comment

> Shared decision making is much more than us all simply agreeing to disagree: it's dirtier and messier

NO HOLDS BARRED Margaret McCartney

The conflict of choice

Shared decision making is the pivot on which modern medical ethics rest. Doctor appraises patient of the choices available. Doctor supplies evidence and lays out the pros and cons. Patient has the intervention of choice. We are all happy.

Except we're not. Doctors deny patients treatments all the time. A patient may want 40 mg temazepam nightly as the only effective long term treatment for insomnia. Evidence may show ineffectiveness, dependence, and associated risks of falls and dementia; the patient may want it anyway, understanding the evidence and fully accepting the risks. I might prescribe if my patient had metastatic cancer and was at the end of life. I wouldn't, however, if my patient was otherwise fit and well, with a history of drug misuse.

Earlier this year Victoria Coren Mitchell, the professional poker player, wrote that her GP would no longer prescribe the combined oral contraceptive for her at age 35 "because I smoked and thus sat badly on the contraindications graph for heart attacks. I pleaded that, as an ageing gambler with a professional understanding of mathematical risk, I should be allowed to make that decision for myself—but no dice. So I gave up and got prescriptions privately at enormous expense."[1]

We do not have a drugs free-for-all. Doctors have duties at the interface of prescription and patient. We are not expected to agree with our patients' choices, and we are definitely not to pressure them into accepting our personal preferences.[2]

But we are in conflict. We are meant to act in the "best interests" of patients, but a patient may have radically different views from us on what those interests are. Our regulator says that we must "follow the advice" of the *British National Formulary*,[3] which advises us to "avoid" the combined contraceptive pill for 35 year old smokers. The risk for doctors is to their registration, reputation, and conscience if the stats play out badly. The patient risks side effects—including death, although rarely.

Where does medical responsibility meet patient autonomy? Shared decision making is much more than us all simply agreeing to disagree: it's dirtier and messier. Coren Mitchell's doctor seems to have refused to sign off on her drug of choice; she went elsewhere and got what she wanted. Another doctor was presumably willing to let the risks play out. But what of diazepam or codeine? Should the patient be allowed to accept all responsibilities for hazards and side effects?

Doctors often do not know the "right" answer, but they at least should acknowledge the irresolvable tension in choice. Mostly, it should be possible to negotiate a reasonable path of mutually acceptable risk—but sometimes it won't be. This becomes even more acute when parents or proxies decide against recommended treatments or threaten complaints for refusal to prescribe. Disagreements are inevitable; they're not necessarily a sign of bad medicine or bad doctors.

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Cite this as: *BMJ* 2015;351:h5312

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ANALYSIS

Not too little, not too much: problems of selecting oral antibiotic dose for children

J A Bielicki and colleagues compare common strategies for selecting antibiotic dose for children and discuss how best to balance usability with accuracy

WHAT YOU NEED TO KNOW

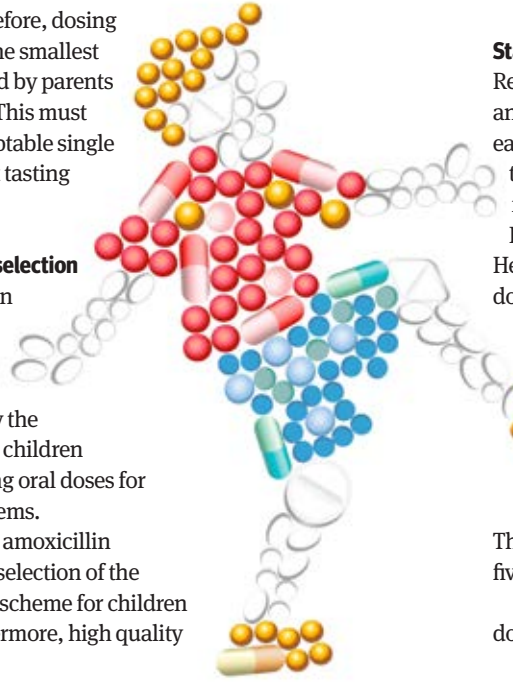
- Methods for selecting dose of oral antibiotics in childhood must balance simplicity with accuracy
- Although using exact weight is most accurate, it requires a recent weight and may not fit with fixed dose formulations
- Age bands result in a substantial proportion of children receiving doses outside the recommended range and are context specific
- Weight banded dose selection is transferable across populations and the most practical choice when up to date weight is available

