



White Rose HIP Health Technology Bulletins

The White Rose Health Innovation Partnership (WRHIP) aims to accelerate new health-related technologies by facilitating interactions between academia, industry and the NHS using an *open innovation* approach.

The new projects funded as part of this initiative are built upon a foundation of excellence in health innovation by the Partnership's members. This series of Health Technology Bulletins offer an introduction to this research excellence and cover a broad range of clinical and technology areas.

Each bulletin is written to give a general introduction to the topic area along with short case studies of clinical applications of new knowledge. Information is also presented on where to learn more about these new technologies and health challenges, and how to access the network of health innovation professionals established by the Partnership.

Designing patient-shaped health care

Hearing Patient Voices

Lord Darzi's Next Stage Reviews emphasise the role of technology, innovation and partnership working in achieving an NHS, with quality of care at its heart, secured for future generations. Innovation is broadly defined – embracing clinical practice, service design and research. The Health Innovation Council is to 'provide leadership and advocacy with key decision-makers in the NHS on the benefits to patients, the NHS and the country, of adopting cost-effective new technologies and models of care'. There are plans to develop new clusters that bring together partners from the NHS, academe and industry to support innovation and the rapid application of advances in health and social care. In this climate of change we should explore the opportunities that exist for patients and carers to engage in partnership working, bringing their own experience, expertise and knowledge to inform innovation. Are the voices of patients and carers being heard?

The traditional view of patients as passive recipients of new technologies or services is slowly changing. There is growing recognition of the value of incorporating the

perspectives, experiences and wisdom of the individuals and communities served by the NHS, in the design, as well as the delivery and evaluation of healthcare. The concepts of 'co-creation', 'co-production' and 'co-design' emphasise the importance of the relationships between service providers and service users, and are becoming more influential as models that support the more radical innovation required. These concepts focus on the value of unleashing and working with the skills, knowledge and capacities of individuals and communities to find better solutions to the complex challenges of 21st century health care.

In this bulletin we describe three initiatives that illustrate the value of creating opportunities to better understand the needs and experiences of patients and build this understanding into the design of patient-shaped health care. We will outline our learning from these initiatives and draw some conclusions about the principles and values that should inform collaborative work that engages people who bring their experiential knowledge and who are often entering unfamiliar places when invited to get involved.



Workshop participants (l-r) Fiona O'Neill, Karen Hoffman, Brian Clark, Jools Symons, Tony Sumner (standing) Carole Carter, Eric Moorhouse.



Arthur and Co.: Digital stories about living with Arthritis

Arthritis affects one fifth of the UK population. 72% of people with arthritis meet the definition of 'disabled' in the Disability Discrimination Act 1995. White Rose Health Innovation Partnership (WRHIP) funding enabled partnership working between researchers at Leeds University, Arthritis Care, and Pilgrim Projects, founders of the Patient Voices Programme, to look beyond these statistics to what living arthritis is like. We set out to make digital stories that would illuminate the storytellers' experiences and, when shared, promote understanding and increased awareness. In keeping with the WRHIP focus on innovation and health-related technology, the storytellers reflected on the role technology and innovation plays in their journey with arthritis. Five informed volunteers from Arthritis Care agreed to take part in the project, which took place in spring and summer 2008.

Patient stories are acknowledged as making a significant contribution to understanding the patient's experience. They acknowledge the patient's own areas of expertise and unique life experiences. Pilgrim Projects have pioneered a carefully-developed methodology that facilitates the creation and sharing of digital stories about health and health care. Patient Voices digital stories are 3-5 minute first-person mini-movies, combining creative writing with the family photo album and created through empowering teaching methods and a carefully-facilitated group process.

Participants draft and edit a script, find pictures to illustrate their story and then create their own video, using video- and photo-editing software. Music provides another dimension, and storytellers are guided to use licensed music or bespoke pieces composed for their stories. The workshop ends with a celebratory premiere of everyone's stories and storytellers leave with a DVD to show friends and family.

