



*Institute for Innovation
and Improvement*

the
ebd
approach™

experience based design

Using patient and staff experience
to design better healthcare services

**Guide
and Tools**

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ebod
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She held my hand. That was a big moment. And it **wasn't patronising**; it was just a **professional** thing. My hand was lying over the side of the bed and she [the speech therapist] took my hand and that gave me a **wonderful message**. And she said something along the lines of, 'I know you've got **worries** at the moment and it's quite **natural** to have those worries but we'll all be working together on this and ...we'll get you speaking again'

And I was **angry** too because they said, 'the doctor's coming', and no doctor came, and I said, 'please stay with me because **I feel I'm going to die**'. And I really did, because the chest pains were so **bad** and I was still **hallucinating** and I just wanted to know that I was **still living** and there was somebody with me. I think it was **absolute terror**.

Introduction

The ebd approach (experience based design) is a method of designing better experiences for patients, carers and staff. The approach captures the experiences of those involved in healthcare services. It involves looking at the care journey and in addition the emotional journey people experience when they come into contact with a particular pathway or part of the service. Staff work together with patients and carers to firstly understand these experiences and then to improve them.

This guide is an introduction to **the ebd approach** (experience based design) and is supported by tools and templates that can be found in the tools section and on the website www.institute.nhs.uk/ebd.

This guide and toolkit has been produced as a result of work that the NHS Institute for Innovation and Improvement has undertaken in collaboration with NHS organisations and external agencies, using the experience of patients, carers and staff to design better healthcare services.

The first section is a guide which provides an overview of **the ebd approach** (experience based design). This will help you to understand how you can start to use patient and staff experience in your area of work. The second part of the publication contains tools and advice which will help you to put **the ebd approach** into practice.

The tools and templates are also available at www.institute.nhs.uk/ebd. Many of them can be customised for your local use.

The ebd approach will help you turn the vision of a patient centred NHS into a reality.

Alongside this guide and toolkit there is **the ebd approach – an introductory DVD** and **the ebd approach – Concepts and Case Studies** book.



Running an **ebd** approach project including co-design

...there is no reason why you shouldn't do this. There are time and resource implications but the rewards are significant.

Read through this guide and look through the tools and you should be ready to get started.

Understanding more background

...look at the **ebd** approach – *Concepts and Case Studies* book.

Just trying something

...it's a great way to see what works for you.

Explore the **ebd** approach further by

Using the **ebd** approach to enhance my existing patient and staff involvement channels

...there are lots of everyday options open to you. Look through the tools and you will have some idea about things you could incorporate or try out.

Involving others

...get others interested and generate some momentum. Showing the introductory DVD usually really motivates people to want to get involved and do something.

Contents

The NHS Next Stage review (2008) led by Lord Darzi is clear in its call for quality of care to be fundamental to the NHS. High quality relates to the clinical care and treatments that people can expect but also that this results in a good experience. **The ebd approach** enables healthcare providers to understand the experience of healthcare from the patients, carers and staff perspective to ensure that what might have been seen as 'little things' in the past will be recognised as an important part of the delivery of high quality care.

The ebd approach involves patients, carers and staff in the design of healthcare in a deeper way than any other process in the NHS. It harnesses the energy of both patients and staff to make meaningful and lasting improvements.

Wherever you see the following icons, they are a reference to a tool relevant to the particular aspect of **the ebd approach**.

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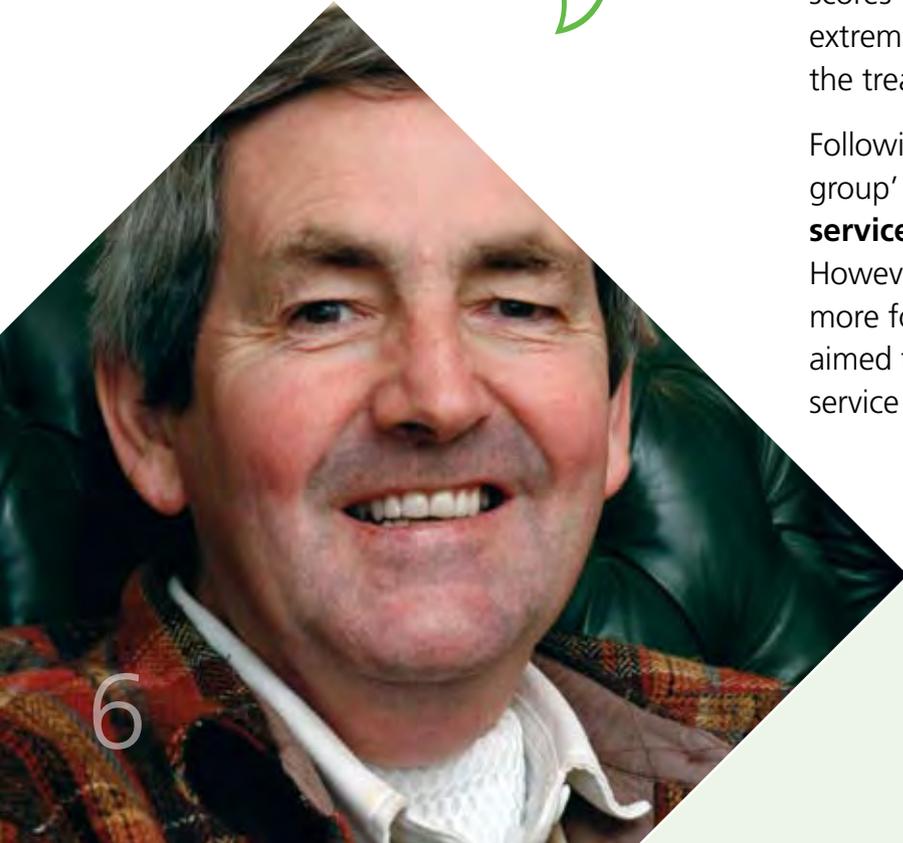
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A foreword from Hugh McGrath

When asked to provide this foreword I felt a great sense of pride and privilege. Indeed I had similar feelings when I initially became involved in the “Your Experience Matters” project that formed part of the basis for this guide – the ebd approach (experience based design).

In March 2004 I underwent surgery at the Luton and Dunstable hospital to remove a tumour that had developed in the region of my larynx. The surgery necessitated the removal of the larynx and re-construction of my oesophagus. Had I been asked at that time to complete a ‘satisfaction questionnaire’ which, I believe, was standard practice at the time, designed to assess the level of service that I had received, I have no doubt that I would have provided very high scores for the survey as I would have found it extremely difficult to express dissatisfaction on the treatment that I had received.

Following recuperation I attended several ‘user group’ meetings that were intended to **improve services** and thereby patients’ experience. However, in my opinion, these groups were more focused on social interaction and were aimed to meet individual needs as opposed to service improvement.



Around September 2006 my wife and I were asked by staff at the Head and Neck Cancer Clinic if we would participate in the Co-Design Advisory group – this participation also included a request to provide an insight to our experience as patient and carer.

At the initial meeting we **were impressed** by the professionalism, dedication and determination of all the group members that the project should be different and should 'make a difference'. Indeed, it was different and has made a difference.

Throughout the life of the project great emphasis was given to ensuring that the principles of the ebd approach would become an integral aspect of the service processes and procedures. Only then would the project have been considered to be a meaningful success.

I am still involved with the service which I attend from time to time as a patient and as an active member of a support group that was one of the improvements that happened as a result of the project. I also meet other patients prior to them undergoing surgery and, where possible, during their recuperation.

Through sharing experience with others I am able, where appropriate, to **provide feedback to the clinicians** on areas where there is a perceived need for improvement.

As a direct result of my involvement with the project I have had the great privilege of meeting and working with many people, both from the medical profession and patients, their carers and families. I have personally **gained a tremendous amount from this experience** and I am grateful to have had the opportunity.

I urge the users of this guide to enter the process wholeheartedly as I know it can **help make a difference.**



Hugh McGrath
Patient, Luton and Dunstable Hospital
NHS Foundation Trust

Why consider experience

We can now point to more than 40 real improvements in our head and neck cancer services as a direct result of this work. That's very exciting.

Stephen Ramsden, Chief Executive

At the moment we're using the 'Lean' principles to help increase the amount of time staff have for direct patient care and anticipating patients' needs. This fits with what patients are telling us through **the ebd approach** about their experiences on the ward.

Elaine Hide, Nurse and Service Improvement Lead

Many improvement projects will include some form of patient involvement – but few focus very closely on drawing out and utilising the specific **experience of patients and staff**.

One way to understand the value of incorporating staff and patient experience into your improvement project is to look at the components of good design.

Healthcare organisations have demonstrated that they have significant skills in improving the performance and reliability of services but they have not always placed equal focus on the **aesthetics** of experience – how it **feels** to use or be part of the service. **The ebd approach** provides the opportunity to build on previous successes by focusing more attention on this third component – **the experience of care**.





Good
service
design
consists of...

Performance

How well does it do the job?

Is it fit for the purpose?

Functionality

+

Engineering

How safe, well engineered and reliable is it?

Safety

+

The Aesthetics of Experience

How is the whole interaction with the product/service felt/experienced?

Usability

(Bate & Robert, 2007, adapted from Berkun)

Within healthcare improvement, there is a tendency to focus a lot of effort on the performance and engineering elements of good service design. This is understandable. Clearly, gaining access to care and having good outcomes (performance) along with safety and consistency of process (engineering) are things that service users care deeply about.

Until now we have lacked practical tools that are linked together to form an overall process to help front-line staff capture, understand and improve the patients' actual experience of care. However, **the ebd approach** has changed that.

Reducing waits and improving the quality of care have been two important outcomes of this approach for us.

John Pickles, Consultant

The four steps of **the ebd** approach

The ebd approach (experience based design) centres on **four key steps**, which form the framework of this guide:



The approach starts with helping people (patients, carers and staff) tell the story of their own experiences, in their own way.

It is through these stories that we can begin to understand not just the care journey, but the **emotional journey** people experience when they come into contact with a particular pathway or part of the healthcare service. When we understand and utilise this, we have a powerful new tool for improving care in the ways that matter most to the people who use it and the people who deliver it.

We can all think of times when we have told a story about a service we have experienced. We tell those stories because the interactions with the service have had a big impact on us – when we tell the stories we are often emotional and use emotion words. The recognition of the importance of emotion is a core principle throughout **the ebd approach**. Whilst relatively new to health services, this principle is used throughout the design industry from which we have taken some of our learning.

Any service, whether it is booking a holiday online through to a healthcare process can be specifically designed to create a **positive user experience**. This experience will usually then be described in terms of positive emotions.

So, this goes beyond finding out what patients liked or didn't like about their care. The aim is to understand how an individual's contact with each part of a service made them feel, for instance:

- confident or confused
- scared or safe
- empowered or insignificant
- valued or overlooked.

Teams in the NHS have ways of identifying patients' views about their service – one of the main ways is through their organisation's annual patient satisfaction survey. This is useful, but does it give us the best insights about where the service needs to change?

The quotes on page 12 provide examples of the rich, experiential detail that have been captured through **the ebd approach**. They give insights into the emotions that individual's were feeling as they came into contact with different parts of a service, and as they experienced different stages of their care journey.

You can see a progressive change over time in the way in which they [staff] get more confident in working with patients and can talk to them about stuff that isn't clinical; I've seen that change. I can see that they seem to be envisaging a future where they will work with patients rather than without them.

Elaine Hide, Nurse and Service Improvement Lead



Experience sharing means giving patients, carers and staff the time, space and support to recall the parts of the service that had the greatest impact on them.

Leaders and managers may have a wide variety of knowledge and specialist skills, but only users have that unique personal knowledge that comes from having experienced the service or product first hand, of being on the receiving end, and the specialist insight that gives as to how it might be made better in the future.

Source: Bate and Robert, 2007

As well as being useful for all frontline staff, **the ebd approach** is the natural next step in any improvement project work. Whether you call your existing approaches Total Quality Management, Continuous Quality Improvement, Lean, Six Sigma, Organisational Development, or any number of other labels, our emphasis here is on building on and extending your work to better include the third and vital element of good service design – **user experience**.

Staff who have used this approach, especially those at the frontline of delivery or patient involvement have been very enthusiastic. It does more than pay lip service to involvement and has a positive impact on patient, carer, and staff interactions.

When I'm **poorly** I like to stay in my pyjamas. But one day the healthcare assistant said in front of everyone – 'Why don't you get some clothes on?' I know she was only trying to **encourage** me, but it made me feel **awful**

I was **desperate** for **encouragement** and **reassurance** – even when the tea lady on the ward said I was looking better than a few days ago – I was **absolutely over the moon**. The right remark at the right time goes such a long way

User Experience

When you come into the mobility office waiting room the chairs are arranged in a way so you have to be an **expert** [wheelchair] driver just to get through the door... It was a **nightmare**...

The clinic itself was a **terrible** place to be. People looked **anxious** and **ill** and I could hear one patient talking about how **horrendous** radiotherapy was. Something inside me died at that point. I thought: is this how it's going to be – is this really **my future**?

Improvements that have been made using **the ebd approach**

NHS teams that have used **the ebd approach** are reporting significant levels of service and organisational improvements and show improved relationships between patients, carers and staff.

Some of the improvements achieved by using this approach include:

- ✓ **Reducing waits and overcrowding** for patients and giving staff more time with them by introducing a new appointment system in the outpatient clinic
- ✓ **Redesign within the post-surgical ward** – giving patients the quiet space they need and making it easier for staff to store and locate vital equipment
- ✓ **Helping staff to respond safely and quickly** to patients with tracheostomy or stoma needs by increasing training and redesigning roles including an extended role for healthcare assistants
- ✓ **Preservation of dignity** by removing weighing scales out of public view
- ✓ **Creation of a safer environment** within a stroke unit by having toilet roll holders on both sides of the toilet
- ✓ **Configuration of a ward** in order to provide space that can be used as a patient /relative sitting area
- ✓ **Design of a 'Patient Passport'** to provide information about inpatient stay and contact details of the different health and social care professionals involved in their care
- ✓ **Colour coding ward bays** through the use of different paints to help patients find their way back to their bed, giving them greater independence
- ✓ **Increase in the level of specific training** to enable 20 more staff to use patient experience in service redesign
- ✓ **Enhancing two roles in the trust** to recognise and support similar patient-focused pathway work

Certainly all the staff I've met have **impressed me with their enthusiasm for the project and enthusiasm for improvement. It's almost as though there's been some sort of injection into the staff. I think it's something that was perhaps waiting to happen, and they needed a catalyst.**

June Edwards, Patient

Help your
patients
feel like
this...

The thing that's amazed me about this whole experience is how much can actually be achieved with little or no money – simply because we're working as equals alongside staff, sharing ideas and finding commonsense solutions.

Sheelagh Wren, Patient

The whole experience has helped me to grow as a professional and an individual. It's prompted me to act on some of the things we've wanted to do for ages – looking at staff competencies on the ward for instance; improving training; and setting up a fund to finance some of the changes we want to make.

Carole Glover, Clinical Nurse Specialist

...and your
staff
feel like
this

The difference between trying to make improvements in the past and this approach is that patients are **involved right from the beginning. And that's why I feel there has been **greater progress and greater improvement in the head and neck service, whereas in the past it's just fizzled out.****

Elaine Hide, Nurse and Service Improvement Lead

Just before you get going

The experience of those teams already using **the ebd approach** has highlighted some important principles that are worth understanding right from the start.

Senior leadership support

For lasting benefits to patients and staff, you need more than the approval of your senior leaders; you'll need their active involvement and visible support. You could start by showing your senior team the short experience based design film on the DVD with the introduction to **the ebd approach**.

Patient consent

The National Research Ethics Service has advised that no formal ethical review is needed prior to using **the ebd approach** and other experience based co-design methods (as long as the work is conducted for service improvement purposes). For more detail, see www.institute.nhs.uk/ebd.

However, you will still need to apply good ethical principles in your work, including getting full, informed consent from all the people who share their experiences and stories.

Because **the ebd approach** involves people's emotions, always try to ensure that the needs of staff, patients and carers are considered throughout the process.



