

Ten Great Myths

of

Patient & Public Involvement

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(The views expressed in this article are personal and should not be read as the opinion of Torbay Primary Care Trust)

The term patient and public involvement is confusing and difficult to grasp. The words can be somewhat unhelpful. It is difficult to measure. The one to one relationship between clinician and patient or carer is patient and public involvement. The mass town meeting of interested people, on a health service issue is patient and public involvement. Everything in between is patient and public involvement.

What it essentially is about - I contend – **is relationships**. It is the relationship in the one to one consultation and it is the relationship between an NHS organisation and patients and public in the town meeting.

William Bridges in his book “Managing Transition” describes the management of change and talks about the “neutral zone” He argues there are three distinct aspects of coping with and living through change. **Stage one** is letting go of the old - **Stage three** is accepting the challenge of the new. **Stage two** he calls the neutral zone and I suggest we in the NHS are in the neutral zone as far as patient and public involvement is concerned. Bridges neatly uses a metaphor to describe the neutral zone. He talks about being a trapeze artist and swinging through the air, in readiness to fly to the oncoming trapeze. There is a split second when we are in what he describes as the neutral zone. It is that moment when you have let go of the old – in the hope that you will meet and grab the oncoming trapeze. When you grab the new trapeze you have moved out of the neutral zone and have accepted the challenge of the new.

When in the neutral zone, as an organisation, it can of course be for many weeks, months – even years and Bridges argues this “transition” needs to be positively managed. It is in this neutral zone that people – if not shown effective leadership – will decide their own future – they will look for opportunities for their own new trapeze and you will lose good folks. Managing this transition is crucial as emotions will be running high and behaviour may not be predictable.

My experience in the NHS tells me that in this neutral zone, one of the defences created “by the nervous” is to create and develop myths. As far as patient and public involvement is concerned I am focusing this talk on what I call **“Ten Great Myths of Patient & Public Involvement”**

This article is based on personal experience, extensive reading and research **but most importantly discussions over many years with patients and their carers.**

This list of myths is not in order of priority

Myth Number One: “They don’t understand”

It never ceases to amaze me that this is said. There are over 60 million people living in the UK. One million of them work in the NHS. A massive workforce but almost arrogant to assume the knowledge of 1 million people exceeds the knowledge of the other 59 million. People know about their body, and therefore their health. I was impressed greatly by Alison Ryan, Chief Executive of the Princess Royal Trust for Carers. Her husband suffered from an illness that required regular injections which she performed. The Nursing profession “establishment” was up in arms about an amateur doing this. Over time she became accepted and now teaches nurses in training how to inject patients with this condition - never underestimate the value of carers.

One of my own mission statements is **“The best way to gain power is to let go of power”** – a total paradox but very real – anyone who has children will understand this

phenomenon. Anyone employing staff will also understand it – get people to do your job
- they usually do it better

Myth Number Two: “Patients are not representative”

Absolutely correct and why should they be?

Patients and carers generally do not profess to be, or ask to be representative. Health is an individual matter – ‘twas ever thus. We should not expect any patient to be representative. Patients and carers have enough to do without the NHS asking them to do more. It is our responsibility to find representative views – if that is possible and that - in itself - is a subject for another day. When I speak to patients and carers they do not see themselves as representing much more than their own view – which to me is all we should expect. Anything more than that is a bonus for the NHS. It is up to the NHS whether we interpret that as a representative view. Mike Farrar a well-known civil servant, in describing individuality of General Practitioners, said “There are some 35000 GP’s in this country and if you’ve seen oneyou’ve seen one” – my contention is **why should we expect patients and carers to be any different.**

Myth Number Three: “Hard to reach groups”

Some groups of the population are described as this. What do we actually mean? One such classic alleged group is young men and another alleged group is middle-aged men who think they are healthy. In Torbay we have decided to go to where those people go. On 15 March Torquay United are playing Scunthorpe United in a Division Three football match. There will be approaching 3000 people at the match – mainly men. We have decided to hold a healthy lifestyle event with the wonderful support of the Football club and we will take the opportunity to invite people to have a “health MOT” and engage in healthy lifestyle discussions with those who are motivated to want to know.

So this is not a “difficult to reach group” – they are easy to reach – the NHS seems to find it difficult to reach them – so the mission statement here is **“GO TO WHERE PEOPLE GO”**

Myth Number Four: “Patients talk about wants we know what they need”

My view – formed over years of listening to patients is yes, they do talk about what they want. Is it unreasonable if you are the parent of a dying child that you want to clutch at every straw – every hope – however challenging that may be to you or the service? Yes, patients talk about their wants. They do not want their child to die.

On the other hand my experience has always been that when patients are told honestly the options open to them – they accept limitations on the service – but only once they have been told the truth.

We have to think very carefully about the word “needs” – for instance - in whose interests are we really acting when we talk about needs?

Myth Number Five: “Demands will mean we can’t cope”

There is a famous story about the birth of the NHS in 1948 when one health centre barricaded the doors and windows fearing they would be overrun by patients stampeding to the new “free NHS”

What happened on day one was that mums turned up in ones and twos for baby milk and the odd cold and cough nervously crossed the threshold – more out of curiosity than anything else.

I am not pretending the NHS has loads of capacity. I am just contending that patients are adult, sensible people who act rationally and reasonably most of the time.

