

MS Life Logging

A research project on the possibilities of using wearables among people with Multiple Sclerosis



Instructions for reading

In this report, the purpose, method and results of the research project MS Life Logging will be presented. The people with Multiple Sclerosis (MS) who have participated in the project are not a representative group for all people with MS in Denmark. Among other things, it is characteristic of the participants in the project that they estimate their eHealth literacy (Table 1) highly, and that several of the participants before the start of the project had a some interest in using wearables in their everyday lives. The results in this report are therefore an expression of the use of wearables among people with MS who already have some interest in health technology as well as assess themselves as comfortable using this kind of technology. Despite this, the results of the report nevertheless paint a picture of what advantages and disadvantages a larger group of people with MS can have from the use of wearables in their everyday lives. Concepts relevant to the reading of the report are presented below in Table 1.

Table 1. Clarifications of concepts

Wearables	Portable technologies carried in the form of an accessory (e.g. as a watch). Within monitoring of health and illness, they can e.g. collect data on heart rate, sleep and physical activity.
eHealth literacy	<p>A collective term for individuals' ability to search for, access, understand and relate to health information from electronic sources and subsequently use this information to address specific health problems (1).</p> <p>In this report, participants' eHealth literacy was measured using the eHealth Literacy Questionnaire (eHLQ). This is a questionnaire based on a conceptual understanding of eHealth literacy based on 7 dimensions related to the user's own experience of competencies, motivation and systems availability (2)</p>
Empowerment	An element of health promotion that aims to give patients and other citizens the ability to act as well as control and ownership of decisions that affect their living conditions and health (3)
Patient-reported outcome (PRO)	Patient-generated data concerning the patient's health condition such as physical and mental health, symptoms, health-related quality of life and level of function (4)

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Background and aim

The spread of wearables has given people with MS new opportunities to keep track of their own health through health data collected from their everyday lives. Existing literature indicates that these new opportunities can potentially contribute positively to life and everyday life with MS (1), (2). Research among other patient groups further indicates that wearables can not only contribute positively to the individual's everyday life but can also support the dialogue between patients and health professionals (6),(7). Nevertheless, it remains uncertain how health technologies, including wearables, actually can contribute to everyday life with MS, as well as whether and how data from these technologies should be implemented in clinical work (5). In order to help fill this knowledge gap, the Danish MS Society launched the research project MS Life Logging in 2017, whose purpose was to shed light on whether and how people with MS can benefit from using wearables, as well as what potential there is in wearables in connection with research within MS. With the project, the Danish MS Society wanted to investigate whether wearables can provide greater insight into own disease and increase the degree of empowerment among people with MS, as well as whether wearable data can be used as patient-reported outcome (PRO).

To shed light on this, the project has focused on the following three tracks and research questions:

Track 1: What needs and desires do people with MS have for wearables, and can wearables give people with MS increased insight into their own disease as well as increase the degree of empowerment in the individual's everyday life?

Track 2: Do wearables have clinical relevance, and how can data collected with wearables be integrated and used in a clinical context as patient-reported information?

Track 3: Can data collected with wearables be used for research in the field of Multiple Sclerosis, or what is expected of wearable data so that it can potentially be used in research contexts in the future?

In the following, the findings from the three tracks will be briefly presented in nine headings. Subsequently, the method, as well as the results that support the individual headings, will be elaborated. In addition to this report, specific recommendations have been prepared targeted at people with MS who are considering using wearables in their everyday lives. These recommendations can be found in Appendix 1.

The project's findings in headings

Track 1

- 1.1 The needs and desires that people with MS may have for their wearable are determined, among other things, by their level of physical and cognitive function as well as by their preferred form of activity.
- 1.2 Wearables can give people with MS a greater understanding of their sleep and activity level, which in particular can make it easier for them to understand and accept perceived fatigue.
- 1.3 Wearables can make it easier for people with MS to act on and change conditions that affect their MS-related symptoms.
- 1.4 Some people with MS may need support to understand and relate to data from their wearable.

Track 2

- 2.1 Wearable data can strengthen the dialogue between people with MS and their healthcare professionals.
- 2.2 Healthcare professionals, who work with people with MS daily, are positive about wearable data, given that certain conditions are met.
- 2.3 The person with MS must present wearable data in the meeting with their healthcare professional. If data is integrated into IT systems, it must not become an additional task for healthcare professionals.

Track 3

- 3.1 In the future, larger studies will be needed if it is to be possible to definitively conclude whether data collected with wearables can be used for research within MS.
- 3.2 It is recommended that it should be investigated on a larger scale how wearable data can be used as an expression of physical and mental health among people with MS.
- 3.3 If wearables should be used in relation to future research, it is relevant to consider the ethical issues that may exist, as well as the indirect effect a wearable itself may have on human behavior and thus any research results.

Method

The results in this report are based on data from the research project MS Life Logging and were collected in the period autumn 2017 - autumn 2018. As a part of the research project, four types of wearables were selected, which were tested over three months by 61 people with MS (Annex 2). Prior to the selection of the four wearables, data were collected that could support this selection. After the participants had tested their wearable, data on experiences with the four wearables were collected (Figure 1). Qualitative as well as quantitative methods have been used to collect data. In the following section, the methodological approaches used will be briefly presented.

Figure 1. Timeline for MS Life Logging



Focus group interviews

Five focus group interviews were conducted with a total of 40 people with MS before the selection of the four wearables. The five focus group interviews focused on everyday life with MS as well as potential needs and desires associated with the use of wearables. Based on these focus group interviews four wearables were selected whose function and design were particularly suitable for people with MS (Appendix 2). In addition, data from the focus groups contributed to answering the research question in track 1.

Individual interviews

Individual interviews were conducted with 12 out of the 61 participants with MS who had tested a wearable. The participants were selected so they varied on gender, age, wearable, etc. The interviews focused on the experiences the participants had had with their wearable in their everyday life as well as in the meeting with their healthcare professionals. The findings from these interviews have contributed to the answer to the research questions in tracks 1 and 2. In addition, 11 individual interviews were conducted with various healthcare professionals (physiotherapists, nurses, neurologists and general practitioners). These interviews

addressed the healthcare professionals' thoughts on the use of wearable data in their clinical work and contributed to the selection of the four wearables as well as to the answer to the research question in track 2.

Survey

In total, three questionnaires were sent out to the participants with MS. Before the participants were given their wearable, they answered a questionnaire that dealt with background variables (gender, age, residence, etc.), previous experiences with different types of technology, as well as what the participants wanted to use their wearable for during the trial period. All 61 participants answered this questionnaire. After the trial period, based on the themes identified in the 12 individual interviews with people with MS, a questionnaire was designed that focused on the experiences the participants had had with their wearable in everyday life as well as in the meeting with their health professionals. A total of 58 participants answered this questionnaire. Finally, all 61 participants answered the eHealth Literacy Questionnaire (eHLQ) (2), which aimed to assess participants' eHealth Literacy via seven dimensions related to user competencies, motivation, and systems availability (Table 1). The results of the surveys have contributed to the answer to the research question in tracks 1 and 2.

Literature review

Existing reviews and professional assessments of various wearables were reviewed before the four wearables were selected. In addition, a systematic literature review of scientific literature regarding the validity and reliability of the selected wearables was conducted. The review of the validity and reliability literature has contributed to the answer to the research question in track 3.

Workshops

In the autumn of 2018, a workshop was held exploring the research potential of wearable data. Relevant researchers from the University of Copenhagen, the Technical University of Denmark, the Danish MS Society and the Multiple Sclerosis Hospitals participated in the workshop. Minutes were taken for the workshop, which has contributed to the report's findings in track 3.

Further description of the research project's design and method as well as characteristics of the participants in the project are available and can be provided.

