

# this week

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## Johnson outlines health and social care tax

The prime minister has announced a UK-wide “health and social care levy” to fund NHS backlogs resulting from the covid pandemic and to overhaul social care.

The plan has been criticised for placing a greater burden on young adults and the lowest paid and for failing to tackle the issue of low pay among care workers. Think tanks have also pointed out that the vast majority of the funds raised will go directly to the NHS, with little left over for social care.

From next April national insurance contributions will rise by 1.25 percentage points for employees and employers, and there will be the same rise in share dividend tax. From April 2023 these rises will be labelled as a health and social care levy and appear as a separate line on payslips. At this point it will also apply to pensioners who are still in work. The plan was due to be voted on in parliament on 8 September, after *The BMJ* went to press.

The rise means someone on a £30 000 salary would pay an extra £255 a year.

Much of the £36bn expected to be raised over the next three years will be initially devoted to cutting waiting lists, with social care receiving only £5.4bn. Scotland, Wales, and Northern Ireland have their own systems for funding health and social

care, but income from the new levy will be distributed across the four UK nations.

The government will also bring in a new cap on social care costs from October 2023, with an £86 000 limit on what people will pay over their lifetime. Anyone who has assets of less than £20 000 will have their care costs fully covered by the state. Those with assets between £20 000 and £100 000 will receive some means tested state support.

Announcing the plan in parliament, Boris Johnson said it would enable the “biggest catch-up programme in NHS history” and remove the “fear of catastrophic social care costs.”

During the 2019 general election the Conservative Party made a manifesto commitment not to raise national insurance, income tax, or VAT. Johnson told parliament he accepted he was breaking that commitment but that a “global pandemic wasn’t in anyone’s manifesto.”

As yet there is very little detail on how the government plans to reform social care. A white paper is expected later this year.

The Labour leader, Keir Starmer, criticised the plan for hitting the lowest paid hardest. “We need to ask those with

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**The prime minister (inset) announced a 1.25 percentage point rise in national insurance rates to fund social care and to cut NHS waiting lists**

### LATEST ONLINE

- Covid-19: “Most complex patient in the world” should have ventilation withdrawn
- Genetics journal that carried articles helpful to Chinese state surveillance is hit by editorial board resignations
- Covid infection increases the risk of kidney disease even in mild cases, finds study



# SEVEN DAYS IN

## BMA refuses to engage with consultant pay review process amid call for reform



Consultants in England will not engage with the Review Body on Doctors' and Dentists' Remuneration (DDRB) process this year and are instead calling for urgent negotiations directly with the government, the BMA has said.

The decision came after a BMA survey of 6000 consultants found that over 80% believed this year's below inflation pay rise of 3% to be inadequate or completely unacceptable, while 91% said it showed the government did not value their work.

The BMA Consultants Committee said the DDRB was set up as an independent body to give doctors assurance their standard of living would not be depressed by arbitrary ministerial action. Instead, after government imposed pay freezes and caps, the estimated take home pay of the average consultant has fallen by more than 28% in real terms since 2008.

In a letter to Sajid Javid, England's health secretary, the committee chair, Vishal Sharma (left), wrote, "No process can be considered independent where the parameters of review can be set arbitrarily by government; the membership of the review body is selected solely by government; the final reports can be held by government indefinitely, without being released to the profession; and the recommendations are not binding."

Elisabeth Mahase, *The BMJ* | Cite this as: *BMJ* 2021;374:n2192

## Covid-19

### Third vaccine dose for immunosuppressed people

The UK's Joint Committee on Vaccination and Immunisation recommended that people aged over 12 with severely weakened immune systems should have a third vaccine dose as part of their primary vaccination schedule against covid-19, including those with leukaemia or advanced HIV or who recently received an organ transplant. The committee did not recommend covid-19 vaccination for all young people aged 12-15 and has instead asked ministers to seek further advice from the UK's chief medical officers on the wider potential benefits of vaccination.

### Vaccines prevented 143 000 admissions in England

Public Health England estimated that the covid vaccination programme had prevented 143 600 hospital admissions of over 65s in England up to 22 August. Its model showed that around 36 100 admissions were prevented in people aged 65-74, 58 800 in those aged 75-84, and 48 700 in people over 85. It said the figures were

likely to be underestimates, as the indirect effects of the vaccination programme were not included in the analysis.

### One in seven children may have lasting symptoms

A large study of children and teenagers who caught SARS-CoV-2 found that as many as one in seven (14%) may still have symptoms 15 weeks later. But this figure is lower than the results of some studies, which have reported a prevalence of long covid in children and teenagers as high as 51%. The lead author, Terence Stephenson (below) of the UCL Great Ormond Street Institute of Child Health, said, "It is reassuring the figures were lower than the worst case scenarios predicted last December. However, they are not of trivial importance."

## Guidelines

### Secukinumab is advised for severe plaque psoriasis

NICE draft guidance recommends secukinumab (Cosentyx, Novartis) for severe plaque psoriasis (above) in children aged

6-17 whose disease has not responded to other systemic treatments or in whom these are not tolerated. NICE said clinical evidence suggested



that secukinumab was at least as effective as adalimumab, etanercept, and ustekinumab, which are already available on the NHS for this group of patients, and the drugs are similarly priced.

### NICE and Cochrane to deliver "living" advice

NICE will be able to respond more quickly to changes in evidence after reaching a collaborative agreement with Cochrane. The partnership will allow NICE to make efficient and effective updates to recommendations in its guidelines as soon as new evidence becomes available. The collaboration announcement follows the recent publication of NICE's new five year strategy, which commits it to finding

more flexible and faster ways of working.

### New epilepsy treatment option recommended

Draft guidance from NICE recommends cenobamate as a third line add-on treatment for focal onset seizures with or without secondary generalised seizures in adults who have epilepsy that has not been adequately controlled with at least two anti-seizure medicines. Treatment should be started and managed in tertiary care, it advises. An estimated 17 000 people with this form of epilepsy will be eligible for treatment with cenobamate.

## Opioids

### Purdue bankruptcy plan is approved by US judge

A US federal bankruptcy judge conditionally approved a controversial plan to dissolve Purdue Pharma, one of the companies blamed for nearly 500 000 opioid overdoses and deaths over two decades. Under the settlement the Sackler family will give up ownership of the company and contribute \$4.5bn (£3.25bn) to compensate people harmed by the OxyContin painkiller but will be freed from any future lawsuits.





# MEDICINE

## Sexual health

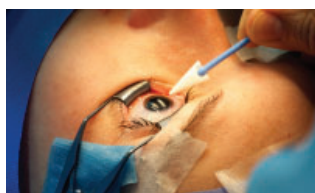
### STI cases fell by a third last year

Diagnoses of sexually transmitted infections in England were 32% lower in 2020 than in 2019, falling to 317 901 cases, show figures from Public Health England. The agency said the decline reflected a combination of reduced STI testing as a result of disruption to sexual health services and changes in behaviour during the covid pandemic. Consultations at sexual health services in 2020 were 10% lower than in 2019.

## Treatment backlog

### Labour: England's recovery plan is "beyond urgent"

Patients in England are routinely waiting longer than 18 weeks for NHS treatment, an analysis of official data by Labour shows. The party has urged ministers to produce a recovery plan before the end of the year to set out what action is being taken to cut waiting lists and ensure



sufficient staff and equipment. The analysis found that in 83 hospitals patients for some treatments—including oral and ear, nose, and throat surgery, and ophthalmology—could expect to wait more than 18 weeks.

## Mental health

### Suicide rates did not rise in first wave of pandemic

Data from the Office for National Statistics showed that suicide rates did not increase during the early stages of the covid pandemic. Suicides numbered 1603 from April to July 2020 in England and Wales, equivalent to an age standardised mortality rate of 9.2 deaths in 100 000

### Cases of gonorrhoea and other sexually transmitted infections fell in 2020

people. This is statistically significantly lower than rates in the previous three years. The lower rate was primarily driven by a decrease among males, whereas the rate among females was similar to earlier years.

## Reproduction

### New limit on storing eggs, sperm, and embryos

The government set out plans to increase the storage limits for eggs, sperm, and embryos to as much as 55 years, up from the current 10 years and renewable every 10 years. The change follows a public consultation and will need to be approved by parliament. It is possible because of modern freezing techniques. The Department of Health said additional conditions will apply around third party donors and posthumous use, which will be consulted on separately.

