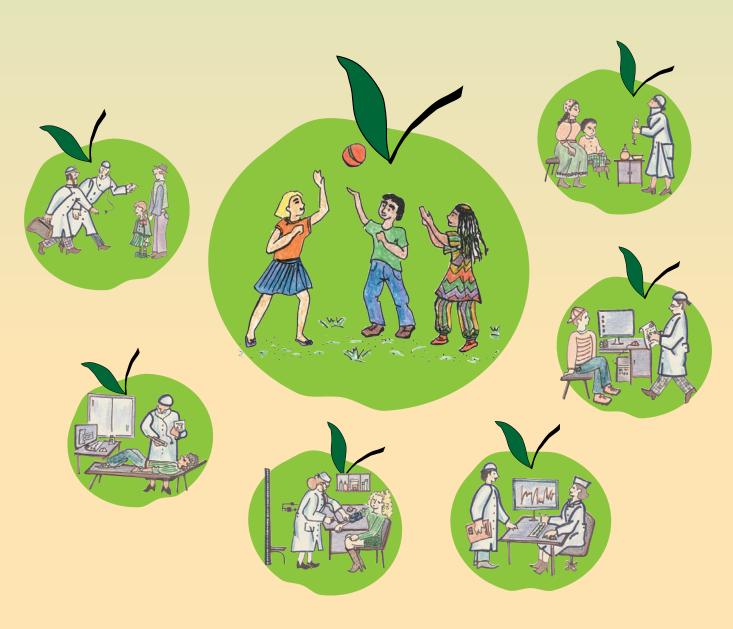
Children's rights in primary health care

Volume 1. Manual and Tools for assessment and improvement





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ABSTRACT

This publication presents a Manual and Tools for the assessment and improvement of children's rights in primary health care (PHC) for five groups of stakeholders, namely PHC services' management, health professionals, parents and carers, children aged 6-11 and children and adolescents aged 12-18. The Manual contains a short methodological guide and the five tools, which may be used through focus group discussions or as a survey.

The series Children's rights in primary health care consists of 6 volumes:

- Volume 1. Manual and Tools for assessment and improvement
- Volume 2. Assessment and improvement Tool for Children aged 6-11
- Volume 3. Assessment and improvement Tool for Children and Adolescents aged 12-18
- Volume 4. Assessment and improvement Tool for Health Professionals
- Volume 5. Assessment and improvement Tool for Management
- Volume 6. Assessment and improvement Tool for Parents and Carers

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ACKNOWLEDGMENTS

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INTRODUCTION

In the 25 years since the adoption of the Convention on the Rights of the Child (CRC) (1), significant experience and knowledge has been generated in relation to the interpretation of article 24 on children's right to health and its respect, protection and fulfilment in children's various life settings. The importance of adopting a human-rights based approach to health is reinforced in the recently adopted WHO Strategy 'Investing in children: child and adolescent health strategy for Europe 2015 −2020', which states that "as human rights become better respected, they become more effective in helping governments to strengthen their health systems, deliver health care for all and improve health (2)."Within children's right to health, the CRC places a great emphasis on primary health care (PHC), which is to be the gateway to pregnant women, mothers, newborns and children throughout their life stages. This is reinforced by General Comment №15 on article 24, which declares that "States should prioritize universal access for children to primary health care services provided as close as possible to where children and their families live, particularly in community settings" (3).

Furthermore, the centrality of the role of PHC within health systems is recognised by WHO in a number of strategies and legal instruments, including the Declaration of Alma-Ata¹ (4) and the European policy for health and well-being - Health 2020 (5). PHC is the closest care to the population and most children will have contact with its services and professionals throughout their development, which makes it a privileged setting to invest in. At the same time, PHC services have a great responsibility to provide quality services to children, to give them a voice and to enable them to reach their full potential.

The development of the Manual and Tools for the assessment and improvement of children's rights in PHC is part of an ongoing process at international level that aims to translate children's rights as enshrined in the CRC into practical principles and actions that health care services can apply in daily practice. The Manual and Tools should serve as a means of assessment, identification of areas for improvement and of raising awareness on children's rights of health professionals and other stakeholders working for and with children in the health sector.