Drug dosing in children is more complex than in adults. As the organs and immune system develop, the way in which drugs are absorbed, transported, and eliminated by the body changes, which in turn affects the drug's action on the body.[4] During the first two years of life, the evolution of renal function and hepatic metabolism have an important effect on the optimal antibiotic dose. Inaccurate dosing can lead to problems because higher antibiotic doses potentiate undesirable side effects, especially diarrhoea, and may promote the selection of resistant bacteria.[5]

Finding suitable formulations for children is also more challenging than for adults. Doses need to be titrated for optimal effectiveness and be adapted to maturational changes.[6] Achieving the correct dose may require splitting or crushing tablets.[7] Although liquids are the most flexible to dose, measuring small volumes can be inaccurate.[8] In one study more than two thirds of preventable adverse drug events outside hospital were due to parental errors in administering drugs.[11] Antibiotics accounted for a quarter of preventable adverse drug events and more than half of non-preventable events outside hospital.[11]

Antibiotic administration to children can be further complicated because many medicines are unpalatable. In addition, liquid formulations are cumbersome to transport and store. Practically, therefore, dosing of liquids in children is dictated by the smallest volume that can be reliably measured by parents with the provided spoon or syringe. This must be balanced against the largest acceptable single dose volume for an often unpleasant tasting medicine.

Clearly, the most accurate way of selecting the amoxicillin dose is to weigh the child and prescribe an exact mg/kg dose



PETER HERMES/ALAMY

Aminopenicillins: case study in dose selection

Aminopenicillins, such as amoxicillin and amoxicillin/clavulanate (co-amoxicillin), are the most commonly used oral antibiotics in children, and amoxicillin is probably the commonest single medicine given to children worldwide.[1 2] Approaches to selecting oral doses for aminopenicillins illustrate the problems.

There are over 50 generic licensed amoxicillin products in Europe alone,[12] making selection of the appropriate formulation and dosing scheme for children of different ages complicated. Furthermore, high quality data on the effect of selected formulations and doses of amoxicillin for children of different ages are lacking.

The summary of product characteristics for amoxicillin gives the target dose as 40-90 mg/kg/day in two or three divided doses for children weighing less than 40 kg; the standard adult dose (500 mg three times daily) is recommended for children weighing more than 40 kg. This wide ranging recommended daily dose represents a pragmatic approach to treatment that is believed to result in a relatively low rate of serious negative outcomes. Although there are no robust data to support this belief, the mortality associated with childhood infections commonly treated with oral amoxicillin is low in most high income countries.[15] However, the effect on development of resistant bacteria is unclear.[5 16]

Standardised dose selection

Regardless of the target dose, prescribers need a simple and rapid approach to identify the appropriate dose for each child. International guidance is inconsistent, with the United States and much of continental Europe favouring exact weight based dosing, the United Kingdom applying age banded dosing, and the World Health Organization recommending weight banded dosing.[17-19]

We compared the three main dose selection methods by simulating the accuracy of amoxicillin exposure using data on age and body weights of children in hospital from the Antibiotic Resistance and Prescribing in European Children (ARPEC) project point prevalence survey of antimicrobial prescribing. The data were collected in 61 UK paediatric units and five African paediatric units.[20]

For our simulation we defined the smallest deliverable dose as 25 mg (1 mL of 125 mg/5 mL suspension) based

Our data suggest that weight bands are relatively reliable in delivering a specific dose range to children

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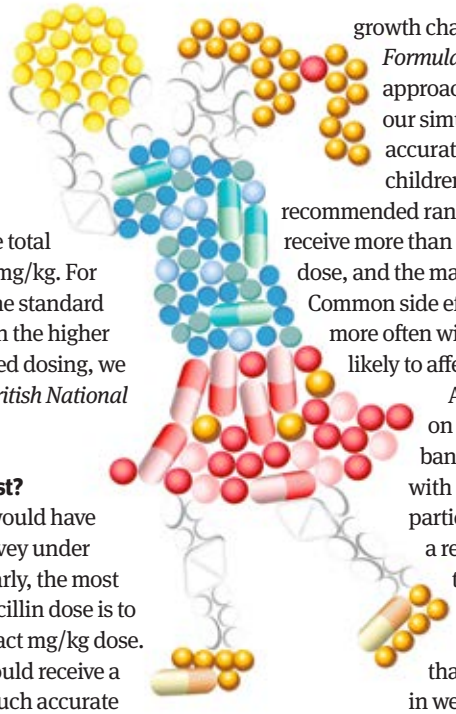
on existing measuring spoons and applied a maximum daily dose of 1500 mg, corresponding to the standard recommended adult dose for non-severe infection. Infants <6 days old or weighing <3 kg were excluded.

