# PARTICIPANT EXPERIENCE IN THE IDEA-FAST CLINICAL OBSERVATIONAL STUDY

*Report*

# INTRODUCTION TO THE REPORT

As part of the Final Conference, all study participants who completed the study were invited to participate online. It was a pleasure to have eight COS participants attend the conference in person and take part in a panel discussion. During this session, several questions, which had also been shared with all study participants before the conference, were discussed.

Based on the feedback and responses received, we have prepared a summary of the key discussion points and findings. The main points are presented in this report.

# HOW EASY WAS IT TO INTEGRATE THE DEVICES INTO YOUR DAILY LIFE?

Most participants found the devices easy to integrate into their daily lives and reported that they were not burdensome. They experienced few difficulties, if any, and most devices were comfortable to wear with minimal impact on everyday activities.

However, some practical and physical inconveniences were mentioned. For example, some participants found the study phone heavy and inconvenient to carry around constantly, which was a reason why it was sometimes forgotten. The VitalPatch and AX6 sensors interfered with activities such as swimming, as they are not waterproof. Furthermore, they caused skin irritation and itching in some cases. The AX6 was sometimes found to be uncomfortable at night due to a feeling of pressure when lying on one's back. Using the digital diary required some adjustment and extra time, particularly for participants with busy daily routines. However, reminders and short questions made it easier to use.

Overall, the clear majority view was that **the devices were easy to integrate into daily life and that participation was manageable.**

# WHICH PART OF THE STUDY REQUIRED THE MOST EFFORT FROM YOU – WEARING THE DEVICES, THE E-DIARY, CLINIC VISITS, OR SOMETHING ELSE?

**Clinic visits were the most time-consuming part of the study**, mainly due to long travel distances involved for some participants. Nevertheless, participants valued the face-to-face consultations and generally considered the effort worthwhile.

Other significant challenges included completing the electronic diary regularly and carrying out the cognitive tests on the CANTAB app. Participants described this as time-consuming and difficult to fit around their daily routines or sleep schedules. Furthermore, they reiterated that carrying a second cell phone was inconvenient, and they found it difficult to attach some of the sensors on their own. However, these **challenges were mainly organisational and practical** rather than being major burdens.

## DID YOUR WILLINGNESS TO PARTICIPATE CHANGE OVER THE COURSE OF THE STUDY – AND IF SO, WHAT CONTRIBUTED TO THAT?

Participants demonstrated a **high level of willingness to take part in future studies.** Most said they would participate again, expressing a positive attitude towards research and scientific progress. Key motivations included the desire to learn more about fatigue and chronic illnesses, the wish to contribute to scientific progress, and the recognition of the importance of research in improving knowledge and treatment.

While some participants' enthusiasm decreased slightly over the course of the study, this generally did not result in them wanting to withdraw.

A few participants said they would not take part in a similar study again due to the time commitment and additional responsibilities involved. Nevertheless, some of these participants said they would be willing to support research by taking part in less demanding activities, such as providing additional blood or saliva samples.

In summary, **the willingness to participate clearly outweighed any reluctance.** Despite some practical or time-related challenges, participants generally found their involvement to be meaningful and worthwhile.

## DID YOU FIND THE E-DIARY USEFUL FOR BETTER UNDERSTANDING YOUR OWN FATIGUE OR SLEEP – OR WAS IT MORE OF A BURDEN?

Participants had mixed experiences with the devices and e-diary, but several reported valuable insights. **In particular, wearable devices and digital measurements were seen as useful** because they can capture objective information about fatigue, sleep, and day-to-day fluctuations that are difficult to describe verbally. Some participants felt that these measurements could support and validate their experiences when communicating with clinicians.

The e-diary helped some participants to become more aware of their sleep, fatigue, personal limits, and daily variations in performance. Short questions and reminders were especially helpful when experiencing fatigue, as selecting answers was easier than providing lengthy descriptions.

