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Using apps to capture personally meaningful data on lived experience from patients with long term conditions

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Abstract

Chronic pain (lasting more than 3 months) can persist despite the best efforts of physicians, and can result in profound mental ill-health and disability. This paper reports on research aiming to find out whether smartphone-based pain diaries are something patients with chronic pain find useful to keep track of whether they are getting better or worse over time, for example in response to new treatments.

The NHS has recently launched a [new digital apps library](#) to help patients to find apps that are supported by appropriate standards of quality, safety and effectiveness. But which types of apps will patients use for a long enough period to allow the full benefits to be measured, particularly with regard to improvements in the quality of their daily lives?

To enable "just-in-time" interventions, patients will need to provide symptom data in real-time or close to real-time. Such user-inputted data would provide a link between physiological measurements and the user's experience. However, it is unclear whether patients are able and willing to provide sufficiently frequent day-to-day symptom data to inform real-time treatment options.

Patients were introduced to 2 simple smartphone apps and were offered the opportunity to continue using these apps to record diary data over a period of up to 3 months. Full statistical analysis of the data will be carried out after all patients have stopped using the apps or when the 3 month trial period has completed. This paper will report on smartphone app usage patterns, personalisation of the apps and qualitative evaluation of the data.

During the trial period, use of the apps was entirely voluntary and the patients input scores, text and activity-durations at a time and frequency of their choosing, they were not prompted to record data at specific times and frequencies. One of the apps had a reminder notification, the other did not. One of the apps allowed rating scores at a point in time, the other allowed diary data from a whole day to be recorded in one entry. Both apps allowed free text entry, in one app a voice-to-text option was available. For both apps, the research team pre-defined the field labels but all patients had the opportunity to request additional fields to be added to suit their needs and preferences.

We observed different patterns of usage within the group. Data are entered at almost any time of day. People may skip a day or so, yet they continue to record data. The use of the two apps varies considerably, as does the frequency of use of the free text and voice-to-text options. Most interestingly, there appear to be two levels of intensity (frequency) of use and the pattern of scores appears to vary strongly between individuals. The choice of additional fields is also very personal.

We will report on the use of smartphone apps to capture “small data” on the day-to-day variations in symptoms, activities and personal experiences of individual patients over 3-4 months and how this can contribute to development of artificial intelligence for mental health patients.