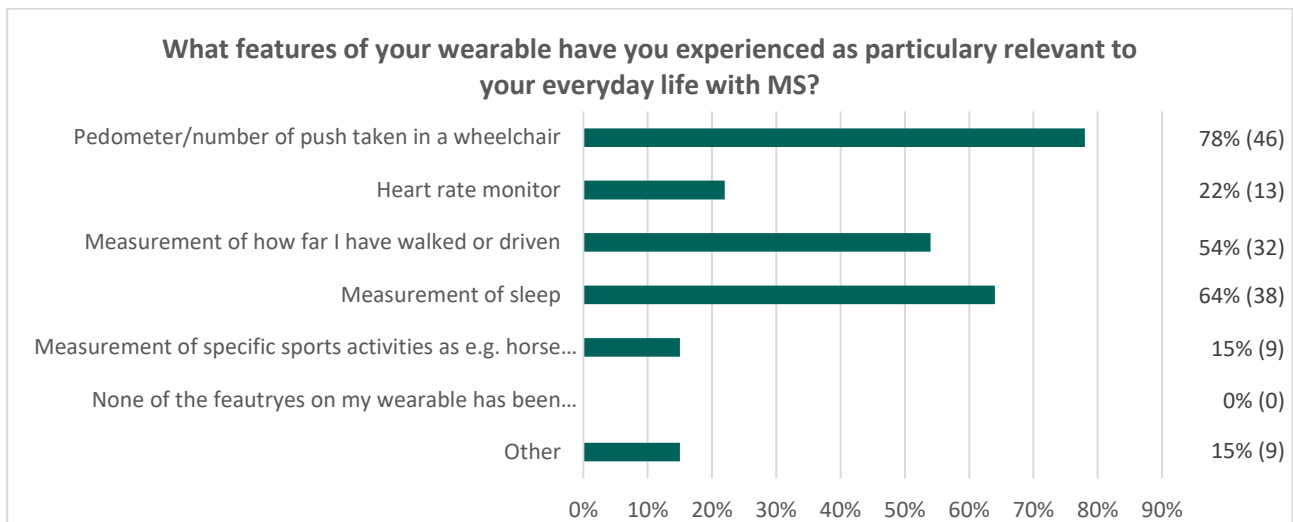
Results

Track 1

1.1 The needs and desires that people with MS may have for their wearable are determined, among other things, by their level of physical and cognitive function as well as by their preferred form of activity.

The wearables functions that the participants with MS found particularly relevant for their everyday life with MS were pedometer, sleep monitoring and measurement of distance walked or driven in a wheelchair (Table 1). In addition, heart rate monitors were assessed as relevant, especially by the participants who wanted to measure their physical activity with the physiotherapist or by other forms of sedentary training, such as weightlifting (quotation 1).

Table 1, Survey after the trial period. 58 answers



Quotation 1, Individual interview with participant with MS

” Then there is something with the watch that I found out. The watch I have had does not have a heart rate monitor. So, when I go to the physiotherapist twice a week, it cannot measure that my heart rate increase when I exercise. So, it does not see at all that I get my heart rate up and get trained what I need. It can register that you are on a cross-machine, but because there is no heart rate monitor, it cannot detect e.g. if I run on the spot or do exercises on the floor.”

In addition, the participants in the project had many different preferences for how their wearable should look, where it should sit, etc. It is therefore not possible to conclude that a particular type of wearable fits particularly well into the needs and desires that people with MS may have. However, there are certain conditions that

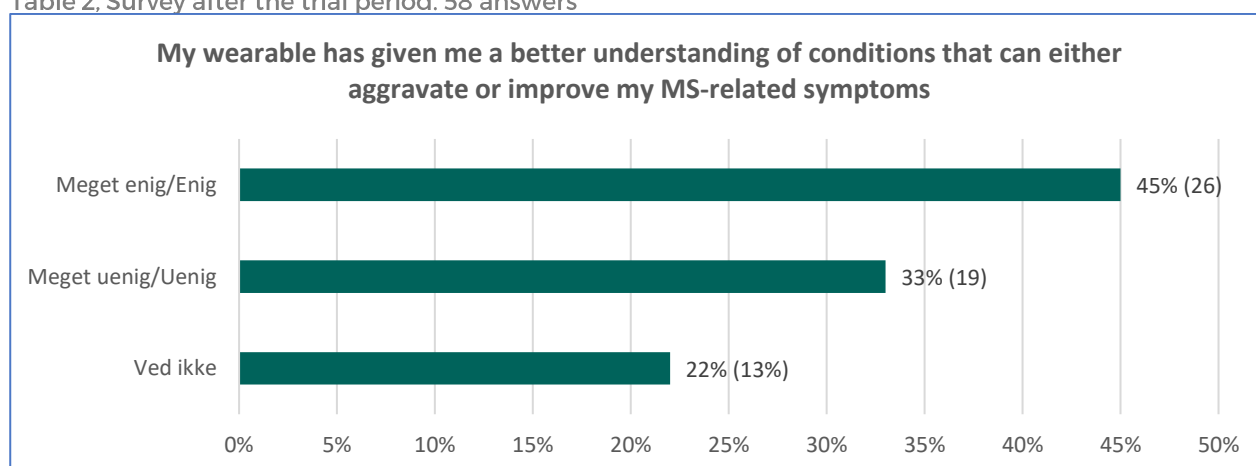
people with MS need to be aware of if they want to make use of wearables. These are presented below and can be found in more detail in Appendix 1.

- Different wearables suit different walking functions (For example, some wearables can measure activity in wheelchair users and others cannot).
- For some participants, notifications from the watch or the associated app were a help and motivation to keep themselves going. For other participants, the notifications were a stress factor that, among other things, could make it difficult to maintain concentration and attention in social situations. This was especially true for participants who reported that they were already cognitively challenged.
- Some experienced it as a defeat if, for example, they did not walk the 10,000 steps a day their wearable, by default, recommended them. Wearables where the user can set a personal goal can therefore be an advantage.
- Participants with vision problems and / or problems with tremor or sensory disturbances in fingers and hands, experienced that a too small screen on their wearable could be problematic.

1.2 Wearables can give people with MS a greater understanding of their sleep and activity level, which in particular can make it easier for them to understand and accept perceived fatigue.

Nearly half (45 %) of the participants with MS experienced that their wearable gave them a better understanding of conditions that could either worsen or improve their MS-related symptoms (Table 2).

Table 2, Survey after the trial period. 58 answers



The participants described in particular their sleep as an unknown factor, which they had gained new and greater insight with their wearables. Several participants described that the wearable data had made them aware of the connection that could exist between their sleep quality and their energy level the next day (quotation 2).

In addition, participants described that the first time they used their wearable, they were surprised that they walked further than they thought, and that this insight helped them accept the tremendous fatigue they might experience some days (quotation 3).

In total 72 % (42) of the participants reported that their wearables' measurements of sleep and / or activity levels had made it easier for them to understand why they felt more tired some days (Table 3).

