

## Working Group : Young Persons Advisory Groups

### Terms of Reference and updated Work Plan

**Chair:** Pamela Dicks (NHS-NRS Children's Research Network)

**Co-Chair:** Jenny Preston (NIHR-Children's)

**Membership:** Joana Claverol Torres and Begonya Nafria Escalera (Hospital Sant Joan de Déu- SAMID), Nathalie Bere (EMA), Irmgard Eichler (EnprEMA), Segolene Gaillard (RIPPS).

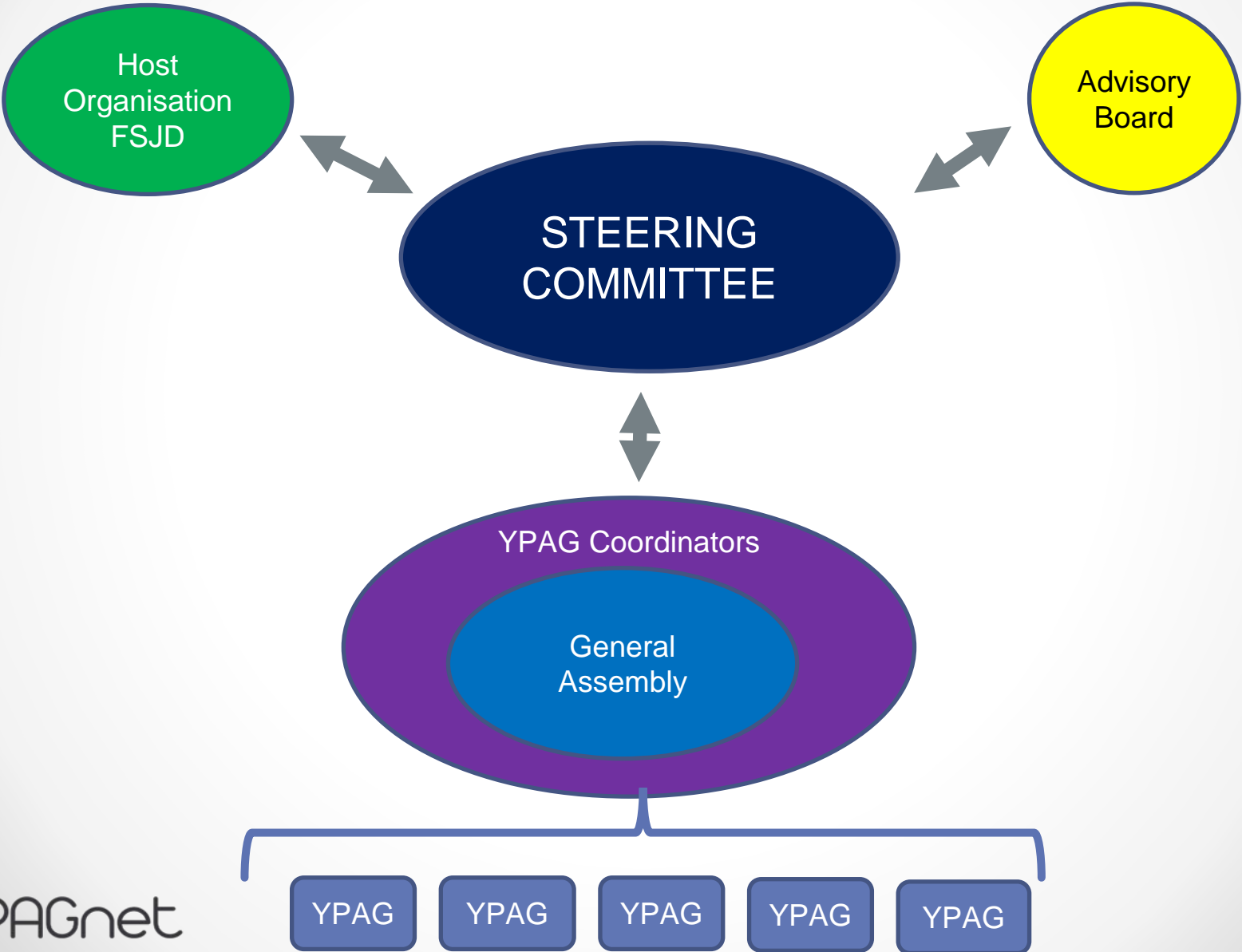
# Strategic objectives of eYPAGnet

1. Work in **partnership with researchers and investigators** to involve **cyp and families in the design and delivery** of paediatric research across Europe.
2. Widen **participation** and **involvement** of all relevant stakeholders in eYPAGnet activities.
3. Grow the **evidence base of the impact** of CYPs involvement and engagement in the design and delivery of paediatric research.

