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**The Bristol Heart Scandal and its consequences**

**politics, rationalisation and information**

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Imagine you are a parent who has just learned that your precious, beautiful newborn baby has a major heart defect, which will need open heart surgery very soon.

Imagine the impact of that news.

Imagine the journey to the specialist hospital, which may be many miles from your home. The uncertainty of what such a place will look like, be like, smell like.

Imagine the competing emotions that would be going through your head; the questions, the tearful silences and the terrible anxiety. Imagine the fear of handing over your precious baby to the care of strangers, confident in their own world.

You would expect to be confident in the knowledge that you are heading for a place that is expert, which is specialized and in which work people who are there because they are highly trained and good at their job, who work in high quality teams, whom you can trust and whom you can believe. People who work in appropriate conditions and have access to everything they need if things go wrong.

Somewhere where your child is going to become the centre of their universe too.

For most of us, our children are the most important people in our lives. Parents usually express extraordinary levels of protection on behalf of their children shielding them from the dangers of the world. Crossing roads, avoiding pit bull terriers, casual violence, and countless other examples. We take on instinctively the role of protectors for our children; we are there to look after them and to nurture them into adult life.

I am going to tell you a story of when that trust in others was misplaced, and the sense of protection was undermined. It is a story, to paraphrase Sir Ian Kennedy, “*not of bad people, nor of those who did not care or who willfully harmed patients. In fact this is a story of people who cared greatly about human suffering, were dedicated and well motivated. But some lacked insight, had flawed behavior, communicated badly and failed to work well together, in the interests of the patient*”. The names of the *dramatis personae* in this saga are highlighted in bold font.

**BRISTOL**

This is the story of what happened at the Bristol Royal Infirmary in the 1980s and 1990s. Many children died there who probably would not have died if they had been operated upon somewhere else or by others. The story only emerged by what has become known as ‘whistle-blowing’ and the tireless demands of affected parents and an appropriately critical and cynical media.

To explain the events in Bristol, we need to start in the 1970’s. At that time, most cardiac surgery in the UK was performed in specialist cardiac units, dominated by adult practice to fix valves and operate on coronary artery disease. Surgery on children was carried out largely by surgeons with a mixed adult and paediatric practice, and there were only a few units and surgeons devoted solely to operating on children. The hospitals in which most worked were set up for adult surgical practice, and rules and procedures were evolved primarily from experience with adults with acquired disease.

In those early days, still only 20 years after the first open heart surgery, diagnosis was made by cardiologists using basic deductive clinical skills (history, examination, the stethoscope, ECG, x-Ray) and the beginnings of ultrasound scanning, or echocardiography. Even if everything looked a bit like a snowstorm, precision diagnosis was emerging. In Bristol, the diagnosis would be made in the Children’s Hospital where the paediatric cardiologists worked, and whilst some surgery could be performed there, open-heart surgery was carried out in the main cardiac unit in the adult hospital, The Bristol Royal Infirmary. That is where the equipment and personnel existed that made repair possible. It is also where intensive care was carried out after the operation. And as I vividly remember from my own training, surgeons managed the intensive care of patients after surgery. There were no intensivists in those days.

In the first half of the 1970s, Bristol was a relatively small center with respect to congenital heart disease, doing only about 100, mostly relatively simple, cases per year. Demand was rising as improved international results emerged and more was becoming possible, and Bristol hired a surgeon specifically to meet this demand. His name was **James Wisheart**. With investment of the regional managers in the South West (at the time, the South West had the worst provision in the country for children with congenital heart defects), and the hard work of Mr. Wisheart and his team, by 1985 the unit was operating on 435 cases per year. It was decided by the Department of Health that Bristol should be designated a specialist children’s heart center and Mr. **Janardhan Dhasmana** was appointed as a junior surgeon in Bristol. This was the same year I was appointed a consultant at Great Ormond Street, and Janardhan was one of my competitors for that post.

You might recall that the 1980’s were a time of great change in cardiac surgery in children. Perhaps the most important shift in practice during that decade was the realization that operative outcomes and long term results could be better if you operated an babies in one stage procedures much earlier in their lives, before f the lungs were damaged or the heart suffered more. This change in practice was driven largely by Aldo Casteñeda in Boston and Roger Mee in Melbourne. Two conditions in particular were benefiting from this approach, atrioventricular septal defect (AVSD) and transposition of the great arteries (TGA).

Surgeons are very competitive, and innovative procedures are contagious. Each time a new operation emerges, especially if it is perceived to be difficult, it can acquire an almost mythical status as the procedure by which surgeons and units judge themselves. It’s how they weigh their cojoñes! The results from Boston and Melbourne were being replicated in other centres, and in the UK in Birmingham by Bill Brawn and his team and at GOSH. Thus is not surprising that the Bristol unit wanted to start these procedures. In 1988, Dhasmana introduced the arterial switch and in the next years he carried out 38 operations with 20 deaths; a mortality rate far in excess of these other units.

Also in 1988, **Stephen Bolsin** was appointed as an anaesthetist with a special interest in congenital heart disease. He had trained in London and immediately noticed that the operations in Bristol were taking much longer than he was used to and he soon became concerned that the outcomes were also much worse. Bolsin started collecting outcome data for the unit himself.

James Wisheart was collecting some results with his cardiology colleagues and these were discussed at intermittent meetings in each other houses each at intervals. In 1989, Wisheart was made Chairman of the Hospital Medical Committee [representing all the consultants in the hospital] and Assistant Director of all Cardiac Surgery. In those days reporting of results was not the norm or the culture. In fact, the cardiac surgeons of the UK had become the first speciality to set up a (voluntary) system of reporting results, but only to themselves and with no data validation. The results were not available to the public, and not everyone joined in. The principle was right, but the practice wrong.

Between 1990 and 1994, James Wisheart’s own results came under scrutiny when he operated on 15 babies with AVSD, 9 of whom died, at a time when GOSH and Birmingham had operative mortalities for this group of <5%. Stephen Bolsin was very worried that something was fundamentally wrong and wrote to **Dr John Roylance** the Chief Executive of the hospital. Bolsin claimed he was confronted by a furious Wisheart, but that is denied.