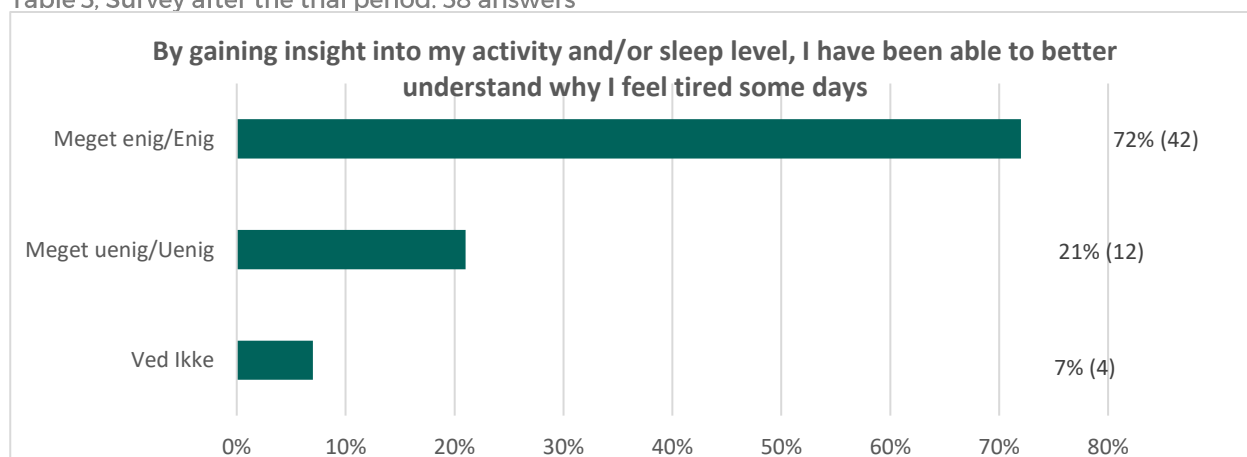
Quotation 2, Individual interview with participant with MS

” Actually, it turns out that I only sleep 9,30 hours at night as max. I pee at night, otherwise I cannot sleep and wake up several times a night. I thought it was exciting to see that I do not over-sleep ad much as you actually think [The participant thought she slept 11 hours per night]. When I got under those 9 hours at night, I needed a nap during the day because my fatigue was worse on the days when I had not gotten enough sleep at night.”

Quotation 3, Individual interview with participant with MS

” I’ve been thinking, wow I’m tired now, and then I’ve looked at it and thought, okay, I understand that. It has made it a little easier to accept that I have become tired. Because I can see that some days, I just walk a lot more without thinking about it.”

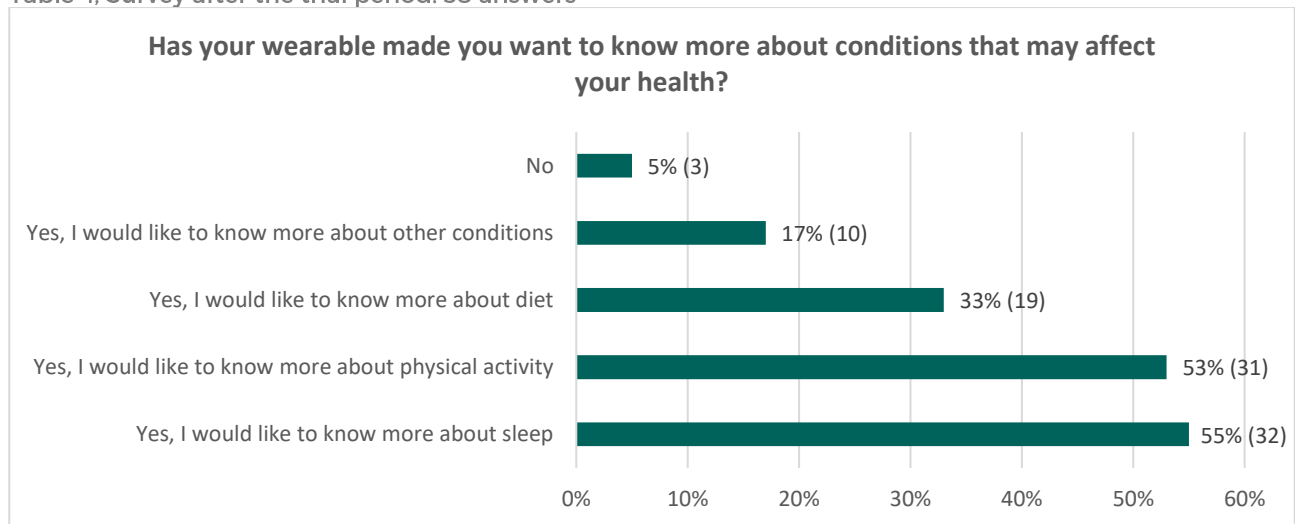
Table 3, Survey after the trial period. 58 answers



1.3 Wearables can make it easier for people with MS to act on and change conditions that affect their MS-related symptoms.

83% (56) of the participants felt that they had a greater desire to seek new knowledge about how conditions such as sleep, diet and activity could have an impact on their health (Table 4). In the individual interviews, some participants reported that they had specifically sought information so that they could change their sleep habits to get a better night's sleep (quotation 4). Half of the participants (53%) agreed that they had tried to change conditions that could have an impact on their sleep quality due to the use of their wearable (Table 5).

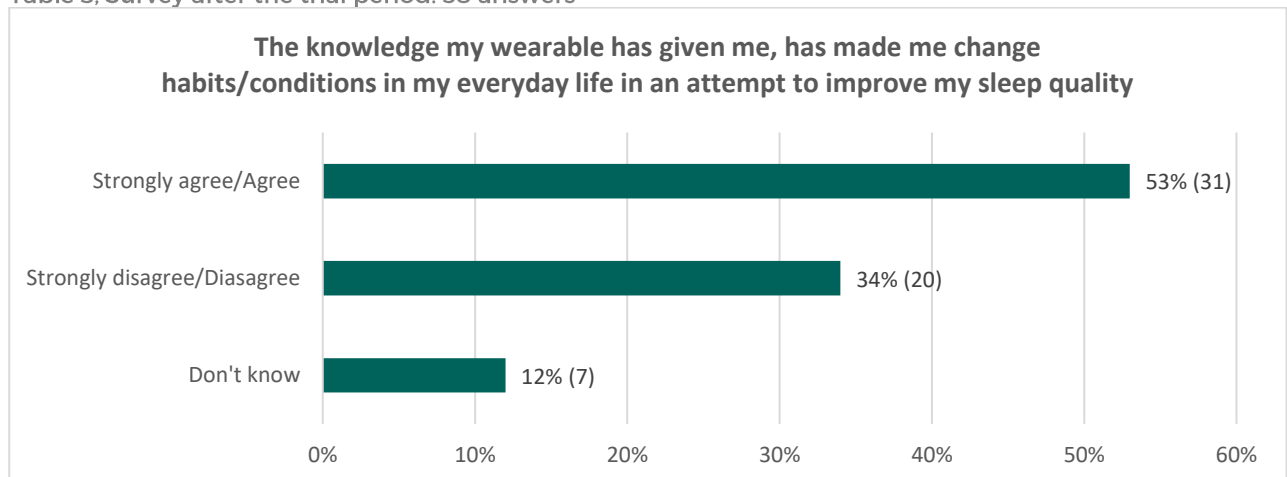
Table 4, Survey after the trial period. 58 answers



Quotation 3, Individual interview with participant with MS

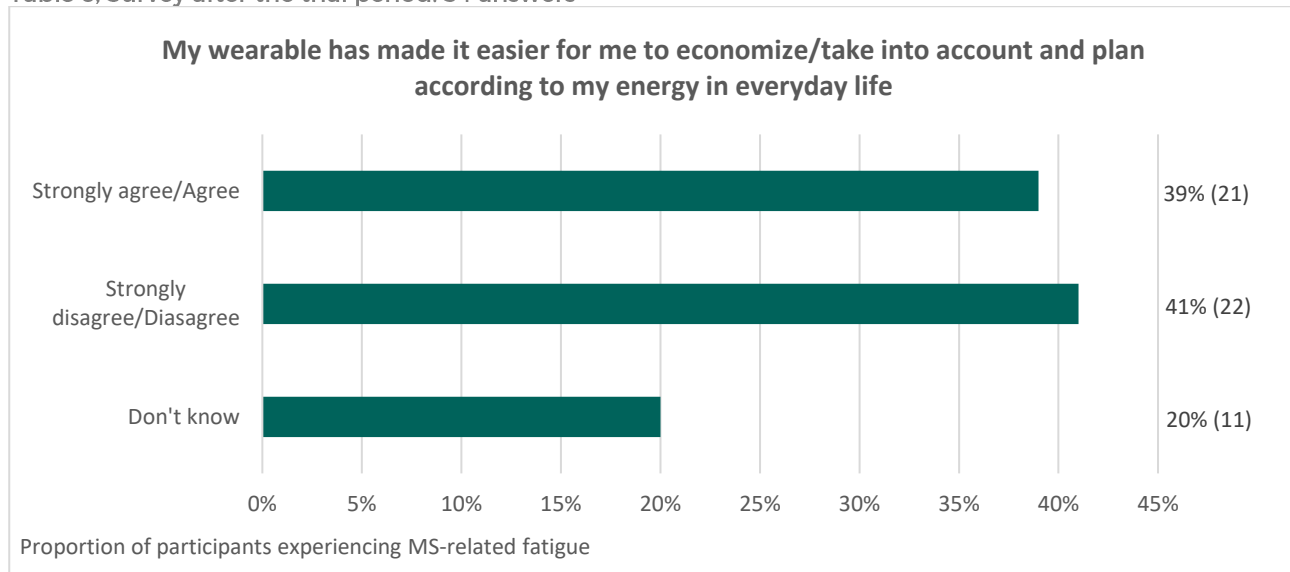
"I have been inspired to try to sleep better and have researched tips online to get into a good routine."

