

# Part VI

## Doing It Together: A Model for Co-production

Pip Hardy and Tony Sumner

One major change to care services design and improvement during the life of the Patient Voices Programme has been the rise of co-design and co-production methodologies, which seek to involve service users in the design and improvement of services. Almost coincident with the start of the Patient Voices Programme, the Design Council published their Red Paper *Health: Co-creating Services* (Cottam and Leadbeater 2004), which would presage the development of Experience Based Design, later Experience Based Co-design, approaches in healthcare. The National Nursing Research Unit review of the process (Donetto et al. 2014) reports the success of this approach and notes that approximately 50% of the projects surveyed used patient videos in their initiatives, which are said to offer ‘an emotionally and cognitively powerful starting point for the co-design process’. The process for gathering these videos as described in the *Experience-Based Co-design Toolkit* (Dale et al. 2013) involves filming 1–2-hour interviews with around ten patients. These videos are then edited down independently of the patients to form one 30-minute composite video. Decisions regarding sense-making, chronology and prioritisation of elements of the interview are taken by the researcher, and then the edited interview replayed to the patient for approval. The patient’s role in the development of their contribution to the evidence that will be used in co-design is largely passive and reactive.

This approach echoes a remark by one of our first storytellers, Monica Clarke, who expressed her concern about the way researchers and interviewers tended to ‘dismember’ her story, picking out the bits that were important to them, regardless of what really mattered to her. We agreed with the authors of a paper that was to influence the early development of Patient Voices that ‘to treat stories in this way is to fail to respect the tellers of these stories. It is to make the assumption that our interpretation of the patient’s experience is more valid than their telling of it’ (Hawkins and Lindsay 2006).

Hence one of our major drivers in the development of the Patient Voices approach was to bring the ethos of co-production and co-design into the patient storytelling process, ensuring that what really mattered to the storyteller was the most important thing. This part highlights the collaborative nature of making and using digital stories and some of the issues and challenges that can emerge in relation to purpose, authorship, power and control. Keeping these issues alive for the facilitators and educators ensures that the stories and the people who make them remain authentically at the heart of the process and gives them their power to move and become effective in teaching the compassion and awareness of patients’ issues that is fundamental to a caring health service.

In Chap. 19 ‘Finding Our Voices in the Dangling Conversations: Co-producing Digital Stories about Dementia’, Jo Tait and Rosie Stenhouse explore how writing about giving other people a voice also meant discovering their own voices and uncovering the relationship between voice and power in possibly conflicting roles. Did adaptations to the Patient Voices workshops to provide support for storytellers with early stage dementia affect the control usually held by the storytellers and the eventual films? They discuss how the flexible, reflective, emergent form of facilitation, aiming to balance the creation of ‘effective’ stories for student nurses and academics, whilst retaining the authentic voices of the participants, eventually revealed the person behind the illness.

Chapter 20 ‘Learning Together with Digital Stories’ concentrates on how digital stories created by service users are used to educate healthcare students to become effective and compassionate health professionals.

Elsbeth McLean details the various ways the storytellers and the stories they created as part of the 'Fit 4 the Future' project enrich the training environment and stimulate active learning in small-group sessions, lectures and a virtual learning environment. In turn, the stories help learning to become student-led. Elsbeth sees the value of the stories in their quality, the knowledge that they were made under the storyteller's control, and that they are stories. They bring 'people' back into learning.

Chapter 21 'Cultivating Compassion in End of Life Care: Developing an Interprofessional Learning Resource Based on Digital Stories' reports on a collaborative project designed to offer clinicians and carers an opportunity to develop some of the so-called softer skills to enhance their care of those facing the end of their lives. Elizabeth Howkins, recent Chair of the Centre for the Advancement of Interprofessional Education, Pip Hardy and Colette Hawkins consider the need for staff working in this challenging and sensitive area to develop self-awareness and resilience as well as empathy and compassion. The focus on interprofessional collaboration is underpinned by a collection of digital stories created by staff as well as service users.

Chapter 22 'The DNA of Care: Digital Storytelling with NHS Staff' focuses on the value of digital storytelling for NHS staff, acknowledging the inextricable links between staff wellbeing and patient care. Head of Staff Experience for NHS England, Karen Deeny, and Pip Hardy describe the challenges facing healthcare staff and their need to be cared for with compassion so that they can, in turn, offer compassionate care. Digital storytelling offers staff a much-needed opportunity to reflect on their personal and professional lives, providing valuable insights into what really matters.

In their conclusion to this book, Chap. 23 '*The Stories Are All One: Care, Compassion and Transformation*', Pip Hardy and Tony Sumner pull together their key learning and salient outcomes from developing and running the Patient Voices Programme, the contributions and experiences of project sponsors and participants, and their hopes for a future that will be characterised by greater humanity and compassion for everyone.

Collette Hawkins

## References

- Cottam, H., & Leadbeater, C. (2004). *Health: Co-creating services*. RED Papers. London: Design Council.
- Dale, C., Stanley, E., Spencer, F., & Goodrich, J. (2013). Experience-based co-design toolkit. *King's Fund*. Retrieved June 2017, from <https://www.kings-fund.org.uk/projects/ebcd>
- Donetto, S., Tsianakas, V., & Robert, G. (2014). *Using experience-based co-design to improve the quality of healthcare: Mapping where we are now and establishing future directions*. London: King's College London.
- Hawkins, J., & Lindsay, E. (2006). We listen but do we hear? The importance of patient stories. *Wound Care*, 11(9), S6–14.