For exact weight based dosing the total daily target dose was defined as 70 mg/kg. For weight banded dosing we applied the standard WHO recommendations (rather than the higher pneumonia dosing).[19] For age banded dosing, we used the recommendations of the *British National Formulary for Children*.[17]



Which dose selection approach is best?

The table compares the doses that would have been received by children in the survey under the three approaches to dosing. Clearly, the most accurate way of selecting the amoxicillin dose is to weigh the child and prescribe an exact mg/kg dose. Using this approach, all children would receive a dose within the desired range, but such accurate dosing may be difficult to achieve. Solid formulations, such as WHO recommended dispersible tablets, cannot be divided sufficiently to produce exact doses for all children and dosing of small liquid volumes may become inaccurate.

These problems can be overcome by using weight bands. When we applied the WHO weight bands to our sample 8% of UK children and 4% of African children would have received a total daily dose below the recommended range (table). This may be a particular problem in settings with high incidence of invasive bacterial infections or high prevalence of antimicrobial resistance, especially pneumococcal penicillin resistance. Daily doses at the upper end of the recommended dose spectrum may be needed to treat infection adequately when there is a high prevalence of pneumococcal penicillin resistance.[21]

The simplest method of dose selection is to use age as a proxy measure for weight, based on the strong association between age and weight as reflected in growth charts. The *British National Formulary* has recommended this approach for 50 years.[17 22 23] In our simulation, this was the least accurate method, with 18% of UK children receiving doses outside the recommended range. Eleven per cent would receive more than the recommended daily dose, and the maximum dose was 179 mg/kg. Common side effects, such as diarrhoea, occur more often with higher daily doses, which is likely to affect adherence.[24]

Although WHO has commented on the advantages of using age banded dose selection for drugs with a wide therapeutic index,[17 25] particularly in situations where a recent weight is unavailable, this approach has some major difficulties. These include defining the age bands so that they reflect rapid changes in weight, accounting for weight being normally distributed around the 50th centile for age, and ensuring that locally relevant weight for age standards are used. In our simulation use of UK age bands would lead to every third African child being prescribed a dose above 90 mg/kg per day.

Total daily doses of amoxicillin in simulation of three dose selection approaches in 1037 children from UK and 252 from Africa with bodyweight ≤40 kg

	Total daily dose (mg/kg)				
	Median (interquartile range)	Minimum	Maximum	No (%) with total dose <40 mg/kg	No (%) with total dose >90 mg/kg
UK:					
Exact weight	70 (68-72)	60	80	0	0
Weight banded	57 (51-65)	31	83	83 (8)	0
Age banded	60 (49-75)	30	179	74 (7)	118 (11)
Africa:					
Exact weight	70 (68-73)	60	80	0	0
Weight banded	61 (53-68)	32	83	11 (4)	0
Age banded	72 (58-96)	20	250	8 (3)	80 (32)

Future options

Dosing is increasingly recognised as an important aspect of appropriate use of medications in childhood, especially for antibiotics. Published dose selection recommendations are now widely accessible and therefore potentially used outside the contexts they were designed for. Consequently, international agreement on the best approaches is needed.

Our data suggest that weight bands are relatively reliable in delivering a specific dose range to children and are not influenced by weight for age patterns. They also allow use of fixed dose formulations, such as dispersible tablets. However, they require an up to date weight. Although age banded approaches are simple, they are influenced by regional weight for age patterns and a substantial proportion of children receive very low or high total daily doses. This may be acceptable in some settings, such as in the UK where serious bacterial infection rates and antibiotic resistance are low. It remains to be seen whether antibiotic dose is an important factor in selection of resistant bacteria in vivo. If this were the case, a strong argument could be made for adopting weight banded dose selection to ensure selection pressure is minimised. Combined age and weight bands may be a partial solution, but they would still need to be tailored to the local context to account for variations in weight for age patterns.

Cite this as: *BMJ* 2015;351:h5447

PERSONAL VIEW Edward R Melnick

Replace unnecessary care with empathy

Sometimes no alternative, conservative option exists

"But how can you be sure, doctor?" the patient asked. "Wouldn't it help to get a CT scan? Just to be sure."

