIN FOUNDATION
58.	Association of Speech Language Pathologists	Norma Camilleri	Malta	
59.	The Coalition of Premies (Koalicja dla Wczesniaka)	Maria Kornacka	Poland	

60.	<p>Public Information and Documentation Center</p> <p>(Centrul de Documentare si Informare Publica)</p>	Costel Batranu	Romania	
61.	<p>Myeloma Euronet Romania</p>	Viorica Cursaru	Romania	
62.	<p>Consumers' Centre of Serbia</p> <p>(Centar potrošača Srbije)</p>	Vera Vida	Serbia	
63.	<p>League against Cancer Slovakia</p> <p>(Liga proti rakovine SR)</p>	Eva Siracka	Slovakia	

64.	Europa Uomo Slovensko	Vasil Koprda	Slovakia	
65.	Slovak association for protection patients and consumers rights	Milan Machalec	Slovakia	
66.	Kultlab Celje Society (Društvo Kultlab Celje)	Alen Novit	Slovenia	
67.	Slovenian Foodbank (Slovenska banka hrane)	Alen Novit	Slovenia	
68.	Association for Justice and Control (Združenje za pravičnost in nadzor)	Mia Novak	Slovenia	

69.	European Leukodystrofy Asociation	Carmen Sever Bermejo	Spain	
70.	Associació de Malalts del Ronyó	Antonio Tombas Navarro	Spain	
71.	Catalan Association Lupus E.G  (Asociación Catalana Lupus E.G)	Pilar Lucas Plaza	Spain	
72.	Asociación de Afectados de Urticaria Crónica	Meritxell Cortada	Spain	
73.	Asociación de lúpicos de asturias	Nélida Gómez Corzo	Spain	

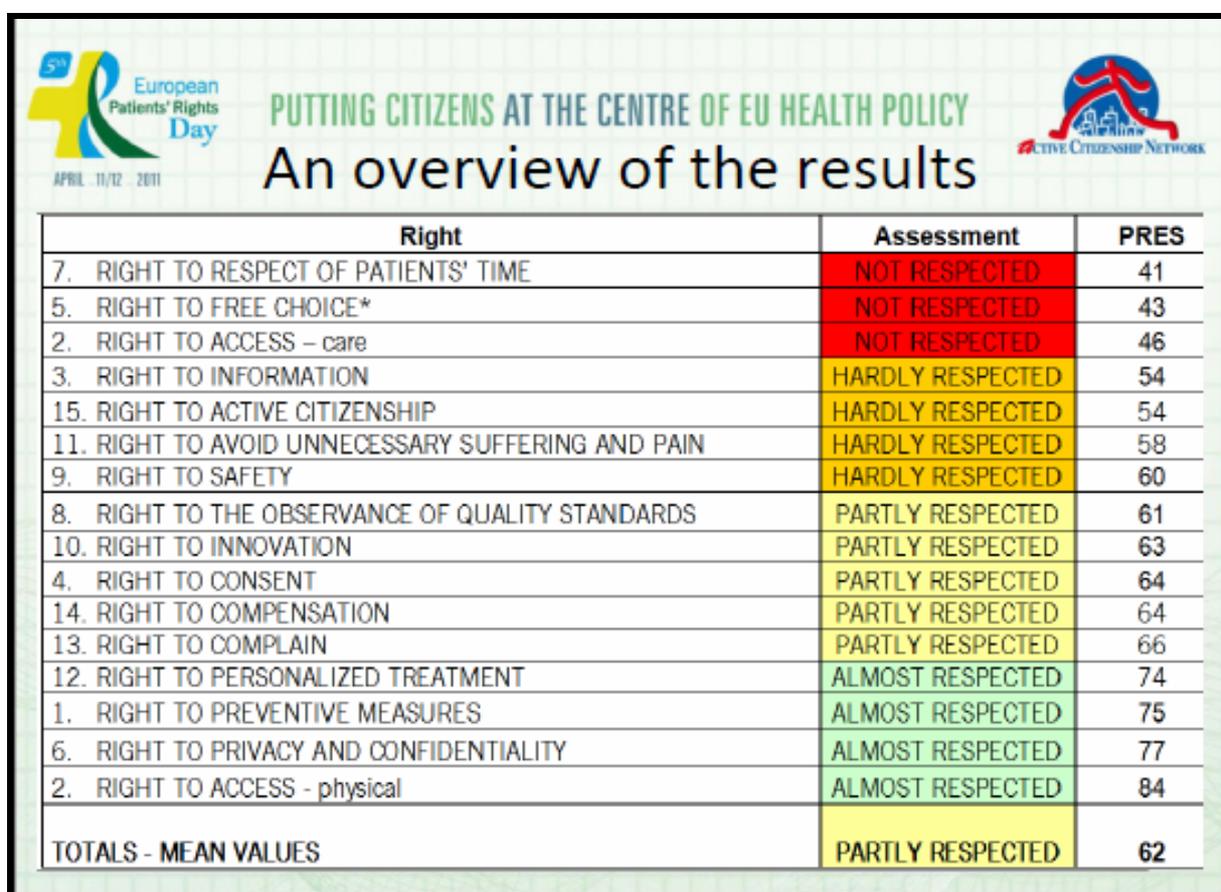
74.	Federación Nacional de Asociaciones de Enfermedades Respiratorias de España	Victoria Palomares	Spain	
75.	Fundacion Ciudadania	Juan José Salado Sanchez	Spain	
76.	Ukrainian Union of Patients' Organizations	Valentyna Ocheretenko	Ukraine	
77.	Ukrainian Diabetes Federation	Valentyna Ocheretenko	Ukraine	
78.	Backcare	Adam Al-Kashi	United Kingdom	

79.	Pelvic Pain Support Network	Judy Birch	United Kingdom	
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***The civic assessment on the  
Respect of Patients' Rights  
at the EU Level***

In the past years, Active Citizenship Network has developed two European Assessment programmes on the Patients' Rights Charter with data collected from 20 European countries. The aim was to put citizens at the centre of health policies, transforming their role from mere targets and users of health services to active citizens participating in healthcare policymaking and, at the same time, to produce information on the actual implementation of patients' rights at EU level.

