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Public engagement and NHS decision making: A legal fiction or a practical reality?

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Can I thank the officers of the Society for inviting me to deliver his lecture on public engagement in the NHS. This is a topic I have been engaged with in one capacity or another for the past 25 years.

Looking around the room, there are a number of people here who may not have been born when I was first troubled by the importance of public engagement with changes to NHS services. Let me describe 2 situations - over 20 years apart but with substantially the same issues.

In 1997 I was elected to be the Member of Parliament for Wyre Forest. As I prepared this lecture this morning, I looked over the beauty of the Wyre Forest - but I suspect many here have never heard of it. It is Britain's third largest forest - located in North West Worcestershire - with Kidderminster being its main town. Kidderminster has a District General Hospital which used to have an Accident & Emergency Department. However, the type of patients a small hospital A & E could safely treat was limited by the specialist services available to support the front line A & E staff. Hence, for example, a patient attending the A & E who turned out to need emergency vascular surgery in the middle of the night would be operated upon by the on-call surgeon who may have had very limited experience of emergency vascular surgery. The death rate from emergency vascular surgery at Kidderminster was very significantly higher than the death rate from patients at hospital

where the surgery was carried out by specialist surgeons. Exactly the same problem arose in respect of children because of the lack of out of hours specialist paediatric support.

A proposal to downgrade the A & E to a minor injuries unit was predictably unpopular. The hospital was reasonably quiet, staff had time to support patients and its convenience was an asset for local people. Also - and this cannot be underestimated - the town's people felt that downgrading their hospital constituted a slur on the importance of their town and its importance.

A vigorous campaign was commenced to oppose the downgrading of the A & E. What position should the local MP take? The problem is that "*those on the inside*" have to move beyond the instinctive reactions of the heart - insiders are required to look dispassionately at the evidence and decide what policy options are safe, deliverable and in the best interests of the citizens of that area. The battle between heart and head in the delivery of local health services is an unequal contest. As long as there is somebody advocating a line that the public wishes to hear, heart will always outvote head.

The campaigners took their case to the court - going as far as the Court of Appeal. They failed. *R (Kidderminster and District Community Health Council) v Worcestershire Health Authority* [1999] EWCA Civ 1525 became authority for the unsurprising proposition that a Health Authority was not required to consult on options which it reasonably believed were incapable of implementation. In Worcestershire the Health Authority had scrutinised all of the options through an extended period of public engagement and reached the view that <u>all</u> of the options favoured by the campaigners were impossible to implement. Politicians can ask for the impossible but public servants should not consult on undeliverable options, however popular they may be.

Despite knowing that the public strongly opposed the Health Authority's plans for the hospital, I could not back and essentially dishonest campaign to save services that were

putting the health and well-being of my constituents in peril. The search for an intermediate solution proved impossible. There was no safe way of operating an A & E in a hospital that was too small and had too few staff to support save services.

An independent campaigner - paradoxically a retired consultant from the hospital - took up the political mantle and was elected to be the MP in my place in 2001. In many ways, it was a release. However, he then spent the next 8 years (since he got re-elected by a reduced majority in 2005) calling for the restoration of the A & E in public whilst privately acknowledging this was a medical impossibility. That type of political duplicity does not appeal to me. It was a political necessity in his case given the stance he had taken get elected. But it shows the inherent difficulties in the toxic cocktail of NHS configuration, political ambitions and public sentiment.

Roll forward 20 years. The neighbouring county of Shropshire has 2 general hospitals, with one in Telford and the other in Shrewsbury, run by the same NHS Trust. It cannot recruit sufficient staff to provide safe A & E services. There have been a series of staffing crises and the existing emergency staff are having to work a ridiculous and unsafe number of additional shifts. There is a serious shortage of qualified emergency doctors and nurses throughout the NHS, and smaller hospitals find recruitment more difficult the larger ones.

A consultation has just been undertaken on proposals to downgrade either Telford or Shrewsbury. The public in Telford are up in arms - in a way that will be familiar to anyone who went through the Kidderminster saga - even though it is only a short ambulance journey along the M54 from Telford to Wolverhampton. The pressures leading to this reconfiguration are, if anything, more significant than those in Kidderminster. The public outcry is just as strong but it may well be that the serious options for the NHS are just as limited.

