

effective  
affective **Voices**  
Patient  
reflective

## Cultivating compassion: Digital storytelling in healthcare

@PatientVoicesUK  
www.patientvoices.org.uk

Tony Sumner

24<sup>th</sup> February 2020 Royal Central School of Speech and Drama

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## Why are we here?

To consider the potential of digital storytelling to transform healthcare...

We will:

- explain why we started Patient Voices
- describe how the programme has developed
- share some stories
- touch on some ethical and practical issues
- offer some challenges and provoke reflection
- (hopefully) inspire your own storytelling and listening.

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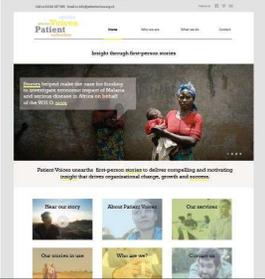
## Patient Voices

**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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## What we've done

- Founded Patient Voices in 2003 to use stories to promote reflection in healthcare
- ~1300 stories facilitated
- ~800 stories freely-viewable
- ~200 workshops, plus some home visits!
- >3 million hits on the website annually
- >200 presentations given
- 14 papers and 6 book chapters published
- 2 books written/edited
- 1 PhD and 1 MSc completed + one on the way!
- 3 international and 2 national awards won




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## Where we've done it



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## Quality, safety and the pursuit of perfection



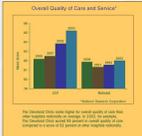


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### Representing patient experience

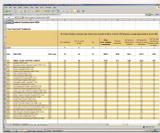


Overall Quality of Care and Patient Satisfaction



Treated with dignity and respect v satisfaction with overall care







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### Re-presenting patient experience







[www.patientvoices.org.uk/flv/0851pv384.htm](http://www.patientvoices.org.uk/flv/0851pv384.htm) Tony Sumner, 2009

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### But who controls the story...



*'[Stories] are a way of gathering data to be manipulated, cut up and placed into categories, themes and sub-themes for analysis.'*

Hawkins and Lindsay 2006



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### ...and whose story matters?



*'...to treat stories in this way is to fail to respect the tellers of these stories. It is to make the assumption that our interpretation of the patient's experience is more valid than their telling of it.'*

Hawkins and Lindsay 2006



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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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### 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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## 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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## Why tell stories?

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

Pascal



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## Why tell stories?

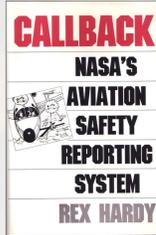
*'Storytelling is the mode of description best suited to transformation in new situations of action.'*

Schön 1988



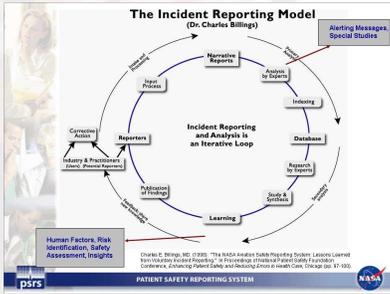
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## Learning from the aviation industry




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## Stories, tacit knowledge and culture change



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## UKHEP e-learning (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.'*



Charon 2002

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**A very short story**

For sale  
Baby shoes  
Never worn  
Hemingway



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**Focus on the story**

**Digital Storytelling**

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**Family ties**



www.patientvoices.org.uk/fw/0773pv384.htm David Gill 2014

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**Reflections?**

The moment?  
The insight/s?  
The feelings?



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**What makes a good story?**

*'I'm sorry to have written you such a long letter – I didn't have time to write a short one.'*  
Mark Twain



*'Show, don't tell.'*  
*'Stories are always true: it's the facts that mislead.'*  
Jeanette Winterson

*'The foundation of a story is an emotional foundation – in other words, a good idea that moves.'*  
Yann Martel

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## What makes a good story?

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*'Sure, a story needs to have a beginning, a middle and an end, but not necessarily in that order!'*

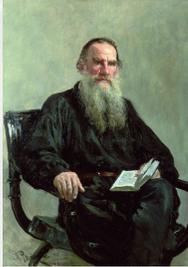


Jean Luc Godard

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## Change

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*'All great literature is one of two stories; a man goes on a journey or a stranger comes to town.'*

Leo Tolstoy

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## The shapes of stories

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[www.youtube.com/watch?v=oP3c1h8vZQ](http://www.youtube.com/watch?v=oP3c1h8vZQ)

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## What makes a good story?

