The Respect of Children’s Rights in Hospital: An initiative of the International Network of Health Promoting Hospitals and Health Services

Final report on the implementation process of the Self-Evaluation Model and Tool on the Respect of Children’s Rights in Hospital

Edited by Fabrizio Simonelli and Ana Isabel Fernandes Guerreiro, in collaboration with the Task Force members

January 2010
Disclaimer:
The opinions expressed in this Final Report do not necessarily reflect the respective organisational views nor do they imply an official endorsement by any of the institutions quoted in the text.

This Report is a technical document based on the local findings within participating institutions of self-evaluations on the respect of children’s rights in hospital. The evidence was collected by and for professionals working for and with children.

Editors:
Fabrizio Simonelli and Ana Isabel Fernandes Guerreiro
Hub, Task Force on Health Promotion for Children and Adolescents in and by Hospitals and Health Services
WHO Collaborating Centre for Health Promotion Capacity Building in Child and Adolescent Health
c/o Health Promotion Programme
Meyer University Children’s Hospital
Viale Pieraccini, 28
50139 Florence - Italy
Tel: +39 055 566 2829
f.simonelli@meyer.it
a.guerreiro@meyer.it
http://who.collaboratingcentre.meyer.it

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Thirdly, I would like to thank all who facilitated and conducted the local self-evaluation processes, in particular Cheryl Williams, Fran Dooley and Matthew Peak at Alder Hey Children’s NHS Foundation Trust (England, UK); Liam Cairns at Investing in Children (England, UK); the Playroom Coordinator and staff at the Meyer University Children’s Hospital; Virginia Binns at Sydney Children's Hospital; Maria Mercedes Roldés Caballero at the Council of Health of the Government of the Canary Islands; Ülle Einberg and Raja Rekkaro at Tallinn Children’s Hospital; Dora Schéiber at the Hungarian National Institute for Child Health; and Maria Josep Planas at Hospital Sant Joan de Déu Barcelona.

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Fabrizio Simonelli
Task Force Leader
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The Task Force on Health Promotion for Children and Adolescents in and by Hospitals and Health Services: composition (January, 2010)

Giuliana Filippazzi (Italy)
European Association for Children in Hospital (EACH)
ffilippazzi@alice.it

James E. Robinson (Scotland, UK)
Royal Hospital for Sick Children,
NHS Lothian University Hospitals
James.Robinson@luht.scot.nhs.uk

J. Raquel Mullen (USA)
Stanly Pediatrics at Troy
docroxm@hotmail.com

Kjersti J. Ø. Fløtten (Norway)
Akershus University Hospital
kjersti.johanne.flotten@ahus.no

Klaus Arbeiter (Austria)
Department of Paediatric and Adolescent Medicine
Medical University of Vienna
klaus.arbeiter@meduniwien.ac.at

Lagle Suurorg (Estonia)
Tallinn Children’s Hospital
Lagle.Suurorg@lastehaigla.ee

Leonor Santos (Portugal)
Instituto de Apoio à Criança (Child Support Institute)
leonor.humanizacao@gmail.com

Les White (Australia)
University of New South Wales and Sydney Children’s Hospital
L.White@unsw.edu.au

Liz McArthur (England, UK)
Alder Hey Children’s NHS Foundation Trust
Liz.McArthur@alderhey.nhs.uk

Micheline Ste-Marie (Canada)
Montreal Children’s Hospital
McGill University Health Centre
micheline.ste-marie@muhc.mcgill.ca

Marija Radonić (Croacia)
Pediatric Department in, County Hospital Dubrovnik
marijarada@bolnica-du.hr

Núria Serrallonga Tintore (Spain)
Hospital Sant Joan de Déu Barcelona
nserrallonga@hsjdbcn.org

Rosa Gloria Suárez (Spain)
General Directorate of Public Heath, Canary Islands Government
rsualop@gobiernodecanarias.org

Stella Tsitoura (Greece)
European Society for Social Paediatrics (ESSOP) and “P & A Kyriakou” Children’s Hospital
stella.tsitoura@gmail.com

Zsuzsanna Kovács (Hungary)
National Institute of Child Health
kovacszs@ogyei.hu

Task Force Hub
Fabrizio Simonelli f.simonelli@meyer.it
Ana Isabel Fernandes Guerriero a.guerreiro@meyer.it
Meyer University Children’s Hospital (Italy)
Introduction and Background

This booklet presents the Final Report on the implementation process of the Self-evaluation Model and Tool on the Respect of Children’s Rights in Hospital (hereafter SEMT) developed and promoted by the Task Force on Health Promotion for Children and Adolescents in and by Hospitals and Health Services (Task Force HPH-CA). The Task Force HPH-CA was officially established in 2004, within the International Network on Health Promoting Hospital and Health Services with the aim “to apply Health Promotion principles and criteria to the specific issues of health promotion for children and adolescents in and by hospitals, by providing an organic conceptual and operational framework for institutions, decision makers, healthcare organisations and their professionals” (Task Force HPH-CA, 2004). The Task Force HPH-CA is coordinated by the Task Force Hub and currently has 15 members.

An exploratory survey carried out in 2004 in 114 European paediatric hospitals and departments of 22 Countries highlighted a gap in the adoption of Charters on Children’s Rights in Hospital and, where these had been adopted, the lack of tools to assess the respect of children’s rights in the hospital setting. Based on the results of this survey, the Task force HPH-CA decided to adopt the issue of children’s rights in hospital as one of its priority work areas, taking into account its value in the field of health promotion for children and adolescents.

Following this, the Task Force HPH-CA prepared the SEMT, in collaboration with experts from relevant agencies and organisations, with reference to the Convention on the Rights of the Child (CRC) and the Charter of the European Association for Children in Hospital (EACH), as well as other relevant documents. This process was lead by the Task Force Hub.

The four principles of the CRC, namely the articles related to non-discrimination (art. 2), the best interests of the child (art. 3 (1)), life, survival and development (art. 6) and the respect for the views of the child (art. 12) served as a theoretical model on which to base the self-evaluation tool. The specific objective of the model is to assess the gap between the full respect of children’s rights in hospital and the actual practice, as a basis on which to promote improvement and change in that setting through the development of standards; and actions, as well as further assessment, evaluation and feedback. This process comprises four phases of assessment, improvement and change, as follows:

1) mapping the reality through the implementation of the proposed self-evaluation tool;
2) planning the improvement, through the identification of a set of standards for the respect of children’s rights in hospital;
3) making improvement, through the implementation of specific actions;
4) evaluating the change, by monitoring progress and gaps.

The figure below provides a representation of this process.
Figure 1. Self-evaluation Model on the Respect of Children’s Rights in Hospital

GENERAL PRINCIPLES OF THE U.N. CONVENTION ON THE RIGHTS OF THE CHILD

Life, survival, development and protection

Respect of the point of view of the Child

Non-discrimination

BEST INTEREST OF THE CHILD

DENIAL OF RIGHTS = DEPRIVATION

FULL RESPECT OF RIGHTS = WELL BEING

HPH Task force on Health Promotion for Children and Adolescents in & by Hospitals and Health Services

MAPPING THE REALITY:
SELF EVALUATION

EVALUATING THE CHANGE:
MONITORING PROGRESS AND GAPS

PLANNING THE IMPROVEMENT:
SET OF STANDARDS OF CHILDREN’S RIGHTS IN HOSPITAL

MAKING IMPROVEMENT:
IMPLEMENTATION OF ACTIONS
The self-evaluation tool is the operational instrument of the SEMT. Its aim is to facilitate analysis and reflection on the respect of children’s and adolescents’ rights in hospital, to understand good practices and as a basis and guide for further improvement. The self-evaluation, assessment and reflection on each of the rights will enable the Hospital Directors and Paediatric Departments to identify some reference standards and to plan actions as well as a timeframe to achieve them. The tool identifies the following twelve rights:

Table 1. List of Rights of the Self-evaluation Model and Tool on the Respect of Children’s Rights in Hospital

<table>
<thead>
<tr>
<th>AREA 1: RIGHT TO THE HIGHEST ATTAINABLE STANDARD OF HEALTH CARE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Right 1.1.</strong> Children’s health care provision should take into consideration all dimensions of health, including physical, mental, social, cultural and spiritual.</td>
</tr>
<tr>
<td><strong>Right 1.2.</strong> Children have the right to access health services without ethnic, racial, class, religious, gender, age, sexual orientation, disability, language, cultural and social discrimination.</td>
</tr>
<tr>
<td><strong>Right 1.3.</strong> Children shall be admitted to hospital only if the care they require cannot be equally well provided and effective at home or on a day basis.</td>
</tr>
<tr>
<td><strong>Right 1.4.</strong> Children have the right to have full opportunity for play, rest, leisure, recreation and education suited to their age and condition and to be in an environment designed, furnished, staffed and equipped to meet their needs.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>AREA 2: RIGHT TO INFORMATION AND PARTICIPATION IN ALL DECISIONS INVOLVING THEIR HEALTH CARE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Right 2.1.</strong> Children have the right to be informed in a manner appropriate to their age, developmental level and understanding.</td>
</tr>
<tr>
<td><strong>Right 2.2.</strong> Children have the right to express freely their opinions on any issue that involves them and the right to be heard and to be taken into consideration in a way consistent with their age and maturity.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>AREA 3: RIGHT TO PROTECTION FROM ALL FORMS OF VIOLENCE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Right 3.1.</strong> Children have the right to be protected from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse.</td>
</tr>
<tr>
<td><strong>Right 3.2.</strong> Children have the right not to be separated from their parents/guardians/caregivers against their will during their stay in hospital.</td>
</tr>
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<td><strong>Right 3.3.</strong> Children have the right to privacy.</td>
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<td><strong>Right 3.4.</strong> Children have the right to a dignified death.</td>
</tr>
<tr>
<td><strong>Right 3.5.</strong> Children have the right not to feel pain.</td>
</tr>
<tr>
<td><strong>Right 3.6.</strong> Children have the right not to be submitted to clinical research or experimentation projects and to have the possibility to withdraw during the process of research.</td>
</tr>
</tbody>
</table>

At the moment, the SEMT is translated in 10 languages: English, Estonian, French, German, Greek, Hungarian, Italian, Norwegian, Portuguese, Spanish and it has been disseminated via websites and through national and international conferences and meetings.

The implementation process of the SEMT is in progress in two ways: as an autonomous process promoted by individual paediatric hospitals/departments and as a guided process in a select group of hospitals, led by the Task Force Hub.
This Final Report presents the implementation process and outcomes of self-evaluation in a select group of 15+2\(^1\) hospitals. Its aims are to:

1. Demonstrate the main lessons learned in relation to the model of the SEMT;
2. Demonstrate the usefulness of the tool as an operative instrument to assess the respect of children's rights in hospital;
3. Present the first results, by means of the good practices identified, with examples of actions for improvements and other considerations.

The first results show that respecting children's rights in hospital may influence positively both the quality of health service provision for children, adolescents, young people and their families, as well as health outcomes.

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\(^1\) A total of 17 hospitals participated in this process, of which 15 have reported or have started to report the results and 2 of which are currently conducting the self-evaluation.
1. THE PROCESS: the pilot-implementation in a select group of paediatric hospitals/departments

1.1 Process Overview

Following the development of the SEMT, Task Force members decided to start a pilot implementation in a select group of hospitals. There was no selection procedure: in six cases the Task Force member works in the hospital where the self-evaluation was carried out; in one case the Task Force member belongs to a non-profit organisation working for children and coordinated the self-evaluation in three hospitals; in one case the Task Force member belongs to a regional governmental body for Public Health and coordinated the self-evaluation in three hospitals; and in one case the Task Force member belongs to the National Institute for Child Health, disseminated the SEMT, which was then implemented in two hospitals independently.

In order to monitor the overall process of self-evaluation, to learn more deeply about practice and, in particular, what emerges in relation to the scientific debate; training; and child participation, 4 Working Groups with specific themes were established within the Task Force, involving all Task Force members, in addition to 8 external participants representing institutions where Task Force members are based and other experts belonging to UNICEF Innocenti Research Centre, UNICEF National Committee for the United Kingdom and the Care Quality Commission, England. The Task Force Hub coordinates Working Group 1 on the overall monitoring process of SEMT implementation, whilst other Task Force members coordinate Working Groups 2, 3 and 4 on scientific debate, capacity building and child participation, respectively. Figure 1 represents the process of SEMT monitoring and implementation.

Between the months of June and October 2009 a select group of 17 hospitals participated in the pilot-implementation of the SEMT.
Figure 2. The process of monitoring and implementation the Self-evaluation Model and Tool on the Respect of Children’s Rights in Hospital

WG1: Monitoring SEMT implementation process
WG 2: Scientific debate
WG 3: Capacity Building
WG 4: Child participation
1.2 Hospital/Departments participating in the implementation process

The paediatric hospitals/departments listed below have participated in the implementation process of the SEMT (For a brief description of each hospital, please see Appendix 1.). The hospitals in bold have concluded the self-evaluation and have prepared a Local Report (See Section 1.3.). The remaining two hospitals are preparing and/or carrying out the self-evaluation at the time of draft of this report. In order to better interpret the results, each hospital was given a letter-code as below, which does not necessarily represent the official acronym, which the hospital may have:

- Medical University of Vienna, Austria (MUV)
- Hospital Sant Joan de Déu Barcelona, Spain (SJDB)
- University Hospital Our Lady of Candelaria, Canary Islands, Spain (HUNSC)
- Mother and Children’s University Hospital of the Canary Islands, Spain (HUMIC)
- Sydney Children’s Hospital, Australia (SCH)
- University Hospital of Canarias, Spain (HUC)
- Heim Pál-Madarász Children's Hospital, Hungary (HPMCH)
- Meyer University Children’s Hospital, Italy (MUCH)
- Caldas da Rainha Hospital, Portugal (HCR)
- Cascais Hospital, Portugal (HC)
- São Francisco Xavier Hospital, Portugal (HSFX)
- Tallinn Children’s Hospital, Estonia (TCH)
- Jávorsky Ödön Town's General Hospital, Hungary (JOTGH)
- "P. & A. KYRIAKOU" Children’s Hospital, Greece (PAKY)
- Alder Hey Children’s NHS Foundation Trust, England, UK (AHCT)
- Akershus university hospital, Lørenskog, Norway (AUH)
- Royal Hospital for Sick Children, Scotland, UK (RHSC)
1.3 Work methodologies

In order to best understand the applicability and potential of the SEMT, a common **Local Report** (See Appendix 2.) was prepared by Working Group 1, to collect the self-evaluation results at local level. It includes a section on general information about the number and type of participants, number of meetings and other; a section on the evaluation results; and a final section on the usefulness of the tool to initiate discussion, raise awareness and improve the respect of children’s rights in hospital. In addition to this, the Local Report aims to:

1. Understand the local results of evaluation of each of the single rights;
2. Demonstrate the different work methodologies adopted;
3. Demonstrate the impact of the self-evaluation process in raising awareness about children’s rights in hospital; and how to involve children and parents in the evaluation of health services;
4. Verify whether the tool is useful in identifying gaps in the respect of children’s rights in hospital and ways to improve them;
5. Identify other lessons learned, which may emerge during the local experiences and that were not previously predicted.

The Local Report proved to be a useful tool to collect results in a common and comparable way. The involvement of international experts was also crucial to make the best out of this experience and to learn to a greater extent possible about work methodologies and concepts.

