

# EPF 2nd Regional Conference on the EU Directive on Cross-Border Healthcare

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## Conference Report

Athens, 7-9 April 2014

Participating countries: Cyprus, Greece, Italy and Malta



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## 1 Introduction

The impact of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare will depend to a large extent on the degree to which patients in Member States are empowered to understand the legislation and benefit from it.

In cooperation with its members, EPF undertook considerable advocacy work on the Directive prior to its adoption, and in July 2012 produced a toolkit on the Directive for patient organisations. As the Directive came into application on 25 October 2013, it is now particularly timely to organise dedicated regional conferences to 'raise the bar' in terms of knowledge and awareness among patient communities.

This conference was the second in a series of four EPF regional conferences for patient communities on cross-border healthcare.<sup>1</sup> It was aimed at patient leaders from the participating countries – Cyprus, Greece, Italy and Malta – who have the capacity to transfer learnings from the conference to peers within their organisations and networks. Participants commit themselves to active follow-up after the event.

The expected outcomes of the conference were:

- Clear identification of the roles of patient organisations in supporting patients' access to cross-border healthcare;
- An informal network of patient leaders in each Member State with a strong knowledge base and understanding of the legislation and with the capacity:
  - to discern the new rights for patients deriving from the Directive;
  - to interact with national governments and other stakeholders and contribute to the effective implementation of the Directive;
  - to explain to fellow patient leaders in their Member State facts how the Directive works in practice;
  - to support the effective dissemination of information to wider patient communities;
  - to be a potential resource to National Contact Points to ensure the information they produce is fit for purpose from a patient's perspective;
  - to participate in monitoring the implementation of the Directive and provide feedback to EPF and the European Commission.

The Conference lasted one and a half days and was conducted in English. It was structured around plenary sessions with interactive debate, as well as parallel working groups, followed by a closing plenary which presented the key conclusions and proposals on the way forward.

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<sup>1</sup> The first conference, involving representatives of patients' organisations from Belgium, France, Germany, Luxembourg and The Netherlands, took place in Brussels (Belgium) on 9-11 December 2013. The conference report is available at <http://www.eu-patient.eu/whatwedo/Policy/Patients-Mobility/>. The next Conference will be held in Ljubljana (Slovenia) on 7-9 July 2014, and the final conference in Tallinn (Estonia) in October/November 2014.

The level of detail contained in this report is intended to capture the priorities and nuances in the different perspectives expressed during the Conference.

## 2 Executive Summary

In his remarks to open the Conference, Greek Minister of Health Adonis Georgiadis emphasised that the ongoing efforts to improve patients' rights represent one of the most crucial issues in today's approach to healthcare in the European Union, as the cross-border healthcare Directive ("the Directive") opens up new prospects for cooperation in delivering treatment to patients across the EU.

However, the context – in Greece just as in other Member States – is a worsening of health inequalities due to the economic crisis, especially in terms of access.

The contributions during Session One demonstrated that although the Directive is in application, there remain significant gaps in implementation: the minimum standards which the Member States have set themselves for universal access to their healthcare systems are still not being met. The European Commission is monitoring the Member States, but it needs feedback from patients' organisations and other stakeholders on the ground, so that it has an idea of how well the Directive is being implemented at Member State level.

Clearly, much work still remains to be done, especially to inform patients of their rights under the Directive and to explain what is covered and how they might go about exercising their rights. Patients' organisations also have a crucial role to play in encouraging Member States to be more transparent and ambitious in order to move beyond the minimum set of patients' rights established under the Directive.

During Session Two, the critical role of the National Contact Point (NCP) in the effective implementation of the Directive was amply demonstrated by the contributions of the small breakout groups as well as the featured presentations. The key issue is not just the quantity of information provided, but also the quality and depth of the information and the methods for delivering it.

The prevailing sentiment was that the NCP must be the gateway to healthcare and not the "gatekeeper" blocking access. It should aim to be patient-centred and accessible, both culturally and linguistically – the human dimension was stressed repeatedly by all of the participants. The NCP must play a convening role for stakeholders, encourage the maximum degree of exchange and employ the broadest possible channels of communication. It should also be responsible for collecting data and monitoring trends on the use of cross-border healthcare. There is a role for patients' organisations in working constructively with NCPs to ensure that the information provided is up-to-date, accurate and of maximum use to patients.

Sessions Three and Four featured intense and detailed discussion about the practical process of obtaining cross-border treatment; improving quality of care and transparency relating to standards and guidelines for patient safety; and the contribution of European Reference Networks (ERNs) to improving the quality of diagnosis and treatment.

The discussion raised a number of key issues and specific recommendations, highlighting the opportunities of the Directive to create change, and at the same time shedding light on some of the flaws and core challenges contained in the Directive as it stands today. Although overall the participants tended to identify the same issues and challenges, these were often expressed in a nuanced way that reflected different national realities. A major and constant element in the views and ideas expressed was the need for NCPs to draw on the knowledge and expertise of patients and invite the participation of all stakeholders – including patients’ organisations as an equal partner – to ensure that patients receive the care that they need in a timely fashion without adding to their burden.

It is clear that national patients’ organisations will continue to play a key role in each Member State regarding further communication and cooperation with other stakeholders in promoting the implementation of the Directive and monitoring its impact, both positive and negative. National organisations will maintain contact with EPF and other leading patients’ organisations in the implementation of the Directive, specifically committing to be part of an informal network of patient leaders across Europe.

With this conference, EPF together with patient communities in the participating countries have taken the first steps towards stronger awareness of this landmark Directive and its implications for patients, as well as creating a network of patient leaders who are committed to disseminating information to their peers and working together with the National Contact Points in their Member States to support effective implementation. During the next two years, EPF and its members will monitor the impact of the legislation closely from a patients’ perspective and ensure that the grassroots patients’ experiences will inform the European Commission’s first progress report, due in October 2015.



### 3 Opening remarks by Adonis Georgiadis, Greek Minister of Health

“As Minister of Health I was determined to participate in this conference – even in a symbolic way by offering opening remarks – because the ongoing efforts to improve patients’ rights represent one of the most crucial issues in today’s approach to healthcare in the European Union.



The cross-border healthcare Directive opens up new prospects for cooperation in delivering treatment to patients across the EU. Greece, both as a Member State and as the current holder of the EU Presidency, is a firm believer in this new era, which places patients’ rights at the centre of European values.

What you are doing through this conference is very important. We have to make the patient the focus of discussions on cross-border healthcare, because ultimately everything we do is about the patient. We need to give patients the right information so that they understand the new healthcare environment within the EU.”

Responding to questions and comments from the floor, Mr Georgiadis agreed with the view that health inequalities are being heightened by the economic crisis. “This is especially true in Greece: a lot of people have lost at least part of their health insurance, so their access to the healthcare system is being limited to a significant degree.” However, Greece is working with the WHO on the issue of health inequalities, and the government expects to be able in June 2014 to present its proposals for ensuring healthcare access for all.

“The Gordian Knot we and other Member States are facing is that a growing ageing population is placing an increasing burden on healthcare systems at a time when financial resources are being cut back year on year throughout the European Union. Innovation in treatments will help towards a solution, but they are costly; the main solution in response to increasing demand for more treatments that are typically more expensive is to reform the existing systems in ways that will redirect the available resources and apply them more effectively.

For example, one of the main tasks in Greece is to increase the volume of generic drugs within spending on pharmaceuticals – we have one of the lowest levels of use of generic drugs in the EU. One key measure introduced recently is that the state only gives full reimbursement for pharmaceuticals when the generic drug is used; if someone opts for the branded drug, they pay the difference. We thought initially that this would encourage people to buy generic drugs, because they are much cheaper. But what we have seen in practice is that people seem to prefer to pay for their familiar branded drugs out of their own pocket, so the uptake of generic drug alternatives is only increasing slowly.



Clearly, we need to find more ways to explain the need to free up resources that could be applied to new treatments. This is a complex issue for all Health Ministers in the European Union, and especially for Greece due to the economic crisis.”

Some Member States have expressed concerns at the potential additional cost burden on their national healthcare systems as a result of the cross-border healthcare Directive. Mr Georgiadis said: “This issue was discussed over many years while the Directive was being prepared, and was addressed from many different perspectives. Now, all the governments know what they need to do, but some of them may need more time to prepare for the new environment. But ultimately they will do it, because it has been agreed and transposed into national legislation. All of us believe that the Directive will help our national healthcare systems become more competitive, which should be beneficial as they are encouraged to become better, faster.”

