ASARM
A System for CFS/ME Monitoring and Treatment

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Abstract: CFS/ME (Chronic Fatigue Syndrome/Myalgic Encephalomyelitis) affects up to 2.5% of adults in the UK and USA and between 1% and 2% of children in the UK. Sufferers report that they are low on energy, and find performing everyday activities difficult. The illness is commonly treated using Cognitive Behavioural Therapy (CBT), which aims to help patients learn how to build up their energy levels in a gradual way, and how best to spend and preserve their energy. A crucial aspect of this treatment is for the health care professional to monitor and record how the patient spends time on a day-to-day basis, then prescribe appropriate and precise baseline levels for periods of rest, sleep and activity. These levels are then gradually adjusted as the patient's condition improves. Current methods typically rely on paper diaries, however, these offer little guidance to the patient and are time consuming for the health care professional to analyse. The ASARM (Advanced Sleep, Activity and Rest Monitoring) system combines an electronic diary with automated recording of actigraphy data, with the aim of improving the process of assessing, monitoring, prescribing for, and then treating patients with the condition.

1 INTRODUCTION

CFS/ME (Chronic Fatigue Syndrome/Myalgic Encephalomyelitis) is a condition characterised by a debilitating fatigue that is not relieved by rest, and persists over at least six months (Reeves et al., 2005; Royal College of Paediatrics and Child Health, 2004; Fukuda et al., 1994). It typically co-occurs with other symptoms such as muscle pain, headache, sore throat and memory or sleep problems. While the prevalence of the illness can be difficult to define, since this depends on the diagnostic criteria used, recent studies suggest up to 2.5% of the population in the UK and USA may be affected (Avellaneda Fernandez et al., 2009; Reyes et al., 2003; Jason et al., 1999), and between 1% and 2% of children in the UK. Approximately one in ten of these will be of a severity that means the illness is disabling, leaving the patient housebound (Farmer et al., 2004). The most recently published UK guidelines (National Institute of Clinical Excellence (NICE), 2007) recommend immediate assessment by a specialist, and (Hinds and McCluskey, 1993) found that children and young people with the condition had a significantly better prognosis than adults if diagnosed early.

Patients with the condition find it difficult to regulate their energy expenditure. They can frequently become very low on energy, which then makes performing everyday activities challenging. A critical aspect of CFS/ME is that an activity can be costly to the energy levels of the person with the condition by being either physically, emotionally or cognitively demanding. This means that a thorough understanding of patients' lifestyles is vital to prescribing effective treatment.

We present a technology-based solution for both monitoring and then treating CFS/ME by collecting and analysing data around patients' everyday activities, making use of subjective metrics recorded by the patients themselves and objective data describing their movements.

2 CLINICAL NEED

Currently, the most prominent and successful treatment of CFS/ME is the use of Cognitive Behavioural Therapy (CBT) to help people with the condition learn how to build up their energy levels in a gradual way, and inform them how best to spend and preserve

the right amount of their energy (Stulemeijer et al., 2005). This approach is applicable to both young people and adults, and a recent randomised control trial (the PACE Trial[1]) using CBT for adults with CFS/ME has further reinforced its clinical effectiveness for treating this condition (White et al., 2011).

