



Patient Voices

Transforming healthcare through
Effective, Affective and Reflective
digital stories

9th December 2011

NTWC Quality Conference
Tuen Mun

Pip Hardy

Pilgrim Projects/Patient Voices
Cardiff University



Slowing down



Transformation and change





Ways of healing





Ways of healing





Bridging the gap






Ways of knowing





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



Reflection: learning from experience

*'We learn not from
experience but from
reflecting on
experience.'*

John Dewey, 1938





Reflection: a valuable activity?

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

Matthew Critchfield,
2008





Matthew's story

'Yeah, I'll go'

www.patientvoices.org.uk/lssc.htm



A model for reflection: EAR

Good stories are

Effective

Affective

Reflective

Tony Sumner, 2008





Stories and transformation



‘Storytelling is the mode of description best suited to transformation in new situations of action.’

Schön, 1988

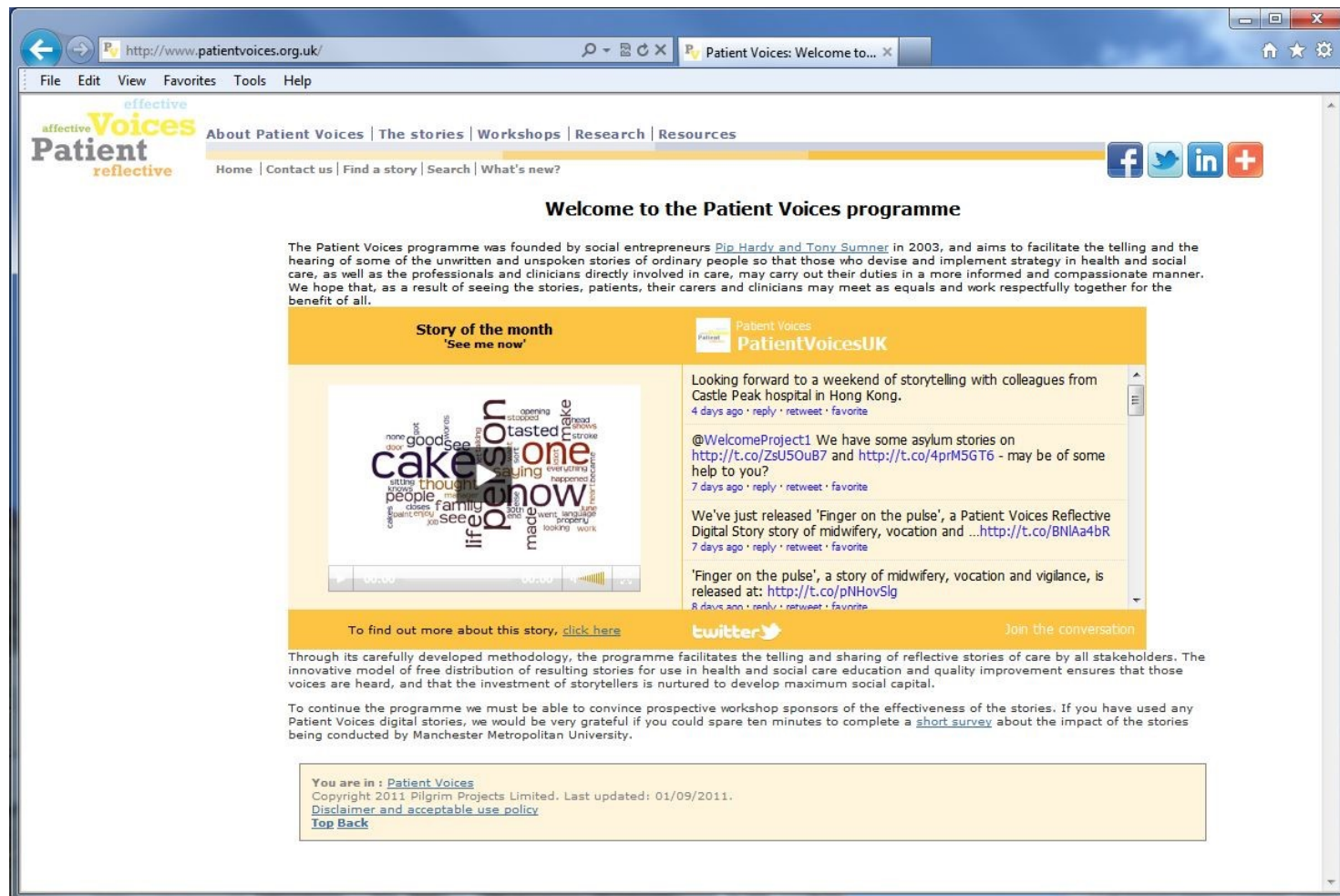
The evidence base: stories or statistics?

