

## 'mihealth' Newcastle: Executive Summary

Building on the success of 'mihealth Liverpool' – an information management resource initially designed to support patients living with breast cancer at the Linda McCartney Unit, Royal Liverpool University Hospital – this report outlines the findings from a second pilot study which has assessed mihealth's effectiveness in another regional site. What will follow in this report describes the process of developing mihealth Newcastle and its evaluation from the perspective of patients attending the Newcastle Royal Victoria Infirmary (RVI).

Working on the basis of a 'user-centred' design, where system development takes into consideration the information needs, strategies and practices of its users, mihealth was created to meet a number of key objectives: to bring together generic, local and personally relevant information on breast cancer; to do so in site-specific, easily accessible and flexible formats so that information could be accessed by patients in ways best suited to their needs; to provide information that would map on to the care pathway and illness career of the patient; and to provide a shared pool of information to support the interface between health and social service providers and their users.

The findings from the pilot are discussed in detail in this report and demonstrate that mihealth has worked well for the patients at the Newcastle RVI and has, in the main, fulfilled all of its objectives. However, the report has also identified a number of areas for improvement, amendment and opportunities for continued development. The following comprises a summary of the study's main findings.

### Strengths

- Though initially developed for the Linda McCartney centre in Liverpool, the customisation of mihealth for the Newcastle RVI has been successful, demonstrating that the system can be implemented in multiple locations on the basis of a robust content building process.
- The processes of content building, development and the implementation of mihealth Newcastle were contingent on the positive relationship fostered between the design team and staff at the RVI. This relationship played a major role in the success of mihealth in this setting.

- Once again mihealth's core strength was shown to be that it provides a patient's eye view of the treatment process in a particular place and its associated clinical sites, modelled around their own specific trajectories along a care pathway. As a consequence, the information it contains makes immediate sense to its users with minimal need for further translations or elaborations. The evaluators believe that this constitutes the unique selling point of the system.
- mihealth was positively received by the patients in the RVI, who valued the further opportunities it offered to become active partners in their health care under circumstances of their own choosing.
- Patients regarded mihealth as an empowering information delivery tool because it enabled them to address immediate questions and concerns at importune times. As a result, miinformation – and the associated audio and video content relaying supportive advice and personal stories from former patients – proved to be the most widely and consistently used feature of the system among this particular group of patients.<sup>1</sup>
- mihealth provided a rich support to the varied forms of information provided in this hospital. Patients commented that it augmented and backed up what they had been told in clinical settings and facilitated their interactions with medical staff. mihealth also helped patients navigate the information-rich environment of health care services more easily, where information overload is an issue, and supported their coping and decision-making strategies.
- mihealth enabled users to see themselves as 'typical' or 'ordinary' breast cancer patients. By providing access to former patients' experiences, in audio and visual formats, mihealth enabled patients to treat the breast cancer journey as a series of steps, with a beginning, middle and end, something that many people go through and survive. mihealth helps patients to gain a foothold on their condition and to see their breast cancer journey as 'normal' and routine – an important, but frequently overlooked, form of reassurance.
- mihealth proved easy to use and navigate and does not require patients to have particular skills or a high level of IT literacy.

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<sup>1</sup> Evidence from the mihealth Liverpool pilot demonstrated that patterns of use change with time, and that other aspects of the information provided through the system – particularly information regarding non-clinical support services – become increasingly important to users as they progress through the treatment process. However, while there was evidence of this in the case of mihealth Newcastle, this evaluation concentrated more on patterns of use among newly diagnosed patients and less on patterns of use among those further along the care pathway.

- The system can be used in a variety of settings in the home, hospital and wider community.
- Patients liked that information was presented in a number of different formats and that they were not steered towards specific messages or content. They liked that it was up to them to decide what information to access, when and how.
- Importantly, the ways in which patients used mihealth clearly reflected the different strategies and techniques they employed to navigate, manage and make sense of information more broadly. Rather than conflicting with patients' settled, familiar ways of working with information, mihealth adapted to them.
- mihealth compares positively when assessed against other websites, but at the same time was also easily integrated with other online sources of health information. mihealth's capacity to provide patients with a blend of both local (institutionally and geographically specific) and generic information contributed to the confidence many patients expressed in the system. Patients felt that in having access to information about their own hospital, clinical staff and breast care supports, mihealth was able to dovetail with the different services provided through Newcastle RVI.
- mihealth supported the needs of family, friends and carers and facilitated communication with those nearest to the patient.
- mihealth was not seen by patients as a replacement for face-to-face interactions or the advice and information provided by clinical staff, but a valuable way of complementing them. The patient-clinician relationship is at the centre of breast cancer treatment, and patients found that mihealth can support that relationship.

### Issues and Amendments

- Before actually using mihealth, a number of patients had extremely high expectations about what the patient specific features of the system would be able to deliver – expectations perhaps buoyed by media coverage of the introduction of electronic medical records (EMRs), and awareness of the EMR pilot also conducted in the Newcastle area. mihealth's claim of offering 'personalised' information led some patients to assume that their medical information would be provided, ready inputted, through the system. As a result of this confusion about what the system was supposed to provide, those

aspects of the system that allow users to personalise the information they access were less frequently used – in particular, the information selector, diary and treatment logging functions. Patients did remark that these features could become more significant in the latter stages of treatment, and that it was important to include these as additional choices for managing information. Nonetheless, the evaluators would stress that tailoring any on-line resource to meet individual requirements may always be a minority pursuit, and have recommended that the design team reconsiders how it markets this aspect of mihealth – particularly in terms of managing user expectations by providing more explanation as to how these functions operate and could benefit them.

- Amendments suggested include; the addition of a ‘Frequently Asked Questions’ section; the inclusion of more photographs, illustrations and other visual material; further explanations as to how the different mihealth functions work; and specific changes to be made to mimoodstates so that patients can change information they had entered at previous dates.

mihealth is not a static, one-size-fits-all resource. Using processes of feedback between design, research, evaluation and development, mihealth is in a very strong position to continue to reflect the changing demands and needs of both breast cancer patients, health professions and services. It will continue to help patients to decide what information is relevant to them, and to fit that information around their personal experiences, providing a resource that supports ‘informed choice’ but also a tool which can help patients exercise those choices in practice.

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