## Regulation

### GMC advisory forum will oversee guidance overhaul

The GMC has set up an advisory forum to help steer the first review of its core guidance, Good Medical Practice, since 2013. The 12 strong group will act as a sounding board for decisions and developments and will provide advice to the GMC. Emma Cave, professor of healthcare law at Durham University, will chair the forum, and a consultation planned for next spring will seek input from healthcare professionals and patients' representatives.

Cite this as: *BMJ* 2021;374:n2188

## SIXTY SECONDS ON... BOOSTER VACCINES



### CAN I GET A COVID BOOSTER SHOT?

Not in the UK (yet), although you may be eligible for a third dose.

### WHAT'S THE DIFFERENCE?

A booster is given to people who have received a full vaccine course and developed a good immune response. That often wanes, so a boost is needed to get the response to previous levels. Third doses are being given to people whose immune response was likely to have been lower. Immune systems can be suppressed because of underlying health conditions or medical treatment.

### WHO WILL GET A THIRD DOSE?

The UK's Joint Committee on Vaccination and Immunisation has recommended offering a "third primary dose" to people aged 12 years and over who had severe immunosuppression around the time of their first or second dose.

### WHAT ABOUT THE BOOSTERS, THEN?

You may get a booster dose later: the committee is still mulling over that. If recommended, boosters may be offered to over 50s and others who are at higher risk from covid, alongside the flu jab.

### WILL I NEED ONE?

Almost certainly, eventually. The good news is that the UK may not need boosters as early as other countries. It controversially delayed second doses of Pfizer-BioNTech and Moderna vaccines by as much as eight weeks—stretching the interval from 3-4 to as much as 12 weeks—to allow more people to get first doses earlier. Studies now show that a longer dosing interval is associated with a better immune response.

### THAT'S A BOOST! WHAT IF I WANT TO TRAVEL ABROAD?

You may need a booster dose earlier to travel to some countries, to avoid many covid tests and quarantine. Croatia and Austria, for example, consider travellers to be fully vaccinated only if their last dose was given within 270 days.

### DOES ANYONE OFFER BOOSTERS?

Some countries have set out plans to give boosters to elderly people and to those who received the AstraZeneca or the single dose Johnson & Johnson vaccines. A few countries are offering them more widely at 4-9 months after the last dose.

Ingrid Torjesen, London

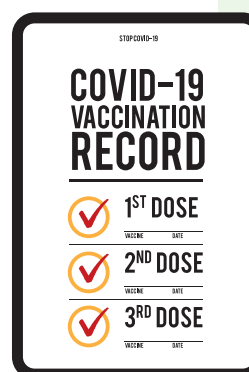
Cite this as: *BMJ* 2021;374:n2179

## DEMENTIA

The number of people in the world with dementia is expected to rise from

55 million today to 139 million by 2050

[World Health Organization]



(Continued from page 295)

the broadest shoulders to pay more. Tinkering and fiddling with the dividend won't do that."

Johnson said that for decades governments had ducked the decision on reforming social care. Ten years ago an independent review by Andrew Dilnot recommended a cap of £35 000 to be set on an individual's contribution. The plan was put into law in 2014 under the Conservative-Lib Dem coalition but was delayed and then eventually abandoned under David Cameron.

Richard Murray, chief executive of the King's Fund, welcomed the government grasping the nettle of social care reform. "However, a large dose of realism is needed in terms of what this money will be able to deliver and how fast. Social care will only see £5.4bn over three years, with no guarantees of sustainable funding beyond this. The cap on care costs—which will consume nearly half of the funding—will protect people from the very high costs of long stays in residential care, but setting it at £86 000 means it will help relatively few people."

The Institute for Public Policy Research said the plan was a clear improvement on the current system but left key problems unresolved. It also fell short of the extra cash needed to tackle the covid backlog, which the institute has

estimated to be £10bn a year. Chris Thomas, a senior research fellow, said, "The new cap and floor still doesn't put social care on the same basis as the NHS, but it will save the family homes of many and help tackle unmet need."

Natasha Curry, the Nuffield Trust's deputy director of policy, said, "After decades of dangerous delay, the broken social care sector will be feeling short changed and bitterly disappointed at the proposed funding levels and timing of reform today. While the decision to raise taxes for social care is bold and welcome action, the reality is the money will only go some of the way to stabilise a dire situation and leaves little for meaningful change."

Jacqui Wise, London

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BSIP/GETTY IMAGES

## NHS's £5.4bn boost must be first of many, say health chiefs

**T**he NHS in England will get an extra £5.4bn in funding over the next six months to help tackle waiting lists and manage the immediate pressures of the covid

pandemic, the government has announced.

England's health secretary, Sajid Javid, said, "The NHS has been phenomenal as it has faced one of the biggest challenges in its history . . . We know waiting lists will get worse before they get better as people come forward for help, and I want to reassure you the NHS is open, and we are doing what we can to support the NHS to deliver routine operations and treatment to patients across the country."

The government has acknowledged that the number of patients waiting for routine operations and treatments such as hip replacements and eye cataract surgery could potentially exceed 13 million.

Healthcare leaders have said that, although this funding is a welcome start, sustained funding in the long term will be vital. The Health Foundation has estimated that it will

cost up to £16.8bn between now and 2024-25 just to enable the NHS to clear the backlog of people waiting for routine elective care, return to the 18 week waiting time target, and treat millions of patients who were expected to receive care during the pandemic but did not.

The foundation's director of research, Anita Charlesworth, said, "It's important that the government recognises that this is only the first instalment of the substantial funding needed to put the NHS on the road to recovery . . . There will need to be realism about the speed at which the NHS can recover waiting times and honesty with the public about what this means for patient care."

### Winter pressures

This message was echoed by the BMA's chair of council, Chaand Naggpaul. He said, "The scale of the backlog is gargantuan and unprecedented in the history of the NHS . . . It will take years—not months—to clear this backlog, in addition to concerns of new winter pressures ahead."

## Price deal leads to cholesterol drug assent

A novel anticholesterol drug, to be given in primary care as a twice yearly injection, has been recommended for people with primary hypercholesterolaemia or mixed dyslipidaemia who have had a previous cardiovascular event.

NICE decided to recommend inclisiran after a "population level" commercial deal between NHS England and the manufacturer, Novartis. The list price is £1987.36 for a 284 mg dose pack, but the size of the discount is confidential.

Meindert Boysen, NICE deputy chief executive,



called inclisiran a "potential game changer in preventing thousands of people from dying prematurely from heart attacks and strokes."

The drug is the first of a new class of cholesterol lowering treatments using RNA interference (RNAi) to boost the liver's ability to remove harmful cholesterol from the blood. In draft final guidance NICE recommended it as an adjunct to diet for

patients with a history of cardiovascular events who have persistently high concentrations ( $\geq 2.6$  mmol/L) of low density lipoprotein cholesterol (LDL-C) despite maximum tolerated lipid lowering treatment.

NHS England estimated that 300 000 people would receive inclisiran over the next three years, a figure that could rise to nearly half a million after that. An estimated 55 000 myocardial infarctions and strokes could be prevented and 30 000 lives saved within the next decade.

Three randomised trials

Nagpaul also highlighted issues predating the pandemic that still need to be tackled, including having about 50 000 fewer doctors than in equivalent EU nations and one of Europe's lowest numbers of hospital beds per capita.

"We have estimated that funding must increase by 4.1% to ensure that the NHS can cope, meaning core health spend must total £174bn by 2023-24. At best this announcement allows for a start to what is needed, but it will soon run out. We need to have continued funding and a backlog reduction strategy that spans the years to come," he said.

Although the extra funding applies only to England, the government has said that in 2021-22 the devolved administrations will receive up to £1bn in Barnett consequentials, a mechanism the Treasury uses to adjust the public expenditure allocated to devolved nations to ensure it reflects spending in England.

Elisabeth Mahase, *The BMJ*  
Cite this as: *BMJ* 2021;374:n2204

#### THE £5.4bn COMPRISES

- **£2.8bn** for costs relating to covid, including infection control measures to keep staff and patients safe from the virus
- **£600m** for day to day costs
- **£478m** to continue the hospital discharge programme so staff can ensure that patients leave hospital as quickly and as safely as possible, and
- **£1.5bn** for elective care recovery, including **£500m** capital funding for extra theatre capacity and "productivity boosting" technology

of 18 months showed that inclisiran notably reduced LDL-C concentrations in comparison with placebo when statins or other lipid lowering treatments had not reduced them enough. But no data directly compare inclisiran with ezetimibe, alirocumab, or evolocumab.