Generally, the CBT approach to managing and treating CFS/ME is to monitor and record, with the patient's help, how his or her time is divided between activities of varying energy-expenditure, specifically periods spent sleeping, resting and being active. Averaged over a period of days, these amounts serve as baselines, which are then rebalanced to more healthy and sustainable proportions. An important aspect of this treatment is the method by which the patient's time is monitored and recorded, since this is the information that setting appropriate and precise baseline levels relies on. In current clinical practice (for example, in (Royal College of Paediatrics and Child Health, 2004)), the process is as follows. In phase one of treatment, baseline levels are established by analysing data recorded by the patient in a paper diary over a set period of time (typically a fortnight). In these diaries, the patient records the amount of time spent doing daily activities (including periods sleeping or resting). This data informs the clinician who establishes, by averaging the figures to remove daily fluctuations, the exact amounts of sleep, rest and activity that the patient is capable of achieving without detrimental effects on his or her health. In phase two, the patient aims to follow these set 'budgets', and over the course of the treatment they are gradually adapted—by the clinician—to achieve a more healthy balance. As part of a more detailed assessment, the patient supplements activity diary information with subjective ratings: a record of reactions to, and appraisals of, the activities being performed. These subjective ratings may be, for example, the sense of mastery achieved or the level of fatigue felt while carrying out a task, or the feeling of refreshment following rest or sleep. These ratings contribute in two ways: they provide additional information for the clinician to aid prescribing a patient's daily schedule, and also help the patient by adding a degree of reflection to his or her daily routine.

The collection of data through paper diaries, and the data itself, can be problematic in three ways. First, the data can be highly subjective, reflecting patients own opinions on how they feel. Second, the diary information relies upon the patient's diligence for its accuracy and completeness. Third, the actual act of data collection places additional strains on the patient, in particular on memory, and especially in the early

stages of care which are often characterised by feelings of hopelessness and disempowerment.

In the following sections, we describe how each of these problems may be addressed, and a system we have built to put these improvements into practice.

3 METHOD

Our method for addressing the shortcomings of the current clinical practice (described in the previous section) is to apply cost-effective, robust, technological solutions to key aspects of the existing methodology, and to integrate and automate processes where possible to provide a complete integrated system for monitoring and treating the condition. Existing work by (Abeles et al., 2009) involving the application of computer-assisted CBT to treat a not dissimilar condition (adolescent depression) has proved successful (also see (Robinson et al., 2011)).

To compliment the subjective diary data used in current practice, more objective data in the form of gross-motor movement measurements can be collected alongside it. This can be captured through an actigraphy device: a small device worn on the body to measure and record the patient's movement throughout the day. A variety of small, lightweight and low-cost devices exist for this purpose, and have been trialled in limited ways as part of clinical research. For example, the Philips Respironics Actiwatch[2] has been used as a secondary outcome measure while monitoring CFS/ME patients (Kop et al., 2005). Prior to our work, however, actigraphy data has not been used directly in treatment settings.

Data gathered using such devices is invaluable in understanding patients' energy expenditure, but does not replace the existing diary system, since not all activities will necessarily afford movement on the part of the patient. A fundamental aspect of the condition is that physical, emotional and cognitive effort affect the overall energy expenditure associated with an activity (Afari and Buchwald, 2003). A cognitively-demanding activity without physical movement, for example, would not be detected by a system relying solely on actigraphy. If diary information is still to be collected, however, the issues of accuracy and completeness must be addressed. Our system uses an electronic diary that can record information, speed up the process of entering, and also serve as a visual aid. Such a diary system can guide patients as they plan and record their activities, helping to account for their

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[1]http://www.pacetrial.org/

[2]http://www.healthcare.philips.com/main/homehealth/sleep/actiwatch/default.wpd

time and to classify it accordingly. Further, the diary can address the third issue described, the cognitive strain on the patient, by being more accessible than a paper system, and by prompting the user where necessary (for example, to record subjective feelings alongside activities). During the first phase of treatment, where the patient is simply recording all activity, the device can assist data entry, reducing the amount of cognitive workload. In the second phase of treatment, where the patient is following a prescription, the device can instruct the user as to what type of activity should be carried out, and when, further assisting the patient in his or her scheduling.

