Public service union mounts legal challenge to government’s health white paper proposals

Caroline White LONDON

Unison, the UK’s largest public service union, is seeking a judicial review of the coalition government’s proposed healthcare reforms, on the grounds that the health secretary has failed to consult the public on the plans.

The move coincides with the launch of a national online petition by an independent pressure group, the NHS Support Federation, which believes that the government’s proposals will result in the break-up of the NHS. These protests signal the start of a concerted union campaign to try to derail the plans.

Unison, which has 1.3 million members, contends that NHS chief executive David Nicholson’s instruction to all NHS chiefs to start implementing “immediately” the proposals outlined in the white paper Equity and Excellence: Liberating the NHS the day after publication was unlawful.

The union says that the proposals would bring about “the most fundamental changes to the way the NHS operates since it was created,” arguing that these should not be implemented until the public has had a chance to consider and comment on them and citing the rights enshrined in the NHS Constitution on the need for public consultation where major changes to services are proposed.

The union says that when it challenged Professor Nicholson on this, he wrote again to NHS chief executives, advising them not to act on the white paper proposals until the consultation period had ended on 11 October.

But he also said that the consultation related to how, rather than whether, the proposals should be implemented.

“I find it incredible that the NHS chief executive would say he believes there is no legal duty on the secretary of state to consult on the merits of the proposals in the white paper,” said Karen Jennings, Unison’s head of health.

“The Department of Health’s refusal to recognise this clear and important legal duty leaves us no option but to issue legal proceedings as a matter of urgency,” she added.

In a statement issued in response to the legal challenge, which it intends to defend, a Department of Health spokesperson said that the government “is engaging fully . . . on how its proposals will be implemented.”

Professor Nicholson had written “to encourage the NHS to begin locally led consultations and take the first steps on the implementation of the White Paper, without pre-empting wider consultation,” the statement continued.

Peter Evans, director of the NHS Support Federation, said that he suspected the public had not appreciated the enormity of the impending plans or how they would be affected.

“These are structural reforms, most of which the public can’t see and find difficult to understand, but they will set the tone for the way in which healthcare decisions are made for the next 10 to 20 years.”

Chief among the group’s concerns were the lack of accountability of the proposed new GP consortia; the costs of abolishing primary care trusts and strategic health authorities; and the opportunities provided for the private sector to get an even bigger foothold in the NHS, he said.

“We are inviting doctors and the public to sign up and approach their MPs ahead of the consultation’s close,” he said.

The petition is at www.nhscampaign.org.

Cite this as: BMJ/2010;341:c4716

One in seven foundation trusts failed to submit data on complaints

Adrian O’Dowd MARGATE

NHS foundation trusts should be forced to submit data on patients’ complaints to the NHS Information Centre, as other trusts have to do, critics have said.

The call is in response to data published on 25 August by the NHS Information Centre showing that 18 of the 130 foundation trusts did not submit any information on patients’ written complaints because, unlike traditional NHS trusts, it is not mandatory for them to do so.

The centre’s new figures show that from 2008-9 to 2009-10 the number of complaints in the NHS rose 13.6% from 89 139 to 101 077, the biggest rise since annual data were first published 12 years ago.

Katherine Murphy, chief executive of the Patients Association, said, “The local communities of those trusts deserve to know how their services compare. And at a time when the new health secretary is urging the NHS to become more open and transparent it is completely unacceptable for these 18 trusts to be acting in a way completely contrary to that ethos. They should be forced to share their data.”

The 2009 complaints regulations places a requirement on all organisations providing NHS care (including foundation trusts) to produce an annual report on complaints, which contains qualitative and quantitative data and has to be made available to anyone who requests it.

A spokesperson for Monitor said that most foundation trusts (86%) had supplied complaints data and had a duty to be publicly accountable.