The Task Force members led most of the self-evaluation processes. The local processes of self-evaluation and the composition of the teams varied quite significantly from context to context: in some cases large multi-disciplinary teams met several times to discuss each right set out in the SEMT; and in other cases smaller groups of health professionals met one or more times. There were also different working methodologies in relation to the involvement and participation of children and parents. Overall, the background of participants included: Task Force member, children, adolescents and caregivers; hospital management and heads of various departments; medical, administrative, health promotion, cultural diversity, patient liaison, play therapists, teachers and other staff; representatives of patients’ and parents’ associations; social services; and other.

In total, **7 different work methodologies** were used, namely joint group discussion; establishment of an ad hoc Steering Committee; Working Groups; one-to-one interviews; discussion between participating hospitals; informal discussions ward by ward; and audits with staff, children, young people and carers. Regarding their effectiveness, the self-evaluations seem to suggest that a mixture is what works best. Regarding the participation of children and young people, a mixture of one-to-one interviews for younger children and focus groups for older children and young people facilitated by experienced professionals may be the best combination to use in similar processes.

The following chart illustrates the methodologies used per single hospital/department, including information on the process leader, number and type of participants, number of meetings held and information on the local work methodologies.
### Summary Chart 1. General information on self-evaluation process and work methodologies

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Process Leader</th>
<th>Number of participants</th>
<th>Type of participant</th>
<th>Number of meetings</th>
<th>Work methodology</th>
</tr>
</thead>
<tbody>
<tr>
<td>SJDB</td>
<td>Hospital Management</td>
<td>14</td>
<td>TF member, head of planning and quality unit, patients' associations, play therapists, other</td>
<td>4</td>
<td>Joint group discussion</td>
</tr>
<tr>
<td>MUV</td>
<td>TF member</td>
<td>5</td>
<td>Nurse, psychologist</td>
<td>2</td>
<td>Joint group discussion</td>
</tr>
<tr>
<td>HUNSC</td>
<td>TF member</td>
<td>18</td>
<td>Head of paediatrics, nurses, 2nd and 3rd year trainee doctors, teacher, social worker, children</td>
<td>3</td>
<td>Joint group discussion</td>
</tr>
<tr>
<td>HUMIC</td>
<td>TF member</td>
<td>21</td>
<td>Head of paediatrics, head of paediatric surgery, nurse, parents, children, social work, teacher, admissions, other</td>
<td>3</td>
<td>Joint group discussion</td>
</tr>
<tr>
<td>SCH</td>
<td>Hospital Management</td>
<td>40+</td>
<td>Chief doctor, Chief nurse, patient friend, play therapy, clinicians, cultural diversity, health promotion, other</td>
<td>5+</td>
<td>Steering Committee + Working Groups</td>
</tr>
<tr>
<td>HUC</td>
<td>TF member</td>
<td>7</td>
<td>Chief doctor, paediatrician, patients' association, chief doctor, teacher, social worker, other</td>
<td>3</td>
<td>Joint group discussion</td>
</tr>
<tr>
<td>HPMCH</td>
<td>Hospital Management</td>
<td>5</td>
<td>Chief doctor, kindergarten teacher, patients' rights advocate and health visitor</td>
<td>2</td>
<td>Joint group discussion</td>
</tr>
<tr>
<td>MUCH</td>
<td>TF Hub</td>
<td>14</td>
<td>Representatives of patients' association, health promotion staff and children;</td>
<td>1+*</td>
<td>Working Group + one-on-one</td>
</tr>
<tr>
<td>TCH</td>
<td>TF member</td>
<td>23</td>
<td>Committee on ethics, pedagogical staff and health promotion staff</td>
<td>3</td>
<td>Joint group discussion</td>
</tr>
<tr>
<td>JOTGH</td>
<td>Medical Doctor</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>HCR</td>
<td>Head, Paediatrics</td>
<td>5</td>
<td>Head of Paediatric department, chief nurse, administrator, head of the social service and patient liaison office</td>
<td>11**</td>
<td>Discussion within and between the 3 hospitals</td>
</tr>
<tr>
<td>HSFX</td>
<td>Head, Paediatrics</td>
<td>5</td>
<td>Head of the Paediatric department, paediatricians and nurses</td>
<td>11**</td>
<td></td>
</tr>
<tr>
<td>HC</td>
<td>Head, Paediatrics</td>
<td>5</td>
<td>Head of Paediatrics, paediatricians, nurses, social worker and psychologist</td>
<td>11**</td>
<td></td>
</tr>
<tr>
<td>PAKY</td>
<td>TF Member</td>
<td>12</td>
<td>Heads of 7 Departments, chief nurse, administrative officer, Parent's Association of children with Oncology diseases, ex-Paediatric Oncology Patient's Association.</td>
<td>***</td>
<td>Informal discussion ward by ward</td>
</tr>
<tr>
<td>AHCT</td>
<td>Patient experience team</td>
<td>Multiple</td>
<td>Patient experience team, children, parents and caregivers, head of department, chief nurse</td>
<td>Multiple</td>
<td>Audits with staff, children, young people and carers</td>
</tr>
</tbody>
</table>
*One group session, in addition to five one-on-one discussion with children aged 6-12.

**The participants involved in the process in Portugal met a total of 11 times: some meetings took place between the internal staff and in other meetings, all participants of the 3 hospitals, in addition to the Task Force Member in Portugal and other external participants (including one meeting attended by one Task Force Hub member).

***The participants involved in the process in Athens did not meet all together. Every participant expressed his own perception after meeting the staff of his/her department. The Task Force representative combined all the opinions to reflect the general situation concerning Children’s Rights.
1.4 Lessons learned about the implementation process of the Self-evaluation Model and Tool

Is the Self-evaluation Model and Tool a useful mechanism to...

... assess the respect of children's rights in hospital?

Overall, it is very positive to see the first impact of the implementation SEMT: globally, the Tool was assessed as a useful mechanism to initiate discussion and evaluate children's rights in hospital and to plan actions for improvement. Specifically, it is possible to observe that assessing the respect of children's rights by means of a self-evaluation carried out with the participation of hospital staff, children, parents and other stakeholders can identify both the strong points of the hospital performance, as well as the existing gaps. The strongest point demonstrating why the self-evaluation Model and Tool can be a good mechanism to assess children's rights in hospital is possibly in using discussion and focus groups to assess the respect. This seems to be particularly true when Hospital Management leads or strongly supports the process; when multidisciplinary teams are involved; when a significant number of people participate and, very importantly, when there is the participation of children and their parents/family, for they are able to report first-hand experience. Such a composition of teams allows for a deeper discussion and interpretation of each of the rights and the identification of a wider range of solutions to improve the existing gaps. The self-evaluations also demonstrate that solutions may already exist within the hospital's human and technical resources. Involving a significant number of stakeholders in the evaluation also means raising awareness of children's rights in hospital with, firstly, greater number of professionals, who in turn are likely to discuss further with other colleagues. The same goes for children, parents and families, as well as patients' associations and other relevant stakeholders. One other aspect, which participants stated as very valuable, is that the good practices identified by the single hospitals/departments may be shared, transferred and applied in other contexts.

... improve the respect of children's rights in hospital?

The awareness raising process may also very well be a first step into improving the respect of children's rights in hospital: firstly, some self-evaluations found that although participants had no prior knowledge about children's rights in hospital, they were pleased to verify how many aspects were already being considered in health service provision. Secondly, as several self-evaluations demonstrate, especially where there is a strong motivation, it is very likely that actions for improvement are identified within the discussions; and also, that some improvement actions and resources (both human and financial) may already be available within the hospital. Involving participants in a larger number and from a greater variety of backgrounds as possible has the potential to put forward a greater amount of improvement options. Children and young people who are experiencing or have experienced hospitalisation have a most valuable knowledge about how children are treated, how their views are taken into consideration, whether they feel protected or informed, empowered and dignified. For this reason, they have to be a key player in self-evaluating, but also in proposing actions for improvement, as well as monitoring the implementation of the actions. Older children (either adolescents or young people) can be involved directly in the focus groups with hospital staff or on their own, as they are able to follow 'adult'
discussion and language. For younger children, it is important to adequately take into account their age and maturity, but the present experiences show that they too not only can participate, but have a meaningful contribution to give. Again, the effective leadership or support of Hospital Management is key to the implementation of action for improvement, based on the self-evaluation findings. In the local self-evaluations, where Hospital Management has not been involved, it is evident that the staff are discouraged from participating and that decisions are most likely impossible to be taken without that crucial support.

... monitor and evaluate the respect of children’s rights in hospital?

It is early to say whether the SEMT can be an effective mechanism to monitor the improvement of the respect of children’s rights in hospital. However, it is possible to draw some realistic expectations. The discussions carried out can serve as a departure for putting in place a monitoring and evaluation mechanism on the respect of children’s rights in hospital. On one hand, the Tool enables participants to record the main points of the discussion, to suggest standards and future actions for improvement. A year after the first actions have been carried out, a new discussion can take place with a relevant group of stakeholders to evaluate progress, against the previous evaluation and, in particular, the previously identified gaps. Hospital management may choose to include the Self-evaluation Model and Tool in Quality Management or another unit with the responsibility to monitor the quality of health service provision; or to constitute a focal point/structure to continuously work on the improvement of the respect of children’s rights in hospital.
1.5. A note on child participation

1.5.1. Considerations about the involvement of children, adolescents, young people and their families in the provision of health services

The discourse of children’s rights in hospital is a legal one, enforced by both the ratification of the Convention on the Rights of the Child (CRC, 1989) and the national legal implications of that ratification process. Article 12 of the CRC reads: States Parties shall assure to the child who is capable of forming his or her 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. The right to information is a prerequisite of Article 12. In line with this, the SEMT identified the right to information and the right to participation as two key areas to assess at hospital level. In addition to the legal discourse, progressively in scientific literature, there is growing evidence of the impact of the respect of Article 12, in particular the health outcomes for children during hospitalisation. Existing consultations with children in hospital show that children want to be consulted and involved in decisions affecting their healthcare and to be respected in relation to their views. Coyne (2006) in a consultation with children found that they:

“(…) spoke about needing information so that they could understand their illness; be involved in their care, prepare themselves for procedures and direct their actions towards ‘getting well again’. (...) It appeared that when children were provided with information and consulted about their care, they felt happy, reassured and treated as a person with rights. They consequently felt prepared and less anxious about undergoing operations and treatment.”

In the same consultation, evidence also emerged about the perception of children in relation to the provision of health services, as children perceived the lack of information and consultation as normal (they were ‘used to it’) and as the businesslike approach that nurses adopted. Alderson and Montgomery (2001) define 4 levels of participation for children: 1) being informed, 2) expressing an opinion, 3) influencing a decision, 4) being the person that decides. All levels represent important methods of participation and the first three lead to the realisation of the fourth. A genuine participation requires that children and adolescents are well-informed in relation to their age and maturity and by taking into account the specific ‘activity’ to which they are participating. For instance, in hospital children should be informed about who is responsible to inform them about what is happening, what are the treatment implications, as well as the effects, the implications of not being treated, whether treatment hurts and how long it may take.

1.5.2. Findings from the self-evaluations

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2 Coyne I (2006); Consultation with children in hospital: children, parents’ and nurses’ perspectives; Journal of Clinical Nursing 15,61–71
Children were directly involved in four self-evaluations, one of which is ongoing, through different methodologies: by participating in the joint discussion (HUMIC, HUNSC), through one-to-one interviews (MUCH) and through a mixed methodology using audits and focus groups with children (AHCT). At MUCH, initially a self-assessment methodology was prepared inspired by the draft self-assessment tools for child friendly cities developed within the Child Friendly Cities Research Initiative, managed by UNICEF Innocenti Research Centre in partnership with Childwatch International, under the coordination of Children’s Environments Research Group (CERG) and with the involvement of the Bernard Van Leer Foundation. The methodology should have been applied by means of three Focus Groups (FG), namely 1) Parents of children aged 0-5; 2) Children aged 6 - 12; and 3) Children aged 13 - 17. However, after several discussions between the Task Force Leaders, Playroom Coordinator and Play Therapists, it was decided that a Focus Group with hospitalised children would not have produced the expected outcomes. For this reason, one FG was carried out with Parents’ Associations in Hospital and the Play Therapists conducted one-to-one interviews with 5 children.

In line with what has been said above, the self-evaluations allow us to make some conclusions about the importance of hearing and involving children in all matters affecting their healthcare and the state of the art of child participation in the hospital setting. The 5 interviews conducted with young children at MUCH show that mostly children either feel that they are not informed or that when doctors/nurses attempt to explain what is happening, they do not understand what is being said. Additionally, the 5 children consulted at HUMIC declared that this right was Slightly Considered. Regarding the right to participation, the children involved in the HUMIC self-evaluation “tend to consider that such right is not taken into consideration, as they are not consulted during their illness process”. The 5 children consulted at MUCH were given the statement ‘The doctor/nurse let’s me explain how I feel and what I want’, to which their answers were all positive. However, there is an obvious limitation of this specific evaluation as it reflects only “their right to participate in their treatment and not in any policy-level decisions (i.e. structure, layout and display of services, wards, architecture, etc)” (for the results of the opinions given by children, please consult the relevant Summary Charts).

1.5.3. Good practice: Self-evaluation at the Alder Hey Children’s NHS Foundation Trust

As mentioned in the paragraph above, the self-evaluation process at Alder Hey Children’s NHS Foundation Trust (AHCT) is ongoing, however the work methodology adopted by the team involved in the process is undoubtedly a good practice that has emerged in the global self-evaluation processes. As seen in Figure 2 below, the team at AHCT is applying the following methodology: at a first stage the institution and staff on one hand, and children, young people and parents on the other hand do an initial scoring of the 12 rights; then an audit is carried out in order to assess the perceptions of staff, children, young people and carers – the audit tools were prepared for staff, children, young people and carers based on the considerations under each of the 12 rights identified in the SEMT (See Appendix 4); after this, institutional/staff meetings, on one hand and children, young people and parents, on the other, meet to assess the existing gap of respect. Children and young people will be key participants throughout the entire process. At the end of this first phase, children and young people will produce a self-evaluation toolkit for children and young people, based on the SEMT and on their self-evaluation experience (See Appendix 5). The results emerging from this self-evaluation process will be important to further understand how can the SEMT be applied to the best extent possible.
Figure 3. Representation of the methodology/self-evaluation process used at Alder Hey Children’s NHS Foundation Trust

Rights 1-12

INSTITUTION/STAFF

SCORE → AUDIT → MEET → GAP

CHILDREN & YP/PARENTS

MEET → AUDIT → SCORE

ANALYSIS

FINDINGS

OUTCOME/CHANGE

RE-SCORE

SELF-EVALUATION TOOLKIT (INSTITUTION)

VALIDATION BY CHILDREN AND YOUNG PEOPLE

SELF-EVALUATION TOOLKIT (C&YP)

Investing in Children (IiC)/Development Agency/Alder Hey/minutes/7th Task Force Workshop, Budapest, 16th Nov 2009
2. THE OUTCOMES: Findings and comments

2.1 Part I: Status of children’s rights in hospital

This section will present, firstly, the findings on the adoption and status of implementation of a Charter on Children’s Rights in Hospital. Secondly, it presents emerging findings related to the issue of children’s rights in hospital. The aim of the section is to demonstrate to which extent children’s rights are already being applied and how.

2.1.1. Status regarding a Charter on Children’s Rights in Hospital

Summary Chart 2 presents the status of adoption of a Charter on Children’s rights in Hospital and its availability for children and parents in hospital. In order to understand how it was made available, the Local Report enquired if the Charter is accessible in print and displayed in all wards/services, as well as the percentage of accessibility. The fourth column presents further information on the status of adoption and implementation of a Charter.

