

# Patient Experience in England



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# Introduction

It is nearly ten years since the publication of the Darzi Review, *High Quality Care for All*. Chapter 4 of that review, “Quality at the heart of everything we do” said, “*If quality is to be at the heart of everything we do, it must be understood from the perspective of patients.*” It went on to list the three cornerstones of high quality care as patient safety, patient experience and effectiveness of care.

Since then, some high profile cases of avoidable suffering and death within NHS services have shown why Lord Darzi was right to identify patient experience as a vital component of quality of care.

The obvious one was Mid Staffordshire, where the subsequent Francis Inquiry was clear about the cause of the disaster: “*[it] was primarily caused by a serious failure on the part of a provider Trust Board. It did not listen sufficiently to its patients.*” Subsequent inquiries into patient deaths at the Morecambe Bay Trust and the Southern Health Trust also referred to poor communications with patients and relatives.

A great deal of time and money is now spent on efforts to understand patient experience. Hundreds of organisations produce thousands of reports every year. It can be hard for health professionals and the general public to make sense of it all. In this overview, we set out to answer three basic questions:

- How is patient experience evidence gathered and disseminated?
- What are we learning?
- Are we acting on the learning?

Our observations come from our unique focus on collating, cataloguing and analysing the nation’s collective intelligence on patient experience. Our evidence base comprises 40,000 documents from Healthwatch, national health charities, think tanks and government bodies such as NHS England and the Care Quality Commission.

This publication is part of our mission to bring patient experience into the light.

# 1. Making sense of the patient experience landscape

There is no shortage of evidence on patient experience. There are at least eighteen different mechanisms for patient feedback that are used throughout England’s health and care services. Making sense of them all can be difficult. Here, we offer an overview and analysis.

## 1.1 Sources of evidence

The table below shows sources of patient experience evidence in England, listed alphabetically.

**Table 1**

<p><b>Care Opinion</b></p> <p><b>Care Quality Commission patient surveys:</b></p> <ul style="list-style-type: none"> <li>• Accident and emergency</li> <li>• Adult inpatients</li> <li>• Children and young people - inpatient and day case</li> <li>• Community mental health services</li> <li>• Maternity services</li> <li>• Outpatients</li> </ul> <p><b>Care Quality Commission inspection reports (especially the “Caring” domain)</b></p> <p><b>Complaints and compliments through Patient Advice and Liaison Services</b></p> <p><b>Hootvox</b></p>	<p><b>LHM rate and review (used by many local Healthwatch)</b></p> <p><b>Local feedback gathered by NHS Trusts, GP practices, Clinical Commissioning Groups etc</b></p> <p><b>Local Healthwatch reports</b></p> <p><b>National feedback gathered by health charities and think tanks</b></p> <p><b>NHS Choices star ratings</b></p> <p><b>NHS England surveys:</b></p> <ul style="list-style-type: none"> <li>• GP practices</li> <li>• Cancer services</li> </ul> <p><b>NHS Friends and Family Test</b></p> <p><b>VOICES survey of bereaved people</b></p>
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*Note: Patient experience/patient engagement leads may also be looking at data from sources such as Patient Reported Outcome Measures (PROMs) and Patient-led Assessments of the Care Environment (PLACE). We have not included these because, while being patient-led, they focus on clinical outcomes (PROMs) and physical environments (PLACE) as opposed to being specifically about patient experience.*

## 1.2 Patient experience evidence – basic typology

The array of evidence sources listed above can be confusing. Here, we break them down into a series of basic types.

