

Summary Report: Cross-Border Healthcare

**Main Conclusions and Recommendations arising from the EPF series of
Regional Conferences 2013-14**

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1. Overview and background

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

During the long “legislative journey” of this directive, EPF and its members undertook considerable work with the EU Institutions and stakeholders to embed patient-centred provisions. Following its adoption, EPF produced a toolkit and recommendations to raise awareness during the transposition phase. As this phase ended on 25 October 2013, the timing was right to organise a series of dedicated regional conferences to raise awareness among patient communities.

Four regional conferences took place between December 2013 and October 2014, in Brussels, Athens, Ljubljana and Tallinn. The objectives of these events were to build knowledge of patient leaders in the different countries about the Directive and about patients' rights; to ensure understanding about the scope of the Directive and also its shortcomings; and to prepare the ground for evaluation of the impact of the legislation from a patients' perspective.

EPF was able to raise awareness and knowledge about the Directive and patients' rights enshrined within this legislation, to ensure understanding about the scope of the Directive and its application at national level, to agree an approach to evaluate the impact of the legislation from a patients' perspective, on a longitudinal basis, and to create an informal network of patient leaders interested and committed in CBHC to monitor developments over the coming year.

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

- Health Ministry representative

With these events, EPF together with the participating patient communities have taken the first steps towards promoting stronger awareness of this landmark Directive and its implications for patients; we have also created an informal network of patient leaders who are committed to disseminating information to their peers and working together with the National Contact Points and their national governments to support effective implementation. During the next years, this network will be engaged in monitoring the impact of the legislation on patients.

Each conference was attended by between 40-45 patient representatives from the participating 20 EU member states. (Countries not covered by these regional conferences will be through national workshops held during 2015.) In addition to patient representatives, National Contact Points were invited to send representatives; European Commission officials participated in each conference.

This summary report presents the main conclusions from the conferences, focusing on the patients' identified priorities: equity of access, information, quality and safety, and the role of different actors. Although overall participants tended to identify the same issues and challenges, these were often expressed in a nuanced way reflecting different national realities. Therefore, we invite readers to study the individual conference reports to get a more comprehensive understanding of the key messages of each conference.¹

¹ The full reports of all four conferences are available on EPF's website: <http://www.eu-patient.eu/whatwedo/Policy/Patients-Mobility/>

2. What does the Directive mean from the patients' perspective?

The patient community welcomed the cross-border healthcare directive, but getting to this point had been a long and sometimes frustrating process from the patient perspective. The result is a compromise, with significant uncertainties and gaps; but even so it represents a big opportunity for patients.

During the series of conferences it became evident that as yet there was not a great deal of practical experience among participants in accessing cross-border healthcare. Primarily, those from the rarer diseases or patients in unusual life situations² had accessed treatment abroad. Patient organisations' involvement in the transposition or implementation process had been low. Previous knowledge of the Directive (and the Regulations) was limited. Considering that patient representatives participating in the conferences are better informed on average, the awareness level of the general public and patient population is probably much lower.

Implementation of the directive by the member states was still uneven. Furthermore, some member states had already pre-existing cross-border arrangements, while others had no previous experience.

Nonetheless, patient representatives eloquently presented the main challenges they perceived in implementing the Directive. The Directive is seen as offering opportunities to enable patients to exercise their rights (faster access to treatment for patients experiencing long waiting times; increasing the transparency of providers and pricing of medical procedures; member states being urged to upgrade and improve national performance) but also challenges (paying for the costs upfront; determining what constitutes "undue delay"; the most affluent and best-informed patients benefiting the most; worsening of existing health inequalities).

Equity of access

The primary context in which the Directive is seen is **access to care**. The potential of the Directive is clearly seen in terms of enhancing access and also quality of care. Persistent health inequalities – including inequalities in access to healthcare – between and among member states and between disease areas are well-established. In our conferences, these inequalities were very strongly highlighted by the participants. Long waiting lists were mentioned by many participants as a barrier to care, particularly when there are shortages of specialists in some areas; other barriers include high co-payments and lack of reimbursement. There is a real fear, particularly in the less-resourced member states, that the current financial crisis (the related freezing or even cutting of healthcare budgets) will negatively affect the implementation of the principles of patient mobility and non-discrimination as codified in the Directive.

