


Patient Voices: Transforming People and Healthcare for 20 Years

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Storytelling and Health Online Event
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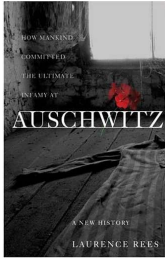
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How to get the patient's story?



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Lies, damn lies and . . .




'As always in history, statistics give little insight into individual experience. That can only be gained by listening to stories.'

Laurence Rees (2005)
Auschwitz: A New History

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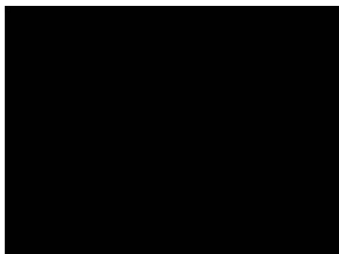
Stories and statistics



www.patientvoices.org.uk/flv/0851pv384.htm Tony Sumner, 2015

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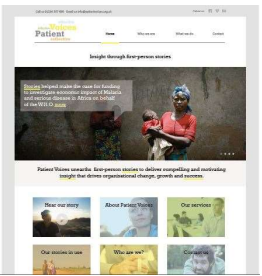
Patient Voices

patience, *noun*. calm endurance of pain or any provocation; perseverance

patient, *adj*. having or showing patience

voice, *verb*. give utterance to, express

Concise Oxford Dictionary, 1964



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Our aspiration

'...to capture some of the unwritten and unspoken stories of ordinary people so that those who devise and implement strategy, as well as clinicians directly involved in care, may carry out their duties in a more informed and compassionate manner.'

From *The Patient Voices Rationale*, Hardy 2004



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Why tell stories?

'Stories promote empathy, which in turn prompts reflection and serves as the motivation for learning and acquiring new knowledge.'

Rita Charon, 2002



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Patient Voices

- Established in 2003
- The first – and only – digital storytelling project focused solely on healthcare
- ~ 1400 stories facilitated/recorded
- ~ 900 stories released
- ~ 200 workshops, plus some home visits!
- ~ 3 million hits on the website annually
- 13 papers and 12 book chapters published
- 3 books edited, 1 PhD and 1 MSc completed
- 3 international and 2 national awards won



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Why tell stories?

'Storytelling is the mode of description best suited to transformation in new situations of action.'

Schön 1988



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Using stories

- Healthcare education
- Uber-qualitative data
- Quality improvement
- Reflective practice
- Culture change
- Interprofessional learning
- Informing practice
- Service user involvement and engagement



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Walking in someone else's shoes

'These stories allow us to walk in someone else's shoes for a few minutes.'

Medical Officer
National Institute of
Medical Research
Dar es Salaam, Tanzania



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Getting to the bottom of things

A word cloud visualization of patient feedback. The most prominent words are 'rheumatoid arthritis', 'independent', 'caring', 'husband', 'same person', 'no help', 'immune system', 'joints', 'painful', and 'care staff'. Other smaller words include 'heart disease', 'active', 'hospital', 'bottom wiper', 'can't stand', 'can't walk', 'bad experience', 'support', 'can't destroy', and 'wiper'.

www.patientvoices.org.uk/fh/0110pv384.htm Jean Bailey-Dering 2007

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Getting to the bottom of things

A solid black square, likely representing a missing image or a placeholder for a video.

www.patientvoices.org.uk/fh/0110pv384.htm Jean Bailey-Dering 2007

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EAR: a model for reflection

- Effective
What did you think?
- Affective
What did you feel?
- Reflective
What will you do?

A photograph of a temple with multiple spires, likely Angkor Wat, silhouetted against a sunset sky. The temple and the sky are reflected in a body of water in the foreground.

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Impact: Getting to the bottom of things

- Highlights impact of Rheumatoid Arthritis
- Reminder that patients are people first
- RCN changed syllabus
- Revelation re continence/mobility led to review of continence questionnaires
- Student nurses recognised the importance of listening to patients' stories
- GPs recognised the importance of listening to patients' stories vs asking about pain
- 35,165 views on Patient Voices website

An infographic titled 'Digital storytelling to improve continence care' from the Royal College of Nursing. It features a central flow diagram with four colored circles (red, orange, green, blue) and surrounding text boxes detailing the project's goals and outcomes.

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Impact: The DNA of Care

'The intertwined relationship between patient care and staff well-being has been likened to the double helix. And so the stories we tell each other are like the DNA of care, transmitting information and shaping cultures, offering learning opportunities and, sometimes, healing.'

Hardy and Sumner 2015

A glowing blue DNA double helix structure, symbolizing the interconnectedness of patient care and staff well-being.

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Impact: DNA of Care participants

*'There's something very important about the **collective process** as well as the **collective product**. My story is the product of everyone here as well as my own.'*

*'The miracle is **looking through each other's eyes**.'*

*'Since sharing the story I have felt a sense a **peace** and **contentment** as it really allowed me to understand exactly why I am here in this job.'*

*'Listening to all the stories gives us **insight** into other people's experiences.'*

*'If we can **connect** with each other then there's hope for the NHS.'*

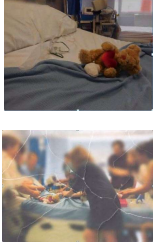
A collage of six small photographs showing diverse individuals in various settings, including a meeting, a person working at a computer, and a group of people in a room.