My heart sank: another patient here for a scan—not for my expertise and recommendations. On the basis of my evaluation, she had sustained a concussion caused by a low risk minor head injury. Good evidence indicates that computed tomography (CT) would be negative for clinically important injury.[1]

"Could I have a concussion?" she asked.

"You can't see a concussion on a CT scan," I explained. We discussed what a concussion is and what to expect after leaving the emergency department. A conversation followed; I listened to her concerns and addressed them. She looked relieved. Would a normal CT scan have given her the same reassurance?

In regions of the United States where people receive more healthcare services, some measures of health are worse.[2] Less overuse of health services (where potential harm exceeds the potential benefits) could result in better health.[3 4]

And yet, overuse continues for reasons including "fee for service" reimbursement, patient expectations, a quixotic quest for certainty, the glamour of technology, and defensive practice.[4 5]

Replace with necessary care

Referring to a patient with a herniated lumbar disc who was successfully treated conservatively with physical therapy instead of surgery, the surgeon and author Atul Gawande argued, "It isn't enough to eliminate unnecessary care. It has to be replaced with necessary care."[6]

For instance, the patient with concussion who would not benefit from diagnostic testing was still in need of necessary care in the form of education, counselling, and reassurance.

Time pressures and incentives that prioritise clinical productivity and patient satisfaction may prevent clinicians from actually caring for patients by creating a perception that it is "quicker to order a test or write a prescription than explain to a patient why they are not being treated."[4]

Such an approach not only contributes to the epidemic of overuse: it does surprisingly little to reassure patients, decrease their anxiety, or resolve their symptoms.[7] Furthermore, it jeopardises the very foundation of

I listened to her concerns and addressed them. She looked relieved. Would a normal CT scan have given her the same reassurance?

HEADS UP Krishna Chinthapalli

Choosing who to treat

When might it be justifiable to refuse to treat a patient?

In the US about 20% of paediatricians have sometimes refused to continue being a child's physician if parents persistently refused vaccination

"Physicians are not bound to treat everybody who walks through their door," except in emergencies, argued a US surgeon in 2004.[1] He had proposed a resolution to the American Medical Association (AMA) that doctors refuse to treat medical malpractice lawyers in response to frustration at mounting malpractice insurance bills. The measure was denounced, with one wit responding, "What [he] is proposing is egregious, both hypocritically and Hippocratically."

But are there circumstances in which refusal to treat (apart from emergencies) is justified if alternative care is available? One accepted scenario is refusal to see new patients if a practice is already full. The AMA's guidelines state that treatment can also be refused if it is beyond the physician's competence or if it is "scientifically invalid."[2] Physical violence and danger to self may also be legally valid reasons.

Breakdown of trust is another reason. In the US about 20% of paediatricians have sometimes refused to continue being a child's physician if parents persistently refused vaccination.[3] This year's measles outbreak in the US has led to some paediatric practices making it a policy to refuse any unvaccinated children. One argument is that such children pose a risk to themselves and others in the waiting room; another is that vaccine refusal suggests a lack of confidence in their physicians' advice.

The AMA guidance also says that treatment can be refused if it is incompatible with the doctor's personal, religious, or moral beliefs. Earlier this year a Michigan doctor gained international notoriety when she decided that she could not care for the baby of a lesbian couple and arranged for another doctor to see them instead. There is no state law in Michigan prohibiting discrimination on the basis of sexual orientation. By contrast, in the UK the General Medical Council says that a physician's personal views cannot affect the care they provide or arrange for a patient,[4] and the UK's Equality Act outlaws such discrimination.

Lifestyle choices

Lifestyle factors are another reason for not treating. Active alcohol misuse is a contraindication to liver transplantation, but that decision is in national guidelines. Last year when vascular surgeons in Edinburgh refused GPs' non-emergency referrals of smokers there was an outcry that it was "very God-like and highly unfair."[5]

On the battlefield, rules are clearer. Military doctors and doctors working

the doctor-patient relationship—a relationship predicated on care.[8]

Regardless of how overuse is curtailed, it must be replaced with empathic care. In our recent qualitative study of non-clinical factors that influence overuse of CT imaging in low risk minor head injury, clinicians and patients alike identified empathic themes—establishing trust, patient engagement, and reassurance—as essential in decreasing the overuse of imaging.[9]

Empathic engagement

A useful definition of empathy in patient care is the "cognitive attribute that involves an understanding of patients' experiences, concerns, and perspectives combined with a capacity to communicate this understanding."[10] The focus on cognition, understanding, and communication suggests that empathy can be taught and learnt (and that it can also decline or be forgotten).[10]

Watchful waiting or active surveillance are not the same as doing nothing; rather, genuine empathic care is fostering an encounter or a relationship in which patients are engaged with, are listened to, and have their concerns attended to.

