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INTELLIGENT MONITORING TOOL

D.T2.1.4 - Testing intelligent monitoring tool

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1. Introduction

The original goal of this deliverable was to present and test the monitoring tool with project partners and target groups during the targeted meetings at the local level (6 meetings). Besides, we planned to gather feedback from future users. Although we planned face-to-face meetings, due to the COVID-19 situation, we performed the majority of meetings online. The feedback from patients was gathered via online questionnaires.

We have split the process into the following parts:

1. Consulting the functionality and the overall concept of the monitoring tool with neurologists (target group) and with project partners (to integrate good practices).
2. Testing the pilot version of the tool.
3. Gathering feedback from neurologists.
4. Gathering feedback from patients.

In total we held 4 online meetings with project partners/target groups, one on-site meeting during the testing phase and 12 meetings with patients (in a form of email communication and questioning via online questionnaires).

2. Involved project partners and target groups

In the frame of this deliverable, we involve the following project partners and target groups:

- Project partners:
  - LEPIDA SCPA, Italy (Teresa Gallelli, teresa.gallelli@lepida.it)
  - Local Health Authority of Bologna, Italy (Cristina Malvi, c.malvi@ausl.bologna.it)
- Target groups:
  - First department of neurology, St. Anne's University Hospital in Brno, Czech Republic (MD Lenka Krajcovicova, Ph.D., lenka.krajcovicova@fnusa.cz; MD Ivona Moravkova, ivona.moravkova@fnusa.cz)
  - Applied Neuroscience Research Group, Central European Institute of Technology, Czech Republic (Mgr. Lubos Brabenec, PhD, lubos.brabenec@ceitec.muni.cz)
  - 12 subjects (patients) in a high risk of developing Lewy body diseases

3. Presentation to project partners

In order to perform an efficient transfer of good practice, we held an online meeting with project partners on April 21, 2020 (Skype). During this meeting, a team of the Brno University of Technology presented their idea of the intelligent monitoring tool with a focus on the remote assessment of sleep disorders (see the presentation in attachment). Consequently, we held a discussion where the project partners provided feedback on this concept and formulated advice. The feedback and advice could be summarised in the following list:

- Previous accuracy of sensors was not acceptable
- Limited life-time of battery and complications during convincing people to use the devices

- Interpretation of measured data was complicated
- Must be noted, that the technology was approximately in 2012 and technology of wearable devices and artificial intelligence has progressed significantly

4. Presentation to the target group

Next, the concept was presented to neurologists from the St. Anne's University Hospital in Brno on May 6, 2020 (Skype). During this meeting, we presented the use case from a neurologist point of view. After this, we received the following feedback from MD Lenka Krajcovicova, PhD:

- The remote sleep analysis should be accompanied by sleep diaries, where the patients input approximate information about the consumption of coffee, alcoholic drinks, resting during a day, wake-ups during the night, etc.
- The actigraphy must be easy to use even for people with mild cognitive impairment or people with Parkinson's disease. Ideally, the device should have no buttons, no screens, the patients will just wear it (i.e. they will not be actively interacting with the device).
- The remote monitoring system should include normative data so that new measures could be compared to norms (in terms of several important features).
- The system should be able to export a protocol about measurement in *.xlsx or *.pdf formats.
- It should be possible to export measured parameters into *.xlsx so that it could be processed in statistical analysis software.
- It would be good to combine the results with scores of the REM Sleep Behavior Disorder Screening Questionnaire (RBDSQ).

Finally, MD Lenka Krajcovicova, PhD and MD Ivona Moravkova expressed interest in the system and agreed to participate on a pilot (testing) phase, where several patients in risk of having Lewy body diseases will be involved. It was planned to conduct this phase in cooperation with neurologists from the Central European Institute of Technology as well.