Upfront payment is clearly seen as the most important barrier in this regard; added to this is the fact that extra costs, such as travel, are not covered. Member states and National Contact Points are asked to proactively work on solutions to alleviate the financial burden on patients, particularly the less well-off. For example, Sweden's approach indicates that patients may not always have to pay upfront – a mechanism could be found within the social benefits system to remove the

"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." – Patient representative

² See case study in the report on the Brussels conference, pp. 9-11.

financial barrier to low-income patients and their families. The contributions heard in the conferences suggest that patient organisations, too, can promote a discussion on how to facilitate access.

Information, or lack of it, was also highlighted. The establishment of the National Contact Points for information was patchy and patients were faced with “a labyrinth of confusing, sometimes insufficient and sometimes too-detailed information”. Patients identified as a major challenge the creation of a

"There has been no reaching out to society to inform patients and citizens – for example the publication of the new national law received no publicity, and the involvement of patient organisations has not been considered. A lot of attention has been given to legal, technical and financial issues rather than the practical implications for patients."

- Patient representative

culture of transparency and cooperation to help patients who are already vulnerable due to the ill-health and so may not have the capacity to battle bureaucracy to make use of their rights. Generally, healthcare systems were perceived as being not used to transparency and reluctant to disclose information specifically on how they operate, the availability and cost of care and its safety and quality. Implementing the Directive will therefore require all stakeholders to address this resistance

to change.

Open questions and uncertainties included the application of prior authorisation and who is responsible for making the decision on access. Patients also want clarity regarding the provisions of the social security Regulations, in particular for patients with (suspected) rare diseases. Some patient representatives worried that if the NCP is only an advisory body, patients may face lengthy delays and bureaucracy from the competent authority or the health insurer, which may undermine trust in the answers given by the NCP.

Diverging clinical guidelines are applied in different member states for the management of certain conditions, which also relates to differential availability of treatments. “Chemotherapy for colorectal cancer has assumed the character of personalised medicine in Germany, which is far from being the case in Latvia.” The lack of harmonised guidelines means accurate information on quality standards in different countries is of even greater importance. In addition, the European Reference Networks could be used as a mechanism for greater convergence between guidelines and generally to improve the quality of care across the EU.

“If there is a better-quality, less invasive breast cancer treatment available abroad, with a similar but not identical intervention covered in my country’s “benefits basket”, will a patient be reimbursed if she goes abroad?”

- Patient representative

Many questions related to how **medical records** travel across borders and with the patient, given that patients’ access to their own medical records currently is not established across the EU. (For more on this, see Chapter 5, “The patient journey”.)

3. The crucial role of National Contact Points

The critical role of the National Contact Points in ensuring that patients have the right information they need to make a meaningful decision about cross-border healthcare was amply demonstrated during the conferences. A number of NCPs participated in the conferences and presented their services, and during a dedicated breakout session participants brainstormed together on what an ideal NCP would look like.

Overall the NCP “landscape” is still very uneven, with wide variations in the practical interpretation of their core functions and therefore in the allocation of resources and visibility. From a patient’s perspective, it appears that some member states regarded the NCP as an afterthought to formally comply with the Directive, rather than a meaningful structure to help patients and citizens navigate a very complex web of interlinking systems. Other NCPs may have the willingness to provide a comprehensive service but have limited financial means.

"It was very useful to build on formal partnerships by coming to this conference to have personal contact [with patients] and hear personal stories. This will help us to move things forward."
- NCP representative

As can be seen from the “checklist” below, patients have high expectations. The prevailing sentiment is that the NCP must be a “gateway to healthcare” and not a gatekeeper blocking access. Rather than behaving like a government bureaucracy, the NCP should have at its disposal the skills, knowledge and attitudes to put the patient first, to serve patients, professionals and policymakers, and to work with the patient.

The aim should be that patients receive the care that they need, in a timely fashion, without adding to their burden and that the existing inequalities between patients are alleviated.

Clearly, funding of the NCPs is of vital importance – many member states seem not to have allocated any dedicated budget. In some member states the NCP actually consists of one single person, while in others (a minority) it is a large structure with many employees to provide services to patients.

Based on the feedback from patients, EPF believes that not only is it crucial to have EU-wide guidelines on how NCPs should function and provide information to patients, but it is also necessary to explore possible mechanisms to support a sustainable network of NCPs from EU funds as well as member states’ budgets.

