

GUIDE TO CHILDREN'S PARTICIPATION IN DECISIONS ABOUT THEIR HEALTH



Steering Committee for Human Rights
in the fields of Biomedicine and Health (CDBIO)

Steering Committee for the Rights of the Child (CDENF)

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Council of Europe

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ABSTRACT

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 provides evidence that there are multiple benefits to involving children in decisions about their health; in fact, meaningful participation of children is considered an important contributor for achieving high-quality care for children.

However, there can be uncertainty as to how to support and foster effective child participation in real-world healthcare situations that are often complex, accounting for differing legislative frameworks and for the varying role played by other actors, namely the parents and health professionals, in the decision-making process.

Children across Council of Europe Member States may currently experience different situations and may encounter varying practices as regards their participation in healthcare decisions. Child participation may be more effective in some settings, but there remains room for improvement in all countries.

The Guide provides information and advice, primarily for healthcare professionals, about how to involve children in decision-making processes regarding their health. It starts by presenting the theoretical and legal context and progresses to describe important components of the decision-making process, helping health professionals to understand their role in supporting children, families, and other professionals to enact this 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.

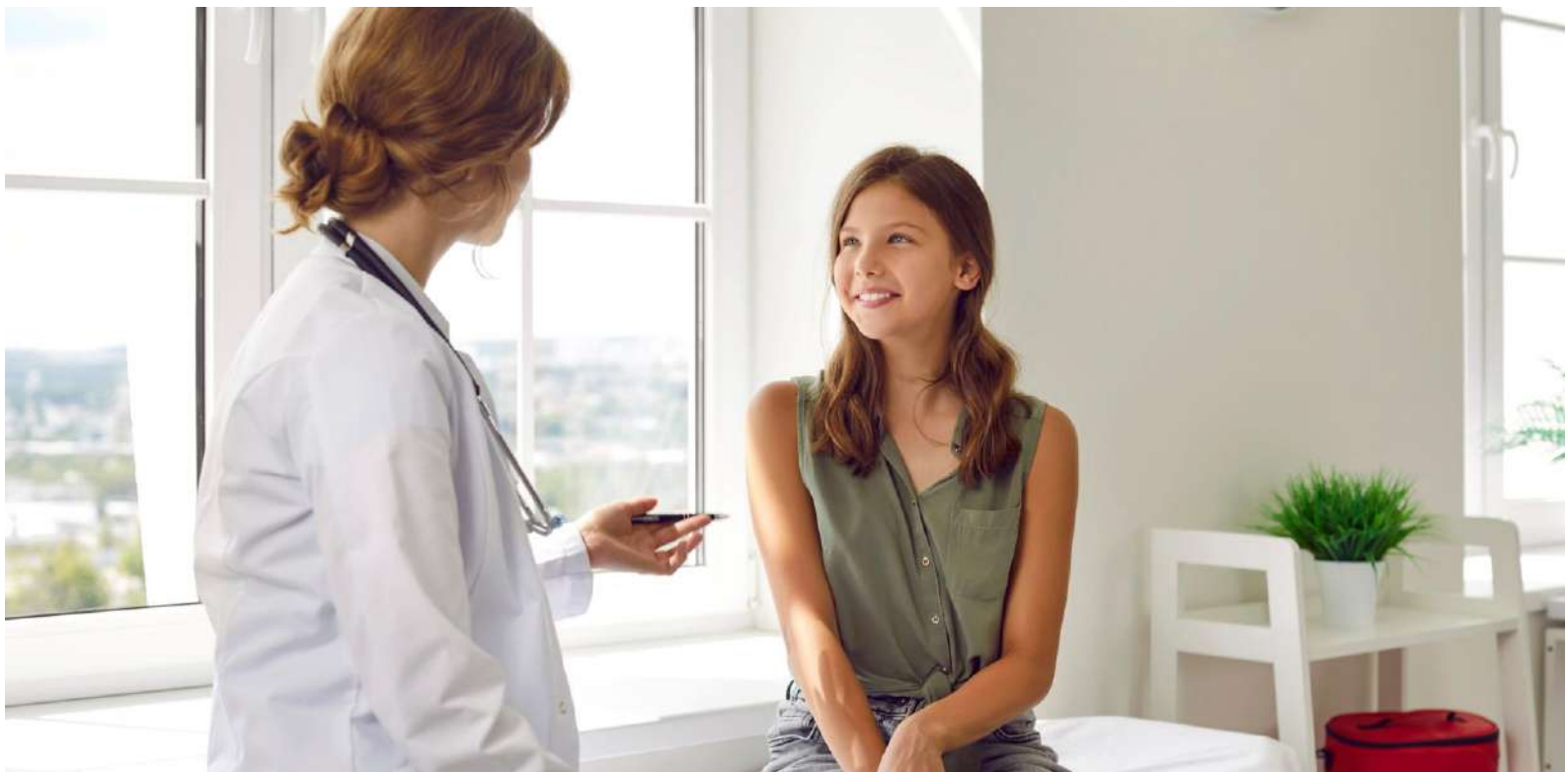
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The Guide was prepared by a group of government and independent experts, who included members of the Council of Europe Steering Committee for Human Rights in the fields of Biomedicine and Health (CDBIO) and of the Steering Committee for the Rights of the Child (CDENF). The Drafting Group was co-chaired by Ms Ritva Halila (CDBIO member from Finland) and Mr Joost Van Haelst (CDENF member from Belgium) and was supported in its work by Dr Annagrazia Altavilla and Mr Andrew Clarke.

A draft was submitted for consultation to key stakeholders (Council of Europe delegates, representatives of scientific societies, research organisations, healthcare institutions, etc.) and was discussed with a group of children from the TEDDY European Network of Excellence for Paediatric Research / TEDDY Kids.¹

The text was revised and enriched based on the contributions received during the consultations.

¹ Focus groups discussions were held with 20 children aged 12-18 from Albania, France, Greece, Italy, Latvia, Malta, and Switzerland.



INTRODUCTION

Human rights instruments, notably the UN Convention on the Rights of the Child (UNCRC), recognise that children are rights holders with a progressively evolving ability to make their own decisions. This reflects a change in the general perception of the autonomy and protection of children regarding their capacity to participate in decision making. Since the adoption of the Convention in 1989, considerable progress has been achieved at the local, national, regional and global level in the development of legislation, policies and methodologies to promote the implementation of the right of all children to express their view.

The UNCRC recognises that children have a right to express their views in all matters that affect them, and to have these views properly taken into account. Health is one such matter.

Through its work, the Council of Europe strives to make this right a reality in its member states and has produced guidance on the implementation of active and meaningful child participation, such as:

- The [Committee of Ministers Recommendation CM/ Rec\(2012\)2 on the participation of children and young people under the age of 18](#).²
The recommendation defines as children having “the right, the means, the space, the opportunity and, where necessary, the support to freely express their views, to be heard and to contribute to decision making on matters affecting them, their views being given due weight in accordance with their age and maturity”, recognising their evolving capabilities.
- [Listen – Act – Change - Council of Europe Handbook on children’s participation - For professionals working for and with children \(2020\)](#).³

² http://search.coe.int/cm/Pages/result_details.aspx?ObjectId=09000016805cb0ca

³ <https://edoc.coe.int/en/children-s-rights/9288-listen-act-change-council-of-europe-handbook-on-childrens-participation.html>

Meaningful participation has increasingly been considered as a key standard for achieving high-quality care for children.⁴ The Council of Europe seeks to further promote a child rights-based and participatory approach to healthcare and research, as reflected in the following guidelines and strategy documents:

- [Guidelines of the Committee of Ministers of the Council of Europe on child-friendly health care](#)⁵ (2011).
- [Strategy for the Rights of the Child \(2022-2027\)](#)⁶, Steering Committee for the Rights of the Child (CDENF).
- [Strategic Action Plan on Human Rights and Technologies in Biomedicine \(2020-2025\)](#)⁷, Steering Committee for Human Rights in the fields of Biomedicine and Health (CDBIO).

Participation in healthcare in general, has been encouraged by the growing recognition that a patient is equipped with personal skills concerning their body and their state of health and that they are capable of actively contributing to the therapeutic relationship by collaborating and negotiating with the health professional in order to achieve the best possible state of health.

Similarly, children have unique knowledge about their lives, needs and concerns and taking their views into account in decisions and actions that affect them brings significant immediate and long-term benefits for them, as well as for the community, and enables to make better, more informed decisions. Children who actively participate in individual decision-making processes which concern them are likely to be more informed, to feel better prepared, and to experience less anxiety about the unknown. Participation instils children with a sense of control, which results in increased cooperation with procedures, better adjustment and adherence to treatment, which helps to reduce conflicts that may arise during these processes. Children develop competence and confidence, leading to their empowerment and increasing ability. Participation also helps to improve care, as the child brings unique expertise from their own experience.

However, there is often uncertainty as to how the increased recognition of children's decision-making capacity in matters concerning their health and general well-being should be addressed in practice. Finding the right balance between autonomy (the right of children to be heard and their opinions considered) and protection (the responsibility of adults to protect children and to provide for them) is a challenge when considering that children's rights are situated within a larger set of parental duties and responsibilities which also focus on their best interests.

⁴ WHO, Standards for improving the quality of care for children and young adolescents in health facilities, Report 2018, <https://www.who.int/publications/i/item/9789241565554>

⁵ https://search.coe.int/cm/Pages/result_details.aspx?ObjectId=09000016805c1527

⁶ <https://rm.coe.int/council-of-europe-strategy-for-the-rights-of-the-child-2022-2027-child/1680a5ef27>

⁷ <https://rm.coe.int/strategic-action-plan-final-e/1680a2c5d2>

SCOPE AND AIM OF THE GUIDE

The Guide is intended to provide essential background information and practical guidance about how to involve children in decision-making processes concerning their health. It aims, first and foremost, to help healthcare professionals, and other professionals involved:

- to understand what their role is in supporting children, families and other professionals to participate in the process,
- to develop their practice in this area, informed by relevant principles, frameworks, legislation, and good practice.

It will also be helpful in sensitising parents and/or legal representatives.

For the purpose of this document, a “child” refers to any person under the age of 18 years. The term “parents” must be understood as “parents or other holders of parental authority”.

The Guide focuses on the participation of children in individual health-care decisions. However, the last section briefly looks at how children’s involvement in the development of health policy and services also contributes to improving paediatric care generally, as well as individual decision-making processes.



LEGAL AND CONCEPTUAL FRAMEWORKS FOR CHILDREN'S PARTICIPATION IN DECISIONS ABOUT THEIR HEALTH

MAIN PROVISIONS OF INTERNATIONAL LAW

GENERAL PRINCIPLES

In 1989, with the adoption of the [United Nations Convention on the Rights of the Child \(UNCRC\)](https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child)⁸, a fundamental value underpinning children's rights was put forward: the vision that children, defined as any person under the age of 18 years⁹, must be agents in their own lives, in particular, through Article 12, which sets out the right of all children to be heard and taken seriously, in a manner consistent with their evolving capacities.

“ Article 12: 1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child. ”

⁸ <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child>

⁹ This definition is in line with the provisions of Article 1 of the UNCRC. Article 6 (2) of the Convention on Human Rights and Biomedicine, refers to the term “minor”. For the purposes of this guide, the term “child” is used, unless direct reference is made to provisions using different terminology.

The right granted by this article later became known as “children’s right to participation”.

Through its [General Comment No.12 \(2009\) - The right of the child to be heard](#)¹⁰, the Committee on the Rights of the Child provides guidance on how to interpret children’s right to participate in different areas of life, including healthcare.

Extract from **General Comment No.12** (2009)

“ 100. Children, including young children, should be included in decision-making processes, in a manner consistent with their evolving capacities. They should be provided with information about proposed treatments and their effects and outcomes, including in formats appropriate and accessible to children with disabilities”.

101. States parties need to introduce legislation or regulations to ensure that children have access to confidential medical counselling and advice without parental consent, irrespective of the child’s age, where this is needed for the child’s safety or well-being. Children may need such access, for example, where they are experiencing violence or abuse at home, or in need of reproductive health education or services, or in case of conflicts between parents and the child over access to health services. The right to counselling and advice is distinct from the right to give medical consent and should not be subject to any age limit.

102. The Committee welcomes the introduction in some countries of a fixed age at which the right to consent transfers to the child, and encourages States parties to give consideration to the introduction of such legislation. Thus, children above that age have an entitlement to give consent without the requirement for any individual professional assessment of capacity after consultation with an independent and competent expert. However, the Committee strongly recommends that States parties ensure that, where a younger child can demonstrate capacity to express an informed view on her or his treatment, this view is given due weight.

103. Physicians and health-care facilities should provide clear and accessible information to children on their rights concerning their participation in paediatric research and clinical trials. They have to be informed about the research, so that their informed consent can be obtained in addition to other procedural safeguards. ”

Article 12 of the UNCRC, or the right of all children to be heard and taken seriously as a general principle, is linked to the other general principles of the Convention¹¹, and, in particular, is interdependent with primary consideration of the *best interests of the child* (article 3). It should therefore also be considered in the interpretation and implementation of all other rights.

The UN Convention makes no distinction based on age or other characteristics: all children have the right to receive appropriate information and to express their views, and therefore to

¹⁰ UNCRC Committee (2009) General Comment No 12 The right of the child to be heard. Paragraphs 98-103 ; available at <https://www2.ohchr.org/english/bodies/crc/docs/advanceversions/crc-c-gc-12.pdf>.

¹¹ such as the right to non-discrimination (article 2), the right to life, survival and development (article 6).

participate in the decision-making process, taking into account their best interests and what is necessary for their well-being and development.

At the European level, the [Council of Europe Convention on Human Rights and Biomedicine](#) (Oviedo Convention, 1997)¹², lays down the general rule that an intervention in the health field may only be carried out after the person concerned has given free and informed consent to it, based on prior relevant information (article 5). An intervention on a child who cannot consent, according to law, requires the authorisation of their representative, usually a parent, but their opinion shall be taken into consideration as an increasingly determining factor in proportion to his or her age and degree of maturity and, as a general rule, an intervention can only be carried out if it is for the child's direct benefit (article 6).

The [Explanatory Report to the Convention](#)¹³ specifies that:

- situations should take account of the nature and seriousness of the intervention as well as the child's age and ability to understand, and that the child's opinion should increasingly carry more weight in the final decision. It states that in some cases, this could even lead to the conclusion that the consent of a child should be necessary, or at least sufficient for some interventions (paragraph 45).
- In some very specific situations and under some very strict conditions in the context of medical research and the removal of regenerative tissue respectively, the rule of direct benefit of the person may be waived." (Articles 17 and 20 of the Convention (paragraph 44)

SPECIFIC SITUATIONS

Additional international legal instruments deal with specific health situations or to particular groups of children and re-affirm and/or complement the principles laid down by the two conventions cited above.

Children's participation in biomedical research

Children's participation in biomedical research, including clinical trials, is subject to additional safeguards.

In particular, research cannot be carried out if a child explicitly objects to it. Even if the legal representatives provide their authorisation, a child's refusal or the revocation of their acceptance cannot be overruled.

This is reflected at European level, in the [Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Biomedical Research \(CETS No. 195\)](#)¹⁴ that stipulates that research must not be carried out if a person who is not able to consent to research objects to it:

¹² CETS no. 164, <https://www.coe.int/en/web/conventions/full-list?module=treaty-detail&treatynum=164>

¹³ <https://rm.coe.int/16800ccde5>

¹⁴ <https://www.coe.int/en/web/conventions/full-list?module=treaty-detail&treatynum=195>



CHAPTER V – Protection of persons not able to consent to research

Article 15 – Protection of persons not able to consent to research

1. Research on a person without the capacity to consent to research may be undertaken only if all the following specific conditions are met:

- i. the results of the research have the potential to produce real and direct benefit to his or her health;
- ii. Research of comparable effectiveness cannot be carried out on individuals capable of giving consent;
- iii. the person undergoing research has been informed of his or her rights and the safeguards prescribed by law for his or her protection, unless this person is not in a state to receive the information;
- iv. the necessary authorisation has been given specifically and in writing by the legal representative or an authority, person or body provided for by law, and after having received the information required by Article 16, taking into account the person's previously expressed wishes or objections. An adult not able to consent shall as far as possible take part in the authorisation procedure. The opinion of a minor shall be taken into consideration as an increasingly determining factor in proportion to age and degree of maturity;
- v. the person concerned does not object.

(...)



Within the European Union, EU Regulation 536/2014 on clinical trials on medicinal products for human use establishes that the explicit wish of a minor who is capable of forming an opinion and assessing the information, to refuse participation in, or to withdraw from, the clinical trial at any time, is to be respected by the investigator.



Article 32 Clinical trials on minors

1. A clinical trial on minors may be conducted only where, in addition to the conditions set out in Article 28, all of the following conditions are met:

- (a) the informed consent of their legally designated representative has been obtained;
- (b) the minors have received the information referred to in Article 29(2) in a way adapted to their age and mental maturity and from investigators or members of the investigating team who are trained or experienced in working with children;
- (c) the explicit wish of a minor who is capable of forming an opinion and assessing the information referred to in Article 29(2) to refuse participation in, or to withdraw from, the clinical trial at any time, is respected by the investigator;

(...)

2. The minor shall take part in the informed consent procedure in a way adapted to his or her age and developmental maturity.

3. If during a clinical trial the minor reaches the age of legal competence to give informed consent as defined in the law of the Member State concerned, his or her express informed consent shall be obtained before that subject can continue to participate in the clinical trial.



Genetic testing

The [Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes \(CETS No. 203\)](#)¹⁵ provides that “(w)here, according to law, a minor does not have the capacity to consent, a genetic test on this person shall be deferred until attainment of such capacity unless that delay would be detrimental to his or her health or well-being” (article 10). And in any case, “(w)here, according to law, a minor does not have the capacity to consent to a genetic test, that test may only be carried out with the authorisation of his or her representative or an authority or a person or body provided for by law. The opinion of the minor shall be taken into consideration as an increasingly determining factor in proportion to his or her age and degree of maturity” (article 12).

Emergency situations

In emergency situations, health professionals may be faced with a conflict of duties between their obligations to provide care and to seek the patient's consent. The law provides for conditions under which medical decisions may be taken without the authorisation of the child's legal representative.

Oviedo convention

“ Article 8 – Emergency situation

When because of an emergency situation the appropriate consent cannot be obtained, any medically necessary intervention may be carried out immediately for the benefit of the health of the individual concerned.

The [Explanatory Report to the Oviedo Convention](#)¹⁶ (paragraphs 56-62) elaborates that the possibility to act without the authorisation of the legal representative is restricted to:

- emergencies which prevent the practitioner from obtaining the appropriate consent and is limited solely to medically necessary interventions which cannot be delayed. Interventions for which a delay is acceptable are excluded;
- the intervention must be carried out for the immediate benefit of the individual concerned;
- in emergency situations health care professionals must make every reasonable effort to determine what the patient would want;
- when persons have previously expressed their wishes, these shall be taken into account. Nevertheless, taking previously expressed wishes into account does not mean that they should necessarily be followed;
- these provisions apply both to persons who are capable and to persons who are unable either *de jure* or *de facto* to give consent. ”

¹⁵ <https://www.coe.int/en/web/conventions/full-list?module=treaty-detail&treatynum=203>

¹⁶ <https://rm.coe.int/1680a8e4d0>

The [EU Regulation 536/2014 on clinical trials](#)¹⁷

According to Article 35, where, due to the urgency of the situation, caused by a sudden life-threatening or other sudden serious medical condition, the subject is unable to provide prior informed consent and to receive prior information on the clinical trial, and it is not possible to obtain informed consent prior to the intervention, patients may be enrolled in the clinical trial under the following conditions:

- the clinical trial relates directly to the medical condition because of which it is not possible within the therapeutic window to obtain prior informed consent from the subject or from his or her legally designated representative;
- there are scientific grounds to expect that participation of the subject in the clinical trial will have the potential to produce a direct clinically relevant benefit for the subject resulting in a measurable health-related improvement;
- the clinical trial poses a minimal risk to, and imposes a minimal burden on, the subject in comparison with the standard treatment of the subject's condition.

Any previously expressed objection by the patient should be respected, and informed consent from the subject or from his/her legally designated representative should be sought without undue delay and the information shall be given as soon as possible to the subject and to his/her legally designated representative.

Children with disabilities

The [Convention on the Rights of Persons with Disabilities \(UNCRPD\)](#)¹⁸ reflects the right to child participation in Article 7.3 whereby “States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right”.

Through its [General comment No. 20 \(2016\) on the implementation of the rights of the child during adolescence](#)¹⁹, the Committee on the Rights of the Child, reaffirms the right to child participation in general by stressing that “adolescents with disabilities should, in addition, be provided with opportunities for supported decision-making in order to facilitate their active participation in all matters concerning them”.²⁰

¹⁷ <https://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:02014R0536-20221205>

¹⁸ <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>

¹⁹ <https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no-20-2016-implementation-rights>

²⁰ Paragraph 32

SUMMARY OF THE MAIN LEGAL PROVISIONS IN INTERNATIONAL LAW:

- > Every child has the right to be informed and listened to before any health intervention.
- > The weight given to the views of the child increases with age and maturity.
- > Decisions should be taken in the best interests of the child.
- > Medical research may not be carried out on a child if they explicitly object to it, even when the legal representatives have provided authorisation.
- > Genetic testing on a child must in principle be deferred unless the deferral would be detrimental to their health.
- > Children with disabilities enjoy this right on an equal basis with other children, and they must be supported to realise that right.

DOMESTIC LAW(S) IN COUNCIL OF EUROPE MEMBER STATES

There are substantial differences across Council of Europe member States in the way children's right to participate in decisions regarding their health is reflected in law and interpreted.²¹²²

CONSENT

To start with, the statutory age at which children can provide their consent varies from 12 to 18 years. Domestic legislations differ as to the way they consider the age criteria:

➤ In some countries, the age of consent is the same as the age of legal majority.

This is the case for instance in France, Italy and the Slovak Republic, where, as a general rule, all interventions on a younger child require the prior authorisation from their legal representatives. The law may provide for special circumstances where the obligation to obtain the authorisation from legal representatives may be lifted. For example, French law provides that healthcare professionals do not have to obtain the parents' or guardian's authorisation when the child expressly refuses their consultation, in circumstances where the concerned treatments are necessary to safeguard the health of the child. In Monaco, health professionals can be exempted from obtaining the authorisation of legal representatives if the child refuses their consultation for the medical acts or treatments that can be carried out anonymously according to legal provisions in force.

➤ In other countries, children who have not reached the age of legal majority may give their consent from a specific fixed age that is below that of legal majority.

In Austria and Latvia, it is assumed that, as a general rule, a child of 14 years is capable of making decisions. Age of consent is 15 in Denmark and Slovenia, 16 in Bulgaria, Ireland, the Netherlands, Norway, and Portugal. Dutch law recognises that in some circumstances, it is however possible to carry out a procedure on a younger patient (aged 12 to 16) without the authorisation of their legal representative, notably in cases where it is necessary to avoid serious harm to the patient.

National laws sometimes provide for exceptions to the general rule of consent. For example, Austrian law provides that, in case a child capable of making decisions gives their consent to a medical treatment which normally induces severe and enduring physical or psychological damage, such medical treatment may only be administered if the legal representative gives his consent as well. Latvian law states that if a patient aged 14-18 refuses to give consent to medical treatment, but the physicians deem that the medical treatment is in the interests of this patient, the consent to the medical treatment shall be given by the lawful representative of the minor patient.

In Ukraine, children from 14 have the right to choose a doctor and treatments according to the doctor's recommendation. Medical treatment shall be provided upon their written consent as well as the authorisation of their legal representative. Similarly in Poland, a child's consent is necessary from age 16 but is not sufficient, and the authorisation from the legal

²¹ European Commission. Evaluation of legislation, policy and practice in children participation in the European Union (EU). 2015, pages 56-61. <https://op.europa.eu/en/publication-detail/-/publication/>

²² 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. Doi: 10.1016/S2352-4642(21)00019-5

representative(s) is also required. In the cases of research or transplant, the age of consent is lowered to 13 years. In cases of conflicting opinions, there are various rules that require the authorisation of a judge.