**Table 2**

Type	Description	Sources
1. Mainly quantitative	Mainly numerical data, presented in spreadsheet format, and capable of statistical analysis. Large sample sizes, with national overviews, broken down to local detail.	Care Quality Commission patient surveys for: <ul style="list-style-type: none"> <li>• Accident and emergency</li> <li>• Adult inpatients</li> <li>• Children and young people - inpatient and day case</li> <li>• Community mental health services</li> <li>• Maternity services</li> <li>• Outpatients</li> </ul> NHS England surveys for: <ul style="list-style-type: none"> <li>• GP practices</li> <li>• Cancer services</li> </ul> The NHS Friends and Family Test The VOICES survey of bereaved people
2. Mainly qualitative	Written reports based on patient stories and observations, often with recommendations for improvements to policy and practice.  Tend to feature small sample sizes, and local focus.	Local Healthwatch reports  Care Quality Commission inspection reports - especially the “Caring” domain.
3. Rate and review systems	“Trip Advisor” style star ratings and snapshot comments direct from service users, backed up with analytics including sentiment analysis.	Care Opinion Hootvox LHM rate and review NHS Choices star ratings
4. Other (local)	Feedback gathered by NHS Trusts, Clinical Commissioning Groups, GP practices etc.	Questionnaire surveys Focus groups Feedback slips and forms on wards Complaints and compliments through Patient Advice and Liaison Services Patient Participation Groups and patient engagement committees and forums Service user comments on social media (Twitter etc)
5. Other (national)	Feedback gathered by health charities, academic researchers and think tanks, for policy papers, discussion papers, etc	Questionnaire surveys, plus literature reviews, secondary research etc.

## 1.3 Quantity of evidence

It may be impossible to get an accurate measure of the scale of patient experience work that is being carried out across England. For example, NHS Trusts and Clinical Commissioning Groups run regular surveys, focus groups and engagement forums through which patients can give feedback. We are not aware of any way in which this is added up across the NHS to give a total sum of activities and participants.

In spite of this, it is possible to get an indication of the scale of patient experience work in two ways: by looking at the number of people contributing to national surveys and by looking at the number of published reports on patient experience.

### 1.3.1 The number of people contributing to national surveys

**Table 3**

Survey	No. of respondents
Friends and Family Test May 2017	1,215,268
GP Patient Survey 2017	808,332
Adult Inpatient Survey 2016	77,850
National Cancer Patient Experience 2016	72,788
National Survey of Bereaved People 2015	21,320
Maternity Services Survey 2015	20,631
Community Mental Health Survey 2016	13,254

In addition, Healthwatch England has stated that the local Healthwatch network spoke to 300,000 people during 2016/17<sup>1</sup>.

### 1.3.2 The number of published reports on patient experience

Again, we are not aware of any way in which this is added up nationally. However, we can report on the number of documents that have been added to the Patient Experience Library over the last year. The library is the most comprehensive national database of patient experience reports, so the figures below are a good indication of the scale of reporting.

Between January and December 2016, we uploaded 14,211 reports to the Patient Experience Library. Some had been published in previous years – the total published in 2016 was 12,394.

We include CQC inspection reports because the “Caring” domain can give insights into patient experience. However, these reports represent the assessments of inspection teams so are not, strictly speaking, patient experience reports. If we discount CQC inspection reports, we are left with 3,932 reports on patient experience and patient/public involvement published during 2016. Of these:

- 2,044 were from the local Healthwatch network and Healthwatch England
- 1,888 were from other sources

## 1.4 Quality of evidence

No feedback system is perfect, and it is likely that all those listed in 1.1 above have their respective strengths and weaknesses. In general, however, we can make the following observations:

### 1.4.1 Quantitative mechanisms (Table 2, Type 1)

These have generally robust methodologies, with consistency in how data is gathered, analysed and presented. However:

- It has been observed in respect of the GP survey that *“there is no standard requirement for practices to review that data or act upon them. As a result there are wide variations in the use of the data and the value that can be derived from them.”*<sup>2</sup>
- The national maternity services survey excludes pregnancies that result in maternal death, miscarriage, stillbirth or neonatal mortality so *“families are not further traumatised.”*<sup>3</sup> Some maternity education and campaigning organisations believe that this excludes important data and learning.
- The Friends and Family Test has been described by the Picker Institute as *“flawed as a performance measure and a comparative tool”* although it *“can be highly useful for improving services and fuelling discussion about patient experience.”*<sup>4</sup> Within GP practices, it has been found that *“...practices were not very engaged with the FFT and rarely did more than the minimum required contractually”*<sup>5</sup> and, further, that *“Overall the impact of the FFT on quality improvement was negligible.”*<sup>6</sup>

### 1.4.2 Qualitative mechanisms (Table 2, Type 2)

The local Healthwatch network is the biggest single contributor to the qualitative literature on patient experience. While much of its work is very good, the network has no nationally agreed standards for how its studies are conducted, and no nationally agreed process for quality assuring its published reports.



