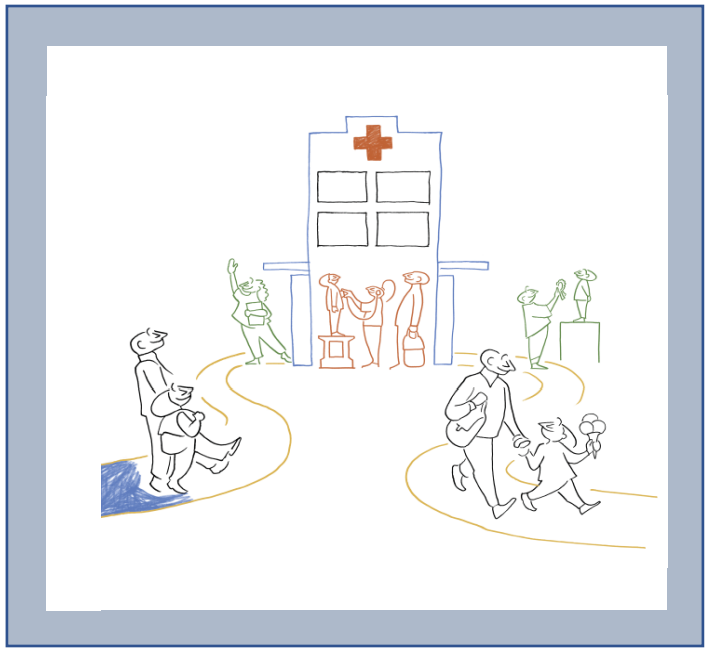
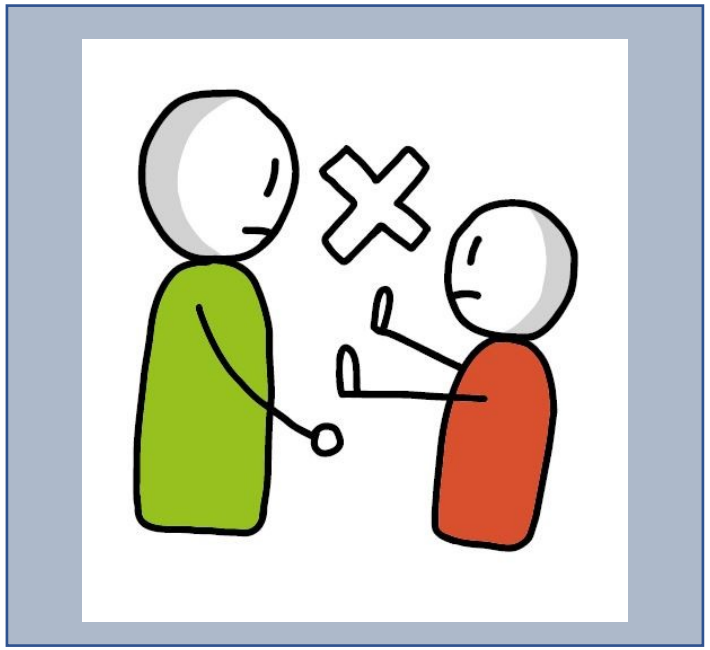
iSUPPORT – the international collaborative rights-based standards to support paediatric patients during clinical procedures by reducing harm and establishing trust.

Professor Lucy Bray

Recognising the contributions of the whole ISUPPORT team





What will I be talking about?

- Children's non-emergency procedures and the use of restraint.
- The development and content of the ISupport standards.

- Acknowledging that health care procedures are often fast-paced and involve complex interactions within complex systems.
- Recognising that every child is an individual with different needs, competence, ability, preferences and experiences.
- Recognising that lots of children have positive procedural experiences – but many do not!
- Acknowledging that some of what happens within health care causes children **harm.**

"Do the best you can
until you know better.
Then when you know better,
do better."

Maya Angelou

- Most children and their parents say they do not have enough information about what is going to happen for their procedure – an '**information hole'.**
- Parents may not know the impact of good preparation and may think they are acting in their child's best interests to 'not tell them'
- Parents may not know the right language to use or how to source or use information and preparation materials.

