

# EPF Workshops on Cross-Border Healthcare – 5th Stop: Dublin

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## Meeting Report

*21 April 2015, Camden Court Hotel, Dublin*



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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 Ireland and the United Kingdom 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). Representatives of the National Contact Points were invited with the aim of facilitating contacts with patient groups.

### STRUCTURE OF THE WORKSHOP

The workshop was conducted in English. The workshop was attended by 16 representatives of patients and healthcare users, as well as representatives of the National Contact Points and the European Commission.

### OBJECTIVES OF THE SESSION

**Kaisa Immonen Charalambous**, EPF Senior Policy Adviser, introduced the session and explained its objectives.

- To raise awareness and knowledge about the CBHC 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, quality and safety, 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.

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

**John Rowan**, representing the European Commission DG Sante, gave a presentation on the Directive and its meaning for patients.

### 2.1 THE EUROPEAN COMMISSION’S PERSPECTIVE

Mr Rowan 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.

#### 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.

#### 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.

## 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.

## 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.

## Prices and reimbursement tariffs

### HOW MUCH DO PATIENTS HAVE TO 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.

### DO PATIENTS 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.

## 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.

## Minimum patients' rights

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

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

## What is new compared to the social security Regulations?

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

There are some important differences between the EU social security Regulations – which still apply<sup>4</sup> – and the new Directive:

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

### Co-operation between health systems

There is a general obligation for Member States to co-operate on:

- Guidelines and standards for quality and safety;
- European Reference Networks (ERNs), especially to ensure that expertise and information on rare diseases is shared across Europe in order to improve diagnosis and access to treatment;
- Health Technology Assessment (HTA), for which voluntary networks already exist and are working, aiming in particular to eliminate duplication of effort among 28 separate HTA bodies and to improve HTA capacity in specific Member States;
- 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.

### 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 Romania 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 Member States 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.

## 2.2 THE PATIENTS' PERSPECTIVE

**Kaisa Immonen-Charalambous** then gave a presentation outlining the European Patients' Forum' perspective on the cross-border healthcare directive. The views expressed in her presentation are based on EPF's position is taken in consultation with our membership.

Although the cross-border healthcare directive is not perfect, and the end result is a significant compromise on the original ambitious proposals from the commission, nevertheless it does have some important benefits for patients – the “minimum set of patient rights” were already mentioned in the previous presentation from Mr Rowan. An important aspect is the increasing transparency of health systems, particularly quality and safety standards, and the legal basis for cooperation between member states on eHealth and HTA, rare diseases, quality and safety.

Areas of uncertainty or concern include the speed of implementation, with many member states being behind. Equity of access will be a question, as cross-border healthcare may not be an option for all citizens; regarding information and support, the NCP concept may evolve into either an enabling service or a gatekeeping mechanism. It is crucial to establish a continuous and transparent dialogue with patient organisations, ministries of health and the NCPs.

Equity: the Directive upholds the principles of non-discrimination, universality, access to good quality care, equity and solidarity – however, the requirement for upfront payment will be a barrier for many. EPF wanted a system of direct cross-border payments, but these are only voluntary. There are also questions around what is considered a “medically justifiable” time-limit for treatment and is this the same in all countries given the variance in medical practice.

Access: Member States must cover only the cost of treatment, although they can decide to reimburse the full cost of the treatment (incl. extra costs). They must have a transparent mechanism for this based on objective criteria, and it is crucial that patients know in advance exactly what the rules are. Patient organisations should advocate for more inclusive provisions on access.

The transparency provisions in EPF's view have more far-reaching potential than just to inform patients considering treatment abroad; they are vital for building and maintaining trust in the health system. Patients can use them to get informed about their rights, check the quality of treatment and see how it compares with other member states, and they can advocate for better quality and better access to healthcare “at home”. But for this, quality and safety information must be communicated in a way that is understandable to lay people.

