The Patient Experience Library

Flying Blind? PALS Teams and Performance Measurement

A response to *Operational productivity and performance in English NHS acute hospitals: Unwarranted variations*

An independent report for the Department of Health by Lord Carter of Coles

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Summary: Main points

Lord Carter's "Unwarranted Variations" report is a rigorous and compelling study. But we were surprised to find no reference within the report to the role of PALS teams and patient experience leads.

If patients go unheard, it can lead to the worst possible performance failure: unnecessary suffering and even death. That, in itself, is bad enough. But it can also cost trusts a great deal of money.

Lord Carter makes the point: "*We know that the link between staff engagement and quality outcomes is well understood and evidenced across high performing organisations*".

He could equally have made the point that the link between patient engagement and quality outcomes is well understood. The Institute for Public Policy Research says "*Patients who are engaged in their healthcare are more likely to say that it is of high quality, and are less likely to report experience of medical errors*".

One of the key causes of the failures at the Stafford Hospital was, ironically, the pursuit of performance targets. With a relentless focus on performance indicators, the Board and management took their eye off the patients. Statistics carried more weight than real people's voices.

Lord Carter makes his own point about the unreliability of statistics: "*hospitals and commissioners were often looking at different datasets and from different perspectives with inevitable disagreements.*"

In the NHS, statistics are often described as "hard" evidence, and patient stories as "soft" or "anecdotal" evidence. PALS teams can easily be marginalised.

PALS teams, like clinical teams, should never act in isolation. To ensure good performance, they need access to national datasets, where professional knowledge is developed and shared.

There is a significant body of qualitative evidence on patient experience. But PALS teams have little or no access to it. Studies and guidance are scattered across hundreds of different websites, all designed and structured differently. For years, it has been almost impossible to get a simple overview of the UK's collective intelligence on patient experience.

To the clinician, the idea of having to practise without access to a full body of professional knowledge would seem inconceivable. To patient experience leads, it appears to be normal.

Patient experience leads within acute hospitals are, at least to some extent, flying blind. This is quite a risk for the Boards and management of NHS trusts to be taking.

Our offer to the Department of Health, NHS England and NHS Trusts, is to look at how PALS teams can get easy and affordable access to the whole of the UK literature on patient experience, and how this might help to mitigate risks in a key area of acute hospital performance.

Introduction
A missed opportunity

Lord Carter's "Unwarranted Variations" report is a rigorous and compelling study. His findings are revealing, and he makes a series of useful recommendations. But the report misses an important opportunity that could contribute both to improved performance and to better value for money.

We were surprised to find no reference within the report to the role of PALS teams and patient experience leads.

The Francis Inquiry showed that feedback from patients is a vital corrective to statistical reports, which can be misleading. If patients go unheard, it can lead to the worst possible performance failure: unnecessary suffering and even death. That, in itself, is bad enough. But it can also cost trusts a great deal of money.

The report of the Francis Inquiry was very clear about the source of the catastrophe at the Stafford Hospital. It "*was primarily caused by a serious failure on the part of a provider Trust Board. It did not listen sufficiently to its patients.*"[1]

The Inquiry produced excellent work. But it is worth reflecting that the £13 million cost of the Inquiry, and the further (far greater) costs[ii] of the ensuing management reforms at the Mid Staffordshire Trust, could have been avoided altogether, had performance of the patient experience and PALS function at the hospital been much stronger in the first place.

Good management of patient feedback is not an optional extra within acute hospitals. It is fundamental to performance standards across the board, and to good use of money.

This response to Lord Carter's review considers the role of PALS teams within acute hospitals, and the opportunity to bolster their ability to provide much needed insights.

Why patient feedback matters

A series of high profile cases in recent years have amply demonstrated the risks of failing to listen to patients. The case of the Mid Staffordshire NHS Trust was just one. More recently, the review of unexpected deaths at the Southern Health NHS Foundation Trust paints[iii] a sadly similar picture. In that case, the people affected were patients with learning disabilities or mental health problems. These are the people who may find it particularly hard to voice their concerns or distress.

Most of the time, a failure to listen to patients or their relatives does not result in death. But it does result in poor quality of care. The Francis Inquiry reported the following[iv]:

- Patients were left in excrement in soiled bed clothes for lengthy periods
- Assistance was not provided with feeding for patients who could not eat without help
- Water was left out of reach
- Wards and toilet facilities were left in a filthy condition
- Privacy and dignity, even in death, were denied
- Staff treated patients and those close to them with what appeared to be callous indifference.

