EUPATI: A Vision for 2020

Report of the first EUPATI Conference, Rome, 19 April 2013

Content

1. Conference structure

This is the report of the first conference of EUPATI, the European Patients' Academy on Therapeutic Innovation, which took place in the Hilton Airport Hotel, Rome/Fiumicino, on 19 April 2013. This report highlights the main points that were raised during a full day's intensive discussion. Presentations from the conference are available on the EUPATI website, www.patientsacademy.eu.

EUPATI is being funded under the Innovative Medicines Initiative, a public-private partnership between the European Union and EFPIA, the European Federation of Pharmaceutical Industries and Associations. So it was important that the conference began with a presentation from the IMI's Executive Director Michel Goldman, that showed the scale, depth and aims of the partnership.

Then the agenda took delegates through the three key visions for EUPATI, all focusing on what it might have achieved by 2020: patient involvement in the medicines R&D process; building knowledge and competences for patients' involvement in medicines R&D; and public awareness about the development of new medicines.

Each vision was presented and debated in the same format. First delegates heard an outline of one of the visions, then listened to speakers from around Europe who have been implementing innovative practices in patient partnership in the area, all brought to life with examples of EUPATI interventions. Each session ended with an open discussion of how to achieve the vision. As EUPATI is a patient-led organisation that involves all stakeholders, sessions were co-chaired by patient representatives along with a co-chair from either

academia or industry. The conference concluded with a general discussion about goals for the future.

2. Introduction and Key Messages

For anyone who has followed the progress of EUPATI from its early beginnings, the project's first full conference was a revelation. Barely two years ago the idea was a mere gleam in the eye, an idea floated in discussion in the PatientPartner project. Patients, so the idea went, need training and education to enable them to play a full part in the medicines research and development (R&D) process. The notion was simple and, once stated, obvious. But equally obvious, and immediately understood, was that to bring this simple idea to reality would be inherently complex.

The Rome conference, held just 14 months after the launch of EUPATI, showed just how far the idea has developed. More than 180 delegates from 28 countries were there to hear about the plans under way for three clear areas of training and education: a certificate level course that by 2017 will produce 100 patient experts from across Europe; less detailed online education for 10,000 patient representatives; and an Internet library with information for anyone with an interest in medicines R&D – hundreds of thousands of people, perhaps millions.

Key messages

Opportunity – and threat. The atmosphere was positive, and for good reason. As several speakers said, there is now a "window of opportunity" for effective patient involvement in medicines R&D. All the stakeholders understand the huge benefits that can flow to them, from early research discussions, to better trial designs, more meaningful patient involvement in the health technology assessment and regulatory processes, and ultimately a quicker stream of properly tested and adapted innovative medicines.

But along with the opportunity comes the threat that there may be too few properly trained patients to take advantage of the seats that it is hoped will be available at the tables where trials are designed and scrutinised, and where decisions on access will be made.

Practical choices. So the Patients' Academy is more than a desirable aim. It is both crucial and urgent. And as delegates heard, a number of hard decisions have had to be made to move the project forward. Lacking the resources to replicate the project in every country and every language of the European Union, EUPATI has had to restrict itself in order to make the Patients' Academy a practical possibility.

The certificate-level course will be English only; online education and the Internet library will be developed in the seven most frequently spoken languages in Europe – English, German, Spanish, Polish, French, Italian and Russian (not strictly a European language, but widely understood by older people in central and eastern Europe). The lynchpin of the project, the National Platforms which will support EUPATI's work on the national level, will be established in 12 countries.

Challenges. There were few illusions about the scale of the task. More work is needed on presenting the project's aims and its value also to lay patients. The broad outlines of the content of courses and material have been established, but finding the right way of teaching them will prove more of a challenge – as will selecting 100 people from across Europe. Even

translation into the chosen languages poses problems when, for example, there just isn't a term for "randomisation" in some languages.

The audience learned why ethical oversight and transparency are fundamental to the EUPATI project and how these concepts are applied in practice. So-called "soft" communications skills are also crucial if partnerships between patients, researchers, industry and regulators are to be as fruitful as possible.

Sustainability is an overarching concern. The project is funded by the European Commission's Innovative Medicines Initiative, but only to January 2017. By then the European Patients' Academy must have established sufficient roots to carry on, along with ways of ensuring that the courses and information it offers continue to be relevant and up-to-date. But going by the conference in Rome, that seems to be a challenge that many will relish.

3. The Innovative Medicines Initiative

Michel Goldman, Executive Director, Innovative Medicines Initiative (IMI)

Michel Goldman got straight to the point of the conference: "More than ever the patients are really the focus of most of our activity," he said of the IMI. He added that the meeting was "really timely", not just in relation to preparations for Horizon 2020, the European Union's successor to the Framework Projects, but also because now is an important time to consider the patient perspective in drug development.

Healthcare budgets are coming under increasing pressure, noted Goldman. Will solidarity be sustainable? So it is more than ever "critical to revisit the whole process of drug development and the conditions of patient access to innovative drugs". For Goldman there is one core concept: collaboration. "It is clear that talking about collaboration, all stakeholders must recognise that patients must be the focus. Patients – and carers – should play a much more active role in the definition of priorities and the assessment of benefits and potential side effects," he said.

After giving delegates a glimpse of the breadth and depth of the IMI's activities, he emphasised the role of his team as a neutral, trusted partner – an "honest broker". All partners need to know there is a body than can help, catalyse and enable projects to deliver, he said. The IMI provides a forum "where the dialogue between patients, regulators, payers, industry and academia can be organised in the right way".

Two examples highlighted the role that patients can and should play. One is an IMI consortium developing tools to measure patient outcomes in chronic obstructive pulmonary disease, or COPD. One strength of the tools is precisely that they are simple: patients themselves report their symptoms via a smartphone through a standard questionnaire, and measure their own physical activities through dedicated tools.

Another is the PROTECT consortium, coordinated by the European Medicines Agency (EMA), which is already delivering important tools to assess the risk–benefit of drugs. Goldman talked about how the consortium had developed a new method for assessing the value of a drug used in multiple sclerosis that was removed from the market because of a very rare side effect. It is now back on the market – because patients wanted it and consciously decided to take the risk of the side effects. There are now tools to identify patients who might develop rare complications. Tools like this might accelerate safer access of patients to potentially beneficial drugs, said Goldman.

