



Charter on
**The Rights of Children
and Young People
in Healthcare Services
in Australia**



CHILDREN'S
HOSPITALS
AUSTRALASIA



association for the wellbeing
of children in healthcare





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Charter of Children's and Young People's Rights in Healthcare Services in Australia.



Dear Colleagues,

In November 1989 The United Nations Convention on the Rights of the Child (UNCRC) was opened for signature and was ratified by Australia in the months to follow. As we progress beyond the 22nd anniversary of that milestone, it is opportune to reflect and to consider further steps in fulfilling those aspirations.

A large number of the articles of the UNCRC apply to aspects of clinical care and health services. "The International Taskforce on Health Promotion for Children and Adolescents in and by Hospitals and Health Services" commenced work in 2004 towards the development of a "Self Evaluation Model and Tool on the Respect of Children's Rights in Hospitals and Health Services". I have had the pleasure of working with the Taskforce and of piloting the model and tool in Australia. Children's Hospitals and Paediatric Units Australasia (CHA) has subsequently extended that work to facilities across all states of Australia. We have documented a great many exemplary findings across our health services, demonstrating both commitment and good practice in the respect of children's rights. We have also found opportunities for improvement; most notably the relative absence of a "Charter of Children's and Young People's Rights in Health Care Services", somewhat in contrast to the use of such documents in comparable European settings.

The consequent development of the attached Charter is a product of exemplary collaboration by CHA partners and of outstanding leadership by members of the Expert Reference Group, along with the hard working Writing Subcommittee. I wish to acknowledge them all: Lizzie Harnett, Joyce Murphy, Lauren Andrews, Paul Watson, Bruce Lord, Anne Cutler, Virginia Binns, Karen Zwi, Shanti Raman, Stephen Simpson, Trish Davidson, Elizabeth Kepreotes, Lynn Gillam, Judith Duncan, Ros McDougall, Sally Haseler, Liz Chatham.

Following the launch of the Charter on the Rights of the Child and Young People, consensus statement, in November 2010, further extensive consultation was undertaken with a range of stakeholders and authorities. That process and the incorporation of the feedback ensured agreement on a uniform final Charter across Australia. We now have the responsibility to promote, support and monitor its implementation through the appropriate state and territory jurisdictions. We make this commitment as we present the revised Charter to colleagues across the nation.



Best wishes,

Prof Les White AM
Chief Paediatrician, NSW
Chair, Expert Reference Group

Introduction

Children's Hospitals Australasia (CHA) is the widely regarded non-for-profit peak body for children's hospitals and paediatric units in Australasia. CHA's vision is to enhance the health and well-being of children and young people. CHA achieves this by supporting member hospitals to aspire to excellence in the clinical care of children by benchmarking, and sharing knowledge. Membership includes the leading children's hospitals and health services located throughout Australia and New Zealand.

The Association for the Wellbeing of Children in Healthcare (AWCH) is a national, non-profit organisation of parents/carers, professionals and community members who work together to ensure the emotional and social needs of children, adolescents and their families are recognised and met within hospitals and the healthcare system in Australia. AWCH's vision is the best possible healthcare for children and young people and to advance the well-being of children and young people in healthcare. AWCH advocates for a family-oriented approach to the care of children, acknowledging that families are the main support and strength for children and young people when they are sick or have a chronic illness or condition.

In 2010, the 21st anniversary of the UN Convention on the Rights of the Child, the CHA Board initiated a project on children's rights in healthcare services. To strengthen this work CHA, invited AWCH to partner with them. This Charter of Rights, and a version in an appropriate format for children and young people, form part of that project. The project is part of a broader initiative undertaken by the Taskforce on Health Promotion for Children and Adolescents in and by Hospitals and Health Services.

The Charter seeks positive approaches in the practical implementation of rights for children and young people in healthcare services. The Charter has been developed with input from CHA and AWCH members and their networks.

