

# comment

Misinformation on the EU flies as frequently and viciously as the Scottish summer midge

**NO HOLDS BARRED** Margaret McCartney

## For facts' sake give us the EU data

**I** like facts, I love evidence—bring it on. “Official information about the referendum,” says one leaflet, pushed through the door because I’m “someone who cares about the future of Scotland and fair access to public services.”

A sum equivalent to building a new hospital, £350m, is spent each week on our EU membership. Five new countries are “in the queue” to join the EU, and I have to decide “whether this will help Scotland . . . and fair access to public services.” It has graphs of increasing “billions sent to the EU” and pointed illustrations of Turkey being next to Syria and Iraq. In small writing, it declares itself to be published by the Scottish Vote Leave campaign.

What is trustworthy—that which is “official”? On the mat I also found a leaflet with the royal coat of arms, complete with lion and unicorn, in the same typeface as other “official” government publications. Should I therefore believe it more readily? “The government believes it is in you and your family’s best interests that the UK remains in the European Union,” it states. Why, then, is the government having a referendum at all? It is, of course, a painful compromise of internal party politics.

Which one to believe? The £350m figure is simply wrong, says the “official” UK Statistics Authority,<sup>1</sup> by £100m.<sup>2</sup> I trust this advice more. Yet that figure has appeared on all of the Brexit leaflets through my letterbox, as well as the one from the Electoral Commission. That leaflet also contained information from the Bremain campaign, saying that, for every



£10 we put in, “we get almost £10 back in lower prices, more jobs and more investment.” The source, infuriatingly, was cited as “HMT, CBI” which I presume are the Treasury and the Confederation of Business Industry, and in two hours of online searching I found nothing resembling a rational, understandable explanation of what is fact and what is approximation. (How long would it take to add hyperlinks on “official” campaign websites? Isn’t that what the internet is for?)

Misinformation on the EU flies as frequently and viciously as the Scottish summer midge. Survey data show that we overestimate the amount of immigration to the UK and overestimate how much child benefit is sent abroad; that we don’t usually know who our MEP is but do know that we put in more, in monetary terms, than we get back; and overestimate how much we pay compared with other countries.<sup>3</sup>

What, then, to go on? I wouldn’t wish to leave a union where the NHS and research community benefit from close ties with colleagues across the EU. Neither side cites evidence well, but the Brexit campaign is using fear mongering about immigration—which, given the ongoing Mediterranean humanitarian disaster,<sup>4</sup> is unforgivable. We should not want to be Little Britain.

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# How to react to the Orlando massacre?

Harm reduction may have something to offer

**I**n the aftermath of the awful killings at an Orlando gay nightclub early on the morning of 12 June, we are numbed and left searching for answers. Who did it? Why? What could have been done to prevent the massacre? How can we protect “soft” targets like nightclubs (and schools, offices, and shops) from future attacks?

This was clearly a hate crime in addition to a terrorist act. Omar Mateen had contacted other gay nightclubs as he methodically planned his attack. He called police directly from the nightclub to pledge his support to the Islamic State organisation (ISIS), known for its antipathy to gay people in particular as well as to Western countries in general. How can we protect our gay and lesbian friends and family members from such atrocities?

In retrospect, Mateen fits all the terrorist profiles: young, male, US born son of Muslim immigrants, a history of violence, heard to utter racist and homophobic threats, and access to guns. Starting in 2013 the FBI correctly identified him,

followed him up, and opened an investigation—twice. In neither case, though, could the agency confirm that he was linked to terrorists, and the inquiries were closed.

## “Self actualised” terrorists

This is a huge problem: the threat of “self actualised” terrorists who respond to calls by ISIS and similar groups to carry out killings abroad. Law enforcement and intelligence agencies work overtime to try to find and assess such people. Even when they do, though, they may not find the evidence of terrorist acts or contacts needed to detain them. “False negatives” in such investigations can have huge costs, as we saw in Orlando. Other home grown terrorists escape notice altogether, such as the San Bernardino couple who also pledged allegiance to ISIS and killed 14 county employees at a reception in December. The FBI just needs to be wrong once, and we have another mass murder on our hands.