As it is possible to see in Summary Chart 2, below, 8 out of the 14 hospitals that have carried out the self-evaluation have adopted a Charter on Children's Rights in Hospital and in 1 hospital (HUNSC) a Charter has not been adopter, however there has been informal work, including the display on a given charter at times. Following the self-evaluation, SCH has decided to adopt a Charter on Children’s Rights in Hospital. It is important to note though, that despite having adopted a Charter on Children’s Rights in Hospital, only one hospital stated that the charter is displayed in all hospital wards (SJDB). It is also important to reflect upon why the Charter is adopted, but not displayed nor given to the children or parents in print.

Other significant information regarding the Charter includes: in 1 hospital there is regular evaluation of the Charter’s implementation and complementing actions, such as conference centred on various issues related to children’s rights in hospital (SJDB); in 1 case the Charter is part of the Quality Management Report (MUV); and in 1 case children’s rights are included in the hospital’s Code of Ethics (TCH). This type of activity ensures the sustainability of hospital programmes on children’s rights, as well as an accountability system within the hospital.
### Summary Chart 2. Status of adoption and implementation of a Charter of Children’s rights in hospital

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Has a Charter on Children’s Rights been adopted?</th>
<th>Is the charter displayed?</th>
<th>Other relevant information</th>
</tr>
</thead>
<tbody>
<tr>
<td>SJDB</td>
<td>Yes</td>
<td>Yes, in all wards</td>
<td>Regular evaluation of the Charter’s implementation and complementing actions (i.e. thematic conferences)</td>
</tr>
<tr>
<td>MUV</td>
<td>Yes</td>
<td>Yes, in approximately 50% of wards</td>
<td>The Charter is part of Quality Management Report</td>
</tr>
<tr>
<td>HUNSC</td>
<td>Not officially, but there has been informal work</td>
<td>Yes, at times a given charter has been displayed</td>
<td>-</td>
</tr>
<tr>
<td>HUMIC</td>
<td>No</td>
<td>Not applicable</td>
<td>-</td>
</tr>
<tr>
<td>SCH</td>
<td>Key action following the self-evaluation</td>
<td>Once adopted, this is planned</td>
<td>Planned establishment of children’s forums</td>
</tr>
<tr>
<td>HUC</td>
<td>No</td>
<td>Yes, at times a given charter has been displayed</td>
<td>-</td>
</tr>
<tr>
<td>HPMCH</td>
<td>No</td>
<td>Not applicable</td>
<td>Participants recognised the importance of this action</td>
</tr>
<tr>
<td>MUCH</td>
<td>Yes</td>
<td>No</td>
<td>Child-friendly version of the SEMT was used</td>
</tr>
<tr>
<td>TCH</td>
<td>Yes</td>
<td>No</td>
<td>Related materials are available through leaflets and the hospital website. Children’s rights are included in the hospital’s Code of Ethics</td>
</tr>
<tr>
<td>JOTGH</td>
<td>Yes</td>
<td>No</td>
<td>-</td>
</tr>
<tr>
<td>HCR</td>
<td>Yes</td>
<td>Yes, in approx. 75% of wards</td>
<td>-</td>
</tr>
<tr>
<td>HSFX</td>
<td>Yes</td>
<td>Yes, in approx. 10% of wards</td>
<td>-</td>
</tr>
<tr>
<td>HC</td>
<td>Yes</td>
<td>Yes, in approx. 50% of wards</td>
<td>-</td>
</tr>
<tr>
<td>PAKY</td>
<td>In course</td>
<td>Not applicable</td>
<td>Planned distribution and awareness raising</td>
</tr>
<tr>
<td>AHCT</td>
<td>No</td>
<td>Not applicable</td>
<td>The hospital carries out regular work on child participation</td>
</tr>
</tbody>
</table>
2.1.2. Self-evaluation findings: good practices and actions for improvement related to children’s rights in hospital

The Charter on Children’s Rights in Hospital is one example of an action of a political and/or advocacy nature that has enabled hospitals to introduce the issue of children’s rights to both health staff, children and their families. However, there are other types of activities, which may lead to awareness raising of health staff in relation to this issue; and that provides them with the necessary skills to effectively respect children’s rights during all phases of healthcare provision. Summary Chart 3 sums-up the good practices reported in individual hospitals; examples of actions that were suggested for improvement in the hospitals; and further considerations and comments, which contribute to understanding what addressing children’s rights in hospital entails; and other key inputs gathered in the analysis of the Local Reports.

**Good practices:** One hospital stated that children’s rights are part of the curriculum of the School of Nursing (MUV); one hospital organises regular National Conferences on Children’s Rights in Hospital (SJDB) and two hospitals have adopted a Welcome Guide for parents, which includes general information about the paediatric services, such as opening times, but also very practical information about the availability of meals for parents and caregivers; how to make suggestions and complaints to the hospital; what type of health staff will be taking care of the child; and other (HCR, HSFX). The two first examples are very close, as they offer learning opportunities for health staff in training about children’s rights. The conferences have the benefit of attracting a range of stakeholders beyond paediatricians and nurses; to provide training of special themes; as well as by providing a platform for exchange of practices between hospitals and health professionals. The Welcome Guide was possibly the most significant information vehicle for parents described in the Local Reports. In the HSFX the Welcome Guide is given and explained to parents by nurses. Although informing parents verbally is a fundamental duty of health professionals, due to the stress caused by a child’s illness, there is a great probability that parents forget key information related to the stay of their child in hospital. If in written form, parents can refer to the Welcome Guide at any time. Furthermore, respecting children’s rights in hospital means “delivering a patient-centred care, which recognises not only the child patient’s individuality and diverse circumstances/needs, but also those of their families/carers” (SCH).

**Examples of actions for improvement:** Enhancing and expanding the collaboration with patients’ associations and the community was the action suggested for improvement given most times (at least 6 hospitals); 2 hospitals mentioned the implementation of patient satisfaction surveys and complaints’ procedures; 2 hospitals mentioned the preparation of a child-friendly version of the Charter on Children’s Rights and 2 hospitals suggested carrying out awareness raising activities for all stakeholders, including health staff, children and families. Other examples mentioned refer to the effective delivery of service, namely ensuring that policies are carried out by health staff and that hospital assessments are reported to relevant local and regional administrative institutions.

**Further inputs and considerations for future developments:** The issue of vulnerability and that of access of adolescents and young people to friendly services, including mental health and sexual education emerged in very few Local Reports, which must be taken into account on future self-evaluations and updates of the SEMT.
### Summary Chart 3. Emerging findings related to the issue of children’s rights in hospital

<table>
<thead>
<tr>
<th>Examples of reported Good Practices</th>
<th>Examples of actions for improvement</th>
<th>Further inputs and considerations for future developments</th>
</tr>
</thead>
</table>
| • Children’s rights are part of the curriculum of the School of Nursing (MUV);  
  • Organisation of National Conferences of Children’s Rights in Hospital (SJDB);  
  • The hospital has a Welcome Guide for parents about hospital services available (HCR, HSFX);  
  • “Delivering a patient-centred care, which recognises not only the child patient’s individuality and diverse circumstances/needs, but also those of their families/carers” (SCH);  
  • Access of adolescences to friendly services, including mental health (PAKY). | • Raise awareness of all stakeholders (TCH, HUNSC);  
  • Overcome the ‘person-dependent’ respect of children’s rights (MUV);  
  • Enhance and expand the collaboration with patients’ associations and the community (HUC, HPMCH, SCH, HUNSC, HCR, HUMIC);  
  • Children’s views: “We believe that it would be necessary to adequately select and prepare the staff dealing with children in the human dimension” (HUMIC);  
  • Carry out patient satisfaction surveys and set up complaints’ procedures (HUNSC, HCR);  
  • Set up ‘external commissions’ to evaluate the various Paediatrics’ Services and report to local and regional administrative institutions (HCR);  
  • Ensure that every child/parent/caregiver is welcomed, given a visit of the ward, information about rights and hospital policies and distribution of the Welcome Guide (HCR);  
  • Assess and improve departments individually and continuously (MUCH);  
  • Prepare a child-friendly version of the Charter on Children’s Rights (HCR, HC);  
  • Adopt, disseminate and make a Charter on Children’s Rights available (HUC, PAKY). | • A patient/child/family-centred care contributes to the fulfilment of children’s rights in hospital;  
  • Promoting and enhancing dialogue between all stakeholders (hospital as an institution, health staff, children, parents, associations, community, etc) is key to a child and family centred care;  
  • Access of adolescents and young people to friendly services, including mental health and sexual education should be further explored in future developments;  
  • Little information emerges from the Local Reports on the rights of children with disabilities or other vulnerable children;  
  • Take into account recent past achievements and build on those successes (HUNSC) – this may be a useful suggestion in the respect of all rights. |
2.2 Part II: Overall results of the implementation of the Self-evaluation Model and Tool in the participating hospitals

2.2.1. Overall evaluation, per single right and individual hospital

Following the analysis of each of the individual Local Reports, it is possible to provide an overall picture of the self-evaluation results in the 14 hospitals. Summary Chart 4 summarises the self-assessment per single right and individual hospital. The Chart has different colours, that correspond to each item of the rating scale, as follows:

<table>
<thead>
<tr>
<th>Colour</th>
<th>Rating Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Green</td>
<td><strong>SA – Significantly achieved</strong>(^5)</td>
</tr>
<tr>
<td>Light Green</td>
<td><strong>MP – Meaningful Progress</strong>(^6)</td>
</tr>
<tr>
<td>Orange</td>
<td><strong>SC – Slightly Considered</strong>(^7)</td>
</tr>
<tr>
<td>Red</td>
<td><strong>CU – Completely Unconsidered</strong>(^8)</td>
</tr>
</tbody>
</table>

On first observation it is apparent that the most frequent and representative findings are those expressed as ‘Significantly Achieved’ and ‘Meaningful Progress’, this is particularly the case for Area 3 (right to protection from all forms of violence). Area 1 (right to the highest attainable standard of healthcare) is the one with most mixed results, whilst Area 2 (right to information and participation in all decisions involving their healthcare) is the one with lowest scores. The analysis of the Local Reports enables us to go further into this analysis: Area 3 is indeed the area that is most covered by policy, practice and monitoring – every hospital has in place specific regulations protecting children from violence; follow-up mechanisms; collaborative protocols with social work and other child protection services at community level; ethical committees; and monitoring of events. Area 2, in particular the right to participation with 6 hospitals reporting ‘Meaningful Progress’, 6 hospitals reporting ‘Slightly Considered’, 1 hospital reporting ‘Significantly Achieved’ and 1 hospital reporting ‘Completely Unconsidered’ is clearly the most challenging right in service provision.

\(^5\) **Significantly Achieved**: Recognition of the right is integral to hospital/ward activities. All staff recognize its importance and are committed to its promotion. There is an effort for continuous improvement.

\(^6\) **Meaningful Progress**: We have made significant progress towards addressing this right. The methods are now evaluated and mature and we increasingly look for further development and adaptation. This is increasingly seen by staff as ‘part of the job’. The activities in this area are usually, though not always integrated.

\(^7\) **Slightly considered**: The need is recognised but there has been little or no action yet. There are not yet examples of consideration for this right, but an approach is being developed; or there are isolated examples of this right being addressed.

\(^8\) **Completely unconsidered**: There are few, if any, examples that show that this right is being considered and that work is being done in order to implement it.
**Summary Chart 4. Overall evaluations, per single right and individual hospital**

<table>
<thead>
<tr>
<th></th>
<th>R 1.1</th>
<th>R 1.2</th>
<th>R 1.3</th>
<th>R 1.4</th>
<th>R 2.1</th>
<th>R 2.2</th>
<th>R 3.1</th>
<th>R 3.2</th>
<th>R 3.3</th>
<th>R 3.4</th>
<th>R 3.5</th>
<th>R 3.6</th>
</tr>
</thead>
<tbody>
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<td>MP</td>
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<td>MP</td>
<td>MP</td>
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<td>SA</td>
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<td>MUV</td>
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<td>SC</td>
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<td>SC</td>
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<td>SC</td>
<td>MP</td>
<td>SA</td>
<td>SC</td>
<td>SA</td>
<td>MP</td>
</tr>
<tr>
<td>PKY***</td>
<td>SC/CU</td>
<td>SC/CU</td>
<td>CU</td>
<td>MP</td>
<td>SC/CU</td>
<td>CU</td>
<td>SC/CU</td>
<td>SA</td>
<td>SC/CU</td>
<td>SC/CU</td>
<td>MP</td>
<td>SA</td>
</tr>
<tr>
<td>AHCT****</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

**Total Evaluations**

- **Overall**: 9 = MP
- **4 = SC
- **5 = MP
- **1 = SA
- **2 = SC
- **1 = CU

*There have been no child deaths in the hospital.

**The hospital does not carry out clinical research.

***The self-evaluation was carried out in several wards and the results integrated, for this reason often there are 2 final evaluations.

****The process at AHCT is ongoing, for this reason not all results are available.
2.2.2. Good practices and actions for improvement, per area and single right

This section of the Final Report describes specific examples of good practices, actions for improvement and other considerations for future developments, which emerged during the self-evaluations and were reported in the Local Reports.
## AREA 1. Right to the highest attainable standard of health care.

### Summary Chart 5. Right 1.1. Children’s health care provision should take into consideration all dimensions of health, including physical, mental, social, cultural and spiritual: inputs from the self-evaluation teams

<table>
<thead>
<tr>
<th>Examples of Good Practices</th>
<th>Examples of actions for improvement</th>
<th>Further inputs and considerations for future developments</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Consistent clinical practice and education philosophy, supported by research and quality improvement projects, all collaborating to deliver a comprehensive approach to care” (SCH);</td>
<td>Enhanced training for staff on how to evaluate all health dimensions (SJDB) and how to adequately fill in a Medical Chart that includes all health dimensions (HUMIC, HUNSC);</td>
<td>Clarification/definition of what each of the dimensions of health mean;</td>
</tr>
<tr>
<td>“Care provided for children incorporate all health dimensions, which is guaranteed by a multidisciplinary team” (HC);</td>
<td>Include the ‘education situation’ of children in the Medical Record (HUMIC, HUC) and the educational activities carried out during their hospitalisation (HUNSC);</td>
<td>Awareness raising on the importance of including and assessing all the dimensions of health in the provision of healthcare;</td>
</tr>
<tr>
<td>Collaboration with community-based NGOs, which provide psychological and health behavioural counselling, including sexual health (TCH);</td>
<td>Create a space in the Medical Record, to incorporate the cultural and spiritual dimensions of health (HSFX, HCR, HC);</td>
<td>“There was much concern in the discussion about patients’ clinical records containing a specific space to record information of the physical, mental, social, cultural and the spiritual dimensions of health. This is often information, which is too confident for patient records” (MUV);</td>
</tr>
<tr>
<td>Regional Public Health Service provides psychological assistance to patients admitted to the hospital and after their discharge (HUC, HUNSC);</td>
<td>Enhance and expand the collaboration with patients’ associations and the community in general (HUC, HPMCH, SCH, HUNSC, HCR);</td>
<td>In some countries, psychological support is offered at the community level by other governmental services, i.e. in Hungary they are provided by the Social Welfare Services and in Portugal by the Local Network of Primary Care Services (Health Centres).</td>
</tr>
<tr>
<td>Psychology Unit available to children and adolescents (HCR, HUMIC, PAKY);</td>
<td>Carry out patient satisfaction surveys upon discharge (HUNSC);</td>
<td></td>
</tr>
<tr>
<td>Spiritual support is guaranteed by the hospital (HCR, HC);</td>
<td>Set up a Unit for Psychological/ Psychiatry Support within hospitals for hospitalised children and their families (MUCH, PAKY), as well as to any other child/adolescent in the community (MUV).</td>
<td></td>
</tr>
<tr>
<td>The ‘Medical History’ includes most or all dimensions of health, except for the spiritual component (HUMIC, HUC, JOTGH).</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Summary Chart 6. Right 1.1. Children’s health care provision should take into consideration all dimensions of health, including physical, mental, social, cultural and spiritual: Children's views and evaluation