The overview of the Report, presented during the 5<sup>th</sup> European Patients' Rights Day in 2011, shows the following results:



Right	Assessment	PRES
7. RIGHT TO RESPECT OF PATIENTS' TIME	NOT RESPECTED	41
5. RIGHT TO FREE CHOICE*	NOT RESPECTED	43
2. RIGHT TO ACCESS – care	NOT RESPECTED	46
3. RIGHT TO INFORMATION	HARDLY RESPECTED	54
15. RIGHT TO ACTIVE CITIZENSHIP	HARDLY RESPECTED	54
11. RIGHT TO AVOID UNNECESSARY SUFFERING AND PAIN	HARDLY RESPECTED	58
9. RIGHT TO SAFETY	HARDLY RESPECTED	60
8. RIGHT TO THE OBSERVANCE OF QUALITY STANDARDS	PARTLY RESPECTED	61
10. RIGHT TO INNOVATION	PARTLY RESPECTED	63
4. RIGHT TO CONSENT	PARTLY RESPECTED	64
14. RIGHT TO COMPENSATION	PARTLY RESPECTED	64
13. RIGHT TO COMPLAIN	PARTLY RESPECTED	66
12. RIGHT TO PERSONALIZED TREATMENT	ALMOST RESPECTED	74
1. RIGHT TO PREVENTIVE MEASURES	ALMOST RESPECTED	75
6. RIGHT TO PRIVACY AND CONFIDENTIALITY	ALMOST RESPECTED	77
2. RIGHT TO ACCESS - physical	ALMOST RESPECTED	84
<b>TOTALS - MEAN VALUES</b>	<b>PARTLY RESPECTED</b>	<b>62</b>

Source: Active Citizenship Network<sup>5</sup>

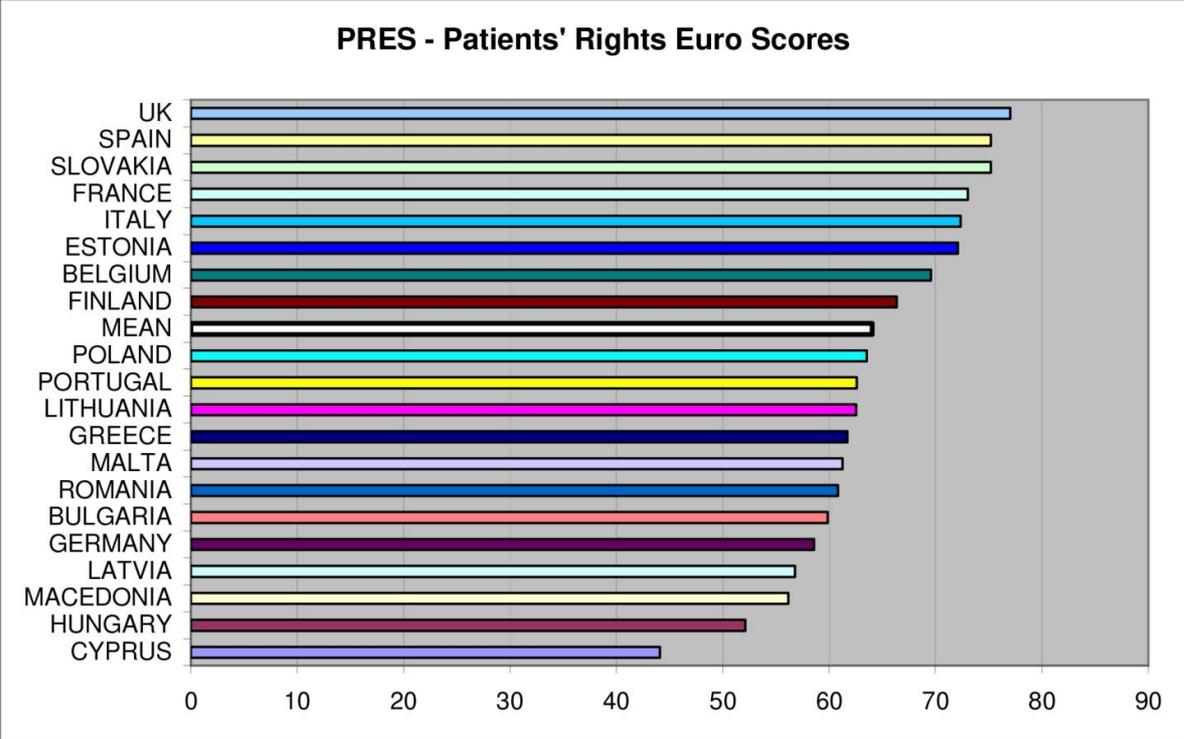
In general, this unacceptably low score average means a lack of respect for these rights.

<sup>5</sup> The EU Charter Of Patients' Rights - A Civic Assessment. 2010.

[http://www.activecitizenship.net/images/patientsrights/abstract\\_eu\\_charter\\_patient\\_rights\\_civ\\_ass.pdf](http://www.activecitizenship.net/images/patientsrights/abstract_eu_charter_patient_rights_civ_ass.pdf).

In order to allow a more immediate reading of the results for each Country, a PRES (Patients’ Rights Euro Score) was calculated to “summarize” the output of 156 indicators used for the Survey.