See page 66 for a *Patient consent form to use in your interviews*

Time and resources

You can add value to any improvement work you are doing by taking a little time to better understand the experiences of those delivering or receiving care. This might range from doing some short interviews in a clinic to find out what the experience is like and then organising your team to act on this, to setting up and running a project that starts from understanding people's actual experiences and then involve them in co-designing and implementing improvement. The amount of time and effort you need will differ and it is important to be realistic about this. For a project that includes co-design as a core element you will need to develop a plan with key people and a shared understanding of the improvement aims, key milestones and timescales.



See page 48 for more information about *Roles and structures*

An introduction to the four steps

There are some important steps that will help you use this approach. Although most of these steps are straightforward, they may involve doing things you've never done before – such as filming patients in their own homes or using an emotional mapping tool.

The ebd approach is an improvement approach and while we suggest that you carry out certain steps, there is no 'textbook' way that has to be strictly followed. The approach recognises that the NHS is complex and diverse and the range of tools and steps presented here are designed so that they can be used flexibly.

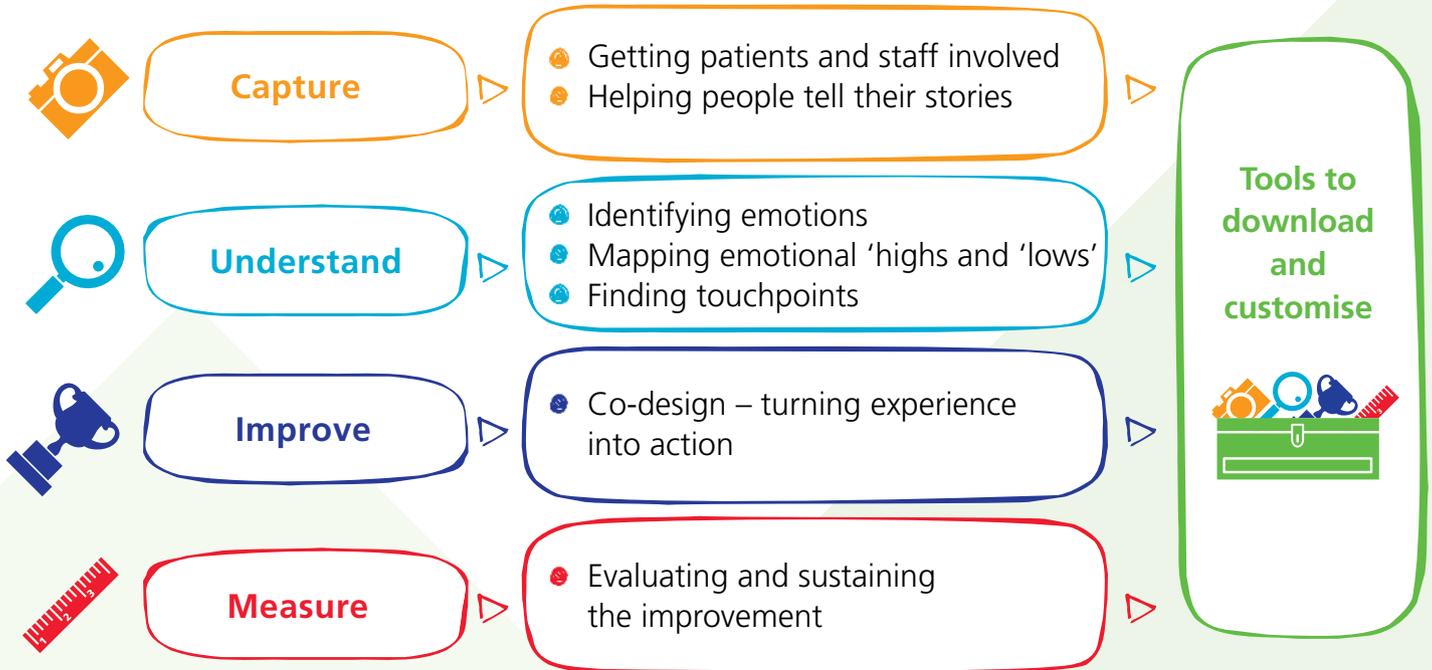
Teams who have used this approach have adapted it to fit local circumstances. And we are constantly learning from other experience-based improvement work both inside and outside the NHS.

Please share your learning and experience of using **the ebd approach** via the website:
www.institute.nhs.uk/ebd

Staff are equals in the process and it's just as essential to hear their stories and emotions first-hand.

Gill Husband, Risk Management Lead

All the tools are available for you to download from the **ebd** approach web pages at: www.institute.nhs.uk/ebd



Capture the experience

Getting patients and staff involved

- **Ensure that you link with a senior leader** – who can provide you with support. Highlight how this work, involving patients, supports the overall strategy for your organisation.
- **Raise awareness** of what you are doing by holding some informal awareness sessions, inviting staff and patients to watch **the ebd approach** introductory DVD and find out why this approach is so different.



See page 50 for more information on Getting patients and staff involved

- **Involve staff** because you need to understand the service from their perspective. Start with one or two staff members and encourage them to help you spread the word.

- **Engage patients and carers through frontline staff** to ensure they (especially those who are ill or vulnerable) are approached sensitively by people who they are familiar with. Staff have very important relationships with patients and can help to get them involved. Consider contacting local patient groups and voluntary agencies and seeing if they can help you to find people who have used a particular service.
- **Understand the roles** and make sure everyone understands what they are being asked to do and what goals and timescales you're working to.



See page 48 for more information about Roles and structures

- **Get a wide range of perspectives.** Some people will not put themselves forward even if they think **the ebd approach** is a good idea. Gentle encouragement can be given to patients and staff who are seldom heard or don't put themselves forward immediately.
- **Be flexible** and aware that different patient and staff groups will have different levels of investment in a service and this might impact on how much time they will want to give.

- **Give people time to think.** This is an exciting process, but don't expect everyone to understand how valuable it is immediately. Create time to build up conversation, understanding and enthusiasm.
- **Persevere** – staff and patients can get more enthusiastic once they have the opportunity to talk about their experiences of the service.
- **Maintain awareness and enthusiasm** by communicating well – remember to thank people for their input and to share insights/results.

Our partners in the Stroke Association do a lot of work locally visiting people in their own homes. We asked them for help and they did an excellent job, not only of selecting potential candidates for us to approach, but also paving the way for us to call them and explain why we wanted their input.

Gill Husband, Risk Management Lead

Expectations

One of the things that makes this approach so different and exciting is that it does seek staff experiences as well as those from patients (perhaps for the first time in any meaningful way). It is really important to give time for both staff and patients to share their experiences. We have found that in the beginning this is best achieved through separate meetings, and later in the process both staff and patients can come together.

Patients' reactions to the approach

Teams have had a lot of positive feedback from patients and carers who have been involved in **the ebd approach**. It is important to recognise that patients have commitments outside of the project and even though they might enjoy the work, they may not remain actively involved throughout the whole project. We have found that some are more active in the beginning, some throughout and some choose to be more involved later on. A small number of patients can provide much valuable information. So do not worry if the number of patients who are actively involved changes. Every input is relevant and important.

How to capture the experience

There are many ways to capture experience, there is no right or wrong approach, here are some ideas, but feel free to experiment...

- **Interviews:** Storytelling is at the heart of **the ebd approach** and centres around giving patients and staff the time, encouragement and help they need to describe their personal experiences in their own words.

One of the most effective ways of gathering stories is through one-to-one interviews with patients, carers and staff. Sometimes this may not be possible and some alternative techniques are outlined in this section.

Interviews can be time-intensive, but teams have found that the richness of the information that comes back is well worth the effort. It is also worth considering filming the interview. Although this may be a little daunting at first, our experience is that it can really help to share the project with a wider group.



See pages 57-63 for more information on interviews and filming them

- **Experience questionnaire:** Asking people to complete an experience questionnaire can be really valuable and provides a simple approach to capturing feelings and experience. With some simple adjustments this questionnaire can also be used by staff to identify their experience of delivering the services, for example frustration at having to wait for results.



See page 54 for more information on experience questionnaires

- **Diaries/journals:** Most people are familiar with keeping a diary or journal and because everyone knows how they work, they can be a good option for patients (those who are well enough to keep them), carers and staff. Diaries can be printed books, simple sheets of stapled paper or you can invest in digital voice recorders.
- **Photographs and photo journals:** Experience can be captured through photographs. Patients, carers and teams can be given disposable 'camera packs' or use of a digital camera to take away and record their experiences.

- **Observation:** Observation is a very important tool when working with patient and staff experience. It can help you really understand different perspectives, but also prompt patients and staff to talk about their experience of specific elements of a service. The benefit in all observation is that it helps you to really focus on the actual environment or service you are trying to improve. This makes sure that any improvement is always grounded in what actually happens, rather than what people think happens.



See [page 25](#) for some quick tips and [pages 64-65](#) for more information on **observation**

- **Shadowing:** Accompanying a member of staff as they go about their normal day or a patient as they experience their care journey, can help you to see things through their eyes. You will need to ask people if they are comfortable with this approach. It is also a method that allows you to ask questions which prompt a 'running commentary' from the person you are accompanying. Recording this will give you a detailed, first-hand picture of the experience, role, approach, philosophy and tasks of the person being shadowed.

I have a lot of experience of doing one-to-one interviews with patients and capturing people's stories on film is not only a lot easier (no need for frantic scribbling and transcribing) but it has an immediacy and impact you can't usually achieve in writing

Gill Husband,
Risk Management Lead

- **Conversation cards:** Conversation cards can help you initiate conversation with patients and family members. In one American cancer centre, patients in a clinic waiting area are routinely invited to look through the cards and choose a topic of most interest or concern to them at that time: e.g. 'waiting', 'parking', 'my test results'. Each manager at the clinic now spends two hours per week in the waiting area with the cards, moving from patient to patient to have conversations. Although met with some resistance by some staff members who were not part of the initial design team, the staff report that the time spent engaging patients with the cards is some of the most rewarding time at work.
- **Focus groups and 'listening labs':** Traditional research makes extensive use of focus groups and listening labs. Listening labs (which can involve a group of people or simply an individual recounting their experiences) can be a useful strand in your experience gathering work. You need to be careful that a group does not work at a superficial level. Skilled facilitators will be able to make people comfortable with sharing personal experiences.
- **Compliments and complaints:** These can be used as a starting point to capture experiences.

See pages 42-43 for more information on using experience when working with compliments and complaints

You can photocopy, download and customise this foldout (pages 23 and 24) to find out how patients felt at different stages of their journey...

Fold back this page



How do you feel?

This experience questionnaire will help you think about how you feel at different stages in your journey.

Circle the words that best describe your feelings at each stage, or write your own words at the bottom.

 See pages 54-55 for more information on experience questionnaires

Why? 

We'd like to know why you felt like this. Was it friendly staff, a nice conversation, or a long wait – whatever it is we'd like to know.

Arriving/Checking In	Information	Waiting	Going to Theatre	Recovery	Check Ups	Leaving
happy						
supported						
safe						
good						
comfortable						
in pain						
worried						
lonely						
sad						
Write your own words here						
<div style="border: 1px solid green; height: 100px;"></div>						



Quick tips on observation

Take a step back and look at what is happening with fresh eyes. Try to imagine that you are a patient, a visitor, or a child – what do you notice and how would you feel?

Just sit and watch what goes on.

Don't forget your other senses; think about what you hear or smell.

Don't jump to conclusions or solutions. Observation helps to inform you, but you need to work with others to understand what changes to the service may be useful.

Get people to show you what they do rather than tell you. You want to see what happens, rather than what people think happens, or what they would like to happen.

Keep an open mind. Try not to correct misinterpretations. It is important to understand that someone's experience is their 'truth', even if from your perspective it is inaccurate.

Look out for pauses, obstacles, body language. What do people care about and, how they have adapted their environment to make it work for them?

Be aware of things that surprise you.

Understand the experience

Whatever your sources of information on patient, carer and staff experiences (e.g. interviews, films, transcripts, forum feedback, surveys, complaints, compliments) you are looking for the same thing – emotions, which are the route to understanding people’s experience of the care process.

In other words:

- **What** people feel when they use your service
- **When** they feel it

This section will enable you to map what people feel and when they feel it. The way in which you do this will be dependent on what you have captured, sometimes you may do all of the elements separately or they can also be combined into one activity. The principles are to:

- Identify **emotions**
- Find the **touchpoints**
- **Map the emotions** to the **touchpoints**

Identify emotions

Identifying emotions involves looking for words or phrases that directly describe the emotional impact of a care experience – whether positive or negative – from the information that has been captured. These words may already have been identified if, for example, you have used the experience questionnaire. They are personal to the individual using them and are crucial in leading us to the parts of a service that have the greatest effect on patients and carers.

Don’t worry about whether you may be missing some words or whether the ones you are identifying really are emotion words – if you think they tell us something about how a person was **feeling**, they are likely to be right.



Guide to identifying emotions

- **Review** the captured material and identify words or phrases that describe the emotion of the individual. Doing this activity with other people in your team, or patients and carers will give you confidence and they may spot other useful emotion words that you might have missed.
- There will be **direct statements** such as 'I felt like', or 'it felt like'. Remember to also look for words or phrases that indirectly describe how the patient is feeling. For instance 'kind staff' indirectly describes a positive emotion. Don't worry about pinpointing the emotion behind these now – just get them on the list.

The **ebd** approach is about capturing emotions, but that doesn't make it a soft or fluffy process.

John Pickles, Consultant

In the early days of the airlines they (touchpoints) were referred to as the "moments of truth", the crucial times when you call to make a reservation to take a flight or when you arrive at the check-in desk when your overall view of the airline, good or bad, is formed.

Carlzon 1987

Identify touchpoints

A touchpoint is any moment where a user interacts in some way with the service. In the NHS, for instance, touchpoints might be:

- When you phone your doctor's surgery for test results
- When you first see a consultant for your diagnosis
- When you go down to theatre for your operation.

A pathway or process map* gives an understanding of the concrete steps or activities of the process. This is a good start, but touchpoints are not limited to the process steps of care, as they are based on the patients' 'subjective' experience of care. By systematically identifying the touchpoints, you can map the most important elements of a service from the point of view of the patients who experience it.

