

Commentary

An NHS for all

The egalitarian reform agenda

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Gordon Brown may be struggling to convince voters that he has a vision, but during the early months of 2008 the Prime Minister set out a challenging and progressive agenda for the NHS in its 60th anniversary year. The headlines have mostly been about health checks and screenings, but a series of thoughtful speeches has seen him reaffirm the government's longstanding commitment to tackling the deep health inequalities that the NHS was brought in to eradicate.

In his speech to Welsh Labour conference, for example, Gordon Brown included the NHS for the first time in his new narrative about his mission in government:

now we must move to the next stage of the Opportunity Revolution and start to offer access to all of us what 10 per cent can already obtain by paying privately – the offer of regular check ups, early screening for cancer and other diseases, weekend and evening access to your GP when you need it, and the personalised care and support reshaped to your needs that will not only cure illness but prevent illness in the first place (Brown, 2008b).

Gordon Brown also made health inequalities central to what he described as the 'third stage' of Labour's NHS reforms. Stage one, he argued, was to set minimum standards, while stage two was to create incentives for better local performance and more choice for patients. Stage three will be to deliver for patients, by increasing preventative care, 'tackling the underlying causes of health inequalities' and acting on failing services (Brown, 2008a).

The challenge of inequality

Labour is not acting before time. Looking back, the policy landscape is littered with major reports that have resonated loudly before being implemented in part, or in pieces, if at all: Black in 1981; Acheson in 1998 (Townsend and Davidson, 1990; Acheson, 1998). There has been plenty of analysis but precious little action. The need for a new commitment from Labour is best demonstrated by the famous tube journey along London's District Line. Life expectancy declines by a year for every six stops you travel eastwards from the City to the East End. Although closely linked, health inequality has been deeper and more persistent

than poverty defined in the narrow sense of low incomes. As Professor Danny Dorling wrote recently:

At some point soon the calculation will be made of the actual absolute number of babies that would have lived to see their first birthday, of men who would have made it to at least a year of retirement, and of women who would not have seen their children die before them – had New Labour achieved its ambitions to reduce inequalities in health in the period May 1997 to May 2007. All these infants and children and adults are now dead (Dorling, 2007).

This is a huge agenda and we eagerly await a new strategy and action plan from public health minister Dawn Primarolo this summer.

Will health inequality be a wedge issue in the competition between Labour and the Conservatives to be seen as the party of the NHS? The task ahead will be to deliver the performance the public expects from the NHS whilst at the same time ensuring that individuals who are poor, excluded or marginalised get the best deal. That is at the heart of Gordon Brown's progressive universalist vision, but in practice it represents a huge challenge at a time of tight finances and economic slowdown. With budgets tight, there are dangers that the Government is already moving in the wrong direction, focusing on cheaper policies that could exacerbate inequalities and not erode them. Meanwhile the Conservatives are developing eye-catching ideas such as the universal home visitor service for new mums. Will Andrew Lansley snatch Gordon's egalitarian clothes?

Labour's fight against income inequality has been closely targeted via the tax and benefits system and, although there is more to do, it has been highly successful in lifting millions out of poverty. In public services, however, quite a different dynamic operates. Demand for health care, for example, increases as people get wealthier and it is generally the middle classes, who know what is on offer and are prepared to push for what they want, who benefit most from new programmes and initiatives. Indeed, it is not obvious who will be the real winners as a result of Labour's reforms, and as a result what the cumulative impact of policy will be on persistent health inequalities. Choice, for example, is known to benefit the better-off more than the poor, old and frail. Co-production is the right aspiration, but can assume high levels of health literacy. Since Gordon Brown became Prime Minister the language of reform has changed (we now speak of 'personalisation' rather than 'choice') but has the underlying policy changed enough too?

