Second Edition

Cultivating Compassion

How Digital Storytelling is Transforming Healthcare

Edited by Pip Hardy and Tony Sumner

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Pip Hardy • Tony Sumner
Editors

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palgrave
macmillan

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ISBN 978-3-319-64145-4 ISBN 978-3-319-64146-1 (eBook)
https://doi.org/10.1007/978-3-319-64146-1

Library of Congress Control Number: 2017953880

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Cover illustration: Maciej Bledowski / Alamy Stock Photo

Printed on acid-free paper

This Palgrave Macmillan imprint is published by the registered company Springer Nature Switzerland AG
The registered company address is: Gewerbestrasse 11, 6330 Cham, Switzerland

Foreword to the First Edition

Humans have probably been telling stories from the moment they invented language. Narrative accounts of people's experiences—factual or invented—have been a central focus of social interaction throughout history, the main means by which our ancestors shared information about the world. Stories are still a central focus of our learning. They create powerful images that help us understand and interpret events. Using stories we can describe events vividly, see them from alternative viewpoints, engage our emotions and our brains, challenge assumptions and aid creative reflection.

This is a book of stories about stories. Each chapter is written by someone who has personal experience of using digital stories to stimulate learning or improve healthcare. They describe how the stories have been used to help trainees understand and come to terms with the challenges of their new roles, how they have helped newly qualified clinicians cope with emotional traumas encountered during their work and how hospital boards have used the stories to recapture their focus on the needs of service users. Here we can learn what it's like to feature in a digital story and how to make them. Like all the best storytellers, the stories about stories are narrated in a direct and compelling manner, with detailed accounts of listeners' reactions and the circumstances in which they viewed them.

Modern healthcare is highly technical. It relies on biomedical science, sophisticated equipment, information technology, data and statistics, complex organisational systems, protocols and project management. This wealth of technologies sometimes threatens to overwhelm us, squeezing out the more personal aspects of healthcare and its essential qualities—caring, compassion and empathy. Digital stories provide a way to redress the balance. They are a powerful means of giving voice to the experiences and concerns of patients and service users, helping to ensure that those working in this complex system maintain their focus on the people they are there to help.

The reader will find here a wealth of practical ideas on how personal narratives can be used as a tool for teaching, learning and quality improvement. It reminds us that compassion must be at the heart of healthcare, and this can be achieved only when those who work in the system listen to and learn from patients' experiences. The book is a fitting celebration of the remarkable ten-year history of the Patient Voices Programme and its crucial contribution to putting the personal back into healthcare.

21 October 2013 Angela Coulter

Foreword to the Second Edition

More than a decade has passed since I first met Pip Hardy and Tony Sumner. During that time their work has evolved in ways I could not possibly imagine. In reviewing this newest edition of this collection of essays, I am struck by several things.

First, I am awed by the sheer volume of insights about the use of Digital Storytelling in the healthcare context and, by analogy, the use of Digital Storytelling as a tool in human services in general. As a story facilitator and creative writing, media and performing arts educator for more than 30 years, I have collected a significant library of books on story and storytelling in the fields of business, education, social services and health. This book is the single most complete summary of the application of story-based communication in any profession I have read.

Second, I am impressed by how completely Pip, Tony and the other collaborating writers have integrated their goals and aspirations for the methods of the Digital Storytelling workshop, this marvellous tool we as facilitators take for granted, with the goals and aspirations of the healthcare entities and institutions that have engaged them. At all points you are made aware of the deep respect that Pip, Tony and company have for the challenges of healthcare professionals, and that these same professionals seem to have for Pip, Tony and their collaborators.

Third, the book reminds me that healthcare provision is an endlessly complex issue. (*Who Knew?* as our unfortunate new US President quipped). For a society to commit to equitable lifelong health services support, the contradicting tensions are enormous, most evidently, the seeming tension between cost and compassion. This book adds weight to the argument that when we take care of people ahead of their crisis (as patients, as caregivers), when we stop and hold each other's stories with dignity and respect, we do in fact create the conditions for more efficient and cost-effective implementation.

