



EUPATI National Platform Network AGM Report

29 June 2017, Berlin

On 29 June 2017, the first EUPATI National Platform AGM was held in Berlin, Germany. Fifteen of the 18 established EUPATI National Platforms were represented at the AGM (Norway, Denmark, Austria, Germany, Switzerland, Ireland, UK, Spain, Portugal, Italy, Malta, France, Belgium, Romania, Slovakia). Representatives from upcoming new EUPATI countries (Turkey and Sweden) were also in attendance.

A EUPATI central update was provided in addition to presentations from platform representatives from Germany, Norway, Ireland, Spain and Romania, detailing progress and challenges in their countries. Attendees also discussed in detail how the platforms can and should work together more across Europe. It was noted that all platforms have different legal and organisational structures, so at times cooperation, coordination and communication can be complex.

A workshop was held in the second part of the meeting to discuss how National Platforms can better leverage synergies and overcome challenges by working with ENPs with whom they have the most in common. Geographical groupings were formed and ENP members discussed the most common issues and brainstormed potential solutions to these issues.

What was covered?

- **EPF-EUPATI Strategic Outlook** (Dominik Tomek, EPF Board Member and Member of the Slovakian ENP)
- **Continuing the Momentum: EUPATI Central Update** (Matthew May, EUPATI Programme Coordinator)
- **National Platform Sustainability: Strategic, Financial and Governance** (Derick Mitchell, IPPOSI)
- **National Platform Coordination Update** (Gemma Killeen, EUPATI National Platform Coordinator)
- **Discussion on The Future of ENPs and the ENP Network** (Facilitated by Beatriz Silva-Lima)
- **Countries in Focus.** Presentations from Germany (Jan Geissler), Norway (Amy Mitchell), Ireland (Derick Mitchell), Spain (Sara Perez), Romania (Rozalina Lapadatu).



- **Workshop Session: Regional Groupings.** How can ENPs explore synergies and how to overcome challenges by working together with those in which they have the most in common.

Issues that arose from General Discussion



1. **EUPATI and EPF:** How important is the EUPATI programme to EPF? It is a major priority. At times countries may get the sense that at the national level it is not a priority.
2. **A New Consortium:** Could EPF and EUPATI (+ EUPATI National Platforms) eventually be competitors under a new consortium? Will there be changes to the consortium over time? Especially if there is a new IMI (or related) funding call?
3. **IMI Exploitation Call:** There is a new IMI exploitation call. One potential issue that this call may look at is the sustainability of EUPATI, including the ENP Network, so that year on year we are not raising the question of how to fund/sustain EUPATI.
4. **ENPs and EUPATI Central:** How much are the National Platforms feeling integrated into EUPATI central? While ENPs do feel connected on most levels some do feel excluded from management at a central level e.g. ENPs are the face of EUPATI in their countries yet when individuals do not get accepted to the Expert Patient Training Course they cannot explain the reasoning why.
5. **New Countries:** A clear roadmap is required for new countries along with clear guidelines, terms and conditions.
6. **Quality and Standards:** The EUPATI course is great. If we implement new national courses how do we maintain the same standard of quality across countries?
7. **Accreditation:** Accreditation was discussed at length. Issues for universities include (a) funding (b) how do we keep it up to date (c) who takes ownership and (d) how do you accredit something that is not a Bachelor or Masters course? Italy spoke about using a private accreditation company. Romania noted that we must remember that it's about patients and patients are on a better footing if they have a recognized accreditation. It was noted that no simple solution exists and we need to be realistic in what we can achieve. Ireland noted that for its national course, accreditation was parked as an issue for the pilot but that Universities taking part in the course will provide a certificate of completion for now, with a view to exploring accreditation at a later stage.



Primary Issues for National Platform Regional Groupings

During the workshop session, National Platforms explored synergies and how to overcome challenges by working together with those in which they have the most in common.

Primary Issues/Themes for Regional Groups:

	Group 1	Group 2	Group 3	Group 4	Group 5	Group 6
Themes/Primary Issues for National Platforms	Norway Sweden Denmark	Romania Hungary Slovakia	Belgium France Switzerland (part also in group 6)	UK Ireland	Spain Portugal Italy Malta Turkey	Austria Germany Switzerland (Part also in group 3)
Translation/Languages	x	x	x		x	
Funding			x	x	x	
Engaging Patients and Pharma Companies for Support					x	x
Integrating EUPATI Material		x	x			
Motivation/Structure within the ENP			x		x	
Establishing Future ENP Initiatives			x			
Utilising the Knowledge of the Fellows				x	x	
Launching a Local Education Course					x	x

Group 1: Denmark/Norway/Sweden

Challenges and Solutions:

For this group, the number of different languages used locally has been challenging as these countries attempt to translate the toolbox and make it accessible and comprehensible for the entire population.



