Patient Experience in England

2019 Edition

Foreword

It is a real honour to write the foreword for the Patient Experience Library annual report, 2019. Patients and carers are central to health care. Improving patient experience is a key aim for the NHS and most health service providers nationally and internationally; and is a central concern for health professionals.

Currently in health, we have ideologies of patient-centredness. These ideologies reinforce the centrality of patient experience to health care practice and service provision. Engaging with patient experience data not only tells us what patients and carers appreciate and value, and what we are doing well, it also helps us to understand the areas for improvement, and how we can respond in more meaningful and appropriate ways to better meet patient and carer needs.

Though considerable amounts of patient experience data are routinely collected, historically it has not always been easy to access reliable patient experience data. The Patient Experience Library is a unique resource, and a rich repository from which we can access patient experience data even from hard-to-reach groups.

Being able to access and draw on patient experience data is important all of the time but even more so when there is a need to redesign and reconfigure services to better meet individual and community needs. The Patient Experience Library is fully searchable, and so represents a realistic strategy to help health service providers, health researchers and clinical staff to gain insights into patient experiences and concerns to ensure that patient voices and patients' perspectives of their care experiences can be used as the basis for service development and service improvement.

As a nurse, I have been privileged to walk alongside people as patients and carers on some of their most difficult life journeys. Over the years of my nursing career, I have come to know only too well how much can be learned from patients, and how the unique patient perspective can reveal things that we ourselves miss, or are unaware of in the rush and busy-ness of providing care.

The Patient Experience Library is an exceptional and essential resource. I commend this important resource, and hope you, the reader, find this report useful.

Debra Jackson AO RN PhD
Professor of Nursing
Faculty of Health, University of Technology, Sydney (UTS) Australia.
Professor of Nursing, Oxford Health NHS Foundation Trust, Oxford UK.
Visiting Professor, Florence Nightingale Faculty, Kings College, London UK.
Editor-in-Chief, Journal of Clinical Nursing.

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1. Introduction

We are on a journey to get patient experience evidence taken as seriously as medical evidence.

High quality healthcare is based on three pillars: clinical effectiveness, patient safety and patient experience. That is not a hierarchy – the three are intertwined and are of equal importance. And yet, as Annie Laverty of the Northumbria Healthcare Foundation Trust has said recently, "*patient experience remains the weakest of the three arms of quality*".

In the last two editions of Patient Experience in England, we have featured studies describing an evidence-practice gap in patient experience work. This year, yet another study confirmed this. It observed the "*overwhelming nature of the industry of patient experience feedback*", and said that "*Ward staff… reported feeling overwhelmed and fatigued by the volume and variety of data that the Trust collected*".

We want to help close the gap. Setting up the Patient Experience Library as the national evidence base for patient experience and involvement is just the start.

Earlier this year we opened the library for free unlimited search and downloads. That's because if people can't find the evidence on patient experience, they can't make use of it. So now it is open to everyone everywhere, all the time.

In a series of articles in BMJ Opinion, we have been making the case for a more evidence-based approach to patient experience work. One in particular, on the language of complaints, triggered a huge response. And we were pleased to see that our key point – that complaints are a form of incident reporting – found its way into the new published national Patient Safety Strategy (p21).

We are working with national bodies to help them get straight to the information they really need. We produce bespoke weekly updates to help the Care Quality Commission keep abreast of new evidence, linked to their key insight themes. And we are helping the NHS Leadership Academy to think about how patient experience evidence might underpin a new national patient leadership programme.

On top of all this, we continue to produce our weekly research-based blogs and our quarterly magazine, and to maintain tools such as our Knowledge Maps.

This document is our annual "state of patient experience" report for the NHS in England. We hope you'll find it an interesting and useful read. If you'd like to get in touch with us, please do.

Miles

Miles Sibley, Editor   *info@patientlibrary.net*

2. What we learned in the last year: Surveys

This year's crop of surveys shows the usual mixed bag of good and bad patient experience.

That should come as no surprise – the NHS is a vast and complex healthcare system, working through the multiple pressures of finances, workforce, changing population needs and, of course, politics. NHS staff get most things right, most of the time. Occasional mistakes and shortcomings need to be seen as opportunities to learn.

So what are the learning points that we can pick out from recent surveys?

The first is that patients' trust in health professionals remains high. In GP practices, 95% of patients had confidence and trust in the healthcare professional they saw. In hospitals, 80% of adult inpatients who had an operation or procedure reported that staff provided clear answers when they had questions. In maternity services, over 80% of women said that midwives introduced themselves and listened well, and that they felt treated with respect and dignity.

Mental health services are faring less well. Here, patient experience has deteriorated across several areas. In some, there has been a consistent decline in results since 2014. In other areas, the results declined significantly this year, having been stable between 2014 and 2017. This is worrying news for a service that is aiming for "parity of esteem".

Hospital discharge continues to be a source of dissatisfaction for patients, who report long delays, often while waiting for medicines. Information is also poor – significant numbers of patients were unsure about things like when they would be discharged, and what would happen next with their care. Concerns of this kind have been reported for years, and yet the problems persist.

All patient experience sits within the context of wider public attitudes about healthcare and the NHS. The British Social Attitudes survey finds that among the general public, the four main reasons for satisfaction were the quality of care, treatment free at the point of use, the range of services available, and the attitudes and behaviour of NHS staff. Conversely, dissatisfaction arose from long waiting times, staff shortages, a lack of funding, and money being wasted. An overview from the King's Fund and Nuffield Trust warns that "*the outpouring of affection that accompanied the NHS's 70th birthday did not stem falling levels of public satisfaction with the service*".

Summaries of survey findings are below – for further detail, click on the report pictures.

2.1 Adult inpatients
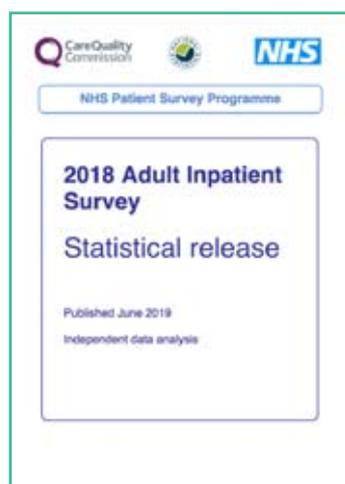
The Care Quality Commission's Adult Inpatient Survey has now been running for 15 years, but as the CQC says, "*every year brings a new perspective*".

