



EUROPEAN MEDICINES AGENCY  
SCIENCE MEDICINES HEALTH

# Involvement of young people and families in Enpr-EMA networks

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An agency of the European Union





# Survey on young people and family involvement in Enpr-EMA Networks (1/4)

## Outline:

- Survey sent to all **39** registered Enpr-EMA Networks (22 Aug to 05 Dec 12)
- Aim: to describe how networks support the **engagement** of young people and families in paediatric clinical research

Results (1/2): overall response rate: 17/39 (44%)

### *Engagement of young people/ family members in Enpr-EMA networks*

Young people/family members engagement	Total	Yes	No
Involvement/consultation with young people/family	17	9	8
Dedicated staff for young people/family involvement	17	7	10
Specific budget for young people/family involvement	17	4	13
Specific strategies for young people/family involvement	17	3	14



# Survey on young people and family involvement in Enpr-EMA Networks (2/4)

Results (2/2): overall response rate: 17/39 (44%)

## *Specific activities undertaken with young people/ families in Enpr-EMA networks*

Network activities with young people/family members	Total	Yes	No
Writing/commenting on participant information leaflets	17	8	9
Promoting the trial to encourage recruitment	17	7	10
Developing the protocol	17	7	10
Disseminating the results	17	6	11
Membership of a management/steering/advisory group	17	6	11
Priority setting	17	4	13
Identifying topics for research	17	3	14
Reviewing/interpreting research results	17	2	15



## Survey on young people and family involvement in Enpr-EMA Networks (3/4)

- 3 Networks developed **strategies or guidelines** for the involvement of young people and families
- Links to strategies are published on **Enpr-EMA website**:

*National Institute for Health Research, United Kingdom: [Medicines for Children Research Network consumer strategy 2012 – 2015](#)*

*Scottish Children's Research Network, United Kingdom: [Young Persons' Group strategy documentation](#)*

*Maternal Infant Child and Young Research Network, Canada: [Creating and connecting networks](#)*



# Survey on young people and family involvement in Enpr-EMA Networks (4/4)

## Conclusion:

- **Availability** of guidelines on involvement of young people and families in research related activities
- Need for **training** and/or support/mentoring for network staff on involvement of young people and families
- Enpr-EMA to encourage those networks with involvement strategies in place to **share** these with others:
  - to increase expertise and knowledge
  - to ensure ethical, responsible and effective involvement of young people and families in paediatric clinical research
- Survey results have been written up on behalf of Enpr-EMA and submitted for publication as a **short report** to *Arch Dis Child*  
4 but due to the low response rate the manuscript was rejected