Patient organisations should become active: they should engage with their NCP, give feedback on how it serves patients, and ask their national government for improvements, for example to set up a system for direct payments and/or prior notification. They should give feedback on their experiences to EPF on all aspects of implementation – how it works, and when it doesn't. Kaisa pointed to a number of EPF resources freely available on its website that patient advocates can use.

## 3 The crucial role of the National Contact Points

### 3.1 PRESENTATION FROM THE UK NCP

**Mr Rob Dickman** from the UK Department of Health's international division gave a presentation on the UK implementation of the directive and the role of the National Contact Point.

The UK undertook a public consultation on the directive, others which some key messages emerged:

There was strong support for centralising functions and the desire for the NCP to play a key role in providing clear, transparent and good quality information to patients. Prior authorisation was seen as a necessary measure but too many restrictions should be avoided. Direct payments and voluntary prior notification were supported. It is vital to have clear and consistent information on patients' entitlement, and crucial to have effective exchanges of information between clinicians, regulators, competent authorities and other Member States. Some questions arose over the responsibility for providing language and translation services.

The UK approach is that it will set up territorial NCPs for each region's capital: Edinburgh (Scotland), Cardiff (Wales), Belfast (Northern Ireland) and Gibraltar. The English NCP is set up within NHS England.

A lot of information already exists in the system, so the NCP will act more as a signpost for people to find it. It does not have any decision-making role and cannot recommend providers. Requests for cross-border healthcare have been low thus far, and the NCP does not anticipate this growing much in the future and so it will exist within existing structures. However, the NCP role received strong support in the public consultation and there is a need to reflect on how to meet these expectations. Some other member states are actively using the NCP function to advance their citizens' rights.

#### POSITIVE EFFECTS?

The directive has the potential to make healthcare more patient-focused: unlike the existing Regulations, it covers all healthcare providers, and it is the first ever EU-wide legal framework confirming patients' rights and entitlements. It requires Member States to provide their citizens with clearly understandable and accessible procedures, and ensures access to information via NCPs.

The directive "sweeps away obstacles to freedom of movement" by effectively extending the concept of patients' choice of provider to Europe and creates a kind of "personal health budget". This may lead to greater choice and more empowered citizens, and may also provide opportunities for UK providers. Finally, it may act as a lever for improvements in NHS provision.

#### Negative effects?

The numbers of patients seeking care abroad have been low, so the Directive may be considered a disproportionate response. There are limited grounds to refuse, or require, prior authorisation. It may have the unintended consequence of reducing healthcare to a "purchase/reimbursement arrangement" and puts the power more in the hands of patients and clinicians rather than the national authorities. In terms of health inequalities, it benefits those who can afford to pay upfront to take advantage for quicker access. Reimbursement money is paid out abroad so does not recirculate into the NHS.

Patients are really on their own during this process, and this may promote the rise of third-party operators or facilitators. There may be liability issues, although this has not yet been tested, and the administration, such as decoding foreign receipts, is complicated possibly giving rise to risk of fraud.

### 3.2 PRESENTATION FROM THE IRISH NCP

**Ms Catherine Donohoe** from the Irish Health Service Executive gave a presentation on the experience to date of the Irish National Contact Point. She presented some key facts and figures.

The cross-border directive became effective in the Republic of Ireland on 1 June 2014. It received few requests for information initially (94 in the 2<sup>nd</sup> half of 2014) but these have increased dramatically during 2015 (377 in the first quarter alone). Forms issued and received by the NCP, and reimbursements paid to patients, have also increased similarly in 2015.

Specifically, she pointed out that 23% of reimbursements were for orthopaedics and 14% for psychiatry; other specialties representing 63%.

Most treatment took place in the United Kingdom (43%) with Poland in second place (20%).

## 4 The Patient Journey in Cross-Border Healthcare

Participants discussed and reflected together on patients' varying needs during the different 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 key message here was predictability of the system. Everything, including logistics, need to be managed from the very start of the process. Issues raised related the best route to treatment abroad (Directive versus Regulation? Referral at home or contact abroad?); What to do in case of financial shortfall due to upfront payment/co-payment; post-care management plans and how they should be agreed; support for family and carers; and the possibility of having a "trip advisor" style resource for patients. It was proposed that fact sheets in "plain English" would be useful for many patients.