This year's perspective contains good news. Trust in doctors and nurses remains relatively high, most patients (over 90%) report that they had enough privacy, and communication between patients and staff remains a positive experience for most.

Alongside this, however, are areas that consistently show poor patient experience, including waiting times, and the quality of information and involvement around hospital discharge.

Dissatisfaction with waiting times has been echoed by the House of Commons Public Accounts Committee, which has deemed it "*unacceptable that less than half of NHS trusts meet the waiting times standard for elective treatment, and only 38% meet the standard for cancer patients*". The committee is concerned that national bodies "*appear to lack curiosity regarding the impact of longer waiting times on patient outcomes and on patient harm*".

Hospital discharge is a longstanding source of dissatisfaction for patients, with Healthwatch reporting back in 2015 (and many times since) on the problems. The CQC survey finds that 18% of respondents said they did not know what would happen next with their care when they left the hospital, and nearly a quarter of patients (24%) said they did not get enough support from health or social care professionals to manage their conditions after leaving hospital.

The CQC concludes that "*While last year we reported on a system still delivering improvements in patients' experiences despite growing pressure, this year, the improvement is not sustained. In 2018, there is a lot of evidence to suggest that pressure on the system is having a real impact on patients' experiences of care*".

2.2 British Social Attitudes
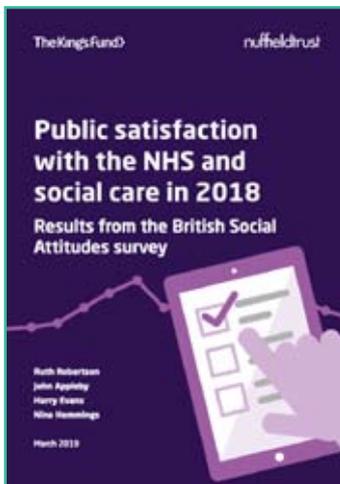
"*In 2018, the outpouring of affection that accompanied the NHS's 70th birthday did not stem falling levels of public satisfaction with the service.*"

So say the King's Fund and Nuffield Trust in their annual overview of public satisfaction with the NHS and social care.

The report highlights various points of detail – for example that older people were more satisfied than younger people, and that supporters of the Conservative party were more satisfied than supporters of the Labour party. And within the overall picture, there is good news – for example, that satisfaction with inpatient services is at its highest level since 1993, and satisfaction with outpatient services is at its highest level since the survey began.

However, the authors point out that the data gives its richest insights when viewed over decades rather than years. So the 2000s were characterised by increasing satisfaction, while the 2010s are characterised by decreasing satisfaction. And although levels have fluctuated, the broad trend shows a falling level of satisfaction, which in 2018 was 16 percentage points lower than in 2010.

The four main reasons for satisfaction were the quality of care, treatment free at the point of use, the range of services available, and the attitudes and behaviour of NHS staff. Conversely, dissatisfaction arose from long waiting times, staff shortages, a lack of funding, and money being wasted.

The report finishes by commenting that the new funding settlement for the NHS and accompanying long-term plan have set the direction of travel for the next 10 years. But we must wait to see when the decade-long slide in public satisfaction with the NHS will come to an end.

2.3 Cancer patient experience
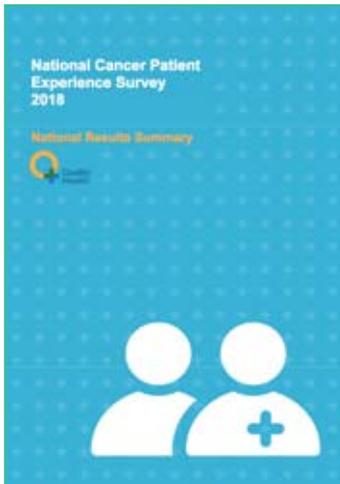
This year's survey shows broadly similar results to last year's, with patients reporting largely positive experiences.

Information and communication are of course important for people who might be receiving distressing news or going through difficult treatments. In this respect, the following results indicate very good service from patients' point of view:

- 97% of respondents said that diagnostic test results were explained to them in ways they understood completely, or to some extent. Only 2% had no explanation, or an explanation they did not understand.

- When people were first told they had cancer, 85% reported that it was done sensitively, and 78% were told they could bring a family member or friend with them. Shared decision-making was good too, with 83% of survey respondents saying that treatment options were explained to them completely.

- 91% of respondents knew the name of their Clinical Nurse Specialist, and most found that they were easy to contact (85%) and gave answers that were understandable (88%).

The survey covers other areas including experience of surgery and inpatient stays in hospital, and home care and support after leaving hospital. In the case of home care and support, satisfaction rates seem to drop, with only 53% of respondents "definitely" getting enough care and support from health or social services during their cancer treatment, and even fewer (45%) once their cancer treatment had finished.

2.4 Community mental health services
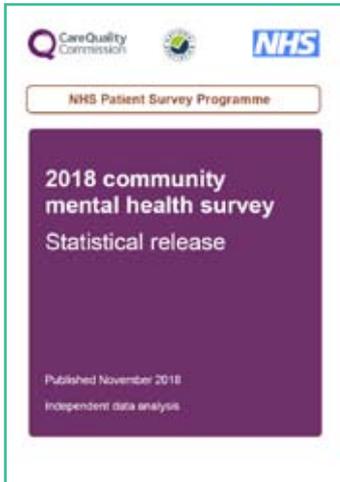
The 2018 community mental health survey shows evidence of worsening quality, with patient experience deteriorating across several areas.

In some areas, this represents a continued negative trend, with a consistent decline in results since 2014. In others, the results declined significantly this year, having remained relatively stable between 2014 and 2017.

The news is not all bad. There has been a steady improvement in people's awareness of who to contact out of office hours when having a crisis. And better than average experiences were identified for people diagnosed with a psychotic disorder. Against this, though:

- Only 43% of respondents had 'definitely' seen NHS mental health services enough for their needs in the previous 12 months.

- The percentage of respondents who 'definitely' felt that staff understood how their mental health affects other areas of their life had decreased.