Of course, the calculation of PRES for each country was not directed towards establishing a classification on the quality or general efficiency of a system but, rather and more simply, towards evaluating the level of awareness regarding the rights mentioned in the European Charter of Patients’ Rights.



Source: Active Citizenship Network<sup>6</sup>

According to the above table, there are no situations in which the implementation of the rights may be considered reasonably complete and, even in the best case (that of the UK), a scant level of respect for the ideal situation remains above 20% and must therefore be considered significant.

For further information:

- [http://www.activecitizenship.net/files/patients\\_rights/civic\\_assessment/european\\_patients\\_rights\\_day\\_report\\_light.pdf](http://www.activecitizenship.net/files/patients_rights/civic_assessment/european_patients_rights_day_report_light.pdf)
- [http://www.activecitizenship.net/images/patientsrights/abstract\\_eu\\_charter\\_patient\\_rights\\_civ\\_ass.pdf](http://www.activecitizenship.net/images/patientsrights/abstract_eu_charter_patient_rights_civ_ass.pdf)

<sup>6</sup> The EU Charter Of Patients’ Rights - A Civic Assessment. 2010. [http://www.activecitizenship.net/images/patientsrights/abstract\\_eu\\_charter\\_patient\\_rights\\_civ\\_ass.pdf](http://www.activecitizenship.net/images/patientsrights/abstract_eu_charter_patient_rights_civ_ass.pdf).

### **Chronic disease and chronic pain**

Regarding the “Right to avoid unnecessary suffering and pain” (one of the rights in the European Charter of Patients’ Rights), Active Citizenship Network has developed, in partnership with Pain Alliance Europe, two European Assessments over the past years (2012/2013) to collect data in 18 European countries, thanks to the involvement of 37 patients/civic associations, 10 Ministries of health and 54 professionals interviewed.

The aim was to keep the attention focused on chronic pain as a health priority at the local, national and EU level, and suggest Civic Recommendations in order to put the topic for the first time in the EU agenda during the Italian Presidency of the Council of the European Union (II° half of 2014).

Country	Scores	Rating
France	67	PARTLY RESPECTED
Portugal	67	PARTLY RESPECTED
Malta	63	PARTLY RESPECTED
Sweden	61	PARTLY RESPECTED
United Kingdom	60	HARDLY RESPECTED
Italy	58	HARDLY RESPECTED
Germany	58	HARDLY RESPECTED
Austria	54	HARDLY RESPECTED
Latvia	53	HARDLY RESPECTED
The Netherlands	53	HARDLY RESPECTED
EU	49	NOT RESPECTED
Bulgaria	48	NOT RESPECTED
Spain	45	NOT RESPECTED
Slovenia	45	NOT RESPECTED
Romania	43	NOT RESPECTED
Cyprus	42	NOT RESPECTED
Belgium	40	NOT RESPECTED
Finland	33	NOT RESPECTED
Macedonia	27	NOT RESPECTED

**Source: Active Citizenship Network<sup>7</sup>**

As a whole, the content shows clearly that something is wrong across Europe. Patients’ associations have done a lot to improve the situation and empower patients suffering from chronic pain, but there is still a general lack of interest from the healthcare society and the Institutions in particular.

<sup>7</sup> Active Citizenship Network. 2015. *Pain: Report on Respect of Patients’ Rights Among the Europe*. <http://www.activecitizenship.net/patients-rights/109-pain-report-on-respect-of-patients-rights-among-the-europe.html>.

These negative results send a precise signal to the civic world and to the European institutions about the work still to be done: it is a difficult challenge which needs to be faced as a joint effort.

For further information:

<http://www.activecitizenship.net/patients-rights/109-pain-report-on-respect-of-patients-rights-among-the-europe.html>

***Key Figures on the Challenges  
of Chronic Diseases and  
Patients' Rights in the  
Framework of EU  
Healthcare Sustainability<sup>8</sup>***

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<sup>8</sup> This document was drafted by Renesa Islam, Active Citizenship Network

## Data on chronic diseases at European level

Chronic diseases represent the major share of the burden of disease in Europe and are responsible for 86% of all deaths<sup>9</sup>. They affect more than 80% of people aged over 65 and represent a major challenge for health and social systems<sup>10</sup>. The challenges become more demanding as Europe is undergoing major economic and social challenges and changes due to austerity measures, which have had a great impact on social protection schemes, especially services related to healthcare. Those affected the most are the vulnerable groups, such as: the children, elderly, migrants, pregnant women, unemployed and chronically ill. World Health Organization estimates that chronic diseases will claim 52 million people in the European region by 2030<sup>11</sup>, which means that out of 528 million people (expected in 2030)<sup>12</sup>, nearly 10% of the European population will lose their life due to chronic diseases. Even though an estimated 700 billion euros are spent per year on chronic diseases in Europe<sup>13</sup>, chronic patients are still not fully covered and undergo private costs. Research shows that deaths can be prevented if the funds are invested on prevention (only 3% is invested) rather than on health expenses (97%)<sup>14</sup>. It is crucial to find new ways of investing in sustainable health systems, moving beyond limiting expenditure to addressing the demand for health and social services, much of which is related to chronic diseases.

## Social, labor and professional factors affecting sustainable Healthcare Systems

Sustainability in the healthcare system is defined as “an effective and efficient healthcare system that provides for equal access to prevention, cure and therapy at the state of science for all people who need it with simultaneous financial viability”<sup>15</sup>.

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9 'Conference Conclusions'. 2015. In *The 2014 EU Summit On Chronic Diseases*, 1. Luxembourg: European Commission. [http://ec.europa.eu/health/major\\_chronic\\_diseases/docs/ev\\_20140403\\_mi\\_en.pdf](http://ec.europa.eu/health/major_chronic_diseases/docs/ev_20140403_mi_en.pdf).

