

# MSc in Lifelong Learning

## Patient Voices: an investigation into improving the quality of healthcare using digital patient stories

Submitted for the module

### PROFESSIONAL PRACTICE: TEACHING AND LEARNING FOR QUALITY

(Part of the University of Ulster's MSc in Lifelong Learning)

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# Introduction and rationale

*'All too often quality is mistaken as the game itself rather than a measure of how the game is going.'*

Ray Watson. April 28, 2005. Online discussion.

How shall we measure the quality of healthcare? This question has vexed many people in recent years. Attempts have been made in the United Kingdom, the United States and elsewhere to discover the most appropriate ways of determining success in caring for patients, whoever and wherever they may be. And since we are, all of us, destined to be patients at some time, the quality of healthcare is of concern to everyone.

Patient safety is high on the agenda of healthcare providers, governments and the media. In the UK, concerns about safety and the quality of patient care have led to the development of what is referred to as 'clinical governance'. Clinical governance is now the primary means through which NHS bodies discharge their statutory duty of quality.

In his Forward to a special issue of the *Journal of Clinical Governance*, to be published in August 2005, Deputy Chief Medical Officer, Professor Aidan Halligan writes:

*'If you pause and think of the NHS, the chances are that you will think of service and people, rather than structures and processes. Healthcare pervades the media and often our personal lives. Mention of it captures attention and makes the audience linger. We respect its practitioners and voluntarily place our lives in their hands. Clinical governance reflects this privileged relationship and seeks to assure our **sacred duty of trust to patients**. It does this by providing "a framework through which NHS organisations are accountable for continually improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish."*

One of the ways that Professor Halligan (and others) espouse as a means to understanding the needs of patients is that of telling – and listening to – stories. Patient stories have come to form a key part of patient-centred care and, assuming the name of 'narrative-based medicine' to support the more deeply-entrenched 'evidence-based medicine' in a balanced approach to healthcare.

The rest of this paper will look at one approach to improving the quality of healthcare by presenting patient stories in a new way – one that aims to reflect the sacred duty of trust.

# The wider context of quality

*'Quality is everybody's business.'*

*'The moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in the shadows of life - the sick, the needy and the handicapped.'*

Hubert Horatio Humphrey, US Vice President (1911-1978)

Quality is a fundamental goal in the provision of health and social care. Quality, according to Paul Stanton (2004) protects individual patients and local communities as well as clinicians, inter-disciplinary teams, the reputation of professionals and organisations. In doing so, the entire financial well-being and the good name of the NHS is also protected. Most importantly, as Stanton reminds us, quality services can reduce levels of human suffering, professional stress and the deep drain on valuable resources arising from clinical negligence or systemic error.

*'The NHS Plan sets out our ambitions to create a patient-centred NHS. Our vision is to move away from an outdated system towards a new model where the **voice of the patient is heard** through every level of the service, acting as a powerful lever for change and improvement. Our goal is to move away from a paternalistic model of decision making towards a model of partnership, whereby citizens have a greater connection with their local services, and have a say in how they are designed, developed and delivered.'*

Department of Health, 2001

## Clinical Governance and the NHS

*The NHS Plan* (2000) sets out the Department of Health's vision of a health service that is modern, flexible and designed around the needs of patients. Clinical Governance is the vehicle for establishing the systems, structures and policies to ensure that this vision of the NHS can be delivered safely, appropriately and in response to the needs of local people. Paul Stanton (2004) offers this definition:

*'Clinical governance defines the values, the culture, the processes and procedures that must be put in place in order to achieve*

*sustained "quality of care" both within and between the organisations that make up the NHS.'*

Clinical governance is a framework that brings together a range of quality improvement activities that seek to safeguard high standards of care. It strives to ensure that patients are placed at the centre of care delivery and promotes a learning culture.

In this respect, clinical governance is closely aligned with international trends in the delivery of healthcare. The Institute of Medicine's report on medical errors, *To Err is Human*, highlighted the need to build safer health systems. The Report of the Bristol Inquiry in the UK made a number of recommendations arising from the needless deaths of a number of children at the Bristol Royal Infirmary. *An Organisation with a Memory* also recommends steps to be taken in order to learn (and improve) from adverse events in healthcare.

In a 'risk-rich' industry such as healthcare, the safety of patients is highly prized. The NHS, along with other healthcare systems, seeks to identify and minimise risks to patients and staff; it does this by encouraging people to learn from mistakes and make the necessary changes to prevent similar mistakes occurring in the future. Sir Liam Donaldson (2005), the Chief Medical Officer, reminded an international audience of people involved in improving the quality of healthcare, that what is most often needed is a change in culture to one that learns from its mistakes.

Quality in the health service is often measured against targets and budgets. New initiatives proliferate and quality improvement forms a huge part of the modernisation agenda – and takes a huge part of its budget. Fellow student, Ray Watson (April 28, 2005) commented in an online discussion that:

*'Services have pumped lots of money into quality measures, but have failed to pump money into the key parts of the organisation, advocacy, person centred plans, community supports. So what exactly are they measuring?'*

Perhaps they have not paid attention to Demings' injunction to 'measure what counts' rather than 'counting what can be measured'.

According to nurse and fellow student, Rita Devlin, we need to 'develop a method of assessing quality related to how academic knowledge gained has improved the nurses interactions with and care of the patient.'

My response to these postings was:

*'I would suggest take that one step further and attempt to find out about the PATIENTS' experience of care - which is what all the healthcare quality initiatives SAY they are about. So whether it's Clinical Governance or Essence of Care or Pursuing Perfection or the Expert Patient Programme or any one of the hundreds of other*

*initiatives, as I see it, the holy grail of all them is to improve the quality and safety of care for patients.'*

Following in the footsteps of many others before me, I would like to suggest that quality in the healthcare industry may reasonably be assumed to cover two aspects of care, reflected in the twin foci of clinical governance:

- the assurance of safe care
- the transformation of the patient experience.

These two elements are not separate but are closely inter-related. Operating together, each reinforcing the other, they characterise what we would call quality care. Such a state will only be arrived at through a culture that acknowledges the existence of a system in operation – where individuals can learn from mistakes in a supportive, just, blame-free environment that encourages a culture of learning.

The Department of Health (2000) comments that ‘...people may come and go, but an effective safety culture must persist.’ Part of developing a safety culture is working in partnership with patients and carers. In his book *The Resourceful Patient*, J. Muir Gray (2002), reveals not only that patients have much to teach clinicians, but also that informed and engaged patients are more likely to be compliant with medication regimes and, therefore, more likely to get well.

Fundamental changes to the NHS, intended to emphasise the patient’s central role in the design and delivery of services, acknowledge that patients and professionals both have their own areas of knowledge and expertise and need to work together. Angela Coulter of the Picker Institute (2001) has suggested the following areas of expertise:

- |                         |                         |
|-------------------------|-------------------------|
| • Patient               | • Clinician             |
| • Experience of illness | • Diagnosis             |
| • Social circumstances  | • Disease aetiology     |
| • Attitude to risk      | • Prognosis             |
| • Values                | • Treatment options     |
| • Preferences           | • Outcome probabilities |

Despite the difficulties in identifying ‘common definitions and conceptual models that underpin notions of patient-centredness... amidst the plethora of policy initiatives and patient-centric phrases’ (Gilbert, 2002), Sir Ian Kennedy (2003), now Chair of the Healthcare Commission, describes how a mature culture will:

*‘settle on sharing power and responsibility, on a subtle negotiation between professional and patient as to what each wants and what*

*each can deliver'. The currency of this exchange is information.  
The mature culture will recognise the value of information within a  
patient-centred system.'*

However, we know that it is difficult to accept change, even when this results from new learning. Galileo Galilei reminds us that:

*"We cannot teach people anything. We can only help them  
discover it within themselves."*

## Clinical Microsystems and the wider agenda

Systems theory is one way of helping to make sense of the complexity and diversity of healthcare systems that make joined-up thinking so difficult. Understanding something of the behaviour of what Nelson et al (2003) refer to as 'clinical microsystems' may make it more likely that we can effect changes that will, ultimately, make a difference and improve the quality of care.

In a book called *Intelligent Enterprise*, Quinn (1992) discovered that a number of world-class, highly successful organisations had focused considerable attention on the interface between the organisation's core competency and individual customer needs. This is the 'frontline' where the delivery process happens. 'Gemba' is the Japanese word that describes this crucial interface: the place where customers (or patients) come into contact with the services offered. Gemba is where the important work of the organisation happens.

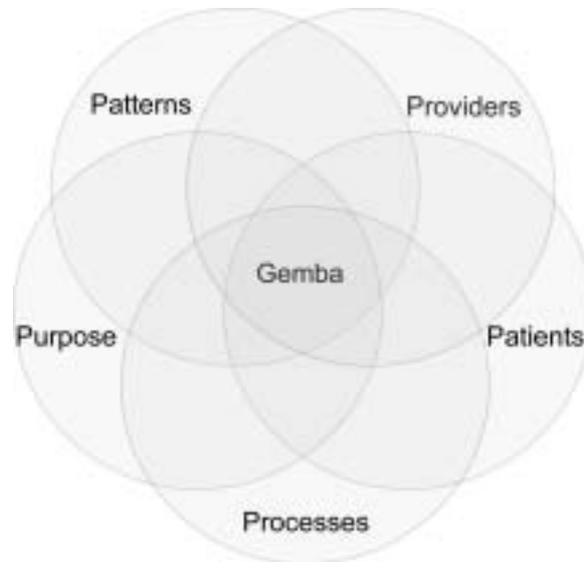
In contrast to traditional models of organisations and care, which are mechanistic and predictable, clinical microsystems are complex adaptive systems (CAS) consisting of five Ps:

- purpose
- patients
- providers, i.e. clinicians
- processes, i.e. tests, treatments, scheduling, etc
- patterns, including both clinical outcomes and culture.

