The Patient Experience Book

A collection of the NHS Institute for Innovation and Improvement's guidance and support

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About the NHS Institute for Innovation and Improvement

The NHS Institute was established in July 2005 to support the transformation of the NHS, through innovation, improvement and the adoption of best practice. We enable and support the NHS system to transform health and healthcare for patients through a strategy of creating inventive, clinically-led and tested practical ideas which will build skills and capability for continuous improvement.

On 1 April 2013, NHS Improving Quality is being established to bring together the wealth of knowledge, expertise and experience of a number of NHS improvement organisations. NHS Improving Quality will be hosted by the NHS Commissioning Board.

Why we have published this book

Change is the inspiration for this book. On 2 April 2013, a number of people working across the health system will be in new roles, perhaps in new organisations. Those remaining in their existing roles will need to communicate and work with any new organisations that have been established. We wanted to pull together our 'institutional memory' and hand it over to everyone who will be working in the new landscape to improve the experiences of people who use health and social care services, their carers and their families. This book is, therefore, a legacy publication.

At the NHS Institute, we have worked on a number of programmes and developed materials that aim to support the NHS to improve patient experience, in particular: the Patient Experience Learning Programme; the Transforming Patient Experience: essential guide; and the NHS Patient Feedback Challenge. In this book, and the CD that accompanies it, we have included a range of content and materials from these programmes.

This book is for people with designated responsibility for improving patient experience – both as providers of services and as commissioners. It is intended to give you the evidence you need to influence others, both at management/board level and team level, to focus on improving patient experience.

The content that follows provides a rich source of research evidence, stories from patients and staff and many examples of innovation. It also illustrates a range of well-tested techniques to help you work more closely with patients to understand their experience and use these insights to improve services.

Thank you

We would like to thank everyone who has worked with us over the years: the patients and family members who have brought their fresh eyes, insights and challenge to our work; the Department of Health which has supported this agenda and ensured investment; our colleagues across the country who have helped us to co-design what we hope are useful and practical products; our colleagues in the NHS Institute who have always contributed their imaginative and innovative insights and professional services; and other partner organisations that have been vital to the success of our programmes.

Foreword

Imagine an NHS service that *starts with the patient* – a service that listens to patient and family needs, and then utilises the skills and expertise of both the clinician and patient to design the experience to meet these needs. That's what using patient experience information is all about.

Ultimately by consistently asking people whether they are receiving the care they need and then improving things on the basis of what they tell you will help patients feel more supported and better cared for.

We have reached a seminal point in our efforts to improve the experience of people who use health and social care services, and their families.

If you have been working hard to promote patient engagement and experience, you will be only too aware that never before has this area of work had such a high profile.

Only a few years ago, you might have focused your efforts on trying to convince people in 'your local area' of the health and social care system to focus on patient experience as much as on clinical effectiveness or safety. Now, the need to improve experience is widely acknowledged in policy, rhetoric and in the new systems and structures.

There have been a number of things that have brought about this shift. At a policy level, the work of Lord Darzi in 2008[1] signalled a need to consider experience alongside safety and quality. This was further cemented by the intentions expressed in the ***Equity and Excellence: Liberating the NHS 2010 White Paper***[2]. Alongside this, the Francis report into care failures at the Mid Staffordshire NHS Foundation Trust[3], published on 6 February 2013, puts the spotlight on the cultural, leadership and system changes that are needed across the NHS.

The question now is, how can we make the most of this opportunity to make a real difference for patients and how can we maintain the momentum of that need to change? It is clear that a culture change is

[1] High Quality Care for All report, 30 June 2008 http://tinyurl.com/34k7ffv

[2] http://tinyurl.com/4naov6

[3] http://tinyurl.com/c3y6p84 , http://tinyurl.com/cepy73t

required and, with the Friends and Family test[4] being implemented in hospital settings this year, closely followed by community settings, the expectation of seeking feedback on services and seeing positive change as a result can only increase.

Any programme intended to improve patient experience needs to influence the behaviours both of staff who have direct patient interaction (such as receptionists, nurses, doctors, porters) and those who work more indirectly (such as managers and corporate staff).

Providers of services and the groups that commission them will need to work in partnership with one another. The development of a new landscape for commissioning is an ideal opportunity to learn from existing effective practice and build on it in innovative ways. In fact, it could be argued that the most 'innovative' thing commissioners can do is to find the evidence-based practice and encourage it to be adopted elsewhere.

What the NHS Institute found when it introduced the NHS Patient Feedback Challenge is that, often, we know what works and there are pockets of excellence, but it is spreading this practice elsewhere that poses the biggest challenge. Commissioners are in a position to act as role models – by understanding what is important to patients in their local area (for example, by setting up systems that enable them to have meaningful conversations) and how the process of better understanding patient experience can be a tool for service improvement and a lever for performance. Commissioners will need to work in partnership with the voluntary sector, patient groups, communities and health and social care services to set realistic goals that enable organisations to implement programmes and sustain improvement.

One of the most important lessons I have learnt in the last few years is that health organisations need to be ambitious. The experience we deliver for patients and their families will only ever improve when an entire organisation or health and social care system examines and re-creates its culture, leadership, service user engagement, staff engagement and measurement systems in order to improve service experience.

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[4] A mandate to ensure that people have a positive experience of care http://tinyurl.com/bvwu54a

An incredible amount of information about what works already exists and hundreds of people have helped to create the knowledge bank represented in this book, and in the guidance and organisations we reference. I hope that what follows will inspire and energise you to continue the brilliant work that you have already started.

Sam Hudson
Head of Experience and Engagement
NHS Institute

What matters to me is being listened to, believed, taken seriously and feeling like what I say matters and having a say in what happens to me.

Patient Interview, What Matters to Patients, 2011

Contents

Section one: What is Experience?

On the face of it, experience can seem quite simple. We all have experiences every day, both good and bad, but have you noticed that the better or worse the experience is, the more people you tell? It's true that we all experience things slightly differently and each experience itself is made up of a number of experiences, or 'moments', that are all measured against our original expectations. In the retail, travel and hospitality industries, these 'moments' are big business and often, without us consciously realising it, our senses are stimulated and emotions evoked by these carefully orchestrated 'moments'. NHS services have the potential to do just that – to *plan* for experience.

'Patient experience' is what the process of receiving care feels like for the patient, their family and carers. It is a key element of quality, alongside providing clinical excellence and safer care. The way that the health system delivers its care and support services – from the way the phone is answered, to the way the GP examines them or the nurse explains what is happening – has an impact on the experience the patient has. If safe care and clinical excellence are the 'what' of healthcare, then experience is the 'how'. Starting with the patient, listening to their needs, and designing the experience to meet these needs is achievable and results in an environment where individual patients feel cared for and supported.

If you think back to your last interaction with a health service, either as a patient, family member, carer or friend, can you remember how you felt and what made you feel like this? Now, imagine an NHS service that *starts with the patient* – a service that listens to patient and family needs, and then utilises the skills and expertise of both the clinician and

patient to design the experience to meet these needs. It sounds like an appealing idea.

While we may aspire to this on a human level, as healthcare providers it can feel overwhelming – how on earth can the service respond to all of these differing patient needs? How can it provide a positive experience for all patients? And, more importantly, how can it support the provision of care generally, including social care? This book sets out to answer these questions and show how you can work to improve the experience of all patients in your service.

> "The NHS should only seek feedback directly from patients that is uniquely available from them – ask them about their experience of care, not how long they had to wait.
>
> Kings College London & Kings Fund, What Matters to Patients, 2011
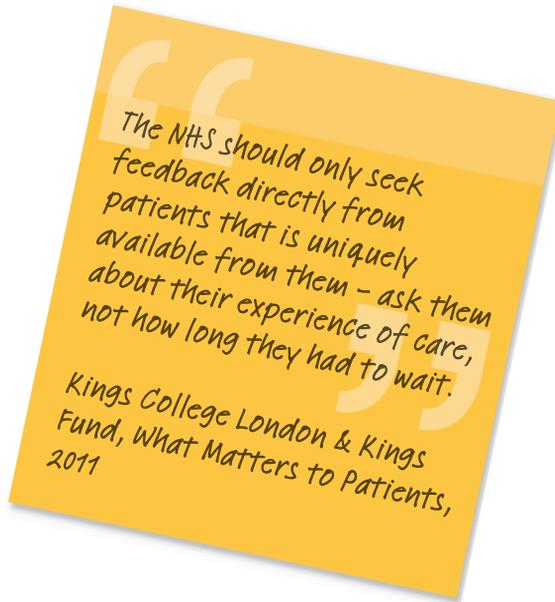
Understanding patient experience and engagement – what's the difference?

The language barrier

Recent research commissioned by the NHS Institute (Gill Ereaut, Linguistic Landscapes, 2013) in partnership with National Voices[5], has revealed that the language we use to try and describe this desire for a different relationship with the people who use health services is often confusing and has some significant features:

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[5] http://www.nationalvoices.org.uk/

- Lots of different terms are used and these are often combined– for example *'Patient and Public Involvement and Engagement'* (RCN); *'Patient and Public Voice and Information'* (NCB); *'Patient and Public Experience and Engagement'* (a network). Terms seem to be piled up like this because none of them quite expresses what people are seeking to do.

- These terms have not been found to be engaging, are often felt to be confusing, and seem to have been unable to help bring about real change.

- The language changes all the time and the terms used are also inconsistent in meaning, even amongst those within the field.

- *The* language contains abstract nouns, for example*; engagement; involvement*; slogans such as *'no decision about me without me'*; and jargon or hard to decipher terms such as *co-production* – all of which make it harder for people to understand what they need to do to make change happen.

So, the language we use to talk about "patient experience and engagement" acts as a distraction from the important issues of professional boundaries, power sharing and the allocation of resources.

The impact of this is that, although the intention behind the language is to support real change in the relationship between people and the health system, the language ends up supporting the status quo. Being aware of this and questioning our language is the first step towards making those real issues more visible.

> " Find out what matters to your patients; and start doing something about it!
>
> NHS Staff member, What Matters to Patients , 2011

A definition: what do we mean by patient and public engagement and patient experience?

It is sometimes helpful to think of patient experience and engagement activities existing on a continuum, where the amount of influence people can have over decisions varies.

Information → Feedback → Engagement → Co-design → Partnership
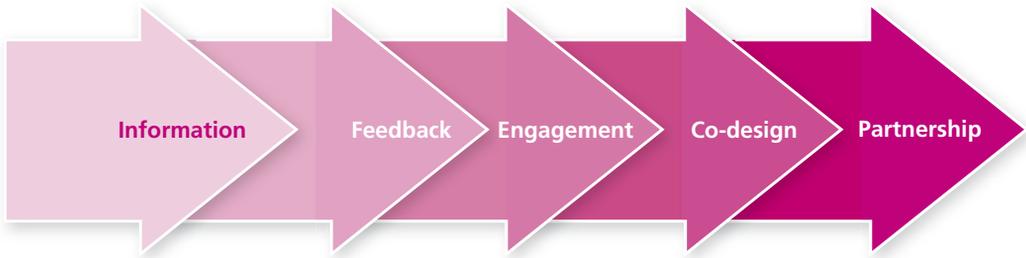
Patient and public engagement is the active participation of patients, carers, community representatives, community groups and the public in how services are planned, delivered and evaluated. It is broader and deeper than traditional consultation. It involves the ongoing process of developing and sustaining constructive relationships, building strong, active partnerships and holding a meaningful dialogue with stakeholders.

Engaging with patients and the public can happen at two levels:

- individual level – 'my say' in decisions about my own care and treatment
- collective level – 'my' or 'our say' in decisions about commissioning and delivery of services.

Effective patient engagement means involving patient cohorts (patients with common conditions) in helping to get the service right for them. It is also about engaging the public in decisions about the commissioning, planning, design and reconfiguration of health services, either pro-actively as design partners, or reactively, through consultation.

Effective engagement leads to improvements in health services and is part of everyone's role in the NHS.

A definition: what is patient experience?

Patient experience is what the process of receiving care feels like for your patients. **Understanding patient experience** can be achieved through a range of activities that capture direct feedback from patients, service users, carers and wider communities. These are used alongside information on clinical outcomes and other intelligence to inform quality improvements, the way local services are designed and reshaped, and contractual arrangements with providers.

There are many different ways to understand the experiences of patients and carers – from questionnaires or analysing complaints, through to Experience Based Design approaches[6]. Using experience to design better healthcare is unique in the way that it focuses so strongly on capturing and understanding patients', carers' and staff experiences of services, not just their views of the process.

"Getting good treatment in a comfortable, caring and safe environment, delivered in a calm and reassuring way; having information to make choices, to feel confident and feel in control; being talked to and listened to as an equal; and being treated with honesty, respect and dignity".

Department of Health (2005) 'Now I feel tall – what a patient-centred NHS looks like'

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[6] www.institute.nhs.uk/ebd

What this book covers: patient experience

> *The way the doctors used to speak to you…they spoke to you like a human being and they spoke everyday language, they didn't use medical jargon, they spoke to you so you could understand what was going on, and that made a big difference.*
>
> COPD Patient, What Matters to Patients, 2011

In this book, we focus on patient experience – how to understand it and how to use it effectively to improve services, and as a lever for performance management.

There is a great deal of work going on across health services to engage patients in decisions about their own care, about the running of services and, increasingly, the prioritisation of services. As with patient engagement, patient experience activities need to focus on helping people to understand the competing pressures within the health system, as well as understanding the ways in which improving patient experience, clinical effectiveness and safety are connected.

Organisations embarking on patient experience work to improve services need to understand both **why and how**. So, we have set out the case for understanding patient experience, with reference to relevant research evidence and the national policy framework.

The next section of this book explains **why** various parts of the health system should improve the experience of patients in their care. From section four onwards, you can read about **how** to improve patient experience.