I should say here that in 1991, I was approached to apply for the post of paediatric cardiac surgeon at Bristol and to discuss the Chair in cardiac surgery there. I decided not to apply, largely because of the split site working and poor operating facilities stating in writing that I thought ‘inefficient, archaic, inhibitory to progress and potentially dangerous”. After operation at the BRI children were at the time cared for by surgeons on rotation through cardiac surgery with little or no paediatric experience. The paediatric cardiologists were on another site, and it was incredibly difficult to get an echocardiogram after surgery to identify any problems with a child’s heart.

James Wisheart had been promoted again, this time to be Medical Director of the BRI, with Dhasmana still having poor result with the switch. **Phil Hammond**, a local GP and comedian who writes as MD in **Private Eye**, was made aware of the story and published his first article exposing the problem, although he had reported in his stage act the ironic naming of the ICU at the BRI as “The Killing Fields” or “The Departure Lounge”.

Bolsin had not completed his audit, but was still worried enough approach the Department of Health, which did not really take much action and were later criticised. The Medical Director of nearby Frenchay Hospital also reported the problems to the Royal College of Surgeons. Although the college had considered removing recognition from the unit as a specialist children’s centre, in 1988 and 1990, but relented.

In 1993, Bolsin’s audit was complete and he concluded that the mortality rates were higher than the national averages available from the UK cardiac surgical register, the UK surgeon’s voluntary registry. Bolsin showed the figures to some anaesthetists and to the Professor of Adult Cardiac Surgery in Bristol. Dhasmana stopped doing switches voluntarily because he felt ‘there were simply too many deaths’.

In 1994 the Royal College of Surgeons inspected Bristol and issued a positive report. Wisheart gave a copy of Bolsin’s audit to another DoH official **Dr Peter Doyle** in a cab! Doyle says he never read the document but was reassured by the professor of cardiac surgery and John Roylance the CEO that ‘action was being taken’.

In 1995, an 18 month old child called **Joshua Loveday** with TGA was decided by the cardiologist to need an arterial switch. There was heated debate behind the scenes in Bristol and Janardhan Dhasmana was persuaded and encouraged by the cardiologists to undertake an arterial switch. They went ahead, even though the Dr Peter Doyle from the DoH had strongly advised against it. Bolsin was horrified; it was not to be an easy operation, Dhasmana hadn’t done a switch for some time, and other units were getting much superior results. Dhasmana apparently quoted a survival rate of at least 80%, much more optimistic than his real results revealed. Poor Joshua died on the operating table.

My colleague at GOSH **Prof Marc de Leval** and **Dr Stewart Hunter** from Newcastle were asked to visit Bristol. They reported that there was considerable confusion in the organisation of the ICU, and generally poor communication. The data available to them were weak, and they thought that the unit required strengthening with an established paediatric cardiac surgeon. The report was accepted by the acting CEO, Wisheart stopped doing paediatric cardiac surgery at that time, and cases would be transferred elsewhere.

Worried anxious and angry parents started the **Bristol Heart Babies Action Group**, publicity increased and a rapid sequence of consequences began. Bolsin resigned from the NHS and went to Australia, Wisheart stopped operating and resigned as medical director, and the GMC began an investigation into allegations that families had been misled. BBC Panorama in a programme made by Sarah Barclay accused the DoH and the Royal College of Surgeons of failing to act on clear warnings of problems. Wisheart retired in 1997.

**GMC**

In 1998, the GMC held a hearing which resulted in James Wisheart and John Roylance being struck off and Dhasmana suspended from the register, all for serious professional misconduct. The following year began the Bristol Royal Infirmary Inquiry, Chaired by **Professor** **Sir Ian Kennedy** a prominent lawyer with a specialist interest in medical ethics, ably assisted amongst others by **Eleanor Grey QC** who, I believe, is here tonight. That was a carefully planned, thorough and transparent review, which delivered 198 recommendations.

I was a witness of fact at both the GMC Hearing and the Kennedy Inquiry and so have my own personal memories of them both. I also was an expert witness at the GMC hearing. I have been in touch with several of the lawyers involved in the hearings at the time both to hear their reflections but also to ask a question that has bothered me as a surgeon since then. Let’s consider what was bugging me, and see if it has any resonance with you.

It takes a remarkable amount of confidence to operate on a child, and one does the procedure within a team that is watching every aspect of your work and performance. Sometimes, when the outcome of a procedure has been poor and a child has suffered, it can be very difficult to operate the next day. I have felt this and I have relied on those around me to ‘get me back on the horse’. In a cardiac unit, and even in Bristol it is extremely hard to imagine that the rest of the team did not know how the results of AVSD and TGA were panning out. This would be particularly true of cardiologists who would have built up relationships with the families preoperatively and be well aware of the subsequent outcomes. I know that results were discussed within the team in Bristol at the time, from my own visits there before I turned down the job. I also know that there was internal pressure to do difficult cases ‘to maintain the status of the unit’ as a recognised children’s centre. So if everyone in the team was involved, why were only the surgeons ‘punished and vilified’ in public? The surgeons may have held the knife in the operating room, but the cardiologists had the right and perhaps the responsibility to refer patients elsewhere, to a centre where results for such cases were known to be good. Just because the consent form is signed by the surgeon, it does not mean that they alone bear the responsibility for the outcome. I understand that, as a surgeon, one should have the insight and strength to be able to recognise that one should not be doing certain operations, but just as one may need moral support to get back on the horse, one may need as much or perhaps even more to be forced off it…and that is most effectively done by one’s immediate colleagues and line management.

I was horrified that other members of the team were not called to the GMC hearing and that a culture of blame was evident with almost a witch-hunt being evident, focussed on the surgeons. Where were the cardiologists? Where were the other anaesthetists? I asked **Mr Roger Henderson, QC** to the GMC hearing, where these people were. His answer was telling; pragmatic and procedural *“the reason that no cardiologist and no anaesthetist was in the frame was that the case which was unwieldy enough as it was would have become wholly unmanageable and hopelessly prolonged had any of them been charged. It took long enough as it was but would have taken even longer had others been charged”.* He added that it was his decision “*again to try to avoid undue complexity and increased time, to focus on only two types of cardiac problem; eg ignoring cases of truncus arteriosus etc.”* I heard at the time that the cardiologists had also been advised by their defence societies not to make statements.