Quoting Demosthenes, who famously said that ‘You have to have money, Athenians, to do even what is necessary’, the Minister added: “It is not the troika that is forcing us to do things in Greece, it is reality that forces us. We simply do not have the money. This year’s health budget will be the lowest in recent history, but next year, as our country’s GDP grows, there will be more money. The issue today is to spend the available money more effectively than in the past, when there was a lot of waste and many people became rich operating in the health sector.

But no single country can do everything in their own country, so while it is true that more efficiency in national healthcare systems will reduce demand for cross-border treatment, the question is how we achieve this.”

## 4 Session One: The first Directive to focus on “Patients’ Rights” – what does this really mean for patients?

**Moderator Tamsin Rose** welcomed the opening remarks by the Greek Health Minister, who gave a notably honest insight into some of the challenges that Member States are facing in implementing the Directive.

It is well-known that before the Directive was passed, there was a lot of discussion on the potential impact on healthcare systems – in particular, there were concerns at Member State level that it might lead to a flood of patients moving across Europe, cherry-picking expensive treatments in different countries and then demanding reimbursement on their return home.

Now the Directive is in application and the Member States are supposed to be ready to implement it in all its aspects. Clearly, much work still remains to be done, especially to inform patients of their rights and to explain what is covered and how they might go about exercising their rights.

### 4.1 GREECE’S PERSPECTIVE

The perspective of the Greek authorities on the Directive was presented by **Christina Papanicolaou**, General Secretary of Public Health.

Despite its official title, the Directive has a much wider scope. It requires new processes and solutions at both national and European levels, which entail a reassessment of health strategies especially with regard to chronic and rare diseases. So although the main issues may appear technical, in fact they have profound policy implications and pose a range of policy choices.

Greece is still in the initial stages of addressing these choices in the new environment created by the Directive, but the most important areas of focus are already apparent.

*Interoperability* between different national systems is crucial to successful implementation of the Directive. This poses the challenge of agreeing on a common codification of rules and guidelines, and of creating shared registries. One example of good progress in this direction is the “patient summary”, which aims to ensure the harmonised transmission of patient data, including ePrescriptions, across Europe. The relevant law has already been passed in Greece, and there is optimism that the target of delivering the first patient summary in June 2014 will be met. This work is being done within the framework of the preparations for the next meeting of the European eHealth Network, to be held in Athens in May, which will aim to produce a series of recommendations for progress on this topic at the European level.

Another important area of focus is *innovation*. Patients, and sometimes patients’ organisations, tend to think that this only applies to pharmaceutical products. This is not the case. Innovation also means reform – the implementation of innovative methods and measures – at the structural level of





healthcare systems in order to ensure sustainability, especially in conditions of economic crisis. So innovation encompasses the restructuring of planning and organisation of care to deliver good public health in these challenging times.

Some steps forward have been taken at European level in this regard; for example, political and technical progress on integrated care and personalised medicine is allowing Member States to respond in a more human and effective way to the needs of patients.

Speaking as a medical doctor, Ms Papanicolaou said that economic constraints impose a range of difficulties especially at the point of delivery, which are often compounded by resistance to change. In answer to the question “what does the Directive mean for patients in Greece?”, she said: “We need to improve awareness of the issues among all stakeholders, especially health professionals, in order to be able to discuss the new policy and move quickly towards its implementation.”

Substantial progress has already been achieved in Greece, which is moving towards a national eHealth system that is much more than just ePrescriptions: it incorporates the codification of diseases, will soon to be interfaced with the “patient summary”, and will integrate registries. Continuing that process in the coming months will set a good example for other Member States.

## 4.2 THE EUROPEAN COMMISSION’S PERSPECTIVE

The European Commission’s perspective on the Directive was presented by **Annika Nowak** from the European Commission’s Directorate-General for Health and Consumers (DG SANCO).

Looking at whether the Member States have done their job in the first transposition phase of the Directive, the situation today is significantly better compared to the October 2013 deadline.<sup>2</sup>

At this stage, the headline messages regarding the Directive are:

- The patient’s right to choose to receive healthcare from a provider outside his/her country has been confirmed (codified in jurisprudence), increased and clearly explained – although the legal text may not be so easy to read. So now the challenge is: what does it mean in practice – how can Member States implement it in a way that is meaningful to patients, and how can the Commission help them do this?
- The lack of information to patients on health systems and treatments that might be available to them has constituted a barrier to access in the past. The Directive now obliges Member States to be much more transparent and to move towards a system where decisions are made for patients, but patients are also empowered to make their own decisions.
- The Directive establishes a minimum set of patients’ rights in the EU, but Member States may choose to exceed this minimum; this is where advocacy by patients’ organisations can push them to introduce more patients’ rights.

The basic principles governing cross-border healthcare are that patients have the right to reimbursement (under certain conditions) when they receive healthcare in another Member State; the level of reimbursement is up to the cost of treatment at home; and the legislation of the Member

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<sup>2</sup> See report from the first conference on cross-border healthcare, 9-11 December 2013, available at <http://www.eu-patient.eu/Events/Archived-Events/2013-Cross-Border-Healthcare-Conference/>

State of treatment applies in relation to quality and safety standards, with a requirement for transparency regarding those standards.

#### 4.2.1 PRIOR AUTHORISATION

Under the Directive, Member States can choose to exercise prior authorisation of treatment, and many of them are doing so. However, there are limitations: there has to be a clearly defined scope for what treatment requires prior authorisation, and patients must be clearly informed of this scope at the point when they are deciding whether or not to seek a specific treatment abroad.

Prior authorisation may be required for healthcare that involves (a) an overnight hospital stay, and/or (b) highly specialised and cost-intensive healthcare. Treatments in these categories must be clearly defined and must feature in a list that is freely available. A National Contact Point should be able immediately to tell a patient if their required treatment is on the list.

A request for authorisation may be refused under certain conditions; for example, if there is no “undue delay” in accessing treatment (no waiting-list or unreasonable wait in the home country). But any refusal must be properly reasoned – there must be an individual assessment of the patient’s situation, resulting in a specific/detailed rationale for the treatment timeframe, which is then communicated in a transparent manner to the patient and can therefore be challenged if necessary. This aspect is already defined clearly in jurisprudence.

During the political negotiations on the Directive, there was a call from the European Parliament to exempt rare disease patients from prior authorisation. This did not happen, but Member States are encouraged to put in place a specific procedure involving assessment by specialists rather than generalists, in order to ensure timely and proper diagnosis and treatment. This is not an obligation, however, and the European Commission is already receiving letters of complaint from individual citizens – so patients’ organisations have an important role in monitoring the response by Member States in individual cases.

#### 4.2.2 NATIONAL CONTACT POINTS TO PROVIDE INFORMATION TO PATIENTS

Information to patients is crucial to implementation, so there is an obligation for each Member State to set up a National Contact Point (NCP); most of them have done so. The NCPs are listed on a European Commission-maintained website<sup>3</sup>, so it would be useful for patients’ organisations review them and provide feedback.

NCPs must be able to inform patients who want to go abroad regarding their rights and entitlements, reimbursement and appeal processes, and to tell incoming patients what to expect – quality and safety standards, complaints and redress procedures. The issue is not just the quantity of information provided, but also the quality – there is a minimum requirement, but some Member States have gone much further, so it would be useful to examine how they are doing it.

NCPs have an obligation to consult with patients’ organisations, healthcare providers and healthcare insurers. The European Commission knows that only a few NCPs have done so. However, consultation

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<sup>3</sup> [http://europa.eu/youreurope/citizens/health/contact/index\\_en.htm](http://europa.eu/youreurope/citizens/health/contact/index_en.htm)

need not only apply to the act of setting up the NCPs, it can also be useful once operations begin. There is still a lot to do, so patients' organisations should request to be consulted because they are in the best position to judge what kind of information should be provided and in what form.

Healthcare providers also have obligations under the Directive. Very importantly, they must provide information on: treatment options; the quality and safety standards they apply; prices; authorisation status; insurance and liability cover. This aspect of increasing information not only benefits patients seeking treatment abroad; it also helps domestic patients to know more about their own health system and their rights within that system.

In 2013, the European Commission initiated an in-depth behavioural study on the NCPs, following a first mapping study commissioned in 2011. Phase I of the study used behavioural economics to pre-test some concepts and thus inform the development of NCPs. Phase II of the study is now underway, involving a survey of selected NCP websites that are already live. This feedback should help in the elaboration of NCPs across all Member States.