- Finally, according to some national laws, consent is not age dependent.

Children who have not reached the age at which they may give their (unconditional) consent can nevertheless provide valid consent if they are deemed mature and competent to do so in relation to the nature of the health issue(s) at hand. In this respect, the notion of children's "competency" has grown in importance and is reflected in some national legislations – for instance in the UK - where children under the general age of consent (age at which the age to consent is unconditional) can be granted the right to consent if they are found to be "competent", i.e. mature enough to decide for themselves and not want their parents involved. This requires professionals to assess competency.

National legislations of Member States generally reflect the fact that, in research settings, the refusal of a child to participate may not be overruled.

RIGHT TO RECEIVE INFORMATION AND/OR TO EXPRESS A VIEW

As stated already, according to the UN Convention, all children have the right to receive appropriate information and to express their views. The Convention makes no distinction based on age. Again, domestic legislations reflect this differently:

- In some national contexts, children of all ages have the right to be informed and to express their view.

This is the case in Italy, Belgium, the Czech Republic, Denmark, France, Finland, Germany, Hungary, Monaco, and The Netherlands, where healthcare professionals must provide information to all children and seek their opinion, in a manner that is adapted to the capacities of the children. This right is sometimes subject to the evaluation of the degree of maturity or of the capacities or of the level of development of the child, but not age.

- Elsewhere, children the right to be informed and to express their view from a certain set age.

This is the situation in Austria, Bulgaria, Ireland, Norway, Poland, Portugal. The age varies from 7 to 16 years (and the age criteria is sometimes combined with different conditions and legal consequences). In Norway, a child has the right to receive information and give their opinion from 7 years of age, and from a younger age if the child is able to form their own opinion. From age 12, a child has the right to refuse to inform parents about their health under certain circumstances.

- In other cases, the law is not explicit.

Some domestic legislations do not refer to the right of children to receive information, and/or to participate in decision making, in the area of healthcare specifically.

WHAT IS MEANINGFUL PARTICIPATION?

There are different principles that can help professionals to promote *meaningful participation* of children in decision-making processes. In this context, meaningful should be understood as involving children in a manner that is respectful, ethical and constructive.²³

Participation in decision-making processes should be:



Transparent and informative: From the start, professionals should inform children about their right to be involved in decisions about their health. This means ensuring children understand their own role, their parents' and that of professionals; and how decisions will take place.



Voluntary: Children should have the possibility to choose the extent to which they want to be involved and the right to withdraw from any process, at any given time. Different children at different times might prefer to have varying degrees of involvement or responsibility. The level of involvement can differ from child to child and between circumstances. The child's wishes in this regard should be respected.



Respectful: Children should be treated with respect and provided with genuine opportunities to express their views and to be listened to. Professionals should also respect, and gain an understanding of, the family, school and cultural context of children's lives. Participation should be a way to help children build knowledge, skills, self-esteem and confidence.



Relevant: Children should be able to give their opinion and contribute to decisions and processes that build on their own knowledge and focus on issues, which are relevant to their lives. This also means that children should be involved in ways, at levels and at a pace appropriate to their capacities and interests.



Child-friendly: Child-friendly approaches should include allocating sufficient time to communicate effectively with children, developing professionals' attitude to children and to child participation itself, their capacity to adapt, as well as ensuring the availability of supportive resources, such as child-friendly information materials and an adequate physical environment.



Inclusive: Children's participation must provide opportunities for children in vulnerable situations to be involved and should challenge existing patterns of discrimination. This means that participation should be flexible enough to respond to the needs, expectations and situations of different groups of children, taking into account their age range, gender and abilities. Professionals must be sensitive to the cultures of all children participating.

²³ This section is informed by the *General Comment 12 of the CRC, paragraph 134* - Basic requirements for the implementation of the right of the child to be heard



Participation is supported by training of adults: Professionals working with children must have the knowledge and capacity to facilitate meaningful children's participation.



Safe and sensitive to risk: Adults working with children have a duty of care. Professionals must take every precaution to minimise the risks to children of abuse and exploitation and any other negative consequences of participation. Professionals should be aware of and adhere to their legal and ethical responsibilities in line with their agency's Code of Conduct and Child Safeguarding Policy.



Accountable: Following their participation, children must be provided with feedback and/or follow up regarding how their views have been interpreted and used, and how they have influenced any outcomes.

- > Children's participation is not a one-off event.

Participation is a continuous process and does not stop with children's views being expressed, it also involves adults - notably health professionals and parents - and children co-producing decisions. Understanding participation in this way encourages children and adults to work together for meaningful participation. Participation contributes to improving practices by developing more effective partnerships with health care professionals.

- > Children's participation should be based on their evolving capacities.

The concept of the evolving capacities of the child is fundamental and enshrined in the Convention on the Rights of the Child as it recognises children's developmental characteristics and needs, their competencies and emerging personal autonomy.²⁴ Children's age, maturity, but also their life experiences should be taken into account when enabling a child to participate. This is not to say that young children should not participate, but that as children grow and develop, they should be ever more involved in decisions. The practical implication of this is that even if a child does not yet have fully developed capacity for all types of decisions and participation, that does not mean that they lack any capacity for taking of decisions.

- > Participation should contribute to achieving the best interests of the child.

The principle of the best interests of the child is enshrined in the Convention on the Rights of the Child and is crucial to any decision that concerns children. This principle, closely linked to the evolving capacities principle, places children at the centre of the decision-making process, looking at what is best for each *individual* child, taking into account their age, maturity, personal characteristics, but also the short, medium and long-term consequences of a given treatment and intervention to the life of that particular child. The child's best interests must not be seen as limiting his or her right to participate; on the contrary, the child's participation is a means of achieving his or her best interests

²⁴ Lansdown, Gerison (2005) The evolving capacities of the child. UNICEF Innocenti Research Centre



SUPPORTING CHILDREN'S PARTICIPATION IN DECISIONS ABOUT THEIR HEALTH

KEY STAKEHOLDERS IN THE DECISION-MAKING PROCESS: THE ROLES OF CHILDREN, PARENTS, AND HEALTH PROFESSIONALS

The therapeutic relationship in child healthcare is typically triadic, involving the young patient, their parents or legal representative, and the health professionals.

Meaningful child participation in healthcare decision making involves doing away with practices based on the assumption that a parent or doctor automatically “knows best” (based on age, life experience and professional expertise). It requires for a shift towards a shared decision-making model which respects 1) the views and the emerging capacity of the child patient, 2) the parental authority and 3) the knowledge and the expertise of the health care professionals. Under this new paradigm, adults and children work together to reach decisions.

A good decision must take account of, consider and balance what the child wants, what is needed to secure the child's health and wellbeing (including their survival, healthy life and development), what the parents and health professionals want, and what is genuinely in the best interests of each child.

CHILDREN

Children should be at the centre of the decision-making process, their views should always be sought, obtained, and given due weight.

A child's age or degree of maturity does not determine the existence of their right to participate, but rather the weight that ought to be given to their view. Children should be considered as individuals, with specific characteristics and needs to be taken into account.

The level of a child's participation will differ according to their capacity, life experience and individuality. While some children will easily take part in the process, others may not feel authorised or comfortable to do so, and will need to be invited, sometimes repeatedly, and encouraged, using appropriate methods. Other children, especially those who are not used to being consulted, may be inclined to self-censorship.

The level of a child's participation also depends on the attitudes of adults, who need to promote and encourage participation and to create an environment and conditions in which it can happen.

Children will have different views as to their parents' involvement in decisions. Many of them will want their parents to be involved. Some will want to be heard and have their views considered but may find it overwhelming to decide and will want to leave the final say to their parents. Such wishes must be equally respected and are an equally valid form of child participation.

While participation in decision making processes is extremely important, and all efforts should be made to ensure the conditions for children to participate (particularly children who have not been previously encouraged to do so), children should not be put in a position where they are asked to carry the burden of decision making if they are not comfortable with this.

Children should be guided by adults -who should draw on their experience and expertise-, but importantly, that should always be from a place of respect and consideration in relation to children and ensuring that there is the necessary space for children to interact.

PARENTS

Parents, and other holders of parental responsibility, are key players in this shared decision-making model.

Parents are legally required to provide their children with "appropriate direction and guidance"²⁵ and are critically important in their protection and in the achievement of their best interests. In many legislations, parents are the de facto decision-makers (or substitute decision-makers), required to authorise medical acts on behalf of their children until the latter reach either a certain age or stage of maturity.

Parental duties and responsibilities are however limited in time, as determined by the evolving capacities of the child, limited in scope, as determined by the child's best interests, and functional

²⁵ UNCRC Article 5: "States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the present Convention".

in nature, as they are to provide for the care, protection and well-being of the child.²⁶ Parental duties and responsibilities change and usually diminish over time: “(T)he more a child knows and understands, the more his or her parents will have to transform direction and guidance into reminders and gradually to an exchange on an equal footing”.²⁷

Parents’ degree of involvement in decision making varies depending on their life experiences, cultural background, parenting culture and degree of health literacy.²⁸ For example, some parents are not involved or listened to by clinicians and may feel powerless and uncertain about their child’s healthcare - which in turn limits their ability to support their child^{29 30}. This will also vary according to the type of medical act that is being considered. In certain circumstances, families may feel that standardised protocols leave them little room for choice.³¹

It is essential that parents are sufficiently empowered to take an active role in the decision-making process and support and guide their child.^{32 33} They are partly dependent on if, how and when healthcare professionals involve them in the decision-making process. Generally speaking, the more parents are informed, the better they will be able to support the child.

While involving parents is crucial, it is important that the process remains child-centred. The child must be informed directly and included in discussions. It should not be assumed that information given to the parents will be shared and discussed with the child. Research on interactions during paediatric consultations has suggested that children’s contribution to the interaction with the doctor tends to be inversely proportionate to the contribution of the parent(s).³⁴

HEALTHCARE PROFESSIONALS

Healthcare professionals, while not decision-makers *per se*, play a significant role in medical decision making regarding children. They have a legal responsibility and professional duty to ensure that the rights, dignity and safety of children are upheld. Consequently, they play a central role in advocating for and facilitating child participation in practice.

²⁶ Roberta R, Volnakis D, Hanson K, The inclusion of ‘third parties’: The status of parenthood in the Convention on the Rights of the Child, Children’s Rights Law in the Global Human Rights Landscape, Isolation, inspiration, integration?, Edited by Brems E, Desmet E, Vandenhoe W, Routledge Research in Human Rights Law, 2017, pp.71-89, pp. 82-83. See also: Jonathan Law, Elizabeth A. Martin, A Dictionary of Law, 7th edition, Oxford University Press, 2014.

²⁷ General comment No. 20 (2016) on the implementation of the rights of the child during adolescence, paragraph 18.

²⁸ [Guide to health literacy – Contributing to trust building and equitable access to healthcare](https://rm.coe.int/inf-2022-17-guide-health-literacy/1680a9cb75), Steering Committee for Human Rights in the fields of biomedicine and health (CDBIO), Council of Europe, page 8. Available here: <https://rm.coe.int/inf-2022-17-guide-health-literacy/1680a9cb75>

²⁹ Tallon M.M., Kendall G. E., Snider P. D. (2015). Development of a measure for maternal confidence in knowledge and understanding and examination of psychosocial influences at the time of a child’s heart surgery. *Journal for Specialist in Pediatric Nursing*, 20, 36–48. 10.1111/jspn.12096

³⁰ Edwards, M. , Davies, M. , & Edwards, A. (2009). What are the external influences on information exchange and shared decision-making in health care consultations: A meta-synthesis of the literature. *Patient Education and Counseling*, 75, 37–52. 10.1016/j.pec.2008.09.025

³¹ Coyne I., Amory A., Kiernan G., Gibson F (2014) Children’s participation in shared decision-making: children, adolescents, parents and health care professionals’ perspectives and experiences. *European Journal of Oncology Nursing* 18:273–280

³² Jackson C., Cheater F. M., Reid I. (2008). A systematic review of decision support needs of parents making child health decisions. *Health Expectations*, 11, 232–251. <https://doi.org/10.1111/j.1369-7625.2008.00496.x>

³³ Uhl T., Fisher K., Docherty S. L., Brandon, D. H. (2013). Insights into patient and family-centered care through the hospital experiences of parents. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, 42, 121–131.

³⁴ Wassmer E., Minnaar G., AbdelAal N., Atkinson M., Gupta E., Yuen S., Rylance G. (2004), « How Do Paediatricians Communicate with Children And Parents? », *Acta Paediatrica*, 93, p. 1501-1506 (2004) cited in Stefania Fucci, “L’écoute des enfants dans les contextes de soins”, *Revue des sciences sociales*, 63 | 2020, 88-95.

This includes a duty to provide patients and other persons involved with the necessary and adequate information. It also requires investing time and building trust so that the child feels comfortable and safe throughout the process³⁵ and can effectively co-construct the decision concerning them. A child's participation will therefore very much depend on how and if the professional(s) or team of professional(s) prompts and supports them to do so.

Most of the time, health professionals partner with parents/legal representatives, for example, to simplify complex treatment regimens whenever possible and educate the family to avoid behaviours that will put the child at risk. However, sometimes they may need to challenge the views of parents when these do not seem to reflect the child's best interests³⁶.

The Guide considers some avenues for to address conflicts that may arise during the decision-making process, among the different stakeholders (see p.44).

FROM THEORY TO PRACTICE

While it is increasingly recognised that child participation is desirable, that children can understand and act competently and that direct communication between health professional and child yields benefits, in practice, adults still often tend not to involve (or to disregard) children in decisions regarding their health.

It has been observed, for example, that in paediatric consultations, the healthcare professional will often involve children by asking them questions, in view of obtaining information, but will then turn to the parent(s) when providing explanations about a diagnosis and children are unlikely to participate in other parts of the discussion, such as treatment planning and discussion, and this regardless of the child's age.³⁷ Moreover, if a health professional is talking with a child and a parent interrupts, the consultation is likely to revert to conversation between adults. As a result, adults often dominate and control these consultations.³⁸

Professionals sometimes justify this by invoking factors such as a lack of time or bad organization or other. It may however also point to other reasons, such as a difficulty to share decision-making power, not knowing the patient well enough, wanting to protect the child or a lack of adapted communication skills.³⁹

A lot can still be done, from the part of healthcare professionals, to ensure that children are enabled to participate meaningfully and actively in decisions regarding their health. Health professionals of all levels need to receive regular training and supervision, about how to support children's (and their families') individual participation needs, capacities, preferences, and expectations, and to help them better respond to those needs and develop their communication skills for children of all ages and all developmental stages.

³⁵ Sjöberg C, Amhliden H, Nygren J M, Arvidsson S, Svedberg P, (2015) The perspective of children on factors influencing their participation in perioperative care, *Journal of Clinical Nursing*, 24, 2945–2953, doi: 10.1111/jocn.12911

³⁶ Beauchamp, T. L., & Childress, J. F. (2013). *Principles of biomedical ethics*. New York, NY: OUP.

³⁷ Favretto A.R., Zaltron F. (2013), *Mamma non mi sento tanto bene. La salute e la malattia nei saperi e nelle pratiche infantili*, Roma, Donzelli Editore.

³⁸ Cahill P, Papageorgiou A. Triadic communication in the primary care paediatric consultation: a review of the literature. *Br J Gen Pract*. 2007 Nov;57(544):904-11. doi: 10.3399/096016407782317892. PMID: 17976292; PMCID: PMC2169315.

³⁹ Coyne I. (2008), « Children's Participation in Consultations and Decision-Making at Health Service Level: A Review of the Literature », *International Journal of Nursing Studies*, 45, 11, p.1682-1689. DOI : [10.1016/j.ijnurstu.2008.05.002](https://doi.org/10.1016/j.ijnurstu.2008.05.002), cited in: Stefania Fucci, "L'écoute des enfants dans les contextes de soins", *Revue des sciences sociales*, 63 | 2020, 88-95.

ACTIONS FOR MEANINGFUL CHILD PARTICIPATION

The participation of children in decision-making processes concerning their care should be seen as a progressive and rolling process. Each visit or hospitalisation is an opportunity to build children's competencies and ability to learn about their health, understand related processes and be more effectively involved in decision-making processes affecting their own lives. Children who are in regular contact with healthcare services, including children with chronic conditions, often have more power to negotiate, more space for participation and more autonomy with their parents and health professionals, as compared to other children.⁴⁰

To ensure that participation happens in a meaningful way, professionals must pay attention to providing appropriate information to children, helping them express their views and listening to them, and taking their views seriously into account. Professionals must also understand how to manage conflict, while respecting children's rights.

PROVIDING APPROPRIATE INFORMATION

Any decision-making process should be based on clear information about what is known and what can be expected both in terms of the process itself and the roles of different stakeholders involved. In healthcare, informing children can help them understand their situation, overcome possible fears and anxiety surrounding treatments and generally empower them. Information is also a pre-requisite for meaningful participation and is applicable to all children, independently of their age, background, or health status.

Some children face additional challenges or barriers to being included in decision-making processes, for example, children with a disability, children experiencing mental health problems or a specific health condition, young children, as well as children from vulnerable groups. Therefore, targeted and appropriate support should be provided on a case-by-case basis, to enable the equal exercise of children's right to participate.

Children should be provided with appropriate and necessary information to enable them to acquire competence for making decisions, to weigh the aim, methods involved, necessity and usefulness of a proposed treatment or intervention against its risks and the discomfort or pain it will cause.⁴¹ Information, communication and education should also enable children and families to play active roles in achieving, protecting and sustaining their own health.

Information should be given about the following aspects:

- > the specific situation the child is going through, such as information about a new illness, developments of a chronic or other long-term illness or planned hospitalisation experience;
- > type of treatments and duration, benefits to the child and related risks or possible effects (for example, what could go wrong, cause problems or make the child worse);
- > any alternatives to treatment that are suitable to the child;

⁴⁰ Stefania Fucci, "L'écoute des enfants dans les contextes de soins", *Revue des sciences sociales*, 63 | 2020, 88-95.

⁴¹ Oviedo Convention Explanatory Report <https://rm.coe.int/16800ccde5>

- any additional needs that may influence the choice of treatment;
- what might happen if the child does not receive the proposed treatment;
- which healthcare professionals they will meet, who they are, and what their role is;
- children's right to be informed throughout the process, to ask questions, express their views and how they will be involved in the decision-making process;
- children's rights concerning their participation in paediatric research and clinical trials, where applicable.

A sensitive issue sometimes is whether and how to talk to children about serious consequences. One may be tempted to avoid mentioning possible fatal outcomes, pain, risks of disability, etc. This requires an assessment of children's maturity in receiving this type of information and their capacity to express their opinion on the subject, as well as a thorough evaluation on the timing and best way to communicate, but it should not be assumed that such serious subjects should be avoided with children. The giving of information actively helps many children to cope with even the most difficult of circumstances, and the absence of information may exacerbate fear and distress. Information to children about serious consequences should always be given carefully and psychological support should be offered to children and their families throughout the information process.

The information provided by healthcare professionals must be sufficiently clear and suitably worded, for example, professionals should avoid the use of medical jargon and include terms that the child can understand. Conversely, if the language used is too childish, the child may feel patronised, so the right balance is important. Sometimes it may be necessary to give information in stages that can be understood and absorbed, and it may be useful to repeat the same information at different times and stages or to complement verbal information with written information where possible and appropriate. In the case of non-native speakers, information should be made provided in a language the child understands (see also examples of linguistic and cultural mediation services p.45).

Child-friendly information materials can be used to support the communication and mutual understanding of children, parents 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. Child-friendly materials may cover any of the topics listed above and can be developed with a participatory methodology to be better adapted to children's needs and understanding. Possible formats of child-friendly information material include brochures and leaflets, videos, information accessible through social media, specific websites or applications, games and other. Professionals may also use dolls or toys for "pretending" or simulating.


In any case, it is important that healthcare professionals who interact with the child make sure they coordinate among themselves to avoid giving potentially contradictory information or repeating the same information too many times.

GENERAL INFORMATION ON CHILDREN'S RIGHTS IN HEALTHCARE

Illustrated EACH Charter



In 1988 European Association for Children in Hospital (EACH) members created a Charter stipulating in 10 points the rights of sick children and their families before, during and after a stay in hospital and in other healthcare services. For each right, the Charter provides interpretative guidance in an “annotation”. Two articles are of particular relevance to the topic of this guide: Article 4.1 (Children and parents shall have the right to be informed in a manner that is appropriate to age and understanding) and Article 5.1 (Children and parents have the right to informed participation in all decisions involving their healthcare).

 [Read the relevant articles and annotations in the Appendix](#) (Item 1)

 [European Association for Children in Hospital \(EACH\)](#)⁴²

Charter on Children's Rights in Primary Healthcare - Ireland



The Charter describes ten key principles in relation to the provision of healthcare for children in Ireland. One such principle is Communications and information. The Charter describes what this means for children and young people.

 [See relevant excerpts in the Appendix](#) (Item 2)

 [National Healthcare Charter for Children](#)⁴³ (page 15 and 16)

Charter on Children's Rights in Primary Healthcare - Portugal



This child-friendly Charter was developed by two Portuguese children's rights organisations, along with the Directorate-General for Health (DGS) and the municipality of Lisbon. The Charter was published in April 2021.

 [Read the translation of the Charter in the Appendix](#) (Item 3)

 [Charter on Children's Rights in Primary Healthcare](#)⁴⁴

⁴² <https://each-for-sick-children.org/each-charter/>

⁴³ <https://www.ncio.ie/wp-content/uploads/2021/12/HSE-National-Healthcare-Charter-for-Children-2018.pdf>

⁴⁴ <https://www.dgs.pt/em-destaque/lancada-a-carta-da-crianca-nos-cuidados-de-saude-primarios-pdf.aspx>

Charter of the Rights of the Child - Poland



This is another example of a child-friendly Charter, developed by the Polish Defender of Children's Rights and the Defender of Patients' Rights.



[Find the translation of the rights in the Appendix](#) (Item 4)



[Charter of the Rights of the Child](#)⁴⁵

Rights-based standards for children having tests, treatments, examinations and interventions - iSupport



iSupport is an international group of health professionals, academics, young people, parents, child rights specialists, psychologists and youth workers who are all passionate about the health and wellbeing of children, especially when they interact with healthcare services. The group has developed and promotes a set of standards that aim to improve the care that all children receive when they have tests, treatments, examinations and interventions. The standards aim to ensure that the short and long-term physical, emotional and psychological wellbeing of children and young people are of central importance in any decision making for procedures or procedural practice. The standards are a set of documents which outline what good procedural practice looks like.

The Standards, which were developed in 2022, exist in several versions: [Standards for professionals](#), [Standards for children and parents](#), as well as [an illustrated version](#). The team also developed a [Prep Sheet to help children get ready for an intervention](#), and a series of case studies illustrating the application of standards.



[iSupport standards](#)⁴⁶



[Discover the different versions of the Standards in the Appendix](#) (Item 5)

⁴⁵ <https://www.gov.pl/attachment/4ea75824-05f4-44ae-a084-129c6439bb73>

⁴⁶ <https://www.isupportchildrensrights.com/english-version>

Child-friendly material about Rights - Children's Hospital in Munich - Germany



The hospital's website contains information for children on different hospital services and about their rights:

What are children's rights? How do we implement children's rights in our clinic? Child Life specialists / Children's Council / "Sick Children Have Rights" Initiative / Child Health Summit.

It includes other child-friendly material such as a video and a brochure.



[Discover the webpage and video on Children right's](#)⁴⁷ (in German)



[Read the brochure on children's right in the Appendix](#) (Item 6)

Child-friendly guidebook - Poland



The illustrated story of *Kuba and Buba at the hospital* teaches children "almost everything about children's rights".



