



International Network of
HHealth
PPromoting
HHospitals & Health Services



Children's rights in Hospital and Health Services:

Manual and Tools for assessment and improvement

Edited by:

Ana Isabel F. Guerreiro

March 2012

Disclaimer:

The opinions expressed in this Manual do not necessarily reflect the respective organisational views nor do they imply an official endorsement by any of the institutions quoted in the text.

Editor:

Ana Isabel Fernandes Guerreiro

Leader, Task Force on Health Promotion for Children and Adolescents in and by Hospitals and Health Services

<http://www.hphnet.org>

For additional information, requests or collaboration with the Task Force HPH-CA, please contact:

Ana Isabel F. Guerreiro

email: ana_isabel_guerreiro@hotmail.com

Skype: ana_isabel_guerreiro

James E Robinson

email: jim.robinson@ed.ac.uk

Skype: jerob52

© International Network of Health Promoting Hospitals and Health Services

Copying and other reproduction are allowed with acknowledgement.

Contents

Foreword	4
Acknowledgments	5
Introduction to the Manual and Tools	6
Methodology	7
Bibliography	13

Foreword

In January 2009, the Task Force on Health Promotion for Children and Adolescents in & by Hospitals and Health Services (hereafter Task Force HPH-CA) published the first edition of the *Self-evaluation Model and Tool on the Respect of Children's Rights in Hospital* (SEMT) (Task Force HPH-CA, 2009).

The SEMT was made available in 10 languages, it was widely disseminated and a pilot project was conducted in a group of 17 hospitals in Europe and Australia. With the development of this process, it became evident that there was need to improve further the technical tools to assess and improve the respect of children's rights in hospital. In line with the HPH Standards and Principles on Health Promotion, the Task Force HPH-CA decided to prepare a set of assessment tools on children's rights in hospital for different stakeholders, namely:

- Self-evaluation tool for management;
- Self-evaluation tool for health professionals;
- Evaluation tools for children aged 6-11 and for children and adolescents aged 12-18;
- Evaluation tool for parents and carers.

Our vision is that child and adolescent health promotion is an integral part of the everyday practice in hospitals and other health services. Specifically, we aim to:

Ensure that children's and adolescents' assets, their empowerment for health and the development of their human potential are consistently and effectively utilised and capitalised in hospitals and health services providing healthcare for children and adolescents.

Ensure that child rights are recognised as a key component of and a fundamental contributor to effective health promotion, by collecting and disseminating knowledge, case-studies and evidence on the practical value of respecting child rights in health settings.

Enhance child participation and promote their effective and equal involvement in the assessment, planning and improvement of healthcare delivered in hospitals and health services, across the HPH Network and beyond.

The aim of this Manual is to provide tools, which can be used in an improvement programme cycle within hospitals and health services, aimed at advancing the respect, protection and fulfilment of children's rights within those institutions. These tools will not be applicable in the same way in all settings across Europe and beyond. In particular we recognise that the tools need further adaptation to make them relevant across a range of cultures and societies. For this reason, we invite hospitals and health services to adapt them to best fit their needs and features. We welcome feedback and collaboration to further develop the standards and their wider social and cultural applicability.

Ana Isabel F. Guerreiro
Task Force HPH-CA Leader

Acknowledgments

This Manual has been prepared by the members and partners of the Task Force HPH-CA, namely Ana Isabel F. Guerreiro (Task Force Leader, Portugal), Fernando Vasco (Portugal), Giuliana Filippazzi (Italy), Isabelle Aujoulat (Belgium), Klaus Arbeiter (Austria), Kjersti J. Ø. Fløtten (Norway), J. Raquel Mullen (USA), James E. Robinson (Scotland, UK), Lagle Suurorg (Estonia), Leonor Santos (Portugal), Virginia Binns (Australia), Liz McArthur (England, UK), Maria José Planas (Spain), Micheline Ste-Marie (Canada), Marija Radonić (Croatia), Núria Serrallonga Tintore (Spain), Rosa Gloria Suárez (Spain), Stella Tsitoura (Greece), Zsuzsanna Kovács and Dóra Scheiber (Hungary), Andrew Clarke, Liam Cairns and Sandra Eismann (England, UK). A special thanks goes to Les White, Joyce Murphy, Lauren Andrew, Elizabeth Kepreotes (Australia), Paul Watson (New Zealand), Matthew Peak and Cheryl Williams (England, UK), for their support and commitment to the fulfilment of children's rights in hospital; and to the children and young people who helped revising the tool for children and adolescents.