Finally, this book is about the experience of being a patient, a carer or a health professional—all people. The most valuable component of Pip and Tony's efforts is how they serve as advocates for the voices of both those who receive and those who deliver healthcare. Big processes, big data, leaves so many, many people invisible; their needs, hopes and traumas, large and small, reduced to small ticks on an accounting sheet. This book reminds us again that every story matters, every story informs. While the great chaos of our mass communication society might privilege and surface certain stories over others, down on the ground, when a nurse or doctor greets their next patient, for that moment, no other stories matter. Two people being present, looking for a way to help or be helped, if not with a solution, then with kindness and understanding.

So as you wander this book's pages, consider yourself fortunate to have so much considered reflection on the way story, and specifically Digital Storytelling, works in our communication processes in one place.

As they delineate and explicate all these unique and wonderful projects, also be reminded that the starting point for all this work is love.

Pip and Tony love what they do.

And they bring love into every aspect of their doing it.

I hope you enjoy it as much as I have.

May 2017 Joe Lambert

Patient Voices: In Celebration

At that first digital story workshop ten years ago, the greeting said it all.

'Hello Monica, how are you?' said Pip, *not* followed by 'How's John?' For I was there about me.

It was the first time that I realised that I had losses too, for I was invited to tell MY story. Up to then it was—as it should be—about how ill my husband, John, was, how he had lost his ability to speak, to read, to eat, to move because of the stroke.

That was the first time that I, as his carer, was given my own platform.

Soon I came to feel the openness and objectivity of that platform, where pain is allowed to reveal its own prose and poetry, feeding on the experiences of others whose pain shadowed mine, yet enriched mine, showing me new ways of being.

There we all were, so different from each other. We started off in faltering, hushed tones, but soon our voices became bolder as we allowed the harshness of our daily lives to break through surfaces of politeness and reserve. That first hour was intense. I tried to find words for emotions which had not been written with, or for, words.

But when the words started to flow, they strung themselves together in a magical way, forming patterns of expression which I did not know existed within me. And pictures started to appear too. With gentle encouragement resting in long silences, the pictures emerged from somewhere within the clouds of my loss and bewilderment, giving meaning to faltering words which became sentences, paragraphs, chapters and then a story.

My story, as I saw it, for the first time being recorded for others also to see.

Not an easy task, for I have this fear of being seen as an 'angel'. It makes my senses go weird when people say, 'I don't think I'd be able to do what you're doing. You're an angel'.

I remember talking about that on that first morning. I told the group about how, returning from a regular early morning swim, my grocer-friend was, as he does each day, putting out his fruit and vegetables on the pavement, and as I passed, he called me over.

'Does John know that you're having an affair?' he asked.

I gasped. I could not believe that he had been watching me coming back from my swim three times a week, which I rushed to do while the home-help gave John his morning bath—he watched me return, not having seen me leave, believing I'd spent the night out!

And there I was on that first morning, able to talk about this. For the first time I could speak about how confused I was by this contradiction within me. For yes, I realised, I do not want to be seen as anything other than a dutiful wife, looking after her man till death us part. Yet I don't want to be seen as an angel.

How relieved I felt that morning when I could talk, and laugh, about this angel business. We talked, said things like they needed to be said, and our stories started to form their own shapes.

Talking about my journey, my understanding, my bewilderment, my anger, helped me to realise that all is well, for the strengths which I did not know I had in me slowly started to reveal themselves. I saw them through the reactions of those around me, whose stories mingled with mine in mutual tenacity and courage. Our tears, our laughter brought us together in an amazing commonality and showed us that pain does not respect education, money or class.

I spoke openly with everyone in the room about all sorts of intimate things, and they understood. Nobody judged. Nobody opinionated. Though I feared criticism, it never came. So I spoke, wrote, captured images and pictures, and, with the Pilgrims' help and careful editing, pulled the different threads into understandable digital stories.

Thank you Pilgrims, not only for the platform you make available through your workshops, but also for the skills which each of us walk away with after a day of speaking our shyness and whispering our private fears to sympathetic others. Thank you for opening up to us the opportunity to place our experiences under the microscope of realisation, acceptance and reality.

Thank you for teaching us a skill which we would otherwise not even have dreamt existed: learning to record our stories digitally for others, including the medical, health and social care professionals, to learn from. And thank you for recording their stories too, for it gives us an equal insight into their world, to learn from their stories so as to show us that we are all on the same side.

