

Patients rights have no borders

EU communication campaign

Report 2016



Patients' rights have no borders

Seeking healthcare in another EU Country





FOREWORD

The following report assesses the current status of progress of the campaign *Patients' rights have no borders*.

It is composed of four main sections:

The first one (A) focuses on the rationale and objectives of the project as a whole.

The second part (B) is the longest and most structured one as it concerns the activities performed and/or planned in the framework of the project. However, they are still preliminary results and data, since many activities are still ongoing and will take place until the end of the year, or further.

It is divided in seven subsections, which thoroughly describe each phase of the campaign from the very beginning.

The third section (C) highlights outcomes and major achievements up to now.

The last section (D) summarizes the main ideas and issues raised by the campaign and it also addresses some suggestions for the next steps.

A. INTRODUCTION

The Directive 2011/24/EU on patients' rights in cross-border healthcare has established a general legal framework aimed at maintaining the sustainability of health systems while protecting patients' right to seek treatment outside their home country. However, the impact of the Directive depends to a large extent on patients' knowledge of their rights across the EU under this legislation and of its potential benefits.

Identification of the problem and the key issues addressed

The report on the state of play of the Cross-border Healthcare Directive, published by the European Commission at the end of 2015, has reported that less than two in 10 EU citizens are informed about their rights in this area, and only one in ten knows role and responsibilities of National Contact Points.

Biggest obstacles and major findings

In addition to that, civic and patient organizations express the following key issues and obstacles on the topic:

- the involvement of organizations is still not considered a priority and a way of ordinary governance of the National Public Health System;
- language is one of the main stumbling blocks in reading/understanding medical prescriptions since the Directive does not indicate that Member States should adopt specific rules about it.
- cooperation among National Contact Points is still largely lacking



These obstacles result from evidence and data gathered by civic and patient organisations of ACN network as well as other national and European authoritative sources.

Objectives of this campaign

- Raise awareness among citizens and patients on cross-border healthcare
- Encourage a cooperation among either National Contact Points and patient organisations, as foreseen by the Cross-Border Healthcare Directive
- Build an informal network of civic and patient organisations committed and informed on the topic for the benefit of citizens and patients needing assistance
- Collect relevant data and share information, case histories and good practices on cross-border healthcare.

B. WHAT WE HAVE DONE SO FAR

As mentioned in the foreword, this section covers all the practical aspects of the project, that is all the activities related to development and management of the campaign.

1) Network

The first half of 2016 (January-March) was dedicated to define the number and commitments of partners of the projects. At that stage, Active Citizenship Network has also established an [informal network](#) of the following 14 patient and civic organisations:

- AT  Lower Austrian Patient and Nursing Advocacy
- BG  Patients' Organizations "With You"
- CY  Cyprus Alliance for Rare Disorders
- DE  Bürger Initiative Gesundheit e.V.
- FR  Inter-Association on health (CISS)
- EI  Irish Patients' Association
- ES  Plataforma de Organizaciones de Pacientes
- 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
- SK  Society of Consumer Protection



2) Informative materials

The second phase (March-July) was focused on the drafting, translation and printing of informative materials about the cross-border healthcare Directive. This work was done jointly with

partners of the campaign and has led to the publication of guides in 14 languages. Each organisation has received about 1500 leaflets.

The informative materials are also available on the [webpage of the project](#). They can also be downloaded [here](#).



3) Media exposure

Active Citizenship Network has drafted [several webpages on the project](#) along with a banner, which recalls the cover of the leaflets produced.



We have also shared both webpages and the banner with all our partners, supporters and – in general – during each promotional activity.

The campaign was extensively promoted through traditional and new media at European, national, local level. Furthermore, the news and contents of the campaign have been disseminated also by media/organisations outside the European Union (Albania).

The following list contains articles/press releases either from newspapers or websites. For each of them it is reported their logo, which links to the external articles/webpages.

EU newspapers and websites

Health Management is an international health journal, which counts 60.000+ readers across the world, 170.000 monthly website visitors. Not only they have recently published an article written by us

(November 2016), but they have already recalled the name of the campaign for their cover page.



