

EUPATI National Platform Network Annual General Meeting Report

20 May 2019, Copenhagen, Denmark



On 20th May 2019, the third EUPATI National Platform (ENP) Annual General Meeting was held in Copenhagen, Denmark. This year, 47 representatives from 23 countries attended the AGM. The number of attendees were in line with the numbers for 2018 (48 attendees in 2018 v 47 attendees in 2019) albeit we had a greater number of countries represented in 2019 (23 countries represented in 2019 v 20 countries represented in 2018), which was wonderful to see.

For the first time, all 19 of the established EUPATI National Platforms were represented (Austria, Belgium, Denmark, France, Finland, Germany, Greece, Ireland, Italy, Luxembourg, Malta, Norway, Poland, Portugal, Romania, Slovakia, Spain, Switzerland, UK) with representatives from upcoming new EUPATI countries (Cyprus, Turkey, Sweden and The Netherlands) also present.



The first part of the ENP AGM provided a EUPATI update at the central and regional level. This was followed by a discussion on how to create a common ENP message. The discussion focused on teasing out what are the roles, goals and added value that an ENP provides. A dedicated workshop was held in latter part of the day to flesh out the discussions around a common ENP message and to develop collateral that could be used to share this common message at the national ENP level. ENP representatives sat in their regional groupings (based on the groups outlined in the EFO-EUPATI project). The first group was asked to create a flyer and/or a poster, the second group was asked to create a set of slides and the third group were asked to develop a short, animated movie.

2019 EUPATI National Platform Network AGM

SESSION 1:

(a) What was covered?

Session 1:

- [EPF-EUPATI Presentation](#) (Marco Greco, EPF President)
- [EUPATI Programme Update](#) (Matthew May, EUPATI Programme Coordinator)
- [National Platform Coordination Update](#) (Gemma Killeen, EUPATI National Platform Coordinator)
- [Update from the Regions](#) (Caroline Whelan, EUPATI, National Platform Officer, Region 1 Leader - Elsa Frazão Mateus, Region 2 Leader - Tamás Bereczky, Region 3 Leader - Derick Mitchell).

Session 2:

- [Discussion: Developing A Common ENP Message](#) (Facilitated by Derick Mitchell, ENP Executive Committee Co-Chair). The purpose of this discussion was to clarify what is (1) the role of an ENP (2) the goal of an ENP and (3) what is the added value that an ENP provides.

Session 3:

- [Workshop Session in Regional Groupings: Creating A Common ENP Message](#)
Task 1: All groups were asked to create a short elevator pitch to outlining (1) the ENP role (2) the ENP goal and (3) the added value that ENPs provide.

Task 2 (Assigned Group):

Each group were then asked to use the elevator pitch they created in task one, to develop the collateral assigned to their group below to attract new members, new funding and new partnerships to their ENP.

- Group 1: Create a flyer and poster (Facilitated by Elsa Frazão Mateus and Stefano Gambardella)
- Group 2: Create a set of slides (Facilitated by Tamás Bereczky & Claas Röhl)



- Group 3: Create a short, animated movie (Facilitated by Derick Mitchell and Roald Nystad)

(b) National Platform Executive Committee and EUPATI Steering Group Representative Elections 2019

At the 2018 AGM it was agreed that the tenure of office for the National Platform Executive Committee and EUPATI Steering Group of 1 year (with the option of 1 year re-election) was too short for meaningful work to be completed by members. Following discussions at the 2018 ENP AGM, a meeting of the ENP Executive Committee members earlier in 2019 and correspondence with the wider ENP Network representatives in May 2019 it was determined that:

- the ENP Executive Committee membership term will move from **a 1 year term with the possibility of a 1 year re-election** to a **3 year term and the possibility of re-election for a further 3 year term**.
- as before, in order to serve a further 3 year term members will have to be re-elected to do so.

The resulting position is that the current ENP Executive Committee and EUPATI Steering Group representatives will remain in place for the next 12 months and the ENP elections will be postponed until April/May 2020.

