



*Institute for Innovation  
and Improvement*

the  
**ebd**  
approach™

experience based design

Using patient and staff experience  
to design better healthcare services

Helen Baxter  
Dr Mark Mugglestone  
Dr Lynne Maher

Concepts and  
Case Studies



## Executive summary

---

The experiences that patients, the public and healthcare staff have when they receive or deliver healthcare services are a valuable source of information that can be used to improve or transform those services.

Capturing experiences in the form of narrative (or stories) and then understanding and making improvements is the basis of **the ebd approach**.

---

**Narrative:** someone telling their experience in their own words

---

The tools and techniques that are at the heart of **the ebd approach** support the feedback of both positive and negative aspects of healthcare services. Already high performing services have used **the ebd approach** and discovered considerable opportunities for improvement. For example in one department, using **the ebd approach** led to over forty significant changes resulting in improvements to quality, cost, patient dignity and safety.

Innovation with and by users (this includes frontline workers as well as patients and the public) of products and services holds the key to better products and services and so better outcomes.

**The Human Factor, NESTA, 2009**

This book introduces the concepts that make up experience based design (ebd) and explains **the ebd approach**. It will inspire you to consider how, by learning more about patient, carer and staff experiences, you can improve services in your workplace and your own personal practice.

It demonstrates that, by taking a few simple steps, you can start to better understand, and therefore improve, the experience of care. You can then build upon this and move towards developing full partnerships with patients, carers and staff to re-design services together.

## Introduction

---

### **Imagine...** a future when staff and patients regularly comment on how good their experience of your health services is

Some people have started to create that future already.

This book provides inspirational examples of patients, staff and carers working together to gain a better understanding of how they experience healthcare services, to improve services for all involved.

It highlights some of the key factors that affect patients' experiences of healthcare services. And it reveals the impact that these factors have both on the patients who receive care and the staff who provide it.

Throughout the book you will discover a range of different approaches that have been used to **gather, understand and use** experiences to **improve** health services.

This book is intended to be thought-provoking. It will introduce you to the concepts of experience based design (ebd) and explain **the ebd approach**. It will inspire you to consider how, by learning more about patient, carer and staff experiences, you could improve services in your workplace and in your own personal practice.

It demonstrates that, by taking a few simple steps, you can start to better understand, and therefore improve, experience of care. You can then build upon this and move towards developing full partnerships with patients, carers and staff to re-design services together.

For more details about **the ebd approach** and how you can get started see:

- **the ebd approach** – introductory booklet and DVD
- **the ebd approach** – guide and tools
- Web-based information ([www.institute.nhs.uk/ebd](http://www.institute.nhs.uk/ebd)).

The first section of this book covers some of the theory behind using the experiences of patients and staff to design services, **key concepts** used in the approach and illustrations of how the different elements fit together.

This section is followed by a collection of **case studies**. These provide practical, real-life examples of how others have used this approach in their own local organisations to create a different experience for patients and staff.

*“Improving the patient experience is critical. It doesn’t matter how many targets we meet if we can’t get this aspect of care right.”*

**Joanne Bolger, Senior Facilitator,  
Bolton Improving Care System (BICS)**

# YOUR EXPERIENCE MATTERS:

# CO-DESIGN IN FULL SWING

**"A GREAT START IN DESIGNING SERVICES TOGETHER..."**

Co-design is now in full swing for the Head and Neck service at Luton & Dunstable Hospital. It is a new experience-based design programme that allows both staff and patients a direct way to modify and design a better, safer and more enjoyable environment for work and recovery. Since the start of the trial run, six co-design teams have been set up, and are already making improvements all around the hospital. *Continues on p. 4*

"Previously, staff at the Luton & Dunstable H&G Trust have involved different groups of patients in service improvement and listened to and captured what they say. Patients have attended stakeholder events, participated in discovery interviews, completed surveys and mapped health care processes with health care staff. Staff have also visited community groups and spoken to patients and their carers about services and asked them what would constitute ideal care, from their perspective."

ARTICLE ON PAGE 2

## WEBSITE LAUNCHED

[www.yourvoice.lincs.nhs.uk](http://www.yourvoice.lincs.nhs.uk)  
Our new patient log is now online at the address above. Much of the information in this newspaper is submitted by you. We'll get you a look and get more information about how to use it.

01535 555555

... describe my PEG as part of the concern by all the staff at the L. & shown to me both pre-op and operation right to the day that it was

... a good experience when I could and have piece of mind in getting assistance immediately following my operation and in the later stages of chemotherapy. At both times oral intake would've been near impossible"...

ARTICLE ON PAGE 11

# Concepts

6-41

This section explains some of the theory and rationale of using the experiences of patients and staff to design and improve services. It includes key concepts of the approach and illustrates how the different elements fit together.

# Case studies

42-85

This case study section provides practical, real-life examples of how people have used **the ebd approach** in their own local organisations to create a different experience and improved services for patients and staff.

EXPERIENCE  
MATTERS:

# CO-DESIGN IN FULL SWING

**"A GREAT START IN DESIGNING  
SERVICES TOGETHER..."**

Co-design is now in full swing for the Head and Neck service at Luton & Dunstable Hospital. It is a new experience-based design programme that allows both staff and patients a direct way to modify and design a better, safer and more enjoyable environment for work and recovery. Since the start up, and are already making improvements all around the hospital.

"Professionals staff at the Luton & Dunstable Hospital have provided efficient services for patients in service improvement and feedback to our staff and what they say. Patients have shared their views, participated in co-design sessions, completed surveys and helped shape the service. Our staff and patients are working together to improve the service and we are looking forward to the next steps in co-designing our services and shared them with you. Thank you for your support and feedback."

## WEBSITE LAUNCHED

[www.lutonanddunstablehospitals.nhs.uk](http://www.lutonanddunstablehospitals.nhs.uk)  
Our new website has been launched. It is a new website for the hospital. It is a new website for the hospital. It is a new website for the hospital.

ARTICLE ON PAGE 1

"I would describe my PEG as part of the care and concern by all the staff at the L & D Hospital shown to me both pre-op and after my operation right to the day that it was removed."

"It was a good experience when I could rely on and have peace of mind in getting sustenance immediately following my operation and in the later stages of radiotherapy. At both times oral intake would have been near impossible."

ARTICLE ON PAGE 11

...NET  
...at the  
...content of  
...online. So  
...for more  
...ed. for the  
...the site email  
...atters.net

YOUR  
EXPERIENCE  
MATTERS:  
CO-DESIGN  
IN FULL  
SWING  
"A GREAT START  
SERVICES TOGETHER..."

YOUR  
EXPERIENCE  
MATTERS:  
CO-DESIGN  
IN FULL  
SWING



# Contents

---

The growing importance of patient experience	10
The performance paradox	12
Healthcare as a service	14
Healthcare as a service – a practical example	18
Patient experience	20
Understanding experience – using narrative	23
Emotions are key elements of the stories	26
Touchpoints – a different meaning to patient pathways	27
Co-design: involving patients, carers and staff in service design	29
Going beyond co-design	34
Measuring experience and showing improvements	35
Satisfaction is different from experience	36
Summing up	38
References	40
Case studies	42

# The growing importance of patient experience

---

Gathering views from users of healthcare services and involving them in activities such as forums, consultation exercises and focus groups is commonplace in the NHS. Compliments, complaints and satisfaction surveys are other mechanisms that organisations also use to drive continuous improvement. But the challenge we face is to go beyond consultation, compliments and complaints, to understand the complete patient experience and use this as the basis to re-design services.

Health policy and direction clearly state that there are three core focus areas to providing high quality care for all. These are<sup>i</sup>:

**Patient safety** – the environment and processes are in place to ensure that no harm comes to patients.

**Patient experience** – understanding patients' satisfaction with their experience of care; the compassion, dignity and respect with which they are treated.

**Effectiveness of care** – understanding how successful the service is in delivering the expected results, through a variety of measures; clinical and patient reported.

Policy documents, research and other emerging evidence all support the notion that involving service users in helping to improve the services that they use makes sense for everyone:

- 'Patient involvement increases patient satisfaction. Benefits include greater confidence, reduction in anxiety, greater understanding of personal needs, improved trust and better relationships with professionals and positive health effects<sup>ii</sup>'
- 'In order to achieve reforms that support patient choice and practice-based commissioning, it is essential that systems are put in place to ensure that views and preferences of patients and the public are listened to and incorporated into the planning, design and delivery of current and future services<sup>iii</sup>'
- 'The biggest untapped resources in the health system are not doctors but users. We need systems that allow people and patients to be recognised as producers and participants, not just receivers of systems<sup>iv</sup>.'

Even greater benefits can be achieved by using approaches that help communities to work as equal partners, or that use approaches which delegate some or all control to these communities. People have reported an increase in their sense of belonging to a community (social capital), a feeling of empowerment and enhanced sense of wellbeing. This is because these approaches:

- Use local people's experiential knowledge to design or improve services, resulting in more appropriate, effective, cost-effective and sustainable services
- Empower people, for example, by giving them the chance to co-produce services. Participation can increase confidence, self-esteem and self-efficacy (that is, a person's belief in their own ability to succeed). It can also give them an increased sense of control over decisions affecting their lives'.



See **page 29** for more information on **co-design and involving patients, carers and staff in service design**

*“When this work commenced, I was concerned that there would be a lot of investment of time and resource for no real benefit. However, this piece of work has been fundamental in allowing us to improve how we listen to and work alongside patients to improve their experience. The patient experience is what it is all about.”*

**Dr Simon Stacey, Consultant Physician and Orthogeriatrician, Royal Bolton Hospital NHS Foundation Trust**

## The performance paradox

---

There has been an enormous investment over the last ten years in many areas of public services, with consequent increases in quality and quality measures. However, when the public are asked how they feel about the NHS, their more general sense of what they are getting is almost always far more negative than the operational measures would predict<sup>vi</sup>. The paradox is that although, when measured using an objective yardstick, they are getting better services, their overall experience is not improving.

‘Describing people as a percentage would dehumanise the physical impact on a real person, someone’s mother, father, sister or brother<sup>vii</sup>.’

Within the data are some interesting relationships that highlight the importance of the less-often-measured aspects of a service<sup>viii</sup>. These are factors not typically associated with a strictly clinical view of a service, but on which people (patients, partners and carers) place a high value.

‘What matters more than raw data is our ability to place these facts in context and deliver them with emotional impact<sup>ix</sup>.’

From its experience of talking to large numbers of patients in interviews, focus groups and surveys, the Picker Institute<sup>x</sup> has identified eight aspects of care that patients consider most important:

- Fast access to reliable health advice
- Effective treatment delivered by trusted professionals
- Involvement in decisions and respect for preferences
- Clear, comprehensible information and support for self-care
- Attention to physical and environmental needs
- Emotional support, empathy and respect
- Involvement of, and support for, family and carers
- Continuity of care and smooth transitions.

---

As you read through the list you will notice that most of these are experiential. They are less about *what* is offered, but *how* it is offered. They relate to trust and respect – the person, not simply the patient.

The NHS will continue to offer world class medical/clinical care. But the challenge for a modern, service-orientated NHS is to build on that foundation and to offer a healthcare experience that is equal to, if not better than, other services available to people in normal, day-to-day life.



---

See **page 36** for more information on ***the difference between satisfaction and experience***

---

*“For most of the NHS this is fairly new and radical. Like many clinicians, I think like a scientist. So my first instinct about how to get people’s views was through research and formal studies. Using experience based co-design has opened up a whole new approach to problem solving and shown me the value of gathering data through non-traditional methods.”*

**Dr Jacques Mizan, London GP and healthcare design researcher with his company The Space Works**

## Healthcare as a service

---

A service is an interaction with a person or organisation from which you expect to gain value. Clearly the National Health Service (NHS), as the very name suggests, is such a service; however, the value to consumers has largely been defined clinically – surgical outcomes, response to drugs, etc.