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

Tony Sumner (2009)



The stories: Patient Voices




The screenshot shows a web browser window displaying the Patient Voices website. The address bar shows the URL <http://www.patientvoices.org.uk/>. The website header includes the logo "effective Patient Voices reflective" and navigation links: "About Patient Voices | The stories | Workshops | Research | Resources". There are also social media icons for Facebook, Twitter, LinkedIn, and a plus sign for more options.

Welcome to the Patient Voices programme

The Patient Voices programme was founded by social entrepreneurs [Pip Hardy](#) and [Tony Sumner](#) in 2003, and aims to facilitate the telling and the hearing of some of the unwritten and unspoken stories of ordinary people so that those who devise and implement strategy in health and social care, as well as the professionals and clinicians directly involved in care, may carry out their duties in a more informed and compassionate manner. We hope that, as a result of seeing the stories, patients, their carers and clinicians may meet as equals and work respectfully together for the benefit of all.

Story of the month

'See me now'



00:00 00:04

Patient Voices

PatientVoicesUK

Looking forward to a weekend of storytelling with colleagues from Castle Peak hospital in Hong Kong.
4 days ago · reply · retweet · favorite

@WelcomeProject1 We have some asylum stories on <http://t.co/ZsU5OuB7> and <http://t.co/4prM5GT6> - may be of some help to you?
7 days ago · reply · retweet · favorite

We've just released 'Finger on the pulse', a Patient Voices Reflective Digital Story story of midwifery, vocation and ...<http://t.co/BNIA4bR>
7 days ago · reply · retweet · favorite

'Finger on the pulse', a story of midwifery, vocation and vigilance, is released at: <http://t.co/pNHovSlg>
8 days ago · reply · retweet · favorite

To find out more about this story, [click here](#)

Join the conversation

Through its carefully developed methodology, the programme facilitates the telling and sharing of reflective stories of care by all stakeholders. The innovative model of free distribution of resulting stories for use in health and social care education and quality improvement ensures that those voices are heard, and that the investment of storytellers is nurtured to develop maximum social capital.

To continue the programme we must be able to convince prospective workshop sponsors of the effectiveness of the stories. If you have used any Patient Voices digital stories, we would be very grateful if you could spare ten minutes to complete a [short survey](#) about the impact of the stories being conducted by Manchester Metropolitan University.

You are in : [Patient Voices](#)
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[Top Back](#)



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)

550+ stories facilitated/recorded

100+ workshops, plus some home visits!

350+ stories released via Patient Voices website

10+ Patient Voices stories WIP

.5 million + 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 role and impact of digital storytelling in healthcare and reflective potential of technology
- 2011 Health Foundation award to improve complaints handling using digital storytelling

Informed consent



Patient Voices

Protocol for storytellers

'One of the hardest things in life is having words in your heart that you can't utter.'
James Earl Jones, actor [1931-]

Respect
Storytellers and their stories will be treated with respect at all times. We will try to interpret accurately the intentions of the storyteller and to preserve the integrity of the story. We will always try to be flexible and sensitive to the needs of storytellers with regard to the place and pace of recording.


Consent
We will not record a story for use as part of the Patient Voices programme unless we have informed and valid written consent from storytellers; we will provide whatever information is necessary about the process and the existing stories to enable such consent to be given.
Storytellers will be asked to sign a consent form which will allow the use of the final version of the story as a publicly available educational and learning resource intended to improve the quality and responsiveness of healthcare services for patients and carers.

Support
Storytellers will be offered emotional support during and after telling their stories. Many storytellers have commented on the therapeutic benefits of telling their stories in this way.

Reimbursement
Storytellers who are patients or carers may be offered repayment for expenses incurred (including, where appropriate, reimbursement for respite care for people for whom they normally care).

