

Patient Experience

and patient/public involvement in health and care services

Autumn 2018



**Patient
Experience
Library**

INSIDE

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Non-compliance



Across health and care services, one of the biggest make-or-break factors for quality of patient experience is “communication”.

That can mean written or verbal communication. It can mean the use of medical jargon, as against language patients can understand. It can mean communicating in accessible ways - sign language or easy-read for example. But sometimes, it can be about sensitivity and tone of voice. And it can be as much about what is not said as what is.

Our contributors to this issue all remind us of the importance of good communications.

Vidhya Alakeson, bringing her elderly father home from hospital, could have done with help to understand what his care needs at home were going to be, and help to understand the roles and responsibilities of multiple health professionals involved in his post-discharge care.

Joanne Hughes, a bereaved parent, asks for a kinder, more healing dialogue with the health professionals who could have helped her to understand why her daughter died.

Julia Jones describes having to stand up for her mother against health professionals who seemed to be following rigid procedures rather than getting to know their patient.

It has been estimated that poor communications cost the NHS in excess of £1 billion per year. But these stories reveal the kinds of human cost that can never be counted.

The evidence on patient experience comes both from personal testimony and from formal studies. So our magazine also features our top picks from recent surveys and research, with summaries of learning points, and links to the original documents.

We're always keen to hear from our readers, so if you know of a stand-out report that we should be featuring, or if you want to submit a comment piece, get in touch!

Miles

Miles Sibley, Editor

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New
documents
Jul-Sept '18
711

During July - September 2018, we added 711 documents to the Patient Experience Library.

Around 278 came from health charities, think tanks and other government bodies, with around 433 coming from the local Healthwatch network.

Subscribers to the Patient Experience Library can view all of these, and search through over 50,000 documents on patient experience and patient/public involvement by logging in from the [Welcome Page](#) of our website. For details of how to subscribe, [click here](#).

Three lessons from lived experience

Vidhya Alakeson, Chief Executive, *Power to Change*



In 2014 I wrote a book about personal health budgets. I don't consider myself any great expert in health and social care but I thought I knew something about how the system worked. I was quickly proved wrong when my eighty-year old Dad had a brain haemorrhage which left him confused and unable to walk. It has to be said that the NHS saved his life. The challenges have all been in what followed.

Six weeks after surgery, my Dad came home, needing 24 hour care. The experience of dealing with the NHS and social care as a family member has been a battle, even though we are definitely better informed than the average. I have worked in health policy and my sister is a doctor.

Here are three things that would have made a big difference.

The first is to have been involved in my Dad's care in hospital. We were never involved in any physio or OT sessions, despite asking. Whenever staff did anything with him, the curtain was drawn around his bed. Everyone knew he would be discharged home but no one supported us with how to take care of him. Suddenly having to care for someone who needs help with every aspect of their life is incredibly daunting when you have no experience. To have been included in his care in hospital would have made a huge difference and would have cost very little.

The second is to have had a single person to coordinate the myriad of health professionals who turned up at my parents' house. We had the dietitian, the district nurse, physios from two different community teams, a nurse from the hospice at home team, nurses to take blood, someone from the incontinence service, on top of carers and my Dad's GP. Often people didn't introduce themselves, leaving us as the family to connect the dots. For my mum, it was mind boggling. A named coordinator to help piece everything together would have reduced the stress a lot.

The third is money. The cost of caring for my Dad in hospital wasn't an issue. But the cost of caring for him at home is. Like a lot of people, my parents have too many savings to qualify for Local Authority support and we're still waiting to see if we win the NHS Continuing Care lottery. At £21 an hour, the waking night care my Dad needs every night so that my seventy

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five year old Mum can rest and look after him in the day will cost them £1500 a week. My Dad's been given a year to live so maybe they will just be financially ok but they have cut back on day time carers to try and save money, putting greater strain on my Mum.

Your likelihood of needing social care is as unpredictable as your likelihood of needing healthcare and yet the state provides large numbers of us no protection against that risk. A fairer deal on financial support feels essential.

If I've learnt nothing else, it's that putting people with lived experience at the heart of policy making and system design is essential. I've been humbled to be reminded that you can know a lot about policy and little about reality. However many clever brains apply themselves to the challenge of social care reform, without the insights of experience, we will fail.