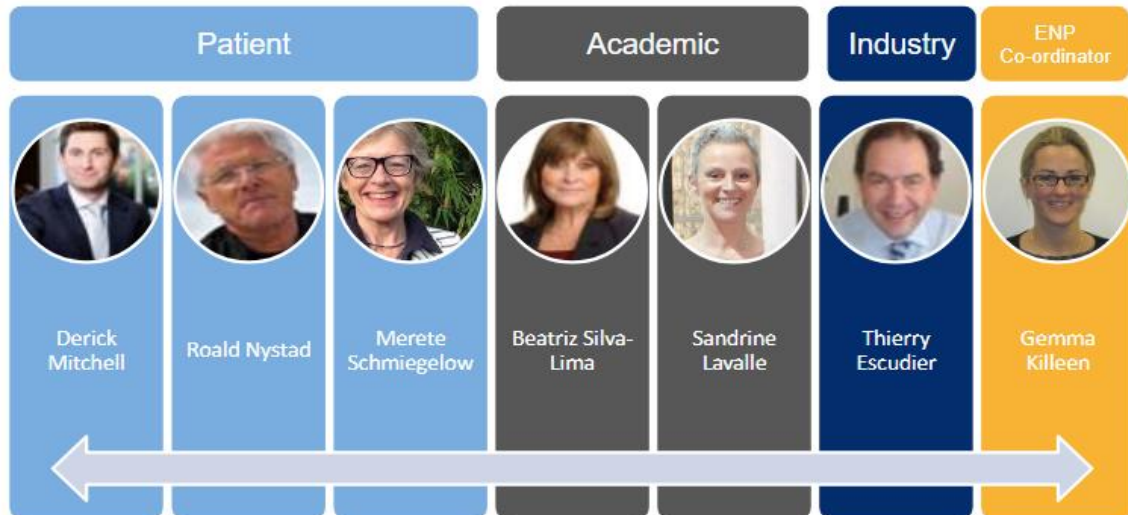
By 2020, the current ENP Executive Committee members Derick Mitchell, Roald Nystad, Thierry Escudier and Beatriz Silva-Lima will all have served a 3 year term. Therefore, next year (2020) they will have the option of rolling off the Executive Committee or running for re-election for a further 3 year term. This will mean that in 2020 there will be 4 places available for nomination – either by the current 4 Executive Committee members seeking a second term or 4 alternative ENP Network Representatives wishing to take a place on the committee.

Sandrine Lavallo and Merete Schmiegelow will only have completed 2 years of their 3 year term in 2020. Therefore, will remain on the committee and have the option to run for re-election in 2021.

This will mean that the ENP Executive Committee is changing on a rolling basis and will ensure stability and sustainability for the future.



Current elected ENP Executive Committee members who will remain in office until May/June 2020:



SESSION 2:

General Discussion on developing a common ENP Message for the ENP Network

As ENPs, we often struggle to articulate what we do, the value we provide and the difference we can make. This can make it difficult to attract and keep members, attract funding or create new partnerships. Indeed, this has been identified as a common thread during the last two ENP AGM's and across all three EFO-EUPATI regional work plans.

