You are receiving this newsletter because you participated in the RADAR-CNS project, which covers three different health conditions. This is the final newsletter of the project providing an update of results, alongside articles featuring the work of our Patient Advisory Board and interviews with some of the members of the project. You can also visit our website: www.radar-cns.org

Thank you for being one of the participants that took part in the RADAR-CNS project across eight study sites in the UK, Denmark, the Netherlands, Spain, Germany and Italy.

As the project comes to an end the number of studies published in scientific journals has been increasing and this newsletter contains an update on the most recent research in our results section alongside a summary of events where they have been presented. Our Patient Advisory Board (PAB) have been co-authors on many of these studies and their insight has been invaluable to making our research meaningful and impactful.

Since 2016, our understanding of this developing area has grown and we have learnt so much from the participants who have so generously given their time and commitment to the project.

Thank you for being a central part of our work. As we continue to publish results we will make them available on our website so they can continue to inform others exploring this exciting field. Your participation has helped us build a much better understanding of how Remote Measurement Technologies (RMTs) can hopefully improve treatments and quality of life, now and for future generations.

In this final bumper edition of RADAR-CNS newsletter we will focus on some of the work from our PAB, including a feature on research exploring what people with epilepsy and multiple sclerosis prioritise in health data collected from smartphones. We also have an article on the data analysis workshops that we ran last year with the PAB and an interview with Ann Little, member of the Board. The newsletter also features research investigating the translation of RMTs into clinical work, including illustrations of what this might look like in the future.

Matthew Hotopf, King’s College London
Vaibhav Narayan, Janssen Pharmaceutica NV
RADAR-CNS Project Co-Leads
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How a series of workshops have helped ensure our data remains connected to real life | PAGE 3

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For many people data analysis can seem somewhat of a black box. Data goes in and results come out, but we don't really know what happens inside. To shine a light on the process of analysis and ensure the results of the RADAR-CNS project are anchored in real-world value, the Patient Involvement team held a series of data analysis workshops during 2021 and 2022; bringing together researchers and members of the Patient Advisory Board (PAB).

The workshops had a variety of themes, spanning from data visualisation to the treatment of missing data and identifying factors that are important across all three conditions such as quality of life and wellbeing.

“The views of our patient advisors have been invaluable for shaping our analyses,” said Dr Sara Simblett, researcher from the Patient Involvement team. “While sometimes challenging to hear, their thoughts have meant that we are using our data in a more meaningful way, which we hope is bringing us closer to a better understanding of health conditions such as depression, MS and epilepsy.”

Feedback from the workshops
The experience of both researchers and members of the PAB was very positive. Those from the PAB felt the workshops provided an in-depth view and valued the insight into the breadth of the project's research and the three conditions studied.

“The workshops have definitely matched our requests around our involvement within the project's data analysis,” said PAB member Simon Lees. “They have shown us more detail about the research analysis in a more expanded way. Personally I have also found it really useful to learn about all three conditions because they can be relevant to each other, for example how depression affects people with all three conditions.”
One area where the PAB’s insight was particularly valued was in the identification of factors that could influence trends in the data. For example, the level of baseline fitness when recording physical measures such as heart rate, and the accent or native language when analysing speech.

“It’s been great that we can give our perspectives from the view of people with these conditions,” said PAB member Janice Weyer. “And I think it’s been really useful for us to look at some of the factors that can affect the results, particularly for a condition like MS which can vary massively with factors such as relapse, weather and time of the year. It’s been good to be able to discuss those factors and have them recognised.”

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Janice Weyer, PAB member

Personalised approaches and implementation

The feedback provided by the PAB in these workshops has validated the general approach taken by our researchers in terms of the design of measuring patient experience over time and confirmed that using data to model predictions is a valuable approach to pick up early warning signs.

The workshops also raised important questions about the possibility to have approaches that could provide more personalised predictions and potentially look at sub-groups within the conditions as a first step to identify different clusters of experience.

Exchanges of insight

The workshops enabled valuable insight on the limitations of the research. Researchers always have to make certain decisions about what to measure, how to measure it and where and when to measure. Although aware of the impact of these decisions it can be very helpful for researchers to have an external and informed viewpoint to question how these decisions could affect analysis.

Members of the PAB highlighted the debate around measuring in controlled conditions compared to more real-life settings. More specifically there was feedback on the focus on lower limb function in the MS study and whether the order of speech tasks should be alternated rather than always placing the scripted task before free speech.

