EUPATI 2015 Workshop

EUPATI TAKING OFF IN YOUR COUNTRY – An Interactive Workshop on Implementing EUPATI in Your Country

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1. Introduction

The European Patients' Academy on Therapeutic Innovation – EUPATI – is a patient-centred team of 30 bodies made up of a combination of patient organisations, universities and not-for-profit organisations expert in patient and public engagement, along with many European pharmaceutical companies. It is a pan-European initiative supported by the Innovative Medicines Initiative (IMI), a partnership between the European Commission and the European Federation of Pharmaceutical Industries and Associations (EFPIA). And it has a simple goal: to provide education and training to help patients become more involved in their healthcare and in the development of new medicines.

EUPATI is just three years old, but it has already established itself as a key player in the involvement of patients in medicines development in Europe. But Europe is a large continent full of variety, and no two countries have identical approaches to involving patients in this process. So EUPATI has set itself the goal of developing a country-specific approach, with an initial target of setting up National Platforms in 12 countries.
On 22 April nearly 190 people came to Dublin to share experience and develop new thinking about how to spur progress at the national level – 102 of them from patient organisations.

2. Key messages

- EUPATI is on the right track, with strong governance, but it still needs to refine its expert patient training course in order to meet the challenges it faces.
- In particular, patients and other stakeholders are keen – not so say impatient – to see the production of the EUPATI Toolbox.
- Individuals matter: finding the right people to lead, inspire and organise National Liaison Teams and National Platforms is of paramount importance.
- The experience of Romania has shown that you don't have to be a "EUPATI country", part of its funded mission, to set up EUPATI in your own country.
- EUPATI can play a particularly important role in the development of national teams by opening doors to government agencies and senior academics.
- EUPATI should circulate case studies of successful national teams in order to share best practice and build confidence.
- The first months of training on the expert patient course suggest that it is working very well, although the amount of work involved may have been underestimated. The pace of learning was seen as about right. Feedback suggests that the face-to-face meetings are of enormous importance in supporting learning and in the exchange of ideas.
- Once trained, the expert patients could play a key role in spreading knowledge about involvement in medicines development throughout their own countries.
- Ways need to be found to prevent conflict-of-interest rules from excluding expert patients from working at both industry/academic and agency level.
- We all have to learn how to work effectively with social media and online technologies – but already there are plenty of excellent examples to inspire us.
- The willingness of professionals to accept the involvement of patients varies from country to country – but things are moving in the right direction.

- Much work remains to be done to ensure that EUPATI is sustained beyond 2017, when its funding runs out.

3. Progress so far

To set the scene, Eibhlin Mulroe from IPPOSI, the Irish Platform for Patients' Organisations, Science and Industry, Ireland, brought delegates up to date with how EUPATI is evolving.

That evolution is itself a response to a set of clearly identified needs. Health research and policy are changing rapidly, but where is the patient voice? "We need more people who can engage on behalf of the patient," said Mulroe, at all stages of research – including before the research is even designed. Against a background of public distrust and a lack of knowledge about medicines research, most cancer patients do not take part in clinical studies, and slow patient recruitment delays three-quarters of post-phase 1 studies.

Patients have – or should have – a key role in all aspects of health-related research, but across Europe there are too few patients equipped to play that role. "We'd need 25,000 patient experts to cover all the ethics committees in Europe," said Mulroe.

Hence EUPATI, formed in February 2012, formed by patients and for patients, is also working closely with other stakeholders such as academics and industry. It aims to develop and disseminate objective, credible, correct and up-to-date knowledge about medicines R&D; to build competencies and expert capacity among patients and the public; and through this to make it easier for patients to become partners at all levels of medicines research.

EUPATI's strategy revolves around three levels. At the top is a training course for 100 patient experts, conducted in English. The first tranche of 50 patients began their training in October 2014 (and their experiences so far and the roles they will be expected to fulfil were the subject of much discussion in the workshop), with a further 50 to start in autumn 2015.

The next level down is represented by the EUPATI Educational Toolbox , a web-based learning-resource with a target audience of 12,000, available in English, French, German, Spanish, Polish, Italian and Russian. It is scheduled for release during 2016. (Delegates generally referred to it simply as "the toolbox", and made it clear they want it to be released as soon as possible.)

At the widest level, there is the planned Internet Library, targeted initially at 100,000 individuals, and available in the same seven languages as the toolbox. Work on that began in 2014, and it is scheduled to go live in 2016.

EUPATI's resources cover the full range of medicines development all the way from planning and early testing, through full-scale clinical trials and on to regulatory issues as well as the principles of health technology assessment. What it does not do, stressed Mulroe, is develop information specific to particular indications or conditions. It is about "what affects us all".

Mulroe stressed EUPATI's "strong governance", evidenced above all by its patient leadership – unique in the IMI. It also has EU-wide coverage, strong impetus from

academics and research organisations, and the addition of industry expertise. That governance – and independence – is ensured, said Mulroe, by input from key advisory bodies and government agencies.

Three years into the project, there are clear signs of progress throughout its "work packages" (seven streams of activity). The preparatory phase is long over. "We have done our homework," said Mulroe, referring to assessments of patient and public attitudes to medicines development. The EUPATI Network is growing too, with 1,200 members, for example, and even more subscribers to the Newsletter.

Mulroe then came to the development at the heart of the workshop: the National Platforms and the National Liaison Teams. "We really need foot soldiers. We need people on the ground," she said.

Here there is evidence of progress, but also of challenges. Put simply, the National Platforms are there to make EUPATI work at a national level, ensuring that it understands educational needs, disseminates training information, raises public interest, and identifies people and resources to help with training. In the first phase, EUPATI aims to establish 12 National Platforms.

The National Liaison Teams are temporary task forces, each made up of between three and eight representatives of patients, academia and industry. Their sole role is to establish National Platforms in their countries.

So far, National Platforms have been established in the United Kingdom, Ireland, Spain, Luxembourg and Italy, with National Liaison teams up and running in France, Italy and Malta. That leaves four target countries – Austria, Belgium, Germany and Poland – where the situation was described, politely, as "challenging".

Finally, Mulroe stressed that EUPATI is not just for the 12 initial countries targeted. "This project is a gift to patient organisations in terms of the richness and objectiveness of the information," she said. "We need you to tell patient organisations this is happening."

4. Hearing from the students

With so much depending on the new patient expert training course, the workshop was keen to hear how things were going. Niels Westergaard of Biopeople, University of Copenhagen, Denmark, had been involved in producing the concept for this course, and has also been one of the trainers. He introduced an interactive session on the course, moderated by Rob Camp of the European Patients' Forum, Belgium. Westergaard gave a brief introduction, running through the rationale for creating the European Patients' Academy, with its three levels of training (expert, toolbox, Internet library). He began with the "paradigm shift": the move to put patients at the heart of the entire process of medicines development.