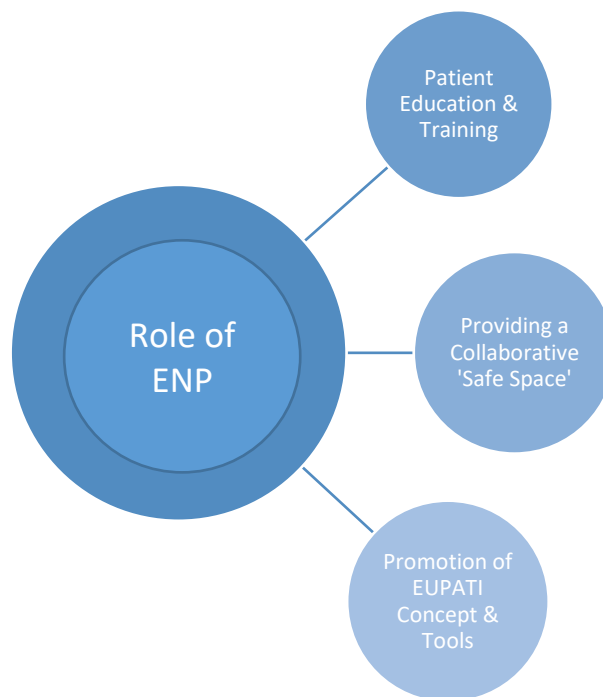
Together as a network we sat down to discuss what is (1) the role of the ENP (2) the goal of the ENP and (3) what is the added value that ENP's provide? How do we pitch ourselves for membership, funding and partnership?

This is what the representatives had to say...



(A) What is the role of the ENP?

Top Themes: Education/Training – Collaboration/'Safe Space' – Promotion of EUPATI



(1) Education/Training

- Training, educating, empowering patient communities.
- Training - to develop skills for patients.
- Education to impart knowledge of medicines R&D, and beyond.
- Develop skills for patients in R&D through training and advocating towards boosting their confidence/empowering them.
- Training patients to be recognized and empowered within national systems.
- Coordinate national level patient education programmes.
- Educating patients on research prioritization.
- Training for patient engagement (in national language and national content).
- Creating competencies.
- Educating to develop the knowledge and skills to be effective patient advocates.



(2) Collaboration/'Safe Space' to Unite Stakeholders

- It is a national platform for patients, industry and academia. The purpose is to bring these 3 strands together.
- Each ENP is a unique forum that provides a safe, neutral, environment that encourages the development of a collaborative mindset.
- Promoting cooperation/collaboration/co-creation/exchange between multiple stakeholders e.g. patient, academia, industry media, government agencies, regulators
- Uniting stakeholders by improving dialogue at the national level towards promoting better R&D with added value in therapeutics.
- Fostering close relationships with patient organisations.
- Providing an infrastructure/platform where dialogue and conversations can take place to bridge European and national level issues.
- Providing a forum/safe space for knowledge, insights and advice exchange for all stakeholders.
- Networking/collaboration and monitoring of national landscapes nationally.
- Point of entry for Patient Engagement
- Develop a community of fellows from diverse backgrounds.
- Networking, collaborating and knowledge exchange.
- Network that initiates projects.
- Host discussions on PE, as a neutral, non-partisan platform between stakeholders.
- Be a forum/safe space for frank exchange/knowledge sharing/advice

(3) Promotion

- To promote the EUPATI concept, ethos and resources.
- To contextualise issues to the local level – information can be too high level at a central EUPATI level or not relevant to the specific local region.
- Increasing the relevance of EUPATI at the national level (e.g. translating and disseminating of EUPATI material, promoting the value of educated patients).
- Monitor national environments and interactions to promote understanding.
- Monitor national issues/developments that will affect patients in that country.
- Maintain strong links to EUPATI central and contribute to central material.
- Raising awareness among stakeholders at the national level on the importance of the patient voice/educated patients.
- Awareness of the need for EUPATI on all sides.

