Statin study finds “nocebo” effect

Patients unaware that they are taking statins do not complain of muscle pains. But the same patients, once told that the drug they are taking is a statin, are much more likely to report such symptoms, shows a new Lancet analysis of data from a trial carried out more than a decade ago in the UK and Scandinavia. The result, says Peter Sever of the National Heart and Lung Institute in London, is an example of the “nocebo effect,” where patients become more likely to report adverse effects of a drug once they are aware of them. This is not the same as saying that the pains are “all in the mind,” he insisted. The pain is no more imaginary than are the improvements enjoyed by some patients who are given a placebo. But it does mean that drug regulators should hesitate before mandating warnings on drug labels, because those warnings may give rise to the side effects they describe and stop patients from taking helpful drugs.

“Neither the Medicines and Healthcare Regulatory Agency nor the US Food and Drug Administration had considered the totality of the evidence when they put warnings on statins,” he said. “They should withdraw the listing.”

When the argument over statins developed, Sever and colleagues realised that data they had gathered during the Anglo-Scandinavia Cardiac Outcomes Trial (ASCOT) could be used to test the hypothesis that knowing of the possibility of adverse events affected the chances that participants would experience them.

The trial compared atorvastatin with placebo. In the first phase, participants were blinded as to allocation, but when the trial ended early because of clear benefits of taking the statin participants were offered the chance of continuing atorvastatin.

In the blinded phase 2.03% of patients per year reported muscle related symptoms in the statin group and 2.00% in the placebo group. But in the extension, patients who took statins were 41% more likely to report muscle related symptoms than those who didn’t take them: 1.26% per year versus 1.00% per year (hazard ratio 1.41 (95% CI 1.10 to 1.79)).

Sever said, “Widespread claims of high rates of statin intolerance still prevent too many people from taking an affordable, safe, and potentially lifesaving medication.”

Cite this as: BMJ 2017;357:j2144

Peter Sever said that drug agencies should review warnings on statins in light of the new evidence
Larger practices must not sacrifice core values

GP have a “window of opportunity” to transform the way they work but should not sacrifice the values of traditional general practice to do so, a GP leader has urged.

Michelle Drage (left), chief executive of Londonwide Local Medical Committees, which represents over 7000 GPs in the capital, urged GPs to take control of their own destiny and not be distracted by “all the noise” around new models of integrated care. Speaking at the Londonwide LMCs annual conference on 27 April, Drage acknowledged the benefits to GPs of working “at scale” in federations and super partnerships and said that a growing number of practices were doing so.

Drage said that transformation of GP services should focus on connecting GPs “across boundaries” to community services, the third sector, schools, and other agencies that can influence people’s health, while retaining the valued elements of general practice such as the registered patient list and continuity of care.

“For must follow function, so let’s stop faffing around creating fake models of care. The things you do daily on the ground—that is what drives improvement and innovation. Plans in the sky just drive more plans,” she said.

Gareth Iacobucci, The BMJ/ Cite this as: BMJ 2017;357:j2109

Sexual health

GP warn on STIs and teen pregnancy

Years of improvement in sexual and reproductive health could be reversed unless the bureaucratic, financial, and training barriers facing GPs are tackled, the Royal College of General Practitioners warned.

Its chair, Helen Stokes-Lampard, said that a consultation with members had highlighted the difficulties faced by GPs and their teams from cuts to funding and to services such as specialist clinics. Examples included patients in rural areas having problems accessing sexual and reproductive health services, as well as younger patients relying on their parents for transport.

PrEP trial in Wales

The Terrence Higgins Trust welcomed the Welsh government’s decision to make pre-exposure prophylaxis (PrEP) available through a three year trial to people who need it in Wales. Sarah Fuhrmann, national director for the trust in Wales, said that the decision to make the treatment available was a “momentous step forward for Wales, where investment in HIV prevention has been patchy at best.”

Cancer Drugs Fund does not “deliver value”

The Cancer Drugs Fund has not “delivered meaningful value” to patients with cancer and may have exposed them to “toxic side effects of drugs,” an analysis found. The fund was established in England in 2010 to give patients faster access to new cancer treatments that were not available through the NHS. A study published in the Annals of Oncology reported that £1.27bn was spent through the fund on 29 drugs for 47 specific cancer indications from 2010 to 2016; but only 18 of 47 indications were supported by clinical trials that showed a statistically significant overall survival benefit.

Cuts affect pupils’ wellbeing, MPs warn

Financial pressures are restricting provision of mental health services in schools and colleges and affect pupils’ wellbeing, a report from MPs found. As part of a joint inquiry into mental health in children and young people, the parliamentary health and education committees found that more education providers are being forced to cut back on mental health services, such as in-school counsellors, despite growing prevalence of mental ill health in children and young people. The committees urged the next government to review the effect of the budget reductions.

