Public Services: E-Governance and E-Health – What are we really talking about? ‘A Cure All for all Ills?’

Bob Roberts and Graham Alsop
School of Computing and Information Systems

Kingston University

Abstract: Patient or citizen centred healthcare is about access, choice, communication and service provision. It implies that one of the prime functions of e-healthcare is to deliver a range of effective and efficient information services based on specific needs of different user groups such as health institutions, health professionals and citizens. This paper offers some reflections from the perspectives of communication and political theory on a project that looked at local people’s need for health information and recommended strategies for change. It is argued that, in the light of major new technological and other developments in the provision of health information, perspectives from other disciplines allow for improved solutions to be established.

Key words: E-Healthcare, E-Governance, Pluralism, Communications Theory

1. INTRODUCTION

The UK government has committed itself to the broad aim of making the UK the best environment in the world for e-commerce, to getting all citizens online and to ensuring that all governmental services are also available online (Office of the E-Envoy, 2002). In the context of the UK, the National Health Service (NHS) is a governmental service and the UK government has declared 2005 as a key target date for the implementation of many aspects of e-government within the healthcare sector (NHSE 2001). A major challenge

The original version of this chapter was revised: The copyright line was incorrect. This has been corrected. The Erratum to this chapter is available at DOI: [10.1007/978-0-387-35617-4_48](https://doi.org/10.1007/978-0-387-35617-4_48)

is to provide healthcare information to a very diverse group of people as effectively as possible using electronic commerce technologies and applications.

To understand the impact and issues of implementing e-commerce technologies to support health promotion there is a need to expand the boundary beyond narrow issues of current or imminent technologies and their management. Given the impetus of e-commerce developments and the imperative of government targets, the paper argues that ideas from communication and political theory may provide additional perspectives in building shared understanding to identify areas for consideration in the design process within the context of e-health.

This introduction is followed by section 2 that highlights the key role of the NHS information strategy and reviews the literature from a multidisciplinary perspective, particularly with regard to how ideas from communication and political theory may inform our understanding of the potentially conflicting interests of diverse stakeholders. Section 3 outlines the building of e-health information services in the local community which will be the building blocks for further information sharing not only between health professionals but also with patients and the general public. Section 4 considers some of the implications of these local developments in terms of the ideas from communication and political theory discussed in section 2. The concluding section argues that patient or citizen centred healthcare is about access, choice, communication and service provision but that a multidisciplinary perspective is required to ensure that an inclusive design approach encourages the effective use of such systems by diverse stakeholders.

2. E-HEALTH INFORMATION: A MULTIDISCIPLINARY PERSPECTIVE

It is increasingly recognised that the internet, as an enabler of new interactions and as a medium which allows digitisation of service content, is fundamentally changing views on the way that information can be provided and used by health services (Syrjanen et al 2000, Bywater & Lloyd-Willimans 2002). E-commerce technologies and ubiquitous, low cost networks are affecting the practice and business of medicine in a number of different ways including the growth of patient power through formation of self help groups and the use of intranets / extranets to support the devolution of all stored knowledge into networks. (Castleman et al 1999, De Moor 1999, Syrjanen et al 2000).

The Information Strategy for the NHS (National Health Service) outlined the need for major changes including the way patients and the public interact with the NHS, the way care is delivered and recorded and the way in which health professionals work (NHSE 1998). The NHS Information Strategy underlines the importance of using information in four broad areas to ensure that patients receive the best possible care:

1. To improve the quality and accessibility of information for health professionals
2. To enable patients to be better informed about their condition.
3. To ensure management of services is based on good quality information.
4. To provide good quality health related information for the public domain.

These four areas represent quite different problems. The first area is about improving the provision of information to a well organised community that share the same language and codes and established electronic means of communication. The second and fourth areas are dealing with a larger and dispersed group of individuals. However, while sharing a common non-expert language, these individuals do not all share the same means of electronic communication and, furthermore, are not always interested in the information offered or wish to understand it (some patients prefer not to know). The third looks to gain information from both the users and providers of the services, an even more diverse set of groups with and without overlapping interests, and an aim that requires complex communication rather than mere broadcast information provision.

Walsham (1993) argues that information systems can be seen primarily as social rather than technical systems and that a multidisciplinary perspective is required. The issues concerning the implementation of e-commerce in the healthcare sector reflect the broader aspects such as the organisation's culture, the nature of power relations between different stakeholders and also its setting within the public sector characterized by complex policies and electoral considerations. To fail to recognise this complexity would lead to a failure in the design of information system solutions.