The Manual and Tools for PHC have been adapted from the *Children's Rights in Hospital: Manual and Tools for assessment and improvement*, published in 2012 (6). The aforementioned tools addressed five groups of stakeholders namely, hospital management, health professionals, children aged 6-11, children and adolescents aged 12-18 and parents and carers.

In 2012-2013, WHO Europe implemented successfully the tools in hospitals in Kyrgyzstan, Tajikistan and Moldova, in the framework of its work on improvement of hospital care for children (7, 8). This experience demonstrated both the importance and the need to address and assess the respect of children's rights in healthcare settings. Taking into account the growing recognition of the importance of children's rights in healthcare and the good acceptance of the Manual and Tools in the aforementioned countries, WHO Europe initiated a process to prepare a similar set of tools on assessing and improving the respect of children's rights in PHC.

For the preparation of the present Manual and Tools for the assessment and improvement of children's rights in PHC, working groups were established in Armenia, Norway, Portugal and the UK. Health

¹ The Declaration of Alma-Ata defines Primary Health Care as essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process.

professionals working at different levels of health care service provision gave their inputs regarding the development and applicability of the standards and sub-standards, as well as, the suitability of the questions in their contexts. The development of the Manual and Tools was prepared in consultation with a team at the WHO European Office and Headquarters.

The contents of the Manual and Tools include:

- Methodology section, which provides general information about assessment processes and a proposed work methodology for the implementation of the tools in PHC settings;
- **Assessment and improvement tool for management.** Depending on the health system, this group of stakeholders may include managers of a health facility and senior health staff. If the PHC facility is organized under a regional structure, it may also include regional managers or equivalent.
- Assessment and improvement tool for health professionals. This group of stakeholders may include any professional working at a PHC facility, from medical to administrative and cleaning staff.
- Assessment and improvement tool for children aged 6-11. This tool does not follow the same structure of the remaining tools. It is adapted to young children and aims to assess their overall experience in PHC services. It is made-up of open-ended questions, which enable children to expand on their views and provide suggestions for improvements.
- Assessment and improvement tool for children and adolescents aged 12-18. This tool
 follows the same structure of the tools for management, health professionals and parents and
 carers. The tool includes a simple template for focus group discussions that can be adapted to
 groups made up of children or parents and carers;
- Assessment and improvement tool for parents and carers. This tool aims to gather the views
 of parents and other carers. As mentioned above, it also includes a template that can be used for
 a focus group discussion.

METHODOLOGY

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. The present tools may be used both for internal (self-assessment) and external assessment. As in the tools for hospitals, these Manual and tools follow the structure of the Manual on Health Promoting Hospitals Standards on Health Promotion (9).

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.

The stakeholders

The provision of a health care service entails the involvement of a variety of stakeholders, namely those who plan and manage the services (management), those who deliver health care 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 health care services. This Manual includes evaluation tools for the abovementioned groups of stakeholders, because only with the knowledge and information gathered from them will it be possible to design, plan, improve and deliver the best possible health care services for children, in line with children's rights.

The standards

The standards presented in this Manual follow closely the standards of the abovementioned *Children's Rights in Hospital: Manual and Tools for assessment and improvement* (4). In the adaptation of the hospital tools to the PHC setting, some standards have been eliminated and others created, while the majority have remained the same. The sub-standards and questions have been adapted individually to PHC.

The tools included in this Manual are organised under eight standards, as follows:

Standard 1 evaluates the best quality possible health care delivered to all children, which includes, *inter alia*, clinical evidence available, adequately trained staff, monitoring and evaluation systems and the adoption of a Charter on Children's Rights in PHC.

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

Standard 3 evaluates PHC services in supporting the realization of the mother's right to health, pregnancy and the role of parents, as a key determinant of children's health, nutrition and development.

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

Standard 5 evaluates to what extent health care services are delivered in a safe environment designed, furnished and equipped to meet children's needs.

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 right of all children to individualized, gender-specific², culturally and age appropriate management of chronic illness and other long-term health care needs.

Standard 8 evaluates the right of all children to individualized, gender-specific, culturally and age appropriate prevention and management of pain and palliative care.

For each standard, several sub-standards and specific questions for the five 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 eight standards has three levels, as follows:

Level one is the level of the **standard** itself. The eight standards address quality services for children; equality and non-discrimination; parenting; information and participation; safety and environment; protection; chronic illness and other long-term health care needs; prevention and management of pain and palliative care. As aforementioned, in the tool for children and adolescents aged 12-18, the standards on parenting and protection and the questions related to palliative care have been removed.

