Cross Border Healthcare Conference

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EPF 4th Regional Conference on the EU Directive on Cross-Border Healthcare

Conference Report

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Participating countries: Denmark, Estonia, Finland, Latvia, Lithuania, Sweden

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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, the European Patients' Forum (EPF) undertook considerable work with the EU Institutions on the Directive prior to its adoption, and subsequently produced a guidance document explaining the Directive, which was disseminated in June 2012 and updated in November 2013.[1] We have participated in a large number of events throughout the EU to raise awareness of patient organisations as well as Member States and stakeholders, during the transposition phase.

About the conference

The Directive entered into application on 25 October 2013, and EPF decided to organise a series of dedicated regional conferences to raise the bar in terms of comprehensive knowledge and awareness among patient communities. This conference was the last in a series of four events held between December 2013 and October 2014. The conference was aimed at patient leaders from six countries – Denmark, Estonia, Finland, Latvia, Lithuania and Sweden.

The expected outcomes of the conference were:

- Clear identification of the roles of patient organisations in supporting patients' access to cross-border healthcare;
- An informal network of patient leaders in each Member State with a strong knowledge base and understanding of the legislation and with the capacity to discern their rights, interact with national government representatives and other stakeholders, disseminate information to fellow patient leaders in their country, and participate in monitoring of the impact of the directive from the perspective of patients, providing 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.

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The content of this document reflects only the author's views and the Executive Agency is not responsible for any use that may be made of the information contained therein.

[1] More information available here: www.eu-patient.eu/whatwedo/Policy/Patients-Mobility/

2 Executive Summary

If steps are taken to ensure that the cross-border healthcare Directive works well in practice, it can serve to reinforce a healthy society and a healthy Europe. Currently, the challenge is to provide the right information to patients about healthcare options that are available outside their own countries, but at the same time to remove barriers to accessing those options.

The previous three conferences in this series have already confirmed that patient organisations can offer new perspectives and suggestions to ensure that the Directive works. Governments, institutions and other stakeholders have their own views, so it is a question of exploring perceptions and perspectives in order to identify the best ways to make effective and patient-friendly cross-border healthcare a reality.

The contributions during Session One demonstrated that although the Directive is in application, there is still much to be done. Implementation so far has been inconsistent; Member States are at different stages, and some appear to be taking compliance more seriously than others. Also, equity of access is a concern: given the financial hardship that exists across Europe, will cross-border healthcare be an option for all citizens in practice? It is widely accepted that providing information to patients is crucial to the impact of the Directive, which places a premium on National Contact Points (NCPs) consulting effectively and responsively with patient organisations and other stakeholders in order to raise standards of content and the way it is delivered.

The Commission's check on transposition of the Directive by Member States is ongoing. However, it is very important that the Commission receives feedback from patient 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 views of patient organisations as expressed in this series of conferences will provide valuable input to the Commission for its first formal progress report (due in 2015), as it works to ensure that there is a fruitful discussion at the political level on how to improve cross-border healthcare.

During Session Two, the critical role of the NCPs in the effective implementation of the Directive was amply demonstrated by the discussions in small breakout groups as well as the featured presentations. 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 patient organisations is to advocate for a closer relations with the NCPs and to set out clearly what patients want and expect, beginning with the provision of information that is up-to-date, reliable, easy to understand 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 dialogue. They should also be responsible for collecting and maintaining comprehensive data on the use of cross-border healthcare, highlighting any gaps or dysfunction to national and European authorities.

Sessions Three and Four featured intense and detailed discussion about the practical process of obtaining cross-border treatment. Session Four 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.

One of the core challenges regarding quality of care and patient safety is to ensure that the relevant information is available to patients, easy to find, expressed in accessible language and presented in ways that allow meaningful comparison across Member States. Patient's organisations can contribute positively to this process.

One of the crucial factors in developing and successfully establishing ERNs will be to ensure that patients can contribute their expertise effectively as equal partners in discussions. A failure to address patient empowerment positively and practically in the criteria and guidance for assessment of ERNs would represent a crucial step backwards.

Session Five featured a panel discussion on the role of patient organisations in securing effective implementation of the Directive. This conference and the previous ones showed clearly that the potential exists for a collaborative partnership approach between NCPs and patient organisations to improve the patient experience of cross-border healthcare.

It is clear that the overall landscape is very uneven, with wide variations in the practical interpretation of the core functions of an NCP and therefore in the allocation of resources and visibility. Patient organisations have a lot of work to do in proactively engaging with NCPs and seeking co-operation with them on key issues.

Financial inequality is a significant barrier; there is a big gap between those who are able to access cross-border healthcare and those who are not. The contributions heard in the conference suggest that patient organisations can promote a discussion on how to facilitate access, and in particular how to remove the financial barrier to low-income patients and their families.

With this series of regional conferences, 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. Over the next year, 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 by October 2015.

3 The first Directive to focus on "Patients' Rights" – what does this really mean for patients?

Opening the conference, EPF President **Anders Olauson** emphasised that if the cross-border healthcare Directive is implemented well, it can serve to reinforce a healthy society and a healthy Europe. The challenge is to provide the right information to patients about healthcare options that are available outside their own countries, but at the same time to remove barriers to accessing those options.

The previous three conferences in this series confirmed that patient organisations have very many new perspectives and suggestions to ensure that the Directive works. Nobody dislikes the principle of cross-border healthcare – not even governments, which can sometimes be the target of strong criticism from patients. It is a question of exploring the different perceptions and perspectives in order to identify the best ways to make effective and patient-friendly cross-border healthcare a reality.

3.1 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). He gave three headline messages regarding the Directive:

- The patient's right to choose to receive healthcare from a provider outside his/her country has been confirmed and clearly explained. The Directive has not created patients' rights out of nothing: part of the foundation was provided by cases at the European Court of Justice that established a series of rights, and 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.[2]
- Information to patients is a crucial aspect. One important theme running through the Directive is patient empowerment, i.e. providing patients with the right information to enable them to make informed choices about their rights and the treatments to which they are entitled.
- The Directive establishes a minimum set of patients' rights throughout the EU for the first time. In many Member States this might not change things in practical terms, but it represents significant progress at the level of EU health policy.

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 the 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

During the negotiations on the text of the Directive, concerns were voiced by some Member States regarding the possibility of national healthcare systems coming under extra pressure due to cross-

[2] Regulation (EC) No 883/2004 and Implementing Regulation (EC) No.987/2009, as amended. Information on the EU social security regulations is available here.

border demand for treatments. As a result, the Directive specifies that in some cases, Member States can require patients to ask for prior authorisation before travelling for treatment.

Prior authorisation may be required for healthcare that involves (a) an overnight hospital stay, and/or (b) highly specialised and cost-intensive healthcare ("hospital care"). The logic for this is to strike a balance between the patient's right to free movement and the need for Member States to plan and invest in certain treatments and to ensure that this planning and investment 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, i.e. if the treatment in question can be given to the patient in their own country within a medically reasonable time-limit. The definition of a "medically reasonable time-limit" depends on the needs and circumstances of the individual patient. 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, so there is an obligation for each Member State to set up at least one National Contact Point (NCP). A Member State can set up more than one NCP depending on how it has structured its healthcare system, e.g. to reflect regional/federal competencies.

