

# Consent in Children

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#### Acknowledgements

Children's Institute (UCT)
<u>www.ci.org.za</u>



#### CHILDREN'S ACT GUIDE for Health Professionals

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**Fifth Edition** 

#### Consider the following scenarios

- 12-year-old Skyler has asthma; repeated exacerbations and hospital admissions. Never actively involved in discussions about her treatment and inhaler choices; all engagement with her mother with instructions from the doctor to Skyler
- 3-month-old Bongi needs surgery for inguinal hernia. His mother is 17 years old. Who should consent to his surgery?
- 3-month-old Bongi needs emergency surgery for intussusception. His mother is 17 years old and estranged from her family. Who should consent to his surgery?

#### Scenarios 2

- 14-year-old Andisa has osteosarcoma; completed chemotherapy; requires amputation. Andisa and her mother say they cannot make a decision without consulting the elders in their family.
- 4-year-old Luke, with medulloblastoma, full surgical resection possible. Luke's mother and father never married; his mother passed away when he was 6 months old. Can the father give consent for the procedure?

### Outline

- Informed consent ethical requirements
- Children and decision making
- Consent provisions in the Children's Act No 38 of 2005
  - Medical and surgical treatment
  - HIV testing
- Consent in other legislation



# Informed Consent

#### What Is Informed Consent?

Consent for treatment or research given by a competent individual who -

Has **received** the necessary information

Has adequately understood the information

After considering the information, has **arrived at a decision** without having been subjected to coercion, undue influence, or intimidation.

# Essential elements for morally valid consent

- **Disclosure** the patient must have access to the information to be able to make a choice
- Understanding able to assess the information
- Voluntariness the patient must feel free to make the decisions reached after discussion
- **Competence** to make a decision



# Informed consent / decision making

 Western view: liberalindividual

 Traditional African context: communitarian



### Children and decision making

le have a voice!

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# Why the increased involvement of children in decision making?

- Respect individuals' right to make decisions about their own bodies
- Recognise child patient's developing personhood
- Confers a sense of control and ownership over the treatment decision



#### Who makes decisions for children?

If children are autonomous and competent, they can make their own decisions related to their healthcare

If children are unable to make decisions for themselves, the parents/guardian make that decision

#### Assent

- Assent to treatment is a bridge between no patient participation (in small children) and full patient decision making (as in competent adults).
- Focuses on <u>capacity</u> rather than <u>competence</u>





# Informed Assent

- Telling the child what tests and treatments are going to be done
- Assessing child's understanding
- Asking the child whether they are willing to accept the proposed care
- Children should not be asked unless their views will be taken seriously. If there is no choice, the child should be told so

Assessing the child's capacity for informed consent



- Reasoning
  - -Age
  - -IQ
  - -Cognitive functioning
  - -Emotional functioning



- Understanding
  - -Experiential factors

-Knowledge of the problem



King Pediatrics 1989;115:10-16

Voluntariness

- Uncoerced patient decision

- Valid consent = free choice



- The nature of the decision to be made
  - -Gravity
  - -Immediacy
  - -Risk-benefit balance



King Pediatrics 1989;115:10-16

Informed Consent and Children SA Legislation



Guiding principles and basic rights in Children's Act

- Best Interests of the Child
- Child Participation (Section 10)
  - "Every child that is of such an age, maturity, stage of development as to be able to participate in any matter concerning that child <u>has</u> <u>the right to participate</u> in an appropriate way and views expressed by the child must be given due consideration."

#### **Current Legislation: SA**

- Legal capacity = age of consent
- Bill of Rights: child = <18 years of age
- Children's Act (38 of 2005): age of majority 18 years



#### Age of decisional capacity

- Described in children as young as 7-8 years
- Experience is the salient factor in children's intellectual and moral competence
- Children who have chronic illness or disabilities have been shown to have higher levels of knowledge and competence related to their condition

### Decision making and minors

- Giving minors a say in their treatment encourages their cooperation and therapeutic goals, but also promotes developing decision making capacity
- In paediatric oncology studies most children older than 9 years are capable of understanding prognosis and the majority older than 11.5 years can make treatment decisions
- By the age of 14 years the typical child demonstrates capacity to reason, including the ability to understand the causes and effects of illness, similar to that of an adult.

