

# Cross-Border Healthcare Conference, 7-9 July 2014, Ljubljana

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## 1 Introduction

One of the main factors governing the impact of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare – the “cross-border healthcare Directive” – will be the degree to which patients are enabled to understand the legislation and benefit from it.

In cooperation with its members, EPF undertook considerable work with the EU Institutions on the Directive prior to its adoption, and subsequently produced a toolkit explaining the Directive, which was disseminated in June 2012. The toolkit was presented at various events throughout the European Union in which patient leaders were involved, to raise awareness during the transposition phase. As this phase ended on 25 October 2013, it is now particularly timely to organise dedicated regional conferences to ‘raise the bar’ in terms of comprehensive knowledge and awareness among patient communities.

### ABOUT THE CONFERENCE

This conference is the third in a series of four EPF regional conferences for patient communities on the cross-border healthcare Directive<sup>1</sup>. The conference was aimed at patient leaders from the five participating countries – Austria, Czech Republic, Hungary, Slovakia and Slovenia – who have the capacity to transfer learning and knowledge from the conference to peers within their organisation 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 patients' 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 compared to (previously existing) rights under the Social Security Regulation;
  - to interact with national government representatives and other stakeholders on the issue and contribute to the effective implementation of the Directive;
  - to explain to fellow patient leaders in their Member State facts about cross-border healthcare and how it works in practice;
  - to support the effective dissemination of information to the wider patient community in the Member State;
  - to be a potential resource to National Contact Points to ensure the information they produce is fit for purpose from a patient's perspective;

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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 second conference took place in Athens (Greece) on 7-9 April 2014, involving representatives of patients' organisations from Cyprus, Greece, Italy and Malta. The final conference will be held in Tallinn (Estonia) in October 2014.

- to participate in monitoring the implementation of the Directive from the perspective of patients 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 thematic plenary sessions and interactive debates with the audience, as well as parallel working groups followed by a closing plenary which presented the key conclusions and proposals on the way forward.

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

The cross-border healthcare Directive is another early step within an ongoing process of developing a European health policy, and another evolutionary step in European healthcare provision, building on existing realities. Although the Directive aims to facilitate the process of patients seeking treatment outside their own country, today we still have an unclear picture of how many patients might take this journey and what their experience is likely to be in practice.

Before the Directive was passed, there was a certain degree of resistance at Member State level to some of its aspects, based mainly on concerns regarding the potential impact on national healthcare systems. Now that the Directive is in force, the discussion should focus on streamlining existing processes to enable patients to exercise their right to timely and high-quality treatment.

One of the gains of the Directive is that a space has emerged for patients' organisations to address two crucial and complementary tasks: firstly, to inform patients of their rights and to explain what is covered and how they might go about exercising their rights; but also to help improve the patient's journey by working more closely with competent authorities, beginning with the National Contact Points (NCPs).

The contributions during Session One demonstrated that although the Directive is in force, there is still much to be done to prepare for implementation. Information to patients is crucial to implementation, which places a premium on NCPs consulting effectively and responsively with patients' organisations and other stakeholders. NCPs will not be able to deliver the service they are supposed to provide to patients unless they are listening to them and taking their views into account.

The Commission's check on transposition of the Directive by Member States is ongoing. However, the Commission is very reliant on feedback from patients' organisations and individual citizens in terms of what is happening in practice, how individual cases are being handled on the ground, etc., so that it can hold national governments to account in terms of meeting their responsibilities.

There is a growing awareness among patients' organisations of how the Directive fits into the existing framework established under the social security Regulations. But patients' organisations also have a clearer view of where the gaps are, especially in terms of the need for reform: for example, financial inequality is still a significant barrier to access to healthcare.

During Session Two, the critical role of the NCPs in the effective implementation of the Directive was amply demonstrated by the contributions of all participants in the small breakout groups as well as the featured presentation. It is clear that the NCPs are a “work in progress” and there is no shortage of ideas regarding how they can be improved. A key role for the patients’ organisations is to advocate for a bigger space within the NCPs and to set out clearly what patients want and expect from the NCPs, beginning with the provision of information that is up-to-date, accurate and of maximum use to patients. The prevailing sentiment was that NCPs must be more than simply providers of information; they should be “enablers”, giving real support to patients. They should also play a convening and mediating role between the various stakeholders, encouraging the maximum degree of exchange and employing the broadest possible channels of communication. They should also be responsible for collecting data and monitoring trends on the use of cross-border healthcare, with a view to triggering change in policy, e.g. reducing financial barriers to access.

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

The discussion shed light on some of the flaws and core challenges contained in the Directive as it stands today. One of these core challenges is to ensure that quality of care and patient safety are not measured by the lowest common denominator. The situation can be summarised as: firstly, the need to resolve financial issues for patients, secondly, the importance of ensuring access to quality healthcare, and thirdly the difficulties arising from cuts in national health budgets.

The current legal status of patients’ organisations in relation to ERNs is a major cause for concern. A failure to address patient empowerment positively and practically in the technical manual and toolbox for assessment of ERNs would represent a crucial step backwards.

Overall, there are a number of recommendations that can be made which require a response by NCPs, healthcare providers and patients’ organisations. But there are also recommendations that address the need to reshape the Directive in the medium-to-long term and are therefore political in nature – the response to these would need to come from the Commission, Council and the national governments.

Session Five featured a panel discussion by NCP representatives, which provided a valuable insight into how the NCPs themselves view the current challenges and how their perceived priorities compare to those of patients’ organisations. The proposed conference in Brussels in June 2015 bringing together NCPs and patients’ organisations will be another opportunity to address the emerging issues and challenges on a collaborative basis.

It is clear that national patients’ organisations will continue to play a key role in each Member State regarding further communication and co-operation 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 Session One

#### THE FIRST DIRECTIVE TO FOCUS ON “PATIENTS’ RIGHTS” – WHAT DOES THIS REALLY MEAN FOR PATIENTS?

**Moderator Tamsin Rose** highlighted the fact that although the Directive – adopted in March 2011 and in force since October 2013 – aims to facilitate the process of patients seeking treatment outside their own country, we still have an unclear picture of how many patients might take this journey and what their experience is likely to be in practice.

Before the Directive was passed, there was a certain degree of resistance at Member State level to some of its aspects, based mainly on concerns regarding the potential impact on national healthcare systems. Now that the Directive is in force, the discussion should focus on streamlining existing processes to enable patients to exercise their right to timely and high-quality treatment.

One of the gains of the Directive is that a space has emerged for patients' organisations to address two crucial and complementary tasks: firstly, to inform patients of their rights and to explain what is covered and how they might go about exercising their rights; but also to help improve the patient's journey by working more closely with competent authorities, beginning with the National Contact Points.

#### THE EUROPEAN COMMISSION'S PERSPECTIVE

The European Commission's perspective on the directive was presented by **John Rowan** from the European Commission's Directorate General for Health and Consumers (DG SANCO).

Today's context for the Directive is that – in contrast with policy areas such as agriculture or the environment – the development of health policy at the European level is still in its early stages. It began in 1992 with the Maastricht Treaty, which included an Article on public health, and policy work at the European level developed from there. Of course, certain aspects of access to healthcare provision have been addressed since the early 1970s under the EU Regulations on the coordination of social security systems<sup>2</sup>, but not as the main focus.

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<sup>2</sup> See Regulation (EC) No 883/2004 and Implementing Regulation (EC) No.987/2009, as amended. For more information on this, please see the EPF guidance document.

In more recent years there has been European policy work on healthcare systems, addressing issues such as patient safety and patient empowerment, and this is where the cross-border healthcare Directive fits in, as another early step within an ongoing process. This will develop further over the coming years, and will require patient involvement to ensure that health policy evolves in the right direction.

With this context in mind, 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, increased and clearly explained. The issue here is patient mobility, set out clearly in law and explained in terms that are immediately understandable.
- Information to patients on health systems and treatments that might be available to them is a crucial aspect. Patients have new rights, but unless they have the right information to make informed choices, they will not be able to exercise those rights.
- The Directive establishes a minimum set of patients' rights throughout the EU. Given that until relatively recently there was no EU role in health systems, the fact that Member States have signed up to a minimum set of patients' rights at this level represents significant progress.

The basic principles governing cross-border healthcare are: patients have the right of 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 State of treatment applies in relation to quality and safety standards, with a requirement for transparency regarding those standards.

### **PRIOR AUTHORISATION**

Under the Directive, Member States can choose to exercise prior authorisation of treatment. Many of them are doing so, due to political concerns regarding their ability to cope with cross-border demand.

Prior authorisation may be required for healthcare that involves (a) an overnight hospital stay, and (b) highly specialised and cost-intensive healthcare ("hospital care"). The logic for this provision is to ensure that the investment and planning carried out by Member States to provide certain treatments should not go to waste.

A request for authorisation may be refused under certain conditions; for example, if there is no "undue delay" in accessing treatment (unreasonable wait in the home country, defined from the point of view of the patient's need rather than the periods set by national waiting-lists). But any refusal must be "properly reasoned" – there must be an individual assessment of the patient's situation, resulting in a specific and detailed rationale for the treatment timeframe, which is then communicated in a transparent manner to the patient and can therefore be challenged if necessary.

### **INFORMATION TO PATIENTS PROVIDED BY NATIONAL CONTACT POINTS**

Information to patients is crucial to implementation, so there is an obligation for each Member State to set up at least one National Contact Point (NCP) – Member States with a federal system may choose to have regional NCPs plus a centralising federal NCP.

