

Building the POLPEDNET KIDS Enhancing Clinical Studies through Young Patient Involvement in Poland

Children's Memorial Health Institute

EPTRI Scientific Meeting 2025; Bologna, Italy– 15/03/2025

Young Patient's Advisory Group – Definitions

- YPAG is a structured advisory group that provides young people's perspective on clinical research, improving its quality, ethics and compliance with the expectations of paediatric patients.
- A Young Persons Advisory Group (YPAG) is a group made up of children and young people actively participating as partners, advising researchers and their teams on a full range of activities in various clinical research projects and initiatives
- YPAGs are youth advisory groups made up of children and teenagers who actively participate in the research process, offering unique insights into research design, information materials and the practical aspects of clinical trials.
- YPAG are groups of young people aged 8 to 18 who play a key role in the development and implementation of clinical trials by actively participating in their planning, evaluation and implementation.

Road Map of



May 2024





Prior to the first meeting with the children and young participants, a series of **informational meetings with parents** was conducted. These sessions aimed to provide a clear understanding of the YPAG concept, its role within **POLPEDNET at IPCZD**, and the broader network of YPAGs operating across Europe and globally.



Key Topics Discussed in Parental Meetings:

- **What is YPAG?**

Parents were introduced to the concept of Young Persons Advisory Groups, their functions, and their impact on making clinical research more youth-friendly.

The Mission of POLPEDNET YPAG at IPCZD:

- Ensuring that **clinical trials and research** consider the perspectives, rights, and concerns of young patients.
- Making studies more **accessible and child-friendly** by integrating youth voices into the design and implementation of research projects.



Group Activities and Engagement:

- Members of the group will actively participate in **developing and implementing scientific projects** that directly affect children, teenagers, and young adults. Activities include:
 - Organizing **scientific workshops** to raise awareness about key health issues.
 - Educating young people about **science, medicine, and clinical research methodologies**.
 - Promoting **healthy lifestyles** among their peers.



Personal Development Opportunities:

The importance of **personal growth** within a safe and encouraging learning environment was emphasized, allowing young participants to develop research skills and scientific literacy.

Upcoming Projects and Collaborations

The group was introduced to the **international and European networks and projects** that it would engage with, including:

- European ColourPills Project
- YPAGNet
- Conect4children (c4c)
- EPTRI (European Paediatric Translational Research Infrastructure)
- Patient in Clinical Trials – project coordinated by Medical Research Agency



At the time of its establishment, the group consisted of **50 children, teenagers, and young adults aged 8 to 19 years.**

During the **first meeting**, the following key aspects were introduced and discussed:

- **Introduction to YPAG** – The concept of Young Persons Advisory Groups was explained, including their purpose and impact on pediatric clinical research.
- **Objectives of POLPEDNET Kids** – The specific focus of the group was outlined, emphasizing its role in supporting pediatric clinical trials, providing feedback on study designs, and engaging young people in research-related activities.



During the **first meeting**, the following key aspects were introduced and discussed:

- **Meeting Frequency** – After an open discussion, the group collectively decided to meet **once a month** to ensure regular engagement while balancing school and personal commitments.
- **Proposed Meeting Agenda** – A draft program was suggested, outlining the topics and structure of future meetings to ensure meaningful participation and continuous learning.



During the initial meetings, the **group agreed to hold monthly sessions** to ensure continuous engagement and learning. A structured educational program was introduced, covering key areas of **scientific research, clinical trials, and hospital operations.**

Key Areas of Training and Workshops:

1. Introduction to Scientific Research in Medicine:

1. Understanding **the role of research in medical advancements.**
2. Exploring **different types of studies, including preclinical and clinical research.**

2. Introduction to Clinical Trials:

1. The fundamentals of **clinical trial phases and regulatory frameworks.**
2. Ethical considerations in pediatric research and the importance of patient involvement.
3. Interactive workshops on **designing child-friendly clinical studies.**



3. Hospital Unit Visits and Practical Learning:

Participants will have **hands-on exposure** to different hospital departments to understand their functions:

1. **Imaging Diagnostics Laboratory** – Introduction to radiology, MRI, CT, and ultrasound.
2. **Hospital Pharmacy** – Understanding the role of a hospital pharmacist, medication preparation, and safety.
3. **Clinical Wards** – Observing daily operations in different pediatric hospital units.

