

EUPATI National Platform Strategy



2020 - 2025

Content

No	Section	Page
1	Executive summary	3
2	Section 1 : EUPATI National Platform Governance Structure 2020 - 2025	4
3	Introduction	4
4	Current EUPATI National Platform Governance Structure v Proposed ENP Governance Structure	5
5	EUPATI National Platform Network - Roles and Responsibilities	8
6	EUPATI National Platform Network - Election Process for ENP Positions	10
7	Section 2 : EUPATI National Platform Operating Structure 2020 - 2025	12
8	Introduction	12
9	Purpose of an EUPATI National Platform	13
10	EUPATI National Platform Network – Revised Definition	14
11	EUPATI National Platform Operating Model	14
12	Requirements to become a EUPATI National Platform	16
13	Process of Setting Up a EUPATI National Platform	16
14	Work Planning & Reporting	17
15	EUPATI Central Support for the EUPATI National Platform Network	18
16	Where will the ENP Network be in 5 years' time?	20
17	Section 1: Appendix 1: Timetable for development of Revised ENP Network Governance	22
18	Appendix 2: Expression of interest in standing for election to the EUPATI Board	23
19	Appendix 3: EUPATI Board Elections June - September 2020 Information and Instructions	24
20	Section 2: Appendix 1 – Current list of EUPATI National Platforms (ENPs) Active, Upcoming and Dormant.	31

1. Executive Summary

EUPATI has undergone significant changes in 2020. The EUPATI Foundation has been established in the Netherlands. Revisions have been made to the structure and governance of EUPATI, shaping its organisation, which in turn has led to the development of a new EUPATI National Platform (ENP) 2020 – 2025 strategy.

The ENP Network continues to expand and has gone global with the inclusion of a Japanese ENP. Whilst the number of countries joining the Network grows, the resulting logistical challenges should always be considered to maintain a strong, effective, and representative national platform network.

The vital contribution which ENPs make in advancing the EUPATI mission through their national patient education goals ensure their intrinsic value to the EUPATI Foundation and the sustainability of its achievements. ENPs will continue to be self-sustaining and their role as fully integrated partners of EUPATI will bring the network closer to the central governance of EUPATI.

To ensure the ENP's sustainability, the new EUPATI National Platform Strategy 2020 –2025 outlined in this document will clarify the structure and operating model of the ENP Network. It is divided into two sections: 1) **a review of the current EUPATI National Platform governance structure** and 2) **the development of a future operational strategy for the ENP Network**.

Both the EUPATI National Platform governance structure and the future operating structure are necessary to clarify the structure and operating model of the ENP Network for the future. Additionally, a projection of where the ENP Network will be in 5 years is proposed.

2. EUPATI National Platform Governance Structure

2020-2025

3. Introduction

2020 has seen EUPATI move into a new phase in its development – moving from a project-led initiative launched by the Innovative Medicines Initiative (IMI) and then hosted by the European Patients' Forum (EPF), to the establishment of a new EUPATI Foundation based in the Netherlands.

This organisational change has meant revisions to the structure and governance of EUPATI as well as the development of a new EUPATI strategy (2020-2025). Along with the changes at the central EUPATI level, changes have also taken place at the national level. The ENP Network has continued to expand with an ever-increasing number of countries from Europe and beyond looking to join the Network. An expanding Network naturally brings opportunity - however, it also brings with it many logistical challenges e.g. the resources, coordination and collaboration required to manage a network of 25+ countries, along with the ability to ensure each member country has a 'representative voice' within the Network and the governance and strategic development of EUPATI.

EUPATI continues to recognise the important contribution which ENPs make in advancing national patient education goals and recognises that the ENP Network remains crucial to the sustainability of EUPATI's achievements. The ENP Network continues to expand the dissemination and use of the EUPATI Toolbox and capacity building at the national level as well as facilitating inter-EUPATI National Platform communication and collaboration. In acknowledgement, special efforts will continue to be made to:

- 1) Incorporating ENP representatives at an operational and supervisory level within the new EUPATI Foundation
- 2) Securing resources for the continuation of a part-time National Platform Coordinator

However, the existence of this mechanism does not negate the fact that ENPs will continue to be required to be self-sustaining, identifying and securing their own funding on the national level to support a planned programme of national activities around patient education and patient involvement in medicines R&D.

For 2020 and beyond, a new ENP strategy is required to clarify the structure and operating model of the ENP Network for the future and to move the EUPATI National Platforms towards becoming fully integrated partners of EUPATI.

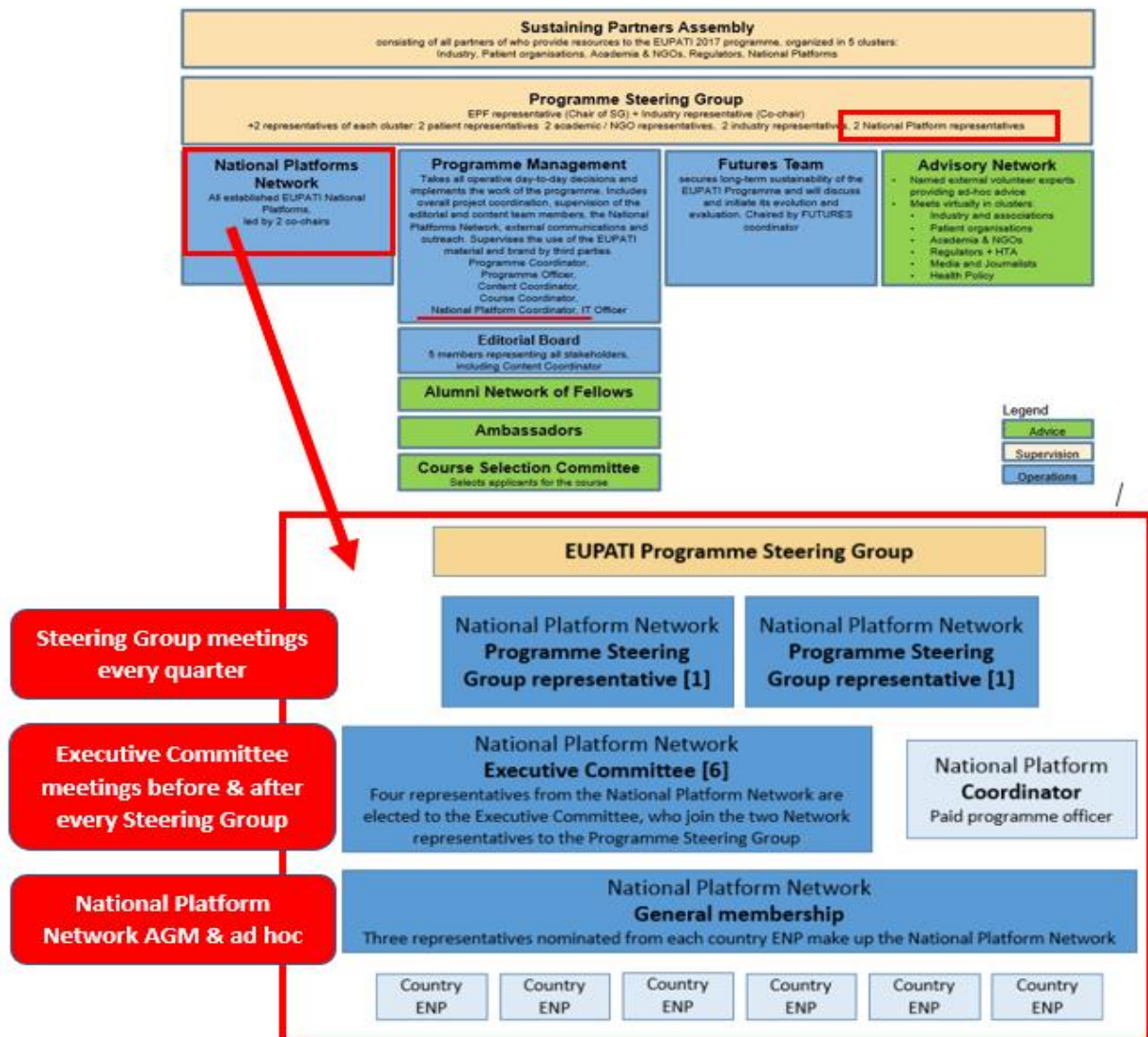
The EUPATI National Platform Strategy 2020 -2025 is divided into two elements (1) The revision of the current governance structure of the EUPATI National Platform

