

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 Autumn 2024 Medical Ethics & Human Rights update

BMA work

Artificial Intelligence

On 1 October 2024, the BMA published its detailed report on AI in healthcare entitled 'Principles for artificial intelligence (AI) and its application in healthcare'. This report sets out how AI is being used in healthcare currently, how it could be used in the near future, and examines both the potential benefits and drawbacks with respect to patients, clinicians, and the efficiency of the overall healthcare system. The report emphasises that AI is only a tool – if implemented appropriately and effectively, it can improve outcomes; if not, it can worsen them. The report includes:

- An understanding of AI usage in UK health services.
- An analysis of the benefits and risks of current and future AI implementation within healthcare.
- A set of principles that the BMA supports for the safe, effective, ethical, and equitable adoption of AI in healthcare.

The report can be read [here](#).

Cass review

BMA Council has decided to undertake an evaluation of the Cass review of gender identity services for children and young people. The task and finish group that will undertake the review will be led by [Professor David Strain](#), BMA board of science chair. [The BMA will retain a position of neutrality regarding the Cass review](#) while the task and finish group does its work.

World Medical Association

The next World Medical Association General Assembly meeting is from 16-19 October 2024 in Helsinki. The BMA will be in attendance. This meeting will aim to ratify a new iteration of the [Declaration of Helsinki](#) (DoH). The DoH outlines universal ethical principles for medical research involving human participants. It is widely recognised as one of the most important documents produced by the WMA. The new iteration of the DoH develops concepts surrounding the autonomy of participants, as well as cultural sensitivities.

International Criminal Court

Between 19-20 September 2024, the BMA was invited to attend a seminar on medical matters in detention at the International Criminal Court in The Hague. The meeting began with a summary of the detention situation at the ICC. The extent of funding, staffing, and resourcing, including in relation to healthcare, presented a stark contrast to typical detention settings in the UK. This is understandable, given the fewer number of detainees and international media focus on the status of suspected war criminals. Dr Leclerc, from the International Committee of the Red Cross, highlighted how detention settings were unnatural to human flourishing, and those could present pronounced medical issues.

Discussions focussed on the role of medical officers in detention settings, their obligations, and medical ethics issues at play, such as the problem of dual loyalties. The risk of medical officers coming under pressure to compromise their professional duties was greater in detention settings, especially if Justice Ministries or Ministries of the Interior had responsibility for healthcare in these facilities, and the need for Health Ministries to have ownership of medical care in detention settings was highlighted.

The issue of medical confidentiality was discussed in depth, as well as the disclosure of the medical records within judicial proceedings. The doctor who reports to the court should be different from the doctor treating the patient as a matter of best practice. The importance of patient autonomy was stressed, and the fact that they patient 'owns' their medical record.

The meeting also explored the power of attorney, the importance of cultural differences (such as language and diet) in detention settings, the role of criminal Defence Counsel from an ethical outlook, and approaches to medical requirements in detention from a human rights perspective.

General updates

Abortion

In June 2024, the [Scottish parliament passed legislation](#) introducing safe access (buffer) zones around clinics providing abortion services. The legislation would prevent any protests or vigils taking place within 200m (656ft) of 30 clinics offering abortion services. The BMA welcomes this news, having being part of a coalition of organisations that have campaigned for the introduction of safe access zones for a number of years. Legislation for safe access zones has now been passed across the UK.

On 18 September 2024, it was announced that safe access buffer zones would come into force in England and Wales on 31 October 2024. The BMA welcomed this news, stating "We lobbied for years for the introduction of safe access zones around abortion clinics, and welcome the news that these will be implemented at the end of October. It is essential that patients and clinicians are not harassed when accessing or providing healthcare."

Puberty blockers temporary ban extended

The Government has [renewed](#) a temporary ban on the sale and supply of puberty-suppressing hormones, known as "puberty blockers". The continuation of the ban applies to the sale or supply of these drugs, prescribed by private UK-registered prescribers for gender incongruence or dysphoria to under 18s not already taking them. It also prevents the sale and supply of the

medicines from prescribers registered in the European Economic Area or Switzerland for any purposes to those under 18.

Review of suicides and gender dysphoria at the Tavistock and Portman NHS Foundation Trust

On 19 July, an independent [report](#) by Professor Appleby was published by the Department of Health and Social Care. Professor Appleby reviewed data provided by NHS England on suicides by young patients of the gender services, based on an audit at the Trust. The specific aim was to examine evidence for a large rise in suicides claimed by campaigners.

