

**BODY POLITIC** Nigel Hawkes

# NHS truths that dare not speak their name

Is the solution to the NHS's woes now a taboo topic?

Trying to make political capital out of the NHS is risky. If the effort fails—as it did for the Labour Party in this year's general election—you are left opening and closing your mouth with nothing much to say.

Labour's bid to "weaponise" the NHS was a failure. Nobody seemed to care that much. The claim that the Conservatives were planning to privatise the service fell on even deaf ears. The NHS Action Party fielded a dozen candidates and polled fewer votes in total than the majority won by the health secretary for England in his South West Surrey seat. Opinion polls indicated not only that electors were tolerant of austerity, they actually welcomed it.

The result has been to close the book for the moment on the default position held by many that more money is the answer to its problems. It doesn't make this position wrong, but it makes it harder to voice. Hasn't the government already promised £8bn? Isn't that enough? Not unless another £22bn can be saved by 2020 from budgets that are already bust, and nobody actually believes that this is likely.

Likewise, very few people except those whose jobs depend on it believe that NHS vanguard projects<sup>1</sup> will transform care in the present parliament (if ever) or that forming hospitals into chains will cut overheads and standardise services in a way that has eluded every previous effort. Or that NHS Improvement (the product of the enforced coupling of the regulator Monitor and the Trust Development Authority) will actually generate much improvement.

## Politics of desperation

Like a drowning man grasping at a straw, the NHS in England is currently prey to the politics of desperation. The financial regulators apparently believe that the total deficit in acute care trusts—£2bn this year and rising—is the result of trusts not

trying hard enough, while the trusts say that they can do no more without affecting services. Hunt has clamped down on agency staff spending, but if trusts cannot find enough permanent staff to fill the gaps, failures of care become more likely. Continuing restraint on pay, another Hunt demand, makes agency work more attractive: reliance on agency nurses doubled from 2012 to 2014. Many NHS workers get the best of both worlds by having a staff job and taking agency work on the side, sometimes in the very same hospital.

The peer Patrick Carter, who has been charged with finding efficiency savings in trusts,<sup>2</sup> says (his fingers crossed behind his back) that there may be £5bn a year to be saved. It's impossible to tell whether he is right, as this figure isn't evidenced, and realising the savings is the hard part. The NHS has travelled this road before many times, most recently in *Better Procurement, Better Value, Better Care*, a strategy published as recently as August 2013.<sup>3</sup> That aimed to save a more modest £1.5bn by 2015-16. Did it succeed? Apparently not, since we heard no more about it.

I could fill this column with hard to believe claims. They mostly go unchallenged, because even the most determined nay-sayers eventually begin to tire. So I'll leave you with one more.

On 2 September NHS England's Simon Stevens announced "a major drive" to improve the health of NHS staff. To pay for this he promised £5m. Since the NHS employs 1.3 million people, and a lot of them are overweight and unfit, this is a conceit of loaves and fishes dimensions. For £5m all we'll get are action plans and frameworks, as if talking about it were a substitute for doing it, until the whole initiative dribbles away into the sand. Meanwhile, the chancellor of the exchequer has cut £200m from local authorities' spending on public health.



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I can't improve on a comment recently attached to an article in the *Health Service Journal* about the vanguard sites. It read, "Somewhere there ought to be an NHS Museum of Pointless Initiatives, where every centralising, witless progenitor of Another Damn Good Idea That Will Save Money After Costing Some should be forced to spend a week or two in silent contemplation before being allowed to proceed with their heroic pilots and their leaden roll-outs and their oddly (but invariably) much quieter windings-up." I'd like to credit the author of this outburst, but, as is invariably the case with the more entertaining comments in the *HSJ*, it was anonymous.

There are of course inefficiencies in the NHS against which the new tigers of NHS Improvement are soon to be unleashed. But international comparisons don't indicate that the situation is hopeless. The service costs rather less than that in similar European countries and a whole pile less than in the United States, whose ideas we are increasingly importing.

The regular comparisons by the US think tank the Commonwealth Fund show that the NHS does well on access, equity, and efficiency, less well on outcomes.<sup>4</sup> While these reports don't quite prove that the NHS is the best in the world, they do suggest that it's decent value for money.

Will the current flurry of initiatives make it better value? Some of them, such as the new models of care being piloted in the vanguard sites, make sense only with a reformed payment system that ceases to reward the volume of activity in acute care. But, like money, nobody wants to talk about that, because large scale reform has got itself a bad name. We're stuck in a world where the things that might make a difference are the truths that dare not speak their name.

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**NO HOLDS BARRED** Margaret McCartney

## One of the best

My father in law, Cyril Daly, has died.