Press releases in Italy



CORRIERE DELLA SERA

Formez_{PA}

Press releases in the Partners' countries

Austria:

NÖ Patienten- und
Pflegeanwaltschaft

PPA



LAZARUS
PflegeNetzWerk

Germany:



fair-NEWS.de

life PR

360° LEBEN

diskussionsforum
Rehabilitations- und Teilhaberecht
www.reha-recht.de

urologenportal.de



Journalist – Publizist – Autor
Hilfeditation – Regelin Roland – politische Reportagen Extra schärfen

[Gesundes Winterberg](#) [Gesundes Essen-Steele](#) [Gesundes](#)

[Friesoythe](#) [Gesundes Neustadt \(Weinstraße\)](#)

[Gesundes Brackenheim](#) [Gesundes Schweinfurt](#) [Gesundes Hagen](#)

[Gesundes Hohenstein-Ernstthal](#)

[Gesundes Jüterbog](#) [Gesundes Bad Münder](#)

Spain:



Coordinadora estatal
de VIH y sida



Bulgaria:

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Medical News
ЗДРАВЬЕ, РАБОТА, ОБЩЕСТВО

НАЦИОНАЛНО СДРУЖЕНИЕ НА
БАКАЛАВЪР ФАРМАЦЕВТИТЕ В БЪЛГАРИЯ

PMR
Pharmaceutical and healthcare market
in CEE and CIS

ДА ОПОЗНАЕМ ЕВРОПА
euranet plus
ИЗДАВАНА РАДИОМРЕЖА ЗА НОВИНИ ОТ ЕС

Ireland:

RTE News

Irish Examiner

Sunday Business Post

Slovakia:

Podtatranský
KURIER

POP RAD
- noviny občanov mesta -

Malta:

MHN
MALTA HEALTH NETWORK

Press releases in the other countries

Albania:

TOGETHER
FOR LIFE

shëndeti online

4) Social Media

The project has also been consistently promoted online, through a campaign on Twitter and other social media. Some examples hereafter:





ActiveCitizenshipNet @activecitnet · 16 set

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

🔄 4 ❤️ 3 ⋮

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 ha ritwittato



Párkinson Federación @ParkinsonFEP · 19 set
Disponible en español

ActiveCitizenshipNet @activecitnet

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

🔄 3 ❤️ 2 ⋮



ActiveCitizenshipNet @activecitnet · 15 set

Need [#healthcare](#) assistance in another
EU member state?Check your
[#nationalcontactpoint](#)
[#PatientsRightsHaveNoBorders](#)
bit.ly/1NJfnZT

🔄 7 ❤️ 4 ⋮



ActiveCitizenshipNet @activecitnet · 23 set

Vuoi curarti in un altro paese dell'UE?Ecco
la guida in italiano bit.ly/2cKwHBL
[#PatientsRightsHaveNoBorders](#)
[@Cittadinanzattivi](#)

🔄 6 ❤️ 1 ⋮

5) Data collection

Italy (source: *Cittadinanzattiva/Tribunal for Patients' Rights*)

Data from 269 reports received by Italian citizens in 2015 and first half of 2016 confirm that there are serious difficulties to travel abroad to receive treatment. Most of them concern the need to obtain from local health services prior-authorization to go abroad: 36% are the complaints of delay in receiving this authorization. 27% concerns the lack of information to complete the entire process, which involves many steps, most of them unclear. For 23% of citizens, another problem is the denied authorization by the local health services. As a result, they have to choose between giving up or paying by themselves, but for many of them this solution is not feasible because of the high costs. The last issue is the difficulty to obtain reimbursements for anticipated expenses (14% of data). These data also clarify that the economic obstacle is one of the most relevant problem. In some cases, the failure or delay in receiving a response becomes dysfunctional, confusing the citizens, being a limit to access therapies, and endangering their health.

The major reasons why Italian citizens go abroad to get treatment are: surgery (35%), innovative therapy (29%), diagnostic (18%), specialized consultation (13%), transplantation (5%).

The main therapeutic areas are: oncology (32%), neurology (30%), rare diseases (17%), cardiology (13%), orthopaedics (8%).

France (source: *CISS - Collectif Interassociatif Sur la Santé*)

Patient organisations have not been involved in the process of implementation of the Directive 2011/24/EU, and the lack of information to both citizens and civic organisations is a major issue along with that of reimbursements and language differences. Requests collected for cross-border healthcare were about 70,

which stands for less than 1% of all the requests the CISS receives every year – a clear demonstration that people are not informed.

Hungary (source: *Hungarian Federation of People with Rare and Congenital Diseases*)

In Hungary, questions to NCP mainly concern rights by National regulation (14%), rights by Directive (24%) and local and EU healthcare information. 9% of questions are about cross-border healthcare services.