**More information about process mapping is available in the improvement leaders guides at:*

[www.institute.nhs.uk/building_capability/building_improvement_capability/improvement_leaders'_guides:_introduction.html](http://www.institute.nhs.uk/building_capability/building_improvement_capability/improvement_leaders_guides:_introduction.html)

The whole emotional mapping exercise was a **clever idea. It helped us **look again** at all aspects of our experience: from the fall itself and the ambulance arriving; to the **pain**; the operation; how much **information** we were given; right through to **going back home**. It helped me think about some of the things that could have been **better**.**

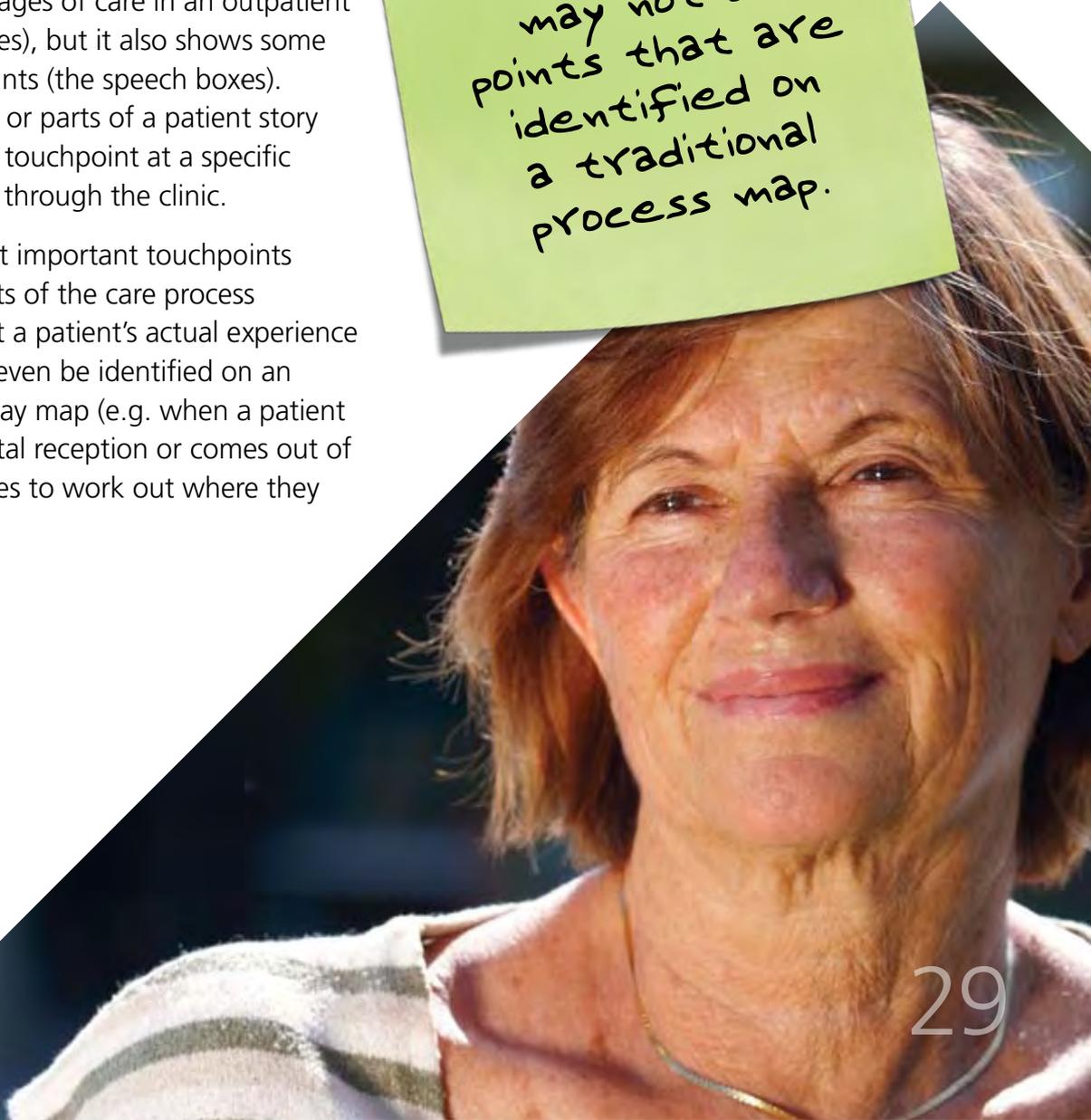
Joan Taylor, Patient



On page 30 is an example of a simple process map. It shows the stages of care in an outpatient clinic (the green boxes), but it also shows some key patient touchpoints (the speech boxes). These are anecdotes or parts of a patient story that have revealed a touchpoint at a specific stage of the journey through the clinic.

Sometimes, the most important touchpoints won't be formal parts of the care process because this is about a patient's actual experience and they might not even be identified on an initial process/pathway map (e.g. when a patient walks into the hospital reception or comes out of a hospital lift and tries to work out where they need to go).

Remember that touchpoints may not be points that are identified on a traditional process map.



Take a look at some real patient experiences in an outpatients clinic.

← touchpoints

stages of care →

“You have to **get there early** to claim a seat”

Patient arrives at clinic

Reception opens at 9.30am

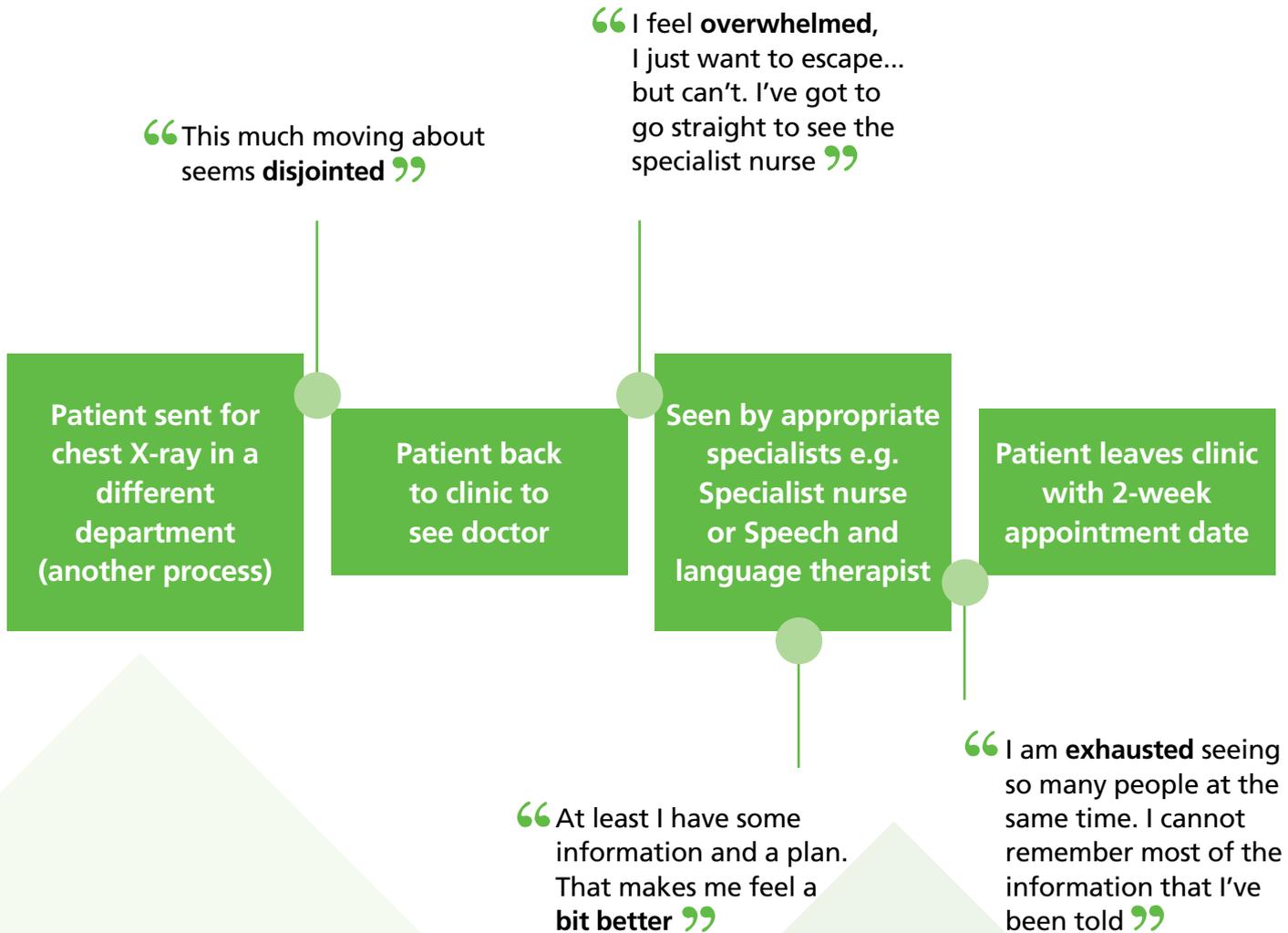
Patient registers with reception

Patient sees surgeon and oncologist

“There was also an orthopaedic clinic going on. I **wonder what happens** if you wander into the wrong clinic? Do they just do something to your hip instead?”

“The receptionist was so **friendly and helpful**”

“Not being able to **take it all in** especially when being told bad news and information about what to do next”



The **ebd** approach to finding the touchpoints

- **Review** the experience resources one by one (e.g. the patient's story, diary, complaint) looking for instances where a patient is describing how they felt during contact with the service (a touchpoint).
- **Patients/carers' focus** may not be what you expect as it is their experience of interaction with the service, not a comprehensive review of the pathway.

Mapping touchpoints to emotions

Having identified the emotions and touchpoints from the patients' perspective there are options about how that might be taken forward. It might be obvious where the emotions map to the touchpoints. Once the emotions and touchpoints are linked then it is important to feedback to the patient, carer and staff groups, or individuals to ensure there is agreed understanding. There are a variety of ways this may be done for example, a specific emotional mapping workshop.



See pages 76-80 for more information on how to run an emotional mapping session

Emotions and touchpoints example

On the next page are some excerpts from a tape-recorded interview where a patient is describing their experience of having surgery. The column on the left gives excerpts from the story. The other two columns give the emotion words and touchpoints that have been identified.

Patient describing their experience of having surgery	Emotion words	Touchpoints
<p>So when I went home, I got on the internet and it actually sounded very daunting. So I had a week. So when I came in on the Thursday morning, I knew I had the opportunity to see the consultant and I got a little green book which was full of questions and all the stuff that I wanted to find out and we went through it again and I asked him what would happen if I decided to withdraw.</p>	<p>Daunting</p>	<p>Searching the internet</p> <p>Information from consultant and written material</p>
<p>He knew that I'd been a nurse and he said, I think you know what would happen next. And then he talked about if you left a lump untreated and everything, and I just said to him, well, I don't have a choice then. You must do it. So that was okay. And ...it was all right, because my husband was able to stay with me.</p>	<p>No choice</p> <p>Okay</p> <p>All right</p>	<p>Discussing decision to have surgery</p> <p>Carer able to stay with patient</p>
<p>And they looked again and said, we'll just release a stitch... and at eleven o'clock at night I was told, you have to go back to theatre. I had to go all the way to the downstairs theatre and I actually didn't say anything to anyone, but I felt that that was one time I could die. I felt so bad about it.</p>	<p>Did not speak</p> <p>Felt I could die</p> <p>Felt so bad</p>	<p>Post-surgical complication</p>
<p>But anyway we got back about five, and at eight o'clock the three consultants were round my bed and I looked at them and said, I think I look better than any of you do! And I found it was very much give and take with them. They were so kind, and Friday was quite a good day.</p>	<p>Give and take</p> <p>Better</p> <p>Kind staff</p> <p>Good</p>	<p>Waking up after surgery</p>

Improve the experience

You can use the rich understanding and insights that you have gathered through the **Capture the experience** and **Understand the experience** phases of **the ebd approach** and link these into a number of core areas of work that you might already be involved in. For instance, this information may provide you with a better understanding of complaints that might have been received; or they could provide valuable information to support a current improvement project or other service re-design work.

Some of the information gathered will lead you almost instantly to be able to make an improvement, but in addition to these you will find areas that are much more complex and require time to develop a number of ideas around potential solutions. If you are looking to generate a number of different or innovative ideas, the book **Thinking Differently** can help to get you started – go to **www.institute.nhs.uk/thinkingdifferently**.

Involving staff, patients and carers in not only sharing their experiences but also in developing ideas and potential solutions is a really good way of making sure that actions are more likely to meet all their needs. This ensures that experience is the focus of the solutions. Working in a collaborative way with staff, patients and carers is called **co-design**.

The benefits of co-design

Co-design does take some planning, co-ordination and a different mindset – not many teams are used to working with patients as genuine partners and this can cause some apprehension at first.

The essence of co-design is to generate a shared understanding between patients, carers and staff. It is this understanding that leads to a different perspective on the service and the improvements that could be made.

Sites who have used a co-design approach have found that it is:

- A natural way to progress the relationships that have already emerged between patients and staff in earlier stages of **the ebd approach**
- A way to actually lessen the workload on staff; with patients and carers taking on many of the improvement actions themselves
- A way to keep up the momentum of change – where patients are part of the change team, they bring enthusiasm, drive, energy and a level of expectation.

Co-design is about getting the right people, setting up the right structures, the right events and being organised. In this respect it is the same as many improvement or redesign initiatives.



See page 48 for more information on Roles and structures

We recognise it is often reassuring to see how others have tackled things and what they learned along the way. The Head and Neck Cancer Service at Luton and Dunstable Hospital NHS Foundation Trust were one of the first NHS teams to use the co-design approach. The next pages show what they did, and some of the reactions they encountered on their journey.

There's a lot of lip service paid to the whole idea of patient involvement. Some services think they can invite a patient to sit on a committee and that's the 'involvement' box ticked. Of course that just isn't enough and we have to get beyond the token gesture.

John Pickles, Consultant



- Invested a lot of time getting staff interested and on board
- Approached patients and built trust
- Asked patients to keep journals; photo diaries and interviewed them on film
- Interviewed staff on film
- Got patients and staff together (separately at first) to:
 - reflect on their stories and experiences (good and bad)*
 - identify and map the touchpoints*
- Brought patients and staff together to share experiences and agree priorities and actions

**Capture
the experience**

**Understand
the experience**

“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”

Nurse specialist

“Working with patients like this was new territory for us, 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”

Nurse specialist

- Created a number of smaller 'co-design' teams of patients and staff to take forward agreed actions
- Involved patients as equal partners in redesigning services
- Made 43 concrete improvements to the service, some of which were simple and others more comprehensive service developments

- Having patients involved throughout give you a kind of instant measure and check that any changes you make are an improvement
- For more comprehensive changes, appropriate measures were developed
- Used the enthusiasm of patients to keep us mobilised

**Improve
the experience**

**Measure
the improvement**

“ The thing that’s amazed me about this whole experience is how much can actually be achieved with little or no money – simply because we’re working as equals alongside staff, sharing ideas and finding commonsense solutions ”

Patient

“ I actually enjoy going to the clinic now for my follow-up appointments. It’s a much more user-friendly place to be ”

Patient



Measure the improvement

As with any improvement work, it is important to be able to evaluate the impact and success of your **ebd approach** intervention. This isn't about measurement for measurement's sake. Measurement will help you understand the difference your work has made and, importantly, enable you to celebrate, share and sustain the improvement.

There is a vast amount of guidance and literature to help the NHS get better at measurement.

In **the ebd approach**, success can be measured in terms of:

- **Subjective outcomes** (for example, the way patients feel – their experience) – you can use experience gathering techniques to capture this information
- **Objective outcomes** (for example, reduced waiting times; fewer critical incidents; improved performance, safety and reliability)

You can think about measurement tools being another touchpoint of your service, and in their own right they should be designed to create the right experience, as well as gathering useful data.

Remember to think about what you will measure and how you will measure it at the start and throughout your project.

By emphasising experience you often find that both patients and staff are more likely to complete your measurement tool. You should also consider ways that the rich, experience data can be fed into the more standard reports that are used within your organisation.

Measurement methods can range from formal to informal and quantitative to qualitative. There is no single best way, but to help you decide on your measurement mechanisms, just think about the following:

- Know what **success** will look like
- **Understand** what matters; measure what matters; change what matters – in other words, assess against what was considered important at the outset
- **Evaluate** for learning, not just for what worked – regardless of what happened there is a chance that you will have learned something that will help you do it better the next time round*

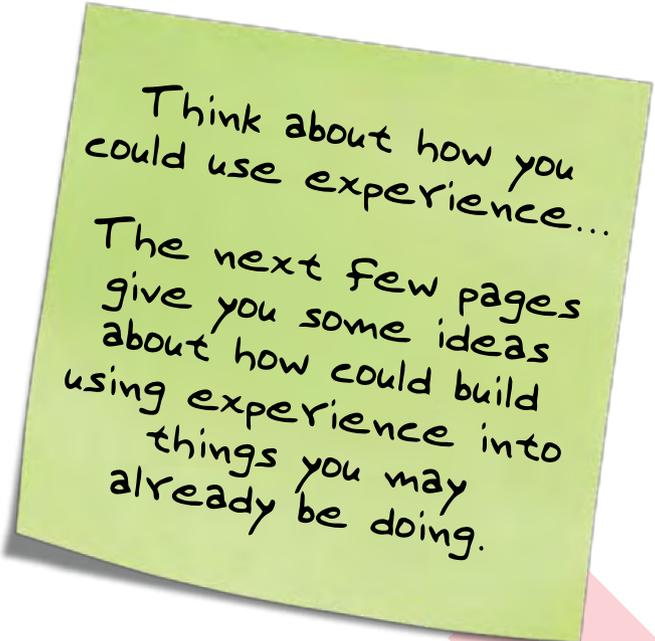
**Source: based on Bate, S.P. and Robert, G (2007) Bringing user experience to health care improvement: the concepts, methods and practices of experience based design. Oxford; Radcliffe Publishing*

And finally...