Health literacy is key to Labour's ambitions. The reality is that patients are hugely diverse, in their knowledge, attitudes and behaviours. On one end of the spectrum, we have the so-called 'DIY doctors' (Penn, 2007). These individuals do their own research on any health condition, devouring any resources at their disposal, from NHS direct and charity websites, to obscure research publications in technical American medical journals. By the time they get to see a doctor, they have a pretty good idea of how and where they want to be treated and, often, who should do the job.

At the other end of the spectrum, however, things look very different. Martyn Partridge, Professor of Respiratory Medicine at London's Charring Cross Hospital, says work in his own clinic has shown that approximately 15 per cent of patients with chronic respiratory disease 'can not use' written materials. Furthermore, the NHS Confederation reports that

there are 'missing millions' who should be getting healthcare but who don't see their GP, nurse or any health professional (NHS Confederation, 2007). This includes more than two million people with undiagnosed chronic obstructive pulmonary disorder (British Lung Foundation, 2007); 750,000 with undiagnosed diabetes (Diabetes UK, 2006); and 350,000 people with heart disease who are not seeing a GP (British Heart Foundation).

Yet much of what we all do in health care provision is targeted at the needs of those best equipped to help themselves. Of course, the DIY doctors are not all rich and the 15 per cent who can't use written materials are not all poor. But there is a strong correlation in both cases and the phenomenon is not restricted to health, as Stuart Weir's recent *Renewal* article on social capital makes plain (Weir, 2008).

An egalitarian reform agenda

The opportunity now is to start the reform process with the needs of excluded people first in mind. To do this Labour needs to give as much attention to health literacy as it has to financial literacy. Millions of pounds have been spent trying to make us better with numbers and better able to plan financially for the future. The argument is that this is about investing to save: if people have saved for the future, they won't be dependent on the state. Just the same argument applies in healthcare. If we all look after our health, we will stay healthy and independent for longer and place less demands on acute health services. But there is a huge way to go to encourage more people to be active in managing their own health and poor health literacy will always undermine attempts to narrow health inequalities.

Of course the fight against health inequality must be a long-term project and one measure of success will be a reduction in the differences in life expectancy symbolised by that District Line tube journey in London. There is no doubt that this will require long-term investment throughout society to tackle poverty, worklessness, health literacy and low levels of education and health literacy. But Labour must also achieve some quick wins, securing improvements in this parliament for those who have been excluded. This can be achieved by making sure the NHS – and patient groups like my own, Asthma UK – are delivering effectively for those in greatest need, because they are poor and ill, otherwise disadvantaged or have poor health literacy. Reforms need to start with the needs of the excluded in mind.

In illustrating my points I shall use asthma as an example of changes that need to be made. This is because asthma is a perfect litmus test for reforms: it is a common long-term condition that affects over five million people, and as such is a core part of the business of the NHS. Gordon Brown acknowledged this transformation in the pattern of need, from acute care to chronic ill-health:

Much of what the NHS delivered [in the past] consisted of brief episodes of increasingly successful acute care. But today, with the ageing population and a rise in so-called 'lifestyle diseases', the NHS finds itself with new challenges in supporting and caring for [17 million] patients with long-term conditions. (Brown, 2008a)

Although most asthma should be manageable in primary care, more than three people a day die from the illness. It is the fourth biggest cause of preventable hospital admissions and,

testifying to the real health inequalities that exist in Britain today, children in most poor urban northern areas are several more likely to be hospitalised by their asthma than those in the affluent southern suburbs (Dr. Foster Intelligence, 2006). (1)

Six steps toward greater health equality

Health education

The government is proud of the health information it makes available via the web, and so it should be. NHS Direct is a fantastic resource on asthma and other conditions. The website NHS Choices also has some first-rate material, and examples of what different conditions mean, how and where you will get the best treatment and how to make the NHS work for you.

