

# **“CROSS-BORDER HEALTHCARE: IS IT WORKING FOR PATIENTS ACROSS THE EU?”**

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## **Conference Report**

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## 1 Introduction

The impact of directive 2011/24/EU on the application of patients' rights in cross-border healthcare – the “Cross-Border Healthcare Directive” – will depend to a large degree on the knowledge of patients across the EU of their rights under the legislation and its potential benefits.

During the long “legislative journey” of this directive, EPF and its members undertook considerable work with the EU Institutions and stakeholders to embed patient-centred provisions. Following its adoption, EPF produced a toolkit and recommendations to raise awareness during the transposition phase. As this phase ended on 25 October 2013, EPF felt that the timing was right to organise a series of dedicated regional conferences to raise awareness among patient communities “on the ground” about the directive, what it can do for patients – and also what it cannot do.

Four regional conferences took place between December 2013 and October 2014, in Brussels, Athens, Ljubljana and Tallinn. Each conference was attended by between 40-45 patient representatives from the participating 20 EU member states. In addition to patient representatives, National Contact Points (NCPs) were invited to send representatives and European Commission officials participated in each conference. National workshops were held in the first half of 2015 in the following countries not covered by these regional conferences: Bulgaria, Croatia, Ireland (also covering the United Kingdom), Poland, Romania and Spain (also covering Portugal).



The objectives of these events were to build knowledge of patient leaders in the different countries about the directive and about patients' rights; to ensure understanding about the scope of the directive and also its shortcomings; and to prepare the ground for evaluation of the impact of the legislation from the patient's perspective. In practice, the participation of NCP representatives gave an initial opportunity for a real exchange regarding the realities of the legislation from the patient's perspective, and how patients' organisations might work together with the NCPs and their national governments to support effective implementation.

Three key themes were identified by patients' organisations as the highest priorities: information; safety and quality of care; and equity of access. Although overall, participants tended to identify the same issues and challenges, these were often expressed in a nuanced way reflecting different national realities. The key messages are contained in the individual conference and national workshop reports produced by EPF.<sup>1</sup>

This latest Conference on the Cross-Border Healthcare Directive aimed to build on this process in order to maintain the momentum towards equal and effective implementation across all the member states. Bringing together representatives of the NCPs, patient leaders, policy makers from the EU Institutions and national levels and key stakeholders, its specific objectives were:

- To provide structured feedback from the perspective of the patient community on successes and challenges in implementation to date;

<sup>1</sup> The full reports of all four regional conferences and three of the national workshops, plus a Summary Report, are available on EPF's website at <http://www.eu-patient.eu/whatwedo/Policy/Patients-Mobility/>

- To galvanise links and exchange good practices with regard to cooperation between representatives of patients' organisation and NCPs; and
- To raise awareness across the EU institutions and member states regarding the realities faced by patients when using the directive.

The Conference lasted one day and was conducted in English. It was structured around thematic plenary sessions and interactive debates with the audience, as well as parallel group sessions, followed by a closing plenary which presented the key conclusions and perspectives for the way forward.

This report presents the contributions made during the Conference in an edited and/or summary form. The full versions of the presentations and other material can be found on the EPF website at: <http://www.eu-patient.eu/News/News/press-release-is-cross-border-healthcare-working-for-patients>.



## 2 Executive Summary

The Cross-Border Healthcare Directive signalled a major change in the EU's involvement in health policy. Since the directive was agreed in 2011, the European Commission has been very active in checking that member states have met their obligations to transpose it by October 2013. Today, the directive is almost completely transposed across the EU, and every member state has set up an NCP. But has it been transposed properly?

From the Commission's perspective, there are four main challenges. The unequal levels of implementation across member states can deter patients from using their cross-border rights in practice; ensuring fair transposition is therefore the first challenge. The second is to better inform patients about their rights, and it is clear that patients' organisations have a key role to play in this process. The third challenge is to address the differences in quality of information available to all patients, and to use the tools we have to promote reform and empowerment most effectively. The fourth challenge is to find a way to deliver real, tangible benefits to patients through greater co-operation and collaboration, without undermining the fundamental responsibilities of national authorities.

This Conference is a natural extension of the process of consultation with patients initiated through the series of regional conferences and national workshops organised by EPF, which involved all 28 member states. The Conference offers an opportunity to continue to share and discuss the key themes that have emerged very clearly from that consultation process, and to explore the positive elements of the directive as well as the challenges and grey areas, both from the perspective of patients and the NCPs.

At this stage, it is not surprising that implementation is uneven; but, importantly, it is also evident that there is little involvement of patients' organisations in the process. A number of potential benefits and challenges seen by patients in the directive were highlighted during the



regional conferences and national workshops organised by EPF. Perhaps the most important potential benefit is for patients to know about their rights and to exercise them – particularly the right to access treatment. The caveats that have emerged relate particularly to equity of access; also to the uneven provision of good information, and concerns regarding the quality and safety of care.

The Conference heard a summary presentation of the key findings of those consultations, as well as a summary description of what the “ideal” NCP should look like from the patients’ perspective. It also heard contributions by the Swedish and Slovenian NCPs regarding the role NCPs can play to facilitate patients’ exercising of their rights, and some of the challenges faced by the NCPs. This was followed by a facilitated debate, during which the significant differences in resources allocated to NCPs were highlighted once again.

The afternoon began with three parallel workshop sessions which explored specific priority topics within the directive: information needs of patients; quality and safety of care; and reimbursement and equity of access. Participation in each group was balanced between patient representatives, NCPs from different regions as well as representatives of the European Commission. The closing plenary session began with brief reports of the conclusions of the three parallel workshop sessions; the workshop discussions produced comments, issues and recommendations which enhance and build on those contained in EPF’s Summary Report of the regional conferences and national workshops.

