

[Vol. 40 No. 7 · 5 April 2018](https://www.lrb.co.uk/v40/n07/contents)
pages 17-30 | 21311 words

**NHS SOS**

**James Meek**

In the year of its seventieth anniversary, the 1.3 million people who work for the National Health Service in England find themselves in a surreal situation. They’re effectively working within two realities at once, expected simultaneously to inhabit an NHS universe where a radical, highly optimistic reform programme is under way, and a second universe in which the organisation is unmistakeably close to breakdown.

In universe one, the NHS will be upturned to give most of the healthcare people need at home or on their doorstep and admit to the big hospitals only patients with major trauma, or suffering diseases that demand intensive care, or complex surgical or biochemical expertise. Big hospitals are to become centres of research, high technology, rare skills and dramatic, life-saving interventions. Everything else will be diffused to the community. Loosely directed by the head of NHS England, Simon Stevens, money, staff and new investment are being directed towards primary care – family doctors, community nurses, souped-up local clinics, systems to help the chronically unwell live at home.

In universe two a counter-reality prevails: the reality of winter, the reality of need, the reality of an ever increasing number of frail, elderly people converging on the help of last resort, the emergency hospital. This winter, as last winter, the system of emergency medical care in England came to the brink of collapse, with untold knock-on effects for the health system as a whole. There is evidence that in at least one part of the country, the east of England, the emergency system just plain broke.

In the whole of England there are only so many hospital beds. The number fluctuates, but there were approximately 97,000 this winter, one for every 550 citizens. At the best of times, most of them are full, not only with people being treated but with patients recovering from planned operations such as joint replacements or cancer surgery. As casualties began to pour into A&E, hospital after hospital began to run out of beds. Staff struggled to free up beds by discharging patients, but an elderly person who’s technically well enough to be moved from a hospital bed isn’t necessarily able-bodied enough to be simply dropped off at the home they left.

The waits for a bed in A&E got longer, and as they did, so did the waits for assessment and treatment. To make matters worse, going into winter, many hospitals were chronically short of nurses. As A&E backed up, patients waiting for beds were left for hours on trolleys in corridors, and ambulances got caught up in the jam. Paramedics aren’t supposed to leave until the patient they’ve delivered has been seen. Increasingly, places couldn’t be found for patients in the A&E reception area and they had to wait in the back of ambulances, sometimes for hours at a time. Queues of ambulances formed outside hospitals, meaning anxious and sick people were left waiting longer and longer for help. In an effort to make more space available, tens of thousands of scheduled operations were cancelled.

Hospitals in Oxford, Derby, Bath, Taunton, Leicester, Torquay, Yeovil, Warwick, Portsmouth, Northampton, Truro, Nottingham, Redhill, Gillingham, Epsom, Dartford, Maidstone, Tunbridge Wells and the Isle of Wight warned they were no longer able to provide comprehensive care. The recommended safe limit for the number of beds that should be occupied by patients in any one hospital at any one time is 85 per cent. Across England as a whole, throughout the winter, bed occupancy averaged 94 per cent. A third of all hospital trusts reported days of 100 per cent occupancy, yet no emergency department closed, meaning those hospitals had to stow crowds of sick people in corridors. Four hospitals – Walsall Manor in the West Midlands; the North Middlesex in Enfield, North London; Hillingdon, the closest emergency hospital to Heathrow Airport; and the James Paget in Great Yarmouth – declared their beds 100 per cent full on more than half the days in that winter period.

Between them, the hospitals in Worcester and neighbouring Redditch had to divert emergency patients elsewhere at least 65 times. At Derriford Hospital in Plymouth, staff were stretched so thin they were unable to take breaks. Memos between managers at Southmead Hospital in Bristol in early January, leaked to the local press, warned that beds were ‘104 per cent full’: ‘Patients are admitted to any available bed,’ the hospital’s clinical director wrote. ‘Speciality patients are scattered.’ At that point, with all overflow beds occupied, the hospital still had 51 patients to find beds for. Stocks of face masks and walking frames were running low. It later emerged that, on various days in December, 122 people at Southmead had been left on trolleys in corridors for more than 12 hours.

In January, with Manchester’s three emergency hospitals close to full, one patient had to wait more than 16 hours to be admitted. An A&E consultant at the Royal Stoke University Hospital, Dr Richard Fawcett, broadcast his frustration on Twitter. ‘It breaks my heart,’ he wrote, ‘to see so many frail and elderly patients in the corridor for hours and hours … I personally apologise to the people of Stoke for the Third World conditions of the department due to overcrowding.’ Patients and their families told the local newspaper, the *Sentinel*, that corridors were so crowded with trolleys it was hard to walk down them. A shortage of cubicles meant patients were seen in disabled toilets. One 80-year-old man, an epileptic with severe dementia who had been diagnosed with pneumonia, waited on a trolley for 36 hours. Photos appeared across the media showing patients – one with a drip attached – sleeping on the bare floors of Pinderfields Hospital in Wakefield. A hospital spokesman claimed that patients ‘may have chosen to lie down as seats were provided’.

A whistleblower told the *Health Service Journal* that ambulance delays in the east of England had led to the deaths of at least 19 patients and serious harm to 21 more. On 1 January, an 81-year-old woman in Clacton, Essex, dialled 999, complaining of chest pains. The ambulance took three hours and 45 minutes to arrive. It was too late. A few days later, a 52-year-old man in Norfolk collapsed with severe chest pain and vomiting. He was taken to the Norwich and Norfolk Hospital, but had to wait in the back of the ambulance that took him there for four and a half hours before being seen by a doctor inside the building. He was told to go home and collapsed again when he got there. Two ambulances sent to get him were diverted to other calls and by the time he returned to hospital, his life couldn’t be saved.

One doctor in a major A&E department in the east of England told me he’d witnessed short cuts taken by staff under pressure. For a time, ambulance crews had been allowed to leave patients in a hospital area that wasn’t technically A&E reception. One elderly patient with abdominal pain was diverted within the hospital from emergency medicine to a GP-style consultation, sent home, returned to the hospital a few hours later, and died. ‘What I’ve seen is the relentlessness of the shifts,’ the doctor said. ‘The intensity. The feeling of higher and higher accountability. And then a lack of investment in staff. Asking them to do more and more and more, to cover more and more patients. There’s no give and take. The staff they should be investing in get more and more demoralised. You’re at risk of creating a Mid-Staffs environment where people don’t really know who they’re working for and start accepting risk that previously would have been deemed unacceptable. They stop reporting things because they reported them before and nothing happened. It’s creating a dangerous culture.’ What should be done? ‘Stop decreasing capacity. Build capacity and build staffing. The party line is always “it doesn’t affect patient care.” Of course it fucking does.’

‘Mid-Staffs’ is a reference to the notorious ethical collapse in the 2000s at a hospital in Staffordshire where, shunned and under-resourced by reckless trust managers pursuing administrative goals, once conscientious staff drifted away from good practice and basic decency to the point where hundreds of patients died in conditions of filth, hunger and pain.[​1](https://www.lrb.co.uk/v40/n07/james-meek/nhs-sos#fn-01)

In a letter to the prime minister on 10 January, the most senior emergency consultants at 68 hospitals in England and Wales warned that the NHS was ‘severely and chronically underfunded’. Chris Hopson, the head of the organisation that represents the corporate interests of NHS hospital, community and ambulance trusts, said the NHS ‘no longer has the capacity to deal with the demand that it is currently facing’. Even before the winter began, Simon Stevens publicly warned his government masters that the entire system, not just emergency medicine, was teetering. Without an increase in funding, he said, five million people – almost every tenth citizen of England – would find themselves on a waiting list for an operation by 2021. (We’re not that far off; at the end of August 2017 the figure was 4.1 million.)



Stevens’s speech, at an NHS bosses’ conference in Birmingham, was surprisingly blunt and political for a civil servant, the more so because he was speaking immediately after his political chief, the health secretary Jeremy Hunt. Provocatively, Stevens compared the situation in Britain now to the time of the NHS’s birth in 1948, seventy years ago – ‘an economy in disarray, the end of empire, a nation negotiating its place in the world, a need for massive house building’. Sticking the knife in even deeper, he reminded the government that it had eagerly taken ownership of a Brexit referendum result partly achieved on the basis of a promise that leaving the EU would free up an extra £350 million a week for the NHS.[​2](https://www.lrb.co.uk/v40/n07/james-meek/nhs-sos#fn-02) ‘Trust in democratic politics will not be strengthened,’ he said, ‘if anyone now tries to argue: “You voted Brexit, partly for a better funded health service. But precisely because of Brexit, you now can’t have one.”’

Stevens’s frustration was understandable. The two clashing universes of the NHS today – the ideal of reform and transformation, the reality of frightened, confused people in pain, waiting for care in ambulances and hospital corridors – were originally linked, in the sense that a system overwhelmed by the needs of an ageing population was the dread dystopia in prospect were the transformation not to take place. But there were always three concerns lurking in the transformation agenda, set out in October 2014 in an NHS England document called, with deliberate banality, the ‘Five Year Forward View’.

First, what if the government didn’t come up with the money to pay for the reforms and the continued running of the organisation while they were carried out? Second, what if, instead of waiting to see whether the reforms, once bedded in, were giving the NHS some room for manoeuvre, the government and local NHS managers banked gains in advance, and ‘transformation’ became a euphemism for ‘cuts’? And third, what if the long-predicted surge in demand from elderly people came sooner, and with more intensity, than had been predicted?

In fact, all three fears were realised. The government’s claim to have protected NHS funding ‘in real terms’ since 2010 doesn’t stand up to inspection much better than the notoriously fraudulent £350 million claim of the Leave campaign. Reform is being executed not under the banner of ‘transformation’ but of ‘sustainability and transformation’, and good but experimental ideas for doing things differently were burdened, even before they started, with unrealistic projections for how much money they’d save. As for the pressures of caring for the health of a population with a growing proportion of chronically unwell older citizens, the data is imprecise, but something dramatic is happening. Between 2011 and 2018, the population of England increased by about 6 per cent. Yet the number of people who were admitted to hospital in an emergency – not those who simply attended A&E, in other words, but those deemed unwell enough to need a hospital bed – went up by 15 per cent. And while the over-65s make up only a quarter of emergency attendees, they make up half of those who are admitted.

To suggest that the balance of England’s population has shifted rapidly to the point at which the great success of the NHS – giving so many people long life – has put it under strain, smacks to some on the left of offering government a get-out. As if the Conservatives were being given an excuse to blame the health service’s difficulties on demographics, rather than admitting that they – that is, we – need to put more money into it. But the two propositions aren’t exclusive. The needs of the growing number of frail elderly people are one of the main reasons the NHS must get more money. And it would be strange if a transformation in society could occur without a transformation, planned or otherwise, properly funded or otherwise, in the organisation that provides its healthcare.

It’s hard to put concepts such as ‘the growing number of frail elderly people’ and ‘NHS in crisis’ in an article together with a slew of statistics and not feel a distancing effect creeping into the text, a certain intergenerational coldness. Unintentionally the writer, or the administrator, or the politician, is the ‘us’, the one who opines and analyses; the elderly the ‘them’, on whose behalf things are done. The civil servants who produced last year’s update to the ‘Forward View’ – which quietly sounded the alarm with the terse admission that ‘demands on the NHS are higher than envisaged’ – presumably meant only to inform and explain when they wrote: ‘It costs three times more to look after a 75-year-old and five times more to look after an 80-year-old than a 30-year-old … today, there are half a million more people aged over 75 than there were in 2010. And there will be two million more in ten years’ time.’ Still, the last sentence strikes an uneasy note. There are shades of the rhetoric of immigrant fear, of the neurosis that a stable, long-established society is on the verge of being swamped by outsiders from far away, except that these ‘outsiders’ were born far away in time, rather than space. Ian McEwan openly expressed the motif last year when he looked forward to a more liberal future Britain in 2019, cleansed of ‘1.5 million oldsters, mostly Brexiters, freshly in their graves’.

It’s odd, and not just because McEwan, at 69, isn’t exactly a youngster. In Britain, thanks to the NHS and the welfare state, our predicted life expectancy leads all, typically, to profound old age, where we will quite possibly be frail, probably carrying around a bouquet of chronic ailments, in many cases in a relationship of deep dependency – being cared for, or caring for someone more frail than ourselves. And yet there exists a psychological boundary between the elderly and the not-elderly. The not-yet-elderly know they will almost certainly cross that boundary, but until it is crossed, it is possible for the young and middle-aged to regard the old as if oldness is their essential nature.