5. Testing phase and feedback from future users

The testing phase began on June 9, 2020 at the Central European Institute of Technology. On this date, we had an on-site meeting with MD Ivona Moravkova and Mgr. Lubos Brabenec, PhD. We provided the neurologists with 10 actigraphs, printed sleep diaries, and printed instructions for patients. Next, we installed the acquisition part of the system to their laptops. We trained the neurologists to set up the actigraphs, to charge them and to download data.

Since this day the neurologists are continuously acquiring data from patients of the St. Anne's University Hospital in Brno and the Central European Institute of Technology. The patients are asked to wear the actigraph for 7 days, more specifically, to wear it during sleep. In addition, they are asked to fill in the sleep diaries. After these 7 days, the patients bring the actigraph back to the neurologists and the data are analysed.

Up to November 12, we have enrolled 23 patients from the Czech Republic. Although the testing phase has finished at the end of October, we continue in the acquisition of new data (to further improve the system and to evaluate it).

6. Feedback from future users and its analysis

During the testing/development phase, we mostly concentrated on two points of view:

1. Patients' – opinion about digital innovations in the field of medical care and health, user experience with the actigraph, acceptability of the technology
2. Neurologists' – user experience with the monitoring system

In both groups, we obtained feedback in a form of questionnaires or letters.

6.1. Feedback from patients

Initially, we planned to get feedback from the patients based on face-to-face meetings, nevertheless, since their mean age is greater than 60 years, they are the risk group in terms of COVID-19. Therefore, we decided to get their feedback utilising online questionnaires.

In the beginning, we asked 9 patients (5 females, 4 males; age 66.44 ± 6.02 years) to fill in the survey on Opinion about digital innovations in the field of medical care and health [1]. A translation of this survey was presented in the deliverable D.T2.1.3 – Design of platform. The survey was distributed via email. Link to the survey: https://forms.gle/SsQKbxhwv9agf5b8A The answers in this survey were used to design the system in a way that it will be easily acceptable and adoptable by elderly as they are in general not that used to modern wearable technologies and if they do not feel comfortable, safe, and they do not believe in the technologies, they are less likely to end up using it.

The answers are anonymised and summarised here: https://docs.google.com/forms/d/1htERzZtkOrIITb0aB7iJJg_UbQu503aZ2BfVjZl0XsY/viewanalytics Since the answers are in Czech and some of the graphs are too complex to be included as an image (the interactive summary under the link is more suitable) we summarise the most important findings in the following list:

1. Most of the participants think that science and technological innovation will have a positive impact on medical care and health.
2. Most of the participants think that technological innovations such as health-apps, wearable devices, and telemedicine services have and will have an impact on medical care and health. Two participants think online social networks will have no impact in this field (in the next 3 years).
3. Almost all participants (some replied: I don't know) think that health-apps and wearables are useful to be engaged in one's own health, to improve patient-doctor communication, and to understand one's own health condition. 6 participants additionally think they are useful to reduce costs of healthcare (2 are against, 1 is not sure).
4. 7 patients already use an informative app (e.g. to search for information about health or disease), 1 uses a monitoring app (to control the disease and symptoms through sensors or external devices), 4 use a self-check app (to check symptoms), 1 uses a services app (to schedule visits/exams or view a medical report), 1 uses a blood pressure wearable (to check heart rate and blood pressure), and 1 uses a sleep wearable (to check rhythm and quality of sleep).
5. Regarding the obstacles in using health-apps and wearable devices, 3 respondents think there are technical obstacles (for example not having a suitable device), then 2 respondents think there is no personal motivation, little faith in the usefulness of data recorded, low trust in confidentiality and privacy of data, low trust in accuracy and reliability of data recorded, and lack of examples of uses for medical assistance.

