

Patient Experience

and patient/public involvement in health and care services

Autumn 2017



INSIDE

Comment

Patient experience as a lever for funding

Recent reports

Our top picks of studies and surveys from the last three months

PX and PPI Support

Training for patients and professionals

**Patient
Experience
Library**



We sometimes think of the summer months as a quiet period, when everyone goes on holiday, and nothing much happens. But July to September was a good time for patient experience reporting, with plenty of valuable evidence coming to light.

In this issue, we review the results of the GP Patient Survey and the Cancer Patient Experience Survey.

Both contain good news, but there are also some findings which strike a warning note.

Academics, both in the UK and overseas, have produced insightful studies: we cover reports on how GPs view patient surveys, how other health professionals regard patient complaints, and how patients can succumb to profound disempowerment, and “hostage bargaining syndrome”. In the area of patient and public involvement, we review “Zombies and Unicorns” - a paper that describes itself as “a provocation” and which will certainly give readers food for thought.

In August, we were pleased to publish our own report on Patient Experience in England. We have looked at the bewildering array of feedback systems that patient experience leads are expected to keep track of. And we have reviewed studies that examine the evidence-practice gap, and show why health professionals can find it hard to act on patient feedback.

Our comment pieces on pages 3 and 4 reflect on the potential of patient experience as a driver for fundraising, and consider how researchers might work more closely with commissioners to support evidence-based commissioning.

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
July-Sept '17
3,119

During July-September 2017, we added **3119 documents** to the Patient Experience Library.

1740 were CQC inspection reports. We collect these because the “Caring” domain in particular can shed light on patient experience.

Of the remaining 1379 reports, 617 were from the local Healthwatch network.

A further 762 were from government bodies, think tanks, academic bodies and health charities.

Subscribers to the Patient Experience Library can view all of these, and search through over 40,000 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](#).

Patient experience as a lever for funding

Duncan Batty



Whatever their size, NHS charities all have one thing in common - their purpose is to enhance the care given to patients at the hospital they are connected to.

Every NHS hospital has a fundraising and grant-giving charity. Many are simply a little-known fund held by the Finance Department. Some, like Great Ormond Street, are household names and part of our shared culture.

Donations may come from one grateful patient, or from large scale national appeals, and if you make a donation to your local hospital, it will end up being looked after by their charity, whether you knew about it or not.

Whatever their size, NHS charities all have one thing in common - their purpose is to enhance the care given to patients at the hospital they are connected to. Income must be used to fund projects that are beyond the scope of 'standard' NHS care. Funds can be used to make the experience of visiting hospital more comfortable and welcoming, improve the quality of shared areas such as hospital grounds or waiting rooms, help family and friends feel welcome, and remain close during care, and develop staff posts that help patients understand and cope with the impact of a diagnosis or the effects of treatment.

Grant giving by NHS charities annual spending might be a fraction of the hospital's total spend, but the projects they support can make an impact on patient experience out of all proportion to the amounts available.

So how can funds best be used? The difficulty is that, with NHS resources stretched and NHS charities often being remote (in management terms and often in being based away from the hospital), it can be very hard to identify which projects would make the most difference to patient care and the patient experience. Funding requests can be *ad hoc* or might grow organically through the Charity's networking with clinicians rather than strategically.

NHS Trusts routinely collect patient experience information to highlight trends and issues in how patients view their time in hospitals. These can offer pointers towards those areas that have the largest impact (positive and negative) on whether a patient feels welcome and supported whilst in hospital. This offers two opportunities for NHS charities, whatever their size:

1. Working with patient partnerships and patient information teams, they can draw out themes and priorities to help them target areas where funding can make the biggest difference for patients.
2. Promoting these themes and priorities, they can encourage local communities, business networks and charity supporters to do targeted fundraising for improved patient experience.

My experience has been that many patients, each and every day, are already asking what they can do to help their local hospital and make it better for others in their community. And in over 5 years fundraising in the NHS, I never once received feedback to suggest local people felt anything other than a deep connection to their local NHS hospital, and a great understanding of the financial pressures it would be under. They were proud to help.

Integrating patient experience information into the grant-making decisions of NHS charities is a good way to ensure that donations go towards projects that are wanted, needed and supported by patients themselves.

Duncan Batty is a previous Head of Fundraising & Development at Sheffield Hospitals Charity, the NHS Charity for the Sheffield Teaching Hospitals NHS Foundation Trust.

