

# Using patient experience data in organisational change

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# Aims today

- Patient experience – why does it matter and what do we know?
- Different kinds of patient experience data and what they can tell us
- Going beyond measurement to improvement
- Quality improvement using narrative and observations, especially ‘experience-based co-design’
- But first.....

# Why me?

- Former UK National Health Service Manager
- Then academic research in healthcare organisations and patient experience
- Health Experiences Research Group at Oxford:
  - Social science, 100+ interview studies with patients and family
  - Aim to cover wide range of perspectives on health and illness experience
  - Disseminated free on [Healthtalk.org](http://Healthtalk.org)
  - Used for medical and nursing education, informing guidelines - and service improvement

# Healthtalk

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  - People's Experiences
  - Young People's Experiences
  - Health Professionals
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## Home

### People's experiences of health

Reliable health information from patients, for patients

Related:

- Find out how we can help you
- Friends, family and carers
- NEW: Giving up smoking



Support, encouragement, empathy is best when it comes from someone in the same situation as you.

PEOPLE'S EXPERIENCES OF HEALTH DONATE TO HEALTHTALK.ORG HEALTH PROFESSIONALS LEARNING & TEACHING



## Welcome to healthtalk.org

Find information and support for a range of health issues from seeing and hearing people's real life experiences. Thousands of people have shared their experiences on film to help you understand what it's really like to have a health condition such as breast cancer or arthritis. Find out more or select from our list of health conditions on the menu above.

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[bit.ly/1W6qKj6 #DCIS](#)

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People's Experiences Intensive care Intensive care: Patients' experiences Topics Experiences in intensive care

Sleep, dreams and hallucinations in ICU

## Intensive care: Patients' experiences

Topics	People's Profiles	Resources & Information	Credits
<b>Overview</b> <ul style="list-style-type: none"><li>Reasons for admission (2)<ul style="list-style-type: none"><li>Emergency admissions to ICU</li><li>Planned admissions to ICU</li></ul></li><li>Experiences in intensive care (8)<ul style="list-style-type: none"><li>Coming round and regaining consciousness in ICU</li><li>Sleep, dreams and hallucinations in ICU</li><li>Intensive care treatments</li><li>Physiotherapy in ICU</li><li>Emotional experiences in ICU</li><li>Nursing care in ICU</li><li>Death and bereavement</li><li>High Dependency Unit (HDUs)</li></ul></li><li>Experiences in the general ward (4)<ul style="list-style-type: none"><li>The general ward: care and environment</li><li>Physical and emotional experiences</li><li>Physiotherapy on the ward</li></ul></li></ul>	<p>Previous Topic</p> <h3>Sleep, dreams and hallucinations in ICU</h3> <p>People in intensive care are given many separate medicines, including sedatives and painkillers, and all of these can affect them in different ways. Policies instructing doctors on how much sedative to give a patient vary greatly - some units keep people in as light a sleep as possible, other units keep people much deeper. Here men and women talk about their experiences of sleep, dreams and hallucinations while they were in the intensive care unit.</p> <p>While some people said they 'drifted on and off', many others found it difficult to sleep well in intensive care. Being attached to lots of equipment and being unable to move often caused discomfort. The ICU environment itself - the lighting, frequent medical interventions, visitors and noise - prevented sleep in some. Others found the environment frightening, hot or busy.</p>  <p>Now Playing <a href="#">view profile</a></p> <p>She slept very little in intensive care because of the lighting, medications and visits from family and medical staff.</p>		

# Experience of services – dignity in prostate cancer

[Video removed]

# Why does experience matter? Icing or cake?

- One of three pillars of quality of care, with safety and effectiveness.
- Link between patient experience, and self-rated and objectively measured health outcomes
- Growing evidence base suggests patient-centred organisations have:
  - better clinical safety, e.g. fewer medication errors, adverse events, hospital-acquired infections
  - decreased mortality
  - improved staff experience, staff morale, retention
  - lower operating costs
  - shorter lengths of stay
  - reduced malpractice claims
- A single bad encounter colours whole experience

# What do we know about what matters to patients?

## About Us > Principles of patient centred care

SHARE THIS

Our work reflects and builds upon the Picker principles of patient centred care that derive from empirical research originally conducted by the Picker Institute in the USA.

Quite a lot!