Summary of conclusions:-

1. The data do not support the claim that there has been a large rise in suicide in young gender dysphoria patients at the Tavistock.
2. The way that this issue has been discussed on social media has been insensitive, distressing and dangerous, and goes against guidance on safe reporting of suicide.
3. The claims that have been placed in the public domain do not meet basic standards for statistical evidence.
4. There is a need to move away from the perception that puberty-blocking drugs are the main marker of non-judgemental acceptance in this area of health care.
5. There is a need to ensure high quality data in which everyone has confidence, as the basis of improved safety for this at risk group of young people.

Martha's Rule oversight group begins work

The new Martha's Rule oversight group, chaired by the Patient Safety Commissioner with a secretariat provided by the Department of Health and Social Care, has begun its [work](#) to support the implementation of the new initiative. Patient Safety Commissioner, Henrietta Hughes, is engaging widely with staff groups and patients from England and internationally to understand their views of the new initiative and to learn from existing patient and family activation systems. The group will also ensure the approach to gathering evidence in support of the initiative is as broad and consistent as possible, to inform the evaluation by the National Institute for Health and Care Research (NIHR) and the potential wider roll-out of Martha's Rule beyond 2024/25.

The Nursing and Midwifery Council Independent Culture Review

The Nursing and Midwifery Council (NMC) commissioned an independent culture review by Nazir Afzal and Rise Associates, after concerns were raised about its culture, including racism, discrimination and fear of speaking up. The [report's](#) recommendations relate to safeguarding people involved in NMC processes, culture and regulation, and senior leadership.

In response to the report the NMC stated "change starts now" with full acceptance of the recommendations. In addition to work already started on safeguarding, NMC has begun to address some of the other regulatory issues identified, including: £30 million investment in an 18-

month plan to make a step change in fitness to practise, and strengthen the guidance used to make decisions on concerns about sexual misconduct and other forms of abuse outside professional practice.

Reforming the Mental Health Act: Research Briefing

A House of Commons Library [research briefing](#) covers reforms to the Mental Health Act 1983, including the independent review, white paper, the draft Mental Health Bill under the previous Government and pre-legislative scrutiny, updated to include the new Government's commitment to legislate in the July 2024 King's Speech.

Mental Capacity Act 2005, Deprivation of Liberty Safeguards Statistics 2023 – 2024

DoLS are a legal framework applying to individuals who lack the mental capacity to consent to the arrangements for their care. Where such care may amount to a "deprivation of liberty" the arrangements are independently assessed to ensure they are in the best interests of the individual concerned.

These [official statistics](#) provide findings for England from the Mental Capacity Act 2005, Deprivation of Liberty Safeguards (DoLS) data collection for the period 1 April 2023 to 31 March 2024. The data are collected from local authorities in England, who are the supervisory bodies for authorising deprivations of liberty of adults in care homes and hospitals.

The aim of the publication is to inform users about aspects of DoLS activity, including the profile of people for whom a DoLS application was received, applications completed and their outcome, and applications not completed.

Ombudsman warns of surge in maternity investigations

The Parliamentary and Health Service Ombudsman (PHSO) has [warned](#) that women and babies are being put at risk after a worrying rise in the number of investigations about maternity care and is urging the Government and NHS leaders to learn from the mistakes being made and take action to protect more families from harm.

In 2023/24 (1 April – 31 March) the PHSO investigated 87% more cases (28) about maternity care than the previous year (15). These are all cases which had already been investigated by the NHS and where they had failed to address concerns.

In the cases investigated, issues identified included delays to treating infection and carrying out an MRI scan, failing to manage an epidural during a Caesarean section, and lack of consent for a procedure. Since April 2020, PHSO has carried out 80 detailed investigations related to failings in maternity care. Investigations concluded in 2023/24 account for over a third of these. During that time the number of investigations upheld or partly upheld has also increased.

Prevent duty: updated guidance for healthcare professionals in England and Wales

On 3 October, the Department of Health and Social Care published updated [guidance](#) for healthcare professionals about the Prevent duty in England and Wales. Prevent is part of the government's counter-terrorism strategy.

New report by the Nuffield Council on Bioethics and Ada Lovelace Institute assesses the potential, risks, and appropriate role of AI-powered genomic health prediction (AIGHP) in the UK health system

This new [report](#) examines the potential of AI-powered genomic health prediction (AIGHP) to transform healthcare in the UK. It emphasizes that AIGHP, while promising, must be carefully regulated to ensure that certain challenges, that could potentially be caused by the technology, do not outweigh the benefits.

