Quality and Patient Safety Directorate

your service your say

National Healthcare Charter
Paediatric Services

DRAFT DOCUMENT FOR CONSULTATION, December 2012

people caring for people

you & your health service
people caring for people
your service, your say
you said...we did

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Tús Áite do Shábháilteacht Othar
Patient Safety First

An Roinn Sláinte
DEPARTMENT OF HEALTH

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Introduction

The Department of Health together with the Health Service Executive (HSE) in 2008 committed to the development of a National Healthcare Charter. In 2010, the National Healthcare Charter, which is titled *You and Your Health Service,* was developed with input from many interested parties, including patient advocacy groups and individual advocates.

Feedback from patient advocacy groups highlighted that while this Charter was suitable for adult services, there were gaps in its application to paediatric care. In response to this need, the National Clinical Programme for Paediatrics worked in collaboration with the National Advocacy Unit, HSE and a Parents Reference Group established under the Paediatric Clinical Programme to develop and adapt the a National Healthcare Charter for paediatric services.

The Draft National Healthcare Charter-Paediatric Services is a Statement of Commitment by the HSE and the Paediatric Clinical Programme describing what children, young people and parents can expect when using health services in Ireland, and what they can do to help Irish health services to deliver more effective and safe services.

This document *"A draft consultation document –The National Healthcare Charter, Paediatric Services"* is based on principles identified in adult health care services but adapted to suit the needs of children, young people, and parents in paediatric services.

National Healthcare Charter
Paediatric Services

This consultation process will inform the development and implementation of a National Paediatric Charter across all children's and young people's services in Ireland (see wall chart below).

<u>**Your feedback about this document matters,**</u> all feedback will be taken into consideration and the final publication will reflect the feedback from many stakeholders who submit their comments, thoughts and ideas for improving services for children and young people in Ireland. Please send all of feedback comments or suggestions to yoursay@hse.ie by 2pm Thursday 31st January 2013.

National Healthcare Charter
Paediatric Services

National Healthcare Charter
you and your health service

	What children, young people and parents can expect	Ways in which children, young people and parents can help
Access	Our services are organised to ensure equity of access to public health and social care services. Children and young people shall be admitted to hospital only if the care they require cannot be equally well provided at home or on an outpatient or day case basis. Children and young people in hospital can expect to have their parents with them as much as possible.	Please let us know if you cannot attend appointments. Help prepare children for hospital. Let us know if you have any special language interpreter or mobility requirements.
Dignity and Respect	Children, young people and their parents shall be treated with dignity and respect, tact and understanding at all times.	Please treat staff, other children, young people and their families with dignity and respect. Let us know if your child was not treated with dignity and respect.
Safe and Effective Services	Children and young people shall be cared for by staff whose training and skills enable them to respond to their physical, emotional and developmental needs. Continuity of care should be ensured by the team caring for children and young people.	Support us to deliver safe and effective services, e.g. if you think that a member of a healthcare team has forgotten to wash their hands, give them a gentle reminder.
Communication and Information	Children and young people can expect to be informed in a manner appropriate to age and understanding. Information for parents should be clear and comprehensive and should consider the parents' present situation, especially their feelings of fear, sorrow, guilt, anxiety or stress regarding their child's condition.	Help us to promote clear communication and information, if there is something that you do not understand about your child's care, let us know and we will endeavor to explain it better.
Participation see leaflet	Children, young people and parents have the right to informed participation in all decisions involving their health care. In order to share in the care of their child parents should be kept informed and their active participation encouraged.	Ask questions and become more actively involved in decision making about your child's care.
Privacy	Regardless of age or state of development the protection of the privacy of children and young people shall be secured at all times. When in Emergency Departments in Ireland, children and young people should have full audio and visual separation from adults.	Support health services to safeguard children's and young people's confidentiality and privacy.
Play	Children and young people should have a full opportunity for play, recreation and education suited to their age and condition and shall be in an environment designed, furnished, staffed and equipped to meet their needs.	Encourage your child to play and engage in play activities. If services do not provide opportunities to support play, education and recreation for your child or young people, please let staff know so that it can be addressed.
Improving Health	We promote health among children and young people support and empower parents, children and young people to self manage long-term health conditions and to mitigate physical and emotional stress.	Learn more about what you can do to promote health in children and young people. Ask your healthcare provider for information about healthy living and about what support services are available in your community for managing long-term conditions in children and young people. Ensure that your child is vaccinated against childhood illnesses e.g. measles, mumps and rubella. Find out about preventing accidents in children and young people.
Giving Feedback	We welcome feedback about children's and young peoples' experience of healthcare services. Tell us about what worked well and the things that we can improve upon. If you wish to make a complaint we will investigate your complaints and work to address your concerns.	Children's, young people's and parents' feedback matters – tell us about your experience so that we can improve health care services for all children and young people in Ireland.