Finally, NCPs should form a network. There was a first meeting in Brussels in February 2014, involving representatives of NCPs – the people who are running them, not just Ministry of Health officials – from all Member States. This meeting was very encouraging, because the participants were very motivated and committed to collaborating more closely in various practical ways.

#### 4.2.3 PRICES AND REIMBURSEMENT TARIFFS

There are three main points: providers must apply the same scale of fees to incoming patients as for domestic patients; the reference point for setting reimbursement tariffs must be treatment in the home Member State by a contracted or public provider, depending on system; and there must be transparency on the “basket of benefits” and reimbursement tariffs.

#### 4.2.4 MINIMUM PATIENTS' RIGHTS

The Directive sets a minimum standard for patients' rights, and includes some new or enhanced rights: the right of appeal on authorisation and reimbursement decisions; the right to a transparent complaints procedure and to seek redress (all treatment providers must be covered by liability insurance or an equivalent guarantee); the right to a copy of one's medical record for all treatments (this may seem obvious, but is not the case in some Member States); and non-discrimination on the basis of nationality.

#### 4.2.5 WHAT IS NEW COMPARED TO THE SOCIAL SECURITY REGULATIONS?

Prior to the Directive, EU citizens already had the right to access healthcare in other Member States in some circumstances governed by the EU Regulations on the coordination of social security systems.<sup>4</sup> The Regulations, which have a different scope compared to the new Directive but still overlap to some degree, will continue to exist and benefit patients: if the conditions of the Regulations are fulfilled, then the Regulations should apply. Why? Because the level of reimbursement under the Regulations

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<sup>4</sup> For more information on this, please see the [EPF guidance document](#) (PDF).

is the actual cost of the treatment, so what the patient receives will not be limited by the domestic tariff for reimbursement set under the Directive.

However, there some important differences between the Regulations and the new Directive:

- The Regulations only cover public-sector or contracted providers, while the Directive covers all providers in the EU;
- Prior authorisation is the norm for planned care under the Regulations, but the exception (if used at all) under the Directive;
- The Regulations cover patient costs at the level of the Member State of treatment, the Directive at the level of Member State of affiliation (the “home” Member State);
- The Directive introduces significant “flanking” measures such as the transparency requirements and procedural guarantees.

#### 4.2.6 COOPERATION BETWEEN HEALTH SYSTEMS

There is a general obligation for Member States to cooperate on guidelines for quality and safety; European Reference Networks; Health Technology Assessment, and eHealth. The European Commission also encourages Member States to conclude bilateral agreements, in particular for border regions.

More specifically, there is an obligation for NCPs to cooperate on resolving any invoicing issues which patients may encounter (e.g. divergent requirements in terms of scope of information or level of detail). The issue of prescriptions is also important: the Directive states that Member States need to recognise prescriptions issued in another Member State, but often these are refused because of language problems or inconsistencies in the information provided. The European Commission together with the Member States has elaborated a cross-border prescription form containing a list of elements that should appear. Patients should ask for this cross-border prescription form when consulting a physician at home or abroad in order to avoid potential problems with continuity of care.

#### 4.2.7 THE NEXT STEPS

- The Commission’s check on transposition of the Directive by Member States is ongoing, involving a detailed assessment of all the measures taken by Member States (sometimes one law, sometimes 30 different provisions) in terms of completeness and compliance.
- The reflection process on the functioning of the NCPs has begun, with the next meeting scheduled for September 2014.
- The Commission requests feedback from patients’ organisations and other stakeholders in terms of what is happening “on the ground” and how individual cases are being handled, so that it has an idea of how well the Directive works for patients at Member State level.
- This monitoring feedback will be incorporated into the regular reporting by the Commission to the European Parliament and Council. The first progress report, with recommendations, is due to be published on 25 October 2015.

### 4.3 THE PATIENT'S PERSPECTIVE

The patient's perspective was given by **Kathi Apostolides**, Vice President of the European Cancer Patient Coalition (ECPC).

The Directive was received with great anticipation by patients, as it was designed to offer more clarification and enforcement of patients' rights in seeking treatment abroad. However, very few Member States were ready by 25 October 2013, the deadline for transposition of the Directive into national legislation.



How ready is Greece? There has been a lack of transparency during the transposition process, which was slow. There has also been a lack of reaching out to society to inform patients and citizens – for example, the publication of the new national law in the Government Gazette received no publicity, and the involvement of patients' organisations was not considered a priority at the time or subsequently. Also, a lot of attention has been given to legal, technical and financial issues relating to the transposition process, rather than considering the practical implications for patients.

It should be said that these criticisms apply equally to other Member States.

The Directive leaves too many issues open to the discretion of Member States, and there is a real fear that the current economic crisis in many European countries – in particular, the lack of investment in healthcare – will negatively impact the implementation of the principle of mobility as codified in the Directive.

Patients' organisations are crucial stakeholders for the successful implementation of the new law. What can patients' organisations do? They should:

- get informed about the content and the implications of the Directive, also in relation to the existing Regulations;
- start a dialogue on the Directive's content with their members and other patients' organisations, in order to get an accurate picture of how it affects patients with various diseases;
- request meetings with the NCPs to discuss how patients' organisations can be involved in the NCPs' operations, based on patients' actual experience of exercising their rights under the Directive;
- propose concrete measures of interest to patients.

The absence of the patients' voice is mostly due to a lack of information, not due to indifference from patients. As patients' organisations acquire more knowledge of how the Directive works in practice, they will become more involved in its successful implementation.

## 4.4 MAIN OUTCOMES

There is a growing awareness among patients' organisations of some of the challenges facing all countries as they move towards implementing the technical details of the Directive. They now have a clearer view of the intention behind the wording of the text from a legislative perspective, but also of where the gaps are, especially in terms of the need for reform: the minimum standards which the Member States have set themselves for universal access to their healthcare systems are still not being met.

The European Commission is monitoring the response of Member States during the transposition process, but it needs feedback from patients' organisations and other stakeholders in terms of what is happening on the ground, so that it has an idea of how well the Directive is being implemented at Member State level.

Patients' organisations also have a crucial role to play in encouraging Member States to be more transparent and ambitious in order to move beyond the minimum set of patients' rights.

## 5 Session Two: The crucial role of National Contact Points and creating a model that meets the needs of patients

At the start of this plenary session, participants broke out into six small groups to discuss the following questions: What would a model National Contact Point look like? What are the quality criteria and critical success factors? How should patients' organisations be involved in the effective evolution of National Contact Points in the participants' countries?

Conclusions regarding these questions were reported by each group in plenary session. The synthesised list of conclusions can be clustered as follows:

### 5.1 CLUSTERED OUTCOMES

#### FUNDAMENTAL PRINCIPLES

- The NCP should have a specific mandate and autonomy in relation to government.
- Its priority should be to protect and defend the patient, not the government's interests.
- Its prevailing culture should be one of providing a service to patients, rather than a typically bureaucratic attitude.
- It should respect human dignity, without discrimination, and ensure the patients' voice is heard.
- It should protect the right to health.<sup>5</sup>

#### VISIBILITY

- The NCP should take measures to achieve and maintain high visibility.

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<sup>5</sup> See for example WHO fact sheet N°323: <http://www.who.int/mediacentre/factsheets/fs323/en/>



## ACCESSIBILITY AND AVAILABILITY

- Different communication channels should be provided to take into account different demographic groups and accessibility concerns: website, social media, 24-hour telephone helpline, printed leaflets, traditional mass media.
- There should be a possibility to take direct contact via telephone, email, visit to a physical office (with disabled access) and helpdesk.
- Language should not be a barrier: the NCP should use simple terminology and provide information in foreign languages, including English and languages of minority/migrant groups.
- Cultural differences and perspectives should be reflected.

## QUALITY OF INFORMATION

- Clear, accurate, reliable and user-friendly information should be provided to guide the patient to the right solution.
- There should be a simplified, step-by-step guide to the application process.
- FAQs should be provided online and via printed leaflets.
- The website should link to relevant legislation, including the Directive.
- The NCP should identify and provide information on common “care packages” on the website.
- Information provided should cover:
  - patients’ rights
  - local legislation, EU legislation and all related information
  - healthcare services and procedures offered in the home country and other Member States
  - updates on regulations, procedures, waiting-lists, etc.
  - reimbursement policies and comparative costs, based on current and reliable economic data
  - registries of health professionals per specialisation, including existing collaborations
  - European Reference Networks and highly-specialised hospitals (or at least links to other NCPs which have that information)
  - contact details of other NCPs
  - sources of legal advice to patients when abroad
  - access to translation/interpreter services.