Write less, talk more

How researchers can help evidence-based commissioning

Dr. Lesley Wye



I have been a researcher for over two decades. In that time, lamentations about the limited influence of research evidence have grown. But I think we researchers are largely to blame. We insist on disseminating our knowledge in ways that we know don't work.

Researchers usually write scientific papers, because publication is a key career performance metric. But scientific papers are read and digested by other scientists, not those who can act on our findings. [Our ethnographic study](#) showed how and why research doesn't reach policymakers, like healthcare commissioners.

We found that local healthcare commissioners cannot retrieve papers from many scientific journals, as they often do not have passwords or subscriptions. Although open access publication helps, commissioners usually use Google, where scientific papers often do not appear. If a commissioner can access a potentially relevant paper, the scientific jargon, 'intro-methods-results' structure and sheer length may be baffling, time-consuming and intimidating.

The next hurdle is in identifying and applying relevant findings. Often, there's no clear, practical message so it's discouraging to spend precious time wading through with a conclusion of 'more research needed'. What's more, successful interpretation requires someone who understands the research and can work with local commissioners to translate it into the local context. Research evidence published in scientific journals doesn't get to commissioners because commissioners can't access, understand, interpret or apply it.

What about guidelines?

Many researchers think that if their research informs guidelines, then job done. Commissioners often look at guidelines (especially from NICE), when revamping a service. But if the service is not under scrutiny, then the guidelines aren't consulted. What's more, commissioners tend to implement the 'doable' guidelines, defined as those that align with current services that don't cost any extra money. So as vehicles for transferring research evidence, guidelines have patchy success.

And evidence briefs?

What about short, punchy summaries of research evidence? Again, access is a challenge. Think tanks tend to distribute their own reports, not summaries of research evidence. Other national organisations producing research summaries are not often on commissioners' radar. And anyway, [evidence briefs made little difference to decision-making](#). Commissioners tended to glance over the brief quickly,

pick out the findings that concurred with their own views and then move on.

Researchers like to write, but commissioners like to talk

So what does this mean for evidence-based decision-making? Well, researchers rely almost entirely on the written word to disseminate their findings, yet systematic reviews consistently find that personal contact between researchers and decision makers is crucial. Researchers like to write, but commissioners like to talk. Through conversations, discussions and stories, commissioners can get timely, relevant, adaptable, contextually-specific information quickly. This suits their information needs and working environment.

Commissioners also need 'research translators' to help interpret findings. In Bristol, we set up a team of embedded commissioners (into academia) and researchers (into commissioning) that, according to independent evaluators, had substantial success in [stimulating conversations between researchers and commissioners](#).

Regardless of how those conversations are fostered, the wider research community needs to start making substantial cultural shifts. If we genuinely want our research to benefit society, then researchers need to write less and talk more. Now.

Dr. Lesley Wye is a Senior Research Fellow at the Centre for Academic Primary Care.



Beware Zombies and Unicorns and Unicorns

A lack of consensus about what effective PPI in research processes might look like

“Lack of clarity on what PPI is (or might be) has given rise to a poorly monitored, complex field of activity...”

This statement is the opener to a paper described by its own authors as a “provocation”. Their concern is that the investment of time and resources in much PPI is taking a form of “busywork”: a time-consuming technocratic distraction.

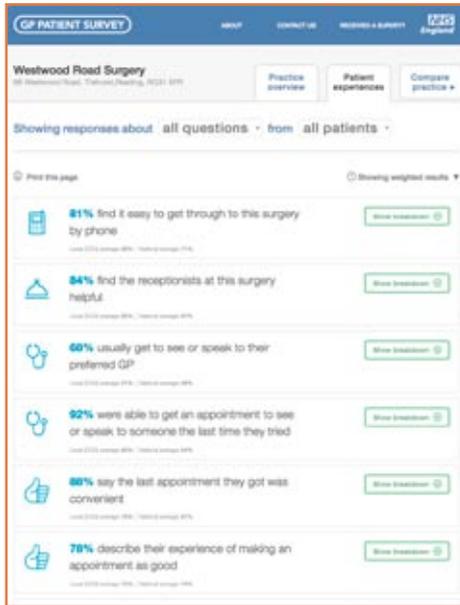
The paper reviews the development of patient and public involvement in health research, and observes that *“there is a lack of consensus about what effective PPI in research processes might look like and ...little conclusive evidence about the best (or worst) ways to invoke PPI in research design, research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

An underlying problem is that *“Different models of PPI carry distinctive and sometimes contradictory assumptions about the types of public to be involved, the knowledge those publics might bring to bear, and their degree of involvement in decision-making processes.”*

Furthermore, people who step forward as patient/public representatives have varying motives for doing so. Some are *“predominantly concerned with promoting and defending their own interests and values against other participants”* while others *“view themselves as interdependent members of a social collective and [are] oriented towards collective ends and the common good”*.

