



“Patients’ rights have no borders” A civic perspective.

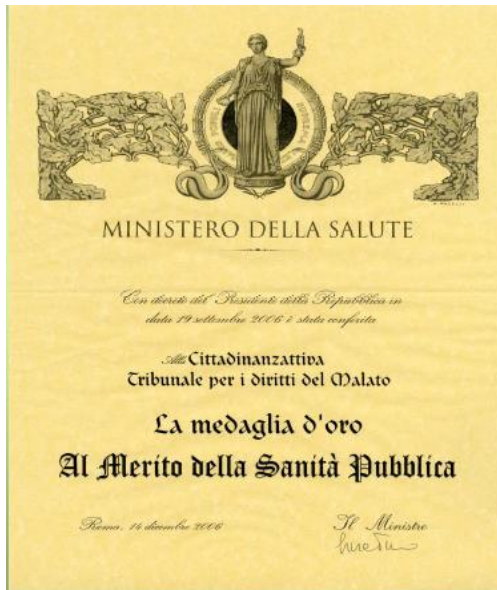
CBBA - Europe Annual Conference ~ Brussels, 28th November 2018

CITTADINANZATTIVA

Italian NGO, founded in Italy in 1978

More than 30.000 members, 250 local assemblies and 84 Citizen Advisory Centres

Mission: to promote active participation of citizens and protection of their rights



ACTIVE CITIZENSHIP NETWORK

The European branch of Cittadinanzattiva, established in 2001

One of the most widespread network, with more than 100 civic, patient and user organizations from all over Europe

Promotes the point of view of European citizens in all public policy areas, focusing on healthcare, consumers and corporate social responsibility issues

What we do at national level



Tribunal for Patients' Rights
(+250 local points & 10.000 volunteers)



84 PIT-Citizen Advisory Centres
+ a back office at national level
and front line in 84 cities.

Each year, all claims & requests
of information (average 25,000
/year) are included in a National
Report submitted to the
national authorities.



National Coalition of Associations
for Patients suffering Chronic
Diseases (CnAMC). Since 2000 it
publishes a National Annual
Report on chronic policies and
manages a dedicated website.



What we do at international level

Active Citizenship Network (ACN) is a member of:

- [EU Health Policy Platform](#) (DG Sante)
- [Active Citizenship Structured Dialogue Group](#) (DG Home)
- [European Consumer Consultative Group \(ECCG\)](#) (DG Justice and Consumers)
- [European Centre for Disease Prevention and Control](#) (ECDC)



- **European Charter of Patients' Rights** (2002): 14 rights
- **European Patients' Rights Day** (since 2007) celebrated every year on 18th April with local, national and EU events across Europe



- [MEPs Interest Group "European Patients' Rights and Cross-border Healthcare"](#) (2015)

The MEPs Interest Group

“European Patients' Rights and Cross-border Healthcare”

The idea to encourage a MEPs Interest Group focused on patients' rights is linked to the **request of 100 civic and patient organizations**, sent to the EU Parliament in May 2015, **to recognize officially the value of citizens' initiatives.**

- **Strengthen the protection of patients' rights in the European legislation**, starting from the adoption of those included in the European Charter of Patients' Rights.
- Promote initiatives that encourage and ensure among EU countries the **respect of the European legislation focused on patients' safety and the protection of their rights.**



For further information, please visit: www.interestgroup.activecitizenship.net

Our commitment on cross-border healthcare (I)

- Daily activity: in Italy, with our **Tribunal for Patients' Rights and Citizen Advisory Centres on Health**, we provide information, advices and assistance also to the citizens who travel abroad for treatment
- Cittadinanzattiva has been the only Italian association involved as **reviewer** for the civic evaluation of the [App "European Health Insurance Card"](#) produced by the European Commission and DG SANCO in 2012
- ["Manifesto for the implementation of the Right of European Patients to make an informed choice"](#), drafted in 2013 with 31 Civic & Patients Associations coming from 13 EU Countries and 2 EU Networks
- May 2013: ["European coordination of patients' associations and other stakeholders"](#), informal EU network coordinated by ACN of 31 Civic and Patients Associations and other stakeholder interested to work together for the implementation of the Directive, sharing information, good and bad practices, etc.
- **European tour to talk about the Directive.** [Public debates](#) with National Institutions and patients associations to share the experience from several Countries.
- May 2013: ["VII European Patients' Rights Day: patients' involvement and Cross-Border Care"](#), attended by EU and National Institutions, 40 patients' associations, healthcare professionals and stakeholder of EU networks
- ["Make them informed! Ask your State to inform citizens on EU health rights"](#). **Online petition**, signed by hundreds of EU citizens to ask their National Parliament to involve the Directive in their legislation

