



ECHO Toolkit:

Supporting Rights of Children in Hospital

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Mary Grehan
Arts in Health Curator
Children's Health Ireland

Begonya Nafria
Patient Engagement in Research Coordinator
Institut de Recerca
Sant Joan de Déu Barcelona Children's Hospital

Maria Dolores Navarro, MD MPH
Director of Patient Services
Sant Joan de Déu Barcelona Children's Hospital

Daniela Papini
Head of Communications and Patient Experience
Meyer Children's Hospital

Carolin Ruther, PhD
Executive Assistant to the Director
Co-Founder Child's Rights Working Group
Dr. von Hauner Children's Hospital

Annemiek Rutters, MSc, MBA
Director
Erasmus MC - Sophia Children's Hospital

Ilaria Simonelli, PhD
Consultant on rights of children and young people

Anastasija Ustinova
Quality specialist
Children's University Hospital Latvia

About ECHO

ECHO's mission is to advocate for children's health and their access to the best quality care through the collaborative work of children's hospitals. To learn more about ECHO go to: www.ECHOhospitals.org.

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Introduction

Patient- and family-centred healthcare are core components of paediatric hospital care. Underlying and woven into the concept of patient-centred care are the rights of children and their families. On November 20, 1989 the United Nations signed the Convention of the Rights of the Child (CRC), establishing universal rights of children¹. This document has implications for the design and delivery of healthcare in general and hospitals specifically^{2,3}. November 2019 marks the 30th anniversary of the signing of the CRC. This anniversary offers a chance to reflect on the progress we have made in promoting the rights of children in hospital and to recommit to continue to protect and promote those rights.

Supporting rights of children in hospital

Although the CRC has been ratified by 196 countries, including all countries in the European Union, there is limited evidence evaluating the extent to which these rights are implemented in paediatric hospitals or paediatric care in general⁴. For example, a study in Italy surveying nurses asking them to assess the implementation of children's rights in hospital found implementation to be limited and varied by geography and type of institution⁵. Similarly, a review of literature examining how children's rights are recognized in family-centred care found little mention of children's rights in the medical literature⁶.



Photo credit: Pixabay

Looking towards the future

To help address this gap and assist hospitals move forward in applying a rights-based approach to the provision of healthcare and quality improvement, the European Children's Hospitals Organisation has developed the ECHO Toolkit on Supporting the Rights of Children in Hospital. This document provides a summary of existing evaluation tools to assist in planning and evaluation, example of reports and research studies addressing the rights of children in hospital, and a sample of existing charters. The Toolkit also includes case studies of some best practices within ECHO member hospitals to provide real world examples of what employing a rights-based approach to healthcare can look like.

This toolkit represents a first step of an ongoing commitment by ECHO to support the rights of children and young people in hospital. We hope these materials will help children's hospital staff and managers on the journey to a creating an environment that protects and affirms the rights of children and young people in hospital.

Section 1: Evaluation and Monitoring Tools

Assessing the baseline status of healthcare is the first step to promoting and protecting the rights of children. To assist hospitals in this process we reviewed both the grey and peer-reviewed literature to identify tools utilizing a rights-based approach to quality assessment. Additionally, we also consulted with experts in the field to ensure our list was complete. A more detailed explanation of the methods is included in Appendix I.

Based on this review, two tools were selected for inclusion. Both of these use the United Nations Convention on the Rights of Children as the framework and both were developed using an international multidisciplinary approach. Each has also undergone field testing and refinement based on that process. Furthermore, both are also open access and can be modified or adapted to meet local needs making them useful in a variety of settings.