Get involved!

Find out about how you can get involved in improving health services in Ireland.

The HSE is actively inviting service users to get involved on patient forums and quality improvement initiatives. To find out more contact:

National Advocacy Unit, HSE,
Quality & Patient Safety Directorate,
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Millennium Park, Naas, Co. Kildare

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Contact the HSE:

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(Monday to Saturday 8.00am to 8.00pm)

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your service your say

As part of this consultation process we would like you to consider the following questions:

1) Do the principles outlined in this document identify the important needs of children, young people and their parents when using health services in Ireland?

2) Have we omitted any important points which should be incorporated in A National Healthcare Charter for Paediatric Services?

3) Do you have any further suggestions for improving this document –The National Healthcare Charter for Paediatric Services?

Any other suggestions or comments are welcome.

If you have any queries or require clarification on the National Healthcare Charter, associated resources or this consultation process, contact: June Boulger, National Advocacy Unit, HSE. June.boulger2@hse.ie .

Dr John Murphy
National Clinical Lead –Neonatology

Prof. Alf Nicolson
National Clinical Lead –Paediatrics

Mary O' Connor
CEO, Children in Hospitals Ireland

You and Your Health Service – Paediatric Services

*You and Your Health Service, **The National Healthcare Charter –Paediatric Services,*** aims to inform and empower children, young people, families and communities to actively look after their own health and to influence the quality of healthcare in Ireland. The Charter will support implementation of the National Standards for Safer Better Healthcare throughout all paediatric services.

Implementation of *You and Your Health Service* will be monitored through gathering of feedback on children, young peoples, and their parent's experience of paediatric services. This will enable the HSE to improve the quality of care for children and young people across Ireland.

The National Healthcare Charter-Paediatric Care, What does it do?

- It outlines supporting arrangements for a partnership of care between everyone involved in healthcare –children, young people, parents, families, carers and healthcare providers.
- It supports a healthcare culture that delivers health and social care services in a predictable, preventative, personal and participatory way.
- It recognises that there are different roles and responsibilities for both parents and healthcare providers.
- It promotes the importance of children and young people as individuals with diverse needs and not just a medical condition to be treated.
- It applies to all public health and social care services which provide care to children, and young people, including community care services and acute hospital services.

As part of the promotional campaign for this initiative, a programme of awareness raising, promotional materials and communications aimed at children, young people, and parents will be available on the HSE website *www.hse.ie* and in all HSE provided and funded paediatric services across the country.

Greg Price, **Director of Advocacy, HSE**	**Dr. Philip Crowley** **National Director, Quality and Patient Safety Directorate**

Glossary

The terms referred to in this document are defined as follows:

Service user - we use the term ‘service user’ to include:

- people who use health and social care services as patients; carers, parents and guardians;
- organisations and communities that represent the interests of people who use health and social care services;
- members of the public and communities who are potential users of health services and social care interventions.

The term ‘service user’ also takes account of the rich diversity of people and their needs in our society, with respect to gender, marital status, family status, disability, sexual orientation, age, religion, race and membership of the Traveller community. We use the term service user in general, but occasionally use the term patient where appropriate’.