Definitions

‘Child or young person’ – every human being from birth to the age of eighteen years unless under the law applicable, majority is attained earlier.

‘Decision-making’ – any choice to receive treatment, to refuse treatment or to withdraw consent to treatment.

‘Family’ – the group of people who constitute the child’s or young person’s family is defined by the child or young person and those close to him or her. It is not necessarily limited to blood relatives.

‘Kinship group’ – in Aboriginal and Torres Strait Islander culture, the group of people who share a relationship with the child or young person, which could go beyond blood relatives, and who constitute their family and community.

For Aboriginal and Torres Strait Islander children and young people, the terms ‘family’ and ‘kinship group’ may be used interchangeably in this document.

‘Parent/Carer’ – an adult in a primary caring role, including biological parents, adoptive parents, legal guardians, grandparent, carers and foster carers. Members of the extended family or community may also be involved in the child’s or young person’s care, depending on the family’s circumstances.

Preamble

There are three reasons why a Charter of healthcare rights specific to children and young people is necessary.

Firstly, children and young people experience illness, injury and disability in a different way from adults, making them particularly susceptible to harm. They are entitled to special care and support.

Secondly, children and young people are vulnerable because of their developmental immaturity. This vulnerability is compounded by the way in which our society is structured. Children and young people lack political and economic power within our society, including

within our health system. This powerlessness is not an inherent or inevitable consequence of childhood, rather, it can be a consequence of social structures.

Thirdly, children's and young people's level of dependence on the adults around them is constantly evolving along a continuum from dependence to independence. This is a result of the rapid physical, cognitive, developmental, social and experiential changes which characterise childhood and adolescence. Many people are involved in decision-making for children and young people. Therefore both co-operation and respect between children, young people, families and healthcare professionals are particularly crucial in relation to children's and young people's healthcare. Children and young people ought to be involved in decision-making about their healthcare to the greatest possible extent, in line with their capacities for understanding and participation. Healthcare providers have an obligation to fulfil their responsibilities to children and young people by providing care that takes into account children's and young people's rights, their evolving capacities, and the rights and responsibilities of parents/carers to provide direction and guidance to their children.

This Charter is a package of eleven rights. Taken together, the rights aim to ensure that children and young people receive healthcare that is both appropriate and acceptable to them and to their families. Children, young people and their families should be able to exercise choice in healthcare services to the greatest extent possible.

Three general principles underpin the Charter. The first is the primary consideration of the child's or young person's best interests. The second is hearing and taking seriously all children and young people. The third is the recognition that the family is the fundamental group in children's and young people's lives. The family is the environment most conducive to children's and young people's growth and wellbeing and ought to be protected and supported by our healthcare system. All three of these principles should be considered in the interpretation and implementation of all of the other rights.

The Charter applies to all children and young people in all healthcare services which they access. It also applies to health promotion and health education activities aimed at children and young people. Healthcare services include (but are not limited to) hospitals, community health centres, general practices and specialists' rooms. The rights are aspirational to the maximum extent of each organisation's available resources. The statement or restatement

of a right in this Charter must not be taken to diminish that of any other right. A right not included in this Charter must not be taken to be abrogated or limited only because it is not included in this Charter or is only partly included. Children, young people, families and healthcare professionals must be encouraged and supported to speak up whenever these rights are breached.

The specific references to Aboriginal and Torres Strait Islander children and young people in the Charter are indicative of the fact that these children and young people face significant challenges in exercising their rights and that they continue to experience serious disadvantage in their health status. Indigenous children's and young people's rights in healthcare services are the same as for every child and young person, but specific actions are needed to address disparities in access to care. In all contexts, Aboriginal and Torres Strait Islander people's self-determination is a vital ingredient for healthcare access and provision.

Some groups of children and young people (such as those in out-of-home care, those with disabilities, those from culturally and linguistically diverse backgrounds, and refugees) will require additional services that address their specific health needs. Particular sensitivity to the backgrounds and abilities of these children and young people will be required in the delivery of these services.