Picker:



Fast access to reliable health advice



Effective treatment delivered by trusted professionals



Continuity of care and smooth transitions



Involvement of, and support for, family and carers



Clear, comprehensible information and support for self-care



Involvement in decisions and respect for preferences



Emotional support, empathy and respect



Attention to physical and environmental needs

# King's Fund/KCL 'What matters?'

*'Relational' aspects of care (dignity, empathy, emotional support etc) are very significant in terms of overall patient experience alongside 'functional' aspects (access, waiting, food, noise etc).*

[http://www.institute.nhs.uk/patient\\_experience/guide/the\\_patient\\_experience\\_research.html](http://www.institute.nhs.uk/patient_experience/guide/the_patient_experience_research.html)

But what do we do with this knowledge?

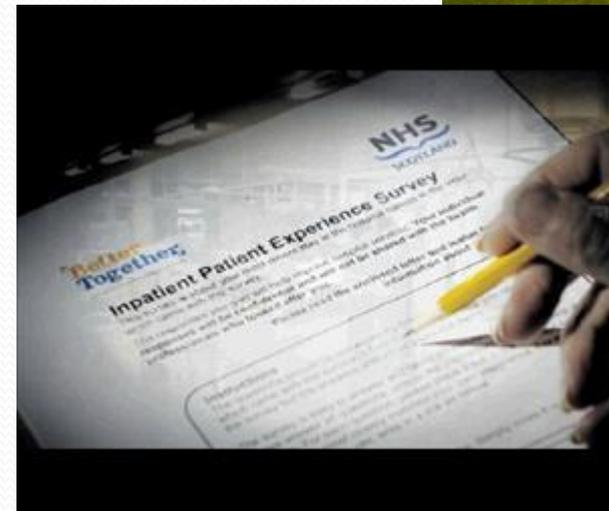
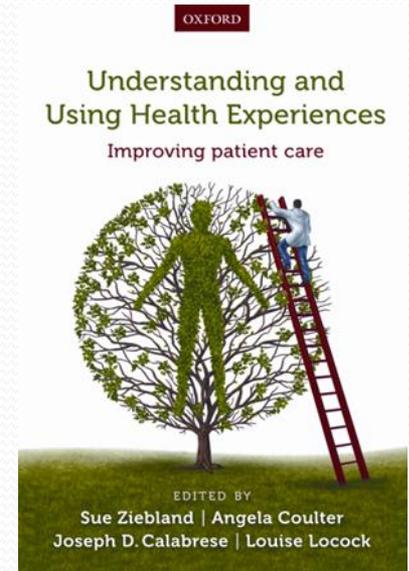
Have we become mesmerised by measuring?

# The turn from understanding to *using* health experiences

- Collecting data on patient experience is not enough: they must be used to improve care

– Angela Coulter, Louise Locock, Sue Ziebland, Joe Calabrese

BMJ 2014; 348



# What do we mean by patient experience (PEx) data?

- Quantitative and qualitative – numbers AND stories, e.g.
- Survey responses
- Complaints, letters and comment cards
- Narrative interviews
- Observations
- Online comment (feedback, twitter, forums, blogs)

# Roles for quant and qual PEx data

- assess *what* experience is currently like, measure if improvement activities make a difference
- understand *why* experience is poor, generate ideas for change
- tell us not just what is wrong, but *what 'good' looks like* and what could be better: patients often suggest simple changes
- *challenge assumptions*; some things matter less (or more) to patients than we think
- powerful *motivator for action* and remind us what we're trying to achieve

# Dials, can-openers...black swans



Carter N, Klein R, Day P. How organisations measure success. The use of performance indicators in government. London: Routledge, 1995, p.49

# Surveys

- Questionnaire surveys good for breadth of coverage, and comparisons over time/between sites, but....
- “...questionnaires define the patient’s response to fit in with the pre-determined issues that are considered important by the institutions that produce them...”
- They may not come close to what really matters to patients

(The patient experience in emergency departments: a review of the literature. Nairn et al, Accid Emerg Nurs 2004)

## What can narrative add? (Thanks to KCL for example)

*“The other thing I didn’t raise and I should have done because it does annoy me intensely, the time you have to wait for a bedpan [bed toilet]....Elderly people can't wait, if we want a bedpan it's because we need it now. I just said to one of them, ‘I need a bedpan please.’ And it was so long bringing it out it was too late. It's a very embarrassing subject, although they don't make anything of it, they just say, ‘Oh well, it can't be helped if you're not well.’ And I thought, ‘Well, if only you'd brought the bedpan you wouldn't have to strip the bed and I wouldn't be so embarrassed.’ Betty*

### Patient questionnaire

Overall, did you feel you were treated with respect and dignity while you were in hospital?

*Yes, always*

Overall, how do you rate the care you received?

