An investigation into the application of the

Patient Voices digital stories in

healthcare education:

quality of learning, policy impact and

practice-based value

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Declaration

'I hereby declare that, with effect from the date on which the study

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Pip Hardy

May 2007

Acknowledgements

'In the middle of the road of my life, I awoke in a dark wood,

where the true way was wholly lost.'

Dante

A work such as this one is the result of myriad influences, a multitude of conversations, and a good deal of support.

Special thanks are due to Brendan, for showing me that first digital story; to Paul, mentor and friend, for believing in us and in the Patient Voices programme from the very beginning – and before; to Joe and Emily for wisdom, inspiration and the discovery of a long-forgotten voice; to my supervisor, Celia O'Hagan, for providing thought-provoking challenges, patient guidance and keeping me on the right track; to Lesley for cheerful friendship and support along the way; and Ray for unflagging encouragement and solidarity to the very end of what sometimes seemed like an endless journey; to all the patients, carers and staff who have done us the great honour of sharing their stories with us, and especially to Ian Kramer, whose wonderful stories will live on after him; to Ros for her generous proofreading and thoughtful comments; and most of all, to Tony, my constant companion, who helped me find the true way, to the far horizon.

'From a little spark may burst a flame.'

Dante

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NOTE: Hyperlinks to the stories are contained within the electronic version of this paper; a CD containing the stories accompanies the printed version

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Abstract

Digital storytelling empowers patients, carers and clinicians to convey their felt experiences of healthcare via new technology so that their voices can be heard in any lecture theatre, Board room or conference venue anywhere in the world.

This paper describes an investigation into the use of the Patient Voices digital stories in healthcare education to encourage reflection, stimulate debate and discussion and promote empathy as a result of empowering patients, carers and service users to tell their stories.

Drawing on principles derived from illuminative evaluation and action research, the research reveals enthusiastic support for the wider use of the stories throughout healthcare education and quality improvement programmes, and a clear impact on how education and healthcare services can be delivered, while keeping patients firmly at the heart of the process.

The study concludes that the Patient Voices digital stories convey key emotional messages to clinicians, managers and decision-makers and, with the proper facilitation and training, have the potential for transforming and humanising the delivery of healthcare through patient-centred education and continuing professional development.

Recommendations include:

- raising awareness of the Patient Voices free-to-use library of stories

- embedding the skills of storytelling – and listening – into healthcare education curricula and CPD programmes

- using the stories to inform more humane and compassionate commissioning

- conducting further research, including exploring uses of the methodology as a means of gathering qualitative data.

Key words

Digital stories, reflection, listening, empathy, interprofessional education, transformation

'Every story brings the imagination and reality together in moments of what we might as well call faith. Stories give us a way to wonder how totalitarian states arise, or why cancer cells behave the way they do, or what causes people to live in the streets…and then come back again in a circle to the wonder of a song…or a supernova…or DNA.

Wonder and wondering are closely related, and stories teach us that we cannot choose between them. If we try, we end up with the kind of amazement that is satisfied with the first explanation, or the kind of curiosity that is incapable of genuine surprise. Stories make the world more real, more rational, by bringing us closer to the irrational mystery at its centre. Why did my friend get sick and die? Why is there so much suffering in the world? Whose land is this we live on? How much is enough?'

Chamberlin, 2006

'The foundation of a story is an emotional foundation. If a story does not work emotionally, it does not work at all. The emotion in question is not the point; be it love, envy or apathy, so long as it is conveyed in a convincing manner, then the story will come alive. But a story must also stimulate the mind if it does not want to fade from memory. Intellect rooted in emotion, emotion structured by intellect – in other words, a good idea *that* moves *– that was my lofty aim.'*

Martel, 2005

Introduction

> *'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 p. 26

> *'I believe the notion of story, transformative reflection, and the capacities of computing machine being forged together into some sort of new life management process is catching on with people.'*

> Lambert, 2000

A parade of policy documents issued by the Department of Health in recent years has trumpeted the message that patients are to be at the centre of healthcare delivery and reform. Since the 2001 *NHS Plan*, these documents have reinforced and clarified the need to attend to patients' views and wishes and to make patients, carers and service users genuine partners in care. Clinical governance upholds the patient experience as a key element of quality in healthcare (Stanton, 2003). *Creating a Patient-led NHS* (DH 2005a) and *Commissioning a Patient-led NHS* (DH, 2005b) demonstrated the intention to commission care that is fit for purpose and determined by the needs of patients. *Now I Feel Tall* (DH, 2005c), highlights the importance of patients' felt experiences, reinforcing their key role in the transformation of healthcare services while *Our Health, Our Care, Our Say* (DH, 2006) draws on patients' views to begin shaping the future of the health service.

These documents, and many others, are shaping a vision of healthcare in the UK characterised by community, patient and carer partnerships, inter-professional working and

use of new technologies in the light of an increasingly diverse population, more people living with long-term conditions and greater reliance on self-care and care in the community than on hospital-based care.

At the National Audit Office's November 2006 conference on stroke care, the Chair of the Public Accounts Committee acknowledged the importance of individual patient stories in any consideration of healthcare reform – a message reinforced in the book that emerged from the conference:

> *'Patients and carers are in a unique position to bring their experience to bear; practitioners can harness the strength of belief, experience and determination of patients and carers to improve services.'*

> Hudson, Ross and Taylor, 2007 p.58

Individual patients' stories will ensure that the vision remains sharp and clear, and they will also form part of the collective story of the communities within which care is commissioned and delivered.

Patient narratives are acknowledged as a valuable contribution to the pool of resources intended to facilitate change and transformation in the health service, both in the UK and elsewhere (Charon, 2006; Greenhalgh and Hurwitz, 1999; Greenhalgh, 2006 and Wilcock *et al,* 2003) and patients are encouraged to become more 'resourceful' (Gray, 2002) and forthright in their expectations of and contributions to their care. Maslin-Prothero (2003) recommends the development of a strategy for involving service users more effectively in research; while employing service users as teachers of medical and nursing students (Wykurz and Kelly, 2002) is gaining popularity.

Despite the Prime Minister's assurance that 'every reform is driven by the goal of ensuring the needs of patients are put first and foremost' (Blair, 2000, quoted in Maslin-Prothero, 2003), it seems that the aspirations and the rhetoric are not matched by the reality (Hawkins and Lindsay, 2006 and Pilgrim Projects, 2007). O'Connor (2006), in an interview with the Institute of Healthcare Improvement, commented:

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

New technology offers us the opportunity to empower patients (Gray, 2002), carers and healthcare staff, and update the ancient art of storytelling by means of 'digital stories', short multi-media clips whose power comes from weaving together images, music, story and voice (Digital Storytelling Association, 2002). The resulting tapestry brings depth and colour to everday characters, situations, experiences and insights. They not only touch hearts and therefore influence minds, but they also provide opportunities for reflection (Boud *et al*, 1985; Moon, 1999; Schön, 1983; McDrury and Alterio, 2002) and collaborative learning with the potential of promoting greater understanding between patients and staff and between different staff groupings, thus playing their part in interprofessional education (Barr *et al*, 2005).

Digital storytelling methodologies are new and little research has been carried out on the impact of the stories. Existing research (Barratt, 2005) indicates that digital storytelling can help to build communities of learning and practice; share tacit learning; aid reflection; contribute to building portfolios; promote dialogue and understanding.

Patient Voices

The Patient Voices Programme has been gathering and disseminating the digital stories of patients, carers and clinicians since 2003. These short, powerful, media-rich presentations enable the voices of ordinary patients and carers to be heard, while empowering and involving service users in the education of health professionals. The digital environment provides a unique opportunity for stories to be shared, combined and connected to other stories in an 'interactive and transformative process' that empowers the author and invests storytelling with new meaning (Digital Storytelling Association, 2002).

Many of the 100+ stories that the programme has created to date are being used in university schools of healthcare, NHS Trust Board teams and conference presentations by educational and healthcare organisations spanning a wide range of clinical conditions, in both formal and informal learning contexts.

Emerging from new technologies that facilitate their creation and dissemination and drive their use, the Patient Voices digital stories are increasingly recognised as having the potential to help NHS staff better meet the needs of patients by involving them more closely, innovatively and collaboratively in service redesign (Hardy, 2005).There is little research on their effectiveness but much interest from universities, other teaching and training institutions, and healthcare organisations worldwide, in their potential for promoting reflection and dialogue and changing practice in health and social care.

The stories have great potential for bringing about positive transformation in the health service, while making excellent use of time and technology, promoting reflection, collaborative and interprofessional working and greater shared understanding.

Literature searching reveals no other significant use of digital storytelling in healthcare, despite its potential as a narrative and reflective tool for patients, service users and staff. In response to requests from users of the stories and policy makers to discover the efficacy of digital storytelling in terms of 'evidenced benefits' and changes in practice, it is now appropriate to discover the extent to which digital storytelling can be used to promote interprofessional working and bring about transformation by combining the ancient skills of storytelling with new technology and using the resulting digital stories in healthcare education and quality improvement programmes.

Research methods

This qualitative and phenomenological study aims to evaluate the actual and potential impact the Patient Voices digital stories can have on healthcare education, practice and decision-making by engaging emotions and promoting reflection. It looks at the nature and meaning of the experiences of patients, carers and healthcare professionals, at the experiences that shape the stories and changes in the attitudes and behaviours of those viewing the stories within an educational intervention.

Design

Action research relies on diplomatic and caring communication between equals – practitioners and service users – in an attempt to create new understanding through negotiating and implementing improvements in the quality of social practices. By building on the principles of co-operation, collaboration, empowerment and participation, it is possible to develop mutual respect and trust that is likely to promote 'inherent creative potential' (Heron, 1996, quoted in Winter, 2003) and 'critical subjectivity' (Heron,1998 quoted in Winter, 2003) that can lead to understanding and transformation.

As a form of self-reflective enquiry intended to improve practice and understanding, the study draws on the British tradition of action research as defined by Carr and Kemmis (1986); in attempting to gather information with the intention of bringing about social change, the study draws on the American tradition of action research (Bogdan and Biklen, 1992, quoted in Smith, 1996; 2001). The spiral of steps comprising Lewin's approach to action research (Lewin, 1948) was broadly followed by the researcher, with 'circles of planning, action and fact-finding about the result of the action' informing each stage of the process. While the research is primarily oriented to problem-solving in social and organisational settings, it parallels Dewey's notion of learning from experience (Smith, 1996; 2001).

In seeking an appropriate model of inquiry, several sources stood out and have directed the course of this study. Illuminative inquiry is a flexible and holistic approach that offers the researcher opportunities to understand the experiences of those involved in testing an innovation (Downs 1992), in this case, the users of the digital stories. It is concerned with discovering and exploring the significant features and critical processes of an innovation and,

it is to be hoped, generating meaningful data to inform future research (Galvin *et el* 2000).
Reliability may be sacrificed, but strong validity is assured, through the depth of
understanding gained by means of such a qualitative approach. Parlett and Hamilton (1972),
however, highlight the main focus of the illuminative approach as being to 'illuminate what
was once murky' and render the researcher more sensitive to the issues involved.

Evaluation criteria suggested by Annells (1999) encompass 'credibility, transferability,
dependability and confirmability' while Crompton (1999) proposes that technology-based
innovations should be evaluated on the basis of 'effectiveness, efficiency and relevance; the
applicability and appropriateness to the intended users'.

Winter (2003) outlines a model of action research that seeks to honour the unique
experiences of individuals, those 'practitioners and patients who are largely excluded from
defining the purposes of research and the meanings of data, i.e. from the purposes and
meanings of their own life-worlds'. This study is not purely action research, but rather an
evaluation. It is, however, concerned with what Winter (2003) describes as the focus of action
research, that is, 'values, collaboration, dialectics, change and creativity', and supported by
Buddhist concepts and practices relating to *karma* (consequences), change and
impermanence, and the cultivation of harmonious speech, empathy and compassion.

The practice of gathering and editing the stories, as well as the development of the website
for their dissemination is founded on these principles and so it was necessary to find a form of
inquiry for the research into their effectiveness that does justice to the 'subtle and complex
qualities' (Winter, 2003) of the relationships between providers of healthcare and those who
receive it and that will incorporate in the data the emotional and spiritual responses of those
involved in the study so that the inquiry may actually and directly enhance practice, whether
educational or clinical (Winter, 2003).

Sample population

The main sample population was drawn from universities, schools of healthcare and healthcare organisations where the Patient Voices digital stories have been used in teaching or in presentations. An email invitation was sent to more than 100 people who were known to be using the stories. 40 people (26 women and 14 men) responded to the invitation to take part in the research. Respondents covered a wide range of groups from undergraduate nursing students through to senior managers in the NHS from clinical, educational and organisational contexts (at different levels and in different parts of England) (Table 1). They had used the stories in settings ranging from small group work to large-scale national conferences and virtual learning environments.

Cardiac and end-of-life care/service improvement	2
Carers' agenda	1
Clinical governance	2
Communication training for medical students/patient involvement	5
Continence care	1
Disability training	1
Ethics and research	2
Home-help training	1
Inter-professional education/patient involvement	4
Language education/Speech and Language Therapy	2
Mental health	2
New technology/service improvement	3
Patient empowerment/healthcare quality improvement	1
Pharmacy	1
Pre-registration nursing (general)	2
Pre-registration nursing (emergency care)	1
Pre-registration physiotherapy (rehabilitation studies)	2
Psychotherapy training, chaplaincy, mental and spiritual health	2
Public health	1
Safety and quality improvement	4
TOTAL	40

Table 1: Clinical, organisational or educational context

Respondents decided whether to participate by completing a questionnaire, engaging in a telephone or face-to-face interview, or taking part in a focus group. The choice of mode depended on available time and geography; some people engaged with more than one mode (Table 2).

Focus group	Face-to-face interview	Telephone interview	Email	Questionnaire	Online discussion group
19	2	1	20	8	4

Table 2: Response mode

Information about the project was provided and all respondents were asked to sign a consent form (Appendix 1).

A second sample consisted of a group of 30 pre-registration, second year undergraduate nursing students studying a module on continence care, who were asked to complete a questionnaire after watching one story.

A summary of all research participants grouped according to organisation type is provided in Table 3.

University/school of healthcare	49
Other education or training institution	5
NHS organisation	10
Other	6
TOTAL	70

Table 3: Research participants grouped according to type of organisation

Instruments and data gathering

Mindful of Winter's view of action research as a way of investigating professional experience that 'links practice and the analysis of practice into a single productive and continuously developing sequence, and which link researchers and researched into a single community of interested colleagues' (Winter, 1989), methods of gathering data were selected that would facilitate and reinforce these links, while encouraging personal and professional reflection and building a community of practitioners.

Emden (1998) highlights the focus of narrative analysis as 'the potential of stories to give meaning to people's lives'. Stories are the way we make sense of the world and the way the world makes sense of us; this is equally true for both respondents and storytellers, and so open-ended questions were used to elicit the 'story' that was important to each respondent.

Questionnaire

The same questionnaire/schedule was used for focus groups, online discussion and interviews (Appendix 2).

The questions fall into three groups.

The first group of questions was concerned to discover:

- the type of group with which the stories were used

- the context within which the stories were used

- the purpose in using the stories

- the stories that were used.

Appendix 3 contains the range of contexts, groups and purposes of respondents.

The second group of questions focused on the impact – both actual and potential – of the stories:

- the effect on the presenter and the audience

- the potential for developing empathy and understanding

     - between patients/service users and professionals

     - between different professional groups

- actual or potential changes in practice

- potential impact on quality and safety of healthcare

- potential impact on individuals and organisations

- potential impact of changes in education (especially interprofessional education), teaching and learning.

The third and final group of questions asked for:

- evidence of any other benefits

- any additional comments.

A separate 'feedback' questionnaire was provided for the student nurses (Appendix 4) and was intended to elicit responses to the story as well as ideas about how the story might bring about changes in provision of care.