In addition to addressing these issues, an electronic system can improve communication between patient and clinician. Both devices—the actigraphy device and diary—communicate with a central server, so that the data can be synchronised and viewed by the clinician. The clinician can view both diary and actigraphy data daily via a web interface, unlike the traditional system whereby access to this data was limited to scheduled appointments, typically occurring only fortnightly. This allows actigraphy data to be used as a primary treatment measure, to inform the clinician at the point at which they are creating a prescription for the patient. Not only can the clinician monitor much more closely the progress of the patient, changes to the prescription can be made much more rapidly: the clinician can revise and then 'push' a new prescription to the patient at any time. It is these small but incremental updates to a prescription that help the patient's condition improve. Not having to wait for more costly and less-frequent face-to-face appointments for each adjustment can potentially speed up the recovery of the patient.

4 RESULTS

The system developed in this work comprises: a central server, used for data storage and communication; a web front-end for the clinician; and a patient package. The patient package comprises: a wrist-worn accelerometer device to measure sleep, activity and rest; a docking station for the device; and an electronic diary (as a smartphone application). An overview of the architecture is shown in Figure 1.

4.1 Server and Web Application

The server combines a Pylons[3] web application and a PostgreSQL[4] database. The database stores infor-

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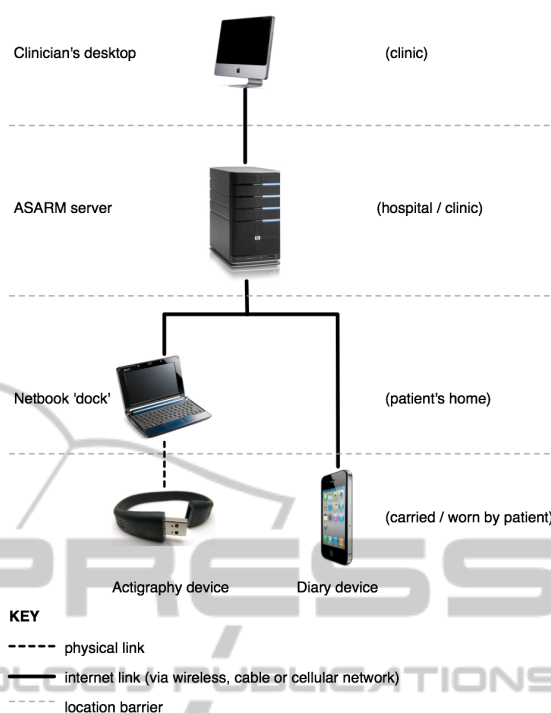[3]http://www.pylonsproject.org
[4]http://www.postgresql.org

Figure 1: Architecture of the ASARM system, showing the relationship between the clinician's interface, the patient's interface and the central server.

mation about registered devices, activities, subjective activity data, actigraphy data, prescriptions and allowances. The web application (Figure 2) lets the clinician view each registered ASARM device, its activity information, and also create, view and amend prescriptions for the patients associated with each device.

The primary role of the server is to provide Representational State Transfer (Fielding, 2000) end-points for the diary application to communicate with. New data, and requests for existing data, are sent asynchronously via HTTP from the mobile device to the server, which in turn communicates with the database and responds appropriately. The web application communicates with the server in the same fashion.