NCPs must be able to inform patients who want to go abroad regarding their rights and entitlements as well as the processes for prior authorisation, reimbursement and appeal; and to tell incoming patients what to expect – how the healthcare system works, the quality and safety standards that apply, and about the complaint and the redress procedures that are available. 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 by liaising with the NCP in the country of treatment.

NCPs have an obligation to consult with stakeholders, especially patient organisations as well as healthcare providers and insurers. They should be dynamic organisations rather than simply a webpage with some information.

Healthcare providers also have obligations under the Directive. Importantly, they must provide information on: treatment options; the quality and safety standards they apply; prices; their authorisation status; insurance and liability cover.[3] Once again, the objective is to ensure that the patient is able to make a properly informed choice.

Prices and reimbursement tariffs

There are three main points to this provision in the Directive. The principle of non-discrimination means that providers must apply the same fees to incoming patients as for domestic patients. The reference-point for setting reimbursement tariffs must be treatment in the home country given by a contracted or public provider, depending on the health system.[4] There must be transparency on the

[3] All treatment providers must be covered by liability insurance or an equivalent guarantee.
[4] There have been cases where Member States set the reimbursement tariff using the cost of private treatment as a reference-point, thus creating an artificially low reimbursement tariff.

"basket of benefits" and reimbursement tariffs – answering the basic question: which treatments, and how much.

Minimum patients' rights

Although the Directive sets a minimum standard for patients' rights, it also contains certain new or enhanced rights: the right to appeal authorisation and reimbursement decisions; the right to a transparent complaints procedure and to seek redress; the right to privacy; the right to access a copy of one's own medical records for all treatments; and non-discrimination on the basis of nationality regarding access and prices.

A few years ago, many Member States still considered that the EU had no real role in health systems, which were regarded as a national responsibility with no European dimension. There is now a law at European level which sets out patients' rights and applies to every patient and every treatment in the EU. This provides a firm basis for developing a European approach to health systems policy in the years to come.

What is new compared to the social security Regulations?

The system for cross-border healthcare under the Regulations worked fairly well for unplanned care, such as patients using their European Health Insurance Card (EHIC) abroad, but not for planned care. The Directive introduced specific measures to ensure the system works also for planned treatment – such as the heavy emphasis on information to patients on their rights, the obligation for transparency by Member States, and the various procedural guarantees.

There are some important differences between the EU social security Regulations – which still apply[5] – and the new Directive:

- The Regulations only cover public-sector or contracted providers, while the Directive covers all providers in the EU, both public and private.
- Under the Regulations, prior authorisation is always required for planned care, but is the exception under the Directive – in fact, some Member States have chosen not to use prior authorisation at all.
- The Regulations cover patient costs in full (with prior authorisation), while the Directive covers only to the level of the treatment in the home Member State. The logic is that cross-border treatment should be cost-neutral to national health systems.

Co-operation between health systems

There is a general obligation for Member States to co-operate on guidelines and standards for quality and safety; 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 among 28 separate HTA bodies and to improve HTA capacity in specific Member States;[6] and eHealth, for which there is a Steering Group working on a

[5] For more information see the EPF guidance document.

[6] There is a continuing debate on the acceptable extent of co-operation and harmonisation of HTA at the European level. A consensus is emerging at least on applying a shared approach to the purely scientific analysis

common eHealth policy across the EU. The Directive also addresses the need to promote more co-operation between Member States on cross-border healthcare in border regions. This is likely to come onto the political agenda in 2015, as more Member States realise that such co-operation offers particular benefits. Working examples – both good and bad – already exist to feed this discussion.

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 by individuals and stakeholders is also very important, to help assess how the Directive is working on the ground. The Commission holds national governments to account in terms of meeting their responsibilities as framed by law; it is therefore very important that the Commission receives feedback from patient organisations and individual citizens in terms of what is happening in practice, how individual cases are being handled, etc., so that it can fulfil this crucial function.

The reflection process on the functioning of the NCPs is ongoing. Individual NCPs are already consulting each other on how best to present information on national health systems, quality and safety standards, etc., so a more systematic approach across Europe would raise the general standard of information being made available to patients.

This monitoring feedback will be incorporated into the regular reporting by the Commission to the European Parliament and Council. The first formal progress report with recommendations is due to be published by 25 October 2015, but the Commission aims to publish it in the summer of 2015.

This series of conferences involving patient organisations will provide valuable input to the Commission, as it works to ensure that there is a fruitful discussion at the political level on how to improve cross-border healthcare.

3.2 THE PATIENT'S PERSPECTIVE

The patient's perspective was given by **Vida Augustiniene** from the Council of Representatives of Patient organisations of Lithuania.

She said that before the Directive, there was already a right set out in the social security Regulations for patients to access healthcare in other Member States, but this only applied in particular cases. The ECJ rulings led to an accumulation of case-law but no clear overall understanding of patients' rights. Therefore, the main aim of the cross-border healthcare Directive was to clarify the legal rights of patients across the EU.

The Directive is not perfect. It took a long time – about 2.5 years – to complete the legislative process, and the text changed quite a lot during that process. The final Directive is in many respects a compromise from the patient perspective – gaps and areas of uncertainty remain – but nevertheless,

of health technologies, but how that information is used by each Member State still varies. Member States have tended to guard their prerogatives regarding the pricing of medicines, but in recent years there has been a significant political shift in terms of increased transparency on the content of price negotiations.

it is a very important milestone for patients as the key benefits outlined by the European Commission showed.

Why is the Directive important to Lithuanian patients?

There are a number of specific issues in the national context to which cross-border healthcare could provide the solution: a lack of specialists; long waiting-lists for consultations in some specialisms; unmet demand for dental care and treatment for rare diseases; high cost of modern treatments and high co-payments. There is also a wider regional context: some Lithuanians routinely go to Poland for treatment.

The Directive therefore offers important advantages, such as the patient's enhanced right to choose, and more flexible options for patients to get medical services as soon as possible. However, patients in the Baltic countries and elsewhere face crucial barriers to access: the requirement for upfront payment, low health literacy, and a basic lack of information about the Directive.

Support is equally important as information: will the NCPs become an "enabling service" for patients or a "gatekeeping mechanism" that negatively affects access? One approach that would influence this outcome would be to establish a continuous and transparent dialogue between patient organisations and Ministries of Health and NCPs. So far, the involvement of patient organisations in this respect has been fairly low.

A crucial concern: equity of access

The Directive is based on the principles of non-discrimination, universality, access to good quality care, equity and solidarity – but in reality, the requirement for patients to pay upfront for treatment will be a barrier for many patients. Normally, the patient must pay the treatment costs upfront and claim reimbursement afterwards. As we know, the amount to be reimbursed is equivalent to the cost of the same or similar treatment "at home", so if the treatment abroad is more expensive the patient is left with more out-of-pocket cost; but if it is cheaper, then the whole cost can be covered. However, the patient can never benefit financially from the reimbursement, and we must also remember that the patient's travel and other costs are not covered.