Table 5, Survey after the trial period. 58 answers



39% (21) of the participants who normally experienced fatigue answered that their wearable had made it easier for them to economize with their energy in everyday life (Table 6). One participant reported that her wearable allowed her to set objective limits on how much she should move as a minimum, but also how much she should move as a maximum (quotation 5).

Table 6, Survey after the trial period. 54 answers



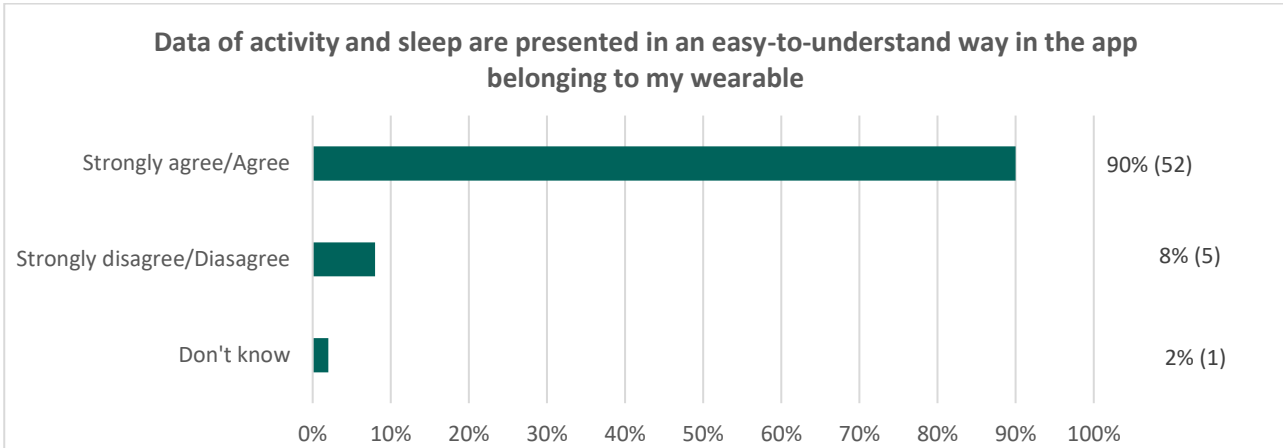
Quotation 4, Individual interview with participant with MS

” It is nice to obtain that knowledge [about activity and sleep levels]. So I can work with it and see if there is anything connected. (...) I have been thinking about my activity. I can be active, but it should not be the case that I just do too much. There must be a balance in the level of activity. When I have made around 2000 (points on her Misfit) or over 2000, then it has been too much. ”

1.4 Some people with MS may need support to understand and relate to data from their wearable.

The majority of participants (90%) thought that activity and sleep data were presented in an easy and understandable way (Table 7) and only a few participants expressed that it could be difficult to know how to act on the data their wearable presented to them (quotation 6). Still, it is a significant conclusion of the project that some participants needed support and advice if they were to successfully use wearables in their daily lives. One participant recounts, among other things, how her physiotherapist was the one who helped her discover patterns in her wearable data that she had not seen herself (quotation 7).

Table 7, Survey after the trial period. 58 answers



Quotation 5, Individual interview with participants with MS

” I have used the watch to look at my sleep, because it goes up and down a lot. And it has actually been very interesting. (...) When I look at the sleep graph, I can see that I have been awake 8 times last night and snored for 2 hours and 44 minutes. But okay, what the hell do I have to do to make it better? ”

Quotation 7, Individual interview with participants with MS

” My physiotherapist looked at my fitbit where he then said it is really strange when you have had a high activity then you do not sleep at night. I had not just noticed, but he did. It was not something I had thought about that it had a connection. That was new information.

In addition to support to understand and act on the presented wearable data, it may also be relevant to provide advice and guidance so that people with MS do not become concerned with their health as a result of the new insights they gain (quotation 8). Even though the vast majority of participants (88%) felt that data from their wearable had not made them further concerned about their health (Table 8). And that several participants in the individual interviews concluded that a disease such as MS could not possibly fill more in everyday life than it already did (quotation 9). The participants who had experienced that their wearable data had made them worried about their health scored particularly low on the domain in eHLQ that describes their experience of being ‘safe and in control’. This may indicate that it is particularly important that people who may already be prone to worry and feel out of control should be especially supported if the use of wearable is not to become an unnecessary concern for them. In addition, it is important to emphasize that the participants in this research

project, as previously mentioned, are not representative of all people with MS in Denmark, and generally value their eHealth literacy highly.

In a wider and more representative group of people with MS, it can therefore be expected that the proportion in need of support is greater.

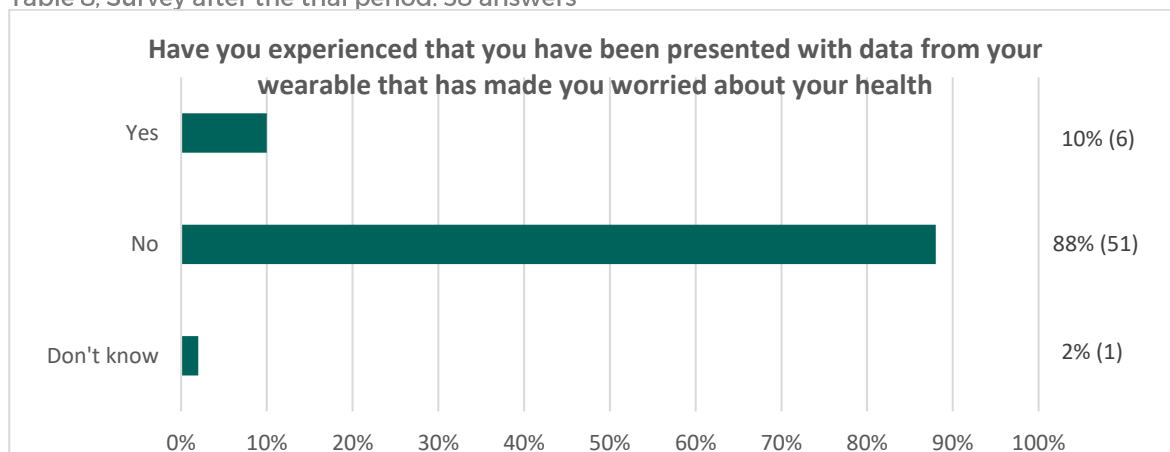
Quotation 8, Individual interview with participants with MS

I'm writing to you to hear more about fitbit's sleep data registration. I'm quite 'wow' because it turns out I sleep heavily very little. I sleep restlessly, go straight from waking state to deep sleep, and skip light and REM sleep. I have been sleeping miserably since 1995, waking up more tired than I ever feel every single morning, where one otherwise must be 'rested'. I have no idea what it is anymore ... And now that I have seen the degrees, the percentages, the rhythm of the sleep stages etc., I have become worried and think about asking a doctor with possibly request to be further investigated. Because I do not think a normal (healthy) person sleeps like I do.

