

The Patient Experience Library

**Twenty
reports to
make you
think**

www.patientlibrary.net

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“Results and analysis of patient feedback including qualitative information need to be made available to all stakeholders.”

THE REPORT OF THE FRANCIS INQUIRY, 2013.

Introduction

The Patient Experience Library is founded on a key recommendation from the Francis Inquiry: that results and analysis of patient feedback must be shared.

We are pleased to have been able to publish the first ever comprehensive overview of the UK's collective intelligence on patient experience. Our **2015 Digest** enables commissioners, providers and patient voice organisations to see exactly who published what on patient experience through 2015.

This time around, we wanted to pick out some hidden gems: reports which offer real insight, but which could easily be missed by people who don't have time to hunt them down.

This publication is not the same as an awards scheme. We haven't asked report authors to compete, and there are no prizes at stake. We are, however, saying that if you don't have the time to read all 16,951 reports that were uploaded to the Patient Experience Library last year, you should at least make time for the ones that we have picked out for this report.

How we made our selection

During 2015, we uploaded 16,951 reports to the Patient Experience Library. They came from the NHS and the Care Quality Commission, from charities and think tanks, from the local Healthwatch network, and more.

Some reports start from a policy perspective. Others give feedback from the front line of service delivery. Still others share knowledge of how to do patient and public engagement well.

For the report writer, the challenge is how to produce a piece of work that is rigorous and credible, but is also engaging and readable. Reports on patient experience must make sense to patients, who may not be familiar with the jargon and technical complexities of service delivery. And they must be helpful to hard-pressed professionals, who may not have the time to plough through hundreds of pages of text before getting to the main points.

We wanted to highlight some reports that struck us as really good exemplars. As we leafed through hundreds of publications, we were looking for clarity, not clutter. We wanted to see plain English. If technical terms had to be used, we wanted them explained. Attractive design and layout was an added bonus. We gave the thumbs up to coherent structure: complex issues are easier to follow if the report has a clear beginning, middle and end. Lastly - and perhaps most importantly - we wanted insights and learning points that would really make us sit up and take notice.

The reports on the following pages are the ones that most impressed us. By the way - this is not a league table! The list is in alphabetical order by title.

What do you think?

Judging excellence is - well, a matter of judgement. We set some broad parameters for what good looks like, but ultimately, had to make judgements that were largely subjective.

So we'd like to know what you think. Do you disagree with any of our choices? Have we left out a report that you would have included? Have our choices helped you find reports that you would not otherwise have known about?

E-mail us at info@patientlibrary.net with your views. And if, as we go through 2016, you think there are new reports that we should be looking out for, let us know!

Nesta...

COLLECTIVE INTELLIGENCE IN PATIENT ORGANISATIONS

Lydia Nicholas and Stefania Broadbent
July 2018

Collective Intelligence in Patient Organisations NESTA

***A cogent and persuasive case for sharing
information on patient experience.***

The report states that patient organisations have played a significant role in health and social care for almost a century. It goes on to say that their participation in knowledge work is critical, and over coming decades will become one of the most important ways they will advance the interests of patients. But it then makes the point that their efforts are hampered by a lack of suitable tools and platforms.

The authors draw three conclusions: there is a need for more appropriate technology; the sector needs to learn from innovative and ambitious approaches; and we need new legal, ethical and scientific frameworks to aid integration of knowledge.



House of Commons
Health Committee

Complaints and Raising Concerns

Fourth Report of Session 2014–15

Report, together with formal minutes relating to the report

Ordered by the House of Commons to be printed 13 January 2015

HC 350
Published on 21 January 2015
by authority of the House of Commons
London: The Stationery Office Limited
£0.00

Complaints and Raising Concerns

HOUSE OF COMMONS HEALTH COMMITTEE

A frank appraisal from the heart of government.

If we're honest, this is a pretty dry read. But it's in our top twenty because it comes from the very top. Here's what the House of Commons Health Committee has to say about NHS complaints processes:

“Where errors occur, patients and their families deserve to be met with a system which is open to complaints, supports them through the process and which delivers a timely apology, explanation and a determination to learn from mistakes.”

“Too many complaints are mishandled with people encountering poor communication or at worst, a defensive and complicated system which results in a complete breakdown in trust and a failure to improve patient safety.”

“The treatment of whistleblowers remains a stain on the reputation of the NHS.”