World Health Organization rapid-assessment checklist



In 2017 The World Health Organization Regional Office for Europe published the *Children's rights in hospital: Rapid-assessment checklists* to assist hospitals "wishing to assess and improve the fulfilment of children's rights in the design, planning and delivery of care for children aged 0-18"⁷. This tool was used to assess the implementation and improvement of the rights of children in hospitals in Kyrgyzstan, Tajikistan, and Moldova.⁸

Summary

- **Target Audience:** Managers
- **Strengths:** Helps hospitals quickly determine their level of progress
- **Limitations:** Does not include patient perspective
- **Additional information:** For a copy of the checklists to the WHO Regional Office for Europe web page on children in hospital:
<http://www.euro.who.int/en/health-topics/Life-stages/child-and-adolescent-health/child-and-adolescent-health/children-in-hospitals>.

International Network of Health Promoting Hospitals

The Task Force on Health Promotion for and with Children and Adolescents in and by Hospitals and Health Services (HPH-CA Task Force) published a series of tools “which can be used in an



improvement programme cycle within hospitals and health services, aimed at advancing the respect, protection and fulfilment of children’s rights within those institutions”⁹ These tools are designed to assess the implementation of rights from the perspective of management, staff, parents or guardians, patients aged 12-17 and 6-11 years.

Summary

- **Target Audience:** Managers, professionals, patients, and families
- **Strengths:** Provides full picture from multiple perspectives
- **Limitations:** Potentially labour intensive
- **Additional information:** Contact Ilaria Simonelli (ilariasimonelli79@gmail.com), HPH-CA Task Force Leader for more information and for versions of the surveys targeted at specific users.

Section 2: Reports and Studies

There is not a one size fits all blueprint to incorporating a rights-based approach into quality improvement and planning processes. The following examples illustrate different strategies and methods ECHO member hospitals have used to incorporating a rights-based approach to quality improvement.

Joining the Dots, Ireland

Aim: Employ a rights-based approach to listening and incorporating the views of children and young people, their parents, and hospital staff into the development and delivery of hospital services.

Sponsoring Organisation: Children's Hospital Group Board (now Children's Hospital Ireland) and the Ombudsman for Children's Office

Where: Dublin, Ireland

Process: In 2017 over 2,530 children, young people, parents, and hospital staff completed surveys looking at a range of topics on the delivery of services to children and young people in hospital. The surveys were based on the HPH-CA Task Force assessment tools and specifically looked at issues that relate to children's rights under the United Nations Convention on the Rights of the Child.

Outcomes: The Children's Hospital Group Board is incorporating the results into the planning process for Ireland's New Children's Hospital. The development of services within other outpatient and urgent care services at existing hospitals are also incorporating the results. The feasibility of rolling out *Joining the Dots* in acute paediatric health services outside Dublin is currently being explored.

Additional information: To obtain a full copy of the report visit the Ombudsman for Children's Office at: <https://www.oco.ie/childrens-rights/consulting-with-young-people/joining-the-dots/>.



Joining the Dots Report Cover

Survey of paediatricians, Germany

Aim: The aim of the study was to examine the awareness and current implementation of the UN CRC in German children's hospitals.

Sponsoring Organisation: Dr. von Hauner Children's Hospital, Ludwig Maximilians University

Where: Munich, Germany

Process: In 2018 all paediatricians working in German hospitals were invited to complete an online survey. The participants were asked to assess their own awareness of the rights of children and to evaluate how these rights are supported in their hospitals. The results were presented at the 1st Children's Health Summit, which was attended by directors of all German university paediatric clinics as well as patient and parent representatives.

Outcomes: The results indicate that there is not sufficient awareness of child rights amongst the paediatricians surveyed. The vast majority of respondents reported that there was a high degree of awareness and effort made to promote the best interest of the child. The protection of patients against the use of physical and mental violence was also seen as a high priority. However, almost 40% of paediatricians felt that their patients' right to education and play as well as their right to the highest attainable standard of health were only somewhat respected.

It is important to note that because the study was only conducted amongst children's hospitals in Germany, it is not possible to generalise these results to other settings. Nevertheless, this empirical study highlights the importance of incorporating the principles of the Convention on the Rights of the Child in the healthcare setting.