*Excellent*

# FFT, complaints, real time feedback

- May be an alarm bell?
- Free text may be more useful than the scores
- How FFT is administered can affect results
- People may worry their comments will affect their care
- Need time to process and reflect

# Online postings, social media

Home

Tell your story

About us

Search



Search for stories about...

eg Leeds General Infirmary, heart surgery, depression, S3 8EN

## "Lack of privacy at Hairmyres Cardiology Dept"

About: Hairmyres Hospital / Cardiology

Posted by [Sandysue](#) (as the patient), 2 months ago

Attended for an ECG. All staff I came into contact with were very pleasant. I did have the misfortune however to be seen in ECG Room 1. This room appears to contain 'equipment' required by all members of staff. While I was lying with my top off having the ECG done various members of staff were in and out making me feel very vulnerable. I was told staff had asked for a curtain round the bed but this would not be done as it would cost too much.

More about [cardiology](#), [ECG](#) and [vulnerable](#)

### CHANGE MADE



This story led to [a change](#)

### Story summary

What's good?

What could be improved?

- [staff](#)

### Activity

**14** [staff members have read this story](#)

[Who has Patient Opinion told about this story?](#)

# Online postings, social media

## Responses

 Response from David Hume, Director of Hospital Services, Hairmyres Hospital, NHS Lanarkshire [2 months ago](#)



Hello Sandysue,

I am sorry to read about your experience in the ECG dept.

I will speak to the team down there as soon as possible next week and ensure that we do something to correct this.

Thank you for bringing it to my attention.

regards

David

1 of 2 people think this response is helpful

Was this response helpful? [Yes](#) | [No](#)

# Online postings, social media

 Response from Anne Leitch, Senior Nurse,  
Medicine, Hairmyres Hospital 2 months ago

 We have made a  
change



Dear Sandysue,

I can appreciate your "vulnerability" in the circumstances you have shared and I would like to apologise for any distress caused during your visit.

I've discussed your feedback with David and we have met with the Cardiology Service Manager. We are in the process of having privacy screens fitted in the department but this work will take another four weeks or so. In the meantime we will be using portable privacy screens, using additional signage to indicate to staff that clinical examinations / investigations are underway and we are also going to revise arrangements for storing equipment in these areas.

The staff were pleased to receive your positive feedback about them and they send their best wishes to you for 2016.

Thank you for taking the time to get in touch.

Kind regards

Anne Leitch

7 of 7 people think this response is helpful

Was this response helpful? [Yes](#) | [No](#)

# Online postings

- Often very specific to a service
- Many are positive and thank staff – not as negative as staff may fear
- Interactivity, quick responses
- May be difficult to analyse
- Confined to those who use the internet (though not as unrepresentative as assumed)
- “Patient Opinion is about empowerment. It isn’t simply a ratings site. It is not about *choosing* your healthcare, it’s about *changing* your healthcare.” James Munro, Patient Opinion

## Experience-based co-design (EBCD)

- EBCD – a participatory action research approach to service improvement
- Local observations and interviews with patients **and staff** – patients on video
- Workshop with staff and patients with ‘trigger film’
- Co-design groups
- Evaluations suggest effective (both changing care and changing attitudes) but time and resource intensive
- What happens if we use nationally derived trigger films rather than local interviews? (Accelerated EBCD)
- Tested in lung cancer and intensive care, in 2 trusts

# Narratives from interviews

- Pros:
- Rich detail, enable people to tell their story in depth
- Allows space for reflection/time to process
- Can generate lots of ideas for improvement
- Moving and insightful for staff – ‘narrative persuasion’
- Well collected and analysed can produce common themes important to patients and families
- Recast the debate – the lightbulb moments
- Evidence *and* ideas; minds *and* hearts

# Narratives from interviews

- Cons:
- Time-consuming to collect
- Skills needed for interviewing
- Analysis takes time and effort
- (Can use existing interview collections)
- Staff used to evidence-based medicine may feel they are misleading/unrepresentative/ 'anecdotal'
- Can't tell you how often something is happening
- People are afraid of what they may hear

# HEALTH SERVICES AND DELIVERY RESEARCH

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## Testing accelerated experience-based co-design: a qualitative study of using a national archive of patient experience narrative interviews to promote rapid patient-centred service improvement

*Louise Locock, Glenn Robert, Annette Boaz, Sonia Vougioukalou,  
Caroline Shuldham, Jonathan Fielden, Sue Ziebland, Melanie Gager,  
Ruth Tollyfield and John Pearcey*

# Staff experience matters in EBCD

“Addressing the issue of values needs to be handled with care. It mustn’t be experienced by those working in the service as an attack on their values, since this will be alienating. Rather it needs to be framed as an appeal to the values that brought them into health care in the first place, and a challenge to go further.”