Network (to tie in with the new governance procedures of the EUPATI Foundation) and (2) the development of a new operational strategy for the ENP Network for the coming years.

4. Previous vs New EUPATI National Platform (ENP) Governance Structure

As previously mentioned, the establishment of the EUPATI Foundation has meant changes to the governance structure of EUPATI, and consequently changes to the National Platform Network governance structure. The first figure below outlines the previous National Platform Network governance structure under the EPF-EUPATI programme (2017-2020).

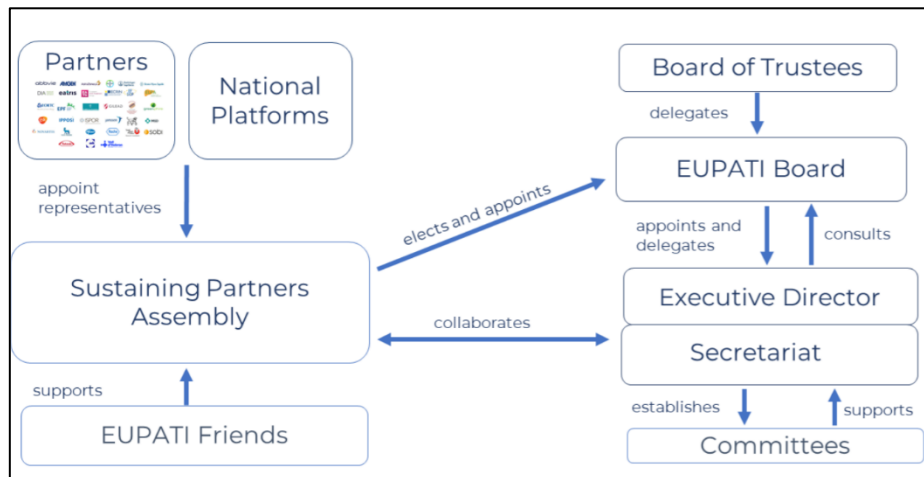
EUPATI Governance Structure Under the Current EPF-EUPATI Programme:



New EUPATI & ENP Network Governance Structure (September 2020)

The new governance structure of the EUPATI Foundation is illustrated in the figure below. The roles and responsibilities of each governance body are defined in the Statutes and Operating Rules of the Foundation. The previous EUPATI Steering Group is replaced by a new EUPATI Board at the establishment of the Foundation. The different clusters (stakeholder groups) of the Sustaining Partners Assembly elect their representatives to the EUPATI Board. The Board Members do not represent their own organisations but their entire stakeholder group. The new EUPATI Board Chair is provided by EPF.

EUPATI Foundation – Governance Structure:

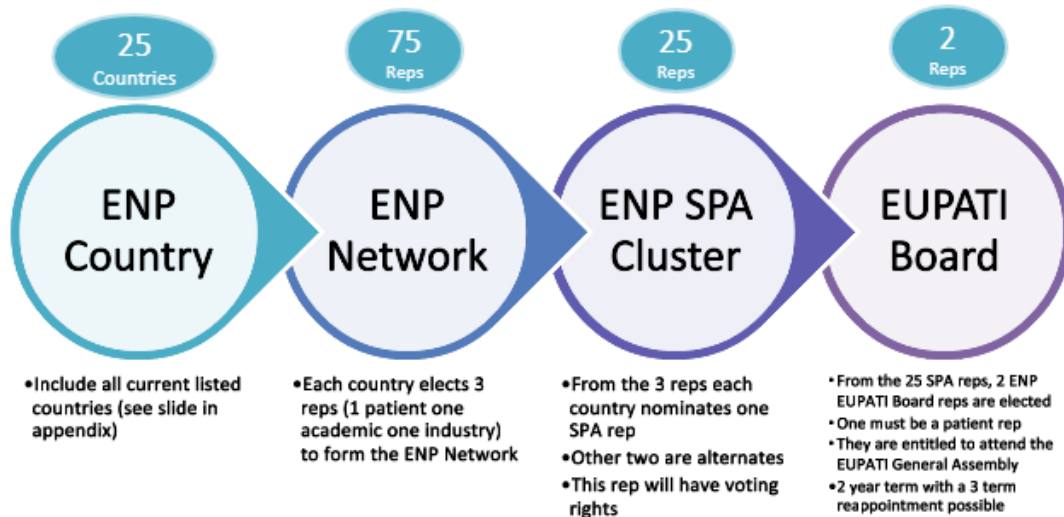


The proposed ENP Network governance structure is also illustrated in the figure below. As before, 3 elected representatives (1 patient, 1 academic and 1 industry representative) from each ENP/country will form the basis of the ENP Network. One representative from these 3 ENP/country representatives will be nominated as the ENP SPA (Sustaining Partners Assembly) Cluster representative (the other two members will remain as alternates).

This ENP SPA Cluster will operate as an expanded ENP Executive Committee to ensure a wider ‘representative voice’ from the ENP Network at the highest levels and to ensure an improved communication flow between EUPATI and the ENP Network.

The ENP SPA representative will have the voting rights for their country and will become part of the EUPATI Sustaining Partners Assembly. From the ENP SPA Cluster, two representatives will be elected to become the ENP representatives to the EUPATI Board (please see below for details of their duties and process of election).

Proposed ENP Governance Structure from September 2020:



What happens the ENP Executive Committee?

2 reps now link in with the other 23 SPA reps into a ENP SPA Cluster (as an expanded ENP Executive Committee)
 6 meetings for the ENP ExCo now becomes the 6 meetings ENP SPA Cluster
 Role of 2 reps needs to be clarified and shared

Differences:

The main differences between the previous ENP Network governance structure and the new ENP Network governance structure are as follows:

1. The 6 member ENP Executive Committee is expanded to a 25 member ENP SPA Cluster.
2. The ENP Executive Committee meetings become ENP SPA meetings (4 times per year).
3. The 2 ENP Board representatives become the ENP Network representatives to the EUPATI Board rather than the EUPATI Steering Group. They are elected by the ENP SPA Cluster.
4. The members of the ENP SPA Cluster will be invited to the EUPATI General Assembly once a year. (It is still envisaged that the entire ENP Network Representatives group will have a separate opportunity to meet once a year whether in person or online to discuss ENP related issues).