Yet many people now excluded by health services do not use these web resources. In fact, they don't use the web at all. This was brought home to me again recently when I met a group of patients at Heart of Birmingham PCT, an under-doctored area which has some of the highest levels of hospital admissions for asthma. Without exception, all of the patients in a group discussion said they would never use the web for information about their condition. They supported Martyn Partidge's argument about written materials too, not least because a great many did not read or speak English, even as a second language. They preferred advice which was delivered face-to-face, by the asthma nurses at the special clinic. Or as second best they wanted pictures – to be shown how to use an inhaler through a DVD, for example, or reminded of what to do in an asthma attack by a card with images rather than words. Funding for these clinics was already stretched in Birmingham but they clearly worked. The NHS has launched a laudable campaign to bring the digitally excluded on-line but health workers in Birmingham and elsewhere say they need DVDs at their clinics and pictorial action plans, not more websites and leaflets from the Department of Health.

Of course, more needs to be done to help those people who do not use the NHS at all, despite having poor health. One project which has a lot of potential is the information prescription scheme. Here, if you are diagnosed with asthma, you aren't sent away with just a prescription for an inhaler or two and some wise words from your doctor. You are also put in touch with extra help – your asthma nurse, a local respiratory clinic or support group, a national charity like mine. People with long-term conditions need to be confident and informed about managing their health – after all, we spend 99 per cent of our lives outside of the NHS. Information prescriptions are likely to be rolled out this year, but if they depend on written information and website support they will benefit the rich and not the poor.

The first step is therefore to start education with those who need it most, not those who are already expert patients.

Extended GP practice

There is a huge debate about the hours GP practices open. It is hugely frustrating when they run 9 to 5, Monday to Friday. I should know; my own does exactly that. Of course, no one's health is so well disciplined that it respects GPs' hours. It is exasperating when you have to take time off work or school to see a GP about a chronic, but not urgent problem, or to get a basic check-up. Longer opening hours are needed and are a key test for how most people

judge GP performance. However, longer opening hours might not be the best way to extend GP practice for excluded groups. Some of the 'missing millions' will be encouraged into primary care by longer GP hours, but most probably will not.

More imaginative commissioning is needed. Clinics may need to be run once a week on isolated estates, for example, or inside mosques. PCTs might need to invest in outreach services, with staff who can arrange to see individuals at home, rather than expecting them to show up in a clinic. Some people with severe asthma make such radical adjustments to their lives that they become prisoners in their own homes. One woman described herself to me as 'a sofa warmer these days'. She is afraid to take her children to school, for fear of an asthma attack. She no longer works. She can't go into friends houses if they have pets. In Heart of Birmingham, someone like this could be visited at home by a nurse, making it much more likely that she will receive good care. Charities often help this effort by taking mobile clinics into city centres – Diabetes UK, for example, runs a successful bus road show that encourages more people to find out more.

Another man with bad asthma works in a market in Hammersmith. Although he has two inhalers, he doesn't know how to use them properly and he is constantly gasping for breath. He hadn't gone to his GP because he hadn't realised he needed to. His asthma was improved when an asthma nurse went out into the market. She did this because Hammersmith and Fulham PCT is serious about tackling health inequalities and has decided to go out looking for people it thinks might not ordinarily access standard services. He was one of the 'missing millions' that the NHS found.

So the second step is to extend GP practice to those who need it most, by going where they are likely to be found, as well as opening at weekends.

Empowered patients

'The NHS of the future will not be the NHS of the passive patient' Gordon Brown declared. 'The NHS of the future will be one of patient power' (Brown, 2008a). This reform, which lies at the heart of Lord Darzi's 'Next Stage Review', is absolutely right. The NHS should keep us well and not just treat us when we are ill, and, if we as patients are engaged in our own health care, we are much more likely to stay well. This sentiment lies behind successful initiatives like Expert Patient programmes.

Yet again there is a risk of being dominated by the articulate and not the needs of the excluded. People marginalised by health services tend not to turn up to scrutiny committee meetings. Indeed, our language itself is at fault. We should not talk about hard to reach people, which assumes you start from the service itself. We should talk about hard to reach services, which starts from the perspective of the people who are missing out.

