European Network of Paediatric Research at the European Medicines Agency

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

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SURVEY 1 : Networks that are Members of EnprEMA

Purpose: 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.

15 Responses

- National Center for Child Health and Development
- Neocirculation
- Newcastle Children’s Cancer and Leukaemia Pharmacology Studies Group
- MCRN NL
- European Cystic Fibrosis Society Clinical Trials Network
- MHRA
- Duke Clinical Research Institute
- Futurenest
- FinPedMed
- NIHR Clinical Research Network
- MICYRN
- TEDDY European Network of Excellence for Paediatric Clinical Research
- Scottish Childrens Research Network
- Hospital Sant Joan de Deu
- RIPPS (Reseau d’Investigation Pediatrique des Produits de Sante)

Overview of 15 responses and key points

41 Questions regarding if they have a YPAG, if yes descriptors of the group and how it was managed.

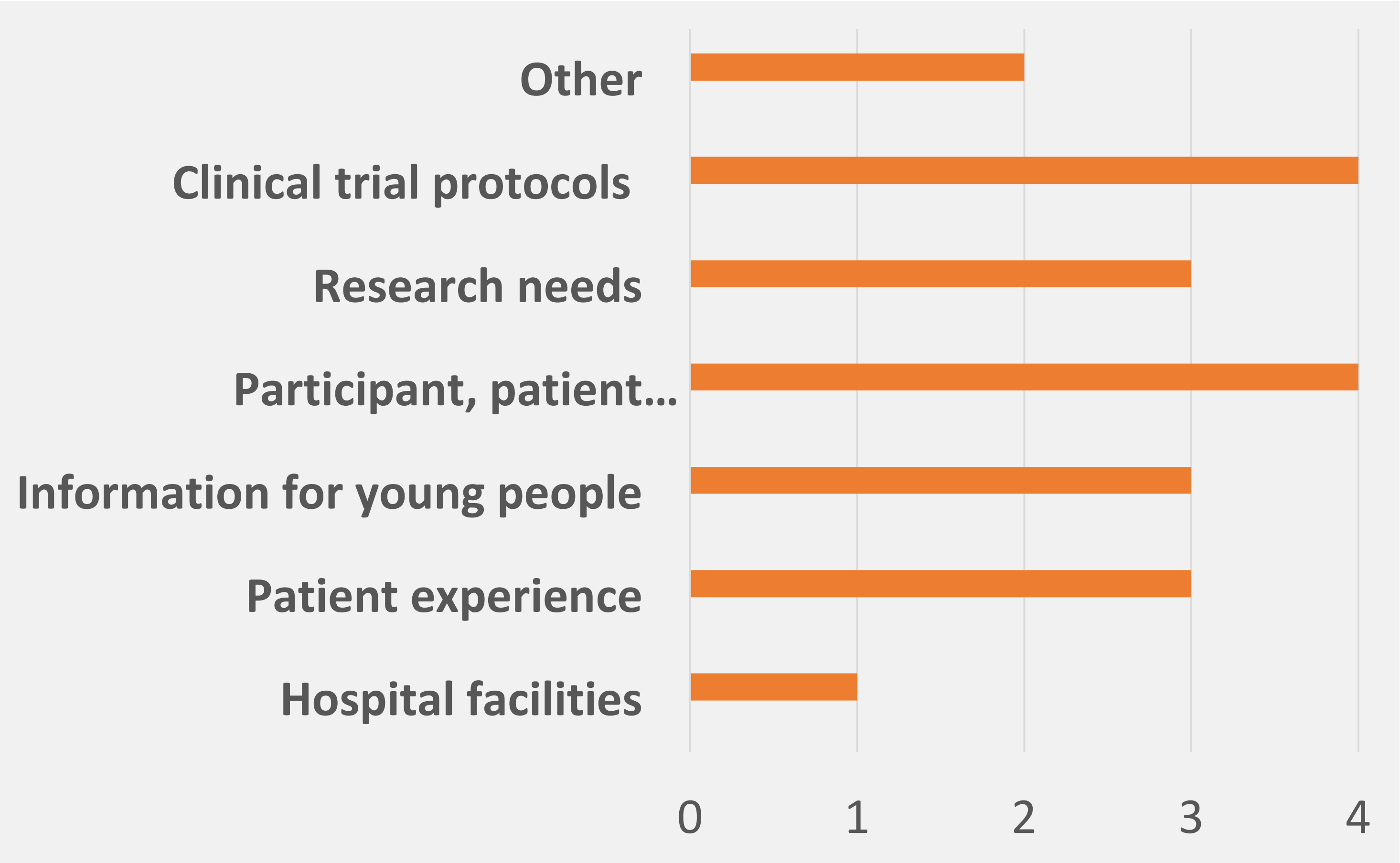
6 responded YES to having a YPAG group

- 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)