He was a general practitioner in the north of Dublin. He was truly singlehanded—just him, no nurse, no secretary, no receptionist. Patients wanting to be seen simply turned up and waited during specified hours.

The surgery, appended to the side of the house, had a waiting room with comfortable chairs and paintings to admire. No health promotion leaflets or posters cluttered the walls. Cyril didn't use a computer. He wrote records on cards and stored them in drawers organised alphabetically.

In Ireland, GPs older than 75 are not allowed to continue looking after “medical card” (state paid) patients; Cyril continued to look after his private patients, however, until shortly before his death at age 82.

At his funeral, people told me that he had been their GP for the past 30, 40, 50 years. He had looked after five generations of the same family. Continuity of care was natural. There was no GP contract to get in the way of the essential question: why is this patient here?

There was no computer screen pinging out instructions on what to say next.

The fittings of his small surgery were clean, modest, and familiar. I can't imagine that a screed of blood tests and scans helped him to answer the existential questions that doctors are often asked about life or death. Medicine was firstly about conversation, and knowing the patients was fundamental. I suspect that this was not only better for patients but also more satisfying for doctors.

But I admired Cyril most for his decades long campaign against corporal punishment in schools. Catholic Ireland in the 1960s held the view that the religious orders charged with teaching in schools should beat and hurt children as a method of discipline. This outraged Cyril. His children were home schooled until he found a (Protestant) school that didn't include violence as part of the curriculum.

He wrote, petitioned, and spoke out about the incompatibility of Christian beliefs with the beating of children. He noted that the only



**The only two professions delivering corporal punishment were prostitutes and Catholic teachers**

two professions in Ireland delivering corporal punishment as part of their services were prostitutes and Catholic teachers. This didn't go down terribly well in the Catholic hierarchy.

The government eventually intervened, outlawing physical punishment in schools in 1982. The full and horrendous story of physical and sexual abuse in Catholic schools in Ireland is only now being fully told.

Cyril was tolerant, kind, generous, and funny. He was the essence of general practice. I will miss him terribly.

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**BLOG** Katherine Sleeman

## What next for care of the dying?

Last month the National Institute for Health and Care Excellence (NICE) published new draft guidance on care for dying adults. The guidance serves partly to fill the gap left by the Liverpool care pathway (LCP), which was phased out in a storm of controversy after the 2013 Neuberger review.

The well intentioned aim of the LCP was to identify the essential elements of good care from hospices and transform them into a series of prompts to guide professionals in hospital and community settings. Given that the new draft guidance is almost 300 pages long, one can understand why the Liverpool team thought that condensing this information into a few pages would be helpful. However, the LCP ultimately failed, not because the essential elements were wrong, but because of the way it was used. How can we avoid repeating this mistake?

I recently wrote a paper, published in *BMJ Open*, which aims to help us understand what went wrong with the implementation of the LCP. We used qualitative data collected from 25 healthcare professionals, who were interviewed about their experiences using integrated care pathways for the dying (including the LCP and its derivatives). Most of the interviewees described benefits of using these pathways, but they related almost exclusively to processes of care and were experienced by the healthcare professional themselves. Although intended as guides, pathways were often interpreted as protocols. Surprisingly, interviewees did not speak of integrated care pathways as directly benefiting patients or their families by helping to ensure better outcomes in death or bereavement. When patient

### **The LCP ultimately failed because of the way it was used**

outcomes were mentioned, it was in the context of harm.

With hindsight it seems extraordinary, if these views were representative of more widely held opinions, that the LCP became so rapidly and universally accepted. Our data provide insights into how this may have happened. Integrated care pathways for end of life care seemed to have symbolic value for healthcare professionals. They legitimised death as an outcome, provided a positive focus to care, and were used as a signal to herald the change in focus from active to palliative treatment. Patchy education in palliative care may have created a vacuum that allowed a tool for which there was no strong evidence to become accepted and valued.

Our study provides important messages for the successful development and implementation of future tools to guide care of the dying. Firstly, comprehensive education and training in palliative care is critical. A Royal College of Physicians audit recently found that mandatory training in care of the dying was only required for doctors in 19% of trusts. Without such training, staff are unlikely to be able to use any pathway well or to recognise when it is being used poorly. Secondly, our study highlights the importance of grounding any future tool around patient and carer reported outcomes. Lastly, the study demonstrates the importance of collecting qualitative data in developing future tools that aim to improve care of the dying.

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In the United States all 50 states and the District of Columbia require children and adolescents to be vaccinated before they attend school, college, or preschool programmes.<sup>1</sup> Rhode Island has the most extensive requirements, including mandates for vaccination against hepatitis A and B, *Haemophilus influenzae* type B, rotavirus, human papillomavirus, and influenza.<sup>2</sup> Medical exemptions are granted in all jurisdictions, and religious exemptions are granted everywhere but Mississippi and West Virginia. Only 20 states grant personal exemptions.