You have helped so many of us start that special process of healing which comes from honesty and acceptance, a path upon which our next generations can build and improve.

And thank you for facilitating the lasting friendships which we have come away with.

To the readers of this book I say, if you are thinking of making your story—or making it possible for others to make their stories—you are in for a surprise, for you are going to receive that special gift of freedom which can come only from acceptance and revelation. Do not be afraid to liberate yourself—and others.

Listen. Learn. Understand. Share YOUR story—your stories—and the stories of those for whom you care and with whom you work. Only then can others gain from your insights and experiences.

25 October 2013 Monica Clarke

Monica's stories can be seen at: www.patientvoices.org.uk/mclarke.htm

Preface

It was a dark and stormy November night, not many years into the new millennium. We were enjoying dinner with old friends. As the evening drew to a close, and our friends were heading for the door, Brendan turned and said ‘Oh, there’s something I’ve been meaning to show you. Have you ever heard of a digital story?’ We had not.

He switched on his laptop, turned up the volume and played a very short video. But it was no ordinary video. It lasted less than two minutes, consisted of a series of still pictures, the voice of the narrator, a bit of piano music in the background and no video footage. It was a story told by a mother about her daughter—and the joy and pain of watching her grow up. Her voice cracked with emotion.

It was one of those ‘Ah ha’ moments.

As we wiped our eyes, we realised that this could be the solution to the dilemma of how we could, creatively and effectively, bring the voice of the patient into e-learning materials that were designed to contribute to the development of effective, safe, humane and reflective healthcare practitioners.

The digital story that we had just seen—told with unquestionable authenticity and undeniable poignancy—conveyed something that really mattered to the storyteller. We walked in the mother’s shoes for those moments, and we learned a great deal about her in a very short space of time. In less than two minutes, it raised lots of questions, inviting the viewer to question assumptions and consider and re-consider values.

This short multimedia form, at that time used almost exclusively in community history and community development, seemed to us to provide the perfect vehicle for conveying 'the patient voice' and utilising these powerful personal stories to promote reflection, prompt discussion and debate, highlight opportunities for learning and improvement, encourage the cultivation of empathy and compassion, and remind all those engaged in the business of healthcare of our shared humanity. We knew that stories like the one we had just seen could transform the learning materials we were designing, by giving people a different kind of learning opportunity: one that engaged hearts as well as minds, one that prompted deep reflection and exploration of values.

A few days later we showed that first digital story to our colleague Paul Stanton, the then head of Board Development at the Modernisation Agency's Clinical Governance Support Team. We had been working closely with him on a large research and development project about clinical governance for primary care trust board teams; he was also one of the expert advisers on the Royal College of Nursing's Clinical Governance e-learning modules.

As *he* wiped *his* eyes, he commented: 'I know what you're thinking'.

And so, in 2003, we, the editors of this book, embarked on a quest or, perhaps, in retrospect, a pilgrimage. We wanted patients everywhere to be treated with justice, dignity, humanity, respect and compassion. We wanted the same for all the people who deliver healthcare.

Actually, our goal was nothing less than a transformation in healthcare which, we believed, could come about if people—healthcare providers, managers, decision-makers, policymakers—would take the opportunity to listen to and learn from the stories of the people they served. We believed that there was a new and important kind of knowledge contained in these stories that was every bit as important as knowing how to take a temperature, measure blood pressure or insert a catheter. While Evidence-Based Healthcare was intended to establish the standard for high-quality, safe and effective clinical care, we wanted to offer the Evidence of Experience to weight the scales a little more towards the person and a little less to the disease. We wanted to offer all those who design and deliver healthcare an opportunity to walk in someone else's shoes for just a few moments—to gain some insight into their experience—and then to reflect on their own practice, their own values.

Quests are rarely easy, and ours has been no exception.

Our journey has, quite literally, taken us around the world. We have been to interesting places, met extraordinary people, faced many challenges and learned many new things. We have taken wrong turns, headed up blind alleys, stumbled and picked ourselves up again. We have definitely encountered some dragons, but with our particular blend of stubbornness and idealism, we have carried on, frequently reminded that the journey is often more important than the destination.

