

Arthur and Co. Digital stories about living with Arthritis

What was the problem?

'One of the things we don't do well in the UK is use patient stories. ... We don't feel comfortable actually standing up there and telling the patient story or the patients wouldn't welcome that. I don't know but it's something that we need to explore because it's a very powerful, impactful way of actually getting that message of patient safety across.' (O'Connor, 2006)

Aims of the project

Involving service users in the design and development of new technology is vital if new products and services are to meet the needs and preferences of people who live with long-term health conditions.

'We need to become involved in the early stages of planning if our world is to become a better place.' (Gill Bowskill, storyteller)

The main aim of the project was to explore the value of digital storytelling as an enabler of collaborative learning that supports health technology innovation.

Patient Voices digital stories are 3-5 minute first person stories which are created through facilitative teaching methods. Using user-friendly and cost-effective video-editing software, patients, carers and providers of care are now able to make their own digital stories and share their experiences.

'**Digital storytelling 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, boardroom or conference venue anywhere in the world.**' (Hardy, 2007)

All of these stories are completely free for use in 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, carers and providers who have shared their stories with us.

The Patient Voices programme (www.patientvoices.org.uk) uses a carefully developed methodology to facilitate the telling and sharing of digital stories of care.

A good Patient Voices digital story is:

- **Effective**
- **Affective**
- **Reflective.** (Sumner, 2008)

The innovative model of free distribution of stories for use in health and social care education and quality improvement ensures those voices are heard, and that the investment of storytellers is nurtured to develop maximum social capital.

'I cannot recommend strongly enough that people should take time out and listen to the stories of people with problems, who could be your neighbours, you would never know.'

(Brian Clark, storyteller)

Storytellers:

Brian Clark, Carole Carter, David Blythe, Eric Moorhouse, Gill Bowskill, Karen Hoffman

Pilgrim Projects/Patient Voices facilitators:

Pip Hardy and Tony Sumner

Leeds University project lead:

Fiona O'Neill

Patient Learning Journeys co-ordinator:

Jools Symons

What did we do?

A series of Patient Voices digital storytelling workshops involved five informed volunteers from Arthritis Care.

Principles that underpin our work are that it should be:

- Facilitative – education not training
- Empowering – storytellers shape their own story
- Collaborative – learning is mutual
- Respectful – non-judgemental, everyone's story is important
- Careful – attention to the needs of the storytellers
- Delightful – having fun, space to reflect, sharing food and drink.

What did storytellers learn?

- How to express their experiences **effectively**.
- How to tell a story that **affects** people.
- How to **reflect** on their experiences and recognise tacit knowledge.
- How to make a digital story.

Careful attention was paid to:

- working with people in a nourishing way
- pacing
- working within people's energy levels
- informed involvement
- an ethical two-stage informed consent and approval process.

What did facilitators learn?

- How best to support people who have Arthritis in the learning process.
- The determination and resilience of the storytellers.
- To walk in another's shoes for a while.
- '*Just because you can't see pain, it doesn't mean that people are not in pain.*'

The success of the process relies on:

- true collaboration
- careful facilitation
- 'co-creation' and 'co-production'
- shared power and shared learning
- respect
- creativity
- nourishment (physical and emotional!)
- attention to participants' needs
- reflection.

What has been created?

- Enhanced understanding of the journey with Arthritis.
- A freely available educational resource/social capital.
- Model of collaborative working.
- Personal development of the storytellers.
- Global visibility of stories via www.patientvoices.org.uk/wr.htm
- Understanding how design of products and services impacts upon the quality of life of people with Arthritis.

References

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