The traditional model of healthcare delivery has been based on a paternalistic or expert model: patients see a professional and the judgement or advice offered by that person was accepted without question. This model has gradually been changing alongside the public's expectations of healthcare as a 'service'. People are now more likely to gather information before seeing a healthcare professional and be keen to have a discussion about what that means for them. People are also more aware of what constitutes good service, which in turn has influenced expectations about healthcare service delivery.

What would have been an acceptable level of service in a supermarket, a bank or an outpatient department ten years ago is no longer acceptable, as users' (customers' or patients') expectations have changed. To coincide with this shift in attitude, the commercial world has expanded the traditional discipline of product design to include a newer discipline of service design.

In recent years there has been a clear recognition of the importance of 'service': the Office for National Statistics (ONS) estimates that 75% of the UK's gross domestic product (GDP) now arises from the service sector<sup>xii</sup>. Increasingly, within the commercial sector, companies distinguish themselves in the marketplace through the provision of exceptional service as well as products. For example, Apple combined a tremendous product – the iPod – with an allied service, iTunes. The combination of product and service created greater impact and the result was a huge commercial success for the company.

Surprising as it may seem, Harley Davidson doesn't focus on selling motorbikes, it focuses on the experience of owning a Harley. In the 1980s the company nearly went out of business and knew it wasn't in a position to compete with the Japanese motorcycle industry, so it rebuilt the business by selling an experience – an evocation of American motoring heritage and industry.

---

Many healthcare organisations have seized on the opportunity to diversify their service provision by allocating space in foyers for shops, food outlets and banking facilities. This shows that thinking is moving towards improving the experience for people, including patients, their families and staff who are using the building and services. To achieve an even greater impact there needs to be a further shift in thinking to consider the experience of our healthcare processes and services for all.

Experience can be seen as the icing on the cake. Tom Peters<sup>xiii</sup> talks about raw materials, which are turned into goods, which we deliver through a service and the experience of the goods and service is what individuals pass on to others. When recommending a service or product to our friends it is the actual user experience that we describe rather than any factual data about that service or product.



See **page 20** for more information on **what is experience and what isn't**

---

*“We wanted to change things for the better but we had no idea what the solution looked like. With experience based design, you don't have an end product in mind. You just start out with a completely blank sheet and use the experience of staff and patients to guide you.”*

**Dr Janet Hegarty, Consultant in Kidney Medicine,  
Wigan Renal Unit**

## Healthcare as a service

---

**the ebd approach** has been developed based on the work that the NHS Institute has done with service designers to focus on improving patient, carer and staff experience of health services. A critical aspect of this is to ensure that we really understand the challenges from the perspective of those who use the service and that we listen to and test a range of options rather than jumping to an early solution based on our professional perspective of what is needed. User-centred design has a continual focus on the user of a product or service. In user-centred design, assumptions are not made about users' requirements, but users are engaged at the start of the design process so that they can describe their requirements. Service designers are experts in exploring users' experiences to discover insights or themes, from which areas for opportunity are identified.

The result of this is that solutions developed meet users' real needs rather than being based on what the 'designer' thinks they need<sup>xiii</sup>.

We are now entering a phase where service design approaches have been translated and are being used to great effect by healthcare staff.



See **page 29** for more information on **co-design and involving patients, carers and staff in service design**

---

Bevan et al<sup>xiv</sup> have identified that having an understanding of design and design science may be useful to healthcare improvement work. To sum up, there is considerable benefit from involving patients, as well as healthcare practitioners, in the design process. **the ebd approach** is a development of the principles of user-centred design<sup>xv</sup>, a process which involves not simply asking patients or service users about their requirements, but understanding experiences and taking a step further by involving both staff and patients in co-designing solutions.

The National Audit Office<sup>xvi</sup> promote the role of customer insight in particular in healthcare situations. They suggest that to be successful, innovative projects could only be delivered by involving service users and citizens.

This book is not designed to cover the entire design process<sup>xvii</sup>; however, it focuses on the benefits that can be achieved by using approaches that help you to better understand how to design and re-design health services so that they really meet the needs of those using or delivering them.



Using a design approach to improve healthcare allows us to draw on evidence and experience from three specific domains:

- The **theory** and wider thinking about how design and design science can be transferred into healthcare processes, ensuring that we build in the human dimension
- The **evidence** that demonstrates how innovation and creativity can be best utilised within organisations
- The **processes** that commercial organisations use for the development of new products and services.

Berkun<sup>xviii</sup> describes three elements of good design. If you consider successful products and services, you will note that they all score highly on each of these elements:

**Performance** – how well it does the job.

**Engineering** – how safe, well engineered and reliable it is.

**The aesthetics of experience** – how the interaction with the product or service feels.

Healthcare organisations have demonstrated that they can improve the performance and reliability of services. This has resulted in tangible differences in how patients access care and how safe that care is. But these same organisations have not always placed equal focus on the aesthetics of experience – how it feels to use or be part of the service. We now have the opportunity to build on previous improvement successes by focusing more attention on this third component – **the experience of care**.

*“Healthcare may sound a far cry from product design and architecture, but one thing that unites them is their shared goal of making something better for the user and doing this by making the user central to the design process itself.”*

**Glenn Robert, Senior Research Fellow,  
King’s College, London**

*Good service design consists of...*



(Bate & Robert, 2007, adapted from Berkun)

# Healthcare as a service – a practical example

This illustration shows how use of the function-engineering-aesthetic framework focused attention on the experiential aspects of re-design work in Luton and Dunstable's Head and Neck Cancer service.

In the left hand column are the design principles used in the project. The middle column then translates those into meaningful statements within healthcare (specifically the NHS) and the final column gives examples of what was actually done in the project.

## *Design principle*

## *What it means in the NHS*

### **Functionality**

How well does it do its job?

### **Performance**

Efficiency  
Reduced waits  
Quality  
Value for money

### **Engineering**

How safe, well engineered and reliable is it?

### **Safety & governance**

Staff training and skills  
Protocols  
Clinical decision making

### **Aesthetics**

How does the whole interaction with the product or service feel for the user?

### **A better experience**

Patient-led NHS  
Patient choice  
Empowerment  
Information

---

*Examples of using the **ebd approach** service change in Luton and Dunstable's Head and Neck Cancer service*

- 1 **Outpatient appointments** rescheduled and spaced out, meaning patients are seen quicker and staff have more time to spend with them.
- 2 **Long-term follow-up appointments** shifted to a separate general clinic, making more time for staff to focus on patients with more immediate needs.

- 1 **Review of training needs** on post-surgical ward and new tracheostomy learning pack.
- 2 **Role of new healthcare assistant** being extended to include stoma care so that there are more staff with the right skills to respond to tracheostomy patients on a routine and emergency basis.

- 1 **Planned new location** for post-surgical ward, to include more rationalised storage for equipment and new day area for patients and carers to sit, with easier access to kit for staff.
- 2 **New mirror with light** purchased for ward, making it easier for patients to look after and clean stoma and feeding tubes.
- 3 **Dedicated quiet time** on ward after lunch, providing a better environment for sleep and rest.
- 4 **Patients and staff reorganised** outpatient clinic, creating a pleasant, less stressful environment.
- 5 **New patient information packs** and improved information for those with feeding tubes, written by patients themselves, ensuring patients have the information and reassurance they need, when they need it.
- 6 **New DVD virtual tour** of radiotherapy centre, which allows a more convenient and effective way for patients and carers to prepare for radiotherapy treatment.

## Patient experience

---

In the commercial world, the definition of service focuses on giving customers a good 'experience'. However, 'experience' can be quite difficult to define: words such as understanding, encounter, event and feeling are synonymous with experience. If you ask someone what it is that makes something a good experience, people often say:

*"I felt they understood what it was that I wanted"*

*"They took care of me as an individual"*

*"She did all she could to help"*

*"I felt that I mattered to them"*

Whenever we interact with systems, processes, environments or other people, we have an 'experience'. This experience is coloured by our own previous experiences, as well as our personal background, our mood on that day, our expectations, and many other factors. Therefore, experience is not just about the actual delivery of the product or service, it is about the reality for the patient and their carers, which may well include anxiety and fear – it is the psychological impact of a service.

So, it is useful to think of the patient experience as an individual's reaction to, and interpretation or perception of, any interaction with healthcare services.

### Understanding our expectations

By their very nature, experiences are heavily influenced by a multitude of complex factors. These reflect the way that we as human beings make sense of, and react to, the world around us.

For example, most of us experience a weekly shopping trip to the supermarket. Before we set off, we have in our minds a number of beliefs or expectations about the trip – where we'll park, a shopping list of the goods we expect to find in this shop – and we may even have worked out which items are best bought in this or in a competitor's shop.


These expectations arise, in part, from past experiences and, in part, from brand messages we pick up from advertising or from other people. Commercial organisations talk of a 'virtuous circle' where the brand sets up expectations (or makes us a promise), which the experience then has to satisfy. If this is satisfactory, it reinforces our perception of the brand and sets up yet more expectations.

Of course this is a simplification; our expectations are the result of interactions with a wide range of influences, internal and external. In the supermarket example, any number of factors might influence the experience, such as: *“I was up all night with my child being sick so I am exhausted”* or *“There was a traffic jam getting to the supermarket, where there is building work so there were no parking spaces.”*

We bring our expectations with us when we interact with or consume any service. Understanding this, and exploring the expectations people have, can help us to

match what the NHS offers with what people actually want/expect from us. It may help to explain some of the ‘performance paradox’ we described earlier. As well as our expectations, we also have certain values which impact on our experience; for example, some people prefer to be called by their title and surname whereas others prefer to be called by their first name. Unless we understand an individual’s values, we cannot provide a personalised care experience.

See also NHS Institute for Innovation and Improvement: Living our local values  
[www.institute.nhs.uk/livingourlocalvalues](http://www.institute.nhs.uk/livingourlocalvalues)

 See **page 23** for more information on **understanding experience using a narrative-based approach**



## Patient experience

---

Taking the 'virtuous circle' as a concept applied to health services, we need to consider what the NHS brand is; i.e. what do we promise? By understanding what we promise, we can start to understand users' expectations and how both will influence the experience of healthcare.

For example, the NHS promises you can access health screening at a time that is convenient for you. So, one evening you call the number to arrange the screening to fit in with your work commitments. There is a voice mail message saying that the telephone will be answered during office hours (8.30am-5pm) Monday to Friday. Immediately, your expectations about accessing the service at a time that is convenient to you are reduced.

This is a small example relating to a specific part of a pathway. Nevertheless, it will have a major impact on the user's experience. These types of experiences are being replicated throughout the NHS, and influence the public's expectations in relation to the NHS brand (and its promise).

*"Minor administrative errors, such as patients receiving a letter with the wrong consultant's name on it, were shown to have a detrimental impact on patients. One patient thought she had something else wrong with her because the admin department had mistakenly put a different consultant's name on the letter."*

**Juliet Pearce, EBD Project Lead,  
Southampton University Hospitals NHS Trust**

## Understanding experience – using narrative

If experience is an individual's perception of any interaction with healthcare, then an excellent way to understand this is by asking them simply to describe their experience. Such qualitative, narrative-based approaches are widely used in the commercial sector and the approach<sup>xix</sup> has been successfully employed in healthcare using discovery interviews (see page 26). Narratives have proven to be a very effective method of personalising an improvement effort and provide a compelling way to engage other clinical staff.

