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 2025 Medical Ethics & Human Rights update

BMA work

Physician-assisted dying update
Over recent months, there has been considerable activity and debate across the UK and Crown Dependencies on proposals to change the law to permit physician-assisted dying. An update on each of the jurisdictions, and a summary of the BMA's activities, is provided below. Up-to-date information can be found at www.bma.org.uk/pad.

House of Commons
The BMA had constructive meetings with Kim Leadbeater MP to discuss the BMA's views in advance of the publication of her Terminally Ill Adults (End of Life) Bill .
The Bill, when published, included many of the BMA's 'asks', including:

- an opt-in model for doctors to provide assisted dying (doctors would choose whether to have the training required to provide assisted dying);
- a general right to decline to participate or assist in the provision of assisted dying (including providing professional opinions for the person assessing eligibility) for any reason;
- protection from detriment on the basis of a doctor's decision to, or not to, participate;
- no duty to raise, or prohibition on raising, assisted dying with patients.

The BMA has provided both written and oral evidence to the Bill Committee, which started its clause-by-clause consideration, and debate on amendments, on 11 February. The committee will now meet on Tuesdays and Wednesdays each week. An initial briefing on the clauses and amendments that relate to the BMA's position has been shared with committee members. All amendments are being reviewed as they are tabled, and updated briefings will be sent to committee members as and when required. The earliest the Bill can reach its next stage in the House of Commons (Report Stage) is 25 April.

Isle of Man
The Assisted Dying Bill 2023, introduced by Dr Alex Allinson MHK into the Isle of Man Parliament (Tynwald), has now been passed by both the House of Keys and the Legislative Council. It will now return to the House of Keys for consideration of amendments passed by the Legislative Council. If the amendments are accepted by the House of Keys, the Bill will then be sent for Royal Assent before passing into law.
Amendments made to the Bill in the House of Keys, after the BMA's communication, include:

- moving to an 'opt-in' system for doctors;
- removing the prohibition on doctors initiating discussions on assisted dying with patients;

- confirming that doctors would not be under any duty to raise assisted dying with patients;
- adding new statutory protection against discrimination for doctors; and
- provision for a review of all assisted deaths.

Although the 'conscientious objection' clause was amended in the House of Keys, it does not provide the 'right to refuse to participate for any reason' that we were seeking. The BMA continued to brief on the Bill in the Legislative Council, at both the clauses stage and, on this specific issue, at the final consideration stage, but we were not successful in getting further amendments to this clause. We will be reviewing the final wording to determine the precise impact of this for our members.

If the Bill receives Royal Assent, the BMA will continue to represent our members working in the Isle of Man throughout the period of implementation. The MEC will now begin to consider how best to do this, including assessing what the BMA would want to see in Regulations, Codes of Practice, guidance etc as well as thinking about practical issues around how the service would be delivered. The MEC is also continuing to consider the impact the introduction of assisted dying in the Isle of Man would have on our members working in England who treat patients from the Isle of Man, and how we can protect them (see below).

Jersey

In November 2021, Jersey's States Assembly decided 'in principle' that assisted dying should be permitted and work to develop policy proposals began. The initial Jersey proposals included many of the things the BMA was seeking:

- an 'opt-in' model for doctors;
- a separate assisted dying service;
- an information and support service for patients; and
- a review of all assisted deaths.

The BMA wrote to the ministerial committee set up to refine the proposals, which published its report - setting out its detailed policy proposals. These proposals were accepted by the States Assembly and the Bill itself is now being drafted – this is expected to take 12-18 months. Following the BMA's interventions, the instructions for drafting the law include the following:

- a right to refuse to carry out assessments or assist those providing assisted dying for any reason (not just on grounds of conscience);
- statutory protection from discrimination;
- no duty to raise assisted dying with potentially eligible patients; and
- the provision of safe access zones.

The MEC chair and secretariat have been in discussion with the Jersey Government's policy and legal advisers about the impact the introduction of assisted dying in Jersey would have on our members working in England who treat patients from Jersey.