Focus groups

Focus groups were selected as the most appropriate method of finding out what the stories could mean to a group (of educators, students, practitioners). Goguen's (1997) social consensus theory states that the meaning of any proposition consists in its designation as meaningful by some social group; the truth conditions are situated, local, contingent, embodied, vague, and open. This is the approach taken by social institutions and it may be called 'truth by social agreement' (O'Hagan, 2006).

Interviews and focus groups were conducted/facilitated by the researcher using the same schedule of questions as the basis for discussion, according to the principles mentioned above in relation to action research, that is, democratic, co-operative and collaborative (Winter, 2003), with a view to cultivating harmonious speech within the groups. Goguen's social consensus theory guided the focus groups, whereby 'debate, dialogue, discussion, and perspective-taking would continue until every qualified member of the community came to see the same truth'. Where possible, new technology was used to increase participation in discussion and debate by people in different time zones, as well as by those whose diaries did not permit face-to-face meetings. Focus groups were held face to face in real time, via telephone conference calls and via an asynchronous online discussion group.

Focus groups and telephone interviews were recorded and transcribed, and transcriptions sent to respondents for checking. Questionnaire responses and emails were collated. A modified framework approach (Pope *et al.*, 2000) was adopted and adapted to analyse the data, using several methods. Results from the questionnaires and emails were sorted according to themes using Excel.

Data from transcriptions of focus groups and interviews were annotated, roughly coded, and analysed thematically using a mind mapping software package. Data was initially categorised under 18 emerging themes (Appendix 4) which were then compared with the original aims of this investigation, conflated and re-grouped into the following final themes:

• The power of the stories	• Interprofessional education and research
• Reflection	• Changes in practice
• Dialogue, discussion and debate	• Concerns, limitations and issues for further exploration
• Empathy and understanding	• Service transformation and system change
• Patients at the heart of care	

Table 4: Final themes

Maslin-Prothero (2003) notes that 'the analysis of qualitative data is a highly personal activity involving interpretative and creative processes while trying to ensure that the results represent the participants' world as they see it.' The researcher regarded this process in much the same way as the creation of the digital stories themselves and attempts were made to be aware of bias and possible misinterpretation.

Findings

The findings are presented under the themes listed above. The relevance and appropriateness of these themes is reinforced by responses to questionnaires and discussions in the focus groups and individual interviews, where the power of the stories was seen to promote empathy and reflective learning, both individually and collectively through dialogue, discussion and debate, while situating patients firmly at the heart of care and recognising the implicit and explicit possibilities for interprofessional education, and the potential for transformation at all levels in the health service. These ideas will be expanded in the Discussion section.

Some digital stories were shown to each focus group to initiate discussion and gently provoke reflection on practice. The distinct professional interests of each group are reflected in the discussions and an attempt has been made to capture something of the flavour of the dialogue and debate, while acknowledging the power of group reflection and the ability to transcend individualised responses through building communities of practice (Smith, 1995).

The immediacy of seeing and listening to the stories, attending to them and evaluating them (Boud, Keogh and Walker, 1985) through discussion and debate provided a direct and unexpected insight into their impact. The extent to which more sceptical participants were sufficiently affected by the stories and the ensuing discussion to adjust their views was also clear. This process, although reflecting on another's experience rather than one's own, echoes Schön's (1983) notion of reflection in action:

> *'The practitioner allows himself to experience surprise,*
> *puzzlement, or confusion in a situation which he finds uncertain or*
> *unique. He reflects on the phenomenon before him, and on the*
> *prior understandings which have been implicit in his behaviour. He*
> *carries out an experiment which serves to generate both a new*
> *understanding of the phenomenon and a change in the situation.'*

<div align="center">Schön 1983: 68</div>

The power of the stories

All respondents commented on the strength and power of the stories, praising their 'honesty', 'veracity' and 'simplicity', their 'versatility', 'compactness', and 'memorableness' as well as their ability to convey strong messages succinctly.

> *'The students were drawn in by the clips through their honesty and genuineness; there is much use of simulation and "staged" videos in healthcare and this DVD was head and shoulders above any of those as the stories and individuals were obviously genuine.'*

Emotional responses ranged from 'touching' to 'profound' with many viewers finding them 'very emotional':

> *'You can't watch them without feeling what the storytellers are feeling.'*

And, on a more fulsome note:

> *'They have an affective as well as a conceptual loading. I also find that – when I re-watch even the most familiar story with an audience my emotional response is re-awakened – which suggests that there is a "collective unconscious" as well as an individual resonance to some of the narratives.'*

The stories convey 'a different perspective' on the lives of patients and carers and one respondent admitted to feeling 'sad and angry that the NHS still doesn't respond to the needs of patients and carers'.

> *'The voices act as a gentle but powerful reminder of what healthcare should be all about.'*

The stories proved popular with medical students:

> *'I noticed there was increasing engagement of the students with each clip. They all thought this was an effective way of getting the*

message across. One of them said "Beats reading this from a

journal; it's more digestible."'

and a student nurse had this to say:

'Really enjoyed the clips; nice to see it from the view of the people

who really matter!'

The stories had a powerful – sometimes 'stunning' – effect on audiences, particularly when care had been taken to provide suitable conditions for viewing.

'Although the students are in regular contact with patients during

placements, they frequently report that there is only limited time

and other barriers exist which restrict opportunities to "really" listen

to people.'

NHS staff (clinicians as well as managers) were also moved by the stories:

'Both audiences were emotionally stirred by the clips; they were

short and made strong points which were memorable.'

'They are generally the most impactful element of a presentation.

They "still" the audience and do not (necessarily) evoke an

immediate response.'

'Setting the scene at the beginning of an event with a story can get

people focussed quickly on what the event is about.'

'The staff found them very valuable and somewhat emotional!'

'Silence at first and then demonstration of some powerful

emotions such as sadness and anger. The audience were very

vocal and were reluctant to leave the topic and move on. They

became quite passionate about the need to involve patients and

how they could do this locally.'

Silence, termed 'the pin-drop effect' by one respondent, is followed by lively and 'passionate' discussion and debate with unusual breadth, depth and feelings expressed, particularly among students.

> '"*Jimmy's story*" generated a lot of discussion around ethics, health
>
> inequalities, professionalism and legal issues.'

> 'The students found the clips very helpful and I think they made
>
> more of an impact as the patients and carers told their own
>
> stories.'

Several respondents appreciated a different kind of opportunity to encourage clinicians to 'engage' with patients.

> 'Many clinicians do not respond to qualitative data and only deal
>
> with hard facts and figures. Because the stories are brief, they can
>
> be shown to teams quickly to set the scene before facts and
>
> figures supporting the evidence in the story are then delivered.'

The powerful impact of the stories was universally acknowledged. Indeed, there were concerns that some stories were too 'emotional' and might need to be accompanied by a 'health warning' before viewing and possibly support afterwards. Several members in different focus groups were unsettled by "For the love of Lee'", a story that was originally intended to convey a message of hope and regeneration. The issues raised are described later in a separate section dealing with concerns and issues for further exploration.

The consensus was that, if a story caused undue upset, this was something to be noted and, perhaps, taken up in supervision.

Several groups discussed the therapeutic nature of the stories – both for storytellers and, sometimes, for viewers (who might see in the story an echo of their own experience, thus reinforcing and validating their own story), and of the potential of the stories to promote holistic or 'spiritual care'. Healthcare workers are not always interested in the spiritual aspects of care, preferring to focus on functional and medical approaches to curing the patient.

> 'They don't want know about what sort of spiritual pain you are in
>
> they just want to know "can we give you more morphine to make
>
> you more comfortable", so in terms of giving an insight into what's
>
> going on in patients' minds, they're brilliant, and I also think that

> *making nurses think that, if this is what patients are actually*
>
> *getting concerned about, maybe this is something that I should be*
>
> *looking at when I'm giving holistic care.'*

Reflection

Although the opportunities for reflection afforded by the digital stories were regarded almost as a given, groups discussed the different approaches and ways of strengthening the reflective process, such as offering a quiet space in which people could 'really listen in the calm of the classroom' to the stories, while at the same time 'energising' the discussion and grounding it in the realities of practice.

> *'Like poems, digital stories are "powerful emotions, recollected in*
>
> *tranquillity" (Wordsworth) and, like them, can convey feelings that*
>
> *are difficult to communicate in more prosaic forms and that often*
>
> *are submerged (for the recipient and the giver of care) by the*
>
> *pragmatic pressure to act in times of heightened stress. Because*
>
> *they can be viewed "in tranquillity" by professional staff, they have*
>
> *the opportunity to "listen with their whole being" (Simone Weil) to a*
>
> *profound truth about the essence of care.'*

Their suggestions echo Moon's conditions for reflection (Moon, 1999):

- time and space

- a good facilitator

- [appropriate] curricular or institutional environment

- emotionally supportive environment.

One respondent noted the combined effect of the reflection that has gone into the story (created in the conditions outlined by Moon above) and the reflection on practice stimulated by the finished story – with the resulting potential for learning, action and change.

> *'The patient gets time to reflect on their experience and put that*
>
> *into a story, making the whole experience more understandable*

for them, and in turn when used with a professional it brings the

patients reflection to them so they can understand the patients

experience and then plan and act to improve the service quality.

Classic Kolb in action! '

A number of different kinds of reflection were explored, and some of these are linked with the

development of empathy and attending to feelings, including:

- examination of one's own practice, including continuing professional development

  'The stories triggered much reflection in students of their own

  practice and of certain situations where similar issues have

  arisen.'

  'There is an opportunity to use [the stories] as a reflective analysis

  of how to support and engage reflective learning throughout your

  career.'

  'I will think more about all the issues that affect people in this

  situation, and not just the immediate solution.'

- reflection on the experience of the storyteller (and others in the story)

  'This is the point of the Patient Voices obviously, to harken to the

  patient's voice, to see [and hear] it with the visuals and to

  empathise with the meaning of the experience from the patient's

  angle.'

  'It made me aware of the problems on a personal level, not just a

  medical problem.'

  'It's made me realise how difficult it can be for the person suffering

  with any condition.'

  'Made me more aware of people's feelings.'

- opportunities to recognise and acknowledge different (and similar!) perspectives

> *'I've used the stories with carers and patient groups to validate and*
>
> *authenticate the value of their perspectives.'*
>
> *'It puts it into perspective, looking at a patient's view.'*

- raising awareness of other's experiences (putting yourself in their shoes)

> *'It really is a wonderful projection to real life and real circumstance,*
>
> *these pictures beautifully take you in to your imagination to those*
>
> *places, you know, you are literally taken and it's like you're in this*
>
> *real intimate place.'*
>
> *'I will put myself in the patient's position in future.'*

- noticing the unusual, the unexpected, the things people are less likely to think about.

> *'But the point is to alert them to things that they are less likely to*
>
> *think about, with the whole range of stories.'*
>
> *'It's made me think about the carers, especially if they are a family*
>
> *member.'*

Links were made between the reflective process and the opportunities for discussion afforded by the stories.

> *'Patient Voices may point up 'glaring instances' a device beloved*
>
> *of Dickens, where people are able to recognise and confront some*
>
> *aspect of themselves when they see it exemplified and magnified*
>
> *in the actions of another. Which nurse will not have behaved, or*
>
> *felt, like the nurses in Alison's* <u>*"Who cares?"*</u> *story?*
>
> *They can explore and discuss with others the issues that generate*
>
> *and sustain this sort of response within a cloak of "vicarious*
>
> *safety", which may or may not enable them to move to a deeper*
>
> *level of disclosure about issues that touch forcefully upon*
>
> *"professional identity".*

Dialogue, discussion and debate

It was clear from the debate within the various groups that the stories are a 'trigger', a 'stimulus', 'good seed material', 'a way of initiating discussion and for bringing issues to people's awareness' (including the spiritual dimension of healthcare), of engaging people and of 'giving permission for people to start to share their own experiences'.

> *'The stories provide a powerful springboard both for individuals and for groups of learners, and can facilitate discourse about feelings.'*

> *'I see it as a way of engaging people emotionally with the topic rather than starting from a very dry and abstract approach; this has dogged previous learning about clinical governance in the past.'*

> *'The clips stimulated a range of opinions and comments regarding … patient care and the importance of maintaining individuality … and resisting the over-medicalisation of individuals. The debate also covered issues to do with loss.'*

One of the ways in which this happens is by allowing people to see themselves, or reflect on their own experiences through the story.

> *'There is something about bringing [a story] that's very human, that goes right to the centre of some painful or controversial issue in to the arena, but that is also neutral to the group because the group doesn't know the person who has written it. So they can share that very personal material, but then they can discuss it at whatever level they feel comfortable. They're not forced to expose their own particular experiences if they don't want to. I think that can be very valuable to groups - it seeks discussion and then gives permission for people often to start to share their own experiences.'*

One group voiced concern that the stories the intimate nature of the stories and the richness of the material would not work well in large groups. Other groups overcame this obstacle by breaking large groups down into smaller groups, with a structured approach to discussion:

> *'We showed the stories in groups of three and then we gave*
>
> *people a chance to discuss [in small groups with a facilitator] what*
>
> *they thought about them, you know, how they felt about it. Then*
>
> *we did some group feedback from the tables.'*

Respondents felt that the stories provide an excellent way to engage groups from all professions and at all levels, from pre-registration nurses to postgraduate researchers, from care-home workers to service improvement managers and policy makers, from health promotion to end-of-life care, particularly where discussion was conducted by a skilled and creative facilitator.

> *'The debate also covered issues to do with loss … where issues*
>
> *regarding loss of identity, body function and loss of individuals*
>
> *through death were all made accessible through the videos.'*
>
> *'Because the resources are so compact and the visual bits help*
>
> *so much, you can actually expose people to a lot in a little time, so*
>
> *you can exchange time for intensity, which if people respond and*
>
> *you got some good interaction around the story, makes incredibly*
>
> *effective training, because you do a lot in a short space of time.'*
>
> *'I think they promote discussion between staff groups and can*
>
> *appeal to the different ways that professionals interpret data.'*

Empathy and understanding

Caring, according to Noddings (2002), is the foundation for ethical decision-making. Her definition of caring as a quality of receptivity and attentiveness, shares some similarities with Carl Rogers' concept of empathy (Rogers, 1951) but also reinforces the need for reciprocity in a relationship that involves dialogue and exchange; these values lie at the core of the Patient Voices digital stories and of this research, and the stories evoke these qualities from listeners.

The opportunity to enter another's world through the story 'gives such an insight', and provides 'a sense of shared experience'. With many patients and service users 'keen to the point of desperate' to tell their stories, the stories have the potential to develop empathy by giving the listener a genuine experience of 'the other' with the possibilities of 'developing new relationships between patients and professionals working with the patients'.

This was thought to be particularly important in relation to cultural diversity and the need for greater understanding of the individuals who inhabit our multi-cultural society.

Through the focus groups, we were able to enter several other worlds, as we discussed the meanings of the stories and then attempted to bring that meaning into the world of the group and invest it with a new, shared meaning. One particular story, "A world of difference", elicited considerable discussion in several groups: the story is told by an English nurse about a Somali woman who goes into labour, having been circumcised. There were multiple interpretations and much discussion, partly in relation to whose story it was.

> *'If we are going to see stories about health professionals, it's got to*
> *be about them, they cannot retell the story from someone else's*
> *perspective.''*

And yet, we are implicitly called upon to empathise with the nurse as much as with the patient; it is as much the nurse's story as it is the patient's story.

This debate went on to raise a number of other important questions:

- Are we being asked to condone or to punish female circumcision (and if the latter, what do we put in its place as a cultural rite of passage)?

- Are we simply being made aware of different cultural practices? If so, does such a story need to be set within an appropriate cultural context?

- Are we to make assumptions about the woman's feelings regarding beauty?

- How do we deal with responses that may include revulsion and judgement?