The Charter is based primarily on: the Australian Charter of Healthcare Rights; the New Zealand Code of Health and Disability Services Consumers' Rights; the United Nations Convention on the Rights of the Child; and, the Charter of the European Association for Children in Hospital.

Children's and young people's rights in healthcare services

Every child and young person has a right:

- 1. to consideration of their best interests as the primary concern of all involved in his or her care.**
- 2. to express their views, and to be heard and taken seriously.**
- 3. to the highest attainable standard of healthcare.**
- 4. to respect for themselves as a whole person, as well as respect for their family and the family's individual characteristics, beliefs, culture and contexts.**
- 5. to be nurtured by their parents and family, and to have family relationships supported by the service in which the child or young person is receiving healthcare.**
- 6. to information, in a form that is understandable to them.**
- 7. to participate in decision-making and, as appropriate to their capabilities, to make decisions about their care.**
- 8. to be kept safe from all forms of harm.**
- 9. to have their privacy respected.**
- 10. to participate in education, play, creative activities and recreation, even if this is difficult due to their illness or disability.**
- 11. to continuity of healthcare, including well-planned care that takes them beyond the paediatric context.**

Explanatory notes

1. Every child and young person has a right to consideration of their best interests as the primary concern of all involved in their care.

The term 'best interests' in this context refers to the child's or young person's overall wellbeing. Wellbeing is a holistic concept incorporating four equally important and inseparable elements: physical, spiritual, family and mental. For Aboriginal or Torres Strait Islander children and young people, their 'best interests' must also consider the family's and community's physical, social and emotional wellbeing.

The course of action that is in the child's or young person's best interests is the course of action that produces the greatest benefit to that child or young person, taking into account any risks or costs as well. Benefit is in part determined by what is important to the child or young person himself or herself, and so the child's or young person's own values and aspirations must contribute to any assessment of what is in his or her best interests.

The child's or young person's own assessment of what would be in their best interests ought to carry great weight, in line with their capacity. The child's or young person's capacity is situation-specific and will depend on their experience in the same or similar situations, rather than on his or her age or intelligence. The capacity of children and young people can be enhanced when they are guided and accompanied by parents/carers and extended family or kinship group in a manner consistent with their evolving capacities. Friends or other adults who have a close relationship with the child or young person can also offer valuable support.

Children and young people should have the right to have a person of their choice with them at all times unless this places at risk their wellbeing or that of another person. The task of assessing a child's or young person's evolving capacity is specific to the particular situation and is best conducted within an ongoing social group of which the child or young person is a part, such as a family or kinship group. This could include seeking input from family members or having family members present.

Considering the collective cultural rights of the child or young person is part of determining the child's or young person's best interests. However, the best interests of the group

cannot be used to justify neglecting or violating the best interests of the child or young person.

In most cases, parents/carers are well-placed to assess what would be in their child's best interests as they know their child most intimately. Healthcare providers also provide an important perspective on the child's or young person's best interests. Their expertise and experience with many children and young people enable valuable insights. Consequently any assessment of what is in the child's or young person's best interests should be a collaborative process that respects and involves the child or young person, and takes into account the rights and duties of parents/carers and the healthcare providers responsible for the child's or young person's care.

The consideration of the best interests of the child or young person is both an individual and a collective right. For all policies and programmes that affect them, children and young people should be consulted and given an opportunity to participate in the process of deciding what is in their best interests. Such consultation should include meaningful participation by all children and young people and their families.

2. Every child and young person has a right to express their views, and to be heard and taken seriously.

Healthcare providers have an obligation to respect the child's or young person's right to express their view in all matters affecting them. Healthcare providers also have an obligation to give due weight to this opinion in accordance with the competence of the child or young person. Children and young people may express their views directly or through a representative. To enable children and young people to participate in decision-making processes, healthcare providers need to create an environment based on trust, the capacity to listen, information-sharing and sound guidance.

