Patient and Public Involvement (PPI) working group

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eYPAGnet

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European Young Persons' Advisory Group Network

PPI WORKING GROUP – MEMBERS

- **Pam Dicks**, SCOT CRN, eYPAGNet, Scotland
- **Myrona Goutaki**, SwissPedNet network, Switzerland
- **Shalom Govere**, TEDDY Network, Italy
- **Tomasz Grybek**, Eurordis, Poland
- **Cornelia Hagmann**, Children’s University Hospital of Zurich, Switzerland
- **Collin Hovinga**, CP-RND, RDCA-DAP, United States
- **Begonya Nafria**, eYPAGnet, San Joan de Deu, Spain
- **Bernhard Sandner**, NETSTAP, Germany
- **Sabine Scherer**, Paediatric and Orphan Medicinal Products,
  Federal Institute for Drugs and Medical Devices, Germany

FIRST MEETING HELD ON SEPT 17, 2024

Review of the objectives, define working plan, tasks and possible outcomes of the WG

PPI WORKING GROUP – BACKGROUND

- PPI Capabilities in paediatrics in EU are not well known & there is a need to develop and strengthen PPI capabilities
- Standardization of processes is required to ensure involvement of paediatric patients and parents across different European countries

PPI WORKING GROUP – OUR OBJECTIVES

Objectives

- To map existing PPI capabilities in paediatrics: Number of existing groups, level of development/expertise, type of expertise (YPAGs, disease groups, POs, ERNs, umbrella organisations…), existing resources…
- To evaluate the needs of PPI groups/people in terms of training, resources…
- As a perspective, to develop appropriate framework to involve children and young people and parents.

PPI WORKING GROUP – NEXT STEPS

1) Definition of PPI groups: What are we going to map?

- Activities in paediatric research focus versus peer support groups...
- Align with stakeholder needs comprising PDCO, sponsors…

2) Mapping existing capabilities

- Expertise and needs of existing PPI groups/persons (survey, contacts…).
- Who are we going to survey : Members of enprEMA, clinical research facilities…How can we actually find where PPI is?

3) Proposals for guidance/training (according to the needs) on PPI activities, (rights and good practices)

4) As a perspective, framework on how to involve CYP at a European level

5) Publication and dissemination

Involvement of young patients and parents in the review of some outcomes of the WG.

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Thank You