Cite this as: BMJ/2010;341:c4735
**Proportion of people dying in hospital is falling, report shows**

**Andrew Cole** LONDON

For the third year running, the proportion of people in England who died in hospital has fallen, while the proportion dying at home continues to creep up, according to the second annual report on the End of Life Care Strategy.

A central objective of the Department of Health’s strategy, which was launched in 2008, is to enable more people to choose where they die. At the moment most people die in hospital despite surveys showing that 56-74% would prefer to die at home.

Latest Office for National Statistics figures reveal that 55% of people died in NHS hospitals in 2008, compared with 20% in their homes, 17% in care homes, and 5% in hospices. This represents a 1.6% rise in home deaths and a drop of nearly 3% in hospital deaths since 2005.

The annual report welcomes the evidence of this “slow trend” towards more home deaths but says it now needs to be speeded up “if end of life care is to deliver its potential quality and productivity gains.”

The report also points to variations across the country in implementing the end of life care strategy, with some primary care trusts failing to spend their portion of the extra £88m (£107m; €109m; $136m) allocated to end of life care in the 2009-10 financial year.

The strategy’s own audit showed that while some trusts invested substantial sums in a range of services, others used the money to support additional posts in services that already existed, whereas others “are making very little or no investment.” So although Hampshire invested £5.4m—equivalent to 8% of the total spend nationwide—Blackburn reported no new investment at all.


Cite this as: BMJ 2010;341:c4722

**PLACE OF DEATH IN ENGLAND (% OF ALL DEATHS)**

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Sources: Department of Health, End of Life Care Strategy: Second Annual Report

**Doctors’ religious beliefs affect their views on end of life care**

**Andrew Cole** LONDON

Doctors who describe themselves as very or extremely non-religious are almost twice as likely as religious doctors to take measures to hasten the death of a dying patient, new research says. They are also more likely to discuss end-of-life options with the patient and to support legislation on assisted dying.

The research, in the *Journal of Medical Ethics* (*doi:10.1136/jme.2010.036194*), also showed that doctors in hospital specialties were 10 times more likely to take measures to hasten a patient’s death than their colleagues in palliative care.

The author, Clive Seale, of the Centre for Health Sciences at Barts and the London School of Medicine and Dentistry, says that patients may want to ask about their doctors’ religious beliefs (or atheism). “It could be relevant to what your doctor is then willing or not willing to do at the end of life,” he said. His study asked nearly 3000 UK doctors from a range of specialties involved in care at the end of life—including palliative care, care of elderly people, neurology, hospital specialties, and general practice—about the care of their last patient who died.

Doctors who were “very or extremely” non-religious were nearly twice as likely as “very or extremely” religious doctors to take decisions they expected or partly intended to end life. They were also more likely to have given continuous deep sedation until death and to have discussed end of life decisions with their patient.

Doctors in palliative care and those with strong religious faith were more strongly opposed to assisted dying.

Specialists in palliative care medicine were more likely to be Christian, to be white, and to report being very or extremely religious than those in other specialties, the survey found.

Overall 13% of doctors said they were very religious (compared with 6.5% nationally), and 20% said they were very non-religious (15% nationally).

Professor Seale said it is difficult to explain the increased

**NICE is likely to reject new bowel cancer drug**

**Caroline White** LONDON

The body that evaluates treatments for the NHS in England and Wales, the National Institute for Health and Clinical Excellence (NICE), is unlikely to recommend bevacizumab (Avastin) for patients with advanced bowel cancer, despite attempts to make it cheaper for the NHS to use.

In an interim ruling NICE has indicated it is likely to reject bevacizumab, in combination with oxaliplatin and either 5-fluoracil or capecitabine, for the treatment of metastatic bowel cancer on the grounds that the costs of the drug outweighed its clinical benefits. It has already rejected the drug in the past.

An estimated 6500 people a year would be eligible for bevacizumab, which costs around £20800 (£25 300; $32 200) for one year. However, if approved by NICE the drug would be free after the first 12 months of treatment under the terms of a patient access scheme. Roche, the drug’s manufacturer, also pledged to cover the costs of oxaliplatin, at £200 to £300 a dose.