When using patient stories or narratives, it is important to remember that the story is what happened to the individual and it is their 'truth'. We have found that when staff listen to patients telling their story, there is a tendency to 'correct' some things that they say. Staff relate the patient story to their own experience of what typically happens during the care process, but if we are concentrating on patient experience, it is the patient's 'truth' that counts. At the same time it is imperative to really listen to the staff stories and not impose our experience or expectations of what we think should have happened.



See **page 26** for more information on **emotions as the key element to patient stories**

Stories are personal; they relate incidents that the tellers have judged to be remarkable. This provides us with rich information about their expectations and their values. Stories are told from a personal perspective – this is what happened to them – and so complement the organisation's view. Stories reveal the user's understanding of the service, how they make sense of it and, right or wrong, this is their 'truth' and it is important to acknowledge it.

The stories tell us of someone's journey through healthcare and allow us to gather insights behind the experience: what went well and what didn't go so well.

*“Working with patient feedback and patient stories on the development of care pathways has radically transformed our approach. I use individual stories that have emerged from this work regularly to talk to staff about how we can truly focus on the real patient experience of the service we provide.”*

**Simon Pleydell, CEO,  
South Tees Hospitals NHS Foundation Trust**

## Understanding experience – using narrative

---

Narratives are incredibly useful in helping to understand patients' experience of care. Another valuable technique is observing users and providers of the service within their environments. Observation is a powerful tool, used as part of all design methodologies to ensure that any solutions developed are grounded in the reality of what actually happens.

Making the effort to observe is the best way to create a deep understanding of needs. The collected insights often provide inspiration for new ideas, which can, in turn, help to re-define the problem. Observing small numbers of people allows you to go to the necessary depth at which the real issues, challenges and behaviours will start to emerge.

Observation can help to identify things that we do not notice during our routine day. It can also prompt patients (or staff) to think about specific details that they may not automatically recall in their story. For example, patients attending a clinic were weighed in view of other patients who were sitting in the waiting room. While none of the patients mentioned this within their stories, an observer noticed that patients did look embarrassed. When we talked to patients later they said that they felt conspicuous and undignified.



---

The principles of observation are already incorporated into a number of NHS Institute products, and a simple tool has been created for use in workshops that demonstrates the power of observation. This tool helps NHS staff to realise that taking a step back and looking at their service with fresh eyes can be an incredibly effective way of understanding how they can improve the care that they deliver.

*“The things people say and what they actually do are often not the same thing. Observation is useful for getting beyond what people say to understand what people do and feel.”*

**IDEO design agency**



See [www.institute.nhs.uk/observation](http://www.institute.nhs.uk/observation) for more information on **observation**

---

## Emotions are key elements of the stories

---

Patient stories are often full of emotion and it is this that makes them so powerful. Understanding a patient's emotional journey is one of the key elements in understanding experience. Healthcare, by its nature, generates strong emotions, as patients are learning things that can significantly alter their life. Understanding and designing services that take into account patients' emotions is the way that patient experience can be improved.

### Discovery interviews

Discovery interviews are one way to collect stories which improve the insight into patients' needs. They are a valuable way of helping staff to understand better patient experiences. Patients', partners' or carers' narratives are shared with clinical teams and other stakeholders who identify issues from them and use them to decide on what improvements need to be made.

Discovery interviews provide new understanding and insights about experiences of health services. These can be built on by involving patients and carers in the subsequent stages of selecting and implementing service improvements.

*"When patients were telling their stories about the outpatient clinic, they described their bewilderment at the bombardment of information from different professionals and the confusion caused by an overcrowded waiting room. Changing this has meant completely rethinking how we pace appointments at the clinic, spacing them out more evenly over the morning and early afternoon, and shifting more routine cases to a separate clinic. And the key thing was, there were things we could do immediately."*

**John Pickles, Consultant Otolaryngologist,  
Luton and Dunstable Hospital  
NHS Foundation Trust**

## Touchpoints – a different meaning to patient pathways

When you listen to patients' stories, they are usually structured along a timeline. This represents the patients' journey, which we have found is often quite different to the clinical pathway map developed by healthcare staff. It typically spans a longer period than the components within a clinical care pathway, with the patients' version starting from before and finishing after our traditional pathway. It consists of process points that we traditionally consider on a process map. In addition to this patients often describe points in the process that relate to their specific experience that is not part of our traditional process map.

What is also different here is the introduction of emotion portrayed through words or physical signs. Emotion words or signs are often clustered around particular points in the process, which are referred to as 'touchpoints' – points in the care pathway that are very significant to the patient – and you can map them along the pathway.

The total patient experience is the result of each and every element in the journey.

For example, this patient story is about an outpatient clinic; it describes multiple touchpoints that we have highlighted:

*"I got **the letter** and felt anxious as **the appointment** was at 9am and I wasn't sure I could get a **bus** in time. When I got to **the hospital**, I went to the **main desk** to ask where to go as I couldn't see any **signs** and **the person on the desk** was very helpful even though the **instructions** that they gave me were a bit complicated. I arrived at **the clinic** and there were so **many people** there, everyone was really crammed in [**the space**] and I felt very uncomfortable and nervous."*

Each of these touchpoints needs to be considered when re-designing this service. Even if the touchpoint is not part of your system or responsibility, it still influences the person's experience of your service and there may be things within your control that can be done to improve that experience.



See **page 20** for more information on **patient experience**

## Touchpoints – a different meaning to patient pathways

---

It is touchpoints that provide us with the potential areas for improvement or innovation and they can be physical or non-physical. Potential areas can include<sup>xx</sup>:

- Physical environment
- Staff
- Service delivery processes
- Other service users
- Support services.

*“For parents of children having intensive care at DeVos Children’s Hospital in Grand Rapids, Michigan, a particularly strong touchpoint was coming to see their child and seeing a frightening mass of tubes, wires and equipment. Parents, family members and clinicians have worked together to design an induction process for new parents coming to the neonatal intensive care unit for the first time.”*

**DeVos Children’s Hospital, Michigan, USA**

## Co-design: involving patients, carers and staff in service design

---

Capturing and understanding experience are essential early steps when trying to understand patients' and staff experience of healthcare services. The next important point is to take action to improve these services based on your new understanding.

Once experiences have been captured, they can be used in a variety of ways. You will find that when the patient stories are fed back to staff, those staff are incredibly motivated to change things. Capturing qualitative narrative really helps to drive improvement. Listening to the patients and staff talking about delivering and receiving services will always identify many areas for improvement.

**the ebd approach** promotes a relational mindset rather than transactional, which builds conversations and relationships and leads to increased levels of compassion and improved teamwork which, in turn, has a positive impact on healing and recovery<sup>xxi</sup>.

Capturing experience is a good starting point, but there will be far bigger gains by actually involving the patients who have shared their experiences in re-designing care. Using this approach, rather than simply acting on patients' stories, patients and staff work together as equal partners to improve the service. This might also be called 'participative design'; increasingly it is called 'co-design'.

Co-design leads to creative and collaborative projects that develop and grow over time. The process moves rapidly from **insights** to **ideas** to **actions**. In many cases these steps happen rapidly because the solutions become obvious and simple to implement. Often, all that is needed is a realisation that everybody shares the same view.

## Co-design: involving patients, carers and staff in service design

---

Occasionally, however, things need more thought. Views seem to conflict and new ideas are needed. Negotiating those ideas through to solutions feels more difficult. In these situations, success is more likely when teams can continue to include and draw on the expertise, intuition and experiences of those who live with the issues and will work with the change.

Good solutions won't just come from better listening; they'll come through better discussion and deliberation. By working together to create solutions, ideas can be articulated without judgement followed by a shared responsibility to explore and learn.

The key to co-designing is creating the facility to share insight, information and ideas irrespective of age or status. Simple visual techniques help – making visual the experiences of patients, carers and members of staff will help to generate insight as well as helping teams to spot practical problems and opportunities, remove redundant steps and get more from existing resources.

Developing what are often called *personas* (quick sketches of real or typical patients) can help to trigger creative questions; for example, "What would be the ideal experience be for this patient?" and "What's stopping us from providing this now?"

Further tools and resources are available from:  
[www.institute.nhs.uk/ebd](http://www.institute.nhs.uk/ebd)  
[www.institute.nhs.uk/thinkingdifferently](http://www.institute.nhs.uk/thinkingdifferently)

*"Creating a level playing field between staff and patients is something new to me. So often we think we know what staff and patients will say. But with this approach you don't make assumptions. Staff are equals in the process and it's just as essential to hear their stories and emotions first-hand."*

**Gill Husband, South Tees Hospitals NHS Trust**

## Prototyping

One of the techniques that predominates within the design process is prototyping<sup>xxii</sup>. Co-design incorporates the idea of **service prototyping** as a route to better results. This includes building rough versions of an end product or quickly simulating how a process might work using a variety of methods including 'walk-throughs', role plays, etc.

Prototyping forms an important part of the overall design philosophy. It is all about thinking by doing, communicating ideas more completely, getting bugs out of the system by 'failing early', and giving permission to explore new behaviours, all of which help to develop the best solution.

Prototyping is distinct from piloting; it is included in the design phase of a project, whereas piloting is part of the implementation phase. Prototyping allows you to test and learn as you develop the idea to be the best solution, which can then be piloted as part of the implementation phase.

A key principle of prototyping is to begin making things tangible as soon as possible, to learn something from doing, then making changes before doing it again. In manufacturing, prototyping is seen as a way to mitigate the risk of investing in change or innovation. In service design, prototyping is also about managing the impact of change on individuals and engaging more people in defining the solution.



See **page 34** for more information on **co-production**

## Co-design: involving patients, carers and staff in service design

---

In co-design, teams manage the implications of change by reaching a consensus of opinion. In a sense, the team trusts the process to help determine what needs to be done. Prototyping as part of the activity of co-design reflects the social, collaborative nature of co-designing services and the adage that people don't resist change, they resist being changed.

Patient co-designers can often be the best people to involve other patients and carers in this iterative process of learning through doing. The objective must be to allow enough time in the design process to create the prototypes and understand their implications.

In practice, service prototyping might mean spending a morning role-playing how a patient would experience visiting a clinic, imagining that the proposed changes had already taken place. It might mean 'mocking-up' a new piece of communication and asking a few visitors to give feedback. It might mean a member of staff trying out a new role for a day and then rethinking that role the following morning and trying it again. It links well with the Plan, Do, Study, Act cycle that many healthcare staff currently use during improvement initiatives:

**[www.institute.nhs.uk/improvementleadersguides](http://www.institute.nhs.uk/improvementleadersguides)**

Co-design extends the engagement of a stakeholder group from the activity of observing and listening to generating new insights and ideas and new evidence for change.

Co-design is particularly relevant for those conditions where the person's lived experience, i.e. the knowledge they gain from daily living with it, matches the medical knowledge of the clinician; for example, people living with long-term conditions. In these cases, the person's contribution is essential.

Co-design is also beneficial when 'acceptance' of a service is paramount: if you acknowledge that people simply wanting to use a service is crucial to their recovery, then getting them to design it is clearly going to help.



By their nature, design techniques are fun, practical and social, and often incorporate a high level of visual communication elements rather than a predominant reliance on good verbal skills. They are suitable for a wide range of people and they are beneficial in and of themselves.

The optimum level of patient or staff involvement in an improvement project will depend on the nature of the project, but **all** projects will benefit from considering patient experience.

The involvement of stakeholders increases the pool of talent from which we can draw ideas. Significantly, it also increases the likelihood that the designed changes will not only be accepted, but will be something that people are delighted with.