NCPs must be both inward-facing and outward-facing, i.e. able to inform patients who want to go abroad (regarding rights and entitlements as well as the processes for prior authorisation, reimbursement and appeal) and to tell incoming patients what to expect (quality and safety standards and systems, complaints and the redress procedure). The issue here is to ensure that the patient receives the specific information he/she needs, e.g. who is responsible in a Member State for registering and monitoring quality and safety standards.

NCPs have an obligation to consult with stakeholders, especially patients' organisations as well as healthcare providers and healthcare insurers. NCPs will not be able to deliver the service they are supposed to provide to patients unless they are listening to them and taking their views into account.

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. Once again, the issue is to ensure that the patient is able to make a properly informed choice.

The role of NCPs also includes practical support relating to invoices: they must be able to help a patient deal with invoices from another country (perhaps issued in a different language and/or using different nomenclature) by liaising with the NCP in the country of treatment.

#### **PRICES AND REIMBURSEMENT TARIFFS**

There are three main points: non-discrimination, i.e. 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/public provider, depending on the health system); and there must be transparency on the "basket of benefits" and reimbursement tariffs (answering the basic question: which treatments and how much?).

The Commission is aware that some Member States are applying higher fees to incoming patients, and that one or two Member States are setting reimbursement tariffs using the cost of private treatment as a reference-point (thus creating an artificially low reimbursement tariff). One of the Commission's tasks is therefore to deal with non-compliance with important principles of the Directive.

#### **MINIMUM PATIENTS' RIGHTS**

Although the Directive sets a minimum standard for patients' rights, it also contains new/enhanced rights: the right of appeal on authorisation and reimbursement decisions; the right to a transparent complaints procedure and to seek redress (all treatment must be covered by liability insurance or an equivalent guarantee); the right to privacy; the right of access to/copy of medical records for all treatments; and non-discrimination on the basis of nationality regarding access and prices.

In some Member States nothing much will change, as these rights are already in place. But this is not the case in all Member States, so the fact that a minimum standard for patients' rights is now set at the European level and applies to all countries represents a major legal step forward. It also means that the concept of patients' rights can continue to be refined and developed further throughout the EU.

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

There are some important differences between the social security Regulations and the new Directive:

- The Regulations only cover public-sector or contracted providers, while the Directive covers **all** providers in the EU (for planned and unplanned care);
- Prior authorisation is the norm for planned care under the Regulations, but the exception (if used at all) under the Directive – in fact, some Member States are not using prior authorisation at all;
- 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 system for cross-border healthcare under the Regulations did not have a healthcare logic; it worked fairly well for unplanned care (patients using their European Health Insurance Card (EHIC) abroad), but not for planned care. The Directive therefore introduces significant “flanking” measures – information (especially the obligation for transparency), procedural guarantees, etc. – to ensure the system also works well for planned care. Currently, just 30,000 EU citizens per year use this system for planned care. Of these, 17,000 are from Luxembourg and 5,000 are from Italy, so just 8,000 patients from 26 Member States are using this system. In other words, it is not well-known or well-used, so this is why the Directive puts heavy emphasis on informing patients of their rights and how to use them.

## CO-OPERATION BETWEEN HEALTH SYSTEMS

There is a general obligation for Member States to co-operate on:

- guidelines for quality and safety standards;
- European Reference Networks (ERNs), especially to ensure that expertise and information on rare diseases is shared across Europe in order to improve diagnosis and access to treatment;
- Health Technology Assessment (HTA), for which voluntary networks already exist and are working, aiming in particular to eliminate duplication of effort;
- eHealth, for which there is a Steering Group working on a common eHealth policy.

Prompted by the European Parliament, the European Commission is also addressing the need to promote more co-operation between Member States on cross-border healthcare in border regions.

## THE NEXT STEPS

- The Commission’s check on transposition of the Directive by Member States is ongoing, involving a detailed assessment of all the notified measures for Member States in terms of completeness and compliance.
- Monitoring of transposition by individuals and stakeholders is also very important. The Commission is very reliant on feedback from patients’ organisations and individual citizens in terms of what is happening in practice, how individual cases are being handled on the ground, etc., so that it can hold national governments to account in terms of meeting their responsibilities.

- The reflection process on the functioning of the NCPs is ongoing – the next meeting is scheduled for September 2014. Patients’ organisations can play a very useful role by providing input on how information – for example, on quality and safety standards – is being presented in different Member States.
- This monitoring feedback will be incorporated into the regular reporting by the Commission to the European Parliament and Council. Major discussions are scheduled for mid-2015, and the first formal progress report (with recommendations) is due to be published on 25 October 2015.

## THE PATIENT’S PERSPECTIVE

The patient’s perspective was given by **Dr Gábor Pogány**, Co-ordinator of the Hungarian Patients’ Forum.

The coming into force of the cross-border healthcare Directive is a welcome step forward, but getting to this point has been a long and sometimes frustrating process from the patient perspective. Within the European troika of Council, Commission and Parliament, it was the Council that caused the initiating process to be extended and sometimes interrupted, due to understandable political concerns over managing national health budgets. The resulting form of the Directive is a compromise; nevertheless, it represents a big opportunity for patients’ organisations to make an important contribution in several ways.

### THE CROSS-BORDER HEALTHCARE DIRECTIVE COMPARED TO THE SOCIAL SECURITY REGULATIONS

Prior to the Directive, access to cross-border healthcare by EU citizens was only covered by the social security Regulations.<sup>3</sup> Under these Regulations, which are still in force, unplanned care in another Member State (e.g. as a tourist) is fully covered if the patient has a European Health Insurance Card (EHIC). Planned care in another Member State is also available, both in hospitals and through other healthcare providers. The costs of planned non-hospital care with prior authorisation (certified by a S2 form, previously form E112) are met in full, with the possibility of additional reimbursement if applicable. Without prior authorisation, these costs are payable by the patient, but reimbursement can be obtained based on the rules in the country where the patient is covered for healthcare. The costs of planned hospital care with prior authorisation (S2 form) are also met in full, with the possibility of additional reimbursement if applicable. Without prior authorisation, there is no guarantee that these costs will be met.

The problem with social security Regulation 883/2004 was that it was in contradiction with EU law governing the free movement of citizens, leading to several cases being initiated by individual citizens at the European Court of Justice (ECJ).<sup>4</sup> The cross-border healthcare Directive was therefore designed to codify the rights to healthcare abroad which derive directly from the free movement provisions of the European Treaty.

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<sup>3</sup> [http://europa.eu/legislation\\_summaries/employment\\_and\\_social\\_policy/social\\_protection/c10516\\_en.htm](http://europa.eu/legislation_summaries/employment_and_social_policy/social_protection/c10516_en.htm)

<sup>4</sup> See, for example, Decker (C-120/95), Inizan (C-56/01) and Stamatelaki (C-444/05). These and other judgments can be found at <http://eur-lex.europa.eu/en/index.htm>.

These new rights under the Directive now exist alongside the rights created by the social security Regulations. In practice, this means that in some cases patients could find it better to apply for treatment under the Regulation (costs met in full) than under the new Directive (costs reimbursed according to a tariff set in the home country).

Example: A patient lives in Italy and goes to the Czech Republic to receive a specific treatment in hospital which is not on the list of treatments requiring prior authorisation under the Directive.

	<b>Regulations:</b> <b>S2 form (previously E112) and prior authorisation required</b>	<b>Directive:</b> <b>No prior authorisation required</b>
<b>Cost of treatment, Czech Rep.</b>	€30,000	€30,000
<b>Cost of treatment, Italy</b>	€26,000	€26,000
<b>Advance payment by patient</b>	€3,000 (sometimes zero)	€30,000 (sometimes zero)
<b>Reimbursement</b>	Remaining costs €27,000 paid by Czech healthcare system to hospital Health insurance in Italy reimburses €3,000 to patient	Health insurance in Italy reimburses €26,000 to patient, not €30,000
<b>Cost to patient</b>	<b>€0</b>	<b>€4,000</b>

This scenario, i.e. treatment with prior authorisation under the social security Regulations, would therefore be more advantageous when a patient from a country with a relatively lower per capita Gross Domestic Product (GDP) receives relatively expensive treatment abroad. Conversely, a patient from a country with relatively higher per capita GDP receiving treatment which is cheaper abroad would receive full reimbursement under the Directive and thus would face less of a financial burden overall.

It should be remembered that prior authorisation under the Cross-Border Healthcare Directive can be refused by a Member State if: the patient seeking cross-border healthcare will be exposed to an unacceptable safety risk; the general public will be exposed to a substantial safety hazard; the healthcare is provided by a healthcare provider that raises serious concerns over quality and safety of care; or if the healthcare can be provided on its territory within a medically justifiable time-limit. The first three reasons are perfectly understandable; however, the last reason could be seen as a “rubber rule”, more in line with the Member State’s priorities rather than the patient’s needs.

Under the Regulation, prior authorisation cannot be refused when “*the list of benefits for which the national legislation provides does not expressly and precisely specify the treatment method applied but defines types of treatment reimbursed by the competent institution*” which reasonably correspond to the treatment in question, or “*if no alternative treatment which is equally effective*

*can be given without undue delay in the Member State on whose territory the insured person resides”.*<sup>5</sup>

However, the level of detail contained in the “list of benefits” is crucial.

