

Authenticity to Action Conference abstract (4)

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Title: Patient Voices: the essential experience

Submitted for a workshop

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'Digital stories are a new medium through which narrative art can be explored and made accessible so that 'ordinary' people can articulate their extra-ordinary understandings.'

Professor Paul Stanton, 2007

Since January 2006, the collection of digital stories in the Patient Voices programme has grown from 23 to over 100, told by people of different ages, from different cultures, about different conditions. Each story is as unique as the person who tells the story.

'Reflection is as natural – and as necessary – as breathing ... or telling stories.'

Joe Lambert, Centre for Digital Storytelling

All of these stories are completely free for use with healthcare education and service improvement initiatives in health and social care and offer opportunities to reflect on practice, discuss key issues and insights and develop empathy and understanding (Hardy, 2007) by stepping into the shoes of the patients and carers who have shared their stories with us..

Our methods and approach to storytelling are adapted from those developed by the California-based Center for Digital Storytelling. Most of the stories are gathered during small, intensive workshops, with a focus on personal reflection and facilitative learning to enable participants to find the 'heart' of their own story.

Digital storytelling workshops combine skills from creative writing, drama, art therapy, and facilitative multimedia production to assist storytellers from diverse backgrounds in recounting their experiences as short 'digital stories'.

Patient Voices workshops offer opportunities to learn a number of hidden skills relating to listening and speaking, communicating in groups, conveying messages appropriately, and teamwork; storytellers grown in confidence as their competence grows and, almost inevitably,

a sense of connection and camaraderie is established, which can be of great benefit to those coming from isolated or marginalised groups.

We have found that 'staff' (i.e. clinicians, managers, educators) derive a great deal of benefit from the workshops also and this is particularly the case when they share the experience with patients/service users.

'What did I learn from the workshop?

- the importance of feelings and passion in telling a story

- the importance of the individual's unique perspective'

Patient Voices workshop participant (2006)

The process begins with introductions and an introductory presentation/discussion on fundamentals of storytelling, with examples of digital stories. Participants then share their stories, connecting their own personal experiences with the collective experience of the group. Participants comment on one another's stories, respectfully and appreciatively. Laughter and tears are commonplace, but most important is the quality of attentiveness and respect which leads to understanding and contributes to a feeling of solidarity within the group (Center for Digital Storytelling).

'It is very easy to tell the story that we want to tell to make our own point and not necessarily 'listen' to and learn from others point of views.'

Patient Voices workshop participant (2006)

Then the work of refining and revising the stories begins, individually and with help from their fellows and recording takes place as people feel ready.

This workshop will provide a 'taster' of the Patient Voices workshop experience, focusing on the non-digital elements of storytelling, with activities and exercises designed to elicit 'good' stories, and supported by just enough theory!

References

Center for Digital Storytelling www.storycenter.org

Hardy, P. (2007) 'An investigation into the application of digital patient stories in healthcare education: quality of learning, policy impact and practice-based value' (in preparation for submission as a masters' dissertation to the University of Ulster)

Patient Voices Programme www.patientvoices.org.uk

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Biographies

Pip Hardy founded the Patient Voices programme in 2003 with the original intention of developing a resource that would carry the experiences of patients and carers into e-learning materials about clinical governance. A degree in English Literature led Pip into education, educational publishing and the development of open, distance and e-learning materials, and a sideline in counseling, until her epiphany in relation to digital storytelling and its potential for transforming health and social care. She is currently writing up a master's dissertation looking at digital storytelling as a means of transforming healthcare education and service delivery.

Joanne Mangnall is a nurse continence advisor employed by Rotherham PCT. She was seconded to the Royal College of Nursing Institute in January 2005 to lead on a Continence Care in Care Homes project. The aims of this year-long project were to develop a care home specific continence assessment tool supported by educational resources that care home staff could utilize within the care home setting. Initial plans in relation to the educational elements focused on the production of a short educational video, however these plans changed once the power of digital storytelling was realized. Since working on the project Joanne has returned to her clinical role and incorporated a number of the continence stories into her training sessions with very positive feedback from staff.