> *You have the right to expect your local NHS to assess the health requirements of the local community and to commission and put in place the services to meet those needs as considered necessary.*
>
> NHS Constitution, 2009

Section two: Why Should we Improve Patient Experience?

Making the case for change

Improving patient experience is about working with the people who use services to make these services better. It is about designing services that meet their needs and it requires a commitment to doing this on an ongoing basis, day-by-day and year-by-year. Evidence from the commercial sector and from across health services shows that the staff who work in the system, at all levels, need to be engaged in the improvement process for it to work.

Evidence from healthcare organisations

There is a growing body of evidence (see **Supporting research** below) to convince business leaders across the service of the importance of investing in improving patient experience. It is likely that structures, such as the NHS Commissioning Board, the new Improvement Body, the NHS Trust Development Authority and Healthwatch England will continue to add to this body of evidence. This evidence illustrates:

- the impact of experience on organisational reputation (ie if patients have a poor experience of care it can damage an organisation's reputation)

- that experience is improved when people have more control over their care and the ability to make informed choices about their treatment

- the link between experience and health outcomes (ie patients who have a better experience of care generally have better health outcomes)

- the link between experience and cost of care (ie poor experiences generally lead to higher care costs as patients may have poorer

outcomes, require longer stays or be readmitted for further treatment)

- the relationship between staff and patient experience (ie if patients are having a poor experience, it has a negative impact on staff experience as well).

Supporting research

1. Feeling better? Improving patient experience in hospital

The report entitled ***Feeling better? Improving patient experience in hospital, NHS Confederation, 2010***[7] provides compelling evidence that hospital boards can achieve better outcomes across their entire organisation when patient experience is a priority.

It contains seven inspiring case studies of organisations that have undertaken patient experience work and concludes that there are a number of factors that are common across all of the organisations featured. These include:

- transformational leadership

- whole-system change

- patients and families that are engaged in care

- an emphasis on continual feedback from patients, families and carers, and measurement for improvement

- an integrated programme of activities, rather than a series of small, random projects

- a recognition of the importance of embedding desired values and behaviours across the organisation

- staff who are enabled to deliver excellent patient experience and empowered to make changes themselves

- greater clinical engagement and professional empowerment.

[7] http://tinyurl.com/a95hykt

2. Costs and Benefits of Implementing a Patient Experience Strategy; Or Why Every Director of Finance Should be Investing in Patient Experience

The Excellence Framework for Patient Experience forms part of a wider piece of work on patient experience, commissioned by the Department of Health and NHS Northwest. Its report ***Costs and Benefits of Implementing a Patient Experience Strategy; Or Why Every Director of Finance Should be Investing in Patient Experience***[8] makes the management case for investing in patient experience, proposing that there are sound management and financial reasons for doing so. It points out that patient experience is now a central issue for the NHS Commissioning Board, Clinical Commissioning Groups and service providers. The ***What Matters to Patients?*** research, explained below, has also shown that is imperative that we start to collect evidence of the link between experience and the cost of care.

> "I have observed remarkable improvements at Trusts in which the CEO or Director of Nursing really drives Patient Experience as an organisational priority whilst empowering frontline staff to contribute to the action planning process and identifying of specific priorities."

[8] http://tinyurl.com/c8u2wng

3. What Matters to Patients?
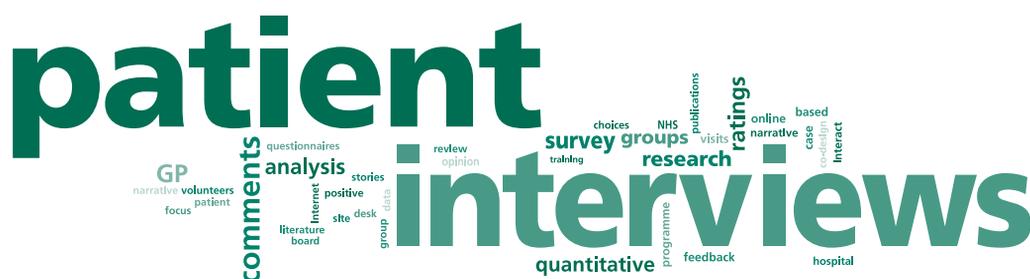
In 2010, the Department of Health and the NHS Institute commissioned King's College London and The King's Fund to undertake a research project entitled: *What Matters To Patients? Developing the Evidence Base for Measuring and Improving Patient Experience*[9].

It was compiled following extensive interviews with patients and carers, patient representative organisations, and NHS organisations, a review of evidence from the voluntary sector and patient care organisations, a series of events, literature reviews and a detailed review of five key conditions, including mental health and long-term conditions. The report covers:

- what matters to patients? – particularly in the non-acute sector

- what do NHS organisations in England currently measure in relation to what really matters to patients?

- examples of NHS organisations that are using information and insights into patient experience to improve the quality and productivity of healthcare services.

The report also includes an annex comprising: a literature review, a survey of voluntary organisations, patient and carer interviews, qualitative and quantitative analysis of NHS Choices datasets, quantitative analysis of Patient Opinion ratings, organisational case studies and the national training survey.

[9] http://tinyurl.com/cc6rtu7

Both The Main Report[10] and The Policy Recommendations[11] are on the CD (in the What Matters to Patients folder) that accompanies this book.

Key findings from What Matters to Patients?

Functional versus relational aspects of care

One of the key findings from interviews with patients with long-term conditions (as shown in the table below) was that it is the **relational** rather than the **functional** aspects of their care that matter most to them. Relational aspects of care include feeling listened to, or informed, while 'functional' refers to the process of delivering care, such as efficient processes. This research shows us very clearly that patients care about their *experience* of care as much as clinical effectiveness and safety. People value efficient processes, they want to feel informed, supported and listened to so that they can make meaningful decisions and choices about their care, and the one thing we hear again and again is they want to be 'treated as a person, not a number'.

The health service has tended to concentrate on improving functional aspects of care, yet this research reveals clearly that the relational aspects of care matter as much to patients.

> "
> The organisations that were most advanced in collecting and using patient experience data systematically saw themselves as being on a journey of cultural change.
>
> Kings College London & Kings Fund, What Matters to Patients, 2011

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[10] http://tinyurl.com/cxrrnzg

[11] http://tinyurl.com/bmhg7jv

Treating patients as people

But, what does being 'treated as a person' mean in practice for patients and how can we make it a daily reality for the health service?

It is about training and focusing on staff delivering the *relational* aspects of care, such as: good communication, emotional support, respect, empathy, involvement in decisions and good information provision. This has to happen alongside the development of systems that support the *functional* aspects of care, like joined-up services and providing physical comfort.

Effective measurement is vital – see section six: Measuring Experience for more information.

4. The King's Fund Point of Care programme

The King's Fund Point of Care Programme[12] aims to help healthcare staff in hospitals to deliver the quality of care they would want for themselves and their own families. The programme works with patients and their families, staff and hospital boards to research, test and share new approaches to improving patient experience.

5. Always Events from the Picker Institute

The Picker Institute is dedicated to enhancing the delivery of patient-centred care across healthcare. Picker has devised Always Events which can help the system to become more patient-cantered[13]. These were in contrast to the well-known Never Events, which refer to incidents that should never happen in the delivery of care, patient-focused Always Events are aspects of the patient and family experience that should always occur when patients interact with healthcare professionals and the delivery system.

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[12] http://www.kingsfund.org.uk/projects/point-care

[13] http://alwaysevents.pickerinstitute.org

Themes from patient interviews	Functional	Relational
Being treated as a person, not a number		✓
Staff who listen and spend time with patient		✓
Individualised treatment and no labelling		✓
Using language that is easy to understand		✓
Finding out about the latest technologies and innovations medications	✓	
Feeling informed, receiving information and being given options		✓
Patient involvement in care and being able to ask questions		✓
More public awareness about condition	✓	
Efficient processes	✓	
Knowledgeable health professionals		✓
Aftercare support		✓
Positive outcomes	✓	
Continuity of care		✓
Good relationships and positive attitudes among staff		✓
The value of support services		✓

Policy Drivers

*"Patients, users and carers are the reason for the NHS existing…
and, as such, must be at the centre of all that the NHS and its
staff do."*

National Quality Board, February 2010

NHS staff have told us:
"A vision that describes how the organisation values staff and patients"
"Have a clear, well-defined understanding of what patient experience is and communicate that in a variety of ways, internally and externally."

1. The NHS Constitution

There are a number of relevant policy documents, drivers, incentives and sanctions that make improving patient experience an imperative, and a useful place to start is always the NHS Constitution. The NHS Constitution was created to protect NHS England and ensure that it will always do the things it was set up to do in 1948 – to provide high quality healthcare that is free and for everyone.

The Constitution establishes the principles and values of high quality healthcare and sets out the rights to which patients, public and staff are entitled.

One of the seven key principles is that the NHS aspires to the highest standards of excellence and professionalism:

"In the provision of high quality care that is safe, effective and focused on patient experience; in the planning and delivery of the clinical and other services it provides; in the people it employs and the education, training and development they receive; in the leadership and management of its organisations; and through its commitment to innovation and to the promotion and conduct of research to improve the current and future health and care of the population."

Providing a poor service costs money and it is clear, from current feedback, that the NHS is not yet providing a consistently positive experience.

2. NICE Quality Standards for Patient Experience in Adult NHS Services

To deliver the best possible experience for patients who use NHS Services, high quality care should be clinically effective and safe. Launched in February 2012, these quality standards and accompanying clinical guidance aim to ensure that patients have an excellent experience of care from the NHS.

3. No decision about me, without me

The philosophy of 'no decision about me, without me' in the 2010 White Paper now sits alongside a number of national policy drivers requiring healthcare organisations and professionals to continually measure and improve patient experience, such as the Outcomes Framework[14] and the NICE guidelines for patient experience[15] and mental health service user experience[16]. The aim of these policy imperatives is to provide a patient-centred healthcare service which meets the physical and emotional needs of the population.

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[14] http://tinyurl.com/cr8qsg6

[15] http://guidance.nice.org.uk/CG138

[16] http://guidance.nice.org.uk/CG136

4. NHS Operating Framework 2012/13

The NHS Operating Framework 2012/13[17] specifically states that the NHS should collect and use patient experience information in real time and use it for service improvements: ***'NHS organisations must actively seek out, respond positively and improve services in line with patient feedback. This includes acting on complaints, patient comments, local and national surveys and results from 'real time' data techniques.'*** The Operating Framework for the NHS in England 2012-13, p.17.

5. NHS Outcomes Framework

The purpose of the NHS Outcomes Framework[18] is to provide a national level overview of how well the NHS in performing, to provide an accountability mechanism between the Secretary of State for Health and the proposed NHS Commissioning Board; and to act as a catalyst for driving quality improvement and outcome measurement throughout the NHS by encouraging a change of culture and behaviour.

The NHS Outcomes Framework is structured around five domains, which set out the high-level national outcomes that the NHS should be aiming to improve. One of the domains (domain 4) is about ensuring that people have a positive experience of care.

6. Commission for Quality and Innovation Scheme (CQUIN)[19]

The CQUIN payment framework enables commissioners to reward excellence, by linking a proportion of English healthcare providers' income to the achievement of local quality improvement goals. Since the first year of the CQUIN framework (2009/10), many CQUIN schemes have been developed and agreed.

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[17] http://tinyurl.com/coo8hbr

[18] http://tinyurl.com/chygct4

[19] http://tinyurl.com/c5vpzp7

7. Quality Accounts[20]

Quality Accounts aim to enhance accountability to the public and engage the leaders of an organisation in their quality improvement agenda.

8. Section 242: The Statutory Duty to Involve[21]

The Statutory Duty to Involve sets out how the NHS is expected to involve and consult communities in the planning and development of services.

9. Essence of Care[22]

Essence of Care aims to support localised quality improvement, by providing a set of established and refreshed benchmarks supporting frontline care across care settings at a local level. The benchmarking process outlined in Essence of Care 2010 helps practitioners to take a structured approach to sharing and comparing practice, enabling them to identify the best and to develop action plans to remedy poor practice.

10. Equity and Excellence: Liberating the NHS[23]

This White Paper and legislative framework sets out the Government's long-term vision for the future of the NHS. The vision builds on the core values and principles of the NHS – a comprehensive service, available to all, free at the point of use, based on need not ability to pay.

11. Healthy Lives, Healthy People[24]

This White Paper sets out the Government's long-term vision for the future of public health in England. The aim is to create a 'wellness' service (Public Health England) and to strengthen both national and local leadership.

"Patient experience is too often pigeon-holed as a nursing problem", says a former director at an acute trust. "The whole board needs to take ownership of it and sent out the message to staff that this is a priority."

The Intelligent Board, Dr Foster, September 2010

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[20] http://tinyurl.com/cz85p3k

[21] http://tinyurl.com/6f2l3o

[22] http://tinyurl.com/3xg2mh9
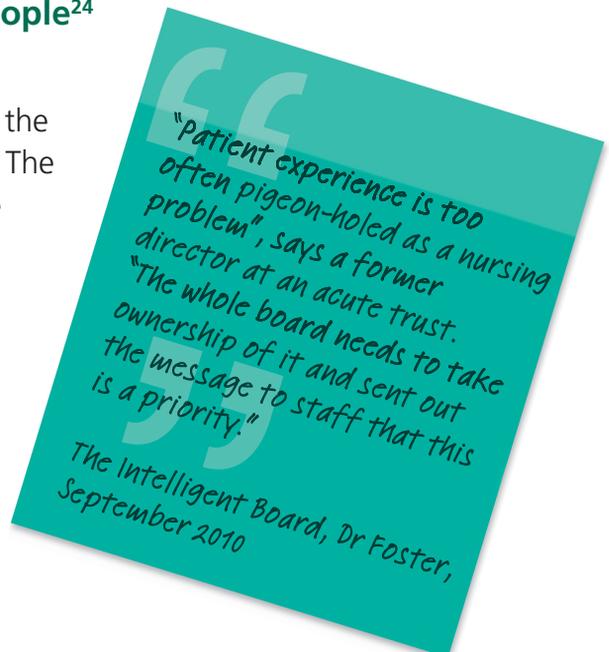
[23] http://tinyurl.com/3328s6x

[24] http://tinyurl.com/cx9wme2

The NHS National Quality Board Patient Experience Framework[25]

In February 2012, the NHS National Quality Board (NQB) published the NHS Patient Experience Framework. This framework outlines those elements that are critical if patients are to have a positive experience of NHS Services.