For example, if the list in Bulgaria says that the type of treatment covered for eye cancer is “radiological or surgical treatment”, then reimbursement of proton-therapy as provided in Germany cannot be refused. If, on the other hand, the list in Bulgaria says that the type of treatment covered for eye cancer is “enucleation only”, then reimbursement of proton-therapy as provided in Germany can be refused, and only the cost equivalent to the cost of enucleation would be reimbursed. Part of the role of a patients’ organisation should therefore be to influence what exactly is contained in its national “list of benefits”.

### **AWARENESS OF THE CROSS-BORDER HEALTHCARE DIRECTIVE**

The results of a recent survey of the 100-plus member organisations of the Hungarian Patients’ Forum indicate the scale of the task in raising awareness of the Directive: only 60% of Hungarian patients’ organisations had heard of the Directive; none were aware of any patient who had used it; some 80% thought that there would be demand for treatment under the Directive in their patient group; and 100% said they would participate in a network to monitor the implementation of the Directive.

It should be noted that these are well-informed patients’ organisations – the level of awareness in the general public or patient population is probably much lower. Other issues raised by respondents to the survey included: the risk of adding another layer of bureaucracy to a decision-making process that is already too long; the requirement for the patient to prepay and then seek reimbursement, which imposes an important financial barrier; and the lack of reaching out to society by the government or competent authorities.

### **TAKE-UP UNDER THE DIRECTIVE AND ITS IMPACT**

Although demand in Hungary for cross-border healthcare treatment is still relatively modest, the number of treated persons is increasing: from 400 in 2009 to 451 in 2010, 648 in 2011, 658 in 2012 and 500 up to 31 October 2013. Similarly, reimbursement costs are increasing overall, from €3.4 million in 2009 to €4.5 million in 31 October 2013.<sup>6</sup>

According to official data, between the Directive coming into force in October 2013 and March 2014 the Hungarian NCP received over 100 requests, some 90% of these from Hungarian patients and healthcare practitioners and the remainder from a wide range of other Member States. Of these requests, 34% were for general information, 17% related to the EHIC, and 4% were complaints from patients. A further 26% related to specific treatment abroad, and 19 % to specific treatment in Hungary.

Contrary to the concerns expressed by some Member States during the negotiations on the Directive, so far there is no evidence of significant impact on national health budgets. Patient mobility remains limited overall (currently 1 %), but the impact for individual patients is high. As the

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<sup>5</sup> ECJ case C-173/09.

<sup>6</sup> Data from National Health Insurance Fund (OEP).

NCPs provide more clarity for all regarding the rules for reimbursement of treatment, overall patients can already be said to have better access to the care they need.

There is also a positive impact at the European level: for every patient treated earlier, there is a gain in EU-wide healthcare efficiency and EU-wide well-being; also, the quality and safety of care is likely to improve through convergence – if not harmonisation – of standards.

#### THE NEXT STEPS FOR PATIENTS' ORGANISATIONS:

- Get informed about the content and the implications of the Directive;
- Raise awareness among patients and help them find the right information;
- At the same time, insist that the NCP involves patients' organisations as regular partners;
- Propose concrete measures of interest to patients;
- Create guidelines for information to patients;
- Feed experiences back to decision-makers at both national and European level.

## 4 Q&A session summary

### **Have there been cases of patients seeking cross-border healthcare being refused prior authorisation on the grounds of exposure to an unacceptable safety risk?**

This provision is the result of theoretical scenarios raised during negotiations in Council, e.g. someone with an infectious disease wanting to travel abroad for treatment. However, in July 2014 five people in Hungary were admitted to hospital to be monitored for possible anthrax infection, so one can see how exceptional circumstances can arise.

### **Regarding non-discrimination, has there been a case of a hospital refusing to provide care when prior authorisation has been given?**

The Directive does allow healthcare providers to restrict access in certain circumstances, e.g. when a hospital has no spare capacity because it is all being used to treat local patients. However, any such restriction must be made public, i.e. it cannot simply be made on the spot. The only hypothetical exception (there have been no cases so far) would be a situation of *force majeure*, e.g. when there is a language barrier making it unsafe to provide treatment in a particular instance. The language gap in cross-border healthcare delivery was addressed during the negotiations on the Directive. The conclusion was that it was extremely difficult to resolve this legally (e.g. by obliging healthcare providers to offer services in various languages), and most likely it would be resolved by market forces: a patient is unlikely to seek treatment from a particular healthcare provider when there are language issues.

### **When a patient is seeking treatment abroad, there are often psycho-social issues in addition to the basic illness issues, which means that the person accompanying the patient abroad can be regarded as part of the support care. Is this covered under the Directive?**

How support care is defined and the extent to which the costs of this are covered depends on the policy in the patient's home country.

**What measures are being taken to ensure that the care received by a patient before and after receiving treatment abroad is fully integrated and monitored to ensure continuity of care?**

The question of follow-up care was discussed during the negotiations on the Directive, with the result that the Directive states that a patient should receive the same follow-up care in the home country that would have been provided if the treatment was provided in the home country. The overall concept of managing the patient journey is not addressed in the Directive, so it falls to the patient to ensure that the linkage exists.

**If treatment for a specific condition, e.g. a rare disease, is not included in the “basket of benefits” of one Member State, how can treatment be sought in another Member State and then reimbursed in the home country?**

A total of more than 50 million people live in Member States with populations of less than 5 million, which means that especially for specialist treatment or in relation to rare diseases there is a significant patient population that must travel abroad for treatment. But even the bigger/richer Member States do not provide adequately for rare disease patients, and it is this overall situation that is driving the process of creating European Reference Networks (ERN) as one EU-wide solution. It is a fundamental point under the Directive (and the Treaty) that each Member State decides what treatment it will or will not provide. In practice, it is for the competent authorities in the home country and the country of treatment to agree how the costs of such treatment should be covered and reimbursed, e.g. by using the S2 system under the Regulations. A number of Member States are using the S2 system exclusively for dealing with rare diseases, and there are bilateral agreements in place across the EU that address this situation.

**Who is responsible for creating European Reference Networks, and what is the potential role for patients’ organisations in Centres of Excellence?**

The process is mainly driven by healthcare providers, who group together and apply to be Centres of Excellence within an ERN. The EU is also driving the process by setting the criteria and quality standards for becoming ERNs and assessing applications. Although so far there is no formal role for patients’ organisations, there is a requirement for ERNs to provide patient-centred care, so assessing the ERN’s relationship to the patient is crucial to the process – patient involvement in this aspect is still being discussed. At this stage, no ERNs exist – the Commission will publish a call for expressions of interest for ERNs – so the question of disease-specialisation and how this might relate to patients in practice is also very much open.

**With the current pressure on national health budgets there is a risk of cross-border healthcare being used politically to fuel nationalistic/xenophobic positions. What are the possible counter-arguments?**

Clearly, the demand for cross-border healthcare will be significantly greater than the current figures for patients treated under the social security Regulations and the Directive, but there is simply no way of knowing in advance how big the flows will be, in which directions, etc. The way the Directive was designed – and the way that the Regulations operate – means that treatment in the receiving country should be cost-neutral in terms of national health budget. In practice, the potential issue in

terms of impact is capacity; a Member State has the ability to restrict cross-border access to particular treatments on the grounds of capacity, but any justification would need to be based on meaningful data.

**As the Directive stands today, with the requirement for patients to pay for treatment and then seek reimbursement, does it not increase inequality of access by facilitating cross-border healthcare for those who possess the necessary financial means and setting a barrier to access for those without those means?**

Financial inequality in healthcare is also being expressed at the European level, for example through the “brain drain”, as healthcare professionals trained in a lower-income Member State migrate to work in other higher-income Member States. The combined phenomenon of ageing populations and increasing demand for healthcare services across Europe is posing serious problems in the poorer Member States.

It is true that as the Directive stands today, it empowers individuals and so there is the risk that one segment of society might benefit disproportionately from the new rights. The Directive encourages Member States to mitigate this by, for example, making direct payments between health systems, but not many Member States can be expected to take up this opportunity. The important point to remember is that the Directive is one evolutionary step in European healthcare provision, building on existing realities. It may be that sometime in the future there will be the political will to design a new EU-wide system based on a European health policy, which would also take into account the impact of free movement on the number of healthcare professionals in each Member State.

One part of the solution to the current situation would be for effective patients’ organisations to be pro-active in raising the issue of health inequalities with other stakeholders, particularly policy-makers in their country.

## **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 in practice. They now have a clearer view of the intention behind the wording of the text from a legislative perspective, and how this fits into the existing framework established under the social security Regulations.

But patients’ organisations also have a clearer view of where the gaps are, especially in terms of the need for reform: for example, financial inequality is still a significant barrier to access.

One of the gains of the Directive is that a space has emerged for patients’ organisations to address two crucial and complementary tasks: firstly, to inform patients of their rights and to explain what is covered and how they might go about exercising their rights; but also to help improve the patient’s journey by working more closely with competent authorities, beginning with the National Contact Points.

## 5 Session Two

### THE CRUCIAL ROLE OF NATIONAL CONTACT POINTS (NCP) AND CREATING A MODEL THAT MEETS THE NEEDS OF PATIENTS

#### PRESENTATION OF THE SLOVENIAN NATIONAL CONTACT POINT

The Slovenian NCP was presented by **Siniša Bošnjak**. The NCP became operational on 6 November 2013, when the relevant national legislation came into force, and its responsibilities are fulfilled by a dedicated unit within the Health Insurance Institute of the Republic of Slovenia (HIIS).

