

**NewMind Plus Feasibility Study Stage 1 – Towards a next generation platform for personalised neuro-therapeutic interventions in chronic pain: qualitative analysis of Stage 1 workshop user feedback and interviews**

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Seven qualitative interviews and two workshop transcripts were analysed in depth. They all discussed the experience of seven patients suffering from different pain conditions when using a smartphone app that tried to record their activities and levels of pain throughout the day. The experience was generally perceived as a positive one, which most people quite liking the fact that they were able to take part in this trial.

However, a number of aspects were recommended to be changed for a future version of the app. The main ones that were mentioned were:

1. Having some sort of reminder for people to remember to fill the app
2. Having some sort of feedback (graphs) accessible through the app itself
3. Including a numerical scale on the sliding scales, to make it more objective
4. Being able to fill in, on the following day, so no data is lost
5. Being able to personalise it more, to avoid confusion between categories and make it more relevant for each individual

The outcome was in general very positive, with 6 of the 7 participants claiming that they found the app very useful and helpful. It helped them manage their pain and understand their condition better, since they could now understand how certain environmental factors were responsible for an increase in their pain levels. This also allowed them to try to avoid those factors or at least to be able to plan around them, so that the effect of pain on their everyday life would be less.

Some of the participants were also very hopeful that a modified version of this app could help them explain themselves better when trying to communicate their condition to health personnel or even family members and friends.

For a more detailed analysis of the interviews we used the categories based on the paper *Acceptability and usability of smartphone-based Brainwave Entrainment (BWE) technology used by*

*individuals with chronic pain in a home setting* (Helen N Locke, Joanna Brooks, Laura J Arendsen, Nikhil Kurian Jacob, Alex Casson, Anthony KP Jones and Manoj Sivan).

*1. Approach to trying out the app: The impact of living with pain and Current management options*

In this analysis, we took a look first at how the individuals described their pain condition and the way their lives unfolded with their pain as well as their current treatment options. Participants were trying to accommodate their conditions to their everyday life, and were therefore keen to try out any new management option that would help them get as closer as possible to a more “normal” life, without pain.

**1.1. The impact of living with pain**

Participants described the restrictions that living with a constant pain level places in their everyday life. All participants had been suffering from pain conditions for at least over 5 years and in some cases much longer. Participants narrate the ways in which they have had to change their lives to accommodate these restrictions, which affects their mood, mobility and their independence. Most of them have become more dependent on other relatives and family members to do the things that they used to be able to do before, but their lives have also become lonelier since they are unable to go out as much or do the things they used to enjoy. Others, however, describe that despite being in constant pain, they still have to undertake a lot of responsibilities, since they are the care providers for other family members.

Some participants also described that since pain is not visible, they are frequently misunderstood and others find their illness hard to believe. All of these restrictions impact on the participant’s psychological wellbeing and all of them describe that the pain condition can usually also lead to depression, tiredness, anxiety and stress. Participants understood that their situation was permanent, but at the same time they were all desperate to gain some inside and better understanding of their condition to try to be able to manage themselves better and have something that could resemble their previous life as much as possible.

Quotes

P2	... but my depression isn't...is caused by the amount of time that I'm ill and I'm not allow...and I can't do what I'd normally like to do.
P4	You know when you’ve always been the care provider to, suddenly, find yourself at the receiving end? You’re very grateful for it, obviously, but you think, ‘that’s my job’, you know? It’s a tricky one.
P5	... so it can be quite hurtful at times that people don’t understand and...

P7	... there's no point in feeling sorry for yourself because there is no cure, at the moment, for this illness... What's important is your mental attitude to how you deal with it.
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## 1.2 Current management options

All of the participants reported that the main treatments available to them were pharmacological therapies, and they were all on some sort of pharmacological treatment. However, all of them were also very weary of these treatments due to the troublesome side effects of these medications. Most of the participants tried to reduce their doses or were against going on some stronger medications, since the side effects were on occasion more debilitating or interfered even more with their daily life. Participants were also concerned about the potential long time effects of these medications, so they were all willing and even actively searching for alternative therapies to manage their pain. All of the participants were involved in some sort of alternative treatment, especially hydrotherapy and Tai Chi were describes as being very helpful. Participants were also very interested in interventions that could make them understand their pain condition better, as well as the factors that affected them the most, as a way of being able to manage their condition better.