If you have got to the end of this guide, hopefully you will feel enthused about trying out some elements of experience based design. We can't emphasise enough that **the ebd approach** is not a prescriptive 'you have to do it like this' approach.

Anything that you can do to start to consider, work with and improve patient, carer and staff experience is great. If you are stuck for the next step, the next few pages give some ideas about how you could build experience into things that you may already be doing. You could also look through the tools, or **the ebd approach** concepts and case studies booklet to see examples of what others have achieved.

Where people have made the first steps to try out **the ebd approach**, they always find that other staff are interested in what they are doing. So don't feel daunted, think about what small steps you can make to start on the journey of designing better healthcare experiences for patients and staff.



Think about how you could use experience...

The next few pages give you some ideas about how could build using experience into things you may already be doing.



Think about how to use experience...

...in your improvement project

...when working with compliments and complaints

...in patient forums

Your **current** approach to engaging patients and staff in your improvement project might include...

- Gathering information about the service area you are seeking to improve, for example:
 - patient surveys and interviews
 - compliments & complaints
 - patient focus groups
 - process mapping
- Inviting patients and carers to become active members of an improvement project's steering group
- Analysing the information gathered through the routes identified above, and using this to identify key points where improvement efforts should be focused. Process mapping is a tool often used in this process – see the Improvement Leaders Guide to process mapping*
- Staff and managers often take action based on their own professional assessment and knowledge of the service area being improved and from good practice elsewhere – some teams create opportunities to 'check back' with the patients and carers involved with the work to ensure the improvement is on the right track

*Find the improvement leaders guides at:
www.institute.nhs.uk/building_capability/building_improvement_capability/improvement_leaders_guides:_introduction.html

An **ebd** approach might include...

- As well as involving patients and carers in your advisory group you could engage a number of patients in your project and ask them to share their own experiences of the service or process



See **pages 54-63** for more information on **sharing experiences**

- Use what you have learned from patients' and carers' stories to identify the emotions and touchpoints (key moments and interactions) in a pathway where people's emotions and experiences are shaped – this information can add important detail to your process map

See **page 28** for more information on **identifying touchpoints**

- Review the process map that has been developed highlighting patient and carer emotions to clearly identify the actions that need to be taken to improve the patient experience of care
- Work with staff to implement and then later review the changes made
- Communicate with patients about the actions being taken, the changes made and invite them to review the improvements

An **ebd** approach including co-design might include...

- In addition to collecting patient and carer stories, collect experiences and stories from staff too, using the same techniques
- Involve patients, families and staff in emotional mapping, helping them to highlight points within their journey which they remember with emotion. These will form the touchpoints in a pathway where emotions and experience are shaped
- Encourage the patients who have provided their stories to continue working together with staff to help with actually co-designing an improved service or process



See **pages 70-75** for more information on **experience events and co-design events**

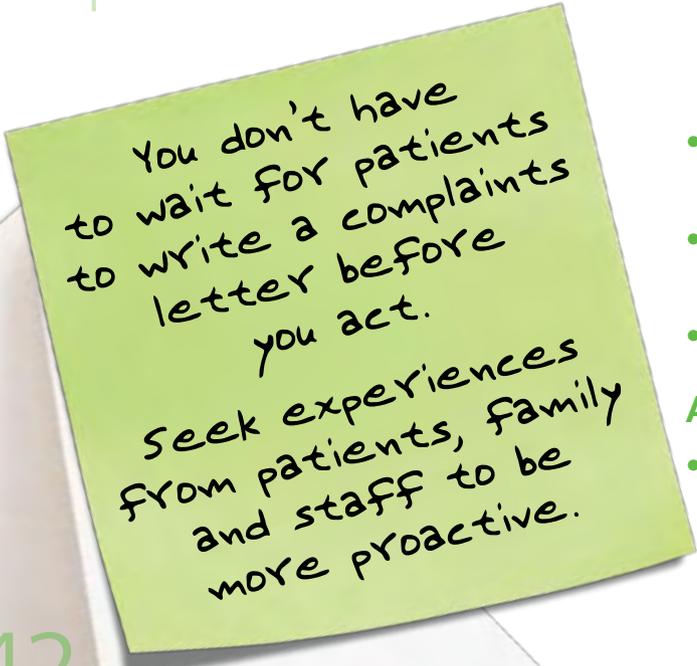
- Invite patients and family members to work with staff to prioritise and implement the actions needed to improve the service
- Bring together patients/family members and staff to review the improvement
- Capture the on-going experience of patients and staff currently using or delivering the service in order to sustain the gains and make things even better

Think about how to use experience...

...in your improvement project

...when working with compliments and complaints

...in patient forums



You don't have to wait for patients to write a complaints letter before you act.

Seek experiences from patients, family and staff to be more proactive.

Your **current** approach to using feedback might include...

- Patients send a letter identifying areas of compliment or complaint
- Staff gather understanding from the information given within the compliment/complaint
- Key aspects of the complaint/compliment are identified e.g. kindness from staff, long waiting time, poor communication
- Staff and managers take appropriate action, based on consultation with colleagues and professional assessment and knowledge about the particular area
- A response is developed and sent to the patient detailing actions that have or will be taken
- Once implemented the changes are reviewed by staff to ensure the problem is resolved
- Compliments and complaints are audited

An **ebd** approach might include...

- Arrange to talk to the person who is making the compliment/complaint, either by telephone or face to face if appropriate (care and advice must be taken if there is any possibility of legal action). This will get you even closer to the person's experience

- Pinpoint the 'emotion' words within the text of the letter, or as you speak to the patient

See page 27 for more information on identifying emotions

- Create an emotional map to help you identify the 'touch points' – key moments and interactions in a pathway where emotions and experience (good or bad) are shaped



See page 76 for more information on emotional mapping

- Talk with staff in the service area too, sharing the compliment/complaint and gathering their views
- Work with staff in the service area to strengthen or replicate areas of compliment or in the case of complaints gather their views on what went wrong and what could have been better. Following this, staff should identify and implement improvement actions
- Communicate with the patient and family about the actions
- Review the improvements made with staff
- Invite the patient and family to review the changes made

An ebd approach including co-design might include...

- Rather than waiting for compliments and complaints you can be proactive in gathering and understanding staff and patient experiences of delivering and receiving care
- Capture these experiences using different mechanisms e.g. through photo journals, diaries or films created by patients and staff
- Identify the emotions in the stories you have gathered
- Involve patients, carers and staff in mapping these emotions. Together, find the touchpoints – the key moments and interactions in a pathway where emotions and experience (good or bad) are shaped
- Invite the patient and/or a family member to actively work with staff to help identify, prioritise and implement the actions needed to improve the service
- Bring together the patient, family and health care staff to review the improvement
- Capture the experience of other patients and staff currently using or delivering the service

Think about how to use experience...

...in your improvement project

...when working with compliments and complaints

...in patient forums

Your **current** approach in using forums might include...

- Patients are invited to participate in a forum which either has a specific focus (for example; about a proposed extension to services) or which is for general commentary (for example; an annual review)
- Comments and feedback from forum members are collated and shared
- Key themes are identified, for example concern about capacity, poor communication, as well as services that have gained positive recognition
- Staff use this information to identify and implement potential changes based on their professional assessment and knowledge
- Changes made are reviewed and fed back to staff and the forum participants

An **ebd** approach might include...

- Invite staff to forum events to hear experiences first hand. Gather their views on what went well or could have been better
- Make contact with any forum members who have given feedback. Explain why their experiences of care and stories are important and ask them if they would talk to you in greater depth. This will get you even closer to their experiences



- Talk with staff involved in any service area identified by forum members as good or poor – explain **the ebd approach** and gather their views
- Use what you have learned by talking to patients and staff in greater depth to identify emotion words – either as you speak with them or by later reviewing what they have said
- Create a map of these emotions to help you identify the touchpoints – i.e. the key moments/interactions in a pathway where people's experiences (good or bad) are shaped

See page 28 for more information on identifying touchpoints

- Work with staff in the service area to identify and implement improvement actions
- Communicate with the forum members about the actions
- Review the changes made with staff
- Invite forum members to review changes made
- Provide feedback on the work and actions undertaken to subsequent patient forums as an example of the work you are doing to capture, understand and action improvements for patient, carer and staff experiences

An ebd approach including co-design might include...

- Proactively seek views and experiences from patients, families and staff on your service or pathway
- Capture these experiences using different mechanisms e.g. through stories, diaries or films created by patients and staff
- Use the stories you have gathered to populate a more detailed process map showing the different stages of the service/care pathway
- Use emotional mapping to identify where the touchpoints occur and involve patients, families and staff in this process



See page 76 for more information on emotional mapping

- Invite patients and carers to actively work with staff to help identify, prioritise and implement the actions needed to improve the service
- Bring together the patient, family and health care staff to review the improvement
- Capture the experience of other patients and staff currently using or delivering the service

Tools and approaches

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This section contains a variety of tools and approaches

These tools have been developed to support you in using the **ebd approach.**

They have been developed with NHS teams who have used **the ebd approach** to design better healthcare services.

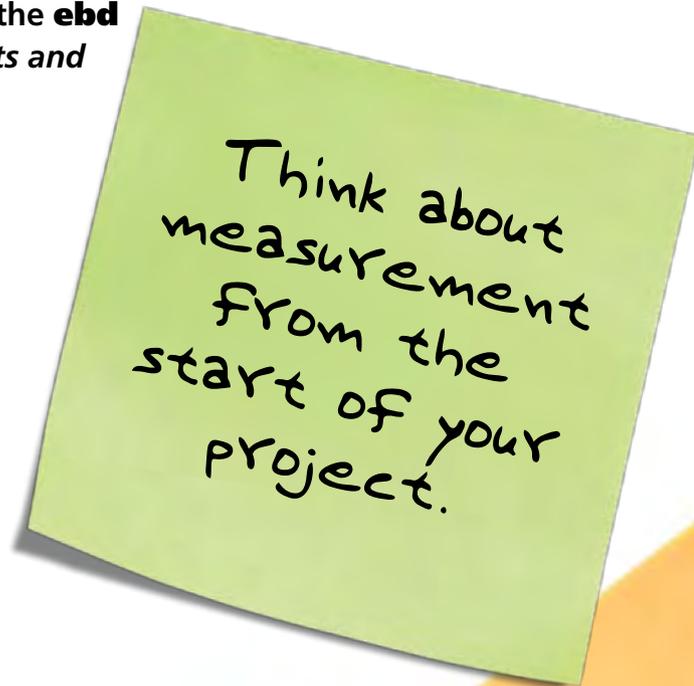
The tools are divided into the four steps of **the ebd approach**:

Remember to refer back to the guide for information on the tools and where they fit into **the ebd approach**. There are examples of them in **the ebd approach – Concepts and Case Studies** book.



All tools are available to download from the website and some of them can be amended for local use.

Look out for this icon.



Roles and structures

Here are some examples of the roles and structures that you might want to consider when using the **ebd** approach. You will recognise many of these as being similar to the roles and structures used in service improvement projects.

Core team

The core team is made up of those people who are directly responsible for delivering a particular service. This will include members of the multidisciplinary team.

It is important that the senior leader responsible for the service is involved. You may want to bring other members of staff into this group, this might include people who are interested in learning about experience based design. The core team will meet regularly and be responsible for all aspects of the initiative just as in improvement projects or any change management.

The patient group

During your **ebd** approach project you should build a group of patients who are willing to participate in the project.

Staff

Once you have identified the pathway or service area that you are working on you should seek to engage staff who work in that area.

Advisory Group

The advisory group consists of key stakeholders. This group meets on a regular basis (1-2 monthly) and provides advice and overall direction to the work. It is recommended that the advisory group includes senior leadership as well as patient and front line staff representatives.

If you are using a co-design approach the following groups are important.

They work together to identify and implement improvements in key work areas which result in the design of different experiences.

Co-design group

The co-design group consists of everyone involved with the process – all staff and patients should be part of the co-design group.

This group comes together to listen to all of the stories and information gathered. They then agree on areas of focus for improvement.

Co-design teams

Co-design teams are groups of patients and staff that form around specific areas of interest that have been identified through the larger co-design group. There may be as many as 6-8 separate co-design teams working on specific areas, for example; dignity when being examined, safety aspects of procedures, waiting times or patient and carer information.



Tools to help raise awareness and engage people to become involved

Posters and leaflets act as useful prompts which lead to further conversation and discussion about the approach and the project.

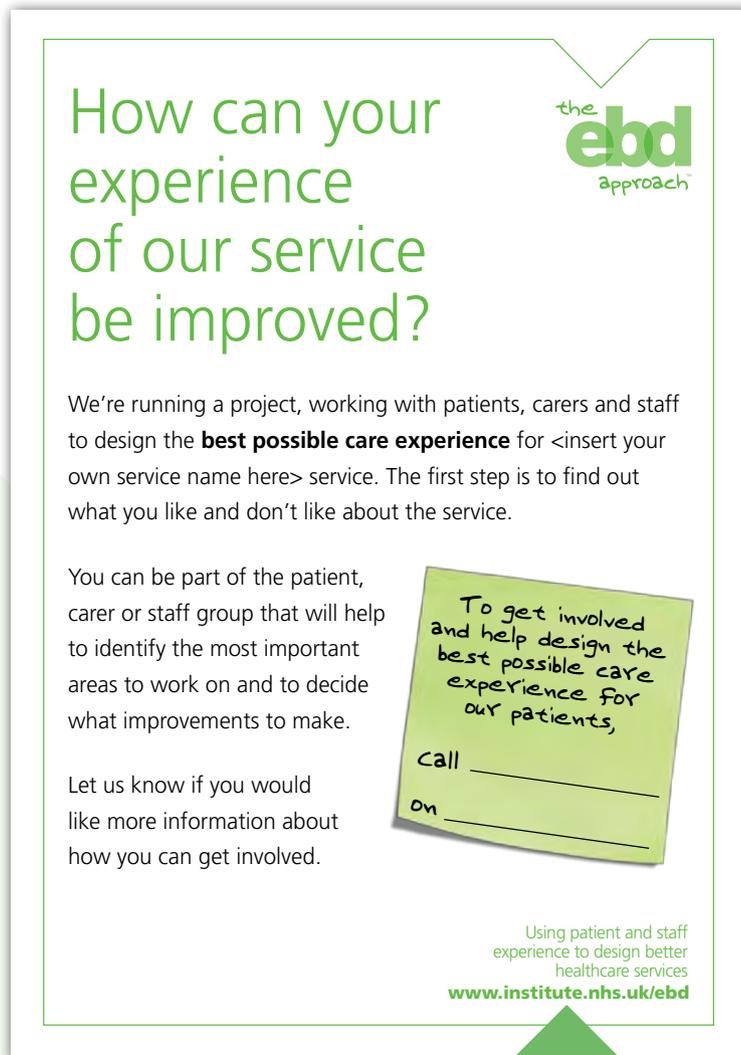
In addition to using posters and leaflets we have found that it is even better to allocate time to talk, 'face to face' with people about **the ebd approach**.

Raising awareness of your plans to use patient, carer and staff experiences to improve service delivery is a critical element of the work. Posters and flyers are useful mechanisms to both raise awareness and let people know how they can get involved.

Posters

If patients and staff understand what the project is trying to achieve then they will be more open to getting involved. Use notice boards or display areas that are prominent within the space that you want to do the work. You can customise, download and print a poster from the website.

**Alternatively make your own!
Ensure the poster has appropriate contact details in the space provided.**



Download this from
www.institute.nhs.uk/ebd

Information leaflets

Information leaflets compliment the posters. Leave them in an area where people will be able to pick them up and read at their leisure. Leaflets contain more detailed information than the posters but still invite people to get involved and provide details about how they can do this.

Customise, download and print off as many leaflets as possible, these are a great way to get people engaged and involved. They can be taken away and shown to family and friends.

The **ebd** approach is here!



The aim

We want to work with patients, carers and staff to **design the best possible care experience** for our patients. The first step is to find out what you like and don't like about the service.

How will we achieve this?