Patients who are engaged by their clinician feel more informed, more accurately understand the potential benefits and harms of appropriate clinical options, and reach decisions that are more consistent with their values. Although not its primary purpose, patient engagement and activation may also simultaneously result in more sensible use of healthcare.[11]

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Cite this as: *BMJ* 2015;351:h5831

for humanitarian organisations are covered by the Geneva Conventions and must treat all injured military personnel equally according to need.

In 2005 the doctor Rafiq Sabir was arrested for agreeing to provide medical services to al Qaida forces in Iraq. He argued that it was his constitutional right to treat whoever he wanted. The jury believed that his actions amounted to more than just a physician's duty (he had allegedly pledged his loyalty to al Qaida), and he was imprisoned.

On the other hand, doctors at a Jerusalem hospital described treating an abdominal gunshot wound in a "leading member of Hamas" who was responsible for attacks on over 140 Israeli citizens. They asked in a medical ethics journal, "Is it in keeping with the fourth bioethical principle of justice to treat terrorists injured in the course of their terror activities, when they intentionally violate the basic principles of humanity and norms of society?"[6] The answer would seem to be yes, however difficult that may be.

What about doctors travelling independently to areas of conflict? In March nine UK medical students studying in Sudan entered Syria. One girl told her family that she wanted "to help wounded Syrian people," but her father asked, "She was living in a land [Africa] which needs a lot of doctors everywhere. Why would she go all the way to Syria for volunteering?"[8]

The Home Office has only said that "fighting in a foreign war is not automatically an offence, but will depend on the nature of the conflict and the individual's own activities."[8]

Choosing who to treat can be just as controversial as choosing who not to treat.

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Cite this as: *BMJ* 2015;351:h5828

ACUTE PERSPECTIVE David Oliver

Scare stories

A recent *Daily Mail* front page screamed, "Over 75? Sign here if you're ready for death."[1] It was referring to GPs planning care for patients with long term conditions who are at high risk of admission to hospital, including discussion of DNACPR (do not attempt cardiopulmonary resuscitation).

A third of hospital patients are in their last year of life.[2] Frailty, many long term conditions, and nursing home residence confer reduced life expectancy. So where's the scandal?

The National Institute for Health and Care Excellence (NICE) has published new draft guidelines on end of life care.[4] The *Daily Telegraph* responded, "The new end of life care guidelines are lethal."[5] The story? One doctor, Patrick Pullicino—not a palliative care specialist but a media savvy critic of the Liverpool care pathway—had dismissed NICE's diligent work. The newspaper presented little expert counterview.

The *Observer*[6] and the BBC[7] have carried more measured analyses, but sensationalism touches a mass circulation nerve, particularly when linked to an emotive subject that readers may be scared to consider or may link to bad family experiences.

Not dying is not an option, but helping people to die as well as possible is. The media narrative could inhibit clinicians from doing the right thing

In the National Survey of Bereaved People one in 10 rated quality of care as "poor,"[10] and the NHS Ombudsman has investigated many complaints involving terrible experiences.[11] Both highlight poor care planning and inadequate discussion of dying or pain relief.

Not dying is not an option, but helping people to die as well as possible is. The media narrative could inhibit clinicians from doing the right thing or prevent patients and families from engaging with skilled support.

Clinicians must show more sensitive and compassionate communication, whatever the pharmacological technicalities of symptom relief. We need better, more consistent training and awareness. We also need to challenge the media narrative with success stories, to counter half truths, and to highlight that the alternatives to care planning and palliative care are infinitely worse.

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Cite this as: *BMJ* 2015;351:h4846

OBITUARIES

Howard W Jones Jr

Reproductive medicine specialist who helped achieve first birth by in vitro fertilisation in the US

Howard W Jones Jr (b 1910; q Johns Hopkins University, USA, 1935), died from respiratory failure on 31 July 2015.

In 1978 Howard W Jones Jr and his wife were grappling with a major decision. They were debating whether to remain in Baltimore as emeritus professors after their mandatory retirements from Johns Hopkins University, or to accept an offer to become co-chairs of the new obstetrics and gynaecology department at the Eastern Virginia Medical School (EVMS), Norfolk.