From harm to healing

Joanne Hughes, Patient Safety Parent Voice, and owner of the [Mothers Instinct Website](#)



Our little girl, Jasmine Elizabeth Ann Hughes, died on 15th February 2011. She was 20 months old.

Jasmine was the centre of our world, a very funny, very feisty, very pretty little flower!

At Christmas 2010 she got a virus. She got 'better' but wasn't herself afterwards. Just over a month later, after a great number of breakdowns in communication within the NHS teams looking after her, a lack of attention to some of her basic observations, and a failure to adhere to safety guidelines by those responsible for administering her treatment, she died.

To watch your child die causes a part of you to die. Ask any parent what is the worst possible thing they could endure in their lifetime, and the vast majority will likely proffer to witness the death of one of their children. The physical pain and emotional injury is indescribable and all consuming.

Health professionals need to give families the whole truth about why their child died, and they need to provide support for families to cope with the enormity of the unexpected and devastating situation they find themselves in.

There needs to be a Bereavement Care package specifically for situations of avoidable deaths. It needs to be delivered by people independent of the healthcare provider, with total assurances to the family that information shared will remain strictly confidential.

The package could improve the offerings of bereavement counselling, and Cognitive Behavioural Therapy. It could include Bereavement Groups specifically for those affected by clinical negligence and avoidable death. Contact details for organisations like [AvMA](#) (Action vs Medical Accidents) and links to websites or blogs other families have produced following the avoidable death of a child could be shared.

In addition to the parents, those siblings left behind must also be considered in any care package being offered. My friends Odette and Lee Mould set up the charity Harry's Rainbow after their son Harry died, and they have a wealth of knowledge to share about the needs of bereft siblings.

www.harrysrainbow.co.uk

Official inquiries into avoidable deaths in the NHS include Mid Staffordshire, Morecambe Bay, Southern Health and Gosport. These often find that "reputation management" is the reason why Trusts fail to talk openly with bereaved relatives, and treat them with care and kindness.

Wouldn't the reputation be better if mistakes were acknowledged, publicised, and learned from, and Trusts could demonstrate the gentle care and compassion they had provided for the family in a care package, along with sincere, face-to-face explanation and apologies from those responsible?

However difficult engaging in this process might be for NHS employees, it comes nowhere near the distress and upset caused to parents who are shut out or told staff must be protected and they must go away and be happy with a vague letter from some manager or another, written with assistance from the legal department.

If things go wrong (and despite longing for a day when they won't, we know occasionally they will), the NHS should consider the 'patient experience' of the avoidably bereaved.

This is the accountability families deserve.

We hear she's not compliant

Julia Jones, Co-Founder, *John's Campaign*



It's 8 o'clock on a Monday morning, and I'm off to London to present the John's Campaign Book of Pledges to the Chief Nursing Officer at NHS England.

The phone rings. It's Jo, the nurse from the dementia suite where my mother lives. Mum has had a fall. She is on the floor, screaming, and the paramedics who are already there think she should be X-rayed.

I burst into tears. The trip to London is the culmination of a three year slog - and now here is Mum, aged 94, with a suspected broken bone for the first time in her life. And here am I, a weeping wreck in my dressing gown because I don't want to stay with her in hospital, I want to go to London.

Finally, I wash my face, get dressed and set off to the hospital.

Mum is there, and we sit waiting until two people - a staff nurse and another - arrive. "We hear she's not compliant" they say, and start telling me about

I feel as if we're on some terrifying conveyor belt going somewhere that we never meant to go.

Mental Capacity and how Mum won't be able to consent to treatment. They sound threatening. I do my damndest to explain Mum's situation; that she is here for an X ray, she does not want any other treatment, unless her bones are broken.

I feel frightened that the staff are going to start sticking needles into Mum. She'll fight. Then they'll need to restrain or sedate her. This will turn nasty.

I claim my right to speak for her, as her daughter. I try the phrase 'primary carer'. I mention power of attorney, and that the CCG accepts my right to advocate for Mum, for her Continuing Health Care assessment. They say that none of this matters - they'll judge what's in Mum's best interests. I get cross. They have only just met Mum, they know nothing about her!

