EUPATI Workshop 2014:
Reaching a Public Audience on Medicines Development

2 April 2014 - Intercontinental Hotel, Warsaw, Poland

Content

On 2 April 2014, more than 150 representatives from patient organisations, industry, academia and the world of regulation met in Warsaw, Poland, to lay plans for a key part of the EUPATI project – the European Patients' Academy for Therapeutic Innovation. In what is probably the first – and certainly the most ambitious – attempt to broaden understanding among tens of thousands of European patients about the medicines development process, delegates spent a day discussing how best to reach this key audience.

EUPATI, funded by the Innovative Medicines Initiative (IMI), a partnership between the European Commission and the European Federation of Pharmaceutical Industries and Associations (EFPIA), was set up 2012. A team of 30 organisations, led by the European Patients' Forum, it is 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.

The meeting was not a simple conference, said Tomasz Szelagowski, from the Federation of Polish Patients, who welcomed delegates to Warsaw. It was a workshop – "a working event" to inform EUPATI's strategy for equipping European citizens with information and tools to understand how medicines are developed and to encourage them to become more involved in the process.

Joining Tomasz Szelagowski in the welcome was Anna Zawada from Poland's Agency for Health Technology Assessment. She explained that her agency had been set up in 2006, had given its first recommendation in 2007, and in January 2008 had issued its first recommendation to take into account the opinion of patients. "So I guess it means that we from the very beginning were interested in patients' opinions, and we try to do our best to involve them," she said.
Zawada outlined an impressive series of procedures the agency has set in place to involve patients. That, though, was the theory: in practice, she said, patient involvement still has some way to go, and for a variety of reasons. Much information is hidden in public consultations because it is classified as confidential company information. Sometimes patients fail to understand the role of health technology assessment. And although some patients are well prepared, not all of them are.

"I say this not to blame the patients, just to stress that there is long list of tasks for agencies to do," she said. "Patient organisations are an important stakeholder group…we greatly need educated and well informed patients involved in the health technology assessment process."

1. The three audiences

That was the perfect cue for Ingrid Klingmann, from the European Forum for Good Clinical Practice and one of the architects of EUPATI. Introducing the workshop, she said she had realised very early in her career as a clinical researcher that medicines cannot be developed without ethics, nor without patient involvement. "That is why we are in the room," she said. Patients need to be not just involved in the medicines development process – they need to be driving it.

Hence EUPATI, the European Patients' Academy. Its existence is founded on three gaps, she said, from which EUPATI has identified the need to concentrate on three key audiences.
The first is that there are too few patients who know enough about medicines development to be helpful to regulators and companies, to give them the information they need to improve the output of their work. From this comes "Audience 1", a hundred expert patients to be trained by EUPATI to drive the process and be involved at all levels.

The second gap is the shortage of material for patients explaining the medicines development process that is, in Klingmann's words, "truly reliable, objective, up to date and top quality". This is the basis for "Audience 2" – patient organisations that in turn will explain to their communities in more detail what the process involves. EUPATI will provide them with the right material in seven European languages.

The final gap is represented by "Audience 3", the subject of the workshop – the public at large, and more specifically the "health-interested" public.

EUPATI, said Klingmann, has created a unique opportunity to create information for that audience. With some 150 delegates from 25 countries, including 74 from patient organisations, the workshop had been called to find common solutions by bringing together needs from different countries and different stakeholders.

"What we want to do is find out, together with you, in the early stage of planning, what we can, should and must do to get a much better understanding among general public about the medicines development process and their involvement in it," she said. "We are not victims – we have an active role here to improve our chances for better health."

2. What do people actually think?

The workshop proper began with the first public presentation of EUPATI-sponsored research into public knowledge of, and attitudes to, medicines development across Europe. Bella Starling from the University of Manchester and the UK NHS's Central Manchester University Hospitals reported on the largest ever survey of public attitudes towards medicines R&D.
Conducted online, the survey covered six European countries, reaching nearly 7,000 people. It was supplemented by focus groups covering more than 200 people in three countries and at the pan-European level.

Perhaps predictably, the research revealed low levels of knowledge of medicines development across Europe, including about how patients can contribute to the process. Depending on the country and the specific area of medicines development, between 13 and 30 per cent of the online respondents said they felt they knew a fair amount about the subject.