### **1.4.3 Rate and review systems (Table 2, Type 3)**

Most rate and review systems are “passive” - that is, they are reliant on patients finding and using the system. Patients can be prompted via promotional and outreach activities, but the targeting is not necessarily systematic. This presents a risk that data may be skewed towards more complimentary or more aggrieved patients, or towards those who are sufficiently assertive and IT aware to seek out the system.

We are aware of just one UK system (Hootvox) which works as an “active” system - that is, all patients (or selected groups of patients) of a service are systematically contacted at a set time after their use of the service. This has the potential to improve both the volume and quality of response.

### **1.4.4 Other (local) mechanisms (Table 2, Type 4)**

Local surveys, focus groups etc, may be run by people with varying levels of skill and experience. Methods may be robust or weak, and findings may or may not be quality assured.

### **1.4.5 Other (national) mechanisms (Table 2, Type 5)**

Studies that are run and published by national bodies are generally reliable in terms of method, and quality assurance of findings. However, readers would need to appraise the quality of studies on a case by case basis.



## 2. What we have learned in the last year

Much of the evidence-gathering on patient experience happens at the very local level. Trusts, CCGs and local Healthwatch produce reports that are specifically intended for local services, and local audiences. There are many thousands of these reports, presented in different formats, and based on different inquiry methods, so large scale synthesis or systematic review is very difficult. In this section, therefore, we concentrate on key findings from the larger national surveys, and take a look at selected highlights from other sources.

The headlines are shown below. Further summaries are in sections 2.1 and 2.2.

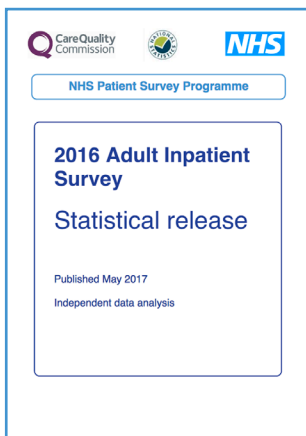
- **Adult Inpatient experience:** There are encouraging signs of improvement in some areas, and confidence and trust in clinical staff has gone up. But there are significant declines in key areas of person centred care.
- **British Social Attitudes:** There is a “yawning gap” between public satisfaction with NHS and social care services. Public satisfaction with the NHS overall is at 63%, while satisfaction with social care services is at 26%.
- **Cancer patient experience:** Experience of cancer patients in England is generally very positive, but at the national level, experience of care is inconsistent.
- **Community Mental Health Survey:** Three quarters of respondents were ‘always’ treated with respect and dignity, and had been told who was in charge of organising their care and services. But substantial concerns remain about the quality of care some people using community mental health services receive.
- **GP patient survey:** For every single key finding under “overall experience” and “access to in-hours services”, patient experience has decreased since 2016.
- **IPSOS Mori/Health Foundation polling:** 44% of people think the general standard of NHS care has worsened over the past year. Almost half think it will get worse over the next year.
- **Maternity Services Survey:** Three quarters of women felt involved in decisions and confidence and trust in midwives has increased. However, some women were left alone at a time that worried them during early labour, and of those who raised concerns, not all felt that their concerns were taken seriously.
- **National Survey of Bereaved People:** 74% of respondents felt that hospital was the right place for the patient to die, despite only 3% of all respondents stating that patients wanted to die in hospital.

- **Neurology patient experience:** Since 2014, patient experience of care has got worse across all key measures. Neurology patients are less likely than in 2014 to say that they feel involved in decisions about their care and patients are often given little information or signposting.

## 2.1 National patient surveys

National surveys are not always carried out annually – for example, surveys for Accident and Emergency, maternity services and children and young people’s services are carried out once every two years.<sup>7</sup> Here, we list those that have been published since January 2016.

Please note that these extracts are highly summarised. We recommend that readers go to the source material for detailed analysis.

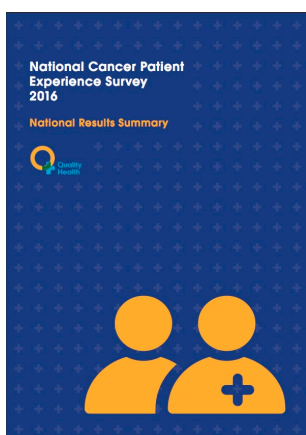


### 2.1.1 Adult Inpatient experience

The Adult Inpatient Survey shows encouraging signs of improvement for those traditional patient bugbears – communication, cleanliness and hospital food. Confidence and trust in clinical staff has also gone up.