Quotation 9, Individual interview with participants with MS

" [Do you find that you have become more aware of your MS, that the disease occupy more of your consciousness now?] No. No more than it did before. It already fills a lot. So the watch makes no difference. The disease takes up space from the moment you open your eyes. It's not something I forget."

Table 8, Survey after the trial period. 58 answers

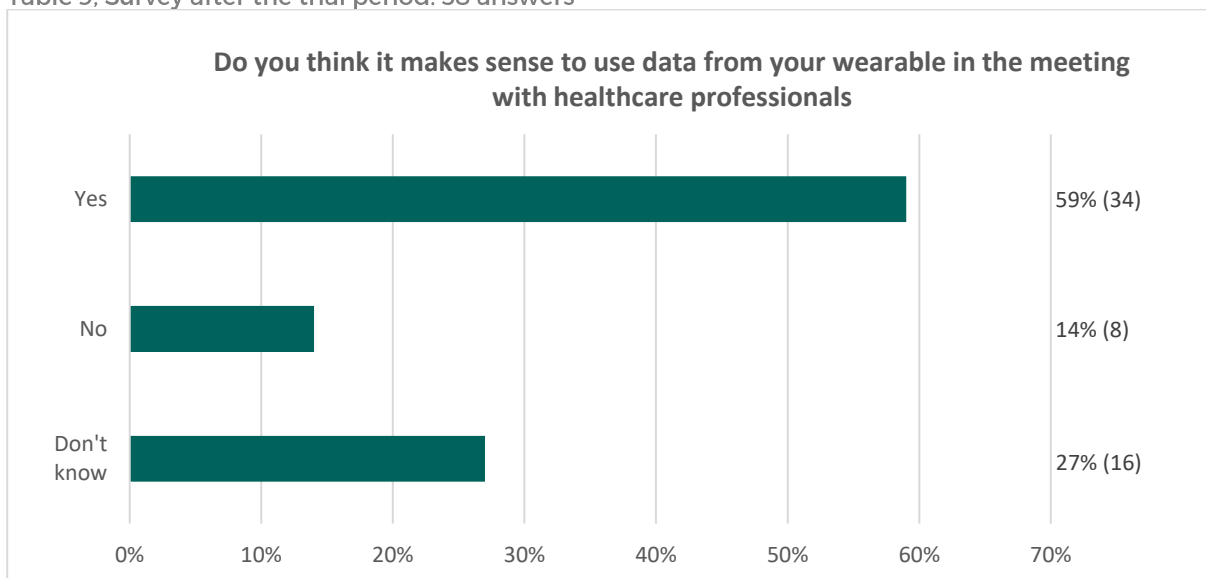


Track 2

2.1 Wearable data can strengthen the dialogue between people with MS and their healthcare professionals.

Over half (59%) of the participants thought that it would make sense for them to use data from their wearable in the meeting with healthcare professionals (Table 9). In total, 36% (21) of the participants had been in contact with a healthcare professional during the trial period and had already included their wearable data in the meeting. Especially based on experiences from the 21 participants, the following section will present when and why people with MS believe that wearable data makes sense to include in the meeting with their healthcare professionals.

Table 9. Survey after the trial period. 58 answers



62% (13) of the participants with MS who had shared their wearable data with a healthcare professional during the trial period had done so with their physiotherapist (Table 10). The fact that the majority of the participants had included their wearables in the meeting with physiotherapists may be due to the fact that it is this professional group that people with MS are most often in contact with. As the trial period lasted over three months, several of the participants did not have the opportunity to be in contact with MS clinics and therefore did not have the opportunity to share their wearable data with nurses or neurologists. In the individual interviews, it emerged that the participants believed that wearable data could be relevant to their dialogue with both physiotherapists, nurses and neurologists. It did not vary much which data the participants chose to share with the different healthcare professionals. With the physiotherapists, the participants most often shared data regarding activity level (number of steps, distance walked / driven), and with nurses, neurologists and general practitioners, it was most often sleep data that was shared (figure 2).

Table 10, Survey after the trial period. 58 answers

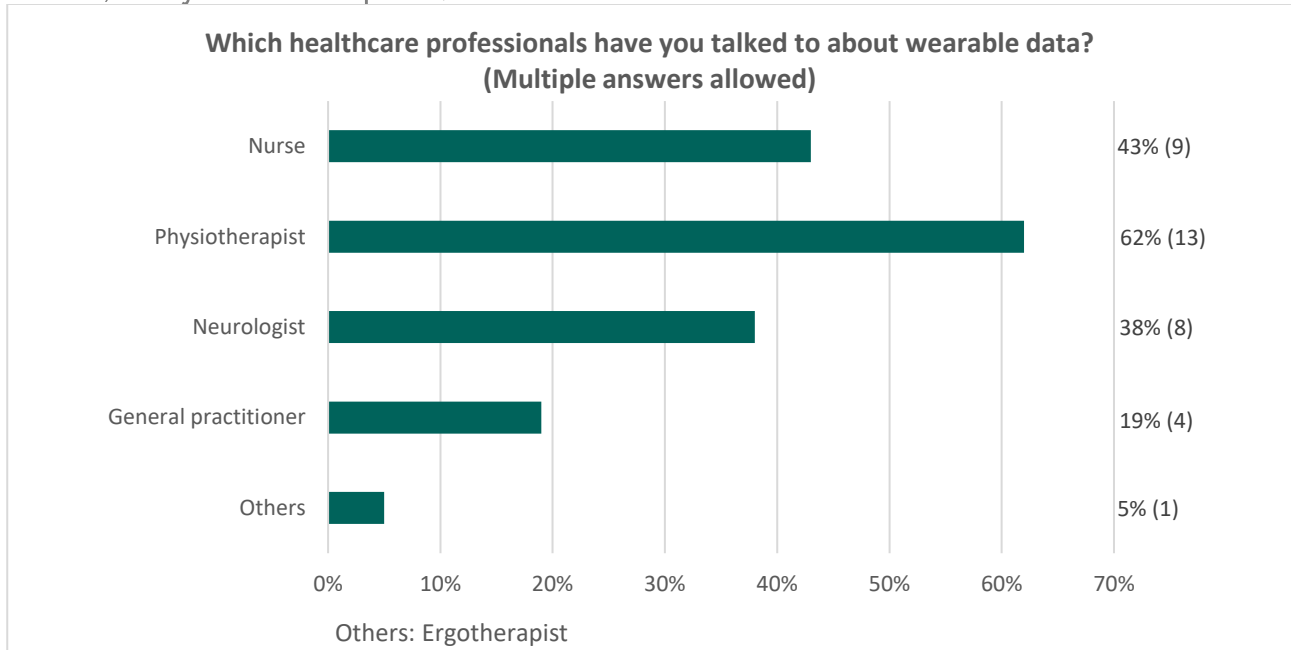


Figure 2, Survey after the trial period. 58 answers

Physiotherapist

84 % (11) shared activity data

77 % (10) shared sleep data

15 % (2) shared pulse data

Nurse

89 % (8) shared sleep data

44 % (4) shared activity data

22 % (2) shared pulse data

Neurologist

100 % (8) shared sleep data

25 % (2) shared activity data

General practitioner

75 % (3) shared sleep data

75 % (3) shared activity data

25 % (1) shared pulse data

Several of the participants explained in the individual interviews that wearable data made it easier for them to enter into a dialogue with the healthcare professionals, because they now experienced being able to answer questions they previously had to guess (quotation 10). As previously described, wearable data has given the participants with MS greater insight into previously unknown conditions such as sleep and walking distance. This meant they found that they could better answer questions such as “*How far can you go?*”, “*Have you been getting worse since the last time?*” and “*How does the new medicine works?*” (Quotation 11 & 12).

Quotation 10, Individual interview with participant with MS

” The neurologist asks if there has been anything since the last time. But it's like when something new comes along, we get used to it. So, when someone asks half a year later, I answer - I do not know. We just get used to it because that's the way it is. So, because of the diary (in the MS Life Logging app) I can now say [to the neurologist that] I have become more tired.”