A straightforward, ethical, two-stage, informed consent and approval process enables the stories to be shared. Approved stories are released via the Patient Voices website under a Creative Commons (attribution, non-commercial, no-derivatives) licence that protects the storytellers as well as meeting licensing requirements for music and images in the digital stories.

The careful, attentive and flexible story creation process is adapted to participants' energy levels, abilities and learning pace and style. This was especially important in making the Arthur and Co stories. Principles underpinning Pilgrim Projects work include a deep respect for individuals and the stories they want to tell.

Everyone's story is important and the process of telling a story is often reported as being a powerful, and, sometimes even transformative, experience, providing opportunities to reflect on life experiences in a supportive and collaborative environment. Indeed, members of this – and other - groups continue to remain in contact with one another and comment on the benefits of sharing stories in this way with others who have similar experiences.

The five stories created are all different and powerfully illustrate how a long-term illness like Arthritis is experienced in a unique way by each individual. However, common themes did emerge across the stories, including the:

- creativity and resourcefulness of individuals in finding ways of adapting their lives to their changed circumstances while remaining true to themselves
- value of involvement in volunteering and motivation to help others
- importance of being believed by health professionals on the (often) prolonged journey to a diagnosis.

The need for more sensible product and service design featured in several stories, including the observation that many with Arthritis cannot operate disabled lifts due to poor design of the operating button!

The stories, launched at the University of Leeds in July 2008, have been shown at conferences and other learning events. Brian Clark, a storyteller, introduced his story with this reflection:

'Arthritis and its associated pain is like three letter I's.

Isolated - when you are first diagnosed, you feel you are the only one who feels like you do.

Invisible - because you cannot see Arthritis or feels someone else's pain.

Individual - as everyone has different types of the disease and different thresholds of pain.

That is why doing this project has opened my eyes to the suffering others go through, mainly in silence, on their own, invisible to outsiders. I cannot recommend strongly enough that people should take time out and listen to the stories of people with problems, who could be your neighbours, and you would never know.'

The stories are available on the Patient Voices website at: <http://www.patientvoices.org.uk/wr.htm>

Preparing for partnership: The Patient Learning Journey Programme

The new willingness to learn from patient experience raises important questions about how people are prepared and supported for involvement. Individuals invited to bring their patient experience and knowledge to inform initiatives and involvement activities in universities and the NHS often report the experience as unsupportive and bewildering.

The Patient Learning Journey Programme, developed by the School of Healthcare and the School of Medicine at Leeds University in partnership with service users from local voluntary groups, including Arthritis Care, is an established and effective way to prepare service users and carers for informed involvement. Facilitators – themselves patients and carers – help create a supportive learning environment where participants feel comfortable and valued. The approach focuses on the individual journeys and experiences of patients and carers. The opportunity to reflect and to listen to others helps participants develop new insights, understanding and confidence, and to recognise that their experiences are valuable to others.

Over 60 people have completed the Strategic Health Authority supported programme. Many go on to involvement in activities including working as simulated patients teaching student doctors and nurses communication skills, and curriculum development, teaching and research. Team members have worked with a local hospital to prepare patients for involvement in service redesign.

The enthusiasm and willingness of participants to contribute to partnership working in order to help the NHS provide a better service is striking. Their insights and knowledge of what makes a difference is an invaluable resource. The group advise and support individual researchers, service development and teaching teams on developing supportive and respectful approaches to involvement as well as facilitating the Learning Journeys programme as the first stage of collaborative working.

One participant captured the spirit of collaboration:

'For many years health professionals have been studying and working extremely hard to provide the best treatments to give to patients. Now here is an opportunity to give something back. By listening to the real life experiences of patients, we can show students something they won't find in their textbooks: a fully interactive human face with genuine heart and spirit'.

For more information contact Fiona O'Neill at the School of Healthcare, University of Leeds. Email: f.h.o'neill@leeds.ac.uk. Tel 0113 343 1300

Patient Voices: World-class digital storytelling

For five years, the Patient Voices programme has facilitated the telling and hearing of the unwritten and unspoken stories of ordinary people. Our hope has always been that the stories would move those who devise and implement health and social care strategy, as well as those directly involved in care, to carry out their duties in a more informed, humane and compassionate manner, and that patients, carers, professionals and clinicians might meet as equals and work respectfully together for the benefit of all.