# Strategic objectives of eYPAGnet

- 4. Assess the **impact of involving CYP** on their **own competencies** and skills, and their role as future research and patient ambassadors
- 4. Standardise a **common curricula** to train young patients advocates around Europe about clinical research.
- 4. Develop a business model to guarantee the **sustainability** of the network.

# Governance Structure



# Governance Structure: Steering Committee



Begonya Nafria



Joana Claverol



Jennifer Preston



## Steering Committee



Pam Dicks



Segollene Gaillard



# Governance Structure: **Advisory Board**

Member of PDCO of EMA -

Dr Angeliki Siapkara

Representative from EUREC-

Dr Dirk Lanzareth

Founder representative of ICAN-

Dr Charles Thompson

Parent representative-

Ms Sammy Ainsworth

Representative from EFPIA-

Ms Silvia Garcia

Representative from TUFTS-

Ms Yari Pena

Science Communications Expert-

Dr Alun Hughes

## **Timeline of events**

**Launched eYPAGnet in 2018**

**Recognised as Cat 4 network in EnprEMA 2018**

**Defined strategy and Terms of Reference of Network**

**Implementation of standard operating procedures**

- Financial Management**
- Membership**
- Communications**

**Website launched- Sep 2018**

**Advisory Board established – first meeting May 2019**

**General Assembly – first meeting May 2019**

Website - launched 2018 new website with membership only areas and toolkit will be launched 2020



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The European Young Person's Advocacy Group (eYPAGnet) is a virtual consortium of existing YPAG's in Europe and was founded by the following groups:



# eYPAGnet activities

*May 2018 - Sept 2019*

- Communication activities
    - 15 Presentations/meetings/congresses
  - 2 publication, 1 book chapter
- 
- EMA activities
    - Working group on Ethics
    - Working group on CT preparedness
    - Working group of parents and young people

# eYPAGnet activities - reporting

*May 2018 - Sep 2019*

- YPAGs activities -
  - 4 contacts from Pharma companies
  - 2 full requests received 2 contracts signed
    - Review of inform assents templates/study and assessment of cartoons
    - Collective report from 4 YPAGS
  - Continuomics workshop of acceptability of monitoring devices
  - PEDCRIN – PIS and assent
  - Clinical Trial Preparedness- structured interviews
  - Underpinning YPAG involvement of C4C activities

# Benefits of membership for YPAG's

- Membership of a European network of YPAG's
- Shared training resources and ideas
- Presence on website
- Support from other experienced members
- Access to members area on website
- Involvement in projects underpinning conect4children
- **Toolkit – involved in development and access to full online resources**