Jeremy Taylor, National Voices

<http://healthfdn.org.uk/4Y2-44Q91-83M3XoS793/cr.aspx>

# Staff, QI and EBCD

- The ‘have you thought of leaving?’ question – someone is listening to *me*
- The ‘bucket of compassion’
- The ‘best thing I have done in 22 years of practice’
- Different feel to other QI
- Genuine frontline leadership and coalition with patients
- Acknowledge healthcare is stressful for all staff – doctors, nurses, healthcare assistants, managers, cleaners, admin
- Partnership and transparency - scary but rewarding

# What happened? AEBCD findings - staff

Using national rather than local narratives did not affect staff engagement – maybe less threatening?

Sense of reconnection with fundamental values

*‘So I can see that this person is not only a human being, but he is also a father, he is a son, he is a brother, he is a friend, he is a cousin, he’s a plumber or an electrician, he is a sportsman, he has an interest in horse riding, whatever it happens to be. He has a dog, he has a budgie, he has plans, he has expectations, he has regrets, he has feelings.’*

*‘I have already changed the way I think and care for patients even though we haven’t started implementing changes yet.’*

*‘Hearing patients’, relatives’ and staff experience acts as a catalyst and gives you energy to keep going and make the change.’*

# Findings - patients

- The national films generally reflected important themes; a minority felt they were more negative than own experience.
- The films served their purpose as a ‘trigger’ to discussion; *what really matters is the co-design process.*
- Surprise they had felt able to contribute as equal partners

*‘I wondered what, if anything, will be taken on board. To be honest with you, everything has been taken on board, and that in itself was a complete surprise.’*

*‘Our views were not dismissed, they were looked at and things changed’.*



# A few examples

- Clocks in intensive care
- Info film on hallucinations
- I-pads for communicating when unable to speak
- Better process for keeping track of possessions (hearing aids....)
- New lung cancer patient support group
- ‘Small’ change is not necessarily insignificant...

# Trigger film excerpt for AEBCD

[Video removed]

# Trigger films available

People's Experiences

Improving health care > Trigger films for service improvement > Topics > Ethnic minority mental health

## Trigger films for service improvement

Topics

Information & Resources

Overview

Asthma

Atrial fibrillation

Autism

Caring for someone with dementia - dealing with the system

Caring for someone with dementia - the experience of carers

Coordinating Care

Desperately not seeking health care; autistic patients and primary care

Diabetes type 2

End of life care

**Ethnic minority mental health**

Experiences of unexpected maternity care

Inpatient Medical Ward Experiences

Intensive care unit

Improving care for people with an indwelling urinary catheter

Intermediate care following a stroke

Learning disabilities & the health service

Lung cancer

Parkinson's Disease

Psychosis

Raising Concerns

Stroke

Young parents

Young people and depression

◀ Previous Topic

Next Topic ▶

### Ethnic minority mental health



This film was developed for health services to use as part of an experience-based co-design (EBCD) process. EB CD is a patient-centred quality improvement process, and if you are planning to implement it in your organisation we recommend you use the online EB CD toolkit to guide you. The Point of Care Foundation is also developing a learning programme on EB CD supported by NHS England. We anticipate that it could also be used as part of an experience-led commissioning process. The film is a 'trigger' film which is intended to get local people, patients, families and NHS staff talking together about how they can jointly improve people's experience. If you plan to show this film, we suggest the person facilitating the session use the following introduction to set the scene.

This film was put together from analysis of a national sample of people who have experience of mental health issues and are from a minority ethnic background. Researchers at the University of Oxford collected interviews with people all round the country, many on video, some audio or written only. They present findings from these interviews on the patient information website [healthtalk.org](http://healthtalk.org). The interviews are not just about NHS care but also much wider experiences, for example their emotional reactions to being in intensive care, how it affected family members, the impact on work, and their recovery at home.

For this project, we looked again at the whole interview collections and this time pulled out specific themes around experiences of services and 'touchpoints' (points of contact with the NHS).

Obviously these are not people at your trust and everybody has a different experience, though some patterns do start to emerge from looking at many stories. Some of the things they say you may think aren't relevant to this hospital or what happened to you. But our hope is that listening to them will help you reflect on your own memories and spark some ideas for what could be done differently here.

There may be some where people are sad or angry. You will hear some negative comments, because we can learn a lot from looking at when things went wrong and what could have been done to make

# Observation and shadowing - 'eyeballs are the best tool'

- A different form of story? See, hear, smell...
- Narratives can only tell us what people think happened, or what they can remember
- Can help access experiences of people who are unconscious or confused
- Shed light on the taken-for-granted – stop and think 'why do we do that?'
- Staff, patients, carers as observers

# Observation and shadowing

- NHS '15 steps' toolkit: *"I can tell what kind of care my daughter is going to get within 15 steps of walking on to a ward"*



Patient and Family Centered Care, as a concept, is health care that is compassionate, includes patients and families as partners and collaborators, is provided with respect, and treats patients and families with dignity. It is care that revolves around the needs and desires of patients and families rather than around the organizations and systems in which it is provided.