Everyone agrees that we should redouble efforts to defeat ISIS abroad

and detect and prevent ISIS inspired attacks at home. Given the difficulty of both endeavours, though, and the seeming ease with which people can launch mass shootings here in the US, perhaps we should also take a page from the drug treatment world and consider possible harm reduction strategies.

Given our history (and constitution), there is no way the US is going to ban private ownership of handguns and rifles. But what about semi-automatic assault rifles? Mateen, like the perpetrators of many mass shootings in the US, whether terrorist killings or not, used an AR-15 type assault rifle. Whether it was fully automatic is not known yet, but all these guns have a semi-automatic mode that allows speedy firing of large numbers of lethal, high velocity bullets in competent hands. It is much more difficult to kill dozens of people with a handgun or rifle than with a semi-automatic assault rifle.

The first tenet of harm reduction is that the alternative is less harmful than the established harm. Handguns and rifles are less harmful



**Handguns and rifles are less harmful than assault rifles in mass killing situations**

## **ACUTE PERSPECTIVE** David Oliver

# Values statements aren't worth the paper

In *A Sceptic's Medical Dictionary*, the great Michael O'Donnell made mischievous fun of mission statements in the NHS, calling them “pious utterances trusts print below their expensively commissioned logo.”<sup>1</sup> Values statements are close siblings; both are ubiquitous in health and social care.<sup>2</sup>

There's nothing wrong with publicising your guiding values. But I suspect that most patients and families would prefer to experience these in the way they're treated rather than see them written on leaflets, posters, and letterheads.

Too often, statements are platitudinous—who could disagree

with them? You can test this by saying the opposite, to see how daft it sounds. For example, try NHS England's six Cs of nursing: care, compassion, courage, communication, commitment, and competence.<sup>3</sup> Very good, but who would value carelessness, callousness, cowardice, or incompetence?

Skilled, compassionate, caring practitioners and teams are legion in the NHS, but certainly not because of meaningless mantras. There's a surfeit of worthy spiel about good care being dignified, person centred, personalised, putting people first, respecting choice, and so on. But does



**Too often, statements are platitudinous**

this describe the care our pressurised, underfunded, and fragmented systems allow us to provide?

The brilliant *Dignity in Practice* study was based on detailed observation of ward care for older people.<sup>4</sup> These observations centred on failing to see patients as individuals and prioritising system priorities, procedures, and pressures from managers.<sup>4</sup>

Here are some things, that in my experience we still do far too often:

- Move people around hospitals, sometimes repeatedly, at cost to them personally, to continuity, to communication, and to bed occupancy and flow<sup>5 6</sup>



DAVID GOLDMAN/APPA

than assault rifles in mass killing situations.

Perhaps banning assault weapons like the AR-15 in the US would decrease the lethality, if not the likelihood, of future mass killings. We had a recent, ineffective ban on assault rifles here for 10 years. It expired in 2004. Maybe it is time to

try again, banning assault rifles while we await the defeat of ISIS at home and abroad.

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- Allow people in subacute crises to be admitted by default into overcrowded hospitals for want of an adequate community response<sup>7,8</sup>
- Pass referrals to intermediate care services in the community in ways too often designed around what providers want rather than what patients really need<sup>7</sup>
- Maroon patients in beds while health and social services argue about funding and take days or weeks to set up meetings or put the case before a funding panel<sup>9,10</sup>
- Argue over means tested packages of social care compared with NHS community rehabilitation, while the patient and family sit bewildered by the difference

- Refuse to take patients back into their residential homes from hospital until they've been reassessed, days after they needed to leave, or refusing them back ever because of needs that were apparent before hospital admission.

Do these represent the person centred values we espouse? Many of these problems indicate a system under extreme funding and workforce pressure.<sup>11,12</sup> But “putting people first,” they are not. We all need to do better at living up to mission statements, or they're not worth the paper they're written on.

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## THEBMJ.COM BLOGS

Bernard Merkel



# What has the EU done for health?

In 1991 I was seconded from the Department of Health to the European Commission. During my time there the prevailing view in the UK was that the European Union had little to do with health and virtually nothing to do with the NHS. So I never thought these issues would be raised in the referendum debate.

