



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), Gareth Veal (Newcastle-CCLG), Anne Junker (MICYRN), Irmgard Eichler (EnprEMA)



Purpose

1. To review the 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.

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.

Outcome



1. Very few disease groups that had a young persons group
2. Interest in participating in YPAGS
3. Through the WP and attendance at EnprEMA meetings and ICAN the leaders of Gen R, Kids France, ScotCRN and Kids Barcelona galvanised and began to share materials and ideas
4. Recognised a need for a European Young Persons Advocacy Group Network formalise that collaboration

Launch meeting of eYPAGnet



- Tuesday, 24 of January
- Location: Schiphol Airport- Amsterdam
- Attendees:
 - Joana Claverol – Kids Barcelona
 - Begonya Nafria –Kids Barcelona
 - Jenny Preston – Generation R
 - Pamela Dicks – ScotCRN
 - Segolene Gaillard – Kids France

eYPAGnet *Steering Committee*



- The steering committee in the first instance are the founder members.
- **2. Objectives of the Steering Committee**
- Devise training plans and related training materials and identify learning objectives
- Approve activities of the network such as conferences, meetings or publications.
- Develop an engagement strategy to support, signpost and promote collaboration both within and among existing eYPAGnet
- And engage with other groups linked with experience of specific conditions or services, and to children and young people in general as well as parents and carers.
- Act as a forum and network to collate and disseminate information about activities relevant to eYPAGnet.
- Approve membership of interested organisations, groups or individuals
- Coordinate European funding initiatives.
- Work together to build an evidence base on the impact of the involvement of the YPAGs in the design of health research, both on the research and on the knowledge of CYP.

Agenda of launch meeting of eYPAGnet



- Agree the constitution of the network
- Work towards accreditation of eYPAGnet as EnprEMA network
- Agree content and design of
 - YPAGnet portfolio: services that the network will provide
 - Logo
 - Brochure
- Discuss our participation in projects (e.g. PEDCRIN, IMI2 Pediatric Network, IMI2 Patient voice)
- Form working groups of eYPAGnet:
- ICAN (single point of contact)