This framework is significant for healthcare organisations because it provides a common evidence-based list of what matters to patients, and can be used to direct efforts to improve services. For example, it can be used to help define what questions to ask patients in surveys and in real-time feedback.

The framework draws on the What Matters To Patients research published by the King's Fund and King's College London. This research suggested it is possible to apply a single generic framework for patient experience to a wide range of health conditions and settings, and recommended that the Department of Health adopts a common framework for this purpose.

The elements that are regarded as critical for a positive patient experience are as follows:

1. **Respect of patient-centred values, preferences, and expressed needs**, including: cultural issues; the dignity, privacy and independence of patients and service users; an awareness of quality-of-life issues; and shared decision-making.

2. **Coordination and integration of care** across the health and social care system.

3. **Information, communication, and education** on clinical status, progress, prognosis, and processes of care in order to facilitate autonomy, self-care and health promotion.

4. **Physical comfort,** including pain management, help with activities of daily living, and clean and comfortable surroundings.

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[25] http://tinyurl.com/c97exc5

5. **Emotional support** and alleviation of fear and anxiety about such issues as clinical status, prognosis, and the impact of illness on patients, their families and their finances.

6. **Welcoming the involvement of family and friends**, on whom patients and service users rely, in decision-making and demonstrating awareness and accommodation of their needs as care-givers.

7. **Transition and continuity** as regards information that will help patients care for themselves away from a clinical setting, and coordination, planning, and support to ease transitions

8. **Access to care,** with attention, for example, to time spent waiting for admission or time between admission and placement in a room in an inpatient setting, also waiting time for an appointment or visit in the outpatient, primary care or social care setting.

For expanded details of The NHS National Quality Board Patient Experience Framework please see the CD that accompanies this book.

> *Each patient is different... my experience is not yours, and is not his...*
>
> *Patient Interview, What Matters to Patients, 2011*

Future policy

It could be said that the only constant is change.

Above we have outlined a range of policies and directives that are important right now. As time goes on, there will be new policies that build on what exists today. The focus on patient experience can only increase, making it imperative for organisations to fully understand how to capture and use patient experience for service improvement.

Section three: Who Needs to be Involved in Improving Patient Experience?

Improving patient experience involves both those staff who have direct patient interaction, such as porters, reception staff, telephonists, doctors and nurses, and those who work more indirectly, such as managers and corporate staff. Everyone needs to understand and subscribe to the organisation's commitment to improving patient experience. Commissioners also have a crucial role to play, as outlined below, and it is impossible to overstate the role of leadership. In section four, we detail the characteristics shared by organisations that have successfully used patient experience to drive service improvement. A management board that is committed to, and accountable for, patient experience comes top of the list.

The crucial role of leaders

Like any improvement programme, strong leadership is vital for improving patient experience.

In order for patient experience to improve across an organisation, the person with primary responsibility for managing patient experience needs to engage colleagues and the senior team so they understand fully what patient experience is and what it means for the organisation. In addition, plans need to demonstrate how to gather feedback; the process of identifying and implementing improvements with patients and staff; and what the benefits will be for patients, staff and the organisation.

For patient experience information to be used effectively within an organisation, that organisation needs to be prepared to change. This requires fully engaged leaders who can act as role models and support the required change. The management board should make a conscious decision to focus on patient experience and support the development of the patient experience improvement priorities, vision and strategy for patient experience.

By linking patient experience with clinical effectiveness and safety, the board has the opportunity to develop a clear picture of quality in the organisation. And, by promoting partnership working, it can establish strong working links with commissioners to ensure that patient experience goals are shared. Board members can ensure that patient experience is always on the agenda by playing a positive role in gathering feedback, 'walking the floor' regularly, and talking to staff and patients.

A recent report from The Institute of Health Improvement (IHI) (***Balik B. Leaders' role in patient experience: Hospital leadership must drive efforts to better meet patients' needs. Healthcare Executive. 2011 Jul/Aug; 26(4): 76-78***.)[26] offers some insight into the leaders' role in patient experience. It says:

"Critical to the entire hospital's success is senior leaders' ability to continually clarify, articulate and model the organisation's goals for patient and family experience and why they matter…

Often missing are leaders skilled in making sense of patient experience for others in the organisation. These leaders commit to creating a positive patient experience and are able to tap into the collective energy of staff members, encouraging staff to test new ideas for change and generating action from everyone in the organisation, rather than relying on direction from leaders or the next new initiative."

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[26] http://tinyurl.com/bdx8j62

10 things that leaders should do

There are 10 key things that leaders need to do to support the improvement of patient experience:

1. Own and drive the patient experience agenda and offer strong direction and leadership.

2. Ensure that leadership is visible and accessible (e.g. executives/board getting out and about).

3. Ensure that staff are empowered to make changes to improve a patient's experience.

4. Model good management from the top: embody behaviour that reflects the patient experience vision and values: kind, compassionate, caring, empathic, respectful, informative, efficient and professional.

5. Enable patients to tell their story of care by providing staff with methods and skills to capture patients' stories.

6. Set up work processes that allow time and space in the day to achieve the patient experience improvement objectives.

7. Ensure that feedback from patients is turned into action plans that are carried out and evaluated.

8. Enable staff to gather feedback from patients and make improvements at the point of care.

9. Set up processes so that staff have a means of capturing feedback in real time

10. Include real time data as part of organisational patient experience data.

Case Study

In NHS Coventry, Arden Cluster board members said they would find it very helpful to be able to hear directly from local people about their experiences of using healthcare. So, a patient, carer or member of the public attends the bi-monthly board meeting to tell their story of using healthcare services in Coventry and Warwickshire.

The patient meets with the Head of Public and Patient Involvement to prepare for meeting the board. This meeting may take place at the patient's home, or at the hospital, whichever is easiest for the patient. Patients have said that it is really helpful to have the preparatory meeting as it helps them to prepare and clarify the points that are really important to them.

The patient has an opportunity to tell their story over a private, informal lunchtime session with the board. Members ask questions and there is a discussion around the issues raised.

Board members have reported back that they find the patient stories very powerful and the time is well spent. They have asked for analysis of the trends and issues that have emerged as common themes and said that this has influenced their decision-making.

Patients have reported that this was a very positive experience, which made them feel as though their story had really been listened to at the highest level of their local NHS organisation. They felt that their story was useful and would result in improved services in the future.

Several people who have shared their stories have had the opportunity to carry on working with specific services to review what changed and come up with solutions and ideas for improving patient experiences in the future.

Commissioners as role models

The development of a new landscape for commissioning is an ideal opportunity to improve patient experience. Commissioners are in a position to act as role models – by understanding what is important to patients in their local area and how patient experience can be used as a tool for service improvement and a lever for improved performance. Commissioners should try to set realistic goals, in partnership with providers, which enable organisations to implement programmes and sustain improvement. Commissioners will need to determine how to work in partnership with the services they commission to enable them to deliver these improvements in patient experience.

"Commissioners and providers need to work together to capture patient stories across organisational and service boundaries, and highlight issues of accessing services, transition and continuity of care that service-specific surveys usually do not capture."

King's College London and The King's Fund,
What Matters to Patients? 2011

The NHS Institute has been delivering support to Clinical Commissioning Groups and their partners during the set up and development phase (http://tinyurl.com/d26fcan). In addition, the Institute commissioned a refresh of the engagement cycle (www.institute.nhs.uk/engagementcycle) in 2012.

Case Study

NHS Leicester has involved patients and the public in the commissioning process to help ensure there are more community-based, patient-focused services in the region. Service users are involved in devising the questions to be asked of bidders and in assessing the tenders and potential bidders. They have also been included in the procurement of services for conditions such as diabetes. Guidance has now been compiled and issued to commissioning managers to make engagement of patients and the public an established commissioning practice in the procurement of services.

Priorities for service providers

At a strategic level, service providers need to use patient experience as an integral and equal part of the quality framework, alongside clinical effectiveness and safety. They should:

- show strong leadership and give the same priority to improvement in outcomes and quality of services as they do to financial and clinical goals

- ensure that the board receives regular and meaningful reports on patient experience. This should include instances where the patient experience has been poor and examples of where joint working between patients and staff has resulted in improvements

- recognise the link between patient experience and staff wellbeing, and develop plans for improving both (including collecting data on staff wellbeing)

- support and encourage leaders at all levels of the organisation to create an organisational culture that prioritises understanding and improving the experience of patients

- build and clearly articulate the business case for investment in measuring and improving patient experience

- make the focus on understanding and delivering a positive patient experience an integral part of staff induction, development and appraisal

- ensure understanding and improving patient experience is an integral part of in-house leadership development programmes (including those for middle managers and clinicians).

"It's impossible to overestimate the value of a really good, efficient, friendly receptionist."

Patient

Case Study

NHS Westminster uses patient experience feedback captured through consultations, to inform and influence service design and delivery. Key performance indicators have been developed and will be added to all contracts. This will ensure that all future service specifications will be developed to enhance basic requirements, such as equality and diversity; patient and user experience; health inequalities and health promotion.

It's impossible to overestimate the value of a really good, efficient, friendly receptionist.

Patient Interview, What Matters to Patients, 2011

Section four: How to Improve Patient Experience

Making it happen

One of the main findings of the **What Matters to Patients?** research was that there is no 'one size fits all' approach to improving experience and that what works really well in one setting might not work so well in another. There are, however, some common themes that are shared by organisations that have successfully improved patient experience.

One way of planning to improve patient experience would be to focus on five key 'workstreams':

- Leadership – how visible is the leadership, are they promoting and supporting the need to improve experience?

- Culture – is improving patient experience 'part of the way we do things here'?

- Patient engagement – is the organisation truly patient-centred? Are service users and their families engaged in improving patient experience?

- Staff engagement – are staff involved and empowered to make improvements? Are staff accountable for improving patient experience?

- Measurement – are there data capture systems in place and effective reporting mechanisms?

What successful organisations do

From the **What Matters to Patients?** research, it is clear that successful organisations recognise and maximise the value of patient experience. They share the following characteristics. These are what you need to have in place if you wish to improve the patient experience:

- The board is accountable for and committed to patient experience and its continual pro-active improvement.

- The organisation is engaged with patient experience and understands and articulates the value of it to the organisation, its staff and patients.

- The organisation has a clear vision (together with values and standards) for patient experience – known and understood by everyone in the organisation, including staff and patients.

- Patient experience is built into the organisation's short and long-term business plan.

- Patient experience is considered an equal partner in quality, alongside clinical effectiveness and safety.

- The link between staff experience and patient experience is recognised; staff experience is also captured and linked into patient experience. The role of teams is recognised.

- Resources (budget, staff, systems) are dedicated to the capture of feedback, analysis of data and implementation of quality improvement to services as a result of that measurement activity. The organisation knows what it costs it to improve patient experience and can measure the impact resulting from that investment.

- The organisation recognises and maximises the value of hearing the patient voice.

Start with the patient

At each stage of an experience, the emotions evoked, senses stimulated and the actual events are all measured against our original expectation of the experience.

Experience is personal and, although some experiences are common to many, everyone experiences things differently and each experience itself is made up of a number of experiences, or 'moments'.

This doesn't mean that you can't plan for experience, however. Starting with the patient, listening to their needs, and designing the experience to meet these needs is achievable and results in an environment where individual patients feel cared for and supported.

These are the top 10 things that patients say would improve their experience of healthcare:

1. I want to feel informed, be given options and take part in decisions about my health.

2. Listen and spend time with me – acknowledge that, whilst health professionals are experts in their field, I am an expert about myself and what is normal/abnormal/unusual for me.

3. Treat me as a person and not a number – put me at ease, ask me what I would like to be called, make me feel welcome.

4. Tell me about support services: the partnership with professionals can be enhanced if they are more proactive about signposting to other sources of support.

5. Ensure continuity of care; tell me about the care plan, what will happen next, who will be providing which part of my care and how I can contact them.

6. Provide efficient process so that I only have to tell my story once.

7. Communicate – make sure that staff introduce themselves to me and my family/carer by saying 'My name is...my role is...I am here to...'

8. Provide good information that is tailored to me and is timely.

9. Ensure that I get the right treatment from the right staff at the right time. (If I have a long-term condition, I might be concerned and want to see a particular GP/health professional who knows me and has some knowledge of me and my condition.)

10. Enable me to have meaningful involvement and engagement.

Remember that, when it comes to what matters most to patients, you need to consider the two aspects of care: relational (such as dignity,

empathy and emotional support) and functional (such as access, waiting, food and noise). The quality of relationships between NHS staff and patients is a key indicator for patient experience – get these right and the experience is more likely to be positive.

Engaging patients

Making a commitment to delivering **patient-centred care that puts the needs of patients and carers at its heart** is the key to delivering a positive patient experience. We all have a complex relationship with our health. Time spent in the health service, or with health professionals, is only a small part of any individual's health journey.

Communication is at the heart of good relationships and health services need to invest, not only in ensuring good face-to-face interactions, but also in the information and technology that can support effective communication between staff and patients and between services.