Our recommendation? Read this.

Dementia in the Family

The impact on carers



Dementia in the family, the impact on carers

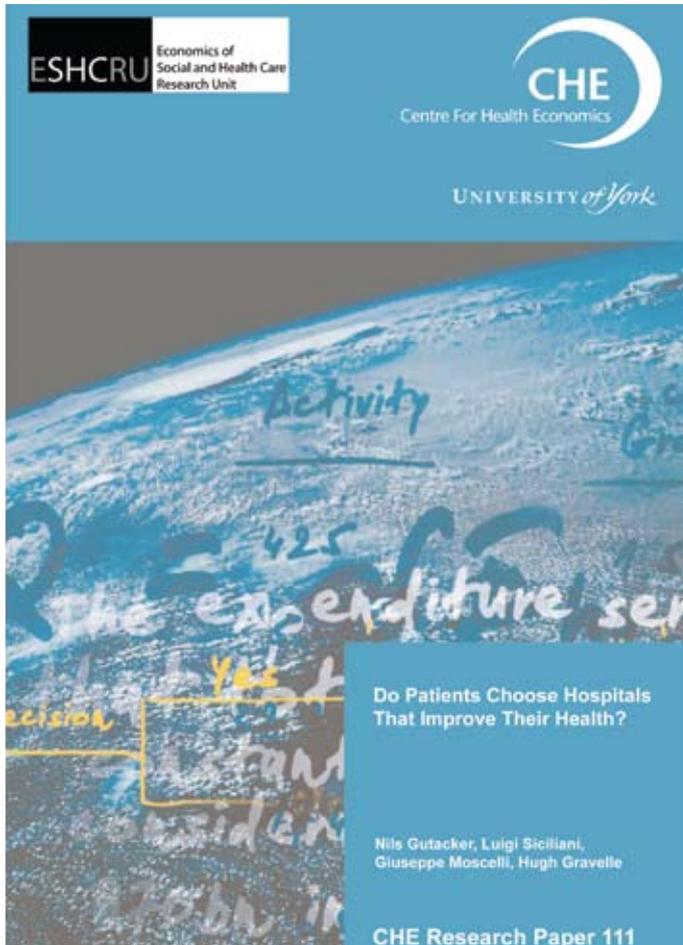
ALZHEIMER'S RESEARCH UK

There are 850,000 people in the UK living with dementia and 700,000 friends and family members caring for a person with the condition.

This series of case studies looks at the experiences of people looking after someone with dementia, and how it affects their own health, wellbeing and personal relationships.

The report concludes that the physical and psychological effects of caring for someone with dementia make this a particularly exhausting and challenging role.

At a time when NHS strategy is focussed on keeping more elderly people in their own (or relatives') homes, this makes for sobering reading.



Do Patients Choose Hospitals That Improve Their Health?

CENTRE FOR HEALTH ECONOMICS

An illustration of the difficulties of attempting to quantify patient experience.

Patient-reported health outcome measures (PROMs) attempt to measure the gain in health that patients experience as the result of care. The hope is that they will be used by patients and GPs exercising choice. This study considers whether hospital demand responds to quality as measured by PROMS.

The authors found that choice does indeed respond to quality, but to a limited extent. Furthermore, the effect of quality on providers' ability to attract patients diminishes rapidly as distance from the service increases. The desired effect of patients 'voting with their feet' and demanding higher quality is likely to be limited.

Just as importantly, the study highlighted that patients may still not know about PROM scores, and that the information may not be meaningful to them in its current format.



Evidence Review: Loneliness in Later Life

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Evidence Review, Loneliness in Later Life AGE UK

A valuable overview of an important social determinant.

Health and care strategies aim to keep older people cared for in their own homes. But with nearly half of all people aged 75 and over living alone, what are the implications for their experience as patients?

This review of existing research shows that loneliness is not good for your health. It can be as harmful as smoking 15 cigarettes a day, and people with a high degree of loneliness are twice as likely to develop Alzheimer's as people with a low degree of loneliness.

The report suggests that loneliness should be a topic of concern to Health and Wellbeing Boards as it increases the need for social care services and residential care. And if schemes to target loneliness in older people are to be effective, they must involve older people at every stage, including planning, development, delivery and assessment.

If I've told you once...