We would like to learn more about how the service looks through your eyes, by listening to your stories and experiences. Your experiences will be used to identify important areas for action and to decide what improvements to make.

Who will decide what improvements if any should be made?

A group of patients, carers and staff will work together to identify areas for improvement and the actions that need to be taken.

How can I help and what will this involve?

You can help by sharing the story of your recent experience of care. If you would like to continue to be involved you can join a group of patients, carers and staff group who will decide what improvements to make.



Using patient and staff
experience to design better
healthcare services

www.institute.nhs.uk/ebd



Download this from
www.institute.nhs.uk/ebd



Capture the experience

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Filming your interviews 60

Keeping a record of your interviews

Observation guide 64

Finding out what people really do

Patient consent form and patient letter 66

Gaining consent for interviews, and a letter explaining the project

Tools to help people tell their stories

Storytelling is at the heart of using experience to design services and the whole approach centres around giving patients and staff the time, encouragement and help they need to tell their experiences in their own words.

We have found that one of the most effective ways of gathering stories is through one-to-one interviews with patients, carers and staff. However there are a range of methods to choose from to suit your local context.

Capturing people's stories, emotions and feelings is key to being able to use experience to design better healthcare services.



Experience questionnaire

The experience questionnaire is a simple way to find out how your patients are feeling as they pass through the various steps of the care process.

It won't tell you everything and is not a replacement for other techniques but it will give some idea of the emotions experienced by people as they pass through your service. The questionnaire is also a way of asking people if they want to get involved in your project.

What is it?

The experience questionnaire is a tool to gather people's feelings/emotions at certain points of the process of care.

Why Use it?

By providing an indication of what people feel at particular points during the process of care, it is possible to celebrate the positives and identify areas that you will want to find out more about and improve.

It is also a useful tool in helping to identify the ideal emotions/feelings you want to evoke at each point in the process of care, when designing a patient journey/pathway.

How do I use it?

You might want to start by asking 5-10 patients to complete the questionnaire, review the information provided and decide what you might explore further. A small amount of this rich feedback can provide useful information.

Teams using the experience questionnaire have found it to be especially useful for patients and carers involved in short stay services, for example an overnight stay or day case procedures.

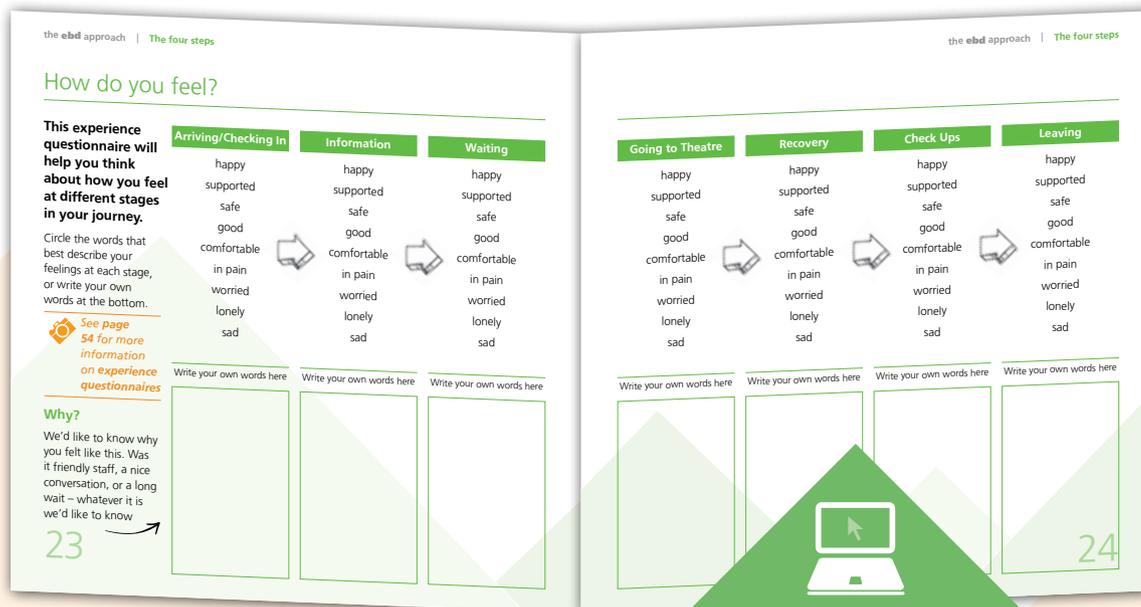
- 1. Download the experience questionnaire** – the word version is amendable so that you can make changes to suit your local context. You can also choose which emotion words you would like to include
- 2. Print and distribute** the questionnaire to patients and provide an explanations leaflet about your **ebd** project or verbally explain

how you will use the information provided

- 3. Allow the patient time and space** to complete the questionnaire. You might also need to provide a pen!
- 4. The information is collated and discussed** with staff and positives are celebrated. Areas for improvement in patients' experience are identified

- 5. The questionnaire can be re-issued** to be used as a measurement tool and/or as a continuous improvement approach

See *page 23-24* for an *experience questionnaire you can photocopy*



Patient and staff experience log

What is it?

The patient and staff experience log is a tool used to capture their experiences of delivering and receiving care. People are able to write notes, capture thoughts and illustrate, through drawings and doodles, how they feel.

Why should I use it?

This tool is particularly useful because it enables a range of different capture methods to be used to suit preferences, time and mood.

How do I use it?

Staff working in any area are able to use this tool as it provides the ability to capture experience throughout the whole range of their working patterns over a period of time.

For patients the log is most suited for use during health care episodes that are over a period of at least several days.

- It is important to stay connected to people who are developing their log and together you should agree a date when the information can be shared
- As with any material that contains patients and staff personal thoughts and experiences you should arrange safe (locked) storage once the log has been handed in

Identifying patients and staff: Make sure all those involved in the project are invited to use the tool, and ask them to identify others who might be interested in recording their experience of the service. Contacting people through someone they already know often helps with engagement of hard to reach groups in particular.

Distribution of the experience log: Maintain a record of who you provide with an experience log so that you can maintain contact with them.

Collecting the experience logs: Ensure everyone knows where to return the completed logs and by when you would like them to be returned.

Collating data from the experience logs: Because the experience logs enable patients and staff to record their experiences in a variety of ways it will be useful to sit down with the owner to help understand their emotions and feelings throughout the process.

Examples of a patient and staff experience log can be download from **www.institute.nhs.uk/ebd**.



Gathering experiences through voice/audio recording

The value of the interview

Interviews can take a long time to set up, undertake and understand the information captured. However, teams that have tried this approach have found that the richness of the information that is gathered is well worth the effort.

This section provides some simple principles which you can follow to make sure that your interview is as successful as possible and as positive as it can be for the person sharing their story.

Although you may want to carry out the interviews yourself, it might be useful to consider asking other staff, patients or carers to help.

Print out the interview guide from the website (see next page) and keep it handy as a prompt when doing interviews.

One opening statement and question that has worked well in previous projects is:
“We really want you to tell us your story in your own words, with as few interruptions from us as possible, but we have some prompts if you would prefer that. So... let's begin at the beginning. Tell us your story in your own words...”

It is really important to enable the storyteller tell their story, so you must avoid interruptions and your opinions about anything that is said. Suspending judgment while you listen to individuals' experiences is essential to being able to get the most from the stories.

It's all about getting the patients to remember their experience.

So questions like: 'what did it feel like?' or 'what did you think when you came onto the ward for the first time?' are good ones.

Interview guide



Fold here

Interview Guide

the **ebd** approach

available to download
www.institute.nhs.uk/ebd

- 1 Prior to the interview make sure that you have the equipment you need:

 - Interview – paper and pen
 - Interview and voice recording – Dictaphone/digital voice recorder (check that the microphone is sensitive enough to pick up the voices)
 - Interview and filming – video camera, including sound recording, and tripod.
- 2 If you are filming the interview read the next section (filming your interviews) before you start.
- 3 Prepare the interview space before the storyteller arrives.

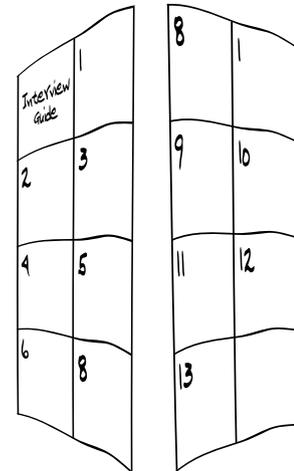
Make it comfortable (to avoid unnecessary fidgeting). Move away from noisy appliances like clocks, TVs and refrigerators. If you can't then think about turning them off or if possible moving them out of the way.
- 4 It is important to make sure that the storyteller understands and consents to telling their story, and for you/your organisation to use it as part of the improvement work that you are doing.

See page 66 and website for more information about consent.
- 6 Make sure you and your story teller are comfortable and take your time to begin. Have refreshments available.
- 5 It is important to find out how much time is available – make sure you keep to the time allocated.
- 7 Start each interview by introducing yourself, the date and the location of the interview.

For example, "Hello, my name is Paul, I'm 47 years old. The date is August 3rd, 2014, and we're sitting here in Doxford Park Community Centre."



download this guide from the website



tape, glue or staple the two A4 sheets together, back to back



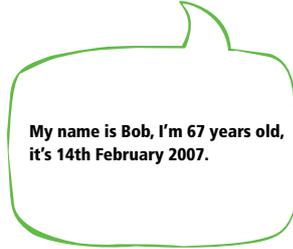
fold up to fit in your pocket, unfold when preparing for interview

Fold here

8 Ask your story teller to state the same information.

Try to start with an easy introductory questions to ease the story teller into the interview, for example:

“Have you travelled far?”



9 Stay quiet when the story teller is talking. Try not to speak over them because it will make the recording unclear as well as making what they say seem unimportant.

Provide non-verbal encouragement to continue such as nodding your head and smiling.

10 Enable the story teller to do just that – tell you their story.

You may need to use prompts at times such as; how did that make you feel, tell me more about that...

11 If you do ask questions, make sure they are ‘open’ such as “what do you do?” rather than closed questions which can be answered with “yes” or “no”.

12 If the story teller is keen on a particular topic or issue, let them stay with it. Ask follow up questions or use prompts as needed.

13 Manage the time and steer the interview to a natural close.

Remember to thank the story teller for their time and for sharing their story with you.

Make sure that they feel OK before they leave.

the ebd approach™

Filming your interviews

Successful interviews depend on building up a rapport with your interviewee – something that can be more difficult if your head is down and you are frantically scribbling notes.

Audio recording and filming are both more effective than note taking alone, a combination is even better. Gathering an accurate record of stories enables you to identify important experiences, emotions and insights of the person's journey through the health care process. You will find that it is this valuable information that provides the basis of all other stages of the ebd approach.

Quick tips on filming

Consent:

Ensure the consent form makes it clear that the interview is being filmed and states exactly how the film will be used in the future.



See page 66 for more information on consent

Security:

The film or any recording should be stored securely.



See page 63 or the website for more information about the Data Protection Act

Positioning:

The camera needs to be positioned in the best place to record the interviewee's voice and face, even if it appears to be prominent. The camera is usually quickly forgotten once people start telling their story.

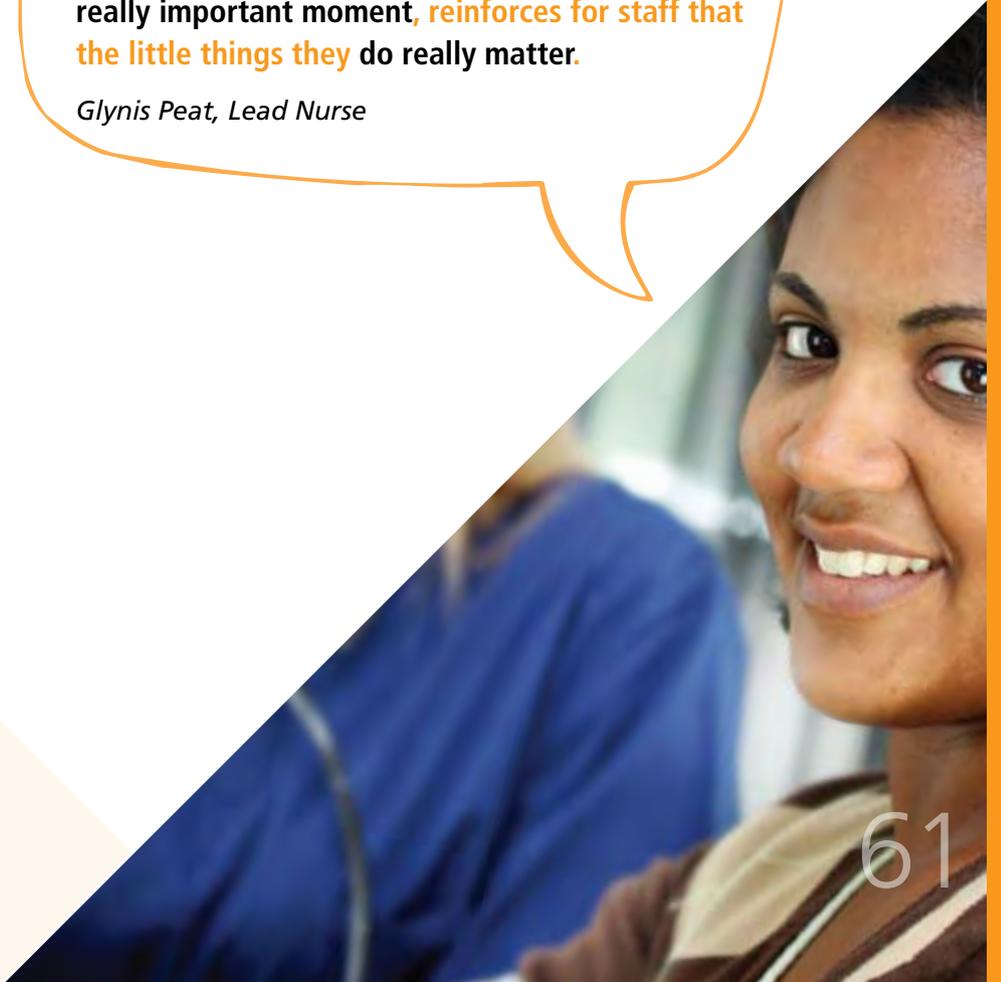
After only a few interviews you will find that you have large volumes of film and/or audio footage. This will need to be edited in order to draw out the important experiences and insights that you will use in the next stage – understand the experience. Editing can be time consuming and does require some skill.

Video editing

Once you've gathered your footage being able to edit your video footage will make it much easier to use and distribute. Often there's someone close to hand who has experience of video editing and is willing to give some support to the project. Find out if you have an audio visual department that might be able to help. Does a member of your staff have the skills and/or a camera that can be used?

For me, the videos have another amazing strength as a staff training and feedback tool. For instance, lots of nurses and health care 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 and seeing patients recall that part of their experience as a really important moment, reinforces for staff that the little things they do really matter.

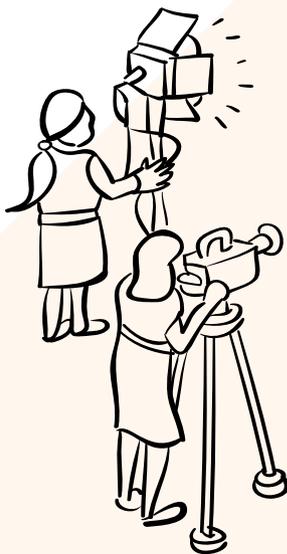
Glynis Peat, Lead Nurse



Film is a fairly new medium for most trusts (including us), and you have to invest a bit of time getting people used to the idea of being on camera. We have tended to phone patients well in advance and ask them to take a bit of time to consider the idea before committing either way

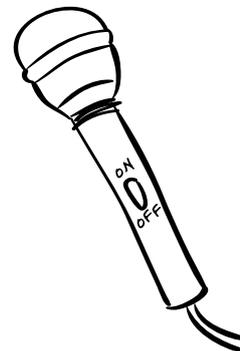
Gill Husband, Risk Management Lead

and how did this make you feel?