The following diagram, originally developed for a degree level online module for nurses (Hardy, 2004), was intended to convey the complexity of the relationships between the original four Ps (patients providers, processes and patterns) and to illustrate graphically how all these elements must be present in any healthcare quality initiative. It has now been updated to include the fifth P, Purpose.

The overlapping areas between the component Ps represent the relationships between the elements of the clinical microsystem. As more components overlap, the complexity of the relationships increases; this is represented by the density of the shaded areas in the diagram.

Similarly, as more Ps are introduced to the model, then the total number of relationships within the quality system increases factorially.



Adapted from Hardy, 2003

These elements interact with one another in more or less unpredictable ways; and since each clinical microsystem is part of a larger organisation that is, in turn, embedded in a particular community or environment (cultural, regulatory, etc), the whole system and its constituent parts are constantly evolving and adapting. As *any* change to any of the elements will affect *all* parts of the system, it is clear that collaboration, co-operation and partnership working will be critical to the success of a microsystem and to the quality of care it provides. It is particularly important to note here that the patient is an integral part of the system, and not external to it.

Clinical governance and clinical microsystems offer helpful and complementary frameworks through which to examine the interaction of patients, providers, processes and patterns and clarify the values of quality healthcare. These two quality frameworks have been particularly influential in my thinking about improving the quality of healthcare and together offer enormous potential to those who are serious about providing excellent patient care.

# Pilgrim Projects' view of quality

*'At Pilgrim Projects we strive to see quality through our clients' eyes.'*

Tony Sumner, director

Pilgrim Projects is a small educational consultancy specialising in the development of open, distance and e-learning materials within the broad context of work-based learning.

Providing flexible educational opportunities aimed at helping people improve their working practices is the core of our business. All our work is, therefore, involved in improving quality in the workplace through increasing the capacity of the workforce, by helping them to develop more appropriate skills, knowledge and attitudes.

Most of our work, therefore, has at least two audiences and often a third:

- the client (who pays our invoices!)
- the target audience (the 'learners' at whom the programme is aimed)
- the patients or students or customers of the target learners (the beneficiaries of learning).

We are passionate about education and learning and about helping people learn to learn; we encourage frequent reflection and offer many opportunities to try out new skills and ideas at work.

Over the years we have built up a reputation for successfully managing the development of large, complex projects within short timescales. In recent years, we have focused on the health sector and have undertaken a number of large projects related to improving the quality of healthcare.

Quality both underpins and arises from our strategy of relationship marketing. As a small consultancy, we rely on repeat business – and we are well aware that we are only as good as our last job. We therefore rely on our ability to build good and strong relationships with our clients. We know what our customers want because we know our customers well; this means that we are more likely to give them what they want.

Part of our role is to help clients determine what constitutes quality. Much is to do with expectations, but also we are aware of the need to measure what counts rather than counting what can be measured (Deming). Unfortunately, most quality systems do just the opposite of what Deming intended.

What counts for us is customer satisfaction; this naturally includes student and patient satisfaction as well. As a small company, we depend on the quality of the products and

services we offer, and not on the thickness of our quality manual. We cannot justify investment in ISO 9000 accreditation, or IIP or even IAQ. But we do strive for excellence in every area of our work.

More than 25 years' professional experience covering:

- software development and quality assurance
- devising and implementing customer support systems
- education and educational publishing
- developing flexible learning materials in both text and electronic format
- presenting information
- consultancy in healthcare quality improvement

has forced us to look closely at what determines quality. While we can guide expectations and therefore, to some extent, predict the level of satisfaction, this is ultimately subjective.

Evaluating quality is an elusive proposition in work such as ours, where there are few quantitative measures. There are a number of quality measures we could use, such as:

- the number of proof-reading or typographical errors in the final manuscript
- the value for money represented by the project
- degree of adherence to SENDA or DDA guidelines
- the extent to which materials cover a particular syllabus
- accuracy and timeliness of content (judged by a subject expert)
- success in meeting deadlines
- number of learners who successfully complete a programme
- number of hits on a website
- satisfaction questionnaires
- amount of repeat business from clients.

Many of these are simplistic measures of quality, and we believe we offer more than simply meeting deadlines in a formulaic manner. Because we work on a project-by-project basis, it almost goes without saying that our aim is always to do an excellent job, on time and within the budget.

Discussions with clients are intended to reveal what is important to them, or how they will evaluate or measure quality. Over the years, we have come to recognise certain characteristics of successful projects and successful working relationships; these also reflect

what clients say they value about working with us. We believe that mindful awareness of these characteristics helps us to offer a quality service and to develop quality products.

These are some of the things that have been said about us by people we work with – both clients and colleagues.

- integrity
- excellence
- imagination
- collaborative and partnership working
- ethics
- flexibility
- awareness of our strengths – and our limitations.
- respect
- passion
- creativity
- attention to detail
- understanding clients' needs
- sense of humour
- the mark of true professionals

<http://www.pilgrimprojects.co.uk/quotes.htm>

Our conclusion is that quality is completely subjective.

Paul Stanton, former head of the European Social Fund Unit at Anglia Polytechnic University, determines quality in education in large part by whether the learning experience is 'delightful'. Here is what he said about Pilgrim Projects:

*'I have employed Pilgrim Projects over a number of years and in relation to a variety of projects. The things I value most about them as a company are their commitment, their flair and their consistent attention to quality, allied to a value-based approach to business that enables me to feel absolute trust in their integrity and their willingness to go the extra mile (and often miles) in order to ensure that our work together produces excellent and imaginative outcomes.'*

Paul Stanton, Director of the Board Team, NCGST, NHS Modernisation Agency

In our attempts to live up to such high praise and to continue to enjoy an excellent reputation for the development and production of high quality learning materials, we aim always to find the best fit between what the client wants, what the target audience needs and the most appropriate medium for delivery.

We enjoy excellent relationship with all our clients and colleagues, who value the supportive and pleasant way in which we work, founded on our values of respect, honesty and openness. We aim to ensure that all our professional interactions are conducted in a physical and psychological environment that is pleasing and calm and that values and supports the contributions made by every member of the team. We feel that this approach contributes

significantly to the quality of the work that is produced and, ultimately, to the quality of the final product.

Our own quality standards are rigorous, drawing on our respective backgrounds in software quality assurance and educational publishing and relying on a number of processes that have been developed as a result of our experiences within these industries. As members of the British Learning Association, we are also bound by their Code of Conduct (see Appendix 1).

We use the tried and tested PDSA or Action Learning Cycle on a regular basis and, as reflective practitioners, we aim to learn something from every project by keeping a project log in which we write down 'lessons learned'. We can then make necessary changes to improve the quality of the next project.

When these quality procedures are added to our commitment to the development of reflective practitioners, and the promotion of learning cultures and learning organisations, the combination is a powerful one resulting in robust and high quality learning experiences. The materials we develop contain frequent invitations to reflect often on what is going on in the learner's place of work and what the impact of changes might be. There are many different ways of doing this, that can help to promote a culture of learning but, unless people want to learn, no amount of quality measures or procedures will be successful.

Equally, if a programme that we have developed causes just one person to discover something about him or herself that was hitherto unknown, or make changes for the better, we would feel that we had made a difference. Such a difference is likely to have a 'ripple effect', especially in the field of healthcare, affecting many lives and not just the one. Small changes really can make a large difference.

At this point, the Pilgrim Projects quality agenda aligns with that of the NHS (and other healthcare systems). We want to make a difference. We want to be part of creating a world in which people care for and respect one another, and where patients receive the safest and best quality care on an equitable and just basis.

# Choice of innovation

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

Pascal

*'Culture of the mind must be subservient to the heart.'*

Mahatma Gandhi (1869-1948)

NHS Primary Care Trusts (PCTs) have what Professor Aidan Halligan, the Deputy Chief Medical Officer refers to as a 'sacred duty of care' to patients. These organisations are at the forefront of achieving the Government's aims, set out in *The NHS Plan*, for a 'modern, flexible and patient-centred NHS'. Members of the Board Teams of PCTs are responsible and accountable for assuring the quality of NHS Trust services.

## Developing quality – identifying the need (the purpose and the people)

Working in partnership with the National Clinical Governance Support Team over the past three years has revealed a lack of confidence among PCT Board teams in the degree of engagement with the patient experience and patient and public involvement elements of clinical governance (Stanton, 2004). The Healthcare Commission (formerly the Commission for Healthcare Improvement and Commission for Healthcare Audit and Improvement) view the patient experience as central to the delivery of excellent, patient-centred care and 'the patient experience' has been one of the strongest targets for Department of Health improvement initiatives.

Despite this encouragement, and despite a widespread recognition of the importance of the patient experience, low scores were common across the board in a survey conducted with PCT Board members to identify their level of engagement with clinical governance. According to Stanton (2004):

*'The failure to measure and actively review the key determinants of the quality of the primary care patient experience reflects the pre-occupation with finance and quantitative targets that characterise the performance culture within which PCTs are required to operate. Nevertheless, most PCTs were keen to embark on the process of defining and tracking the component elements of quality as they map against the experience of their patients – and they recognise that (in the light of commissioned services) this needs to be done in relation to the entire 'patient journey'.*

Further, he reminded PCT Board members that 'CHI (2003) will put patients' experiences, including clinical outcomes of care, at the centre of its concerns and analyses.'

While continuing to work with the NCGST to find ways of helping PCT Boards embed clinical governance in its truest sense, I was at the same time searching for an 'innovative' way to embed the stories of patients and carers in an e-learning module on clinical governance that I had been commissioned to write for the UK Health Education Partnership.

In his book *The Medici Effect*, Frans Johansson (2004) calls the kind of happy coincidence that occurred next 'an intersection'.