## The work on AIDS is only one of many health areas where the EU has played a significant part

I was invited to work in the commission to set up a new public health programme, “Europe against AIDS.” This was an archetypal EU health initiative, in that it dealt with an issue that required an international response—in this case, tackling a serious communicable disease that “respects no borders.”

It complemented national efforts by fostering cooperation and the exchange of best practice between countries; providing funding for prevention and health education activities; helping to improve data and information on the epidemic; and building expertise and capability in countries with the poorest resources. It also promoted policies on what would be most effective in public health terms rather than pandering to fears and prejudice—for example, imposing mandatory screening of travellers at national borders. The programme was accompanied by EU funded research and by work on safeguarding blood supplies, and it was followed in 2005 by the creation of the European Centre for Disease Prevention and Control in Stockholm, to bolster capacity for tackling communicable diseases across Europe and beyond.

The work on AIDS is only one of many health areas where the EU has played a significant part: from tobacco control to food and consumer safety; from regulating medicines and medical devices to rules on tissues and organs; from health research and technology to development and humanitarian aid; from health and safety at work to the European health insurance card; from clinical trials to environmental pollution; and from alcohol and drug abuse to the free movement of health professionals and patients.

But, although the current Brexit debate may notionally be putting a focus on health issues, in reality the two sides talk about health and the NHS only in so far as they connect with the two over-riding themes of the campaign: money and migration.

No discussion has arisen on important questions about how to maintain and improve public health and health services, or what the effect of EU membership has been in these areas.

Bernard Merkel retired last year from the European Commission



## OBITUARIES

### Gillian Gandy

Consultant neonatologist (b 1928; q Royal Free Hospital Medical School 1953; MD, MRCS, MRCP, DCH), d 4 February 2016.

In 1964 Gillian Gandy ("Jill") moved to the Mill Road Maternity Hospital in Cambridge, as a research assistant. She began her pioneering work on the chemistry and histology of hyaline membrane disease, which led to her MD in 1971. She received full time clinical assistant pay in 1975 and was upgraded to associate specialist shortly after. She was awarded an MRCP for published work and then appointed a consultant neonatologist. After she retired in 1989, she worked for the East Anglia perinatal mortality survey, spending hours coding, computing, and meticulously recording data. This was a forerunner of the national neonatal database. Activities in retirement included cross country skiing and amateur music making. It was through hosting music groups in her house that she met her long term partner, Jane, who shared her life for 18 years until her death.

Colin Morley, Jane Cursiter

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### David Stanley Hinchcliff Cannon

Former medical missionary and general practitioner (b 1927; q London Hospital 1950; MRCS, DOBst RCOG, FRCGP), died from ischaemic heart disease

and oesophageal cancer on 11 February 2016. David Stanley Hinchcliff Cannon's Christian faith prompted him to apply for service overseas, and he spent a term at Selly Oak theological college before departing for Nigeria in May 1952. As medical officer and deputy medical superintendent of the Wesley Guild Hospital he was anaesthetist, general surgeon, obstetrician and gynaecologist, as well as lecturer in midwifery. In 1962 David returned to the UK with his wife, Margaret, and three children. It quickly became clear that the best way of giving his family a stable life was by entering general practice, and he joined a practice in Watford, where he stayed until he retired in 1987. Predeceased by Margaret and by one of his sons, David leaves his second wife, Sally; a daughter; a son; and their families.

Rosemary Courtney

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### Richard Nesbit Evans

General practitioner (b 1944; q King's College, London/St George's Hospital, London, 1972; MRCP, FAFOM), died from glioblastoma multiforme on 22 December 2015.

Richard Nesbit Evans read politics, philosophy, economics, and natural sciences at Magdalene College, Cambridge. He worked as a journalist for the *Economist* before turning his hand to medicine. His working life was diverse, running the gamut from chief medical officer for commercial airlines to resident doctor at a BP refinery, from consultant in occupational medicine to outback Aussie GP. Richard was an avid fisherman, birdwatcher, handyman, and gardener; an active member of the Australian Baha'i community; and a Rugby Union international—playing "hooker" for Ghana while on medical elective. He died in Perth, Western Australia, and leaves his wife, Faeghe; four sons; and two grandsons.