It isn’t a lack of compassion; after all, for the not-elderly, the elderly are their parents and grandparents and great-grandparents. Partly it’s a problem of scale. Your mother with dementia is special: the collectivity of all mothers with dementia is a hard-to-grasp concept. Partly it’s a problem of fellow-feeling, of immense sympathy and weak identification. It’s a paradox. You can’t discuss the state of the NHS without referring to elderliness as a group identity, and yet to do so is imaginatively to cut elderly people off from the accumulated selfhood of their long lives, from the greater portion of their life when they were not elderly. Which is a way the not-elderly have of insulating themselves from the inevitability of their own old age and everyone else’s. Which is, in turn, a form of mass denial that makes acceptance of the health service’s requirement for more cash difficult.

Chronic illnesses are common among the non-elderly, of course – diabetes, asthma, depression, eating disorders – but when we’re younger, we tend to think of healthcare in linear terms: either the emergency route or, less urgently, you have symptoms, go to the GP, they prescribe something or send you to the hospital for further diagnosis, and treatment follows. In fact, as any GP will tell you, most of their work consists of managing chronic conditions. The difficult stage in the later decades of life, for elderly patients and for those treating them, is when one condition can’t be tackled without taking into account a whole lot of others. In medical jargon, they’re known as ‘multiple co-morbidities’, when in a short space of time symptoms, diagnoses and treatments begin to crowd in, overlap, interact. You can no longer be identified as a sufferer of a familiar condition: ‘I’m diabetic,’ ‘Sarah’s mum’s got Parkinson’s.’ You become a bearer of a disease combo that probably has no name. It’s possibly as unique as you are. Encounters with the health system become a struggle to make sure everyone is up to speed with your multiple conditions. It’s one of life’s tricks. Just when it becomes essential for strangers to care about who you are, just when your personal history is at its ripest, your medical history starts to crowd it out.

\*

In September last year, in Lutterworth in Leicestershire, I met Wendy Warren. She was born in Kent in 1935 and moved to Leicester just after the Second World War when her father, an engineer, found work there. She did well at school and was set to go to college, but her father lost his job and she chose to help her mother by bringing a wage into the house. She became an assistant manager in a department store. On midsummer’s night in 1955 a tall, broad-shouldered farmer 17 years her senior, John Warren, took her to the stock car racing, and a year later, when Wendy was 21, they got married. John Warren rented 175 acres from the local squire in Dunton Bassett, a village in the south-west of the county. He’d been farming it in partnership with his widowed mother, a woman tough enough to steer the tenancy after her husband died of Spanish flu in 1918. She retired and moved out after her son’s marriage, and for the next 36 years Wendy and John Warren farmed together, growing their holding to 265 acres and living rich, busy lives. They kept a dairy herd of sixty cows. They had two daughters. John Warren raced in a motorbike and sidecar pair. Wendy Warren was a magistrate. She researched local history. She ran as a Liberal in local elections, though she quit the party over its support for joining the EEC. They decided to give up the farm in 1991 and retired to another village, South Kilworth, to a house with fine views across the countryside. Every year in early spring they spent a month in Tenerife.

When John Warren died in 2000 his widow was 65, and although she was on medication for an underactive thyroid and had, unusually, developed type 1 diabetes when she was 60, she was otherwise fit, healthy and comfortably off, able to roam the county and beyond and socialise and volunteer as busily as before.

In her early seventies, she began to suffer from macular degeneration, which made driving difficult after dark. There’s no street lighting in South Kilworth and the country lanes are narrow. The village post office and shop and almost all its bus services had gradually disappeared and in midwinter, after four o’clock in the evening, Warren found herself trapped at home. A family conference was held and it was decided she should move to the market town of Lutterworth. In 2011 she was installed in a neat modern bungalow in a town where everybody knew her, with shops and its own cottage hospital and her family nearby: the community ideal.



In 2014, her eyesight deteriorated to the point where she could no longer drive. Emergency hospital visits became an annual occurrence: a diabetic coma, an ear infection. In February 2015, on her regular holiday in Tenerife, she picked up a chest infection, aggravated by a previously dormant condition called farmer’s lung, caused by years of exposure to mouldy hay. Her body reacted against the antibiotics prescribed by the Canary Islands doctors and her Achilles tendons began to soften and collapse. At about the same time she developed an autoimmune condition in her leg muscles, myositis. Finding it harder to see and walk, Warren began to pay for a home help to come in the mornings. Life was becoming more constrained, although she was determined to cast her vote for Leave in the Brexit referendum in June. The chest problems never fully went away and in September 2016, after the GPs had tried three different courses of antibiotics, she was admitted to Glenfield Hospital in Leicester with pneumonia. Just before she was due to be discharged she experienced agonising abdominal pain. Her colon was leaking into her bladder through a fistula. She was taken to a second hospital, Leicester General, where surgeons performed an emergency ileostomy to divert waste from the colon to an artificial opening, or stoma, in her stomach, and allow the gut to heal. She was sent to a cottage hospital in Hinckley, ten miles west of Lutterworth, to recuperate, but in November the infection flared again and she was admitted to Leicester’s third and biggest hospital, home of its emergency department, the Royal Infirmary. In December she was operated on again, the ileostomy was reversed and replaced with a colostomy, and she was transferred to Lutterworth cottage hospital to recover just before Christmas. In January, after more than three months and two major operations in five different Leicestershire hospitals, Wendy Warren finally went home.

At first she seemed to be recovering well. With the help of her daughters she was able to go down from three care visits a day to two. Then in early March she had to be readmitted to the Royal Infirmary. Another fistula had formed. The surgeon had to perform a second ileostomy, but couldn’t reverse the previous colostomy. In April, after another short stay at the cottage hospital, she was discharged, but rehabilitation was difficult, and she moved into a care home. It was supposed to be temporary but she hasn’t been able to return to her own home, except for brief visits, since then. Throughout 2017 she was a regular visitor to the Infirmary’s A&E department.

When I met Warren with her daughter Joanne at her house in Lutterworth in September, I was struck by how well she appeared, despite the evidence of her medical file, how alert and full of good humour and lacking in self-pity. She had bruising from the steroid-induced thinness of her skin and, as she told me, she couldn’t see my face, a few feet away. She had her legs up on the sofa (on top of everything else, she has a collapsing spine) and when she moved it was with the aid of a walker. But she came across more as a wounded soldier than a stricken old lady. When I went over the recording of our interview I noticed how full and precise her stories of her life were before her complex of conditions and how, as the narrative shifted to the last couple of years, it was her daughter who took over the role of witness.

The NHS that Joanne Warren described was one where the big central hospitals are struggling with shortages of staff and beds while the transformational steps that are supposed to ease the pressure by providing better primary care have yet to kick in. In Leicester Royal Infirmary in the winter of 2016-17, nursing staff were so pressured that they left the incontinent Warren alone in a cubicle for two hours till she was lying in her own urine. She was rescued only when the ambulance driver who was supposed to take her back to the care home found her and summoned a nurse to clean her. A shortage of pharmacists meant that patients who were ready to be discharged in the morning often weren’t able to leave until late at night because their medication hadn’t been approved. Administrators were so desperate to free up beds that, as Wendy Warren witnessed, porters would rouse patients with dementia in the small hours to rush them off to some part of the county where a community bed had become available. Even after the Royal Infirmary got a new, bigger A&E building in April 2017, at a cost of £48 million, the Warrens found themselves waiting outside it in the back of an ambulance, in summer as well as winter.

Against this, the Warrens can see only one clearly announced local transformation in the NHS, and it doesn’t make sense. Amid all the rhetoric of shifting more services from the big city hospitals to the community, the plan is to close Lutterworth cottage hospital.

\*

In many ways, Leicestershire, although landlocked, is England in miniature. It contains a densely populated, dynamic, rapidly growing city, Leicester, with a young population, full of students and immigrants, reasonably prosperous but with areas of extreme deprivation. It’s on the south-eastern rim of the great jug-handle of 19th-century industrial boom-time cities that curves round the hills of the Peak District: Liverpool, Manchester, Leeds, Sheffield, Nottingham, Leicester, Coventry, Birmingham. Fewer than half of its 350,000 citizens described themselves in the last census as ‘white British’. A third are foreign-born. It has almost as many Hindus as Muslims, and the irreligious are a larger group than the believers in any one of the big religions. All three of its MPs are Labour, among them Jon Ashworth, the shadow health secretary. It voted, narrowly, for Remain.

The vales and wolds surrounding the city are very different. The 670,000 people who live in rural Leicestershire take the county’s population over the million mark. There’s a lot of accumulated wealth in its pretty villages and grand manor houses. Five hunts – the Atherstone, the Belvoir, the Cottesmore, the Quorn and the Fernie – still go through the motions of chasing foxes within the bounds of the law. In bleaker districts of small post-industrial towns like Coalville and Loughborough, there is poverty, low wages and anomie. Demographically it’s a whiter, older world; its population is growing much more slowly than Leicester’s, and that growth is among the elderly. The working age population is shrinking. The number of over-85s is forecast to grow by 187 per cent by the late 2030s. All seven of its MPs are Conservative, among them Nicky Morgan, the chair of the Treasury Select Committee. It voted, narrowly, for Leave.

If there is to be a transformation in the way Leicestershire’s million people are to be helped to good health, there has to be a plan, and an organisation to carry it out. One of the curious aspects of the NHS in the Stevens era, however, is that instead of there being an organisation which made a plan, the plan came first, with the intention that it would seed the spontaneous growth of dozens of new regional organisations to tailor it to local conditions and deliver it.

As everywhere in England, the way the NHS is now set up in Leicestershire, town and country, reflects both the hospitals and surgeries it inherited in 1948 from the old, pre-NHS world, and the successive waves of reorganisation, new builds and closures it has undergone since. Most recently, it has been shaped by three factors: the big budget increases it received under the Labour government of Tony Blair in the early 2000s, rescuing the service from 18 years of Conservative neglect and, at the cost of some ruinous public-private mortgages, covering the land with shiny new hospitals; the steady increase in the role of profit-making firms as NHS subcontractors, which both New Labour and the Conservatives have encouraged; and the inept restructuring carried out under David Cameron in the early 2010s, sometimes called the Lansley reforms after their patron, the erstwhile Conservative health secretary Andrew Lansley.

The Lansley reforms left seven local organisations responsible for healthcare in Leicestershire. Five are part of the NHS and two aren’t. There are three consortia of GPs called Clinical Commissioning Groups, or CCGs – one each for the east and west of the county and one for the city of Leicester. There’s the acute trust, the University Hospitals of Leicester Trust, which runs the A&E at the Royal Infirmary (England’s biggest emergency department), carries out high-end medical research and treats an array of grave illnesses. There’s the community trust, the Leicestershire Partnership Trust, which treats mental illness, runs cottage hospitals like the one in Lutterworth, organises health visitors and district nurses, and operates the primary care system in the county’s three prisons. Two local authorities, the county council and the city council, are responsible for public health, as well as being obliged by law to look after children in difficulty and to be the carer of last resort for adults.

Post-Lansley, hundreds of these organisations – more than two hundred CCGs, and 135 acute trusts – were patchworked across England. Stevens’s NHS England, with the government’s blessing, laid another map on top of the old one. The country was divided into 44 areas, each covering between three hundred thousand and three million people. Each area had to come up with a scheme for transformation. They weren’t told what to do. They were given a broad menu of options and desirable outcomes and promises of packages of money if they did this or that thing. The ‘they’ in each of these areas was whatever set of GP consortia, hospitals and councils existed inside them. The fragmented bits of the NHS, in other words, were expected to reorganise themselves and create a radical plan for change without an explicit template being provided from above, without new legal responsibilities or powers or budgets or staff.

