BMA Medical Ethics & Human Rights

The BMA medical ethics & human rights team and BMA medical ethics committee have decided to make quarterly updates publicly available. This covers some information regarding the BMA's work in medical ethics and human rights, and general updates in the field.

BMA Winter 2024 Medical Ethics & Human Rights update

BMA work

Human rights

Letter to the Burundi Ambassador about the removal and withholding of life-sustaining medical treatment from Dr. Christophe Sahabo

The BMA wrote to the Burundi ambassador to the UK to express our concern regarding the withholding of medical attention and treatment from Dr Christophe Sahabo. We took action following the confirmation of this case by Amnesty International. In our letter we stressed that the right to health is a human right under International Human Rights treaties and urged the ambassador to ensure that the relevant prison authorities allow Dr Sahabo to be provided with appropriate medical attention, treatment, and care.

World Medical Association

On 17 October 2024, the World Medical Association General Assembly unanimously passed the BMA resolution calling for a sustainable ceasefire in Israel and Gaza. The resolution further calls for:

1. A bilateral, negotiated and sustainable ceasefire in order to protect all civilian life, secure the release and safe passage of all hostages and to allow the transfer of humanitarian aid for all those in need.
2. The immediate and safe release of all hostages.
3. Pending their release, humanitarian aid and healthcare attention to be provided to the hostages.
4. All parties to abide by international humanitarian law and the principle of medical neutrality to safeguard the rights and protection of healthcare facilities, healthcare personnel and patients from further threat, interference and attack.
5. Unimpeded and accelerated humanitarian access throughout all of Gaza, including the entry of humanitarian aid and safe passage of medical personnel. This also includes the evacuation of urgent medical cases to reduce secondary morbidity and mortality, public health risks, and alleviate pressure on hospitals inside Gaza.
6. The re-establishment of access to healthcare and the creation of a safe working environment for healthcare personnel to work in through the restoration of medical capacity and essential services.
7. Verified investigations into alleged gross violations and abuses of human rights and international humanitarian law including attacks on healthcare staff and facilities and the misuse of those facilities for military purposes.
8. The upholding by physicians of the principles in the WMA Declaration of Geneva and other documents that serve as guidance for medical personnel during times of conflict.

The full text of the resolution can be read on the WMA website.

Declaration of Helsinki

The World Medical Association General Assembly unanimously passed the latest iteration of the Declaration of Helsinki, which sets out ethical principles for medical research involving human participants. The latest revision follows 30 months of collaboration between an international working group that included

the BMA. It is its most significant revision for over 20 years, and includes updating human 'subject' to human 'participant' throughout, to recognise the agency of those who participate in research. It also further recognised the nuances surrounding groups/individuals in situations of particular vulnerability. Several articles have been written summarising the changes that have been agreed.

General updates

Abortion

The US state of Georgia has dismissed the entirety of its Maternal Mortality Review Committee. This follows the sharing of confidential information to sources outside of the committee. The information shared regarded the deaths of two women which the committee had deemed preventable. The women had not sought care due to restrictions on abortion access in the state of Georgia, which generally does not allow abortions beyond six weeks.

London NHS Trust on trial for corporate manslaughter over death of mental health inpatient

An NHS Trust and former ward manager will stand trial for manslaughter of 22-year-old Alice Figueiredo. Alice died on 7 July 2015 whilst a mental health inpatient at Goodmayes Hospital, run by North East London NHS Foundation Trust (NELFT). NELFT is charged with corporate manslaughter as well as a health and safety breach. The ward manager at the time of Alice's death, is charged with manslaughter by gross negligence and a health and safety breach. This is the first time an NHS Trust has been charged with corporate manslaughter over a death in a mental health unit. The trial opened on 29 October and is expected to last 9 weeks.

Care Quality Commission – Dr Penelope Dash publishes final report.

Dr Penelope Dash has published her final report on her Cabinet Office commissioned review into the operational effectiveness of the Care Quality Commission. In line with her interim report published in July 2024, Dr Dash's final report finds that there have been '*significant failings in the internal workings of CQC, which have led to a substantial loss of credibility within the... sector, a deterioration in the ability of CQC to identify poor performance and support a drive to improve quality and a direct impact on the capacity and capability of the social care and healthcare sectors to deliver much-needed improvements in care'*. The report recommends that CQC should:

- Rapidly improve operational performance (around numbers of assessments and the backlog in the registration of new services);
- Fix the provider portal and regulatory platform;
- Improve the quality and timeliness of assessment reports;
- Rebuild expertise within CQC and relationships with providers in order to resurrect credibility;

In addition, Dr Dash's report makes conclusions about wider aspects of CQC's work, finding that there is:

- A need for improvement in CQC's assessment of local authority commissioning of adult social care services;

- A need to pause the roll out of CQC's assessments of Integrated Care Systems whilst further development is undertaken;
- A need for CQC to do more to support improvements in quality across the health and care sector; and
- A need to improve the sponsorship relationship between DHSC and CQC

Dr Dash's report also states that over the next 12 months the Single Assessment Framework (SAF) needs to be fundamentally enhanced and improved. As part of this approach, alongside Dr Dash's report, the CQC has therefore published the independent review from Professor Sir Mike Richards which it commissioned into the working of the SAF.