[Kuba and Buba in hospital](#)⁴⁸ (in Polish)

⁴⁷ <https://www.lmu-klinikum.de/hauner/kinder-und-kinderpoliklinik/kinder-und-elternportal/kinderrechte/57fdc79f42d69171>

⁴⁸ https://www.wydawnictwo-literatura.pl/pub/uploads/fragmenty/Kuba_i_buba_w_szpitalu_str_1-21.pdf

CHILD-FRIENDLY INFORMATION ABOUT CONSENT

Leaflet on consent to medical research - Switzerland



The Swiss University Hospital of Vaud canton in Lausanne has produced useful material informing children and young persons about their rights when taking part in medical research. These include a leaflet and a video and cover detailed information about what consent means and entails, according to the child's age (under or above 14 years of age) and to Swiss law. It is also good practice that the leaflets are available in several languages, on the hospital website.



[Discover the leaflet in the Appendix](#) (Item 7)



[Find the different linguistic versions of the leaflet Taking part in Research](#)⁴⁹



[Video](#)⁵⁰ (in French only) Le consentement général pour les enfants et les adolescent-e-s - Consentement général pour la recherche - CHUV

"What is consent and why am I being asked for it?" - United Kingdom



Likewise, the Great Osmond Street Hospital for Children, has produced useful information sheets that explain to children the notion of consent, according to UK legislation, in a manner that is detailed yet accessible.



[Read the information sheet in the Appendix](#) (Item 8)



[Visit the webpage](#)⁵¹ - Great Osmond Street Hospital for Children

⁴⁹ <https://www.chuv.ch/fr/consentement-general/cg-home/participer/quelles-decisions-dois-je-prendre/le-consentement-general-pour-les-enfants-et-les-adolescent-e-s/le-consentement-general-pour-les-mineurs-en-plusieurs-langues>

⁵⁰ <https://www.chuv.ch/fr/consentement-general/cg-home/participer/quelles-decisions-dois-je-prendre/le-consentement-general-pour-les-enfants-et-les-adolescent-e-s>

⁵¹ <https://www.gosh.nhs.uk/your-hospital-visit/coming-gosh-day-or-inpatient-admission/consent-giving-permission-your-child-have-treatment/>

USING INNOVATIVE DIGITAL FORMATS

Serious game



Photo credit : www.teddynetwork.net/

My Clinical Trial Center is an innovative serious game application. It aims at explaining to children in a fun way what clinical trials are, how they work and why they are so important to developing medicines that are suitable for children.

The game is informative, as game-players learn about clinical trials, study protocols, informed consent and assent, phases and procedures of clinical trials, data collection, and pharmacovigilance.

The application was developed with a participatory methodology by members of the TEDDY KIDS network (KIDS Bari and Albania young) and received approval of the International Children's Advisory Network (iCAN).

The game can be downloaded in Play Store and Apple Store. It is currently available in English.

 [Learn more here about this initiative](#)⁵²

The development of eHealth technology - Sweden



The development of eHealth solutions and tools can assist with self-care for children with long-term illness and their families. One such tool is currently being evaluated in an implementation study at Skåne University Hospital where children and parents in several specialties use eHealth solutions (tablet and app) during the periods children spend at their home with residual care needs. This facilitates and promotes direct online communication between children and health professionals.

 [Read more about this project and similar initiatives in the Appendix](#) (Item 9)

 [eHealth in Paediatric Oncology - Lund University - Sweden](#)⁵³

⁵² <https://www.teddynetwork.net/2021/06/29/4676/>

⁵³ <https://portal.research.lu.se/en/projects/ehealth-in-paediatric-oncology>

TRAINING FOR BETTER INFORMED CHILDREN

Providing continuous and comprehensive education to children with diabetes and their carers - Slovenia



Photo credit: <https://www.kclj.si/>

The Division of Paediatrics of the University Medical Centre Ljubljana provides comprehensive education to children with diabetes and their parents in order to improve decision making. Children and parents receive an initial course on health education. This is followed by further courses during which technological devices (online tools) are introduced.

The centre also organises a yearly rehabilitation retreat, with the Association for children with metabolic disorders.

Each year, a training is organised for educators, teachers and sports trainers who care for children with diabetes. To further improve the care for diabetes and the involvement of patients and parents, the team has also produced several publications covering different aspects of diabetes management (at school, in sports, regarding nutrition...). There is also a website dealing with patient's rights in diabetes care.

Furthermore, during the coronavirus pandemic disease 2019 (COVID-19) the vast majority of appointments for individuals with type 1 diabetes were successfully transitioned online.

Learn more about this initiative here:

 <https://www.sladkorcki.si/o-sladkorni-bolezni/pravice-otrok-s-sb/> (in Slovenian)

 <https://vestnik.szd.si/index.php/ZdravVest/article/view/3104> (in English)

HELPING CHILDREN EXPRESS THEIR VIEWS

Enabling children to express their views is a crucial element of the decision-making process.

The ability of children to express their views and opinions can be influenced by many factors, including their age, capacities and maturity; whether they have or have not had any experience of participation either in healthcare or other relevant decision-making processes (at home, school or other); the extent to which they understand their situation; and how comfortable and engaged they feel within the decision-making process. Professionals should not assume children will share their thoughts voluntarily.

To support children in expressing their views, healthcare professionals should build a trusting relationship to ensure mutual respect, both in the short- and long-term perspectives. They should consider children's needs, including privacy and confidentiality issues that are important for children, but often neglected, and are particularly relevant for older children.

Children are more likely to express their views when they trust the person they are talking to. To the extent possible, healthcare professionals should get to know the child and their personal needs and characteristics, and always be honest.

Children may need to be reassured that their opinions and thoughts are important, even "small" concerns that may not seem important to the health professional.

Creating a trustful interaction with children entails, for example:

- making sure healthcare professionals introduce themselves by name and talk to the child using their name;
- supporting and inviting children to talk about to what extent they wish to participate, in what way and when;
- asking and clarifying the children's preference about talking with a health worker in the presence of parents or alone;
- playing with the children while talking to help reduce the stress of discussing difficult topics and to be able to express themselves more freely;
- carrying out both active questioning and active listening;
- checking that the children understand the information that has been given;
- asking the children what they think, as this gives the children permission to express.
- encouraging them to ask questions and reply;
- avoiding making judgements in all interactions;
- allowing more time for children to think, if they want and need it;
- respecting a child's silence while ensuring that the child has opportunities at later stages to express their views if they wish to do so;
- taking into account the child's biological rhythm, tiredness and length of appointments.

Privacy is an important issue when working with children, especially when sharing or discussing information concerning their own health. Even with younger children, it may be important, or even necessary, to allocate time alone with the child to provide space for them to discuss whatever matters to them. It is critical to discuss confidentiality issues with children, at the outset and allow them time to ask questions. Access to confidential medical counselling and advice without parental authorisation should be ensured, irrespective of the child's age, where this is needed for the child's safety or well-being, for instance in cases of suspected child abuse and maltreatment.

All healthcare professionals working with children must be trained, including on communication skills. Training and practices should involve all team members and a continuum should be ensured, for example, with good communication between nurses, doctors or other professionals involved.

In some national contexts, health workers with a specific training, such as health play specialists or Child Life specialists, positively reinforce teams, supporting children and families by using age and developmentally appropriate methods to help them better understand and cope with healthcare situations and treatments, and by being a learning resource for other health professionals to develop similar skills.

The physical environment can also play an important role. For example, ensuring that children can express their views in a private office or room or that there are no interruptions, such as a support or other professionals often coming into the office or room. With younger children, having a room with toys, sitting down on the floor with them, or other strategies, can create a more friendly environment and help them to feel at ease.

TRAINING RESOURCES FOR PROFESSIONALS

Listen – Act – Change - Council of Europe Handbook on children’s participation - For professionals working for and with children.

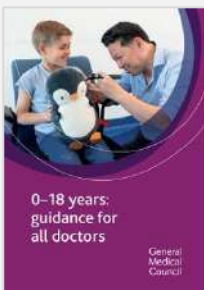


This reference document provides very hands-on guidance and tips for professionals working with children on how to connect with children and establish a trustful relationship with them.



[Read the relevant section of the Handbook in the Appendix](#) (Item 10)

0 - 18 years - Guidance for doctors - General Medical Council - United Kingdom



This is an example of national guidelines and professional standards which include practical advice on how to create effective communication between doctors and children.



[Read the relevant section](#) in the Appendix (Item 11)



Discover the Guide in full here : [0-18 years - professional standards - GMC \(gmc-uk.org\)](https://www.gmc-uk.org/professional-standards/professional-standards-for-doctors/0-18-years/communication)⁵⁴

iSupport Case studies - Applying standards to real-life clinical scenarios.



The team behind the iSupport Rights-based standards for children has developed four case studies (scenarios) that aim to demonstrate how the standards for child-centred healthcare can be applied in a range of clinical contexts and procedures. In each case, a clinical situation is given and explored, first without applying the standards and then, applying the rights-based standards. Whilst the first example within each case study results in a procedure being completed, this is often at the detriment of a child’s short and long-term well-being as their interests are not prioritised over those of the parent/carer, professional or institution.



[Discover the iSupport Case studies](#) in the Appendix (Item 12)

⁵⁴ <https://www.gmc-uk.org/professional-standards/professional-standards-for-doctors/0-18-years/communication>

SPECIALISED STAFF

Children's Hospital in Munich establishes ChildLife Specialist programme - Germany

In 2020, the Child Life Specialist flagship programme was implemented at the Dr von Hauner Children's Hospital in Munich as the first Child Life Specialist programme in Germany, building up on US-based experiences.

To ensure that these children receive the best possible child-centred and holistic support, Child Life Specialists work alongside doctors and nurses to help address the specific needs of children in hospital:

They help as comforters when sick children and their parents need them.

They help as caregivers who have time when the child needs them.

They help as contact persons for all questions concerning the daily routine and stay in the hospital.

They help as educators who teach children about illnesses and treatments.

They help as counsellors who provide competent assistance to parents and families.

They help by giving time and attention.

They help by taking care of the rights of sick children.



 [Find out more about the role and missions of Child Life Specialists](#) in the Appendix (Item 13)

 Read more about the [ChildLife Specialist programme in Munich](#)⁵⁵

⁵⁵ <https://www.care-for-rare.org/en/the-child-life-specialist-program-at-dr-von-hauner-childrens-hospital/>

CHILD- AND FAMILY-FRIENDLY HOSPITAL ENVIRONMENT

Sant Joan de Déu Children's Hospital, Barcelona - Spain



Photo credit : www.sjdhospitalbarcelona.org/

Sant Joan de Déu Children's Hospital has a range of initiatives aiming to provide children and families with a comprehensive child- and family-friendly environment. Some measures include information for patients on how the visit to the hospital will take place, a comprehensive welcome guide, information for international patients, cultural mediation and other information of relevance.

There is a dedicated webpage for children and families, where all this information is gathered. [!\[\]\(7f05b059bc0583c5dd3385c0ccddbce0_img.jpg\) Para pacientes y familias | Hospital Sant Joan de Déu⁵⁶](#)

SJD Barcelona Children's Hospital has also started using a new magnetic resonance device that help in reducing the duration of anesthesia, which some patients need for these procedures, as well as an improved and safe experience for the patient and the family members who accompany them. The magnetic resonance facility has also been made more child-friendly, with themed decoration based on the planets, outer space and magnetic fields. This means that children will find a spaceship with an astronaut and information about gravity, the planets and the distance between objects and planet Earth, as well as the friendly dog Laika. This theme-based decoration has been used around the entire Diagnostic Imaging Area, creating a much brighter and more orderly ambiance.

[!\[\]\(711f81de5648ddf918583603859123f4_img.jpg\) The Diagnostic Imaging Department, a ground-breaking initiative in Europe⁵⁷](#)

⁵⁶ <https://www.sjdhospitalbarcelona.org/es/pacientes-familias>

⁵⁷ <https://www.sjdhospitalbarcelona.org/en/news/diagnostic-imaging-department-ground-breaking-initiative-europe-implementation-new-15t-resonance-system>

CONSIDERING CHILDREN'S OPINIONS

Participation is a rolling process that encompasses different considerations.

Children's views and opinions should be taken seriously and given due weight in any final decision. Importantly, even where, according to national legislation, children may not be able to give their consent to a treatment or intervention, their views and opinions should nevertheless *genuinely* influence decisions. This means that children's views and opinions should be taken seriously and given due weight in any final decision.

This should be done by taking children's evolving capacities into account. Childhood is not a single, fixed, universal experience. At different stages in their lives, children require different degrees of protection, provision, prevention, information and participation. Children's wishes should be considered seriously, most of all in relation to healthcare and biomedical research.

Respect for evolving capacities

“ Children can form and express views already from an early age but the nature of their participation, and the range of decisions in which they are involved, will necessarily increase in accordance with their age and evolving capacities. This requires professionals to recognise the diverse capacities of each individual child and tailor their interactions with them in a way that neither overestimates nor underestimates their capacity.

For some professionals or other adults, this may be a fundamental shift from the way they view children, by not seeing age as a barrier. Clearly, very young children or for instance, some children with disabilities, cannot do certain things just as some adults have limited capabilities. This should not bring into question or negate the capacities that they do have, nor the need to support them in expressing these or having them recognised.

Children can make or contribute to complex decisions.⁵⁸ ”

The need to consider children's opinions applies to all types of health issues. In practice, at times, children may be listened to only when the issue at stake is trivial. The more serious the situation, the less likely it may be that the child's views are considered, particularly where they may be different from the views of adults. Conversely, matters that may appear trivial to adults can have great importance for a child. When children's views differ from those of adults, whether parents or professionals, they might be simply disregarded and children do not receive explanations as to why another option was finally decided upon, other than the one they preferred. However, professionals *do* have a duty to ensure that children's rights to participate in their own care is respected and the severity of a situation does not alter this right, which is equally important in all situations.

Failure to consider children's opinions may have damaging effects. Neglecting to recognise children's participation in those decisions can erode the child's trust in larger ones and in the people around them. In more severe circumstances, failure to recognise and facilitate a child's

⁵⁸ “LISTEN – ACT – CHANGE” - Council of Europe handbook on children's participation (page 40)

right to participate in significant decisions and ensure that these are demonstrably given consideration, may not only erode a child's trust, but also create further divisions and difficulties later, at a time when the supportive relationships that are often so important for a child, may already be strained or damaged. This may be particularly so in situations where a child may be considered as competent and their viewpoint well-informed.

The level of children's participation should be informed by their abilities and preferences.⁵⁹ Children must be guided throughout the process and adults must ensure the conditions in which these can be met, by providing appropriate information, listening to the children and taking their opinions seriously into account.

All efforts should be done to maximise the opportunity for any child to choose to participate in decisions regarding their health if they choose, at the highest level of their ability. The confidence and competence to be involved will be gradually acquired through practice, but this does not mean that young children should not be involved as well as older children. For example, enabling children to take part in decisions of "lesser importance", such as whether they would prefer an injection on the right or left arm or to be seated or lying down during a treatment, can instil a culture of child participation in daily clinical practice.

A starting point for identifying a reasonable treatment decision for a child involves weighing the benefits against the burdens of a proposed treatment or research in the context of what is known of the patient's values, beliefs, family relationships and cultural norms.

⁵⁹ McCabe MA (1996) Involving children and adolescents in medical decision making: developmental and clinical considerations. *J Pediatr Psychol* 21:505–516.

REACHING A DECISION

DETERMINING CHILDREN'S BEST INTERESTS

Reaching any decision concerning a child's care must be based on what is in the best interests of the child. Assessment and determination of the child's best interests must be centred on the individual child and include consideration of the child's health needs, their own views, safety, protection, care and overall well-being.⁶⁰

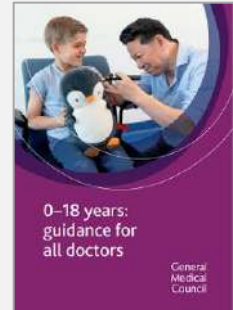
Many aspects should be given due weight to assess and determine a child's best interests. However, there is no fixed recipe for every situation. Respect for the best interests of the child and, indeed, respect for children's participation requires a balance between what professionals (ideally all professionals working in a multidisciplinary team with an integrated approach to care) and parents consider to be the best for the child, given the illness or health problem, available treatments, effects and so on; and the child's views on what is 'best' for them. Exploring children's preferences, family culture (including participation culture), past experiences and other factors will help professionals support and facilitate the best possible decision for the child. Consideration must also be given to the children's right to an open future, meaning that preference should be given, when possible, to options which least restrict their future choices.

ASSESSING A CHILD'S BEST INTERESTS

Example of national guidelines - General Medical Council Guidance (United Kingdom)

“ An assessment of best interests will include what is clinically indicated in a particular case. You should also consider:

1. the views of the child or young person, so far as they can express them, including any previously expressed preferences
 2. the views of parents
 3. the views of others close to the child or young person
 4. the cultural, religious or other beliefs and values of the child or parents
 5. the views of other healthcare professionals involved in providing care to the child or young person, and of any other professionals who have an interest in their welfare
 6. which choice, if there is more than one, will least restrict the child or young person's future options.
13. This list is not exhaustive. The weight you attach to each point will depend on the circumstances, and you should consider any other relevant information. You should not make unjustified assumptions about a child or young person's best interests based on irrelevant or discriminatory factors, such as their behaviour, appearance or disability. ”



🔗 [Guidance on Assessing a child's best interests during healthcare decision-making processes \(General Medical Council, UK\)](https://www.gmc-uk.org/professional-standards/professional-standards-for-doctors/0-18-years/assessing-best-interests)⁶¹

⁶⁰ UNCRC General comment No. 14 (2013) on the right of the child to have his or her best interests taken as a primary consideration (art. 3, para. 1)

⁶¹ <https://www.gmc-uk.org/professional-standards/professional-standards-for-doctors/0-18-years/assessing-best-interests>

CONSENT, ASSENT AND DISSENT

For certain treatments or interventions, through protocols specified by law, professionals will need to obtain the formal agreement of parents or of the child themselves.

According to the Oviedo Convention, the term “*consent*” is used when the formal agreement is given by the person concerned by treatment or act, whereas the term “*authorisation*” refers to the formal agreement given by the parents/legal representatives or body provided by law.

According to the World Health Organization (WHO), informed consent “relates to the formally expressed (usually written) agreement or permission for any health intervention, such as vaccination, effective surgery, choosing or terminating a treatment”.⁶²

As mentioned in the section dealing with national legislations (p.17), children’s right to informed consent to treatment can be based on age criteria. Additionally, another concept has emerged, that of children’s competency.

The notion of *children’s competency* was discussed in a case brought to court in the UK in 1986, where the court’s ruling stated that “whether or not a child is capable of giving the necessary consent will depend on the child’s maturity and understanding and the nature of the consent required. The child must be capable of making a reasonable assessment of the advantages and disadvantages of the treatment proposed, so the consent, if given, can be properly and fairly described as true consent.”⁶³

The so-called *Gillick competency* grew in importance and is increasingly recognised as a determining factor for giving children the right to consent to treatment. Assessing competency is left to the healthcare professionals and there is no universally agreed-upon method to do so. However, guidance will usually include assessing children’s ability to understand their situation, to weigh the different options available to them and to understand the consequences of each.

The emergence of methods and practices to assess competency have been intended to increase child inclusion, participation and rights in decision making. This places a duty on health professionals to ensure that children are given appropriate information in a way that is understandable to them in order to facilitate their competence. It also requires that health professionals recognise that some children may require information in different ways in order to achieve the same level of understanding and competence.

Children can also, according to national legislation, provide their assent or express their dissent. The terms assent and dissent generally describe when children give their agreement or disagreement to a treatment, in situations where they do not yet have a legal right to give their consent.

If children are considered capable of assent, their assent should be sought in addition to parental authorisation. In many European countries, written authorisation of parents in addition to the child’s own assent is required.

⁶² Pocket book of primary health care for children and adolescents: guidelines for health promotion, disease prevention and management from the newborn period to adolescence. Copenhagen: WHO Regional Office for Europe; 2022. Licence: CC BY-NC-SA 3.0 IGO. Page 666

⁶³ The so-called Gillick competency derives from the *Gillick v West Norfolk and Wisbech AHA Case* (1986), *In Hastings AM & Redsell S Listening to Children and Young People in Health care Consultations* (2010)

In order to ensure that children can exercise their right to consent or assent, hospitals and other health services should put in place different measures, including:

- > adopting a hospital or health service consent policy, reflecting national legislation;
- > ensuring that health professionals are aware of this policy;
- > promoting capacity building of professionals to ensure they have the knowledge and competencies to engage and involve children in the decision-making process in a meaningful way and that they ask for their consent to treatment whenever it is required;
- > engaging with children regularly to assess existing policies and practices, as a way to improve these and also children's experiences of care.

Taking into account the national legal framework, seeking agreement should put in balance the emerging capacity of an adolescent for independent decision making with the need for continued special protection as provided by the parents/legally designated representative in compliance with national laws. The specific aspects of disclosure to parents of information concerning adolescents should be made clear to the adolescent concerned.

For younger or non-verbal children who are not able to raise or express verbal objections, any signs of resistance or protest should be identified and discussed with the parents to assess and recognise whether the behaviour is merely an expression of an acceptable burden or can be considered a concern on intervention continuation. It should also be recognised that for many children, the people best placed to understand or interpret non-verbal indications will be the parents.

In all circumstances, and regardless of the outcome or direction of a decision, the conclusions of any decisions made should be carefully and kindly explained to the child.

ASSESSING CHILD'S COMPETENCY - Guidelines

Guidance Notes on Young People and Consent - Cheshire West & Chester Council - UK

The guidelines set out the following criteria for a child to be considered competent.

- ☞ - the ability to understand that there is a choice and that choices have consequences;
- the ability to weigh the information and arrive at a decision
- the ability to communicate that decision;
- a willingness to make a choice (including the choice that someone else should make the decision);
- an understanding of the nature and purpose of the proposed intervention;
- an understanding of the proposed intervention's risks and side effects;
- an understanding of the alternatives to the proposed intervention and the risks attached to them;
- freedom from undue pressure;
- the ability to retain the information. ”



🔗 Find the Guidance notes in full here : [Cheshirewestandchester.gov.uk](https://www.cheshirewestandchester.gov.uk)⁶⁴

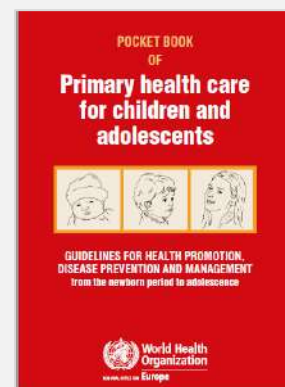
WHO guidance on assessing the competence of children.

WHO guidelines also stress the need to assess and regularly reassess a child's competence and decision-making capacity. This entails evaluating the child's ability:

- to understand different aspects of the given situation;
- to choose between different options, and appreciate their differences;
- to understand the outcomes resulting from different decision(s).

📄 [Read more in the Appendix](#) (Item 14)

🔗 [WHO Pocket book of primary health care for children and adolescents](https://iris.who.int/bitstream/handle/10665/352485/9789289057622-eng.pdf?sequence=2&isAllowed=y)⁶⁵



⁶⁴ <https://www.cheshirewestandchester.gov.uk/documents/social-care-and-health/children/team-around-the-family/young-people-and-consent-guidance-notes-130219.pdf>

⁶⁵ <https://iris.who.int/bitstream/handle/10665/352485/9789289057622-eng.pdf?sequence=2&isAllowed=y>

MANAGING DISAGREEMENTS AND CONFLICTS

Inevitably, situations will arise when there is a difference of opinion or disagreement. This may typically be between children and their parents, or children and health professionals, or both.

It is important to support and manage disagreements with care and according to rights-based principles, so as to enable the best decisions to be made, to protect the ongoing relationships that are often vital to children's continuing healthcare, and to enable all parties to move forward beyond the current situation.

The role of health professionals to protect, facilitate and advocate for each child's right to participate remains unchanged in any circumstance. However, that does not imply that health professionals should agree with or take sides in any disagreement, it is about ensuring that the child is supported to express their opinion, and to ensure that this opinion is considered properly and with due weight in accordance with their rights. Each situation brings its own challenges for health professionals to try to navigate in order to support each child to achieve this right to the greatest extent; whilst enabling the important supportive relationships between the child, parents, and health professionals to remain intact.