Our commitment on cross-border healthcare (II)

- October 2013: Presentation to the Italian Institutions of the [Report](#) “Care Without Borders: is it possible now?”
- October 2013: “*The right to information and free choice in a European perspective. Patients' Rights Have No Borders*”, a [report](#) with an updated state of the implementation of the Directive in 12 EU Countries and Civic Recommendations, presented also to the DG SANCO by a delegation of **Active Citizenship Network** (composed by 10 Association coming from 8 Countries)

- [2015: Tour of Rights in 35 Italian cities](#)



- [Mobility, healthcare centers and rights' protection](#)



Being treated abroad: what happens in Italy



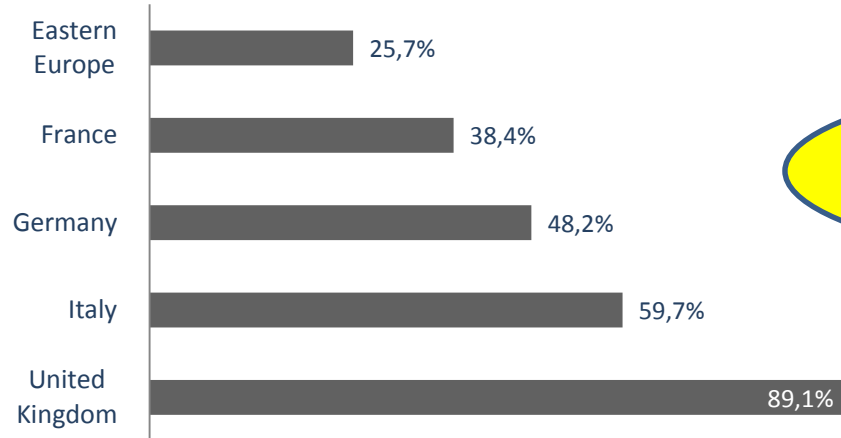
Reasons	%
Surgery	35
Innovative therapies	29
Diagnostics	18
Specialized consultation	13
Transplantation	5

Therapeutic area	%
Oncology	32
Neurology	30
Rare diseases	17
Cardiology	13
Orthopedics	8

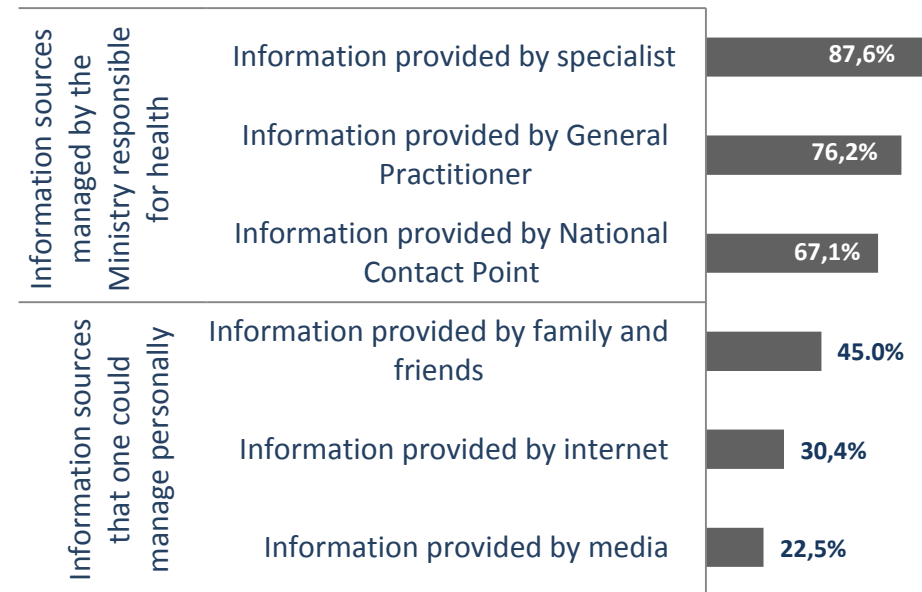
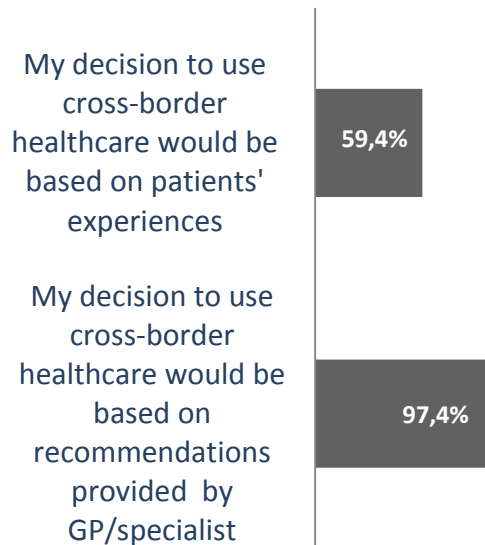
Problems	%
Prior-authorization delayed	36
Lack of information	27
Authorization denied	23
Difficulty to obtain reimbursement	14