#### RESPONSIBILITIES AND TASKS

In common with NCPs in other Member States, the basic responsibilities of the Slovenian NCP include providing information to patients regarding basic questions; healthcare providers and services; patients' rights and obligations; reimbursement of costs; other NCPs; and specific processes. Other responsibilities include consultation with patient organisations, healthcare providers and health insurance providers; co-operation with other NCPs and the European Commission; and exchange of information between NCPs.

The aspect of working closely with other NCPs is likely to provide the basis for the future evolution of the NCP concept. Although there might already be expectations – within the European Commission, for example – that the NCP will act as a kind of “agency” for the patient, facilitating his/her journey rather than simply offering information, right now the task of making the right choices still remains the patient's responsibility.

#### CHANNELS OF INFORMATION

The Slovenian NCP makes information available via:

- Website ([www.nkt-z.si](http://www.nkt-z.si)), which provides all the information a patient will need to make the right decision. It is hosted by the HIIS, but the information it contains comes from three different sources: the Health Ministry (quality and safety in healthcare; professional liability insurance for healthcare professionals; patients' rights and obligations), the National Institute of Public Health (waiting periods and healthcare providers) and the HIIS for other information. The information is presented in Slovene and English (although not all content has been translated into English) and it complies with the Web Content Accessibility Guidelines (WCAG) for users with special needs prepared by the World Wide Web Consortium (W3C).
- E-mail ([kontakt@nkt-z.si](mailto:kontakt@nkt-z.si)).
- Telephone call-centre (00 386 1 30 77 222), operating Monday-Friday.
- Personal consultation – in the nine months from November 2013, just five people used this option.

Currently the Slovenian NCP handles around 200 telephone and email enquiries per month. There was a relative spike in the number of requests as a result of media focus in November 2013 (when the NCP was launched) and February 2014 (when the Health Ministry announced the list of

treatments requiring prior authorisation), which demonstrates that awareness campaigns are crucial.

The most commonly-asked questions:

- What are the patient's rights to access cross-border healthcare and what procedures must be followed;
- Which treatments are subject to prior authorisation;
- What are the reimbursement procedures – the formula for calculating reimbursement in Slovenia is fairly complicated, so explaining this can be time-consuming;
- What tariffs apply.

### **EXPERIENCE AND CHALLENGES SO FAR**

The website contains a lot of information, and there is already some feedback from patients that it might not be easy to understand. One factor may be the media coverage to date, which has tended to focus on just a few areas and so may have created a misleading impression and inflated certain expectations among patients. The amount which may be reimbursed to a particular patient cannot be determined definitively in advance of the treatment; without all relevant details of the specific treatment to be accessed, the NCP can only give a provisional indication of what the reimbursement amount might be. The plan is to devise an application on the NCP website that will allow a patient to obtain a reasonably accurate indication of the reimbursement amount by inputting certain data.

So far, few patients' organisations have contacted the Slovenian NCP. This apparent lack of interest may suggest that the NCP is already providing sufficient information of a high-enough quality. However, patients' organisations are the best source of information regarding patients' needs under the Directive, so an exchange of information between NCPs and patients' organisations can only improve delivery to patients and the overall performance of the NCP. The proposed conference in Brussels in June 2015 bringing together NCPs and patients' organisations should be a valuable forum in this respect.

Regarding procedures and rights, most often the challenges relate to the documents that are required, translation of medical documents, and invoices. Clearly, these are challenges which all NCPs face, especially when navigating the distinctions between different national procedures and different national legislation. One avenue for progress may be the development of eForms that will enable patients to file more documentation online in a more standardised manner, thus reducing physical paper trails and shortening procedural timelines.

### **WORKING GROUPS – DESIGNING A MODEL NCP**

The participants then broke out into eight groups of 5-6 people 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:

### **FUNDAMENTAL PRINCIPLES**

NCP is governed by legislation, is independent of governmental processes and has its own operational budget

It focuses on the patient's entire journey, proactively helping the patient to manage the hurdles and providing solutions rather than just telling him/her which forms to fill or just providing information

It is communicative towards government, media, patients' organisations and other stakeholders

### **VISIBILITY**

Implementing a defined strategy, it actively promotes visibility with the general public, healthcare practitioners and patients' organisations

It conducts awareness campaigns and takes other specific measures, e.g. ensures there is a link to its website on websites of other stakeholders (government ministries, health insurance providers, patients' organisations, professional associations)

### **ACCESSIBILITY AND AVAILABILITY**

Free flow of information towards patients and healthcare professionals, via:

- patient-friendly website/email
- call centre
- brochures/handout material distributed via the premises of healthcare providers, e.g. waiting-rooms
- personal consultation (e.g. at regional office)
- designated contact person at healthcare providers
- media coverage
- patient education (roadshows, etc.)

Information should be freely available in formats that are easy to understand (including video clips) and should also be accessible to people with disabilities; present/refer to real patients' stories to make the information more accessible

### **QUALITY OF INFORMATION**

Information should be full, clear, understandable and reliable

Provide customised information packages for specific conditions or disease groups – aim to educate particular patient groups

Provide answers to FAQs

Information provided at first contact should cover:

- available treatment options, including the procedures to access them
- registries of health professionals per specialisation and per country

- an indication of the approximate costs of treatment both at home and abroad (not just basic tariff)
- specialised tests/treatments for “informed” patients who already have basic information

List of possible treatments should reflect best practice

Access to medical data from health authorities, also access to financial, organisational and professional information on healthcare providers

## **OPERATIONS**

Open-minded, proactive, helpful towards patients – show initiative and aim to help by providing solutions that meet the patient’s needs

Co-operative with national and European institutions/agencies, other NCPs, patients’ organisations, professional associations and advocacy groups

Communicative operationally with health insurance providers, patients’ organisations and other stakeholders

Transparent procedures and timelines

Knowledge of foreign languages

Well-informed generally in health matters and other specifics (e.g. relevant domestic and foreign legislation); well-informed on national healthcare systems of other Member States, beginning with those most in demand

Liaise with other NCPs to facilitate patient access to specialist treatment (mediating role, providing solutions);

Act as mediator between healthcare providers and patients’ organisations, facilitating exchange of information

Facilitate translation of documents into patient’s normal language

Offer patients support in case of problems with reimbursement

Give patients advice on refused authorisations

Aim to harmonise methods and attitudes of NCPs across Member States – equality in patient experience

Continuous education of NCP representatives

## **QUALITY STANDARDS**

Clear and quantified definition of “reasonable waiting period”

Answer all enquiries within 1-2 weeks, have a “fast-track” option for emergency situations

## **ACTION AT THE EUROPEAN LEVEL**

Feedback from individual patients and patients’ organisations to be monitored at national and European levels

Gather data on necessary treatments that are not currently authorised – aim to influence policy (trigger changes)

Provide consolidated data on treatment costs to national competent authorities and European Commission in order to promote a reduction in financial inequalities (if not standardisation of costs)

Make funding available to cover ancillary costs incurred by patients and their families (e.g. translation, travel).

**COMMENT BY JOHN ROWAN (EUROPEAN COMMISSION):**

The Commission's initial vision for NCPs contained in its proposal was closer to what was outlined by the breakout groups than what is contained in the final form of the Directive. The initial idea was for NCPs to play much more of an active advocacy role involving patients and including much more information about how to help them on their journey. That was not the final result, as Member States argued that this approach would require too many resources, was disproportionate, and that they were only prepared to provide enough resources to enable NCPs to provide information.

In common with the patients' views expressed, the Commission thought initially that NCPs should be independent of government departments. However, it has changed its position over the last two years, having accepted the argument by Member States that expertise in this field is quite rare, and that the people with the skills to fulfil the role of NCP already exist within governmental administrative structures.

Whether the NCPs can move more towards an advocacy role in the future is a political discussion which needs to take place between the Commission and the national administrations, starting from an acknowledgement that there is demand for this from patients. Other elements of the patients' "wish-list", for example NCPs being able to provide recommendations as to which healthcare providers to choose, would require specialised knowledge and skills and would need many more resources for this function to be carried out to a high standard. The development of cross-border healthcare and the role of the NCPs in the direction outlined in the breakout groups will depend on increasing demand and an identified added value for both patients and health systems – which would make it easier to have this discussion with the Member States when the Directive is reviewed in the future

**COMMENT BY SINIŠA BOŠNJAK (SLOVENIAN NCP):**

There has already been an exchange of information between NCPs that will be useful in improving delivery. One idea being floated is to use the national data being collected by individual NCPs to create a centralised database of information at the European level that could be used by different NCPs. Exchange of information and co-operation within a network of NCPs and between NCPs and patients' organisations will be crucial to the evolution of the cross-border healthcare system.

**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 presentation.

It is clear that the NCPs are a “work in progress” and there is no shortage of ideas regarding how they can be improved. A key role for the patients’ organisations is to advocate for a bigger space within the NCPs and to set out clearly what patients want and expect from the NCPs.

## 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 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 RAPORTEURS ON THE KEY ISSUES AND RECOMMENDATIONS FROM SESSION THREE

Due to the commonality and clear overlap of the reports by the three workshop rapporteurs, they were amalgamated into a single report-back presentation.

