Involving patients and families in redesigning care and services

Dr. Lynne Maher
Director for Innovation and Design
“But the NHS too often asks insufficiently penetrating questions, insufficiently often, of too few patients.....And the NHS Patient Survey, asking if patients were satisfied with the care they received, is too much like asking patients whether they were grateful”

Secretary of State 2010
We need to move away from this....

“When we want your opinion, we’ll give it to you”
We as clinicians and managers worry about this ......

"I'M SORRY DOCTOR, BUT AGAIN I HAVE TO DISAGREE."
We think patients want this.....

Or there's a hospital in Doncaster...bourne style, ensuite... à la carte organic snacks... one cataract op... or one breast enlargement, free with every hip replacement....
“we need to move from a service that does things to and for its patients to one where the service works with patients to supports them with their health needs”
What Matters to Patients (England 2011)

- Feeling informed and being given options
- Staff who listen and spend time with me/patients
- Being treated as a person, not a number
- Being involved in care and being able to ask questions
- The value of support services, for example patient and carer support groups
- Efficient processes

(Robert, Cornwall, Brearley et al 2011)
Functional or Relational?

Two aspects of experience need to be considered

The ‘relational’ aspects of care (like dignity, empathy, emotional support) are very significant in terms of overall patient experience alongside the ‘functional’ (sometimes referred to as transactional’) aspects (like access, waiting, food, noise)
The components of good design

- **Performance**: How well it does the job /is fit for the purpose
- **Functionality**: How well it does the job /is fit for the purpose
- **Engineering**: How safe, well engineered and reliable it is
- **Safety**: How safe, well engineered and reliable it is
- **Usability**: How the whole interaction with the product/service ‘feels’/is experienced
- **The aesthetics of experience**: How the whole interaction with the product/service ‘feels’/is experienced

Berkun, 2004 adapted by Bate
Using patient and staff experience to design better healthcare services
The ebd approach is...

...about using *experience* to gain *insights* from which you can identify opportunities for *improvement*

...about *experiences* not attitudes or opinions
How might you use the EBD approach?

- As a regular way to understand patient experiences
- In an area where you have challenges—perhaps where you know you have a number of complaints
- As part of an improvement project
3 Ways to do service improvement

1. Don’t listen very much to our users and we do the designing

2. Listen to our users then go off and do the designing

3. Listen to our users and then go off with them to do the designing

(Professor Paul Bate 2007)
Experience Based Design is about designing better experiences…

Introduction to the tools

- Roles and structures
- Tools to help raise awareness

Capture the experience
- Tools to help people tell their stories

Understand the experience
- Tools for understanding patient and staff experiences

Improve the experience
- Tools to turn experience into action

Measure the improvement
- Tools for evaluating and measuring the improvement

Download this from www.instituta.nhs.uk/ebd
Core Principles of the ebd approach

- A **partnership** between patients, staff and carers
- An emphasis on **experience** rather than attitude or opinion
- Narrative and storytelling approach to identify ‘**touch points**’
- An emphasis on the **co-design** of services
- Systematic **evaluation** of improvements and benefits
Tell your story...

We’re looking for budding Steven Spielbergs to film and make a documentary about their experiences of head and neck services.

Why don’t you take the opportunity, you can work with our professional film maker to produce your own documentary.

For more information contact:

The Luton and Dunstable Hospital
Innovate Learning Network 0345 458 1923

Institute for Innovation and Improvement
Capture experience…

• Collect stories and thoughts from both patients and staff
  – Interviews
  – Story boards
  – Still photography and film provides compelling illustration

• Observe patients and staff delivering and receiving the service
Story Boards

Photographer's Journal:

What is this? A TYPICAL FARM SALE
Why did you choose to take this photograph? No. 13

I do love going to farm sales with my brother because we always meet up with old friends we've known for years.

Your experience matters:
Discussions, interviews

Understanding the needs of people living with Multiple Sclerosis
Diary and Film

The Productive Ward

Claire’s (HCA) Day

“I know I’m doing a good job when patients have smiles on their faces, I also get a thank you from the sister.”

“This is a boring day when nothing happens.”

“This is a good day with a mixture of activity.”

“At this point you don’t know what’s going to happen next!”

“It’s like a conveyor belt, but you don’t know what is going to happen next! …I enjoy that.”

HCA 10% Activities:

- Hygiene: 8%
- Aids: 8%
- Documentation: 8%
- Personal Care: 8%
- Meal: 8%

Breakdown of Total Motion Time:

- Looking: 5%
- Scraping: 5%
- Walking: 90%

Institute for Innovation and Improvement

NHS
Film and Interviews

Hospital Portering services
Observation

- People do not always do what they say they do
- People do not always do what they think they do
- People do not always do what you think they do
- People cannot always tell you what they need
- Observation lets you find out what people really do and need

IDEO 2006
The story of the toilet roll holder

Action: Toilet roll holders now on both sides to help the patient feel more independent and be safe.
Blisters/Lumps/Ulcers/Polyp/WartyThings/Necrosis/Lesions/NaughtyTumour/Agressive/Progressing/Precancerous

**Action**: awareness has resulted in change
Experience Questionnaire

This is a tool:

• that can be used on its own or as a starting point for understanding which part of the pathway you might want to focus on…

• Is often used in short stay or outpatient environments
Experience questionnaire

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.

