Rights based standards for children having a health care procedure (test, treatment, examination, or intervention)

- The standards have been developed by an expert international collaborative group through extensive consultation with children, parents and professionals.
- The standards are framed by a commitment to prioritise the rights of a child (United Nations Convention on the Rights of the Child, 1989) and ensure that their short- and long-term physical, emotional and psychological well-being are of central importance in any practice and decision-making related to health care procedures.
- These international standards recognise that all children have rights that should be respected regardless of their age, disability, race, religion or belief, sex, sexual orientation, ethnicity, language, ability, or any other status.
- These standards aim to provide broad principles for practice to support all children aged from 0 to 18 years undergoing a health care procedure. These standards should be applied in practice to recognise and respect each individual child's needs, competence, ability, preferences and experiences.

The intention of these standards and how they should be applied in practice are outlined below.

These standards intend to:

- Propose an approach to minimise any anxiety, distress and harm experienced by children when undergoing health care procedures;
- Propose an approach to establish trust with children undergoing health care procedures;
- Contribute to describing good procedural practice with children;
- Define and promote supportive holding as an approach to prioritise children's rights and well-being;
- Challenge the use of restraining holds for health care procedures, whether intended or labelled as such, by raising awareness that whilst restraining holds occur in procedural practice and may be necessary to provide life saving care for children or prevent significant harm, holding a child against their will can be harmful and should be minimised, openly acknowledged and documented;
- Support health professionals and other health care workers (hereafter referred to as professionals) in advocating for children's rights and positive procedural experiences;
- Be of value internationally and across different clinical settings;
- Support 'open and transparent' reflection and learning between professionals, children and parents/carers;
- Act as broad principles which will need consideration and adaptation within different local regulations, laws and resources; and
- Act as broad principles, to be considered alongside professional judgement.

The standards do not intend to:

- Endorse the use of restraining holds with children; rather they call for an honest and transparent acknowledgement and documentation of when such holds are used within a health care procedure;
- Override or replace country or discipline specific laws, regulations, frameworks, policies, standard operating procedures or guidance; and
- Provide specific guidance on the use of pharmacological interventions for procedures, for example procedural sedation and/or analgesia.

To achieve good practice for children undergoing health care procedures, professionals should recognise that:

1. A child has rights to be cared for by professionals who have the appropriate knowledge and skills to support their physical, emotional and psychological well-being and rights before, during and after their procedure.

a) A child is cared for by a professional who has the appropriate knowledge and skills and who is competent to conduct the procedure.

b) A child is cared for by a professional who has access to appropriate equipment and resources (e.g. staff, environment) to conduct the procedure.

c) A child is cared for by a professional who has confirmed the clinical need for the procedure.

d) A child is cared for by a professional who has the appropriate knowledge and skills to assess a child's individual needs, competence, abilities, preferences and experiences.

e) A child is cared for by a professional who demonstrates respect for children's rights and who can work in a child-centred manner to support and advocate for these rights.

f) A child is cared for by a professional who has the appropriate knowledge and skills to promote procedural comfort and to reduce the potential for traumatic procedural experiences.

g) A child is cared for by a professional who can work in partnership with a child and their parents/carers and who can utilise the skills and knowledge of the wider multidisciplinary team (if available).

2. A child has rights to be communicated with in a way which supports them to express (verbally or behaviourally) their views and feelings and for these views and feelings to be listened to, taken seriously and acted upon.

a) A child is communicated with directly in an open, honest, supportive and caring way to appropriately acknowledge their feelings and in a way a child can understand and that is consistent with their individual needs, competence, abilities, preferences and experiences at the time of the procedure.

b) A child is provided with the time and environment to develop trust and rapport with those present at their procedure.

c) A child is provided with the time and environment to feel able to communicate and freely express their views and feelings before, during and after their procedure.

d) A child is encouraged and supported to express their views and feelings freely without pressure, coercion or manipulation.

e) A child is encouraged and supported to recognise and communicate their rights.

f) A child's parents/carers are supported to recognise and communicate their child's views, choices and rights.

