TEDDY NETWORK European Network of Excellence for Paediatric Research

COUNCIL OF EUROPE
CONSEIL DE L'EUROPE

CHILDREN PARTICIPATION IN DECISION MAKING IN BIOMEDICAL FIELD - GOOD PRACTICES

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TEDDY HEARING WITHIN THE COUNCIL OF EUROPE

Hybrid Meeting from the Palais de l'Europe, Room 7

7th of July 9.30 - 14.00

According to international instruments, all children capable of forming their own views, have the right to express their views freely in all matters affecting them. Children's views shall be given due weight in accordance with their age and maturity (art. 12 of the United Nations Convention on the Rights of the Child, art. 6 of the Oviedo Convention).
The recognition of this right, along with greater acknowledgement of children's evolving capabilities, has led to an increasing awareness that children's views must be given value in European and national policies.

The right to participate is important [not only as a right and a general principle but also] because taking children's views into account in decisions and actions that affect them brings significant immediate and long-term benefits for them. Children have unique knowledge about their lives, needs and concerns. Using this knowledge, their ideas and views can lead to more improved individual decisions for children, and enhanced fulfilment of children's rights.

The level of involvement, especially in the health field, can differ from child to child and from circumstances. Information-sharing involving the child thus requires that the child is included, and duly guided by adults with the opportunity to enhance his/her competences, while giving due weight to the child's perspective.

Appropriate and accessible information is an important pre-requisite for the ability to speak out, express views and discuss decisions. Healthcare professionals and legal representatives (parents, guardians…) have a responsibility to find ways in which to enable children to communicate their views, concerns, or ideas.

Child-friendly informative material helps to support the communication and mutual understanding of children and healthcare professionals. It also helps children to reflect on the information they received orally and to identify questions for a follow-up conversation with the healthcare professionals. Medical conditions and the diversity of the groups are important aspects to be considered in developing materials.

Promoting children rights, needs, and resources, empowering children at every stage and giving them a voice in the design and implementation of healthcare and research processes, contributes to create a collaborative process improving children's access to health care and optimal health outcomes. To this aim, the Steering Committee for Human Rights in the fields of Biomedicine and Health (CDBIO) and the Steering Committee for the rights of the child (CDENF) are developing a Guide aimed at highlighting relevant international frameworks and standards and practical guidance and examples of national legislation and good practices to involve children in individual decision-making processes affecting their health.

In this context, TEDDY has been invited by the Council of Europe to present some activities to be considered as good practices promoting the empowerment of children and facilitating their participation in decision making process. This hearing, chaired by the co-chairs of the Working Group in charge of the Guide, will be also the occasion to present the video of the Council of Europe developed by TEDDY with a participatory methodology involving the TEDDY Kids, which are groups of healthy and sick children all over Europe aimed at encouraging active participation and self-determination of children and parents in caring and research procedures contributing also to the empowerment of children in health sector.

At the end of the hearing, the TEDDY General Assembly, reserved to TEDDY members, will take place with the aim to update on the activities carried out by TEDDY and plan the next steps.

HEARING PROGRAMME

7th of JULY 9.30 - 14.00

LINK FOR CONNECTION:
BLUEJEANS HTTPS://BLUEJEANS.COM/632428255/2638

9.30 - 10.00 INTRODUCTION

- **Laurence Lwoff – Head of Bioethics Division of the Council of Europe - CDBIO Secretary**
- **Katrin Uerpmann - CDENF Secretary**
- **Annagrazia Altavilla - TEDDY Network Chair**

10.00 - 10.30 COE VIDEO

- Presentation of the video of the Council of Europe on children participation in decision making process regarding their health - **Maria Cavallo & TEDDY Kids** who contributed to the video (**Mattia Bonifazi, Hortense Peretti, Maria Michela Balice**)

10.30 - 10.40 Coffee break

GOOD PRACTICES FROM TEDDY REPRESENTATIVES AND PARTNERS

Chairs: Ritva Halila, Joost Vanhaelst

(Co-chairs of the Working Group in charge of the COE Guide)

10.40 - 11.10 EMPOWERMENT ACTIVITIES

- Training course for paediatric expert patients on rare diseases developed within the European Joint Programme on Rare Diseases – Methodology and tools - **Roseline Favresse, EURORDIS / Adriana Ceci, EJPRD Programme Committee representative - EPTRI**
- Play to learn: TEDDY "My CTC" serious game - **Maria Cavallo, TEDDY Network**

11.10 - 11.40 CHILD-FRIENDLY MATERIALS

- PPI in research projects: the EPTRI toolkits for translational paediatric research – **Begonya Nafria Escalera, Fondation Sans Joan de Deu**
- Age tailored materials: the assent forms for processing and sharing data within ERNs (European Reference Networks for Rare Diseases) - **Annagrazia Altavilla, TEDDY Network - Espace Ethique PACA/Corse (AP-HM)**

11.40 - 12.10 ACTIVITIES TO EMPOWER AND ENHANCE CHILDREN'S COLLECTIVE OR GROUP PARTICIPATION

- The International Children Advisory Network (iCAN) - **Christine Woods, iCAN**
- The iCAN summit: objectives and tools to enhance children empowerment - **Segolene Gaillard, Kids France - Hospices Civils de Lyon**
- The engagement of paediatric patients to improve policies: roundtables & consultations - **Donato Bonifazi, EPTRI (European Paediatric Translational Research Infrastructure)**

12.10 – 12.40 POLICIES AIMED AT FOSTERING CHILDREN PARTICIPATION

- Good Lay Summary Practice Guidelines including aspects relevant for children developed by a multidisciplinary and multistakeholders working group – **Solange Corriol-Rohou EFGCP (European Forum for Good Clinical Practice)**
- Recommendations for the Integration of Paediatric Patients in the R&D Process of Medicines - **Inmaculada Calvo Penadés, La Fe Hospital /Valencia University and Spanish Paediatrics Association (AEP)**

CONCLUSIONS

12.45 - 14.00 TEDDY GA FOR TEDDY MEMBERS

LIST OF SPEAKERS

Read the speakers short bio

Annagrazia Altavilla, TEDDY Network - Espace Ethique PACA/Corse (AP-HM)

Adriana Ceci, EJPRD Programme Committee representative - EPTRI (European Paediatric Translational Research Infrastructure)

Donato Bonifazi, EPTRI (European Paediatric Translational Research Infrastructure)

Inmaculada Calvo Penadés, La Fe Hospital / Valencia University and Spanish Paediatrics Association (AEP)

Maria Cavallo, TEDDY Network - KIDS Bari

Roseline Favresse, EURORDIS

Segolene Gaillard, Kids France - Hospices Civils de Lyon

Begonya Nafria Escalera, Fondation Sans Joan de Deu

Solange Corriol-Rohou, EFGCP (European Forum for Good Clinical Practice)

Christine Woods, iCAN (International Children Advisory Network)