

Editorial

Emerging technologies for developing and improving patients' health experience

A Niroshan Siriwardena MMedSci PhD FRCGP
Foundation Professor of Primary Care, School of Health and Social Care

Shaun Lawson BEng(Hons) PhD
Senior Lecturer, Co-Director, Lincoln Social Computing Research Centre, Department of Computing and Informatics

Martha Vahl MSc
Research Consultant, Community Operational Research Unit (CORU), Faculty of Business and Law
University of Lincoln, UK

Hugh Middleton MA MB MRCP MRCPsych MD (Cantab)
Associate Professor, School of Sociology and Social Policy, University of Nottingham, Nottingham, UK

Gerard de Zeeuw MSc PhD
Professor of Management Systems, Faculty of Business and Law, University of Lincoln, UK

Patients' health experience and healthcare interactions

Interactions between patients (or users), professionals and provider organisations in health and social care are increasingly being seen as part of a complex adaptive system. In such interactions the story or narrative that is told is not only a powerful expression of the contacts, connections and communications between these agents, but also serves both as a model of, and as a model for the development of their co-operation. Such a system is self-organising and allows users to contribute, but also enables them to develop as autonomously participating systems themselves, hence increasing control over their own experiences. It may give rise to consequences, therefore, for the way future health provision is organised, because in such a paradigm stories are more than just reports (or representations): they identify how people like to organise their lives.

Looking at patients and how they interact with various service systems can be expected to have a number of advantages. In the present, so-called input-output, system, a great deal of valuable information is 'lost'. In the healthcare setting this may be because of the nature of clinical interactions – which are often short in duration and constrained by professional considerations rather than patients' needs. Therefore,

a major challenge for health and social care, within an increasingly fragmented system, is to create a more patient-centred experience and a patient story that is coherent as well as constructive. It will require a change in the type of interactions between users and service providers, as indicated; it will also require the introduction and use of recently introduced technologies.

The concept of harnessing so-called Web 2.0 technologies for improving healthcare interactions has recently been suggested.^{1–4} The underlying notion put forward is that through sharing experiences in terms of stories as well as via websites that facilitate social networking and self-organisation, patients may be able to conceive of their condition and symptoms firstly in such a way that less is lost in their own life model, but also in the transfer to fellow patients, volunteer groups or expert healthcare professionals. The sharing that is necessary for this is becoming increasingly possible nowadays via the ubiquitous platforms of mobile and smartphones, as well as through conventional computers by way of devices such as wikis and blogs. Sharing of stories in this way supports the self-organising nature of the system as well as that of its parts (users as well as providers).

How might such a development be envisaged, where could it be used and what are the implications for service development and research?

Mental health problems and stories

Dissatisfaction with professional interactions is particularly the case for those with mental health difficulties. This is often centred on concerns that practitioners 'don't listen'. This simple worry strikes at the very heart of issues that highlight shortcomings of a medical, professionalised approach to the experience of emotional and psychological distress. Part of the problem lies in the fundamental distinction between 'explanation' of psychological difficulties as illness (*Erklären*), and 'understanding' of psychological distress as a feature of individuals' lived experiences (*Verstehen*).⁵ Expert approaches favour the former, but critics of contemporary practice,⁶ as well as proponents of a 'recovery' model of mental health services,⁷ expressions of public policy,⁸ increasing attention to the importance of personal psychological growth as a determinant of outcome,^{9,10} and concern for services to respect diversity all emphasise a need for greater attention to the latter. Broadly, these alternative approaches share a framework that emphasises the development of individualised meaning, or narrative, of the illness experience – as part of the experience of how one functions in daily life – that often forms the focus of a truly therapeutic encounter. The contrasting biomedical approach to common mental health problems is largely maintained by practical exigencies. These include the fact that they are a frequently occurring reason for consultation, that practitioners can only offer relatively short consultation times and that there is a paucity of NHS-provided 'listening', or psychological therapies. This is despite evidence that clinical outcomes are improved by collaborative interventions which include 'listening', or attention to and validation of users' lived experiences.¹¹

Mental health problems are also common and costly, affecting one in six of the adult population at an estimated cost of £25 billion each year (or 2% of gross domestic product).¹² Despite huge investment to address this growing problem,¹³ and plans for further funding in psychological therapies, the increasing professionalisation of mental health provision, particularly for common mental health problems including mixed anxiety and depressive disorder, mild to moderate depression and generalised anxiety disorder, has not led to significant improvements. Some would argue that it is unlikely to do so. An extensive literature review and resulting National

Institute for Health and Clinical Excellence (NICE) guidance suggest that drug treatments and specific focused psychological treatments have a limited evidence base for these conditions. This, and their high prevalence, have led to calls for a less medicalised approach to management,¹⁴ and proposals to invest in simple talking treatments as an alternative to the widespread use of antidepressants.