Situations of disagreement may test the willingness and skills of health professionals to promote children's right to participate, who may also worry about damaging relationships with those in disagreement. But the protection of this right is a central duty of health professionals and the principles for meaningful participation (p.19) can help.

Similarly, whilst health professionals have a duty to support and enable children's rights to participation, they should not be expected to go beyond the laws of their own country. Therefore, it is important for health professionals to know the legal parameters in their country.

Cultural differences may at times contribute to misunderstandings. Where appropriate, a translator and/or a cultural mediator should be available during the process of information and consent/assent and in the planning of the research. This person should be familiar with the language, including medical terminology, but also social habits, culture, traditions, religion, and particular ethnic differences. This person may need to be available throughout the medical intervention and/or clinical trial, for example to facilitate exchanges, or when dealing with adverse events reporting.

LINGUISTIC AND CULTURAL MEDIATION

Services at Hôpital Necker in Paris - France



Transcultural mediation services were established at Necker Children's Hospital in January 2014. They were set up with a view to helping medical teams deal with issues of therapeutic blockages or non-adherence to treatment, particularly when cultural elements appear to be a determining factor.

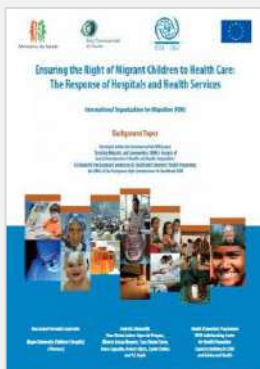
They started off as a pilot project in Paris and resulted from a collaboration between the Centre BABEL and the child psychiatry departments of Necker and Cochin Hospitals.

Transcultural mediation helps medical teams better understand patients' problems by considering them within their cultural context. In hospital environments that are increasingly concerned with cultural diversity, transcultural mediation helps to establish a dialogue between different worlds, that don't necessarily speak the same language and have very different codes.

Thanks to this dialogue, the patient will be able to better understand what is implied by the medical intervention, which can help avoid misunderstandings that can be detrimental to the patient's care. For their part, caregivers will adapt care plans taking into account the significance of the disease in the patient's life.

 [Centre Babel](https://centre-babel.fr/)⁶⁶ (in French)

Services in Azienda Ospedaliero-Universitaria (AOU) Meyer University Hospital in Florence - Italy



Already nearly two decades ago, in a national and regional context of increasing immigration, the Meyer University Children's Hospital took steps to respond to the health needs of migrant children and their families, particularly by ensuring appropriate information.

The hospital introduced cultural and language mediation in different languages (including Albanian, Arabic, Chinese, Romanian, Somali, French, English, Spanish, Polish, Czech, Slovak, Macedonian, Serbo-Croatian, German and Filipino). An interpretation service was also made available via telephone, used especially in cases of emergency.

Upon suggestion from the hospital staff, the "SOS Intercultural Team" was set up. This group was composed of professionals working in the hospital with language competence in 10 different languages (Albanian, Arabic, Bulgarian, French, English, Iranian, Romanian, Spanish, German and Hungarian). This team did not substitute the formal cultural and language mediation services, but provided an emergency substitute, face-to-face or by telephone.

⁶⁶ <https://centre-babel.fr/mediations/>

To ensure the respect for the spiritual and cultural dimensions of health, the hospital undertook the dissemination of the contacts of the religious entities present in the region in all departments and services. It also established a protocol between the hospital and religious communities to ensure the necessary religious assistance to the patients of migrant background and it prepared of 'Intercultural' Calendars, which were disseminated in every department and service to increase awareness of the main religious events. The hospital also provided 'free and flexible' menus, which were translated into different languages, in order to guarantee, as much as possible, the respect of the different cultural and social eating habits.



Read more: [Ensuring the Right of Migrant Children to Health Care: The Response of Hospitals and Health Services, Background Paper](#)⁶⁷, International Organization for Migration (IOM), 2009, p.32-33.

Episodes where there may be different views, or where children may express disagreement with a proposed action, range across a wide spectrum of focus and severity. Scenarios where there may be different views and disagreement occur in all areas of healthcare.

Below are examples of situations that may occur, along with suggestions about how to deal with them:

- Disagreements may arise in situations where no procedure as such is involved, such as in areas of information-giving.

For example, a child may wish to take part in a health survey or needs assessment, and the parents may disagree. In such circumstances, any reasons for parental reluctance should be explored and where possible, any unfounded fears met with reassurance where possible (for example about how information is used or how data is stored). However, when assessing 'best interests', health professionals also need to remain objective and open to the possibility that in some circumstances (for example, violence in the home), parents may seek to block their child from disclosing concerns and needs; in which case the child's 'best interests' may lie in advocating internally for a way to enable this child to participate, assuming this is possible within the legal framework of the country.

- In primary healthcare, immunisation can also be a controversial issue within some families, and it is not uncommon for children or adolescents to want a vaccination and the parent be reluctant, for example for COVID-19 or for HPV.

This can reflect parents' own concerns and sometimes be the result of misunderstanding or misinformation. Providing accurate and clear information about the purpose of the intervention is important and can be reassuring and helpful, ensuring that this is objective and not directive. Similarly, explaining to parents about the rights that their child has and why these are important can be helpful, as parents are sometimes not aware of these or may be sceptical.

⁶⁷ <https://migrationhealthresearch.iom.int/ensuring-right-migrant-children-health-care-response-hospitals-and-health-services>

Sometimes, moral, religious or cultural beliefs contribute to conflict around medical decisions. Such concerns should be identified and addressed in a respectful manner as early as possible and discussions should be truthful and transparent, always assuming that the primary focus of decision making remains the child patient's best interests. Getting the support and mediation of a trusted religious or community leader where available, can be helpful.⁶⁸

➤ In situations requiring urgent decisions or actions, such as procedures to insert an intravenous cannula to give medicines to treat a serious infection or take blood for an important test, it is not uncommon for children to initially refuse or not to want this, particularly being young.

In such circumstances, the conclusion may be non-negotiable and that it is in the child's best interests to have the treatment. However, this should be explained kindly and carefully to the child concerned, and the child concerned should still be given choices that enable some sense of control and influence on other elements of the care provided, such as sitting position, which arm/hand is used, etc. It is also important to choose the least intrusive treatments possible and to seek alternatives that would be acceptable to the child.

➤ Differing views may also arise in situations relating to sexual and reproductive issues, for example if an adolescent seeks advice or healthcare in relation to concerns about a sexually transmitted disease and does not wish to tell their parents.

The child's right to confidentiality and access to counselling is important and should be respected. In such circumstances, health professionals may encourage children to open up to their parent(s) and offer support and mediation between the child and the parent(s) if necessary. In parallel, health professionals also have a duty to assess the circumstances to consider if the child is in an abusive situation and needs protection, or if the child's mental and physical wellbeing is at risk. These and other factors need to be balanced by health professionals in determining the 'best interests' of the child and whether parents should be informed.

➤ There are some situations where the focus of disagreements has particularly serious implications, for example, disagreements between children and parents or health professionals about whether to continue active treatment or interventions when there is little hope of recovery (maybe in the case of continuing treatment for cancer, after previous treatments have failed).

In such cases proposed intervention should be delayed while an attempt at resolution is made. Such situations are always very emotive and health professionals should be compassionate but objective in supporting every effort to understand and respect differences of opinion between the children and their parents/legally designated representative. Objections from children, capable of forming an opinion, should be advocated for and respected; and the opinion of legal representatives should be taken into account in interpreting the wishes of children.

⁶⁸ Kevin W. Coughlin, Medical decision-making in paediatrics: Infancy to adolescence, Canadian Paediatric Society, Bioethics Committee, Ottawa, Ontario

There are some situations where the physical holding of a child who resists a procedure may be used to provide healthcare or to prevent greater harm to the child. These typically occur with young children requiring urgent care, as described in the paragraphs above, and sometimes in complex mental healthcare settings. Situations like these often create ethical conflicts for health professionals and challenge the application of children's rights. Physical holding is subject to strict safeguards⁶⁹. It is important that healthcare professionals receive appropriate training and support regarding the resort to such exceptional measures and be trained in alternative practices.

Alternatives to restraint or physical holding - France




Sparadrap (which literally translates into “Band-aid” or *plaster*) advocates for the rights of children in healthcare and refers to itself as the “Association to help children feel less fear and pain during care and in hospital”.

The association's mission is: 1) to inform, advise and prepare children for any situation involving care, medical examinations, medical visits and hospitalization, and to support their families in this regard; 2) to take part in prevention campaigns aimed at children and adolescents; 3) to raise awareness and provide training to healthcare and childcare professionals to help organizations and practices evolve towards greater respect for children's needs; 4) to promote better pain management of children; 5) to promote the presence of family and friends when children are being cared for or hospitalized.

The association issued guidance on child restraint, meant for practitioners. It aims to have them reflect on and question the use of restraint in their day-to-day practice and suggests alternatives for avoiding or limiting the use of restraint. Such strategies include, for example: using analgesia to limit pain induction, getting the child settled and positioning them in a way that helps (semi-seated position vs laying down), anticipating the procedure by informing and discussing beforehand, distracting the child's attention, pausing during the intervention, asking the child to reproduce the carer's actions on a doll, etc.

 [Sparadrap](#)⁷⁰ (in French)

 [Read the translation of the factsheet in the annex](#) (Item 15)

⁶⁹ By way of example, in the UK, the Royal College of Nursing has issued specific guidance on [Restrictive physical interventions and the clinical holding of children and young people](https://www.rcn.org.uk/-/media/Royal-College-Of-Nursing/Documents/Publications/2019/October/007-746.pdf) (<https://www.rcn.org.uk/-/media/Royal-College-Of-Nursing/Documents/Publications/2019/October/007-746.pdf>). The guidelines emphasise that physical holding should only occur when there is serious risk to the child's health if the intervention is not performed, if proactive and preventive strategies have been exhausted. The legal guardians would as a main rule need to approve of the action. The action must be justified and proportionate to the health risk one is seeking to mitigate, and there are legal requirements for this that will vary between member states. All efforts should in any case be made to reduce the level and intensity of this situation and the degree of force should be confined to only what is necessary to hold the child for the shortest amount of time whilst minimising injury to all involved. Decisions to use any form of restrictive physical intervention must be based on the assessment that no other method is available and that its use will cause less harm than not intervening. Even if the necessity has been explained before the intervention, it should always be followed by a discussion where the professional explains why this has been necessary and the child should be given an opportunity to debrief, including emotionally.

⁷⁰ <https://www.sparadrap.org/professionnels/eviter-et-soulager-peur-et-douleur/eviter-la-contention-de-lenfant-lors-des-soins>

Enabling open communication is often key to resolving issues. However, sometimes serious disagreements over what are the children's best interests remain among parents, children and healthcare professionals, even after a collaborative decision-making process. It is part of the health professional's role to mediate and help to restore positive relationships following this.⁷¹

The following actions may be helpful in mitigating conflict:

- Children, parents/legal representatives and healthcare professionals should be helped to clearly identify the values contributing to conflict and discuss the goals of the proposed treatment and/or research;
- Early discussion around the expectations, limitations and uncertainties of treatment options and outcomes may help establish mutually agreeable treatment/research plans;
- Cases should be discussed within multidisciplinary teams;
- Further discussions and/or referral for a second, independent medical opinion, should be promoted;
- Consulting with and mediation support from a spiritual care leader, social worker, relevant peers, patient relations expert, bioethicist or a bioethics committee, or with institutional or personal legal counsel;
- In very serious or complicated situations, for example when the child's life is at risk or where a severe permanent injury can occur, a court can be asked to decide whether it is right to proceed with a particular treatment.

GUIDELINES AND MECHANISMS FOR MANAGING CONFLICTS

MoH Guidelines on managing conflicting views - France



The French Ministry of Health has issued guidelines for helping health professionals deal with instances when the child refuses, and when the parent(s) or holder(s) of parental authority refuse(s) an intervention. It also tackles the specific situation when there is an opposition to blood transfusion. The guidelines are in line with national legislation. They distinguish between emergency and non-urgent situations.



[Discover the guidelines in the Appendix](#) (Item 16)



[Fiche n°3 : Information et consentement aux soins d'un mineur](#)⁷² (in French only)

⁷¹ Kevin W. Coughlin, Medical decision-making in paediatrics: Infancy to adolescence, Canadian Paediatric Society, Bioethics Committee, Ottawa, Ontario

⁷² https://sante.gouv.fr/IMG/pdf/dgos_onvs_fiche_03.pdf

Children's Hospital sets up Clinical Ethics Committee to advise and resolve conflicts - Italy



In 2016, the Ospedale Pediatrico Bambino Gesù in Rome set up a Bioethics Function, a Clinical Ethics Service and in 2021 it established a Clinical Ethics Committee with the aim of providing advice and specialist training in Clinical Ethics for children.



[Read more about the issues brought forward to the Clinical Ethics Committee since 2021](#) (Item 17)



<https://bambinogesupatrons.org/about-us/ethics-committee/>



CHILDREN'S PARTICIPATION FOR BETTER HEALTHCARE

This Guide mostly focuses on how a child can be involved and supported in individual decisions regarding their health. However, greater routine integration and inclusion of child participation and perspectives at other levels of policy, planning, service design, delivery and evaluation can result in better informed decisions that also bring great benefit to children, in general and individually.

General Comment 12 of the CRC states that children should “contribute their views and experiences to the planning and programming of services for their health and development”, including on “how to promote children’s capacities to take increasing levels of responsibility for their own health and development”.⁷³

In relation to healthcare delivery, children should be given the opportunity to provide confidential or anonymous feedback on their healthcare experience after they have used services by means of “experience of care” feedback, satisfaction questions or other methods. Tools such as Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs)⁷⁴ are increasingly being adopted in paediatric population.

Similarly, engaging children in the design of training curricula for health professionals, of information material or of new health facilities brings important insights and benefits for children that use services in future.

⁷³ paragraph 104

⁷⁴ PREMS are validated questionnaires, that gather patients' and families' views of their experience receiving care and are commonly used to measure the quality of care, with the goal to make care more patient and family centred. PROMs are questionnaires measuring patients' views of their health status. PREMs and PROMs have been fast developing in over the last 15 years. The OECD monitors PREMS in outpatient care in 19 countries, the results of which are published every two years in 'Health at a glance'. The OECD has also launched the PaRIS (Patient-reported Indicators Survey) initiative on PROMS and PREMS that can be compared internationally (<https://www.oecd.org/health/paris/>).

Enabling and facilitating children to discuss and share their views collectively, by participating in regular children's councils, advisory groups (for example groups of expert-patient children with specific chronic conditions) or other forums and networks, not only provides channels for informed feedback to influence change in care delivery or design but can also increase mechanisms of peer-support between children.

Young Persons Advisory Groups (YPAGs) have already been set up across Europe and at international level to underpin clinical trials. The YPAGs include young people aged between 8-19 years (although some groups have older young adults up to the age of 21) who are patients, regular attenders at hospital, and/or healthy youths having an interest in science and healthcare. YPAGs are predominantly facilitated by a professional involved in a clinical research facility, children's hospital, or academic institution. They are recruited by means of schools, associations, hospitals and the patients' and families associations, and were selected according to their motivation and interest in being involved in this kind of empowerment activities. YPAGs provide a platform for children and young people to have a voice, share their opinions, and apply their experience to a variety of issues relevant for biomedical research.

This type of structured participation is increasingly institutionalised in hospitals or other health organisations and rely on participatory approaches where the child is not only a respondent but also engaged in meaningful dialogue. When integrated and facilitated on a regular basis within health services, these approaches also provide platforms to increase the accountability of decision-makers and health professionals to children.

INDIVIDUAL AND GROUP PARTICIPATION OF CHILDREN

A network of paediatric hospitals involves children and young patients in view of improving quality of care - Sweden



adviser groups (YPAGs).

The network aims at improving the quality of paediatric care, with the involvement of young patients, parents and staff. It has its foundation in a set of quality criteria derived from national legislation, professional standards, knowledge of the care environment, and the expressed opinions of children (of primary and high school age) from Patient Reported Experience Measure (PREM) surveys and young

The health facility self-evaluates its practices and includes children and families in the process. The evaluation reports are developed by receiving feedback from children and families and are exchanged with a similar clinic to do a thorough mutual collegial examination. When the final reports have been exchanged the clinics have a clear idea of what to improve, including improvements to be done with children. In terms of methodology, routines for how staff involve children patients in planning their care, communicating their opinions and preparing for medical measures or interventions are required. The clinic carrying out the evaluation on its practice has to demonstrate how the staff has these skills.

The network offers advice and sample questions to be used, for example in PREM surveys, and methods for involving children in care environment surveys.

"Imagine Your Hospital" – Hospital selects three projects presented by children during its first-ever Children's Users' Commission - France

In France, each hospital has a users' commission (*commission des usagers*) that examines complaints addressed to the establishment and makes proposals to improve the stay and care of patients and their relatives. The committee is typically composed of adults.

In 2022, the University Hospital (CHU) in Reims set up its first users' commission exclusively dedicated to children, with the aim of collecting their voices, regardless of their age and hospital experience. It was composed of ten children aged 4 to 17 years, of parents, hospital director, other representatives of the hospital and of external related organizations. This was a first-time experience in France.



For an entire month, hospitalised children were asked to fill in a questionnaire similar to the user satisfaction surveys that are usually released to adults at the end of their hospital stay. Topics included the manner in which patients had been welcomed to the hospital, quality

of meals, accommodation or pain management. Children and parents were also invited to submit ideas and projects. The following four proposals were selected for implementation: 1) allowing children to meet with their pets during hospitalization; 2) creating an app for parents to be informed of how their child's stay at the hospital is going; 3) providing all children with access to Disney+ platform; 4) introducing *à la carte* meals (rather than a set menu for all).

 [Find out more about this initiative](#)⁷⁵ (in French)

 [Find more about the 2022 and 2024 editions](#)⁷⁶ (in French)

PEDSTART and Kids France get children involved in pediatric clinical research - France

A unique initiative in France, the KIDS France group (Involving young people in clinical research in France), supported by PEDSTART, the INSERM/F-CRIN network of excellence in paediatric clinical research, regularly brings together young people aged 11 to 19, both patients and nonpatients, around a common goal: to make pediatric clinical research more adapted to young patients, and more accessible and understandable to all. Recognized by international institutions such as the European Medicines Agency for its contribution to improving understanding, communication and innovation in pediatric medical research, this initiative has already led to the completion of numerous projects.

⁷⁵ <https://www.chu-reims.fr/le-chu/engagements-qualite/indicateurs-qualite/premiere-commission-des-usagers-dediee-aux-enfants>

⁷⁶ <https://www.chu-reims.fr/le-chu/engagements-qualite/indicateurs-qualite/commission-des-usagers-des-enfants-deuxieme-edition>

Over the past 6 years, these young people have been involved in selecting European projects, writing information leaflets for therapeutic studies, disseminating clinical study results, running disease awareness campaigns, creating mini-films on clinical research (e.g. "Clinical research: from molecule to drug"), and reviewing pediatric research protocols (design, procedures, ethics, etc.).

They have also taken part in national and international conferences, in the production of a TEDx, of booklets for young children (e.g. on the ophthalmological effects of a rheumatoid arthritis) and in the creation of a national vaccinology platform for children (COVIREIVAC enfant).

Through these activities, the young people in the group learn about clinical research methodology and help to improve therapeutic innovation in paediatrics.



Learn more here: <https://www.fcrin.org/en/node/105>

Advice and resources for setting up and facilitating the work of a YPAG – UK and Europe

The first YPAG emerged in the UK (GenerationR) in 2006 with and is now a model adopted across Europe (see European YPAG network or eYPAGnet) and globally via the International Children's Advisory Group Network.



GenerationR, has developed, sometimes in partnership with YPAGnet, extensive resources on how to involve children and young people in health research, including:

- Guidance on how to involve young people in research design
- Activities (icebreakers, ideas for agendas, etc)
- Online Toolkit on how to set up a Young Person's Advisory Group
- Resources on designing age-appropriate patient information sheets (Guidance for patient information sheets, Checklist for patient information sheet, Strategies for improving assent forms for children's participation in health research).



[About | Generation R](https://generationr.org.uk/about/)⁷⁷



[Toolkit Archive - eYPAGnet](https://eypagnet.eu/toolkit/)⁷⁸

⁷⁷ <https://generationr.org.uk/about/>

⁷⁸ <https://eypagnet.eu/toolkit/>

CONCLUSION

Children are rights holders with a progressively evolving ability to make their own decisions. They have the right to express their views on all matters that affect them, namely in the field of healthcare, and to have their view taken into account.

This requires paying particular attention to children's participation in decision making processes on matters related to their health.

Benefits of child participation are many. They are not only beneficial to individual children but serve the community as a whole and improve the general quality of healthcare delivery.

In this context, healthcare professionals and other professionals involved need to understand the importance of their role in supporting children and their families in this process.

The [Guidelines for child friendly healthcare](#)⁷⁹ adopted by the Committee of Ministers of the Council of Europe in September 2011, requested member states to support programs and policies aimed at raising the awareness of children and their parents of their rights to active participation in decision making and the promotion and protection of their health, by creating legal structures and policies that support the promotion of children's rights in healthcare.

How to enable and facilitate the participation of children in decision-making processes on matters relevant to their health, and how to give information to children and their families, should be subject of training and education of health professionals that work with children. Good practices and tools relevant to children's participation, including in the research context, need to be developed and promoted.

Special attention and additional support must be given to children who may face additional challenges or barriers to participate in decision making processes (including but not limited to, children with disabilities, with mental health problems, migrants, linguistic, cultural and other minorities).

⁷⁹ https://search.coe.int/cm/Pages/result_details.aspx?ObjectId=09000016805c1527

APPENDIX

1 – EXTRACT FROM ILLUSTRATED EACH CHARTER

Article 4.1: Children and parents shall have the right to be informed in a manner appropriate to age and understanding.

Annotation on article 4:

Children, and their parents, are entitled to know what is going to happen to them before undergoing an examination, treatment or other procedure.

Timely and accurate information allows children to retain a sense of control about their healthcare, particularly in hospital.

Information for children

Information given to children should:

- be based on the child's age and understanding and take into account their level of development;
- be informed by what the child already knows or imagines;
- include honest and simple explanations about their condition and treatment outcomes;
- explain the course of events to come, including what the child may see, smell, hear and feel;
- include appropriately prepared verbal, audiovisual and written information, supported by illustrative models, play or other media presentations.

Staff giving information should appreciate the child's capacity to comprehend information and express his or her views. Staff should:

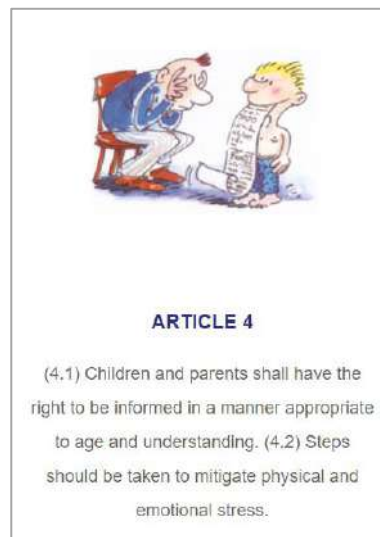
- encourage and answer questions, offering comfort when concern or fear is expressed;
- help the child to select and practice strategies for coping;
- make sure that all explanations given have been properly understood.

Preparation will only have a positive effect if the child feels safe. Therefore, information should be given, whenever practicable, in the presence of the parents. Parents need to know what information the child has, so that they can refer to it and repeat it until the child has understood the information correctly.

Information for parents

Information given to parents should:

- be clear and comprehensive;
- consider the parents present situation, especially feelings of fear, sorrow, guilt, anxiety or stress regarding their child's condition.



Staff giving the information should:

- encourage questions;
- introduce parents to a 'named person' whom they can contact whenever they are in need of information;
- satisfy the need for more information by directing parents to additional sources and support groups;
- provide parents with unrestricted access to printed or digital documentation regarding the illness of their child;
- not use the sick child or a sibling as an interpreter for the parents.