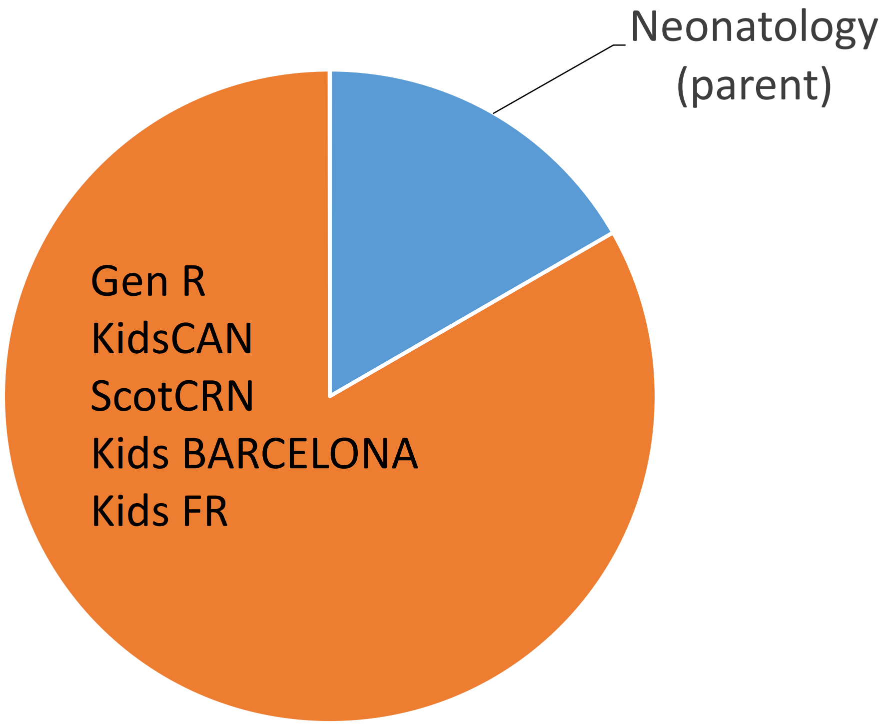
- The majority of groups have 10-20 members
- Age range 11-20 years 1 group neonatal-adults
- All located in a Children's hospital
- 3 groups have funding direct/indirect
  - Gen-R
  - ScotCRN YPG
  - Kids Barcelona

YEAR Formed	
2000	1
2006	2
2011	1
2013	1
2015	1

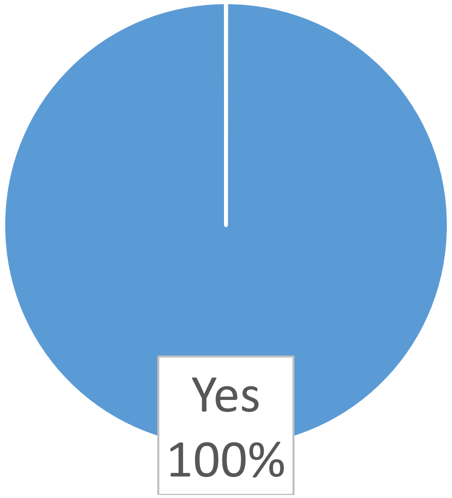
Q4: If they have an advisory role what do they advise on?



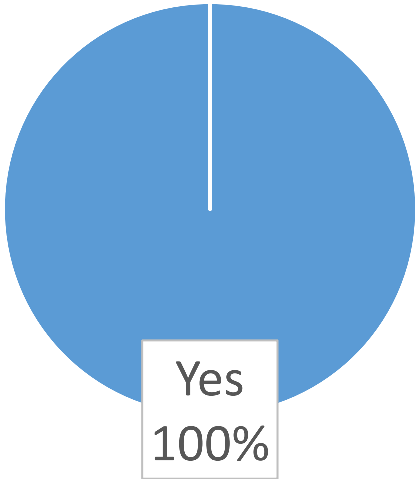
Q18: Is your group associated with a specific condition or disease?



Q34: Do members of your group wish to be part of EU clinical trials focused YPAG?



Q35: Can we contact your group to comment on patient documentation for clinical trials?



Further questions regarding the running and management of the groups. Agreements, contracts, training, meeting content, publicity, social networking. This will be collated and shared.

Next steps

Encourage all parties to reply

Collate the responses and produce a short report: EnprEMA to publish on website

It would be useful to have processes in place if anyone wants to access existing YPAGs
(with clear guidelines and young people's agreement between researchers)
Resources to get this documented.