Finally, a warm thank you goes to Fabrizio Simonelli, former Task Force HPH-CA Leader, who initiated, lead and pushed forward the respect of children's rights in hospitals within the HPH Network and beyond.

Introduction to the Manual and Tools

The context in which hospitals and health services function varies across countries, regions and continents and, often, within the same country. For this reason, the issues affecting and influencing the respect, protection and fulfilment of children's rights may vary from setting to setting. On the other hand, often children in distant countries have similar experiences of healthcare and the solution to a given problem may be the same for hospitals and health services in distinct contexts.

This Manual does not address the global dimension of issues, which affect and influence the respect, protection and fulfilment of children's rights in every local context worldwide, but it does enable hospitals and health services to assess a variety of issues, which seemed crucial for the respect of children's rights and the improvement of health promotion activities and the overall provision of healthcare services.

The Manual was prepared as a guide with tools for improvement of the respect of children's rights in hospital and health services, which can be used as a starting basis for an improvement cycle. Any hospital or health service within and outside the HPH Network is free to use it and adapt it fully or partially to its own needs and circumstances.

Methodology

The role of hospitals and health services in children's rights

Increasingly, children are being considered as subjects of rights in all their life settings, including healthcare. There is growing evidence of the translation of children's rights and the principles and norms enshrined in the Convention on the Rights of the Child (OHCHR, 1989) at health provision level, which allows to inform hospitals and health services how to understand and improve the respect, protection and fulfilment of children's rights within healthcare.

The implementation of the *Self-evaluation Model and Tool on the Respect of Children's Rights in Hospital* (SEMT), provided a range of examples of what hospitals within and outside the HPH Network across Europe and Australia are doing to include children's rights in daily hospital practice (Simonelli F and Guerreiro AIF, 2010). At the same time, it demonstrated the importance of respecting children's rights, as a way to improve healthcare delivery within the context of hospitals and health services. For this reason, the Task Force HPH-CA recognises the respect of children's rights as a key component of health promotion and of a child and family-centred care. This Manual was prepared for all hospitals and health services interested in improving the respect of children's rights in hospitals and health services, as well as, their health promotion activities.

Internal and external quality assessment

Internal and external quality assessment in hospitals and health services are the most common methods of assessment, accreditation and quality improvement. This Manual follows the Manual on HPH Standards on Health Promotion and deals with self-assessment on the respect of children's rights in hospitals and health services, as well as, the opinions of children, adolescents and parents and carers.

Self-assessment is understood as:

“A process used by healthcare organisations to accurately assess their level of performance in relation to established standards and to implement actions for continuous improvement. Self-assessment may cover all the hospital's activities or it may focus on specific issues, such as health promotion. It enables staff to identify areas of good practices and areas where there is a need for improvement. Hospital staff can then prioritize and plan the actions needed or replicate good practices in other departments of the hospital (WHO, 2006).”

There are benefits and constraints of using a self-assessment approach. Benefits can be a low cost opportunity to embed such methods within the quality assurance systems of a health facility or health service. This can result in a sustainable approach to addressing children's rights and improving the experience of care within health systems. It can also increase a feeling of ownership and empowerment in health workers involved in the process of making improvements in care.

Constraints include challenges of gathering views and opinions from stakeholders (particularly children, families and junior health professionals) in a way that is freely given and independent.

External assessment methods can ensure all participants can give their views freely and can also ensure that assessment findings can be transparently presented. However costs and resources required can restrict the options for adopting an external assessment approach.

In some places civil society organisations, academic institutions or patients associations may provide valuable assistance in the assessment. Institutions or services that are interested in conducting an assessment may wish to consider engaging with such organisations to assist in the assessment, the improvement process, and the subsequent evaluation of changes made.