- How are we to understand stories that are told from different cultural perspectives and arise from different narrative traditions?

The notion of evaluating stories in the light of different cultural perspectives was also touched on in relation to "A brighter world waiting", in which the storyteller draws on her own cultural tradition of meditation to 'heal' herself. We are invited to experience linguistic differences in the telling of the story, related both to aphasia and to the fact that the storyteller's first language is not English. Through the story, we have an opportunity to experience Rizia's personal challenges in ways that would not otherwise be possible.

There was felt to be real potential for change as a result of watching, reflecting upon and considering the stories.

> *'[The stories] put the professional in the patient's shoes.'*
>
> *'I will respect patients more – I had limited knowledge before.'*
>
> *'I will be more patient.'*
>
> *'I will make more time.'*
>
> *'I will not judge so quickly and will think of people's capabilities.'*

Most respondents felt that the stories could contribute to greater empathy and understanding between patients and staff, particularly in a world characterised by 'tick boxes, audits, targets, league tables and activity recording' where

> *'NHS workers can, over time, become rather immune to and*
> *detached from their feelings, as they deal with patients every day*
> *and the system forces them to behave in this manner.'*
>
> *'The stories can help develop empathy between patients/clients*
> *giving the listener some experience of "the other", with the*
> *resulting possibilities for change and developing new and different*
> *sorts of relationships.'*

The student nurses were moved by the story they watched:

> *'I felt sad for Jean and for her husband.'*
>
> *'I must just continue to put myself in the place of others for the*
> *level of care I try to give.'*

'I realise now how important it is to communicate with patients

about their condition.'

There is a clear advocacy element, with patients and carers feeling empowered to tell their stories in a powerful and succinct way. Two people commented on the validating effect of the stories for carer and patient groups.

There was also felt to be potential for promoting greater understanding between staff groups.

'Raises the importance of a seamless service to prevent the

frustrating circumstances Monica experiences in "[Nobody told](#)

[me.](#)"

'They can also facilitate greater understanding across the

manager/professional & professional/manager chasm.'

Patients at the heart of care

There was clear consensus about the ability of the stories to situate patients/service users firmly at the centre of health and social care.

'Because the stories are so short, you're really left with the feeling

that this is something this individual really wants me to know.'

'The clips stimulated a range of opinions and comments regarding

a variety of issues to do with patient care and the importance of

maintaining individuality of patients and family and resisting the

over-medicalisation of individuals.'

The stories highlight that 'patients are experts in their own condition'. Several people commented on one story that makes this particular point very clearly:

'When you first come across the Patient Voices you actually

realise that this opportunity is right under your nose that is just

being missed. I thought the Ian Kramer's story "[Another pair of](#)

[eyes](#)" was very good in terms of who's the expert here, you've got

somebody coming along and auditing – something around nurses

and whether they are gloved up or not – and he said "you can just

ask me and I'll tell you".'

Through their stories, patients are seen as individuals, with their own values, challenges and aspirations, with unique life journeys, of which healthcare and the patient journey is only a part. Often what is important to the patient is not necessarily the most important thing to the clinician – and the stories offer a way of finding out what matters to patients.

The student nurses who viewed Jean's story, "Getting to the bottom of things", were particularly struck by Jean as a person who had travelled from health to disability, and not just a patient.

'It helps bring to light that people are not just patients, and that

they have had different lives.'

'It's made me think more about how the person used to be and

how they are now… and how much people's lives change due to

their condition.'

'Stories such as Jean's should be included in all healthcare staff

training.'

'I will always respect people's inability to do things even when

health promotion and independence issues are trying to be

encouraged.'

Perhaps the most surprising – and pleasing – finding was from the group which describes the way in which the stories caused them to rethink their education curriculum around clinical governance and continence care, to:

'… develop education around the stories, trying to get people to

think about specific situations rather than conditions, treating

patients as individuals rather than treating conditions.'

Their intention translated into radical actions. Instead of shaping the stories to fit pre-determined learning outcomes, the original outcomes were discarded and new ones created, after the development of the stories, according to 'what really mattered to the patients'.

'My original idea was to have certain stories about certain

situations and stick them within a framework, but looking at how

the stories have developed, it's now looking at the stories and

seeing how we can build learning outcomes around those stories

to make them more…patient-centred.'

'The approach that we are trying to take … is the reverse of what

we have done in the past where we worked on the materials and

then inserted Patient Voices at various points to enhance certain

issues that we wanted raised. I've actually resisted starting on the

clinical governance area before I've had the stories in front of me

and I think that should make them more as the starting points and

triggers for reflection.'

'I want to grow the learning area from the stories and not the other

way round; you tend to be asked to write your learning outcomes

and then you develop case studies associated with them. I want

that situation to be changed.'

The magnitude of the change has placed patients firmly at the centre of the learning

programme and provided a new sense of purpose to those developing the learning resources.

'And our original idea of where the framework was going to sit is

not there any more because the stories wouldn't fit with that.'

So the framework now has to fit the stories. The learning now fits the needs of the patient

rather than the treatment of the patient being determined by the framework. The hope is that

the creation of the learning materials in this way would result in changes to the way care is

delivered, despite turning the entire programme on its head.

'I'm hoping that the learning will have more impact on patient care

because we are actually building the learning outcome based on

what the patient is identifying as the important issue. Instead of

building learning around the issues that I feel are important and

what I think is important to the patient, we are actually doing it the

other way, building it on what the patient thinks is important and

then adding on the clinical issues as well.'

'It's like Sue says in her story [She always liked to feel useful",](#)

about putting the care back into caring.'

Another participant remarked, 'the students of today are our future'. If their ways of engaging

with patients and reflecting on practice can be changed as a result of seeing the stories then,

in time, that practice will change.

Interprofessional education and research

Different professions and different organisations in the health service tend not to share

learning and may have little understanding of the challenges, issues and successes of other

groups.

'The stories provide an opportunity to develop empathy between

the various professions working with the patient.'

Groups without an explicit focus on interprofessional education also highlighted ways in which

the stories could be used to 'reduce the silo mentality', promote working across teams, share

knowledge and understanding to work more effectively for and with the patient.

'Most of what we do involves lots of disciplines, different levels of

staff and, we try to deliver the message in various ways that will

appeal to different members of the audience. You try to get a

punchy message across and engage people in different ways.'

'The stories have something to say to all disciplines.'

Patients as part of the team

Patients, carers and service users were considered to be an important part of the

interprofessional team and all respondents acknowledged the need to involve service users in

healthcare education. It is important to listen to patients, not least because:

'A lot of the stuff that the patients are talking about isn't what a

health care professional would think of.'

> *'Ian Kramer's [*"Measured innovation"*](#) story illustrates the power of*
>
> *true partnership'.*

Debate focused on how to involve patients and service users in the inter-professional (teaching) team, particularly as patients, by definition, may have difficulties with travel or may find themselves subjected to close questioning and public scrutiny.

One group discussed concerns about replacing real (or simulated) patients with digital stories, while another felt that the stories offered something better than drama and simulation.

> *'They've got to be better [than actors performing a prepared*
>
> *script] unless you've got absolutely brilliant actors you always feel*
>
> *like you are watching a play.'*

Discussion led to a consensus that it does not have to be an either/or situation; both ways of involving patients are desirable and the stories could also provide valuable data.

> *'Patient Voices form the core of the online learning resource*
>
> *developed as part of the project. I thought I would let you know*
>
> *what positive feedback I have received when using patient stories*
>
> *once back in my clinical role. I have framed them in various ways*
>
> *and used them in sessions for District nurses, Hospital staff and*
>
> *pre-reg students. Feedback has been excellent. The power of*
>
> *each story is invaluable and [they] enable me to deliver sessions*
>
> *which truly include the patient's perspective.'*

Evaluating narrative

One focus group noted the potential of the stories to teach students about 'the role of evaluation in the narrative', with a view to gaining a better understanding of the storyteller's experience and point of view.

> *'It's important to note that no matter what intention you've had*
>
> *when you first recorded [the stories], the users can use it for many*
>
> *other reasons and many other purposes according to what they*
>
> *need in that environment. Because it's a narrative, people can*

interpret the story from different angles according to their

experience, their care with patients, or other issues, or educational

environment.'

Students could be encouraged not only to reflect on the 'content' themes of the stories, but also to consider:

- the narrative themes, including:

  - the point of the story

  - the extent of personal evaluation by the storyteller

- why this story is told in this way

- how it might have been told differently

- the different perspectives of other people in the story.

  'If I were going to use it in an interprofessional context, I would

  want to pull out those different perspectives and ask people to

  think about the different ways that they are all viewing the same

  segmented piece, and why, and what's going on.'

The final stage of such an exercise might be to tell the story from those different points of view. This, it was felt, could offer opportunities for creative and active reflection resulting in new understanding and empathy.

Research and data-gathering

All groups felt that the digital stories could form a useful way of gathering data about service-user experiences, as they reveal things that are unlikely to surface from research based on questionnaires, which ask questions that are important to the researcher, but may have little relevance to the service user.

  'Instead of having your survey that you send out randomly to so

  many service users every so many months – were you happy with

  this bit or that bit – I'm asking those patients about things that I

  want to know about and I'm really not finding out what was

important to them, maybe, instead, we could have some kind of

forum where we have stories or experiences of using the services,

that might be a way of getting service user input.'

Not only could digital stories be used as a means of feedback on service provision, but they could also play a part in academic (post-graduate) research.

'If your PHD is around patient experience you might want to look

at this because it may give you some ideas for questions or

directions of study.'

'The Patient Voices tell [students] the things that health

professional don't tell them, and that's really what people need.'

In response to the criticism that they must be too short to provide reliable and valid information, one respondent had this to say:

'People will argue that if you've got more information you've got

richer information, you've got deeper information, but that's not

necessarily the point. If you have got a seventeen page narrative

to plough your way through, by the time you are on page 10,

you're skim-reading at best, so you might miss the key thing, or

you might think that the key thing is something that you've picked

up on as an issue which the person themselves doesn't really

think is that important, whereas with the Patient Voices, they're …

three minutes long.'

Their brevity was felt to be more than adequately compensated for by their intensity, and the two/three minute format was a decided benefit, with the combination of visual images, voice and music providing a richly textured opportunity to understand another's world.

And the stories could provide a useful balance for theory:

'You can theorise as much as you like, I mean you could do all

sorts of thinking about the theories and the opinions on loss and

bereavement and people's motivation for taking part in voluntary

work, and that would be very rich and very valuable, but three

minutes watching "For the love of Lee" makes you realise the

depth of someone's commitment doesn't come from all those

theories, it comes from the relationship she had with her dead

boyfriend.'

Changes in practice

Some changes have already been highlighted above, under the headings 'Patients at the heart of care' and 'Developing empathy'. Other possible and actual changes resulting from use of the stories were identified, both with colleagues, wider organisations and in respondents' own practice…

'As for myself, my teaching practice has changed as I now attempt

to use patient stories in as many relevant lectures as possible

without slipping into over-using the clips.'

'I think more deeply about the issues – and I am grateful to be

able to draw upon authentic 'first hand' accounts – rather than the

(sometimes patronising) stories 'about' patients that are

sometimes recounted by the 'great and the good'.'

'In one of my areas, the staff in a cardiology setting have decided

to introduce the Liverpool Care Pathway for the dying as a result

of the day.'

'It has made me aware of the different ways I could listen to a

person's story, hearing the ironies and the contradictions.'

'It's made me more open to the idea, with my research hat on, to

user participation. This really highlights the contribution that

people could make.'

Some felt that the stories could have an impact on the quality and safety of care by raising awareness, encouraging reflection and promoting empathy.

*'The stories can have an impact on patient care as they forcibly
remind practitioners of the importance of maintaining the dignity
and individuality of patients and their families. The stories
demonstrate that maintaining and building a relationship with
patients based on trust and partnership can avert problems and
ensure a better quality of care.'*

*'I think a greater understanding and "seeing the other side of the
story" will improve [quality and safety] and will help people to think
outside the box.'*

*'The stories provided thoughts on individuals' practice with people
questioning things they had done routinely and might approach
differently in the future. Any change in quality and safety has to
have an organisational impact.'*

But it was noted that, for this to happen,

*'at an organisational level, there has to be real commitment by
senior managers/CEOs.'*

A hopeful comment on the versatility and creative potential of the stories from one lecturer:

*'From a simple video we have developed a whole host of themes
which can be discussed and shaped for the purpose of getting
professionals and students to question practice using different
examples and although the video talked about Haemophilia, in this
case it was not the main element of interest.'* [Alison Ryan's story:
"Who cares?"]

is balanced by scepticism on the part of another:

*'The issue is that while professionals may say, sure this is great,
will they do anything about the messages they receive? Will the
digital stories become a tokenistic exercise?'*

The most remarkable change (described on pp 25-26) has been by someone who had initially been uncertain about the use of digital stories. In her mind they were elided with video diaries, case studies, training videos, etc. Her plan had been to make some digital videos to educate students about continence care; the stories would thus have a highly informative function. When, after much discussion, she realised the potential of a short, personal story, partly through creating her own digital story, she became a zealous convert to the potential of Patient Voices digital stories in education and training.

> *'It is something so different, it's really worth giving it a go and*
>
> *seeing what happens.'*

The changes in education practice she has made in a national programme of learning delivered by one of the Royal Colleges may yet have a real impact on how healthcare is delivered in the future.

One interviewee, who initially thought she would have little use for the stories, as she is not currently teaching, changed her mind:

> *'It's made me more open to the idea of using participation [in*
>
> *research]….this really highlights the contribution that people could*
>
> *make, and having somebody who's had that experience*
>
> *contributing to, say, your research project, it's not just a token, it's*
>
> *a genuine contribution because they've got these genuine*
>
> *experiences and feelings that sometimes researchers don't pick*
>
> *up on, so I think it has made a difference to how I view that.'*

There was much discussion as to how the stories could be used to change practice, particularly in education. A good deal of creative thinking and new ideas spilled into the discussions; the stories could be useful in podcasts and virtual learning environments, in small and large group work and across a number of contexts. Relevant stories could be shown to patients in GP surgeries and in specialist clinics in hospitals, and used as part of continuing professional education for health professionals.

The stories have caused many people to look more carefully at their own practice with the prospect of change in many ways, from individual changes in outlook to the potential for

changes that would have a national effect, such as the introduction of a care pathway for the dying.

Concerns, limitations and issues for further exploration

Some concerns were expressed about ownership of the stories, highlighting the importance of the storyteller's central role in the finished story; this comment was particularly with respect to the story told about a patient by a nurse: "A world of difference".

> *'They are so powerful, I think it's an excellent opportunity but I also*
>
> *think there is something about the process of who owns that*
>
> *experience.'*

One respondent expressed reservations about the 'coercive' nature of the stories, which he regarded as akin to propaganda, notwithstanding their ability to make a powerful point:

> *'I think it [digital storytelling] has a very strong sort of propagandist*
>
> *value. It's a very good way of getting a point across or a theme*
>
> *across, but I don't know if it brings out, necessarily, the subtlety or*
>
> *ambiguity of things. I mean, at best, they give a strong message*
>
> *very effectively and usually make one central point.'*

This did not seem to be a general concern and, indeed, his remark about a central point was regarded as a strength by others who felt that this revealed what was truly important to the storyteller.

Some respondents were concerned about the strength of the emotional content and felt that, in some cases, a 'health warning' might be appropriate before showing certain stories. Discussion about "For the love of Lee", in which the death of the storyteller's boyfriend leads her to follow a career in health promotion, revealed some interesting paradoxes and pertinent questions in relation to:

- what is upsetting or distressing for one person does not bother another (it is not always possible to predict individual responses to the stories)

- unexpected situations do happen, and that is part of life – and clinical practice

- in practice, one does not always have the luxury of a warning when a patient dies or a service user brings up a painful or difficult issue or responds 'badly' to bad news

- whether it is appropriate to warn people that a particular story may be upsetting, and thereby possibly pre-determine their response to the story

- whether there is a sound basis for using such stories as an opportunity to practise dealing with grief, loss, bad news, the unexpected

- the extent to which the ability to deal with 'sad' stories, may affect the ability to deal with the deaths, losses and problems that are the everyday reality of working in the NHS?