GRIP Start up tool online platform ypag-grip-network.org

Host workshop to networks and non-Enpr-EMA networks on how to set up a YPAG or how to involve young people in health research?

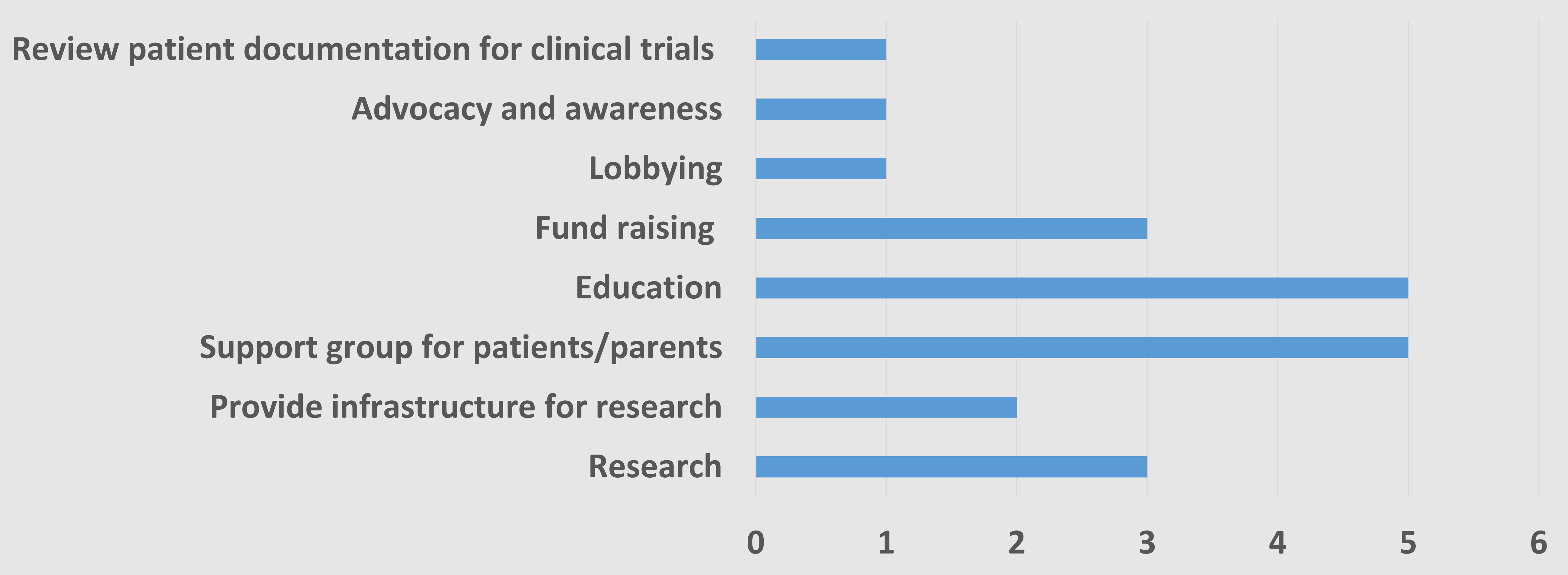
Survey 2 Non EnprEMA members

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.

6 responses

- BDFA Batten’s disease family association
- Epilepsy Scotland
- paediatric oncology reference team PORT
- Tourettes Action (x2)
- AACIC, Associació de Cardiopaties Congènites de Catalunya

Role of the group



2 youth groups	Epilepsy action – Lighthouse project	AACIC- Grup de Joves
Role-	Advocacy for children, participants in clinical trials Raising Public Awareness Peer support Education	Patient documentation Peer support Education
Who-	Researchers, pharma companies, government agencies	They define their needs to improve services and care, prepare documents based on experience and training
Age-	11-21	14-25
Inclusion-	Confirmed diagnosis	Confirmed diagnosis
Would members of your group wish to be part of a research, clinical trials focused YPAG?	yes	no

All responders

- **BDFA- Batten disease family association**
- **paediatric oncology reference team PORT**
- **Tourettes Action (x2)**
- **AACIC, Grup de Joves**
- **Epilepsy Scotland- Lighthouse Project**

Can we contact your group to comment on patient documentation for clinical trials? YES

Can we contact your group to comment on identifying priorities for research in your disease area? YES

Next steps

- Non EnprEMA members survey-
  - Need to identify more groups to contact?
    - EURORDIS
    - EUPATI
  - Work with Nathalie Bere (EMA-Patient Organisations – EMA will ask their patient organisations to complete the questionnaire and we will share the information with EMA. Identify youth groups within those organisations
  - This questionnaire response time will be left open so that we can continue to collate information about patient groups that can be a resource for EMA and EnprEMA.