



# EUPATI beyond January 2017

**Nicola Bedlington  
and the EUPATI Team**



# The EUPATI journey so far – what have we achieved after 5 years?



- **A trusted and credible public-private partnership between patient organisations, science and industry**
- The Patient Expert Training Course, 97 Fellows trained in 58 disease areas
- Deployed EUPATI Toolbox and EUPATI Library in 7 languages: 75.800 visitors to date
- Released EUPATI material under “Creative Commons”
- Established EUPATI National Platforms in 18 countries
- Developed guidance documents on patient Involvement with regulators, HTA bodies, industry, ethics committees; identified best practices and next steps
- Established EUPATI as quality brand for patient education about the entire medicines R&D process

# EUPATI Fellows from 58 disease areas, 31 countries: influencers and leaders



**EUPATI Fellows are increasingly taking leadership roles and are engaging with pharma, regulators and HTA bodies.**

Role	Before	EUPATI	After
Member of patient organisation, not actively involved	17%	➔	2%
Active role in a patient organisation	62%	➔	71%
Leadership role in a patient organisation	62%	➔	71%
Employee of a patient organisation	25%	➔	23%
Volunteer role in a patient organisation	60%	➔	67%
Presenting at conferences, workshops etc.	63%	➔	83%
Advising a pharmaceutical company	13%	➔	44%
Advising a regulatory agency	21%	➔	42%
Advising a reimbursement agency	4%	➔	8%

# What are our National Platforms in 18 countries doing?



**ENP workshops & conferences**



**ENPs on the TV**



**ENP MoUs with partners**

**National platforms in AT, FR, DE, IE, IT, LU, MT, PL, ES, CH, UK, DK, SK, PT (+NO, GR, RU, SRB, BE)**

**ENPs in the papers**



**ENP learning webinars**



**ENP social media campaigns**



# The bigger picture... EUPATI as a game-changer...



- The world has changed since 2011:

*Patient education is essential for true patient engagement in the medicines lifecycle - which is a condition for valuable innovation*

- Discussions with regulators / HTA leaders re: patients informing their decision-making process
- A key driver for a patient engagement strategy within IMI:
  - New IMI Call Topic 10 - “Enhanced patient voice in medicines life cycle”
- New Global Initiative: ‘Patient Focused Medicines Development’ (PFMD)



# Is our job done then?

# NO!



# EUPATI must continue.

## Why?



- There remain too few patients who are able to engage where it matters. **Demand and need is enormous across Europe**
- We need patients with the **knowledge and skills** to ensure medicines development and related projects (IMI and beyond) bring **optimal value to patients and society**
- We are a **unique patient-driven multistakeholder** platform – the potential of which is only starting to be realised
- EUPATI is the only **central** location of **accessible, validated, multilingual** open-sourced information and resources on medicines R&D relevant for **all players**

[www.eupati.eu](http://www.eupati.eu)



European Patients' Academy

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# Patient education! The A to Z of medicines development

