YOUR HEALTH, YOUR SAY!

KEY MESSAGES FOR CHILDREN

from the Council of Europe's Guide to children's participation in decisions about their health





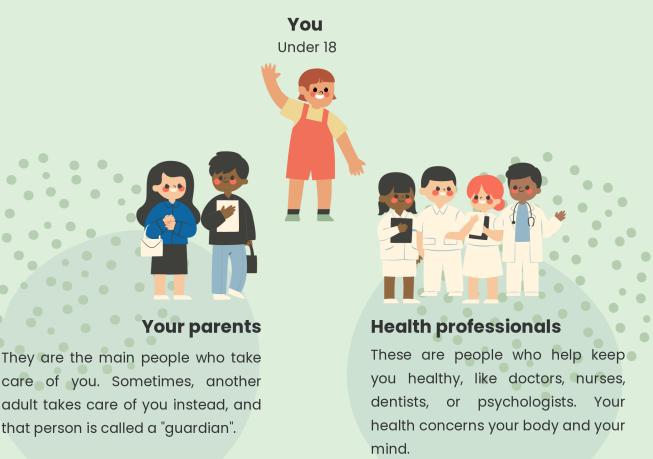


HELLO!

Your health is important.

As a child, you may not be able to make decisions about your health on your own. But you have **the right to be involved** in those decisions, just as other children have the right to be involved in decisions that concern their own health.

When a decision is taken about your health, different persons are usually involved:



This booklet describes how you can be involved in your healthcare and how important it is that doctors, nurses, and other **adults include you in decisions**. It gives examples of how they can do that so that good decisions are taken.

You will read and learn about some important aspects of the decision-making process, including:



YOUR RIGHT TO BE HEARD

INFORMATION IS KEY

EXPRESSING YOUR VIEW

OPEN AND SAFE COMMUNICATION

THE ROLE OF PARENTS

MAKING DECISIONS

DISAGREEMENTS

At the end of the document, you will find **additional information**, including **useful definitions**, if you wish to know more about this topic.



YOUR RIGHT TO BE HEARD

When you go for a routine visit to a doctor, get a blood test or an eye test, or when you need to get a treatment or operation in a hospital, many small and some big decisions are taken with you and for you.

You have the right to share your thoughts and feelings about your health. You can say what you want or don't want. There is no age limit — every child can have a say, even young children can say what they want and prefer.

It's good to practice giving your opinion in all situations. Adults, including doctors and nurses should help you practice this.

Let's look at some examples:

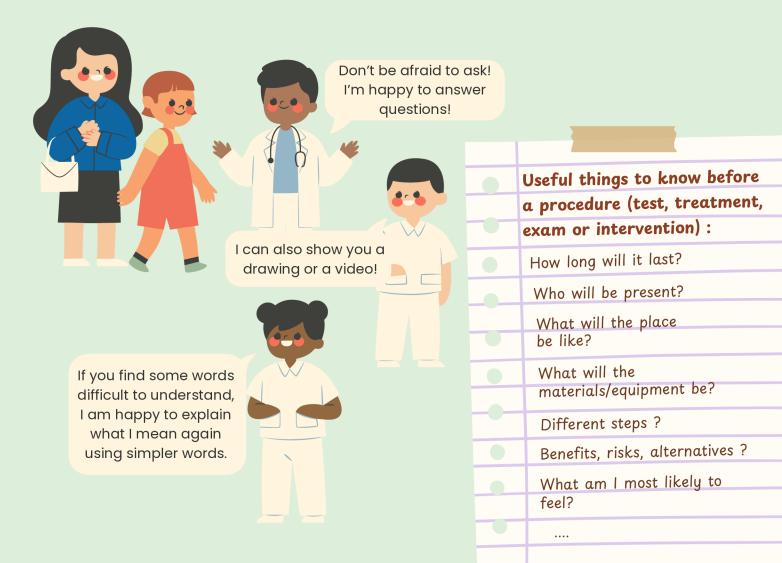


INFORMATION IS KEY

It's very important that you **understand your health situation as best as possible** before you can decide what to think about it.