Additional information: To obtain a full report of the results or to learn more about child rights initiatives at Dr. von Hauner Children's Hospital, contact Dr. Carolin Ruther (Carolin.Ruther@med.uni-muenchen.de).



Conference materials from 1st Children's Health Summit in Munich, Germany

Design thinking pilot workshop, Spain

Aim: Conduct a pilot study to develop a methodology for identifying which rights are most important to patient's families and which rights the hospital should focus on improving.

Sponsoring Organisation: Department of Patient Experience, Sant Joan de Déu Barcelona Children's Hospital

Where: Barcelona, Spain

Process: Utilizing a combination of nominal group technique and design thinking, a two-hour workshop was conducted with 6 family members representing a range of different patients. Participants were asked to rank the rights of children in hospital based on importance to them and fulfilment by the hospital. Ranking was done individually, but participants could change the ranking after group discussion.

Outcomes: Of the rights ranked most important to parents some, but not all, were also ranked as being well supported by the hospital. The process provided guidance on areas for improvement and reinforcement for what is working well. The workshop process will be repeated with group of patients and professionals and the combined results will be used to guide future patient experience initiatives.

Additional information: To learn more about this project contact Maria Dolores Navarro, Director of Patient Services, Sant Joan de Déu Barcelona Children's Hospital at: mnavarror@sjdhospitalbarcelona.org.

To learn more about nominal group techniques, including how to run a group, see "Gaining Consensus Among Stakeholders Through the Nominal Group Technique" from the Centers for Disease Control and Prevention, available at: <https://www.cdc.gov/healthyyouth/evaluation/pdf/brief7.pdf>.



Participants in the design thinking workshop on child rights

Section 3: Charters and Supporting Documents

Another step towards incorporating a rights-based approach to healthcare is adopting a charter of rights for children in hospital. ECHO recognizes that the content and implementation of a charter on the rights of children and young people in hospital will vary depending local and institutional culture, existing national and regional legislation or professional standards. Therefore, ECHO encourages all children's hospitals to adopt a charter of rights that works within the legal and policy framework of the local health system but that also upholds the core principles of the United Nations Convention on the Rights of Children.

Table 1 outlines a sample of existing documents that are used in Europe and internationally to define the rights of children in hospital. Although the United National Convention on the Rights of the Child provides the standard for defining the rights of children and young people, there is no absolute list of rights of children and young people in hospital. An illustration of this is decision by Children's Healthcare Australasia to produce two separate charters, one for New Zealand and another for Australia. This was done to reflect the unique cultures of each country. So, although the principles are the same, the execution is tailored to the local environment.



Photo credit: Pixabay

Table 1. Key documents outlining rights of children in hospital

Year updated	Document name	Notes
1986	European Charter for children in hospital ¹⁰	<ul style="list-style-type: none"> This was a resolution approved by the European Parliament calling on the Commission to submit a European charter on the rights of children in hospital and outlines recommended content for this charter. This document informs many country and hospital level charters in Europe.
1989	United Nations Convention on the Rights of the Child (UN CRC) ¹	<ul style="list-style-type: none"> This is unquestionably the foundation for most, if not all, child rights charters worldwide. Additional guidance on interpretation is provided by General comments on Article 24, which specifies a child's right to highest attainable standard of health¹¹. General comment No. 4 provides guidance on adolescent health and development¹².
2001	European Association for Children in Hospital (EACH) Charter ¹³	<ul style="list-style-type: none"> EACH is an international umbrella organisation of associations involved in the welfare of children in hospital and other healthcare services. The Charter was initially adopted in 1988 and annotated in 2001. It is used by multiple member and non-member organisations throughout Europe. The Charter is based on the UN CRC and related general comments.
2004	Children's Healthcare Australasia Charters ^{14,15}	<ul style="list-style-type: none"> Based on a review of international document, Children's Healthcare Australasia drafted and adopted two charters, one for New Zealand and one for Australia. These charters take into account the culture and kinship structure of the aboriginal populations unique to those regions.