I have a moment of inspiration. "When Mum did have the capacity to consent, she said No. We have a Preferred Place of Care form - it's with her care plan and her DNR (Do Not Resuscitate) form."

They look bemused and tell me to talk to the doctor, who has just arrived. She says Mum may have fallen because she's getting an infection. She tells me about blood tests and a precautionary chest X-ray, taking blood pressure,

various samples, possibly a scan and then maybe keeping her in and giving intravenous antibiotics.

I feel as if we're on some terrifying conveyor belt going somewhere that we never meant to go. I dig my heels in hard - when Mum did have capacity she would not have consented to all of this. I mention Mum's Preferred Place of Care form, saying that she wants to be treated by her own GP in her own place. We are only here for an X-ray.

Suddenly the doctor gets the point that we are refusing all other treatment than what we came for - an X-ray. It seems like a light bulb moment! She explains that the 'routine' blood tests and 'precautionary' X-rays and possible admission are "just the way we do things here".

A couple of hours later, we'd finally had the X-ray. Mum had had no pain relief, and nothing to eat or drink. She was exhausted and agitated. In came someone from the dementia department to make an assessment. FGS! Mum was diagnosed in 2010. She lives in a specialist dementia nursing suite. She needed to go home.

The medicine came, my daughter came. The paper work didn't. We bundled Mum into the car and left without it.

Mum was constipated for the next 12 days and didn't eat properly for three weeks, losing 7kgs in weight. She's picking up now but I still wonder why it had to be like that - and how much longer the process would have extended if I hadn't been non-compliant.

RECENT REPORTS

Here, we review our top picks of studies and surveys from the last three months. Some are newly published - others are featured because they shed useful light on recent issues and developments. For full attributions, and copies of the original documents, click on the report pictures. Do you know of a stand-out report that we should be featuring? Contact us! info@patientlibrary.net



Patient Experience in England

NHS strategies, from the Five Year Forward View down, state that an understanding of patient experience is central to development of “person-centred” services. We hope that our annual overview of patient experience evidence will help to develop that understanding.

The report’s content is assembled from some excellent work that has been produced over the last twelve months via national patient surveys, academic research, think tanks and official inquiries. Together, the documents offer a compelling overview of the state of patient experience and patient/public involvement in England.

A year ago, when we published our [first such report](#), we said that we had three ambitions:

1. To offer a single point of knowledge on patient experience and patient/public involvement. Much of the evidence resides in the realms of “grey literature”, and it has been far too difficult for people to track it down. We want to make it much easier to find.
2. To preserve the literature. Over a forty year period, Community Health Councils, PPIFs, LINKs and now Healthwatch have made valuable contributions to the collective intelligence on patient experience. But there has been no archive, so vital knowledge has been lost. Without access to their own history, health services risk repeating the same mistakes. We want to help the NHS to learn from past experience.
3. To give patient experience leads parity with clinicians. Happily, clinicians have open access to professional databases to guide their practice and professional development. Unhappily, patient experience leads don’t. We want to even up the professional playing field.

We intend to carry on with our mission of bringing patient experience into the light. And we’d like to extend our thanks to the many people who have helped us on our way, and whose contributions are acknowledged on page 3 of the report.



A letter from the doctor

In an important development for person-centred care, the Academy of Medical Royal Colleges is encouraging doctors to write outpatient letters directly to patients, copying in the GP. This reverses the traditional approach of writing to GPs and (sometimes) copying in the patient.

The move matters for two key reasons.

Firstly, it shifts the power balance. Patients become primary recipients of information about themselves. They are no longer positioned as bystanders in their own care, watching passively while professionals talk to one another above their heads.

Secondly, GPs benefit as well. The Academy states that “Doctors who have adopted the practice say their communication style has become more patient-centred. GPs find the letters easier to understand and spend less time interpreting the contents for the patient”.

The new guidance does not come out of the blue. It reflects statements about patients’ rights in the NHS Constitution, and GMC guidance on good medical practice. And while it is based in policy, the Academy recognises that it cannot take implementation of the guidance for granted. It calls on “hospital trusts and clinical teams to support this initiative and provide help and training to all who need it”.

Addressing letters to patients first and GPs second may seem like a very small step. But in an NHS where the term “person-centred care” is scattered liberally through policy documents *without necessarily being well defined*, it is good to see some very practical guidance being issued. Particularly guidance that should be achievable at little or no extra cost.