The defence lawyer for John Roylance was a barrister destined to become famous in later life. He is Robert, now **Sir Robert Francis**. I asked him what his recollection of the GMC hearing was. His answer surprised me; he said he felt *like emigrating after the hearing*, which he described as the ‘*apotheosis of the blame culture’*. He said the atmosphere was punitive throughout; someone had to pay. Given his later pronouncements over mid-Staffordshire and whistle blowing, these are interesting observations. I was at the GMC hearings and, whilst my primary sympathies lie with the poor parents who lost their children, the daily humiliation of the surgeons and the lack of criticism of wider system issues were very distressing. The adversarial nature of the GMC hearing narrowed the focus of debate and increased its emotiveness, exposing it to simple headlines of blame and accusations of murder. I have no doubt, knowing both the surgeons as I did then, that neither of them would ever have had such a thought in their head. However, their decisions to proceed and do what they did were wrong and clearly misguided.

But people need *help* at that time, guidance and support to give up all of that to which they had devoted their life and skills. They need to be helped to give up or to retrain, instead of being encouraged by their peers and others to go on. Paradoxically, our health service seemed designed to punish and not to help. There is such a contrast with the airline industry where safety is dominant and repeated simulation training weeds out weak practice, and investigation of incidents is non-punitive. We have much to learn.

**KENNEDY**

I subsequently discussed some of these points with Sir Ian Kennedy, and his reflections are also clear. He feels “*it would have been much better to hold the public inquiry before any involvement of the GMC. The wider brief and more effective and open process was better suited to explore the complex issues involved and to hear in detail the harrowing tales of the families involved*”. There were so many factors leading to the disaster that Bristol represents that focussing on only three people was naïve in the extreme and fed a sound bite culture in the media. The recommendations of the Kennedy report properly reflect this complexity, and I would like to agree with the conclusion of the then editor of the BMJ, Richard Smith, that ‘*all had changed, and changed utterly’.* Sadly, whilst a great deal has changed we have continued to see failings of performance, organisation, probity and transparency. A lot of lessons were there for the learning. There is not time to analyse every single recommendation of the report, much as I should like to, so I will list the broad themes and select some that have been implemented and highlight some that have not. These are the themes that Kennedy highlighted: -



The report led to some important changes in the supervision of doctors, namely the introduction of more sophisticated clinical governance, a system of regular revalidation of doctors, more robust annual appraisal and job planning, systems of reporting incidents and sharing learning were established. There was a renewed focus on the importance of truly informed consent and team working. A national advocate post for children was created and systems of outcome reporting were strengthened, but these remain simplistic and benchmarking is often limited to single binary outcomes which lack the sophistication needed to reflect the complexity of work done. The introduction of satisfactory IT systems is still to come, following the catastrophic failure of connecting for health. Until there is a fully integrated Electronic Patient record across the NHS, there will be significant opportunities for inadequate reporting and monitoring to occur.

However, what has not happened is any significant revision of medical negligence laws and patients still have to prove negligence to get adequate compensation for harm that happens to them. As a result, I am far from convinced that we have got much further in creating a *just* rather than a *blame* culture. The cost of litigation in the NHS is at an all-time high, and the process remains adversarial rather than built on mediation and resolution.

I have discussed before the desire of cardiac surgeons to be at the forefront and to ‘just get better’; a relentless pursuit of excellence. That concept was clearly not in place in Bristol at that time, although the desire to do new operations perhaps reflected some of that ambition, however flawed the implementation. The NHS has great opportunity to deliver the best practice, and accepting second best should not be part of its ethos.

Other specialities were affected by events in Bristol. The publicity surrounding both the events in Bristol and the organ storage scandal in Alder Hey put great pressure on the paediatric pathology department in Bristol, and then regarded as one of the best. The head of the Department, **Professor Berry,** took early retirement and **Dr Charles** emigrated to Australia. The Trust decided there was no funding for to replace them and paediatric pathology was merged with adult services. The two remaining pathologists felt so undermined that they moved to other centres in the UK to be excellent, paediatric services need to be fully integrated. Pathology is a special skill and within that paediatric pathology more so. Teaching, training and understanding cardiovascular pathology is vital to the development of a good paediatric cardiac unit, and the disintegration of this service is disconcerting. **Mr Richard Spicer**, made many representations on this basis to the senior management team in Bristol, but to no avail. Samples and specimens are still sent to GOSH for review to this day. This issue exemplifies a problem defining the border between ‘raising issues’ and ‘whistle-blowing’, which both exposed the Bristol scandal and was the basis of the recent Francis review.

I want to concentrate on some of the recommendations that specifically relate to paediatric cardiac surgery. After the report came out, there was a great deal of public and private soul-searching, and the press release issued by Ian Kennedy when his report came out contained some telling quotes, not just about heart surgery in Bristol, but about the way we work generally and in relation to the wider NHS.

Sir Ian said Bristol was a hospital that had “*over-reached itself*”, where clinicians only had “*limited experience*” at the time it became a regional center.

“*Clinicians were ambitious to expand – the ambitions were too ambitious*.”

“*The management of the hospital was flawed – too much power was in too few hands*.”

“*There was a club culture where it was hard to raise matters of concern and harder to get anything done*.”

And he said wider problems in the NHS were also to blame.

“*There were no agreed national standards as to what amounted to good quality care for paediatric cardiac surgery – no agreed measure or benchmark*.”

“*Bristol was awash with data ... [but] there was confusion in the NHS from top to bottom as to where responsibility lay for monitoring the quality of paediatric cardiac surgery.*”

NHS Inquiries are frequent, and fraught with implementation difficulties. But Sir Ian was clear in his view that there were too many cardiac surgery centers in the UK, that complex surgery should be done in centers of excellence, and not in centers which do not meet a defined minimum number of procedures. The whole process of care should be both standards-based and better governed. He concluded his report by stating explicitly “*considerations of ease of access to a hospital should not be taken into account when considering whether cardiac surgery should be undertaken there.”* I return to this point later.

As you can imagine, there was a great deal of discussion within the profession, locally and at national meetings, about the implications of these observations. Our professional body the Society of Cardiothoracic Surgeons, whose then president was the late **Professor James Monro**, himself a paediatric cardiac surgeon, carried out a review to define the appropriate size and volume of a cardiac unit. That review group recommended in 2003 that a unit should do no less than 300 relevant operations per year. At the time, that would have meant that 50% of the units in the UK would have closed. The governance of services within the NHS remained largely unchanged, and no action was taken by NHS leaders, justifying their position on the grounds that ;‘no concrete evidence of unsafe practice had emerged’. For me, this was a disastrous judgment, using lowest common denominator performance as a benchmark. There was a great window of opportunity post-Kennedy to implement change. The public saw the need for excellence, and recognized that is what they would want for their children.