4. NCP “checklist” of key recommendations

Fundamental principles

- The NCP adopts a multi-stakeholder approach. It cooperates with the domestic social security system, patient groups and professionals, as well as treatment providers abroad and with NCPs across Europe.
- The NCP demonstrates independence and transparency in its functioning, even if it is formally part of the government structure. It should have a specific mandate and operational budget and be independently appraised for its performance.
- The NCP prioritises the protection of the patient’s interests over other interests.
- The NCP’s prevailing culture is one of providing a service to patients across their entire journey, helping the patient to manage hurdles and providing solutions rather than just providing information.
- The NCP is supportive, co-operative, customer-oriented, friendly and reliable.
- The NCP adopts a high degree of professionalism and empathy; it has personnel trained in dealing with patients, and includes (volunteer) expert patients.
- The NCP provides a human response, being able and willing to take time to listen to patients and offer solutions; it acts as a patient’s advocate, offering advice on rights, helping to “read between the lines”, and acts as a mediator towards healthcare providers and authorities.
- The NCP respects human dignity and is non-discriminatory, respecting cultural differences and ensuring equal access and quality of service all.

- The NCP is able to offer informed assistance regarding rare diseases and specialised treatments.
- The NCP works with other stakeholders to identify and implement solutions to mitigate patients' financial difficulties regarding upfront payment, thus upholding the principle of equity of access based on needs, not means.

Accessibility and visibility

- The NCP is highly visible, easy to find and to contact, ideally with a name that is easy to recognise.
- The NCP communicates using simple language that all patients can understand.
- The NCP provides information in foreign languages, at least English and relevant minority languages as well as ideally the language(s) of the most common cross-border flows.
- The NCP is accessible in real-life situations, not just via its website or only during office hours.
- The NCP can be accessed via multiple channels – website, email, free telephone line, 24-hour emergency hotline, as well as physical premises with barrier-free access for personal consultations.
- In member states with significantly large rural or dispersed populations there are regional contact points in addition to the central NCP.

The NCP website:

- ✓ is easy to find through Google
- ✓ is easy to navigate
- ✓ has content that is informative and clearly structured
- ✓ includes visual tools where appropriate, such as infographics and video
- ✓ includes real patients' stories and testimonies
- ✓ includes FAQs, guides and checklists
- ✓ includes a simple mechanism for patients to submit applications
- ✓ has an interactive feedback facility
- ✓ links to other relevant websites, such as the national health authorities, health providers and patient organisations.

Operation

- The NCP has transparent procedures and clear timelines.
- The NCP process provides for individualised guidance with case managers.
- The NCP communicates also with advocates and/or legal representatives nominated by individual patients.
- The NCP facilitates the translation of documents.
- The NCP supports the patient in his/her contact with foreign bodies and legislation, by liaising with other NCPs, e.g. in facilitating patient access to specialist treatment, playing a mediating role and providing solutions.
- The NCP offers patients support and advice in case of complaints, problems with reimbursement and refused authorisations.
- The NCP maintains a list of patient organisations in the country and makes this available.
- The NCP acts as a one-stop agency towards the patient, as opposed to referring enquiries to other government authorities or agencies.³

³ In some countries, such as Belgium, patients are referred to their healthcare insurance fund for personalised advice since this is the entity in Belgium that knows the most about the patient's file. In such cases it makes sense to avoid duplication, but the process and structure should be clear and transparent to the patient.

Quality of information⁴

- The information provided is accurate, reliable, up-to-date and easily understandable to lay people, “designed for and by patients”.
- Simple step-by-step guides on the application processes are available to the patient, with clear information on how to apply, how long the process will take, etc.
- Frequently Asked Questions are provided online and via printed leaflets.
- The NCP provides customised information packages for specific conditions or disease groups.
- The NCP collaborates with other NCPs to provide information on ongoing clinical trials.

Quality standards

- The NCP answers all normal enquiries within 1-2 weeks and includes a “fast-track” option for emergency situations.
- The NCP has in place a continuous improvement system including training of staff.
- The NCP is assessed for its performance independently from the national authorities.
- A quality control system is in place to monitor performance indicators such as: response time to applications; accuracy and patient-friendliness of information; and whether the service meets patients’ needs.
- The NCP is able to give a clear explanation of all decisions.
- The NCP has an effective complaints management and feedback process.
- The NCP seeks feedback from enquirers on its performance and the quality of information provided. It acts on this feedback, aiming for quality assurance.
- The NCP collects data, including numbers of enquiries, timing of outcomes, proportion of acceptances/refusals, volumes and direction of traffic for specific cross-border treatments, safety and quality, etc., and highlights any gaps and dysfunction to the national and European authorities.

