ERDERA
European Rare Diseases Research Alliance

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Children right to participate in decisions regarding their health

Annagrazia ALTAVILLA

PhD Sciences/Ethics – HDR Public Law

Espace Ethique PACA - Corse

Hôpitaux Universitaires de Marseille | ap hm

LEGAL CONTEXT ON CHILDREN PARTICIPATION in decision-making process

International Convention of the Rights of the Child (UN)
Fundamental principles underpinning the rights of the child in Europe
Principles of the "Best interests" "Evolving capacities" of the child

INTERNATIONAL LEGISLATION

POLICY REPORTS & YOUTH HEALTH STRATEGIES

POSITION PAPERS OF PROMINENT MEDICAL SOCIETIES

'ENGAGE WITH YOUNG PEOPLE' IS A PRIORITY AT EMA LEVEL
(EMA, Patients and Consumers Working Party – 30th November 2016

EU-COE PROJECTS & STRATEGIES

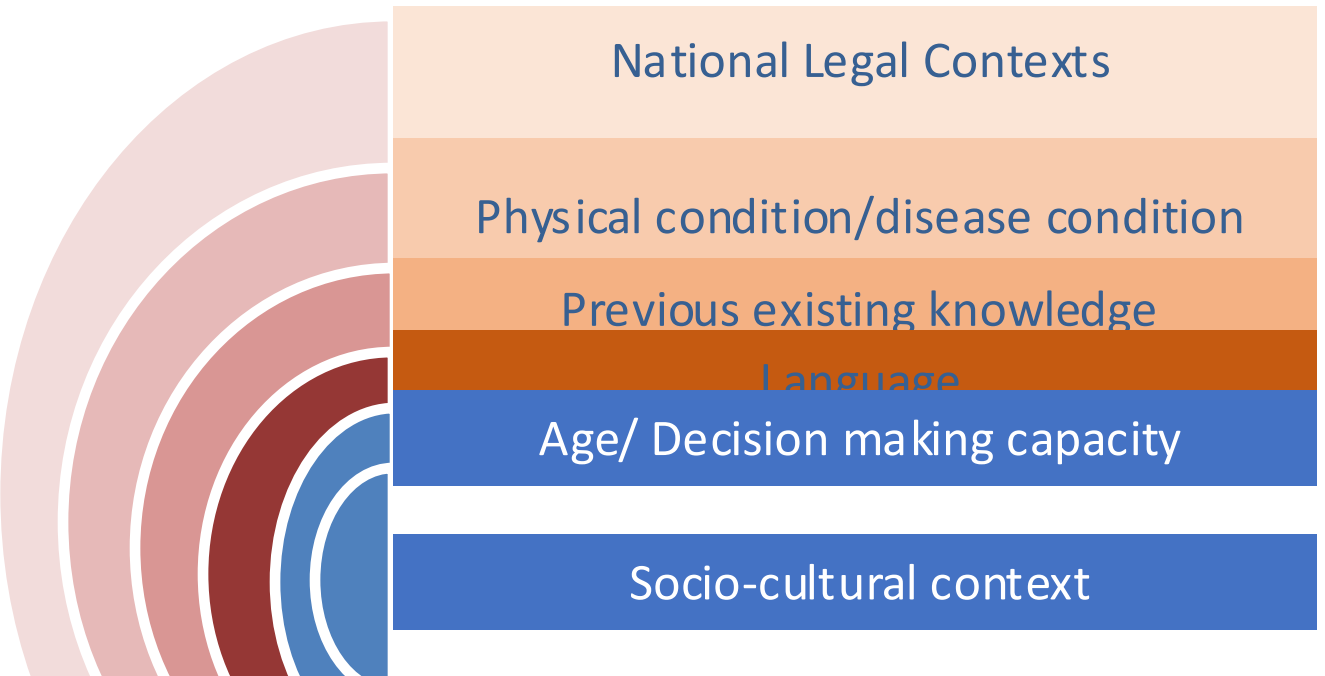
Children's participation in the decision-making process regarding their health