On the other hand, it is not too hard to understand why politicians and NHS leaders did not want to take action. The NHS is not independent of politics. Indeed, it often forms a significant part of the battleground on which elections are fought. That no politician would support the closure of a hospital was, in 2003, *Realpolitik.*

In the 2001 general election, **Richard Taylor**, a hospital physician in Kidderminster, was elected with a massive majority, beating a sitting minister, standing on a single ticket campaign to save Kidderminster hospital. This inability for politicians to risk support for changes to local health services has become known as ‘the Kidderminster effect’. This effect, and the complexity of relationships between the NHS and government, form the background to many of the problems we have faced in the last decade in trying to achieve excellence in my specialty. However ‘arms-length’ politicians have tried to make the NHS, perhaps because of the Kidderminster risks, in the end they all want to fiddle with it. More to come I suspect!

However, the majority of my profession were incredibly anxious a) to resolve the outstanding issues following Bristol, and put in place systems to prevent a recurrence, b) to regain the trust of our patients, c) get out of the headlines and b) to pursue excellent, not average, performance, get better year on year and make UK paediatric cardiac surgery the best in the world, as the core integrated structure of the NHS should really make possible; better and easier than anywhere else. We weren’t going to give up.

Concerns persisted; in 2006 a national workshop of experts chaired by **Professor (now Sir) Roger Boyle** (a cardiologist and national cardiac ‘Tsar’) and **Dr. Sheila Shribman** (who held a similar role for paediatrics) concluded that the current configuration of services was **unsustainable**. All the surgical units sent representatives to this meeting to discuss rationalization, and they agreed that the number of units should be reduced, probably to about 7 from the 11 that were then open. Each unit was challenged with the argument that the consequence of rationalization might be that their  own unit would be scheduled for closure. They **all** agreed on the need for change.

In 2007, the Royal College of Surgeons of England called for the concentration of surgical expertise into fewer, larger specialist centers. A year later, **Professor Sir Bruce Keogh**, NHS medical director and himself a cardiac surgeon, instigated the Safe and Sustainable (S&S) review, which began in 2008. His frank public warning was that failure to re-organize paediatric cardiac services this time round would be “*a stain on the soul of the specialty*”. In 2007, there were only 31 surgeons doing surgery for congenital heart disease in the UK, and only about 10 of them were solely paediatric. They were working in 11 centers, operating on about 2400 cases per year between them. The work was not evenly distributed with some centers doing several hundred cases a year and some doing < 100. Some centers had just two surgeons, making 24/7 cover very challenging and leaving no reserve if anyone became ill or services stretched. There was clearly a risk of something going wrong again, and these fears were borne out in 2010 when the smallest unit in England, Oxford, was suddenly suspended because of an increased mortality rate, fortunately detected relatively early.

Rationalization of services to smaller number of expert services has worked very well in the NHS. Even in our area, we only have 2 paediatric transplant services, 3 ECMO centers and one tracheal unit. These units deliver world-leading results at relatively low cost, concentrating research output and expertise. Why not go further and reduce the number of cardiac units and deliver the very best for our patients?

**SAFE AND SUSTAINABLE**

The Safe and Sustainable Review (I’ll call it S&S from now) was managed under the auspices of The National Specialist Commissioning team on behalf of the 10 specialist commissioning groups in the UK and their 152 Primary Care Groups. This very sentence demonstrates how hard it can be to make change in the NHS. The NHS is not like a company, despite the so-called internal market, which Margaret Thatcher’s government established. It has a board, but not one that issue orders like might happen at Apple or Virgin. There are immense numbers of layers between Board and Ward, and many of these layers are representative rather than executive. When S&S was established, Primary Care Trusts held health care budgets for the majority of conditions, with some money being top-sliced from the NHS budget for commissioning the highly specialized services. These were contracted directly with the provider units. NHS hospitals strive to become Foundation Trusts, which gives them a little financial freedom to evolve, but also sets them in supported competition with each other, for business share, staff and reputation.

The S&S team realized that in this context, an open and visible governance process would be critical. They chose to have an advisory Steering Group comprising representatives of parent associations and professional groups. The steering group had no decision-making rights. These rested with a new body which had to be created by the Secretary of State called the Joint Committee of PCTs made up of SCG leads and chaired by **Sir Neil McKay**, from East Anglia region, which did not have a congenital heart unit and could thus be seen to be neutral.

A Standards Group was also established with a wide professional and lay membership to define and publish appropriate standards of care, just as Sir Ian Kennedy had recommended almost a decade before. These standards are available, clear and were widely supported.

I can see your eyes glazing over at all this. Even in retrospect it seems an incredibly complex way to do the obvious, after all everyone involved, and especially the parents groups thought it was the right thing to do. But two factors made it necessary. Firstly, a perceived political and sociological need to engage the wider public in the process, and to make it ‘fair’; the politicians and NHS leaders at the time wanted maximum public consultation. Secondly, the NHS management structure was and is a bureaucratic nightmare. Whilst democracy is well known to be a messy business, the British seem to have a unique ability to create structures with way too many interactions to be effective.

It gets worse though. Whilst in the law the JCPCT had legal authority to make the final decision, other legislation enabled local Health Overview and Scrutiny Committees (of which there are hundreds in England) to challenge any decision by referral to the Secretary of State. The committees (made up of local councilors) must by their very nature have a local focus and it was apparent from the start that no such group would dare incur the wrath of its local electorate by supporting the closure of its local heart unit. A challenge from a scrutiny committee was inevitable, and given the referral route, it was clear that the ultimate decision would rest with a politician; the Secretary of State, just as it did in 2003 when Jim Monro’s report had been disregarded.

The likely success of any Scrutiny Committee’s challenge to the JCPCT decision would be dependent on proving a flaw in the process of decision-making – which was hardly an incentive for positive engagement from local politicians and campaign groups. Campaigners against reduction of the number of units realised early on that the best was to influence ministers was to make S&S as public and controversial as possible. This they did, and ministers were always careful to note the *professional consensus* for the need for change, but never actually give a commitment to make the changes. The role of the JCPCT as decision maker was emphasized with only a nod and as wink to the eventual pivotal role of the secretary of state.