In his response to the Conference’s work, the European Commission representative outlined the next steps in addressing specific challenges relating to the proper implementation of the directive, including a major focus on information and raising awareness in each member state. From the Commission’s perspective, patients’ organisations and other stakeholders have an important role to play in addressing these challenges. This Conference has provided several good illustrations of the extremely valuable function of patients’ organisations in identifying needs and gaps in implementation, and then – importantly – proposing solutions and initiatives for resolving them. Some of the ideas that have emerged here will be fed into the discussion on the directive under the Luxembourg Presidency.

The Commission’s progress report on implementation is now due to be delivered to the Council and the Parliament in September. EPF looks forward to reading the Commission’s progress report in the autumn, and will then consult its membership and its network of patient leaders and take a position on what needs to be improved.

Closing the Conference, EPF Board Member Marco Greco said:

*“We have the experience, we have the capacity and we have the knowledge to lead the discussion on what is best for the patients, whom we represent. The hardest part has been done – now it is important to keep focusing on what is still not working properly. But we must always keep in mind that very often patients are obliged to move from one country to another for healthcare – it is not a free choice or some version of tourism. We are all aware of the impact of the crisis on many countries, so we understand that this is a difficult moment from the economic point of view. Somehow even the idea of Europe is struggling, but here we are not simply talking about solidarity, we are taking about a fundamental human right. Cross-border healthcare is a fundamental right, because without access to healthcare you cannot have full citizenship.”*



## 3 Setting the scene

### 3.1 WELCOME AND INTRODUCTION

*Marco Greco, EPF Board Member*

The directive on patients' rights in cross-border healthcare is undoubtedly one of the most important pieces of EU legislation from the patient perspective. The patient community welcomed it, after a long and sometimes frustrating legislative process. The result is inevitably a compromise, with significant uncertainties and gaps. However, the real impact of the directive will depend on the approach taken by the member states, which are obliged to transpose its provisions in their own national legislation and implement them in practice.

Through a series of regional conferences and national workshops, EPF has reached out to patient communities in all the member states, and created an informal network of patient leaders committed to disseminating information to their peers and actively monitoring developments in their countries during the next years.



From these initial consultations, it is clear that implementation of the directive is still patchy, exacerbated by the fact that some countries have long-standing pre-existing cross-border arrangements, while others had no previous experience. And of course, many member states are experiencing financial pressures and difficulties in healthcare provision.

Nevertheless, patients see the directive as offering opportunities to enable them to exercise their rights – for example, allowing faster access to treatment for patients experiencing long waiting times, and increasing the transparency of providers and pricing of medical procedures.

Naturally, there are also challenges: primarily, the burden on the patient for paying the costs of cross-border healthcare upfront; low awareness of the directive; and the risk that it could benefit only those who are already affluent and well-informed.

This Conference is a natural extension of the events of the past eighteen months, offering an opportunity to continue to share and discuss the key themes that have emerged very clearly from EPF's consultations with patients, and to explore the positive elements of the directive as well as challenges and grey areas, both from the perspective of patients and the NCPs.

### 3.2 OPENING REMARKS<sup>2</sup>

*Dr Vytenis P Andriukaitis, European Commissioner for Health*

The directive signalled a major change in the EU's involvement in health policy. Since the directive was agreed in 2011, the Commission has been very active in checking that member states have met their obligations to transpose it by October 2013. Today, the directive is almost completely transposed across the EU, and every member state has set up an NCP. But has it been transposed properly?

<sup>2</sup> The full transcript of the Commissioner's remarks can be found at: [https://ec.europa.eu/commission/2014-2019/andriukaitis/announcements/european-patients-forum-conference-cross-border-healthcare-directive\\_en](https://ec.europa.eu/commission/2014-2019/andriukaitis/announcements/european-patients-forum-conference-cross-border-healthcare-directive_en)

Although a number of member states appear to have done a good job of transposition, there are others where the Commission has a number of serious concerns. For example, some countries have very elaborate systems of prior authorisation, others seem to use lower reimbursement tariffs than they should, and some have very difficult administrative requirements.



Each of these concerns can deter patients from using their cross-border rights in practice. *Ensuring fair transposition is therefore the first challenge*, and the Commission will focus on monitoring this.

Data provided to the Commission by member states show that so far – with a few notable exceptions – relatively few patients have used the directive to get treatment abroad. A recent Eurobarometer survey<sup>3</sup> showed that around half of patients said they would consider doing this, yet only 5% said they had received treatment abroad.

Why does this discrepancy exist? Firstly, some countries have been late in transposing, so the directive is still rather new; secondly, some countries have implemented the directive in such a way that there are numerous deterrents and hurdles for patients; and thirdly – and crucially – the number of patients who know their rights is still very small. The same Eurobarometer survey showed that fewer than 20% of patients feel informed about their cross-border rights and only 10% knew of the existence of NCPs.

*This is the second challenge – to better inform patients about their rights.* It is clear that patients' organisations have a key role to play. The directive's provisions on transparency and information are relevant for all of those who advocate empowering patients. These provisions provide policy tools that can be tied in to wider discussions at national level on reforming health systems.

However, currently the quality of information given by NCPs and healthcare providers varies considerably across the EU. The directive provides a framework in which the member states and the Commission can share ideas on how best to deal with this. *This is our third challenge: to address the differences in quality of information available to all patients, and to use the tools we have to promote reform and empowerment most effectively.* This also relates to the use of eHealth technologies. National health systems must work together to ensure smooth and timely sharing of information, so the systems need to be interoperable in order to share patient records, exchange e-prescriptions or provide e-consultations. This means that issues regarding data protection must be addressed without delay.