The difference this time is that there has been an extended, informed and focused public debate. However, there are legitimate concerns that this has not done anything to quell public concerns. Indeed there are arguments that the opposite has happened. The consultation process has simply given campaigners multiple opportunities to repeat the same message of victimhood.

It raises the difficult problem about how public views should be factored into decisions about the future of public services. To what extent are these "*expert*" decisions which have to be taken in a dispassionate way based on the best interests of the population as a whole - and to what extent should deeply held views from the public sway NHS decision-making, even if those views are not properly evidence-based.

There is no difficulty whatsoever in analysing the issues in circumstances where the public's perspective is legitimately different from the perspective of the suppliers of the public service. Left to themselves, suppliers of public services will inevitably arrange services predominantly for their own convenience. Thus NHS services are arranged for the convenience of the doctors and the NHS managers. If there is travelling to be done, the focus traditionally has been on making the patients travel to the doctor rather than the other way round. The justification is that this makes better use of the doctor's time because the doctor can see one patient after another. However, that is just one factor in the decision-making process. The patient often finds travel extremely difficult - because of the underlying medical condition which led to the need for medical services in the first place.

Further, imposing a requirement to travel will dissuade a number of patients from seeking services - they will be put off by the need to travel and thus delay seeking medical advice. The articulate, the well-informed and the affluent will get into their own cars to travel to access specialist health services. In contrast, those who rely on bus services, work long hours for minimum wage or survive on benefits, or have caring responsibilities of their own may find that same journey to be practically impossible.

The social determinants of health are now widely understood. As the Court of Appeal noted in a recent case in which I was involved[1], life expectancy reduces one year for every stop on Central Line going east from central London. So making services convenient for doctors but more difficult to access for patients cuts across any commitment to tackling health inequalities.

The problems are far more difficult where the reorganisation is genuinely about making the best use of limited medical staff, the best use of limited financial resources or ensuring the delivery of safe services for a population. Health economists and population medicine doctors can identify risks across a population and the benefits of specialist services, but these factors are largely unseen by the general public who accessed those same services. They are, interestingly, also unseen by the doctors and nurses to deliver services under an existing arrangement. These doctors and nurses are often doing their very best in difficult circumstances, and any suggestion that the services they deliver produce suboptimal outcomes is taken as an attack on their professionalism and competence. Hence, the most the vociferous opponents of changes to NHS services can often be the doctors and nurses delivering existing services with sub optimal outcomes.

The travails around Kidderminster hospital produced the first statutory provision requiring the public to have a say in NHS changes. That arose in section 11 of the Health and Social Care Act 2001 which imposed a duty on a Health Authority and a Primary Care Trust (the newly emerging form of NHS Commissioner) to make "arrangements"

> " … with a view to securing, as respects health services for which it is responsible, that persons to whom those services are being or may be provided are, directly or through representatives, involved in and consulted on—

[1] See *R (The Pharmaceutical Services Negotiating Committee & Anor) v The Secretary of State for Health [2018] EWCA Civ 1925* at https://www.bailii.org/ew/cases/EWCA/Civ/2018/1925.html

(a) the planning of the provision of those services,

(b) the development and consideration of proposals for changes in the way those services are provided, and

(c) decisions to be made by that body affecting the operation of those services"

This provision has been amended a number of further occasions but the essential structure of the legal obligation has remained unchanged. The primary duty is on a public body to have "*arrangements*". The word "arrangements" is a term of art within NHS law. It appears numerous times in the National Health Service Act 2006 - the consolidating statute which governs the majority of the law of the NHS. It means that the public body is required to have a defined procedure - usually set out in a policy document - which explains how it's officers will follow a defined decision-making process.

Today, these arrangements are usually encompassed in "*Patient and Public Involvement*" policies. In the jargon of the NHS - and the NHS has more impenetrable management jargon than any other form of public service I have ever encountered - these are known as PPI policies. They have nothing to do with payment protection insurance.