<table>
<thead>
<tr>
<th>Examples of reported Good Practices</th>
<th>Examples of actions for improvement</th>
<th>Further inputs and considerations for future developments</th>
</tr>
</thead>
</table>
| MUCH: The statements presented to young children for the consideration of this right were: 'I feel good in hospital. I feel well cared for in hospital'. Children’s comments were as follows:  
- “I don’t know, I think a little... according to my mum here they don’t treat properly, but if in Africa there were all these things, everyone would heal” (aged 7);  
- “Quite” (aged 9);  
- “I feel very good and very well cared for” (aged 6);  
- “In the beginning I was afraid, now for me it’s like a second home. I feel well cared for” (aged 10);  
- “Yes, sometimes” (aged 9). | Nothing to report | Nothing to report |
Summary Chart 7. Right 1.2. Children have the right to access health services without ethnic, racial, class, religious, gender, age, sexual orientation, disability, language, cultural and social discrimination: inputs from the self-evaluation teams

<table>
<thead>
<tr>
<th>Examples of reported Good Practices</th>
<th>Examples of actions for improvement</th>
<th>Further inputs and considerations for future developments</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Delivering a patient-centred care, which recognises not only the child patient’s individuality and diverse circumstances/needs, but also those of their families/carers” (SCH);</td>
<td>Make staff aware of the existing and available protocols, i.e. translation system (HUMIC, HUC);</td>
<td>A patient/child/family-centred care contributes to the fulfilment of this, but also all rights, in general;</td>
</tr>
<tr>
<td>Cultural mediators are guaranteed by the hospital and/or associations (MUCH, HSFX, HUMIC, JOTGH);</td>
<td>Prepare or enhance continuous cultural competence training for staff (HUMIC, HPMCH, SCH, HUC, HUNSC, MUCH, SJDB, HSFX, HCR, HC);</td>
<td>Expand on the meaning of accessibility;</td>
</tr>
<tr>
<td>Translation system available in multiple languages (HUMIC);</td>
<td>Understanding culture-specific parenting beliefs and expectations (SCH);</td>
<td>Develop ways of assessing the services provided and of asking children and young people whether there has been discrimination of any kind;</td>
</tr>
<tr>
<td>An English teacher is available for Resident doctors (HUMIC);</td>
<td>Guarantee competent interpreters and/or cultural mediators (HUC, HC);</td>
<td>Cultural competency courses should possibly have a greater focus on how to ‘welcome, treat and communicate’ with patients and families from other cultures, rather than ‘country-specific’ training;</td>
</tr>
<tr>
<td>Language and Sign Language translation services are guaranteed by the hospital (HPMCH);</td>
<td>Involvement of Hospital Management in order to improve the respect of this right (HUC, HUNSC, PAKY);</td>
<td>Access of adolescents and young people to friendly services, including mental health and sexual education should be further explored in future developments;</td>
</tr>
<tr>
<td>The hospital is a barrier free environment (HPMCH);</td>
<td>Development of Health Promotion Programmes (HPMCH);</td>
<td>Little information emerges from the Local Reports on the rights of children with disabilities;</td>
</tr>
<tr>
<td>Associations promote events to raise cultural awareness to hospital staff (HUC);</td>
<td>Provide training in conflict mediation (HPMCH).</td>
<td>Inform the Government about the need of changes in the Hospital Status, in order to improve the care of immigrants (e.g. part-time translators as hospital staff) (PAKY).</td>
</tr>
<tr>
<td>Cultural competence training is part of professional training and seen as part of a family-centred care (TCH).</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Summary Chart 8. Right 1.2. Children have the right to access health services without ethnic, racial, class, religious, gender, age, sexual orientation, disability, language, cultural and social discrimination: Children’s views and evaluation

<table>
<thead>
<tr>
<th>Examples of reported Good Practices</th>
<th>Examples of actions for improvement</th>
<th>Further inputs and considerations for future developments</th>
</tr>
</thead>
<tbody>
<tr>
<td>• “Adolescents have a different perception and they comment that they have always been provided healthcare without any discrimination” (HUMIC).</td>
<td>Nothing to report</td>
<td>• <strong>Note:</strong> “For this right, children were not presented any statements, due to a difficulty in formulating a statement that would be understandable by them and whose assessment would be relevant to understand to which extent this right is respected” (MUCH).</td>
</tr>
</tbody>
</table>
Summary Chart 9. Right 1.3. Children shall be admitted to hospital only if the care they require cannot be equally well provided and effective at home or on a day basis: inputs from the self-evaluation teams

<table>
<thead>
<tr>
<th>Examples of reported Good Practices</th>
<th>Examples of actions for improvement</th>
<th>Further inputs and considerations for future developments</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Protocols between the hospital and community services are in place to ensure the respect of this right (MUCH, HUC, SCH, HSFX);</td>
<td>• Enhance the collaboration with the Primary Care Nursing Services (SJDB), as well as with other resources identified elsewhere in the system (SCH);</td>
<td>• Patients preference of hospitalisation was pointed out in one Local Report (SJDB);</td>
</tr>
<tr>
<td>• Team of ‘home attention’ favours early discharge in premature babies (SJDB);</td>
<td>• To extend ‘Home Hospitalisation’ service to a wider territorial area (HUNSC);</td>
<td>• In item 1 of the self-evaluation tool the word ‘inadequate’ hospitalisation should probably be ‘inappropriate’ or ‘avoidable’ (SCH);</td>
</tr>
<tr>
<td>• Team of ‘home attention’ in Palliative Care (SJDB);</td>
<td>• Design of appropriate monitoring, evaluation and survey instruments (SCH, TCH, HCR, HC);</td>
<td>• “Although there is no monitoring system, prolonged hospitalisations are discussed in ‘clinic sessions’” (regular meetings between the health professionals) (HSFX);</td>
</tr>
<tr>
<td>• Existence of a specific ‘Home Hospitalisation’ Service (HADO), which is particularly important for children with chronic diseases (HUNSC);</td>
<td>• Establish a “Home care” team/services for terminally ill children (PAKY);</td>
<td>• Lack of sufficient human resources to provide home care in paediatrics and neonatal care (HCR);</td>
</tr>
<tr>
<td>• “There is increasing emphasis on health promotion, prevention of illness and education to both professional and consumer target audiences” (SCH);</td>
<td>• Evaluate the respect of this right adequately on a annual basis and report the results to health professionals (HUMIC).</td>
<td>• Some children are admitted for economic reasons and social reasons (MUV, HC);</td>
</tr>
<tr>
<td>• Existence of home services providing continuous care to low birth weight newborns (HUMIC);</td>
<td></td>
<td>• Lack of “Primary Health Care” within the National Health System often makes it impossible to prevent hospitalisation (PAKY).</td>
</tr>
<tr>
<td>• Existence of “home care” team for oncology paediatric patients in order to reduce hospital admissions (PAKY);</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Good coordination between Primary and Hospital Care (HUMIC).</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Summary Chart 10. Right 1.3. Children shall be admitted to hospital only if the care they require cannot be equally well provided and effective at home or on a day basis: Children’s views and evaluation**

<table>
<thead>
<tr>
<th>Examples of reported Good Practices</th>
<th>Examples of actions for improvement</th>
<th>Further inputs and considerations for future developments</th>
</tr>
</thead>
</table>
| **MUCH**: The statements presented to young children for the consideration of this right were: ‘The doctor visited me at home when I was ill, before I came to the hospital’. Children’s comments were as follows:  
  - “Yes” (aged 7 and 9);  
  - For the 6 years old participant, the play specialist stated: “The child is followed by the Family Doctor in case of illness that is not associated with the main pathology. The child is followed continuously in the hospital and the mother provides the link between the paediatrician and the hospital”;  
  - “I call the Family Doctor when I have the flu. Sometimes the Doctor also comes to visit us and see how I am doing. The Doctor is very kind.” (aged 10);  
  - “I never needed to be treated at home.” (aged 9);  
  - “It must be pointed out that the perception of children is very positive in relation to this right, since they analyse and very much value the fact of not having to stay in the hospital, and this is enough for them” (HUMIC). | Nothing to report | Nothing to report |
**Summary Chart 11. Right 1.4. Children have the right to have full opportunity to play, rest, leisure, recreation and education suited to their age and condition and to be in an environment designed, furnished, staffed and equipped to meet their needs: inputs from the self-evaluation teams**

<table>
<thead>
<tr>
<th>Examples of Good Practices</th>
<th>Examples of actions for improvement</th>
<th>Further inputs and suggestions for future developments</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Hospital policy guarantees trained Play Specialists and/or a playroom and/or a library and/or a school with a trained teacher (MUCH, MUV, HPMCH, SCH, HUC, HUNSC, TCH, HUMIC, HSFX, HCR, SJDB);</td>
<td>• Extend 'child-friendly' environment to all hospital wards (SJDB, MUV);</td>
<td>• It is always possible to improve hospital practice, “to evaluate if the environment design is adequate for children depends on personal likings” (SJDB) – this may be an indication of the need to involve children and young people in the design of the environments?</td>
</tr>
<tr>
<td>• Philosophy of a child-centred care, which includes a friendly environment, architecture, services and activities (MUCH, HUNSC, SJDB);</td>
<td>• Expand and improve leisure activities to include the interests of older children/young people (i.e. rooms with internet access) (MUCH, MUV, SCH, HUNSC, HCR);</td>
<td>• Take into account recent past achievements and build on those successes (HUNSC) – this may be a useful suggestion in the respect of all rights;</td>
</tr>
<tr>
<td>• Interactive internet-based programme connecting hospitalised children to their school (MUCH, TCH);</td>
<td>• Expand the outdoor play space for children and young people (SCH);</td>
<td>• “Children’s complaints are expected to be taken into account in structuring the leisure areas” (HUMIC);</td>
</tr>
<tr>
<td>• Associations provide pet therapy, clowns, musicians, clowns and other recreational activities (MUCH, SCH, HSFX, HCR, HC, PAKY);</td>
<td>• Improve the access to leisure and play of children with limiting physical conditions (SCH, MUCH);</td>
<td>• Involving school students in recreational activities may be a good way to raise awareness in the community about how the hospital ‘works’ and to enhance collaborations.</td>
</tr>
<tr>
<td>• There are no age restrictions for visitors (HUMIC, HSFX, HCR, HC, PAKY);</td>
<td>• Increase the participation of health professionals in the recreational activities (HUC);</td>
<td></td>
</tr>
<tr>
<td>• Secondary School students carry out recreational activities for hospitalised children (HCR);</td>
<td>• Increase the collaboration between hospital and local schools, to enable follow-up of educational activities carried out in the hospital (HUC);</td>
<td></td>
</tr>
<tr>
<td>• There are no architectural barriers in the hospital (HCR, HSFX);</td>
<td>• Enhance multi-disciplinary team work (HUC);</td>
<td></td>
</tr>
<tr>
<td>• PAL Programme (SJDB).</td>
<td>• Overcome temporary barriers to the respect of this right (SJDB, HUMIC).</td>
<td></td>
</tr>
</tbody>
</table>
Summary Chart 12. Right 1.4. Children have the right to have full opportunity to play, rest, leisure, recreation and education suited to their age and condition and to be in an environment designed, furnished, staffed and equipped to meet their needs: Children’s views and evaluation

<table>
<thead>
<tr>
<th>Examples of reported Good Practices</th>
<th>Examples of actions for improvement</th>
<th>Further inputs and considerations for future developments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MUCH:</strong> The statements presented to young children for the consideration of this right were: ‘I have fun playing in the hospital. I have never played in the hospital. I do my homework in the hospital with a teacher’. Children’s comments were as follows:</td>
<td>• Increase awareness of children and families about the availability of a school teacher in the hospital (MUCH);</td>
<td>• Concerning diverging opinions: “The children’s view is somewhat different, as they can see daily the deficiencies that may be in certain moments during their stay (as shown in the previous column) (HUNSC);</td>
</tr>
<tr>
<td>- “Yes (I have fun). The teacher makes me do little work. The Playroom is good as it is.” (aged 9);</td>
<td>• “The areas are not adequately adapted for the development of recreational, cultural and educational activities; sometimes breaks are not respected; the hospital does not have staff, other than the staff provided by the associations, trained to work with us; there are associations that promote fun activities, but there is no involvement of the health staff” (HUMIC);</td>
<td>• Children’s participation strongly demonstrates that they are experts in their own experience – this is one more reason to involve them in all processes affecting them and, in these present processes, to involve them in the self-evaluation, the planning of actions and in the monitoring and evaluating the respect of each right;</td>
</tr>
<tr>
<td>- “I have fun playing in the hospital. Because there are many games and we do so many activities.” (aged 6);</td>
<td>• “We believe that if health care staff got involved in the recreational, cultural and educational activities that are carried out, everything would work better” (HUMIC);</td>
<td>• <strong>Note:</strong> the evaluation from children at MUCH is somewhat biased as the ‘interviews’ carried out with them, were done in the Playroom. This means that they are able to physically move around in some form. It would be important to interview children who are not able to leave their rooms/bed (MUCH);</td>
</tr>
<tr>
<td>- “I go to the Playroom to play. When I was in the ward I played with the volunteers and the Playroom Specialists. With the teacher I did my maths (division).” (aged 10);</td>
<td>• “In the computer room I cannot use Messenger or access certain web pages that are useful for my studies due to filters (14 year old)” (HUNSC);</td>
<td></td>
</tr>
<tr>
<td>- HUNSC:</td>
<td>• “A 9 year old schoolgirl states that there are a lot of toys and a big room to play, clowns and that there is also a computer room that she likes a lot;</td>
<td></td>
</tr>
<tr>
<td>- “A 9 year old schoolgirl states that there are a lot of toys and a big room to play, clowns and that there is also a computer room that she likes a lot;</td>
<td>• A female 11 year old pre-adolescent feels that there are very few toys of her interest and that most of them are old” (HUNSC);</td>
<td></td>
</tr>
<tr>
<td>- A 8 year old schoolgirl states that she likes all the things that there are in the hospital and that her parents are always there and help her with her homework and go with her to the computer room”.</td>
<td>• “A 9 year old schoolgirl complains that the pedagogue assigns her a lot of homework and that she feels tired with her illness” (HUNSC).</td>
<td></td>
</tr>
</tbody>
</table>
Concluding observations for AREA 1.