During the period from October 2013 to March 2015, Hungarians' requests to go abroad were 665, 662 of which needed pre-authorisation. Citizens authorized were 491, authorizations refused were 67, simply not-authorized cases were 62 and process cancelled 45.

On the other hand, foreign citizens seeking care in Hungary were 2519, 1135 of which were Romanians. The therapeutic areas were mainly outpatient care (74%) and hospital care (20%).

Belgium (source: *ECAS - European Citizen Action Service*)

The enquiries received in 2015 were more than 22.000, 14217 of which concern social security. 30% of the requests on social security were about healthcare. More specifically, questions asked by the citizens' enquiries concern healthcare abroad and the European Health Insurance Card (45%), forms and procedures (24%), sickness benefits (16%), planned treatment (12%).

On the other hand, main issues raised were about access to information (45%), quality of information (14%), awareness of national authorities (12%), communication among national authorities (11%), enforcement (9%), conformity of national provisions (5%), excessive administrative formalities (3%), gaps and "grey" areas in EU law.

Most frequently, EU patients' requests for information and concerns were about prescriptions recognised in other countries, or the

possibility to receive care abroad and cases when a prior authorisation from a national authority is needed.

On the other hand, most frequent complaints concern denied reimbursements, authorisations refused and non-recognition of medical prescriptions.

Malta (source: *University of Malta*)

In Malta, as for the choice of countries in which respondents are willing to access treatment abroad, patients' expectations often compromise patients' medical needs, trust and geographical proximity. The 89.1% would be willing to go to the UK, despite the great geographical distance, because of the common language and the 59.7% would go to Italy because of the proximity with Malta. 97.4% of respondents indicated that they would base their decision on seeking healthcare in a foreign country on the recommendations from the GPs, but the 59.4% prefers other patients' experiences.

In terms of sources of information on treatment abroad, the results show that patients rely more on information sources managed by Ministries of Health (specialists, GPs, National Contact Points) rather than on information sources available on the Internet or provided by family/friends or media – and these are reassuring data too.

Regarding patients' medical needs, data show that patients are most willing to consider cross-border care for cancer (83.2%), rare disease (77.7%) and lung conditions (73.0%). Dental problems were the only disease category for which a minority of respondents are willing to access treatment abroad (43.3%). For all the other conditions the majority of respondents stated that they agreed to access treatment abroad.

In terms of numbers, in 2014, 26 Maltese patients went abroad to get pediatric cardiac surgery, 46 were treated for hematological reasons, 18 for neuro-surgery, 36 for ophthalmological reasons and 22 went abroad for oncology.

German-French border (source: *Centre for consumer protection in Europe/ Centre Européen de la Consommation*)

Directive 2011/24 on the application of patients' rights in cross-border healthcare only had a moderate effect at the German-French border. This seems to occur because of 3 main reasons:

- 1) legal complexity and lack of transparency;
- 2) a need for enhanced information and a real guidance, as confirmed by the recent report from the Commission as well. The contact points for patients, to enquire about their rights, provide very differently in the Member states: some give only very limited information, some have extensive websites, others don't, some can be reached by phone, others not, some have quite long response times etc. In any case a vulgarisation of the very technical information is desperately needed, simple language should be used. Indeed, enquiries made show that even for health practitioners the situation is very complex and often they do not inform consumers about the possibility to seek healthcare abroad as they are not aware this possibility or they cannot provide answers to the question if the patient will have to bear costs. Even social security services cannot answer as they do not know about the costs for the services provided abroad or receive necessary information from the other Member state only after very long waiting times. But patients need to have this prior information before engaging in health care in another country.
- 3) restrictive interpretation of prior authorisation from social security services: Directive 2011/24 coexists with regulation 883/2004 focusing on emergency care (and 987/2009). So several set of rules need to be applied, which for patients, doctors, hospitals and social security systems is not that easy. Also, the directive foresees a margin of decision for the patient, who in certain cases can opt for either or of the two systems. There are situations in which prior authorisation was required even in cases of extreme urgency with regard to the health of

the patient and the foreseen evolution of the sickness. And this even though regulation 883/2004 foresees that in case of emergency, both for ambulatory and hospital care no prior authorisation is necessary. Similar refusals happened also in cases of planned long-term ambulatory treatments, even though in principle no prior authorisation was necessary.