10 'Recipes For Sustainable Healthcare: Introduction To The European White Paper Initiative & Background Information ESG Roundtable On Prevention And Early Intervention' 2014. Presentation.

11 'Answer To DG SANCO Consultation On Chronic Diseases'. 2012. In *Health Policy Forum*, 5. European Commission. [http://ec.europa.eu/health/interest\\_groups/docs/euhpf\\_answer\\_consultation\\_jan2012\\_en.pdf](http://ec.europa.eu/health/interest_groups/docs/euhpf_answer_consultation_jan2012_en.pdf).

12 *European Demographic Data Sheet*. 2010.

[http://www.oeaw.ac.at/vid/datasheet/download/European\\_Demographic\\_Data\\_Sheet\\_2010.pdf](http://www.oeaw.ac.at/vid/datasheet/download/European_Demographic_Data_Sheet_2010.pdf).

13 'Conference Conclusions'. 2015. In *The 2014 EU Summit On Chronic Diseases*, 1. Luxembourg: European Commission. [http://ec.europa.eu/health/major\\_chronic\\_diseases/docs/ev\\_20140403\\_mi\\_en.pdf](http://ec.europa.eu/health/major_chronic_diseases/docs/ev_20140403_mi_en.pdf).

14 'Answer To DG SANCO Consultation On Chronic Diseases'. 2012. In *Health Policy Forum*, 7. European Commission. [http://ec.europa.eu/health/interest\\_groups/docs/euhpf\\_answer\\_consultation\\_jan2012\\_en.pdf](http://ec.europa.eu/health/interest_groups/docs/euhpf_answer_consultation_jan2012_en.pdf).

15 'Focus: Chronic Diseases Approaches For Concrete Solutions For People In A Sustainable Healthcare System'. 2014. In *Recipes For Sustainable Healthcare*, 21.



*Source: Sustainable Development Unit<sup>16</sup>*

It is easy to imagine a sustainable healthcare system without financial, environmental and social limits – it would improve patients’ lives drastically. But the challenge lies here: delivering high quality care and an improved health system without exhausting natural and financial resources<sup>17</sup>.

The main problems in the European healthcare are: demand for health services at a time when public spending is under pressure and an expanding elderly population<sup>18</sup>. In other words, how to balance the impact of the economic crisis on access to healthcare in Europe and the patients’ rights, as mentioned in the European Charter of Patients’ Rights<sup>19</sup>, to access innovative procedures both in diagnosis and treatment according to international standards?

16 Sustainable Development Unit. 2015. *Sustainable Health & Care System*. Image. <http://www.sduhealth.org.uk/policy-strategy/what-is-sustainable-health.aspx>.

17 Sustainable Development Unit. 2015. *Sustainable Health & Care System*. Image. <http://www.sduhealth.org.uk/policy-strategy/what-is-sustainable-health.aspx>.

18 ‘*Reforming Healthcare in Europe*’. <http://www.reforminghealthcare.eu/>

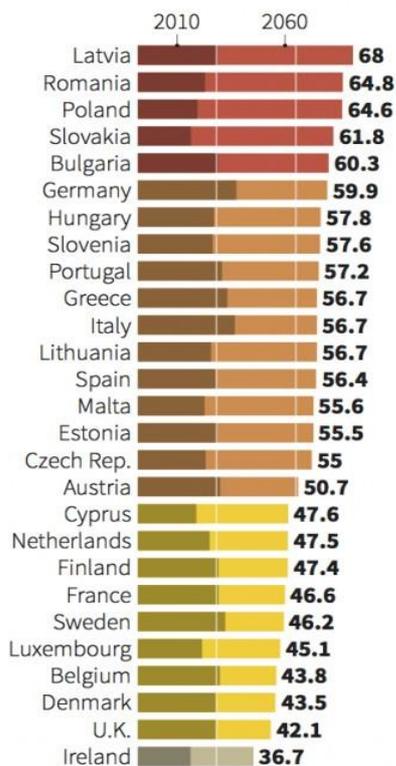
19 Active Citizenship Network. 2002. *European Charter Of Patients’ Rights*. Rome. [http://ec.europa.eu/health/archive/ph\\_overview/co\\_operation/mobility/docs/health\\_services\\_co108\\_en.pdf](http://ec.europa.eu/health/archive/ph_overview/co_operation/mobility/docs/health_services_co108_en.pdf).