Implementation of the guidance would mark a welcome cultural shift in how professionals communicate with patients. This is important guidance that should be required reading for Trust Boards.



Gosport: an end to anecdote

The Gosport inquiry must - surely - mark the point at which dismissal of patient feedback as “anecdote” finally comes to an end.

NHS culture is much better than it used to be. Patients are now encouraged to give feedback - and complaints, compliments and concerns are seen by the best providers as learning opportunities. But in a science-driven system, there is a lingering sense that “hard” evidence - statistically based - is more reliable than the “soft” stuff of patient stories.

We cannot go on with this dangerous and damaging myth.

A 2015 report from Dr. Foster explored the uses and abuses of performance data in healthcare. It found plenty of ways to manipulate statistics, including bullying of staff, “gaming” waiting time and mortality data, distorting patient pathways to meet treatment targets, and arguing about data quality in order to divert attention from poor care.

At Mid Staffordshire, the Healthcare Commission (predecessor to the CQC) followed rigorous inspection criteria and gave the Trust a clean bill of health. The Trust’s Board were looking at key performance indicators that showed steady progress towards Foundation status. But it was patients and relatives, with no statistics, no performance data, and no research methodology, who got much closer to the truth of what was happening on the wards.

Even when statistics are reliable, professional and organisational fear can put reputation before truth. At Morecambe Bay and Southern Health, and in the *Hyponatraemia inquiry*, defensiveness, collusion and cover-up were common factors. Patient stories may indeed be unreliable at times. But, sometimes, the same can apply to professionals’ stories.

We need to end the reverence for statistical evidence, and accept that it can, sometimes, be flawed. And we need to stop seeing patient testimony as “soft” and acknowledge that it can, sometimes, provide better insight than the numbers.

The plain fact is that qualitative and quantitative evidence, taken together, give us the best chance of getting an all-round understanding of how well our healthcare systems work for patients.

For too long, patient feedback has been described as “anecdotal evidence”. After Gosport, we need to recognise that it is, simply, evidence.



The evidential value of lay knowledge

“They seem to need a disaster to change regulations, rather than evidence.”

This 2013 quote comes from the secretary to the Parliamentary Fire Safety and Rescue Group, after government had ignored the Group’s recommendations on fire safety in tall buildings. Four years later, Grenfell Tower burnt down.

Warnings about the specific risks at Grenfell Tower had come from residents and from the Grenfell Action Group. But their “lay knowledge” of the building’s attributes was not acted on.

The scenario would be familiar to patients and relatives at Mid Staffordshire, Morecambe Bay, Southern Health or Gosport. In each of those cases, evidence – in the form of personal observation, feedback and complaint – was ignored until it was too late.

This paper considers the question of lay knowledge, and the extent to which it is recognised – even permitted – by professionals.

The authors trace the value of people’s experiential knowledge all the way back to Aristotle, who described it as “practical wisdom”. But they say that lay knowledge can be marginalised in policy and practice.

Sometimes this is because it is seen as “oppositional discourse”, of a “political nature”. Rebuttals of this kind have certainly been experienced by groups such as maternity rights campaigners, and by people expressing concerns about Sustainability and Transformation Plans.

It can also be because “the evidence movement remains obsessed with a hierarchy in which quantitative research-based knowledge reigns supreme”. This means that “Knowledge... can be used to... exercise discursive power in ways that privilege some definitions of health and social problems and marginalize others”.

The opinion of the authors, however, is that, “Like all evidence, the ‘trustworthiness’ of experiential knowledge should be assessed... but it should not be ignored.”



GP patients move online

The 2018 GP Patient Survey offers some good news, with generally high levels of satisfaction at the NHS's front line of care. 93% of patients felt involved in decisions about their care and treatment. 87% felt their healthcare professional was good at treating them. And of everyone who wanted a same day appointment, 66% got one.