People's views on record sharing between the health and social care professionals involved in their care

October 2015

Summary report

In the summer of 2015 Healthwatch Surrey carried out a survey investigating the views of people in Surrey around sharing of health and care records between the health and care professionals involved in their care. The survey was commissioned by Surrey County Council as data sharing is considered a key enabler to integrating health, care, and support services, and hence of providing greater person-centred coordinated care.

The survey was distributed via a variety of channels both in hard copy and online, and excited considerable public and professional interest. 577 surveys were completed. The issue was also explored in four focus groups with people over 65 years of age in locations across the county.



If I've told you once...

HEALTHWATCH SURREY

Patients speak out on record sharing.

NHS England's "care.data" initiative in 2013 was something of a shambles. A well-intended attempt to talk to the public about sharing patient records ended with politicians, general public and bodies including the BMA calling for the whole thing to be shelved.

This report shows that that need not have been the case. The title recognises that many people are fed up with having repeatedly to explain their condition, and would welcome more joined-up record keeping. One third of respondents were not even aware that health and care records are not readily shared between health and care professionals.

91% of respondents would share all or part of their records, and only 7% would opt out of sharing completely. The authors conclude that if record sharing is kept within the medical and care professions, and there are procedures to ensure security, confidentiality and accuracy, there is strong support among patients.

Independent review of deaths of people with a Learning Disability or Mental Health problem in contact with Southern Health NHS Foundation Trust April 2011 to March 2015

December 2015

FINAL VERSION FOR PUBLICATION



Independent review of deaths of people with a Learning Disability or Mental Health problem in contact with Southern Health NHS Foundation Trust April 2011 to March 2015 NHS ENGLAND

The end of a patient's life does not mean the end of the story for families and friends.

Their experience matters too, as does their voice. This review looks at the Trust's failure to adequately involve families in investigations into unexpected deaths. It found that a culture had developed that resulted in lost learning, a lack of transparency when care and delivery problems occurred and a lack of assurance to families that deaths had been properly investigated.

The report advocates "compassionate enquiry", and calls on serious incident investigators to "review and challenge the incident from the service users' perspective, listening carefully to the experience of carers and families and seeking to learn from real experiences with an open mind". It would seem that some of the lessons from the Francis Inquiry have yet to be learned.

Is the NHS becoming more person-centred?

by Suzanne Wood,
Dr Alf Collins and
Angelina Taylor

This is one of a series of overviews looking at key areas of quality: safety, waiting times, mental health, person-centred care and international comparisons. See: www.health.org.uk/qualityoverview

5%
Only 5% of people with a long term condition have a written care plan

This overview examines how the NHS in England has performed over this parliament in relation to indicators that reflect person-centred care. We consider a range of measures including: dignity, respect and compassion; patient involvement in decisions; support for self-management and care planning.

Key points

- **Successive governments, since at least 2000, have made a commitment to person-centred care.** The serious failings in care at Mid Staffordshire NHS Foundation Trust and the current government's early commitment to the principle of 'no decision about me without me' have underpinned the focus on person-centred aspects of care during this parliament.
- **National measurement of person-centred care is conducted through NHS surveys.** These surveys give an indication of how the NHS is performing in some areas, such as treating patients with dignity and respect. However, in others, such as coordination of care, there are very few national measures to draw on, so we do not know how well health and care services are performing.
- **While there are signs of improvement in some areas of person-centred care, in many others there has been no real improvement over the last five years.** For example, the percentage of patients who reported that a nurse spoke in front of them as if they were not there has reduced but there has been no change in the 16 percent of patients who say they are not involved in decisions about their discharge from hospital.
- **In some key areas, there remains a large gap between the ambition to have a health service that is person-centred and the reality of patients' experience.** Only 5% of people with a long term condition have a written care plan and almost 20% of inpatients say they are not always treated with dignity and respect.

The Picker Institute published a paper in 2007 titled 'Is the NHS becoming more patient-centred?' Although this overview contains similar ground, it is not an update to the Picker paper. For the full paper see Richards N, Goshier A. Is the NHS becoming more patient-centred? Picker Institute, 2007. www.pickerinstitute.com/sites/default/files/paper07_teach_2007_00aP65016133.pdf

Is the NHS becoming more person-centred?