The Steering Group, with near complete professional and lay support, published in 2010 “The Need for Change”, summarized here, but bearing a remarkable resemblance to the Recommendations of the Kennedy report. A full decade later.

The Need for Change; Children’s heart surgery was becoming increasingly complex

* Services had developed on an ad hoc basis; there was a need for a planned approach for England and Wales
* Surgical expertise (31 surgeons) was spread too thinly over 11 surgical centers
* Some centers were reliant on one or two surgeons and could not deliver a safe 24 h emergency service
* Smaller centers are vulnerable to sudden and unplanned closure
* Current arrangements were inequitable as was too much variation in the expertise available from centers
* Fewer surgical centers were needed to ensure that surgical and medical teams were seeing a sufficient number of children to maintain and develop their specialist skills
* Available research evidence identified a relationship between higher-volume surgical centers and better clinical outcomes
* Having a larger and varied caseload would mean that larger centers are best placed to recruit and retain new surgeons and plan for the future
* The delivery of non-surgical cardiology care for children in local hospitals was inconsistent; strong leadership was thought to be required from surgical centers to develop expertise through regional and local networks
* Increasing the national pool of surgeons was not considered the answer, as this would result in individual surgeons performing fewer surgical procedures and increase the risk of occasional surgical practice

The ‘Need for Change Document’ also predicted significant benefits if the change was carried through:-

* Better results in the surgical centers with fewer deaths and complications following surgery
* Better, more accessible diagnostic services and follow up treatment delivered closer to home within regional and local networks
* Reduced waiting times and cancelled operations
* Improved communication between parents and all of the services in the network that see their child
* Better training for surgeons and their teams to ensure the sustainability of the service
* A trained workforce expert in the care and treatment of children and young people with congenital heart disease
* Centers at the forefront of modern working practices and innovative technologies that are leaders in research and development
* A network of specialist centers collaborating in research and clinical development, encouraging the sharing of knowledge across the network

Who could argue against such a well-argued case and such, and measurable, benefits? Bristol was still very much in the public memory, and certainly in that of the professions. This looked like the right thing to do. What Ian Kennedy describes as ‘unfinished business’.

Developed from the Need for Change came a new “model of Care’ document built around the network concept, the features of which were: -

* Strengthened arrangements for the delivery of non-interventional diagnostic and follow-up care in local hospitals
* Formal pathways from antenatal screening to the transition to adult services formal protocols agreed by the surgical center with local services delivered in local settings
* Development of the role of Paediatricians with Expertise in Cardiology across the networks
* Strengthened Cardiac Liaison Teams

Whilst these were important, they were clearly medium to long-term changes. But more and more people were being drawn into the debate. Everyone had a view, and on everything. The necessary reconfiguration was going to be challenging! I have said how integral to this process the Secretary of State was, and he laid down 4 generic criteria against which any NHS service reconfiguration should be judged, and which also had to be fulfilled for it to proceed. These criteria were: -

1. Support from GP commissioners

2. Strong public and patient engagement

3. A clinical evidence base

4. Developed and supported patient choice.

There was complete unity of support from the professional bodies. This was unique in my experience. There was total support from the National parents and patients associations. However, because of the risk of challenge for lack of public consultation, the JCPCT launched the largest public consultation exercise in NHS history. It lasted 4 months from March to July 2011, involved videos, a 234-page publication of explanation available in summary, easy to read and multi-lingual versions. You could text back responses, which were formally sought as well. Town hall style meetings were held, and focus groups created and consulted, concentrating on young people themselves. Minority groups of all kinds were approached directly. In total thousands of people attended over 50 consultation events, workshops and focus groups in major cities throughout England and Wales. Ipsos Mori was commissioned to design an independent survey to avoid criticism of ‘leading the jury’. Over 75,000 responses were received from throughout the country and the rest of the world. Media interest was significant.

The JCPCT was also conscious that circumstances may have changed over the course of the process, and so set up an expert team led by Sir Ian Kennedy and involving James Monro, which in May and June of 2010 visited all the units in the UK and scored them against the proscribed standards. The scores were used but were not meant to be decisive.

When Kennedy reported to the JCPCT he said; *“During the current assessment process I and my colleagues on the panel found many examples of commendably high commitment and dedication by talented NHS staff delivering congenital cardiac services. But we found exemplary practice to be the exception rather than the rule. Mediocrity must not be our benchmark for the future.”*  I could not agree with him more. A country like ours, with the amount of investment we have made in these services and with the talent we have and can grow, deserves excellent services. Tolerating the mediocre reflects badly on our politicians, the NHS and all of us in the field.

The JCPCT obtained additional evidence on demographic change, transport time and other modeling data, all managed be external, independent consultants. The Resultant “decision making business case” was submitted to the JCPCT and a formal, public, webcast and media-heavy Board meeting was held in London on 4th July 2012. The JCPCT decided to reduce the number of centers from 11 to 7, de-designating the Royal Brompton in London, Leeds, Leicester and Oxford (which had already ceased operating).

A few days later The Times printed a letter from the Presidents of The Royal Colleges in which they said;

“*Maintaining the status quo was simply not an option. For too long surgical expertise has been spread too thinly across too many hospitals, and services need to be better coordinated to deliver expert care closer to where families live. The decision will mean that children's heart surgery will be provided in fewer larger centers with the expertise and volume of cases to ensure that outcomes for children improve. New congenital heart networks of care will be developed to ensure that services for children are more joined up, meet new national quality standards and deliver better monitoring of outcomes, allowing for services to be continually reviewed and improved.”*

Unsurprisingly, and despite their agreement in 2006to abide by the outcome, the units earmarked for de-designation were far from happy and used all the tools at their disposal to both influence public opinion and, where possible, to take legal or procedural proceedings against the JCPCT process. There was much media coverage and in the summer of 2012 the streets of Leeds city center were closed to make way for an organized march by thousands of demonstrators. Bitter arguments between senior clinicians played out in the media, including claims by supporters of Leeds that children would die on the “road to death” to Newcastle. Both the Prime Minister, David Cameron, and Deputy Prime Minister, Nick Clegg, were door-stepped by journalists asking questions about the review. The JCPCT asked the clinicians on the steering group to front up to the media, not to defend the decision but to explain for lay-people the clinical rationale for change. Perhaps predictably, given the extent of negative campaigning by disaffected units, much of the debate became heated and personal rather than objective and cool. Social media and blog sites did not make pleasant reading for many of us who were involved.