*"I knew the emphasis on co-design (getting the patients involved in the whole design process) was key, but I kept thinking: 'How hard can it be?' Surely it's just more of what we've already been doing – listening to patients; acting on what they say? But there is a difference. I'm starting to realise now how experience based design encourages you to keep putting the power back into the patients' hands."*

**Gill Husband, South Tees Hospitals NHS Trust**

## Going beyond co-design

---

Motivation of the patient is often a key component in healthcare interactions and interventions (in particular in management of long-term conditions), and as such, participative methods are invaluable. In co-design, the boundaries between gathering insight, service design and service delivery can become blurred.

Through prototyping in increasingly realistic ways, co-design can move seamlessly into co-production, a situation in which patients feel not only listened to, but also that they have invested in the services that they are benefiting from. Co-production means that service users are actively involved in the delivery of the service as they are, for example, in the Expert Patients Programme: [www.expertpatients.co.uk](http://www.expertpatients.co.uk)

There are many improvement projects that have strong internal focus (e.g. pharmacy, pathology, etc.). For these projects, it is still important to understand the impact on patient experience, even if it is an indirect impact. However, the experience of staff using these internal processes is key. There should be a shift in emphasis, from thinking about these internal processes as functions, to thinking of them as services. This makes the staff that interact with these service the customers. If they are satisfied, then it's more likely they will pass that on to other people.

This focus on the end user – with everybody considering the experience of the patient, directly or indirectly – is a core principle of good service design.

*“Experience based design approaches an issue in a sympathetic and empathetic way, developing outcomes that will benefit the end user. Co-production takes this one stage further by involving end users in the development of the solution. The process is simple, fun and very engaging. In essence, you are getting the patients to do a lot of the work for you.”*

**Martin Bontoft, service designer**

# Measuring experience and showing improvements

---

As we have discovered, experience is both complex and individual, which often creates a tension when considering how you measure experience and quantify any improvements. Yet, we need to be able to do this, firstly to know that we are being successful, and secondly to prioritise investment in change as we don't have unlimited funds.

The issue is summarised very nicely below:

*"The actual experiences of people, rather than the detached measurements of customer satisfaction and proxy measures of performance, such as waiting times, should be used as drivers for service transformation. The trick is to measure performance in ways that illuminate the quality of the experience rather than focusing solely on operational performance. Organisations need to measure what users value, as well as what organisations and service systems value."*

**Journey to the Interface, Demos, 2006**

Clearly, there is a danger in trying to measure experience using processes that have been developed to look at the 'performance' and 'engineering' aspects of healthcare. The danger is that we ignore the 'aesthetic' or experiential component.

Smart commercial organisations use a balanced set of measures but with emphasis on tracking what consumers actually think of the service – the ultimate expression of its success. The Net Promoter Score<sup>® xxiii</sup> describes customers in terms of detractors, passives and promoters; if you're prepared to recommend the service/product then you're probably happy with the experience.

## Satisfaction is different from experience

---

A growing theme within healthcare is to equate 'satisfaction' with 'experience'. Hopefully, if you have read through the previous sections, you will understand that the two are very different. You may well be satisfied with an outcome even though you received an indifferent service – think of the last time you rang a call centre!

Experience is complex, rich, multi-sensorial and changes over time.

Measures of satisfaction are useful, but it is important that they are not used in place of 'experience'.

This issue is complex and there is a range of different approaches that have been used to measure experience. The most important point to remember is to include both quantitative and qualitative measurement systems:

- As with most types of measurement, there is a difference between breadth and depth. Giving out 100 questionnaires will give you good breadth and a few ideas for improvement. Capturing a smaller number of patient stories will give you depth, a real insight about how the service feels and many more ideas for improvement
- The national patient survey<sup>xxiv</sup> questions relate to experience; however, a score of 1-5 on a Likert scale may not fully reflect the complex nature of experience, emotions and expectations



See **page 12** for more information on the **performance paradox**

---

- Care pathways will be changed by designing services based on the insights gathered from patient and staff experiences. Many quality measures can be used to capture improvements; for example, timeliness of care, changes to process steps, usefulness of information and improvements to safety and equality. These will undoubtedly be useful, but it is still essential to include qualitative elements in order to really understand the difference in experience. These might include how easy the process has been to navigate through, how involved people feel in their care and decision making, improvements in dignity and ability to self-manage and so on.

More information can be found at:  
**[www.institute.nhs.uk/ebd](http://www.institute.nhs.uk/ebd)**

*“Certain areas that staff and hospital managers think are performing well, and which meet their targets or operate smoothly on a day-to-day basis, do not always deliver a good patient experience. For example, the Treatment Centre is a flagship for the trust; however, patients commented how uncomfortable it was to leave their husband or partner at the door.”*


**Cate Hillman, Service Improvement Lead,  
Milton Keynes Hospital NHS Foundation Trust**


## Summing up


---


In our partner publication, '**the ebd approach** – guide and tools', we describe a process, distilled from best commercial practice and translated for the NHS to support us to design better healthcare experiences.

It has four steps, each of which contains simple, practical and engaging activities that could be carried out by staff, patients and carers.

 Firstly, you must capture the current experiences of people as they consume, provide or otherwise engage in your service.

 Then, you should try to understand what that data is telling you, organise it and let the main issues come to the fore.

 Once you have identified areas for improvement, you can focus your energy on creating solutions.

 By reflecting on what worked and what didn't, you can improve and increase the sustainability of what you're doing.

---

Organisations delivering high quality care will be doing some of this right now. This process aims to consolidate current practice, fill some gaps and introduce some new concepts. It has been extensively trialled in several centres and with a number of conditions and pathways. The following section describes a number of case studies arising from these trials.



---

See **page 17** for an example that uses the **three elements of good design**

---

*“This work has transformed our understanding of how patients experience our services. Many lean efforts in healthcare fail to address this key issue. We will be placing it at the centre of our drive for improvements.”*

**David Fillingham, Chief Executive,  
Royal Bolton Hospital NHS Foundation Trust**

## References

- i Darzi, A, 2008. *High quality care for all: NHS Next Stage Review Final Report*. London: Department of Health.
- ii Department of Health, Farrell, C, 2004. *Patient and public involvement in health: The evidence for policy implementation*. London: Department of Health.
- iii Department of Health, 2005. *Creating a patient-led NHS: Delivering the NHS Improvement Plan*. London: Department of Health.
- iv Cottam, H and Leadbetter, C, 2004. *RED PAPER 01 Health: Co-creating Services*. London: Design Council.
- v NICE, 2008. *Community Engagement to improve local health: public health guidance 9*. London: NICE.
- vi Parker, S and Gallagher, N, 2007. *The Collaborative State: How working together can transform public services*. London: Demos.
- vii Levy, P, 2008. *Running a hospital*. Available at: <http://runningahospital.blogspot.com/2008/08/next-stage-of-transparency.html> [Accessed December 2009].
- viii Cabinet Office Strategy Unit, 2008. *Realising Britain's Potential: Future Strategic Challenges for Britain*, p143. London: Cabinet Office.
- ix Pink, D H, 2008. *A Whole New Mind*. London: Marshall Cavendish.
- x Richards, N and Coulter, A, 2007. *Is the NHS becoming more patient centred? Trends from the national surveys of NHS patients in England 2002-07*. Oxford: The Picker Institute.
- xi Office for National Statistics, 2009. *The Monthly Index of Services*. Available at: <http://www.statistics.gov.uk/CCV/nugget.asp?ID=163&Pos=3&ColRank=2&Rank=448> [Accessed December 2009].
- xii Peters T, 2003. *Re-imagine!* London: Dorling Kindersley.
- xiii Burns, C, Cottam, H, Vanstone, C and Winhall, J, 2006. *RED PAPER 02 Transformation Design*. London: Design Council.
- xiv Bevan, H, Robert, G, Bate, P, Maher, L, Wells, J, 2007. Using a Design Approach to Assist Large-Scale Organizational Change: 10 High Impact Changes to Improve the National Health Service in England. *The Journal of Applied Behavioral Science*, 43(1), pp.135-152.
- xv Bate, P, Robert, G, 2007. Toward More User-Centric OD: Lessons From the Field of Experience-Based Design and a Case Study. *The Journal of Applied Behavioral Science*, 43(1), pp.41-66.



- xvi National Audit Office, 2009. *Innovation across Central Government*. London: HMSO.
- xvii Mugglestone, M, Maher, L, Manson, N, Baxter, H, 2008. Accelerating the improvement process. *Clinical Governance: An International Journal*, 13(1), pp.19-25.
- xviii Berkun, S, 2004. *Programmers, designers and the Brooklyn Bridge. Essays on design, engineering and project management*. Available at: <http://www.scottberkun.com/essays/30-programmers-designers-and-the-brooklyn-bridge/> [Accessed December 2009].
- xix Greenhalgh T, Russell J, and Swinglehurst D, 2005. Narrative methods in quality improvement research. *Quality and Safety in Health Care*, 14(6), pp.443–449.
- xx Department of Trade and Industry, 2007. *Innovation in Services*. Occasional Paper no. 9. London: HMSO.
- xxi Manning, C F, Acker, M, Houseman, L, Pressman, E and Goodman, I F, 2008. *Schwartz Center Rounds © Evaluation Report, Executive Summary*. Available at: <http://www.theschwartzcenter.org/Final%20Executive%20Summary%20Rounds%20evaluation.pdf> [Accessed December 2009].
- xxii Coughlan, P, Suri, J, Canales, K, 2007. Prototypes as (Design) Tools for Behavioral and Organizational Change: A Design-Based Approach to Help Organizations Change Work Behaviors. *Journal of Applied Behavioral Science*, 43(1), pp.122-134.
- xxiii Shaw, C, 2007. *The DNA of Customer Experience*. Basingstoke: Palgrave Macmillan.
- xxiv Department of Health, 2009. *National Survey of NHS Patients*. Available at: <http://www.dh.gov.uk/en/Publicationsandstatistics/PublishedSurvey/NationalsurveyofNHSpations/index.htm> [Accessed December 2009].



# Case studies

This case study section provides practical, real-life examples of how people have used **the ebd approach** in their own local organisations to create a different experience and improved services for patients and staff.

In the following case studies, we have highlighted the different phases of **the ebd approach** by using the following icons:



This symbol highlights where a case study has **captured** experiences



This symbol highlights how a case study has **understood** experiences



This symbol highlights how a case study has **improved** experiences



This symbol highlights the **impact** of a case study



# Contents

---


<b>Co-design in healthcare</b> Learning to be confident in co-design	<b>46</b>	<b>Focus on the support staff</b> By placing porters at the centre of service improvements, a hospital re-designs the service for the 21st century	<b>66</b>
<b>Alzheimer 100</b> How the experiences of sufferers, their carers and service providers led to creative new ideas in the treatment of dementia	<b>48</b>	<b>Flexibility is the key</b> Using experience to identify improvement opportunities in emergency care	<b>68</b>
<b>The diary room</b> Real-time video feedback reveals what patients and carers think, leading to positive changes	<b>50</b>	<b>Making the space work</b> Considering the environment can have a major impact on patient experience	<b>70</b>
<b>Looking at service through new eyes</b> Using patient experience for new insights into service challenges and to co-design improvements	<b>52</b>	<b>Making choices meaningful</b> How involving service users led to bottom-up improvements in mental health and learning disability services	<b>72</b>
<b>Voice of youth</b> Finding out what young people think about emergency services to help design improved access	<b>54</b>	<b>Getting inside the minds of people with mental health problems</b> Using patient experiences as part of training for emergency care practitioners	<b>74</b>
<b>Making life better for people with Multiple Sclerosis</b> How insights from patients and carers helped to design a service that better meets the needs of people with Multiple Sclerosis	<b>56</b>	<b>From patient-centred to patient-driven</b> Becoming more effective at delivering what patients value	<b>76</b>
<b>Precious and extraordinary change</b> Placing patients and service users at the centre of service development	<b>58</b>	<b>the ebd approach: fundamental to the future of healthcare</b> How using patient experience led to improvements in the appointments system	<b>78</b>
<b>Wigan's shining star</b> How listening to patients has transformed services and won national recognition	<b>60</b>	<b>Capturing views that can go unheard</b> Giving a voice to service users who do not normally have an opportunity to express their views	<b>80</b>
<b>Change in the air</b> How understanding what it is like for patients receiving the services will help to transform patient experience	<b>62</b>	<b>Yes, but how does it feel?</b> Using the experience of staff and patients to identify where a well performing service could be improved	<b>82</b>
<b>First impressions count</b> Using parents' and families' experiences to reduce the anxieties in a newborn intensive care unit	<b>64</b>	<b>Acknowledgements</b>	<b>84</b>


# Co-design in healthcare

## Learning to be confident in co-design


While many health professionals are comfortable when it comes to talking to patients about their illness and treatment, engaging with them face-to-face over service re-design can seem a challenging prospect, even for experienced clinicians.