Patient access schemes are put together by drug companies as a way to curb the costs of introducing new drugs to the NHS and are subject to approval by the Department of Health.

In 2009 the health department approved the scheme proposed by Roche for bevacizumab, but during the initial consultation on the drug it voiced concerns to NICE, suggesting that Roche’s proposed patient access scheme was overly complex and would cost more to administer than the company had suggested.

A department letter in October 2009 said, “We also have concerns, strongly reinforced by NHS colleagues, that a further consequence of the complexity of the scheme will be to limit its uptake by the NHS. Again, this is a point of which the Appraisal Committee may wish to be mindful.”

A NICE spokesperson described these comments as “quite unusual.”

As a result Roche submitted an amended patient access scheme and included an additional upfront payment to the NHS for every patient starting first line treatment with bevacizumab.

The revised proposal triggered the decision by NICE to hold a second consultation on the drug, which runs until 15 September.

The NICE spokeswoman said that evidence of the drug’s clinical effectiveness was “not definitive.” One study indicated that it could extend life by six weeks, but that this could have been a chance finding, she said.


Cite this as: BMJ 2010;341:c4728
Non-religious doctors are more likely to take decisions they expect or partly intend to end life

He also believes that doctors need to be more alert to how their religious values may affect their practice. “What this survey shows is that doctors appear to be influenced by religious and atheist beliefs in their decision making at the end of life, and it seems quite plausible that this is not an entirely conscious process.”

The BMA said that doctors’ religious beliefs should not be allowed to influence objective, patient centred decision making.

Cite this as: BMJ 2010;341:c4732

Judge halts US funding of stem cell research

Bob Roehr WASHINGTON, DC

Research and patient communities were shocked by a federal judge’s decision that all US government funding for research using embryonic stem cells is to be blocked immediately, pending the outcome of a trial into the legality of such funding.

Judge Royce Lamberth issued the decision on 23 August in Washington, DC. The next day the Obama administration said it would appeal the injunction, probably within a week.

Judge Lamberth originally ruled that the plaintiffs lacked standing to bring the lawsuit. An appeals court agreed in part but said two researchers working with adult stem cells did have standing and ordered a trial. Judge Lamberth then found that the plaintiffs were likely to win their case and issued the injunction on all government spending on such research, pending that trial.

The lawsuit highlights differences between scientists and patients who wish to use embryonic stem cells to develop medical cures and those who believe that human life begins at conception and that use of embryos to create those cell lines therefore constitutes murder.

Congress has prohibited the use of federal funds to create embryos or destroy them for research purposes in every budget since 1996. Politicians and regulators have skirted the issue by declaring a wall between the destruction of embryos to create cell lines and the subsequent use of those cell lines.

President George W Bush went further in 2001, declaring that only 21 existing embryonic cell lines qualified for federal funding and new ones would not. President Barack Obama partially reversed that policy in 2009, allowing for use of cell lines that were the product of in vitro fertilisation and were no longer needed.

Judge Lamberth said there was no wall between creating embryonic stem cell lines and their further use in research. “The plain language of the statute” was, he said, “unambiguous.”

He added that research was a continuum that could not be partitioned to avoid the intent of Congress. If one piece of the research resulted in the destruction of an embryo, then none of the downstream research that flowed from that cell line could receive federal funding, he said.

The US National Institutes of Health has spent $522m (£336m; €410m) on embryonic stem cell research since 2005, $127m this year alone. It immediately stopped all those activities.

Lisa Hughes, president of the Coalition for the Advancement of Medical Research, called the injunction “a blow to the hopes of millions of patients and their families suffering from fatal and chronic diseases and disorders.”

Cite this as: BMJ 2010;341:c4689

Experts warn against “tourist trap” stem cell therapies

Mark Pownall LONDON

Hundreds of clinics around the world are offering unproven and potentially dangerous stem cell treatments to desperate patients willing to travel thousands of miles in the hope of successful treatment.