Slovakia

According to their experience, it is crucial that patients are well informed about what they are entitled to in advance. They report that in Slovakia, in most cases patients have to seek information about cross-border healthcare from independent experts, outside of hospitals and national insurance funds. This happens because healthcare providers and insurers are still not very used to cross-border healthcare Directive. Very often, they do not even know its content and, thus, they have not clear ideas about patients' rights and duties.

The percentage reported by the Eurobarometer study of 2015 about Slovak citizens knowing the existence of National Contact Points (stated as 20%) is far too high. There is very little knowledge in Slovakia.

But a very interesting thing is that media are interested in the phenomenon, especially when it comes to real stories of enforced patients' rights due to cross-border healthcare directive.

6) Collection of case histories

The campaign was an important occasion for collection and sharing of case histories of citizens experiencing cross-border healthcare. Hereafter some of the most relevant ones, which help identify challenges and barriers to a complete implementation of patients' rights in this area, but also, at the same time, fields of actions where to invest energies in the future.

"I am Romanian woman who has received a medical appointment in Germany. I paid for that but the clinic is now refusing to send me my patient chart and pictures they had made to my eye. What shall I do?"

~

"I have contacted so many times my local health provider so far because I haven't get any feedback yet concerning my request of prior authorisation to receive healthcare abroad (Switzerland). I am leaving next week for the therapy, and the local provider is not answering to my requests for more than a month now. Furthermore, I sent a formal request of reimbursement for the same therapy through registered mail, asking also for a feedback by 30/12/2015, but, still, they gave me no reply".

~

"I suffer from Fuchs' dystrophy, first diagnosed in March 2015 in Holland, because the doctors in Italy were unable to give me any indications. As my visual conditions were getting worse day by day. So I addressed once again to Italian doctors but, regardless of the diagnosis, they still were unable to help me. So I came back to Holland (March 2016) where I was told I need a endothelial transplant. I applied to get prior authorisation but it was refused on the grounds of the existence of are specific centres in Italy. On the grounds of the right of free choice, can I ask the reimbursement up to the cost of the same operation in Italy?"

~

"I was diagnosed with SLA between November/December 2015. The hospital told me I was excluded from experimentation with stem cells – which should slow the disease progression – because of my age (I'm older than 75 y. o.) I would like to go abroad but the hospital told me they don't have the resources, while the local health provider told me that I can do it, I just need to find a public healthcare provided abroad. What shall I do?"

~

"I had surgery in Austria. Despite I had informed my health insurance fund about the treatment abroad, they refuse to cover the expenses for the treatment now".

~

"In July 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 a more uncertain outcome in terms of 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. Despite him stressing out extensively that Italy could ensure a rapid response, essential for my disease, which cannot be ensured in Belgium instead. After two long weeks, I get the official answer of the health insurance: they need a document from a Belgian doctor. All of 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? Of course I can go to Italy and pay by myself the private surgery. But it is unfair, as also the EU directive foresees cross-border healthcare for conditions requiring prompt intervention. What are my rights? What can I do without wasting too much time?"

~

"I am a 69 years old. Foreign woman, suffering from chronic pain. I have managed to get some relief, but my family doctor knows little about pain management. I desperately need a specialist located in middle Italy. I am unable to walk well, or drive. Can you help me? My family will appreciate. I was afraid of moving from my Country for this reason.

Thank you"

~

"I live in Strasbourg and I was diagnosed with a possible vascular accident in 2014. My doctor - knowing about a waiting time of more than a month in Strasbourg - sent me directly to a colleague in Kehl where I was taken in charge by a bilingual doctor and his team. I could have passed the MRI the next day but I couldn't recover the costs. My social security scheme in France argued that this was a programmed ambulatory service for which prior authorisation was requested".

~

"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 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?"

7. Dissemination activities

The following is a list of the main events and dissemination activities performed at local/national level in the framework of this campaign. In all cases, all the partners promoted the campaign through traditional and/or new media and distributed the leaflets in their headquarters or during *ad hoc* activities.