It was bold and risky, potentially fruitful and potentially chaotic. Politicians and health administrators in some areas, like Greater Manchester, seized the chance for a radical integration of acute and primary care, with a new set of public bodies to control a joint budget. Elsewhere, as in Leicestershire, change has been more hesitant and secretive.[​3](https://www.lrb.co.uk/v40/n07/james-meek/nhs-sos#fn-03)

The fuzziness of the process is exemplified in the acronym that was originally attached to it, STP. Normally when you introduce an acronym you spell it out. I can’t with this one. The T definitely stands for ‘Transformation’. The S, added at the insistence of the Treasury, stands for ‘Sustainability’ – a reminder that the programme is supposed to slow cost increases. But when it comes to the P, there’s ambiguity. Sometimes it stands for ‘Partnership’, the coming together of GPs and hospitals and councils to create a single local healthcare leadership. Sometimes it stands for ‘Plan’.

STP, in other words, is both chicken and egg. Leicestershire seems to have settled on the egg, the plan. Which raised the question – at least with me, when I tried to ask about it – where is the chicken? Whose plan is it? When I talked to people in Leicestershire who follow healthcare, they used two expressions: ‘the footprint’ to describe the area the plan covers, and ‘the system’ to describe the administrative machinery that produced it. Conceptually, in Leicestershire, there is a body called the ‘system leadership team’ – you can see public minutes of its meetings – but to the world at large this creature is shy, legally ill-defined and mute, in the sense that it lacks the equipment to respond to questions.

According to NHS England, the master of Leicestershire’s STP is a long-term NHS administrator called Toby Sanders, who’s also managing director of West Leicestershire CCG. But when I approached Sanders in August, I got nowhere: initially a flat refusal, through an intermediary, to have anyone talk to me about anything to do with Leicestershire NHS, then months of vague, unrealised undertakings. It turned out that although each of the five CCGs and hospital trusts in Leicestershire has its own team of media wranglers, none of them deemed it their job to handle questions or arrange interviews about the STP. Whichever of the five I spoke to seemed unable to respond without having a meeting with all the others – and then wouldn’t say anything. (Much later I heard from an insider that the predominant mood in those meetings, when the issue came up of whether it was appropriate for the NHS in Leicestershire to answer questions from a journalist about its work, was: ‘What’s in it for us?’)

I went to a public meeting held by the University Hospitals of Leicester NHS Trust. The chief executive, John Adler, and the chairman, Karamjit Singh, held forth confidently and pleasantly about the successes and difficulties of their hospitals, without once mentioning the radical plan that was supposed to change everything – the STP. When members of the public asked questions, each one asked about the STP. Adler and Singh seemed surprised, looked at each other, and murmured that really Sanders needed to get out and spread his message.

As the months went by, I began to wonder whether Toby Sanders existed. I’d never met him or spoken to him, there was no video of him on the internet, and his Twitter feed wasn’t unequivocally personal. But nobody else in Leicestershire’s NHS management was ready to take up my offer of listening while they explained the virtues of the STP to me. Doctors and nurses were off-limits too. This was made clear to me when at one point, knowing better services for stroke patients recovering at home was an element of the plan, I contacted the Stroke Association, a national charity, which put me in touch with a therapist working for Leicestershire’s Stroke Early Supported Discharge service. Initially she seemed happy to help, but after a few weeks of silence I called her. She said she’d checked with the University Hospitals Trust, her employer, and they’d instructed her not to talk to me. ‘They told me: “Yes, we know about him,”’ she said. ‘“He’s been going around asking questions.”’

Still, there was a plan. The publicly available version of Leicestershire’s STP, published in 2017, reflected the two universes of reform evangelism and crisis, but because it was a single document, ways had to be found to bring the universes together, and this was awkward. That which transformed had to be shown to save money, even when there was no obvious reason it would; that which saved money had to be shown to contribute to the transformation agenda, even though, in at least one case, it blatantly contradicted it.

At the heart of the plan were two enormous amounts of money and a slogan. The amounts were £399 million – the amount by which the Leicestershire healthcare system reckoned it’d be in the red by 2020-21 if nothing changed, a fifth of its combined budget – and £350 million: the amount of capital the planners thought they’d need to invest to transform the system. The slogan was ‘Home First’ – the distillation of the idea that the people of England needed, for their own good, to be weaned off an over-reliance on hospitals.

‘Home First’ entered the culture of the Leicestershire health system in 2014 in a report by a consultant, Dr Ian Sturgess, who was called in by the University Hospitals Trust. At the time, measured by the government’s national target of patients being seen within four hours of arriving at A&E, the Royal Infirmary was one of the weakest emergency hospitals in England. Sturgess saw that patients either found themselves stuck in hospital longer than necessary or were discharged in such a way that they soon bounced back. Home First, his recommended fix, focused remorselessly on unwell people spending as little time in hospital as possible: intervene early to prevent patients needing an emergency hospital admission, intervene again if a patient spends a day in hospital without something being done to speed their journey home, send them home in such a way that you minimise the risk they’ll have to come back. Tag at-risk patients so that if they do return to A&E, there will be plans in place to get them home even before they arrive.

Parts of Sturgess’s report found their way word for word into the Leicestershire STP two years later: ‘60 to 70 per cent of emergency admissions are of people with long-term conditions or frailty,’ Sturgess and the STP declare, continuing in terms unintentionally redolent of the bureaucracy of criminal justice: ‘These patients are known to the system.’

Home First is an admirable idea, but when it made its way from the challenges facing a single hospital into Leicestershire’s broader plan, its prime aim became blurred. Was it a defensive step required by any 21st-century rich-world health system to prevent hospitals being overwhelmed by an ever increasing number of frail, mainly elderly patients with multiple illnesses? Was it simply a better way to offer healthcare? Or was it a way to save money? These are three different goals, yet in the STP they’re treated as if they were benefits from a single source, like a list of claimed ailments cured on a bottle of quack tonic.

Some of Leicestershire’s ‘transformation’ elements are already in place. The area has set up a virtual 256-bed ‘hospital’ called Intensive Community Support, or ICS, where recovering patients are treated by nurses and therapists who drive to visit them in their own homes. Following a scheme pioneered elsewhere, most famously in Dorset, ten joint teams have been set up across the county where professionals who would previously have worked separately – district nurses, community mental health nurses, GPs and social workers – combine to give hospital dischargees a soft landing on their return home or try to find ways to treat urgent problems without hospital care being necessary.

Much else is behind schedule, unfunded or aspirational. According to the plan, everyone across Leicestershire was supposed to be able to get access to a local doctor until 8 p.m., seven days a week, by October 2017, but this remains patchy. An essential part of the programme was to move massive numbers of outpatients – 150,000 a year, not far short of a fifth of the total – away from the big Leicester hospitals to new groups of GPs called ‘federations’, who will employ occasional consultants at new or re-equipped clinics and health centres in the small market towns. The STP runs until 2021, but this ambitious programme has hardly started. The acute hospitals were desperate to buy a new system to digitise patients’ medical records, but the Department of Health wouldn’t fund it.

Despite the freshness, incompleteness or uncertainty around so much of the transformation aspect of the plan, it was treated as if it had already proved itself and made it safe for Leicestershire to cut hospital beds and staff to save money. In urban Leicester, one of three acute hospitals, the General, was effectively to close. Overall acute beds would be cut by an eighth, from 1940 to 1697. So hopeful were Toby Sanders and his planners about the power of virtual beds and joint local teams to keep the frail unwell at home that they didn’t feel the need to compensate the loss of so many big city hospital beds with an increase in rehab beds in small-town Leicestershire. Hence the axe falling on Lutterworth’s cottage hospital, which was likely to be sold for development; Rutland would lose the only hospital beds it has, in Oakham.

More surprising still, given Stevens’s emphasis on boosting primary care at the expense of the big hospitals, the plan called for the staff of the University Hospitals Trust to be cut by 1500, while primary care staff would only go up by 234. In the whole of Leicestershire and Rutland, there are 568 GPs, and the STP envisaged increasing that number by a mere 1 per cent a year. Since that’s the same as the area’s annual population increase, it meant no real increase at all.

There were points in the plan where the measured discourse of sustainability and transformation frayed and the extreme financial pressures on the NHS glared out. One was the £250 million needed by the University Hospitals Trust to close acute services at the General and move them to the Royal Infirmary and the Glenfield. The plan envisaged that most of the money would have to come from a PFI deal, which risks adding to the deficit of the trust, which is already, like so many acute trusts, deep in the red.

The other was a severe cut of 40 per cent – £29 million – to an NHS programme called Continuing Healthcare, which funds care for severely disabled people with long-term, complex health needs, such as sufferers from Parkinson’s disease or people left with spinal injuries after accidents. Across Leicestershire and Rutland, more than 1300 people are supported in this way. For some it means they can continue living at home. Critics point out that the cut could split families, with disabled people now living at home being pushed away to private care facilities. I understand that changes to the STP may result in an ever harsher cutback. Home First, in other words, as long as it isn’t too expensive.

Bart Hellyer, a former chair of the Spinal Injuries Association and a member of Rutland Healthwatch, one of the local organisations set up under the Lansley reforms to provide a voice for patients in the NHS, challenged the STP proposals at a public meeting with local NHS officials last year. When he tried to attend a similar meeting a few weeks later, he was intercepted by a security team with instructions to bar him entry, on the grounds that his wheelchair – Hellyer is paralysed from the chest down – was a safety hazard.

\*

I visited Hellyer at his home in Rutland one day in October. The land is Anglo-Arcadian, pretty and domesticated, green and hedgerow-veined, neither hilly nor flat but gently swelling, like a sea just before the waves begin to break. It is thinly populated, with a high proportion of retirees. Wendy Warren referred to it as ‘the empty quarter’. Hellyer lives in a comfortable former lodge house in open fields near the village of Ridlington. His wife died in 2004, but he’s well-off enough to pay somebody to help him do what he can’t – ‘a mixture of housekeeper, carer, gardener and quite a good handywoman’, he said.

Hellyer grew up in the area, went to Uppingham (a nearby private school) and studied law at Exeter. While he was there, he took part in a point to point race, his horse hit a fence, and he was shot against the ground with shattering force, breaking his spine. After treatment and therapy at Stoke Mandeville Hospital he returned to finish his degree and went on to become a pioneer of personal injury law in Britain, importing from North America the previously alien idea that damages should include the cost of rest-of-life care for people catastrophically injured in accidents. Now retired, he breeds racehorses from a stable in Shropshire. He’s shown extraordinary resilience in the wake of his accident, his legal work gave him prosperity and, as he readily admits, he started life with advantages. But even if he were much wealthier than he is, he couldn’t avoid dependency on the NHS system.

It isn’t just the ambulance service, which not long ago blue-lighted Hellyer to A&E when he fell downstairs. The NHS also provides a whole set of lesser-known mobile services, obscure until you need them, whose effectiveness depends on skilled staff being able to zoom across the countryside to people’s homes when required. When she was sent home from hospital, Warren came to depend on Leicestershire’s small team of mobile stoma nurses. Similarly, Hellyer relies on a handful of mobile catheter crews who, in the event of a problem, are what stands between him and a potentially fatal condition called autonomic dysreflexia.

‘If you have a blocked catheter, they have three hours to reach you or you could be dead,’ Hellyer said. ‘The times I’ve needed it, they got to me within an hour and a half. It’s a well-run service … but … if things like that are going to be needed more for people at home, what extra resources are they going to put in? If you’ve got all these people being treated at home, you’re assuming you’ve got adequate transport for nurses, therapists, doctors, whatever … they’re assumed to be able to rush around the county in the depths of winter, in the dark and cold. I’ve not seen one bit of paper addressing those issues. The practicalities.’

Unease has spread through the well-heeled parishes of rural Leicestershire and Rutland as the old geography of the NHS is redrawn. ‘You’ve got big hospitals, you’ve got people at home, you’ve got the bit in the middle, the community hospitals,’ Hellyer said. ‘In the STP plan you’re talking about taking a heck of a lot of beds out. You’re taking out Lutterworth, you’re taking out Oakham. The community hospital element is going to be decimated.’

When Warren was recovering at Lutterworth after her surgical odyssey through the big Leicester hospitals, it was December, and she was able to get a pass to join her family for Christmas. What will happen in similar cases after the community hospital loses its beds is murky. The ‘Five Year Forward View’ evoked a shift of money from big acute hospitals to local primary care, but Warren’s daughter Joanne’s sense that the opposite is happening isn’t surprising. While the Leicestershire STP calls for £250 million to reconfigure acute hospitals in Leicester, it envisions raising £3 million by selling off the Lutterworth hospital site, and only spending £1 million on whatever replaces it.

