

EPF Workshops on Cross-Border Healthcare – 3rd Stop: Poland

Meeting Report

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1 Introduction

GENERAL BACKGROUND INFORMATION ON THE WORKSHOP

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.

EPF has undertaken considerable work, in cooperation with our members, with the EU Institutions on the Directive prior to its adoption, and has subsequently produced and disseminated a toolkit explaining the Directive and presented it at various events throughout the European Union in which patient leaders were involved, to raise awareness during the transposition phase. As this phase ended on 25 October 2013 and the European Commission is due to report on the implementation of the Directive by October 2015, it is now particularly timely to organise dedicated national workshops to ‘raise the bar’ in terms of comprehensive knowledge and awareness among patient communities.

TARGET AUDIENCE

The workshop was aimed at patient leaders from Poland who have the capacity to transfer learning and knowledge from the conference to peers within their organisation and networks (such as board representatives, directors, policy and communication specialists within the organisations). A representative of the Polish National Contact Point was invited with the aim of facilitating contacts with patient groups within Poland.

STRUCTURE OF THE WORKSHOP

The workshop was conducted in English, with simultaneous interpretation in Polish.

The event was structured around thematic plenary sessions and interactive debates with the participants, as well as working groups followed by a closing plenary, which presented key conclusions and proposals on the way forward.

OBJECTIVES OF THE SESSION

Stanisław Maćkowiak, President of the Federation of Polish Patients, welcomed the participants to the meeting.

Nicola Bedlington, EPF Secretary General, introduced the session and explained its objectives.

- To raise awareness and knowledge about the CPHC Directive and patients' rights enshrined within this legislation;
- To ensure understanding about the scope of the Directive and its application at national level;
- To ‘unpack’ various aspects of the Directive which have wider policy and systems implications of interest to patients (eHealth provision, HTA provision, general provisions on Quality of Care and Patient Safety, specific provisions linked to Rare Diseases etc.)

- To facilitate greater understanding regarding the role on National Contact Points and how patient groups could support their effectiveness;
- To agree an approach to evaluate the impact of the legislation from a patients' perspective, on a longitudinal basis;
- To create an informal network of patient leaders interested and committed in CBHC to monitor developments over the coming years

Participants were invited to introduce themselves (see list of participants in the annexes).

2 The first Directive to focus on “Patients’ Rights” – What does this really mean for patients?

Nicola Bedlington, EPF, gave a presentation on the Directive and its meaning for patients.

2.1 HEADLINE MESSAGES

She gave five 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: 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 European Court of Justice’s 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.
- **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.** Patients will have a right to a copy of the medical record; to appropriate medical follow-up; the prescription made abroad will have to be recognised. 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 Directive states that **quality and safety standards for healthcare have to be transparent.**

- Finally, the Directive also provides **legal basis for co-operation between Member States on eHealth and HTA, rare diseases and quality/safety standards.**

2.2 BASIC PRINCIPLES OF THE DIRECTIVE

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;
- The legislation of the Member State of treatment applies in relation to quality and safety standards, with a requirement for transparency regarding those standards.

2.3 PRIOR AUTHORISATION

Prior authorisation is not the rule. However, 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-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.

2.3.1 WHEN CAN MEMBER STATES REQUIRE PRIOR AUTHORISATION?

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.

2.3.2 CAN A REQUEST FOR AUTHORISATION BE REFUSED?

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.

2.4 PRICES AND REIMBURSEMENT TARIFFS

2.4.1 HOW MUCH WILL I PAY?

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.
- In any case, there must be **transparency on the “basket of benefits”** and reimbursement tariffs – answering the basic question: which treatments, and how much.
- **What about travel costs?** Member States are obliged to cover only the cost of treatment but they can decide to reimburse the full cost of the treatment and extra costs.

2.4.2 DO I HAVE TO PAY UPFRONT?

One of the main gaps of the Directive is that patients will have to pay upfront and claim back the expense afterwards. This creates a problem in terms of equity of access: indeed, although the directive states that there should be no discrimination, upfront payment will be a barrier for many.