A Member State is obliged to cover only the cost of treatment itself but it can decide to reimburse the full cost of the treatment and extra costs if it so chooses). Member States must have a transparent mechanism for reimbursement – it must be based on objective, non-discriminatory criteria and it must be publicly available.[7]

Sometimes it may be better for the patient to access treatment abroad under the social security Regulations rather than the Directive, as was explained by the European Commission. This may be a better option for patients with rare diseases, for example, where the treatment may not be available in the home country. The important point to bear in mind is that the NCP must inform the patient which option is better for them.

It is important to know that there is a provision in the Directive that allows Member States to reduce the financial burden on patients by using *prior notification* (Article 9(5)). This means that before having

[7] Article 7 of the Directive

the treatment, the patient could receive a written confirmation of how much he/she would be reimbursed, which would help towards calculating the actual costs more accurately. Member States can even choose to go further and opt for a direct payment mechanism to transfer costs across borders. Patient organisations can and should advocate in favour of these options to their governments in order to improve equity of access.

The transparency provisions have much more potential than just to inform patients who are considering treatment abroad: patients and patient organisations can use them to get informed about their rights, the safety and quality of treatment, and how it compares to other Member States. This information can then be used to advocate for better quality and more equitable access also "at home". This can stimulate providers in Lithuania to strive to improve quality, which is important for patients who access care "at home".

Implementation and monitoring – the next steps

The first implementation report by the European Commission is a key opportunity to assess whether the Directive is a success from the patients' perspective. Member States must help the Commission by providing all the information they have, but patient organisations should also take up the Commission's invitation to give their feedback on the strengths and weaknesses of the Directive to both the Commission and national authorities, both directly and via EPF. In practical terms, patient organisations can:

- Engage with their NCP and give feedback on how it functions to serve patients;
- Ask their government to set up a system for direct payments and/or prior notification;
- Give feedback to EPF and the European Commission on all aspects of implementation – how it works for patients, and when it does not;
- Provide information on cross-border healthcare on their organisation's website, including links to useful sources of information;
- Check the information provided on quality and safety standards: is it useful, is it understandable? How can it be used to call for improvements in quality of care in your country?
- Use the EPF tools, such as the guidance document and policy recommendations!

3.3 KEY POINTS FROM THE DISCUSSION

The Directive can sometimes overcome restrictions imposed in some Member States such as Estonia, where the costs of treatment by a private healthcare provider are not reimbursable under the national health insurance system. The Directive provides that any EU patients who travel to another Member State for treatment are entitled to have their costs reimbursed in line with the national tariff even when the provider is in the private sector.

Patients need to become knowledgeable on what the Directive means to them in practice, especially with regard to specialised treatments. Where gaps or vague definitions are identified in a national "basket of benefits", patient organisations can take this opportunity to engage national authorities in dialogue to improve patient entitlements. The European Commission would also welcome information on such cases from patient advocates.

Lack of data: So far there is little data regarding patients with chronic conditions travelling abroad for treatment, for example dialysis. In fact, there is little data generally regarding patients, so the Commission would welcome any feedback that patient organisations could provide.

Availability of specific treatments: Some treatments may not be available in all Member States, so they would not be included automatically in the national "basket of benefits" with a fixed reimbursement tariff. In such cases, it is at the discretion of each Member State whether or not to grant reimbursement. The decision of the European Court of Justice (ECJ) in the Elchinov case[8] in 2010 established that the way in which patient entitlements are described in a Member State's "basket of benefits" is very important. In practice, it is hoped that specific cases in cases where there is lack of clarity could be resolved through negotiation with the authorities to agree a reasonable tariff for reimbursement.

Patients with rare diseases: The reason patients with rare disease seek treatment abroad is usually its unavailability in the home country. The Directive, with its "basket of benefits" principle, does not work very well for these patients; instead, it would be more appropriate for the Member State to refer the patient to another Member State under the social security Regulations. This has the advantage that once approved, the cost of treatment is covered in full via direct payment between the authorities. However, the Directive can help patients with suspected rare diseases to access diagnostic services, given that most diagnostic tests are covered in the national benefits.

Direct payment versus reimbursement: Given the evolution of the negotiations on the Directive, it is hard to avoid the conclusion that despite direct payment being included as option for Member States, they will systematically avoid this option (in contrast with the social security Regulations). So far, there has been reluctance among Member States to address the technical aspects of using direct payment under the Directive due to a lack of demand, but the Commission hopes that as more patients begin to use the Directive and more data on take-up is gathered, it will be possible to assess the impact of the different options in the 2015 progress report.

4 The crucial role of National Contact Points and creating a model that meets the needs of patients

Working Groups – Designing a model NCP

The participants broke out into six groups of 6-8 people to discuss the following questions:

1. What would a "model" National Contact Point look like?
2. What are the quality criteria and critical success factors?
3. How should patient 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:

[8] For more information see the ruling: ECJ case C-173/09.

FUNDAMENTAL PRINCIPLES

- The NCP is independent of government authorities, especially in terms of policy and performance assessment.
- It ensures equal access and equal quality of service.
- It is not a gatekeeper but looks after the patients' interests.
- It is supportive, co-operative, customer-oriented, friendly and reliable, and communicates effectively.
- It is accessible in real-life situations, not just via its website or only during office hours.
- It provides a human response and acts as a patient's advocate (offering advice on rights, helping to "read between the lines") and as a mediator towards healthcare providers, authorities, etc.
- It provides patients not just with information but with real-life solutions based on solid medical and legal knowledge.
- It offers informed assistance regarding rare diseases, specialised treatments and transplants.

VISIBILITY

- The NCP is highly visible at all levels; it is easy to find and contact.
- It conducts awareness campaigns and is active in print, broadcast and social media.
- It organises conferences and roadshows for patients, healthcare providers and other interest groups.

ACCESSIBILITY AND AVAILABILITY

- There are regional Contact Points in addition to the central NCP, especially in Member States with significantly large rural or dispersed populations.
- It communicates information in a form that is readily accessible and useful to patients, medical practitioners and nurses on the ground.
- The NCP uses a wide range of channels of information:
    - Website that is easy to use and includes links to relevant sites of governments, patient organisations and other stakeholders in most popular destination countries and is accessible for patients with impaired vision;
    - Printed materials available in locations frequented by patients;
    - Accessible physical locations for personal contact;
- The NCP provides information in different languages, reflecting the most common cross-border traffic.
- It collaborates with other NCPs to provide information on current clinical trials.

QUALITY OF INFORMATION

- The NCP provides information that is up-to-date, reliable, accessible, easy-to-understand and tailored to particular needs.
- It makes the right information available at the right stage in the patient's journey.
- It provides a comprehensive range of information:
    - on the availability of different treatments abroad as well as the national benefits;

- lists or registries for specific medical conditions detailing the medical expertise available both at home and abroad, including user-generated content (patients);
- data and statistics on the destination country (on safety, quality, etc.);
- manuals or guidelines for accessing treatment for specific conditions – both online and printed;
- price-lists for the cost of treatment, both home and abroad;
- information on travel and extra costs that may be incurred during treatment;
- summaries of administrative processes – how to apply for prior authorisation and how long it will take to receive it, how long will it take to receive reimbursement, etc.;
- information and guidance regarding complaints procedures.