The research also covered what people would like to know more about. The answer was how safe medicines are, followed by personalised medicine, predictive medicine and drug discovery. The topics eliciting the least interest – in all six countries – were regulation and, right at the bottom, pharmacoeconomics. In the middle sat health technology assessment, patients' roles and responsibilities, and clinical trials.

But that is not the whole story: there is also considerable public interest in the area generally, though accompanied by a lack of trust in the authorities and the industry in some countries.
Generally, the public is only likely to be interested in medicines R&D if they have had a family experience of illness. And they are likely to prefer to be informed about medicines R&D by websites or by their family doctor (with television programmes coming third).

When asked not how they wanted to access information, but who they thought would be best to give it to them, the top response across all six countries was the family doctor, followed by patient advocates and university academics. Preferences for the government, family or pharma companies or medical research charities varied greatly across Europe.

The research evidence will help EUPATI as it develops its plans to communicate with the health-interested public. Those plans will be supplemented by suggestions made at the workshop – and by some of the more than 800 live Tweets coming in from outside as the workshop progressed.

Starling outlined the next steps in working out how EUPATI can engage people with medicines R&D to enable them to make informed choices about clinical research. The project will develop high-quality, impartial, honest and trusted information in a variety of formats, delivered via what she called "trusted touch points". The National Liaison Teams will play a key role in "tempting" less interested people to look further. They will also ensure that the material is tailored to individual countries, and to various literacy levels. It is not "public relations", she stressed. Rather, it is about "starting a conversation" to help informed choice and decision-making.

What topics might public engagement with medicines R&D focus on? The research has yielded a number of suggestions. These range from questions about the role of R&D in developing medicines, how long it takes to develop a medicine, who does it and who regulates the process, through to price, access and clinical trials. Social and ethical considerations, though "quite tricky to navigate", can also be an effective way of engaging, said Starling.

She finished with videos showing a lively variety of ways of engaging the public. One video centred on "OK to Ask", a campaign run in the UK on International Clinical Trials day with the basic message that it is OK to ask your health professional about research and what it means to you. The second showed part of a play produced by a theatre company that specialises in working with young people. The last, from Starling's own organisation, featured the Manchester Minute Microlectures, a challenge to the academic and clinical community to talk to a public audience about their work in less than one minute.

That rich variety of forms of patient participation, all relating to projects in the UK, prompted a question from Cees Smit, of the European Genetic Alliance Network. "Is the trick in the UK that the government and the NHS support patient participation?" he asked.

Starling agreed that the UK funds a great deal of public and patient engagement through various bodies, including the Wellcome Trust. But it is not just the result of funding. In part it has evolved in response to a report from the UK House of Lords Science and Technology Committee in 2000, which famously identified a "crisis of trust". But it goes beyond attitudes to research: the level of engagement also reflects a social and cultural shift about patient empowerment in healthcare, and the acceptance of the idea of shared decision-making. "That has helped to make it a fertile ground for patient and public engagement," she said, before adding: "We don't have all the answers, though."

Pedro Montellano from Brussels-based Gamian-Europe, the mental health advocacy network, asked how many in the hall were from the general media. "You have to get the help of the media to disseminate the message," he said. Finding the best way of communicating with the media is on EUPATI's to-do list, said Ingrid Klingmann, though for a number of reasons journalists are not included within EUPATI itself.

Susanna Leto di Priolo, head of patient advocacy for Novartis Oncology Region Europe, said that the 14 companies supporting EUPATI all have communications departments and developed channels to reach the scientific and lay press. "We can help to get journalists to attend and listen."

In a brief discussion about how to maximise the effectiveness of communication, Anastassia Negrouk from the European Organisation for Research and Treatment of Cancer, Belgium, noted from Starling's presentation that good communications requires a number of skills, and people need to learn how to do it. That pointed to the importance of training our own community to communicate.

EUPATI's approach

The focus of discussion now turned towards EUPATI's approach to communications. What does it want to achieve, and how will it achieve it? Tomasz Szelagowski introduced "the man in charge", Jan Geissler, EUPATI's project director, who works for the European Patients' Forum.

Geissler set out to present the framework within which the project operates and the limitations as well. He began by saying that as a cancer survivor for more than 10 years – and still under treatment – he had learned the hard way about the importance of making information more patient-friendly. Even so, neither he nor EUPATI had developed a clear concept about how to inform the health-interested public. That was the job of the workshop. "Workshop means work," he said. "We want to learn from you, because we are still in the phase of the project where we are developing concepts."

