

Patient Voices®:

a short history of digital storytelling in healthcare

@PatientVoicesUK
@PilgrimPip

Pip Hardy and Tony Sumner

21st February 2020 NTNU Gjøvik Norway

Why are we here?

The aim of our talk is to demonstrate the power and utility of digital storytelling in healthcare.

We will:

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

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2003: In the beginning...

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Quality, safety and the pursuit of perfection

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In the beginning...

'Our vision is to move away from an outdated system towards a new model where the voice of the patient is heard through every level of the service, acting as a powerful lever for change and improvement.'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

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Re-presenting patient experience

effective **Voices**
Patient
reflective



www.patientvoices.org.uk/fiv/0851pv384.htm Tony Sumner, 2009

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But who controls the story...

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Patient
reflective

'[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?

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Patient
reflective

'...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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Our first storytellers

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Ian Kramer Monica Clarke

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The intersection

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'The crisis of my life'

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'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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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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Jimmy's story



www.patientvoices.org.uk/ftv/0047pv384.htm Betty Mauchland, 2006

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EAR: a model of reflection

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



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Research and audit: stories as uber-qualitative data



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2007: the end of the beginning...




An investigation into the application of the Patient Voices digital stories in health-care education: quality of learning, policy impact and practice-based value

Ph. Hardy
University of Ulster
Faculty of Social Science
School of Education
MSc in Lifelong Learning
May 2007



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Focus on the story

Digital Storytelling

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Facing 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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Developing the Programme

Some issues we wrestled with:

- ethical considerations
- curating and managing digital media
- evaluation
- product, process or programme?



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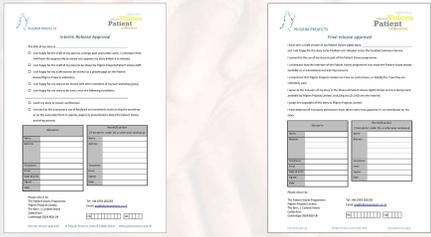
Consent as process: reciprocity



Hardy 2015

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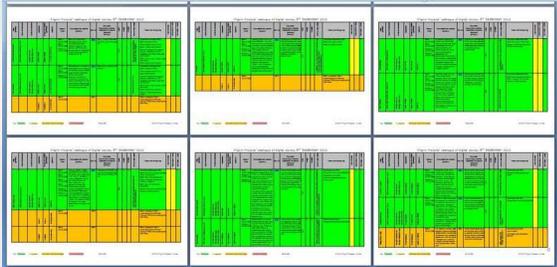
Consent as process: retaining control



Hardy 2015

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Managing digital media



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Patient Voices: the vision

Empowering patients to tell their stories offers a chance for patients to reflect and engage in dialogue and discussion (both internal and external). Discussion reduces the reflection and leads to empathy and understanding, which leads to the realisation that patients are central to the delivery of healthcare.

As an integral part of the team they should be involved in the initiation of health professionals as well as participating in initiatives rather than as aggregated members in research.

Inter-professional education that not only crosses professional boundaries but also invites patients firmly at the centre of care stands a good chance of promoting individual changes in practice. These individual changes lead to collective changes that contribute to transformation in organisations, which are at last looking like the high-quality care with patients at the centre.

The Patient Voices journey from story to service transformation ©2017 by Hardy and Pilgrim Projects Limited

- Stories
- Reflection
- Discussion
- Empathy
- Patients at the centre
- IPE and research
- Individual changes in practice
- Organisational change
- Service improvement
- Transformation

- 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

The Patient Voices Mandala
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What research revealed

The stories are valued for their:

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

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What research revealed

... 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: ends and means

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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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

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Yeah, I'll go

www.patientvoices.org.uk/flv/0257pv384.htm Matthew 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

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Storytelling with students

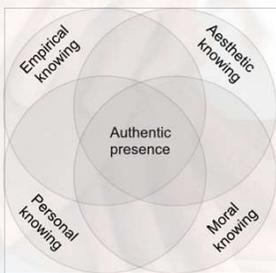


'We get used to being told exactly how things are; these are the facts, this is the law, this is how you treat someone – sometimes we forget that our own experiences and opinions are important.'

David Gill, 2014

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Ways of knowing



Hardy and Jaynes 2010 after Carper 1978

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Overcoming 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.'