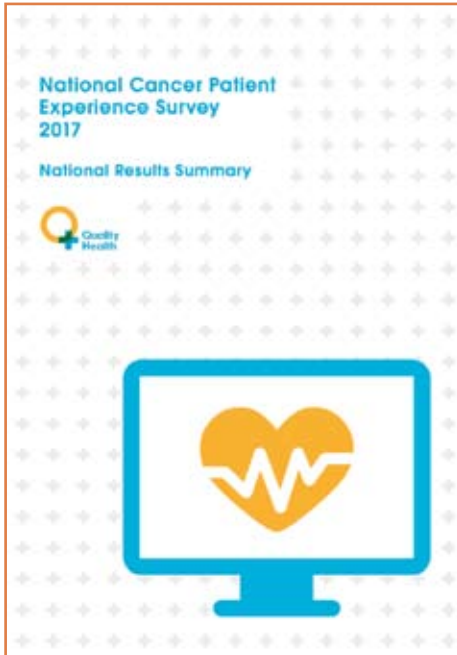
The survey method has changed this year, which means that comparison with previous years' results is problematic for some questions. So we looked at patients' online access to some aspects of GP services, but had to take previous years' results as a general contextual guide rather than a statistically reliable result.

With that caveat, it would appear that fewer people are booking appointments by phone (78% as opposed to 86% in 2017). But more are booking online (10%, against 9% in 2017 and 7% in 2016).

Growing numbers are also aware that they can access medical records online. In 2016, just 6% of patients knew this. In 2017, it was up to 9%, and this year, the figure has risen to 13%.

For repeat prescriptions, there is a similar trend. 14% of respondents had used online services in the last 12 months to order repeat prescriptions, up from 12% in 2017 and 11% in 2016.

Again, changes in the survey method mean that statisticians cannot be 100% reliant on a comparison of this year's results with those from previous years. But for practical purposes, GP practices can probably take it as read that more patients are looking for the convenience of online access, and that a good digital offer will contribute to a better patient experience.



Living with and beyond cancer

This year's Cancer Patient Experience Survey brings encouraging findings, with significant improvements across a range of indicators.

91% of respondents said that they were given the name of a Clinical Nurse Specialist who would support them through their treatment. And 86% said that it had been 'quite easy' or 'very easy' to contact their Clinical Nurse Specialist.

Alongside that, 89% of respondents said that they were treated with respect and dignity in hospital, and 79% said they were definitely involved as much as they wanted to be in decisions about their care and treatment.

As always, it is worth comparing the survey's findings with patient feedback coming from other sources.

We revisited the recent *CQC Adult Inpatient Survey*, which reported that a quarter (25%) of patients thought their family (or someone else close to them) were not given all the information they needed to care for them after leaving hospital. That means that three quarters (75%) did feel adequately informed. But in the cancer survey, only 59% of respondents said that the doctors or nurses definitely gave their family or someone close to them all the information they needed to help care for them at home.

Additionally, the Adult Inpatient Survey found that less than two-thirds of patients (62%) left hospital with written information telling them how to look after themselves post discharge. For the cancer survey, patients were asked if they had a written care plan, but found that only one third (35%) said that they had been given one.

Since NHS strategies stress the importance of "self-management" for people with long term conditions (including living with and beyond cancer) the issue of information-giving is crucial. Differences in the way questions are asked may mean that the Cancer Patient Experience Survey and Adult Inpatient Survey are not directly comparable. But the similarities are striking, and taken together, the surveys seem to be pointing to an area that is ripe for improvement.



Patients or consumers?

There is a perpetual debate in the world of patient experience and patient/public involvement about how to describe anybody who is not a health professional. The terms “patients”, “service users” and “consumers” are all used - with varying degrees of comfort or conflict.

This report from the Beryl Institute sheds interesting light on the matter. They looked at “Consumer Perspectives on Patient Experience” (possibly hedging their bets with that title) and found that for most people, “patient experience” matters more than “consumer experience”.

The report states that “Most people... would not suggest that individuals in healthcare facilities are simply customers in the traditional sense of the word”. But it goes on to say that “While it is often suggested that healthcare is not the hospitality business or primarily a retail environment, those leading healthcare would be naive to think they are not being compared to those other experiences people are having”.

In other words, in the commercial sphere, people - as customers - have come to expect convenience, responsiveness and personalisation. In the healthcare sphere people - as patients - may well have similar expectations.

In spite of this, when people were asked “Why is having a good patient experience important to you?”, the top three answers all touched on physical needs and how patient experience contributes to healing and health outcomes. By contrast, the bottom three answers were all about customer-focused items such as time and money.