Data refer to 269 reports received by citizens

Being treated abroad: what happens in Malta

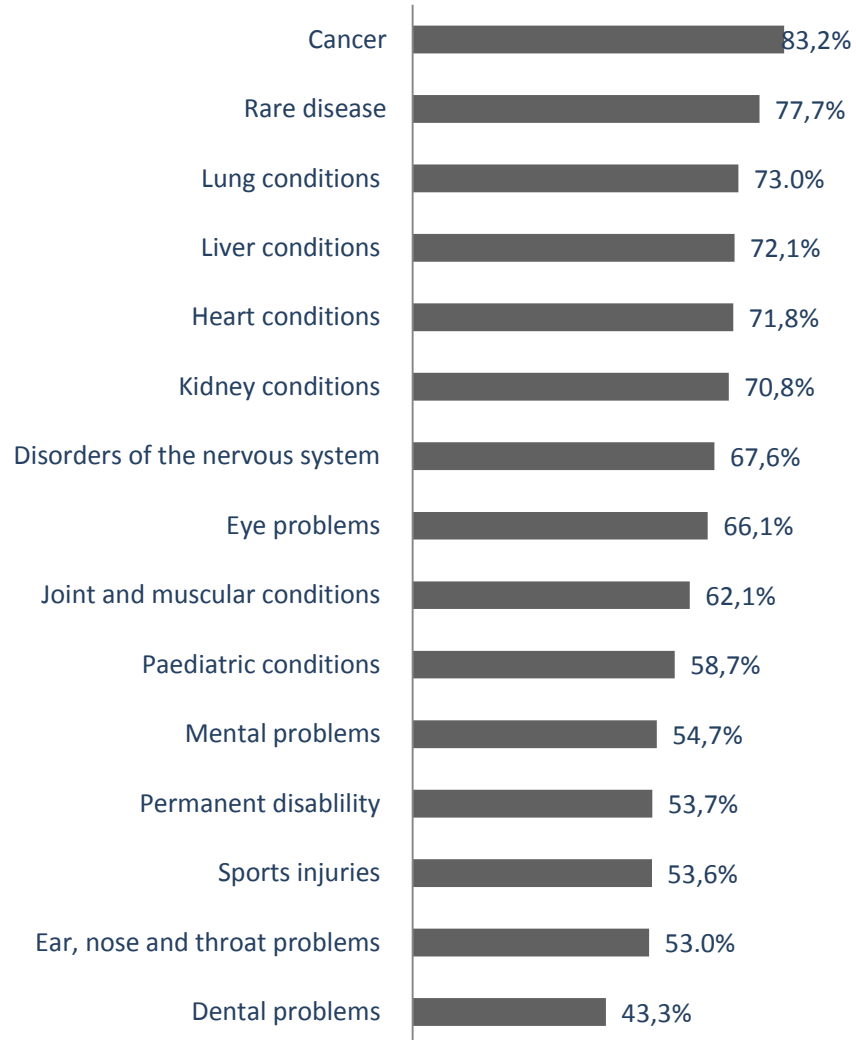


Patients' expectations often compromise patients' medical needs, trust and geographical proximity





