Text of lecture: Why do all the forbidden words in the NHS begin with R: “Rationing”, “Reorganisation” and Rationalisation.

by davidalock

Over the next 40 minutes or so I will attempt to explore a serious problem of resource allocation and health rationing in the NHS and, I hope, show that this problem is far from unique to the NHS but also exists in healthcare systems throughout the world. And I will end with a call for those who are leading the NHS in our communities up and down the country to play their part in leading public debate on these difficult issues.

First, a health warning. I am a practising lawyer who has spend time as an MP, government minister and over a decade acting for and against NHS bodies in a wide variety of challenging situations. My views are anecdotal not systematic. I hope they are emerge of my various experiences but they are not supported by volumes of academic research.

It is a highly appropriate time to be considering the processes of managing change in the NHS for 3 reasons. First, because the NHS has just lost – by retirement – a significant figure in Sir David Nicholson and welcomes Simon Stevens – not yet Sir Simon – who takes over as Chief Executive of the NHS Commissioning Board, known as NHS England. A change of leadership gives a window of opportunity for an incoming leader to set a new agenda. However the importance of these issues is shown by the fact that Sir David, free of the chains of office, tweeted a link to an article I wrote for the Guardian sketching out these issues, hence inviting his 4000+ twitter followers to read it.

Secondly, the NHS is also facing an unprecedented financial challenge in 2015/16. This is, "coincidentally", the year immediately after the next General Election. As all politicians and senior civil servants know, nothing serious happens in the year before a General Election. Policy must be implanted in the first 18 months of a Parliament or the political vested interests will create political inertia and the chance for change has been lost.

Thirdly, public expectations of some public services are very different to before the 2007 financial crash. At this time the public appears to accept that public sector financial constraints mean that tough decisions need to be taken in some areas of public service. My experience - as a somewhat electorally unsuccessful politician - suggests to me that this mood music will not last. It will not be long before strident voices will assert the need for completely comprehensive and perfectly functioning public services, paid for by someone else. I exaggerate for effect of course –
but there is an element of truth in the caricature.

I start by setting out the premise of this lecture: The NHS is not spending the money it gets from our taxes in a way that delivers cost effective and clinically effective healthcare for the population it serves. As a service, it has the tools to deliver effective change but key decision makers have too much timidity about using these tools to do their job properly.

Why do I say the NHS is not spending our money effectively enough? First, some of the things our clinicians do – spending NHS money – are a complete waste of money; but identifying those “things” is fraught with difficulty. A senior clinical director told me that the most expensive thing in a hospital was a pen. Doctors use pens to order tests, sign off investigations and set out clinical requirements in clinical notes. The way that our hospitals and GP practices are organised means that doctors exercise their professional discretion to do things – all of which cost taxpayers money – with little or no enforceable financial accountability for their individual decisions. There are, for example, no legal restrictions on the drugs that a GP can prescribe for a registered patient of his or her practice, regardless of the cost or potential benefit[1]. That is not to suggest that our doctors are routinely acting in an irresponsible way; but I do suggest that there are no clear limits on the interventions that the NHS will finance – at least at GP level - for that individual patient sitting in front of the doctor. The duty of care to the patient implies a duty to do the best for that patient but there is no clear balancing duty to make effective use of scarce publicly funded resources.

The Dartmouth Institute for Health Policy and Clinical Practice has estimated[2] that 30% of spending on healthcare in the US is wholly ineffective. That means that money is spent on medical interventions which not only are not clinically effective but had no reasonable prospect of being clinically effective – all arising from clinical discretion. However that number must be treated with some caution because, as Lord Leverhulme once said, he knew half of his advertising was wasted, but didn't know which half[3].

Secondly, with the growth of evidence based medicine, there is an increasing understanding of what works and what does not work in medicine – at least at the population level and the best way to organise services to deliver the best outcomes. That growing body of understanding does not, of course, mean that medical interventions delivered in accordance with the evidence will work for the patient at the individual patient level. One of joys of life – reflected in medicine – is that we are all different but we are increasingly understanding more about how to organise services so that, with pooled disciplines and clear protocols, outcomes will improve for a greater number of patients. The improvements in outcomes for patients with strokes in London which centralised initial treatment at a limited number of hospitals is a well-known example of this working in practice.