A group of UK specialists says that patients are mortgaging their houses and raising tens of thousands of pounds from their communities to pay for stem cell treatments. They are attracted by promotional material on the internet for treatments for which there is no evidence of benefit other than patients’ testimonials. The clinics attract patients with conditions such as multiple sclerosis, Parkinson’s disease, and degenerative retinal conditions for which conventional treatments have temporary or limited effectiveness.

Tighter regulation in the European Union will be introduced in 2011 under the Advanced Tissues Directive, but such clinics are a “global issue,” said Chris Mason, professor of regenerative medicine at University College London and a member of the group.

He identified three potential sources of harm for patients: physical, psychological, and financial. “We too often forget the psychological effects that ‘stem cell tourism’ can have,” he said at a press conference. “Patients dealing with the stress of a serious condition already have to go back to their communities and explain where the £30 000 they raised to send the patient to the clinic went.” It was not surprising, he added, that in these circumstances patients reported treatment to be a success.

Physical adverse effects of unproved stem cell treatments were under-reported, he said.

He added that patients have an unrealistic sense of risk, because they believe that if clinicians are offering a treatment “there must be something in it,” even though evidence of effectiveness is lacking.

Cite this as: BMJ 2010;341:c4772

Human embryonic stem cells: hype, hope, and heartbreak

Cite this as: BMJ 2010;341:c4772
Oesophageal cancer in UK men rises by 50%: The incidence of oesophageal cancer in men has risen by 50% over the past 25 years, show new figures published by Cancer Research UK. The number of cases diagnosed was around 9.6 in every 100 000 men in 1983 and 14.4 in every 100 000 in 2007. The most dramatic rise was among men in their 50s, among whom the incidence rose by 67%. In women the incidence rose by only 8%, from 5.1 to 5.5 per 100 000 people. See http://info.cancerresearchuk.org/.

Experts urge repeal of leprosy laws: A UN panel of independent experts on human rights has urged the repeal of all laws discriminating against people with leprosy. They also called for countries to enact legislation to ensure that people affected by leprosy are not discriminated against, including in employment and health. The World Health Organization estimates that in just 25 years more than 15 million cases of leprosy have been cured, but 249 000 new cases were reported in 2008 alone.

US births fell during recession: Provisional data from the US National Center for Health Statistics show that the national number of births was 4136000 in 2009, a fall of 2.6% from 2008. The fertility rate (live births per 1000 women aged 15–44) fell from 68.4 in 2008 to 66.8 in 2009. Births fell in all age groups except women aged 40 years or older.

NICE agrees new drugs for rheumatoid arthritis: The UK National Institute for Health and Clinical Excellence has recommended that patients with severe rheumatoid arthritis who cannot take rituximab or have found that it doesn’t work can take tocilizumab plus methotrexate instead. It has also recommended rituximab, adalimumab, etanercept, infliximab, and abatacept, in certain circumstances, as possible treatments for rheumatoid arthritis after treatment with a tumour necrosis factor inhibitor has failed. (See http://guidance.nice.org.uk/)

Ugandan drugs are sold across border: Large quantities of drugs stolen from Ugandan public health units are being sold in neighbouring Sudan and the Democratic Republic of the Congo, Uganda’s president, Yoweri Museveni, has said. He blamed unscrupulous health workers illegally reselling government drugs (BMJ 2010;341:c611).

Coding errors in NHS cause up to £1bn worth of inaccurate payments

Adrian O'Dowd MARGATE

Errors in clinical coding in England have meant that primary care trusts have made about £1bn worth of mistaken payments over the past three years, sometimes paying too little and sometimes too much.

The mistakes were spotted by the spending watchdog the Audit Commission, which published a new report on the quality of use of data in the NHS on 26 August. The commission had audited the data that underpin England’s Payment by Results system, which generates a payment per patient, depending on the treatment given, and which hospitals use to charge primary care trusts.