Healthcare providers must be attentive to the many bodily ways in which children and young people express their views. Expression begins at birth and can include cries, gestures, posture, verbal communication, changes in physiological parameters and interactions with others, particularly parents/carers. Children's and young people's views may also be expressed through play, art and other activities. Healthcare providers should attempt to

understand and make sense of children's and young people's communications, rather than assuming that they do not make sense.

Some children and young people may need or want help to express their views both verbally and non-verbally. Some children will require communication assistive devices in order to meet their right to be heard. The right to be heard includes the right to a representative who will advocate on the child's or young person's behalf in such cases. The right to be heard also includes the right to culturally appropriate interpretation. Further, the right not to express one's opinion is also part of the right to be heard.

The right to be heard and taken seriously also applies at a policy level. Children's and young people's views should be sought when making decisions about healthcare in general and to improve their experience of healthcare. This consultation needs to be appropriate and enabling for children and young people; what works for adults is not necessarily the right approach for engaging children and young people.

Children and young people have the right to be empowered to voice any concerns that they have about their healthcare and to have these dealt with appropriately. A child's or young person's complaint should always be investigated and addressed. Children and young people should be encouraged to speak up about their concerns to family members or staff. In some circumstances, a child or young person may need assistance to do this from an advocate. The advocate might be a parent/carer or an independent person. When a child or young person makes a complaint, he or she (not just their family) should be informed about the investigation and outcome.

3. Every child and young person has a right to the highest attainable standard of healthcare.

Every child and young person is entitled to the highest quality, safe and expert care.

Children's and young people's health services should take a comprehensive approach to the wellbeing and development of children and young people, addressing the four inseparable and equally important elements of the physical, spiritual, family and mental. Children and young people should be cared for by healthcare providers with knowledge of children's and young people's culture, health, development and learning. The physical environment of a

healthcare service should be welcoming for children, young people and their families. The layout and decoration should facilitate feelings of comfort, safety and control.

Health services should be accessible to children and young people without discrimination on the basis of their ethnicity, race, social economic status, religion, gender, age, sexual orientation, disability, illness, appearance, language or culture.

As much as possible, healthcare should be provided in the home and community. Health services should be planned and administered in co-operation with the communities concerned. When a child or young person is admitted to hospital, this should be as close to home as possible within the bounds of quality and safety, and consistent with good clinical outcomes. Travelling to access healthcare services can involve significant stress and cost for a family, but is sometimes necessary for the child or young person to receive the best possible care. Children and young people living in cities, regional areas and remote locations are all equally entitled to high quality healthcare that addresses their needs.

Health service providers have a duty to ensure information is available to Aboriginal or Torres Strait Islanders and special consideration should be given to providing information in other languages. Special consideration should be given to ensuring that all healthcare services are both developmentally appropriate and culturally safe (Ramsden, 2002).

Healthcare service providers have a positive duty to ensure that Aboriginal or Torres Strait Islander children and young people have equal access to health services. Aboriginal or Torres Strait Islander children and young people are also entitled to specific services aimed at redressing current health inequalities. Employment of Aboriginal or Torres Strait Islander healthcare workers should be available across healthcare services wherever possible.

All healthcare services should encourage optimal nutrition for infants, children and young people. Extensive resources that are culturally safe and free of charge should be available to help new mothers establish breastfeeding. Breastfeeding mothers should also be supported to continue breastfeeding while in any health care setting.

4. Every child and young person has a right to respect for themselves as a whole person, as well as respect for their family and the family's individual characteristics, beliefs, culture and contexts.

All children, young people and their families are entitled both to respect for their culture and beliefs and to culturally appropriate care. Discrimination against children or young people and their families on the basis of ethnicity, race, economic status, religion, gender, age, sexual orientation, disability, illness, appearance, language or culture is unacceptable. Healthcare providers must be sensitive to the values of different cultural groups, and provide services in ways that respect the dignity of each child or young person and their family and cultural group.

