

# EPF Roundtable on the implementation of patients' rights in cross-border healthcare, Brussels 4-12-2017

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## Conference report



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## Glossary

<b>CBHC</b>	Cross-Border Health Care
<b>EC</b>	European Commission
<b>EPF</b>	European Patients' Forum
<b>EU</b>	European Union
<b>HCPs</b>	Health Care Professionals
<b>MS</b>	Member State(s) (of the European Union)
<b>NCP(s)</b>	National Contact Point(s)

## 1. Introduction

The European Patients' Forum (EPF) is an umbrella organisation that works with patients' groups in public health and health advocacy across Europe. Our members represent specific chronic disease groups at EU level or are national coalitions of patients. EPF was founded in 2003 to become the collective patients' voice at EU level, manifesting the solidarity, power and unity of the EU patients' movement.

Although the organisation, management, financing and delivery of healthcare are the responsibility of the EU Member States (Art. 168 TFEU), European health systems and policies have become increasingly inter-connected. This is due to many factors, including increasing cross-border movement of patients and health professionals, and the dissemination of new medical technologies. Cross-border healthcare has been a policy priority for many years as shown by EPF's long-lasting engagement in this area dating back to 2006.<sup>1</sup>

EPF engaged intensely with the draft law during its development. We felt that the final Directive fell short of the ambitions of the patient community, but it nevertheless marked a milestone for European patients. It created a legal framework for the patient's right to seek healthcare in another Member State and to be reimbursed. This has potential for improving access to as well as the quality of healthcare – if it is implemented in a patient-centred way by the Member States.

In our view, the impact of the Directive 2011/24/EU will depend to a large degree on the knowledge of patients across the EU of their rights under the legislation and its potential benefits; for this reason, EPF has undertaken extensive awareness-raising among patient communities across the EU.

We published a toolkit in 2012, with guidance to patient organisations and recommendations for implementation of the directive.

During 2013-15 we ran a series of regional and national meetings with patient representatives, National Contact Points and policymakers, covering all EU Member States, with the aim to support the engagement of patient organisations at national level. The Cross-Border Healthcare Conference, held in Brussels on 4 December 2017, was organised as a continuation of our ongoing work on the topic.

All of this work and the feedback we received are reflected in the summary report of the conferences, and in our Position Statement published in 2016, all available on our website.

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<sup>1</sup> <http://www.eu-patient.eu/whatwedo/Policy/Patients-Mobility/>

## 2. Plenary session 1 – overview

The first plenary set the scene for discussions during the day. The session, like the Roundtable overall, was moderated by **Tamsin Rose**. She reminded the participants that the purpose of the roundtable was not to inform participants about the cross-border healthcare directive, since everyone was already expected to be familiar with it and with EPF's work to date. Instead, the day's focus would be on discussing together about where we are now regarding the implementation process, where are the gaps, and what more should be done. She then handed the floor to Juan Fuertes for a formal welcoming address.



From left: Juan Fuertes (EPF Board Member), Philippe Pakter (patient advocate), Elen Ohov (Counsellor, Permanent Representation of Estonia to the EU), Tamsin Rose (Moderator)

**Juan Fuertes** (EPF Board Member) welcomed the 116 registered participants on behalf of the European Patients' Forum's governing board. He gave a brief overview of developments leading to the adoption of the Directive 2011/24/EU on the application of patients' rights in cross-border healthcare and reviewed the objectives of this legislation. He explained the objectives of the EPF event: given that in the next year, the European Commission will publish an update on the state of implementation of the Directive, EPF wanted to hold this Roundtable to bring together patient representatives, policymakers and other stakeholders discuss the state of implementation of the Directive; provide feedback from the perspective of the patient community on their experiences across the EU; reflect on what needs to happen at policy and practice levels, EU and national level to realise patients' rights; and take the first steps towards a proposal for ways to collect feedback from patients and the patient community that could be useful in future monitoring of the implementation Directive, both by the European Commission and the Member States.

