

PATIENT VOICES: A VALEDICTION

'Patient Voices are a distillation – they capture the spirit of the story.'

Professor Paul Stanton, 2006

Stories are one of the most ancient of teaching – and learning – techniques, and are effective within and across cultures. The use of stories as an educational resource acknowledges that behavioural and systemic change often stems from a felt understanding of the implications of decisions rather than from a purely abstract or theoretical one. Stories can be used to communicate visions and needs in a powerful way; they offer a compelling and practical means of exploring issues and experiences from different perspectives, while promoting reflection and stimulating dialogue and debate.

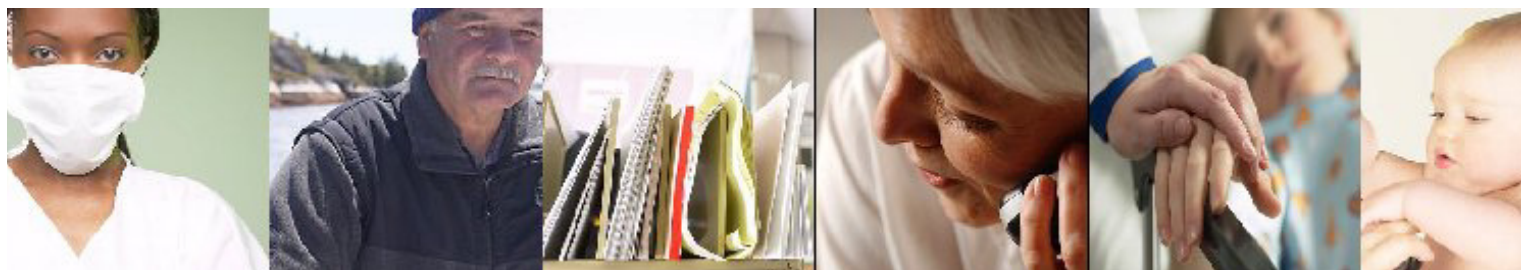
The Patient Voices programme was initially set up by Pilgrim Projects with two main aims:

- to give a voice to people who are not heard, while helping them to tell their stories in a way that might affect clinicians, managers and decision-makers and thus help them to realise the effects of their actions and decisions
- to provide a free, and highly accessible, resource to anyone and everyone who wishes to improve the quality of health and social care.

The Patient Voices programme is highly regarded in the UK and elsewhere. It has won two awards and the website is now receiving in the region of 1200 hits per day, with a significant number of stories being downloaded for use in education and quality improvement programmes. No charge is made for access to, or use of, the stories.

We believe that the Patient Voices programme now offers the largest resource of freely accessible digital stories about health and social care anywhere in the world. Since the beginning of 2006 year, the collection of stories in the Patient Voices programme has grown from 23 to over 100. The stories are told by people of different ages, from different cultures, about different experiences and a wide range of conditions. Each story is as unique as the person who tells the story and, at the same time, each story reminds us of our shared humanity.

The stories are all released under a Creative Commons licence; Pilgrim Projects retains copyright; this enables us to give them away, while restricting their commercial use and prohibiting any changes to the story which has been approved by the storyteller.



All of these stories are completely free for you to use in education and service improvement in health and social care, where they are helping to provide a balance for evidence-driven healthcare provided on the basis of statistical evidence.

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

Laurence Rees (2005) *Auschwitz: A New History*

Increasingly, the stories are used in conference presentations, lectures, workshops and other events, as well as in schools of medicine and healthcare (face-to-face and virtually) in the UK and elsewhere.

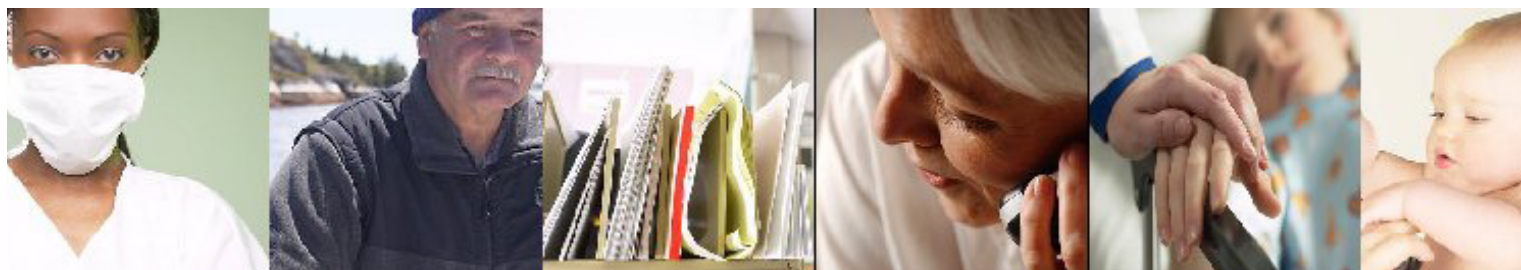
Research that we have just concluded indicates that the stories have a powerful impact on viewers and are beginning to change practice. Education programmes are also changing as educators realise what is really important to individuals and adjust learning outcomes and delivery methods in the light of this realisation.

In return for what we believe to be a valuable resource, we ask only that you let us know how you use the stories and what, if any, changes result from their use. You are warmly invited to join the Patient Voices online discussion group at

<http://health.groups.yahoo.com/group/patientvoices/> where a growing community of practice can engage in discussion about the ways in which stories can be used to improve the quality of health and social care through education and reflection. We are also always happy to hear from you with comments or questions about any aspects of the stories or the programme.

The Patient Voices digital stories are not simply what Ed Morrow called 'wires and lights in a box'. Drawing on more than two decades of experience in education, lifelong learning, instructional design, training, software engineering and quality assurance, counselling and group work, we have developed a methodology that is, as far as we can determine, unique.

To our knowledge, no-one else is doing this kind of work in the health sector, in this country or elsewhere. Our digital storytelling methodology complements a substantial practice base developed by the Center for Digital Storytelling (in Berkeley, California) over 15 years. The specific Patient Voices methodology has been refined and rendered sufficiently flexible to meet the particular needs of patients, carers, service users and service providers with a wide range of conditions and from a wide range of circumstances.



Our methodology is also recognised by the National Audit Office, and others, as providing an excellent way to gather qualitative data about what really matters to patients, carers and service users – and to make this widely and freely available. Indeed, the work we have done on stories and storytelling in healthcare is a key element in a new initiative concerned with ‘humanising healthcare’ that involves the NAO, the Appointments Commission, the Royal College of Nursing and others.

We are grateful to those organisations that have sponsored the gathering and editing of the stories – it is their support that enables the collection of stories to grow to cover a wide range of conditions, issues and experiences. Development of the website, research, and all other activities related to the Programme has been funded entirely by Pilgrim Projects as part of our commitment to operating as a social enterprise.

If you are moved by the Patient Voices stories, or have found them to be useful in your work, please consider sponsoring a storytelling workshop, where we will work with storytellers to help them shape, craft and refine their stories. In this way, the collection will continue to grow and inform the planning and delivery of humane and compassionate health and social care.

‘What did I learn from the workshop?’

- the importance of feelings and passion in telling a story*
- the importance of the individual’s unique perspective’.*

Patient Voices workshop participant (2006)

Pip Hardy

May, 2007