Quotation 11, Individual interview with participant with MS

” The good thing is to be prepared before going to such an appointment [with healthcare professionals]. The conversation would be helped if you could give more precise answers, and this one can actually help (her Fitbit).”

Quotation 12, Individual interview with participant with MS

” I used it to measure sleep and, in that case, it worked really well. I even talked to the neurologist regarding this as I have trouble sleeping. I then changed medication to something that makes me sleep better and it could be seen clearly via the app that my sleep patterns changed. I slept 2-3 hours more and was less awake at night. This was a great help.”

Figure 3 below shows a screenshot of the sleep data that the participant from quotation 12 took as a starting point when he had to tell his neurologist if his new medication had given him a better night's sleep. The participant started on the new treatment on May 28th and stopped taking the medicine again on June 3rd (the participant stopped to test whether the medicine actually helped him).

Figur 2. Screenshot of participants with MS's sleep data.

Translation of text:

- 1: Started with new medicine for nerve pain.
- 2: Stopped with new medicine for nerve pain



2.2 Healthcare professionals, who work with people with MS daily, are positive about wearable data, given that certain conditions are met.

Most healthcare professionals who participated in the project were in favor of wearable data being included in their clinical work with people with MS. Among the 11 healthcare professionals, only 1 denied that wearable data was relevant to her work with MS patients (quotation 13). However, none of the interviewees ruled out that wearable data would be included in their clinical work in the future.

Quotation 13. Individual interview with nurse from MS clinic

"I cannot really see what I should use it for, to be completely honest, not directly."

The healthcare professionals said that they find that many of their patients are good at answering questions when they meet them in the clinic. However, for some patients it may also be too abstract to have to explain / put into words their activity, sleep, MS-related symptoms and general well-being (quotation 14). Like several of the participants with MS, the healthcare professionals also saw the potential in wearable data to make it less abstract for people with MS to engage in a dialogue with their neurologist or others. In addition, the physiotherapists also saw the possibility that wearable data can function as a tool that can be used to follow the patient's development and set objective goals that the patient can follow in connection with a training or rehabilitation process (quotation 15).

Quotation 14. Individual interview with physiotherapist

" Many of my patients have come to a level [in their disability] where I can see, it has become a habit for them to "I feel this way". So it's hard for them to see themselves whether it's gotten better or not. "

Quotation 15. Individual interview with physiotherapist

" So, you could easily do that in relation to, in terms of training you could use it to say well where am I now before I start training. What is it that I need to aim for or what do I need to do to stay level. "

Although healthcare professionals could see the potential of wearable data becoming part of their clinical work, there were also several who emphasized that certain conditions must be met if they are to acknowledge this new kind of data. For many, it was important that they can trust the data quality, and that they know that the measurements, the patients present, actually say something about the patient's activity and sleep level (quotation 16). In addition, the healthcare professionals believed that it is important that technology does not become the center of the meeting between them and the patients, and that the patient does not forget that it is

still important to “experience” and feels one’s own body (quotation 17). Finally, the healthcare professionals expressed concern that the introduction of wearable data into their clinical work would be another task in an otherwise busy day. This finding will be further described in the following section.

Quotation 16, Individual interview with physiotherapist

” At first, I think that if I were to be able to use it, then I should be absolutely sure how the validity is in relation to the measurements that the watch makes. ”

Quotation 17, Individual interview with physiotherapist

” It is also important that MS patients experience their disease physically and not only understand it through a technology, they must also remember to feel. ”

2.3 The person with MS must present wearable data in the meeting with their healthcare professional. If data is integrated into IT systems, it must not become an additional task for healthcare professionals.

Several of the healthcare professionals expressed that the patient, according to them, should be the one who “owns” data and thus the one who brings data into the clinical meeting. A physiotherapist described that, according to her, it is interesting that it is the patient herself who presents data, because it can give her insight into which conditions matter to the individual patient (quotation 18). As previously described, several of the participants with MS expressed that data collected with their wearable is a tool that can, for example, help them prepare for the meeting with their healthcare professionals (section 2.1, quotation 11). For them, wearable data is thus also something they own and even bring into the meeting with their healthcare professionals if they think it is relevant.

Quotation 18, Note from individual interview with physiotherapist

” A physiotherapist says that she thinks it works well when wearable data is presented orally from the patient even at the consultation. The reason for this is that it must be the human being and not the measurement that is at the center. How the patient itself presents and interprets data to her is also useful feedback. For example, it can reveal what motivates and drives, or vice versa inhibits the patient. ”

Among both the participants with MS and the healthcare professionals, there were some who thought that it would be optimal if data collected from wearables in patients' everyday lives were automatically collected on a database which healthcare professionals could access and follow. The participants with MS thought it would be best because then, they can avoid questions that might otherwise be too abstract for them to answer

(quotation 19). Among the healthcare professionals, a neurologist told, among other things, that data should be transferred directly to the clinics because it loses its objectivity if it is the patients themselves who present the data. However, there were several healthcare professionals who expressed that they were afraid that if wearable data were implemented in existing IT systems, then it would mean extra work for them.

Quotation 19, Individual interview with participant with MS

It could be really useful that instead of asking the patient how you sleep or how much you walk, it was perhaps more useful that they got a fitness watch on and then they used that data. Why should I sit and explain how far I have gone or how I sleep? It is much more useful to have it on the monitoring. This is already done in some cases, for example with pacemakers, where they contact the patient if they see something abnormal.”

Track 3

3.1 In the future, larger studies will be needed if it is to be possible to definitively conclude whether data collected with wearables can be used for research within MS.

At the workshop on research with wearable data, it was agreed among the participants that data collected with wearables can be used to investigate whether there is a connection between, for example, activity level and sleep quality in the individual with MS (quotation 20). At the workshop, however, it was emphasized that the correlations that can potentially be found using wearable data cannot be directly used to conclude whether high activity generally worsens or improves sleep quality among people with MS (quotation 20). This is because the causal relationship behind such a relationship is still unknown and could potentially be due to other unknown factors (confounders). Instead, large studies using wearable data can be hypothesis-generating and form the basis for further studies. In such studies, it may be further relevant to compare data collected with wearables with data from, for example, registers.

Quotation 20 Workshop with relevant researchers

” Can we find patterns that show covariance and correlations, for example between steps and sleep. This we can use, but then the interpretation lies in the causal connection with ourselves – and we can only point out causal connections for the individual. ”

3.2 It is recommended that it should be investigated on a larger scale how wearable data can be used as an expression of physical and mental health among people with MS.

If wearable data is to be used as a measure of activity and sleep among people with MS in research projects, it is important that the data generated by the individual wearables is accurate and reliable and that the data reflects

the actual activity level and sleep pattern of the user. Generally for both Apple watch, Fitbit, Misfit and Garmin wearables is that their measurements of number of steps are often underestimated compared to manually counted steps or validated accelerometers, and that the length of sleep compared to validated sleep monitors or self-reported sleep is often overestimated (8), (9), (10), (11), (12). Existing literature regarding the data quality of the wearables used is briefly presented below and appears in Appendix 3.

A review concludes that, among other things, Fitbit wearables particularly underestimate the number of steps among people with lower walking speeds (13). Another study concludes that Fitbit has low validity when it comes to measuring the activity at the physiotherapist among people with chronic diseases (14). However, based on the studies reviewed in the appendix, it is assessed that Fitbit wearables make the most accurate measurements of the number of steps (Appendix 3). A 2017 study comparing the quality of sleep measurements performed with Fitbit Flex, Misfit Shine and Garmin Vivofit concluded that Garmin Vivofit makes the most valid measurements of sleep length, but that this wearable still overestimates sleep length (8). The study finds that the average measurement for Garmin Vivofits is 44.9 minutes longer than the average measurement for a validated sleep monitor (95% LoA, -176.0; 86.3) (8). In addition, it was repeated in the literature that there was sparse knowledge about the quality of sleep measurements made with, for example, Fitbit and Garmin among people with sleep problems (15). These trends in the literature thus argue against wearable data being directly used as a measure of activity and sleep in research contexts, as the quality is still too poor or unknown among people who may have problems related to walking or sleep.