Two key groups are involved: health professionals (experts) and patients/public (novices with different levels of interest). These two groups have sub-groups within them. Furthermore, individuals, as members of overlapping groups/communities in society, have multiple and often conflicting interests. As an individual within the health service, one could be a doctor, a patient and a carer at the same time and hold conflicting interests. This reflects a diverse range of power sharing and information needs and is well aligned to the notions of pluralism in political theory, where power is shared among groups in a state, and communication theory where different groups have different information needs (Dunleavy & O'Leary 1987 and Fiske 1990 respectively).

By considering communication theory critical issues come into focus. Schramm's (1972) diagram shows the exchange of communication between a sender and receiver and builds on the model initially created by Shannon and Weaver (1949). In the diagram (not reproduced here) the delivery of a message moves through the following stages: It begins at a source (1), is then encoded (2) and sent through a signal (3) to be decoded (4) and then delivered (5) at its destination. However, here Schramm considers that stages 1-3 are bound within the sender's field of experience and stages 3-5 bound by the receiver's field of experience. Thus the sender and receiver share a common area between their fields of experience. This differs from the focus of Shannon and Weaver's concern with the delivery of a message, but echoes well the conception of political pluralism and overlapping interests between different groups. Individuals are members of multiple groups with competing and often conflicting interests and Pluralism is a political theory that views power to be shared, not necessarily equally, among these competing groups in society (Dahl 1956, 1971, Barber 1985).

Designing information provision for such different groups does not rely only upon the medium used for communication, but also on the language used. This does lead to a power relationship, between those who understand and those who do not. Medical information for some communities is necessarily heavy in jargon because this is the nature of the vocabulary used by professionals in the field. However, the needs of patients and the public differ from experts and the medium is unavoidably tied up with the message itself. It is possible here to consider Elite Theory (Mosca 1939) and the concept of Technocrats (Roszack 1969). Although not in the context of government, many decisions in the NHS are made by those with expert knowledge and are mostly made on the basis of knowledge of the natural rather than social sciences. Citizens may be intimidated by this expertise and in any case have few avenues and little opportunity to contribute to the way in which the service is run. Murray (2001), for example, argues that there is very limited involvement of patients and non-medical healthcare professionals on the bodies determining the development, direction and content of health promotion material on NHS Direct Online (a major NHS health portal for the public). However, such involvement would require the sharing of its development. Furthermore, if health promotion information excludes certain alternatives this can be seen as a form of social power (Cooper 1986).

There is no doubt that the Internet is playing an increasingly important role in the possibility of greater self-help through a better understanding of alternatives in terms of healthy lifestyles or treatment options. Eysenbach (2000), for example, outlines a series of ways in which the potential of patients and their families can be realised through their utilisation of electronic health information. These include being able to control their own

health care, thereby using healthcare resources more efficiently and also helping patients attain a healthy balance between self-reliance and seeking professional help. However, this access to information that leads to better informed patients also has implications for patient handling skills that clinicians need to develop (Kaplan 2000).

Naidoo and Wills (2000) argue that health is a human right and that it is also a social issue rather than just an individual one. Developments over the last century in health promotion have shifted the emphasis on the prevention of specific diseases toward the health of the population as a whole and it is therefore important to the community who may decide what health issues affect them. Health promotion therefore involves not just medical practitioners but other relevant parties such as teachers, occupational health workers, churches, shopping centres and so on. Reflecting this holistic view current government policy is full of rhetoric about partnership between patients and clinicians. On the other hand, Solovitch (2001) argues that patients and carers, increasingly frustrated by the attitudes of many clinicians, are increasingly becoming the driving force in the development, not only of health information on the Web, but even of health and disease research. This challenges the assumptions of an elite that control events through their sole access to knowledge and supports the concept of pluralism as a potential model for design.

3. BUILDING E-HEALTH SERVICES IN THE LOCAL COMMUNITY

In view of the NHS Information Strategy the local Health Authority commissioned a project board to look at local people's need for health information, particularly in the light of major new technological and other developments in the provision of health information. The authors were commissioned to carry out an audit of the current provision of information for health to the public. The aim was to synthesise the views of a range of local health information intermediaries and consumers as to how information delivery can be improved. The subsequent report included a review of developments in the electronic provision of health information, a review of best practice and the issues faced when evaluating the effectiveness of health information.

Figure 1. E-Health projects

As a result of the report work has been carried out on two key areas for e-commerce development; a redesign of the local web site for the public and the continuing development of the Intranet for the generation of effective local information. These two projects support the design of an inclusive system that would enable local people and professionals to access targeted, effective and up to date health information available both locally and nationally. Over the next three years these will be the technological building blocks to enable the provision of and sign posting to effective local information across the whole range of health information from local services to health promotion. A top level schematic of these two areas is included in figure 1.