‘Our worry is that the acute hospitals are sucking in huge amounts of money and resources,’ Joanne Warren said. ‘What’s being done out in the rural areas with these new plans? To the huge number of older users with chronic illnesses in the rural areas it feels as if we’re losing to allow that money to be sucked into the centre. Lutterworth hospital is going to be closed before they’ve fully proved what they’re going to put in its place. That’s our worry, that we’re going to get a third-rate system here with fabulous super hospitals in the centre.’

Simon Hill, a campaigner against Lutterworth’s closure, who praised the care his terminally ill father received at the hospital before he died in 2016, articulated the same sense of services thinning out in the countryside. ‘It’s not like London,’ he said, ‘where you can throw a stone and hit a hospital … There’s going to be a lot of old people just dying in their homes, waiting for care.’

Joanne Warren made clear she carried no torch for the Lutterworth hospital building. ‘I’d be quite happy to see it flattened and something newer and smarter put there,’ she said. She was well aware of how much the NHS had improved since she was young (she’s 60). ‘I remember queueing up in the old part of the Royal Infirmary. I remember this huge barn of a room where you went for a consultant’s appointment. Row upon row of hard wooden seats and you could wait for hours until you were called. There is so much that’s so much better. That’s not what I feel we’re about. If they could absolutely say: “Right, Wendy, you don’t need to be in a hospital bed, we’re going to send you home, because we’re going to do all this at home.” Are they going to provide hospital beds in people’s homes?’

Warren’s fragile skin makes her vulnerable to pressure sores and Lutterworth hospital, like the acute hospitals, put her on an expensive pumped air mattress. ‘So where’s the hospital bed that she would have needed, who’s going to take her observations three or four times a day, who’s going to check on all the other signs that need checking by a qualified nurse?’

\*

In fact, hospital beds are being provided in people’s homes in Leicestershire and Rutland. In February, six months after I’d asked the local NHS if I could meet some of the people involved in its transformation, I was finally given access to the nerve centre of Leicestershire’s virtual hospital, the ICS. There isn’t much to see: a small, bare-walled, carpet-tiled room in Leicester General, with a handful of people arrayed around the edge, talking on headsets and tapping on a variety of models of well-worn computer. These were the gatekeepers of the ICS, fielding requests from other corners of the NHS to ‘admit’ patients to a form of hospital-like care in their own homes.

Susannah Ashton, the hospital matron, told me that while they might often order a hospital bed to be put in a patient’s house, they generally deemed the conceptual ‘bed’ to be the patient’s home. And these virtual beds might be anywhere in the thousand square miles of Leicestershire and Rutland, in the city of Leicester or out in the market towns and villages, from Sheepy Magna in the west to Frisby on the Wreake in the east.

The ICS has a staff of about 170 nurses, therapists and administrators divided into five district teams, spread out across the area, corresponding to about five ‘wards’ of about fifty ‘beds’ each. Like community hospitals, they don’t have doctors on duty; medical cover is provided by nurse practitioners, or GPs when required. Rather than a ward round, the virtual wards are subject to a board round – each team’s patients and their conditions are written up each day on a whiteboard at the team base for their progress to be discussed. I saw the columns of names scrawled on the whiteboard for Leicester city: dozens of episodes of personal misfortune, predominantly falls and infections.

Rather than duty nurses in a traditional ward, with its daily cycle of meals, medication, pulse and temperature-taking, bedlinen changing and physiotherapy, the patients will see nurses and therapists more rarely, often once a day, or even less; sometimes, if a patient is deemed to have improved enough, the ICS will check in by phone. Visiting twice daily is reserved for patients whose condition is deteriorating.

Unlike the traditional district nurse or home-visit therapist, who follow a schedule of particular tasks, the ICS team, like ward nurses, are expected to react to whatever situation the patient’s changing condition throws at them, even if it puts their timetable out. They can order minor modifications to a patient’s home – to install a key safe, for instance, if a patient has trouble answering the door. And the therapists and nurses have some training in each other’s basic skills: an ICS therapist, for example, will be expected to be able to check a patient’s vital signs.

On average, a patient ‘stays’ in an ICS ‘bed’ for ten days. As Ashton described it, the prime reason for setting up the virtual hospital is to keep its predominantly elderly patients out of an actual hospital. The ICS is there to reassure doctors that a patient can safely do without a conventional hospital bed, and to reassure patients whose illnesses have temporarily robbed them of confidence in their ability to cope with everyday home life. ‘A GP might go to see a patient at home who has an exacerbation of a chronic lung condition,’ Ashton said. ‘Normally the doctor would send them into hospital to get their antibiotics because they know they’re quite poorly. But we can go in and support them for the next five to seven days, get them through that episode.’ Compared to an actual hospital, the ICS is stripped down. It doesn’t operate at night, so patients who need night care can’t be admitted. There’s no call button for a nurse; in a crisis, the patient has to fall back on the phone. Against that are the advantages of staying at home.

Ashton was enthusiastic and persuasive, bringing energy and thoughtfulness to an admirable idea. She was circumspect – a press officer from the Partnership Trust sat in on our interview – but as we talked it became clear the ICS was having to fight to realise its potential. And it wasn’t hard to see why. I thought back to the post office and shop that closed in South Kilworth, one of the many reasons Warren found it tough to stay there as she got older and more infirm. It wasn’t that local people didn’t want those services: they did. It was that the local community couldn’t offer the post office and shop a high enough reward to stay. The NHS is different: it’s a nationally funded service set up to serve a common need. If it decides it’s necessary to have more services dispersed to the community – if it decides it needs to set up virtual hospitals to treat people in their own homes – it can. But it’s hard to see how they won’t either cost more than the services they’re intended to replace, or be worse.

The numbers in Leicestershire’s STP were extremely specific: a 256-bed virtual hospital would speed the consolidation of the big Leicester acute hospitals and save money by allowing the closure of 65 acute beds. The reality is that while the 256-bed ICS is up and running, no acute beds have closed. Had everything stayed the same, this would have left the ICS as an extra service. But things haven’t stayed the same. Even without closing any acute beds, and with the ICS operational, the system can barely cope with demand. A leaked memo from John Adler to staff last year said the University Hospitals Trust was 105 beds short.

The NHS has long since ceased using the expression ‘flow of patients’ – staff simply refer, obsessively, to ‘flow’. In Leicestershire, as everywhere else, ‘flow’ keeps being blocked. The consequence is that those in the NHS system whose job it is to unblock the flow – by discharging patients as quickly as possible – now try to treat the ICS not as it actually is, a useful but lightly resourced bridge to health for frail elderly people facing a spell of illness, but as the fantasy of a virtual hospital that was supposed to replace real wards in a real one. Why wouldn’t they? The ICS is constantly referred to in Leicestershire’s NHS documents as a hospital, and its ‘beds’ as if they were hospital beds.

Through the winter, particularly when Leicester’s Royal Infirmary said it was so overwhelmed by emergency cases that it could no longer provide comprehensive care – this was once known as a ‘black alert’ and is now known as ‘level 4’ – Ashton and her team found themselves having to dig in, and say ‘no’ when the NHS tried to discharge patients to the ICS that the ICS couldn’t cope with. The tension was between one transformational organisation and another: on one side, the virtual hospital, on the other, a new organisation called the Integrated Discharge Team, which has NHS staff working alongside adult social care specialists from local councils. The team is based at the Royal Infirmary, but headed by a civil servant from Leicester City Council. ‘We were finding that if people didn’t know what to do with patients they would end up with us, or, at the end of the day, we were the only service still working, so they would come to us,’ Ashton said. ‘We weren’t doing our core business because we were picking up everyone else’s … in the last six months we’ve gone, “Actually, no … just because you’re at level 4, our taking an inappropriate patient doesn’t help you in any way, shape or form because actually it blocks the flow. They’ll just block a bed with us rather than with you, so in ten days you won’t have another bed coming free, so there’s no point.”’

If saving money were the only object, there are some ways it’s cheaper to have patients at home: they eat their own food, they pay for their own light and heat, they have their own sheets. But if the objective is replacing real hospital beds with equivalent care, another factor comes into play. In a traditional hospital ward, patient A is only a few yards away from patient B. In one ICS ‘ward’, patients A and B can be 30 miles apart. It doesn’t snow inside a hospital; punctures aren’t an issue when you move from bed to bed. ‘The Melton Mowbray team, for example, they might have a patient on the Nottingham border and a patient who needs an IV antibiotic on the Northamptonshire border,’ Ashton said. ‘Well, the Northamptonshire border patient is going to take one member of staff out for pretty much the whole of the day. It’s the daily game of logistics. The level of nursing staff is probably pretty similar to what you’ve got on an acute ward. Our challenge is the geography. The geography isn’t factored into the staffing.’

Did she think the ICS would work better if they increased staff numbers to deal with the vast size of the ‘hospital’?

‘If you’re going to really do it properly,’ she said, ‘yes.’

Sally Ruane, a health policy researcher at De Montfort University in Leicester, points out that all the indications are of a need for more general and acute hospital beds, not fewer, when numbers have already been cut to the bone. In an analysis published last March, she wrote that the Leicestershire STP ‘is premised upon a belief that expanding community-based services will permit the net closure of acute hospital beds. This is almost certainly a false premise.’

The STP’s assumptions about new ways to care for people closer to home, Ruane told me, weren’t evidence-based policy, but policy-based evidence. ‘You can have really good community-based care, if you’ve got plenty of experience, good community-based staff, and you’ve got a bed available in hospital,’ she said. ‘But the context here is they’re trying to do it with limited resources.’

I asked Ruane about something else that had been bothering me. The winter scenes of sick old people waiting on trolleys and in ambulances for treatment were distressing, but they did at least draw the nation’s attention to the fact there was a crisis in the NHS. Might a more diffuse kind of healthcare allow deficencies in care for the elderly to fester unnoticed by the public at large?

‘It will be much harder to know if people aren’t getting the care they need,’ she said. ‘If an A&E is under threat, everyone in the city will know. When services are dispersed in the community, information is dispersed. It’s difficult for people to know what service exists, when it’s under threat, and when it needs defending.’

I asked if she’d ever met Toby Sanders. She had. ‘He’s young, he’s slick, he’ll talk you under the table. He can persuade you. He’s always got an answer for everything. He’s very personable.’

\*

It wasn’t until my fifth visit to Leicestershire that the system drew back the curtain a fraction and I was able to meet Sanders, in a small conference room in a modern ten-storey office block near Leicester railway station, away from hospitals and clinics, on a floor that housed only NHS administrators. The decor was quite new, but the reorganisations come fast. Over one door was a sign for a regional NHS body abolished six years ago.

Sanders sat across the table, flanked by Andrew Furlong, the University Hospitals medical director, and Azhar Farooqi, the chairman of Leicester City CCG, who is also a practising GP. It was January and the crisis in A&E departments was the lead item on the news. Furlong and Farooqi looked exhausted. Sanders was tense with energy. Tall and lean, with the physique of a dedicated cyclist (which he is), he has thick-framed glasses that make him look younger, and a slightly alarming intensity of focus. He spoke rapidly and fluently, in perfect administrative paragraphs.

‘If you look at the pressures we’ve had over the last couple of months, and you imagine a scenario where we didn’t have something like the ICS service in place, it is just a statement of fact that we would have more pressure washing back up the system,’ he said. ‘Could we point at [the ICS] and say we’re absolutely confident it’s a cheaper model? Pretty difficult to do that. Is it a model that’s allowed us to expand and provide better care? Definitely.’

The University Hospitals Trust has struggled in recent years. In the winter of 2016-17, the A&E at the Royal Infirmary almost jammed solid, and when last year the opening of the new emergency department didn’t have a swift impact, the trust got a stern letter from NHS England, warning that its consistent position among the bottom ten English emergency hospitals ‘cannot continue’. In his leaked memo, Adler said there were weeks when the Royal Infirmary was the worst-performing emergency hospital in the country. ‘Our position,’ he wrote, ‘disproportionately affects frail older people.’