## Ageing population

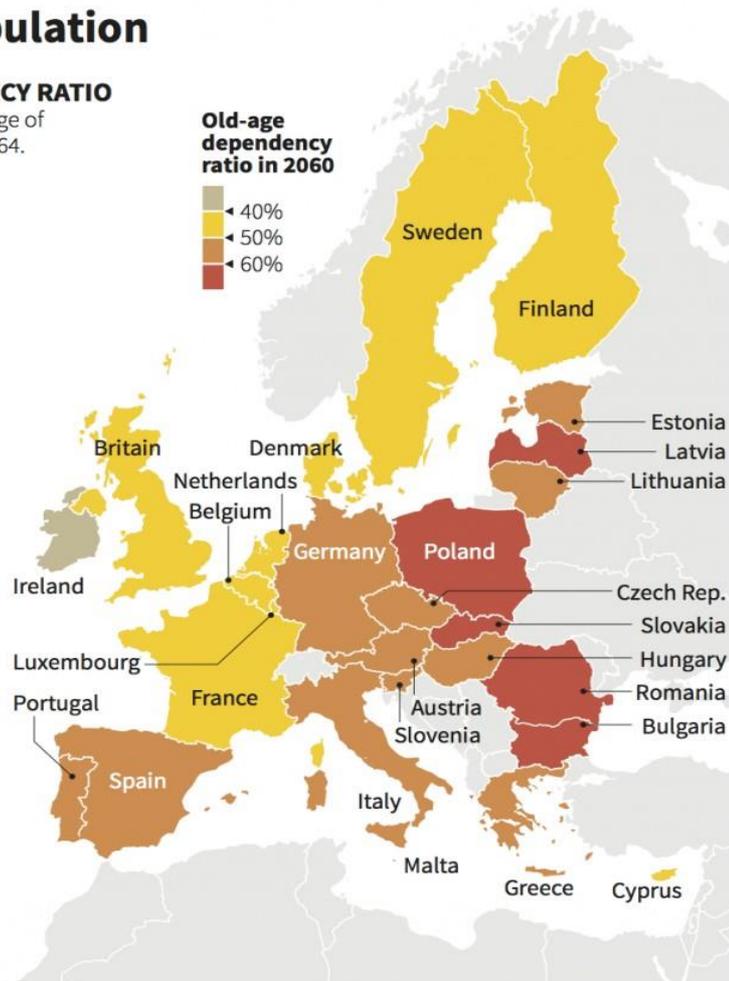
### Europe's ageing population

#### PROJECTED OLD-AGE DEPENDENCY RATIO

Number of persons aged 65 as a percentage of number of persons aged between 15 and 64.



Source: Eurostat



Source: Thomson Reuters<sup>20</sup>

From the above graph, it can be seen Europeans life expectancy will increase but at the same time might also experience many years of illness. In 2016, one in ten European will have a longstanding disability, underlining the magnitude of the problem<sup>21</sup>.

That is why we need to act now. Health promotion and disease prevention are key factors for the long-term sustainability of health systems as well as for increasing

<sup>20</sup> 'Europe's Ageing population'. 2015.

<http://blog.thomsonreuters.com/index.php/europes-ageing-population-graphic-of-the-day/>

<sup>21</sup> 'European Healthcare 'not equipped' to meet future challenges'. 2014.

<http://www.euractiv.com/sections/health-consumers/european-healthcare-not-equipped-meet-future-challenges-301195>

healthy life years; integrated care models, innovative and promising ways would improve the quality and efficiency of health systems and therefore improve their sustainability; health investments can be an important factor for the health systems' sustainability<sup>22</sup>, and a transition from medical paternalism to citizen empowerment, from hospital dependency to integrated care, and from volume to value based payments<sup>23</sup>.

## Social and labor factors

The World Economic Forum and Harvard School of Public Health estimate that chronic diseases will cause 47 trillion dollars of global economic output loss over the period 2011-2030<sup>24</sup>, which will have an impact on consumption, savings decisions, labor market performance and human-capital accumulation. Moreover, there is a lack of research on the economic implications of chronic diseases<sup>25</sup>, which makes it difficult for governments from assessing the impact and effectiveness of national chronic diseases policies, programmes and treatments<sup>26</sup>. This gives the governments the perfect excuse to not intervene in the market to subsidize the costs of healthcare. These 'private' costs represent “the largest share of the costs of diseases are borne by the individual directly concerned”<sup>27</sup>, adding to the economical burden for the patient and their family.

This situation will get worse due to workforce shortages: the EU commission estimates a shortage of one million health professionals by 2020 if action is not taken. A lack of health professionals will result in 15% of care services not being delivered due to lack of resources. This is particularly relevant in the context of the on-going economic and financial crisis, which has triggered cuts in healthcare and increased cross-border of health professionals at all levels<sup>28</sup>.

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22 'Reflection Process On Modern, Responsive And Sustainable Health Systems'. 2013. In *Employment, Social Policy, Health And Consumer Affairs Council Meeting*, 3. Council of the European Union. [http://www.consilium.europa.eu/uedocs/cms\\_data/docs/pressdata/en/lisa/140004.pdf](http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lisa/140004.pdf).

23 'What Is Sustainable Healthcare'. 2015.

24 'Answer To DG SANCO Consultation On Chronic Diseases'. 2012. In *Health Policy Forum*, 3. European Commission. [http://ec.europa.eu/health/interest\\_groups/docs/euhpf\\_answer\\_consultation\\_jan2012\\_en.pdf](http://ec.europa.eu/health/interest_groups/docs/euhpf_answer_consultation_jan2012_en.pdf).

25 The Oxford Health Alliance. 2015. 'Chronic Disease: An Economic Perspective'.

<http://archive.oxha.org/initiatives/economics/chronic-disease-an-economic-perspective>.

26 'Answer To DG SANCO Consultation On Chronic Diseases'. 2012. In *Health Policy Forum*, 7. European Commission. [http://ec.europa.eu/health/interest\\_groups/docs/euhpf\\_answer\\_consultation\\_jan2012\\_en.pdf](http://ec.europa.eu/health/interest_groups/docs/euhpf_answer_consultation_jan2012_en.pdf).