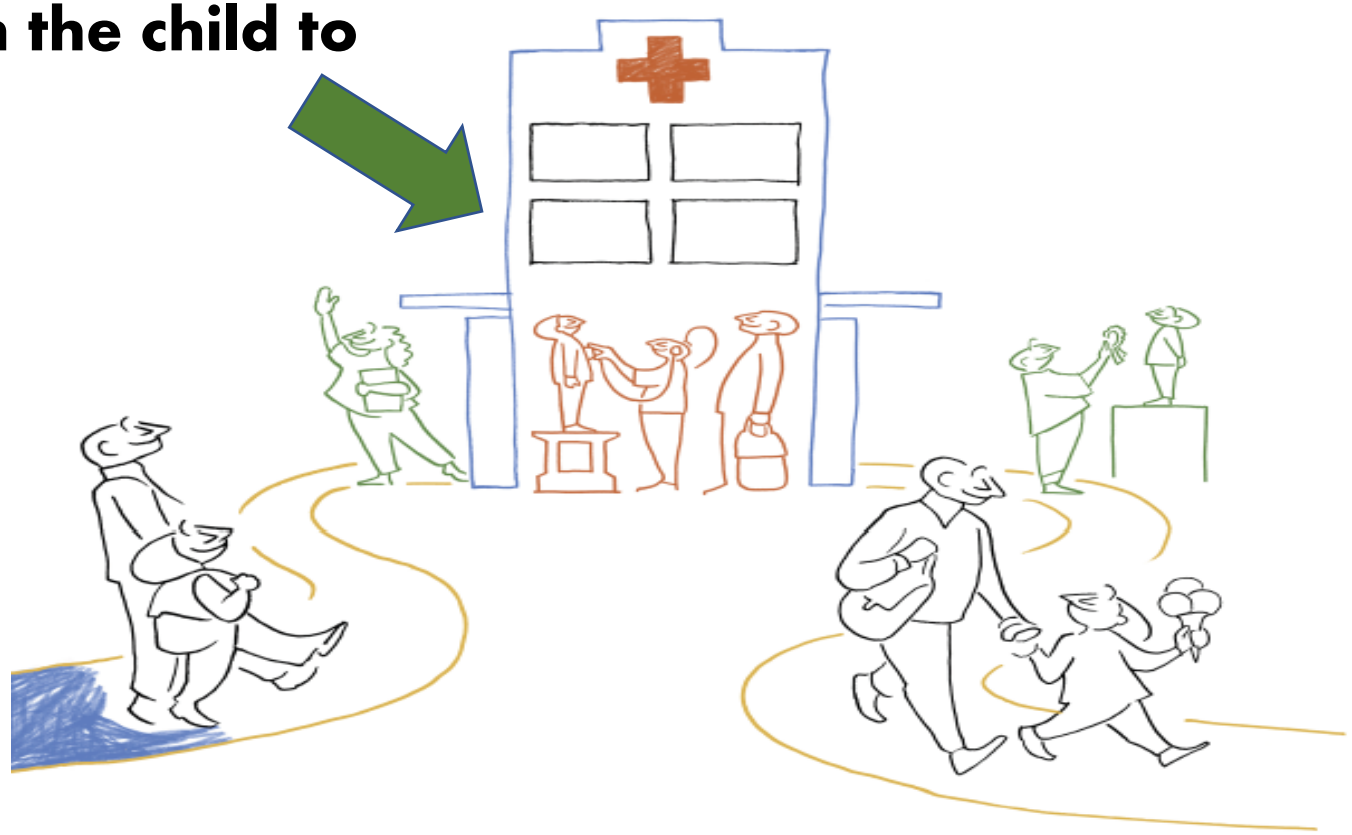
Preparation and information

- Some of the **environments and spaces** we ask children to enter can cause them to become dysregulated.
- **First impressions count** – it is so important to develop rapport, trust and connect with a child.
- There is often a very tight window of opportunity to '**see the child**' - to look beyond first impressions and pay attention to what is not being said (Pearson 2023).

Arriving at the hospital or clinic.

- Children report feeling **excluded from communication** and not listened to when they have procedures.
- All forms of communication (verbal, non-verbal, behaviour)
- We often underplay rather than **validating** a child's emotions
  - 'I am scared' ……'you are fine'
  - Stop stop -----'be brave, we are nearly done'

Communication and engagement with the child to develop trust.



- Parents do not always have the skills, knowledge or ability to prepare, involve and support their child through a procedure.
- Parents may not want to **advocate** – labelling as 'difficult'.
- Children report not feeling involved or supported to **make choices** when they are having a procedure
- Children need to be regulated and feel they can trust adults before they can make choices.

Choices - Analgesia, distraction, positioning

Coaching parents

- Children continue to be **frequently held against their will** for non-emergency procedures.
- Professionals can struggle to know when **holding tips to restraint** and can struggle to 'step-back' or see alternatives when a procedure has started - momentum.
- Remains **uncertainty around boundaries** and definitions of holding
- Restraint and the holding of children continues to be an accepted and unspoken part of children's care.
- Children do remember and poor experiences have **long lasting effects**.

Making a plan A, B or pause point

Bravery to stop and rethink

- Do we see the use of restraint or a distressed child as an **event to report** and learn from?
- Do we **debrief and re-shape** children and parent's procedural experiences?
- Do we consider the '**next time**' the child needs a procedure?

After the procedure.

Choices - Analgesia, distraction, positioning

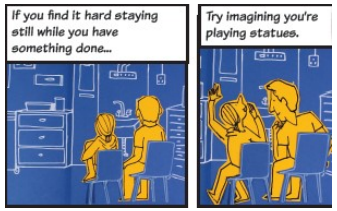
Coaching parents

Communication and engagement with the child to develop trust.

Knowledge of previous experience

Making a plan B or pause point

Bravery to stop and rethink



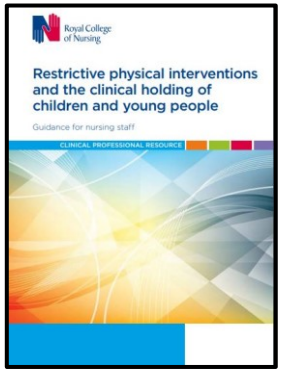
Arriving at the hospital or clinic.

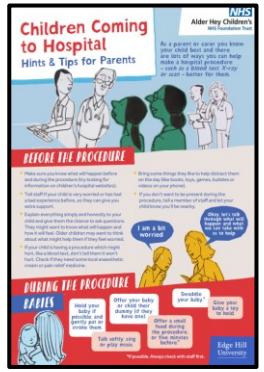
After the procedure.