The background is that medicine is in the middle of a massive transition, with innovation in a number of fields opening up opportunities for patient involvement. These include personalised medicine and the need for more post-marketing data. "We are being asked as patients what our priorities are," said Geissler, noting a "window of opportunity" for patients to change how things are done.
The trouble is that the requests for patient involvement are outstripping the ability of today's patient advocates to respond. "Do we have enough patient advocates if we are asked to have seats on all these committees?" he asked. "I get lots of requests, and sometimes we just don't have the people."

Hence the core of the EUPATI project: to increase the number of people who understand enough of the process to represent patients. But focus is crucial. "We cannot fix everything," he said.

Geissler ran through the three key audiences that EUPATI is seeking to reach: the 100 patient experts for whom an in-depth, certificated course is being planned (50 applicants will be selected in May, with training starting in September); the Educational Toolbox for 12,000 patient advocates; and the website for the broader health-interested public, produced in seven languages and with a target of 100,000 visitors.

Why a website? Because, said Geissler, that's the digital reality today. As the May 2012 EuroBarometer report on patient involvement showed, everyone in the 15 countries studied had Internet access themselves or could reach the Internet through friends and family. Of course, if EUPATI had a bottomless chest of wealth then it would consider newspaper and TV advertising. "But EUPATI is not yet a consumer brand…we're not Coca-Cola," he said. "So we decided to focus on citizens that have an inherent interest in health. We can't afford to address the whole general public. Our outreach largely depends on grassroots momentum of the patient community."

That, said Geissler, is why National Platforms are extremely important. Here, too, focus was evident. The platforms are being built in 12 countries because "that's what we have budget for", though others will be included if possible.

Content production is in full swing, said Geissler. All the information will be open-source and under a Creative Commons licence, so that any patient (or other) group can integrate it with their own

material. He stressed, though, that all the information will refer to the medicines development process in general, rather than indication- or therapy-specific knowledge.

How will the information be chosen? "We need to get your own experience and learn from your best practice in engaging the lay public – especially those with low literacy." One thing EUPATI has learned, though, is that writing and editing will take longer than translation rather than, as was initially thought, the other way round.

When discussion opened, Šarūnas Narbutas from the Lithuanian cancer organisation Pola was quickly in to back Geissler up over translation. "Whenever information is high-quality and clear, people pick it up," he said. "We are willing to get our own money to translate material into Lithuanian and use it to develop local expert patients." The problem is that among the patient community in central and eastern European countries the capacity to advocate for patients is "not that well developed". His conclusion: Lithuania and countries like it need to plan a series of training events for people interested in health.

Geissler responded that EUPATI "can only do so much", adding that organisations such as Pola should join other pan-European networks, such as the EPF or EURORDIS. "We don't want to duplicate," he said.

Encouragement for Lithuania came from Eibhlin Mulroe, CEO of the multistakeholder platform IPPOSI, Ireland, who is also coordinating EUPATI's National Liaison Teams. "We were in exactly the same place three or four years ago," she said. "Then within IPPOSI we developed training modules, and it didn't cost us much." Acknowledging that the UK is still well ahead of Ireland in this regard, Mulroe said to Narbutas, "We've a lot to learn…we totally understand where you're coming from."

The issue is not restricted to central and eastern Europe. Dimitris Athanasiou, a parents' representative from MDA Hellas Duchenne, Greece, acknowledged that funds are limited. How, he asked, could Greece get some help to build up its own National Liaison Team and start training inside the country? Perhaps, suggested Cees Smit, the Innovative Medicines Initiative's next round could find some money to address these national capacity-building needs. That is certainly a possibility. EUPATI has been too busy delivering the core aims of the project to open talks on the issue, said Geissler, "but we will certainly need to discuss it."

Nicola Bedlington from the European Patients' Forum, Belgium, added that the EPF and its member organisations are interested in exploring both "IMI2", the next stage of the Innovative Medicines Initiative, and Horizon 2020, the European Union's research and innovation programme. Her aim is to ensure a more systematic approach to patient involvement in future projects.

