

# Challenge 2020: Engagement and experience Harnessing the power of patient experience

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#### We are working to radically improve the way people are cared for and to support the staff who deliver care



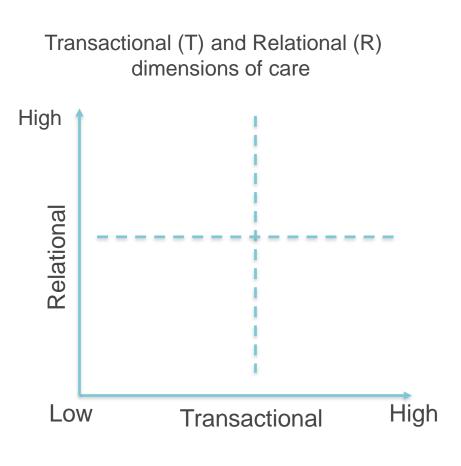
#### Dimensions of patient-centred care

- 1. Compassion, empathy and responsiveness to needs, values and expressed preferences
- 2. Co-ordination and integration
- 3. Information, communication and education
- 4. Physical comfort
- 5. Emotional support, relieving fear and anxiety
- 6. Involvement of family and friends
- 7. [Access]

Institute of Medicine (2001) Crossing the quality chasm: a new health system for the 21st century. Washington DC: National Academy Press

#### A more simple way to think about patients' experiences

- 1. Compassion and empathy (R)
- 2. Coordination and integration (T)
- 3. Information, communication, and education (T+R)
- 4. Physical comfort (T)
- 5. Emotional support (R)
- Involvement of family and friends (T + R)
- 7. Access (T)





[The doctor] did not start the conversation with the conclusions of the last MDT. She simply asked, "Well, with all this going on, how are you feeling? How is it affecting your life and that of your family?" For the first and only time since my recurrent inoperable cancer was detected, I was moved to tears. I was being seen as a person first, rather than another case with interesting pathology (although that has its upsides).



Tessa Richards, BMJ blog 2016

- 1. Team work
- 2. Trust
- 3. Responsiveness, treating me as a person, compassion

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## Challenges





#### Normalisation - the perennial challenge



Dr Kieran Sweeney GP, academic, patient

"Mesothelioma: A patient's journey" Sweeney, Toy and Cornwell: BMJ 2009 "The health professional does a job, and for many people this job is pretty mundane. They're doing the same kind of thing to the same kind of people pretty well every day. So for them that activity becomes completely routine.

For the individual patient it's anything but that. Every individual that comes through a hospital is apprehensive. It's a strange place, you lie in a strange bed, you have strange sheets, you have odd tea in a plastic cup. The whole thing is vibrantly different." Empathy can be switched off or impaired when we 10 are

- Tired
- Stressed or burned out
- Under pressure to do something else
- Emotional distressed, frustrated, angry or frightened
- Working with digital equipment
- Working with challenging or unpopular patients

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## New capabilities to shape working practice



# There is a powerful rationale for patient-centred improvement...

The arguments are both moral and practical ...

It is the right thing to do

It supports staff and reconnects them with their mission

It works and has an evidence base behind it

These approaches are often absent or neglected

It provides a direct line of sight between our mission and patients' experience



Involving patients helps address the difference between the work "as imagined" and the "work as done"

## "

"... hearing about long and painful journeys to the hospital, getting lost, how taking blood can make the boys – and mothers – cry, and how clinic scheduling or delays can mean the families miss meals.





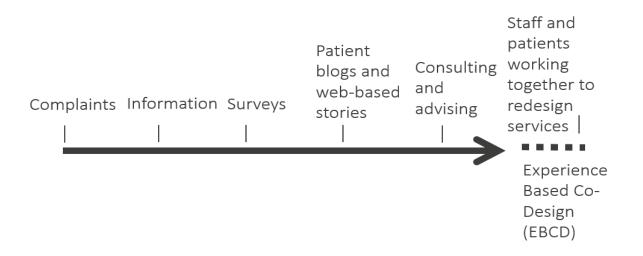




#### Methods to get at patients' experiences

- 1. Observations of waiting and care
- 2. Shadowing patients
- 3. Discovery interviews/ guided conversations with patients and carers
- 4. Patients' stories

#### Different ways of involving patients



Adapted from Bate P, Robert G (2006). 'Experience-based design: from redesigning the system around the patient to co-designing services with the patient'. *Quality and Safety in Health Care* vol 15 (5), pp 307–10

# An approach that combines a focus on patients and a collaborative change process: EBCD

Step-by-step manuals on the Point of Care website

1. Experience-based co-design

https://www.pointofcarefoundation.org.uk/resource/experiencebased-co-design-ebcd-toolkit/

2. Patient and family centred care

https://www.pointofcarefoundation.org.uk/resource/patientfamily-centred-care-toolkit/

3. Using patient experience for improvement <u>https://www.pointofcarefoundation.org.uk/resource/using-</u> <u>patient-experience-for-improvement/</u>

#### Thank you



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