The appraisal committee said it was concerned about a lack of long term data on cardiovascular outcomes from trials that compared inclisiran with placebo, but it noted that ongoing clinical trials would provide more data.

Jacqui Wise, Kent  
Cite this as: *BMJ* 2021;374:n2143

**Inclisiran is a potential game changer in preventing thousands of people from dying prematurely**  
Meindert Boysen

## Q&A

# What caused the blood tube shortage, and how is it affecting healthcare?



### What's happening?

Becton Dickinson (BD), which makes most of the blood tubes the NHS uses, has alerted NHS England to a global shortage of blood tubes with a yellow or purple top.



### What caused the shortage?

BD says the pandemic created the most unpredictable demand it has seen in the past 70 years. Customers have also found it difficult to predict the types and quantities they will be using from month to month, affecting manufacturers' abilities to meet demand. "Adding to the issue are global transportation delays that have resulted in more products being tied up in transportation than is normal, creating additional delays in deliveries," BD said in a statement. "Raw material suppliers are also challenged to keep up with demand for materials and components."



### What's being done to tackle it?

In the UK BD has been authorised to import blood tubes that are approved for use elsewhere, including the US. It plans to deliver nine million of these to the NHS for immediate distribution. Ahead of this, the tubes were assessed and approved by the MHRA. BD says it has also improved its manufacturing facility in the UK to increase production capacity by 20%.

"We expect the situation to stabilise and recover through September, based on the volume of tubes we are supplying," it said. NHSE is coordinating the response in the country. It said supplies will improve from the middle of this month but warned that "overall supply is likely to remain challenging for a significant period."



### Can't the NHS use different tubes?

NHSE said alternatives were being sought and that labs that will switch to them have received testing samples. But it said it will take time for them to be delivered in any substantial volume. A further complication is that the machines the NHS uses to run tests often use tubes from a particular manufacturer. Machines may need to be recalibrated, and staff may need extra training.



### What kinds of test will be delayed?

In its letter to all GPs and trust medical directors in England, NHSE said that all primary care and community testing must be halted until 17 September, except for clinically urgent tests. These include bloods that are needed for a two week wait referral or are extremely overdue or essential for safe prescribing or monitoring of a condition; bloods that could avoid hospital admission or prevent onward referral; and tests for patients with conditions with a risk of death or disability.

Acute and mental health trusts have been told to reduce their demand for tubes by a minimum of 25% until 17 September, such as by reducing non-essential testing or encouraging add-on testing to reduce tube use.

The Royal College of Pathologists said that extending the interval between tests may help conserve tube stocks.



### What's the effect on GPs?

Martin Marshall, chair of the RCGP, said the shortage was frustrating for GPs who were unable to deliver tests and had to explain the delay to patients. "Although some blood tests that are considered less urgent are being postponed, they are still necessary to the health of patients; otherwise, GPs would not have organised them in the first place," he said.

Graham Jackson, a GP and senior clinical adviser at the NHS Confederation, said GPs had reportedly received abuse from anxious patients. "Thousands of appointments will be cancelled, adding additional burden to a workforce already under significant pressure," he said.



### What about hospitals?

Vishal Sharma, chair of the BMA's Consultants Committee, said he was shocked the shortage had been allowed to develop, particularly the over-reliance on one source and the lack of a reserve supply. He warned, "If we don't get on top of this shortage—and quickly—then we could very easily end up in a catastrophic position."

Abi Rimmer, *The BMJ*  
Cite this as: *BMJ* 2021;374:n2174

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# Is the NHS able to deliver its GP data extraction scheme?

With the flagship programme facing further delays, **Helen Macdonald** examines what it is trying to achieve and the concerns surrounding it



**The public and GPs can be assured data collection will only begin once NHS Digital's TRE has been fully developed**

Simon Bolton



**What matters is that the purpose of the data use is clear and that it is clearly for public benefit**

Cathie Sudlow

**L**aunch of the GP Data for Planning and Research (GPDPR) programme—initially set for 1 July and then pushed back to 1 September—has been further delayed with no fixed start date. NHS Digital said that data collection will begin only when three criteria are met: that patients can opt in and out, with previously held data being deleted; that a trusted research environment (TRE) is available; and that there has been a thorough campaign to engage, communicate, and make people aware of the programme.

## ? What is new about GPDPR?

The programme plans to upload the medical codes from the electronic health records of around 55 million patients in England into an improved national, routine database to support services, planning, and research. NHS Digital already operates the GP extraction service that is linked to how practices are paid. During the pandemic this service was altered and expanded for covid related work. GPDPR is an evolution of these projects rather than a totally new programme. The project is not linked to 2014's care.data scheme, which saw plans to extract GP patient data into a central database abandoned after complaints about confidentiality and business use.

Several other routine datasets based on primary care records already exist in England, including Clinical Practice Research Datalink and QResearch, but these do not provide national coverage. Routine datasets derived from universal healthcare systems are particularly valuable to the international research community. Scandinavian countries are known for such datasets. Their populations are relatively small, however, and can lack diversity in comparison with England.

## ? What are the concerns about privacy and security?

Coding of diagnoses, tests, treatments, and referrals will be extracted rather than free text notes. These codes will include diagnoses, symptoms, observations, test results, drugs, allergies, immunisations, referrals and recalls, and appointments, including information about people's physical, mental, and sexual health. It includes coding on sensitive topics such as sexually transmitted infections (STIs) and coding concerning health related consequences of domestic violence.

Natalie Banner, who leads Understanding Patient Data, an initiative run by the Wellcome Trust, explained that understanding what the public expects from programmes such as GPDPR is challenging because most people don't know that the data from their healthcare records can be used for purposes beyond their care. "People want to know the data is being secured and handled safely and, as far as possible, that it's not easy to identify individuals—recognising, of course, that truly anonymising data might not be possible or it might make the data not that useful for research," she said.

Data will be pseudo-anonymised, which means that NHS number, date of birth, and full postcode are replaced by other codes before the data are shared with NHS Digital. But there are concerns that this is not enough. Groups such as the UK Health Data Research Alliance (UKHDRA) and Understanding Patient Data have argued that it is both feasible and desirable to protect privacy to a greater extent in GPDPR through a TRE.

## ? What is a TRE, and is it the answer?

TREs—a relatively new and evolving concept—are secure spaces where researchers can access sensitive data.

Last year UKHDRA published a green paper on TREs that included the "five safes" it deemed necessary to protect patients' privacy. These were to provide approved researchers (safe people) with an approved project (safe project) access to the data needed, which is de-identified (safe data) and provided within a secure environment (safe setting) to generate outputs without disclosing a person's identity (safe outputs). Broadly this means that trained researchers with a clear and important research question come to the de-identified data (rather than downloading it to other locations). Only necessary data are visible to them, and their work is recorded to discourage researchers straying beyond their remit.

When announcing the latest delay to GPDPR in July, NHS Digital's interim chief executive, Simon Bolton, said, "The public and GPs can be assured data collection will only begin once NHS Digital's TRE has been fully developed, in line with best practice, including projects like OpenSAFELY and the Office for National Statistics' Secure Research Service, and to the satisfaction of the BMA, the Royal College of GPs, and the National Data Guardian."

Cathie Sudlow, director of the BHF Data Science Centre at Health Data Research UK, has been involved in a project to develop a TRE for use during the pandemic. Although supportive of research in TREs, she said, "There are good arguments for retaining a data export or dissemination solution for particular purposes, especially where there is individual level consent for this or when the research would be impossible using the TRE model."

She added. "Good examples are large data and sample resources like UK Biobank, which has both consent from all 500 000 participants and rigorous and robust data access procedures of its own, with a substantial track record of sharing de-identified data with an increasing community of researchers globally. UK Biobank is a massive, highly specialised dataset that NHS Digital couldn't handle within its TRE now or at any time in the future—neither would that be an appropriate thing for NHS Digital to do."