Mental health

Alcohol

Industry floated advertising rules during Euro 2016

Some type of alcohol advertising appeared once every other minute in every televised match during the Euro 2016 football championships in three countries—the UK, France, and Ireland—despite it being illegal in France, where the tournament was held. Most of the marketing was at the pitch side. The findings of a new report “show that alcohol companies are following in the footsteps of their tobacco colleagues by bending the rules on marketing restrictions, putting children’s health at risk,” said Katherine Brown, director of the Institute of Alcohol Studies.

General election

NHS must be an election priority, says BMA chair

The NHS needs the unrelenting focus of politicians and must not be sidelined by Brexit in the upcoming general election, said Mark Porter, the BMA’s chair of council. In its manifesto for the 8 June election the BMA also urged all political parties to commit to a long term funding solution for the NHS by increasing health spending from 9.8% to 10.4% of UK gross domestic product, bringing it into line with other leading EU economies.

Labour pledges pay rise for all NHS staff

The Labour Party pledged to give NHS staff a pay rise if it wins the election on 8 June. It would also legislate to make the treatment available to services such as specialist clinics. Examples included patients in rural areas having problems accessing sexual and reproductive health services, as well as younger patients relying on their parents for transport.

Cancer

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**Brexit**

**DH is not prepared for Brexit talks, MPs warn**

An influential group of MPs expressed concern that the Department of Health in England has not allocated sufficient resources to playing a key role in Brexit negotiations on health and social care issues. In a new report the House of Commons health select committee said that contingency planning will be needed where Brexit will have a critical effect in health and social care—including on the workforce, reciprocal healthcare coverage between countries, medicines and devices, research, and public health.

**Research news**

**Need for urine test for cystitis is queried**

Women who consult their GP with symptoms of an uncomplicated urinary tract infection can probably be treated without a traditional urine test, researchers said in *Clinical Biology and Infection*. They found that nearly all women reporting cystitis symptoms had a bacterial infection even when nothing was detected in traditional urine testing. Bacteria were detected in 80.9% of urine samples in standard testing and in 95.9% when using a highly sensitive quantitative polymerase chain reaction test.

**Fasting diet seems no better than cutting calories**

Obese patients randomly assigned to fasting on alternate days lost no more weight after a year (6%) than those who were instructed to lose weight by reducing calorie intake (5.3%), a study in *JAMA Internal Medicine* found. Those in the fasting group ate more than prescribed on “fast” days and less than prescribed on “feast” days, while those in the daily calorie restriction group generally met their prescribed energy goals—leading the authors to conclude that “alternative day fasting may be less sustainable in the long term, compared with daily calorie restriction.”

**End of life care**

Cancer patients are denied wish to die at home

Tens of thousands of people with cancer in the UK die in hospital each year even though they would rather spend their final days at home or in a hospice, research by Macmillan Cancer Support found. Its study of 2005 people with a cancer diagnosis found that only 1% would prefer to die in hospital but that 38% do, equating to 62,000 people a year throughout the UK. The charity cited a lack of services outside hospitals, such as district nurses to support people in their homes, as a reason for the discrepancy.

Cite this as: *BMJ* 2017;357:j2137

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**AAA**

30 day mortality after endovascular repair of abdominal aortic aneurysm

was 2.3% in women and 1.4% in men (*Lancet*)

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**SIXTY SECONDS ON…**

**CANCER**

**ARE CANCERS CAUSED BY BAD LUCK OR BAD CHOICES?**

Tricky question, which is why it’s led to a long running dispute. It kicked off when two scientists from Johns Hopkins in Baltimore, Cristian Tomasetti and Bert Vogelstein, showed in a paper in *Science* that two thirds of cancer causing mutations arise from unavoidable copying errors when cells divide.

**SO ONLY A THIRD ARE PREVENTABLE?**

Not so fast. That’s what a lot of people inferred, but it’s wrong.

**WHY?**

Because it takes more than one mutation to cause cancer. Let’s assume, as the authors do, that it takes three. Two of these could be random mutations, and outside anybody’s control. But the third could be caused by an exposure, to tobacco smoke, for example. So even if you accept that most mutations are random, it doesn’t follow that most cancers are.

**GIVE ME AN EXAMPLE**

Tomasetti and Vogelstein reckon that a third of the mutations causing lung cancers are random. But only about 10% of lung cancers occur in non-smokers, so not smoking prevents about 90% of lung cancers.

**SO THEIR ESTIMATES AREN’T HELPFUL?**

They may help people who feel guilty because their children have died from cancer. The estimates show that this can happen and be nobody’s fault. The focus by campaigners about healthy lifestyles has stigmatised people unlucky enough to get cancer by implying that it’s their own fault.