6. Regarding the question on which health-apps and wearable devices might the developers focus to give more useful tools to improve medical assistance and health, all patients consistently replied the developers should focus on monitoring apps (to control the disease and symptoms through sensors or external devices), blood pressure wearables, glycemia wearables, and sleep wearables. Concerning the rest of the technology, we haven't observed a clear consensus.
7. Regarding the negative aspects related to a constant adoption of health-apps and/or wearable devices, 4 participants think there is a risk of dependency and no privacy, 6 participants think there is a risk of excessive control of one's own health and increasing medicalisation, 2 participants think there is a risk of compromising patient-doctor communication.

To sum up, generally, the responses support our goal to develop an app, that could be used for sleep monitoring (see point 6 above), and that could have a positive impact on patients' quality of life. Almost all participants believe the new technology can have a positive impact on medical care and health. Majority of participants already use some health apps, at least to get information about a disease or a symptom. Some of the participants already use wearables. On the other hand, 6 participants think there is a risk of excessive control of one's own health and increasing medicalisation, in other words, they think the new technology can bring some negative impacts as well. Some expressed concerns regarding security and privacy issues. These issues were thus carefully addressed in our system. Next, some participants think there could be an issue with the so-called drop-off effect, i.e. patients can lose motivation to use a technology longitudinally. We believe that one way how to mitigate this limitation is to provide patients with some visualisations and reports regarding their health state.

After questioning the patients in the first survey, we selected 12 (out of 23; 6 females, 6 males; age 65.58 ± 8.86 years) who finished the testing study (i.e. they were wearing the actigraph for 7 nights) and sent them an email asking to fill in the simplified version of the Service User Technology Acceptability Questionnaire (link: https://forms.gle/8iPxZ1LzkuyisnX66). The original version could be found in [2]. The simplified questionnaire is reported below:

Service User Technology Acceptability Questionnaire (simplified)

1. The kit I received has interfered with my everyday routine.

○	○	○	○	○	○
Strongly agree	Moderately agree	Mildly agree	Mildly disagree	Moderately disagree	Strongly disagree

2. The kit I received has invaded my privacy.

○	○	○	○	○	○
Strongly agree	Moderately agree	Mildly agree	Mildly disagree	Moderately disagree	Strongly disagree

3. The kit has been explained to me sufficiently.

○	○	○	○	○	○
Strongly agree	Moderately agree	Mildly agree	Mildly disagree	Moderately disagree	Strongly disagree

4. The kit has made me feel uncomfortable, e.g. physically or emotionally.

○	○	○	○	○	○
Strongly agree	Moderately agree	Mildly agree	Mildly disagree	Moderately disagree	Strongly disagree

5. I am concerned about the level of expertise of the individuals who monitor my status via the kit.

○	○	○	○	○	○
Strongly agree	Moderately agree	Mildly agree	Mildly disagree	Moderately disagree	Strongly disagree

6. The kit makes me worried about the confidentiality of the private information being exchanged through it.

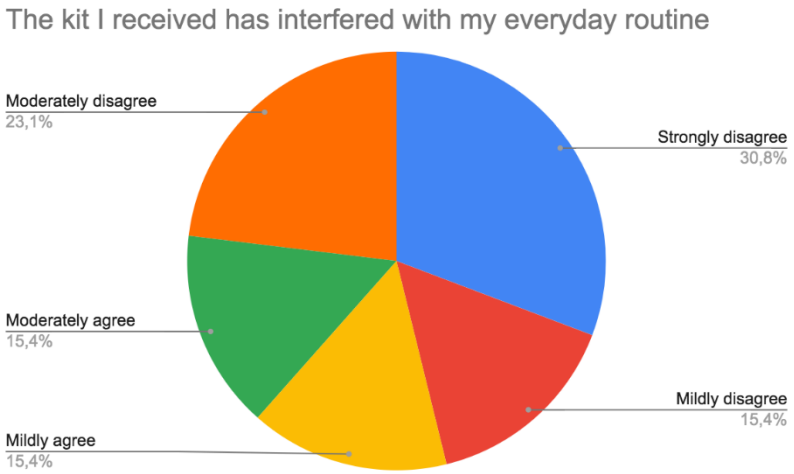
○	○	○	○	○	○
Strongly agree	Moderately agree	Mildly agree	Mildly disagree	Moderately disagree	Strongly disagree