5. EUPATI National Platform Network Roles and Responsibilities

ENP Category	Role	Responsibilities
1. ENP Countries	<p>The role of each ENP country is to inspire momentum on patient empowerment and education on medicines R&D at a national level and to represent and replicate EUPATI at the national level.</p>	<p>ENP Countries commit to:</p> <ul style="list-style-type: none"> - Represent the EUPATI model and ethos at the national level - Raise awareness of EUPATI in the respective country among relevant audiences - Identify best ways to implement EUPATI in the country - Recruit members to the ENP and maintain and strengthen the national network
2. ENP Network Representatives	<p>Each ENP will nominate 3 members to form the EUPATI National Platforms Network (1 patient, 1 industry and 1 academic member). This Network is a representative group of all the countries who are part of the ENP Network.</p> <p>The Network representatives will meet annually in person/online and on an ad hoc basis online where necessary. The Network will provide an opportunity for ENP Network representatives to input into the EUPATI programme decision-making structures and to promote inter-ENP communication and cooperation. Each ENP within the Network is entitled to nominate a representative to the ENP SPA Cluster.</p>	<p>Network representatives commit to:</p> <ul style="list-style-type: none"> - attend the annual meeting of the National Platform Network meetings in person/online (where such a meeting is possible). - attend ad hoc National Platform Network meetings by phone/online. - act as the ENP contact point and share regular ENP updates with the ENP Coordinator. - complete actions requested by the ENP Coordinator to the required quality and timeframe. - make proposals to the Network and to the ENP SPA Cluster which reflect the needs of the ENP.

ENP Category	Role	Responsibilities
		<ul style="list-style-type: none"> - circulate ENP SPA Cluster minutes and other public minutes of the EUPATI Board to other ENP members.
<p>3. ENP SPA Cluster Representatives</p>	<p>Under the new EUPATI governance structure the ENP Network will become part of the EUPATI Sustaining Partners Assembly (SPA).</p> <p>Each ENP is entitled to nominate one member from their 3 country representatives to the National Platforms Network to become their ENP SPA representative. (The remaining two members can act as alternates).</p> <p>The current number of ENPs within the ENP is 25. This 25-member group will support the effective management of the Network. The ENP SPA cluster will be an expanded version of the previous ENP Executive Committee and will meet online 4 times a year as requested by the ENP Coordinator.</p>	<p>ENP SPA Cluster members commit to:</p> <ul style="list-style-type: none"> - set the agenda for the ENP portion of the EUPATI Sustaining Partners Assembly. - attend ENP SPA Cluster meetings organised by the ENP Coordinator. - replace ENP Network representatives to the EUPATI board (upon request). - review and advise on practices and policies being tested or adopted by individual ENPs. - prepare written updates from EUPATI Board meetings which relate to ENPs (ENP Coordination to circulate to Network members). - scrutinise proposals received from individual ENPs before forwarding to the EUPATI Board. - prepare proposals to the EUPATI Board which reflect the needs and interests of ENPs. - lead on issues relating to National Platform Network sustainability.
<p>4. ENP Representatives to the EUPATI Board</p>	<p>The EUPATI Board is the governance body which is responsible for the EUPATI programme's strategy and implementation. The Group is</p>	<p>ENP Network representatives to the EUPATI Board commit to:</p> <ul style="list-style-type: none"> - represent the interests of the Network rather than of their individual ENP.

ENP Category	Role	Responsibilities
	co-chaired by a patient and industry representative.	<ul style="list-style-type: none"> - attend EUPATI Board meetings in person/by phone/online. - complete actions requested by the EUPATI Board to the required quality and timeframe. - serve as co-chairs of the ENP SPA Cluster. - attend ENP SPA Cluster, organised by the ENP Coordinator. - recommend proposals agreed by the ENP SPA Cluster to the EUAPTI Board. - circulate the of the EUPATI Board meetings to the ENP Network and ENP SPA Cluster. <p>As members of the EUPATI Board:</p> <ul style="list-style-type: none"> - Safeguard the Foundation’s mission. - Define and supervise organisational values. - Ensure that the Foundation has adequate resources. - Approve EUPATI's policies and procedures. - Approve the Foundation’s budget plan. - Recommend the auditor or auditing company to the Board of Trustees, and supervise that auditing is conducted appropriately by the Secretariat. - Promote the Foundation by serving as a link with members, donors, beneficiaries and other stakeholders.

ENP Category	Role	Responsibilities
		<ul style="list-style-type: none"> - Adopt Advisory or Operational Committees. - Appoint an Executive Director. - Evaluate the performance and remuneration of the Executive Director.

6. EUPATI National Platform Network - Election Process for ENP Positions

(1) EUPATI National Platform Network

Procedures for nominating ENP representatives to the National Platform Network

- Each year, each ENP will nominate three representatives (one patient, academic and industry representative) to join the National Platform Network.
- It is up to each ENP to determine how the 3 representatives are selected.
- Each of these ENP representatives to the National Platform Network are also eligible to become the ENP country SPA Cluster Representative.
- ENPs can also nominate alternates, but these alternates cannot be elected to become the ENP SPA Cluster representative, they only replace a nominated ENP representative.

(2) ENP SPA Cluster Representative

- Each ENP is entitled to nominate one member from their 3 country representatives to the National Platforms Network to become their ENP SPA representative.
- It is up to each ENP to determine how the 3 representatives are selected.
- The remaining two ENP Network representative will act as ENP SPA Cluster alternates.
- The ENP SPA Cluster representatives will represent their ENP for a period of one year (*to be confirmed*) at an annual meeting.

(3) ENP Representatives to the EUPATI Board

- Each ENP SPA Cluster representative is entitled to stand for election as ENP Representative to the EUPATI Board.
- Interest in standing for election should be expressed in writing by the deadline set by the ENP Coordinator. (*NOTE: See Appendix 1 for proposed deadlines and Appendix 2 for template*).

- All written and eligible expressions of interest received by the deadline will be balloted
- Voting will run using an online voting software.
- The two SPA Cluster Network representatives who are eligible and who receive the largest number of votes will be considered the ENP SPA Cluster representative to the EUPATI Board.
- ENP Representatives to the EUPATI Board:
 - o **Duration of appointment:** The Board Members are elected for 1 or 2 years to avoid the changing of the entire Board in 2 years' time. Reappointment of Board Members is permissible for a maximum of three terms.
 - o **Term:**
 - National Platforms Board Member 1 - term 2 years
 - National Platforms Board Member 2 - term 1 year
 - o **Voting:** Each ENP SPA Cluster representative has two votes as there are two seats for the Board roles.
 - o **Alternatives:** No alternates are appointed for any role in the EUPATI Board.
 - o One of the two Network representatives to the EUPATI board must be a patient representative (*NOTE: the patient representatives will be elected in the first instance*).
 - o If an open vote fails to elect one representative from two of the stakeholder groups, the nomination with fewest votes (*from a community with at least one representative nominated*) becomes ineligible and the nominee from the missing stakeholder group with the largest number of votes will become the ENP representative to the EUPATI Board.
 - o Voting remains confidential and open only to EUPATI Secretariat Staff.
- *For additional detail see Appendix 3 EUPATI Board Elections June - September 2020 Information and Instructions*

7. EUPATI National Platform Operating Structure

2020-2025

8. Introduction

As mentioned throughout this document 2020 has witnessed a lot of changes for EUPATI, both centrally in its governance structure as well as its establishment into a new EUPATI Foundation. Subsequently this new EUPATI National Platform Network strategy will accommodate those changes in the governance and operation of EUPATI centrally.