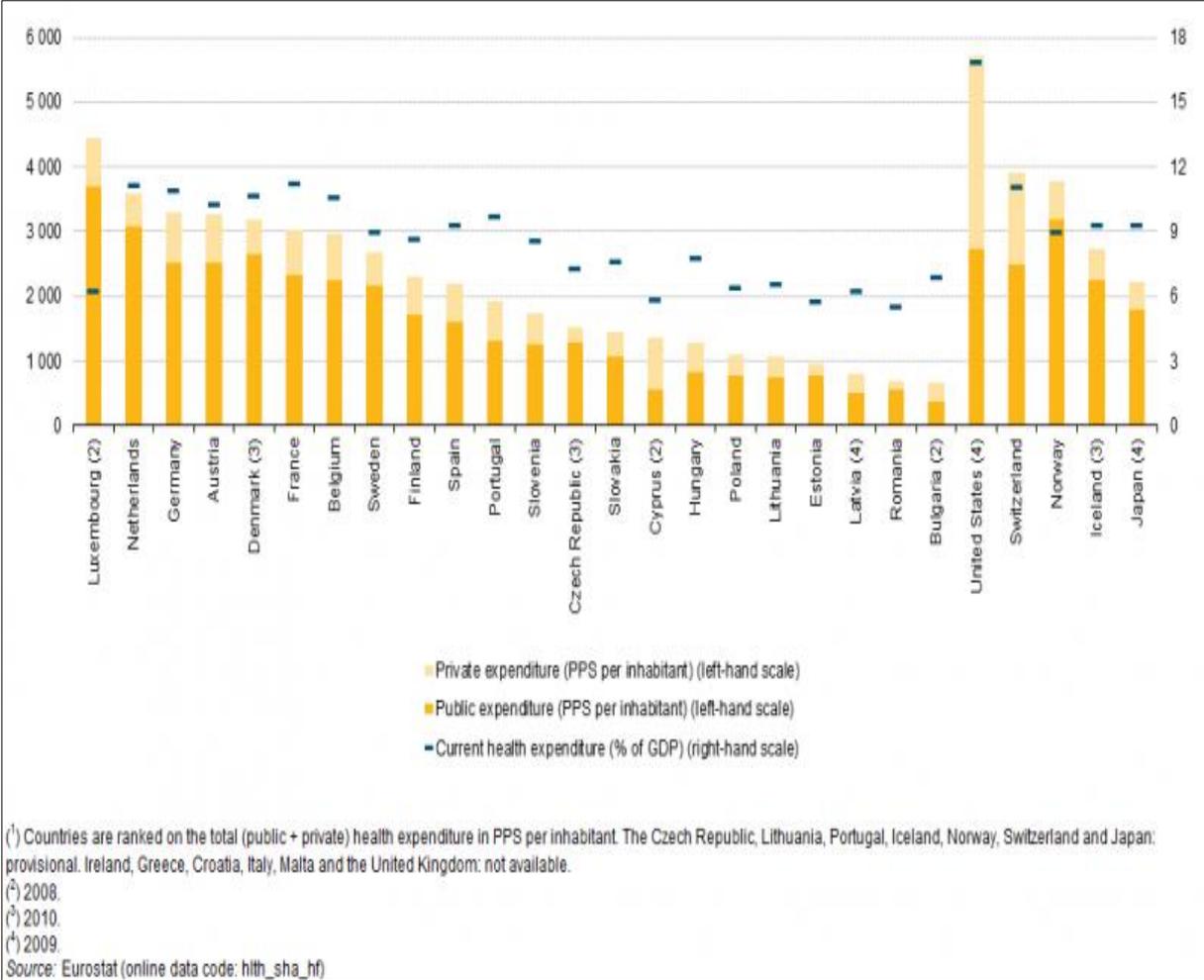
27 The Oxford Health Alliance, 2015. 'Chronic Disease: An Economic Perspective'.

<http://archive.oxha.org/initiatives/economics/chronic-disease-an-economic-perspective>.

28 'Answer To DG SANCO Consultation On Chronic Diseases'. 2012. In *Health Policy Forum*, 18. European Commission. [http://ec.europa.eu/health/interest\\_groups/docs/euhpf\\_answer\\_consultation\\_jan2012\\_en.pdf](http://ec.europa.eu/health/interest_groups/docs/euhpf_answer_consultation_jan2012_en.pdf).

### Costs of Healthcare

The table below shows the recent health expenditures in Europe<sup>29</sup>.

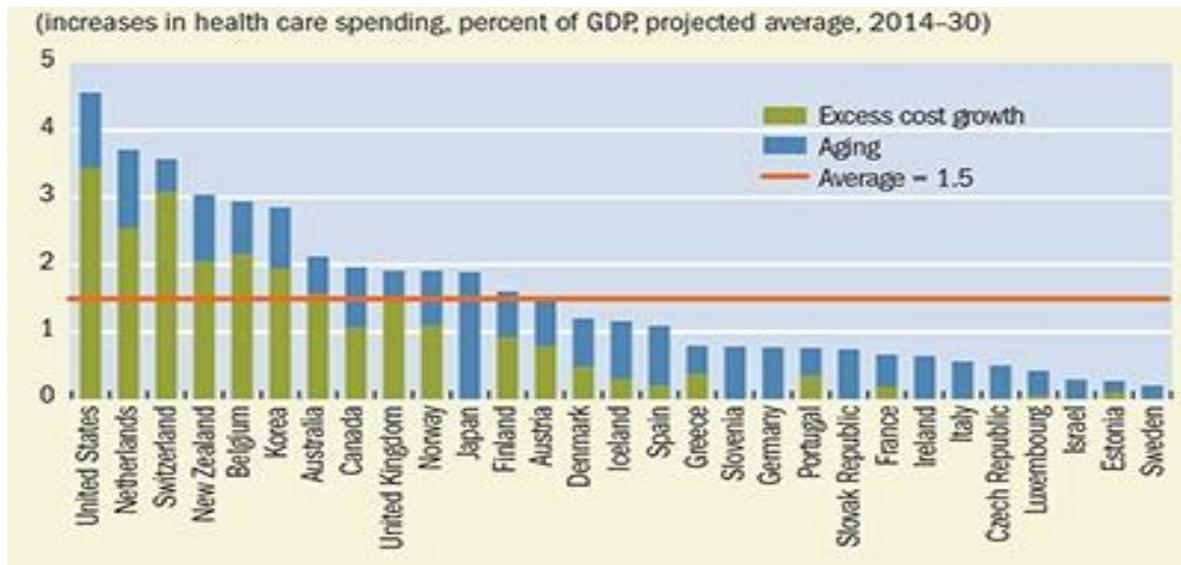


### Spending on the Rise

Public healthcare spending will increase by about 1.5% of GDP in advanced economies over the next 15 years. Less than half will be from aging populations; the rest is from technology, rising incomes, and structural factors<sup>30</sup>.