Disease/conditions that would lead to seeking treatment abroad:



Total Number of Maltese patients receiving treatment abroad in 2014	Speciality
26	Paediatric Cardiac Surgery
46	Haematology (Oncology)
18	Neuro-Surgery
36	Ophthalmology
22	Oncology

Being treated abroad: what happens in the German-French border region



The German-French border region is one of the most actives within the EU:
approximately 40.000 persons cross the border between Strasbourg and Kehl every day

Directive 2011/24 on the application of patients' rights in cross-border healthcare only had a moderate effect at the German-French border

3 main reasons:

1. Legal complexity and lack of transparency

Directive 2011/24, allows every patient to **seek ambulatory healthcare without prior authorization** from his/her social security system. The **patient will be reimbursed according to the rates of the country where he gets treatment.**

In conformity with article 8, **every Member State has its own list of exceptions** about which prior authorization is necessary. So, in a border region the exceptions may differ.



Every Member State should make available to the public the list of exceptions and all relevant information concerning prior authorization.

Being treated abroad: what happens in the German-French border region



2. The need of enhanced information and a real guidance

The NCPs work very differently in the Member States.
A vulgarisation of the very technical information is desperately needed:
simple language should be used.



To make the directive work, **appropriate information are needed for both citizens and doctors, hospitals and social security services alike.**

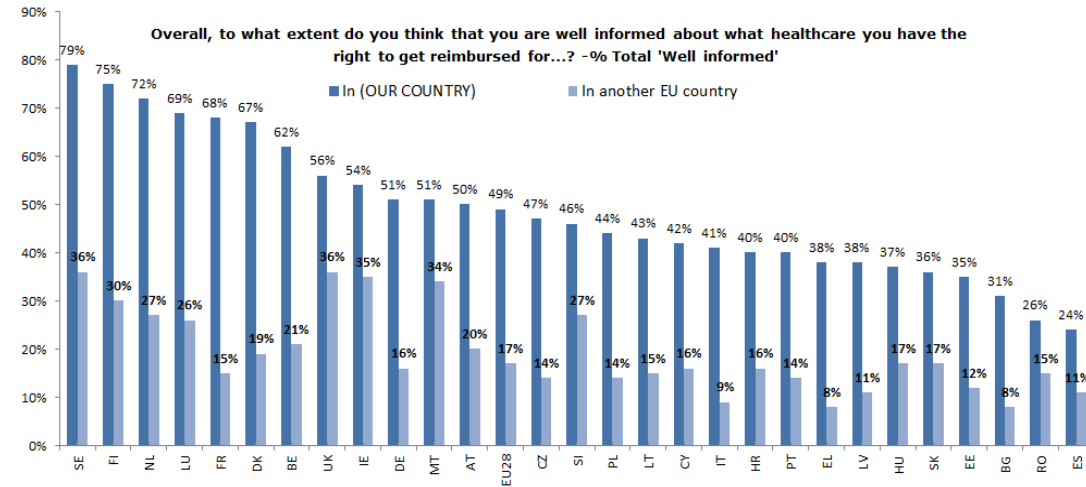
3. Restrictive interpretation of prior authorization from social security services

Directive 2011/24 coexists with regulation **883/2004 on emergency care (and 987/2009)**.
In some cases happened that **prior authorization has been required even in cases of extreme urgency**, even though regulation 883/2004 foresees that in case of emergency, both for ambulatory and hospital care, no prior authorization is necessary.
Directive 2011/24 states in article 8.1 that **prior authorisation should only be restricted “if necessary and proportionate”**.