**BUT SOME OF IT IS?**

Cancer Research UK has long argued that about 42% of cancers are preventable by changes in diet, the environment, and lifestyle.

**THAT’S NOT VERY DIFFERENT FROM WHAT YOU JUST SAID WAS WRONG**

True. But it isn’t a conclusion you can properly draw from Tomasetti and Vogelstein, as they have conceded in a new paper that has mollified at least some of their critics.

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Nigel Hawkes, London

Cite this as: *BMJ* 2017;357:j2084
Breast surgeon is convicted of 20 counts of unlawful wounding and wounding with intent to cause harm

The rogue breast surgeon Ian Paterson, believed to have carried out negligent or unnecessary surgery on more than 1000 women, has been convicted of 17 counts of wounding with intent to cause grievous bodily harm and three counts of unlawful wounding.

Paterson, 59, who worked mainly at Solihull Hospital in the West Midlands, sobbed quietly as the verdicts were announced at Nottingham Crown Court and faces sentencing at the end of May. The maximum sentence for wounding with intent is life imprisonment.

The charges related to just 10 of his private patients, including one man. All underwent breast surgery that, prosecutors said, “no reasonable surgeon at the time would have considered justified.” Paterson misrepresented biopsy results to patients and GPs, played on fears raised by family histories, and claimed that mastectomies were essential to prevent cancer.

But though the criminal case focused on unnecessary surgeries performed on healthy patients, most of the hundreds of civil claims against him involve insufficiently thorough mastectomies for real cancer.

Paterson specialised in “cleavage sparing” breast surgery, associated with a much higher recurrence rate than full mastectomies, and continued to practise this technique after he was told to stop, following an investigation at Heart of England NHS Trust in 2007. Eventually over 1100 of his patients would be called back for further tests and treatment.

The trust has since paid out nearly £18m in damages and costs to settle 256 claims involving Paterson’s NHS work. Spire Healthcare, which owns the private hospitals where he worked, faces hundreds of claims, but compensation is uncertain because he was not employed by Spire and because the Medical Defence Union has refused to cover him for claims lodged after

Gluten-free diet is not recommended for non-celiacs

Gluten is not associated with a risk of coronary heart disease in people without celiac disease—and restricting gluten may result in a low intake of whole grains, which are associated with cardiovascular benefits, a study in The BMJ has found.

The researchers said that promoting gluten-free diets among people without celiac disease should not be encouraged. For the study a team of US based researchers analysed data on 64 714 female and 45 303 male US health professionals with no history of coronary heart disease who completed a detailed food questionnaire in 1986 that was updated every four years until 2010. During this 26 year period, people with a gluten intake in the lowest fifth had an incidence of coronary heart disease of 352 per 100 000 person years, and those with the highest fifth of gluten intake had a rate of 277 events per 100 00 person years. After adjusting for risk factors, no significant association was found between estimated gluten intake and the risk of subsequent overall coronary heart disease. In contrast, the estimated gluten consumption was associated with a lower risk of coronary heart disease.

Zosia Kmietowicz, The BMJ
Cite this as: BMJ 2017;357:j2135
RESEARCH, p 219

Baby thought to have been shaken has rare syndrome, court finds

A baby who was thought to have been shaken by one of her parents actually has a rare syndrome that affects her blood vessels, Ehlers-Danlos syndrome type IV, a family court has heard.

Effie Stillwell was taken from her parents and placed with foster carers last September, after she collapsed, at nearly 3 months old, and was taken to hospital unresponsive and with difficulty breathing. Retinal haemorrhages and bleeding on the brain were identified, and police began a criminal investigation. But the medical evidence that emerged during the family court hearing persuaded Buckinghamshire County Council to drop its application for a care order.

The baby was “the first child with a known diagnosis of EDS IV to be the subject of
his commercial insurance coverage lapsed.

Paterson’s motives remain “obscure,” said prosecutor Julian Christopher QC at his trial, “whether to maintain his image as a busy successful surgeon in great demand and at the top of his game, whether to earn extra by doing extra operations and follow-up consultations . . . or because Mr Paterson enjoyed the responsibility that came with helping people.”

**Patient reports**

Patients said that he had the perfect bedside manner and radiated competence. “He spoke on your level,” said one, interviewed for a 2013 report compiled by Ian Kennedy, former chair of the Healthcare Commission.

But colleagues had been raising doubts about Paterson for more than 10 years when the General Medical Council suspended him in 2012.

Staff described Paterson as “arrogant,” “aggressive,” “autocratic,” and “a bully.” This had meant that he often worked in isolation, which suited his purposes, one surgeon said.