## OPERATION

- The NCP should adopt an efficient and transparent process, respecting the patient and resulting in a timely response with accurate, up-to-date information.
- There should be minimal bureaucracy and the operation should be flexible, responsive and reliable – it should inspire confidence.
- Enquiries should be dealt with by providing solutions – such as advice on various options – rather than just information.
- The NCP should support the patient in his/her contact with foreign bodies and legislation; the home NCP should pose questions to other NCPs, not the patient.
- Patient organisations, not just individual patients, should be able to make an enquiry to the NCP.

- There should be an active networking approach with all stakeholders:
  - Working relationship with patient organisations both at home and abroad for exchange of experiences and transfer of knowledge; patients' organisations can help provide solutions and facilitate direct contact with patients.
  - Direct contact between the NCP and the treatment providers abroad and at home, to facilitate follow-up and ensure continuity of care.
  - Network with other NCPs across Europe, beginning with the most popular host countries.

## QUALITY STANDARDS

- The NCP should adopt a high degree of professionalism and empathy; it should be able and willing to take time to listen to patients and offer solutions; it should have personnel trained in dealing with patients, but should also include (volunteer) expert patients.
- It should collaborate with the Health Ministry, health providers and insurers to provide consistent and up-to-date information on a “one-stop” basis – it should not simply refer patients to other government entities.
- It should have expert groups for offering guidance to patients and decision-making.
- It should be able to offer solutions to any issues arising from gaps in legislation.
- It should be able to give a clear explanation of decisions.
- It should have an efficient complaints management and feedback process.
- It should collect data, e.g. numbers of enquiries, timing of outcomes, proportion of acceptances/refusals, volumes and direction of traffic for specific cross-border treatments, and generate statistics for policy-makers.

## ACTION TO BE TAKEN AT EUROPEAN LEVEL

- Equal access to information across the EU, to remove barriers and reduce inequalities.
- Interoperability and information exchange among NCPs across the EU – existing databases, lists of medical centres, specialisations, NGOs, voluntary organisations; data protection must not be allowed to be a barrier.
- To be clarified which NCP should provide assistance to patients who are working or studying abroad.
- To be clarified who is responsible for contact when the patient is abroad for treatment: the “home” NCP, the “host” NCP, or the hospital.

## 5.2 PRESENTATION OF THE GREEK NATIONAL CONTACT POINT

The Greek NCP was presented by **Kalliopi Koumbi**, Head of the International Affairs Division of the National Organization for Healthcare Services Provision (EOPYY).

Work to implement the Directive began two years ago with the creation by the Health Ministry of working groups to design a framework for aligning Greek law with the Directive's provisions. The International Affairs Division of EOPYY was designated as the Greek NCP for cross-border healthcare last year, under the transposition law (Domestic Law 4213/2013). Participation in the first coordination meeting of NCPs in Brussels on 4 February 2014 provided an overview of the progress

being made by various NCPs and permitted a good exchange of knowledge and experiences among participants. It also provided the framework for the first benchmarking of the Greek NCP against core requirements of the Directive:

- clarifying patients' rights to planned healthcare in any Member State – beginning to identify specific contexts in which these rights would be examined;
- explaining the procedures to access cross-border healthcare, including the Greek criteria regarding prior authorization and reimbursement; and
- ensuring that the process is as clear and transparent as possible for citizens, through consultation of stakeholders, close cooperation with other NCPs, and mutual assistance in the supervision of service providers.

The Greek NCP has registered with the Internal Market Information (IMI) system to ensure compliance with the Directive's provision regarding exchange of information on health professionals' right to practise, which is listed in the national or local registers of the Member States.

The Greek NCP makes information available via:

- the Internet ([www.eopyy.gov.gr](http://www.eopyy.gov.gr)): as well as featuring basic information in Greek and English on patients' rights, the provisions of the Directive, contact details for other NCPs, etc., the website will be updated regularly to reflect the latest information obtained from various stakeholders (the European Commission, other NCPs, social insurance institutions, patients' organisations, healthcare providers, the national network of primary and secondary healthcare supported by the seven regional healthcare authorities, and the rare diseases network);
- telephone (providing information in Greek and English during office hours) and fax;
- e-mail ([ncp\\_gr@eopyy.gov.gr](mailto:ncp_gr@eopyy.gov.gr));
- standard application forms, which can be sent by mail to the EOPYY in Athens or any one of its regional healthcare divisions;
- personal consultation (prior appointment required); and
- an interactive front desk at the NCP GR Department situated in 12 Apostolou Pavlou Str, in Maroussi, Athens.

For people with disabilities, information is made available via:

- direct communication with the NCP by electronic means as described above;
- personal consultation (prior appointment required); and
- the use of freeware facilitating alternative ways of communication (options provided by the Speech and Accessibility Laboratory of Department of Informatics and Telecommunications of the University of Athens).

Ms Koumbi said the Greek NCP will "continue to work systematically and methodically, and we believe that within a short timeframe we will be adequately prepared so that information regarding cross-border healthcare will be widely known and easily accessible through our NCP. We express our willingness to co-operate with all patients' organisations, competent authorities, networks and everyone who could possibly contribute efficiently to our scope."

## 5.3 MAIN OUTCOMES

The critical role of the National Contact Point in the effective implementation of the cross-border healthcare Directive was amply demonstrated by the contributions of all participants in the small breakout groups as well as the featured presentations.

The prevailing sentiment was that the NCP must be the *gateway to healthcare* and not the gatekeeper blocking access. Rather than behaving like a government bureaucrat, a typical NCP staff member should have the skill-set and attitude to put the patient first, understanding his/her role as serving patients, professionals and policy-makers, and working with the patient.

As an entity, the NCP must play a convening role for stakeholders, encourage the maximum degree of exchange and employ the broadest possible channels of communication, thus guaranteeing the availability of the most up-to-date and accurate information to patients.

## 6 Session Three: Parallel Workshops – The Patient Journey in Cross-Border Healthcare

On the afternoon of the first day, participants split into three parallel workshops, each with 12 or so people. Each workshop group discussed the four major stages of the patient journey:

- **When deciding whether or not to seek cross-border healthcare:** Prior authorisation; rights under the Directive versus the Regulation; referrals/dialogue with health professionals; assessing medical need; what information patients need to make a decision.
- **Before leaving:** What practical arrangements patients need to think about before leaving.
- **When accessing care abroad:** What information patients need to know regarding the Member State of treatment and healthcare providers, e.g. quality and safety standards, administrative processes, prices and payment, etc.
- **When returning home:** Issues regarding reimbursement; complaints and redress mechanisms; continuity of care; cross-border prescriptions.

The outcomes were reported in the plenary session on the following morning.

## 7 Session Four: Feedback from the workshop rapporteurs from Session Three

Note: In response to requests from workshop participants, this written report of the report-back presentations was expanded to incorporate points that were excluded from the verbal report purely due to time constraints.

## WORKSHOP GROUP 1:

### KEY ISSUES

#### When deciding:

- Obtaining information about potential treatments can be time-consuming and complicated.
- If a specialist is involved, what is his/her competence, what kind of certification does s/he have, is the standard of certification in the host country the same as that in the home country, etc.?
- Quality of life – comparing measurable outcomes when trying out options.
- Estimating the total costs accurately.

#### Before leaving:

- Practical logistics regarding travel, accommodation, etc. including for accompanying person(s).
- Ensuring that medical notes will be conveyed to the healthcare provider in the host country.
- Ensuring the patient has all the necessary forms for completing the whole cross-border journey.
- Need for an accurate picture of the “real” (itemised) cost of treatment and the payment schedule.

#### During stay:

- Knowing what the treatment involves and how long will it last.
- Language issues.
- How is it going – in line with expectations or not? There may be a need to liaise with the home doctor during stay abroad.

#### After returning home:

- Ensuring proper follow-up and rehabilitation.
- Possible complications – need for a back-up plan to ensure continuity of care.
- Paperwork, including obtaining an accurate translation of medical notes.



## RECOMMENDATIONS

### When deciding:

- Accurate, reliable information about potential treatments should be provided by the NCP in collaboration with patients' organisations and professional bodies.
- Patients should check the certification of the healthcare provider or professional with the NCP.
- Need to promote health literacy so that a patient can decide on the appropriate treatment by considering the outcomes based on the scientific evidence-base.
- Address the issue of upfront costs to reduce burden on patients.

