



# Patient Voices

## THE NEWSLETTER

Issue 3, April 2008

### A global perspective

Not only are tellers and users of Patient Voices digital stories spread across the planet, they are, in creating and using the stories, part of a wider global movement to acknowledge the importance in education and healthcare, government and governance, of peoples' life stories.

May 16<sup>th</sup> will be the first International day for sharing life stories ([www.ausculti.org](http://www.ausculti.org)). As part of this celebration and affirmation of the importance of story, we will be inviting all those who have shared their stories with us to join an informal gathering at Pilgrim Projects to mark the day.

### Out and about

As mentioned in the last issue, Pip has been to North America twice recently to co-facilitate with the Center for Digital Storytelling at healthcare-related workshops. At the University of Denver in



Colorado, and in Canmore, Alberta, she worked with nursing staff on stories of their professional experiences.

In Saskatoon, Saskatchewan, she had the privilege of working with First Nation Peoples as part of the evaluation of their experiences of the Stanford Chronic Disease Self-Management Program.

While Pip was away, Tony attended a two-day conference-cum-workshop at SCEPTRE (Surrey Centre for Excellence in Professional Training and Education, [www.surrey.ac.uk/sceptre](http://www.surrey.ac.uk/sceptre)), based at the University of Surrey, on the nature, development and use on immersive experiences, in which he was so immersed that he actually sang...

Later, quieter, and closer to home, we ran a one-day workshop on the nature of telling and hearing stories for midwife researchers at City and Hackney PCT which underlined the common humanity of experiences and stories.

We've also had visits from Terry Tellep, Integrative Medicine Clinical Nurse Specialist from San Francisco, California, and Lauren Aylward, Community Participation & Projects Coordinator for Bayside Health in Melbourne, Australia. We hope that their

enthusiasm for Patient Voices may result in more stories from interesting places!

### Patient Voices workshops and stories

With the publication of 'Caring for vulnerable babies', the NAO report on neonatal services, the stories told by mothers of premature babies to accompany the report have been released on the Patient Voices website and on a DVD to accompany the report.

After their completion and release to the website, the 'Interpreting Tales' stories were used to great effect at the Cintra AGM. Developing these stories gave us useful insight into working with storytellers whose first language is not English – in one case through simultaneous interpreting.

In Essex, we ran a workshop with a group of disabled people to create their stories about disability and employment. The workshop gave us the opportunity to work with storytellers with a wide range of disabilities, from Aspergers' syndrome to Tetraplegia; we were struck, as we often are at Patient Voices workshops, by their astonishing determination, enthusiasm and good humour.



The stories in the 'Work in Progress' series provide first-hand accounts of employment and its effect on the storytellers. They challenge attitudes which can prevent disabled people from securing and maintaining employment. The stories will be used with disabled people, employers and decision-makers to make the labour market more inclusive and efficient. There will be a formal launch at Anglia Ruskin University in Chelmsford on the 21<sup>st</sup> April, accompanied by a DVD, complete with subtitles. The stories are available on the website at: [www.patientvoices.org.uk/exdra.htm](http://www.patientvoices.org.uk/exdra.htm).

We ran a successful and affecting workshop at Sheffield Hallam University Department of Occupational Therapy, and post-production work on these eight service users' stories, provisionally titled 'Healing Journeys', is under way.

Initial stages of a project with patients affected by Rheumatoid Arthritis are underway in Leeds, with two introductory days for storytellers held in February and March, and we are looking forward to creating stories during workshops there later in the spring. The

stories are intended to inform the design and development of assistive devices for people with Rheumatoid Arthritis.

### **Introduction to Digital Storytelling workshops**

The introductory workshops in January and March 2008 were both well-attended, by storytellers with a range of backgrounds and interests – from UK healthcare educators to Norwegians embarking on a project to celebrate the centenary of a famous poet. We all benefited from the presence of our 'apprentice', Jenny Gordon, who skilfully juggled developing her skills in digital storytelling facilitation with keeping us all well-provided with tea, coffee and cakes.

The schedule of workshops for the rest of the year is now available. If you are interested in



attending an introductory workshop, please contact us, or see the Patient Voices website for details.

### **Facilitator training workshops**

The first of our facilitator training workshops is planned for July this year and will be presided over by Joe Lambert from the Center for Digital Storytelling. This intensive training programme takes place over five or six days and is intended for those who have attended an Introduction to Digital Storytelling workshop, carried out some further digital storytelling work, and who expect to be helping others to make digital stories in the longer term. These workshops are intended to provide sponsoring organisations with a better understanding of the process of creating digital stories, and prepare their staff to co-facilitate with us on large-scale digital storytelling programmes.

### **The website and discussion group**

Since the last newsletter, fourteen new stories have appeared on the website, bringing the number of stories available for use to over 130. Approximately 20 stories are at post-production stage, so the resource continues to grow.

Hit rates remain between 1200 and 2000 per day, and we are starting to see more links to stories from external sites, in particular from within the Virtual Learning Environments of universities – ranging from the UK and USA to Holland and Australia!

If you, or your organisation, are linking to stories, please do let us know, so that we can try to ensure your link does not get broken when we update the site.

### **Using the stories in your practice**

Our work on the Patient Voices stories began as part of our work in developing open, distance and e-learning materials. We are now seeing the stories used in many education programmes that have been developed independently of us.

In order to share the learning and experiences of educators who have used the stories in their own programmes, we are collecting case studies to add to the website so that others can see, and learn from, how they have been used. If you have an example of how you have used stories or seen them used, please let us know so that your experiences may be shared. We recently had a call from a storyteller to let us know that Lord Darzi had used a story at a recent conference. Viewings of that story rose by a factor of three in the following weeks!

### **Looking ahead**

Over the next few months, we will be presenting the Patient Voices work at a conference in the Isle of Wight focusing on managing long term conditions; at the Quality Improvement for Cancer Services conference in Leeds, focusing on palliative care, for Macmillan professionals; at the East of England Deanery conference in Cambridge focusing on general practice; the Nurse Education International conference in Dublin in June and the Nurse Education Tomorrow conference in Cambridge in September. At both of these, we will be leading symposia on the role of storytelling in Humanising Healthcare.

Pip will also be presenting at the Healthcare Perspectives in Digital Storytelling Retreat in Vancouver, Canada in May; please go to [www.storycenter.org](http://www.storycenter.org) if you are interested in attending; details are also available on the Patient Voices website.

The Humanising Healthcare initiative that emerged after last year's masterclass is gathering momentum, and we are now planning to hold an event in early 2009 to explore the key issues arising from the challenges of humanising healthcare. Details will be posted on the website [www.humanisinghealthcare.org](http://www.humanisinghealthcare.org) when available.

We are in the planning stages for a workshop on the in-patient experiences of people with Diabetes to be held in June, and would be delighted to hear of any potential storytellers. If you, or someone you know, might like to take part, please contact us for further details.

### **And finally...**

We send you our good wishes for the spring, our thanks to all of you who have shared stories with us, and our hopes that as many of you as possible can join us on May 16<sup>th</sup>.

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