Preparation and information

ISupport

- Minimal progress or changes to holding practices ‘whilst re-named’ have been made in the last 20 years despite research, publications and guidance.
- A visit from Katie Dixon 2019.
- ISupport collaboration was born and we started our 2 year multi-phase multi-stakeholder development project.
- The departure point was to clearly define restraining and supporting holds.





ISUPPORT

International collaboration

50 experts (anaesthetists, clinical psychologists, nurses (acute setting and CAMHS), young people, health play specialists, consultant doctors, youth workers, parents, academics and child rights experts.

Stage 1

Rights based standards for children undergoing clinical procedures version 1

Six international collaborative group online meetings

Online meetings with three youth forums and two parents/carer groups in the UK.

Two one to one meetings with young people advising on the project.

Stage 2

Rights based standards for children undergoing clinical procedures version 2

Online consultation survey with children, parents and professionals (n=155) from 18 countries.

Three international collaborative group online meetings.

Online meetings with two youth forums and a parent forum.

Stage 3

Rights based standards for children undergoing tests, treatments, interventions and examinations

Online consultation survey with children and young people, parents and professionals (n=301).

One online meeting with a youth forum and a parent forum and one face to face consultation with young people at the iCAN conference.

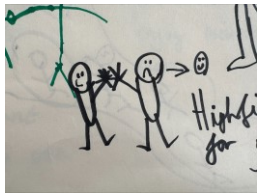
Three international collaborative group online meetings with Katie present.

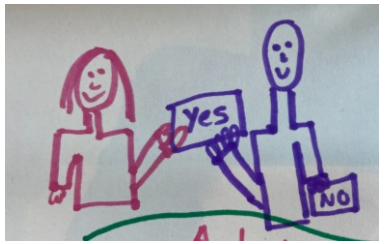
Attendance face to face at a local young peoples' group
Attendance face to face at a group within a primary school.

Two one to one meetings with young people advising on specific parts of the project.

Three international collaborative group online meetings

- **2 year development**
- **Consulted internationally** with 203 children and young people, 78 parents and 418 multi-disciplinary professionals including those who may be 'less heard'.
- **Consensus** building.
- **Broadening** of focus





What are the ISupport rights-based standards?

- The standards are for **ALL** children and young people (aged 0-18 years) undergoing tests, treatments, examinations and interventions, based on internationally agreed children's rights set out by the UNCRC (1989).

- The standards aim to ensure that the short and long-term physical, emotional and psychological well-being of children and young people are of central importance in any decision-making for procedures or procedural practice.

- Propose an approach to minimise the anxiety, distress and harm experienced by children and establish trust with children having clinical procedures.

What are the standards about?

- Challenge the use of restraining holds for clinical 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 or emergency care for children, such holds can be harmful and their use should be minimised, openly acknowledged and documented.

- First consensus definition of supportive and restraining holds

- Act as broad principles which will need further consideration and adaptation based on local regulations, laws and resources;

Rights-based standards for professionals

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

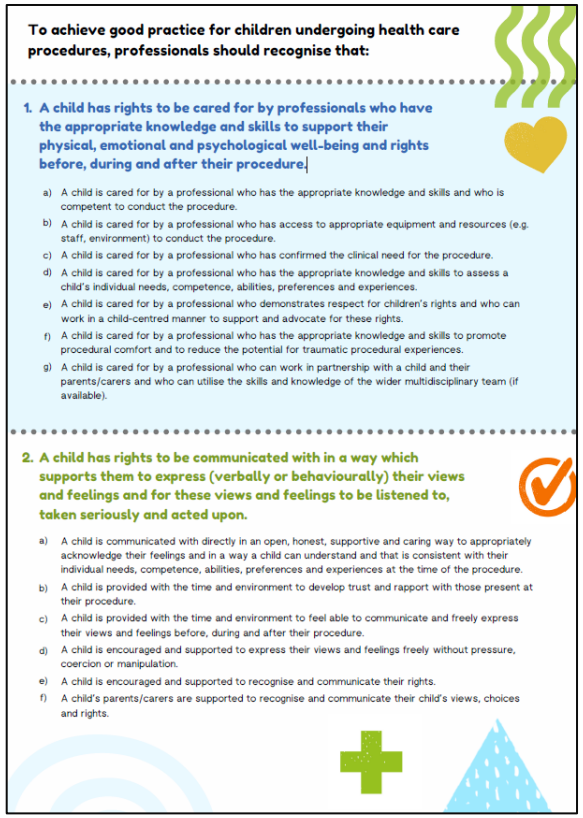
- The standards have been developed by an expert international collaborative group through extensive consultation with children, parents and professionals.
- The standards are framed by a commitment to prioritise the rights of a child (United Nations Convention on the Rights of the Child, 1989) and ensure 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 rights-based 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, 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.