Art. 3 UN Convention

Art. 5 UN Convention

Art. 12 UN Convention

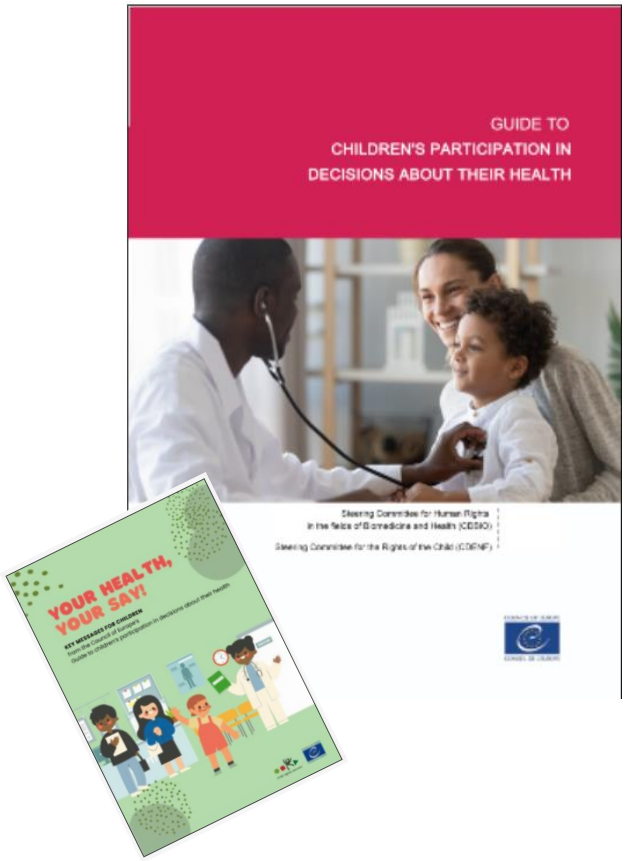
Some key factors influence children comprehension of the information and the consequent involvement in decision-making process





At different stages in their lives,
children require different degrees of protection, provision, prevention and participation
CHILDREN'S VIEWS SHOULD BE GIVEN DUE WEIGHT

COE Guide to the participation of children in decisions about their health



OBJECTIVES

- **To provide essential background information and practical guidance** about how to involve children in decisions concerning their health
- **to help healthcare professionals:**
  - **to understand their role** in supporting children, families and other professionals
  - **develop their practice** informed by relevant principles, frameworks, legislation, and good practice



TARGET

- **healthcare professionals, and other professionals involved**
- **helpful in sensitising parents and/or legal representatives**

COE GUIDE APPROVAL PROCESS

FOR EACH STEP WE HAD TO OBTAIN THE AGREEMENT OF THE COE CDENF AND CDBIO MEMBERS

NOTE OF CONCEPT ON THE TOPIC AND ACTIONS TO BE UNDERTAKEN

SURVEY to identify national provisions, guidelines and practices

REPORT OF THE SURVEY OUTCOMES (185 responders from 36 countries)

Discussion on the content and the structure of the Guide

NOTE OF CONCEPT ON THE CONTENT OF THE GUIDE

Analysis of the scientific literature

REPORT WITH SYSTEMATIC LITERATURE REVIEW

Drafting WG including members from COE CDENF, CDBIO

First draft Guide

CONSULTATION

- **MAIN STAKEHOLDERS CDENF/CDBIO members representing COE states AND**
- **CHILDREN**

Children from 7 countries (12-17)

Implementation of consultation results in the final Guide



THE LANCET Child & Adolescent Health

Altavilla A, Halila R, Kostopoulou M-A, Lwoff L, Uerpmann K, Strengthening children's participation in their health: the new initiative of the Council of Europe, Lancet Child & Adolescent Health 2021 Feb 10: 1-2.

Conditions for a child meaningful participation



- **Transparent and informative**
- Voluntary
- Respectful
- Relevant
- **Child-friendly**
- Inclusive
- **Supported by training of adults**
- Safe and sensitive to risks
- **Accountable**

Feedback to the children on how their opinion influenced the final decision

PARTICIPATION IS A RIGHT NOT AN OBLIGATION

Children are entitled to choose whether or not to express their views or participate in decisions

DECISIONS SHOULD BE TAKEN IN THE BEST INTERESTS OF THE CHILD

COE Guide to the participation of children in decisions regarding their health

Actions to be undertaken

Providing appropriate information

Helping children to express their views

- Building trust
- Privacy
- Involving all team members
- Adequate Environment

Considering children views

- Taken seriously and given due weight

Reaching a decision

Determining children's best interests

Assessing child competency

Managing disagreement/ conflicts

Given the best interests of the child, **the choice that least limits future options should be prioritized**