Some groups of children and young people (such as those in out-of-home care, those with disabilities, those from culturally and linguistically diverse backgrounds, and refugees) will require additional services that address their specific health needs. Particular sensitivity to the backgrounds and abilities of these children and young people will be required in the delivery of these services.

5. Every child and young person has a right to be nurtured by their parents and family, and to have family relationships supported by the service in which the child or young person is receiving healthcare.

Every child and young person has the right to be cared for by their parents/carers in a manner consistent with the evolving capacities of the child or young person. Members of the extended family or community may also be involved in the child's or young person's care, as provided for by local custom. Healthcare organisations and healthcare providers need to support family and kinship relationships, and respect the responsibilities of parents/carers to care for and guide their children and young people. This is achieved by actively facilitating participation by families in decision-making, planning and the day-to-day care of their child while he or she is in a healthcare service. Parents/carers should be encouraged to stay with their children, and offered support and services to facilitate this.

Children and young people are entitled to their parents/carers' and family/kinship group members' advice and emotional support when participating in decisions about their healthcare. Close family relationships mean that parents/carers are often uniquely

positioned to provide advice and support to their children. Family and kinship relationships need to be recognised, encouraged and supported in healthcare services by involving families or the kinship group in decision-making, in a way that reflects and respects the capabilities of the child or young person.

Healthcare for children and young people needs to be family-centred. The healthcare provider needs to encourage a parent/carer (or person trusted by the child or young person) to accompany and support the child during any procedures.

6. Every child and young person has a right to information, in a form that is understandable to them.

Children and young people have a right to information that they can understand about their health and healthcare. This includes information about the choice of healthcare services available. Special attention and some creativity are often necessary to ensure that children have the freedom to seek, receive and impart information and ideas, not only orally but also through other means of the child's or young person's choice such as play and art. Ensuring that the language and format used are appropriate to the child's or young person's abilities and level of understanding is essential, as is ensuring that they have understood the information given and had every opportunity to participate in the conversations about their health and care. This right to information includes the right of Aboriginal or Torres Strait Islander children and young people and those from culturally and linguistically diverse backgrounds to have access to information in their own language when possible.

It is crucial that healthcare providers talk directly to children and young people, as well as to their families, even if the child or young person may seem unable to comprehend.

Healthcare providers and families should be as open as possible with children and young people about their health and healthcare. Like all patients, children and young people are entitled to know what is going to happen to them before a procedure occurs and to be given honest information about their condition and treatment outcomes, and to be helped to select and practice strategies for coping.

Giving children and young people timely and accurate information means that they can retain a sense of control about their healthcare, particularly in hospital. Advance preparation for hospitalisation, healthcare procedures or impending surgery provides

children and young people with a sense of mastery over the healthcare environment and helps them to cope more effectively with potentially stressful situations.

7. Every child and young person has a right to participate in decision-making and, as appropriate to their capabilities, to make decisions about their care.

Children and young people have a right to be involved in decision-making about their healthcare, to the greatest extent possible in line with their capacities for understanding. Children and young people should be offered healthcare choices wherever possible. Further, they are always entitled to a second opinion. Whenever a child or young person has questions and ideas about their healthcare, these should be heard. If their views cannot be acted on, they are entitled to an explanation.

In order for children and young people to participate in decision-making, the healthcare providers caring for them ought to be available, trained and committed to communicating with children and young people. Effective communication is critical in healthcare as children, young people and their families require appropriate information in order to provide informed consent to treatment. A child or young person needs to be able to talk with the staff caring for him or her, to understand who they are and what they do, and to question them about his or her condition and treatment. Participation can include both verbal and nonverbal communication by children and young people with healthcare providers. It should also include opportunities to communicate through play, art and other media of the child's or young person's choice. Health professionals need to pay attention to ensure that appropriate responses are made to the nonverbal cues and communication by children and young people who use this as their main form of communication (for example, very young children and those with disabilities).