4. Patients' Involvement in the Medicines R&D Process in 2020

Vision – here we are, and where we want to be in 2020: Nicola Bedlington, European Patients' Forum

It is clear that there is a "window of opportunity" for patients and their organisations to become fully involved in the development of new medicines, said Nicola Bedlington. Innovation is already transforming the lives of patients with serious lifelong conditions, but much more can be done. With long-term pressures on health budgets across Europe, patient involvement offers the best chance of reaching the right solutions in a cost-effective manner.

Patients, said Bedlington, have a key role to play. They are best placed to identify unmet needs, optimise the design of clinical trials and measure improvements in their quality of life. They know what value really means.

The challenge is that patient involvement on the scale needed will require "a huge number of really qualified patient experts that can work with all stakeholders involved alongside the research process", said Bedlington. The task is made more difficult by the poor public image of medical research.

The greatest progress seems to have been made at the European level. The European Medicines Agency is providing an "excellent model" in involving patients, said Bedlington, and the patient perspective has been "reasonably successful" at the European level through bodies such as the Pharmaceutical Forum. But that involvement is often "woefully lacking" in a national context – "often where it happens at all it happens by accident."

But the scale of the challenge is daunting, with 5,000 clinical studies started in Europe each year, a quarter of them multinational studies. "So we need lots of advocates," she said. "Patients want a seat at the table. More and more we are enabling patients to be at the table. But the risk is that there may be empty seats. That's why EUPATI is so important."

EUPATI aims to effect a paradigm shift in empowering patients in the development of new medicines. "We will disseminate objective, credible, correct knowledge about medicines R&D," said Bedlington, and shift the environment towards "meaningful patient involvement in R&D".

To enable this, by 2017 EUPATI aims to have created a robust platform complete with training materials, crucially in multiple languages, to have good practice guidelines not only established but in use, and to have developed an extensive network of patient experts through EUPATI's training courses. On the country level, EUPATI's National Platforms in 12 countries will be bringing together academia, industry and patients.

All this will be rounded off by a strong sustainability strategy to move things forward. "We need to make sure that EUPATI is well placed to benefit from Horizon 2020 [the planned successor to the European Union's Framework Research Projects]," said Bedlington.

But almost as soon as you define what's happening, it changes. "Is there not a danger that soon the tools will be outdated?" asked Hildrun Sundseth from the European Institute of Women's Health. EUPATI, said Bedlington, wouldn't take a static approach to knowledge: "That's why sustainability is so important". And for Michel Goldman, the priority now is "to apply the knowledge which is there for the benefit of patients" – and for that it is "critically important to empower patients".

Following those visionary presentations about EUPATI, best practice examples from outside of EUPATI were presented where patient involvement in medicines research is already reality today.

Best practice: The DAWN2 Study, Denmark – Søren Skovlund, Patient Research and Engagement, Novo Nordisk, Denmark

The DAWN2 study, a long-standing initiative going back over 10 years, is one of the biggest studies on patients' needs in type 2 diabetes. It is also notable for the extent of patient involvement in the project, as Søren Skovlund explained.

"First of all, patient involvement creates value for everyone," said Skovlund. "That also means it is the responsibility of all parties." Patient involvement also takes time – "the long haul" – to deliver its full potential, he said. Sustainable partnerships are much more valuable than fragmented efforts.

So part of EUPATI's task must be to help build the long-term capacities for patient engagement. That requires an organisational approach "that clarifies patient-centricity as a target", he said. Meanwhile, a major challenge in many countries is that patient organisations and involvement are not strong enough. But, he insisted, the solution is not for individual companies simply to engage with patient organisations – rather, it's about facilitating patient organisations to engage with all stakeholders.

The lesson from the DAWN2 study is that it is a "no brainer" that patient involvement is crucial to the development of better medicines. And the reaction from within Novo Nordisk has been "extremely positive", said Skovlund, making people think about how the company might do things differently when designing trials or communicating with patients: "People seek a meaning in their daily life. Knowing your organisation is really dedicated to bringing the field along gives pride and meaning to your work."

Collaboration as best practice: All Together Now! – Filippo Buccella, Parent Project Onlus, Italy

Many parents become involved in research when a child is diagnosed with a rare disease. But then the challenges can seem immense, as Filippo Buccella explained. When his son was diagnosed with Duchenne muscular dystrophy (DMD) in 1992, he was told there was no cure, and little help. "We were lost in a deep blue sea," he said.

So they invented their own "submarine" to help them navigate that sea: Parent Project Onlus, an Italian parents' organisation inspired by Parent Project Muscular Dystrophy, which had been set up earlier in the United States. Meanwhile, the Dutch patient organisation Duchenne Parent Project (also known as Treat-NMD) was created.

In 1997, the Dutch group raised $70,000 to send a young Dutch scientist, Judith van Deutekom, to do research at a top US DMD laboratory. She came back to Leiden University, and her research on RNA modulation, funded by the patient organisation, led to the creation of a spin-off company, Prosensa. That company eventually won €80 million in venture capital funding, followed in 2009 by an agreement with GlaxoSmithKline that committed the giant multinational to paying €680 million in upfront fees and milestone payments.

Meanwhile, back in Italy, Parent Project Onlus had been investing in research at Giulio Cossu's laboratory in Rome since 1998. Cossu had a longstanding interest in muscle cells

and developmental biology, and when in 2006 he identified a novel and promising population of stem cells, big funding followed from Italian regional and national funds as well as non-profit organisations. A clinical trial of the therapy began in 2011.

To make these advances, parents' organisations have had to develop a broad range of skills. They have adopted a team approach, understanding that patients, clinicians, researchers and industry need to be "side by side". They have learnt to attract seed capital, build patient registries, fund research, raise awareness and knock on every door. You need to take your chances in rare diseases, said Bucella. "It's the wild, wild west – and we were lucky indeed." But, he added, if the EUPATI initiative had been around when they started, it would all have been very much easier.

Abstract presentation: The EATG's European Community Advisory Board – David Haerry, European AIDS Treatment Group (EATG)

David Haerry took the conference through the history of the EATG's European Community Advisory Boards (E-CAB), set up 15 years ago. At the time the EATG had been in existence for five years and was already interacting with stakeholders – but frustrated with progress.

Each time there was a new trial, it set up a new advisory board. Then the EATG changed tack, and set up a standing community advisory board. "Industry pays a fee to meet us," said Haerry. The EATG negotiates the agenda, discusses the pipeline, and gives input on the design of clinical trials from phase II to phase IV.

Does it work? Certainly, the E-CAB model is still seen as useful and meaningful. And unlike the early years, activists are no longer dying: "We have survived." Along with that survival comes a storehouse of knowledge and commitment. His suggestion: that the EATG's European Community Advisory Board is a model that could be transferred to other patient organisations.