Getting the basics right is so important. It is often the small things that make the difference between a good or poor experience, for example: surly versus smiling staff; availability of attractive and nutritious food; provision of information that is clear and meaningful; availability of staff, who are trained, confident and empowered to ensure that these important 'moments' in care are delivered well.

Engaging with patients in all aspects, including the design of your patient experience programme and subsequent service improvement, will provide you with valuable insights. In addition, staff who are engaged, feel valued and are working in an environment where they can act to improve experience on the spot are more likely to ensure positive patient experiences.

These ideas seem simple but, in practice, can be less straightforward and involve commitment at all levels of the organisation.

"Nobody visited me and talked to me about it, I was just given a lot of booklets and pamphlets. I didn't have any visit or a one-to-one with anybody when I was diagnosed. So, maybe a one-to-one with somebody would have helped because I didn't know anything about diabetes."

Patient

How to collect patient feedback

There are many different tried and trusted approaches to collecting patient feedback:

1. Surveys and questionnaires

The researchers for **What Matters to Patients?** found that most NHS Trusts conduct surveys as part of the National Patient Survey Programme[27]. They tend to supplement these with local surveys of patient experience in some, or all, of their services. There is a wide range of methods for administering questions in local surveys, including:

- postal or email questionnaires

- questionnaires in clinics, waiting rooms or patients' homes

- mobile patient experience tracker devices (PETs) or hand-held electronic devices (often referred to as PDAs).

In addition, a range of different means are used to gather the responses:

- self-completion by patients reading questions and recording answers

- self-completion, with support and explanation

- assistance provided through a face-to-face interview, with a volunteer, audit nurse or link worker asking the questions and recording the answers.

Local versions of the national surveys are now available, which means that organisations have some choice as to which questions to use.

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[27] http://www.nhssurveys.org/

Case Study

Hertfordshire Partnership NHS Foundation Trust

The trust is committed to seeking the views of all of its users. One of the practical innovations that it has introduced is to produce easy-read versions of its Having Your Say questionnaires, concerning hospital services and community services. These easy-read versions are attractive and brightly coloured, with illustrations. The questions are easy to understand and there are just three options for responses; a smiley face symbol, an unhappy face and a neutral face to signify yes', 'no' and 'don't know'.

"It's the small things that matter really. A lot of the time, the frustration is the people who man the reception. Too often you feel as though you're in the way. The X clinic, there's always a lady, be at the other side of the receptionists, 'Hello, Mr X, how are you today? Now you're going to see Dr So-and-So and Dr So-and-So. We want to take some bloods from you. Will you sit down over here?' It's being treated nicely as opposed to, 'No, we haven't got your name. We don't know which clinic you're going to. Wait here.' Sorry, I sound bitter and twisted, but it's the way it comes across.

Patient Interview, What Matters to Patients, 2011

"It certainly happened very quickly for me and I think for other people – your GP refers you to them, you get seen by a psychiatrist, and you get given some medication. I never sensed, you know, they talk about a care plan approach, and I never sensed that there was any kind of discussion with me, or I think with anybody else, about what treatments were suitable for me and what would help me to get through and recover. It really was just a case of, 'We dish out pills, you can try these.'

Patient Interview, What Matters to Patients, 2011

2. Patient participation groups/patient panels/service user groups

Service user groups and forums can be a good source of patient experience data and can support the collection of data using other methods, such as surveys. Patient participation groups (PPGs) in primary care are a good example of this method.

Case Study

South Street Surgery has had a patient participation group for the last three years. The group was, initially, chaired by an external facilitator, but is now chaired by the business excellence director. The group has 24 members and has been involved in discussions taken to them by practice staff, including appointment systems; and the design and relocation of services.

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3. Focus groups and one-to-one interviews

A focus group is a group of participants who are invited to share their thoughts, feelings, attitudes and ideas on certain subjects, with the guidance of a facilitator. Focus groups can help you get a deeper understanding of the patient experience in an identified service improvement area.

A one-to-one interview enables the interviewee to explore people's feelings and concerns in more depth. The interviewer aims to cover a range of pre-determined topics, but without limiting the range of possible answers. Both methods produce qualitative data that needs to be anonymised and analysed before reporting.

The **National Association for Patient Participation (N.A.P.P)**[28] has over 30 years' experience and expertise in promoting, supporting and developing patient participation groups and has developed a full range of resources that can support practices.

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[28] http://www.napp.org.uk/

4. Patient stories

Stories are a powerful way of engaging staff, including senior leaders. They can be collected in a number of ways. There is considerable value in staff hearing patients' stories directly. It can help staff really understand how patients experience services, helping them to 'own' the data and acting as a motivator to do something about things that aren't working well.

Case Study

The **NHS Wales 1000 Lives Plus**[29] programme promotes stories as an effective and powerful way of making sure that the patient's voice is heard and that improvement of services is centred on the needs of the patient. It is a requirement of the programme that stories are used to ensure that managers at the highest level hear the patient's voice. The website provides an overview of the programme process and offers advice on the development and use of stories. It also provides a range of resources for collecting and using patient stories, including a 'how to' guide, video and tools.

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5. Patient Experience Trackers

New technologies have the ability to transform health services and engage the public, patients, staff and carers in new and more effective ways of improving services.

The *What Matters to Patients?* research found that over seven million individual responses have been collected using mobile hand-held devices called Patient Experience Trackers (PETs) over the last few years, and this is a current rate of over 300,000 responses per month. The majority of organisations that use PETs are service providers.

There are advantages and disadvantages to using new technology and its success depends upon the patient group. The Institute's Armchair Involvement site[30] provides information on choosing the right technology for your patient group.

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[29] http://www.1000livesplus.wales.nhs.uk/home

[30] www.institute.nhs.uk/armchair

Techniques	Advantages	Disadvantages
Surveys and Questionnaires	• Able to gather data from large numbers • Out-source collection to provide independence • Can provide base-line data • Provide quantitative data	• Question bias • Analysis of data • No opportunity to explore further feedback • Accessibility re: language, literacy, etc
Patient Participation Groups/patient panels/service user groups	• Can provide practical support for the team by supporting feedback collection, or volunteering to support patients, e.g. prescription delivery • Members bring their own experience and expertise to issues • In the long-term, positive relationships can be built • Activity of the group is determined by needs of local community	• May be unrepresentative of wider population • Cannot capture concerns of those unable or unwilling to use the service • Need commitment from teams
Focus Groups and 1 to 1 interviews	• Can provide a good cross-section of people • Provides a framework for discussion • Reach people who feel inhibited in larger groups	• Expertise needed preparing questions and interviewing • Analysis can be time consuming and difficult • Without investment of resources numbers can be low (However, using the EBD Approach can mean quality of feedback wins over quantity of patients.)
Use of film	• It gets the person being interviewed to talk about their experiences, feelings, options and knowledge • Allows the story to be shared with a wider group • Can be done using a range of devices including digital camera, camcorder and smart phones • Interviews can take place in the patients home	• Can be time consuming • Interviewer needs to be objective and to have a neutral stance • Can be daunting for the person being interviewed for the first time
Patient Stories	• Therapeutic value of involving patients in making their views known • Captures issues of continuity of care • Conveys experience effectively • Raising important issues from patient point of view	• Will need ethical approval if being used in research • May require recording via audio or visual approaches • Can be time consuming to analyse
Patient Experience Trackers	• Generation of easy to read data • Quick access and timely reporting • Effective in obtaining feedback in larger services, e.g. health visitor services • Check consistency of service quality across time	• Wide variation in the wording of questions leading to confusion • Patient concerns over anonymity • Accessibility re: language, age disability etc. • Expensive to buy • Requires regular updating of units and data
Mystery Shoppers	• Mystery shopping can help to assess the customer care aspect of services • As real patients are not involved, there are no confidentiality issues raised	• This method cannot be used when mystery shoppers would have to display symptoms or be prescribed medication for their condition • Mystery shoppers are not generally able to explore an issue in-depth • Mystery shoppers do not necessarily bring expertise of a service as a users

Involving staff

There is a demonstrable link between staff having clear and planned goals, and patients who report good communication, such as being involved in decisions about their care.

"I think not being patronising is important. I think listening to the patient too. It's having a sense of humour. It's having a bit of empathy with the patient and the fact that it's not always easy. And yeah, generally, you know, having a little bit of time."

Patient

Case Study

NHS Leicester City undertook a co-production programme to put people's experiences and needs at the heart of commissioning and shaping services. They involved staff, partners and patients.

They used story gathering to find out about peoples' experiences of services. Staff conducted interviews with members of the local community in their own homes, using materials such as pictures and objects that people could use to tell their story. A short film was created from these interviews.

Commissioners were invited out of head office to carry out 'patch walks' in the community, visiting local landmarks, schools, community venues, etc. This was followed up by an event, where participants were shown the film of local people talking about their experience of living in their community and accessing health services. The participants were then asked to align what they had seen and heard with their current commissioning arrangements for the area.

One member of staff said: "This reminds me why I joined the NHS in the first place...it's a real eye-opener. Statistics are not enough, this sort of understanding is critical to put people at the heart of health commissioning...the whole of the PCT should see this."

Case Study

The experiences of people in care homes (residents, relatives, carers and staff) are being used by the NHS Institute as part of its care homes programme.[31] The experience approach focuses on capturing and understanding people's views and feelings at crucial points in their care, not just their perspectives of systems and processes.

'What is my story?' is a tool that gives people the time, encouragement and help they need to describe their life story and personal care home experience in their own words. In a care home setting, these stories enable staff to learn about past experience so that they can understand current behaviour and aspirations more fully. The insights gained from listening to people's stories can also inspire ideas for change.

"You can see staff having a lightbulb moment as we talk about the past life of a resident. It is important for them to understand how the past might shape who that person is today. It is about thinking outside the box and being pliable. You need to be able to gain an understanding of the person's behaviour and enter the situation with them. Their life stories help us do that, so that we can switch our responses on and off, according to what they need."

Care Home Manager

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[31] http://tinyurl.com/dyuvfv2

Tapping into staff values

Many different people, including staff, talk about and share their experiences and, therefore, have the power to influence an organisation's reputation. What we can learn from the commercial sector is that the staff experience and the organisational culture that supports it are extremely important to the success of any customer experience programme. It is the staff who are on the frontline, after all, and who represent the organisation's culture through their interactions with customers. In successful commercial organisations, customer experience is always at the forefront of recruitment decisions – 'we hire for attitude, not fire for attitude.' Customer experience data constantly informs training and support decisions made for staff. Often it is these 'empowered staff' who are free to 'go the extra mile' for the customer and are rewarded by the organisation for doing so.

In the health service, we have an added advantage. There are a number of reasons why people choose to work in the NHS but, in many cases, these include values that can be a powerful lever to build interest in delivering positive patient experiences and the service improvements that are required to make this happen. Partly, this is an engagement exercise: patient experience improvement programmes need to use the right language in order to be inclusive and accessible; they need to stir desire to improve things by using patient and carer stories and they need to create a sense of the team working towards a common goal. In addition, it is important to celebrate success and share learning across the system.

> *It was only when we realised the link between staff and patient experience that we started to make real progress in the Trust.*
>
> Director of Nursing – London Acute Trust

"Time, and caring healthcare professionals is important. They need to take an interest so you don't feel neglected. You need to feel secure. No-one has got any time for you anymore, it's just like, you know, they try and get you out of hospital as quick as they can anyway, don't they? So, it would be nice if they just took a step back, sort of thing."

Patient

Changing the organisational culture

Organisations need to be prepared to change for patient experience to be used effectively. This is no 'tick box' exercise, but rather a fundamental engagement that starts with the patient.

NHS organisations involved in the **What Matters To Patients?** research reported that, to achieve a real change in culture, you need to invest in understanding patient experience and provide support for staff at all levels.

One senior manager explained, just having a nice big action plan was not enough, there was a need for staff to believe in what they were doing:

"It's addressing staff attitude and values head on, and as quickly as you can, through prompt feedback from managers...that's what we try and model and encourage. Find out what matters to your patients; and start doing something about it."

Service Manager, What Matters to Patients, 2011

From this...

- Organisation focused – work is arranged around the needs of the business.
- Information is presented from the viewpoint of staff.
- Any changes made are as a result of being reactive to patient demands.
- Teams do not routinely collect, or do much with, experience feedback.
- The focus is on functional aspects of care.
- Most staff feel that they are not empowered to change things for patients and people are only rewarded for efficiency.
- There is a silo working culture.
- Efficiency, productivity and clinical outcomes are considered most important.

...to this

- Patient focused – see the organisation through the lens of people who actually use the services.
- Information provision is planned with patients and is two-way.
- Service users are part of the decision making process and the organisation can demonstrate that this leads to service improvement.
- Pathways are mapped to illustrate experience and patient experience data is routinely collected and acted upon.
- The focus is on relational aspects of care and the emotional side of care is widely recognised.
- Staff experience is aligned to patient experience and people are rewarded for providing a positive patient experience.
- Work is based around the patient journey, providing more consistent/integrated care.
- There is a positive learning approach to complaints handling and complaints and compliments are shared widely.
- Patients are supported to be partners in their care and share decisions.

The board and management team taking a lead

As we outlined in section three, the management team and board executives have a key part to play in providing high quality, patient-centred care for patients.

By linking patient experience with clinical effectiveness and safety, the senior leadership team and the board has the opportunity to develop a clear picture of quality in the organisation. And, by promoting partnership working, it can establish strong working links with commissioners to ensure that patient experience goals are shared.

In addition, board members can ensure that patient experience is always on the agenda by playing a positive role in gathering feedback, 'walking the floor' regularly, and talking to staff and patients.

Planning

An effective way to organise a patient experience improvement programme is to determine which parts of the system to focus on, as the improvement activities will vary depending on whether the focus is at patient, individual staff member, team, service, organisation or whole health system level.