Section 4: Putting it into Practice – Implementation Examples

Everyday ECHO member hospitals are working at protecting and promoting the rights of children and young people. They employ evidence-based strategies delivered with creativity and compassion to provide care that treats the whole patient—not just the illness.

Using the rights standards from the WHO rapid-assessment checklists as a framework (Table 2), the following examples illustrate best practices in rights-based care from ECHO member hospitals. The list is not meant to be exhaustive, but to show how a rights-based framework can be used to evaluate new and ongoing hospital initiatives and the examples are only a slim subset of the types of activities that can be undertaken within each rights standard. Many of the examples provided also address more than one rights standard. For example, the KIDS Barcelona Scientific Advisory Council is included under rights standard six, protection from harm, as the Council supports the evaluation of clinical trials in children which ultimately protects them from potential harm associated with research. The Council could have easily been included in right standard four, information and participation. This example illustrates how these rights are intertwined and none of them stand alone.

The practices described here can be adapted and applied to a variety of settings, and we hope these examples will serve as an inspiration to other children’s hospitals and paediatric medical centres on their quality improvement journeys.

For additional resources on promoting child- and family-centred care in hospital see the Standish Foundation at: <https://standishfoundation.org>.

Table 2. Rights standards, aims, and ECHO examples

Rights Standard^{7,8}	Aim	ECHO Implementation Examples
1. High quality healthcare	To assess adoption of evidence-based clinical guidelines; monitoring and evaluation activities, and; provision of adolescent-friendly health services.	<ul style="list-style-type: none"> • Challenge: Quality of care during transition to adult care • Approach: La Suite transition unit • Challenge: Incorporating the patient experience into quality improvement • Approach: Standardized patient surveys and implementation of in-room family breakfasts
2. Equality and non-discrimination	To assess rights of accessibility and acceptability; delivery of patient-centred care that recognizes the child's individuality, diverse circumstances, culture, and needs; right to privacy.	<ul style="list-style-type: none"> • Challenge: Impact of racism on health outcomes • Approach: Staff training and needs assessments
3. Play and learning	To assess adoption and implementation of play and learning activities; and whether children's views are taken into account in the planning and improvement of playrooms/play spaces.	<ul style="list-style-type: none"> • Challenge: Using the power of play • Approach: Pioneering the profession of play • Challenge: Incorporating arts in the hospital • Approach: Integrating arts from planning to implementation
4. Information and participation	To assess policies and practices on right to information and participation in children's own care and in the development of services.	<ul style="list-style-type: none"> • Challenge: Children's voices can be overlooked • Approach (1): A rights-based patient advisory group • Approach (2): Incorporating the voice of children and young people in planning

Table 2 (continued). Rights standards, aims, and ECHO examples

Rights Standard^{7,8}	Aim	ECHO Implementation Examples
5. Safety and child-friendly environment	To assess friendliness, safety, cleanliness, and appropriateness of hospital infrastructures; and - right to food.	<ul style="list-style-type: none"> • Challenge: Avoidable harm in hospital • Approach: Safety videos for parents and kids
6. Protection from harm	To assess the existence and implementation of a child protection system within the hospital; and - existing regulations on clinical research and trials.	<ul style="list-style-type: none"> • Challenge: Protecting children and young people during research • Approach: Youth scientific advisory council
7. Pain management and palliative care	To assess the appropriateness and effectiveness of pain management and palliative care services.	<ul style="list-style-type: none"> • Challenge: Children in hospital are still in pain • Approach: Hospital Without Pain certification

Rights standard 1. The right to high quality healthcare

A foundational right of children in hospital is to receive the highest quality care available.

Challenge: Gaps in quality during transition to adult care

Although young people may be receiving the best possible treatment in a children's hospital setting, transitioning to adult care can cause significant disruptions¹⁶. Young people may be inadequately supported through the process, resulting in disengagement and worsening health outcomes^{17,18}.