Along the way, we have facilitated nearly 200 projects and workshops, met well over 1000 storytellers and recorded their stories, conducted research into the uses and impact of the stories, produced several publications, contributed chapters to books on digital storytelling and presented our work at dozens of conferences around the world.

As a means of educating clinicians through involving patients, carers and service users, the Patient Voices approach to digital storytelling has gained recognition throughout the international healthcare community as well as the international digital storytelling community.

The first edition of this book was published in 2014 to mark an important milestone: the celebration of ten years of the Patient Voices Programme. Now, three years on, we still haven't reached the end of our journey, and there is still more to say.

But by now, you may be asking yourself: What are Patient Voices? Who are Patient Voices? What are digital stories? How do they work? What happens in the workshops? Who actually creates the stories? What happens to them? Who benefits from the stories? Can you quantify the benefit? Why should providers and commissioners of healthcare services be interested in digital stories? Can you teach compassion and empathy? Is digital storytelling a therapy? How could I use Patient Voices digital stories in my work/with my team? Can the stories be used in education? Can they be used in research? These are some of the questions that arise when introducing Patient Voices and which this book will try to answer.

About This Book

It is a common literary device for a group of friends, colleagues, travellers or, as in Chaucer's *Canterbury Tales*, fellow pilgrims, to share their individual stories while on a communal journey. We've invited our colleagues to share with you their stories of their part of the Patient Voices journey. So, this book is written in the spirit of co-production and collaboration and in recognition that the Patient Voices Programme would not exist if it were not for all those with whom we have partnered on Patient Voices projects and workshops.

Every one of the chapters is written by someone who has commissioned or participated in at least one Patient Voices Reflective Digital Storytelling workshop as part of a larger project. When authors refer to digital storytelling, they are referring to Patient Voices. When we refer to digital storytelling, we are referring to what has become known as the 'classical' digital storytelling form, developed in the mid-1990s by Joe Lambert and StoryCenter (www.storycenter.org).

Most of the authors, whether health professional, educator or service user, made their own digital stories before advocating and facilitating their further use with other health professionals or service users. They are thus able to speak from their own personal experience while also addressing fundamental theoretical, therapeutic or practical benefits and legitimate questions and concerns about the use of digital stories and digital storytelling in healthcare.

In the chapters that follow, you will read many stories of transformation, both personal and professional. People who once thought of themselves as patients have discovered their strengths, their courage and their resilience, while people who think of themselves as clinicians have become aware of their vulnerabilities—and the courage that enables them to share their stories.

Like many of our storytellers, we have also been transformed by this work that affords us the extraordinary privilege of hearing about what matters most to people. The Patient Voices Programme has become a way of life for us, a vocation, a commitment, a call to action, an opportunity to relieve suffering through a willingness to walk alongside storytellers, to listen to and accept their stories and, through the alchemical process of digital storytelling, to see storytellers grow in confidence, gain insight and come to accept themselves and their stories with new respect and, sometimes, even love.

We hope you will enjoy reading about this work as much as we have enjoyed doing it.

Cambridge
May 2017

Pip Hardy
Tony Sumner

Acknowledgements

To all the people who have given generously of their time, expertise and experiences to contribute to this book: we are more grateful than we can say. Without you there would be no book.

To all those people (and their organisations) who have sponsored workshops: thank you for your imagination, your belief in Patient Voices and your determination to find new and wonderful ways to use stories to improve the quality of the learning and care you deliver.

To more than 1000 storytellers—patients, carers, relatives, staff, managers and commissioners—all those people who have shared stories with us: thank you for giving so graciously of yourselves; you are true heroes and heroines. We would be nothing without you.

To Paul Stanton: thank you for sharing our vision and finding funding for the very first Patient Voices stories and for continuing to recognise their value even after all these years!

To Monica Clarke and the late Ian Kramer—our very first two storytellers: we are deeply indebted to you for your intelligence, generosity and honesty in sharing your stories with us and for opening our eyes to the true meaning of consent.