The bad news comes from what the Picker Institute (which co-ordinated the survey) describes as “significant declines in key areas of person centred care.”<sup>8</sup>

Fewer patients feel involved in decisions about their care and treatment. Fewer report positive experiences of leaving hospital. And fewer believe they are getting enough help to recover and manage their condition.



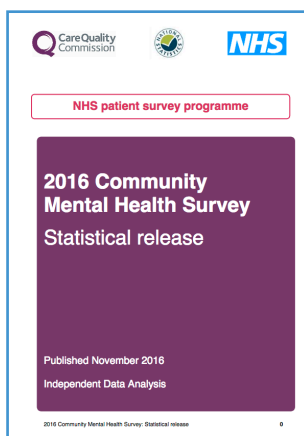
### 2.1.2 Cancer patient experience

The results of the 2016 survey indicate that the experience of cancer patients in England is generally very positive. Asked to rate their care on a scale of zero (very poor) to 10 (very good), respondents gave an average rating of 8.7.

Highlights were in respect of Clinical Nurse Specialists, where 90% of respondents were given a named contact, and 86% found it easy to get in touch with the nurse. Personal contact also featured on leaving hospital, where 94% of respondents said they were told who to call if they had any worries.

Other aspects of care fared less well – for example, fewer than two thirds of respondents (62%) thought the GPs and nurses at their general practice definitely did everything they could to support them while they were having cancer treatment.

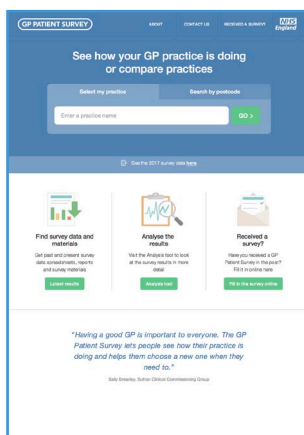
At the national level, experience of care is inconsistent – for example, patients appear to get more information on some areas (e.g. free prescriptions) than on others (e.g. benefits); information about chemotherapy/radiotherapy appears to be better before treatment than during it; and care and support from health and social services at home appears to be less positively experienced than care received in hospitals.



### 2.1.3 Community Mental Health Survey

Three quarters of respondents were ‘always’ treated with respect and dignity (74%) and had been told who was in charge of organising their care and services (76%). Of these 97% said that they knew how to contact this person, if they had a concern about their care. However, 32% said that they did not know who to contact out of office hours if they had a crisis.

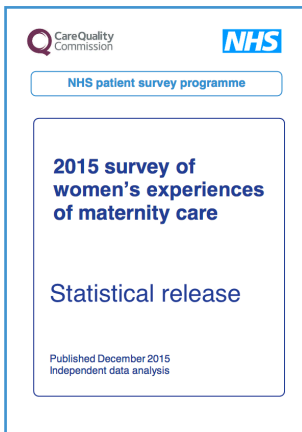
The Care Quality Commission, who run the survey, have stated that “substantial concerns remain about the quality of care some people using community mental health services receive. There has been no notable improvement in survey results in the last year.”<sup>9</sup> They suggest that there is “scope for further improvements in a number of areas including: involvement in care, crisis care, care planning and reviews.”<sup>10</sup>



### 2.1.4 GP patient experience

The 2017 GP Patient Survey provides information on patients’ overall experience of primary care services and their overall experience of accessing these services. The key findings contain plenty of good news – for example, that 85% of patients rate their overall experience of their GP surgery as good, and that 87% say the receptionists at their GP surgery are helpful.