4.2 Diary Application

The primary interaction with the ASARM system for the patient is through the diary application, implemented as an app for the iPhone (Figure 3). The diary app's main purpose is to provide a quick and easy method for the patient to record day-to-day tasks. It can be in one of two modes: data collection mode or prescription mode. Data collection mode is used to learn how the patient's time is spent. Prescription mode is used once a prescription has been cre-
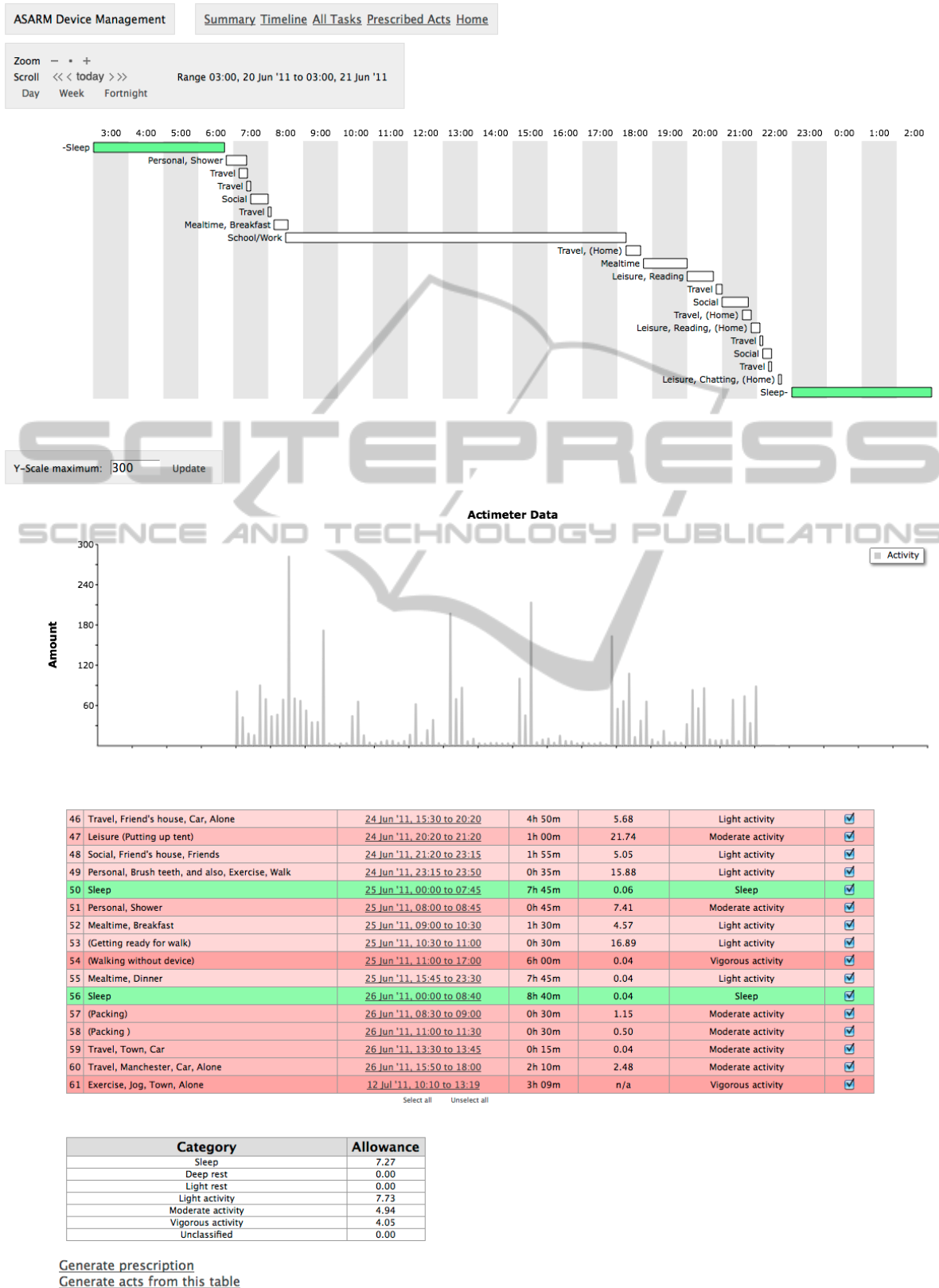
Figure 2: The clinician's web application, showing task timeline and actigraphy data, activities and calculated baselines.
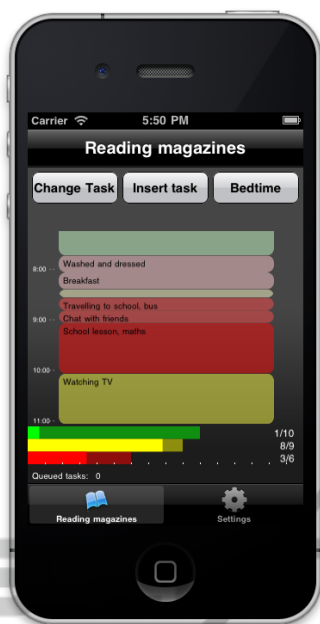
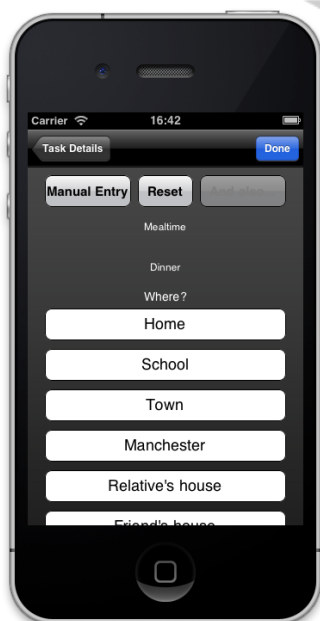Figure 3: The diary app, in prescription mode.