To Cathy, Grete, Sissel, Kristin, Henrik, Darcy, Heather, Ragnhild, Veronique, Ann, Angeline, Heather, Steve, Karen, Michael, Burcu, Brooke, Tricia, Alex, Satu, Yuko, Akiko, Daniel, Amy, Emily, Rob, Stefani, Andrea and so many others in the international digital storytelling

community: thank you for encouragement and enthusiasm, for making conferences so interesting and so much fun, for wonderful conversations, for sharing food, wine, hopes, dreams and, always, stories.

To Trish Greenhalgh, Iona Heath, Angela Coulter, Robin Youngson, Rita Charon, Brian Hurwitz and many others who have paved the way for patients, stories and the humanities to play their rightful part in making healthcare more humane and more compassionate: thank you.

To Ros Connelly: a very special thank you for rescuing us from a moment of despair, bringing your editing skills and your experience of our workshops to bear on the almost-final manuscript and guiding us to the finish for the first edition—and then doing it all again for the second edition!

To Fiona O'Neill: we are grateful for that much-needed nudge and for the reminder that: 'You owe it to the storytellers to get this book finished!'—and for so much else over the years.

To Dr Jo, a thousand thanks for being such a willing apprentice/accomplice, for always knowing what needs to be done and doing it, for your quiet and gentle wisdom, for so many gifts large and small, and for taking the lead in establishing the Patient Voices Advisory Board.

To aforesaid Advisory Board, thanks in anticipation of your wise counsel and support during the next phase of our journey.

To Joe Lambert, the father of digital storytelling, and to StoryCenter: thanks is inadequate to express our gratitude for your vision, inspiration and generosity. You have shared the gift of story in and with a world filled with the technology that makes it possible for anyone and everyone who is willing to take time, reflect and consider, to create a compelling personal story that can explore identities, create and strengthen relationships, break down boundaries and promote greater understanding within and between cultures—including the vastly different cultures of patients and professionals. Your work and your lives have inspired us and hundreds of thousands of others around the world.

And finally, to our grandchildren: Lola, Otis, Luna, Martha and Isaac, for giving us an excuse to fly kites, smell flowers, feed fish, swing on swings, inspect beetles, watch clouds, read stories—and for reminding us of the things that *really* matter.

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Part I

A Tale of Two Decades

Pip Hardy and Tony Sumner

I keep six honest serving-men
(They taught me all I knew);
Their names are What and Why and When
And How and Where and Who. Rudyard Kipling. (Kipling 1902)

The impetus for this book was to document some of the Patient Voices projects that have taken place since the beginning of the programme, to share the experiences and learning from those projects and to explain the history and development of the programme.

In order to understand the projects described in Parts II–VI, there needs to be an understanding of, to use Kipling's "six good serving men and true", what the Patient Voices Programme is, why it was set up, when it came to be, how it works, where it operates and who created it.

Explaining the genesis, nature, purpose and benefits of the Patient Voices Programme has always been a complex task, despite the delivery of many presentations and keynotes (please see www.patientvoices.org.uk/present.htm), completion of research studies (Hardy 2007, 2016), articles and publications in journals (please see www.patientvoices.org.uk/articles.htm and www.patientvoices.org.uk/papers.htm), contributions to books on digital storytelling (Hardy and Sumner 2010, 2014, 2017; Hardy 2017; Jamissen et al. 2017; Dunford and Jenkins 2017) and the production of a documentary film (Patient Voices et al. 2017).

In this first part, Hardy and Sumner address these questions as they take us through the context and conception of Patient Voices, its establishment and consolidation, development and evolution, and methodology and approach.

Chapter 1 "The Journey Begins" explains the initial inspiration for the Patient Voices programme and the way in which technical, philosophical and educational factors and movements influenced early work.

Chapter 2 "Pilgrims' Progress" covers the period from 2004 to 2010, when the programme developed and refined its processes and approaches, coming to situate itself firmly with the Classical Digital Storytelling model created by StoryCenter.

From 2010 to 2017, covered in Chap. 3 "To the Far Horizon", the programme began to identify broad themes within its work and to look at more deeply and employ more directly the power of the process—rather than the product—to effect change in attitudes amongst healthcare staff.

Finally, Chap. 4 "The Patient Voices Approach" looks at the derivation of the approach, what happens within a Patient Voices workshop, and the processes that have been developed by the programme to provide appropriate consent and release of stories, protection of intellectual property and effective distribution of the stories.