#### Children's Act 38 of 2005 (Section 129 – promulgated in April 2010)



#### **Older children and consent**

- Children > 12 years consent to medical treatment provided they are of sufficient maturity to do so
- Children > 12 years consent to surgical treatment provided they are of sufficient maturity to do so and assisted by parent or guardian
- How is **maturity** determined?
- And what does **assisted** mean?



### **Sufficient maturity**

- Child's participation as well as age of consent based on whether child is of sufficient maturity to make expected decisions
- Sufficient maturity could be measured by e.g.
  - (a) biological age
  - (b) mental age
  - (c) maturity compared to peers
  - (d) circumstances at home
  - (e) cognitive abilities
  - (f) level of understanding
  - (g) participation in decision making at school
  - (h) easily influenced etc.



### Younger Children

- Children < 12 years: parental, guardian or caregiver consent for medical management
- Surgical procedures < 12 years: parental or guardian consent
- Law makes no mention of level of risk or invasiveness of treatment



## Section 130(2)

- HIV testing
- <u>></u> 12 years may give consent
- < 12 years may give consent if sufficiently mature to understand the benefits, risks and social implications of the test
  - If not sufficiently mature and in their best interests to have the test, consent may be given by *parent or caregiver*, the provincial head of social development, or a designated child protection organisation



# HIV testing cont'd

- If consent is unreasonably withheld and in child's best interests to be tested, application may be made to Children's Court
- Court application may also be made if child, parent or caregiver incapable of giving consent

A caregiver is anyone who cares for a child

- Grannies, aunts and other relatives who care for the child with the consent of the child's parents or guardian;
- A foster parent;
- Someone offering temporary safe care;
- The head of a shelter or child and youth center;
- A child and youth care worker supporting children in the community; and a child (of 16 years and older) heading a child-headed household.

#### Consent in other legislation

#### Choice on Termination of Pregnancy Act 92 of 1996 Consent

5. (2) Notwithstanding any other law or the common law, but subject to the provisions of subsections (4) and (5), no consent other than that of the pregnant woman shall be required for the termination of a pregnancy.

(3) In the case of a pregnant minor, a medical practitioner or a registered midwife, as the case may be, shall advise such minor to consult with her parents, guardian, family members or friends before the pregnancy is terminated: Provided that the termination of the pregnancy shall not be denied because such minor chooses not to consult them.

#### Court orders Gauteng Health to provide pregnancy termination services to a teenager following SECTION27 intervention

28 May 2023, Johannesburg – SECTION27 launched a successful urgent application on behalf of a pregnant minor who was denied access to termination of pregnancy (TOP) services at a primary public healthcare facility in Gauteng. The minor made multiple attempts to access these services, in accordance with her rights under the Choice on Termination of Pregnancy Act 92 of 1996 (CTOPA). She was denied access to this right repeatedly. The healthcare provider at the primary healthcare facility where the girl attended incorrectly told her that the position of the foetus meant that she was disqualified for a TOP and did not refer her to a tertiary hospital. This denial delayed access to the TOP.

https://section27.org.za/2023/05/court-orders-gauteng-health-to-providepregnancy-termination-services-to-a-teenager-following-section27-intervention/ The CTOPA provides that women and girls are legally permitted to obtain a TOP up to and including the 20th week of pregnancy, on non-medical grounds. The minor is now 20 weeks and 4 days pregnant, with only 2 days remaining to obtain the TOP lawfully. The application having been first argued on 27 May 2023, today Thompson AJ granted an order compelling the Gauteng Department of Health to make arrangements to provide the minor with a TOP by Monday, 29 May 2023.

The minor's right to reproductive health services, bodily autonomy and access to healthcare services was violated when the primary healthcare facility failed to refer her to a tertiary healthcare facility. In our view, the respondents in the case (the Member of the Executive Council in the Gauteng Department of Health and the Head of Department of Health in Gauteng) failed to fulfil their constitutional obligation in terms of section 27(1)(a) of the Constitution, which states that "everyone has the right to access health care services, including reproductive health care".

#### The scenarios

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## Summary

- Health professionals have a moral and legal obligation to involve children in healthcare decision making
  - Provide child-friendly information
  - Take children's views seriously
  - Respect children's evolving capacity and entitlement to consent to healthcare services
  - Respect privacy and confidentiality
- Protect children from harm

# **Thank You**

