



# Patient Voices

## THE NEWSLETTER

Issue 6, January 2010

### New Year, new beginnings

After the bumper harvest of the last issue, we welcome you to the slim, first Patient Voices newsletter of the new decade – and we want to share with you some good news. In the middle of December, we were delighted receive a letter telling us that we had been shortlisted for the prestigious BMJ group awards in the *Health Communicator of the Year* category.

To our even greater delight, in the last post before Christmas, another letter arrived telling us of our shortlisting in a second category: *Excellence in Healthcare Education*. Please see the release (attached and on the website) for more details. We look forward with eager anticipation to the awards ceremony on 10th March and would be thrilled to see any of you who are able to attend the gala dinner in London (<http://groupawards.bmj.com>)

### Patient Voices workshops and stories

The ever-changing tides of Patient Voices work carried us, for the most part, away from storytelling workshops in the last few months of 2009, steering us instead towards consolidation and conferences... However, Pip did travel to San Jose, California, to co-facilitate, with Joe Lambert of the Center for Digital Storytelling, a workshop to create stories about air medical transport for the Center for Medical Transport Research. The stories are already being used in training for the emergency services as well as medical transport personnel – they can be seen at [www.tcmtr.org](http://www.tcmtr.org) and they will soon be on the Patient Voices website. The workshop continues the ongoing thread of our work with Dr Cathy Jaynes of the University of Colorado, focused on creating and using stories to help to create a culture of safety in healthcare.

We have been delighted to participate in several successful and well-attended launches of stories created



earlier in the year. The University of Liverpool's *Get involved 4 the Future* stories were launched in September at a celebratory evening

event at the university. Excellent food and music were

enjoyed by all before Eileen Thornton, head of the school of healthcare, introduced the stories. Storytellers received certificates in recognition of the important role they play in the education of the health professionals of the future. You can see the stories at [www.patientvoices.org.uk/ul.htm](http://www.patientvoices.org.uk/ul.htm)

October saw the launch of the NHS Leeds *Patient Involvement* stories at a PPI networking event in the Community Centre in Pudsey. Feedback on the day was really positive and the stories are now being used in induction and staff training. You can see the stories at



[www.patientvoices.org.uk/leedspct.htm](http://www.patientvoices.org.uk/leedspct.htm)

A slightly different flavour characterised the launch of the Sheffield City Council *Carers' Voices* stories and accompanying DVD at the Riverside Public House in Sheffield on a sunny October afternoon. An introductory presentation by Professor Paul Stanton of the University of Northumbria set the tone for the event, attended by about 75 storytellers, social workers and clinicians, many of whom wrote very moving responses to the stories. Please see [www.patientvoices.org.uk/sheffcc.htm](http://www.patientvoices.org.uk/sheffcc.htm)

### Out and about

September saw what has become an annual appearance at the NET conference in Cambridge, where a workshop looking at the Effective, Affective and Reflective nature of the Patient Voices stories was well attended and generated good discussions around using the stories.

In November, the Authenticity to Action workshop in the Lake District was the venue for a presentation about the Liverpool stories, entitled *Going digital but staying personal!*. One of the storytellers was there to tell her side of the story... and there was scarcely a dry eye in the room.

In November, a presentation at the University of Nottingham's *Interprofessional Learning Day* provided an opportunity to highlight the potential for using the Patient Voices stories in interprofessional education.

The last presentation of the year was at the University of East London's *Mindfulness and Well-being* conference, where the mindful elements of our Patient Voices work were highlighted in the context of wider interest in mindfulness-based approaches to coping with mental health issues and chronic conditions.