Approach: La Suite-Necker

To address this issue, Necker-Enfants malades University hospital in Paris, France, along with 40 national reference centres for orphan diseases and the hospital's research unit, Institute Imagine, designed and implemented a unique and first-of-its kind transition unit to support young people moving to adult care called La Suite-Necker.

La Suite-Necker is a separate space in the hospital dedicated to young adults who have complex chronic and rare diseases. It was designed to be a connection between the hospital and community for both patients and professionals. Beyond helping young people deal with the medical side of their transition to adult care, La Suite offers support on issues that all young people deal with like sexuality, nutrition and obesity, physical activity or substance misuse. A grounding philosophy of La Suite is to create a space where young people are able to interact with each other and healthcare providers in a setting that focuses on the individual and not the disease. La Suite-Necker opened in October 2016 and since that time has welcomed more than 200 patients.

For more information on La Suite-Necker visit their website at:

<http://www.la-suite-necker.aphp.fr/>.



Interior space of La Suite-Necker, photo credit: Brandimage

Challenge: Incorporating the patient experience to improve quality

Patient experience is an essential component of delivering high quality healthcare¹⁹. More research is pointing to the fact that improving patient experience can help achieve both better health and safety outcomes²⁰. In the case of children's hospitals, patient experience refers to not only the patient but also the experience of the entire family. Sophia Children's Hospital in Rotterdam is addressing the patient experience to improve quality in a variety of ways.

Approach (1): Standardized patient surveys

To ensure that patients are a part of the quality improvement process, two weeks after they go home all patients who were admitted to Sophia Children's receive a survey. The survey was developed by Picker, an international non-profit organisation that specializes in assessing and helping institutions improve patient experience. Surveys are available for patients ages 0-7 and 8-15 years old. The results feed into ongoing quality improvement initiatives using co-design methods to identify solutions that meet patient needs.

Approach (2): Family breakfast in the hospital

Family accommodation that provides support and proximity to the hospital improves the overall patient experience and can positively influence the involvement of families in their child's recovery^{21,22}.

Sophia Children's has taken the concept of supporting families and their proximity to their children one step further to provide breakfast to parents or caregivers staying in hospital. The programme started because staff noticed parents were skipping breakfast to be sure they were present for morning rounds. Now parents can stay in the room and share a meal with their children and more fully participate in the care of their child. The shared meal is important to both the parents and children and is rated very highly on patient experience surveys.



Photo credit: Rawpixel

Rights standard 2. The right to equality and non-discrimination

Every child has the right to access healthcare regardless of their individual or family circumstances. This includes physical access as well as freedom from discrimination when receiving healthcare services. In short, children and young people have the right to healthcare that affirms and respects who they are.

Challenge: Impact of racism on health outcomes

Discrimination and differential access to care are significant issues that impact the health of children and young people. In Europe, health outcomes ranging from infant mortality to diabetes outcomes vary with geography²³. Racism, both systemic and interpersonal, also affects health. The American Academy of Pediatrics recently issued a statement on the impact of racism on the health outcomes, and in 2018 the World Health Organization Regional Office for Europe issued a report calling for the creation of culturally- and migrant- sensitive health systems^{24,25}

Approach: Staff training and needs assessments

To ensure that staff have the appropriate training to serve a diverse patient population, every year Sophia Children's Hospital partners with local organisations to host four training sessions for all staff on the impact of culture on healthcare and overcoming language barriers. The goal is to raise awareness in a fun setting, but with the serious objectives of improving access to healthcare.

In response to a growing international patient population, in 2019 Sant Joan de Déu conducted a needs assessment to identify gaps in training in cultural competence. The results of this analysis are being used to develop staff training to provide optimal care to the entire patient population, regardless of their country of origin, language, or culture.



A Muslim mother and her child

Rights standard 3. The right to play and learn

No matter if they are at home or in hospital, children and young people have the right to play and learn.