- People's experiences of how services plan their care are at their lowest point since 2014.

As far as overall experience is concerned, 71% of respondents felt they were 'always' treated with respect and dignity by NHS mental health services. This compares with 82% of adult inpatients in acute hospitals (physical health), who felt they were 'always' treated with respect and dignity. It seems that "parity of esteem" is still some way off.

2.5 GP patient survey
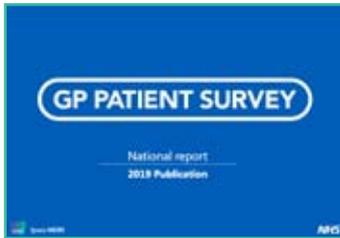
The latest GP patient survey shows high levels of satisfaction with GPs. More than 9 in 10 patients reported that, during their last appointment, they had confidence and trust in the healthcare professional they saw (95%) – in spite of the fact that only half (48%) saw their preferred GP 'always or almost always'.

Almost all patients (93%) felt that during their last general practice appointment they were involved as much as they wanted to be in decisions about their care and treatment, and had their needs met (94%).

One of the areas where patient experience showed a deterioration was in contacting practices by telephone. Most patients (78%) choose to book appointments by phone, but it is getting harder to contact GP practices in this way. One third of survey respondents (32%) said that it was not easy, against one fifth (19%) in 2012.

Awareness of online services has improved – for example, 44% of survey respondents were aware that appointments can be booked online, and 41% were aware that repeat prescriptions can be ordered online. But awareness does not always translate into practice – only 12% had actually booked an appointment online, and three quarters (76%) had used none of the online services available to them.

Awareness of appointments outside traditional practice hours has increased, but is still relatively low. Only 10% of patients were aware of appointment times available on a Saturday and 2% of patients were aware of appointment times available on a Sunday.

2.6 Maternity care
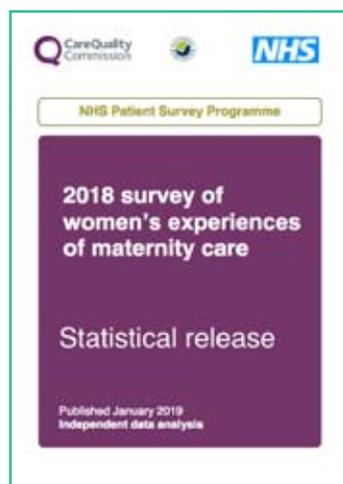
Last year's maternity survey reported small improvements across most questions from 2013 onwards. However, the latest survey shows very few questions continuing this trend, with some questions showing a decline.

More women reported being asked how they felt emotionally during their antenatal care (68% – up from 57% in 2015). And more women in hospital said that birth partners could stay as much as they wanted (71% – up from 63% in 2015). Communication is generally good, with over 80% of women saying that they are spoken to in ways they can understand, that midwives introduce themselves and listen well, and that they felt treated with respect and dignity.

There is room for improvement in "choice". For example, most women were not offered a choice about where their antenatal care or their postnatal care would take place.

Worryingly, there has been no change in the number of women who gave birth using stirrups – in spite of the fact that this is contrary to best practice guidance.

Continuity of carer also remains elusive. Most women said that the midwives who cared for them during labour and birth had not been involved in their antenatal care. And most women were not seen by the same midwife every time for their postnatal care at home.

Questions on postnatal care remain less positive than other aspects of the maternity pathway. For example, only 56% of survey respondents were 'definitely' given enough information about any emotional changes they might experience after the birth. And only 53% said that they were 'definitely' given enough information about their own physical recovery after the birth.

2.7 Neurology

Most of the national patient experience surveys publish the results by provider. The surveys are, essentially, a test of people's access to, and satisfaction with, services.

But there is another dimension to patient experience which is less well explored. That is people's experience of living with long term health conditions. And this really matters, given the increasing emphasis on "self-management" within NHS strategies.

Neurological conditions can be very common – one example being dementia. Others are less common, but relatively well known – for example Parkinson's disease or Tourette's syndrome. Some are rare – for example Rett syndrome. Taken together, the range of neurological conditions affects some 16.5 million people in England. Even rare conditions affect at least 150,000 people.

The third biennial survey into the patient experience of people with neurological conditions suggests that little has changed over the six years since the first survey. The latest findings highlight key areas for improvement, based on the following:

- Long delays, and a lack of access to specialists. Nearly one third (29%) of survey respondents had waited more than 12 months to see a neurologist. 38% did not have access to a specialist nurse.

- A lack of personalised care. 43% were not given written information at the time of diagnosis, and 23% were not given an explanation of their diagnosis that they understood. Only 10% had been offered a care plan.

- Access to social care is also a problem, with 38% of respondents reporting that their needs are not being met at all.

This year for the first time the survey results are broken down to regional level, based on the Sustainability and Transformation Partnership (STP) footprints. The findings reveal wide geographic variation, representing a postcode lottery in access to care. They also show that people in the most deprived areas report the poorest experiences of care.

2.8 Personal Social Services Survey of Adult Carers in England (SACE)
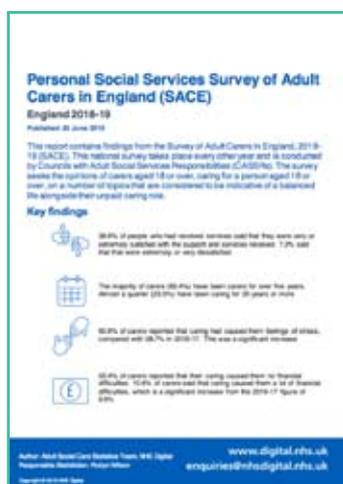
This national survey takes place every other year and seeks the opinions of carers aged 18 or over, caring for a person aged 18 or over. Key findings include the following:

Two thirds of carers (65%) have been carers for over five years. Almost a quarter (23.5%) have been caring for 20 years or more.

More than half of carers (57%) are retired. The largest group of carers is aged between 55 and 64 years, and most carers over 75 years of age are caring for someone who is also over 75. Over two thirds of carers are female.

Well over one third of carers (39%) spend over 100 hours per week on their caring duties. 61% reported that caring had caused them feelings of stress, with one in ten reporting that caring caused them a lot of financial difficulties.