Copyright
One of the primary goals of the Patient Voices programme is to build up a library of resources that can be shared for use in healthcare education and quality improvement, while protecting the integrity of the stories and the contributions of those who created the stories.
To this end, completed and approved stories are released under the Creative Commons licence 2.5 (attribution-non-commercial-no derivatives), with copyright retained by Pilgrim Projects. This aims to ensure that:
a) the stories are freely useable by anyone involved in healthcare education and quality improvement
b) no profit can be made from the stories
c) the integrity of the story, as told by the storyteller, is retained
d) all who have contributed to the story are appropriately acknowledged
Final control over what is included in the digital story will rest with the storyteller. A rough cut will be sent for comment and a final version will be sent for the storyteller's approval before the story is released.

www.patientvoices.org.uk © Pilgrim Projects Limited (2010) www.pilgrimprojects.co.uk



Patient Voices

Consent form

I, _____, have read the Protocol for storytellers and other information relating to the creation and use of digital patient stories for the Patient Voices programme.

I understand that I will have editorial control over my story or stories, but that copyright will be held by Pilgrim Projects Limited.

I agree to the inclusion of my story/stories in the growing library of Patient Voices digital stories and may be made publicly available by Pilgrim Projects Limited, including via CD, DVD and the Internet.

I understand that the intention of the Patient Voices programme is to make the Patient Voices stories available as an educational and learning resource as part of the international drive to improve the quality and responsiveness of healthcare services for patients and carers, but that Pilgrim Projects Limited can have no control over, or liability for, how they are ultimately used.

I consent to the use of my story as part of the Patient Voices programme.

I have obtained all appropriate permissions for materials used in the story.

Signed _____ Date _____
Email: _____ Tel: _____

Name _____
Address _____

Pilgrim Projects Limited
The Barn, 1 Corbett Street
Cottenham
Cambridge CB24 8QX

Tel: +44 1954 202158
Email: ppp@pilgrimprojects.co.uk

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Considered release



Digital Stories Release Consent Form

The title of my story is: _____

- I wish my story to remain confidential.
- I am happy for my story to be shared with other members of my own workshop group.
- I am happy for my story to be shared with the growing community of Pilgrim digital storytellers and future workshop groups, including via a private page on our website.
- I am happy for my story to be used in future storytelling workshops.
- I am happy for my story to be used in other workshops and presentations.
- I am happy for my story to be put up on one of Pilgrim Projects' publicly accessible websites (such as www.patientvoices.org.uk), following a review to ensure that the story is free of any copyright restrictions.
- I am happy for my story to be used under the following conditions:

Name: _____ Signature: _____

Email: _____ Phone: _____

Address: _____

Date: _____

Please return to: Pilgrim Projects, The Barn, 1 Corbett Street, Cottenham, Cambridge CB24 8QX



Patient Voices

Final release approval

I have seen a draft version of the story entitled _____ and I am happy for the story to be finalised and released under the Creative Commons licence.

I agree to the inclusion of my story in the growing library of Patient Voices digital stories and it may be made publicly available by Pilgrim Projects Limited, including via CD, DVD and the Internet.

I understand that the intention of the Patient Voices programme is to make the Patient Voices stories available as an educational and learning resource as part of the international drive to improve the quality and responsiveness of healthcare services for patients and carers, but that Pilgrim Projects Limited can have no control over, or liability for, how they are ultimately used.

I consent to the use of my story as part of the Patient Voices programme.

OR

I would like you to make the following changes to my story before it is finalised. I understand that I will be able to see another draft incorporating the changes.

(Please continue on the other side if necessary.)

Name _____ Signed _____

Address _____ Date _____

Please return to:

The Patient Voices Programme
Pilgrim Projects Limited
The Barn, 1 Corbett Street
Cottenham,
Cambridge CB24 8QX
UK

Tel: +44 1954 202158
Email: pip@pilgrimprojects.co.uk

FN [] [] [] [] [] [] [] [] [] [] CN [] [] [] [] [] []

www.patientvoices.org.uk

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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)

Walking in someone else's shoes



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effective
affective **Voices**
Patient
reflective



Jean's story

Getting to the bottom of things

www.patientvoices.org.uk/rcnqip.htm



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





Vicky's story

Locked door



Vicky's challenge

'I was worried about how people my judge my practice and what was the message they would take from the story. I was worried that, potentially, I could do more damage than good so I wanted to give a resolution to the story and how I see it now.'



