



Patient Voices

THE NEWSLETTER

Issue 5, September 2009

Transformation and change

As the beginning of a new academic year approaches, a short break snatched before the days really draw in and the country returns to work gives us a perfect opportunity to reflect on the year so far and anticipate what the next



nine months may hold for Patient Voices.

A record number of workshops in the first few months of the year combined with the

joyful arrival of our first grandchild leave us wondering, just as many of you may be, where the year has gone.

It is with some embarrassment that we realise our last newsletter was sent out in December. Despite our best intentions to produce four two-page newsletters a year, we have failed to meet this stringent target and hence this bumper issue is a little longer than usual so that we can keep you abreast of all our news.

We are constantly reminded of change and impermanence by the events in our lives and the lives of our friends and family, as well as by the stories people



tell us about the changes in their own lives. The potential for transformation is also ever-present as storytellers let us know of the ways in which the stories are having an impact on their own lives, teachers and lecturers tell us how the stories are having an impact in education and even, perhaps, in the higher echelons of the health service.

We were delighted to receive, early in the year, letters from both the Chief Medical and Chief Nursing Officers commending the Patient Voices programme and letting us know that they are showing the stories in their own presentations, thus ensuring that storytellers are receiving a platform to share their experiences at the highest levels.

Here and there

The year began with presentations at the Universities of Nottingham, Surrey, Coventry and East London, on topics ranging from mindfulness and the therapeutic aspects of digital storytelling through the thoughtful use of technology to promote reflection and an exploration of the ways in which digital storytelling can be used as a powerful means of reflection in medical education.

One of the highlights of the year was the launch in Harrogate of 12 stories from some of the most elderly Sisters of



the Society of the Holy Child Jesus. Their stories reveal and affirm the importance of individual choice and vocation as well as the firm foundation for their faith and their work provided by their community. Their stories can be seen at www.patientvoices.org.uk/shcj.htm

Reconnecting in California with Dr Cathy Jaynes from the University of Colorado School of Nursing has resulted in collaboration on a couple of papers focusing on the links between stories, patient safety, ways of knowing, different kinds of intelligence and the kind of teaching that Malcolm Knowles defined as 'andragogy' – we are now in the ever-hopeful process of submitting these papers for publication. Journeys to less far-flung places, such as Leicester, have formed the backdrop for the preparation of a paper describing the outcomes of our work with the junior doctors last year. This too will be submitted for publication in the next few months.



The mediaeval town of Obidos in Portugal was the setting for the International Digital Storytelling Conference organised by the

Center for Digital Storytelling in June.

People from Europe and the US met to share different approaches to creating and using stories. It was a pleasure to meet old friends and make new ones and a privilege to present our Patient Voices work to such a group.

Patient Voices workshops and stories

Our only 'overseas' work so far this year has been in the



Isle of Wight ... we became very familiar with the ferry from Portsmouth (and a delightful little Indian restaurant in Newport called 'Nabab') ... as the

workshop, for members of the Isle of Wight Stroke Club, was run over four consecutive Tuesdays in order to give storytellers time to recover from the intense demands of each day of a digital storytelling workshop. Their stories reflect individual experiences of stroke and the crucial role the Stroke Club played in their recovery. They can be seen at www.patientvoices.org.uk/iowsc.htm

We returned to the London Borough of Newham to facilitate a group of Albanian and Kosovan refugees creating their stories about war and migration, difficulties of settling in a new country and the importance of community and culture. We were honoured to participate in an important community ritual – that of a delicious lunch, cooked each day by different storytellers. Perhaps it's just as well, for the sake of our waistslines, that tiramisu isn't served at every workshop! Their stories join the Communities of Health collection at www.patientvoices.org.uk/newham.htm.



All these stories carry important messages about public health and have profound implications for commissioning care for diverse communities.

A group of newly-qualified nurses from the University of Nottingham came to Cambridge to create stories about the shock of reality as they move from the relative comfort of academic life to the harsh and sometimes shocking world of practice. Their stories are being used to help preceptors offer more realistic preparation for the reality of work after university – they can be seen at www.patientvoices.org.uk/un.htm

The thirst for digital storytelling in and around Leeds has continued with a well-attended workshop sponsored by Leeds Primary Care Trust intended to highlight the importance of Patient and Public Involvement (PPI). Ten storytellers

revealed what involvement has meant to them and veteran storyteller Brian Clark was on hand to show



first-time storytellers the ropes – at the same time as making his second story. Their stories will soon be available on the Patient Voices website.

