

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 Spring 2024 Medical Ethics & Human Rights update

Physician-assisted dying

BMA webpages updated

The BMA's webpage on physician-assisted dying (www.bma.org.uk/pad) has been updated to include the outcome of the BMA's work on this topic and with a new engagement section setting out how we are using that information within the UK and Crown Dependencies.

It has been pointed out that a few amendments are needed to the international map of jurisdictions where assisted dying is lawful and we hope to have this done very shortly.

House of Commons Health and Social Care Committee

The House of Commons' Health and Social Care Select Committee published its [report on assisted dying](#) on 29 February 2024. We provided written evidence to the Committee, ahead of its oral evidence sessions with a range of stakeholders. Policy insight from ourselves and others shaped the Committee's ultimate recommendations to the Government – these can be viewed in full [here](#).

It is worth noting that one of the Committee's recommendations was that the BMA and GMC should revise their guidance for doctors to enable them to assist their patients by writing medical reports to facilitate assisted dying abroad. We sent [a letter to Mr Steve Brine MP](#), Chair of the Committee, explaining that whilst doctors can and must provide copies of patients' medical records on request – in line with their obligations under the GDPR – writing a report specifically to assist patients who are seeking assisted dying overseas could, in our view, breach the law. Therefore, we advised the Committee that we would not be in a position to revise our guidance in the way that the Committee had recommended, as this would potentially leave our members open to criminal and professional sanctions.

Assisted dying legislation in the Crown Dependencies

Since the last meeting, and following discussions with BMA members locally, we have engaged with proposals for legislation to permit assisted dying in the Isle of Man and Jersey.

Isle of Man

A letter was sent to the [House of Keys Clauses Committee](#) considering the Assisted Dying Bill in the Isle of Man, following up on our earlier [letter to Dr Alex Allinson MHK](#) who introduced the Bill. The Committee had planned to report by the end of February but has announced that its report is being delayed but should be published by the end of March.

Jersey

A [letter was sent to Deputy Tom Benet](#), Minister for Health and Social Services, to share with the ministerial committee that is currently considering Jersey's policy proposals, following its 'in

principle' vote to change the law. Veronica English and Caroline Harrison subsequently had a useful and positive meeting with the policy lead for the Jersey Government where we discussed the BMA's views as set out in the letter. The committee is expected to publish its proposals on 22 March for debate in the States Assembly on 21 May.

Report on assisted dying in Ireland due for publication

The special Oireachtas committee in the Republic of Ireland is due to publish its report on assisted dying on 20 March. It has been [reported](#) that, following votes that took place on 6 March, the committee will recommend that assisted dying should be legalised. A previous Bill debated in the Republic of Ireland extended to residents of Northern Ireland.

Plans to legalise assisted dying in France

It was reported on 11 March that Emmanuel Macron plans to [introduce legislation on assisted dying in France](#). He announced that the new bill will be restricted to adults with capacity who are suffering from an incurable illness who are expected to die in the "short or middle-term" and who are suffering "intractable" physical or psychological pain. It is expected that the legislative process will begin in May.

FGM

A woman has been found guilty of assisting another person to carry out FGM, in first conviction of its kind. After a trial at the Old Bailey, Amina Noor, 39, was [convicted](#) of assisting a Kenyan woman to carry out the procedure in 2006. The conviction, which carries a maximum sentence of 14 years, is the first for assisting in such harm under the Female Genital Mutilation Act 2003. Noor travelled to Kenya with the girl in 2006 and while there took her to a private house where the child was subjected to FGM. The crime only came to light years later when the girl was 16 and confided in her English teacher at school. During the sentencing, Mr Justice Bryan said this 'truly horrific and abhorrent crime' had left the victim's life 'irrevocably altered'. Noor was given a sentence of seven years in prison. The only other successful prosecution under the act was in 2019 when a Ugandan woman from Walthamstow, east London, was jailed for 11 years for cutting a three-year-old girl.