The downside is that for every single key finding under “overall experience” and “access to in-hours services”, patient experience has decreased since 2016. Sometimes it is not by much: a 0.3% decline for “convenience of appointment” for example. Other decreases, however, are larger, and NHS England makes the point that “Given the size of the survey, even small changes in percentages are likely to be statistically significant.”<sup>11</sup>

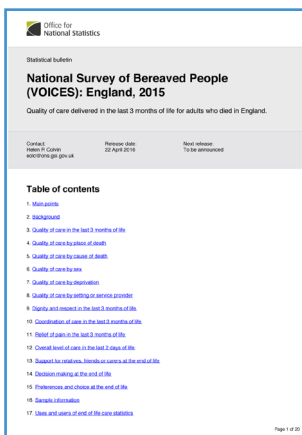


## 2.1.5 Maternity Services Survey

Three quarters (75%) of women felt they were always involved in decisions and 95% reported that partners or companions were able to be involved. Confidence and trust in midwives during labour and birth has increased (80%, up from 78%).

On the other hand, some women were left alone at a time that worried them during early labour (14%). Of those who raised concerns during labour and birth, not all women (18%) felt that their concerns were taken seriously.

1 in 5 women who had a normal vaginal delivery gave birth in stirrups (22%), which is contrary to best practice guidance.



## 2.1.6 National Survey of Bereaved People

75% of respondents to this survey rated the overall quality of end of life care for their relative as outstanding, excellent or good.

Two thirds (69%) rated hospital care as outstanding, excellent or good, but more people gave these ratings for hospice care (79%), care at home (79%) and care homes (82%).

74% of respondents felt that hospital was the right place for the patient to die, despite only 3% of all respondents stating that patients wanted to die in hospital.

One third of respondents (33%) reported that the hospital services did not work well together with GP and other services outside the hospital.

## 2.2 Other highlights from the last year

Last year, we uploaded 14,211 reports on patient experience and patient/public involvement to the library. Every week, we picked just one of them to take pride of place as the “Featured Report” on the Welcome Page of our website.

Here we feature the “best of the best” – the top ten reports that, over the last year, really made us sit up and take notice. Readers should note that this is not a league table. The list is in alphabetical order by title. Report titles are hyperlinked to the actual documents.



### Beware Zombies and Unicorns: Toward Critical Patient and Public Involvement in Health Research in a Neoliberal Context <sup>12</sup>

This paper offers a remarkably frank analysis, described by its own authors as a “provocation”.

It reviews the development of patient and public involvement in health research, and observes that *“there is a lack of consensus about what effective PPI in research processes might look like and ...little conclusive evidence about the best (or worst) ways to invoke PPI in research design, research practice, or research commissioning”*.

The authors conclude that *“formal PPI can be seen as a ghastly composite of a zombie policy that continually pops up, offering (but never providing) a solution to purported deficits in democratic engagement, despite being useless in the last policy round, and a unicorn policy, a mythical beast, prevalent, and much discussed but never discovered in replicable form in any health-care system. This zombie/unicorn hybrid creates PPI as a form of busywork in which the politics of social movements are entirely displaced by technocratic discourses of managerialism”*.

The paper may be “a provocation”, but it is well-founded, well argued, and raises important issues that deserve serious consideration.



### Designing a High-Performing Health Care System for Patients with Complex Needs. Ten Recommendations for Policymakers <sup>13</sup>

Care for older people with long term and complex conditions is a driver of much of current health and care planning. Most Sustainability and Transformation Plans feature references to the need to look after more people in older age.

It is welcome, therefore, to see this publication setting out “Ten Recommendations for Policymakers” in respect of services for patients with complex needs. Not least because of the recognition that patients themselves, and their carers, must be partners in devising new approaches.

We hear much about the NHS and care services being under pressure. They would undoubtedly be under more pressure were it not for the army of family and friends who help to provide care for elderly and frail loved ones. Better support for caregivers must be part of the long term future for the NHS. This concise and lucid report offers some clear pointers.

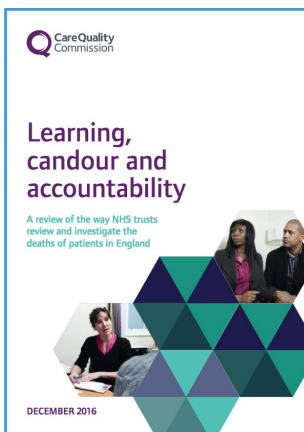


### **Falling short. How has neurology patient experience changed since 2014?**<sup>14</sup>

This important report from the Neurological Alliance is based on a survey of 7,000 patients, and follows up a similar exercise carried out in 2014.