The projects are concerned with the more effective management and sharing of local data to improve service delivery enabled through the utilisation of internet based network communications and applications. The need for greater value for money while also increasing the quality of healthcare provision will act as a driver for further integration and information sharing not only between health professionals but more importantly with the public itself.

Following a recent review of health promotion resources and the reorganisation of Health Authorities into fewer and larger entities, there is also now an opportunity for implementing a dedicated health promotion portal for the local Strategic Health Authority (SHA). The new SHA covers an area previously covered by three regional health authorities and therefore covers a significantly larger geographic area. A schematic of the proposed portal is shown in figure 2.

Figure2. Health information portal

In hardware and software terms, the set-up of such a portal need not be prohibitively expensive. As the number of visitors increase, however, investment would need to be made to maintain performance. Furthermore, where a site is a portal with access by multiple user types and with multiple links to other sites for further searching or data extraction, the establishment of clear user profiles is paramount for design or operation. With regard to content the considerations fall broadly into the areas of readability, currency, appropriateness, cost, access and quality. Many guidelines are available for evaluating and ensuring the quality of health information on the Web

although this continues to be a problematic area of concern which raises contentious issues (Ward et al 2002).

4. IMPLICATIONS OF E-HEALTH INFORMATION INITIATIVES

Health is at the forefront of one's mind when one is ill and in the background when one is well. Health messages like 'you are what you eat', 'exercise is good for you' and 'smoking is bad for you', still have limited impact, particularly among some groups, despite overwhelming evidence. The challenge will be in accessing those areas through appropriate communication channels for the groups requiring information when they need it in the format that suits them. This will require the careful consideration of the medium to be used, the language necessary and the communication method. Access to knowledge bases, reference material and guidelines through links to professional portals and virtual libraries will enable easier access to resources outside normal library hours and provide a 'climbing net' for both health professionals and the public. The local health portal will not aim to duplicate national developments but will aim to supplement and link to such initiatives to provide an integrated approach to accessing e-resources for health promotion.

People's use of technology, understanding of its potential, and access to it, are often slow to change. Language is a fundamental means by which we communicate; it defines the communities that we are members of but can also exclude from some communities those that do not use the same language, terminology and jargon. Furthermore, through using electronic communication many of the codes that we use to communicate are lost and yet using electronic means will not be mutually exclusive from other ways of communicating such as face-to-face. In fact access to the information alone is not enough to ensure that it is read and understood and some of the key groups that this information needs to reach are likely to not have access or easy access to electronic information resources. This implies that the choice of the medium used is important and ICT is an excellent way of repackaging information for different groups. The place to target such repackaging that requires language changing is the area where groups have a common interest. The appropriate medium also needs to be used and paper can still be a very effective medium. Having a common file source that allows web or print versions to be generated is necessary and worthwhile.

Some form of authority rules all services, be they organised as hierarchies with chains of command or flat co-operatives that take decisions in common and we are, therefore, also dealing with the concept of

'governance'. These e-healthcare developments are being driven by the current theme of 'patient power' and consumer health informatics. However, the use of the term 'patient power' implies that a power gap exists between the user and provider and in the area of health services there is a distorted conception of 'expert' power given to the service by its users. The local web site was seen as an opportunity to encourage public involvement through online citizen's panels in local health issues by providing, for example, an additional channel for feedback and comments on consultation documents made available in electronic format.

The potential empowerment of the public to take responsibility for their own health through greater access to appropriate health related information therefore has implications for a shift in the power dependence in the relationship between health professionals and their patients. There was, however, general consensus on the need to carefully consider what information should be made available to the public in terms of the impact that such information may have on local services. With inclusion of local statistics and/or performance figures, for example, there was concern at raising unrealistic expectations or creating new problems as the public changed their options in response to the information. It may prove politically problematic as better informed consumers may no longer be willing to accept restricted treatment options brought about by government spending decisions.

The ability to see a health provider's record and experience, and easily gain some information on the current research in the field pertaining to them, will also allow patients to make informed requests for referral to consultants and ask better questions about their condition and treatments options. Such discussion and development can only lead to a better knowledge base for both the patient and the provider of care. However, a more informed public raises issues for educating and training health professionals for the information age. This does not mean in technical areas only, but in how they behave in an age when they will be expected to use information and knowledge tools to confer with patients as equals and partners. Here the consideration of communication theory is necessary to ensure the accessibility of the resulting information and knowledge tools. This shift in relationships looks toward a sharing of the responsibility for health.