I happened to mention to an old friend my search for a vehicle to convey the feelings and experiences of patients and carers in a way that would touch the hearts of nurses, managers, clinicians and others striving to improve the quality of health care. Once a school teacher, but now a technology advisor to Suffolk Schools, Brendan Routledge offered to show me one of the 'digital stories' that he had been developing with school children. Brendan refers to these short clips that use video, audio, text and music to convey individuals' own stories in a unique way as 'powerpoint for the soul' (Routledge quoted in Davitt, 2004)

I watched, with tears in my eyes, and realised that this was exactly the format we had been searching for to touch the hearts of busy managers and healthcare leaders.

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 journey is, of course, only one part of a person's life. It is easy to forget that all human beings are subject to birth, old age, disease and death and these are stages in the human journey when many people require care and become patients.

Here are two views of patient journeys: one from a doctor and one from a patient:

*'Patients make two types of journey – disease journeys and healthcare journeys. The disease journey progresses through diagnosis to treatment which leads to cure or lifelong co-existence. The healthcare journey is punctuated by events like consultations, operations and prescriptions, and each journey is unique.'*

J. Muir Gray (2002) author of *The Resourceful Patient*

*'There's a phrase that's very fashionable at the moment, I think, in health care which is talking about 'the patient journey' and all too often, I think, when a healthcare team sits down to, as they say*

*'map the patient journey', all they're doing is listing the encounters that the patient has with the healthcare system.'*

Ian Kramer, patient and storyteller (2004)

Patient stories provide a way of approaching a patient's condition holistically. According to Greenhalgh and Hurvitz (1999), the study of narrative offers much to both patients and healthcare professionals in that they are:

- often memorable
- are grounded in experience
- encourage reflection.

The patient story has a particular resonance with one of the fundamental principles of clinical governance – patient centred care. Patient stories can – and do – contribute to the patient-centred agenda. They can challenge thinking about existing structures, processes and outcomes by opening up new possibilities and re-vivifying key values.

The skills of story telling, and their ability to evoke sympathy and compassion have much in common with the core clinical skills of 'listening, questioning, delineating, marshalling, explaining and interpreting' (Greenhalgh and Hurvitz 1999). Just as the storyteller uses narrative skills to connect with an audience, so clinical skills provide a means of 'mediating between the very different worlds of patients and health professionals'.

Professor Aidan Halligan (2005) reflects that

*'influence is achieved less through analysis, which alters thinking, than through offering a truth, which affects feelings. At the core of all the work we have carried out over the years has been the principle of 'holding up a mirror', getting groups and individuals to agree that the image reflected is a truth that they can relate to, and helping them to move from where they are to where they want and need to go.'*

Members of Primary Care Trust Boards are busy people, already struggling with the amount of information they are expected to absorb and deal with. Nurses and Allied Health Professionals who are also studying are under enormous pressure. However, they are human, and likely, at some stage, to be patients too. We needed to find a powerful and innovative way of conveying our message concisely and in such a way that people would be touched profoundly by it.

Our idea was to use new technology and the digital story format to present patients' stories in an attempt to improve the quality of healthcare by:

- allowing voices of patients and carers to be heard
- educating healthcare providers at all levels about felt experience of patients and carers

- educating patients and carers affected by long-term conditions.

There is a body of evidence to suggest that informed, involved and engaged patients are more likely to benefit from healthcare interventions. One of the aims of the Department of Health is to increase both the amount and quality of patient information that is available.

*'The quality of the patient experience can be improved by ensuring that patients (and their own carers):*

- are actively involved in the process of diagnosis
  - are full and active partners in the identification and management of risks
  - make informed decisions about treatment options
- see themselves as active and key partners in their own care.'*

Clinical Governance Bulletin, December 2001

Since, as the *Talmud* reminds us, 'we see things not as they are, but as we are', it seems all the more important to encourage healthcare providers to step into the shoes of the people they aim to serve.

## Developing quality – meeting the need (the product)

With all of this in my mind, the choice of the Patient Voices videos as an effective quality improvement measure was uncontested as an appropriate way to meet the needs of our various audiences. The videos are intended to be shown to healthcare practitioners and managers to give them an opportunity to see healthcare through the eyes of patients but ultimately they are intended to benefit patients and all who receive and provide care.

Placing patients firmly at the very heart of health care, their stories could be used to reinforce the values of clinical governance and to illuminate the twin themes of assurance and transformation.

*'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.'*

Hardy, 2004a

And so we began to record the stories of patients and carers. Treading a little carefully at the start, and with limited funding, our first two storytellers were drawn from the Department of Health's Expert Patient Programme and from the Clinical Governance Support Team's Patient

Experience team. We briefed them carefully as to what we wanted. Both were articulate, experienced speakers, accustomed to telling their stories. We developed a storyboard and briefing notes (Appendix 2), together with a consent form (Appendix 3), designed to protect them as well as us. They were asked to think about the kind of music they would like and to bring or send photographs. Finally, we asked them not to script their story, but to prepare it so that it could be told in about three minutes.

The first two storytellers spoke afterwards about the therapeutic benefits of telling their stories – this was an ‘added value’ feature that we hadn’t anticipated. We had, however, foreseen the possibility that telling painful stories might cause some distress and it was decided that a trained counsellor should always be present during recording sessions. We have continued this practice and have received a number of favourable comments about the sensitivity and concern of the filming team.

The stories were duly edited and pictures and sound were added before the first cut was reviewed by

- the storytellers
- Paul Stanton, who had commissioned the work
- two colleagues from the CGST
- myself
- the film-maker.

We watched each clip and assessed it for

- overall impact
- quality of the sound and the image
- emotional impact.

The storytellers were asked how they felt upon seeing their stories edited and whether there was anything else they wanted to add. In both cases, they were very happy with the results and felt that their stories had been thoughtfully edited.

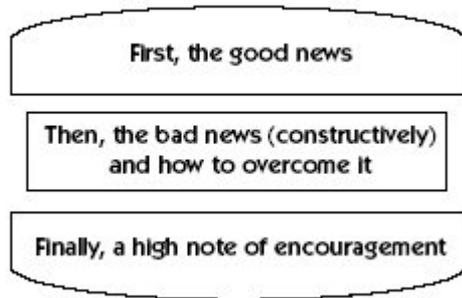
## Developing quality – meeting the need (the process)

The actual development process of the Patient Voices videos reflects the process we have used for many years to develop educational materials. Here are some of the main elements of the process:

- know the purpose and aims of the project
- know the audience

- work with people who excel in their line of work (whether this is graphic design, writing or film editing)
- be aware of people's strengths (and weaknesses) and offer praise liberally
- establish clear responsibilities and roles
- involve and work closely with subject experts
- prepare schedules and project plans
- review and gain approval at significant developmental stages
- check and check again
- communicate regularly with all members of the project team, whether they are clients or 'suppliers'
- encourage autonomy through adequate support and regular feedback (using the feedback sandwich as illustrated below!)

The feedback sandwich – go large on it!



Hardy and Sumner (2001)

These working precepts are not dissimilar to those proposed by John Adair and others. Indeed, we also follow his guidelines for Action Centred Leadership in terms of the functions we perform when managing and leading projects:

- Planning - seeking information, defining tasks, setting aims Initiating - briefing, task allocation, setting standards
- Controlling - maintaining standards, ensuring progress, ongoing decision-making
- Supporting - individuals' contributions, encouraging, team spirit, reconciling, morale
- Informing - clarifying tasks and plans, updating, receiving feedback and interpreting
- Evaluating - feasibility of ideas, performance, enabling self assessment

<http://www.johnadair.co.uk/>

I regard it as my role as a manager to be able to hold both the bigger picture and the detail of a project in my head at the same time; I believe this is also part of the creative process, for the large picture is only composed of many smaller elements.

This means paying close attention to detail, which we do through the involvement of critical friends and subject experts and by assiduous checking at all stages of the development process. In this way we are able to ensure error-free, up-to-date, accurate and relevant materials that are suitable for their purpose and contribute to the overall picture.

Similarly, it is my long-held view that the process is as important as the product. The development process must embody all the values that we are trying to convey through the materials we develop or, in this case, through the videos. Only by working in this way can we maintain integrity and an internal consistency and produce something which fulfils its potential.

Thus, after the first round of comments on the rough cuts, a number of small but significant changes were agreed. The most important of these was to include several screens containing quotations of certain of the words spoken by the storytellers, to emphasise the points they were making. We carefully picked out which words were to be included for maximum impact.

With these changes complete, the videos were ready for their first showing.

We have always worked collaboratively and have sought to develop relationships of trust and openness with both clients and suppliers. In addition, we have regarded as essential the embodiment of the values of clinical governance (respect, justice, equity and trust) in all the work we do for the National Health Service and we attempt to observe ethical procedures at all times. Our concern to provide a different kind of learning experience for trust board members and busy nurses could not put patients at risk, hence our careful rendering of an explanatory protocol and a consent form, with equal responsibilities and privileges on both sides.

Many people want desperately to share their stories but find it incredibly painful to do so. A trained counsellor attends each recording session in case emotional support is needed, but most storytellers comment on the therapeutic, even cathartic, nature of the experience. We value the carer's contribution and time so, generally, recordings take place in the storyteller's home, but if travel is desirable, expenses are reimbursed on the day; carers without other income are paid for their time.