- **Children-**we use the term children to refer to babies and children,
- **Young people** –we use the term young people to describe teenagers and adolescents.
- **Child centred-**refers to children and young people
- **Parents-**we use the term parents to refer to mothers, fathers and guardians.

Health - a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (World Health Organization 1948).

Charter - a Statement of Commitment by the HSE on healthcare expectations and responsibilities. Outlining what service users can and should expect every time that they use health services and what service users can do to help deliver safer and more effective health services in Ireland.

Expectations - what service users expect to experience when they use health services in Ireland.

Health responsibilities - the duty of people to do their best to maintain and improve their health, to respect the health of others and to support the Irish health and social care services to run efficiently.

Predictable - knowing what to expect from a procedure, treatment and all Irish health and social care services.

Health services - all Irish health and social care services delivered within acute hospital and community care settings.

National Healthcare Charter Paediatric Services

National Healthcare Charter Paediatric Services

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Access:

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Children and young people can expect to have their parents or parent substitute with them when receiving care in hospital or community services.

What children, young people and parents can expect:

- Care for your child that is appropriate, timely and based on need, not the ability to pay.
- That you and your child be registered with a general practitioner (GP) and be able to change GP easily if necessary.
- Emergency medical treatment from your GP and/or your emergency department should your child need it.
- A referral to a paediatric consultant when your GP thinks it necessary, and be referred for a second opinion if it is required or requested.
- Reasonable access to the most appropriate public health services regardless of physical, sensory or intellectual ability.
- To be transferred to another paediatric public health and social care facility if a recommended medical treatment is not available at the health and social care facility first attended by you
- Any waiting period for an appointment, test or a treatment for your child will be kept as short as possible.

You should receive clear information:

- on appointment dates, times and locations.
- about the estimated cost of a health provider's services for your child before you avail of the treatment, where relevant and possible.
- on the estimated waiting times for a health provider's services and, where known, information about alternative service providers.
- on what you can expect to happen to you on the day of any intervention such, as a CT scan or ultrasound.

Knowing who is caring for your child

- Staff should always introduce themselves, wear name badges or have name plates on their desks. You should be told the name and role of everyone who cares for your child, and the name of who is in charge of your child's care.

When in hospital

- Before admitting a sick child or a young person to a hospital, all forms of appropriate care shall be explored whether at home, in a day clinic or comparable forms of treatment, in order to find the most suitable solution.

- There should be a regular review of the type of care according to the child's or young person's condition so that there is no unnecessary continuation of a hospital stay.

- All necessary information, assistance and support shall be given to parents if their child or a young person is cared for at home or on a day case basis.

Children and young people can expect to have their parents or parent substitute with them as much as possible.

- All children and young people can expect to have their parents with them at all times without restriction; this is an integral part of the care for children and young people in hospital.

- If parents are unable or unwilling to take an active role in the care of their child or a young person, the child / young person is entitled to receive this care from a suitable substitute carer, who is accepted by the child/ young person

- Accommodation should be offered to all parents, where possible, and they should be helped and encouraged to stay. Hospitals shall endeavour to provide sufficient and suitable space and infrastructure to enable parents to be admitted along with their sick children.

WHAT YOU CAN DO TO HELP

Ways that you can help health services to become more accessible for children and young people*:*

Waiting times and appointments:

- Please be on time for all appointments. If late, please phone ahead to let staff know.
- Ensure to ask your healthcare professional how long you may expect to wait before receiving certain kinds of appointments, tests or treatments for your child.
- If a member of staff (such as a public health nurse) is due to visit your home to see you and your child, please make sure that you are there at the agreed time.
- If you cannot keep an appointment for your child, inform your healthcare provider in plenty of time so that your appointment can be given to someone else.
- If you or your child has any special requirements, such as alternative methods of communication, please let healthcare services know in advance of visits where possible.

Contact details:

Make sure that your GP surgery, dental surgery or any hospital or healthcare service you attend has up-to-date information about how to contact you. If you change address or phone number, please inform all relevant healthcare providers as soon as possible.