#### KEY ISSUES

When deciding:

- What treatment options are there in other EU countries and would I benefit from them (cost and waiting time)?
- What is reimbursed by my home healthcare system and do I need prior authorization?
- What is the reputation of the healthcare provider and the experiences of other patients of this treatment, especially regarding quality and safety issues?

Before leaving:

- Who will help or support me during the treatment abroad, especially if there are complications?

- How well are the doctors at home and abroad linked? What medical records would be needed, who owns this data and how is it shared (data protection)?
- What will be the total cost of the trip and what amount would I have to pay?

During stay:

- Timeline and steps of procedure and treatment. Who is my contact person, who can I turn to for help?
- What happens if something goes wrong, it does not go as planned or there are negative side effects? (complaints procedure)
- What about continuity of care (e.g. prescription drugs not available in the home country) and ensuring free flow of information between host/home country systems.

After returning home:

- Is all of the information completely transferred and paperwork completed (including translation of reports)?
- What is the follow-up and after-care, who manages the side-effects?
- What are the reimbursement procedures?

## RECOMMENDATIONS

When deciding:

- Patients need support to guide decision-making, including information on the full costs of care abroad and reimbursement, translation needs, management of medical records, safety issues, etc.
- NCP could create lists of medical services where it feels that there is special expertise or high quality (and share this with other NCPs). NCP to indicate what is reimbursed by the home system and provide comparable data about healthcare in home/host country.
- Patients' organisations can gather information about treatment options available in other countries (without implying endorsement). Patients' organisations can help to bridge language issues.

Before leaving:

- Indication of real cost in home country (transparency) and real opportunities to make an informed choice of specialist in another country.
- NCP to clarify the uses of the Regulation vs the Directive and give clear answers on what is reimbursed by home healthcare system.
- Patients' organisations to provide practical support on what to expect in another health system and checklists of how to plan / what to take

During stay:

- Need an identified person within host healthcare provider as a patient contact or advocate (existing patient ombudsman may only deal with domestic patients).
- Healthcare provider to have responsibility for sharing information (within limits of data protection regulations) between home and host country to ensure continuity of care, e.g. replacement medication if it is not available in the home country.
- NCP to provide harmonised forms for invoicing, reimbursement claims and documentation on healthcare provided.

- Patients' organisations could provide local support and advice for patients.

After returning home:

- All stakeholders (NCP, healthcare providers and patients' organisations) have a mutual responsibility to share their experiences and contribute to better knowledge about cross-border healthcare.
- Patients need to know what follow-up care rehabilitation is needed. Clarity on the procedures for reimbursement and complaints mechanisms (process, deadlines, responsibilities, appeals).
- Patients' organisations can offer opportunities for feedback to NCP and health system on the experience of healthcare abroad, publication of case studies and real "patient stories" (positive and negative). Patients' organisations can help raise awareness, provide training and disseminate information.
- NCPs could provide check-lists for reimbursement and publish statistics on outcomes of healthcare abroad. Although there are success stories, there is also a fundamental contradiction in the system for some patients: especially in smaller or poorer Member States, some patients are seeking treatment abroad because it is not available at home, but this is not provided for under the Directive. Concerted political action is required to address the flaws in the Directive and remove such barriers.

## PLENARY DEBATE

Expectations in countries with smaller populations differ in terms of the ready availability of particular treatments – having to travel abroad for treatment is more commonly accepted. Currently there are cut-backs in healthcare staffing in a context of increasing demand on health services, so the demand for cross-border treatment can be predicted to increase as the efficiency and sustainability of particular national health systems come under pressure.

Regarding access to and reimbursement for non-registered drugs after treatment abroad, a system of sorts already exists. If a required drug is not registered in a patient's home country, the patient's physician must ask the Health Ministry for an exemption to use non-registered drugs; after this exemption is granted, the health insurance provider must be asked to pay for the drug as a special import. If a drug is registered but not reimbursable, then the patient's physician must ask the health insurance provider for an exemption to reimburse the drug. Finally, in cases where a registered drug is not available due to a shortage (mostly due to parallel export/import), the patient has the right to buy the drug abroad under prescription and to be reimbursed in his/her home country.

It is important to guarantee patients' rights in practice and to provide an effective remedy when these are violated. A standard European complaint form would be a good start, and perhaps in the future there could be a European-level complaints agency.

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

**Dominik Tomek** of the Association for the Patients' Rights Protection (AOPP) 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:

- Member States should take into account the principles of universality, access to good quality care, equity and solidarity and to apply the principle of non-discrimination [Art. 4(1) and (3)];
- Member States should have in place and apply clear quality and safety standards for healthcare providers... as well as European Union legislation on safety standards (e.g. in relation to blood products or human tissues) [Art. 4(1)b-c];
- This information has to be made available to patients [Art. 4(2)a];
- Healthcare providers must give patients the information they need to make an informed choice [Art 4(2)b].

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 “render mutual assistance and to cooperate with each other”, particularly concerning standards and guidelines for quality and safety of healthcare, and the exchange of information between the national contact points [Art. 10(1-2)];
- Information regarding a professional's status and right to practise must be given upon request to other Member States [Article 10(4)].

This last point does not explicitly state that the relevant information must be shared with patients, but patients can check with their NCP regarding the status and qualifications of a specific healthcare provider.

Continuity of care is another area where quality and safety are particularly important. The Directive states:

- If a medical follow-up proves necessary after their return home, the home country must provide the same follow-up as for treatment received at home [Art 5(c),(d)];
- Patients are entitled to a copy of their medical record [Article 4(2)(f)].

But there are practical hurdles: medical guidelines and protocols vary from Member State to Member State, and there is uneven availability of follow-up treatments (particular drugs and levels of reimbursement). Also, who is to provide an accurate translation of a patient's medical record? The Directive is very vague in these respects, so patient 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 [Article 4 (2)(c) and Article 5 (3)], and that remedies must be available if they suffer harm. But these are not set out at

European level; they are set out in national laws, so potentially we will have 28 different regimes for complaints and remedies.

One important detail is contained in Recital 23 of the Directive, which says that since Member States will already have a system in place for covering such issues in their domestic healthcare systems, they can choose to simply extend this to apply also to cross-border healthcare. 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 ARE WE TALKING ABOUT?**

Patient safety is a new healthcare discipline that emphasises the reporting, analysis and prevention of medical error that often leads to [adverse healthcare events](#).

Two types of patient safety event can be distinguished:

- sentinel events that should never occur, such as failure to remove foreign bodies (e.g. gauze swabs) at the end of a surgical procedure; and
- adverse events, such as post-operative sepsis, which can never be fully avoided given the high-risk nature of some procedures, although increased incidence at an aggregate level may indicate a systemic failing.

The EU regularly publishes a report on patient safety; the 2014 report shows<sup>7</sup> that the most frequent adverse effect is healthcare-associated infections (HAI) – which are directly responsible for 37,000 deaths per year and contribute to a further 110,000 deaths per year – followed by medication-related errors, surgical errors, medical device failures, errors in diagnosis and failure to act on the results of tests. Some 53 % of patients think that they can be harmed by hospital care, and 91 % of physicians and other stakeholders think that patient safety is an issue.

### **QUALITY OF CARE – WHO IS MEASURING?**

Probably the best measuring is done by the Organisation for Economic Co-operation and Development (OECD) as part of benchmarking countries' progress on quality of care. Since 2002, the OECD has been collecting comparative data on the quality of care for: chronic conditions and related acute exacerbation, patient safety, mental disorders, cancer care, communicable diseases and primary care.

### **HOW DOES A PATIENT FIND INFORMATION AND MAKE SURE IT IS THE RIGHT INFORMATION?**

A patient can begin by looking at the NCP website of the Member State in question – a European Commission webpage links to all of these national websites. However, it is hard for a patient to find the relevant information on the national safety and quality standards/guidelines, but it is even harder to find these standards in another Member State – even if you speak the language. Then, assuming they are found, it is extremely hard for a patient to compare different standards and make any kind of meaningful judgement.

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<sup>7</sup> See the infograph “Patient safety in the EU: 2014” (released 19 June 2014) at [http://ec.europa.eu/health/patient\\_safety/policy/index\\_en.htm](http://ec.europa.eu/health/patient_safety/policy/index_en.htm).

There is also the European Commission's website on patient safety<sup>8</sup>, which offers a lot of information on what is being done on patient safety and quality of care at European level, and special reports produced by Eurobarometer<sup>9</sup>.

A patient can then look at specific websites of information sources about healthcare providers, e.g. the hospitals that are members of the European Association of Hospital Managers ([EAHM](#)). However, although the OECD can publish tables of incidence of particular adverse effects – e.g. for postoperative pulmonary embolism or deep vein thrombosis – a patient cannot be sure if this is an accurate guide to the quality of surgery in a particular country.

Hospitals that specialise in certain procedures and actively seek foreign patients will usually have dedicated webpages that allow a patient to learn about their staffing and training levels, the type of equipment used, etc., but they will not readily provide data on service failures, adverse events, deaths linked to surgery, etc.

“Natural” sources of information about quality and safety:

- personal experience (patient's own, that of family and friends);
- doctor/specialist who is recommending the patient;
- insurance provider within the prior authorisation process; and
- personal testimony of fellow patients, including reliable websites (e.g. of the relevant patients' organisation).