Several groups touched on the possible benefits of a surrounding 'pack' or the provision of users' notes to accompany the stories. Some felt that knowing something of the background to the stories might enhance their power/usefulness but others were concerned that this might reduce their flexibility.

> *'But the point is to alert them to things that they are less likely to think about, with the whole range of stories, you don't want a recipe for each story - that would be a reading comprehensive approach, as it were.'*

> *'You know, if it says its for teaching they won't think about using it for research, if it says its for research they wont use it in conferences, whereas at the moment they are just there for any body to use however they wish.'*

Service transformation and system change

> *'I am currently exploring various ways in which I can include patient stories into my clinical care as a quality improvement tool.'*

Despite general recognition of the failure to learn and share lessons within and between organisations, there was a sense that digital storytelling could, through empowering

individuals to share their realities with viewers, create a sense of shared ownership that one respondent hoped would

> *'liberate real enthusiasm and determination to deliver better care*
>
> *for patients.'*

The potential for transformation and change at all levels could be enhanced by digital storytelling with its opportunity to connect both with values and with patients, and provide:

> *'a mechanism to create change through showing what can be*
>
> *achieved to individuals, their teams and the broader community'.*

Communities of practice

Communities of practice would seem to emerge naturally from this desire for connectedness and shared learning. However, despite a good deal of talk about communities of practice, they are not yet routine in the health service. Some felt that this was a result of reluctance to show feelings or admit failure, but that a more managed way of sharing experiences, giving them a point and containing the emotions, could be achieved within the relative safety of the facilitative group process and tight structure of digital storytelling.

> *'Indeed the storytelling is the centre piece of Wenger's community*
>
> *of practice model. The digital stories provide an excellent*
>
> *mechanism to bring these stories into the middle. I also liked the*
>
> *centring of the patient in the healthcare community through the*
>
> *process. Wenger states that at the heart of us all there is a desire*
>
> *to be part of a community, and the patients, whether with other*
>
> *patients or in collaboration with the carers and professionals have*
>
> *that desire.'*

Online communities and virtual learning environments offer opportunities for the dissemination and discussion of the stories with students, teachers and clinicians all able to take part on an equal footing.

Improving quality and safety

There was an earnest desire among these groups to provoke and promote change that would lead to genuine improvements for service users and it was felt that digital storytelling has a place in that process.

> *'What you hope that they do, even if it's just in some small way,*
>
> *you hope that they change people's practice or make them think*
>
> *about their practice, but it's not always in ways that people can*
>
> *say, "you know as a result of that I've done this…"'*

The ultimate goal of all this thought, consideration, education, training, discussion and debate is to improve service users' experience of healthcare. This need not be difficult – it may be as basic as a smile or a friendly touch – although the routine things do need to be in place.

> *'The stories demonstrate that, like love, good care often lies in*
>
> *"those endless trivial things that at the time we glance at and*
>
> *dismiss". It is when simple things are not routinely done well that*
>
> *damage can occur, like the brother's preventable death from a fall*
>
> *in* [*"Jimmy's story"*](#) *.'*

Providing safe, high-quality care relies on finding out what's important to individual patients, their carers and other service users, and is not necessarily about making assumptions based on aggregated statistics that are taken as 'evidence'.

> *'I think it would be a recognition of the value of capturing*
>
> *individual stories, that you don't have to have something that is*
>
> *statistically significant to learn something about getting the basics*
>
> *right. It's about re-visiting and re-packaging the service, getting*
>
> *the basics right. And actually you get the basics right by being in*
>
> *tune with the patients and really learning about what does this*
>
> *team and this ward get right and what it doesn't, and what needs*
>
> *to change.'*

If organisations would just listen to patients and service users, services might improve.

'It's just getting organisations to think about how they do things

and who it is they really should be asking if they want a view on

things. We all talk about getting the patient experience right and

improving the patient experience, but how do we know how well

we're doing that and are we doing it at all?'

Pulling several strands of discussion together, one respondent suggests that:

'Patient stories, teamwork, education and development, better

services and supreme patient experience can all be integrated…

through better commissioning.'

Stories can be used to monitor progress and provide evidence of change and improvement:

'If the stories change, things must be getting better!'

'It's just getting organisations to think about how they do things

Discussion

> **patience,** *noun.* calm endurance of pain or any provocation; perseverance
>
> **patient**, *adj.* having or showing patience
>
> **voice**, *verb.* give utterance to, express
>
> *Concise Oxford Dictionary, 1964*

NOTE: For the purposes of this discussion, patients, carers, clients and service users will all be referred to as 'patients'. While mindful of the arguments for more 'politically c2orrect' terminology, with special respect to those who have been concerned that the name 'Patient Voices' may reinforce a medical model of illness and disability, the researcher would like to clarify the play on the word 'patient', which is intended to convey the 'calm endurance and perseverance' that characterises so many of the people who have told their stories, whatever their role in healthcare.

> *'Every light was a story and the flashes themselves were the*
>
> *stories going out over the waves, as markers and guides, comfort*
>
> *and warning.'*

Winterson, 2005

The journey from storytelling to service transformation

Early consideration of the findings revealed a pattern, somewhat hazy at first, emerging through the themes; initially it appeared as a journey from story to service transformation, as shown in Figure 1 on the next page.
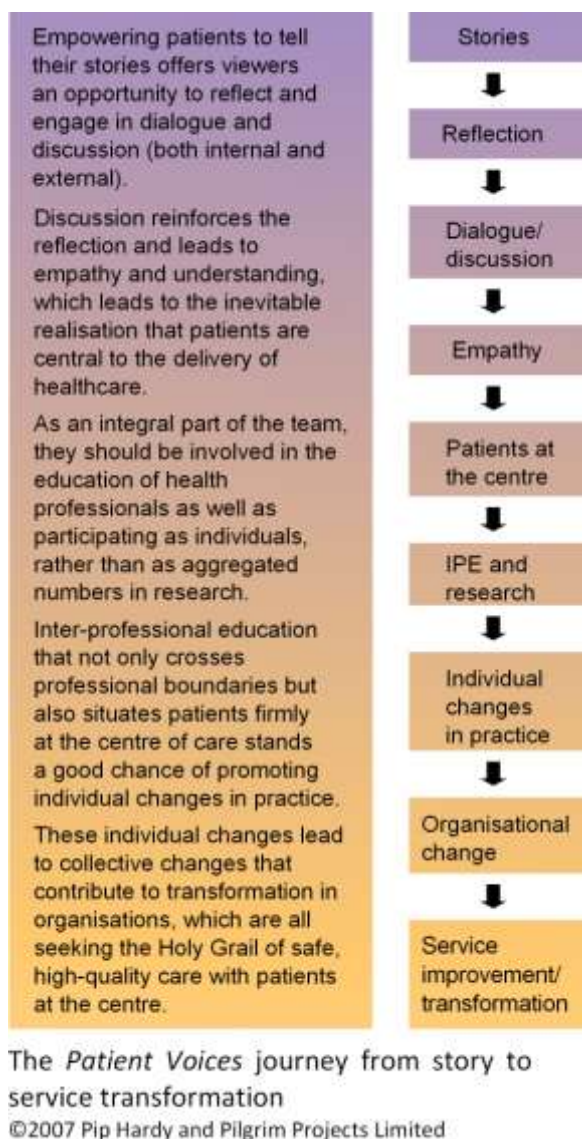
Empowering patients to tell their stories offers viewers an opportunity to reflect and engage in dialogue and discussion (both internal and external).

Discussion reinforces the reflection and leads to empathy and understanding, which leads to the inevitable realisation that patients are central to the delivery of healthcare.

As an integral part of the team, they should be involved in the education of health professionals as well as participating as individuals, rather than as aggregated numbers in research.

Inter-professional education that not only crosses professional boundaries but also situates patients firmly at the centre of care stands a good chance of promoting individual changes in practice.

These individual changes lead to collective changes that contribute to transformation in organisations, which are all seeking the Holy Grail of safe, high-quality care with patients at the centre.

Stories
⬇
Reflection
⬇
Dialogue/ discussion
⬇
Empathy
⬇
Patients at the centre
⬇
IPE and research
⬇
Individual changes in practice
⬇
Organisational change
⬇
Service improvement/ transformation

The *Patient Voices* journey from story to service transformation
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Figure 1: The journey from story to service transformation

Reflection, discussion, dialogue and empathy

> *'We do not learn from experience, but by reflecting on experience.'*

Dewey, 1939

Reflection, says Joe Lambert (2006) of the Center for Digital Storytelling, is 'as natural as eating, breathing, or telling stories'. Reflection is a key lifelong learning tool for all professionals (Schön, 1983; Eraut, 1994), offering a structured means of studying processes and challenges and making connections in their personal and professional lives.

Many participants spoke of the emotional content of the stories. The importance of emotion during the reflective process was articulated by Wordsworth (1798), when he described

poetry as 'emotion recollected in tranquillity', and subsequently highlighted by other

humanistic practitioners including Rogers and Freiberg (1993); Schön (1983); Boud *et al*

(1985) and Heron (1999).

Although John Dewey (1933) explored the idea of reality in relation to reflection on

experience, he did not attend to the ways in which people's sense of themselves and their

frames of reference are formed in dialogue with others (Smith, 1996; 1999).

The digital storytelling process begins by enabling storytellers – patients – to make sense of

their experiences; then allowing professionals to reflect on practice by seeing things through

the eyes of others, thus creating a kind of dialogue between the storyteller and the listener.

This process of 'sense-making' (Weick, 1979), relies as much on emotions as on reason

(Mezirow, 1991). The evidence of experience provides an essential balance to the evidence

that comes from clinical trials and patient surveys and is revealed through statistics and

reports. Weick further suggests that you need people's *attention* before you can get their

intention – that is their commitment to go out and actually do something; there is little doubt

that the stories grab the attention and thus help to instigate the first step on the journey to

transformation; they do this in part by engaging all parts of the brain (Zull, 2002).

In the words of one participant in a pilot study for this investigation:

> *'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.'*

<div align="center">Hardy, 2005</div>

Learning does not happen in a vacuum. As Smith (1999) reminds us, we all live, work and

function as part of a group or groups, and dialogue with others is crucial to forming a sense of

self and shaping the frames of reference through which we engage with the world. Digital

storytelling not only facilitates such a dialogue, but also offers the opportunity to 'name' reality

'with our own voice'. This 'naming', according to Mezirow (1991), allows us to negotiate

meaning, purpose and values, and frees us from the passive acceptance of what is taken for granted. This is the first step on the way to transforming ourselves, our perspectives and our worlds.

This 'encounter between men, mediated by the world, in order to name the world' (Freire, 1972) can lead us to deeper individual and collective understanding, through the telling of our own stories and making sense of other people's stories. Stories and narrative are part of both the individual and the collective reflective process, as we 'tune our relations with each other and with the world' (Wenger, 1999) through this form of dialogue.

So, the development of empathy does not happen in isolation, or arise only from reflection, but is enhanced by discussion, which can be both reinforced by and lend strength to a structured programme such as those provided by interprofessional education (IPE).

Interprofessional education, learning and change

Interprofessional education is defined as 'occasions when two or more professions learn from and about each other to improve collaboration and the quality of care' (CAIPE, 2002). Since the stories are not explicitly about particular conditions, but about the human condition, they are suitable for all audiences; exposure to the stories, like IPE itself, 'forces students to experience ways of seeing the world that are different from their own' (Slavin, 1983, quoted in Clark, 2006).

> *'I can see the potential for using these for initiating discussion with*
> *researchers or research participants or also training users who are*
> *going to be taking part in research to get them listening to what*
> *people are saying and what they are meaning and what the story*
> *behind what they are saying is.'*

There was little doubt in the collective response that some kind of change occurs as a result of seeing the stories, reinforcing Schön's (1983) recognition that

> *'the unique situation is understood through the attempt to change*
> *it, and changed through the attempt to understand it'.*

Barratt (2005) offers us useful links between Moon's stages of learning (Moon, 1999) and

McDrury and Alteiro's (2003) *schema* of learning through storytelling (please see Table 5).

Creating – and watching – digital stories gives us a chance to move from finding a story

(telling it or viewing it) through a series of stages to the reconstruction of a new understanding

and a new story and the transformative learning that can occur as a result.

Moon's map of learning	McDrury and Alteiro's learning through storytelling
Noticing	Story finding
Making sense	Story telling
Making meaning	Story expanding
Working with meaning	Story processing
Transformative learning	Story reconstructing

Table 5: Links between learning and storytelling

Just as individual learning and action are entwined (Kolb, 1984) effective education informs

and is informed by research. The digital stories tell us 'stuff that isn't what a healthcare

professional would think of' and, in so doing, provide high-quality 'data', revealing the

uniqueness of individual experience and offering the potential to monitor changes in service

provision by 'testing' improvements against the stories to see whether they have changed.

Stories prompt other stories and, with the loudening call for collaboration and a collective

response to the changing needs that will characterise 21st century healthcare, the skills not

only of telling stories, but of listening to them and evaluating them are crucial for all those who

wish to play a part in transforming healthcare.

The focus is shifting from educating individual professionals to the facilitation of team and

system learning (Stanton, 2007a). Micro- and meso-systems that include patients as full

participant learner/educators are more likely to see changes that lead to improvement.

> *'Improved health outcomes usually lie outside the scope or control*
>
> *of any single practitioner. Real improvements are likely to occur if*

> *the range of professionals [including patients and their own carers]*
>
> *are brought together to share their different knowledge and*
>
> *experiences, agree what improvements they would like to see, test*
>
> *these in practice and jointly learn from their results.'*

Headrick, Wilcock and Bataldan (1998)

Linde (2001) and Cortazzi and Jin (2005) have examined the ways in which stories and narrative help people to make sense of their own lives and the ways in which evaluation of these narratives, by both narrators and listeners, help to achieve coherence in the world; their research is borne out by the experiences and comments of the participants in this study.

What has also been reinforced by this investigation is the hypothesis that shaping – and viewing – the story in the digital genre seems to give wings to hitherto unrecognised creative potential, and creates possibilities for new meaning to come to light.

Through making sense of our own lives and the lives of others around us, and as a result of growing empathy with others, we may take steps towards making changes in practice, first at an individual level (perhaps in response to a particular story, as illustrated in the case study below); then, as attitudes change, behaviours may also change at a departmental level and finally, as the collective story reveals itself, changes will be felt – and perhaps even formalised – into transformation at organisational level.

Transformation

Transformation of any element at any level of the health service will affect other elements at other levels. As one respondent commented, 'the students of today are our future'. They have the power to change not only themselves but the way healthcare services are delivered in the future.

Already creation and use of the stories have resulted in radical changes to an educational curriculum, based on what is important to patients, rather than what is important to providers, counter-balancing Patricia Hewitt's (2005) declaration that 'the interests of the providers of services came to take precedence over the interest of the users of services'.

The case study below illuminates the significance of adopting such an approach and, incidentally, reveals the power of one story to transform the views and perceptions of one student – who is likely to carry out her duties very differently in the future.

Case study: Why don't people listen to patients?

Student nurses often spend time with me as part of their clinical placements. Many come with no clear idea about what they want to know but often have developed beliefs and attitudes towards continence care via previous clinical placements.

The student who spent time with me yesterday was on her care of the elderly placement and had witnessed several things that had made her question aspects of care. My clinical work for the day was a full clinic with patients arriving every half hour. It is difficult in this environment to provide appropriate learning, the best you can do is, with the patient's permission, talk through each clinical case, explaining as best you can. You do have to be careful clinic slots do not run over, therefore you have to be selective in discussions and sometimes finish ones before their natural conclusion.