Search the Toolbox by keyword

Browse the Toolbox by category



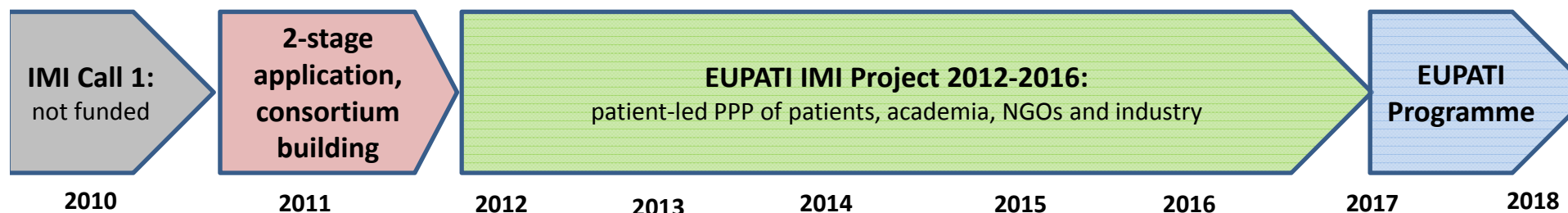


# EUPATI future in the short-term (2017-2019)



## EPF-led, permanent programme

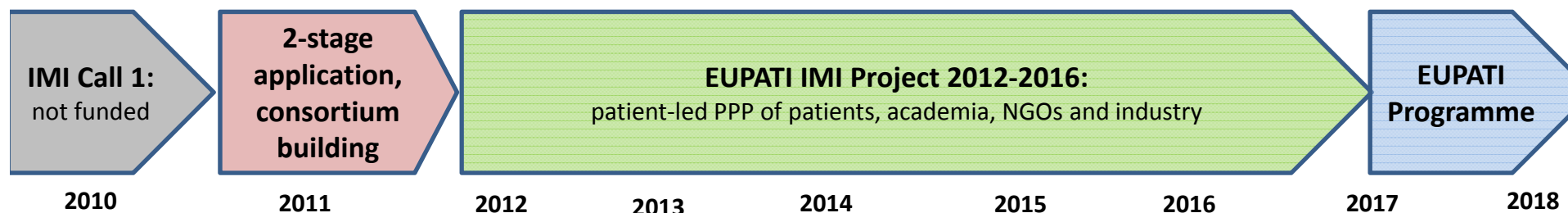
- Coordination and management in the PPP spirit
- **Optimising use of the EUPATI Toolbox** in all languages
- **Toolbox-based “Mini-Course Starter Kits”** for community-run, practical training / capacity building,
- **Content updates** (~10 Toolbox elements updated p.a.)
- **IT platform** (Toolbox, e-learning system, project tools)