This was certainly true for Luton and Dunstable Hospital NHS Foundation Trust – one of the first NHS organisations to pilot **the ebd approach**.

 Film, written diaries and photo journals had all proved powerful mechanisms for capturing and mapping the stories and emotions of patients and staff – but the next stage would see the trailblazing teams move into the new territory of co-design.

 The emotional mapping stages of ebd had helped highlight a common theme: some of the most confusing and stressful moments for patients in the Head and Neck Cancer service involved the way the PEG (percutaneous endoscopic gastrostomy) feeding tube was explained, fitted and removed.

The team needed to know more. That meant recruiting extra patients and carers with PEG experience into a small co-design group, and charting unfamiliar territory in terms of actively involving them in service re-design.


 A dozen PEG patients were sent a letter inviting them to take part in the ebd process and asking them to complete a simple list of unfinished statements such as: ‘I would describe my PEG as...’.

Nine responded, saying they were happy to get involved and share their experiences. The PEG team in turn spent some valuable time together thinking about the stories they wanted to tell.

For staff, the initial meeting with patients was a nerve-wracking prospect.

*“Working with patients like this was new territory for us and we were glad to have a separate facilitator from the ebd project,”* said Jacqui Arnold-Jellis, nutrition nurse specialist with the PEG team.

*“But we needn’t have worried. The meeting soon developed into a fascinating and rewarding session as patients began to tell their stories and we all worked together to map the experiences and emotions being described on the day.”*

 One patient described feeling rushed from having been informed of her diagnosis to an appointment with the PEG nurse – with no time to take in what had happened. Discussions also revealed that some patients were opting to have their feeding tube removed without the aid of sedation, and there was a feeling that the information available was confusing and wasn’t always offered at the most appropriate time.

Some of the changes were immediate, including giving patients a choice of appointments to see the PEG nurse where possible and giving fuller advice to patients about their pain relief options – sedation or an anaesthetic spray. Other improvements would take more teamwork.

A second co-design meeting was set up. More confident now, the PEG team knew they could expect some keen insights and valuable ideas from patients; what they were less prepared for was the growing sense of camaraderie and the willingness of their patient co-designers to take on the workload themselves.

*“At one point, all the patients were talking about the fact a PEG leaves you with a second belly button and how this isn’t explained in any of the patient leaflets,”* remembers one member of the PEG team.

*“Suddenly, everyone had their jumpers hoisted up comparing PEG scars. That was just another poignant moment when you didn’t know whether to laugh or cry because there was such a powerful sense of patient and staff togetherness.”*

While there were lots of laughs, there were also plenty of tasks – many willingly shouldered by the patients themselves. One patient offered to edit down a wordy leaflet into a more manageable single side of A4. A week later it was done. Another patient, with a background in information analysis, worked on rationalising the weightier booklet on PEG procedure.

*“There’s a greater sense of community,”* observed one patient. *“We know the staff and I think that’s benefited us as well. It’s a bit like being on a train – everyone sitting there in stony silence at first. But if the train breaks down, people start to talk.”*



# Alzheimer 100


---

## How the experiences of sufferers, their carers and service providers led to creative new ideas in the treatment of dementia

Currently, one in every 88 people in the UK – around 700,000 a year – will develop dementia. That figure is set to rise to 1.7m by 2051. The disease has no cure and requires increasing levels of care as it progresses.

Alzheimer 100 was a project initiated by the Alzheimer's Society as part of Design of the Times 07 (Dott07) – a year-long project based in North East England which explored how design can make a difference to our daily lives. The idea was to come up with creative solutions to the challenges presented by dementia.

Thinkpublic is an agency that focuses on using design to improve service experiences in the public sector. It was invited to work with North East of England branches of the Alzheimer's Society, to investigate new methods for improving the everyday lives of people with dementia, their carers and service providers.

 In order to hear the experience of dementia sufferers first-hand, people with dementia, along with their carers and service providers, were invited to record their experience in their own words, using video, photographs, journals, weblogs and other means.

The result was a moving insight into the day-to-day lives of people touched by the condition. This information was shared at a series of workshops with teams made up of designers, service professionals, people with dementia and their carers.

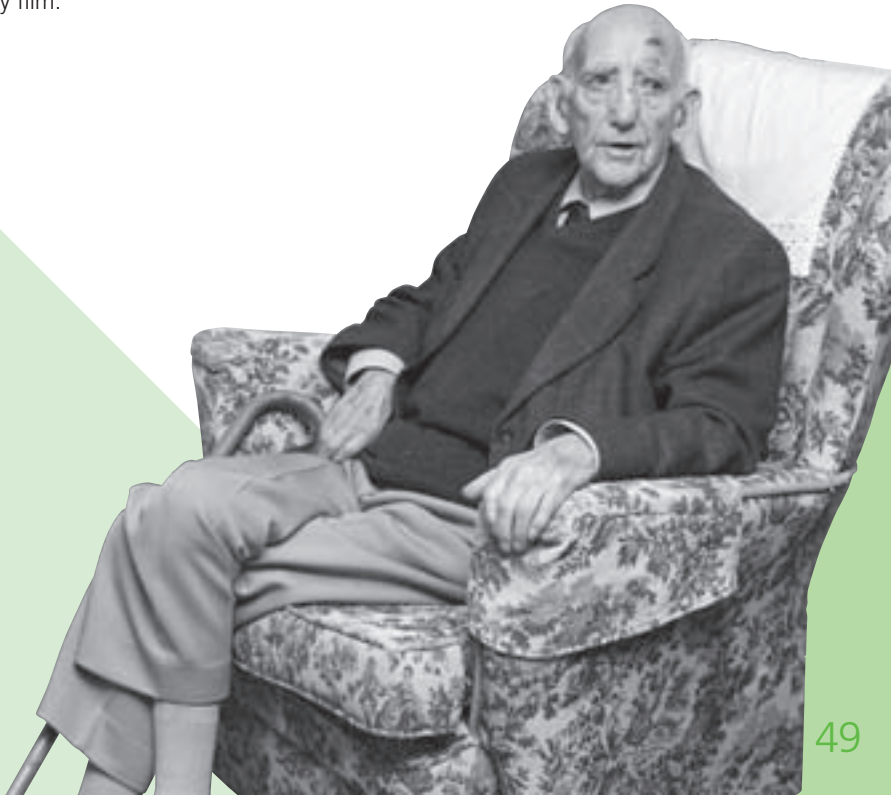


🔑 Among the ideas to emerge from the project were:

- A Dementia Signposting Service, a service which helps dementia sufferers and their carers know what services are available to help
- A Mentoring Programme for Carers, which provides support for carers of people with dementia
- A safe 'Wandering Garden', developed by a local artist, that provides an opportunity for people with dementia to be close to nature without putting themselves at risk.

Clips from the interviews were used to create an emotive 18-minute documentary film.

📺 The recommendations have since informed the National Dementia Strategy launched in June 2008. Thinkpublic, the service design agency leading this work, is continuing to work with the Alzheimer's Society to develop a Dementia Signposting Service, which will ultimately provide a national information and signposting service.




## The diary room

---


### Real-time video feedback reveals what patients and carers think, leading to positive changes

Wrightington, Wigan and Leigh NHS Foundation Trust borrowed the 'diary room' idea from TV's Big Brother to capture on-the-spot experiences from patients and carers, to gather feedback and prioritise changes.

 The Big Brother concept was familiar to people and proved to be enormously popular. The diary room was set up in a private space away from main hospital areas. The team borrowed a camera from the trust's digital imaging department and put posters up to let people know about the filming. Patients and carers were invited to take part. In the genito-urinary medicine clinic, the team made audio recordings rather than video recordings so that patients could participate without feeling uncomfortable.

While much of the patient feedback was extremely positive – just being asked was welcomed – there were some great insights:

*"There's no way of attracting anyone's attention in the A&E reception,"* said one participant. *"The swing doors in rheumatology ward are too heavy for most patients to open by themselves,"* said another. One person pointed out that the patient information booklet had been photocopied and amended so many times, it was difficult to read.

 It was important for staff, as well as patients, to feel comfortable with the process. Video recordings were always shared with them before being shown to the wider trust so that they could see and hear what patients were saying.

✦ The diary room work has helped to produce changes both large and small in acute services and community settings. These include:

- A new call bell installed at A&E reception
- A new dedicated chute installed between the emergency floor and pathology lab to reduce waiting time for test results
- New electronic doors fitted in the rheumatology ward
- A new patient information sheet developed for the elderly care ward, giving useful numbers for patients or relatives once discharged
- 'You said – we did...' posters were used to let patients know how the trust responded to their feedback.

✦ The diary room project demonstrated the power of video as a tool for service improvement. In the light of its success, the team is now beginning to visit patients at home to record their personal stories. These will be played to the Trust Board to help shape future commissioning plans. The team is also planning to move into co-design by helping the PCT and local GP practices work more closely with local patients to inform practice-based commissioning.




## Looking at service through new eyes

### Using patient experience for new insights into service challenges and to co-design improvements

*“It’s like looking at the service through a new set of eyes and it’s hard for anyone to ignore.”* That was the assessment of Glynis Peat, Lead Nurse for Trauma and Project Lead for South Tees’ Fractured Neck of Femur pathways, following a series of patient interviews.


The aim was to find out what patients like and don’t like about the Fractured Neck of Femur service as part of the drive for improvement. The team was already aware that one of its biggest challenges was lack of theatre time, which meant patients had to wait for surgery, but staff didn’t fully appreciate the implications of this for individuals. *“The issue of delays came out loud and clear in patient interviews. That didn’t surprise us, but what did is just how powerful it can be to hear and see the effects on patients and families.”*

 By giving patients a voice, the team learned a great deal about the impact of its services – good and bad. *“Lots of nurses and healthcare assistants will instinctively know that holding a patient’s hand and reassuring them that things will be okay is a good thing to do. But hearing patients recall that part of their experience as a really important moment reinforces for staff that the little things do really matter.”*

The Chief Executive of South Tees Hospitals NHS Trust, Simon Pleydell, is a keen advocate of **the ebd approach** as a technique for improving services.

He points out: *“Working with patient feedback and patient stories on the development of care pathways has radically transformed our approach. I use individual stories that have emerged from this work regularly to talk to staff about how we can truly focus on the real patient experience of the services we provide.”*

Within South Tees Hospital, both the Fractured Neck of Femur team and the Stroke team have been using **the ebd approach** techniques since 2007.

 By listening to patients and acting on their suggestions, a number of simple improvements have been identified and implemented, including:

- Installing toilet roll holders on both sides in patient toilets so that patients who've had a stroke can reach on their stronger side. This has had an impact on dignity and safety for patients
- Reconfiguring a ward to encourage more social interaction
- Giving out information while relatives are present and developing a Patient Passport containing information about the patient's stay in hospital and contact details for the different professionals involved in their care.