Currently in many border regions, it seems that **prior authorisation is used to control the patient flow, even if a service cannot be adequately provided or provided at all.**

Less than 20% of citizens feel that they are informed about their cross-border healthcare rights (2016)



Low awareness of cross-border healthcare directive and rights

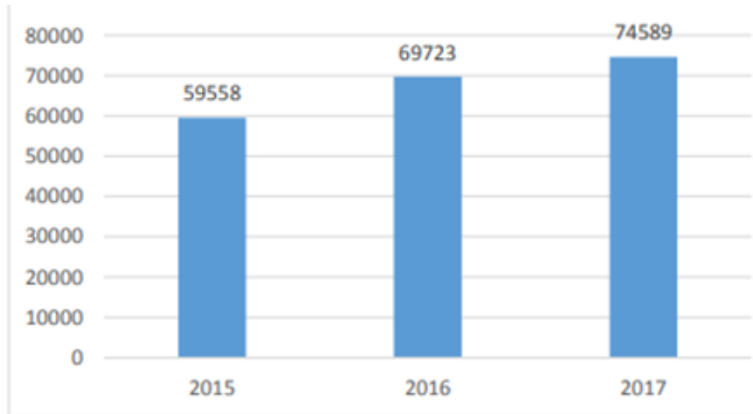


Lack of homogeneous information and assistance:

- complicated system of prior authorization, different from MS to MS;
- little or denied reimbursements
- long or complicated administrative procedures
- disparities amongst NCPs in the way they operate and the information they provide

Major concerns

Total number of requests for information made to NCPs:



Theory:

INFORMATION ON CROSS-BORDER HEALTHCARE SHOULD BE EASILY AVAILABLE

The National Contact Points (NCPs) should have an essential role to play, providing information and in raising awareness on patients' rights and responding to information needs

Reality:

In-depth information on patients' rights is generally lacking on NCPs websites, including insight into what to do in the case of undue delay.

Information on **complaint procedures and settlement** of disputes was also **scarce**, as well as information on the time period required to process **reimbursements and prior authorisation requests**.

Information was variable also on **which treatments are reimbursed**.

What is still missing?

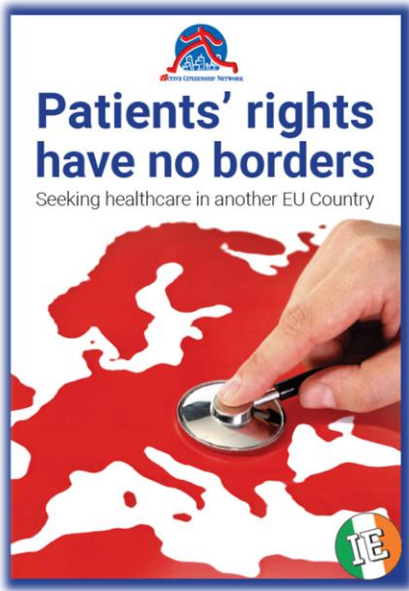


- **Appropriate information**, not only for patients, but also for medical practitioners and health insurers
- **Awareness** of role and potential of **National Contact Points**
- **Cooperation among stakeholders**: to date, the article no. 6 of the Cross-border Healthcare Directive is still not implemented: “[...]Member States shall ensure that the National Contact Points consult with patient organizations, healthcare providers and healthcare insurers”

WHAT WE DID (and how)



European communication campaign “Patients’ rights have no borders”



Network of 26 patient & civic organizations in 24 Member States

- AT  Lower Austrian Patient and Nursing Advocacy
- BE  Active Citizenship Network
- BG  Patients' Organizations "With You"
- CY  Cyprus Alliance for Rare Disorders
- CZ  Klub pacientů mnohočetný myelom, z.s.
- EL  Greek Alliance for Rare Diseases
- DE  Bürger Initiative Gesundheit e.V.
- DK  Rare Disease Denmark
- FI  Association of Cancer Patients in Finland
- FR  Inter-Association on health (CISS)
- IE  Irish Patients' Association
- ES  Plataforma de Organizaciones de Pacientes
- HR  Croatian Association for the Promotion of Patients' Rights
- HU  Hungarian Federation of People with Rare and Congenital Diseases
- IT  Cittadinanzattiva - Tribunal for patients' rights
- LT  Council of Representatives of Patients' Organizations of Lithuania
- NL  European Patients Empowerment for Customised Solutions
- MT*  Malta Health Network
- PL  Institute for Patients' Rights & Health Education
- PT  Azorean Chronic Pain Patients Association
- RO  Romanian National Alliance for Rare Diseases
- SL  SIBAHE Slovenian Foodbank; Kultlab Celje Society;
Association for justice and control
- SK  Society of Consumer Protection
- UK  Pelvic Pain Support Network