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

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



2017 GP Patient Survey

Good and bad news, but no requirement to act

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

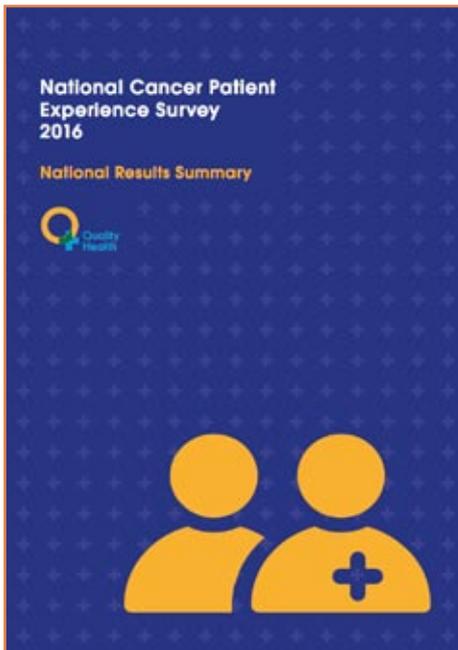
There are also useful insights into changing behaviour among patients – particularly in respect of engaging with GP practices online. 8% are booking appointments online – tiny when compared with the 86% who prefer to use the phone, but an increase nevertheless on last year’s 7%. Awareness of online services is also increasing, with over a third of patients knowing that they can book appointments online, and a third also knowing that they can order repeat prescriptions online. Only 2% of patients, on the other hand, access their medical records online.

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

Should we be worried? Well, yes – on two counts. Firstly because Sustainability and Transformation Plans, with their mantra of “care closer to home” will rely on primary care services to help keep the pressure off acute services. Any reduction in patient experience of primary care must be worrying for STP leaders.

The second cause for concern is that, as stated by the [National Institute for Health Research](#), “While the GP Patient Survey data for any given practice is used as part of its CQC inspection record, there is no standard requirement for practices to review that data or act upon them. As a result there are wide variations in the use of the data and the value that can be derived from them”.

So we know two things about the 2017 GP Patient Survey results. One is that there are statistically significant declines in patient experience since 2016. The other is that GPs don’t have to do anything about it. That’s not to say they won’t. But at the whole system level, we have an NHS that seems content to gather patient experience data, while acknowledging that “there are wide variations in the use of the data and the value that can be derived from them”.



2016 Cancer Patient Experience Survey

Satisfied patients in spite of worse survival rates

The results of the 2016 National Cancer Patient Experience Survey are now available, published as national data plus reports at CCG and Trust level.

This is the sixth annual survey, so a longitudinal body of knowledge is starting to emerge, allowing for comparisons over time.

The National Results Summary states that *“the experience of cancer patients in England continues to be generally very positive”,* and that *“compared to last year’s survey, there were significant improvements on 13 questions; scores deteriorated significantly on 1; there was no significant difference on 35”.*

Communication with patients seems to be generally good. 78% of respondents said that they were definitely involved as much as they wanted to be in decisions about their care and treatment. And 94% of respondents said that hospital staff told them who to contact if they were worried about their condition or treatment after they left hospital.

The report does, however, make the point that *“the national picture of experience of care remains inconsistent... for example, patients appear to get more information on some areas (e.g. free prescriptions) than on others (e.g. benefits); information about chemotherapy/radiotherapy appears to be better before treatment than during it; and care and support from health and social services at home appears to be less positively experienced than care received in hospitals”.*

With impeccable timing, the Association of the British Pharmaceutical Industry (ABPI) has also [published a report](#), giving a UK perspective on patient access to cancer medicines. They state that British cancer patients have worse survival rates after five years compared to the European average, in nine out of ten cancers, and that the UK spends over 20 per cent less per person on cancer than the top five EU economies.

It would appear that despite poorer access to cancer medicines, and lower survival rates, English patients remain satisfied with their experience of cancer services. This must be at least in part because of the high quality of non-medicinal aspects of cancer care. For example, access to information, and help from a Clinical Nurse Specialist are rated highly by respondents to the National Survey as factors that improve experience of care.