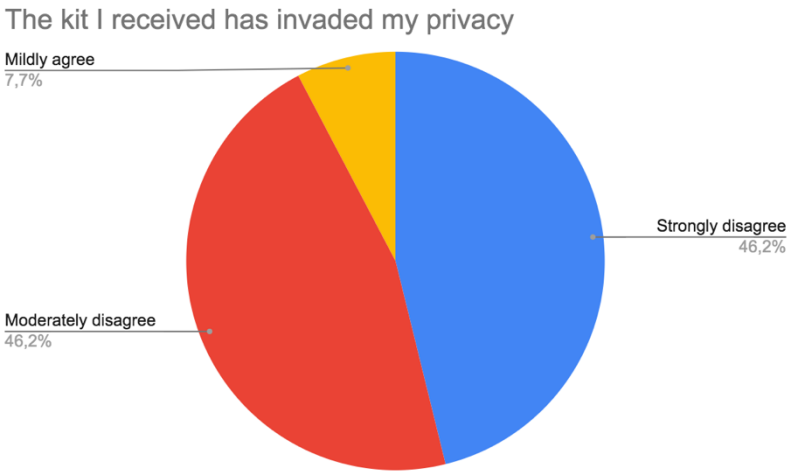
7. The kit allows the people looking after me, to better monitor me and my condition.

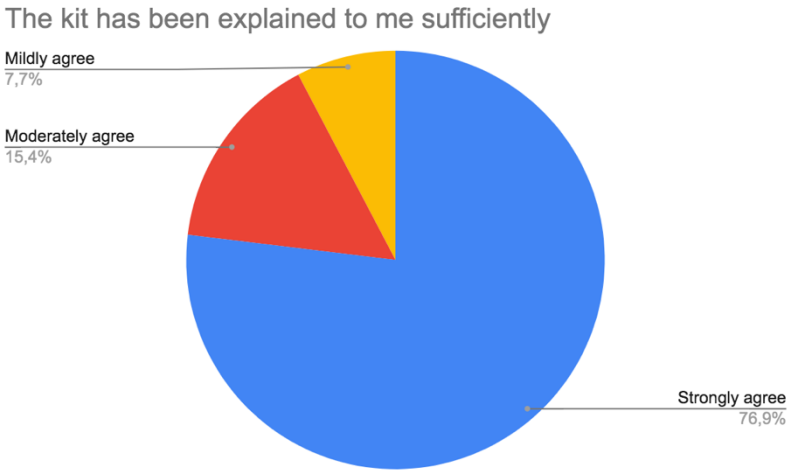
○	○	○	○	○	○
Strongly agree	Moderately agree	Mildly agree	Mildly disagree	Moderately disagree	Strongly disagree

8. Is there anything more you would like to tell us? Do you have any ideas on improving the technology?

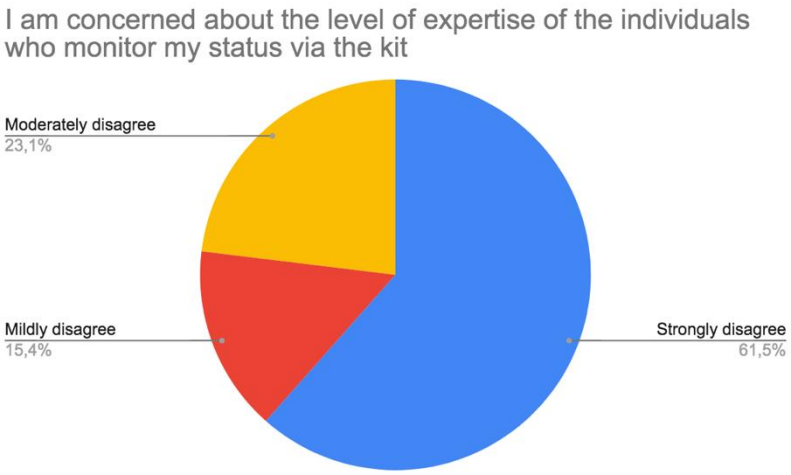
The responses are summarised in the following charts (the interactive charts in Czech are available here: https://docs.google.com/forms/d/1fvuK0q2xa9V22oOL2tv5KELrdV9QlLnVPrsPw83MfMs/viewanalytics).