Juan then encouraged everyone to participate actively in the discussions, as the purpose of the event was not to be only critical, but to really reflect together on what can and should be done to address patients' concerns and needs; and especially on what could be the role of the patient community and of patient organisations going forwards.

## View from the Estonian EU Presidency

**Elen Ohov** (Counsellor, Permanent Representation of Estonia to the EU) gave a statement on behalf of the Estonian EU presidency. She focused her intervention on the potential of digital services to enhance access and quality of healthcare. Estonia raised the potential of digital health as a priority during its Presidency in the context of the digital single market and including cross-border eHealth services; the country has since 2008 been applying a nationwide electronic health record (EHR) system and is thus a recognised leader in this field. In future, there will be more demand for such services. Patients and citizens will be expecting access to their own health data, even when moving across borders.

The Council conclusions adopted by the Estonian presidency include a call to enable people to control and access their health data online securely and conveniently, and to ensure the reuse of such data for research in a secure and ethical way. Wider access to health data requires also an increase in trust from patients. Currently, there are barriers but also opportunities, and is progress happening in many EU Member States, particularly regarding e-prescriptions and EHRs. In a recent new development, Estonia has agreed with its neighbour Finland to start recognising each other's e-prescriptions. Sixteen Member States have joined the Digital Service Infrastructure for eHealth<sup>2</sup> and others will be joining by 2020. Ms Ohov also referred to the European Reference Networks (ERNs)<sup>3</sup> and their potential particular for patients with rare conditions, through the exchange of data and knowledge via digital tools, to respect the principle that medical expertise should travel rather than the patient. She concluded by stating that the digital single market when developed correctly will help realise better health for European patients, better treatment, more continuity of care and efficient and effective research and development.



Some of the participants during the Roundtable's plenary session

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<sup>2</sup> For more info: <https://ec.europa.eu/cefdigital/wiki/display/CEFDIGITAL/2017/05/30/eHealth>

<sup>3</sup> ERNs are virtual networks involving healthcare providers across Europe, designed to facilitate exchange of knowledge on complex or rare diseases and conditions that require highly specialised treatment and concentrated resources. The first 24 ERNs were launched in March 2017 and they encompass over 900 specialised healthcare units from over 300 hospitals in 26 EU countries. More information [here](#).

### Keynote presentation: the patient's experience

The keynote presentation was given by **Philippe Pakter**. Philippe is the father of Lysiane, who was born with a rare disease called Pierre Robin Sequence. Lysiane remained in a French hospital for five consecutive weeks, in the intensive care ward, where she was connected to a ventilator machine to help her breathe. With no scheduled release date from intensive care, Philippe and his wife finally decided to transfer Lysiane to an Orphanet Center of Expertise in Tübingen Germany. The purpose of this decision was to allow Lysiane to receive, for her rare disease, a highly specialised and medically proven treatment, the “TPP Treatment”, which is not available in France, where they live. The French administration rejected the family's request for an S2 form<sup>4</sup> authorising Lysiane to receive this highly-specialised rare disease treatment in Germany. The family is currently appealing the rejection.

Philippe began his presentation by describing the symptoms of Lysiane's rare disease. He then explained the medical advantages which the TPP treatment provides over other medical treatments. He went on to outline the steps he and his family have taken as part of the appeals process. They started by submitting a formal administrative appeal on the domestic level, in France. They also submitted the case to the EU's SOLVIT Network, which agrees that based on EU law, the rejection is unfounded.

*“If a new-born baby suffering from a rare disease, immobilised in an intensive care ward and connected to a ventilator machine, doesn't have the right to obtain a highly specialised, medically proven and cost-effective treatment for her rare disease in another EU Member State – then who does have the right to obtain cross-border medical care?”*

- Philippe Pakter

Philippe's family has obtained the support of EURORDIS, a Member of France's Parliament, as well a Member of European Parliament.<sup>5</sup> Philippe, who is a lawyer, said that he and his family are committed to taking their appeal all the way up to the European Court of Justice, until Lysiane receives her S2.

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<sup>4</sup> Form for prior authorisation, previously E112.