Reorganising the locations at which NHS services are delivered improves outcomes and saves
lives in 2 ways. First, directly, lives are saved by the delivery of better organised services. Secondly, better use of NHS resources in one area of medical treatment frees up resources to be used in less glamorous areas, and thus delivers better outcomes for those patients.

What are the principles that should drive decision making? At the policy level, it seems a statement of the obvious to say that, outside proper research studies, the NHS should only invest its resources in medical treatment that is both cost effective and has proven clinical effectiveness. The NHS has developed many statements to that effect but – to pick one – this is the relevant paragraph from the NHS England Ethical framework[4]:

“The NHS Commissioning Board should only invest in treatments and services which are of proven cost-effectiveness unless it does so in the context of well-designed and properly conducted clinical trials that will enable the NHS to assess the effectiveness and/or value for money of a treatment or other healthcare intervention”

The justification for this approach is that, in an NHS where demand far outstrip supply, every decision to invest resources in treatment of one patient means fewer resources to treat other patients. The opportunity cost of treating each patient can only be justified if there are proper grounds for believing that the treatment is both clinically effective and cost effective. That may sound harsh because it proposes denying clinically effective medical treatment to someone who may be able to benefit from that treatment. However that approach is a consequence of an important principle that the NHS should value all lives equally. That means valuing the life of the patient who is not immediately in front of a doctor on an equal basis to the patient who is seeking treatment.

But this type of resource based decision making rarely happens in the NHS. The NHS continues to spend our money in ways that deliver less healthcare benefit than it could.

Let me explain by way of some examples. There has been a wide professional consensus for at least a decade that the NHS is spending too much on too many hospital buildings that the NHS cannot afford. There is an urgent need to transfer funding to community based services. However in England, 10.55% of the NHS budget was spent on general practice in 2004-2005. By 2011-2012, this had fallen to 8.5% and last year dropped to 8.39%[5] even though this represents 92% of patient encounters within the NHS. So policy says one thing but the “payment by results” system we have for funding NHS hospitals does not deliver the policy outcomes.

Secondly, as Dr Ben Goldacre has demonstrated by his brilliant writing which is both informed and readable[6], healthcare systems around the world, including the NHS, are failing to reduce spending on drug treatments that do not work due to a combination of commercial interests. Despite that the pressure to spend more on drugs of dubious efficacy grows each year and investment in hospital buildings is forever increasing, even though the inevitable result is a
reduction in the level of resources available to the community.

For this evening, I am not so much interested in whether the NHS fails to make change where the evidence suggests that better use of NHS resources could deliver better outcomes for patients but why the NHS fails to take these decisions.

The “why” is – I would suggest – much more interesting than the “whether”. Any analysis of the mechanisms for change in the NHS must start with asking “who are the decision makers” for these key decisions?

The NHS has been divided into commissioners and providers for over 20 years[7]. With a few exceptions, such as drugs which have a NICE Technology Appraisal Guidance for patients within defined clinical cohorts[8], NHS commissioners have a wide area of discretion to decide what services to commission on behalf of NHS patients. Local Clinical Commissioning Groups and, for specialised services and primary care, NHS England have a wide discretion to decide what services should be commissioned for patients as part of NHS funded healthcare. They have extensive duties to involve patients in their decision making but, subject to that, they are the bodies that decide who gets what medical drugs. They decide whether to commission – i.e. pay for – an A & E at the local hospital, how community services should be organised and how nearly all of the local NHS is to be set up. However the GP contract has not historically placed limits on the drugs GPs can prescribe for their patients.

Subject to this constraint, the legal position in the NHS is reasonably clear. The fact that a medical intervention is likely to be clinically effective for a patient or even safe the patient’s life places no duty on the commissioners to fund that treatment for a patient[9]. CCGs are entitled to work out where their priorities lie and how the NHS funds will be spent.

But my experience is that local NHS commissioners remain very timid about making changes to the services they commission. It would be easy to say that changes to NHS services are delayed for fear of upsetting politicians who fear not being re-elected. But actually there is a more serious problem.

The real problem – I suggest - is that the concept that the “NHS is free at the point of use” is translated by the public into “NHS care should not be constrained by money”.