3. A child has rights to be supported to make procedural choices and decisions and for these choices to be acted upon to help them gain some control over their procedure.

a) A child is assumed to have the ability to be involved in choices about their procedure even when they are not able to make bigger decisions on their own.

b) A child is provided with sufficient information, including alternate options and the potential outcomes of those options, in ways that enable them to form their own views and be involved in choices and decisions about their procedure.

c) A child is actively encouraged from the earliest opportunity and throughout the procedure to share their views, feelings, procedural preferences and choices. This may include analgesia, methods of distraction, relaxation techniques, positioning, who supports them for their procedure and sources of comfort.

d) A child is supported through their choices and decisions to have optimal control during their procedure.

e) A child and their parents/carers are provided with the opportunity to discuss previous procedural experiences to inform procedural choices and decisions.

f) A child's parents/carers are supported by a professional who works with them to consider their child's views, preferences and choices for pharmacological and non-pharmacological interventions.

g) A child's views and expressions of refusal must be listened to, considered, taken seriously and given due weight.

4. A child has rights to be provided with meaningful, individualised and easy to understand information to help them prepare and develop skills to help them cope with their procedure.

a) A child is provided with tailored, easy to understand, meaningful, honest and appropriately timed information to help them prepare for a procedure, understand what is happening and have the opportunity to ask questions to check their understanding.

b) A child shall receive specific, honest and clear information at key points before, during and after their procedure.

c) A child's questions and expressions of concern should be responded to in a calm and honest manner in accordance to their individual needs, competence, abilities, preferences and experiences.

d) A child's parents/carers are provided with tailored, appropriately timed, easy to understand, meaningful and honest information to ensure they are aware and prepared for their child's procedure and have been able to ask questions to understand what is happening and their role in supporting their child before, during and after a procedure.

5. A child has the right for their short- and long-term best interests and well-being to be a priority in all procedural decisions.

a) A child's best interests must be prioritised in all decisions and actions before, during and after a procedure. A child's interests should be prioritised over those of their parents/carers, professionals and the institution.

b) A child's short- and long-term best interests are openly considered and collectively discussed by health professionals, parents/carers and the child (where appropriate) in the preparation phase prior to the procedure.

c) A child is protected from harm; any potential or actual harm to a child caused by unnecessary procedures or overriding their expressions of dissent should be carefully considered and mitigated wherever possible.

d) A child is supported to feel calm, secure and settled during a procedure.

e) A child who becomes upset or resistant before or during a procedure is helped as quickly as possible, if it does not cause harm, to take a supported break. Professionals should be confident to stop and reconsider the procedural plan.

f) A child and their parents/carers are supported after a procedure to talk through their experiences and reflect on positive or any challenging aspects.

g) A child's health records will include clear documentation of what worked well during a procedure and what procedural support or techniques would help for future procedures.

6. A child has the right to be positioned for a procedure in a supportive hold (if needed) and should not be held against their will.

a) A supportive hold involves supporting a child to feel calm, secure and settled during a procedure. ln a supportive hold a child agrees to the procedure and positioning and/or does not express signs of refusal.

b) Supportive holding is a way of providing comfort to the child and helping them to maintain a good position for the procedure.

c) A child is only held using a supportive hold for their procedure.

d) A child is encouraged to express their views and choices about who will supportively hold them for their procedure.

e) A restraining hold is any action to prevent a child moving freely against their choice or will while expressing signs of refusal.

f) Regardless of who holds a child, if it is against their will (expressed verbally and/or behaviourally) the hold is a restraining hold. A restraining hold should be recognised as such and not labelled as a clinical, supportive or comfort hold.

g) A child is not held against their will (restrained) at any point in a procedure unless the procedure is lifesaving or where there is a likelihood of significant harm if the procedure is not carried out.

h) Any child who has been subjected to a restraining hold during a procedure must receive appropriate support from a professional to help them understand their experience and re- build trust.

i) A child's health records will include clear documentation if they have been held without their agreement (restraining hold), regardless of who held the child. This would include the rationale for using a restraining hold, who made the decision that a restraining hold was necessary, the restraining hold/technique(s) used, and the outcome for the child.