### Quotes

P1	... I'm not willing to take stronger pain killers that interfere with cognitive function... so I'm very keen to find alternative things.
P3	I'm on quite decent meds. That helps. I'm doing Tai Chi at the moment...
P6	... I've been reading a load and I would love to do some kind of, you know, mindfulness?
P7	. I'd, rather, go down the alternative therapy route, if you like.

## 2. Perceived effectiveness

Here it was analyzed how useful did the participants find the app. The perceived effectiveness of this app combined things such as the participants expectation of what they would obtain from it, as well as the technological result of whether the app did in fact delivered that.

### 2.1. Effectiveness of the app in pain management

This study focused on the functionality of the pain app and participants gave their feedback on their perceived usefulness of it. Some participants believed the pain app could be very useful when trying to manage their pain. Others believed it could be a good thing, but there was still room for quite some improvement. One participant saw absolutely no use in it.

In general the participants considered that the pain app was effective when it came to measure their symptoms. It was frequently stated that the app would give them the opportunity to start seeing patterns for themselves. Seeing correlations between different factors and possible patterns for when they would be in more pain seemed to be the main beneficial effect mentioned by participants. That allows participants to be able to plan in advance and prepare for the coming day. The main worry was that they couldn't go back to fill in the previous day, which led them to have missing data. Some participants even declared that they kept using the pain app even after the trial period had ended, because it helped them focus. Some participants considered that a definitive version could be even used by doctors to track how the patients have been doing. Being able to see the data back was also found to be quite useful.

#### Quotes

P2	... I could use that data along with other data that I keep and try and get round as many as the bad bits as I can the good bits so I would then be able to work out what's causing it and then try and avoid what's causing it as much as I could.
P3	I liked that it made me think about my pain in relation to what I was doing.
P4	you could see patterns emerging, you know, and I just found that, to be able to have that correlation between two was quite interesting
P5	It made me plan better. (...)It made me more aware.
P6	: I think it's very useful 'cos it makes you more aware of what you're doing and how much you're...you know, how things affect you, day-to-day, so I think it's a useful thing to do.

## 2.2. Additional positive effects

Participants also mentioned that it made them think about their illness differently and it helped them realize that they have good days and bad days, which helps them feel less depressed. Most participants mentioned that they would rather use an app on the phone, instead of a written diary, since it was much easier to use, while being in pain and they wouldn't misplace it.

Participants also liked the fact that they could use the app to show it to their GP's and other people as a tool to help them explain what their condition has been, so they would feel less misunderstood.

#### Quotes

P4	I think it enables you to put stuff into perspective.
P5	... give evidence really of what, what's actually happening 'cos if I start trying to write things down, I invariably lose a pad or paper or misplace it, put it somewhere safe, so having it on the phone, all in one place, was a good idea.

P6	...you could then explain why you've got certain things, yeah. I think it did help.
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### 3. Opportunity costs and burden

Here we are looking at how the participants reported that they were able to fit the use of the app into their everyday life and whether it had some sort of negative impact on their regular activities.

#### 3.1. Fitting app use into everyday life

Most participants found that they could fill in the pain diary without major difficulties or disruptions to their everyday life. People used different strategies to fill it in, some people would fill it in throughout the day, whenever they found a chance, but others decided it was better for them to wait until the evening and then fill the whole day retrospectively. The main drawback with it was the fact that they couldn't go back on the previous day to fill it, if they had missed an evening. Several participants suggested that the app could include some notifications to remind them to fill it if they hadn't done it.