First, though, these organisations will need to map and monitor members' skills and knowledge. Then they will need a training programme – the EATG wants to have a "school of excellence" for AIDS patients. And experience suggests that they will need proactively to recruit members with specific skills.

Abstract presentation: Young people's involvement in medicines R&D – Jennifer Newman, National Institute for Health Research, Medicines for Children Research Network, UK

Adults should not assume that they know what young people want. But how do you involve young people in the research process? Jennifer Newman, who runs the UK's Medicines for Children Research Network, explained how it works.

The network currently has 90 young people aged from 8 to 18, most of them consumers of healthcare, advising it. As one of those young people put it, "To make research in young people for young people, you should involve young people and listen to what we want." That means working hard on making information understandable – and avoiding 20-page informed consent documents. In fact, said Newman, parents faced with information overload often prefer to read the children's version themselves.

The young people are not just involved in the design of clinical trial information, but also in observational studies, ethical guidance, training and education, and outreach and awareness

in the community. The network is also working with industry, although Newman admitted it had taken "quite a few years to get that partnership built". But now, she said, pharmaceutical companies are approaching the group to get support from the network's young people.

Bring to life with EUPATI examples: Jan Geissler, Director, EUPATI

Given the vision and the opportunities, how is EUPATI going about its task? Jan Geissler took delegates through the organisation and ethos of the European Patients' Academy.

It is, said Geissler, a project close to all our hearts, something patient advocates had hoped to do for many years. Now we can actually do it. But along with the window of opportunity, there are still challenges. First and foremost there are many "empty seats" – opportunities for patient involvement but insufficient numbers of trained and confident patients to take advantage of them. It has also been a "hard learning curve for all of us" to engage with all the different stakeholders on research, which all collaborate with EUPATI today.

Public opinion remains to be changed. EUPATI needs to work with policy makers, not least because "when they introduce regulations they don't always do us a favour even though they intend to speak in our interests". Health Technology Assessment is a thorny area: Geissler detected patient involvement in the UK, "but patients really had to fight for becoming part of the team". So the project is and has to be about partnership and participation, hand in hand.

The key concept is the "pyramid". At the top there will by 2017 be 100 "expert" patient advocates, trained and certificated; a further 12,000 patient advocates educated via the online modules and different types of educational material that will make up EUPATI's Educational Toolbox; and at the foot of the pyramid perhaps 100,000 individual patients who have taken advantage of the public Internet library that EUPATI is establishing on the medicines development process.

EUPATI itself is a consortium including four leading European patient organisations and strong input from academia, research organisations, NGOs and companies, all underpinned by funding from the Innovative Medicines Initiative. Geissler acknowledged that as a public–private partnership EUPATI is open to the criticism that it is working with the pharmaceutical sector. But he stressed that EUPATI is not talking about particular products. And EUPATI has built advisory bodies including regulators as well as experts on ethics and evidence-based medicine, to ensure independence and good governance. "We want to be challenged in how we implement things," he said. Among other aspects, all members of the consortium must declare their interests publicly.

The project is being brought to life by work packages on the one hand, and National Platforms on the other. Seven work packages handle the various aspects of EUPATI's work, beginning with Work Package 1 on coordination and communication, and ending with Work Package 7 on sustainability (for a full breakdown, see the conference slides on www.patientsacademy.eu).

The National Platforms are crucial, said Geissler: "We cannot do what we have to without your knowledge at the national level." Their role is: to ensure that EUPATI understands educational needs on a national level when developing content; to disseminate material on the national level; to raise public interest about EUPATI and patient involvement generally; and to identify training faculty, logistics and financial support on the national level.

Open discussion on how to achieve the vision

The first question concerned definitions: Is medicines R&D restricted to drugs and clinical trials? What about devices, surgery and radiology? On the one hand, as Michel Goldman from the IMI said, we should be inclusive rather than exclusive; increasingly, the IMI looks at medicines R&D as encompassing all aspects, including patient access. On the other, resources are limited, and Jan Geissler made it clear that for the time being EUPATI's focus will be on how new medicines and treatments are being developed, even though the R&D methodologies covered by EUPATI might be similar for other treatment types.

Other areas, such as devices – raised, for example, by Lynn Van Poelgeest from the World Federation for Incontinent Patients – will need to be addressed in the future, but Geissler would not promise that they would be addressed in this phase of the project. As various people were to say throughout the meeting, resources are limited, and EUPATI has to focus and restrict its spread if it is to get established, while extensions of the scope might come later.

What does patient representation mean? The question goes to the heart of the EUPATI initiative, and delegates took the opportunity to air some of the questions around the issue. The idea that "we are all patients" is a dangerous one, said Michael Emanuel, from the UK National Research Ethics Service. "I have been an asthma patient. But in no way am I a typical patient," he said. "You cannot say that you can represent patients because you are one. You need patient representatives who represent patients."

Hildrun Sundseth warned against restricting patient representation to what she called "professional patients" – more or less full-time representatives – and perhaps losing much of the real-life experience of actual patients.

That is not just a question of training patients in how R&D works, said Søren Skovlund, you also have to ensure they are experts in bringing the patient perspective into the discussion. It is not always a comfortable role, said David Haerry: "You can be grilled on both sides." Geissler agreed that there might be a difference between what academics want patients to understand and what patients want to learn. "That's where EUPATI is so interesting."

You will need expert patients and real-life patients, said Susanna Leto di Priolo, Head of Patient Advocacy and Professional Relations for Novartis in Europe. In her ideal world, there will be EUPATI's core of 100 trained experts to help design clinical trials that are more patient-centric, but supplemented by patients with the relevant disease or condition who can say whether the design really matches "the need and life of the patient".

Both Jack Nunn, from Macmillan Cancer Support UK, and Sundseth raised the issue of carers: it's important not to exclude them. "I have taken patients to mean patients, carers, everyone who is interested in supporting patients," said Sundseth.

Sue Pavitt, from the Leeds Institute of Health Scientists, UK, is one of many who has "gone through the battle" of working with clinicians who initially do not understand the importance of patient and public involvement. She works with carers as well. In palliative care, for example, patients "don't always last for a five-year project". Others mentioned patients with cognitive difficulties, such as those with Alzheimer's disease.

Neil Betteridge, from the European League against Rheumatism, pointed to the importance of governance: "If I represent [patients] badly they can throw me out…It is fantastic that EUPATI is training people, but the question of who is accountable to whom is central."