Jones, at the time 67 years old and officially retired, had been allowed to remain two additional years in the office he had shared with his wife and long time research partner, Georgeanna Jones. But at 65, she was now also on the verge of mandatory retirement.

Howard and Georgeanna Jones duly considered the advice of their children—and then they followed their hearts. They accepted the job offer and began a new adventure that would not end for Jones until he died this year, at the age of 104.

Indeed, at EVMS they opened the first in vitro fertilisation (IVF) clinic in the US, recruiting talented staff to work towards the goal of achieving the first American "test tube baby."

In 1981, after dozens of failed attempts, Jones and his team finally succeeded. The result was the birth on 28 December 1981 of Elizabeth Carr by caesarean section, an event that made headlines around the US. In 1983 their IVF clinic was named the EVMS Howard and Georgeanna Jones Institute for Reproductive Medicine.

BILL TIERNAN

Marriage of true minds: Jones took his wife along to scientific meetings

Howard Wilbur Jones Jr was born on 30 December 1910 in Baltimore. His father, a physician, died when Jones was 13 years old. Jones graduated in 1931 from Amherst College in Massachusetts, where one of his English teachers was Robert Frost, whose poetry Jones liked to quote. In his first year of medical studies at Johns Hopkins, Jones met Georgeanna Seegar, whose father had been the attending doctor when Jones was born.

After earning his medical degree in 1935, Jones completed an internship and residency in general surgery while working with gynaecologist Howard Kelly and then Kelly's successor, Thomas S Cullen. During the second world war, Jones served as a general battlefield surgeon with US General George S Patton Jr's Third Army as it moved across France into Germany. After the war, Jones continued training in gynaecology. In 1948 he and his

Mirza Basheer Baig

Former medical assistant/associate specialist in orthopaedic surgery West Suffolk Hospital (b 1926; q Osmania University, India, 1954; q Edinburgh 1971; FRCS Ed), d 26 January 2015.

Mirza Basheer spent his most productive years on the wards of the West Suffolk Hospital. His career was cut short when he was involved in a serious car crash while responding to an emergency call in 1979. He still took an active interest in medicine, but he missed performing surgery. He leaves his wife, Shahnaz; two daughters; and three grandchildren.

Samina Baig

Cite this as: *BMJ* 2015;351:h4794

David Richard Firth

General practitioner (b 1932; q Oxford and St Thomas' 1957; MA, MRCS, DRCOG, MRCGP), died from metastatic carcinoma of the prostate on 22 November 2014.

David Richard Firth was a singlehanded GP in the Devon village of Shaldon from 1963 to 1994, familiar to everyone doing his rounds on his bicycle or on foot. He often had three generations in one family. He leaves his wife, Dorothy; four children; 11 grandchildren; and a great granddaughter.

Dorothy Cullen

Cite this as: *BMJ* 2015;351:h5588

Joshy John

Consultant physician in genitourinary medicine (b 1940; q Kerala University, India, 1966; MD), d 18 December 2014.

Joshy John was awarded his first consultant post at the Royal Infirmary Derby in 1976. Throughout his career he published widely and gained professional respect through presenting at international conferences. He is best remembered for his charm, wit, and kindness, which captured the heart of so many. Predeceased by his daughter, he leaves his wife, Tresa; two sons; and two grandchildren.

Gay Francis

Cite this as: *BMJ* 2015;351:h4904

Anne Dollar Schofield

Former general practitioner and clinical medical officer in community health (b 1921; q Edinburgh 1945), d 9 January 2015.

Anne Dollar Schofield (née Davies) worked in paediatrics before moving to St James' Hospital, Balham, London. She returned north of the border, where she continued to work as a GP until she married Graham. After raising two daughters, Anne returned to work part time as a clinical medical officer in community health. Predeceased by Graham in 2010, she leaves two daughters and five grandchildren.

Janet Tulloch

Cite this as: *BMJ* 2015;351:h4907

Howard Jones was a pioneer in reproductive medicine and an outstanding surgeon

wife became part time faculty members at Johns Hopkins while operating a private practice, which they left in 1960 to teach full time at Johns Hopkins until their move to EVMS.

Over the years Jones was author of more than 300 research papers and a dozen books. With Georgeanna he served as co-editor in chief of *Obstetrical & Gynaecological Survey* and was a member of more than 20 scientific societies around the world. In 1986 he and Georgeanna were named fellows *ad eundem* of the Royal College of Obstetricians and Gynaecologists.