Both the EUPATI National Platform governance structure and the future operating structure of the EUPATI National Platform Network will form this new strategy. The first section of this document clarifies the new ENP governance structure and has resulted in the following changes:

1. Each ENP nominated 1 representative (from their selection of 1 patient, 1 academia and 1 industry representatives) to join the ENP Sustaining Partners Assembly (SPA) Cluster.
2. The ENP SPA Cluster will operate as an expanded ENP Executive Committee to ensure a wider 'representative voice' from the ENP Network. This concept has replaced the previous 6 member ENP Executive Committee.
3. The ENP Executive Committee will now become the ENP SPA meetings (4 times per year).
4. 2 ENP Board Representatives will become the ENP Network representatives to the EUPATI Board instead of the EUPATI Steering group. All Clusters are invited to express an interest in becoming a member of the ENP Network Board.

These above revisions have been made in an effort to ensure a wider representation of the Network. The creation of an ENP SPA Cluster group, instead of a 6-member Executive Committee, naturally incorporates more viewpoints from a wider group which will better represent the ENP Network. This new governance structure also allows the ENP Network to become part of the Sustaining Partners Assembly. These measures hope to bring the Network closer to the central governance of EUPATI and on an executive level rather than a separate network outside of EUPATI.

EUPATI continues to support ENPs as it recognises their important contribution to the EUPATI mission in advancing their national patient education goals. EUPATI central will seek to incorporate ENP representation at an operational level and supervisory level within its new Foundation. It has also secured resources for the continuation of a part-time National Platform Coordinator. Along with the continued efforts to improve the Toolbox and capacity building at a national level, facilitating communication and collaboration within the ENP Network, EUPATI will continue to support the sustainability of ENPs.

The second section of the document will focus on how the ENPs will operate in the future. Additionally, there is a sub-part (part b) to be considered and plan for which asks; where will the ENP Network be in 5 years.

6 main topics have been identified to help clarify how ENPs can operate in the future;

1. Purpose of an ENP
2. Operating Model
3. Requirements to become an ENP
4. Process of setting up an ENP
5. Work planning and reporting
6. EUPATI Central Support for the ENP Network

This section will address the second element of the strategy – the EUPATI National Platform Operating Structure.

9. Purpose of a EUPATI National Platform

The purpose of a EUPATI National Platform is necessary to be defined and agreed upon before an operating plan is constructed. According to the *ENP Network Terms of Reference 2017*, an ENP sets out to accomplish the following:

Goal: A Network of members of the three collaborating groups in the EUPATI project (patients, academic and industry) which come together to meet the following aims:

- o To ensure EUPATI understands the educational needs of patients and the lay public on medicines R&D and other health technologies
- o To disseminate the existing training and education material (and information like newsletters, potentially translated into the local language) that EUPATI develops into the community in the ENP countries,
- o To raise public interest in EUPATI at a national level,
- o To identify training and education faculty, logistics and financial support for national training and education opportunities.

According to the new ENP Governance document, the ENP’s roles and responsibilities include:

ENP Category	Role	Responsibilities
I. ENP Countries	The role of each ENP country is to inspire momentum on patient empowerment and education on medicines R&D at a national level and to represent and replicate EUPATI at the national level.	ENP Countries commit to: <ul style="list-style-type: none"> - Represent the EUPATI model and ethos at the national level - Raise awareness of EUPATI in the respective country among relevant audiences - Identify best ways to implement EUPATI in the country - Recruit members to the ENP and maintain and strengthen the national network

Regarding the below objective:

- o To raise public interest in EUPATI at a national level,

a more specific responsibility of an ENP will be outlined to help achieve this. The extension of this objective will also help to evaluate the interaction between the EUPATI Fellows and graduates from national programmes and their respective local ENP. It would be the responsibility of an ENP to maximise the relationship between the network and the students as well as other stakeholders. In effect, this will help grow the Network and raise awareness for EUPATI.

Therefore, this newly revised definition to an ‘ENP purpose’ will be the following:

- o To raise public interest in EUPATI at a national level – i.e. **this local Network will be the names and faces of those with whom graduates can interact with at a national level post-graduation.**

10. EUPATI National Platform Network – Revised Definition

The newly revised definition would hope to raise awareness and to automatically help build the Network.

Purpose of an ENP is as follows:

- To ensure EUPATI understands the educational needs of patients and the lay public on medicines R&D and other health technologies.
- To disseminate the existing training and education material (and information like newsletters, potentially translated into the local language) that EUPATI develops into the community in the ENP countries.
- To raise public interest in EUPATI at a national level, i.e. this local Network will be the names and faces of those with whom graduates can interact with at a national level post-graduation.
- To identify training and education faculty, logistics and financial support for national training and education opportunities.

11. EUPATI National Platform Operating Model

It is important to outline how an ENP will operate moving forward. An ever-expanding Network although brings opportunity, it can also bring logistical challenges from a central operational point of view. To combat such challenges, the below process will now be in place;

- 1) **Partnership role of EUPATI and ENPs:** A 'light touch' partnership approach has been adopted by EUPATI. A Memorandum of Understanding (MOU) will formalise this approach and the partnership between EUPATI and ENPs. Under the new EUPATI Foundation, it will be necessary for all ENPs to sign an MoU as part of an agreement to establish a new ENP as well as for remaining ENPs.

The following points will also establish the partnership role between EUPATI and ENPs:

- ENPs and EUPATI Central will continue to operate in a **partnership/franchise model** going forward.
- An ENP cannot be authorised without approval by EUPATI Central.
- However once approved, ENPs are entitled to operate under the EUPATI brand, use of the EUPATI trademark and brand name, use of the educational resources, access to the ENP Network and they are entitled become part of the governance of EUPATI via the ENP Network seats on the EUPATI Board.
- Each individual ENP is now recognised as a Sustaining Partner in the EUPATI governance structure via the Sustaining Partners Assembly (SPA).