Scotland

Liam McArthur MSP published his Assisted Dying for Terminally Ill Adults (Scotland) Bill on 27 March 2024. BMA Scotland sent a letter to Mr McArthur setting out the BMA's position in relation to his Bill and met with him to discuss this. The Bill is particularly concerning for our members in Scotland because at various points in the documents it makes clear that "it is expected that that this [the coordinating doctor] will usually be the terminally ill adult's GP or specialist care doctor" and that ‘it is anticipated that the [Registered Medical Practitioners] would undertake the role as part of their existing employment and thus that costs would be absorbed by existing budgets.’ There are also other areas of concern with this Bill which we have communicated to Liam McArthur.

The Bill has been allocated to the Scottish Parliament’s Health, Social Care and Sport Committee for consideration and the BMA has provided both written and oral evidence. The Committee is expected to report in the spring.

Cross jurisdiction issues

The MEC previously discussed the position of doctors who are working in England and treating patients who are considering or receiving an assisted death in the Isle of Man (or Jersey) should the law change in one of those jurisdictions. If, in the course of providing care and treatment for the patient, the doctor were to do or say something that could be seen as ‘encouraging or assisting the suicide’ (in contravention of section 2 of the Suicide Act) there is a risk they could face criminal and/or regulatory sanctions. We are continuing to explore how we would advise doctors, should that situation arise, and how we can best protect them. In addition to opening discussions with the Director of Public Prosecutions and the GMC, we have had discussions with the policy and legal advisers to the government of Jersey and called for protection for doctors to be included in Kim Leadbeater’s Bill, should that progress. If the law In the Isle of Man receives Royal Assent, we will progress discussions with the DPP and GMC to ensure we can protect and properly advise our members.

Communicating the MEC’s work on assisted dying to members

The chair and secretariat are keen to ensure that BMA members are kept informed of the work that we are doing on their behalf, and the progress of the various Bills across the UK and Crown Dependencies. We have:

- kept our website up-to-date with the latest developments (www.bma.org.uk/pad);
- offered presentations to all BMA committees, a number of which have accepted;
- arranged to have stands at most of the conferences where we can talk to members about the work of the MEC (on this and other topics);
- have requested a presence at the Annual Representatives Meeting in June so that we can speak to reps about their views and any concerns; and
- worked with the doctor on an article on how, from our position of neutrality, the BMA has helped to shape the debate on the Leadbeater Bill and working on a longer piece setting out how the MEC developed the BMA’s position and has sought to influence legislative proposals.

Data (Use and Access) Bill

As previously reported in *ethics*brief, the BMA has been lobbying on the government’s Data (Use and Access) Bill which has completed its House of Lords stages and had its second reading in the Commons in February. If the Bill becomes law, it will amend the UK GDPR and the Data Protection Act 2018.

A number of the shared concerns of the BMA and the National Data Guardian (NDG) were mentioned by MPs at second reading, including the weakening of transparency standards when data is re-used for research purposes. Both the BMA and the NDG are concerned that any weakening of transparency standards would have the potential to undermine people’s trust in how healthcare data is used for research. The BMA is also concerned about the potential threat to the regulatory independence of the Information Commissioner’s Office.

The BMA’s briefing for second reading is available here. We will be submitting evidence to the House of Commons Public Bill Committee which will consider the Bill in March.

Human rights update

BMA Statement on Israel and Gaza - January 2025

With more reports of abuses to medical neutrality and international humanitarian law unfolding, by reputable human rights organisations such as Amnesty International and Human Rights watch, in January 2025 the BMA published a renewed position statement on the conflict in Israel and Gaza, where we reaffirmed our concerns and asks from our statement in 2023 and highlighted new issues as well. This included the alarming reports of attacks on medical personnel, the destruction of medical facilities and infrastructure essential for maintaining population health, the denial of healthcare, the arbitrary detention and torture of Palestinian doctors, as well as reports of clinicians’ involvement in torture. We called for independent investigations into these issues, as well as for the siege of Gaza to end and further medical evacuations to be conducted. The statement underwent a minor update to acknowledge and welcome the ceasefire agreement in January 2025.

As with all our human rights work, our response has been governed by our longstanding criteria for intervention.