EUPATI's vision for 2020 is of a society where patients are active "from A to Z". He talked about the need to build capacity, to ensure that patients are trained in the right way, and to make a reality of patient centricity in medicines R&D. The key outcomes will be better health for all, making sure that investment goes "to the right place at the right

time", a true partnership of all stakeholders, and patients "actively and systematically involved" in all stages of medicines R&D.

The expert training course combines e-learning with face-to-face meetings (the first had taken place in Barcelona a few weeks before the workshop). The course designers estimated that it would involve 150 to 175 hours of learning, but that "might be a bit low", said Westergaard. And, indeed, course workload was one of aspects mentioned by the trainees later.

Westergaard explained that the first 50 students had already completed two of the six modules, and were moving through the third and fourth modules. Their course ends in December, by which time the second tranche of 50 will have started their own training. How are the students finding it so far? To find out, he and Camp were joined on the stage by three students on the expert course: Dimitrios Athanasiou from Greece, Peter Lack from Switzerland, and Sharon Thompson from Ireland.

Camp kicked off the discussion by asking the three why they had signed up, and what their expectations had been. The answers were, perhaps predictably, highly varied. "I signed up in ignorance, to be honest," admitted Thompson. Her daughter had recently died from a rare dystrophy, and she received an email about EUPATI. "And I thought, Why not?" Her goal was to learn more about the involvement of patients in medicines development. She was also conscious that many patients need less medical jargon and more interaction with the people who have the means to make their lives better. "So my expectation was that I would learn more. I didn't realise how much more!"

Reviewing the reasons

Lack was introduced to the idea of the course from a group he was already working with. Already involved with patient organisation Childhood Cancer Switzerland, he could see the potential of patient involvement – "but I also saw the requirements". Like Thompson, he felt he needed to know more about the process, as well as basic medical information. Unlike Thompson, he had already taken part in a EURORDIS course, driven by a desire to see how other patient groups worked with industry and academia. What he wanted from EUPATI was to develop the ability to review research projects critically.

"My motives were very egoistic and personal," said Athanasiou, "because I also have a son with muscular dystrophy." We have to be informed to protect our loved ones, he said: "Usually naïve patients are the ones who die first." And, he said, he is getting what he has been looking for: information that he can use, and is using. "We can exchange and learn from each other," he said. Injecting a note of urgency, he noted that progress is rapid – but "we need to move a little faster".

From the floor, course student Noirin O'Neill, from the United Kingdom, said she was one of the lucky patients, having been able to take part in a trial for acute myeloid leukaemia ten years ago. Since then she has spoken at conferences about excellence in medicines, and hopes that the course will help her to make a contribution at the European level.

Bringing it back home?

That was a cue for Camp to ask about the national level – halfway through the course, did the students think what they are learning would be helpful there? "Sure. Definitely,"

said Lack, although he noted the need to know more about legislation and regulation in Switzerland (which is not part of the European Medicines Agency system).

Lack then opened up what proved to be a theme of the workshop: the relationship between the expert course and the development of National Liaison Teams and National Platforms. "For me EUPATI is more than just this course, it's really about patient involvement." Switzerland has a National Liaison Team already, but there is a long way to go, he said. "Just the idea of patient involvement and its added value is not really there."

Greece lacks the backup of a Liaison Team or Platform, said Athanasiou, so everything takes more time – and has to be sustainable from day 1. "We try to handpick the willing in order to move forward," he said, looking to international companies to provide "more willing and open-minded partners". He saw the information he is learning as "very important" at national level, enabling him to train others. "We have to be focused on training local patients," he said. But with developments taking place rapidly, he noted the need to "work harder on updating information".

Thompson had yet to reach a conclusion about the extent to which what she was learning would help build patient involvement in her country, Ireland. "What we would bring back I don't know. I suppose the first thing you learn is not to volunteer!" she confessed. Patient representatives are naturally cautious about what they say, how they say it, and how they engage. "You don't want to rock the boat," she noted. "I think it is very difficult for us to know how we are going to make a difference. That's why we joined EUPATI – to get pointed in the right direction." She hoped that becoming trained and recognised would make students more visible. "Although we don't want our hands held, we do need a certain engagement from partners at a national level. People have to come to meet us."

Other students came forward with their views. Carol Hagan, from the Tuberous Sclerosis Association, United Kingdom, didn't have an answer to the question of impact at the national level, but halfway through the course she had now realised she was "part of a huge thing", and was developing a vocabulary and confidence. And a National Platform is clearly not the end of it: "We have a National Platform, but there is not a level playing field in the UK about access to medicines."

Alwyn Rowlands from Cynws Pobl/Involving People, United Kingdom ("but really Wales") said she is taking forward a "vast fund of knowledge, sometimes too much, but everything is relevant". She intends to pass on her knowledge to a new body, Healthwise Wales, which is being set up to involve patients in research.

For student Pedro Montellano from GAMIAN-Europe, Belgium, one of the most valuable outcomes is the network. In particular, learning how problems have been overcome in other countries makes it easier to implement changes in our own countries, he said.

Paul Carey from Move4Parkinson's, Ireland, a patient advocate himself, professed his admiration for the students taking the course. "We need you to come back enthused, to show us what we can do," he said. "It has to percolate down to my level, to Parkinson's patients." Carey was clearly looking to the students to make a difference at national

level. "What we need from you is to find a way to get a paradigm change in the way our ministers and our organisations think."

Too cosy?

EUPATI student Russell Wheeler from LHON UK, United Kingdom, declared himself as representing "the elephant in the room". He called for a radical seventh module: "the health system in Europe is broken. EUPATI is teaching the system that there is…We have to go further and find ways of changing the system." Wheeler said he was worried that he would become "part of the system".

Is being a patient advocate "cosy"? It certainly worried Thompson, and Lack also said he could relate to Wheeler's concerns. He referred to a thin line between cosiness which might have the potential to create partnerships between academia and industry, and being too cosy. "For me it's not so clear yet how we achieve the best results." On the other hand, one of the things Lack appreciated about EUPATI – "perhaps because we are cosy" – is that patient groups are learning that they can achieve more together and perhaps "work to change the system" – but that they have to collaborate with each other, learning what is in the interests of patients and patient groups in the long run.

Perhaps the answer is that you have to be able to rock the boat some times and keep it steady at others, said Camp. "One thing I learned from Jan Geissler is the concept of the 'disrupter'. I really like that word," he said.