How do we know what patients and families truly want and need? Is there an approach, an implementation mechanism, which will transform care delivery in any care setting from any current state to the ideal? The Patient and Family Centered Care Methodology and Practice does that and more.



# Pictures New South Wales ED



And staff experience



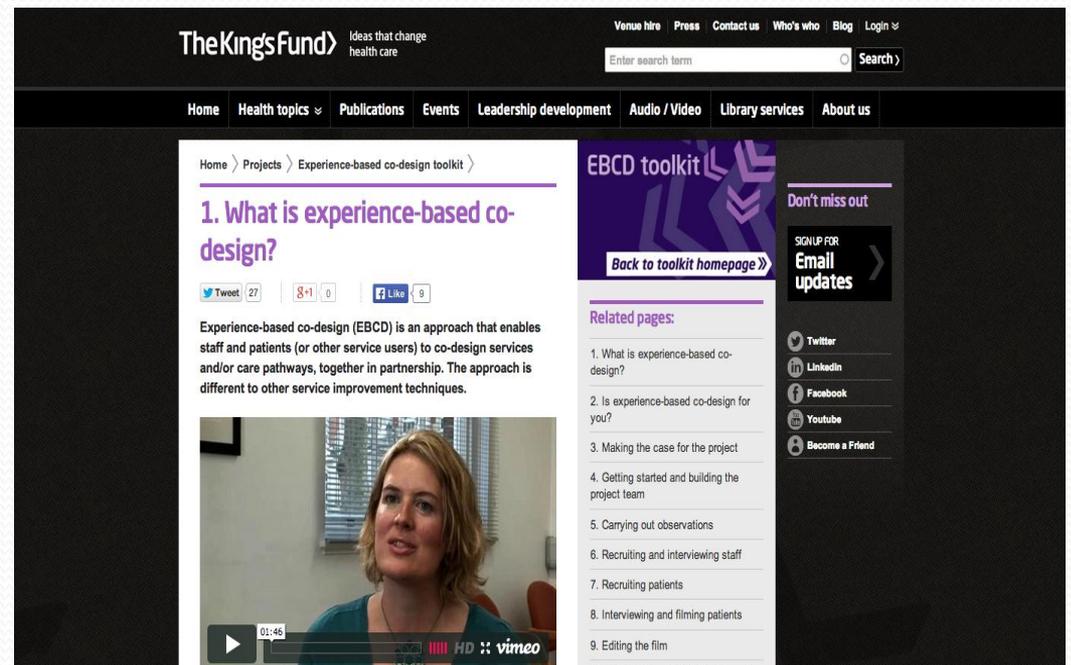
# How it was redesigned



(We are grateful to the New South Wales Agency for Clinical Innovation for permission to reproduce these photographs)

# Toolkits for EBCD and PFCC

- <https://www.kingsfund.org.uk/projects/ebcd>
- <https://www.kingsfund.org.uk/projects/pfcc>



The screenshot displays the website for The Kings Fund, featuring a navigation menu and a main content area. The main content area is titled "EBCD toolkit" and includes a video player and a list of related pages.

**The Kings Fund** Ideas that change health care

Venue hire Press Contact us Who's who Blog Login

Enter search term Search

Home Health topics Publications Events Leadership development Audio / Video Library services About us

Home > Projects > Experience-based co-design toolkit >

## 1. What is experience-based co-design?

Tweet 27 +1 0 Like 8

Experience-based co-design (EBCD) is an approach that enables staff and patients (or other service users) to co-design services and/or care pathways, together in partnership. The approach is different to other service improvement techniques.

**EBCD toolkit**

Back to toolkit homepage >

Don't miss out

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**Related pages:**

1. What is experience-based co-design?
2. Is experience-based co-design for you?
3. Making the case for the project
4. Getting started and building the project team
5. Carrying out observations
6. Recruiting and interviewing staff
7. Recruiting patients
8. Interviewing and filming patients
9. Editing the film

01:46 HD vimeo

# Thanks

To our participants, to our user advisers, to our funders: ESRC (ES/L01338X/1 ) and NIHR for the original AEBCD study

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## **Department of Health Disclaimer:**

The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the HS&DR Programme, NIHR, NHS or the Department of Health.

# Some evidence....

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