The ABPI report makes some important points, and is to be commended. But the National Cancer Patient Experience Survey shows that good quality healthcare is not just about medicines. Patients want to be looked after. And the human touch - kindness and good communication - is a vital part of the mix.



Improving patient experience in primary care

Patients are reluctant to be critical when completing feedback questionnaires

“...surveys are a valuable resource for monitoring national trends in quality of care [but] may be insufficient in themselves to fully capture patient feedback, and in practice GPs rarely used the results of surveys for quality improvement.”

This document - at some 450 pages - gives a whole new meaning to the term “in-depth study”. There is, however, an excellent summary, as well as a [helpful blog](#). The report offers some thought provoking findings, including these:

- Patients are reluctant to be critical when completing feedback questionnaires. Reasons included the need to maintain a relationship with the GP, gratitude for NHS care, and power asymmetries. Patients find questionnaires to be limited tools for feeding back concerns about consultations.
- Ethnic origins of patients have a bearing on patient experience. Low scores given by Pakistani patients in surveys such as the GP Patient Survey reflect care that is genuinely worse, and possibly much worse, than that experienced by their white British counterparts.
- GPs are positive about the concept of patient feedback, but struggle to engage with and make changes under current approaches to measurement.
- Within practices, and in out-of-hours settings, staff neither believed nor trusted patient surveys. Concerns were expressed about their validity and reliability, and the likely representativeness of respondents.

The authors conclude that there is “a huge gap” between the measurement of patient experience, and the actions being taken as a result. Importantly, they state that *“the major question for the future is how we are going to take the wealth of data on patient experience and make experiences better, rather than simply better understood”*.

It is impossible, in this short review, to do justice to such a wide-ranging and in-depth study. We recommend a read of the report.



Patient Experience in England

NHS staff bombarded by 18 separate feedback sources

NHS strategies state that an understanding of patient experience is central to development of “person-centred” services. But our latest publication reveals that NHS staff are bombarded by eighteen separate reporting mechanisms on patient experience. Data arrives in different formats and at different times, and some of it is of questionable quality.

The report, “Patient Experience in England”, cuts through the muddle, explaining how patient experience evidence is gathered and disseminated. It shows what has been learnt about patient experience in England over the last year. And importantly, it looks at whether health service providers are acting on the learning.

Good news from the last year includes generally positive experiences for cancer patients, and a sense among hospital inpatients that confidence and trust in clinical staff has gone up. However, other findings strike a warning note:

- There are “significant declines” in key areas of person-centred care.
- “Substantial concerns” remain about the quality of care some people using community mental health services receive.
- In maternity services, some women were left alone at a time that worried them during early labour, and of those who raised concerns, not all felt that their concerns were taken seriously.

The report goes on to list recent research studies that have shown an “evidence-practice gap”, with Trusts, CCGs and GPs all having difficulty in translating patient experience evidence into better service delivery.

NHS Trust Boards, for example, spend substantial amounts of time reviewing patient satisfaction, listening to patients’ stories and discussing quality and safety. But they do not always use the feedback from surveys explicitly to monitor or assure the quality of care.

On the wards, healthcare staff often find it difficult to act on patient feedback in order to make improvements to services. This may be partly down to how or whether individuals value patient voice. But importantly, *“Insufficient organisational readiness usually blocks action planning”*.

And within CCGs, commissioners may be reading reports and recommendations from public engagement exercises, but they *“tend to implement the ‘doable’ ones, defined as those that align with current services that don’t cost any extra money”*.



When Patients and Their Families Feel Like Hostages to Health Care

Patients understate concerns, or remain silent against their better judgment

There is much talk in the NHS these days of “person-centred care”, and of patients and clinicians being “partners in care”. The aim is to move on from the old “doctor knows best” attitude, and to encourage “empowered patients” to participate in decision-making.

Of course, culture change is often easier said than done, and this paper from America’s Mayo Clinic describes how some patients can succumb to “hostage bargaining syndrome” (HBS), whereby they behave as if negotiating for their health from a position of fear and confusion.

The paper observes that medical care has recently become more focused on serving patients as consumers. But most commercial services are “want” services, while medical care is a “need” service that consumers-turned-patients often dread and may delay receiving.