After the break, there was a panel discussion involving the European Commission, NCPs and a patient representative (Robert Johnstone of National voices, UK).

Robert referred to the institutional resistance due to the "fear factor" on the part of governments that a lot of patients would suddenly opt for cross-border healthcare. He stressed, however, that most

patients prefer to be treated near where they live, and they only want to go abroad when there is a real need and treatment nearer to home is not available. He saw benefit in driving up quality of care through competition. Promotional publicity to make citizens more aware of their rights needs to combine a top-down approach with a bottom-up approach, involving patient organisations as well as national authorities.

Mr Dickman reiterated that in the UK the directive is widely seen as being a bad law and it is a big job to implement compared to the benefits. He also agreed that driving up standards member states would be a good thing. Engagement with patient groups would be important but also for patients to understand the Member States' perspective in terms of administrative resources they need to commit.

Mr Rowan said it was clear that there were still practically no knowledge in the patient communities or among the general public about the cross-border directive. This echoes what EPF has found during our regional events. Transparency should help drive up standards in healthcare across Europe, and get the 28 Member States to work better with each other. It is important to have regular monitoring and feedback, particularly from healthcare users. Patients can complain to the European Commission if they deem that their member state is not in compliance with the directive.

Ms Donohoe stressed that expectations need to be managed – the directive is not going to provide a solution to all patients' problems, particularly rare disease patients. It is vital to engage consultants (specialist doctors) because a referral is needed for patients to get access to cross-border healthcare.

All agreed that information is key and vital to good implementation of the directive and for patients to make use of their rights. Asking for (and receiving) better services at home is probably the key to future healthcare, not necessarily accessing care abroad.

For rare diseases, due to the global lack of expertise, better connectedness and communication between health systems is vital: a patient representative said that “to go abroad and receive a care plan that accepted and recognised at home would be phenomenal.”

## 5 Discussion points and recommendations

Pertinent issues raised in the discussions during the day are summarised below.

To a question about the impact of the minimum patient rights contained in the directive, Mr Rowan responded that this depends on the status of the member state in question. In some member states, nothing changes but in others it is quite a lot.

A question was raised regarding “undue delay” versus an “unreasonable distance” for a patient to travel; a patient representative pointed out that the nearest facility for treatment may be across the border. It would make sense for patients to be able to access treatment nearest to their home.

There was some discussion regarding the reluctance of governments to promote the option of cross-border healthcare. In the case of the UK, it does not see a benefit in promoting cross-border healthcare

as it is taking funds out of the system. Moreover, because it has a devolved health system, the priorities may be set differently in different regions. This will have an impact on access as what treatments are available in one region may not be available in another region.

For rare diseases, the directive is clearly still not a perfect solution as it refers only to treatments available in the national benefits basket – which are not necessarily applicable to rare diseases. There is potential in the European Reference Networks at least in the long-term.

It was suggested that the NCPs could refer to patient organisations as an additional resource and support, but patient organisations should be appropriately funded for providing such services.

Patient stories of their experience would be helpful resource for other patients who consider cross-border healthcare. These could be collected by patient organisations but also by NCPs.

Hospitals should ideally have a dedicated liaison person or ombudsman for patients, which would be useful not only for cross-border patients but also domestic patients.

Participants felt that it is important to establish continuity in the process, and patients need to know everything in advance including what will happen afterwards. The principles and main patient needs will be very similar when accessing care anywhere, whether at home or abroad. It was suggested that EPF should compile a document, or possibly a checklist for this purpose.

Complaints and redress mechanisms should be very clear and easy to use, with clear information on how it works available in advance.

Mr Rowan informed the participants that a *special Eurobarometer survey* will be published in on patients' rights in cross-border healthcare. This will look at peoples' experience so far, examine willingness to travel, and citizens' awareness of their rights. It will also look at prior authorisation, information provision under national contact points.