Adults, especially doctors and nurses, must explain what's wrong, how they can help you feel better, and what will happen next. They should explain it in a way that makes sense to you. Every child is different, so the way they explain things may change. You can get this information by talking to your parent or nurse or doctor.

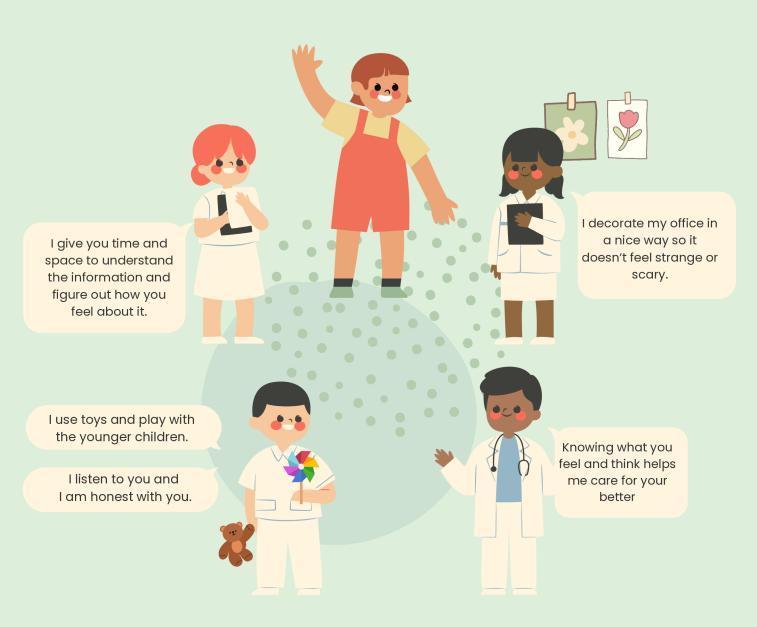
Adults must make sure that you have understood things well. They should also explain to you who is who, and who does what, especially in a hospital, where you may meet with many different people.



OPEN AND SAFE COMMUNICATION

Information is important to help you form an opinion and influence decisions about your health. It must be shared in a way that you feel **comfortable and safe**.

Adults are here to support you and help you express your feelings and opinions, think things through and reach your own conclusions. There are many ways in which health professionals can help you feel comfortable and encourage you to take an active role in decisions. Let's see some examples!



The information about your health will stay between you, the healthcare professionals caring for you and your parents or those responsible for you.

Some information might be hard to hear, but adults should always tell you the truth. They need to explain any risks and if something might be uncomfortable or painful.



I will do everything to reduce the pain. You can squeeze my hand when it hurts.

If you'd like, we can show you a video during the procedure. How do you feel about that?

Children can understand a lot and often want to know as much as possible, it helps them be prepared for what's going to happen

THE ROLE OF PARENTS

Your parents are important persons to support you. Your parents or people who care for you know you very well and will often know what to do and how to help you when consulting a doctor or going to the hospital.

It is important that you discuss things with your parents and let them know what you feel, so they can support you, and because **in many** cases, it is them who will have the final say about a decision concerning you.

How do you feel about the visit to the doctor today?

What are the things you are still wondering about and concerned with?

You have the right to have your parents with you during visits (called consultations), treatments or when you have to stay in a hospital. If your parents or carers cannot be present, you can have another adult you trust to help you.



EXPRESSING YOUR VIEW

You can **express your opinion in different ways**: you can speak, write, even draw. Sometimes, we show that we agree by the way we act, without using words. By giving your arm to have your blood pressure checked, you are expressing the fact that it is ok. That's why health professionals have to pay attention to **body language**, including of children who cannot speak.



Sometimes a health professional **will ask you** orally if you agree and then they will sometimes write your answer down in your medical file.

And in some cases, you and/or your parents may be required to **sign** a **special form** or write what you want or what you don't want, in a more formal way.

Adults are here to help you express your opinion. But it's also ok for you to say that you're not sure or if you prefer that your parents decide for you.

MAKING DECISIONS

A good decision means the decision is discussed, that it is good for the child, and that it takes into account what the child wants.

In other words, when adults take a decision about you, they should have in mind what you think and want. That means that **adults must** listen to you and take you seriously. They should think about how their decisions will affect you, and do what is best for you now and for your future.