Ways in which parents can help –preparing your child for hospital[1]

If your child needs to go to hospital, especially for an overnight stay, you can help by preparing your child for hospital. Bring your children up with the idea that doctors and nurses are nice people who try to make you better and that a children’s ward is a nice place, where parents can stay and children play.

Preparing your children for hospital can be fun, for instance, play doctors and nurses at home. You will have to help a little unless they have been in hospital before; they cannot imagine it all on their own. Get them to play at being in bed and having breakfast in bed – this helps them realise patients stay in overnight. Play at visiting. Play at operations, but don’t go into too much detail!

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[1] Age appropriate guidance will be developed as part of the suite of resources for implementation of the National Healthcare Charter in Paediatric Services, including resources aimed at parents, children, young people and staff.

Dignity and respect:

Children, young people and their parents shall be treated with dignity and respect, tact and understanding at all times.

Children and young people shall be treated with dignity and respect, tact and understanding at all times.

- Tact and understanding in dealing with children and young people requires the need to:
  - include the right to be a child;
  - consider their dignity, view, needs, individuality and their state of development, taking account of any disability or special need;
  - make the willingness of the staff for dialogue apparent;
  - create a friendly and trusting atmosphere;
  - take into consideration the religious belief and cultural background of the child, young person and the family.

- The environment should be adaptable to the needs of different age groups and not be focused on one particular age group.

- The rights of sick children must be respected whether they are cared for at home or in hospital.

- When a child or young person is dying or dies, the child / young person and his/her family must be given whatever support, care and assistance they need to help them cope. Information regarding the death of the child or young person should be given sympathetically, sensitively, in private and in person.

Parents advice, what you can do to help

Don't forget – as a parent, you have a responsibility for your child's welfare. Bad things can happen everywhere, even in a hospital where children and young people can be at their most vulnerable.

It is up to you to ensure that your child is treated with dignity and respect and to protect him or her from invasions to their privacy.

Speak-up and let the healthcare team know if your child has not been treated with dignity and respect.

Safe and effective care:

Children and young people shall be cared for by staff whose training and skills enable them to respond to the physical, emotional and developmental needs of children and families. Continuity of care should be ensured by the team caring for children. Every child and young person shall be protected from unnecessary medical treatment and investigation.

You and your child can expect:

- Services that are provided with professional care, skill and competence.
- Informed and clinically appropriate care for children
- That there will be continuity of care and smooth transitions between services which are involved in your child's care. Continuity of care should be ensured by the team caring for children and young people. When your child is referred from one part of the health service to another service or team, all relevant details of your child's health and care plan are forwarded as appropriate.
- There should be continuity of care and smooth transitions of care when young people are being transferred from paediatric to adult services
    - All relevant details of the young person's health and care plan should be forwarded as appropriate
    - A contact / liaison between the adult and the paediatric services in relation to the young persons care should be maintained until the young persons care plan is well co-ordinated and the transition has been made successfully
- An environment where systems and structures work effectively to ensure safety and to ensure that your child's care is well coordinated.
- Healthcare professionals to do everything that they can to control children's and young people's pain.
- That our services have processes in place to ensure safe healthcare is reliably delivered irrespective of the healthcare setting and that healthcare-associated infection is prevented
- Qualified staff are capable of recognising and reacting in an appropriate way to all forms of child abuse.
- Staff members will support parents in particular to cope with critical situations a child or young person might endure. This applies especially to life-threatening situations.
- Every child and young person shall be protected from unnecessary medical treatment and investigation. In this context any form of medical treatment or investigation of a child is unnecessary, if no benefit for the individual child can be derived

WHAT YOU CAN DO TO HELP

Ways that you can help promote safe and effective services for your child / young person:

Parents and family members who are more informed and involved in their child's / young person's healthcare and who work closely with the paediatric healthcare teams often experience safer and better care and have improved outcomes quality of life afterwards for their children / young person. To ensure that you or a member of your family receive the best care possible you should always:

- ask questions;
- talk to your healthcare team;
- Listen and note down the information they give.
- See www.hse.ie for a copy of **It's Safer to Ask** (questions to ask your healthcare team).