The What Matters to Patients research shows that we need to switch from approaching patient experience in **research mode** – measuring what happens and what people say about it; to quality improvement mode – measuring achievement against a standard. In **quality improvement mode**, first you seek to understand the patient experience, then identify opportunities for improvement and, finally, design services with patients to create a desired experience. Refer to the EBD Approach, later in this section, for information about tools to help you do this.

Switching to a mode of quality improvement will take time, and people across the organisation will come to understand what this means for them at different times and in different ways – be patient with them and the

process, but maintain the momentum. It helps to have quick wins in the early stages to boost confidence.

The Challenge	Questions to ask to address the challenge
Structural	How is the patient experience improvement effort being structured, planned and co-ordinated and embedded within the organisational fabric?
Political	How are the politics of change associated with implanting and sustaining efforts to improve patient experience being negotiated? Including: • securing stakeholder buy-in and engagement • dealing with conflict and opposition • building change relationships • agreeing and committing to a common agenda for improvement
Cultural	How is a shared understanding, commitment and community around improving patient experience being built?
Learning	How is a continuous learning process in relation to patient experience issues being embedded and nurtured? Including: • both formal and informal mentoring, instruction, education and training • the acquisition of relevant knowledge, skills and expertise
Emotional	How are staff and other stakeholders energised, mobilised and inspired to: • want to join in the effort to improve patient experience by their own volition • sustain its momentum through individual and collective motivation, enthusiasm and movement?
Technical	How is the physical, informational and technological infrastructure designed and used to improve the patient experience of care?

A quick checklist for improving patient experience

1. Build the business case

Build and articulate clearly the business case for investing in the measurement and improvement of patient experience. Dedicate resources to capturing, understanding and using patient experience, through both storytelling and numerical data.

2. Understand the current experience

The first thing a system, organisation, team or member of staff needs to do if they want to understand patient experience is to understand what it's like now. This involves working closely with patients and families to capture exactly how the process of care feels for them. Ask yourselves, do you

know how experience is currently measured in your service and whether improvements are made as a result? Do you know what this activity costs and what the benefits are? Once you have a plan, you will need to create a compelling vision for the culture change that will be required.

3.   Give experience some 'air time'

How much time do you spend each week talking about patient experience as compared to time spent discussing financial, safety and clinical issues? For an experience programme to be successful it needs to be embraced by leaders, central to your core organisational vision and strategy, and considered equally alongside clinical effectiveness and safety in your quality reporting. Commissioners need to make sure that their decisions are informed by knowledge of patient experience.

4.   Motivate your staff

Evidence shows that happy staff equals happy patients. Recognise the link between patient experience and staff wellbeing and develop plans for improving both. Make the focus on understanding and delivering a positive patient experience an integral part of staff induction, development and appraisal.

5.   The power of stories

Stories are a powerful tool for engaging staff, including senior leaders. They can be collected in a number of ways and there is considerable value in staff hearing patients' stories directly. It can sensitise them to patient experience, helps them to 'own' the data and acts as a motivator to do something about it.

6.   Give equal status to experience

Patient experience is of equal importance to clinical quality and patient safety. Demonstrate organisational commitment to understanding patient experience and co-designing improvements with patients as partners by discussing patient experience at your key meetings.

7.   Incentivise improvement

Providers and commissioners need to develop shared patient experience goals as part of developing good working relationships. Incentive systems need to be aligned so that they recognise and reward innovative patient experience measurement and improvement in local organisations.

> "
> The doctor made me feel that I was part of my care. Together we built up a picture of my health problem and worked out the best means of treating my condition. I went away feeling confident that I was being properly looked after and I understood what I needed to do to aid my recovery.
> "
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> Patient interview, What Matters to Patients, 2011
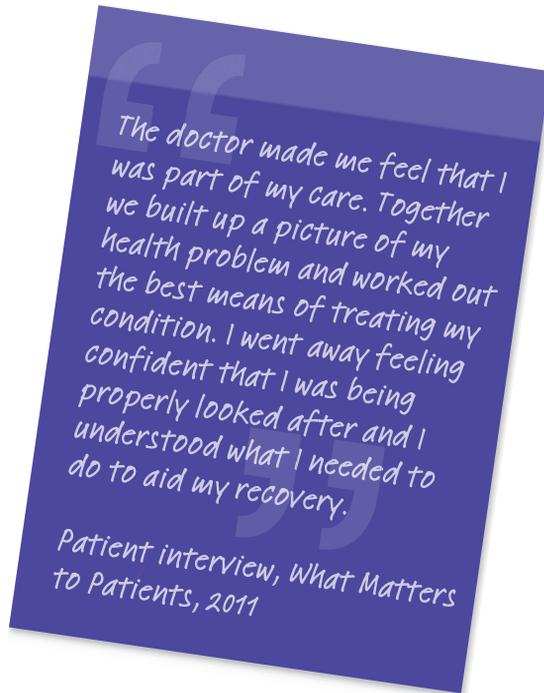
Section five: NHS Institute Tools that Can Help You Improve Experience

1. The EBD Approach

Experience Based Design (the EBD approach[32]) is a way of using experience to design better healthcare. The NHS Institute has developed a range of tools to help organisations to use experience to improve their services. The tool, initially, focuses on capturing and understanding patients', carers' and staff experiences of services; not just their views on the process they go through, but the way it actually feels to experience services. The EBD approach then helps organisations to use these experiences to redesign the way care is delivered, using patients and staff as partners in the quality improvement process. The experience experts and the service experts work together to make the changes.

By using the EBD approach, teams are able to determine the desired experience for both staff and patients and then measure against this promise.

What is different about EBD?

This approach deliberately draws out the subjective, personal feelings a patient and carer experiences at crucial points in the care pathway. It does this by:

- encouraging and supporting patients and carers to 'tell their stories'

- using these stories to pinpoint those parts of the care pathway where the users' experience is most powerfully shaped (the 'touchpoints')

- working with patients, carers and frontline staff to redesign these experiences rather than just systems and processes.

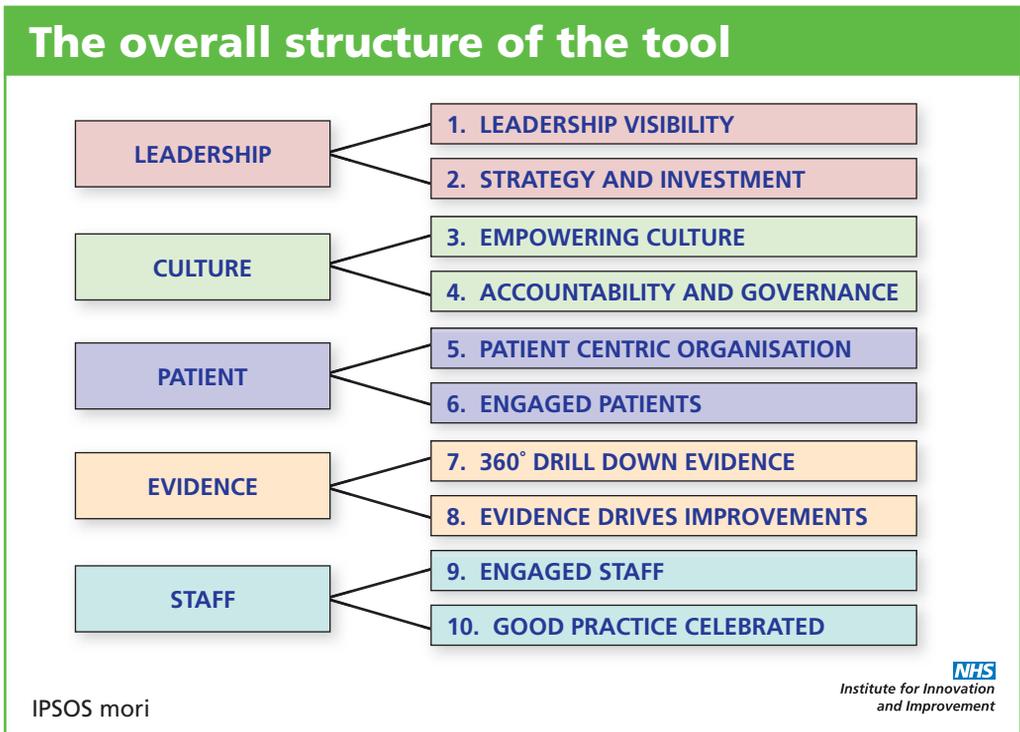---

[32] http://tinyurl.com/c4qtue8

"EBD has prompted me to act on some of the things we've wanted to do for ages."

Clinical nurse specialist

2. The Self-Assessment Tool

People with designated responsibility for improving patient experience are faced with a mix of guidance and frameworks to work to. They reported feeling overwhelmed and not knowing where to start with implementing the requirements and objectives of this plethora of policy and practice guidance. This is how the self assessment tool came about. It is an attempt to pull all of the requirements together in one place and enable organisations to plan their patient experience improvement work in a strategic and practical way.

The Self-Assessment Tool was commissioned by the NHS Institute and developed by Ipsos MORI. It provides a framework for improving patient experience.

The overall structure of the tool

LEADERSHIP	1. LEADERSHIP VISIBILITY
	2. STRATEGY AND INVESTMENT
CULTURE	3. EMPOWERING CULTURE
	4. ACCOUNTABILITY AND GOVERNANCE
PATIENT	5. PATIENT CENTRIC ORGANISATION
	6. ENGAGED PATIENTS
EVIDENCE	7. 360° DRILL DOWN EVIDENCE
	8. EVIDENCE DRIVES IMPROVEMENTS
STAFF	9. ENGAGED STAFF
	10. GOOD PRACTICE CELEBRATED

IPSOS mori

NHS
Institute for Innovation and Improvement

The Self-Assessment Tool is:

- a systematic, **evidence-based** way to review how well your organisation is using patient experience feedback **to promote improvements**

- a **challenge process** to encourage you to **focus on the current gaps** in the way you are using patient feedback to promote service improvements

- a process to support you in **planning your strategy** to make **better use of patient feedback to improve your services**

- a '**behind closed doors' exercise** within your organisation to encourage you to be as **self-reflective and self-critical as possible.**

It is not a performance management tool: it has been designed specifically to support internal review processes. The more self-reflective and self-critical you are, the more effective it will be in revealing gaps, which you can address in your improvement strategy.

> "
> Organisations with a reputation for delivering great patient experience only reach that stage when they have included patient experience in a strategy that has prioritised quality and patient safety over a long period, have sustained an investment in infrastructure and management process, and embedded the systems and processes required to create the conditions for better outcomes in the organisation's culture and the way it does its business.
> "
>
> Kings College London & Kings Fund, What Matters to Patients, 2011

How it works

The tool comprises five domains of activity (leadership, culture, patient, evidence and staff), each with two sub-domains (such as leadership visibility and strategy and investment for the leadership domain).

The Self Assessment Scoring Scheme

0	1	2	3	4	5	6	7	8	9 SILVER	10 GOLD
No activity	Minimal activity		Some activity – but in the minority		Considerable activity – but there are gaps		Consistent, organisation-wide activity		Collaborative activity across pathway	

You:

- score your performance on each sub-domain

- provide evidence to support your scores (eg patient experience strategy)

- identify improvement actions.

Your scores across the ten sub-domains are totalled up to provide a baseline measure of your current performance. The improvement actions you identify can be developed into a service improvement strategy for the organisation. If you choose, you can also set improvement targets for each domain, as a basis for tracking your improving performance.

You will find the full Self-Assessment Tool, including supporting documentation, on the CD (in Patient Experience Learning Programme Resources folder) that accompanies this book.

3.   The Fifteen Steps Challenge

"I can tell what kind of care my daughter is going to get within 15 steps of walking on to a ward"

quote from parent that sparked the Challenge

The 15 Steps Challenge is a series of toolkits which are part of the resources available for the Productive Care workstream. They have been co-produced with patients, service users, carers, relatives, volunteers, staff, governors and senior leaders, to help look at care in a variety of settings through the eyes of patients and service users, to help capture what good quality care looks, sounds and feels like.

Case Study

Nottingham University Hospitals NHS Trust rolled out the 15 Steps Challenge to all 80 of its wards on the same day! Find out how the Trust prepared and rolled out the Challenge in its acute wards. www.institute.nhs.uk/productives/15stepschallenge.

Other useful tools

The Sustainability Tool[33]

The most successful organisations are those that can implement and sustain effective improvement initiatives, leading to increased quality and patient experience at lower cost. The Sustainability Tool has been developed to support health leaders to do that.

The Observation Tool[34]

The Observation Tool is one of the key tools we use within the NHS Institute, a technique adapted from the worlds of design and ethnography.

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[33] http://tinyurl.com/7ackzcj

[34] http://tinyurl.com/buzxh4b

The tool helps NHS staff to realise that taking a step back and looking at their service with fresh eyes can be an incredibly effective way of understanding how they can improve the service they deliver.

Service Safari[35]

Service Safari is a method used by many top organisations and adapted by the NHS Institute for healthcare settings. It enables a team to observe a range of service experiences in a short space of time and is a fantastic source of ideas. The safari has three phases – **before, during and after: Before** is about defining purpose and capturing individual expectations. **During** is about exploring, observing, taking notes and photographs, recording feelings. **After** is about going back to the original purpose. You will find more about service safari on the CD (in the Patient Experience Learning Programme Resources folder) that accompanies this book.

Plan, Do, Study, Act (PDSA)[36]

You can use plan, do, study, act cycles to test an improvement idea by temporarily trialling the proposed change and then assessing its impact. Using PDSA cycles enables you to test out changes before wholesale implementation and, so, gives stakeholders the opportunity to see if the proposed change has worked and to adapt the approach before it is implemented more widely.