As you get older, you understand more and better, and can be more actively involved in decision-making. Therefore, your opinion will "weigh" more over time. But this doesn't mean that the opinion of a young child does not count!



DISAGREEMENTS

A good decision requires that all people concerned speak together and listen to each other to find the best solution.

But there can be situations where persons involved in making a decision about a child have **different opinions**. For example, you may disagree with your parents, or your parents may disagree with the health professionals.

Taking your opinion seriously doesn't always mean that the final decision will be what you wanted or everything that you would want. Sometimes that won't be possible. But when looking for the best possible solution for you, **health professionals should have your preferences in mind**, they will know what they must absolutely avoid and try to do the best to respect your wishes.

In all cases you need to be told exactly what was decided and why.



I understand and I wish we could arrange that, but your birthday is still in a few months time and if we wait that long, the treatment may not give the best results.



Let's see **what can be done to help** in complex situations where people disagree or think differently:



We discuss the situation together, with you and your parents, several times if necessary, to find a suitable solution.

In most cases, this will be enough to solve the problem.



If needed, another person, called a mediator, can be called in for help and advice.

Mediators help people understand each other's positions and find a solution together to resolve a conflict.



Some hospitals have special boards or commissions that can be asked to advise when persons involved cannot find a common position.



Exceptionnally, someone responsible for the protection of children (like a judge) may be asked to decide.



All these people will always have in mind what is best for you, this is called your "best interests".

GOING FURTHER





YOUR HEALTH, YOUR RIGHTS

There are two important documents for the rights of children in the field of health.

The **United Nations Convention on the Rights of the Child** explains all of the rights of children so they can enjoy a good life in all places where they live and to stay safe from danger.

Regarding **healthcare**, it says that children have the right to enjoy the best state of health possible. That means that children need to receive healthcare of good quality and the care which is best for them.

The Convention also says that children have the **right to participate in decisions** that concern them in different areas of life. This means that children have the right to express their opinion, including regarding their health and well-being, and they have the right to be listened to and taken seriously.

These rights concern **all children equally,** regardless of where they are coming from, what they look like, what language they speak, who their parents are or whether they have a disability.

The **Council of Europe** has a convention called **Oviedo Convention** that deals with medical interventions. It talks about adults and children.

It says that in general, persons must give their free and informed consent, meaning they must agree to have the intervention. In the case of children, it says that if in the country they live in, the law does not allow them to decide on their own, still the opinion of a child must be considered, according to their age and maturity. Also, the intervention can only happen if it is good for the child.

DIFFERENT COUNTRIES, DIFFERENT RULES?



Countries have specific laws, rules and cultures. In some countries, as long as a child is a child, their parents need to give their authorisation. In other countries the law makes it possible for older children, for example, starting when they are 15 or 16 years old or when they are mature enough, to formally make decisions about their health on their own: this is known as "consent".

But remember, in all cases and in all countries: a child must be explained what the problem is, and what is about to happen to them. They must be asked what they think!

Also a child who is allowed to make a formal decision still needs support and advice; it doesn't mean they are left alone!

INFLUENCING POLICIES AND LAWS

This booklet explains how you and other children have the right to be involved in health decisions that concern them directly.



But children and groups of children can also give their opinion about the laws of the country where they live. They can take part in the planning and programming of health services, or even participate in the design and running of training for health professionals.

If children are consulted about law projects related to healthcare and health policy, everyone will benefit from better decisions!

CHILD-FRIENDLY DEFINITIONS OF USEFUL TERMS

Authorisation or consent: a formal agreement to accept medical care, given by the parents or carers of the child, or, if the laws of the country allow it, by the child themselves.

Best Interests: this means that people should always think about the effect any decision they are making will have on a child and if that decision is really the best for a child.

Child: a person who is younger than 18 years old. Adults are 18 or older.

Child participation: ensures that children can have a say about decisions which concern them individually or as a group.

Children's rights: are what every child should have or be able to do. Almost all countries have agreed that children have special rights and governments have promised to make sure all children have the important things they need to live a safe and good life.