The directive has served to highlight the fact that health systems across the EU face similar challenges, including: pressures on resources; an ageing population; increasing expectations and possibilities for treatment; and workforce shortages. The directive identifies a number of areas where co-operation across borders really is the solution to the eternal problem of how to do "more with less". For example: EU-wide co-operation on Health Technology Assessment (HTA) makes perfect sense, avoiding replication; some conditions are simply too rare for all countries to possess the necessary expertise, so European Reference Networks (ERNs) for rare diseases can help solve this problem.

Although there is increasing desire to co-operate across the EU in many areas within the framework of the Single Market, there are 28 national health systems which historically have been 28 closed systems. Our systems cannot continue to operate as they have always done and yet still satisfy the

<sup>3</sup> Special Eurobarometer 425, "[Patients' rights in cross-border healthcare in the European Union](#)", May 2015.

demands of patients, not least because patients are increasingly aware of what is going on in other member states. *So the fourth challenge is: to find a way to deliver real, tangible benefits to patients through greater co-operation and collaboration, without undermining the fundamental responsibilities of national authorities.*

Finally, Article 7 of the directive leaves it to the member states to decide whether to reimburse costs related to care, such as accommodation and travel expenses. Family or friends who are needed to accompany the patient also face costs, including that of having to take days off from work. The Commission would like to encourage member states to work more closely across sectors in looking for solutions to these real issues.

### 3.3 THE VIEW FROM THE LUXEMBOURG PRESIDENCY OF THE EU

*Anne Calteux, Ministry of Health, Luxembourg*

The patient and innovation will be the focus of health-related priorities during the Luxembourg Presidency, within the overall theme of “A Union for citizens” – since all citizens are patients.

The Luxembourg Presidency shares EPF’s approach to cross-border healthcare: to explore the positive elements of the directive as well as the challenges and grey areas. The directive will be addressed during the informal Council on 24-25 September, focusing on the conclusions and recommendations of the Commission’s progress report, which is due in September. The aim will be to actively encourage health ministers to reflect on what the directive has really delivered to patients and the member states: is there added value, or has the directive made things more complicated? One key message which is already emerging is that implementation is happening, but more can be done – the question is: how?



The concrete objectives include providing more clarity on: existing rights and new opportunities for patients; the inflow and outflow of patients; and the impact on the rules regarding reimbursement and prior authorisation – do the rules really work for patients? Another element is to promote and enhance cooperation by member states in regions where there is already demand for cross-border healthcare. Also, the official launch of the ERN will take place in Lisbon on 8-9 October, as a concrete outcome of the directive.

Luxembourg was active from the outset in advocating a separate directive on cross-border healthcare, taking healthcare out of the Bolkestein directive on services in the internal market. Healthcare is not a normal service; it is something special and must take patients’ rights into account. As a small member state with relatively fewer patients with particular conditions, Luxembourg implements cross-border healthcare on a daily basis, so transposition of the cross-border healthcare directive has not required many changes in the national health system. However, the Luxembourg Presidency looks forward to working with patients’ organisations over the next six months, to improve implementation across the EU.

### 3.4 THE PATIENTS' VIEW – KEY FINDINGS OF THE EPF REGIONAL CONFERENCES AND NATIONAL WORKSHOPS

*Kaisa Immonen-Charalambous, Senior Policy Adviser, EPF*



It is clear from the reports of EPF's regional conferences and national workshops on the directive – also from the Commission's evaluation report and other documents – that currently there is not a lot of practical experience among patients of cross-border healthcare. The patients who have experienced it are mostly those living with a rare disease or patients with a complicated or unusual life situation.

At this stage, it is not surprising that implementation is uneven; but, importantly, it is also evident that there is little involvement of patients' organisations in the process. This aspect ties in with the limited knowledge of the directive among patients' organisations prior to the EPF regional conferences and national workshops, which may indicate even lower awareness among the general population – but this situation is changing quickly.

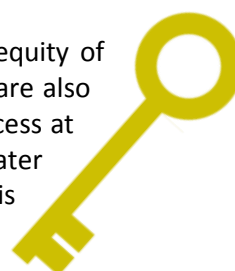
A number of potential benefits and challenges seen by patients in the directive were highlighted. Perhaps the most important potential benefit is for patients to know about their rights and to exercise them – particularly the right to access treatment. The caveats that have emerged relate particularly to equity of access; also to the uneven provision of good information, and concerns regarding the quality and safety of care.

**Equity of access:** Financial barriers are seen by patients as the major threat to equity of access. Interestingly, the directive has highlighted the fact that barriers to access are also seen within countries, so some member states may have to address barriers to access at the systemic level. The transparency provisions will inevitably lead to greater awareness among the patient community of where the gaps are and what is happening in those countries.

**Information needs:** Information is fundamental to accessing care under the directive. The transparency provisions offer huge potential, not only to individual patients but also to patients' organisations, empowering them as advocates for improvements in the provision of national as well as cross-border healthcare. Knowing one's rights and how to make use of them is crucial, but information needs are complex, and the current level and quality of what is provided is too often patchy and not geared to patients' needs. Patients' organisations can play an effective role, not only in highlighting the challenges to national authorities and the Commission, but also in facilitating and participating in the solution to those challenges.

**Quality and safety:** Patients need to be able to trust that the treatment they receive – whether at home or abroad – is safe and of good quality. There is a real challenge regarding the complexity of medical guidelines, especially when comparing what is applied in one country to another country. Continuity of care is another safety issue for patients, as is the need for transparent and effective complaints and redress mechanisms if something goes wrong. On the plus side, ERNs have the potential to improve quality in a way that involves patients.

At each of the regional conferences and national workshops, the patient's journey under the directive was explored in workshops, in four sections: when deciding (enabling trust); before leaving (mitigating risks); during the stay (dealing with the unexpected); and after returning (continuity of care, continuous improvement). Through this process, several key issues from the patient



perspective and specific solutions were identified.<sup>4</sup> There are already some very good solutions and practical tools being provided by patients' organisations, so the challenge is how best to incorporate these widely into implementation of the directive through collaboration between patients' organisations, NCPs and healthcare providers.