Meanwhile, said Geissler, a survey of 47 IMI projects had been published three weeks before the conference. "It's worth a read," he said, as it lists which IMI projects have involved patients and why (or why not). One conclusion: patient organisations sometimes find it hard to engage with IMI projects because "they are not so interested in the European level". Clearly, country-level activity will be a considerable focus for EUPATI.

3. Examples of good practice

Delegates then split into two groups to look in detail at two examples of good practice in a total of four separate sessions, with each group looking separately at each example. The idea was to be able to go into a little greater detail, and give more time for questions. The chosen examples were European Rare Disease Day and the Swedish medicines information database FASS.

Rare Disease Day

The starting point for this activity, explained EURORDIS Therapeutic Development Director Maria Mavris, was the desire to raise awareness for a large group of rare diseases. The initiative began in 2006 at the Council of National Alliances, EURORDIS's equivalent of the National Liaison Teams, so it was immediately apparent how the example might transfer to EUPATI. The Day targets the general public (and that includes the media), patients and their organisations, policy makers at EU and national level, health professionals and care givers, researchers and academia, and industry.

In fact, so successful has Rare Disease Day become that it has extended well beyond the 33 National Alliances in Europe, and now reaches 80 countries around the world with thousands of events. Along with the National Alliances, there are also Friends of Rare Disease Day – organisations that can support it without any obligation or written agreement and can, for example, download the Day's banner to use on their own websites. These Friends include national competent authorities.

What roles might be transposed to the EUPATI environment? Mavris explained how responsibilities are divided between the central body and the National Alliances. EURORDIS itself chooses the date, the themes and the content, coordinates the Day via its website, and manages its graphic identity with a special logo. It also manages a "Friends of Rare Disease Day" list, provides tools for social media, evaluates the results at the international level, and monitors media coverage.

For their part, the National Alliances coordinate activity in their own countries, update information, link national and local partners to "Friends", adapt common tools to national needs, secure funding for local actions, organise press and media events, and gather data for evaluation. They all share common features, such as a patron, video or written support message, and plans to reach out to researchers.

For EURORDIS the website is the central tool. The organisation uses it to provide an information pack with a logo, standard emails, banners for social media and logos. It also provides an official poster, a press kit and the official video. The website features country pages with local information, plus the facility for patients to upload their own stories, along with photos and videos. This year EURORDIS added another element – a Rare Disease Day Ambassador (Sean Hepburn Ferrer, Audrey Hepburn's son) to spread the message further.

The presentation prompted lively discussion in each group. In one, points raised included the importance of the public and patients "owning" the material, rather than the Day being seen as professionals communicating with the public. In the second group, one key message was how vital the Internet is to spreading the message.

Other forms of communication can work as well, and there was agreement that EUPATI could consider working with doctors and families to offer training and encourage joint working. One suggestion was to approach families in hospital.

Delegates from various countries were able to add their own experiences of the Day. Flóra Raffai from Findacure, UK, said the Day was "massive", with many events for students and young people, and good interactions with museums and universities. Eibhlin Mulroe from IPPOSI, Ireland, talked about the importance of telling the patient story when seeking media coverage: "Their words are far louder than anything we can communicate." (There was one proviso here – patient stories can backfire if they lead to concentration on the cost of treatment.)

FASS – Sweden's drug information database

Ann Maliniak from the Swedish Association of the Pharmaceutical Industry (LIF) explained Sweden's unique system of managing information about medicines. Called FASS, which stands for

Pharmaceutical Specialities in Sweden, it is an online database of company-supplied information on medicines, paid for by industry and freely available to health professionals and the general public. It is, said Maliniak, almost as famous in the country as Volvo or SAAB.

FASS began as a printed book some 50 years ago. At the time, physicians looking for information on a medicine had to remember not only its name but which company produced it, as all the companies had their own catalogues. So in 1966 all the catalogues were assembled into one and it soon became the primary source of information on medicines.
But it was available only to physicians, and the original book weighed a hefty 6 kilograms. Scroll forward to 2001, and FASS became something that patients and the general public could consult when the first website was built. It was relaunched last year, with a new search interface. It is available on smartphones and tablets. Access is important: the information can be spoken, text can be enlarged, there's an online lexicon, and Braille formats can be ordered.
Available 24/7, FASS now has three million visits a month (Sweden has a population of nine million), almost equally divided between the general public and physicians. Other users include ambulance workers and pharmacists. If you enter it as a member of the public and search for a brand name, it serves up the package leaflet. There is a separate portal for health professionals that deliver information in a different, and quicker, format. But there are no restrictions: the general public can use the physicians' portal, and vice versa.

