Why patients need to understand the NHS

  Laura Fulcher -30 October 2017

It is high time the NHS leadership promote a new vision with enhanced patient involvement that will empower the users of the service.

At the *All Party Parliamentary Group for Cancer’s* call for evidence last week, the panel of NHS bosses offered a plethora of excuses, suggesting a report was the answer to all recruitment issues and seemingly deaf to complaints that the five-year cancer strategy is stuck in turgid mud.

Meanwhile, Steve Brine, the minister for cancer, offered a more passionate vision of health services, albeit with an ardency that was sometimes misplaced. He stated *that patients needn’t understand cancer strategy in much the same way that he need not understand the inner workings of a car*. We should leave things *in the capable hands of the experts sitting around that table!!*

My tongue is still sore from where necessity made me bite it.

Window dressing

None of us would drive an old banger, down two tyres and with no brakes. So why would patients have blind faith in a health system faltering behind other countries in cancer survival rates?

My own naïve trust in the NHS led to a 15 month wait for a cancer diagnosis. I’ve learnt through terrible experience that patients need to champion themselves. They cannot do this without the knowledge of the NHS.

But Brine is far from unique in his opinions. The view that patients should stay well clear of strategy is played out in the window dressing of “patient involvement” across the country. Patient voice is just not taken seriously.

The Cancer Alliances, set forth glowingly as potential bastions of active patient involvement are now two years old, but have barely crawled.

Their online profiles provide little indication of how a patient might get involved and I encountered radio silence when contacting my own Alliance in the West Midlands.

Many of the patient involvement meetings that do occur are held to empty rooms during working hours, and rest on death inducing PowerPoint presentations, offering scant chance to answer questions and boring with irrelevant historical context, or jargon filled detail.

There’s little time for the public to say anything, so fixated on the tangential slides are the presenters. Learning is better promoted through discussion, not through the Victorian pedagogy of oppression, with the teacher at the front, students doodling crude symbols on their workbooks.

You leave these meetings dazed and wonder at the waste of a few hours, learning little of the system.

Distancing patients from strategy has more disastrous effects beyond the detriment to self- empowerment. Ill-informed patients make bad consumers, attending accident and emergency rather than calling nurse specialists; or badgering GPs for antibiotics.

Reinforcing individual agency, rather than state responsibility, will result in savings.

And think of the improvements. Who better to passionately campaign for improved services? Patients are the best of ambassadors, with the ability to cut through NHS England obfuscation, the bureaucratic stance that seemed so palpable at the meeting last week.

Evasive NHSE

NHSE has long been demonised as the faceless entity that Clinical Commissioning Groups and Trusts seem unable to confront. At the call for evidence, we heard CCGs tell of the millions of pounds ring fenced for cancer services that NHSE had not passed to the front line.

It seems engagement must always be on NHSE’s terms, with no mechanism to instigate communication. Try calling them, and you’re told to read their website.

Yet, when I asked as a CCG lay member why we couldn’t be more assertive with NHSE, they looked at me like I’d been pilfering drugs. NHSE, the commissioners of commissioners, were apparently a law unto themselves, preaching the need for CCGs to engage others, while themselves evading equal partnerships.

I’m still waiting for a response to the Freedom of Information request of two years ago, chased many times, requesting information on the decommissioning of second stem cell transplants for leukaemia patients.

Last year, the NHS Ombudsman instructed them to apologise for my treatment. I’ve received no acknowledgement, let alone contrition.

What of leadership? What of setting a good example?

Knowledge is Power

Knowledgeable patients are already proving they can play a pivotal role. Take the great work of Independent Cancer Patients’ Voice empowering patient involvement within research; or the movement that is “Use MY data”, harnessing the patient voice to build confidence in the use of data for improvements.

The NHS has a duty to share, educate, and involve, and to eradicate jargon, seemingly set to befuddle and distract from the key issues

Myself, I founded Mission Remission, a place for cancer survivors to share practical strategies for moving forward.

Many patients have given up working within the evasive beast that is the NHS, so isn’t it time for leaders to promote a new vision? One, not of slogans, but that will form the basis of a genuine equal relationship – and that applies to all patients, including those with less high- profile conditions who might otherwise languish in the shadows.

The health service should be embracing technology as a means to do this, not hide behind a smokescreen of confidentiality concerns.

The King’s Fund does much to champion patient voice. Perhaps it is time they look towards their lead?

*[Laura Fulcher is the founder of Mission Remission - a platform dedicated to life after cancer and a place for survivors to share experiences and practical strategies that help.]*

[*https://www.mission-remission.com*](https://www.mission-remission.com)