

Improving experiences of care:  
***Our shared understanding and ambition***

National Quality Board – January 2015



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This document has been developed by the National Quality Board, which comprises:

- Department of Health
- NHS England
- Care Quality Commission
- Monitor
- NHS Trust Development Authority
- National Institute for Health and Care Excellence
- General Medical Council
- Nursing and Midwifery Council
- Health Education England
- Public Health England
- Social Care Institute for Excellence
- Healthwatch England
- Parliamentary and Health Service Ombudsman for England
- Expert and lay members

In partnership with:

- Health and Social Care Information Centre
- NHS Improving Quality

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# Foreword

Having a good experience of your care, treatment and support is an essential part of an excellent health and social care service. This document, *Our shared understanding and ambition*, sets out a common way for us, as national organisations on the National Quality Board (NQB), to talk about what we mean by people's experiences and what our roles are in improving experiences of care. The NQB brings together leaders of the national statutory organisations across the health and care system, alongside expert and lay members. We also include here our shared ambition for improving people's experiences of care, and evidence, such as examples of good practice and resources, to support organisations and individuals in improving experiences of care.



**Don Breerton**, *Chair, NQB Patient Experience Sub-group, and NQB Lay Member*

Both as a carer of a young man with learning disabilities, and as a lay member of the National Quality Board, I feel passionately about this subject. Excellent health and social care are invariably linked with a good experience for those using services and their family carers. I do hope *Our shared understanding and ambition* will help to make universal the many good practices we found during this project.



**Margaret Goose**, *NQB Lay Member*

Evidence has shown that a good experience leads to better outcomes for the individual (and organisation). The ["I" statements](#) illustrating a good experience work at all levels, and I would urge everyone to bear them in mind in the same way that they use clinical effectiveness recommendations when treating people or designing delivery of care.



**Hilary Chapman**, *Chief Nurse, Sheffield Teaching Hospitals NHS Foundation Trust, and NQB Expert Member*

At Sheffield we strive to put people's experiences at the heart of everything that we do. We work with our patients, seeking their opinion on how we can improve our services and share their stories, both positive and negative, across the organisation. However, we know that we can always do more. *Our shared understanding and ambition* helps to continue to shine a light on the importance of people's experiences, provides a much-needed shared view on experiences, and brings together useful evidence and resources for individuals and organisations to use.



**Amanda Edwards**, *Director of Knowledge and Evidence and Deputy Chief Executive, Social Care Institute for Excellence, and NQB member*

People who use services do not necessarily distinguish between health and social care, so, although this document has a health focus, the language throughout aims to be applicable to both. Current work on the experiences of people who use social care services is in many ways complementary, so some examples are included. We hope therefore that *Our shared understanding and ambition* will be useful to individuals and organisations working in the wider health and social care system.



**Neil Churchill**, *Director for Patient Experience, NHS England, and NQB Patient Experience Sub-group member*

The NHS Mandate has charged us with the goal of achieving over time world-class experiences of care. Just as importantly, it requires us to significantly improve the experiences of vulnerable people, such as those with dementia and learning disability. Collectively, the national organisations in health and social care are ambitious about what can be achieved and we recognise the part that each of us has to play. Delivering improved experiences consistently cannot be a top-down process. At the heart of a positive care experience, is a new relationship between staff and users of services, based on partnership.

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What does  
*Our shared understanding and  
ambition* cover and who is it for?

## What does *Our shared understanding and ambition* cover?

Having a good experience of your care, treatment and support has increasingly been seen as an essential part of an excellent health and social care service, alongside clinical effectiveness and safety.

**Our ambition is that the experiences all people have of our health and care services become amongst the best in the world.** Yet, in a system that has undergone significant change following the Health and Social Care Act (2012), we are aware that as national organisations we do not have a common way of talking about, or understanding, what we mean by people's experiences and what our roles are in improving experiences of care.

As a result, the [The National Quality Board \(NOB\)](#) has developed a shared understanding of what we mean by:

- **experience of care;**
- **why it's important;** and
- **a good experience of care.**

We are committed to using our shared understanding in how we work together to improve people's experiences.

We recognise that much of the activity that truly impacts on experience takes place within care environments, between individuals and those directly providing care, and that our roles as national organisations involve working with, supporting and influencing other parts of the system that commission and provide that care. While we have already achieved a lot in improving people's experiences, we know that, as national organisations, and as a system as a whole, we still have more to do.

So, we have also set out:

- **our shared ambition** for improving people's experience of care;
- **our roles** in helping to achieve this, including our current work; and
- **evidence**, examples of **good practice** and **resources** on improving experiences.

*Our shared understanding and ambition* replaces our earlier framework (the NHS Patient Experience Framework, 2011) which was published before the changes to the health and care system following the Health and Social Care Act (2012).

## Who is *Our shared understanding and ambition* for?

***Our shared understanding and ambition* is for all individuals and organisations within, or with an interest in, the health system.**

**It also aims to provide people who use services, their carers, families and the public with an understanding of what they can expect from their experiences of care.**

Although this document focuses mainly on health (due to the evidence available), we have tried to write it so that it applies to both health and social care, as people who use our services do not distinguish between the two. While we acknowledge the limitations of not being able to include specific experiences of social care, current work on the experiences of people who use social care services is in line with this work ([more information](#)). We hope that *Our shared understanding and ambition* will also be useful to individuals and organisations within, or with an interest in, the social care system.

**Find out more about why we developed *Our shared understanding and ambition*.**

**Information for those who use services, their carers, families and the public**

## Why we developed *Our shared understanding and ambition*

Our performance in the new health and care system (established under the Health and Social Care Act, 2012), is measured by the outcomes we achieve for those that use our services. For the NHS, this is measured by the three components of high quality care – clinical effectiveness, safety and experience – through the [NHS Mandate](#) and the [NHS Outcomes Framework](#) (with a specific measure on experience: ‘ensuring people have a positive experience of care’). Our responsibility is to continuously improve the quality of care and, over time, to reach our ambition for experiences of care – that the experiences people have of our health and care services become amongst the best in the world.

We are aware that, although there is a considerable amount of work being undertaken to improve experiences of care, the shocking examples of neglect and poor care found at Mid-Staffordshire NHS Foundation Trust and Winterbourne View show that sadly not everyone is having the experience they should, and there is still some

way to go before experience is viewed as equal to clinical effectiveness and safety.

If we are to truly align our efforts to improve the experiences of care people have, it is important that, as a foundation for our work, we have a common understanding of what we mean by ‘experience’. Yet, with new organisations across the health and care system, including at a national level, we were aware that we did not yet have a shared understanding of what we mean by ‘experience of care’. We therefore made achieving this a priority, using the best available evidence to enable us to work with common purpose and align our work in support of our ambition.

Yvonne’s story

David’s story

Kate’s story



# Improving experiences of care: *Our shared understanding*

**As national organisations, we commit to use this shared understanding in how we work together to improve people's experiences.**

It is important that other parts of the health system – regional organisations, commissioners, providers, staff who provide care and all those with an interest in health – are aware of our shared understanding and use it to hold us to account and guide their work. This shared understanding will also give people who use services, their carers, families and the public an understanding of what a good experience means and what they should expect from their NHS care.

# What is 'experience of care'?

The experience that a person has of their care, treatment and support is one of the three parts of high-quality care, alongside clinical effectiveness and safety. A person's experience starts from their very first contact with the health and care system, right through to their last, which may be years after their first treatment, and can include end-of-life care.

'Experience' can be understood in the following ways:

**1. What** the person experiences when they receive care or treatment – for example, whether they knew who to contact if they had a problem, whether the nurse explained the procedure to them, and whether the doctor asked them what name they would like to be called by. The 'what' of people's experiences can be thought of in two ways:

- the interactions between the person receiving care and the person providing that care, for example how a member of staff communicates with the person (this is known as the 'relational' aspects of experience);
- the processes that the person is involved in or which affect their experience, such as booking an appointment (this is known as the 'functional' aspects of experience).

**2. How** that made them feel – for example, whether they felt treated with dignity and respect, and whether they felt that the doctor told them about their diagnosis in a sensitive way.

We know that some people use different words to describe the quality of care, all of which have a role to play:

- Surveys sometimes ask people to describe their **satisfaction** with services. However, the results can be superficial and questions about experience can result in fuller answers;
- **Engagement and involvement** are important parts of care. They help us to understand people's experiences as well as being, in themselves, part of a good experience;
- Some people use the term '**patient-centred care**' to describe high-quality care. This has much in common with a positive experience of care. While we are committed to providing patient-centred care, the purpose of this document is to explain what we mean by 'experiences of care', which is how the NHS's performance is being measured.

# Why is experience important?

Experience is important in a number of different, but related ways:

As a key part of providing high quality care	<ul style="list-style-type: none"> <li>For many people, their experiences of the services they use are fundamentally important – at a time when they may be feeling scared, confused and worried, what happens to them and how this makes them feel is crucial. Those providing health and care services view experience as a natural part of providing high-quality care, and a good experience is now seen as an important ‘outcome’ in its own right.</li> </ul>
As a way of improving outcomes	<ul style="list-style-type: none"> <li>There is strong evidence about the links between experience and the other aspects of high-quality care (clinical effectiveness and safety). For example, there are strong links between being involved in decision-making and being communicated with effectively, and improved safety and better clinical outcomes. On the other hand, there are poorer outcomes, and health resources are wasted, when people do not feel involved or do not understand the treatment they are offered (<a href="#">more information</a>).</li> </ul>
As a way of indicating value for money and whether services are appropriate	<ul style="list-style-type: none"> <li>Only by understanding what people want from their services and continually focusing on their experiences will we truly be sure we are delivering value for money.</li> </ul>
As a way of supporting staff engagement	<ul style="list-style-type: none"> <li>There is strong evidence to show the links between staff engagement and the experience of service users. For example, the quality of experience is lower when staff are not supported by managers, experience bullying and work pressures, and have a poor work-life balance (<a href="#">source</a>). Organisations that provide a good experience to people are likely to have higher levels of staff wellbeing and be more likely to keep their staff. In considering how to improve the experiences of care they provide, organisations should use the potential of their staff and focus on supporting staff to deliver a good experience.</li> </ul>

Staff quotes

# What is a good experience of care?

*While we recognise that people's experiences are individual to them, and are many and complex, as national organisations we must have a shared understanding of what we mean by a good experience. In defining what we mean by a good experience of care we need to look at what the evidence tells us matters most to people who use our services.*

*Our "[I](#)" statements set out the things that have been shown to have the greatest effect on whether someone has a good experience of care.*

The evidence used to develop this shared understanding of what makes up a good experience of care is the Warwick Patient Experiences Framework, used for the [National Institute of Health and Care Excellence's \(NICE\) guidance](#) and [quality standard](#) on patient experience. Our shared understanding relates only to experience, which is linked to, but not the same as, other concepts, such as person-centred care ([more information](#)).

Andrea's story

Sheila's story

Anonymous story

# What is a good experience of care?

All users of health services should be able to say the following:

I am involved as an **active partner in my care** – this means playing an active role, when I'd like to, in making decisions about my care, treatment and support, and being supported to look after myself day-to-day.

I am treated as an **individual** – my needs, values and preferences are respected.

I am able to access services when I need them, and my care is **coordinated** so I know where to go next and where to turn if I have a problem.

The people providing my care recognise that I am the **expert on me** – this means that my knowledge, skills and expertise as a result of living with my condition, as well as the effect that this has had on my life and on the lives of those who are important to me, are respected.

I am asked how I would like to be communicated with so that **communication** is tailored to me and is delivered with care and compassion, and I have the opportunity and time to ask questions and have a conversation about my care, treatment and support.

I have access to the **information** I need, which is presented in a way that is right for me, to make sure I understand what is happening and can play a role in making decisions if I'd like to.

I have access to the **support** I need and is right for me, including emotional and practical support, and I am able to involve my loved ones in decisions about me.

The **environment** in which I receive my care is clean and comfortable and makes me feel dignified.

WHAT DOES IT COVER  
AND WHO IS IT FOR?

OUR SHARED UNDERSTANDING

OUR AMBITION

NEXT STEPS

GOOD PRACTICE, RESOURCES AND  
EVIDENCE BASE

ANNEX

OUR AMBITION

OUR ROLES AS NATIONAL ORGANISATIONS  
IN ACHIEVING OUR AMBITION

EVIDENCE AND RESOURCES TO SUPPORT  
THE SYSTEM TO IMPROVE EXPERIENCES

# Improving experiences of care: ***Our ambition***



# Our ambition

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**Our shared ambition is that the experiences all people have of our health and care services – both in terms of what happens to them and how this makes them feel – become amongst the best in the world.**

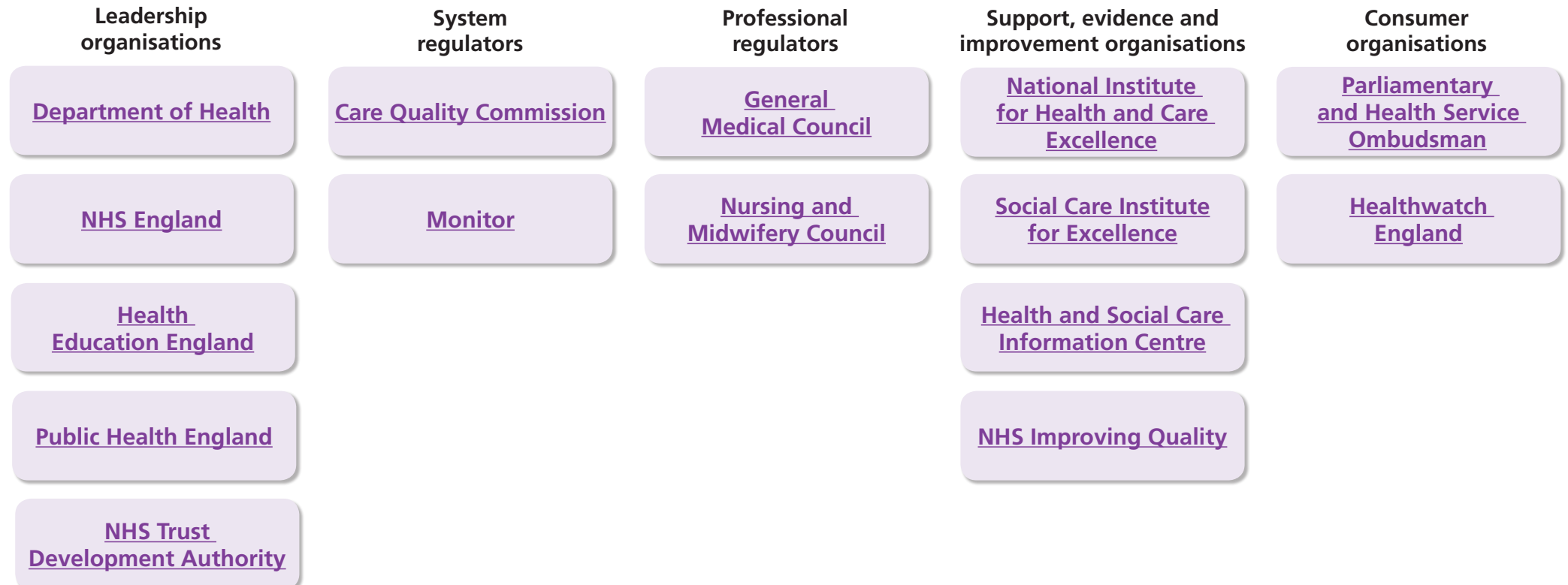
There have been significant developments in how experience is viewed across the health system, with it becoming more of a priority both at a national and local level. However, we know we are not getting it right every time ([more information](#)).