Paterson was able to keep working. Kennedy concluded, because the Heart of England Trust focused on “secrecy and containment,” rather than putting patients first, and because fellow clinicians failed to alert the GMC. Chief Superintendent Mark Payne called Paterson a “controlling bully, who played God with people’s lives so he could live a luxurious lifestyle.”

Clare Dyer, The BMJ  
Cite this as: BMJ 2017;357:j2134

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**FIVE MINUTES WITH . . .**

**Susie Perks-Baker**

The head of a programme to support women in leadership roles explains the need for single sex courses

“W

hen I was asked to take on the role of leading the Athena programme for senior female leaders in health and social care at the King’s Fund last year, my initial response was ‘no,’ because I thought the need for single gender schemes was obsolete. I then revisited the data. Global, national, and NHS data all show that—even after motherhood and part time working are taken into account—unconscious bias, ways of behaving, and organisational culture can keep women out of the top roles.

“As part of refreshing the programme, we interviewed many programme alumni to gain insight into how it helped them (or otherwise). The biggest theme was the lack of ‘psychological safety’ in the system (by which we mean health and care organisations, their regulation, and resourcing), which can be highly challenging, punitive even. This impacts an organisation’s culture, how staff get treated, and expectations of them. Though we have been trying to get away from the macho culture for a long time, the messages about being more inclusive and employing more distributed or collective, compassionate leadership have not landed everywhere. The lack of clarity around role purpose and role boundaries is also very common and complicates the issue. While there are fewer reports of racism, sexism, and bullying, these have certainly not gone away.

“The programme helps women to explore how they take up their roles at work and what the implications are for their leadership. We challenge them to consider if this might sometimes include a victim mentality or a learnt helplessness among the other, more purposeful roles they commonly enact. We also encourage them to distinguish between power and authority and identify their own sources of ‘personal power.’ It forces women to get out of their comfort zone and to reflect, which is often a deep learning experience.”

Zosia Kmiotowicz, The BMJ

Cite this as: BMJ 2017;357:j2114

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**The BMJ**  | 6 May 2017

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**EDITORIAL**

Syndrome, court finds

been shaken has rare

Baby thought to have

vascular EDS. This

related to Ehlers-Danlos

clinical presentation was

This in my opinion

would adequately

explain the presenting

clinical findings that

might otherwise point to

abuse.”

He explained that

Effie had a susceptibility

to easy bruising. She had

vascular fragility that

in other patients with

the syndrome had given

rise to bruising from

handling that would

otherwise be regarded as

normal.

Of the five other

experts, only one did

not accept that Effie’s

clinical presentation was

related to Ehlers-Danlos

syndrome type IV.

Clare Dyer, The BMJ

Cite this as: BMJ 2017;357:j2136

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Clare Dyer, The BMJ  
Cite this as: BMJ 2017;357:j2134
Workload pressure would not be a defence against clinical negligence, barrister warns

Financial and staff shortages would not be taken into account by judges, conference hears. Abi Rimmer reports

Judges considering gross negligence manslaughter prosecutions against doctors would not view a lack of NHS resources as a defence against clinical negligence, a barrister who specialises in medical law and clinical negligence has said.

At a conference on litigation against doctors at the Royal Society of Medicine, James Badenoch QC said that he was often asked whether judges would take into account “the impossible conditions in which some doctors work.”

“The answer, to be relatively frank with you, is no,” he said.

“We’ve often had discussions about whether financial constraints might be a defence against what otherwise might be called negligent failure to treat. And we have to conclude that, as yet, it would not.”

He added, “I don’t think that the limitations of finance, of staffing, of equipment, and the dreadful conditions that sometimes people in the NHS are working in has yet been considered a defence to negligent behaviour or treatment.”

Ian Barker, senior solicitor at the Medical Defence Union, said, “Should extra pressures and the impossible tasks you are being asked to do be relevant, and should that play a part in terms of culpability—yes. The Adomako ruling says that you look at all the circumstances of the case and that means you look at those pressures.”

Robert Francis, who led the public inquiry into failings at Mid Staffordshire NHS Foundation Trust, spoke to BMJ Careers about this issue.

He said that, despite increasing financial pressures on the NHS, he did not expect there to be an increase in gross negligence manslaughter prosecutions against doctors.

“That’s not to deny the financial pressures,” he said. “And that’s not to deny that those pressures may lead to less safe practice than has otherwise been the case.”

He added, “I would like to think that prosecutors and courts will take into account the environment in which the doctor works in order to understand whether what happened is ‘gross’ or not.

“From what we have heard today it is probably time that the definition of manslaughter is looked at again because I’m not sure, in the context of medical cases, it’s satisfactory.”

Francis said that doctors and hospitals needed to do the best that they could for their patients with the resources available to them.