Information for children and parents

Information to meet the needs of both the child and parents should:

- be provided continuously during the whole period of care;
- include information regarding care after discharge;
- be provided in a stress free, secure and private environment without pressure of time;
- be given by experienced staff trained and competent to communicate with children and parents in a way which can be readily understood;
- be given, preferably, in the family's language, with the assistance of a translator if required;
- be repeated as often as necessary to facilitate understanding, checking to ensure that the information has been properly understood by both the child and the parents.

Children have the right to express and have their views taken into consideration. Providing they have sufficient competence to understand the matter, they may veto their parents' access to their health information, depending on the stipulations of national laws. In such cases staff are required to proceed with the utmost care to evaluate the situation properly. Protection, counseling and support should be given to the child. Hospital staff should ensure that necessary counselling and support are also given to the parents who may be in need of psychological and social help and advice at this time. ”

Article 5.1: Children and parents have the right to informed participation in all decisions involving their health care.

Annotation on article 5:

Participation in decision making requires advance information about all measures that need to be taken.

The right of children to participate in their healthcare requires that staff members:

- create an environment based on trust;
- have the capacity to listen;
- share information and give sound guidance;
- respect the right of children to express their view in all matters affecting them;



- give due weight to their opinion in accordance with their competence;
- render a culturally appropriate interpretation of the child's view;
- accept that children have the right to not express an opinion or to express their views through their parents.

Communication and interaction with others, in particular with parents, starts at birth. As parents know their children best, their observations relating to their child's expression of stress, discomfort or pain have to be taken seriously. Additionally:

- children may express their views through play, art and other activities;
- staff members must be attentive to the body language used by children when expressing their views;
- excluding children from information may increase their fear;
- staff should respect and take into account signals or nonverbal responses from children who are too young or otherwise not able to express themselves verbally.

The rights of the children and parents to informed consent requires that staff members:

- respect the child's and the parents' ability and competence;
- provide adequate and timely information to the child and the parents regarding their child's health condition, the purpose and value of treatment, the process and the risks;
- offer adequate, reliable information on alternative forms of treatment;
- advise and support the child and the parents to evaluate the proposed course of action;
- acknowledge and take seriously the child's and parents' knowledge and experience relating to the their child's general health condition or present condition.

Children have the right to express their views and may disagree with their parents. Providing they are mature enough to make decisions in their own best interests, staff should respect the child's opinion, depending on the stipulations of national laws. Staff are required to proceed with the utmost care to properly evaluate the situation. Hospital staff should also ensure that the necessary counselling and support is given to the parents. ”

 [Illustrated EACH charter](#)⁸⁰

⁸⁰ <https://each-for-sick-children.org/each-charter/>

2 – EXTRACT FROM NATIONAL HEALTHCARE CHARTER FOR CHILDREN - IRELAND



Communications and information

Every child has the right to information, in a form that they can understand. Every child can expect open and appropriate communication throughout their care.

Children have the right to information that they can understand about their health and healthcare. Information for children should take into account the child's age and level of development, and;

- appreciate their capacity to understand information and express their views;
- be conveyed using language that is accessible to the child or young person with appropriate verbal, audio-visual and/or written information, supported by illustrative aids, models, play or other media presentations;
- whenever practicable and appropriate, involve parents in the communication process.



What this means for you:

Information provided to you about your healthcare needs should:

- be provided continuously throughout your journey through healthcare services;
- take account of your evolving capacity to understand, respond to and engage with the information received;
- include information regarding care after discharge;
- be provided in a safe, secure and private environment without pressure of time;
- be communicated in different ways, using different methods where necessary to facilitate understanding;
- be checked by the staff member to ensure that the information given has been correctly understood by both you and your parent(s);
- provide your parents with access to written or pictorial documentation regarding your illness.

It is crucial that healthcare workers talk directly to you as well as to your family, even if you don't seem to understand. Healthcare workers and families should be as open as possible with you about your health and healthcare. You are entitled to know what is going to happen to you before a procedure occurs and to be given honest information about your condition and treatment outcomes, and to be helped to select and practice strategies for coping.

Communication and information in relation to your care:

What this means for children and young people. Every child can expect open and appropriate communication throughout their care:

- about your health and what the proposed treatment or care aims to do especially when plans change or if something goes wrong;
- concerning the results of any proposed treatment and medication, including the possible risks and alternatives;

- regarding the type of continuing healthcare or therapy that you may need, including medication, continuing care in hospital, timely and appropriate, referrals, convalescence or rehabilitation;
- regarding discharge arrangements and follow-up support in the community.

You should be given:

- the opportunity to ask questions and receive answers that you can understand;
- be supported to ask questions and to make the most of consultations;
- benefit from interpretative services where possible. A child or a sibling should not be used as an interpreter for the parents.

What you can do to help:

Children together with the support of their parents can promote improved communication:

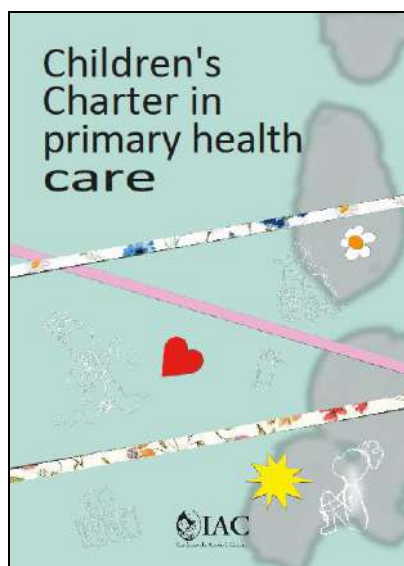
- If there is something that you do not understand about your condition or treatment, let your healthcare worker/team know. Ask your healthcare worker to explain it better, to draw a picture, or explain it in a way that you will understand. Never be afraid to ask.
- Together with their parents, children can provide information about their medical history, current treatment, medication and alternative therapies. It may be helpful for you to carry a healthcare record with you including information about vaccinations etc. ”



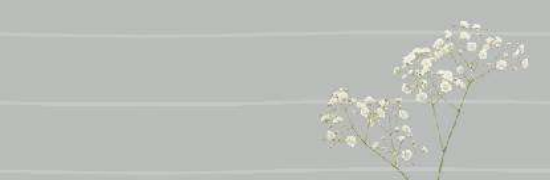



[National Healthcare Charter for Children](#)⁸¹ (page 15 and 16)




⁸¹ <https://www.ncio.ie/wp-content/uploads/2021/12/HSE-National-Healthcare-Charter-for-Children-2018.pdf>


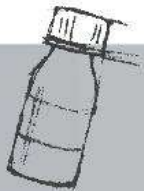


3 – EXTRACT FROM CHARTER ON CHILDREN'S RIGHTS IN PRIMARY HEALTHCARE – PORTUGAL






 <p>1 Children and parents/carers have the right to receive information adapted to their age and understanding.</p>	 <p>2 Children have the right to express their opinion.</p>
<p>The team of health professionals should use language adapted to the understanding of the child and the parents/carers. The child and parents/carers have the right to obtain information about the state of health and the treatment indicated by the team of health professionals. The explanation to the children, with the prior authorisation of the parents/carers, may and should include a playful component in order to demystify healthcare and some associated fears.</p>	<p>It is considered essential to listen to children not only about their state of health and treatment, but also about other issues that directly or indirectly concern them, such as reception, care, the presence of parents/carers, intimacy/privacy, the adaptation of information, play areas, among others.</p>
	

<p>3</p> <p>Whenever possible, children should be cared for by professionals trained in paediatrics or child health.</p>	 <p>4</p> <p>The space should be as adapted as possible to the children's needs.</p>
<p>Users' recourse to non-urgent healthcare for children in the SNS occurs at the level of child health consultations in health centres. The team of health professionals must have training in paediatrics or child health as well as experience with children, skills and sensitivity to working with children and families.</p> 	<p>Children should be offered an environment that meets their physical and emotional needs, in terms of equipment, staff and safety. The health centre must be accessible to all users, especially children. Spaces should be adapted to children's needs ("child-friendly") through illustrations, for example, as well as the provision of hygienic play equipment adapted to the different age groups.</p> 

<p>5</p> <p>Children should be treated holistically, as a psychological, social and physical whole.</p>	 <p>6</p> <p>Children have the right to be accompanied by their parents/carers at all times during their care.</p>
<p>In primary health care, although there is no permanence in the health unit, the offer of services must go beyond physical healing, also including psychological and religious well-being, treating the child as a whole. Likewise, the healthcare team must have the appropriate training to respond to the psychological and emotional needs of children and their families.</p> 	<p>Children have the right to have their parents or carers with them during the care they receive while in the health centre. From the age of 16, children should be able to choose whether they want to be accompanied by their parents/carers or whether they prefer to be alone during care.</p> 

<p>7</p> <p>The team of health professionals must be organised in such a way as to support and empower all those involved in the child's networks.</p>	 <p>8</p> <p>Each child's privacy must be respected.</p>
<p>Parents/carers or teachers/carers should be able to take an active part in caring for a child with a chronic illness, end-of-life palliative care and pain management. If the child needs care at home, parents/carers or teachers/carers should be trained in how to care for the child so that they feel comfortable providing it. Home visits by professionals should be guaranteed.</p> <p>In order for parents/carers to be able to look after their children, they need to be informed of existing resources in the community (IPSS) or others such as Social Security (SS).</p>	<p>Children should be treated with care and understanding in all circumstances, regardless of their age or level of development. The child's privacy must be protected in all situations, including communication and observation.</p>
	 

<p>9</p> <p>The team of health professionals must ensure a continuity of care plan for the child with a complex chronic illness.</p>	 <p>10</p> <p>Children have the right to be treated equally regardless of their race, religion, age, social class, etc.</p>
<p>The child with a complex chronic illness must have an individual intervention plan that also covers the transition between primary healthcare, hospital care and integrated long-term care (ICC), as well as the intra/inter-institutional transition.</p>	<p>All children are equal and deserve to be treated with respect, equality and without any discrimination. It is up to each health centre to ensure that this happens. They must ensure that there are no children discriminated against for any reason and, above all, that this does not jeopardise the treatment they receive.</p> <p>The child should feel that everyone is treated equally at the health centre, and that there are no children who benefit from discrimination.</p>
	

4 – CHARTER OF THE RIGHTS OF THE CHILD - PATIENT DRAWN UP BY THE CHILDREN'S RIGHTS DEFENDER AND THE PATIENTS' RIGHTS DEFENDER - POLAND

1. A child is a person under the age of 18.
2. If you become ill, medical staff must do everything possible to treat you and provide care during your treatment.
3. When your health improves enough for you to go home, you have the right to do so.
4. You and your parents or carers have the right to know how the doctors intend to treat you and what the effects will be.
5. Your parents or carers have the right to obtain the documents in which doctors describe your illness and treatment.
6. Decisions about treatment cannot be taken without your participation; however, up to the age of 16, your parents or carers will make the decision for you; after that, you will also be a co-decision-maker.
7. Without your permission, no one has the right to spread the news that you are ill; you have the right to keep it a secret known only to you, the medical staff and your parents or carers.
8. No one has the right to hit, embarrass, belittle or intimidate you. During your illness, adults must give you special support and look after your well-being.
9. You have the right to be in constant contact with your loved ones. They have the right to be with you in a hospital, sanatorium or thermal station. Only in exceptional circumstances will doctors decide that your loved ones cannot be with you.
10. While you're in a hospital, sanatorium or thermal station, you can always call or write to your loved ones.
11. A hospital, sanatorium or spa is a place where you are supposed to recover, but you also have the right to study, play and rest. You'll recover faster if you don't constantly think about your illness.
12. If you wish, you can meet a member of the clergy of your denomination.
13. You have the right to place valuables in the hospital depot.



Remember that every child has the right to express his or her opinion on all matters that concern them. The medical staff and those caring for you are obliged to listen to you and take your opinion seriously.

 [Charter of the Rights of the Child - Patient drawn up by the Children's Rights Defender and the Patients' Rights Defender in Poland](https://www.gov.pl/attachment/4ea75824-05f4-44ae-a084-129c6439bb73)⁸²

⁸² <https://www.gov.pl/attachment/4ea75824-05f4-44ae-a084-129c6439bb73>

Version 1: Standards for professionals

Rights based standards for children having a health care procedure (test, treatment, examination, or intervention)



- The standards have been developed by an expert international collaborative group through extensive consultation with children, parents and professionals.
- The standards are framed by a commitment to prioritise the rights of a child (United Nations Convention on the Rights of the Child, 1989) and ensure that their short- and long-term physical, emotional and psychological well-being are of central importance in any practice and decision-making related to health care procedures.
- These international standards recognise that all children have rights that should be respected regardless of their age, disability, race, religion or belief, sex, sexual orientation, ethnicity, language, ability, or any other status.
- These standards aim to provide broad principles for practice to support all children aged from 0 to 18 years undergoing a health care procedure. These standards should be applied in practice to recognise and respect each individual child's needs, competence, ability, preferences and experiences.

The intention of these standards and how they should be applied in practice are outlined below.

These standards intend to:

- Propose an approach to minimise any anxiety, distress and harm experienced by children when undergoing health care procedures;
- Propose an approach to establish trust with children undergoing health care procedures;
- Contribute to describing good procedural practice with children;
- Define and promote supportive holding as an approach to prioritise children's rights and well-being;
- Challenge the use of restraining holds for health care procedures, whether intended or labelled as such, by raising awareness that whilst restraining holds occur in procedural practice and may be necessary to provide life saving care for children or prevent significant harm, holding a child against their will can be harmful and should be minimised, openly acknowledged and documented;
- Support health professionals and other health care workers (hereafter referred to as professionals) in advocating for children's rights and positive procedural experiences;
- Be of value internationally and across different clinical settings;
- Support 'open and transparent' reflection and learning between professionals, children and parents/carers;
- Act as broad principles which will need consideration and adaptation within different local regulations, laws and resources; and
- Act as broad principles, to be considered alongside professional judgement.

The standards do not intend to:

- Endorse the use of restraining holds with children; rather they call for an honest and transparent acknowledgement and documentation of when such holds are used within a health care procedure;
- Override or replace country or discipline specific laws, regulations, frameworks, policies, standard operating procedures or guidance; and
- Provide specific guidance on the use of pharmacological interventions for procedures, for example procedural sedation and/or analgesia.

To achieve good practice for children undergoing health care procedures, professionals should recognise that:



1. A child has rights to be cared for by professionals who have the appropriate knowledge and skills to support their physical, emotional and psychological well-being and rights before, during and after their procedure.

- a) A child is cared for by a professional who has the appropriate knowledge and skills and who is competent to conduct the procedure.
- b) A child is cared for by a professional who has access to appropriate equipment and resources (e.g. staff, environment) to conduct the procedure.
- c) A child is cared for by a professional who has confirmed the clinical need for the procedure.
- d) A child is cared for by a professional who has the appropriate knowledge and skills to assess a child's individual needs, competence, abilities, preferences and experiences.
- e) A child is cared for by a professional who demonstrates respect for children's rights and who can work in a child-centred manner to support and advocate for these rights.
- f) A child is cared for by a professional who has the appropriate knowledge and skills to promote procedural comfort and to reduce the potential for traumatic procedural experiences.
- g) A child is cared for by a professional who can work in partnership with a child and their parents/carers and who can utilise the skills and knowledge of the wider multidisciplinary team (if available).

2. A child has rights to be communicated with in a way which supports them to express (verbally or behaviourally) their views and feelings and for these views and feelings to be listened to, taken seriously and acted upon.



- a) A child is communicated with directly in an open, honest, supportive and caring way to appropriately acknowledge their feelings and in a way a child can understand and that is consistent with their individual needs, competence, abilities, preferences and experiences at the time of the procedure.
- b) A child is provided with the time and environment to develop trust and rapport with those present at their procedure.
- c) A child is provided with the time and environment to feel able to communicate and freely express their views and feelings before, during and after their procedure.
- d) A child is encouraged and supported to express their views and feelings freely without pressure, coercion or manipulation.
- e) A child is encouraged and supported to recognise and communicate their rights.
- f) A child's parents/carers are supported to recognise and communicate their child's views, choices and rights.



3. A child has rights to be supported to make procedural choices and decisions and for these choices to be acted upon to help them gain some control over their procedure.



- a) A child is assumed to have the ability to be involved in choices about their procedure even when they are not able to make bigger decisions on their own.
- b) A child is provided with sufficient information, including alternate options and the potential outcomes of those options, in ways that enable them to form their own views and be involved in choices and decisions about their procedure.
- c) A child is actively encouraged from the earliest opportunity and throughout the procedure to share their views, feelings, procedural preferences and choices. This may include analgesia, methods of distraction, relaxation techniques, positioning, who supports them for their procedure and sources of comfort.
- d) A child is supported through their choices and decisions to have optimal control during their procedure.
- e) A child and their parents/carers are provided with the opportunity to discuss previous procedural experiences to inform procedural choices and decisions.
- f) A child's parents/carers are supported by a professional who works with them to consider their child's views, preferences and choices for pharmacological and non-pharmacological interventions.
- g) A child's views and expressions of refusal must be listened to, considered, taken seriously and given due weight.

4. A child has rights to be provided with meaningful, individualised and easy to understand information to help them prepare and develop skills to help them cope with their procedure.

- a) A child is provided with tailored, easy to understand, meaningful, honest and appropriately timed information to help them prepare for a procedure, understand what is happening and have the opportunity to ask questions to check their understanding.
- b) A child shall receive specific, honest and clear information at key points before, during and after their procedure.
- c) A child's questions and expressions of concern should be responded to in a calm and honest manner in accordance to their individual needs, competence, abilities, preferences and experiences.
- d) A child's parents/carers are provided with tailored, appropriately timed, easy to understand, meaningful and honest information to ensure they are aware and prepared for their child's procedure and have been able to ask questions to understand what is happening and their role in supporting their child before, during and after a procedure.



5. A child has the right for their short- and long-term best interests and well-being to be a priority in all procedural decisions.



- a) A child's best interests must be prioritised in all decisions and actions before, during and after a procedure. A child's interests should be prioritised over those of their parents/carers, professionals and the institution.
- b) A child's short- and long-term best interests are openly considered and collectively discussed by health professionals, parents/carers and the child (where appropriate) in the preparation phase prior to the procedure.
- c) A child is protected from harm; any potential or actual harm to a child caused by unnecessary procedures or overriding their expressions of dissent should be carefully considered and mitigated wherever possible.
- d) A child is supported to feel calm, secure and settled during a procedure.
- e) A child who becomes upset or resistant before or during a procedure is helped as quickly as possible, if it does not cause harm, to take a supported break. Professionals should be confident to stop and reconsider the procedural plan.
- f) A child and their parents/carers are supported after a procedure to talk through their experiences and reflect on positive or any challenging aspects.
- g) A child's health records will include clear documentation of what worked well during a procedure and what procedural support or techniques would help for future procedures.

6. A child has the right to be positioned for a procedure in a supportive hold (if needed) and should not be held against their will.



- a) A supportive hold involves supporting a child to feel calm, secure and settled during a procedure. In a supportive hold a child agrees to the procedure and positioning and/or does not express signs of refusal.
- b) Supportive holding is a way of providing comfort to the child and helping them to maintain a good position for the procedure.
- c) A child is only held using a supportive hold for their procedure.
- d) A child is encouraged to express their views and choices about who will supportively hold them for their procedure.
- e) A restraining hold is any action to prevent a child moving freely against their choice or will while expressing signs of refusal.
- f) Regardless of who holds a child, if it is against their will (expressed verbally and/or behaviourally) the hold is a restraining hold. A restraining hold should be recognised as such and not labelled as a clinical, supportive or comfort hold.
- g) A child is not held against their will (restrained) at any point in a procedure unless the procedure is lifesaving or where there is a likelihood of significant harm if the procedure is not carried out.
- h) Any child who has been subjected to a restraining hold during a procedure must receive appropriate support from a professional to help them understand their experience and re- build trust.
- i) A child's health records will include clear documentation if they have been held without their agreement (restraining hold), regardless of who held the child. This would include the rationale for using a restraining hold, who made the decision that a restraining hold was necessary, the restraining hold/technique(s) used, and the outcome for the child.



Standards for children having a health care test, treatment, examination or intervention



- These standards show health professionals* the best way to prepare and support me if I need a health care test, treatment, examination or intervention (procedure).
- The statements are based on my rights as a child** to make sure my well-being is the most important thing when making choices and decisions about my procedure.
- The statements and my rights apply no matter who I am, how old I am, where I live, if I have a disability, what I think, who I identify as, what my religion is or how I communicate.



When communicating with me you will..

- Communicate with me directly in a caring, clear and supportive way.
- Communicate with me in a way I can understand.
- Check my understanding of what has been communicated.
- Ask me and my parents/carers how I want to share my ideas.
- Let me have time to share my ideas.



When making choices and decisions with me you will..

- Help me be involved in choices about my procedure even when I am not able to make big decisions on my own.
- Offer me choices and options to help me manage my procedure. These options might include things to distract me, things to help me relax, who stays with me, pain medicine and the best position for me to be in for my procedure.
- Support me to share my ideas and choices, before, during and after my procedure.
- Talk with me about what is best for me before my procedure starts.
- Pay attention to my views and choices, and if I say or show I mean 'no' you will take this seriously.
- Act on my choices and decisions whenever possible.



*A health professional is anyone providing health care to me.

**These Rights-based standards for children undergoing clinical procedures are framed by the United Nations Convention for the Rights of the Child which are a list of rights which apply to every child under the age of 18 years old, no matter where they live in the world.

When sharing information with me and helping me prepare you will....

- Give me information that is honest and easy to understand.
- Help me understand what is happening and give me time to ask questions if I want.
- Give my parents/carers information to make sure they understand what is happening and have the chance to ask questions.



When acting in a way where my well-being comes first you will...

- Think about what is best for me in all decisions and actions before, during and after my procedure.
- Make sure that what is best for me comes first before what is best for my parents/carers, the health professionals and the hospital or clinic.
- Help me to feel calm and listened to during my procedure.
- Support me to take a break if I become upset or show I mean 'stop' or 'no' to help everyone rethink how to help me have my procedure.
- Consider how it will make me feel if you do not listen when I say or show I mean 'stop' or 'no'.
- Support me after my procedure to help me understand my experience.
- Write down in my health records what helped me and what did not help me to make it better next time.



If you are holding me to help me keep still you will.....

- Only hold me in a supportive hold which helps me feel calm, safe and settled
- Ask me how I would like to be held and who I would like to hold me.
- Explain to me why I am being held.
- Stop holding me if I say or show that I want you to.
- Not hold me against my wishes or expect my parent/carer to hold me against my wishes to get a procedure done, unless the health professional in charge decides it is lifesaving or I will be really harmed if it is not completed.
- If I have been held for a procedure against my wishes you should explain why and discuss with me what follow-up support I would like.
- If I have been held for a procedure you will write down notes about this in my health records.





iSupport Standards

These are the things which health care staff can do to help you if you need a health care test, treatment, examination or intervention.

Communicate with me in a way I can understand

Let me have time to share my views

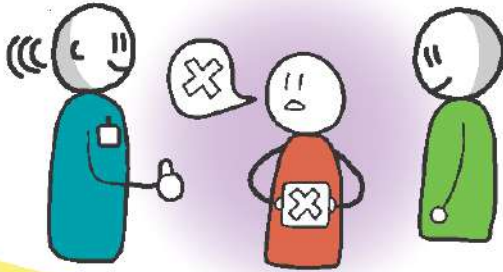
Give me information that is honest and easy to understand.

Help me understand what is happening.
Give me time to ask questions.

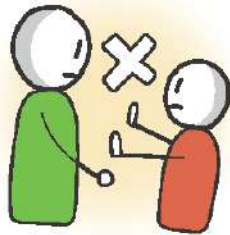
Offer me choices.
Pay attention to my views.

Do what is best for me at all times

If I say or show 'stop' or 'no' then take this seriously and stop.



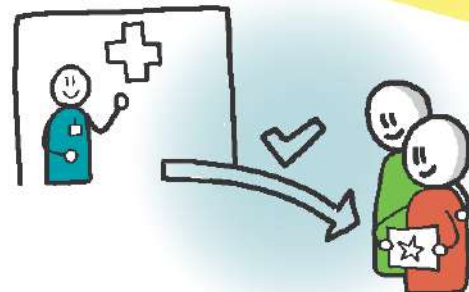
Only help me to keep still in a way which makes me feel calm and safe.