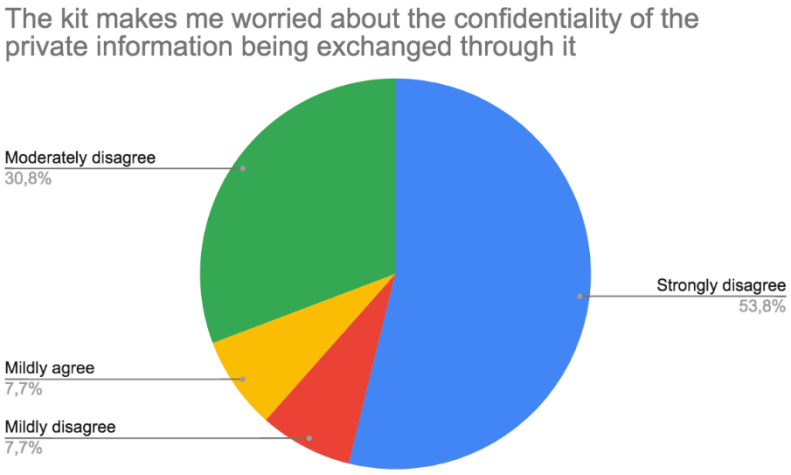


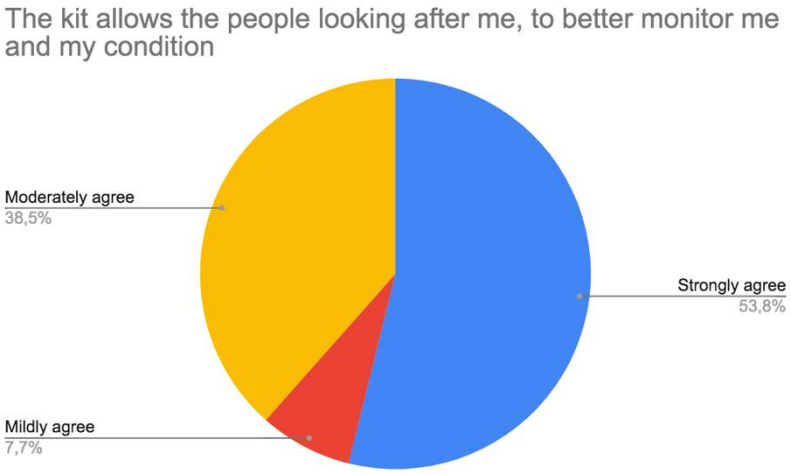

The kit I received has invaded my privacy
Mildly agree
7,7%
Strongly disagree
46,2%
Moderately disagree
46,2%


The kit has been explained to me sufficiently
Mildly agree
7,7%
Moderately agree
15,4%
Strongly agree
76,9%


The kit has made me feel uncomfortable, e.g. physically or emotionally
Mildly agree
15,4%
Strongly disagree
30,8%
Mildly disagree
7,7%
Moderately disagree
46,2%







To summarise this survey, 30 % of the respondents reported that the actigraph at least partially interfered with their everyday routine. Just 1 participant reported that technology invaded her/his privacy. All participants reported that the technology was sufficiently explained to them. 2 participants (15 %) reported that the actigraph made them uncomfortable. None of the respondents had worries about the expertise of

people managing the system and analysis of data. 1 participant mildly agrees she/he has worries about the confidentiality of the private information being exchanged through the actigraph. All participants agree the technology help neurologist to better monitor them (or their symptoms).