We want improving people's experiences to be as important as improving clinical outcomes and safety and we want to make sure we continually learn from and improve people's experiences. As national organisations, we are committing to playing an active part in delivering our shared ambition to achieve the highest standards of care for all those who use our services.

# Our roles as national organisations in achieving our ambition

Our role as national organisations is to work with, support and influence other parts of the system that commission and provide care, including the voluntary sector. Here we set out how we currently see our roles in working with and supporting the system to achieve our ambition on experiences of care and our current projects. At the same time, we recognise that we all can and must do more, including being more aligned in our work to improve experiences. Our next steps can be found [here](#).

Our organisations are grouped by our main functions.





# Evidence and resources to support the system to improve experiences

**We understand that improving experiences and achieving our ambition will be a challenge. We know that much of the activity that truly impacts on experiences takes place within care environments and between individuals and those directly providing care. In addition, we are aware that change can be driven in a number of ways, from ‘the little things’ that individuals can do, through to organisational and system-level change that can support improving experiences.**

Here we provide a summary of the evidence that exists on the organisational-level factors that can help to support the improvement of experiences – this is particularly relevant for providers and commissioners. These factors are illustrated by a range of examples of good practice.

We have also brought together a number of resources which are aimed at a range of individuals and organisations to support work to improve experiences.

Organisational-level factors

Examples of good practice

Resources

# Organisational-level factors – what can providers and commissioners consider when improving experiences of care?

There is a growing evidence base which sets out the key organisational-level factors that contribute to improving quality of care, including experiences. While much of this evidence is focused on the actions that providers can take, many of the factors below are applicable to commissioners too:

- **meaningful involvement and engagement** with those that use health and care services, their families and the public throughout the process of designing, running, monitoring and reviewing services.
- strong, committed **senior leadership** (chief executives, boards and senior leaders), including:
  - setting out a clear strategic vision on quality;
  - clear and consistent communication of vision and strategy which frame experience as an integral and equal part of the quality framework (alongside clinical effectiveness and safety);

- modelling behaviours, including promoting a culture of continual improvement and learning;
- empowering people at all levels of the organisation to drive change;
- adequately resourcing service redesign that improves experiences.

- an emphasis on **data and intelligence on experiences** gathered from continual feedback from those who use services, their carers, families and the public to measure and manage performance on experience.
- a **focus on the workforce**: embedding experiences into HR processes such as induction and appraisal, and prioritising and improving staff engagement, which is strongly linked to improving people's experiences of care.

More information on the evidence base for these factors can be found [here](#).

Examples of good practice:

Meaningful involvement and engagement

Senior leadership

Data and intelligence

Workforce

# Next Steps

**If we are to make sure experience is thought of in the same way as other aspects of high-quality care and that people's experiences continually improve, there will need to be a fundamental shift in how people's experiences are viewed and valued.**

*We must all work together if we want to achieve our ambition that the experiences that people have of our services are amongst the best in the world. We know that as national organisations we still have more to do. We will work with providers, commissioners and professionals to make sure that they have the support they need to put experience on the same footing as clinical effectiveness and safety.*

## Next steps

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We commit to the following:

- Always **meaningfully engaging and involving people** who use our health and care services, their carers, families and the public when carrying out our roles and promoting this way of working as 'everyone's business' throughout the NHS.
- Actively **promoting and communicating *Our shared understanding and ambition*** throughout the system.
- **Supporting the health and care system** to improve people's experiences of care through our main roles and responsibilities.
- Making sure we all **use *Our shared understanding and ambition to work together*** to make the most of opportunities to improve experiences.

# *Good practice, resources and evidence base*

Examples of good practice

Resources

Evidence base

# Examples of good practice

## Meaningful involvement and engagement

- [NHS West Hampshire CCG](#) – Improving services for people with long-term conditions in West Hampshire
- [South London and Maudsley \(SLaM\) NHS Foundation Trust](#) – SLaM Recovery College
- [NHS Greater Huddersfield CCG](#) – Remote monitoring pathway for coeliac patients
- [NHS East Leicestershire and Rutland CCG](#) – Urgent care consultation
- [NHS Coventry and Rugby CCG](#) – Targeted involvement of local people in the development of a new DEXA scanning service
- [Kent Community Health NHS Trust](#) – Partnership working to develop services
- [Bridgewater Community Healthcare NHS Trust](#) – Patient Partners Programme
- [Central Manchester University Hospitals NHS Foundation Trust](#) – Valuing the Voices of Young People
- [Manchester Mental Health and Social Care Trust \(MMHSCT\)](#) – Involvement to Innovate – “Patient Voices”

- [Nottinghamshire Healthcare NHS Trust](#) – Partnerships inspiring change

## Senior leadership

- [The Hillingdon Hospitals NHS Foundation Trust](#) – Improving staff and patient experience through our CARES values
- [Imperial College Healthcare NHS Trust](#) – Embedding improving experiences into how we work
- [Isle of Wight NHS Trust](#) – Developing and Embedding our Trust vision and values
- [South West Yorkshire Partnership NHS Foundation Trust](#) – Implementing a trust-wide system for capturing people’s feedback
- [NHS Tameside and Glossop CCG](#) – Embedding improving experiences throughout our organisation

## Data and intelligence

- [Northumbria NHS Trust](#) – Improving experiences through collecting and using experience data

- [Sheffield Teaching Hospital NHS Foundation Trust](#) – Collecting and using feedback from patients and their families to improve services
- [County Durham and Darlington NHS Foundation Trust](#) – Keeping it Real: Making it Right
- [Walsall Healthcare NHS Trust](#) – Engaging with patients, using their feedback

## Workforce

- [Northumbria NHS Trust](#) – Dignity in Practice: Our Shared Purpose
- [Wrightington, Wigan and Leigh NHS Foundation Trust](#) – ‘The WWL Way’ – Implementing sustainable staff engagement
- [Birmingham Children’s Hospital](#) – Engaging staff in developing tools and guidance for building stronger teams
- [St George’s Healthcare NHS Trust](#) – Improving patient experience of cardiac services using the Listening into Action approach
- [Derbyshire Healthcare NHS Foundation Trust](#) – Improving levels of staff engagement

## Meaningful involvement and engagement

### **Title:** Improving services for people with long-term conditions in West Hampshire

**Who:** NHS West Hampshire Clinical Commissioning Group (CCG)

**What:** There are around 100,000 people in West Hampshire with a neurological condition – that's nearly one in five of the population. We recognised the urgent need to review and improve services for this group to make sure they had fairer access, both in terms of geography and age, to better services that offered more value for money.

Extensive engagement with patients, carers, third sector organisations including Carers Together, the Hampshire Neurological Alliance, Parkinson's UK, the Epilepsy Society, the MS Society and the Stroke Association as well as providers, Public Health and Adult Social Care, revealed many issues. These ranged from long delays in accessing neurological expertise, both in hospital and the community, to poor access to information and advice for patients and clinicians and inequitable and fragmented services.

At the same time, a survey of GPs revealed long waits, gaps in services and a lack of knowledge of pathways and services from both a GP and patient perspective.

The engagement findings were shared with patients, carers, patient groups, health professionals, consultants, GPs and Public Health at a 'Neuro Action' workshop in October 2013, where people talked about their experiences

of current services, ranging from inflexible appointment systems and lack of information, to the lack of self-referral and peer support, and identified potential improvements and priorities.

This led to the development of a neurology strategy for West Hampshire that responds to the needs identified during engagement and sets ambitious priorities for the next three years (2014/15 – 2016/17). There are multiple strands to the strategy, some of which cover specific conditions and some that are looking at improving access to community services across all neurological conditions. The strategy, which dovetails with the CCG's over-arching strategy for long-term conditions and aligns with the work programme of the Wessex Mental Health, Neurology and Dementia Strategic Clinical Network, also identifies some quick wins for 2014/15.

The promotion of supported self-care is central to the strategy, reflecting the wishes of patients and carers. It focuses on conditions resulting from neurological injury or disease (around 50-60 conditions) with the exception of dementia and acute stroke care, which have their own strategies and work programmes. It was co-produced with the CCG's Neurology Steering Group, which includes patients and carers who took part in the initial engagement, and so ensures that patients' own experiences have contributed to the action

(continued)

## Meaningful involvement and engagement

### **Title:** Improving services for people with long-term conditions in West Hampshire (continued)

plan. The Steering Group reviews the strategy regularly and progress is tracked and reported on an ongoing basis.

From autumn 2014, the CCG will also be devoting part of its website to hosting a condition-specific information resource for patients, carers and GPs. As well as sharing key information about the full range of neurological conditions, more importantly it will signpost patients, carers and GPs to a host of additional support and information, from local therapy providers and exercise classes to advocacy services or how to claim a bus pass, making it as quick and simple as possible to find the guidance or help they need. It will also play an essential role in ensuring that people feel supported to manage their condition and enhance the quality of life for carers.

Patients and carers will be encouraged to feed back their experiences through the website, so leading to continuous improvement of both the website's content and the services themselves.

**Outcome:** The activity outlined above is expected to result in a reduction in emergency department attendances and admissions, a specific service for people who experience their 'first seizure' and fewer people having avoidable seizures, as well as ensuring that services meet or exceed the standards set by the National Institute for Health and Care Excellence (NICE).

In addition, patients are already benefiting from a successful neurology turnaround in Hampshire, which is raising awareness, securing early wins, supporting self-care and encouraging innovation and service improvements through a strategy built by stakeholders, approved by stakeholders and in partnership with stakeholders.



# Meaningful involvement and engagement

## Title: SLaM Recovery College

**Who:** South London and Maudsley (SLaM) NHS Foundation Trust

**What:** SLaM NHS Foundation Trust's Recovery College has been offering courses since 2013, and is funded by the Maudsley Charity.

Recovery is about people with mental health difficulties having the same opportunities in life as everyone else. It is about a personal journey towards a meaningful and satisfying life. It is about living as well as possible.

The College works with people to offer hope, control and opportunity. The workshops and courses run at the College aim to provide the tools to make this happen, to help people become an expert in their own recovery or that of someone they care for or work with.

Co-production is at the heart of everything the College does. Every course and workshop offered is co-designed and co-run by trainers with lived experience working alongside trainers from the mental health professions. People with personal and professional experience of mental health were also actively involved in the development of the College, from initial concept through to launch, and in the running of the College.

The courses are free of charge and open to people who use or have used SLaM services, their supporters, volunteers and peer supporters and SLaM staff. No referral is necessary. Further information on the work of the College and the courses available is at: <http://www.slamrecoverycollege.co.uk>.

**Outcome:** Many students have given feedback about the positive impact the stories of the peer recovery trainers (and those of their fellow students) have had on their understanding of recovery. Students have said this has given them hope and evidence that they, or the people they care for, or the people they work alongside, can and do recover from mental health difficulties and lead lives that feel meaningful and full of opportunity. We have learned that informal peer support in the classroom is an important third element in the co-production of our courses and are grateful to our students for the way they have shared their own experiences and knowledge.

The generosity of the trainers who have volunteered time to use their expertise to support the development and delivery of courses has been outstanding. Trainers have embraced the concept of co-production and finding co-production can be a challenging, exciting and rewarding way of working.

(continued)

## Meaningful involvement and engagement

### **Title: SLaM Recovery College** (continued)

Feedback from people who have attended the courses includes:

*"The experience is empowering. I feel this is the way forward."*

*"Fantastic! The trainers worked extremely well together and brought different, valuable perspectives."*

*"I'm so happy I came today. It is a very good project. Thank you so much to both of the trainers. They helped me to feel so welcome and they ran it great! Thanks."*

*"Excellent, skilled trainers. They excelled in their expertise, shared so many strategies and really empowered me."*

*"I felt the course inspired me. The group aspect also enabled me to feel a part of something and I was sharing the experience with others and listening to their stories."*

*"Absolutely fantastic – excellent facilitation and just wanted to congratulate both trainers for developing and delivering a well-planned and useful course."*

*"The trainers were lovely, down-to-earth and understanding."*

*"Thank you...for your generous sharing of knowledge, skills and experience which 'buoyed' us up and kept us motivated to the very last minute."*

*"I had some really important realizations about myself. I heard some beautiful stories and experiences of others. It was a very safe and comfortable group to be a part of."*

*"Brilliant! It was open and relaxed with no one judging you."*

*"This was the best course I have been part of in a number of years!"*

## Meaningful involvement and engagement

### **Title:** Remote monitoring pathway for coeliac patients

**Who:** NHS Greater Huddersfield CCG (GHCCG)

**What:** As part of its work in 2013/14 on the remote monitoring enhanced service, GHCCG worked on a remote monitoring pathway for coeliac patients, as this was felt to be a group of patients who received an inconsistent service across the area.

To ensure a pathway was developed that met the needs of the patients as well as primary and secondary care providers, we invited the Calderdale and Huddersfield voluntary coeliac support group to meet with some of our clinicians to provide their experiences of living with coeliac disease. At that meeting we identified that there were a number of things that would be useful, especially for newly-diagnosed coeliacs. As a result, alongside the work required for the enhanced service, we also undertook a project to ensure our coeliac population were supported in other ways.

Before undertaking any further work we liaised with Coeliac UK, with the dieticians and gastro consultants at Calderdale and Huddersfield NHS Foundation Trust and continued to work with the local support group. We undertook a series of engagement events – focus groups at various locations, including: a Huddersfield University open day and food fayre to target 18-25 year olds; a local support group cookery demonstration; a monthly coffee morning held at Sainsbury's supermarket; and, also hosted a number of events at our office.

Throughout our engagement it became clear that a number of coeliacs were missing their annual check-ups, there was a gap in support for newly diagnosed patients, and that patients felt their GP did not understand about the food available on prescription and what a difference it actually made to them.

Outcome: To address the issues identified a number of steps were taken:

- all practices in GHCCG implemented a new care pathway (which was developed with GPs, consultants, patients and dieticians), contacting their registered coeliac patients to ensure they were receiving an annual review;
- the CCG decided to provide support films for not just coeliacs but friends, relations and anyone else who wanted to know about coeliac disease so that in the eight weeks between being diagnosed and seeing a dietician, patients had something to refer to. To produce the films we worked with Huddersfield University: students in their final year of a media degree undertook the filming for us. The films are available on our [website](#);
- we ran a training session to ensure all our clinicians were fully informed about the condition. Coeliac UK and the local support group also attended the training session and we provided samples of gluten free bread, crackers and cereal for the GPs to taste, which was very much appreciated by the coeliac patients who were present.

