

# Speaking from the heart

*Much lip service has been paid to the notion of fostering patient-centred care – but one award-winning project is doing just that*

**I**N 2003, Pip Hardy and Tony Sumner, founding directors of educational consultancy Pilgrim Projects, were asked to produce some materials on clinical governance for the Royal College of Nursing. In the brief they were charged with being innovative and creative and also with making sure the patient's voice could be heard throughout the materials.

At around the same time they stumbled across what they felt was a powerful concept, digital storytelling, which involved the creation of a short personal story using video, audio, still images and music. It was a lightbulb moment: what better way, they thought, to 'hear the patient's voice' than to actually hear it?

As Tony explains: "We saw it as a methodology we could apply to the e-learning materials we were developing, to make them richer and more pertinent and get across the emotional point. So we had to persuade people that we could put patients talking about their experiences into the learning materials and it wouldn't make them less valid."

Having convinced the RCN to let them embed stories in this way, and delighted with the feedback they received, the pair decided to apply the concept more widely and set about persuading others in the healthcare sector of the validity of the method and the need to hear people's experiences directly rather than reflected through long reports filled with dry statistics.

"We were driven by our experience, and the experiences of people that we knew in healthcare, that healthcare wasn't always humane," says Pip. "It seemed that there was a real need to re-inject some humanity."

## Building 'social capital'

The result of this drive is the award-winning Patient Voices programme, a series of digital stories illuminating the experiences of people from all over the healthcare spectrum, including patients, doctors, nurses, managers, chief executives and carers. In the last six years some 400 stories have been created – through the likes of NHS Leeds, the NHS Heart Improvement Programme, the University of Nottingham and the Isle of Wight Stroke Club. Of these, more than 250 are available for free download from the Patient Voices website as an educational resource to stimulate discussion and reflection. It's what Pip and Tony, who describe themselves as social entrepreneurs, call the "building of social capital".



Patient Voices participants. Above: BMJ Group Awards with Pip and Tony front right and middle

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This means that, for example, Jimmy's Story, created in a workshop around patient safety for NHS Tayside and told by his sister Betty, is just a few mouse clicks away from anyone with internet access. In the story Betty recounts how, after her brother fell in hospital, he died three weeks later following a series of mishaps, lost notes and uninvestigated injury. Despite all her efforts at the time, she says she was ignored.

Then there's Monica Clarke's story, in which she describes the frustration she faced feeding her husband after he had a gastrostomy. Every time she had a problem to deal with, whether it was to do with the pump, the feeding tube, the attachment or a leak, she was told to contact a different person. In what is a call for some kind of central control, she asks: "How can we manage a simple thing like giving a feed when there are four or five different specialists all over the country?"

These short, poignant and highly affecting stories are, like all the others on the website, the result of workshops run by Tony and Pip and commissioned by healthcare providers and educators. A workshop might be based around patient safety,

as in Jimmy's Story, a condition such as rheumatoid arthritis or a theme like patient involvement.

## The story is the agenda

As facilitators in the workshops, Pip and Tony adhere to a strict methodology which aims to let people come up with and tell their stories in the way they want, thereby achieving a direct line of communication between storyteller and audience with no over-arching agenda.

At the start of the workshop, says Pip: "We don't know what stories people are going to tell, and because we don't have an interview spine of questions, it really is a question of saying: 'What's the most important story you want to tell us around this issue?' Then our task is to help them make that the best, most powerful, effective and affective story it can possibly be."

Workshops vary in length, but usually last around three days. In groups of about six to eight – big enough to stop a dominant personality from taking it over, yet not so big for it to fracture into smaller groups – participants share their initial ideas for a story and use the group feedback, as well as the experience of Pip and Tony, to begin to home in on what it is they want to say.

Tony explains: "We are there in an editorial role and one of the things we always say when we're running the story circle is that the point is not to fix the NHS or to turn into a talking

shop about the way healthcare service should be better. The point is to fix that story so that it becomes the most effective way of conveying that experience."

Over the following days, participants prepare their own script ready for recording on to an audio track. They are then shown how to bring in their pictures and audio and how to assemble their stories themselves. "It's within the creative bounds of everyone, ranging from those with learning difficulties to tetraplegics. It's an accessible medium within which they can express their experiences," says Tony.

With the uploading of these stories on to their website, it means that instead of them being watched by friends and family and perhaps a few members of the sponsoring organisation and then disappearing into a filing cabinet or down the back of a sofa, they begin a journey of their own.

Searchable by title, description or keyword, or alternatively by the body that sponsored them, this tapestry of stories has found its way into a plethora of educational environments, including in-house education programmes, nursing education, interprofessional education and a large number of medical schools across the UK.

## 100 per cent personal

One of the things Tony and Pip have been fascinated by is the way the stories take on a life of their own in terms of their applicability. Jimmy's Story, for example, is used by one educator to underpin a whole series of lectures, starting with record-keeping and moving on to issues of corporate liability and the responsibility of directors on health boards.

"There are lots of interesting things that can be done with the story that go far beyond the original intention," says Pip.

It hasn't all been plain sailing, however, and some doubters have suggested that the stories are anecdotal and not statistically valid. To which Pip counters: "Well they are 100 per cent of one person's experience and that's a really valuable thing."

Tony adds: "The stories actually tell you what it's like to be that patient or that doctor. So the statistics tell you how the system experiences the individual, whereas the stories tell you how the individual experiences the system."

After a little over six years since starting the programme, Pip and Tony were delighted earlier this year when their work was acknowledged at the BMJ Group Awards (with MDDUS as headline sponsor), where they won the Excellence in Healthcare Education Prize and were runners-up for Health Communicator of the Year. Recognition like this will, they hope, raise their profile further and allow them to continue what they both admit is a "mission" to spread the stories of individual healthcare stakeholders and thus oil the wheels of communication and understanding.

"We put all our time into it because it seems very important to us," says Pip. "And it's nice to be able to say after working for six years, in the face of some difficulties and resistance, that the BMJ has acknowledged that these stories are important."

■ Adam Campbell is a freelance journalist in Edinburgh and regular contributor to *Summons*