Nobody needs tables of statistics to recognise these as features of desperately poor performance.

In "Unwarranted Variations", Lord Carter makes the point: "*We know that the link between staff engagement and quality outcomes is well understood and evidenced across high performing organisations.*"[v]

He could equally have made the point that the link between patient engagement and quality outcomes is well understood. The Institute for Public Policy Research, for example, has observed that "*Patients who are engaged in their healthcare are more likely to say that it is of high quality, and are less likely to report experience of medical errors*".[vi]

Macmillan Cancer Support has joined the dots between Lord Carter's and the IPPR's comments. They say "*Macmillan's research...shows that the treatment of hospital staff is linked to patient experience. Happy staff mean happy patients.*"[vii]

The learning from all of this is clear. When patients go unheard, the result can be the worst performance failure of all – an unnecessary death. Lesser failures can cause misery for patients and relatives alike. And patients who are not looked after well in acute hospitals can present significant costs to the NHS. Costs can be incurred through unnecessary repeat admissions, individual legal challenges, and – more often than might be imagined – the need to run official inquiries and then undertake extensive local reforms.

Why PALS teams matter

Acute hospitals have various ways of hearing from patients. Feedback can come through questionnaires, patient representatives, the friends and family test, formal complaints and so on.

Feedback is received and acted on by patient experience leads, who may be located in Patient Advice and Liaison Services, customer care teams, communication teams etc. In this paper, we will use the term "PALS" to cover all of these.

Patient voice matters, for all the reasons set out in the section above. And as a conduit for patient voice, PALS teams really matter. Their qualitative evidence can be a much needed corrective to the kinds of statistical analysis on which performance indicators are usually based. Again, the Francis Inquiry is a useful starting point for explaining why.

One of the key causes of the failures at the Stafford Hospital was, ironically, the pursuit of performance targets. The Board and management of the trust "*chose to rely on apparently favourable performance reports by outside bodies, such as the Healthcare Commission, rather than effective internal assessment and feedback from staff and patients*".[viii] With a relentless focus on performance indicators, they took their eye off the patients. Statistics carried more weight than real people's voices.

Lord Carter makes his own point about the unreliability of statistics, and how they are read. He found that "*hospitals and commissioners were often looking at different datasets and from different perspectives with inevitable disagreements.*"[ix]

Further evidence of the need to treat statistics with caution comes in a recent study from Dr Foster. The authors state that: "*Hopes of improving healthcare through better measurement and the use of information in healthcare management are being undermined by weaknesses in the generation and use of data and metrics.*"[x] They list various ways in which performance measurement can be undermined, including bullying of staff, "gaming" waiting time and mortality data, distorting patient pathways to meet treatment targets, and arguing about data quality in order to divert attention from poor care.

In the medical culture of the NHS, where science is king, it is common to hear statistics described as "hard" evidence, and patient stories as "soft" or "anecdotal" evidence. PALS teams can easily be marginalised. But anyone with an interest in rigorous risk and performance management should remember: statistics never tell the whole story.

Flying Blind?

PALS teams are under pressure. The point is well made in a report that describes patient experience teams as small, and having limited resources. The authors observed PALS teams facing challenges including gathering an ever-increasing amount of data; bringing data into one place; and having the time to make sense of it. A telling comment is that "*Staff are so busy gathering data and compiling reports, that less time is available to do something with the data – efforts to improve services are in danger of being squeezed out*".[xi]

The situation, as described, presents significant risk to acute hospitals. We have seen, in the previous section, that statistical performance indicators cannot always be relied upon. Qualitative evidence is a vital corrective, and trusts ignore it at their peril. If PALS teams are unable to use patient feedback to help improve services, trusts are not managing their risks well.

As well as hearing from patients in their own hospitals, PALS teams also need access to wider sources of evidence. Like clinical teams, they should never act in isolation. To ensure good performance, they need access to national datasets, where professional knowledge is developed and shared.

Some statistical datasets are readily available – for example the Care Quality Commission's annual patient surveys (inpatients, outpatients, A&E, maternity and cancer). There is also a significant body of qualitative evidence on patient experience. However, this is knowledge to which PALS teams have little or no access.

Every year, health charities, think tanks, government bodies and the whole Healthwatch network produce thousands of reports on patient experience. These reports contain the kinds of insights and case studies that can inject deeper meaning into statistical analysis. But the reports are scattered across hundreds of different websites, all designed and structured differently. Healthwatch alone has around 150 separate websites. For years, it has been almost impossible to get a simple overview of the UK's collective intelligence on patient experience.

