



Patient Voices

Stories from the heart of healthcare

5th September, 2006
NET Conference, Durham

Pip Hardy
Pilgrim Projects




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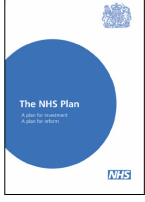
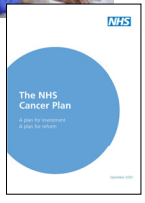






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A patient-centred NHS

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The first question

How can we communicate patients' and carers' needs, experiences, opinions and expectations in order to design better (inter-professional) healthcare education and deliver better, safer healthcare?



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How to get the essential story







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Monica Clarke's Story 'Nobody told me'




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UKHEP e-learning

The University of California Health Care Centre at Irvine makes use of the 20 tips to encourage patients to share in decisions.
<http://www.ucsb.edu/ucsf/patient-fact-sheet.htm>

The Minnesota Alliance for Patient Safety encourages patients and their families to become involved and to work in partnership <http://www.mnallianceforsafety.org/faq.htm>, using patients to speak up if they perceive a safety risk with the caption: "If I look wrong, it is wrong"

Empowerment takes many forms and, as we have seen in Clinical Governance Meetings, small changes can make a big difference. Peer or patient support groups can help to share information, explore concerns, expose issues for examination, as well as provide an open forum for discussion. Some patient groups are more disadvantaged than others. As the basis of empowerment is communication, it is particularly important, especially with these groups, not to overlook basic, simple communication principles.

Activity


Very often we take communication for granted, except when it is clear that English is not the mother tongue of the patient or the patient is too young or too ill to understand.

What happens to people who are unable to communicate effectively? What if a patient has aphasia or dementia or hearing difficulties or learning disabilities, the ability to communicate is compromised.

Watch all three of Emma's stories at <http://www.pilgrimprojects.co.uk/directs/home/index.htm>

How are these patients dealt with in your practice? What protocols are in place for empowering them to participate as fully as possible in their care?

Even, if necessary, a simple plan to ensure that this most basic principle can be adhered to in your work with patients.

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Emma's story



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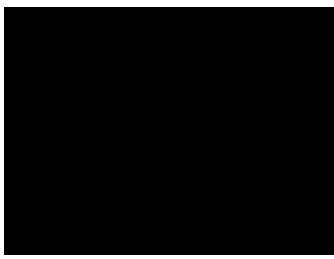
Patient Voices: a new way of telling stories


- Still images
- Music
- Voiceover
- Video
- Real people
- Real experiences
- Real stories

THE ESSENTIAL STORY

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Alison Ryan's story 'Who cares?'



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The two-minute story

- Tell a patient story to your partner – try to keep it to two minutes.
- Stop! Listeners, what did you notice?
- Now use the storyboard template to plan your story.
- Tell your story again.
- What were the differences between the two stories?

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Digital storyboard example

The storyteller has made brief notes of what he wants to say at each point in the story – there isn't much detail, just an outline of each main point. The first statement gives a brief introduction to the story and the last point is the 'punch line' – this is the thing the audience is most likely to remember.

At the bottom is an indication of the type of music he wanted for his story.

STORY TITLE: Working Together

PHOTO OF HAND HOLDING A FEW TABLETS	PHOTO OF HAND HOLDING A LOT MORE TABLETS	PHOTO OF CONSULTANT	PHOTO OF PHARMACIST	PHOTO MONTAGE OF TALKING, DRUGS AND PHARMACIST
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Opening statement: "I'm very lucky as a person with MS – I have access to some very effective drugs"

Problem: taking drugs early morning, evening, seven tablets and then, because I stop treatment from time to time – not soon"

Interpreting: treatment causes vital food to increase


Consultant proposed: taking the two sets close together and the evening dosage manufacturer's recommendations

Pharmacist test a check: on drug levels in blood and found that it was working just as effectively

Final statement: "Patients & professionals working together can make an enormous difference"

The type of music I would like to use for this story is: 'Gentle piano music'

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Ian Kramer's story
'Working together'




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Digital storytelling:
a chance to reflect

'Reflection is as natural – and as necessary – as breathing ... or telling stories.'



Joe Lambert, Centre for Digital Storytelling



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Digital storytelling:
building communities



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

Mitch Albom



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Jimmy's story




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The second question

How can we use digital patient stories to educate clinicians, managers and decision makers about the need to work in true partnership with patients, carers and service users?



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How the stories can be used

To increase understanding between teams	Process mapping
Inter-professional education	Building social capital
Continuing Professional Development	Project feedback
Sharing good news and good practice	Reminiscences
Reminder of patients' existence/raison d'être of NHS	Elearning and eportfolios
PALS and Mental Health	Digital executive summary
Sharing experiential learning	Commissioning
Reflective practice	Frontline teams
Improving patient safety	Organisational development
	Team building
	Patient education and information



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'In my end is my beginning'



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The last question

What stories do you (or your organisation) need to capture and convey in order to promote true partnership working between patients, carers and clinicians?



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Patient Voices

Telling the right stories
At the right time
In the right way

www.patientvoices.org.uk

www.pilgrimprojects.co.uk



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