The authors found that since 2014, patient experience of care has got worse across all key measures. More neurology patients have to see a GP five or more times before being referred to a specialist. A greater number of patients report that the professionals providing care do not always work well together. Neurology patients are less likely than in 2014 to say that they feel involved in decisions about their care and patients are often given little information or signposting.

For this group of patients, there is clearly room for improvement by providers.



### **Learning, candour and accountability, A review of the way NHS trusts review and investigate the deaths of patients in England**<sup>15</sup>

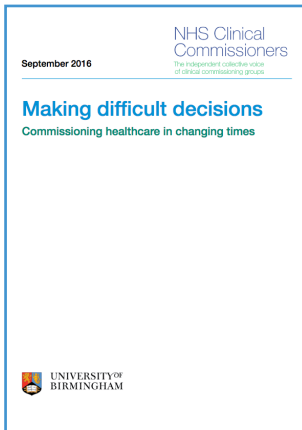
Parts of this report make for grim reading. It is, for example, depressing to read - yet again - that “*families and carers ... are not always treated with kindness, respect and honesty*”. In spite of this, we welcome the report as further evidence of a changing culture within the health sector.

The NHS historically has been addicted to a “doctor knows best” attitude. And for the NHS, as for any addict, the first step towards recovery is to admit that it has a problem.

Cover ups, intimidation of whistleblowers, and dismissal of patient feedback as “anecdotal evidence” are all classic avoidance behaviour. Admission of failure, and apologies to people who have been hurt are indicative of remorse, and a desire for healing.



“Learning, candour and accountability” adds to a body of work demonstrating that – slowly but surely – the old NHS culture is changing.



### **Making difficult decisions: Commissioning healthcare in changing times**<sup>16</sup>

*“The NHS in England is going through a period of major change. As this gathers pace and some of the drivers of change grow stronger, some potentially hard choices are becoming increasingly unavoidable”.*

This report from the University of Birmingham with NHS Clinical Commissioners addresses the challenges faced by CCGs tasked with implementing Sustainability and Transformation Plans. Some common themes emerged from a series of interviews, and the report notes that *“Many spoke of a ‘learning curve’, particularly around how to handle external communication and public engagement”*.

It is clear that some CCGs struggle with the perils and pitfalls of public engagement. This guide lays down some handy markers.



### **Negotiating the Care Maze - In Poetry. The process of decision-making when a family member or friend needs full-time residential care**

This report is based on a series of interviews with people who have had to arrange residential care for a loved one. The interviews were transcribed and thematically analysed so as to draw out poems from people’s experiences.

The result is powerful and moving testimony, describing the love, pain, guilt, sadness and loss that people feel when having to “put someone in a home”.

There is much talk in health and care services about “person-centred care”. Some of it can be convoluted, focusing on definitions and procedures. This report (perhaps we should call it an anthology) shows what caring for someone really means, and takes us deep into the experiences of people trying to do their best for loved ones who are moving beyond their reach.

A wonderful piece of work, displaying an innovative approach, and true compassion.





**Patient and public participation in commissioning health and care. Statutory guidance for clinical commissioning groups and NHS England**<sup>17</sup>

“Participation should be natural” says Rob Webster, Lead CEO for the West Yorks and Harrogate STP, in the opener to this guidance document. We agree – it should be. But in reality, it tends to come with toil, sweat, and – sometimes – a few tears.

Patient and public participation is not easy. And that’s why this excellent guide is so welcome. At 32 pages, it is comprehensive. But it is broken down into clear sections, with lots of hyperlinks to take readers to further guidance and resources if they want.

The sections cover matters such as the policy and strategy context, participation frameworks and principles, and ten “key actions” for CCGs on how to embed involvement in their work.

Participation in NHS commissioning should be natural. This guide is an important help for people who are trying to make it so.

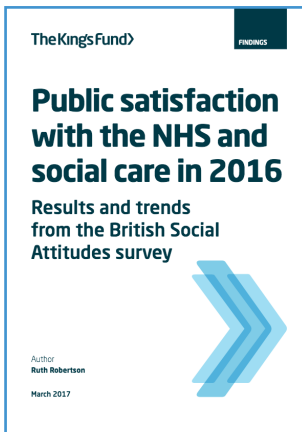


**Patient Experience Library Knowledge Maps**<sup>18</sup>

We have included our own work in this “top ten” list because we are proud of this real breakthrough in making patient experience more visible.