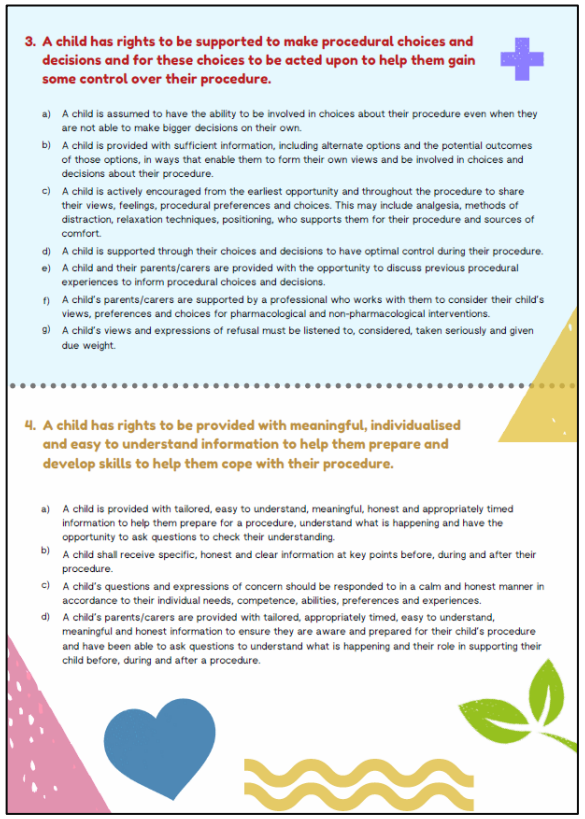
To achieve good practice for children undergoing health care procedures, professionals should recognise that:

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.

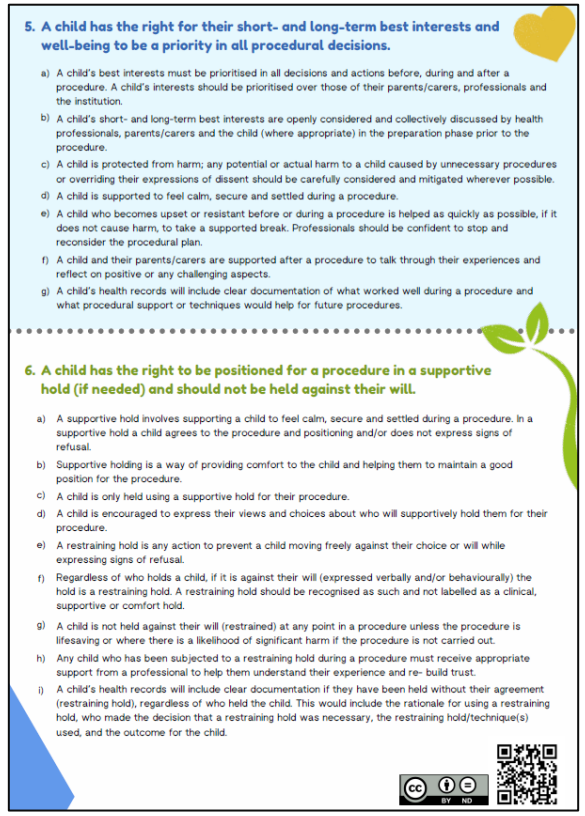


3. A child has rights to be supported to make procedural choices and decisions and for these choices to be acted upon to help them gain some control over their procedure.

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. In 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.

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 or intervention.

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.
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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.

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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.
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 serious due weight.

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

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

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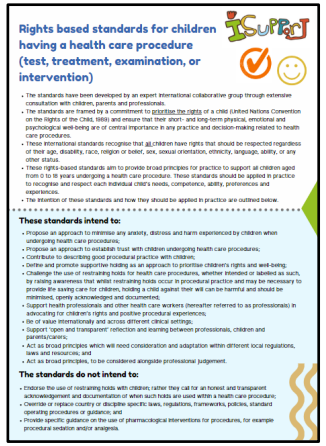
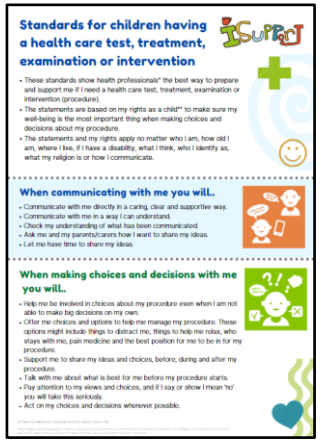
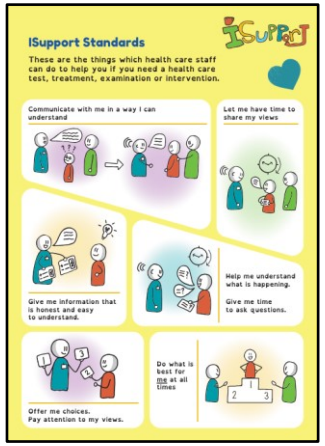
For professionals



For families



Comic version



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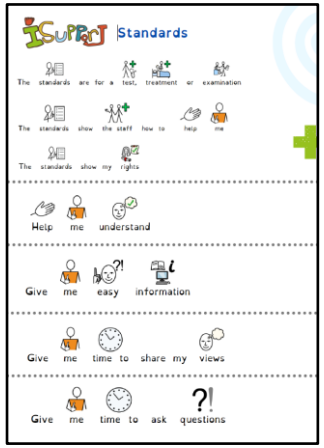
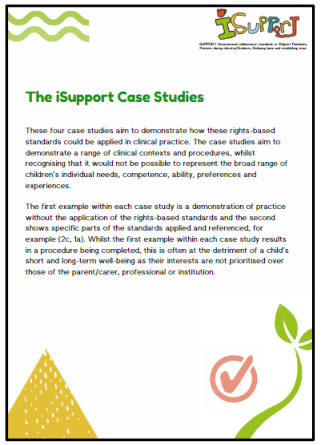
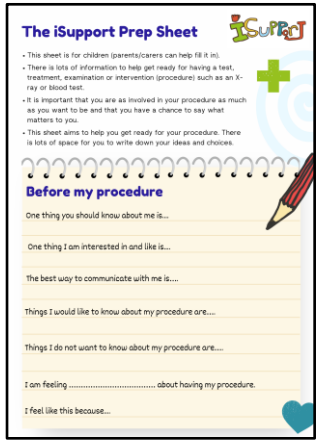