<sup>5</sup> EPF has also added its support following the Roundtable.

### 3. Plenary session 2 – patients’ rights in the EU. Where are we now?

The second plenary session of the morning focused on patients’ rights, and a reflection on the impact of transnational on patients. Two keynote presentations from external experts set the scene. Tamsin Rose again moderated the session and led the discussion.

#### Patients’ rights in the European Union: from recognition to implementation

**Willy Palm** (Senior Adviser, European Observatory on Health Systems and Policies) presented an overview of patients’ rights focusing on those rights that are particularly relevant to the Directive. The Patients’ Rights in the European Union Mapping eXercise (PRE-MaX). The rationale behind the study was a mapping exercise of existing patients’ rights in 30 countries (EU28 + Norway and Iceland). This study provides an overview of the various legal frameworks as well as other policy tools and mechanisms in place (or in the making) to define, implement and enforce patients’ rights.

After this, Willy presented the different international frameworks promoting the development of patients’ rights comparatively. He also gave an overview of national codification of patients’ rights.

Willy insisted that patients’ rights laws help to raise awareness, empower patients and guide policy makers. They become more widely accepted and more firmly established in countries but national variation in definition, approaches and practice. Enforcement is usually the weak link, but progress is made with increased awareness, better monitoring and alternative dispute resolution. The EU Patients’ rights Directive contributes to the development and implementation of patients’ rights at national level.



From left Tomas Mainil (Senior lecturer, NHTV Breda University of Applied Sciences), Sabina Stan (Lecturer, Dublin City University, Ireland), Willy Palm (Senior Adviser, European Observatory on Health Systems and Policies), Tamsin Rose (moderator)



### **How transnationalisation of healthcare in Europe affects patients**

In their research, **Sabina Stan** (Lecturer, Dublin City University, Ireland) and **Tomas Mainil** (Senior lecturer, NHTV Breda University of Applied Sciences) looked at transnationalism in healthcare. The definition they use in their research is “sustained linkages between people, places and institutions across borders”. They show that border-crossing policies, provision and patients (transnationalism) have contributed to the mix of public and private provision and coverage of care, and that the patient journey is much more complicated as a result.

Sabina and Tomas identified two potential scenarios for cross-border situations involving the Directive.

In the first scenario, the EU focuses on economic growth of transnational healthcare and fiscal sustainability of public finances. This leads to cuts in public health expenditure and a reduced “basket of services”. In this scenario, the EU becomes a leader in transnational healthcare, but inequalities in access to healthcare also grow.

In the second scenario, initiatives such as the EU Social Pillar are taken further and the focus lies on universal, timely, affordable access to good quality care. National Contact Points are adequately funded and transnational healthcare is used to reinforce national public provision of quality and timely care.

Their conclusion was that the EU Directive could be a driver for change, but that a balance needs to be found between equity and capacity-building in patient mobility in the EU.

## 4. Parallel breakout sessions

After the lunch break, participants divided into three parallel sessions, which explored one specific topic in depth. Each session was facilitated, and rapporteurs selected from amongst the participants presented key messages to the plenary.

### SESSION 1 – INFORMATION FOR PATIENTS

The first session was facilitated by **Tamsin Rose**, the rapporteur being **Charlotte Roffiaen** (European Consultant, France Assos Sante). The questions posed in this session included whether the EPF “Checklist for the Ideal National Contact Point” has been useful; what kind of feedback from patients would be useful to the work of an NCP; what (if anything) more should be done at European level; and what should be the role of patient organisations at national or EU level.

**Bernd Christl** (Head of the German NCP) gave a presentation of his organisation. Patients and citizens can find the relevant information on the website of the German NCP.<sup>6</sup> In 2016 the majority of inquiries (60%) concerned Germany as the country of treatment, while the rest were about other EU Member States (38%). The requests for treatment outside Germany concerned almost every country of the EU.

The main points discussed during this session included the big variety among NCPs in various aspects, such as funding, reporting and the number of patients served. There was agreement on the fact that NCPs need feedback from patients (for example, on whether the information received was useful, and did the patient succeed in getting treatment). Methods for achieving this could range from developing general surveys to following up individual cases.