However, participants also noted that e-diary responses could be influenced by mood or external circumstances. Repeatedly answering similar questions became tedious when there was little change from day to day. Some participants reported no personal benefit or new insights and experienced this part of the study primarily as a burden.

Overall, though, **many participants saw the devices and e-diary as valuable tools for raising self-awareness and objectively recording symptoms and fluctuations** that might otherwise be difficult to notice or communicate.

## DO YOU THINK DIGITAL DEVICES CAN HELP YOUR DOCTORS UNDERSTAND YOUR FATIGUE OR SLEEP BETTER THAN QUESTIONNAIRES ALONE? – WHAT CAN THE DEVICES CAPTURE THAT WORDS HAVE NOT BEEN ABLE TO EXPRESS?

Participants generally viewed digital devices and sensors as useful because they can provide more objective, accurate, and detailed information than questionnaires alone. They were particularly valued for assessing sleep, activity, and fatigue, where subjective experiences can be difficult to describe or estimate accurately.

These devices can capture factors such as sleep stages, night-time awakenings, activity levels and changes in typing behaviour.

One key benefit is the ability to make invisible symptoms and functional limitations more visible. This could help patients to communicate their experiences more effectively to clinicians, reducing the need to explain or justify their limitations constantly.

However, **participants emphasised that objective data should complement, rather than replace, personal experiences.** This data must be interpreted in the context of the individual's situation, alongside a trusting, equal relationship between patient and clinician. For some participants, the study also helped them to understand the importance of sleep and fatigue better, enabling them to identify previously unrecognised sleep problems. Participants particularly valued the possibility of objectively documenting changes in performance, activity and personal limits, particularly in relation to fatigue.

Some practical limitations were mentioned, such as app schedules being too rigid for everyday routines. Overall, however, **participants strongly believed that digital monitoring could play a significant role in improving our understanding of fatigue and chronic illness**, and in making the often invisible limitations experienced by patients more visible and understandable.

## HAS YOUR PARTICIPATION IN THE STUDY CHANGED YOUR OWN PERSPECTIVE ON YOUR CONDITION – FOR EXAMPLE, HOW YOU THINK ABOUT FATIGUE OR SLEEP PROBLEMS?

For most participants, the study did not significantly alter their overall perspective on their diagnosis. Several participants explicitly stated that their view remained unchanged after taking part in the study. However, participation led some to consider their personal limits and fatigue management more closely. Some became more aware of how little physical activity they engage in, and how much certain exertions affect their recovery. This resulted in a greater awareness of the need to take personal limits seriously, plan activities according to available energy, prioritise sufficient rest and sleep, and slow down or stop when experiencing fatigue, rather than pushing through it. Another important point was that, while objective study data can show what is happening, it may not explain why. Individual circumstances and personal limits therefore remain essential when interpreting the results.

In summary, while the study did not fundamentally change most participants' view of their diagnosis, **for some it encouraged a more conscious approach to their limits, fatigue, activity levels and need for recovery.**

## DO YOU BELIEVE THE RESULTS OF THIS STUDY WILL MAKE A DIFFERENCE TO THE TREATMENT OF YOUR CONDITION IN THE FORESEEABLE FUTURE?

Most of the participants expressed hope that the study's findings will contribute to better long-term treatment options, particularly by generating new data and improving our understanding of fatigue, sleep disturbances and reduced physical capacity caused by different conditions.

However, some participants were unsure how the findings could influence their individual treatment, suggesting that this would require a more detailed medical consultation. There was also some uncertainty about how quickly research findings could be implemented.

A particularly strong theme was the desire for greater recognition and understanding of symptoms that are often invisible. Participants hope that future research will help to identify affected individuals earlier, increase the use of objective measurement methods in healthcare, tailor treatments more individually, and reduce the need for people with fatigue to constantly explain or justify their condition. Participants also emphasised that research can benefit not only those taking part, but also future patients.

Overall, **there is a strong desire for greater awareness, understanding, and recognition of fatigue and other invisible limitations within healthcare, government agencies, and society.**

## WHAT WOULD NEED TO HAPPEN FOR YOU TO FEEL THAT YOUR PARTICIPATION WAS WORTHWHILE – NOT JUST FOR SCIENCE, BUT ALSO PERSONALLY?