What research reveals

The stories are valued for their:

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



What research reveals

...and for their ability to:

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

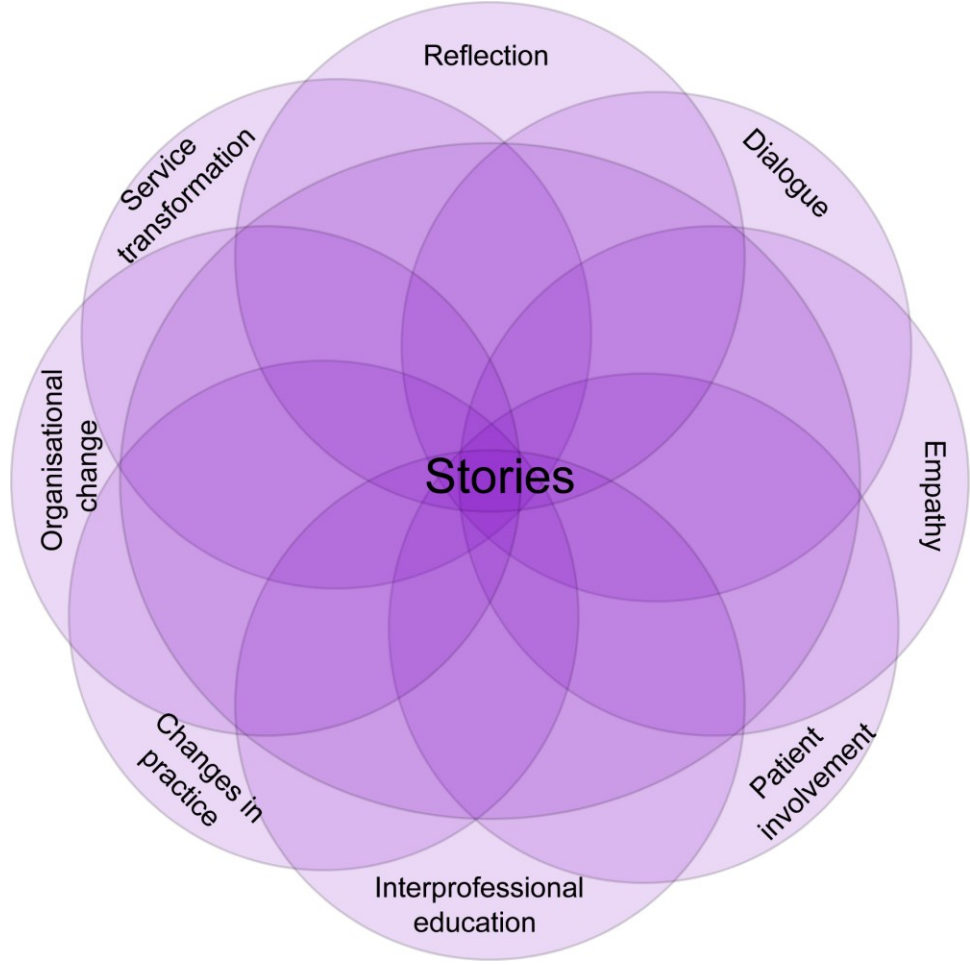
Hardy, 2007



From stories to transformation

Markers

Guides



Comfort

Warning

‘Stories work on many levels.’



