London and South East COVID -19 Paediatric Bioethics Support Group

Advice and Guidance from Joe Brierley & the London and South East COVID-19 Paediatric Bioethics team

COVID 19 seems to have a less severe course in most children than adults, but this is not necessarily the case in the complex cohort that paediatric teams currently care for, which includes children with complex and rare diseases, neuro-disability and palliative care needs, with some already living on organ support such as ventilation.

Nevertheless, during the COVID-19 pandemic, paediatric capacity will be reduced to free up capacity for adult life-sustaining treatment.

Children, families and child-health professionals can be affected in several ways by this, these include:

1) Children may be admitted with acute infection to children's wards, high dependency units or intensive care units depending on need for organ support some with SARS- CoV-2, others with alternative infective aetiologies.
2) Long-term patients may become infected, and this may worsen their underlying disease by a direct infective effect or by compromising usual treatments e.g. immunosuppression may be reduced, or renal replacement less available.
3) Children with complex care needs in the community may have a reduced service (e.g. decreased LTV nursing team or lack of usual access to acute care facilities)
4) Children requiring elective surgery may deteriorate as there disease progresses due to lack theatre space, e.g. some forms of congenital heart disease or continued reflux without a Nissen fundoplication.
5) Children with new incident or continuing illness will have limited access to ward, HDU and critical care facilities, whilst community support (GP, community nursing teams) will also be reduced (see 6, 7).
6) Staff members may become infected and so pose risks to patients and/or not be able to work
7) Staff may need to care for dependent relatives or be bereaved.

ETHICS

There are 2 standard ways ethics can help.

Decision–making for and during a pandemic outbreak ought to be:
1) Guided by ethical decision-making processes &.
2) Informed by ethical values

5 procedural values to guide to ethical decision-making in pandemic outbreaks[1]

- **Reasonable**
- **Open and transparent**
- **Inclusive**
- **Responsive**
- **Accountable**

An Ethical Guide for Pandemic Planning

- Individual liberty
- Protection of the public (our patients and staff from harm)
- Proportionality
- Privacy
- Equity
- Duty to provide care
- Reciprocity
- Trust
- Solidarity
- Stewardship e.g. infection control

***New RCPCH pandemic ethics guidance will be available soon as part of a UK CMO Ethics document, our support and guidance will always be in line with that guidance.**

Child health professionals must consider four Key Ethical Issues:

1. Duty to Care

2. Restrictive Measures

3. Priority Setting

4. Governance

5. Procedural values to guide to ethical decision-making in pandemic outbreaks [1]

[1] Stand on Guard for Thee: Ethical Considerations in Preparedness Planning for Pandemic Influenza. Toronto. University of Toronto Joint Centre for Bioethics, 2005 November; 27 p. [Online].

1. Duty to Care

• As child health professionals our first priority is the children and families we care for, followed by ourselves (staff).

• However, in a pandemic we have to understand our duties as part of the greater healthcare environment.

• We have a duty to all patients, staff and communities this is best maintained by operational integrity from Government, NHS, Institutional management (e.g. local Gold, Silver and Bronze command) with necessarily top down infection control safety practices.

• Communication throughout organisations is vital – including top down command, but also directly from the coal-face – Re equipment provision (e.g. PPE) and staff numbers/shortages in any environment.

There will be difficult issues, and decisions to make, over the next few months due to:

(i) Risk of infection in our patients and staff.

[1] Stand on Guard for Thee: Ethical Considerations in Preparedness Planning for Pandemic Influenza. Toronto. University of Toronto Joint Centre for Bioethics, 2005 November; 27 p. [Online]. Available: http://www.utoronto.ca/jcb/home/documents/pandemic.pdf [4 January 2006]

(ii) Limitations on Paediatric ICU/HDU and acute paediatric inpatient beds due to need to support adult critical care throughout the region with necessarily relocation of acute paediatric care from usual centres. (E.g. capacity for adult ICU in collocated PICUs).

(iii) Absence/illness in all our teams and the families we care for.

(iv) Loss of the protective aspects of school on child well- being and families in difficulty.

Elective surgery delays and amended treatment regimens will all be challenging – as children may deteriorate due to delays, or not receive high-risk or innovative treatments due to the risk of organ dysfunction.

The above values - **Reasonable; Open and transparent; Inclusive; Responsive; Accountable -** should guide how we work with children and families during this time – we must always care, but tough treatment decisions must be honestly and openly communicated.

2. Restrictive Measures

Usual leave will be necessarily compromised. Paradoxically some may not be permitted to work as they are in 'isolation' either with the pandemic illness or as a contact precaution or have high-risk medical conditions. Staff may be deployed outside usual areas – they should receive adequate training and supervision as appropriate. Visiting to Trusts will be restricted, even for parents – security may need to be empowered to control flow, all should support this.