Letter to the Foreign Secretary regarding the arbitrary detention of Gazan healthcare workers by Israeli forces

The MEC and IC (International Committee) chairs wrote to the Foreign Secretary, David Lammy MP, to express the BMA’s concern about the reports of doctors from Gaza being arbitrarily detained by Israeli forces. The letter also notes that several doctors have died in Israeli custody, and that the ICRC (International Committee of the Red Cross) has been prevented from carrying out humanitarian visits to the detention centres - amplifying our concerns. We called for the UK government to push for an independent investigation into these allegations and for the ICRC to be granted access.

Human rights webpage update

The BMA’s human rights webpage has been updated and standardised. The webpage includes all of our interventions in relation to health and human rights concerns across the world. We regularly update this webpage to keep members informed of the work we do.

Ethics guidance update

Three new toolkits on children and young people have been published and added to our *Core Ethics Guidance*. These are: Children and young people under 16; Treating 16 and 17-year-olds in England, Wales, and Northern Ireland; and Treating 16 and 17-year-olds in Scotland. These toolkits set out the legal and ethical factors doctors need to consider when provide care and treatment for children and young people under 16 and for 16 and 17-year-olds, respectively. Amongst other topics, they cover, consent, refusal of treatment, confidentiality, and child safeguarding.

Updates have also been made to the other toolkits within Core Ethics Guidance to ensure that it is up to date in terms of statutory and GMC guidelines.

We have also extensively reviewed and updated the following guidance:
- Access to health records
- Access to medical reports
- Doctors with competing interests
- GPs as data controllers under the UK General Data Protection Regulation
- Medical student toolkit
- Responding to patient requests about physician assisted dying
- Social media, ethics and professionalism
- Focus on Subject Access Requests for insurance purposes
- Doctors responsibilities with anti-radicalisation strategy
- Doctors and industrial action
- Patients recording consultations
- GDPR privacy notices for GP practices

All our guidance are available to access via our Ethics webpage.

General updates

Commission on Human Medicines report on puberty blockers for under 18s.

The Commission on Human Medicines (CMH) has published an independent report on the safety implications of the government's proposal to restrict the availability of puberty blockers for under 18s. The CMH has concluded that the current prescribing and care pathway for GnRH agonists for gender incongruence and/or gender dysphoria presents an unacceptable safety risk for children and young people under 18 years and has therefore made a number of recommendations:-

- The current restrictions that are set out in the temporary prohibition order should continue indefinitely for prescribers registered outside the UK.
- For UK private prescribers, the current restrictions in the temporary prohibition order should continue and there should be a review of the order in April 2027 and, if required, at a later appropriate date, but no later than the end of the puberty suppressing hormone trial.
- The additional safeguards which should be put in place to facilitate safe UK prescribing of GnRH agonists for gender incongruence and/or gender dysphoria outside the puberty suppressing hormone trial should include:
  - Prescribers completing a risk acknowledgment form with the patient and/or parents or carers when prescribing GnRH agonists for puberty suppression in children and young people under 18 years of age. This form should be identical across the UK's 4 nations.
  - The development of a set of consistently audited common care standards for specialist gender services for children and young people under 18 years for use in all parts of the UK by April 2027, in both public and private sectors, and adherence regularly assessed by the healthcare regulators.
  - The development of a funded strategy for capturing and reporting long term safety and efficacy data across all UK gender specialist services.

The CMH has also made recommendations in respect of wider implementation considerations including mental health and wellbeing support for all children and young people with gender incongruence and/or gender dysphoria to be expedited and enhanced, and rapid assessment and support by the NHS of those children and young people who have been unable to find an NHS prescriber willing to manage prescribing of their GnRH agonists, where the prescribing had previously been by an EEA prescriber.

The government has published a factsheet to accompany the CMH report.

Healthwatch England report on the NHS complaints system finds it 'lets people down'

Written complaints in the NHS reached a record high in 2024. Healthwatch England commissioned a YouGov poll to find out whether people know how to make complaints about their NHS healthcare and get support to do so, following Lord Ara Darzi's independent investigation into NHS performance last year. The investigation found serious failings in how the service listens to and responds to patient feedback. Key recommendations in the report include making the complaints process easier for patients and their families to navigate, monitoring and improving the performance of organisations that handle complaints and developing a culture of listening to and learning from complaints.