My student was trying to clarify in her mind what a continence assessment was & I was trying to think of a way of illustrating how we adapt the assessment based on the patient's needs.

A patient cancelled at short notice leaving a half hour slot free, so I decided instead of showing the student various aids, documents, etc. I would show her Jean's story, "Getting to the bottom of things".

We watched the story together and I noticed her reactions at key parts of the story. She was horrified, sad and angry at various stages and commented "I have heard people say that!" when Jean talks about being told to pick her feet up.

After watching the story I asked her to "Think about Jean's situation and think what you might be able to do to help her address continence issues".

I told her to think of assessment as something that is not a tick-box exercise but as something where the patient's needs are explored.

She was able to correctly identify Jean's continence needs and think of strategies to help her cope. She also spoke about how simple, throwaway remarks from staff like "pick your feet up" can have such a devastating effect.

It was quite a surreal day because the last patient we saw told us how thrilled she was with the care she had received from our service and that she was now symptom-free. She told us she had been telling various health care professionals about her continence problems and no-one had taken any notice. She had self-referred and what we had done was very simple but cured the problem. The student then said "Why don't people listen to patients?".

With thanks to Joanne Mangnall for permission to use her story

The journey comes full circle

> *'Stories move in circles. They don't move in straight lines. So it helps if you listen in circles. There are stories inside stories and stories between stories, and finding your way through them is as easy and as hard as finding your way home. And part of the finding is getting lost. And when you're lost, you start to look around and listen.'*

Metzger quoted in Lambert, 2007

Closer examination of the findings revealed that the linear journey depicted at the beginning of this section does not accurately reflect the true nature of the journey, the process or the reality of people's experience of working with the stories.

Attempting to make sense of all the convolutions, intricacies, inter-relationships and facets of elements of the journey resulted in an attempt to distil the process. The image (Figure 2) that emerged reflects the essential interconnections that occur whenever the stories are used as a catalyst for change.

> *'Each affects the other and the other affects the next, and the world is full of stories, but the stories are all one.'*

Albom, 2004

The Patient Voices Mandala
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Figure 2: The stories move in circles or *The Patient Voices Mandala*

Mandala (Sanskrit for circle or completion) resembles the form into which the linear journey eventually evolved after repeated attempts to represent the experiences described above.

Every part of the story that emerged from the research data affects every other part. Every element overlaps with every other element and, although each element appears to be separate, it is actually interconnected with every other element.

Equally, it is possible to enter the *mandala* at any point, with any one of the 'petals' as the main purpose, and find that all of the other elements will contribute to the fulfilment of the original purpose.

Transformation surrounds and permeates the *mandala*, not only as a result of change which is occurring all the time, but as the result of changes in perspective (Mezirow, 1991). These are themselves the result of conscious attempts to learn, to understand and to change behaviour, emerging from a deeper sense of connection and community that emerges from telling and listening to carefully crafted stories.

The stories are both the beginning and the end of the circle/journey, going out initially 'as markers and guides, comfort and warning' (Winterson, 2005). They form the main element of a kind of alchemy, incorporating all the other elements. When the alchemy is complete, and all elements have combined and transformed into something more precious, the stories return once again to the centre, as part of the collective story of transformation.

Thus an immediate feeling of empathy with the storyteller ('You couldn't help but feel what that woman felt') might be followed immediately (or even accompanied by) reflection on the implications of the story and the effects of actions taken by health professionals. In other cases, the silence of reflection was the first step on a journey towards understanding and empathy that could result in changed practice and, ultimately, in healing.

Baldwin (2005) notes the healing nature of stories for individuals:

> *'To remember requires language: to heal requires story.'*

She goes on to suggest that untold stories emerge as trauma or depression in individuals and, in relation to larger groups, she warns:

> *'Unarticulated, collective experience that is not allowed into the*
> *social story shows up years later as political upheaval, violence,*
> *resistance, revolution, fundamentalism, spiritualism,*
> *disconnection, apathy, and disassociation with reality. But when*
> *these same experiences are shifted into language and*
> *successfully worked through, they lay the groundwork for*
> *transformative cultural development.'*

If we are to have a National Health Service that actually promotes healing, then stories must be told – and heard.

> *'A knowledge born of compassion aims not at exploiting and*
>
> *manipulating creation, but at reconciling the world to itself. The*
>
> *mind motivated by compassion reaches out to know as the heart*
>
> *reaches out to love… In such knowing we know and are known as*
>
> *members of one community and our knowing becomes a way of*
>
> *reweaving that community's bonds.'*

Palmer, 1983

Patients, acknowledged now to be a key part of the interprofessional team, must be supported if they are to offer the 'unique qualities that can improve the acquisition of ….skills, communication, instil confidence and change attitudes towards patients' (Wykurz and Kelly, 2002).

As they become more conversant with the 'activities, identities, artefacts, and communities of knowledge and practice' (Lave and Wenger, 1991), patients will be able to master knowledge and skills that enable them to move closer to the centre of the community and participate more fully in its socio-cultural practices. In order for this to happen, there must be opportunities for dialogue and for exchanging stories.

Transformative learning occurs as we understand and seek to be understood in a dialogue that opens language to 'redefinition through reflection and the accretion of new layers of meaning' (Mezirow, 1991). The creation and use of digital stories, through careful facilitation, offers patients and providers the opportunity to grasp and transform their experiences and, in so doing, participate more fully in the community, learning from peers and colleagues rather than from 'experts'.

Our *mandala* brings us full circle to the beginning of this paper and to the model provided by Winter (2003) (see p.6). The principles of change, responsibility and consequences, empathy and compassion, and harmonious speech have implicitly or explicitly permeated every part of this study. Working on the principle that 'Good [action] research is informed by the values practitioners want to realise in their practice' (Elliott, 1995, quoted in Winter, 2003), the values of care, co-operation, participation and collaboration have underpinned all 'attempts to create new understanding through negotiating and implementing improvements in the quality of

social practices' as the researcher has attempted 'close the gap between theory and practice' (Winter, 2003). Recognising the inherently spiritual dimension of the kind of 'person-centred, experiential, creatively co-operative aspect of the research, the researcher has attempted to adopt a 'skilful' approach to the inquiry process by remaining mindful of what Buddhists call 'The Four Boundless States', which are:

- loving-kindness: that is, positive feelings towards oneself and others, including those one does not care for!

- compassion: for the general suffering of humanity, expressed through words and actions

- sympathetic joy: that is, an empathic, joyful pleasure in the achievements or success of others

- equanimity: joy and compassion combine in a deep understanding of both the difficulties and the potential of the human condition.

This study has attempted to recognise and cultivate the sense of 'developmental creativity, optimism and imaginative compassion that is inherent in relationships of inquiry and professional 'care' (Winter 2003).

Each of us is, according to a Buddhist metaphor, a single drop of water, but also part of the river. Each story forms part of the collective story and each story finds a place in the world because others are there to listen to it. Organisations and systems are made of individual human beings. How we tell and listen to our stories will shape the future of healthcare. The capacity to recognise the value of stories, guided by compassionate and skilful facilitation, will increase the capacity for transformation.

We must, as Gandhi said, 'be the change we want to see in the world'.

Conclusion

Nowhere is reflection more important than in the health service where the challenges of illness, pain and death must be met afresh and attended to many times each day, and risks must be assessed and evaluated quickly and accurately. It is particularly important for providers of healthcare to be able to integrate their feelings as they proceed on this journey and not simply to build defences in an attempt to allay the inevitable anxieties incurred in this work (Menzies-Lyth, 1988), lest they fall even deeper into a chasm where care is careless and impersonal, rather than careful and valuing.

Karen Taylor, Director, Health Value for Money Audit at the National Audit Office, is aware of this problem – and of its effect on patients and carers.

> *'Sometimes there is a real lack of humanity in healthcare and a*
> *need for healthcare practitioners to treat patients and their*
> *carers as they would want themselves or their family members*
> *to be treated, but all too often the examples we get tell a*
> *different story.'*

<div align="center">Taylor, 2007</div>

The risk of the chasm widening grows as the expectations and wishes of patients to be treated with dignity and respect (Page, 2004, cited in Hardy, 2004 and Pilgrim Projects, 2007) fail to be met by staff working in a culture where humanity may be valued less than targets.

If the situation is to change, it is more important than ever to listen to stories.

This study has revealed key emotional messages for health professionals, summarised in the following comment from a respondent:

> *'I think this collection of stories must be one of the most valuable*
> *ways of understanding what the NHS really needs to do in order to*
> *give people a better experience with the management of illness. It*
> *is so easy to follow directives, respond to RCTs [sic] and statistical*
> *analysis, but nothing, in my opinion, matches listening to people's*
> *actual experience.'*

The emotional power of the Patient Voices digital stories provides an effective – and affective – method of conveying experiences and engaging a variety of audiences – from clinicians to managers, and Non-Executive Board members to policy makers.

The brevity of the stories makes them versatile and useable in a wide range of contexts and teaching modalities, especially where time may be short and attention spans curtailed by everyday, urgent pressures.

The creation of a still and quiet space in the otherwise turbulent lives of health service staff allows for 'reflection in tranquillity' so that the effect of a story can spread like ripples on a still pond.

The veracity of the stories gives them greater credibility and weight than those of simulations or reconstructions, and confers authenticity and immediacy on the message that they convey.

The stories can be distributed and used globally without the patient/storyteller being physically present, but retaining the veracity conveyed by their presence in the story, and a freshness that is not diluted by endless repetition.

The balance of power is adjusted to permit storytellers to convey what really matters to them rather than having to respond to questions that are important to other people.

The Patient Voices digital stories, in their particular uniqueness, have a universality that crosses boundaries and reminds us of our shared humanity in much the same way that Loengard (2004) describes the work of Life photographers in World War II:

> *'None of them photographed a general's strategy, or the tactics of*
> *a platoon. No one could do that. But they proved that the*
> *expression on the face of a single solder could describe war best.'*

The art of storytelling helps to humanise us in a potentially de-humanising environment (Lambert, 2007), one that is characterised, in the words of one respondent, 'by targets, tick boxes, audits, league tables, activity recording'.

The creation of a story as an artistic endeavour allows the storyteller to express, in a particular form, those things that may not easily be expressed in words; mindful of Dewey's statement that 'science *states* meaning while art *expresses* meaning' and Polanyi's (1967)

notion of tacit knowledge: 'We know more than we can tell', the stories often reveal an inner and tacit wisdom.

The editorial processes, safeguards and support built into the Patient Voices programme's digital storytelling methodology create a safe space for storytellers to find and express this knowing and meaning, and protect storytellers by allowing them full control over how their story is told. The role of the facilitator is, therefore, crucial in the development of the stories.

The short format of the stories and the licensing conditions under which they are released prevent proscribing, mis-quoting or manipulation of the stories after release; thus the integrity and vitality of the stories – and the storytellers – is retained in a way that is quite different from the more usual dissecting and dismembering of stories to suit the needs of researchers (Hawkins and Lindsay, 2006).

The benefits that accrue from the process of telling and listening to stories, hailed as an integral part of reflective learning, experiential learning and community learning (Kolb 1984, Dewey, 1939, Boud *et al.,* 1985; Wenger, 1999, Moon, 1999, etc.) and increasingly recognised by the medical and healthcare professions as an appropriate balance to the benefits of evidence-based medicine (Greenhalgh and Hurwitz, 1999; Greenhalgh, 2006 and others), have been borne out by the findings of this study.

Schön (1983) reminds us, however, that while 'stories are products of reflection, we do not usually hold onto them long enough to make them objects of reflection in their own right'. As artefacts, digital stories *can become* these objects of reflection, taking us one step further down the path of experiential learning and transformation by allowing storytellers and all those who view them to look at them again – to review them and to see them differently, 'attending to the meanings built into them as well as to our strategies of narrative description' (Schön 1983).

The digital story format provides an opportunity for patients to shape their stories so that they can more effectively engage in a virtual dialogue with healthcare professionals, allowing their stories to be heard by clinicians and decision-makers in the health service. At the same time, the creation of a digital story can foster in patients a more confident and concise language and a more competent and appropriate voice in which to conduct their own future discourse

with healthcare professionals and the 'system'. This creates the opportunity for a different kind of relationship to form between them, one founded on greater understanding and resulting in a different power balance. One respondent sums up this potential:

> *'The stories can help develop empathy between patients/clients giving the listener some experience of 'the other', with the resulting possibilities for change and developing new and different sorts of relationships'.*

With patients and healthcare professionals engaging via a new medium and a new genre, one of which neither group is likely to have experience, we may begin to see the kind of knowledge that Parker Palmer (1983) calls 'one that begins in a different passion and is drawn to other ends' – a knowledge that originates in compassion rather than that resulting from scientific curiosity or 'knowledge as a means to practical ends' (Palmer, 1983). This kind of knowledge may result in communication which, as Lindsay (2005) says, is 'created and stems from understanding' and is itself a key factor in the healing process.

This new way of knowing creates a new balance of power in the communication process. Patients are empowered to say what is in their hearts rather than simply answering clinicians' questions, that is, patients now shape what *they* want to say rather than having what they say shaped by the questions they are asked or the answers they are expected to provide.

Recommendations

'All of us carry within ourselves something that is waiting for the

right moment when it can burst out and repair the particular

separation that we are experiencing.'

Baldwin, 2005

Learning, healing, knowing and transformation

Learning is a kind of healing; education a progression towards wholeness (Heron, 1999; Palmer, 1983). The power of the Patient Voices digital stories as a reflective learning tool allows people the space to consider and respond in a unique way, to boost lifelong learning skills and to recognise the interconnectedness of patients, carers, clinicians and staff: all must be involved in what Lord Wanless (2002) referred to as 'the fully engaged scenario' if healthcare is to be transformed in any meaningful way.

Recognising the 'pain of disconnection' as one of the greatest of human miseries, we find, along with digital storytellers in America (Lambert, 2006), that these short stories can lead us to a place of knowledge by encouraging us to 'welcome diversity and conflict, tolerate ambiguity and embrace paradox' (Palmer, 1983) and to participate more fully in the various groups and communities of which we are all a part.

There must also be new ways of knowing. Since this new knowing is fundamentally collective, it is crucial that patients are empowered to participate in the healthcare community (Wenger, 1999) and enabled to engage in the kind of discourse that Paolo Freire (1972) called 'the encounter between men, mediated by the world, in order to name the world'.

The creation of digital stories has the potential to connect patients, carers, providers and decision-makers in an unusual and powerful way through deepening relationships and reinforcing the sense of community while reinforcing and affirming individual and collective knowledge.

Awareness should be raised through:

- publication of the results of this research

- publication of other articles covering the methodology of developing stories and their uses and impact in healthcare education and practice

- engagement of the Royal College of Nursing, the Royal College of Physicians and other Royal Colleges as co-producers of new digital stories and of novel applications of their learning potential

- embedding story-catching methodology into the pre-registration curriculum of all new health and social care professionals

- dissemination of the learning through, for example, RCN communication channels

- presentations and talks incorporating the stories at conferences, workshops, training and education events.

Humanising healthcare

The desire to tell and listen to stories must be re-awakened in the hope that a greater awareness of our shared humanity, rather than the need to meet targets and tick boxes, will lead to transformation in the quality of care. As de St Exupery (1943) said:

> *'If you want to build a ship do not gather men together and assign*
>
> *tasks. Instead teach them the longing for the wide endless sea.'*

The aspiration to 'humanise' healthcare should be brought one step closer to reality through the formation of an 'alliance' that would harness the skills of storytelling with patient involvement, patient choice and a 'patient-led NHS' to transform the patient experience through more informed and humane service provision and commissioning.

Commissioning has a vital role to play in safeguarding the quality and humanity of provision in the new pluralist market-place of healthcare. Commissioners, those who draw up contracts for publicly-funded care provision and those charged with the governance of these processes face a crucial challenge in maintaining a 'felt understanding' of the impact of their own decisions and actions on the well-being of individuals and communities.

