



IBMT

**Patients' rights have no borders.
A civic perspective**



Milano 26 October 2018

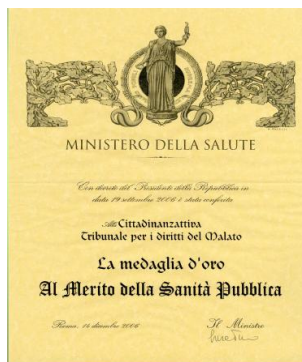
CITTADINANZATTIVA/ACTIVE CITIZENSHIP NETWORK: A SHORT INTRODUCTION

Cittadinanzattiva

Italian NGO founded in Italy in 1978.

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

Mission: 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 the 100 civic, patients and user organisations.

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

WHAT WE DO AT NATIONAL LEVEL



Tribunal for Patients' Rights (+250 local point & 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 authorities



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



AT INTERNATIONAL LEVEL



Active Citizenship Network (ACN), is

member of:

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

Our main instruments at EU level:

- **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)



PATIENT'S RIGHT TO CROSS-BORDER HEALTHCARE: OUR COMMITMENT



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.

CAMPAIGNS AND PROJECTS



Lo sai che...

Se la Sanità locale (ASL, Regione o anche Nazione stessa) non è in grado di erogare la prestazione di cui hai bisogno, per mancanza di strutture specialistiche o macchinari o perché la lista d'attesa è troppo lunga per le prescrizioni mediche, è possibile chiedere alla propria ASL di rimborsare le eventuali prestazioni che si effettuano fuori dai confini italiani nei Paesi dell'Unione Europea.

Per avere accesso a questo tipo di tutela, è necessario che:

- la prestazione sia inserita nell'elenco LEA (Livelli Essenziali di Assistenza),
- che un Medico pubblico specialista testimoni che la prestazione di cui hai bisogno debba essere effettuata in tempi e modi precisi e di non essere a conoscenza di una struttura che possa erogare la prestazione in tempo e nei modi opportuni.

La richiesta di rimborso per cure transfrontaliere va effettuata prima della partenza! Le ricevute dei pagamenti effettuati all'estero vanno inviate alla ASL entro tre mesi dall'ultima spesa, che provvederà in un secondo momento al rimborso.

Ricorda!

Puoi avere informazioni su come avere accesso alle cure in Europa dal Punto di Contatto Nazionale del Ministero della salute; la sezione del Tribunale per i diritti del malato a te più vicina è a disposizione per aiutarti.

www.sonomalatoanchio.org

Con il sostegno non condizionato di
abbvie

Partner tecnico
epiela



2015, Tour of Rights in 35 Italian cities



Mobility,
healthcare
centers and
rights
protection

Our commitment on cross-border healthcare (II)

- 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
- 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 DGSANCO by a delegation of **Active Citizenship Network** (composed by 10 Association coming from 8 Countries)

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 the website: www.interestgroup.activecitizenship.net

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

MAJOR CONCERNS

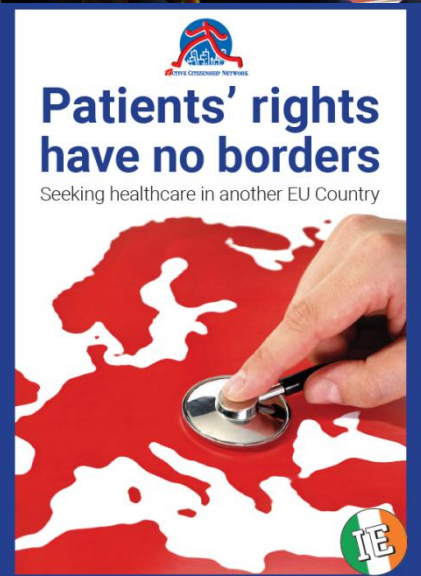
- Low awareness of cross-border healthcare
- Lack of homogeneous information and assistance:
 - complicated systems of prior authorization, different from MS to MS;
 - little or denied reimbursements
 - long or complicated administrative procedures
 - disparities amongst NCPs in the way they open information they provide