James Evans, Matthew Evans, Stephen Evans, Eric Evans

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### Colin Deas Campbell

General practitioner Waddesdon (b 1927; q St Thomas' Hospital Medical School 1953; MBE, FRCGP), d 9 May 2016.

Colin Deas Campbell entered general practice after qualifying. After several jobs he was offered the position of GP for the village of Waddesdon, Buckinghamshire, in 1960. A singlehanded, dispensing practitioner, supported by a district nurse and community midwife, he was on duty 24 hours a day until he made an arrangement with a surgery in

**GP for Waddesdon, he lived in a tied house owned by the Rothschilds**

Aylesbury to help with cover. His wife, Daphne, covered the phone and helped with the running of the surgery, alongside looking after their family. Colin was a GP for 31 years and was on the local medical committee. He retired in 1991 and had to move as the house was a tied house belonging to the Rothschild estate and designated the doctor's house. He leaves Daphne, his wife of 61 years; five daughters; and 10 grandchildren.

Heather Chan

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### Jean Forbes Trainer

Former locum doctor in accident and emergency medicine and general practice (b 1929; q Edinburgh 1952), d 13 April 2016.

Jean Forbes Trainer (née Brown) worked for a short time only in Stracathro Hospital, Brechin, and Law Hospital, Carluke, before marrying James, a Lanark farmer, and bringing up five children. A chance visit to Law Hospital when she was in her 50s led to her taking a post as clinical assistant in the accident and emergency department. Having a cool head, an excellent memory, and lots of quiet common sense, Jean enjoyed a late flowering of her career, doing locum work in accident and emergency and general practice until she retired in 1995. Latterly she developed Parkinson's disease. Predeceased by James, she leaves five children, seven grandchildren, and one great grandchild.

Nancy D Rigg, Alastair W Rigg

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### Barbara Williams

Former anaesthetist (b 1930; q London 1954; MRCS Eng, DOBst RCOG, DA), d 23 April 2016.

Barbara Mary Williams (née Isles) married Michael Williams in 1955, and two years later they moved to Canterbury, where Michael was a consultant general surgeon. After a break to have four children, in less than five years, Barbara returned to her career in anaesthesia at the Kent and Canterbury Hospital and other hospitals in the county. Meanwhile she also ran a busy house and offered hospitality to everyone around her. After retiring when she reached 65 she moved to a smallholding outside Canterbury. Barbara bequeathed her body to medical science at the Royal College of Surgeons. It was very important to her that the next generation of medics should learn from her body as she had done at St Thomas' all those years ago. She leaves four children and 10 grandchildren.

Rachel Miller

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# Quentin Young

Doctor and activist

Quentin David Young (b 1923;  
q Northwestern University  
1948), d 7 March 2016.

Quentin David Young was born and raised in Chicago and was closely associated with Cook County Hospital, the city's only public hospital. It was during one of the institution's many crises that Young, an internist by training, was asked to become chief of medicine. Young, who had done his residency and internship at the hospital, was a radical with a strong sense of outrage at social injustice.

## Cook County Hospital

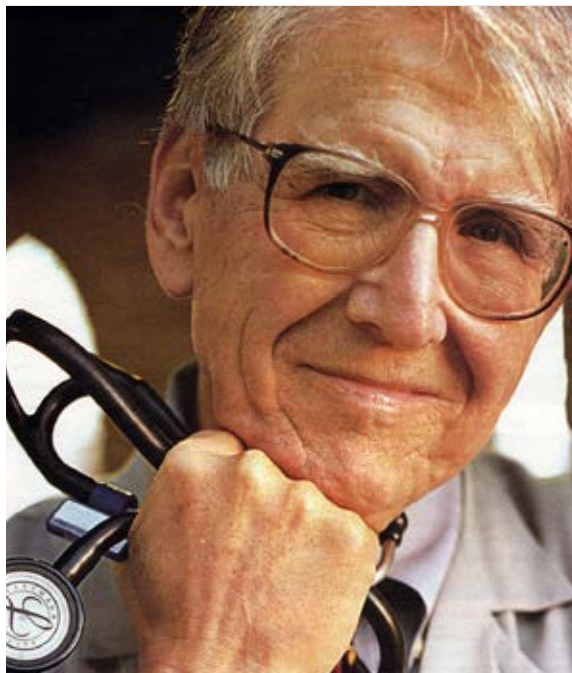
The hospital was falling apart—both physically and metaphorically. Young was fired twice during his tenure because of his support of, but not participation in, a strike by the hospital's house staff. Firing someone with such a strong sense of workers' rights was a foolish decision—Young argued that he was dismissed without due process and was reinstated both times.