Over two thirds (70%) of people who had received services were "quite", "very" or "extremely" satisfied. Feeling involved in discussions about care was the greatest factor influencing carers' overall satisfaction. Carers who found it easy to access information also reported a greater level of satisfaction.

# 3. What we learned in the last year: Research

Every year, thousands of reports on patient experience and involvement are published – by government bodies, health charities, patient voice organisations and academic institutions. We cannot hope to cover them all here, so this overview simply outlines a few of the key themes that have emerged over the last twelve months.

If you are looking for more regular summaries of the literature as it gets published, please sign up for our free weekly newsletter. Or, to get the whole lot all in one place, search here.

For full attributions, and copies of the documents mentioned on the following pages, click on the report pictures.

3.1   Some patients are more equal than others

The Annual Report of the Chief Medical Officer has recently made the point that "*Since the founding of our National Health Service in Britain in 1948, the UK has played a lead role in developing the concept of universal health coverage*". But as society changes we need to continually revisit our understanding of what "universal" means, and to think about how people are included or excluded by our healthcare system. The following reports offer some pointers.
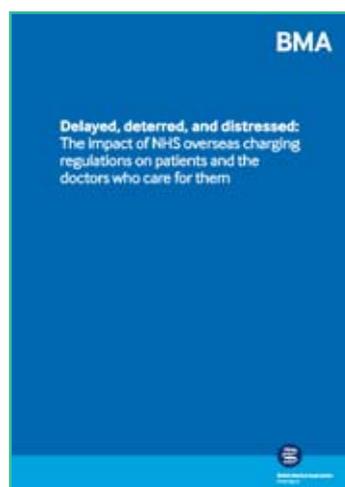
This BMA report challenges government on its rules for charging 'overseas visitors' for accessing NHS services in England.

It refers to the government's "hostile environment" for immigration and finds "*clear evidence that The National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2017 are deterring vulnerable groups from accessing NHS treatment, threatening public health, and taking vital clinical time away from patient care.*"

The Department for Health and Social Care (DHSC) announced a review in December 2017, less than two months after the updated rules came into force, and before some providers had had time to fully implement them, let alone assess their impact. DHSC says that the review found no evidence of the regulations deterring patients from accessing care – but it has also said that the findings of the review will not be published.

The BMA finds that patients are, in fact, deterred from seeking care, "*including for treatments that are not chargeable*". It states that "*vulnerable groups are being, and will continue to be, negatively affected by the regulations*".

This study takes as its starting point the fact that most LGBT people aged over 50 were born when being gay was effectively illegal in the UK. Some may have hidden their LGBT identity – and from a health perspective, this could have led them to hide aspects of their own health for fear of "outing" themselves. For others, it could have fostered a reluctance to engage with health services for fear of discriminatory attitudes by health care providers.

It finds that LGBT men and women aged 50+ have poorer self-rated health and are more likely to have other conditions that impact their health and wellbeing. This matters because poor self-rated health is a strong predictor of future mortality and is also used to determine healthy life expectancy and disability-free life expectancy.

Policy responses are patchy. For example, an information standard for monitoring sexual orientation is now available to all NHS organisations but use of the standard is not compulsory.

The report makes the point that specialist or targeted services rarely exist outside certain cities in which there are higher concentrations of LGBT people. But it goes on to say that while there is value in targeted/specialist services in certain areas of the country, greater effort must be made to improve the inclusivity of mainstream service provision.
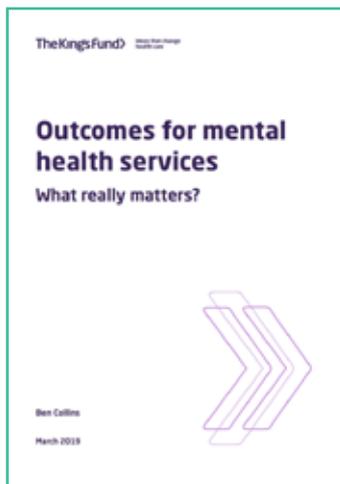
For some years now, there has been talk of "parity of esteem" between physical and mental health. This has been defined as "*valuing mental health equally with physical health*".

But how do we assess "value" in mental health services and treatments? What outcomes should we be looking for, and how would we measure them? This paper makes the point that "*Even the briefest discussion with service users shatters the illusion that agreeing these outcomes will be an innocuous administrative exercise*".

It goes on to say that, "*While there are many strong partnerships between service users and NHS services, there was also evidence of profound differences in perspective on what is important and even, at times, outright hostility and distrust between the two sides*".

Some service users are suspicious of "narrow clinical" responses to illness, and "oppressive interventions" such as restraint and seclusion. NHS staff, for their part can feel "*accumulated demoralisation when they see the same patients in their clinics, caught up in the same cycles, struggling to make progress*".

In this context, the task of defining "value" in mental health services, along with desired outcomes, is very difficult. "*The outcomes prioritised, and those discounted, inevitably reveal the degree of influence of different voices in the discussion – those around the table and those outside the room.*"

The report concludes that "*we cannot usefully direct mental health services to the dogged pursuit of particular outcomes until there is a broader consensus on which outcomes really matter*".

And with "*service users, professionals and different professions... pulling in different directions... it is also clear that some sort of reconciliation is urgently needed*".

The NHS Long Term Plan says that health services will do more to ensure that people with learning disabilities and autism can live happier, healthier, longer lives.

That is welcome news, given that MPs have described waiting times for support for autism as scandalous. This report sheds some light on why – from the point of view of families – there is a need for change.

The study found that some families felt that once they were "in the system", the service they received was good. But "*many described the continuous fight they had to undertake to get the right support for their child*".

Difficulties included the following:

- There is frustration amongst parents about the long waits they experienced to access health and social care services including an Autistic Spectrum Disorder (ASD) diagnosis.

- Families felt that professionals did not understand what it was like to live with ASD.

- Physically getting to an appointment could prove a challenge.

- Parents stated the need for reasonable adjustments to be made in health and social care services, with particular regard to waiting rooms in clinical settings.

- A lack of communication led to parents often feeling forgotten due to the considerably long waiting times they experienced and not knowing where they were in the process.

The report's focus is the experience of families in Norfolk, but its findings will echo with similar families right across England. Equally, the recommendations are aimed at health services in Norfolk, but should be read by commissioners and providers everywhere.