“Artificial” sources of information about quality and safety:

- NCPs, which tend to relay information without guaranteeing its accuracy or usefulness;
- media outlets, which tend to only cover errors, “tragedies” and sensational events; and
- internet (unapproved/unreliable websites).

## LANGUAGE ISSUES

Errors and treatment failures can be due to inappropriate communication and, especially in the context of cross-border treatment, bridging the language gap is crucial. Usually, a patient's recommending doctor or specialist should provide an abstract of the medical file in English. If not, what are the options? Google Translate is inappropriate and unreliable, so ideally the NCP should give assistance. Then the question is: should the translation cost be covered by health insurance?

One solution when treatment is being accessed could be to hire a local tourist guide to accompany the patient on the first day in hospital, when most information is exchanged; however, most people are not knowledgeable on medical terminology, so a better alternative would be to find a knowledgeable volunteer (e.g. from a local patients' organisation, NGO or university) or to be accompanied abroad by someone with the relevant language skills.

## WHAT CAN PATIENTS' ORGANISATIONS DO? THEY CAN:

<sup>8</sup> See [http://ec.europa.eu/health/patient\\_safety/policy/index\\_en.htm](http://ec.europa.eu/health/patient_safety/policy/index_en.htm).

<sup>9</sup> See Special Eurobarometer 411, “Patient Safety and Quality of Care” (June 2014) at [http://ec.europa.eu/health/patient\\_safety/eurobarometers/index\\_en.htm](http://ec.europa.eu/health/patient_safety/eurobarometers/index_en.htm).

- Draw on their extensive expertise and channel direct patient experiences to point out weaknesses and system failures – a valuable source of information for better health policy;
- Raise awareness and help patients find the right information;
- Approach NCPs and offer advice on how to provide information well; in fact, patients' organisations should insist that NCPs involve them as regular partners. This would require giving patients' organisations the right form of support (and perhaps compensation) for their expert input;
- Feed experiences (of actual cross-border healthcare, of working with an NCP or of working at the policy level with a national Health Ministry) back to EPF and the European Commission, at least 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;
- Guidelines for information to patients?
- Easy-to-find place – is it possible to set up a “one-stop shop” for quality and safety at EU level?

There is growing recognition that quality of care and patient safety should be addressed at European level as well as at national level. In future, Member States may be able to 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 within this process, it is very important to establish the quality elements that matter to patients and what patients understand to be good quality care, so the patient community must ensure that the indicators that are chosen will measure the things that matter for patients.

#### EUROPEAN REFERENCE NETWORKS

**Matthew Johnson** of EURORDIS focused on what the role of European Reference Networks could be in delivering cross-border healthcare, especially from the perspective of the rare disease patient.

The emerging landscape is one of big ambitions for rare diseases, based on the promise of the Directive:

- Individual ambition (patients and patients' organisations): “No decision about me, without me!” Equal partnership when discussing (if not deciding) issues which impact patients' lives;
- National ambition (European Committee of Experts on Rare Diseases – EUCERD): All rare diseases covered by at least one ERN which will focus on groups of diseases such as rare hematologic diseases, rare pulmonary diseases, etc. Currently there are more than 7,000 individual rare diseases in the Orphanet database;
- European ambition (International Rare Diseases Research Consortium): 200 new therapies for rare diseases and the means to diagnose most rare diseases by 2020. This is a very ambitious target, which shows the level of commitment at European level, especially by clinicians.

These themes are transferable to other conditions – ERNs will cover more than just rare diseases.

#### INTEGRATION AND INTEROPERABILITY

One of the crucial factors in successfully establishing ERNs for rare diseases will be to ensure that patients can contribute their expertise effectively as equal partners in discussions; the European Patients' Academy on Therapeutic Innovation ([EUPATI](#)) is one initiative that will help develop that expertise.

There is also an emerging need to connect “big data” (involving the collection, storing and analysis of data on a large scale) for rare diseases, e.g. genetic data (including [omics](#)), registries and clinical data (correlation between diseases, pre-symptomatic disease factors).

Other related initiatives include: a European Commission programme for the integration of research infrastructure (reducing duplication/redundancies), which over the next three years will focus on a transitional research pathway for rare diseases that will shorten the timespan between laboratory development and clinical trials; and national plans for the accreditation of Centres of Expertise for rare diseases, with the aim of these being connected up with Centres of Expertise of other Member States within ERNs.

The development of ERNs has now moved beyond advocacy and the formulation of legislation and policy, reaching the Delegated Acts (adopted in March 2014, entered into force in May 2014) that allow ERNs to exist legally. With implementation comes the need for patients' organisations to ensure that what they need is carried out in practice.

#### **TESTING THE CONCEPT OF A EUROPEAN REFERENCE NETWORK**

The rationale for focusing on ERNs rather than national reference networks for rare diseases is easily understandable and is defined in the Delegated Acts; factors such as rarity of expertise, low prevalence, complexity of care and high cost of treatment all point to the need to centralise expertise and resources.

The Commission has identified key elements within the concept of ERNs connecting national Centres of Expertise across different Member States:

- “Added value” at an EU level should be clearly demonstrated;
- ERNs are about providing high-quality healthcare and improving access – research is a secondary activity;
- The experience of the pilot schemes has demonstrated that there is a risk of ERNs being exclusive in their networking. Dissemination of knowledge is crucial, so the emphasis must be on outward-facing and effective networking based on enhanced communication, with the aim of raising the level of knowledge, expertise and treatment across Europe;
- There is a requirement to be responsive: the ERN model must be flexible enough to accommodate the practical realities of a patient and his/her family travelling abroad to access treatment;
- Referral networks versus centralised care: within a referral network, a Centre of Expertise in Sweden might diagnose a patient remotely and then provide advice and a care plan to the local Centre in the Czech Republic (shared care arrangements); whereas centralised care would be more appropriate when there are clear advantages for the patient to travel to a particular Centre, e.g. for specialised surgery;
- ERNs must be built on collaboration and co-operation, countering the prevailing tendency for Centres of Expertise to be competitive with each other.

## THE LEGISLATIVE FRAMEWORK AND IMPLEMENTATION

The dynamic has shifted from common policy and legislation to implementation. Since healthcare is a “shared competency”, in terms of driving the process the baton now passes from the Commission to the Member States, with the Commission focusing on co-ordination and monitoring of the process for assessing ERNs.

One key issue is that the Commission does not have funding to support ERNs; it is the Member States that retain control over the funding, so they have the responsibility for leading the effort to get healthcare providers to co-operate within ERNs. Another issue is that the timeline for accrediting the first ERN under the Commission’s roadmap is quite short, so there is the risk that some Member States will be slow to stimulate debate and appetite for ERNs rather than national networks. Also, experience and expectation at Member State level is variable, so the lack of an articulated commonly-shared vision or a co-ordinated strategic approach might hinder the development of ERNs – National Plans for rare diseases are therefore a key lever at national level.

Under the Delegated Acts, patient’s organisations are not specifically included in the governance, assessment and evaluation of ERNs. However, the legislation does not exclude ERNs from involving patient’s organisations in these functions: it specifies that ERNs are required to demonstrate patient-centric care and patient empowerment.<sup>10</sup>

The Commission’s Expert Group on Rare Diseases, which replaced EUCERD and held its first meeting in February 2014, has continued the work on best-practice guidelines and Recommendations for Centres of Expertise and ERNs. Unfortunately, the Delegated Acts omitted a recommendation from the Expert Group that – specifically for rare diseases – patient’s organisations are integral in the governance, assessment and evaluation of ERNs. Patient’s organisations for rare diseases are experts themselves, and so are ideally-placed to assess a proposed ERN. In July 2014, the Commission is to issue its call for tenders for the development of a technical manual and toolbox for the assessment of ERNs; it is to be hoped that this manual will include the aspects of the Expert Group’s recommendation regarding patient’s organisations being not only members of the ERNs’ boards (influencing their delivery) but also being members of the independent assessment bodies. How can ERNs be accredited meaningfully and transparently as empowering patients and being patient-centric in providing care, without patient’s organisations being able to articulate the patient’s perspective within the independent assessment process?

## THE CHALLENGES WE FACE

One of the most important challenges is the risk of fragmentation, especially in relation to rare diseases; without a co-ordinated strategic approach at European level, the result may be ad hoc responses to single diseases or a variation in response across Member States.

Another challenge is the risk of dilution of the patient’s voice or even its exclusion from crucial aspects of developing ERNs. Patients’ organisations acting in solidarity have a very strong voice, which can be best used to remind Member States that if the patient perspective is not integrated into ERNs, the result will be a disastrous loss of opportunity. Patients’ organisations are fundamental

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<sup>10</sup> See [http://www.rare-diseases.eu/wp-content/uploads/2014/05/0102\\_Enrique\\_TEROL2.pdf](http://www.rare-diseases.eu/wp-content/uploads/2014/05/0102_Enrique_TEROL2.pdf) for a more detailed presentation of the assessment and membership criteria for ERNs as specified in legislation.

to the development of services for rare diseases: there are very many examples of patients' organisations working with clinicians who have an interest in a particular condition to develop a service that ultimately benefits from national funding schemes. Patients' organisations need to explain to Member States the economic benefits of rare disease patients being treated at home through ERNs: the very nature of rare diseases means that significant numbers of patients are misdiagnosed or not diagnosed for several years, resulting in misdirected healthcare provision over time. A more focused approach to ERNs for rare diseases can therefore reduce waste in national health systems instead of posing an additional financial burden, and can release existing capacity.

