Part V

Contributing to Evidence: The Evidence of Experience

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Stories are always true – it's the facts that mislead. (Winterson 2007)

Until recently, stories did not have a place in the generally accepted hierarchy of evidence. However, as patient experience data is becoming increasingly more frequently gathered in the search for evidence to underpin initiatives within care, and a widening range of approaches and technologies are being applied to the task, this is gradually changing, and digital storytelling is included within the methodologies discussed in the literature (Coulter et al. 2009).

Most methodologies that involve the use of patient stories capture or harvest accounts of patient experience and then the processing of that data to extract meaning is done by professional researchers or academics. The reflective digital storytelling process used within a Patient Voices workshop allows patients to do more than simply provide their experiences as data. The processes of reflection, sense-making and distillation used within the workshop empower them to become analysts of their own experiences. Their stories become auto-analysed data, 'facilitated digital micro auto-ethnographies' (Sumner 2014) that turn patient experience data into patient experience information that carries the meaning important to them.

Part V moves to consider Patient Voices stories as a valid form of evidence, the evidence of experience. By its very nature, the impact of qualitative evidence on change is difficult to quantify, but evidence of patient experience, in particular through patient stories, is gradually being acknowledged as a way of promoting patient-centred change. Digital stories provide a rich and multi-layered resource for research into patients' true concerns and needs and into the effects of personal development training that places empathy and compassion at the centre of the therapeutic relationship.

In Chap. 16 'Measuring What Counts: The Stories Behind the Statistics', Karen Taylor describes the power of digital stories to place patients—and not just statistics—at the centre of high-level debates and at conferences where a large number of people, including policymakers, can be reached. She believes that stories commissioned by the National Audit Office about stroke, neonatal nursing and end-of-life care have contributed greatly to changes and improvements, and will continue to do so as the stories are increasingly used in teaching and board rooms. She argues for the greater use of technology to drive change and improvements and shift the balance of power.

'What *Really* Matters to Patients? Digital Storytelling as Qualitative Research' is the subject of Chap. 17. Carol Haigh and Eula Miller find this question is best answered through the emancipating medium of Patient Voices digital stories, enabling patients' concerns, rather than the researcher's agenda, to emerge. Using two case studies, the authors describe first a workshop with six 'survivors' of mental health services, with clear messages of forgiveness and the need for reassurance from their experiences of failures in the health services. Faced with an impenetrable wall of 'protectiveness' barring vulnerable patients from being heard, the authors then found stories on the Patient Voices website provided those voices and valuable post-hoc data for research, often in unforeseen directions.

In Chap. 18 'Increasing Empathy: Digital Storytelling in Professional Development', Nick Harland's personal awareness of the transformational benefits for staff to take time out to reflect, together with his belief that the empathic relationship between therapist and patient is key in defining the clinical outcome in physiotherapy, led to his setting up a research

project centred around a Patient Voices workshop for physiotherapists. The conflicting strands of a research and personal development training project produced some anxiety pre-workshop, but Nick believes, despite the difficulties of measuring such experiences, that they have the potential to affect real change from the personal to the organisational, and perhaps even cultural level.

References

Coulter, A., Fitzpatrick, R., & Cornwell, J. (2009). *The point of care: Measures of patients' experience in hospital: Purpose, methods and uses*. London: Kings Fund.

Sumner, T. (2014). *From data to insight: Obtaining the patient/service user voice*. Paper presented at the Independent Information Governance Oversight Panel, London.

Winterson, J. (2007). *The stone gods*. London: Hamish Hamilton.