Informative materials in different languages



Brussels events at the European Parliament

3^o May 2016



1st March 2017



27th February 2018



Case histories

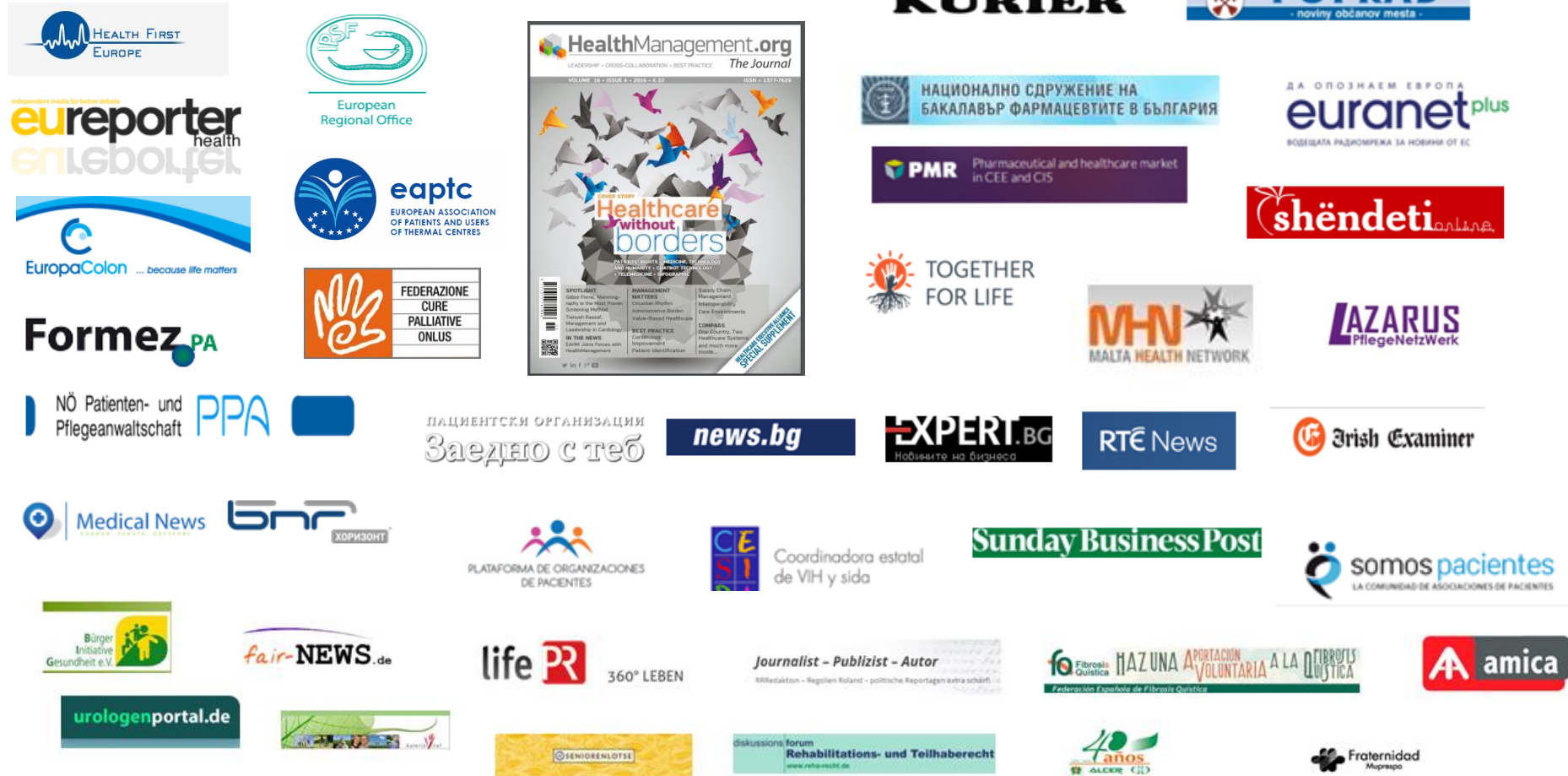
*“I live in Austria
and I am insured with an Austrian fund,
but I would like to get surgery in Slovakia.
What am I entitled to? Will my health
insurance cover the costs of the surgery?
What are the procedures to follow?”*