AIGHP uses AI and polygenic scoring, a form of genomic analysis, to predict individuals' future health risks and drug responses based on their genetic data. While AIGHP promises benefits like personalized healthcare, disease prevention, and better resource allocation, its accuracy, especially for non-European populations (due to inequity in genomic research leading to a focus on individuals from European ancestry), remains a concern.

The report investigates the ethical issues arising from the convergence of AI and genomic science. This includes privacy risks around consent and data sensitivity, the potential for (genomic) discrimination in areas such as healthcare and insurance, surveillance and the risk of undermining individual autonomy, as well as complications that may arise from relying on private sector technology and the need to agree on desirable contractual terms and data ownership. It recommends a cautious, targeted use of AIGHP rather than a widespread rollout, suggesting that policymakers should strengthen laws around data protection and discrimination. It encourages that the NHS should adopt high standards of accuracy and ensure proper governance before deploying AIGHP. The report concludes that while AIGHP could shift healthcare towards prevention, uncertainties surrounding its effectiveness, cost, and ethical implications must be resolved before full implementation.

ICO review of period and fertility apps

The Information Commissioner's Office (ICO) has issued a reminder to all app developers to ensure they protect users' privacy, following a review of period and fertility apps.

Last year the ICO carried out a review of period and fertility apps to understand how they process personal data and identify whether there is a negative impact on users as a result. The ICO contacted various app providers and engaged with app users to understand their experiences.

While no serious compliance issues or evidence of harms were identified in the review, the ICO has used the review as an opportunity to issue [a reminder to all app developers about the importance of protecting users' personal information](#).

The [ICO has shared four practical tips](#) to support app developers comply with their data protection obligations and maintain the privacy of their users.

- Be transparent

Ensure privacy information is right – it must be clear, concise and easily accessible

- Obtain valid consent

Consent must be explicit, unambiguous and involve a clear action to opt-in. It must also be easy for people to withdraw their consent at any time.

- Establish the correct lawful basis

Ensure the right lawful basis to process data has been identified whether it is consent, legitimate interests or a contract.

- Be accountable

App developers must be accountable for the personal information they hold.

To build on this work and to help people to check how an app plans to use their personal information before they sign up, the ICO has produced a [series of short videos](#) for people using apps, including period and fertility apps.

Since the ICO's review, a new study from King's College London and University College London published in May found female health monitoring apps were exposing users to privacy and safety risks through substantial shortcomings in data handling practices. The [research](#) uncovered several inconsistencies, as well as problematic privacy practices which saw data transmitted through complex chains of third parties.¹

Given the ubiquity of female health apps, the research demonstrates the need for app developers to acknowledge privacy and safety risks to users as a priority and to change and improve their privacy practices accordingly.

ICO reviews public sector approach trial

The Information Commissioner's Office (ICO) is reviewing its trial of a specific approach to enforcing the law on public sector organisations. The two-year trial announced in June 2022 involved a discretionary approach to reduce the impact of fines on the public sector. At the time, Commissioner [John Edwards said](#): "I am not convinced large fines on their own are as effective a deterrent within the public sector." In practice, this has meant that the ICO has increased its use of public reprimands and enforcement notices, with fines only issued in the most extreme cases.

In a [statement](#) released in June, the ICO said that "while we have continued to issue fines to public bodies where appropriate, we have also been using our other regulatory tools to ensure people's information is handled appropriately and money isn't diverted away from where it's needed the most." The ICO will now review the two-year trial before making a decision on the public sector approach in the autumn. In the meantime, it will continue to apply this approach to regulatory activities in relation to public sector organisations.

¹ Malki, L. M., Kaleva, I., Patel, D., Warner, M., & Abu-Salma, R. (2024). *Exploring Privacy Practices of Female mHealth Apps in a Post-Roe World*.

Provisional ICO decision to fine software provider following 2022 ransomware attack on NHS services

In 2022 a ransomware incident caused significant disruption to NHS services. The cyberattack was [widely reported at the time](#) and included staff being unable to access medical records and disruption to NHS 111.

Following an initial finding that Advanced Computing Software Group Ltd (Advanced) failed to implement measure to protect the personal information of 82,946 people, the [ICO has provisionally decided](#) to fine them £6.09 million. Advanced acts as a data processor and provides national IT and software services to the NHS and other healthcare organisations. It handles personal data on behalf of these organisations.