Instead of using wearable data as an expression of actual number of steps walked or number of hours slept, there may be a potential in using wearable data as an expression of self-rated sleep or activity (quotation 21). Based on what people with MS perceive as important, it may be interesting whether there is a correlation between subjective experiences and wearables objective goals (quotation 21). For example, it is interesting to investigate whether self-reported sleep quality correlates with the sleep quality that wearables can measure. If this is the case, in the future it will be possible for wearable data to be used in research contexts as a measure of sleep quality among people with MS.

Quotation 21 Workshop with relevant researchers

”Wearable data are proxies. Compare sleep data with self-reported sleep to see if it is a good or bad proxy.”

3.3 If wearbles should be used in relation to future research, it is relevant to consider the ethical issues that may exist, as well as the indirect effect a wearable itself may have on human behavior and thus any research results.

In future studies with wearables, it is important, among other things, to take into account the indirect effect it may have to give the participants a wearable. (A trial participant may be moving more than usual because their watch motivates them to do so). To avoid this, it is important to consider whether the wearables that are handed out should be blinded so that the participant cannot access their own data (quotation 22). In addition, the indirect / invisible urge to move more can be problematic if wearables are handed out to participants who are mobility impaired and therefore at risk of falling and/or injuring oneself from increased activity. It may therefore be relevant to consider whether people with greatly walking difficulties should be excluded if the risks are assessed as high.

Quotation 22 Workshop with relevant researchers

” We need to do intervention studies. For example, a patient gets the watch, and we make it clear that we do not relate to data, nor does the patient need to relate to data. Then correlations can be found without us affecting data. In order to use data for research contexts, the Danish MS Society must not set normative conditions, there must be no alarm on the watch. Do a natural history study where they cannot relate to data. You must not set discourses and be normative. There must be as little impact as possible.”

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Appendix 1 – Recommendations for you who are considering using a wearable in your everyday life

In the research project MS Life Logging, 61 people with MS have worn a wearable (activity watch) over three months. As part of the project, we have collected the participants' experiences with their wearable, and on the basis of these prepared recommendations for you who are considering acquiring a wearable. If you want to know more about the project itself and its results, you can read about it [here](#).

Before you buy your wearable

Recommendations for the watch's functions

Consider what activities you would like your wearable to measure. Would you like to measure how far you walk during a day and / or how much you sleep at night? Choose a wearable that can measure exactly what you are interested in knowing more about. Be aware that if you want to measure your sleep, then you need to sleep with your wearable. It is therefore important to choose a wearable that does not bother you during the night.

In addition, it can be an advantage to acquire a wearable with a built-in heart rate monitor. Wearables without a heart rate monitor may, for example, have difficulty measuring training with a physiotherapist, or if you practice other sports "on the spot" without moving over a distance. In addition, a heart rate monitor can mean that you experience the measurements of your sleep and activity more accurately because the watch uses your heart rate to assess how deep you are sleeping or how high your activity is.

Choose your wearable based on your walking ability.

Before investing in a wearable, consider whether you need a wearable that you can use, for example, if you use a wheelchair or walker. Not all wearables can measure activity levels (wheelchair grip or upper body movements) in people in wheelchairs or using a walker. If you use a wheelchair, it is important that your wearable has a wheelchair function (In MS Life Logging, the Apple Watch was used by the participants who were in a wheelchair). If you use a walker, you must have a wearable that you can put elsewhere on the body than on the wrist. For example, it can be on the shoe or at the waist, so that the watch can still measure your activity (In MS Life Logging, Misfit Shine was used by participants who used a walker. Be aware that there may be other makes and models).

Be aware of the functions and size of the screen when choosing your wearable

For several participants in MS Life Logging, it was important that their activity and sleep data were presented on the dial of their wearable. This meant that they could easily follow and quickly get an overview of their measurements of activity etc.

If you experience impaired vision or impaired function/sensory disturbances in your fingers, it is also important that you contemplate to the size of the screen. Try different wearables in the store, to test if you can easily read what is on the screen and press all buttons without difficulty.

A water-repellent wearable can be smart if you swim or want to take off your wearable as little as possible

Consider whether you need a wearable that is water-repellent. This is especially relevant if you do water sports or need to not take off your watch when taking a shower. This can be beneficial, for example, if you are worried that you forget to get the watch back on and thus risk missing measurements or important notifications such as medication intake or calendar appointments.

Get started using your wearable

Consider how you feel about notifications and small messages from the watch

When using wearables, it can be beneficial to be aware of whether you want to turn notifications and activity alarms on or off. Ongoing reminders of how much you need to achieve today's goals can be motivating for some and stressful and distracting for others. If you experience in advance that you are easily distracted and torn out of the context you are sitting in, messages from your wearable can be frustrating. In that case, it may be a good idea to turn off all alarms. However, if you find that you need a loving reminder to get up one more time during the day or to do a few pushes in the wheelchair, small messages from your wearable can also help with this. Try it out and remember that your wearable is there to help you. It must not become something in your everyday life that stresses you or gives you a bad conscience.

Give yourself time to find and set your own personal goals and sub-goals

It is important that you find out for yourself what your personal goal for your activity during the day or week should be. Many wearables are set by default so that one should walk 10,000 steps a day. However, this is not realistic for anyone with MS. Therefore, use the beginning (a few weeks) with your wearable to assess what your personal goal should be. Is it realistic for you to walk 3,000, 5,000, 7,000 or 10,000 steps a day? It is all crucial for the motivation that you set a goal that suits you. So, take your time to reach this.

In addition to setting a goal for how much you want to move at least, it can also be helpful to set a goal for how much you want to move at most. In the MS Life Logging project, some participants experienced that after a while with their wearable, they could see a pattern in that they became very tired, for example, when they surpassed a certain number of steps a day. In the quote below, one of the participants explains how she used the watch to economize with her energy.

” It is nice to obtain that knowledge about my activity level. So I can work with it and see if there is anything connected. (...) I have been thinking about my activity. I can be active, but it should not be the case that I just do too much. There must be a balance in the level of activity. When I have made around 2000 (points on her wearable) or over 2000, then it has been too much.”

In the MS Life Logging project, four different wearables were tested. None of the four wearables stood out in the participants' reviews as being particularly good or particularly bad. It is therefore not possible to recommend a specific brand or model. Instead, relate to the points that have been described above if you are to acquire a wearable and are in doubt as to which wearable it should be and what it should be able to do.



Appendix 2 – Wearables used in MS Life Logging

The chosen wearables

The four wearables selected for the project's trial period were the Apple Watch Series 3, Fitbit Alta HR, Garmin Vivofit and Misfit Shine. Apple Watch was chosen because it has a function for wheelchair users and, among other things, can measure activity in the form of movement with the arms in a manual wheelchair. Misfit Shine was chosen because the dial can be cut out of the watch strap and put on the user's shoes, belt or similar. This feature is particularly relevant for people with MS who often use a walker, as there is a risk that the watch will not capture all of the participant's activity if the watch is worn on the wrist. For participants who did not use a walker or wheelchair, Fitbit Alta HR and Garmin Vivofit were primarily chosen because of their simple display on the watch strap in addition to the included app. Of the 61 participants included in the project's trial period, 32 received a Garmin Vivofit, 22 received a Fitbit Alta HR, four received a Misfit Shine and four received an Apple Watch 3.