Without easy access to the UK literature (as opposed to statistics) on patient experience, PALS teams will struggle to compare and contextualise their own learning alongside that of patient voice champions outside the NHS, and around the country.

Sir Robert Francis recognised this problem in the course of his Inquiry. One of his recommendations was that *"Results and analysis of patient feedback including qualitative information need to be made available to all stakeholders."*[xii] But within the last year, Nesta, the innovation charity, has reported that "*efforts [to gather collective evidence on patient experience] are hampered by a lack of suitable tools and platforms. Tools that currently exist to aid the collection and exchange of different sources of clinical and experiential information are often laborious to use, and severely limited.*"[xiii]

Nesta's observation is borne out by our own enquiries. During 2015, in the course of developing the Patient Experience Library, we asked patient experience leads in a range of organisations how they track down the qualitative knowledge and evidence they need. They told us that:

- On-line "knowledge banks", resource databases and publications listings are inadequate for people looking for patient experience reports. Even the best stocked contain only a couple of hundred publications, as against the thousands that are actually published every year.

- Existing on-line "libraries" have poor quality search functions that are clunky to use, and which all too often return a "No results found" message. An extremely well known internet search engine was problematic because it linked through to websites which (especially in the case of public bodies) could easily go out of date. Hitting a "Page Not Found" message was a common frustration.

- Existing resource databases are a one-way street. The people operating each database decide what is uploaded to it. Users simply get what they are given.

All of this is additionally confirmed by Lord Carter's point that "*We were struck by the immaturity of trusts' use of ... technology.*"[xiv] His recommendation was that "*NHS Improvement needs to incentivise trusts to fully utilise their existing digital systems, and where necessary, enable them to access some of the Spending Review commitment to invest in digital technologies.*"[xv]

It is hard to imagine a clinician within an acute hospital having to resort to Google to try to track down information resources that would support professional development, and ensure an evidence-based approach. To the clinician, the very idea of having to practise without access to a full body of professional knowledge would seem inconceivable. To patient experience leads, it appears to be normal.

Conclusion

The Carter Review focuses on operational performance and financial efficiency. But Lord Carter himself states that "*All trusts should ...grasp the use of their resources more effectively, the most important of which is their people.*"[xvi]

Our response is that failure to listen adequately to that most important resource (and for us, "people" means patients as well as staff) can result in the worst performance failure of all: unnecessary suffering and even death. As well as causing misery, failings of those kinds can be extremely costly.

In the preceding sections, we have shown that

- The Francis Inquiry recommended that "*Results and analysis of patient feedback including qualitative information need to be made available to all stakeholders*"
- PALS teams are under too much pressure to be able act on their own data. And three years on from the Francis Inquiry, they still lack access to a comprehensive (qualitative as well as statistical) body of professional knowledge relevant to their discipline
- Nesta has said that "*Tools ... to aid the collection and exchange of different sources of ... experiential information are often laborious to use, and severely limited*"
- Lord Carter has been "*struck by the immaturity of trusts' use of ...technology*"

Patient experience leads within acute hospitals are, at least to some extent, flying blind. This is quite a risk for the Boards and management of NHS trusts to be taking.

Lord Carter has said that "*Until trusts ... create more open and respectful working environments we stand little chance of improving performance and productivity. In short, a mind-set shift from seeing people as the problem to seeing them as the solution is needed.*"[xvii]

We could not agree more. But "*Moving towards a patient-centred organisation design*"[xviii], as called for by Lord Carter, means that trust Boards and management must understand the patient experience. They cannot do this if their own PALS teams do not have full access to the collective intelligence on patient experience in the UK.

We spent the whole of 2015 working on a solution to this problem. On our own initiative, and without recourse to state funding, we found a way to put the entire output of the local Healthwatch network in one place, and to place alongside it the rest of the UK literature on patient experience from health charities, think tanks and others.

Our offer to the Department of Health, NHS England and NHS Trusts, is to look at how PALS teams can get easy and affordable access to this body of knowledge, and how this might contribute to improved performance in acute hospitals, with less risk of very large unforeseen costs.

Appendix

About the Patient Experience Library

The report of 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 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**.

References

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c) Dissolution of Trust and transfer of services costs – "well over £300m": https://en.wikipedia.org/wiki/Mid_Staffordshire_NHS_Foundation_Trust

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xii Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry House of Commons, 2013. Recommendation 255.

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xv Ibid.

xvi 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. Page 3.

xvii 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. Page 81.

xviii Ibid.

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