



PILGRIM PROJECTS

effective
affective **Voices**
Patient
reflective

Hearing voices: transforming cultures


Part of the Global Mental Health Exhibition

London School of Hygiene and Tropical Medicine


8th October 2013

Pip Hardy and Tony Sumner

Pilgrim Projects/Patient Voices




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The sleepless ones



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The sleepless ones


What if all the people who could not sleep at two or three or four in the morning left their houses and went to the parks? what if hundreds, thousands millions went in their solitude like a stream and each told their story? What if there were old women fearful if they slept they would die and young women unable to conceive and husbands having affairs and children fearful of falling and fathers worried about paying bills and men having business troubles

and women unlucky in love and those that were in physical pain and those who were guilty? What if they all left their houses like a stream and the moon illuminated their way and they came, each one to tell their stories? Would these be the more troubled of humanity? Or would these be the passionate of this world or those who need to create to live or would these be the lonely ones? And I ask you if they all came to the parks at night and told their stories would the sun on rising be more radiant and again I ask you would they embrace? - Lawrence Tirnauer

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Why are we here? Henri's story

Meet Keshava, meet father

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Why are we here? A global problem

- The scenario of mental health is dismal across the world.
- In the UK alone, one in four people will experience mental illness.
- The prospect of dementia looms large.
- Stigma and discrimination lead to persistent suffering, disability and economic loss through violation of human rights.
- Mental health care is often lacking in dignity and respect.

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Why are we here? Improvement

'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 2010



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Why are we here?
Evidence of experience

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



Tony Sumner, 2009

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Why are we here?
Compassion

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



Ben Page, 2004

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Why are we here?
Transformation

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



Schön, 1988

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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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Patient Voices:
some facts and figures

- 700+ stories facilitated/recorded
- 120+ workshops, plus some home visits!
- 500+ stories released via Patient Voices website
- 15+ Patient Voices stories WIP
- 750,000+ hits on the website annually
- 1100-2400 hits per working day on PV website
- 40,000 stories viewed during the year

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Patient Voices:
where we work



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Saskatoon, Canada: 'Live well with chronic disease'



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Living well: Ericka's story

A second chance

www.patientvoices.org.uk/flv/0197pv384.htm


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Impact of the stories

The stories have been used to:

- educate First Nation peoples about chronic disease, self-management and healthy lifestyles
- promote LWWCD programme
- encourage aboriginal youth to healthier lifestyle choices
- educate health professionals
- 'encourage each person to take control of their own lives, so they too can live full meaningful lives despite their chronic conditions, just as the authors in the DVDs have done.'



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Mental health: creating ourselves



'Narrative is radical, creating us at the very moment it is being created.'

Morrison, 1994

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Sheffield, UK: Healing journeys




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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...'



O'Connor 1969

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Healing and recovery: Julie's story

Surviving

www.patientvoices.org.uk/flv/0168pv384.htm

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Stories change lives



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Impact of the story/stories


- Three workshops in Sheffield focusing on needs of MH service users and carers
- Keynote at British Association for Counselling and Psychotherapy
- conference presentations about use of DS in occupational therapy
- Research on mental and emotional impact of workshops on storytellers (Shea, 2009)
- Further research into DS in occupational therapy



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Manchester, UK: Dignity and respect



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The challenge

- Poor patient and staff satisfaction survey scores in relation to dignity, respect and communication




Manchester Mental Health and Social Care Trust 

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Aims of the project

- create a bank of stories to enhance and complement training and education around dignity, respect and privacy.
- focus on dignity as expressed through empathy, compassion and sensitivity
- develop an online educational resource
- enable staff to engage with the affective (emotional) dimension of care
- encourage reflection on impact of care that promotes dignity



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Why digital stories?

- put healthcare professionals right into the shoes of a patient or a carer
- help doctors, nurses, accountants, managers and board members to really experience and appreciate the impact of care from a truly personal perspective
- create an instant connection to the patient
- remind staff that kindness, compassion and dignity often make the biggest difference
- stories are created by the storytellers themselves



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What happened?


- Six workshops over two years
- 39 participants
- 43 stories created
- 33 stories released (to date)



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What happened?

- friendships and support networks established



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How are the stories being used?


- Stories shown at the start of every Board meeting
- used in recruitment and selection interviews



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How are the stories being used?

- induction and staff training
- public screenings to raise public awareness of mental health



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How are the stories being used?

- strengthening the patient voice
- reminding staff, patients and carers of our shared humanity



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What stories do they tell?

Markers

Warning



Guides

Comfort

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Transformation: Lindsey's story

Rites of passage

www.patientvoices.org.uk/flv/0647pv384.htm

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Themes

- strength and resilience
- isolation
- importance of communication
- lack of dignity and respect
- lack of care co-ordination
- need for more and better information
- needs of family and carers




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Themes

- need for empathy and compassion
- need for regular assessment and review
- need for greater involvement in decision-making
- importance of self-help and peer support
- importance of voluntary sector



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What's changed?

- patient-led 'dignity walks'
- more confident patients *and* staff, able to tell their stories
- increased involvement of patients and carers in creation of care plans
- greater recognition of 'experts by experience'
- more engagement with family members

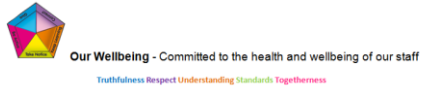


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Impact on the organisation

- 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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Impact on the organisation

- Reduction in staff time spent investigating complaints
- Improvements in patient/carer communication and relationships = better care and increased confidence
- Overall quality of care is good/excellent
- 95% of 2018 patients would recommend the Trust



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Impact on storytellers





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Impact on storytellers

'I have more empathy now!'

'I found myself released after telling my story.'

'This [workshop] has been better than years of group therapy!'



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Impact on storytellers

'To be able to see my transitional period in a visual way has made me realise that life isn't always going to be easy and fun but how we deal with life's ups and downs is essential to staying on the road to recovery.'



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Impact on storytellers

'It's reminded me of how our creativity connects with part of our soul - how wonderful it is to be part of something that does not have measurable targets or hard matrices.'



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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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Transformation: Brenda's story

Freedom

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The end...

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

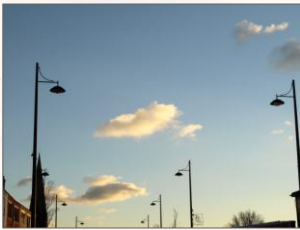


Albom, 2004

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... or the beginning?

- What stories do you need to tell?
- How will you tell them?
- What stories do you need to hear?
- What will you do with them?



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Thank you.

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