The ICO's initial findings include that hackers initially accessed a number of Advanced's health and care systems via a customer account that did not have multi-factor authentication.

The ICO, John Edwards, stated that:

For an organisation trusted to handle a significant volume of sensitive and special category data, we have provisionally found serious failings in its approach to information security prior to this incident. Despite already installing measures on its corporate systems, our provisional finding is that Advanced failed to keep its healthcare systems secure. We expect all organisations to take fundamental steps to secure their systems, such as regularly checking for vulnerabilities, implementing multi-factor authentication and keeping systems up to date with the latest security patches.

The ICO's findings are, at this stage, provisional. The Commissioner will consider any representations Advanced make before making a final decision, with the fine amount also subject to change.

The ICO has taken this opportunity to highlight its guidance to [support organisations to protect their systems from ransomware attacks](#), as well as guidance on the [responsibilities and liabilities of both data processors and controllers](#).

Legal cases

Judgment on the application of the Mental Health Act on treatment decisions - North Tees and Hartlepool NHS Foundation Trust V KAG and Ors [2024] EWOP38

The legal position regarding the application of the Mental Health Act 1983 (MHA), and the interface with the Mental Capacity Act (MCA) for treatment decisions, can at times, be complicated, and this case highlights the importance of understanding which is the most appropriate legal framework to use in order to avoid unnecessary court applications.

KAG is a woman with a history of depression. In late December 2023 she underwent emergency surgery for a serious condition, which was successful, but on returning home, she developed severe depression which led her to neglect herself, including by not eating or drinking. Since the middle of January 2024, she had been cared for in hospital. There were two short periods of detention under s.2 MHA, at the end of January, and the end of April. Neither was converted to detention under s.3, as each time, KAG agreed to remain in hospital and to continue to receive treatment. A nasogastric tube was inserted to provide KAG with clinically assisted nutrition and

hydration (CANH) in January 2024, apparently in reliance on the MCA, and without KAG actively objecting. KAG had also been receiving psychiatric medications. KAG was discharged from s.2 of the MHA on 15 May 2024 by a mental health tribunal, since when she had not continued to engage with treatment. She had also declined medication at times and had expressed dissatisfaction with being fed by nasogastric tube.

KAG's treating doctors were of the opinion that the insertion of a PEG was now clinically appropriate, to provide a safer, more comfortable and more effective means of administering nutrition and hydration. A MHA assessment also concluded that KAG met the criteria for detention under s.3 of the MHA, but the s.3 application could not proceed due to an objection from the Nearest Relative.

The local authority, which was responsible for the process of arranging admission to hospital under s.3 MHA was initially not in agreement that the PEG could be inserted in reliance on powers under the MHA. The Trusts therefore wrote to the local authority on 17 June explaining the legal framework and inviting them to agree to progress the s.3 admission, including by applying to displace Mr G as KAG's Nearest Relative. The Trusts also explained that if the local authority did not agree, then they would make an application to the High Court (not the Court of Protection).

Within the displacement proceedings, confusion arose as to whether this was a 'Serious Medical Treatment' case, necessitating an application to the Court of Protection. This led to a stay of the displacement proceedings, with the Trust being 'invited' to make an application to the Court of Protection.

The Hearing took place on 12th July 2024, with Victoria Butler-Cole, sitting as a deputy High Court judge. The judge made a declaration, under the High Court's inherent jurisdiction, that in the event KAG is detained under the MHA, the proposed (PEG) treatment falls within s.145 and under s.63 of the MHA, as it was necessary for the treatment of her mental health condition. However, the judge also made it very clear that the application was unnecessary. She stated:

'Before setting out my reasons for making the declaration, I must state clearly – as the Official Solicitor invited me to – that this application was not required. The AMHP rightly determined that the MHA was the correct legal framework to provide treatment to KAG for her mental disorder, including the provision of CANH, and that is the framework that should have been applied.'

Whilst the judge noted, that in some cases where a person is detained under the MHA an application may be required if an issue arises as to whether treatment falls under the MHA and so 'where the scope of s.63 MHA is in question', this case however 'was not one of them'.