Pavitt pointed to the importance of mentoring to ensure that patient representative is truly representative. "The way we have set up our academic partnerships with patients is always to have an academic mentor who looks after the patient representative on the clinical trial. We bring the patient in very early and engage with them about what 'hat' we want them to wear."

Peter Singleton from University College London is researching the various types of patient voice – personal, expert, group, etc. – and how they could be involved in different types of research projects. "Grab me and let me know what you are doing," he said. Meanwhile Moira Howie, Director of Global Advocacy for Eli Lilly, said there was a "great opportunity" for EUPATI to show what impact patients and the public actually have on the research process and its outcomes – there is "very little health technology evidence" about this, she said.

Some are clearly impatient to get on with the initiative. "I look at the website and I'm raring to go," said Van Poelgeest. "We want to make a real contribution. That's why we are here. So how do we practically go about it? I hear all the overviews, but I want to know what I can do from my patient advocacy group to bring things forward."

Patience, patience, said Ingrid Klingmann from the European Forum for Good Clinical Practice and co-chair of EUPATI's Work Package 2, charged with building the EUPATI Network. EUPATI needs to get a bit further into year 2 to work out how EUPATI's partners can bring in as much as possible from their perspectives. "We will need you in different areas…One is to provide EUPATI with all the educational material on R&D you have. We want to have your input into our plans. And we will need you in the production of the material because we will need to adapt what we have from a variety of sources…There will be lots of opportunities for all of you." The big challenge for EUPATI is to have a concrete plan to manage all the activities.

5. Building Knowledge and Competences for Patients' Involvement in Medicines R&D

Vision – here we are, and where we want to be in 2020: Ingrid Klingmann, European Forum for Good Clinical Practice

"You've heard a lot about the needs and challenges of partnering," said Ingrid Klingmann. "This second part of the conference is about how to do it." Then she laid down a challenge for everyone: "We need a paradigm shift. We cannot go forward in little steps – we need a cohesive approach to change the landscape."

Klingmann started with the realisation a few years ago in the European Forum for Good Clinical Practice that patients had to be "at the table". The Forum achieved that through a new working party set up with EGAN, the European Genetic Alliances' Network – in particular, she said, with Ysbrand Poortman and Coor Oosterwijk. "It became very clear very early in this working party that the only way to bring this topic to a wider audience is to have more patients with the necessary knowledge about medicines development," she said. From this collaboration emerged the PatientPartner project, which in turn gave birth to EUPATI, the European Patients' Academy.

EUPATI's vision of increasing the number of patients knowledgeable in the development of medicines has three elements: the certificate level course for 100 patient experts; the Toolkit for patient organisation representatives generally (and for journalists, too, "who often lack good, honest information about the drug development process"); and a Wiki-type database,

routinely translated into many languages, for patients and their carers at large interested in how medicines are developed. Klingmann wants to have hundreds of thousands of patients using these resources by 2020, so that EUPATI becomes a recognised brand.

But the Internet is not everything. “It is also very important that we reach out to patients who have difficulties with reading and with Internet access,” said Klingmann. So one of EUPATI’s missions is to find ways of reaching those patients. To do that, the initiative aims to involve journalists. It also wants “ambassadors” who can help to raise awareness nationally and at the European level.

Behind Klingmann’s involvement in EUPATI is an intensely personal story. Experience as a General Practitioner had made her realise that we needed new and better treatments for many diseases, and so she moved into pharmaceutical research. And then she discovered she had advanced breast cancer. “I was in complete emotional turmoil. I had no idea what to do, whether I would survive, whether I would be able to go back to work.” Once her brain was back in gear, she realised how helpful it was for her to be a clinician – “getting back control over my life, being able to discuss therapy options rationally”.

But the big change in Klingmann’s thinking came during a second round of surgery and chemotherapy, when she spent three weeks in hospital. Surrounded by 30 other women who realised she was a doctor and came to her with questions, she realised how privileged she was to know about treatment, trials, risk benefit analysis and so on. When she was a General Practitioner, she recalled, she told her patients what the best treatment was, but could see the information going in one ear and out the other. In the hospital, she too was a patient, and when she sat down with other patients they listened. “All this influenced me when we were looking at what EUPATI could do. Patients believe patients, so we need to enable more patients to really understand the medicines development process,” she said.

Back, then, to Klingmann’s overall vision: that after a successful EUPATI project millions of people will have greater success in regaining control over their own lives because they understand existing and experimental treatment options better.

Best practice: The Plus and Minus Foundation, Bulgaria

Picking up from where Ingrid Klingmann left off, Svilen Konov (Plus and Minus Foundation, EATG) drew some conclusions from the project’s training of more than 1,000 people from the HIV community. Training, he said, works better if provided by a peer: “People feel more comfortable.” The European Advisory Board run by the European Aids Treatment Group, to which Konov belongs, tends to have patient experts who are trained in academia. The foundation avoids training provided by the pharmaceutical industry. “People don’t take training from industry as seriously [as academic training]. This has to do with perceptions of ethos,” he said, though adding that he personally did not agree.

Konov’s experience suggests that a variety of means of delivery works best. Some courses start from scratch. Others involve testing and follow-up. “We do an in-depth needs assessment and face-to-face teaching,” he said, with an electronic component in the follow-up. But perhaps worryingly for EUPATI’s plans for online training, which makes up a major part of EUPATI's training courses in addition to face-to-face trainings, Konov reported losing many people in webinars. “We don’t establish sufficient contact,” he said.

What do people like in training? Above all, said Konov, hands-on elements, such as illustrating randomisation through tossing coins. People also like case studies and exercises

looking at protocol review, and they like to be able to go through their notes on their own. But Plus and Minus's experience is that Facebook is not a preferred medium for training.

Finally, Konov had a message about language. Multilingual himself, he said the motto has to be go local. Much English terminology simply does not exist in languages such as Russian and Bulgarian, and sometimes you need to introduce or borrow new terms. Bulgarian, he said, had no word for "randomisation" (though after Plus and Minus started its training, it does now!). And different systems of public health mean that, for example, terms such as prevalence and incidence "mean nothing in Russian". Konov also warned against assuming that English is a universally preferred alternative to people's mother tongue – in some parts of Europe, for example, French is better known.

Abstract presentation: Essential principles for training and support for public involvement in research – Lucy Simons, INVOLVE/University of Leeds, United Kingdom

INVOLVE is a national advisory group set up by the UK's National Institute for Health to support greater public involvement in research in the NHS, public health and social care. But as Lucy Simons made clear, along with its interest in learning and development needs for patients and the public, INVOLVE is also looking at what researchers need if they are to help put this all into practice.