After the strikes he set up a committee to save the hospital, which culminated in its being completely rebuilt in 2002, with its future secured. Young himself had left County in 1981 and in 1983 was appointed president of Chicago's board of health.

Young's work at the hospital was not all controversy—he set up an occupational health department in partnership with the University of Illinois, and he restricted the prescription of tranquillisers and sedatives in the outpatient clinic by insisting that prescriptions be countersigned by senior doctors.

## Early years

Young was born to Jewish parents, Abe and Sarah, who had fled Europe. His father trained as a pharmacist. It was during visits to see his maternal grandparents in North Carolina that the seeds of Young's political activism were sewn. In the racially segregated south, he would see black women and children toiling in the tobacco fields for white landowners.



Young felt that President Obama's health reforms gave too much power to the insurers

In 1940 he enrolled at the University of Chicago but enlisted in the army in 1943, with dreams of fighting the Nazis. Instead he continued his medical training with the army in the US, first at Cornell University and then at Northwestern University.

While in the army, Young married his childhood sweetheart, Jessie, with whom he had five children. They divorced after 15 years, and he became the first father in the state of Illinois to secure joint custody of his children. He married his second wife, Ruth Weaver, in 1980, who predeceased him by nine years.

After serving his residency and internship at County he set up private practice in Hyde Park, on Chicago's south side, with attending privileges at Michael Reese Hospital. He continued with this until he was 86.

## Social justice

At the beginning of his career Young helped found the Committee to End

Discrimination in Chicago's Medical Institutions. Segregation of hospitals was not an official policy, and it was only when the committee obtained figures showing that most births and deaths among the black population happened in the poorer hospitals that Chicago city council ruled that it was unlawful to deny treatment to a patient because of race. Two years later the city ruled that it was unlawful to racially discriminate against staff.

Young was invited to run for secretary of the local chapter of the American Medical Association, on the grounds that the hierarchy did not want a black person gaining the position. Secretary was a stepping stone to chair, and Young knew that he would be able to nominate his successor. He duly nominated a black colleague, Clyde Phillips.

Young was also involved in the wider civil rights movement through the Medical Committee for Human Rights, which he helped found. He provided medical support to those taking part in the historic march from Selma to Montgomery, and he became Martin Luther King Jr's personal doctor when he visited Chicago. Young treated him only once, when someone hurled a rock at him during a march for fair housing.

In the 1980s Young was a tireless advocate of single payer national health insurance and became president of the organisation Physicians for a National Health Program. He met Hillary Clinton when she began her healthcare initiative as first lady but was unimpressed with her ideas. He was also disappointed by President Barack Obama's health reforms, which, he felt, gave too much power to the health insurers.

Paragraphs about his political activism could give the impression that Young was a dour man, but he was the eternal optimist, the happy warrior who would gladly march out to battle again and again. Nothing bothered him more than a cynical or conservative young person. He was a great raconteur and loved the arts, visiting the Shakespeare festival in Stratford, Ontario, every year.