Medication safety:

- Try to follow any advice or treatment that has been agreed with you for your child.
- If you are worried about doing this, or do not fully understand what is required, discuss it with the person giving the advice or treatment, or contact your GP.
- Take care with medicines. Give children or young people medicine in line with instructions and finish the course of treatment.
- Please discuss with your doctor or pharmacist, before you decide to change or stop your child's medication, particularly if your prescription says that your child should continue to take it.
- Store medicines safely and out of children's reach.
- If you go into a hospital, let the staff know about any medicines that your child is already taking, for example by bringing a list of all the medicines and giving this to a member of staff, and tell staff about any allergies that your child may have.
- If you feel that your child's condition has got worse, you should consult your GP, who can, if necessary, consult further with the paediatric hospital or relevant service.

Help prevent the spread of infection:

- Hand washing is the best way to prevent germs from spreading. Encourage hand washing in children. Wash your / help your child wash their hands after coughing/sneezing, after going to the toilet, after touching anything wet (e.g. ooze from your wounds, urine from a catheter, from blood stained dressings) and before mealtimes.

- If you can’t get to a sink to wash your /help your child wash their hands, ask healthcare staff to provide you with a means to clean your child’s hands (e.g. basin of water and soap/wipes/alcohol hand rub).

- Avoid touching any wounds or the area around drips, drains or catheters.

- Ask your doctor or nurse why your child has a drip or catheter and how you can help prevent it from getting infected. Let staff know if the area around the drip becomes sore or red or if the bandage falls off or looks wet or dirty.

- If you or your child have diarrhoea and are on an antibiotic or have recently been on one – let your doctor know.

- If you are given a prescription for antibiotics to take at home for your child, it is very important to give your child the full course of antibiotics as prescribed (i.e. finish the course) even if your child begins to feel better. Do not keep antibiotics at home for your child for future use and do not share them with other people or other people’s children.

- If you think HSE premises are not as clean as they should be, let a member of staff know.

- If you think a staff member has forgotten to hand wash before examining your child, give a reminder.

Communication and information:

Children, Young people and parents shall have the right to be informed in a manner appropriate to age and understanding.

Information for children and young people should be based on age and understanding and take into account the child's level of Development;

- understand the child's immediate situation;
- appreciate his/her capacity to comprehend information and express his/her views;
- encourage questions, answer the questions raised and comfort children when they express concerns or fears;
- include appropriately prepared verbal, audio-visual and written information, supported by illustrative models, play or other media presentations;
- whenever practicable information should be given in the presence of the parents.

Information to meet children/young peoples and parent's needs should

- be provided continuously from admittance to discharge;
- include information regarding care after discharge;
- be provided in a stress free, secure and private environment without pressure of time;
- be given by experienced staff competent to communicate information in a way which can be readily understood:
- repeated as often as necessary to facilitate understanding;
- be checked by the staff member to ensure that the information given has been properly understood by the child / young person and the parents

A child/ young person or a sibling should not be used as an interpreter for the parents.

Communication and information in relation your child's care

You can expect open and appropriate communication throughout your child's care:

- about what is wrong and what the treatment or care aims to do;
- especially when plans change or if something goes wrong
- concerning the results of any proposed treatment and medication, including the possible risks and alternatives;
- regarding the type of continuing healthcare your child may need, including medication, continuing care in hospital, timely and appropriate, referrals, convalescence or rehabilitation;
- regarding what discharge arrangements are in place for your child.

You and your child should be given:

- The opportunity to ask questions and to receive answers that you (if appropriate what your child) can understand.
- Advice on how to ask questions and how to make the most of consultations and obtain information about your child's diagnosis, treatment, and care from members of the paediatric healthcare team.
- Information in a language that you can understand.
- Access to interpretative services where possible.