Monica Clarke (2004), a carer, and a Patient Consultant with CGST, said

*'I was so pleased that I had this opportunity to let others hear my experiences. If what I and my colleagues, who also told their stories, had to say helps improve how other people in our position are treated, then it will all have been worthwhile.'*

# Evaluation and analysis

*'Culture of the mind must be subservient to the heart.'*

Mahatma Gandhi (1869-1948)

*'Knowing ignorance is strength; ignoring knowledge is sickness'.*

Lao-Tzu, philosopher (6th century BCE)

Since the first Patient Voices videos were first shown in the spring of 2004, embedded in a powerpoint presentation to a PCT Board, we have asked for feedback from the people who have shown them. Several themes have emerged, together with what has been affectionately dubbed 'the pin-drop effect', describing the moment of hushed silence that invariably falls at the end of each story. One of the earliest showings was at a conference entitled 'Narratives and Action'. The results of the conference evaluation is included here as Appendix 6. In brief the stories were described as 'powerful', 'excellent and emotive', 'a real eye opener'.

The stories have been well-received and applauded for their freshness, brevity and power. We have been approached by a number of people, both within and without the NHS, requesting permission to show the videos as part of training programmes. Most importantly, perhaps, Pilgrim Projects were invited to submit the videos to a Film Festival to be held as part of the Clinical Microsystems Annual Invitational Conference where they were viewed by an international audience of healthcare quality improvers. Not only did they win the prize for the best film in their category, but they also won The People's Choice award for the best film of the conference. They were touted as being 'original', 'unusual', 'powerful', 'succinct' and 'professional'.

Two more formal, but small, studies have been carried out:

- a questionnaire was sent out in December 2004 to nurse and AHP students studying an online course on clinical governance, asking for their views about the different ways stories had been presented in the modules
- a questionnaire was sent to healthcare managers, educators, quality improvers and others who have used the Patient Voices videos.

These questionnaires are attached as Appendices 4 and 5.

Although the number of students following the online course was small, the response rate was good (six students out of eight responded) and indicated that learners preferred the digital story format to either written or audio. Learners felt that the videos presented patients' stories in an unusual and appealing manner and that they helped to illuminate the material they were studying.

The second questionnaire was sent to 35 people in April 2005. 14 responses were received and these are broken down into the following groups:

Two storytellers

One nurse (organ donation co-ordinator)

Three patient and public involvement managers

One change facilitator

One PA

One film editor

One Programme Director, National Clinical Governance Support Team

Two Associate Directors, National Clinical Governance Support Team

One Associate Director, Coronary Heart Disease Collaborative

One university lecturer

A summary of responses is included as Appendix 7.

## Main themes

The Patient Voices videos have been shown in a number of **contexts**, including:

- presentations to NHS Trust Boards
- national and international conferences on quality, patient safety, patient focussed care,
- Intensive Care Units as part of educating staff about organ donation
- online modules related to clinical governance and improving the quality and safety of care
- part of a training module on Fostering Dignity and Respect in Health settings with local Trusts
- staff training and development days
- Patient and Public Involvement/improvement education and training events.

Here are some of the things people said **they particularly liked**:

- simple and accessible
- succinct and clear
- authenticity
- powerful and moving
- highlighting of key points with words on dramatic black background
- ease and flexibility of use (can be embedded in PowerPoint presentations)
- professional and well-made

- brings patients and carers into the boardroom
- ability to elicit a strong emotional response
- puts quality of care right at the centre of the debate, where it ought to be.

**But they didn't like:**

- the size of the videos (when embedded in Powerpoint presentations)
- the volume balance between music and speech
- repetition of title and 'lead-in' sequence if viewing a number of the stories sequentially
- the use of the same or similar (stock) photos in many of the stories
- the music (in some cases – others applauded the choice of music) NB the genre of music is chosen by the story teller and, in most cases we felt that their choices were very apt.

One respondent commented that perhaps the pendulum had swung too far in favour of the patients, to the detriment of staff.

In terms of the **effect** the videos had on people, the word 'powerful' turned up several times, as did the term 'thought-provoking'. Two people were embarrassed by the quality of services and staff that led to the stories. One person was reminded that she missed having direct contact with patients and another of his own experiences within the healthcare system! Several people mentioned feeling sad or having their eyes opened to the experiences of others.

Audiences have also been profoundly affected. Respondents spoke of 'silence filling the room'; 'the pin-drop effect', 'recognising that involvement doesn't have to be complicated and small changes can make a difference'; 'reactions range from "elight at the fact that Patient Voices offers people a chance to have their say to anger at the way some of the storytellers have been treated"'. Even long-term clinicians welcomed some insight into the patient experience.

Most respondents felt strongly that the Patient Voices stories could help to promote **greater understanding** between clinicians, managers and patients and carers. They welcomed the opportunity to work more closely with patients and carers to examine what is really going on in the health service and to consider what changes could be made that would benefit everyone. One respondent sums up the thoughts of many:

*'It is rare that one is given a real insight into the patient experience I felt these short clips did just that. Real understanding comes from experiencing as near as possible to first hand and I think these stories are a real way of making this possible.'*

A number of people regarded them as another useful tool in the armoury to be used for education and training of clinicians and others involved in healthcare. It is not surprising then,

that all respondents were positive about further NHS investment in the Patient Voices programme.

Suggestions for improvement will be considered in the next section of this paper.

The storytellers also found the stories to have their uses. Initially somewhat suspicious, all the storytellers have been completely won over to the notion of patient voices and to the process that creates them.

Storytellers, although acknowledging the emotion and the drain on already stretched resources, commented on the therapeutic value of the telling their stories and the relief at sharing something that must often weigh heavily. All the storytellers have commented on the quiet attention of the film crew and how easy it felt to tell their stories. One early storyteller commented that it was 'better than an hour of therapy'!

It is clear from responses to the survey as well as from anecdotal evidence gathered over the year that the Patient Voices digital stories have had a profound effect on people, both in expected and unexpected ways. We had only been dimly aware of the potential therapeutic value for storytellers, but this seems to be a significant feature of storytellers' experience and one that should be investigated further.

Friere, Gadamer and Socrates before them realised that dialogue is a necessary to facilitate learning and to unravel our own assumptions in order to enable understanding of another's position. This is why, so often in the learning materials I develop, I ask learners to put themselves in the shoes of another: whether it is a customer, a manager, a patient or even, perhaps in the future, a clinician!

I believe that this small research project has demonstrated that the Patient Voices videos can help to improve the quality of healthcare by operating at the highest levels within the health service. They can help to initiate the dialogue and debate that is necessary in order to begin to comprehend another's world. With this comprehension is the beginning of empathy and compassion, which must lie, along with the patient, at the very heart of healthcare.

It has also become clear that the uses for Patient Voices extend far beyond the Boardroom. They have been embedded in several online courses where the experiences of patients have formed an important part of the educational experience. They are used in training and education sessions and shown at both national and international conferences. Within weeks of the completion of the first stories, members of the Expert Patient Programme realised that the stories could travel more easily than they could: they could be shown at national and international conferences reducing the wear and tear of travel on people who are, by definition, already ill. Ian Kramer, one of the first storytellers, presented them at a conference about narrative and healthcare, where they were greeted with enthusiasm.

The Patient Voices videos were presented at the Clinical Microsystems European Festival in March, 2005 and in the USA, won two awards at the 2004 Dartmouth Clinical Microsystems

Film Festival, including best overall entry. Paul Barach (2004), Medical Director of Quality and Safety at Jackson Memorial Hospital and Associate Dean of University of Miami Medical School, commented: 'These remarkable short vignettes are the most powerful stories I have seen on these topics. Elegant, short and yet they deliver a real punch. I believe they could be very useful as an educational tool for medical students, registrars and faculty. They might help to ensure greater patient safety awareness as well as going some way towards improving the quality of the patient experience. They might also assist in providing encouragement to people dealing with long-term conditions.'

## Room for improvement

The results of the survey suggest a number of improvements that might enable the Patient Voices videos to have an even greater impact.

- Offer a better balance of stories – not just rare and unusual conditions and events, but also some more common experiences for people to relate to.
- Sort out remaining technological problems around the use of the videos in powerpoint.
- Consider providing 'sets' of stories, removing some of the introductory sequences to provide a better flow of stories from one storyteller.
- Produce some 'good news' videos.
- Produce some 'clinician' stories.
- Increase the variety of photos used.
- Make links between the videos and 'the big issues' (such as long-term conditions) for CEOs.

Many of these suggestions reflect our original ambitions for the programme, which had to be curtailed when funding was reduced as a result of changes in the Modernisation Agency.

There is always room for improvement. However, I believe that we can be justifiably proud of the impact of Patient Voices to date, given their relatively small exposure.

I will go on to look at some of the implications of change in the next section.

# Implications for change

*'Small changes, big difference...'*

## Quality costs....

It sometimes seems to me that quality is equated with cost. If you can or choose to spend money, it is possible to be approved or authenticated or endorsed as a quality organisation. If you want to make changes that are likely to have a significant impact, they are likely to incur a cost. Thus, one of the most important implications of all that has been written here is cost.

Many of the plans that were hatched for the Patient Voices programme were put on hold because of the enormous changes taking place within the Modernisation Agency. The original intention had been to produce a DVD containing a sizeable library of stories told by patients, carers, clinicians and managers, depicting experiences of the health service from all angles. This resource was then intended to form part of a training pack that would include:

- notes about the videos and the storytellers
- suggestions for ways of using the different videos (highlight particular issues for each video)
- illustrations and quotes of how people have used them to date, especially with different audiences
- questions and other resources to stimulate debate.

It may still be possible to do this.

Although the reception and impact of Patient Voices has been tremendously encouraging, there is no question but that it could be enhanced in a number of ways.

We have been extremely satisfied with the ways of working together that have developed between Pilgrim Projects and the other people involved in the project and so many of the changes are relatively minor, at a technical level.

Problems with technology have dogged the footsteps of Patient Voices, from the first time it was decided to show them within PowerPoint presentations. While there are extremely valid reasons for doing this (they can be seamlessly integrated with presentations to Board Team members), the quality suffers considerably. This is particularly painful at large conferences where people at the back find it almost impossible to hear what is being said.