3.2 Online feedback can build community

Last year saw the appointment of Matt Hancock as Secretary of State for Health and Social Care. This is a minister with an unsurpassable enthusiasm for tech so we were keen to see how his vision for a digitally-driven NHS would play out in respect of patient experience.

Unfortunately we are still waiting. There is much talk of apps, wearables and AI. But little sign of a helping hand for the less glamorous basics of patient experience work. The daily struggle to make sense of data pouring in from Friends and Family Test, surveys, complaints and more looks set to continue.

As usual, the world moves on regardless. So more and more patients these days simply bypass official surveys and complaints mechanisms, and give their feedback online. This matters because traditional ways of seeking patients' views do not always correspond with what patients themselves are talking about.

This paper looks at the requirement to include patient views in regulatory processes such as medical revalidation. It asks whether questionnaires are tackling the right questions in the right way, and whether they align with the kinds of issues that patients address in online feedback. The study focused specifically on patient experience of psychiatric care.

A key finding is that patients describe different measures of psychiatric care quality online and use different terminology to those used in questionnaires. This may reflect the acknowledged exclusion of patients and the public in the design, administration and evaluation of patient feedback questionnaires.

Timeliness matters too. Working online, patients can offer feedback as and when they need to. But, say the authors, "*The current requirement to collect patient feedback so infrequently (once every five years) sends the message, whether intentional or not, that patient feedback is unimportant*".

In day-to-day practice, online patient feedback arrives not so much once every five years, as daily or even hourly. It is fast – but not necessarily furious. Often it is friendly. Either way, it is a source of learning and relationship building - especially if healthcare professionals respond appropriately.

This study looked at replies to online patient feedback via the widely used Care Opinion platform. It found considerable variation in how individuals and institutions respond to comments posted by patients. These are helpfully summarised in an infographic which could potentially be used as a training handout, or wall poster. There are five basic types of response:

- Not responding at all. This could be due to a lack of awareness by staff that feedback is being posted on the Care Opinion site. But in some cases, there was evidence that messages had been read, but still not responded to.

- Generic "cut and paste" responses. These were somewhat formulaic statements that acknowledged the feedback but did not actually address the patient's comments in a personal or meaningful way.

- Appreciative responses. These tended to thank patients for their feedback (and to apologise for any negative experience that was reported) but they also contained elements of generic text, creating a hybrid personal/formulaic response.

- Offline responses. These encouraged the patient to pursue their enquiry via direct contact (phone, email, formal complaint etc.).

- Transparent conversations. These were appreciative, personalised and visibly aiming to understand and learn from the feedback being offered by patients.

A separate study found that over time, "transparent conversations" can help to build a sense of community.

Findings indicated that patients and professionals valued the Care Opinion platform because it is well moderated and trustworthy. "Identity sharing" by staff (ie posting replies in person, rather than from "the PALS team" or similar) was welcomed by patients, as was the narrative style of interaction and the use of "socioemotional language".

Both staff and patients liked the feeling that their participation could make a difference. A "stand out value" for patients was the importance of a timely reply, while for staff, the ability to give a personalised reply was highly valued.

3.3 Involvement in research is good in parts

Patients and the public are frequently invited to get involved in the commissioning of health services, in quality improvement exercises, and in healthcare research. It is easy to assume that there is a consensus about the need for, and benefits of, involvement.

Within the research community, however, agreement cannot be taken for granted.

This report states that researchers often recognise and build on patients' motivations for getting involved. But that is not always the case. Sometimes, for example, patients and public are included in research simply because that is a condition of the funding.

The report aims to build a better understanding of patient and public involvement (PPI) but finds that "*there is limited agreement about how, when, and why [PPI] should best be done*".

Definitions are often blurred, and PPI "lacks standard terminology". Furthermore, "*Few studies evaluated the fidelity of their PPI approaches, making it difficult to know whether the approaches discussed were implemented as intended*". Under these circumstances, "*PPI can sometimes become a tick-box exercise*".

This paper largely agrees. Looking more specifically at co-production, it says that "*Despite the multiplicity of reasons and incentives to coproduce, there is little consensus about what coproduction is, why we do it, what effects we are trying to achieve, or the best coproduction techniques to achieve policy, practice or population health change*".

The paper argues that coproduction is not free of risk or cost. From the framing of research questions to the development and dissemination of recommendations, coproductive research can cause conflict, consume resources and lead to misunderstandings. Indeed, the very purpose of a collaboration may not always be clear to all, or be shared.

The authors explore risks and costs, and in the absence of strong evidence about the impact and process of coproduction, they advise a cautious approach. This, they say, would involve "*conscious and reflective research practice, evaluation of how coproduced research practices change outcomes, and exploration of the costs and benefits of coproduction*".

The theme of "conscious and reflective research practice" is picked up in this paper. The authors argue that PPI professionals are unduly influenced by clinical practice, which uses interventions to treat medical conditions in ways that can be objectively evaluated. But is it sensible to conceptualise involvement as a "measurable intervention"?

The paper suggests an alternative approach that sees involvement as "conversations that support two-way learning". Instead of a "correct method" for involvement, it advocates varying approaches, tailored to the context and the needs of the individuals involved. Crucially, the quality of the interaction between professionals and public becomes more important than the process.

Still – the question remains: how do we know whether involvement actually makes a difference? According to the authors, obtaining "robust evidence" of the outcomes of involvement may not be possible or appropriate. For them, researchers' subjective accounts of what they learnt through involvement represent an equally valid way of knowing whether involvement has made a difference.

So where does all this debate leave the individual researcher? This study started from the premise that "*much previous research has focused primarily on implementation of, and barriers to, PPI*". There appears to be much less research on how health researchers feel about the expectation to involve people: "*how they go about it; their emotions, fears and hopes; and their personal perspectives on managing potential dissonance between policy [and] practice*".

It found that while engaging patients and public, researchers often needed to manage their feelings and emotional responses in line with their professional context. This included "*having to be polite when they felt they wanted to be otherwise and wrestling with the need to involve people in tasks that researchers had spent a significant amount of time training to do*".