You can expect health information about:

- Information for parents should:
- be clear and comprehensive;
- consider the parents' present situation ,especially their feelings of fear, sorrow, guilt, anxiety or stress regarding their child's condition;
- encourage questions;
- satisfy the need for information by directing parents to extra information sources and support groups;
- provide parents with unrestricted access to all written or pictorial documentation regarding the illness of their child;
- how to prevent further illness
- the services and sources of help (such as further information and self-help groups) that are available for children and young people
- support in managing a chronic (long-term) condition.;

WHAT YOU CAN DO TO HELP

Ways that you can support improved communication:

- If there is something that you do not understand about your child's condition or treatment, let your paediatrician know. Never be afraid to ask.
- You should provide information about your child's medical history, current treatment, medication and alternative therapies. It may be helpful for you to carry a healthcare record with you for your child including information about their vaccinations etc.
- See page 20 for questions to ask about your child's healthcare plan

Participation:

Children, young people and parents have the right to informed participation in all decisions involving their health care.

In order to share in the care of their child, parents should be kept informed about ward routine and their active participation encouraged.

NOTE: the HSE National Consent Policy which is currently being considered for approval will inform the content of this section and provide guidance on informed consent in paediatric services.

Children, young people and parents have the right to informed participation in all decisions involving their healthcare, this will require:

- adequate information for the child, young persons and their parents regarding their child's immediate health condition, the proposed forms, risks, and merits of treatment or therapy and its goals as well as the measures to be taken.
- adequate information on alternative forms of treatment
- advice and support to parents enabling them to evaluate the proposed way of proceeding

Children and young people have the right to express their own views and providing they have sufficient competence to understand the matter

Children and young people have the right to have their parents with them at all times, including all situations where they need or possibly might need their parents, e.g.

- during the night, whether or not the child may wake up;
- while having treatments and/or examinations with or without local anaesthesia, with or without sedation during induction anaesthesia and immediately upon recovery;
- during periods of coma or semi-consciousness;
- during resuscitation, when parents must be offered full support.

Participation in hospital

In order to share in the care of their child, parents can expect to be kept informed about ward routine and their active participation encouraged. The staff shall facilitate the parents' active participation in caring for their child by:

- giving parents full information regarding their child's care and about ward routine;
- arranging with parents the elements of care they want to take over;
- supporting the parents in doing this;
- accepting their decisions;
- discussing with them changes needed if their care is not helpful to the child's recovery

Parents should be informed if student healthcare staff are involved in delivering child's care and have these students seek your permission before any medical examination or interview.

WHAT YOU CAN DO TO HELP

Ways that you can support participation:

Prepare a list of questions, concerns, and symptoms to discuss with your GP or paediatrician in relation to your child's care. Here are a few suggested questions to get you started:

- Can you please tell me more about my child's condition?
- Do you have any information that I can take away with me?
- Can you tell me where I can find out more information?
- Why does my child need to have this particular test?
- What are the different treatments for this condition?
- How will this treatment help my child?
- What does the treatment involve?
- What are the risks of this treatment for my child?
- What is likely to happen if my child does not have this treatment?
- What should I look out for?
- When should I bring my child back to see you?

- Ask what your child's treatment plan is before discharge and for it to be explained to you. Make sure you get the results of any tests or procedures.

- If your child is having surgery, clarify with your child's surgeon that everyone is clear about exactly what is going to be done.

Play:

Children and young people shall have full opportunity for play, recreation and education suited to their age and condition and shall be in an environment designed, furnished, staffed and equipped to meet their needs.

Children, young people and parents can expect that:

- Healthcare environments meet the needs of all ages and situations wherever in the hospital they are being cared for. This applies also to day facilities or other areas where children and young people are being treated or examined.

- there will be possibilities for play, recreation and education and that these possibilities should:
  - be available in the form of appropriate play materials;
  - ensure adequate periods of time for play seven days a week;
  - provide for the abilities of all age groups cared for in the facility;
  - inspire creative activities by all children;
  - Allow for the continuation of the level of education already reached.

- Sufficient suitably qualified staff should be available to meet the needs of children and young people for play, recreation and education regardless of the state of health and age. All staff in contact with children and young people should have an understanding of the needs of children and young people for play and recreation.