Challenge: The importance of play

Play is essential for growth and development. Children use play to communicate and process emotions—something that becomes even more important in hospital²⁶. Trained play specialists can help to minimize anxiety associated with hospitalisation in general or around specific procedures, like surgery²⁷. ECHO members integrate age-appropriate play throughout the hospital experience. Whether they are building a new hospital, redesigning an existing space or developing a new service, creating an environment where kids can be kids, no matter how sick they might be, sets children's hospitals apart.

Approach: Pioneering the profession of play

SJD Barcelona Children's Hospital has pioneered the development of the profession of child life specialist in Spain. The team of child life specialists support both children and their families to ease anxiety and improve the recovery process. Working in a space that was co-designed with families and patients, the child life team uses structured play to help children better understand what to expect, both before and after surgery. It is currently the only Spanish hospital with a dedicated team providing pre- and post-surgical emotional support.

Dr. von Hauner Children's Hospital in Munich, Germany is on the road to developing a similar service with the launch of a pilot project to introducing an independent Child Life Specialist Unit. As in many countries, these services are not financed by the German health system. The programme aims to close this gap and will be one of the first hospitals in Germany to provide these services.



Photo credit: Rawpixel

Challenge: The need for arts in hospital

There is growing evidence that art can have a positive and transformative impact on the experiences of children in hospital. From improving health outcomes to creating an increased sense of calm for families and staff, there are multiple benefits to incorporating the arts^{28,29}. When talking about the arts in health, this can refer to experiencing art, such as listening to music or viewing a painting, but also includes creating and performing art. All of these artistic forms support a child or young person's right to play and learning.

Approach: Integrating arts from planning to implementation

In the development of their new hospital, Children's Health Ireland is placing arts, creativity and imagination at the heart of the hospital experience. The selection of commissioned art for the hospital was done in consultation with the Youth Advisory Council and AsIAm, an advocacy group representing the needs of children and young people on the autism spectrum. CHI is also working with experienced professional artists to develop an arts programme that engages children in a range of creative experiences that will take place at the bedside, play areas, and in public areas.

This initiative gives children the possibility to influence and leave their mark on their own clinical environment, truly incorporating the patient voice, art, and play into the new children's hospital.



Photo credit: Pixabay

Rights standard 4. The right to information and participation

Children and young people have the right to be heard and to have their opinions considered. This includes clinical decision making, but also means that they are systematically involved in shaping the policies and procedures that influence the design and delivery of healthcare.

Challenge: Children's voices can be overlooked

Although there has been progress in promoting the voice of children, there is evidence that more work needs to be done. A review of literature examining how children's rights are recognized in family-centred care found little evidence that children actively participate in medical decision making⁶. Similarly, in a survey of over 2,500 patients, family and staff in three children's hospitals in Dublin, both families and staff identified the need to improve practices informing young people of their right to participate in care³⁰.

Approach (1): A rights-based patient advisory group

To create an opportunity for patients to provide feedback on their hospital experience and to guide the hospital's work around supporting the rights of children, Dr. von Hauner Children's Hospital in Munich, Germany, established a Child's Rights Working Group (AG Kinderrechte) in March 2019. Formation of the group was partly motivated by survey results showing that German paediatricians reported low levels of implementation and support of child rights in their practice settings (see Section 3 for additional details). AG Kinderrechte works to jointly develop concrete proposals for better implementation of the rights of children and young people and is currently producing a child-friendly version of the von Hauner Charter on Rights of Children in Hospital. The charter will be distributed as a book to all patients. The group also presented at the 1st German Children's Health Summit in April 2019 where they received positive feedback from attendees. They hope this rights-based approach will be a model for other youth advisory groups in Germany.