“That may not be enough but, obviously, you do your best. What your best is when you have fewer resources must be different from what your best is if you have every resource. I would hope that it does not lead to an increase in cases, they are very rare as an event.”

He added, “There will be much greater public discontent with the service received and that will lead to issues that are difficult to confront.”

Abi Rimmer, BMJ Careers
arimmer@bmj.com

Cite this as: BMJ 2017;357:j2103

FIVE FACTS ABOUT THE PAEDIATRICIAN WORKFORCE

The Royal College of Paediatrics and Child Health has published a report on the UK paediatric workforce. The report is based on figures from the college’s 2015 workforce census, Office for National Statistics data, and information from the college’s trainee recruitment processes.

1 Workload
Hospital admissions of children in England rose by 25% between 2013-14 and 2015-16, from 1.2 million to 1.5 million. Over the same period, the number of completed consultant episodes rose by 23%.

2 Official shortage
The college has asked for paediatrics to be placed on the official list of occupations for which there are not enough UK workers to fill vacancies. “Numbers have failed to keep pace with patient numbers, leading to pressure on an already stretched service,” said the report.

3 Trainees
The government needs to fund 465 more paediatrics training places each year for the next five years to expand the consultant workforce by 752 doctors, the college says. However, applications for specialty training in paediatrics fell from 800 in 2015 to 580 in 2017.
NHS MANAGERS SHOULD FACE THE SAME REGULATION AS DOCTORS

NHS managers should be subject to professional regulation in the same way that doctors are, according to Robert Francis, who led the public inquiry into failings at Mid Staffordshire NHS Foundation Trust.

Speaking at a conference on litigation against doctors at the Royal Society of Medicine, Francis said that he thought doctors and managers should be on a “level playing field” in terms of regulation.

Francis’s 2013 report on the Mid Staffordshire NHS Foundation Trust catalogued the managerial failings that led to the deaths of hundreds of patients. In the report, he stopped short of calling for professional regulation of NHS managers. Instead he said that only people who passed a “fit and proper person” test should be allowed to become board level executives of trusts and other providers of NHS services.

The fit and proper persons requirement for directors came into force for NHS bodies in November 2014 and is overseen by the Care Quality Commission (CQC).

Speaking at the conference last week, Francis said that the test would not, on its own, be enough to regulate those working as managers in the health system. “I do believe that, if we are going to have regulation of healthcare professionals, those that manage the health service should be within that system,” he said. “The system that we currently have is unlikely to solve the problem or to put everyone on a level playing field.”

Speaking to BMJ Careers, Francis said that there had been some difficulties with the fit and proper person test. “When we look at what really goes on in a hospital, in the engine room, we’ve got consultants and, alongside them, managers. Together they are meant to manage a service and yet one side is subject to a regulator, and could be in jeopardy for any decision that they make, whereas the other side is not.”

Any regulatory system that was introduced for managers, Francis said, should be supportive rather than punitive. “If you have a supportive regulatory system then people are supported to train, to learn about values, and about doing things properly. If you have a putative regulatory system—even if it’s not meant to be but feels that way—then people will fight each other.”

Abi Rimmer, BMJ Careers
arimmer@bmj.com
Cite this as: BMJ 2017;357:j2101

4 Vacancies

There are currently an estimated 241 whole time equivalent career grade vacancies in paediatrics. Between 2013 and 2015, the number of specialty and associate specialist paediatricians fell from 923 to 808, a decline of 12.5%. Over the same period, the UK paediatric consultant workforce grew from 3718 to 3996, a rise of 7.5%.

5 European staff

Paediatric consultants who graduated outside the UK but within the European Economic Area make up 6% of the workforce. Their numbers increased from 140 in 2009 to 238 in 2015. But the number of applicants to paediatrics training who are EEA graduates declined from 97 in 2015 to 41 in 2017.

NHS survives because of the dedication of its staff, says NHS Providers chief

The NHS continues to survive because of the dedication of its staff, the chief executive of NHS Providers has said.

Speaking at a Westminster Health Forum conference in London last week, Chris Hopson (below) warned that the goodwill of staff may not last forever. “The NHS never goes off the edge of the cliff,” he said. “It tends to go into a slow decline and the primary reason for that, in our view, is the dedication and professionalism of our staff who are resilient in the face of extraordinary pressure. But there are only so many times that you can go to that particular well.”

Hopson said that the biggest concern faced by the members of NHS Providers, such as NHS trusts, was their workforce. “They are saying that workforce challenges are now the biggest problem,” he said.

He added, “When we asked our members last November, 59% said they didn’t believe they had the right numbers, quality, and mix of staff to deliver high quality care in six months’ time.”