This is another compelling reason for developing a DVD with high- AND low-resolution versions of the stories so that people can choose which to present.

At a practical and operational level, this is a new medium for us to work in, with a more heavily sub-contracted development methodology than is customary for Pilgrim Projects. In addition, this was a project of an unusually developmental nature (even for Pilgrim Projects). Funding for the project was unexpectedly halted part way through the project. This made us even more aware of the need to develop an appropriate understanding of the development technologies involved in the project at the start so that we could better ensure that:

- no gathered material is lost
- appropriate backups of data are kept
- processes and procedures are documented (thereby ensuring reusability of materials and processes)
- ownership and copyright issues are clarified with each storyteller.

At a slightly higher level, we have always intended to develop a much wider range of stories, to present a wide range of issues and responses. This would address requests for more 'normal' conditions and more 'good news' stories. Clinician's stories were also on our 'wish list', and would, we feel, be particularly appropriate where a clinician has been involved in an adverse incident.

The programme has never been marketed or properly distributed and, given its almost universally positive reception, would benefit from greater exposure.

Technology is developing all the time. We would like to explore new programmes that enable viewers to stop videos, respond to questions or make comments which can be reviewed and reflected upon at a later date. I would like to investigate further the possibility of developing a community of learners and of learning, by encouraging people to feed ideas into the stories.

The development of new and longer stories, perhaps, or at least with more 'chapters', and including stimulus questions to stimulate reflection would add to growing body of experience and knowledge, particularly around transitions and frontiers. Using digital stories as stimuli for discussion, debate and personal reflection could make a major contribution to growing communities of practice, as practitioners debate, from different angle, the issues emerging from the stories.

The implications for large-scale change are enormous, as a result of opening people's eyes to the experiences of patients. However, in order for genuine and constructive change to come about, there need to be some cultural adjustments within the health service, to promote more open and honest dialogue and to be able to discuss emotional responses to patient stories.

I am mindful of one viewer's comments that the pendulum may have swung too far in favour of the patient. It is crucial that clinicians and practitioners are not alienated by what one (thus far, a lone voice) has referred to as 'doctor bashing', but instead are able to share the

experiences of others through this medium. The creation of some clinician stories would help to redress any imbalance.

On the other hand, Monica Clarke, one of the first storytellers, feels that it is 'time for carers to come out of the closet – just like gay men and lesbians.' Her feeling is that the voices of carers and patients have been silenced for too long and that the time has come for them to be heard. The implications of this are profound and far-reaching, offering the opportunity of liberation from silence for some five million people in the UK alone. Patient Voices are a remarkable opportunity for healthcare managers and clinicians to gain a deep understanding of what it means to feel ill, alone, bewildered, powerless, at the mercy of bureaucracy and systems that are inimical to patients.

Ian Kramer (2003), another storyteller, sums up the need for patients and clinicians to travel on the patient's journey together.

*'I think when you're thinking about the journey the patient is making, it is very important to remember that the patient's journey begins at home; if all ends well, it ends at home and that much of the journey is made by the patient at home, or at work, or out there in their lives and on their own. Waking up at one in the morning in a cold sweat of anxiety or having to tell one's family and friends some bad news, all of those things are as much a part of the patient's journey as submitting to an x-ray or a colonoscopy or whatever else it is that might be in store for us. And yet the system doesn't give us any support in those parts of the journey where the healthcare professionals are perhaps not on the spot and are not present. And I think that it would be much more helpful to us as patients, if the healthcare system would think of the journey the way we think of it, which is throughout our whole lives. What we want is to be accompanied on the journey; you can't make the journey for us, but you can be with us.'*

# Conclusion and reflections

*To do things differently, we must see things differently. When we see things we haven't noticed before, we can ask questions we didn't know to ask before.*

John Kelsch, Xerox

If we want to learn how to improve the quality of care for patients and carers, then we must see them clearly and listen to their stories. Patient Voices enable the voices of patients and carers – who have been patient for long enough – to be heard.

The results of my research have confirmed the words I wrote in 2004 as part of a rationale for the Patient Voices programme, and which have subsequently appeared in an article to be published in *the Journal of Clinical Governance* in August of 2005:

*'The Patient Voices stories, created in the spirit of collaboration and partnership, have been shown to:*

- highlight gaps in the system*
- reveal near-misses*
- form 'free learning opportunities'*
- promote healing and reconciliation*
- allow the voices of patients and carers (and clinicians) to be heard*
- capture and share stories that might otherwise be lost .*

*The actor James Earl Jones said, 'one of the hardest things in life is having words in your heart that you can't utter'. Clinical Governance aims to assure the safety and quality of care and to transform existing models and patterns of care in order to realise the values of respect, dignity, equity and trust. In seeking to uphold these values, storytellers are given plenty of information, before the recording session, about what we would like them to do and what they can expect from us.*

*We discuss the stories they are likely to tell, describe the process, give briefing notes and blank storyboards, and deal with questions in a timely manner. We are mindful of issues relating to ownership and copyright, although this is tangled issue that has not been entirely unravelled. As with most worthwhile projects and products, the end result is represents the input of many people. We attempt*

*to respect the contributions of everyone who is involved in the making of the patient voices videos.'*

Hardy and Clarke, 2005

In developing the Patient Voices videos, we have tried at all times to 'walk our talk' and practice what we preach in terms of our personal values and our approach to education and learning.

As a result of carrying out this research, I believe we have been justified in taking the risk that was involved in developing Patient Voices and also that we would be justified in taking the developments to the next stage. On the basis of these findings, I intend to propose that we should embark on a properly phased development programme of:

- creating more patient and carer videos depicting a wider range of more common experiences
- recording the stories of some clinicians
- improving the sound and picture quality of new and existing videos
- producing a DVD and trainers' notes
- continuing to embed the stories in online courses and other educational programmes
- seeking endorsement from the Deputy Chief Medical Officer
- publicising the stories more widely
- exploring the technology to see how patients' stories may be used as part of growing communities of practice and embedded in learning organisations.

Although perfectly capable of standing alone, within the context of a programme of learning, particularly, the Patient Voices videos rest firmly on the 1996 Unesco Report's four pillars of learning for life:

- learning to know
- learning to do
- learning to live together
- learning to be.

The Patient Voices videos offer, to those who wish to look and listen, the heartfelt experiences of patients and carers. They have the ability to change lives and to create a different kind of learning and knowing, such as that described by Roger Bacon (which echo the words of Aidan Halligan quoted earlier in this paper):

*'There are two modes of knowing, through argument and experience. Argument brings conclusions and compels us to concede them, but does not cause certainty nor remove the doubts in order that the mind may remain at rest in truth, unless this is provided by experience.'*

*Roger Bacon, 1268*

By sharing the experiences of patients, carers and clinicians, we hope to bring about a different kind of knowing among healthcare managers, clinicians and all who are responsible for improving the quality of care. This new kind of knowing will be reflected in a change of hearts and minds and from this change it is hoped that greater wisdom and compassion will lead, in turn to the kind of changes in the health service that will embody the 'sacred duty of trust' to patients by placing them firmly at the heart of healthcare.

It is to be hoped that funds will be found to develop the programme as it deserves to be developed.

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The Patient Voices videos can be seen at

<http://www.pilgrimprojects.co.uk/clients/nhsma/pv/index.htm>

and at [http://www.cgsupport.nhs.uk/Programmes/Board\\_Development\\_Programme.asp](http://www.cgsupport.nhs.uk/Programmes/Board_Development_Programme.asp)

# Appendix 1



## Code of Conduct for Organisational Members of the BLA

### Why we have a Code

The Code of Conduct indicates the standards of professionalism expected of a member of the British Learning Association. It sets out, in general terms, the standards and duties, which it is reasonable to expect a member to adopt.

The adoption of this Code is an integral part of membership and provides the basis through which the Association promotes the status of its members and their commitment to quality and good practice.

It is also part of a process by which the BLA seeks to encourage its members to adopt a more formal approach to quality assurance and continuous improvement with the overall aim that members seek onsite verification of their learning services and the achievement of the Association's Quality Mark.

The BLA anticipates that members will have stated policies that follow these principles.

### In providing learning services, members have a responsibility to:

- 1 give accurate details of the service, who it is for and how your organisation commits to quality and good practice for those services. The level and detail of the information you provide should be sufficient so that those with whom you deal on a professional basis can match their needs against the service that you offer. Information should be clearly stated, readily understood and easily accessible.
- 2 maintain customer satisfaction by:
  - a) having feedback mechanisms that elicit the views of your customers, clients and learners
  - b) having a formal customer complaints procedure
  - c) regularly reviewing the effectiveness of your services and implementing improvements based on this review.
- 3 uphold the reputation, the mission and values of the Association and support this actively when the opportunity arises. In your use of the BLA membership logo, members shall agree to the following terms:
  - a) The logo should be used only to show that the organisation is a member of the British Learning Association, committed to the principles of the BLA Code of Conduct
  - b) The logo should not be used in such a way that it implies accreditation of your organisation or of any course or programme that you provide
  - c) Where the logo is used on a website, it should be hyperlinked to [www.british-learning.com/PDF/orqcodeofconduct.pdf](http://www.british-learning.com/PDF/orqcodeofconduct.pdf)

# Appendix 2: Patient Voices protocol and consent form

## Patient Voices

### *Protocol for story tellers*

#### Respect

Storytellers and their stories will be treated with respect at all times. We will try to interpret accurately the intentions of the storyteller and to preserve the integrity of the story. We will always try to be flexible and sensitive to the needs of storytellers with regard to the place and pace of recording.

#### Consent

We will not record a story unless we have prior informed and valid written consent from storytellers; we will provide whatever information is necessary about the process and the existing stories to enable such consent to be given.