The database is populated by the companies themselves – some 200 of them – with information that has been approved by the authorities. Once a year the database is cleaned and a new set of data is imported from the regulator. That means that FASS has basic information even if the company has not updated its own files.

In May, said Maliniak, FASS will launch short videos about medicines, how they are developed, how they function in the body and how they get to where they deliver the effect. These have been produced by an educational foundation, and are short enough (between 3 and 20 minutes) for web use.

All that was impressive, but it seemed to leave FASS as a website that gives information to patients rather than interacts with them. During discussion, it became apparent that it does somewhat more. The website organisers work with patient organisations, and listen to patients on how the drugs work and interact with disease. Views from patients fed back into the recent website redesign. The site also has its own forum for patient organisations, and helps put patients in contact with them. A Danish delegate (FASS is used in Denmark as well) praised how individual drug pages will link to relevant patient organisations, making it easy to find more help.

Among the possible lessons for EUPATI was that the best way to tackle issues of health literacy was to involve patients in writing the information – in this case, the package information. Another interesting pointer was that pharmacies – which, after all, are frequently visited by the health-interested public – can play an important role in raising awareness among patients of new information sources.

But there were less positive lessons, too. When it came to discussion later in the day, during one of the breakout sessions, some delegates expressed the view that FASS does not fit the EUPATI mission.

There was particular criticism of the impression given that FASS is seen as a government initiative (which in itself does not necessarily mean it is good practice), while in fact it is a public–private partnership funded by industry. That may run counter to the concept of transparency, which is central to EUPATI. In addition, it is not an EU-wide platform, and thus perhaps not a relevant example for EUPATI's content generation. Maliniak apologised if she had not been clear enough that industry produces FASS. "We are transparent, but since there is no advertising the general public may not be aware of that," she said.

One important point – raised in a discussion following the presentation of Rare Disease Day – was that while the examples can inspire, they are both old, with FASS going back 50 years and Rare Disease Day almost two decades. EUPATI needs its own fresh thinking to target new generations and new people.

4. Reports from the three parallel working groups

How to raise interest in medicines development?

Facilitator: Rob Camp, European Patients' Forum (EPF), Belgium
Co-facilitator: Daphnee Pushparajah, UCB, Belgium
Rapporteur: Pim de Boer, Leiden University Medical Center, Netherlands

In this working group delegates were split into a number of tables, given 12 possible topics, and asked to choose the four they thought most important. The answers give an insight into ways in which the public might become further engaged – though, as Pim De Boer reported, some tables discussed *how* rather than *what* to communicate.

First came the idea that "My knowledge is my wellness/wellbeing/health". So knowing about medicines is part of being well. And the "my" might be turned into "our", so generalising a message to everybody.

The second proposal was to use food as a hook: "You care about your food: are you curious about what goes into your medicine?" Delegates saw this as a message for everyone, perhaps mainly for adults but for children, too.

Thirdly, delegates considered the message that "Without you there is no research". Some wondered whether every patient would understand what the statement means. It could, thought delegates, be shared by patient organisations and public bodies.

The fourth point was "Know your drugs". The idea here is to encourage people to visit the forthcoming EUPATI website for reliable and independent information – though delegates recognised that this was not really a solution, more an advertisement for EUPATI.

What were the success factors in this morning's good practice examples, what about your own experience?

Facilitator: Bella Starling, Nowgen, University of Manchester, United Kingdom
Co-facilitator: Eibhlin Mulroe, IPPOSI, Ireland
Rapporteur: Šarūnas Narbutas, Pola, Lithuania

The delegates in this breakout session split into four groups to address insights from the morning sessions, share personal experience and brainstorm keywords for the generation and dissemination of material.

The morning sessions yielded four main areas of focus: identifying the best approach, visual impact, multistakeholder content creation and, last but not least, credibility. In terms of approach, delegates noted the importance of ambassadors, who could be celebrities or well known patients. The right audience needs to be targeted, and delegates here concentrated on three: health professionals, the medical schools that train them, and young people.

Delegates also appreciated the importance of a visually attractive and easily memorable logo, coupled with a positive message, a strong slogan and the use of emotions rather than dispassionate language alone to help deliver a stronger message.