The group launched a training resource last year setting out some essential principles. "But we have moved on," said Simons. "We were originally taking an organisational view. Our early thinking is to turn this around." The thinking now is to start with the researchers who are going to be involving the public.

What does this mean? First, said Simons, education needs to be adapted to people's needs. "What does the person have already in terms of skills and experience, what are their gaps, what do they need the information for?" The group is also interested in the quality of learning and development opportunities – basically, whether it is worth people and organisations investing their time in training.

Simons said that INVOLVE had not yet fully developed its thinking about this approach. But two ideas have emerged: co-learning, where patients and members of the public learn alongside researchers and research organisations; and co-construction, where patients and members of the public are in design of information materials.

Abstract presentation: Patients' perceptions of "informed consent" – Elizabeta Zisovska, University Clinic for Gynecology and Obstetrics, Macedonia

The importance of educating both the public and medical students in the R&D process was underlined by Elizabeta Zisovska, reporting to the conference on a survey she had made of mothers delivered in the university clinic in Skopje, the capital of Macedonia.

The survey covered only healthy mothers with healthy babies – a group of women who had no particular worries. "Our idea was to identify the level of understanding of informed consent," said Zisovska. But the results were "very frightening: many had no idea what informed consent means; only 4.6% knew how medicines get to market; and only 5.8% were clear about where patients sit in the process. Her conclusion: patients need to be taught about their rights in the R&D process – for example, whether they wish to take part or not.

Zivoska is currently conducting the same survey amongst her students and "If my students give the same results, we teachers have failed," she said. They have to learn about the whole R&D process "because it is they who will recruit patients to clinical trials". And if her students do yield the same results as the mothers, Zisovska says she will build a special course for them.

Macedonia is one of many countries that have little experience of clinical trials. Only seven trials are registered there, of which four are variations of the same trial from Novo Nordisk. Zisovska hoped that she would be able to develop contacts made at the conference to get more trials under way.

Bring to life with EUPATI examples: Niels Westergaard, BIOPEOPLE, University of Copenhagen, Denmark

The classical view of drug development is an interplay between industry and doctors. "Hopefully EUPATI will create a triangle," said Niels Westergaard, "and try to introduce a paradigm shift." That shift involves patients giving input to industry and clinicians, with the overall goal of getting the right treatment to the right patients at the right time. We are some way from that: today's patients are largely unaware of how to take part in clinical trials, or of translational research, personalised medicine and pharmacoeconomics, leave alone how they might support development in these areas.

So EUPATI's vision is one of education so patients can be active across the full range of the drug development process. That includes: participation in clinical trials, protocol design, informed consent, ethical review, marketing authorisation, assessments of value, and healthcare policy.

When Westergaard talked about a paradigm shift, he was explicit about what it would look like in EUPATI. "What is important and would be a huge change is to get the right information to the right people at the right time in a useful format." So far, so simple. But Westergaard acknowledges that such a statement entails the need to define what is the right information, what is a useful format, what the right time is and who the right people are. EUPATI aims to do this through an iterative and diligent process of consultation and discussion within the consortium, its advisors and what he called EUPATI's "tools" – its Resource Review, focus groups across Europe, and the National Platforms and National Liaison Teams.

Westergaard added further detail about the three levels of training that EUPATI will bring. The certificated course for the 100 patient experts will be divided into six modules covering the medicines development process from A to Z. At the end of it students should be familiar with the language of drug development and be able to understand the guidelines that regulate it. It will be delivered via a combination of e-learning and classroom-style face-to-face teaching, all in English.

The six modules will be: the discovery of medicines and the planning of medicines development; non-clinical testing and pharmaceutical development; exploratory and confirmatory clinical development; clinical trials; regulatory affairs, medicinal product safety, pharmacovigilance and pharmaco-economics; and health technology assessment and the economics of healthcare. Each module will have a number of topic points (37 in the clinical trials section, for example), each linked to specific learning outcomes.

EUPATI's Educational Toolbox, designed for a wider audience of, hopefully, between 10,000 and 12,000 patient representatives, will be strictly an online-based resource (which will allow

access to print-ready material as well). It will be built on the same principles as the certificate course, with the same six modules. “But here it is up to the learner to decide which modules they need,” said Westergaard, and there will be no specific learning outcomes. “It will be up to the person seeking the information to determine whether they feel equipped for their situation,” he said. All material will be available in English, French, German, Spanish, Polish, Russian and Italian.

EUPATI “has not talked much” about the Wiki-style Internet library earmarked for patients and the public generally. “We will move to that soon,” said Westergaard.

Open discussion on how to achieve the vision

There was no shortage of hands going up to contribute from the floor of the conference. The overall tone was one of positive impatience, exemplified by Irmi Gallmeier from Roche Pharma, Germany, who said it was “brilliant” to hear how the project is going. She was “very proud” to see how much work had been done, and agreed that it was important to go ahead, start the project, and add to it once it has started. The National Liaison Teams should be discussing “how we can support EUPATI, rather than endlessly discuss what patient advocacy is”, she said.

So, when do we start? Westergaard responded that the modules will be live next year. The 'table of contents' of 133 topics to be covered has already been finalized, and. more in-depth discussion about the format for training is imminent.

Isabelle Moulon from the European Medicines Agency was also “very happy to see we now have concrete deliverables”. She wanted to know how thinking had developed within EUPATI about who would teach the expert course. Ingrid Klingmann said it is “absolutely clear” that EUPATI will need to develop a group of teachers who can speak lay language. “We need to make sure that we are extremely efficient with our teaching,” she said. To that end, EUPATI will develop a required skill-set for teachers.

The overall question of who will do the teaching is still being worked on, said Westergaard. “We have teachers in the consortium,” he said, “but it’s something we need to discuss further.” If the course is attached to a university, that university would want to be involved, for example, but he didn’t think it was fair to go into details yet.

Likewise, ideas are not yet fixed about how the learning will work at the Toolbox and Library levels. That concerned Moulon. Without learning outcomes or interactive ways of learning, she said, the way people will interpret information “can go very wrong”. So is there a plan to make those training levels more interactive? “We don’t have the details in place yet,” said Westergaard, but he went on to talk about modules with different ways of acquiring knowledge – such as a video or a quiz – and at the end the opportunity to pass some kind of test, “some recognition that you have done a module”.