The commission found that accuracy of payments was improving overall in the NHS but that wide variation between the best and worst trusts persisted.

Its report shows that the average error rate in clinical coding fell from 16% to 11% in the three years since 2007, when the commission began to audit random samples of data from four specific specialties at all trusts that have them: general medicine, trauma and orthopaedics, cardiology, and paediatrics.

The commission estimated that of the £21bn paid over the three years for treatments in these specialties £1bn (about 5%) was incorrectly paid because of wrong data. The commission also looked at over £200m worth of payments...
Fertility regulator seeks views on donation compensation

Adrian O’Dowd MARGATE

People who donate eggs or sperm for other people to be able to conceive could receive higher financial compensation after a review by the UK’s fertility regulator.

The Human Fertilisation and Embryology Authority (HFEA) has launched a review to seek opinions on whether the money paid to egg and sperm donors should be increased to deal with current shortages.

The review will also look at the number of families that donors can donate to; donation between family members; the conditions that donors can place on the use of their gametes or embryos; and the upper age limit for sperm donation.

In the UK, egg and sperm donors are not paid but can claim a maximum of £250 (€305; $385) as compensation for loss of earnings and also claim travelling expenses.

The UK has a shortage despite increasing numbers of donors because demand is growing more steeply than availability.

In 2004, there were 1676 patients treated with donors’ eggs and this fell to 1306 patients by 2008. Infertility is estimated to affect around one in six or one in seven UK couples—about 3.5 million people—at some point.

To tackle the shortage of sperm and eggs donated for in vitro fertilisation treatment, the HFEA is gathering views before it carries out a full consultation into its donation policies beginning next January.

A spokesman for the authority told the BMJ: “We are not putting a possible [new] figure on the compensation given to donors. We have not come to a figure but an increase is a possibility.”

Authority chair Lisa Jardine was quoted in the Sunday Times (22 August) as saying the authority was considering adopting the Spanish system, which would see the payment cap rise to £800.

Professor Jardine was quoted as saying: “We are suggesting moving closer to the Spanish system.”

Tony Rutherford, consultant gynaecologist at the Leeds Centre for Reproductive Medicine and chair of the British Fertility Society, the representative body for professionals practising in reproductive medicine, told the BMJ it was time to deal with the issue of compensation.

“We ourselves in Leeds have paid patients to donate eggs for research, and the ethics committee felt that a payment of £1500 was fair compensation for them going through the process without providing too much of a monetary incentive to take part.”

Mr Rutherford said another important issue was to increase awareness.

“Having information and being aware of the plight of infertile couples and what people would need to go through to egg donation is important,” he added. “We could get far more egg donors by making people more aware of that.”

Details of the review are at www.hfea.gov.uk/5605.html.

Cite this as: BMJ 2010;341:c4688

Bethlem tapestry celebrates art therapy

Lynn Eaton LONDON

Patients, carers, staff, and volunteers at the Bethlem Royal Hospital in south London have been working on a 10 metre long woven tapestry depicting their experiences and thoughts.

The initiative is the idea of the psychiatrist Sukhi Shergill, who works in the psychosis unit, and the local artist Mark McGowan, who was a patient at the hospital from 1992 to 1998 and wanted to give something back.

“I was very ill and came to the South London and Maudsley Trust in a really bad state,” said Mr McGowan. “As a patient I was given access to the arts facilities and never looked back.”

He went on to complete an art degree and now teaches at the Chelsea and Camberwell Colleges of Art and travels the world with his art projects.

“None of this would have been possible without the help and support I was given while a patient at Bethlem,” he said. “I wanted to create a special body of work that I hope lives on at the Bethlem for years to come.”

Pictured is a panel from the tapestry, showing an image created by Holly, one of the patients.

The exhibition opens on 22 September. For further details see www.bethlemgallery.com.

Cite this as: BMJ 2010;341:c4740