Vanier 2004

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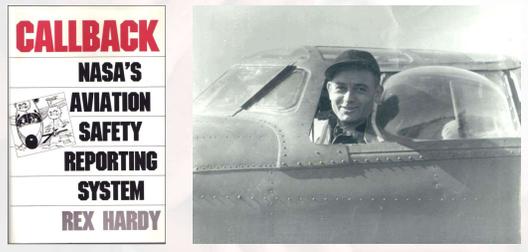
2010: the journey continues

- BMJ award
- Changing cultures
- Making a difference to organisations and systems
- Improving outcomes for patients



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Learning from the aviation industry



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Stories, tacit knowledge and culture change

The Incident Reporting Model (Dr. Charles Billings)

Alerting Messages, Social Studies

Incident Reporting and Analysis is an Iterative Loop

Human Factors, Risk Identification, Safety Assessment, Insights

PSRS PATIENT SAFETY REPORTING SYSTEM

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Transforming culture

'If we want to create a culture of safety, a culture of quality, a culture of humanity, then it is necessary, first, to understand the individuals who form that culture.'

Hardy and Jaynes, 2010

'Culture is the way we do things when no one is looking.'

Hart, 2013

'We can't create a culture of safety because we don't know what one looks like.'

Jaynes, 2013

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Transforming culture

Future clinicians told us they wanted a culture that was:

- open and transparent
- respectful and dignified
- kind and compassionate
- just and equal
- humane and compassionate
- trustworthy and blame-free
- characterised by continuous learning.

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Dignity and respect

Manchester Mental Health and Social Care Trust

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What we did....

Over four years:

- 11 workshops
- 72 stories

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 in education, rather than as aggregated numbers in research.

Inter-professional education that not only crosses professional boundaries but also situates patients firmly at the centre of care stands a good chance of promoting individual changes in practice. These individual changes lead to collective changes that contribute to transformation in organisations, which are all seeking the real goal of safe, high-quality care with patients at the centre.

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

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Freedom

www.patientvoices.org.uk/ftv/0643pv384.htm Brenda Cullen, 2012

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How are the stories used?

- Stories 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
- reminding staff, patients and carers of our shared humanity



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Impact on the organisation

After two years, the Trust reported:

- reduction in complaints related to care (45%)
- reduction in complaints related to staff issues (9%)
- reduction in complaints related to communication (22%)
- reduction in CNST claims (50%)
- reduction in management costs.



Our Wellbeing - Committed to the health and wellbeing of our staff
Truthfulness Respect Understanding Standards Togetherness

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Learning from stories

'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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What we've done

- Founded 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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Patient Voices: where the stories come from



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Working with staff and students




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Stories empower medical students

'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

www.patientvoices.org.uk/pkt.htm

David Gill, 2014

Stories teach empathy

'I was now seeing each one as an individual and deeply reflecting on their story, their experience and truly empathising with sincerity. This SSC went beyond my expectations and has equipped me with skills - the ones which may not pass contribute to the passing of exams as we're so conditioned to think - but the ones which will make me a better doctor.'



Chidi Amadi

www.patientvoices.org.uk/pkt.htm

I am now not just a doctor with patients, I am a fellow human being. Just as I would expect to be respected as such, I should and will continue to go beyond the confines of a checklist giving the intangible gift of a listening ear and heart.'

Stories and transformation: School for Health & Care Radicals



THE EDGE ISSUE TEN #TheEdge10

The power of storytelling as a force for transformational change

By Pip Hardy of Patient Voices

Our first Edge Talks webinar explored how stories are an essential ingredient in transforming health and care. This was held on Friday, 5 June 2015. It explored the rationale, how stories can be gathered and, most importantly, how the process puts people at the heart of care.

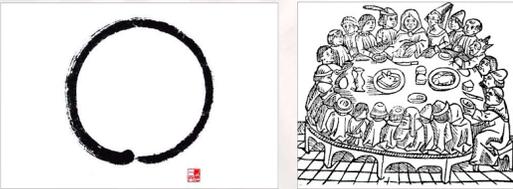
Resources:

- You can view Pip's slides here.
- A full transcript of the session can be found here.
- A copy of the Story from Pip's session can be found here.
- A copy of the Story from the Newsletter on Wednesday can be found here.

The full recording of the session can be viewed

<http://bit.ly/1KRUSTr>

End of life care: an interprofessional approach



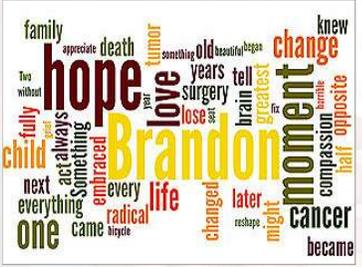
Markers and guides



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

Jeanette Winterson, 2005

The gift of hopelessness



www.patientvoices.org.uk/flv/1180pv384.htm Rita Berglund 2018

Patient Voices: humanity



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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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Thank you

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Winner
The **BMJ** Group Awards
Excellence in Healthcare Education
Finalist
Health Communicator of the Year
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