Patient Voices

Using digital storytelling and digital stories in medical education

PedSIG

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Pilgrim Projects/Patient Voices

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Aims of the session

- to explain the origin and intentions of the Patient Voices programme
- to explore the use of stories and storytelling
  - what makes 'good' stories
  - impact on a range of audiences
  - 'usefulness'
- to consider the potential of digital stories and digital storytelling in medical education.

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Why are we here?

'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.'

Francis Peabody (1927) *The care of the patient*

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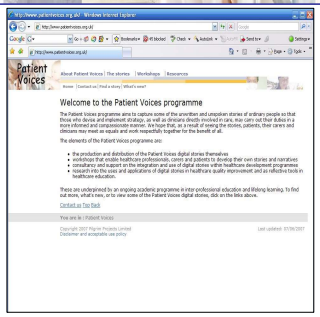
Patient Voices



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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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Why tell stories?

'We tell stories to entertain and to teach.'

Pascal

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Why tell stories?

'We tell stories to learn and to heal.'

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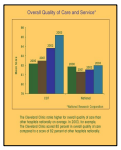
How to get the patient's story



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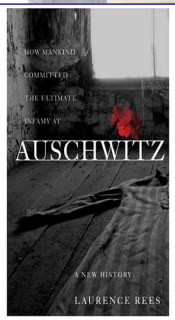
Lies, damn lies and . . .



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

Laurence Rees (2006) *History of Auschwitz*

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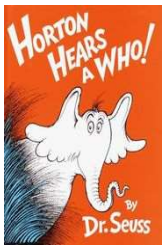
From a doctor who knows



'Even if you can't hear or see them at all, a person's a person, no matter how small.'

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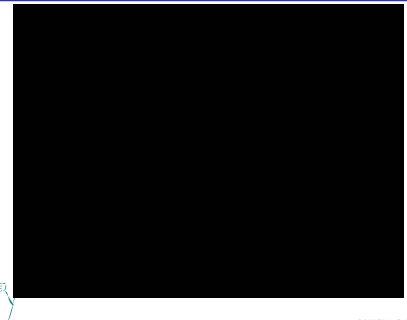
Bicycle clips



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Bicycle clips

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What are digital stories?

Digital stories consist of still images, music, voice-over and video (sometimes); the stories are told by *real* people about their own *real* experiences.

Digital stories are a *distillation* – they move us from the narrative to the *essential story*.

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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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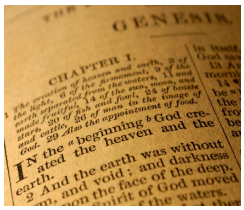
Telling the right stories



'How can I help people if I don't know the right stories to tell them?'

Jack Cash

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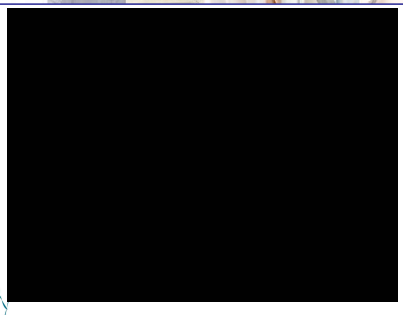
Leanna



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Leanna

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The essence of medicine

The A, B, C, D of care

- **A**ttitude
- **B**ehaviour
- **C**ompassion
- **D**ialogue

Harvey Chochinvov, 2007

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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) *Intoxicated by my illness*

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Digital storytelling: how it's done

Typically, digital stories are produced in small, intensive, carefully facilitated workshops.

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Digital storytelling: a chance to reflect

'Reflection is as natural – and as necessary – as breathing … or telling stories.'

Joe Lambert, Centre for Digital Storytelling

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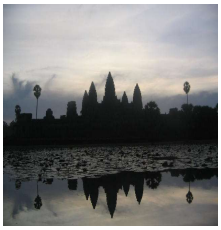
Digital storytelling: a chance to reflect

- Reflecting on experience
- Reflecting on stories
- Reflecting on practice
- Reflecting on learning



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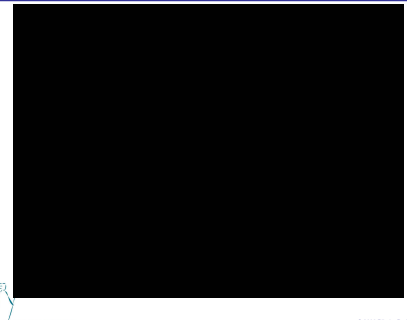
Yeah, I'll go



