ISPN
INTERNATIONAL SOCIETY FOR
PEDIATRIC NEUROSURGERY

ISPN Statement on Informed Consent – An ethical and professional framework

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Statement of purpose:

Providing information and obtaining informed consent in paediatric neurosurgery has both legal and ethical requirements. Parents have a legal and moral authority to make decisions on behalf of their children (although their decisions must be in the best interests of the child) and clinicians must assess capacity and provide adequate and accurate information to children and their parents or surrogates.

A successful informed consent process protects patient/family autonomy and empowers their decision making. It also ensures ethical practice and provides the best clinical care whilst minimising legal risk for Neurosurgeons.

There are significant legal differences in definitions, and requirements for consent across the globe and neurosurgeons must be aware of those relevant for their area of practice. This statement aims to provide an ethical guide and practical framework to informed consent noting that in complex or extenuating circumstances specific legal and ethical advice should be sought locally.

Guiding ethical principles

- All treatment and communication about treatment should aim to maximise benfits for children
- Neurosurgeons should respect parents’ responsibility to be the primary decision makers for their children
- Neurosurgeons should respect a child’s developing autonomy and capacity to contribute to medical decisions

Key Components of consent

- Disclosure of ***information***
    - Proposed treatment incluing type, method and duration
    - Benefits of the treatment
    - Risks / negative effects of the treatment / common and expected side effects / *material risks* to the patients unique circumstances (for example motor deficit in the setting of a pre-exisiting hemiparesis)
    - Explanation of the alternative treatments and discussion on why the proposed treatment is recommended over the alternatives
    - Explanation of the consequences of not undergoing treatment
    - Anwers to any questions
    - Discussion of any other relevant information likely to influence their decision

- ***Comprehension*** of the information
- ***Compentency*** of patient / guardian or surrogate to make a decision, without impairment.
- The ***voluntary*** nature of the decision
    - Given freely without duress or to please / influence another
- ***Documentation*** of the consent process
- ***Withdrawal*** of consent may occur at any time

What is consent required for ?

- Treatment / procedures
- Surgery
- Blood and medication administration
- Anaesthesia – including scans under anaesthesia
- Dissemination / publication of patient information
- Provision of patient information to third parties
- Research / new procedures or therapies

Who can provide consent ?

- The patient if of age and capacity to consent
- A mature minor if competence is formally assessed
- Parents
- Legal guardians

Age of consent

Whilst there are substantial differences in the legal age at which minors can make healthcare decisions across the world, generally the Age of Majority (18) from the Convention on the Rights of the Child (CRC) is used as the standard.

However

- Many contries allow minors to consent to specific medical treatments (for examples contraceptives, vaccinations or STD testing) at a lower age.
- Specific Jurisdictions are common and Neurosurgeons should be familiar with the Laws and Acts pretainent to their region and scope of practice.

Mature Minor

The concept of a mature minor is a legal concept that recognises that minors become increasingly autonomous as they develop, and respects the ethical principle of autonomy of patients’ wishes.

The definition of a mature minor is based on specific tools that assess competency and may be specifically defined in local legislation.

- Gillick competency (Gillick v West Norfolk and Wisbech Area Health Authority which established the principle that parental authority deiminshes as a child's maturity increases.)
    - A defined assessment that a child is able to achieve a sufficient understanding and intelligence to enable them to fully understand what is proposed.
    - May be invidiualised for each procedure as the level of understanding required can vary.
- MacArther Competence Assessment Tool for Clinical Research

Informed consent and the **mature minor**

- Can **consent** to their own medical treatment.
- Is entitled to the same level of **confidentiality** regarding their medical information as an adult.
    - Parents are generally not required to be informed about medical decision unless the minor chooses to share the information.
    - It is generally advisable for minors to discuss their medical decisions with parents and guardians – parental consent whilst not legally required may also be obtained and documented.
- Asessment of competence must be **documented** (prior to the consent process).

Assessing Capacity to consent

To be competent to give consent the patient or their parent / surrogate must be able to

- Understand the information.
- Remember the information.
- Use or weigh the information – understand the impact of making and not making the decision.
- Communicate their decision.

In assessing this the Neurosurgeon should note that

- Capacity change over time and is influenced by dynamic factors such as age and illness.
- Communication barriers or other disability do not negate capacity.

Barriers to consent

During a the informed consent process the Neurosurgeon should be assessing for any factors that would affect the comprehension of the information provided such as

- Language / reading level / comprehension
- Emotional state
- Cultural background
- Duress or influence such that autonomy is threatened
- Impairment

When may consent be waived ?

Surgery may be performed without consent when the patient cannot communication and no surrogate decision-maker is available under certain circumstances as defined by local legislation such as

- To save a life
- To prevent serious damage to a person health
- To prevent the person from suffering or continuing to suffer from significant pain or distress

Special circumstances requiring nuanced processes

- Separated parents.
- Parental disagreement
    - There is significant variation in legal requirements across the world. Time permitting, involvement in of supporting legal teams, clinical ethics committees and family supports is recommended.
- Legal care family or guardianship orders.

Who should be involved in the consent discussion ?

Encouraging children and their parents to be involved in discussion and decisions is part of good clinical care

- Providing information respects parents role as their child guardians and respects the childs developing capacity to know about and contribute to decision about their healthcare.
- When information is not shared with children they can be left in a lonely place without the ability to discuss their fears or ask questions.
- Patients who are well informed about medical procedures require less pain medications and are less anxious.

What are families seeking ?

- Information that is consistent, up-to-date, comprehensive, evidence based, value free and tailored to their needs and reading level.
- Information presented in comparative risk terms or using a question and answer format rather than information presented as probabilities or using vague descriptors such as “rare”.
- Information that is tailored to their individual needs, and available in a variety of formats e.g. written text, DVD, face-to-face or telephone conversations and appropriate languages.
- Direction from health professional about where to find “good” information sources
- Time to process and discuss information both during and otside the consultation.
- The opportunity to talk with other parents in the same situation to share knowledge, expericne and feel reassured, to counterbalance the information received from official sources.
- Consultation to take place in a relaxed and unhurried atmosphere where possible.

- Having written information in advance of a consultation to be better prepared to ask questions.
- Information written in “plain language”.
- Addressing “what does it mean for me and my family and what should I do about it.