With these series of opportunities for researchers and members of the PAB to exchange views, the hope is that the process of data analysis in RADAR-CNS has become more grounded in the real-world experience of the three conditions. The data analysis workshops have allowed researchers to not only explain the complexities and structure of their analyses but to take a step back and consider influences they may not have thought about without these discussions.
The vital role of patient input in research on Remote Measurement Technology for epilepsy

Ann Little has been Executive Director at the International Bureau for Epilepsy until the end of 2021. She has also been a member of the RADAR-CNS Patient Advisory Board (PAB) since 2017. Here she discusses the importance of the patient voice in research and the potential that RMT holds for those with epilepsy.

In recent years, the role of the patient in decisions taken on their care and treatment has begun to change for the better. The International Bureau for Epilepsy (IBE) – a network organization of patient associations in 109 countries worldwide – has welcomed the call from the World Health Organization, the European Union and social and political scientists, for a redistribution of power between patients, experts and policy makers in decision-making issues that concern patients. We see this as a huge step in the right direction.

Involvement of the IBE in the PAB has been extremely valuable in providing the opportunity not only to be engaged in this important research project but, also, to witness the significant contribution that patients who are part of the project have brought to the table. And it has also allowed us to share this knowledge with our members.
While I have represented the IBE on the PAB, with a focus on epilepsy, there is also interest in the other conditions. This is particularly the case with depression, which, for a high percentage of people with epilepsy, further negatively affects their quality of life.

It has been said that the stigma associated with epilepsy is often more difficult to deal with than the epilepsy itself. Not knowing when a seizure will happen can lead to reduced self-confidence, depression, or self-isolation. This lack of control can be devastating. For people with epilepsy, the ability to detect the possibility of a seizure before it happens is welcomed. The promise that RADAR-CNS brings of alerting a decline in health status is therefore of major significance and seeing the project unroll has been extremely exciting.

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Ann Little, PAB member

Being part of the project has allowed me to witness at first hand the exciting possibilities that this technology brings. The option of remote assessment through the use of a wearable device is now even more important as COVID-19 brings changes to how we live, not only as we battle the pandemic but, also, in the possibilities it has identified for remote medical care in the future.

It has been a real privilege to be part of the incredible journey that started at the first meeting in Brescia, Italy in 2017 and to witness the efforts of the highly skilled scientific team and contributions of the dedicated patients in driving the project forward with incredible determination. The future presents untold possibilities – here’s to more exciting times!
A new multi-national study has shown that data detected by Bluetooth sensors can approximate behaviours and social indicators that are associated with depression.

The study found a number of significant associations between Bluetooth measurements and the severity of depressive symptoms. Over the two weeks when symptoms of depression worsened, there was a change in one or more of the Bluetooth features. Yuezhou Zhang from King's College London, who led the study said: “We demonstrated that the nearby Bluetooth device count data collected by mobile phones have the potential to reflect changes in individuals' behaviours and what is going on in their life and this is concurrent with the changes in their depressive state.”
DATA FROM WEARABLES AND OTHER DEVICES INFORMS THE CLINICAL CARE OF PEOPLE WITH EPILEPSY, MS OR DEPRESSION

Our researchers at University of Nottingham have conducted a large-scale survey of more than 1000 clinicians to learn about current use of smartphones and wearable technologies in healthcare practice. The findings showed that over 50 per cent of clinicians used smartphones in their clinical practice, and over three quarters reported that patients in their care use wearables or smartphones for healthcare purposes. Most of the respondents (54 per cent) said that the data from their patients’ technologies informed the decisions they made about patients’ care. First author on the paper, Dr Jake Andrews from the University of Nottingham, said: “The findings from this survey show just how beneficial Remote Measurement Technologies could be in helping healthcare teams to better support patients with MS, epilepsy or depression.”

FITBIT MEASURES OF HEART RATE COULD IDENTIFY COVID-19 INFECTION

A new machine learning method has been developed by RADAR-CNS researchers to recognise people with COVID-19 from heart rate data provided by wearable physical fitness monitors. Machine learning is an approach that uses algorithms or learning rules to find patterns in large amounts of data. Results showed that this machine learning approach was able to effectively identify those with COVID-19 and its performance was better than other standard deep learning methods. First author on the study Shuo Liu, from University of Augsburg said: “We were surprised by how impressive these results were, demonstrating how heart rate data could be used to detect COVID-19 and potentially other diseases.”