OPERATION

- The NCP has its own operational budget with sufficient resources dedicated to specific functions.
- It is transparent regarding procedures and timelines.
- It acts as a one-stop agency as opposed to referring enquiries to other government authorities or agencies.
- It networks effectively and cultivates dialogue with stakeholders, especially patient organisations – it maintains a list of patient organisations, making it available to enquirers.
- It works closely with other NCPs, social security agencies, health insurance providers and healthcare providers to ensure delivery of real-world solutions.
- It facilitates complaint resolution (including collaboration with other NCPs) and legal assistance.
- It liaises with other stakeholders (especially with patient organisations) to mitigate patients' financial difficulties regarding upfront payment and reimbursement, ideally before travelling.

QUALITY STANDARDS

- The NCP is assessed for its performance independently from the national authorities.
- It seeks feedback from enquirers on its performance and the quality of information provided. It acts on this feedback, aiming for quality assurance.
- It has clearly defined response times, e.g. provides requested information within 1-2 weeks, plus a "fast-track" process for emergencies.
- It proactively collects and maintains comprehensive data on cross-border healthcare take-up, safety and quality, etc. and highlights any gaps and dysfunction to the national and European authorities.

4.1 PRESENTATION OF THE ESTONIAN NATIONAL CONTACT POINT

The Estonian NCP was presented by **Siiri Pűvi**.

The Estonian NCP became operational on 21 October 2013, four days before the Directive entered into force. It operates within the Ministry of Social Affairs in collaboration with the Estonian Health Insurance Fund (HIF), the Health Board and the State Agency of Medicines, and employs one person. The NCP has its own website (http://kontaktpunkt.sm.ee) and can be consulted by email, by phone or

in person. The website – which has been translated into English, Russian and Finnish – contains information on the Estonian healthcare system, domestic healthcare providers, patients' rights in Estonia (including the appeal system), as well as information on accessing treatment abroad, applying for reimbursement, etc.

Estonian citizens intending to seek treatment abroad must have health insurance and a medical referral by a physician. The list of reimbursable health services ("basket of benefits") and the applicable domestic tariff is maintained by the HIF. For reimbursement, patients need to submit an application to the HIF accompanied by the necessary documentation (invoice, proof of payment, medical referral and medical report). The average time for processing an application for reimbursement is two weeks.

Level of interest and take-up of cross-border healthcare

Out of a total of 18,000 visits to the NCP website since October 2013, 15,000 originated in Estonia. Visits from other EU Member States originated mostly in Italy (516), the United Kingdom (348), Finland (317) and Poland (271). Many requests for information were received in October-November 2013 following major media coverage of the Directive, but since then the monthly volume of enquiries has been lower.

In the first half of 2014, the NCP generated 43 applications to the HIF for reimbursement. Of the 36 decisions reached, 28 were positive and 8 were negative – either because required documents were missing or the treatment was not covered by the Estonian health insurance system. The NCP had no involvement in the decision-making process. The most popular destination countries were Finland, Germany and Lithuania. Reimbursements mostly covered operations and medical consultations, with two reimbursements given for chemotherapy/radiation treatment.

At this point there is not sufficient data to measure patient visits to Estonia under the Directive, but an indication of future take-up may be found in more general statistics for patient visits from abroad. The number of foreign patient visits almost doubled from 2012 (5,025) to 2013 (9,064). Most patients came from Finland (50.9%), followed by Russia (13.2%) and smaller percentages from the United Kingdom, Germany, Sweden, Norway and Latvia.

This data shows that Estonian citizens are beginning to take up the opportunity to access treatment in other Member States under the Directive, adding to those who are already working in other Member States while retaining their Estonian health insurance. The Directive offers new healthcare options particularly to patients living in border areas, such as Valga (Estonia) and its twin town Valka (Latvia). The Estonian NCP would welcome co-operation with patient organisations, as it seeks to apply its vision of sharing high-quality information and helping patients to access high-quality healthcare in other Member States.

4.2 PRESENTATION OF THE SWEDISH NATIONAL CONTACT POINT

The Swedish NCP was presented by **Kristian Lindström**, Försäkringskassan (Swedish Social Insurance Agency).

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

- County Councils: Each one 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 National Board of Health and Welfare, which covers patients from the EU and European Economic Area (EEA) seeking healthcare in Sweden[9], and the SSIA, which acts as NCP for persons with social insurance in Sweden seeking healthcare abroad.

The responsibilities of the SSIA include providing information about patients' rights, the conditions that apply for prior authorisation and reimbursement, and application forms. The SSIA informs patients through various channels: its website (www.forsakringskassan.se/privatpers, translated into English and 18 other languages), local offices (offering face-to-face meetings) and a national Customer Centre in Visby which houses around 60 administrative and case officers who can be contacted seven days a week by phone,[10] email or post. Managers, specialists and other support personnel are also located at the Customer Centre, which links up with the SSIA's country-wide network of local offices. The SSIA pays particular attention to making its information easily understandable, where necessary working with language experts.

Implementation of the Directive in Sweden

The Directive was implemented in Sweden via a national law that came into force on 1 October 2013. Swedish patients are reimbursed for planned medical care in the EU/EEA if the care has been provided by medical staff and if the costs would have been covered by public funds had the care been given in Sweden. It is optional for patients to apply for prior authorisation; however, obtaining this may speed up the reimbursement process as well as providing an advance guarantee of reimbursement to the patient.

The national law also stipulates that patients should not be denied the right to reimbursement solely on the basis that the treatment is not used in Sweden, as long as the treatment is based on "international medical science and generally recognised good medical practice" – this legal formulation is notably broader than that used in other Member States. The maximum amount of reimbursement is limited to the equivalent care costs in Sweden.

The SSIA makes a decision on reimbursement after consulting the patient's home County Council, which provides documentation and information about the treatment to allow an accurate comparison with the costs of treatment abroad (or to allow an estimate of cost for a treatment not available in Sweden). The SSIA is required by law to make a decision within 90 days; where prior authorisation has been obtained, the decision can be made much more quickly because the relevant documentation has already reached the SSIA. In practice, decisions can be delayed beyond 90 days due to administrative bottlenecks within the County Councils, which are responsible for covering the costs of treatment. The

[9] See www.socialstyrelsen.se/healthcare-visitors-sweden
[10] Call-centre number: +46 (0)771 524 524

SSIA is investigating how to make this process more efficient and quicker for patients; some County Councils have a high level of autonomy, which creates the need for greater consultation.

Take-up of cross-border healthcare

A total of 4,889 applications for reimbursement were approved in 2013 (300 in the first nine months of 2014). The most typical Swedish patient accessing cross-border healthcare in 2013 (also in the first half of 2014) lived in the south of the country and travelled to neighbouring Denmark, which shares commonalities in terms of the health system and language for cataract surgery due to long waiting-lists in the home County Council. The proximity of the health provider may also have been a factor: some health centres in Denmark are closer to towns in southern Sweden than Stockholm or Uppsala. It was also quite common for patients with psoriasis or other dermatological diseases to travel abroad for climate treatment in Spain and other countries in southern Europe. The most popular destination countries in 2013 were Denmark (60% of approved cases), Finland (11%), Spain (9%) and Norway (5%).