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# Sharing decisions about preventive treatment

Guidelines for treating risk factors should include tools for shared decision making. Otherwise patients aren't getting the full picture, say **John S Yudkin and colleagues**

## KEY MESSAGES

- Guidelines on preventive treatment are generally based on population data
- Strict adherence to recommendations may not benefit individuals
- Guideline writers should provide guidance to help the clinician and patient consider not just the risks of treatments but also the likelihood of benefit for that individual

In a recently published case report titled “The tyranny of guidelines,” Sarosi recounts the story of an 86 year old man living on his farm in Wisconsin and caring for his 92 year old brother with early dementia.<sup>1</sup> Six years earlier he had been started on an angiotensin converting enzyme inhibitor and metformin after a health check, with other oral drugs subsequently added. But, when his family practice was taken over by a large organisation, he was given a copy of the American Diabetes Association guidelines and started on insulin because his haemoglobin A<sub>1c</sub> concentration was 8.5%; his antihypertensive dose was also doubled because his blood pressure was 154/92 mm Hg. Three weeks later he was admitted to hospital hypotensive and hypoglycaemic, with a hip fracture and a stroke. Both he and his brother subsequently needed residential care.

**When linked to quality measures and reimbursement, guidelines can morph into orders**

## Importance of individual benefit

The clinicians might claim that they were only following guidelines. But, when linked to quality measures and reimbursement, guidelines can morph into orders. These guidelines suggest a target HbA<sub>1c</sub> below 8% and blood pressure <140/90 mm Hg in elderly patients unless their health status is “very complex/poor... (long term care... end-stage chronic illnesses or moderate-to-severe cognitive impairment)” with limited remaining life expectancy.<sup>2</sup> And though the American Diabetes Association and the European Association for the Study of Diabetes recommend that “where possible, such decisions should be made with the patient, reflecting his or her preferences, needs, and values,”<sup>3</sup> they provide no tools for quantifying the harm associated with a particular risk factor or information comparing likely benefits and risks of treatments.<sup>4</sup> We argue that such tools, based on outcomes relevant to patients and likely gains in healthy life expectancy, are vital—not just for shared decision making but also better to inform clinicians, guideline committees, and comparative effectiveness agencies. In this man's case, an outcome model would have estimated that the changes to his treatment would have extended his healthy life expectancy by no more than five weeks.<sup>5,6</sup>

The UK National Institute for Health and Care Excellence (NICE) updated its guidelines for management of adults with type 2 diabetes in December 2015.<sup>7</sup> The NICE targets are similar to, but in some cases more aggressive than, the US and European guidelines. They recommend HbA<sub>1c</sub> of 7% (or 6.5% if it can be achieved by a single drug that does not cause hypoglycaemia) and blood pressure <140/80 mm Hg, although these targets can be relaxed

in “people who are older or frail... or with a reduced life expectancy.”

NICE also states that “patients should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals.” But although the guidelines provide a useful decision aid for assessing risks of treatment—giving rates of adverse effects, including hypoglycaemia, with pictograms<sup>8</sup>—the only information on possible benefits is provided separately in the “decision aid user guide for healthcare professionals” and in the form of relative risk reductions.<sup>9</sup> No information is provided to allow clinicians to quantify the risks associated with different levels of risk factors, or likely benefits with their reduction.

For a patient resembling the man we described above, a conversation about his glycaemic control using the information in the NICE guideline might go as follows. With the information in the user guide, he would be told that getting his HbA<sub>1c</sub> down by 1% might reduce his risk of a non-fatal myocardial infarction by 13% (a relative benefit), but the healthcare professional could not give any indication of his baseline risk or the possible gains in healthy life expectancy (box 1). He might be told, based on the guidelines, that it was important to improve his glycaemic control to prevent blindness or renal failure. However, he would not be told that the evidence for this benefit is extrapolated from a 20%-25% reduction in surrogate endpoints (retinal photocoagulation and proteinuria changes) and that there is virtually no evidence for glucose control actually reducing risks of blindness and end stage renal disease.<sup>10</sup> He would also not have been told his lifetime risks of these events are at most 1-2%.<sup>11</sup>

## Box 1 | Likely benefits of starting insulin in patient described\*

### Glycated haemoglobin

Reduction of 1%

### Cardiovascular disease

Fatal event—no effect

Non-fatal event—13% reduction in relative risk

Absolute risk reduction—3.7% at 10 years

### Blindness

25% reduction in relative risk (from surrogate endpoints)

Absolute risk reduction 2.3% at 10 years

### End stage renal failure

25% reduction in relative risk (from surrogate endpoints)