- The architecture and interior design of such an environment must incorporate appropriate features for all age groups and types of illnesses treated in the facility. The environment should be adaptable to the needs of different age groups and not be focused on one particular age group.

Privacy:

Regardless of age or state of development the protection of the privacy of children and young people shall be secured at all times:

Children, young people and parents can expect:

- that regardless of age or state of development the protection of the privacy of children and young people shall be secured at all times and must include:
- protection against physical exposure;
- protection against treatment and behaviour which diminishes self respect or makes the child feel ridiculous or humiliated;
- the right of personal retreat, to be alone;
- the right of private communication with staff;
- the right of undisturbed association with close family members and friends
- audio and visual separation from adults in ED services;
- to obtain and inspect a copy of your child’s health information;
- That a child’s or young person’s personal health information will be stored securely and not disclosed to others without your consent. Your child’s personal health information will only be accessed by those who need it for your child’s care;
- to be facilitated to complain if you are unhappy with how health services have used or protected your health information;
- to be given enough personal space when being examined, receiving treatment and when discussing your child’s condition and treatment;
- That healthcare records may be accessed for audit purposes to provide assurance to the HSE about the quality of service provision.

Improving health:
Promoting health among children and young people, disease prevention, and supporting and empowering parents and children and young people to self manage long-term health conditions and to mitigate physical and emotional stress.
Steps should be taken to mitigate physical and emotional stress.

Children, young people and parents can expect information and advice about:
- How to stay as healthy as possible, and the necessary support and encouragement to do so.
- support on how to self-manage an existing health problem and where to access support services in the community for children and young people
- Opportunities to take part in screening and immunisation programmes to prevent illness where available and appropriate.
- rehabilitation programmes where available and appropriate.

When in hospital children, young people and parents can expect:
- that preventive measures will be taken to reduce physical and emotional stress and pain experienced by children, young people and their parents e.g.:
- encourage continuous contact with parents, siblings and friends;
- ensure effective up-to-date pain management to avoid or reduce pain incurred by medical treatment, whether during examination, intervention or pre- or post-operatively;
- grant sufficient periods of rest between treatments;
- support parents whose children are receiving palliative care;
- prevent feelings of isolation and helplessness;
- try to avoid or reduce situations or actions described by the child as stress inciting;
- recognise fears or concerns of the child whether or not explicitly expressed and act upon them;
- be aware that a child may become stressed by being isolated or as a reaction to the condition of other patients and take appropriate action;
- feature stress free and appropriately equipped rooms allowing children and parents the opportunity to retreat;
- avoid use of restraints.

To mitigate unavoidable physical or emotional stress, pain, and suffering children, young people and parents should be offered:
- ways of dealing with painful situations or actions experienced as negative;
- support for parents as well as measures ensuring their protection from too much strain while caring for their sick child;
    - Contact with social services, psychologists, minister of religion, self-help groups, patient / parent-help groups and cultural groups.

WHAT YOU CAN DO TO HELP
Ways that you can improve your child's and family's health:

- Learn more about what you can do to improve your children's health, ask your healthcare provider for information about healthy living and about the support services in your community, ask your health care professional to help you to set goals to improve your child's health.

- Look after your and your child's health. Remember that children learn from their parents: if they see you living a healthy lifestyle they too are more likely to practice healthy behaviours.

Promoting healthy living in children, this could mean:
  - taking more exercise, encouraging your child to live an active life;
  - eating a healthy diet, promoting healthy eating in your child;
  - managing your weight and supporting your family to maintain a healthy weight through all of their life stages;
  - stopping smoking, not exposing your children or young people to passive smoking in cars or in their home and creating awareness around the dangers of smoking;
  - not drinking too much alcohol;
  - not using drugs.

- Seek information and advice from any healthcare professional or other sources such as *www.hse.ie* on how to prevent disease, including immunisation, and on how to protect your health and your family's health.