On the question of what EU collaboration can bring for NCPs, the group felt that the main benefits would be in benchmarking and sharing of best practices. Bernd shared good practices from Germany, but also what Germany had used from good practices of other countries.

It was generally agreed that it would be useful for NCPs to develop relationships with patient organisations. Member States have very different experiences in this area, ranging from simple referral from a patient organisation to a closer two-way collaboration.

In some countries NCPs do not see the added-value of collaborating with patient organisations. another challenge is that even patient organisations are sometimes not aware of the details of the Directive, and they see the benefit of European networks to educate them on this topic.

*EU collaboration can be beneficial for National contact points in terms of benchmarking and sharing of best practices.*

Healthcare professionals play an instrumental in informing patients about their rights under the Directive. It is vital that doctors and pharmacists are aware of such legislations and the rights they grant to patients. Many pharmacists, for example, often face prescriptions from a different EU Member State, and they would like to be able to assist patients with information regarding reimbursement.

<sup>6</sup> [www.eu-patienten.de](http://www.eu-patienten.de)

## SESSION 2 – ACCESS AND EQUITY

Session 2 was facilitated by **Juan Fuertes** (EPF Board Member) and the rapporteur was **Geoffrey Henning** (Europacolon).

**Cathrine Donohoe** (General Manager, Health Service Executive/*Irish National Contact Point*) gave an overview of the Irish experience. In Ireland, if a patient is entitled to a treatment at home s/he is entitled to reimbursement for that treatment if availed of in another EU/EEA country. For some treatments, prior authorisation might be required. The UK and Poland are by far the most sought-after countries for treatments to take place. Catherine presented some study cases of patient experiences with seeking treatment abroad. She called for a mechanism whereby the 32 National Contact Points can meet as a group to discuss the implementation of the Directive around the EU.

The participants explored the gaps and obstacles that exist for patients to access care, and whether the directive has made any difference. They considered solutions for increasing patients' access to high-quality healthcare. The main points of agreement were as follows.

As has already been identified clearly in EPF's work to date, upfront payment to access treatment under

the Directive creates a problem for most patients. Non-reimbursement of travel costs also remains a problem. Moreover, differences in approaches to reimbursement of medicines (prescriptions or over-the-counter medicines) need to be equalised across the EU to ensure equity of access. This aspect of access is not covered under the Directive.

The Directive 'discriminates' against low-income EU Member States because patients are reimbursed according to their national rules for any treatments received abroad. Usually, in low-income Member State, the costs relating to healthcare are lower, and this results in patients having to make a proportionally greater out-of-pocket contribution to treatment received abroad. Therefore, the group recommended that appropriate and sustainable investment in health should be ensured especially in lower-resource countries.

Communication needs to improve, and information should be made more available to all interested parties: the European Commission should annually publish a list of disease areas where support is requested, the information for which should be collected from the NCPs. This would give an indication of where the needs are greatest and will help focus activity. The relevant patient organisations could then develop suitable tools and resources to raise awareness of the Directive and support these patients in their country.

The group stressed that NCPs need to be suitably resourced so that they can actually provide the support patients need, and be available for patients. Currently, the situation is far too variable according to how each country's NCP is set up, with some Member States only having one person as the contact point, while others have dozens of staff.

*"The introduction of the CBD has provided unparalleled access for Irish patients (and indeed EU patients) to timely healthcare. The direct impact of the Directive on individual patients, their quality of life and by default their families, is a credit to the EU and to every country like Ireland which has implemented it in a non-discriminatory and open manner."*

- Cathrine Donohoe

European Reference Networks<sup>7</sup> have the potential to improve the quality of and access to healthcare in future in specific disease-areas by establishing clinical pathways, recommending interventions and treatment centres or physicians most likely to provide the best care for these diseases across Europe. These recommendations should be adopted by the European Commission and publicised. Prescriptions issued by a centre of expertise which is included in an ERN should be accepted for reimbursement in any EU Member State.



