

Targets for dementia diagnoses will lead to overdiagnosis

The government is putting pressure on commissioners, who in turn are putting pressure on general practitioners, to make more diagnoses of dementia. Why has no analysis been done of the harm that such targets can cause, asks **Martin Brunet**, and where does it leave the doctor-patient relationship?



Imagine the scene: you are about to review Mrs Jones in the memory clinic. When you saw her six months before you diagnosed mild cognitive impairment (MCI). But that was before your locality appeared on the wrong list on the UK government's "name and shame" Dementia Challenge website,¹ which publishes rates of dementia diagnosis for every clinical commissioning group (CCG) in the country. And it was before you viewed the accompanying video of Jeremy Hunt lambasting the "laggards" for their poor performance. And it was before your clinical commissioning group made raising diagnosis rates a priority, with financial strings attached, and started leaning heavily on you to make diagnoses—any diagnosis, it would seem; they just need to get the numbers up.

Would it really harm Mrs Jones to give her diagnosis an upgrade, to confirm her fears and call it dementia? Aren't we supposed to diagnose it earlier these days? She'll probably progress towards it anyway. As you call her in from the waiting room you wish that you could forget the inconvenient research that MCI often does not progress to dementia and can even improve.²

Medicine depends on a fundamental, unspoken agreement between patients and doctors. Patients make themselves profoundly vulnerable as they reveal their stories and subject themselves to examinations and investigations. Doctors promise to use all their skills to try to find an explanation for patients' symptoms, by forming a diagnosis. It is implicit in this diagnostic process that the only factor influencing the decision to diagnose should be the best interests of patients. The idea that doctors should be motivated by self interest, such as personal or corporate gain, is abhorrent and undermines the basis of the relationship.

The making of a diagnosis is a key moment in a patient's journey. It can bring great benefit by opening the door to effective treatments and support as well as giving a much needed explanation for worrying symptoms. But it can also bring great harm if incorrect.

Screening for dementia is not recommended in the UK³ and has been the subject of much debate in the last year.⁴ However, the setting of target rates for the diagnosis of any condition is a novel and unstudied concept that has



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now arisen in dementia care, and one which has largely gone unchallenged despite its potential to lead to substantial harm.

In its rhetoric on diagnosis rates, NHS England has been careful to use words such as "ambition" and "goal,"⁵ perhaps finding "target" too inflammatory, but it is the degree of pressure applied to achieving these goals that matters. CCGs listed among the 10 worst in the country will be desperate to remove themselves from such scrutiny, and at least one CCG has made the goal into a financial target. In response to a freedom of information inquiry, Herefordshire CCG has confirmed to me the incorporation of a target for dementia diagnosis rates as one of its local measures within the quality premium payment. The CCG has written to local general practitioners, stating, "The CCG needs to increase prevalence to 40% by April 2014 and 50% by April 2015—and will lose significant income if we miss these targets."⁶ Accompanying the letter was a graph detailing the diagnosis rates of each practice in the CCG, with the implication that those with lower rates needed to work hardest to help the CCG earn this income.

The potential harms inherent in setting targets for diagnoses have not been analysed, despite the obvious danger that working towards targets can lead to perverse behaviours and outcomes, because the needs of patients are made secondary to the requirement to fulfil quotas. What is more, the figures themselves are highly questionable. The Delphi analysis used to estimate diagnosis rates⁷ is an extrapolation of data that are more than 20 years old, and the latest evidence indicates that there could be at least 200 000 fewer cases than previously thought.⁸ Estimates have inherent statistical error but the figures are never quoted with confidence intervals. At population level these intervals might be quite small, but when data intended for a population of 60 million are applied to a practice of 6000, the error bars must be magnified to a degree as to make the numbers meaningless—but they are quoted with an absurd degree of precision. My own practice apparently has a diagnosis rate of 126.7%,⁵ which can only be explained by overdiagnosis, highly erroneous figures, or both. If our practice figures are wrong by at least 30 percentage points, then this could also apply to every so called "laggardly" practice in the country.

Dementia is big business, and there are many vested interests that stand to benefit from a rise in the number of diagnoses.⁹ Currently the use of diagnosis target rates is proving to be a highly successful strategy for politicians and industry. If we fail to question their validity, the ethical concerns that underpin the making of a diagnosis and the danger of overdiagnosis, then we risk replication of this strategy in other areas of medicine. The diagnosis must always belong only to the patient, and never to government, policy makers, or commissioners. An urgent debate is needed before this gets out of hand.