## Meaningful involvement and engagement

### Title: Urgent care consultation

**Who:** NHS East Leicestershire and Rutland CCG (ELR CCG)

**What:** ELR CCG has been reviewing urgent care services (minor injury and illness) in the area to ensure local people are getting the best quality services in an accessible way. Between February and April 2014 the CCG ran a formal consultation process to seek public, staff and other stakeholders' views. As well as distributing over 10,000 copies of the consultation document, engaging with stakeholders and holding eight public meetings, the CCG also used a listening booth to reach out to encourage engagement from a number of different communities.

The listening booth is a portable, purpose built engagement tool which allows us to speak to the public, patients and carers outside of health locations to find out how people feel about healthcare, their recent experiences, what people would like to see in their local area and what matters most to people about their healthcare.

During the consultation period, 691 individual questionnaire responses were received, with 191 participants attending one of the eight public meetings. In addition to these formal meetings, the listening booth visited 23 locations across the ELR CCG area, including:

- three mental health drop in groups

- two learning disability day groups
- a male community group
- an older persons drop in session
- two parents and children groups (including one at an army barracks)
- two groups for parents of children with special needs
- two colleges
- three libraries
- two leisure centres
- five markets

The purpose of seldom heard and listening booth outreach activities was to pay due regard to the views of the wider community. As a result of this focused outreach work, ELR CCG was able to seek the views of representatives of each of the nine protected characteristics on the future of urgent care services in the area. At both the listening booth and at the community group meetings, people were given the opportunity to ask questions on the project, give their views, and were encouraged to fill in the consultation documents. Wherever possible, notes from these interactions were also fed into the consultation.

(continued)

# Meaningful involvement and engagement

## Urgent care consultation (continued)

As well as being used as a tool to consult with patients about their views on the urgent care consultation, three simple questions were asked to people visiting the Listening Booth:

- Have you had a recent experience of the NHS or social care?  
Tell us about it...
- What stood out as really positive?
- What could have been done differently?

These questions allowed people to tell us the story of their experience of accessing healthcare from any provider. We deliberately kept the questions as open as possible to allow us to get as full and unbiased a story as possible from the people that chose to talk to us.

The information gathered anonymously from this exercise was used to ensure that patient views remain at the heart of ELR CCG's quality monitoring and decision making. The information has also been used to spot themes and trends about local services, inform service improvements and to make changes to the services we provide.

Selected patient stories are presented to the public section of the governing body to encourage clinical discussion about commissioning issues and changes needed to pathways of care. These stories offer the governing body the opportunity to see accounts of patients' experiences in their own words. As a result of one of our patient stories, relating to a patient's experience of mental health services locally, we were able to discuss changes to the way services are commissioned with the provider.

**Outcome:** By using our listening booth, combined with the formal consultation process, ELR CCG was able to be assured that we had reached out to a wider audience and more seldom heard groups, than if we had run formal public meetings alone. The feedback received from the outreach work directly influenced the design of Urgent Care Services in the ELR CCG area. Going forward, the listening booth will continue to be used to communicate the new Urgent Care Services, to ask for feedback on the public marketing campaigns and to promote the services when they open next spring. When the services have gone live, the listening booth will continue to be used to gain feedback from patients of their experiences of the services as part of the CCG's wider 'We are Listening' programme.

## Meaningful involvement and engagement

### **Title:** Targeted involvement of local people in the development of a new DEXA scanning service

**Who:** NHS Coventry and Rugby Clinical Commissioning Group (CCG)

**What:** DEXA (Dual-Electron X-ray Absorbiometry) Scanning is used to diagnose weak or brittle bones and is largely used by patients over the age of 65. There had not been a DEXA scanning service in Coventry previously, meaning that Coventry patients had had to travel to Rugby or Nuneaton – patient feedback suggested that this journey was problematic for patients, particularly older people and those with mobility problems. The location of the new service (the City of Coventry Health Centre in central Coventry) was chosen as it is central, with good transport links and parking is available.

As this was a completely new service that had not previously been provided in Coventry, the CCG was required to select a service provider through a competitive tender process. To ensure that patients were at the heart of the decision to select a service provider, the CCG worked closely with members of the Coventry and District branch of the National Osteoporosis Society (NOS) to find out what makes a good patient experience. There was enthusiasm from the group to be involved further with this project so two representatives from NOS were asked to develop questions for potential bidders on how they would ensure a high quality patient experience according to what really mattered to them.

The tender process for selecting a service provider covered a wide range of topics including sections on patient experience, patient safety, service delivery and value for money. All bidders were required to answer the questions developed by NOS which were:

- How will you ensure you will deliver a high quality patient experience? Please include details of your process for measuring patient satisfaction and your processes for dealing with complaints and compliments.
- How will you work and communicate with other care providers to help to ensure the patient continues to get the right care even after they have left your service?
- How would you make sure that the service is suitable and accessible for all patients who could benefit from using the service?

The responses to these questions were evaluated by two members of the NOS and the scores that they gave counted for 25% of the overall quality score. In addition, question 1 was a “red flag” question meaning that any bidders who scored less than “acceptable” (less than 3/5) for this question were eliminated from the tender process. This way, NOS were able to have a real and meaningful influence on the final decision.

(continued)

## Meaningful involvement and engagement

### **Title:** Targeted involvement of local people in the development of a new DEXA scanning service (continued)

The contract was awarded to the highest scoring bidder and the service started in December 2013. Since this time, a number of the NOS members have used this facility and continued to feed back their comments to the service provider and to the CCG.

Question 2 (above) was formulated from the experiences of patients from NOS who wanted to ensure that they received appropriate care and advice after they had had a DEXA scan. Some patients previously reported that their results were given to them only as a number which was not meaningful and could not help them manage their conditions.

The chosen service provider gives detailed practical clinical guidance in the letter to the referring GP which explains the results in a way that can be understood by the patient and it includes advice on how they can help to manage their conditions, for example, through lifestyle changes.

**Outcome:** There are a whole range of positive outcomes from this project including the continued involvement between the CCG and NOS and now the on-going communication between the service provider and NOS, ensuring that patient views continue to be heard. The design and evaluation of the tender process took into account the views of NOS on what makes a good patient experience and ensured that their experiences would impact on the decision to choose a provider.

Combining the experience and expertise from the CCG and NOS enabled a new DEXA scanning service to be provided that would ensure a safe and clinically effective service that provides value for money as well as the best possible patient experience.

# Meaningful involvement and engagement

## **Title:** Partnership working to develop services

**Who:** Kent Community Health NHS Trust

**What:** Kent Community Health NHS Trust has a range of ways in which it works with patients and families to develop its services.

Children's Speech and Language Therapy services.

The children's speech and language therapy services have had two active Parent Involvement Forums for over two years, that have been involved in a number of service changes.

Each group meets three times per year, and the parent volunteers are given an induction to the organisation, given a volunteer badge and offered travelling expenses.

### **Outcome:**

Examples of this engagement changing processes/procedures include:

- Kent Parent Partnership Service contact details are on each speech and language report. With feedback from parents, an additional couple of sentences have been added to explain what this service can provide, therefore encouraging more parents to make contact.
- Following feedback on the Parent Advice sheet, which details clinic processes and parents'/Speech and Language Therapists' commitment and expectations, this has been adapted.

- Discussion on changing the speech disorder care pathway – suggestions were made to include both types of opportunities to be offered i.e. in school and clinic. The group asked about electronic sessions and accessing therapy online, e.g. via Skype. It was also suggested that video clips be included on the Trust's website of the techniques used regarding development and production of sounds.

### *District Partnership Groups*

Our Engagement team has worked with District Partnership Groups (which bring together people with learning disabilities, their carers and families to talk about the things that are important to them in their lives) to develop easy read information, including service leaflets and our quarterly Community Health magazine.

The leaflets and magazine can be used for everyone including children, people with English as a second language and travellers.

### **Outcome:**

These groups have helped us adapt our style and format over time. Over 600 Easy Read magazines are printed and distributed, mainly to these groups and members. The magazine is currently being evaluated.

(continued)



# Meaningful involvement and engagement

## **Title: Partnership working to develop services** (continued)

### *Patient Engagement Network (PEN)*

We have an active Patient Engagement Network (PEN) with members involved in a range of the Trust's groups and committees, on interview panels, and in staff training, commenting on leaflets and helping with surveys.

The Network has 130 members, all of whom joined the Network after an informal interview with the Trust's Public and Patient Engagement Manager. They have a role title and can claim travel expenses. There is a PEN Membership Pack in both standard and Easy Read.

Around 35 PEN members are involved in 19 different committees and groups across the Trust, both strategic groups (for example Equality and Diversity, Clinical Audit, Patient Experience and Research and Development) and more operational (Medicines Management, Falls Prevention, Infection Control). PEN members provide the patient/carer voice on these groups, are able to challenge the received wisdom, and bring external scrutiny to the work of these groups.

PEN members have taken part in a number of interview panels for posts in both corporate and clinical services (recent examples include Wheelchair Service staff and a Trust Customer Care Officer). They are able to help the Trust assess the candidate's ability to communicate with patients/public and their customer service skills.

PEN members take part in patient-led assessments of the care environment (PLACE) visits each year and form the bulk of the patient/lay-members.

### **Outcomes:**

- PEN members have recently been involved with developing patient videos specifically around holistic assessment and diabetes care. These videos will be shown in our staff training.
- Patient representation on the validation panel for all of our clinical training.
- Patient Experience Committee advised on communications used to advise patients about changes to podiatry services, and the new eligibility criteria for the wheelchair service.
- PEN members attend some of the Patient Experience groups in our community hospitals. They helped approve new menus and fed into ideas for improving patient experience such as buying one use ear plugs and eye masks for patients to reduce impact of noise and light at night.
- PEN members took part in PLACE, which led to catering trolleys being replaced across a large number of our community hospitals and space between beds being immediately changed to address a privacy and dignity issue.
- PEN members were involved in the consultation on the Trust's quality goals as part of the annual Quality Account development, and this has led to a quality goal around medicines management.

# Meaningful involvement and engagement

## Title: Patient Partners Programme

**Who:** Bridgewater Community Healthcare NHS Trust

**What:** We run a Patient Partners programme, where patients and their families are involved in service development and redesign. There are currently 190 Patient Partners involved with the Trust and a plan to roll this out to all services in the Trust. A wide range of services have worked with Patient Partners across the Trust.

**Outcome:** Examples of the improvements and developments that have resulted from the engagement of Patient Partners are:

### *Community Neurosciences Service (Warrington):*

Changes include designing a person-centred psychological support service for people who have suffered a stroke, setting up an effective person-centred approach to staff training and supporting the development of a befriending service.

### *Health Visiting (Halton):*

Patient Partners identified possible improvements to access and information and as a result the service has trialled an evening clinic and reviewed the amount of paperwork given out at birth visit.

### *Surgical Appliances Service (Wigan):*

Patient Partners identified improvements needed to the access and information received from the service. As a result the service has redesigned their information leaflet, now sends out acknowledgement letters when a referral is first received and also offers their patients a telephone review with the clinical specialist instead of having to attend a routine appointment.

### *Adult Speech & Language Therapy (Halton & St Helens):*

Patient Partners identified the need to develop a support group for people with head and neck cancer, the importance of psychological support provided by a speech and language therapist and the need for longer sessions to enable identification of full care needs and signposting.

# Meaningful involvement and engagement

**Title: Valuing the Voices of Young People**

**Who:** Central Manchester University Hospitals NHS Foundation Trust

**What:** Children and young people who use health services have very specific needs and no one is better placed to tell us what it feels like to be a child or a young person in hospital than young people themselves. The Royal Manchester Children's Hospital (RMCH) Youth Forum was established as part of the new Youth Engagement Structure. The Forum is run entirely by its youth members aged 11 – 25, with staff attending for support, who feel strongly about improving services for children and young people. The members represent themselves and provide a voice for young people's thoughts on health issues and are, therefore, an important influence on Trust policy and procedure, and Trust design and delivery.

**Outcome:** Youth Forum members have provided invaluable input to the development and delivery of hospital services for children and young people. Achievements include inputting into the design of the new Children's Hospital, as well as being invited to represent the Trust in local, regional and national conferences and events.

## Meaningful involvement and engagement

### **Title:** Involvement to Innovate – “Patient Voices”

**Who:** Manchester Mental Health and Social Care Trust (MMHSCT)

**What:** The creation of a collection of innovative digital stories was put in place to enable MMHSCT to build dignity and respect into its procedures. We wanted to bring our patient experience to life, and to the attention of commissioners, in more innovative and emotive ways. The programme allows service users to share their experiences of healthcare via short movies created in carefully facilitated workshops. These stories offer an opportunity to learn important lessons by walking in the storyteller’s shoes for a few minutes. The stories explore themes around compassionate personalised care, the importance of swift interventions and involvement in care planning processes. The stories are shown at the beginning of each Board meeting, they are used to support value-testing exercises during recruitment, to challenge mental health stigma, and to promote recovery. They also contribute to a much wider patient experience programme to improve clinical outcomes and increase confidence in MMHSCT services.

**Outcome:** In 2013, MMHSCT received the highest score in England in ten questions in the national patient survey. Over the course of the year there has been a shift in complaints about care (reduced by 45%) and a reduction in management costs associated with investigations. There was a reduction in clinical negligence claims of 50%. In a recent survey, out of 2018 patients, 94% indicated that the staff who provided their care were helpful and 95% of service users would recommend the Trust to friends and family.

The programme has facilitated improvements and efficiencies in patient communications as staff are spending less time investigating complaints, and more time providing patient care. Because of the innovative approach, the Trust anticipates a more efficient use of resources to promote learning and improve clinical outcomes. This programme is already starting to impact in a positive way upon existing feedback systems, adding value by bringing to life what we already know. This in turn enhances the patient experience, increasing public confidence at a time of funding restraints and major service transformation.

# Meaningful involvement and engagement

## **Title:** Partnerships inspiring change

**Who:** Nottinghamshire Healthcare NHS Trust

**What:** The Trust aims to be the most open and responsive organisation in the NHS and to achieve this in a way that puts care, compassion and the courage to make change at the heart of everything our teams do.

We wanted to develop a transformational and ambitious project to:

- Develop teams that are excellent at listening and responding to feedback;
- Create a patient experience website that is public, accessible, improves accountability and drives change.

The aim was also to build on the award-winning, innovative and systematic approach we had already taken across the organisation, developed with service users and carers. This involved a variety of methods to capture feedback and to track and report changes. To enhance our unique approach we seized upon the opportunity of the £1 million NHS Patient Feedback Challenge (PFC). This programme spreads great approaches which use feedback from patients to improve services. We were one of nine successful projects and wanted to use the Feedback Challenge to inspire changes to organisational culture, services and people's lives.

We therefore supported ten teams across the Trust's three Divisions to become beacons of good practice for all aspects of patient feedback and to spread this to other teams.

Four key elements were identified for our teams to work on:

1. Capturing feedback;
2. Sharing and discussing feedback with all team members;
3. Acting on both positive and negative feedback;
4. Sharing the changes that have been made as a result of feedback.

