



Patient Voices

The nurse, the nerd and the narrator:
creating and using Patient Voices
reflective digital stories

Cathy Jaynes
University of Colorado Denver

Pip Hardy and Tony Sumner
Pilgrim Projects/Patient Voices Programme



© 2010 Pilgrim Projects



In the beginning...

*'In the case of nutrition and health, just as
in the case of education, the Gentlemen
of Whitehall really do know better what is
good for the people than the people know
themselves.'*

Douglas Jay (1937) *The Socialist Case*



© 2010 Pilgrim Projects



'The care of the patient'

*'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.'*

Francis Peabody (1927) *The care of the patient*



© 2010 Pilgrim Projects



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)



© 2010 Pilgrim Projects



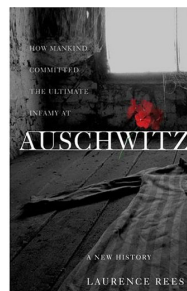
The narrator: it was a dark and story night



© 2010 Pilgrim Projects



Measuring what counts



*'As always in history,
statistics give little insight
into individual experience.
That can only be gained
by listening to stories.'*

Laurence Rees
Auschwitz: A New History



© 2010 Pilgrim Projects



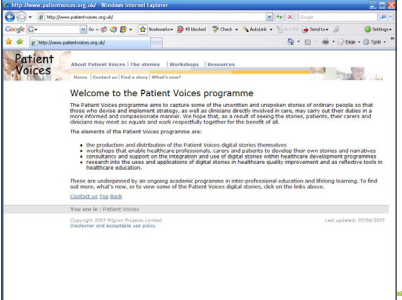
'The culture of the heart...'



PILGRIM PROJECTS © 2010 Pilgrim Projects

effective
Voices
Patient
reflective

Patient Voices



PILGRIM PROJECTS © 2010 Pilgrim Projects

effective
Voices
Patient
reflective

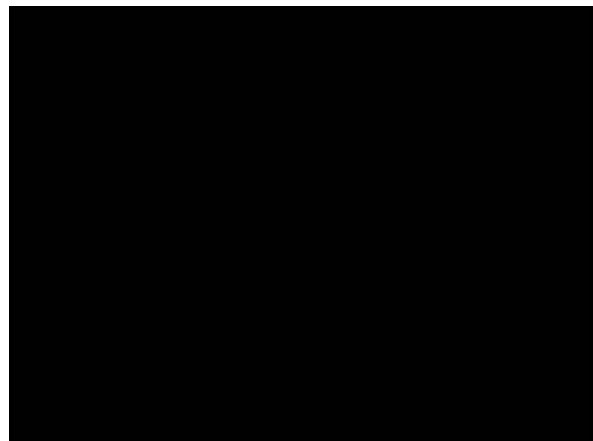
Jean's story

Getting to the bottom of things

www.patientvoices.org.uk/rcnqip.htm

PILGRIM PROJECTS © 2010 Pilgrim Projects

effective
Voices
Patient
reflective



Time to reflect: EAR

Good stories are

- Effective
- Affective
- Reflective



PILGRIM PROJECTS © 2010 Pilgrim Projects

effective
Voices
Patient
reflective

The nerd:
going to the dark side





PILGRIM PROJECTS © 2010 Pilgrim Projects

effective
Voices
Patient
reflective

Facts and figures (and some statistics)

- 450+ stories facilitated/recorded
- 60+ workshops, plus some home visits!
- 350+ stories released via Patient Voices website
- 10+ Patient Voices stories WIP
- 620,000+ hits on the website in 2009
- 1500-2000 hits per working day on PV website
- 200 Gigabytes of data downloaded in 2009
- 40,000 stories viewed during the year

© 2010 Pilgrim Projects




Techie stuff





© 2010 Pilgrim Projects

How it's done

© 2010 Pilgrim Projects

How it's done








© 2010 Pilgrim Projects

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)

© 2010 Pilgrim Projects


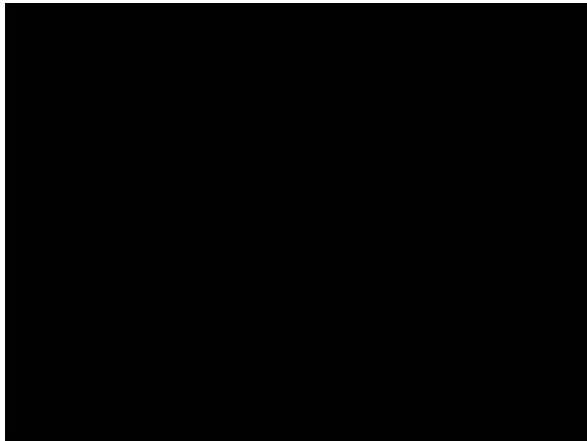
Wee Haan's story

'Can I have a hand, please?'

www.patientvoices.org.uk/lssc.htm






© 2010 Pilgrim Projects



The two-minute story

- Think of a story. Make a few notes if you wish.
- Now tell your story to your partner in two minutes.
- Stop! Listeners, what did you notice?
- Have a conversation... and plan the story together.
- Tell your story again.
- What were the differences between the two stories?



© 2010 Pilgrim Projects



The nurse: far away in another galaxy...



© 2010 Pilgrim Projects



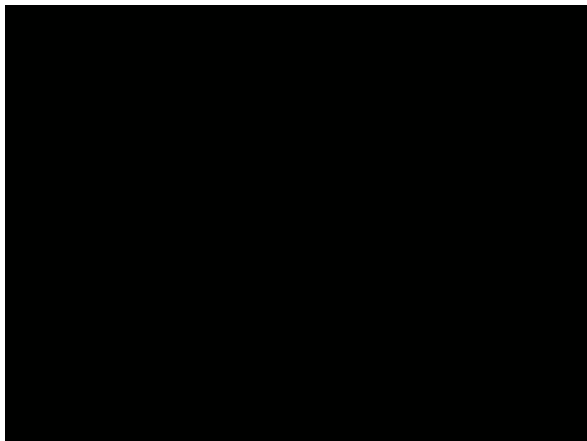
Cathy's story

'Go around'

www.patientvoices.org.uk/pilgrim.htm



© 2010 Pilgrim Projects



Thank you

The Center for Medical Transport Research
www.tcmtr.org

The Patient Voices Programme
www.patientvoices.org.uk



Winner
Excellence in Healthcare Education
Finalist
Health Communicator of the Year



© 2010 Pilgrim Projects