The task of emotionally supporting PPI contributors could be burdensome and was magnified when contributors were unwell (physically or mentally). Researchers were also subject to criticism by PPI contributors, and some described feeling upset and insulted.

Despite this, researchers often described the experience of PPI positively, using terms like "energising". There was an emotional return for involvement, providing positive feedback in an otherwise slow process of research. These mixed feelings about the emotional pro's and cons of PPI work are reflected in the paper's title: "*About sixty per cent I want to do it*".

3.4 Patient voice funding: drug companies move in

The levels of feedback through national patient surveys, the Friends and Family Test and Healthwatch (Appendix A.2) show that huge numbers of people want to share their experiences and have their say in how healthcare is delivered. But evidence over the last year indicates significant changes to infrastructure support for patient voice.

In May, the Point of Care Foundation announced that the Heads of Patient Experience Network was to be taken in-house by NHS England. Soon after, NIHR, the National Institute for Health Research announced the formation of a new NIHR centre for patient and public involvement, engagement & participation and research dissemination. This would be via a contract let to "global life science company" the LGC Group. The move sparked concerns that patient and public involvement (PPI) in research is being privatised.

Last autumn, Sir Robert Francis's first official act as the new Chair of Healthwatch England was to write to Secretary of State Matt Hancock to warn of "*the perilous state of the Healthwatch network's funding*".

The network's State of Support briefing revealed that while health spending had increased by 8.5% since 2013, funding for Healthwatch had dropped by 35%. Francis made the point that "*Half of local Healthwatch are now receiving less than their predecessors the 'Local Involvement Networks' – the ineffectiveness and limited remit of which was apparent in my investigations into the failings at Mid-Staffs NHS Trust*".

He goes on to say that "*...if one thing was clear to me from my enquiries into the incidents at Mid-Staffs, it was that to do public engagement well it needs to have a professional infrastructure. Without this, people are too easily ignored and the NHS ignores the voice of patients at its peril*".

User-led organisations (ULOs) are run by people who use health and social care services. They have become firmly embedded in the health and social care environment, particularly since the principles of involvement and 'user-centred care' were enshrined in legislation in the early 1990s.

This briefing describes a crisis among ULOs, arising from cuts in grant funding from local government, coupled with loss of service contracts to large, often private, operators. It states that "*This is creating tensions, pressurising ULOs not to speak out about damaging local service cuts because they fear losing contracts if they do*". The consequence is that ULOs' "*resilience and ability to struggle both personally and on behalf of others is now greatly diminished*".

While public funding to patient voice organisations has been in decline, private funding has been increasing. This study found that from 2012 to 2016 the drug industry donated over £57m to UK patient organisations, with the annual sum more than doubling over the period.

This can be problematic – for example, "*patient organisations contributing to appraisals by the National Institute for Health and Care Excellence (NICE) have widespread, and often not entirely transparent, financial relationships with drug companies*".

The authors observe that "*the emerging picture of industry funding shows that companies might seek to use some patient organisations as 'third parties' in reaching other audiences*". But, they say, "*the picture is not fully clear, given the transparency shortcomings*".

Improving transparency "*would require an integrated, regularly updated payment database with robust quality assurance policies. The ABPI [Association of the British Pharmaceutical Industry] is not currently considering such a database, but it should at least introduce a standardised disclosure template, perhaps modelled on the one used for Disclosure UK*".

3.5 Learning from deaths: culture impedes progress

The final report of the landmark Francis Inquiry into the Mid-Staffordshire scandal was published six years ago, in 2013. Since then, we have seen further inquiries into avoidable harm and death at Morecambe Bay, Southern Health, and Gosport. In Northern Ireland, the Hyponatraemia Inquiry has published its findings, as has the Cwm Taf investigation in Wales. Meanwhile, the Shrewsbury and Telford investigation rolls on.

That makes six official investigations in the six years since Francis. In every case, a failure to act on concerns raised by patients and families was central to the failure to provide proper care. And in every case, bereaved relatives have spoken of delays, dismissiveness and outright denial when they sought explanations and redress – sometimes for years – after the death of a loved one.
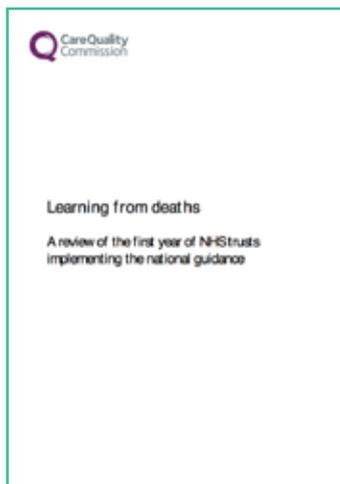
Against this background, the National Quality Board has issued guidance on learning from deaths. And this report from the Care Quality Commission looks at how – and whether – NHS Trusts have been implementing the guidance.

It paints a mixed picture. Right at the start of the report, the Chief Inspector of Hospitals says, "... *we are still seeing the same issues persist in some NHS trusts more than two years on. Issues such as fear of engaging with bereaved families, lack of staff training, and concerns about repercussions on professional careers, suggest that problems with the culture of organisations may be holding people back from making the progress needed*".

Happily, some Trusts have been more active in adopting the guidance, and the report gives examples, along with detailed case studies illustrating both challenges and practical solutions. It states that "*the existing culture of an organisation can be a key factor in trusts' implementation of guidance*". And on this point, the Chief Inspector sounds a warning note: "*Cultural change is not easy and will take time. However, the current pace of change is not fast enough*".

The independent review of gross negligence manslaughter and culpable homicide was mainly concerned with professional regulation, and concerns that doctors are unfairly vulnerable to investigation and prosecution for patient deaths. But it made the point that "*it is not possible to examine the position of doctors without also considering the vulnerability and expectations of patients and their families*".

Echoing the Chief Inspector of Hospitals, it says that "*we have heard repeatedly about the failure of local systems to engage effectively and inclusively with families. The principles and frameworks for doing so exist, but implementation is, at best, variable across the countries of the UK*".

This matters, it says, "*because the longer that families feel they are denied the answers they are seeking, and the more they feel excluded from the investigatory process, the greater their sense that the truth is being concealed from them, and that there has been a cover-up*".