Overall, it was notable that the participants in the four regional conferences tended to identify the same issues and challenges, although these were often expressed in a nuanced way reflecting different national realities. The Summary Report contains the main recommendations for member states, NCPs and the Commission derived from this feedback, in the following key areas:

**Quality and safety of care:** It is crucial to have comparable information on quality and safety, both across institutions (within countries) and across member states. Convergence of standards and guidelines should be encouraged, not only for the benefit of patients but also to inform policy-makers' decisions. This in turn highlights the need for benchmarks and key indicators for quality of care, which must include "patient-centredness", so a first step would be to identify and share good practices and facilitate their transferability from one context to another. It is vital to have a mechanism for addressing patients' complaints at national level, but there might also be benefits in a European-level mechanism.

**Information to patients – NCPs:** There must be EU-level guidelines on how to provide information to patients, in order to guarantee equal quality of information. There is also a clear need for guidelines for patients on how to interpret quality and safety information, as too often this is given by member states in an inaccessible, legalistic way. The Commission should encourage member states to adopt standardised templates across the EU for all forms. Patients' organisations would be willing partners in all of these processes; they can also be providers of information to patient communities in collaboration with NCPs, but to do so they must be supported.



**Health inequalities and equity of access:** Evidence on inequalities in access to healthcare needs to be collected at European level; this necessarily begins with the collection of data on treatment costs and on treatments that are not authorised/available in individual member states. Conversely, when good practices and solutions are found in different member states, these should be shared in order to "raise the bar". Specific aspects of the directive can help to relieve the financial burden for patients, based on need: implementation of the "prior notification" system, or use of direct cross-border payment systems (removing the requirement for upfront payment). One creative solution that emerged from one of the conferences is for a cross-sectoral "social funds" approach, where the NCP and health authority would work with the social security system to help patients who are facing particular financial hardship.

Finally, the reality of cross-border healthcare is always more complicated than the expectation, so cooperation and collaboration on implementation between stakeholders is vital. Involving the patient's voice at European, national, regional and even local level will make this much easier.

<sup>4</sup> For full details, see the Summary Report or the individual reports of the regional conferences and national workshops, on EPF's website at <http://www.eu-patient.eu/whatwedo/Policy/Patients-Mobility/>

## 4 Exploring the role of the NCP

### 4.1 THE “IDEAL” NCP FROM THE PATIENT’S PERSPECTIVE

*Kaisa Immonen-Charalambous, Senior Policy Adviser, EPF*

Each of the series of regional conferences and national workshops organised by EPF included a workshop session to devise the “ideal” NCP from the patient’s perspective. The ambitious list of suggestions which resulted<sup>5</sup> would provide a useful basis for discussing how to progress from the current real situation.

The fact is that today, patients face what has been called “a labyrinth of confusing, sometimes insufficient and sometimes too detailed information”. NCPs play a critical role in providing the information that patients need to make meaningful decisions, beginning with deciding whether to seek treatment at home or abroad. A very strong message from the EPF events is that the NCP should be a *gateway* rather than a *gatekeeper* in healthcare, “working with the patient, for the patient.”

The following are some examples within each of the key categories identified by patient leaders:

**Fundamental principles:** The NCP should be independent, with a specific mandate and its own operational budget, even when officially structured within the national health ministry. It should work with the stakeholders to find solutions to ensure the principle of equity of access. In practice, this means that its starting-point should always be to protect the patient’s interests as a priority, based on a culture of helping and providing solutions. It should be staffed with personnel who are trained to interact with patients and provide information. It should therefore offer a human response that shows respect for dignity and is non-discriminatory.

**Accessibility and visibility:** The NCP should be highly visible and easy to find and contact, and should communicate in simple language – also providing information in other languages (e.g. of national minorities or the countries where most foreign patients originate). It should be accessible in real-life situations, not just via a website: email, free telephone access, 24-hour emergency hotline and physical premises. In countries with large rural areas or decentralised healthcare provision, there should be regional contact points in addition to the NCP.

**Operation:** The NCP should have transparent procedures and clear timelines for delivery. Ideally, it should have case managers who can guide the patient through his/her whole journey, but it must be able to deal with patients’ advocates or legally-nominated representatives (e.g. in relation to patients with mental health issues). It should mediate patient contacts, e.g. by liaising with other NCPs regarding access to specific specialist treatment, and offer support and advice in case of complaints or problems. In its role of facilitator, it should maintain a list of patients’ organisations which can provide useful information when appropriate,



<sup>5</sup> For full details, see the Summary Report or the individual reports of the regional conferences and national workshops, on EPF’s website at <http://www.eu-patient.eu/whatwedo/Policy/Patients-Mobility/>

and should operate as a “one-stop shop” as far as possible.

**Information:** This must be accurate, reliable, up-to-date and easily understandable. The guiding principle should be “designed for and by patients”. Specific information elements should include: simple step-by-step guides on application processes; FAQs online and in print; customised information packages for in-demand or specialist treatments; and information on ongoing clinical trials. The NCP’s website should be user-friendly and include a feedback facility.

**Quality standards:** The performance of the NCP should be assessed independently from the national authorities. Quality indicators could include: timeliness of answer (e.g. 1-2 weeks plus a “fast-track” option for emergency situations); clear explanations of all decisions; and patient-friendliness. The NCP should have in place an effective complaints management and feedback process which is linked to a continuous improvement system, including the training of staff. The NCP should engage with patients’ organisations to ensure continuous improvement. To this end, it should also collect data on various aspects of its activities and highlight any gaps and dysfunction to the national and European authorities.