We have long argued that the wealth of evidence on patient experience in England is too hard to find. Healthwatch reports can be very good – but they are published across 150 separate websites. And while Healthwatch “Enter and View” reporting can often complement CQC inspection reports, the two strands of reporting are not correlated.

Our Knowledge Maps put both bodies of literature in one place – making them more visible and accessible to professionals, patients and researchers. This is part of our mission to bring the evidence on patient experience into the light.



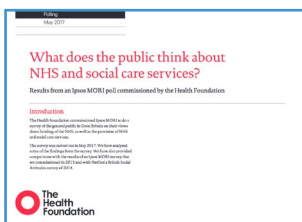
**Public satisfaction with the NHS and social care in 2016. Results and trends from the British Social Attitudes survey**<sup>19</sup>

This report reveals a “yawning gap” between public satisfaction with NHS and social care services.

The study summarises results and trends from the British Social Attitudes Survey. That survey reveals that while public satisfaction with the NHS overall is at 63%, satisfaction with social care services is at a shockingly low 26%. It goes on to say that “*the gulf between satisfaction with the services provided by the health system and by the social care system is wide and persistent*”.

*the social care system is wide and persistent*”.

NHS strategy makes reference to being “person-centred” and aiming for improved patient and service user experience within an integrated “whole system” approach. The 26% public satisfaction with social care services sets a benchmark from which – surely – the only way is up.



**What does the public think about NHS and social care services? Results from an Ipsos MORI poll commissioned by the Health Foundation**<sup>20</sup>

NHS England’s Five Year Forward View promises a “radical transformation of patient experience”. But this report from the

Health Foundation indicates that the general public expect their experience to get worse, not better.

According to polling by Ipsos Mori, 44% of people think the general standard of NHS care has worsened over the past year. And almost half (48%) think it will get worse over the next year.

The Five Year Forward View is to be implemented through 44 Sustainability and Transformation Partnerships. Their published plans all mention improved patient experience. But few, if any, of them have set baselines for current levels of patient experience, or set targets for how and when patient experience will be improved. This report could, perhaps, provide the missing baseline.

## 3. The evidence-practice gap

The previous sections to this report indicate the large volume of output that comes from organisations investigating patient experience. But what about outcomes? Does all that evidence actually get used to improve service quality and manage risk?

The answer is yes - and no.

At the local level, and at the front line of delivering care, there are undoubtedly efforts to act on patient feedback. Evidence of this can be seen in many places - in NHS Trust Quality Accounts, on “You said, we did” pages on Trust and CCG websites, and in the minutes of patient engagement committees.

The Care Quality Commission’s “Driving Improvement”<sup>21</sup> report is just one illustration of a responsive health and care system. Actually, eight illustrations, as the report offers eight examples of how NHS Trusts have acted to improve service quality. As the report says, *“trusts reached out to their communities and encouraged staff to use social media to share stories and interact with patients and the public. They also involve patients and the public in the work of the trust, shaping services and providing feedback. Some of our case studies show how collaboration with local people and patient groups such as local Healthwatch has helped to drive improvement in a trust.”*

This is all good news. But responsiveness to patient feedback in some parts of the NHS is countered in other parts by inertia and resistance. In this section, we look at the evidence-practice gap, and the barriers to an evidence-based approach.

### 3.1 Providers and commissioners do not necessarily act on the evidence

Four sets of observations in recent months suggest that patient experience evidence is not always made best use of.

#### 3.1.1 Boards

At the governance level, NHS Trust Boards spend substantial amounts of time reviewing patient satisfaction, listening to patients’ stories and discussing quality and safety. But they *“do not always use the feedback from surveys explicitly to monitor or assure the quality of care.”*<sup>22</sup> Further, *“discussion of surveys and other kinds of feedback does not of itself lead to action or explicit assurance.”*<sup>23</sup> In the light of Mid Staffordshire, this is a worrying observation.