Usefully, the report cites this comment from the British Medical Association (BMA): "*Families and carers can offer a vital perspective in helping to fully understand what happened to a patient as they see the whole pathway of care the patient experienced, which clinicians conducting the investigation may not have seen*".

The Chief Inspector of Hospitals points to organisational culture as a major barrier to learning from deaths. But is there also a problem with the way in which official inquiries make their recommendations?

This paper travels back in time to revisit recommendations from the Ely (1969), Bristol (2001) and Mid Staffordshire (2013) inquiries. It starts with the observation that "*...one of the key reasons for an inquiry is to learn lessons and prevent similar events from reoccurring... but it is clear that lessons have not been learned and recommendations not implemented*".

The paper compares the "implementability" of recommendations from the three inquiries. There are two key questions:

- Who: is it clear who the recommendations are aimed at?

- What: is there a clearly identified policy tool, or mechanism, which suggests a clear course of action?

On the "who" question, the study finds that about 7 per cent of Ely's forty-four recommendations have a clearly identified agent, compared to 15 per cent at Bristol and 41 per cent at Mid Staffordshire. It suggests that "*more could be done to arrive at practical recommendations… that are clearly 'owned' by an identifiable agent*".

For the "what" question, the study considers three types of policy tools: carrots (eg financial incentives), sticks (eg regulation and sanction) and sermons (normative and moral-based arguments). It appears that "*sermons are the main policy tool, accounting for some 89 per cent of Ely recommendations, compared to 66 per cent at Bristol and 63 per cent at Mid Staffordshire*".

The study concludes that "*given the large number of potentially responsible agencies, recommendations should be 'active' with a clearly identified agent… and a clear policy tool or mechanism should be identified rather than rely on a vague tendency to sermonise*".

Avoidable deaths do not always occur in the context of large-scale scandals, or lead to official inquiries. Sometimes, concerns about individual deaths end up in the hands of the Parliamentary and Health Service Ombudsman.

One example, from the last twelve months, was a PHSO report on "*serious failings in the North Essex Partnership University NHS Foundation Trust (NEP) over a period of more than a decade*". One patient , Matthew Leahy, died shortly after admission to a mental health unit. A subsequent investigation found that Matthew's care plan had been written after his death.

Another recent PHSO report concerned the avoidable death of Averil Hart, a young woman who had anorexia nervosa. That report was followed by a House of Commons inquiry which looked further into the matter, taking in not just the clinical care of the patient, but also the treatment of bereaved relatives who subsequently tried to find out what had gone wrong.

We submitted evidence to the inquiry, setting the PHSO's findings alongside similar findings from academic research, regulatory bodies, and other official inquiries. We made a series of recommendations, including the following:

- Change the language. Recognise patient stories as valid evidence, and abandon the term "anecdotal evidence".

- End the double standard in preservation of evidence. Stop treating patient experience evidence as disposable.

- Abandon "process for its own sake" – complaints managers spending more time processing complaints than learning from them.

- Be responsive. Patient experience teams should not have e-mail autoreplies switched on as a matter of course.

The full set of recommendations developed some of the themes we had addressed in an earlier BMJ article on patient safety. And we are pleased to see that the new NHS Patient Safety Strategy has taken up our points about understanding patient complaints as a form of incident reporting.

3.6 Social care: the crisis continues

In the March 2017 Budget, the Conservative Government said that it would publish a Green Paper on social care. This followed its decision in July 2015 to defer the introduction of a cap on lifetime social care charges and a more generous means test – these changes have since been postponed indefinitely.

During the subsequent 2017 General Election campaign, the Conservative Party made a manifesto commitment to introduce the Green Paper and also made a number of pledges regarding how individuals pay for their social care. The publication of the Green Paper has been delayed several times: it was originally due to be published in "summer 2017". The latest position is that it will be published "at the earliest opportunity", although the Health and Social Care Secretary had previously said in January 2019 that he "certainly intend[ed] for [publication] to happen before April [2019]".

These, by the way, are not our words. They come directly from a briefing paper published by the House of Commons Library. So while we continue to wait for government proposals on social care, how are care users faring?

This report, commissioned by Age UK, looks at the geographical lottery for residential and domiciliary care. It argues that some parts of the country are turning into 'care deserts' – areas where even if you have money to spend on care, you will be unable to get it.

The report says that "*With still no sign of the Government's green paper, the social care system has been left waiting for over two years*". It observes that "*There have been four independent reviews, five consultations and seven government policy papers focused on social care in the last 20 years without a meaningful change to the system*".

The result, it says, is a dysfunctional market for social care: "*The needs of some older people must be going unmet, or they face travelling a long way to get into a care home, or their families and friends have to care for them instead. In [some] areas the care market has ceased to function and there is no care to be had*".

The report pulls no punches about the lack of an effective political response. It states that "*while 'Brexit sucks all the political oxygen out of the air'… social care is gradually rotting away*".

The Salvation Army reports that through its work with older people in its care homes, drop in services, lunch clubs, churches and community work, it is seeing the deepening impact of the crisis in adult social care funding first hand.

It recaps the essentials – people are living longer, and the adult social care bill is rising. But local authority funding streams are shrinking – especially in areas where there are not many businesses or people to tax. A Government Green Paper must respond to the locality-based funding crisis and not just the national one. However, it is now two years overdue. In the meantime, the crisis is escalating.

The consequence, it says, is that vulnerable people and their families are paying the price – left with devastating social and financial consequences. They have heard from people who say that when a loved one requires funding from their local authority, many care homes will simply tell the family that they should pay an additional fee to meet the costs.

Families who are unable to pay turn to The Salvation Army to help. All Salvation Army care homes are subsidising the costs of providing care from Salvation Army funds. The report calls on government to prioritise its spending and properly fund adult social care. Local authorities, it says, are being asked to achieve the impossible.
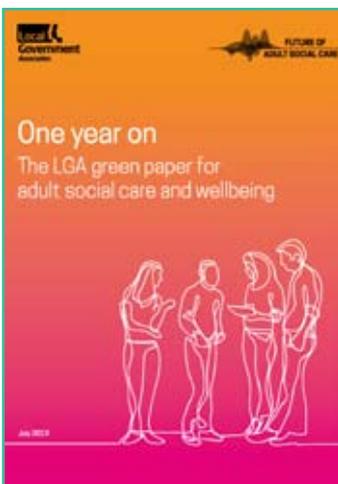
Local government has published its own take on the crisis. This report starts with a reminder that a year ago, after the government announced a further delay to the social care green paper, the Local Government Association (LGA) responded by publishing its own green paper. In the twelve months since then, it says, "*the Government has delayed, delayed again, and delayed once more*".