By establishing communication plans and talking to other ENP's, these platforms can help each other. Additionally, one suggestion was to get regulatory authority support to back up their various initiatives.

Finally, these platforms want to expand the view and perspective around clinical trials, and one way they suggested doing that is to call them clinical studies as opposed to clinical trials because the process is about more than just the actual trial.

Synergies and Opportunities:

By inviting each other to meetings one platform gets invited to or organises, there will be more shared infrastructure. Additionally, quarterly or half year meetings would bring more collaboration. These platforms also identified that Finland should be added.

Group 2: Romania/Hungary/Slovakia

Challenges and Solutions:

One shared challenge of this group was the variety of languages spoken in the countries. Additionally, Eastern European countries are home to civil society weaknesses. Also, the ENP's are relatively young, so they have had to learn as they grow gradually over the past couple of years. Finally, a lack of understanding on how to translate EUPATI to the national level has led to a lack of clarity on the functions of the ENPs.

To address these challenges, it was recommended that EUPATI establish general guidelines with a mission statement, criteria, standard forms and agreements, etc. so that the national platforms can fit it to their own legislation. Furthermore, the national platforms should play an active role in EUPATI's development in the future. One suggestion was to examine the EURORDIS model for governance because of their high level of organisation on all levels.

Synergies and Opportunities:

Future meetings with more time for interactions and less for presentations would allow synergy to grow. Together, these countries can decide what their main points and objectives are and work to empower the EUPATI executive committee to represent these points in EUPATI Steering Group meetings. In addition to an increase in communication among members of the same regions with similar experiences, personal networks provide an opportunity for more growth.

Group 3: Belgium/France/Switzerland

Challenges and Solutions:

The high number of different languages spoken in this group is a major challenge. This relates to the translation of the toolbox material and the confusing status of these toolboxes. It is unclear which toolboxes are translated, by whom and if they are



complete. Funding to complete the translations and course were a further issue identified. Also, determining actions that the ENPs should do in the future, such as activities and workshops, has been a challenge. Specifically, France identified that it is difficult to keep its team motivated.

The sharing of material, like stakeholder mappings, newsletters, activities, and Belgium's ambitious roadmap, would help guide others and increase motivation. Likewise, more physical and virtual meetings could be organised on a regular basis to keep momentum going.

Synergies and Opportunities:

Because these countries share similar languages, material can be shared in the desired language to spread knowledge. Specifically, cooperation between the Netherlands, France, Switzerland, Belgium and Luxembourg would allow toolbox material and other content to be shared.

Group 4: UK/Ireland

Challenges and Solutions:

One unique challenge of these countries is bringing the high number of fellows together with the pre-existing networks of patient organisations, academia and industry to build networks and get to know each other better. Currently, there are nineteen fellows in the United Kingdom and eleven in Ireland who know each other very well, but have not been embraced by other networks, partly because of the high cost of transportation and the lack of budget. Also, regulatory environments can be different within the devolved nature of the UK (e.g. for Northern Ireland this is problematic). Furthermore, Brexit has given rise to new challenges.

More face to face meetings with fellows and patient organisations would provide knowledge about medicines research and development to the organisations as well as keep the fellows engaged to build a larger network. At this face to face event between patient organisations and fellows, an additional half day was suggested where the fellows could learn about a topic they want more training in like social media, communication skills, how to facilitate groups etc. to engage and continue to educate them. Additionally, centralising and leveraging the financial links would help with funding and collaboration. Currently, the UK National Platform has connections with the British Pharmaceutical Industry Representative Body (ABPI) while IPPOSI has various other links and contacts that can be brought together to potentially sponsor a joint event.

Synergies and Opportunities:

Embracing the skills and knowledge that the fellows have as well as opening events to the larger Anglo-Irish community and platforms will benefit all parties as more



collaboration occurs. More training events, which is a topic of high interest to the fellows, in October and November will further engage the fellows and expand their skill set.