Appendix 3 – Validity and reliability studies

Measurement of number of steps



Wearable label and model	Settings (range of measurements)	Golden Standard	N (Characteristics)	Walking pace (km/h)	Test-retest reliability ICC (CI 95%)	Correlation coefficient (95% CI)	Mean difference \pm SE ³ (Lower or upper estimates)	95 % limits of Agreement (Lower ; Upper)	MAPE (95 % limits of agreement, Lower ; Upper)	Article number in the bibliography
Apple										
-	Treadmill (6 minutes)	Manually counted steps	71	Combined	-	0,96 ^{b*}	1.07 (U) ³	-82,6 ; 84,8.	-	(10)
2	Treadmill (400 m)	Manually counted steps	44	Walking	-	-	-	-	0.43	(18)
			44	Running	-	-	-	0.06		
Sport	Treadmill (10 minutes)	Manually counted steps	30	3,2	0.38*	0.57 ^{c*} (0.27;0.77)	18 (U) \pm 9 ³	-74 ; 111	1.9	(11)
			29	4,8	0.48*	0.93 ^{c*} (0.86;0.97)	0 (-) \pm 3 ³	-36 ; 35	0.0	
			30	6,4	0.80*	0.91 ^{c*} (0.82;0.95)	6 (U) \pm 5 ³	-45 ; 56	0.5	
Garmin										
Vivosmart	Treadmill (10 minutes)	Manually counted steps	31	3,2	0.79*	0.95 ^{c*} (0.78;0.98)	10 (U) \pm 2 ³	-15 ; 34	1.0	(11)
			31	4,8	0.51*	0.57 ^{c*} (0.27;0.77)	- 2 (O) \pm 7 ³	-81 ; 77	-0.2	
			31	6,4	0.72*	0.10 ^c (- 0.14;0.36)	114 (U) \pm 27 ³	- 177 ; 404	9.0	
Misfit										
Flash	Treadmill (10 minutes)	Manually counted steps	25	3,2	0.48*	0.06 ^c (- 0.21;0.38)	144 (U) \pm 45 ³	-298 ; 586	15.2	(11)
			25	4,8	0.03	0.26 ^c (- 0.10;0.58)	60 (U) \pm 31 ³	-241 ; 362	5.4	
			28	6,4	0.14	0.11 ^c (- 0.24;0.45)	75 (U) \pm 47 ³	-409 ; 560	6.0	
Shine	Free living (48 hours)	Tri-axial accelerometer	21	-	-	0.94 ^{e-} 0.90 ^{c-}	-1054 (U) ³	-4395 ; 2288	-	(16)
Shine	Free living (7,5 hours)	ActivePAL	56	-	0.86 (0.73 ; 0.93)		- 46 ³	-743 ; 657		(17)

Wearable label and model	Settings (range of measurements)	Golden Standard	N (Characteristics)	Walking pace (km/h)	Test-retest reliability ICC (CI 95 %)	Correlation coefficient (95% CI)	Mean difference \pm SE ³ (Lower or upper estimates)	95 % limits of Agreement (Lower ; Upper)	MAPE (95 % limits of agreement, Lower ; Upper)	Article number in the bibliography
Fitbit										
Charge HR	2 min walk test	Manually counted steps	31 (mean age 74,2)	Combined	0.96 (0.91 ; 0.98)	0.95 ^c (0.92;0.97)	-6 (U) \pm 1.17 ³	(Bland-Altman Plot exist) ^a	-	(12)
Charge HR	Treadmill (10 minutes)		31	3,2	0.73*	0.62 ^c * (0.35;0.80)	-7 (O) \pm 9 ³	-101 ; 87	-0.7	(11)
			31	4,8	0.70*	0.20 ^c (-0.14;0.50)	22 (U) \pm 13 ³	-118 ; 162	2.0	
			31	6,4	0.65*	0.31 ^c * (-0.05;0.60)	65 (U) \pm 14 ³	-83 ; 214	5.2	
One	Free living (48 hours)	Tri-axial accelerometers/multi-sensor devices	21	-	-	0.99 ^e -0.95 ^c	464(O) ³	-813 ; 1980	-	(16)
One	Protocol with everyday activities such as vacuuming ect. Performed in a controlled environment (19 – 33 minutes)	Manually counted steps	46 (e.g. osteoporosis or COPD)	-	-	-0.15 ^e -	-29.7 (U) \pm 22.87 ³	-367.8 ; 308.6	-	(14)
Flex	2 min walk test	Manually counted steps	31	Combined	0.79 (0.57 ; 0.90)	0.77 ^c (0.57;0.88)	-29 (U) \pm 0.92 ³	(Bland-Altman Plot exist) ^a	-	(12)



Wearable label and model	Settings (range of measurements)	Golden Standard	N (Characteristics)	Walking pace (km/h)	Test-retest reliability ICC (CI 95 %)	Correlation coefficient (95% CI)	Mean difference \pm SE ³ (Lower or upper estimates)	95 % limits of Agreement (Lower ; Upper)	MAPE (95 % limits of agreement, Lower ; Upper)	Article number in the bibliography
Flex	Treadmill (4 minutes)	Manually counted steps	27	8	0.994 (0.986 ; 0.998)	0.997* ^c	0 (-) \pm 3.08 ³	-	0 (0 ; 1)	(20)
			26	10	0.999 (0.997 ; 1.00)	0.994* ^c	0 (-) \pm 3.92 ³	-	1 (-1 ; 1)	
			24	12	0.986 (0.961 ; 0.995)	0.829* ^c	-7 (U) \pm 6.12 ³	-	1 (-5 ; 7)	
			10	14	0.996 (0.976 ; 0.999)	0.999* ^c	1 (O) \pm 6.64 ³	-	0 (0 ; 1)	
			5	16	0.896 (0.083 ; 0.993)	0.409 ^e	-11 (U) \pm 12.07 ³	-	4 (-11 ; 19)	

*P <0,05, ^a Estimate not stated in the article or possible to read from the plot, ^b Lin's concordance correlation, ^c Pearsons (r) , MAPE: Mean absolut procent error

Measurement of sleep



Wearable label and model	Settings	Golden Standard	N (Characteristics)	Test-retest reliability ICC (CI 95 %)	Pearsons correlation	Mean difference ± SE (lower or upper estimates)	95 % limits of Agreement of Bland-Altman plots (Lower ; Upper)	Article number in the bibliography
Garmin								
Vivofit	Free living (1 night)	Sensewear	24	-	0.80*	-44.9 (O)	-176.0 ; 86.3	(8)
Misfit								
Shine	Free living (1 night)	Sensewear	21	-	0.82 ⁻	44.2 (O)	-46.9 ; 135.3	(16)
Shine	Free living (1 night)	Polysomnography	40	-	0.76	Bland-Altman plot exist (O) ^a	Bland-Altman plot exist ^a	(19)
Shine	Free living (1 night)	Sensewear	24	-	0.59*	-98.0 (O) ^a	-281.3 ; 85.2	(8)
Fitbit								
One	Free living (1 night)	Sensewear	21	-	0.92 ⁻	15.9 (O)	-51.0 ; 82.9	(16)
Flex	Free living (1 night)	Polysomnography	40	-	0.97	Bland-Altman plot exist (-) ^a	Bland-Altman plot exist ^a	(19)
Flex (normal)	Sleep laboratory (1 night)	Polysomnography	21 (with depression)	-	-	46.0 (O)	Bland-Altman plot exist ^a	(9)
Flex (sensitive)	Sleep laboratory (1 night)	Polysomnography	21 (with depression)	-	-	-86.3 (U)	Bland-Altman plot exist ^a	(9)
-	Sleep laboratory (1 night)	Polysomnography	24	-	-	Bland-Altman plot exist (O) ^a	67,1 (O) ^a	(15)
Flex	Free living (1 night)	Self-reported (Time they have been lying down)	22	-	0.68 *	20.7 (U)	-96.9 ; 138.2	(8)
Charge HR	Free living (1 night)	Self-reported (Time they have been lying down)	14	-	0.58*	0.0 (-)	-158.4 ; 158.4	(8)

*P <0.05, ^a Estimate not stated in the article or possible to read from the plot