The innovative model of free distribution of the stories for use in health and social care education and quality improvement ensures those voices are heard, and that the investment of storytellers is nurtured to develop maximum social capital.

The website offers what we believe to be the largest freely-available resource of digital stories of healthcare in the world. The stories are in use in UK, North American, and Australian healthcare organisations and universities – and even further afield. Indeed, the number of hits on the website in 2008 is expected to reach half a million.

A product is only as good as the process used to create it. Storytellers comment on the power of the process and viewers on the power of the stories. We think the stories have such a powerful impact and touch people's hearts because of their brevity, veracity and simplicity, but also because they are:

Effective
Affective
Reflective.

(Tony Sumner, 2008)

We hope that the stories will touch your heart as they touch ours.

To find out more about the Patient Voices Programme, contact Pip Hardy at Pilgrim Projects on 01223 440257 or via patientvoices@pilgrimprojects.co.uk



Brian Clark and Karen Hoffman working on their stories

Founding partners in the Programme include:

University of Leeds
University of Sheffield
University of York
University of Bradford
Medipex
Medilink Yorkshire & the Humber
The Leeds Teaching Hospitals NHS Trust
Sheffield Teaching Hospitals NHS Foundation Trust
Bradford Teaching Hospitals NHS Foundation Trust
Yorkshire Forward
Health Technologies Knowledge Transfer Network
New Jersey Biotechnology Life Science Coalition
Rutgers, The State University of New Jersey
University of Medicine and Dentistry of New Jersey
New Jersey Institute of Technology
Princeton University
International ARI Institute, University of Toledo, Ohio
Polymer Centre for Industrial Collaboration
Biomaterials and Tissue Engineering Centre for Industrial Collaboration
Pharmaceutical Innovation Centre for Industrial Collaboration
Wireless Technologies Centre for Industrial Collaboration
Particles Centre for Industrial Collaboration

Conclusion

In the 19th century the greatest healthcare improvements came from social advances, particularly in public health. In the 20th century, discoveries of new medicines and technological advances in surgery drove fantastic increases in life expectancy and quality of life in industrial and post-industrial economies. In the 21st century, the challenges call for a different kind of innovation; the development of healthcare systems centred around the person, not the disease, and validating and responding to personal experiences of illness and medical care. These experiences become the source of wisdom and knowledge that often remain tacit and unavailable to others.

One valuable aspect of digital storytelling is that it enables these experiences to be explored and made accessible so 'ordinary' people can articulate their extra-ordinary understandings. As the initiatives outlined here demonstrate, people are very willing to share these understandings and actively contribute to the co-design of services and new technologies to achieve the common aim of truly patient-shaped healthcare.

There is a new willingness and many reasons to harness the creativity and innovation of patients, carers and communities through respectful, productive, processes of co-design. Stories and storytelling offer accessible ways of deeply appreciating and understanding patients, carers and professionals' experiences. Listening to these unique experiences, whether of care or caring, treating or treatment, or just getting through an ordinary day with arthritis, reminds us of our common humanity and shared purpose to make our healthcare system 'better' for those who turn to it, often in times of deepest need. Please, take time to watch the stories on the Patient Voices website and reflect upon the potential for expanding and enriching healthcare innovation of working with patients and carers, and harnessing this previously missing expertise.

Authors: Fiona O'Neill, School of Healthcare, University of Leeds F.H.O'Neill@leeds.ac.uk

Pip Hardy, Pilgrim Projects/Patient Voices pip@pilgrimprojects.co.uk

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White Rose Health Innovation Partnership
Enterprise & Innovation Office
Charles Thackrah Building
101 Clarendon Road
Leeds LS2 9LJ
UK
Tel: +44 (0)113 343 0923
Fax: +44 (0)113 343 0949
Email: whiterosehip@adm.leeds.ac.uk

www.wrhip.org