So the primary duty under section 11 of the 2001 Act was for a public body to adopt a scheme which explained how it proposed to involve the public in its decision-making - and - at least at that stage - to consult people before key decisions are made. However the means by which this involvement can occur was somewhat ambiguously described as being "*directly or through representatives".* Therein lay a problem. The only true "representatives" of the public are elected politicians - in this case local councillors or Members of Parliament. But, in practice, the "*representatives*" who were most engaged in the change processes were the self-selected local patient representatives sitting on Community Health Councils or on the patient groups set up by GP practices.

I am not sure if anyone here has ever been to a meeting of a patient's forum in any of the multiple forms under which they now presently exist or have existed over the years. The statutory successor is of Community Health Councils are now known as "Healthwatch". It is perhaps sufficient for present purposes to say that the degree to which they are genuinely representative of the patient population as a whole varies enormously. Some of these organisations are excellent but many are the vehicles of an informed and vocal minority. My experience is that these bodies get terribly agitated about changes to emergency all maternity services, but I do not recall outrage over cuts to mental health services ever figuring highly on the agenda.

The question as to "*when*" the duty of involvement arose under the statutory provision is worth examination. There were 3 limbs to this duty. First, patients were entitled to be involved or consulted in decisions about "the planning of the provision of NHS services". Next, and separately, patients were entitled to be involved and consulted in "the development and consideration of proposals for changes in the way those services are provided". Finally, the involvement consultation duty was engaged in "decisions to be made … affecting the operation of those services".

Thus - perhaps somewhat surprisingly - the public had a statutory right to be involved in NHS decision-making from the initial consideration of future plans through to final operational decisions which affected the NHS services in their locality.

The true effect of this statutory duty of involvement was tested in *Smith v North East Derbyshire Primary Care Trust* [2006] EWCA Civ 1291. Dr Khan ran a general practice in Langworth in rural Derbyshire. When he retired the practice was taken over by a nurse and her husband who hired doctors to deliver the services but that model was unsuccessful. When the contract was terminated, the PCT carried out a tender process which resulted in a decision to engage an American-based healthcare provider to deliver the services known as

United Health Europe Limited. The outcome of that tender process was, to say the least controversial locally.

The case originally came before Mr Justice Collins – [2006] EWHC 1338. In a style which is familiar for those of us who have had the privilege of appearing before Mr Justice Collins over the years, he said:

> *"It is clear from all this that s.11 has a very wide application. However, the language is somewhat imprecise. When I asked counsel what the words 'involved in' added, I received no satisfactory answer. I make it clear that I do not in the least blame counsel. Mr Pittaway, Q.C. and Mr Herberg submitted and Ms Grey accepted that they could not mean that the public had to be parties to the making of any relevant decisions. Thus 'involved in' really means no more than informed and able to express a view (which adds little to 'consulted on'). What is important is that the public must know what is proposed or what changes are to take place or how the services which affect them are to be operated and must have the opportunity, at least through a representative body, to comment on such matters. Their views must be obtained"*

The complaint here was that, notwithstanding a fair tender process, the absence of public views were not properly taken into consideration by the PCT and so no weight was attached to them. But lack of engagement might have made a difference because, as the judge noted at paragraph 14 "*At the very least the PCT might have been more reluctant to contract with UHE, a large impersonal business, rather than a local practice which could maintain the trust of the potential patients*".

The PCT and the Secretary of State argued that replacing one GP practice provider with another who was contracted to provide an identical service did not give rise to the public involvement duty. The Judge disagreed and said that any changes which gave rise to "*a degree of public concern about the manner in which the service is to be provided*" triggers

the involvement duty. However, the Judge decided that it was sufficient for the PCT to involve the Patient's Forum after the decision was made, and the wider engagement with the patient population was outside the scope of the duty.