5. The patient journey

Each conference included parallel workshops exploring different aspects of the “patient journey”, and what specific information needs they presented for patients. Participants divided the journey broadly into four stages: making a decision about whether to access cross-border healthcare; before leaving; whilst receiving treatment abroad; and after returning home. The earlier information needs are addressed, the easier it will be to foresee and manage unexpected events, minimise difficulties, and ensure safety and continuity of care.

The most frequently mentioned considerations **at the decision-making stage** related to: finding out about the treatment options that are available, both in the home country and abroad; information on waiting lists both at home and abroad; the process of getting a decision on reimbursement or prior authorisation; information about safety and quality of the treatment and of providers; the total cost including reimbursement and out-of-pocket costs; information on the clinical guidelines applied in different member states; the language capacities of health providers; complaints and redress mechanisms; safety risks such as infections; and protection/transfer of patients’ medical data.

⁴ See the next section on what information should be provided and when.

Financial barriers were seen as a major threat to equity of access: many patients would not be able to afford cross-border healthcare due to the requirement for upfront payment of the treatment and having to cover other related costs, such as travel.

Before leaving, patients would want to know: exactly what information, documents and other provisions they would need to take with them; making sure that their medical files were accurately translated and transferred; ensuring that the treating doctors at home were connected with the treatment providers abroad. Patients would also need information regarding logistics, including travel, accommodation and provisions for eventual accompanying persons. The step-by-step timeline and process for receiving the treatment (what happens and when) was considered important, including knowing in advance to whom to turn for help and who would be responsible in case of complications. An accurate picture of the real (itemised) cost of treatment and the payment schedule would be needed at this stage at the latest. Patients also want information on which patients' rights are applied in the member state of treatment.

During the stay, it is important that the patient and the healthcare team have a common understanding of the treatment process, the patient's medical records, informed consent and any other issues such as allergies, diet needs, etc. Language or cultural communication issues might arise at different times. The most common concern was unforeseen events, such as a complication which might lead to an extension of the hospitalisation, an arising safety issue, or unexpected additional costs. Some patients were also concerned about discrimination by healthcare staff, who may regard them as "health tourists". It is vital that there is assistance available in such cases and the patient knows what to do and whom to contact.

The most common concerns **after returning home** include reimbursement issues such as delays and complex administrative procedures. Continuity of care is also a major concern, including: obtaining the prescribed medicines, rehabilitation or repeat treatment (which may not be reimbursed in the home member state); knowing how to manage side-effects and complications; and how to handle potential medical disagreements or diverging clinical guidelines. Other issues include: obtaining an accurate translation of the medical record and ensuring that all the information is completely transferred; knowing how to complain in case of problems; and having the opportunity to give feedback in order to improve the system for other patients.

6. Recommendations for each stage of the patient journey

When deciding: enabling trust

- Information should be given on opportunities to access specialist treatment in another country by disease area. NCPs could create lists of medical services where it feels that there is special expertise or high quality, in collaboration with patient organisations and professional bodies, and share this with other NCPs.
- Patients' organisations can provide information about treatment options available in other countries (without implying endorsement), as well as checklists for practical arrangements – "what needs to be done and when".
- Information should be given on waiting lists in the home country and other countries.
- Accurate information about health professionals' and providers' language capacity should be made available in advance in order to minimise problems further on in the process.

- Information should be provided on the full costs of care abroad in a comparable and understandable format. This should not only give basic tariffs but indicate what is reimbursed by the home healthcare system, and what extra costs would need to be covered by the patient.
- NCPs should provide “checklists” for patients to check if they are eligible for reimbursement and what documentation is required. This could be provided in collaboration with patient organisations.
- Clear information should be available on patients’ rights, on the uses of the Regulations versus the Directive, and their respective advantages and disadvantages (e.g. in cases of suspected rare diseases)
- Comparable information should be given on quality and safety – across institutions and across member states – and should be made available in an understandable manner. Reliable, unbiased and comparable information on the quality of hospitals and doctors should be provided, for example through a collaborative registry of quality-controlled healthcare providers maintained jointly by the NCPs.
- NCPs and healthcare providers abroad should offer advice on financial support if needed, to cover advance payment of treatment. NCPs should actively work with relevant national authorities (e.g. social security) to provide solutions for those patients who need treatment abroad but face financial burden. This should include support for reasonable extra costs (e.g. travel, disability).
- Member states should actively promote health literacy so that patients can interpret information on safety and quality of healthcare, outcomes data, etc. to make meaningful choices concerning their own healthcare.