The ten teams worked with service user and carer volunteers and rose to the challenge. The volunteers helped develop and implement the programme and working with teams to collect and respond to feedback in innovative ways.

We also wanted the range of feedback collected to be online rapidly, visible and easily usable by staff and the public. As a result the 'Your Feedback Matters' website was developed with service users, carers and staff. This enables the public to leave feedback in a variety of ways. It also enables the public and staff to see all the feedback (data, comments and stories) for all our teams as well as having a section on what services have done in response to feedback.

**Outcome:** The initiative has had an incredible impact given that it initially ran for only five months.

(continued)

## Meaningful involvement and engagement

### **Title: Partnerships inspiring change** (continued)

For example, in a first for prisons, HM Prison Stocken posted the views of current prisoners online via the Patient Opinion feedback website. In their first ever Health Fair, attended by over 700 prisoners, they collected comments and posted them on Patient Opinion. In addition, Ashfield Sure Start Children's Centres worked with parents and volunteers to leave feedback online. They published 12 stories in four months and recorded four changes as a result.

Each team captured how they had improved against the four elements of the Feedback Challenge. This is reported in our [Information Pack](#) (pages 15-34) and [PFC 2013-14 Achievements](#).

Specific changes to services as a result of the PFC include:

- Cherry Ward provides mental health services for older people. The staff worked with volunteers to collect feedback and posted it on Patient Opinion. In response, pharmacists now offer appointments to speak to patients and their families about medication
- The Podiatry Service received feedback that there was difficulty in booking appointments. They have set up a single point of access and more flexibility for podiatrists to meet demand.
- At the Peaks Unit at Rampton Hospital, patients fed back that they felt frustrated when weekend gym sessions were cancelled. A system has now been set up to facilitate gym sessions every weekend.

When the national PFC finished we continued and built on the programme: 16 other teams came forward to take part in the next wave of our work. These teams completed the challenge and this year another 11 teams are working at being exemplars in all aspects of feedback.

The website has received excellent feedback from staff and its usage is increasing rapidly. We have received over 55,505 comments about what can be improved and what works well in our services via the Trust's Feedback Survey, which can be filled in via the website. All the comments have been analysed by theme and are visible to staff and the public on our website.

The initiative has had a wider impact due to promotion, Board support and the way our Involvement Team has led this work across the Trust. For example, we have increased our number of Patient Opinion postings from 305 to 609 stories in the last year as well as increasing the number of service changes to 123 on the site. In addition, the Trust's Service Quality Rating has increased from 89% in 2012/13 to 92% in 2013/14.

The increased focus on responding to feedback has meant teams have taken action on a whole range of issues. Over 40 changes are already recorded on the website; these can be seen on the ['What we've Done'](#) section and many more can be found in our [Annual Involvement Report 2013-14](#).

## Senior Leadership

### **Title:** Improving Staff and Patient Experience Through Our CARES Values

**Who:** The Hillingdon Hospitals NHS Foundation Trust

**What:** Feedback from patients identified consistent themes around poor communication, attitude and lack of involvement in decisions about treatment/care. Furthermore, on-going themes around poor behaviours were highlighted in employee relations issues. As a result, in November 2010 the Trust undertook the exciting journey to review our values to improve staff and patient experience.

A gap was identified around the underpinning behaviours expected of staff and embedding them into everything we do. We wanted to clearly define and constantly reinforce the minimum standard of behaviour that is expected across the Trust from our staff, regardless of job role.

We engaged staff early on to decide what our values should be and to identify an acronym that would remind staff what these values are. We did this through focus groups with staff and at our Patients in Partnership annual meeting. The acronym CARE received the highest votes to represent the values of Communication, Attitude, Responsibility and Equity. It was recognised that the word 'Safety' was a much needed addition to CARE, so it was added, making the acronym 'CARES'.

We recognised the need to bring our values to life by embedding CARES across the organisation through everything we do. The Putting People First (PPF) steering group was set up, chaired by the Director of People to ensure that the Trust's operational and corporate processes were underpinned by CARES.

**Outcome:** Only a few months after the CARES launch, 86% of our staff said they knew about the values.

We use questions within the National Staff Survey to give us an indication of the impact of implementing our CARES values. We saw an increase in our 2012 survey when compared to the 2011 survey in key areas and further increases in 2013 in the following areas [as a result of how scores are calculated on these measures, the increases below may appear small, however in fact they represent meaningful improvements]:

- Overall Engagement score increased from 3.75 (2012) to 3.77 (2013);
- Staff recommendation of the Trust as a place to work or receive treatment score increased from 3.66 (2012) to 3.70 (2013).

Improvement in our Friends and Family test scores and positive patient comments about staff behaviour and attitude on the NHS Choices website are also indicators that CARES is having a positive impact.

## Senior Leadership

### **Title:** Embedding improving experiences into how we work

**Who:** Imperial College Healthcare NHS Trust

**What:** A Trust-wide drive to improve experiences must start from the top. Because of this, experience has clearly been built into our Trust's corporate objectives and quality strategy. As a result, patient experience Key Performance Indicators (KPIs), which carry just as much weight as other performance measures, have been included in the Trust- and divisional-level scorecards.

A small patient experience team has also been established to support the delivery of improvements and the Trust patient experience work. Their work includes bringing patient stories to the Board, designing and developing welcome materials for patients and supporting initiatives such as intentional rounding and multi-media options for presenting patient information.

**Outcome:** Anecdotally, we are seeing more of a focus on patient experience at the local level, for example frontline staff reviewing, displaying and discussing patient feedback. Also, patient experience is now the first and main item on the corporate welcome (induction) so its importance is stressed right from the outset with new starters.



## Senior Leadership

**Title:** Developing and embedding our Trust vision and values**Who:** Isle of Wight NHS Trust

**What:** Launched in March 2014, the Quality Champions initiative aims to ensure the Trust's vision of 'quality care, for everyone, every time' is delivered across all areas of our unique, integrated organisation which includes ambulance, mental health, acute hospital and community services. So far, 72 members of staff have volunteered their time to become Quality Champions and help to promote and raise awareness of the Trust's quality goals. Every month, the Quality Champions meet with members of the Trust's Senior Executive Team and carry out a range of quality control tasks. The ultimate aim is to improve the quality of care for our patients and help improve staff engagement and two-way communication with senior leaders.

**Outcome:** We hope to see a change in the scores of the annual staff survey regarding communication and staff engagement (the survey will be taking place during September and October, results in January / February 2015.)

## Senior Leadership

### **Title:** Implementing a trust-wide system for capturing people's feedback

**Who:** South West Yorkshire Partnership NHS Foundation Trust

**What:** The aim of this initiative was to implement a trust-wide survey to capture patient experience that could be used to act as a barometer on important aspects of clinical care. It was commissioned by our Director of Corporate Development and driven by the values of the organisation to uphold our commitment to the people who use our services to 'Listen, Act and Respond' to feedback they provide to us, which is one of our quality priorities.

Our vision was that the feedback from the survey would be triangulated against other sources of patient feedback which the Trust received and reported 'from ward to board' on a quarterly basis. Alongside the implementation of the survey a real time patient feedback system was being introduced in the organisation.

Deliverables to date include:

- Implementation of a trust-wide patient feedback survey, in a staged process, across the organisation.
- Test out the impact of technology as an additional method of collecting patient feedback, with a vision to develop a real time patient experience system.

- Ward to board patient experience reports.
- Portfolio of evidence to demonstrate improvement in the quality of care as a result of patient feedback.

**Outcome:** Measures of success and outcomes achieved include:

- Phase 1 of this project has made a considerable difference to the way staff respond to feedback from patients. The questions that are asked in the survey all relate to aspects of care that the Trust had received negative feedback on, either through national and local surveys, clinical audit, complaints, serious incidents and existing feedback methods.
- Improvement in engagement between staff and patients: the questions focused on care and care planning, 1:1 engagement, involvement in decisions about care and medication and the Friends and Family Test. The survey feedback has been used by ward managers to plan interventions. Interventions demonstrate increased interaction between the clinical staff and patients, with time being spent listening to patients and ensuring they are partners in their care, rather than recipients of care.

(continued)

## Senior Leadership

### **Title: Implementing a trust-wide system for capturing people's feedback** (continued)

- Response rate to patient experience feedback: the implementation of this system has demonstrated that giving people the option of using technology has increased the response rate of feedback received from a twenty per cent response rate to a sixty per cent response rate. This makes the feedback more robust and gives the Trust assurance that the feedback we are receiving is from a representative sample of the inpatient population.
- Ward engagement: all of the 29 clinical teams are engaged and actively participating in the patient experience cycle.
- Dashboard development: dashboards have been developed for ward teams and the Trust board.
- Triangulation of information: a by-product of this project is a coordinated approach to triangulating all the patient experience information in one place so an analysis of the key themes can be undertaken. This triangulation allows the Trust to be assured that we are utilising our resources to focus on the key themes that people are telling us matter to them and on those areas where we are doing less well.

## Senior Leadership

### **Title:** Embedding improving experiences throughout our organisation

**Who:** NHS Tameside and Glossop CCG

**What:** Our commitment to improving people's experiences and involving service users and the public in our work is led from the very top – there is a clear commitment at corporate level within the CCG objectives and we have a culture of ensuring engagement is promoted in all areas of the organisation.

We have also adopted the 6Cs [more information [here](#) – the '6Cs' are: care, compassion, competence, communication, courage, commitment] within our CCG. By embedding the 6Cs in our mission statement we have ensured a focus on these throughout our leadership and, more broadly, in our practice and culture. Our recent away day focused on the 6Cs and how as a CCG we can demonstrate these in practice as strategic leaders, commissioners and with our local population through proactive meaningful involvement and engagement. Our strategic alliances are crucial and we are proud of the relationships we hold with our partners in the Local Authority, Community and Voluntary Action Tameside (CVAT) and Healthwatch.

This strong corporate message means that we have embedded involvement in the way we carry out our commissioning functions. For example, we use data on people's experiences to enhance and inform our future commissioning decisions. We are currently developing our communication and engagement strategy to ensure we are not only meeting statutory requirements but also so that we can implement proactive engagement with our local population. In addition, we have strong links to our patient participation groups, while also engaging people on specific areas of work, for example in developing our local integration plans we are reliant upon the involvement of our patients, service users and carers to ensure we understand their experiences. Engaging at the earliest opportunity allows us to ensure meaningful involvement at every stage (more information [here](#)).

**Outcome:** It is envisaged that, as a result of the work we are currently undertaking at both a strategic level and a local level, we will be able to demonstrate improved experiences and feedback through a variety of mechanisms.

## Data and intelligence on experiences

### **Title:** Improving experiences through collecting and using experience data

**Who:** Northumbria NHS Trust

**What:** The Trust relies on national surveys to benchmark their data. Last year, Northumbria Healthcare also sought 34,500 responses from patients about their experiences of care within the Trust. This information is independently provided by Patient Perspective, a contractor approved by the Care Quality Commission. The surveys are deliberately sent out in the two weeks after discharge, when patients are statistically at their least satisfied and perhaps more free to tell us why.

A 'Two minutes of your time' exit survey is in place to cover the friends and family question. In June 2010 Northumbria developed their real-time programme designed around eight core domains of care (coordination, respect and dignity, involvement, doctors, nurses, cleanliness, pain control, medicines). Feedback is given to staff within 24 hours and shared with patients, families and the public. Consultants get individual feedback on what patients have said about them, which is then included in their appraisal.

The Trust also works with a team of patient advocates from Age UK who consider the experience of the service from the perspective of a person with dementia who is unable to provide feedback.

Across the Trust, feedback scores in key domains (such as respect and dignity or cleanliness) are high and a level of 90% across all areas of care is set as the bar. Wards or services falling below this are supported to improve. Teams are expected to review patient feedback and use this to consider changes and improve.

One outlying medical ward team, for example, came up with the idea of dignity boxes which included nightwear and basic toiletries for those patients arriving in hospital without these. One of the unintended consequences was the opportunity for staff to spend more time with patients, talking whilst applying hand cream which was in the box. Wards are also supported to improve, with staff released for person-centred training in dementia and delirium where appropriate.

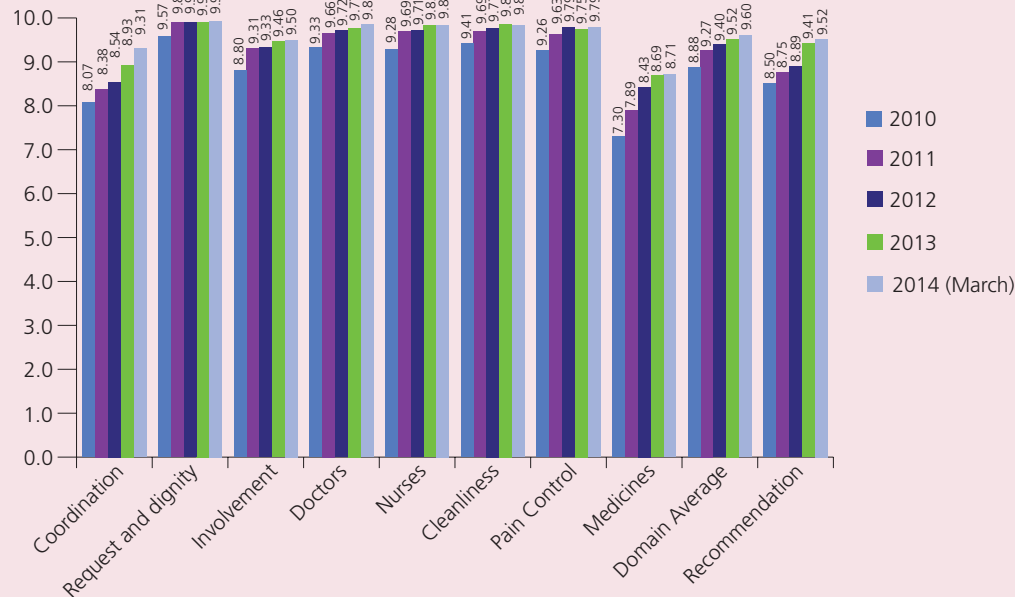
In the annual NHS staff survey, the Trust performs exceptionally well, with 91% feeling that their work makes a real difference to patients. The latest national inpatient survey results in 2013 are similarly positive – Northumbria was ranked 13th out of 165 participating trusts, their performance beaten only by 12 specialist hospitals.

(continued)

## Data and intelligence on experiences

### Improving experiences through collecting and using experience data (continued)

#### Outcome:



**Real-time improvements; Feedback on eight domains over 4 years, from more than 17,000 patients.**

We now also ask our patients simply whether they have been treated with kindness and compassion by everyone involved in their care. Latest results reveal 99% of our patients feel they are treated with kindness and compassion.

The Trust is currently being funded by the Health Foundation to carry out a project known as 'Shared Purpose', which aims to ensure that older people receive kind and compassionate care, in environments where their needs are understood and met. We have 8 'Shared Purpose' wards, in which we are using patient experience to drive and measure some of the interventions in this project which include testing the value of nutritional assistants in encouraging our older patients to eat and socialise, the use of independent observational volunteers to provide staff with independent feedback on their practice, and experience-based co-design of the new 'transfer out of hospital' service, to ensure integrated care and avoid unnecessary admissions and readmissions.