Level two is the level of the **substandards**. Substandards operationalise the standard and break it down into its main components.

Level three are the **measurable elements.** The measurable elements aim to enable PHC services to assess compliance with the standard. Listing the measurable elements is intended to provide greater clarity to the standards and help organisations in the improvement of the respect, protection and fulfilment of children's rights in PHC services. Measurable elements are those requirements of the standard that will be reviewed and assessed to be or not fulfilled. In the tool for management, under each measurable element, between brackets, is a component entitled **evidence**. The aim of this component is to provide guidance to assessment teams on where to find the relevant information to assess the measurable element. Finally, there is a box where teams can add comments and select whether the given question is fulfilled, partly or not fulfilled. Teams responsible for conducting and participating in the assessment should look at the tools not merely as a checklist, but as a dynamic means to continuously improve and define more effective responses to children's needs in their various life stages, from a child rights perspective.

At the end of the assessment tool for parents and carers and the tool for children and adolescents aged 12-18, there is an example of a possible template to use for a Focus Group discussion with children or parents and carers.

² Gender-specific strategies acknowledge the differences in norms and roles for women and men (boys and girls) and any associated control over resources. These strategies accommodate women's and men's (boys and girls) different roles, norms and responsibilities and their specific needs within a programme or policy. Such interventions make it easier for women and men to fulfill duties ascribed to them based on their gender roles (Level 4 on WHO Gender Responsive Assessment Scale).

Proposed methodology for programme implementation

The tools may be implemented as part of a national programme on improvement of primary health care for children or on an individual facility basis.

In the hospital assessments carried out by WHO in Kyrgyzstan, Tajikistan and Moldova, national experts were assigned to be responsible for the overall data collection. The experts travelled to the participating hospitals and conducted briefings of respective hospital staff or focal points on the self-assessment process: tools, methodology and time frame. Prior to this visit each hospital assigned two staff members that carried out a self-assessment (hospital study team) (5, 6). Especially in Kyrgyzstan and Tajikistan, all groups of stakeholders were involved. The hospital assessments were carried out through a mixed methodology, namely individual interviews with children, parents and carers; and focus groups with health professionals and hospital management. The results of all hospitals were collated and analysed on a national basis. After this, a comparative report was prepared for Kyrgyzstan and Tajikistan and another one for Moldova. The reports include work methodology, analysis of results per standard, lessons learned and recommendations for Ministries of Health and hospitals. A national assessment such as this one has the advantage of identifying strong points and common challenges across a country, which enables central authorities to plan nation-wide strategies. The assessment carried out by WHO in the three countries has demonstrated the value of using the tools for assessing and identifying measures for improvement, as well as, the benefits of involving children, parents and carers in the assessment.

The actual process of assessment in an individual PHC facility is similar to the methodology proposed in the hospital tools, as presented below:

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 PHC facility. If the PHC facility is organised under a regional structure, it will be useful to engage the regional manager, director or equivalent. Even if the assessment is conducted on an individual level, 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 or team may already be responsible for other quality improvement initiatives and/or have a sound knowledge of children's rights in health services.

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

Management:

- Regional managers;
- 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. social workers, psychologists, school nurses, etc);

- Reception or administrative staff;
- Cleaning staff.

Children:

- Children who are chronically ill and have long-term experience of accessing PHC services, of different age groups;
- Children who have been at the PHC facility few times for regular check-ups, appointments or other motive, of different age groups;
- · School-aged children;
- Vulnerable groups of children, who may face barriers in accessing PHC services.

Parents or Carers:

- Representatives of patient associations;
- Parents or carers, whose children are chronically ill and have long-term experience of accessing PHC services, of different age groups;
- Parents or carers, whose children have been at the PHC facility few times for regular check-ups, appointments or other motive, of different age groups;
- Other groups of parents or carers.

In addition to these stakeholders, external participants may be invited. These may include, among other, child rights experts, professionals with prior experience in assessing and planning improvement on the respect of children's rights at PHC level, representatives of central authorities or other, as deemed relevant to the PHC facility in question.

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 an 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:

<u>Health professionals</u> – in a small facility it is best to include all, or as many as possible. In larger health care 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).

<u>Children and families</u> – 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 PHC services.

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.

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