Austria

- Promotion of the campaign through local/national media
- Distribution of the leaflets in their headquarters and to the following institutions: ombudsmen offices in 25 public hospitals in Lower Austria, 360 self-helping-groups in Lower Austria, 573 local authorities in Lower Austria, all patient advocacies in Austria
- Presentation of the project at the Austrian Pain Congress in Harbach on 29 April 2016
- Article about cross border healthcare in the newspaper of the umbrella-organisation of Lower Austrian self-helping-groups (June 2016)
- Lower Austrian Patient Advocacy Newsletter Article with more than 2000 subscribers
- Distribution of the leaflet to all self-helping groups and hospital ombudsmen in Lower Austria
- Presentation to all Austrian Patient Advocates at the annual meeting of the patient advocates on 24 November 2016 in Vienna



Bulgaria

- Promotion of the campaign through local/national media
- Distribution of the leaflets in their headquarters
- 2-day conference with the National Hospital Insurance Fund – which is the national contact point on the European Directive on cross-border healthcare (December 2016).

Cyprus

- Promotion of the campaign through local/national media
- Distribution of the leaflets in their headquarters

- Promotion of the project during many activities held in Cyprus, such as the event held for the International Patients' Day, 19 April at the Presidential Palace
- Translation of the Patients' rights booklet
- Active presence in the media through articles and presence on local TV shows, such as:



France

- Promotion of the campaign through local/national media
- Distribution of the leaflets in their headquarters
- Promotion on the occasion of celebrations of the X anniversary of the European Patients' Rights Day (18 April 2016).
- Information about the campaign has been spread to member organisations of the CISS (40 national patients and healthcare users associations, as well as their network of regional representation).
- These actions are further added to other national initiative they have arranged to inform the public about legal and practical dispositions on cross border healthcare.

Germany

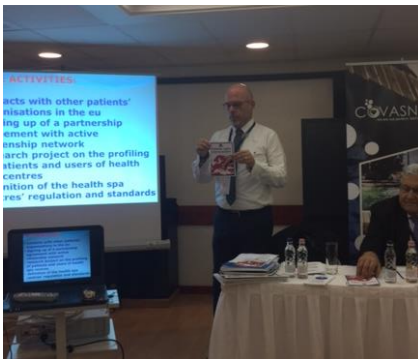
- Promotion of the campaign through local/national media

- Distribution of the leaflets in their headquarters
- Distribution of the leaflets to their partners in Germany and Austria with an excellence response

Hungary

- Promotion of the campaign through local/national media
- Distribution of the leaflets in their headquarters
- Dissemination of information through their social media accounts
- Letters with all the information (and asking for further sharing) sent into different mailing lists: HUFERDIS (45 member organizations), HAPO (Hungarian Alliance of Patient Organizations – 12 member org.), HPF (Hungarian Patients Forum - 110 member org.)
- The campaign was promoted to all the above mentioned organizations together with the distribution of the Hungarian leaflets and its downloading site
- Also the organizations started - or intend to do so - to spread them on their programmes, especially on their world days (e.g.: 1 October – Gaucher day; 12 October – COPD day; 13 October – World Sight day; 14 November – World Diabetes day; 25 February – World Rare Disease day; etc.)
- The campaign and its information have also been shared with all of the most important medical teams in Hungary and with the students of medical universities.
- They have printed some bigger posters (using the cover page of the leaflet) displayed on their office's windows and doors. They will also give some posters to their members.

- Presentation of the project on the next Rare Disease Day in February 2017
- Counsellors of their “Lifebelt” Information Centre and Helpline are also continuously spreading this info to enquirers
- Furthermore, [the European Association of Patients and Users of Thermal Centres](#) has promoted the project in Hungary on 17-19 November 2016



Italy

- [EU webinar](#) in Rome at Istituto Luigi Sturzo on 4 March 2016





- Promotion of the campaign through local/national media
- Distribution of the leaflets in the headquarters
- Presentation of the project during a local event in Rome on 9 November 2016



- Presentation of the project during local events in Naples on 29 November 2016, in Latina (December 2016), Val d'Aosta (December 2016) and Sicily (29th November and 22nd December)



Ireland

- Promotion of the campaign to local/national media
- Distribution of the leaflets in their headquarters

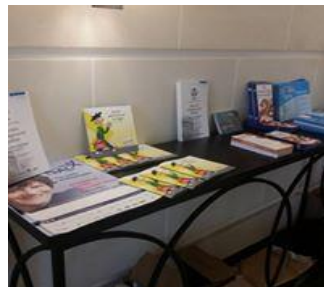
Lithuania

- Promotion of the campaign through local/national media
- Distribution of the leaflets in their headquarters

- Conference “Patient organizations’ and patients’ rights in Lithuania” on 27 April 2016 for patient organizations in Lithuania