In particular, it was stressed that this judgment '*should not be taken as any sort of encouragement to statutory bodies to seek the court's intervention where there is no uncertainty on the part of a treating Trust as to whether treatment can be provided under s.63 and s.145 MHA, even in the face of objection by a patient.*'

The Court of Appeal finds the established legal approach to the relevance of a patient's belief in their illness and prognosis is wrong in law - Thirumalesh Chellamal Hemachandran and Ors v Sudiksha Thirumalesh (dec'd) (By her litigation friend, The Official Solicitor) and University Hospitals Birmingham NHSFT and Ors [2024] EWCA 896

The Court of Appeal has [held](#) that the previously established legal approach to the relevance of a patient's belief in their illness and prognosis is wrong and contrary to Court of Appeal authority. The successful appeal against the first instance [Court of Protection decision of Mrs Justice Roberts](#) that Sudiksha Thirumalesh lacked capacity to make decisions about her medical treatment, was brought by her parents as Sudiksha sadly died shortly after the Court of Protection decision.

ST was a 19-year-old, who suffered from an exceptionally rare form of mitochondrial disease which had led to the dysfunction and death of cells in a variety of her organs, resulting in generalised muscle weakness, respiratory muscle insufficiency, swallowing difficulties, and aspiration pneumonia. She was admitted to hospital with Covid in August 2022, and had been in intensive care since December 2022, on a ventilator and undergoing dialysis. She and her family wanted her to receive experimental therapy in trials in the US or Canada.

Her treating clinicians were of the view that she had a vanishingly small chance of recovery, even if accepted for a trial, and they did not anticipate her ever living outside of an intensive care setting. However, ST told her doctors that her belief in her ability to survive is 'unshakeable', and 'I want to die trying to live. We have to try everything.'

In her judgment, at first instance Mrs Justice Roberts stated:

'ST is well aware that she has been offered a very poor prognosis by her doctors. She acknowledges that they have told her that she will die but she does not believe them.'

The judge found that it is a fundamental prerequisite of the test for capacity that if a person is to understand, use and weigh relevant information, the information must be believed by the person. She therefore found on the balance of probabilities that ST's complete inability to accept the medical reality of her position, or to contemplate the possibility that her doctors may be giving her accurate information was likely to be the result of an impairment of, or a disturbance in the functioning of, her mind or brain, which led to her failing the functional test.

The Court of Appeal concluded that there was an error of law in regarding the 'absence of belief as determinative of the functional test' and set aside the Court of Protection's declaration of incapacity with the presumption of capacity applied.

The Court of Appeal decision is significant for a number of reasons. Firstly, the judgment clarifies the 'functional' aspect of the statutory test used to determine whether a person over 16 years has the mental capacity to make a decision. The issue on appeal was whether a person's ability to understand, use and weigh information relevant to a decision depends on that person believing that the information is reliable and true. This view that the functional test contains such a belief is referenced in the *Re MM* case in which Mr Justice Munby, as he then was, said:

'If one does not "believe" a particular piece of information then one does not, in truth, "comprehend" or "understand" it, nor can it be said that one is able to "use" or "weigh" it. In other words, the specific requirement of belief is subsumed in the more general requirements of understanding and of ability to use and weigh information.'

The Appeal Court found that Mr Justice Munby's view, that a belief requirement is subsumed in the requirements set out in the MCA, was wrong and based on wrongly interpreting the case of *Re MB (Medical Treatment)*.

'..The Official Solicitor submitted that a person who does not believe relevant information, whether it be factual or opinion, may lack capacity, but equally they may not. The meaning of each of the words “understand”, “use” and “weigh” is, she submits, different from the meaning of the word “believe.” The statutory language Miss Gollop submits is complete in meaning: there is no missing meaning, and no implicit or subsumed meaning that needs to be made explicit and no addition or embellishment is required. I agree.'

The decision has also put beyond doubt the ordering of the mental capacity test:

'bound by the Supreme Court decision in JB namely that questions under section 2(1) MCA should be first as to whether P is unable to make a decision for themselves by reference to section 3(1), the functional test. If they are not so able, consideration is given at the second stage to whether that inability is because of an impairment of, or a disturbance in, the functioning of the mind or brain (section 2(1), the mental impairment test).'

The appeal succeeded because the Court found that Mrs Justice Roberts through no fault of her own and relying on Re MB, made an error of law and 'failed to give sufficient reasons for disagreeing with the unanimous view of the experts that Sudiksha had capacity to make decisions as to her medical treatment.'

In allowing the appeal and setting aside the High Court's final declaration of incapacity, the Court concluded that 'the presumption of capacity applied, and this remarkable young woman therefore had her wish to *'die trying to live'*.