Participants discussing during one of the parallel sessions

Patient organisations can provide feedback on access issues, help promote awareness and highlight bad practice by collecting and sharing patient stories. They can consider working with local and national media to publicise patients' experiences. Social media might also be an effective way for patient organisations to promote the Directive and the related EU Regulation.

Participants considered that although the principle of subsidiarity is of importance in European health law, it needs to be reviewed as it was put in place before many of the newer Central and Eastern European countries acceded to the EU. Health needs to be redefined for the future of patients, also in Central and Eastern European countries. Inequalities in health will continue to persist as long as the current system is in place. The group thus sent a strong message of solidarity and the importance of prioritising health in EU policy.

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<sup>7</sup> European Reference Networks (ERNs) are virtual networks involving healthcare providers across Europe, which aim to facilitate the care of complex or rare conditions requiring highly specialised treatment, concentrated knowledge and resources. The first 24 ERNs were launched in 2017. The list can be found at [https://ec.europa.eu/health/ern/networks\\_en](https://ec.europa.eu/health/ern/networks_en)

## SESSION 3 – PATIENT INVOLVEMENT IN FUTURE MONITORING

This session was facilitated by **Kaisa Immonen** (Director of Policy, EPF) with **Christopher Vella** (Malta Health Network) as rapporteur. The aim of the session was to explore ideas for gathering feedback from patients in future monitoring of the implementation of the directive, which could be used by the European Commission as well as Member States in evaluating the status, and also potentially by the National Contact Points to monitor their own performance.

**Ulrich Heiduck** (Head of the Office for Cross-border Healthcare, Forsakringskassan) presented the situation in Sweden; and **Pia Blomqvist** (International Affairs Counsellor, Finnish National Contact Point) presented how the NCP is organised and how it serves customers. The NCP provides information in five languages on their website.<sup>8</sup> It actively cooperates with other authorities, meets citizens in events, and collects information from citizens and patients to develop better services. In the summer of 2017 the NCP conducted an online survey about cross-border health care, which showed that citizens do not know cross-border healthcare well and more information is needed. Patients heading abroad are interested in knowing about places of treatment, costs, and medicines.

The group discussed what kind of feedback from patients would be important to collect – content that would be useful for patients and patient organisations; useful for national governments; and useful for NCPs – and how/when should feedback be collected (time / critical moments, place, how / tools); who should collect it; and what role patient organisations can play.

There was agreement that the questions what feedback should be collected, how and by whom are to some extent context-specific; at the same time, it would be ideal to have some comparable information. The group's suggestions are summarised below (page 14).

The role of patient organisations was seen mainly in terms of providing information, both to the patient community but also to healthcare professionals and health system; acting as a link and facilitator between patients and the national NCP; lobbying governments for change; and potentially in establishing a pool of experts by lived experience (patients, family members) who could be called upon by other stakeholders to advise on various issues.

*Patient organisations can provide information to the patient community but also to healthcare professionals and the health system; act as a link and facilitator between patients and national NCPs; lobby governments; and establish a pool of patient experts who can be called upon by other stakeholders to advise on various issues.*

One critical issue that would need to be resolved is how information collection and awareness-building can reach beyond the obviously advantaged groups in society, i.e., those who are educated, have the knowledge to make choices, and ultimately the financial means to access care. For this reason, it will be important to have a whole of society approach, not only targeting patients even though their specific experiences and perspectives are key to the exercise.