Another lesson was that all parties need to be involved in the design and creation of material, with a grassroots approach. That was seen as the way to make things relevant.

When it comes to credibility, patients are seen as the key. They need to input directly into coverage, for example on TV, and help to develop content. Beyond that, delegates looked forward to the development of "brand EUPATI" as a seal of approval that content has been reviewed and verified.

The results of the keyword brainstorming exercise are in the Appendix.

How to attract people with low literacy?

Facilitator: Kay Warner, GlaxoSmithKline, United Kingdom
Co-facilitator: Gábor Pogány, Hungarian Patient Forum & Hungarian Federation of People with Rare and Congenital Diseases (HUFERDIS), Hungary
Rapporteur: Lynne van Poelgeest, World Federation for Incontinent Patients, Netherlands

The breakout session began with a five-minute video produced by ECRAN, the European Communication on Research Awareness Needs project, which was also played to the whole workshop in the report-back. It was intended as a way of reaching out to people with reduced literacy, and most of the – literate – people in the breakout session liked it.

But there were reservations. Information came too quickly, people thought. Better to give one message at a time, and use repetition to get ideas across. The words were seen as too difficult, the sentences too long and there were too many messages within the graphics. One general comment: "People with reduced literacy don't necessarily have reduced intellect."

One conclusion drawn was that video cannot be the be-all and end-all; it can only be used as a supplement. Patients need to know in advance about the message you are trying to put across. Proper patient involvement requires informed conversations, maybe face-to-face, with sufficient time for discussion. And that can only happen if the healthcare provider is trained in how to give the information.

On the other hand, videos are easy to distribute and can be accessed via various media, including social media – which is the first place young people go for information.

Successful communication, reported Lynn van Poelgeest, had both a personal dimension and the ability to tap into people's motivation. "For most patients it's an emotional journey. You have to be involved."

Cost, or lack of it, is another key factor. "Information needs to be free. As soon as people have to start paying for information they shy away from it," she said, adding, "But it has to be reliable, trustworthy and safe." It would be good to involve patient organisations in videos about clinical trials, she said. "In my own organisation in the Netherlands we discuss all sorts of things other than clinical trials when we come together." So a major task for EUPATI – "but a task we are dedicated to" – is to take the various messages on board and get through to populations with low literacy in the various countries.

Video apart, the breakout group looked at an example from Scotland where readable, easy, user-friendly colour leaflets were produced for a group of disadvantaged patients. The leaflets, reported van Poelgeest, showed the importance and value of patient stories. And taken together with examples from Rare Disease Day, showed just how many tools are actually out there already. Rather than reinventing the wheel, we could use what we have, she said.

5. Lessons learned and next steps

It was left to Nicola Bedlington from the European Patients' Forum to sum up the day's work. EUPATI had, she said, brought together a huge diversity of individuals committed to the project, half of them from patient organisations.

Communications

Bedlington identified communications tools, and the need to explore them, as one theme emerging from the workshop. Social media are used extensively by young people (and in fact 629 Tweets were sent about the workshop during the day). "We need to be open to the possibilities of technology, not fearful," she said, pointing to the EuroBarometer survey of 2012 as further evidence of the value of the Internet.

The trick is not just to get information in an accessible format, but to communicate effectively with patients and the public. "That points us to the need for EUPATI to link up with other capacity-building work to empower patient advocates more generally," she said.

She picked out the comment from Susanna Leto di Priolo of Novartis that companies can really help in engaging with the media –highly relevant to reaching the general health-interested public. All companies in EUPATI have fairly large media departments, said Bedlington, but warned, "This will have to be done with utmost attention to transparency." And she noted the particularly encouraging message from Šarūnas Narbutas, from Lithuania, summarising it as "Don't get too cut up about dissemination. Get the quality right and it will be easier."

Another theme, picked out at the very beginning by Anna Zawada, was the value of patient involvement and public engagement – though these are still more evident in theory than in practice. "We need better methodology," she said. "And that's everyone's business. What's really important from my perspective is that EUPATI has a significant role to play in this."

Turning to Bella Starling's presentation of the results of EUPATI's survey of public interest in medicines R&D, Bedlington noted that interest tends to be greatest in people directly involved in a condition. The survey highlighted the key role of healthcare professionals. "We need to think about how to engage with that community in terms of reaching the public via those stakeholders." The media will be critical in this, she said.