29 Eurostat,. 2011. *Current Health Expenditure*. Image. [http://ec.europa.eu/eurostat/statistics-explained/index.php/File:Current\\_healthcare\\_expenditure,\\_2011\\_\(1\)\\_YB14.png](http://ec.europa.eu/eurostat/statistics-explained/index.php/File:Current_healthcare_expenditure,_2011_(1)_YB14.png). The purchasing power standard (PPS) is the name given by Eurostat to the artificial currency unit in which the PPPs (Purchasing Power Parities) and real final expenditures for the EU.

30 Clements, Benedict. 2014. *Bill of Health*. Vol. 15, No.4. International Monetary Fund. <http://www.imf.org/external/pubs/ft/fandd/2014/12/clements.htm>



As can be seen from the graph above, the projections for the future in Europe do not look optimistic for the health sector.

### Focus on Italy

In 2013, the Italian health expenditure amounted to 109,254 million euros but the percentage of GDP remained unchanged from 2011. As the table below shows, in the last four years, the total amount of the public healthcare expenditure decreases<sup>31</sup>.

Health Expenditure 2010-2013				
	2010	2011	2012	2013
<b>Health Expenditure</b>	112,53	111,09	109,61	109,25
<b>GDP %</b>	7.3%	7.0%	7.0%	7.0%
<b>Variation in health expenditure %</b>	1.9%	-1.3%	-1.3%	-0.3%

**Source: Italian Ministry of Economy and Finance 32**

31 CnAMC-Cittadinanzattiva. 2014. *Servizio Pubblico: Diritto Di Accesso?* 13<sup>th</sup> ed. <http://www.cittadinanzattiva.it/primo-piano/salute/6971-xiii-rapporto-sulle-cronicita-e-ancora-pubblico-accesso.html>.

32 CnAMC-Cittadinanzattiva. 2014. *Servizio Pubblico: Diritto Di Accesso?* 13<sup>th</sup> ed. <http://www.cittadinanzattiva.it/primo-piano/salute/6971-xiii-rapporto-sulle-cronicita-e-ancora-pubblico-accesso.html>.

The situation is getting worse as the Italian government has announced last February the cut of 2,352 million euros from the National Health System (NHS) budget in 2015, which will lead to patients either to pay from their own pockets or decide to give up some treatments. Indeed, a total of 57% of the Italians have declared that they have given up some medical services such as the dentist, echograph, radiography and diagnostic tests<sup>33</sup>, as it will affect their household finances. Moreover, 21% of the population in Italy is over the age of 74 and in 20 years' time, the over-78 will make more than 30% of the Italian population<sup>34</sup>, increasing the reliance on the Italian healthcare system, already on a tight budget.

Also, it does not help that for patients and their families, all the costs related to chronic diseases have become a luxury. In 2012, 12.7% of Italian families were relatively poor and 6.8% were barely able to survive. These families do not or cannot have: a protein meal every 2 days (16.6%), one week off from work per year (50.4%), adequate heating in their homes (21.2%), late payments for bills and loans (13%), and cannot afford to pay for unforeseen circumstances (41.7%)<sup>35</sup>.

<b>Annual costs (on average) privately incurred by a family with a chronically ill elderly<sup>36</sup></b>	
<i>Nanny</i>	€ 8.488
<i>Specialist visits or rehabilitation activities at home</i>	€ 3.718
<i>Purchase of prostheses and aids</i>	€ 944
<i>Fee for residential and /or semi-residential structures</i>	€ 13.946
<i>Specialist visit carried out in the private or intramural</i>	€ 855
<i>Investigations carried out in the private or intramural</i>	€ 1.034
<i>Purchase of necessary drugs that are not reimbursed by the NHS</i>	€ 1.127
<i>Purchase of para-pharmaceuticals (i.e. food supplements, skin cosmetics, creams, ointments, artificial tears, etc...)</i>	€ 1.297
<i>energy bill that a family forced to use electro-medical equipment</i>	€ 1.150

**Source: Cittadinanzattiva – CnAMC, 2012**

33 Musto, Beniamino. 2014. 'Salute: Gli Italiani Pronti A Tagliare Le Spese'. *Insurance Daily*.

34 Minns, Jeanette. 2014. 'Healthcare: The Italian Project'. *POLITICO*.

35 Cittadinanzattiva. 2014. 'Permesso Di Cura' Ovvero Quando Potersi Curare Diventa Un Lusso'. *CARE*. <http://careonline.it/2014/01/incontri-e-confronti/permesso-di-cura-ovvero-quando-potersi-curare-diventa-un-lusso/>.

<sup>36</sup> <http://www.cittadinanzattiva.it/comunicati/salute/4158-xi-report-on-the-policies-of-chronicity-by-cittadinanzattiva.html>

<http://www.cittadinanzattiva.it/progetti-e-campagne/salute/4405-energy-and-chronically-ill.html>

***Cittadinanzattiva***  
***Official Presentation***

Cittadinanzattiva (Active citizenship) is an Italian **non-profit organization** founded in 1978. It is independent from political parties, trade unions, private companies and public institutions. It is recognized as a consumer organization since 2000.

### **Mission**

Cittadinanzattiva's main objectives are the promotion of civic participation and the protection of citizens' rights in Italy and in Europe. It considers citizens a fundamental resource for democracy who play an active role in society and should have the opportunity to participate in everyday policy-making.