## Data and intelligence on experiences

### **Title:** Collecting and using feedback from patients and their families to improve services

**Who:** Sheffield Teaching Hospital NHS Foundation Trust

**What:** We engage with and seek feedback from patients and their families and then use that data to improve services in a number of different ways:

- The Friends and Family Test (FFT): one way in which FFT data is being used to improve services is through identifying both organisation and local level themes which generate the most feedback.
- The Frequent Feedback survey programme: this is a more detailed, electronic survey which is carried out on a rolling programme across all wards and captures the views of around 500 patients per month. The survey is undertaken by trained volunteers who interview patients. Data is near real-time and reports are provided to individual wards for action planning within one week of the survey being completed. The survey has the flexibility to be tailored to seek feedback on specific issues.
- Website feedback/comments cards: these provide unsolicited feedback enabling patients and families to comment on things which are important to them. The themes of 'staff attitude' and 'communications' together account for over half of the comments received (both positive and negative). Therefore, a programme of 'customer service' training, which includes communication skills, is now in place.

- National patient surveys: these provide a Trust-level overview of patient feedback. Reviewing a more detailed breakdown of data, for example by age, provides greater insight into the survey results.
- Complaints: individual complaints often provide detailed insight into a patient's experience which can bring to life quantitative data. As well as prompting actions at Trust level, this information also enables issues to be identified and followed up at local level.
- Triangulating and benchmarking data: triangulating data ensures that we are able to make sound and well-informed judgements in relation to patient feedback regarding our service. Benchmarking enables performance to be viewed comparatively. For example, every three months aggregate ward level FFT scores are reviewed and benchmarked against the England average score.

**Outcome:** Changes have been made across the Trust as a result of patient feedback. One example is the development of the meal time volunteer programme which followed negative feedback regarding the lack of assistance available to patients at meal times.

(continued)

## Data and intelligence on experiences

### Collecting and using feedback from patients and their families to improve services (continued)

- The programme was initially piloted on one ward with four trained volunteers attending at meal times and providing assistance to patients, for example by cutting up food, opening wrappers, and talking to patients encouraging them to eat and drink. Following the success of the pilot the programme was further developed, with the range of volunteer tasks increasing to include feeding patients. A more comprehensive training programme was also developed, delivered by speech and language therapists, dieticians, the oral health team, and the catering team.
- The Trust currently has 73 trained volunteers involved in the meal time programme, which is offered on 17 wards, with plans to eventually expand to every ward.
- Volunteers have time to spend with patients and help make meal times less stressful and more enjoyable. Some patients only need a little encouragement and look forward to seeing the friendly face of a volunteer at meal times, whilst others benefit from being helped to eat and drink at meal times.
- Volunteers who participate in the programme report it to be a very rewarding experience. The Trust has in place a robust recruitment procedure and provides comprehensive training, which is followed up by a competency assessment with nursing staff that must be passed, before volunteers can assist patients with eating and drinking.

One of the measures used by the Trust to evaluate the project has been feedback from patients captured on the ward during their hospital stay through the Frequent Feedback survey programme. During 2011/12, 62% of patients said they got the help that they needed to eat at meal times. As a result of the meal time programme being rolled out more widely during that year, the score increased significantly to 88% during 2012/13 and has remained consistent since then.

The Trust is about to start a formal evaluation of the project to measure the benefits of the scheme on patient outcomes such as length of stay, mood, and nutrition and hydration levels. It will also measure the impact on other staff groups, for example the amount of time freed up for nursing staff.



## Data and intelligence on experiences

### Title: Keeping it Real: Making it Right

**Who:** County Durham and Darlington NHS Foundation Trust

**What:** The aim of this initiative was to encompass a whole range of patient experience measures carried out within the Trust in order to identify key themes and actions which could be addressed and monitored systematically, in order to improve the patient experience. In essence we wanted to capture, triangulate, measure and feedback key themes which would require focused service improvement attention.

As an organisation we were conscious of collecting both real time and right time feedback from service users and carers in a variety of innovative ways, however we needed to develop and focus on a system whereby such feedback could be effectively measured and acted upon. This initiative looked at a reporting mechanism which could capture and analyse both real and right time qualitative and quantitative data and be used to develop an improvement programme shared with staff and service users.

The Patient Experience Thematic Action Plans (PETAPs) were therefore developed which are populated quarterly using a range of measures. PETAPs are presented at local Care Group Governance Meetings in order to plan and deliver actions as a result of feedback and learn lessons from issues raised. The PETAPs are progressed and reviewed at a sub group of the Trust Board, issues are identified and measures adopted to make improvements.

**Outcome:** A broader, more productive understanding of the importance of patient involvement and feedback has been achieved across the Trust. It has

become embedded across the organisation. The PETAPs are seen as a routine, viable and reliable method of measuring quality within the organisation.

For example, attitude of staff was identified as a particular issue, especially within the Emergency Departments and within the Maternity Department. Actions were put in place as a result which included:

- Development of a Patient Story DVD. Patients were invited to Board and Sub-group meetings to share experiences and highlight specific issues. A quarterly review of attitude of staff data is shared routinely. There has been a reduction in the number of issues raised regarding staff attitude: specific complaints data reveal a 33% reduction in complaints where attitude is the primary issue.
- Turning complaints into contributions: all complainants are invited to contribute to the actions identified as a result of a complaint. Regardless of involvement, all complainants receive an action plan together with their investigation report following a complaint. Following the introduction of the above process, a reduction in the number of requests for second responses (over 60%) has been noted indicating a higher level of satisfaction with the complaints process. Useful actions have also been adopted as a result of direct patient feedback to specific actions.

We have also noted a general rise in the number of compliments and a reduction in complaints throughout the period of PETAP. The local media has highlighted this success via local newspaper and radio coverage.

## Data and intelligence on experiences

### **Title:** Engaging with patients, using their feedback

**Who:** Walsall Healthcare NHS Trust

**What:** Walsall Healthcare NHS Trust had a long history of performing badly in the national inpatient survey. The whole organisation was affected every year by the results and our response was one of reaction and planning to improve the scores rather than looking at why the scores were poor.

We therefore wanted not only to improve our position, but also to understand why people were rating us at this level.

We agreed that the national inpatient survey did not give us the level and frequency of data we needed. In order to understand why patients were scoring us badly we agreed that we needed to understand the results by ward area. As a result we commissioned a replica survey which included 200 patients per ward area. These results were owned by the ward teams who developed actions to improve their own scores.

Twenty of the questions that scored very poorly on the replica survey were put into a questionnaire along with the questions: 'how would you score us on a scale of 0-10' and 'what could we do better?' All patients were asked to complete this questionnaire on discharge and, where they were not able to, their relative was asked to complete the form. This level of detail by ward area enabled the staff to really understand what their patients were saying about them and where they had to improve.

**Outcome:** As a result of this work our inpatient survey results have improved. Our scores now range from being either average or higher than average compared to those of other trusts across the country.

There are two other strands to the impact this work has had:

- Most importantly, patients are telling staff about their experiences and can see that this has made a difference, from stopping the housekeepers vacuuming very early in the morning to having larger mugs for drinks available for people if they want them. Patient feedback has resulted in additional staff on one ward and a complete refurbishment of the arrivals area. Most of the comments have resulted in the ward teams taking action and improving the service for patients, they monitor the responses and they are shared at ward meetings. In monitoring the trends it is interesting to note that once an action has been completed then it is unusual for negative comments about the same aspect to be received again.
- Secondly the reputation of the Trust has improved as a result of this openness and sharing of information. We now have the highest return rates for the Friends and Family test in the country, were cited by Jeremy Hunt MP in his launch speech for the Friends and Family Test and have been visited by Dr Dan Poulter MP as a result of our success with asking patients in A&E about their experiences.

# Workforce

## Title: Dignity in Practice: Our Shared Purpose

**Who:** Northumbria NHS Trust

**What:** Numerous reports have exposed shortcomings in the care of frail older people and the gap between the principles and rights outlined in the NHS constitution and the reality of care experienced by many has been highlighted.

Within our own organisation we are aware that a training gap exists. An internal audit highlighted that only 10% of our newly qualified doctors felt confident about meeting the needs of frail older people. Additionally one of our consultant psychiatrists, Dr ATeodorczuk, carried out a mixed method study to establish the learning needs of staff in relation to caring for the older confused person. Our aim has been to align the work of two corporate services – Human Resources and Patient Experience – with the work of clinical teams delivering dignity in practice to all patients – but particularly those frail elderly with complex needs.

**Outcome:** Results to date include:

- Between Jan – Aug 2013, 1392 staff completed the new Trust induction programme using the DVD 'Tale of Two Wards' to highlight the Trust's commitment to dignity and compassion from all clinical and non-clinical staff.
- Development and piloting of values-based questions framework to use at interview. There is a question bank of 36 to choose from, and to date this tool has been used in interviews with band two nutritional assistant posts, band five staff nurses and band six physiotherapists.
- Ten multidisciplinary teams have completed the patient-centred training, reporting a marked increase in their confidence in recognising, treating and interacting with people with delirium and dementia.
- Preventing readmissions – there has been a more than 50% reduction, with a high volume of support calls via the telephone helpline and good use of the rapid access wound clinics.
- Observational Visits from Age UK – participating wards (six wards up to Oct 2013) are provided with verbal feedback straight after an observational visit, then a written report within seven days.
- One ward team is piloting a communication board which displays their key priorities, actions and progress to date to ensure their quality improvement measures are visible and measurable to staff, patients and visitors. This initiative links to increasing the numbers of staff having training relating to dementia and making their environment more dementia friendly.

# Workforce

## Title: 'The WWL Way' – Implementing sustainable staff engagement

**Who:** Wrightington, Wigan and Leigh (WWL) NHS Foundation Trust

**What:** 'The WWL Way' is a vision for understanding, implementing and embedding sustainable staff engagement in WWL NHS Foundation Trust. The impetus for this work was that in 2011 the Trust only achieved 21% of staff survey measures above the national average.

The approach evolved from three interventions:

- 'Staff Involvement Delivers' offering a range of longstanding partnership initiatives between managers and 'staff side' encouraging honest and open employee dialogue, including senior walkabouts, shadowing and director led staff conversations.
- 'Listening into Action' (LiA) providing a compelling approach releasing organisational energy, creativity and ideas.
- 'The Unipart Way' providing discipline and sustainability, maintaining engagement and improvement through visual performance management and enhanced team communication.

The Trust created their own unique brand of staff engagement – “the WWL Way” – which involved developing a staff engagement pathway model: a framework for understanding staff engagement more deeply via a diagnostic tool. The tool tracks engagement over time by gauging levels of engagement and identifying the factors that help enable improved engagement. The tool works at a Trust-wide and service level, and informs staff engagement practice. At Trust level there is an on-going emphasis on large-scale staff engagement events, interventions and visible leadership. At service level, teams can embark on the “Staff Engagement Pioneer Teams Programme” – a training and support programme which encompasses a staff engagement toolkit and empowers local teams to improve their own engagement levels by applying their own combination of tools in response to their own diagnostic data.

**Outcome:** In 2012, the organisation saw major improvements in national staff survey results. Above average scores have increased by 64% from 2011, and increased again by another 15% in 2013. In addition WWL has seen significant and sustained reductions in sickness absence (down from 4.62% to 4.17%) and expenditure of temporary staffing (down from £15 million to £12 million).

By applying their continuous data driven improvement approach, WWL hope to enhance staff engagement yet further in the future in the strong belief that 'if they get it right for their staff, they get it right for their patients'.

# Workforce

## **Title:** Engaging staff in developing tools and guidance for building stronger teams

**Who:** Birmingham Children's Hospital

**What:** In the wake of the Francis Inquiry, which highlighted the need for improved compassion in care and stronger healthcare leadership, staff at Birmingham Children's Hospital (BCH) identified a need to improve team work both within and across teams.

This became the focus of BCH's annual InTent week, which draws on staff feedback and the NHS Staff Survey results to focus on a different staff issue each year.

More than 600 staff attended interactive workshops and leaders' masterclasses under the theme of 'Building Team BCH' and Professor Michael West of Lancaster University Management School presented some of his research into the impact team working has on patient outcomes. Throughout the week, staff views were captured and developed into an action plan.

**Outcome:** As a result of the week, tools and guidance were developed to support staff as team members or team leaders and the Team Maker programme for managers was launched. Shadowing schemes, mentoring and further InTent to Listen events were organised to keep feedback going.

# Workforce

## Title: Improving patient experience of cardiac services using the Listening into Action approach

**Who:** St George's Healthcare NHS Trust

**What:** The reporting of cardiac investigations by Cardiologists at St George's was subject to capacity issues. This resulted in significant delays – on average five weeks – between the investigation being performed by the Cardiac physiologists and the results being sent to GPs for onward communication to the patient. This was confirmed by a year-long retrospective audit of the Murmur Clinic, which investigates abnormal heart sounds. A patient experience survey also reported low levels of satisfaction with the waiting times for results, although the service held up well overall.

The Cardiology team at Queen Mary's Hospital, Roehampton, were keen to change their reporting procedures. They knew that their fire-fighting attempts to minimise delays were not sustainable and that a permanent solution had to be found.

Using the Listening into Action (LiA) approach ([more information here](#)), the Cardiology team quickly identified that by making the clinic physiologist-led, they would be able to achieve a same-day service. This would speed up the service for patients and free up consultants to focus on more complex and urgent issues.

To do this the team undertook a patient survey, consulted GPs, reviewed the patient pathway, created new templates with extended slots, arranged the

necessary training for staff, sought accreditation with the British Society of Echocardiography (BSE), reviewed appropriate policies and protocols to codify practice, and agreed a business plan and risk assessment with their Divisional Management and Governance Boards.

This was not without its hurdles, but the focus remained the improvement of clinical effectiveness, patient experience and patient safety.

Nolan Stain, Cardiology Manager said: "The staff engagement approach provided by Listening into Action gave us the perfect starting point, with a structure and set timeframe. By involving all the right people – across the usual boundaries – right from the start, we knew that we were working towards something with the full support of a broad multi-disciplinary team and for the benefit of our patients".

**Outcome:** The physiologist-led Murmur Clinic went live on Friday 30th May 2014. The results will be audited at three months, six months and 12 months to ensure compliance with agreed standards. So far, the team has achieved the same-day target at 100% and the five week wait has been completely eradicated.

Adapted from: <http://blog.listeningintoaction.co.uk/article/86/5-week-wait-for-Cardiology-patients-completely-eradicated-at-St-Georges-.html>

# Workforce

## Title: Improving levels of staff engagement

**Who:** Derbyshire Healthcare NHS Foundation Trust

**What:** A few years ago, the Trust was not in a very good place in terms of employee engagement. In 2010, Derbyshire Healthcare languished in the bottom 20% in 18 areas of the staff survey. Steve Trenchard, Chief Executive of the Trust since early 2013, explained that this had been due to a 'command and control' and autocratic culture, and a view held by employees that the Trust had been single-minded in its drive to get foundation trust status.