Happy now?

Now that the students were halfway through, how did they see the "road to the finish line", as Camp put it? "I'm pretty happy with the pace [of learning]," said Athanasiou – and happier after the face-to-face meeting in Barcelona, where the motivation he received from other students "recharged my batteries". Thompson noted that you could do the online course at your own pace, and talked about having "a great time" in Barcelona. "EUPATI brought us all together and has shown us that a lot is happening for patients in Europe."

Lack said he was looking forward to the next modules and in particular the next face-to-face event. The event in Barcelona sparked off ideas about what to do in Switzerland – "you don't get that in e-learning". He also mentioned the need for information resources that students can access once the course is over. He was happy to hear about developments in relation to the Internet library, but he wanted EUPATI to go further, with forums where patient representatives can discuss problems they are encountering.

Montellano, too, was looking forward to the final six months. But he also wanted to emphasise the importance of what happens next. "You get all this training and information, and you put it into practice."

Finally, it was left to Westergaard to sum up quickly. The project has really moved on, from an abstract idea to real students, the first face-to-face meeting – and the first feedback. "We are well aware that everything is not tip-top," he admitted. "We still need to make small adjustments." But above all he really appreciated the positive attitude shown by all the students.

5. Case studies: Italy, Spain, Romania

Before the workshop split into smaller break-out groups to look at specific aspects of developing the EUPATI presence at the national level, it heard three case studies: from Italy, Spain and Romania. Each dealt with a different kind of experience. Italy and Spain are both core countries of the EUPATI project; Italy has an established National Liaison Team (and, it transpired, a two-week-old National Platform!), and Spain an established National Platform.

But although EUPATI has had to limit the scope of its funded operations – the money simply isn't there for complete European coverage at this stage – this has not stopped other countries from seeking to set up their own Teams and Platforms. Romania is one such country.

Italy – central and local

The case studies began with Italy. Silvio Berioli from the European Forum for Good Clinical Practice, Italy, introduced the members of the Liaison Team and then dived straight into the difficulties. One complication in Italy is the sheer number of patient organisations – somewhere between nine and ten thousand, with some local, others regional or national, large variations in experience, and with many organisations for the same disease or condition.

Among the hurdles listed by Berioli were variations in management expertise, the difficulty in finding human and financial resources, and the fact that each patient organisation is jealous of its own network. "We have to be willing to share. Not just to talk about it, but [share] doing things," he said.

As if all that were not enough, Italy has no established, standard way in which patient organisations work with pharma companies. Sometimes, as well, patient organisations are led by ex-politicians or "prima donnas", VIPs, each with their own agendas. And the media aren't much help. "We have to explain to them that this is not 'a problem'. It is 'the problem'," he said.

With all those problems, where do you start? "Our crucial approach was to have a central and a local strategy," said Berioli. Centrally, the aim was to invent the idea of the "mentor", someone with recognised experience of Italy's political and institutional environment. Locally, the first task was to find the right people for the initial Liaison Team nucleus.

Here Berioli was quite specific: they were looking for people at what he called the "intermediate level", from organisations that were neither too big nor too small, but with plenty of experience – "people with friends everywhere". Once they were found, the next job was to decide how to work together and divide up the tasks. Then they set out to identify institutional and academic partners to endorse EUPATI.

Here they struck lucky, becoming the first organisation in Italy to be endorsed by both AIFA (Italy's medicines agency) and the Rome Chapter of ISPOR, the International Society for Pharmacoeconomics and Outcomes Research. These successes were followed up with the creation of a scientific board for the National Platform (launched 12 days before the Dublin workshop).

A two-day workshop is planned for the autumn, which will spend the first day looking at best practice in patient partnership and stakeholder views, and showcase EUPATI's patient expert course on second day. So far, the Platform includes more than 200 patient organisations.

Spain – first find your stakeholders

The Spanish experience was presented by Daniel Gil from Spain's industrial association, Farmaindustria. Spain's EUPATI National Platform, he explained, began in 2013 with the creation of a National Liaison Team with four partners: two patient organisations, Spain's main university (Complutense University of Madrid) and, like Italy, the country's pharmaceutical industry association. The next key step was, like Italy's, the appointment of someone to drive the work forward – Laura Kavanagh, the National Platform network coordinator.

Then, in what might turn out to be a cul-de-sac, they approached Spain's health ministry, including the official responsible for relations with patient organisations. As Gil put it, "In our opinion they are still not ready to engage with EUPATI until they learn more about the role of industry and [its] influence on patients within the project." (The experience here is not unique…Others, later in the workshop, talked about the problems persuading people that cooperation with industry is just that, cooperation, rather than domination by industry.)

After the National Platform was launched in December 2014, nine were elected to form the executive board at a meeting held with all the organisations interested in EUPATI. Six are from patient organisations, two from academia and one from industry.

The National Platform then set about enthusiastically spreading the word about EUPATI, with a series of events in Barcelona, Toledo and Madrid during the spring. Further events are planned for later in the year. Work is being developed around three themes: content (for EUPATI's expert patient courses, toolbox and Internet library); activities, centred around education; and communication via mass media and social networks.

Stakeholder work has a high priority. The Platform is already working with MSD and Novartis in educational activities, and hopes to involve other companies too. It also plans to ask Spain's medicines agency (AEMPS) to collaborate in informational and educational work – something that might be a more effective route to work with the regulators than via the health ministry. Meanwhile, communication with patients is assured through the representation on the Platform of Spain's two main patient organisations.

High on the agenda for future work is Spanish participation in the patient expert course. Only one of the first tranche of 50 is from Spain, but there are now 20 Spanish candidates for the second course. Meanwhile, the Platform is waiting for publication of the expert course material in English, so that the team can see how this might be translated and used to mobilise patient engagement in Spain. And (like many others at the workshop) the team is looking forward to seeing the EUPATI Toolbox sooner rather than later.

Gil finished on a note of optimism. He described the "new landscape" being created in Spain that will allow patient advocates to take part in ethics committees, in the design of clinical trials, and in the writing of therapeutic recommendations. EUPATI's existence and resources will be crucial in making such collaborations work, he said.

Romania – on the way

Romania may not be on EUPATI's initial list of 12 countries, but with 22 million people (and 3 million Romanian-speakers in Moldova) it is the second most populous country in central and eastern Europe. And it is pressing ahead with plans to set up a National Liaison Team, as Rozalina Lapadatu from Romania's Autoimmune Diseases Patient Association explained.

On paper, the country's health law provides for a fair amount of patient engagement, but in practice it is "not well implemented", said Lapadatu. Patients are represented in what she called "legal debates" about the health system, and on hospital ethics committees, but not in the Romanian Drug Agency's ethical committees and not at meetings on health technology assessment.