One result of a talking therapy is, of course, a more constructive personal narrative or story. Narratives are particularly important in mental health because mental health issues are culture bound, have a socio-political as well as scientific context, and are often the only valid way of expressing illness for which there is not always a clinical (drugs) solution (compared with physical diseases which can also be expressed as abnormal numerical biophysical data and be treated effectively with medication), and unique in that talking and listening to stories may themselves be therapeutic.¹⁵

Stories of (or for) recovery or surviving with mental illness

Dingwall elaborates on this relationship between persons and professionals as they interact to define a shared view of the problem and its consequences, which he refers to as illness action:

Illness action is the outcome of continuing efforts on the part of the sick person, and those with whom he associates, to make sense of what is going on in the light of the knowledge, resources and motivations available to them.¹⁶

In other words the success with which a coherent narrative account of an illness or disability is negotiated reflects the ease by which the sick person and those around them, in particular health professionals, can arrive at or agree upon a shared account of what is happening. Rapid and successful achievement of an agreed narrative strengthens its coherence and enables constructive illness actions; continuing differences debilitate and hinder constructive progress.

Launer agrees that a narrative or story-telling approach with its search for shared meaning between patient and professional is of particular value, especially in mental health consultations.¹⁵ Primary care mental health difficulties occupy a 'grey' space where diagnostic clarity and mutually agreed agendas are difficult to find. The developing narrative may be helpful to users and professionals, even before professional intervention is needed, increasing the potential for self-care.¹⁷ Health information might also support this. Healthcare and other social interactions will affect the course and nature of 'recovery', whether

this is an acute (short-lived), chronic (long-term) or life-changing event or illness. In this context, technology might facilitate development of a jointly agreed narrative.

Understanding and analysing stories

The wider non-medical narrative literature draws attention to the ways in which different approaches to 'narrative' can be considered. Narratives, on one hand, may provide a representation of human experience that is self-selected and self-constructed; they are therefore determined by the perspective from which they are obtained. Structural dimensions of a narrative are as important as content, particularly in relation to the purpose of the story telling, making sense of illness and the psychological, social and economical wellbeing of the story teller.^{18,19}

There is a significant quantity of published material that refers to narrative analysis in relation to primary care practice, but very little of this refers specifically to mental health issues, and even less refers to patients' constructions of their condition. Formal searches of AMED, CINAHL, ENBASE, MEDLINE, International Bibliography of the Social Sciences, PsychInfo and ISI Web Science, using search terms seeking narrative literature relevant to mental health difficulties, have revealed very little previous research addressing these issues. There is a considerable literature that refers to practitioners' communication skills; there is a literature that concerns analysis of terms and expressions that patients might refer to in the course of a consultation, as keys to 'diagnosis'; and there is literature concerning practitioners' perspectives and experiences in dealing with the emotionally and psychologically distressed (Sargeant S and Middleton H, personal communication, 18 November 2007).

The role of technology

Although the developing electronic health record has the potential to improve the interaction between different providers and professional groups, a great deal of information will be lost unless we can understand how technology can help us to develop a more meaningful story for users and professionals, which acknowledges the contribution of both. There is also a lack of a system that enables potentially useful communication and interaction between patient-orientated and professional information on diseases and health issues –

the net result is that these essential elements develop in isolation from each other. Initiatives in the UK such as NHS Choices²⁰ attempt to provide an acceptable and modern interface to correct medical information, but often fail to inform patients in a format that is truly useful and engaging.

Technological approaches to measuring, recording, and analysing quantitative data over time are familiar for ambulatory blood pressure recording, 24-hour electrocardiograms, cardiomemo, serial peak flow readings or, more recently, regular vital signs monitoring as a component of preventative health technology. For mental health problems, quantitative data on mood, for example using PHQ-9 may also be collected. However, narrative data have not been collected in the same way, largely because of the technological and scientific challenges to recording, analysing, understanding and presenting such data.

Novel techniques are now being considered to develop, retrieve and analyse narratives using social networking technology. The rise of computer-mediated social networking has been facilitated by the development of technologies sometimes referred to as Web 2.0 (the second phase of the worldwide web). These technologies include interactive forums, social networking sites (such as FaceBook and MySpace), wikis, blogs, instant messaging, RSS feeds, podcasting user-generated audio, images and video, and specialised searches. The combination of Web 2.0-driven social networking and the increasing ubiquity of mobile technology, has the potential to create a paradigm shift away from the traditional flow of information as defined by healthcare professionals and providers, and to greater possibilities than ever before for better sharing of information between users themselves, between users and providers, and between providers themselves.