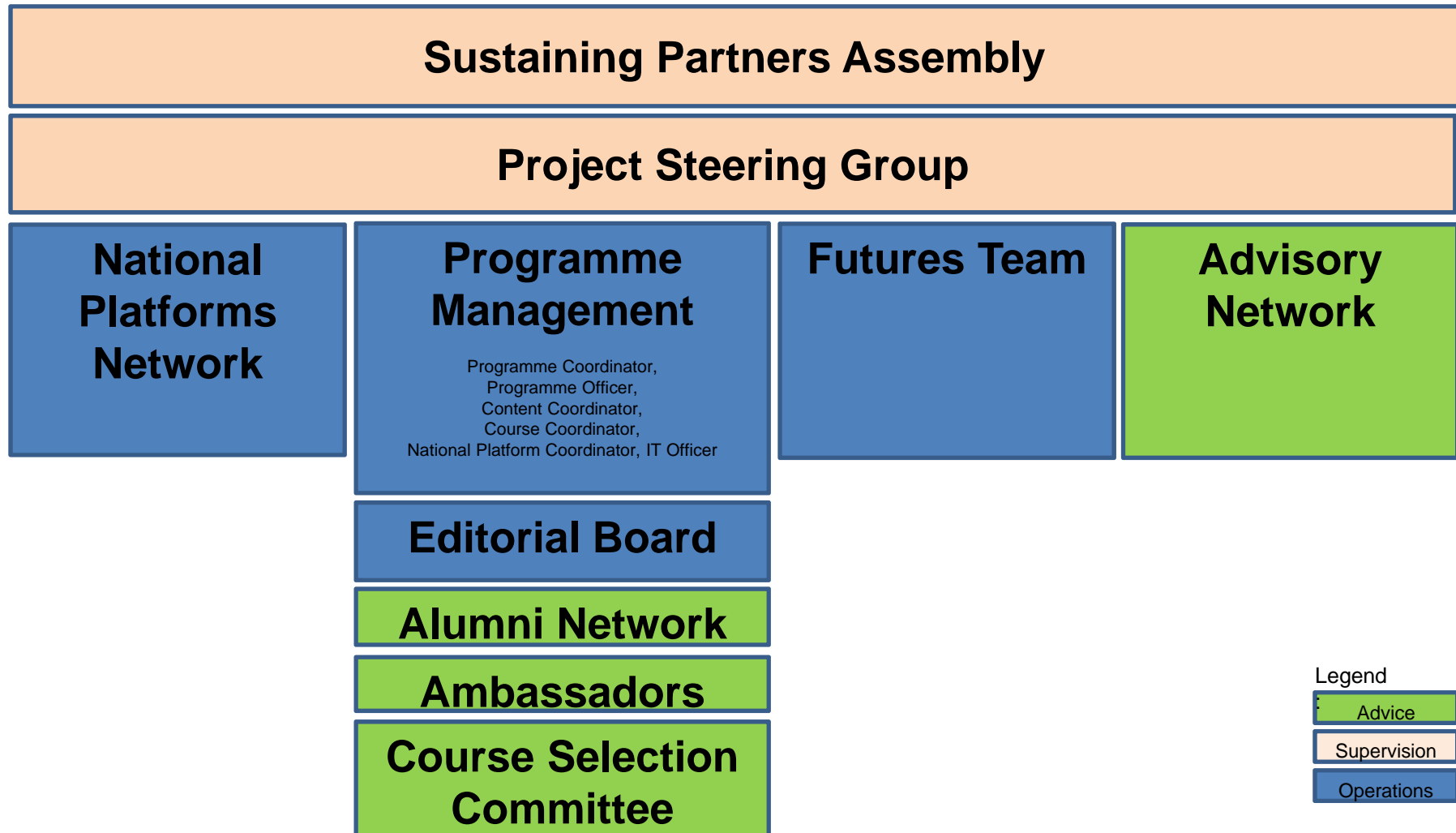
# EUPATI 2017-2019



- **Evaluation and evolution (“EUPATI Futures Team”)**
- **EUPATI National Platforms & coordination support**
- **Patient Expert Training Course 2017-2018**
- As of now, in terms of resourcing  
~~meetings, events, ↘staff, ↘development,~~  
↗use of material



# Governance model of the new EUPATI Programme





# Long-term sustainability beyond 2019: Evolution, Business Development, Evaluation



## EUPATI FUTURES TEAM:

- **Programme evolution new topics:** paediatrics, geriatrics, generics, medical devices, vaccines, etc.
- **Building international traction** (PFMD, ISPOR, outreach in other regions)
- **Exploring innovative business models and future funding sources** (e.g., European Institute of Health (EIT), Horizon 2020, future IMI2 calls, IMI exploitation call)
- **Evaluation** of the programme's performance, outcomes and impact
- **Synergies with national activities** (e.g., course recognition, national expert-level courses)

# Conclusions – All aboard!



- EUPATI is now entering a key transitional phase with huge enthusiasm and commitment but only 25% of resources - **reality check!**
- As active participants in this conference – and ‘**EUPATI believers and shapers**’, we count on you to play a vital role



# Conclusions – All aboard!



- Your role:
  - **Communicate** about EUPATI, **use** the starter kits and tools in your events and activities, **reach out** and engage with the EUPATI Alumni
  - Continue to use the **blogs /postcards** to **draw new people** in to different areas of the website/Toolbox
  - Tell us how you use the toolbox by completing the **short questionnaire** on the website
  - Continue to **network** in your communities and ecosystems - encourage your colleagues to join the EUPATI national platforms
  - Think about embedding EUPATI work and **esprit** in current and new projects that you are driving
  - **Share** any ideas for the **long-term sustainability** of EUPATI

# Reflections – the bigger picture



- Meaningful patient engagement requires continued effort and **'gold standard'** patient education
- **Systematic and structured patient engagement** across the medicines life cycle is **key**
- **Co-creating** a receptive environment and systems readiness for this (tools, infrastructure, trust)
- Other stakeholders, not only patients, need training/ support

# Reflections



- **All** stakeholders need to identify ways patients can be involved in their activities. EUPATI can only guide
- We need patient engagement within the overall research agenda, **prioritisation of research topics**, the **body politic** and governance of IMI
- The importance of patient engagement in **wider health system design** – sustainable, quality-driven and truly patient-centred