### **INNOVATIVE HEALTH TECHNOLOGIES PROGRAMME**



## The Role and Effectiveness of Collaborative Knowledge Systems in Health Promotion and Health Support

# **KEY FINDINGS**

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

What kinds of health information and support systems, like 'NHS Direct On-line', are currently being developed? Who uses them and for what purposes? What are the benefits of these problems for citizens, patients and practitioners? What problems and unforseen effects can be identified? Do these systems contribute to 'citizen and patient empowerment'? What impacts will these systems have on future health policy and health service delivery?

- 'Knowledge sharing technologies' are both under-developed and unsophisticated compared with other forms of health technologies, such as electronic patient records and hospital information systems
- However, these types of 'collaborative knowledge systems have a number of benefits. They can:
  - support the management of a personal health condition and provide valuable peer support;
  - contribute to the continuing professional development of health workers
  - increase accessibility to resources and life opportunities for both patients and health professionals
- But problems and issues identified include:
  - the over-representation of professionals and 'educated classes' in developing and managing the technology;
  - the need for a 'human touch' as a bridge between the technologies and their users;
  - the need for more user-friendly functionalities and larger bandwidth capacity to handle content such as video
- Users particularly patients and citizens find these systems are more helpful and more effective if they have played an active part in their development
- The participation of users is a crucial part of the process of 'technical coding'. How the different stakeholders involved in the development of new health technologies invest them with beliefs and values and how these different beliefs and values are resolved plays a big part in the subsequent evolution and application of the technologies.

#### **RESEARCH TEAM**

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A key finding of the study is that 'knowledge sharing technologies' are both underdeveloped and unsophisticated compared with other forms of health technologies. Of the current range of commercial health technology products available in the UK, for example, less than 4% are 'collaborative knowledge systems' (within the terms of the study definition). Much of the investment in health technologies has focused on systems designed to increase the efficiency of health service administration and delivery (electronic patient records and hospital information systems) and in telediagnosis and remote image processing. Similarly, in the 'blue sky' research and development sector, attention has been concentrated on remote sensing, 'bio-wear' and robotics. This limited interest and investment in collaborative knowledge systems mirrors the limitations of the systems and services themselves. Of the fifty examples evaluated in an 'audit' of systems and services on the market or under development, around 40% were classified as 'basic'. This type of system creates an illusion of collaboration and engagement for users, but invariably adopts a conventional 'transmissive' knowledge creation and learning model, in which health content is produced by 'experts'. Typically, such content acts as a 'lure' to encourage users to become consumers of health-related products. For example, one service included in the study provided an interactive chat room to enable users to discuss 'womens' health' issues. Content analysis of the communications traffic indicated that discussion themes were mainly shaped by two particular users, who turned out to be 'product champions' for a particular (commercial) 'weightwatchers' organisation. Three other main types of collaborative knowledge system were identified by the study: 'public health' systems, aimed mainly at reducing risk behaviours of 'susceptible groups' like people at risk of coronary heart disease; 'communities of practice', targeted primarily at health professionals with an interest in exchanging information on new knowledge and medical advances and 'multi-modal systems', acting essentially as 'bridging points' for complex new partnerships in the health sector.

This is not to say that collaborative knowledge systems do not make a contribution to health improvements. As the results of intensive case study analysis of three 'live' examples showed, collaborative knowledge systems can: support the management of a personal health condition and provide valuable peer support; contribute to the continuing professional development of health workers; open up access to life opportunities for both patients and health professionals. However, a number of issues around the development and adoption of such systems were identified by the study. These included: 'colonisation' of systems by interest groups particularly professionals and 'educated classes'; the need for a 'human touch' as a bridge between the technologies and their users; the need for more user-friendly functionalities and larger bandwidth capacity to handle content such as video.