The authors conclude that “while people do acknowledge that to some extent in healthcare it is about being a customer, their health and their humanity are of greater importance”. Indeed, “experience is not about just satisfaction, but the real outcomes people hope for in their healthcare encounters. [The reason] why experience is important to consumers is that it’s first about their own health”.

One further point worth noting is that 91% of survey respondents said that patient experience was “very” or “extremely” important to them. So patient experience is “not just an idea at the softer edges of healthcare, but rather it sits at its heart and has significant impact and serious implications for how healthcare is led into the future”.



How PPI changes professionals

People with an interest in patient and public involvement (PPI) spend a lot of time talking about definitions.

There is, for example, the question of whether members of the public should be described as “patients”, “service users” or “consumers”. Another question is whether they are “involved”, “engaged” or “participating”. Deeper debate considers whether people are “co-producers”, “co-creators”, or simply “experts by experience”.

What all of these debates have in common is that they reflect a discussion among health professionals about the status of patients.

Language reveals culture. And the debate about how to describe PPI reveals a culture in which power is firmly held by health professionals. It is about how those who hold power choose to define the terms on which patients and public will be invited to the table.

This paper makes the often overlooked point that “measures to strengthen the position of service users not only change the position of the users, they also alter the position of the professionals involved”. The paper examines different types of involvement, and their implications for the positioning of professionals.

So efforts to encourage self-management of long term conditions may be framed as empowering patients through self-determination and participation in decisions about their own treatment and care. This positions health professionals as educators, advisers and supporters.

Efforts to encourage sharing of lived experience can move professionals into a different position. In professionally-led groups, they can be seen as facilitators. In self-help groups, they may have no role at all.

Finally, in efforts to improve services through awareness of user perspectives, the service users may take the role of educators, while professionals become positioned as learners.

Health professionals managing PPI activities will - rightly - continue to debate the nature of public involvement. But they should not assume that their own role and purpose runs unchangingly through different types of engagement. Whether they know it or not, the very act of engagement changes their own position and status as much as that of patients.



What actually is peer support?

Read any NHS strategy and sooner or later you'll come across a reference to the fact that more and more people are living with long term health conditions. The favoured responses involve "self-management" – enabling people to look after themselves by, for example, monitoring and medicating their condition.

Children with long-term conditions will get help from parents and carers. But at school and in friendship circles, they may also look for "peer support".

This study asked pre-adolescent children with Type 1 diabetes what peer support actually meant to them.

Virtually all children described having a small number of close friends who were interested in learning about, and helping with, their diabetes. These friends provided support in three overlapping ways.

"Monitors and prompters" offered reminders of diabetes-related routines (eg blood glucose self-monitoring or administering insulin), for example on occasions when the diabetic child became so engrossed in activities that they lost awareness of time.

"Helpers" offered practical support - for example, by alerting adult caregivers when a friend needed assistance to manage hypoglycaemia.

"Normalizers" might make adaptations to their own lives so that friends with diabetes need not compromise self-management activities to fit in. One example was a girl whose friends delayed having lunch at school until she had completed self-management tasks so they could eat together.

Interestingly, the children interviewed were ambivalent about meeting other children with type 1 diabetes at organized groups or events. Some children speculated that speaking to peers with diabetes might help reduce social isolation, but several cast doubt on whether such encounters would lead to lasting and supportive relationships. One girl said that she would prefer to develop friendships of her own volition rather than as a result of being brought together on the basis of a shared disease status.

Rethinking engagement



Traditional methods of gathering patient feedback are “stuck in child-parent mode”, according to this thought-provoking editorial from the British Journal of Psychiatry Bulletin. The author, David Gilbert, writes from his experiences as both professional and patient, and calls for a fresh approach to patient engagement.

For Gilbert, “Patient and public engagement, as traditionally conceived, buffers power by distancing patients from decision-making.”

With conventional patient feedback, people are invited to “fill in questionnaires, attend focus groups or tell their stories...The focus is what happened to them in the past, mostly about their experience of services (rather than living with a condition, or about their lives beyond the institutional scope of interest)”.

