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What price patient voice?

Is patient feedback worth having? The Dept of Health and NHS Trusts seem to think so, given their investment in Patient Advice and Liaison Services, the Friends and Family Test, local Healthwatch and so on.

But what actually is the value of patient feedback? How do we know exactly what it is worth? There is little evidence of Clinical Commissioning Groups and NHS Trusts carrying out cost benefit analysis of their spending on patient feedback mechanisms. Neither do local authorities, who procure local Healthwatch services, seem to have any kind of benchmark for the value of those services.

This is problematic, because if we do not understand the value of patient feedback, we cannot know whether the NHS should be investing more in it, or writing it off as a waste of money. Tellingly, Lord Carter's recent review¹ of productivity and financial efficiency within the NHS had nothing whatsoever to say about dialogue with patients.

Patient feedback – a soft option?

The problem is compounded by the fact that, without a clear understanding of the value of patient feedback, it is easy to dismiss it. Patient experience leads are used to hearing the qualitative evidence they collect from service users described as “anecdotal”. Their “soft” evidence can be seen as carrying less weight than the “hard” or “robust” evidence found in statistical measures and key performance indicators.

This is a mistake. The Marie Curie organisation has published evidence² that the cost to the NHS of poor communication with patients is in excess of £1 billion. Costs include litigation, non-adherence to drug

programmes, and unnecessary treatment. This, by the way, is an annual cost. Every year, a huge amount of money goes down the drain because patients are not being talked to in the right way, or listened to carefully enough.

Patient stories may well be “anecdotal”. But if it is ignored, this “soft” feedback translates into some pretty hard numbers.

Scaling up

The Marie Curie report is a valuable piece of work, concentrating on communication between health professionals and individual patients. The costs that it itemises are the costs that arise from individual complaints, individual failures to adhere to drug programmes, and so on.

But there is another area of patient communications, which also results in significant cost when things go wrong. That is the area of communications with whole groups of patients and service users.

The obvious case in point is the Mid Staffordshire scandal, where there was a widespread failure within the management and staff of the NHS Trust to hear from hundreds of patients and their relatives, and to detect patterns of poor practice over a period of years. The ensuing Francis Inquiry was unequivocal about the reason for what it described as “appalling suffering” and unnecessary death: “[it] was primarily caused by a serious failure on the part of a provider Trust Board. It did not listen sufficiently to its patients.”³

When patient feedback – as a whole – goes unheard, the financial consequences pile up rapidly. The Francis Inquiry alone cost

over £13 million.⁴ But that was just the start. Putting the Mid Staffordshire Trust into special measures cost another £19 million.⁵ And the task of dissolving the Trust and transferring the services elsewhere is reckoned to have cost over £300 million.⁶

Mid Staffordshire may be the best known example of colossal costs arising from failures to act on patient feedback. But it is by no means the only one. At the Morecambe Bay NHS Trust, an inquiry into unnecessary deaths in the maternity unit stated that “*The treatment of complainants ... exemplified the problems commonly reported, including defensive ‘closed’ responses, delayed replies, and provision of information that complainants did not find to be accurate.*”⁷

Yet another recent review⁸ – this time into unexpected deaths at the Southern Health NHS Foundation Trust – described “*an ad hoc and inadequate approach to involving families and carers in investigations*”.

These are repeated examples within the NHS of large scale organisational failure to value patient voice. The consequence is repeated investigations and inquiries at huge (and wasteful) cost.

The human cost

There is a greater value in listening carefully to patients and their relatives: the human value. People who feel heard, feel cared for. People who feel cared for get better faster.

Conversely, people who do not feel heard, feel dismissed, rejected and ignored. The cash cost of investigations like the Francis Inquiry is easily counted. But the “appalling

suffering” described by Francis relates to a human cost that can never be quantified. It is known only to those who have experienced it.