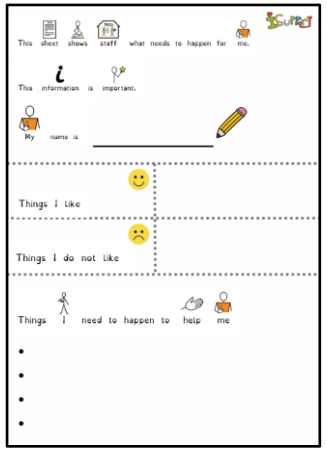
Case studies



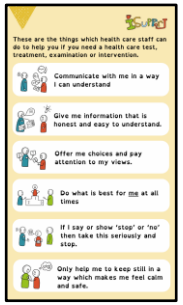
Evidence

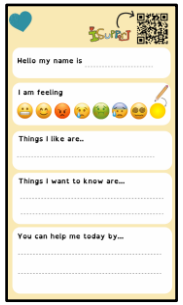
For preparation





Lanyard/card based version



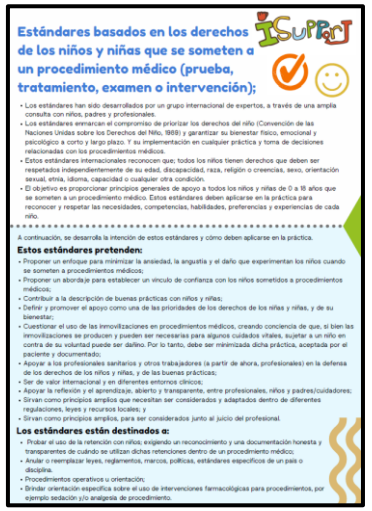


Translations

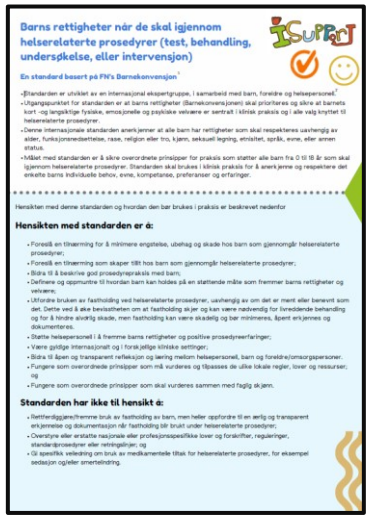
Portugese

Dutch

Swedish



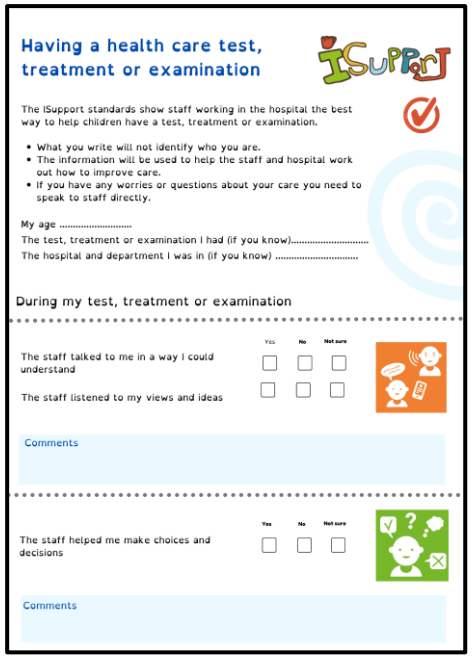
Spanish



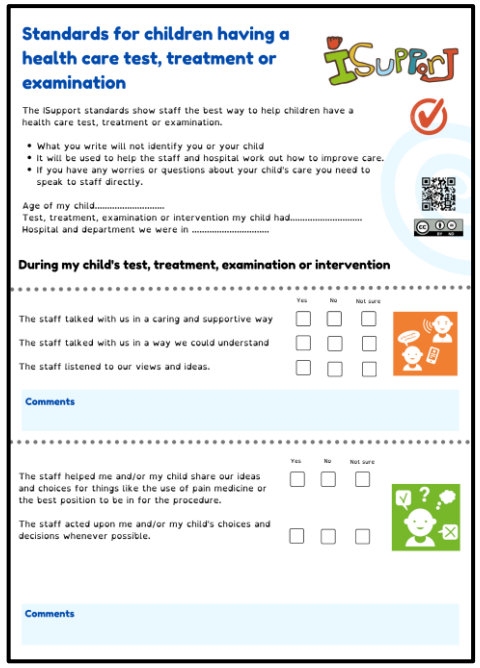
Norwegian

Danish

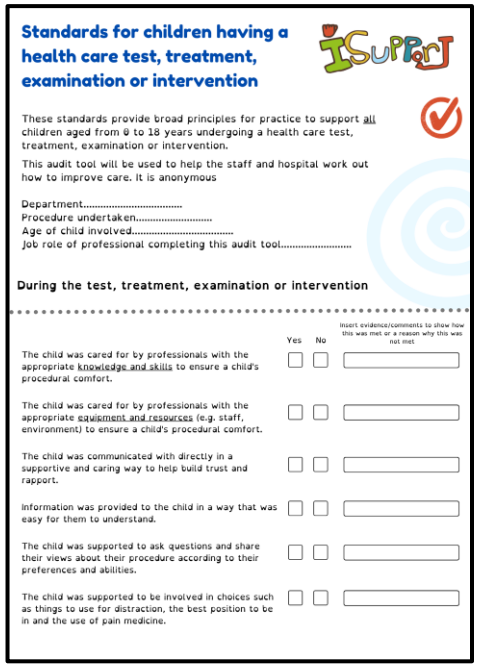
Auditing practice to impact on practice



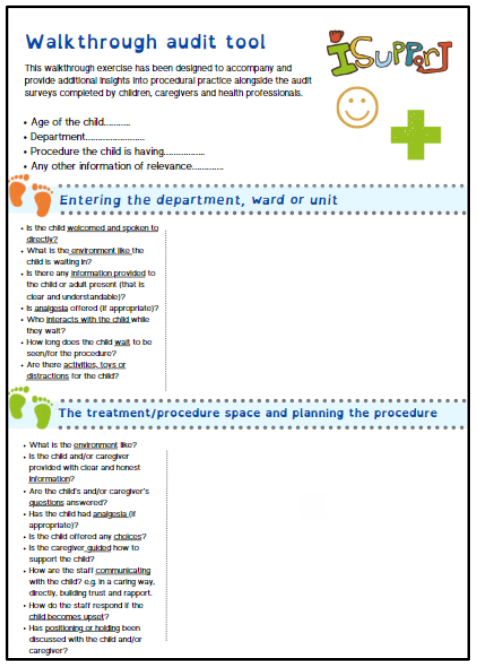
Audit tool for children and young people



Audit tool for parents

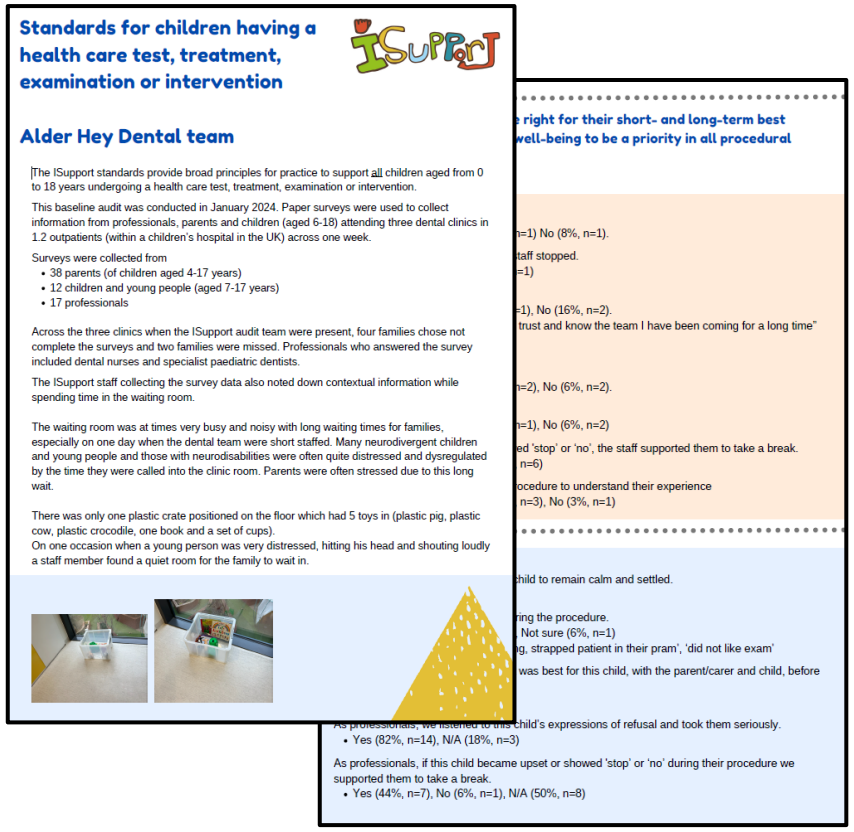


Audit tool for professionals



Walk-through tool

Auditing practice to impact on practice



Standards for children having a health care test, treatment, examination or intervention

Alder Hey Dental team

The ISupport standards provide broad principles for practice to support all children aged from 0 to 18 years undergoing a health care test, treatment, examination or intervention.

This baseline audit was conducted in January 2024. Paper surveys were used to collect information from professionals, parents and children (aged 6-18) attending three dental clinics in 1.2 outpatients (within a children's hospital in the UK) across one week.

Surveys were collected from
- 38 parents (of children aged 4-17 years)
- 12 children and young people (aged 7-17 years)
- 17 professionals

Across the three clinics when the ISupport audit team were present, four families chose not complete the surveys and two families were missed. Professionals who answered the survey included dental nurses and specialist paediatric dentists.

The ISupport staff collecting the survey data also noted down contextual information while spending time in the waiting room.

The waiting room was at times very busy and noisy with long waiting times for families, especially on one day when the dental team were short staffed. Many neurodivergent children and young people and those with neurodisabilities were often quite distressed and dysregulated by the time they were called into the clinic room. Parents were often stressed due to this long wait.