Key to the NHS delivering is to empower the frequent users of services. Someone who has been hospitalised for their asthma is much more likely to be hospitalised again. The same rule applies elsewhere. Older people who have falls, for example, are more likely to fall again, with increasingly traumatic consequences. If there is a system behind the NHS, then someone who has been hospitalised should be followed up with additional support, to explain what has happened, identify risks and try to limit them. This is what the guidelines recommend. It happens in places like Guildford, which has very low levels of hospital admissions. It often fails to happen in poor inner city areas. This is clearly wrong. The NHS must deliver the same level of service no matter where you live. Not only is this fair, it is

also cost effective: hospital admissions cost much more than targeted case management and basic communications. Connecting for Health is the key government programme that will enable information on patients to be shared across the NHS. Local funding and adequate training must be provided to make it an effective tool for PCTs.

The third step is therefore to empower those who are frequent users of services and to minimise their risk of repeat hospitalisations.

Public health

Prevention must be at the heart of the NHS. Again, this has been clear from Gordon Brown's speeches. It has been accepted for many years now that if we are successful at keeping people healthy, we will face lower costs in acute care. Of course, in reality it is often harder. As Julian Le Grand commented: 'if a commissioner is faced with a choice of bailing out the local acute trust or engaging in a preventative programme which is not going to pay out for twenty years, which are they going to do?' (Evans, 2008).

However, there are some quick wins in Labour's grasp. One concerns the Quality and Outcomes Framework (QOF), which provides incentives for GPs. Its critics – and these are often GPs themselves – argue that QOF rewards 'second-rate care' rather than the care we wish to see in the NHS of the future. Here are some examples.

For asthma, doctors score QOF points if they keep a list of patients with asthma and if they conduct an annual asthma review with each patient. In practice asthma reviews vary enormously. Many GPs offer superb service: at my last asthma review, I was asked intelligent questions about my asthma and was also given a blood pressure test and checked for inhaler technique. But GPs don't have to do this. In fact they don't have to do anything. A previous asthma review consisted entirely of a GP asking me how I was. That was it. No mention of asthma. But a point scored against QOF.

More serious perhaps is the list of asthma patients. Doctors could use this to refer patients who smoke to cessation services, or people who are obese to weight-loss clinics, as smoking and obesity both have a bad effect on asthma. All too often they do neither. You see, you get points for having the list. Not for doing anything with it.

The fourth action is to reform QOF, so that doctors deliver the best quality care. This would be possible by making sure GPs are rewarded for actions and not just making lists. For asthma, the points should come for checking inhaler techniques, delivering flu vaccinations and making referrals to allergy testing and smoking cessation programmes. Not for making lists no one uses.

Prescription charges

One thing Gordon Brown hasn't mentioned is prescription charges. It is not surprising. Charges have been abolished in Wales and are about to be abolished in Scotland and the Prime Minister wouldn't want to remind English voters about that. However, the government has promised to review prescription charges, albeit on a nil-cost basis.

Many people on low incomes do get free prescriptions. That is a good starting point – but there are other targeted reforms which could be tried. For a start, if you have a number of health problems and need multiple prescriptions, you can buy an annual pass which will save you money – that's if you know where to look. I have to say, when I heard about this I didn't know where to start, and I am well versed in government programmes. This looks

like a good policy that is shockingly almost guaranteed to exclude those who need it most: many of whom will be on low incomes or in real need because of their poor health. If the government accepts that people need decisions made easier for them in pension saving, surely this service could be much more accessible too.

And then there are students. Free prescriptions stop at the age of 19 and many parents worry that young people with long-term conditions like asthma will stop taking their medication when they go to college. Many do, and there are some nasty consequences. Students already face mounting financial pressures and worries about large future levels of debt. Wouldn't it be good to ease the pressure for once and stop them having to pay for prescriptions too? Especially if it meant better continuity of care.