If we can just learn to be a bit brave we may well be surprised. I well remember when a residential unit for people with learning disability decided to allow every family to have a guaranteed minimum of three weeks respite care per year. This was more than had

been offered in the past and equalized some inconsistency because some families got more than others did with no clear reasoning. What actually happened was that families did not take up their three weeks - but they knew it was there in case they needed it.

Myth Number Six: "The New Way is best"

The health service has existed since 1948. Over fifty years old and many dedicated staff delivering the service with all its warts and wrinkles. To assume that only new ways can work is naïve in the extreme.

Let me be clear though. That is not to say lets not change. I am a great believer in the new approaches to patient & public involvement and generally – I have learned to welcome change – even look for it and create it. I am nevertheless an advocate and fan of the NHS – a proud lifelong NHS worker with many friends and colleagues in whom I have great belief and faith. Some people's dedication to patients in particular, and the NHS in general, has sometimes moved me. To throw away experience as if it is irrelevant, is very unwise at best and we do it at our peril. I was very attracted to a recent quote from one of my management gurus. He said he was fed up with reading annual reports that said in many different ways "Our staff are our greatest asset..... His response **"NO, NO, NO, staff are our only asset!"**

Myth Number Seven: "It will all cost too much"

Doing things differently is one way to look at this – if we always do what we always did we will always get what we always got. I like Harry Cayton's story about dead flowers in a vase on a bedside cupboard in the hospital. It was said that we just don't have the staff to do everything. Taking out dead flowers..... not a big job..... lack of money and staff cannot be accepted as a reason for saying dead flowers cannot be removed.

I went to a GP and said I was very interested in this new way of getting a cholesterol test. He pricked my finger, placed the blood sample in a machine and within two minutes I had my result – happily it was ok. He explained that to do the same thing in his neighbouring practice would have involved an appointment with the practice nurse,

sending the blood to the local hospital waiting two days for the result and the patient ringing to get the result three days after having the test. I am not saying it is affordable to have this type of service in every practice. I am not suggesting this particular test is urgent enough to justify a Rolls Royce service. I am simply arguing that lack of money is always a good reason not to do things. Maybe the service needs to be braver – always remembering this is public money.

Myth Number Eight: “Staff don’t have time to do all this as well”

It is my contention that staff do not need to find time to “do” patient and public involvement – they already do it all the time. All we need to do is to make sure that the NHS culture is about partnership with patients not a master servant control command relationship. Everyone has something to bring to the party – patients, staff and carers. The relationship needs to be on an equal basis. The seven-hour shift of the typical nurse is all about patient and public involvement – and if it is not – then it should be. Let patients and front line staff make the rules and make managers responsible for making the job easier for front line staff and therefore a better experience for the patient – not rocket science but seemingly not palatable to some people.

Myth Number Nine: “All this stuff cannot be measured”

Why oh why do we have to measure everything? Of course as a gnarled twisted old NHS manager, I know the answer to my rhetorical question. It is simply untrue that we cannot measure patient and public involvement. There are creative people around who can help us measure anything. Patient and Public involvement is just another challenge. If we can measure teachers and the teaching experience for children, if we can measure policemen's productivity and crime, I simply cannot accept it is not possible to measure patient and public involvement. There will be work going on currently fathoming out how we can measure the most complicated processes in the world of business – we just need to be creative. This needs to be done by more skilled, experienced, creative and innovative people than managers like me perhaps we need to ask those people we often call them patients and carers.

Myth Number Ten: "Patients and the Public are not really interested in all this anyway"

The Audit Commission January 2003 report entitled "**Connecting with Users and Citizens**" offers an interesting insight to this.

I quote from Page 4 of the report

***"Ordinary folk don't want to be involved. That is a fact of life
Our own consultation with service providers highlights the difference in approach between those who feel that they are achieving a good standard of public involvement, and those who don't. For those who don't, a major stumbling block is the sense that the public are not really interested in taking part in consultation."***

I rest my case – if it good enough for the Audit Commission through valued research it is good enough for me.

Conclusions

The NHS is changing month by month– sometimes it seems like day to day. We should celebrate this change – not create and perpetuate myths. We all have that responsibility. Your position enables you to influence your own organisation. Please take that opportunity. Why can't all Board Reports have a heading "**How have patients and carers been involved in this proposal?**"

I have always wanted to be brave enough to suggest a payment reward system for all NHS managers, based on how many patients' problems they can prove they have actually resolved in the preceding month.

Board members – particularly Non-Executive Directors - should challenge managers to justify how decisions are made without patients being involved in the decision making process.

Finally I would commend to you Harry Cayton's three messages about Patient & Public Involvement?

Trust me I'm a patient - I use the services you provide. I have views on how you could make them better for me and people in my community. I understand my illness better than you do – I am the one suffering from it. I have views to offer about the way I am treated. Trust me, listen to me, trust my expertise – we can both benefit from this relationship.

Tell me the truth – I know that the NHS has a strong political influence. I know that there are uncertainties in medical practice. But I have a right to be given the opportunity to understand what these are, to make choices about my care, to be involved in the service I pay for. Share the truth with me.

Nothing about us without us – You decide on our behalf the services you think we want, and how you think we want them. Ask us; involve us in your decisions. Bring us inside for the benefit of all.

Please give me feedback on this article

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