Building on these research findings, the project also carried out an 'action research experiment' in collaboration with the 'HERO' project. HERO health and educational support for the rehabilitation of offenders was funded by the European Commission to develop methods and technologies to support offender rehabilitation. The focus of the project was to build a collaborative knowledge system to address problems around different stages in the 'offending life cycle'. HERO targeted two main groups: 'first time' offenders, and offenders who were in the process of being re-settled. A key aim of the project was to encourage the different actors in the criminal justice system offenders, prison officers, health providers to 'step into each others shoes', and to use the insights gained from this process to develop new, collaborative approaches to rehabilitation. The action research involved two activities: firstly, supporting the continuing development of the HERO tools and services (for example through improved website and tools design). The second, more intensive action research activity involved using the insights gained from our research results to build an additional set of tools. We then tested their 'value added' through an additional pilot site 'One Spirit'. This new pilot site focused on a new and key - aspect of the 'offending life cycle': offending prevention'. We worked with a group of 'at risk' young people in Hackney, London and with a group of inmates on 'Death Row', San Quentin to develop and test innovative collaborative knowledge tools to deliver 'e-health' programmes aimed at drugs harm minimisation; sexual health awareness; mental and psychological well-being and skills development. The pilot was delivered using a 'blended e-learning and e-health' model which included creative activities (singing; song composition; film-making and filmediting; graphic design). The results showed that the learning from the project had made a significant contribution to the health awareness, learning and self-

development of the participating young people.

Another key research theme explored in this project was the concept of 'technical coding'. The technical code embodies two key principles: the principle that technologies do not evolve in a stable, linear progression but embody a 'multiplicity of possible innovation trajectories' and the principle that technologies have 'civilisational choices'. The main point about 'technical coding' is that technologies evolve through 'discourses' between the various stakeholders involved in their design, development and use. The very technology itself becomes established through these discourses, and through the practices through which they become understood within the context of 'illness' and 'cure'. In this study of 'collaborative knowledge systems' one key conclusion was that the symbolic meaning attached to technology directly affects how it comes to be applied in the future, and has a great effect on its continual development. Ultimately, it is through the early use of a health technology that much of its sense of purpose is established. The initial establishment of health technologies involves a 'contest of meanings' between different actors and protagonists: surgeons; neuroscientists; schizophrenics; people with depression; concerned citizens; representatives of patients groups, and so on. How this contest is resolved initially will shape the parameters for the ensuing and ongoing process of establishing technological meaning and functionality. Crucially, it will also shape the conditions for how users establish, and extract 'value' from these technologies.

## About the Project

Recent initiatives in public health and health service delivery policy aim to promote greater involvement by patients and citizens in shaping and managing their own health. Obstacles working against this vision of an 'e-health society for all' include issues around how knowledge is created and shared between different groups of stakeholders. This project explores these problems and their implications for creating a more accessible health service.

'Collaborative knowledge systems' are part of a family of health technologies, like NHS Direct Online, that provide digital health information and support services. In this project, we were interested in a particular type of technology one that allows both experts and laypeople to work together to produce new knowledge about health. This includes technologies that: allow for evaluation of the information provided; promote interaction between 'producers' of health information (like health professionals) and 'consumers' (like citizens and patients); use 'tacit' knowledge, based on real experience, in health promotion and support; use tools to represent and present knowledge in more intelligible and meaningful ways (for example using video, discussion groups and 'real life' stories); allow different perspectives and narratives about health to be shared to enable a new perspective to emerge.

Our investigation of these technologies combined research with 'action research'. The project's starting point was a review of 'state of the art' a literature review of current theory and practice, with a particular focus on 'patient and citizen empowerment'. This first phase of research also included an 'Audit' of around fifty specific examples of innovative health technologies providing health information and support services, and involving the use of collaborative knowledge systems. The audit combined secondary data analysis (for example content analysis of documents and web site evaluation) with interviews, to map the size and characteristics of systems and services on the basis of indicators like delivery type; target users; content portfolio and mode of interactivity. The audit also included a 'discursive' analysis of the technologies (how they reflected particular 'visions' and 'beliefs' about health and illness). The second phase of the study focused on intensive case studies of examples of the technologies. Two types of case studies were carried out: analysis of three specific examples of operational digital health information and support services using collaborative knowledge systems, selected to reflect the main types identified in the literature review and audit: two crosscutting', or thematic case studies reflecting kev issues identified in the Review of state of the art on finance and the economics of health technologies, and one focusing on health collaboration and partnership innovations that were not enabled by technology. The third phase of the project involved applying the earlier results in an 'action research' experiment intended to improve the effectiveness of the health information and support tools developed in a service called HERO Health and Educational Support for the Rehabilitation of Offenders.

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