Hopson also said that NHS Providers’ members were struggling to recruit enough staff. “There is definitely a mismatch between the number of staff that they need and the current financial envelope. Pay is becoming uncompetitive, the workload burden and the pressure on staff are making NHS jobs less attractive, and we are struggling to engage and retain the next generation.”

Also speaking at the conference, Nick Bosanquet, emeritus professor of health policy at Imperial College London, said that it was a myth that “there is a pool of staff out there that could be hired in months to solve the health service’s problems.”

“We’ve got to start focusing on capability and experience, and not on numbers,” he said. “The numbers aren’t there. There is, however, the potential for using the 1.3 million people who are already on the payroll more effectively.”

Abi Rimmer, BMJ Careers
arimmer@bmj.com
Cite this as: BMJ 2017;357:j2133
A former soldier who is thought to have had the longest single stay of any patient in the UK has died after spending 54 years in hospital.

James Morris was admitted to hospital with a broken leg in 1962 after a car crash but never returned home after he had a cardiac arrest on the operating table during surgery in Scotland and was left permanently disabled and with little speech. He died last month aged 75.

Morris had been serving in the Cameronians (Scottish Rifles regiment) in Germany when the crash occurred. After the cardiac arrest he spent more than five decades at Wester Moffat Hospital in Lanarkshire, an institution that specialises in providing long term care. An NHS spokesman said that he was not aware of anyone having spent longer in an NHS hospital.

Helen Ryan, senior charge nurse at Wester Moffat, paid tribute to Morris. “Jimmy touched the lives of many . . . and he will be sorely missed by everyone at the Heather Ward,” she said.

Morris’s brother Karl, aged 62, said that the family was grateful for the “outstanding” care his brother had received from staff over the years. “To care for a man throughout his entire life is quite something, and we couldn’t be more grateful to the NHS,” he said.

Gareth Iacobucci, The BMJ

Cite this as: BMJ 2017;357:j2149
This spring Stockholm, the last of Sweden’s 22 counties to implement patient accessible electronic health records, is rolling out the country’s Journalen patient portal service. The portal is part of the national e-health strategy, which states that “all residents from 16 years should by 2020 have access to all information documented in county funded health and dental care.”

Sweden is leading the way in offering all patients universal access to medical records—all its hospitals, primary care centres, and psychiatric facilities already use electronic health records. The figure in Europe is 65% overall and 81% in hospitals. By February 2017, 3,773,178 Swedes, or 37.9% of the population, had set up accounts.

Patients can log in to the Journalen system using either an electronic identifier or their Swedish personal identity number. They are able to see notes from all healthcare professionals, a list of prescribed medications, test results, warnings, diagnosis, maternity care records, referrals, and vaccinations as well as a log of everyone who has accessed the record.

**Clinician concern**

The process was long and fraught, necessitating legal changes and research to allay a series of concerns, raised mostly by clinicians. The journey began in 1997 in the Uppsala region, a county north of Stockholm, with a project called Sustains—an attempt to set up an “internet health account,” much like an online bank account. Sustains was initially hampered by Swedish data protection laws, which did not allow patients to access records. It took the introduction of the Patient Data Act in 2008 to let patients in, and

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All patients in Sweden will shortly have access to their full medical records. **Stephen Armstrong** reports on the country’s 20 year struggle to achieve this and what the UK can learn.
Uppsala County Council then issued a trial group of 300,000 patients access to their full electronic health record in 2012.

There was still resistance. “When we launched at the end of 2012, the region’s oncologists wanted to be excluded—almost all physicians thought that full access might upset the patients,” says Benny Eklund, one of the founders of the Uppsala project and a senior adviser at a pain clinic in Ystads, a town on Sweden’s southern coast. Eklund’s team agreed to investigate what patients with cancer thought about having full access to their records.

“We asked if patients would be afraid of seeing their lab results in real time,” Eklund explains. “They replied, ‘Of course I’m afraid, but not knowing is no alternative.’ Some said they looked at lab results with a friend—they’d rather cry with a friend than in front of their oncologist. They wanted to be prepared for the next meeting. Those patients that were too scared didn’t log in. Patients are smart—they can take the responsibility themselves.”

Gradually, other counties rolled out the system, although there were setbacks. Press reports included the 2015 case of Birgitte Holmbom, who unexpectedly discovered she had lymphoma while making a routine online check on her diabetes records.7 Clinicians continued to be wary,1 but Uppsala’s—and ultimately all of Sweden’s—doctors agreed to take part.

They worried that patients would only access their records during weekends and evenings, when no one at the surgery or hospital could answer questions or deal with concerns. But an ongoing research project at the Karolinska Institute in Stockholm has found no evidence for this concern—user activity decreases during weekends and there was no spike in phone calls.