4.3 KEY POINTS FROM THE DISCUSSION

Under the Estonian health system, a *medical referral* is required in order to access specialised care both at home and abroad. The Commission respects this national policy, but thinks that Member States should also accept applications for reimbursement based on referrals obtained abroad – i.e. where a patient travels to another Member State, obtains a referral there and receives specialised care, then returns home and claims reimbursement.

Direct payment: There does not appear to have been any political discussion in Sweden regarding the option of direct payment as a means of mitigating financial barriers to cross-border healthcare. As the SSIA already manages more than 40 social welfare benefits and allowances, in practice it should be possible to devise a mechanism which specifically enables lower-income patients to avoid the burden of upfront payment for treatment. Respecting the principle of equal access to healthcare, the SSIA is prepared to address this issue.

5 Parallel Workshops – The Patient Journey in Cross-Border Healthcare

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

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

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

- How can I know that the treatment is safe and of good quality?
- Does this hospital have good results? (Objective criteria) What will it be like for me when I go over there? (Subjective criteria)
- Do I qualify for reimbursement?
- What will the total cost be?

Before leaving

- What exactly is going to happen and when?
- What should I bring?
- Who is responsible if there is a complication?

During stay

- Are my expectations correct? Are the expectations of the medical staff correct, e.g. regarding knowledgeable consent?
- Will the care personnel understand and interpret correctly my medical documentation?
- The “what if” factor: what will unexpected developments mean in terms of cost, liability and logistics?

After returning home

- How to receive reimbursement and what documentation is involved?
- Will I have a copy of my medical record, in a translation that is accurate and understood by my own doctors?
- Will everything go smoothly with regard to continuity of care and administrative procedures?

RECOMMENDATIONS

When deciding: enabling trust

- Transparent, comparable and understandable information should be given by healthcare providers, insurers and the national healthcare system in a timely manner on the full costs of care abroad.
- Information on quality and safety should be available in an open, transparent, comparable and benchmarked manner. This could be made available via a collaborative registry of quality-controlled healthcare providers.
- Patients should have a checklist to check if they are eligible for reimbursement and what documentation is required. This should be provided by the NCP in collaboration with patient organisations.

Before leaving: mitigating risks

- The process should be mapped out with a clear timeline, ensuring that the patient agrees and that everyone has a common understanding of the medical and administrative procedures involved.
- Patients should have a packing-list of basic necessities to take with them, e.g. routine medication, things needed in a hospital in another country. Patient organisations could play a role in this.
- Healthcare providers abroad should provide a checklist of the necessary documents.
- NCPs and healthcare providers abroad should offer advice on financial support if needed, to cover advance payment of treatment.
- Written agreement should be made on the detailed medical procedure, including how possible complications would be handled. This could be the result of remote consultation with the treating clinical team (through telemedicine). Could a standard form be created at European level?

During stay: dealing with the unexpected

- Good communication should be ensured between doctors at home and abroad to co-ordinate care.
- Healthcare providers should proactively document all the steps of the treatment.
- European interoperable electronic health records should “follow the patient”.
- Language support needed by patients and/or healthcare professionals should be provided – patient organisations could help in this.
- Healthcare providers abroad should give the patient a package of documents about what has been done and recommendations for the future (e.g. rehabilitation, lifestyle advice).

After returning home: continuity of care and continuous improvement

- Simple, clear and timely reimbursement procedure: patients should have a checklist of what documents must be sent to which institution, and there should be reasonable and clear timeframe for reimbursement.
- In order to promote best practice and enable benchmarking, easy and accessible evaluation forms should be available to record patient satisfaction and complaints. These could be anonymised.
- Evaluation of the process should be reported to the NCP, national authorities and the European Commission.

The participants suggested that EPF could act as a conduit for feedback to the Commission and support the patient organisations national level to share their experiences. Sharing experiences/feedback and using the complaints system if anything goes wrong could be a core function for patient organisations in Member States, making sure the law works.

6 Quality and safety and European Reference Networks

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

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

The Directive contains provisions regarding quality and safety of healthcare designed to ensure care is safe and of good quality, and to enable the patient to make a fully-informed choice about accessing cross-border healthcare. But these provisions also have much wider implications for healthcare generally. The main points are to be found in Articles 4 and 10 of the Directive.

Article 4 requires Member States to provide cross-border healthcare according to the applicable standards and guidelines for quality and safety. Information about these has to be made available to patients. Healthcare providers should give patients the information they need to make an informed choice. Article 10 looks beyond the individual patient's experience to the scope for improving quality and safety standards overall across the European Union: Member States should "render mutual assistance and to cooperate with each other", particularly concerning standards and guidelines for quality and safety of healthcare; National Contact Points are obliged to exchange information between them. Information regarding an individual professional's fitness to practise must be given upon request to other Member States.

This last point does not explicitly state that the information must be shared with patients, but it is perfectly reasonable for patients to be able to check with their NCP regarding the status and qualifications of a specific healthcare provider. Some Member States already have in place registers of health professionals for the wider public.

It is important to remember that the text of the Directive does not actually contain a legal requirement for Member States to have quality and safety standards in place; each Member State is free to decide whether to have them and, if so, what they should be. However, Member States must be transparent (via the NCP) regarding what they have; this will create pressure on those Member States that do not have standards in place to develop them.

How does the patient find the right information, the information s/he needs?

In theory, all Member States should at least have an NCP website. A European Commission webpage links to all of these national websites.[11] At the time of the conference, three Member States – Italy, Portugal and Romania – had not yet provided their NCP website contact details; Italy has since done this.

It is difficult enough for a patient to find information on the national safety and quality standards/guidelines, but it is even more difficult to find these standards in another Member State.

[11] See http://europa.eu/youreurope/citizens/health/contact/index_en.htm. This website contains links to all the main websites of national health and social-insurance bodies, not just those relating to cross-border healthcare.

For some Member States, the patient has to follow a series of links across different websites; for others, there simply is no specific information on quality and safety standards available.

Assuming the right information is found, it is very difficult for a patient to compare different standards and make any kind of meaningful judgement, because the language used is complicated and often legalistic. Clearly, much work remains to be done to ensure that information can be easily found and is patient-friendly. Patient organisations could contribute positively to this process, given their experience in communicating complex health-related issues to their communities.

Continuity of care

This is another area where quality and safety are particularly important. The Directive states that the patient is entitled to the same medical follow-up on returning from abroad as they would be entitled for treatment received at home. Patients are also entitled to a copy of their medical record. But there are practical hurdles: medical guidelines and protocols vary from Member State to Member State, and the availability of follow-up treatments also varies across Member States – particularly in terms of specific medications or levels of reimbursement. It is an open question as to who should provide an accurate translation of a patient's medical record. The Directive is very vague in these respects – it sets out a basic right without indicating how this right can be achieved. Patients need to take care to obtain as much information as possible on the real-life processes. Their feedback to NCPs and national competent authorities regarding what actually happens – 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 under national legislation if they suffer harm. Patients must also have transparent information regarding both legal and administrative options for settling disputes. Each Member State decides separately on these issues, so potentially there could be very different regimes for access to remedies across the EU.