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NO HOLDS BARRED Margaret McCartney

Welcome to the two tier NHS

The healthcare company Better as.one has a vision: “Your dream NHS, made a reality.”¹ Sadly it doesn’t include George Clooney; it’s a new scheme in which people pay a few hundred pounds a year for insurance that entitles them to one or two “free” specialist consultations a year. The website says that no one is turned down and that “as.one is responsible for your medical welfare from diagnosis through to full recovery. We arrange all tests, procedures and treatments to ensure your complete peace of mind.”

With “no waiting for your GP,” it says, you can see “top consultants” who have been “peer recommended.” Within five days of contact the company promises a phone call from an “on-call consultant triage team” and “essential tests arranged for you quickly.”

So you don’t need to bother with primary care and can go straight to a consultant. However, you’re likely to go back to the NHS for the tests. Better as.one says that if these are “available



The truth, though, is that patients who cannot pay will have to wait for longer behind those who can

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on the NHS there is nothing for you to pay including follow-up visits with your consultant. 98% of tests are available on the NHS.”

It goes on to say that GPs often delay referral with watchful waiting or maybe a prescription “to see what impact this has,” and that signing up for Better as.one’s service will result instead in a “fast track to treatment on the NHS.”

But this proposition undermines the entire construct of the NHS. Primary care is not the slovenly enemy but a solution to increased demand, rising costs, and overtreatment. General practice protects colleagues in secondary care from unnecessary referrals and provides care that does not require their input. Each needs the other. Getting rid of primary care would simply lengthen hospital waiting lists, meaning that patients who needed to be seen sooner would miss out.

More troubling is Better as.one’s insinuation that the NHS should

take the strain for interventions recommended in a private consultation. Why should the NHS have to bear the costs of sorting out non-evidence based interventions that began in the private sector?

Some patients pay to be seen privately in the hope that any tests or treatment covered by the NHS will be done more quickly. The truth, though, is that patients who cannot pay will have to wait for longer behind those who can. The Better as.one business model attempts to put its patients at the front of the NHS queue, and doctors are playing along with this arrangement. This is contrary to the spirit of the NHS—that is, it allows the ability to pay to trump need.

Companies like Better as.one may divide and fracture the NHS.

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BMJ BLOG OF THE WEEK Richard Smith

Rediscovering a *BMJ* gem

After a class I taught recently one of the students came up to me and said, “My mother was fond of you. Her name was Clare Vaughan.” I remembered. I met Clare only once, shortly before she died in July 1996 in her early 40s. My memory of the meeting is hazy. But what I remembered clearly and have now reread many times is the piece Clare wrote for the *BMJ* as she was dying (*BMJ* 1996;313:565). It’s a gem that deserves a special place in the profusion of medical writing, most of it unprecious.

Clare describes being with her five year old daughter when she discovered that her breast cancer had recurred. The initial diagnosis, four years before the recurrence, gave Clare, clearly a high achiever, great energy. Everything—mothering, working, teaching, doctoring—had to be

perfect. But it was dying, which she describes as “the biggest adventure of all,” that gave Clare insights into her life “in a totally unexpected way.”

She describes herself as a “doer and a fixer.” “Doctors,” she observes, “have this terrible problem: they need to be needed so badly.” She candidly observes that, like many doctors, she was “quicker and brighter and more impatient than most other people.” She had been plagued with anger. She hadn’t dealt with these things, but dying allowed her, taught her, to do so.

Should she have more chemotherapy? She decided against. “My heart told me to nurture all the wonderful bits of my life rather than to try again . . . to poison the tumour.” That must have been a hard decision for a woman with three young

children and a husband who was “desolate.” But surely it was the right decision. I’d like to think that I will be brave and sensible enough to decide the same when my time comes—perhaps very soon.

Most people when dying, she observed, “get medicalised and pitied and feared and isolated.” She concluded that “advanced cancer is a curious condition” and she believed that we “understood it very poorly.” The appearance since Clare’s death of new, often very expensive drugs that offer a few extra weeks of life may mean that we often don’t even try to understand advanced cancer. We simply try to defeat it. This may often be the wrong choice.

Memorably Clare thought we needed “midwives for dying,” people with “the particular skills



of companionship, passage, and journey with a prescribed endpoint.” There are such people; her Macmillan nurse was one. But there aren’t enough of them. We’ve invested instead in oncologists, perhaps another wrong choice.

Richard Smith was the editor of the *BMJ* until 2004 and is director of the United Health Group’s chronic disease initiative.

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