Since my medical career began in 1962 I have seen the harmful effects of nearly all of the vaccine preventable diseases on the US immunisation schedule. I have enthusiastically administered many thousands of vaccine doses and am glad that my children and grandchildren are well vaccinated. However, the current attitudes of public health officials in the United States about vaccine mandates and exemptions are arrogant and patronising.

The recent US measles outbreak has given rise to a lot of media hyperventilation about vaccine exemptions. There have been calls for outright bans on non-medical exemptions and financial penalties for parents whose children are not up to date with the immunisation schedule. Some of the rhetoric directed against parents who obtain non-medical exemptions has been venomous.<sup>1</sup>

Vaccines are among the greatest medical advances of modern times,<sup>3</sup> but public health officials have become intoxicated by success and have lost their sense of perspective. A case can be made for mandating vaccination against measles, which used to infect 3-4 million US children a year,<sup>4</sup> but it is over-reach to mandate vaccination against hepatitis B, which was reported to infect only 300 children aged 1-9 years annually in the US.<sup>5</sup>

#### Strict adherence

It may seem invidious to suggest that anything but humanitarian motives drive vaccine policy,



Some US public health experts want fewer exemptions for vaccination

## Vaccine mandates can do more harm than good

They increase parental mistrust and resistance when evidence is equivocal, argues **Allan S Cunningham**

but it is hard not to notice the professional and financial incentives that encourage strict adherence to the standard immunisation schedule, and the tendency for officialdom to report the good news about vaccines but not the bad news. Most vaccine research is sponsored by the manufacturers and consists mainly of studies to establish short term efficacy with little real effort to look for rare but serious adverse effects. Our vaccine adverse events reporting system is passive and records only a tiny percentage of adverse events after vaccination.

Natasha Crowcroft and her public health colleagues in Toronto have been concerned about the safety, effectiveness, and cost of some of the newer vaccines, and they worry that expanding vaccine schedules threatens children's uptake of truly life saving and cost effective vaccines such as the measles vaccine.<sup>6</sup> Furthermore,

**Herd immunity is an important concept, but it has been used to bully parents into rigid adherence to the immunisation schedule**

they perceive serious ethical problems in the vaccine approval process and suggest that public trust has been undermined by allowing manufacturers and professionals with close links to industry to be involved in lobbying and decision making. I share their concern. We have forgotten that children given the DPT vaccine (against diphtheria, pertussis, and tetanus) during the 1949 British polio epidemic had a 20-fold risk of developing paralytic polio,<sup>7</sup> and there have been other unpleasant vaccine surprises since then, such as intussusception with the first rotavirus vaccine.<sup>8</sup>

In retirement, I am still asked questions about vaccine safety and effectiveness by parents and grandparents; they are not "vaccine sceptics" and they are not given to "free riding" at the expense of their neighbours. They simply want to protect the health of their children and grandchildren. Nevertheless, vaccine hardliners have lumped them together, mostly in the name of "herd immunity."

Herd immunity is an important concept, but it has been used to bully parents into rigid adherence to the immunisation schedule. It is

commonly suggested that 90-95% of children should be vaccinated to maintain herd immunity and prevent the spread of infections to vulnerable individuals. These numbers come mainly from mathematical models pertaining to measles, but their estimates actually range from 55% to 96%.<sup>9</sup> The numbers are irrelevant to other vaccine preventable diseases. Nevertheless, they have been used to foster public disapproval of parents who decline any vaccine—and to enforce mandates.

#### Knowledge is incomplete

Public health and paediatric officials in the US want to reduce the number of non-medical exemptions by increasing the cost and inconvenience to families who request them.<sup>1</sup> This is a mistake and will only increase mistrust and resistance. In general, Canada has better vaccine coverage than the US, mostly without mandates. Without mandates 96% of 2 year olds in Newfoundland and Labrador receive the MMR vaccine (against measles, mumps, and rubella);<sup>10</sup> the figure is only 86% in West Virginia, which has rigid mandates and no non-medical exemptions.<sup>11</sup> A case can be made for mandating vaccines with a long record of safety and broad protection against highly contagious diseases. Even for these vaccines, however, knowledge is incomplete and some flexibility must be allowed for non-medical exemptions. In any case, we should not force parents and children into a procrustean bed of rigid mandates for every vaccine on the immunisation schedule.

Canadian scientists recently published data suggesting that this season's flu vaccine doubled the risk of illness from influenza in children (crude odds ratio 2.18, 95% confidence interval 1.03 to 4.61, calculated from their table 3A).<sup>12</sup> This is unpleasant news, particularly for jurisdictions that mandate flu vaccine for children, but it is not likely to be publicised in the US.

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