



## **Working Group : Young Persons Advisory Groups Terms of Reference and updated Work Plan**

**Chair:** Pamela Dicks (ScotCRN)

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

**Membership:** Salma Malik (RIPPS), Joana Claverol Torres and Begonya Nafria Escalera (Hospital Sant Joan de Déu- SAMID), Nathalie Bere (EMA), Irmgard Eichler (EnprEMA), Gareth Veal (Newcastle –CCLG), Segolene Gaillard (Kids France).



## 2016 Reported on two surveys

Survey 1 : Review of current Young Person Advisory Groups (YPAGs) that have been established within the EnprEMA members and to develop a database of YPAG's that can be used as a resource for EMA and Pharma.

Outcome: To develop operational links between the groups, so that their projects can be cascaded amongst the groups in a timely manner and that they can work collectively on providing their expertise, attitudes and advice.

The Canadian and US groups will be involved via the iCAN umbrella.

# Overview of 15 responses and key points

- GenerationR (R for Research)
- KidsCan
- ScotCRN YPG
- KIDS BARCELONA
- KIDS Fr
- Local: Neonatal Parent Forum  
International: European Forum for Care  
of the Newborn Infant (EFCNI)

The majority of groups have 10-20 members  
Age range 11-20 years 1 group neonatal-adults



# Survey 2 Non EnprEMA members



Purpose: To identify additional young persons groups that are disease specific support groups, patient groups, or associated with charities that may be interested in providing disease specific expert advice.

- BDFA
- Epilepsy Scotland
- paediatric oncology reference team PORT
- Tourettes Action
- AACIC, Associació de Cardiopaties Congènites de Catalunya

# Mapping of networks and groups within EURORDIS and EUPATI

42 groups responded

Majority interest but not actively  
involved in research

# Scope of the groups within EUROPE

Disease focussed groups tended to be

- Support groups
- Information
- Sign posting
- Social interaction
- Fund raising
- Political advocacy

YPAG's

- General not disease specific
- Research focussed
- Training
- Hospital focus group
- Political advocacy
- Raise awareness of research
- University – pharma

Collaboration between ScotCRN, GEN-R, Kids Barcelona and Kids France Met at EnprEMA, iCAN

Sharing of good practice, training

- International projects
- Training materials
- Standard curriculum for members
- Website

Formalise that arrangement -





European Young Persons' Advisory Group Network

## Steering group of founder members

Begonya Nafria

Joana Claverol Torres

Jen Preston

Segolene Gaillard

Pamela Dicks

Agreement of collaboration  
between our employers of non  
profit organisation

The aim of this collaboration is to engage children to participate in an European framework through their involvement in an YPAG, by giving their advice and feedback to different scientific issues, such as clinical trials or other kind of clinical research projects, amongst others. The eYPAGNet shall facilitate a single point of contact at a European level, but shall continue working in collaboration with the ICAN regarding projects or initiatives that could have a worldwide perspective and a wider frame than the European environment. Furthermore, the eYPAGNet shall work hard for obtaining the EnprEMA's accreditation.



European Young Persons' Advisory Group Network

- Applied for Cat 4 membership of EnprEMA
- Applying for funding to provide resources
- Developing current resources, training packages- languages, web based
- Agree a curriculum for current members- standardise level of training and education regarding clinical trial design, ethics, drug development
- eYPAGnet – single point of contact for all YPAGs providing access to many groups with coordination of the facilitation and collation of the responses
- Develop training packages for other groups in development
- Set standard criteria for other groups, provide support
- Provide a service to pharma, investigators and regulators access to CYP advisory groups
- Discussing a business model with a set fee for certain tasks and activities to provide sustainability
- Provide Patient and Public Involvement support to European Networks and Programmes
- In collaboration with iCAN

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**Principles on the involvement of young patients/consumers within  
EMA activities**

**Author- Nathalie Bere**

Agreed published on website

Working with EMA to develop operational guidance.