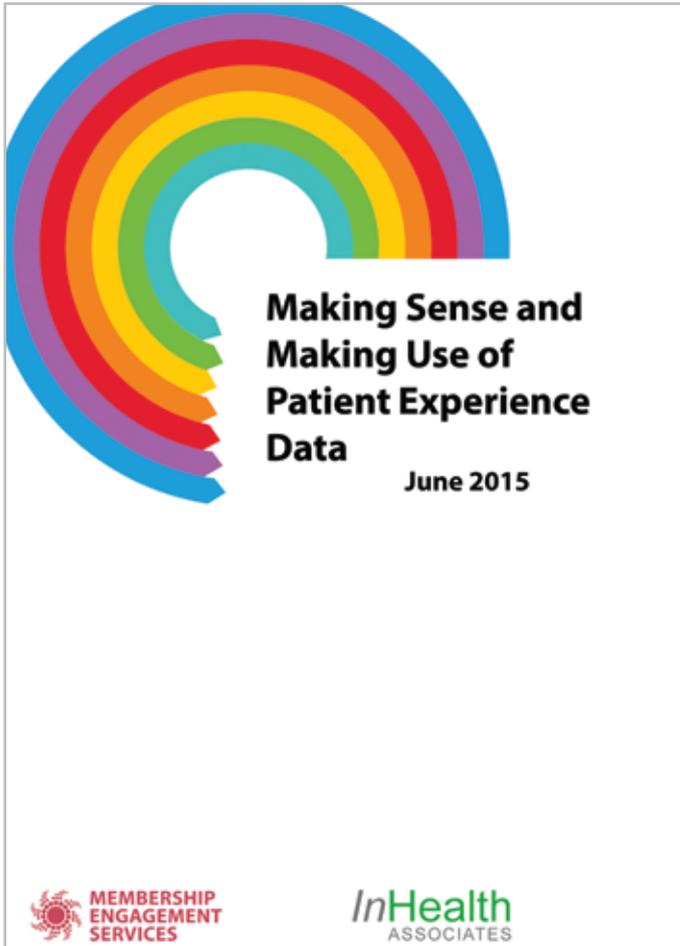
THE HEALTH FOUNDATION

A complex story, simply told.

Sometimes, trying to make sense of what is going on in the NHS is a bit of a nightmare. This wonderfully clear overview brings together data from various sources and sets it out in a document that is both comprehensive and comprehensible.

The Key Points start with the observation that successive governments, since at least 2000, have made a commitment to person-centred care. One of the ensuing points is that while there are signs of improvement in some areas of person-centred care, in many others there has been no real improvement over the last five years. Another is that in some key areas, there remains a large gap between the ambition to have a health service that is person-centred and the reality of patients' experience.

The findings are backed up by charts, infographics, and tables of statistics, which manage to be both highly informative, and easy to get to grips with. A model for how to tell a compelling story, and look after your readers at the same time.



Making Sense and Making Use of Patient Experience Data

INHEALTH ASSOCIATES AND MEMBERSHIP ENGAGEMENT SERVICES

A must-read for patient experience leads and PALS teams.

A topic that is dear to our hearts at the Patient Experience Library. The Foreword asks some key questions: Is the collection, analysis and reporting of data on patient experience being done by people with the right skills and knowledge? Is patient experience linked to feedback from staff about their experience and well-being? Does patient experience command the same level of organisational resource as other dimensions of quality of care?

The study finds that patient experience teams are small and have limited resources. Challenges include gathering an ever-increasing amount of data; bringing data into one place; and having the time to make sense of data. A telling comment is that “Staff are so busy gathering data and compiling reports, that less time is available to do something with the data - efforts to improve services are in danger of being squeezed out.”

**Overseas Students
Access and Entitlement
to Healthcare**

October 2015

Overseas Students Access and Entitlement to Healthcare

HEALTHWATCH MANCHESTER

Shedding light on an overlooked group.

Patient voice organisations have an interest in “seldom heard” groups. Special efforts are often made to hear from people whose experiences in the health and care system might otherwise be poorly understood. Healthwatch Manchester chose to look at one particular group that could easily be overlooked.

The survey found that overseas students have a generally good understanding of what the NHS provides, as well as the purpose of Accident and Emergency departments, GPs and dentists. However, there was limited awareness of free and urgent need services such as Walk-in Centres and the Dental Hospital, and mixed perceptions regarding services which are free of charge, and how to access them. There are concerns that people may be paying unnecessarily for private healthcare. A useful exercise that could perhaps be replicated in other university towns.