In 2002 Edwards published *Tribute to Georgeanna and Howard Jones*, recalling his working visit to Baltimore in 1965, and subsequent relationship with the Joneses. In 2010, when Edwards won the Nobel prize, Jones spoke of a much deserved honour for Edwards that should have happened 15 years earlier.

Jones officially retired in 1997 to care for Georgeanna, who had developed Alzheimer's disease. She died in 2005. Until being admitted to hospital in July this year, Jones remained active, keeping regular office hours, writing, and attending conferences.

"What most stands out in my mind," Zev Rosenwaks, director of the Ronald O Perelman and Claudia Cohen Center for Reproductive Medicine at Weill Cornell Medicinal College in New York City and a former student of Jones's, says, "is the way Dr Jones took care of his wife when her health deteriorated later on in her life. In spite of her health issues, he took her along to all the scientific meetings and supported her with remarkable care and dignity. This underscores his wonderful human quality, which even transcends his unique contributions to medicine."

Howard Jones leaves a daughter, and two sons.

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Cite this as: *BMJ* 2015;351:h4975

John Brian Taylor

General practitioner senior partner Paignton, Devon (b 1924; q Queens University, Belfast, 1948; FRCGP, DCH, DRCOG), d 20 October 2014.

During his years as a GP in Paignton, John Brian Taylor published papers showing increased risk of pre-eclampsia in women with a high height:weight ratio, originated preconception clinics for young women, and chaired the district medical committee during the building of Torbay Hospital. He and his wife, Bryony, a fellow GP, had three children, who followed their parents into dentistry or medicine.

Peter Taylor

Cite this as: *BMJ* 2015;351:h4909

John Gordon Weir

Consultant psychiatrist (b 1921; q 1952; MD. DPM Eng, FRCPsych), d 2 September 2014.

John Gordon Weir ("Jack") held successive posts at mental hospitals in England, before becoming consultant psychiatrist at St Mary's Hospital, London, and the Mildmay Mission Hospital. He also worked in private practice. Ishbel, his wife of 62 years, predeceased him by four months. He leaves two daughters.

Judith Weir

Cite this as: *BMJ* 2015;351:h4908

5 MINUTES WITH . . .

Joanna Rose

The winner of a test case that led to legislation banning anonymous sperm donation tells *The BMJ* why that legislation did not go far enough

Ten years ago a landmark change in UK law gave children conceived through donated sperm or eggs in the UK the right to identifying information about their donor parent once they reached 18. This followed a test case in 2002 brought by Joanna Rose, who argued that she had the right to know her genetic identity.

When she was 8 years old Rose found out that she was conceived from donated sperm, yet even today she does not know the identity of her genetic father, as the law does not apply retrospectively. "It has had such a huge impact," she says. "I saw it as blocking my way, and I wanted to resolve it."

"The rights of the children in donor conception cases have never really been properly considered"

After the court case Rose completed a seven year PhD on sperm donation practices, and she continues to fight for parity with adoption, where in 1975 the law was changed retrospectively, removing the anonymity of parents, because it was deemed in the best interests of the adopted children.

In donor conception the focus is on helping adults with infertility and supporting the industry that has grown up around it, she says. The rights of the children in donor conception cases have never really been properly considered, she adds, and as a result the effects on them are barely acknowledged.

"I don't think that conception between strangers should be funded and facilitated, especially when we have got thousands of children swashing around the care system. You can't say that these couples don't want to adopt a child because biology matters and then at the same time say that biology matters for the adults but that it doesn't matter so much for the children.

"There are lifelong issues expected in adoption, and it is intergenerational. Adoptees are over-represented in crisis care, and because it is on the birth certificate we know that there are more adoptees in psychiatric hospitals, in prison, and having learning difficulties. It's not on our birth certificates, but you can bet your bottom dollar we are over-represented in crisis care too."

Sperm or egg donors who are willing to waive their anonymity can register at the UK Donor Conceived Register (www.donorconceivedregister.org.uk), a service that enables donor conceived children to find out information about their genetic parents and any siblings.

Joanna Rose was interviewed by Ingrid Torjesen

Cite this as: *BMJ* 2015;351:h5864

ADDENBROOKE'S

Why Addenbrooke's was rated as inadequate

Care Quality Commission inspectors had no preconceived ideas about Addenbrooke's (Feature, 10 October). We knew that performance and finances had declined but did not expect sufficiently severe safety, quality, and leadership issues to merit an "inadequate" rating—real and immediate risks to safety.