Despite the recognition in other areas of public services that the “cloth must be cut”, when it comes to the NHS there remains a measure of disconnect between the money that people pay in their taxes to support the NHS and the quality of service that taxpayers expect to receive. This feeling that “we cannot say it’s about the money” makes it very difficult for those concerned with NHS reform to have a sensible dialogue with the public.

I cannot count the number of times that I have read NHS consultation documents which try to
pretend that proposed changes to NHS services are only all about improving the quality of services as if the issue of money and resources was irrelevant. In contrast the internal documents leading to the proposals make it abundantly clear that the drivers for change are a desire to deliver the best quality of services within the financial and human resources available.

But NHS managers are not alone because this disconnect does not just exist in the UK. Professor (and Doctor) Greg Bloche has accurately said that “withholding beneficial care to control costs is a radioactive proposition in American politics”. Tea party darling Congresswoman Michelle Bauchmann said the proposition that doctors should take account of the cost of treatment was “an horrific notion to our nation’s doctors [and] to each American”.

However if – in my anecdotal experience - NHS managers are asked “why” they are colluding with the idea that changes to NHS services are not about making the best use of available resources, legal problems are often cited as a reason. In fact, I would suggest that the opposite is the case. The approach of the courts actively recognises and supports the need to ration health along with other public services.

In contrast to the political rhetoric, the courts in both the UK and in the United States have accepted that rationing is part of the healthcare delivery business in both the public and private sector. The Supreme Court has approved healthcare rationing and supported paying doctors to ration care. In Pegram v Herdrich the US Supreme Court said “...no HMO organisation could survive without some incentive connecting physician reward with treatment rationing”. The Court of Appeal in this country has repeatedly held that it is lawful for the NHS to ration access to healthcare. As long ago as 1997 Lord Bingham said in R v Cambridge Health Authority ex parte B[10]:

"I have no doubt that in a perfect world any treatment which a patient, or a patient's family, sought would be provided if doctors were willing to give it, no matter how much it costs, particularly when a life was potentially at stake. It would however, in my view, be shutting one's eyes to the real world if the court were to proceed on the basis that we do live in such a world. It is common knowledge that health authorities of all kinds are constantly pressed to make ends meet.... Difficult and agonising judgments have to be made as to how a limited budget is best allocated to the maximum advantage of the maximum number of patients. That is not a judgment which the court can make. In my judgment, it is not something that a health authority such as this authority can be fairly criticised for not advancing before the court."

That approach has recently been approved in a series of recent decisions, including R (Condliff) v North Staffordshire PCT[11] which decided that the human rights of the patient under article 8 of the ECHR were rarely if ever engaged in medical rationing treatment decisions.

Further commissioning decisions are public law decisions. The House of Lords has held that, save in a case where it is misfeasance in public office with its incredibly high hurdles including
showing malice, NHS commissioners cannot be sued for damages for public law decisions[12]. Hence, at least in the UK, it is not legal constraints that hold back NHS reform.

So I return to the central problem which – as a non-doctor I diagnose as – there has been a fear amongst NHS leaders that the NHS is a public service where the public do not have an appetite for reform. Those who make decisions about public services rightly feel themselves to be accountable to the public for these decisions and, at present, fear the public have no mood to accept the types of reform that are essential if the NHS is to achieve its twin objectives of (a) delivering the best care it reasonably can to vulnerable patients and (b) remaining within a largely static budget. The losers from this state of affairs are vulnerable patients who don’t get the treatment they need because it is spent on treatment that does not work, on hospitals that are not justifiable or services of marginal benefit.

But perhaps we are at a tipping point. The in-coming NHS England Chief Executive, Simon Stevens, said last week[13] that NHS England wanted local CCGs to come up with sustainable and future proofed local health systems, and then tellingly said:

“If you’re going to get a sustainable and future proofed local health system, what are the longstanding assumptions and constraints we’d need to say goodbye to?”