Children's choir at the 1st German Children's Health Summit

Approach (2): Incorporating the voice of children in planning

Children's Health Ireland in Dublin (CHI) is building a new and ambitious children's hospital that will be a reference centre for the entire island. The planning process for the CHI hospital adopted multiple strategies to incorporate the opinions of children and young people. Researchers used verbal and visual participatory methods to get the opinions of the youngest children (aged five to eight). Older children (aged 12 to 18) provided their input during a two-day workshop at Dublin Castle. Their input not only fed into the evolving design of the hospital but also resulted in the formation of the Youth Advisory Committee (YAC) to provide further input in the hospital design. Once the hospital is complete, the YAC will continue to provide guidance on the operational policies and services in the new children's hospital.

Children's University Hospital Latvia in Riga is also incorporating play into their planning and construction process. As part of their hospital redesign they will be introducing a new play space into the waiting area of the hospital.



Concourse concept of new Children's Health Ireland hospital

Rights standard 5. The right to a safe and child-friendly environment

Children and young people in hospital have the right to a safe and friendly environment.

Challenge: Children face avoidable harm in hospital

Even in the best hospitals, some preventable harm can occur. Parents know their children best and involving parents and patients is an important part of improving safety, for example, in the case of handwashing. To improve hand hygiene, the World Health Organization encourages partnerships between patients, families, and healthcare workers, although literature shows this recommendation is often overlooked by health systems^{31,32}. Harm from medicines are also an important safety issue for patients in hospital. As with handwashing, involving parents can help. One study found that parental involvement in medical round helped reduce harmful medical errors³³.

Approach: Safety videos for parents and kids

To improve patient safety and more actively involve families, Meyer Children's Hospital in Florence, Italy, developed a series of animated videos in partnership with the Tuscany region's Clinical Risk Management Center and the WHO

Collaborating Center in Human Factors and Communication for the Delivery of Safe and Quality Care. The videos highlight the active role that children and families can play in four common sources of harm: lack of information, poor hand hygiene, interruptions in therapy, and issues at discharge. Videos are shown in waiting rooms and play spaces throughout the hospital with simple and clear messages that can be understood by children and families who do not speak Italian.



Screen shots from "In terms of safety, we are a great team" safety videos developed at Meyer Children's Hospital

Rights standard 6. The right to protection from harm

Children and young people in hospital have the right to protection from all forms of physical or mental violence, which includes of abuse and unintentional injury. It also means that clinical trials or research involving children and young people should be strictly regulated^{7,13}. All researchers must provide participants with age appropriate information and, when possible, involve patients in the design, implementation, and analysis of the study.

Challenge: Protecting children and young people during research

Children and young people have not historically been included in clinical trials, and most medicines were only tested in adults. In 2007 new European legislation was passed mandating that new drug approval applications include paediatric investigation plans³⁴. This has helped spur the development of new medicines for children and young people, but also meant more children are participating in clinical trials.

Approach: Developing a youth scientific council

As more children and young people are involved in clinical trials, it is important to develop mechanisms to incorporate their input into the research process. To address this, SJD Barcelona Children's Hospital spearheaded KIDS Barcelona where children and young people are part of a Scientific Council for the hospital^{35,36}. The Council is made up of 22 adolescents with different diseases as well as some healthy participant. The Council provides input on clinical trials design as well as biomedicine, research, and innovation initiatives. It supports the rights of children and young people by giving them an opportunity to provide feedback on research questions to ensure the studies are truly meeting the needs of patients.

Another important way KDIS Barcelona contributes to the research process is by ensuring that all information about clinical trials is presented in a way that is understandable to patients and families, allowing them to make informed decisions about participation.