There is a provision by which Member States can arrange direct payment (the Member State of affiliation pays the cost of the treatment directly to the Member State where the patient receives the treatment), but this is a voluntary provision.

Patient organisations should challenge their national authorities and advocate in favour of direct payment to increase equity of access.

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

2.6 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.

2.7 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 apply⁴ – 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.

2.8 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;
- EHealth, for which there is a Steering Group working on a 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.

2.9 SOME CONCERNS... BUT AN IMPORTANT STEP FORWARD

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 Poland 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.

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 Poland to strive to improve quality, which is important for patients who access care “at home”.

In conclusion, the Directive is not perfect: it is in many respects a compromise from the patient perspective – gaps and areas of uncertainty remain – but nevertheless, it is a very important milestone for patients.

2.10 DISCUSSION

For some participants, the benefits of the Directive will be very limited for Polish patients, given that the price of procedures and treatment in Poland are still quite low compared to other countries. According to them, the regulation offers more benefits than the directive.

Ms. Iwona Grabowska, Representative from the National Contact Point, reassures the participants by saying the Directive does not prevent patients from benefiting from tools that existed prior to the existence of the Directive, such as the regulation or the European Health Insurance Card.

Some participants complain about the low level of reimbursement of many procedures in Poland. Nicola Bedlington answers that even though the Directive does not have an influence on the reimbursement decisions made at national level, the possibility for patients to compare standards and prices thanks to the transparency provision of the directive should encourage member states to raise their standards.

3 The crucial role for the National Contact Points

3.1 BRAINSTORMING SESSION ON THE IDEAL NCP...

Camille Bulot, EPF Membership Officer, introduces the session. Participants were broken into two groups and asked to reflect and 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 Poland?**

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

3.1.1 AWARENESS-RAISING ROLE OF THE NATIONAL CONTACT POINT

- The National Contact Point should actively disseminate information on the cross-border healthcare Directive and on the role of the NCPs;
- This information should be disseminated through a variety of channels, including: a patient-friendly website, media coverage (printed media and online media), leaflets (to be disposed at pharmacies, in hospitals), etc.



3.1.2 QUALITY INFORMATION

- The NCP should be able to provide information on the right to treatment and the right to reimbursement;
- The NCP should provide guidance, more than information;
- A database of healthcare providers should be built, and accessible via mobile applications;
- Credible information on waiting lists should be made available;
- A feedback system to record and verify opinions from patients having been through the cross-border healthcare journey should be set up;
- Decisions not to grant prior authorisation should be explained.

3.1.3 ACCESSIBILITY

- Access to the NCP should be easy (through a hotline, at national and/or provincial level);
- The language barrier should be overcome and the documents available on the website should be translated;
- The information should be provided in an intuitive way;
- An advisor (real person) should be available to answer more complex cases.

3.1.4 INDEPENDENCE

- There should be an independent supervision of the work performed by the National Contact Point.

3.2 PRESENTATION FROM THE POLISH NATIONAL CONTACT POINT

The National Contact Point's perspective was given by Ms Iwona Grabowska, who works within the International Cooperation of the National Health Funds. The Polish National Health Funds has been selected to act as the Polish National Contact Point, as it has been a liaison body for EU cooperation (beyond health) since the beginning of Polish EU integration.



3.2.1 FUNCTIONS

The main functions of the Polish National Contact Point are to provide information on service providers, healthcare professionals, licenses, quality and safety standards, accessible hospitals and complaints and redress systems.

From its creation until November 7th 2014, the NCP received 124 requests.

3.2.2 ACCESSIBILITY

In order to get information, patients should fill in an application. This can be done via a written request, via email or by phone.

The majority of the employees of the NCP also speak English.

3.2.3 COOPERATION

The Polish NCP cooperates with the European Commission and with other NCPs.

A Pan-European Platform (as suggested by the participants) is difficult to imagine but there are indeed a lot of exchanges between NCPs.