## ? Who should be able to access the data and for what purpose?

NHS Digital will conduct its own work using the data—for example to produce national statistics. Third parties such as government departments and research organisations can also apply for access. Studies have shown that members of the public have concerns about commercial access to data that are not unique to this scheme. Currently there are costs attached to accessing the data, and this has given the impression that data are being sold.

“There are challenging questions around commercial involvement of what it means to charge,” Banner said. “When you say ‘sell data’ it suggests that data are being given over to a third party and then you have no further control or say what happens to it. That’s not the case, and I think the narrative around the selling of data can be a bit misleading.”

But she added, “People don’t want to see the NHS being exploited. Something we’ve heard when speaking to the public is the only thing worse than selling data is giving it away free.”

Sudlow said, “What matters is that the purpose of the data use is clear and that it is clearly for public benefit.” She also emphasised the importance of transparency in “who is using health data for what purposes (through clear and accessible data use registers), in what way each use will benefit the public, and how data use and access decisions are made.

“NHS Digital has robust processes already in place for all of this, but the clarity and transparency part definitely needs improvement,” she said.

Banner said her work showed there was appetite among the public for information about “what’s happening to this data, how it’s being used, who it’s benefiting, and who’s making decisions about it.” She said, “Ideally, there should be a level of public involvement in those mechanisms of governance and accountability.”

NHS Digital said data will not be used for insurance or marketing purposes and that requests for access will be assessed by its Independent Group Advising on the Release of Data. Under the proposals, commercial organisations such as drug companies can apply to use GP data—for

**NHS Digital said that patients being able to remove their entire record at any stage is a criterion to be met before extraction**

example, to assess outcomes for trials of their products or to monitor for longer term or rarer outcomes after drugs are approved for market access.

## ? What’s the situation with opting in, opting out, and deleting data?

There has been confusion about how patients can opt out, whether there is a deadline for doing so, and whether—if they do opt out—their entire record (or just new records) can be deleted. When announcing the delay, NHS Digital said that patients being able to remove their entire record at any stage is a criterion to be met before extraction.

Service planners and researchers will hope this control will mean that fewer people will opt out.

Banner said it was important to provide information on the impact of choosing to opt out. “Opting out won’t affect your individual care, but if a lot of people choose a type 1 opt out and prevent data leaving the GP surgery then at a wide population scale that’s going to have an impact on the NHS’s ability to plan services,” she said. “That hasn’t come through in the narrative so far.”

Missing data, including those on conditions that might be considered sensitive, such as STIs, or the absence of data from particular communities, will compromise the quality and inclusiveness of service design and research, Sudlow said. “Research uses of data without the need for people to actively engage in studies—through answering questions, providing samples, and so on—provides the opportunity for studies to be far more inclusive and representative of—and so relevant to—the entire population,” she said. “This would include those with health conditions such as mental health disorders and STIs or from

ethnic minority or socioeconomically disadvantaged backgrounds, and those with the poorest health, who have been under-represented to date in most types of research studies.”

## ? How will communication and understanding be improved?

NHS Digital has promised to initiate an engagement and communications campaign with the profession and the public to ensure they are aware and understand what is being planned, can make informed choices, and can input into the programme.

Banner emphasised the importance of proactive and accessible communication. “There’s a lot to do to build public confidence, but this is not just a problem for NHS Digital to fix,” she said. “Unless you take a whole system approach, you’re going to miss the opportunity to articulate what the potential benefits are of being able to use data for purposes beyond care, but also to be clear about the risks and what it takes to use this data well.”

Sudlow said the scheme had the potential to be “transformational” for researchers by giving wider access to “richer, more diverse data” on many conditions such as diabetes, mental health disorders, and long covid. “It will save and improve millions of lives,” she said.

But she expressed concern that the government and NHS bodies “may lapse into ‘long grass’ mode or become distracted by other priorities so that several months delay turns into several years. Given the potential for substantial public health benefit, that would be a disastrous outcome, resulting in several more years of unnecessary morbidity and mortality.”

Helen Macdonald, *The BMJ*  
Cite this as: *BMJ* 2021;374:n2170

**There’s a lot to do to build public confidence, but this is not just a problem for NHS Digital to fix** Natalie Banner





MARTIN POPE/SOPA IMAGES/SHUTTERSTOCK

## THE BIG PICTURE

# Anger greets new Texas abortion law

Several thousand people rally at the State Capitol in Austin, Texas, on 1 September to protest against or, in some cases (above), to support a bill that severely restricts access to legal abortions in the state.

The law outlaws abortion procedures after detection of a heartbeat, generally six weeks after conception or about the time a woman is aware of a pregnancy. There is no exception for rape or incest, although abortion in certain medical emergencies is permitted.

The US Supreme Court refused to block Senate Bill 8 (SB 8) despite appeals from reproductive and civil rights organisations, and clinics. Its 5-4 decision was condemned by President Joe Biden, Vice President Kamala Harris, and medical organisations, who described it as a direct attack on medical practice and women's rights.

The law is unusual in that it will not be enforced by state authorities but by private citizens. Any person can file a lawsuit against anyone who provides or "aids or abets" an abortion, including a clinic receptionist, anyone who drives a woman to an appointment, and many others. If the person who files the lawsuit wins the case, they will be rewarded by \$10 000 (£7 000) paid by the defendant—the abortion provider or anyone assisting the woman. The woman herself would not face a penalty.

Janice Hopkins Tanne, New York

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BOB DAEMMICH/ZUMA/ALAMY

Allowing dying people legal access to medical help to die has broad support from the UK public, but politicians—and doctors—are divided. Many medical organisations have no stance, but the BMA and RCGP oppose legalisation, **Jo Best** reports (p 308).

**Richard Hurley**, **Tessa Richards**, and **Fiona Godlee** (p 304) say change is inevitable and call on all doctors to engage with the debate and for their representatives to take a neutral stance. For religious doctors who struggle with the idea, faith leaders **George Carey** and **Jonathan Romain** (p 305) offer reassurance that nothing in scripture directly prohibits assisting a death to end suffering. Proponents of assisted dying often cite patient autonomy. But **Ole Hartling** asks whether patients can make truly autonomous decisions to end their lives. Evidence is vital, before and after assisted dying becomes legal; **Jacky Davis**, and **Katherine Sleeman** and **Gareth Owen** (p 318) call for urgent research

## EDITORIAL

# A question of when, not if

Why doctors should now join the assisted dying debate

**W**orldwide, some 200 million adults will soon have legal access to medical help to die in specific circumstances. People in Spain,<sup>1</sup> New Zealand,<sup>2</sup> and Tasmania and Western Australia are joining those in Canada, Switzerland, Belgium, Luxembourg, the Netherlands, Colombia, 11 US jurisdictions, and Victoria and South Australia in being permitted access to the option.<sup>3</sup>

An assisted dying law is expected to be proposed in the Scottish parliament this year,<sup>4</sup> and the UK parliament is considering a bill that would permit doctors in England and Wales to prescribe lethal doses of drugs for dying patients to take themselves. Two independent doctors would have to agree that an adult had less than six months to live, had mental capacity, and had been informed of all care options.<sup>5</sup> High Court approval would be needed.

Currently, about 50 British citizens a year seek help to die in Switzerland.<sup>7</sup> Robust data are lacking, but 14% of suicides are among people whose death certificates record cancer or neurological, respiratory, or heart disease as a contributory cause.<sup>8</sup> Some people ask loved ones or doctors to help.<sup>9</sup> Those who agree risk investigation and, in rare cases, prosecution.

The UK public is consistently sympathetic to assisted dying for terminally ill people, with representative polls finding 73% support in 2021,<sup>10</sup> 84% in 2019, and 82% in 2015.<sup>11</sup> The 2019 poll found support at a similarly high level among religious people and people with long term conditions or disability. MPs have not reflected their constituents' support, however: a 2015 bill was defeated 330 to 118.<sup>12</sup> A recent poll found only 35% support among MPs.<sup>10</sup>

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**The UK public is consistently sympathetic to assisted dying for terminally ill people**

## Engaged neutrality

Doctors' views on assisted dying are split, and most doctors' organisations take no position on the issue; a few—including the BMA—oppose legalisation.<sup>13</sup> Their stance matters: lawmakers and judges regularly seek, and listen to, their views. *The BMJ* has called for the professions' representatives to take a position of neutrality—neither in support nor opposition—on the grounds that doctors should not obstruct a decision that is for society and parliament to make.<sup>14</sup>

Engaged neutrality is far from an abdication of responsibility. It honours the diversity in professionals' opinion. We believe that it also enables organisations to facilitate and fully engage with much needed societal conversations about death and what it means to die well.