The right to participation extends beyond the right of every individual child and young person to participate in their care. It includes encouraging and supporting children and young people as groups to be involved in consultation on the development, implementation and evaluation of the services, policies and strategies that have an impact on them.

Informed consent must be sought from children, young people and their families before they are involved in teaching or research. Also, those who do agree to participate must

have the opportunity to withdraw at any time without having to give a reason, even if they consent initially. The decision not to participate in teaching or research must not alter access to treatment. All research projects conducted in child healthcare services must be overseen by a Human Research Ethics Committee.

8. Every child and young person has a right to be kept safe from all forms of harm.

Children and young people, like all patients, are entitled to high quality healthcare. They have a right to safe and appropriately expert care, delivered in a child and family-centred organisation. Healthcare organisations should ensure that their staff and physical environments comply with appropriate standards relating to the care of children and young people. This includes providing a developmentally and culturally safe environment. Co-operation between healthcare organisations, including timely sharing of information, is also essential to ensure that children and young people receive safe healthcare.

Taking steps to minimise distress to children and young people in healthcare services is critical. All children and young people, including newborns, are entitled to adequate pain relief. They should be protected from unnecessary pain, investigations and treatment. Wellbeing, however, encompasses more than just the absence of physical suffering. Children and young people should be treated kindly, sensitively and in an individually appropriate and culturally appropriate way at all times. As far as possible, children and young people ought also to be protected from upsetting experiences during their care. If such experiences are unavoidable, the impact should be minimised using all available strategies. Opportunities to debrief should be available for children, young people and their families if distressing events occur. Seclusion and restraint should be minimal and used only as a last resort.

Children and young people also require protection from the potential harm and burden associated with their involvement in research or teaching (including training of healthcare providers) while engaged in the healthcare system.

Children and young people have the right to be protected from abuse, neglect and exposure to family violence. If abuse, neglect or family violence is disclosed, confirmed or suspected health professionals must intervene appropriately in the best interests of the child. All

Australian jurisdictions have laws and regulations that mandate and support such actions. Co-operation between healthcare and other agencies, including timely sharing of information, is also essential to ensure children and young people are kept safe and receive safe healthcare.

9. Every child and young person has a right to have their privacy respected.

The privacy of children and young people must be respected. Privacy is not limited to personal information. A child's or young person's body is an important part of their identity and bodily privacy should be addressed in all aspects of care. This is particularly important in physical examinations and personal hygiene activities such as dressing, toileting and bathing. Children's and young people's religious and cultural beliefs may also require special responses in relation to the privacy of their bodies. Children and young people may request a staff member of the same gender and this should be accommodated whenever possible. Healthcare providers should be alert to the fact that children's and young people's wishes around bodily privacy may change as their bodies develop. These wishes should be respected.

The confidentiality of children's and young people's personal information is also important. Proper handling of children's and young people's personal health and other details is necessary to ensure that their information remains private. Keeping children's and young people's details confidential (except where this places them or others at risk), and assuring children and young people that their privacy is important, encourages them to share all of the information relevant to their care with health professionals.

Information should not be communicated outside the healthcare team or clinical consultation without the child's or young person's permission. In the event information is shared due to the risk of harm or due to legal reasons, the child would be entitled to know with whom the information has been shared.

Where it is needed for the child's or young person's safety or wellbeing, healthcare providers should ensure that children and young people have access to appropriate and confidential health advice and counselling, with or without their parents/carers' consent or presence, irrespective of age. Children and young people may need such access when, for

example, they are experiencing abuse at home or are in need of reproductive health education or services. They may also need such advice and counselling in cases of conflict between the child or young person and their parents/carers over access to healthcare services. The right to counselling and advice is distinct from the right to give consent and should not be subject to any age limit.

10. Every child and young person has a right to participate in education, play, creative activities and recreation, even if this is difficult due to their illness or disability.