PEOPLE WITH SEVERE DEPRESSION EXPERIENCE CHANGES IN SLEEP PATTERNS DURING COVID-19 LOCKDOWN

The impact of the COVID-19 lockdown on those with Major Depressive Disorder was investigated with data from the RADAR-CNS project. The study found no evidence that depressive symptoms or self-esteem changed between pre-, during- and post-lockdown periods. Results did show that average sleep duration (in minutes) decreased significantly coming out of the lockdown period. First author on the study Dr Daniel Leightley from King's College London said: “The results of this work enhance our understanding of the impact of lockdown for those with major depression by monitoring through Remote Measurement Technologies.”
POTENTIAL FOR WEARABLE DEVICES TO DETECT CONVULSIVE SEIZURES IN EPILEPSY

Researchers have used a machine learning approach on data collected with wearable devices to detect the presence of convulsive seizures in people with epilepsy. Lead researcher, Sebastian Böttcher from University Medical Centre Freiburg, said: “We hope that our comprehensive and open description of the methodology will lead to more researchers using this kind of wearable data to develop even better seizure detection systems.”

RELATIONSHIP BETWEEN MAJOR DEPRESSION SYMPTOM SEVERITY AND FITBIT DERIVED MEASURES OF SLEEP

A new study has devised and extracted sleep features from data collected using a wearable device and analysed their associations with severity of depressive symptoms severity. The team identified 14 sleep features that were associated with depression severity including time spent awake, insomnia, time of going to sleep and hypersomnia. Yuezhou Zhang from King’s College London, who was first author on the paper said: “We demonstrated that several derived sleep features extracted from consumer wearable devices (such as the Fitbit) show potential for the remote measurement of sleep as indicators of depression in real-world settings.”

SPENDING MORE TIME AT HOME IS LINKED TO MORE SEVERE SYMPTOMS IN PEOPLE WITH DEPRESSION

Using geolocation data obtained from smartphones and wearables, RADAR-CNS researchers have determined the amount of time people with major depressive disorder spent at home and showed that individuals who spent more time at home reported more severe symptoms. Further analyses revealed that those who were older and more severely affected by depression spent more time at home and the association between time spent at home and symptom severity was stronger on weekdays compared to weekends. Joint first author on the study, Dr Petroula Laiou from King’s College London said: “Future work will investigate whether changes in home stay can be used to predict relapses in MDD, which could ultimately provide an important approach to monitor severity of symptoms in a continuous and informative way.”

“We demonstrated that several derived sleep features extracted from consumer wearable devices (such as the Fitbit) show potential for the remote measurement of sleep as indicators of depression in real-world settings.”

Yuezhou Zhang, King’s College London
What might RMT look like in future clinical practice?

Researchers from RADAR-CNS have been working on developing ‘use cases’ or descriptions to portray how the RADAR-CNS remote measurement technology system might be implemented in clinical practice in the future. Creating these ‘use cases’ involved different approaches to understand how patients are currently cared for and how this might change with the introduction of RMT.

To begin with, researchers looked at how care was currently managed for each of the three conditions (epilepsy, MS and depression) by looking at government and health organisation guidance about the three conditions online.

Next, through a series of studies, researchers invited clinicians, patients and researchers - both inside and outside the RADAR-CNS consortium - to share their views on how care would have to change if RMTs were introduced. This provided insight into what difficulties there might be and how these could be overcome. It also helped researchers to understand realistic hopes from patients, clinicians and other researchers about the benefits the RADAR-CNS system might offer.
Based on the findings from these studies, researchers worked with clinicians inside the RADAR consortium to come up with ‘use cases’, or descriptions about how the RMT system could be applied in practice. This allowed researchers to think through various implications of their use, and to consider how to conduct future research to test whether these uses of technology are effective and affordable.

Below are three examples of the use cases, one from each condition, summarised in diagrams. Thirteen use cases were developed in total and the three featured here were among those recognised by clinicians as showing greatest promise, with strong potential to benefit patients and healthcare services, if further testing shows good evidence that they work in practice.

**Depression - Self management**

Patient uses RMT to actively and passively collect data on symptoms of depression. RMT provides both visual and auditory alerts to encourage patients to engage in activities known to help with the symptoms they are showing.

