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Digital
Storytelling
in times
of Crisis

The crisis of my life
digital storytelling as a radical
response to crises in health and care

Pip Hardy

Pilgrim Projects/Patient Voices National and Kapodistrian University of Athens, 10th May 2014


Thanks



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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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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...'

Flannery O'Connor 1969

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Overcoming dragons



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'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.'

Jean Vanier 2004

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Healthcare in crisis

- More people than ever before
- People living longer (in developed countries)
- More complex chronic disease
- Increasing mental illness
- Looming spectre of dementia
- People still dying from preventable deaths (in developing countries)
- Pressure to 'do more with less'

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A challenge

‘Challenging dominant narratives and the status quo may be achieved through new genres (e.g. DS) and different people telling stories.’

Ochs and Capps, 1996



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Transformation

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

Schön, 1988



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Crises in healthcare

- A team in crisis
- An organisation in crisis
- A global crisis




Manchester Mental Health and Social Care Trust 

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A team in crisis

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

Professor Tricia Hart, CEO
James Cook University Hospital




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The problem

- Very sick patients
- Not enough beds
- Not enough staff
- Not enough time
- Poor management
- Records in disarray
- Medical model of care
- No one listens
- Culture of fear



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What staff said

‘I would not want a member of my family nursed on this ward.’

‘I dread coming to work. I hate it here.’

‘I check the off-duty to see who I am working with.’

‘I had no assurance that patients were safe; I felt helpless, hopeless and powerless.’ (Senior nurse)



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What families said

'I continue to see him in such pain, no one should die like that.'

'I want to meet all of those nurses and ask them why?'

Result:
93% of staff would **not** want their relatives cared for on the ward



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A conventional response

Special measures

- Organisational Development Team
- New nursing leadership
- Honest conversations
- Holding the boundaries; Code of Conduct
- Staff engagement



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A conventional response

- Move back to original ward
- Team nursing
- Move to more holistic model of care
- Appreciation
- Openness
- Focus on staff well-being



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Result!



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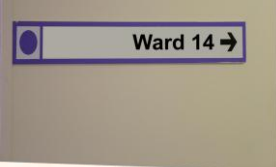
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But...

'The team was left in a dark place; a place of torn relationships, mistrust and broken spirits.'

'The stories teams tell each other are their lifeblood.'

Amy Stabler, OD lead



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A radical response

A digital storytelling project intended to:

- provide closure on a difficult experience
- support the development of emotional resilience
- deepen a culture of care and compassion
- develop a learning resource for others in the organisation
- provide qualitative data to help with evaluating the experiences of the ward team

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The man in Bed 5

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Laura Mett, 2013

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Impact on storytellers

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'It's helped me get a lot off my chest – I've put it to bed now.'

'I didn't realise how sad everyone was.'

'I'm still angry, but making the story helped me process those feelings and I'm not as angry now.'

'I feel like we've learned a lot about each other's stories that we didn't know before. This has brought home what the ward means to everyone.'

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Impact on staff

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maxine craig
@maxine_craig
MT via @BevRodgers : @PilgrimPip @kaymc64@ Kath "making digital story changed me always loved job but now love it more"
@TriciaHartz6
04:23 AM - 03 Oct 13

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Impact on staff

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Pip Hardy,
You were mentioned in a conversation!

Bevley Rodgers @BevRodgers
@PilgrimPip @metty2 @Staceygill17 @kaymc64 Another day of awesome stories. So proud of my team. 14 likes
More Tweets

Stacey gill @Staceygill17
@BevRodgers @PilgrimPip @metty2 @kaymc64 looks like everyone has been having a fab time looking forward to tomorrow x 14 likes

Bevley Rodgers @BevRodgers
@Staceygill17 @PilgrimPip @metty2 @kaymc64 We are. I would really like all of the team to experience. So insightful.
17:27 AM - 08 Dec 13

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Impact on patients

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'I've been looked after so well here – and not just by one person, but by everyone!'

'All the staff here are so kind.'

'We wanted to take him home but he was too ill, but he was looked after like a prince. Thank you.'

Kath Murray
Health care assistant

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Impact on the ward

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97% of staff would now be happy to have their family cared for on the ward

Kath Murray
Health care assistant

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An organisation in crisis

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'If there is one lesson to be learnt, I suggest it is that people must always come before numbers.'