The instinctive response of many staff was: "you can't film in clinic; it's not allowed; patients won't like it". But once staff saw patients were comfortable with the idea, it wasn't a big issue. In fact staff (consultants as well as ward staff) are still talking about the film and still asking to see it

Elaine Hide, Nurse and Service Improvement Lead



Think about who else you could approach to provide support:

Is there a University or College near by that you could work with? Often students are keen to work on a project that has some real purpose. Find out the name of the tutor of the most relevant course (media studies/film/multimedia) and ask if it's something their students might be interested in. Editing this footage is a big responsibility so make sure that you are happy with whoever is recommended, and that they agree to work within your clear ethical principles for the project and agree a clear timetable.

See page 15 for more information on ethical issues

What do you need to know about data protection?

The Data Protection Act 1998 came into force on 1 March, 2000. The Act governs the collection, retention and transmission of information about living individuals and the rights those individuals have to see this information.

There are eight key principles which anyone who interviews patients, carers or staff must adhere to – these principles can be found at:

www2.warwick.ac.uk/services/gov/legalservices/whentouse/dataprotection/dppprinciples.



See page 66 for more information on consent

Remember that all interviewees must give their explicit consent before any data they provide can be used.

Observation guide

Another way of understanding what happens within your service is to observe. This will add to the information that you gather from other 'capture' tools and it will also result in new insights.

Observation lets you find out what people really do and how they carry out their work. Observation inspires new ideas and can help to redefine the problem or challenge that you are working on. Observation as a technique is used in many different settings especially within the design industry.

If you want to find out about water, don't ask a fish.

Chinese proverb

When you are trying to design services, you often find that:

- People do not always do what they say they do
- People cannot always tell you what they need
- Things are not always as they seem

(adapted from IDEO design company)

How can you use observation?

There are two main reasons for carrying out observation:

- Observation for understanding – stand back and observe what is really happening in your area of interest. Look at the area with 'fresh eyes' and from different perspectives – for example the patient, visitor, porter, clinician (see the **Thinking Differently guide** available from www.institute.nhs.uk/thinkingdifferently)
- Observation for inspiration – look at other situations or organisations and see what ideas you can adapt

Think about how a growing number of organisations have taken 'lean' principles from the manufacturing sector and

adapted them for healthcare in order to reduce waste and increase efficiency. What can we learn from hotels in relation to hospital bed usage? How can we learn from airports or shopping centres about parking?

Using observation for experience

Observation is a very important tool when working with patient and staff experience. It can help you to really understand different perspectives, but also to prompt patients and staff to talk about their experience of specific elements of a service.

When observing the clinic area during one of the projects it was noticed that patients were on view when being weighed. When gathering experiences, this was not mentioned.

You often cannot see
the wood for the trees

However when patients were asked how they felt, they then said they felt conspicuous and embarrassed. As a result of this observation and feedback, every set of weighing scales in every clinic was moved within 24 hours.

The key points about using observation

- Take a step back and look at what is happening with fresh eyes. You may know the system very well indeed, but if you are a patient or carer who has not been before what would you see? Try imagining you are a visitor, or a child or someone else – what do you notice?
- Try just sitting somewhere and watching what goes on around you.
- Don't forget your other senses, think about what you hear or smell. How do you feel when you put yourself into other people's shoes?
- Be careful not to jump to conclusions or solutions. Observation helps to inform you but you need to work with others to understand what changes to the service may be useful.
- When working with others get them to show you what they do rather than telling you. Being in the place where things actually happen ensures you get what happens, rather than what people think happens, or what they would like to happen.
- Always keep an open mind. Try not to correct misinterpretations. It is important to understand that someone's experience is their 'truth', even if from your perspective as a healthcare professional it is different.
- Look out for pauses, obstacles, body language, what people care about, how they have adapted their environment to make it work for them. Be aware of things that surprise you.

The key element in all observation is being out there in the actual environment, talking to the people who actually deliver or receive care. This makes sure that any improvement is always grounded in what actually happens and what is important, rather than what people think happens or think is important.

The NHS Institute has developed a tool which provides more information about the value of observation and contains an easy to use exercise.

See www.institute.nhs.uk/building_capability/thinking_differently_observation.html

Patient consent form

Use this form to gain consent from patients for interviews.

There is also a separate consent form for filming available on **the ebd approach** website.

Write the name of your project here

Write the name of the person conducting the interview here

Ask people to read the statements and tick/cross these boxes

Participant to sign here

Interviewer to sign here

Consent form for interviews



1 COPY FOR PARTICIPANT, 1 COPY FOR INTERVIEWER

TITLE OF PROJECT

INTERVIEWER (NAMED INDIVIDUALS CONDUCTING THE INTERVIEWS)

		PLEASE INITIAL
1	I confirm that I have read and understood the information sheet for the above project and have had the opportunity to ask questions.	<input type="checkbox"/>
2	I understand that my participation is voluntary and I am free to withdraw at any time.	<input type="checkbox"/>
3	I understand that I can ask for any comments I have made on tape, in writing or on film to be removed.	<input type="checkbox"/>
4	I understand that my comments (or part of them) may be used in different formats such as video, paper and/or electronic to share with others the benefits of designing services that are based on patient experience. This will include staff in health and other related industries both within and outside the UK.	<input type="checkbox"/>
5	I understand that any of my comments used may be edited and will appear anonymously.	<input type="checkbox"/>
6	I agree to take part in the above study.	<input type="checkbox"/>

NAME OF PARTICIPANT	DATE	SIGNATURE
NAME OF INTERVIEWER	DATE	SIGNATURE

Using patient and staff experience to design better healthcare services

www.institute.nhs.uk/ebd



Patient letter

This letter can be used to explain the project to patients when asking them to participate in telling their story.

You can find this letter as a word template on the website – you are able to adapt the template to suit your local context. There are also paragraphs which can be used if you decide to use film as well as tape recording.

Write the name of the person
this letter is for

Write the name of your
project here

Sign your name here

Dear _____

TITLE OF PROJECT

Thank you for recently expressing an interest to [named staff member], in the work we are doing on improving services for patients in [relevant health care organisation]. We enclose a patient information sheet summarising our project.

As part of this work it would be very helpful if we could come and hear about your own experiences. We have enclosed some suggested topics and issues that you might like to talk about or you might prefer to just retell your story. We think that it will take about an hour of your time and we would like - with your consent - to tape record our conversation so that we can try to make improvements to services based on your own experiences in your own words. Any tape-recordings will be treated as confidential and remain anonymous.

[Delete if not using film] We are also hoping to film patients whilst they are talking about their experiences, so again with your consent we would like to film our conversation with you when we meet. The film will be returned to you so that you can view it and decide whether and where it can be used. Again we would emphasise that your participation is entirely voluntary and that none of the film will be used without your prior permission.

Regards,

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experience to design better
healthcare services
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Download this from
www.institute.nhs.uk/ebd



Understand the experience

Tools to help understand experiences **69**

An introduction to understanding experiences

How to run experience events **70**

Patients and staff meeting together to produce a list of priorities for change

Emotional mapping session **76**

How to run an emotional mapping session to understand people's journeys

Tools to help understand experiences

This part of the **ebd approach is where you really begin to understand your service in terms of how patients, carers and staff experience it.**

Now is the time to use the information that has been gathered (e.g. interviews, films, transcripts, forum feedback, surveys, compliments, complaints) to understand how people feel when receiving or providing care.

See page 20 for more information on capturing experiences

In addition to the insightful comments, phrases and sentences that you will have gathered, it is important now to start to identify points in the service that staff and patients feel are good or need improving. Identifying the emotion words used by the staff and patients will help to do this.

In other words:

- What people feel when they use your service
- And when they feel it.

As people share their stories, their personal experience of care is often expressed using words that portray emotions.

Using emotional mapping to identify touchpoints (both explained later in this section), will help you to identify the right improvement priorities for your service. This technique will help ensure that you are focusing your improvement efforts where they matter most.

There are three key techniques to understand experience:

- Identifying emotions
- Finding the touchpoints
- Mapping the emotions (highs and lows) to the touchpoints.

This section includes tools to help you with these techniques.

How to run experience events

If you are using the ebd approach to co-design services – these events can also be known as co-design events.

What?

Experience events are meetings where the staff and patients that you have been working with share their experiences of receiving and providing health care services. These events should be planned for after the capture of the experience, as you are starting to synthesize the rich information gathered.

Teams using **the ebd approach** have found it particularly helpful to hold three events:

- One that brings together staff to share, listen, talk about and further draw out key themes that have emerged
- One that brings together patients/carers to share, listen, talk about and further draw out key themes that have emerged
- A co-design event that brings together patients, staff and carers to share and understand each other's experiences, to identify areas to work on and to plan the next steps (including the development of the project teams and actions)

Why?

The idea is to share experiences to generate a better understanding of the service or pathway and to identify areas for improvement action.

How?

You may already have some experience of facilitating meetings or events that bring patients and staff together, if so you can draw on your skills. There are a few important elements to running successful patient and staff events.

Patients and staff may have particular concerns that need to be overcome in order for the group to be productive.

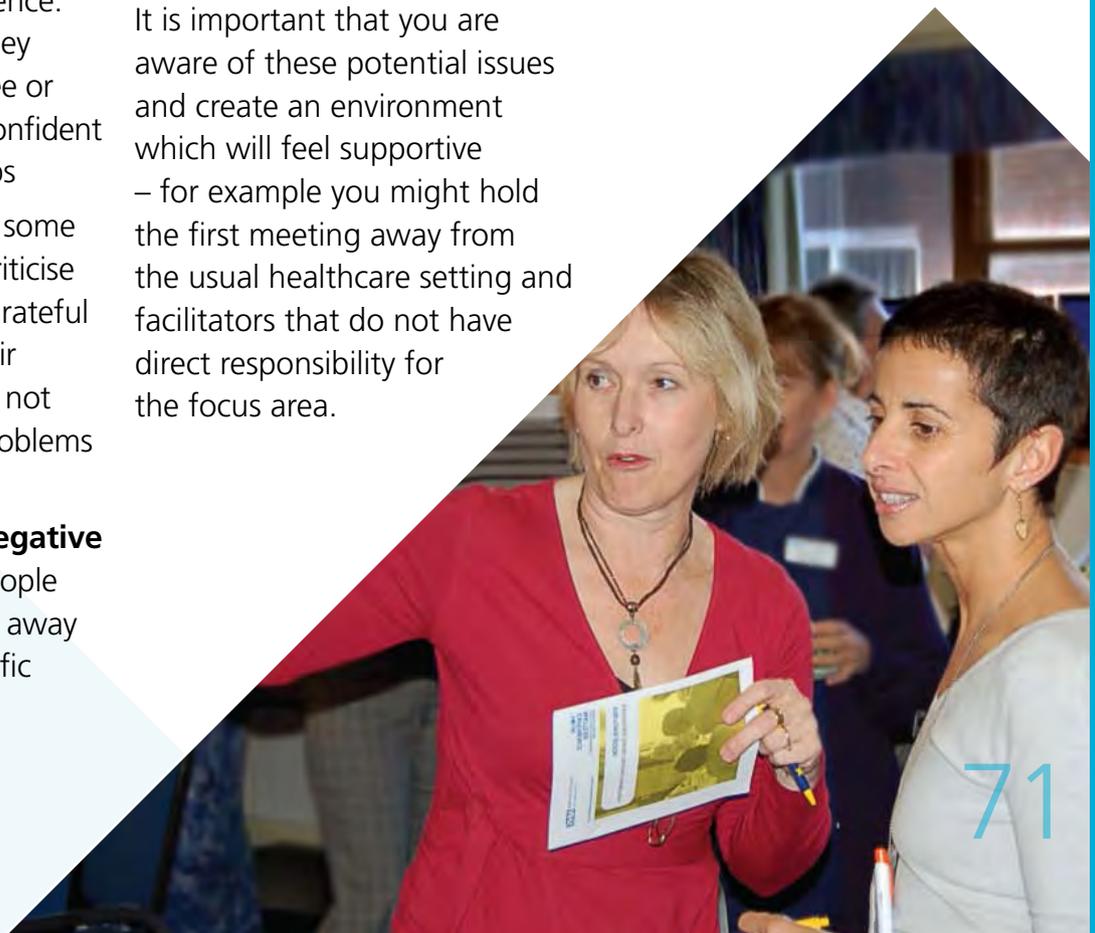
These might include:

- **Reticence** – a patient or staff member who is worried about presenting their experience. This may be because they fear others may disagree or because they are not confident speaking in large groups
- **Inability to criticise** – some people are unable to criticise a service, they feel so grateful for the outcome of their treatment that they do not want to identify any problems with the service
- **Focus on a specific negative experience** – some people find it difficult to break away from describing a specific negative experience

- **Dominance** – some patients or staff members will appear to dominate discussions with lengthy descriptions of their experiences which can leave other patients feeling frustrated and that their time is being wasted

It is important that you are aware of these potential issues and create an environment which will feel supportive – for example you might hold the first meeting away from the usual healthcare setting and facilitators that do not have direct responsibility for the focus area.

It's a good idea to provide some information ahead of the event so people know what to expect. You also need to include practical information, such as how to get to the venue.



The session should be planned so that there is an initial icebreaker which enables participants to begin to know who else is in the room.

They should include different activities that support the telling of stories about the experience participants have had and they need a clear way of identifying the next steps for the next session.

It is important to explain the potential benefits of the session to participants at the beginning.

Activities should not rely heavily on any one particular way of joining in or encouraging expression e.g. some patients are reluctant to write while others may be less willing to talk.

If it is possible to capture the session by using video, this can be useful when reviewing stories and identifying touch points. The aim is to facilitate fun, playfulness and creativity while respecting the knowledge of the experience that only these people can provide.

Patients

Creating a comfortable environment is much more than just choosing a nice quiet room.

You have to take into account the specific needs of the particular group and help to create an environment in which people feel comfortable to be open, creative and productive.

Carers

Some patients may not want to attend events alone and often a carer has played an important role in the patients care. Always offer the opportunity for a patient to bring a carer or friend along with them for support.

Carer's experiences provide a useful alternative perspective which adds to the richness of information gathered.



Staff

Healthcare staff are busy and often wary of events that will take them away from their work. This can result in resistance to attending the event and some reluctance to take part during the event.

During the engagement stage of the project you will have successfully engaged key members of the service that you are working with. This will help with encouraging people to attend. It is a good idea to get them to take an active role in presenting and organising the session.

It's also a good idea to try and represent a range of people involved in the project.

To allay some of the staff's fears about the value of the time spent it is important to explain the benefits this session will have to them at the beginning. These benefits include:

- It is a good chance to be heard
- It is an opportunity to improve your working life
- It is a new way of working
- It is a chance to work our solutions with your whole team
- It will make things better for patients

A major challenge of organising this session is to get the right balance between seriousness and creativity.

It is important to make sure that everyone has a chance to speak and that everyone gets input into every exercise and that the benefit of each exercise is explained.

Timing

Make sure that you keep your event on time and let people know the time constraints of the event. It's important that you allow everyone equal opportunity to speak, it may be a good idea to use a timer (remember to explain to the group why you are using the timer.)

The experience event will include:

- Sharing experiences
- Identifying touchpoints
- Emotional mapping
- Identifying priorities

Sharing experiences

The benefits of sharing experiences are:

- To bring people together
- To show that the project values individual experiences
- To show the value of experiences as core to healthcare improvement
- To explore the issues
- To help form consensus
- To show that you have been listening
- To provide a group perspective

In the case of the patient event, only patient (and carer) experiences should be shared.

In the case of the staff event only staff experiences should be shared. In shared events, it is important to share patient, carer and staff insights and experiences.

Sharing experiences can be done in a number of ways:

- If you have video of patient/ staff experiences, arrange a screening of a range of clips.
- If you have been working with photography then arrange a display. You could give each contributor a chance to present their images and describe what they represent.
- If you are working from complaints then having a summary of your complaints book anonymised might be a good way of doing this.

Another approach is to ask participants to share experiences directly through speech. Each participant an allotted amount of time to talk about their experiences. If you are using this approach it is useful to have a few prompt questions and a supportive environment as it can be quite frightening sharing experiences for the first time in a public place.