Before leaving: mitigating risks

- The entire cross-border healthcare process should be mapped out with a clear timeline, ensuring that everyone has a common understanding of the medical and administrative procedures involved. The patient should have a printout of this from the NCP.
- A detailed financial pathway should be established: timeline, additional costs, reimbursement rates. The patient should have a printout of this.
- Standardised templates should be defined at EU level for all types of forms required in cross-border healthcare: applications for prior authorisation and reimbursement; requests for information from the NCP and health providers; forms to facilitate the transportation of medicines or appliances through customs.
- Patients should have clarity early on to know what follow-up care or rehabilitation will be needed. Respective responsibilities, e.g. in the case of medical complications, should be clearly defined.
- 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 by developing guides or checklists of questions to ask.
- Healthcare providers abroad should provide a checklist of the necessary documents and other items the patient should have with them.
- Patient organisations could provide disease-specific “travel” guides, possibly in the form of mobile apps developed in partnership with other stakeholders.

During stay: dealing with the unexpected

- Host healthcare providers should proactively document all the steps of the treatment.
- Healthcare providers should be responsible for sharing information between home and host country to ensure continuity of care, e.g. replacement medication if it is not available in the home country.
- European interoperable electronic health records should “follow the patient”. Best practices for transfer of patient data (safe, effective and respecting patients’ privacy) should be developed at EU level.
- Within the host healthcare provider there should be an identified patient contact person or advocate who can provide practical assistance and support, including language help. Voluntary organisations could also help plug the linguistic “gap”, seeking out potential language resources and providing peer-to-peer buddies who can help with problems with logistics and communication.
- In case of unforeseen complications, the patient should be covered for the cost of extra stay, either by the home member state’s health system or via liability insurance. Patients should be clearly informed of the options.
- NCPs should have a hotline for emergency situations. Patient organisations could potentially help share the operation of such a hotline. NCPs and providers should have dedicated patient support persons linked to other NCPs and providers through a formal network.
- Harmonised forms for invoicing should be developed at EU level.

After returning home: continuity of care and continuous improvement

- Healthcare providers abroad should give the patient a standard “package” of documents about what has been done and recommendations for the future, e.g. rehabilitation, lifestyle advice.
- NCPs should ensure that the administrative paperwork is interoperable so that patients can be easily reimbursed, including accurate translations of medical notes.
- The reimbursement procedure should be simple, clear and timely, following the checklist developed by the NCP. A clear timeframe for processing reimbursements should be set by the European Commission.
- 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, the national authorities and the European Commission. In addition, NCPs could interview a certain number of individual patients to have more detailed information about their experience.
- Patients’ organisations can offer opportunities for patients to provide feedback on their experience of healthcare abroad - publication of case studies and real “patient stories” (positive and negative).

The participants believed that all stakeholders – NCPs, healthcare providers and patient organisations – have a responsibility to share their experiences and contribute to better knowledge about cross-border healthcare. Information should be collected at European level. The EPF could act as a conduit for feedback to the European Commission and support patient organisations at national level to share their experiences. Giving feedback and using the complaints system in case of problems could be a core contribution of patient organisations in member states to ensuring that the Directive works well.

7. Quality of care and patient safety

Each conference contained a specific session on safety and quality, with the aim to ensure a full understanding of how the provisions of the Directive promote safety and quality of healthcare and transparency towards patients and citizens, setting this in a wider policy context. Safety is not a trivial issue. As the 2014 European Commission report shows, healthcare-associated infections are the most common adverse events (responsible for 37,000 deaths per year), followed by medication-related errors, surgical errors, medical device failures, errors in diagnosis and failure to act on the results of tests.⁵

The **transparency requirements** are potentially a huge step towards patient empowerment, as patients will be able to compare standards between different countries and patient organisations can use this information to advocate for better quality healthcare, both at home and abroad. However, the Directive does not contain a definition of quality or safety. This is an area where patient organisations can play a valuable role, including by participating at EU level discussions around a common understanding of quality of care.