Subsequently, “the meaning of their data is left to professionals to assess... based on... institutionalised thinking (often what is seen as feasible rather than necessary)”. For Gilbert, this approach “mirrors traditional medical paternalistic models - you tell us the symptoms and we will provide the diagnosis and treatment. It is stuck in child-parent mode”.

The article makes the important point that “Patients are not permitted to eyeball the data or bring their own interpretations to it”. At the local level, patient access to feedback data may vary between Trusts and CCGs. But at the national level, Gilbert’s observation chimes with our own view that feedback data is held by so many different organisations in so many places and so many varying formats that even dedicated patient experience staff can struggle to keep up with it all. For patients and public, the task is nigh on impossible.

The editorial goes on to explore committee processes that invite patient representatives but then marginalise their contributions. The consequence, says Gilbert, is that “committees lapse into a default ‘us and them’ mode. Frustrated, marginalised and unprepared representatives start finger-wagging or fall silent. This is adolescent-parent style engagement”.

The analysis may be critical, but it follows through with pointers to better ways of doing patient engagement. In particular, a case study of a real-life exercise in rethinking engagement (via the Sussex Musculoskeletal Partnership) shows that alternatives are possible - and that they work.

Patient leadership summit

Monday 15 October 2018
De Vere West One Conference Centre,
London

This national summit chaired and co-produced with Jonathon Hope MBE will focus on the important issue of Patient Leadership and how you can support patients in your organization to co-design and improve services, how you can help patients to develop patient leadership skills and how to effectively work with patient leaders.

Patient and public engagement: where next?

Monday 15 October 2018, 1.00-2.00pm

This free online event will explore where patient and public engagement is right now in the NHS and what needs to change.

The King's Fund recently published a report arguing that patient and public engagement is still seen by some in the NHS as something that 'has to be done' rather than providing key insight and understanding into local populations and their needs. Our speakers will discuss why this is and what might need to change to ensure engagement moves beyond being seen as a 'nice to have' to a 'must have'.

Learn about the value of online feedback

Manchester, Wednesday 7 November
London, Tuesday 13th November

Whether you are brand new to Care Opinion and need to understand what we do and why we do it, or you are an old hand but want to catch up with latest developments (and even influence what we do next), this workshop is for you. It will be informal, informative and, we hope, inspiring too!

We know that some really important changes are coming down the line: *"Rather, the NHS needs to work differently by providing more care in people's homes and the community and breaking down barriers between services. Breaking down barriers means co-ordinating the work of general practices, community services and hospitals to meet the needs of people requiring care."* Kings Fund 2018

The workshops will examine how our fully integrated platform can help meet these future challenges, and are likely to be useful for providers, commissioners and other stakeholders too.

Help NHS England spread the word about cancer feedback

NHS England is asking colleagues and partners to help spread the word, right through autumn, about the importance of hearing ALL voices in feedback about cancer services.

The push is designed to coincide with the sending out of questionnaires for the national Cancer Patient Experience Survey from October. We are keen to increase awareness of the survey and increase the number of responses.

You can view and download an A3 or A4 poster, or order printed copies free of charge, by clicking on these links to product pages on the Health and Social Care Publications Orderline or by telephoning your order to 0300 123 1002. The ordering codes for the posters are: [BMEA3PSTER](#) for the A3 size; and [BMEA4PSTER](#) for the A4 size.

You can also download other materials that might be useful: sample [promotional text](#); digital and print resources - [web banner](#), [Facebook promotion image](#), [Twitter promotion image](#) and "advertising" artwork suitable for print publications such as a local community publication or newsletter, available in [A5](#) or [A6](#).

If you have any queries, please do get in touch with [Gillian Radcliffe](#), Communications Manager for the Insight & Feedback team.



The Patient Experience Library

Our ground-breaking initiative has collated and catalogued the whole of the UK's collective intelligence on patient experience. We can offer access to over 50,000 documents on patient experience and patient/public involvement, from government bodies, Healthwatch, think tanks and health charities.

[Visit our website](#) to get free access to our weekly newsletter, *Knowledge Maps* and other good stuff.

[Contact us \(info@patientlibrary.net\)](#) to ask how we can help you with *Insight Reports* on service design, commissioning and policy matters.

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Can't wait a whole week? Follow us: [@patientlibrary](#) 

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