Royal Pharmaceutical Society responds to consultation on puberty blockers

The Royal Pharmaceutical Society has published its response to the Government's consultation on the proposed change to the availability of puberty blockers, together with its position statement, which can both be accessed here.

Nuffield Council on Bioethics sets out proposals to bolster governance of stem cell-based embryo models including a call for legislation to ensure that research does not cross ethical 'red lines'

The Nuffield Council on Bioethics has published a report which covers the ethical and governance concerns arising from research involving human stem cell-based embryo models (SCBEMS) and lays out recommendations to address these concerns. Where research involves SCBEMS, the report recommends a phrased approach which combines ethical guidelines and codes of practice with stricter legal measures to adapt to the evolving science whilst still allowing innovation. Areas which would require legislation are those that need protection from crossing ethical 'red lines', for example transferring a SCBEM into a human or non-human animals, or creating SCBEMS which would be able to feel pain. Additionally, the Council recommends that SCBEMs should be considered different to embryos and so should not be covered under the Human Fertilisation and Embryology Act 1990 (as amended). This distinction should be reflected in the act.

The Maternal Mental Health Alliance and British Psychological Society Faculty of Perinatal Psychology publish report on maternal health services.

The Maternal Mental Health Alliance (MMHA) and the British Psychological Society (BPS) faculty of Perinatal Psychology have produced a report which maps the progress of Maternal Mental Health Services (MMHS) across England. Based on survey responses from 41/46 MMHS, for the first time, the report provides a detailed look at how MMHS are being delivered at the local level. The report finds that there has been welcome progress with the establishment of these services in most areas of England. However, it also highlights that many of these small services are struggling to cope with levels of demand and highlights that there is wide variation between the care that is provided for women and their families, the criteria to access this care, and waiting times for assessment and treatment in different parts of the country. These inconsistencies suggest there are currently not enough resources to meet the need. In particular, the report data shows that:

- Only 11/41 maternal mental health services support women who have had their babies removed through care proceedings, a group at particularly high risk of developing perinatal mental health issues and dying by suicide.
- One maternal mental health service has already closed due to funding issues.
- Waiting times for assessment ranged from 0–26 weeks.

- For those who met the criteria for treatment, waiting times ranged from 0–52 weeks.

Data (Use and Access) Bill

Changes to UK data protection law have been proposed in the government's new Data (Use and Access) Bill which had its second reading in the House of Lords in November. If the Bill becomes law, it will amend the UK GDPR and the Data Protection Act 2018. The BMA's briefing for second reading highlighted concerns about the potential impact on health data should there be a departure from existing high standards of data protection. The BMA is particularly concerned about the erosion of transparency standards when data is reused for research purposes and the threat to the regulatory independence of the Information Commissioner's Office. Our concerns about the dilution of transparency standards were highlighted by Labour peer, Lord Davies at second recording where our briefing was quoted.

On a positive note, the Bill also provides for the government to introduce common IT standards and increased interoperability for the sharing of health data. IT system suppliers will be compelled to ensure their systems meet the common technical standard (the standards have yet to be set). This proposal is a welcome development which the BMA has long called for.

The BMA has re-issued its briefing for committee stage which began on 3rd December. The secretariat has also been in contact with the Office of the National Data Guardian (ONDG). The ONDG shares our concerns, particularly in relation to the dilution of transparency standards and will submit its own briefing for committee stage. We will continue to lobby to preserve high standards of data protection for health data as the Bill progresses.

Legal cases

An NHS Trust v Mother and others [2024] EWHC 2207 (Fam) - Court authorisation unnecessary for restraint required for treatment where there is parental and clinical agreement.

In this case, Francis J held that a declaration or authorisation of medical treatment and consequent restraint, amounting to a deprivation of liberty of a child who lacked Gillick competence is unnecessary where the clinicians and the parents agree that it is in the child's best interests.

G is a 12-year-old girl who has a diagnosis of anorexia nervosa and depression. G was admitted to her local hospital on 20 June 2023 and subsequently transferred to an intensive intervention unit in a specialist hospital in August 2023. Following her admission to the unit, G refused food and liquid orally and attempted to refuse food through her NG tube. This resulted in her having to be restrained to receive NG feeds, with up to four staff being required on some occasions. G was not however, detained under the Mental Health Act 1983 (MHA).

