

BORDER CROSSING Tessa Richards

# Enlist the patients' help

Supporting people to self manage chronic disease could help reduce its global burden

Next week the United Nations will unveil its blueprint for tackling the global epidemic of chronic non-communicable disease, which threatens economic and social development in poor countries and is putting unsustainable burdens on all countries' health systems (*BMJ* 2011;343:d5762).

The UN's initiative has provoked much debate. The decision to focus solely on cardiovascular disease, diabetes, chronic respiratory disease, and cancer was criticised. Mental health should also have been on the list, because it's the coexistence of depression and fatigue that erodes patients' quality of life and accounts for most of their loss of productivity. Obesity, musculoskeletal disorders, and neurodegenerative disease should have been included too, and more emphasis put on drivers such as population ageing, malnutrition, and the wider determinants of health.

Although there has been broad consensus on the "asks" from the summit (*BMJ* 2011;342:d3823) and the need for multisectoral action to tackle shared risk factors, successive "tinkering" to the draft outcomes document has led to accusations that it lacks teeth (*BMJ* 2011;343:d5836; 2011;343:d5336).

Amid the controversy scant attention has been paid to the patients. This is surprising. There is convincing evidence that supporting patients with chronic disease to self manage their conditions and make informed choices about treatment is a good way to improve the quality and safety of care and reduce costly and inappropriate over use of healthcare resources (*BMJ* 2011;342:d1513). Their input into service design and delivery and the research agenda is valuable too.

Most of the research on patient empowerment and shared decision making has been conducted in rich countries, where its promise is recognised by policy makers and the principles incorporated into new integrated care initiatives in the United States and the United Kingdom. Last

week, British general practitioners were urged to help patients with chronic disease play an active part in managing their own conditions (*BMJ* 2011;343:d5623).

But there is also good evidence, from a wide range of community based studies in low and middle income countries, that engaging patients and supporting them to play an active role in managing their disease holds promise in all countries, researchers at the George Institute for Global Health underline. The institute, which has hubs in Australia, China, India, and the UK, has spent the past 12 years investigating innovative affordable strategies for managing chronic disease, mostly in disadvantaged populations in low and middle income countries.

At a parallel meeting in New York next week, to which UN summitteers are warmly invited, the institute will launch a new policy document, *Patient Empowerment: A Fundamental Building Block for Tackling Chronic Disease*, to push this view. The paper defines the fuzzy concept of empowerment, describes how it can be "operationalised," and argues that it's not just a nice thing to do but a cost effective intervention that can be implemented widely and should be at the heart of health system reform in poor as well as rich countries.

Patients with complex chronic disease consume the lion's share of health budgets, and a few run up spectacular bills. In a compelling essay in the *New Yorker* Atul Gawande brings the concept of empowerment to life by describing how doctors have been able to help individual "superutilizers" of services by recognising that it's essential to forge close ties with them (<http://nkr.kr/g3Qqw1>).

Rushika Fernandopulle, a primary care physician in New Jersey, is one of the "pioneers" whose work he cites and is among a growing cadre of health professionals urging for root and branch reform of self serving paternalistic health systems that frustrate patients and doctors alike.



“Patients in all countries can play a part in tackling the burden of chronic disease—if given the chance

”

#### bmj.com

● Feature: UN high level meeting on non-communicable diseases: an opportunity for whom? (*BMJ* 2011;343:d5336)

● Analysis: Nutritional change is not a simple answer to non-communicable diseases (*BMJ* 2011;343:d5097)

● Feature: Trans fats: chasing a global ban (*BMJ* 2011;343:d5567)

● Feature: Will industry influence derail UN summit? (*BMJ* 2011;343:d5328)

#### bmj.com/blogs

● The final declaration for the UN summit on NCDs

● UN meeting on NCDs goes wobbly

● More on the United Nations meeting on NCDs

“We mostly deliver care the wrong way,” he says. “It’s doctor led, episodic, reactive, and [in the US] obscenely expensive. We are good at managing single diseases such as coronary artery disease but poor with the comorbid conditions such as obesity and depression, which are killing us.”

His practices have replaced fee for service payments with per capita charges; provided lay health coaches for patients with chronic disease; and “totally changed the way IT systems are used.” The health coaches are selected for “attitude,” not pre-existing knowledge and a background that chimes with the patients’. They build long term, supportive relationships with patients (not dragoon them to comply with doctors’ orders) to promote their confidence and skill to self manage disease.

Patients have full online access to their medical records and relevant information, organise their own blood tests, feed in test results, schedule their own surgery visits, and let the practice know how they are getting on. The primary care team keeps a daily vigil on the data and the information that patients feed in; check whether prescriptions are collected, appointments kept, and unscheduled visits to secondary care made; and springs into action at the first sign of trouble. It’s a vision that most patients with chronic disease, and those who care for them, can only dream of.

The World Health Organization sees patients’ growing interest in self management as a positive development and has flagged up the scope for new technologies to support it.

A new book, *Engaging Patients in Healthcare*, by Angela Coulter, provides comprehensive guidance on “how to do it.” Its message echoes the one being sent out by the George Institute: patients in all countries want and can play a part in tackling the burden of chronic disease—if given the chance.

**Tessa Richards is assistant editor, *BMJ* [trichards@bmj.com](mailto:trichards@bmj.com)**

Cite this as: *BMJ* 2011;343:d5827

LOBBY WATCH Jane Cassidy

## Jewish Medical Association UK

### What is it?

The Jewish Medical Association UK (<http://jewishmedicalassociationuk.org>) promotes academic, clinical, professional, and social links between Jewish doctors and other healthcare professionals in the United Kingdom, as well as between the UK and Israel. Supporting UK Jewish doctors and informing them about Jewish and Israeli medical approaches and achievements, the association also awards bursaries for UK medical students to spend an elective period in Israel and provides scholarships for attendance at conferences. It acts as the UK link organisation to the Israeli Medical Association.