Lapadatu described a situation that is not unusual in many parts of Europe: "We need stakeholders to listen to what we have to say, because physicians, academia and pharma are focused on their own goals, but forget that it should all be for our benefit as patients."

Against this background, they have set up a National Liaison Team in Romania and are working to establish a National Platform. The team consists of Romania's three expert patient students (including Lapadatu), a key academic (the chair of internal medicine and rheumatology at Bucharest University), and two media partners. Contacts with industry have been encouraging, and the team is waiting for some internal approvals before they can announce the names of industry partners. Discussions have begun with the Ministry of Health and medicines agencies.

As in Spain, the team has been promoting EUPATI and its values to media audiences and at professional meetings. "We believe the first brick in our wall is education," said Lapadatu. "We have to start there." She believes that EUPATI will give patient representatives the authority to make industry and government listen to them. On a visit to the Ministry of Health she recalled an official asking why she was there. "I said I was here as a patient. Now I can also say I am here as a patient expert."

6. Break-out groups: Making EUPATI work now and in the future

The case studies informed four break-out groups dealing with: countries with an National Platform established; countries with a National Liaison Team but as yet no National Platform; countries without a EUPATI presence; and the general issue of sustainability – how to make EUPATI a success over the long term. Due to a shortage of time, the reports were given without further discussion.

Break-out 1: Making it work nationally (for EUPATI countries where an National Platform is set up).

"We had a very vibrant discussion," said rapporteur Karin Holm, Patient Advocates for Cancer Research and Treatment (PARCT), Switzerland. The group looked at some of the benefits of having a National Platform – some disliked the word "platform", so sometimes they talked about a "network"" – and found it could be a central point for national policy and regulatory organisations to ask questions.

Platforms are also a way to bring a diverse group of national partners to speak with one voice, to "connect the dots between organisations". And the existence of a national network itself eases the path to multisectorial cooperation between academia, government and pharma. Other benefits include having one group to address key issues across the nation, and getting all the funders around one table.

Who are some of the national partners? What might their contribution be? The first answer was "all interested patients" – quite a task with typically thousands of patient groups in a country. The group considered the need to reach out to academic and research groups, and to clinical trial organisations. The list of partners went on: ministries of health, other national institutions and regulators; healthcare professional organisations; ethics committees at hospitals and within geographic jurisdictions; pharma associations and individual companies; and the media.

There were many questions about what the strategic priorities might be, but there were also suggestions. Holm reported that the group placed a high priority on passing on the knowledge gained in EUPATI training to the wider audience. There was much discussion about how to do that, bringing together the different players and communicating the existence of new tools.

What does success look like? The group listed five clear signs of success: making people aware of each other; getting all the partners on board (in whatever way works in your country); securing sustainable funding; developing new ways of thinking, and opening up new avenues for engagement; and making your Platform (or network) the "go to" organisation for patient engagement.

The group also tried to identify the characteristics that all EUPATI National Platforms have in common. Holm reported the outcome. Each builds relationships, strategic partnerships and networks, the group decided. Each has to decide its main role: is it to be a router, a doer, a signposter or a portal? It was suggested that case studies of those National Platforms that have made greatest progress might be very helpful to others. National Platforms also recognise that each partner has its own partners and affiliates – so use the multiplier effect to spread the word. Each Platform will have some country-specific issues to address. And, finally, the networking created by the Platforms also generates an informal forum to share ideas and materials.

Break-out 2: Making it work for countries where no EUPATI National Platform has been established.

As rapporteur Sue Pavitt from the University of Leeds, United Kingdom explained, this breakout group set out to identify the steps National Liaison Teams need to take to get a EUPATI National Platform effectively established in their country. (And in the words of session chair Jan Geissler, they did so, producing "almost a cookbook for how to set up a EUPATI National Platform".)

First, what are the considerations in setting up a National Platform? And what are the obstacles? As Pavitt reported, the group spent most of the time on the obstacles. It took from the Italian example the need to find the "drivers", people with vision to enthuse others, such as Ireland's Michael Griffiths, from IPPOSI. The challenge – and it is a challenge – is to find the right champions in patient organisations, academia and industry. There was also talk of bringing clinicians on board, not just academics.

If that is difficult, it is even harder to navigate the large companies to find the right people. One short cut might be to tap into those companies already engaged with EUPATI. The group spent time talking about Germany and Austria, where there is "quite a lot of angst" over engaging with pharma. The moral: as you start to break down barriers, "keep your enemies closer".

Moving on to what the ideal Platform would look like and who the stakeholders would be, the group agreed that it had to be patient led. Then it must create effective partnerships with other stakeholders, such as pharma, academia and the media. One message is that funding matters: once government agencies in the United Kingdom endorsed the value of patient and public involvement in their funding schemes, the concept "snowballed" from the Department of Health to research councils and charities. Perhaps, people thought, inserting requirements for patient and public involvement into grant funding schemes might be the most effective way of shifting cultural attitudes in Germany and Austria towards working with pharma.

The ideal EUPATI National Platform would be highly inclusive. It would have a governance code, strong involvement of patient organisations and the desire to involve patients and the public in research, an effective scientific board, excellent communications, a commitment to raising its own standards, and a progressive division of labour as the National Liaison Team evolves into a National Platform. National endorsement from, for example, health ministers would also raise its stature.

How do you reach key stakeholders and convince them to sign up to the Platform? It starts with having belief in the vision, yourself, and then finding others who share that. You need to meet up and fire off each other to keep your enthusiasm, said Pavitt. To convince others, you need to provide evidence of a real practical benefit for patients (there's certainly evidence from, for example, insulin inhalers of the costs of not involving patients). One "huge resource" on the impact of patient and public involvement which can be used to convince others is the INVOLVE website in the United Kingdom.

So why should we join forces? Above all, because knowledge transfer and the sharing of best practice enabled informed treatments. "Patients know best. That's something we should take as one of our phrases to move our cause forward," said Pavitt. Joining up also creates opportunities for improved medicines development, and enables us to become part of the paradigm shift where patients are actively involved in research and patient benefits are central to the research rationale.

What can EUPATI offer? As Pavitt said, the report from Break-Out Group 1 had covered that well. But her group looked at several opportunities for embedding EUPATI's ideals and experience into undergraduate healthcare professional courses; providing students access to present their research to patient forums for feedback before they start; and introducing the idea of patients coming in to medical schools to discuss with students about what it is like to live with conditions.