In August 2023, a locum consultant Child and Adolescent Psychiatrist assessed G as not being 'Gillick competent' and deemed the restraint necessary to carry out NG feeding. G's mother and father consented to both the treatment and the restraint. However, in September 2023, the Trust made an application to the High Court under its inherent jurisdiction to permit NG feeding and restraint in respect of G. A Guardian was appointed to represent G's interests. The parties reached an agreement, and a consent order was approved by the Court. However, the Court was invited to produce a reserved Judgment in order to resolve what was referred to as 'an apparent tension' between the common law authorities concerning consent to treatment and restrictions for children and the Mental Health Act Code of Practice (the Code).The issue of parental consent is covered at paragraphs 19.39 to 19.41 of the Code as follows:

Confidential

'In some circumstances, it will be possible for children lacking competence and young people lacking capacity to be admitted to hospital and/or treated on the basis of parental consent (see paragraphs 19.52-19.70). However, before relying on parental consent, practitioners must be satisfied that it is appropriate to do so. This is important because court decisions relating to parental consent have emphasised that there are limits to both the types of decisions that can be made by those with parental responsibility on behalf of their child, and the circumstances in which these decisions can be made.45 For example, when making decisions on behalf of their child, parents must act in their child's best interests and those with parental responsibility cannot authorise the deprivation of liberty (discussed below) of their child. This guidance uses the term 'the zone of parental control' to highlight the need to establish whether the particular decision can be authorised by parental consent or not. Those cases in which parental consent provides sufficient authority for the proposed intervention to go ahead are described as falling within the zone of parental control.'

Francis J referred to the earlier case of AB v CD [2021] EDWHC Civ 741 (fam) [116] where Mrs Justice Lieven stated:

'The analysis of the caselaw shows that the cases supporting a special category of treatment of children which require Court approval are very limited. In fact, the only case where the Court has found a legal requirement to come to Court in respect of treatment of a child, where both parents consent, is Heilbron J Re D, the case of a "non-therapeutic" sterilisation of an 11 year old. In all other contexts, including where the parental decision will lead to the child's life ending, the Court has imposed no such requirement. There are a range of cases where there does have to be Court approval, but this is where there is a clinical disagreement; possible alternative treatment of the medical condition in issue; or the decision is, in the opinion of clinicians, finely balanced. These are fact specific instances rather than examples of any special category of treatment where the Court's role is required simply because of the nature of the treatment.'

Francis J therefore concluded that *'where a child lacks Gillick competence to make their own decision, and there is agreement between the clinical team and parents as to the best interests of the child, a parent can consent to both medical treatment and any consequent deprivation of liberty. This enables clinicians lawfully to carry out the treatment plan. In those circumstances, no court authorisation is required.'* He was also of the view that the guidance in the Code (which has not been updated since 2015) suggesting that there were limits on the decisions which can be taken by parents in relation to treatment of their children under the age of 16 'is erroneous.'

He concluded that *'in G's sad and difficult situation, where the parents and the treating medical team are "at one", it is lawful to rely on parental consent, that an application is not only unnecessary, but would make an already almost unbearable situation in respect of G (from her family's perspective) even more difficult, and would also cause huge expense and delay. Accordingly, a declaration that it is in G's best interests to receive the treatment and, if needed, to be restrained in order to receive the NG treatment, is unnecessary.'*

Leicestershire County Council v P & Anor (Capacity: Anticipatory declaration) [2024] EWCOP 53 (T3) - Decision about when and whether P has capacity to make decisions, and the power of the Court to make anticipatory declarations.

P has a diagnosis of Dissociative Identity Disorder (DID). She has suffered significant trauma in her life, and this has had a huge impact on her mental and psychological health. At times, P has been detained under the Mental Health Act 1983 (MHA) and has had extended periods in specialist placements. More recently

she has lived in her own home, with care and support provided by a number of domiciliary care agencies in accordance with section 117 MHA aftercare. P also receives long-term psychotherapy from the Clinic for Dissociative Studies.

The proceedings were commenced by the local authority following a significant number of safeguarding concerns. It was agreed between the parties that when P was not in a state of dissociation, she had capacity (generally). However, her ability to make decisions fluctuates, particularly during dissociative episodes so the central issue was the Court of Protection's power to make an anticipatory declaration and whether it should do so in this case.

Mrs Justice Theis the Vice President of the Court of Protection accepted that there is jurisdiction under section 15 of the Mental Capacity Act (MCA) that enables the court, in principle, to make anticipatory declarations. Such declarations are not dependent on P lacking capacity at the time such a declaration is made. However, when deciding whether to exercise jurisdiction under section 15 of the MCA, the court will need to consider a number of factors, including:

- Whether there are other ways in managing the situation, for example whether section 5 of the MCA can be utilised.
- The need to guard against any suggestion that P's autonomy and ability to make unwise, but capacitous decisions is at risk or any suggestion that the court is making overtly protective decisions.
- To carefully consider the declaration being sought, and whether the evidence establishes with sufficient clarity the circumstances in which P may lack capacity and in the event that P does the circumstances in which contingent best interest decisions would need to be made. This is to guard against the risk that if the facts on the ground were analysed contemporaneously the court may reach a different conclusion.

Mrs Justice Theis found that *'whilst most of the time P is able to make decisions about her care and contact with others there are limited times when she is unable to do so when she dissociates'*. However, she declined to make an anticipatory declaration preferring instead to rely on the on the framework in the MCA as this gives '*general authority to those caring for P who reasonably believe both that P lacks capacity in relation to the matter and that it will be in P's best interests for the act to be done. Using this framework will have the advantage that decisions are taken contemporaneously both as to capacity and best interests, having up to date information on matters such as P's wishes and are more appropriate to guard against such infrequent occasions as in this case'*

The full judgment can be found here.