The other issue that was presented in this topic, was that sometimes, people would forget to fill it in, so it was mentioned that it would be useful if the app could send some sort of reminder to do it.

#### Quotes

P1	... it would be useful if you could set up notifications to remind you to do it...
P2	... if I could do it in the evening I would, probably, start to sit down, have my evening meal and then do it.
P3	It didn't interfere with any activities, I suppose, but I got bored of it very quickly
P5	It was difficult at time because I, I go out visiting people in the homes so it, I, kind of, just do it at set times. Worktime was difficult, yeah.
P6	think the main one was putting it all and remembering, you know, like, morning, afternoon, night
P7	it's when I remembered to use the app, it was really good but it's when you're in really bad pain and you've got the fibrofog and you forget to add it,

#### 3.2. Negative effects of app use

In general, most participants were happy with the app and were able to use it without major difficulties. There were some advices and suggestions for improvements, but none of them hindered the use of the app or affected the users in a negative way. In the case of the single participant who did not like the app, he was simply able to uninstall it and not use it again.

The major negative point that was mentioned involved the categories, which some people found some of them to be overlapping. The participant who didn't like the app claimed that it was too subjective and that he would have preferred to use a normal calendar app.

Quotes

P3	Too subjective I would say.
P4	... sometimes there was an overlap. If, for example, you had the category of exercise, and then there was a category that was active, and it's like, well, I'm active trying to do housework.

*4. Intervention coherence and self efficacy*

Here we analyzed how participants were able to deal with the technological aspects of the app and whether they found it easy and functional to use. We also compiled together the main aspects of the app that the participants mentioned would be useful to add or modify.

**4.1. Understandings of and familiarity with technology**

Participants reported that the app was easy enough to understand and to use. Most of them considered that the concept was easy and useful and that it helped them understand their condition better. They would also talk in positive terms of the fact that the app could be individually tailored to make it more relevant for each individual, considering that everyone's experience with pain is so personal. Several participants continued using the app even after the trial period, because they felt it had been beneficial for them, while others agreed that it could be very useful if a final version was released.

Participants generally felt that confidence in the use of technologies was an important issue when dealing with a new app, but they all found the app easy to use. That was despite the fact that some of them classified themselves as not being very comfortable around technology, and needed some help when setting it up.

Quotes

P1	I'm quite good with apps so I found it very straightforward to set up and start using...
P2	It was...it was a very easy app to use and for somebody who could be in quite a lot of pain its...you don't have to think about it.
P4	... and it was quite straightforward and I'm not the greatest person with technology but it

	was fine. It was easy to deal with.
P5	Setting it up? I struggled a little bit. I'm not very technical so (...) helped in the group.
P6	... there's so many columns but, and you could add things yourself, which is better than the, somebody else adding everything that might not be relevant to you. Then, obviously, because it was, you know, you like colour coding and charting...I just found, I don't know. It was just straightforward.

#### 4.2. Intervention usability and suggestions for development

Participants considered that the app was easy to use and quite straight forward. The fact that there was no need to type much, but was just moving a slide was very appreciated, since typing on a screen was sometimes painful in their conditions. Some people mentioned, however, that not having a numerical scale made it hard to be consistent. Most participants found it very useful because it helped them identify factors which could increase or decrease their pain level and could help them therefore manage their life better.

Participants suggested that the app could include some feedback for them to be able to see how they did over a certain period of time and that the feedback should be within the same app and not for them to have to look for it in a different place. Participants would also like to have reminders to log on, in case they haven't done it.

#### Quotes

P2	If I could see my results, I would say it would be very useful because if there was an option, ... use I could use it in trying...if I couldn't explain myself properly with a doctor
P3	I would've preferred it to be integrated into an existing calendar database sort of app.
P5	It's just that you could never go back. So once you'd gone past 12 o'clock you couldn't go on the day before.
P5	Maybe something on the app that you could just click on and it will take you to it. That would be good. (The Charts)
P7	... a numbers column might help better indicate pain, as well.