To the greatest extent practicable, children and young people should be assisted to participate in their regular activities and routines while in a healthcare service. This minimises anxiety and maintains their development and learning. Children and young people ought to remain engaged in education while they are in a healthcare service. They also need an environment in which play and recreation are facilitated, by staff with appropriate knowledge and skills where possible. Play has a particular role in healthcare: it supports the ability of children and young people to cope with their experiences in healthcare services. This requires both a physical environment conducive to play and recreation, as well as a commitment across the organisation to giving children and young people the time, encouragement and support to play and participate in therapeutic activities. Opportunities to participate in education, play, creative activities and recreation should be suited to the child's or young person's age, condition and culture. To the greatest extent possible, these activities should take place in an environment designed, furnished, staffed and equipped to meet the child's or young person's needs, interests and abilities.

11. Every child and young person has a right to continuity of healthcare, including well-planned care that takes them beyond the paediatric context.

Healthcare providers need systems to promote continuity of healthcare. This includes care co-ordination both between and within the various services working with children, young people and their families. Continuity of healthcare between all healthcare services is essential. Children and young people who move across different geographical locations and health services are also entitled to continuity of care.

For children and young people with long term health issues, planning for their care as they become adults is crucial to their wellbeing. Ideally, healthcare professionals should aim for a smooth transition of the child or young person and their family to appropriate adult services. This process of transition should begin some years before transfer to adult healthcare services is complete. The process of transition should be based on the rights described in this document.

This right to continuity of healthcare also requires health services to adopt a 'whole person' approach, recognising that children's and young people's health and development needs go beyond the health sector. Children and young people need solutions that cross sectors such as health, education, welfare and housing.

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APPENDIX 1: Version for children

Let everyone know these are the rights of every child in healthcare:

1. Know that children are special and always do what is best for us.
2. Listen to us when we tell you how we are thinking and feeling, when we are upset, when we have problems or worries or when we need to talk to you. We may not be able to use words, so take notice of what we do and how we look because this can tell you what we are thinking and feeling.
3. Give us the very best possible care and the comfort we need.
4. Let us and our families be who we want to be, whatever our beliefs and customs, so that we feel safe at all times.
5. Let our families and others who are important to us, be with us to care for us and love us.
6. No matter how big or small we are, tell us what we need to know in a way we can understand.
7. Let us have a say in things that are happening to us now and in the future.
8. No one has the right to harm us, not doctors or nurses and not even our Mums or Dads. Protect us always from anyone who would harm us or treat us badly.
9. Our bodies belong to us. Ask us if you want to share information about us and make sure we stay safe. Give us space and privacy, as well as the chance to be with others.
10. Help us grow up to be the best we can. Let us learn, let us play and discover some things for ourselves.
11. When you care for us, make sure that everyone is working together to do what is best for us, until we are grown up and can decide things for ourselves.

APPENDIX 2: Version for young people

Young People’s rights in healthcare: “Be in the Know”

Young People’s Rights	What this means for you
<p>You have the right to what’s best for YOU.</p>	<p>Together with you, everyone involved in your healthcare should always work towards what is best for you. What you value in terms of your physical, spiritual, family and mental well-being is important in deciding what is best for you.</p>
<p>You have the right to express your views respectfully, be HEARD and have something done about it.</p>	<p>You have the right to express yourself and share what you are thinking and feeling with others in any way you are able to communicate. Others around you are responsible for learning how you communicate so your views can be understood. You have the right to have your views heard, considered and taken seriously, especially when decisions are being made that affect you. If you feel like you are not being heard you can choose to have an independent person advocate for you. The right to be heard includes the right to complain about your healthcare. Health services should provide you with a safe and simple way to complain and a fair and speedy way to sort out your complaint.</p>
<p>You have the right to use and receive the BEST available healthcare.</p>	<p>You have the right to the best healthcare available in all situations. The best healthcare available should attend to all aspects of your well-being including physical, spiritual, mental and relationships with family and friends. You also have the right to a safe environment to help you enjoy the highest achievable standard of health. The people caring for you should understand your needs and requirements and try to meet them.</p>
<p>You have the right to be treated with RESPECT in regards to your values, beliefs and culture. You have a right to be you.</p>	<p>You should be treated with respect and dignity and encouraged to respect others’ rights and values. You have the right to practice your own culture, customs, language and religion. Whoever you are and whatever your culture, customs, language, or religion you have the right to special protection that makes sure you can practice your ways of life, unless those practices are likely to put you at risk.</p>