Patients are often reluctant to assert their interests in the presence of clinicians, whom they see as experts. The higher the stakes of a health decision, the more entrenched the socially sanctioned roles of patient and clinician can become. HBS is especially seen when serious illness unfolds over the course of multiple, complex, emotionally laden interactions with clinicians. Cancer care and intensive care, for example, are characterised by a high degree of dependence and powerlessness for patients.

HBS can manifest as understating a concern, asking for less than what is desired or needed, or even remaining silent against one’s better judgment. When HBS persists and escalates, a patient may succumb to learned helplessness, making his or her authentic involvement in shared decision making almost impossible.

The authors conclude that clinicians often have the power to arrest and reverse HBS by appreciating, paradoxically, how patients’ perceptions of their power as experts play a central role in the care they provide.



‘It’s sometimes hard to tell what patients are playing at’

How healthcare professionals make sense of why patients and families complain about care

This report looks at the position of health professionals, and considers how they react to more assertive patients - the ones who are (or are perceived to be) complaining.

Interviews with 41 staff in eight different NHS settings explored how they made sense of complaints and of patients’ (including families’) motives for complaining.

The authors found that complaints were seen as a breach in fundamental relationships involving patients’ trust or recognition of professionals’ work efforts. For front-line staff, the experiences of patients complaining were highly emotive. Interviewees described feelings of ‘gutting’, ‘devastation’, ‘awful shame’, ‘disbelief’, ‘shock’ or ‘incomprehension’ that a complaint should be raised about themselves or colleague and, as often, about the service where they worked.

There is evidence that events of complaint are rationalised by care professionals as signs of ingratitude or disregard for the individual efforts or services involved in providing care. At the same time, hospital staff expected patients to recognise, and adjust their expectations to, the time and service constraints that staff had to deal with.

The authors conclude that complaints were most often regarded as coming from patients who were inexpert, distressed or advantage-seeking. Accordingly, care professionals positioned themselves as informed decision-makers, empathic listeners or service gate-keepers.

Troublingly, the authors note that it was rare for interviewees to describe complaints raised by patients as grounds for improving the quality of care.

Empowering citizens and patients to participate

Who is it for? Patients and members of the public who want to find out more about the health system and how they can get involved in shaping it.

Type of learning: Workshop materials to run local workshops.

Duration of course: Half day.

Course dates: A time to suit you.

NHS England Patient and Public Voice (PPV) Partners' Induction Webinars

Who is it for? New NHS England Patient and Public Voice Partners sitting on NHS England boards and advisory groups (specifically PPV Partners acting in an individual capacity rather than those representing charities and other groups). **Type of learning:** online webinar

Duration of course: 1 hour

Developing patient and public participation skills and understanding

Who is it for? People working in Commissioning and in health planning and service delivery.

Type of learning: Workshop materials to run local workshops.

Duration of course: Half day.

Course dates: A time to suit you.

Understanding the value of engagement

Who is it for? People working in health planning and service delivery who need to understand the legal context, benefits and practicalities of engagement.

Type of learning: Workshop materials to run local workshops.

Duration of course: Half day.

Course dates: A time to suit you.

Measuring the impact of engagement

Who is it for? People working in health planning and service delivery with responsibility for showing that engagement is happening and having an impact on services.

Type of learning: Workshop materials to run local workshops.

Duration of course: Half day.

Course dates: A time to suit you.

Planning your engagement activities

Who is it for? People working in health planning and service delivery with responsibility for understanding the legal requirements to engage and consult on changes to services.

Type of learning: Workshop materials to run local workshops.

Duration of course: Half day.

Course dates: A time to suit you.



Working with patients and the public: designing care around your population's needs

Tuesday 7 November 2017
9.30am-4.30pm, The King's Fund,
London W1G 0AN

The need to engage the public in changes that affect their health care services is vital, but it is not always easy to do. This event, run in partnership with NHS Clinical Commissioners and National Voices, is designed for people leading local health care service redesigns to help them understand what good public engagement looks like.

The event will be relevant for you if you're working on changing services as part of delivering:

- new care models
- new care pathways in hospitals
- sustainability and transformation partnerships (STPs)
- new models of social care
- accountable care systems (ACS).

You will learn how to:

- engage in a meaningful ongoing conversation with your population
- incorporate the experiences of patients and the public in service design and delivery
- ensure that you engage with all parts of your community so that all those affected by change are able to contribute.

[More details here](#)

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 40,000 documents on patient experience and patient/public involvement, from government bodies, Healthwatch, think tanks and health charities.

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