One important detail is contained in Recital 23 of the Directive[12], 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 system to apply also to cross-border healthcare, if they wish to do so. This would offer a clear solution to patients, since they would know that they could refer to a single complaints and remedies process for both domestic and cross-border healthcare. So it is important for patients seeking cross-border healthcare to check with the NCP whether a particular Member State has opted for this approach.

Some recommendations

When implementing the safety and quality provisions of the cross-border healthcare Directive, *Member States* should refer to already existing EU instruments and actions – in particular the Council Recommendation on patient safety and quality of care (2009), which contains recommendations on information and empowerment of patients, and involvement of patient involvement in quality and

[12] Recitals explain the reasoning behind a Directive. They are not strictly part of the Directive, that is they are not legally binding, but they can be used to assist in interpreting the legislative provisions.

safety policies. Member States should patient organisations particularly in the development and implementation of guidelines and standards. They should commit fully to sharing experiences, good practices, research outcomes, quality assurance systems, etc., for example through the European Commission's Working Group on patient safety and quality of care (EC PSQC) as part of the current Joint Action (JA-PASQ, 2012-2015).

Patient organisations have a lot of expertise and can channel direct patient experiences to point out weaknesses and system failures – a valuable source of information for better implementation;

Patient organisations can raise awareness and help patients find the right information. They should approach their national NCP and offer advice on how to provide information to patients, and insist that NCPs involve them as regular partners. Patient organisations can also feed their experiences, including how they work with NCPs, back to EPF and the European Commission for the 2015 progress report.

At EU level, information on quality of care and patient safety needs to be made comparable across countries. Information should be easy to find –ideally through a "one-stop shop" for quality and safety at EU level.

Over recent years there has been significant progress and more recognition that quality of care and patient safety is actually a European issue and not only a national issue. From the patient community's point of view, it is important to have benchmarks (and agreed "key indicators") for quality of healthcare, allowing us to identify and share best practices for the benefit of patients and to raise the quality of care in national health systems overall.

But in this context, it is very important to establish what "good quality care" actually means from the patient's perspective. The indicators currently in use may not reflect the patient experience. EPF plans to focus on this issue in 2015, working to ensure that quality performance measures address the things that really matter for patients.

6.2 EUROPEAN REFERENCE NETWORKS

Matthew Johnson of EURORDIS focused on what the role of European Reference Networks (ERN) could be in delivering cross-border healthcare, especially from the perspective of the rare disease patient, although ERNs will not be limited to rare diseases.

The emerging landscape is one of big ambitions for rare diseases, based on the promise of the Directive: patients and patient organisations are demanding equal partnership on issues which impact patients' lives ("No decision about me, without me!").

Currently there are more than 7,000 individual rare diseases in the Orphanet database. All rare diseases will be covered by at least one ERN, which will focus on groups of diseases such as rare hematologic diseases, rare pulmonary diseases, etc. There is also a strong argument for creating an ERN for undiagnosed rare diseases. The ambition of the International Rare Diseases Research Consortium is to develop 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.

The strategy at European level is to achieve greater interoperability and reduce duplication. For the success of ERNs for rare diseases, it is vital that patients contribute their expertise effectively as equal partners. 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 (the collection, storing and analysis of data on a large scale) e.g. genetic data, registries and clinical data.

Other related initiatives include a European Commission programme for the integration of research infrastructure, 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 connecting these with Centres of Expertise of other Member States within ERNs.

Testing the concept of a European Reference Network

The rationale for European Reference Networks rather than national networks is easily understandable and is defined in the 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 challenged prevailing attitudes regarding networks, which have tended to be research-based, inward-facing and single-professional rather than multidisciplinary), and 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, e.g. a higher volume of chronic patients being treated resulting in a health benefit;
- ERNs are about providing high-quality healthcare and improving access – research is a secondary activity.
- The experience of 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.
- The ERN must be responsive and flexible enough to accommodate the practical realities of a patient and their family travelling abroad to access treatment.
- ERN could be referral networks or provide 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 arrangement); 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: Delegated Acts – the legislative formulation of the "what" and "how" – were adopted in 2014.[13] Since healthcare is a shared competency between Member States and Commission, the baton for driving the process now passes to the Member States and the Commission will focus on co-ordination and monitoring of the process for assessing ERNs.

[13] Adopted in March and entered into force in May 2014, the Delegated Acts enable ERNs to exist legally.

One key issue is that although the Commission has contributed financially towards the set-up process, mainly through pilot schemes, it does not have funding to support ERNs as they begin to be created and operated. The Member States retain control over funding, so they have the responsibility for ensuring ERNs operate on a sustainable basis. One of the anticipated benefits of grouping diseases is that industry will have the opportunity to engage with concentrations of specific patients, which could improve the prospects of funding the ERNs. However, although research is an important aspect of ERNs, their focus will be to improve access to high-quality healthcare, so the proper balance needs to be struck.

Another issue is that the timeline for accrediting the first ERN under the Commission's roadmap is quite short, so some Member States may prefer to focus on national networks. Experience and expectations at Member State level vary, so the lack of a shared vision and strategy might hinder the development of ERNs. For this reason, national plans for rare diseases continue to play a key role.

The application and assessment process for each ERN contains clear criteria, including the requirement for a minimum of 10 healthcare providers from 8 Member States, and the endorsement of the centres of expertise by the Member States. Under the Delegated Acts, patient organisations are not specifically included in the governance, assessment or evaluation of ERNs. However, the legislation specifies that ERNs are required to demonstrate patient-centred care and patient empowerment.[14]

The Commission Expert Group on Rare Diseases, which replaced EUCERD and held its first meeting in February 2014[15], has continued the work on best-practice guidelines and recommendations for centres of expertise and ERNs. In July 2014, the Commission issued its call for tenders for the development of a technical manual and toolbox for the assessment of ERNs, which ideally would include a review process. It is to be hoped that this manual will include the Expert Group's recommendation regarding patient organisations being members of the ERNs' boards and also members of the independent assessment bodies, thus giving concrete expression to the term "patient empowerment". Once it is known who is preparing the manual, the Commission Expert Groups, patient organisations and other stakeholders can pursue the discussion on what "patient-centred" should mean in practice.[16]

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. Patient organisations acting in solidarity have a very strong voice, which can be used to remind Member States that if the patient perspective is not integrated into ERNs, the result

[14] See 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.
[15] http://ec.europa.eu/health/rare_diseases/expert_group/index_en.htm
[16] Guidelines and technical documents for centres of expertise and ERNs should be in development and the independent assessment bodies selected by the end of 2014. The call for ERNs will be made in early 2015 and technical assessment is scheduled to be completed by the end of 2015, when the first ERNs could be established formally.

will be a disastrous loss of opportunity. Patient organisations are fundamental to the development of services for rare diseases: there are many examples of patient organisations working with clinicians to develop services that ultimately benefit from national funding schemes. Patient 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.