When I met them, Sanders and Furlong reckoned there were reasons for hope at the Infirmary, in the sense that bad as things were, they hadn’t got worse. Emergency admissions had levelled off; in December, attendances had fallen slightly compared to the previous year. Whether that was a result of alternatives to traditional hospitals like the ICS, or measures inside the hospitals themselves, was hard to say. In autumn the infirmary was ‘buddied’ with England’s best-performing emergency hospital, Luton and Dunstable. Staff are now trained to designate frail, elderly people as such from the moment they arrive in A&E, which, in the new transformational world, is equally likely to mean swift admission to a hospital bed or a rigorous questioning of the assumption that a hospital bed and subjection to a cascade of tests is in that person’s best interests.

‘The way we’ve trained doctors and clinicians is that there’s almost an expectation you investigate everything,’ Furlong said. ‘It’s about de-escalating care sometimes. Where you’ve got the very frail patients, it’s not appropriate necessarily to do that MRI or that nth investigation – but then it’s also getting people to think about the alternatives. What other sorts of care can we wrap around people? Being in hospital if you’re very old and frail isn’t necessarily the best place for you to be.’

Despite Sanders and Furlong’s wary optimism, despite the new emergency department of glass pods and digital displays, there were still Level 4 crises at the Infirmary last winter. The hospital has moved up the national league tables. But on the day I spoke to them, eight of the 165 patients brought to the A&E by ambulance had to wait more than an hour to be seen. In January as a whole, later figures would show, 18 per cent of patients recognised as sick enough to need admission had to wait more than four hours for a bed. After the meeting, I discovered that a few days before, at a meeting of the system leadership team, Adler had warned that the winter emergency at the Infirmary was having a ‘major detrimental effect on cancer patients’. ‘We’ve had a lot of people come in and look at us and try and support us,’ Furlong told me, ‘and we are sort of standing still in a system that’s deteriorating. It’s very difficult to improve in a system that’s going this way.’

In an organisation as corporately taciturn as the Leicestershire NHS, you look for clues in the institutional body language. I’d wanted to meet Sanders, and somebody from the primary care system, and somebody involved in running A&E – but not all at the same time. Was it intended as helpfulness, to give me the chance to bullet-point the entire Leicestershire healthcare system in 60 minutes, get on the train and leave, or was the tension in the system such that there had to be one person from each pillar of the NHS triad – hospital, surgery and office – listening in to make sure no one departed from the party line? Either way it was striking how ready Sanders was to adopt the role of primus inter pares – how ready he was to speak for the healthcare system as a whole, as if Lansley had never happened. It fitted in with a wider national trend of the STPs mutating, when they’re hardly born, into a much more radical change for the NHS.

\*

There was always something a little fake about the Leicestershire STP, not in a way that reflects badly on Leicestershire, but in the sense that it’s a mixture of transformational actions the NHS and local councils were planning to carry out anyway, impractical ideas born of financial desperation, and things imposed on them by NHS England. The plan for two acute hospitals instead of three has been in the works for years and there were high hopes of getting money for it from the national budget under an earlier Home First-type partnership called Better Care Together: the advent of STPs actually blocked this, rather than enabling it. The ICS was set up in 2012, four years before the first draft of the STP. The STP’s plans for fewer acute hospital beds, always contradicted by growing need, are likely to be supplanted by plans for more, perhaps as many as 170. And the cut in the Continuing Health Care budget is the local response to a directive from the NHS nationally.

None of this means the transformation agenda is dead, just that it’s increasingly clear the existing, fractured NHS landscape of trusts and CCGs, of hospitals and GP surgeries, will look quite different when it’s carried through. The most significant achievement of the STPs won’t be the results of the plans, or the plans themselves, but the genesis of ad hoc integrated organisations which resulted from the requirement to produce them.

These ad hoc organisations, in turn, are the larval stage of another organisational creature. There is extreme uncertainty as to what it will look like, because none has yet appeared. As if to confuse the picture deliberately, and deter the public from taking an interest out of sheer exasperation, these mysterious bodies have already spawned multiple three-letter acronyms. NHS England envisioned that at least some STPs would evolve into something called Accountable Care Systems (ACS), which would eventually become Accountable Care Organisations (ACO). In February, dismayed by hostility among healthcare adepts to the American associations of ‘accountable care’, NHS England came up with a new name: Integrated Care Systems.

Since we’ve already had ICS standing for something else, let’s stick with ‘accountable care’. What is it? In the United States, it was spelled out in the Affordable Care Act, also known as Obamacare, as a way for hospitals, community practitioners and local clinics to integrate into a single system to provide complete healthcare to a set of elderly Americans receiving the form of US healthcare that most resembles Britain’s NHS – the mainly taxpayer-funded, partly free at the point of delivery system for over-65s known as Medicare. Although life expectancy in the US is significantly lower than in Britain, and health spending much higher, Medicare, like the NHS, is straining to cover the medical needs of a growing population of frail elderly people. The hope was that accountable care would save money without worsening health. Instead of Medicare refunding individual doctors’ practices and hospitals, and letting patients choose whom they wanted to see, primary care and acute care in an area would link up into an integrated system called an ‘accountable care organisation’. Medicare would assign the organisation a lump sum, a population and a set of goals (that’s the ‘accountable’ part, the organisation being accountable to its paymasters) and let the system work out the best way of achieving them.

To some on the left, bringing accountable care to England is a privatisation Trojan horse with the spears sticking out, and not merely because of its US antecedents. Campaigners including the late Stephen Hawking and the health policy writer Allyson Pollock have argued that the stealthy introduction of accountable care, without public debate or legislation, is illegal. Without explicit legislation, they argue, there’s nothing to stop accountable care organisations being or becoming commercial organisations, creating a new, controlling, for-profit layer between the government and the health service – a form of privatisation.

To Simon Stevens, the government and the King's Fund think tank, accountable care is simply a way for the NHS in some parts of England, such as Labour-controlled Manchester, to build on the STPs to break down the institutional and contractual barriers between hospitals, primary care, mental health care and social care.

It was politically inept to bring American terminology into the fraught debate over the NHS, and critics of accountable care in England are right to question the stealthy way the idea has crept towards realisation, without democratic scrutiny or legislation. For-profit health organisations are on the lookout for, and lobbying for, ways to get a foothold in the new set-up. In Nottinghamshire, for instance, the administrators behind the local STP have hired the outsourcing firm Capita to advise on the shift to an accountable care system; Capita, in turn, outsourced part of the contract to the Centene Corporation, a private US health giant, much of whose income comes from acting as intermediary between the US government and recipients of publicly funded programmes like Medicare.

But there is something familiar about the concept of ‘accountable care’. A single taxpayer-funded organisation working to a single integrated plan, promoting healthy lifestyles, uniting doctors and hospitals and mental health care, striving to keep an entire population well in the most efficient way possible: doesn’t that sound like, well, the National Health Service?

From the point of view of a conspiracy-minded American libertarian, accountable care in the United States could be portrayed as the Anglicisation of their private healthcare system – a Trojan horse for their nightmare of an American NHS. Vigilance against free market fanaticism in the UK is seldom wasted, but the accountable care idea isn’t yet doomed to lead to more commercialisation of the NHS. In some ways, as sketched out, it more resembles the beginning of a return to the early, more integrated NHS. More integrated, in some respects, with the formally independent outliers of 1948, GPs, forced into a new, closer relationship with hospitals. The Americanisation of the NHS, in terms of its being twisted into a wannabe imitation of a private insurance system, is what’s been happening from the early 1990s until now – first under John Major with the introduction of the ‘internal market’, then under Tony Blair with ‘patient choice’, then under Lansley with the ‘purchaser-provider split’ and obligatory tendering of services to private firms.

After all these changes, the GPs, organised into CCGs, designated ‘commissioners’ of healthcare, and the hospitals, designated as ‘providers’, were set up in such a way that each side had to meet financial targets. The trouble was they were all using the same basic sum of money from the same limited source – the government – and had no control over the price of their services. The result has been chaotically misaligned incentives: it is in the hospitals’ interest to see as many patients as possible, because they are paid per procedure, but it is in the CCGs’ interest to refer as few patients as possible, because that keeps their costs down. To add to the confusion, providers have to compete with private contractors for the CCGs’ – that is, the NHS’s – cash.[​4](https://www.lrb.co.uk/v40/n07/james-meek/nhs-sos#fn-04)

One way of visualising each geographical area of the NHS post-Lansley was as a football team reorganised in such a way that the defenders, midfielders and forwards have to contract formally with one another for a certain number of tackles, saves, passes and goals, according to a general plan laid out by the manager, even though all the money comes from the same source: the club, and ultimately the fans. To make things more complicated, on match days, fans are encouraged to swap their tickets for another game, at another stadium, with other teams. Without the bitter memories of the ruling Conservative Party, which, having been responsible for the Lansley reforms, is now trying to bury them, Stevens would probably be more forthright in proclaiming the return, area by area, of one team, one manager, one club.

\*

Last summer, nudged by NHS England, the Leicestershire NHS system leadership quietly took the first steps towards the accountable care system. Sanders was among those who drew up a plan: accountable care, it said, wasn’t ‘if’, but ‘when’. The draft scheme was quite vague, but seemed to evoke a tearing down of the contractual barriers between the CCGs and the trusts and the creation of a single NHS organisation in the county with one plan and one budget. The councils, which hadn’t been consulted, protested, but even before its STP has been finalised, Leicestershire is looking to the next acronym. The reward for those managers willing to sacrifice the time required to comprehend the full bewildering bureaucratic algebra of the new NHS may or may not be a better NHS, but is certainly a chance to define the scope of powerful new managerial jobs they alone will be qualified for.

‘I’m not a big fan of the accountable care language,’ Sanders said. ‘I think it has all sorts of American, privatisation connotations which are just frankly unhelpful and don’t reflect what we’re trying to do locally. In simple terms, it’s about a more collaborative, less competitive environment. Whether you call it ACS, whether you call it a partnership … it doesn’t really matter.’

It remains to be seen how accountable care will play out in the British context. Many communitarians don’t trust Stevens, who was Blair’s health adviser. They see the STPs as a realisation of a 2012 report for the World Economic Forum, aka Davos, prepared by the consultancy firm McKinsey with Stevens, then working for the US conglomerate UnitedHealth, leading the expert input. Indeed, the report calls for ‘home-based, patient-driven models’ of care and ‘capacity reductions in higher-cost channels’. And yet privatisation of the NHS as a whole isn’t on the agenda: one poll suggested the public would rather see the armed forces privatised than the NHS. The current direction of travel is away from patient choice and quasi-market contracts towards planning and integration. If that sounds unlikely – if the idea that a Conservative government might allow the NHS to be more, rather than less, monolithic doesn’t compute – there’s more to this. Right now the risk to the NHS is not so much that it might be privatised outright as that it might be starved to death.

‘It’s not that we’re getting less funding,’ Sanders said. ‘The funding allocations into Leicestershire will continue to increase year on year over the next five years, and that’s in real terms, but the level of growth is lower than anything the NHS has known … if you put that alongside changes in the growth of the population, in the health of the population, it’s clearly outstripping the growth in the system.’ According to Farooqi, contrary to what the Leicestershire STP and many of its peers suggest, shifting more of the burden of healthcare from hospitals to the community isn’t going to save money, even if ‘the aspiration is right’. ‘I don’t think the NHS is going to be able to manage on less money just because we manage people in the community,’ he said.

The Conservative Party claims to have protected the NHS from the ravages of its austerity programme since 2010 – even to have increased its budget, in real terms. It’s true that compared to other areas of government spending – local government, the Home Office – the NHS has got off lightly. It’s also true that the NHS budget has increased by slightly more than inflation. That’s the usual meaning of the expression ‘in real terms’. But in the context of the NHS, the usual meaning is wrong. In real real terms, the government is cutting the NHS budget. Who says so? The government’s own Office for Budget Responsibility (OBR).

Because the NHS is there for everyone in Britain, and the population of Britain is growing, the NHS needs to grow to keep pace: more staff, more facilities, more money. It’s a second kind of inflation on top of the more familiar one: demographic inflation. You can measure it for the NHS by working out spending per head of population. According to the OBR, when you combine financial inflation with population growth, spending on the NHS is being cut by 0.9 per cent per head between 2016 and 2020.