Storytellers will be asked to sign consent form agreeing to the use of the final version of the story as an educational and learning resource intended to improve the quality and responsiveness of services for patients and carers.

#### Copyright

Final control over what is included in the digital story will rest with the storyteller. A 'first cut' will be sent for comment and a 'final version' will be sent for the storyteller's approval before the story is used elsewhere.

Copyright will rest with the National Health Service (but consent will not be withheld for reasonable use of the stories by the storyteller).

#### Support

Storytellers will be offered emotional support during and after telling their stories. Many storytellers have commented on the therapeutic benefits of telling their stories in this way.

#### Reimbursement

Storytellers will be repaid for expenses incurred in the recording of their story (including, where appropriate, reimbursement for respite care for people for whom they normally care).

# Patient Voices Consent Form

I, \_\_\_\_\_, have read the protocol and other information relating to the creation and use of patient digital stories. I understand that I have editorial control over the finished story but that copyright will rest with the National Health Service.

I consent to the use of my story as an educational and learning resource as part of the international drive to improve the quality and responsiveness of services for patients and carers.

Signed \_\_\_\_\_

Date \_\_\_\_\_

Name \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Tel: \_\_\_\_\_

Please return to:

Patient Voices Programme

Pilgrim Projects Limited

91 Waterbeach Road

Landbeach Cambs CB4 8EA

# Appendix 3: Patient Voices briefing notes and storyboard

## Digital storyboard

Please use the storyboard below to help plan your story. Here's how you might want to use it.

In each of the six boxes make a note of the kind of image you would like. In other words, what do you want the viewer to see as the opening image and what do you want to be the last thing they see as the story ends?

Use the lines to make a note of what you wish to say at this point in the story – don't go into too much detail, just an outline of the point you want to get across. Your first statement should give a brief indication of what you are going to be talking about and your last point should be the 'punch line' as it were – remember that this is probably the bit they are most likely to take away with them.

At the bottom please indicate what style of music you might like to use for your story (i.e. classical, jazz, rock, guitar, orchestral, etc).

Remember that much of the power of the stories lies in their brevity – between one and two minutes is the ideal length for a story.

Opening statement:					Final statement:
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The type of music I would like to use for this story is: -----

# Digital Storyboard Example

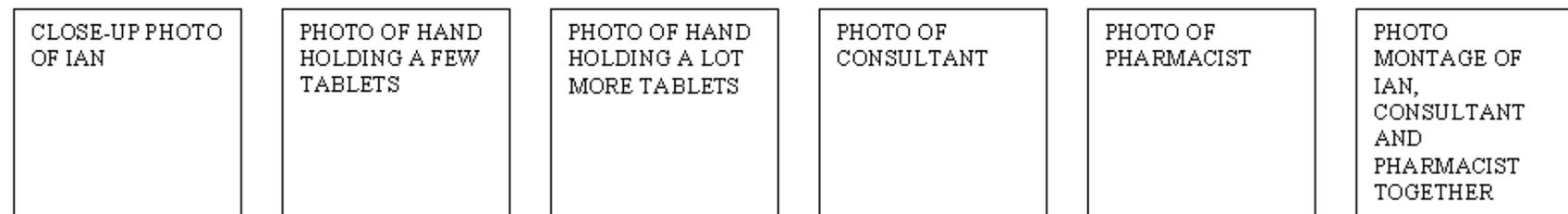
Please use the storyboard below to help plan your story. Here's how you might want to use it.

In each of the six boxes make a note of what kind of image you would want to see at the start of your story i.e what do you want the viewer to see as the opening image, what do you want to be the last thing they see as the story ends?

Use the lines to make a note of what you wish to say at this point in the story – don't go into too much detail, just an outline of the point you want to get across. Your first statement should give some brief explanation of what you are going to be talking about and your last point should be the 'punch line' as it were – remember that this is probably the bit they are most likely to take away with them.

At the bottom please indicate what style of music you might like to use for your story.

**STORY TITLE: Working Together**



**Opening statement:**  
"I'm very lucky as a person with HIV – I have access to some very effective drugs"

Problem – taking drugs early morning can cause me severe nausea and has caused me to stop treatment from time to time – not good!

Interrupting treatment causes viral load to increase

Consultant proposed taking the 2 daily doses together in the evening despite manufacturers recommendations

Pharmacist kept a check on drug levels in blood and found that it was working just as effectively

**Final statement:**  
"Patients & professionals working together can make an enormous difference"

**The type of music I would like to use for this story is: 'Gentle piano music'**

# Appendix 4: Extract from a questionnaire sent to eight students on UKHEP online modules

We have used **patient stories** extensively in both modules. It would be helpful to have your views on the different ways these have been presented.

8 What is your response to the short audio clips at the beginning of *Clinical Governance Matters*? (Please try to describe how they make you feel.)

9 What is your response to the audio stories told by Ian and Monica in *Clinical Governance Matters*? (Again, please try to describe how they make you feel.)

10 What is your response to the text stories in the modules? (Again, please try to describe how they make you feel.)

11 What is your response to the Patient Voices video clips in *Clinical Governance Works*?

12 How far do you feel the Patient Voices video clips have helped your learning with respect to....

a) your understanding of the module?

b) your understanding of the patient experience?

c) your understanding of your own practice?

13 Overall, which format do you feel most enhances the module (if you feel that they add nothing to the module, please say so)?

# Appendix 5: Questionnaire sent to 33 healthcare managers and others who have used the Patient Voices videos

## Patient Voices: an investigation into improving the quality of healthcare using digital patient stories

I would be grateful if you could spend a few minutes answering some questions about the Patient Voices videos.

1 In what context have you seen or used the Patient Voices videos?

2 What do you particularly like about the Patient Voices videos?

3 What do you particularly dislike about them?

4 What was their effect on you?

5 What was their effect on your audience?

6 How far do you think Patient Voices can promote a greater understanding of patients' and carers' needs?

7 What impact do you think the Patient Voices programme has (or could have) on changing the quality of healthcare?

8 How do you currently use (or how have you used) the videos to maximise their impact?

9 How do you think the Patient Voices videos themselves could be improved to enhance their impact?

10 Do you think the NHS should invest in developing the Patient Voices programme?

11 Finally, if you have been a storyteller, please comment on the experience – how did you feel; what did you think?

Many thanks for taking the time to answer these questions.

Pip Hardy  
April, 2005

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# Appendix 6: Evaluation of Patient Voices as used at a national conference

## Using Health Services - a personal perspective

*By Ian Kramer*

Excellent very powerful, short to the point stories

Excellent, powerful x 12

Thought provoking

Excellent video x4

Excellent session and good overview of patient experience from personal perspective but also by “stepping out of the box” some good anecdotes and thoughts

Very thought provoking x2

Powerful video x2

Valuable to hear real stories

Clips were excellent but so were his words

The examples are very much reality bare

I felt very moved by this presentation

Useful

Excellent and emotive

A different and powerful approach

Made us look at what evidence really is and focused everyone very much and patients and their experience

Video clips- an excellent method of giving a message

A real eye opener

Very powerful examples of using stories to improve

Fantastic food for thought

Useful

Interesting way of delivering the presentation

It would have been useful to have subtitles on the clips

Just the perspective needed.

Have heard before but still very captivating

The examples of the gloves audit was excellent

# Appendix 7: Summary of responses to questionnaire

Here are the responses to the survey '*Patient Voices: an investigation into improving the quality of healthcare using digital patient stories.*' Respondent ID numbers are given in the left hand column. Blank responses to questions have been omitted for space reasons.

## Question 1 In what context have you seen or used the Patient Voices videos?

	RESPONSE
1	I have only used "Daryl's Story" (re organ donation) within the team and also for a couple of teaching sessions with ICU nurses
2	We participated in the interview on the life, death and organ donation of our son Daryl Desa.
3	I use them in my own presentations to Boards and at national and international conferences on quality, patient focussed care etc,
4	Haven't yet but plan to do so in module on Fostering Dignity and Respect in Health settings with local Trusts.
6	I first saw the Patient Voices when they were in their raw/draft state, then when Paul Stanton did a conference for Carers I saw them incorporated into his slide show. I have now listened to them on my computer at work.
7	At 2 sessions with boards around governance. At the carers conference.
8	I have seen the videos used with members of PCT Boards in order to reinforce and illuminate important policy issues
9	In staff training and development days
10	As the editor and producer
11	I have used them at the Stroke Survivors project to demonstrate the importance of communication. I was involved in making one to underline the difference that can be made to improve patient care if patients are given information in a way which is accessible to them.
12	Could use them in professional leads forums, clinical governance groups and INDUCTION COURSES (PPI)
13	As part of PPI/improvement education and training events
14	I have seen them demonstrated to health service workers, and used at events for the same group as a means to remind staff of patient perspectives.
15	With Board teams
16	At a conference called 'Narratives and Action'
17	I have seen them at two patient safety conferences in London and one in the US. I have used them to teach medical students about patient voices and concerns.