'Martha's Rule'

The NHS intends to roll out 'Martha's Rule' in hospitals across England from April. The BMA's medical ethics committee discussed this at their meeting in December 2023. [The patient safety initiative](#) is set to be rolled out to at least 100 NHS sites and will give patients and their families round-the-clock access to a rapid review from an independent critical care team if they are worried about their or a loved one's condition. The three proposed components of Martha's Rule are:

1. All staff in NHS trusts must have 24/7 access to a rapid review from a critical care outreach team, who they can contact should they have concerns about a patient.
2. All patients, their families, carers, and advocates must also have access to the same 24/7 rapid review from a critical care outreach team, which they can contact via mechanisms advertised around the hospital, and more widely if they are worried about the patient's condition. This is Martha's Rule.
3. The NHS must implement a structured approach to obtain information relating to a patient's condition directly from patients and their families at least daily. In the first instance, this will cover all inpatients in acute and specialist trusts.

Thirteen-year-old Martha Mills died from sepsis at King's College Hospital, London, in 2021, due to a failure to escalate her to intensive care and after her family's concerns about her deteriorating condition were not responded to promptly. Extensive campaigning by her parents Merope and Paul, supported by the cross-party think tank Demos, has seen widespread support for a single system that allows patients or their families to trigger an urgent clinical review from a different team in the hospital if the patient's condition is rapidly worsening and they feel they are not getting the care they need.

Mental Health Act

[Data released by NHS England](#) showed the number of detentions under the Mental Health Act 1983 in England has fallen for a second consecutive year, but significant racial disparities persist. MHA detention numbers fell by 7.7% on a like-for-like basis from 2021-22 to 2022-23, following a 5.7% drop the year before. The reductions followed increases in detentions over the previous three years. However, as in previous years, the detention rate was highest among black or black British people in 2022-23 at 227.9 per 100,000 population, 3.5 times the rate for white people. The rates were 74.7 for Asian people, 157.9 for those from a mixed background and 107.2 for those from the 'other' ethnic group. The figures drew a critical response from mental health charities. Mind chief executive Sarah Hughes said the data illustrated the urgency of MHA reform, a point echoed by her counterparts at the Centre for Mental Health and the Race Equality Foundation, Andy Bell and Jabeer Butt. [However, whilst the government has pledged to overhaul the Act, it has ruled out doing so before the next election.](#)

Prison healthcare must be improved finds National Confidential Enquiry into Patient Outcome and Death

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) in its [report](#) published on 26th January has called for improvements in prison healthcare. The report finds that people in prison have a significantly reduced life expectancy, with a median age of 67.5 compared to 86.7 in the community. Further, the report highlights the need for healthcare in prison to be underpinned by robust and well communicated processes to ensure needs are properly identified and managed.

The enquiry reviewed the care of 247 prisoners who died from natural or other 'non-natural' causes, such as an accidental overdose. Over two thirds (68%) of patients who died had evidence of clinical deterioration prior to their death. The report underlines the importance of improving processes for the timely assessments, monitoring, and interventions to better manage acute illnesses.

Clinicians reviewing the data concluded that 23 deaths from natural causes were potentially avoidable. Sadly, 11 of these deaths were due to a lack of recognition of an acute deterioration in health. The report also finds that the end-of-life process could have been improved in almost half (45.2%) of patients where the death was from a natural cause.

The NCEPOD puts forward a set of recommendations, including steps to:

- Improve healthcare assessments and the monitoring of long-term conditions, by providing enough appropriately skilled healthcare staff.
- Recognise and act quickly on clinical deterioration, using the National Early Warning Score (NEWS2) to aid recognition.
- Plan for emergency transfer to hospital, to minimise delays when it is needed.
- Provide basic life support training.

- Improve palliative and end of life care services.

Data Protection and Digital Information Bill

As previously reported in *Ethicsbrief*, 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 now progressed to the House of Lords. The BMA briefed at second reading in the Lords highlighting our ongoing concerns about the potential downgrading of high standards of data protection should the Bill be passed unamended. It is likely that the Lords' stages will provide greater opportunities for the BMA to lobby for amendments which would address the concerns in our briefing. Committee stage will commence on 20 March.