Investigating suspected criminal activity in healthcare settings

The government has published a Memorandum of Understanding (MoU) for investigating suspected criminal activity in healthcare. This follows the report in 2018 from Professor Sir Norman Williams looking at gross negligence manslaughter in healthcare settings. The MoU covers any incidents occurring in the course of healthcare delivery where suspected criminal activity on the part of an individual is believed to have led to or significantly contributed to the death or serious life-changing harm (whether of a physical or psychological nature) of a patient or service user. The MoU sets out how healthcare organisations, regulatory bodies, investigatory bodies, and prosecutorial bodies will work together in cases where there is suspected criminal activity on the part of an individual in relation to the provision of clinical care or care decision-making.

Study on admissions to acute medical wards for mental health concerns among children and young people in England

University College London, and Great Ormond Street Institute of Child Health have published an article in the Lancet on their research into child admissions to medical wards for mental health concerns in England between 2012 and 2022. The research found that there were large increases in the number of children and young people admitted to acute medical wards for mental health concerns over a 10-year period, and that further work is needed to understand factors driving these trends and how to improve care for children and young people with mental health concerns admitted to medical wards. The research identified:-

- There were 34,2511 admissions for any cause in children and young people aged 5–18 years in 2021–22 in England, of which 39, 925 (11·7%) were for mental health concerns.
- Between 2012 and 2022, annual admissions for mental health concerns increased from 24,198 to 39,925 - a 65% increase.
- Increases were particularly steep in females aged 11–15 years, rising from 9,091 to 19,349 - a 112·8% increase.
- In 2021–22 there were 21,337 (53.4%) of admissions for mental health concerns due to self-harm.
- Of 23,9541 children and young people who were admitted for mental health concerns between 2012 and 2022, 32107 (13·4%) had a repeat admission within 6 months. The odds of long-stay admission and hazard ratios for being readmitted were significantly

higher for children and young people aged 11–15 years, those who were female, those from less deprived areas, and those with eating disorders than among other groups.

Tackling inequalities in care for people with people with learning disabilities and autism

People with learning disabilities and autistic people continue to experience unacceptably poor health outcomes in comparison to the rest of the population, leading to lower life expectancy and a higher number of avoidable deaths. This guidance aims to close the gap in skills and knowledge across the adult health and social care workforce. It gives commissioners and practitioners the practical steps, confidence, and legislative awareness needed to improve experiences of care and support for people with learning disabilities and autistic people.

Royal College of Physicians report on Bridging the gap: a guide to making health equalities a strategic priority for NHS leaders

This report argues that health inequalities are avoidable and unfair, and that tackling them is the key to improving the health of the country and reducing preventable demand on health services. It emphasises that addressing these inequalities should be a key focus for NHS organisations, and that NHS leaders, and clinicians play an important role in pushing this forward.

Handbook to the NHS Constitution for England

The Health Act 2009 requires the Secretary of State for Health and Social Care to carry out a review of the Handbook to the NHS Constitution for England every 3 years. The last review was carried out in January 2022. The handbook has now been updated to ensure that it reflects changes to the law, the healthcare system and the current supports available to NHS users.

Registration of stillbirth – House of Commons Library paper

There is currently no provision to allow the registration of stillbirths before the 24th week of pregnancy although since February 2024 hospitals in England and Wales may issue a commemorative certificate when the stillbirth cannot be registered formally, and in Scotland the Memorial Book of Pregnancy and Baby Loss Prior to 24 Weeks was introduced in October 2023. There is no comparable scheme in Wales or Northern Ireland,

Calls have been made for some time, both inside and outside of Parliament, for the law to be changed.
Former Conservative MP, Tim Loughton, previously spoke of the arbitrary nature of the 24-week threshold. He highlighted one case where twins had been stillborn either side of the threshold and were treated differently for registration purposes. This Commons Library paper deals with the current registration provisions relating to stillbirths, and consideration of whether the law should be changed.

ICO approach to the public sector

The ICO has concluded its review of its trial approach to enforcing the law on public sector organisations. As previously reported in *ethics*brief, the two year trial involved a discretionary approach to reduce the negative impact of fines on the public sector.

