## **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 Summer 2024 Medical Ethics & Human Rights update**

Note: this update was developed and agreed prior to the announcement of the 2024 General Election

#### **BMA** work

#### **Data Protection and Digital Information Bill**

As previously reported in Ethics*brief*, the BMA has been lobbying on the Data Protection and Digital Information Bill (No.2) (DPDI). The Bill has completed its journey in the House of Commons and has progressed to the House of Lords where it recently completed its Committee Stage. The BMA's briefing was sent to peers and co-badged with the National Data Guardian (NDG) who shares our concerns about the downgrading of high standards of data protection should the Bill be passed unamended. Our briefing indicated support for a number of peers' amendments which proposed to delete some of the clauses which the BMA has identified as an erosion of protections for personal data. The problematic clauses include those which would erode transparency standards when data is processed for research and the threat to the regulatory independence of the Information Commissioner's Office.

We expect Peers to press these issues further at the upcoming Report Stage – the BMA will continue lobbying ahead of this debate (date to be confirmed). This will include further joint working with the NDG.

### Welsh government consultation: Children missing education

The ethics secretariat worked with the BMA's Welsh office to respond to the Welsh government's <u>consultation</u> on draft regulations that would require each local authority (LA) to set up a database of all compulsory school age children in their area, for the purposes of identifying which children are potentially missing education (CME). The regulations would place a requirement on local health boards (LHBs) and GMS contractors to share confidential demographic information about children, with the relevant local authority, for the purposes of establishing the databases. The data on the children who are deemed to be in education (ie not missing) would be deleted.

Our response to the consultation highlights certain fundamental flaws about the legal basis and clarity of purpose of the Regulations. We have also sought reassurance on a number of data protection requirements and concerns, including ensuring appropriate access to the data and timely deletion.

### **Criminal Justice Bill**

The BMA have briefed parliamentarians ahead of the Criminal Justice Bill.

#### Abortion

We have indicated our support for the decriminalisation of abortion. We have signed up to a joint briefing with the RCOG to oppose two amendments which aim to restrict abortion access: NC15 and NC41. Amendment NC15 seeks to amend The Abortion Act 1967 and The Infant Life (Preservation) Act 1929 to reduce the time limit from 24 weeks to 22 weeks for abortions under Ground C and Ground D. Amendment NC41 seeks to make it illegal for doctors to provide an abortion beyond the 24 week time limit due to a diagnosis of Down's syndrome. BMA policy states our support for the current time limit of 24 weeks. We also support the option for an abortion after 24 weeks in the case of severe or fatal fetal abnormalities. The wording of amendment NC41 does not account for the severity of the Down's syndrome diagnosis, which can include increased risk of specific heart problems, digestive system anomalies and ventriculomegaly (fluid on the brain), which can present a highly negative prognosis for a pregnancy.

#### Conversion practices

Our briefing on the Criminal Justice Bill also indicates our support for an amendment which looks to ban conversion practices in the UK. The BMA has long supported a ban on conversion practices. Conversion practices have been debunked countless times as unethical and damaging practice that preys on victims of homophobia, transphobia, discrimination and bullying. The Government's own analysis has found that conversion practices can result in negative mental health effects like depression and feeling suicidal. Given that transgender people are already most vulnerable to being subjected to conversion practices, with nearly one in seven reporting that they had been offered or had conversion practices, it is vital that any ban extends to gender identity.

#### **Mandatory Reporting of Child Sexual Abuse**

Following the publication of the final report by the Independent Inquiry into Child Sexual Abuse (IICSA) in October 2022, and the Government responding with a call for evidence and a subsequent consultation process, the Government has confirmed a mandatory reporting duty will be introduced through amendments to the Criminal Justice Bill. Initial proposals had included the introduction of a criminal offence for mandated reporters, including doctors. The policy proposals used a definition of sexual abuse that would have included consensual underage sexual activity where one of the partners was over 16. The BMA argued strongly against this provision, which would undermine trust in the doctor-patient relationship and would deter young people from seeking advice on contraception and sexual health. We argued that doctors should be able to use their judgement about when it was appropriate to report, and when it was not, using well established guidance on child safeguarding, including from the General Medical Council.