The stakeholders

The provision of a healthcare service entails the involvement of a variety of stakeholders, namely those who plan and manage the services (management), those who deliver healthcare services (health professionals), those who receive them (children and adolescents) and other key stakeholders involved (parents and carers). Each of these groups of stakeholders has a unique role and experience within the provision of healthcare services. This Manual includes evaluation tools for the abovementioned four groups of stakeholders, because only with the knowledge and information gathered from them will it be possible to design, plan, deliver and improve the best possible healthcare services for children, in line with children's rights and the HPH principles of health promotion.

The standards

The standards presented in this Manual are based on the results of the implementation of the SEMT in 17 hospitals, the implementation of the tool for children aged 6-11 at the Meyer University Children's Hospital in Florence (Italy) and Sydney Children's Hospital (Australia) and the inputs provided by children and adolescents with experience in assessing healthcare service in Durham city (UK), facilitated by the NGO Investing in Children. Furthermore, the tools draw from the Task Force HPH-CA members' direct experience and other examples and studies around the world. The standards are not binding, however the Task Force HPH-CA strongly encourages HPH members providing healthcare to children to use the Manual and adapt its tools within their quality improvement activities.

The tools included in this Manual are organised under seven standards.

Standard 1 evaluates the 'best quality possible care' delivered to all children, understood as a care that takes into account the clinical evidence available, the respect of children's rights and patient and family's views and wishes.

Standard 2 evaluates to what extent the healthcare services respect the principles of equality and non-discrimination of all children.

Standard 3 evaluates how play and learning are planned and delivered to all children.

Standard 4 evaluates the rights of all children to information and participation in healthcare decisions affecting them and the delivery of services.

Standard 5 evaluates to what extent healthcare services are delivered in a safe, clean and appropriate environment for all children.

Standard 6 evaluates the right of all children to protection from all forms of physical or mental violence, unintentional injury, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse.

Standard 7 evaluates the provision of pain management and palliative care to children.

For each standard, several sub-standards and specific questions for the four groups of stakeholders were identified. The questions are adapted to each of the groups, however they aim to address and gather information on the same issues.

In line with the HPH Manual on Health Promotion, each of the seven standards has three levels, as follows:

Level one is the level of the **standard** itself. The seven standards address quality services for children; equality and non-discrimination; information and participation; safety and environment; protection and pain management and palliative care. In the tool for children and adolescents aged 12-18, the standard on protection was removed.

Level two is the level of the **substandards**. Substandards operationalise the standard and break it down into its principle components. The tools addressed to management, health professionals and parents and carers have overall 22 substandards; the number of substandards per standards varies from 3 to 5.

Level three are the **measurable elements**. The measurable elements aim to enable hospitals and health services to assess compliance with the standard, however they do not provide an exhaustive list of the full requirements or dimension of the standard and principles in question. Listing the measurable elements is intended to provide greater clarity to the standards and help organisations in the improvement of the respect, protection and fulfillment of children's rights in hospitals and health services. Measurable elements are those requirements of the standard that will be reviewed and assessed to be or not fulfilled.

At the end, there is an example of a possible template to use for a Focus Group Discussion with children or parents/carers.

Proposed methodology for programme implementation

The complete set of tools has not yet been piloted within a consistent framework or methodology. But based on the experiences gained and collated during their development, the Task Force HPH-CA would suggest the following:

The first step towards a successful evaluation and improvement programme implementation is the involvement and commitment of **management**, such as the chief executive, governing body and senior managers of the hospital. In some settings it may also be valuable to liaise with the Ministry of Health.

Secondly, a **Project Leader or Team** must be identified and appointed to lead the process. This person/team may already be responsible for other quality improvement initiatives and/or have a sound knowledge of children's rights in hospital and health services.

The next step is to identify the **components of the four groups of stakeholders**. It is suggested that the following figures are involved:

Management:

- Senior manager;
- Senior nurse;
- Senior doctor;
- Human Resources member;
- Administration staff.

Health Professionals:

- Doctors and nurses of different categories and levels;
- Other medical staff (i.e. radiology, anaesthesiology);
- Reception or administrative staff;
- Cleaning staff.

Children:

- Children who are chronically ill and have long-term experience of hospitalisation, of different age groups;
- Children who have been at the hospital or health service few times as either in-patient or out-patients, of different age groups.