The results of the trial were published in December. The ICO has decided to continue its policy of issuing reprimands to public sector organisations, rather than imposing fines. Public reprimands are thought to increase accountability and transparency within healthcare organisations. Feedback from the review said that public authorities saw the publication of reprimands as effective deterrents, mainly due to reputational damage and potential impact on public trust, and how they can be used to capture the attention of senior leaders.

During the trial around 60 reprimands were issued to public bodies and made available on the ICO website. The ICO, John Edwards, has said that this has produced noticeable results, with organisations subsequently making significant changes. Examples include an NHS trust no longer sending bulk emails with sensitive information.

The review showed that central government and wider public sector echoed the sentiment around the negative impact of fines on frontline services, and how fines can disproportionately affect the budget of smaller organisations. The review also highlighted potential areas for improvement, specifically what type of infringements could lead to a fine and greater clarity on the parameters of the ICO discretion not to issue a fine.

Legal cases

Declaration to grant posthumous use of embryo in treatment via a surrogate - EF -v- Human Fertilisation and Embryology Authority [2024] EWHC 3004 (Fam)

Mrs Justice Theis sitting in the Family Division of the High Court, made a declaration on 22 November 2024 that it is lawful for the applicant to use an embryo created using his sperm and his late wife's eggs in treatment with a surrogate, notwithstanding the absence of signed, written consent for that use.

EF and his wife AB had undergone fertility treatment in 2017 at a clinic licensed by the Human Fertilisation and Embryology Authority (HFEA), during which an embryo had been created which was stored by the clinic. Tragically, AB died unexpectedly in childbirth, and she had not signed the necessary consent form for the use of the embryo. One of the couple's core beliefs was in the sanctity of life and the divine purpose in all life forms. AB had believed that every living being had a soul and in their religion's belief in reincarnation and considered that the divine soul entered the embryo at the point of conception.

The HFEA consent forms were in identical terms to those in the case of Jennings -v- Human Fertilisation and Embryology Authority [2022] EWHC 1619 (Fam) (Jennings) where Mrs Justice Theis held that the woman's consent form was not sufficiently clear and did not give Mr Jenning's partner Ms Choya sufficient opportunity to provide consent in writing to use of the embryos with a surrogate. In Jennings the judge stated 'I am satisfied that, in the circumstances of this case, the court can infer from all the available evidence that Ms Choya would have consented to Mr Jennings being able to use their partner-created embryo in treatment with a surrogate in the event of her death. This is being considered in the context where, in my judgment, she had not been given relevant information and/or a sufficient opportunity to discuss it with the clinic.'

As with Mr Jennings, the HFEA refused EF permission to use the embryo with a surrogate, and he sought a declaration that it would be lawful for him to do so, based on the contention that the HFEA's refusal constituted a significant and disproportionate interference with his Article 8 rights under the European Convention on Human Rights ('ECHR'), alone and interpreted in light of Article 9, and those rights in the context of Article 14. Furthermore, EF would be deprived of being able to honour or fulfil AB's religious wishes for the embryo to be used in accordance with her beliefs to give the life form a chance and, 'if unused, the embryo would be left to perish which is contrary to both EF and AB's strongly held religious beliefs.' It was also argued on behalf of EF that AB was not given an opportunity to provide her written consent to her embryos being used after her death in surrogacy due to the format of the consent forms published by the HFEA, the same forms as in Jennings, which have since been updated by the HFEA.

On behalf of the HFEA, it was submitted that the declaration sought should not be granted because:

- the 1990 Act provided ‘a clear and unambiguous framework for the use of embryos, which requires informed consent to be given in writing and to be signed’;
- it was common ground that AB had not given such consent, and the evidence filed demonstrated AB had had sufficient opportunity to provide effective consent;
- the Act did not permit the exercise of any discretion in respect of the requirement for ‘effective consent’ and ‘cannot be read down to remove the requirement for signed written consent without crossing the boundary from interpretation to amendment’; and
- any interference with EF’s Article 8 rights, either alone or together with Article 9 and/or 14, was necessary and proportionate to the underlying legislative objectives: ‘The fact that the strict application of its requirements may result in individual hard cases does not make it disproportionate’.