Recent legal cases

NHS Trusts need to pay heed to the Serious Medical Treatment Guidance - GUP v EUP and UCLH NHS Foundation Trust [2024] EWCOP (25 January 2024)

EUP had been an active carer for various members of her family, including her husband who died with dementia. She was admitted to hospital in October 2023 after a stroke which left her with dysphagia. She was readmitted on 28th October, one day after discharge following a fall, and thereafter suffered several more strokes and progressive decline.

When her NG feeding tube dislodged in mid-December it could not be replaced despite concerted efforts over many days (that were causing her distress). The clinical team considered further attempts to re-insert the NG tube were futile and alternative placement of a percutaneous gastrostomy tube (or PEG) or a total parenteral nutrition (or TPN) line in a major vessel were contra-indicated given her incredibly poor prognosis. However, hydration and glucose via an IV line was continued.

The hospital wished to put in place a regime focused on palliative care rather than active treatment, but her family, who still held out hope for recovery, believed that nutrition should be reinstated. At the family's insistence a further attempt to site the NG tube was attempted on 3 January 2024, but this too failed. Two external second opinions were then sought, and these agreed with the hospital that there was no clinical potential to restart provision of artificial nutrition in an ethical way and that palliation was the way forward.

Her family were strenuously opposed to this, and when discussions did not achieve agreement, the Trust advised the family that they were going to make an application to Court of Protection. However, on 16 January 2024, the Trust confirmed to the family that they had been advised by their lawyers that it was not necessary for them to issue a Court application, as there was no appropriate option to re-start feeding. P's son, GUP therefore made an application to the Court of Protection himself.

Although the Trust's position at the outset of the hearing was that as their staff would not deliver nutrition there was nothing for the court to decide, Hayden J did not agree. Rather the Trust were asked to call evidence about the entirety of the care being delivered to EUP, which included the question of why the artificial hydration and glucose was being provided. In the course of the hearing, a best interests issue that had not initially been in dispute was identified as the Official Solicitor queried the continued provision of hydration with additional glucose to EUP. Hayden J considered that this was being done as a compromise between medical staff and family. After reviewing the relevant law and the medical evidence, the judge came 'to the

clear conclusion that neither provision of nutrition nor hydration is in EUP's best interests'. He also commented agreeing with the Official Solicitor that GUP should not have had to bring the application himself, but rather it was for the Trust to do so promptly following the judge's own [guidance](#), as Vice President.

The expectation is and remains, that where there is dispute as to a patient's best interests, it will be the Trust who will bring the application to court and not family members as happened in this case. However, this case has raised interesting questions about the extent to which the guidance applies when clinicians do not believe the treatment could achieve its clinical aim (and so is inappropriate) and it is therefore not an available option upon which the court is entitled make a best interests decision. Members of the secretariat will therefore be meeting with interested stakeholders to discuss its wider implications. The judgment can be accessed [here](#).

Court of Appeal upholds decision of the High Court that long waiting lists for Trans healthcare are lawful - AA & Ors, R (On the Application Of) v National Health Service Commissioning Board England and Wales Court of Appeal (Civil Division) Jul 31, 2023

Since 2012, NHS England has had the function of commissioning specified services for rare and very rare conditions, including gender identity development services for children and adolescents, and gender identity disorder services for adults ('GID services'). The capacity for delivering these services did not match the exponential increase in demand which took place between 2012 to 2017. The resultant delays and very long waiting times for the children, adolescents and adults referred for these services led to six claimants arguing that the NHSE had acted unlawfully. The Claimants pursued five grounds of challenge. The first three alleged that NHSE were in breach of its statutory duty:-

- Under reg. 45(3) of the NHS Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012 ('the 2012 Regs') to ensure that 92% of NHS patients referred have commenced appropriate treatment within 18 weeks of referral; and
- Under s.3B of the National Health Service Act 2006 by delaying puberty blocking treatment in such a way that children are unable to access the services before the onset of puberty; and
- Under s.2 of the Health Act 2009 by failing to have regard to the right of adult gender dysphoria patients under the NHS Constitution to commence treatment within 18 weeks of referral.

