



Patient Voices: the rationale

'Nothing about us without us'

The Patient Voices programme is partly an attempt to redress the balance of power between healthcare clinicians and managers and the people they serve, and partly an attempt to give decision-makers a different kind of opportunity to understand the needs of patients – other than the dry results of surveys and statistics. If patients are really to be 'at the heart of healthcare', as the Department of Health suggests they should be, then their views and their stories are of paramount importance in any attempt to reform health care services.

Patient Voices are short (typically less than three minutes) digital stories combining video, audio, still images and music that reveal patients' stories in a unique way. They:

- can highlight gaps in the system
- can reveal near-misses and form 'free learning opportunities'
- promote healing and reconciliation
- can allow patients' and carers' (and professionals if appropriate) voices to be heard
- can carry forward stories that might otherwise be lost (like Fred's)
- are created in a spirit of collaboration and partnership
- are intended to touch hearts, thereby reinforcing the notion of patients at the heart of care.

'There are two reasons we tell stories, to entertain and to teach.'

Patient stories have been recognised (Greenhalgh and others) as making a significant contribution to understanding the patient experience; they acknowledge the patient's own areas of expertise, i.e. his or her own life and unique experience of illness. Further, research on public perceptions of the NHS (Page, 2004) reveals that patients care much more about being treated with dignity and respect than they do about mortality rates.

The Patient Voices programme aims to capture some of the unwritten and unspoken stories of ordinary people so that those who devise and implement strategy, as well as clinicians directly involved in care, may carry out their duties in a more informed and compassionate manner. We hope that, as a result of seeing the stories, patients, their carers and clinicians may meet as equals and work respectfully together for the benefit of all.

'One of the hardest things in life is having words in your heart that you can't utter.'
James Earl Jones

References

Greenhalgh, T., and Hurwitz, B., (1999) Why study narrative? *BMJ* 318:48-50 (2nd January 1999)
Page, B. Mori Research Institute Director (2004) 'What they really want' *HSJ* (8th April 2004).