



European Young Persons Advisory Group Network (eYPAGnet) – Terms of reference for eYPAGnet membership

Written by: eYPAGnet Steering Committee

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1. Introduction

The model of engaging and involving Children and Young People (CYP) in the forum of Young People's Advisory Groups has had a substantial amount of success in empowering CYP in the decision-making process of paediatric clinical trials and this has been witnessed in the growth of YPAGs across the Globe (GenerationR, ScotCRN, Kids Barcelona, Kids France, International Children's Advisory Network (iCAN) etc). The formation of YPAGs has enabled CYP to become more involved in the research process by giving them the confidence, information and opportunities to be able to contribute at all levels. Age appropriate information and trial design that considers the specific requirements of CYP improves communication with CYP and thereby facilitates consent and assent and recruitment to clinical trials.

However, to achieve the greatest benefit from the involvement of CYP, participation should be integral to the entire process from the outset in a consistent way in all European countries. The establishment of a European YPAG network (eYPAGnet) is one way to achieve this aim. The primary goal of the network is to give CYP a voice in the research process by promoting the creation of YPAGs across Europe and sharing best practices and learning between existing YPAGs.

The eYPAGnet will develop a centralized approach for the collaboration of YPAGs with the different working parties and committees of the European Medicines Agency (EMA), EnprEMA and to provide feedback to the scientific consultations that they receive from the research institutions and pharmaceutical companies. The network will endeavour to strengthen collaborations and partnerships with members of the EMA and wider stakeholders (academics, researchers and pharmaceuticals) to ensure CYP have a voice throughout the entire research pathway, from definition of research priorities to dissemination of the research.

We will provide expertise and help to anyone who wishes to effectively involve and engage CYP in clinical research, educate young people about drug discovery and development and more importantly develop the tools to build on the evidence base of the impact of CYP involvement in the design and delivery of paediatric clinical research.

The main goals of eYPAGnet members include:

- Developing a standardised working process with all stakeholders involved in paediatric clinical research and drug development processes.
- Developing a guide/toolkit for working with CYP at different stages of the research process and support the creation of new YPAGs.
- Strengthening the collaboration of YPAGs throughout the research pathway.
- Designing a common curriculum that educates, informs and equips YPAGs with the knowledge of drug development and discovery.
- Providing the necessary skills for YPAG members to communicate their learning to wider audiences thereby complementing their research ambassadorial roles.

2. Objectives

The eYPAGnet will:

- be responsible for developing an engagement strategy to support, signpost and promote collaboration, both within the network and more widely, for example, looking outward to other CYP and patient organisations with experience of specific conditions or services.

- act as a forum and network to collate and disseminate information about activities relevant to the eYPAGnet
- work together to build an evidence base, internationally, on the impact of the involvement of CYP in Health research, both on the research and on the knowledge of CYP.
- standardise a common curricula to train CYP around Europe aligned with the contributions that the different stakeholders involved in clinical research and in clinical trials require

3. Membership

Interested organisations, groups or individuals should register their interest using the online registration form on the eYPAGnet website to initiate discussion of possible involvement in and contributions to the network.

4. Coordination of eYPAGnet

eYPAGnet will be led by a Steering Committee which will oversee the activities of the eYPAGnet to:

- monitor and ensure it meets and adheres to its objectives (see section 2 above)
- approve membership of interested organisations, groups or individuals
- coordinate funding initiatives
- coordinate eYPAGnet activities
- organise regular meetings with eYPAGnet facilitators which may be face to face, or virtually
- the Steering Committee will meet monthly, including at least 2 face-to-face meetings
- Agendas and Minutes will be posted on the eYPAGnet website (see Dissemination, point below)
- share good practice

5. Benefits:

The benefits of joining eYPAGnet are as follows:

- be a member of a European Network recognised by the European Network of Paediatric Research at the European Medicines Agency
- participation in joint eYPAGnet projects
- access to training materials, support, guidance and best practice
- membership listed on eYPAGnet website
- use of the eYPAGnet logo in presentations, promotional materials and website

6. Commitments of eYPAGnet member

eYPAGnet members agree to:

- complete tasks and projects in an agreed time frame and to an agreed standard
- comply with the ethics code of the network
- contribute to the dissemination of best practices and to publicise eYPAGnet in appropriate meetings and conferences
- report annually activities and update the inclusion criteria as a member of the network
- use the official educational materials to ensure the training following the standards of the network and provide feedback to improve the materials
- include the link of the eYPAGnet website in the YPAG website and maintain their own website and keep updated
- use the official templates (presentation slides, posters, flyers etc) of eYPAGnet following approval of the Steering Committee in writing

7. Communication and Dissemination

The eYPAGnet website will be the main portal of communication and dissemination, listing:

- structure, purpose and activities of the eYPAGnet
- list of affiliated members, with links to their respective websites
- current work streams and their membership
- all outputs and work of the eYPAGnet
- blog and interactive section for comments/suggestions