Brian Clark, Storyteller



The lesson

'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, QC



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

Reflection and professional development



Evaluation and research





Health promotion





Involving patients



Creating a culture of safety



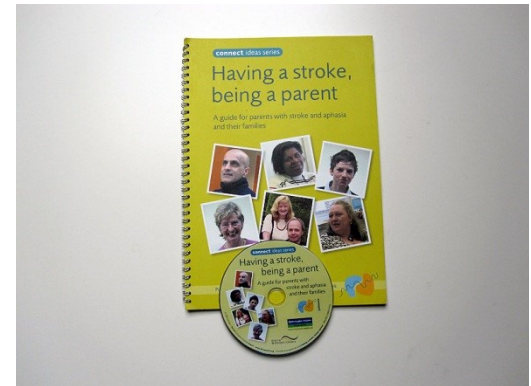
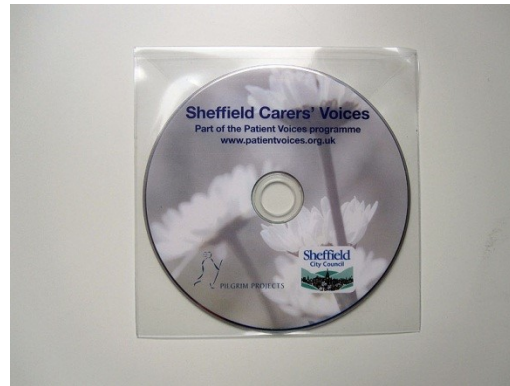
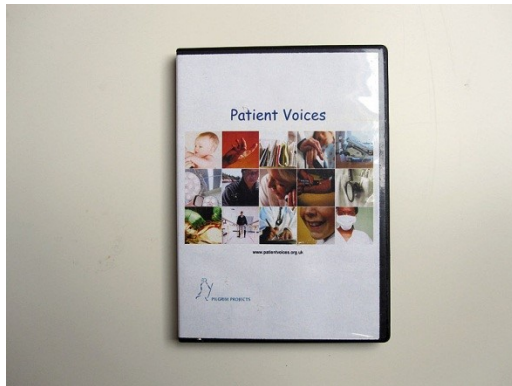
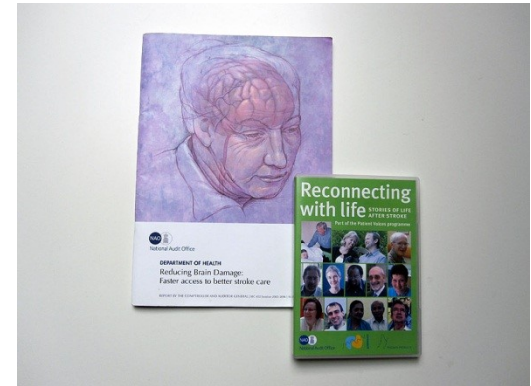
Improving the patient experience



Sharing understanding across cultures



Research, audit and evaluation



Illuminating threshold concepts





Culture of the heart



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reflective



Culture of the heart

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

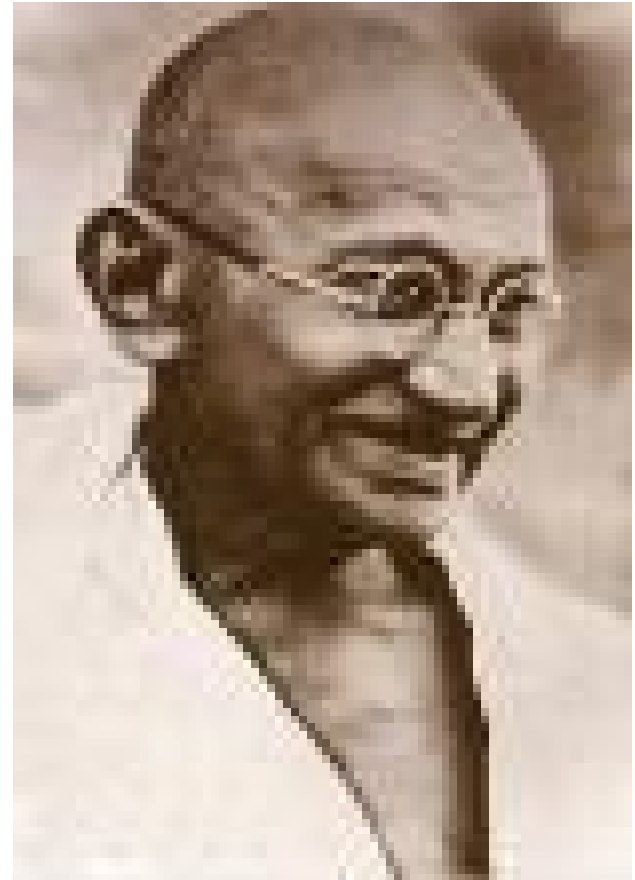
Kotter and Cohen (2002)



Culture of the heart

‘The culture of the mind must be subservient to the culture of the heart.’

Mahatma Gandhi





Thank you

pip@pilgrimprojects.co.uk

www.patientvoices.org.uk

Distribution of the Patient Voices digital stories
is funded by

www.pilgrimprojects.co.uk



Winner
Excellence in Healthcare Education
Finalist
Health Communicator of the Year