The Claimants also alleged that NHSE directly, or alternatively, indirectly, discriminated against the first to fourth Claimants with regard to their protected characteristic of gender reassignment and also failed to comply with its public sector equality duty to make arrangements for the provision of services for people seeking treatment for gender dysphoria.

The Court dismissed the appeal by the Claimants and held that:-

1. The duty under Regulation 45(3) requiring NHSE to make arrangements with a view to meeting the waiting time standard, is a target duty, rather than an absolute duty to achieve it.
2. The duty under Regulation 45(3) applies only to referrals for consultant-led services.

The Court acknowledged that NHSE had been slow to respond to the increase in demand for gender identity services but noted that steps were being taken to address the long waiting times.

The NHS's continued failure to meet target waiting times was already on a concerning trajectory before the outbreak of COVID-19. However, this judgment illustrates that provided the NHS can show that it is trying to take proactive steps to reach the set standard, resorting to the courts is unlikely to provide a remedy. The judgment in the case can be accessed [here](#).

Hospital Trust not liable for a third party's unauthorised use of patient data - Underwood v Bounty UK Ltd & Hampshire Hospitals NHS Trust EWHC 888 (QB)

The First Defendant Bounty UK Ltd, ('Bounty') had contracts with the Trust whereby the Trust would provide Bounty access to maternity ward patients to enable Bounty to provide the expectant mothers with a maternity package so as to provide Bounty the opportunity to 'register' expectant mothers in order to harvest their personal data. Unknown to the Trust, Bounty intended to sell that data and failed to obtain informed consent before passing on the data.

The Claimants, Mrs Underwood and her son Dominic, alleged that after Mrs Underwood gave birth at the Trust in October 2017 their personal data was obtained without permission from medical notes at the foot of the bed. On 23 May 2019, Bounty responded to a subject access request submitted by Mrs Underwood, confirming that it held data relating to her (and her son) being: 'her name, date of birth, child's name, child's gender, child's date of birth, home address and email address'. Bounty also confirmed that some, or all, of the data was shared with nine other companies. Bounty subsequently entered into administration following a substantial fine from the ICO in April 2019 relating to breaches of the DPA 1998.

In their claims against the Trust the Underwoods alleged that the Trust acted in breach of the first, second, sixth and seventh data protection principles by granting Bounty access to the antenatal ward with the consequence that Bounty staff could obtain their private information. The Underwoods further alleged that the Trust had misused their private information by granting Bounty access to the antenatal ward and by leaving private information relating to Dominic Underwood at the foot of the bedside.

Nicklin J rejected the argument that the Trust had 'made available' private information relating to the Underwoods by storing limited information at their bedside. The information had been stored for the purposes of providing essential clinical services and measures were taken by the Trust to ensure that Bounty staff (and other third parties) were not provided access to sensitive personal data relating to patients. This included a mandatory Code of Conduct that required all personal data to be processed by Bounty strictly in accordance with DPA 1998.

In respect of the claim for misuse of private information Nicklin J applied the recent judgment in *Warren v DSG Retail Limited* [2021] EWHC 2168 in holding that the Trust could not be liable to the Underwoods unless it itself had carried out a positive act of 'misuse'. In this case the allegations against the Trust could at best be described as omissions (although no omission was in fact found by the Court).

Finally, of interest is the Court's decision that even if the Trust had been liable for a breach of the DPA 1998 and/or for misuse of private information, the claim would have failed on the basis that the information obtained about Dominic Underwood (name and gender) was so trivial such that no damage could reasonably have been suffered as a consequence of it having been obtained by Bounty. The judgment can be accessed [here](#).