Gill Husband, Risk Management Lead, explains why she believes that **the ebd approach** goes further than other patient involvement techniques:

*"the ebd approach focuses on the experiences of staff, not just patients. Creating a level playing field between staff and patients is something new for me. So often we think we know what staff and patients will say. But with this approach you don't make assumptions. Staff are equals in the process and it's just as essential to hear their stories and emotions first-hand. Perhaps even more importantly, I'm starting to realise now how experience based design encourages you to keep putting the power back into the patients' hands."*




## Voice of youth


---

### Finding out what young people think about emergency services to help design improved access


Twenty eight percent of people who visit Accident and Emergency departments in England each year are children and young people. A team from the NHS Institute was keen to involve this sector of society in helping to improve emergency and urgent care services.


The Emergency and Urgent Care for Children project was established by the NHS Institute in 2008 with the aim of finding out how much young people knew about accessing appropriate emergency and urgent care services. The project covered the entire patient journey, from the moment young people first come into contact with the service (for example, via the GP's out of hours service) through to final discharge.

 Children and young people, their parents and guardians were invited to take part in the consultation and design process. A series of vox-pop street interviews were carried out. Parents were asked what they knew about the range of emergency services that were available to their children, their experience of using these services and how they thought the services could be improved.

 A workshop for 13 and 14 year olds was arranged as a follow-up to the vox-pops. The idea was both to listen to young people's ideas and experiences and to improve their understanding of local emergency and urgent care services.

The team learned that it is vital for communications to be appropriate for modern teenagers: *"Traditional questionnaires just won't cut it. But by using methods like going into schools, teenagers are keen to become involved."*

 The workshop included a range of creative activities to explore young people's knowledge of emergency services, such as emergency department, walk-in centre, NHS Direct, what services they thought these provided and how they would navigate themselves around the different options. Participants were asked to design ways in which they would let their peers know about the range of services available and suggest how they could be involved in improving, planning and delivering local healthcare services.

 Following the consultation exercise, the team developed a new service involvement product, including a DVD and lesson plan aimed at teachers who want to try this approach in their school.

Sarbjit Purewal, Programme Lead, sums up what the team learned from the project:


*"Working with service users adds valuable insights and learning to your service improvement work. It's important to go to where the users are, and where they feel comfortable, rather than asking them to come to you. Everyone needs to be on a level playing field – service users and health professionals – and to feel their opinions are equally valuable and important."*





# Making life better for people with Multiple Sclerosis


## How insights from patients and carers helped to design a service that better meets the needs of people with Multiple Sclerosis

Multiple Sclerosis (MS) is the most common disabling illness of young adults in the UK. Ealing PCT was keen to understand the experience of having MS from the patient's perspective, as well as that of their family/carer, frontline staff and other stakeholders. The idea was to build on existing healthcare provision and develop an improved and sustainable service for the area.

 At the start of the project, the team conducted in-depth interviews with nine people and their families. These interviews took place in people's own homes, and were largely led by the person themselves. They talked about their background, work and social life, their experiences of living with MS and interacting with health and social care services. As well as understanding the patients, it was important to understand the experiences of professionals as well.

 The project team shadowed a community therapist in order to observe interactions with a range of MS patients and social services. Patients were asked to map significant events in their lives since being diagnosed with MS: personal and health-related. This revealed strong correlations between low emotional feelings and a lack of support.


 The team held a half-day working session, attended by commissioners, clinicians and managers from health and social care, with the aim of identifying key opportunities for service improvement.


 Using a range of examples drawn from everyday life, the group discussed what makes a good experience and what makes a bad one. Almost every negative experience was associated with a feeling of not being in control and not knowing what was going on. Examples of good experiences helped the team to identify some innovative delivery mechanisms that might be applicable to services for people with MS. From this, the team began to identify what patients might need at different stages of the illness, based on their stories.



The ideas put forward included:

- Post-diagnosis – a greater emphasis on learning and counselling services for the family
- Onset of the condition – an increased focus on self-management tools and self-referral
- Crisis situations – fast access to specialist advice
- Post-crisis situations – a good opportunity to introduce future planning.

 After developing these initial ideas into service concepts, the team set up a number of working sessions with patients and their families. They were asked what they thought of the concepts, and this feedback was used to develop and refine the ideas.

 As a result of this work, a community service (ENABLE) for people with long-term neurological conditions has been developed within Ealing.

The service consists of:


- Co-ordinated access to community multidisciplinary team (including physiotherapy, occupational therapy, speech and language therapy, specialist nurse, counselling and social worker)
- Single point of contact which facilitates self-referral once a person is known to the team
- Telephone advice
- Weekly outpatient gym physiotherapy sessions.





## Precious and extraordinary change

### Placing patients and service users at the centre of service development

The Renal team at Guy's and St Thomas' NHS Foundation Trust has succeeded in bringing about 'a precious, extraordinary' cultural shift using **the ebd approach**.

 The team pioneered a new approach to caring for patients with kidney disease based around what works best for the patient rather than what works best for the organisation. This meant placing patients and service users at the centre of the development process and giving them an active role in helping to shape services to meet their needs better. The resultant changes are making a profound difference to people's lives.

 Both patients and staff participated in one-day service improvement events. In the morning sessions, patients and staff worked independently of one another, considering what works well and where the service could be improved. During the afternoon, the groups came together to compare notes and agree on actions. Patients then became part of the delivery team responsible for implementing an action plan.

 The service improvements introduced as a result of this process were developed in direct response to the feedback from staff and patients. They included:

- Three social marketing campaigns aimed at African, West African and white men. The aim was to raise awareness of the importance of getting their blood pressure checked regularly to help prevent kidney disease
- A programme to empower patients to learn to self-care
- A DVD, 'Living Life to the Full on Dialysis', in which patients tell their own stories about managing dialysis. The project manager who made the film spent months visiting patients in their homes, encouraging them to recount their own experiences
- Peer support provided by trained volunteers who talked to other patients about a range of issues.

The service improvement team learnt a lot through this process and has produced a useful step-by-step guide called 'Improving services by involving patients, carers and staff' ([www.modernisation-initiative.net](http://www.modernisation-initiative.net)). The guide points out:

- You may have to dig deeper to understand the full meaning of patient feedback
- Really involving patients may mean letting go of systems and processes that you have worked hard to set up
- Patients are usually very fair and constructive in their feedback, but they will tell you about things that are wrong. Staff can find this challenging and need to be prepared for it and supported through the process.

The team at Guy's and St Thomas' has achieved significant and lasting improvements as a result of the Modernisation Initiative. For staff and patients that have been involved so far, the involvement of patients has become the accepted norm. The challenge now is to ensure that staff and patients who are new to the process continue this hugely positive work.





## Wigan's shining star

### How listening to patients has transformed services and won national recognition


The Wigan Renal Unit (WRU) has won national recognition and scooped a top award after using experience based design (**the ebd approach**) to implement service improvements. Better still, patients there have responded positively to the changes and the improvements are making a real difference to their lives.


The changes at WRU have been led by Consultant in Kidney Medicine, Dr Janet Hegarty. Janet explains: *"Dialysis is a very mechanical process and patients can feel like they're on a conveyor belt. It is challenging for staff, too, as often they don't feel like they are able to make much of a difference and can easily become demotivated. The challenge is, how do you get at the problems and make them better?"*

 The unit called in several experts, who specialise in using experiences and co-production to design services. Martin Bontoft is a design consultant who undertook some of the work. He explains: *"Experience based design approaches an issue in a sympathetic and empathetic way, developing outcomes that will benefit the end user. Co-production takes this one stage further by involving end users in the development of the solution. The process is simple, fun and very engaging. In essence, you are getting the patients to do a lot of the work for you."*

 The team believed that doing lots of 'little' ebd projects, each highly likely to succeed, would demonstrate that change was possible and give staff and patients a reason to participate in other initiatives. One of the first ideas to be introduced was the Wish Wall.

Located outside the WRU, the Wish Wall featured coloured post-it notes with problems or issues written on them. Different coloured post-it notes were also used to write solutions on. Patients in the unit were invited to share both problems and solutions. As well as providing practical support for patients, the Problem Wall signalled the new sense of openness in the WRU.

 During discussions with patients, it became clear how frustrating it can be when new staff come onto the unit who do not know the patient's name or individual preferences, despite the fact that the patient may have been coming to the unit for years. In response, and in conjunction with patients, the unit has developed a patient-held care plan. This has received national recognition.

 Other improvements have resulted from involving patients, some of them simple, some of them highly innovative. The WRU now has its own in-house patient multi-media library and a garden designed in conjunction with a local Groundwork charity.

Crucially, there has also been a culture change across the unit. Janet concludes: *“Experience based design taught us that much of the experience of both staff and patients is determined by things within our control, in our culture and approach and not, therefore, all about resource.”*

In 2008, The Wigan Renal Unit came first in the British Journal of Renal Medicine Awards. The judges commented:

*“Dr Janet Hegarty and colleagues have used a quality improvement approach to develop a community-based dialysis facility that focuses not just on quality of care, but also patients’ and staff experience. The results are impressive.”*



## Change in the air

---

### How understanding what it is like for patients receiving the services will help transform patient experience

After re-designing the structure of therapy and dietetic services, Airedale Hospital is now preparing to involve patients, carers, volunteers and staff in improving service delivery from a position of increased strength.

Therapy and Dietetic Services had always been structured around a very traditional model at Airedale NHS Trust in Keighley. However, under the guidance of a newly appointed Head of Therapies, Enid Feather, the team was keen to move forward towards a multi-disciplinary structure that would improve patient care, communication and team working.

Project Implementation teams mapped out the current structure by putting the names of each member of staff onto pieces of cardboard and positioning them in their relevant departments. They then mapped the patient pathway and compared the two. This highlighted the strengths and weaknesses of the existing structure and clearly illustrated where it is difficult for patients to access the services they need.

After experimenting with a number of potential structures, the teams came up with a new model, with services falling into five categories – Paediatrics and Speech & Language Therapy, Inpatients and Community Rehabilitation, Dietetics, Mobility Services and Musculoskeletal Outpatients.

The result is better co-ordination of patient care, increased flexibility, greater staff satisfaction and improved cost-effectiveness. Building on this work, which took place at the start of 2007, Airedale Therapy services is now focusing on improving the patient experience by involving patients, carers, volunteers and staff in co-designing services.

The aim is to understand what it feels like for patients receiving services and to work together to re-design services so they meet patient needs better. Ultimately, by transforming the patient experience, the team aims to transform patient care.

🔗 This project involves groups of patients and carers who will be sharing their experiences and talking about their feelings when they interface with staff (touchpoints).

🔗 Service Managers are involved from the outset to ensure that they are fully committed to **the ebd approach** and to embed it into future planning. Frontline staff, too, are crucial and staff at all levels are involved in the project, learning how to engage with patients and carers, both for the benefit of this project and their day-to-day work.

Enid Feather, Head of Therapy Services, concludes:

*"It is too early as yet to have any clear outcomes from the project; however, we are committed to using the experience of patients and staff to help us improve service delivery. Our comprehensive restructuring demonstrated how valuable it is to involve staff in assessing strengths and weaknesses and identifying possible improvements. We are taking this one stage further by asking patients, carers and volunteers to become involved and to share their knowledge and insights. This information will help us to design services around the needs of patients and to make sure they meet their needs more effectively. It will also help to smooth the process for staff and increase satisfaction levels."*




## First impressions count

---


### Using parents' and families' experiences to reduce the anxieties in a newborn intensive care unit

Seeing their newborn baby in intensive care can be a traumatic experience for parents.