<sup>8</sup> [www.choosehealthcare.fi](http://www.choosehealthcare.fi)

**Table: proposals from Parallel session 3 on patient feedback**

What	How	Who
<ul style="list-style-type: none"> <li>• Testimonials from patients who have used cross-border healthcare, the “full story” of the entire journey</li> <li>• Experiences of patients’ contacts with their NCPs and their evaluation of the advice and support received (both negative and positive)</li> <li>• Patients’ experience of the application process and admin procedures, whether or not they ultimately ended up accessing cross-border treatment and whether or not this was pre-authorized</li> <li>• Weaknesses in the system as witnessed by patients</li> <li>• Cost of treatment and reimbursement received and to what extent it was sufficient for the patient</li> <li>• Information of health and quality of life -related outcomes of treatment received</li> <li>• Patients’ experiences of accessibility of treatments in their country/disease-area, including waiting times, and other relevant issues such as shortages (this is not specific to cross-border healthcare but to have better overall information on access gaps from the patient perspective)</li> <li>• Feedback on feedback itself, i.e. important to establish what feedback matters to patients, given that collection of information is always a burden on patients, too.</li> </ul>	<ul style="list-style-type: none"> <li>• A survey with precise questions should be done at national level to encompass the whole population (also to gauge awareness of cross-border healthcare)</li> <li>• Media campaigns can support such data collection</li> <li>• There should be guided/structured feedback (i.e. targeted questions); a “core” questionnaire for cross-country comparison plus nationally/regionally-specific questions</li> <li>• Quantitative data combined with qualitative information (the patient experience)</li> <li>• NCP’s could conduct their own surveys of their patients</li> <li>• Meetings or focus groups with patient representatives to define the priority questions for patients; other stakeholders could also be involved.</li> </ul>	<ul style="list-style-type: none"> <li>• The information already collected by case handlers within NCPs should be analysed and used to gain insights as far as possible</li> <li>• NCP/patient ombudsmen in countries where they exist could be used to identify best practices or highlight bad ones</li> <li>• The governments should be responsible for media campaigns and awareness surveys to reach wider audiences</li> <li>• Patient organisations should be involved as a matter of course, with the recognition that they do not reach everyone in society: there is a need to address both the specific (patients and their individual experiences) and the general (the wider public)</li> <li>• Medical professionals working with patients could be useful sources of feedback, especially in rare diseases and other areas where people often seek healthcare across borders or have significant access needs/barriers</li> <li>• Conflicts of interest should be avoided where possible, e.g. not having government departments evaluate their own performance; multiple perspectives would be more useful.</li> </ul>

## 5. Closing plenary – direction of travel

The closing plenary session started with quick feedback from the three parallel workshops.

**Balazs Lengyel**, (Legal Officer, DG Sante, European Commission) gave a short statement on behalf of the European Commission. He thanked EPF for organising a useful event where national administrations and the Commission can get direct feedback from patient organisations about cross-border healthcare. He confirmed that the Commission is aware of the difficulties in implementing the Directive, stressing that since it is not a regulation, it leaves room for Member States to adapt the transposition to their national circumstances. Nevertheless, he confirmed that checking Member States’ implementation of the provisions during the compliance check is still a priority for DG Sante.

The Commission is working on the next report on the operation of the Directive, due to be published in October 2018. In preparation, technical studies are already underway on cross-border cooperation and information provision to patients. Initial findings show that many NCPs have improved their operations since their establishment in 2013. Balazs recalled that the primary objective of the Directive was not patient mobility, and stressed that under the co-operation chapter, the Directive creates a legal basis for long-term co-operation between Member States in critical areas, such as Health Technology Assessment, eHealth, and the European Reference Networks.



From left: Nicola Bedlington (EPF Secretary General), Balazs Lengyel, (Legal Officer, DG Sante, European Commission), Tamsin Rose (moderator)

**Tamsin Rose** then reflected on the day’s discussions and wrapped up the event. She invited **Nicola Bedlington** (EPF Secretary-General) to close the conference.

In her closing words, Nicola referred to the extensive work EPF had done on the topic over the past years, as laid out by Juan Fuertes in the morning. She emphasised that cross-border healthcare is one aspect of access to healthcare – and equitable access to high-quality healthcare remains one of EPF’s key strategic priorities. Therefore, we will continue engaging in this area together with all relevant stakeholders to ensure that the Directive is correctly implemented, and that patients can have easy access to all the information they need in order to make the most out of their rights under this legislation.

As the event showed, many barriers still exist. Nicola reflected that if even educated, professional and experienced individuals like Philippe Pakter, who is a lawyer, face difficulties in trying to overcome barriers posed on them, how can “ordinary” patients find their way?