The primary mode of attack in the courts was via Judicial Review of the whole JCPCT decision- making process. Such reviews were launched by the Royal Brompton & Harefield NHS Foundation Trust in 2010, who won the first round but lost on appeal, and later, in 2012, by a campaign group based in Leeds called ‘Save our Surgery’ Ltd.

It is important to bear in mind that the Courts were not interested in whether the JCPCT had made the correct decision (the Court recognizes that it has no expertise in this regard) but whether the JCPCT had followed a proper and lawful process. The Royal Brompton’s challenge was brought in March 2010 – some two years before the JCPCT actually made a decision. The Royal Brompton objected to the process of public consultation (held between March and July 2011) on a number of grounds:

* that the public consultation was a sham, as the JCPCT members had secretly pre-determined the outcome;
* that the proposal for two units in London, rather than three, was irrational;
* that there was bias within the steering group in favor of certain units;
* that there was mis-information in the consultation document;
* that there was a failure properly to consider the knock-on impact of ceasing paediatric cardiac surgery to the hospital’s respiratory services.

The Court rejected all of these challenges but upheld the hospital’s challenge that the JCPCT’s process for assessing the hospitals against one of the assessment criteria (research and innovation) had been flawed. This ruling paralyzed Safe and Sustainable because it meant that the entire process of a 4-month public consultation (the largest ever national consultation held by the NHS) was now null and void.

The decision was over-turned by the Court of Appeal in March 2012, putting the process was back on track – but much damage had been done by way of delay and adverse publicity. It had made very public the inter-unit animosity that was infecting the process, including between clinicians who had previously regarded themselves as colleagues and friends (and who had previously been in open agreement about the plan). The total cost of legal fees incurred by the NHS on this case alone was around £2,000,000 of taxpayers’ money.

The second legal challenge was brought in October 2012 after the JCPCT’s decision to reduce the number of units. It was brought by a campaign group called Save our Surgery (SoS) Ltd, formed to promote the paediatric cardiac service based at Leeds Teaching Hospitals NHS Trust and whose directors included clinicians working in the Leeds cardiac service. This challenge was brought on the narrow ground that the JCPCT had failed to publish 450 sub-scores generated by the  panel.

The group argued that, by only publishing a limited number of headline scores, respondents to public consultation had been denied the opportunity to make a more informed judgment about the quality of the service in Leeds (the service in Leeds had received the second lowest score (out of 11 units) by Sir Ian Kennedy’s panel against the assessment of standards). This challenge once again highlighted the acrimony between units, to the extent that the Newcastle- upon-Tyne Hospitals NHS Foundation Trust felt  obliged to join the legal proceedings against SoS Ltd to counter what it perceived to be unfair and improper attacks made by the Leeds group in pursuance of its campaign to keep surgery in Leeds at the expense of Newcastle.

The JCPCT argued, with the support of Sir Ian Kennedy, that the sub-scores were irrelevant to the process of consultation and decision making, and that even had they been published they could not have been used by respondents to second-guess the Kennedy panel’s eventual conclusions – which had been reached using subjective expert judgment based on written and oral evidence submitted by the units to which respondents had no access.

The judge, Mrs Justice Nicola Davies, found in favor of SoS Ltd in March 2013. She said that “as the scores were relevant to the assessment, the breakdown of the scoring should have been disclosed to the centers whether or not the JCPCT proposed to look at it ...if there is a public law duty to make information available to a ‘consultee’, disclosure cannot be denied simply because one party does not wish to look at that information.”

On that narrow ground, the entire process of consultation and decision making between 2009 and 2012 was declared unlawful. Sometimes the law just looks ridiculous; that so much could rest on so little.

Whilst preparing for a second appeal from the JCPCT, events were taken out its hands by the predicted referral of the process to the SoS by Health and Overview Scrutiny Committees from Leeds and Leicester. The established procedure available to the Secretary of State was to ask yet another group, called the Independent Reconfiguration Panel (IRP) to advise him as to whether the JCPCT decision would actually lead to safer and more sustainable services in the future. The secretary of state would then decide.

Although chaired by a past president of the Royal College of Surgeons, the IRP did not comprise experts in the specialty but rather experts in hospital configuration, NHS managers and public engagement specialists. The IRP carried out yet another 5-month review, visiting every paediatric cardiac unit, interviewing those involved in the process, local campaign groups and took evidence from members of the public similar to a public consultation. This did not help to mitigate against an increasing sense of ‘consultation fatigue’ within the specialty.

To many of us involved over the years, the resulting report by the IRP appeared to lack substance, insight or even understanding of the issues when compared to the detailed analysis of the Safe and Sustainable process. But it was sufficiently critical of the JCPCT’s process to allow the Secretary of State for Health, Jeremy Hunt, to inform the House of Commons in April 2013 that:-

“*The IRP report also concludes that the outcome of the Safe & Sustainable review was based on a flawed analysis of the impact of incomplete proposals, and leaves too many questions about sustainability and implementation. This is clearly a serious criticism of the Safe & Sustainable process. I therefore accept their recommendation that the proposals cannot go ahead in their current form and am suspending the review today. “*

He said the consultation, which has already cost more than £6,000,000, ‘did not have the confidence of the public’ with some feeling the decision was predetermined. He said choosing which hospitals provided surgery was one of the most flawed areas of the review, but added “*we need to get on with this*” as the original argument for improving care was unchanged. The IRP’s report said: “*The Panel’s advice addresses the weaknesses in the original proposals, but it is not a mandate for either the status quo or going back over all the ground in the last five years.*” That may be so, but the date of the election had already been fixed and there was a strong suspicion that the ball of reform had been punted firmly into the political long grass.

There is a terrible irony in all this that everyone realised and realises that reduction of the number of centers was appropriate, and most agree with the pursuit of excellence, but our obsession with fairness and process has prevented a necessary and urgent change. It is particularly galling for me as a surgeon that Lord Ribeiro (a former president of The Royal College of Surgeons), the chairman of the IRP, said access to services was one of the panel’s main concerns, thereby overturning Sir Ian Kennedy’s previous recommendation in the Bristol Inquiry that issues of access and convenience should not be a consideration in any future process to decide the number and location of surgical units, and contrary to what partners had told the JCPCT during the Safe and Sustainable process.