Parents or Carers:

- Representatives of patient associations;
- Parents or carers, whose children are chronically ill and have long-term experience of hospitalisation;
- Parents or carers, whose children have been at the hospital or health service few times as either in-patient or out-patients.

There are different methodologies for **gathering information**, which will have to be decided by the project leader or leading team. It may be decided to do a in-house **survey** or **focus-groups**.

The tools can be adapted to both formats, however it is suggested that both formats are used to the extent possible, as they complement each other and may enable to gather different key information. It is important, particularly in a self assessment, that all participants are able to give their views freely and confidentially.

There is no specific number agreed on how many participants to interview or include in the assessment. This will vary with the size of facility to be assessed, the resources available and the methods chosen. The following suggestions may help:

Health professionals – in a small facility it is best to include all, or as many as possible. In larger healthcare environments a representative number is needed, preferably with a representative mix of different types of health professionals. Ideally, participants should be selected systematically and randomly (for example from staff lists).

Children and families – as many as the time and resources will allow. Enough to provide a representative sample of children and parents using the services in the area to be assessed. Further advice can be sought in relation to the optimum sample for size of facility. Like health workers, it is best to select randomly and not rely on volunteers due to potential for bias.

After the collection of information, the project leader or leading team will have to **collate the information gathered from the different stakeholders**. In some places the availability of computer equipment and software for collating the information may be limited, so this needs to be considered at the planning stage of the assessment exercise.

The results should be summarised in a **report in different formats**, including a child-friendly format, which is distributed to all participants. It is suggested that the **results are discussed** within or between the groups of stakeholders that assessed the standards.

At this point, the project leader or leading team should be able to put together an **Action Plan** shared by all stakeholders. The next step is the **implementation of actions for the improvement** of the respect, protection and fulfilment of children's rights in hospital or health services. These actions do not necessarily entail spending significant amounts of human and financial resources.

The final step of the programme cycle is the **monitoring and evaluation** of the implementation and impact of actions. In many cases it will be useful to repeat the tools, or parts of the tools, in order to reassess and demonstrate change. In other situations the selected area for improvement may not require this. It is recommended that there is a strong focus on the perspectives of children and families (service users) when confirming that change or improvements have occurred.

Good practices on the Respect of Children's Rights in Hospital

The final product of this Manual is a small collection of Good Practices from HPH Members on how to respect, protect and fulfil children's rights in hospitals and health services. The Good Practices aim to provide examples of how different health facilities around the world are

working and implementing children's rights. This section is currently under preparation and will be published soon after the Manual and tools for assessment and improvement.

Glossary

The Task Force HPH-CA also planned to prepare a Glossary to be included in the Manual, with the main terms used in the Manual and Tools, however this was not possible. A Glossary may be prepared and published in due course.

Bibliography

The final section of this Manual is a short Bibliography of documents published by policy-makers, nurses, doctors and other experts on children's rights in hospital, health services and health, in broader terms. Hospitals and health services may wish to consult them for further information on legislation, consultations with children and terminology on children's rights.

Bibliography

Alderson and Montgomery (1996) in Alderson, P (2007) Competent children? Minors' consent to health care treatment and research; *Social Science and Medicine* 65; 2272:2283

Alderson P and Montgomery J (2001) *Health care choice: making decisions with children*. IPPR. London

Committee on the Rights of the Child (2009) General Comment No. 12: *The right of the child to be heard*. CRC/C/GC/12 1 July 2009

Committee on the Rights of the Child (2003) General Comment No. 4: *Adolescent health and development in the context of the Convention on the Rights of the Child*

Council of Europe (2011) *Guidelines on Child Friendly Healthcare*

Council of Europe (2011) *Lisbon Declaration on Child Friendly Healthcare*

Council of Europe (1996) *European Convention on the Exercise of Children's Rights*

Coyne I (2006); Consultation with children in hospital: children, parents' and nurses' perspectives; *Journal of Clinical Nursing* 15,61–71

Franklin, Anita and Sloper, Patricia (2006) *Listening and responding? Children's Participation in Healthcare within England*; in Freeman, Michael (ed); *Children's Health and Children's Rights*; Martinus Nijhoff Publishers

Freeman Michael (edited by) (2006) *Children's Health and Children's Rights*; Martinus Nijhoff Publishers