Medical vs surgical termination where patient lacks capacity - need to uphold individual autonomy alongside the opinion of clinicians - H, Re (An Adult; Termination) [2023] EWCOP 183

Ms H is 26 years of age and diagnosed with schizoaffective disorder and is detained in hospital under s3 Mental Health Act 1983.

The NHS Trusts were seeking declarations from the Court of Protection that Ms H lacked the capacity to conduct legal proceedings and make decisions regarding the termination of her pregnancy. They also sought an order that a medical termination is in her best interests. There were two NHS Trust's making the application as one of them was responsible for Ms H's obstetric care and one was responsible for the care of her mental health. With one exception, Ms H had been consistent in her wish to have a termination of the pregnancy. She also met with the Judge via Microsoft Teams before the hearing and remained consistent in her wish. No one disputed the evidence that Ms H lacked capacity to decide whether to terminate the pregnancy, and the Judge declared that she lacked the necessary capacity to make this decision herself.

The Judge considered the interplay between Section 1 of the Abortion Act 1967 (medical termination of pregnancy) and Sections 1-4 of the Mental Capacity Act 2005. The Judge had to apply s4 Mental Capacity Act 2005 in deciding (1) whether the termination was in her best interest and if so, (2) what form that procedure should take. The Judge noted that she had a 'sustained negative view of her pregnancy and a sustained wish for a termination'. The Judge emphasised this being a deeply personal and profound decision for Ms H and attached significant weight to her wishes and feelings in reaching a decision in her best interests. The medical professionals also supported a termination of the pregnancy, expressing concern about the risks to her mental health should the pregnancy continue. The Judge determined that it was in her best interests for her pregnancy to be terminated.

The second decision of what form the termination should take (medical or surgical) was more finely balanced and required careful consideration. Both kinds of procedures brought risks to her mental health (in addition to the risks to her physical health). However, what swayed the balance in favour of a medical termination was consideration of H's wishes, feelings and beliefs and regard being given to her reproductive autonomy. The Judge stated 'Having heard all the evidence and met with Ms H, when she clearly told me she wants a medical termination, respect for her autonomy and dignity in matters of her reproductive health, lead me, by applying section 4 of the 2005 Act, to authorise a medical termination in her best interests. I will make that order accordingly pursuant to section 16 of the 2005 Act.'

The case highlights the legal intricacies surrounding best interests decisions in respect of pregnancy termination where someone lacks mental capacity to make that decision due to a mental impairment, and that balancing the individual's wishes and medical evidence requires very careful consideration. The judgment can be accessed [here](#).

Human rights

Rwanda Bill

On 4 March 2024, the Government's Rwanda Bill suffered [five defeats in the House of Lords](#) and further defeats on 6 March 2024. The BMA has consistently opposed the government's plan to offshore asylum seekers to Rwanda for processing. Our concerns focus on the impact it will have on the health, wellbeing, and safety of already extremely vulnerable people. These problems are further outlined in an [open letter](#) to Prime Minister Rishi Sunak, signed by the BMA, Royal Colleges, MSF, Medical Justice, and more than 840 individual healthcare professionals expressing grave concerns about the health implications of the Government's offshoring policy and calling on him to abandon it.

The use of offshoring has previously led to asylum seekers being accommodated in countries where they are unable to access medical care they may need and has had a detrimental impact on the mental health of those removed. This is evident in problems created by Australia's offshoring of asylum seekers to countries like Manus Island in Papua New Guinea, which the UN has declared "violates the convention against torture" and the ICC prosecutor has described "unlawful".

In the UK, clinicians have found that the prospect of removal to Rwanda has exacerbated the mental health conditions (including post-traumatic stress disorder and depression) of the men, women and age-disputed children threatened with removal, causing increased risks of self-harm and suicide. Medical reviews of 36 people under threat of removal to Rwanda revealed that 26 displayed medical indicators of having been tortured, with 15 having symptoms or a diagnosis of PTSD and 11 having experienced suicidal thoughts while in detention.

The Government has made assurances around the level of healthcare it says will be available at detention centres in Rwanda, including that the country has agreed to provide accommodation that is "adequate to ensure the health, security and wellbeing" of those relocated.