Although the issue of a child-centred service is crucial for the respect of all rights, for the rights 1.1. to 1.3.; the provision of healthcare in a comprehensive and multidisciplinary manner seems to be particularly important. On one hand, because it enables all staff to understand what health, in all its dimensions means, and how best to respond to it. On the other hand, because strong collaborations between all hospital services; between the hospital and community services; and between the health provider and the health consumer; respond in a better way to the needs of every child, independently of their age, condition, maturity or background. One of the strongest needs that emerges from this area is that of training all staff in cultural competency: this should be done appropriately and some of the information presented above give important suggestions on how to do this, for example to understand parents’ different beliefs and expectations. The good practices reported also put into evidence the different types of solutions available, i.e. to ensure an adequate psychological support to all children.
**Summary Chart 13. Right 2.1. Children have the right to be informed in a manner appropriate to their age, developmental level and understanding: inputs from the self-evaluation teams**

<table>
<thead>
<tr>
<th>Examples of reported Good Practices</th>
<th>Examples of actions for improvement</th>
<th>Further inputs and considerations for future developments</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Health professionals inform parents and children about the medical situation (SCH, HSFX, HCR, HC);</td>
<td>- To prepare child-centred/friendly health education materials in different formats and languages (HPMCH, SCH, MUCH, HCR, HC);</td>
<td>- Clarification/definition of what information means;</td>
</tr>
<tr>
<td>- Daily explanation to parents and children about the medical situation (HCR);</td>
<td>- To organise open days to show children how hospital life is (HPMCH);</td>
<td>- Diverging opinions regarding informed consent for adolescents over 16 (SJDB);</td>
</tr>
<tr>
<td>- “The hospital has a ‘virtual tour’ designed specifically for children prior to their admission to hospital” (SCH);</td>
<td>- Awareness raising and continuous training for staff and students on the importance of communicating with patients of all ages and ways to do this (skills) (SCH, MUCH, HUC, HUNSC, HUMIC, HCR, HC, HSFX);</td>
<td>- Regarding children’s own death, participants debated about how and if to inform children about it. In particular: at what age should children be informed, who should do it, should children know at all, etc (MUCH);</td>
</tr>
<tr>
<td>- Engaging children and young people in their transition to adult services (SCH);</td>
<td>- Organise training courses that are accessible for staff (cost-free/controlled and during work hours) (HUMIC);</td>
<td>- Participants discussed that “maybe the information is not provided in a way agreed by all professionals” (HUNSC);</td>
</tr>
<tr>
<td>- Child-centred/friendly information leaflets (SJDB); Health education materials are available in the native and a major foreign language (HUMIC, TCH, HSFX);</td>
<td>- “Create a multidisciplinary team made up by the professionals that usually assist children in order to provide the most adequate and complete information” (HUMIC);</td>
<td>- Participants discussed that “at the moment of admission, patients and their families are given a great amount of information, (which they are not able to register), thus perceiving that they are not informed” (HUNSC);</td>
</tr>
<tr>
<td>- ‘Child Life’ Programme (psychological support in preparation for surgery) (SJDB);</td>
<td>- To ensure that every child/parent/caregiver is welcomed, given a visit of the ward, information about rights and hospital policies and distribution of the Welcome Guide (HCR).</td>
<td>- To inform better the parents of oncology patients about the importance of talking to their child and having the courage to listen their feelings and also to leave professionals to talk in an appropriate way to the terminally ill children (PAKY).</td>
</tr>
</tbody>
</table>
Summary Chart 14. Right 2.1. Children have the right to be informed in a manner appropriate to their age, developmental level and understanding: Children’s views and evaluation

<table>
<thead>
<tr>
<th>Examples of reported Good Practices</th>
<th>Examples of actions for improvement</th>
<th>Further inputs and considerations for future developments</th>
</tr>
</thead>
</table>
| **MUCH:** The statements presented to young children for the consideration of this right were: ‘My doctor/nurse explains and makes me understand what is wrong inside me’. Children’s comments were as follows:  
- “A nice nurse explains to me what I must do and also a doctor. In general all doctors are good.” (aged 6);  
- “Some doctors explain to me what I have and what treatment I must do. If I make questions they reply and explain it better to me.” (aged 10). | • “The 5 children consulted declared that this right was Slightly Considered” (HUMIC);  
**MUCH:** The statements presented to young children for the consideration of this right were: ‘My doctor/nurse explains and makes me understand what is wrong inside me’. Children’s comments were as follows:  
- “More or less. Yes, they came to explain it to me, but I didn’t understand much.” (aged 7);  
- “Sometimes yes, sometimes they are not very clear but then my mum explains it to me.” (aged 9);  
- “Some nurses don’t tell me what they have to do.” (aged 6);  
- “I don’t like one of the doctors and one of the nurses because they are not friendly.” (aged 10);  
- “They tried to explain but I didn’t understand. They used difficult sentences. Only those of anaesthesia explained well what would happen and it happened.” (aged 9). | • “What seems to emerge from children’s statements is the need to improvement doctor/nurse-patient communication and also that this communication is highly dependent on the individuals” (MUCH). |
### Summary Chart 15. Right 2.2. Children have the right to express freely their opinions on any issue that involves them and the right to be heard and to be taken into consideration in a way consistent with their age and maturity: inputs from the self-evaluation teams

<table>
<thead>
<tr>
<th>Examples of reported Good Practices</th>
<th>Examples of actions for improvement</th>
<th>Further inputs and considerations for future developments</th>
</tr>
</thead>
<tbody>
<tr>
<td>• The views of adolescents are taken into consideration, as well as parents (HCR, HC, SCH, MUCH, MUV);</td>
<td>• Make children’s participation and giving their opinions a systematic hospital practice, as well as informing younger children (HSFX, HCR, HUNSC);</td>
<td>• Once again, from the Local Reports it emerges that the respect of this right is highly dependent on the health professionals;</td>
</tr>
<tr>
<td>• There is a Children’s Forum in collaboration with the Parents’ Council (TCH);</td>
<td>• Put in place child-friendly complaints’ mechanisms (TCH, HUMIC, MUCH, HSFX);</td>
<td>• Clarification/definition of what participation means;</td>
</tr>
<tr>
<td>• Quality Manager administers complaints by children and families (TCH);</td>
<td>• To review the Medical Record and include a space to register children’s perceptions and comments (HUMIC, MUCH, HSFX, HC);</td>
<td>• “There is need for improvement in increasing the voice of children both in their own care and the performance of the hospital as a whole. How best can this be achieved and to what extent?” (SCH);</td>
</tr>
<tr>
<td>• Organisation of 2 Annual “Participate and give opinions” campaigns (SJDB);</td>
<td>• Promote and/or constitute discussion forums and Children’s Councils (HUNSC, HSFX, HCR, SJDB, HC);</td>
<td>• It is crucial to know what is children’s, adolescents’ and young people’s views and perceptions of this right;</td>
</tr>
<tr>
<td>• Virtual community with a direct link to the Chief Executive Officer (SJDB);</td>
<td>• Promote training courses on child-centred approach to healthcare (HUC) and communication with patients of all ages (HSFX, PAKY);</td>
<td>• “Even though this right in not fully contemplated, there are no complaints from patients or parents in relation to it” (HUNSC) – this may be due to several reasons, i.e. patients and their families do not regularly complain in writing or because patients and families are not aware of this right or other.</td>
</tr>
<tr>
<td>• The hospital has in place a patient friend (liaison officer), website access and/or suggestion boxes in all wards (SCH, HCR, HC);</td>
<td>• Survey with adolescent patients across national hospitals to address their specific expectations and needs (SCH);</td>
<td></td>
</tr>
<tr>
<td>• Survey with adolescent patients across national hospitals to address their specific expectations and needs (SCH);</td>
<td>• Projects are exploring family experiences (i.e. patient journey, essentials of care), including the voice of the child (SCH);</td>
<td></td>
</tr>
<tr>
<td>• Several hospital staff speak foreign languages (HC).</td>
<td>• “Focus Groups have been planned to give children and young people the opportunity to express their views about the hospital, their stay and their treatment” (SCH);</td>
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<td></td>
<td>• To promote a ‘satisfaction scale’ for children about how they are feeling in hospital (HPMCH, HC).</td>
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</tbody>
</table>
Summary Chart 16. Right 2.2. Children have the right to express freely their opinions on any issue that involves them and the right to be heard and to be taken into consideration in a way consistent with their age and maturity: Children’s views and evaluation

<table>
<thead>
<tr>
<th>Examples of reported Good Practices</th>
<th>Examples of actions for improvement</th>
<th>Further inputs and considerations for future developments</th>
</tr>
</thead>
<tbody>
<tr>
<td>MUCH: The statements presented to young children for the consideration of this right were: ‘The doctor/nurse let’s me explain how I feel and what I want’. Children’s comments were as follows:</td>
<td>• “It calls to our attention the comments made by children regarding this right, as they tend to consider that such right is not taken into consideration, as they are not consulted during their illness process” (HUMIC).</td>
<td></td>
</tr>
<tr>
<td>- “Yes, they pay attention to what I say and for this reason I think they are good.” (7 and a half years old);</td>
<td></td>
<td>• Note: “This evaluation with children is very limited as it only reflects their right to participate in their treatment and not in any policy-level decisions (i.e. structure, layout and display of services, wards, architecture, etc)” (MUCH).</td>
</tr>
<tr>
<td>- “Yes (they do), I am not afraid of telling them things.” (9 and a half years old);</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- “They let me explain how I feel.” (6 years old);</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- “Yes, they have always let me explain myself. When I asked something to make me feel better they brought it to me.” (10 years old);</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- “Yes (they do).” (9 and a half years old).</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Concluding observations for AREA 2. AREA 2 is evidently the most challenging one for hospitals to respect and deal with. The right of children to express their views, meaning their right to participation, seems to be particularly difficult: overall it has the worse reported results with 6 hospitals reporting Meaningful Progress, 6 reporting Slightly Considered and 1 hospital reporting Significantly Achieved. It is also important to state that information and participation was only considered in relation to children’s condition and their treatment. The overall results demonstrate a pressing need to raise awareness amongst staff about the importance of communicating with children and their parents and to give staff the adequate skills to do this in the most effective way (this is also put in evidence by children’s comments).
### Summary Chart 17. Right 3.1. Children have the right to be protected from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse; inputs from the self-evaluation teams

<table>
<thead>
<tr>
<th>Examples of reported Good Practices</th>
<th>Examples of actions for improvement</th>
<th>Further inputs and considerations for future developments</th>
</tr>
</thead>
<tbody>
<tr>
<td>- There are adequate hospital protocols and/or referral mechanisms in place, including with associations and social services and/or Courts (MUCH, HPMC, MUV, HUC, HUNSC, HUMIC, TCH, JOTGH, HSFX, HCR, HC);</td>
<td>- Continuous awareness raising/training courses for staff, also to promote awareness about existing mechanisms (HUC, HUNSC, HUMIC, HSFX, HCR, AHCT) and in relation to victims of domestic violence (SJDB, HSFX);</td>
<td>- “Should we provide education related to this issue not only to health professionals but also to other professionals connected with childhood? How about the parents and society?” (SJDB) — Overall, what is the role of the hospital as an institution towards the community in relation to education and engagement on children’s rights and protection?</td>
</tr>
<tr>
<td>- Regular conferences and/or training and/or awareness raising activities are promoted in and by the hospital about the issue of violence against children (MUCH, HCR, TCH, HC);</td>
<td>- Put in place standardised procedures (MUV);</td>
<td>- As in relation to other rights, some evaluations found that although protocols and mechanisms exist in the hospital, staff are not aware of them (HUC, PAKY);</td>
</tr>
<tr>
<td>- Relevant Hospital Units: Child Protection (SCH, SJDB); Children and young people at risk (HSFX, HCR, HC); Domestic Violence (SCH); Prevention and Treatment of Child Abuse and Neglect (SJDB); Social Work (HUMIC, PAKY);</td>
<td>- Set up a Child Protection Group (MUV);</td>
<td>“It is surprising to see that, even though it is a totally established right and there is a universal protocol within the Canary Islands Health Service and particularly within the hospital, there are persons who do not know about the system (HUNSC, HUMIC).”</td>
</tr>
<tr>
<td>- Child Protection and Advocacy is included in the School of Paediatrics and Children’s Nursing (SJDB);</td>
<td>- Promote a protocol on the prevention of child abuse (HUMIC, PAKY);</td>
<td></td>
</tr>
<tr>
<td>- Pathways for management of painful procedures e.g. removal chest drains following cardiac surgery (AHCT).</td>
<td>- Constitute teams to support/monitor regularly children at risk in their homes; Education and monitoring of parental skills; Support from Legal Medicine, especially in suspected cases of child abuse (HCR);</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Development of teaching nursing staff in the supervision of children self-administering Entonox® during painful procedures. Includes physiology of pain and stress, planning for procedures and monitoring of children having Entonox® (AHCT).</td>
<td></td>
</tr>
</tbody>
</table>
### Summary Chart 18. Right 3.1. Children have the right to be protected from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse: Children’s views and evaluation

<table>
<thead>
<tr>
<th>Examples of reported Good Practices</th>
<th>Examples of actions for improvement</th>
<th>Further inputs and considerations for future developments</th>
</tr>
</thead>
</table>
| **MUCH:** The statements presented to young children for the consideration of this right were: ‘At times I have been afraid in the hospital. The doctor/nurse helped me when I was afraid’. Children’s comments were as follows:  
- “Yes, I was so afraid of being abandoned and the doctor and nurses helped me.” (7 and a half years old);  
- “Yes, the doctors helped me, for instance when I was shaking and I had to be put the needle.” (9 and a half years old);  
- “Yes and the doctors helped me. Now I am no longer afraid in the hospital.” (6 years old);  
- “When I have to put the Central Venous Catheter I am afraid of the Operations’ Room and I am afraid of the sounds of the MRI. Once I was screaming whilst I did the MRI and no one would listen to me. My favourite nurse always reassures me and tells me that nothing will happen.” (10 years old);  
- “Yes, of the blood test. They tried to reassure me but it was useless.” (9 and a half years old). | **Nothing to report** |  
• **Note:** “The evaluation team found that it was difficult to ask questions about protection from any form of violence and particularly we did not want to invade the privacy of children nor to make them feel uneasy. With asking them about whether they had ever ‘been afraid’ in the hospital, we expected to understand to what extent children feel they are in a protected environment. Children’s statements did reflect this, so this may be a question to keep for future evaluations with young children” (MUCH). |
### Summary Chart 19. Right 3.2. Children have the right not to be separated from their parents/guardians/caregivers against their will during their stay in hospital: inputs from the self-evaluation teams

<table>
<thead>
<tr>
<th>Examples of reported Good Practices</th>
<th>Examples of actions for improvement</th>
<th>Further inputs and considerations for future developments</th>
</tr>
</thead>
<tbody>
<tr>
<td>• At least one parent is allowed to stay for free with the child at all times, with few restrictions (TCH, HUMIC, MUCH, HUNSC, MUV, SCH, HPMCH, HSFX, HCR, HC, PAKY, AHCT);</td>
<td>• Increase the financial aids to hospitalised children, i.e. meals and parking (HUMIC);</td>
<td>a) The principle of the best interest of the child is determined by: Parent’s wish, legislation and child’s health condition (TCH); Good management (HUMIC); Providing the best quality of life (MUCH); Health professionals together with parents or caregivers (HSFX);</td>
</tr>
<tr>
<td>• When parents are not allowed to stay with their child, they are properly explained why not (HSFX, HCR, HC, HUMIC, PAKY);</td>
<td>• Enhance collaboration with associations to subsidise hospital stay for parents (HUNSC);</td>
<td>• “In determining and serving the child’s best interests there are occasions when the parents are found not to meet those expectations. This is a serious and rising challenge where there is always room for improvement” (SCH);</td>
</tr>
<tr>
<td>• At least one of the parents is entitled to eat for free (MUCH, HUC, HSFX, HC);</td>
<td>• Improve the conditions of stay offered to parents (HUNSC);</td>
<td>• Consider improving arrangements for seating and beds for parents to remain on the ward area whilst promoting a better, more comfortable and safe environment (AHCT);</td>
</tr>
<tr>
<td>• Parents are allowed to stay in “operating theatres up to the point of the impact of anaesthesia and the commencement of surgery” (SCH, PAKY, AHCT);</td>
<td>• Individual boxes in the Paediatric Intensive Care Unit, with parents’ presence 24 hours a day (SJDB);</td>
<td>• Different hospitals have restrictions concerning the presence of parents in some units, namely: Neonatology (HUMIC); Emergency Services (HUMIC, HUC); during reanimation (MUCH); Nephrology (MUCH); Paediatric Intensive Care Unit (HUNSC, SJDB, PAKY); during anaesthesia induction and post-operation reanimation (SJDB).</td>
</tr>
<tr>
<td>• The hospital provides information about the wards where parents are and are not allowed to stay with their children (TCH);</td>
<td>• Parents’ presence in induction of anaesthesia in all desired cases (SJDB);</td>
<td></td>
</tr>
<tr>
<td>• “Often the hospital guarantees that a third person can alternate parents’ stay, in order to minimise the impact of hospitalisation in the household” (HC);</td>
<td>• Parents’ presence during reanimation in all desired cases (MUCH);</td>
<td></td>
</tr>
<tr>
<td>• “Special menus are prepared for children and oncology child patients are given the possibility to have their meals à la carte and outside meal hours” (HUC, AHCT).</td>
<td>• Utilizing current work involving patient experiences within the Trust we are hoping to improve the way children and their parents / caregivers / guardians are able to function within the Trust (AHCT);</td>
<td></td>
</tr>
</tbody>
</table>