Mobile technology and persuasive systems

The use of mobile devices for allowing patients to generate self-reported information about their condition is a well-established concept. For instance, Bielli *et al* (2004) describe a system in which a health and quality of life questionnaire is delivered to recovering cancer patients via their mobile phones,²¹ Kearney *et al* (2006) describe a more recent system with similar scope,²² Collins *et al* (2003) describe how mobile phones were used to collect so-called 'ecological momentary assessment' data regarding alcohol use by social drinkers,²³ and Anhøj and Møldrup (2004) describe a study in which mobile phones were used to improve the self-management of asthma.²⁴ All such studies utilise mobile phones as unobtrusive probes to generate

regular snapshots of self-reported patient information. This idea has parallels with the concept of the experience sampling method (ESM),²⁵ first used with pager technology, but now often deployed using mobile phones.²⁶ Mobile phones, as well as acting as information recorders, have also been proposed, as part of wider networks of ubiquitous computers, as context-aware information providers; in particular, a number of researchers are reporting work on how mobile phones can be used as persuasive appliances,²⁷ which attempt to influence the ways we act and think in our everyday lives. Suggested areas of application in this respect include persuading people to take increased exercise.

Because of their ubiquity in society and increasing processing and communications capabilities, mobile phones have great potential power as facilitating devices, not only for prompting and storing self-reported information, but also for autonomously recording other contextual data such as activity,²⁸ location, or, more abstractly, social activity, as well as distributing or uploading data to central repositories. The use of phones as probes to generate more qualitative data and narrative around people's everyday activities is far less well studied. However, mobile devices are increasingly being used in a different sense as self-reporting tools by people in a social networking context – recent micro-blogging applications such as Twitter and Jaiku²⁹ allow people to update their friends and contacts on their whereabouts and activity on a minute-by-minute basis with the resultant data potentially forming a rich narrative history on a person's everyday life and context.

It is possible that Web 2.0 and mobile technology have the potential to enable the psychologically or emotionally distressed to 'tell their story', in ways that are at the same time both secure and discreet, but which could also provide an experience of 'being listened to' by users themselves, carers and professionals. This might be therapeutic in itself, but also has the potential to enable earlier detection of problems, better decisions about appropriate support and, if needed, prompts for professional intervention. This could fill an important gap in healthcare provision for service users with mental health problems, providing an extremely powerful means of developing a user-centred narrative for patients and professionals. Currently there are significant barriers to the successful development and implementation of this idea, including technical, technological, organisational, professional and ethical challenges.

Future potential

As yet, no wide-scale studies exist of how Web 2.0 technology could bring about change in health care.

Indeed, the use of any web technologies by either patients or healthcare professionals remains fragmented and disjointed. In some ways this is unsurprising given the scepticism of the quality of information available through, for instance, search engines such as Google,³⁰ and on online community driven encyclopaedias such as Wikipedia. However, the professional alternatives available are also of little clear benefit. Initiatives in the UK such as NHS Choices²⁰ attempt to provide an acceptable and modern interface to correct medical information, but often fail to inform patients in a format that is truly useful and engaging. As well as problems in communication between different professional groups, there is also a lack of a system which enables potentially useful communication and interaction between patient-orientated and professional information on diseases and health issues, which means that these essential elements develop in isolation from each other.

The potential for technology to enable stories to be created, to develop greater meaning in both the user and professional, and to support self-care, as well as to improve the quality of professional care remains to be implemented and evaluated. The future could see users being able to use their unfolding story to organise their environment and to address their needs, with social and healthcare networks operating together as a sound support system. To achieve the vision of a coherent system to provide meaning to users, as well as to improve the efficiency, effectiveness and access to support would be a remarkable achievement of such developments if it can be realised.