Council of Europe: a European organisation of 46 countries, called member states. It was set up to make sure that all these countries protect human rights, including children's rights, by supporting children and young people to develop their full potential, and by preventing any harm.

Healthcare: a general term for medical care, it includes seeing a doctor, getting a treatment or intervention, staying at a hospital.

Healthcare professionals: include doctors, nurses, dentists, or psychologists, anyone who works in healthcare.

Governments: the people who make rules for a given country or society and administer them. At a country level, a government can be a big system that encompasses a lot of institutions and leaders such as legislatures (the group of people that make laws), administration (those that help society run and provide services), judiciaries (courts where judges help settle conflicts between people or organizations, solve problems and find the right justice for a crime)

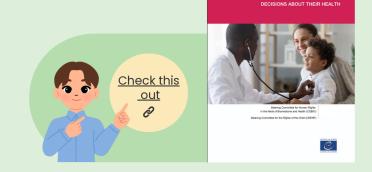
Legal representative: a person who represents a child legally, either the parents or a legal guardian if the parents cannot be there for the child.

United Nations Convention on the Rights of the Child: an important document that lists and explains all of the rights of children, as well as the responsibilities of governments. All the rights are connected, they are all equally important and they cannot be taken away from children.

WHY THIS BOOKLET?

In 2024, the Council of Europe published a <u>Guide to Children's</u> participation in decisions about their health.

It was written to help doctors, nurses, and other adults make the best health decisions for a child. It shows them how to include the child and gives helpful advice and examples.





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.

They wanted to help children understand their rights and how they can take part in decisions about their health. Child Rights Connect and the Council of Europe supported them.

Child Rights Connect is an independent, nonprofit organisation founded in 1983 which is today one of the largest international child rights networks with more than 120 member and observer organisations.

www.childrightsconnect.org

This project was led by Zsuzsanna Rutai, Child Empowerment and Safeguarding Officer and Imen Talhaoui Advocacy Officer in 2024.



The **Council of Europe** is a European organisation of 46 countries, called members states. One of the reasons it was set up is to make sure that all these countries protect human rights, including children's rights, in view of helping children develop their full potential, and protecting them from any harm.

www.coe.int





FOR ADULTS USING THIS BOOKLET WITH CHILDREN

These notes are intended for adults – including parents, educators, social workers, and healthcare professionals – who would like to use the booklet with children to discuss the participation of children in individual health decisions.

The booklet can be used whether the children are actually dealing with a health situation or not – before or after a visit to the doctor or the hospital, or at any time to build general knowledge around the topic.

You may want to engage with children on this topic individually, or in a group. The booklet was written for children aged between 9 and 15 years, but older adolescents may find it interesting too.

If you work in a setting where you can display this booklet in a way that it is accessible to children, you can encourage them to take a copy home and engage with you or other trusted adults later on.

This booklet is a summary of the Council of Europe's <u>Guide to Children's participation in decisions about their health</u> published in 2024 with the aim to provide information and advice, primarily for healthcare professionals, about how to involve children in decision-making regarding their health.



The Guide starts by presenting the theoretical and legal context and progresses to describe important components of the decision-making process, helping health professionals understand their role in supporting children, families, and other professionals to enact child participation in practice. Key concepts of consent, assent, and best interests are

discussed, as well as common healthcare situations where participation in decision making may sometimes be perceived as more challenging. Examples and links to good practice are provided throughout the Guide.

KEY MESSAGES

Below are the most important takeaways of the document. In your discussions with children you may want to cover all key messages or focus on the most important or more relevant considering the situation of the child.

Your right to be heard

In accordance with Article 12 of the UN Convention on the Rights of the Child, children have the right to participate in and influence decisions in all matters that affect their lives. That includes their health. This ensures that their best interests are always considered and that they receive the best health care possible.

____ Information is key

Children have the right to receive information about their health that is given in a way that they can understand. The information needs to be accurate and enough for them to make an informed decision.

Open and safe communication

Children have the right to receive support to form their opinion and feel safe during their interaction with adults. They also have the right to privacy and confidentiality which means that information about their health should not be shared with anyone unless it is necessary for their best interests.