Group 5: Spain/Portugal/Italy/Malta/Turkey

Challenges and Solutions:

For these ENP's, starting the national course is a challenge because of translations. There is confusion on whether they should utilise Lionbridge, because of the high price, and also how to proceed with a translation company in general. An additional challenge is engaging industries; there seems to be interest initially, but when it comes to putting money on the table, it falls through. Likewise, engaging patients is challenging as there is no mandatory way to do it. A lack of communication makes these challenges more difficult. These ENP's attempt to look at what other countries are doing as an example, but do not find this information readily. Additional platforms cited other challenges in their discussions;

- Turkey has found it challenging to gain support from the pharmaceutical companies for the course.
- Malta has had difficulty integrating the original national platform with the fellows and does not have enough awareness or interest to run a course.
- Spain's national platform lacks structure, which has been a challenge as the fellows are not collaborating with the ENP as much as they would like.
- Italy has found it complicated to launch a course, define the role of patient engagement in the health sector and raise industry engagement and support.

Establishing a budget for translations and using local translators could save these platforms money. Also, learning of the example of other countries would be beneficial because their examples would be a guide for other platforms, as well as leverage when talking to other institutions. Norway and the United Kingdom were cited because for these countries, it is mandatory that patients are engaged and involved in publicly-funded research proposals/projects. To keep in contact, these platforms also want to establish a mailing list and set up virtual regional meetings. Finally, it was suggested that EUPATI establish regional groupings and that a representative from each region oversee communication so lots of email isn't sent to everyone.

Synergies and Opportunities:

Setting up a network online to allow platforms to collaborate and share experiences would bring these countries together. Specifically, sharing the Moodle platform will allow other countries to access extra information. Also, each of these platforms are at different levels. If the more advanced platforms share knowledge with the newer ones, they can also hear about the experiences of these other platforms and learn.



Group 6: Austria/Germany/Switzerland

Challenges and Solutions:

Recently, Austria has been challenged because of mobilisation problems. It is difficult to spread the word about their platform and get the patient communities to attend their events and meetings. Also, it is challenging for these platforms to establish an education course. Another challenge is the reoccurring question of “who does it” with regards to the individual platforms and the larger EUPATI programme.

Having meetings at regional events or joint events would allow platforms as well as patients to get together. Specifically, there is a three-country congress taking place in 2018 for clinical research in the German speaking communities that these platforms plan to meet at. Until then, there is a meeting scheduled for September and workshop in October that these platforms will be able to communicate and work together at.

Synergies and Opportunities:

There are many opportunities for synergy because of the similarities between these platforms and the key topics applicable to all, like involvement in ethics committees, setting up research priorities, informed consent and the continuum of patient information. There was a previous effort to combine the material of these platforms that needs to be reinitiated in addition to the platforms working to create new material.

Overall Conclusions:

Challenges:

- Language barriers and the translation of EUPATI content such as the course and toolboxes, was cited as a major challenge by many of the platforms.
- Adapting the larger EUPATI programme to the national level has challenged many of the platforms, and some believe this is because of a lack of communication.
- Generating interest from patients, fellows and pharmaceutical companies was identified as a challenge. As a result, it is difficult for some platforms to run an education course.

Solutions:

- A suggested solution to the identified challenges was creating a budget and exploring new ways to raise funds which could assist with the translation costs that many of the platforms face.
- It was suggested that EUPATI establish a set of guidelines with a mission, standard forms, agreements, etc. as something general that can be molded to fit the legislation of each country.
- Using the EUPATI network to share information would bring platforms together for collaboration and spread knowledge as well as resources. Specifically, using



EUPATI fellows as a resource and keeping them engaged by planning events where they can continue to learn would help generate interest.

Synergies and Opportunities:

- The establishment of regional communities of ENP platforms presents an opportunity for collaboration as they meet to share toolboxes, resources and experiences. These regional platform groups could meet face to face and virtually to communicate with each other.
- The groups could meet as a united force within the larger EUPATI programme to play a greater role in its continuing development.
- Planning more collaborative events to increase communication, which could be done by pooling resources, would increase synergy.

Suggested Follow Up Actions:

Follow Up Actions	Detail
1. Regional Groups	Maintain regional groups and facilitate these groups coming together on a regular to explore opportunities and overcome challenges. Attending meetings + inviting others to attend their events.
2. Meet more regularly	Explore the possibility of ENP's meeting more regularly than once a year.
3. Strengthen relationships	Explore how to build and sustain relationships both within ENP's and outside e.g. Pharma, Academia, Funding Partners.
4. Sharing of Material	Have a central repository for all National Platform related material e.g. Terms of Reference, ENP Statutes etc. open to all ENP's and potential space where ENP's can share useful documentation.
5. National Training Courses	ENPs to consider running national training courses and mini trainings using the EUPATI Starter Kits and by utilising their fellows.