**Epilepsy - Seizure counting**

RMT is used to collect a more accurate record of seizures than is currently possible. This record is shared with the clinical team via the electronic patient record.

**Multiple Sclerosis - Detecting silent progression**

1. The patient uses their RMT and smartphone at home to collect active and passive data. The patient can review their own data and use this to evidence changes they have noticed.

2. Data are sent to the clinical team in real-time. Progression of MS is detected from RMT data, even where progression of the disease cannot be detected by standard clinical measures. Improvements in patient condition are also detected.

3. Relevant treatments and therapies are provided/monitored sooner, as fine changes in the condition can be detected, rather than waiting until an attack. The app provides information about the daily practices that support positive change in MS (e.g., sleep, diet, exercise) and provides encouragement to the patient to implement these strategies.
Katie White is a research assistant in the Department of Psychological Medicine at King’s College London. She has conducted and managed participant recruitment for the Major Depressive Disorder branch of the RADAR-CNS study in London, England.

“Meeting and working with the participants has been the most enjoyable part of my work on the project. Each person that takes part in the study makes a commitment to remotely collecting data about their condition over the length of the project, and it has been my job to make sure that they can do this with maximum ease and comfort. I have learnt so much about individual experiences of depression, how people understand and engage with technologies in healthcare and the benefits that remote symptom monitoring might hold for the future of mental health treatment.

“RADAR-CNS is one of the largest remote health measurement studies in Europe and has a wealth of applications for research and clinical practice. In the depression branch, we are seeking to understand whether the remotely collected data can be predictive of depressive relapse. If successful, this work will lead to explorations of how wearables can be used to complement clinical practice and self-management. Certainly from anecdotal experience of chatting to participants, this is an exciting and highly anticipated prospect.”

Sebastian Böttcher is a member of the Epilepsy team. He is a PhD student at the Freiburg Epilepsy Center, part of the Department of Neurosurgery at the University of Freiburg – Medical Center in Germany. He has been coordinating the technical and clinical aspects of the epilepsy study in Freiburg and working towards the analysis of the data collected during the study.

“My main focus is the analysis of wearable data that we collect during our in-hospital and ambulatory studies, where patients wear a wrist-band device for extended periods of time that collects data like movement activity, heart rate, or electrodermal activity. With the help of this data, we want to assess if it is possible to detect epileptic seizures without the use of a video-EEG system. While these systems are the gold standard in epilepsy diagnosis and research, they are only feasible for short-term in-hospital use. If wearables could be used to build a robust seizure detection system even for less severe focal seizures, it would help in creating automated and accurate seizure diaries. These diaries are needed on an individual level to build proper treatment plans, or on a larger scale to develop new anti-epileptic drugs.

“I see RADAR-CNS as very pioneering and forward-looking for the field of wearable devices, while also exploring tangible benefits to society and medicine.”
Choosing what’s important in health data from mobile phone technologies

We make choices about our mobile phone technology everyday to fit with our consumption of information, how we take pictures and videos and other aspects of our lifestyle. But what if we were choosing our mobile phone on the basis of the data it provides on our mental and physical health for research and healthcare purposes? What would we consider important if that were the case?

Remote Measurement Technologies (RMTs) have the potential to change the face of healthcare. Not only do they provide an objective means of monitoring symptoms, but they can collect large amounts of data continuously. As the clinical potential of mobile health data becomes more apparent, researchers from RADAR-CNS have started to look at what people consider important in data and how it can best help them manage their condition.
“There always tends to be a need to balance costs against rewards when deciding about the use of mobile technologies,” explained Patient Involvement researcher Dr Sara Simblett from King’s College London. “The rationale behind this study was to analyse these trade-offs to help provide a more sophisticated understanding of which factors most influence engagement amongst patients. The hope is that this will enable us to develop technology that is more acceptable to people with neurological conditions such as MS and epilepsy which will ultimately provide more value to these patients in terms of research findings and their application to healthcare.”

**USING HEALTH ECONOMICS TO EXAMINE PATIENT PREFERENCES**

To better understand how people prioritise different features of data, researchers from the RADAR-CNS project conducted discrete choice experiments (DCEs) with patients with epilepsy and MS. This approach involved participants making choices between different scenarios to assess which characteristics about data and its collection are considered important.

To identify which characteristics to investigate, a shortlist of 15 was presented to members of the PAB who identified four important attributes: detection, privacy, having clear benefits to users and scope for support.