Thinking Differently[37]

If we, the staff, clinicians, managers and leaders within the NHS, continue to think as we have always thought, we are likely to get the same results have had had before, regardless of the new structure and priorities that surround us. Thinking differently can help to ensure that services are not just improved but transformed and this tool is designed to assist with this process.

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[35] http://tinyurl.com/c3az99j

[36] http://tinyurl.com/25pvog5

[37] http://tinyurl.com/92p5pvk

Section six: Measuring Experience

Using patient experience information requires organisations to have the capacity to collate and analyse data. It is also important to have good systems for managing and tracking data. The measuring experience section of this guide provides you with the tools and evidence to use data to improve services. You will find more about measurement on the CD (in the Patient Experience Learning Programme Resources folder) that accompanies this book.

Why patient experience measurement is important

The data that is collected from patients can help organisations to make better decisions about how to improve services. But, in order to use patient experience information effectively, you must be able to collate and analyse data. That's why it is essential to have good measurement systems for managing and tracking the data you collect.

No single approach

To ensure that data leads to positive change for patients, organisations need a mixture of measures that give them immediate and recent data that is sufficiently detailed and meaningful to influence staff, managers and executives. No single approach is sufficient and you should not rely exclusively on annual patient experience surveys. Numbers (quantitative data) and stories (qualitative data) are of equal importance and can be collected in a variety of ways. They should be considered together, a process which is referred to as 'triangulation'. Compliments and complaints are also equally valuable.

Patient experience measures can also be used in a multitude of ways, for example, real time patient experience information is of use directly by teams, but can also be collated and compared across services and at board level.

Case Study

Sheffield Teaching Hospital produces a quarterly patient experience report bringing together patient experience information, including a wide range of data and qualitative feedback. The report is highly visual and has enabled the hospital to have more meaningful discussions around patient experience information. Feedback on the report has been overwhelmingly positive.

NHS North Staffordshire uses a computer system that records, aggregates, and identifies trends in patient experience. This gives it the ability to drill down and analyse themes by organisation, individual and by the five domains of patient experience. The result is a cohesive database that is able to record Patient Advice and Liaison Service (PALS) contacts, complaints and feedback from patient and public involvement and engagement workshops, and to make tangible improvements to patient experience.

"
Using Patient Experience information requires that organisations have the capacity to collate and analyse data. It is also important to have good systems for managing and tracking the data collected. The most important issue is how Patient Experience information leads to change.

Kings College London & Kings Fund, What Matters to Patients, 2011
"

Who needs to measure patient experience?

According to the *What Matters to Patients?* research:

- methods of collecting and reporting patients' feedback should be tied as closely as possible to clinical services so that **clinicians** identify with the results

- **middle managers and clinical teams** should monitor quality of care as often as they monitor budgets. They need relevant, accurate, timely, frequent information from their own patients to compare their own services with others and make improvements. This means access to 'near real time' feedback, based on standard questions, with demographic information to allow for assessment of population mix

- NHS trust **commissioners, planners and policy makers** should make use of the data collected to support the management and improvement of frontline services and should avoid demanding fresh collections of data for their own purposes.

How to measure patient experience

You need to commit resources to developing a local infrastructure for collecting, analysing, interpreting and reporting on patient experience data.

This may include:

- staff with dedicated responsibility for overseeing and coordinating the work and providing expertise

- a budget for training, creating feedback materials and drawing on external expertise

- protected time for staff to review feedback and learn from patient experience.

Collecting data

Data should:

- be collected regularly and systematically and as near to real time as possible, using a range of technologies, as appropriate, such as patient experience trackers

- be collected for specific services, and as close to clinical teams as possible (so that feedback can be as direct and relevant as possible) For example, daily and weekly reports at team level

- be collected along care pathways, as well as for single episodes of care

- allow for comparisons over time, and for benchmarking within and between services and organisations

- work across organisational boundaries

- focus on patients' and service users' feelings about the way they are treated, as well as on what actually happens to them

- focus on what really matters to patients (see page 19 of this book **Key findings of *What Matters to Patients?***), and not try to measure everything.

In order to obtain a complete picture of the patient experience, you need to collect data from a range of different sources, including:

- patient stories
- surveys (both local and national)
- complaints
- PALS data
- incident reports
- general feedback.

"What NHS staff have told us: reflect outwards, work with other services – with patients at the centre of care; work closely with partner providers to monitor consistent patient experience; network with local organisations – work in partnership."

NHS South Birmingham, ***What Matters to Patients?*** 2011

If feedback is collected in isolation, it often does not lead to service improvement. It is important to have a mechanism whereby that feedback is arranged so that it can help teams to understand what is working well and what can be improved. The next stage is for staff and patients to work together to identify and implement improvements. The EBD approach provides a structure and set of tools to help teams achieve this.

> We collect data from patients about their experience (both qualitative and quantitative), we analyse it (turn it into a format that helps us see patterns, trends) and then review our service in the light of this intelligence. In other words the data we have gathered help us make better decisions about how to move the service forward.
>
> Patient Experience Lead, Acute Trust

Techniques	Advantages	Disadvantages
Surveys and Questionnaires	• Able to gather data from large numbers • Out-source collection to provide independence • Can provide base-line data • Provide quantitative data	• Question bias • Analysis of data • No opportunity to explore further feedback • Accessibility re: language, literacy, etc
Patient Participation Groups/patient panels/service user groups	• Can provide practical support for the team by supporting feedback collection, or volunteering to support patients, e.g. prescription delivery • Members bring their own experience and expertise to issues • In the long-term, positive relationships can be built • Activity of the group is determined by needs of local community	• May be unrepresentative of wider population • Cannot capture concerns of those unable or unwilling to use the service • Need commitment from teams
Focus Groups and 1 to 1 interviews	• Can provide a good cross-section of people • Provides a framework for discussion • Reach people who feel inhibited in larger groups	• Expertise needed preparing questions and interviewing • Analysis can be time consuming and difficult • Without investment of resources numbers can be low (However, using the EBD Approach can mean quality of feedback wins over quantity of patients.)
Use of film	• It gets the person being interviewed to talk about their experiences, feelings, options and knowledge • Allows the story to be shared with a wider group • Can be done using a range of devices including digital camera, camcorder and smart phones • Interviews can take place in the patients home	• Can be time consuming • Interviewer needs to be objective and to have a neutral stance • Can be daunting for the person being interviewed for the first time
Patient Stories	• Therapeutic value of involving patients in making their views known • Captures issues of continuity of care • Conveys experience effectively • Raising important issues from patient point of view	• Will need ethical approval if being used in research • May require recording via audio or visual approaches • Can be time consuming to analyse
Patient Experience Trackers	• Generation of easy to read data • Quick access and timely reporting • Effective in obtaining feedback in larger services, e.g. health visitor services • Check consistency of service quality across time	• Wide variation in the wording of questions leading to confusion • Patient concerns over anonymity • Accessibility re: language, age disability etc. • Expensive to buy • Requires regular updating of units and data
Mystery Shoppers	• Mystery shopping can help to assess the customer care aspect of services • As real patients are not involved, there are no confidentiality issues raised	• This method cannot be used when mystery shoppers would have to display symptoms or be prescribed medication for their condition • Mystery shoppers are not generally able to explore an issue in-depth • Mystery shoppers do not necessarily bring expertise of a service as a users

Case Study

Nottinghamshire Healthcare NHS Trust
As part of its programme of improvement work, Partnerships Inspiring Change, Nottinghamshire Healthcare NHS Trust has ten teams linked with service users, carers and governor members. These teams are working in partnership to ensure that they develop excellence in four areas: capturing feedback; sharing feedback within service teams; acting on feedback; and sharing changes made as a result of feedback with patients.
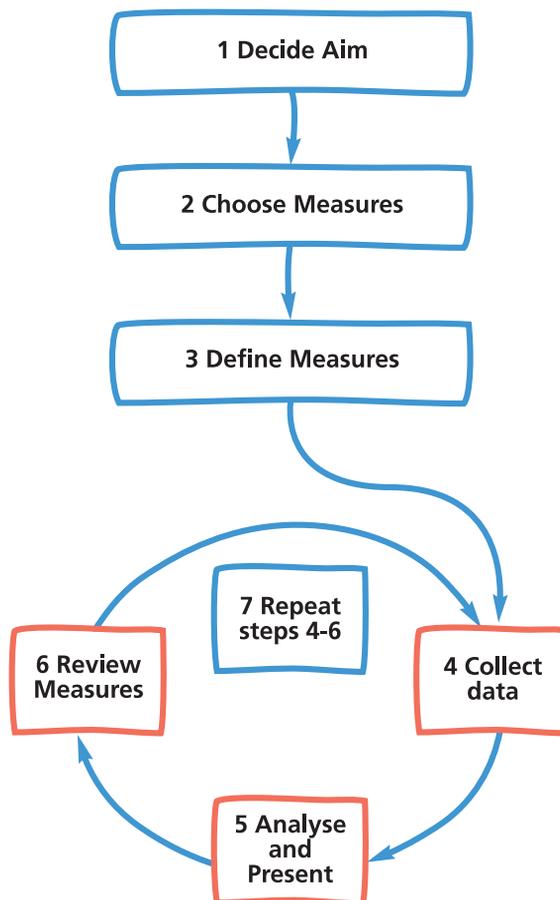
Some of the highlights from the teams include:

- early intervention in psychosis team: they now record all service user comments in a logbook and discuss them at weekly team meetings. They post comments on the Patient Opinion website so that they are publicly responded to

- acute mental health ward: training 12 student volunteers to capture feedback as they take the tea trolley around the ward

- older people's mental health ward: feedback champion volunteers received Patient Opinion and iPad training to be able to sit with patients and collect feedback at the patient and carer meetings. EBD (Experienced Based Design) is going to be piloted on this ward and it will be looking at other creative ways to gather feedback with volunteers, staff and patients (such as video and making recovery cards).

The seven-step measurement process

The seven-step measurement process is a structured process for effective measurement. Following the seven steps helps to ensure that any data that is collected from patients is used to make better decisions that, ultimately, improve services. The seven-step process makes the link between data collection, analysis, finding and reporting patterns and communicating both the decisions and the process to patients and the public.

Using patient experience information requires that organisations have the capacity to collect and analyse data. It is also important to have good systems for managing and tracking the data collected. However, the most important thing is to ensure that patient experience information leads to change, and using this process can help you to achieve that.