A potentially thorny question is who the students will be. Westergaard said it would be “surprising” if it were difficult to find 100 patients to be trained as experts. But as Susanna Leto di Priolo from Novartis asked, what if EUPATI finds 200 willing patients? How then will the 100 be chosen? Westergaard confirmed that there will be criteria for the expert course – relating to language skills and pre-existing knowledge, diversity of disease areas and regions – but that those have not yet been defined. (The issue resurfaced in the final session of the conference. Sue Pavitt, from the University of Leeds, UK, wondered then how people would start to form criteria. “In the UK it will be very challenging because we have so many active

patient organisations and individuals," she said, urging caution not to "ostracise people's interests" and stressing the need to manage expectations.)

Others wanted to ensure that wheels were not re-invented. So Moira Howie from Eli Lilly wanted to know how EUPATI is incorporating materials and resources that are already in existence. Westergaard explained that EUPATI had already done a resource review – the results are available on the website – and that with the syllabus in place, the project can be much more specific about asking other organisations for further content relevant to the specific topics.

Along the same lines, Jack Nunn from Macmillan Cancer Support asked whether EUPATI might work with the European Medicines Research Training Network (EMTRAIN), another IMI initiative. Mike Hardman from AstraZeneca, who is involved with that network, confirmed that all five IMI training projects, including EUPATI, work together. The idea is to make them a continuum, so that information available to researchers, for example, is available to all. The five training projects are coordinated, he said, even though different.

Other training initiatives will be valuable, too. For example, Sarah Masefield mentioned a "much simpler" education package from the European Lung Foundation, covering research, policy and working with the media, and designed for patients at all levels and with any condition. Westergaard was keen to talk further with her about exchanging information.

Klingmann's discussion at the start of the session about the importance of peer-to-peer information sharing was greeted with enthusiasm by Paul Arteel from Gamian-Europe. He was also happy to hear Elizabeta Zisovska talking about educating healthcare professionals. All this prompted Arteel to suggest an eighth Work Package – on holistic methodologies. That seemed to strike a chord with Susanna Leto di Priolo, from Novartis, who called for the 2020 vision to incorporate "a bilateral vision of patient education" in which patients also teach healthcare workers. "Patients don't always have to be experts to be involved," she said.

Not for the first (or last) time, the limitations of the project came to the fore. "If your country is not one of the twelve with a National Platform, will there be a possibility to create a liaison team?" asked Lynne Van Poelgeest, who is based in the Netherlands. "We can only support twelve countries," said Jan Geissler. "It's what we are resourced for." But he also called on people to go ahead on their own if they can find the additional resources (indeed, the EUPATI website exists in eight languages already today, having added Hungarian to its "official" seven on initiative of the Hungarian patient community): "Where another country can resource translations and its own network, then that would be good." Coor Oosterwijk added that EUPATI has some specific ideas on working with Netherlands institutes to start some kind of national platform there.

The last word on limitations went to Thomas Szelagowski, from the Federation of Polish Patients. "Look at EUPATI as the first project of its kind in Europe, maybe in the world," he said. "We don't have all the answers. What we want is as many questions as you can ask. They give us a hint of other things that we should think of. But please don't get confused if you don't get an answer!" The answers may be partial, he said, but that's "absolutely normal" for this stage of an organisation.

6. Public Awareness about New Medicines Development in 2020

Vision: Peter O'Donnell, European Voice, Belgium

"I'm just a journalist," said Peter O'Donnell. "I don't specialise in health. But I do know a little bit about communications." And as he pointed out, the discussion for the session was as much about communications as it was about research and health.

Communication, said O'Donnell, is changing "almost out of recognition". We are in the middle of an "earthquake for the media that I work in, and for everyone involved in healthcare communication". His point was simple but powerful. In the past, most technologies made it easier for one person to give information to many other people. Then technology advanced and communication became no longer just "the man at the top addressing everyone else"; everyone has the power to communicate with as many people as they want.

The "big beasts" no longer rule. "The old form of doing things has largely disappeared. It's certainly under attack. Instead, people are talking to one another," he said. "The monopoly on information has started to crumble."

O'Donnell gave some idea of the scale of person-to-person communication: 30 billion comments on Facebook each month. Health is one of the most-discussed topics on the Internet, with some 60 per cent of people looking there first for health-related information.

But, he warned, wider access to knowledge does not automatically mean improved knowledge, or better understanding or trust. "The public can no longer be taken for granted," he said. Those traditionally towards the top – such as doctors or pharmaceutical companies – are not necessarily wrong, nor is everyone else always right: "Healthcare issues are not always solved by a form of democracy." There will, though, be issues of trust "right across the spectrum". Patients, he said, should be "healthily sceptical about all sources of information, including other patients".

And the future? O'Donnell offered a ray of hope: "In the best case scenario there could be some greater alignment, with the leaders of the old order winning back some trust…but a lot of that depends on you. I wish you good luck."

Best practice: Public awareness about new medicines development in 2020: the ECRAN project – Paola Mosconi, Istituto Mario Negri, Italy

ECRAN is a project that has much in common with EUPATI, being designed to impart information to a wide audience about independent, multinational clinical research. It aims to develop a number of tools to communicate key messages about this research, and in the first instance it is aiming at citizens, patients and their organisations, and society at large.

The project is due to end next year, and Paola Mosconi was able to share with conference delegates some of the lessons that had already been learned.

First, patient participation is something that needs to be actively encouraged through programmes of empowerment organised by independent institutions. Anyone involved needs to have access, not only to the scientific evidence, independent information and the clinical research protocols, but also to tools that can help them assess the quality of this evidence.

Mosconi also suggested that we need to explore methods whereby citizens and patients can actively participate in medicines development. These include not just ethics committees, for example, but also tools such as consensus conferences and "citizen's juries". And lastly, the

scientific community needs to overcome the difficulties it seems to have in accepting consumers as what she called "privileged interlocutors".

With ECRAN's focus on the importance of public understanding of the need for multinational clinical trials and of the basic principles that underlie them – coupled with its desire to foster the active involvement of citizens – there is obviously scope for working with other initiatives. Mosconi confirmed that ECRAN is "very interested" to have collaboration with others at the European level.

Abstract presentation. The benefits of benefits: A qualitative study exploring opinions on the inclusion of benefit information about medicines in Patient Information Leaflets – Rebecca Dickinson, University of Leeds, United Kingdom

European legislation requires that medicines be accompanied by written information – but, as Rebecca Dickinson explained, these concentrate on harm information, "which people may find frightening". Some people have suggested that there should also be information about possible benefits of taking the medication, but very little is known about what patients think of this approach.