### Before leaving:

- A checklist for the whole process should be elaborated by NCPs.
- Information channels should be established by NCPs and supported by patient organisations and professional bodies.
- A detailed financial pathway should be established: timeline, additional costs, reimbursement rates.

### During stay:

- Information should be provided on the full treatment protocol and any special requirements in the host country.
- Language requirements should be addressed; voluntary organisations could help plug this linguistic gap, seeking out potential language resources.
- There should be open channels of communication between patients and healthcare professionals in both the home and host country.

### After returning home:

- Respective responsibilities, e.g. in the case of medical complications, should be clearly defined.
- NCPs should ensure that the administrative paperwork is interoperable so that patients can be easily reimbursed; this includes obtaining accurate translations of medical notes easily and cheaply.

## WORKSHOP GROUP 2:

### KEY ISSUES

#### When deciding:

- Financial implications: the cost at home vs. abroad; potential extra costs; payment practicalities – what, where and when; would the patient need to take large sums of money with them when travelling abroad, e.g. for down payments?
- Unequal access: costs of cross-border healthcare, out-of pocket and upfront, are still a barrier for many. How can access be improved?



- What are the treatment options? Patients should be aware of all available options, both at home and abroad, based on an accurate assessment of their illness and medical need including the “reasonable” time to wait for treatment, referrals and prior authorisation.
- Awareness of patients’ rights, both generally and under the Directive, and the difference between Directive and Regulation. Which is better?

#### Before leaving:

- “Linking up” your doctor at home with the treating doctor abroad.
- Knowing what information and documents to take with you.
- Knowing what rules apply for accompanying persons regarding for example accommodation and other costs.
- Knowing about the safety and quality standards of the care provided, as well as more general information such as the medical and accommodation facilities, language help, liability insurance in case of infection.
- Knowing that a medical record of the treatment abroad will be provided to the patient, at least in summary, including translation.

#### During stay:

- Language and communication issues arising at different points in process; cultural barriers.
- Possible discrimination against “foreigners”.
- Knowing who to turn to for support, e.g. queries, complaints, practical assistance.
- Unexpected difficulties while travelling.
- Issues with accommodation, e.g. unforeseen expense, also for accompanying person or family member.
- Complications leading to longer stay, complaints or concerns.

#### After returning home:

- Reimbursement issues: when it will be paid, procedures, possible delays.
- Obtaining an accurate translation of medical records.
- Continuity of care, including potential medical disagreements, divergent clinical guidelines, need to repeat treatment.
- Side-effects or complications that occur after returning home.
- Negative attitudes of “home” medical professionals.
- Complaints: procedures, compensation, etc.



## RECOMMENDATIONS

- National ministries/NCPs should set up a mechanism to define clearly the level of costs and payments resulting in clarity for the patient on who pays for what, when.
- There should be a resource with information on all existing and experimental treatments for a given condition, like [Orphanet](#).
- The NCP should ensure its information is accurate and validated when it is put online.
- Standardised templates should be defined at EU level for all types of forms: applications, requests for information, transportation of medicines or appliances through customs.
- NCPs and patient organisations should provide information on cross-border healthcare and how to benefit from it.
- NCPs and providers should have dedicated patient liaison persons providing support across borders and in cooperation with other NCPs/providers through a formal network.
- A directory of (main) hospitals with information about their medical and accommodation facilities should be prepared by national NCPs and shared between NCPs.
- Providers should give patients the summary medical record and follow-up instructions in English.
- In case of complications, the patient should be covered for the cost of extra stay – either by the home Member State’s health system or via liability insurance (in case of negligence by provider). Patients should be clearly informed of the options.
- NCPs should provide comprehensive information on follow-up on issues other than medical.
- NCPs should set up a feedback system to improve cross-border healthcare and the functioning of the NCP, including individual “exit interviews” with patients to check what went well and what problems were encountered.
- The EC should set a clear deadline for when patients must receive reimbursement.

## WORKSHOP GROUP 3:

### KEY ISSUES

#### When deciding:

- Assessing the urgency/justification of “undue delay” – for patients seeking cross-border healthcare is typically the last resort, especially if the required treatment is not available at home.
- Not having the right information on prior assessment and reimbursement entitlements.
- Mobility and access issues, including the location of the treatment.
- Need for reliable information on the quality of the healthcare provider.
- Lack of ability to pre-pay expenses.

#### Before leaving:

- Family/employment/financial considerations, also for the person accompanying the patient.
- Dialogue with doctors and possible culture or attitudinal barriers.

### During stay:

- Language barriers regarding communication with health professionals and authorities.
- Knowing what happens in the case of an emergency or need for additional consultations or treatments? What would be considered to be an extra cost?

### After returning home:

- Lengthy and complex reimbursement procedures.
- Varying reimbursement levels across the EU, which can exacerbate inequalities.
- Continuity of care and the need for comprehensive information regarding additional examinations, new treatments, side-effects, etc.
- Complaints and redress procedures.

## RECOMMENDATIONS

### When deciding:

- Patients should be able to explore all available treatment options in order to assess correctly the benefit of cross-border care.
- NCPs should work in parallel with a dedicated support unit within the target treatment facility.
- Financial support for prepayment could be provided via philanthropic charities or patients' organisations.

### Before leaving:

- There needs to be less red tape, simplified procedures and more dialogue between medical practitioners before the patient travels.
- Employment legislation should be non-discriminatory towards employees (and their support network) who might need to travel more than normally for healthcare reasons.

### During stay:

- Data should travel with the patient, medical information shared using eHealth tools, in order to for example avoid duplication of tests.
- There should be a voluntary registry of cross-border patients, useful especially in case of medical emergency.
- Patients' organisations in the host country should be involved in providing support.

### After returning home:

- Reimbursement should be timely with agreed time-limits and a "one-stop" process, consciously avoiding delays ascribable to "national specificities".
- There should be consensus or harmonisation across Member States regarding fair levels of reimbursement.
- Patient groups should lobby hard for implementation of prior notification (direct payment) to avoid reimbursement complications.
- There should be easy and accessible evaluation forms to record both satisfaction and complaints, which could be anonymised; EPF could provide feedback and support participation of patients' organisations in the process of obtaining cross-border treatment.

## 7.1 THE ROAD AHEAD – WHAT SHOULD BE DONE?

- Promote **e-health interoperability** to improve doctor-doctor access to updated patient medical records and thus continuity of care.
- A **patient ombudsperson per country** (enhancing patient advocacy) and a **dedicated focal point for quality and safety** (link between patients, hospitals and healthcare systems).
- Collect hard evidence on cases of **widening inequalities** and influence the European Commission's evaluation report in a compelling way.
- **Involvement of medical/scientific bodies** with patients' organisations for a more successful implementation of the Directive.
- Patients' organisations appoint **former patients as volunteers** to be a contact point for incoming patients (human side of treatment abroad).

## 7.2 QUALITY OF CARE AND PATIENT SAFETY – CORNERSTONES OF THE LEGISLATION

**Kaisa Immonen-Charalambous** of the European Patients' Forum (EPF) focused on two crucial aspects of the Directive.

The main legal provisions regarding quality and safety of healthcare, designed to enable the patient to make a fully-informed choice about accessing cross-border healthcare, are to be found in two Articles of the Directive:

Article 4 states that Member States should provide cross-border healthcare according to the fundamental principles of universality, access to good quality care, equity and solidarity; and they should apply the principle of non-discrimination. Member States should have in place and apply clear quality and safety standards for healthcare providers, and this information must be made available to patients. Healthcare providers should give patients the information they need in order to make an informed choice.

Article 10 looks beyond the individual patient's experience to the scope for improving quality and safety standards overall across the European Union: Member States should cooperate particularly concerning standards and guidelines for quality and safety of healthcare, and the exchange of information between the National Contact Points; they must provide information to other Member States regarding a specific professional's right to practise.

While this last point does not explicitly state that the information must be shared with patients, it is reasonable for patients to be able to check with their NCP regarding the status and qualifications of a specific healthcare provider.



## SO HOW DOES A PATIENT BEGIN TO GATHER THIS INFORMATION?

In theory, all Member States should at least have an NCP website, and a European Commission webpage links to all of these national websites. However, a spot-check carried out the day before the Conference to seek out national legislation on quality and safety via the NCP websites revealed that there are still significant gaps.