- There is no financial or in-kind commitment required from ENPs as part of this model.
 - ENPs will continue to operate with a 'light touch' operating model ensuring ENPs operate independently but in collaboration with EUPATI central.
 - The responsibility of success rests with an ENP.
- 2) **ENPs and NLTs:** Each ENP is recognised as a Sustaining Partner and there is no financial commitment required to that.
- An NLT '*National liaison Teams*' was the term used to describe the initial process of becoming an ENP. There is no need to use this term going forward. An initial task force will be the reference for the initial process of setting up an ENP.
 - Once a country is authorised to become an ENP and a Memorandum of Understanding (MOU) is established, they automatically become an ENP.
- 3) **Composition of an ENP:** It is largely the responsibility of each individual ENP to define their structure.
- Each ENP should continue to be made up of initially of 3 main stakeholders – patient, academia & industry (other stakeholders such as regulators etc can also be included additionally).
 - EUPATI will provide an ENP statute template for guidance, but it is the responsibility of each national ENP to decide how an ENP is structured.
- 4) **Central support for ENPs:** It is important to note, however, that ENPs are to remain self-financing and self-resourcing. Support from EUPATI Central will be as follows:
- EUPATI will provide budget support in the form of the ENP Coordinator for 3 days a week (guidance, coordination, etc.) and potentially an annual ENP event.
 - EUPATI will also provide ENPs with the tools and guidance required to set up an ENP. However, the day to day running of the ENP is the responsibility of each ENP in question.
 - ENPs are expected to be self-financing and self-resourcing.
 - Going forward the previously available 'fledgling pot' will cease to exist. However, support may instead be provided via 'project-based' support (in development) – e.g. capacity building, translating of LMS, trainings etc.

12. Requirements to become a EUPATI National Platform

The ENP Network has continued to expand at pace. With limited resources available to manage this growing network, concrete rules must be put in place to clarify the requirements before a country can become established as an ENP.

1. Memorandum of Understanding:

- Going forward every new ENP will require a Memorandum of Understanding (MOU) to be in place before they can be established as an ENP.
- All existing ENPs will need to complete an MOU in retrospect.

2. EUPATI Board Approval:

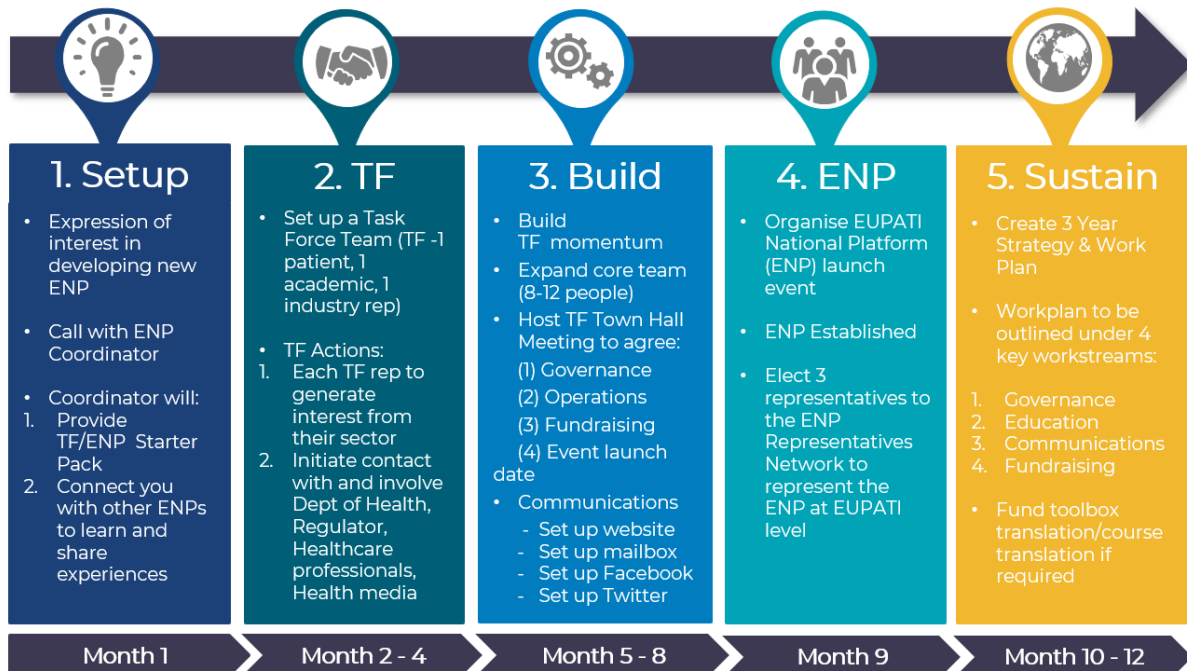
- EUPATI Board approval will be required for any new country who wishes to become an ENP and join the ENP Network.

There is widespread concern that the scale of expansion of the growing Network could jeopardise certain functionalities of the Network. Particular care needs to be taken as the ENP Network continues to grow to ensure the ENPs currently in place are adequately resourced.

13. Process of Setting Up a EUPATI National Platform

The current process of setting up an ENP is shown in the figure below. An indicative timeline has been outlined as an approximate timeframe of how long the process of setting up an ENP might take.

Process of setting up a National Platform:



A few slight adjustments have been made to the original template to accommodate the now obsolete term *'NLT'* with the revised term of *'Task Force'*.

The term *'Cluster'* relates to the 4 groups of the *Sustaining Partners Assembly* that of; the patient, ENPs, Industry and Academia organisations. Each individual ENP country can nominate 3 representatives, 1 patient, 1 academic and 1 industry plus alternates. Collectively they form the EUPATI National Platform Network.

The term *'ENP Sustaining Partners Assembly (SPA) Cluster Representative'* is 1 representative from each individual country from a patient, industry or an academic organisation. As explained in the new governance structure document:

- Each ENP is entitled to nominate one member from their 3 country representatives to the National Platforms Network to become their ENP SPA representative.
- It is up to each ENP to determine how the 3 representatives are selected. The remaining two ENP Network representative will act as ENP SPA Cluster alternates.
- The ENP SPA Cluster representatives will represent their ENP for a period of one year (*to be confirmed*) at an annual meeting.

14. Work Planning & Reporting

Along with the increasing network of 25+ countries, are the logistical challenges of coordination and collaboration, resources as well as a sense of 'isolation' or 'feeling alone' from ENPs who continue to struggle at a national level. As a Network, it is important to share knowledge and update the Network on national activities or events. It is perhaps even more important to share experiences and how those activities functioned. Such information would be of benefit to all ENPs, particularly for those ENPs who are struggling.

For smaller ENPs and indeed for countries who wish to set up an ENP, it would be beneficial to identify common experiences and challenges. In terms of reporting and work planning, increasing levels of reporting may not work for individual ENPs, when considering all ENPs are in different stages of their evolution. Therefore, increasing reporting requirements can often make matters worse for the ENPs with little resources or national support.

Due to the partnership nature between ENPs and EUPATI Central, ENPs will **not** be required to provide formal annual work plans. However, it is advised that ENPs create a national annual work plan to guide their individual work and to track progress.

In future and in order to share what's happening at the national level with the ENP Network and the ENP SPA Cluster the following will occur:

1. **ENP Network Catch Up Meeting (formerly known as 'ENP SPA Cluster Representative Meeting'):**
 - There will be a standing item at each of the 4 ENP Network Catch Up Meetings.
 - It will include a presentation containing one PowerPoint slide from each ENP sharing the activities that ENP is currently doing.
 - This information will be collated by the ENP Coordinator by asking each ENP to complete a tick box form.
2. **EUPATI Newsletter 4-6 times per year:**
 - As in the past, the ENP Coordinator will continue to collate what's happening at the EUPATI and ENP level and share this information via the EUPATI newsletter 4-6 times per year.

Subsequently, there is no need to add onerous reporting requirements to ENPs. Indeed, some reporting is useful to share the experience of what's happening at the local level (in particular the sharing of useful training material which can be helpful to others).