The fifth step would be to target free prescriptions to those who could do with them, even if Brown won't go as far the governments in Scotland and Wales.

Quality of life

So far we have been talking about health, but there is another dimension to health inequality which is worth considering. This is the effect that poor health has on quality of life. We know that a quarter of school children with asthma miss over six days school a year. Six days is regrettable but manageable. But some children miss almost half their school year because they are sick and either at home or in hospital. And I have met other children who are unable to go into particular classrooms because they are damp, which brings on an asthma attack. The lessons are not rescheduled. Instead, the pupils just miss out. Such exclusions we know all too well can result in lifelong disadvantage. Here public services should work together to make sure that children with long term conditions get the best support and do not miss out on their right to an education. The same lessons apply to the workplace. Some people with asthma struggle to hold down jobs in the face of pressure from employers worried at their sickness record. Another example of the need for joined up thinking by public services.

The final step therefore is to think of health more broadly than the NHS. Our schools can play a role too, as can employment policies and welfare to work schemes.

Prospects

What are the prospects for reform starting with the poor and excluded rather than the assertive and wealthy? Gordon Brown makes many of the right policy commitments and he and Health Secretary Alan Johnson are clearly determined to make a difference.

But are there already signs that we are moving in the wrong direction? No national standards of care have been set for asthma, one of the most common long-term conditions. So local initiative is taking place in a vacuum, leaving large variations in quality. Without national standards, the likelihood is that PCTs will move towards the goal of 'world class commissioning' in different ways, targeting local problems, but allowing a postcode lottery to remain for many common conditions like asthma. Information prescription pilots for several long term conditions like asthma, diabetes and arthritis are being evaluated, but with finances tight officials appear to be concentrating more and more on their websites as information tools. Alan Johnson is taking on the doctors, but even if GP practices open for longer, outreach services remain under severe funding pressure.

By contrast, NHS staff are doing some fantastic work on the ground to make a differ-

ence: nurses taking clinics out onto estates; doctors pioneering outreach services and new accessible education materials; PCTs demonstrating world class commissioning by taking account of the needs and characteristics of their local populations when designing services; managers using data to monitor and improve performance. But they are often doing this despite the system – not with its encouragement. For example, there are reports of a significant increase in the number of nurses who are paying for their asthma training out of their own pocket. Other nurses, with lead responsibility for respiratory clinics, have not had any training in asthma. What seems to have happened is that GPs have delegated asthma management to nurses, but have not delegated budgets required for training and staying up to date with changes in treatment.

Ministers can make the system work by ensuring that all health care professionals get the training they need and by supporting best practice of health care professionals by putting in place national standards and making available the right material, championing and encouraging others to adopt good practice. All PCTs and NHS trusts must be encouraged to make it a priority to target health inequalities on their patch, and join up with efforts being made by local councils too. This will require a system that works intelligently across health, social care and education.

This is a defining year for Brown's government and health inequality is perhaps the key defining issue. Will Labour's NHS reforms provide further opportunity for the middle classes and the worried well, leaving people who are already excluded further behind? Or will reforms begin with the needs of people who are currently losing out: the missing millions lost to the NHS, the poor and marginalised, those with low health literacy and self-confidence? Polly Toynbee rightly says that in this year of tight budgets, 'Labour can't splash out but it must make a political splash' (2008). Health inequalities will only be eroded with investment over the long-term. But many interventions we can make today will save, not cost, money by preventing expensive hospital admissions. Tackling health inequality is a generational programme and is rightly at the heart of Brown's vision. We can't afford to wait a generation to see results. There are some quick wins. Labour should seize them.

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Note

1. This refers to ACS (ambulatory care sensitive) and there are 19 such ACS conditions accounting for 695,000 hospital 'spells' in 2004/05. Asthma is fourth on this list with 67,921.