The second reason we might be at a tipping point is finance. The NHS is facing a funding gap in the next few years up to 2021 of between £30Bn and £12Bn depending on whose estimate you accept. As the Kings Fund said in their impressive interim report “A new settlement for health and social care[14]” published in the last few weeks:

“. the NHS faces a severe and continued financial challenge …. there are some intense short-term pressures to be dealt with and some long hard term and unavoidable choices ahead”

The NHS has had an expanding budget for almost all of its life, but that luxury is no longer going to be available.

The third reason that changes need to be made is demographic. Everyone knows that we are getting older as a nation, and our services need to be organised to deliver care for the next generation rather than the last generation. But we also have far more people with long term conditions surviving into adulthood. Barely half social care spending is spent on people over the age of 65[15] and there are more people under the age of 65 with 2 or more serious long term medical conditions than those over the age of 65. The Better Care Fund will kick in in 2015 to tie resources to better integration of health and social care, leaving much less in the NHS kitty for traditional acute care.

So why when there is an impeccable health economics case for change in NHS services, is there no public appetite for that change? That is not a straightforward question. Nigel Lawson
observed that “the NHS is the closest thing the English have to a religion”. Yet, as with all religions, informed debate is clouded by myths.

The first myth is that the problems of the NHS could be solved with more money. Spending on the NHS rose 7 fold between 1949 and 2002 (allowing for inflation) and has continued to rise since then. More money might delay difficult decisions or cushion the fall, but more money of itself is not the answer. A high proportion of NHS acute care is provided to the frail elderly and, with an aging population, we need maybe 4/5% additional resources each year to carry on delivering the same level of services to our population. Although numbers of patients attending A & E are not rising dramatically, an NHS England report[16] noted:

“There were 10.6% more emergency admissions in 2012/13 than in 2009/10. There is general consensus (though it is hard to identify the evidence) that patients presenting are more ill and hence more likely to need admission and have longer stays”

New, expensive drugs are coming off the pharmaceutical production line every year, offering marginal improvements on existing drugs but at a much higher cost. I could go on but please be assured that we can never spend “enough” on healthcare because the more we spend, the more demand there will be for state funded healthcare.

The second myth is that investment in the NHS is the best way to improve the nation’s health. Sorry but this is just not true. According to the WHO, around 80% of deaths from the major diseases, such as cancer, are attributable to lifestyle risk factors such as excess alcohol, smoking, lack of physical activity and poor diet. Extra spending on medical treatment for people with preventable diseases is not top of the list of effective interventions. So if we care about the health of our people, extra spending on the NHS is not necessarily the right answer. It may be on rare occasions but prevention is better than cure.

The third myth is that the NHS equates to hospitals, and that the NHS delivers most of its care in hospitals. This is also simply not true. 92% of NHS care is delivered by GPs or in the community. A significant proportion of NHS money is spent on managing people with long term conditions. However most of this case is or should be delivered outside a hospital setting. And the paradox is that the better that long term conditions such as COPD or diabetes are managed in the community, the less unplanned care has to be provided in hospitals.

But the NHS only really makes savings if it closes or substantially scales back hospital buildings. Removing one service from the acute sector but leaving the building and staff in place will simply result in those staff delivering care in those buildings to other groups of patients, with little if any overall saving.

These “myths” have made it virtually impossible to have a sensible discussion about what drugs or medical treatments the NHS should fund and how we should change the footprint of NHS
buildings to get better value for money. We have NICE in the UK and US has the Patient Centred Outcomes Research Institute. But they are underfunded, dominated by supplier interests and can only scratch the surface of the rationing debate.

A nationally set list of drugs and treatments that are funded and not funded across the whole of the NHS is probably an expensive paperchase that will get nowhere apart from endless legal challenges. As the kings Fund Report noted:

“Experiences from New Zealand, Chile, the US state of Oregon, Spain, Israel and Germany are not encouraging. There have been problems over enforcement and perverse outcomes in some cases. One of the best-known attempts to ration care was the Oregon approach that ranked treatments by priority and then set a cut off decided by the budget available. It led to treatable cancer being excluded from the benefits package”

That approach is, in any event, a non-starter in a system where politicians are the ultimate decision makers. The line “this was a locally made decision” has been seen as essential to insulate our politicians from disappointed patients.