**DATA CHARACTERISTICS IDENTIFIED AS IMPORTANT**

- Accuracy of detection
- Privacy
- Benefit to users
- Scope for Clinical Support

Board member Sarah Thorpe has epilepsy and advised on which attributes to include in the research. “With my seizures – I don’t always know whether I’ve experienced one or not,” she explained. “For me I really like the idea of RMTs because they can back you up and give you an idea of what’s going on, even when you aren’t aware. For this reason I definitely agree that accuracy of data is important …I want to know that the technology will be collecting data that would give me a better idea of my seizures.”

The research assessed the importance of these four characteristics by giving them three possible levels of value - high, moderate and low - and generating scenarios of different combinations of values on each characteristic. These were presented to 141 people with a diagnosis of MS and 175 with epilepsy to select their preferred technology.
ACCURACY AND PRIVACY OF HEALTH DATA ARE TOP PRIORITIES

The study found that participants valued accuracy in data above all other attributes with privacy of data coming second. When asked to make compromises between levels of privacy, clinical support, accuracy, and benefit to the user it was discovered that people were willing to trade some accuracy for greater privacy but were less influenced by the other factors.

Receiving clinician support based on the data came last in the list of priorities. “People didn’t feel that the clinical support was as important if the other requirements were met,” commented Dr Simblett. “Our study showed that if they trusted that the device would keep their data private and that the data were accurate they were willing to take on some of the management themselves.”

The preferences expressed by people with MS and epilepsy will be valuable to factor into the design of mobile health technologies in the future. Firstly to give people what they want from data and secondly to optimise engagement with the RMTs. Studies like this can also help to identify possible knowledge gaps around new technologies that need to be addressed to improve engagement.

Raluca Nica - a psychologist who heads the Romanian League for Mental Health and is a charity representative on the PAB – said: “I think that the future of healthcare will incorporate technology more and more. We have to be really attentive to the confidentiality and security of the systems and, as part of this, I believe education in the use of RMTs in healthcare is central to bring about a mind shift to engage with and trust the technology so it can bring the optimum benefit. Future generations will have had technology embedded in their lives from an early age but there is still a need for research such as this study to inform what we should tell people about the use of RMTs in healthcare.”

“I definitely agree that accuracy of data is important...I want to know that the technology will be collecting data that would give me a better idea of my seizures.”

Sarah Thorpe, Patient Advisory Board member
Highlights of recent RADAR-CNS presentations, events and prizes

NEW FINDINGS FROM THE RADAR-CNS PRESENTED AT EUROPEAN-WIDE PUBLIC EVENT

The team investigating Major Depressive Disorder (MDD) returned to the European Researchers’ Night in 2021 to present new findings on the use of wearables and mobile phones to track and predict depression.

Gemma Riquelme, from Institute de Recerca Sant Joan de Deu spoke to an audience about the use of remote technology to monitor possible indicators of depression. Gemma also discussed findings on the experience of participants in Spain. The EU-funded event aims to connect researchers with the public and show the impact of research on our day to day lives.

FIRST RADAR-CNS PAPER ON ACCEPTABILITY OF SPEECH RECORDING PRESENTED AT MAJOR SPEECH CONFERENCE

A study into how comfortable people with Major Depressive Disorder felt about completing two different speech tasks on a smartphone app was presented at the Interspeech Conference 2021 by first author Dr Jude Dineley from King’s College London. The study showed that participants were more comfortable completing a task that involved reading a script than a task that involved free speech and that individuals with more severe depression felt less comfortable recording their speech.

RADAR CNS EPILEPSY TEAM RECEIVES THE HARALD FEY PRIZE

The Michael Foundation have awarded the 2021 Harald Fey Prize to Dr Elisa Bruno, Sebastian Böttcher, Andrea Biondi and Nino Epitashvili, who lead the epilepsy study. The team received the prize for their research looking at the potential of wearable devices to identify and characterise life-threatening seizures in patients who are at risk of sudden unexpected deaths in epilepsy (SUDEP). Their paper found that accelerometers from wearable devices can indicate post-ictal immobility, the lack of motion following a seizure, which has been associated with SUDEP in patients known to be at high risk.

• This newsletter appears in German, English, Spanish, Italian, Dutch and Danish. It is available on the website.
• You can also find more information about the project on our website: www.radar-cns.org
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