In fact, it’s worse. The NHS, like other health systems around the world, faces other cost pressures. After inflation and population growth, there’s the growing proportion of elderly people; the chronic conditions of modernity, particularly diabetes; and the cost of new ways to treat and diagnose people. And there’s another financial pressure, perhaps the biggest of all. In 1966 the US economist William Baumol noted a divergence in modern rich-world economies between industries in which people could easily be replaced by technology, such as manufacturing, and industries fundamentally reliant on people, like healthcare and education and, the subject of his study, the performing arts. His diagnosis came to be known as Baumol’s cost disease.

‘If car manufacturing is automated, the workers that remain share in the productivity gain with higher wages,’ the economist Anita Charlesworth told me, explaining Baumol. ‘If you take the viola out of a string quartet, it isn’t a quartet any more. The string quartet’s wages have to keep pace with the wages of the car worker, because if they don’t, nobody will go and be a violinist, so all you can do is increase the price of the tickets.’

The price of the tickets, in the context of the NHS, is its budget. Unable to replace its doctors and nurses or, for the time being, cleaners and porters with machines, it is obliged to try to compete in the labour market with organisations that are doing more than they did seventy years ago with a fraction of the workforce.

To keep pace with all these pressures, until 2010, the NHS saw its budget increased, after inflation, by an average of 4 per cent a year, faster than the economy, which grew on average after 1945 by 2.6 per cent. Most of the NHS’s budget increase didn’t come from higher taxation. Rather, it took a bigger share of public spending as other government departments, such as defence, took less. In 2010, with austerity, all that stopped. In Britain, perilously, spending on health as a share of the economy is falling. ‘Pressures on the system continue to grow at 4 per cent, and funding is increasing by 1 per cent,’ Charlesworth said.

In November, the three big health think tanks – the Nuffield Trust, the Health Foundation and the King's Fund – blamed the funding gap for rising waiting times, routine breaches of patients’ rights and rationing of services. ‘The amount the government currently plans to spend,’ they warned, ‘is not enough to maintain standards of care and meet the rising demand for health services … Even if the government met all its manifesto commitments to raise NHS funding, this would still not come close to giving the NHS the resources it needs.’

‘There’s no easy way out of this,’ Charles-worth said. ‘We have held healthcare spending down below the growth of the pressures on it in large part by holding the wages of healthcare workers and trying to squeeze out efficiencies for seven years. It’s pretty clear that that has run its course and we need to have a serious debate about whether we want to have a health service that’s able to meet increasing needs and give access to new therapies, and if we do, we will need to pay for it.’

Baumol, who died last year aged 95, worked out in 2012 that if healthcare spending in the United States continued to rise at its then rate, it would account for 60 per cent of GDP by the next century. Applying Baumol’s measure to Britain, the *Economist* suggested the corresponding figure would be 50 per cent. Baumol was much more positive about these figures than one might imagine. He cautioned against a panic-stricken reaction of cuts and privatisation. Precisely because manufactured goods were becoming far easier and cheaper to produce, he argued, plenty of resources would be available in the economy as a whole to allow the people-heavy services such as health, education and the arts to keep on growing. By extension, robot fear – what will all the workers do when the robots come? – is misplaced: the answer is heal, nurse, teach and make art.

I see Baumol's point, but I also see, in the globalised economy in general and in Britain in particular, a massive set of cultural and institutional barriers to transferring the economic gains of automation to ordinary people. The Davos report Stevens contributed to presented the general expansion of healthcare’s share of GDP while other sectors of the economy automated as a looming catastrophe. The response of modern British manufacturers to efficiency gains is seldom to increase wages, because they can always find cheaper workers abroad: the reward of efficiency isn’t a wage hike but the fact that you get to keep your job. Except that often you don’t. The whole philosophy underlying privatisation in Britain has been that when a privatised water or energy company makes efficiency gains, it gets to keep them – generally, these days, transferring them to its overseas owners. Indeed, one of the concerns underlying the advent of accountable care in the NHS is that in the US version, when the government gives an accountable care organisation a lump sum to provide healthcare to a population, it gets to keep the difference if it does the job more cheaply. Will the same happen here? And will the money be reinvested in health, or siphoned off to managerial bonuses and private contractors? It remains unclear.

\*

Five thousand miners lost their jobs in Coalville in Leicestershire when the pits closed. (The mines were shut in the 1980s because the coal was exhausted, rather than because of automation or foreign competition.) At about the same time, Coalville saw the closure of Palitoy, one-time maker of Action Man and *Star Wars* toys; Palitoy was bought by a US company and production moved to Asia. Recently new jobs have come to Coalville. The town is on the M1, and has become a centre for goods distribution. Amazon has built a million square foot warehouse there, which employs 600 people on mainly minimum-wage work, although there are chances for overtime. More jobs are created in parcel delivery. The Amazon system is a highly efficient way for British consumers to get the manufactured goods they want, most of them made in other countries in factories that are low wage or high tech or both: it has replaced, or wiped out, thousands of inefficient (or, to put it another way, perfectly good) retail jobs in British shops. But a Britain committed to the global economy – more so than ever, since the Brexit vote – is finding it hard to capture a share of Amazon’s productivity gains to spend on the health needs of Amazon’s British customers, because it’s so easy for Amazon to shift them elsewhere. Last year it emerged that Amazon paid £7.4 million in corporation tax despite having a UK turnover of £1.46 billion. Jeff Bezos, Amazon’s founder and chief executive, says he sells a billion dollars' worth of Amazon stock each year in order to fund his Blue Origin rocket firm. Bezos is engaged in a private race with another US tycoon, Elon Musk, to be the first to commercialise space travel. If Leicestershire wonders where the money for its NHS went, the answer is that some of it is on its way to Mars.

Charlesworth, who works for the Health Foundation, doesn’t believe there’s a political appetite for radical changes to the way the NHS is funded, even among Conservatives. Not only is it popular, it is relatively cheap, fair and, at least until very recently, effective. It’s also efficient, lacking not only the casual cruelty but also the massive layers of private bureaucracy involved in the US model.

Moving to a system of workplace national health insurance, as many European countries have, would, Charlesworth points out, shift the burden of paying for the NHS onto employers and employees. The NHS system spreads payment more widely: wealthy retired people, for instance, contribute to the NHS because they pay taxes on their income if their pension is big enough. Another idea is to separate out the health element from general taxation, so that people pay a ‘health income tax’ – the theory being that people would be more willing to pay more tax if they knew it was going straight to the NHS. The problem with hypothecation is that it makes health funding dependent on the ups and downs of the economy. If there were a slump and millions of people lost their jobs, NHS income would fall.

In its election manifesto last year, Labour promised to fund a hefty increase in NHS and social care spending from tax hikes on the highest-earning 5 per cent, higher taxes on private medical insurance and cutting management consultants’ fees. In a globally dependent, capital-mobile Britain, will that raise enough?[​5](https://www.lrb.co.uk/v40/n07/james-meek/nhs-sos#fn-05)

Walking past Leicester Royal Infirmary one day, I caught sight of a large sports stadium a few blocks away. Ah yes, I thought, the home of Leicester City football club, improbable underdog Premier League champions of 2015-16. But it wasn’t. It was the home ground of the Leicester Tigers rugby club (it seats 26,000). I went to a game one night at Leicester City’s King Power stadium. Leicester was playing Liverpool in a low-stakes competition called the Carabao Cup, but every seat in the stadium – and every room in the city centre’s hotels – was full. The strain on post-industrial Leicestershire’s public services goes hand in hand with a vast, thriving leisure economy. Oakham, the town in Rutland which is set to lose the beds in its cottage hospital, has another extremely advanced, well-equipped hospital, with expert surgeons performing remarkable operations. On horses. I’m not sure what proportion of the estimated million horses in Britain are in Leicestershire and Rutland, but with such a busy hunting scene, it must be high.

Since at least the 1960s, mainstream British politics has supported, or at least failed to be greatly bothered by, the community-sapping effects of globalised consumer capitalism. People have been encouraged to believe that good public services are compatible with the frictionless movement of capital and the individualistic pursuit of play and pleasure. Suddenly, through their support for the STP process, now morphing into accountable care, the Conservatives are thrusting the sick back into the community without restoring to it the tools, the funds or indeed (how could it?) the motivation to organise their care. What the STPs offer to the ‘community’ is evident: responsibility without money. More subtly, it is responsibility without power. And it isn’t clear that Labour’s modest redistributions really get to the heart of the problem: not just a reckoning with globalisation, but a reckoning between generations.

\*

Outside the hospital, out there in the community, people struggle with the unexpected complexities of long life and unwellness. The first time I visited Leicester, in August last year, I went for a walk around the terraces east of the River Soar, between the railway line and Spinney Hill Park, where many Muslims live. It’s an area of mosques, and few pubs, and shops that sell cumin by the pound, the area of Mohammad’s Halal Fish & Chips. A woman in black drove by, her face, hands and wrists fully covered; I saw her tapping her fingers on the wheel to the beat of pounding music. It was Friday and the sun made the white garments of the men and boys gathering to go to prayer shine dazzlingly bright against the dark red brick of the houses. Watching the boys flock and jostle I felt I’d wandered into somebody’s future nostalgia for an idyllic childhood. Perhaps the boy in the white dhoti who had Down’s syndrome; who knows?

On one of the streets that leads steeply up towards the park I got chatting to Ahmed, who was toiling uphill with his walking frame. He had MS. He had nothing but good words for the NHS, although he noticed there were fewer nurses around these days. A man came out of his house to join the conversation. Initially he repeated the trope that Muslims have less need of public care services, that they have community, that they look after their own. Gradually he conceded that many houses in the street were regularly visited by care workers, private or state, paying their 15-minute visits to administer personal care to elderly people who depend on them. The street is narrow, the pavement narrow, the doors open straight onto the pavement. What made him sad was when the care workers came out of the house, ripped off their blue gloves impatiently, dropped them in the gutter and drove off to their next appointment, as if – he made the gesture of someone wiping their hands in repugnance.

Wendy Warren was an independent, civically active working woman, and in her later years she has benefited from the full spectrum of 21st-century medicines and therapies, but there’s still something timeless about her life story. She married a tenant farmer who paid rent to the lord of the manor: it’s a bio that goes back centuries, perhaps millennia. Many of the generation entering old age now, those who are about as old as the NHS, had young adulthoods of determined hedonism and conscious self-destruction in the individualistic, libertarian, consumerist era that began in the 1960s. They can be shocked to find themselves forced into situations of communitarian dependency now.

John Knapp was the pianotron player with a Leicester band called Legay. They first gigged at the Casino ballroom on London Road in 1966, with some of their own songs and many R&B covers. They saw The Who and the Kinks. They played in, and were in the audience at, the Latin Quarter, Il Rondo, the Dungeon in Nottingham. They drank coffee in the White Cat on Duns Lane and the juke box fired them up. As mods they skirmished with leather-jacketed rockers in Nottingham. Knapp still carries a scar from where one guy stuck a screwdriver into him. The band bought the first Marshall stacks in Leicester and blew everyone’s ears off. They wore make-up and got clothes from fans who worked at a theatrical costume hire shop. They wore their mod hair like crash helmets, with full fringes and luxuriant sideburns. They hid their girlfriends from their adulatory cohort of female followers. In 1967 they embraced psychedelia. They criss-crossed middle England in a van playing gigs in small towns. After they played there would be battles with local men who didn’t like their effeminate clothes, or that their girlfriends fancied them. Microphone stands and cymbals were wielded as weapons. They drank and did weed, acid, coke, speed, mandrax. After their 1968 single ‘No-One’ failed to chart, Legay rebranded as the California Sound-inspired Gypsy, signed to United Artists, supported Led Zeppelin, did Top of the Pops, had their single ‘Changes Coming’ banned by the BBC as too political, and, in 1974, broke up. Gypsy still has a fan base, but all that remains of Legay is memories, some scratchy recordings on Spotify and a recent book by John Knapp’s brother Shaun, *High Flying Around.* It was a bestseller in Leicester.

Knapp assumed he’d die before he was thirty. But he didn’t. The band broke up before he was able to take enough drugs to finish him off, although when I met him in a pub in Leicester city centre he mused, with perverse regret, that the coke he snorted at the Speakeasy and in LA was probably of too high a quality to do the job anyway. He’s 69 now, but looks younger, with a dot of a beard and an elegant green linen V-neck. Rod Read, Legay’s George Best lookalike vocalist, and Legay Rogers, the original drummer, have died of cancer, but there’s not much wrong with John Knapp. The unexpected, for him, is not just that he’s alive, or that he’s not in the least bit frail at 69, and doesn’t depend on anyone to look after him. It’s that other people depend on him. He’s ended up as a paid carer at a charity-run residential centre for people with learning disabilities, many of them born with Down’s syndrome.