Figure 4: The diary app, showing the task builder.

ated by the clinician and delivered to the patient: this mode is designed to help patients follow their prescription as closely as possible. Data collection generally lasts around two weeks, during which time the patient uses the Task Builder to quickly describe the activity he or she is engaged in. The Task Builder presents high-level types of activity to the user (i.e. the patient), such as leisure, household, travel, etc., followed by additional types of information, such as

location, company, and so on, to quickly and accurately describe an activity (see Figure 4). For example, the user could create the activity 'Doing homework at home with a friend' in 5 touches, or the activity 'travelling to school on the bus, alone' in 4 touches. This input mechanism is designed to minimise the interaction with the diary as much as possible: it is vital that the monitoring and treatment of the patient do not increase the workload—either physically or cognitively—unnecessarily, and become a significant activity in itself. For instances where the use of the task builder do not enable the user to describe the activity fully, manual entry using the device's keyboard is possible. When the diary is in prescription mode, instead of the Task Builder the user chooses an action from a list of prescribed activities, grouped by energy-expenditure. This encourages patients to follow the prescription set for them, and allows the application to keep track of their time more accurately. When an activity is not in the prescribed list, the patient can use the Task Builder or manual entry to add the new activity.

The diary application communicates with the server using standard HTTP requests over the cellular phone network (or a wireless broadband connection if available). When a connection cannot be established, the diary application queues requests to be sent when a connection becomes available.

4.3 Actigraphy Device and Dock

The actigraphy device used is a 3-axis accelerometer unit[5]. The device is small and lightweight, worn on the wrist in a small pouch, and can record data for up to 60 hours. It charges and transfers data via USB. For this system the device is set to sample at a rate of 10Hz in +/-2g range. When uploaded to the ASARM server, these raw values are processed to take the change in magnitude of the three-dimensional vector each 1/10th of a second, and then the mean is taken over each minute for display purposes.

A netbook is used as a 'docking station' for the actigraphy device: when it is plugged into the docking station (using a standard USB connection), all new data on the device is backed up and uploaded to the ASARM server. The netbook is configured to use the iPhone as an internet 'hotspot' and so can automatically upload data to the server without additional configuration at the patient's home. This obviates the need for the user to provide an internet connection for the system to work. Unlike tele-medicine systems that may need to optimise the use of a narrow-band phone

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[5]specifically, a Gulf Coast Data Concepts X6-2mini http://www.gcdataconcepts.com/x6-2mini.html

line (for example, (Lai et al., 2005)), or make use of an existing broadband connection (for example, (Lai et al., 2007), high-throughput is not a requirement of this system, and so ease of use can be given a higher priority.

The netbook additionally acts as a power source and charges the actigraphy devices while they are docked. In operation, a pair of these devices is actually used: one is worn throughout the day, while the other is worn at night. The night time device is plugged into the docking station during the day, and at bedtime (when the user of the diary selects 'bedtime' as the current activity), the two devices are swapped, so that night time movement is recorded whilst the day time device uploads data and recharges.