## 4.2 WHAT ROLE CAN THE NCP PLAY TO FACILITATE PATIENTS’ EXERCISING OF THEIR RIGHTS, AND WHAT ARE THE CHALLENGES?

### 4.2.1 THE PERSPECTIVE FROM SWEDEN:

*Maria Lidström and Elisabeth de Verdier, Försäkringskassan (Swedish Social Insurance Agency)*

In Sweden, three organisations are responsible for health and therefore for cross-border healthcare:

- County Councils: Each of the 21 County Councils has the prerogative to tax the local population and has responsibility for providing healthcare;
- The Swedish Social Insurance Agency (SSIA): Administers more than 40 social welfare benefits and allowances and executes cash transfers;
- The National Board of Health and Welfare: Directs the work of the County Councils through legislation and information.



For cross-border healthcare, there are two NCPs: the SSIA, which acts as NCP for persons with social insurance in Sweden seeking healthcare abroad, and the National Board of Health and Welfare, which covers patients from the EU and European Economic Area (EEA) seeking healthcare in Sweden.

The Swedish national law (2013:513) transposing the directive came into force on 1 October 2013. A new law (2013:711) concerning reimbursement of costs due to healthcare given in another EEA country also came into force on the same date, giving the SSIA the right to receive reimbursement from the county council where the patient is resident.

The main challenges facing the Swedish NCP relate to reimbursement.

- The patient has received a treatment which is not provided in Sweden:

Reimbursement shall be granted if the treatment method is *“evidence-based and in accordance with clinical practice”*. This means that a thorough investigation by the SSIA is necessary, which also requires the SSIA case handlers and the county council staff to have a high level of knowledge about different treatment methods.

- The SSIA makes the decision on reimbursement but the county council is liable for the costs: The SSIA’s decision in most cases is based on an opinion from the county council where the patient is resident. The county council must indicate whether the treatment received or sought is included in the Swedish “basket of benefits” and fulfils the criteria for reimbursement, including information on the equivalent care costs in Sweden. Unfortunately the opinions supplied are not always sufficient, which results in a new inquiry by the SSIA. As a result, the legally-set time limit of 90 days for the patient to receive a decision is exceeded in some cases – this can feed patient perceptions of the county council as a gatekeeper.

#### 4.2.2 THE PERSPECTIVE FROM SLOVENIA:

##### *Siniša Bošnjak, Slovenian NCP*

Although Sweden and Slovenia are some 1,000 km apart, their NCPs face the same challenges. It is no accident that the wording of the directive itself contains numerous references to information, as this forms the foundation for the patient’s informed choice regarding where to seek treatment. However, under Slovenian law as it stands today, the ideal of a “24/7” fully responsive NCP is impossible.

Recital 4 of the directive throws up another contradiction: NCPs are obliged to provide all necessary information for the patient’s informed choice, but at the same time the *“application should not result in patients being encouraged to receive treatment outside their Member State of affiliation.”* Some Slovenian health stakeholders choose to interpret this by providing requested information to the NCP while asking that this information should not be volunteered to patients.



The Slovenian NCP offers four channels for patients to request information: a telephone call-centre, email, personal consultation and postal enquiry. Of the 4,570 requests received in 2014, just over 3,500 were to the call-centre and just under 1,000 were received via email – so the option of a personal consultation was barely used.

In 2014, the NCP received just one request for information on standards and guidelines on quality and safety. It should be pointed out that Slovenia does not currently have measurable lists of quality and safety standards, so the NCP would not be able to provide meaningful information on this aspect.

A particular challenge is finding the right balance between providing comprehensive information and information that is simple enough to be understood. When the NCP first started operations, it provided comprehensive information on how the patient’s new rights under the directive compared to those under the Social Security Regulation. The amount of information proved to be overwhelming, so the approach was changed to providing selected information. This proved to be

insufficient. So there is no single formula for providing a body of information in a way that *every* patient can understand. The NCP is trying a case-by-case approach, tailoring the volume and complexity of the information to what it perceives to be the capacity of each enquiring patient to absorb the information provided.

Meeting patients' expectations is also a challenge, due mainly to media coverage that is often inaccurate, but also to the attitude of some healthcare providers abroad who seek to attract Slovenian patients by being selective with the information they highlight.

Because the Slovenian NCP is a dedicated unit within the Health Insurance Institute of the Republic of Slovenia (HIIS) – the public authority that is bound by statute to provide compulsory health insurance – this can affect how it is perceived by the public in terms of independence, but it can also impact the quality of information provided to patients (e.g. discouraging the full disclosure of HIIS information on entitlements).

The Slovenian NCP faces particular challenges relating to raising awareness. It discovered that the waiting-lists and waiting-times supplied by healthcare providers via the National Institute of Public Health were inaccurate. This poses a problem to both the patients and the HIIS, which must decide on eligibility for reimbursement, so the NCP has raised the issue with the Health Ministry. Another problem is that one of the criteria for seeking healthcare abroad – that options for treatment at home have been exhausted – is not defined precisely in Slovenia in terms of different methods of treatment. So if a patient wants to seek a less invasive treatment method abroad compared to the treatment that is available in Slovenia, it is difficult to decide with confidence that all options for treatment at home have been exhausted.

### 4.3 PLENARY DEBATE – THE KEY OUTCOMES

- The fear of some member states – articulated before the directive was adopted and came into force – that there would be new and massive demand for cross-border healthcare, putting extra pressure on national health systems, has not materialised. In Slovenia, for example, demand has been within the predicted parameters, as it appears that not all patients who request information from the NCP then seek prior authorisation for treatment abroad.
- One illustration of the differences in NCP resources: the Finnish NCP has five staff members who deal with requests from both incoming and outgoing patients, while Sweden's SSIA (the NCP only for patients seeking healthcare abroad) has 60 staff in a dedicated call-centre providing a two-tier service (front office interacting with the patient, supported by a back office staffed by medical specialists).
- A particular challenge for patients is that currently they do not have an overview of the healthcare providers who might provide the treatment they need. The German NCP has addressed this by offering access to particular search engines on its website; if the patient knows the relevant [ICD-10 code](#) (the World Health Organisation's International Classification of Diseases), he/she can look for possible solutions directly on the website. However, one weakness in this approach is that the patient may follow a link to a webpage that is only in German. This



weakness has also been identified by the Dutch NCP. It is very important that NCPs provide information in more than one language, despite the fact that the directive does not oblige them to do so – patients’ organisations can help to highlight language gaps and difficulties to the Commission.