In terms of the difference a EUPATI National Platform can make, the break-out group singled out the concept of "stronger together", along with greater opportunities to advance international research and more opportunities for joint ventures.

The group also discussed briefly how to convince others of the added value of EUPATI, concluding that patient organisations will need to be shown that EUPATI can ensure access to the training that they want. Academics and clinicians, on the other hand, need to be made more aware of the benefits of patient and public involvement – in the United Kingdom, this involvement has to be incorporated into grant proposals, and people looking for research funding need to know that grant panel members know when a proposal is merely tokenistic.

Finally, the group suggested some new terminology. Instead of patient or public representatives, talk about patient or public contributors. "That would avoid some of the barriers we get in terms of lay persons and expert persons," said Pavitt. "Everyone has a role to contribute."

Break-out 3: Making it work nationally (for non-EUPATI countries)

As session chair Tanja Keiper from Merck in Germany and EUPATI Director Jan Geissler reminded the workshop, EUPATI has had to concentrate on a limited number of countries. But, he said, the question of how to support countries not part of its funding is "very important". It is also complex.

Rapporteur Ingrid Klingmann from the European Forum for Good Clinical Practice, Belgium, related that the workshop found it difficult to come to a clear picture of what to do, faced with the whole of Europe minus the EUPATI 12 – so another 16 countries plus those European countries not in the European Union – with different backgrounds and starting positions. Indeed, 17 countries were represented in the break-out– including Turkey and the US. "But we did what we could," she said.

We know that there are proactive supporters driving patient involvement in non-EUPATI countries, and there have already been discussions internally on how to facilitate and utilise this enthusiasm. The group set out to identify which steps individual supporters of EUPATI can take and what support is available.

It began with a simple question: Why do you want to install EUPATI in your country? The main answer can be summed up in one word: information. Patients need more correct information, and they need to know where to find it. That includes information about patients' roles both as participants and advisers. But crucially, the information that EUPATI provides must be "absolutely credible", reported Klingmann. In this context, the national organisations have to be responsible for taking over EUPATI's central information into their own countries and languages "in a reliable and professional way".

Other drivers included a perceived need for a "common language" to enable communication between the stakeholder groups – and EUPATI is or could be that joint language. Break-out participants also mentioned a lack of understanding about the relevance of treatment instructions.

Patients want more respect from other stakeholder groups for themselves and their experience, and it was felt that EUPATI National Platforms could really help in this. But there was a warning, too: empowerment does not come about just like that – it takes time, and stakeholder expectations will need to be managed.

When it came to how EUPATI could support their activities, the group came up with a number of practical suggestions, most of which seemed easy to organise. Letters of intent or introduction could help with approaches to academia ("of course", said Klingmann, "just ask us"). They also wanted speakers from EUPATI's core team at their national events ("definitely, we have presentations on EUPATI available, we also have others, more tailored"). An important aid would be support in involving competent authorities and bodies such ministries and health technology assessment agencies ("we have experience doing this").

Another topic was that the EUPATI Toolbox should be available "earlier rather than later".

Beyond that, the group said that confusion around what being "representative" meant was causing problems. "We haven't found an easy answer to that," admitted Klingmann. People also wanted clarification of the rules on conflict of interest when working with industry on an IMI project.

The break-out group mentioned a raft of obstacles to implementing EUPATI at a national level, from patients not being seen as influential in their own country to substantial gaps between patients and industry. Another issue was how to organise translations that

meet quality requirements, especially if there is no money for them. And without EUPATI funding, the overall issue of how to get money was inescapable. Others cited the importance of creating an organisation that can sign a contract with industry and open a bank account.

It was not easy to see how EUPATI might be able to help with all these hurdles – apart, that is, from training more "professional" patient representatives and establishing the concept of a "patient key opinion leader". On a more positive note, non-EUPATI countries could share experience and learn from each other about how to collaborate effectively with the competent authorities, and how to gain public funding. Another suggestion was to "buddy up" with a EUPATI country in a twinning arrangement.

Sustainability is a big issue for EUPATI, and break-out participants were asked to consider how they would enable their organisation to cope beyond 2017, when the IMI funding runs out. The answer was salutary: since they have no seed money from EUPATI, they have to think about sustainability from day 1.

Break-out 4. Keeping it going over the longer term/how to make EUPATI a long-lasting success

Now is the time to look at EUPATI's long-term future, said rapporteur Per Spindler from Biopeople, University of Copenhagen, Denmark. He reported that the break-out group had looked at what he called the micro and macro dimensions: the micro being the country level, the macro being EUPATI as a whole.

The approach they took was to draw on national experiences and examples of best practice. At the micro level, that suggests the importance not just of engagement with local stakeholders, but also of a formal structure for doing it. Break-out members suggested that a "concept paper" could be useful in terms of driving the National Platform, and could also be used for promotion and funding. They also stressed the importance of transparency, and the role activities such as events can play. Communication was also seen as a key part of activities and events. Young people need to be included in communication, and we should use our partners' communications and social media to widen our reach.

When it came to the macro level, "the voice from the group was that EUPATI provides access to information and tools," said Spindler. As other break-out groups had also concluded, credibility is crucial – in EUPATI as a whole, in its training and in its training material. Impact can be gained by linking EUPATI into European decision making. Collaboration will be increasingly important as EUPATI evolves. In any future system, patient leadership must be seen as a legitimate voice in decision-making.

But the micro and macro worlds are not totally separate. Spindler finished his report with a reminder that activities at the national level facilitate impact at the European level.

7. Communication and social media: "Building an online voice and working smart in a digital world"

Rob Camp kicked off this plenary session by declaring that his fellow moderator had done 99 per cent of the "heavy lifting" on the subject. But he had been sending out tweets for the past couple of days, looking for answers about two questions: What do patients need to communicate? And how do patients need to communicate? He read out a selection of words from the responses as something to think about when considering "messaging to the outside world": engagement, meaningful involvement, patient centred, useful, trustworthy, need to be involved as patients, need more skills, need more skills support and confidence, transparency, transparency, transparency…and so on. His implied message: think about your audience.

He left it to his fellow moderator, Denis Costello from Eurordis, Spain, to deliver an eye-opening presentation on where you can get by being smart online. "It was too tempting to focus only on EUPATI," said Costello, "so I took a lot of examples from people I know who use these tools." He hoped that workshop delegates would be able to take away ideas for their own organisations as well as for EUPATI. Because as he said, if EUPATI is to develop to the scale it can be and needs to be, social media is going to be a big part of the answer.

But you have to be smart about it. And, indeed, Costello's presentation focused more on smart thinking about how to gain attention than on the technologies of social media.