In the amendments to the Criminal Justice Bill tabled by the Government, the proposal for a criminal sanction has been dropped, with those who fail to comply with the 'duty to report' being liable for sanctions from their professional regulator or being barred from working with young people. Criminal sanctions will only apply if someone deliberately tries to stop a report of child sexual abuse, which could result in up to seven years in prison. Our concern that it would include a duty to report consensual underage sexual activity also appears to have been addressed with the introduction of the following clause, in particular (4) (c): -

'(4) The duty under subsection (1) does not apply to a person—

(a) if the person reasonably believes that another person has previously made, or will imminently make, a notification under this section in connection with the suspected offence; (b) for such time as the person reasonably believes another person who engages in a relevant activity in England has made or will make a notification under this section on their behalf; (c) for such time as the person reasonably believes that it is not in the best interests of each relevant child to make a notification under this section.'

Given that the BMA's significant concerns about the proposals have now been addressed, we are not currently briefing on these amendments. We will, however, monitor the debates and the points raised and can brief at a later stage if that is considered appropriate.

#### **Human rights**

#### Israel-Gaza

The BMA submitted an emergency resolution to the World Medical Association Council in April 2024, calling for a sustainable ceasefire in Israel and Gaza. The resolution was unanimously supported; more information can be found <a href="here">here</a>.

#### Republic of Korea

The BMA is deeply concerned by the suppression of the Korean Medical Association by the Republic of Korea's government during strikes in the country regarding concerns about the future of healthcare. We have written to the KMA to express our solidarity and raised concerns with the UK ambassador to the Republic of Korea

#### **UK Rwanda Bill**

The BMA has consistently opposed the UK Government's plan to offshore asylum seekers to Rwanda due to the negative impact on the wellbeing of those deported. The Bill was eventually passed in late April 2024 and the BMA issued a statement denouncing the plan, which can be found here.

#### General updates

#### Government response to the Joint Committee on the draft Mental Health Bill published

The Government has published its long awaited <u>response</u> to the <u>report</u> of the Joint Committee on the draft <u>Mental Health Bill.</u> The Committee, chaired by Professor Sir Simon Wessely, the former President of the Royal College of Psychiatrists in December 2018 made 55 recommendations to the Government regarding the draft Mental Health Bill.

The Government has accepted or agreed to consider further a number of these, including:

- Reviewing the wording of the amended section 2 MHA detention criteria, in relation to "how soon" harm may occur.
- Considering how to ensure that Care (Education) and Treatment Reviews are conducted at "appropriate intervals" (i.e. more regularly than the maximum of 12 months, as currently provided for in the bill).
- Considering renaming the "risk register" as the "dynamic support register", and consulting with people with learning disabilities and autistic people to see how they can build trust in this mechanism.

- Placing a duty on services to "carry out activity" in relation to Advance Choice Documents (ACDs), exploring how to implement this initiative and how to store ACD information digitally, so that it can be shared easily and readily accessed.
- The need for greater clarity about holding powers in A&E departments.

The Government has however, rejected several recommendations, including:

- The creation of a statutory mental health commissioner.
- The proposed abolition of Community Treatment Orders (CTOs) for patients under Part II of the MHA (civil patients) and a statutory review of CTOs for Part III (forensic patients).
- A standalone role of 'responsible person' to monitor inequalities.
- The extension of the new 'opt-out' approach for advocacy services to voluntary patients, and the creation of a specialised central advocacy service.

The Government has committed to providing a revised bill, but at present, no formal timetable for this has been given.

# The Children's Commissioner for England publishes a report on children's access to mental health services

The Children's Commissioner for England has published a <u>report</u> on children's access to mental health services from 2022 to 2023. Recent figures from the NHS and other organisations have shown a large increase in the number of children suffering with mental health issues. The NHS estimates that in 2023 approximately 1 in 5 children (20%) had a probable mental health condition, a stark increase from 1 in 8 (12.5%) in 2017. The data shows that children are still waiting far too long to access the help they need – with over 270,000 children still waiting for support, and in the last year nearly 40,000 children experiencing a wait of over 2 years. In 2022-23, the most common primary reason for referral was 'unknown', making up 34% of those entering treatment within the year. This is followed by anxiety, 'in crisis', neurodevelopmental conditions (excluding autism), depression, and self-harm behaviours.

#### The Law Society publishes updated guidance on deprivation of liberty

The Law Society has updated its <u>guidance</u> on the law relating to a deprivation of liberty. It has been updated to take account of important developments in the law relating to deprivation of liberty, including clarification of the position of those under 18, and those in receipt of lifesustaining medical treatment. The guidance applies the framework to settings in:

- Hospitals
- Psychiatric care
- Care homes
- Supported living/shared lives/extra care
- At home
- Palliative care and hospices

The guidance can be downloaded as a whole, or as individual chapters covering specific care settings.