Alongside quantitative clinical outcome data and the results of Patient Satisfaction Surveys that provide cognitive insight into the standard and quality of care, digital patient stories can

provide essential qualitative and affective feedback on the personal realities of the experience of care – and service-user-led insight into the key constituent elements of quality and of system shortcomings.

Commissioners' stories could be developed to show the challenges and successes faced by those commissioning care, and non-executive stories to capture the vital value that engaged governance can add to the ways in which care is commissioned and evaluated.

Workbooks, workshops and/or other events using stories and storytelling should be offered to inculcate the development of the skills of 'listening deeply and telling stories' (Center for Digital Storytelling website).

Stories and storytelling can be used as a way of convincing nurses, GPs and acute clinicians that they all have an important part to play in the commissioning process – since it is an essential element in the eventual quality and safety of care.

Education

The Patient Voices digital stories should, as more than one respondent suggested, 'be shown to every medical and healthcare student in every medical and healthcare school in the world' as a reminder that care should be careful and that listening deeply can, of itself, promote learning and healing. This can be done by embedding storytelling – digital and otherwise – into medical education as a powerful means of reflection, particularly with respect to developing professional identity.

> *'I am more convinced than ever that the ability to facilitate the*
>
> *gathering of digital (and other) stories (and to share this ability with*
>
> *colleagues, service users and local communities and to use it as*
>
> *a means to reflect upon one's own developing professional*
>
> *identity) should be an integral part of the repertoire of 21st century*
>
> *public service professionals.'*

<div align="center">Stanton, 2007b</div>

The skills of listening and telling stories should be taught to all students, across the health and social care professions, and modules on digital storytelling, with a particular reference to its

use in health and social care, should be developed and embedded in health and social care curricula. This learning can and should begin at the highest and lowest levels simultaneously so that what is happening at grass roots level can also be 'blessed' by those with the power to fund and accredit it.

It is equally important to ensure that not just clinical but managerial audiences are exposed to the learning and humanising potential of the Patient Voices digital stories. The Lawrence enquiry into successive failures to change the culture of the Metropolitan Police pointed to the profound problems that arise when middle managers are not pro-actively engaged with, and owners of, a process of system-wide change. It is essential that this lesson is learned in healthcare. Middle and senior managers are as much a target audience for (and creators of their own stories) as are their clinical colleagues.

Education programmes, conferences, training events and learning resources (electronic and otherwise), including workbooks such as that attached as Appendix 6, should be developed around the stories to highlight particular issues and stimulate reflection and debate.

The range of stories in the Patient Voices collection should be increased to include more conditions, experiences and issues, and reflect change; this will help to expand their use in health and social care, medical and interprofessional education curricula at every level.

Careful thought and consideration must be given to 'framing' the stories within appropriate educational contexts.

Stories should also be used with patients in GP surgeries and in hospitals, shared in disease-specific clinics (e.g. breast cancer, Parkinson's disease, arthritis) and offered to people in difficult or challenging situations such as adoption and fostering, caring for elderly parents or those with dementia or mental illness, or for those with disabled children.

Contact should be made with specific charities, such as the Alzheimers' Society, Headway and many others, to set up facilitator training programmes so that they can gather stories relevant to their user groups.

Facilitation, integrity and standards

> *'This instrument can teach, it can illuminate, and, yes, it can*
>
> *inspire. But it can do so only to the extent that humans are*
>
> *determined to use it to that end. Otherwise it is merely wires and*
>
> *lights in a box.'*

Murrow, 1958

Digital stories are not 'just wires and lights in a box' but rely on a complex blend of values, understanding and skills designed to elicit and refine narratives so that they are a pure *distillation* – the *essence* of the story. Thus facilitation skills need to be learned to ensure that safety, integrity and high creative standards are maintained at every stage of the process, while enabling stories to be gathered locally, thus building smaller, local communities of learning and practice.

'Good' facilitation should be defined and, possibly, accredited to ensure that appropriate standards are maintained.

Bearing in mind Carl Roger's (1951) principle that 'we cannot teach another person directly, we can only facilitate his learning', education and training programmes should be established that would enable all medical, health and social care educators – and through them, their students – to acquire the tools of storytelling and storycatching.

Further expansion of the programme must lie within existing protective guidelines/protocols for workshops such as those developed as part of the Patient Voices programme.

If the potential of the Patient Voices programme is to be fully realised, support and funding are necessary to demonstrate the concrete commitment of the system to match its patient-centred rhetoric.

Further research

Further robust research should be funded and conducted into changes in clinical practice that may be attributable to the stories – ideally by gathering 'before and after' stories from nurses and other clinicians: 'If the stories change, then practice must be changing.'

In addition, further research is needed in order to:

- investigate the use of digital storytelling as a qualitative research methodology, as a 'powerful and effective way of understanding the patient's perspective'

- monitor the success of the RCN programme and other educational programmes where the Patient Voices digital stories have been used

- discover the extent to which stories and storytelling impact outcomes of care

- investigate benefits and potential for reflection and transformational learning provided by the storytelling process with individuals, teams, organisations and communities.

The process of change and transformation can be hastened by iInviting health professionals to watch patients' stories, and offering an opportunity to re-evaluate their own attitudes and practice and asking the questions:

'What can we do differently – how can this be improved?'

This begins, of course, with the changes that occur with individuals, as they recognise that some of the responsibility for change rests with them.

'How wonderful it is that nobody need wait a single moment before

starting to improve the world?'

Anne Frank, 1945

By encouraging people to think in this way, the stories – both individual and collective are moved on – to another page or even another chapter.

Paul Stanton (Pilgrim Projects, 2007b) refers to the Patient Voices stories as

'narrative art in verse; digital stories are a new medium through

which narrative art can be explored and made accessible so that

"ordinary" people can articulate their extra-ordinary

understandings'.

This, then, is where transformation begins.

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Appendix 1: Subject information sheet

An investigation into the application of digital patient stories in healthcare education: quality of learning, impact on policy and value in practice

Invitation

You are invited to participate in a research study. Before you decide whether or not to take part, it is important that you understand what the research is for and what you will be asked to do. Please read the following information and do not hesitate to ask any questions you may have about anything that may not be clear to you. Make sure that you are happy before you decide what to do.

Thank you for taking the time to consider this invitation.

Purpose of the study

The Department of Health says that it wants and intends to place patients at the heart of care. If we really 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.

Reflection is a key lifelong learning tool for all professionals (Schön, 1983, Eraut, 1994 and others), who must develop the ability to reflect on their experience if they are to change, grow and develop their practice. Reflection is as important, and should be as natural, to us as eating – or, as Joe Lambert of the Centre for Digital Storytelling suggests, as telling and listening to stories.

New technology offers us the opportunity to 'empower' patients, carers and healthcare staff and to update the ancient art of storytelling through 'digital stories', short videos whose power comes from weaving together images, music, narrative and voice. Digital patient stories enable the voices of patients and carers to be heard and to initiate a dialogue with those that make decisions in the health service.

Little research has been carried out on the effects of either creating or viewing digital stories. Existing research indicates that digital storytelling can help to build communities of practice and share tacit learning; aid reflection; contribute to building portfolios; promote dialogue and understanding (Schön, 1983; Moon, 1999; Barratt, 2005 and others). I believe that the stories have considerable potential for bringing about change in the health service through greater understanding of other people's experiences, while making excellent use of time and technology, and promoting closer working together.

I want to discover how digital storytelling can be used to bring about change, improve services and promote interprofessional working by combining the skills of storytelling with new technology.

Why have you been chosen?

You have been invited to participate in this study because either you or one of your lecturers has shown an interest in the creation and use of digital stories. If you are making a story, you will be working with up to 20 other people in a one day workshop. If you are viewing the stories, this will be done in the context of a class, lecture or tutorial.

Your decision

It is entirely up to you to decide whether or not to take part in the research. You can still make a story, even if you do not wish to participate in the research. If you do decide to take part, you will be given a copy of this information sheet and asked to sign a consent form. Once you have signed the consent form, you can still change your mind and withdraw from the project at any time.

What will happen if I do decide to take part?

Your participation in the project will depend on whether you are creating or viewing stories.

If you are storyteller, before the workshop you will be asked to sign a separate consent form agreeing to the use of your stories as part of ongoing education in the service of improving the quality of healthcare.

At the completion of the one day workshop, you will be asked to complete a questionnaire about your experiences during the day. You will also be invited to keep a reflective journal for the next three months, in which you can note any thoughts or ideas that you have as a result of creating your digital story. At the end of the three month period you will be invited to complete another questionnaire to see what, if any changes have resulted.

If you are a viewer, you will be shown some digital stories as part of a lecture, tutorial or workshop. You will be invited to complete a questionnaire and you may be asked to participate in a short focus group to discuss your response to the stories. Three months later, you will be invited to complete another questionnaire, to discover whether any changes have been made and sustained as a result of seeing the stories.

Advantages and disadvantages

The potential advantages to participating are numerous. Storytellers will learn new skills which will be readily transferable to other situations. Both storytellers and viewers are likely to see things they haven't seen before, and to see things differently; this is a good way to

improve your ability to reflect on your own experiences and those of others and to have a beneficial effect on your practice.

The biggest disadvantage may also be the greatest advantage. Digital stories are very powerful. It is possible that either telling or viewing digital stories may cause you some emotional discomfort. In the past, storytellers have reported feeling that the experience was therapeutic or even cathartic; and viewers have reported that the 'discomfort' they may have experienced has led to changes in their perceptions and even to changes in practice.

What will happen to the results of the study?

First of all, please be assured that any data about you will be held securely and in confidence. All results will be anonymised. Storytellers will have to make decisions about how much they reveal of themselves in their digital stories.

I am hopeful that the results will be published in journal articles and disseminated through workshops. If you have given consent for your story to be used in healthcare education, then it may be shown in lectures, tutorials and workshops; there is a possibility of a conference to be held later in the year, focusing on the uses of digital storytelling in healthcare, to which you would be invited and where your stories may be shown; in addition, the results of the research are likely to be presented as a paper there.

The results may reveal a need for further research but, more importantly, they may lead to some improvements in the quality of care experienced by patients, carers and staff. Additionally, my hope is that the results will stimulate interest in digital storytelling and provide opportunities for more patients, carers and staff to learn the skills of good storytelling.

Funding

Currently, this research study is funded by myself; I am, however, paid a fee for running digital storytelling workshops.

Review

The research proposal has been reviewed by Celia O'Hagan, my supervisor on the MSc in Lifelong Learning. She can be contacted by email on c.ohagan@ulster.ac.uk

It has also been reviewed by an ethics committee in accordance with the University of Ulster's procedures. You may contact the University's Research Governance section should you need further details.

In the meantime, if you have any comments or queries, please do not hesitate to contact me by any of the means listed at the bottom of the attached Consent Form.

Thank you for taking the time to read this information sheet. If you are happy to participate, I would be grateful if you would sign and return the consent form below.

Consent Form

Title of Project: An investigation into the application of digital patient stories in healthcare education: quality of learning, impact on policy and value in practice

[ ] I confirm that I have been given and have read and understood the information sheet for the above study and have asked and received answers to any questions raised.

[ ] I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my rights being affected in any way.

[ ] I understand that the researchers will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study (except as might be required by law) and I give permission for the researchers to hold relevant personal data.

[ ] I agree to take part in the above study.

Name of participant_____

Signature _____ Date _____

Name of person taking consent _____

Signature _____ Date _____

Name of researcher _____

Signature _____ Date _____

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Appendix 2: Patient Voices research questionnaire

1a) In what context have you used – or do you intend to use – the Patient Voices digital stories (i.e. lecture, tutorial, presentation, conference, etc., and with what kind of group)?

  b) Which stories have you used or do you intend to use?

2 What is your purpose or aim in using the stories?

3 What was their effect on you? (How did you feel? What did you think? What particularly strikes you about the stories?)

4 What was their effect on your audience/students? (Think about, for example, the quality/depth of any debate that ensued, the comments made by students, etc.)

5 To what extent do you think the digital stories can promote greater understanding

a) between patients and healthcare staff (including managers and decision makers)?

b) between different staff groups?

6 What changes have you noticed in your own – or your students' or colleagues' – practice since watching the digital stories?

7 What has been – or could be - the impact of these changes on

a) patient safety?

b) the quality of care?

c) individual practice?

d) the organisation within which you work?

e) interprofessional working/interprofessional education?

f) your teaching and learning strategies?

8 Can you see any actual or potential 'evidenced benefits' to you, your colleagues, students or patients? Please say what these are.

9 Please note any other comments.

Please return this form to
Pip Hardy
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Appendix 3: Range of contexts and purposes within which the stories were used

Context of use: group	Context of use: setting	Purpose
Undergrad nurses	Virtual Learning Environment	To provide students with insight into the patient and carer perspective of healthcare.
Frontline staff (health visitors and district nurses) and health service managers involved in clinical microsystems	Part of a session around why there is a need to involve patients in healthcare.	To stimulate discussion. To get both audiences to see the power of stories and encourage them to use these as part of PPI work
1st and 2nd year undergraduate nursing students	Lecture and small group work	To introduce students to the patient's perspective, to get the students to listen in the calm of the classroom to people's experiences.
Student nurses, researchers and service users (haven't been used yet)	Could use with all HCPs!	To initiate discussion and to train service users who might take part in research.
NHS Boards; front line professional staff, senior and middle managers, risk managers medical and senior nurse educators. Carer and patient groups	Workshops, conference presentations	To sensitise all members of the health community to the immediate or mediate impact of their actions on those who use health and social care services – for good and for ill. To validate and authenticate the value of their perspectives.
Health and social care professionals and potential funders	During meetings, presentations and conferences	To raise awareness of carers' needs and in turn raise the awareness of the need for our services.
At a palliative care conference involving 200 delegates	Highlighting issues subsequently discussed in workshops	To stimulate thinking and provoke discussion in a very succinct way.
Eight second year medical students in the "Medicine in Society" programme	Small group work	To look at current NHS policy re capturing patient and carer experience, and using this to improve services for patients.
Student nurse	Part of a lecture	
Service improvement managers	Part of a service improvement module for the NHS Institute for Innovation and Improvement	To use patient stories to enable participants to identify triggers for improvements in service design and delivery.
Undergraduate nurses	Lectures	As a visual impact tool – as an example of an element of healthcare, then students were asked to transfer the meaning behind the story in the video into an experience they have been involved in during their practice.

Appendix 4: Feedback sheet – Jean's story

I would appreciate it if you could take a couple of minutes to answer a few questions about Jean's story, "Getting to the bottom of things", which you watched earlier today.

1 How did the story make you feel?

2 Were there any issues within Jean's story that you have come across in practice?

If yes, can you briefly explain?

3 Has watching Jean's story changed any of your thoughts or views in any way? Yes/No

  If yes, can you briefly explain?

4 D you have any ideas of how stories such as Jean's can be used in healthcare?

Please add any comments you might have, including your thoughts about including Jean's story in today's session.

Thank you for your time.

Appendix 5: Emerging themes

• The power of the stories	• Considerations, issues and concerns
• Promoting reflection	• Developing empathy
• Stimulating discussion and debate	• Patients as teachers
• Involving patients/working in partnership	• Patients at the heart of care
• Using the stories in research	• Building communities of practice
• Improving quality and safety	• System change/organisational learning
• Service improvement	• Changes in practice
• Spiritual/holistic care	• Interprofessional education
• Evaluating narrative	• Advocacy and empowerment

Appendix 6: Patient Voices: the rationale

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

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

• can highlight gaps in the system

• can reveal near-misses and form 'free learning opportunities'

• promote healing and reconciliation

• can allow patients' and carers' (and professionals if appropriate) voices to be heard

• can carry forward stories that might otherwise be lost

• are created in a spirit of collaboration and partnership

• are intended to touch hearts, thereby reinforcing the notion of patients at the heart of care.