However, Rwanda faces a critical shortage of skilled health workers, as evidenced by its inclusion in the [WHO health workforce support and safeguards list 2023](#). In response, the UK government has also added Rwanda to the list of countries that should not be actively targeted for health worker recruitment by the UK as this could exacerbate existing workforce shortages. Consequently, the BMA is concerned that due to these serious shortages, the complex physical and mental health needs of asylum seekers will not be met, especially as their needs are likely to be intensified by the removal process.

Migrant detention

Following the Brook House Inquiry, the BMA hosted a [joint event](#) with Medical Justice at BMA House on 30 January 2024 on the findings of the Inquiry and the healthcare failings in immigration removal centres (IRCs). The event focussed on the institutional and systemic shortcomings of IRCs and how this let down both detainees and healthcare staff who worked there. Attendees heard from a variety of speakers including Kate Eves, the Brook House Inquiry chair, a former detainee, and an expert panel. The Government will be responding to the Inquiry imminently and the BMA will consider its response.

Myanmar

On 1 February 2024, BMA House was [lit up](#) to mark the three year anniversary of the Myanmar coup and in solidarity with the healthcare workers in Myanmar who continue to be subject to violence and suppression from the Tatmadaw. The BMA provided a briefing for a House of Lords debate on Myanmar, which was [referenced](#) during the discussion. The BMA is exploring what further action we can take.

South Korea

The BMA is deeply concerned by the [aggression of the South Korean government](#) towards striking doctors and the Korean Medical Association. This could potentially constitute a violation of the rights of doctors and has a sinister echo of the suppression of the Turkish Medical Association by the Turkish government. The BMA is exploring what action it can and should take.

Israel-Gaza

The BMA continues to be alarmed by the situation in Israel-Gaza, including the destruction of medical facilities and deaths of healthcare staff. The BMA has heard from many organisations since 7 October 2023 with a variety of perspectives. This includes the Jewish Medical Association, the British Islamic Medical Association, Médecins San Frontières, the Israeli Medical Association, and different groups of BMA members. The BMA has written to the WMA asking the organisation to call for a ceasefire and we continue to discuss the humanitarian crisis with them. Following our communications with other national medical associations and the WMA on this issue, the WMA has now released [a new statement](#) calling for a humanitarian pause in the conflict. A summary of the BMA's interventions can be found [here](#).

Conversion practices

The BMA strongly supports Labour MP Lloyd Russell-Moyle's and Liberal Democrat peer Baroness Burt of Solihull's Private Members Bills to ban conversion practices in their entirety. 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 therapies 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.

Abortion

In March 2024, France became the first country in the world to guarantee a right to abortion in its [constitution](#). Though there has been a campaign for this legislative change in France for a number of years, the amendment only gained the necessary support and momentum following the overturning of Roe v. Wade in the US. Many who previously felt the amendment was unnecessary, as abortion is legal and widely supported in France, changed their mind in the wake of the US Supreme Court ruling acknowledging that they could not be complacent regarding the security of fundamental rights.

Contrarily, the Alabama Supreme Court on 16 February 2024 ruled that stored embryos are afforded the same legal protection as children under the state's Wrongful Death of a Minor Act of 1872. The impact was that legal action could be taken against medical professionals in Alabama performing IVF due to the destruction of embryos involved in the process. The outrage this triggered has led to Alabama hastily passing legislation in early March 2024 that [protects IVF clinics and doctors from lawsuits and criminal prosecution](#). Nevertheless, the legislation is limited and narrow in scope; it does not address whether an embryo outside the uterus is classed as a child. This is one example of the far-reaching consequences of the overturning of Roe v. Wade by the US Supreme Court.

In the UK, the BMA has been supporting Diana Johnson's amendment to the Criminal Justice Bill which seeks to decriminalise abortions for women in relation to their own pregnancy. The BMA believes this should be extended to health professionals administering abortions within the context of their clinical practice and have made this clear in our briefings on the issue.