The King's Fund

picker
Institute Europe

Patients' experience of using hospital services

An analysis of trends in inpatient surveys in NHS acute trusts in England, 2005–13

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December 2015



Patients' experience of using hospital services

THE KING'S FUND AND PICKER INSTITUTE

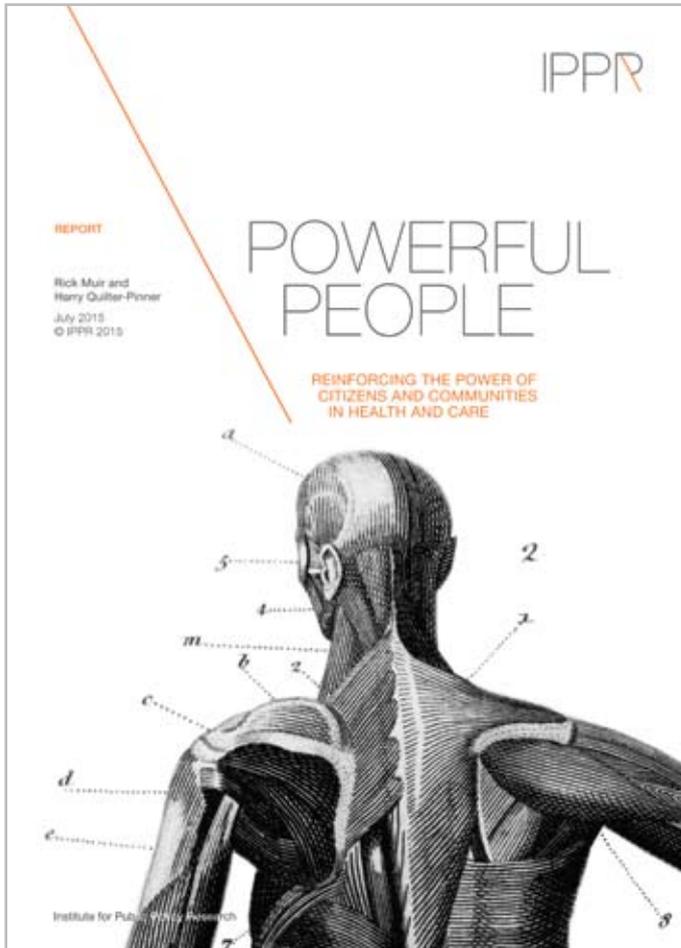
Important insights for policy makers, commissioners and NHS Trusts.

This study is based on the observation that there have until now been no systematic analyses of long-term trends in the experience of inpatients admitted to individual NHS trusts.

Analysts looked at data from the 2005-13 inpatient surveys for all acute trusts in England to examine trends in patient-reported experience at trust level over a nine year period.

In headline terms, it looks as though trusts tend to do well (from the patient perspective) on respect and dignity, privacy while being treated, and not being talked about by nurses as if you weren't there. Trusts did less well on noise at night, hospital food, and delays on discharge from hospital.

There is a mass of other findings, with important implications for NHS policy-makers, commissioners and trusts. Patient voice organisations should also get familiar with this study.