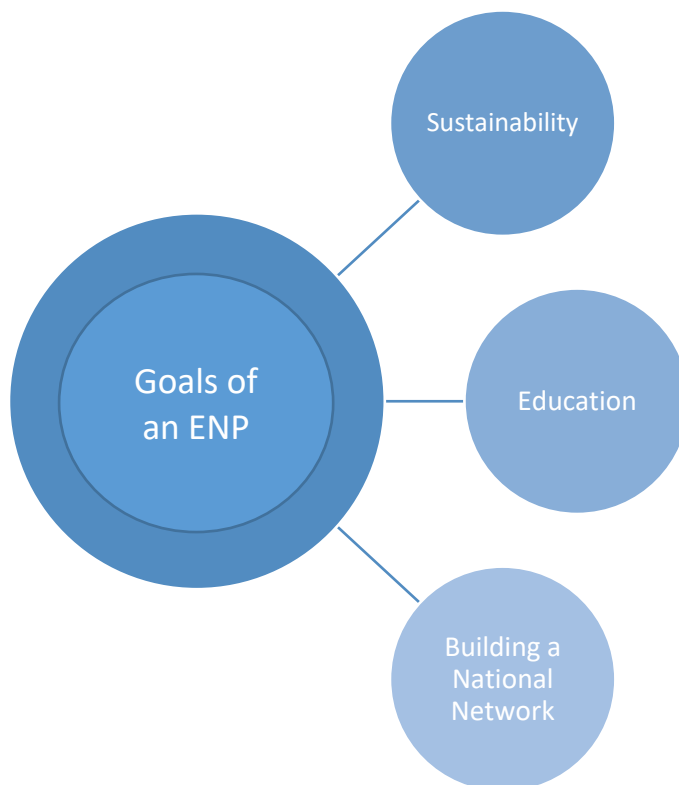


(4) Other:

- **ENP:** **E** for Education & Empowering Patients; **N** for Networking, **P** is for Patient Engagement. Put patients in the centre and discuss why that matters.
- We need to discuss funding – it should be neutral - government v industry funding etc. Government funding is also an interest. True neutrality is funding from all partners.
- **Keywords:** vehicle for education, trust, neutrality, transparency in all aspects of work, reliable, consistent information, knowledge, abilities, respect (mutual),

(B) What are the goals of an ENP?

Top Themes: Sustainability - Education - Network



(1) Sustainability

- Sustainability towards an independent entity.
- Find the right model of ENP sustainability for each country - in one country that might be a volunteer-led ENP, in another country it may mean the establishment of a legal entity.



- How do we make sustainable what we already have?
- To ensure sustainability within the national context, ENPs need to be able to work on a 3-5-year outlook and not a 6 month – 1 year one.
- It may be too much to say that each country must set up a legal entity.
- Each ENP needs to establish its market value in terms of funding and sustainability.
- Defining market value for EUPATI will be an important parallel activity.
- Become the sustainable national platform for R&D education and multi-stakeholder dialogue in your country.

(2) Education

- Education, Education, Education.
- Providing a single point of contact for patient education is key.
- ENP to provide local-level training on specific issues – e.g. mini-trainings in local languages on locally relevant topics.
- Position EUPATI training as THE patient education platform.
- Provide education taking into account national/regional/language variances.
- Contributing to the professionalizing of PE? i.e. contracts, value, etc.
- Provide a structure that maps constantly the environment for patient involvement.
- Become the trusted training environment information provider for up to date information relevant to R&D.
- National approach to patient engagement.
- Setting the standards for patient engagement.
- Remove the competency barriers that prevent patient collaboration in getting the medicines they need.
- Create an open patient orientated and patient integrating environment
- ENP Goals in Education may be:
 - that having educated patients involved in drug development is a normal part of R&D process in their country
 - to become a key opinion leader in a country for patient involvement
 - To generate and support a cohort of empowered patients at the national level
 - To promote the need to educate patients
 - To be the major provider of education for Patient Engagement (all stakeholders) at the national level
 - to make PE an integrated, normalized accepted part of R&D in your country