Of the other clear challenges – which include economic pressure and financial sustainability (especially as national health systems come under increasing pressure), transparent pricing and reimbursement of the true cost of treatment, etc. – one could highlight communication and language barriers: eHealth is one component of ERNs that will depend on efficient communication between Centres of Expertise.

Finally, there has been a lot of discussion about ERNs developing EU-wide best practice guidelines, but the implications of specifying required resources need to be tested. Variation is the hotbed of innovation in terms of refining or developing practice, so standardisation of practice should not be sought on principle – it should only be pursued when there is clear evidence of improved outcomes.

### **UNLOCKING THE POTENTIAL**

Experience with pilot schemes has shown that face-to-face meetings are essential for promoting a culture of learning among ERN partners, which also promotes quality and safety benchmarking. Co-production of outcomes with all partners is integral to the functioning of ERNs, which is likely to result in improved clinical outcomes and quality of life. This aspect can improve timely diagnosis and reduce the rate of undiagnosed and misdiagnosed conditions: for example, research has shown that only 40 % of sarcoma cases were diagnosed correctly at the first reading.

The development of ERNs gives renewed hope to some 30,000 patients in Europe with rare diseases, who can now look forward to more timely and improved access to accurate diagnosis and new treatments. The completion of a long legal process for the Directive marks the beginning of the implementation phase; advocacy by patients' organisations must therefore continue at national level to encourage Member States to champion the patient's perspective for ERNs, but also at European level, in order to provide the Commission with a mandate to challenge Member States to take the necessary action.

### **MAIN OUTCOMES:**

Through serious and detailed discussion about the practical process of obtaining cross-border treatment, the participants succeeded in shedding light on some of the flaws and core challenges contained in the Directive as it stands today. One of these core challenges is to ensure that quality of care and patient safety are not measured by the lowest common denominator. The situation can be summarised as: firstly, the need to resolve financial issues for patients, secondly, the importance of ensuring access to quality healthcare, and thirdly the difficulties arising from cuts in national health budgets.

The current legal status of patients' organisations in relation to ERNs is a major cause for concern. A failure to address patient empowerment positively and practically in the technical manual and toolbox for assessment of ERNs would represent a crucial step backwards.

Overall, there are a number of recommendations that can be made which require a response by NCPs, healthcare providers and patients' organisations. But there are also recommendations that address the need to reshape the Directive in the medium-to-long term and are therefore political in nature – the response to these would need to come from the Commission, Council and the national governments.

## 8 Session Five

### EXPLORING THE ROLE OF PATIENTS' ORGANISATIONS IN SECURING EFFECTIVE IMPLEMENTATION OF THE DIRECTIVE – PANEL DISCUSSION WITH NCP REPRESENTATIVES

**Csaba Kiss** (Hungary), **Margit Gombocz** (Austria), **Adam Ander** (Czech Republic) and **Klemen Ganziti** (Slovenia) reflected on patient involvement in the work of the NCPs and how patients' organisations might support them.

As NCPs are defined by law and are constrained to act within governmental or public sector guidelines, this has a bearing on the manner and extent to which they can collaborate with patients' organisations. This aspect is linked to the basic issue of identifying which patients' organisations could be involved: should it just be one or two big/umbrella national organisations, or should all patients' organisations – however small – have the opportunity? At the practical level, currently both NCPs and patients' organisations often do not know who to talk to in order to initiate collaboration.

The number of enquiries made to NCPs will vary according to how effectively patients' organisations themselves provide basic or general information to patients regarding cross-border healthcare. This means that there are clear opportunities for better co-ordination between NCPs and patients' organisations to ensure that patients can access specific information in the first instance without necessarily using NCP resources – which can then be better planned and targeted. The drive to improve the resources and functioning of NCPs could be helped overall by collaboration with patients' organisations.

Communication between NCPs and national authorities appears to be displaying the usual governmental dynamic. Solving the emerging issues – e.g. improving the quality and scope of the information communicated to patients, which is a core function of the NCPs – will therefore require courage to push for change.

In Austria, the bar was set quite low in terms of allocating resources to the NCP. There is no call-centre, and the NCP responds to general enquiries by email; it forwards detailed enquiries (e.g. on reimbursement) to health insurers or institutions that can provide the answers. In Slovenia, the media's approach to the cross-border healthcare Directive in October/November 2013 provided the

NCP with the opportunity to put out the right message through TV and radio channels, which resulted in a significantly increased response (although still modest overall). In Hungary, a good start has been made, but more needs to be done; one possibility being considered is a roadshow to healthcare providers in bordering countries to identify specific healthcare solutions.

Regarding the possibility of a differentiated approach by NCPs to enquiries from patients with chronic conditions as opposed to acute conditions, at the moment volumes are still quite low, so data cannot be segmented meaningfully to allow a distinction to be made. NCPs are therefore focusing currently on providing the right information to each enquiry under the Directive. However, other solutions are available: in Slovenia, for example, dialysis and similar treatments accessed abroad are dealt with under the social security Regulations.

We are still in the early stages of implementing the Directive, so all stakeholders must be flexible in seeking out the right solutions. The NCPs need active feedback, e.g. from patients' organisations, to help them improve their responsiveness and overall performance. The proposed conference in Brussels in June 2015 bringing together NCPs and patients' organisations will be another opportunity to address the emerging issues and challenges on a collaborative basis.

#### **TAKE HOME MESSAGES**

**Moderator Nicola Bedlington** invited representatives from the various participating countries in turn to tell the Conference what message they will be taking away and what actions they will take on returning home:

#### **SLOVENIA**

"This Conference was a very good opportunity to meet other stakeholders and build our network. It has opened up a new channel for mutual support as we work to improve the system."

"Although there is a national association of patient organisations that can speak with one voice at the political level, it is also important that every patients' organisation focuses on interacting with the NCP on its own account."

#### **SLOVAKIA**

"The most important task for us is to wake up our NCP; the first step is to communicate the messages from this Conference, and we are already talking about arranging a meeting. It is also vital that we discuss within our own organisation how to make maximum use of this Conference for the benefit of our patients."

"Although we have a wide range of formal partnerships, we do not have the capacity to cover all the issues. Dealing with the NCP is crucial, and this may require dedicated resources."

"The project to create ERNs is the best possible answer to Euroscepticism."

"My organisation is a member of an umbrella organisation for rare diseases, so our first task is to spread the information from this Conference to our partner organisations."

#### **AUSTRIA**

“Patients’ organisations dealing with rare diseases are probably better placed to promote the benefits of the Directive to patients and the general public, so it is important that the rare disease organisations which were not at the Conference are informed of the issues. We will also make sure that we maintain close contact with the NCP and keep our patients informed.

There are still issues with the Directive as it stands. For example, the prospect of having to travel further than a bordering country for treatment represents a significant expense to patients and their families, in addition to the fundamental issue of upfront payment before reimbursement. Also, some health insurers seem to actively look for reasons to say no to reimbursement – as long as loopholes to say no still exist, there is a lot of work to be done.”

### **CZECH REPUBLIC**

“After initiating contact, we have made progress in identifying with the NCP those areas in most need of work, e.g. raising awareness of the Directive and improving access to information. We will also consider inviting representatives of the NCP to our conferences, and will be happy to liaise with the Czech umbrella organisation in maintaining contact with the NCP.”

“As representatives of the Czech NCP, it was very useful to build on formal partnerships by coming to this Conference to have personal contact and hear personal stories. This will help us to move things forward.”

### **HUNGARY**

“The strength of our participation in this Conference reflects the hard work that went into founding the national coalition of patients’ organisations. Visibility is a crucial issue for patients’ organisations as well as NCPs, which we need to address – this Conference provides another opportunity to build visibility and pursue the objectives of the Directive.

In former Soviet-bloc countries, the state still plays a predominant role, to the extent of suggesting that patients’ organisations are part of the governmental structure. On the positive side, in contrast with other Member States the national health budget is not being cut, but it has been frozen, which means a reduction in real terms on an annual basis.

In my personal view, the Hungarian NCP seems to be using its budget to maintain itself rather than to help patients access cross-border treatment. In this Conference we have made recommendations for patients’ organisations to work closely with NCPs, but where will the funding come from for these actions? Perhaps we can address this problem in collaboration with EPF.”

“As the Hungarian alliance of patients’ organisations, which is an independent body, we are working to raise awareness of the Directive; this will include inviting the NCP to participate in our conference activities. Our national conference in November 2014 will be a significant step forward for us, and we will use this as a platform for spreading information.”

Giving the **closing remarks**, **Boris Sustarsic** of the European Alliance of Neuromuscular Disorders Associations (EAMDA) recalled the journey the participants made over the last two days, and reflected on the next steps.

The series of conferences on the cross-border healthcare Directive organised by EPF is about empowerment and capacity building for patient leaders. It relates to the strength of the patients' movements in the participating countries. Several contributions during the Conference highlighted the view that countries which have a national coalition of patient groups working together in unity are much stronger than those that do not; for example, Slovakia has a national platform, and after a great deal of work an umbrella organisation was created in Hungary. EPF will continue to support patients' organisations in any way possible to create national platforms in all Member States. One EPF initiative that focuses specifically on capacity building is the European Patient Academy on Therapeutic Innovation (EUPATI).