5. CONCLUSION

Patient or citizen centred healthcare is about access, choice, communication and service provision. It implies that one of the prime functions of e-healthcare is to deliver a range of effective and efficient

information services based on specific needs of different user groups such as health institutions, health professionals and citizens. The scope and complexity of systems required to support an e-healthcare environment presupposes networks linking many different stakeholder communities. There is therefore a need to develop a shared understanding between users, health professionals, technology suppliers and government policy makers on the future of e-health and healthcare delivery. Current e-commerce developments may potentially offer a technological cure all for the information needs of such stakeholders. However, ideas from communication and political theory discussed in this paper may provide perspectives in building shared understanding in the new context of e-health and to identify areas for consideration in the design process.

1. References

- Barber, B. (1985). *Strong Democracy*. University of California Press.
- Bywater & Lloyd-Willimans 2002, Understanding the market potential for eHealth in UK and Europe, *Proceedings of Current Perspectives In Healthcare Computing HC2002 Conference*, Harrogate 18-20 March, 277-284
- Castleman T., Swatman P. & Parker, C. (1999), Issues In The Implementation Of Electronic Commerce In The Human Services: Reflections On The Victorian Initiatives, *Proceedings Of 9th International EDI Conference*, Bled, Slovenia, June, 59-76
- Cooper, R. (1986), Organisation / Disorganisation, *Social Science Information*, 25, (2), 299-335
- Dahl, R. A. (1971): *Polyarchy*, New Haven. Yale University Press.
- Dahl, RA, (1956). *A Preface to Democratic Theory*, University of Chicago Press.
- De Moor, G.J.E. (1999), The Promise of Medical Informatics in Europe, in Van Benmal, J.H & McCray, A.T (Eds), *Yearbook of Medical Informatics*, Schattauer
- Dunleavy, P and O'Leary, B. (1987). *Theories of the State*. Palgrave Macmillan.
- Eysenbach G. (2000), 'Consumer Health Informatics', in *British Medical Journal*, 320, 1713-1716
- Fiske, J. (1990). *Introduction to Communication Studies*, 2nd Edition. Routledge. London and New York.
- Kaplan, B. (2000), Culture Counts: How Institutional Values Affect Computer Use, *MD Computing*, January/February, 17, (1), 21-26
- Mosca, G. 1939. *The Ruling Class*. McGraw Hill, New York
- Murray, P. (2001), Consumer health informatics - now it's getting personal, *British Journal of Healthcare Computing and Information Management*, Vol 18 (9)
- Naidoo, Jennie and Wills, Jane. (2000), *Health Promotion; Foundations for Practice*. 2nd Ed, Harcourt Publishers, London
- NHSE (National Health Service Executive), (1998), *Information For Health*, Document Ref A1103
- NHSE (National Health Service Executive), (2001), *Implementing the NHS Plan: Building the Information Core*. Accessed March 2002, <http://www.doh.gov.uk/nhsexipu/strategy/update/index.htm>
- Office of the E-Envoy, UK Cabinet Office, Accessed April 2002, <http://www.e-envoy.gov.uk/>
- Roszak, T. (1969). *The Making of an Elite*. Garden City, New York, Anchor.

- Schramm, W in McGarry, K. J. (Ed). (1972). *Mass Communications Selected Readings*. Clive Bingley publishers
- Shannon C.E., Weaver W., (1949), *The Mathematical Theory of Communication*, Urbana: University of Illinois Press.
- Solovitch, S. (2001), The citizen scientist, *Wired*, September, 141-51. (Accessed April 2002, www.wired.com/wired/archive/9.09/disease.html)
- Syrjanen, E., Puhakainen, J., & Regan, H, (2000), Electronic Services In Healthcare, *Proceedings of Current Perspectives In Healthcare Computing HC2000 Conference*, Harrogate 22-22 March, 245-253
- Urquhart, C., Yeomen A., Coopoe J. and Wailoo A. (2002), Supporting clinical guidelines and knowledge management: how effective is the NeLH? *Proceedings of the Healthcare Conference: Current Perspectives in Healthcare Computing*, Harrogate 18-20 March, pp. 98-105
- Ward, R. Cooke, A. & Gray, L. (2002), The evaluation of Internet healthcare resources, *Proceedings of the Healthcare Conference: Current Perspectives in Healthcare Computing*, Harrogate 18-20 March, 91-97
- Walsham, G. (1993), *Interpreting Information Systems In Organisations*, Wiley