Stop holding me if I say or show that I want you to



What else might help you? Why don't you draw it here?



Help me understand what happened before I leave.

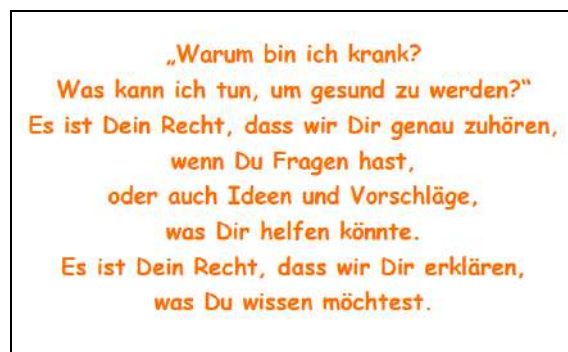


With support from



Illustrations Leonie Sonneveld

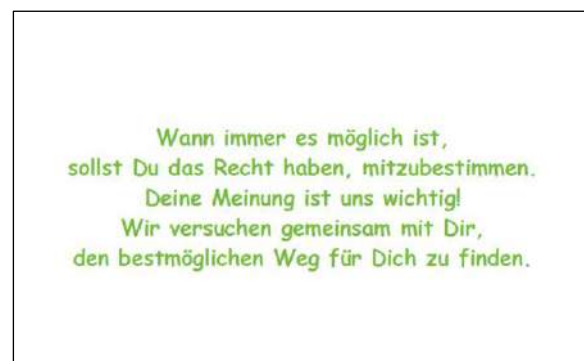
6 – EXTRACT FROM CHILDREN'S RIGHTS, MUNICH CHILDREN'S HOSPITAL (BROCHURE) - GERMANY



Why am I ill? What can I do to get better?"
It is your right that we listen to you carefully,
if you have any questions, or ideas and
suggestions about what could help you.
It is your right that we explain to you
what you want to know.



Sema has to stay in hospital today. The doctor explains everything to her in detail.
(Now I have understood why I have to sleep in hospital tonight. I'm glad that my Mum always stays with me. That's why it's okay for me.)



Whenever possible, you should have the
right to have a say. Your opinion is
important to us!
Together with you, we try to find the best
possible way for you.



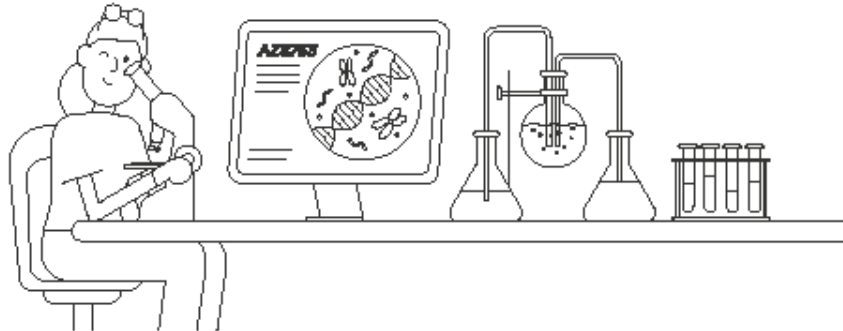
Marie needs special medicine.
(Hello Maria! We have already discussed.
The fact that you need a medicine. It is
important that you take it. Today you may
decide whether you want to take your
medicine in the form of a juice or in
in the form of a tablet.)

 [Brochure Children's rights, Munich Children's Hospital](#)⁸⁴

⁸⁴ https://www.lmu-klinikum.de/_scrivito/to_binary?encrypted_params=eyJiaW5hcnlfaWQiOiJmOGExMDZiZmViZTlxODNlLzcxNWl5MzAyZTg2MC9QaXhpZS1Kay1QcmVmaW5hbDQucGRmliwib2JqX2lkIjoiZjhMTA2Y2ZlYmUyMTgzZSIsInRyYWF5Zm9ybWF0aW9uX2RlZmluaXRpb24iOjnsid2lkdGgiOiE4MDAsInF1YWxpdiHkiOiJ1fX0%3D--f01e16266e5b86f250ca9b9b65538b570314fd4f

Taking part in research

How might your medical data and samples be useful for researchers?



What you need to know about general consent to keeping and using samples and data for research purposes

CHUV is a research centre as well as a hospital

Its mission is to care for patients but also to carry out research and teach. In this leaflet, you can find out about how CHUV carries out research to learn more about diseases and how to treat them. It will help you decide if you want to take part in research.

What does “carry out research” mean?

There are still lots of things about how the human body functions and what causes diseases that we do not yet understand. Researchers are like detectives who try to solve puzzles. They therefore study tiny amounts of substances (such as blood, urine (wee) and saliva), which are called samples, taken from people who are ill. Sometimes, once the puzzle is solved, it can help to develop medicines or tests to discover diseases more quickly and therefore help cure them.

All different kinds of research can be carried out on how the human body works, organs (such as the heart, lungs, etc.), the cells that make up your body and genes.

Your samples and data may be sent for research purposes to laboratories, hospitals and universities but also to businesses that make medicines and tests to diagnose diseases.

What are genes?

You could think of your body as a house with lots of rooms: those are your cells. Each room has a bookcase with 46 books: your chromosomes. And each book has chapters: your genes.

Half of the books come from your dad and half from your mum. Genes are like an instruction manual or a dictionary that allow all the parts of your body to work.

Sometimes, the writing in the books is different, which is why certain diseases occur, and it is these differences that researchers study. When several people in the same family have the same “sick” gene, they can develop the same diseases.

CHUV 04 2021 | 51888



Consentement général

1/4



[Taking part in Research](#)⁸⁵

[Find](#)

⁸⁵ <https://www.chuv.ch/fr/consentement-general/cg-home/participer/quelles-decisions-dois-je-prendre/le-consentement-general-pour-les-enfants-et-les-adolescent-e-s/le-consentement-general-pour-les-mineurs-en-plusieurs-langues>

How can you take part in research?

If you wish, you can take part in research by agreeing that your medical data and samples (blood, wee and saliva), which are collected when you are being cared for in hospital, are kept to be passed on to researchers. This is called consent.

Taking part is voluntary and your decisions are entirely up to you, but **it is important that you tell us what you decide. You and your parents can complete and sign the consent form attached.** The form covers the data and samples collected in the past, but also any that might be collected at CHUV in the future.

Your and your parents' decision will remain valid until you are 18 years old, unless you and your parents change your mind.

If you do not sign the consent form, the hospital still has the right to ask the Research Ethics Committee for a special authorisation to use your samples and data without your consent as an **exception**. A special authorisation is requested when it is very difficult or impossible to contact the patients concerned. It is therefore important for you to make your wishes clear.

If you decide not to take part in research by ticking "NO" to statement A, your data and samples cannot be used by researchers under any circumstances.

This decision does not have any impact on how you will be treated at CHUV.

What happens if you change your mind?

You can change your mind and **withdraw your agreement** at any time. You will not have to explain why you have made your decision. You will simply need to phone the Research Consent Unit or write to the address shown on the back of this document.

If you decide to withdraw your agreement, researchers will no longer be able to use your data and samples from that point on. **Withdrawing your consent will not have any effect on the care you receive.**

How are your data and samples protected?

Your name is not shown on your data or samples as it is replaced by a code (for example: AZ8765). All the information remains secret so that the researchers cannot know who the samples and data they are working with belong to.

The key to the code is kept by a doctor who is caring for you or someone who is not involved in the research project. If a research project discovers any results that are important for your health and you need to be informed, the group of experts and the hospital can then give the key to the code to the researchers.

More rarely, data and samples are anonymised. In this case, the key to the code is destroyed and no-one can know who the data or samples belong to.

Will you and your parents be informed of the results of the research?

In principle, no. In rare cases, it may be that the researchers find a result that is important for your health, and they can offer you a medicine or medical follow-up. In this case, you and your parents would be informed, as long as your data and samples had not been anonymised.

Will you receive any money if you decide to take part?

Taking part is a voluntary contribution to research. You will not be paid for agreeing to take part, even if products are developed following the research carried out using your data or samples, for example, new medicines or new tests.

What is CHUV's Genomics Biobank?

CHUV's Genomic Biobank (BGC) organises the collection and storage of blood samples donated by patients at the hospital. It makes these available to researchers at CHUV, in Switzerland and abroad. Samples are kept in the BGC's freezers for a very long time, perhaps even more than 100 years. The biobank was created especially for research on genes.

What does this mean for you in practical terms?

If you decide to take part in the BGC, a blood sample may be collected **at the same time as another blood sample during your stay at CHUV, if your state of health allows it. This means there will not be any additional needle prick or pain.** The quantity of blood taken will depend on your weight but will not exceed 7.5 ml (the equivalent of a tablespoon). The sample taken will be kept in the BGC and used for research.

Your decision will not have any effect on your medical treatment or the quality of care you receive.

If you decide not to participate any longer and you withdraw your consent, the blood sample collected specifically for the BGC will be destroyed.

Does your consent remain valid once you become an adult?

Once you are 18 years old, we will contact you again to ask for your decision on general consent to research.

If you are under 14 years old when you sign the consent form, your data and samples will no longer be able to be used for research at all unless you give your consent again after your 18th birthday. The same rules apply if your parents and/or your legal representative signed the consent form by themselves when you were a teenager.

If you gave your consent as a teenager when you were between 14 and 17 years old, and you do not respond to our request, your data and samples may still be used for research. However, no genetic analyses can be carried out using samples unless you confirm your consent again.

You can let us know your decision by completing and signing the consent form.

The form is in three sections:

- A** Once you have checked that your last name, first name and date of birth are correct, decide whether or not you agree to researchers using your medical data and samples for their projects.
- B** If you agree to the use of your medical data and samples for research (by answering "YES" to statement A), decide whether or not you are willing to give another small blood sample to CHUV's Genomic Biobank.
- C** *If you are less than 14 years old*, we encourage you to sign the consent form below the signature of your parents or the person who looks after you.

If you are more than 14 years old and you have understood this information in full, you can sign the consent form yourself but it is advisable for one of your parents or your legal representative to sign it too. You do not have to make the decision by yourself. If you prefer, your parents can make it for you.

The consent form can be sent to the address shown on the back of this leaflet, using the pre-paid envelope. You can also give it to your doctor on your next visit to the hospital.

Would you like to know more or do you have any questions?

You are welcome to send us an email or phone us.

By post:

CHUV-Département de la formation et recherche
Unité consentement général
Boîte aux lettres N°47
Rue du Bugnon 21
1011 Lausanne

By email:

info.cg@chuv.ch

By phone:

021 314 18 78
Mon-Fri 07:30-12:00 and 13:00-16:00

You can also visit our website for more information and videos:
www.chuv.ch/fr/consentement-general/cg-home.



What is consent and why am I being asked for it? Information for young people

Consent is the word we use in healthcare to mean 'agreeing to something' – this might be having an operation or procedure, using a photo or video with you in it or sharing your experience with other people. There are different times when we ask for your consent and different ways we ask you too. This information sheet from Great Ormond Street Hospital (GOSH) explains a bit more about consent and how you can make the best decision for you.

Consent is ...

A process rather than a one-off conversation that should involve you and your clinical team as well as your parents if you want them involved.

You don't always have to sign a form or tablet to give your consent – there are other ways too. For example, you could tell us you agree to something (verbal consent) or hold out your arm to have your blood pressure checked (non-verbal consent).

We will always ask your consent if you are due to have an operation or procedure under anaesthetic, but we might ask for consent for other things too, such as having a medicine or taking part in research.

Can I give consent myself?

This depends on your age mainly – the law about consent changes as you grow older.

If you are under 16 years old, the clinician will assess whether you can understand about the proposed treatment, any risks associated with it and what might happen if you don't have it.

This is called 'competence' and will vary depending on your age – some 12 year olds might be competent in the eyes of the law, but some 15 year olds might not be. The clinician will assess whether you are competent for each decision you take – some decisions are easy to make but others are harder.

If you are assessed competent, you can agree to the proposed treatment without your parents' involvement. They cannot overrule you if you have agreed.

However, if you disagree with or refuse the proposed treatment but clinicians think it is the best option, your parents can overrule your decision and give their consent instead.

If the clinicians don't think you are 'competent' to make a specific decision, your parents can give permission for you to have treatment.

If they think you don't have the competence to make this decision, it doesn't mean your parents will always have to decide for you – our clinicians will take into account what you are being asked to decide as well as your competence each time.



⁸⁶ <https://www.gosh.nhs.uk/your-hospital-visit/coming-gosh-day-or-inpatient-admission/consent-giving-permission-your-child-have-treatment/>

If you are 16 or 17 years old, we assume that you can understand about the proposed treatment, any risks associated with it, what might happen if you don't have treatment and you can tell us clearly what you want.

This is called 'mental capacity' – it is governed by a law called the Mental Capacity Act that applies to every aged 16 years or older in England and Wales.

If the clinician assesses that you have the capacity to make this specific decision, they must ask you directly, not your parents. If you have capacity, your parents must not give permission on your behalf.

If the clinician isn't sure whether you have capacity to make this specific decision, they will assess you to decide. If they think you lack capacity for this decision, your parents can still give permission for treatment.

When you are 18 years old or more, the law changes again. We assume that you have the capacity to make a decision unless the clinician isn't sure about this particular decision when they will assess you.

If the clinician assesses you to have capacity for a decision, they will ask you directly.

However, if they think you lack capacity, your parents cannot give permission on your behalf. The only exception is if they have successfully applied for an Order from the Court of Protection.

If you lack capacity and your parents don't have an Order from the Court of Protection, the decision whether or not to have treatment is made by two doctors who decide if it is in your 'best interests'.

Your 'best interests' are not simply whether treatment is 'a good thing' or not. The doctor should take into account other things, such as your feelings about treatment previously, your quality of life and also your family life and circumstances.

What should I understand before I make my decision?

We want to make sure you understand everything about what's proposed before you make a decision. The person asking for your consent should explain clearly and in words you understand:

- What the proposed treatment is
- What it involves
- Whether anything could go wrong, cause problems or make you worse
- The benefit or good that having the treatment will bring you
- Whether there are any alternatives that are suitable for you
- What might happen if you don't have the proposed treatment

This varies from procedure to procedure and is also influenced by you and your underlying health condition and any additional needs. The clinician should explain the general risks, benefits and alternatives and then explain what they could mean to you and you alone.

The clinician may give you an information sheet to read afterwards as a reminder of what they've said but remember, these are written to cover everyone so some bits might not be relevant or apply to you. You can ask questions when the clinician is talking to you about treatment or afterwards. We want you to understand what's proposed so please ask us – no question is too silly.

Thinking it over

In most cases, it will be fine to take some time to think about the proposed treatment and how it could impact you.

Remember if anything is unclear, ask a member of your clinical team to explain it again. If you have any questions, ask them.



9 – eHEALTH TOOLS FACILITATE DIRECT ONLINE COMMUNICATION BETWEEN CHILDREN AND PROFESSIONALS - SWEDEN

Children with cancer often undergo treatment for long periods where they alternately stay in the hospital and in the family home. Even during periods at home, the children can experience severe side effects of the illness and the treatment, and the family's care needs regarding care can be complex and extensive. In a structured development process with participatory design, families and professional caregivers have contributed to further adaptation and development of an eHealth solution for paediatric oncology care. The technology being studied is an application in an e-tablet where parents and staff communicate via chat, photo, text message, film, and repeated reports about the child's condition. The goal is to give the child and the family security and support at home and reduce the family's need for travel and return visits to the hospital.

The eHealth solution is now being evaluated in an implementation study at Skåne University Hospital. Children and parents in several specialties use the eHealth solution during periods at home with residual care needs (self-care). Evaluation takes place with the help of digital questionnaires for children and parents as well as via interviews with family members and professional caregivers with a focus on children's participation in care, as well as family members' satisfaction with care and perceived usefulness of the eHealth solution. Data collection is planned to continue during 2023.


The project is part of a broader research programme on eChildhealth funded by FORTE which started in 2018 and is on-going until 2025, with the aim to develop safe and satisfactory child-centred care with the support of e-health. It includes projects in different countries including Sweden, Denmark, and Ethiopia. The focus is on complex, long-term, and costly challenges in paediatric care.

In Sweden, the programme applies to surgery for children born with malformations of the gastrointestinal tract and/or with heart defects, children born prematurely, and children with cancer. In Denmark, it investigates how a mobile application can be used as an aid for the early identification of cerebral palsy in children and how e-health can be used as a tool for intravenous treatment at home for children and young people with acute or long-term illnesses. In Ethiopia it is investigating whether reminders sent via text message are an effective strategy to increase adherence to treatment for young people living with HIV.

The end-users (the parents, or the children/adolescents, as well as the professional caregivers) participate throughout the research process.

Learn more about these initiatives in the following articles:

 [eHealth in Paediatric Oncology — Lund University – Sweden](https://portal.research.lu.se/en/projects/ehealth-in-paediatric-oncology)⁸⁷

 [eHealth as an aid for facilitating and supporting self-management in families with long-term childhood illness – development, evaluation and implementation in clinical practice — Lund University](https://portal.research.lu.se/en/projects/ehealth-as-an-aid-for-facilitating-and-supporting-self-management)⁸⁸

⁸⁷ <https://portal.research.lu.se/en/projects/ehealth-in-paediatric-oncology>

⁸⁸ <https://portal.research.lu.se/en/projects/ehealth-as-an-aid-for-facilitating-and-supporting-self-management>

Connecting with children

- Participation depends on both adults and children believing in each other and in the process. Children need to know that professionals are interested in their opinion and want to find a solution which takes their views into account. Where professionals involved in decision making are doctors, nurses, teachers, social workers, early years workers or managers who already know the child or children involved, children will use past experiences of those individuals as the basis for decisions about whether to trust them. For example, children who feel their teachers listen to and take seriously their idea during day-to-day classroom activities are more likely to talk to that teacher about serious concerns when they arise, such as bullying or sexual violence. Known professionals can build trusting connections with children through respecting their views.
- Professionals should provide information about themselves, their role, the limits of confidentiality that will apply and the length of time they are likely to be involved in a child's life. This can be done with the support of accessible information (e.g. leaflets or videos) prepared as described in the subsection above. But it is also important that this is provided to children in a personalised way. Sometimes known professionals will need to provide this kind of information because the decision-making process is new to the child. When the meeting is with a new person, and is not an emergency, children should be given information beforehand about what will happen. Where possible, professionals meeting children for the first time should be introduced by someone a child knows. For example, a parent or foster carer might introduce a new social worker to their child and stay with them until the child feels confident to meet with the social worker alone. Information is often best provided through a personalised conversation, so that children are encouraged to speak and feel listened to at the very start.
- Even in the shortest encounter and in difficult circumstances, research evidence shows that effective communication can be established when professionals, such as immigration workers, share a little of themselves. With one question, about for example hobbies, doctors can create an atmosphere in which it is easier for a child to speak. One of the goals of this interaction is to ensure that children feel comfortable in stating or showing their preferences, and that they feel their wishes will be taken into account. Professionals should consider how they can build at least one moment of human connection into their first encounters with children.
- The extent of time taken to build effective connections will depend on each child's circumstances and on the skills of the professional. Investing the necessary time in this phase will help improve the quality of the process for everyone concerned. There may also be times throughout the participation processes where returning to this phase of building a connection and rapport becomes necessary. This is particularly likely in circumstances where a child has lost trust in adults who are meant to be responsible for them or their care. Professionals can promote sustained meaningful connections with children by being honest and available. ”

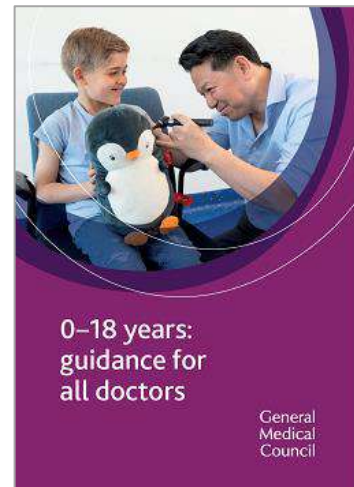
 [Listen – Act – Change - Council of Europe Handbook on children's participation - For professionals working for and with children](#)⁸⁹ (p.37)

⁸⁹ <https://edoc.coe.int/en/children-s-rights/9288-listen-act-change-council-of-europe-handbook-on-childrens-participation.html>



14. Effective communication between doctors and children and young people is essential to the provision of good care. You should find out what children, young people and their parents want and need to know, what issues are important to them, and what opinions or fears they have about their health or treatment. In particular you should :

- involve children and young people in discussions about their care;
- be honest and open with them and their parents, while respecting confidentiality;
- listen to and respect their views about their health, and respond to their concerns and preferences;
- explain things using language or other forms of communication they can understand;
- consider how you and they use non-verbal communication, and the surroundings in which you meet them;
- give them opportunities to ask questions, and answer these honestly and to the best of your ability;
- do all you can to make open and truthful discussion possible, taking into account that this can be helped or hindered by the involvement of parents or other people;
- give them the same time and respect that you would give to adult patients.



15. You should make it clear that you are available to see children and young people on their own if that is what they want. You should avoid giving the impression (whether directly, through reception staff or in any other way) that they cannot access services without a parent. You should think carefully about the effect the presence of a chaperone⁵ can have. Their presence can deter young people from being frank and from asking for help.

16. You should take children and young people's views seriously and not dismiss or appear to dismiss their concerns or contributions. Disabled children and young people can feel particularly disadvantaged in this respect.

17. Children and young people usually want or need to know about their illnesses and what is likely to happen to them in the future. You should provide information that is easy to understand and appropriate to their age and maturity about:

- their conditions
- the purpose of investigations and treatments you propose and what that involves, including pain, anaesthetics and stays in hospital
- the chances of success and the risks of different treatment options, including not having treatment
- who will be mainly responsible for and involved in their care
- their right to change their minds or to ask for a second opinion.

18. You should not overburden children and young people or their parents, but give them information at an appropriate time and pace, and check their understanding of key points.

19. You should talk directly and listen to children and young people who are able to take part in discussions about their care. Young people who are able to understand what is being said and who can speak for themselves resent being spoken about when they are present. But younger children might not be able to understand what their illness or proposed treatment is likely to involve, even when explained in straightforward terms.

20. You should only keep the type of information described in paragraph 17 from children or young people if:

- it would cause them serious harm (and not just upset them or make them more likely to want to refuse treatment)
- they ask you to, because they would prefer someone else to make decisions for them.

21. You have the same duty of confidentiality to children and young people as you have to adults. But parents often want and need information about their children's care so that they can make decisions or provide care and support. Children and young people are usually happy for information to be shared with their parents. This sharing of information is often in the best interests of children and young people, particularly if their health would benefit from special care or ongoing treatment, such as a special diet or regular medication. Parents are usually the best judges of their children's best interests and should make important decisions up until children are able to make their own decisions. You should share relevant information with parents in accordance with the law and the guidance in paragraphs 27, 28 and 42 to 55. ”



[Communication - ethical guidance - GMC \(gmc-uk.org\)](https://www.gmc-uk.org/professional-standards-for-doctors/0-18-years/communication) (p.8)⁹⁰

⁹⁰ <https://www.gmc-uk.org/professional-standards/professional-standards-for-doctors/0-18-years/communication>



SUPPORT: International collaborative standards to Support Paediatric Patients during clinical prOcedures, Reducing harm and establishing trust.

The iSupport Case Studies

These four case studies aim to demonstrate how these rights-based standards could be applied in clinical practice. The case studies aim to demonstrate a range of clinical contexts and procedures, whilst recognising that it would not be possible to represent the broad range of children’s individual needs, competence, ability, preferences and experiences.

The first example within each case study is a demonstration of practice without the application of the rights-based standards and the second shows specific parts of the standards applied and referenced, for example (2c, 1a). Whilst the first example within each case study results in a procedure being completed, this is often at the detriment of a child’s short and long-term well-being as their interests are not prioritised over those of the parent/carer, professional or institution.