Neutral organisations can be closely involved in drafting laws and guidelines, which would be impossible if they opposed their existence.<sup>15</sup> They can lobby for the interests of doctors who do not wish to participate, as well as of doctors who do.<sup>16</sup>

Perhaps many UK doctors see assisted dying as irrelevant to their practice: just 19% participated in the BMA's landmark membership survey on the issue last year. Of those who responded, 40% wanted the BMA to switch to support legalised assisted dying, 21% wanted a neutral stance, and 33% said it should remain opposed.<sup>17</sup> Doctors working in palliative care were most strongly opposed, with 70% of those voting wanting the BMA's to keep its stance.

The BMA is scheduled to debate the survey at its annual meeting on 14 September, with motions calling for it to move to a neutral stance.<sup>19</sup> The Royal College of Physicians moved to a neutral position after a survey of eligible members and fellows in 2019 (just a fifth voted).<sup>20</sup> The Royal College of General Practitioners is facing legal challenge after interpreting its split 2019 membership survey as a mandate to continue opposition.<sup>21</sup>



### Oregon's experience

Experience elsewhere in the world suggests that assisted dying becomes less contentious once legalised.<sup>22</sup> In Oregon, where assisted dying has been legal for nearly 25 years and maintains public support, assisted dying is strictly monitored, and there are no reports that the law has been misused. In 2020, 370 people received prescriptions, a number that has steadily risen each year, and 245 took assisted dying drugs (0.7% of all deaths).<sup>25</sup> The Oregon Hospice and Palliative Care Association supports the rights of Oregonians to choose any and all legal end-of-life options, and Oregon's nurses' and medical associations are neutral on the issue.

While advocating for a change in the law in the UK, we also recognise the need for careful collection and scrutiny of data on patients' and families' experiences to ensure that safeguards are sufficient and to improve our understanding of how best to help those who choose an assisted death.

The debate has created friction between advocates for assisted dying and the palliative care community. But access to assisted dying and high quality palliative care are not mutually exclusive, as Oregon's experience has shown. There is no evidence that palliative care deteriorates if assisted dying is available.<sup>26 27</sup> Investment in palliative care is sorely needed—over 100 000 people in the UK die each year without receiving the care they need.<sup>28 29</sup> The goal must be that all patients receive the best end-of-life care aligned with their preferences.<sup>30</sup>

No professional should be obliged to participate. But doctors who oppose assisted dying should not stand in the way of colleagues who find it ethically justifiable to assist a dying patient's death. Nor should they stand in the way of terminally ill patients who reasonably ask for doctors' help to end their life.

Given public support and broad shifts in the developed world to permit assisted dying, it seems more likely a question of when, not if, for legalisation in the UK. When it comes, it is doctors who will counsel and refer patients—and assenting doctors who will do assessments and prescribe the drugs. This is an issue on which all UK doctors should now engage.

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# There is nothing holy about agony: religious people and leaders support assisted dying too

As a new faith alliance is formed, the former Archbishop of Canterbury **George Carey** and rabbi **Jonathan Romain** argue that nothing in scripture directly prohibits assisting a death to end a person's suffering

**W**e are leaders of a new religious alliance in support of doctor assisted dying (along with

Archbishop Desmond Tutu and Reverend Canon Rosie Harper). We have launched this initiative because we are concerned about the impression being conveyed that all faith groups are implacably opposed to changes in the law to help people longing to die on their own terms, without discomfort, indignity, or extreme pain. This is not the case.

A massive change is going on in religious attitudes to assisted dying (by which a person is given a prescription for life ending drugs, which they themselves then order

and take). Not least the fact that most churchgoers are in favour of assisted dying; a 2019 poll, for example, found that 84% of the British public, 82% of Christians, and about 80% of religious people overall supported assisted dying for terminally ill, mentally competent adults.

Far from being modern, the problem of having to endure a painful end to your life has long been recognised in religious circles. The Book of Ecclesiasticus, for example, which is accepted in the Roman Catholic canon and is non-canonical but esteemed for Jewish and Protestant people, even expresses the view that "Death is better than a miserable life, and eternal rest than chronic sickness" (30:17).

A key motivation for people who want to die is the desire to avoid pain. It is not just physical suffering that appals them, but a range of other situations: the humiliation (in their eyes) of failing powers; the limitation of their ability to enjoy life; their dependency on others; the lack of control over their bodily functions; the sense that they have nothing to look forward to, except ever worsening decline; and the unwelcome image of being sedated into a state of narcotic stupor in their final days, or with their bodies sprouting a forest of tubes.

Of course, many people regard such a death as a regrettable part of the natural cycle of life, to be mitigated through medical care if possible and to be endured if not. That is entirely their prerogative and must be respected. But should people who want to avoid pain and indignity in death have the right to do so? And should others have the right to prevent them making that choice about their own life?

A biblical passage that—deliberately or accidentally—may be relevant to the challenge today is the line in the Hebrew Bible and Old Testament: “There is a time to be born and a time to die” (Ecclesiastes 3.2). Notably, it does not say who chooses that time. In previous eras, theologians and leaders assumed both were pre-ordained by God and human interference was sinful, but now it can be read differently. The time to die could just as well be our decision.

Some mainstream faith leaders might claim that this is contradicted by the verse from Job: “God gives and God takes” (1:21), and we cannot usurp that prerogative. Yet the God barrier has long been pushed aside both at the beginning and end of life, with humans acting in lieu of God, whether by doctors’ efforts to create life using test tubes or to postpone death through heart transplants.

If the religious ideal is to imitate God’s ways, then it is our duty to use our God given abilities as much as possible. We could argue, therefore, that assisted dying is part of the constant act of playing God in the sense that God wants us to help people in distress: to heal where possible, to comfort when needed, and to help let go of life when desired—this is what being religious means.

Belief in the sanctity of life—in other words, how precious it is—does not mean believing in the sanctity of suffering or disregarding steps to avoid it. There is nothing holy about agony. If terminally ill people do not want to live out their last few months in pain, for what purpose should they be forced to do so, and in whose interest is that life being prolonged?

One concern, though, is that the right to opt for assisted dying might have a deleterious effect on others, especially people in a similar position who do not want to end their life. Might they feel pressured to do so?

## The God barrier has been pushed aside, with humans acting in lieu of God, by creating life using test tubes or postponing death through transplants

The legislation to permit assisted dying currently proposed in parliament by Molly Meacher, who chairs the Dignity in Dying campaign, replicates the 2015 Marris-Falconer Bill and is based on the law in the US state of Oregon, where assisted dying has been legal since 1997. It includes several safeguards that should allay any fears. It stipulates that its provisions would apply only to an adult who is terminally ill (defined as with six months or less to live), mentally competent, fully informed of all options, and making a settled request of their own free will in writing. Two independent doctors would have to approve a request, and a High Court judge would have to approve it.

As a result of the experience in Oregon, we are in the fortunate position of knowing in advance what the likely effects of permitting assisted dying will be. The Oregon Death with Dignity Act has remained tightly controlled and has provided choice and reassurance to dying Oregonians. Of the 370 people who received a prescription for assistance to die in 2020, only two thirds (245) took the drugs, comprising a total of 0.7% of all deaths in the state.

This figure has increased steadily over 20 years and is not shooting up. This indicates that many people want to have the emotional safety net of knowing they can resort to getting help to die if their situation makes life intolerable, but never find they reach that stage. Those who do take the option tend to be people who are used to controlling the course of their life and want to determine the nature of their end too. This may not be everyone’s choice, but why should some be denied it because others do not want it?

**M**odern Britain faces two challenges in relation to assisted dying: the one that medical and legal professions face and the one that churches, synagogues, and other establishments of faith must confront.

The challenge facing medicine and law is the area of consent—a crucial factor. Individual autonomy is a major principle in treating other people with serious medical conditions. *Whose Life is it Anyway?* was a major film starring Richard Dreyfuss about a successful sculptor who has a car crash that leaves him a paraplegic. In the four decades since the film’s release, the right to die has been explored over and over again. Yet many people have been forced to choose the option of going to another country to end their lives according to their own wishes.

