

## 'Mihealth': understanding local contexts of use in HICTs for breast cancer

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*'Mihealth' is an information delivery system that has been shown to support breast cancer sufferers.*

The focus of this short review is 'Mihealth' <[www.mihealth.info/](http://www.mihealth.info/)>, an information delivery system established to support breast cancer sufferers. Conceived by a former patient at the Linda McCartney Centre in Liverpool, Mihealth provides a database of accurate, up-to-date, authoritative information that reflects how individual patients connect with the health care services they rely upon. Mihealth is currently being piloted in Liverpool, Newcastle and Carlisle. Where much innovation in the field concentrates on what information patients should access and what they should do with that information,<sup>1</sup> Mihealth, instead, attempts to provide an intuitive, user-friendly information platform that supports what patients actually want information to do for them. As our recent independent evaluation has shown,<sup>2</sup> by taking this user-centred design approach to patient information Mihealth helps patients address their own information needs as they themselves interpret them in actual situations.<sup>3,4</sup>

Overall, the evaluation demonstrated that Mihealth worked in a variety of ways to expand: (i) the pool of resources available to patients; (ii) the strategies patients used to make those resources work; and (iii) the strategies used to manage, search for and evaluate further information resources subsequently. While it was clear that Mihealth should not be seen as a once-and-for-all substitute for other types of information, the system added a new and welcome dimension to the often confusing 'information landscape'<sup>5</sup> that patients with serious conditions must navigate. Rather than detail all the findings from the report, the main aim here is to discuss how

Mihealth helped patients deal with some of the problems they encountered when accessing and using information.

### Navigating between the generic and the local

At present, individuals who want online medical information from the NHS can access the main NHS Web site, local NHS Web sites or visit NHS Direct Online. However, this means individual patients have to access local and generic information separately through these different sites. In practice, this division of labour across sites means that patients have to navigate between levels when working out how information applies to them, with paper documentation (leaflets, appointment cards, etc.), trial and error, face-to-face interactions with medical personnel and prior experience used to fill in the gaps.

In contrast, Mihealth provided information that was immediately relevant to the person who accessed it, without the need to cross-reference. The system combines generic and specific information in a single resource that can be changed, by the individual user, to reflect the medical services they receive, from the personnel they receive them from. By moving closer to the user, Mihealth enabled patients to both access and manage the information received as they moved from one stage of treatment to the next.

### How Mihealth works

Mihealth works by providing patients with a number of innovative functions:

### MiInformation

This database of information is structured around 'the breast cancer patient journey'<sup>6</sup> and is presented using 2-D and 3-D imagery, photographs, audio and video-clips of interviews with former patients to convey information along with text. Unlike most conventional Web sites, users could personalise information to reflect their own progress through treatment.

### MiDiary and MiTreatments

Supporting MiInformation are the linked MiDiary and MiTreatments functions which helped patients track their consultations, tests, medications and treatments, as well as record the details of all contacts with healthcare professionals as they moved through the treatment process. Both functions reduced the problems associated with negotiating the complex interface between the health service and the patient.

### MiContacts and useful information

MiContacts provides a personalised list of specialist contacts, local and national networks and support facilities. Recognising that no list will ever be comprehensive, patients had the facility to add in further service provider details or personal contacts.

### MiMoodstates

MiMoodstates is a function that allows the individual patient to input and track their mental and physical health status graphically. This enabled patients to document and relay information about recovery in an accessible format, and facilitated more accurate assessment at different stages of treatment.

# He@lth Information on the Internet

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## **Multiplatform compatibility**

Information is delivered to multiple communication platforms: desk top computers, hand held computers, mobile phones, information kiosks, plasma screens and interactive TV. Mihealth, therefore, takes advantage of the growing ubiquity of communication devices.

## **Designing HICTs for real-world applications**

In health and medicine, figures suggest that up to 50% of IT projects fail, with a growing body of qualitative research arguing that the best-designed system in the world may be effectively unusable if it does not fully take the local context and practices underpinning the patient-technology interface into consideration.<sup>4</sup> To understand how patients make technology work for them and the problems they encounter when trying to do so, it is important to recognise that new technology ultimately succeeds or fails, less on the intrinsic merits of the design itself, and more in terms of its reception within the local social, cultural and organisational settings that users operate within.<sup>3,7,8</sup> As a result, any evaluation of health information communication technologies (HICTs) needs to look at the relative importance of 'intrinsic factors' (is the system technically reliable?) and 'extrinsic factors' (does the system meet user-requirements?; is the system straightforward, and intuitive?; can users access the information they want?; does the system 'fit' into users' everyday patterns of living?). Working with patients showed that the capacity of the system in both areas represented a keystone of Mihealth's success.

## **Technology in context: some lessons from the evaluation**

If the above is correct, developing successful HICTs means understanding what the user wants to do with technology, why they want to do that, and the contexts within which those objectives become relevant. In the course of the evaluation, it became clear that the

following 'extrinsic' social and cultural factors had a particular influence on how well Mihealth was received by the patients it was designed for.

## **Surface-depth considerations**

The evaluation demonstrated that Mihealth was simple enough for a first-time user, but sophisticated enough to satisfy someone who was computer literate. It allowed the user to dip in for specific information, but also had the depth for some extended reading around topics. As the designers envisioned, the system enabled the user to access information in different ways and in different formats. Some users, for example, used the system as a back-up resource, to clarify what they had been told in face-to-face interactions with health professionals or simply to provide practical information on car parking arrangements or contact details.