Participants' wishes mainly focused on better information, personalized feedback, improved medical care, and greater social recognition. A frequently expressed wish was for simple, clear, and concise information about the current state of research, potentially including realistic forecasts that could provide hope.

Some participants would also appreciate a personalized written interpretation of their study results, ideally including practical suggestions for possible behavioral changes.

Another major theme was the need for better education and awareness among doctors and other professional groups about fatigue and its impact on everyday life. Participants want fatigue to be taken more seriously and to receive greater attention in medical training. Comments such as “you look fine” or the suggestion that nothing can be done about fatigue were perceived as unhelpful. Participants also hoped that research findings would actually reach treating physicians and be implemented in everyday healthcare, leading to better ways of objectively measuring fatigue and functional capacity. Practical digital tools could also be valuable, for example, a tool that reminds someone when it is time to take a break and helps them recognize their limits before becoming exhausted. At a societal level, participants called for greater recognition of fatigue and Long COVID, particularly in the workplace and among government agencies.

Overall, **they hope research will help ensure that people affected are taken more seriously, face less need to explain or justify their limitations, and receive greater understanding of their often invisible symptoms.** At the same time, some participants already felt that their involvement had been meaningful and worthwhile in itself.

## IMAGINE A DIGITAL TOOL IS DEVELOPED BASED ON THIS STUDY: WHICH FEATURE WOULD BE MOST VALUABLE TO YOU AS SOMEONE LIVING WITH THIS CONDITION?

Participants had varying ideas about future digital tools. In general, they would like simple, discreet, and practical solutions that continuously capture relevant health information and make it useful for clinical care. Frequently mentioned features included monitoring sleep, activity and rest, fatigue, cognitive capacity, pain, and overall well-being. Participants also valued reminders for medication, breaks, or questionnaires, as well as easy-to-understand summaries and a data export that could be shared with healthcare professionals. Some suggested directly transmitting information such as blood pressure, heart rate, and e-diary data to clinicians. A particularly important feature would be a tool that can detect early signs that someone is approaching their personal limit and needs more rest. This could help people plan their daily activities more effectively while also making their often invisible symptoms easier for doctors and others to understand. Specific support for sleep and pain management, as well as reminders to go to bed on time, were also mentioned.

Overall, **future digital solutions should be patient-centered, minimally intrusive, easy to use, and focused on the symptoms that matter most to each individual.** Participants also hope that the data collected will not only benefit them personally but contribute to a better understanding of fatigue and other non-motor symptoms and ultimately improve quality of life for future patients.

## WOULD YOU RECOMMEND THAT OTHER PEOPLE WITH YOUR CONDITION PARTICIPATE IN A SIMILAR STUDY – AND WHAT WOULD YOU WANT TO TELL THEM BEFOREHAND?

**Participants would strongly recommend taking part in research studies.** The main motivation was the desire to advance research, generate new knowledge, and ultimately contribute to better treatments and support services for future patients. Many considered their participation meaningful and rewarding and appreciated the opportunity to help both researchers and other people affected by the condition.

At the same time, participants acknowledged that taking part requires time and commitment, and wearing monitoring devices around the clock can have an impact on everyday life. Some therefore recommended discussing participation with a partner or family beforehand. Nevertheless, the effort was generally considered worthwhile, particularly given the relatively short study period.

Important factors supporting a positive experience included a competent and friendly study team, the opportunity to ask questions whenever something was unclear, and the ability to withdraw from the study if necessary. For people experiencing fatigue, participants particularly emphasized that they should not feel guilty if they cannot complete everything perfectly or have less energy on some days.

In sum, participants expressed a strongly positive attitude toward patient involvement in research. **They viewed digital technologies as a valuable complement to traditional assessments** and emphasized that research needs not only objective data but also the personal experiences and voices of the people behind the data. Most of them would recommend other people to take part in a similar study.

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