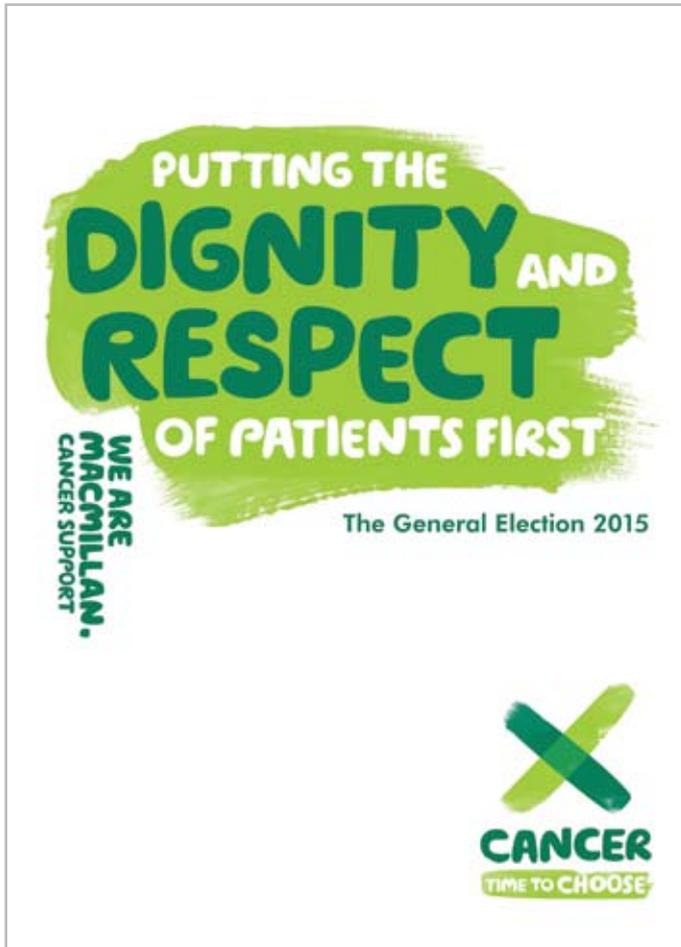


Powerful People: Reinforcing the Power of Citizens and Communities in Health and Care IPPR

A paper with a bold ambition: to show how we can shift power away from big bureaucracies and medical professionals and towards people and communities.

Patients who are engaged in their healthcare are more likely to say that it is of high quality, and are less likely to report experience of medical errors. But in spite of programmes aimed at empowering citizens, NHS patients still do not feel sufficiently empowered or involved. The authors contend that empowerment has remained at the margins rather than at the centre of our health and care system. There has been no fundamental change in where power lies in the NHS.

The report recommends adoption of empowering care models to create a system that is focused on the social determinants of health not just the symptoms, that provides people with personalised and integrated care, which focuses on capabilities not just needs, and which strengthens people's relationships with one another. A series of recommendations show how - finishing with a call for "a more active role for citizens".



Putting the dignity and respect of patients first: The General Election 2015

MACMILLAN CANCER SUPPORT

Happy staff mean happy patients.

Produced ahead of the 2015 general election, this can come across as a campaigning document. But it is addressed to all parties, and takes as its starting point the question of whether cancer patients experience dignity and respect in the course of their treatment.

Some of the issues are absolutely basic – for example, 40% of patients said that not all doctors and nurses had always asked them what name they prefer to be called by. Others are worrying – 30% of patients said they didn't have confidence and trust in every ward nurse treating them. A map of patient experience indicates that the quality of follow-through care on leaving hospital varies considerably, county by county.

Importantly, Macmillan's research (drawn from the Cancer Patient Experience Survey and the NHS Staff Survey) shows that the treatment of NHS staff is linked to patient experience. Happy NHS staff mean happy patients.

Right here right now



People's experiences of help, care and support during a mental health crisis

Summary

JUNE 2015

Right Here, Right Now

CARE QUALITY COMMISSION

“Our findings point to people in crisis having a much more positive experience of voluntary sector services compared with services provided by the statutory health sector. This should act as a challenge to providers”.

The CQC is sometimes thought of as the Ofsted of the health world, visiting institutions with a checklist of quality requirements, and passing judgement on service standards.

This report shows the Commission in a different light – taking a highly patient-centred approach, and showing that it understands the value of experiential evidence. The authors looked at three different pathways of care and at the services with which people in crisis most often come into contact, and found poor experiences and considerable variation across England at almost every point in the process.

The authors challenge conventional notions of patient safety, stating that “It is not just about making sure that people are physically safe, it is about preventing unnecessary mental distress to people when they are vulnerable”. And they make the point that “The level of variation also presents a challenge about whether services are fair, and whether people are receiving unacceptable responses because of where they live”.



Safely Home

HEALTHWATCH ENGLAND

A report that demonstrates the value of shared intelligence.

This special inquiry on hospital discharge mobilised the power of the local Healthwatch network to hear from thousands of patients across the country. Their stories highlight shortcomings in discharge processes, and powerfully illustrate the human cost. Some people spoke of delays and a lack of co-ordination between different services. Others felt left without the services and support they needed after discharge. Still others were not involved in decisions about their care or given the information they needed.

The report makes the point that none of this is new - reflected by the more than 20 pieces of guidance produced over the last decade in an attempt to address the issue. An excellent presentation of collective testimony from people at the sharp end.

*The experience of Reading women
who have been diverted from giving
birth at their place of choice*

August 2015

1

The experience of Reading women who have been diverted from giving birth at their place of choice HEALTHWATCH READING

The gap between the illusion of choice and the reality.