## <u>Death certification reform and the introduction of medical examiners in England and Wales</u>

A new <u>statutory medical examiner system</u> is being rolled out across England and Wales to provide independent scrutiny of deaths, and to give bereaved people a voice. From 9 September 2024 all deaths in any health setting that are not investigated by a coroner will be reviewed by NHS medical examiners. The changes, which form part of the Department of Health's <u>Death Certification Reforms</u>, were announced by the government on 15 April 2024, and come into force on 9 September 2024. As part of the changes, there will be a new medical certificate of cause of death, which can be completed by a doctor who attended the deceased at any time.

From September 2024, medical examiners will have a statutory right of access to records of patients under section 3 of the Access to Health Records Act 1990, as amended by the Coroners and Justice Act 2009. (Until September 2024, healthcare providers can share the medical records of deceased patients with medical examiners under section 251 of the NHS Act 2006 and Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 ('section 251 support')).

## The Department of Health and Social Care (DHSC) is reviewing the statutory duty of candour and has launched a call for evidence

In November 2014, the government introduced a statutory (organisational) duty of candour for NHS Trusts and NHS foundation Trusts via Regulation 20 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014. The duty places a direct obligation upon NHS trusts to be open and honest with patients and service users, and their families, when something goes wrong that appears to have caused or could lead to moderate harm or worse in the future. The most significant consequence of the duty of candour is the extent to which leaders within health and care organisations create and support the systems and cultural conditions by which mistakes and errors enable learning and support a process of continuous improvement. DHSC's review is being conducted to understand to what extent the duty of candour is honoured, monitored and enforced. The call for evidence closes on **Wednesday 29 May 2024**, and details can be accessed here.

#### ICO publishes new transparency guidance for health and social care sectors

In April, the Information Commissioner's Office (ICO) published new guidance to help organisations meet the transparency obligations of the UK GDPR and the Data Protection Act 2018. Specifically designed for health and social care sectors, the new guidance is aimed at organisations which deliver health and social care services or process health and social care information, including for secondary purposes. The aim of the guidance is to help organisations to understand the definition of transparency and assess appropriate levels of transparency. The guidance provides examples and case studies of how organisations can be transparent with people about how their personal information is being used and provides practical steps for developing effective transparency information.

The publication follows a public consultation that took place earlier in the year. MEC members may recall the BMA's response, drafted by the ethics secretariat, which was submitted to the ICO.

#### Legal cases

### Abassi & Anor v Newcastle upon Tyne Hospitals NHS Foundation Trust

The BMA has intervened in a Supreme Court case which concerns Reporting Restriction Orders which protect the identity of clinical staff involved in court proceedings. The BMA believes that it is imperative that clinicians, who will not have chosen to become involved in court proceedings, do not, in consequence of those proceedings, face vilification, threats, and other adverse treatment simply for doing their job. Although the case relates to paediatric intensive care and end-of-life decision-making, similar considerations can and do arise in a range of other clinical settings where medical treatment is being provided, and the outcome of this appeal is therefore likely to have significant consequences for all doctors. The Hearing took place on 15<sup>th</sup> and 16<sup>th</sup> April, and we are awaiting the outcome.

#### Re A (Covert Medication: Residence) [2024] EWCOP 19

A had been subject to Court of Protection proceedings for five years and was placed in a specialist care home, separated from her mother. Throughout her stay, A consistently refused hormone replacement treatment (HRT) for the treatment of primary ovarian failure, as a result the Court had previously approved its covert administration - a decision not known to her or her mother. Covert HRT had produced a significant medical benefit for A by ensuring she went through puberty and had protected her against the loss of bone density and the very significantly increased risk of cardiovascular disease.

The Court was asked to determine A's residence, whether covert medication should continue, and her mother's application to resume A's care. The Court considered A's past and present wishes and feelings, her beliefs and values, as well as the potential for her to gain capacity regarding her treatment decisions in the future. The Court was also mindful of the European Convention on Human Rights, including Article 8 (right to respect for private and family life) and Article 2 (right to life), and the potential infringement upon these rights by the covert medication.