A chance meeting while presenting at the 2007 Authenticity to Action conference led to a workshop as part of the University of Liverpool's Get involved 4 the Future project. Experiences of health and social care related by members of the Forum of Carers and Users of Services can now be used even more widely in medical and social care education. Their stories can be seen at www.patientvoices.org.uk/ul.htm

Pip will be returning to the 2009 A2A conference, along with Elspeth McLean from the University of



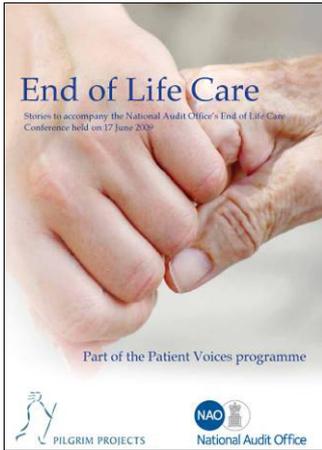
Liverpool to present some of the learning from the project.

Inspired by the Healing Journeys stories created at Sheffield Hallam University in 2008, Sheffield City Council sponsored a workshop for mental health service users and carers in July. Ian and Pep, two storytellers from the first Healing Journeys workshop, returned after more than a year to share, through two new digital stories, the ways in which the digital storytelling process has affected their lives – for the better!

All of these stories, heart-warming and heart-rending in almost equal measure, will soon be available on the Patient Voices website in the Carers' Voices collection.

Our work with the National Audit Office continues: our latest project with them is a series of stories and a DVD accompany their End of Life Care conference held in London in June. Two existing stories joined four newly-created stories, one of which was told by Barbara Pointon,

who featured, together with her husband Malcolm, in a TV documentary about their struggle with Alzheimers.



One of the other storytellers was Derek Whitehead, whose first story, 'Imagine', told three years ago as part of the Reconnecting with Life project, envisages a world in which timely and effective stroke care would put an end to the kind of suffering endured by his wife, Barbara.

Derek has recently been honoured with an OBE for his tireless work in campaigning for better services for stroke patients and their carers. The end of life stories can be seen at www.patientvoices.org.uk/naoeol.htm

Introduction to Digital Storytelling workshops

Workshops in Cambridge continue every couple of months. These intensive weekends are a great way for potential Patient Voices workshop organisers to experience at first-hand what storytellers will go through –

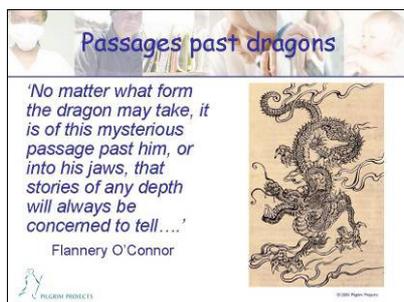


and usually result in great creative thinking about how stories can be used. We see collaborations created and communities

forming during these weekends and are delighted when people tell us that they feel rested and rejuvenated despite – or perhaps because of – the hard work of creating a digital story.

Humanising healthcare

The Patient Voices programme began as part of an attempt to instil more humanity in healthcare through the creation and intentional use of stories of all stakeholders in health and social care. One of the recurring themes of our work is the transformative nature of storytelling. We continue to be humbled by the courage of storytellers who



persevere in what one storyteller called 'naming the beast', and amazed by the healing that can take place as a result of the all-too-human experience of facing that which we most fear, what Flannery O'Connor referred to as a passage past a dragon.

In April we held a retreat in Cambridge for a small but committed group to celebrate and reflect on five years of Patient Voices, consolidate the work that has been done so far and contemplate the future. Techniques drawn from Appreciative Inquiry and World Café guided us through a creative exploration of various possibilities, more than ably facilitated



by Dr Fiona O'Neill, who kept us to task in the most compassionate manner! Many excellent ideas were captured on flipcharts, table cloths, photos, video and audio recordings – and a good time was had by all!