The report offers commentary on the consequences – starting with care service users, and informal carers. Other perspectives come from charities, care providers and local authorities. The LGA itself offers to "*host and facilitate cross-party talks aimed at building cross-party cooperation*".

The LGA accepts that there have been welcome injections of funding in the past year. However, it says that these "*do little to enable efforts to plan for the medium to long-term...Another year of inaction has passed, leaving the system creaking under further, unsustainable pressure. More importantly, this continues to impact everyone with care and support needs, preventing them from living their life to the full*".
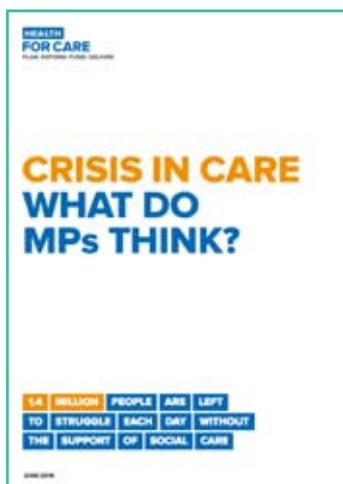
The Health for Care coalition, which includes patient voice organisations such as Healthwatch and National Voices, states in this report that "*Unlocking a solution to the social care crisis will require political leadership and, ideally, a cross-party consensus*".

To inform government thinking ahead of the green paper and the expected spending review in autumn 2019, the coalition wanted to test the views of MPs on whether they believe there is a crisis in social care, whether they have noticed an increase in their constituency casework regarding social care, and what options for reform they would favour. The results show that:

- Three quarters of MPs (76%) agree there is a crisis in social care. This includes more than half (58%) of Conservative MPs.

- Six in ten (60%) believe their constituents are suffering because of cuts in social care. However, there is a significant difference across political parties, with a third of Conservative MPs (32%) saying this compared to 94% of Labour MPs.

- Two thirds of MPs (65%) say their social care casework has increased during their time in office, with nearly half (46%) saying it has increased significantly.

- There is little faith among MPs that the green paper will improve standards of social care provision – only half (49%) agree it will. Again, there is a big split along party lines with 82% of Conservative MPs believing that the promised green paper will improve provision as against just 10% of Labour MPs.

- While there is consensus among MPs about there being a crisis in social care, politicians are evenly split in their support for different reform options.

The coalition reports that "*the most striking elements of our research has been the sheer number of MPs who agree there is a crisis in social care, alongside the vast numbers who have noticed a significant increase in social care cases raised by their constituents*". But, they say, "*there is a marked lack of consensus on the potential options for reform*".

4. About the Patient Experience Library

The Patient Experience Library is the national evidence base on patient experience and patient/public involvement, with over 50,000 studies and reports from government bodies, patient voice organisations, academic institutions, health charities and more.

We are pleased to be working with organisations such as the Care Quality Commission and the NHS Leadership Academy, as well as voluntary sector partnerships, to mobilise the intelligence they need for policy development, quality improvement and risk management.

Visit *our website* to get free access to our *weekly newsletter*, *quarterly magazine*, *Knowledge Maps* and other resources.

Contact us (*info@patientlibrary.net*) to ask how we can help you to develop evidence-based approaches to understanding patient experience.

Follow us on Twitter: *@patientlibrary*

www.patientlibrary.net

Appendices

A.1 Sources of evidence

There are multiple mechanisms for patient feedback and multiple sources of patient experience evidence. Making sense of them all can be difficult. Here, we offer a basic analysis.

Table 1

Type	Description	Sources
1. Surveys	Mainly numerical data, often 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: • Accident and emergency • Adult inpatients • Children and young people – inpatient and day case • Community mental health services • Maternity services NHS England surveys for: • GP practices • Cancer services The NHS Friends and Family Test
2. Studies	Written reports, often with qualitative evidence based on patient stories and observations. Tend to feature small sample sizes, with a focus on specific named services and/or health conditions. Often with recommendations for improvements to policy and practice.	"Patient voice" bodies including Healthwatch, National Voices, Patients' Association, health charities and think tanks. Care Quality Commission inspection reports – especially the "Caring" domain.
3. Research	Academic papers, usually featuring rigorous methodology, theoretical frameworks and peer review.	Health research bodies including NIHR, NICE, Academic Health Science Networks, Collaborations for Leadership in Applied Health Research and Care. Universities
4. Online feedback	Direct comments from service users, sometimes backed up with analytics including sentiment analysis.	Care Opinion Hootvox LHM rate and review (used mainly by local Healthwatch) NHS Choices star ratings Twitter
5. Other (local)	Feedback gathered via complaints and compliments, Patient Participation Groups, patient engagement committees and forums etc.	NHS Trusts, Clinical Commissioning Groups, GP practices etc.

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.

A.2 Quantity of evidence

We are not aware of any way in which the scale of patient experience work is added up across the NHS to give a total sum of activities and participants. However, 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.

A.2.1 The number of people contributing to national surveys

Table 2

Survey	No. of respondents
GP Patient Survey 2018	758,165
Adult Inpatient Survey 2017	72,778
National Cancer Patient Experience 2018	73,817
Emergency Department Survey 2016	44,500
Children and young people 2016	34,708
Maternity Services Survey 2017	18,426
Community Mental Health Survey 2017	12,139

In addition:

- Healthwatch England's 2017/18 annual report states that the Healthwatch network heard from 406,567 people about what they think of health and social care services.

- The NHS England Friends and Family Test hears from very large numbers of people every month. In June 2019, there were 1,269,846 responses.

A2.2 The number of published reports on patient experience

Again, we are not aware of any way in which this is added up nationally. However, a useful guide is the number of reports 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 August 2018 and July 2019, we uploaded 7,952 reports to the Patient Experience Library. Some had been published in previous years – the total published between August 2018 and July 2019 was 3,637.

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 2,314 reports on patient experience and patient/public involvement published between August 2018 and July 2019.