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Summary Chart 20. Right 3.2. Children have the right not to be separated from their parents/guardians/caregivers against their will during their stay in hospital: Children’s views and evaluation

<table>
<thead>
<tr>
<th>Examples of reported Good Practices</th>
<th>Examples of actions for improvement</th>
<th>Further inputs and considerations for future developments</th>
</tr>
</thead>
</table>
| **MUCH:** The statements presented to young children for the consideration of this right were: ‘My parents sleep with me in the hospital. My parents stay with me during the day.’ Children’s comments were as follows:  
- “Yes (they sleep with me). Yes (they stay with me during the day), but sometimes they leave. Mum has to work to pay the bills.” (7 and a half years old);  
- “Yes. Mum gives me courage.” (9 and a half years old);  
- “Yes (they sleep and stay with me). If I had been left alone I would have ran away.” (6 years old);  
- “In the ward mum came at night and dad during the day. They brought me things to eat that they cook at home because I did not want to eat here. My aunts, my brother and my grandmother also came to visit me.” (10 years old);  
- “Yes (my parents sleep with me and stay with me during the day).” (9 and a half years old). | Nothing to report | Nothing to report |
<table>
<thead>
<tr>
<th>Examples of reported Good Practices</th>
<th>Examples of actions for improvement</th>
<th>Further inputs and considerations for future developments</th>
</tr>
</thead>
</table>
| • There are (some) single rooms available (HUC, HUNSC);  
  • All bedrooms are single or double (MUCH, SJDB, HSFX);  
  • Children have the possibility to be examined by a doctor of the same sex upon request (MUCH, HUNSC, HUMIC, HC);  
  • Each bedroom has a private bathroom (MUCH, HUC, HUNSC, HUMIC, TCH, HSFX);  
  • “Usually during the recording of the medical history and examinations, the relatives of other patients who are in the room are asked to leave” (HUMIC);  
  • There are private areas for informing and performing examinations (TCH, HSFX). | • “Use the possibility to lock a room for important and undisturbed discussions with patients and parents” (MUV);  
  • In shared rooms, doctors should ask relatives of other patients’ to leave the room during examinations (HUNSC);  
  • Set up specific areas for informing and performing examinations (HUMIC). | • Clarification/definition of what privacy means;  
  • It would be important to ask further questions to children about this right and to understand what their perception of privacy is;  
  • Overall, there is particular attention to adolescents’ needs and requests;  
  • “The global evaluation of this right was the most diverging one, with quite equal votes for each of the four levels of evaluation” (HUMIC);  
  • As opposed to most of the other rights, during the discussion of this particular one, no further considerations were made in addition to the ones already present in the Self-evaluation Tool;  
  • The possibility of being examined by a doctor of the same sex is reduced because most paediatricians are women (HSFX, TCH). |
### Summary Chart 22. Right 3.3. Children have the right to privacy: Children’s views and evaluation

<table>
<thead>
<tr>
<th>Examples of reported Good Practices</th>
<th>Examples of actions for improvement</th>
<th>Further inputs and considerations for future developments</th>
</tr>
</thead>
</table>
| **MUCH:** The statements presented to young children for the consideration of this right were: “When I am treated I am always alone or with my parents”. Children’s comments were as follows:  
- “I am always with my parents.” (7 and a half years old);  
- “I am with my parents.” (9 and a half years old);  
- “I am always with my parents.” (6 years old);  
- “My mother always goes in with me. In the Day Hospital I am alone because I have the CVC and I know that I will not feel bad.” (10 years old);  
- “With my parents and also alone.” (9 and a half years old). | ● “The opinion of children diverges from that of the group. They indicate that their privacy is not considered, as they are sometimes examined in their own room, with no curtains or screens” (HUMIC). | ● “It would be important to ask further questions to children about this right and to understand what their perception of privacy is” (MUCH);  
● “The children answered that they are explored by the doctor that they were assigned on admission, but it is not a matter of worry to them” (HUMIC). |
### Summary Chart 23. Right 3.4. Children have the right to a dignified death: inputs from the self-evaluation teams

<table>
<thead>
<tr>
<th>Examples of reported Good Practices</th>
<th>Examples of actions for improvement</th>
<th>Further inputs and considerations for future developments</th>
</tr>
</thead>
<tbody>
<tr>
<td>There are specific programmes and protocols for a dignified death (TCH, HUNSC, HUC, MUCH, SJDB, SCH, HCR, HC);</td>
<td>“To organise annual multidisciplinary forums in order to analyse existing protocols and to evaluate the ways to communicate with families” (HUNSC);</td>
<td>Clarification/definition of what <em>dignified death</em> means;</td>
</tr>
<tr>
<td>The culture of children and families is considered during bereavement care (HCR, HC);</td>
<td>Give equal attention to different religions (MUCH);</td>
<td>“We possibly can define death as ‘dignified’ is it is possible to achieve that: there is no pain, the loved ones are present, private room and spiritual/psychological assistance if required” (SJDB);</td>
</tr>
<tr>
<td>Specific Unit for Paediatric Palliative Care (HUMIC, SJDB, SCH);</td>
<td>Enhance the capacity to educate clinical staff on the care of dying children and on how to communicate the death of the child (SCH, HUNSC, HSFX, HCR, HC);</td>
<td>“Bereavement care is client-centred and specific to the needs of the family. This statement is intended to incorporate all facets of the unique child/family situation including cultural, religious, spiritual (the broadest meaning of ‘culture’) as well as other specific personal circumstances” (SCH);</td>
</tr>
<tr>
<td>In the last year, 1 or 2 training courses were carried out on how to act during mourning (HUMIC, HSFX);</td>
<td>“Review current practice of bereavement follow-up for parents and siblings and identify a uniform standard of bereavement care for all families (with additional goals for the future if applicable)” (SCH);</td>
<td>“It may not be appropriate to use media stories as a positive marker of service quality” (SCH);</td>
</tr>
<tr>
<td>Families are provided psychological, social and religious support (HUNSC);</td>
<td>Enhance bereavement care appropriate to the culture of the child (HSFX, HCR, HC);</td>
<td>“Child death is very rare. Professionals mention that they are very sensitive about this issue, but feel insecure and without adequate training to deal with death and give support to parents” (HCR);</td>
</tr>
<tr>
<td>Immediate psychological support is provided to parents or appropriate information for subsequent support if they so wish (HCR);</td>
<td>Develop a “home care” programme for children with terminal illness in order to offer palliative care to the dying child and support his/her family for a long period during and after death (PAKY);</td>
<td></td>
</tr>
<tr>
<td>A room can be exclusively used by the family of a dying child, with the possibility of religious service (MUV);</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There is an attempt to respect all religions in the hospital and the space provided for prayer has been called ‘The Space of the Spirit’ in order to respect all faiths (MUCH).</td>
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</tr>
</tbody>
</table>
Children's views and evaluation
For this right, there is nothing to record regarding children's views and evaluation. At MUCH, children were not presented any statements, because the team found they did not know how to present the right to children, other hospitals did not report any information either.
### Summary Chart 24. Right 3.5. Children have the right not to feel pain: inputs from the self-evaluation teams

<table>
<thead>
<tr>
<th>Examples of reported Good Practices</th>
<th>Examples of actions for improvement</th>
<th>Further inputs and considerations for future developments</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Protocols and procedures are in place for pain prevention and treatment (TCH, HPMCH, SCH, SJDB, MUCH, MUV, HUC, AHCT, HUMIC, JOTGH, HSFX, HCR, HC, PAKY);</td>
<td>• Continuous training in the area of pain management for health staff (SCH, SJDB, HUNSC, HUMIC, HCR, AHCT);</td>
<td>• “The wording of this “right” needs significant review: children will feel pain at times (so a “right” to not feel pain is an unreasonable expectation); however, the pain they experience needs to be acknowledged, assessed and managed appropriately.” (SCH, AHCT);</td>
</tr>
<tr>
<td>• The Pain Score is included in the Medical Report (SCH, MUCH, JOTGH, HSFX, HCR, HC), or there is an ad hoc pain assessment chart (AHCT);</td>
<td>• Maintenance of standard procedures (MUV);</td>
<td>• “Canadian Pain coalition has a charter of rights (and responsibilities) which is worth noting:” (SCH) <a href="http://www.canadianpaincoalition.ca/index.php/en/about-us/the-charter">http://www.canadianpaincoalition.ca/index.php/en/about-us/the-charter</a>;</td>
</tr>
<tr>
<td>• The Pain Research Unit is an active component of the Pain and Palliative Care Unit (SCH);</td>
<td>• “In relation to the use of analgesics in the prevention and treatment of pain, professionals mention the need for a more uniform, rigorous and systematic procedure” (HCR).</td>
<td>• “What proposals for ‘needle-phobic’ children?” (SJDB)</td>
</tr>
<tr>
<td>• All health staff have been trained in pain care (HC);</td>
<td>• 85% of nurses dealing with children in acute pain procedures and post-surgical treatment have been trained (TCH);</td>
<td>• Diverging opinions on the minimum age for Patient Controlled Analgesia system (SJDB).</td>
</tr>
<tr>
<td>• There is continuous training for staff in pain care (HUC, HSFX, HCR, HC, JOTGH, AHCT);</td>
<td>• Pain service participated in the development of the Royal College of Nursing Guidelines for the Recognition and Assessment of Pain in Children (AHCT).</td>
<td>• Registered nurses to improve their communication with children regarding the explanation of the pain service, pain assessment tools and the child’s bedside folder (AHCT);</td>
</tr>
<tr>
<td>• Registered nurses to improve their communication with children regarding the explanation of the pain service, pain assessment tools and the child’s bedside folder (AHCT);</td>
<td></td>
<td>• Trust needs to improve the evidence obtained from children and families relating to pain experiences and pain management during their stay in the Trust and at home e.g. postoperative and chronic pain (AHCT);</td>
</tr>
<tr>
<td>• Trust needs to consider that pain management education is considered mandatory for all registered nurses within the Trust (AHCT).</td>
<td></td>
<td>• Trust needs to consider that pain management education is considered mandatory for all registered nurses within the Trust (AHCT).</td>
</tr>
</tbody>
</table>
### Summary Chart 25. Right 3.5. Children have the right not to feel pain: Children’s views and evaluation

<table>
<thead>
<tr>
<th>Examples of reported Good Practices</th>
<th>Examples of actions for improvement</th>
<th>Further inputs and considerations for future developments</th>
</tr>
</thead>
</table>
| **MUCH:** The statements presented to young children for the consideration of this right were: ‘The doctor/nurse asked me if I was in pain. They did something to make it go away’. Children’s comments were as follows:  
- “Yes, they ask it. For example in order to make me feel better when they take my blood they ask me to look away.” (7 and a half years old);  
- “Yes (they asked me). And they give me the things t feel better.” (9 and a half years old);  
- “Yes. For the CVC and the jabs they put cream.” (6 years old);  
- “The doctors ask me frequently if I am in pain.” (10 years old);  
- “I have never been in pain.” (9 and a half years old).  
• “Children evaluate the Pain Unit very positively, saying that they are always ready to alleviate our pain or to avoid that it appears” (HUMIC). | **AHCT:**  
- Re-issue pain assessment tool charts to all ward and clinical areas to ensure each child has access to this in their bedside folder. <50% children included in the 1-day snap shot audit (01/07/09) did not have a pain assessment chart in the bedside folder.  
- Registered nurse education to promote the use of treatments for adverse effects of analgesia. 41% children reported feeling nauseous or having vomited in the 1-day snapshot audit (01/07/09). 29% of these children were not offered antiemetic treatment.  
- Registered nurses to improve the monitoring and documentation of pain scores (33% of children included in the 1-day snapshot audit did have a pain score documented at all during their stay. 47% children had no pain score documented, or had no evidence of an observation chart available at the time of the audit). | Nothing to report |
Children have the right not to be submitted to clinical research or experimentation projects and to have the possibility to withdraw during the process of research: inputs from the self-evaluation teams

<table>
<thead>
<tr>
<th>Examples of reported Good Practices</th>
<th>Examples of actions for improvement</th>
<th>Further inputs and considerations for future developments</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Clinical research is strictly regulated by protocols (HPMCH, HSFX, HUMIC, HUNSC, HUC, MUCH, SCH, PAKY);</td>
<td>• Prepare protocols for informed consent (HSFX);</td>
<td>• “The distinction between quality improvement project and research remain contentious. The process undertaken for research projects may be too demanding for many non-interventional quality improvement projects” (SCH);</td>
</tr>
<tr>
<td>• There is an Ethics Committee for clinical research (TCH, HSFX, HUMIC, HUNSC, MUCH, SJDB, SCH, PAKY);</td>
<td>• Enhance the availability of information leaflets (HUMIC, SCH);</td>
<td></td>
</tr>
<tr>
<td>• There are specific protocols to obtain informed consent from parents and children (TCH, HUMIC, HUNSC, HUC, MUV, MUCH, SCH, PAKY);</td>
<td>• Set up auditing procedures to ensure that the standards are observed (HUNSC);</td>
<td></td>
</tr>
<tr>
<td>• Children can withdraw at any time of the research (TCH);</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Information leaflets about research are distributed (HSFX);</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• All reports undergo independent ethical review (HSFX, HUMIC, PAKY);</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• There have been no accidents in clinical research (HSFX, HUNSC, HUC);</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Children’s views and evaluation

For this right, there is nothing to record regarding children’s views and evaluation. At MUCH, children were not presented any statements, because the team found they did not know how to present the right to children, other hospitals did not report any information either.
Concluding observations for AREA 3.

AREA 3 is undeniably where there is more attention: protocols are clearly established and regulated; hospital policies, monitoring mechanisms, reviews, legislation and other mechanisms are in place; as well as specific child protection units, are in place to support the protection of children from physical and mental harm. It also seems that attention is high and continuous. Regarding the right to privacy the self-evaluations reported are lower, but it is possible to see that actions are undergoing and that there is awareness about what needs to be done in order to improve its respect.
3. CONCLUSION

This Final Report is the first evidence-based document on the application of the Self-evaluation Model and Tool on the Respect of Children's Rights in Hospital in a select group of 17 hospitals. Over 200 people in 17 hospitals and in 10 countries participated in this first pilot-implementation. No additional financial resources were allocated to the Task Force, nor to the paediatric hospitals and departments conducting the self-evaluations. These were done with already existing hospital resources. The coordination of these local processes at international level by the Task Force Hub confirmed the validity and possibility of carrying out a comparable self-evaluation process across countries, in all the phases of the programming cycle. Indeed, this experience may not have been so significant for the single hospitals, without the possibility to collaborate; share good practices, challenges and work methodologies; and, overall, without the possibility to come together to reflect on the differences and similarities, as well as the successes and difficulties.