Malta

- Promotion of the campaign through local/national media
- Distribution of the leaflets in their headquarters
- Two presentations to students of the Bioethics Masters Programme
- Presentation to Physiotherapists
- On the occasion of the launch of Pain tool kit in Maltese and Maltese Health Minister & Shadow Minister presentation of the project and leaflet made. During the pain workshops for patients and professionals they have given out copies of the leaflet and promote the project to them
- Slots on local TV and radio programmes



The Netherlands

- Promotion of the campaign through local/national media
- Distribution of the leaflets in their headquarters and within the province of Limburg (the south of the Netherlands)
- Drafting of a booklet with experiences of citizens about their rights, with a focus on cross border situations
- Activities planned for 18th of April 2017
- A national action planned for the first quarter of 2017 to spread the brochures in the whole of the Netherlands.
- Workshop in European Health Forum Bad Gastein about cross border health care
- Meetings with the National Institute of Healthcare to discuss cross border care

Poland

- Promotion of the campaign through local/national media
- Distribution of the leaflets in their headquarters
- Information about the campaign and related promotion on their website and social media.
- Two workshops for 40 Patient Advocacy Groups.
- At the end of November, they will be partner of conference for 30 Patient Advocacy Groups.
- Promotion of the project on 1st December 2016, during a conference on the occasion of World AIDS Day. The conference will be for over 400 people.
- In February they are going to organize a forum for more than 150 patient organizations.



Slovakia

- Promotion of the campaign through local/national media
- Distribution of the leaflets in their headquarters
- Press conference on 9 November 2016 on cross-border healthcare. Two information agencies, three TV stations and three newspapers attended and they will help spread our project activities.
- Open days in their hospital until the end of November
- Promotion on social media
- They organised another press conference about the Slovak situation in the framework of the cross-border healthcare Directive (December 2016)

Spain

- Promotion of the campaign through local/national media
- Distribution of the leaflets in their headquarters
- Promotion on social media
- They organised a conference on patients' rights and specifically about CBHC (December 2016)



C. SOME MAJOR ACHIEVEMENTS

- Active Citizenship Network has received the official endorsement of the DG-Santé «e-Health & Cross-Border Healthcare Unit», which has also invited Active Citizenship Network to the conference on cross-border healthcare Directive “Towards amplified awareness of EU rights to cross-border care” held on 24 October 2016. The event was addressed to relevant stakeholders only: Ministries representatives, National Contact Points, patient organisations, healthcare providers, insurers, policy makers, journalists, etc.
- Also, the MEPs Interest Group «European Patients’ Rights & Cross-Border Healthcare» has endorsed the project, and hosted the [launch event](#) of the campaign on 3 May 2016 at the European Parliament in Brussels.





- The campaign has grabbed the attention of other European and national organisations who have decided to support officially the project: 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.).



- 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 in the remaining EU countries in 2017 (such as Portugal, Croatia, Slovenia, Greece).



- Other applications from new organisations in the countries already involved in 2016 (Bulgaria, Cyprus) and proposals of campaigning also in 2017 from some official partners (Poland, Hungary).

D. CONCLUSIONS & PROPOSALS

The experiences as well as data and case histories collected so far have been crucial to identify the major challenges faced by patients in the framework of cross-border healthcare.

These include but are not limited to:

- need of appropriate information: the patient often suffers from incomplete or incorrect information when it comes to the possibility to seek healthcare abroad and he is not guided throughout the process. Another bigger issue concerns proper information about costs and procedures for reimbursements. Furthermore, the need of information applies also to medical practitioners and health insurers, who need to be well informed;
- low awareness of role and potential of national contact points: indeed, national institutions have not promoted their national contact points accordingly; as a result, they are still almost unknown;
- inadequate and insufficient protection of rights; this implies that protection centres should be strengthened;
- data collected show that the most relevant case histories in cross-border healthcare come mainly from patients affected by rare or oncological diseases;
- European and national institutions should foster 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”;

- organisations involved in the campaign report a significant number of case histories related to emergency care abroad, which have not been included in this document as they fall outside the scope of Directive;

Based on the outcomes of this initiative, Active Citizenship Network addresses the following proposals:

- ❖ implementation of the campaign also in the Member States that have not been involved in 2016;
- ❖ support to the activities of the partner organisations in 2017 as well, but trying to extend the geographical impact by increasing the number of associations per country involved;
- ❖ information gathered shall give a civic insight on cross-border healthcare to the European Institutions, starting from the EU Commission Cross-Border Healthcare & eHealth Unit, European Reference Networks Team and the MEPs Interest Group *“European patients’ rights & cross-border healthcare”* within the EU Parliament;
- ❖ after the dissemination of the campaign in all the Member State, as a second step, Active Citizenship Network plans - on one hand - to reinforce and address the campaign to specific patients, that is those suffering from rare diseases, who can benefit enormously from knowing well and firsthand the European Reference Networks. This implies also the involvement of organisations focused on rare or chronic diseases, ERNs, EU networks, such as EURORDIS;
- ❖ on the other hand, there is the idea to disseminate the campaign also in specific areas, such as the border areas. As

highlighted also by the EU Commission in his last publication¹, the border areas and regions show better cooperation, sometimes also because framework agreements formerly existed (this is the case, for example, of the French-Belgian border);

- ❖ identify also pharmacies as main stakeholders of cross-border healthcare, as they have a key role when it comes to understanding and recognising prescriptions made in other countries;
- ❖ if the EU Commission foresees an update of the conference held on 24 October 2016 *“Towards amplified awareness of EU rights to cross-border care”* at the end of 2017, Active Citizenship Network would be glad to be involved and help with its organisation.
- ❖ an integration of different European policies (which may end up being also a cost-effective and cost-efficient strategy):
 - introduction of rules on mediation, ODR/ADR. If we consider cross-border disputes and the rules on mediation/alternative dispute resolution promoted in several sectors by the European Commission, we feel that these issues should be introduced also in the framework of cross border healthcare.
 - integration of the principles of the Directive in the context of the EU mobility policy, considering the enormous work that is being done at European level on the issue of mobility and on the protection of passengers. The Directive can increase a new category of passengers,

¹ http://ec.europa.eu/health/cross_border_care/docs/hci_frep_en.pdf

which is that of citizens with their specific needs as patients and as users of transportation. Hence, to promote knowledge amongst citizens, it would be useful to integrate the principles of the cross-border Directive in the context of the EU mobility policy. On the other hand, the means of transportation should also adapt to the needs of mobility of those who travel not for business or pleasure, but for healthcare reasons (multiple languages, specific comfort facilities, prices, etc.).

- work for a better coordination of the EU agencies and structures (Solvit, Your Europe Advice, National Contact Points, Europe Direct, European Consumers' Centers-Network) which help and inform citizens, so that they can cooperate more, and more efficiently, keeping one another informed on their role and activities.
 - the experience of the ECC-Net in healthcare, as follows;
- ❖ starting from the experience of the European Consumer Centres Network (ECC-Net)², Active Citizenship Network proposes to integrate this ECC-Net, or to build a **European Patient Centres Network (EPC-Net)** in order to improve citizens' protection in the framework of cross-border issues with the direct involvement of patient organisations. Here are the following main added values provided by a European Patient Centres Network:
- It will be a reference point for patients seeking care abroad when they need advice or support before, during or after their stay in another country, as well as to give

² A network supported both by the European Commission and Member States with consumer organisations for the management of cross-border disputes in consumer policies.

specific information on the local healthcare system - with a focus on the implementation of patients' rights – to answer the questions citizens shall ask them.

- It will facilitate the exchange of information, data collection and best practices, monitoring – at the same time – citizens' problems and identifying common solutions on cross-border healthcare.
- It will strengthen the cooperation among other actors involved, such as National Contact Points and European Reference Networks;
- ❖ build a network of all the NCPs in order to have a proper dialogue with the stakeholders identified by the Directive - including patient associations - and arrange annual meetings with patient organisations at national level to assess the situation;
- ❖ develop guidelines, together with the European Commission and patient organizations, to better inform citizens, and support an information campaign, with the direct involvement of civic and patient organisations;
- ❖ keep monitoring the situation and collect data at European level, with the direct involvement of both civic and patients associations, to identify, in each Member State, evidences on inequalities in access to healthcare and how they affect patients as well as on good practices to share;
- ❖ provide professional trainings for National Contact Points and leaders of patient organisations to avoid, for example, confusion between the legislation under Regulation and the legislation under Directive for emergency care and planned treatments;



- ❖ foster and apply this experience of a network of patient associations located in several Member States to other contexts as well, such as, for instance, prevention from infections to contribute to the EU Health Programme on cross-border infections and health threats.



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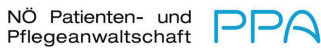
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Partners



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