ROLE OF PARENTS (legal representatives), CHILDREN AND HEALTHCARE PROFESSIONALS



HEALTHCARE
PROFESSIONALS
Central role in facilitating children and parents involvement in decisions

HPs advocate and ensure that parents and children have opportunities for participations also providing an adequate information

Authorisation prior an intervention after having obtained an appropriate information about child health, different options, risks

Decision-making process regarding children health

Children views should be obtained and respected as much as possible prior to decisions

PARENTS – LEGAL REPRESENTATIVES
Natural, essential partners who provide an authorisation

CHILDREN
Rights holders who express their views
Once obtained an adapted information

COE Guide to the participation of children in decision-making processes regarding their health

The **involvement** of children is a **progressive process,** according to their evolving capacities, and implies **four levels of participation**:

1) **being informed**
2) **expressing a view**
3) **influencing a decision**
4) **being the main decision-maker**



Engaging with children as a means to improve individual decision-making processes

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INFORMING CHILDREN

Children have to receive **appropriate and accessible information**
in accordance with their evolving capacities and degree of maturity
to be able to speak out, express views and discuss decisions

Child friendly information materials about relevant topics should be developed and made available
to help communication and mutual understanding

Developed with participatory methodology (involving children)

Examples:

✓ Brochures and leaflets
✓ Videos
✓ Information accessible through social media, specific websites or applications
✓ Games
✓ Other



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EXPRESSING A VIEW

Example to help children express views

✓ Take time alone to discuss with children

✓ Check that child understands the information received

✓ Ask the child what he/she thinks

✓ Reassure that children opinions are important

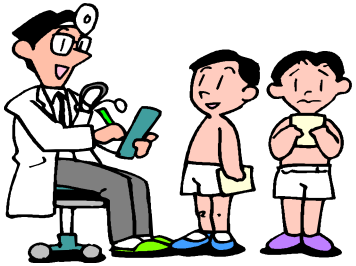
Environments, both physical (office, rooms, furniture…) and psychological (privacy, safety…)

are important to enhance a child's participation

- To make children feel more welcome, reduces fears and anxiety and empower children
- to speak freely about his or her health status and concerns

Children should contribute to developing these environments, tailored and engageable for both children and families





Child life specialists



COE Guide to the participation of children in decision-making processes regarding their health

INFLUENCING A DECISION & GIVING CONSENT

Children views and opinion should be taken seriously and given due weight in the final decision

As children grow, they should be more involved in decisions

According to national law,
PARENTS should provide an authorization prior to medical acts
children can provide ASSENT and express DISSENT
(that should be respected taking into account the clinical context and the best interests of the child)

THE DECISION TAKEN MUST BE EXPLAINED

- **Provide feedback to the children on how their views have influenced the final decision**
- **In the best interests of the child, the option that least restricts future choices should be given priority**



COE Guide to the participation of children in decision-making processes regarding their health

ENGAGING WITH CHILDREN AS A MEANS TO IMPROVE INDIVIDUAL DECISION-MAKING PROCESSES

Children may participate collectively to improve the policies of healthcare institutions and practices also in research

By participating :

- ✓ in awareness campaigns, survey, debates, research projects,
- ✓ In evaluation/complaints mechanisms
- ✓ In advisory groups (e.g. hospital based)
- ✓ In helping information materials for children …
- ✓ In designing activities in hospital







COE VIDEO ON THE RIGHT OF CHILDREN TO PARTICIPATION
DEVELOPPED FOR CHILDREN BY CHILDREN

Objective :
to use appropriate language and an exciting, interesting scenario

Participatory methodology

- **Children trained** about child rights / right to participation
- **Script** -developed on the basis of relevant international documents- **discussed with COE representatives and TEDDY kids**
- **Brainstorming sessions** to collect ideas and raise consensus on scenario, format, animations, animated characters …



https://vimeo.com/712037980?share=copy

COE CHILD FRIENDLY GUIDE ON CHILDREN PARTICIATION





In Autumn 2024, a group of teenagers from different countries — Denis, Throstur, Lana, Nick, Molly, Dion, Sara, Leonardo, Christina, Rayan, Elodie, Sarah, and Jose — worked together to prepare this summary for you and other children.

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Annagrazia ALTAVILLA

annagrazia.altavilla@univ-amu.fr

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