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**Richardson (2000) on what is good auto-ethnography**

- Substantive contribution:** does the piece contribute to our understanding of social life?
- Aesthetic merit:** Does it succeed aesthetically, is it artistically shaped, is it satisfying, complex, not boring?
- Reflexivity:** Is the author's subjectivity in the text, is the point of view clear, is there adequate self-awareness and self-exposure?
- Impact:** How does the work affect us emotionally, intellectually, and as a scholar. Does it generate new questions? Does it move us to try new research practices? Does it move us to action?
- Expressing a reality:** Does this text embody a fleshed-out, embodied sense of lived experience? Does it seem 'true' – a credible account of a cultural, social, individual or communal sense of the 'real'?

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## EAR: a model of reflection

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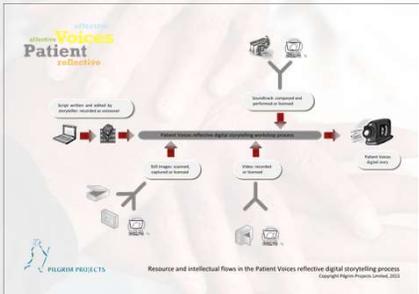
- Effective**  
What did you think?
- Affective**  
What did you feel?
- Reflective**  
What will you do?



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## Patient Voices Process Flow

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Resource and intellectual flows in the Patient Voices reflective digital storytelling process  
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**The story journey**

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- Story
- Script
- Recording
- Organise your assets
- Storyboard
- Images
- Editing
- Bells and whistles



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**Seven steps**

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- Owning your insight
- Owning your emotions
- Finding the moment

Seeing your story  
Hearing your story  
Assembling your story  
Sharing your story

**STORYCENTER**  
LISTEN DEEPLY. TELL STORIES

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**Finding the insight(s)**

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**Finding the feelings**

effective **Voices**  
Patient  
reflective



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**Finding the moment**

effective **Voices**  
Patient  
reflective



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**The story only you can tell**

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## DS facilitation and the story circle

akin to Liz Lerman's Critical Response Process:

- The Artist == the storyteller with their draft or ideas for a story
- The Responders == the other storytellers and facilitators in the story circle
- The Facilitator == the DS facilitator(s) 😊

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## Distillation



Clear  
Pure  
Potent

Jo Tait

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## Passages 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...'*



Flannery O'Connor

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## Floristry, perhaps?



www.patientvoices.org.uk/fw/1118pv384.htm Lizz Summers, 2016

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## Transformation

*'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.'*



Vanier 2004

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## 4 Cs

- Connection
- Context
- Crisis
- Closure



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**Your story**

What is your story about?  
 What is your story *really* about?  
 What is your story really, really about?



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**Seeing your story**

Seeing the images  
 Locating/creating the images to use  
 Understanding the images  
 Explicit vs implicit imagery

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**Seeing your story**

- Use your own photos if possible
- Take photos
- Draw pictures
- Landscape rather than portrait
- Make use of image editing software
- Stretch images to fill gaps
- Think metaphorically – use abstract images
- Avoid Googling for images
- Less is more!

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**Seeing your story**

*'When words become unclear, I shall focus with photographs. When images become inadequate, I shall be content with silence.'*



Ansel Adams

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**Hearing your story**



*'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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**Assembling your story**

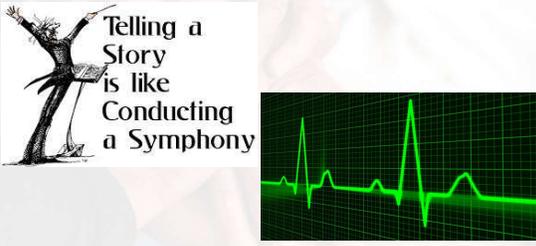
(Less is more!)




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## Assembling your story

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**Telling a Story is like Conducting a Symphony**

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## The stories are all one

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

Mitch Albom

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## Sharing values and vision

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*'If you want to build a ship, do not start by gathering wood, cutting planks and assigning tasks. Instead, inspire a longing for the wide, endless sea.'*



Antoine de St Exupery, 1943

Compassionate leadership: a part of the DNA of Care facilitator's guide programme © NHS England and Pilgrim Projects

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## Facing dragons

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*'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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## Patient Voices: the vision

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Empowering patients to tell their stories offers viewers an opportunity to reflect and engage in dialogue and discussion both internal and external.