Stand out from the crowd

To illustrate the potential, Costello showed three examples, starting with Paco Monfort. A Spanish father of a child with atypical haemolytic uremic syndrome, Paco has built up a lively online presence publicising a potential lifesaver for people with the syndrome – a colourful bracelet holding their medical history that doctors or nurses can access via a smartphone.

What has really built that online presence is Paco's knack of photographing famous people wearing the bracelet, including the Queen of Spain, and footballer Luis Suárez. "We are all Paco. You can be Paco," said Costello – anyone can become a key patient opinion leader with just a mobile phone. "The first step starts with you. Bring your personality into [your] cause." He cited other individuals including two patients, Dave deBronkart (Twitter handle @ePatientDave) and Alfonso Aguarón (@AlfonsoAguaron), and genetics professor Kate Bushby (@BushbyKate) as examples of what individuals can achieve as "real ambassadors for the rare disease world".

Costello's second example was of a slightly different, less individual, approach: Nic Sureau, co-founder and chairman of British rare disease research charity Findacure. Costello singled out Findacure's site for its "clear and captivating message" – one that has made it stand out among rare disease patient groups in the United Kingdom. The message he took from this example was the importance of the brand and how, in this

case, it combined idealism, hope and also energy. "We need to think about how to position our brand," he said.

For his next example Costello took Téléthon set up by AFM, France's muscular dystrophy association. Back in 1987, they persuaded French public TV to give them 30 hours of broadcasting time, mobilising hundreds of thousands of volunteers and literally lit up the Eiffel Tower. The Téléthon had five core objectives – not unlike EUPATI, in fact: to make rare diseases visible, to heighten public awareness, to convince government and institutions, to share knowledge, and to be accountable. The Téléthon now raises around €100 million a year. The AFM is moving on to other media, developing an Internet strategy through which they aim to raise 20 per cent of their donations.

Build your brand

"When you create a voice you need to go back to your identity," said Costello. In the AFM's case, these are: solidarity, efficiency, innovation and transparency. What does this mean for National Platforms? Above all, they have to choose the brand "archetypes" that best accord with the sensitivities of their own audiences. Brand matters. "You want to position yourself," he said. "How do you differentiate from the nearest people in your space? There has to be a meaningful difference that would convince somebody that you are there for them."

So how do you create a voice, a brand? How do you position yourself or your organisation? Costello talked about constants and variables. The constants, which underpin all brands, are integrity and nurturance (the idea that you care for your audience). The variables – where you sit in between dynamic and passive leadership, in between being sophisticated and being "tough and simple" – will need to be determined when you position your brand.

Positioning your brand involves being able to answer questions like "What's innovative or different about my group?"; "Are we straightforward enough?"; "Does our mission to care come across?"; and "Are we playful or serious?".

When it comes to putting the brand over, we need to use all the tools at our disposal, within the time available to us, in the most intelligent way possible. That means being multichannel – but it doesn't mean you have to use every channel. So a campaign can be conducted entirely via social media, or with social media plus a website or "microsite". And noting EUPATI's ambitious goals, Costello mentioned two other tools: mass emailing, and advertising via Facebook or Google.

Does online advertising work, interjected Camp, and if so, is it the best way to spend the money we have? It certainly does work, said Costello, because people with rare diseases are looking online for help. As to money, he said that Google has grants (in the form of free advertising) that charities can apply for, though they have to do it in their own country, and not all countries are part of the scheme.

Ways of campaigning

Costello then moved on to three examples of different ways of online campaigning. In the first – a battle for access to medicines – a patient group brought stakeholders together to set up a microsite to contest a decision by NICE not to fund a drug for atypical haemolytic uremic syndrome (the condition for which Paco in Spain is a patient

advocate). He described the site, aHUS-action.org, as "very evidence-based, sober, but also very dynamic, calling for action". The campaign worked, engaging payers in the United Kingdom and leading to negotiations with the company over price.

His next example was "more of an advocacy approach". EURORDIS, which advocates for rare diseases generally, surveyed 5,000 patients and summarised the results in a book presented to the EU Health Commissioner on Rare Disease Day, backed up with live tweeting from the event, video on demand and links to a PDF of the book. The result: a European recommendation on action on rare diseases. "Social media…should always be part of a communications and advocacy strategy," said Costello.

Costello then turned to a campaign run by EUPATI's own Jan Geissler – "I like this one a lot" – conducted solely on social media. Called "Patient In, Not Out", it was light and agile, cost-effective, and with eye-catching images of patients holding up placards had the potential to go viral.

Awareness campaigns are all-important. "If your disease hasn't got awareness, it doesn't exist in the minds of healthcare professionals and policy makers," said Costello. One example: the "blue lips" Pucker Up for Pulmonary Hypertension Campaign, which resulted in record numbers of postcards bearing a blue kiss – and an entry in the *Guinness Book of Records*.

Never mind that some say every day is a "day for something" and that saturation point has been reached – getting everyone together to do something, and seeing that grow over the years, has an enormous impact on your own community, said Costello.

Another key tool, maybe not for EUPATI but for patient organisations, is crowdfunding. Costello's tips here: think about who your members are "because they are the ones who will get it off the ground"; have a video – it can be simple, but it must make an impact within 30 seconds; and "front-load" the campaign so that on the day of the launch there is already some money there. EURORDIS ran just such a campaign with a patient group in Spain that needed an extra €14 thousand euros, centred around a volunteer running in the Barcelona marathon: it raised 75 per cent of the total within 72 hours.

Costello ended his presentation with a list of useful tools, starting with rareconnect.org, a EURORDIS initiative to connect rare disease patients globally, and including tools such as hootsuite.com (to listen to social media and schedule tweets), Google alerts and AdWords, and so on.

National directory

It was then the turn of Laura Kavanagh from IPPOSI to introduce EUPATI's new directory of National Platforms, available on its website. It links to each country, with details of national teams (if they are in place). Of particular interest to this discussion, it also has links to Facebook and Twitter feeds, video walls, and so on. "The idea is that you can get more information about what the national team committee has planned and share this further with your organisation – and vice versa," she said.

Just how active they are depends on the individuals involved – volunteers all. But for a good example, said Kavanagh, take a look at the Spanish entry. Costello noted that Spanish social media activity had started slowly, but then picked up when a woman from the lupus association in Madrid assumed leadership of the Platform's social media

profile. So the message, added Camp, is that each national team has to find someone good who wants to do the job.

Discussion

Costello had laid out a rich menu of social media techniques, and Camp opened the discussion by asking him whether there is a right or a wrong way of doing social media – or should we try everything he listed? Costello strongly recommended not doing everything. "We all have very limited time," he said. "Pick one or two priorities and one or two channels that would work for us, get it to something credible, grow – and then use tools for the voice you want in the country you are in."