‘What does it involve?’ he asked rhetorically, sipping his vodka tonic. ‘Feeding them, doing personal care. They’re getting old now. Dementia. Anger problems. All sorts of stuff. Don’t ask me if I get something good out of it.’

Did he get something good out of it?

‘Or rewarding.’

Was it rewarding?

‘You now know the answer. And most people who are doing this job feel exactly the same way. It’s a thankless job. It’s a taxing job.’

Surely sometimes he felt quite protective towards the residents?

‘You want me to be honest, don’t you? No, I’m not. Because I now know these people. They’re very selfish, very lazy, yeah? They are. I’ve worked with them now for 14 years. The same people. You get no reward from it really.’

I looked up the centre later on the website of the Care Quality Commission, which inspects all health facilities and care homes in England. They rated it as effective, caring, responsive and well-led, but warned that it didn’t have enough staff to keep residents safe.

It’s minimum wage work. Knapp is expected to do a sleep-in – an eight-hour afternoon and evening shift, then an eight-hour ‘sleep’ on a bed in the office, then a seven-hour shift. For the entire night, when he’s always on call, he gets £26.

The centre is on the wane. As Knapp described it, a kind of cascade is under way: ‘You know what you were talking about, the NHS doing this thing. It’s the same thing, cutting down the residential and trying to get them to stay with parents … When anybody goes to hospital from our homes, because they’ve got learning difficulties, the quicker they get them out of there the better. They send them home even when they’re not ready. And then they go back again.’

The way Knapp talked about his life, it was as if he was re-enacting the end of the band, when he was suddenly thrust into labouring jobs. ‘It’s so totally demoralising because you think you’ve cracked it, you’ve had a fucking incredible life, know what I mean? I can remember always coming home at seven o’clock in the morning thinking: “All those twats going to work.” When you’re 18 to 22, thirty is kind of like quite a way off. And the lifestyle you’re living you’re thinking there’s no way I’m going to get to thirty. You know. Cause we’ve all got addictive personalities and drugs are readily available and it’s a great life so I don’t want to live to thirty anyway, I don’t want to be like them.’ And at 69, he still doesn’t want to be like them. ‘I would rather die of something than end up in a home with Alzheimer’s. I’d rather die than have somebody like me looking after me.’

One of the great uncertainties of the new regime is what happens to the vast realm of care that’s related to health, and will regularly involve the NHS, but takes place outside the NHS’s boundaries. Prominently this is about adult social care and care for children, the responsibility of local authorities, but it’s also about charity-run residential centres like the one where Knapp works, about private care homes and nursing homes, and, in Leicestershire and Rutland alone, about the estimated 100,000-plus people caring for unwell or disabled family members – around one in ten of the population.

Steven Forbes, who runs Leicester city’s adult social care services, pointed out to me that people with life-shortening inherited conditions like Down’s were experiencing the same lifespan-lengthening marvel as everyone else, except that in their case, lifespans were doubling. ‘When I started in social care someone with Down’s living into their mid-thirties was exceptional,’ he said. ‘We now have significant numbers of people with Down’s syndrome and learning disabilities who are in their sixties and seventies … People with Down’s syndrome are particularly prone to cardiac issues, some of the neurological conditions they have as youngsters play out significantly, we’ve got early onset dementia. So the nature of care changes for somebody with Down’s syndrome from potentially having an active life in society to caring for someone with a profound learning disability with a huge range of additional co-morbidities in their fifties and sixties and what we haven’t done as a society, and a health system, is acknowledge that change. We have to acknowledge it now because it’s literally standing on us. It’s here. All this winter pressure is because that change we should have seen coming progressively over thirty years has now happened.’

\*

One afternoon in September last year I took the bus from Leicester to Coalville to visit Lee Knifton. He is a carer with an organisation called Shared Lives Plus, which matches people who need care – people who, thirty years ago, would have been institutionalised – with a caring lay person who has room in their home and their life to take somebody in. By mutual agreement, and with the appropriate background checks and training, the cared-for person becomes part of the carer’s household, and to some extent family, with as much freedom and responsibility as they can manage. Because of the high cost of conventional residential care, there tends to be enough in the personal budget allocated by the state to the person who needs care both to support them – to pay for their food, for instance, for outings and holidays – and to recompense the carer.

I’m not sure what I expected when I got to Coalville – maybe it was the name; something grimmer? In fact the bus delivered me to a pleasant green suburb of broad streets and the spacious 1970s bungalows that have begun to look modish these days. In one of them, a sprawling, many-bedroomed place with low ceilings and fitted carpets, impeccably clean and tidy but rich with possessions, Lee Knifton lives with three men with Down’s syndrome. They are clients, but they are also, in a sense, family, although Knifton has a big kindred family too: his father was one of seven brothers, all coal miners.

Knifton and two of the men he cares for – I’ll call them Clem, William and Gareth, not their real names – have lived together for more than twenty years, the third moving in later. Knifton heard about Shared Lives soon after he graduated from a care course at college. It was 1997 and residential care homes were steadily shedding their clients. Like Knifton, Clem, William and Gareth were in their twenties. William and Gareth had been given up to children’s homes by their parents when they were two weeks old; Clem, who as well as having Down’s is autistic and has had a stroke, was looked after, on and off, in residential care until his father died, aged eighty.

The men are all in their mid-forties now. They’re bound by ties that could not exist in an institution: by shared lives. Knifton is single, but not alone. ‘I’m mum, dad, auntie, uncle, granny and grandad rolled into one,’ he said. ‘If I was having the lads now, they would only let me have Clem. I have to do everything for Clem, dress him, toilet him, feed him, give him his liquids. He can’t hold a cup any more. Clem doesn’t like to be touched. William and Gareth are very loving. Clem has never been able to work, whereas William and Gareth have got City & Guilds in cookery, only they can’t communicate very well. William can read … he’s good at that but not much in using initiative. Gareth, he can’t read much, but he’s very caring, on the ball. He’ll empty the dishwasher for me.’

We were talking over tea and biscuits at the kitchen table; the men were out. Clem was having paid recreation elsewhere. For all the comfort and security of the house, there’s a slight precarity to the situation. Knifton, a tall man with short, bright blond hair, suffers from osteonecrosis, and, courtesy of the NHS, has two new hips. His joints are still causing him pain. Early last year he had a steroid injection into his femur. It was a reminder of how interconnected the NHS is to the wider social safety net. An elderly person can’t be discharged from hospital because austerity-wracked social services can’t place her in a care home; for that reason, an emergency patient has to be shunted into a post-op rehabilitation bed; for that reason, a hip operation is delayed; for that reason, a carer can no longer do his job; for that reason, social services have another crisis.

‘If I died tomorrow, they’d be all right next week,’ said Knifton. ‘They’ve got survival mechanisms because they’ve moved around so much, it’s their way of coping. They are self-centred, but that’s a survival mechanism. Sometimes I get tired and wish I could do something different but the reward outweighs that. I don’t go without, and I’m never alone. None of us do it for money. I do love my lads. They’re my family.’

Each of the men brings his own personal budget, which Knifton must keep scrupulous accounts for (they’re regularly inspected). At the centre where Knapp works, the charity charges residents about £700 a week. William and Gareth have budgets of £315 a week each; Clem – ‘after a long, long fight with social services’ – has £1215 a week. ‘Just to give you an idea of how cheap we are, somebody like Clem would be boarding on £2000 a week in a residential home,’ Knifton said.

As social care budgets have been slashed under austerity, local authority support for full-time carers has been pulled back. The day care centre where William and Gareth used to hang out with their peers has shut. ‘They’ve lost their friends network,’ said Knifton. ‘I know society says we are clumping them all together. But people with learning disabilities like to be around other people with learning disabilities because they don’t have the pressure they have when we are there. Even if I’m in the room they’re always checking they’re doing the right thing or not, but when their friends are there, they’re always laughing and joking. We’ve destroyed their network of friends.

‘We released people from hospitals in the 1990s and we’re slowly locking people back up in nice houses in the community. There’s no day care and no services for them and all they’re doing is sitting at home. I can reel off ten homes now where parents are in their eighties, their children are at home with challenging behaviour, they get three days a week day care, they’ve been looking after them all their lives – there’s going to be a crisis.’

The money councils get from central government and local taxes has fallen by 26 per cent since 2010, and the amount they can raise taxes by is tightly restricted. In the past ten years the privatised water monopolies have been allowed to increase the private tax they levy in England by 34 per cent, and keep the profits of any efficiencies they make; the government has choked council tax increases back to 16 per cent, and whenever a council shows it can scrape by after a money-saving cutback, the Treasury banks the gain and asks for more.

Like Leicestershire County Council, which is responsible for Coalville, the city council has scraped by. Before Steven Forbes joined it in 2015, his department saved millions of pounds by closing and selling off care homes for the elderly and shutting day care centres – a significant part of the savings coming from the fact that private and charity-run residential homes don’t pay their workers as well, or give them such good pensions, as a local authority. Increasingly the council’s adult social care clients are between their mid-eighties and mid-nineties, often living at home, often having outlived the remainder of their family. If they live at home, need care and have less than £23,250 in savings and assets, the council is legally obliged to help them out. The service is driven by need, not resources, and if the two clash, Forbes’s duty is to go to the mayor and tell him the city doesn’t have the cash to stay inside the law.

Already, nationwide, there are circumstantial signs of the austerity-related funding crises in different public services starting to join up. In Northamptonshire, where the Conservative county council went bust, a leaked memo from A&E over the death of a man waiting to be seen by doctors said: ‘Last night a patient died due entirely to the dangerous overcrowding of the department.’ The squalor of Liverpool’s vermin-infested prison, and the lousy management of the recently disbanded NHS trust that provided its healthcare, were linked to each other, but were also not unconnected to the funding cuts each had suffered.

There are no signs of anything like this happening in Leicestershire yet. But Forbes looks ahead anxiously to an unaddressed funding chasm at the end of the decade. ‘I think over the last seven or eight years, with austerity, adult social care across England has been the victim of its own success,’ said Forbes. ‘We have gone out of our way to deliver those efficiencies and savings that have been demanded by central government. Now … the cliff edge is here. I can begin to feel the updraft from the edge. The measure of success in making reductions and savings – all of that’s gone now.’

Forbes sits alongside senior NHS managers on the system leadership team. He and his department have bought in to Home First, transformation and integration, up to a point. They’ve achieved remarkable things. Putting adult social care staff into the Infirmary to work alongside NHS staff to co-ordinate the discharge of patients hasn’t gone smoothly – the difference of culture between a free service and a means-tested service has been hard to bridge – but, remarkably, during the winter, only a handful of delays in getting patients home from hospital were attributable to Leicester council. Forbes has kept a reserve of social workers to go into the wards and, as he put it, ‘pull those people out’.

The most striking success has been with falls. As I saw on the ICS whiteboard, a fall can quickly become a crisis for a frail elderly person. But it can also be, as it is for anyone, just something they get over. The extent to which care is still not integrated in England was brought home to me when I visited Wyggestons Hospital in Leicester, a care home and sheltered housing complex founded by a philanthropic local oligarch in the early 16th century. Wyggestons houses privately funded and council-funded residents. The rules are such that if a privately funded resident falls over, staff are allowed to pick them up; if a council-funded resident falls over, staff have to call an ambulance, although they are allowed to put a cushion under the resident's head.

In an effort to avoid taking people to hospital after a fall if they don’t need to go, the council, funded by the NHS, runs something called the Integrated Crisis Response Service, or ICRS. In Leicester, if someone dials 111 or 999 after an elderly person has fallen, they may well get not an ambulance but a team of council care workers to make the first assessment. Last year, of 1500 calls for help, only 7 per cent ended up going to A&E. According to Forbes, his teams haven’t made a duff call yet.

‘They’ll assess the individual there and then, they’ll comfort them because falling is frightening, you can end up with scratches and bruises and whatever. None of that needs A&E … So as long as you ensure that actually nothing significant of risk has happened to them, it’s mainly about the stabilisation, and if our staff think they need the paramedics’ input, they bring it in.