### **Strategy**

Cittadinanzattiva's strategy is threefold:

- empowerment of individuals and organizations, i.e. strengthening of their capacity to defend fundamental rights, take care of the common goods and participate in policy-making. The main instrument to reach this goal is the training of citizens in the use of civic tools such as Charters of rights, advice services, monitoring, promotion of good practices, etc;
- production of civic information, i.e. data on the situation of citizens' rights collected and analysed by citizens themselves. The main sources of civic information are the monitoring activities and the advice and assistance services of Cittadinanzattiva, PIT salute (welfare and health) and PIT servizi (general interest services);
- advocacy, which includes the protection of single citizen's rights (PIT salute and PIT servizi), as well as the promotion of citizens' rights in general. It is mainly implemented through a constant dialogue with public institutions and political parties.

### **Fields of activities**

The fields in which Cittadinanzattiva is particularly active are health, with the Tribunal for Patients' Rights, consumer and users' rights, with the Citizens' Advocates, education and training, with the School for active citizenship, justice, with Justice for Citizens' Rights, European citizenship, with Active Citizenship Network and Corporate Social Responsibility.

## **Organization**

Cittadinanzattiva counts around 115.000 members (individuals, associations, groups and networks). It operates at the local level through 250 “Active Citizenship” Assemblies electing their representatives to the respective regional Congress (19) and subsequently to the national Congress. The headquarters, located in Rome, coordinate and support the national and European activities.

## **Funding**

The organization is funded mainly on the basis of projects, by private and public bodies, as well as by donations from the general public. The complete list of funding sources can be found on Cittadinanzattiva’s website. However, the primary and most substantial form of funding comes from its members themselves in terms of time, activities and services they provide to the organization at the grassroots level.

## **Support us**

Help us support our activities. There are many different ways we can stand by your side. You can donate through

- Bank transfer

IBAN: IT14J0200805240000401362508 in the name of Cittadinanzattiva Onlus

and

- Online both effectively and safely at:

[www.cittadinanzattiva.it/sostienici](http://www.cittadinanzattiva.it/sostienici)

***Active Citizenship Network***  
***Official Presentation***

Active Citizenship Network (ACN) is part of a widespread European open and flexible network of more than 100 civic, patients and users organizations. Established in 2001, it is coordinated by Cittadinanzattiva, an Italian non-profit & consumer organization founded in 1978. As a European and international interface of Cittadinanzattiva, ACN focuses on the following two objectives:

- ✓ encourage active participation of citizens in European policy-making in order to promote the construction of a European citizenship as an “active citizenship”, meaning the exercise of powers and responsibilities of citizens in public policies. This includes:
  - recognizing the primary role of citizens and civic organizations in the care of the common good;
  - supporting citizen’s participation in policy making at local, national and EU level;
  - involving them in the defence of their fundamental rights as citizens, patients, consumers, passengers, users, savers, etc.
- ✓ promote abroad all the successful experiences achieved by Cittadinanzattiva in Italy. For this reason, ACN mirrors Cittadinanzattiva's Italian policies, such as patients’ and consumers’ rights, civic activism, education, etc.

## **Our Network**

Since its inception, the partnership within the network has been enhanced by the activities of partners in common projects, discussions and participation in initiatives founded on strong co-operation ties.

This network of diverse civic organisations is both the strength and the uniqueness of ACN. Together with its EU partners, ACN operates in several different fields and this makes it unique in its kind and one of the most extended communities of active civic associations in Europe. It is therefore an ideal subject to cooperate with for those organisations who consider important the involvement of citizens in their activities.

Over the past 10 years, ACN has promoted several political activities and carried out more than 30 EU projects together with partners from 30 Countries (inside and outside the EU), working as leader coordinator, partner in a consortium or consultant as civic advisor in the following areas:

- Assessing, monitoring and promoting the respect of Patients' Rights in Europe
- Research on patients involvement
- Fight against unnecessary suffering and chronic pain
- Collecting best practices

- Volunteering and elderly activism
- Corporate social responsibility
- Civic evaluation in the Public Services
- Sustainable Mobility and passengers' rights
- Renewable energy

ACN is also active in Colombia since 2009 with 3 Citizen Advisory Centres on Public Services and Health.

### **Milestones of ACN activities**

- 2002: drafting of the **European Charter of Patients' Rights** which has become a reference for EU citizens' rights in the healthcare.
- 2005-2006: in collaboration with FONDACA, drafting of the **European Charter of Active Citizenship** to bridge the gap among the EU rules about the rights, duties, powers and responsibilities of civic organisations acting in public policies.
- 2007: launching of the **European Patients' Rights Day**, celebrated every year on 18th April with local, national and EU events all over Europe.
- 2007: awarded the **Civil Society Prize** of the European Economic and Social Committee for its work on citizens' rights.
- 2009: in Colombia, **technical advisor to the United Nation Development Programme** for the development of activities in the field of civic participation.
- 2011: proclamation of the First **Charter of Patients' Rights in Colombia**.

### **ACN is official member of ...**

- "EU Health Policy Forum", led by DG Health & Consumers, an EU platform dealing with health and patient's rights
- "Active Citizenship Structured Dialogue Group", led by DG Education and Culture, an EU platform dealing with civic participation

### **...and official partner of**

- "European Mobility Week", led by DG Environment
- "Your passenger rights at hand", led by DG Move
- "Connect4Climate", initiative for global cooperation on climate change led by World Bank

### **Be informed, follow us on**

- Free monthly newsletter "Active Citizenship Network News"
- Twitter and Facebook ([www.facebook.com/activecitizenshipnetwork](http://www.facebook.com/activecitizenshipnetwork))

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