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

Patient stories have been recognised (Greenhalgh and Hurwitz, 1999, and others) as making a significant contribution to understanding the patient experience; they acknowledge the patient's own areas of expertise, i.e. his or her own life and unique experience of illness. Further, research on public perceptions of the NHS (Page, 2004) reveals that patients care much more about being treated with dignity and respect than they do about mortality rates.

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

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

References

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Page, B. (Mori Research Institute Director) (2004) 'What they really want' *HSJ* (8th April 2004).

Appendix 7: E-Health Connections Nursing workshop:
Connecting to the Future Preparatory Workbook

E-Health Connections Nursing Workshop: Connecting to the Future

Preparatory workbook

6th February, 2007

Written by:

Pip Hardy
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Advisor on Standards, Department of Health and facilitator of the day

E-Health Connections Nursing Workshop: Connecting to the Future

Introduction

This workbook contains preparatory reading and activities to be completed ahead of the Nursing Workshop on February 6, 2007. Its aim is to act as a prompt to critical reflection and imaginative engagement with the many ways in which Information Communications Technology (ICT) and the nursing task can interact. This preparatory reflection will enable you and your fellow delegates to make the fullest possible contribution on the day itself and thus to gain the most benefit from the day.

The Workshop is designed to provide a different forum for critical reflection from those with which you may be familiar. This workbook introduces you to some of the approaches and the issues that will form the substantive content of the day.

The workbook provides you with the opportunity to watch, read and think about patient stories – and to develop your own stories about the process of care and its future in a new technological age. You are free to give full rein to your own creativity – use photos, poems, songs, drawings or whatever helps you to think 'outside the box'.

> *'We are, after all, seeking to create the future story of healthcare, and this will, in turn, be shaped by the ongoing stories – both individual and collective – of those who deliver and receive healthcare. Indeed, it may be appropriate to consider nurses, in their future role, as keepers of the stories – the personal stories of individual experience as well as the careful documentation that will safeguard patients throughout their journey.'*
>
> Pip Hardy, 2006 'Proposal for planning and facilitation of a nursing visioning day'

In the days before the Workshop, try to make at least a little time to attend to those things that inspire and move you. The enormous pressures and stresses of working life within the NHS can drain creative energy and degrade our capacity for imaginative thought

'How wonderful it is that nobody need wait a single moment before starting to improve the world?'

Anne Frank (1929-1945) *The Diary of Anne Frank*

But yield who will to their separation,

My object in living is to unite

My avocation and my vocation

As my two eyes make one in sight.

Only where love and need are one,

And the work is play for mortal stakes,

Is the deed ever really done

For Heaven and the future's sakes.

Robert Frost (1936) *'Two Tramps in Mud Time'*

'Beauty and the sense of belonging it evokes introduce us to a new standard of care--a quality of attending-- which we may extend to our sense of stewardship in creating communities of care. Perhaps in the future a well lived life will involve the shift from a focus on utility to the combined search for signs of the beautiful.'

Michael Jones

Aims and objectives

One key aim is to generate a number of exemplary stories from the day - stories that capture and illuminate some of the key issues, problems and transformational possibilities to which ICT gives rise. These stories will be disseminated to the wider healthcare community.
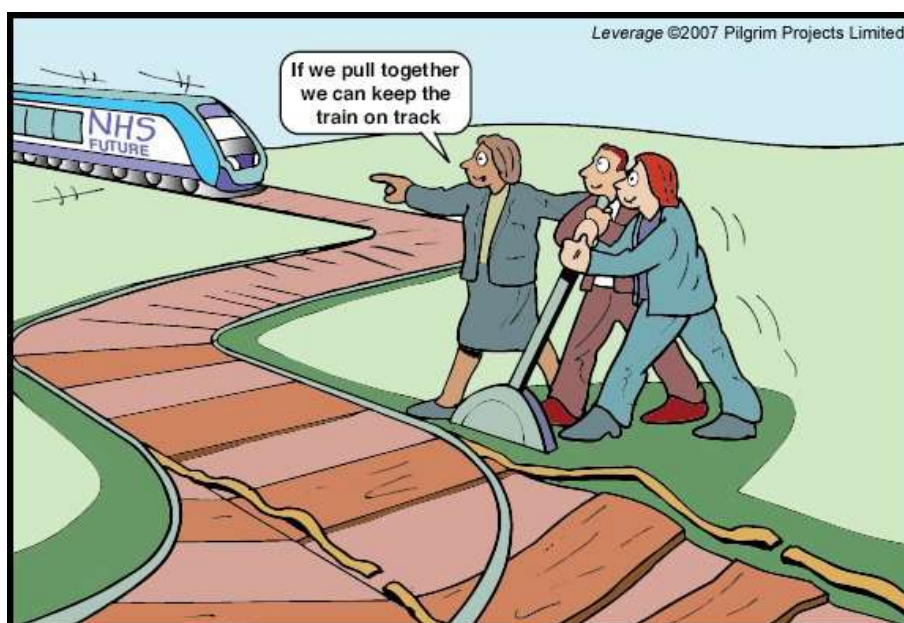
This workbook will help you prepare to contribute to the collective stories. As you go through the workbook, you will be asked to:

- reflect on the influence of creativity and technology on your life

- recognise the characteristics of a 'good' story

- tell a story about a patient

- read outside references

- reflect on your patient story and consider how it would be transformed by technology.

We hope that this workbook will be a stimulus to creative engagement with the topics considered and will cultivate a different approach to the day – one which is founded in creativity and openness and a willingness to share your experiences as well as your aspirations with your colleagues.

'Find purpose, the means will follow.'

M K Gandhi

'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

'At times of profound structural and/or organisational change not only anxiety but energy is generated. If this energy can be channelled in positive directions, it becomes possible to challenge the tyranny of habit, to tackle chronic problems, to liberate creativity and thus to initiate radical improvements.'

Paul Stanton, 2007

Outcomes of the day

'How can I help people if I don't know the right stories to tell them?'

Jack Cash (From the film 'Walk the Line')

The day will culminate in an agreed plan of action and a set of activities that will help to move this vital work forward. In order to build on the foundation laid by the day itself, a number of participants on the day will need to commit an additional day of time to attend a workshop where the stories from the day will be refined, distilled and captured digitally so that they can be shared with the nursing profession, other health professionals, with technologists and with service users.

The follow-up storytelling workshops will offer an additional opportunity to refine the skills of storytelling and explore how these may be used in organisations as prompts to learning and engagement as well as distilling the stories from the day.

This will enable the work you do on the day to become an important element within the ongoing development of a co-produced vision of the future role of the nursing profession and the future development and impact of ICT as a transformational means to improved public service quality.

Note: The dates for the two storytelling workshops will be 26th February and 5th March. Please consider whether you may be able to make time to attend on one of these days.

We recognise that people work under considerable time pressure – and that it will not be easy to make the time to carry this work forward. However, those who have taken part in past workshops have found the process to be both challenging and rewarding – and the use of time to have been an investment – rather than a cost.

'We will have an alternative means of communication which is both powerful and emotive.'

'I appreciate more than ever the importance of a personal perspective, and how even the most abstract presentation can be told as a personal story.'

Workshop participant

'To remember requires language: to heal requires story.

Unarticulated, collective experience that is not allowed into the social story shows up years later as political upheaval, violence, resistance, revolution, fundamentalism, spiritualism, disconnection, apathy, and disassociation with reality.

But when these same experiences are shifted into language and successfully worked through, they lay the groundwork for transformative cultural development.'

Christina Baldwin, 2005

The narrative art in verse

'Digital stories are a new medium through which narrative art can be explored and made accessible so that 'ordinary' people can articulate their extra-ordinary understandings.'

Paul Stanton, 2007

Using this e-workbook and the website

The e-workbook contains some tasks and activities, some quotations and readings, some policy documents and some links to websites containing relevant background information.

As you work through the activities and materials, we encourage you to share your thoughts and experiences with other workshop participants via the dedicated website, which has been set up at www.networks.nhs.uk/

called 'Connecting to the Future'.

There you can upload and download documents and files, pose questions and offer insights, and engage in discussion with other delegates. In this way we can begin to build a community of practice and share a vision of nursing in the future as our understanding grows.

'The limits of my language are the limits of my mind. All I know is what I have words for.'
Ludwig Wittgenstein (1889-1951)

'Dialogue is the encounter between men, mediated by the world, in order to name the world.'
Paulo Freire, 1972 *Pedagogy of the Oppressed*

Reading and resources

Few of us have time to read all that we might wish to. We have, therefore, divided the readings into several categories to help you plan your reading and make the most of the time you have available.

Essential reading – these are the minimum necessary to make the most of the day and we strongly urge you to read these materials.

Recommended reading – these are valuable documents which we encourage you to read if at all possible.

Further reading – if you are really keen, then there are additional suggestions to extend your knowledge further.

'Only connect. Only connect the prose and the passion and both will be exalted.'
E M Forster, 1910
Howards End

The pre-work tasks

There are four tasks contained in the workbook. You can expect to spend between two and four hours if you engage fully with this workbook.

If you do not do this work, not only you, but also your colleagues, will be disadvantaged during the workshop sessions.

The pre-work tasks are an essential pre-requisite to your attendance on the day.

'We do not learn from experience. We learn from reflecting on experience.'
John Dewey, 1939
Experience and education

Creativity and technology

Please begin by doing pre-work task 1.

Pre- work task 1: think about creativity

As part of your preparation for the Visioning Day, begin with a consideration of some of the influences on your life and your work.

1. A profound creative influence

Think about a poem, novel, film, play, painting, etc. that has had a profound impact on the way you understand the caring task and/or the nursing role.

In the box below, describe, in a couple of sentences, the work you have in mind.

Summarise, in 100 words or less the impact it had upon you - and why.

If you wish, please feel free to share these thoughts with others, via the website.

"Forty-two!" yelled Loonquawl. "Is that all you've got to show for seven and a half million years' work?"

"I checked it very thoroughly," said the computer, "and that quite definitely is the answer. I think the problem, to be quite honest with you, is that you've never actually known what the question is."

Douglas Adams ,1978
Hitchikers' Guide to the Galaxy

Nobody heard him, the dead man,

But still he lay moaning:

I was much further out than you thought

And not waving but drowning.

Poor chap, he always loved larking

And now he's dead

It must have been too cold for him his heart gave way,

They said.

Oh, no no no, it was too cold always

(Still the dead one lay moaning)

I was much too far out all my life

And not waving but drowning.

Stevie Smith, 1957
 'Not waving but drowning'

Pre-work task 2: think about technology

2. A profound technological influence

Think about a technological innovation that has had a profound impact (since the millennium) on

a) your personal life

b) your working life.

Describe the innovations in a couple of sentences.

Summarise, in not more than 100 words in each case, the impact it has had upon you, and why.

If you wish, please feel free to share your thoughts with others, via the website.

'Convivial tools are those which give each person who uses them the greatest opportunity to enrich the environment with the fruits of his or her vision.'

Ivan Illich, 1973 *Tools for Conviviality*

'More and more I come to value charity and love of one's fellow being above everything else... All our lauded technological progress--our very civilization--is like the axe in the hand of the pathological criminal.'

Albert Einstein (1879-1955)

Activity

Technology should always be a means – rather than a self defining end. This activity will give you an opportunity to think about the impact technology can have on ordinary, everyday stories.

Keeping patients safe lies at the heart of what nurses do. Documentation plays a key role in ensuring patients' safety. Consider what happens when there is a failure of communication.

> As a full-time carer, Monica Clarke was intimately acquainted with all aspects of her husband's condition following a stroke that left him without the power of speech. He relied on her to convey important information to the medical professionals. Monica relates her experience of handing over to the paramedics when her husband is taken into hospital in an ambulance. Upon arrival at the hospital, the paramedics fail to inform hospital staff that John is allergic to penicillin. Monica is never asked for any information.

Please watch Monica's digital story, called 'A part of the team' at

www.patientvoices.org.uk

You will need Windows media player in order to play it.

When you have watched it, give some thought to the following questions:

1. How does the story make you feel?

2. What does it make you think?

3. What does it make you want to do now?

4. How could this situation have been prevented?

5. What part could new technologies and information systems play in this scenario?

Adapted from 'Dynamic Documentation' part of the RCN Learning Zone. Written by Pip Hardy, 2005

'Assure a substantial flow of vital information … so that the information derived would be helpful to all and harmful to none'.

Bobbie R Allen, quoted in R Hardy, 1990 *Callback: NASA's Aviation Safety Reporting System*

'Listen deeply. Tell stories.'

Center for Digital Storytelling
www.storycenter.org

Reflect on stories

Stories are powerful learning resources both for storytellers and for their many and multiple audiences.

Capturing stories digitally enables them to be shared and to be used to illuminate a number of issues that may otherwise appear to be dry, arid and remote. At their best they are what Brendan Routledge (2004) calls *'powerpoint for the soul'.*

But, what makes a good story? Most of us instinctively recognise and respond to a 'good story', but we may not have thought much about the elements that generate its impact… You might begin by asking yourself what differentiates a story from a set of case notes, or a list of events?

'Reflection is as natural – and as necessary – as breathing … or telling stories.'

Joe Lambert, Centre for Digital Storytelling

Activity

Please go to the Patient Voices website (www.patientvoices.org.uk) and look at the following three stories.

- Joan Spurden's 'My Michael' (Carers' Resource)

- Andrew's 'Fast, appropriate responses' (Reconnecting with Life)

- Mike Barton's 'The Nurse's Tale' (Connecting for Health)

After you have finished viewing each one, please ask yourself (and note your answers to) the following questions:

1 How does the story make you feel?

2 What does the story make you think?

3 What do you think needs to be done now, as a result of seeing the story?

4. What was it about the story that made it memorable?

'Patient Voices are a distillation – they capture the spirit of the story.'

Paul Stanton, 2006

Patients at the heart of healthcare

The work of the NHS is to commission and to provide care for patients. With patients and local communities central to the Government's system reform agenda, it is crucial to focus on patients and their carers – to place them at the very heart of care, and therefore to ensure that any consideration of ICT engages patients actively and focuses upon the patient experience.

'It is very easy to tell the story that we want to tell to make our own point and not necessarily 'listen' to and learn from others point of views.'
Patient Voices workshop participant (2006)

> *'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, 2002 *Shifting the Balance of Power: Securing Delivery*

As part of your preparation for the workshop, please take every opportunity to look at issues through the eyes of patients and to read, view and respond to patient stories that convey poignant messages about care (such as the digital stories mentioned above and those identified below)

Pre-work task 3: Follow a patient journey

Think about a patient – it could be a patient of yours, or a friend, relative or someone you know. Alternatively, you may want to reflect upon your own experience as a carer for a friend or relative. Try not draw on your own experience as a patient. Although we are all registered with the NHS from birth and thus, as healthcare professionals, are dual stakeholders, our knowledge of and our links to the system can change our perspective and affect the power dynamic – in ways that are sometimes subtle and sometimes dramatic.

You do not need to be concerned with the details of the patient's condition – we are focusing on the patient's journey rather than on the reasons for it.

Consider this patient's experience of care. Locate that within the context of the patient's whole life. In other words, think about all the people who are touched and affected by their health problem (family, friends, carers, colleagues, etc)

'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
The Resourceful Patient

Then think about how many organisations and how many health and other caring professionals they come into contact with in the course of their journey. To what extent is the patient's experience a seamless transition or to what extent are there unintended discontinuities or dislocations in their care?

Finally, think about the processes and outcomes of care, BUT think about the patient's experiences as a story and not simply as a case study of events and treatments.

Although all of us have grown up with stories, in helping to frame the patient story, it may be helpful to reflect on the characteristics of stories.