Following the initial period of activity monitoring, using the data from the web application (the diary and actigraphy data in Figure 2) the clinician categorises each activity into sleep, rest, or activity, or even more precisely (deep or light rest; light, moderate or vigorous activity). The rating of activity will depend on both the actigraphy data and the description of the task, thereby allowing both physical and cognitive aspects to be taken into account. For example, watching a favourite television programme, whilst being physically undemanding, is cognitively much more demanding than spending the time just sitting. When the clinician has completed the categorisation, the application automatically generates starting baselines using the mean values of these categories over the monitoring period, as well as a set of rated activities to be sent to the diary application (Figure 2). This prescription—the baselines and set of rated activities—is sent to the diary app, which then changes mode from data collection to prescription mode. From this point, the patient has a predefined set of rated activities and daily baseline amounts to follow. The diary app interface changes accordingly as described above, to show the patient his or her activity choices, baseline amounts and 'budgets' of time for each category. The clinician continues to monitor the patient's activities, and can change and update the prescription—either by altering the baselines or by adding or removing rated activities—-at any time.

5 PRELIMINARY TESTS

The system as described has been 'field-tested' over a number of weeks to ensure each component works as expected and reliably. This testing was successful, and led to minor user interface improvements in the diary application and docking station. The output of

the actigraphy device was compared with a commercially available actigraphy device, and found to be of comparable precision. It has not yet been used clinically: this will be the next stage of the work.

6 CONCLUSIONS

The ASARM system described herein was developed to address issues identified in the current best practice methods to treat CFS/ME. The current method is to use paper diaries to collect data on the patient's day-to-day activities, then prescribe (and periodically update) baseline targets for levels of energy expenditure. Using this method, it is difficult for the clinician to accurately analyse and categorise the patient's activities, since there is a lack of objective movement information to compliment the diary information. Additionally, the paper diary system is reliant on the patient's diligence, and can increase cognitive strain. The ASARM system combines the collection of objective movement data with diary information and subjective ratings, presenting them together to the clinician so that a more informed judgement can be made on the patient's condition. This data is available remotely, and is updated much more frequently then in current practice. These features allows the clinician to monitor the patient's progress much more closely without disrupting the patient's schedule with formal appointments.

The ASARM system aids the treatment process in additional ways. The electronic diary provides finer-grained timetabling than the existing paper system, increasing the accuracy of recorded periods of rest, sleep and activity. The diary app also automatically prompts patients to answer questions about their current state of wellbeing at the appropriate time, rather than the patient recording this information at a later stage (with the paper diary system this is often only at the end of each day). The task builder in the diary application reduces the physical and cognitive demands of filling in a paper diary—and reduces memory load—by speeding up diary entry and by automatically recording start and end times of activities. Finally, the application allows a regular bedtime to be prescribed and suggested to the patient, and can be used to inform the patient of sleep periods. This can be useful where the patient's regular sleeping pattern is inverted, a regular feature of CFS/ME.

7 FUTURE WORK

The next clinically relevant stage in the ASARM pro-

ject is to use the system in a formal pilot trial, with a select group of CFS/ME patients. The planned trial would be performed in two stages as follows. In stage one, an initial sample of five patients with the condition will be offered traditional CBT, but will use the ASARM system alongside the CBT and the completion of paper diaries. Qualitative responses from the use of the devices will also be captured. This stage will lead to the development of a clinical ASARM protocol which will subsequently be followed for stage two, with a further 25 patients, as well as allowing iterative refinement of the ASARM system and software. All participants will use the ASARM devices at the various stages of treatment: assessment (establishment of baseline activity level), early treatment phase and late treatment phase. Relevant clinical outcome measures will also be collected, pretreatment and post-treatment, as well as information on the patient experience of the ASARM devices.

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