### 3.1.2 Healthcare staff

Meanwhile, on the wards, it has been found that *“healthcare staff often find it difficult to act on [patient] feedback in order to make improvements to services.”*<sup>24</sup> The authors of this study point to three reasons for the difficulty. Firstly, there must be a *“moral imperative to listen to the patient voice.”*<sup>25</sup> Staff have to believe that patient experience, however subjective, is valuable and valid. Secondly, staff must have sufficient autonomy, ownership and resource in relation to a problem in order to enact change. Finally, they need back-up from the team beyond the ward. *“Insufficient organisational readiness usually blocks action planning.”*<sup>26</sup>

### 3.1.3 Commissioners

Acting on patient feedback is equally problematic in Clinical Commissioning Groups. Much useful research on patient experience is published in scientific journals, but *“commissioners cannot retrieve papers from many scientific journals, as they often do not have passwords or subscriptions.”*<sup>27</sup> Some research finds its way into guidelines that commissioners do have access to. But here, *“Commissioners tend to implement the ‘doable’ ones, defined as those that align with current services that don’t cost any extra money.”*<sup>28</sup>

### 3.1.4 GPs

Finally, GPs may also fail to make use of patient experience evidence from surveys: *“surveys are a valuable resource for monitoring national trends in quality of care. However, surveys may be insufficient in themselves to fully capture patient feedback, and in practice GPs rarely used the results of surveys for quality improvement.”*<sup>29</sup>

## 3.2 Patient experience leads need better support

Patient experience leads within the NHS are (as the name suggests) tasked with leading on the understanding and use of patient feedback. They are the people who can help CCGs improve service design and commissioning, and help Trusts with service quality and - crucially - risk management.

When it comes to professional training and development however, patient experience leads lack parity with clinicians.

NHS clinicians work in a culture that takes their practice and professional development seriously. They undergo years of training before being allowed to practise. After qualifying, they are subject to clinical supervision, and are required to undertake refreshers, updates and new learning. Their skills, and their roles, are taken seriously.

For patient experience leads, on the other hand, there is no professional qualification. They seem to be expected to use personal initiative and commitment to develop their skills and proficiencies.

Patient experience leads also lack access to professional knowledge. This matters because CCGs and Trusts wanting to understand patient experience need to learn lessons from elsewhere around the NHS. As the report into the Morecambe Bay deaths said *“It is vital that the lessons, now plain to see, are learnt and acted upon, not least by other Trusts, which must not believe that ‘it could not happen here.’”*<sup>31</sup>

To be effective, patient experience leads need access to patient experience literature emanating from government bodies, health charities, academics and think tanks. But it needs to be presented in a highly accessible and searchable format, so that vital learning can be quickly and easily identified.

Again, the contrast with clinicians is instructive. NHS clinicians have access to comprehensive professional databases as a matter of course. Patient experience leads have a similar need for access to knowledge that can guide their practice and professional development. And yet they are expected to resort to Google.

The Patient Experience Library solves the problem - putting the whole of the UK's collective intelligence on patient experience in one place, with fast and precise search functionality. We think that Trusts and CCGs should have access to it as a matter of course.

# About the Patient Experience Library

We set up the Patient Experience Library because:

- Health professionals and patients need easy access to the collective intelligence on patient experience. If we can't get to the knowledge, we can't learn.
- Patient voice has been championed for over forty years by Community Health Councils, Patient and Public Involvement Forums, Local Involvement Networks, and Healthwatch. They have all produced valuable intelligence, but there is no archive, so vital knowledge has been lost. Without the knowledge of our history, we're condemned to repeat our mistakes.
- Clinicians have access to comprehensive professional databases as a matter of course, to guide their practice and professional development. Patient experience leads don't. We created a resource for them because they need professional parity with clinicians. Without professional parity, the patient voice is too easily dismissed.

We built the Patient Experience Library to bring together the whole of the UK's collective intelligence on patient experience: 40,000 documents so far, from Healthwatch, national health charities, think tanks and government bodies such as NHS England and the Care Quality Commission.

We did it because we want patient experience leads to have parity with clinicians, and we want professionals and patients together to share knowledge and learn from mistakes.

***Our mission is to bring patient experience into the light.***

[www.patientlibrary.net](http://www.patientlibrary.net)

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The Patient Experience Library is provided by Glenstall IT, 28 Glenstall Road, Ballymoney BT53 7QN.

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