The DeVos Children's Hospital in Grand Rapids, Michigan, asked several parents who had recently had their children cared for in the neonatal intensive care unit to help identify opportunities for improvement. As part of this, parents and families were asked to share their own experiences of this highly emotional pathway.

 Parents recounted their experience of coming into the unit to see their child for the first time. Having already endured the trauma of learning that their newborn required intensive care, families told emotional stories of the experience, ranging from simply trying to locate the unit within the hospital, to walking up to their baby's bedside and seeing a frightening mass of tubes, wires and equipment.

This was a powerful piece of learning for staff, fuelling a strong desire to make things better.

 In response, several improvement teams were formed to improve this 'first impression' experience. Each team included a parent or other family member.



 Working together, the teams:

- Re-designed 'way-finding' pamphlets and improved signage leading to the unit
- Designed and set up a dedicated welcome desk immediately outside the lift closest to the unit. The desk is now staffed by parents of former patients who greet new parents and offer details about accessing the unit
- Came up with the idea of parent volunteers who advise new parents and family members on hand hygiene and show them a brief video that explains the common equipment that their infants may need at their bedside.



## Focus on the support staff


---

### By placing porters at the centre of service improvements, a hospital re-designs the service for the 21st century

Hospital porters are one of the most overlooked teams in the NHS. Yet they are crucial to the smooth and efficient running of any modern hospital. Walsall Hospitals NHS Trust decided to focus its service improvement efforts on portering. It set out to involve porters in making their service and working environment better.


The service improvement team began by gathering a group of porters, nurses, administration staff and marketing staff who would play a crucial role in the process. Over the next few months, this new team would work alongside the NHS Institute and the service improvement people to generate some exciting new ideas, to test them out and to begin the process of change and improvement.


To get the project off to a flying start, the team held a launch event at the NHS Institute in Coventry. They focused on building a real sense of teamwork and developing a project plan for the first three months.


 The first stage was to understand the day-to-day work of porters. By ‘walking the floor’ with porters, the team could observe the interaction between portering and other services and really get to understand the issues. Talking and listening was vital, too.

*“Doctors and nurses provide care, but porters are not recognised for providing a service,”* said one porter, while another observed: *“There is a class system based on the colour of your shirt.”* The team took photographs and made a porter’s eye view video to cement their understanding and communicate it to others in the trust.

A user survey established what nurses thought of the portering services provided. It asked users to identify what was good, what could be better and what a gold standard service might look like.

 The team turned to the private sector for new perspectives and novel approaches. Behind-the-scenes visits to organisations like John Lewis superstore, Tesco Extra, the Royal Mail sorting centre and a high street retailer helped to identify some great ideas that could be brought into the hospital context. Private sector partners also attended an event designed to encourage blue-sky thinking. An astonishing 286 ideas came out of the blue-sky-thinking day.

 Using a three-stage elimination process, the team focused in on the nine ideas it considered to be the best. These included the creation of a portering hub, which would give porters a more visible, central location in the hospital and improve co-ordination of their activities. Another idea was to help porters plan for busy periods by creating a simple set of hospital-wide routines that would help them to identify and prepare for peak times.

 The ideas were given an overwhelmingly positive response from the board, and the portering service hub and proactive planning initiative have been earmarked for testing, with the full support of the Chief Executive. Amanda Baugh, who headed up the service improvement project, commented:

*“One of the most important lessons for Walsall hospital porters has been to have confidence in their own knowledge and expertise. They understand their service area best of all and, often, they already know what could be done to make it better.”*




## Flexibility is the key


---

### Using experience to identify improvement opportunities in emergency care

**the ebd approach** can make a difference to just about any hospital department, even those where patients stay for just a matter of hours. The key is flexibility, as one hospital in Australia has shown.

Bankstown Hospital in New South Wales, Australia, is using experience based design to improve patient and staff experiences across its large and busy emergency department.

 Interviews with 40 patients and carers and more than 45 staff helped to generate a wealth of improvement opportunities, from waiting times and parking difficulties, to workload, skill mix and staff retention.


 The hospital organised separate staff and patient focus groups, followed by two co-design sessions. Five patients and eight staff formed themselves into three action groups, each of which focused on one of the following areas:

- Triage and registration
- Managing the order
- The waiting room.

As Danielle Kerrigan, Senior Project Officer at the New South Wales Department of Health, explains: *“Flexibility was essential, particularly when patient recruitment became problematic.*

*“We found that not all the patients wanted to keep returning to more events,” she explains. “We respected this and, although we did hold a second co-design session where participants validated the solutions from the action groups, we brought in three new participants. These replaced some of the original co-design group who were unable to attend a second time.*

*“Two of these were actually staff who had been patients or carers themselves. That helped us get over the difficulties with recruiting patients in the latter stages of the project. You have to stay flexible and try to keep the process going – the end result is definitely worth it.”*

 Changes made as a result of using **the ebd approach** include:

- The re-design and remodel layout of clerical areas, triage office and waiting room
- Engaging volunteers to provide attention, emotional support and comfort, assisting with visitor/carer access to patients, keeping visitors informed and connected with patient
- Arranging after-hours security in Emergency Department, especially in the waiting room
- Standardisation of Emergency Department information – video and written information.



## Making the space work

### Considering the environment can have a major impact on patient experience

Can the physical space have an influence on the way patients heal? London GP and healthcare design researcher, Jacques Mizan, believes so and he is testing the idea that getting the setting right is as important in a GP's surgery as getting the right treatment or prescription. Through his design consultancy, The Space Works, Jacques is examining what it takes to create a healing space and looking at where co-design (the technique of working with patients to design something that is of real value to them) comes in.

*"There is growing evidence (from both the US and the UK) that well designed hospital environments can improve people's rate of recovery and reduce their length of stay,"* says Jacques.

*"It's good to have that hard evidence, but the fact that our physical environments are such an important influence on how we feel and behave is obvious to me. What I'm really interested in is seeing how we can use this in primary care; particularly in improving communications between patients and GPs."*

Jacques believes that if the consultation between the GP and the patient is good – with the patient feeling relaxed and comfortable about talking to their doctor and being in the surgery – then people's health outcomes really improve. Under these circumstances, patients can make more informed decisions about their care and be more confident about managing their health day-to-day.

 His team has been working with patients and communities to find out and understand what they value in a healthcare environment. Jacques admits there have been some surprises: *"We recently did some interesting co-design work with local children, giving them a whole load of materials to create their dream surgery in a box. What surprised us was how scarcely toys and Gameboys featured. The children were more concerned about how comfortable and inviting the environments were – not primarily for them, but for the parents and carers who bring them along. Smell too came out as a big factor: 'Surgeries should smell nice!'"*

Jacques believes that, while the NHS is getting better at listening to people, it is important to value what those people are saying in real terms. That means getting them involved in co-creating better services – in essence, thinking through doing. He concludes:

🔗 *“For most of the NHS this is fairly new and radical. Like many clinicians, I think like a scientist. So my first instinct about how to get people’s views was through research and formal studies. Using **the ebd approach**, co-design has opened up a whole new approach to problem-solving and shown me the value of gathering data through non-traditional methods.*

*“What we do with that knowledge is the crucial and difficult question. The first step is really to raise awareness right across the NHS that good environments aren’t just a nice-to-have. When people are ill and anxious, they need an ideal environment – but so often they get a poor one.*

*“We need to understand what makes a difference for our patients and communities (and that isn’t always about high-cost solutions) and then find ways that the community itself can help us to make improvement happen.”*

🔗 This approach has led to development of supportive environments for healthcare, through community engagement, which provides a positive experience.




## Making choices meaningful


### How involving service users led to bottom-up improvements in mental health and learning disability services


Choice is important for both patients and staff. But how do you deliver meaningful choices? South Staffordshire and Shropshire Healthcare NHS Foundation Trust embarked on an ambitious project to try to answer this and other questions.

The trust provides a comprehensive range of mental health and learning disability services across South Staffs, Shropshire, Telford & Wrekin and Powys. The Choice project was divided into six different mini-projects: Working age adult mental health; Forensic mental health; Learning disabilities; Older people's mental health; Children; and Staff.

 Each mini-project was led by a member of the service improvement team and recruited a 'super-enthusiast' whose ability to motivate and enthuse other staff would be critical to the project. Service users were also represented.


Therèsa Moyes (Director of Clinical Development) commented: *"The idea was to change the culture of the trust from the bottom up. Service users played a vital part in this work. We were keen to encourage innovative ideas and to increase confidence in the trust's ability to deliver these ideas quickly and effectively."*

 The project was structured around a series of workshops. The first set out to understand the idea of choice, both within an NHS context and in other aspects of people's lives. Participants identified what constitutes a meaningful choice and came up with a vision of how the trust might look when choice was offered in an effective and consistent way. From this, the teams developed a Charter for Choice.

 The teams then went away to consider how choice was working within their area. Service users and staff were invited to say what worked well and what didn't. This produced a list of potential improvement opportunities. At the next workshop, the teams used what they had discovered to identify specific challenges. Teams looked both within and outside the NHS for examples of best practice and then came up with some possible solutions to the issues they faced.



The solutions were then divided into 'quick wins' and ideas that would take longer to develop but that would have a high impact. These were related back to the Charter for Choice.

 Within the Children's team, for example, one of the quick wins was to produce a DVD explaining the assessment process and how families can exercise choice. A more long-term improvement strategy was to develop a more accessible review process that was easier to understand.

The teams then went away to test and validate these ideas amongst staff and service users who were not involved in the project. A workshop called Planning for Success helped to shape both the quick wins and the more long-term Big Ideas. The final workshop celebrated what teams had achieved, and provided a forum to plan for the future. Most of the projects have already achieved their quick wins and are well on their way to delivering the Big Ideas.

A spokesperson for the project summarised some of the most important lessons learned:

*"Having a super-enthusiast to lead the work really does make a difference and energetic, focused events are a great way of driving innovation and improvement work. It can be hard to get people to be really innovative, but we found that visuals helped a lot."*




# Getting inside the minds of people with mental health problems

---


## Using patient experiences as part of training for emergency care practitioners

Ambulance staff in the East of England are being given a unique insight into mental health problems as part of improvements to their training.


 During a session dedicated to mental health, trainee ambulance staff are given headphones to wear so they can understand what it is like to hear voices and, effectively, get inside the mind of someone with mental health problems. The trainer, Janey Antoniou, has first-hand experience of schizophrenia, depression, psychiatric hospitals and the Mental Health Act 1983. This enables her to explain to non-sufferers what it feels like to have these conditions and what she has found helpful in the past.

As well as learning the facts about mental health problems, trainees can gain a personal insight into the issues that sufferers face, and can ask questions from someone who has first-hand experience of mental health problems and who is well enough to explain exactly what happens. The half-day training session also covers symptoms and treatments and gives ambulance staff the opportunity to examine their own mental health in the face of the demands of their job.

One paramedic student, Sarah Whiterod, commented: *“Janey’s session made her condition real for us and gave us a much better understanding of what she copes with on a daily basis. Janey was very open and honest and the session was very interesting to be part of.”*

 The East of England Ambulance Trust (formerly the Bedfordshire & Hertfordshire Ambulance Service) introduced the new training to improve the skills of ambulance personnel in dealing with people suffering from mental health problems.

While many ambulance personnel may have experienced what an acute physical problem feels like and can empathise with the patient, only one person in four will have some kind of mental health problem during their lifetime. It is increasingly likely that ambulance staff will encounter people with mental health problems and it is important that they know how to respond appropriately, particularly as it may not always be obvious what kind of mental health problem a person is suffering from. For example, people with severe mental illnesses such as psychosis may also have medical problems such as diabetes, cardiac and cholesterol problems, which may necessitate emergency admission to hospital.