In line with this aim, this month members were being offered the chance to travel to Israel for a week long course that aims to help them prepare for a terrorist attack. The event, “9/11 ten years after: what have we learned?” is part of its Emergency Response Group course and offers to teach doctors working in emergency medicine procedures that they can implement in their home communities. Doctors are to be paired with counterparts at the Western Galilee Hospital in Nahariya, Israel’s northernmost coastal city. They will also visit Israeli Defence Force border facilities, where a mass casualty event will be staged with actors as patients.

Israeli clinicians are at the forefront of the specialty known as terror medicine, a discipline that tackles the medical challenges facing nations that experience regular terrorist attacks. It considers areas such as preparedness for, incident management in, injuries resulting from, medical responses to, and psychological consequences of terrorism.

In 2009 more than 700 doctors from 43 countries called for the president of the Israeli Medical Association to step down from his role as head of the World Medical Association (*BMJ* 2009;338:b2556, doi:10.1136/bmj.b2556). In a letter they claimed that Yoram Blachar had turned a blind eye to the “institutionalised involvement of doctors” in torture in Israel. In correspondence in the *BMJ* Dr Blachar has several times denounced the use of torture by Israeli doctors. In 2003 he wrote, “I repeat, for the hundredth time, that the IMA [Israeli Medical Association] and I as its president oppose torture in any form” (*BMJ* 2003;327:1107).

### What agenda does it have?

The Jewish Medical Association UK responds to questions about Jewish observance, employment rights, and medical ethics. It also helps with applications for trainee posts and offers career advice. It refers members and others to medical guidance produced by the Board of Deputies of British Jews. David Katz, who chairs the association, is also a member of the Board of Deputies’ executive committee.

The board monitors campaigns against circumcision and makes statements on the safety of the procedure and the Jewish community’s right to carry it out. The Jewish Medical Association’s website also has a statement outlining Jewish principles relating to transplantation. Blood donation, bone marrow transplants, donating corneas after death, and donating kidneys in “live related donor” programmes are all permitted.

A key area of concern is that death as defined in Jewish law has occurred before any organ may be removed. The London Beth Din rabbinical court has ruled that organs from Jews may be removed for transplantation only at the point of cardiorespiratory failure and not at brain stem death.

Members of the association help on an informal basis by matching trainees seeking help with doctors who are willing to support them. Building on the history of Jewish doctors’ associations that helped refugee clinicians desperate to secure permission to enter the UK in the 1930s, they also run a programme to support refugee doctors.

### Where does it get its money from?

The association is a charity and charges a membership fee. For the financial year ending 31 July 2010 it registered £46 532 in income and £49 184 in spending with the UK Charity Commission.

Jane Cassidy is a freelance journalist  
[janecassi2@googlemail.com](mailto:janecassi2@googlemail.com)

Cite this as: *BMJ* 2011;343:d5730

Lobby Watch is a regular column that looks at people and organisations who have an influence on public health and on how healthcare is delivered.

### [bmj.com/archive](http://bmj.com/archive)

- ◉ Christian Medical Fellowship (*BMJ* 2011;343:d4586)
- ◉ Islamic Medical Association (*BMJ* 2011;343:d5592)

BMJ.COM BLOGS

## Is prostitution really the answer?

I have recently been enjoying a brief flurry of reviews of Catherine Hakim’s *Honey Money: The Power of Erotic Capital*.

Hakim—a senior researcher at the London School of Economics—declares that a conspiratorial alliance of religious fundamentalists, feminists, and male chauvinists has for too long suppressed the real value of the “sexual capital” of young women.

She identifies what she calls a “sex deficit,” a disequilibrium in desire between men and women so significant that if sexually attractive (and therefore, in her view, younger) women were able to claim their real value in the market place, a sea-change in power relations between men and women would surely follow. Prostitution, to put it baldly, will be the undoing of patriarchy.

Among the many political currents that were tugging at me when I was a downy youth, far and away the most vigorous was feminism. Needless to say as a man I tread gingerly here. There were—there still are—many different voices in feminism.

Some of them, influenced by Marx, declared marriage to be an economic arrangement no different in kind from prostitution. Women traded their reproductive and domestic labour in the marriage marketplace, just as, later, they would trade their productive labour in the workplace.

Hakim suggests instead that young women should rejoice. They should sweep away the veils of sentimentality and joyfully trade their sexual capital in the open market.

One of the memories I have of those early years of exposure to feminism is of the heady perfume of idealism, and among the more melancholy aspects of Hakim’s thesis is the loss of this.

The high call of justice gives way to the low calculus of self-interest. What happened to the desire to liberate women from the need to trade their sexual capital?

Perhaps every age gets the theories it deserves, and ours is the age of science and self-interest. But just as I am tempted to write us off for our low materialism a lively conversation in the parlour of a modest Georgian country house comes to mind.

“At all costs follow your heart, Miss Eliza Bennet,” I hear Jane Austen say in *Pride and Prejudice* with a little sparkle in her eye, “but whatever else you do, make sure you marry a rich man.”

**Julian Sheather, ethics manager, BMA. The views he expresses in his blog posts are entirely his own.**

◉ Read this blog in and others at [bmj.com/blogs](http://bmj.com/blogs)



Advice to daughters: Mrs Bennet