‘In the city, in this last quarter, we have actually reversed the presentation and admission of older people against the national trend. We’re one of the few places that’s actually stopped and slowed the increase in older people’s admission to A&E. The one thing I’ve learned over my twenty-something years in this business is the resilience of older people and the determination of older people to remain at home, and what I would term the compromises people will make in their own lifestyle to ensure their independence. We should support that. We shouldn’t rush in to prevent it. Ultimately, the prize is living at home.’

Forbes, an affable Scot with a luxuriant beard who began his social work career closing wards in a 600-bed Aberdeen geriatric hospital, was convinced that the thrust of the STPs was right. After 70 years, the model of primary care based on a small private contractor – the GP practice – and the acute hospital had to change. ‘We can’t revert to the expectation that all older people are cared for in hospital and all people’s long-term conditions are cared for in hospital. That just won’t work any more. But we haven’t tipped the balance of funding and investment to deal with this issue that was coming at us for thirty years.’

He was all for closer integration of primary and acute care, and a shift of funding to primary care, but the idea of integrating his service with the NHS horrified him. ‘We have spent twenty years demedicalising people with learning disabilities’ lives. My greatest fear is that there will be a huge and significant loss for people with learning disabilities back in a combined NHS social care entity.’

\*

Forbes’s aren’t the only institutional anxieties in the age of integration. The willingness of the hospital system to integrate with the primary care system – with GPs, with community nursing – may not signify the end of a tussle over resources, but the beginning of one. In parts of England, hospital trusts are already taking over GP practices. One institution’s ‘integration’ can be another institution’s ‘swallowing up’. What do people mean when they talk about ‘keeping old people out of hospital’? Sometimes it sounds wonderfully positive, as if GPs and virtual hospitals and social workers are to be catchers in the rye for the elderly, letting them play, stopping them tumbling off the cliff of mortal illness, the cliff of an ill-judged hospital admission. Sometimes it sounds as if the hospitals are looking for bouncers.

Hospitals – particularly university hospitals – have admirable, lifesaving and often very expensive institutional goals. In any integrated county NHS set-up, they have the advantage of staff, facilities and budgets over primary care. How much will they be willing to shift the balance in the community’s favour?

Shirley Barnes, a retired social worker I met in Leicester, has a 21-year-old son who was born with a congenital heart condition. The children’s heart unit at Glenfield operated on him and saved his life. Barnes was a stalwart of the successful campaign to save the heart unit from closure by NHS England. The intention of the closure was not to save money, but to concentrate expertise in a children’s heart unit in Birmingham. A new system was introduced in London in 2010 to treat major trauma: after accidents the severely injured now often find themselves blue-lighted not to the closest A&E but to one further away that has more specialists and equipment. Results suggest this has saved lives. In other words, even as hospital trusts like Leicester’s are being pressured to redistribute resources to the community, they are struggling for resources of their own to compete with NHS rivals to be picked as high-tech regional megacentres. Hospitals are caught between extraordinary individual global dramas at the frontier of modern medicine – it was at Glenfield, in December, that surgeons saved the life of a baby born with her heart outside her body, a story that went around the world – and wards filled with frail elderly people, whose stories the world is less interested in.

As well as a son with heart disease, Barnes had a father with dementia, Albert, who died of stomach cancer in 2012, aged 91. He was a Japanese prisoner of war from 1942 to 1945: a prisoner transfer ship he was on was torpedoed and sunk, he was rescued by a Japanese trawler, and lived out the rest of the war as a prisoner in Japan. Seventy years later, demented, cancerous, deaf, half-blind with cataracts, diabetic and plagued by mini-strokes, he sneaked onto a train with £1300 in out-of-date ten pound notes and was found by the police, unconscious as a result of hypothermia, curled up in a front garden in Hertfordshire. There were many such sprees in the last four years of his life, when he lived with Barnes and her family.

‘It was horrendous. Absolutely horrendous,’ she said. ‘My dad was lovely, the life and soul of the party, absolutely hysterical, really kind, give you the shirt off his back, he was just a really, really cracking bloke, and he became this horrible – it was like invasion of the body snatchers. I was convinced that my dad was wrapped up in a pod in somebody’s greenhouse cause it looked like my dad and it sounded like him but it weren’t him.’

When Barnes took her two-week-old son to the Glenfield, a surgeon with hands like paving slabs opened up his tiny chest, went to work on his walnut-sized heart and mended it. When she went to hospital with her 90-year-old father, they did all they could, medically; but then they sent him home, where she could never find the help she needed. The council social work department, her employer, wouldn’t help, because her father didn’t fit into any of their categories. In her diary she described a battle with a doctor who was reluctant to arrange a referral to get a definitive dementia diagnosis because her father had shown an occupational therapist he could climb a few stairs and make a cup of tea. ‘I tell him … he cannot shop, cook, clean, change his bed, manage money, his paperwork, pay bills … I say that I have to tell him to bathe and change his clothes … He hides filthy clothes under his bed, behind furniture … I point out that I am managing all of this, along with working full-time, a husband with MS and a son who is coming up for more open heart surgery … He starts to say: “We can manage the situation when he gets home.”’

\*

When you look back at life before the NHS, at local newspaper reports of people who died because they couldn’t afford a doctor, the absence of indignation is palpable – indignation, that is, at the lack of free medical care. Powerful social movements and campaigning thinkers were at work, providing that indignation, but in the crowded small-font columns of the provincial press in the first half of the 20th century another world is visible, of middle English complacency and inertia, and a feeling that if children died it was their parents’ fault.

At an inquest in Tonbridge in 1914 into the death of a six-year-old girl from diphtheria, her 19-year-old mother, Evelyn Lambert, was accused of neglect. She said she hadn’t been able to afford a doctor, and had gone on the word of a pharmacist that her child would be all right. ‘The Jury expressed sympathy with the mother of the child,’ the report concludes, ‘and hoped that this would be a lesson to her.’ In 1923, in Hammersmith, Lily Macherson, ‘a poor person, of middle age’, couldn’t afford a doctor. Before she died, a friend tried unsuccessfully to get a police surgeon to help. The coroner asked why the police surgeon hadn’t gone; ‘it was a question of expense,’ the police said. In 1934, Amy Bourne of Margate, starving, sick and unable to pay a doctor while her husband was out of work, lost her mind and tried to gas her two children. In Lincoln in 1924, Maud Elizabeth-Norman, a 24-year-old former domestic servant, was found guilty of the attempted murder of her newborn. ‘I did it because I was homeless, out of work, and starving, and I could not bear to see the child want. She had been ailing for some time. I could not afford a doctor. I threw the child in the river … She did not scream, and I did not see her again.’ Neither the reporter who wrote the article nor the court showed the slightest curiosity as to the father of the child, although the journalist did praise the honest citizenry of Lincolnshire: ‘One could not hear the story told by the various witnesses – simple, kindly country folk – without marvelling at the kindliness and charity of the people of that county towards those who wandered hungry amongst them.’ Sentencing her to 12 months, the judge said: ‘I hope you will take the opportunity while you are in prison to think over your unsatisfactory past.’

I’d like to think those attitudes have gone away; that the spirit of postwar communitarianism, of solidarity, in which the NHS was founded, prevails. But I’m not sure. Clearly a libertarian attitude of everyone for themselves isn’t solidarity; nor is a religious attitude of ‘God provides, God punishes, God rewards.’ But an assumption that if only the very richest people, whom most of us neither know nor meet, were made to stick their hands deeper in their pockets, the NHS would flourish – that doesn’t sound much like solidarity either. Even ‘save our hospital’ activists can be ambivalent. Campaigners against the closure of Lutterworth hospital assume it is a straightforward money-saving step, and ridicule the idea of replacing it with community care; there simply aren’t the funds to do it properly. But when I asked them whether they would personally be prepared to pay higher taxes to fund a better NHS, they equivocated. They began to talk about how much waste there was in the health service.

Soon after I met Wendy Warren last autumn, her heart and kidneys failed, she returned to hospital, and was told she didn’t have long to live, perhaps only a few days. The family found her a nursing home in Wigston, on the southern outskirts of Leicester, and she moved in, her palliative care there funded by the NHS.

She didn’t die. She got through the winter. I went to see her towards the end of February. The part of Wigston where the nursing home is has the largest proportion of over-90s – 2.6 per cent of the population – and the third largest proportion of over-80s, almost one in ten, in Leicestershire. Wendy has a small, comfortable room off a long corridor in a facility that feels more domestic than institutional. She can’t leave her bed without a hoist, but she seemed the same as before, alert, with all her wits about her. At one end of the blue blanket her bare feet stuck out, the nails elegantly painted aubergine by her granddaughter, and her hair was nicely waved on the pillow.

Joanne couldn’t make it; her other daughter, Louise, was there, a former care worker who now runs lunch groups for disadvantaged women and works weekends at a women’s refuge. We sat and chatted and talk turned to the NHS. I wish I could say the Warrens were wholeheartedly in favour of the country coming together, the middle classes as well as the rich, well-off pensioners as well as workers, to give the service the extra money it urgently needs. It would be convenient to be able to say that there, in the presence of somebody who’s been cared for by the NHS for as long as it has existed, but who still remembers the monthly doctor’s bill, there was an unshakeable belief not just in the skill of its surgeons and the care of its doctors and nurses but the strength of an ideal of fairness, mutual sacrifice, a community that was national rather than local. But it would be dishonest, and patronising, not to report what was said, and it was doubt, not belief. Actually rather more than doubt. It was a first for me to hear somebody say, as Louise did: ‘Don’t get me wrong, I’m not for the workhouse. But …’

Building up slowly, then with increasing enthusiasm, determination and evidence of considerable prior thought, Louise Warren laid out an ideal of healthcare and welfare in general that lay somewhere between early Dickensian England and the modern, pre-Obamacare (I think pre-Medicare, too) United States: an England of private medical insurance, self-reliance, self-help, of a reckoning for feckless welfare recipients who don’t understand that pay TV is a luxury, of decent poor people fallen on hard times being helped by acts of charity in the same way the *Lincolnshire Chronicle*’s ‘simple, kindly country folk’ helped Maud Elizabeth-Norman in 1924, an England which (despite 70 years of evidence to the contrary) simply could not afford to run a national health service from public funds.

I hadn’t expected to find myself suddenly having to defend the existence of the NHS in a room in a nursing home. The Warrens hadn’t complained to me about the medical care Wendy Warren received. In some cases they went out of their way to praise it. When I suggested that inherited wealth in a private insurance based health system was more unfair than small-time gaming of benefits in a welfare state, Louise Warren invoked fate as an inevitable leveller of family riches: ‘My dad used to have a saying, clogs to clogs in three generations. In other words, it’s not going to last for ever.’

She was anxious not to be seen as hard-hearted, although she had her own take on the founding of the NHS. ‘I used to be a support worker for drug and alcohol rehab,’ she said. ‘I’ve helped people access the benefits, I’ve gone with them to their interviews and I’ve helped them claim, I’ve done all sorts of things, but … when the welfare state was set up it was never meant to be ongoing. It was actually to help people get back on their feet after the war.’

She’d like Britain to be more like the United States?

‘They don’t have as much of a welfare entitlement mentality as we do over there,’ she said.

I turned to Wendy Warren, who’d been following the discussion attentively. ‘What do you think, Wendy?’ I said. ‘Are you a liberal Liberal or a neoliberal?’

‘I’m neoliberal, I suppose,’ she said. ‘I’m well aware that people fall on very hard times …’

‘Absolutely,’ her daughter chimed in.

‘… and that they need support through those times. But it’s very difficult. We’ve lost the differentiation between the deserving poor and the undeserving poor and I think that’s the place where it’s difficult to draw the line.’

**Letters**

[Vol. 40 No. 11 · 7 June 2018](https://www.lrb.co.uk/v40/n11/letters#letter8)

James Meek mentions in his piece on the NHS that he tried and failed to interview Jon Ashworth, MP for Leicester and shadow health minister ([*LRB*, 5 April](https://www.lrb.co.uk/v40/n07/james-meek/nhs-sos)). I can assure him that Ashworth at least read the article, as I bumped into him in a park in Leicester a couple of days after the issue came out. We had a discussion about how the NHS’s complex privatisation could be reversed.

**John Perry**
Masaya, Nicaragua