- It may sound logical for NCPs to cooperate in regional networks, but this is not necessarily straightforward in practice. All NCPs do not have the same capacities, and patients across the EU do not all use their NCP in the same way, so some NCPs would benefit more than others from such cooperation. A European portal or database of commonly requested information (e.g. healthcare providers) for use by the NCPs would help them answer patients’ questions at the first request rather than having to refer the patient to the NCP of another country. One solution that is already feasible at national level would be for patients’ organisations to collaborate in providing information and/or guidance on providers of treatments for specific conditions.

## 5 Interactive workshop sessions

Three parallel workshop sessions explored specific priority topics within the directive: information needs of patients; quality and safety of care; and reimbursement and equity of access. Participation in each group was balanced between patient representatives, NCPs from different regions as well as representatives of the European Commission.

Discussions were based broadly on the recommendations for member states, NCPs and the European Commission contained in the Summary Report on EPF’s four regional conferences on cross-border healthcare, including questions such as:

- What kind of collaboration is needed to optimise the implementation of patients’ rights?
- Whom should the collaboration involve?
- What are the key challenges in different areas?
- What is needed in terms of support for sustainable collaboration?
- How can implementation be supported in countries where there are problems?
- What is the added value of European Commission action, and how can it help?



### 5.1 WORKSHOP 1: INFORMATION NEEDS OF PATIENTS

Participants were asked to brainstorm on the information needs of patients and came up with the following points:

- Information is a politically-sensitive subject. The lack of political will can be a major barrier to good provision of information, or even to basic provision of information. For example, in Poland the government has lagged behind in terms of transposition and then implementation: it provides no real information on cross-border healthcare, the NCP is practically invisible, and it refuses to work with patients’ organisation if this involves spending money;

- Significant gaps still exist in the function of NCPs as information providers. Only the larger patients' organisations have sufficient resources to plug the information gaps for patients left by the NCPs and to collect useful data on demand and uptake;
- In some countries, there is no national umbrella patient organisation. For example, in Germany, there are around 250 patients' organisations. Without an umbrella organisation, how can patients' organisations consult with NCPs in a meaningful way?
- From the NCP point of view, when patients' organisations are perceived as lacking political weight or not being genuine channels for a distinct patient community, it is easy to succumb to pressure of workload, bureaucratic attitudes and other factors, resulting in a lack of real consultation with them;
- Given the prevailing financial constraints for member states, the issue is about the most efficient flows of information. Patients doing Internet research can result in identifying a solution that involves domestic rather than cross-border treatment. The NCP's responsibility is not to help a patient navigate the domestic healthcare system, it is to facilitate treatment abroad. In Holland and Belgium, social security is laid down in law, but it is executed by private insurers – so because the NCPs in Holland and Belgium refer questions from domestic patients to the health insurers, they tend to be outward facing, i.e. dealing with patients seeking to come to those countries for treatment;
- The underlying data for information on healthcare is often not comparable, particularly on quality and safety. Therefore the information provided by NCPs cannot give the full picture, especially for actual reimbursement levels;
- One of the key sources of information to patients is healthcare providers such as public hospitals, but generally these are not geared up to handle enquiries directly from patients, so the NCP should mediate. The NCPs should have annual meetings with healthcare providers in parallel with their consultations with patients; perhaps the Commission could facilitate this?
- Quite apart from the issue of what kind of information about healthcare providers should be provided consistently by NCPs, without a “one-stop” EU portal – or at least a European-level coordination or network of NCPs – the task is impossible.
- To create a “one-stop” EU portal, especially in relation to quality, all the information used must be comparable, which depends on how the data is designed (which indicators are chosen, e.g. volumes of treatment, survival rates, adverse events), derived and collated – a monumental task. The issue is not only an EU portal, but also effective and reliable national portals;
- Having standard templates for documenting the patient's journey does not address the more fundamental and practical issue of how treatments are coded within national health systems: whether [DRG](#) codes are used, how treatments are described, etc. Mismatches in coding and lack of precision as to what the treatment entails exactly can mean that the patient will not be reimbursed for part of the overall treatment, so the basic issue of being able to identify the elements of the treatment for reimbursement is not addressed by standardisation.



In the discussion, the participants identified the following recommendations for future action:

- Patients' organisations with the resources to plug information gaps for patients must be integrated into the NCPs' channels of information;

- The Transparency Directive should be used to obtain an accurate picture of what is happening on the ground in terms of tariffs, actual costs of treatment and information on quality and safety. Patients' organisations should aim to gather such data and share it with the Commission;
- Differences in language are a fundamental barrier to cross-border healthcare. The exchange of information must be improved across the full spectrum, from quality standards to delivery;
- Healthcare professionals need to be more informed and willing to empower patients;
- Existing channels of information, e.g. for the Social Security Regulation, could be used/networked to improve information for cross-border healthcare under the directive.