“Although the research indicates that patients’ experience mainly benefits, the fears among healthcare professionals remain high,” says the project leader, Maria Hagglund, programme director for the institute’s global masters programme in health informatics. “Hypotheses are many, but one stresses the power balance between patients and healthcare professionals as a reason for clinicians’ reluctance to share.”

Slow international progress

The problem is not confined to Sweden. Clinicians in many countries, including the UK, have opposed efforts to allow patients to see their medical records. At around the same time as the Uppsala project began, a US trial of OpenNotes, a system for sharing doctors’ notes from appointments and visits with patients, met similar resistance.

The Canadian University Health Network (UHN), which includes Toronto General and Toronto Western Hospitals, Princess Margaret Cancer Centre, and the Toronto Rehabilitation Institute, carried out a similar trial to make laboratory results, diagnostic imaging reports, pathology reports, clinic notes, and mental health notes available in real time. It found the move had no significant effect on patient anxiety but did improve both clinical and service efficiency because there were fewer telephone calls about results and appointment schedules and fewer requests for copies of health records; 96% of patients using the portal said they prefer real time access to their health record, even before seeing their doctor.8

As a result, this year UHN has started expanding the portal across all four hospital sites. “We will measure pre- and post-implementation results again after we complete roll-out,” explains Selina Brudnicki senior project manager at UHN. “Currently, we have over 14,000 patients accessing their portal, and increasing at a rate of 1000 new patient registrations per week as part of roll-out. We expect to offer over 250,000 patients access to their portal within the first year.”

In 2013, fewer than 30% of UK doctors believed patient access to electronic health records was a good idea, largely because of concerns about the security of online medical records.4 And a 2015 survey of UK and US doctors found that two thirds (66%) were reluctant to share health data with patients and 17% were completely opposed to the idea.15

“It’s the same story all over the world,” says Mohammad Al-Ubaydli, chief executive of the patient portal Patients Know Best, which allows patients to create and control a single electronic health record hosted by the NHS N3 network. The patient can also grant access to specific care providers. “Swedish democracy is the kind where, when the government realises something is good it passes a law ensuring everyone does it. American democracy is the opposite. The UK is somewhere in between. Ultimately, the government has said that by 2018 all patients should be able to access their GP records online in full. The question is, will doctors help people access it or hang back through needless worries?”

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**OPENNOTES IN THE US**

The 12 month OpenNotes study took place at Beth Israel Deaconess Medical Center, a large teaching hospital in Boston; the Geisinger Health System, which has clinics in rural Pennsylvania; and Harborview Medical Center in Seattle. A total of 105 primary care physicians completed the study, but 143 declined to participate. Nevertheless, some 20,000 patients were given access to their notes—and more than 80% of patients opened at least one note.4

Two thirds of patients reported a better understanding of their health and medical conditions and that they were taking better care of themselves, doing better with taking their medications, and feeling more in control of their care. For clinicians, only 3% spent more time answering patient questions outside visits and 11% spent more time writing or editing notes—with a fifth reporting changes to the way they wrote about cancer, mental health, substance misuse, or obesity.8

After the trial, some 99% of patients and 75% of doctors wanted to continue using OpenNotes, explains Janice Walker, assistant professor of medicine at Harvard Medical School and cofounder of OpenNotes. “We now have about 12 million patients and 50 institutions, but we’ve got a long way to go,” she explains. “We’ve got all the big academic medical centres on board—but they are well resourced and interested in the new thing. Smaller places with fewer resources is where we get real push back from doctors. If you tell a doctor that everything they write will be open to patients they turn pale. Once they try it, its fine, but its hard to get them to try it.”

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**Two thirds of patients reported a better understanding of their health and medical conditions**

Janice Walker

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**BMJ** 2017;357:j2069

**Cite this as:** *BMJ* 2017;357:j2069

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“Before we had 23 clinics involved in cancer care. Now we have one cancer theme, which makes it much easier to focus on an overarching strategy”

Melvin Samsom

Melvin Samsom arrived at the Karolinska University Hospital in Stockholm in 2014, fresh from transforming the Radboud University Medical Centre in the Netherlands. Radboud had hit the headlines in 2006 because death rates in its cardiothoracic centre were three times the national average. Samsom, a professor of gastroenterology, was brought in to drive quality improvement, and under his leadership Radboud became lauded as a model for patient participation.

“What I am most proud of achieving at Radboud was we really saw a significant increase in quality of care, not just in our heart patients but also in general,” Samsom says. “We also involved patients a lot and learnt a lot from our patients.”

After Samsom’s reforms, Radboud became ranked highly in national comparisons of care quality and outcomes, with cardiothoracic surgery results among the best in Europe.

Samsom recalls his first impression when he arrived at the Karolinska. “At leadership level we did not talk about the core of what makes a university hospital, which is quality of care, the highly specialised care, whether patients were satisfied, and the connection with research and education.”