European Association for Children in Hospital (1988) *European Charter for Children in Hospitals*

Guerreiro AIF *et al.* (2009) *The right of migrant children to healthcare: the response of hospitals and health services*; WHO Collaborating Centre for Health Promotion Capacity Building on Child and Adolescent Health and the International Organisation for Migration (IOM)

Hodgkin R, Newell P. *Implementation Handbook for the Convention on the Rights of the Child*; Fully Revised third Edition. UNICEF, 2007

Huertas JAD and Guerreiro AIF (2011) *Child Friendly Healthcare for and with children in Europe*. Council of Europe

Instituto de Apoio à Criança (2006) *Acolhimento e Estadia da Criança e Jovem no Hospital*; Lisbon: Instituto de Apoio à Criança, Sector da Humanização dos Serviços de Atendimento à Criança. Portugal

International Children's Palliative Care Network. ICPCN Charter. Available at <http://www.icpcn.org.uk/page.asp?section=000100010014>

- Kilkelly U (2011) *Child-friendly healthcare: the views and experiences of children and young people in Council of Europe member States*. Council of Europe
- Kirby P, Lanyon C, Cronin K, Sinclair R (2003) *Building a Culture of Participation: Involving children and young people in policy, service planning, delivery and evaluation*. Handbook. Department for Education and Skills. UK
- Lansdown G (2005) *The evolving capacities of the child*. Innocenti Research Centre, UNICEF/Save the Children, Florence
- Lansdown G (2000) Implementing children's rights and health. *Arch Dis Child* 2000; 83: 286-288
- Lansdown G (1995) *Taking part: Children's participation in Decision Making*. London: Institute for Public Policy Research.
- Moore L, Kirk S (2010) A literature review of children's and young people's participation in decisions relating to health care; *Journal of Clinical Nursing*, 19, 2215-2225
- Nicholson S, Clarke A (2007) *Child Friendly Healthcare: A manual for health workers*; Maternal & Childhealth Advocacy International, UK. Available in English and Spanish at www.cfhiuk.org
- OHCHR (1989) *Convention on the Rights of the Child*
- Santos Pais M, Bissell S. *Overview and implementation of the UN Convention on the Rights of the Child*. *Lancet* 2006; 367
- Schwethelm B, Brylske P, Munn E, Capello C (2010) *Child-Centred Health Care Trainer Manual: A 5 Day Inservice Training Course for Pediatric Health Care Workers*, Partnerships In Health - Suisse / John Hopkins Hospital Children's Center, Baltimore. ISBN 9782839907170
- Simonelli F, Guerreiro AIF, Zappulla A and Simonelli I; Children's rights in health settings; *Prospettive Sociali e Sanitarie*; Year XLI - n. 2 - 1 February 2011
- Simonelli F and Guerreiro AIF (eds); *The respect of children's rights in hospital: an initiative of the International Network on 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*. January 2010
- Simonelli F, Guerreiro AIF and Sereni N (2009) *The respect of children's rights in hospital. A model and tool of self-evaluation by the International Network of Health Promoting Hospitals*; *Educazione Sanitaria e Promozione della Salute*
- Southall D *et al* (2000) The Child-Friendly Healthcare Initiative (CFHI): Healthcare Provision in Accordance with the UN Convention on the Rights of the Child; *Pediatrics* Vol. 106 No. 5 November 1, 2000 pp. 1054 -1064
- Task Force HPH-CA (2009). *Self-evaluation Model and Tool on the Respect of Children's Rights in Hospital*. Available at http://www.hphnet.org/images/stories/Final_Self-evaluation_Tool_EN.pdf

Webb E and Sergison M (2003) Evaluation of cultural competence and antiracism training in child health services; *Arch Dis Child*. 88: 291–294

WHO (2006) *Implementing health promotion in hospitals: Manual and self-assessment forms*; available at http://www.euro.who.int/_data/assets/pdf_file/0009/99819/E88584.pdf

WHO (2005) *European strategy for child and adolescent health and development*. Copenhagen: WHO Regional Office for Europe; EUR/05/5048378

WHO (2002) *Adolescent Friendly Health Services — An Agenda for Change*; Geneva. WHO/FCH/CAH/02.14