So she designed leaflets with benefit information, for a curative and a preventative condition, to see whether that had an impact on what people thought. The information was presented in two different forms, one a generalised statement of benefit and the other a statistical likelihood of benefit.

In this research, only a small number of people liked the benefit information; they felt it treated them with respect and helped them to make informed decisions. But for most the numerical information provoked "complex responses", said Dickinson. Some thought it was up to their doctor to provide this information. And some did not understand it. Textual statements were more popular, she said, but failed to help people quantify the potential benefit of the medication. Numerical benefit information, though, proved difficult to understand, and percentages were viewed as "complicated".

For some the provision of benefit information seemed to reduce their confidence in the medication, and they were surprised that the benefits were described as lower than they had expected. And yet the research also uncovered a strong desire for information: "People still want the facts." Dickinson's conclusion: finding ways of effectively communicating benefit without also creating unease is a challenge that needs more research.

Abstract presentation: User testing of an EPAR Summary – Does it meet people's needs? – Rebecca Dickinson, University of Leeds, United Kingdom (presenting on behalf of Prof Theo Raynor, University of Leeds, and Dave Bryant, Luto Research, United Kingdom).

European Public Assessment Report summaries – known as EPARs – are prepared by the European Medicines Agency to inform the public about how the agency assessed the risks and benefits of a medicine before licensing it for use. In the study that Dickinson presented, the researchers had employed standard user testing to assess the readability of an EPAR.

The study involved 40 members of the public, divided into four rounds of testing with 10 each, covering a range of gender, age and educational abilities. Subjects were shown a printed or screen-based version, then tested via a questionnaire on their ability to understand

19 points considered to be crucial. All this against the background that the target for an EPAR is that 90% of readers will understand the points.

So how did the EPAR fare? Not that well, as it turned out. In the first rounds of testing, whether with printed material or on screen, only 6 of the 19 points met the target. The main complaint was that the information was not very clear and not user-friendly. The researchers then redesigned the EPAR, introducing new main headings and sub-headings. The revised summary performed much better, hitting the target for 14 of the 19 points in print and 16 of the 19 on screen, and the qualitative comments were "much more positive".

In discussion, Isabelle Moulon from the EMA conceded that EPARs are "not user tested as such" – but added that all of them are reviewed by patients before being issued. The patients have to come from what the EMA calls "eligible organisations", checked against criteria including whether they represent European patients and are legitimate, accountable and transparent.

In fact, Moulon said, the people behind the EPAR research had shared their conclusions with the EMA a while ago. "We took the opportunity to revise the way we do them," said Moulon. "I am not saying we have taken on board all the remarks, but we have certainly changed the way we do them." Susanna Leto di Priolo noted that EPARs are available on the EMA website in multiple languages – and wanted to know whether the EMA had checked the translations. No, said Moulon: the English text is checked, and it is then translated, but the EMA does not and cannot check those translations.

Later, during the final session, Hildrun Sundseth returned to the issue of the EMA, hailing the agency as "a model of how to interact" – and that's not something that can be created overnight. "Our national agencies don't have that," she said, and patients do not generally have the opportunity to be involved as they are with the EMA. She called for EUPATI's National Platforms to have the target that at least five national medicine agencies should have a dialogue with patient organisations.

Bring to life with EUPATI examples – Barbara Haake,
Die forschenden Pharma-Unternehmen (vfa), Germany

Looking into the future, wondered Barbara Haake, how much of a difference might the tools and knowledge provided through EUPATI make to patient advocates, patient organisations and the general public? Her comprehensive vision summed up EUPATI's ambition not just for its period of funding, which ends in 2017, but into the future.

By 2020, said Haake, the Patients' Academy will have developed and disseminated accessible, well structured and user-friendly information and education on R&D in medicines. Its certificated training for patient experts will be established. Its EUPATI Toolbox for a broader audience of patient representatives will provide a variety of distributable formats, including booklets, leaflets, e-learning, webinars, videos, YouTube, film, cartoons and so on. Its Internet Library for the public – "not just patients but consumers at large, at all literacy levels" – will be the leading Internet library on medicines R&D, available in seven and perhaps more languages, built up by many patient organisations, and all under a Creative Commons licence which allows free re-use and transformation of EUPATI's materials in the context of those that use it.

As a result, by 2020 EUPATI will have built expert capacity by training patient advocates and competences among patients and the public. Patient ambassadors – "famous people

supporting our aims", celebrities from TV and film, and Nobel laureates – might be spreading the message. There will be patient journalists, who will contribute to raising awareness among hard-to-reach patients and the lay public. Patient facilitators and trainers will be using the outcomes of their training in a variety of settings, said Haake.

As the morning's sessions showed, EUPATI will have developed "new and innovative concepts for the involvement of patient experts", best-practice guidelines both for interaction between stakeholders and for patient involvement, and a road map for future collaboration with "highly innovative sectors of industry" and health authorities.

Haake can already see a track record of achievement. EUPATI will have reached out to many patient organisations, as well as to representatives of academia and pharmaceutical companies who will be "proactively supporting" the Patients' Academy. It will have organised many conferences, workshops and meetings on national and international levels. National Liaison Teams are being established in 12 countries, with national representatives from a patient organisation, academia and industry from those regions.

By 2020 the National Platforms – "in at least 12 countries" will be raising awareness and public interest right across Europe. They will be fostering contact with national patient organisations, collecting nationally available information, translating material, and using and adapting EUPATI's IT platform to spread the word nationally. The National Platforms will also be identifying training faculties, originating stories in national media, and identifying how best to raise awareness in their own countries. And they will be looking forwards, identifying future topics of national interest as well as ensuring they are self-sustainable.

With all this activity, EUPATI will have helped to balance public scepticism about the value of medicines research, built up public confidence through better understanding of the R&D process and improved the image of research in the population at large. EUPATI, meanwhile, will be accepted as a trustworthy source of information – "an established, effective, transparent and credible partnership of all involved in R&D". It will have created an "exceptional learning experience for academia and industry representatives to work with patient organisations". It will, said Haake, be seen as a role model for other environments.

Finally, by 2020 the network will have transformed itself. Via its digital platforms, including social media, it will have expanded from a few centres of activity to a highly interconnected hive of interaction.

Open discussion on how to achieve the vision.