Other challenges include financial sustainability, especially as national health systems come under increasing pressure; transparent pricing and reimbursement of the true cost of treatment; and communication and language barriers: eHealth services, for example, will depend on effective communication between centres of expertise.

Finally, there has been a lot of discussion about ERNs developing EU-wide best practice guidelines, but as variation is the hotbed of innovation in terms of refining or developing practice, standardisation 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, for example improving understanding of the natural history[17] of a rare condition. They also promote quality and safety benchmarking in a way that is positively engaging rather than punitive. Co-production of outcomes with all partners is integral to the functioning of ERNs and can result in improved diagnosis, better clinical outcomes and quality of life. ERNs are also likely to reduce the burden of care on national health systems caused by inappropriate hospital attendances and treatments. Moving from competition between clinical centres to co-operation and collaboration within structured networks, thus cross-fertilising knowledge and expertise, represents a big step forward.

7 Exploring the role of patient organisations in securing effective implementation of the Directive – Panel discussion with NCP representatives

Jan Bouveng and **Kristian Lindström**, Försäkringskassan (Swedish Social Insurance Agency) and **Meelis Joost**, Estonian Chamber of Disabled People, reflected on patient involvement in the work of the NCPs and how patient organisations might support them.

This conference showed clearly that the potential exists for a collaborative partnership between NCPs and patient organisations to improve the patient experience of cross-border healthcare. One

[17] "Natural history" is the scientific term to describe how a disease would progress with no treatment – how it evolves, rates of progression, but also how the patient lives with it.

important take-home message for the SSIA is that in addition to making the decision-making process on reimbursement more efficient, more resources need to be focused on providing better information and guidance to patients before they travels for treatment. The SSIA will therefore work more closely with patient organisations on this aspect.

Although the SSIA considers that it performs well in providing information to patients, the fact that today many people are still unaware of the Directive's existence proves that there is no room for complacency. This key issue could be addressed by, for example, including a reference to cross-border healthcare on all health-related websites, with all the relevant links to further information.

The Directive represents an opportunity for patient organisations to advocate for improvements in national health systems. For example, the presentation on the Swedish NCP served to highlight the fact that dental care for adults is not part of the "basket of benefits" in Estonia.

It is clear that the overall NCP landscape is very uneven, with wide variations in the practical interpretation of the core functions and therefore in the allocation of resources and visibility. Patient organisations have a lot of work to do in proactively engaging with NCPs and seeking co-operation with them on key issues.

Financial inequality is a significant barrier; there is a big gap between those who are able to access cross-border healthcare and those who are not. The contributions heard in this conference suggest that patient organisations can promote a discussion on how to facilitate access. For example, Sweden's approach shows that perhaps patients do not have to pay upfront – a mechanism could be found to remove the financial barrier to low-income patients and their families.

8 Closing session: take-home messages and closing remarks

Moderator Kaisa Immonen-Charalambous 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. Below, we present a selection of take-home messages from participants:

SWEDEN

"This conference has highlighted the gaps in our organisation's knowledge. We now have a much better knowledge-base for responding to enquiries from patients; we will begin by providing better information and links on our website. We have also had the opportunity to meet representatives of the Swedish NCP, which has resulted in an invitation from them to meet more formally in the future to discuss areas where we can co-operate." – Patient representative

"The Swedish NCP will be having a meeting in November with the Danish, Finnish and Norwegian NCPs – we will share our experiences of this conference with them." – SSIA representative

FINLAND

"The Finnish health system is being reorganised, so nobody really knows what it will look like in 2015! There will be economic consequences, which will require priorities to be set in terms of operation and patient access. This means that cross-border healthcare may open up new possibilities, but it will also pose questions as to how Finnish patients access and receive treatment in their own country."

– Patient representative

"I have learned a lot about the Directive and the NCP, and how dialysis patients in particular may be affected. I will feed this information into our working groups and the parliamentary group in which we participate." - Patient representative

DENMARK

"This conference has been an eye-opener – we are winning new ground for patients. I already had a mandate to write an article on the Directive for three patients' organisation newsletters and to provide content for patients' organisation websites. I plan to contact the Danish NCP to suggest that I write an article on this conference which they might use in their own publication or website."

- Patient representative

"I contacted our network last night and asked if they knew about the Directive. They didn't – but they do now! I will also report back to my organisation on this conference, as it is very important for patient organisations to know what is happening. - Patient representative

LATVIA

"When I heard about the Directive a few years ago, I was excited because it would mean that we would have access to diagnostic tests and treatments that are subject to shortages or are not available in our country. The problem is that one particular medication we would want to access in Lithuania is very expensive compared to the one in the Latvian "basket of benefits", so even if a patient travels abroad with large amounts of money (as we were told to do by the Latvian NCP) s/he would not be reimbursed fully – an impossible situation financially. We intend to examine the Latvian "basket of benefits" more closely and compare it with other countries to identify what our patients need, and we will push the authorities to address any important gaps we find." –

LITHUANIA

"Those NCPs which were not present have missed an opportunity to get valuable feedback from patients' representatives on how they could improve things. We will invite a representative of our own NCP to our next council meeting of patient organisations to discuss how we might work together in the future." - Patient representative

"Before attending this conference I thought that the Lithuanian NCP was doing a good job, but now I realise that patients need much more information – a point which needs to be made widely and insistently at the official level." – Patient representative

"Treatment for MS is very expensive, and access to all the reimbursable drugs is not always possible in Lithuania. Before… we have relied on MS organisations in other countries for information on the latest treatments. Every year in December my organisation holds a conference hosted in the Lithuanian parliament – this year we will invite the NCP representative, whose name I now know. It was particularly valuable to hear how the other NCPs work."

- Patient representative

ESTONIA

"Before coming here I had some information on the Directive, but I have learned so much more from the presentations and comments. The conference has shown what is being done and what is possible in different countries; this opens up a range of new possibilities for our various patient organisations."

– Patient representative

"I believe that the Directive is a good thing, but in the former Soviet bloc countries very few people have the financial resources to access cross-border healthcare. The Directive has not only exposed financial inequalities, it has highlighted the fact that in some ways our countries are not as similar as we would like to think: for example, we have been talking about quality and safety standards as if every Member State has them, when in fact Estonia does not. "

- **Patient representative**

8.1 CLOSING REMARKS

Giving the closing remarks, **Anders Olauson**, President of the European Patients' Forum, recalled the journey the participants had made over the previous two days, and reflected on the next steps.

"We have shown overwhelmingly through this series of conferences that patient organisations can make a valuable contribution to ensuring that the Directive is a success, because we – as both individual patients and patient organisations – know the reality. We know what works, we know what doesn't work, and this concrete knowledge needs to be introduced into the process," he said.

EPF now has the responsibility of consolidating the network of patient organisations brought together by the conferences and keeping it alive, beginning by ensuring that the contributions made during the conferences are publicised widely. As well as disseminating the conference report, EPF will also look at setting up a space for all participants to continue to exchange ideas and views with each other. "We would love to know how the Finnish parliamentary group will respond to the information coming from this conference; similarly, we would welcome feedback on the Scandinavian NCP meeting due to be held in November," said Anders.