## HOW DOES THE PATIENT FIND THE INFORMATION S/HE NEEDS?

It is difficult enough for a patient to find the relevant information on the national safety and quality standards; it is even harder to find these standards in another Member State. Then, assuming they are found, it is very difficult to compare the different standards and make any kind of meaningful judgement. The language these documents use can be convoluted and legalistic. So, it is simply not enough for national authorities to put their legislation online – they have to ensure that the legislation is explained in a lay-friendly language and format, which patients can understand and use.

Clearly, much work remains to be done to ensure that the relevant information is both available and patient-friendly.

## CONTINUITY OF CARE

Continuity of care is one area where quality and safety are particularly important. The Directive states that if medical follow-up proves necessary after return home, the home country must provide the same follow-up as for treatment received at home; and that patients are entitled to a copy of their medical record. But there are practical hurdles: medical guidelines and protocols vary from Member State to Member State, quite apart from the uneven availability of follow-up treatments in terms of availability and reimbursement. Who is to provide an accurate translation of a patient's medical record? The Directive is very vague in these respects – it sets out a basic right without indicating how this right can be achieved. Patients need to be vigilant, and their feedback to NCPs and national competent authorities regarding what happens in practice – with all the gaps and mismatches – will be key to improving the implementation of the Directive.

## WHAT IF SOMETHING GOES WRONG DURING THE STAY ABROAD?

Every Member State must have a complaints procedure and mechanisms in place for patients to seek remedies if they suffer harm. The Directive also says that patients must have transparent information regarding the legal and administrative options for settling disputes. But these are subject to national laws, so potentially we will have 28 different regimes in place.

One important detail is contained in Recital 23, which says that Member States can choose to simply extend their domestic system to apply also to cross-border healthcare. This would offer a clear solution to patients, since they would know that they could refer to a single complaints and remedies process for both domestic and cross-border healthcare. So it is important for patients seeking cross-border healthcare to check with the NCP whether a particular Member State has opted for this approach.

## WHAT SHOULD MEMBER STATES DO?

- They should refer to existing EU instruments, in particular the Council Recommendation (2009) on patient safety, which includes a section on information and empowerment of patients and citizens, and involvement of patients' organisations in national policies.
- They should co-operate fully with each other and involve patients' organisations and health professionals in the development and implementation of standards and guidelines.
- They should commit fully to sharing experiences, good practices, quality assurance systems, etc., through for example the European Commission's [Working Group on patient safety and quality of care](#) and the current Joint Action on safety and quality ([JA-PASQ](#)).

## WHAT CAN PATIENTS' ORGANISATIONS DO?

- They can channel direct patient experiences to point out weaknesses and system failures – a valuable source of information for better policy.
- They can raise awareness and help patients find the right information.
- They should approach NCPs and insist to be involved as regular partners in providing information. This would require giving appropriate support and compensation for their expert input.
- They should feed their experiences of cross-border healthcare, of working with NCPs and with national Health Ministries back to EPF and the European Commission in preparation for the 2015 progress report.

## WHAT SHOULD BE DONE AT EU LEVEL?

- Information on quality of care and patient safety needs to be made comparable across countries.
- The Commission should consider developing guidelines for information to patients.
- Information should be in an easy-to-find place – the possibility to set up a “one-stop shop” for quality and safety information at EU level should be considered.

Over recent years there has been significant progress and more recognition that quality of care, including patient safety, is actually an issue that needs to be addressed at European level. It may be that in future Member States can agree on some “key indicators” for quality of healthcare, allowing them to identify and share best practices for the benefit of patients and raise the quality of care in national health systems. But, in this context, it is very important to establish what are the quality elements that matter to patients, and what patients understand to be good quality care. Currently, this is far from clear at the European level, and the patient community must ensure that the indicators that are chosen will measure the things that matter for patients.



### 7.3 EUROPEAN REFERENCE NETWORKS

**Marianna Lambrou** of the Greek Alliance for Rare Diseases (PESPA) focused on the role of European Reference Networks in delivering cross-border healthcare.

Rare diseases affect a small percentage of the population – in Europe, a disease is considered rare if fewer than 5 in 10,000 people are affected by it. Most rare diseases are genetic and appear in childhood. There are more than 7,000 of them in the Orphanet database, and new ones are being discovered every day.

PESPA has already been working in collaboration with the Athens Medical Society to promote better Continuous Medical Education for doctors in the field of rare diseases. It now hopes to contribute towards the creation and evolution of national Centres of Expertise and participate in connecting them with Centres of Expertise of other countries within European Reference Networks (ERNs).



The goal of an ERN is to improve the quality of care of a single rare disease – or a group of diseases with similar healthcare needs – by sharing knowledge and expertise of various Centres of Expertise and thus complementing and supporting the existing services of a particular Member State.

This approach promotes the sharing and moving of expertise instead of forcing patients to travel to another country, but it also allows patients to travel to Centres of Expertise in other Member States when necessary. Patients in every European country can benefit from an ERN, although not all countries have Centres of Expertise that belong to an ERN.

Under the Directive, ERNs need to set themselves at least three of the following objectives:

1. to help European cooperation regarding specialised healthcare for patients and healthcare systems, by taking advantage of innovations in science and health technologies;
2. to contribute to the collection of knowledge regarding sickness prevention,
3. to improve diagnosis and the delivery of high-quality and low-cost healthcare for all patients with a rare disease;
4. to maximise the use of resources by bringing them together when necessary;
5. to promote research and provide training for health professionals;
6. to assist in the movement of expertise and to share information, knowledge and best practices, and to help in the diagnosis and treatment of rare diseases, within and outside the networks;
7. to develop the quality and safety criteria and to help spread best practices within and outside the network;
8. to help countries with an insufficient number of patients with a rare disease, or without the needed technology or expertise (like Greece), to provide high quality services.

According to EURORDIS' Declaration of 2008, the over-arching aim of Centres of Expertise is to provide multi-disciplinary and patient-centred care. They do so, among other things, by actively involving

patient representatives in the establishment, functioning, management and evaluation of the centre. Centres of Expertise and ERNs will try to share information with other stakeholders, and will provide training and guidelines to healthcare professionals, patients and their representatives. They have to work together to organise clinical research, including clinical trials, registries, biobanks, innovative techniques and more.

Although clear guidelines for Centres of Expertise have existed since December 2012<sup>6</sup>, Greece has no Centres of Expertise that match the standards set by the European Union Committee of Experts on Rare Diseases (EUCERD). Centres for various rare diseases fall short of official standards; the only centres for example that can enable the transition of child patients to adult care are Cystic Fibrosis and Thalassaemia. The main issues are related to education, research, sharing of information and collaboration with patients' organisations.

This last issue is of great importance, since Centres of Expertise and patients' organisations share common objectives in delivering high quality care. Collaboration to develop partnerships based on complementary skills is very effective; patients' representatives have been very important in creating National Plans for Rare Diseases, as PESPA did for the Greek National Plan; and through PESPA's efforts, the Greek rare diseases expert Dr Christos Bartsocas participates in EUCERD.

The basic principles of collaboration between patients' representatives and Centres of Expertise that are part of an ERN are:

- Participation in the governance of the network;
- Offering personal experience;
- Sharing information regarding actions taken by other patient organisations and society;
- Evaluation of the network and the individual Centres of Expertise that are part of it;
- Participation in training, research, clinical trials, pharmacovigilance, sharing of information about biobanks, standards of care and diagnosis, social guidelines and helplines.

Ms Lambrou concluded: "All European stakeholders are convinced that patients' organisations can help effectively in different aspects of Centres of Expertise, with their extensive knowledge on rare diseases from personal experience. It is time for us in Greece to finally understand and realise that we must have the same opinion about the patients' and patients' organisations experience, and how important it is to improve the situation in our country."

## 7.4 MAIN OUTCOMES:

The discussions highlighted some of the flaws and challenges in the Directive as it stands today. Although overall the participants tended to identify the same issues and challenges, these were often expressed in a nuanced way that reflected different national realities. A constant element in the views expressed was the need for NCPs to draw on the expertise of patients and invite the participation of all stakeholders – including patients' organisations as an equal partner – to ensure that patients receive the care that they need in a timely fashion without adding to their burden.

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<sup>6</sup> EUROPLAN 2 conference organised by PESPA, see [www.europlanproject.eu/\\_europlanproject/index.html](http://www.europlanproject.eu/_europlanproject/index.html)

## 8 Session Five: Exploring the role of patients' organisations in securing effective implementation of the Directive – the case of Malta

**Gertrude Abela Parnis** of Europa Donna Malta and **Ann Marie Borg** of the Malta Health Network (MHN) highlighted the role of patient advocacy in achieving progress (pictured).

