

## Patient Voices

Involving patients,  
educating clinicians and  
transforming healthcare

20th October 2011

Educating for Patient and Public Involvement  
London Southbank University

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Pilgrim Projects/PatientVoices  
Cardiff University and University of Bedfordshire

Patient

## In the beginning....

*'In the case of nutrition and health, just as in the case of education, the Gentlemen of Whitehall really do know better what is good for the people than the people know themselves.'*

Douglas Jay (1937) The Socialist Case

## One size doesn't fit all!



## People before numbers

*'If there is one lesson to be learnt, I suggest it is that people must always come before numbers. It is the individual experiences that lie behind statistics and benchmarks and action plans that really matter, and that is what must never be forgotten when policies are being made and implemented.'*

Robert Francis, 2010

## The evidence of experience

*'Statistics tell us the system's experience of the individual, whereas stories tell us the individual's experience of the system...'*

Tony Sumner, 2009



## Becoming (a) patient

*'To the typical physician, my illness is a routine incident in his rounds, while for me it's the crisis of my life.'*

*I would feel better if I had a doctor who at least perceived this incongruity... I just wish he would... give me his whole mind just once, be bonded with me for a brief space, survey my soul as well as my flesh, to get at my illness, for each man is ill in his own way.'*

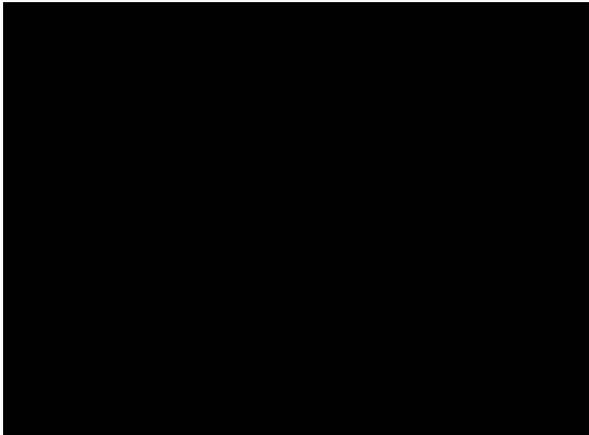
Anatole Broyard (1992)

Jean's story

'Getting to the bottom of things'

[www.patientvoices.org.uk/rcngip.htm](http://www.patientvoices.org.uk/rcngip.htm)





A model for reflection:  
EAR

Good stories are

- Effective
- Affective
- Reflective

Tony Sumner, 2008





The stories: Patient Voices





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*




Facts and figures  
(and some statistics)

- 500+ stories facilitated/recorded
- 90+ workshops, plus some home visits!
- 350+ stories released via Patient Voices website
- 20+ Patient Voices stories WIP
- 550,000+ hits on the website in 2010
- 1100-2400 hits per working day on PV website
- 200 Gigabytes of data downloaded
- 35,000 stories viewed during the year




## Patient Voices: a short history

- 2003 Patient Voices Programme founded by Pip Hardy and Tony Sumner
- 2004 Dartmouth Hitchcock Clinical Microsystems Film Festival 'People's Choice'
- 2005 First use of Patient Voices stories by UK National Audit Office VFM
- 2006 CDS workshops in California
- 2007 MSc research into digital storytelling in healthcare complete
- 2008 Creating an Inter-professional workforce Innovation award
- 2009 .5 million hits on Patient Voices website
- 2010 BMJ award for Excellence in Healthcare Education  
Shortlisted for BMJ Health Communicator of the Year *and*  
MJA Healthcare Champion of the Year
- 2010 Three papers published
- PHD research into impact of digital storytelling on healthcare and reflective potential of technology
- 2011 Health Foundation award to improve complaints handling using digital storytelling

## Transformation

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

Schön, 1988



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## Why tell stories?

*'We tell stories to entertain and to teach...*



## Why tell stories?

*'We tell stories to entertain and to teach...*

*... and to heal.'*



## Ways of healing



## Ways of healing



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## Humanising healthcare



*'One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient.'*

Peabody, 1927

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## Dignity and the essence of medicine

**The A, B, C, D of care**

- Attitude
- Behaviour
- Compassion
- Dialogue

Chochinov, 2007

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## Digital storytelling: finding a voice



*'One of the hardest things in life is having words in your heart that you can't utter.'*

James Earl Jones

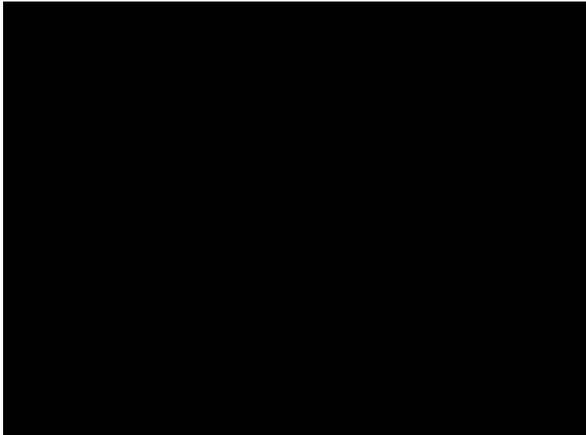
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## Finola's story

What do you say?

[www.patientvoices.org.uk/sheffcc2.htm](http://www.patientvoices.org.uk/sheffcc2.htm)

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## Creating ourselves



*'Narrative is radical,  
creating us at the very  
moment it is being  
created.'*

Morrison, 1994



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## Life changes stories



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## Stories change lives



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## 'Stories work on many levels.'



Brian Clark, Storyteller



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## Two-minute story

*'If we communicate for two  
minutes only, it will be a start.'*

Paul Weller



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## The two-minute story

- Arrange yourselves in pairs.
- Decide who will be the storyteller and who will be the listener.
- Take a few moments to think of a story. Make a few notes if you wish.
- Now tell your story to your partner in two minutes.
- Stop! Listeners, what did you notice?
- Have a conversation and plan the story, thinking of images that might tell part of the story.
- Tell your story again.
- What were the differences between the two stories?



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## Getting to the heart of the story

- Small group workshops
- Careful facilitation
- De-mystifying technology



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## Getting to the heart of the story

- The story circle
- Mindfulness and attention
- Creating space and community



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## Changing the world: one workshop at a time

*'Never doubt that a small group of thoughtful, committed people can change the world. Indeed it is the only thing that ever has.'*

Margaret Mead



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## Passages past dragons

*'People reach greater maturity as they find the freedom to be themselves*

*and to claim, accept and love their own personal story, with all its brokenness and its beauty.'*

Jean Vanier



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## Healing and recovery



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## Culture of the heart

*'The culture of the mind must be subservient to the culture of the heart.'*

Mahatma Gandhi



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Thank you

[www.patientvoices.org.uk](http://www.patientvoices.org.uk)

Twitter @patientvoicesuk

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