She also stressed that structures such as the National Contact Points should be properly funded, and their work should be facilitated. That so many NCP representatives were present and showed their commitment to providing information to patients in the best possible way was very positive. Collaboration with patient organisation in this process is vital and should be institutionalised and used to its fullest potential.

Nicola reminded everyone the importance of political will and the tremendous achievements that can be made: the history of this Directive is a great illustration of that. When the proposal for a Services Directive was presented by the European Commission, the European Parliament voted for the exclusion of healthcare services from it under the understanding that a separate legislative initiative would be proposed focusing exclusively on healthcare. This was the beginning of a long legislative journey, resulting in the Directive that we discussed today. Although it might not be perfect from a patient’s perspective, it has given impetus in specific areas for driving better access, quality and safety of healthcare.

Nicola closed with a few words about EPF’s ongoing Access Campaign, “Universal Health Coverage For All” and stressed EPF’s commitment to work towards the implementation of the UN Sustainable Development Goals during the coming years. EPF’s ambition is to align the access agenda with the patient empowerment agenda, linking to and building on our previous work on patient empowerment. To this end, EPF developed a document entitled “Taking Action – A Roadmap to Achieving Universal Health Coverage for All by 2030”<sup>9</sup>, which provides concrete recommendations to EU and national decision-makers and asks for commitment to a long-term vision where equity of access is a reality for all.

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<sup>9</sup> The Roadmap is available at <http://www.eu-patient.eu/campaign/access-to-healthcare/epf-roadmap-to-achieving-universal-health-coverage-for-all-by-2030/>



## Annex: Agenda

<b>AGENDA</b>	
<b>09:00-10:00</b>	<b>Registration and coffee</b>
<b>10:00-11:00</b>	<p><b>Plenary session 1: Overview</b>  <b>Moderator: Tamsin Rose</b></p> <ul style="list-style-type: none"> <li>• Welcome and introduction <i>Juan Fuertes, EPF Board Member</i></li> <li>• View from the EU presidency <i>Elen Ohov, Counsellor, Permanent Representation of Estonia to the EU</i></li> <li>• Keynote: the patient's experience <i>Philippe Pakter</i></li> </ul>
<b>11:00-11:30</b>	<b>Coffee break</b>
<b>11:30-12:30</b>	<p><b>Plenary session 2: Patients' rights in the EU: where are we now?</b>  <b>Moderator: Tamsin Rose</b></p> <ul style="list-style-type: none"> <li>• Results of an EU mapping study of patients' rights: focus on rights relevant to the Directive <i>Willy Palm, European Observatory on Health Systems and Policies</i></li> <li>• How transnationalisation of healthcare in Europe affects patients <i>Sabina Stan, Lecturer, Dublin City University, Ireland</i>  <i>Tomas Mainil, Senior lecturer, NHTV Breda University of Applied Sciences</i></li> </ul>
<b>12:30-13:30</b>	<b>Networking lunch</b>
<b>13:30-15:00</b>	<p><b>Parallel break-out sessions</b>  Each session will have a facilitator who will lead the discussion and a rapporteur, who will present key points to the plenary</p> <ul style="list-style-type: none"> <li>• <i>Session 1: Information for patients</i></li> <li>• <i>Session 2: Access and equity</i></li> <li>• <i>Session 3: Patient involvement in future monitoring</i></li> </ul>
<b>15:00-15:30</b>	<b>Coffee break</b>
<b>15:30-16:30</b>	<b>Closing plenary</b>

	<ul style="list-style-type: none"> <li>• Quick feedback from the 3 parallel session <i>Rapporteurs</i></li> <li>• Perspective of the European Commission <i>Balazs Lengyel, DG SANTE</i></li> <li>• Wrap up of key messages, next steps <i>Tamsin Rose, event moderator</i></li> <li>• Closing statement <i>Nicola Bedlington, EPF Secretary-General</i></li> </ul>
<b>16:30</b>	<b>Closing of the conference</b>



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