One aspect of transparency in which patients are very interested is information regarding specific professionals, including their qualifications and fitness to practice. Whilst member states are required to share information with each other on this point, it is not explicitly stated that the information must be shared with patients. However, some member states already have registries of health professionals in place. More information could be collected on what use patients make of such registries, and whether the information is meeting their information needs.

Challenges to patients include the complexity of standards and guidelines on quality and safety. National standards are difficult to identify, and sometimes inconsistent. Very few patients are able to compare the standards of care to member states.

Concerns were also raised regarding **continuity of care**. The wording of the directive is rather vague, only stating that the same follow-up must be provided for care received abroad as would be provided for care received at home. However, as mentioned above, access to treatments (including medicines), the applicable guidelines, and reimbursement rules vary significantly between member states. Rehabilitation in a specialist facility, for example, is as a rule covered in Germany and substantially improves recovery and quality of life; such care is however not reimbursed in many other member states.

Similarly, **complaints procedures** and mechanism for remedies are subject to member state legislation, and patients would like clear information on this topic. A simple, patient-friendly solution would be for member states to extend their domestic system to apply also to cross-border healthcare (Recital 23 in the Directive), so patients would know that they can refer to a single process for both domestic and cross-border healthcare.

European Reference Networks were covered in all conferences, as they are one of the specific tools put in place to facilitate access to high-quality care for rare diseases. Although the focus of ERNs is currently on rare diseases, they can provide a model for future application to other chronic conditions as well, in order to enhance quality of care across the EU.⁶

⁵ Infographic "Patient safety in the EU: 2014" of 19 June 2014. http://ec.europa.eu/health/patient_safety/policy/index.htm

⁶ For a detailed discussion of European Reference Networks, please see the individual conference reports.

Finally, in this context it is very important to establish what “good quality of care” actually means from the patient’s perspective. The indicators currently in use may not reflect the patient experience of priorities. EPF plans to focus on this issue in 2015-16, exploring approaches to measure quality from the patient’s point of view.

8. The role of patient organisations

The series of conferences on cross-border healthcare confirms that there is a very real interest among patient organisations to understand the technical details of the Directive and how these might be implemented in practice. A space has emerged for patient organisations to address two crucial and complementary tasks: to inform patients of their rights and how to go about exercising them; but also to help improve the patient journey overall by working more closely with competent authorities and NCPs. Patient groups now have a clearer view of the intention behind the words of the Directive and where challenges may arise in real life, bearing in mind that implementation is a “work in progress”. It is fundamentally about patients’ rights, so patient organisations play a crucial role in monitoring progress and impact.

“The absence of the patient voice is mostly due to lack of information, not due to indifference of patients. As patient organisations gain more knowledge of how the Directive works in practice, they will become more involved.”

- Patient representative

The events highlighted the valuable contribution which patient organisations can make towards ensuring that the Directive, as well as other health-related EU legislation, reflects the realities of patients living with a condition and has the maximum positive impact on the lives of European citizens. Patient organisations see the provision of information as a core activity. Many already have advisory services in place and are willing to disseminate information on cross-border healthcare-related issues. Some have organised seminars for patients on the topic. Given the sometimes limited resources of NCPs, patient groups can be effective conduits of basic and general information to patients, which could lessen the number of enquiries made to the NCP.

Patient organisations and NCPs often do not know who to talk to in order to initiate a partnership – both patient representatives and NCP representatives found the EPF conferences enormously helpful in establishing these contacts. Patient organisations face a particular challenge, also, regarding their capacity. Most patient organisations function on a voluntary basis, so the members must contribute their time and energy on top of the commitments of a normal life and managing a chronic condition. In addition, due to limited capacity and more pressing priorities, there can be a lack of interest in “European” issues.

“It is unfortunate that patient organisations were not consulted [prior to producing a leaflet on CBHC]. We would have flagged up the bad translation and prevented distortion of information.”

- Patient representative

Patient organisations should get informed about the content and the implications of the Directive, also in relation to the existing social security Regulations, and provide information to their members. They should start a dialogue with their members as well as other patient organisations in order to get an accurate picture of how cross-border healthcare affects patients with various conditions. They should insist on meetings with their own NCP to discuss how

they can be regularly involved in the NCP’s operations and propose concrete measures that are of interest to patients. Patient organisations should also give feedback on experiences of the Directive in the country, both to the national ministries of health and to the European Patients’ Forum.