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                    ┌─────────────────┐
                    │  1 Decide Aim   │
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                    │ 2 Choose Measures│
                    └────────┬────────┘
                             ↓
                    ┌─────────────────┐
                    │ 3 Define Measures│
                    └─────────────────┘
```

1 Decide Aim

2 Choose Measures

3 Define Measures

7 Repeat steps 4-6

6 Review Measures

4 Collect data

5 Analyse and Present

"Good measurement doesn't happen by chance. We get to it by following the seven-step process shown in the diagram. The first step is to think carefully about what we want to improve. Then we choose and define measures appropriate to that aim."

Mike Davidge, Head of Measurement, NHS Institute

How to use the seven-step process

Step 1: Decide aim

Think carefully about what it is you are trying to improve. Together with your team ask: 'What are we working towards; what is our aim?'

Your aim needs to be SMART – simple, measureable, aspirational, realistic and with clear time limits. For example – We will reduce our falls to less than one per week by 31 December this year.

If the aim seems quite a long way from where you currently are (your baseline), break it down into smaller stages, eg achieving 80% within one year, but improving this to 95% within 18 months.

Step 2: Choose measures

With your aim firmly in mind you now need to choose and develop appropriate measures. Keep things simple. You could, potentially, come up with lots of measures but it is important that you focus on just a few at first; building these up once you become more confident. For example, you might choose to measure the number of falls per week, or the number of days between falls.

Step 3: Confirm collection and display

When you have selected your measures, you need to be clear about what data you are collecting (qualitative and quantitative), where this will come from (eg surveys, service user stories, manual data collection), who will do the data collection and how often.

Measures nearly always require some kind of definition. This means specifying exactly what some terms mean and applying this definition consistently to ensure that all staff collect the same data in the same way.

For example, what is the definition of an accident? You don't want to end up comparing apples and oranges.

Good measures are linked to your aim – they reflect how the aim is achieved.

You will need to identify the data you need and where it comes from. Sometimes the data is already being collected but, often, you may need to set about collecting it yourself. The process of working this out helps you to define exactly what it is you are measuring and, sometimes, you will find that it might be so complex that you need to rethink what the best measure is to ensure the data is collected reliably.

The way you present your data is extremely important, too. It will have a crucial impact on how others react to your improvement work. Data isn't always very useful in its raw form and usually needs to be converted into something that helps you and others understand what is going on.

Quantitative data (data about numbers) is often better displayed as a graph rather than as a table. Turning your measures into line and bar chart tools will help you with this – helping you see what's happening at a glance and to pick up patterns.

Qualitative data (experiences, anecdotes and observations) is much more about the story itself. You need to think about how you will use the story, for instance as a written narrative by pulling out key quotes from feedback, as a video clip or a storyboard on a wall.

Step 4: Collect data

You will need to know how you are doing now (baseline) before you can track the progress of your aim against it. It is important that you collect data over time so that you can see any improvements that are happening. If you just compare one month to another month you will always be either higher or lower than the month before.

In order to have enough data so that it creates a pattern, or story, of what is happening you will need to collect around 25 data points. A data point is one individual piece of data. For example, the number of minutes taken to do a handover would be one data point. If we collected this for 25

handovers, this would give us the 25 data points we need to ensure we can see any patterns. However, 20 data points will provide a robust representation. One way to ensure you get enough data points is to measure frequently. For example, rather than measuring the number of falls on a monthly basis, or even weekly, do it daily to get seven times as many data points! This is easy if historic data is available for you to use but, often, the data you need to measure is not being collected. If this is the case, you should start collecting your data straight away in order to create a useful baseline.

This is where you start the 'collect, analyse and review', often referred to as the CAR, measurement cycle.

If the data you need to collect is difficult to obtain, or the measures are not correctly defined, you will need to go back to the previous step.

Remember, timely monitoring allows timely intervention.

Step 5: Analyse and present

Once you have collected your data, you are ready to analyse (look for patterns) and present it. As part of step three, you will already have agreed the process for presenting your data.

This process will need to be repeated depending on how often you decided to monitor and review your measures.

You will need to update your charts regularly as you continue to collect more data.

When entering your data there is also an opportunity to write on the chart. This is an extremely useful way of noting when you have made changes so that you can see whether they are having any effect.

Step 6: Review measures

It is vital that you set aside regular times where you and your team can come together to look at what the data is telling you and use this information to decide what you might need to do next. If you don't have an existing meeting that includes the right people, you will need to set one up. It needn't be a long meeting – 15 to 30 minutes is perfectly adequate

to review where you are and decide the next actions. Remember that the purpose of measurement is to lead you to making the right decisions about your improvement work. Working with your team, ask:

- what outcomes did we expect?

- do the results indicate we are achieving those outcomes?

- are we confident we have arrived at the correct conclusion?

- do the results indicate that we should be doing something else?

- would any other measures tell us more?

A measures checklist is available on the CD (in the Patient Experience Learning Programme Resources folder) that accompanies this book, to help you structure the meeting.

Step 7: Keep going (repeat steps 4-6)

Now go back to step four and repeat the 'collect, analyse, review' (CAR) process. While you may want to continue collecting certain data because it is telling you something important about how well you are doing, you may, in time, be able to stop collecting other measures because they related to a very specific part of your improvement project and have served their purpose.

> I feel like they're trying to treat too many people at once, so everyone becomes a low priority. And their priority is getting people off their waiting list. And you just feel like a statistic rather than a person with problems.
>
> Patient Interview, What Matters to Patients, 2011

When do I stop measuring?

The simple answer is 'you don't'. If you are consistently meeting your goal you should still look to see if there are further improvements that could be made. If, for example, you aimed for 100% of staff trained in a tool and are meeting it consistently, you should still continue to measure so that any deviations are picked up and acted upon quickly. In these cases you may decide to measure slightly less frequently. However, be aware that the process of measuring does have a positive effect in keeping awareness high and demonstrating that the goals you are measuring are important to the organisation.

Remember that once you start measuring, you have established definitions and need to ensure they are applied consistently. If you do change them, for any reason, you will need to write on your charts stating what you have changed about what you are measuring or the way that you measure it.

Using patient feedback to improve services

In order to use patient experience to improve services, you need to:

- make improving patient experience an explicit part of the remit of local quality improvement/change teams

- develop and support the development of relevant expertise in local quality improvement/change teams, so they are empowered to make the changes that need to be made

- make patient experience an integral part of all local quality improvement/service redesign projects.

Involving patients

A key component of service improvement and redesign work should be patient involvement. You need to:

- work with patients during the process of collecting data to provide opportunities for staff to hear directly from patients

- get staff and patients to work together on projects to co-design/ co-produce existing or new services

- include patients whose experiences are seldom heard, for example patients with communication difficulties and people with learning disabilities. A useful approach is to identify people who are already part of the patients' trusted networks, such as a bridge worker who they already know well through other service interactions. At Homerton University Hospital, for example, a patient with sickle cell anaemia was the key to engaging many other patients and keeping them on board for the duration of the service improvement project. They trusted him and saw him as being 'one of them' which meant they felt comfortable opening up to him

- feed back to patients what happens after the information is collected and analysed, for example by using posters, letters and celebration events

- improvement/service redesign projects.

Equipping staff

You need to prepare staff and equip them with the skills and knowledge to be able to respond effectively to patient feedback. You can do this by:

- feeding back to staff, information about patient experience, and the need for improvements, so that they can recognise the value of patient experience feedback alongside feedback on patient outcomes and safety

- developing staff – this goes hand in hand with improving patient experience. Staff need help to 'own' feedback about the service they provide and to act on it. They also need support to hear and respond positively to difficult feedback. In order to achieve this, it is important to engage staff in any patient experience programme from the start, so that they are part of the solution. Often, staff have great ideas for how things could be improved and this insight, along with service user insight, will ensure that workable solutions are identified

- making sure you 'catch people being good' and celebrate success.

An example of good practice

Integrating patient experience measurement systems into existing work practices is vital and some excellent examples of this are emerging. At Birmingham and Solihull Mental Health NHS Foundation Trust, for example, 'mystery shoppers' audit mental health service standards (set by patients and carers), send the results to managers, publish action plans and take part in staff training. As a result of this work, users and carers report feeling part of the setting and the enhancement of standards.

At NHS Camden Provider Service said:

"We operate an integrated governance system and each service then monitors a range of metrics, and it expected to triangulate them. So, clinical outcomes, patient satisfaction, complaints, incidents are all analysed up to service line level and presented... each service line knows where it stands on all those areas, so you can see a pattern coming up."

> "
> Time, and caring healthcare professionals is important. They need to take an interest so you don't feel neglected. You need to feel secure. No one has got any time for you anymore, it's just like, you know, they try and get you out of hospital as quick as they can anyway, don't they? So it would be nice if they just took a step back sort of thing.
> "
>
> Patient Interview, What Matters to Patients, 2011

Section seven: Commissioners and Patient Experience

The new commissioning landscape requires a new perspective and Clinical Commissioning Groups (CCG) need to obtain a thorough understanding of the needs of their population and then use a robust and collaborative process to agree local priorities. In addition, CCGs need to performance manage the services they commission on an on-going basis. In order to do this, commissioners will need to know where to focus their efforts, what skills they should invest in and which methods of engaging and involving people will have maximum impact.

Why should commissioners measure patient experience?

Commissioners need to make sure that their decisions are informed by knowledge of patient experience because, only then will they know whether they are commissioning the right kind of services and of the right quality. Shared patient experience goals can help providers and commissioners to develop good working relationships that deliver the improvements that really matter to patients. Measures and rewards (incentive systems) need to be aligned so that they recognise and reward innovative patient experience measurement and improvement in local organisations.

> "Commissioners and providers noted the need for a mature relationship between the two kinds of organisation – both commissioning organisations and those delivering care."
>
> Kings College London & Kings Fund, What Matters to Patients, 2011

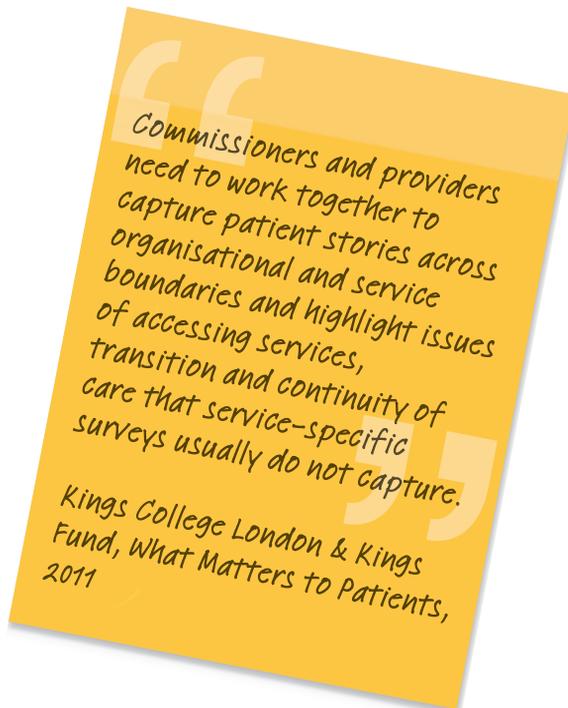## Measures and rewards commissioners can use to promote improvement

Commissioners can use both qualitative and quantitative approaches to measure and reward patient experience improvements. The key approaches are:

NICE Quality Standards for Patient Experience in Adult Services

To deliver the best possible experience for patients who use NHS services, high quality care should be clinically effective and safe. Launched in February 2012, this quality standard, and accompanying clinical guidance, aims to ensure that patients have an excellent experience of care from the NHS.

Commissioning for Quality and Innovation (CQUIN)

CQUIN is a national framework for locally-agreed quality improvement schemes, where commissioners reward providers for achieving quality improvement goals.

> "Commissioners and providers need to work together to capture patient stories across organisational and service boundaries and highlight issues of accessing services, transition and continuity of care that service-specific surveys usually do not capture.
>
> Kings College London & Kings Fund, What Matters to Patients, 2011

Quality and Outcomes Framework (QOF)

The Quality and Outcomes Framework is a voluntary annual reward and incentive programme for all GP surgeries in England. Patient experience is one of the four domains and has three indicators that relate to length of consultations, patient experience and access to GPs.

Quality Accounts

Now published annually, acute trusts have to produce and present Quality Accounts to the Department of Health. This information is publicly available. The quality improvement agenda includes patient experience and the priorities chosen can be linked to the CQUIN goals.

National Patient Survey Programme

The NHS in England has a National Patient Survey Programme, which is continuously being refined and improved.

Patient-Reported Outcome Measures (PROMS)

PROMs measure a patient's health status or health-related quality of life at a single point in time, and are collected through short, self-completed questionnaires. This health status information is collected from patients through PROMs questionnaires before and after a procedure and provides an indication of the outcomes or quality of care delivered to NHS patients.

PROMs have been collected by all providers of NHS-funded care since April 2009.

The Friends and Family Test

The Friends and Family Test is, effectively, the Net Promoter Score (NPS) adapted from the commercial sector for the NHS. A standard net promoter question is 'How likely it is that you would recommend our company to a friend or colleague?' and respondents indicate this likelihood on a 10-point rating scale (with 10 being 'highly likely' and 1 being 'not at all likely').

Those people who score services with a 9 or 10 are referred to as 'promoters', while those who score 0-6 are 'detractors' and those who score between 7-8 are 'passively satisfied' or 'neutral'. The NPS is the difference between the percentage of users who would recommend your

services minus the percentage of those who would not. A score of 75% or above is considered quite high.

From April 2013, all hospital patients will be asked a simple question to identify if they would recommend a particular A&E department or ward to their friends and family. The results of the test will be used to improve the experience of patients by providing timely feedback alongside other sources of patient feedback. It will highlight priority areas for action.

See http://tinyurl.com/c5cgzws for further information on the test.

Building patient experience into the new commissioning structures

As the new commissioning arrangements come into place, there are a number of opportunities for commissioners to build the need for positive patient experience into the vision, strategy, systems and structures for commissioning. There is a need for commissioners to:

- work in partnership

- consider patient experience as a key dimension of quality

- ensure that the services they commission provide personalised care

- ensure continuity of care and track experience along patient pathways, as well as by individual service

- understand the challenge and scope for improving patient experience in individual organisations

- evaluate and support provider organisations to deliver a positive patient experience.

The Engagement Cycle

Engaging with patients and the public can happen at two levels:

- individual level – 'my say' in decisions about my own care and treatment

- collective level – 'my say' or 'our say' in decisions about the commissioning and delivery of services.

The Engagement Cycle is a strategic tool that helps commissioning teams understand who needs to do what, in order to engage communities, patients and the public at each stage of commissioning. It is also for local stakeholders who need to understand, have input into, and influence commissioning.

The Engagement Cycle identifies five different stages when patients and the public can and should be engaged in commissioning decisions:

Community engagement to **identify** needs and aspirations.

Public engagement to **develop** priorities, strategies and plans.

Patient and carer engagement to **improve** services.

Patient, carer and public engagement to **procure** services.

Patient and carer engagement to **monitor** services.

At each of these five stages, The Engagement Cycle provides simple advice on what to do in order to undertake high quality patient and public engagement that will enhance and support the decisions that commissioners need to make.