WHAT WE DID (and how)



European communication campaign “Patients’ rights have no borders”



Network of 26 organizations in 24 MS

- 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)
- EI  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



EU events

European Parliament, 3 May 2016

European Parliament, 27 February 2018



Dissemination activities (I)

Media exposure



CORRIERE DELLA SERA

Podtatranský KURIER

POP RAD
- noviny občanov mesta -

Independent media for better debate
eureporter health
GRI/GO/DF/EL



eaptc
EUROPEAN ASSOCIATION
OF PATIENTS AND USERS
OF THERMAL CENTRES



НАЦИОНАЛНО СДРУЖЕНИЕ НА
БАКАЛАВЪР ФАРМАЦЕВТИТЕ В БЪЛГАРИЯ

ДА ОПОЗНАЕМ ЕВРОПА
euranet plus
ВОДЕЩАТА РАДИОМРЕЖА ЗА НОВИНИ ОТ ЕС

EuropaColon ... because life matters

**FEDERAZIONE
CURE
PALLIATIVE
ONLUS**

PMR Pharmaceutical and healthcare market
in CEE and CIS

shëndeti online

Formez PA

NÖ Patienten- und
Pflegeanwaltschaft **PPA**

**TOGETHER
FOR LIFE**

MHN
MALTA HEALTH NETWORK

LAZARUS
PflegeNetzWerk

RTÉ News

Irish Examiner

Medical News

bnf
ХОРИЗОНТ

ПАЦИЕНТСКИ ОРГАНИЗАЦИИ
Заедно с теб

news.bg

EXPERT.BG
Любимите на бизнеса

Sunday Business Post

Bürger
Initiative
Gesundheit e.V.

fair-NEWS.de

PLATAFORMA DE ORGANIZACIONES
DE PACIENTES

**CE
SI
DA**
Coordinadora estatal
de VIH y sida

somos pacientes
LA COMUNIDAD DE ASOCIACIONES DE PACIENTES

urologenportal.de



life PR 360° LEBEN

Journalist - Publizist - Autor
Bildredaktion - Reginen Roland - politische Reportagen extra schärfen!

60 años
Fibrosis Quística HAZ UNA APORTACION VOLUNTARIA A LA QUÍMICA
Federación Española de Fibrosis Quística

A amica

ACTIVE CITIZENSHIP NETWORK

SENIORLOTSE

**diskussions forum
Rehabilitations- und Teilhaberecht**
www.reha-recht.de

40 años
ALCER CID

Fraternidad
Muprespa

Dissemination activities (II)

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 (III)

Local events



Austria



Malta



Dissemination activities (III)



Italy



Dissemination activities (IV)

Poland



Data & 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?"*

Major achievements

- ✓ **Endorsement of the DG-Santé «e-Health & Cross-Border Healthcare Unit»**
- ✓ **Endorsement of the MEPs Interest Group «European Patients' Rights & Cross-Border Healthcare»**
- ✓ **Support from European and national organisations:** EuropaColon, Global Myeloma Action Network (GMAN), World Alliance of Pituitary Organizations (WAPO), the Bulgarian Association for Patients Defence and LHRM e.V. (Leukämiehilfe RHEIN-MAIN e.V.)



Major achievements

- ✓ A range of approximately **1000-5000 citizens** per country reached through the dissemination activities (online and on the spot).
- ✓ Calls of interest to **extend the campaign**.
- ✓ **Other applications** from new organisations in the countries already involved



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 amongst 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 organisations, healthcare providers and healthcare insurers**”.

FUTURE CHALLENGES AND OPPORTUNITIES

- **2018/2019: campaign focused on rare diseases and on the newly established European Reference Networks.**
- **A European Manifesto to foster the cooperation on cross-border healthcare**
a concrete proposal to **encourage, for each ERN, the establishment of a multi-stakeholder group of interest**, opened to all the actors already involved in the Cross-border healthcare and in the implementation of its Directive.





Thank you!

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