There was only one plastic crate positioned on the floor which had 5 toys in (plastic pig, plastic cow, plastic crocodile, one book and a set of cups).
On one occasion when a young person was very distressed, hitting his head and shouting loudly a staff member found a quiet room for the family to wait in.

right for their short- and long-term best well-being to be a priority in all procedural

=1) No (8%, n=1).

taff stopped.
=1)

=1), No (16%, n=2).
trust and know the team I have been coming for a long time"

=2), No (6%, n=2).

=1), No (6%, n=2)

ed 'stop' or 'no', the staff supported them to take a break.
n=6)

ocedure to understand their experience
n=3), No (3%, n=1)

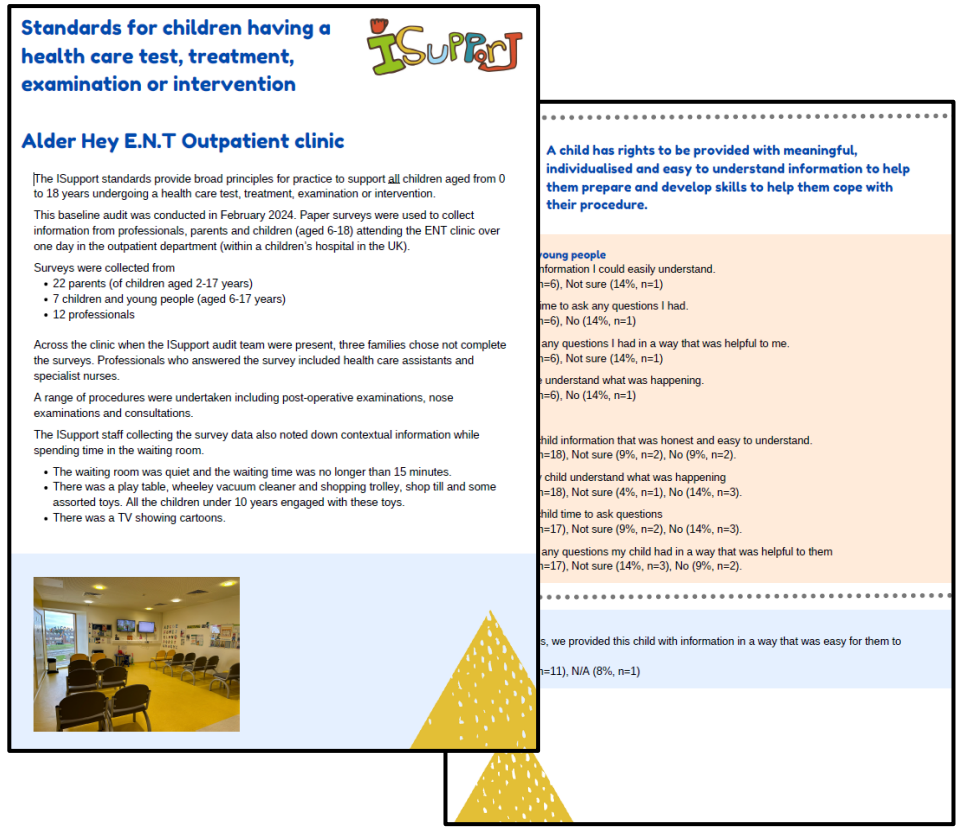
hild to remain calm and settled.

ring the procedure.
Not sure (6%, n=1)
g, strapped patient in their pram', 'did not like exam'

was best for this child, with the parent/carer and child, before

As professionals, we listened to this child's expressions of refusal and took them seriously.
- Yes (82%, n=14), N/A (18%, n=3)

As professionals, if this child became upset or showed 'stop' or 'no' during their procedure we supported them to take a break.
- Yes (44%, n=7), No (6%, n=1), N/A (50%, n=8)



Standards for children having a health care test, treatment, examination or intervention

Alder Hey E.N.T Outpatient clinic

The ISupport standards provide broad principles for practice to support all children aged from 0 to 18 years undergoing a health care test, treatment, examination or intervention.

This baseline audit was conducted in February 2024. Paper surveys were used to collect information from professionals, parents and children (aged 6-18) attending the ENT clinic over one day in the outpatient department (within a children's hospital in the UK).

Surveys were collected from
- 22 parents (of children aged 2-17 years)
- 7 children and young people (aged 6-17 years)
- 12 professionals

Across the clinic when the ISupport audit team were present, three families chose not complete the surveys. Professionals who answered the survey included health care assistants and specialist nurses.

A range of procedures were undertaken including post-operative examinations, nose examinations and consultations.

The ISupport staff collecting the survey data also noted down contextual information while spending time in the waiting room.
- The waiting room was quiet and the waiting time was no longer than 15 minutes.
- There was a play table, wheeley vacuum cleaner and shopping trolley, shop till and some assorted toys. All the children under 10 years engaged with these toys.
- There was a TV showing cartoons.

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.

oung people
nformation I could easily understand.
=6), Not sure (14%, n=1)

me to ask any questions I had.
=6), No (14%, n=1)

any questions I had in a way that was helpful to me.
=6), Not sure (14%, n=1)

understand what was happening.
=6), No (14%, n=1)

hild information that was honest and easy to understand.
=18), Not sure (9%, n=2), No (9%, n=2).

child understand what was happening
=18), Not sure (4%, n=1), No (14%, n=3).

hild time to ask questions
=17), Not sure (9%, n=2), No (14%, n=3).

any questions my child had in a way that was helpful to them
=17), Not sure (14%, n=3), No (9%, n=2).

s, we provided this child with information in a way that was easy for them to

=11), N/A (8%, n=1)

Audit reports and recommendations
Over 20 hospitals involved internationally

Impact on practice – marginal gains

Focusing on making small changes helps focus teams away from it being 'too hard' to make big changes or that there is an easy one-off solution.