There are a number of ways in which the Trust has improved levels of staff engagement, including:

- Values: Both senior managers and staff at Derbyshire Healthcare are keen to emphasise the strong set of organisational values. Employees, alongside patients and carers, were very much involved in developing the values. The values at Derbyshire Healthcare are deeply embedded in the organisation and intended to underpin everything the Trust does. Values also form a central part of the recruitment process, with applicants assessed on alignment to Trust values even before technical competency is looked at.
- Visible and approachable leadership: The Board make an effort to get out onto wards and community teams as much as possible. The 'walk in your shoes' initiative involves each Director shadowing a number of employees from across the Trust over the year. This helps to lessen the sense of hierarchy and makes leaders seem approachable.

- Change management: Leaders at Derbyshire Healthcare recognise the importance of involving employees in change at the Trust. The Trust has set up a Transformational Change Board to guide organisational change. Led by clinical staff, the Board includes both staff and patients, and over 700 employees have engaged with the process so far. Underneath the Transformational Change Board are Patient Pathway Teams (PPTs). These are groups of around 50 people – nurses, doctors, patients and carers – coming together to look at particular services. The PPTs meet for three separate days; first to identify the challenge, then to set out where they want the service to go, and finally to plan how this can be delivered before feeding back recommendations to the Board.
- Empowerment and professional autonomy: Emphasis on these concepts comes from a belief that employees are best placed to make decisions on their work and the care they give, and that it is staff themselves rather than senior leaders that can really drive change in the organisation. As one senior nurse described, staff are encouraged to 'own' their roles and to make and share suggestions. They are then supported by senior management to take those ideas forward. In addition to this, there is a growing focus on coaching in the organisation.

(continued)

## Workforce

### **Title: Improving levels of staff engagement** (continued)

- **Compassion:** Compassion is right of the heart of the approach to care at Derbyshire Healthcare. The Trust does monthly Schwartz Centre Rounds that provide a session for employees to discuss difficult emotional and social issues arising from patient care. These aim to support staff to deal with issues and provide compassionate care. Some members of the Board also practise 'mindfulness' and the Board is working to introduce this approach to improving staff resilience across the Trust.

In addition, a programme which came to be known as Strengthening Our Compassionate Care Culture was introduced. It was aimed at Health Care Assistants (HCAs), to help them look at their impact on the patient experience and identify how they could support compassionate care. It was co-produced with HCAs and the day-long sessions were initially jointly facilitated by Sue Stocks – Assistant Director for Education and an experienced senior nurse. Since a successful pilot, the programme has since been rolled out and is now delivered solely by HCAs and patients to other HCAs, with a quarter of the staff group having been through it so far.

**Outcome:** The Trust has seen substantial improvements in its employee engagement scores over the last three years. Derbyshire Healthcare is now in the top quartile of mental health and learning disability trusts for engagement.

Derbyshire Healthcare also scores far higher than the average in terms of staff perceptions that patient care is the Trust's top priority.

Adapted from: <http://www.ipa-involve.com/resources/publications/case-studies/employee-engagement-at-derbyshire-healthcare/>



# Resources

Here we set out resources on improving experiences.

For everyone

For professionals providing care

For commissioners

For providers

For service users and the public

# Resources

## For everyone

- Kissing it Better – a forum for sharing simple, practical healthcare ideas: <http://www.kissingitbetter.co.uk/>
- NICE guidance and quality standard for patient experience in adult NHS services: <http://www.nice.org.uk/guidance/cg138>; <http://www.nice.org.uk/guidance/qs15>
- NICE guidance and quality standard for service user experience in adult mental health: <http://www.nice.org.uk/guidance/cg136>; <http://www.nice.org.uk/guidance/qs14>
- House of care model – a framework, adopted by NHS England, for enhancing the quality of life for people with long term conditions: <http://www.england.nhs.uk/house-of-care/>
- NHS Institute for Innovation and Improvement – Transforming patient experience: the essential guide. A resource for people with designated responsibility for improving patient experience – both as providers of services and as commissioners: [http://www.institute.nhs.uk/patient\\_experience/guide/home\\_page.html](http://www.institute.nhs.uk/patient_experience/guide/home_page.html)
- National Voices – evidence from 779 systematic reviews of ways to make person centred care happen: <http://www.nationalvoices.org.uk/evidence>
- Picker Institute Europe – a not-for-profit organisation that makes patients' views count in healthcare: <http://www.pickereurope.org/>
- The Point of Care Foundation – an independent charity working to improve patients' experience of care and increase support for the staff who work with them: <http://www.pointofcarefoundation.org.uk/Home/>
- The King's Fund – projects, articles, blogs and events related to patient experience: <http://www.kingsfund.org.uk/topics/patient-experience>
- The Patient Experience Network – a membership network with a key emphasis on learning from each other and best practice: <http://patientexperiencenetwork.org/>
- Macmillan Values Based Standard® – an innovative framework and methodology for improving both patient and staff experience: <http://www.macmillan.org.uk/Documents/AboutUs/Commissioners/Macmillan-Values-Based-Standard-Overview.pdf>
- Sense – report on what good care looks like for deafblind people: <http://www.sense.org.uk/publications/what-does-good-care-look-deafblind-person>
- Think Local Act Personal – 'Making it Real': a project which sets out what people who use services and carers expect to see and experience if support services are truly personalised: <http://www.thinklocalactpersonal.org.uk/Browse/mir/>
- The Beryl Institute: a global community of practice and thought leader on improving the patient experience in healthcare, publishing papers on key issues, case studies and an annual programme of research grants: <http://www.theberylinstitute.org/>

**For professionals  
providing care**

- 6Cs Live! – supports the delivery of the six areas of action defined by the Compassion in Practice strategy and vision based on the 6Cs – care, compassion, competence, communication, courage and commitment:  
<http://www.6cs.england.nhs.uk/pg/dashboard>
- Hello my name is – campaign to encourage and remind healthcare staff about the importance of introductions in the delivery of care:  
<http://hellomynameis.org.uk/>
- NHS Institute for Innovation and Improvement – Helping staff to improve patient experience:  
[http://www.institute.nhs.uk/patient\\_experience/guide/helping\\_staff\\_to\\_improve\\_patient\\_experience.html](http://www.institute.nhs.uk/patient_experience/guide/helping_staff_to_improve_patient_experience.html)
- Mencap – Videos and guides for GPs about how to provide accessible services:  
<http://www.mencap.org.uk/gptoolkit>
- The National Autistic Society – Information for health professionals on working with people with autism:  
<http://www.autism.org.uk/Working-with/Health.aspx>
- The Royal College of Nursing – guidance and tools: Patient focus:  
[http://www.rcn.org.uk/development/practice/clinical\\_governance/patient\\_focus/other\\_support/guidance\\_and\\_tools](http://www.rcn.org.uk/development/practice/clinical_governance/patient_focus/other_support/guidance_and_tools)
- SCIE – Living with dementia: four people share their experiences and give a moving and personal insight into often overlooked aspects of the condition:  
<http://www.scie.org.uk/socialcaretv/video-player.asp?v=living-with-dementia>
- SCIE – Personalisation: 11 films, linked to relevant resources, six told from the perspective of people who use services,  
<http://www.scie.org.uk/socialcaretv/topic.asp?t=personalisation>

<b>For commissioners</b>	<ul style="list-style-type: none"> <li>● NHS England – Resources and case studies aimed at commissioners on ensuring that people have a positive experience of care: <a href="http://www.england.nhs.uk/resources/resources-for-ccgs/out-frwrk/dom-4/">http://www.england.nhs.uk/resources/resources-for-ccgs/out-frwrk/dom-4/</a></li> <li>● NHS Institute for Innovation and Improvement – Commissioning for a positive patient experience: <a href="http://www.institute.nhs.uk/patient_experience/guide/commissioning_for_a_positive_patient_experience.html">http://www.institute.nhs.uk/patient_experience/guide/commissioning_for_a_positive_patient_experience.html</a></li> <li>● NHS England – practical guidance for commissioners on transforming participation in health and care: <a href="http://www.england.nhs.uk/wp-content/uploads/2013/09/trans-part-hc-guid1.pdf">http://www.england.nhs.uk/wp-content/uploads/2013/09/trans-part-hc-guid1.pdf</a></li> <li>● NHS England – summary of the key themes and discussion from an event on commissioning for improved patient experience: <a href="http://www.england.nhs.uk/wp-content/uploads/2014/09/simulation-event-rep.pdf">http://www.england.nhs.uk/wp-content/uploads/2014/09/simulation-event-rep.pdf</a></li> <li>● SCIE – Advice and support about how to involve people who use services and carers in designing, delivering and co-producing care services: <a href="http://www.scie.org.uk/key-topics/co-production">http://www.scie.org.uk/key-topics/co-production</a></li> </ul>
<b>For providers</b>	<ul style="list-style-type: none"> <li>● NHS Institute for Innovation and Improvement – Helping leaders to improve the patient experience: <a href="http://www.institute.nhs.uk/patient_experience/guide/helping_leaders_to_improve_the_patient_experience.html">http://www.institute.nhs.uk/patient_experience/guide/helping_leaders_to_improve_the_patient_experience.html</a></li> <li>● NHS Institute for Innovation and Improvement – 15 steps challenge: a series of toolkits that help organisations to understand and identify the key components of high quality care that are important to patients, services users and carers: <a href="http://www.institute.nhs.uk/productives/15stepschallenge/15stepschallenge.html">http://www.institute.nhs.uk/productives/15stepschallenge/15stepschallenge.html</a></li> </ul>
<b>For service users and the public</b>	<ul style="list-style-type: none"> <li>● Healthwatch rights and responsibilities in health and social care: <a href="http://www.healthwatch.co.uk/rights-and-responsibilities">http://www.healthwatch.co.uk/rights-and-responsibilities</a></li> <li>● NHS Constitution – sets out people’s rights as NHS patients: <a href="https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/170656/NHS_Constitution.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/170656/NHS_Constitution.pdf</a></li> </ul>

## Evidence Base

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Here we provide the evidence that has been used to inform the development of *Our shared understanding and ambition*.

Experiences of social care

Why is experience important?

What is a good experience of care?

The current situation

Organisational-level factors

## Experiences of social care

The evidence on experiences of health services has been synthesised and drawn together by a number of reviews to an extent that social care evidence has not been. It was beyond the scope of this work to commission or conduct the reviews and synthesis necessary to fully incorporate the social care evidence into this work. We recognise however that for the many people who use both health and social care services, this means this narrative can only partially consider their experiences.

However, the following might be helpful regarding what a good experience of social care services means:

- The Social Care Institute for Excellence (SCIE) has drawn together eight main factors that promote [dignity in care](#),
- the Making it Real framework for what people want to experience from their care services from the [Think Local Act Personal \(TLAP\) programme](#) is based in evidence.
- SCIE has produced two films in which older people talk about what is important in their lives and how they like to be treated: "[Better life in residential care](#)" and "[Better life in the community](#)".

**Why is experience important?**

The key evidence base for the links between experience and other outcomes is:

[Doyle C, et al. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. \*BMJ Open\*. 2013. 3: e001570](#)

It states that:

- The results show that patient experience is consistently positively associated with patient safety and clinical effectiveness across a wide range of disease areas, study designs, settings, population groups and outcome measures.
- The data support the case for the inclusion of patient experience as one of the central pillars of quality in healthcare.
- Patient experience is positively associated with self-rated and objectively measured health outcomes; adherence to recommended medication and treatments; preventative care such as use of screening services and immunisations; healthcare resource use such as hospitalisation and primary-care visits; technical quality-of-care delivery and adverse events.

We recognise that separating out 'experience' from 'clinical effectiveness' and 'safety' when considering an experience of care from a user's perspective is potentially unhelpful. However, research on experiences has focused on a person's experience without the inclusion of clinical effectiveness and safety and the NHS Outcomes Framework and NHS Mandate follow this division too.

It is also important to note the strong evidence base which illustrates the links between staff engagement and other outcomes, including improved experiences. The Report of the Review of Staff Engagement and Empowerment in the NHS, [Improving NHS Care by Engaging Staff and Devolving Decision-Making](#), brings together this evidence.

## What is a good experience of care?

The evidence base for 'What is a good experience of care' is the Warwick Patient Experiences Framework, with the addition of a reference to the physical environment. The Patient Experience Sub-group of the National Quality Board agreed that this was the strongest evidence-base currently available due to its use by NICE in developing its Patient Experience guidance and Quality Standard. More information on how the Warwick Patient Experiences Framework was developed can be found here: [Staniszewska S et al \(2014\). The Warwick Patient Experiences Framework: patient-based evidence in clinical guidelines. International Journal of Quality in Health Care, 2014, pp 1-7.](#)

We recognise that there is currently a lack of consensus about the relationship between 'patient experience' and related concepts including 'person-centred care' (as expressed by [Picker's principles of patient-centred care](#)) and '[person-centred coordinated care](#)' (as developed by National Voices, which puts care planning at the centre of achieving person-centred coordinated care), as well as the articulation of people's rights in the [NHS Constitution](#) and by [Healthwatch England](#). *Our shared understanding and ambition* sits alongside these important pieces of work, however our aim here is to set out a definition of 'patient experience' since this is how the accountability and measurement of the NHS is framed in this area (in the NHS Outcomes Framework and NHS Mandate).

We also recognise that there are some limitations of the evidence base that we have used to underpin our shared understanding. These include:

- **Carers:** in the development of the Warwick Patient Experiences Framework, research on carers' experiences was not included.
- **Children:** in the development of the Warwick Patient Experiences Framework, research on children's experiences was not included.
- **Mental health:** the research that was used in the development of the Warwick Patient Experiences Framework focused on three clinical areas: cardiovascular disease, diabetes and cancer. Therefore there was not an explicit focus on experiences of mental health care. Think Local Act Personal and National Voices have published a [narrative for personalised, coordinated care and support in mental health](#).

In addition, as noted above, our shared understanding does not explicitly consider and try to encapsulate the potentially different experiences of people who access social care services compared to those who access healthcare services, or how the two might interact.

Finally, we note that, looking more generally at the evidence base in this area, there are still some gaps in our understanding, for example in terms of people's experiences of transition points in their care. A recent summary of new evidence in this area can be found [here](#) (scroll down to 'Patient experience').



**The current situation**

While in some cases people report very good experiences of care, in others experiences falls short for some, and on occasions quality of care can be unacceptable. We also do not yet achieve the standards of consistency that people expect, and evidence shows that we have further to go to systematically use the patient feedback we are now collecting to drive improvements ([Coulter, A, et al. Collecting data on patient experience is not enough: they must be used to improve care. \*BMJ\* 2014;348:g2225](#)).