Performance on national inpatient diabetes and heart attack audits were below the national average. The stroke audit scored D. Only 79% of patients had venous thromboembolism risk assessments (national average 96%).

In maternity services we found serious concerns regarding fetal heart rate monitoring. Staffing levels in critical care fell below national guidelines; staff knew this, but it was initially refuted by the chief executive.

Staff told us about the disconnect between the ward and senior executives, as corroborated by the 2014 NHS staff survey—16 of the 28 items were in the bottom 20%, none were in the top 20%.

The trust has responded positively and I am confident it will take the actions needed for improvement.

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Cite this as: *BMJ* 2015;351:h5719

What in fact went wrong at Addenbrooke's

The Feature article on Addenbrooke's was ill informed and misleading. Many of the Care Quality Commission's conclusions are based on what staff told inspectors. The report repeatedly highlights failures in systems and processes, ineffectual senior leadership, and a disconnect between trust hierarchy and staff.

The departed chief executive officer was ultimately responsible for strategic blunders. His "grip" on how to run a hospital like Addenbrooke's was non-existent. I agree that these inspections are perhaps not geared to evaluating a major teaching hospital and that external factors also contributed to our current circumstances. However, several problems we face today are of our own making.

Our clinical outcomes are good despite all this, reflecting the calibre of our staff. We are determined to get through this difficult phase and make Addenbrooke's world class again. Consultants must engage more with trust level decisions and facilitate culture change—our responsibilities extend beyond our wards and clinics.

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Cite this as: *BMJ* 2015;351:h5787

LETTER OF THE WEEK

Prescription zopiclone easily available online

The use of "Z drugs" has recently increased; in 2013-14 zopiclone was the sixth most common drug in enquiries to the UK National Poisons Information Service's online database, TOXBASE.

We recently managed a patient whose overdose of 100 tablets of 7.5 mg zopiclone, bought on the internet without prescription, highlights these problems.

In an internet survey we identified 37 websites selling zopiclone tablets in quantities of up to 2000. Thirty five also sold other benzodiazepines/Z drugs and 15 offered bulk purchase discounts. Most (24) provided information/warning about dosage, but 22 stated that no prescription was needed for purchase, while 14 made no mention of this at all. Only one stated that a prescription was needed.

In 2014, zopiclone was controlled in the UK as a class C drug, owing to concerns about dependence and potential misuse. Despite this, zopiclone is available from internet sites without prescription. Not only do these websites bypass necessary oversight required for supply, they provide access for vulnerable people to buy it for self poisoning, suicide, or misuse. Regulatory authorities must take measures to ensure that these websites comply with medicines and other regulations for the supply of this prescription only drug.

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Cite this as: *BMJ* 2015;351:h5710

ACCESS TO PATIENT DATA

HSCIC's response to article on access to patient data

The Health and Social Care Information Centre is committed to supporting research and ensuring that data are available for researchers (Views and reviews, 17 October).

When applicants request data that might identify individuals we are lawbound to ensure safeguards are in place—all applicants must show that data will be used to provide or promote health or social care, and that appropriate security and any legal permissions needed are in place.

I realise that such scrutiny may be daunting or frustrating to researchers, and that the recent changes caused delays. We now have a larger specialist team and will give applicants more clarity about timelines.

To earn and maintain public trust we must ensure that data are shared in a legal, controlled, safe, and transparent way. Only with this trust will we be able to release data to support the innovation that can unlock future improvements in care and treatment.

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Cite this as: *BMJ* 2015;351:h5820

DRUGS FOR TYPE 2 DIABETES

Basing approval of drugs on real world outcomes

Naci and colleagues (Analysis, 17 October) point out that drugs for type 2 diabetes are often approved on the basis of glucose lowering efficacy, whereas outcomes such as symptomatic microvascular disease and cardiovascular events are more important.

At the University of Surrey we have entered into partnership with Eli Lilly to provide essential outcomes data using primary care records. Our preliminary analysis highlights the need to extend studies into the real world. In practice, people treated with glucagon-like peptide-1 (GLP1) agonists and sodium-glucose co-transporter-2 (SGLT2) inhibitors have a significantly higher body mass index than do those in clinical trials (GLP1 agonists: 37.5 *v* 31.8, P<0.001; SGLT2 inhibitors: 34.7 *v* 30.6, P<0.001).

Trial populations are therefore not representative of the people treated with these new drugs, and only well constructed studies in the real world will confirm the effectiveness of new and existing drugs.

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Cite this as: *BMJ* 2015;351:h5829