Looking across the child's whole procedural journey for the small differences which can make a big impact

"I used the info and forms yesterday with a teenager in a session as a reflective tool and it was amazing to see her responses and the validation of her experiences." (health professional)

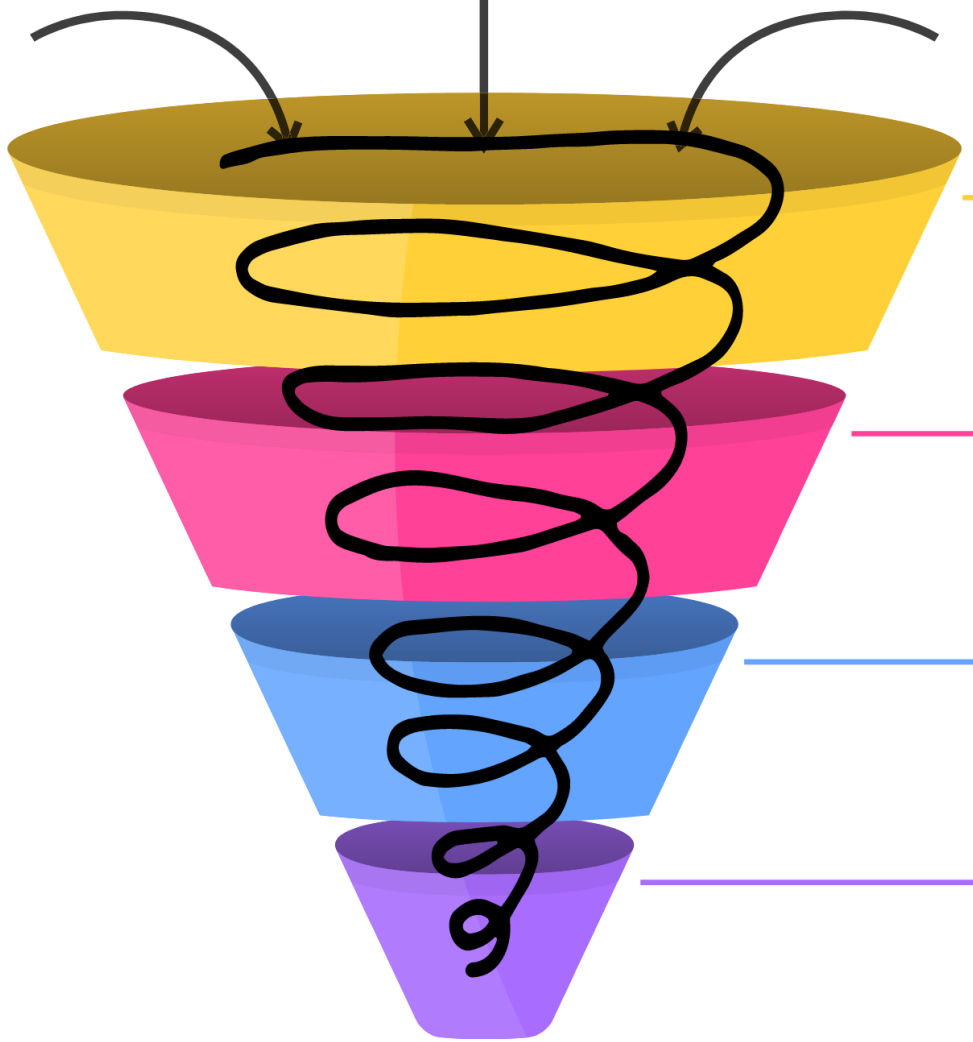
The statement 'give me information that is honest', really helps him as he is often told things won't hurt and they do hurt him. He has therefore lost trust with hospital staff. (parent)

Off the back of the ISupport audit, we had interest from the Exec Board and I'm in the process of pulling quotes together for a significant redecoration to hopefully get funding through the Charity! (health professional)

Evidence and policy

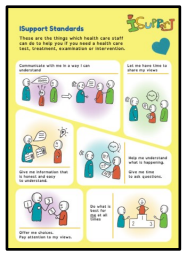
National level constraints on health services

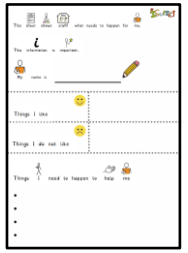
Societal beliefs about children's abilities and agency

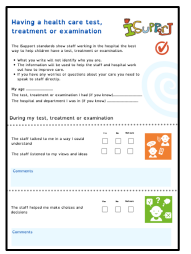


Child's health care procedure

- **Organisations**
  - Reporting targets
  - Over burdened services
  - Cost-effectiveness
  - Limited time and resources
- **Professionals**
  - Accepted learnt practices
  - Good intentions
  - Short-term task focus
  - Service pressures
  - Assumptions
- **Parents**
  - Uncertainty
  - Limitations in knowledge
  - Good intentions
  - Disempowerment
  - Assumptions
- **Children**
  - Uncertainty, anxiety & fear
  - Limitations in knowledge
  - Previous experiences
  - Disempowerment







Thank you

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ISupporT →