The self-evaluations and their comparison have also been useful in highlighting what is being at hospital level and how. The summary charts provide valuable examples of reported good practices and actions for improvement, which may be shared within and between hospitals at local, national and international level. These examples, together with the processes and the working methodologies used, provide a stimulating platform for scientific considerations and exchange. The comparison of the results of each of the self-evaluations provides a comprehensive picture of the status of children's rights at hospital level. It can be said that for some rights in particular, such as the right to protection from all forms of violence, there is special attention, sensitivity and adequate services and response. On the other hand, it is obvious that some rights receive less attention, such as the right of children to information and participation. The respect of these rights seems to be particularly susceptible to the sensitivity of each professional that assists children. Moreover, there seem to be fewer instruments available: a lack of communication skills and training on specific issues related to children's rights was identified by most hospitals; and the views of children and young people demonstrate that they are not adequately involved in their treatment plan nor do they participate in other matters affecting their hospitalisation experience. In relation to the right to participation, an important finding may be that children were not involved in the self-evaluations neither in a large number nor in every participating hospital.

Regarding the limitations of a self-evaluation on the respect of children's rights in hospital, the most obvious finding is that the evaluation is very dependent upon the awareness, knowledge and sensitivity of the members of the self-evaluation teams on the issue of children's rights, as well as on the local culture. On the other hand, the participation of the local actors is crucial in this process, as they are the key and active players in the provision of healthcare.

On the whole, the local processes have shown that there is a growing awareness among all the actors involved (i.e. health professionals, hospital management, patients' and parents' associations, etc) of the importance of children's rights across countries and that there is attention at hospital policy-level. Most hospitals had adopted and/or prepared a Charter on Children's Rights in Hospital; in different cases hospitals promoted or had in place conferences, training events, a patient liaison/friendly/experience group or other; and in at least two hospitals,
children’s rights were integrated into regular monitoring and evaluation mechanisms. However, what seems to be common across the countries is that often policies do not translate into practice. Only in one hospital among all that had adopted a Charter on Children’s Rights in Hospital, was the Charter displayed in all wards; in other individual examples, it was reported that although hospital policy provided for a specific service (i.e. school in hospital, pain assessment charts and other) these were unknown to the patients and/or not always available. These few examples serve to highlight the need to follow-up on the policies written down and on the mechanisms that are available to patients and families.

Assessing and fulfilling children’s rights in hospital requires a strong motivation of the staff and a strong support from the Hospital Management. The process of self-evaluation implies discussion on what is working and what is missing, as well as the identification of actions for improvement, which must be translated into concrete initiatives. Only then will a programming cycle be meaningful and lead to change.

The way towards the full respect of children’s rights in hospital is long and in constant progress. However, it is crucial to take a strong step from the declarations to the effective protection, respect and fulfilment of children’s rights. It is fundamental to translate rights into actions and to translate the cultural representation of children as ‘objects of protection’ to that of children as ‘subjects’ of rights, who are capable of participating and have the inherent right to the highest attainable provision of healthcare in all its dimensions.

The Task Force on Health Promotion for Children and Adolescents in and by Hospitals and Health Services recognises the respect of children’s rights as a key component of health promotion, of a child and family-centred care and advocacy. Moreover, it recalls all participating hospitals and respective States that the ratification of the Convention on the Rights of the Child is a legal obligation that requires States to respect, protect and fulfil children’s rights in all their life settings, including healthcare. The 17 participating hospitals have shown that they value the opportunity, recognise their shortcomings and are enthusiastic to address gaps. The Task Force should not lose this momentum, on the contrary, it should continue to work together and coherently in order to produce and replicate the best outcomes for children within and outside the Task Force and the International Network of Health Promoting Hospitals and Health Services. The Task Force welcomes and hopes to maintain and enhance the collaboration with agencies in national and international settings.
Appendix 1. Brief description of the participating hospitals and partner organisations

Alder Hey Children’s NHS Foundation Trust (AHCFT) (England, UK) is recognized as the largest children’s hospital in Western Europe and provides general and all specialist paediatric services at secondary and tertiary levels, including services for pharmacy, dentistry and clinical genetics. Community child health services are provided alongside services for school nursing, home carers and a child development centre. A community-based child and adolescent mental health service (CAMHS) is provided, with an inpatient unit based at the trust. The full range of paediatric services is provided at a single site with 325 beds, and additional community facilities are provided at 40 venues throughout Merseyside. AHCFT activity data for 2008/09 include 120,000 out-patient episodes, 26,000 inpatient admissions, 70,000 A&E attendances; 1,000 critical care admissions, and 13,000 CAMHS episodes at AHCFT (with 14,400 CAMHS out-patient episodes in community teams). AHCFT has contracts with 42 primary care trusts throughout the North West and all six purchasing authorities in North Wales, and acts as a tertiary referral centre for much of the North West of England and North Wales. In addition to this activity, AHCFT conducts over 800 peripheral clinics annually, covering district general hospitals in Cheshire, Merseyside, Greater Manchester, Cumbria, Lancashire, Shropshire, Staffordshire, North Wales and the Isle of Man. The Paediatric Intensive Care Unit is the largest in the UK (23 beds) and admits over 1,000 children per year. Of these, around 80% are ventilated. Approximately a third of the admissions are children with cardiac problems. The majority of the remainder have acute medical problems. There is a transport team that transports the most critically ill children from other hospitals in the region. About 40% of the PICU’s admissions originate from outside RLC. In addition, the trust provides additional 15 and 6 beds, respectively, in general and neurosurgical high-dependency units.

Akershus University Hospital (Norway) is one of fourteen hospitals owned by South-Eastern Norway Regional Health Authority, whose vision is to provide “High quality health services equal to all, regardless of age, place of residence, ethnic background, gender or personal economy”. Over 4800 employees work at Akershus university hospital to deliver healthcare to a catchment area of 340,000 inhabitants in Akershus County. The hospital currently has 820 beds. Our vision is to be the most patient focused and patient friendly hospital in Norway, as well as an attractive work-place with highly skilled employees. The hospital is located in Lørenskog municipality outside the capital of Oslo. As the only Norwegian hospital Akershus university hospital has a Centre for health promotion. The centre is home to the secretariat of the Norwegian HPH network. The Children’s clinic at Akershus university hospital is among the largest in Norway with 220 employees and 6 units.

Caldas da Rainha Hospital (Portugal) is part of a Hospital Network (Centro Hospitalar do Oeste Norte), which is a public institution that includes four hospitals: Caldas da Rainha, Peniche and Alcobaça, as well as, the Thermal Hospital de Caldas da Rainha. Caldas da Rainha Hospital has a general paediatric service with Maternity. The network serves a population of 237,673 inhabitants. Caldas da Rainha Hospital has a paediatric unit with 22 beds, which provides healthcare to children up to the age of 16 (in day surgery unit up to 18 year old children).
Cascais Hospital (Portugal) serves a population of 230,000 inhabitants. It covers all the city of Cascais. The emergency level is medical and surgical. It has a paediatric service with 18 beds and the age limit to hospitalisation is 15. It has an emergency paediatric service receiving all types of pathologies. There is a neonatal intensive care unit with 3 incubators and 5 cradles.

The Child Support Institute (Instituto de Apoio à Criança, Portugal) is a non-governmental organisation, which was established in March 1983 by a group of professionals of different backgrounds: doctors, judges, teachers, psychologists, sociologists, social services' officers and other. Its main objective is to contribute to the holistic development of the child, by protecting and promoting his/her rights in every life setting, including health, education, social security and play. In accordance with its policy, the Child Support Institute promotes awareness raising projects; research, seminars and other initiatives that facilitate debate and reflection of challenges in childhood in contemporary society; policy recommendations in relation to children's rights. As a member of the European Association for Children in Hospital, the Child Support Institute has carried out extensive awareness raising, training and research in hospitals throughout Portugal. It has been the main trigger of the work related to the Self-evaluation Model and Tool on the Respect of Children's Rights in Hospital, in Portugal.

EACH – the European Association for Children in Hospital – is the umbrella organisation for non-governmental, non-profit associations involved in the welfare of children before, during or after a hospital stay. Starting in the 1950s, research by psychologists and paediatricians had shown that the care children received in hospital and their almost complete separation from their families were detrimental to their emotional and psychological wellbeing. In more and more European countries voluntary associations for the welfare of children in hospital started promoting the involvement of families in the paediatric health care services, separate wards for children/adolescents, full opportunity for play and education, information appropriate to age and understanding. In 1988 twelve of these voluntary associations met together in Leiden (NL) and drew up the Leiden Charter. This name was changed to EACH Charter in 1993, when these voluntary associations established the European Association for Children in Hospital (EACH). Presently 18 European countries and Japan are represented in EACH.

Heim Pál – Madarász Children's Hospital (Hungary) is owned by the municipality of Budapest – the capital of Hungary. It is one of the biggest children's hospitals in the country. The hospital currently has 543 beds distributed in 17 departments in 2 sites. The staff provides care in all specialities of paediatrics. It is also a centre of postgraduate education for young doctors, nurses and health visitors. The hospital has close contacts with the primary paediatric care and the local social welfare service. The staff is devoted to provide a child friendly care and to implement children's rights in health care.

The Hospital Sant Joan de Déu Barcelona (Spain) is a private, not-for-profit hospital that belongs to the Hospitable Order of the Brothers of Saint John of God. It is associated with the University of Barcelona and with Barcelona's Hospital Clinic (Hospital Clinic), which help the hospital to provide top-level technological and human care. The hospital is dedicated to providing care for children and expectant mothers. As one of the most important paediatric medical centres in Spain, the hospital combines basic general paediatrics with a solid reference hospital constitution for
all tertiary-level pathologies in the field of paediatrics (Ex.: neonatology, neuroscience, oncology, cardiology, etc.). It is a proximity hospital serving a population of some 1 500 000 inhabitants and it has 339 beds.

**Investing in Children** is an organisation concerned with the human rights of children. It was created in the 90s by public service agencies in England. Over the last 15 years, **Investing in Children** has developed a range of different ways in which children and young people are supported to say what they want to say, and help to improve services used by them, by discussing their ideas with the adults who run the services. **Investing in Children** is working in partnership with Alder Hey Children’s NHS Foundation Trust.

**Jávorszky Ödön Hospital** (Hungary) is owned by the municipality of Vác, which is a small town in the Northern part of Hungary. The general hospital cares for 167 000 inhabitants. The paediatric department currently has 20 beds, where the patients get emergency care; the baby unit connected with maternity ward has 18 beds. There is 6 specialist’s consultation for out-patients. The personnel of the paediatric department is devoted to health promotion and implementation of children’s rights.

The Clinic of Paediatric and Adolescent Medicine is part of the **Medical University of Vienna** (Austria) and the largest paediatric hospital in Austria divided in four departments containing all subspecialties. The emergency room has an admission rate of more than 20,000 children per year. More than 4000 children per year are admitted to one of the hospital wards. The medical staff has the responsibility for patient care, education and research.

The **Meyer University Children’s Hospital** (Italy) founded in 1884, was one of the first hospital institutions in Italy exclusively devoted to the problems of child healthcare from birth to adolescence. Today, it is characterised by high standards of care and research in the specific paediatric health areas. In 1995, the Meyer Hospital—with the Department of Paediatrics of the University of Florence—became an autonomous health institute of the Tuscan Health System, due to recognition of its role as a highly specialized paediatric institution. For years, the Meyer University Children’s Hospital has addressed issues related to health promotion of child and adolescent and has constituted a specific Health Promotion Programme. This unit of the hospital aims to develop a culture of health promotion inside the hospital and its community of reference, taking into account the perspective of the socio-economic determinants of health. It has collaborated with regional, national and international organizations to develop and implement health promotion activities targeting the youth. As a result, the Health Promotion Programme of the Meyer Hospital was designated an official World Health Organisation Collaborating Centre for Health Promotion Capacity Building in Child and Adolescent Health in May of 2006. The hospital has 200 beds, of which 50 in day hospital, 7 surgery rooms, 9 diagnosis rooms and 5,000 square metres of green areas.

**The Mother and Children’s University Hospital of the Canary Islands** (Spain) is located in Las Palmas of Gran Canaria, Canary Islands. The paediatric specialities available in the out-patient services include: Oncology, Haematology and Immunology; Endocrinology, Pneumology, Allergology, General Paediatrics, Nephrology, Neurology, Cardiology, Gastroenterology, school consultation, Rheumathology, Dermatology and
Surgery. An average of 36,267 children are provided out-patient healthcare each year. In the area of hospitalisation, 223 paediatric beds are available, which can be extended to 20 extra beds. An average of 3,228 children are hospitalised every year.

**P & A KYRIAKOU Children’s Hospital** (Greece) is one of the largest children’s hospital in Greece and its a referral centre for all the country. It has one University Paediatric Clinic and three more Paediatric Clinics that belong to the National Health Service, two Surgery Departments, two Orthopaedic Departments, ERL, Ophthalmology, Nephrology, Cardiology, Neurology, Endocrinology, Neonatology, Allergology, Cytarogenetics, Child Psychiatry, Dentistry, Social Medicine, Neurosurgery Departments, Intensive Care Unit, Adolescents Medicine Unit and Radiotherapy Unit.

It is the only Children’s hospital in Greece that has the last three Units plus the Social Medicine Department. It has 380 beds, 346 Doctors, 372 Nurses, 290 Administrators and 46 persons as Technical personnel. Officially it can offer any kind of service to the sick children.

The **Royal Hospital for Sick Children** (Scotland, UK) is part of NHS Lothian University Hospitals Division. Located in the city of Edinburgh the hospital provides general and specialist paediatric services for local children and young people and for those living in South-East Scotland. The hospital also provides a number of specialist services nationally including one of Scotland’s two paediatric intensive care retrieval teams. In addition to hospital services care is also provided to children with complex and continuing care needs within their own homes and in two purpose-built units. Built in 1895 the current hospital has 138 beds for in-patient and day care. There are also an accident and emergency and out-patients departments. Activity figures for 2008/9 included 9,171 in-patient cases, 7,170 day cases and 12,080 out-patients. A new hospital is being planned in consultation with children and young people and is expected to become operational in 2013.

**São Francisco Xavier** (Portugal) is a Central Hospital where the General Emergency of degree 4, the Paediatric Emergency and the Obstetric Emergency of all the west zone of Lisbon are based, covering about 400,000 inhabitants. There are 49 beds in the paediatric service, which provides healthcare for children up to the age of 18. The multi-trauma situations are treated at the central emergency and the paediatrics assistance is eventually called on.

**Sydney Children’s Hospital** (Australia) is a state-wide tertiary specialist facility for paediatrics and child health. It provides a comprehensive range of services and is the hub of an extensive and well developed clinical network. Sydney Children’s Hospital is part of the Randwick Hospitals Campus adjacent to the adult Prince of Wales Hospital, the Royal Hospital for Women and the Prince of Wales Private Hospital and is located in close proximity to the University of New South Wales and several Research Institutes. Together, they are the largest complex of health facilities in Australia with a scope comparable to any in the world. Shared laboratories, imaging and scanning services, operating theatres and other infrastructures provide “state of the art” equipment and cost effective healthcare. Sydney Children’s Hospital employ the equivalent of 1032 full time staff, including 510 nurses. The Hospital had a 2008/09 budget of over $125 million and currently operates 159 beds. Sydney Children’s Hospital’s annual activity for 2008/09 included: 44,456 bed days; 318,550 non admitted patient occasions of service; 14,985 hospital separations, and; 36,120 emergency department attendances.
Tallinn Children’s Hospital is the only regional multi-professional specialised hospital for children’s healthcare in Estonia. The hospital consists of paediatric, surgical in-and out-patient clinics with neonatal and paediatric intensive care unit. Our vision is to be a centre for child health and well-being, to provide high quality family-centred healthcare and to be innovative and open to the reforms. From 2002 the hospital is a member of International Network of Health Promoting Hospitals and Health Services and member of Task Force on Health promotion for Children and Adolescents in and by Hospitals and Health Services. Over 700 employees work in Tallinn Children’s Hospital to deliver healthcare to a catchments area of 250,000 children’s population in North-Estonia. The hospital currently has 190 beds with trend to decrease inpatient beds and increase out-patient and day care. Over 11,000 in- and 160,000 out-patient children are provided healthcare every year.