**Question 2 What do you particularly like about the Patient Voices videos?**

	RESPONSE
1	I think that it captures the true essence of how a family actually felt and highlights their experience as a positive one. Especially in relation to donation issues, showing this to staff who are generally frightened of approaching a family about donation, helps them feel a little more at ease.
2	That it conveys a message to those who may not have experienced the tragedy that has befallen us.
3	Their authenticity, their clarity and their brevity. They allow me to convey important and complex points in a memorable, engaging and accessible way.
4	Useful trigger to raise awareness of user perspective and what can be done to improve practice
5	Patients & staff talking to camera not only about their experiences, but also about the perceived impact of their experience: EG. the patient who talked about the nurse who only wore gloves when she was being inspected – and how the lack of gloves might impact on him, and other patients.
6	Many things including:- The way they educate other people about patients concerns. The way in which the messages are emphasised by reiterating the patient's words on screen. The use of props – ie. Telephones/machinery was good. The fact that one of the videos showed people in their own home environment which made me feel they were 'very real' and brought the message home to me more. It was almost like watching the news.
7	It brings people who are patients or carers into the board room, reminding members of the ultimate goal their discussions should be focused upon. It brings a sense of humility into the room and cuts through the 'rhetoric'. It reminds those who hear that 'quality' should remain centre stage. It also physically suggests that patients look just like staff.
8	They are short but very professionally presented to deliver very clear and 'punchy' messages.
9	The simplicity and powerful messages
10	The fact that they are 'real' and that comes across very strongly in the final versions. I also like the fact they are short enough to keep viewers engaged from beginning to end. The format also makes them very easy to use and to distribute. We live in a world where the moving image is king and whether we like it or not people will generally be willing to sit down to view a 3-minute film where they would not read a 10-page report about patient care.
11	I like that they are just a brief snapshot of a much larger story but still convey a highly valuable lesson.
12	Very important messages, well presented, good length.
13	Well chunked down, each clip with an almost stand-alone message that could be incorporated into specialist training, e.g. for organ donation, equipment training and pharmacy training. Overall, absolutely great and a valuable piece of work.
14	Their accessibility - simple stories told succinctly; their simplicity - using audio and 'slide show' enhances focus on the story; their ease of use - files size not huge, don't need complicated technology to show; the choice of material - the content highlights particularly useful aspects of care; the 'packaging' of a message - the highlighting in text at the end of a couple of key points from the story.
15	V. powerful. Music is excellent. Black background is dramatic. Emphasis of the words on the black background.
16	I really like the idea and the way it was implemented. The final product looks great. The stories certainly deserve a thumbs up!
17	Great texts. Brevity. Clear message. Great music. These remarkable short vignettes were the most powerful stories I have seen on these topics. Elegant, short and yet deliver a real punch.
18	The stories are well made and pertinent.

**Question 3 What do you particularly dislike about them?**

	RESPONSE
1	I have no dislike of the particular story that I use.
2	Nothing at all, in fact their diligence and thoughtfulness encouraged us to talk about our beloved son who we miss so very much.
3	Nothing.
4	Nothing
5	The music was too loud and detracted from the speech content.
6	Only that the videos are shown in a small box with black background – I would have preferred to have seen the screen larger. I appreciate the clips go into Powerpoint presentations but I still was not that keen on the background. I also wish that the clinicians/people in the videos had faces – rather than just the patient and carer's having their faces in the shot. There could be a note that the people were just acting in the shots, but seeing faces rather than just body parts maybe.
7	Too small and hard to hear.
8	I cannot think of anything I dislike about them. My only concern is that we (the Board Team) need to look at how we can improve our technology to ensure that our presentations of the videos are also first class. (Participants get annoyed if they are unable to see the pictures clearly or hear the sound resulting in messages being lost)
9	Nothing
10	Nothing
11	Nothing
12	The music in some is a little sombre. Neutral or silent would be better. Not certain to what extent 'established' professionals would be influenced.
13	Music is a bit downbeat. The stories tended towards the 'unusual' and would benefit from more emphasis on commoner scenarios and conditions.
14	A minor quibble - when viewing a number of them, the lead-in and lead-out sequences become a little repetitive. Might there be a way to package a few stories so that they play one after another with the 'credits' sequence only occurring once? Mind you, this wouldn't be so much of a problem if using them interspersed with other things (e.g. using them to initiate discussion, introduce an exercise etc.).
15	Too small
16	If you see more than one story, you get the same photos....
17	I think they can be a bit hard for people outside the UK to appreciate as well.

**Question 4 What was their effect on you?**

	RESPONSE
1	Very positive and heart warming. Didn't at all appear staged and was a true reflection of a families honesty
2	It gave us great consolation to know that his valuable organs were utilised for a very worthy cause, give a better life to those who have been suffering with the own illnesses.
3	Powerful when I first saw them – and their power is undiminished when I watch them again.
4	Good to hear voice of users and carers without the sometimes inappropriate emotional impact that f2f presentations can have- sometimes students find it difficult not to be defensive in such situations.
5	Very powerful, esp. see 1. above
6	The effect was quite moving and sad – especially the one about the young boy – where his parents live on to tell his unhappy tale. But it also gave hope with the donor aspect coming into play. The videos also made me feel frustrated that clinicians sometimes miss the bigger picture as with Alison Ryan's story where she injected her patient to the disgrace of the nurses. The stories helped me understand that carers of patients should be taken more seriously instead of being pushed away as soon as clinicians take over.
7	Frustrated by the fact that so many of our discussions bare little relevance to making a positive impact upon these stories. Made me miss being a nurse and having direct contact
8	As a somewhat hardened manager of 20 years standing, they reopened my eyes to some issues within the NHS!
9	Thought provoking, made me see things from a different perspective.
10	As the author this is a bit difficult to answer.
11	I was moved by each of the stories. I felt challenged to continue improving all that I do for the Stroke Survivors I interact with. It reminded me that even little changes have the power to effect people's lives.
12	Thought provoking - a little embarrassing.... Are our srVICES and personnel really that bad in places? Why aren't obvious procedural matters seen and addressed?
13	Thought-provoking - and I;m starting to consider how I can use them in my own work.
14	Reminded me of a number of my own experiences of the care system!
17	A greater appreciation of patient needs.
18	I have always sought, when I was mainstream NHS, to achieve a balance between staff and patient concerns and have been concerned for some time at the way the pendulum has swung too far towards patients' interests. As a management we have treated our staff abysmally as do a significant minority of patients. Some staff stories to show patient groups would not be a bad thing!

**Question 5 What was their effect on your audience?**

	RESPONSE
1	As above. They felt that it was good to see how a family have responded in this situation and how positively a family could feel about donation. When they talk about “not having a second thought”. I think that is quite impactful
2	We have received positive feed back from the many family and friends who enquire about Daryl constantly.
3	Hard to judge with Conference audiences – though I have had some very positive anecdotal feedback from Non Executives and from some senior executives on their impact. With Boards and PCT PECs they have always had both a powerful and a positive impact. I am particularly struck by their impact on clinicians who have first hand and immediate access to patient and carers almost every day of their lives. I suspect that as the audience, rather than the professional managing a ‘consultation’, the power dynamic is fundamentally altered – their lips need to remain sealed while the patient or carer talks – and therefore their ears (and perhaps their hearts) are opened.
4	Those I have shared it with –staff – feel it has potential for use in teaching.
5	(HS managers) Powerful, esp. one about different quality of accommodation for liver and heart transplant patients’ relatives, i.e. what message (management) action can signal to patients – even when that action is not necessarily directly about clinical care. (Clinicians) Powerful, esp. one about staff member talking about doctor’s reluctance to change system to benefit (aphasic) patient. (NEDs) See a) and b) above, esp. b)
6	The only audience I saw was at the Carer’s Workshop where Paul Stanton facilitated a presentation – where the audience seemed to be taken aback by them – I think it made them realise we could get messages across in this unique way.
7	Silence filled the room, eyes were wide, and most remained quietly reflective
8	Similar. They ‘get through’ to Boards – particularly NEDs. In one of my present projects the Board is asking for more information on patients experiences.
9	Got rid of assumptions that some people have of involving patients in service development, In particular it made people realise that involvement does not have to be complicated and that simple changes can be effective and have an impact
10	I have not shown them in any formal setting. However when I have shown them to friends and family they are always engaged, often very moved and they produce a reaction every time. This reaction ranges from delight at the fact that Patient Voices offers people a chance to have their say to anger at the way some of the storytellers have been treated.
11	Genuine interest and concern about the issues shown.
12	Operational managers - very little. Senior managers - some. May improve awareness/practice among clinicians though most would argue they would never make such mistakes. Might generate more change champions among Non-execs, provide a way into Boards.
13	Thought provoking - although there may be an element of 'we don't do that' or 'that couldn't happen here' - would be a big eye-opener for non-execs.
14	Most of the audiences I've seen them used with have been 'improvement workers' in health systems, yet there was clearly still an affecting quality that generated an emotional response, as well as the 'professional' appreciation for how they could be 'used'.
17	Attentiveness to patient needs

**Question 6 How far do you think Patient Voices can promote a greater understanding of patients' and carers' needs?**

	RESPONSE
1	I think that it could be quite a valuable tool in the right settings
2	It helps people like us who have been bereaved to express our feelings, whilst extremely sad, just to ease the pain slightly in the knowledge that the messages will be heard from a few who will be brave enough to make the decision to donate their loved ones organs in the hope that it will offer others a better life.
3	In a number of ways. To Patients and Carers themselves they validate and authenticate individual experiences. To carers they provide a fascinating sidelight that casts a new shadow from their own habitual practice. To those who govern NHS organisations, they act as a forceful reminder of the micro-dynamic and thus the overall purpose of organisational existence – and they act as a powerful emotional prompt to question whether such experiences are replicated in their own Trusts.
4	To a considerable extent.
5	Will depend on how used, i.e. as a training tool, with discussion of and challenges to staff values, perceptions and actions.
6	Given the opportunity I think they could educate the needs of patients and carers to clinicians/nurses – especially for training purposes to open up the eyes of new and old recruits in the NHS. To have some 'Good' stories where patients had made a difference – i.e. Ian's story of the newly opened pharmacy store for HIV and Aids at Kings, and to also show the 'Bad' stories where clinical care had been neglected.
7	There needs to be feasible first steps for organisations to capture their own patients' voices, or apply the national voices to their own service provision. We need to treat the patient survey differently. How do we take 2 or 3 issues from this survey each year, and design a process to capture patient voices to generate solutions, implement and then capture patients' responses but more frequently (how do we use run charts to performance manage co-production with customers?). How can we look at continuous quality improvement together. We need to go beyond the patient survey.
8	I think they are very effective. Perhaps some more positive ones eg examples of things that went well could also help to get these messages through,
9	I think patient voices and other similar resources should be integral to staff training and induction
10	I think that we have only scratched the surface so far and that the potential for offering patients and carers an opportunity to 'talk' directly to policy-makers is immense.
11	It is rare that one is given a real insight into the patient experience I felt these short clips did just that. Real understanding comes from experiencing as near as possible to first hand and I think these stories are a real way of making this possible.
12	Helpful as part of a wider strategy.
13	Use individually to support specific and relevant service improvement/clinical quality improvement initiatives
14	I think that they're a useful addition to the 'armoury' of things to get people thinking about P&C issues, and they're a fresh and easy way to start that sort of debate - their use in this context is particularly needed.
17	They are an important tool in a very long and needed transformation. They might also assist in providing encouragement to people dealing with long-term conditions.