### Introduction to Digital Storytelling workshops

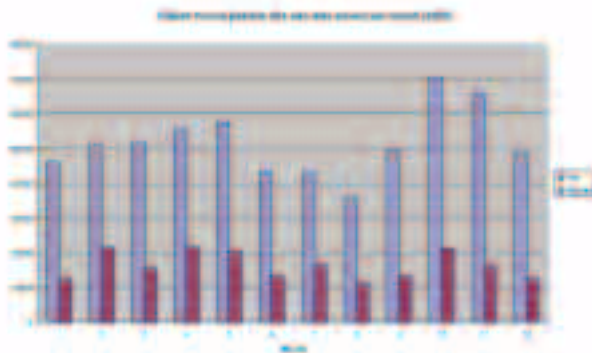
The last two workshops in Cambridge were well-attended and we were especially pleased to welcome three colleagues from Denmark, who went away enthused about the possibilities offered by the facilitative model that characterises our workshops. The schedule for workshops in 2010 is now on the website and we look forward to seeing any of you who would like to experience the process of creating a digital story at first-hand.

### Research

We are pleased to feel that we are in the forefront of a quiet movement to ensure that care is careful, healing is holistic and individuals are enabled to live their lives as fully and as mindfully as possible for as long as possible. But we are also interested in finding out more about the impact of the storytelling process and of the stories themselves on viewers. To that end, Pip has started a PhD at Cardiff University to carry out a qualitative study of *Mindfulness-influenced digital storytelling in health and social care* – a long journey no doubt, but one that it feels good to have begun. If anyone else's research is following a similar path, it would be great to have some company on the way – please get in touch.

### The website and discussion group

Lots of people have been visiting the website and viewing stories – there were over 600,000 hits on the site in 2009.



We've welcomed a bit of a lull in workshop bookings as it's allowed us to review the website and user feedback. Recent visitors in recent weeks may have noticed some improvements, part of a plan to refresh and restructure Patient Voices' online presence over the next few months. To make the stories more easily playable by users of Macintosh computers, we have moved to Flash format for

the stories, although this has resulted in a nearly three-fold increase in site storage space and bandwidth.

Each story now has its own individual page, so linking to individual stories becomes easier. Eventually, each story page will contain a 'wordle' that provides a simple, quick, and easy-to-assimilate graphical representation of the main themes in the story.



The website now has a Google custom search (accessed from the 'Search' tab at the top of the page). We hope this will help those searching for particular stories or themes. We have also moved to using Google Analytics tracking code to follow website access and story usage.

In the next few months we will review the Yahoo group, look at ways of providing a simpler feed of Patient Voices Programme news, and try to lighten the appearance of the website and reduce the amount of text on some pages.

### Looking ahead

We are eagerly looking forward to the publication in late January of the next edition of *Capturing Lives, Creating Community* by Joe Lambert, Founding Director of the California-based Center for Digital Storytelling ([www.storycenter.org.uk](http://www.storycenter.org.uk)). We contributed a chapter about the Patient Voices Programme – the first published attempt to describe what we do and why we do it.

### Settling in

After a few teething troubles with broadband and phone suppliers, we are happily settled into the new office at:

The Barn, 1 Corbett Street

Cottenham

Cambridge CB24 8QX

Our new phone number is: +44 1954 202158

Due to the very small number of faxes we receive, we've given up our fax line. Our mobile phone numbers and email addresses have not changed, so please do get in touch with us – we always enjoy hearing from you.

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## MEDIA RELEASE

### PATIENT VOICES HEARD IN BMJ AWARDS

Pilgrim Projects' Patient Voices Programme has been shortlisted for the prestigious BMJ awards in two categories:

*Excellence in Healthcare Education* recognises an individual or team who has demonstrated outstanding leadership and/or innovation in healthcare education and performance improvement.

*Health Communicator of the Year* celebrates an individual or individuals who have shown excellence in promoting understanding of medicine and health through the media.

The BMJ Group Awards recognise individuals, organisations and initiatives that have demonstrated outstanding and measurable contributions to health care.

Pilgrim Projects is an education consultancy based in Cambridge, UK that specialises in healthcare quality improvement. Directors Pip Hardy and Tony Sumner pioneered the use of digital storytelling in healthcare with the Patient Voices Programme. Established as a social enterprise in late 2003, the Programme aims to promote greater understanding by facilitating the telling and sharing of the stories of all stakeholders in healthcare - patients, carers, clinicians, managers and policy makers.