Emotional Mapping

Completing this exercise will help to identify the areas in the service or pathway that evoke deep emotions from those who use it (patients and carers) and those who deliver it (staff).



See page 76 for more information on emotional mapping

Identifying touchpoints

Through the emotional mapping exercise participants have an opportunity to identify key moments and interactions in the pathway where emotions have been shaped – the touchpoints. These touchpoints map to the flow of the service or pathway but are often areas not identified through the use of traditional process mapping, rather they are specific points that patients or staff identify ‘inbetween’ traditional points of a process map.

See page 28 for more information on identifying touchpoints

Identifying priorities

Use the last section of your event to decide on what the priorities for improvement are. Use your emotion map as the basis for this and then check that everyone is happy with the list. If there is confusion or conflict you can use voting to prioritise the activities.

If you have time you may want to start developing some kind of creative thinking in your group by starting to help them generate ideas for solutions to some of the challenges they have identified.

You should end the meeting with an agreed list of priorities.

Emotional mapping session

How to run an emotional mapping session.

Understanding the emotional journey of those receiving and giving care can really help to improve your service and this is where a technique called emotional mapping comes in.

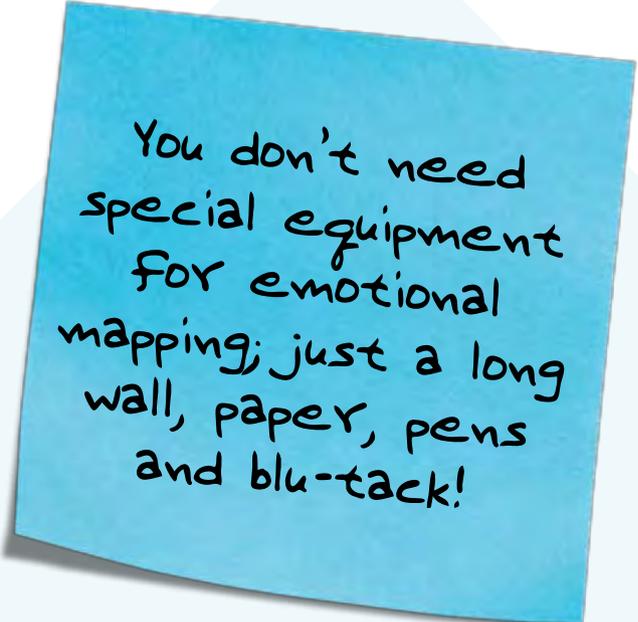
This technique will help you to highlight where your service is working well and where it can be improved from the perspective of your patients, carers and staff.

Emotional mapping is a technique that can be used by patients and staff to describe in detail the emotions (positive and negative) experienced along the patient journey.

It helps to highlight emotional 'highs and lows' of the service or pathway.

Different patients may have experienced different emotions at similar points in the service.

This isn't a problem. It's actually a great opportunity to get people discussing in detail what it was about their personal experience that led to these different emotions.



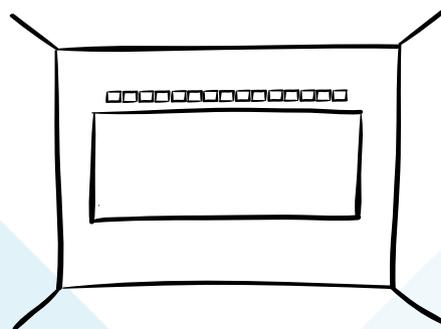
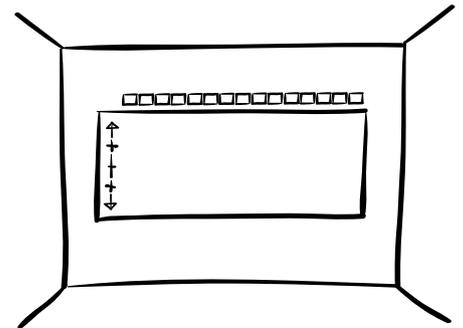
You don't need special equipment for emotional mapping; just a long wall, paper, pens and blu-tack!

Preparing the session

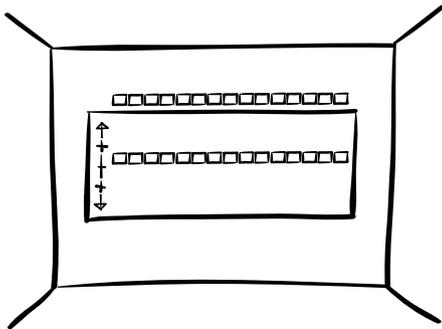
- Emotional mapping is best done as a group activity involving a number of patients, carers and staff. We suggest a group of about 10 people though it is possible with more or less
- Remember to allow at least 35 minutes for the mapping exercise alone.
- Emotional mapping can be built into patient and staff experience events or take place as a separate session
- Ensure the room has a large blank wall space or if you are working with a less physically-able group, you may want to consider doing the mapping as a table-top activity.

- Prepare a large strip of paper approximately 3 metres long (lining wall paper is ideal) and attach it firmly to the wall.
- Along the top edge of the paper, set out the 'process' stages of the patient journey, drawing on your process or service map (e.g. for an A&E attendance, you might start with: pre-arrival, arrival, triage, consultation, transfer/discharge, follow-up). It is important to leave space in between each of the processes because patients and staff may identify touchpoints 'in between'.

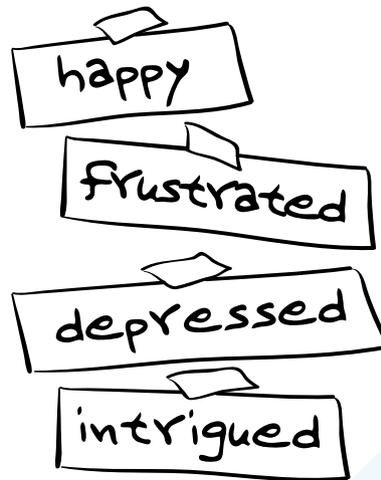
- Add a scale on the left or right hand side to indicate that low positioning is negative and high is positive.



- During the 'capture' phase you might already be able to identify some touchpoints (see pages 27-33) – key moments and interactions in the pathway where emotions are shaped. It is helpful to use a few of these as an illustration for the group.



- Identify the specific point in the process that relates to an emotion word. Then place the emotion words or phrases that have been drawn directly from the patient/carer stories and their experiences, next to the appropriate area or touchpoints on the process map.



- Ensure that you have a range of blank paper, cut to size, that people can use to write touchpoints and emotion words. Even though you have started to form the emotional map using material you have gathered during the 'capture phase' it is important that participants are able to build and add onto it.

See page 27 for more information on Identifying emotions



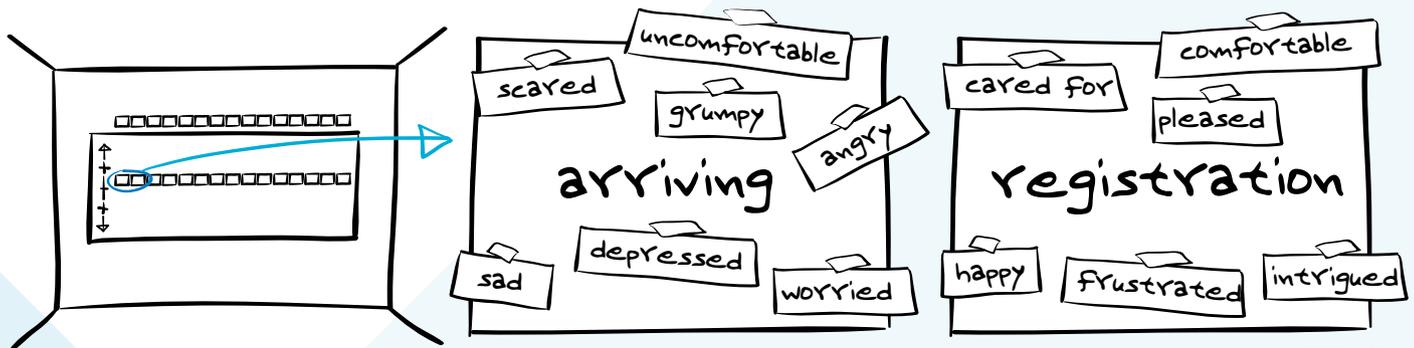
Running the session

- Explain to participants why you are doing this exercise and what it will involve.
- If you have film footage of patients or patient stories, it's a good idea to share excerpts with the group to show where the emotion words and touchpoints have come from.
- Ask if there are any further touchpoints identified and give everyone the opportunity to add new ones.
- Working as a group, add any new touchpoints to the map, you may have to adjust the

flow of the pathway that you prepared earlier but this is to be expected. Ask the group to be honest and to think about their experience of each of the touchpoints mentioned on the list and try to remember how they felt at each stage

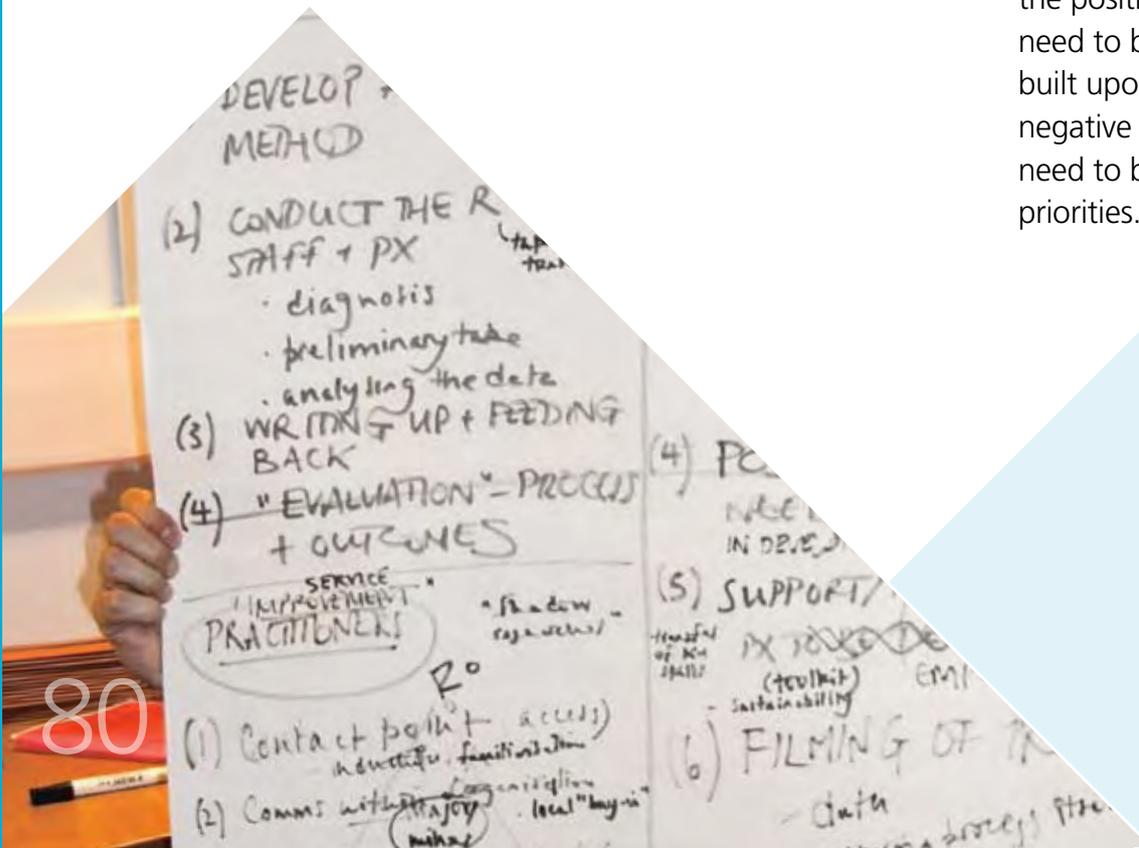
- Give everyone some blu-tack and ask them to select from the emotion words and stick these ON the touchpoints they feel gave rise to these emotions. Give people pens to add new emotion words or repeat words that others have used on other touchpoints.

- Now, help the group to agree the position of each touchpoint in relation to the overall emotion map. Are the emotions related to the touchpoint more positive (place in the higher positive section of the map) or more negative (place in the lower negative section of the map). By doing this you will start to see a picture emerging of the touchpoints that lead to mainly negative emotions and these are the ones that should become priorities for action.



Summarise the session

- Read out the touchpoints and emotions and discuss their high or low positioning. Give the group a chance to review and change the map if they choose.
- When everyone has had their say and consensus has been reached, work together to agree and list the most positive and the most negative touchpoints.
- These touchpoints will be used to highlight the areas of focus for your improvement work. If you're doing full co-design, both staff and patients work together to prioritise improvement actions and develop co-design teams. Remember when you are reviewing the map to identify the positive touchpoints that need to be celebrated and built upon as well as the negative touchpoints that need to become improvement priorities.



Check your progress

By now, you're probably getting much more familiar with the whole concept of emotions and touchpoints and how they can lead you to some important and effective improvements.

Remember, you are learning skills that you can apply in all sorts of ways – even if that's just having the confidence to ask patients how they feel about a service, and knowing how to use the information you get back from them.

Why not drop us a few lines about how you've got on so far at:

theebdapproach@institute.nhs.uk

'Although I've never done anything like the emotional mapping exercise before, I enjoyed it. It was also a chance to even things up a bit and tell the team about all the good experiences as well. The nurses were really pleasant, for one thing, and the A&E and ambulance staff were wonderful'

Peggy Evans, patient

'We've just started reviewing all the film footage of our patient interviews to identify the emotional touchpoints. We could just take these straight into the co-design stage. But with this approach, we will be offering all of the touchpoints back to patients and staff, getting them to reflect as a group on which they feel are the most important to act upon. The point is, it's their decision, not ours.'

Gill Husband, Risk management Lead



Improve the experience

Tools for turning experience into action **83**

Acting on the information gathered

How to run an ideas and action event **84**

Bringing staff and patients together to form co-design teams

Experience improvement sheet **86**

Changes to the service can be recorded and tracked against experiences

Individual action card **88**

A simple card to record individuals' responsibilities in the project

Group action statement **89**

A document to record who's in your team and what their aims are

Tools for turning experience into action

The most important part of any improvement is acting on the information gathered.

The **ebd** approach is different from many other improvement or change initiatives in that it encourages you to work closely with both patients, carers and staff in developing a better experience for all. Working with patients as genuine partners can create some apprehension, but it has the potential to transform health services.

The learning from sites that have used co-design (patients and staff as partners) is that it is:

- a natural way to progress the relationships that have already emerged between patients and staff earlier in the **ebd** process

- a way to reduce the workload on staff; with patients and carers taking on many of the improvement actions themselves
- a way to keep up the momentum of change – where patients are part of the change team, they add further enthusiasm, drive, energy and a level of expectation.

We recognise, however, that involving patients, carers and staff as partners in designing solutions for the service can be a big step.

Be reassured that others have already achieved great improvements through this approach. See **the ebd approach – Concepts and Case Studies** book for many examples.



YES
 NO

How to run an ideas and action event

Ideas and action events aim to bring staff and patients together, to form co-design teams and to begin co-design activity.

This event can be the launch of the activity stage of the project.

The patient and staff priorities from the previous work should be collated and shared with the participants.

It builds upon the work you have done during the 'capture' stage and utilises the emotion maps and touchpoints identified during the experience event or co-design event.

1. Establishing your

environment: Make sure everyone feels comfortable in the area. Introduce the project from a number of perspectives, for example, staff and patient. Involve a representative from these groups in the organisation of the event.

2. Show experiences:

As an introduction to the event, some information from previous patient and staff events can be presented. Use a range of different media for example photographs, film, exhibition, a powerpoint presentation and it would be good to include the emotion map and the priorities that emerged.

3. Sharing priorities:

Now is the time to identify the priorities identified as most important. When preparing for the event it might be useful to collate or identify groups or themes that the priorities link to. Participants should be given time to look at and discuss all of the priorities before any joint decision is made about what to work on. There should be an agreed process for choosing the priorities to work on, previous teams have used a voting mechanism. Teams have found that initially it is best to focus on a few (4-5) areas of priority.

