## Objective 5: Giving a voice to every child



# Session on promoting children's participation in decisions about their health

Mid-Term Review Conference for the Strategy for the Rights of the Child (2022-2027)







# Promoting children's participation in decisions about their health

Children have a right to express their views in all matters that affect them, and to have these views properly taken into account – whether at home, at school, or in the community. How does this translate in healthcare situations? How does one ensure that children effectively and meaningfully participate in decisions about their health?

Child participation is the fifth pillar and an important objective of the <u>Council of Europe's Strategy for the rights of the Child</u>. The Council of Europe strives to mainstream this principle across its standard-setting, monitoring and sector-specific work, including in the field of health and biomedicine.

International human rights instruments recognise that children are rights holders with evolving abilities to make decisions in all aspects of their lives, including their health. Research in the field of healthcare indicates that there are many benefits in involving children in decisions. Their participation is considered important for achieving high-quality pediatric care. Encouraging child participation in decisions about their own health is not only about respecting their rights, it is also about fostering trust, improving communication and enhancing the effectiveness of care.

This said, there is often uncertainty as to how this translates in practice. Healthcare professionals may sometimes find it challenging to turn this principle into action, particularly when faced with complex situations.

In 2023, the Steering Committee for the rights of the child (CDENF) and the Steering Committee for Human Rights in the field of Biomedicine and Health-(CDBIO) jointly developed a <u>Guide to children's participation in decisions about their health</u>, with a view to supporting healthcare professionals and helping them develop their practice, informed by guiding principles, examples and good practice from across Council of Europe member states.

The Guide first presents the legal and conceptual framework for children's participation in the field of healthcare, and then provides guidance and practical advice for engaging with children throughout the decision-making process. It stresses the importance of providing appropriate and adapted information and of creating a safe and inclusive environment where children feel comfortable to express themselves. Finally, it looks at how to effectively consider children's opinions and balance them with the guidance of parents and health professionals, ensuring that decisions remain in their best interests. The Guide is available in a dozen languages.

A group of children developed an adapted version of the guide, with a view to further empowering children and helping them take an active and meaningful part in decisions about their health.

With this work, the Council of Europe hopes to contribute to improving the way in which children are involved and listened to when it comes to their health, an area where all too often still, children's opinions remain overlooked, dismissed or undervalued, especially when adults perceive them as being too young or too uninformed to contribute meaningfully.

#### Aim of the Session

Building on the participation of experts, healthcare professionals and a group of children, this session will provide a platform for exchanges on the important topic of child participation in decisions about their health, and will be an opportunity to increase awareness, discuss challenges as well as opportunities.

The session will include a presentation of the Council of Europe's resources on the topic: the <u>Guide to children's participation in decisions about their health</u>, and related material developed with children.

Invited practitioners will present and discuss some of the examples of good practice that are highlighted in the guide.

Part of the discussion will focus on how to deal with situations where disagreements arise between children/parents/healthcare professionals.

#### **Practical information**

Session	Promoting children's participation in decisions about their health
Strategic objective	Objective 5 - Giving a voice to every child
Day & time	Friday 4 April, 09:00 – 12:30
Venue	Agora Building, Council of Europe
Room	G03 and online
Languages	English and French

#### **Speakers**

- **Imelda Coyne**, Professor and researcher in children's nursing and healthcare, Trinity College Dublin, Ireland
- Lucy Bray, Professor in Child Health Literacy in the Faculty of Health, Social Care and Medicine at Edge Hill University, UK
- **Maria do Céu Machado**, Pediatrician with competence in Management, retired Full Professor at the Faculty of Medicine of the University of Lisbon (FMUL), Portugal
- Amalini Simon, Psychologist and Director of Centre Babel, Paris, France
- Laura Palazzani, Professor of Philosophy of law and biolaw at Lumsa University, Italy
- Moderator: Andrew Clarke, Senior Health Advisor for the NGO Save the Children, UK

### Programme

9:00	Opening statements	
	<ul> <li>Tomas Dolezal, President of the Steering Committee for Human Rights in the fields of Biomedicine and Health (CDBIO)</li> </ul>	
	<ul> <li>Joost van Haelst, member of the Steering Committee for the Rights of the Child (CDENF) and Co-Chair of the Drafting group of the Guide to children's participation in decisions about their health</li> </ul>	
9:15	I. Children's participation in decisions about their health: from theory to practice	
	<ol> <li>Setting the scene: defining and exploring children's participation in the context of individual health decisions</li> </ol>	
	2. Presentation of Council of Europe resources:	
	- Guide to children's participation in decisions about their health	
	- Your Health, Your Say: key messages for children	
	<ol> <li>Panel discussion on implementation, challenges and good practices - based on questions prepared by the group of children advisors</li> </ol>	
10:30	Coffee break	
11:00	II. Managing opposition, disagreements and conflicting views	
	1. Common situations and guiding principles –from the CoE's guide	
	Panel discussion - based on questions prepared by the group of children advisors	
11:45	Q & A session	
12:15	Closing statements	
12:30	End of the session	