Sir Liam Donaldson, Chief Medical Officer, comments: 'Projects such as Patient Voices give patients and carers a chance to make themselves heard and are an essential part of the process of improving quality and safety in healthcare.'

Described by Dr Jean Watson, Professor of Nursing at the University of Colorado, as 'exciting, cutting edge work, informed by creativity and scholarship', the Patient Voices digital storytelling methodology makes it possible for ordinary people to share their often-extraordinary experiences and insights. The compelling medium of digital stories weaves together a voiceover scripted by the storyteller, still images and music into a rich multi-media tapestry that touches hearts as well as minds. Innovative and facilitative approaches ensure that storytellers are fully involved in every stage of the process of creating their own video, and a robust consent and release process mean that they are fully informed at every stage. The thoughtful and reflective storytelling process, combined with the judicious use of new technology, 'empowers patients, carers and clinicians to convey their felt experiences of healthcare via technology so that their voices can be heard in any lecture theatre, board room or conference venue anywhere in the world' (Hardy, 2007).

Chief Nursing Officer, Dame Christine Beasley, says: 'I am very impressed with the work you are doing in relation to the patient experience. The patient experience is a fundamental element of the Quality Agenda, outlined in 'High Quality Care for all' – Next Stage Review Final report. The work you are doing also allows others to hear their stories but even more powerfully in their own voices with the messages of patients, carers and healthcare professionals who all have an important role to play in the journey patients have and the care they receive.'

Nominating the Programme, Valerie James, Independent Consultant and Honorary Senior Fellow at St George's, London & Kingston Universities says: 'By offering people the opportunity to tell, hear and share personal stories of birth and death, health and illness, care or the lack of it, Pilgrim Projects hoped to develop a sense of community with the values of humanity and compassion taking precedence over the "tyranny of the urgent" or the need to accomplish more with less.'

The awards ceremony, hosted by Tony Hawks (author of *Round Ireland with a Fridge*), will be held at the London Hilton in Park Lane on 10<sup>th</sup> March 2010. Confirmed guests include Sir Liam Donaldson, Andrew Lansley and Jon Snow.

BMJ Group Awards [www.groupawards.bmj.com](http://www.groupawards.bmj.com)

Patient Voices Programme [www.patientvoices.org.uk](http://www.patientvoices.org.uk)

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### **Editor's notes:**

In 2000, Pip Hardy and Tony Sumner brought together many years of experience in education, educational publishing, counselling, software engineering and quality assurance to set up Pilgrim Projects, an education consultancy specialising in the development of open, distance and e-learning materials and healthcare quality improvement. They founded the Patient Voices Programme in 2003 to communicate patients', carers' and clinicians' experiences to healthcare designers, deliverers and educators of healthcare, and to support and enrich the development of 'delightful' and reflective learning.

Pip Hardy has a degree in English Literature, an MSc in Lifelong Learning, and many years' experience developing and consulting on open and distance learning programmes. She also holds qualifications in adult education, learning strategies, group work and counselling. She is currently investigating the impact of the Patient Voices digital stories for her PhD at Cardiff University. Pip serves as Vice Chair on the Board of Directors of Cintra, a Cambridge-based public sector interpreting and translation agency and was elected a Fellow of the Royal Society of Arts, Manufactures and Commerce in 2008.

Tony Sumner is a physics graduate with a Postgraduate Diploma in Astronomy and Astronautics and twenty years' experience in the computer industry where he was involved in software development, quality assurance and testing and project management as well as the development and delivery of support systems and technical training programmes. Tony sits on the Cambridgeshire Community Services Patient Focus Committee. He was elected a Fellow of the Royal Astronomical Society in 1989 and a Fellow of the Royal Society of Arts, Manufactures and Commerce in 2008.

### **References**

Hardy, P. 2007. 'An investigation into the application of digital patient stories in healthcare education: quality of learning, policy impact and practice-based value' (masters' dissertation, University of Ulster), <http://www.patientvoices.org.uk/research.htm>