Robert Francis QC, 2010

Manchester Mental Health and Social Care Trust 

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Dignity and respect

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



Ben Page, 2004

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The problem

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




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A radical response

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Create a bank of stories that would:

- complement and enhance training around dignity, respect and privacy
- focus on dignity as expressed through empathy, compassion and sensitivity
- contribute to an online educational resource
- encourage staff to engage with the affective (emotional) dimension of care




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A radical response

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- increase Board intelligence of the patient experience
- involve service users and carers in design of services
- promote patient-centred care
- encourage reflection on impact of care that promotes dignity
- learn from expertise of patients and carers
- improve patient and staff satisfaction



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Why digital stories?

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



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What the CEO said

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Sometimes we just don't get it right, despite our best intentions – and for that I apologise to staff unreservedly. What I would say though is that in order to ensure that we can "Listen, Believe, Act", we need everyone to play their part. Before we can improve things, we need to understand what it is that is not working and acknowledge the very difficult and highly pressured circumstances in which staff often find themselves. We need to acknowledge – and applaud – the fact that, despite real difficulties, they continue to put the service user first, keep them safe and manage their recovery.

I recognise that, as a Board, we will need to listen more carefully and more often to our staff. We need to trust and believe the feedback we receive from those on the frontline. And we need to act on that feedback as vital intelligence which will help us all to do a better job, whatever our role in the organisation. We are all in it together, after all.

Michelle Moran, 2014

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Impact: what's changed

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- 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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Benefits

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For patients	For staff	For the organisation
A therapeutic and cathartic experience	More time to focus on patient care	Positive local and national PR coverage (press and radio)
Recognition of expertise	Reduction in negative feedback	Positive external assessment
Better communication, improved care	Better communication, more confidence	Huge savings in money and time

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Impact on quality

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- 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 quality

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- 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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Truthfulness Respect Understanding Standards Togetherness

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A global crisis

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- Malaria kills a child somewhere in the world every minute
- It infects approximately 219 million people each year
- estimated 660,00 deaths, mostly children in Africa
- Malaria accounts for one in six of all childhood deaths in Africa
- Malaria has serious economic impacts in Africa, slowing development and perpetuating poverty

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A global crisis

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Saving brains:
Long-term neurocognitive assessment of children following an episode of severe malaria: the artesunate suppository trial cohort



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A global crisis

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'Within low resource settings, children with impairments are considered a family and social liability and seldom receive the resources needed to support their development.'



'Outline for disseminating results from the research "A neurocognitive assessment of Study 13 children"'
Burness Communications and Pilgrim Projects Limited June 2012

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A traditional response

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Give everyone a mosquito net!




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A radical response

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- involve patients and communities in the dissemination of their experiences and of the results of the research study
- enable children and parents affected by malaria to tell their own stories
- illuminate what it is like to live with a severe disability arising from childhood malaria
- form a plea for malaria control.



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Insight

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'These stories allow us to walk in someone else's shoes for a few minutes.'



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A warning

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'Please control your emotions. These people don't need your pity. They need your empathy.'



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A hope for help

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Rehema, 2014

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Reactions

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Storytellers said:
*'Three words:
Like. Enjoy. Accept.'*
*'There is no harm in sharing
this story.'*
*'I'm not just happy with it:
it is beyond happiness.'*
*'It exceeded my expectations
– it is time well spent.'*

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Reactions

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NIMR researchers said:
*'There are many long term and
short term measures on how to
live with disability but perhaps
these stories can also help to
prevent malaria?
How can we focus these stories
so that they can be used as part
of prevention and also provoke
thought and discussion and
debate?'*

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Reactions

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NIMR researchers said:
*'These stories highlight
twin problems in Africa:
poverty and malaria, and the
complex relationship between
them.'*
*'[This project] has brought
people together in a
community to share stories.'*
*I will 100% use these stories to
influence policy-makers.'*

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Possibilities

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*'I have consistently asked for the
addition of some funds to capture
the economic consequences of
malaria.
It is clear to me now, that some of
these stories make the case for
looking at the economic
consequences of severe disease
and sequelae far more powerfully
than I can (or have!).'*

Dr Melba Gomez
Principle Investigator, WHO

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Let us be radical!

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

Toni Morrison, 1994

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The stories are all one

'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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Thank you

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@PilgrimPip

The Patient Voices stories can be seen at:
www.patientvoices.eu
@PatientvoicesUK

Winner
Excellence in Healthcare Education
Finalist
Health Communicator of the Year

The **BMJ** Group Awards
in association with **MDDUS**

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