



PATIENT VOICES: THE NEWSLETTER

Issue 1

August 2007

Where we are now

When we recorded Ian Kramer and Monica Clarke telling the first Patient Voices stories in 2003, we had no idea that what began as an attempt to convey the authentic voices of patients and carers in a flexible resource for healthcare education and quality improvement would grow to be an internationally-acclaimed, award-winning project.

The stories are now used in schools of medicine and healthcare in the UK, US and Canada, in Eastern Europe and as far away as Japan. We have met wonderful people with whom we have laughed and cried and shared wonderful stories.



In April, we had the pleasure of 'hosting' a masterclass facilitated by Joe Lambert and Emily Paulos from the Center for Digital Storytelling. Some 20 people created 'analogue' stories and discussed ways of

using digital storytelling in healthcare.

The overwhelmingly enthusiastic response to the masterclass has led to, among other developments, an initiative called 'Humanising Healthcare', supported by the Royal College of Nursing, the Kings Fund, the National Audit Office and several universities, to explore, in the words of one member, 'ways of integrating patient (and carer) stories, teamwork, education and development, better services and supreme patient experience' – to use stories to inform, educate and enlighten with a view to engendering more compassionate care through more human and humane commissioning.

'I am more convinced than ever that the ability to facilitate the gathering of digital (and other) stories (and to share this ability with colleagues, service users and local communities - and to see it as a means to reflect upon one's own developing professional identity) should be an integral part of the repertoire of 21st century public service professionals.'

Paul Stanton

The stories

The growing collection now includes stories of experiences of long-term carers and people affected by stroke, stories of ways that new technology could improve care, the RCN 'continence' stories, considering the effects of conditions such as Parkinson's Disease and Rheumatoid Arthritis – and a wide variety in between. All of the stories highlight the deeply-felt desire of storytellers to be treated with respect and dignity, to be listened to and to be informed and involved in their care.



Most of the stories are gathered in small workshops for particular groups of patients, carers or service users. Storytellers value sharing common and diverse experiences and having their voices heard, while learning to convey important messages powerfully and succinctly.

As a way of powerfully engaging patients, the Patient Voices approach has attracted the interest of the NHS Institute for Innovation and Improvement, while the Health Foundation Leadership Fellows have recognised the fundamental place of stories at every level in NHS organisations.

Interest is gradually spreading into social care and public sector services generally, and we are currently working on a storytelling project intended to highlight the importance of using professional interpreters when working with people whose first language is not English when delivering any public sector service.

We hope that organisations will continue to sponsor the collection and creation of the stories, as it is only in this way that the resource will continue to grow. If you, or anyone you know, is interested in gathering stories of your particular client or service user group, please contact us.

'Thank you for giving Ian and me the opportunity to voice our feelings.'

Marilyn Kramer



The website

The distribution of the stories via the website as a free resource for use in health and social care education and quality improvement is a small piece of social enterprise that has always been at the heart of our ambitions for the programme. We now have over ninety stories on the site – over four hours of shared healthcare experience – and another 50 stories in production or awaiting final release approval!

The website now receives around a thousand hits per day, with about a thousand stories viewed and downloaded around the world every month. Because of the number of stories and downloads and the amount of data shifted, we are looking at technologies that will allow us to provide a gallery-based site where stories can be searched for, rated and recommended by users, to the benefit of all.

The discussion group

One underused aspect of the programme is the Yahoo discussion group. Joining this is free and easy, will ensure that you receive notification of changes and new stories as they happen and contributes to building a community of learning and practice. Part of our strategy for the website is to look at moving the discussion group to the Patient Voices site, as some organisations do not allow access to Yahoo groups.

The research

Pip submitted her MSc dissertation in May and received a distinction for her research into the applications of the Patient Voices digital stories in healthcare education and quality improvement. Conducting the research has brought us into contact with a number of wonderful people doing innovative and imaginative work in the fields of patient involvement and inter-professional education. There is now the small matter of preparing the work for publication...

We expect research into both the creation and uses of the stories to continue and welcome suggestions and/or collaborations that would enable us to evaluate the effects of the stories in practice.

And, as ever, we really are keen to know how you are using the stories – please let us know what you do with them, who you do it with, and what the effects are!

Conferences and presentations

In response to frequent requests to talk about the Patient Voices programme, Pip has emerged, somewhat reluctantly, from the relative safety of the office ... and has been encouraged by the positive reactions.