The role of parents

Children have the right to have their parents with them when receiving healthcare and rely on them for support when making decisions. In many cases, the parents are the ones who formally give their authorisation for an intervention.

It can happen that children wish to discuss or access healthcare without their parents being present.

Expressing your view

Children have the right to express themselves and must be encouraged and supported to do so, regardless of their age. Nonverbal expressions, such as body language, count too. This is true in all cases, regardless of the rules for consent.

Making decisions

Children's views must be taken into consideration, according to their evolving capacities. When the final decision is not what the child wanted, the reasons for reaching this decision must be explained to them.

Disagreements

There can be differing opinions and disagreements between a child, parents or health professionals. Such situations may often be solved through further discussion. However, there may be cases of conflict where an external person or body need to be involved to decide what is in the best interest of the child.

Going further

This section provides additional information, especially on relevant legal texts. It also mentions that children can be involved in the development and review of national legislations and policies.

NATIONAL CONTEXT

The topic of the Guide is governed by national legislation and bylaws. You may need to do some research about the legal framework in your country related to healthcare systems, patient rights and children's rights, to make sure that you are able to answer questions.

Is there a law in my country on children's rights? Does it mention participation?

Is there a law on healthcare and patients' rights in my country? If so, what are the relevant provisions regarding children and their participation in decisions? For example, right to be informed, right to have an opinion and have it considered?

Is there an age when children can formally consent to a medical intervention earlier than their 18th birthday? If yes, according to which criteria (age or maturity or other)?

Are there any other laws, regulations or guidance relevant to the participation of children in health related decision-making?

Are there any guidelines applicable to situations of disagreements or conflicts: for example, if a child / parents or caregivers / healthcare professionals do not agree. What do they provide for?



It is also important that you think about the necessary safeguarding measures you need to put in place. Children, whether in an individual or a group setting, can share personal details and stories that may reveal that they don't feel comfortable accessing healthcare. If they've had a bad experience or feel afraid, even though they understand their rights in this context, they might not be able to exercise them. It is always good it to follow-up on those cases.

ONE-TO-ONE DISCUSSIONS

In an individual setting, you may want to ask the child one of the following 3 options depending on the situation, your relationship to the child and their level of maturity. If you see hesitation, try offering another option.



Would you like to read the booklet first and then we talk about it?



Would you like me to explain what the booklet is about and then you can read it too? Of course we can talk about it again, anytime and I am happy to answer if you have questions.



Would you like us to read the booklet together? Then we can talk about it?

GROUP ACTIVITIES

This booklet can be used to prepare your group for a session about child participation in health-related decisions or as a resource recommended after such a session. Following are some simple activities, using non-formal means, that can help share the key messages with the group.

If you are planning to work with a group, prepare and plan your session in a way that suits the needs of the participants and the setting.

The booklet can be used to raise awareness and build capacity of children on the topic and it can form part of children's rights education, focusing on the field of health and the right to participation.

In group settings, non-formal educational methods can be used.

According to the Compass – Manual for human rights education with young people, non-formal education refers to planned, structured programmes and processes of personal and social education for young people designed to improve a range of skills and competences, outside the formal educational curriculum.



LET'S QUIZ

You can prepare a short quiz either to introduce the topic and prompt the discussion or to use it at the end to check whether the children understood everything well and have no more questions. You can use the key messages to prepare the quiz.

With a bigger group of children, you can divide the group in sets of 4 or 5 to discuss their individual replies before calling the whole group again. You can also award points or offer a prize for those who get correct answers!



PERSONAL NOTES:

FOUR CORNERS

If you have enough space or if you can go outside, you may use this this activity to have the group move around.

You will need to prepare statements, scenarios or questions with 4 answers or options, based on the key messages. You then assign each of the four corners of the room (or areas) one of the options: A, B, C, D.

The children are grouped in the middle of the room, then you read out the questions or statements one by one. Each time, the children move to the corner or area that corresponds to the option they choose. Once they've moved, you can ask them why they chose that option.

For example, "What are the ways in which children can express their wishes when a decision is taken about their health? A) They need to say what they want. B) They can use gestures or show what they want. C) They need write an official letter and sign it. D) I have another idea!".

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