**Informed consent entails considering the interests of the dying person as well as those of society**



Informed consent entails considering the interests of the dying person as well as those of society. There are still implications from the 2014 Supreme Court judgment on the case of Tony Nicklinson, who was paralysed from the neck down after a stroke and wanted help to end his life but was denied permission. David Neuberger, former president of the Supreme Court, pointed out the legal asymmetry between the legality of permission to switch off a life support machine and the illegality of allowing certain drugs to be taken by a dying person.

Of course, on the same moral grounds that dying people should be allowed to choose their end, it would be outrageous if doctors were given no choice about taking part. The current bill states that professionals with conscientious objection for religious or other reasons would have no obligation to be involved.

And what of those of us whose lives are shaped by our beliefs? The challenges posed by people dying in pain have led to substantial developments in the religious world. Although many Christian and Jewish clergy—especially those in the highest ranks of the hierarchy—hold to the traditional opposition to assisted dying, a growing number of ministers now favour it.

**R**eligious opposition to assisted dying is not uniform. Certain faiths are undoubtedly opposed, such as Roman Catholicism, Anglicanism (as far as the highest ranking clergy are concerned, with all 26 Lords Spiritual following Canterbury's line), Jewish Orthodoxy, and Muslim sects. But Liberal Judaism and Unitarians back the bill, as do the chief executives of the think tank Ekklesia and the liberal Christian society the Modern Church.

But people ask why there has been such strong opposition to assisted dying by some religious groups. Strangely, it is not largely on theological grounds, because there is nothing in our bibles or prayer books that directly mentions this matter. The principal reason is the threat to vulnerable people—an unintended slippery slope if unscrupulous people try to bend the law. That has not been the case in Oregon and should not be so in the UK as we take steps to legalise assisted dying.

The Religious Alliance for Dignity in Dying is composed primarily of Anglican leaders, but a wide range of other denominations are represented—Methodist, Baptist, Congregationalist, Unitarian—along with Reform and Liberal rabbis. We offer an alternative view and show that there can be religious reasons for it.

We may have different beliefs but are one in affirming that dogma is there to serve, not to dictate. There is nothing in our religious texts that

opposes tender care at the point of death, to help those people who need it to take medication to end their lives. And, sadly, religious opposition to medical science has hindered a closer relationship between faith and science for centuries. In areas such as obstetric anaesthesia, birth control, stem cell research, and more recently mitochondrial replacement therapy, the response has been fearful and negative. We can surely do better than that.

Our alliance seeks to do more; we want to provide guidelines for the pastoral care of individuals and their families before and after death and to develop rituals for people undergoing the process of assisted dying.

## We want to provide guidelines for the pastoral care of individuals and their families before and after death

Attitudes are changing among the laity too. Poll after poll has shown that most of the population support assisted dying. What about parliament? The House of Lords has supported assisted dying in recent years by comfortable margins. But the bill introduced into the House of Commons in 2015 by Rob Marris failed to get support, largely because a new House was not ready to legislate on such a controversial social matter. There is a new mood in the House, however, and members of parliament have been moved by the cases of people like Debbie Purdy and Noel Conway and seem ready now to change sides in view of the overwhelming public support.

Clergy who oppose assisted dying have a right to their opinions, but they do not speak for all believers. There is not a monolithic religious view but a diversity of views, with a considerable number sympathetic to it. In a recent poll, over half of religious people said that religious leaders should not have campaigned against the assisted dying bill that was debated in parliament in 2015; only a fifth (22%) said that they should have.

This is undoubtedly difficult territory, but it is religiously appropriate to try to navigate it. The right to live your life to the very end does not imply the religious obligation to do so, especially if that end is a travesty of that person's life and everything that has gone before. If there is a right to die well—or at least to die as well as possible—it means having the option of assisted dying, regardless of whether it is taken up. That, surely, is a truly compassionate and very religious response.

Jonathan Romain, rabbi, Maidenhead Synagogue, and vice chair, Dignity in Dying

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## BIOGRAPHIES



Rabbi, writer, and broadcaster, Jonathan Romain is minister of Maidenhead Synagogue. He is visiting chaplain to several hospitals and hospices in Berkshire and Buckinghamshire. As vice chair of Dignity in Dying, he founded the Religious Alliance for clergy and laity of all faiths who wish to express their support for assisted dying to be legalised in the UK



George Carey was Archbishop of Canterbury from 1991 to 2002. In retirement, he continues to be involved in areas of development and inter-faith matters. His views on assisted dying changed through contact with those going through end-of-life crises

# Doctors' organisations, neutrality, and the assisted dying debate

Some doctors say that neutrality is the best way for organisations such as the BMA to represent members' diverse views on legalising medical help to die, while others say that it indicates tacit support and can mask strong objections. **Jo Best** reports

**O**n 14 September the BMA will debate motions on doctor assisted dying, including calls for the association to change its stance opposing legalisation to one of neutrality. A membership survey last year found diverse views: 40% of respondents said that the BMA should support legalisation, 33% said that it should remain opposed, and 21% wanted it to take a neutral stance.

Such surveys among healthcare professionals often find broad splits. Adopting a position of "considered neutrality," like the Royal College of Physicians and the Royal College of Nursing (table), avoids committing to a single stance shared only by a minority of members.

David Nicholl, consultant neurologist and supporter of the Dignity in Dying campaign for assisted dying, told *The BMJ*, "There's a lobby of doctors on both sides of the argument: a lot of people are very pro or very anti, but I don't think it's healthy for organisations to be strongly one way or the other. Decisions can get made by a very small number of people who may not necessarily be representative of the organisation as a whole."

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## "Neutral" or "no position"?

The UK healthcare bodies that replied to questions from *The BMJ* had a current stance of opposition, neutrality, or no position (table). "Neutral" or "no position" may seem similar, but organisations with no position tend not to canvass members' opinions, publish research or policies, or contribute to discussions on proposed legislative changes to permit assisted dying. "Neutral" bodies, however, may do all of these things.

One argument proposed for neutrality is that it should be society in general, through parliament, that debates and decides whether to change the law, rather than the medical profession acting as arbiter. The public has shown consistent support for legalisation.

Neutral organisations say that they can better reflect the spectrum of opinion held by their membership and remain inclusive of individual doctors who hold their own views and campaign accordingly. They argue that neutrality allows them to stay out of campaigning for or against legalisation while being able to facilitate debate and provide medical input to proposed legislation, they argue. Some UK palliative care doctors have said that their association's opposition has been a factor in stifling debate on assisted dying in the specialty.

Should a law pass, neutral bodies believe they could better

## DEFINITIONS UNDER DISPUTE

Proponents and opponents of assisted dying do not all agree on the terminology used to describe the process

### ASSISTED DYING

Proponents of Molly Meacher's 2021 Assisted Dying Bill in England and Wales argue that this term best describes prescribing life ending drugs for terminally ill, mentally competent adults to administer themselves within strict legal safeguards. Assisted dying, as defined like this, is legal and regulated in the US states of California, Colorado, Hawaii, Maine, Montana, New Jersey, New Mexico, Oregon, Vermont, and Washington, as well as in Washington, DC. Similar legislation has passed in New Zealand and the Australian states of South Australia, Tasmania, Victoria, and Western Australia.



**It's not healthy for organisations to be strongly one way or the other**  
David Nicholl



**Doctors who participate are more likely to require support**  
Michael Gannon



**If you expect doctors to do something, they can't be neutral**  
Ilora Finlay

represent the views of people who wish to take part in doctor assisted dying and those who don't, including advocating for the rights of conscientious objectors. The Canadian Medical Association has said that being neutral allowed it to "lead national discussions and to give evidence before Canada's Supreme Court" regarding the country's legalisation of assisted dying and voluntary euthanasia in 2016.

Some bodies that oppose assisted dying also purport to support all members. Even though four Australian states have legalised assisted dying, the Australian Medical Association opposes such moves—but it also "recognises there are divergent views within the medical profession and the broader community" and "acknowledges that laws in relation to euthanasia and physician assisted suicide are ultimately a matter for society and government."

The association's former president Michael Gannon said in 2017, "We have not and will not describe doctors who support or participate in euthanasia or physician assisted suicide as unethical . . . doctors who participate in euthanasia or physician assisted suicide are more likely to require the industrial, professional, medicolegal, and pastoral support of organisations like the Australian Medical Association."