Several members of the group reconvened in July to focus on drawing up a list of actions so we are now trying to find time to do some research, write some papers and revamp the website, while other members are writing abstracts, helping to draw up plans of various kinds, searching for funding and offering support in other ways.

Reflection and mindfulness

Reflection on our own practice over the past few years has made us increasingly aware of the part that mindfulness plays in our work. In order to deepen our understanding of



mindfulness practice, Pip recently attended a seven-day retreat in Germany led by Drs Jon Kabat-Zinn and Saki Santorelli from

the Center for Mindfulness in Healthcare and Society at the University of Massachusetts Medical School. It was gratifying to discover that much of what we do as digital storytelling facilitators and informed by Buddhist practice is closely aligned to the more formal practices of mindfulness that have helped to improve the lives of thousands of participants in Mindfulness Based Stress Reduction Programs over the past 30 years.

Coincidentally, we were intrigued to hear on BBC Radio 4 recently a programme about the famous 1976 experiment conducted by Ellen Langer into how self-determination

and choice can vastly improve the quality and quantity of life of elderly patients in care homes. She also shared her views on the role that mindfulness can play in improving the quality of care for elderly patients.

So 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.

Research

There are now so many different strands to our Patient Voices work and so much interest in the effects of both the stories and the storytelling process that we are keen to do some research that will enable us to reveal the potential of digital stories and digital storytelling in health and social care to a wider audience.

If you are interested in becoming involved in research projects or have ideas about sources of funding, please do get in touch with us.

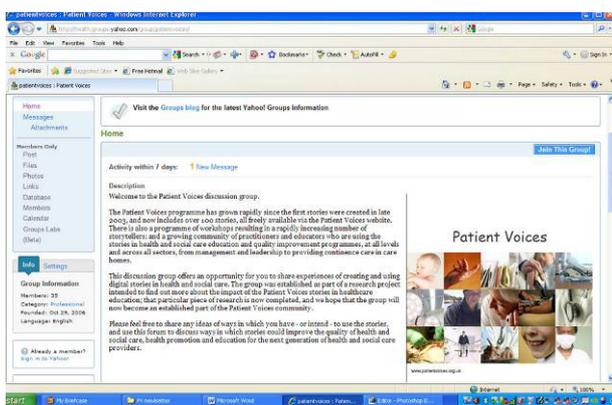
The website and discussion group

There are now in excess of 200 stories on the main Patient Voices website and approximately 20 stories waiting for release. Hit rates remain close to 2000 per day, with approximately 30-40 stories being downloaded every day – we expect to have half a million hits by the end of the year.

The website has grown organically over the years since its launch in 2003. Despite the best efforts of Tony and his ‘hobgoblins of consistency’, the time has come to review the structure, layout, content and functionality of the website. If you have any suggestions, requests or views, please send him an email at tony@pilgrimprojects.co.uk

In the meantime, the Resources section of the website has been re-organised to include separate pages for presentations we have given, papers we have written and abstracts that have been accepted.

The Patient Voices discussion group is where we post when new stories are put up on the website, so it's a great way to keep up to date with new developments. Please do consider joining our growing community of practice to share experiences of making or using the stories.



Some useful links

The discussion group

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

Papers we have written

www.patientvoices.org.uk/papers.htm

Abstracts that have been accepted

www.patientvoices.org.uk/abstracts.htm

Presentations we have given

www.patientvoices.org.uk/present.htm

The stories www.patientvoices.org.uk/stories.htm

Looking ahead

We were delighted to be asked by Joe Lambert, Founding Director of the California-based Center for Digital Storytelling (www.storycenter.org.uk) to contribute to the third edition of his book *Capturing Lives, Creating Community*. His thoughtful questions gave us a chance to think deeply about what we do and why we do it and we look forward to seeing the book in print later this year.

On the move

After many years of working from home, we are currently in the throes of moving to a *real* office.



The new headquarters of the Patient Voices programme will be a spacious converted barn in the next village.

We are looking forward to having a bit more space for the growing number of laptops ...and to going home at the end of the day!

Our new address will be:

The Barn
1, Corbett Street
Cottenham
Cambridge CB24 8QX

Our mobile phone numbers and email addresses will not change, so please do get in touch with us – we always enjoy hearing from you.

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