## 5.2 WORKSHOP 2: QUALITY AND SAFETY OF CARE

In considering quality and safety of care, participants were asked to address the diversity of services and differences among countries in terms of healthcare delivery, and came up with the following points:

- Patients can contribute to establishing indicators, but they need to be provided with the information that will allow them to decide what is best for them. In this context, what is the value of patient surveys – are they too subjective?
- Healthcare professionals play a central role in giving information to patients. Some patients' organisations – mostly dealing with rare diseases – collate their own information to plug possible gaps in information provided by healthcare systems. This valuable resource should be incorporated more systematically. Patients' organisations could also "certify" the patient-friendliness of the content of disease-specific information provided by expert sources;
- Guidelines relating to specific conditions may not be available in every member state, so common ground should be found to ensure easier transitions between healthcare providers in different countries as patients seek treatment under the directive;
- At macro level, there is a good example in the UK, where the [Care Quality Commission](#) provides detailed information on the services provided by healthcare providers in a transparent way;
- With neuromuscular diseases, the quality of medical devices (e.g. of a wheelchair) can make a big difference in terms of a patient's life expectancy. For example, the life expectancy of patients living with such conditions might vary from 16 in the Eastern European countries to 30+ years in the Western European countries. Therefore, quality is not always about treatment or services; it can also be about other related aspects of ensuring assistance to a patient;
- NCPs that are located within a governmental agency are sometimes under-resourced, and the civil servants working there are more technical in their approach instead of communicating practical information to patients. In such situations, the involvement of patients' representatives should be considered as essential to providing information on quality and safety of care;
- In general, patients do not think of quality and safety until something goes wrong when provided with healthcare – it is a matter of trust;



- The biggest challenge for patients is the language used in legal documents (jargon), which needs to be “translated” into human language;
- Patients’ organisations are open to collaboration with NCPs on quality and safety of care, possibly within the framework of a joint project that could be funded from a third source. This collaboration could involve organising conferences at national level on the quality and safety of care aspect of cross-border healthcare, to make the information from the directive widely available and to create the opportunity for dialogue and clarifications among NCPs, patients’ organisations and policy-makers.

In the discussion, the participants identified the following recommendations for future action:

### Comparable information on quality and safety of care:

- Key indicators need to be defined and made available at the national level;
- There must be transparency of institutions in terms of information on quality and safety of services provided in a member state;
- Indicators should focus on extending the life and quality of life of patients;
- Indicators should be based on patients’ perspectives and needs;



### How to ensure that information to patients is accurate, understandable and meets patients’ needs? What information should be provided on quality and safety?

- Patients should be involved at the administrative and NCP levels; patients can be a “human face” when providing information about services available in other countries;
- Especially in situations where the NCP is under-resourced, the involvement of patients’ representatives should be considered as essential to providing information on quality and safety of care.
- Information must be translated into clear and understandable language. Information should focus on the goals and outcomes expected by patients when going abroad for healthcare;
- Information should be evidence-based and up-to-date;
- Identify significant common indicators, whilst being aware of the differences among member states.

### What can patients’ organisations do?

- Patients’ organisations should be the bridge between NCPs and the patient community, including their participation in the “advisory committees”;
- Patients’ organisations should be invited to collaborate with NCPs on quality and safety of care. This could involve organising conferences at national level on the quality and safety of care aspect of cross-border healthcare.
- Recognise that different systems for delivery of cross-border healthcare exist in the 28 member states, which can mean that the reimbursement decision is taken by health insurers rather than the NCP;

- Organise cross-border healthcare conferences at the national level, bringing together the NCPs and patients' organisations.

### 5.3 WORKSHOP 3: REIMBURSEMENT AND EQUITY OF ACCESS

Participants were asked to brainstorm on issues linked to the Directive and equity of access and came up with the following points:

- There is a lack of clarity on the prices of medicines and costs of treatment and on reimbursement in the home country. Lists should be available with this information;
- The rate of reimbursement is decided by the home country; this is a huge barrier to access when it is lower than the costs of the treatment and the patient cannot afford to cover the difference;
- "Quality" of healthcare is an important aspect in equity of access;
- Upfront payment for healthcare in another country should be seen as an "unlawful deterrent" under EU law;
- Private healthcare organisations sometimes recruit patients for cross-border healthcare, rather than patients being referred to them, and then it is not always clear who is requesting the treatment and reimbursement;
- Cross-border healthcare is in danger of becoming a marketing tool for providers;
- ICD-10 codes could be a useful tool for addressing language barriers.

Specifically relating to rare diseases:

- Rare diseases should have a European dimension with transnational knowledge sharing;
- Centres of Excellence: European standards outlining how these centres should be structured and should operate would be useful in order to provide comparative information, and networking across Europe should be improved and encouraged;



In the discussion, the participants identified the following recommendations for future action, grouped under four headings:

#### Information

- Improve the information provided by NCPs and enhance the advocacy role of patients' organisations to ensure that the information provided is accessible. This is particularly important for patients who are vulnerable to social exclusion as they must get the right information at the right time in order to fully benefit from the directive;
- The rights-based approach of the directive must be better explained to patients to help strengthen their position in accessing cross-border healthcare;
- Patients' organisations should be involved in monitoring the directive and provide information on best and worst practices;

## Cost and payments

- There should be a proforma invoice with guarantees before treatment, so that the patient knows exactly how much he/she will be reimbursed and the costs of the treatment are transparent;
- There should be a direct payment system between countries to take the financial burden away from the patients;
- The uncertainty of treatment and payment for rare diseases needs to be addressed with a view to establishing clear guidelines on which treatment will be covered in the patient's home country;

## Reimbursement

- In order to address the barrier to access created when the patient cannot afford to cover the difference between the national tariff and the actual costs of the treatment abroad, a European Solidarity Fund should be established based on the principle that the richer countries pay for the poorer countries;
- Certain countries could be clustered together into two or three bands based on a similar level of costs per treatment. This would reduce out-of-pocket payments on the part of patients (but should not compromise quality);
- There should be more independence of the decision-making processes on the rejection of prior approval and the application of complaints and appeals procedures. These should be handled by different organisations to ensure the process is fair and transparent;
- A European Patients' Ombudsman should be established with the power to investigate situations where countries have a large number of unexplained rejections on prior-authorisation. The role of a European Ombudsman was raised in the previous conferences, but only from the perspective of safety and redress;

## Raising awareness of the NCP and the directive

- Networking and co-operation at European level should be improved by encouraging centres of expertise with the same quality criteria across the EU. This would be taking the European Reference Network one step further;
- Specialisation, use and uptake of specialised services in countries where they exist should be promoted and improved, with the aim of sharing the responsibilities across the member states;
- Political pressure should be developed for setting up an ancillary fund at EU level to support patients and their families in accessing cross-border healthcare;
- The "S2 Policy" under the Social Security Regulation for payments between governments should be better promoted as this could help reduce the financial burden on patients.