## ASSISTED SUICIDE

This term is often intended to describe giving assistance to die to people with long term progressive conditions and other people who are not dying, in addition to patients with a terminal illness. The drugs are self-administered. Assisted suicide, as defined like this, is permitted in Switzerland. Some opponents of assisted dying do not accept that it is different from assisted suicide.

## VOLUNTARY EUTHANASIA

This term describes a doctor directly administering life ending drugs to a patient who has given consent. Voluntary euthanasia is permitted in Belgium, Luxembourg, and the Netherlands. In Canada voluntary euthanasia and assisted suicide are legalised for people with a "grievous and irremediable medical condition," in what it calls "medical assistance in dying."



## Neutrality is "not neutral"

Some opponents of legalised doctor assisted dying, however, view neutrality as anything but neutral. For a professional organisation to adopt a neutral stance on an issue is to signal that it no longer opposes it, they argue, which could be seen as tacit support for change, precipitating legalisation. They note that in territories including the US states of Oregon and Vermont the legalisation of assisted dying was preceded by local medical organisations moving to a neutral stance.

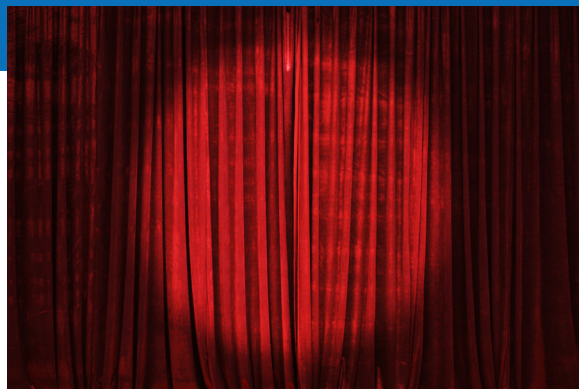
Neutrality could be seen as implying disinterest, they say, when many doctors are strongly invested in the debate, whichever side of the argument they favour. They argue that an organisation's neutral stance could, then, leave many members' views obscured or misrepresented.

Ilora Finlay, professor of palliative medicine and a crossbench peer in the UK House of Lords, told *The BMJ*, "If you're neutral about something, it may be that you don't know about it, or haven't thought it through, or because it doesn't apply to you."

"But if you expect doctors to do something, they can't be neutral about it. A majority who look after dying patients are clear that they don't want to be involved in assisting suicide and carry that responsibility for ending life. The BMA should respect their professionalism."

## Where do UK healthcare bodies stand on legalising assisted dying?

Organisation	When and how did it decide?	Does it plan to review its stance?
<b>NEUTRAL</b>		
Royal College of Physicians of London	2019, by its council after survey of UK fellows and members	Members to be resurveyed in 2024
Royal Pharmaceutical Society	2013, reviewed in 2019. Council decided after consulting an expert working group and members	Currently under review
Royal College of Nursing and Royal College of Nursing Scotland	2009, after consultation with members	Will continue to monitor any legal developments
<b>OPPOSED</b>		
BMA	2006, reaffirmed in 2016 by a 198-115 vote among delegates at its annual representative meeting (ARM)	At 2021 ARM
Royal College of General Practitioners	2020, by its council after survey of members	Will resurvey members no sooner than 2025 unless there are "significant developments"
Royal College of Surgeons of England	2015, after formal debate by the council	Is following the wider discussion including at the RCP and will consider further at council level as this develops
Association for Palliative Medicine	2015, after survey of members	Will resurvey members if any legislation is proposed that is substantially different from previous bills
<b>NO POSITION</b>		
Academy of Medical Royal Colleges	2014, reaffirmed 2019, by council that this is an issue for individual colleges and faculties and a decision for society as a whole and lawmakers	No plans
Royal College of Anaesthetists		No plans
Royal College of Psychiatrists		
Royal College of Emergency Medicine	Expects always to defer to the Academy of Medical Royal Colleges on assisted dying	
Faculty of Pharmaceutical Medicine		No plans, but continues to monitor professional and public opinion
Royal College of Paediatrics and Child Health		
Association of British Neurologists	2021, after a vote among members, who affirmed that it is for society through parliament to determine	Most policy is reviewed after 3 or 5 years
Royal Society of Medicine	Not a policy making organisation	
<b>DECLINED TO COMMENT</b>		
Royal College of Surgeons of Edinburgh		
Royal College of Physicians of Edinburgh		
Royal College of Physicians and Surgeons of Glasgow		



## ESSAY

# Euthanasia and assisted dying: the illusion of autonomy

**Ole Hartling** questions whether patients can ever have complete freedom over the decision to end their lives

**A**s a medical doctor I have, with some worry, followed the assisted dying debate that regularly hits headlines in many parts of the world. The main arguments for legalisation are respecting self-determination and alleviating suffering. Since those arguments appear self-evident, my book *Euthanasia and the Ethics of a Doctor's Decisions—An Argument Against Assisted Dying* aimed to contribute to the international debate on this matter.

I found it worth while to look into the arguments for legalisation more closely, with the hope of sowing a little doubt in the minds of those who exhibit absolute certainty. This essay focuses on one point: the concept of “autonomy.” (While there are several definitions of voluntary, involuntary, and non-voluntary euthanasia as well as assisted dying, assisted suicide, and physician assisted suicide, for the purposes of brevity in this essay, I use “assisted dying” throughout.)

## BIOGRAPHY

**Ole Hartling** is a physician of over 30 years standing, doctor of medical sciences at the University of Copenhagen, professor of health promotion at the University of Roskilde, and an author and coauthor of several books and scientific articles published mainly in Scandinavia.

Between 2000 and 2007 he was a member of the Danish Council of Ethics, and its chairman for five years. During this time, the council extensively debated the ethics of euthanasia and assisted dying.



## Self-determination

Currently, in richer countries, arguments for legalising assisted dying frequently refer to the right to self-determination—or autonomy and free will. Our ability to self-determine seems to be unlimited and our right to it inviolable. The public's response to opinion poll questions on assisted dying show that people can scarcely imagine not being able to make up their own minds, nor can they imagine not having the choice. Moreover, a healthy person answering a poll may have difficulty imagining being in a predicament where they simply would not wish to be given the choice.

I question whether self-determination is genuinely possible when choosing your own death. In my book, I explain that the choice will always be made in the context of a non-autonomous assessment of your quality of life—that is, an assessment outside your control.

All essential decisions that we make are made in relation to other people. Our decisions are affected by other people, and they affect other people. Although healthy people find it difficult to imagine themselves in situations where they do not decide freely, it is also true that all of us are vulnerable and dependent on others.

Yet autonomy in relation to assisted dying is often viewed in the same way as our fundamental right to choose our own course in life. If we are able to control our lives, then surely we can also control our death. Autonomy with respect to your own death, however, is already halved: you can choose to die if you don't want to live, but you cannot choose to live if you are about to die.

Decisions about your own death are not made in normal day-to-day contexts. The wish to die arises against a backdrop: of desperation, a feeling of hopelessness, possibly a feeling of being superfluous. Otherwise, the wish would not be there. Thus, it is under these circumstances that the right to self-determination is exercised and the decision is made. Such a situation is a fragile basis for autonomy and an even more fragile basis for decision making. The choice regarding your own death is therefore completely different from

most other choices usually associated with the concept of autonomy.

Here are just some of the critical matters that would arise if assisted dying were legalised.

## A duty to die

The possibility of choosing to die would inhabit everyone's consciousness—the patient, the doctor, the relatives, and the care staff—even if not formulated as an out-and-out offer. But if a law on assisted dying gives the patient a right to die,

**The wish to die arises against a backdrop: of desperation, of hopelessness, a feeling of being superfluous**

that right may turn into a duty to die. To illustrate, the American Oregon Public Health Division report from 2019 shows that in 1998 (when the law was introduced), 12% of patients in hospitals and care homes reported feeling like a burden on their relatives. One year later this figure had risen to 26%. In 2018 this figure had risen further to 64%. How autonomously can the weakest people act when the world around them deems their ill, dependent, and pained quality of life as beyond recovery?