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1

The Journey Begins

Pip Hardy and Tony Sumner

Introduction: The Lie of the Land

> *What we're experiencing is not simply the acceleration of the pace of change, but the acceleration of acceleration itself. In other words, change growing at an exponential rate.* (Kurzweil and Van Dusen Wishard 2006)

The world today is a very different place from the world in which we began our Patient Voices journey, way back in the dawning years of the twenty-first century. The technology revolution has changed the way we live irrevocably: our grandchildren will not be able to imagine a world without mobile phones, instant access to the world wide web, and the ability to communicate with friends, family, and colleagues at anytime from anywhere in the world.

In the early years of the twenty-first century, compassion was something practised by Buddhist monks, and the voice of the patient was

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P. Hardy, T. Sumner (eds.), *Cultivating Compassion*,
https://doi.org/10.1007/978-3-319-64146-1_1

largely heard with scepticism at best and mistrust at worst. Education was, by and large, conducted in physical places in real time by experts in their subject. Stories were something you read to young children, and doctors were unquestioned in their knowledge and their position in health services everywhere, including in the UK National Health Service.

We would like to highlight some of the features of the landscape in which our journey began and that were particularly relevant to that journey, in particular, the political, educational, and technological aspects, which are inevitably also affected by social and economic factors.

The journey that the Patient Voices Programme has followed in the years since 2003 is, as so many journeys are, as much a journey *from* a place as a journey *to* a place. That place, in 2003, was set in a landscape that had been, just as the physical landscape is, shaped over time by a variety of forces of change. However, where the forces of wind, rain, and geophysics act on the landscape over millennia, the landscape from which our Patient Voices journey sets out was largely laid down in the seemingly antediluvian past of the years preceding and following the Second World War, then sculpted and shaped by technological, political, and social forces over the decade preceding 2003. Let us consider the impact of these various, interconnected forces, illustrated in Fig. 1.1.

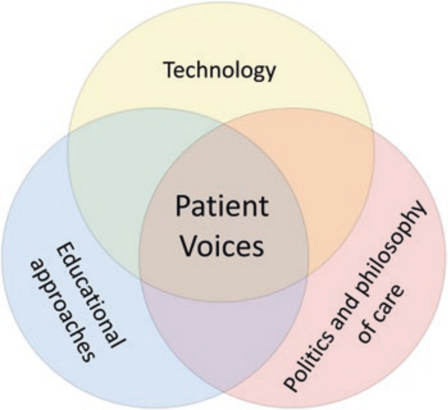

Fig. 1.1 Environmental forces shaping the landscape around Patient Voices

Educational Approaches

In the late twentieth century, open learning was still regarded by many academics as a threat to their expertise and centrality in the learning process. The majority of adult education still took place in classrooms and lecture theatres; research was done in libraries, and information was gathered from books and printed papers. The term 'Lifelong Learning' had yet to come into common usage; learning that was centred on the learner was still considered to be moderately radical, and approaches such as Malcolm Knowles' theory of 'andragogy' (Smith 2002) were far from the norm.

Gradually, appearing on the horizons of educationalists, instructional designers, and educational developers like us were the opportunities afforded by changes in technology to rethink the way educational opportunities were created and delivered, particularly in the field of distance and open learning. In the mid-1990s, computer-based learning meant either painfully slow interactions over modem or ISDN connections or laboriously created interactive materials delivered on CD-ROM. Even as late as 1999, organisations devoted to open learning, such as the Open University and the National Extension College in the UK, were still sending out boxes of weighty ring binders filled with printed materials, sometimes accompanied by video or audio cassettes, to their students.

Pilgrim Projects' work environment shifted with these forces. We went from producing print-based workbooks to creating interactive CD-ROMs containing the learning materials. Virtual Learning Environments (VLEs) appeared but when we developed 21 online accountancy courses in 2000, the limitations of the VLE technology at the time (such as Lotus LearningSpace) and the constraints of connection speeds (still mainly 56 kbit modems), meant that the creativity of our instructional designs was constrained to text and simple graphics.

By 2003, e-learning was no longer experimental but was becoming more common and millions were poured into the UK e-University, the NHS University, and other large e-learning programmes, including one that would be a key trigger for us, the UK Health Education Partnership.