A number of abstracts have been accepted for presentations at conferences; past appearances include 'All Together Better Health III', 'NET 2006', and a storytelling session at the Clinical Microsystems 2005 Fall Invitational, as well as a number of smaller events, and we now look forward to presenting at 'NET 2007' and to demonstrating the values of 'co-production' by presenting jointly with storytellers and sponsors at 'Authenticity to Action'. Abstracts will soon be available on the Patient Voices website.



The workshops

Following the April Masterclass, a number of people were keen to learn more about the digital storytelling process. This encouraged us to put into effect one of our long-term plans, to offer training in digital storytelling to those who hope to use and promote digital storytelling within their work. The first two such workshops were held in June and attended by 14 people who produced 14 incredible stories.

We hope that these workshops will become a regular fixture and that people will use them as a jumping-off point to do further training in digital storytelling. We are currently in discussions with several universities and expect these to result in accreditation for our digital storytelling process, probably at masters level.

Our programme of workshops is appended to this newsletter – and there are still places on the September workshop!

And finally...

We'd love to hear from you.

pip@pilgrimprojects.co.uk

tony@pilgrimprojects.co.uk



Pilgrim Projects / Patient Voices Digital Storytelling Workshops

Autumn/Winter 2007/8

<i>Dates</i>	<i>Workshop title</i>	<i>Venue</i>
Sept 7-9	Introduction to digital storytelling	Cambridge, UK
Sept 13	Practice day	Cambridge, UK
Oct 1-5	Humanising healthcare digital storytelling retreat	San Francisco, California
Oct 19	Practice day	Cambridge, UK
Nov 2-4	Introduction to digital storytelling	Cambridge, UK
Nov 17	Practice day	Cambridge UK
Jan 11-13	Introduction to digital storytelling	Cambridge, UK
Jan 14	Practice day	Cambridge, UK

Dates are subject to change

Except where indicated, all workshops will take place in Landbeach, a small village just north of Cambridge, UK, easily reached by rail, road and air (via Stansted airport).

The workshops in brief

Introduction to digital storytelling workshops are for people who want to learn more about the process of digital storytelling, possibly with a view to exploring its use in their organisation and/or with patients, clients or service users.

Beginning on Friday evening with a gentle introduction to the weekend, participants will complete 2-3 minute personal digital story during the course of the 2.5 days. We will cover the Seven Elements of Digital Storytelling as well as teaching some of the basics of Photoshop Elements and Premiere Pro – and there will be a celebratory premiere of all stories at the end of the workshop.

Practice days provide an opportunity for those who have completed the *Introduction to digital storytelling* workshop to deepen their technical skills. Each day will focus on a particular aspect of creating and using digital stories, for example, recording a voiceover, editing audio, rendering stories at different resolutions for different uses, using stories in PowerPoint



presentations, etc. Participants are encouraged to come along with questions and issues, and to share experiences with other storytellers.

For those who envisage embedding digital storytelling within their organisation and who want to become digital storytelling facilitators, we encourage you to attend at least three *Practice days*, to undertake reading and reflection and to work with us to practise and deepen your appreciation of storytelling as well as your facilitation skills.

After some months of practice and the creation of several stories, participation in a *Facilitator Training* workshop, extending over five days, will help to prepare you to facilitate your own workshops.

We are currently seeking accreditation for this process, which we hope will result in the award of a post-graduate certificate.

Cost

Introduction to digital storytelling workshops = £400 + VAT at 17.5%

Practice days = £150 + VAT at 17.5%

Fees include coffee, tea, lunches, etc., but exclude accommodation and dinner. Reasonably-priced accommodation is available nearby and Indian food from our local takeaway has proved to be a popular option for dinner on Saturday night!

Places are limited – small numbers ensure a conducive atmosphere for storytelling and plenty of individual attention.

Your place will be reserved on receipt of a deposit of 50% of the fee. The balance is payable two weeks before the workshop. If you subsequently find that you are unable to attend the workshop, we reserve the right to retain your deposit. In the event that a workshop is cancelled, your deposit will be returned in full.

From time to time, special events, such as retreats and masterclasses will be held. If you are interested in receiving further information about such events, please let us know.

If you would like to discuss any aspect of this programme, talk about your particular needs or those of your organisation, or if you would like to organise an in-house workshop, please contact Pip Hardy or Tony Sumner at Pilgrim Projects on +44 1223 440257, or email pip@pilgrimprojects.co.uk