Not everyone was completely comfortable with the vision of a public no longer sceptical about the value of research. "I need to express some slight negativity in order to encourage us to think creatively," said Robert Johnstone, from the European Patients' Forum. "Many of my friends are resistant to the idea of pharmaceutical research and how it is presented to doctors." We should not think that the only thing wrong in medicines development is that patients have not been involved, he said. "We cannot pretend those mistakes haven't been made. We have to acknowledge them and work to do better in the future." There is a huge benefit in most pharmaceutical research, said Johnstone, but he noted "underlying uncertainty from the mistakes made in the past". The remedy is not just patient involvement but measures such as the full disclosure of trial results and full transparency on risks and benefits, as well as information about complementary therapies.

The session's two co-chairs, Matthias Gottwald from Bayer Pharma, Germany, and Kim Wever, from the European Genetic Alliance Network (EGAN), responded positively. Gottwald referred to a "broad acceptance in pharma that many aspects have not been optimal", while Wever called on anyone with concerns to start the dialogue with EUPATI to make sure it gets things right."

Along the same lines, Jack Nunn from Macmillan Cancer Support, UK, said that scepticism, even cynicism, can be healthy. Some of the scepticism in working with pharmaceutical companies – or any company with a shareholder – is the thought that primary motivation is the interest of the shareholder. "I encourage EUPATI to be absolutely transparent about its interactions," he said. Then, perhaps, some of the cynicism or scepticism might disappear.

Ingrid Klingmann agreed absolutely. "One of the big problems we have is that we are tapping into an area where a lot has happened in the past," she said. "We have spent a lot of time on figuring out the safest way to give this project a chance, and one fundamental principle is that this is a patient-led project." All its Work Packages are led by people from not-for-profit sectors. As for transparency, EUPATI requires everyone involved in the project to file a declaration of interest, which can be viewed on the website.

Jane Lamprill, a paediatric research advisor from the UK, saw in company shareholders a potential opportunity. She said she had just come from the first conference of the International Rare Diseases Research Consortium in Dublin. People need to work together, she said, and one idea mooted in Dublin was to utilise the expertise and position of shareholders who may have a child with a disability.

7. Closing Discussion: Achieving Goals

Kay Warner from GlaxoSmithKline, co-chairing the conference's final session with Nicola Bedlington of the European Patients' Forum, referred delegates to the conference's stated aims: that by the end of the day each delegate will have understood the value of the courses, materials and information currently being developed by EUPATI; will see how these different resources can be applied to shape the future of medicines development; and have influenced and informed the EUPATI project.

Summarising, Warner referred to a "clear message" about partnership and collaboration to achieve EUPATI's aims. Yes, there are "empty seats" waiting for patient representatives, but everyone in industry and academia needs to put the chairs there. It is challenging and "not always comfortable" being a patient representative at the table, so soft skills, how we discuss, are as important as the actual content of what we discuss. "We need to work on this," she said.

It is clear, too, that training should be adapted to people's needs, matching the skills that they have and the role they are expected to perform. "We have been challenged today around not only the content but the importance of the method of teaching," said Warner. She noted also the discussion about who the students might be for the patient expert programme, and how they might be chosen: "We are working to define the criteria," she said.

Warner stressed the aim of changing public opinion. EUPATI affirms that patients and carers throughout Europe can influence and drive research. "Patients have unique experience to place in the discussion," said Warner. " We need to get that message out."

Communication has been a key theme throughout the conference, said Warner, and EUPATI aims to "answer the call for improvement" through creating better information on the Internet for patients across Europe, in multiple languages. In this, we have to remember cultural differences and sensitivities. Translation is not always simple: sometimes terms used in English don't exist in other languages, so it is important to avoid making assumptions. Personal communication is important, too: "I hope you have benefited from making new contacts and joining the dots."

"You have told us you are ready to become involved," noted Warner. "We have heard this, and from this event will come other opportunities to be involved."

Nicola Bedlington detected "a big thumbs up" in relation to the work EUPATI is doing. She also drew from the afternoon session the clear message that communication is changing more rapidly than ever before. While this is certainly an earthquake for the media, it also "raises issues of trust for a technology-based democracy".

Referring to EUPATI's ambition for what it wants to achieve in relation to the general public audience, Bedlington acknowledged that "perhaps we haven't unpacked it sufficiently at this meeting" and that it needs more work. But she affirmed that the lay patient is "absolutely critical for us".

Bedlington said that Robert Johnstone had raised "a very important point about being upfront about some of the challenges and history in the relationship with the pharmaceutical industry". That, she said, is why transparency is of critical importance in everything EUPATI does – "And not just what we do…it is about how we communicate that."

Responding to a request from Gillian Ivey, Public and Patient Involvement in Research, Leeds, UK, for feedback from the focus groups that had taken place the previous day, Bedlington outlined the breadth of the surveys that EUPATI is doing to gauge opinion and awareness, including not just focus groups but also a survey of 6,000 people in six countries. Christine Mullan-Jensen, a psychosocial researcher from Novo Nordisk who is deputy leader of Work Package 3 (which is responsible for needs assessment and gap analysis) confirmed that there will be both an interim and a final report on the focus groups. But there would be no resumé at this conference, as the results from all the groups need to be considered together.

Ivey had also said she had heard little about how the proposed training would actually benefit patients. Bedlington stressed that EUPATI was "not by any means a project imposed on patients". The European Patients' Forum and other patient organisations thought long and hard about how to improve patient involvement in R&D, she said.

One issue for the future, raised by Sarah Masefield from the European Lung Foundation, is training for industry and for research funders. "A fundamental point," said Bedlington, noting that the issue had come up also during EUPATI's annual general meeting. Ingrid Klingmann agreed. There is, she said, a great deal happening in relation to educating researchers, for example, about medicines development. "But there is no structured approach towards industry and academia learning from the patient side," she said. "It is something we need to take up."

The last contribution came from Johnstone, a question for further consideration: Even if patient representatives are clearly chosen by patients and their organisations, how representative will they continue to be after training and long exposure to industry? His answer was that the sooner we move away from just training in silos – patients to be patient representatives, doctors by doctors, regulators by regulators, and so on – and the sooner we

move into a community where we are learning together, the more successful we will be. “It’s not what we do and how we do it, it’s how we are perceived to be doing it,” he said.

/ends

Document Title:	EUPATI Conference Rome: „A Vision for 2020“
Document Version:	Final, 30.05.2013
Author:	Peter Wrobel
Status (Draft/Final):	Final

Disclaimer:

The EUPATI project is receiving support from the Innovative Medicines Initiative Joint Undertaking under grant agreement n° 115334, resources of which are composed of financial contribution from the European Union's Seventh Framework Programme (FP7/2007-2013) and EFPIA companies.