## 6 Conclusion and Next Steps

**Kaisa Immonen-Charalambous** invited the participants to share the message they will be taking away and what actions they will be taking when returning home. She thanked the participants for their enthusiasm and active participation, 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.

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.

Kaisa also announced that a conference gathering patient leaders and representatives from the NCPs across the 28 countries would take place on 2 July 2015 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.

## 7 Agenda

09.00-09.30	<i>Registration/welcome coffee</i>
09.30-10.00	<b>Welcome and presentations</b> <ul style="list-style-type: none"> <li>Kaisa Immonen-Charalambous, EPF Senior Policy Adviser</li> </ul>
10.00-11.00	<b>The first Directive focussing on ‘Patients’ Rights’ – what does this really mean for patients in this region?</b> <ul style="list-style-type: none"> <li>EC perspective: John Rowan, DG SANTE, European Commission</li> <li>Patient Perspective (tbd)</li> </ul>
11.00-11.30	<i>Coffee break</i>
11.30-12.30	<b>The crucial role of National Contact Points (NCP) and creating a framework model that meets the needs of Patients</b> – Moderator: Kaisa Immonen-Charalambous  <b>Plenary debate</b> – What would a “model” of National Contact Point looks like? What are the critical success factors? How patient organisations should be involved in the effective evolution of National Contact Points in the selected countries?
12.30-13.00	<b>Exploring the role of NCPs and patient organisations in securing effective implementation of the Directive</b> <ul style="list-style-type: none"> <li>Rob Dickman, Department of Health, British National Contact Point</li> <li>Catherine Donohoe, Health Service Executive, Irish National Contact Point</li> </ul>
13.00-14.00	<i>Networking lunch</i>
14.30-15.15	<b>The Patient Journey in Cross Border Healthcare</b> Moderator: Kaisa Immonen-Charalambous (EPF) <i>Objectives :</i> <ul style="list-style-type: none"> <li><i>To address specific aspects of the Directive from the perspective of “the patient journey” and will both provide more detailed information on what aspects of the Directive are relevant at different stages and what specific information needs patients will have</i></li> <li><i>Aim to generate a discussion identifying critical issues from a patient’s point of view, and develop recommendations for Member States and patient organisations in this regard, to create a sense of “ownership”</i></li> </ul>
15.15-15.30	<i>Coffee break</i>
15:30-16.00	<b>Conclusions, take home message and next steps</b> <ul style="list-style-type: none"> <li>Discussion</li> </ul>

## 8 List of participants

Liz	Carroll	Chief Executive	The Haemophilia Society	UK
Patrick Joseph	Creedon	Secretary to the Management Board	The RISE Foundation	Ireland
Rob	Dickman	Senior Policy Advisor	Department of Health	UK
Catherine	Donohoe	Head of National Contact Point	Health Service Executive	Ireland
Michele	Dunne	Research and education coordinator	Asthma society	Ireland
Laura	Fee	Clinical Research Associate	Alpha One Foundation	Ireland
Kate	Fleck	National Director Northern Ireland	Arthritis Care	UK
Debbie	Greene	Office Manager	Irish Haemophilia Society	Ireland
Jacinta	Hastings	Chief Executive Officer	Bodywhys – the Eating Disorders Association of Ireland	Ireland
Kaisa	Immonen-Charalambous	Senior Policy Advisor	European Patients' Forum	Belgium
Robert	Johnstone	Patient representative	National Voices	UK
Avril	Kennan	Head of Research and Advocacy	DEBRA Ireland	Ireland
Anne	Lawlor	Information Officer	Genetic and Rare Disorders Organisation (GRDO)	Ireland
Patrick	Little	CEO	Migraine Association of Ireland	Ireland
Peter	McCann	UK Representative Former Board Member	International Council on Alcohol and Addictions (ICAA), Scottish Patients Association	UK
Tom	Monks		Department of Health, Ireland	Ireland
John	Rowan	Policy Officer	European Commission DG SANTE	Belgium
Sharon	Thompson	Member	Our Children's Voice	Ireland



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