*“Hello,
I went to Switzerland to get surgery for eye
melanoma.
The local health system approved my request of prior
authorization but they still have not given any
reimbursement for that (medicines, etc.).
What can I do?”*

*“I was diagnosed with a tumour
on my right knee. I live in Belgium but I decided to turn
to a doctor in Italy. He told me I needed surgery urgently,
as long waiting times would have implied complications and uncertain
recovery. So I have sent the request of reimbursement for planned treatment
to the health insurance I am affiliated to. They have told me twice the Italian
doctor should have submitted the application. So I asked my doctor to prepare
the required documents. After two long weeks, I got the official answer of the
health insurance asking for the same document from a Belgian doctor. This
lengthens the time further, as I have to take a medical appointment here in
Belgium, then have a biopsy and after that the surgery.
And what about the patient's right
to choose his own doctor?”*

Dissemination activities - Media exposure

CORRIERE DELLA SERA



Dissemination activities - Social media



ActiveCitizenshipNet ha ritwittato

EU_Health @EU_Health · 3 mag
 Congratulations on the campaign launch! Info on #EU #crossborder #healthcare legislation europa.eu/!YB49PJ

ActiveCitizenshipNet @activecitnet
 S.Belfiore @activecitnet officially introduce the european communication campaign to implement the European Crossborder healthcare #eprd16

10 8

ActiveCitizenshipNet ha ritwittato

consumi&consumi @consumieconsumi · 17 set
 Una buona notizia dall' #Europa

ActiveCitizenshipNet @activecitnet
 Need #healthcare assistance in another EU member state? Check your #nationalcontactpoint #PatientsRightsHaveNoBorders bit.ly/1NJfnZT

6 2

ActiveCitizenshipNet @activecitnet · 23 set

Vuoi curarti in un altro paese dell'UE? Ecco la guida in italiano bit.ly/2cKwHBL
 #PatientsRightsHaveNoBorders @Cittadinanzatti

6 1

ActiveCitizenshipNet @activecitnet · 16 set

Download free guides in 14 languages to learn more about #Patients'RightsHaveNoBorders & #CBHC #ActiveCitizenshipNet ow.ly/zAIF3043z87

4 3

ActiveCitizenshipNet @activecitnet · 13 set

Seeking #healthcare in another member state? #patient #associations can help you! #PatientsRightsHaveNoBorders bit.ly/2crgkXc #CBHC

8 4

Dissemination activities – Local events



Major achievements

- ✓ **Recognition of ACN as relevant stakeholder** on cross-border healthcare and **endorsement** of the **DG-Santé** «e-Health & Cross-Border Healthcare Unit»
- ✓ **High attention of the Institutions** thanks to the support of the **MEPs Interest Group** «European Patients' Rights & Cross-Border Healthcare»
- ✓ New connections established
- ✓ A range of approximately **5000 citizens** per country reached through the dissemination activities
- ✓ Call of interest to **extend the campaign**
- ✓ **Other applications** from new organizations in the countries already involved



Future challenges and opportunities: our proposals



- **ERNs multi-stakeholder forum** to enhance patients' rights: access, information and innovation
- **Communication campaign** with dissemination activities aiming at informing and raising awareness among European patients on ERNs.
- **Study visits**
- **Integration of different European policies:**
 1. introduction of rules on **mediation**, ODR/ADR
 2. integration of the principles of the Directive in the context of the **EU mobility policy**
 3. work for a **better coordination** of the EU agencies and structures (Solvit, Your Europe Advice, NCPs, Europe Direct, ECC-Net)
 4. integrate the existing **ECC-Net**, or to build a **European Patient Centres Network (EPC-Net)**



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