REFERENCES

- 1 O'Reilly, T. *What is Web 2.0. Design patterns and business models for the next generation of software*. www.oreilly.com/pub/a/oreilly/tim/news/2005/09/30/what-is-web-20.html (accessed 6 December 2007).
- 2 Giustini D. How Web 2.0 is changing medicine. *BMJ* 2006;333:1283–4.
- 3 Deshpande A and Jadad AR. Web 2.0: Could it help move the health system into the 21st century? *Journal of Men's Health and Gender* 2006;3:332–6.
- 4 Kamel Boulos MN and Wheeler S. The emerging Web 2.0 social software: an enabling suite of sociable technologies in health and health care education. *Health Information and Libraries Journal* 2007;24:2–23.
- 5 Jaspers K. *Allgemeine Psychopathologie* (6 unveränderte Aufl edn). Berlin: Springer, 1953.
- 6 Double DB. *Critical Psychiatry: the limits of madness*. Basingstoke: Palgrave Macmillan, 2006.
- 7 Repper J and Perkins R. *Social Inclusion and Recovery. A model for mental health practice*. London: Baillière, 2003.
- 8 Department of Health. *Our Health, Our Care, Our Say*. London: Department of Health, 2006.
- 9 Rogers CR. *On Becoming a Person: a therapist's view of psychotherapy*. London: Constable, 2004.

- 10 Joseph S and Linley PA. *Positive Therapy: a meta-theory for positive psychological practice*. London: Routledge, 2006.
- 11 Bower P and Rowland N. Effectiveness and cost effectiveness of counselling in primary care (Cochrane review). *The Cochrane Library, Issue 3*. Oxford: Update Software, 2006.
- 12 Layard R. *Mental Health: Britain's biggest social problem?* Paper presented at the No10 Strategy Unit Seminar on Mental Health, March 2007. Oxford: Oxford Economics.
- 13 Department of Health. *National Service Framework for Mental Health, Modern Standards and Service Models*. London: Department of Health, 2000.
- 14 Middleton H, Shaw I, Hull S and Feder G. NICE guidelines for the management of depression. *BMJ* 2005;330:267–8.
- 15 Launer J. Narrative based medicine: a narrative approach to mental health in general practice. *BMJ* 1999;318:117–19.
- 16 Dingwall R. *Aspects of Illness*. London: Martin Robertson, 1976.
- 17 Orner R, Siriwardena AN and Dyas JV. Anxiety and depression: a model for assessment and therapy in primary care. *Primary Care Mental Health* 2004;2:55–65.
- 18 Mattingly C and Garro LC. *Narrative and the Cultural Construction of Illness and Healing*. Berkeley: University of California Press, 2000.
- 19 Radley A. *Making Sense of Illness: the social psychology of health and disease*. London: Sage, 1994.
- 20 NHS Choices www.nhs.uk/Pages/homepage.aspx (accessed 6 December 2007).
- 21 Bielli E, Carminati F, La CS *et al*. A Wireless Health Outcomes Monitoring System (WHOMS): development and field testing with cancer patients using mobile phones. *BMC Medical Informatics and Decision Making* 2004;4:7.
- 22 Kearney N, Kidd L, Miller M *et al*. Utilising handheld computers to monitor and support patients receiving chemotherapy: results of a UK-based feasibility study. *Supportive Care in Cancer* 2006;14:742–52.
- 23 Collins RL, Kashdan TB and Gollnisch G. The feasibility of using cellular phones to collect ecological momentary assessment data: application to alcohol consumption. *Experimental and Clinical Psychopharmacology* 2003;11:73–8.
- 24 Anhøj J and Møldrup C. Feasibility of collecting diary data from asthma patients through mobile phones and SMS (short message service): response rate analysis and focus group evaluation from a pilot study. *Journal of Medical Internet Research* 2004;6:e42.
- 25 Barrett LF and Barrett DJ. An introduction to computerized experience sampling in psychology. *Social Science Computer Review* 2001;19:175–85.
- 26 Palen L and Salzman M. Voice-mail diary studies for naturalistic data capture under mobile conditions. *Computer Supported Cooperative Work Conference Proceedings* 2002;87–95. <http://portal.acm.org/> (accessed 10/11/07).
- 27 Fogg BJ and Books I. *Persuasive Technology: using computers to change what we think and do*. San Francisco: Morgan Kaufmann Publishers, 2003.
- 28 Jovanov E. Wireless technology and system integration in body area networks for m-health applications. *Conference Proceedings: Annual International Conference of the IEEE Engineering in Medicine and Biology Society* 2005;7:7158–60.
- 29 McFedries P. Technically speaking: all a-twitter. *IEEE Spectrum* 2007;44:84.
- 30 Tang H and Ng JH. Googling for a diagnosis – use of Google as a diagnostic aid: internet based study. *BMJ* 2006;333:1143–5.

ADDRESS FOR CORRESPONDENCE

A Niroshan Siriwardena, Foundation Professor of Primary Care, School of Health and Social Care, University of Lincoln, Lincoln LN6 7BG, UK. Tel: +44 (0)1522 886939; fax: +44 (0)1522 837058; email: nsiriwardena@lincoln.ac.uk