# European YPAGs

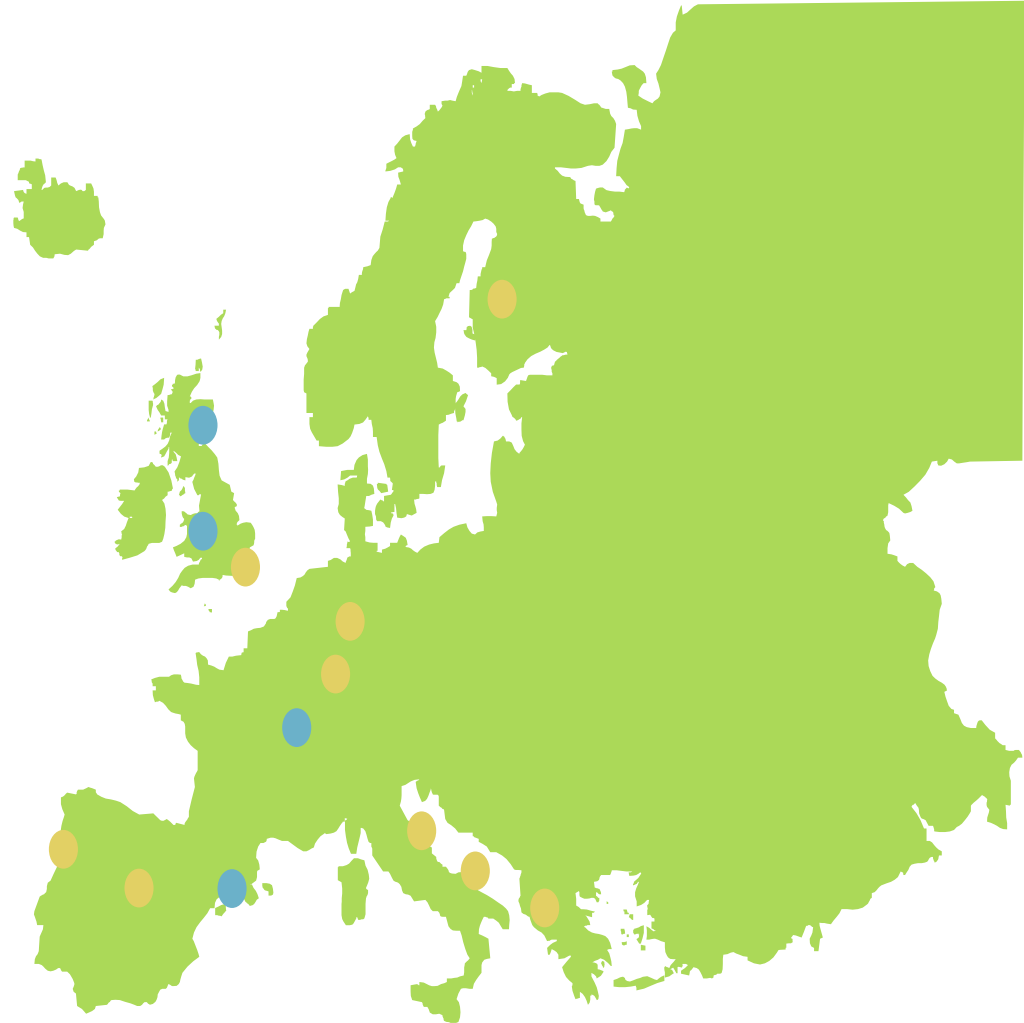


## Funder teams

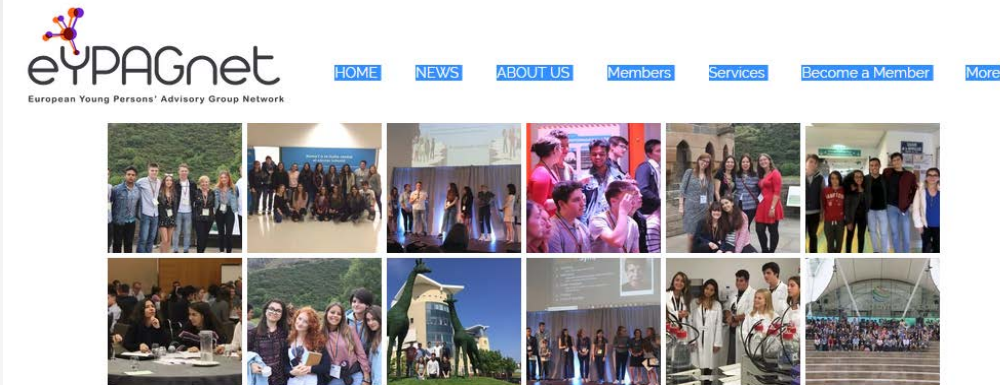
- Generation R
- Kids Barcelona
- Kids France
- ScotCRN

## New teams

- Kids Albania
- Kids Bari
- Kids Belgium
- Kids Finland
- Kids Germany
- Kids London
- Kids Madrid
- Kids Portugal
- Kids Rome



# Application process via website



The European Young Person's Advisory Group Network (eYPAGnet) welcomes applications from active YPAG's in Europe.

## Application for YPAG membership of eYPAGnet

Thank you for your interest in applying to eYPAGnet. Please complete the information below.

Name of YPAG Coordinator \*

Phone number

Email \*

Name of YPAG

Host Organisation/Hospital

Criteria for membership - please refer to application process guidance.

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

# Future Opportunities

- **Projects -collaborative EU projects with other YPAGS**
  - Industry
  - Conect4children (where appropriate)
  - European Joint Action for Rare Diseases
  - Others

## **Funding generated**

- Bespoke website
- Publicity materials
- Training for coordinators and youths



The European Young Person's Advocacy Group (eYPAGnet) is a virtual consortium of existing YPAG's in Europe and was founded by the following groups:

**GenerationR (England)**  
**Kids Barcelona**  
**Kids France**  
**ScotCRN (Scotland)**

The network was established to support the development of new YPAG's within Europe, and to provide the necessary infrastructure to support meaningful and valued involvement of children and young people (CYP) in clinical trial design and health research.

# Thank you!

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

[info@eypagnet.eu](mailto:info@eypagnet.eu)

[@eYPAGnet](#)