

Book reviews

Evaluating Mihealth Liverpool: Assessing the effectiveness of new health information and communication technology in providing support to patients with breast cancer receiving treatment in Liverpool

By Michael Mair and Ciara Kierans,
Centre for Public Health,
Liverpool John Moores University, 2006.
The report can be downloaded from: <http://www.mihealth.info>

Mihealth is an innovative on-line service for breast cancer patients developed by a team at Liverpool John Moores University in collaboration with patients and clinicians from the Royal Liverpool Hospital. The system was piloted at the hospital's Linda McCartney Breast Cancer Centre and is very much the brainchild of Jane Wood who was herself diagnosed with breast cancer in 2000.

This report presents the findings from an evaluation of the pilot studies conducted over a period of 2 years and funded by the North West Development Agency. What makes it particularly interesting is that in answering the question 'did *mihealth* work for the patients it was designed to support?' it also offers an insight into the way patients search for and use information in the digital age.

The report begins with a policy background, which establishes this new information system within the context of informed choice and shared decision-making. The authors argue that digital technology is increasingly seen as the channel for the exchange of health information and point to government initiatives like NHS Direct Online.

But they argue that to focus on large-scale generic NHS information sources undermines the importance of specialist, local sources providing the kind of information which patients often find more useful because it is more relevant to them. This was the rationale behind *mihealth*, which aims to combine generic and specific information in a single resource that brings the information closer to the user's own experience.

Mihealth is built around a database based on the breast cancer patient journey developed by the Cancer Services Collaborative and mapped to cancer services in the Merseyside area. Patients can use a drop-down menu to access information on, for example, 'Your Diagnosis and Treatment Options', that will lead them to details of the local breast care nurses, the service they provide and how to contact them. The designers have used a multimedia approach to present the information, including text, diagrams, photographs, and audio and video clips of interviews with former patients. Breast cancer patients can personalize the system further by recording appointments, tests, medications, etc in *MiDiary*. Other elements include *MiTreatments*, *MiContacts* and *MiMoodstates*.

The report draws evidence from three pilot studies in which patients were given access to *mihealth* at various stages of their treatment via desk-top machines, hand-held computers and kiosk. The researchers adopted a qualitative approach and focused on how well the system fitted into the user's everyday life and how easy it was to use. Thus before they felt able to judge *mihealth's* performance, they needed to investigate what patients actually do with information and what they need it for.

For this reader it was the authors' analysis of these patterns of information-seeking that provided the most interesting material. They believe that existing models for the way patients use information are misleading and simplistic. In numerous studies on the subject, health information is seen as a right, a commodity or a form of medical intervention. They argue that it should be seen as a tool because from the perspective of the patients they interviewed, what mattered was not simply to have information, but to be able to do things with it. It follows that patients cannot just be divided into the informed and the uninformed. Patients use information in different ways, including choosing not to be informed on some occasions.

Similarly, they argue that patients will use a variety of techniques to navigate their way through information. Although anything that appears to be too complex will be off-putting and therefore not used, the patients in the pilot studies tended to adapt familiar ways of seeking information to the *mihealth* system. Research studies often distinguish between different formats, but these distinctions were less important to the patients in this study. Indeed information that could not be readily transformed by being printed out, audio-recorded, written down or turned into a question, was generally regarded as useless. The report identifies horizontal and vertical information seeking behaviours. Patients wanted information about what will happen next, but they also wanted the option to delve deeper into any particular aspect of their disease.

The authors see the clinical setting as an 'information hub' but recognize that what doctors think patients should know and what patients actually want to know can be quite different. They therefore conclude that a successful information resource should help patients work with their doctors, but also stand back and assess the treatment they receive.

Having provided an insight into the complexities of the way patients search for and use information, the second part of the report applies this knowledge to *mihealth* to evaluate how well it responded. The authors acknowledge that recruitment to the study was slow and offer

possible reasons for this. However, they found that for those patients who did participate, the system performed extremely well. The *MiInformation* function was the most popular, allowing patients to search for as much or as little information as they wanted. The less successful elements were those that enabled patients to personalize information, for example, *MiDiary* and *MiMoodstates*. They argue that this could be because the core function, *MiInformation*, operated so well, patients did not feel the need to go beyond this.

The authors make a small number of suggestions for its further development, but essentially conclude that *mihealth's* flexible and multi-functional design proved very successful in meeting the needs of patients with a range of skills and competencies. They found that the non-patronizing, user-centred design of *mihealth* works because although it depends on very new technology, it builds upon patients' existing patterns of information use. In providing information that is relevant and enabling patients to manage that information on their own terms, it supports shared decision making in a real and meaningful way.

This is a thoughtful and well-written report which is strongly recommended for anyone involved in the development of patient information services.

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A New Voice in Science. Patient participation in decision-making on biomedical research

By Francisca Caron-Flinterman, 2005

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This book sits at the intersection between science and technology studies and the emerging field of public participation in health decision-making.