> *'The foundation of a story is an emotional foundation. If a story does not work emotionally, it does not work at all. The emotion in question is not the point; be it love, envy or apathy, so long as it is conveyed in a convincing manner, then the story will come alive. But a story must also stimulate the mind if it does not want to fade from memory. Intellect rooted in emotion, emotion structured by intellect – in other words, a good idea that moves – that was my lofty aim.*
>
> Yann Martel, 2005 *The Facts Behind the Helsinki Roccamatios*

Now tell your patient's story in words, pictures, photos, audio or video.

Reflect on what you have learned. To what extent does the patient's journey reflect what Paul Stanton (2003) has referred to as the *values* of clinically governed care, i.e.

1 humanity

2 equity

3 justice

4 respect?

Please be prepared to share your story with colleagues at the Workshop and to reflect upon and refine it with them. It will form an important focus for thinking about some of the future possibilities and changes that could be opened up through the sensitive application of new technologies and information systems.

'What did I learn from the workshop?

- the importance of feelings and passion in telling a story

- the importance of the individual's unique perspective'

Patient Voices workshop participant (2006)

'A story with the sense of value [and personal meaning] taken out would simply be a list of events, not unlike a case history.'

Pip Hardy and Ross Scrivener (2003) 'Time + value = story'

'Each affects the other and the other affects the next, and the world is full of stories, but the stories are all one.'

Mitch Albom, 2003 *The Five People you Meet in Heaven*

The future of care

Now turn your attention to the future of care. The government is committed to profound reform of all of our public services to make them more responsive to the emerging needs of individuals and local communities in the 21st century. The landscape of care is changing. Greater emphasis upon whole system thinking, the promotion of health and well being, needs-led NHS commissioning and a pluralist market place in health and social care provision inevitably generate profound and far reaching change. The structural architecture of the NHS has altered dramatically and further reconfiguration in models, patterns and locations of care seem inevitable. These changes, alongside profound demographic, socio-political and technological developments will pose major challenges to long standing assumptions about the nature of professional roles and tasks.

'Having to cope with constant organisational change, at the same as continuing to cope with the unchanging demands of responding to the needs of the vulnerable and the sick, can leave professionals feeling lost in familiar places.'
Shapiro and Carr, 1991
Lost in Familiar Places: Creating new Connections Between the Individual and Society

Included with this work book is Dame June Clark's C2 paper – which forms essential pre-reading for the conference. (You may also want to read the fuller version of June Clark's ideas, entitled *The impact of ICT on health*.)

Perhaps one of the greatest challenges in harnessing the power of new technologies in the interests of improved safety and quality of care is that posed by the need (and a statutory duty under Section 11 of the Health & Social Care Act 2002) to involve patients and local communities at all stages in the planning, development, implementation and evaluation of these innovations and developments.

And the one throwing the lifebelt,
Even he needs help at times
Stranded on the beach
Terrified of the waves.
Brian Patten (1946-)

Just as the 'co-production' of solutions to the challenge of long term conditions can transform the quality of life and of service provision (see 'The Year of Care' Degeling et al 2006), so tri-partite partnerships between nurses, service users and technologists can ensure that technology is a flexible servant of individual and professional need – rather than appearing to become a remote and tyrannical master.

'Patients should have 'choice, voice and control' at every stage of their care.'
Department of Health, 2000 *The NHS Cancer Plan*

> *'My best advice to health providers is to think of us as partners. Treat us like partners. Tell us that you need our help too. You might think about setting up training sessions to help staff know how to ask questions that get the best answers. …. We need to take responsibility also. We need to learn to ask questions better. I would recommend more training for us. Remember we want to be part of the solution.'*
>
> Toni Cordell, Adult Learner and Literacy advocate
> www.tonicordell.com

Pre-work task 4: the impact of new technologies

Begin to think about the contribution and impact of new technologies and the 'information revolution' on the process of care, on the nature of the relationship between service users and service providers and on the professional nursing identity and task.

Reflect, in particular, on the potential impact of new technology on the patient experience, and on stories such as the one you have told. Here are some questions to prompt your thinking – add to them other questions that you would wish to pose.

1 How will new technologies and information systems change all of our lives?

2. How might new technologies promote health and well being and prevent episodes of ill health?

3. How might new technologies enable patients and professionals to manage the treatment of illness more effectively?

4 How will the interface between health and social care systems and new technologies and information systems change the nature and processes of care?

5 How will that interface change the nature of the role and competence set of the nursing profession and other professional groups?

'The principle of continuity of experience means that every experience both takes up something from those which have gone before and modifies in some way the quality of those which come after ...'

Dewey, 1938

'Tele-informatics "presents new opportunities to deliver and configure services and…new opportunities for professional development"…If we are to realize [its] potential, we must be willing to communicate and work across professional and organisational boundaries."'

May, C, Finch, T, Mair, F, Mort, M (2005) 'Towards a Wireless Patient: Chronic Illness, Scarce Care and Technological Innovation in the United Kingdom'

Your own additional questions:

In the first workshop session of the day you will be invited to share your patient story. Your workshop group will select two stories that have the potential to capture the transformational possibilities presented by new technologies and identify two storytellers who are able and willing to participate in one of the follow up Storytelling days.

In the second workshop session, , small groups, will help the nominated storytellers to refine the stories, to identify the ways in which ICT could profoundly improve the quality and outcome of care – and map the challenges that will need to be overcome if this potential is to be realised.

There are many examples of patients, carers and professionals telling their stories at www.patientvoices.org.uk

NB If you use a Macintosh, please go to 'The Stories' page, where you will find instructions about how to download the software you will need to view the stories.

In particular, you may like to watch:

- Ian Kramer's 'Measured innovation: working together' (Ian Kramer's stories)

- Monica Clarke's 'Nobody told me' (Monica Clarke's stories)

- Graham Williamson's 'A permanent holiday' (Carers' Resource)

- Bernie Cottam's 'Imagine a world…' (RCN PDF stories)

- Carolyn Basak's 'A world of difference' (RCN PDF stories)

- Sue Brown's 'She always liked to feel useful (RCN Quality Improvement Programme)

- Mike Connolly's 'Getting the balance right' (HIP stories)

- Marilyn Kramer's 'A tribute to St Nicholas' Hospice (Pilgrim Projects stories)

- Iain Norrie's '60 seconds' (NHS Tayside)

- Derek Whitehead's 'Imagine' (Reconnecting with Life)

You may also, as a bit of light entertainment, enjoy watching 'The Dormouse and the Doctor' (Pilgrim Projects stories) which offers some insight into the relationship between patients and professionals and the unintended damage that can occur when patients are denied choice, voice and control.

'The role of the nurse of the future will encompass elements of social education and the key question, therefore is, how can new technology support the nurse in this element of his/her role and, more generally, how can it support citizens in their ownership of and quest for sustained health and well-being?'
Paul Stanton, 2007

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

'I believe the notion of story, transformative reflection, and the capacities of computing machine being forged together into some sort of new life management process is catching on with people.'
Joe Lambert, 2000

Summary

This workbook is intended to be helpful and stimulating. We hope you will be encouraged to participate in the online community established to take this work forward.

We will ask you, in the wake of the conference, to critique it and to contribute your own ideas as to how it could be improved so that it could become a source of critical reflection and learning for nurses at all levels within the NHS and within other provider organisations.

If you have worked through the tasks and the activities, and done some of the reading, you will be well-prepared to take an active part in the e-Health Connections Nursing Workshop: Connecting to the future, and play a key role in shaping the future of nursing in the 21st century.

In the meantime, you might like to note some of your reflections on the process of working through this workbook in the space below.

'The hallmark of a community of truth is in its claim that reality is a web of communal relationships, and we can know reality only by being in community with it.'

Parker Palmer, 1998 *The Courage to Teach*

Reading and resources

This list has been compiled to help you make the most of the workshop day itself, but also to whet your appetite for further reading. You will find links to most documents and several documents, including the two essential articles by Dame June Clark, can be downloaded from the 'Connecting to the Future' network at www.networks.nhs.uk

Essential reading

Clark, C (2006) The impact of ICT on health
The document can be downloaded from the 'Connecting to the future' network at
www.networks.nhs.uk

Clark, J (2007) C2 Culture change
The document can be downloaded from the 'Connecting to the future' network at
www.networks.nhs.uk

The National Programme for IT Implementation Guide (VERSION 4.1 Dec 2006)
www.connectingforhealth.nhs.uk/implementation/

Recommended reading

BT (2006) Vital Life http://btplc.com/Innovation/HelpingSociety/health/health.pdf
www.networks.nhs.uk
Systematic application and mass customisation of current technology to individual needs.

Cayton, H (2007) 'Mediocre no more' Society Guardian
http://society.guardian.co.uk:80/health/story/0,,1991632,00.html
Shows how patient entrepreneurscan shape health services around their needs and includes interesting case studies that illustrate how patients can lead change.

Connecting for Health (2005) *Global Vision, Local Insight: Report for the World Summit on the Information Society* WHO www.who.int/ehealth/resources/countries/wsis_country_profiles.pdf

Connecting for Health (2006) 'Tele-informatics' I: Using Technology to Traverse Space at the Speed of Care www.connectingforhealth.nhs.uk/worldview/protti12?searchterm=ehealth

Connecting for Health (2006) Tele-informatics II: An Information Renaissance in Healthcare
www.connectingforhealth.nhs.uk/worldview/protti13?searchterm=ehealth
These two reports take a look at the potential of ICT to solve health challenges across the globe.

Department of Health (2002) *Delivering 21st century IT support for the NHS*
http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4008227&chk=8ivkEI

Department of Health (2006) *NHS Operating Framework 2007-2008*
http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4141091&chk=JENnyc

Department of Health (2007) *Equality and Human Rights in the NHS – A Guide for NHS Boards*
http://www.dh.gov.uk/PolicyAndGuidance/EqualityAndHumanRights/fs/en

Farringdon-Douglas, J and Brooks, R (2007) *The future hospital – the progressive case for change*
Institute for Public Policy Research
www.ippr.org.uk/members/download.asp?f=%2Fecomm%2Ffiles%2Ffuture%5Fhospital%2Epdf

Gray, JM (2002) *The Resourceful Patient* www.resourcefulpatient.org/

Hardy, P and Scrivener, R (2003) 'Time + Value = story' extract from *Clinical Governance Matters*
an online module published by UKHEP www.city.ac.uk/ukhep/

The document can be downloaded from the 'Connecting to the future' network at
www.networks.nhs.uk

RCN (2004) The future nurse, the future patient (an RCN document)
www.rcn.org.uk/aboutus/policy/futurenurse.php

RCN (2004) *The future nurse: the RCN vision*   www.rcn.org.uk/aboutus/policy/futurenurse.php

RCN (2004)The future nurse: the vision explained www.rcn.org.uk/aboutus/policy/futurenurse.php

RCN (2006) e-Health – Putting information at the heart of nursing care CN
http://www.rcn.org.uk/publications/pdf/e_health.pdf

Royal Society (2006) *Digital healthcare: the impact of information and communication technologies on health and healthcare* www.royalsoc.ac.uk/displaypagedoc.asp?id=23425

Stanton, P (2003) *The Strategic Leadership of Clinical Governance in PCTs*. National Clinical Governance Support Team, especially Section 2: Clinical Governance – An Overview
www.pilgrimprojects.co.uk/clients/nhsma.htm

Further reading

Boyle, D Mulgan, G and Ali, R (2006) *Life begins at sixty: what kind of NHS after 2008?* Young Foundation www.youngfoundation.org.uk
Looks at some of the current challenges in the NHS and new approaches including co-production and community based self help. Raises the question of what would a national wellness service look like? The report is published by nef (the new economics foundations) and the Young Foundation.

Degeling, P Close, H and Degeling, D (2006) *A report on the development and implementation of co-produced, year based integrated care pathways to improve service provision to people with long term conditions*. Durham University Centre for Clinical Management Development
www.networks.nhs.uk

Part of The Year of Care programme, this paper looks at co-production of healthcare.
The document can be downloaded from the 'Connecting to the future' network at
www.networks.nhs.uk

Fadiman, A (1997) *The Spirit Catches You and You Fall Down.* Farrar, Straus and Giroux.
Can technology help to resolve differences in culture and language?

Frumkin, H. Frank, L. and Jackson, R. *Urban sprawl and public health: Designing, planning and building for healthy communities.* Island Press.
This book takes a holistic approach to health, examining the extent to which our environment predisposes us to an ever-increasing range of long-term conditions.

Websites and other resources

NHS Networks www.networks.nhs.uk

Connecting for Health www.connectingforhealth.nhs.uk/

E-Health Insider newsletter
www.e-health-insider.com/index.cfm

Europa e-Health
http://europa.eu.int/information_society/eeurope/2005/all_about/ehealth/index_en.htm

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Appendix 8: Patient Voices protocol, consent and release approval forms

Patient Voices

Protocol for storytellers

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

James Earl Jones, actor (1931-)

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 for use as part of the Patient Voices programme unless we have 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 a consent form which will allow the use of the final version of the story as a publicly available educational and learning resource intended to improve the quality and responsiveness of healthcare services for patients and carers.

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 who are patients or carers may be offered repayment for expenses incurred in the recording of their story (including, where appropriate, reimbursement for respite care for people for whom they normally care).

Copyright

One of the primary goals of the Patient Voices programme is to build up a library of resources that can be shared for use in healthcare education and quality improvement, while protecting the integrity of the stories and the contributions of those who created the stories.

To this end, completed and approved stories will be released under the Creative Commons licence 2.5 (attribution-non-commercial-no derivatives), with copyright retained by Pilgrim Projects.

This aims to ensure that:

a) the stories are freely useable by anyone involved in healthcare education and quality improvement

 b) no profit can be made from the stories

 c) the integrity of the story, as told by the storyteller, is retained

d) all who have contributed to the story are appropriately acknowledged.

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

Patient Voices

Consent form

I, _____, have read the *Protocol for storytellers* and other information relating to the creation and use of digital patient stories for the Patient Voices programme.

I understand that I will have editorial control over my story or stories, but that copyright will be held by Pilgrim Projects Limited.

I agree to the inclusion of my story/stories in the growing library of Patient Voices digital stories and may be made publicly available by Pilgrim Projects Limited, including via CD, DVD and the Internet.

I understand that the intention of the Patient Voices programme is to make the Patient Voices stories available as an educational and learning resource as part of the international drive to improve the quality and responsiveness of healthcare services for patients and carers, but that Pilgrim Projects Limited can have no control over, or liability for, how they are ultimately used.

I consent to the use of my story as part of the Patient Voices programme.

I have obtained all appropriate permissions for materials used in the story.

Signed _____   Date   _____

Email: _____   Tel: _____

Name   _____

Address _____

           _____

           _____

Pilgrim Projects Limited
Progress House
91 Waterbeach Road
Landbeach, Cambridge   CB25 9FA

Tel: 01223 440257
Fax: 01223 863826
Email: pip@pilgrimprojects.co.uk

Patient Voices

Release approval

I have seen a draft version of the story entitled_____
and I am happy for the story to be finalised and released under the Creative Commons licence.

I agree to the inclusion of my story in the growing library of Patient Voices digital stories and it may be made publicly available by Pilgrim Projects Limited, including via CD, DVD and the Internet.

I understand that the intention of the Patient Voices programme is to make the Patient Voices stories available as an educational and learning resource as part of the international drive to improve the quality and responsiveness of healthcare services for patients and carers, but that Pilgrim Projects Limited can have no control over, or liability for, how they are ultimately used.

I consent to the use of my story as part of the Patient Voices programme.

OR
I would like you to make the following changes to my story before it is finalised. I understand that I will be able to see another draft incorporating the changes.

_____
_____
_____
_____

(Please continue on the other side if necessary.)

Name   _____   Signed _____

Address _____   Date _____

        _____

        _____

Please return to Pip Hardy at
Pilgrim Projects Limited   Tel: 01223 440257
Progress House   Fax: 01223 863826
91 Waterbeach Road   Email: pip@pilgrimprojects.co.uk
Landbeach, Cambridge   CB25 9FA