Next year will be particularly important: the Commission will for the first time assess the implementation of the Directive in the Member States. The Commission has stressed the importance of feedback from patient organisations. This is a strong reason for being active in advocacy and putting forward the patients' views. In June 2015, EPF will hold a European conference that will bring together patient leaders and NCPs from all Member States. This will offer the opportunity to discuss the Commission's draft report, so again the views of patient organisations will be extremely important.

We hope that this conference and the three that were held previously have together vitalised the links between the NCPs and the patient organisations.

9 Annex: Conference agenda

6-7-8 October 2014 Tallinn, Estonia

CROSS BORDER HEALTHCARE (CBHC) CONFERENCE

Day 1

19.30	**Welcome Reception and Buffet** Quiz on CBHC

Day 2

8.00-9.00	**Registrations**
9.00-10.30	**Introduction by Anders Olauson, European Patients' Forum (EPF) President** **The first Directive focussing on 'Patients' Rights' – what does this really mean for patients in this region?** EC perspective : John Rowan, DG SANCO European Commission Patient Perspective : Vida Augustiniene, Council of Representatives of Patients' Organisations of Lithuania **Plenary debate**
10.30-11.00	**Coffee Break**
11.00-12.30	**The crucial role of National Contact Points (NCP) and creating a framework model that meets the needs of Patients –** Moderator: Tamsin Rose **Working groups –** What would a "model" of National Contact Point looks like **Plenary debate** – What are the critical success factors? How patient organisations should be involved in the effective evolution of National Contact Points in the selected countries? **Presentation of the Estonian National Contact Point, Siiri Püvi**
12.30-13.30	**Lunch**
13.30-14.45	**Workshops : 3 parallel workshops on the Patient Journey in Cross Border Healthcare** Moderators: Tamsin Rose, Camille Bullot (EPF), Matt Johnson (EURORDIS)
14.45-15.15	**Coffee Break**
15.15-16.30	**Continuation of workshop: The Patient Journey in Cross Border Healthcare**
16.30-17.00	**Meeting room available for the rapporteurs to work on the feedback of the working groups to the plenary on Day 2**
19.30	**Dinner**

Day 3	
9.00-9.50	**Feedback from the rapporteurs on the core questions, discussions and recommendations from the workshops – Kaisa Immonen-Charalambous, EPF**
9.50-10.40	**Quality of Care and Patient Safety – Cornerstones of the legislation** Kaisa Immonen-Charalambous, EPF **European Reference Networks** Matt Johnson, EURORDIS
10.40-11.10	**Coffee Break**
11.10-12.15	**Exploring the role of NCPs and patient organisations in securing effective implementation of the Directive** Panel: Jan Bouveng and Kristian Lindström, Försäkringskassan (Swedish NCP), Meelis Joost, Estonian Chamber of Disabled People Moderator: Kaisa Immonen-Charalambous, European Patients' Forum
12.15-12.30	**Take home message – Anders Olauson, EPF President**
12.30-14.00	**Goodbye networking lunch**

10 Annex: List of participants

First Name	Surname	Organisation
Jeanette	Andersen	Lupus Denmark
Cristian	Andriciuc	Centre for Community Policies
Cibiriene	Audrone	Ministry of Health of the Republic of Lithuania
Marta	Augucevica	Patients' Ombud Office of Latvia
Vida	Augustiniene	Council of Representatives of Patients' Organizations of Lithuania
Elizabeth	Bergsten-Nordstrom	Swedish Breast Cancer Association, BRO and Europa Dona, The European Breast Cancer Coalition
Hanno	Bohl	Estonian Cancer Society
Jette	Boje	The Society for patients with late effects after cancer treatment
Camille	Bullot	European Patients' Forum
Lina	Buzermaniene	Lithuanian Council of Asthma Clubs
Jan	Bouveng	The Swedish Social Agency - NCP
Charles	Charalambous	European Patients' Forum
Blou	Dorte Birgitte	KIU – patient organization for women with gynaecological cancers
Aldona	Droseikiene	Lithuanian multiple sclerosis union
Maie	Egipt	Estonian Cancer Society
Lizzie	Enemark	KIU – patient organization for women with gynaecological cancers
Lina	Gulbine	Lithuanian Disability Forum
Sofia	Hallström	Barnlängtan (National infertility organisation in Sweden)
Sari	Högström	Kidney and liver association Finland
Karen Binger	Holm	Danish Haemophilia Society
Pille	Ilves	Estonian Patient Advocacy Association

Kaisa	Immonen-Charalambous	European Patients' Forum
Matthew	Johnson	EURORDIS
Meelis	Joost	Estonian Chamber of Disabled People
Timo Juhani	Kallioaho	The Mental Health Association in Seinäjoki Region
Dagmara	Kazlauskiene	People with the Down syndrome and their carers Association
Marta	Kozireva	The Latvian Umbrella Body For Disability Organizations SUSTENTO
Kirke-Anneli	Kuld	Estonian Kidney Patients Association
Kaspars	Kviesons	Association of Multiple Sclerosis in Latvia
Ligita	Liepina	Latvian Association for Kidney Patients
Dace	Likanse	Patients' Ombud Office of Latvia
Dorthe	Lykke	Foreningen for Ataksi/HSP
Āboliņa	Māra	National Contact Point Latvia
Pilar	Martin	Tallinn City's Board of Disabled People
Michael	Mogensen	Nationwide Hepatit C organistation
Anders	Olauson	European Patients' Forum Swedish National Coalition of Rare Disease
Ann	Paal	Estonian Spina Bifida and Hydrocephalus Society
Heli	Parjanen	Crohn ja Colitis ry
Jenni	Parkkonen	Allergy and Asthma Federation
Claus Zimmermann	Pedersen	The Swedish GBS/CIDP Patient Support Group
Katja	Peltoniemi	Finnish Hemophilia Society
Ingrid	Põldemaa	EYRA/Lupus Estonia
Inara	Pomere	Kolarda Foundation
Siisi	Püvi	National Contact Point Estonia
Satu Heidi Hannele	Rautakallio-Hokkanen	Finnish Infertility Association Simpukka

Kristi	Rekand	Estonian Patient Advocacy Association
Tamsin	Rose	Tamarack
John	Rowan	European Commission - DG Sanco
Jelena	Sabinina	Estonian Union of Multiple Sclerosis Societies
Anette	Soosaar	Estonian Health Insurance Fund
Danguole Regina	Survilaite	Club 13&Co. (National Association of Persons with Mental Disorders and Their Friends)
Beryl	Svanberg	The Swedish Rheumatism Association
Véronique	Tarasovici	European Patients' Forum
Anne	Teisseire	Uniliitto ry: Finnish Sleep Federation
Vladislava	Vassitškina	Estonian Union of Multiple Sclerosis Societies
Reigas	Viljaras	Palliative Care and Family Health Center
Susanna	Vilkamaa	Kela/FPA/Social Insurance Institution of Finland Contact Point for CBHC
Sofie	Winding	CCHS Denmark
Baiba	Ziemele	Latvia Hemophilia Society