In reality, experience is not always regarded as equal to clinical effectiveness and safety, for example:

- the importance of experience of care to trust boards varies considerably ([Dr Foster. \*The Intelligent Board 2010: Patient Experience. September 2010\*](#)) In addition, boards on the whole are not giving enough priority to staff engagement which has been shown to be strongly linked to people's experiences ([West, Baker, Dawson, Dixon Woods, Liford, Martin, McKee, Murtagh, Wilkie. \*Quality and Safety in the NHS: Evaluating progress, problems and promise. Final report to the Department of Health. 2013\*](#)),
- attitudes remain that providing a good experience is essentially an aspect of nursing rather than something that is affected by every interaction a person has with everyone involved in their care and treatment (this is illustrated by the fact that responsibility for experience of care at trust board level usually sits with the Nursing Director), and
- a lack of priority is given to research on experiences and how to improve them ([Staniszewska, Churchill. \*Patients' experiences in the UK: Future strategic directions. Patient Experience Journal 2014: Vol. 1: Iss. 1, Article 18\*](#)).

**Organisational-level factors**

The organisational level factors included here have been drawn together using a number of different sources, including [NB. some of the evidence supporting the organisational factors is drawn from studies that focus on the improvement of quality of care as a whole, which includes experience]:

- [Coulter, A, et al. Collecting data on patient experience is not enough: they must be used to improve care. BMJ 2014;348:g2225](#)
- [NHS Institute for Innovation and Improvement. Transforming Patient Experience: the essential guide.](#)
- [The King's Fund. The Francis Inquiry: creating the right culture of care.](#)
- [NHS Confederation. Feeling Better? Improving Patient Experience in Hospital. 2010](#)
- [Luxford K, Safran DG, Delbanco T. Promoting patient-centered care: a qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience. Int J Qual Health Care. 2011 Oct;23\(5\):510-5](#)
- [Shaller, D. Patient-Centered Care: What does it take? October 2007.](#)

Please note that the selection of these sources was not the result of a systematic literature review.

In addition, National Voices has [collated evidence from 779 systematic reviews looking at ways to make person centred care happen](#). 'Person centred care' here includes enhancing experiences, as well as a number of aspects that *Our shared understanding and ambition* defines as being part of experience, such as supporting shared decision-making.

WHAT DOES IT COVER  
AND WHO IS IT FOR?

OUR SHARED UNDERSTANDING

OUR AMBITION

NEXT STEPS

GOOD PRACTICE, RESOURCES AND  
EVIDENCE BASE

ANNEX

INDIVIDUAL STORIES

STAFF QUOTES

WHAT IS A GOOD EXPERIENCE OF CARE?

OUR ROLES AS NATIONAL ORGANISATIONS  
IN ACHIEVING OUR AMBITION

# *Annex*



## Yvonne's story

All three of my children with disabilities are now on the brink of adulthood.

Looking back, things were often very hard, with many times when I felt lost, frightened, exhausted and completely alone. It wasn't just because the caring responsibilities I was shouldering were often beyond my capacity, but also because the people who were supposedly there to support our family often made that burden intolerably heavier. Some were excellent; many were not.

Parents of children with disabilities or medical conditions generally know their children inside-out and we care passionately about their well-being.

We are their experts, we're the people who sit up all night while they struggle to breathe or have countless seizures. If only every professional we encountered understood this basic fact and used it as their starting point.

Instead, medical professionals often disregarded my experience and knowledge, and frequently didn't listen to anything I tried to tell them. It's frightening enough having a desperately ill child in hospital. It's terrifying to know that a treatment plan is being put in place that failed dismally last time it was tried. We've repeatedly tried to tell them. We are the closest thing to the child's voice in the room, yet we are silenced.

When I've been confined in that tiny space around my child's bed for day and night for several weeks watching him deteriorate, a touch, a kind word or an offer to sit in my place for the time it takes to grab a coffee is

something I've yearned for, yet disappointingly, many times it simply hasn't happened. Sometimes staff have been sitting at a distant desk completing paperwork when I'd have done anything for someone to share the load in caring for my child.

Over time I got better at being heard, but it didn't work every time. I got better at a lot of other things too, and this made me determined to write a book to pass on all I had learnt to help other parents in similar situations.

Sadly, I might not have had to write the book at all if professionals were better equipped at working with parents, instead of making us sometimes feel they are working against us.

If every professional could work in partnership with parents, valuing the input of parents and trying to bridge the gap between "them" and "us", everyone would benefit, particularly the children. Our experience coupled with their training is the basis of great teamwork.

Additionally, kindness costs nothing, but on a busy ward it seldom takes priority in the way that the paperwork does. If we could cut back on the systems and processes and instead invest in putting people at the heart of all care, the NHS could be transformed.

**Yvonne Newbold**  
(Author of *The Special Parent's Handbook*)

## David's story

I was a police officer, diagnosed in 2000 with Non-Hodgkin's lymphoma in my chest. I discovered this a year after I'd been to the doctors in 1999 complaining of heart palpitations and shortage of breath. I had been told that it was stress. After falling off my motorcycle and fracturing my ribs in 2000, a six inch tumor was discovered in my chest cavity.

As they could not operate I received an extremely aggressive regime of chemotherapy. I complained of loss of feeling in my extremities (fingers, toes etc) and burning in my legs and spine. I was told it was the steroids, however I collapsed after number eight of 12 in my chemotherapy treatment from anaphylactic shock. Since my chemotherapy I have been diagnosed with chemotherapy-induced neuropathy. This means I have damage to my central nervous system, resulting in numbness in my legs and hands, lack of feeling, and acute burning to my lower legs/feet and spine, which has to be controlled by drugs, as well as delayed responses.

All this severely restricts my mobility. I have to use a wheelchair and crutches due to my lack of mobility. The condition has also affected my memory and my ability to take in information.

As a cancer patient, I found that my medical treatment was departmentalised, and that none of the professionals I dealt with seemed to communicate with one another. It seemed that my cancer specialist post-treatment was not interested in my so-called "side effects". My current GP is too busy to offer any in-depth advice or care only seeming to be interested in referring to consultants, who then shunt me back to the 'care of my GP.'

Overall, I feel alone and rejected by the system. I wish there had been more of a holistic approach, and a designated point of contact who both me and my partner could call, and who might also keep in contact with us to provide ongoing support. This role was never offered to us. Having access to forums and support groups would have significantly assisted me in coming to terms with the disabilities affecting me post-treatment.

My wife has chronic ME and mental health issues and I am her carer.

David

## Kate's story

As a doctor I have become a keen observer of the healthcare I receive since my diagnosis of cancer nearly three years ago. In August 2013, I became unwell with an infection following some routine surgery to replace the stents that drain my kidneys. This necessitated a trip to the emergency department and a subsequent short admission to hospital.

One of the starkest observations I made during this particular episode was the absence of introductions from the staff delivering my care. It wasn't just the occasional slip but something that seemed to permeate through the professional groups and support staff. When someone did offer a friendly introduction, however, it made all the difference. It began a relationship, helped to put me at ease relieving my anxieties and humanised what can in many circumstances be an extremely dehumanising experience. When introductions were missing, I was left wondering who the person was and feeling that I was just another body with a disease in a hospital bed.

As a patient, you are in a vulnerable position. The healthcare team knows so much personal information about you, yet you often know nothing about them. This results in a very one-sided power imbalance. A simple introduction can help to redress this imbalance. I also believe it is the first rung on the ladder to providing compassionate care by establishing a human connection and building trust with a person.

I discussed the absence of introductions with my husband during visiting time one evening. We decided to do something positive to remind and encourage healthcare staff about the importance of introductions.

The result was the social media campaign I launched using the [hashtag #hellomynameis](#). I began to tweet frequently about the topic and [invited healthcare staff to pledge their support](#) for the campaign on my blog. It became clear fairly rapidly that my experience was not unique with many patients and carers contacting me with their own observations.

The campaign seemed to strike a chord, and soon I was inundated with messages of support from people across health and social care interested in promoting it in their own workplaces. The idea was the focus of many trust board meetings; lanyards, badges and pens with the logo were produced; reminders popped up in clinics and on wards, on computer screensavers and trust intranets; chief executives began to blog about the campaign; students started to collate selfie photo walls, and it was a frequent topic of conversation at many healthcare conferences. It has made more than 63 million Twitter impressions in 13 months, averaging four tweets per hour and there have been nearly 30,000 visitors to my blogpost. It has had a global impact with healthcare staff in Australia, America, Canada, Europe and even South Africa embracing the idea.

My prognosis is predicted to be only months but I would love to think one of my legacies will be an NHS that recognises the importance of treating patients as people, and one where every single member of staff knows about #hellomynameis and is inspired to take the campaign to heart to change their own behaviour.

**Kate Granger, doctor and terminally ill cancer patient**

## Andrea's story

My son Michael was diagnosed with cystic fibrosis aged 16 months old and was part of the Sheffield Adult Cystic Fibrosis (CF) centre from when he turned 16. He had many stays on the CF ward, a lot of which were lengthy ones. The new ward is a fabulous place with state of the art facilities all under one roof, with excellent medical care as well as pastoral care. Michael developed strong bonds with all the staff and had ultimate faith in them. Michael always felt safe on the ward and as a parent I knew that he was not only being treated but that he was cared for too.

Michael's health deteriorated over Christmas 2012, and he was admitted to the ward on New Year's Eve for what was to be his final stay as he sadly lost his battle with CF in October 2013.

Michael's last night was an absolute triumph. He had a lot of laughter with the staff in the daytime and in the evening his brother Daniel, his Dad and a friend came to watch the football match on the TV and share a beer (or two!) a perfect night for a young man – a night with the boys! When he went to bed that night, he said to me "I've had a really good day today mum", what lovely final words from a boy who fought so hard to beat this disease. He left us silently in his sleep that night.

The care and affection shown to Michael (and to us) at the end of his life was second to none, he was still able to have control over his treatment and the ability to make his own decisions. He was supported and comforted and his last days were filled with smiles and laughter thanks to the dedicated staff. The whole team supported us through our worst day with kindness and compassion and have continued to do so.

I can look back and know that Michael was happy on the ward, he said on many occasions during those 10 months "this is a good place to live mum", a sentiment we echo. I can never thank the staff enough for helping Michael to live his life to the full despite all his setbacks, the unit enabled him to live, laugh, work, get married, have a child and ultimately die with dignity and love around him. These people are our family and will continue to be so, it was his and our safe place and second home.

**Andrea Blackett**

## Sheila's story

My husband and I were going to catch the train to London and I was all dressed up in my finery. We were half way across the rail crossing when the warning started that a train was coming. I tried to go quicker but I fell, and knocked myself unconscious.

The next thing I know there were two men saying 'Get to the other side of the barrier!' and they were carrying me one under each arm.

I couldn't stand up. I'd damaged myself badly – my ribs were broken, and my face was bleeding. I'd broken my glasses, bitten through my lip, damaged my knee – which still is a bit naughty. I was taken to hospital in an ambulance and every single member of staff was wonderful with both me and my husband. They were very, very busy but they genuinely made time for me. I couldn't believe they were caring about me – I felt so silly and embarrassed that I'd fallen. Anyway they let me go home, which I was so pleased about.

The ambulance crew that took me home were lovely. I'd started to feel upset and sad in the ambulance and they were friendly and homely and made me feel much better. They brought me all the way into the house and chatted for a while. It was like having grandchildren talk to you. It's the caring that mattered and that you don't see a lot of today.

When I felt better I really wanted to let the staff know what a great job they did. I think it's important because they are regarded so much as just part of society and yet they are so much more than that.

They were so busy and yet they had the time to make me feel like I really mattered. They were lovely.

It was a bad fall. It keeps me awake at night sometimes when I think about it but the care I got reassures me.

**Sheila**  
([Source: Patient Opinion](#))



## Anonymous story

I attended an appointment at outpatients at Seacroft Hospital today, to see my consultant for an initial assessment by the Chronic Pain Service here in Leeds.

Despite feeling very vulnerable after filling in a huge questionnaire that really encouraged me to think about the pain I live with, and feeling sad that this is how my life is, I was pleasantly surprised by the excellent care I was given.

The Consultant (who introduced herself and stood up to shake my hand, immediately signalling respect) was very thorough in her questions and in her examination. She apologised for the inevitable pain caused by the examination, which in itself is sadly rare.

We had a great conversation to examine all the options and she referred both to the NICE guidelines for this, her specialism, and to other research that existed in support of my experiences. I appreciated feeling that she valued my experiences and treated me with enough respect to share her clinical reasoning with me.

We discussed both medication and non-medical interventions, and I was grateful that she acknowledged the limits of medication in mediating my pain, whilst still offering to adjust the balance of medications to get a better management of the pain in place.

At the end of the appointment, she dictated the letter back to the GP right there, with me sitting with her. She used the opportunity to double-check both my understanding of the next steps, and to check my agreement with the options we had decided on with regard to my treatment. By behaving in the way she did, demonstrating the ease at which she could run her clinic and take regard for the choices, fears, preferences and unique situations of her patients, I felt valued and validated in my experience of chronic pain.

**Anonymous**  
(Source: Patient Opinion)

## Staff Quotes

Listening to how patients feel about their care and treatment is one of my personal priorities. Knowing that patients feel safe and are being given the care and attention they need makes me feel that I am doing what I can each shift to help improve their stay on Ward 9. This might mean responding to concerns about noise at night or making sure patients and their relatives have all the information they need. As a staff team we regularly meet to talk about our patients' feedback and agree improvements where necessary such as providing patients with both the name and a photograph of their named nurse.

**Amy Bartholomew, Senior Staff Nurse, Ward 9, Moseley Hall Hospital,  
Birmingham Community Healthcare NHS Trust**

Patient Opinion has proved a fantastic tool for us to listen to our patients more effectively, to find out what is important to our patients and what they want to make the service the best it can possibly be. It has helped us identify what we are doing right, and more importantly where we could improve.

And more than just listening, it has helped us to focus on what we can change to improve our service. We've learnt that Patient Opinion gives patients a powerful voice, which in turn has empowered us, with the support of our managers, to change things for the better.

**Lisa Metcalf, Community Specialist Podiatrist,  
Nottinghamshire Healthcare NHS Trust**

My name is Constance, and I am a staff nurse on Ward Purley 3 at Croydon Healthcare.

It's really important for staff to feel they can go the extra mile to ensure patients have a good experience of care. The other day one of my patients was feeling anxious that her dignity would not be preserved during a planned procedure, I made sure she was adequately covered and reassured, and although we don't normally accompany patients to theatre I went with her so I could continue to offer support. The patient was really grateful.

**Constance Gaan, Staff Nurse, Ward Purley 3,  
Croydon Health Services NHS Trust**

## What is a good experience of care?

*I am involved as an active partner in my care – this means playing an active role, when I'd like to, in making decisions about my care, treatment and support, and being supported to look after myself day-to-day.*

The consultant introduced himself, got a good history, examined me, and was sympathetic to what for some people is a minor complaint but has a big impact on my quality of life when it's bad. He drew a diagram of what my options were including the anatomy that would be affected in different procedures, as well as a flowchart of what we could try in what order along with a % risk rate of recurrence. And then he went through it all again a second time to ensure that I really got it. With all that in mind (and after some reassurance that my self management was going well) we decided to take the most conservative approach and not have surgery at this time. I didn't feel like I was being pressured out of it though, far from it.