That latter aspect was subject to challenge in the Court Appeal. The Court of Appeal decided that this was wholly inadequate. The key passage is at paragraph 9 where the Court said:

> *"The simple fact is that the defendants had a duty to consult and they did not properly perform it. Mobilising the patients' function after the decision had been taken without proper consultation was no remedy. The possibility that the Patients' Forum might have been mobilised before the decision was made, when it was not, neither provides a remedy nor relieves the defendant from their breach of duty. There is little basis for saying that this litigation would have been avoided if the claimant had gone to the Patients' Forum after the decision was made, when the defendants were wrongly contending that section 11 of the 2001 Act did not apply at all"*

A second case concerning the section 11 duty came before the Court in 2006: *R (Morris) v Trafford Healthcare NHS Trust* [2006] EWHC 2334 (Admin). It concerned a decision by the Trafford Healthcare NHS Trust Board to cease to admit patients as inpatients to wards at Altrincham General Hospital with immediate effect. The Trust accepted that the wards were closed without public consultation. However it said the decision was taken "*urgently on the grounds of clinical safety*". As the Judge noted, by the time of the trial the decision had been implemented, further consultation on healthcare services in Altrincham is promised, and in the circumstances the Trust argued that it would be wrong of the Court to order the reopening of the 2 wards.

There were 2 primary issues in this case. First, the Trust argued that the public involvement duty could not possibly prevent it taking urgent decisions when this was required to protect

patient safety. Secondly, the Trust argued that the Court should not require the Trust to reopen wards which it had closed. The Trust lost on the first issue but won the second. Both have continuing significance.

On the first issue, Hodge J said:

> *"The section 11 duty to consult is of high importance. The public expect to be involved in decisions by healthcare bodies, particularly when the issues involved are contentious as they clearly were with AGH. I do not accept that the need to close the wards at Altrincham General Hospital was so urgent that it was right that no public consultation should take place. There ought to have been consultation under section 11 about the closure of the wards in so important a local provision as Altrincham General Hospital. In those circumstances I regard the decision to close the wards as unlawful and will quash it"*

However, the horse had well and truly bolted by this stage and the Court was not in a position to do anything about it. Hence the Court did not order the Trust to reopen the closed wards. It was thus a pyrrhic victory for the campaigners.

The statutory involvement duties have gone through a series of legislative changes since they were first brought into existence in 2001. The present rules are in 2 different places. Providers of NHS services have engagement duties under section 242 of the National Health Service Act 2006. This duty is largely the same as the duty under section 11 of the 2001 Act, save that there is now a specific "post-*Smith*" provision which provides that the duty to involve the public only arises if implementation of the proposal would have an impact on—

> (a) the manner in which the services are delivered to users of those services, or
>
> (b) the range of health services available to those users.

In contrast, the public involvement duties for clinical commissioning groups - the new form of local NHS commissioner created by the Health and Social Care Act 2012 - is a significantly wider duty. The key difference is that it is a duty to make arrangements to secure that individuals to whom the services are being or may be provided are involved in NHS decision-making. Thus the provision in section 11 of the 2001 Act - replicated in section 242 of the 2006 Act - to discharge the duty through self-selected "*representatives*" has been removed. Accordingly, on the face of the statute, the duty is to offer all patients the opportunity of having their say before decisions are made.

Section 14211 of the 2006 also requires each clinical commissioning group to prepare an Annual Commissioning Plan, and there is a statutory duty on each CCG to consult the public about the contents of its plan prior to adoption: see section 14Z13(2). Interestingly, very few clinical commissioning groups comply with this legal obligation. They are far more concerned with complying with NHS England guidance which recommends an entirely different form of statutory planning process.

Section 14Z2(4) provides that NHS England has the right to publish Guidance for CCGs on the discharge of their public engagement functions. NHS England has published this guidance "*Patient and public participation in commissioning health and care: statutory guidance for CCGs and NHS England*"[2]. It contains large number of high-level statements in favour of public engagement and notes the conclusions of the Francis Inquiry into Mid Staffordshire Hospitals NHS Trust which concluded that there were real risks to patients if NHS bodies stopped listening to the views of patients, carers and their own staff.

The Guidance sets out 10 Key Principles which, if they were followed consistently in practice, would revolutionise the way some NHS bodies operated. It says:

[2] See https://www.england.nhs.uk/wp-content/uploads/2017/05/patient-and-public-participation-guidance.pdf

"NHS England has developed 10 principles of participation based on a review of research, best practice reports and the views of stakeholders.