Mrs Justice Theis concluded from the evidence that an inference could be drawn that AB would have wanted EF to use their embryo in treatment with a surrogate in the event of her death and would have recorded this in writing had she been given the opportunity to do so. She was also satisfied that
‘AB was not given the opportunity to consent to EF being able to use their partner-created embryo in treatment with a surrogate in the event of her death due to an omission in the HFEA scheme’.

The Mrs Justice Theis held that Schedule 3 of the HFEA 1990 should be read down to introduce an implied discretion for the court to accept evidence of consent provided other than in writing where a failure to do so would result in a breach of Article 8. She stated that ‘This conclusion does not go against the grain of the legislation, it supports the fundamental principle that the wishes of gamete providers should be paramount. It does not dispense with the requirement of consent, it provides for the possibility of it being provided other than in writing in circumstances where there is clear evidence of the gamete providers wishes and the only reason written consent was not given was due to the lack of opportunity to do so. There is nothing in the legislative history that suggests this situation was considered by Parliament’.

Judge finds that the wider considerations about the child’s quality of life had to be fairly considered in application to withdraw life – sustaining treatment - Birmingham Women's and Children's Hospital NHS Foundation Trust v KB & Ors [2024] EWHC 3292 (Fam)
Fatima, a ten-year-old Muslim girl, was a patient in the hospital. She had a rare genetic condition which had affected her since birth and caused profound disability. She was on a ventilator and could hear, but not speak, and she was subject to seizures. Her older brother had the same condition and had died shortly after his first birthday. At the time of the hearing, Fatima had been in intensive care for over a year, following an infection and then the displacement of her nasogastric tube which caused her to aspirate.

The Trust applied for a declaration that it was ‘not in her best interests to continue to receive life-sustaining treatment in the form of ventilation (whether invasive or non-invasive) and in her best interests to be extubated and for palliative care and treatment to be provided to her under medical supervision such that she suffers the least distress and retains the greatest dignity until such time as her life will come to an end’. Her parents opposed the application, but her Children’s Guardian supported it.

The Judge, Morgan J formed the view that ‘this is a family for whom their faith is a strong thread running through their lives and their thinking’. She also formed the view that ‘Fatima, though still young, is already, to the extent that she is able to be, a member of that faith by reason of her place in her family…I agree that all things being equal and absent the disabilities imposed on her by her condition, her religious beliefs as a pre-teenager and young person would more likely than not align with those of her parents and family. Accordingly, I give the question of religious faith strong, though not determinative weight as I consider the application for the declaration sought’.

Morgan J found that the senior clinicians at the Trust had underestimated F’s ability to experience pleasure, having regard to the parents’ evidence and the notes of other professionals such as play facilitators who had spent time with F and who had reported many examples of her expressing pleasure and excitement earlier in her admission. At the time of the hearing, Morgan J found that F was able to respond to her family and other people, including by smiling, and was more responsive when they or others spoke to her in her first language, and that she was able to experience pleasure, albeit in a limited way, as had been the case throughout her life due to her disabilities.

Morgan J did not accept that there was clear evidence of significant neurological decline over the period of the admission, noting that there were other possible explanations for a change in F’s presentation and expressed concern about the transparency of decision-making by the Trust and its failure to keep minutes of MDT meetings at which parents are not present.

The decision as to what was in Fatima’s best interests amounted to a choice between two options: ‘withdrawal of life-sustaining treatment with the expectation that the inevitable consequence will be that her life comes to an end … [*or*] surgery for a tracheostomy with a view to long term ventilation at home (in which long term is quantified variously as an estimate of some months or a small number of years)’

In what was a finely-balanced decision, Morgan J was not satisfied that, in the particular factual circumstances of the case, it was appropriate to grant the declarations sought by the Trust. She was clear that, although the medical evidence of the burdens of treatment was relevant and important, the wider considerations about the child’s quality of life, having regard to emotional and psychological factors, had to be fairly considered, and set in the context of the child’s previous life experiences. She therefore dismissed the Trust’s application although she acknowledged it was not ‘without risk or uncertainty and, as her Guardian has been astute to point out, is one that carries with it its own burdens’. The judgment can be accessed here.