Each stage of the cycle provides useful intelligence for the next (like a baton being passed on from one stage to another) and can assist commissioners by helping to:

- develop a shared understanding of what good engagement looks like

- provide a strategic direction and basis for planning

- clarify relationships, accountabilities, roles and responsibilities.

You can find more information about The Engagement Cycle at www.institute.nhs.uk/engagementcycle

From April 2013, InHealth Associates will lead the development of the Engagement Cycle.

Armchair Involvement

New technologies have the ability to transform health services and to engage the public, patients, staff and carers in new and more effective ways for service improvement. That's what Armchair Involvement is about.

The Armchair Involvement guidance will help you find out about the new technologies available to engage patients, carers, staff and public for service improvement. It is called armchair involvement because new

technology enables public service providers to enable participation from the participants' own 'armchair', or anywhere else they find convenient to participate from.

The guidance features:

- Case studies of what other people have been doing.

- A guide to some of the tools you might want to use.

- Recommendations from the armchair involvement research.

Here is a list of principles to bear in mind when planning your armchair involvement project:

Technology alone is not the answer: Armchair Involvement is about participation and engagement first and foremost, the digital tools available are a supplement, not a substitute for face to face and more traditional communication methods.

Understand your participants first: Before beginning to choose tools, it is always best to know your participants' preferred ways of engaging, and to involve them in the design process where possible.

If you build it, they might not come! Go to where the people are – if you are going to run an online engagement project, for example a discussion forum, it is always best to see if people are already engaging in existing forums. That way you might not need to build your own.

Look beyond healthcare for inspiration: There are lots of inspiring examples of engagement using a mixture of new and old technologies, whether in local government, campaigning or private sector customer services – open your eyes to new ideas that could work for healthcare.

Evaluate and share your learning: Armchair Involvement is an emerging field so sharing your own experiences of trialling new technologies is very important. The Armchair site is here to help.

You can find more information about Armchair Involvement at www.institute.nhs.uk/armchair. From April 2013, Involve will lead the development of Armchair Involvement.

Section eight: The NHS Patient Feedback Challenge

The NHS Patient Feedback Challenge was a competition to find some of the most promising approaches to measuring and improving patient experience. NHS organisations bid for a share of the £1 million Challenge fund, which was provided by the Department of Health. The aim of the challenge, which was created and managed by the NHS Institute, was to support the spread of great approaches to using patient experience to improve services.

Nine Challenge projects, led by different NHS organisations, were chosen, and each won a share of the £1 million fund. All of the projects built specialised project teams to share and spread their successes, including specialist collaborators from the commercial and third sector, along with spread partner organisations from within the NHS.

The NHS Patient Feedback Challenge was a very different programme of improvement for health and social care.

At the outset of the Challenge, the NHS Institute put out a call for projects that could demonstrate progress in working with patient experience and had an ambition to expand that work throughout their organisation and across boundaries. It wanted to identify projects that were keen to share and support the wider adoption of their idea.

Four key factors made the Challenge particularly unusual:

1. The money (£1 million fund) – this provided a great opportunity for organisations wishing to do some ambitious work.

2. Crowd sourcing – the Challenge only funded ideas that were successful at attracting support via the web channel. This challenged participants to explain their project well and to engage people (including patients) in the activity. In addition, all project reporting was conducted via the web channel, making it transparent to a wider community.

3. The emphasis was on adoption of good practice – no more theorising about what does and doesn't work, this Challenge was about services

getting on and doing it – at scale. The message to organisations was 'you can copy someone else's idea and gain their support to do it!'

4. Support – the Challenge recognised that what it was asking wasn't easy. It provided a wide range of support, including specialist collaborators from other sectors. The aim was to create fruitful and sustainable partnerships.

Three 'Hot House' events took place and formed part of the application process. The process was intended to provide critical challenge to funding applicants, leading to fewer (but better quality) applications. The Web Channel and Hot Houses both provided opportunities for lead NHS organisations to meet with potential spread partners and specialist collaborators. The Hot Houses also enabled projects to access both generic and bespoke project support around issues such as measurement.

One project described the opportunity for funding through the NHS Patient Feedback Challenge as:

"good timing because we are on the road to culture change in a few areas – around teams not seeing patient experience as a 'nice to do'. There is the aim that they will see it as an integral part of their work, a natural 'loop' to listen to people and feedback to them."

Project lead

A range of innovative approaches were adopted by the projects. Many used digital and/or online technology to facilitate capturing patient experience data, whilst some projects focused on more direct engagement between staff and patients, enabling staff to hear first-hand about patients' experiences. Others enabled staff to 'echo' patient experiences that they heard about.

A widespread theme across the funded projects was the concept of 'board to ward', e.g. using patient feedback to inform improvements to frontline services. This highlights the importance of strategic buy-in and strong leadership involvement in the projects.

Many projects saw the NHS Patient Feedback Challenge as an opportunity to create cultural change in their organisation around how staff listen and respond to feedback. Creating a culture change was seen by some as an inherent part of the Patient Feedback Challenge.

A motivating factor when applying for funding was the fact that projects could shape their individual NHS Patient Feedback Challenge project design and focus. Project leads and collaborators felt this made the programme stand out from other funding opportunities.

Spread and adoption

The spread partners included a wide range of different types of NHS organisations and settings, including acute trusts, community healthcare trusts, ambulance trusts, mental health trusts and social care providers.

The projects varied in their approach to the 'spread and adoption' element of the Patient Feedback Challenge. Whilst some projects were aiming for wide spread of the approaches across different NHS settings, others were aiming for spread *within* the lead NHS organisation, testing how effective this was and refining the approach.

The NHS Patient Feedback Challenge clearly demonstrated the potential for patient experiences to be captured innovatively by NHS organisations, and for service improvements to be made as a result. The nine winning projects have secured new spread partners, which is leading to the spread of good practice across other organisations. The aim is to continue spreading best practice long after the Challenge has finished.

You can find case studies from of all nine of the winning challenge projects in the CD that accompanies this book (in the Patient Feedback Challenge folder).

An overview film of the winning challenge projects is also on the DVD that accompanies this book.

Case studies and films can be viewed at www.institute.nhs.uk/patientfeedback

The resource materials for this programme are included on the CD that accompanies this book.

> Make it easy for people to give you their views.

Section nine: The Patient Experience Learning Programme

In the new landscape, it will continue to be important to build the capability of providers and commissioners. We have included a summary below of the Patient Experience Learning Programme as we hope that it will be a useful starting point for anyone attempting to develop similar initiatives in the future. The materials for this programme are included on the CD that accompanies this book.
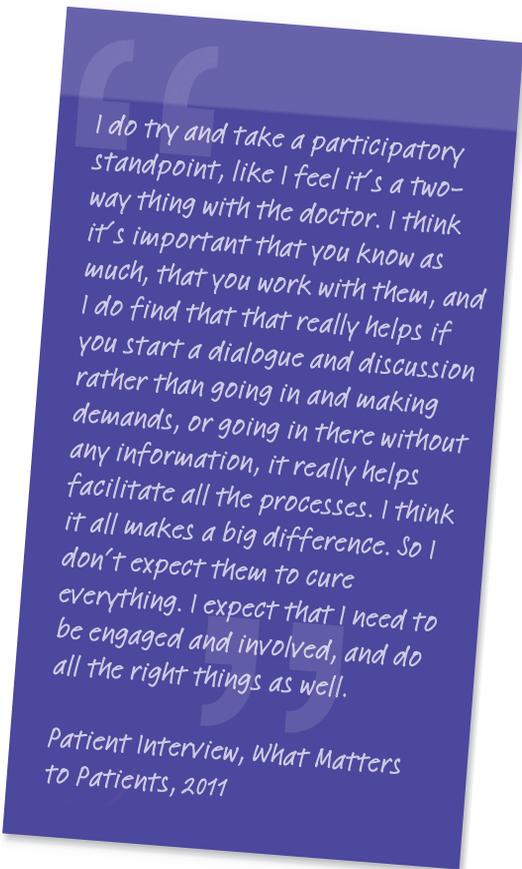
> "
> I do try and take a participatory standpoint, like I feel it's a two-way thing with the doctor. I think it's important that you know as much, that you work with them, and I do find that that really helps if you start a dialogue and discussion rather than going in and making demands, or going in there without any information, it really helps facilitate all the processes. I think it all makes a big difference. So I don't expect them to cure everything. I expect that I need to be engaged and involved, and do all the right things as well.
>
> Patient Interview, What Matters to Patients, 2011
> "

What was it?

The Department of Health commissioned the NHS Institute to deliver the Patient Experience Learning Programme[38], a 10-month training and development programme focused on collecting and using patient experience feedback to inform commissioning decisions, support contract management and improve services.

During the programme, delegates – who ranged from commissioners, change management leads, patient experience and engagement leads, and directors of nursing to consultants and heads of clinical governance – shared their experiences and identified good practice. Learning focused on change management, as well as improvements in patient experience.

What the programme covered

We have already established that, in order for a patient experience improvement project to be successful, there needs to be organisational change. For this reason, the Patient Experience Learning Programme focused on **programme management** and **patient experience** in equal measures.

The programme consisted of a mix of interactive training sessions and webinars (delivered by Impact Innovation). There was a blend of information and interaction, with fun exercises to support discussion and embed learning. The programme was responsive to feedback from delegates, organising an additional networking session to allow delegates and members of the online network to keep building the patient experience community, in line with their wishes.

Each participant was asked to identify a project in their organisation (a current project or one which they wished to undertake) into which they could incorporate and practice the learning and skills gained from the programme.

You can see details of the projects on www.institute.nhs.uk/pen

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[38] http://tinyurl.com/d5hmzks

Case Study

Whipps Cross University Hospital NHS Trust

Whipps Cross University Hospital NHS Trust wanted to embed the ethos of patient experience into patient pathways. The trust was rated amongst the bottom 20% of trusts for two thirds of questions asked, particularly around staff behaviour. It began with a series of projects, in particular a pilot focusing on the Plane Tree Centre, which offers day surgery and investigative procedures. The trust wanted to reduce complaints about long waiting times prior to surgery on the day of surgery itself.

Experience Based Design methodology was used to capture the pathway through day surgery, as perceived by staff. Two workshops explored issues among staff about the management of day surgery and the organisation of space. Patient feedback cards and discussions were used to collect patient feedback.

At an organisational level, the patient experience team (led by the deputy director of nursing) initiated what it called a 'patient experience revolution', including 'in your shoes events', which involved the executive team, the development of a manifesto on core standards of behaviour in the trust, customer service training for staff and the regular collection of the feedback data.

As a result of this work, the Plane Tree Centre reorganised the reception area. It devised a new patient information leaflet and a generic discharge leaflet, which provided a useful checklist for patients. The patient experience revolution has changed the culture of the trust. Patient representatives are routinely involved in clinical pathway redesign. There are systematic ways of collecting data about patient experience (the 'Just a minute' cards). One staff member commented: "It seems like people are listening, people are learning and talking about the feedback. Patient stories are being heard at board level and we [are supporting] that process."

The Patient Experience Learning Network session themes were:

1. What makes a great patient experience – what it is, why we need to improve it, what makes a great experience, emotional journey map.

2. Creating/designing a great patient experience – a brief introduction to the roadmap, change management, creative engagement of stakeholders, archetypes.

3. Sustainability, evaluation and measurement – articulating the change, translating change into measurable outcomes, how to measure.

4. Experience and service safari – opening your eyes to experience/ service, observation skills, landing the experiences, using story telling.

5. Leadership in patient experience – good for staff and good for the balance sheet, emotional/rational flooding, reaction awareness, my personal patient experience story.

6.   Patient experience past, present and future – programme project presentations and celebration of success.

You will find more details about these sessions on the CD (in the Patient Learning Programme Resources folder) that accompanies this book.

Patient Experience Network

An important component of the Patient Experience Learning Programme was the Patient Experience Network, a group of people, working nationally and internationally, who came together as part of a virtual network to share ideas and learning.

The online network was co-designed with users. One of its most successful features was the 'Call to Action', which enabled delegates to post a challenge or issue on the site and invite other delegates to give advice, help or share experiences they may have had in a similar situation. By clicking on the interactive map on the Patient Experience Learning Programme home page, you can search for patient experience colleagues in your region.

Section ten: Over to you...

There are a number of ideas and ways of working set out in this book, but the secret ingredient to making this happen is you.

You are already 'converted', skilled, passionate, experienced and well connected.

So, it's time to build your story, bringing together everything you know about why patient experiences have to improve, how this could work in your organisation and what needs to happen first.

In our time at the NHS Institute we have recognised that there is a wealth of knowledge and skill out there and a willingness to share and support each other.

We hope that you have been energised and inspired by the ideas in this book.

The Patient Experience CD

4. **Service Safari**

   To develop service and experience consciousness and skills. To learn from others. Innovation and idea generation

   - Adapt and Fit Template

5. **Staff Role in Patient Experience**

   To understand how and what we can learn from others. To have a greater understand and knowledge of personal leadership skills to improve patient and staff experience

   - Overview of Service Leadership

   - Story Cards Exercise

6. **Creative Visioning Exercise**

   - Slides from Creative Visioning Session

Online Webinars

1. **Sustainability**

   An introduction the Sustainability Tool and demonstrate how to use it

2. **Roadmap for Patient Experience and an introduction to Evaluation**

   An introduction the Roadmap for Patient Experience and Evaluation of Projects

3. **Learning from others – A case study**

4. **Learning from others and Implementation and Embedding**

   An introduction to different ways of learning from others and how to manage a project from start to finish

5. **Engaging Clinicians and Measurement**

   To provide a follow up discussion on clinical engagement and measurement

Transforming Patient Experience: the essential guide

1 **Transforming Patient Experience: the essential guide PDF**

2 **Transforming Patient Experience: the essential guide full slide set**

3 **What Matters to Patients Research Report**

4 **What Matters to Patients Research Policy Report**

5 **Transforming Patient Experience Top Ten Tips**

Self Assessment Tool for Patient Experience

This tool has been developed in partnership with Ipsos Mori and the NHS Institute. You can use this tool to self assess your organisations readiness to deliver or commission a positive patient experience

Commissioning for a Positive Patient Experience

The NHS Institute developed a series of free learning and development opportunities to anyone involved in commissioning health services or primary care improvement. As part of this programme of support Commissioning for a Positive Patient Experience looked at how commissioners need to work in partnership with providers to evaluate and support them to deliver a positive patient experience and track that experience along patient pathways as well as by individual service.

- Slide Set from 1 day workshop

- Creative Visioning Template

- Patient Experience Self Assessment Template

NHS Patient Feedback Challenge

The £1million Department of Health funded NHS Patient Feedback Challenge was launched in March 2012. The programme has developed and spread good and innovative practice for using patient feedback to improve healthcare services.

Here is a collection of case studies from the funded projects across England, each presenting a summary of the project aims, emerging impacts and lessons learnt.

- Valuing Front Line Feedback – Ashford and St Peter's Hospitals NHS FT

- Kinda Magic – Peninsula Community Healthcare CIC

- iCARE if you are Smiling – Yeovil District Hospital NHS Trust

- Patient Partners – Bridgewater Community Health NHS Trust

- Patient and Family Echo – East Cheshire NHS Trust

- Creating and Organisation that Values, Listens and Responds – Nottinghamshire Healthcare NHS Trust

- Improving Healthcare Together – Norfolk and Norwich University Hospitals NHS Foundation Trust

- Both Sides Now – NHS North East London and the City.

Patient Feedback Challenge overview DVD

An overview film telling the story of all projects awarded as part of the Patient Feedback Challenge Prize.

www.institute.nhs.uk/pen
www.pfchallenge.clearvale.com
www.institute.nhs.uk/patientfeedback