[\(Source: Patient Opinion\)](#)

My dad was asked about what he thought and felt about the best treatment for him, the consultant and specialist nurse gave lots of time to listen (and they really listened), everything was explained and my dad's understanding of what was being discussed was consistently checked out. Fundamentally my dad felt he was very involved in the decisions made and felt very reassured about what is going to happen next.

[\(Source: Patient Opinion\)](#)

*I am treated as an individual – my needs, values and preferences are respected.*

Having had a difficult experience with my first delivery in 2009 I was a little apprehensive about returning to Jessops. However the experience was excellent. Our midwifery team were excellent, incredibly supportive, genuinely caring/interested, respectful and keen to understand our preferences. I delivered in the birthing pool which was great.

[\(Source: Patient Opinion\)](#)

The people were polite, focused, professional but also treated me as a person, remembering I had a small child, making sure I had privacy to undress, and even a choice of biscuits! I read a book during the 40 minute operation I was so relaxed!

[\(Source: Patient Opinion\)](#)

*The people providing my care recognise that I am the expert on me – this means that my knowledge, skills and expertise as a result of living with my condition, as well as the effect that this has had on my life and on the lives of those who are important to me, are respected.*

Our mum first was admitted to the hospital in February this year where she spent six weeks in A32, the staff were very sympathetic and caring and made this stay as comfortable as possible. When the family needed to visit which included overnight stays it was accommodated without any fuss and made sure we had everything we needed.

[\(Source: Patient Opinion\)](#)

I would like to express my sincere thanks to the anaesthetists who all respected my wishes to keep my insulin pump on so that my diabetes control was not interfered with, the staff in the Breast Unit who are always professional and kind, and the staff on ward M2 who took such good care of me.

[\(Source: Patient Opinion\)](#)

*I am able to access services when I need them, and my care is coordinated so I know where to go next and where to turn if I have a problem.*

The GP also took the time to highlight the out of hours and emergency contacts and options at the end of the appointment, and for me, that really showed their dedication towards their patients around the clock, and not just the hours of work.

(Source: [NHS Choices](#))

The GP practice that I use is one which has I think maybe five partners and then other doctors as well. So there are quite a lot of people involved. [...] Now that I'm pretty much housebound, we try to arrange for the same doctor to come every now and again, just to sort of keep in touch with a home visit. And that system has worked reasonably well so far. We also have a district nurse come in once a week from the same practice. And that's been working very well. In fact it has to be said that the district nurses have been a tower of strength when it comes to fighting our corner with problems with the agency for example or with the local Social Services or whatever. They really have been very supportive.

(Source: [healthtalkonline](#))

*I am asked how I would like to be communicated with so that communication is tailored to me and is delivered with care and compassion, and I have the opportunity and time to ask questions and have a conversation about my care, treatment and support.*

The doctors, nurses and anaesthetists were all very professional and friendly, introducing themselves to me, explaining things clearly (including the risks and benefits of treatment) and answering my questions fully.

[\(Source: NHS Choices\)](#)

I've been in drug treatment for nearly 8 years since I was pregnant with my boy. I was very nervous of meeting new people and had panic attacks if I had to, but my worker spent a lot of time getting to know me. I learned to trust her because she never waffled she always told it like it was and made me sure I understood about my treatment and how I could help myself. [...] I know I can tell my keyworker anything. She won't ever be shocked or think badly of me. Sometimes I even text her in the night if I'm worried about something. It feels like I'm talking to her. I wouldn't change anything at all.

[\(Source: Patient Opinion\)](#)

*I have access to the information I need, which is presented in a way that is right for me, to make sure I understand what is happening and can play a role in making decisions if I'd like to.*

My mum has been coming to Kings for a long while since her diagnosis with diabetes 14 years ago and her diabetes care has always been really good. When she came to Kings, she was referred to some classes to help her understand about the condition and also how to manage it. These were really good and really helped her to understand how to manage her diet, information about different foods and blood sugar levels. This really increased my mum's confidence and has been really reassuring so that mostly her levels have been better controlled so that there have not been much urgent care needed.

[\(Source: Patient Opinion\)](#)

I am 8 years old. The nurse once drew me a picture to explain my body for me, which was good. It helped me to see what was going on and it made me feel better.

[\(Source: Patient Opinion\)](#)



*I have access to the support I need and is right for me, including emotional and practical support, and I am able to involve my loved ones in decisions about me.*

I was prescribed hearing aids by my GP. I was initially apprehensive about using them because of the stigma attached to wearing them and the worry of losing the small ends in my ear. After a phone call I got excellent support and reassurance from audiologist Jon Tandy at LGI. Without his support I think I would have left them unused in a drawer – a waste of health service resources and detrimental to my mental well being.

(Source: [Patient Opinion](#))

Initially I was referred to Ashley House by the police – who found me collapsed on the street. I would normally run a mile from support groups of all kinds, I have always done this. I have, what I consider to be, a complex lot of problems, and I had no escape or outlet for these. Attending the group has made me confront life, the friendship and camaraderie from some very generous people makes me feel as though oblivion is not the only way forward.

(Source: [Patient Opinion](#))

*The environment in which I receive my care is clean and comfortable and makes me feel dignified.*

I was on Oaks, but have no reason to think the other ward wasn't just as good. The building itself is clean, bright and airy and although everyone is fanatical about infection control, the whole place just smells clean & fresh without that typical 'hospital' smell.

[\(Source: Patient Opinion\)](#)

I had to call 999 for an ambulance at about 1am. It came within 20-30minutes. It's the first time I had called an ambulance (I'm 82) and was very impressed with the service. The two paramedics made sure I was comfortable and warm. I had to stay in hospital for a while. All the staff were kind and caring. My privacy was always their top priority. The cleanliness on the ward (4 bedded) was excellent. I was most impressed.

[\(Source: Patient Opinion\)](#)

# Our roles as national organisations in achieving our ambition

Our role as national organisations is to work with, support and influence other parts of the system that commission and provide care, including the voluntary sector. Here we set out how we currently see our roles in working with and supporting the system to achieve our ambition on experiences of care and our current projects. At the same time, we recognise that we all can and must do more, including being more aligned in our work to improve experiences. Our next steps can be found [here](#).

Our organisations are grouped by our main functions.

Category	Organisation	Role	Projects
System regulators	Care Quality Commission	The <a href="#">Care Quality Commission (CQC)</a> , as the independent regulator of all health and social care services in England, registers and inspects services to ensure they meet fundamental standards of care, including how caring and responsive organisations are to those in their care. CQC's work supports providers to understand areas for improvement.	<ul style="list-style-type: none"> <li>Roll out of a new approach to inspection and rating in NHS Trusts, GP practices and Adult Social Care providers – including a focus on experience through key questions about how caring and responsive services are.</li> </ul>

Category	Organisation	Role	Projects
System regulators	Monitor	<b>Monitor</b> , the sector regulator for health services in England, ensures that performance on experience forms part of the approval process for trusts wanting to become foundation trusts, and takes prompt action where poor performance is detected, including on experiences, through support to trusts, the use of special measures, and ultimately special administration (if required).	

Category	Organisation	Role	Projects
Professional regulators	General Medical Council	The <b>General Medical Council (GMC)</b> , as independent regulator of doctors in the UK, sets, promotes and assures standards for medical and educational practice, including those relating to experiences of care, and takes action against those that are failing to meet these standards.	<ul style="list-style-type: none"> <li>● Roll out of revalidation for every doctor practising in the UK – service user feedback is part of the model</li> <li>● Review of postgraduate medical curricula to include more generic professional capability training – often associated with poor patient experiences of care</li> <li>● Promotion of 'What to expect from your doctor', a guide for patients explaining the standards patients should expect from their doctor and what to do when they experience care which does not meet those standards</li> <li>● Publication of new resources to support doctors improve the care – and experience of care – received by elderly patients</li> <li>● Review – including a public consultation – of GMC's sanctions which it can impose on a doctor when their fitness to practise is in question. This review will attempt to ensure GMC's fitness to practise sanctions are aligned with public expectation of what they expect of their doctors.</li> </ul>
Professional regulators	Nursing and Midwifery Council	The <b>Nursing and Midwifery Council (NMC)</b> , the national regulator for nurses and midwives, sets educational and professional standards, including for experience, and takes action when these standards are not met.	<ul style="list-style-type: none"> <li>● Holding meetings of regular Patient and Public Engagement Forums across the UK</li> <li>● Consulting on revised professional standards</li> <li>● Introducing revalidation including reflection on service user feedback</li> <li>● Promoting materials for patients and the public explaining the role of the NMC and how to raise concerns about nursing or midwifery.</li> </ul>

Category	Organisation	Role	Projects
Consumer organisations	Parliamentary and Health Service Ombudsman	<b>The Parliamentary and Health Service Ombudsman</b> investigates complaints regarding government departments or other public organisations, working with the health and care system to learn from complaints.	
Consumer organisations	Healthwatch England	<b>Healthwatch England</b> , the consumer champion for health and social care, listens to people, especially the most vulnerable, to understand their experiences, influencing others to make changes to improve experiences and empowering people to get more from their experience of health and social care.	<ul style="list-style-type: none"> <li>Developing a tool to measure and report how far people's legal rights are being met and whether or not their actual experiences of health and social care provision live up to their expectations.</li> </ul>

Category	Organisation	Role	Projects
Leadership organisations	Department of Health	<b>The Department of Health</b> , as steward of the health system, is responsible for ensuring action is taken across the system to listen to and act on feedback from those using health and care services, and to drive improvements in experience.	
Leadership organisations	NHS England	<b>NHS England</b> improves the health outcomes of people in England through its support to commissioners and the commissioning of some services. It plays a leadership role in identifying key issues and effective solutions for improving experiences, ensuring a focus on reducing poor and very poor care, monitoring progress and promoting and supporting those who use services to play a prominent role in defining, measuring, assessing and improving quality, which includes experience.	<ul style="list-style-type: none"> <li>● Compassion in Practice programme (more information <a href="#">here</a>);</li> <li>● Leading on the development and roll-out of the Friends and Family Test for service users and staff (more information <a href="#">here</a>);</li> <li>● 7 Day Services (more information <a href="#">here</a>);</li> <li>● Always Events – NHS England is developing a partnership with Picker Institute Europe and the Institute for Health Improvement to run a collaborative programme utilising the Always Events approach (more information <a href="#">here</a>) in the NHS in England;</li> <li>● PLACE (more information <a href="#">here</a>);</li> <li>● NHS England has supported Clinical Commissioning Groups to set local ambitions to improve experiences of care over the next five years, which collectively represent a step change in determination to improve the quality of care (more information <a href="#">here</a>);</li> <li>● Adopting the ‘House of Care’ model – a framework to enhance the quality of life for people with long term conditions (more information <a href="#">here</a>);</li> <li>● Producing <i>NHS England’s Commitment to Carers</i>, including next steps (more information <a href="#">here</a>).</li> </ul>

Category	Organisation	Role	Projects
Leadership organisations	NHS Trust Development Authority	The <a href="#">NHS Trust Development Authority (NHS TDA)</a> oversees all NHS trusts. Its role is to ensure that trusts deliver high quality, sustainable services thereby helping trusts to achieve NHS foundation trust status or another more appropriate organisational form. Ensuring that NHS trusts provide the highest quality services is central to the work of the NHS TDA, and it has an important role in supporting the development of NHS trusts in this area.	<p>The NHS TDA has developed two tools with NHS Trusts:</p> <ul style="list-style-type: none"> <li>● The NHS TDA Patient Experience Headlines Tool utilises all nationally reported Patient Experience measures to enable trusts to track their progress and compare themselves with their peers.</li> <li>● The NHS TDA Patient Experience Development Framework is a self-assessment tool which enables trusts to fully explore factors improving patient experience and supports trusts to improve.</li> </ul>



Category	Organisation	Role	Projects
Leadership organisations	Health Education England	<b>Health Education England (HEE)</b> , is responsible for ensuring the healthcare workforce has the right numbers, skills, values and behaviours to deliver excellent healthcare, which includes experience.	<ul style="list-style-type: none"> <li>● Pre-degree nursing pilot: this allows potential nurses to get a years' worth of work experience before starting a degree (more information <a href="#">here</a>);</li> <li>● Values-based recruitment: HEE is working to ensure that selection into all new NHS funded training posts incorporates testing of values by March 2015 (more information <a href="#">here</a>);</li> <li>● Development of a Care Certificate for healthcare assistants and social care support workers (more information <a href="#">here</a>).</li> <li>● Health Education England (HEE) has established a new Patient Advisory Forum (PAF) as a means by which HEE is able to make decisions in an open and transparent way and to ensure that decision making is influenced by patients and the public and to provide assurance to the Health Education England Board that the patient and public voice are at the heart of the education, training and workforce planning process (more information <a href="#">here</a>).</li> </ul>
Leadership organisations	Public Health England	<b>Public Health England's</b> role is to protect the nation's health and address health inequalities, supporting the improvement of experiences by proactively providing central and local government, the NHS, public health professionals and the public with evidence-based advice.	

Category	Organisation	Role	Projects
Support, evidence and improvement organisations	National Institute for Health and Care Excellence	The <a href="#">National Institute for Health and Care Excellence (NICE)</a> provides national guidance, standards and advice to the system to improve health and social care, including updating and publishing <a href="#">guidance</a> and <a href="#">quality standards</a> for experience, namely for adult NHS and mental health services.	<ul style="list-style-type: none"> <li>NICE is looking at how to expand its work to provide additional guidance and standards on people's experience of social care services and carers' experiences.</li> </ul>
Support, evidence and improvement organisations	Social Care Institute for Excellence	The <a href="#">Social Care Institute for Excellence (SCIE)</a> collects and synthesises up-to-date knowledge about what works in social care – including on personalisation, integration and dignity of care – making it available and accessible to those working in and using social care services.	<ul style="list-style-type: none"> <li>SCIE has an active co-production network and has produced a range of guides, resources and research briefings on co-production and participation in social care (more information <a href="#">here</a>).</li> </ul>

Category	Organisation	Role	Projects
Support, evidence and improvement organisations	Health and Social Care Information Centre	<b><u>The Health and Social Care Information Centre</u></b> , the national provider of information, data and IT systems for health and social care, collects, analyses and disseminates data on experiences that can be used by organisations and individuals to drive improvements in care and to empower people to demand more from their experiences.	
Support, evidence and improvement organisations	NHS Improving Quality	<b><u>NHS Improving Quality (NHS IQ)</u></b> works to improve health outcomes across England through the provision of improvement and change expertise, including on experiences.	<ul style="list-style-type: none"> <li>● NHS IQ is supporting some of NHS England's key projects, such as 7 Day Services.</li> <li>● The Experience of Care team is working on three priority areas: <ol style="list-style-type: none"> <li>1. Partnership for improvement (to empower and support individuals and communities to get involved in their health economy to co-produce quality improvement and new ways of working to meet local needs);</li> <li>2. Promoting excellence (to co-ordinate a national hub of good practice in engagement, experience and insight to stimulate, learn, share and spread opportunities for quality improvement);</li> <li>3. System improvement (to promote, enable and support the necessary conditions and infrastructure for commissioners and providers to use experience of care as a key driver for quality improvement).</li> </ol> </li> </ul>