University Hospital Our Lady of Candelaria, Canary Islands (Spain) is located in the island of Tenerife in the Canary Islands. The paediatric specialities available in the out-patient services include: Day hospital, Oncology, Haematology and Immunology, Endocrinology, Unit of Education Diabetes, Pneumology and Cystic Fibrosis, Allergology, Nephrology, Neurology, Gastroenterology, Nutrition, Neonatology, and Surgery, covering General, Urology, Thorax and Neonatology. An average of 14,324 children are provided out-patient healthcare each year. In the area of hospitalisation, 122 paediatric beds are available. An average of 3,700 children are hospitalised every year.

The University Hospital of Canarias (Spain) is located in the island of Tenerife in the Canary Islands. It is a Paediatric Ward, which provides care in the following out-patient specialities: Day Hospital, Oncology, Haematology and Immunology, Endocrinology, Pneumology, Gastroenterology, Rheumatology and Surgery. An average 6,856 children receive out-patient healthcare every year. In the area of hospitalisation, 54 paediatric beds are available. An average of 2,219 children are hospitalised every year. Both hospitals of the island of Tenerife, which are located at only a few kilometres distance and which attend to the Northern and Southern area of the island respectively, are in process of transformation, for the extension services offered.
Appendix 2. Sample Local Report

Self-evaluation Model and Tool on the Respect of Children’s Rights in Hospital: Local Report

1. General information

In this first section of the Report please provide general information related to the hospital, the delegated team responsible for the self-evaluation process/implementation of the tool and other introduction questions:

1.1. Name and address of the hospital:
1.2. Name of the Departments/Services where the tool was implemented:
1.3. Name and email address of the person in charge of filling out the local report:
1.4. Date of completion of the Local Report:
1.5. Who was responsible for leading the process of implementation of the tool in the hospital (please select accordingly):
   - Parent/Family Council
   - Youth Forum/Association
   - Task Force HPH-CA Member
   - Hospital Management/Direction
   - Head of Department
   - Ombudsman for Children
   - Other Please specify

1.6. Who was the delegated team responsible for implementing the tool, composed of:
   - Children Please specify age group
   - Parents/caregivers
   - Task Force HPH-CA Member
   - Head of Department
   - Chief Doctor
   - Chief Nurse
   - Patients’ Association
   - Other Civil Society Association
1.7. What was the total number of participants in the discussion?
1.8. How many times did the team meet?
1.9. What was the duration of the process of implementation of the Tool (from the acceptance of the hospital to take part in the process up to the completion of the Local Report)?
   - 1 month
   - 2 months
   - 3 months
   - 4 months

1.10. Has the hospital adopted a Charter on Children’s Rights in Hospital, in line with the Convention on the Rights of the Child?
   - Yes
   - No
   - If yes, please indicate when it was adopted and submit a copy of the Charter

1.11. Is the Charter accessible in print and displayed in all wards/services?
   - Yes
   - No
   - If yes, please provide an estimated percentage of accessibility

1.12. Was a child version of the tool adopted by the hospital to enable the participation of younger children?
   - Yes
   - No
   - If yes, please indicate whether it was useful?

1.13. Are there any lessons learnt in relation to the implementation of the tool in your hospital/department?
   - Yes
   - No
   - If yes, please give examples
2. Main findings
In this section of the Report, please provide information on the main findings of the self-evaluation process/implementation of the Self-evaluation Tool carried out in your hospital or department.

AREA 1. Right to the highest attainable standard of health care.
Right 1. 1. Children’s health care provision should take into consideration all dimensions of health, including physical, mental, social, cultural and spiritual.

2.1. What was the overall evaluation of the respect of this right in the hospital:
- Significantly achieved □
- Meaningful progress □
- Slightly considered □
- Completely unconsidered □

2.2. Please describe the main results of the discussion in relation to:
   2.2.1. The strong points identified in the hospital regarding the respect of this right.

   2.2.2. The areas in need of improvement identified in the hospital regarding the respect of this right.

   2.2.3. The diverging opinions in the team regarding the respect of this right.

2.3. Were there any standards suggested in relation to the right?
- Yes □ If yes, please specify which
- No □

2.4. Were there any future actions suggested in relation to the right?
- Yes □ If yes, please specify which
- No □

2.5. Is there anything else you would like to tell us in relation to this right?
Right 1. 2. Children have the right to access health services without ethnic, racial, class, religious, gender, age, sexual orientation, disability, language, cultural and social discrimination.

3.1. What was the overall evaluation of the respect of this right in the hospital:
- Significantly achieved □
- Meaningful progress □
- Slightly considered □
- Completely unconsidered □

3.2. Please describe the main results of the discussion in relation to:
   3.2.1. The strong points identified in the hospital regarding the respect of this right.
   3.2.2. The areas in need of improvement identified in the hospital regarding the respect of this right.
   3.2.3. The diverging opinions in the team regarding the respect of this right.

3.3. Were there any standards suggested in relation to the right?
   - Yes □ If yes, please specify which
   - No □

3.4. Were there any future actions suggested in relation to the right?
   - Yes □ If yes, please specify which
   - No □

3.5. Is there anything else you would like to tell us in relation to this right?
Right 1.3. Children shall be admitted to the hospital only if the care they require cannot be equally well provided and effective at home or on a day basis.

4.1. What was the overall evaluation of the respect of this right in the hospital:
- Significantly achieved □
- Meaningful progress □
- Slightly considered □
- Completely unconsidered □

4.2. Please describe the main results of the discussion in relation to:

   4.2.1. The strong points identified in the hospital regarding the respect of this right.

   4.2.2. The areas in need of improvement identified in the hospital regarding the respect of this right.

   4.2.3. The diverging opinions in the team regarding the respect of this right.

4.3. Were there any standards suggested in relation to the right?
- Yes □ If yes, please specify which
- No □

4.4. Were there any future actions suggested in relation to the right?
- Yes □ If yes, please specify which
- No □

4.5. Is there anything else you would like to tell us in relation to this right?
Right 1.4. Children have the right to have full opportunity for play, rest, leisure, recreation and education suited to their age and condition and to be in an environment designed, furnished, staffed and equipped to meet their needs.

5.1. What was the overall evaluation of the respect of this right in the hospital:
- Significantly achieved [ ]
- Meaningful progress [ ]
- Slightly considered [ ]
- Completely unconsidered [ ]

5.2. Please describe the main results of the discussion in relation to:
   2.2.1. The strong points identified in the hospital regarding the respect of this right.
   2.2.2. The areas in need of improvement identified in the hospital regarding the respect of this right.
   2.2.3. The diverging opinions in the team regarding the respect of this right.

5.3. Were there any standards suggested in relation to the right?
- Yes [ ] If yes, please specify which
- No [ ]

5.4. Were there any future actions suggested in relation to the right?
- Yes [ ] If yes, please specify which
- No [ ]

5.5. Is there anything else you would like to tell us in relation to this right?
AREA 2. Right to information and participation in all decisions involving their health care.

Right 2.1. Children have the right to be informed in a manner appropriate to their age, developmental level and understanding.

6.1. What was the overall evaluation of the respect of this right in the hospital:
- Significantly achieved □
- Meaningful progress □
- Slightly considered □
- Completely unconsidered □

6.2. Please describe the main results of the discussion in relation to:
   2.2.1. The strong points identified in the hospital regarding the respect of this right.
   2.2.2. The areas in need of improvement identified in the hospital regarding the respect of this right.
   2.2.3. The diverging opinions in the team regarding the respect of this right.

6.3. Were there any standards suggested in relation to the right?
- Yes □ If yes, please specify which
- No □

6.4. Were there any future actions suggested in relation to the right?
- Yes □ If yes, please specify which
- No □

6.5. Is there anything else you would like to tell us in relation to this right?
Right 2.2. Children have the right to express freely their opinions on any issue that involves them and the right to be heard and to be taken into consideration in a way consistent with their age and maturity.

7.1. What was the overall evaluation of the respect of this right in the hospital:
   - Significantly achieved □
   - Meaningful progress □
   - Slightly considered □
   - Completely unconsidered □

7.2. Please describe the main results of the discussion in relation to:
   2.2.1. The strong points identified in the hospital regarding the respect of this right.
   2.2.2. The areas in need of improvement identified in the hospital regarding the respect of this right.
   2.2.3. The diverging opinions in the team regarding the respect of this right.

7.3. Were there any standards suggested in relation to the right?
   - Yes □ If yes, please specify which
   - No □

7.4. Were there any future actions suggested in relation to the right?
   - Yes □ If yes, please specify which
   - No □

7.5. Is there anything else you would like to tell us in relation to this right?
AREA 3. Right to protection from all forms of violence.

Right 3.1. Children have the right to be protected from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse.

8.1. What was the overall evaluation of the respect of this right in the hospital:
   - Significantly achieved
   - Meaningful progress
   - Slightly considered
   - Completely unconsidered

8.2. Please describe the main results of the discussion in relation to:
   8.2.1. The strong points identified in the hospital regarding the respect of this right.
   8.2.2. The areas in need of improvement identified in the hospital regarding the respect of this right.
   8.2.3. The diverging opinions in the team regarding the respect of this right.

8.3. Were there any standards suggested in relation to the right?
   - Yes
   - No

8.4. Were there any future actions suggested in relation to the right?
   - Yes
   - No

8.5. Is there anything else you would like to tell us in relation to this right?
Right 3.2. Children have the right not to be separated from their parents/guardians/caregivers against their will during their stay in hospital.

9.1. What was the overall evaluation of the respect of this right in the hospital:
- Significantly achieved □
- Meaningful progress □
- Slightly considered □
- Completely unconsidered □

9.2. Please describe the main results of the discussion in relation to:
   9.2.1. The strong points identified in the hospital regarding the respect of this right.
   9.2.2. The areas in need of improvement identified in the hospital regarding the respect of this right.
   9.2.3. The diverging opinions in the team regarding the respect of this right.

9.3. Were there any standards suggested in relation to the right?
- Yes □ If yes, please specify which
- No □

9.4. Were there any future actions suggested in relation to the right?
- Yes □ If yes, please specify which
- No □

9.5. Is there anything else you would like to tell us in relation to this right?
Right 3.3. Children have the right to privacy.

10.1. What was the overall evaluation of the respect of this right in the hospital:
- Significantly achieved ☐
- Meaningful progress ☐
- Slightly considered ☐
- Completely unconsidered ☐

10.2. Please describe the main results of the discussion in relation to:
   10.2.1. The strong points identified in the hospital regarding the respect of this right.
   10.2.2. The areas in need of improvement identified in the hospital regarding the respect of this right.
   10.2.3. The diverging opinions in the team regarding the respect of this right.

10.3. Were there any standards suggested in relation to the right?
- Yes ☐ If yes, please specify which
- No ☐

10.4. Were there any future actions suggested in relation to the right?
- Yes ☐ If yes, please specify which
- No ☐

10.5. Is there anything else you would like to tell us in relation to this right?
Right 3.4. Children have the right to a dignified death.

11.1. What was the overall evaluation of the respect of this right in the hospital:
- Significantly achieved ☐
- Meaningful progress ☐
- Slightly considered ☐
- Completely unconsidered ☐

11.2. Please describe the main results of the discussion in relation to:
   11.2.1. The strong points identified in the hospital regarding the respect of this right.
   11.2.2. The areas in need of improvement identified in the hospital regarding the respect of this right.
   11.2.3. The diverging opinions in the team regarding the respect of this right.

11.3. Were there any standards suggested in relation to the right?
- Yes ☐ If yes, please specify which
- No ☐

11.4. Were there any future actions suggested in relation to the right?
- Yes ☐ If yes, please specify which
- No ☐

11.5. Is there anything else you would like to tell us in relation to this right?
Right 3.5. Children have the right not to feel pain.

12.1. What was the overall evaluation of the respect of this right in the hospital:
- Significantly achieved □
- Meaningful progress □
- Slightly considered □
- Completely unconsidered □

12.2. Please describe the main results of the discussion in relation to:
   12.2.1. The strong points identified in the hospital regarding the respect of this right.
   12.2.2. The areas in need of improvement identified in the hospital regarding the respect of this right.
   12.2.3. The diverging opinions in the team regarding the respect of this right.

12.3. Were there any standards suggested in relation to the right?
- Yes □ If yes, please specify which
- No □

12.4. Were there any future actions suggested in relation to the right?
- Yes □ If yes, please specify which
- No □

12.5. Is there anything else you would like to tell us in relation to this right?
Right 3.6. Children have the right not to be submitted to clinical research or experimentation projects and to have the possibility to withdraw during the process of research.

13.1. What was the overall evaluation of the respect of this right in the hospital:
- Significantly achieved □
- Meaningful progress □
- Slightly considered □
- Completely unconsidered □

13.2. Please describe the main results of the discussion in relation to:
   13.2.1. The strong points identified in the hospital regarding the respect of this right.
   13.2.2. The areas in need of improvement identified in the hospital regarding the respect of this right.
   13.2.3. The diverging opinions in the team regarding the respect of this right.

13.3. Were there any standards suggested in relation to the right?
- Yes □ If yes, please specify which
- No □

13.4. Were there any future actions suggested in relation to the right?
- Yes □ If yes, please specify which
- No □

13.5. Is there anything else you would like to tell us in relation to this right?
3. Overall result/impact

In this section of the Report, please provide information on the overall results and impact of implementing the Self-evaluation tool in the hospital/department.

14.1. Have there been any decisions regarding the next steps (i.e. actions, projects and policies) to take towards the improvement of the respect of children’s rights in hospital, in relation to:

14.1.1. Specific rights identified in the Self-evaluation Model and Tool □ Please give examples
14.1.2. Child Participation □ Please give examples
14.1.3. Capacity Building and Communication □ Please give examples
14.1.4. Standards and Scientific Debate □ Please give examples
14.1.5. Other □ Please specify
4. Usefulness of the Self-evaluation Tool

In this section of the Report, please provide information on the usefulness of the tool and suggestions on how to improve it.

15.1 Did participants find the tool a useful mechanism for assessing the respect of children's rights in hospital?

- Overall, yes □
- Overall, no □
- There were mixed feelings about it □

15.2. Was the tool useful to plan improvement of hospital activities towards the respect of children's rights in hospital?

- Yes □
- No □
- Other □ Please specify

15.3. Was the tool useful in initiating discussion on children's rights in hospital?

- Yes □
- No □
- Discussion on children's rights is a common practice in the hospital □
- Although we discuss children's rights regularly, we found new inputs □

15.4. Was the tool useful in raising awareness about children's rights amongst the health staff?

- Yes □
- No □
- It is difficult to say □

15.5. Was the tool useful in raising awareness about children's rights amongst children themselves and their parents/caregivers?

- Yes □
15.6. Was the tool useful in increasing the participation of children and caregivers in the processes affecting them?

- Overall, yes □
- Overall, no □
- We already have a strong tradition of child and family participation □

15.7. Was the electronic format (working template) useful?

- Yes □
- No □
- Other □ Please specify

15.8. Would a child-friendly version be useful?

- Yes □
- No □
- Other □ Please specify

15.10. Would you like to give any other comments or suggestions to improve the tool?

Thank you for your time!
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