It is an uncomfortable truth that, in a modern democracy, politicians are only able to “do politics” in the space in which public opinion allows them to operate. Politicians rarely lead public debate outside that legitimate area of public opinion and then they are described by the Sir Humphreys’ as being “brave, Minister”, with all its connotations of a lack of electability.

So who can move the space for public debate about change in the NHS? The answer is that there are many candidates and some are stepping up to the plate. This is the classic area where NHS England have the chance to lead – and their independence from government precisely creates the space that allows them to flourish. Special credit must go to NHS England’s medical director, Sir Bruce Keogh, for his work on the future shape of Accident and Emergency services even though NHS England is, of course, not the primary decision maker for commissioning these services. I may have disagreed with him about Lewisham but overall he has been brave on the future shape of A & E care.

The Medical Royal Colleges have a key role to play, as to academics those who work with the NHS on a daily basis in fora such as this.

And now – ladies and gentleman – I get on my soapbox and make no apologies for it. This essential debate is most important at the local level because, in a federated service like the NHS, delivering change is a bottom up process. That means the local NHS leaders – which primarily after the Health and Social Care Act 2012 means the GPs who sit on the local Clinical Commissioning Groups – have to make the case for change locally.

And that cannot happen unless those who make NHS decisions locally invest far more time,
energy and resources in educating the public about the choices that need to be made and actively lead local debate.

Local NHS leaders need to explain some home truths as opposed to colluding in the myth that health is too important to be about money. If my treatment, my A & E unit or my maternity unit is allowed to be seen to be too important to allow money to be mentioned, it is someone else’s elderly care services, mental health services or respite care that will pay the price. Taking on the role of being a local commissioner means that these GPs have to shout loudly that not every cancer drug can be financed, not every small A & E unit should remain open and many community hospitals are totally uneconomic. It is their job to drive local public debate in order to counter the myths of objectors waving shrouds.

To date the role of being the “big bad wolf” who cuts A & E or maternity units has been left to faceless NHS managers and the occasional brave public health doctor, or even worse accountants within the Trust Special Administrator process. But the financial challenges facing the NHS are now so vast and so close that the NHS has an urgent need to move services into the community in order to support the growing elderly population. These challenges are urgent and the NHS needs unprecedented levels of structural change.

As a lawyer you would expect me to end with the law. The legal duties on commissioners under the NHS Act require every part of the NHS to engage with patients but in particular local CCGs. NHS managers have, by and large, been rubbish at genuine patient engagement, often because it is an afterthought. The traditional NHS way is to make reconfiguration or drug rationing decisions first and then consult the public afterwards. Not only is this now unlawful due to the wide duties under section 14Z2 of the NHS Act 2006, it shows a short-sighted approach to the local politics and leads terrible decision making because supplier interests dominate the decision making process.

The public will only believe change is needed if they are trusted with all the data, and all of the options are openly debated at an early stage. But they also need to be repeatedly told as part of that consultation process that “we can only spend the money once”. To give credit, NHS England is trying hard to lead debate but the real debate needs to be led at a local level. The job of GP commissioners is to be community leaders for change. It means facing the local press and the radio, and crucially getting into the debate ring with the vested interests, including aspirant politicians, who are well-financed and will fight dirty. NHS commissioners need to fight back, holding on to the moral high ground at all costs and exposing the real costs of the choices that need to be made.

If the local NHS does not invest in and lead public debate, political “space” will never be created to give politicians the opportunity to do the right thing. It’s a public service and commissioners must engage with the public – the great unwashed as they were referred to in previous
generations.

If local commissioners do not lead the debate on the reasons for NHS changes, elected politicians will have to oppose clinically required change. That will slow the change process or even prevent change happening. And the losers will be those with mental health conditions, those suffering from chronic conditions and the frail elderly patients who don’t get the services they need because they are still being wasted on too drugs of marginal benefit and too many hospital buildings.

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[1] For the details see Professor Chris Newdick’s Chapter at paragraph 1.184ff in “Principles of Medical Law” (3rd Edition) (OUP).


[3] This quotation has been ascribed to a number of people who have purchased advertising over the years.


[7] Since the NHS and Community Care Act 1990 was brought into force in April 1993.

[8] See Regulation 4(2) of the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012.


[16] See http://www.england.nhs.uk/2013/05/09/sup-plan/
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