- Reach out to people rather than expecting them to come to you and ask them how they want to be involved, avoiding assumptions.
- Promote equality and diversity and encourage and respect different beliefs and opinions.
- Proactively seek participation from people who experience health inequalities and poor health outcomes.
- Value people's lived experience and use all the strengths and talents that people bring to the table, working towards shared goals and aiming for constructive and productive conversations.
- Provide clear and easy to understand information and seek to facilitate involvement by all, recognising that everyone has different needs. This includes working with advocacy services and other partners where necessary.
- Take time to plan and budget for participation and start involving people as early as possible.
- Be open, honest and transparent in the way you work; tell people about the evidence base for decisions, and be clear about resource limitations and other relevant constraints. Where information has to be kept confidential, explain why.
- Invest in partnerships, have an ongoing dialogue and avoid tokenism; provide information, support, training and the right kind of leadership so everyone can work, learn and improve together.
- Review experience (positive and negative) and learn from it to continuously improve how people are involved.
- Recognise, record and celebrate people's contributions and give feedback on the results of involvement; show people how they are valued.

There are many examples of excellent engagement processes which involve the NHS bodies guiding the public through the process of taking difficult, unpopular but clinically appropriate decisions after full public engagement. There are others which demonstrate a continuing failure to engage with these difficult issues. The contrast between the exercises undertaken in Manchester - which led to *R (Keep Wythenshawe Special Ltd) v NHS Central Manchester CCG & Ors* [2016] EWHC 17 (Admin) and a process in Corby - which led to *R (Buckingham) v NHS Corby Clinical Commissioning Group* [2018] EWHC 2080 (Admin) could not be starker. So there is good practice in the NHS but there are also pockets - possibly large pockets - of practice which not only depart from anything that could be described as "good practice" to even basic compliance with statutory obligations.

The *Wythenshawe* case involved a major reconfiguration of acute health services in Manchester. The familiar challenges of making the best use of resources, the availability of staff on the proper arrangement of specialist services led to the inevitable decision to concentrate acute services at a smaller number of sites. That meant that one of 2 existing major hospitals needed to have services downgraded - and it came to a choice between Wythenshawe and Stockport. The CCG commissioners came down in favour of Stockport for a variety of reasons, but it was a close run decision. Frankly, either hospital could have been lawfully chosen as the one to retain its full range of services - and get new investment - and the one to be downgraded.

The process followed the NHS England major reconfiguration guidance - virtually to the letter. Public engagement occurred at all stages and detailed technical information was made available through a dedicated website. The consultant staff at Wythenshawe refused to accept the result and formed a company to challenge the final decision which went against them. The key question was whether the consultation was "fair", bearing in mind the observations of Mr Justice Sullivan, as he then was, in *R(on the application of Greenpeace Limited) v Secretary of State for Trade and Industry* [2007] EWHC 311 at paragraphs 62 and 63 who said:

"In reality, a conclusion that a consultation exercise was unlawful on the ground of unfairness will be based upon a finding by the court, not merely that something went wrong, but that something went 'clearly and radically wrong'."

In any consultation process, the proposals will adapt as the process unfolds. Indeed, the process of consultation inevitably gives rise to information which ought to change the proposals as the process continues. Absent such change, consultation can become a series of empty gestures. However, there is a high threshold before changes to the proposals require a further round of consultation. In summary, the Judge decided the consultation was not unfair and therefore was lawful. The merits of the final choice are, of course, solely a matter for decision maker - subject only to *Wednesbury* irrationality challenges.

However there are cases where a Judge has picked through the minutiae of a consultation exercise to find unfairness at what, from the outside, appeared to be a minor aspect and then strike down the consultation. That occurred in *R (Save Our Surgery Ltd) v Joint Committee of Primary Care Trusts* [2013] EWHC 439 (Admin) which was one of the endless round of cases involving challenges to the NHS's attempt to reduce the number of hospitals undertaking paediatric heart operations. There was consensus that the number should be reduced but every centre advanced compelling reasons why their centre should not be the one to close.