3. Priority setting

Depending on the stage of the pandemic, the disease prevalence – case fatality rate and organ support required for those affected, service may be entirely geared towards care for those affected – this will have serious repercussions for routine paediatric practice. a) ICU provision. Elective surgery requiring ICU cover will be stopped – sadly some children's physiology can deteriorate during such time and the management of semi-elective/urgent surgery will need to be clearly planned. Usual ICU prioritisation will be superseded by new SOPs. This is likely to focus on treating life-saving emergencies, and may - if resources are overwhelmed - restrict ICU admission based on the ability to recover during the pandemic Similarly, continuation of ICU treatments with a reducing chance of achieving cure, such as ventilation for a trial of experimental treatment, may need to be halted.

ICU mortality prediction based on organ failure at admission and pre-existing relevant conditions are well validated, and may need to be used to limit ICU admission to those likely to recover in a time frame that cannot prevent many others dying from lack of ICU provision.
Such restrictions will affect different teams in different ways – e.g. therapies with lower risk of a deterioration requiring organ support in ICU may be preferred, despite reduced long term benefits.

Rationing

Usual avoidance of the term rationing may be counterproductive, as open and transparent communication is the bedrock of child health. Decisions about who is allocated limited resources may become more overt and increasingly unavoidable in a pandemic, necessitating a utilitarian component too daily practice that many in child health may find troubling. Such decisions must be based on sound ethical principles – many versions of which can be found. We choose to prioritise one further principle to those above, *justice*.

Resources should be used wisely and fairly, without discrimination or preference, yet maximising their utility – which may mean the use of high intensity treatments with prolonged resource use or treatment with a limited chance of success will be avoided to allow multiple patients more likely to benefit and return to a better quality of life to benefit.

This may mean not just decisions to withhold life sustaining therapies, but decisions to withdraw life sustaining therapies.[2]

4. Governance

It is crucial that individual clinicians are not left isolated in managing these challenging decisions. Team support in terms of MDT planning, peer support in specialities and communication considering the values above with children and their families is required.

Rapid referral to command structures and optionally the Pan-London/Local Bioethics team for support, should occur from clinicians on the floor making difficult decisions.

Clear communication about the ICU situation and other restrictions on availability, as well as plans for extension of some ICU services to none-ICU areas, will be clearly communicated to all staff in acute Trusts. Similarly, other restrictions e.g. acute beds for community teams, and reduced community services must be communicated to all affected.

Lastly, accurate and contemporary recording of any challenging decision-making is necessary, sensible and protective. Decisions made during a crisis when resources are overwhelmed may need to be accounted for when the acute situation is long resolved.

Bioethics Team

The London and South East Bioethics Support Group is a collaboration between ethics teams/ethicists from St Mary's, Queen Charlottes, The Royal Brompton, The Evelina, St Georges, the Children's Trust (Tadworth), Kings College and Great Ormond St
We will also access others who may be useful to your situation e.g. legal, chaplaincy/spiritual help or specialists such as palliative care.

The Bioethics team can be contacted by email: **Clinical.Ethics@gosh.nhs.uk**
Rapid supportive review via BlueJeans or Zoom is available.

Our usual process of meeting with families is under review, given restrictions, and will be managed on a case by case basis. It is unlikely physical meetings with families can occur.

It is important to understand that despite the pandemic situation, unless communicated to the contrary, the law has not changed. However, the current effects of the pandemic will necessarily be considered in any review of decisions taken during it.

We cannot make decisions for you, but will help ensure those you do make meet ethical standards, have been through an external supportive review process and that the considerations made in such challenging circumstances recorded for your future need.

Finally, however bad the situation we aim to get through it, and emerge to work in the usual manner again.

Options that give the child the best open future are sensible. We must work together as a one healthcare team, and care for ourselves as well as our patients and their families.

Be kind to each other, some may be struggling with not managing things as they usually do, others may have sick family members and/or friends and colleagues.

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[2] Larcher V, Craig F, Bhogal K, Wilkinson D, Brierley J; Royal College of Paediatrics and Child Health. Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice. Arch Dis Child. 2015 May;100 Suppl 2:s3-23.

Some of us may be bereaved during a pandemic, and there may be severe effects on colleagues from these most difficult times we face – be reassured, we will focus on the recovery of all of us from any such situation.

Remember **'*Kindness* is mankind's greatest delight'** Marcus Aurelius.
Joe Brierley & the London and South East COVID-19 Paediatric Bioethics team