(3) Build A National Network

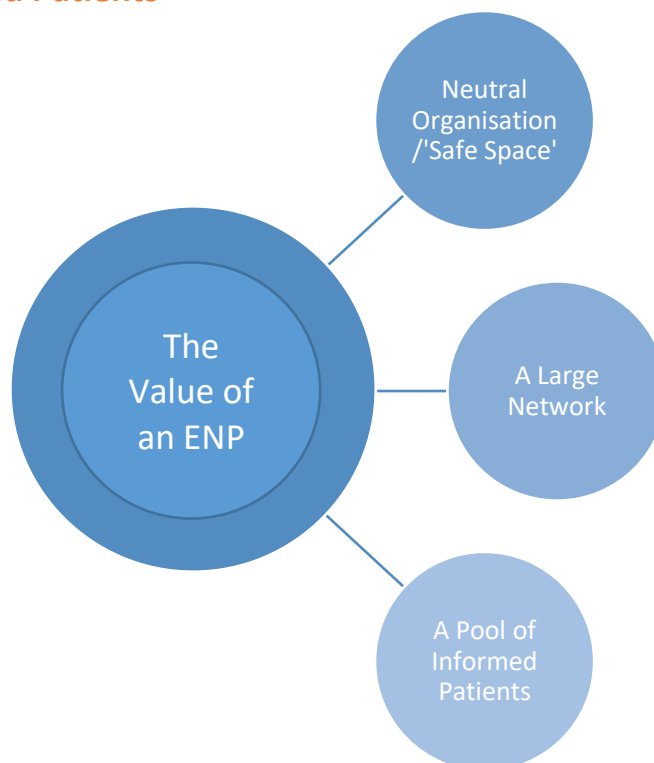
- Building an international network of ENPs.
- A network within which ENPs can easily communicate with EUPATI fellows and national-level graduates across the network.
- Building a multi-stakeholder network at national level
- Create a network of partners to work together and initiate projects at a national level.
- Be a strong network for PE, built on mutual trust.

(4) Other

- Build progress within a country using innovative communications.
- Foster mutual trust between stakeholders.

(C) What value does an ENP provide?

Top Themes: Neutral Organisation/'Safe Space' – Large Network – Pool of Informed Patients



(1) A neutral organisation/'safe space'

- A neutral organisation that which does not focus on specific diseases or promote a particular product. No commercial influence or agenda.



- An ENP is a safe space/forum for knowledge sharing and advice between all stakeholders. 'How things work' or 'what the barriers are' or 'how to change things' in different healthcare and research systems.

(2) A large network

- An international network spans a large number of countries.
- The network provides an opportunity to involve other people & stakeholders. It is a medium for exchange - not just about education but also about introducing people to each other who are in a similar situation.
- This large network promotes the principles of EUPATI at the national level.
- Local knowledge of the environment in which R&D operates.

(3) A pool of informed patients

- Informed and educated patient voices.
- It's a place that facilitates opportunities for patients to get involved or to facilitate further education for patients.

SESSION 3:

Workshop Session: National Platform Regional Groupings

The final session of the AGM was a workshop session. Representatives sat in their EFO-EUPATI regional groupings to work together to complete the tasks below. The workshop session ran for an hour, followed by a group feedback session and plenary discussion.

Task 1: All Groups were asked to create a short elevator pitch to outlining (1) the ENP role (2) the ENP goal and (3) the added value that ENPs provide.

Task 2 (Assigned Group):

Groups were asked to use the elevator pitch created in task one and develop the collateral assigned to their group below to attract new members, new funding and new partnerships to an ENP.

- **Group 1:** Asked to create a flyer and poster (Facilitated by Elsa Frazão Mateus and Stefano Gambardella)
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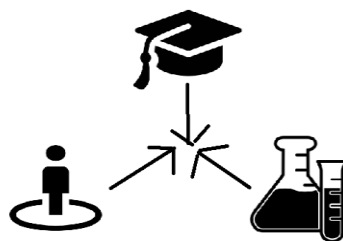


Group 1: Poster/Flyer

Group one spent their time creating a common ENP flyer/poster. The following is what they suggested could be included on the poster:

- Short sentences should be used at all times.
- Describe what EUPATI is/What an ENP is/What the difference is
- Potential Subtitle: Uniting stakeholders in promoting better R&D with added value in therapeutics
 - Uniting relevant stakeholders
 - Exchanging of expertise
 - Improving dialogue at the national level
 - Promoting training and education
- A unique forum, where patient, academia and pharma can collaborate in a safe neutral space.
- *(Note: Instead of forum - a platform of fellows, patients, academia and industry could be used but discussion mentioned that the word 'fellows' might not be understood outside the EUPATI sphere).*