3.2.4 A COMPREHENSIVE WEBSITE

Ms Grabowska explained the different sections and features of the website. The National Contact Point's website includes a calculation device to estimate the cost of the care procedure as well as links to different patient organisations' website. She invited participants to add the contact details of their own organisation.

More information on the Polish National Contact Point can be found here: www.kpk.nfz.gov.pl

4 The Patient Journey in Cross-Border Healthcare

In the afternoon, participants broke again in groups and 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 of the discussion were then reported in the plenary session.

4.1 WHEN DECIDING

When deciding whether or not to get healthcare abroad, I need to make a mental and financial calculation:

- Can I be reimbursed for this procedure? If yes, to what extent?
- What kind of documents do I need to submit to get prior authorisation and to get reimbursed?
- How do I select and find the healthcare provider to perform the procedure?
- In case language is an issue: can I bring a friend? Is there an interpreter on the spot?
- Is it possible to make a site visit?
- Is there a patient organisation I can get in touch with?

4.2 BEFORE LEAVING

- Do I need approval from the National Health Funds?
- What are the necessary documents I need to bring with me?

- Can I afford a longer stay?
- Do I need to take an additional insurance (for travel expenses, absence from work...)?
- What will be the total price for me (treatment + travel + accommodation)?

4.3 WHEN YOU ARE ABROAD

- Is there a special format for the invoice?
- Will my member state of affiliation be able to read the prescription?
- Is the prescribed drug available in my country? Will it be reimbursed?
- Can my doctor at home and my doctor abroad get in touch?
- What happens if something goes wrong?
- In case of complication, do the extra treatment I get depend on the directive or on the regulation? Can I go and visit a private care provider?

4.4 RETURNING HOME

- How can I be sure of the quality of the replacement drugs (in case the drug prescribed is not available in my home country)?
- How can I give feedback about my cross-border healthcare experience?
- How do I ensure follow-up and continuity of care?

5 Conclusions, Take Home Message and Next Steps

Nicola Bedlington, EPF Secretary General, invited the participants to share the message they will be taking away and what actions they will be taking when returning home.

All participants said they had learned a lot about the directive. They committed to different actions to raise awareness about the directive and to spread knowledge within their own networks and beyond: via media actions, through information on their own webpage, by publishing a leaflet with recommendations for the four stages on their website. One participant proposed the creation of a “FAQ for patients” at European level, maybe hosted on the EPF website.

It was also suggested to collect feedback and case studies, maybe through interviews, and to exchange good practices on cross-border healthcare, be it under the regulation, the directive or the European Health Insurance Card.

In general, participants regretted the absence of pan-European guidelines in quality and safety of care, and encouraged the EU to do more in the field of standardisation.

Finally, some participants took on the offer from the National Contact Point to include hyperlinks to their organisation’s website on the NCP’s website. The representative from the NCP invited participants to contact her for further information.

Nicola Bedlington thanked the participants for their enthusiasm, and invited the participants to think of the wider implications of the directive.

The Directive is not a panacea: however, even though patient mobility and cross-border healthcare remains an option for a limited number of patients only given the shortcomings of the directive, it also is an opportunity for patients to advocate for better healthcare and more transparency on the quality and safety standards in their own country.

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.

Nicola Bedlington announced that a conference gathering patient leaders and representatives from the NCPs across the 28 countries would take place in early July in Brussels. This will be the occasion to take stock of the state of implementation of the directive and to share some feedback with the European Commission on its benefits but also on the recommendations that can be made to further advance patients' rights in Europe.

Witold Michalek, Director of the Federation of Polish Patients, committed to relay the knowledge developed during the workshop on the Federation's website and to continue the dialogue initiated with the National Contact Point. He concluded by announcing the projects of the national coalition for the coming months: enhancing the cooperation with the European Patients' Forum and starting a discussion with the Ministry of Health on various topics, including on the reimbursement of healthcare expenses.

Stanisław Maćkowiak, President of the Federation of Polish Patients, thanked the participants for the active participation and closed the meeting.



CB, 30 March 2015