In marked contrast in *R (Buckingham) v NHS Corby Clinical Commissioning Group* [2018] EWHC 2080 (Admin) the Court was concerned with a CCG who had repeatedly promised to consult local people before changes were made to an Urgent Care Centre but then took the decision to make fundamental changes to the structure of care at the centre without consultation – mainly because NHS England advised them, in effect, to just get on with it.

This was primarily a case about breach of a legitimate expectation created by the promises of the CCG that they would be public consultation. The Claimant succeeded on that ground. However, the Claimant also succeeded in showing a breach of section 14Z2. The CCG relied on 2 factors, namely a workshop in December 2017 that was supposed to formulate proposals for public consultation and the final Governing Body meeting on 30 January 2018 which took the decision to press ahead with the changes without public consultation. The key passage from the Judgment is as follows:

> *"[for compliance with the statutory duty] there must be involvement in the consideration of the proposal. Ms Morris relied on the December 2017 workshop and the 30 January 2018 meeting. In my judgment the former did not involve consideration of the proposal. The stated purpose of the workshop was to develop proposals on which to consult. As for the meeting, this was a meeting in public rather than a public meeting. The limited opportunity to put questions (rather to provide information or to give views) and the absence of any opportunity to respond to the response did not, in my judgment, amount to the involvement contemplated by the subsection. It follows from that conclusion that CCG were in breach of its duty thereunder"*

Thus the decision to make changes to the Urgent Care Centre without public consultation was quashed. As a footnote, it is worth noting that the CCG subsequently abandoned its proposals to make changes to the Urgent Care Centre - presumably because it could not face the prospect of attempting to explain the justification for those proposals in a public consultation exercise.

That was reminiscent of a senior NHS manager who I advised should consult the public about the closure of an NHS facility. He said – trenchantly – "*why should I ask the public how I should do my job*". That attitude remains entrenched in much of the NHS – despite clear statutory obligations to the contrary. The 3 plain answers are:

1. The law says you have to.

2. The public are your customers and good businesses don't make changes without knowing what their customers think.

3. The public are your paymasters. If they didn't vote for politicians who decided that taxes should be used for the NHS, and they didn't pay their taxes to fund your job, you would be out selling the big issue.

So drawing the threads together – what can be said about public engagement in changes to NHS services. It seems to me that the following points emerge from the statutory scheme and the cases:

1. The duty to involve the public is a key part of the statutory apparatus of the NHS. The NHS decision making process is a 3 legged stool line with commissioners, providers and the public all having a say. A 2 legged stool will, of course, fall over.

2. There is a simple, practical reason why public engagement is essential; namely trying to deliver high quality public services in the face of public opposition is virtually impossible. The public have, to a greater or lesser extent, have to "buy in" to – or at least not actively oppose - changes to their health services.

3. Public input is essential to prevent NHS decision making being "supplier dominated"; with the organisation of NHS services being arranged for the convenience of those delivering the service regardless of its impact on those who receive it.

4. There are few if any exemptions from the duty to involve the public in NHS commissioning decision-making, but an ex-post factor challenge to a failure to

involve the public can leave objectors with a pyrrhic victory – A declaration and costs but with no effective remedy.

5. Those who object to the fairness of largescale NHS consultation exercise almost always loose; but not always as was seen with the paediatric heart transplant cases.

6. Those who challenge the processes successfully often prevent a "re-run" of the decision-making processes because of weariness on the part of NHS officials. Having lost once the horses are rarely sent around the same track.

However there is no answer to the "Brexit" problem in the NHS. There is no real solution to the problem where the public demand that those in charge of the NHS should not make change or should deliver services which are impossible, in practice, to deliver or where popular services cannot continue be to be delivered without prejudicing funding for unpopular services. In such cases the only option is for NHS managers and doctors to face down the public honestly and to tell them that they cannot work miracles – that demanding the undeliverable does not make that delivery possible. There are times when both politicians and the public need to be told – in simple language – what is possible and what is not possible. They also need to be told about the trade-offs between the benefits of local access and the benefits of better outcomes for specialised services. In the end public officials have a duty to deliver the best NHS that the resources provided by parliament can deliver. That means having the courage to do the right thing, based on the hard "head" evidence even if the public's "heart" is objecting strongly.