Potential Logo Group 1 Created for Flyer/Poster:



Group 2: Set of PowerPoint Slides

Group 2 were tasked with coming up with a set of slides that ENPs could use to explain what an ENP is, what it does and the value it brings. The following are the items that they felt should be included in such a set of slides. You can find their sample slide set here <https://eupati.box.com/s/g28n2r2zstdyeupcmi2xep1kj8bu9igr>

Slide 1: Explain what EUPATI is and why it is here – Start with a local story – a local problem statement.



Slide 2: Group 2 came up with an acronym. E – Education - Empowering Patients, N – Networking, P – Patient engagement. An ENP should explain why patients need to be put in the centre and why that matters.

Slide 3: Explain what you offer. This should be tailored to the local context e.g. ENP features, ENP outlook, state the ENP has a pool of patient experts, local language, state the offerings of EUPATI. Current offerings of local ENP, point that it belongs to a wider network. What the future holds for your ENP.

Slide 4: Explain the membership – what's in it for your audience to join? Internal and external. What are the benefits for the person you are trying to convince to join?

Slide 5: Explain how to join? What do we want from you? What do we offer in return?

Slide 6: Include any necessary back up slides as an appendix.

Group 3: Animated Movie

Group 3 were tasked with coming up with an animated movie. Some of the ideas they had were as follows:

Video Ideas:

- The primary purpose of the video should be to connect with people
- The video could follow the patient journey along with the journey of other stakeholders.
- Potential Parable – bear, wolf, dog =>sheep
- Potential starting point: The Patient as a change agent
- Educating – to have patients as equal partners, to improve relationships, to improve decision making
- Educating to increase the success of the outcome
- Potentially up to 4 videos/stories (not only videos, but 'journeys'). The same story could be told from different perspectives. Key reasons and value will be different for each of these:
 - Individual patient
 - Patient organisation
 - Industry rep
 - Academic
- Emphasis on increasing standards for changing healthcare environment
- Forward looking towards the horizon with a focus on the patient
- Common goal – patient voices included in medicines R&D decision-making



- Video = the road towards that destination and how patient education can help
- Potential Connection => Complexity:
 - Italy = spaghetti, patients are the parmesan on the top, EUPATI is the chef.
 - Germany = engine, patients voices is the oil that makes the engine run
- Combining national reality with pan-European/international perspectives
- Providing education to make patient engagement happen.

Overall Conclusions

As always, it was very useful for ENPs to meet in person to discuss the opportunities and challenges they have faced over the last year, The AGM provides ENPs the opportunity to talk to each other, solve problems or at least know they are not on their own with the challenges they face.

It is important that the roles, goals and added value that ENPs provide can be articulated by all ENPs. While ENPs will always have their differences at the national level, (due to the inherent political and environmental challenges faced in different countries), nevertheless it helps the ENP Network come together and operate as a cohesive unit if ENPs have the same vision and mission about who they are and what they are trying to achieve.

Regional Group 3 of the EFO-EUPATI project will take the outputs of this meeting and create the collateral which has been started in the workshop session above. These tools – flyer, slides and movie can then be used by all ENPs at the national level.

Maintaining the sustainability of EUPATI and ensuring that individual ENPs become self-sustaining must remain a priority for the ENP network.

2019 Suggested Follow Up Actions:

Follow Up Actions	Detail
1. Clarify the roles, goals and added values of ENPs	Take the outputs of this meeting and create a document setting out the roles, goals and the added value that ENPs provide.
2. Finalise an elevator pitch for ENPs	From point one above, create an elevator pitch for ENPs.
3. Finalise collateral for ENPs to use	Finalise a flyer/poser Finalise a set of slides Finalise an animated video



4. Sustainability

Ensure sustainability remains at priority for ENPs both nationally and at the EUPATI level.