If patient organisations are to be meaningfully involved in working with the NCPs, national authorities, insurers and other relevant stakeholders they need support - including financial support – as well as capacity building. There is currently no clear vision by the Member States or the European Commission of how to provide appropriate support to patient organisations at different levels. This should be addressed as part of efforts to involve patient organisations in health-related policy-making.

9. Conclusions and recommendations

If the cross-border healthcare directive is implemented well, it can serve to reinforce a healthy society and a healthy Europe. The challenges not only to provide the right information to patients about healthcare options that are available outside their own countries, but also at the same time to work contentedly to remove barriers to accessing healthcare. The directive serves to highlight the importance of viewing health and healthcare as a vital investment rather than a mere cost item.

The recommendations here arise from overall feedback received from patient communities across the EU. Although participants in all four conferences tended to identify the same issues and challenges, these were often expressed in a nuanced way reflecting different national realities. Therefore, we invite readers to study the individual conference reports to get a more comprehensive understanding of the context of each regional conference.⁷

Recommendations for member states, NCPs and the European Commission

Information to patients/National Contact Points

1. The European Commission should coordinate an initiative to develop guidelines for information to patients on quality and safety, with the involvement of patient organisations.
2. Guidelines should be provided for patients on how to interpret safety and quality information – including explanation of key terms used in quality assurance.
3. Information for patients should be in an easy-to-find place through a “one-stop” portal at European level, ideally linked to safety and quality information on medicines and medical devices.
4. NCPs should hold annual meetings with patient organisations at the national level to review the situation and plan on how best to work together to resolve practical issues arising from different aspects of the patient journey.
5. European-level dedicated funding should be made available to support the functioning of NCPs, particularly in resource-poor member states.
6. Standardised templates should be developed at EU level for all types of forms required in cross-border healthcare.

Quality and safety

7. Member states should co-operate with each other and involve patient organisations as well as health professionals in the development and implementation of standards and guidelines for safety and quality of care.

⁷ The full reports of all four conferences are available on EPF's website: <http://www.eu-patient.eu/whatwedo/Policy/Patients-Mobility/>

8. A link-up should be ensured between the personnel/institutions responsible for quality and safety aspects of the Directive and those involved in the EU Network on Patient Safety and Quality of Care (PASQ).⁸
9. For meaningful and comparable information, interoperability of databases should be ensured. Data being collected nationally by individual NCPs could be used to create a centralised database of information at European level that could be used by NCPs and the European Commission.
10. Information on quality of care and patient safety should be made comparable across institutions (within countries) and across member states. Convergence of national standards should be encouraged.
11. Member states should work together and with the European Commission and stakeholders to establish benchmarks and key indicators for quality of healthcare, including “patient-centredness”; this would allow the identification and sharing of good practices, also concerning transferability.
12. A mechanism for addressing patients’ complaints at European level should be considered.

Health inequalities and equity of access

13. Evidence should be collected at European level on inequalities in access to healthcare and how they affect patients with chronic conditions and their families, as well as on good practices and solutions to these problems identified in different member states.
14. Harmonisation of methods and functions of NCPs should take place across member states to achieve equality in the patient experience across the EU.
15. Data should be collected on treatments that are needed by patients but not authorised in their member state, with the aim to effect policy changes for equity of access. Data on treatment costs should be provided to national competent authorities and the European Commission in order to promote a reduction in inequalities.
16. A mechanism should be created for providing financial support to cover ancillary costs for patients and their families based on need; as a first step, implementation of the “prior notification” and direct cross-border payment systems.

Other recommendations:

17. Promotion of e-health interoperability should be a priority to improve global patient records and continuity of care; (free, timely) access by patients to their own medical records should be implemented across the EU.
18. A patients’ Ombudsman could be set up at European level as well as per country, acting as a dedicated focal point for quality and safety issues, complaints and redress, and linking patients, hospitals and healthcare systems.
19. Basic financial support to at least maintain Secretariat capacity should be provided to patient organisations from the appropriate government body at national/regional level.

⁸ Website of the Joint Action and wiki of good practices: www.pasq.eu