<p>You have a right to be with and guided by your FAMILY, unless this is against your best interest.</p>	<p>You have the right to have your parents/carers and those important to you with you, unless this will harm you. You have the right to be given guidance by your parents/carers and family. You have the right to have a support person of your choice with you in any situation you wish, unless this breaks the rights of others or will harm you.</p>
<p>You have the right to be FULLY informed, ask questions and be given answers about all matters concerning you. Because being in the know is important.</p>	<p>You have the right to find things out and to be informed. This means having access to information you can understand, trust and that's important for you to know. This includes:</p> <ul style="list-style-type: none"> • Being given realistic information about your condition and treatment in a way that you can understand • Being able to ask questions and be given honest answers you can understand • Being provided with choices for treatment, where available and realistic • Being aware of how to access information about you if you wish to.
<p>You have the right to be INVOLVED in making decisions that affect you.</p>	<p>You have the right to be involved as much as you wish in making decisions that affect you. Depending on the situation, your experience and understanding, and the adults available to support you, you may wish to be informed, to express your views, to have your views taken seriously, to share decision making with parents/carers and healthcare providers or to be the main decision maker. However you wish to be involved, your involvement should be taken seriously. If your views cannot be taken into account, you have the right to be told why.</p> <p>The right to be involved in making decisions includes the right to be involved in making decisions about taking part in teaching or research, and, about the use, return or disposal of any bodily parts or substances removed, changed or added in the course of your healthcare.</p> <p>Healthcare services should enable young people to be involved in decisions about planning services and developing policies that impact on young people.</p>
<p>You have the right to be PROTECTED from harm.</p>	<p>You have a right to be safe from all forms of harm. This includes being protected from anyone who would harm you including people in your family. Some things that happen to you in healthcare services may be painful but things should always be</p>

	done to prevent or relieve your pain.
You have the right to PRIVACY.	<p>You should be treated with dignity. You have the right to a private life, which includes keeping your body, mental, spiritual and social life private. Health professionals should take all necessary steps to ensure your privacy during medical examinations and treatments.</p> <p>Healthcare providers caring for you are aware that your privacy and confidentiality are necessary if you are going to trust them. In some situations, a parent/carer of a young person under 16 years of age will be involved in making decisions about the young person's healthcare and information about them may be shared with a parent/carer. However, your parents/carers do not have an automatic right to information about your healthcare if you do not wish them to. There are some situations in which information about you cannot be shared with your parents/carers without your permission e.g. abortion or contraceptive advice. In other situations healthcare providers may have to share information with others to prevent a serious threat to your life or health. Healthcare providers should tell you what information you give to them might be shared with others, including your parents/carers, in order to provide you with the best possible care.</p> <p>You have the right to legal protection from unlawful or unreasonable interference with your privacy.</p>
You have the right to education, rest, play, creative activities and recreation.	<p>Whether you are well, ill or have a disability you have the right to good quality education that helps you develop your personality, talents and abilities to the full. You have the right to rest, play and to be involved in things you enjoy. Sometimes you may not be able to do things you enjoy because they can harm you, especially if you have an injury or illness.</p>
You have the right to planned coordinated healthcare.	<p>You have the right to cooperation among the people providing healthcare to you. This includes having continuity of carers and support, as well as access to ongoing health services as you require them. As you move from children's health services into adult health services, you should be introduced to the new services and health professionals. Your transition from children's to adult services should be made as easy as possible and start early.</p>



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