4. Specialized Practical Workshops:

1. **Compounded Drug Formulation** – Hands-on training in preparing personalized medications.
2. **Medical Devices and Innovations** – Learning about cutting-edge medical technologies and their applications.
3. **Artificial Intelligence in Medicine** – Exploring AI's role in diagnostics, treatment planning, and personalized healthcare.



Following the initial sessions, the group participated in a series of engaging and educational activities aligned with the planned agenda. These sessions provided hands-on experience, fostered creativity, and deepened participants' understanding of clinical research and hospital operations.



Introduction to Clinical Trials – Designing a Study

- To introduce the concept of **clinical trial design**, children and young participants worked together to create their **own mock clinical study**.
- The chosen research question: “**Which candy is better?**”
- Participants learned about key **study components**, such as control groups, randomization, data collection, and ethical considerations.



Hospital Pharmacy Workshop & Tour

- A dedicated workshop led by **pharmacist Marta Szymańska** provided insights into the **unique challenges of hospital pharmacy work**.
- Participants explored the **medication preparation process**, safety protocols, and the role of hospital pharmacists in pediatric care.
- A guided **tour of the hospital pharmacy** allowed participants to see real-life pharmaceutical operations.



Internal Project: Board Game on Pediatric Clinical Trials

- The group initiated the development of a **board game** aimed at **educating young patients about clinical trials in pediatrics**.
- The game will provide an interactive way to understand the steps of clinical research, ethical considerations, and patient involvement.

Holiday Gift Drive for Hospitalized Children

- In the spirit of giving, the group organized a **holiday gift collection** for children staying in the hospital during the holiday season.
- Members gathered **toys, books, and games**, ensuring a brighter and more comforting hospital experience for pediatric patients.





Pediatric Cardiology Workshop

Dr. Adam Koleśnik, a pediatric cardiologist, conducted an engaging session on **the fundamentals of pediatric cardiology**.

• Hands-on workshops included:

- **Echocardiography (ECHO)** – Understanding heart imaging and its role in diagnosis.
- **Cardiac Catheterization** – Explanation of the procedure and its applications in pediatric patients.

Participants also had the opportunity to **visit the hospital's hemodynamics lab**, where Dr. Koleśnik provided an exclusive tour of the advanced equipment used in interventional cardiology.





That was first 10 months...



As the group has evolved, approximately **30 children and young people** remain actively engaged in various initiatives. The group has expanded its focus and is now divided into specialized **sections**, each dedicated to different aspects of research, healthcare innovation, and community project.




- Medical Devices Section
- Scientific Research Projects
- Structural Projects
- International Projects
- Clinical Trials Section
- Social Projects & Community Engagement




The group members **bring incredible knowledge, enthusiasm, and creativity**, making them a valuable resource for both research and practical innovation.



 Need fresh ideas, unstoppable energy, and a youth-driven perspective in your research? Look no further!

At POLPEDNET Kids, we're not just a group—we're a powerhouse of **creativity, curiosity, and clinical research enthusiasm!** Whether you need insights on making studies more **patient-friendly**, help designing a **pediatric clinical trial**, or just a reality check from the **most honest critics (aka kids)**—we've got you covered!

 Got a project? A challenge? A wild idea?

 Call our mastermind-in-chief: **+48 503 173 651**

 Drop a line to our research HQ: a.wisniewski@ipczd.pl

polpednet_kids on Instagram!!!

Warning: Side effects of working with us may include **innovative solutions, unexpected humor, and a totally new way of seeing research.** Proceed at your own risk.