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**Children's informed, signified and
voluntary consent to heart surgery**

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Heart surgery

High risk of mortality and morbidity, brain injury, stroke
complex decisions

distressing, painful, frightening

blood tests, >1 hour echocardiograms, MRI scans

mask or cannula for anaesthetic

intensive care unit, sore throat, pain

Alternative –

mortality and morbidity risks

longing 'to be like my friends'

Many parents do not want their child to be informed

Competence? At what age can children begin to be informed,
to give consent to surgery, and to refuse surgery?

Methods November 2018 to May 2021 part time

Funding by British Heart Foundation (applied 2016→)

November 2018 to October 2019 wait for RECs approval

Literature reviews

October 2019 to February 2020

Observe two London children's heart surgery centres

Interview staff and 16 families (plan 45 staff and 60 families of children aged 6 to 15 years) after non-urgent heart surgery

March 2020 to April 2021: Continue interviews by 'phone,

Online survey and group discussions with children and parents

Writing and resubmitting papers

Opposition from funders, peer reviewers, journal editors

<https://www.ucl.ac.uk/ioe/departments-and-centres/centres/social-science-research-unit/consent-and-shared-decision-making-healthcare/childrens-and-parents-consent-heart-surgery>

The law on ages of consent?

South Africa **The Children's Act 2005**

Section 129

Children aged 12 or more - Provided they have the maturity “to understand the benefits, risks, social and other implications of the treatment” ...may consent to medical treatment on their own behalf...[and to surgery] a sufficiently mature child may still consent, if he or she is “duly assisted by his or her parent or guardian”.

Children under 12 or over 12 but lacking the maturity to make an informed decision - A parent, guardian or care-giver of the child may consent on behalf of the child to medical treatment.

English and Commonwealth case law

53 countries <2 billion people, Gillick case 1985

US mature minors

No lower age specified

But usually assumed to be >12 years

Reflected in law reports and ethics
and health research literature

– most reported research on consent to children's treatment
is about parents' consent

a few reports on young people's consent

children may make minor decisions

– which arm to have the injection in

Adult right to consent includes
right to be informed, right not to be coerced or deceived

Problems discussed during interviews:

Non-competent children do not have these rights

Competent children may consent to treatment,
but not refuse it

so treatment can be enforced

children may be confused, afraid, 'terrified',
resistant and lose trust

Those who need life-long cardiac care may not cooperate
or become responsible for their healthcare

Struggles over anaesthesia

Non-compliance with heart transplant follow up care

45 interviewees: doctors, nurses, play specialists, psychologists, chaplains, social worker and experts in law and ethics

Children's ages	Begin to inform children	Begin to respect children's consent	Begin to respect children's refusal
0-4 years	25	4	5
5-7 years	11	13	8
8-10 years	2	11	7
11-13 years	2	6	4
14-16 years	0	3	3
No reply/Uncertain	5	8	18

Interviewer: So what would you do about the operation if a 4-year-old very firmly resisted and struggled against the anaesthetic mask or cannula?

Surgeon: Cancel it.

(Followed by multidisciplinary team work)

Several interviewees said that if, after weeks when every effort is made to to inform and prepare them, children still refuse a heart transplant, “Of course, there's no point in doing it because they'll destroy it by not taking their medication...it [consent] is vital” (cardiologist).

Participatory research: Co-authored papers with interviewees – five anaesthetists co-authored with us the paper on anaesthetists and children’s consent to heart surgery and their zero-coercion policy . Paper rejected.

Why do the law and literature differ so much from hospital practice?

Law and literature theories

Informed consent – Law, *Helsinki* 1974/2013

Voluntary consent – unpressured – *Nuremberg* 1947

Signified consent – legally valid person's signature

OR Ontology of consent, actual practice

Informed consent – inner understanding, weigh values, motives, risks,

Signified consent – actual active cooperation or resistance

Voluntary consent – free choice, willing consent, trust, hope, real emotions, motivations

Ontology of consent

Informed consent

- Law, *Helsinki* 1974/2013

Voluntary consent

- feel unpressured – *Nuremberg* 1947

Signified consent

- legally valid person's signature

OR

Informed consent

- understanding, weigh values, motives

Voluntary consent

- free power of choice, willing consent

Signified consent

- active cooperation or resistance

Empirical	Actual	Real
x		
x		
x		
		x
		x
	x	

Epistemic fallacy do not inform children
– as if the word for them is worse than the deed

Semiotic triangle remember the referent, the actual experience of surgery, scar and the reality consented to

Internal conversations children are meaning makers, unless adults explain their motives children risk assuming they are being punished

Four planes of social being overcome mind/body, individual/social, adult/child splits

MELD See children's competence and consent as relational processes not as fixed, static, atomised

Social positioning theory children's present and future interests, rights and obligations

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Details of research reports: <https://www.ucl.ac.uk/ioe/departments-and-centres/centres/social-science-research-unit/consent-and-shared-decision-making-healthcare/childrens-and-parents-consent-heart-surgery>