



# Patient Voices

## THE NEWSLETTER

Issue 2, December 2007

### Why tell stories?

We tell stories, not only, as Pascal suggested, 'to entertain and to teach', but also to heal; storytellers tell us that they benefit enormously from telling and sharing their stories. Perhaps most importantly, however, we tell stories because of our belief that a more human – and humane – approach to health and social care education, policy and practice will come about only if these stories, and others like them, are heard. We cannot eliminate war or disease or man's inhumanity to man, but we can make sure that stories of pain, loss and grief, love, commitment and redemption, are not lost, and that others may learn from them.

### Talking to friends and colleagues

This 'season of mists and mellow fruitfulness' has seen a change in our routines, with a good deal of travelling and a number of workshops and conference presentations.

A visit to California at the end of September combined work and family – if meeting with our friends and colleagues at the Center for Digital Storytelling (CDS) in Berkeley to share stories and discuss strategies for ongoing collaboration can be called work. These discussions were followed by a delicious and convivial meal at the legendary Chez Panisse restaurant in Berkeley, all enhanced by the presence of Professor Paul Stanton of Northumbria University, who happened to be in California at the time.



### Workshops and conferences

The NET (Nurse Education Tomorrow) Conference was held in Cambridge this year, and Pip presented work that

had been done with the Royal College of Nursing and Connecting for Health using digital storytelling as a means of exploring the future of nursing and technology.

Our third *Introduction to Digital Storytelling* workshop in Cambridge was attended by five remarkable women who produced, not surprisingly, five remarkable stories. One of these, 'Surviving', by Julie Coleman, can now be seen on the Patient Voices website, at [www.patientvoices.org.uk/pilgrim.htm](http://www.patientvoices.org.uk/pilgrim.htm) along with some stories from the June workshops.

A busy few weeks of presentations and workshops began with a trip to Calgary, where Pip had the pleasure of meeting, staying and working with Michelle Spencer, Canadian representative of CDS, and jointly presenting at the international Chronic Disease Prevention and Management conference.



Digital storytelling is an effective way of involving patients in the co-creation of healthcare. Four presentations at the Authenticity to Action conference in the Lake District, together with workshops at the NHS Institute of Innovation and Improvement and the NHS Live! 'Energising 2007' event in Birmingham (where one delegate described the workshop as 'a breath of fresh air') focused on this particular aspect of the Patient Voices programme.

Abstracts and most presentations from these conferences are available on the Patient Voices website at [www.patientvoices.org.uk](http://www.patientvoices.org.uk)

## The stories

After this flurry of travel and development activity, we welcomed a relatively quiet couple of weeks of editing and post-production, concentrating on completing a collection of stories to accompany the National Audit Office's forthcoming report on neonatal services: 'Caring for vulnerable babies'.



We then moved swiftly on to finish 'Interpreting Tales', stories intended to highlight the need for qualified interpreters to widen access to health and social care, funded by the European Social Fund. Released stories can be seen at [www.patientvoices.org.uk/interps.htm](http://www.patientvoices.org.uk/interps.htm)

## The website and discussion group

We continue to make the stories freely available via the Patient Voices website and are pleased to see a steady increase in the number of stories being downloaded, with an average of 1600 hits per day on the website in November. The NHS alone downloaded over 700Mb of data – equivalent to about 200 digital stories – a great free resource by anyone's calculations!

Tony has plans in place for developing a gallery-based site, which would make it easier to find stories, and allow users to rate and recommend them to others.

Stories appear on the Patient Voices website as they are finalised and approved. To be kept up to date with new stories as they appear, please join the discussion group.

## Free stories and a growing community

In return for all these free stories, we ask only that people tell us when and how the stories are used, and what the responses are. We need this information to answer the inevitable question from potential funders – 'How do you know the stories make a difference?' Our research, experience and hearts tell us that they do, but we always need more evidence, case studies and examples of the uses and efficacy of the stories in healthcare education and quality improvement programmes. So please, when you show or use a story, tell us what you are doing, who you are doing it with, and how it works.

Our community of practice continues to grow and we invite you all to join the Patient Voices discussion group to make connections, share experiences and exchange

ideas for collaboration and research.

<http://health.groups.yahoo.com/group/patientvoices/>

## Research

We are delighted that Pip has been invited to be an Honorary Research Fellow at the University of Salford Centre for Nursing, Midwifery and Collaborative Research; at a more practical level, we will take part in a project evaluating digital storytelling in medical education with the University of Calgary.

## Looking ahead

Collaboration with CDS will mean an increased carbon footprint as a result of invitations to co-facilitate workshops with CDS staff at the University of Colorado Center for Health Sciences, University of Calgary medical school, and Saskatoon Health Region. We are also planning an open workshop in Chicago in March.

Closer to home, we are about to embark on a project related to disability and employment in Essex and we look forward to working with the University of Leeds on a storytelling project intended to inform the development of technological aids for people with rheumatoid arthritis. Work with the Royal College of Nursing is ongoing; having finished the Continence Collection, we eagerly anticipate the next project, looking at the nature of teamwork. We have strengthened relationships with the universities of Leeds, Leicester, Huddersfield, Bradford and Salford and have had provocative discussions with people from the universities of Liverpool and Surrey.

The re-scheduled 'Humanising Healthcare' retreat, intended to consider how digital storytelling can contribute to more human and humane healthcare, is likely to take place in British Columbia, in May, 2008; please contact us if you are interested in participating.

## The workshops

In our spare time, we continue to run workshops to give professionals an insight into the digital storytelling process, so that they may be better informed should they decide to undertake digital storytelling projects. These are increasingly popular (please see the website for workshop dates), as are our bespoke workshops for groups of colleagues interested in digital storytelling in healthcare.

## And finally...

We send you all good wishes for a joyful holiday and a peaceful 2008.

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