To sum the testing phase up, although 30 % of the patients reported that the actigraph at least partially interfered with their everyday routine, just 15 % responded it made them uncomfortable. Moreover, these two patients have not expressed that the level of uncomfortability is high. Generally, based on the above-mentioned findings, we believe the proposed technology/system is well acceptable for the patients. In addition, most of them trust the experts dealing with data and all of them think they can benefit from the system.

6.2. Feedback from neurologists

On November 18th, we had an online meeting (Google Meet) with Mgr. Lubos Brabenec, PhD from the Central European Institute of Technology. In the frame of this meeting, we were asking him about the system, his experience using it, some identified advantages and disadvantages, and some proposals for further enhancement. We followed the same agenda on November 19 during an online meeting with MD Ivona Moravkova from the St. Anne's University Hospital in Brno. More specifically, we asked these questions (a summary of the answers is given in bold):

- Is the system easy to use? Have you identified anything that could make the system more user-friendly?
  The system is easy to use and except for one patient, there were no issues in explaining the use of the actigraph. Also, the neurologists understood how to work with the system. Generally, the neurologists had nothing to add.
- Does it help you to better and objectively quantify sleep disorders?
  The system helps neurologists to objectively quantify sleep (e.g. to calculate number interruptions in sleep). Nevertheless, they would welcome to include a comparison with normative values (e.g. using z-scores or boxplots) and diagnosis of specific disorders, e.g. the rapid eye movement (REM) sleep behaviour disorder. In other words, the system should enable to include norms and mathematical models that would be able to diagnose a specific disease with some probability. Next, it would be good to extend the actigraphy by scores from questionnaires.
- Is there anything you would like to add/improve?
  The results (i.e. the calculated parameters and information about diagnosis) should be possible to export to an Excel sheet so that they can consequently process the results by some external statistical software. It would be good to have the possibility to monitor changes in sleep in time (i.e. over several sessions).
- Do you have any worries regarding security and privacy issues?
  Although during the development of the system, we paid significant attention to security, the neurologists decided to make the profiles of patients anonymised (i.e. instead of a name, date of birth, ID, etc., they just use codes), which makes the data processing even more secured. Next, they require to see, what changes (e.g. data upload, change, analysis) were performed by whom (based on user accounts).
- What is the feedback you get from the patients when returning the actigraph?
  Except for one patient (who had issues with filling the sleep diary), the feedback was always positive.

In addition, we asked them to summarise their experience and feedback into a letter. Both letters are attached to this deliverable.

7. Conclusion

In the frame of this deliverable, we focused on meetings with stakeholders involved in the development of the intelligent monitoring tool. In the beginning, we had a meeting with project partners to discuss the idea of the system, to get their experiences and to better transfer their good practice. Also, we had a meeting with the target group to better identify expectations and needs. Next, we installed the system into two centres in the Czech Republic, and we began enrolment of patients and testing of the system. After the testing phase, we gathered feedback from experts performing data acquisition and analysis, and from patients, who were the subjects using the acquisition part of the system.

Based on online meetings, online questionnaires and letters, we got valuable feedback that helped us to further improve the system so that it could be better integrated into clinical practice and used in more significant cohorts.

8. References

[1] Mosconi, P., Radrezza, S., Lettieri, E., & Santoro, E. (2019). Use of health apps and wearable devices: survey among italian associations for patient advocacy. JMIR mHealth and uHealth, 7(1), e10242.

[2] Dario, C., Luisotto, E., Dal Pozzo, E., Mancin, S., Aletras, V., Newman, S., ... & Saccavini, C. (2016). Assessment of patients' perception of telemedicine services using the service user technology acceptability questionnaire. International journal of integrated care, 16(2).