The father of a patient who died in the care of the Southern Health Trust said, “*I had a meeting with a trust member and the analogy he used was that they were a bit like British Airways and it was like losing baggage. I really couldn’t believe what the person was saying to me. It was harrowing.*”⁹

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Andrew McDonald, author of the Marie Curie report cited above, makes this point:

“It is surely telling that nobody has yet sought to put a price tag on the money wasted through poor communication and nobody has articulated the comprehensive spend-to-save case to justify a determined assault on the prize.”

He asks, “*Why has central funding for training programmes been dropped?*” And he states that “*those charged with delivering these critical changes would do well to have a clear line of sight to how fundamental cultural change is customarily delivered and embedded. In particular, we would urge clarity of leadership, engagement of stakeholders and the allocation of a dedicated budget. All of this must rest on a business case which articulates the resources currently being wasted and the benefits to be derived in savings, health outcomes and demonstrably improved patient experience of healthcare.*”

These are valid and pressing points. We would add these further questions:

- Why, just three years after being established as a strengthened “consumer champion” for the health and care sector, is the funding to Healthwatch (nationally and locally) being cut?
- Why does the NHS have no benchmark for understanding the value of patient feedback, and knowing how much it should be investing in patient experience leads?
- Why do staff in the Healthwatch network and in NHS PALS teams - uniquely among health sector professionals - lack access to a comprehensive body of knowledge that can guide their practice and professional development?

Good communication within the NHS does not rest solely on the relationship between clinician and patient. It also depends on Trust Boards and management understanding the combined experience of whole groups of service users. Good understanding is fundamental to good risk management, and to ensuring that organisational culture - just as much as individual behaviour - is attuned to good care and good clinical outcomes.

NHS Trusts and Clinical Commissioning Groups have, at best, a rudimentary understanding of how much they invest in patient voice, and why. They need to get much better at it - preferably before the next large-scale failure comes to light.

Appendix:

About the Patient Experience Library

The Francis Inquiry said that intelligence on patient experience should be shared. But until now, no-one has found a way to do it. Thousands of patient experience reports are published every year - by charities, think tanks, government bodies and Healthwatch. But they are scattered across hundreds of different websites. It has been impossible to get access to all the knowledge in one go.

Aware of this problem, we set to work to see if we could crack it. It took us a year to work out how to get all the publications into one place - and then how to catalogue and

index them so as to make them instantly accessible via a powerful search tool.

The Patient Experience Library was launched in December 2015. It has, for the first time ever, put the whole of the UK literature on patient experience in one place. A glimpse of the volume and nature of content stored in the library can be seen in our 2015 Digest.

The Patient Experience Library receives no funding from government or charitable sources and does not accept advertising.

www.patientlibrary.net

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| 1 | Operational productivity and performance in English NHS acute hospitals: Unwarranted variations. An independent report for the Department of Health by Lord Carter of Coles, February 2016. | 7 | The Report of the Morecambe Bay Investigation. An independent investigation into the management, delivery and outcomes of care provided by the maternity and neonatal services at the University Hospitals of Morecambe Bay NHS Foundation Trust from January 2004 to June 2013. Dr Bill Kirkup CBE, Morecambe Bay Investigation, March 2015 |
| 2 | A long and winding road: Improving communication with patients in the NHS. Marie Curie, February 2016. | 8 | Independent review of deaths of people with a Learning Disability or Mental Health problem in contact with Southern Health NHS Foundation Trust April 2011 to March 2015. Mazars LLP, December 2015 |
| 3 | Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry House of Commons, 2013. | 9 | Father's comment on Southern Health Trust communications: http://www.bbc.co.uk/news/uk-england-hampshire-35066079 |
| 4 | Inquiry costs - £13,684,100: http://www.midstaffpublicinquiry.com/inquiry-costs | | |
| 5 | Special measures costs - £19.5 million: https://www.gov.uk/government/news/final-cost-of-trust-special-administration-at-mid-staffordshire-nhs-foundation-trust | | |
| 6 | Dissolution of Trust and transfer of services costs - "well over £300m": https://en.wikipedia.org/wiki/Mid_Staffordshire_NHS_Foundation_Trust | | |