- 4. Forming teams:** Set up tables representing the touchpoints that have been identified as most important and allow staff and patients to choose which they would like to work on. Try to organise this so that you have equal numbers of patients and staff on each team. Remember to be flexible and enable people to work on the touchpoints that they are interested in. Other priorities can be reviewed and worked on at a later stage. It is useful to complete the experience improvement sheets at this point (see page 86).
- 5. Facilitating discussion/ development:** The teams should have some time to discuss how they would like to improve the touchpoint they are working on based on their experiences. They should also have some time to plan the next steps for their team. Tools are available to help the teams stretch their thinking about potential solutions, for example **Thinking Differently Guide** which you can find at **www.institute.nhs.uk/thinkingdifferently**.
- 6. End of the day:** By the end of the session you should have 1-6 co-design teams composed of patients and staff who are ready to start work on improving their touchpoint. It is important that they have completed some documentation to identify what they aim to do, by when and who is involved. Previous teams have found the experience improvement sheet, individual action card and group action statement helpful (see pages 86-89). Teams should have identified dates for future group meetings and someone to report back on progress.

Experience improvement sheet

A sheet on which changes to the service can be recorded and tracked against experiences.

Remember there may be 3-5 different actions and a new sheet is needed for each one. Patients and staff within the team might all take a specific action – these will also be noted on the group action sheet.

Write down the name of the group

Write the experience that needs improving

Write what needs to be done here

Write whose responsibility this is

Write the date here

Write the time/date this should be completed

Write down when each action gets completed

Experience Improvement



NAME OF GROUP _____

Experience to be improved:

Improvement focus – what we will do:

Who is responsible:

Today's date:

By when:

Completed:

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Two examples of Experience improvements

Experience to be improved

Providing important information about benefits available

"I did not have the right information and did not know what benefits were available to me"

"I suffered because I did not get the benefits that I could have"

Improvement focus – what we will do

Make sure everyone is aware of the benefits that might be available to them and who can help. We might develop a new set of information or add this to existing information. It will include details of who can help e.g. social worker, benefits advisor, Citizens Advice Bureau

Who is responsible

Jim (patient)
Sally (administrator)

Today's date

15th June

By when

28th July (6 weeks)

Completed

Packs in use on 28th July

Experience to be improved

Speed and safety for patient care

"My drip felt sore and when the nurse came she then went away to look for equipment – it seemed like ages" (Patient)

"I needed to attend to a patient's drip and none of the equipment was where I thought it should be – I think someone had moved it and it took a while for me to find it all" (Nurse)

Improvement focus – what we will do

Examine the storage and labelling of equipment; reorganise the storage and labelling; make sure all staff aware of new plans; test how long it takes to gather equipment

Who is responsible

Jane (patient)
David (ward orderly)

Today's date

12th July

By when

15th August (4 weeks)

Completed

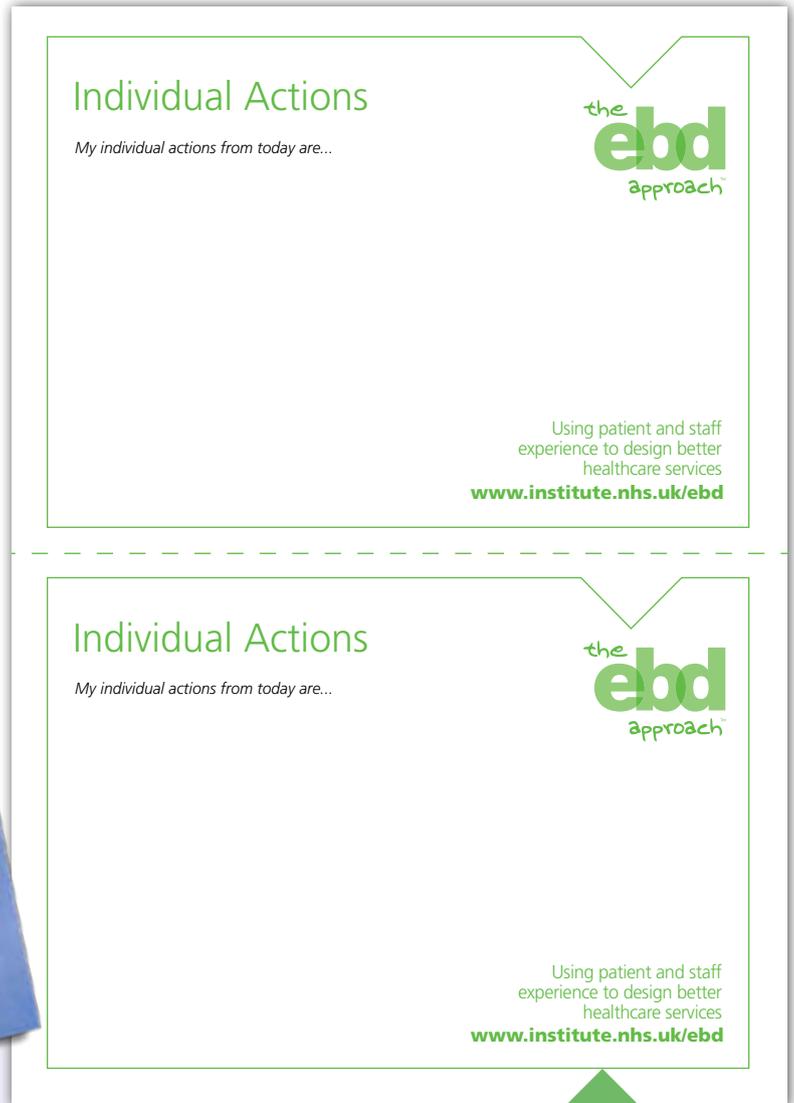
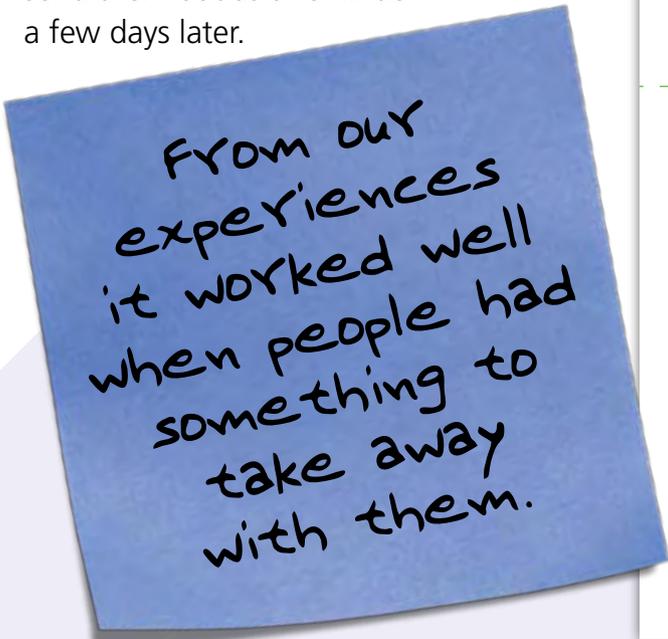
New systems in place/tested 15th August

Individual action card

A simple card to record individuals' responsibilities in the project.

Some teams included a photograph of each team member on this sheet.

You might want to record (photograph/copy) these and send them out as a reminder a few days later.



Group action statement

A document to record who's in your team and what their aims are.

It is a good idea to have a space for these to be on display (if you have a project space) and for each person to have their own copy of the group action statement – maybe this whole sheet...

The group decides on their action statement

Each member writes their name

Each member of the group agrees their individual actions and writes them here

The date to complete the action is written here

Each member of the group 'signs up' to their actions here

Group Actions



A FINAL COPY OF YOUR ACTION STATEMENT
WILL BE DISPLAYED IN THE HEAD AND NECK CLINIC

Name: Individual actions: By when:	Name: Individual actions: By when:	Name: Individual actions: By when:
Name: Individual actions: By when:	Group action statement: By when:	Name: Individual actions: By when:
Name: Individual actions: By when:	Name: Individual actions: By when:	Name: Individual actions: By when:
Each group member signs here: _____		

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Measure the improvement

Tools for measuring improvement 91

An introduction to evaluating and measuring improvement

Measurement principles 92

Considerations for measurement of **ebd approach** projects

Sustainability Model/Guide 93

A guide to assessing if your project is sustainable

Project newspaper/newsletter 94

A newspaper you can customise with your own content

How to run a celebration event 95

Recognising success

Tools for measuring improvement

Improved experience? What to measure (and how)?

As with any improvement work, it is important to be able to evaluate the impact and success of your ebd approach intervention. This isn't about measurement for measurement's sake.

Measurement will help you understand the difference your work has made and, importantly, enable you to celebrate, share and sustain the improvement

There are a variety of ways improvement can be measured. These include subjective and objective measures which can be monitored throughout the project and will help to identify improvements for patients in both process and experience.

Subjective outcomes (for example, the way patients feel – their experience) – you can use experience gathering techniques to capture this information

Objective outcomes (for example, reduced waiting times; fewer critical incidents; improved performance, safety and reliability)

It is also worth considering what a proxy-measure for improved patient experience might be.

For example:

- Number of incidents reported
- Thank you letters
- Sickness and absence
- Number of hand-offs during a process



Measurement principles

Running the project again is one of the best ways of measuring the success of our project.

You can use many of the improvement tools that you are used to. For example, statistical process control charts, process mapping, capacity and demand analysis. In addition make sure you capture subjective measures of experience including stories, emotions, touchpoints.

The results of the work you have completed so far will have identified your areas of improvement and will enable you to select the appropriate measurement systems. See the Improvement Leaders Guide.*

**Find the improvement leaders guides at: www.institute.nhs.uk/building_capability/building_improvement_capability/improvement_leaders'_guides:_introduction.html*

Measuring actions taken throughout the project can be really valuable – sometimes the actions might seem small but they can make such a difference.

Any of the capture and understand tools can be used to provide assessments of how you are impacting on patient experience, for example:

- Running the experience questionnaire with a follow-up group
- Ask people to identify their emotions, against specific touchpoints

Using patient and staff interviews and emotional mapping you can identify if the priorities have changed.

Comparing experiences of the improved service with those of the old service provides detailed insight into any improvements in the service.

Think about how you might use experience in usual reporting mechanisms - try using patient narratives within board meetings

Sustainability model/guide

The NHS Institute for Innovation and Improvement has developed a sustainability model and guide.

The Sustainability Model is a diagnostic tool that is used to predict the likelihood of sustainability for your improvement project.

The Sustainability Guide* provides practical advice on how you might increase the likelihood of sustainability for your improvement initiative.

One of the primary reasons why quality improvement is difficult to integrate into an organisation is that many of the changes that are put into place fail to survive.

The NHS Sustainability Model is an easy-to-use tool which aims to help NHS improvement teams:

- Self-assess against a number of key criterion for sustaining change
- Recognise and understand key barriers for sustainability, relating to their specific local context
- Identify strengths in sustaining improvement
- Plan for sustainability of improvement efforts
- Monitor progress over time.

Using the sustainability model at the start of your project will help you identify what it is that you are working on so that you can be clear about what it is that you need to measure to show the improvement.

**Find the Sustainability Model at:*
www.institute.nhs.uk/sustainability



Project newspaper/newsletter

This tool tells people about stories, ideas and news in your project.

The newspaper template is in word format (see www.institute.nhs.uk/ebd) and will help you produce a professional document, which can be written, printed and distributed easily. Consider these elements: planning, capturing, editing and production.

Planning your newspaper

The most important element of developing the newspaper is the content. Planning how you capture content whilst you are running your project will save a lot of time and effort.

It is best to have a small team but make sure that everyone has input during the capture and production stages.

Set yourself a launch date for your first issue (we recommend doing this following an event early in the project, providing you with plenty of content as well as an opportunity to invite other people to get involved).

Capturing content

Now you have planned the content you would like to capture, ensure you take lots of photographs of people and events and write down what people say. This will make for a more engaging newspaper. Some things you might like to capture include: events and meetings; interviews with staff and patients, before/after stories; games/puzzles about the project.

Think about how you will tell it back to people in a short amount of text. What would the headline be? Why would someone want to read it?

Editing your newspaper

You will need to decide what will be included in the newspaper and in what order. You can do this quickly by printing a blank copy of the tool and planning your newspaper roughly. Write down what will sit on each page. Break down the stories into headings, subheadings, body text and ensure that your most interesting points are communicated clearly.

Producing your newspaper

Print out a copy to check everything is ok; run it past anyone who features in it and ask someone else to check through to ensure there are no mistakes. Work out how many copies you need and how you will distribute them.

Finally, photocopy your finished newspaper and distribute. Congratulations on publishing your **ebd** newspaper!

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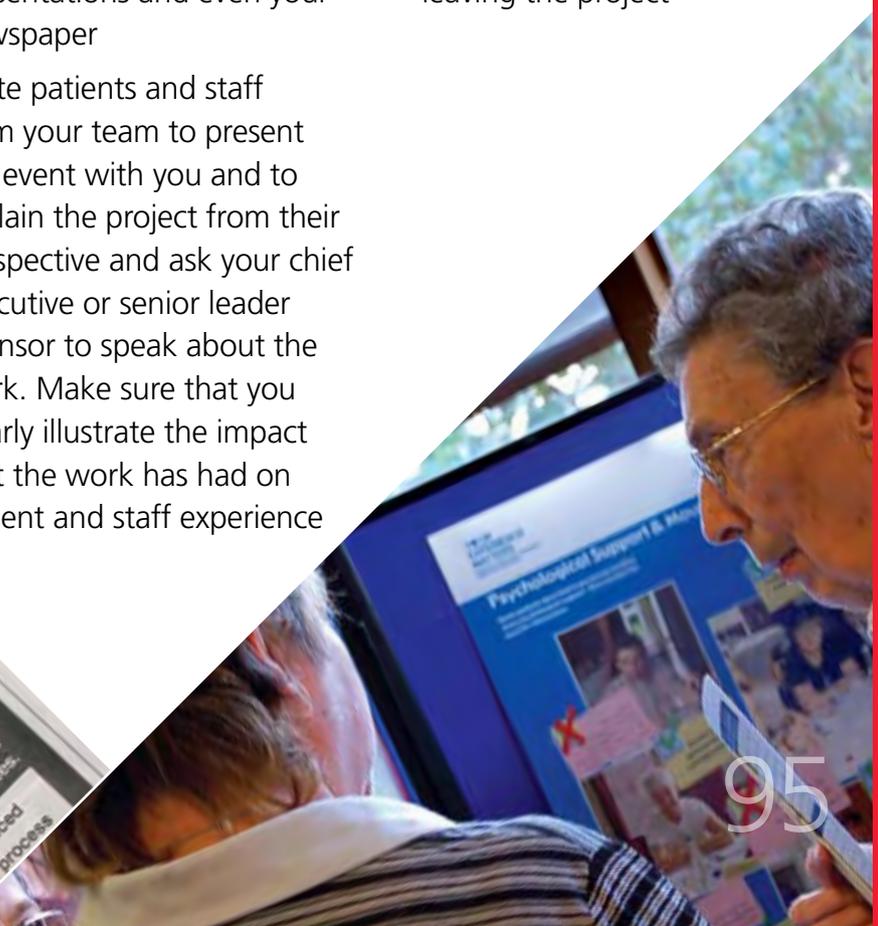
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How to run a celebration event

A celebration event is a good way of recognising the successes of your project and building momentum for continuing to use the ebd approach.

- Work with your team of staff and patients to choose a suitable date for your celebration
- Find a good location, somewhere in or near the organisation is probably best
- Invite a broader group of people; invite relevant patient groups, representatives from other hospitals and local media
- Work out the best way of displaying information about your project. Use a variety of media, pictures, posters, videos, powerpoint, presentations and even your newspaper
- Invite patients and staff from your team to present the event with you and to explain the project from their perspective and ask your chief executive or senior leader sponsor to speak about the work. Make sure that you clearly illustrate the impact that the work has had on patient and staff experience
- Use the event to publicise the project and to build momentum for it to continue. The event will also offer closure to people who are leaving the project



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