Children’s and Parents’ Consent to Heart Surgery.
End of project report
for all the healthcare professionals at Great Ormond Street
and the Evelina Children’s Hospitals, and related experts
who took part in interviews and helped in other ways.

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July 2021.

Thank you very much to everyone who helped with the research.

Setting up the project
We started applying to the British Heart Foundation in 2016. The now retired surgeons
David Anderson and Martin Elliott were very helpful. The reapplication in 2017 was awarded
in April 2018 (BHF546781: 176835), to support part-time research from November 2018 to
May 2021.

We began applying for ethics approval in April 2018, but the NHS HRA did not grant final
approval until September 2019 (NHS HRA (19/LO/0073), Hampstead Research Ethics
Committee (ID 248332), Institute of Education University College London (REC1188), HRA-
Confidentiality Advisory Group (19/CAG/0148).) The research protocol and information
leaflets are on the research website.

We then arranged access to GOSH and the Evelina hospitals. The Principal Investigators in
the two hospitals, paediatric cardiologists Dr Hannah Bellsham-Revell and Dr Nathalie
Dedieu, always quickly replied to any questions and requests we sent to them, put us in
touch with families, and gave us very helpful advice.

We observed and interviewed in the hospitals from October 2019 to February 2020. Then
because of COVID-19 we had only online and phone contact with interviewees. We hoped to
interview 60 young patients aged 6 to 15, but elective surgery was cancelled from March
2020 and it was hard to contact families by phone or email. So Little Hearts Matter, ECHO
and the Children’s Heart Federation helped us to conduct an online survey with parents and
children, and LHM and ECHO each ran a discussion group.

A very useful advisory group was set up and met in February 2019 and 2020 and by zoom in
2021. We are grateful to the members: Dr Hannah Bellsham-Revell (Evelina), Prof Deborah
Bowman (St George’s University), Dr Joe Brierly (GOSH), Dr Nathalie Dedieu (GOSH), Liz King
(Children’s Nursing, LSBU), Prof Jonathan Montgomery (UCL) and Prof Judith Trowell
(Tavistock Clinic).

Data collection
We made notes of our observations and informal conversations in the two London
paediatric cardiology departments in wards, clinics and multidisciplinary meetings.
We conducted semi-structured interviews with:
45 healthcare professionals and related experts chosen to represent the range of relevant
professions;
16 parents/guardians of children and young people aged 6 to 16 (14 mothers, one father
and one grandmother), but only 6 children agreed to be interviewed. They were all the
families who agreed, after everyone aged 6 to 15 years having elective surgery between October 2019 and February 2020 was invited to take part in the research.

With the online survey:
15 children and young people replied, aged 6-17, average age 14;
23 parents replied. Their children were aged 1 to 17, average age 10.

With the online discussions led by LHM and ECHO:
9 children aged 6 to 13 sent written replies with help from their parents, average age 10;
7 young people aged 14 to 17, took part in an online forum, average age 16.

We gathered much information from the internet.
We reviewed the healthcare, ethics, social science and law literature on children’s consent to surgery and major treatment, and conducted a systematic review.

All interviewees gave their informed written consent. Encrypted audio recordings of interviews were professionally transcribed, then anonymised. Even so, some interviewees’ personal account might be identifiable. All the research data will therefore remain confidential and not be open to being read or used by other researchers.

Research reports
We analysed our notes and interview transcripts thematically. For example, we were surprised at the care given to children who resisted or refused interventions, and this became a major theme.

Another surprise was how much the range of hospital staff we interviewed contributed to supporting children’s informed willing consent, including play specialists, chaplains, social workers and psychologists, as well as doctors and nurses. Our papers report the mosaic of multi-disciplinary information and support during the families’ consent process.

A third main theme was the great difference between views in the mainstream law and ethics literature, which set high ages for competence to consent to or refuse surgery, and the low ages cited by many interviewees for when they begin to inform children and respect their consent or refusal. The literature tends to reduce consent to words: doctors give information, patients sign the form. Hospital staff are also very concerned with children’s feelings of fear and doubt or hope and trust, and with their physical reactions when they signify their consent by cooperating with their tests and treatment, or by resisting them. The staff had much richer and more practical insights into children’s consent than most experts in law and ethics report.

There is a list of reports below.

Interviewees as co-authors
Some interviewees have kindly agreed to be named in the acknowledgements or as co-authors. Our papers can only exist because of the decades of thought and practical work by many of the interviewees on changing systems to respect children more. The interviews provide the main intellectual content of the papers. The papers are likely to be taken more seriously when authorised and validated by the actual practitioners’ names. Some co-authors also edited and improved the texts.

We have noted our surprise at differences between the conservative journals versus actual practices of respecting and listening to children in the Evelina and GOSH departments. It seems that peer reviewers who reject progressive papers play a part here. Several of our papers have been rejected for minor reasons, to which the text could easily be adjusted. We are revising these papers and sending them to other journals.
Former BMJ editor Richard Smith said the medical journals ‘can afford to be a only whisker ahead of those they are attempting to lead’. Peer review ‘is slow, expensive, ineffective, something of a lottery, prone to bias and abuse, and hopeless at spotting errors and fraud. The benefits of peer review have been much harder to establish.’ Smith added that ‘with help from the internet, patients can become very well informed and ‘there is growing evidence that doctors and patients taking decisions together—rather than doctors taking decisions on behalf of patients—leads to patients doing better and feeling more satisfied’ (Richard Smith. The trouble with medical journals, J R Soc Med 2006;99:115–119).

This view can apply to children as well as adults.

The future
We will continue to write research reports for the journals. We hope the reports will:
- help to support and endorse the high standards of respect for children’s consent or refusal practised in the two hospitals;
- encourage other hospitals and specialties that have not yet done so to adopt these standards; and
- maybe persuade the main medical, law and ethics journals and their readers to revise their views too.

Papers: published, in press or in progress


Sutcliffe, K., Mendizabal, R., Alderson, P. The extent and range of research on children’s consent to surgery or major medical treatment: A systematic review. In preparation.


Alderson, P., Cohen, M., Johnson, M., Lotteria, A., Mendizabal, R., Stockton, E., Sutcliffe, K., Wellesley, H. Anaesthetists and children’s consent to heart surgery. Submitted to Pediatric Anesthesia 25/3/2021, rejected 27/4/2021. We have appealed on the grounds that the reviewer’ criticisms were of minor points.


Also planned

A report of the parents’ and children’s views and experiences of heart surgery.

Papers on the specific contributions to the multidisciplinary mosaic of support for children’s consent to heart surgery by psychologists, chaplains children’s information and support heart charities.

A history of paediatric cardiology and children’s consent 1960-2020

Conference papers


Mendizabal, R., Alderson, P. Parents’ and children’s consent to heart surgery. Clinical Cardiac Meeting, Great Ormond Street Hospital. 25/10/2019.


More details, including the longer end-of-project report to the funder and news of papers as they are published, are on the project website https://www.ucl.ac.uk/ioe/departments-and-centres/centres/social-science-research-unit/consent-and-shared-decision-making-healthcare/heart-surgery.