15. EUPATI Central Support for the EUPATI National Platform Network

In 2020 the ENP Coordinator resource was provided on a reduced basis in order to assist EUPATI Centrally. The ENP Coordinator was available 1 day a week for ENP work and 2 days a week for EUPATI business development work. It is recognised that this level of resourcing is not sufficient to support the ENP Network going forward.

Therefore, the following procedures have now been implemented:

1. **Resourcing**
 - ENP Coordinator is available for at least 3 days per week for ENP work only.
2. **Separated from current business development role.**
 - A separate EUPATI resource is now employed to undertake the EUPATI business development role.

Such provisions will ensure ENPs have a dedicated Coordinator for their needs from EUPATI Central. Equally, there is a dedicated business development role, which is now separate and solely focusing on exploring new business partnerships.

To help ENPs in their coordination and collaboration the following initiatives will be in place;

- **Central repository** of resources has been created. ENP templates and documents e.g. in relation to setting up a national course or general EUPATI files are available.
- **ENP SharePoint** will host these resources. This dedicated and exclusive ENP area has been created to allow all ENPs to access useful resources at their will.
- **Microsoft Teams** - To complement these resources a '*Microsoft Teams*' chat and communication platform will be available to aid cross-network communication.
- Both aspects will help in sharing information and help in the interaction between each other.

It is hoped these initiatives will further address the feelings of isolation some ENPs have reported and help in exchanging key challenges for sustainability which ENPs constantly face.

Sustainability is a constant concern for some ENPs. The issue of fundraising has been an issue most ENPs struggle with. The network agrees that without some degree of funding it is difficult to sustain a national platform, as the responsibility

and commitment rests on volunteer hours. Separately, it is sometimes the case whereby EUPATI Central may have secured support from organisations, yet it is difficult for those same organisations to support the national ENP. This duplication of efforts needs to be alleviated to improve efficiency going forward.

EUPATI Central provided fundraising training sessions which were opened to all ENPs in the autumn of 2020. It is hoped that further fundraising training sessions will continue in the future to assist ENPs.

Other sustainability solutions will also be considered, such as the training provision at the national level to different kind of stakeholders (patient, industry, academia) for a fee. Close partnerships with schools and universities whereby training could be provided might also be an option.

Current modifications and additions are being worked on with the EUPATI Toolbox. However, as translations are expensive and a separate fundraising campaign, the pace of work is quite limited. EUPATI Central are working with a translation agency, nevertheless, progress in the same quick fashion as before is unrealistic at present.

16. Where will the ENP Network be in 5 years' time?

Along with the huge progress made over the years, it is important to project forward as to what the ENP will look like and where the Network will be in 5 years' time. The establishment of EUPATI as a Foundation will help in the process of sustainability. It is indeed important EUPATI continues to work as an umbrella foundation for all individual national ENPs. EUPATI needs to become active and work must continue to ensure it is recognised at a national level.

For ENPs it is hoped that in 5 years' time the below aspects will have been achieved:

- **To not feel alone** – to feel part of a strong network
- To continue to exist as a **European organisation** providing courses and high standard education while consolidating what has been done at the national level.
- EUPATI needs to become **active** and **recognised at the national level** in all countries. Industry and academic institutions need to help at the national level as a minimal supply of money is necessary for the existence of an ENP in a country. It is noted that ENPs will not be able to operate on a voluntary basis forever.

It is also important to note the commitment of EUPATI Fellows at a national level in an ongoing issue. More needs to be done to encourage EUPATI Fellows to contribute to their national ENP once they have graduated from training. As they are the lifeblood of the network and are essential to help keep the national ENPs alive.

Appendices

17. Section 1: EUPATI National Platform Governance Structure

2020 - 2025

Appendix 1: Timetable for development of Revised ENP Network Governance

No	Action	Original Due Date	Revised Due Date
1	ENP SPA representative roles are defined and finalised by EUPATI in collaboration with ENP ExCo members. (By July 31	Completed (by virtue of this Governance document)
2	ENPs to confirm 3 individuals to represent their ENP, as well as any nomination for SPA representative. (See attached excel document for list of current representatives).	By Aug 3	By Aug 24
3	ENP Coordination Unit requests nominations for EUPATI Board ENP Representatives	Not included before	By Aug 31
4	ENP Election is held over the first 10 days in September 2020. (September 1 to 10).	By Sept 10	By Sep 10
5	Dedicated ENP sessions on the ENP Strategy as well as an introduction to the elected ENP SPA representatives	Sept 17	Sept 17, 2020

18. Appendix 2: Expression of interest in standing for election to the EUPATI Board

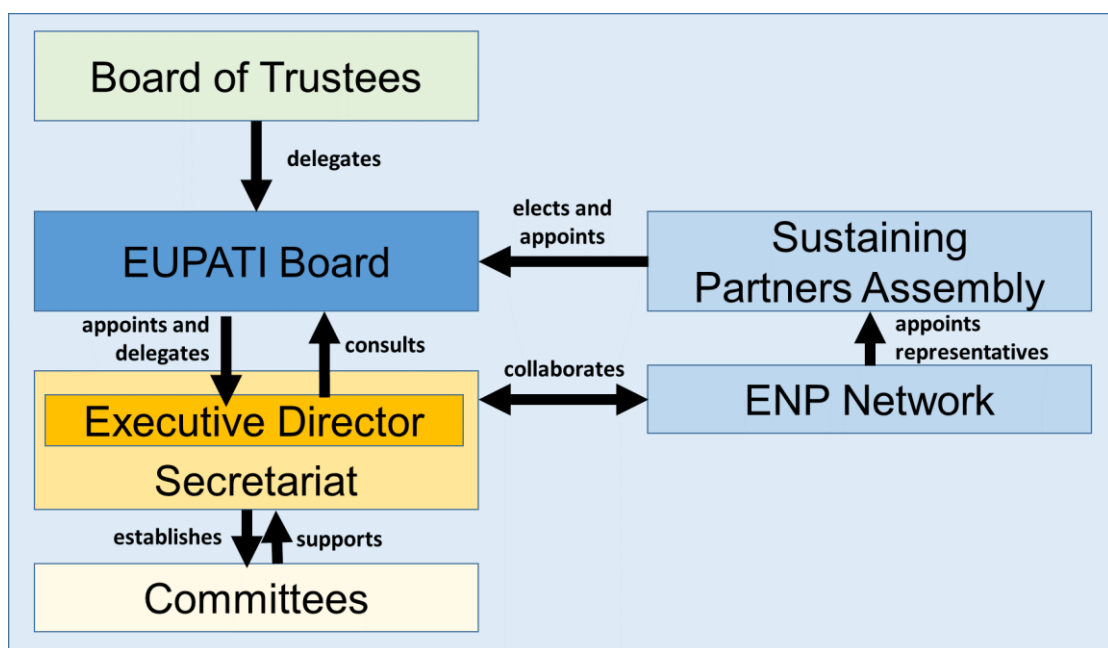
Election of two National Platform Representatives to The EUPATI Board:

The EUPATI Board is the highest-ranking governance body which is responsible for the EUPATI programme’s strategy and implementation. Each sector nominates two representatives (patients, academics/NGOs, industry and ENPs). The EUPATI Board will meet 4 times per year. The two EUPATI Board Network Representatives will be the de facto co-chairs of the ENP SPA Cluster. If you would like to nominate yourself for a seat at the future EUPATI Board, kindly complete this document and send it to Gemma Killeen gemma@eupati.eu by 31 Aug EOB. Please respect the maximum length of 2 pages.

