



International Digital Storytelling Conference
Current Trends in Digital Storytelling
 Edited by Pip Hardy
 21-22 September 2018, Laboratory of Digital Storytelling, Department of Educational Studies, University of Zakinthos, Greece

**effective
 affective
 Patient
 reflective** **Voices**

*'The end is where we start from':
 Learning from 15 years of Patient Voices*

Dr Pip Hardy
 Patient Voices and Manchester Medical School

September 2018 * Current trends in digital storytelling research and practices', Zakynthos, Greece

Thanks



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2003: In the beginning...



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What we've done

- Established in 2003
- 1000+ stories facilitated/recorded
- ~ 800 stories released
- ~ 180 workshops, plus some home visits!
- + 2 million hits on the website annually
- ~ 3500 hits per working day on PV website
- ~ 80,000 stories viewed during the year
- + 200 presentations given
- 9 papers and 5 book chapters published
- 1 book written (second edition available now)
- 1 PhD and 1 MSc completed
- 3 international and 2 national awards won



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Where we've done it



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Some context: policy, education and research



'Our vision is to move away from an outdated system towards a new model where the voice of the patient is heard through every level of the service, acting as a powerful lever for change and improvement.'

'Clinical governance can be defined as a framework through which NHS organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care.'

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Quality, safety and the pursuit of perfection

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Representing patient experience

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What patients *really* want

'Patients care more about being treated with dignity and respect than they do about mortality rates.'
Page, 2004

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The culture of the mind...

'The culture of the mind must be subservient to the culture of the heart.'
M K Gandhi

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Learning from stories

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The first digital story we saw

Judd, J. 2002. Don't judge a book by its cover [Online]. E2BN. Available:
<http://clips.e2bn.org/view.php?id=110>
[Accessed March 2014]

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The intersection



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The first storytellers



Ian Kramer



Monica Clarke

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'The crisis of my life'

'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

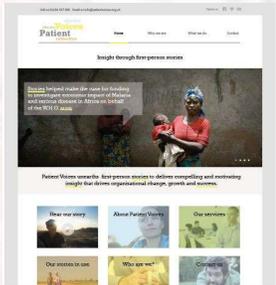
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Patient Voices

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

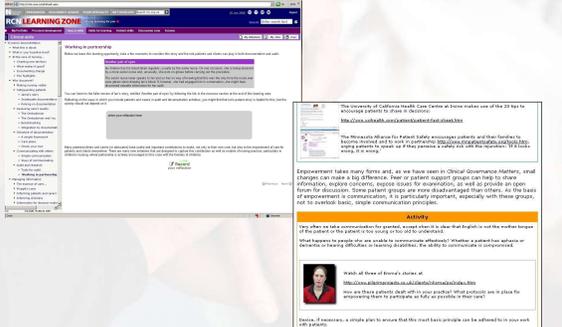
'...to capture some of the unwritten and unspoken stories of ordinary people so that those who devise and implement strategy, as well as clinicians directly involved in care, may carry out their duties in a more informed and compassionate manner.'



Hardy, 2004

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The ultimate re-usable learning object



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Re-presenting patient experience

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



Summer 2009

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Getting to the bottom of things



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

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Patient Voices: from story to transformation



- Involving and engaging patients
- Placing patients firmly at the heart of care
- Listening to their stories
- Learning from their stories
- Promoting reflection
- Prompting discussion and debate
- Strengthening inter-professional education and collaborative practice
- Contributing to research
- Improving quality and safety
- Touching hearts and minds
- Stimulating organisational change

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Patient Voices: a mandala



The Patient Voices Mandala
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So... what have I learned?

Ways of knowing

- Empirical
- Aesthetic
- Personal
- Moral

Carper, 1978

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Preparing



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Creating: safe space, safe stories



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Suffering



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Connecting



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Listening

LISTEN



SILENT

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Reflecting

A model for reflection:
 Effective
 Affective
 Reflective

Tony Sumner, 2009



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Reflecting with medical students

'We are asked to reflect all the time, and then to reflect on our reflection until we're sick of it.'

Critchfield, 2008



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Yeah, I'll go

www.patientvoices.org.uk/flv/0257pv384.htm Matthew Critchfield, 2008

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Warning

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Loving

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Keeping track (and knowing what works)

	SCALIF	REGARD	SPRATCH RD	SCAF	ROBIN WALKER	ANCA CAT	TIBBETTS	ANCA C	WALKER	COLLECT	WIP	REGISTRATION
ANU	✓	✓										
ELAINE	✓	✓	✓	✓	✓							
TABRUELI	✓	✓	✓	✓	✓	✓						
ROSECH	✓	✓	✓	✓	✓	✓						
SHAWOL	✓	✓	✓	✓	✓	✓						
STEPHANE	✓	✓	✓	✓	✓	✓						

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Curating

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Disseminating

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Passing past dragons

'No matter what form the dragon may take, it is of this mysterious passage past him, or into his jaws, that stories of any depth will always be concerned to tell....'

O'Connor 1969



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Balancing: purpose vs prosperity



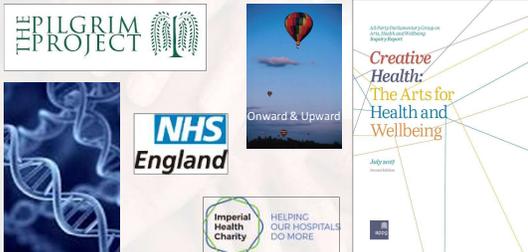
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Speaking



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What next?

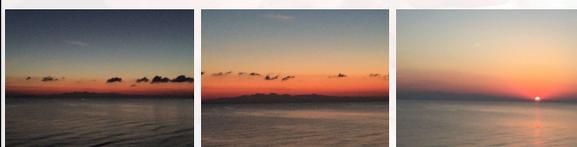


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Gratitude

'Each affects the other and the other affects the next and the world is full of stories and the stories are all one.'

Mitch Albom, 2004



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'In my end is my beginning'

*'What we call the beginning is often the end
And to make an end is to make a beginning.
The end is where we start from.'*



TS Eliot Little Gidding

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