Absolute risk reduction 0.03% at 10 years

### Life expectancy gain

About 5 weeks

\*Estimates are derived from the UKPDS outcomes model 2<sup>5</sup>



## Box 2 | Tools for estimating benefits of interventions to lower cardiovascular risk factors<sup>20</sup>

- Absolute cardiovascular disease risk/benefit calculator (<http://chd.bestsciencemedicine.com/calc2.html>)
- Mayo Clinic heart disease risk calculator (<http://www.mayoclinic.org/diseases-conditions/heart-disease/in-depth/heart-disease-risk/itt-20084942>)
- Mayo Clinic diabetes decision aid (<https://diabetesdecisionaid.mayoclinic.org/index.php/site/compare?PHPSESSID=k3sgf2rju1t2bpo8738bf95354>)
- Healthy Living for People with Diabetes, a web-based self-management programme<sup>21</sup>
- United Kingdom Prospective Diabetes Study outcomes models 1 and 2<sup>22</sup>
- London School of Economics statin ranking tool\* (<http://www.lse.ac.uk/IPA/ResearchAndEngagement/ProjectArchive/VisualisingData/StatinRankingTool.aspx>).

\*Although this is not a diabetes decision aid, it shows how it is possible to integrate comparative treatment rankings from network meta-analysis with patient preferences in decision making.

### Fully informed decisions

Fully informed decision making needs fully informed clinicians as well as patients. Absolute risk reductions and numbers needed to treat are now more widely disseminated, but when benefits are expressed as likely gains in healthy life expectancy these are, at best, moderate.<sup>12</sup> In people at much lower risk, or in those treated with less effective strategies (like glucose lowering),<sup>13</sup> the interventions are more for the benefit of population health than individual health. Many clinicians are unaware of this when they write prescriptions.<sup>2-15</sup>

In its professional guidance, the UK General Medical Council (GMC) advises doctors that their role is to outline the benefits, risks, and burdens of a treatment or procedure in clear and understandable fashion, but it is the patient who weighs up the information, together with other relevant issues, and makes the decision.<sup>17</sup> A recent UK Supreme Court judgment concerning the information provided to Nadine Montgomery about the benefits and risks of a caesarean section for her and her baby has now configured legal obligations with ethical guidance.<sup>18</sup> The Montgomery judgment highlighted the importance of shared decision making that is properly informed; this may be interpreted as establishing a new legal requirement that information about the potential harms and benefits of a proposed course of action should be communicated accurately.<sup>19</sup>

In the context of treating risk factors, two other considerations often apply—the patient has no symptoms and the treatment has the potential to be lifelong. Although many patients will still defer to their clinician on decisions about such treatment, guideline developers should surely include, or at least provide some directions to, shared decision making tools that could be used (box 2). Because people differ widely in their willingness to take preventive medication,<sup>23,24</sup> and their responses to different formats for explaining benefits,<sup>21</sup> such tools need to show estimates of benefit in a variety of formats—absolute risk reductions (ARR), numbers needed to treat (NNT), and gains in healthy life expectancy.<sup>6,22</sup> The multiplicity of complications of diabetes, which benefit to different degrees from improved glycaemic control, make it difficult to express benefit as absolute risk reduction or number needed to treat.<sup>13</sup> Because of this, a model derived summary measure, such as gains in

**Fully informed decision making needs fully informed clinicians as well as patients**

healthy life years, may be more relevant for intensive glucose lowering.<sup>6</sup>

Use of summary measures might permit a more patient specific assessment of the value of glucose lowering medication. Token statements such as “patients should have the opportunity to make informed decisions about their care and treatment” do not make for patient centred guidelines. If guideline writers with all their expertise and resources can’t come up with specific tools or approaches, individual users are unlikely to be able to fill in the knowledge translation blanks left by these guidelines.

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Calculating likely risks and benefits of treatment is vital for informed decision making

## GUIDELINE DRIVEN CARE

### NICE gold standards don't work in a rusty metal NHS

Haslam argues that NICE guides on gold standard practice (Analysis, 28 May). NCAS (National Clinical Assessment Service) used NICE guidelines to judge me for prescribing lamotrigine for a patient with possible epilepsy; the neurology clinic had a three month waiting list for urgent cases.