1- First Name and Family Name:
2- Which organisation are you representing?
3- Which role would you like to occupy? (N.B. Industry representatives can select both Co-Chair and Board Member seat) <ul style="list-style-type: none"> <input type="checkbox"/> Industry Co-Chair – term 2 years <input type="checkbox"/> Patient Organisation Board Member 1 - term 2 years <input type="checkbox"/> Patient Organisation Board Member 2 - term 1 year <input type="checkbox"/> Industry Board Member 1 – term 2 years <input type="checkbox"/> Industry Board Member 2 – term 1 year <input type="checkbox"/> Academia/Non-Profit Board Member 1 - term 2 years <input type="checkbox"/> Academia/Non-Profit Board Member 2 - term 1 year <input type="checkbox"/> National Platforms Board Member 1 - term 2 years <input type="checkbox"/> National Platforms Board Member 2 - term 1 year
4- Why would you like to occupy this specific role (and with this specific duration)?
5- Could you please briefly describe your experience with EUPATI since its establishment in 2012?
6- Would you like to add anything else to your nomination?

19. Appendix 3: EUPATI Board Elections June - September 2020 Information and Instructions

EUPATI will be established as a non-profit Foundation in the Netherlands during the summer 2020. The new governance structure will be as illustrated in the figure below. The roles and responsibilities of each governance body are defined in the Statutes and Operating Rules of the Foundation.



The EUPATI Foundation governance structure

The current EUPATI Steering Group will be replaced by a new EUPATI Board when the Foundation is established. The different clusters (stakeholder groups) of the Sustaining Partners Assembly elect their representatives to the EUPATI Board. The Board Members do not represent their own organisations but their entire stakeholder group. The new EUPATI Board Chair is provided by EPF.

Please see the diagram of the EUPATI Board structure on page 7.

Timeline:

The election process is initiated during the week of 29 June 2020. Formally, the new Board will be assigned at the EUPATI Annual General Meeting (AGM) on 17 September 2020.

Seats open for election:

1. Industry Co-Chair – term 2 years
2. Patient Organisation Board Member 1 - term 2 years
3. Patient Organisation Board Member 2 - term 1 year
4. Industry Board Member 1 – term 2 years
5. Industry Board Member 2 – term 1 year
6. Academia/Non-Profit Board Member 1 - term 2 years
7. Academia/Non-Profit Board Member 2 - term 1 year
- 8. National Platforms Board Member 1 - term 2 years**
- 9. National Platforms Board Member 2 - term 1 year**

No alternates are appointed for any role in the EUPATI Board.

Duration of appointment:

The Board Members are elected for 1 or 2 years to avoid the changing of the entire Board in 2 years' time. Reappointment of Board Members is permissible for a maximum of three terms.

Who can nominate:

Any individual belonging to the organisations within the Sustaining Partners Assembly can nominate themselves for the roles listed above. **One Sustaining Partner (organisation) has one nomination.** The Sustaining Partners must internally decide who from their organisation will be nominated. Nomination of current EUPATI Steering Group members is permissible. In the case of the industry cluster, an individual can run for the Co-Chair AND a Board Member position.

Who can vote:

All Sustaining Partners (organisations) can vote for the nominees within their cluster. **One Sustaining Partner (organisation) can vote once and the number of votes correspond to the seats available.** The Sustaining Partners must internally decide on who they vote for and who casts their vote. An individual can vote for themselves. In the case of Industry Co-Chair, the voting for the Co-Chair position is conducted separately.

Sustaining Partner eligibility criteria:

To be part of the SPA, a partner needs to have committed substantially to the continuation of EUPATI through contributing in-cash or in-kind to the EUPATI 2020 Programme and beyond.

A signed bilateral agreement or a written commitment to EUPATI in 2020 by the closing of the nominations is required for the partner to be eligible to nominate and/or vote in the Board elections.

All currently existing National Platforms (25) are also eligible.

List of EUPATI 2021 Sustaining Partners:

Industry	Patient Organisations	Academia/Non-Profit	National Platforms
Abbvie	EATG	BioPeople	Austria
Amgen	EPF	DIA	Belgium
AstraZeneca	EURORDIS	EATRIS	Cyprus
Bayer	IPPOSI	EFGCP	Denmark
BI	ELPA	FindMeCure Foundation	Finland
BMS		ISPOR	France
Gilead		EORTC	Germany
GSK		Sant Joan de Déu Research Institute	Greece
Janssen			Ireland
LEO Pharma			Italy
Merck			Japan
MSD			Luxembourg
Novartis			Malta
Novo Nordisk			Netherlands
Pfizer			Norway
Roche			Poland
Sanofi			Portugal
Takeda			Romania
UCB			Scotland
			Slovakia
			Spain
			Sweden
			Switzerland
			Turkey
			UK

Nominations - How is it going to work?

- Nominations are sent via email by filling in a provided template and submitting it to the EUPATI Secretariat
- Nominations are sent by the nominated individual themselves (as representatives of their respective Sustaining Partner organisation).

Voting – How is it going to work?

- Profiles of candidates are sent out to the SPA representatives
- The voting is conducted online via a voting software.
- Each Sustaining Partner has one vote in their respective stakeholder group
- The votes remain confidential and only accessible to the EUPATI Secretariat Staff.

Annex: Extract of the current draft of EUPATI Foundation Operating Rules (25/06/2020)

EUPATI Board

The EUPATI Board is elected by the Sustaining Partners and oversees the implementation of EUPATI strategy and goals.

a. Composition

The composition of the EUPATI Board must reflect the diversity of the stakeholders represented in the Sustaining Partners Assembly. The number of members and who they represent are defined by the Sustaining Partners Assembly.

At the time of establishment of the Foundation, the representation of Sustaining Partners in the EUPATI Board is as follows:

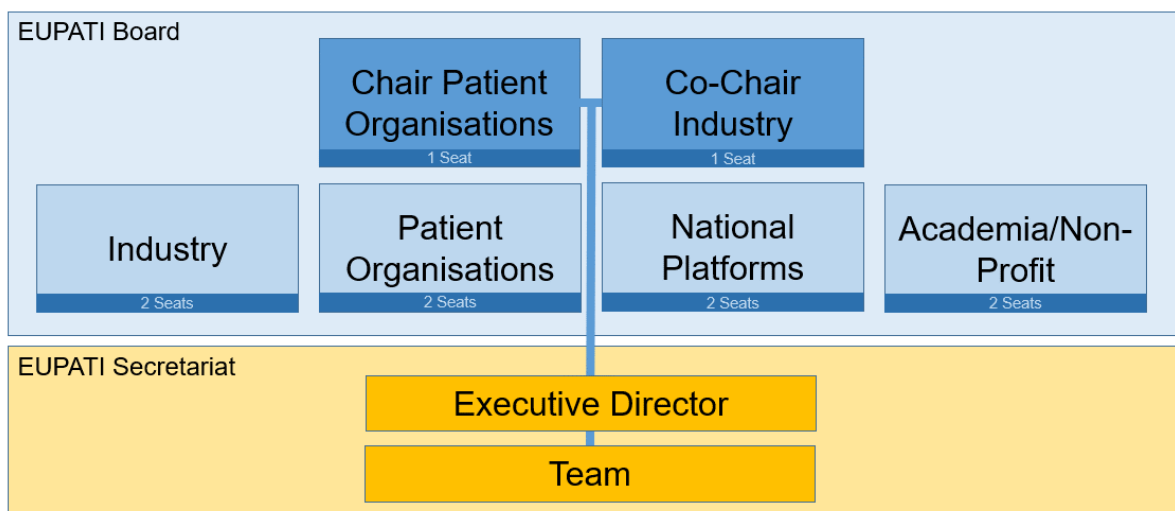


Figure 2: The EUPATI Board structure

b. Appointment of EUPATI Board Chair and Co-Chair

According to the Foundation’s patient-led public private partnership spirit, the EUPATI Board is always led by a patient representative as the Chair and an industry representative acting as the Co-Chair. In case of a draw in votes of the EUPATI Board, the Chair, and in his/her absence the Co-Chair, has the casting vote.

In the spirit of a public-private partnership, the Chair and Co-Chair have the following shared responsibilities:

- Presiding over EUPATI Board meetings
- Ensuring the effective operation of the EUPATI Board
- Managing any Board conflicts to ensure the best interests of EUPATI are being served
- Maintaining regular and ad-hoc contact with the Executive Director, supervising him/her, monitoring his/her performance, and recruiting the Executive Director
- Providing employee support and as the final arbiter in any disciplinary or grievance matters with an employee
- Being spokespersons for the EUPATI Board if required
- Ensuring that all actions are recorded, delegated and completed
- Liaising with the Chair/Co-Chair, Executive Director and Board Members regarding EUPATI Board meetings and setting the EUPATI Board meeting agenda based on input from the aforementioned.

It is foreseen that the European Patients' Forum (EPF) will propose the Chair, in consultation with the Patient Organisation representatives of the Sustaining Partners Assembly.

The Sustaining Partners from the industry stakeholder group propose the Co-Chair.

The term for the Chair and Co-Chair is 2 years. Reappointment is permissible for a maximum of three terms.

c. Elections of EUPATI Board Members

The Sustaining Partners Assembly elects the EUPATI Board members.

A call for nominations of candidates for the EUPATI Board must be announced to all Sustaining Partners at least four weeks before elections. The current composition of the EUPATI Board, with number of seats available per stakeholder group, as well as deadlines and procedures for nominations of candidates must be included in this announcement.

Nominations of candidates for the elections must be submitted to the Secretariat at least 2 weeks before the election.

Profiles of candidates and related information about the candidates must be sent to the representatives of the Sustaining Partners Assembly at least six days before elections.

Nominations of candidates should be discussed by each stakeholder group represented in the EUPATI Board. Elections will be held at the Sustaining Partners Assembly or when being called by the Chair and Co-Chair of the EUPATI Board. Each stakeholder group elects their representatives.

Board Members are elected if they receive at least 50% of the votes of representatives of their stakeholder group cast at the Sustaining Partners Assembly Meeting. EUPATI Board seats will remain vacant if the number of candidates meeting the threshold of votes is not sufficient.

The mandate of EUPATI Board Members is 2 years, with the exception of the first election upon the establishment of the Foundation, when 1 of each of the 2 seats available per stakeholder group will be assigned a mandate of 1 year. Reappointment of Board members is permissible for a maximum of three terms.

If possible, the entire Board should not change at the same time.

d. Termination

Membership on the EUPATI Board terminates by the expiration of the term of office, by resignation, by dismissal upon the decision of the Board, by death or when the individual changes their affiliation affecting the stakeholder cluster. The respective stakeholder group should nominate candidates for the vacancy and elect a candidate, who will serve until the end of the term of the previous member.

A Board Member can be dismissed with a vote of more than half of the remaining members of the Board, stating the reasons, e.g. by not fulfilling their responsibilities as stated in section 3.e of the Operating Rules, gross misconduct or negligence, exposing the Foundation to reputational damage, direct conflict with the Foundation's statutory mission, objective and interests.

e. Roles and Responsibilities

The EUPATI Board develops the strategy and sets goals within the priority areas defined by the Sustaining Partners Assembly and supervises their implementation.

The EUPATI Board has no executive or operational functions. The EUPATI Board has the following responsibilities:

- Safeguard the Foundation's mission.
- Define and supervise organisational values.
- Ensure that the Foundation has adequate resources.
- Approve EUPATI's policies and procedures.
- Approve the Foundation's budget plan.
- Recommend the auditor or auditing company to the Board of Trustees, and supervise that auditing is conducted appropriately by the Secretariat.
- Promote the Foundation by serving as a link with members, donors, beneficiaries and other stakeholders.
- Adopt Advisory or Operational Committees.

- Appoint an Executive Director.
- Evaluate the performance and remuneration of the Executive Director.

f. Meetings

EUPATI Board meetings are attended by the Executive Director. The Executive Director has a supportive role and can be asked by the EUPATI Board to give input and advice on topics of the agenda.

Exceptionally, EUPATI Board meetings may be attended by a different member of staff (in addition or as a replacement of the Executive Director) if asked to do so by the Chair or Co-Chair. The Executive Director may also be asked by the EUPATI Board not to attend a certain part of a Board meeting.

At its discretion, the EUPATI Board may decide to invite other non-Board members to participate in a Board meeting.

EUPATI Board meetings follow a formal structure and process determined by the agenda. Supporting documents will be provided at least one week in advance and EUPATI Board members are required to digest the information and contribute to discussions at the meetings.

Minutes are produced by the Secretariat for each meeting, circulated within 2 weeks and approved by the EUPATI Board Members at latest at the next meeting.

g. Representation

The Executive Director represents the EUPATI Foundation externally. Members of the EUPATI Board may join as appropriate, related to its roles and responsibilities listed in 3.e. and as further defined by the EUPATI Policies.

h. Delegation of tasks

All operational responsibilities are delegated to the Executive Director who is running the Secretariat, ensures execution of all programmes and projects, recruits and supervises all staff, and undertakes all financial transactions. Clear-cut criteria and thresholds when financial or other operational decisions need an interaction of the Executive Director with the EUPATI Board will be defined in the Foundation's Financial Policy. The Financial Policy will be defined by the EUPATI Board.

Section 2: EUPATI National Platform Operating Structure

2020 - 2025

20. Appendix 1: Current list of EUPATI National Platforms (ENPs) – Active, Upcoming and Inactive

No	Active ENPs	Upcoming ENPs	Inactive ENPs
1	Austria	Dominican Republic	United Kingdom
2	Belgium	Argentina	Romania
3	Cyprus	Brazil	
4	Switzerland	Czech Republic	
5	Netherlands	Hungary	
6	Sweden	Israel	
7	Luxembourg	Macedonia	
8	Italy	Russia	
9	Scotland	Serbia	
10	Portugal	Ukraine	
11	Malta		
12	Turkey		
13	Japan		
14	Denmark		
15	Finland		
16	France		
17	Ireland		
18	Spain		
19	Norway		
20	Germany		
21	Greece		
22	Poland		
23	Slovakia		