## 6 Where do we go from here?

### 6.1 REACTION AND NEXT STEPS – THE PERSPECTIVE OF THE EUROPEAN COMMISSION

*John Rowan, European Commission's Directorate-General for Health and Food Safety (DG SANTE)*

A useful starting-point would be to address the challenges, particularly relating to the proper implementation of the directive. The European Commission is aware that there are problems with how the directive has been implemented by some member states, for example relating to the use of prior authorisation, the administrative requirements on patients, the reimbursement tariffs, etc.

The second challenge is information. First and foremost, not enough people are aware of their rights – this was clear in the latest Eurobarometer survey, which also highlighted the fact that people do not know about the existence of NCPs. The second aspect of information is that, although there are many references in the directive to providing information, there is still a very wide scope for interpreting what that information is and how it should be provided.



Thirdly, the question is how to leverage the uptake of cross-border healthcare into raising standards of healthcare *for all citizens*. This question relates partly to information, partly to the European Reference Networks, Health Technology Assessment, eHealth, etc.

From the Commission's perspective, patients' organisations and other stakeholders have an important role to play in addressing these challenges. In relation to the member states' compliance with their obligations under the directive, patients' organisations can play a very valuable role in monitoring what is happening on the ground and relaying that feedback to the Commission. Another aspect is how best to raise awareness in each country, and the work being carried out on this by patients' organisations is extremely valuable.

This Conference has provided several good illustrations of the invaluable function of patients' organisations in identifying needs and gaps in implementation, and then – importantly – proposing solutions and initiatives for resolving them. Some of the ideas that have emerged here will be fed into the discussion on the directive under the Luxembourg Presidency.

As a next step, the Commission's progress report on implementation is due to be delivered to the Council and the Parliament in September. The Commission will not hesitate to use the tools at its disposal to address non-compliance by member states. One of the sources of information for the preparation of the report has been the series of regional conferences organised by EPF, which were very helpful.

## 6.2 THE PERSPECTIVE FROM THE EUROPEAN PARLIAMENT

*Françoise Grossetête, MEP (video message)*

Before the cross-border healthcare directive was adopted, patients faced many difficulties in accessing healthcare abroad and getting reimbursed. With this piece of legislation, the situation has been made clearer and fairer: for patients, for healthcare professionals and for healthcare systems.

However, although the directive has brought more legal certainty, in practice it has not yet delivered on its promise to patients. The transposition deadline of the directive was in October 2013 – almost two years ago. Yet today, many barriers to the healthcare to which patients are entitled still remain.

“To give a personal example: months ago, a friend from France asked me to help her son to receive treatment in Italy. Well, despite the first-hand knowledge I have of the legislation and the rights it gives to patients, the dossier is still not closed; and after countless meetings, phone-calls and exchange of emails between the mother and the administration, I had to write to the French Health Minister to ask her to end the deadlock.”



The implementation problem revolves around two issues in particular:

- The lack of awareness on the part of national administrations regarding the directive and the rights it grants to patients; and
- The lack of visibility and accessibility of the National Contact Points in many countries, often due to poor resources.

The French authorities have very recently made a major effort to build a genuine contact point that can be useful to the patients, and it is clear that the situation can also improve in other countries. But to achieve this, the pressure must be maintained by patients’ organisations and other stakeholders.

## 6.3 CLOSING REMARKS

*Marco Greco, EPF Board Member*

Today the focus has been on information, quality and safety of care and equity of access. These are clearly the three main themes on which a high level of attention must be maintained, to ensure that any difficulties that arise in practice are dealt with.

It was especially gratifying to hear the Commissioner’s positive message, when he referred to the need to ensure **fair** transposition and implementation of the directive for member states and for patients. The Commissioner also referred to some barriers that patients are facing: the elaboration of systems that are difficult to navigate, inequalities on reimbursement and authorisations, and the complexity of information that is not always patient-friendly.

Another strong theme that has emerged is that patients’ organisations can and must play a key role in ensuring that the directive will work in practice in the coming years. This can be done by

supporting the delivery of information, drawing on precious expertise gained in situations that are often difficult, involving a lack of resources and a range of different legislation.

EPF looks forward to reading the Commission's progress report in the autumn, and will then consult its membership and its network of patient leaders and take a position on what needs to be improved.

“ I think a lot has been done, and I see some difficulties, but overall I am optimistic. There have been many times in the past when a situation has seemed too difficult– 12 years ago it seemed impossible to achieve common EU rules for pharmacovigilance, for example – but then consensus was found on the legislation and we moved forward. We have the experience, we have the capacity and we have the knowledge to lead the discussion on what is best for the patients, whom we represent.

The hardest part has been done – now it is important to keep focusing on what is still not working properly. But we must always keep in mind that very often patients are obliged to move from one country to another for healthcare – it is not a free choice or some version of tourism. We are all aware of the impact of the crisis on many countries, so we understand that this is a difficult moment from the economic point of view. Somehow even the idea of Europe is struggling, but here we are not simply talking about solidarity, we are talking about a fundamental human right. Cross-border healthcare is a fundamental right, because without access to healthcare you cannot have full citizenship.”