Ethics and engagement

Starling had also raised the fundamental importance of a social and ethical dimension to medicines R&D, and shown how this could and should be used in communications. Bedlington was struck by the example of Manchester Microlectures. "Jan [Geissler] should prepare one on EUPATI!" she said.

There is a link between patient engagement and informed choice, she said. It's a two-way exchange, not just the transmission of information. And even though the survey revealed that knowledge of pharmacoeconomics is low on most people's agendas, perhaps that reflects the fact that most people don't know about it and how important it is.

Expansion

Bedlington noted some emphasis during the day on how to include other countries in a project that is actually focusing on its 12 core countries – Lithuania, but also Greece. "Lithuania clearly has its own plans," she said. "We need to mobilise patients to be really ready for EUPATI when materials become available in Lithuania." Preliminary capacity building could help in this and in other countries.

Sustainability

A constant background to any EUPATI discussion is its future as a project, and how to ensure sustainability and replication. Should that be through a continued European project, or as national projects? "We need to consider that," she said.

Meanwhile, there is the window of opportunity referred to earlier by Jan Geissler. "We have proof of concept with EUPATI. That has to be systematically embedded in IMI2 and Horizon 2020," she said.

Capturing curiosity

Referring to the two examples of good practice, FASS and Rare Disease Day, Bedlington identified some critical success factors: the Internet, a true spirit of collaboration and ownership, strong branding, a strong membership base (companies with FASS, membership with EURORDIS), and adaptation to the national context. She also drew from Rare Disease Day possible opportunities for EUPATI to contribute to countries outside Europe.

The challenge is to capture people's curiosity about medicines R&D, she said. The evidence suggests it is there. "Patients are going to exhibitions about R&D in the UK," she said, saying there were enormous lessons to be learned about the whole approach to patient empowerment.

And that, after all, is the rationale for EUPATI.

6. Appendix: Keywords

A feature of the day, as part of a conscious move to involve as many people as possible, was the generation of keywords or phrases that summarise what delegates were thinking. They are presented here as they were given.

From discussion on Rare Disease Day

Participants were each asked for one word (some expanded this to a phrase) to summarise what EUPATI should do to raise awareness. This is what they said:

Cooperation; Dissemination; Stakeholder Involvement; Mass Media; Patient Story; Information; Communication of Patient Story; Build Trust; Reliable Knowledge; National and Local Relevance; Alignment of Objectives; Stakeholder Involvement (again); Stakeholder Empowerment; Involvement; Patient Stories; Creative Patient Empowerment; Information and Communication; Efficient Management of Collaboration; Crisis in Funding; Involving Physician and GP; Communication with Patient Organisations, Patients, Suppliers of Healthcare and Politicians; Cooperation; Persistence; Sharing Best Practice; International Alignment but Local Action; Relevance; Involve Public; Passion; Creativity; Fantasy (Imagination); Sharing; Show Your Drive and Be Different.

From discussion on FASS

Participants were each asked for a quick reaction to summarise what their reaction to FASS:

Role Model; Balancing Stakeholder Interests; Cooperation; In English (Please!); Paving a Way Forward; Embrace New Technology; Backing from Competent Authority; What Do Public Want, and How Do You Know; Impressive Cooperation; Example of Companies Addressing Patient Needs; Wish I Could Learn More from Sweden; Targeted and Updated Information; Trust; Italy Has Something Similar, but Doesn't Work with Patient Organisations Enough; Inspirational; Needs Propagation; Important for Patients and Doctors; Easy Navigation Essential; In English (Please!) (Again).

From breakout group 1: What makes for good public engagement: content (generation)

Informative/Usable/Simple/Straightforward/Accessible/Concise; Clear/Strong Messages; Factual/Learning; Participatory/Representative; Reliable/Trusted; Evolving/Up-To-Date; Attractive/Interesting; Branded; Positive Message about Involvement; Inspirational/Empowering; Altruistic; Quality; Transparent; Realistic; Not Condescending; Linking/Collaboration.

From breakout group 2: What makes for good public engagement: content (generation)

Solution-oriented; Intergenerational; Targeted; Personal; Localised (vs international/Multicultural; Interactive/Fun/Creative; Doing and Learning While Doing.

/ends

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