Barcelona KID Youth Scientific Council 2019

Rights standard 7. The right to pain management and palliative care

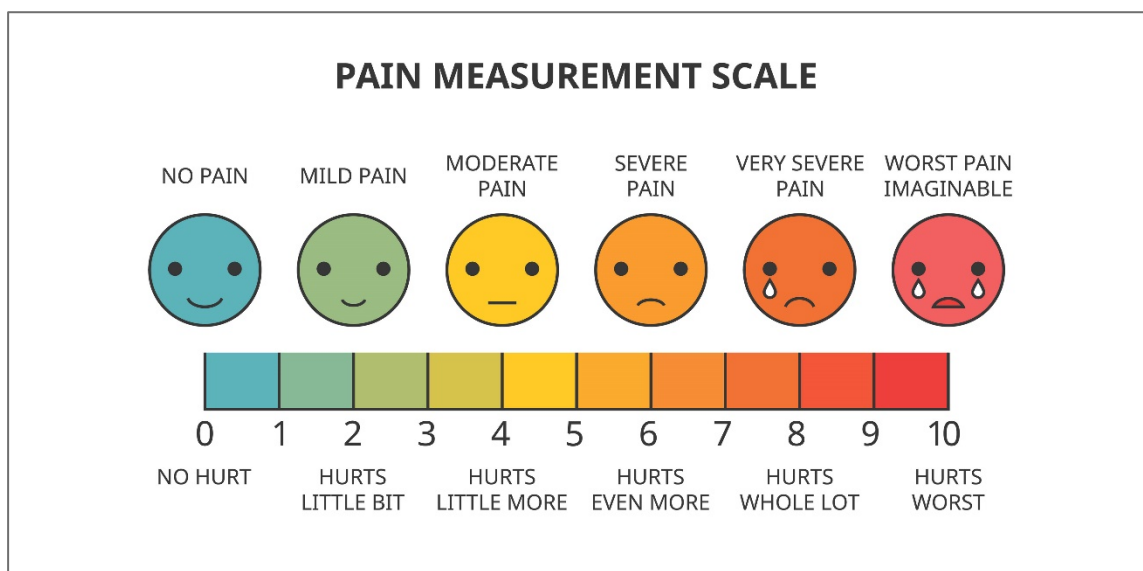
Children have the right to be protected from pain and discomfort. This includes physical pain and emotional stress and discomfort.

Challenge: Children in hospital are still in pain

Although in recent years there has been significant attention paid to pain management, it can still be an issue for children in hospital. Rates of pain in children and young people remains high, with patient factors such as age, gender, and race all influencing pain scores^{37,38}. A recent multi-centre study found that as many as three out of five children (62%) in hospital reported experiencing their “worst” level of pain³⁹. Multiple barriers to adequate pain management have been identified including prescribing patterns and a lack of physician documentation of pain assessment³⁸.

Approach: Hospital Without Pain certification

In Poland, the Hospital Without Pain initiative is one strategy being used to address this challenge⁴⁰. This initiative provides certification to hospitals that have undergone an audit of their pain management practices. Certification requirements include staff training, pain monitoring programmes, communication with patients, record keeping, and side effect management. In Poland two different certificates are available. This first, initiated in 2010, applies to postoperative wards. The second, initiated in 2017, applies to non-surgical wards and was launched in recognition that patients have the right to pain relief. In October 2019 Warsaw Memorial Children’s Institute was certified as a Hospital Without Pain.



Visual pain measurement scale used to assess pain in children

Appendix I: Methods and references

Detailed search strategy

We conducted a search of both the grey and peer-reviewed literature to identify evaluation and monitoring tools assessing rights of children in hospital. We searched PubMed using the key words “children’s rights,” and “hospital” and reviewed articles that reported using a rights-based framework for analysis. Bibliographies of included articles and review articles were also searched.

Grey literature was searched by reviewing websites of organisations working on child health or child rights. These included the World Health Organisation, UNICEF, International Network of Health Promoting Hospitals, European Association of Children in Hospital, the American Academy of Pediatrics, Children’s Healthcare Australasia, the Children’s Hospital Association, USA, and the European Academy of Paediatrics. The European Observatory on Health and the European Commission Public Health pages were also searched.

Finally, we contacted authors of what we determined to be key publications to assess if any other tools or resources should be included here.

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