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Impact: Changing culture

'I am so glad I made this story. I was also really, really pleased to learn that our bereavement team has started doing workshops with nurses for emotional support.

Shockingly, a few said, that the finger of blame is often pointed by doctors, especially in non-paediatric specialties. This is so upsetting and so unnecessary.'



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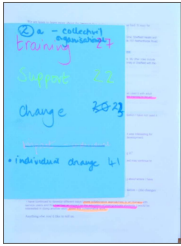
Impact: the cost of (a) change

Cost of DNA of Care programme = £50,000

Number of changes* = 100

Cost of each change = £500

* as of December 2017



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Impact: on one organisation



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Impact: Dignity and respect in Manchester


6.5 years

12 workshops

74 participants

87 stories created

250,000 hits on the Manchester stories



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Impact: how the Manchester stories have been used

- shown at the start of every Board meeting
- used in recruitment and selection interviews
- induction and staff training
- public screenings to raise public awareness of mental health
- strengthening the patient voice
- triangulating themes and trends
- within recovery networks and recovery education



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Impact: changes in culture

Changes within the Trust include:

- patient-led 'dignity walks'
- more confident patients *and* staff, able to tell their stories
- increased involvement of patients and carers in creation of care plans
- greater recognition of 'experts by experience'
- more engagement with family members
- use of Patient Voices stories in recruitment.

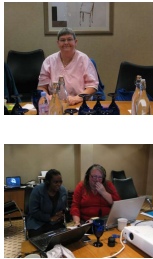


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Impact on quality

- Reduction in staff time spent investigating complaints
- Improvements in patient/carer communication and relationships = better care and increased confidence
- Overall quality of care is good/excellent
- 95% of 2018 patients would recommend the Trust
- In its October 2015 report on the Trust, the Care Quality Commission said:

'The trust was one of the first mental health trusts in the country to introduce the patient stories initiative, which involved a range of patient stories being used at the trust board meetings for learning and sharing purposes. Patient stories highlighted how services had responded to people's care and treatment needs. We observed a trust board meeting and saw the powerful nature of starting the formal board meeting with one of these stories.'



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Impact on individuals: What people have said over the years....

'Since making my digital story, I feel like I've grown wings.'

'A truly cathartic experience.'

'I felt that it was like 10 years' worth of therapy in 3 days.'

'It moved me on seismically – it released me.'

'It felt like an almost spiritual journey.'

'It was quite transformative in that way of actually viewing myself and my situation through quite a different lens ...'

'I feel like it has been the best reflective practice I have undertaken throughout my career and that it has also provided me with clinical supervision that I have never achieved in the same way within work.'



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Impact on individuals: a research project

'A good phenomenological description is collected by lived experience and recollects lived experience – is validated by lived experience and it validates lived experience.' van Manen, 1990

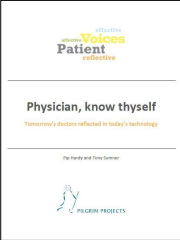
'Transformative and therapeutic benefits of digital storytelling: a phenomenological lifeworlds study of Patient Voices participant experiences'

Mazzoli Smith, L., Hardy, P. and Thompson, K. (In press)



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Storytelling with medical students



Learning outcomes


By the end of the SSC, you will be able to:

- articulate and reflect on your learning from experience in the clinical setting
- appreciate the power of personal stories
- create a digital story
- reflect on the creation of the digital story
- develop empathy and compassion
- enhance your presentation skills.

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Impact: reflection

'But now, with the digital storytelling, I understand for the first time what it really means, and how powerful reflection can be for me, and as a way of sharing my experiences with others.'




Matthew Critchfield, 2008

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Impact: Six years on

'The story I produced ... tells of how, when I jumped at the chance to practise a clinical procedure, what I actually learnt about was compassion and what it really means to provide medical 'care'.'

I am certain that this is the most considered and thought-out piece of formal reflection that I have produced to date.'



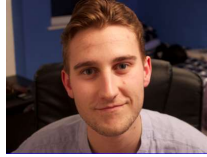
<http://patientvoices.org.uk/lssc.htm>

Matthew Critchfield, 2014

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Impact: Empowerment

'It strikes me that if all medical students could make these stories, or even just watch them, perhaps we would all feel more empowered and actually more energised to learn as we would feel part of a team, we would feel we had an important role and we would feel we could actually be 'producers' of patients' good health and happiness.'



David Gill, 2014

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Impact: 'Medicine isn't about passing exams'

'I take time now. I stop and think now. I've learnt medicine isn't about passing exams; it isn't about getting the best marks or impressing your consultant the most. It's about people. Sick people who need to know you're there, that they aren't alone.'



Lizzie Pollard, 2014

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Questions, comments and discussion



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Thank you!



www.patientvoices.org.uk/present.htm

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