Arriving/Checking In
- happy
- supported
- safe
- good
- comfortable
- in pain
- worried
- lonely
- sad

Information
- happy
- supported
- safe
- good
- comfortable
- in pain
- worried
- lonely
- sad

Waiting
- happy
- supported
- safe
- good
- comfortable
- in pain
- worried
- lonely
- sad

Going to Theatre
- happy
- supported
- safe
- good
- comfortable
- in pain
- worried
- lonely
- sad

Recovery
- happy
- supported
- safe
- good
- comfortable
- in pain
- worried
- lonely
- sad

Check Ups
- happy
- supported
- safe
- good
- comfortable
- in pain
- worried
- lonely
- sad

Leaving
- happy
- supported
- safe
- good
- comfortable
- in pain
- worried
- lonely
- sad

Write your own words here

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.
<table>
<thead>
<tr>
<th>Arriving/Checking In</th>
<th>Information</th>
<th>Waiting</th>
<th>Going to Theatre</th>
<th>Recovery</th>
<th>Check Ups</th>
<th>Leaving</th>
</tr>
</thead>
<tbody>
<tr>
<td>happy</td>
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<td>supported</td>
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<td>sad</td>
</tr>
</tbody>
</table>

Write your own words here

*Very Scared
*Easy to find
*Information was fine
*Allow 2-4 hrs - quite vague

Slightly blurred
*Clearer
*Still a little scared

FP

- Very Comfortable
- Didn't feel any pain
- Less scared
- Terrific staff

Relieved

no pain
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Understand the experience

There are three key techniques in this section – they are closely linked and one leads naturally on to the other:

• Identifying emotions

how people feel through their journey
e.g. scared
Understand the experience

There are three key techniques in this section – they are closely linked and one leads naturally on to the other:

• Finding the ‘touchpoints’

• Mapping the emotions (highs and lows) to the touchpoints.
Identifying Emotions

Watch this film and write down the emotions that the patient talks about.

*Remember that they may not be ‘pure’ emotion words but that you are gathering the emotions and memories from the patient story to understand the experience.*
Shelia- video showing emotions
Feedback

• Discuss the emotions you heard or saw
• Remember that they may not be ‘pure’ emotion words but gathering the emotions and memories from the patient story
Patient story and a process map…

It took ages to find a car parking space and then I found it was a 15 minute walk to the outpatients clinic. How frustrating!

The room was cluttered with out of date magazines and notices on the walls and I was already feeling really nervous.

I wasn’t sure where to go – the signs were difficult to follow.

I see to be waiting a long time, have I been forgotten or missed my name being called out? Feeling anxious.

Consultant was really helpful.

Patient goes to different department for investigations (X-Ray/Pathology).

It took ages to find a car parking space and then I found it was a 15 minute walk to the outpatients clinic. How frustrating!

How do I find out where to go...I think I am lost. I am worried that I will be late.

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Planning an experience event

working in partnerships with patients can create some apprehension, but it has the potential to transform health services

• Plan the date in advance
• Make sure everyone can get to the event
• Use ‘simple English’
• Remember that staff are often as nervous as patients/family members
• Staff may try to ‘take control’ facilitation is important
• Do not leave without next action steps
Problems cannot be solved by the same level of thinking that created them.

Albert Einstein
Action Planning

A personal responsibility…

• Hugh McGrath-Patient
• Julie - Clinic Receptionist
• John Pickles-Consultant
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The seven step process makes the link between data collection, analysis, finding and reports patterns and communicating both the decisions and the process to patients and the public.

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

- Reduction in time
- Reduction in duplication
- Reduction in steps
- Clinical efficiencies
- Increase in safety: reduction in error and cost
- Consistency
- Adherence to process
- No of handoffs
- Complaints/compliments
Measure improvement

- Collect stories
- Observe
- Use mapping techniques
- Before and after – from and to
“what matters more than raw data is our ability to place these facts in context and deliver them with emotional impact”
Daniel Pink – A whole new mind 2008

“the point is to emphasize that each of the cases involved an actual human being. Describing them as a percentage would dehumanize the physical impact on a real person, someone's mother, father, sister, or brother”
Paul Levy CEO 2008
What do we learn from our experiences?

- **Bust the myth** – Patients do not want a ‘gold plated service’
- They want a good experience
- Patients and staff see each other in a different way…as people
- Confidence for improvement action grown for all
“The two main attributes of the organisations that were collecting experience data and using it to make changes were visible leadership and an organisational culture in which staff know that Patient Experience was a priority”

King’s College London and The King’s Fund, What Matters to Patients, 2011
What is happening now?

WWW.institute.nhs.uk/theguide

WWW.institute.nhs.uk/patientfeedback
“The ebd approach is about sharing and understanding the experiences of patients, carers and staff together to design better services.”
“This work has transformed our understanding of how patients experience our services. Many lean efforts in healthcare fail to address this key issue. We will be placing it at the centre of our drive for improvements.”

Chief Executive, David Fillingham

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

Dr Simon Stacey, Consultant Physician and Orthogeriatrician
“Sometimes we think we can invite a patient to sit on a committee and that’s the ‘involvement’ box ticked. That just isn’t enough and we have to get beyond the token gesture”.

“there is scepticism in some parts of the health service about just how useful it is to involve patients in detailed decision-making about service design. And in truth, I did have to sell the idea to some of my own colleagues. But the important thing is they all agreed to give it a go – and together we’ve seen how genuinely effective experienced-based co-design can be as a way of improving services for everyone – staff as well as patients

John Pickles- Medical Director and Consultant Otolaryngologist
“As a consultant who has always tried to listen to the patient, I feel the patient project has been the most powerful way of demonstrating the experience of treatment from the patients’ perspective. I feel the patient experience videos should be compulsory viewing for all medical staff.”

Steve Hodgson-Consultant Orthopaedic Surgeon and Associate Medical Director.
Reports and Papers


Reports and Papers

