

Patient perspective

Using a virtual community to support healthcare

Andrew Cox MSc MA ALA

Research Student, Department of Information Science, Loughborough University, Leicestershire, UK

Maria Boehm RGN(Dip) LLB(Hons)

CELL (Clinical Engineering at Loughborough and Leicester) Coordinator, University Hospitals of Leicester, Glenfield Hospital, Leicester, UK

Ron Summers PhD CENG MInstMC

Professor of Information Science, Department of Information Science, Loughborough University, Leicestershire, UK

Tom Spyt MD FRCS CTh

Consultant Cardiothoracic Surgeon, University Hospitals of Leicester, Glenfield Hospital, Leicester, UK

It appears that the once apparently simple idea of being a patient has become rather complex and confusing. In this paper we suggest that part of the answer to untangling this complexity, and to delivering coherent healthcare, may be found in the idea of 'communities'.

The range of access points to healthcare is much more diverse than it was just a few years ago. Professionals such as pharmacists are increasingly given responsibility for minor treatment while the emergence of NHS Direct has provided convenient means of access to health-related advice. Walk-in centres are available to supplement traditional general practitioner (GP) practices and hospitals. Whatever the many benefits of this diversification of healthcare service, it can potentially be confusing for those using the services. This is reflected in how we identify 'patients'. Increasingly they are at turns a customer, consumer or an information seeker. One Oxfordshire hospital now even refers to them as users.

We are also seeing the creation of both the 'knowledgeable patient' challenging the expertise of the GP and the 'litigious patient', challenging the clinician's ability to conform with a responsible body of medical opinion.¹ These concepts have arisen from a decline in simple trust in the medical profession, fuelled, on the one side, by increasing education and access to information (e.g. through the Internet) and, on the other side, by 'scandals' such as the Shipman case and Bristol Inquiries.^{2,3}

Increasingly, NHS policy is premised on the existence of the 'expert patient'.⁴ Patient involvement in their own healthcare is recognised as an

important motivational factor to improving their health, while their participation in diagnosis is seen as providing subtle but important data about their condition.⁵

Yet the more traditional models of patient identity still survive. The simple, stable high trust model of the personal or familial relationship with a GP, even if it smacks of Dr Finlay's casebook, exists and is seen as desirable by many. Similarly, in acute illness the 'sick role' still models well the socialisation process through which the patient passes out of normal life into illness.⁶

The evolution of the Internet has created a model based on a 'virtual community of information seekers'. Increasingly the NHS is seeking solutions in inclusive 'community' models, often mediated by ICT, as virtual communities. These offer a scaleable way to deliver information and support to large groups of patients as well as their carers, from a diverse multidisciplinary team of practitioners.

In turn this identifies a process of socialisation as a 'member of a community'. The community model also potentially satisfies the patient's move from wishing to find information and support, to giving it certainly via 'Internet chat forums'.⁷ Equally it helps the practitioner to understand the patient better and find ways to explain patient choice appropriately.

To illustrate these points its useful to look at some of the initiatives at the university hospitals of Leicester. The concept of creating an (interactive website) on-line patient support community for cardiac patients evolved here from an audit of cardiac

interventions. The audit system has been an integral part of the service management within the hospital. The long-term follow-up and subsequent patient interviews suggested a need for an improved means of communication. To investigate the demand further we conducted a survey of nearly 1400 patients, relatives and friends attending cardiac outpatients to establish accessibility to email and the worldwide web and if a specific interactive website would be beneficial. There was considerable interest in such a virtual community.⁸

www.yourheart.org.uk was set up to inform patients about the facts of their condition and to allow direct access via email and an 'ask the expert' forum to healthcare professionals. It was based on asking patients what they wanted. It builds on existing communities such as Link-Up, the adult cardiac patient support group. Through these initiatives the trust is exploring models of how to build appropriate communities to support patients through acute and chronic heart conditions, and in life after treatment.

The website was launched on 12 June 2002, and apart from providing general health information, explanations of medical terms, and direct communication with medical staff, patients can interact with one another through a discussion forum, providing each other with useful tips, advice and peer support. Eventually it will be possible for patients to book their own appointments for rehabilitation classes and outpatients consultation.

We believe this to be one of the first cardiac interactive virtual communities for patients, relatives and healthcare professionals in the UK.

Since its launch, comments via the completed online feedback forms have been positive and encouraging. The following are examples of comments received:

'At last a site that seems to cover a multitude of heart problems and explains them all in an understandable way. Thank you. I feel much more informed about my condition and forthcoming treatment.'

'I think the website is excellent. I only wish it had been up and running when I needed info on my bypass op last year.'

'I am waiting for a triple bypass open-heart surgery, and after visiting your website I feel more at ease with my intended operation. I now know what to expect before, during and after my surgery. I will recommend it to other people as I am sure they will find it as useful as I have.'

'www.yourheart.org.uk was featured in an ITV news programme, copied the address. Was diagnosed with a heart problem at age 8 will be 67 soon. Childhood spent at special school under care of Birmingham's Children's Hospital. Two years ago a double wire pacemaker was

inserted as my health deteriorated quite suddenly; fine now. Very many thanks for the website, for the first time in my life I have some understanding of my health problems.'

The future

The information that is currently on the website is a fraction of what the YourHeart website working party would like to make available. We plan to create direct access to the University Hospitals of Leicester NHS Trust patient choice advisor, providing another way of assisting patients on the cardiac waiting lists. We intend to publish details of waiting times for in- and outpatients' appointments and surgical results in terms of mortality and morbidity. A cyber cafe is proposed for the cardiac outpatients department where in addition to the existing information, videos of routine heart operations, cardiology treatments and a visual tour of the hospital will be accessible. We also aim to expand on the communities currently using the site to incorporate information specific for primary care professionals including GPs and ultimately to provide a direct online referral system.

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ADDRESS FOR CORRESPONDENCE

Miss Maria Boehm, University Hospitals of Leicester,
Glenfield Hospital, Groby Road, Leicester LE3 9QP,
UK. Tel: +44 (0)116 256 3996; fax: +44 (0)116 232
2511; email: maria.boehm@uhl-tr.nhs.uk.

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