



## On-line Resource Supports Breast Cancer Patients and Pleases Professionals

Jane Wood was diagnosed with breast cancer in 2000. "I went home," she remembers, "and spent hours searching on the Internet. There was so much information but the worst cases, and the most negative messages, somehow seemed the most relevant to me. I had no doubt that I'd be dead in five years. And as I searched, I had so many questions, and so much difficulty in remembering some of the details of my conversation with the consultant."

Jane's experience is typical of the 300,000 people who are diagnosed with cancer each year. As she became aware of this - and as, thankfully, her worst fears receded as her condition improved - she decided to develop a solution in the form of a personalised web service for cancer sufferers. This was possible because she worked as a research project manager at Liverpool John Moores University's International Centre for Digital Content (ICDC).

In October 2004 Jane's dream became reality when ICDC tested a pilot *mihealth* with 25 patients at the Royal Liverpool Hospital's Linda McCartney Breast Cancer Centre. Users accessed the password-protected service using PDAs (Personal Digital Assistants, or hand-held computers) donated by Hewlett-Packard.

### Patients and professionals are very positive

One patient, Maureen Burke, found the service to be "great because you have all the information at your finger tips and you don't have to worry that you have forgotten anything, or don't know the answer to something. It's like having a link to your breast nurse when she isn't there."



*Jane Wood sketching mihealth's future growth*

*"Far-reaching benefits, regionally, nationally and internationally"*

### Key Facts

- **A personalised web service for breast cancer patients, combining their medical details with background text and videos on the disease and its treatment**
- **Achieves key NHS goal of empowered and better-informed patients**
- **Now being extended to other NHS areas, and new versions being considered for other conditions.**



## *“It’s like having a link to your breast nurse when she isn’t there”*

Clinical Nurse Specialist Joan Spencer also found it to be a “wonderful idea. Patients can access information which is tailored to their own needs and revisit it at any time. It helps patients and healthcare professionals to openly discuss any issues pertaining to their diagnosis and treatment, and reinforces any verbal information they have been given.”

The service they used has six sub-areas:

**MiInformation** - providing comprehensive text and video material on the 12 main stages of a patient’s ‘journey’ through diagnosis, treatment and recovery.

**MiDiary** - a calendar of past and planned appointments, with a notes feature for questions.

**MiTreatment** - a record of all treatments received.

**MiContacts** - details of consultants, treatment centres, patient groups, and other relevant medical resources.

**MiMoodstates** - daily recording of levels of anger, happiness, depression, and anxiety.

**Useful information** - covering non-medical topics such as benefits and hospital transport.

### **Pictures speak a thousand words**

*mihealth* contains a large amount of photo and video material. Jane believes that “No amount of words can describe what, for example, a mastectomy actually looks like.” Patient Linda Thurlow agrees, commenting that the site’s “simple format and logical approach, coupled with the sympathetic and supportive video interviews, really inspired me and filled a void.”

Doctors and nurses at the Linda McCartney Centre provided much of the content, approved its final form, entered the treatment information, and incorporated this and the patient’s personal material into their consultations.

### **Extending to other areas, and other diseases**

Consultant Dr. Alison Waghorn has found *mihealth* to be “innovative and very accessible” with, potentially, “far-reaching benefits, regionally, nationally and internationally.”

This potential is now being developed by a university spin-out company, *mihealth* Ltd. This has funding to extend the pilot to a much larger number of patients in Merseyside and Cheshire. Jane Wood - now the new company’s Managing Director - “hopes that these will prove the concept on a large scale, and hopefully enable us to implement the service for all breast cancer patients in many NHS areas. We can also see great opportunities to extend the service to cover other conditions.”

Jane understands that everyone can’t access the Internet. She comments that “most content can be printed out when necessary, and costs for the really needy may need to be supported. But I know, from my own experience, that almost all people with cancer will make a lot of effort to access user-friendly information, especially when it’s available - as *mihealth* is - through different platforms such as cable TV and mobile phones. After all, it achieves what patients have told NHS surveys they want. The right information, at the right time, as well suited to personal needs as possible.”

### **Further Information**

The Northwest Regional Development Agency wants the region’s people and businesses to benefit from the new opportunities created by the digital revolution. It has worked with partners to establish Digital Development Agencies in Cheshire and Warrington, Cumbria, Greater Manchester, Greater Merseyside and Lancashire to achieve this at local level. The agencies help identify ICT priorities for their areas, work with local organisations to identify projects to address them, and secure the resources to make these projects happen.