Importantly, the entire structure of the NHS had changed after the last election with the introduction of the controversial Lansley reforms. That new structure meant that the PCTs, and hence their committees, were no longer relevant. Jeremy Hunt has commissioned yet another review, this time led by NHS England, which is considering simultaneously changes to the delivery of adult congenital cardiac services. The Steering Group of the original review had, at the outset, asked politicians and the DH to consider this, but were instructed to consider only considering children’s services. The new review has some heavy hitters on its panel. It is chaired by Sir Malcolm Grant, the Chairman of NHS England. Sir Bruce Keogh, the NHS Medical Director and himself a cardiac surgeon, sits on the panel. The new review is once again reviewing quality standards and developing a new process for change.

Concerns persist at the planning blight and low morale amongst staff, exacerbated by consultation fatigue and an entrenched culture of review without actual change. Despite the IRP’s assurances that its recommendations were not intended to prolong the status quo, we are back to square one, **14 years** after the Bristol report. Yet, almost without exception, people have agreed with the core recommendation that there should be a reduction in the number of centers. In view of the continuing public interest, and the comments of the IRP that some views were not heard (despite the extensive consultation), absolutely everything this new group does, says, hears or reads is made public, and can be read on line via this blog: http://www.england.nhs.uk/2013/06/28/john-holden/

The process goes on and it will be another year before we hear the next set of options, which will no doubt themselves be subject to judicial review and other legal challenge. There is no ducking the fact that health is a political issue, especially when played out on a national stage. Obamacare and recent NHS reforms exemplify this. Political careers can be made or lost over it, and views are strong. Politics also get played out locally; by physicians, patients, hospitals and local politicians. This reflects that everyone cares, but also that often they put more weight on local issues than national, and sometimes in the face of overwhelming opinion and evidence. This is prominent in the lessons learned.

**The Blunders of our Governments**

These lessons are manifold, and I thought it would be interesting to use the observations of others more experienced in analyzing the implementation of policy I turned to the work of Anthony King and Ivor Crewe, published in a brilliant book *“The Blunders of our Governments” 2013;Oneworld Publications, Bloomsbury, London.* They note that errors are repeated generation after generation, and the characteristics of such policy implementation failure are clearly not learnt. They list some common themes; Cultural Disconnect; Group Think; Prejudice and Pragmatism; Operational Disconnect; and Panic, Symbols and Spin. I tested our S&S process against these criteria.

**Cultural Disconnect**

King and Crewe define cultural disconnect as ‘*the failure of those making the plans to empathize with the users of the product of the plan*’. In other words, perhaps the planners simply cannot understand what happens on the shop floor because  they have never been there. I really don’t think this was the situation with S&S. Pretty well everyone involved had been directly involved with care at shop floor level as surgeon, nurse, patient, administrator or visitor. There had to be some element of ‘disconnection’ otherwise we could not have been objective, faced with the harrowing stories we heard. I think that S&S achieved a good balance, and that is clearly reflected in the subsequent documentation.

**Group Think**

Group think exists *when members of a group feel under pressure to maintain the groups cohesion, and often happens when outside people are regarded as hostile.* Is it possible that we all convinced ourselves that the argument over the number of operations a surgeon or center should undertake should really have been the dominant argument and we ‘group thought’ our way into believing it, as pressure from outside grew from the smaller centers? It could also be interpreted the other way round, as the Brompton tried to do that we already had predetermined views based on our center of origin. However, it may have been better to engage the opposition to the process more directly and abandon the idea of professional representation as a way of ensuring fairness. Having sat on the committees involved, my recollections are not of bias or predetermined thought, but of a very upfront desire to do the best of the UK patients. We also tried at various public meetings to engage those with opposing views. Engagement proved not to be possible; those opposed seemed to have more group think than we did!

**Prejudice and Pragmatism**

*An unquestioning belief that some kinds of policies can be counted on to work better than others.* King and Crewe also describe these as pre-judgments or hunches. Certainly, there was a very strong view that there should be a minimum number of operations per surgeons to reduce risk. I have yet to meet a surgeon who does not agree with the contention that the more they do the better they get. Maybe this is prejudice, but is also a truism. Yet that was quite hard to prove certainly to the satisfaction of the IRP. We were only dealing with mortality data; there were no other datasets to consider for example looking at complications. Given the relatively low mortalities for cardiac surgery in the UK and the skewed distribution of complex cases to the larger units, it proved very difficult to separate out mortality data. Complication information was not then available, and although lengths of stay data were available, showing wide variation, they were not used.

**Operational Disconnect**

*Disconnecting those who make the policy from those who have to implement it.* It relates to the whole concept of ‘do-ability’. Crewe and King point to many examples, many of which are IT projects. In the context of S&S the policy decision, reduce the number of units, was actually widely supported, the real issue was *which* units to close. As the day of decision approached, individuals began to realise that something might actually happen (not something they were really used to in the NHS) and began to think about themselves, their families, the children’s schooling, new towns, new homes, new life. One can easily understand the anxiety, and in truth there was little open debate about this, largely because S&S had (rightly) been squarely focused on patient benefit. The anxiety may have hardened opposition, but only at the end.

**Panic, Symbols and Spin**

This usually refers to ministers, and is thus a bit harder to define in relation to S&S, but here is the definition: *The response of ministers to media and public outcry. They need to decide or do something in response, especially if the outcry is from their core support, often under intense pressure to act or respond quickly and to be seen to respond. They often blunder under these circumstances.* The whole of S&S was played out, deliberately, in the public eye. It was recognized from the start that any future service reorganisation in the NHS, would need to go through a repeatable and safe process. That is why so much planning and money went into it. Public awareness and ‘stakeholder’ involvement were seen as critical to the process. However, the desire to engage the public more and more meant that the more organized the NHS became in managing the review and putting forward its messages, the more organized became the opposition campaign groups because of a genuine fear at local level that it might be implemented.

Massive sums were spent on public consultation to ensure that all views were taken into account and the process was ‘fair’. But public consultation in the traditional sense appears dead is age of social media. What’s the point of the NHS spending lots of money responsibly to communicate a message, or question when postings by anonymous people on social media are  capable of building up a head of steam that undermines the process? Why are campaigners more susceptible to believing an anonymous posting than something said by an expert such as Sir Roger Boyle? Maybe it is because they want to and they pass it on to friends and family who want to believe also, and before long the mis-truth is so embedded that it appears in speeches by MPs in parliament and in an (independent) IRP report, set up ‘to hear all views’. How should we respond to Mr. or Ms. Anonymous?