## **Institutional arrangements and contexts**

HICTs can get in the way of what people normally and routinely do as part of their day-to-day activities. In medical settings, studies have shown that medical personnel have been resistant to new technology because they find it interferes with their jobs and normal working practices. Working with technology is often seen as extraneous, getting in the way of what a professional should be doing. Mihealth worked best where it helped create a bridge between the activities of the patient and the medical professionals they interacted with, without impeding those interactions.

## **The 'networked' user**

The evaluation showed that Mihealth was not just used by patients but was also accessed by friends, family and carers on behalf of the patient. The information, therefore, proved relevant to the people in these networks and what they wanted to get out of that information. This suggests that systems should be offered to the

widest possible numbers of patients, independently of whether medical personnel believe they will personally or directly access that information.

## **'Retrospective-prospective' character of information use**

Mihealth succeeded as a health information 'tool' that not only supported but helped patients make informed choices about their treatment, because users recognised that what they put into the system they would get back out. The records built up by using features like electronic diaries or mood states are not immediately meaningful. They are cumulative, and it is not until a patient has entered information for an extended period of time, that they start to see the benefits. For those who wanted to take a much more active role in managing their own conditions, through using the system, there was a pay-off connected with recording information in this way.

## **Contexts of use**

Finally, the evaluation showed that people do not access systems like Mihealth in the same way, in the same places, for the same reasons all the time. The circumstances within which they access the system change, and Mihealth proved flexible enough to respond to those changes in context. Making the system available on the Internet, on PDAs and on kiosks situated in breast care clinics was one way in which the design team responded to this challenge. Another part of the challenge was making sure that information was quick and easy to download and access. By making the system more accessible, the design team created a resource that patients found useful because it did not disrupt the settings within which it was being used.

## **Conclusions**

While we found clear evidence that the informed choice 'culture change'<sup>10</sup> the Government has called for in healthcare is under way, it was also

clear that it still has some way to go. It seems likely that new HICTs, like Mihealth, will continue to face resistance from within the healthcare system itself, with existing working practices and patient perceptions acting as a barrier between those who provide information and intended users. Indeed, we believe that the more local a system is, the more it needs to work in close proximity with service providers, the more pronounced these problems could potentially become, leading to situations where novel projects are abandoned before they have a chance to properly deliver. Despite this, within the current policy climate, potential problems are more likely to be overcome where the implementation of new technologies, as was shown to be the case with Mihealth, are able to link together the not always convergent interests of health service professionals, those responsible for managing the healthcare system, and patients themselves. In the context of the current Government's 'information revolution',<sup>10</sup> we suggest that the lessons learned from the evaluation go beyond immediate development issues relating to Mihealth alone, to a wider public audience with a growing interest in the provision of health-related information in a digital age.

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## TRIP Database – now free access

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*How a subscription service has been able to revert to a free-access model.*

The TRIP Database <[www.tripdatabase.com](http://www.tripdatabase.com)> is a clinical search engine with a focus on covering high-quality 'evidence-based' material. After 3 years as a subscription service, it has now reverted to a free-access model.

We initially made the decision to move to a subscription service to fund increasingly sophisticated upgrades to the site. This funding generated the changes but usage figures dropped significantly, making us question the purpose of TRIP.

The TRIP Database started in 1997 as a search tool for featuring only secondary reviewed articles (such as systematic reviews and clinical guidelines). However, it became apparent that users (mainly clinicians) needed more 'rounded' search support. In other words, they wanted the best available evidence. So if there were no systematic reviews then 'lesser' evidence would suffice. As a result, TRIP incorporated a wider level of material, which allowed considerably more clinical questions to be answered.

TRIP currently indexes a large number of sites (over 200) including Bandolier, NICE, Cochrane Systematic Reviews, SIGN, Royal College guidelines, MeReC, DARE, NHS EED and Clinical Evidence. This allows users to search all the sites effectively via one, easy-to-use, interface. In addition to 'evidence', TRIP also searches a number of e-Textbooks and patient information resources as well as a 50,000+ medical image collection.

The move to a free-access model has resulted in the adoption of a new business model, relying on three income streams:

1. **Google ads, situated on the results page.** Every time someone clicks on an advert, Google gets paid

by the advertiser and we get paid a proportion of that. The use of adverts is, alas, a necessary evil. I'm sure users would prefer free-access to TRIP and put up with fairly unobtrusive adverts as opposed to an 'ad free' subscription service.

2. **Sponsored links.** This allows organisations to purchase certain keywords. In return, they will have exclusivity on that term to display their banner advert at the top of the results page.
3. **Web-service.** This will allow third parties to integrate the TRIP search seamlessly into their own clinical applications via a SOAP/XML interface. This is really a backdoor way of searching TRIP that allows applications to search TRIP and manipulate the results and display them as they see fit.

In the 3 weeks since launch of the free-access TRIP, we have seen some interesting stats:

- we have increased the number of searches carried out from around 5000 per week when subscription-only, to nearly 50,000
- the most frequently looked at article in the first week reflected the tragic death of Steve Irwin; it was the eMedicine article 'Stingray Envenomations'
- in the evaluation of the subscription version of TRIP (carried out by Professor Paul Glasziou from the Centre for Evidence-Based Medicine, Oxford), around 50% of searches resulted in someone following a link to an actual article. The new search interface has significantly improved that, increasing to 73%. Is it appropriate to say that our new search interface is a 50% improvement on the old one?