Simone Silenzi from the Italian brain cancer association agreed. His organisation had created a Facebook group in 2009, with 5,000 members. But he warned of the danger of "dispersion, fragmentation" if communication is misdirected. "So consider your goals," he said.

The urgent need for the EUPATI toolbox was underlined by Hursh Joshi from pharma company Novo Nordisk, Denmark. "It is great that we are going to have 100 people trained by the end of next year, but the way the project can really take off is at the national level, using the toolbox."

For Joshi, the national level is the key theatre of operations. He talked of the importance of getting stories out at the national level, talking to national politicians, regulators and the media. "That really requires people in the National Platforms to create networks and to use those networks…We can make all the strategies and plans at the European level and have some influence, but we need to have a communications plan at each national level."

Using social media can also throw up unexpected challenges. The greater the level of interactivity, the more likely a site is to receive information about adverse events. As a delegate from pharma put it, any adverse events have to go to the pharmacovigilance department, which then has to research it, contact whoever has posted it, communicate with them and ask if it has already been reported to their doctor. No wonder pharmacovigilance departments can be cautious about social media! And it's not just a problem for companies. Claire Jacklin from the National Rheumatoid Arthritis Society, United Kingdom, said her organisation also had an obligation to pass on adverse events: "It does add on lots and lots more work."

(New technology might be able to help here. Costello pointed to a pilot project with the US FDA called Webradar which analyses social media and maps slang terms onto medical vocabularies, capturing adverse events in real time and creating automatic reports for the FDA. "Exactly the same results as normal pharmacovigilance, but at a fraction of the cost," said Costello.)

When looking at brands and image, one inevitable issue is EUPATI's relationship with industry. "How do we voice our integrity to the world?" asked Camp. That brought a robust response from Susana Leto di Priolo, Novartis, Italy, who said her company was proud of what it does with special groups, is transparent, and has a code of conduct for its relations with patient organisations. "I have seen the advance of the involvement of patient organisations," she said, "so I feel offended at comments that patient groups are

in the pockets of pharma. Every patient group that is really serious knows how to relate with pharma, and vice versa."

8. Stakeholder views: Why is EUPATI important?

The final plenary session was a panel discussion discussing an issue that at first glance might have appeared self-evident, but which threw up a number of interesting questions. Why does EUPATI matter?

The panel was formed by Róisín Adams from Ireland's National Centre for Pharmacoeconomics, Simon Denegri, chair of the United Kingdom's INVOLVE project, Cordula Landgraf from Swissmedic, and Birka Lehmann from BfArM, one of Germany's two medicines agencies. Chairing was shared between representatives of patients and industry, Anders Olausen from the European Patients' Forum, Belgium, and Kay Warner from GlaxoSmithKline, United Kingdom.

The representatives of government agencies were looking forward to greater involvement from patients. "It's really good that we will have a little army of 100 people who are really informed," said Adams from the health technology assessment side. "We want to involve patients, so they need to know what the whole R&D and registration process is all about," said Landgraf – and she, too, is eager to see the EUPATI Toolbox. From Germany, Lehmann said it was "brilliant" to have patients in all areas, and she hoped the EUPATI students would become "multipliers" in the other Member States.

"The more people who are involved in research, the healthier all of our nations will be," said Denegri. "EUPATI is a very good start and a potentially very important vision." But he then borrowed the language of marketing to say that EUPATI needs to crystallise three USPs – unique selling propositions: the learning and development agenda; working across nations; and the linkage with industry. "[Industry] is where we really need to build bridges," he said. "I absolutely accept the difficulties in some nations, but we cannot stand on opposite sides of the river and point fingers at each other."

Over to you

Olausen then put the panel on the spot, asking what steps they would take to make patient involvement a reality in their own country. "We are moving as quickly as we can," said Adams. It's not easy fitting patients into a process that wasn't patient-centric to begin with, but she pointed to the need for a broader acknowledgement of the core values patients want in every decision – that would make it easier to measure how well patient involvement is working. She also called for support for patients wishing to initiate research themselves. Another important step would be implementing the idea of patient key opinion leaders. (Later in the discussion, she added that she saw an important role for expert patients in research, "so if patients do want to collect data they know what to collect and how to collect it.")

Denegri seemed less enthusiastic about the key leaders idea. "Leadership is very important, but it's a heavily loaded term – as is 'expert'," he said. Even in the UK, with government funding and established ways of involving patients and the public, there is still much to learn and to do. "We need to make patient involvement more visible and help patients see how they can contribute to healthcare as part of their [own] care

pathway," he said. "I am all in favour of spreading expertise, but I want contributions from many people at all levels." He added that we need to move from seeing public involvement as enabling individuals to contribute to enabling communities and regions to contribute. "That won't happen through a few highly specialised individuals."

That elicited a response from expert student Russell Wheeler. He pronounced himself a little confused: "There seems almost a suggestion that the EUPATI project is training people who aren't needed." Along the same lines, he had heard much talk in regulatory circles of the importance of the "naïve" patient. On the other hand, "It seems EUPATI is trying to remove the naïve patient, which I applaud," he said, adding that in wanting "naïve" patients, the European Medicines Agency (EMA)is looking for patients "who don't ask difficult questions".

Denegri came straight back. "We get ourselves into unnecessary tangles when we talk about professional patients and naïve patients," he said. And he clarified his comments about "a few highly specialised individuals" by saying: "I applaud what EUPATI has done in building up a broad cadre of people like you, but for sustainability it's about how it can support you to spread the message among others."

Adams also responded, seeing an important role for expert patients in research, "so if patients do want to collect data they know what to collect and how to collect it."

From Switzerland, Landgraf said the most important challenge at the moment is raising awareness of EUPATI. The team there are working on a "concept paper" to establish "a clear vision of what we want to do with the EUPATI National Platform". Once it is written, they want to take the concept paper out to the general public and use it to get involvement and funding.

Lehmann's institute already involves patients in two of its national committees, and has reached out to several patient organisations in a move to increase transparency and improve communications. But things are clearly at an early stage. "We don't know how patients want to contribute to our ideas – we will see how it works," she said. "We have to think about how we can work with EUPATI, from the point of view of a federal institute." She noted that patient involvement in marketing authorisation is already established at the level of the EMA. Rather than duplicate that, she talked about having "a bridge to the national level".

What about the professionals?

Olauson then threw the discussion out to the workshop as a whole. First in was Pedro Montellano, one of the expert students. Patients want to be involved, he said, but what about the professionals? What has to be done to convince them?