⁹¹ <https://www.isupportchildrensrights.com/english-version>



Case Study 1

Without application of the standards:-

Susie is a 6 year old girl who needs to have a laceration to her knee glued after an accident. Susie is on the examination table and is a bit upset, the nurse in the clinic sits next to her on a chair, and her father is next to her on the other side. The nurse explains that the cut needs to be cleaned and then have glue applied. The nurse gets the equipment out and tells Susie it is really important to keep still and that the procedure will only take a minute and will not hurt much. The nurse then checks that Susie has had some oral analgesia. The nurse asks Susie's father if he can hold her knee and give her a big hug to help her keep still. The nurse tells Susie that she is going to start, Susie sits still but starts to cry. The nurse starts to clean the laceration and Susie cries out "stop it hurts", the nurse stops for a moment and tells Susie that she is nearly done and she needs to try and keep still, Susie's father holds her leg with a little more force and says "it is nearly done you have to be brave now". Susie is sobbing and crying "please let go, it is hurting me, ow, ow, ow". The nurse finishes cleaning the laceration and applies the glue. When the procedure is finished the nurse asks Susie if she is okay, and says that she was really brave. The nurse tells Susie and her dad what she did and what they need to do next when they leave the hospital/clinic. The nurse then leaves the room.

With the application of the 'Rights-based standards':-

Susie is a 6 year old girl who needs to have a laceration to her knee glued after an accident. Susie is on the examination table and is a bit upset, the nurse in the clinic sits next to her on a chair, and her father is next to her on the other side. The nurse asks Susie some questions about what she was doing to cut her knee and spends time talking about the games she likes to play and asks the name of the toy dog Susie has tucked under her arm (2b). The nurse then explains to Susie that the cut on her knee needs to be cleaned and then have glue applied (4a). The nurse asks Susie if she has had a procedure like this before; Susie hesitates, the nurse gives her time to respond (2b, 2c) and Susie then whispers "no I haven't, I am a bit scared" (2c, 3e, 4c). The nurse says she understands that Susie feels scared (4c), she will be really gentle and she will explain everything that is going to happen (4a). The nurse then checks with Susie and her father that Susie has had some medicine (analgesia) and that it is working to make her sore knee feel better. The nurse explains to Susie and her father how the laceration will be cleaned, who will do it, what Susie is likely to feel whilst it is being cleaned and how long it should take (4a, 4b). The nurse asks if Susie has any questions and makes sure she knows that whatever she wants to ask or say is okay (4c, 2d). Susie says "I do not want to know anymore, I am really scared" (3c, 3d).



The nurse suggests to Susie that they practice on her toy dog first, and together they clean the dog's knee and put some steristrips on. Susie enjoys doing this. The nurse acknowledges that Susie now looks settled and calm (5d). She asks Susie and her father if they want to ask any more questions about Susie's procedure (4b). She asks Susie's father if he is happy to stay whilst Susie's cut is being cleaned and steristripped (1g, 4d). He is happy to stay and wants to know what he can do to help (1g, 4d). The nurse then explains that Susie may find it helpful if she chooses what she wants to do to help sit still and be distracted whilst her laceration is being cleaned and steristripped (1f, 1g, 2d, 3a, 3c, 3d, 5b). Susie, chooses that she will spot things with her father in a book she sees (3a, 3c, 3d). The nurse agrees with Susie that someone will hold her leg gently above the knee just to help her keep still (1g, 3a, 3c, 3d, 4a, 5b) and asks whether Susie would prefer this to be her father or another nurse (6d). Susie says that she wants "dad to hug me and hold my leg" (2d, 4a, 4c, 4d, 5b, 6a, 6c, 6d). The nurse starts to clean the laceration and Susie starts to move her leg and cries out "stop it hurts", the nurse stops (2c, 3g, 4c, 5c, 5e) and checks with Susie that she is okay and goes through again what needs to be done to help support her through the procedure (1g, 2a, 3a, 3b, 3c, 3d, 4c). Susie says "please just get it done quickly", (2c, 2d, 3a, 3c), the nurse checks with Susie that it is okay to start again, that she is okay still being held on her leg by her father and reassures her that she will stop if Susie asks her to (1f, 2a, 2b, 3a, 3c, 3g, 6a, 6c). The nurse then checks are you ready? Susie says "yes" and focuses on the videos and talks to her father while he holds her leg as Susie agreed (2c, 2d, 3a, 3c, 3d, 3e, 5d). The nurse finishes cleaning the laceration, while Susie stays still and calm and then the nurse applies the glue. When the procedure is finished the nurse checks with Susie if she is okay, and says that she did really well to sit still and that she and her father make a great team (2c, 4d). The nurse tells Susie and her dad what she did and what they need to do next when they leave the hospital/clinic (4a, 4b, 4d). She then checks if Susie and her father have any questions (2c, 4a, 4b), Susie says "I do not have anything to ask". The nurse leaves the room and notes down the completion of the procedure in the health care records, that Susie used a book as a distraction which worked well and that she had agreed to her leg being held supportively by her father (5g).



Case Study 2



Without application of the standards:-

Ashan is a 10 year old boy with autism who has a learning disability. Previous visits to the hospital have been challenging for him, he has resisted procedures and experienced restraint in the form of his mother and health professionals holding him against his will which has made him more distressed. He has an appointment to have a blood test at the hospital. Ashan's mother has been told that he can have extra time at his appointment but he is still scared of the hospital. He has to wait for his turn in the busy waiting room and he and his mother are both anxious. When he enters the room Ashan becomes very agitated and distressed and his mother tries to calm him down by reassuring him that they can go home soon and can get a hot chocolate. Mum is keen to get the 'bloods' taken quickly so they can leave the department as she knows Ashan will settle as soon as he leaves the hospital. The phlebotomist tries to reassure Ashan, that it will be done really quickly and that he is okay. Ashan's mother sits on a chair and pulls Ashan gently onto her knee and places her arms around his middle to keep him still. Ashan is very vocal and continues trying to move. The phlebotomist calls for assistance and a nurse enters the room, says hello to Ashan's mother and starts talking calmly to Ashan saying that if he can sit still it will be over soon. Ashan remains on his mother's knee and the nurse helps by holding his arm still for the phlebotomist, Ashan continues to shout "ow, ow it hurts". The blood test is completed quickly and Ashan is told "well done" and he immediately tries to leave the room. There is no time for the phlebotomist, nurse or mother to discuss the procedure as Ashan wants to leave immediately and go home. Ashan and his mother leave the room.

With the application of the 'Rights-based standards':-

Ashan is a 10 year old boy with autism who has a learning disability. Previous visits to the hospital have been challenging for him, he has resisted procedures and experienced restraint in the form of his mother and health professionals holding him against his will which has made him more distressed. He has an appointment to have a blood test at a local clinic. His mother has discussed the planned procedure with staff at the clinic and has booked a double appointment and informed them Ashan requires additional support (2f, 3e, 5a, 5b)*. Ashan's mother knows that pictures support Ashan's understanding and she has spent time with him at home going through his social story (a picture book of what will happen when he comes to the clinic) (4a, 4b). As Ashan has struggled previously, the staff at the clinic have agreed that they can provide a quiet space and a longer appointment to facilitate Ashan's procedure being completed within a positive environment (1f, 1g, 5a, 5b).



As Ashan arrives at the clinic the nurse and phlebotomist that Ashan has seen a picture of in his book, greet him (2a, 2b) and they go to the room he has been shown and recognises as part of his picture book (4a). The lights are dimmed in the room as this helps Ashan feel less anxious (3a, 3c). The picture book story includes some of the toys and distractions that Ashan has chosen to help him while he is there having his blood test (3a, 3c, 3f). The timeline within the story allows Ashan to predict the things that will happen and the nurse and phlebotomist discuss each picture with him (2a, 2b, 4a). Ashan wants to quickly move onto the next stage so he can get to the end which is his favourite treat of a hot chocolate in the hospital coffee shop (2c, 4a, 4d). Ashan sits on a chair, with his mother sitting next to him and Ashan gets his electronic tablet ready with his favourite cartoon playing through his headphones (3c, 3f, 5d). The phlebotomist and nurse wait until Ashan looks ready for the procedure to start (2b, 5d), and his mother indicates that now is a good time to start (2f, 3f). Ashan is held by his mother on his arm, in the position that Ashan has practiced at home, and that has been agreed with the staff (6a, 6b, 6c, 6d). When Ashan indicates that he is uncomfortable and getting upset, by starting to wriggle and make noises that his mother knows means he is anxious, Ashan's mother tells the professional that Ashan is getting upset (2f). The phlebotomist stops the procedure (3f, 3g, 5c, 5e) as soon as it is safe to do so, and encourages Ashan to move and get comfortable again (2b, 4c), with his mother holding his arm (6a, 6b, 6c). The phlebotomist begins the blood test again and although Ashan 'pulls back' as the needle is inserted he remains calm and distracted by the cartoon on his electronic tablet (5d, 6c). When the blood test has been completed and the picture before the hot chocolate is reached, Ashan is pleased and keen to leave. Everyone smiles and gives Ashan the sign for 'finished' in Makaton (sign language) (2a, 4a). He signs back 'goodbye'. The nurse then records the procedure in Ashan's health care records with information about the preparation, reasonable adjustments which worked well and how Ashan was held supportively by his mother (5g). Ashan's mother notes down on an iSupport preparation sheet what worked well for her son this time to help her tell this information to future professionals involved in conducting procedures with Ashan.

*In some clinical contexts local anaesthetic cream could be sent with the appointment letter and applied at home.



Case Study 3



Without application of the standards:-

Nala is a 4 year old girl who has injured her wrist and has been referred for an X-ray from accident and emergency. She has not had an X-ray before and while sitting in the busy waiting room for her procedure she starts crying quietly and saying to her mother and father that she is scared the machine will 'zap her' arm. Her mother and father tell her that she needs to be brave and it will be okay. When the radiographer calls Nala from the waiting room, she asks her who she would like with her while she has her X-ray taken. Nala chooses her mother. She has also brought her favourite teddy with her and the radiographer says teddy can come too. Nala is very pleased about this. Her parents have told her to be brave so she quietly walks into the room. When she enters the room the radiographer asks her mother to confirm Nala's date of birth and her address and checks Nala had oral analgesia before coming to the department. As Nala enters she looks worried and clings to her mother's side. The radiographer asks Nala to sit with her mother on a chair. The radiographer asks Nala to choose what lead apron her mother should wear and Nala chooses a blue one. The radiographer explains what will happen and that Nala needs to stay really still while the picture is being taken. Nala sits quietly on her mother's knee and winces as the radiographer positions her arm. She cries quietly as the machine moves towards her and she wriggles on her mother's knee and says "it is going to zap me". Her mother tells Nala that she needs to be brave and quiet and that it will only take a minute and then turns to the radiographer to say that her daughter is always a bit dramatic. The mother places her arms around Nala's middle to keep her still and the radiographer tells Nala that the machine will not zap her. The radiographer goes behind the screen and takes the picture, Nala manages to keep her arm still but is crying a lot and is saying "it really hurts, can you stop?". The radiographer tells Nala from behind the screen that they are nearly done, keep still and the X-ray picture is taken. Nala is given a sticker as she leaves the room.

With the application of the 'Rights-based standards:-

Nala is a 4 year old girl who has injured her wrist and has been referred for an X-ray from accident and emergency. She has not had an X-ray before and while sitting in the busy waiting room for her procedure she starts crying quietly and saying to her mother and father that she is scared the machine will "zap her" arm. Her mother and father tell her that she needs to be brave and it will be okay. The radiographer calls Nala from the waiting room and bends down to say hello as Nala walks slowly over to her (2a).

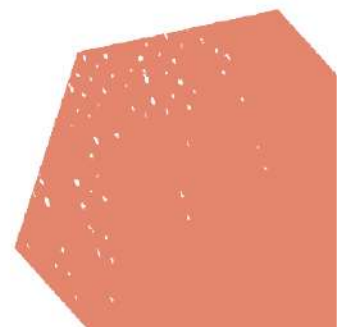


The radiographer introduces herself (2a) and asks Nala who she would like to come with her while she has her X-ray taken (3a, 3d). Nala chooses her mother (2c, 3a). The radiographer asks Nala and her mother to follow her into the room so she can take a picture of Nala's sore arm. Her parents have told her to be brave so Nala walks quietly into the room. As Nala enters she looks worried and clings to her mother's side. The radiographer asks Nala to sit with her mother on a chair and looking at Nala's teddy bear, she bends down to ask Nala who she has brought with her today (2a, 2b, 2c). Nala pauses then quietly says that her bear is called "Mr Bear", the radiographer says hello to Mr Bear and asks if Nala and Mr Bear have ever had an X-ray before (2b, 2c, 2d, 4e). Nala says "no". The radiographer sits down next to Nala and asks her if she knows when her birthday is, Nala is not sure and looks to her mother who answers the question for her as well as confirming their address (1g, 2b, 3c). The radiographer checks with Nala's mother that Nala has had some analgesia before being sent to the department and asks Nala how her arm is feeling now, Nala says "it is feeling a bit better" (2c, 4c). The radiographer explains to Nala that she needs to take a picture of her sore arm and that the machine will move to take the picture. She explains that there will be a light but the special camera will not touch her arm at all (4a, 4b). The radiographer then checks with Nala's mother if she might be pregnant, which she is not, so the radiographer tells Nala that her mother will have to put a special coat on (4a) and asks Nala to choose the colour of lead gown her mother should wear (3a, 3b, 4c). The radiographer explains to Nala that she needs to sit really still otherwise the picture taken will be blurry (4a). Nala is given the choice to sit on the chair by herself or sit on her mother's knee (3a, 3b, 3c, 3d). She chooses to sit on her mother's knee and the radiographer begins to set up for the examination. Moving the x-ray tube is noisy and Nala starts to become frightened, especially when the radiographer asks her if she can touch her sore arm. Nala pulls away and begins to cry and wriggle and shouts "I don't want it, it is going to zap me" (2c). The radiographer stops moving the X-ray machine and gives Nala a few moments to cuddle up to her mother (3g, 5c, 5d). The radiographer acknowledges to Nala that it is alright to feel a little worried as she has not had an x-ray before and that the machine does sound a bit noisy (2b, 4c). She then quietly asks Nala if they should take a picture of Mr Bear first so that Nala can see what having an x-ray is like (4a, 4b, 4d). With the help of Nala, the radiographer sets up to take a picture of teddy, making sure he is sitting nice and still with his arm out (4a, 4b). The radiographer shows the X-ray tube moving and how it does not touch Mr Bear (4a, 4d). They all walk behind the lead equivalent screen and the radiographer pretends to take an X-ray picture. Nala is comforted that the machine doesn't 'zap' teddy (2b, 3a).





Nala returns to sit on her mother's knee with Mr Bear, but she is still very nervous about the radiographer touching her arm and pulls it away when the radiographer reaches out to position her arm. The radiographer pauses (2c, 3d, 3g, 5c, 5e). Nala's mother says to her daughter that the picture needs to be taken and that the lady has already spent lots of time with her. The radiographer says to the mother that it is okay, it is important that Nala is happy to have her X-ray taken (1e, 2c, 2f, 3f, 3g, 4c, 5a, 5c, 5d). The radiographer then explains that she doesn't really need to touch her arm if Nala can help by moving her arm herself (2b, 2e, 3b, 3a, 4b). The radiographer shows Nala what she needs to do with her arm and Nala is able to reach it out into the correct position (posterior-anterior (PA)) (4a, 4b). The radiographer asks Nala to keep her arm still for one minute while she takes the picture and reminds Nala that the machine will move, just like it did for Mr Bear (4b). A diagnostic PA wrist is achieved, but a fracture is noted by the radiographer which will make it difficult and painful for Nala to turn her wrist into the lateral position. The radiographer makes the decision to modify her technique to a horizontal beam lateral as this only requires Nala to remain in the PA position (5a). The radiographer lets Nala and her mother know that the picture is good and that she just needs to take one more X-ray picture but that Nala does not need to move at all (3b, 3e). The radiographer tells Nala that she is doing really well to stay still just like a statue. Though not as successful as a true lateral, the image produced is diagnostic for Nala's injury. Once both images are completed, the radiographer tells Nala how amazing she was to sit still even though she was a bit scared and offers her a choice of stickers for her and for Mr Bear. The radiographer notes down on the health system the procedure completion and what had helped Nala cope with her procedure (5g).



Case Study 4



Without application of the standards:-

Miguel is a 11 week old baby who has a high temperature, poor feeding, vomiting and lethargy. His mother has brought him to the emergency department. He is seen by a doctor who is concerned that he may have sepsis and/or meningitis. It is decided that he should have blood tests and a lumbar puncture as soon as possible, followed by intravenous antibiotics. The doctor suggests it would be best if his mother leaves the room as it is likely that Miguel will be upset during the procedures. Before Miguel's mother leaves the doctor gains verbal consent for the procedures to go ahead. Miguel's mother leaves Miguel in the care of the doctor (who will perform the procedures) and two nurses. One of the nurses positions Miguel whilst the other nurse and the doctor get the equipment ready. One nurse holds Miguel in the correct position for a lumbar puncture whilst the doctor and the second nurse perform the lumbar puncture and then the blood tests. The room is noisy during the procedure with lots of conversation. Miguel is very upset during the procedure. When the procedure is finished, the nurse who held Miguel picks him up and cuddles him. His mother is invited back into the room and cuddles him to comfort him further. Miguel's mother is asked to wait in the room while his samples are processed.

With the application of the 'Rights-based standards:-

Miguel is a 11 week old baby who has a high temperature, poor feeding, vomiting and lethargy. His mother has brought him to the emergency department. He is seen by a doctor who is concerned that he may have sepsis and/or meningitis. It is decided that he should have blood tests and a lumbar puncture as soon as possible, followed by intravenous antibiotics. The doctor explains what the procedures will involve and why they are necessary, explains that Miguel will likely become upset and asks if the mother feels able to stay to comfort and be with her baby during the procedures as this could help him (2f, 3f, 4d, 5a, 5b, 5d). The doctor gives the mother time to consider the information and if she feels able to stay with her son or would prefer to leave the room during the procedures. Following a few minutes, Miguel's mother gives informed consent for Miguel to undergo these procedures. Miguel's mother opts to stay in the cubicle, but tells the doctor she does not want to see any of the equipment (3f). There is a doctor (who will perform the procedures) and two nurses in the room. Miguel's mother cuddles her son while the equipment is prepared.

One of the nurses stays with Miguel's mother to offer support (support nurse). The other nurse and the doctor get the equipment ready. The support nurse checks that Miguel has had sucrose administered, local anaesthetic is applied and appropriate oral analgesia has been administered (1b, 1f, 3f). The support nurse holds Miguel in the correct position for a lumbar puncture whilst the doctor and the procedure nurse perform the lumbar puncture (6e), Miguel is screaming loudly. The support nurse tells Miguel's mother that she is doing really well and his mother remains calm and continues to talk to Miguel in a soothing voice (5d). Miguel's position is then changed by the support nurse who is holding him to make it easier for the doctor to insert an intravenous catheter, to take blood tests and for the procedure nurse to administer the intravenous antibiotics that have been prescribed (1b, 1f, 6e, 6g). On completion of the procedures the support nurse encourages Miguel's mother to pick him up and cuddle him. As he is too poorly to take a feed, Miguel's mother is encouraged to continue to cuddle him skin to skin and offer non-nutritive sucking* (5d). The doctor and support nurse give feedback to Miguel's mother about what will happen now while they wait for the results of the tests (3d). The support nurse gives Miguel's mother time to talk through the procedure, Miguel's mother says it was upsetting to watch her son cry so much, but she is glad she stayed with him (5f, 6h). The doctor makes an entry in Miguel's health care records clearly explaining the indications for the procedure, how that procedure was carried out, what was explained to the mother, and what the results of the procedure are. The support nurse makes an entry into Miguel's health care records explaining why a restraining hold was necessary, how this was undertaken, what the result of this was, and what role Miguel's mother had during the procedure (6i). The doctor and the nurses ask Miguel's mother if she has any further questions and once these have been answered they leave the cubicle (4d). Miguel is then admitted to the hospital with his mother.

*non-nutritive sucking is where a baby sucks without receiving any nutrition, for example on a dummy/pacifier, their thumb or your clean (gloved) finger.




Case Study 5



Without application of the standards:-


Amari is a 6 year old boy who is seeing the dentist for a dental extraction. Amari has had repeated infections of one of his back teeth which have resulted in pain, sleepless nights and days off school. These have been managed with several courses of antibiotics. He has been to the dentist three times for a fluoride varnish application and placement of a temporary filling in an attempt to familiarise him with dental treatment. He has not had local anaesthetic before and the dentist does not have access to inhalation sedation. The waiting time for a dental general anaesthetic is four months. The family has agreed with the dentist that this posterior milk tooth needs to be extracted. As Amari enters the room he looks nervous and clings to his mother's leg. His mother tells him to "be brave" and that "it won't hurt too much". The dentist asks Amari to sit on the chair and explains that they will make his tooth go to sleep before they take out the bad tooth and he "will be fine". Amari starts crying and says to his mother "please take me home". His mother explains that in order for him to stop being in pain he has to let the dentist help him and "get rid of that naughty tooth". Amari reluctantly agrees to lie down in the chair and opens his mouth a little bit. The dentist talks to Amari's mother to ask if she is happy to hold Amari when they do the extraction. Amari's mother agrees. The dental nurse tells Amari that he is doing well and that it will only be quick. The dentist places topical gel onto Amari's gum next to the bad tooth, and Amari grimaces slightly. Then, after a minute the dentist gives the first of several injections. Amari complains the injection hurts and starts to cry and mutter "I do not like it". He sits up, pushes the dentist away and asks "to go home" but the dentist and mother convince him to lie back down, keep still and it "will all be over quickly". Once the local anaesthetic has had time to work, the dentist starts to extract the tooth. Amari starts screaming, reaching towards his mouth with his hands and tries to sit-up, his mother holds his hands down tightly against his legs to prevent him moving; throughout Amari is yelling loudly. The dentist completes the extraction. Amari is then told "well done, it is all done now" and Amari, still sobbing, gets off the chair and goes to sit on his mother's lap for a cuddle. The dentist puts a swab in his mouth and asks him to bite down. He refuses to bite on the swab, wriggling in his mother's lap and keeps holding his cheek. His mother has to hold the swab in place and tells Amari to "stop being silly, it is all done now". The dental nurse tells Amari that he has been brave and gives him a sticker. Amari leaves the room in tears.



With the application of the 'Rights-based standards:-

Amari is a 6 year old boy who is seeing the dentist for a dental extraction. Amari has had repeated infections of one of his back teeth which have resulted in pain, sleepless nights and days off school. These have been managed with several courses of antibiotics. He has been to the dentist three times for a fluoride varnish application and placement of a temporary filling in an attempt to familiarise him with dental treatment. He has not had local anaesthetic before and the dentist does not have access to inhalation sedation. The waiting time for a dental general anaesthetic is four months. The family has agreed with the dentist that this posterior milk tooth needs to be extracted. At the previous visit the dentist speaks to Amari's mother and explains the plan for the dental extraction, signposts her to some free online preparation videos and asks her to try and avoid language like 'hurt' or 'pain' when Amari attends for this appointment (4d). Amari's mother agrees and asks a few further questions about what will happen (4d). At this previous visit the dentist also explained to Amari why the tooth needs to come out, what will happen and showed Amari the topical anaesthetic and put a small amount on his gum so that Amari can understand what it feels like (4a, 4b). Amari and his mother are advised to bring something with them next time which will help distract Amari (3a, 3c, 3f). On the day of extraction, as he enters the room Amari looks nervous and clings to his mother's leg. The dentist asks Amari to sit on the chair and spends some time talking to him about what he did today and what his favourite TV shows and video games are (2a, 2b, 5d). Amari appears to become more relaxed and starts to smile. The dental nurse, working with the dentist, is setting up the equipment out of Amari's line of sight whilst the dentist is talking so that this does not upset Amari (1e, 1f, 5a). The dentist then explains to Amari that they need to take the bad tooth out as it is making him sore and poorly, but first they will use some special medicine to make it all go numb and reminds Amari about the gel they tried at his last visit (4a). The dentist explains that Amari might feel 'pushing and/or squeezing' when the tooth comes out, but that he should not feel any pain or discomfort (4a, 4b). Amari starts to cry and say "I do not want it done, I am scared, it is going to hurt". The dentist gently explains that they will make the tooth feel numb so that it does not hurt and his mother will stay with him to help him (2c, 2d, 4a, 4c, 5d). Amari's mother gives him a hug and the dentist asks Amari if he has brought anything with him to help him be distracted whilst he is having the tooth taken out (3a, 3c, 3d). Amari says he is going to listen to an audiobook with songs, as it showed this on the preparation video he watched at home (2c, 3a, 3b, 3c).