NICE recommends that such patients are seen within two weeks, but this has never been achieved locally.

A 2012 lecture by an expert advised that lamotrigine is the simplest drug to start and covers most scenarios—useful guidance for GPs faced with excessive NHS waiting times.

Although lamotrigine is licensed, valproate was listed as first choice by NICE, and NCAS judged I had not followed guidelines.

I explained to NICE that GPs need interim treatment guidance but NICE said it only issues gold standard advice.

Gold standards from planet NICE are no use on planet NHS, where rusty metal is traded because the treasury cannot afford to pay for gold.

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## INTEGRATED PRIMARY CARE

### Lack of evidence hinders integrated primary care

O'Dowd's piece on integrated primary care may be laudable, but the NHS has a history of plans that fail from lack of evidence (This week, 28 May). The aims represent excellent ambitions, but are they being achieved? Where is the evidence that such models are "optimal"?

Such initiatives need careful evaluation. Researchers could do this for the NHS, but blocks



## LETTER OF THE WEEK

### Olympics mean Zika precautions before travelling

The Olympic Games are a popular but vulnerable global event and thus intrinsically raise the expectations of the international community on all aspects of preparedness, including public health. Coombes reports that WHO's statement advised athletes and visitors travelling to the games in Rio to practise safe sex, choose air conditioned accommodation, use insect repellent, and wear light coloured clothing that covers as much of the body as possible (Seven days in medicine, 28 May).

Nevertheless, the Brazilian market does not have repellents with  $\geq 20\%$  diethyltoluamide (DEET), which the Centers for Disease Control and Prevention recommends. The directions for repellents are written such that we cannot read their small, out of focus letters. Generally, higher concentrations of the active ingredient provide longer protection and longer reapplication intervals.

Regarding the Aedes mosquito, DEET at concentration of  $\geq 20\%$  can provide 10 hours' protection. Combining DEET and permethrin impregnated clothing enhances protection against arthropod bites. Generally, clothing treated with 0.5% permethrin aerosol or pump spray is effective at preventing arthropod bites for at least two weeks. But these products are not available in Brazil, either: to avoid arthropod-borne diseases, repellents should be purchased and clothing treated before travelling to Brazil.

Despite the precautions recommended in this letter, it is time to light the Olympic cauldron in Rio.

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in the system must be tackled. The country cannot afford the cycle where researchers face obstructions in securing finance and permissions. By the time the evidence is available the question has often changed.

Until careful coordination exists between the NHS and the National Institute for Health Research to

streamline research systems, we cannot know whether the work seen in Larwood and Bawtry should be replicated elsewhere. The new model may actually worsen the challenges facing primary care professionals.

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## BISPHOSPHONATES

### Drug holidays from long term bisphosphonates

At my practice we are designing a bisphosphonate protocol.

In the 10 minute consultation on bisphosphonates beyond five years (23 April), in the paragraph on offering drug holidays under the heading "What you should do," do patients have to fulfil all three criteria—that is, be under 75 years old, have a favourable T score, and be low risk as defined by FRAX? Or can they be offered the holiday if only one of the criteria is present?

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## Author's reply

Yes, patients should have all three criteria.

Decisions should be based on risk factors and calculated risk. Rather than thinking about the criteria for a holiday, think about those for continuing treatment. The FLEX study showed a reduced relative risk of vertebral fracture from continuing alendronate for 10 years in those with femoral neck T scores  $\leq -2.5$ . If the drug was stopped, risk of fracture, particularly vertebral fractures, increased with age and reducing hip bone mineral density (BMD).

It makes sense not to offer a drug holiday to someone who has developed additional risk factors, such as starting steroids or aromatase inhibitors or being diagnosed with a disorder associated with secondary osteoporosis—for example, hyperparathyroidism.

For a practice protocol, if any high risk characteristics (previous vertebral fracture; age  $>75$  years; femoral neck or hip BMD  $\leq -2.5$ ; new risk factors for fracture) are present, I would suggest continuing treatment for 10 years.

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