“Actions not words”

Samsom said that putting patients first had been the stated vision at the Karolinska for many years but that it was not what was happening in practice. “I asked the question, if you look at the patient journey are we organised in the best possible way? And the answer was probably not.”

He cites the example of a patient with breast cancer who meets professionals from the radiology clinic, the surgery clinic, the radiotherapy clinic, the medical oncology clinic, and the plastic surgery clinic. “All these clinics work in collaboration, but they are also silos within the organisation so optimising flows is quite difficult.”

“If you want to really put patients first you have to organise around their journey,” says Samsom. “This meant facilitating interprofessional teams, increasing patient involvement, and measuring meaningful outcomes.”
Fundamental redesign
Samsom proposed a fundamental redesign—getting rid of the old departmental structure based on specialist expertise and focusing instead on the patient’s pathway throughout the entire care process. An analysis of the hospital identified 400 patient groups—200 adult and 200 paediatric groups with similar medical conditions.

The new structure is based on patient flows that allow a patient group to be followed through the care pathway. Similar patient groups are organised into patient areas, which in turn are organised into seven themes: children’s and women’s health, heart and vascular, neurological, cancer, trauma and reparative medicine, inflammation and infection, and ageing. In addition, there are five functions that cut across the themes: emergency medicine, perioperative medicine and intensive care, radiology and imaging, laboratory services, and allied health professionals.

The reorganisation is now 70% complete. The move to a new state of the art hospital building in Solna is under way, and the new organisational structure will be fully operational in 2018.

Medical resistance
It has not all been plain sailing, however. Samsom says that in March this year a survey of 1394 physicians at the hospital found that only 3% have confidence in him, with 59% saying that they do not have confidence in him and the remainder neutral. Almost 90% of respondents were unhappy with the reorganisation, saying they wanted the current clinic structure maintained. The survey also found that 53% of doctors said that the lack of care facilities was the most urgent priority.

“I do understand that this very fundamental change causes discussion among doctor groups,” Samsom says. “I was a doctor myself and grew up in the system with clinics so I do understand a lot of their concerns. Clinics have been more or less a synonym for the home of a medical specialty.” He says working with medical specialties is essential so that they can ensure they can continue to develop their profession with ongoing education and research programmes.

Patient involvement is key to the new approach. For example, a patient representative is involved in the management of each patient flow. Within a single patient flow healthcare professionals and patient representatives draw up outcomes that are relevant to patients. These outcomes, which measure the value for the patient, can relate to survival, pain level, being able to return to work, and degree of depression. There is also a patient flow manager, who coordinates the various healthcare professionals into a patient focused team.

Samsom emphasised the importance of patients having full access to their own medical records. “It really empowers patients. A lot of patients have a very high knowledge of their disease, and they can contribute a lot. I work a lot with a young patient with Parkinson’s disease, and she explains that more than 90% of the time she is managing her disease herself. So providing her with the information that she needs is very important.”

But he adds, “You need to recognise that it is not one size fits all, and you need to fine tune to fit to the wishes and abilities of the patient.”

The new organisational model has been developed in collaboration with the world renowned Karolinska Institute so that they can work more closely together. “We wanted to focus much more on the integration of care, research, and education,” says Samsom.

Each of the seven themes has a person responsible for research and education. Samsom says, “We now have a better awareness of what research is going on in a particular area. For example, before we had 23 clinics involved in cancer care. Now we have one cancer theme, which makes it much easier to focus on an overarching strategy.”

Fine tuning
Samsom says he had a lot of contact with the Mayo Clinic and the Cleveland Clinic in the US while developing the new model. But he says, “Our solution is unique, and we are fine tuning it on a day-to-day basis. A lot of hospitals start working in a thematic way but very often without restructuring the departments or the clinics. That was a crucial step when we decided to redesign our structure.”

Samsom is enthusiastic about the future. “There is so much professional knowledge within the university hospital environment and so much energy that if we can release that energy and knowledge we can achieve so much.”

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Cite this as: BMJ 2017;357:j2088

PATIENT COMMENTARY Paul Buchanan
The new building at Solna is a public-private partnership, which is very rare in Sweden. The UK has some experience of funding new healthcare facilities through such partnerships: they proved to be poor value for patients and taxpayers at the expense of private investors.

The Karolinska’s reorganisation of care also seems to have been led by economics rather than patient need, with an operating model called value based healthcare underpinning the new ways of working. It essentially defines “value” as outcomes that make a difference to patients divided by cost.

The proof will be in the delivery of healthcare, not in the design, and this depends as much on the people responsible as on the technology, the equipment, the process, or the building.
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[Image of Paul Buchanan]