The dentist talks to Amari's mother to ask if she is happy to hold Amari's hands when they do the extraction, Amari's mother agrees (3f, 4d, 6b). He also asks Amari if his mother holding his hands will help him feel better, Amari thinks that this is a good idea (3d, 6a, 6b, 6d). The dentist says that Amari can squeeze his mother's hands if he wants to (4b, 3d). The dentist advises Amari's mother to concentrate on her son during the procedure and makes sure she is standing where her son can see her (5d). The dentist agrees to a stop signal with Amari, where he will raise his hand, so that if the procedure is too difficult they can take a break (3c, 3d, 4b, 5b, 5e). Amari asks the dentist to tell him when he is about to take the tooth out and the dentist agrees (2c, 3c, 3d). The dentist then asks Amari if they can start slowly, Amari agrees (2c, 3a, 3c). The dentist shows Amari the topical anaesthetic and then places it on his gum with some cotton wool for the required amount of time (4b). Whilst the dentist does this, the dental nurse is smiling at Amari, and gives him a thumbs up and Amari gives a thumbs up back (2a, 2c, 2d, 3a, 5d). Amari's mother sets up his headphones for the audiobook. The dentist then tells Amari he is going to make the tooth numb now and checks with Amari that his gum is numb and Amari says it is, it "feels weird I cannot feel it" (3a, 3c, 4b). Amari's mother tells Amari to press play to start the audiobook and Amari is moving his toes along with the music. The dentist starts to give the first injection but Amari feels some discomfort, does not like the taste and uses the stop signal (3d, 5c, 5e). The dentist stops, and Amari pauses his audiobook. The dentist agrees with Amari that they will take a short break and have some water to get rid of the taste before they start again and that each application of the 'special numbing medicine' will take 10-20 seconds (3g, 4b, 5e). He asks Amari if he would like his mother to count the time down on her fingers for him or whether he would prefer to just "chill and keep his eyes closed" (2c, 3c, 3d). Amari chooses to 'chill' and he lies back down, gets comfortable and closes his eyes and starts his audiobook again before giving the dentist a thumbs up (2c, 3a, 3d, 5d). His mother gently holds his hands (6a, 6b, 6c). This time Amari does not feel any discomfort. Between each injection the dentist gently touches Amari's arm to prompt him to open his eyes and checks with Amari that he is okay by giving a thumbs up and gets a thumbs up back (2c, 3d, 5d). When the injections are complete the dentist checks they have worked and that Amari cannot feel anything (2a, 3c). The dentist then asks Amari "are you ready to get this tooth out?" and Amari says "yes" (3a, 3d, 4b, 5d). The dentist explains that Amari will feel a little bit of pushing and squeezing for a few seconds and then there will be a break for a few seconds before some more pushing (4b). The dentist says he will check each time he takes a break that Amari is okay by touching his arm (3a, 3d, 5d). Once the tooth is loose and ready to be extracted, and as agreed, the dentist lets Amari know that the tooth is ready to come out now, Amari gives a thumbs up (4b, 3a).

The dentist starts to extract the tooth, as they get near to the end of the procedure Amari cries out in pain and gives his mother's hands a tight squeeze (2d). As the tooth is very mobile the dentist completes the extraction in seconds with a quick short movement (1a, 1f). The dentist tells Amari his tooth is out and that he did really well (4b, 5d). Amari is a bit upset but stays in the chair holding his mother's hands whilst his mother says "well done" and gives Amari a big smile. He is given a swab to bite down on which he does. He is given a sticker and asked if he wants to choose one more for doing such a good job of keeping still (3a). Amari is happy and wipes away his tears. The dental nurse checks with Amari that he is okay, and says that he did really well to sit still and that he and his mother make a great team (2c, 4d). The dentist tells Amari and his mother what they did and what they need to do next when they leave the dentist surgery (4a, 4b, 4d). The dentist then checks if Amari and his mother have any questions (2c, 4a, 4b, 4c, 4d), Amari says "I do not have anything to ask", Amari's mother asks a question about pain medicine at home which the dentist answers. The dentist notes down the completion of the procedure in the health care records and that Amari used an audiobook as a distraction which worked well (5g).



13 – CHILDREN'S HOSPITAL IN MUNICH ESTABLISHES CHILDLIFE SPECIALIST PROGRAMME - GERMANY

Someone must defend the child against the system¹
quotes a pediatrician in the forward of Emma Plank: Working With Children in Hospitals: A Guide for the Professional Team in 1962.





Care-for-Rare Foundation
Foundation for Children with Rare Diseases

THE CARE-FOR-RARE CHILD LIFE SPECIALIST PROGRAM

A model to implement the principles of the United Nation convention on children's rights into pediatric clinical care

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Care-for-Rare flagship program
 In 2020, the Child Life Specialist flagship program was implemented at the Dr. von Hauner Children's Hospital in Munich as the first Child Life Specialist (CLS) program in Germany. CLS programs, originated by Emma Plank in the US, have been implemented to protect a child-specific perspective, complementary to medical, nursing, and psychological therapies. CLS are committed to respect a holistic appreciation of children in hospitals. In Munich, building on the experiences in the US where CLS programs are quite common, we have established a CLS unit as a fourth pillar in the clinical care of sick children, complementing the efforts of expert medical, nursing, and psychological teams. Since children with Primary Immune Deficiencies (PID) are often in need of long hospital stays, this group of patients will benefit from our CLS program.




Evaluation: in conjunction with LMU public health experts the implementation of the CLS program is scientifically evaluated.*

Background
 The United Nation (UN) Convention on the rights of the Child has been adopted in 1989. Ratified by almost all UN member states, the convention recognizes the roles of children as social, economic, political, civil and cultural actors. The Convention guarantees and sets minimum standards for protecting the rights of children in all capacities, amongst others the need to respect provisional, participatory and protective rights in hospitals. The implementation of these principles remains

challenging, particularly in children's hospitals. There is often a lack of financial and personal resources in order to sufficiently protect children's rights and meet the patient's need. These problems are intensified in those clinical institutions in which children hospitals are embedded in adult patient care⁶. Aware of these problems, the European Association for Children in Hospital (EACH) has summarized and highlighted the rights of all children before, during and after a hospital stay⁵.

Care-for-Rare Alliance
 In addition to the CLS program, Care-for-Rare has initiated the global Care-for-Rare Alliance Program which comprises a large network of physicians and scientists working at academic pediatric centers and science institutes to support the foundation's mission: From discovery to cure.



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⁵ First European Convention Children in Hospital. EACH-Charta. European Charter for Children in Hospital. London. 2015. <https://each-for-children.org/each-charta/>

[ChildLife Specialist programme in Munich](https://www.care-for-rare.org/en/the-child-life-specialist-program-at-dr-von-hauner-childrens-hospital/)⁹²

⁹² <https://www.care-for-rare.org/en/the-child-life-specialist-program-at-dr-von-hauner-childrens-hospital/>

8.2 Competence, consent and confidentiality

When caring for adolescents the following three principles enshrined in the United Nations Convention on the Rights of the Child (p.4) need to be considered:

Assess competence:

Competence is a legal concept that grants the right to make an autonomous decision (i.e. a decision taken without third-party authorisation, i.e. from parents or guardians). While competence is a legal concept, capacity is a clinical concept. It is defined as the ability of an individual to form an opinion and make an informed and autonomous decision, notably in respect of health and health care. Children and adolescents' decision making capacity develops with age: as they mature cognitively they can begin to make autonomous decisions regarding more complex issues. Some countries set an age limit for the competence of minors (often at 14, 15 or 16 years), but others leave the assessment of competence to the health care provider. In some instances, a provider can even declare an adolescent competent to make a decision in his or her own best interest before the adolescent attains the age defined by national laws as that of legal competence.

- Be aware of your country's legal framework concerning health care.
- Establish an empathetic relationship with the adolescent.
- Assess the adolescent's competence and decision-making capacity. Evaluate the adolescent's ability :
 - To understand different aspects of the given situation
 - To choose between different options, and appreciate their differences
 - To understand the outcomes resulting from different decision(s).
- Reassess the adolescent's cognitive skills regularly, as they may develop from one encounter to the next. ”

 [WHO Pocket book of primary health care for children and adolescents](#)⁹³ (p.666)

⁹³ *Pocket book of primary health care for children and adolescents: guidelines for health promotion, disease prevention and management from the newborn period to adolescence. Copenhagen: WHO Regional Office for Europe; 2022. Licence: CC BY-NC-SA 3.0 IGO. Page 666*
<https://iris.who.int/bitstream/handle/10665/352485/9789289057622-eng.pdf?sequence=2&isAllowed=y>

15 – ALTERNATIVES TO RESTRAINT OR PHYSICAL HOLDING – FRANCE

Avoid restraining the child during treatment | Plasters



Avoiding the use of restraint on children in healthcare (treatment).

When young children are anxious or frightened, they are naturally not inclined to accept healthcare. They may struggle and become agitated, and this can sometimes lead to them being restrained by force during a treatment or intervention. In such situations, which are relatively commonplace, health professionals face the dilemma of using force for the child's "own good". It is a source of great dissatisfaction for all those involved in the care process: children, parents and professionals.

The aim of this note is to prompt professionals to reflect on the use of restraint in their day-to-day practice, and to suggest alternatives to restraint so that it can be avoided or limited.

Understanding restraint

Restricting a child's movements to provide care seems to be a fairly common practice in healthcare.



This is not a trivial problem for children, as it could have long-term negative effects on their physical and emotional well-being. It can lead to a feeling of fear, or even a real phobia, of healthcare and it can complicate the child's healthcare journey in the long run.

Restraint is most often seen as unavoidable by professionals when care becomes difficult, even though it is difficult and a source of discomfort: priority is given to performing the procedure to the detriment of respecting the child's reactions.

Restraint seems to be the result of a deleterious chain of events, forming part of a vicious circle: the child's distress, which may stem from intense worry, anger at being ill, fear of being hurt, difficult past experience of healthcare interventions, the absence of his loved ones to support them, this often contribute to the child being agitated during the procedure. This agitation often reinforces the restraint, itself a source of distress.

<https://www.sparadrap.org/professionnels/eviter-et-soulager-peur-et-douleur/eviter-la-contention-de-lenfant-lors-des-soins>

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 [Sparadrap](https://www.sparadrap.org)⁹⁴

⁹⁴ <https://www.sparadrap.org/professionnels/eviter-et-soulager-peur-et-douleur/eviter-la-contention-de-lenfant-lors-des-soins>

Restraint can also be experienced as so stressful or even "violent" by parents that they refuse to be present during the procedure, adding to the child's distress.



Preventing and limiting restraint

Inadequate management of the child's pain and emotional state leads to distress and agitation. Organisational constraints and the need to perform the procedure sometimes lead to restraint. Alternatives therefore come into play at several levels.

The essentials

Analgesia

Firstly, it is important to ensure that everything is done systematically to avoid or to limit the pain caused by care.

The most common methods are painkillers, anaesthetic cream, EMOLO.

> See also: [Pain in children - the essentials](#) (Pediadol)



Installation

Getting the child settled (or placing the child in a good position) is essential to the smooth running of the treatment.

To optimise this, it is advisable to anticipate everyone's place: child, parent, practitioner.



1. As a general rule, avoid laying your child down.

When they are lying down, children are not free to look at what is happening around them, and they may feel they are losing control of the situation. Prefer a semi-seated position.

Avoiding the use of restraints on children in healthcare | Sparadrapp

2. Get the child into the right position by offering an attractive distraction. For example, offer them a screen with a cartoon at an angle that forces them to turn their head if it's an ear test. Or ask them to do on a doll what you're doing to them, with the doll in the right position.

See also: [Conducive positions: 21 examples of situations with photos](#)
(21 situations with photos to help professionals find a comfortable position for everyone, depending on the care and age of the child.)

Prior to treatment

The main alternatives to restraint should be implemented before the child becomes agitated, to prevent distress.

Making contact

Making contact is crucial.

1. Allow the child to acclimatize and get used to an unfamiliar environment and people by leaving them for a while in their parents' arms or at a distance from the practitioner. Take the opportunity to ask parents what will best attract their child's attention.
2. Reach out to the child by entering his world, approaching him with a toy or something attractive.
3. Only once a climate of trust has been established can explanations about the treatment be given or reminded, depending on whether or not the child wants it, and whether or not the procedure is planned.

Informing and preparing children and their parents

To control the situation as much as possible, the child needs to know what is going to be done to him, who is going to look after him, how long it is going to last, what is likely to be difficult, painful or uncomfortable and, above all, what solutions are proposed to avoid or limit these difficulties... Otherwise, they run the risk of feeling betrayed and abandoned in the process if the treatment proves more difficult than expected.



There are many ways of providing information: using films, videos, the internet, photos, posters, illustrated written documents, dolls or puppets to demonstrate care and give children the opportunity to role play, to familiarise themselves with medical equipment, etc.

>See also: [SPARADRAP fact sheets](#)
(also available as posters)
aids to explain certain treatments or examinations to children.

During treatment

Getting children not to move

When a medical act requires a part of the child's body to remain motionless, it is advisable to encourage movement of the opposite part of the body to the one that must not move.



Examples:

- + Wave a rattle with the arm, which must not remain motionless
- + Clap your hands while your leg is being treated, or while a vaccination is being administered to your thigh...

Moreover, giving the child something to do distracts their attention from the treatment and helps them to forget about the act. For example, for a child aged 5 or over, you could offer them a game of 7 errors and challenge them: "I bet you I'll have finished the treatment before you've found all 7 mistakes!"

Diverting attention

Distraction works by saturating the child's senses. It involves stimulating different senses (sight, hearing, touch, taste, smell) to compete with the unpleasant or painful sensation associated with the treatment.



In addition, using playful objects, songs and nursery rhymes, puppets, soap bubbles, giving cuddles, help to create a relaxed atmosphere and gain the child's trust. When they are required to use their own skills, children become actors where they were initially subjected to events.

From the age of 3 or 4, it is also possible to use the child's imagination to help dissociate him or her from the reality of the treatment thanks to hypno-analgesia.

Taking breaks

For long paediatric treatments, which can be a source of agitation for the child, it is useful to take short breaks throughout the procedure.

Similarly, if the child becomes agitated, the first step is to stop the treatment and give them a few moments to recover. Ask them or their parents what may have triggered their distress:

- + Sometimes a simple explanation or a short break is all that is needed to resume the treatment calmly;
- + In other cases, the pain has been incorrectly assessed and a readjustment of the analgesic allows the patient to continue.

Suspending the care also shows the child that you are taking his or her words into account, which has the effect of reinforcing the child's confidence.

Avoiding the use of restraints on children in healthcare | Sparadrapp

If, despite all these simple measures, the child does not calm down, and when their medical condition allows it, it is recommended to postpone the treatment to another day.

This postponement is particularly appropriate in the case of chronic pathologies that require long-term treatment, or in the case of a highly anxious child who could develop a phobia of treatment.

Here are the warning signs that should encourage you to stop:

1. The child's disordered agitation, which prevents any approach;
2. The need to hold several parts of the child's body;
3. Calling in colleagues to immobilise the child.

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16 – EXTRACT FROM GUIDELINES ON MANAGING CONFLICTING VIEWS - MINISTRY OF HEALTH - FRANCE

2-4-Refusal of care expressed by the minor

The minor's participation in the decision and the collection of his or her point of view cannot take precedence over the decision of the holders of parental authority.

Minors may not refuse hospitalisation.

When a minor expresses a refusal out of weariness, fear of pain or even in the event of irreversible consequences, appropriate dialogue will be required. The medical team, in conjunction with the family, should try to convince the minor.

When the medical acts performed on the minor are not necessary for his or her health, the child has a right of veto prohibiting the holders of parental authority from imposing the act in question. This applies to bone marrow collection for the benefit of a family member or participation in biomedical research.

2-5-Refusal of care expressed by one or more holders of parental authority

It may happen that the parents or legal representatives of minors object to treatment or surgery being carried out or that they decide to take the child out of the health establishment against the advice of the doctors.

The question is to what extent hospital staff can intervene to protect the child against the parents' wishes.

The law states that the doctor must respect the parents' wishes after having informed them of the consequences of their choice.

When the health or physical integrity of the minor is in danger of being compromised by the refusal of the minor's legal representative or the impossibility of obtaining the latter's consent, the doctor must inform the doctor in charge of the service who may refer the matter to the public prosecutor in order to initiate educational assistance measures enabling them to provide the necessary care.

In the event of extreme urgency, the law requires the doctor to provide essential care, i.e. that which will protect the young patient from serious consequences for his health. In this case, the doctor will decide to intervene after consulting another doctor and will then draw up a certificate of the urgency of the situation, without waiting for an educational assistance measure from the public prosecutor.

In the absence of an emergency, if the parents or legal representative refuse to sign the authorisation for care or if their consent cannot be obtained, no act of care can be carried out, they must sign a certificate of refusal of care. The parents may avail themselves of the provisions of the Public Health Code when the care does not significantly affect the minor's state of health or if the abstention from care is in keeping with the family's cultural background and its own health beliefs.

If there is no emergency but the medical or surgical procedure is essential, the doctor must inform the director who will alert the public prosecutor so that an educational assistance measure can be taken. The duty public prosecutor should be contacted.

- The doctor should mention in the medical file the need for the treatment, the proportionality of the procedure, the impossibility of obtaining the agreement of the holders of parental authority and the means used to change their minds.
- The decision to operate must be signed by the doctor and co-signed by a representative of the hospital administration or by a doctor with no hierarchical link (check feasibility)

2-6-The case of refusal of blood transfusion

In case of emergency, the parents must be informed of the risk to the child if he/she is not transfused.

If the opposition persists, an educational assistance procedure must be initiated by the public prosecutor's office to lift parental authority.

The doctor then takes the decision to transfuse the child because of the urgency of the situation. If the blood transfusion is not essential for the child's survival and the parents or legal representative refuse it, they must sign a certificate of refusal of care. ”



[Fiche n°3: Information et consentement aux soins d'un mineur - Direction générale de l'offre de soins \(DGOS\) -ONVS Observatoire nationale des violences en milieu de santé⁹⁵](#) (in French)

⁹⁵ https://sante.gouv.fr/IMG/pdf/dgos_onvs_fiche_03.pdf

17 – CHILDREN’S HOSPITAL SETS UP CLINICAL ETHICS COMMITTEE TO ADVISE AND RESOLVE CONFLICTS - ITALY

The purpose of the Clinical Ethics consultancy within the Ospedale Pediatrico Bambino Gesù in Rome is to identify, analyse and propose solutions to ethical problems and conflicts that arise in patient care.

There were 12 cases involving children brought to the attention of the Committee in 2021, 15 cases in 2022, and 11 cases between January and July 2023. The numbers include all the ethical consultancy of Bioethics Resource some of which were discussed and evaluated together with the Committee.

Clinical cases are analyzed using four criteria: 1. Indications for medical intervention: what is the medical problem and how can it be solved; 2. Patient preferences: what the parents want and, when the child can express themselves, what the patient prefers; 3. Quality of life: compared to the present conditions, how can the future life of the patient be improved; 4. Contextual aspects: for example the needs of siblings, closeness or distance from the hospital, economic or social problems.

The main and frequent ethical questions raised to the Bioethics Resource and to the Committee of Ethics concerns therapeutic obstinacy. Above all in paediatrics, clinical persistence and experimental obstinacy are often practiced because almost instinctively, even at the request of parents (due to understandable emotional feelings), the physician is inclined to do as the parents wish and do everything possible (both pharmacologically and technologically) to preserve the child's life, without considering the negative effects in terms of outcomes and further pain and suffering. Sometimes, clinical persistence is consciously practiced as a defence against any possible accusations of failure to provide medical assistance or active interruption of care or life-sustaining treatments (the so called 'defensive medicine'). In the majority of cases, clinical persistence is accompanied by the use of often sophisticated technologies. For this reason, the term "clinical persistence" is also associated with "technological obstinacy". Issues involving clinical persistence in paediatrics need to be addressed on a case by case analysis which takes into account the specific circumstances prevailing in the different concrete realities: An increase of these situations is foreseeable in paediatrics environment given the rapid developments in science and technology.

The main 'lessons learnt' in the Committee in this context are the following:

In the first place, the need for the identification of clinical obstinacy through scientific and medical elements that describe the patient's clinical condition, as in paediatrics the subjective elements that refer to the patient's experience are often lacking. In the case of children, there is a lack of a sufficiently conscious participation in the choice, as they may not be able to express themselves because of their age or immaturity, or in any case be in a condition incompatible with autonomy or full awareness. The description of the clinical condition is necessary in order to justify a possible gradual suspension of an ongoing medical treatment in children with a negative prognosis and in conditions of limited life expectancy, excluding any reasonable possibility of recovery and improvement of the clinical conditions, but only increasing the pain and suffering of the child. The reality is often even more complex: some children do not have a diagnosis (as, for example, is the case with rare diseases); others have a diagnosis but not a prognosis. It should always be considered that in children the unpredictability of the evolution of the clinical framework calls for special attention in careful consideration of each term used ; even the reference to "incurability" is dynamic, revisable in relation to the evaluation moment by moment of the evolution of the pathology, of the rapid progress of medical science; even more so with the expressions 'terminality' or 'imminence of death' which are temporally and clinically

vague given the prognostic difficulty. And even pain and suffering are not easily detectable and still difficult to measure above all in children. The best interest of the child should be the inspiring criterion in the situation and should be defined starting from the contingent clinical condition. Doctors should avoid implementing ineffective and disproportionate clinical pathways only in order to comply with parental requests and/or to meet defensive medicine criteria. The Committee helps doctors and parents (often through hearings and direct dialogue during meetings) to base their reflection on the best interest of the child.

A second important element is communication. The decision of the medical team should necessarily be made by involving the parents in the cure and care of the children, devoting particular attention to the empathic understanding of the dramatic situation that the parents are facing and guaranteeing them time and space in communication. Information to parents should be provided by a multi-specialist medical team, of variable composition in relation to the typology of the child's illness, the examination of the possible clinical implications associated with it, the risks and benefits of treatments and their burden. It should be kept in mind that the information cannot always have clear and definitive contents, given the complexity, uncertainty and unpredictability of the condition. However, the information should be continuous for the duration of the entire therapeutic process, also through the elaboration of shared treatment plans or decisions, according to the evolution of the child's conditions in the context of a care relationship, which contributes to the construction of a climate of trust between doctors and family. Often in the process psychologists need to be involved to support both the parents and the children. The quality of life of both the children and parents should be considered, as well as the context (cultural, socio-demographic conditions).

A third element is the need to implement the training of doctor and healthcare personnel, to create a core group of professionals (together with social workers, psychologists, bioethics experts, family associations) able to support parents on an emotional and practical level and accompany them in the difficult path given by the conditions of illness and vulnerability of the child in extremely precarious clinical conditions. There should also be recognition of the important role of the Associations of the parents of sick children in order to consolidate the networks for joint support from parents and from society itself.



<https://bambinogesupatrons.org/about-us/ethics-committee/>

www.coe.int

The Council of Europe is the continent's leading human rights organisation. It comprises 46 member states, including all members of the European Union. All Council of Europe member states have signed up to the European Convention on Human Rights, a treaty designed to protect human rights, democracy and the rule of law. The European Court of Human Rights oversees the implementation of the Convention in the member states.