- Seek information about accident prevention in children and young people and how to keep your home safe for your child. For more information see www.hse.ie

- Always ensure that your child is appropriately strapped in their car seat see www.rsa.ie

- Help stop the spread of infection: wash and dry your hands before preparing and or eating food.

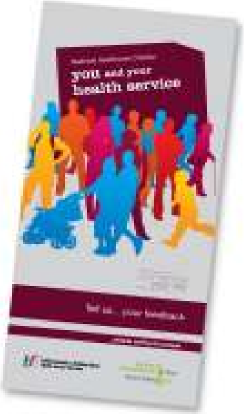
- All HSE provided services aim to be smoke free by 2015 – many are currently smoke free. Please support your services to achieve this goal by not smoking on health service premises.

Accountability:

We welcome feedback about you and your child's experience of health services

Healthcare teams learn about improving services when they hear about what worked well and also what can be improved upon

- Please tell us about your experience so that we can meet your needs and your child's needs and deliver more child centred care.
- Talk to staff when they are engaging with your child, if you feel that we could do something better tell us at the point of care so that it can be addressed immediately and so that your and your child's experience of health services can be improved.



What children, young people and parents can expect:

- To have an opportunity to comment on the care that your child has received.
- Information about how to give feedback about your child's experience, whether it was positive or negative.
- To have any concerns dealt with properly and in a timely manner.
- To receive feedback in relation to what changes or improvements have been made in response to your feedback.
- Information on how to make a complaint if you are not happy with the care that your child received.
- If you are unhappy with the way your complaint was dealt with, you can request that your complaint be reviewed by contacting the Director of Advocacy, National Advocacy Unit, HSE

Advice for parents

You must be an advocate for your child especially when things go wrong as they sometimes do. Children and young people often don't have the words to explain feelings or problems. Let your child know that you will voice their worries or problems to hospital staff for them.

If you have a complaint, do not be afraid to express it. It is better to solve problems at an early stage rather than to allow them to grow or fester. Be firm but never rude. If it is serious, it may be necessary to put the complaint in writing.

Find out about children's and young people's advocacy and support services.

Appendix 1: Terms of Reference for Paediatric Reference Group

The establishment of the children's and parents reference group for the neo-natal and paediatric programmes is integral to the successful development of policy and establishment of paediatric clinical programmes.

- The overarching aim of the paediatric programme -*'To provide maximal care to children at the point of first contact*
- The overarching aim of the neo-natal programme -*To provide high quality neonatal care to all 75,000 babies born in Ireland annually.*

In November 2011 the paediatric reference group was established to:

1) ensure that children's voice / experience of health care is central to identifying health needs and improving their experience of services

2) Inform the design, delivery and evaluation of the paediatric and neo-natal programmes.

Stakeholders from advocacy organisations, the Department of Children, researchers, special interest groups and parents with experience of health services have been invited to participate on this reference group.

Scope and deliverables 2012-2013

The reference group will support the programmes development and implementation by helping to:

1) identify important issues which effect children, young people and their families who use health services (community and acute hospital) in Ireland
2) adapt the national healthcare charter for use in paediatric services in Ireland
3) inform the development of a plan for services to systematically gather feedback from children and young people and families about their experiences
4) inform the development of an advocacy framework for paediatric services
5) develop handheld records for children and young people and their families

Consultation and input from the reference group will be sought throughout the development and evaluation of the programmes.

Representation on the parent's reference group for the national neo-natal and paediatric clinical programme

Prof. Alf Nicolson-National Lead Paediatric Programme
Prof. John Murphy –National Lead Neo-natal Programme
Grace Turner-Programme Manager
June Boulger, National Advocacy Unit, HSE
Heart Children Ireland
Children in Hospital Ireland
Children with Liver Disease
Hydrocephalus Association
Representative of disability services
Cystic Fibrosis, Ireland
Representation from rare diseases
Department of Children
NUIG –Health Promotion Dept.
Neonatal advocacy groups –representation
Feileacain Ireland
Other representatives as appropriate

NOTES:

Comments and suggestions:

National Healthcare Charter
Paediatric Services