It was an interesting question, and received quite varied answers. Adams was on the positive side. A recent workshop her organisation had run on how to make decisions in healthcare had found that those of patients and patient representatives were "spot on", and probably more sensible than those of the professionals. "I don't need to be convinced. I am, and most people in my organisation are convinced," she said. Lehmann has seen more and more involvement from patients in the advice given to companies and researchers. "I get the impression that researchers are taking more notice of patient input – especially in rare diseases," she said.

A different view came from Landgraf: "In Swissmedic we have a lot of professional personnel. From experience I can say it is not always easy to convince them that there are other stakeholders who have a stake." Change can happen, she said, but it takes time. Professional boundaries and systems are indeed hard to shift, said Denegri, but they are having to shift – because they can't meet the health challenges without involving patients. "There is a recognition that it has to be done," he said. He talked about the "classic carrot and stick" approach, where younger people thinking about a research career know they have to embrace public involvement.

How can EUPATI help?

Warner turned the discussion to what EUPATI could do to support government institutions in their goal of patient involvement. Once again, the responses from the panel were varied.

Adams took a top-down approach: "It's about mobilising and supporting a pan-European project that would look at core values and then drill down into individual countries," she said.

Denegri stressed first how important it was for EUPATI to publish the educational material it is preparing, in particular the EUPATI Toolbox: "Get them out there. People need to see the product. Get it out as soon as possible." He also called on EUPATI to help the UK build links with other countries ("we have a lot to learn"). And he asked EUPATI to support people in building bridges with industry. "Frankly, I'm a little tired of beating up industry. We all know [negative] things that have happened, but for the sake of patients and families we have to get things to a better place."

In the short term, said Landgraf, EUPATI should support national teams to exchange information and expertise, as well as act as a coordinator for media enquiries received at a national level. "EUPATI should speak as one voice, with consistent answers," she said. In the long term, she looked to "a smooth transition" after 2017, when IMI funding ends, with "people like Jan [Geissler] and Ingrid [Klingmann] still around."

Germany is less far down the National Platform road than Switzerland, and Lehmann wanted to see the EUPATI concept distributed to all Member States so that patients could begin to speak the same language about medicines development and clinical trials.

Conflict of interest?

Irmi Gallmeier of F. Hoffmann-La Roche, Switzerland, was impressed by the spirit of the expert students and looking forward to having "all these wonderful people" and – like many – to having the toolbox. But then she raised a problem for industry: if we involve patients in trials, those patients will not be able to take part in advisory boards in the authorities, due to conflicts of interest.

It seems as though different countries, and the EMA as a whole, have different ways of coping with such conflicts. Lehmann said such declarations were "a very important tool for scientific bodies" at the EU level. "The only option at the moment is to have more people trained, so some can go to industry and some to the EMA." But, she added, that would take time.

With a typical UK view, Denegri took a practical approach. "There are conflicts all the time. The important thing is that they are declared, known and can be managed both inside and outside the committee room."

"We have the same problem with healthcare professionals," said Landgraf, noting that in rare diseases it is very hard to find experts who don't have an interest in some form. "The solution is a 'smart' declaration of interest," she said.

Go forth and multiply

EUPATI's aim is to educate people in medicines development – not just to have experts in committees but also an educated broader population. "We hope some of our students will take up this role," said Ingrid Klingmann. Would that make the panel's work easier? Absolutely, said Denegri. But he added a note of caution: it's one thing to do the training, quite another to perform in the outside world. "You need to support people really well, give them a defined area to work in. We have a few patient ambassadors who work within a hospital, not across a whole nation." Make the task more manageable and achievable, he said.

"We do need the trained experts to be involved at the high level," said Landgraf, "but there are so many demands for patients to be involved at all levels." And, she added, perhaps a more naïve patient would be better when it comes to looking at the patient information leaflet. But she had a problem with the word "patient". "We are all patients – we have to talk about people." Anybody, of any age or ethnicity, with or without a condition, should be able to participate in research right across the world, she said. "We need the experts to feed [their knowledge] down in bite-sized pieces."

Olausen concluded the session on a note of optimism. "We have been knocking on the door for years…Now the door is open – and it's very complex," he said. "What I have learned is very good. The regulators are changing, saying they want to change, to play with us, to build bridges. I think this is great!"

9. Conclusion

It was left to Nicola Bedlington from the European Patients' Forum, Belgium, to reflect on the day's discussion. "We're definitely on the right track," she said, noting Graham Love and Eibhlin Mulroe's presentations at the beginning of the day. Love had talked about moving to a more systematic approach, with patient involvement becoming mandatory. "What I really liked about his presentation was the honesty. They're not there yet but they are on a journey."

The openings had set EUPATI's mission in context. Mulroe had described medicines research and development around a moral imperative, and after her Niels Westergaard had talked about the wider perspective – it's about better health, not just better medicines.

Russell Wheeler had talked about "the elephant in the room", the fact that health systems are broken. Yes, we need to be active. "We need to rock the boat, be 'disrupters'," said Bedlington. "But in reality EUPATI is not a patient advocate. We have those organisations."

A highlight had been the session with contributions from the pioneers on the course.

Westergaard had stressed that EUPATI is not perfect. "We are learning a lot. We are not yet 'tip-top' and there is much refining to do," said Bedlington. There is also a sense of urgency, of a need to move faster. That came over particularly in discussion of the importance of the EUPATI toolbox. "One hundred expert patients are critical, but we shouldn't underestimate the importance of the toolbox in seven languages," she said. "We should accelerate that."

Discussion in break-out groups around National Liaison Teams and National Platforms had yielded a great deal of information and general feedback – amounting, indeed, to a "cookbook" of how to go forward at a national level. It was, she said, particularly encouraging that three of the student experts had been stimulated to set up a Liaison Team in Romania. Another key concept to emerge had been that of patient key opinion leaders.

The "splendid" presentation by Denis Costello on social media – learning to work smart in the digital world – was followed by a fascinating debate on how the different players in our public-private partnership can use EUPATI. We are moving from being a niche topic to a mainstream one, building capacity so that our partners can meet patients halfway.

One big question was raised but not really answered: "EUPATI 2", or the future after 2017. "We need a robust sustainability structure," said Bedlington. "How can we move forward collectively and resource it?"

Appendix: Abbreviations used

EMA	European Medicines Agency
EFGCP	European Forum for Good Clinical Practice
EUPATI	European Patients' Academy on Therapeutic Innovation
EURORDIS	European Organisation for Rare Diseases
IMI	Innovative Medicines Initiative
IPPOSI	Irish Platform for Patients' Organisations, Science and Industry
NLT	National Leadership Team

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