 The new training gives ambulance staff a better understanding of mental health problems and makes them more confident in dealing with people with such problems. For end users, this will result in a more positive and less stressful experience when they come into contact with ambulance staff.




## From patient-centred to patient-driven

### Becoming more effective at delivering what patients value


The Royal Bolton Hospital NHS Foundation Trust introduced the Bolton Improving Care System (BICS) three years ago to become more effective at delivering what patients value and find important.


 The organisation is committed to involving patients in service improvements and uses a range of methods to gather feedback, including surveys, questionnaires, observation and face-to-face discussions. It believes that combining process re-design using 'lean' principles with genuine patient involvement is the key to transformation.


Joanne Bolger is Senior BICS Facilitator: *"Improving the patient experience is critical. It doesn't matter how many targets we meet if we can't get this aspect of care right. Experience based design (ebd) is a way of capturing and understanding how patients actually feel – their experience. It's about moving from being patient-centred to being patient-driven."*

 The Bolton team concentrated initially on Orthopaedics. It invited patients to be filmed in hospital or their own homes. There was no formal interview structure. Patients were simply asked to talk about what they remembered and how it made them feel. The films were then edited and shown to staff over four sessions. Staff reactions were filmed using a Big Brother-style diary room format. It demonstrated to staff the impact of their interactions with patients.

Steve Hodgson, Consultant Orthopaedic Surgeon and Associate Medical Director, comments: *"As a consultant who has always tried to listen to the patient, I feel the patient project has been the most powerful way of demonstrating the experience of treatment from the patients' perspective."*

 Staff and patients then collaborated on ideas that could improve experiences for patients.

 Suggestions varied widely, from developing a 'Top 10 Tips for Patients Undergoing Joint Surgery' written and compiled by other patients, through to improving pain control and setting up an informal patient support group. From watching the videos, staff learned that the practicalities of leaving the hospital after surgery were particularly difficult for patients. In response, all patients now practise getting in and out of a car before they leave the ward and they are accompanied to their vehicle by a nurse or physiotherapist.

 Such has been the success of **the ebd approach** in Orthopaedics that it is now being rolled out across other departments. Experience based design forms the bedrock of cultural change that aims to see staff and patients becoming everyday problem-solvers.

Chief Executive, David Fillingham, points out: *"This work has transformed our understanding of how patients experience our services. Many lean efforts in healthcare fail to address this key issue. We will be placing it at the centre of our drive for improvements."*

Even staff who initially had reservations about the process have become convinced of the value of using ebd. Dr Simon Stacey, Consultant Physician and Orthogeriatrician, concludes:

*"When this work commenced, I was concerned that there would be a lot of investment of time and resource for no real benefit. However, this piece of work has been fundamental in allowing us to improve how we listen to, and work alongside, patients to improve their experience. The patient experience is what it is all about."*



# the ebd approach: fundamental to the future of healthcare


---


## How using patient experience led to improvements in the appointments system

*"I think experience based design is very exciting. We pay a lot of lip service to patient involvement in the NHS, but this is a systematic way of getting them involved. Patients can make a real difference."*

This was the assessment of Juliet Pearce, Project Lead for a pilot programme in experience based design at Southampton University Hospitals NHS Trust Gynaecological Outpatients.

 The department had received a number of complaints from patients who were experiencing problems booking appointments. It was also facing increased competition from a new independent treatment centre locally that offered patients elective treatments. For these reasons, the Gynaecological Outpatients department was chosen as the focus for an experience based design (ebd) project. The idea of ebd is to use the experience of staff and patients to identify where services could be improved. Co-design events are held so that staff and patients can also be involved in designing and implementing these improvements.


 At Southampton, the project considered a number of key 'touchpoints', where patients and the service interact. These included making appointments, letters from the hospital and attending the outpatients department. Juliet, the Project Lead, observed patient care, talked to staff, consultants and outpatients, consulted with the complaints department and the Governance Lead, and recorded interviews with patients.

 The results revealed that many of the problems in booking appointments had already been resolved, thanks to a new computerised booking system. However, it highlighted some areas that patients and staff were unhappy with. For example, confidentiality was not always maintained at reception with patient details – something that was also commented on by patients in feedback cards. Minor administrative errors, such as patients receiving a letter with the wrong consultant's name on it, were shown to have a detrimental impact on patients. Juliet pointed out: *"One patient thought she had something else wrong with her because the admin department had mistakenly put a different consultant's name on the letter."*

Other issues highlighted included an advertisement for a child's prep school at the entrance to the fertility clinic, which patients deemed insensitive, and confidentiality concerns over receptionists asking patients to confirm their telephone numbers in a busy reception area.

Overall, the problems seemed relatively minor, although the impact on the patient's experience could be significant, for example:

- Transport issues: for patients using hospital transport there can be problems if appointments run late, causing patients to miss their lift home. Staff suggested that the ambulance crews should tell staff what time they are leaving so that patient appointments can be prioritised, if necessary
- Privacy and dignity issues: staff commented that they have been asked to weigh patients in the busy reception area as there is so much pressure for clinic space. Staff are unhappy with this and so are patients. Understanding the patient experience has given the staff confidence to ensure that patients are weighed in a private area.

 The Project Lead held a co-design event with key stakeholders from the department. Ideally, Juliet would have liked to involve patients, but she found that outpatients are reluctant to come back into the hospital once their appointment is finished. The event identified 15 quick wins, which were implemented the following month, and five streams of work requiring further review and planning. For Juliet, ebd emerged as an approach that is fundamental to the future of healthcare. She comments:

*"The NHS Next Stage Review (2008) led by Lord Darzi is clear in its call for quality care to be fundamental in the NHS. The organisation can adopt **the ebd approach**, which enables us to ensure that the efficient and effective services we create also provide a quality experience for our patients."*



## Capturing views that can go unheard

---


### Giving a voice to service users who do not normally have an opportunity to express their views

Ridgeway Partnership NHS Trust was determined to give a voice to service users who do not normally have an opportunity to express their views.

The trust provides integrated learning disability care services in Buckinghamshire. Service users live in a range of environments and have mild to severe learning disabilities, often with additional health needs. All service users have a statutory annual review and it was this aspect of the service that the experience based design (ebd) project decided to focus on. The idea was to find out what the experience was like for patients and staff and where services could be improved.

Project Lead, Karen Howsam, made the decision to concentrate on service users with more complex problems who tended to have the most difficulty in expressing their views. As a pilot project, she felt this would help to test the approach to its fullest extent and benefit the users.


The people who took part in the project included a service user who is profoundly deaf, another with Down's Syndrome and limited communication skills, and someone with dementia.

 One of the biggest challenges facing the project was the issue of consent. The plan was to video the reviews, but carers and advocates were concerned because the service users were not able to give consent. Eventually, three service providers agreed and the videoing went ahead. The team made sure that service users were involved by demonstrating to them how the video camera worked. If anybody showed signs of distress, filming was immediately halted.



 The project revealed huge variations in the quality of reviews between different areas, providers and care managers. People came with different agendas for the review and it was not always clear who should arrange the reviews or implement the actions discussed. Some members of the care team brought written reports, despite the fact that service users could not read. Many service users felt that the reviews went on too long and expressed obvious signs of boredom.

 A co-design event was held, with service users, carers and care managers taking part, to identify how the process could be improved.

 From that, the team drew up an action plan which proposed a number of changes, including using photographs and videos in reviews to act as visual cues for service users, shortening the duration of reviews, ensuring clients are more involved and giving guidance to homes to help them prepare more effectively for reviews.

Karen concluded: *“We are now in the process of reporting our findings about reviews and sharing our experience of **the ebd approach.**”*





## Yes, but how does it feel?

### Using the experience of staff and patients to identify where a well performing service could be improved


The Breast Screening Unit at Milton Keynes Hospital does very well when peer reviewed and it delivers against targets. However, the Director of Organisational and Service Development, David Radbourne, wanted to know how the service feels for patients. He commented: *“The service performs well from a provider/technical perspective, but we were really aiming to ensure the patient experience of the service was made more explicit in order that we had a comprehensively excellent service.”*


The unit was chosen to take part in a pilot project for experience based design (ebd). The aim of ebd is to use the experience of staff and patients to identify where services could be improved. Co-design events are held so that staff and patients can play a role in designing these improvements. At Milton Keynes Hospital, Project Lead, Cate Hillman, and Assistant Project Co-ordinator, Sue Morris, examined key touchpoints on the patient journey. These are the points that patients come into contact with the service and they included: referral by the GP, tests and investigations, diagnosis and treatment.

 Thirteen breast cancer patients took part, recruited from across the whole pathway – some at an early stage in their treatment, others ten years post-treatment. The team had hoped to be able to recruit non-cancer patients as well, but unfortunately this proved impossible. The ebd project used patient surveys, patient videos and staff interviews to find out how the service was experienced by patients and staff.

 Some of the results were quite surprising. Certain areas that staff and hospital managers think are performing well, and which meet their targets or operate smoothly on a day-to-day basis, do not always deliver a good patient experience.

For example, the Treatment Centre is a flagship for the trust; however, patients commented how uncomfortable it was to leave their husband or partner at the door. Other issues identified by patients included the Breast Unit’s automatic doors which open and shut as people walk past to the canteen, causing the unit to become cold in the winter. Some of the information provided to patients was poorly photocopied and stapled, in contrast to the literature from the Macmillan chemotherapy unit, which was professional and personalised.

 The ebd team recognised that many of the improvements that would be needed were about personalising and increasing the feeling of caring back into lean pathways, so that no matter how unpleasant the experience, patients felt that someone cares.

 They held a co-design event involving staff and patients, and from this identified the following key action points:

- Developing a 'Buddy' system for patients going through the pathway
- Developing a breast microsite within the trust website, aimed at meeting the specific needs of the patients coming to the trust for breast investigations and treatment
- Improving the breast health awareness in the community
- Improving all the information given to patients to ensure it is personalised and appropriate (using the Macmillan information as a template)
- Improving the poor experiences reported by patients, e.g. journey to theatre, dignified waiting, not waiting alone
- Improving the patient appointment system in the Breast Screening Unit.

Cate commented: *"ebd was a new concept in improvement for me. I knew it would be a steep learning curve, but what really surprised me was how it made me feel listening to patient stories and trying to remain emotionally detached and project-focused. When delivering aspects of this approach, do not underestimate how harrowing it can feel and the emotional load on the project lead. I think this is worthy of note, also, when considering how staff may feel at both the staff and co-design event."*



## Acknowledgements

---

We would like to thank the following for their contributions to this publication:

Paul Bate

Martin Bontoft

Ivo Gormley

Joe Heapy

Paul Plsek

Glenn Robert

Julia Schaeper

Deborah Szebeko

Paul Thurston

Impact Innovation

Live|work

Thinkpublic

and the Innovation Practice team,  
NHS Institute for Innovation  
and Improvement

### **A big thank you...**

A warm thank you to the many patients, NHS staff and other individuals and organisations who have generously given their time and shared their experiences to help us create this book of case studies.

We are also very grateful to our international partners who have kindly shared their experiences with us.





***Institute for Innovation  
and Improvement***

the  
**ebd**  
approach™

**experience based design**

Using patient and staff experience  
to design better healthcare services

To obtain additional copies of  
this publication (quoting reference  
number IN051) call 01922 742555

or go to: **[www.institute.nhs.uk/ebd](http://www.institute.nhs.uk/ebd)**

Alternatively you can write to:

New Audience Limited  
Unit 26  
Empire Industrial Estate  
Empire Close, Adridge  
West Midlands WS9 8UQ

© Copyright  
NHS Institute for Innovation  
and Improvement 2009

ISBN 978-1-907045-57-8