Referring specifically to the cross-border healthcare Directive, it is clear that national patients' organisations will continue to play a key role in each of the Member States, especially in terms of communicating and co-operating with other stakeholders to promote the implementation of the Directive and monitor 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 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 regarding information about this Conference, and should express their willingness to co-operate with other stakeholders in creating optimal information to both patients and healthy citizens.

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.

## 9 Annexe 1 – Conference programme

### CROSS BORDER HEALTHCARE CONFERENCE

7-8-9 July 2014

Ljubljana, Slovenia

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#### Agenda

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##### Day One – 7 July

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| 19.30 | <b>Welcome Reception and Buffet</b>                              |
|       | <ul style="list-style-type: none"> <li>• Quiz on CBHC</li> </ul> |

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##### Day Two – 8 July

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|-------------|---|
| 8.00-9.00   | <b>Registration</b>   |
| 9.00-10.30  | <p><b>The first Directive focussing on ‘Patient Rights’ – what does this really mean for patients?</b></p> <p>EC perspective: John Rowan, DG SANCO European Commission<br/>         Patient Perspective: Dr Gábor Pogány, Hungarian Patients’ Forum</p> <p><b>Plenary debate</b></p> <p><i>Objectives:</i></p> <ul style="list-style-type: none"> <li>• To provide a clear overview of the scope of the Directive and its application</li> <li>• To highlight its strengths but also potential barriers in implementation, new rights compared to existing social security legislation</li> </ul> |
| 10.30-11.00 | <b>Coffee Break</b>   |
| 11.00-12.30 | <p><b>The crucial role of National Contact Points (NCP) and creating a framework model that meets the needs of Patients</b> – Moderator: Tamsin Rose</p> <p><b>Presentation of the Slovenian National Contact Point</b> – Siniša Bošnjak</p> <p><b>Working groups</b> – What would a “model” National Contact Point look like?</p>  |
| 12.30-13.30 | <b>Lunch</b>  |
| 13.30-14.45 | <p><b>Workshops: 3 parallel workshops on the Patient Journey in Cross Border Healthcare</b><br/>         Moderators: Tamsin Rose, Camille Bullo (EPF), Nicola Bedlington (EPF)</p> <p><i>Objectives :</i></p> <ul style="list-style-type: none"> <li>• To address specific aspects of the Directive from the perspective of “the patient journey” and will both provide more detailed information on what aspects of the Directive are relevant at different stages and what specific information needs</li> </ul>  |

- patients will have*
- *Aim to generate a discussion identifying critical issues from a patient's point of view, and develop recommendations for Member States and patients' organisations in this regard, to create a sense of "ownership"*

14.45-15.15	<b>Coffee Break</b>
15.15-16.30	<b>Continuation of workshops: The Patient Journey in Cross Border Healthcare</b>
16.30-17.00	<b>Meeting room available for the rapporteurs to work on the feedback of the working groups to the plenary on Day 2</b>
19.30	<b>Dinner</b>

### Day Three – 9 July

9.00-9.50	<p><b>Feedback from the rapporteurs on the core questions, discussions and recommendations from the workshops – Moderator: Nicola Bedlington (EPF)</b></p> <p><i>Objectives:</i></p> <ul style="list-style-type: none"> <li>• <i>To reinforce information gleaned on the thematic topics and the issues raised</i></li> <li>• <i>To enable the participants to obtain a clear overview on the outcomes of the workshop in which they were not involved</i></li> </ul>
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9.50-10.40	<p><b>Quality of Care and Patient Safety – Cornerstones of the legislation</b> Dominik Tomek, Association for the Protection of Patient' Rights, Slovak Republic and EPF Board Member</p> <p><b>European Reference Networks</b> Matt Johnson, Eurordis</p> <p><i>Objectives :</i></p> <ul style="list-style-type: none"> <li>• <i>To ensure a full understanding of the provisions within the Directive that will focus on quality of care, transparency of safety and quality standards ,and the impact of this for the Patient seeking treatment abroad, and the wider policy context</i></li> <li>• <i>To discuss European reference networks and their contribution to improving the quality of diagnosis and treatment</i></li> </ul>
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10.40-11.10	<b>Coffee Break</b>
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11.10-12.15	<p><b>Exploring the role of patients' organisations in securing effective implementation of the Directive – Panel discussion</b></p> <p>Moderator: Nicola Bedlington (EPF)</p> <p><i>Objectives:</i></p> <ul style="list-style-type: none"> <li>• <i>To outline possible actions based on previous experience,</i></li> <li>• <i>To develop a plan of action in terms of cascading knowledge from the conference,</i></li> <li>• <i>To support and to ensure the commitment of the participants to pursue this and be part of an informal network for evaluation.</i></li> </ul>
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12.15-12.30 **Take home messages – Closing remarks: Boris Sustarsic (EAMDA)**

12.30-14.00 **Farewell networking lunch**

## 10 Annexe 2 – Participation list

First Name	Last Name	Organisation
Abele	Maria	Union of Patients with Hemochromatosis
Ander	Adam	National Contact Point for Cross-Border Healthcare CMU (Czech Republic)
Andriciuc	Christian	Centre for Community Policies
Arellanesova	Anna	Czech Association for Rare Diseases
Baraga	Dusan	Association for IBD
Bardos	Dora	Vertebra Foundation
Bedlington	Nicola	European Patients' Forum
Bence	Rita	Hungarian Civil Liberties Union
Biziak	Anastazija	SLOVENIAN TRANSPLANT ASSOCIATION
Bošnjak	Siniša	National Contact Point for Cross-Border Healthcare (Slovenia)
Bouskill	Kathryn	Europa Donna Austria
Buechler	Ekkehard F	Selfhelp Prostatecancer
Bujdosó	Gergely	Misko Foundation
Bullot	Camille	European Patients' Forum
Charalambous	Charles	European Patients' Forum
Daru	Katalin	Hungarian Crohn's and Ulcerative Colitis Patients' Association
Drdulova	Terezua	Slovak association for spina bifida and hydrocephalus

Dušek	Karel	The Czech association of patients with IBD
Dvořáková	Jitka	National Contact Point for Cross-Border Healthcare CMU (Czech Republic)
Farsky	Stefan	Slovak League against Hypertension
Fedorova	Katarina	Slovak Myeloma Society
Foltánová	Tatiana	Slovak Alliance for rare diseases
Frank	Natalija	Europa Donna Austria and PAN Austria
Gombocz	Margit	National Contact Point for Cross-Border Healthcare (Austria)
Gorjup	Nataša	National Contact Point for Cross-Border Healthcare (Slovenia)
Gross	Evelyn	ÖMCCV - Austrian Crohn and ulcerative colitis association
Hadfi	Bernadett	Hungarian Cancer League
Ilencikova	Juliana	Multiple Sclerosis Association Hope
Johnson	Matthew	EURORDIS
Judit	Varadine Csapo	Hungarian Muscle Dystrophy Association
Kiss	Csaba	National Contact Point for Cross-Border Healthcare - OBDK (Hungary)
Kněžická	Šárka	National Contact Point for Cross-Border Healthcare CMU (Czech Republic)
Koltai	Tunde	Hungarian Coeliac Society
Koprda	Vasil	Europa Uomo Slovakia
Krajnc	Bogomir	ŠENT - Slovenian Association for Mental Health
Kramárová	Patrícia	Europacolón Slovakia
Kržan	Mateja	Slovene Association for Fibromyalgia

Kucera	Petr	Association for the Protection of Patients' Rights Slovak Republic
Kucerova	Eva	Adam Česká Republika
Kurka	Zdenek	CREDUM PRAGUE, EATG
Kustura	Goran	National Council of DPOs
Likar	Cvetka Pavlina	Društvo Trepetlika
Lorencic	Mojca	Slovenian Kidney Patients' Association
Michalov	Lubos	Gift of Life
Mrak	Branko	SLOVENIAN TRANSPLANT ASSOCIATION
Niranjan	Emil	Ozara Slovenia
Nose	Tanja	National Contact Point for Cross-Border Healthcare (Slovenia)
Novak	Krisztina	National Contact Point for Cross-Border Healthcare - OBDK (Hungary)
Pirnat	Nina	Ministry of Health of the Republic of Slovenia
Pocsai	Fruzsina	FCFBE , Hungarian Cystic fibrosis association of Adults
Pogány	Gábor	Hungarian Patients Forum
Röhl	Claas	NF Kinder- Verein zur Förderung der Neurofibromatoseforschung Österreich
Rowan	John	European Commission DG SANCO
Sasinkova	Pavla	Czech Huntington Association
Stefánkovits	Ildikó	HOPA - Hungarian Osteoporosis Patient Association
Strečková	Izabela	Europacolon Slovakia
Sustarsic	Boris	EAMDA
Svetlovska	Elena	Europa Uomo Slovakia

Takáts	Annamária	Delta Hungarian Parkinson's Association
Tamsin	Rose	Tamarack
Tomek	Dominik	Association for the patient' rights protection Slovakia EPF Board Member
Varga	Gábor	Hungarian Haemophilia Society
Wisak	Tobias Herbert	PAN - Patient Advocacy for Adolescents and young Adults with Neoplasia
Zavillová	Nicolette	Association of diabetic patients of Slovakia
Zlobec	Stefania	Alzheimer Slovenija- Spominčica
Zsuzsanna	Kapitány	Recovering Together Association