**Question 7 What impact do you think the Patient Voices programme has (or could have) on changing the quality of healthcare?**

	RESPONSE
1	I'm not sure, but perhaps in the case that I use, it helps nurses feel more comfortable, that families don't mind being approached about donation
2	For us personally, we have made friends with Pippa, Brendan and Roberta Brown of the South Thames Transplant Coordination Service who have been extremely supportive during this difficult time in our lives.
3	At the moment they do not have the exposure they deserve. If they were used by the CMO, the DCMO or by the Secretary of State their impact would be multiplied significantly. We probably need a strategy to try to achieve this.
4	Useful if followed by an action plan and taken up and resourced by employing authorities. Otherwise staff left being guilty. We use "Pledges for change" with workplace mentor follow up and require students to write a) a piece on putting themselves in the shoes of one of their clients and b) what they will do differently as result of module
5	See above.
6	I think if they were shown as part of a national training programme when clinicians/nurses entered into the NHS – they would educate the patients' needs at the very onset of their work. Also if they were shown at most national healthcare events – the more exposure would help spread the messages across. The donor card example could help to make an impact – the story was very positive about that in a case of 'life after death'. There could be stories of patients on the receiving end of organs and how it has given them that 'second chance' – encouraging others to carry a card.
7	Alone I think they are in danger of being lost. Linked to performance, duty of involvement, clinical governance and role of non-executive directors.... They could sit at board level where they belong.
8	I think it is an important part of the 'tool-kit'
9	It can help ensure that involvement is mainstream and considered at all stages of service development and change. It can also help ensure resources to support involvement are identified in business plans and proposals so that there are budgets to support patient involvement.
10	In public-sector institutions in particular, change should come from the bottom up and this means that patients, carers and those who work closely with them need a way to make their voice heard. Patient Voices seems to offer a very easy, cost-effective way to do this.
11	I think it has a real chance of improving healthcare by making key professionals think about how their decisions and practice influences patient experience.
12	To an extent they can be a useful tool within a wider strategy. Over-reliance on 'individual' stories not enough alone.
13	As 6
14	Help people start to think in a less blinkered way about patient involvement/perspective; a good way to work with 'front-line' staff and show some things that will stimulate thoughts in a constructive manner.
17	I believe they could be very useful as an educational tool for medical students, registrars and faculty. They might help to ensure greater patient safety awareness as well as going some way towards improving the quality of the patient experience. As part of a larger campaign, it has great potential to assist in this revolution.
18	If used sensitively to raise questions and to explore good patient care, these could be useful. But in the wrong hands they could be counter-productive and lead to a widening divide between patients and staff.

**Question 8 How do you currently use (or how have you used) the videos to maximise their impact?**

	RESPONSE
1	When doing a teaching session on organ donation issues, I let them reflect on a donor families experience
2	We have showed it to all family and friends, and have made copies or advised the web site so that it can be viewed and the message heard and spread.
3	I embed them within powerpoint presentations so that they are an embedded and integral part of our 'message' and I often leave the last word of my presentations to one of the story tellers.
4	Not yet used. Will use in parts of module where we seek to raise awareness. Currently we use American productions OK but culture different.
5	Yes, see 5 – audiences would be staff (& possibly patients) in a [facilitated] training situation
7	I have not used them in the PCT, but within the board development programme. Are there other PCTs who have ?
8	I use them as part of my Board development work, to expand and illustrate the responsibilities of Board members. They are much preferred to powerpoint presentations and stimulate much debate. (I have also used them on my physician partner to influence his work on the development of national policy!)
9	In staff training and development /study days; We have given staff scenarios to work with and then shown the DVD to give the patients perspective ( which often brings up things they did not consider)
10	Not applicable
11	I have only shown them to a select few. I could definitely make more of them by incorporating them within the empowerment section of our training for volunteers. I haven't done as much as I would like to with them- Sorry!
13	Selected stories in induction training and as 6.
14	Haven't as yet, but have identified some future events where they might be very useful.
17	As part of a larger patient safety curriculum.

**Question 9 How do you think the Patient Voices videos themselves could be improved to enhance their impact?**

	RESPONSE
1	Perhaps another couple of families could talk on their experience who have donated
2	No others can experience the pain and sadness that we feel, so it is difficult that when they watch the videos they can share our emotions, although it does not affect those who have not been through this, it does reach to those who care.
3	A little more refinement of the edits – so that composite stories can be separated. A number of stories that exemplify the Standards from Patient or Carer perspectives would be very topical and high impact. They could be complemented by Clinical Voices, Executive and Non Executive Voices
4	Link to specific professional requirements such as communication, assessment, care planning and evaluation- pretty generic.
5	See 3 above – they were always more powerful when patients were talking to camera, rather than just music and narrator. Only had time to listen to x3 – all mentioned above. I think examples in specific specialties would have more impact in those specialties, although some issues are general across all specialties.
6	Although I like the soothing music, I would like to hear more dramatic tones when videos showed clinician mistakes – to push the messages across. (Sound can have a very profound effect – like in horror movies etc, when on the edge of your seat – so to speak). May be if the patients/carers end their stories looking directly into the camera with one main message/question back to target the audience to make the audience feel part of the process and get them thinking right there and then.
7	I am not sure how many are available. It would be great to connect the stories to the big issues for CEO's - Long term conditions, aspects of care within the quality and outcomes framework. How could health care commission use this evidence.... That would encourage investment in the process ?
8	As stated above, I think some examples of things that went well could also be effective (Apologies if this has been done and I am out of date)
9	Made more widely available to services to be used (with guidance) to enhance other methods /tools to ensure patient/carer involvement is integral to service design / improvement
10	Again, as the author, I find this question hard to answer but am very interested in the response of others to this question. Gathering the stories together, perhaps in DVD format might be helpful at some point. The DVD could include background info, further reading, case studies, links to associations alongside the stories themselves.
11	No real suggestions.
12	Record a wider range to target different audiences. Do more stories that show how a situation has been positively improved by a change and development in PPI. Depending on how controversial you want to be, generating 'significant impact' is easiest through encouraging high expressed emotive response, best achieved by focussing on children/hereditary conditions - family impact.
13	All the storytellers were quite eloquent and part of British culture - could include some minority groups' cultural issues. Could also develop the innovation aspect - this could be a useful way of spreading good ideas too. Need to be careful to select stories that reflect '80%' issues rather than unusual conditions such as haemophilia and adolescent deaths – don't leave these out, but include some more mainstream stories.
14	Other than stuff in section 3 above - work with someone to provide some supporting materials to build on their impact
15	Could be shown larger
16	There could be more variety of photos -
17	Enhancing issues of patient hand-offs, teams, technology challenges, medication errors, etc.

**Question 10 Do you think the NHS should invest in developing the Patient Voices programme?**

	RESPONSE
1	Possibly
2	Yes, definitely, without a doubt, it requires a great organisation as the NHS to promote awareness, not only for the causes of illnesses, but also solutions that are available, but the decisions hard at the time to make, but in the knowledge that it offers someone else the chance of a better and much improved life.
3	Yes – so long as the feedback you get is positive
4	Definitely- but please can the content continue to be used by many professions and take account of community and group care settings.
5	Yes, in that a small library covering most common specialities + general issues would be useful as a central resource – although my trust already use patients in this way. Overall, I think this is a really good idea for the NHS to develop as a central resource. Here at King's we are already incorporating patients' voices into training, e.g. in pain control and in older people's services.
6	Yes!
7	YES if there is dissemination beyond London!! and support to create local stories.
8	Of course! – particularly to make them more widely available
9	Yes
10	Yes (but then I would say that wouldn't I?)
11	Definitely- I love the thought that people everywhere would get some first hand experience of how easy it is to improve things.
12	Yes
13	Definitely - need a larger library so relevant stories can be selected for specific audiences and to avoid 'flooding' the market with the same stories.
14	See above (section 9)
17	YES! Great investment. I am hopeful that the NHS might find a way to support these innovative efforts to get the patients' voice heard.

**Question 11 Finally, if you have been a storyteller, please comment on the experience – how did you feel; what did you think?**

	RESPONSE
1	Both the family and myself felt very at ease and welcomed the opportunity to tell a story. The crew were amazingly understanding, supportive and appropriately empathetic towards the family involved. The family enjoyed the opportunity to be able to speak of their experience and found that it helped them.
2	It was extremely emotional for us in doing the interview, but also we felt so proud to share our beloved son's life and courage during his illness and death, with the world, it has made us stronger people. As stated, we have the greatest admiration for the dedication of the people who bring this kind of videos to the public at large, who think of donating their organs, but sadly never get round to doing so.
11	I felt a huge sense of relief in sharing my story. It felt as if something good would come out of a terrible experience. I enjoyed the opportunity to tell it immensely, partially as a self healing process but also because in telling it out loud to someone else I realised the scale of the injustice but also the real power to change it.
17	An incredibly exhilarating and humbling experience (not actually a storyteller).