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Yeah, I'll go

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Linking learning and experience

- Learning from experience
- Vicarious experience
- Seeing the world in new ways
- Seeing new worlds

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Ways of knowing, ways of teaching

Epistemology	Hermeneutics	Worldview
Knowledge and validity	Art and science of interpretation	Assumptions Values Culture
Curriculum and learning design	Syllabus and pedagogy (andragogy!)	Context and starting point of learners (cultural and individual)
What needs to be learned? *What is the best way to learn it?*	*What knowledge is valued?* *How is it taught?*	*What are appropriate teaching resources?* *How do we engage students?*

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What research reveals

The stories are valued for their:

- authenticity
- veracity
- flexibility and versatility
- brevity and succinctness
- emotional power…..

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What research reveals

…and for their ability to:

- prompt reflection
- stimulate discussion and debate
- promote empathy
- encourage creativity
- change practice.

Hardy, 2007

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How are the stories being used?

- Service user involvement
- Learning from patients/carers
- Sharing experiential learning
- Knowledge transfer
- Promoting reflective practice
- Sharing good news and good practice
- Qualitative research
- Inter-professional education
- Mental health/health inequalities/DRE
- Building social capital
- Informing design (products and services
- Professional formation/CPD
- Building/strengthening teams
- Reminder of patients' existence/raison d'etre of NHS
- Commissioning
- Patient/carer/service user education
- Leadership
- Project feedback and evaluation
- E-learning
- Guideline implementation
- Hearing student voices

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Some facts and figures

- 300 stories facilitated/recorded
- 56 workshops (plus some home visits!)
- 170 stories (approx) released via Patient Voices website
- 25 (approx) stories WIP
- >1500 hits per day on PV website
- on target for 0.5 million hits in 2008
- >30 stories viewed each day

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Patient Voices: a unique model

- carefully developed methodology
- facilitates telling and sharing of stories of *all* stakeholders
- empowers patients/service users
- free distribution of stories
- ensures that stories are heard
- builds social capital
- robust consent and release process

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Don't let the voices go quiet

A sustainable model

- Independence
- Organic growth
- Storytelling with a purpose
- Appropriate technologies
- Ethical approach

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Stories that move

'Behaviour change happens in highly successful situations mostly by speaking to people's feelings.'

Kotter and Cohen (2002)

'Culture of the mind must be subservient to the heart.'

Mahatma Gandhi

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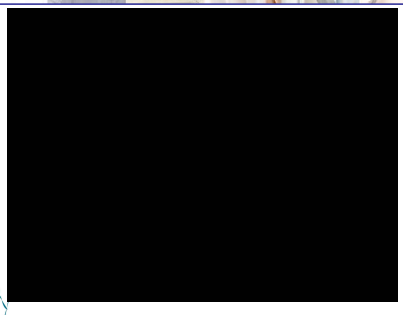
Emaan



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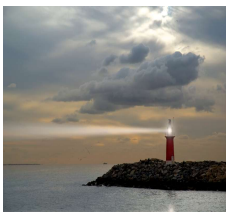
The power of stories



'Every light was a story and the flashes themselves were the stories going out over the waves, as markers and guides, comfort and warning.'

Winterson, 2005

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EAR

Why are the Patient Voices stories so popular, and so powerful?

Effective

Affective

Reflective

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Preserving stories

Which stories need to be told?

Why are they important?

How would you preserve them?

What would you do with them?

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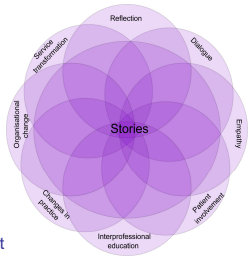
From stories to transformation

Markers

Guides



Comfort

Warning

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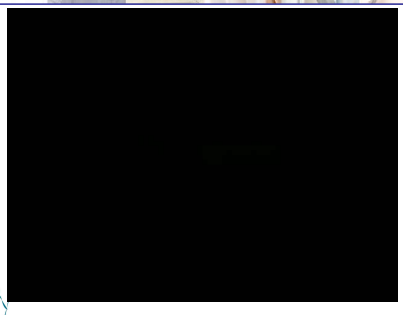
The real nurse



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The real nurse

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In my ends are my beginnings

Product or process?

Process *and* product

A means to an end….

(apologies to TS Eliot)

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