Guidelines from the National Institute for Health and Care Excellence (NICE) advise that all healthy women with 'straightforward' pregnancies should be able to choose where to give birth. But Healthwatch Reading has found that some women are being diverted from their chosen place - not because of health concerns, but because of staffing and capacity issues at the local acute trust.

Women who spoke about their experiences reported a lack of sensitivity from the midwives informing them about the change in their choice of birth; lack of information about the hospital they were diverted to; and poor follow-up care in Reading following births at hospitals outside Reading. The report makes a series of recommendations, and includes a considered response from the Berkshire West Clinical Commissioning Group and the Royal Berkshire NHS Foundation Trust.

Nesta...

THE NHS IN 2030

A VISION OF A PEOPLE-POWERED,
KNOWLEDGE-POWERED HEALTH SYSTEM

Jessica Bland, Halima Khan, John Loder,
Tom Symons and Stian Westlake | JULY
2015

The NHS in 2030

NESTA

This report abandons the usual five year horizon for future-scoping the NHS, in favour of a longer view.

Equally, it avoids the habit of starting with problems – ageing population, less money, etc. Instead, it considers how a combination of people power and knowledge power could offer new opportunities for how the NHS is designed and run.

A key premise is that information technology and social innovation remain underexploited by today's NHS.

The report works from this to a vision of a health system in which people have much greater opportunities to help themselves and others achieve a healthy life, and are better supported by the NHS to do so. A timely and thought provoking document.

The Patient Experience Library



www.patientlibrary.net

Digest 2015

The Patient Experience Library 2015 Digest

The first ever comprehensive overview of the UK literature on patient experience.

Ok - we admit it. We're blowing our own trumpet. But that's because we genuinely think this is a bit of a breakthrough.

One of the most challenging recommendations from the Francis Inquiry was that "Results and analysis of patient feedback including qualitative information need to be made available to all stakeholders". Until now, no-one has found a way to do it.

Thousands of patient experience reports are published every year - by charities, think tanks, government bodies, Healthwatch and more. But they are scattered across hundreds of different websites. It has been impossible to get access to all the knowledge in one go.

The Digest shows who published what on patient experience during 2015. The overview helps patient voice champions to see what is already known, and could help to prevent costly and time-consuming reinvention of wheels.

If you have an interest in patient voice, you should have this on your shelves.



The Power of Connection

PATIENT OPINION

“Exit - the ability to use the market and choose a different provider - may have been the health policy darling of the last 30 years but in the 21st century it is voice that will dominate.”

Paul Hodgkin, Founder of Patient Opinion, opens this report with a disarming admission that the feedback sharing platform has not achieved the reach of YouTube or Facebook. He wryly observes that ‘liking’ a picture of your friend’s colostomy is more problematic than ‘liking’ a picture of their kitten.

Through patient case studies, and professional comment, the report shows how social networking can be used to build new forms of dialogue and mutual learning between health service users and providers.

An important observation is that “Patient Opinion is living proof that it is possible to build a platform which avoids the trolls, is not unremittingly negative, and really does create concrete improvements. Even when people are justifiably angry they mostly still want to help”.

Uses & Abuses of Performance Data in Healthcare DR FOSTER

A key aspect of legitimate performance measurement is that measures should capture the patient's experience and outcome.

This one is for anyone who sees patient feedback as “anecdotal evidence” that does not stand up against statistically valid “hard evidence”. The authors pull no punches, kicking off with this: “Hopes of improving healthcare through better measurement and the use of information in healthcare management are being undermined by weaknesses in the generation and use of data and metrics.”

Ways to undermine performance measurement include 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. The report suggests five ways to significantly reduce data abuse and increase the benefit that could be gained through use of performance data.

Anyone looking for evidence to show that stats are not as hard as they think they are need look no further.



About us...

The Patient Experience Library offers a comprehensive overview of the UK's combined knowledge on patient experience. We built the library because we believe in maximum public access to information, and minimal professional hoarding of knowledge.

We could see that a whole series of patient voice organisations were doing a great job. But their reports were scattered across hundreds of websites, all designed and structured in different ways. No-one could get a simple overview of the UK's collective intelligence on patient experience.

We're here to make it easy for people to get a patient's-eye view of service quality. We'll keep adding useful stuff to the library so that you can get your hands on it when you need to.

Sign up for our **free weekly bulletin** to find out more, or contact us at **info@patientlibrary.net**