Poole J carefully analysed the benefits and burdens of A returning to her mother against her continued stay. On balance, and contrary to the position advanced by the local authority, the Trust and the Official Solicitor, he decided it was in her best interests (i) to return home to her mother's care; (ii) for covert medication to cease; (iii) for her to be informed that she has been covertly administered HRT and that it has been of benefit to her health and stopping it would be harmful to her health; (iv) to allow her mother to try to persuade her to take HRT voluntarily; and (v) for support to be provided to her in the community whilst she is living at home. Poole J held:

'The assessment of best interests in this case is complex. Whatever decision is made, or if no decision is made, there will be both positive and negative consequences for A. I acknowledge the risk that my determination of A's best interests will result in her returning home to an unhealthy relationship and will expose her to the harmful consequences of ceasing HRT. However, those risks are outweighed by the benefits of ending the deprivation of A's liberty and the serious interference with her Art 8 rights, and of avoiding the risk of an unmanaged disclosure to her of the covert administration of HRT. The Court is enjoined to seek to achieve purposes "in a way that is less restrictive of the person's rights and freedom of action" (MCA 2005 s1(6)). Here, severe restrictions have been imposed in order to achieve the benefit of medical treatment. Now, the continuing and remaining benefits of treatment are not sufficient to justify the continued restrictions.'

Accordingly, he directed, a plan should be prepared for her return home and for the release of information to be carried out in stages.

The judgment can be accessed here.

## Re J (Transgender: Puberty Blocker and Hormone Replacement Therapy) [2024] EWHC 922 (Fam)

This case concerned the capacity of 'J', a 16-year-old transgender male to consent to hormone treatment and whether the court should exercise its powers to prevent further hormone treatment.

J was assigned female at birth and has regarded himself as male for some time. J has a history of mental health issues, including anorexia and autism and was sectioned under the Mental Health Act in 2021 after incidents of self-harm. In October 2022 as he had been unable to obtain treatment from the NHS J (aged 15) obtained a prescription for testosterone and puberty blockers from Gender GP, an unregulated internet provider of cross-hormone treatment. No medical examination, blood testing or other clinical evaluation was undertaken, and J did not have any direct communication with a doctor at any stage with Gender GP. Although the prescription was from a private doctor, J was given injections of testosterone by his local NHS GP every six weeks between January and August 2023.

J's parents are divorced, and his father is opposed to J being treated with puberty blockers and/or cross-sex hormones without the court's approval. However, his mother supported his treatment. J's father sought that:

- The court should rule on J's capacity to consent to any further treatment from Gender GP;
- Even if J does have capacity to consent to further treatment at Gender GP, the court should override his consent by exercising the inherent jurisdiction (as identified in Re W) and that decision should be taken at this stage;
- The court should rule now on the father's wider legal case and hold that, irrespective of the consent of a capacitous child and/or one parent, treatment with puberty blockers or hormones should only be authorised with the approval of the court;
- The court should make the declaration sought at this stage; and
- General guidance should be given for deployment in other similar cases.

The Court heard evidence on J's capacity from Dr Eyre a consultant child and adolescent psychiatrist working at Oxford Health NHS Foundation Trust. He was of the opinion that 'the combined effect of all four of the identified conditions from which J has suffered/is suffering from does not render him unable to make a decision about treatment for gender dysphoria within the meaning of the MCA 2005. He understands the nature of that condition and its impact on identity, and he has had the recent experience of receiving treatment.'

After an extensive, but ultimately unsuccessful, exercise to identify an endocrinologist in the UK who was prepared to accept instruction as a single joint expert in the proceedings, Dr Jacqueline Hewitt, a consultant paediatric endocrinologist based in Melbourne, Australia agreed to accept the parties' instruction to advise the court. Dr Hewitt, was critical of the lack of physical and psychological checks carried out by Gender GP on J. Dr Hewitt also raised concerns about the size of the doses of testosterone given to J, describing the level of the hormone in his blood during his treatment as 'dangerously high'.

J's guardian, who had acted in that role for nearly a year, was clearly of the opinion that it was in J's best interests to access further hormone treatment for gender dysphoria. She favoured assessment work being undertaken by Gender Plus, a private London-based clinic, which was supported J's Mother, and not opposed by his father. The Court therefore deferred the determination of the principal issues due to an agreement by the parties on the way forward for J's treatment and endorsed the plan for J to undergo an assessment with Gender Plus. However, Judge Sir Andrew McFarlane said:

'if the option of J resorting once again to Gender GP for a further prescription is raised, then there will be a need to consider very carefully (a) his capacity to consent to that particular option and (b) whether the circumstances are such that the court should exercise the inherent jurisdiction to prohibit him from doing so. There must be very significant concern about the prospect of a young person such as J accessing cross-hormone treatment from any off-shore, online, unregulated private clinic. The evidence relating to Gender GP that is currently available, as analysed by Dr Hewitt, gives rise to additional serious concerns as to the safety of patients accessing cross-hormone treatment from that particular clinic. If a further referral to Gender GP is to be proposed by any party, the court will expect a detailed account from the clinic setting out their proposed course of assessment and treatment.'

The judgment can be accessed here.