A useful starting-point when considering the role of patients' organisations in securing effective implementation of the Directive is to look at some of the mixed messages and distortions that were presented by mainstream media channels at the Directive's inception in 2008: newspaper headlines declared that this was an easy way to get free healthcare, or conversely warned their readers to "proceed with caution" down a threatening path.

So one of the initial challenges for patients' organisations was – and to some extent still is – to clarify and dispel some of these misconceptions and to focus the discussion more on the intended outcomes. By 2011 in Malta, the press were focusing more on the Directive as a way of solving the problem of long waiting-lists for particular treatments.

Another challenging element is the fact that a Directive is a form of EU law that sets the goals to be achieved but gives Member States discretion to choose the means. As we have already seen, this may give rise to difficulties in transposition and implementation – difficulties that patients' organisations can help to overcome.



The Malta Health Network (MHN) got involved in the pre-implementation phase of the Directive in 2011, and continued its efforts as the implementation phase began. MHN organised a seminar on patients' rights and involvement in cross-border healthcare in June 2013, which was attended by Malta's Health Minister and the Health Commissioner, and in October last year attended a briefing on the status of the Directive's implementation with Active Citizenship Network and DG SANCO.

Ms Borg said: "At that October 2013 meeting, we had first sight of the Commission's information leaflet translated into Maltese. It is unfortunate that patients' organisations were not consulted prior to the leaflet's production, as they would have flagged up the bad translation and hence the danger of information being distorted during transmission. Also, the Maltese Health Ministry produced its own leaflet, again without consulting patients' organisations."

On the other hand, MHN was more involved in the Malta EU Steering & Action Committee (MEUSAC), which through MHN's efforts organised a citizen dialogue on the Directive in October 2013.

One example of the benefit of correctly identifying patients' needs was provided by a 2013 Eurobarometer report<sup>7</sup>, which showed that 68% of Maltese citizens would like to receive more information about their rights as EU citizens. Out of these respondents, 32% consider receiving medical assistance in another EU country as the most important right on which they would like to be more informed on.

This is perhaps an indication of the way forward, with patients using the Directive to exercise their rights as EU citizens – but how? Malta has a well-established and long-standing cross-border healthcare set-up for specialised and oncology care through bilateral agreements with the UK, so the question that patients' organisations must seek to answer convincingly is: "What does the Directive add?"

Answering this question involves moving from theory to practice. The Directive states that patients are entitled to all information relevant for making informed decisions on their health and cross-border healthcare options, but patients' organisations were not consulted or involved much in the process of setting up the Maltese NCP website, which as a consequence is difficult to access and is not user-friendly.

The experiences of Europa Donna Malta serve to highlight another area where patients' organisations can usefully contribute: breast cancer is the most prevalent cancer type in Malta with approx. 300 cases a year, and breast reconstruction may take years due to long waiting-lists in comparison with the available infrastructure. Can this be regarded as "undue delay" under the Directive? The waiting time does not pose a health hazard, but it certainly has psychological implications.

Another example is, if there is a better-quality and less invasive breast cancer treatment available abroad, with a similar intervention covered by Malta's healthcare "basket", will the patient be reimbursed if she gets treated abroad? There is a lack of clarity of information from the Ministry level to patients' organisations; hence, patients' organisations have difficulty in transferring information to end-receivers – the patient communities.

The Directive offers opportunities, such as faster treatment access for patients experiencing long waiting times; increased transparency of providers and pricing of medical procedures; Member States being urged to upgrade and improve national performance, leading to better quality of care for the patient. However, it also poses challenges; paying for treatment costs upfront; determining what is "undue delay"; affluent patients benefitting the most as they search for the best treatment with the latest technologies, hence amplifying existing health inequalities. It can therefore be seen both as *enabling patients* to exercise their rights and *worsening existing health inequalities*.

According to the speakers, the role of patients' organisations in the implementation of the Directive can cover three main aspects:

- *Capacity-building*: Under the proposed MHN Action Plan, each MHN member organisation appoints one representative as the "contact point" for cross-border healthcare who will represent that organisation in a MHN sub-committee on cross-border healthcare. One representative from MHN will then represent Malta in an (EPF) informal network on cross-border healthcare composed of patient leaders from all Member States and wider European

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<sup>7</sup> Standard Eurobarometer 80 / Autumn 2013, Public Opinion in the European Union: National Report – Malta.

health NGOs. The informal network will facilitate the exchange of good practice, lessons learnt, monitor and evaluate implementation, and perhaps report to the Commission.

- *Collaboration with national health authorities:* patient organisations can work closely with the local NCP and health authorities; collaborate with health authorities to ensure that information given to patients is consistent, conveying the right message, readily available and widely disseminated; and encourage authorities to be more politically committed to patients' rights on cross-border healthcare.
- *EU projects/funding:* The 2014-2020 Health Programme gives considerable weight to health systems and can provide funding for initiatives on cooperation in eHealth, patient safety and ERNs, and grants for evaluation studies on patients' rights and the Directive's implementation.

Clarifying and communicating “new” patients' rights to patients may well be a path to patient empowerment. Ms Borg concluded that, just as patients' organisations need to be proactive in ensuring effective and beneficial implementation of the Directive, so do individual patients need to exercise their rights to cross-border healthcare in a positive and confident manner: “If you believe that you can make a difference, then you will bring out the positive aspects and benefits of the Directive for patients, recognising the barriers that hinder the effective implementation of the Directive and finding solutions to overcome them.”

## 9 Closing session: take-home messages and closing remarks

In the closing plenary session, moderator **Nicola Bedlington** invited representatives from the various participating countries in turn to tell the Conference what message they would be taking away and what actions they would take on returning home. Below, we present the main take-home messages :

### CYPRUS

“Before we came here we did not even know each other. Now we have met and discussed, and we know that we can move together in the same direction and achieve things for patients in Cyprus. We have already exchanged our contact details and have agreed to start by working together on the National Contact Point, since this is crucial for effective implementation.”

“We have a lot of work to do in terms of basic information to patients about their rights under the Directive. Very little is known about these at the moment, so we need to put more pressure on the government to rectify this.”

“Our biggest concerns are to do with the peculiarities of the health system in Cyprus. We have two sub-systems, private and public, high out-of-pocket expenditure, and a range of bureaucratic restrictions. We want a uniform system across Europe, transparency, and we do not want to create any disparities for poor people. With all of this mind, we have asked to have a patient representative in the NCP. So far we have been formally included in the committee that will consider complaints and refusal of prior authorisation. We really need to organise another, bigger, event similar to this one in Cyprus, to discuss some of the points raised at this Conference and maybe come up with new ideas on how to move things forward.”

### ITALY

“This was a great opportunity to network and share a lot of ideas – in fact, we learned that we actually have an NCP! Now our next steps are to understand how it works and work together to improve it. It is also clear that we have to share feedback at the European level – nobody is quite sure how exactly things are supposed to work, which means that we must share best practices between us. Perhaps we should meet again in 6 months’ time to see where we are.”



“We have to deal with a lot of peculiarities – of disease, of different health systems – so in order to work together effectively we have to find the commonalities, to decide to face up to our common problems. We need to focus on finding the solutions.”

## GREECE

“I was impressed by the fact that each workshop identified the same key issues and recommendations for improving the Directive. But one aspect that struck me when I first read the Directive it is that people in poorer countries will not be able to afford to access cross-border healthcare in richer countries; this means that in practice it will enable the countries of northern Europe to have access to healthcare in southern Europe. Therefore, since the principle of non-discrimination and equal access is at the heart of the European Union, I think one of our major tasks is to raise this issue of disparate national tariffs with the relevant institutional stakeholders.”

“I am very grateful for this opportunity for cooperation, and I hope we will go forwards, not backwards – because if we only believe what the politicians tell us, we will only go backwards.”

## 9.1 CLOSING REMARKS

Giving the closing remarks, **Philip M Chircop** of the Malta Blood Donors Association recalled the journey the participants made over the last two days, and reflected on the next steps.

He also shared some information about two initiatives of EPF that relate strongly to the scope of the Conference, because they are about empowerment and capacity-building for patient leaders: the European Patient Academy on Therapeutic Innovation ([EUPATI](#)) Certificate level distance learning course that will start in September, and the [EPF Manifesto](#) for the European Parliament elections on 22-25 May 2014.