Patients can find themselves directly or indirectly under duress to choose that option if they consider themselves sufficiently pained and their quality of life sufficiently low. Patients must be at liberty to choose assisted dying freely, of course—that is how it is presented—but the point is that the patient cannot get out of having to choose. It has been called the “prison of freedom.”

## Internalised external pressure

Pressure on the patient does not have to be direct or articulated. As pointed out by the US professor of biomedical ethics Daniel Sulmasy it may exist as an “internalised external pressure.” Likewise, the French bioethicist Emmanuel Hirsch states that individual autonomy can be an



illusion. The theologian Nigel Biggar quotes Hirsch saying that a patient “may truly want to die, but this desire is not the fruit of his freedom alone, it may be—and most often is—the translation of the attitude of those around him, if not of society as a whole which no longer believes in the value of his life and signals this to him in all sorts of ways. Here we have a supreme paradox: someone is cast out of the land of the living and then thinks that he, personally, wants to die.”

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## The end of autonomy

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An inherent problem of autonomy in connection with assisted dying is that a person who uses his or her presumed right to self-determination to choose death definitively precludes himself or herself from deciding or choosing anything. Where death is concerned, your right to self-determination can be exerted only by disposing of it for good. By your autonomy, in other words, you opt to no longer have autonomy. And those around must respect the right to self-determination. The respect refers to a person who is respected, but this is precisely the person who disappears.

In my book I quote the Danish philosopher Johannes Sløk, who supported legalisation but said, “The actual concept of death has no content, for death is the same as nothing, and one cannot choose between life and nothing. Rather, therefore, one must speak of opting out; one opts out of life, without thereby choosing anything else. Death is not ‘something other’ than life; it is the cessation or annihilation of life.”

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## Autocracy

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Autonomy is a consistent principle running through the care and management of patients and is enshrined in law. However, a patient’s autonomy means that he or she has the right to decline any treatment. It does not entail a right to have any treatment the patient might wish for. Patients do not have the right

to demand treatment that signifies another’s duty to fulfil that right. If that were so, autonomy would be the same as “autocracy”—rule of the self over others. Even though patients have the right to reject any intervention, they do not have the right to demand any intervention. Rejecting any claim that the person might make is not a violation of a patient’s self-determination—for example, there may be sound medical reasons for not complying with a demand. The doctor also has autonomy, allowing him or her to say no. Refusing to kill a person or assist in killing cannot be a violation of that person’s autonomy.

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## The killing ban

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Assisted dying requires the doctor’s moral and physical help. It is a binding agreement between two people: the one who is to be killed and the one who is to kill or assist in killing. But our society does not condone killing as a relationship between two legally competent, consenting people. Exemptions from the killing ban involve war or self-defence and are not justified on the grounds that the killing is done for the “benefit” of someone else.

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## Valuation of a life

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If the action is to be decriminalised, as some people wish, it means the doctor will have to enter into deliberations and arguments for and against a request for assisted dying each time. That is, whether he or she is willing to grant it. The alternative would be to refer the patient to another doctor who might be willing to help—that doctor would still have to assess whether the patient’s life was worth preserving.

Thus, autonomy is not the only factor or even always the key factor when deciding whether assisted dying can be granted. It is not only the patient’s own evaluation that is crucial. The value of the patient’s life must also be assessed as sufficiently low. This demonstrates the limitation of the patient’s self-determination.

## Why should we not perform assisted dying on people who are not in a position to ask for it themselves but are also suffering?

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### Relieving suffering

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If a competent and legally capable person must have the option of voluntarily choosing assisted dying in the event of unbearable suffering, why does suffering have to be a requirement? The answer is straightforward: our concepts of assisted dying imply that compassion must form a crucial aspect of the decision—mercy killing and compassionate killing are synonyms. But this leads instantly to the question of why we should not also perform assisted dying on people who are not in a position to ask for it themselves but are also suffering.

Some people find the reasoning unproblematic. It stands to reason that relieving suffering is a duty after all. But in this context it is not unproblematic, because it effectively shifts the focus from the autonomy claimed. According to prevailing ideas about autonomy, patients initially evaluate their quality of life themselves, but ultimately it is those around them who end up gauging that quality and the value of their life. That is to say, the justification for assisted dying is borne on the premise that certain lives are not worth living rather than the presence of a request. The whole point is that in the process, respect for the right to self-determination becomes relative.

Autonomy is largely an illusion in the case of assisted dying. A patient overwhelmed by suffering may be more in need of compassion, care, and love than of a kind offer to help end his or her life. It is not a question of whether people have a right to say that they are unworthy. It is a question of whether they have a right to be believed when saying it.

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**Where death is concerned, your right to self-determination can be exerted only by disposing of it for good**

# Emergency action to control global temperatures

Wealthy nations must do much more, much faster

**T**he UN General Assembly in September 2021 will bring countries together at a critical time for marshalling collective action to tackle the global environmental crisis. They will meet again at the biodiversity summit in Kunming, China, and the climate conference (COP26) in Glasgow, UK. Ahead of these pivotal meetings, we call for urgent action to keep average global temperature increases below 1.5°C, halt the destruction of nature, and protect health. Reflecting the severity of the moment, this editorial appears in health journals across the world. We are united in recognising that only fundamental and equitable changes to societies will reverse our current trajectory.

The risks to health of increases above 1.5°C are now well established.<sup>2</sup> Indeed, no temperature rise is “safe.” In the past 20 years, heat related mortality among people aged over 65 has increased by more than 50%.<sup>4</sup> Higher temperatures have brought increased dehydration and renal function loss, dermatological malignancies, tropical infections, adverse mental health outcomes, pregnancy complications, allergies, and cardiovascular and pulmonary morbidity and mortality.<sup>5,6</sup> Harms disproportionately affect the most vulnerable, including children, older populations, ethnic minorities, poorer communities, and those with underlying health problems.<sup>2,4</sup>

Encouragingly, governments, financial institutions, and businesses are setting targets to reach net-zero emissions. Many countries are aiming to protect at least 30% of the world’s land and oceans by 2030.<sup>11</sup> But these promises are yet to be matched with credible short and longer term plans to accelerate cleaner technologies and transform societies.

This insufficient action means that temperature increases are



**Urgent, society-wide changes must be made and will lead to a fairer and healthier world**

likely to be well in excess of 2°C,<sup>16</sup> a catastrophic outcome for health and environmental stability. More can and must be done now—in Glasgow and Kunming—and in the immediate years that follow.

## Equity

Equity must be at the centre of the global response. Contributing a fair share to the global effort means that reduction commitments must account for the cumulative, historical contribution each country has made to emissions, as well as its current emissions and capacity to respond. Wealthier countries will have to cut emissions more quickly, reaching net-zero emissions before 2050. Similar targets and emergency action are needed for biodiversity loss and the wider destruction of the natural world.

To achieve these targets, governments must intervene to support the redesign of transport systems, cities, production and distribution of food, markets for financial investments, health systems, and much more. Global coordination is needed to ensure that the rush for cleaner technologies does not come at the cost of more environmental destruction and human exploitation.

Huge investment will be needed, beyond what is being considered or delivered anywhere in the world.

But such investments will produce huge positive health and economic outcomes, including high quality jobs, cleaner air, increased physical activity, and improved housing and diet. Better air quality alone would realise health benefits that easily offset the global costs of emissions reductions.<sup>22</sup>

Countries that have disproportionately created the environmental crisis must do more to support low and middle income countries, going beyond their outstanding commitment to provide \$100bn a year. Funding must be equally split between mitigation and adaptation, including improving the resilience of health systems.

Financing should be through grants rather than loans, building local capabilities and truly empowering communities, and should come alongside forgiving large debts, which constrain the agency of so many low income countries.

As health professionals, we must do all we can to aid the transition to a sustainable, fairer, resilient, and healthier world. We must hold global leaders to account and continue to educate others about the health risks of the crisis. We must join in the work to achieve environmentally sustainable health systems before 2040, recognising that this will mean changing clinical practice. Health institutions have already divested more than \$42bn of assets from fossil fuels; others should join them.<sup>4</sup>

The greatest threat to global public health is the continued failure of world leaders to keep the global temperature rise below 1.5°C and to restore nature. Urgent, society-wide changes must be made and will lead to a fairer and healthier world. We, as editors of health journals, call for governments and other leaders to act, marking 2021 as the year that the world finally changes course.

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