What became very difficult to bear was that we had to remain professional, polite and balanced with no such obligation on the other side (including from some clinicians it seemed).

The public meetings themselves were very difficult. They were big, town hall meetings with aggressive questioning and high emotions. The expert panels were not prepared for the abuse they received. The original intention in 2010 was to hold interactive workshops rather than town-hall meetings, but it was quickly apparent that the units and local groups would not allow this because they wanted an opportunity for heated public debate. It was in their interests so to do. Each local team presented highly emotive, individual cases, with the child and its family often present, and arguing in favor of the unit. Sometimes this clearly exposed poor treatment masquerading as great care because of a longtime spent in the intensive care unit (ICU) being looked after by wonderful nurses. It was especially upsetting to hear repeatedly from parents of certain units (but not others) how good were the bereavement support care.

Several senior clinicians, myself included, were put up to the media as spokespeople for the program. As a result, we got a great deal of flak from colleagues and support groups in the areas scheduled for de-designation of services. It became very personal and quite difficult. For a while I was very angry and upset, and thought putting us up for this was a mistake, and protecting the back of the NHS administrators who sat on the JCPCT. Now however, I have become convinced that there was no one better to put across the voice of reason. Who else would the public trust? We were not asked to defend the decision, we were asked to explain the case for change. Perhaps we just failed.

What is the lesson learned here? Is it that no matter how credible and respected the spokesman, the media will cheat by portraying him or her as the decision maker just for good TV? That as soon as a heavyweight and respected clinician dares to defend a process those clinicians on the other side will quickly break ranks and resort to attacking him or her personally? Or perhaps that, despite all appearances to the contrary the professional consensus on the need for change was never really there? It was all a lie. Clinicians in potentially threatened units had no option but publicly to back the case for change at the outset in the knowledge that change would happen “over their dead bodies”.

The final decision-making meeting of the JCPCT was held in public, broadcast on the web from a room full of stakeholders and journalists. TV cameras were waiting outside to interview whoever was most affected. It was rolling news in action. There was criticism at the time that the process was stage managed, largely because people were polite and argument mild. In my experience that is how good committees work, but that cut no ice with critics. The work had indeed been done in advance, but the decision was made in public.

We had stepped into the world of the public politician, and had to live that life for a while. The pressure on our families was immense. We had started by wanting to provide optimum care for children in the UK, and had ended up being vilified. It was a salutary experience and required patience and fortitude to survive. Panic, symbols and spin were well in play in this saga.

On further reflection, I am horrified that this process has taken so long to implement following Kennedy almost 15 years ago. The horrible and ever changing complexity of the NHS structure has not helped, and it has been disappointing to see ‘nimbyism’ triumph of common sense. Local parents have been astonishingly supportive of their local units, even when it has been assessed as ‘dangerously poor service” as was the case in Oxford in 2010. It has also been galling to think note that despite the discipline of paediatric cardiac surgery being one of the first to be open and public about its results, the depth of data we need to make change was simply not there. I have learnt that the English Civil War has not really been forgotten. Deep regional differences were exposed, and arguments, especially between Leeds and Newcastle were particularly vitriolic. My Australian and Canadian colleagues simply could not credit the anxiety expressed by the families of Leeds about the ‘road to death’ that their children might have to travel to Newcastle. Patients from Darwin frequently have to go to Melbourne. They do so safely, because that is where the best care is. In the UK, it seemed local ‘patriotism’ trumped the desire for excellence in care.

Whenever I travel to other countries, and discuss organisation of paediatric cardiac services, I have been struck by the admiration of my peers for the English system of care delivery. This system is characterized by (generally) regional services, a limited number of centers and a commitment to open presentation of (limited) outcomes to the public. And the English results are rather good. Those same peers were almost unified in their support for the underlying principles behind the Safe and Sustainable process, namely ‘the more you do the better you get’, and that concentration of services would permit better training, sub- specialization and succession planning, as well as delivering a better quality of life to all staff, and particularly surgeons.

I was proud to be part of that process. It turns out that some people were of the view that the process was flawed, and that has brought it to its knees and we must start again. That there remains an appetite to do this within the NHS is a tribute, I think, to the quality of the underlying idea. So why is it taking so very long, when the logic is so widely supported and has been so for over 20 years?

The detailed lessons listed above reflect the importance to health and children to communities, local and national, and the unavoidable link between health care and politics. In England, the various governments have attempted to place the NHS into arms-length organisations, currently exemplified by NHS England. But when push comes to shove, every secretary of state for health is under pressure from party and constituents to apply local rules to national issues. The media love a good fight, and fan the flames of local disputes. We have created a system in which consultation trumps decision making; in which everyone has equal say, even when they don’t know much about the specialty involved; one in which emotional views are given the same or greater weight than objective evidence or common sense;

One might argue that one could let the market decide, but that can only work if there is a true market, and in none of our systems is that really the case. In the USA, where market forces have been dominant for several years, the expenditure on health is more than twice the percentage of GDP as Europe, and results are not better for the population. In the UK, where there is artificial completion via an internal market (the purchaser: provider split), it seems that local or regional pressures trump competition in the end. In Scandinavia, rationalization has occurred, and results are excellent, costs low, and data collected nationally and well over the course of patients’ lives.

Michael Porter has long argued that what really matters is the **value** of health care interventions for the patient, dividing the outcome of the intervention (over life) by the cost (over life). We need to know the outcomes and reduce cost. Rationalization of services in large, efficient centers has to be part of that process. It is very depressing that many cardiac units in the UK remain vulnerable because of low volumes and too few surgeons. That families still have cause to complain about standards of care and staffing levels in relation to the care of both our elderly, and our vulnerable children is a terrible indictment of our system. There is to be yet another public inquiry in to paediatric cardiac services in Bristol, this time chaired by Eleanor Grey. It will be fascinating in due course to read her report and learn whether the lessons of Kennedy had really been learned, even locally. There really is no excuse for us not concentrating expertise and making the services robust and future proof. However painful and bruising it has been so far, we must not give up now. As Sir Ian Kennedy said, mediocrity must not be the benchmark for our future.

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