One of the important take-away messages relates to the strength of the patients' movements in the participating countries, as evidenced by their work in the Conference. However, it was highlighted by several people that countries which have a national coalition of patient groups working together in unity are much stronger than those that do not. A great

deal of work is going on in Greece to create an appropriate structure, and EPF will continue to support those efforts in any way it can.

Looking specifically at the Athens Conference, Mr Chircop asked: “Where do we go from here?”

He said that national patients’ organisations will continue to play a key role in each of our countries regarding further communication and cooperation with other stakeholders in promoting the implementation of the Directive and monitoring its impact, both positive and negative.

National organisations will maintain contact with EPF and other leading patients’ organisations in the implementation of the Directive, specifically committing to be part of an informal network of patient leaders across Europe.

The Commission’s implementation report in 2015 will provide a crucial opportunity to review the Directive and propose improvements. As an important first step, national organisations should adopt a proactive approach towards NCPs and Health Ministries, informing them about this Conference, and should express their willingness to cooperate with other stakeholders in creating optimal information to both patients and citizens.

With this conference, EPF together with patient communities in the participating countries have taken the first steps towards stronger awareness of the Directive and its implications for patients, as well as creating a network of patient leaders who are committed to disseminating information to their peers and working together with the National Contact Points in their Member States to support effective implementation.

During the next two years, EPF and its members will monitor the impact of the legislation closely from a patients’ perspective and ensure that the grassroots patients’ experiences will inform the European Commission’s progress report in October 2015.



## 10 Annex 1 – Conference programme

### Day One – 7 April 2014

19.30 **Welcome Reception and Buffet**  
Quiz on cross-border healthcare

### Day Two – 8 April 2014

8.00-9.00 **Registrations**

9.00-10.30 **Opening statement** from the Minister of Health of Greece, Adonis Georgiadis  
Moderator: Tamsin Rose

**The first Directive focussing on ‘Patient Rights’ – what does this really mean for patients?**

Greek perspective: Cristina Papanicolaou, General Secretary of Public Health

EC perspective: Annika Nowak, DG SANCO European Commission

Patient Perspective: Kathi Apostolidis, European Cancer Patient Coalition (ECPC)

**Followed by plenary debate**

*Objectives:*

- *To provide a clear overview of the scope of the Directive and its application*
- *To highlight its strengths and potential barriers, new rights compared to existing rights.*

10.30-11.00 **Coffee Break**

11.00-12.30 **The crucial role of National Contact Points (NCP) and creating a framework model that meets the needs of Patients**

Moderator: Tamsin Rose

**Working groups** – What would a “model” National Contact Point look like?

**Plenary debate** – What are the critical success factors? How should patients’ organisations be involved in the effective evolution of National Contact Points in the five participating countries?

**Presentation of the National Contact Point of Greece**

Kalliopi Koumbi, Head of International Affairs, National Organization for Healthcare Services Provision (EOPYY)

12.30-13.30 **Networking lunch**

13.30-14.45 **Workshops: Patient Journey in Cross-Border Healthcare**

Moderators: Tamsin Rose, Kaisa Immonen-Charalambous (EPF), Nicola Bedlington (EPF)

*Objectives:*

- *to address specific aspects of the Directive and identify those aspects that are relevant at different stages and specific information needs of patients*
- *to identify critical issues from a patient’s point of view and develop recommendations for Member States and patients’ organisations to address them.*

14.45-15.15 **Coffee Break**

15.15-16.30 **Continuation of workshops: The Patient Journey in Cross-Border Healthcare**

16.30-17.00 **Meeting room available for the rapporteurs to work on the feedback of the working groups to the plenary on Day 2**

19.30 Conference dinner

### Day Three – 9 April

9.00-9.50 **Feedback from rapporteurs on the core questions, discussions and recommendations from the workshops**

Moderator: Nicola Bedlington (EPF)

*Objectives:*

- *To reinforce information gleaned on the thematic topics and the issues raised*
- *To enable the participants to obtain a clear overview on the outcomes of the workshop in which they were not involved*

9.50-10.40 **Quality of Care and Patient Safety – Cornerstones of the legislation**

Kaisa Immonen-Charalambous (EPF)

**European Reference Networks**

Marianna Lambrou, Greek Alliance for Rare Diseases

*Objectives :*

- *to ensure full understanding of the provisions that focus on quality of care, transparency of safety and quality standards, and the impact of this for the patient seeking treatment abroad as well as the wider policy context*
- *to discuss European Reference Networks and their contribution to improving the quality of diagnosis and treatment.*

10.40-11.10 **Coffee Break**

11.10-12.15 **Exploring the role of patients' organisations in securing effective implementation of the Directive**

Moderator: Nicola Bedlington (EPF)

Speakers: Gertrude Abela Parnis, Europa Donna Malta and Ann Marie Borg, Malta Health Network (MHN)

*Objectives:*

- *to outline possible actions based on previous experience*
- *to develop a plan of action in terms of cascading knowledge from the conference*
- *to support and to ensure the commitment of the participants to be part of an informal network for evaluation.*

12.15-12.30 **Take home messages and closing remarks**

Nicola Bedlington (EPF), Philip Chircop (MHN) and the participants

12.30-14.00 **Farewell networking lunch**

## 11 Annex 2 – Participation list

First Name	Last Name	Organisation
Gertrude	Abela Parnis	Europa Donna Malta
Stelios	Agapitos	Prometheus - Hellenic Liver Patient Association
Ioanna	Alissandratou	Hellenic Pulmonary Hypertension
Yiannakis	Antoniades	PANCYPRIAN ASSOCIATION FOR ULCERATIVE COLITIS AND CROHN'S DISEASE
Kathi	Apostolidis	ECPC-European Cancer Patient Coalition
Caroline	Attard	Caritas Malta Epilepsy Association
Aikaterini	Argyri Stara	THE ARTHRITIS FOUNDATION OF CRETE
Persephone	Augoustides-Savvopoulou	Krikos Zois Society for patients and friends of patients with inherited metabolic diseases
Sofia	Barera-Galanopoulou	Greek Coeliac Society
Ann Marie	Borg	Malta Health Network
Joseph	Borg	MOUNT CARMEL HOSPITAL SOCIETY, MALTA
Maria-Louisa	Busuttil	Malta Association of Physiotherapists
Paul	Calleja	Transplant Support Group Malta
Tracey	Calleja	Richmond Foundation Malta
Martha	Carabott	Malta Health Network
Efstratios	Chatzicharalampous	HELLENIC RETINA SOCIETY
Philip M	Chircop	Malta Blood Donors Association
Stella	Eleftheriadou	The Association of Parents and Friends of Children with Heart Disease
Peter Anthony	Fenech	HEALTH, PENSIONERS AND HEALTHY AGING
Adonis	Georgiadis	Hellenic Ministry of Health
Vassilis	Georgakopoulos	Hellenic Minister of Health
Christina	Georgiadou	ADHD HELLAS



Anna	Guerrini	The Mad Hatter
Vassilis	Kafiris	Patients in Power conference
Dimitra	Kalogianni	Greek MS society
Chrisanthi	Kantziou	Hellenic Ministry of Health
Spyridon	Katsoulas	HPH
Salvatore	Leone	AMICI Onlus
Souzi	Makri	ENFA - Lupus Cyprus League Against Rheumatism
Stavros	Michael	CYPRUS DIABETIC ASSOCIATION
Evi	Papadopoulos	Europa Donna Cyprus
Paola	Papaphilippou	Cyprus Coeliac Association
Teresa	Perrone	APMAR ONLUS
Nicolas	Philippou	The Cyprus Association of Cancer Patients and Friends (PASYKAF)
Irene	Pitsillidou	CYPLAR - CYPRUS LEAGUE AGAINST RHEUMATISM
Jane	Pittadaki	GREEK HAEMOPHILIA SOCIETY
Angeliki	Preftitsi	ASSOCIATION FOR CYSTIC FIBROSIS
Erveda	Sansi	ENUSP
Polycarpos	Stavrou	IDF-Europe
Dimitris	Synodinos	Greek Alliance for Rare Diseases
Eleftherios	Tampouridis	NGCCA (Northern Greece Crohn & Colitis Association)
Vassilis	Tsiaras	Hellenic Federation of Persons with Multiple Sclerosis
Marija	Vella	Arthritis and Rheumatism Association Malta
Spyridon	Zormpas	KINAPSI