Discussion reinforces the reflection and leads to empathy and understanding which leads to the inevitable realisation that patients are central to the delivery of healthcare.

As an integral part of the team, they should be involved in the education of health professionals as well as participating as role models rather than an aggregated number in research.

Inter professional education that will only create professional bureaucracies but also allows patients firmly at the centre of care stands a good chance of providing individual changes in practice.

These individual changes lead to collective changes that contribute to transformation in organisations, which are all seeking to help Great and safe, high-quality care with patients at the centre.

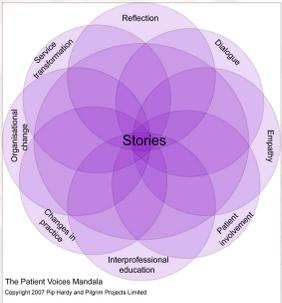
The Patient Voices journey from story to service transformation  
©2020 The Hardy and Pilgrim Projects Limited

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

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## Patient Voices: the mandala

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The Patient Voices Mandala  
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## What research revealed

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The stories are valued for their:

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

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## What research revealed

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... and for their ability to:

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

Hardy 2007

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## Process and product: the means and the ends

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The means and the ends:

- the process is as important as the product
- learning how to 'craft' stories informs and develops understanding of their potential applications
- the process of telling a story can be – and usually is – therapeutic, as well as reflective.



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## Getting to the bottom of things

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

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## Reflections?

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The moment?  
The insight/s?  
The feelings?



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## Learning from stories

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*'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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## Stories, values, identities



The image shows an iceberg floating in the ocean. The tip of the iceberg, which is above the water, is labeled 'Stories'. The much larger part of the iceberg, which is submerged below the water, is labeled 'Identity' and 'Values'. The background of the slide features a close-up of several hands clasped together in a supportive grip.

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## Reflection: the power of the process

Qualifying doctors are expected to *'continually and systematically reflect on practice and whenever necessary, translate that reflection into action ...'*

General Medical Council 2009

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

Matthew Critchfield, 2008



The image shows a young man in a red and white striped shirt sitting at a desk with a laptop. He has his hand to his face, looking thoughtful or stressed. The background of the slide features a close-up of several hands clasped together in a supportive grip.

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## Yeah, I'll go



The word cloud contains various medical and professional terms. The most prominent words are 'doctors', 'registrars', 'nurses', 'patients', 'family', 'just', 'trying', 'catheter', 'blood', 'know', 'result', 'away', 'experience', 'urine', 'think', 'catheterise', 'seemed', 'understand', 'needed', 'never', 'right', 'gas', 'procedure', 'get', 'training', 'good', 'done', 'blood', 'know', 'result', 'away', 'experience', 'urine', 'think', 'catheterise', 'seemed', 'understand', 'needed', 'never', 'right', 'gas', 'procedure', 'get', 'training', 'good', 'done'. The background of the slide features a close-up of several hands clasped together in a supportive grip.

www.patientvoices.org.uk/fiv/0257pv384.htm Critchfield 2008

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## Reflection in action

*'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.'*

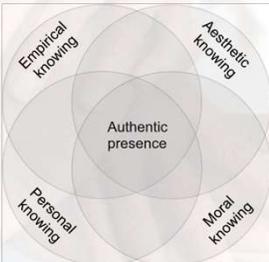
Matthew Critchfield, 2008



The image shows two people sitting at a desk with a computer. One person is wearing a headset and looking at the screen, while the other is looking at the screen. The background of the slide features a close-up of several hands clasped together in a supportive grip.

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## Ways of knowing



The diagram consists of four overlapping circles representing different ways of knowing: 'Empirical knowing' (top-left), 'Aesthetic knowing' (top-right), 'Personal knowing' (bottom-left), and 'Moral knowing' (bottom-right). The central area where all four circles overlap is labeled 'Authentic presence'. The background of the slide features a close-up of several hands clasped together in a supportive grip.

Hardy and Jaynes 2010 after Carper 1978

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## Storytelling with students

*'We get used to being told exactly how things are; these are the facts, this is the law, this is how you treat someone – sometimes we forget that our own experiences and opinions are important.'*

David Gill, 2014



The image shows a young man with short brown hair, wearing a light-colored shirt, looking directly at the camera. The background of the slide features a close-up of several hands clasped together in a supportive grip.

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