

HERMES project and EpilepsyNL: preliminary findings from the joint workshop

On June 17, 2023 on the premises of the Auditorium van Radiotherapie of the University Medical Center Utrecht, on the behalf of the HERMES project, **DEN Institute organized a workshop to engage stakeholders in the reflection about barriers and obstacles but also wishes and hopes about the future of the research to cure epilepsy.** The event has been organized in the framework of the annual event organized from the **Dutch association EpilepsyNL**, and also thanks to the collaboration of the **HERMES project partner, the Radboud Universiteit**. The workshop was open to all people interested in the topic, but was attended mainly from patients and caregivers that attended the annual event of the EpilepsyNL.

The event started with a presentation about the innovation proposed by the Hermes project explaining the concept of regenerative medicine using AI. Then, the participants were invited to join a focus group discussion organized in different sessions.

The methodology and the analysis

The audience, composed of 21 people, was divided in three groups to perform facilitated focus groups. All the groups were composed by people with high familiarity with the disease, being patients or caregivers. Each group had a moderator trained for the workshop attending on the behalf of the organizers, namely from the HERMES project or EpilepsyNL. All the moderators had access to the same set of questions prepared in advance before the event. However, each moderator managed the discussion focusing on the points that were more relevant for the group. The questions have been prepared to allow HERMES's researcher to understand how patients and caregivers perceive the framework proposed by HERMES in terms of skepticism, openness and reflect together on how to ensure that patients will feel safer and more comfortable with the future of the research and the technological advancement for the cure of epilepsy. Data were collected recording the conversations, these have been then transcribed. Transcription have been analysed¹ and aggregated performing thematic analysis. This last step allowed to aggregate results from the three different tables, selecting more recurring topics of discussions and select main conclusions and recommendations. Full results will be accessible on the HERMES Project in a dedicated publication "D9.2. Ethical framework around enhanced regenerative medicine".

The main results

Even if discussions were running in parallel and independently, it recurred several times that from one hand the innovation proposed by HERMES is interesting and potentially exciting. In particular, it emerges that the worst is the situation of the patient, the higher is the readiness to explore new treatments. Most of the comments and reflections were about the need to better understand how the technology would work, specifically in reference to the Artificial Intelligence (AI) chip to be implanted in the brain. In fact, while some of the topics mentioned during the HERMES presentation like organoid, and brain cells from stem cells were not seen as a problem or as a difficult issue, most of the conversations focused on the concerns of the patients regarding the use of AI in the brain. The main concerns expressed by the patients are related to the fact that the implant operation could be too invasive and irreversible, highlighting the fear that it could be manipulated from the outside, being hacked, collecting data or exposed to errors in coding and programming. The resistances seem to lower when it is discussed the opportunity to remove or switch off the chip once it has reached the final goal to avoid seizures.

In addition to the need to be better informed and prepared on the specific functionalities of the innovation, some general skepticism and more general worries emerged in the use of AI for the cure of the disease. Participants were less prompt to welcome such an innovation due to its connection to AI and its negative connotation: often AI has been connected to science fiction. On the other hand, when discussing the chip as an implant, like a pacemaker, people feel more comfortable and open to a possible adoption. While talking about the need to communicate such an innovation to the general public, participants stressed that they would omit something related to AI to avoid being misunderstood.

¹ Recording has been possible after had received the informed consent and explicit permission from the participants. However, participation was anonymously and from the data gathered it is not possible to retrieve the name of the participants.

In collaboration with:

Epilepsi**NL**
Epilepsie verstoort levens

Radboud University



To learn more about the workshop: info@den-institute.org

To learn more on the project: info@hermes-fet.eu

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In terms of trust in science and technology, participants were confident in the research development. However, they also shared a caution attitude to be opened to new solutions. Most of the participants, clearly, need to check information on trusted sources (e.g. scientific publications, hospitals or associations specialized in the disease) and the majority stated that the big part of the acceptance of a new treatment pass through the surgeon and the hospital that is taking care of the patient. So, there are two level of discussion to be mentioned. First, the patient always needs to make informed and autonomous decision to accept or not a specific treatment. This decision is based on knowledge collected by the patient in accordance with what is suggested by the surgeon. Secondly, accepting a new solution takes time: what can be very scary today will not be any more in 5 years. This is why all the groups stressed the importance of sharing knowledge and working on the increased awareness of what could become a regular procedure in 5-10 years, to let people familiarize and normalize the topic, increasing openness and acceptability. This should be done also to start preparing people to participate in trials in the next years, avoiding being too scary when the trials will be finally possible on the humans.

To encourage this process, the role of researchers and scientists should be to foster research and dissemination of the results. In the meantime, there is the need to let people talk openly about the problem, while also sharing testimonial and personal experiences. The role of other stakeholders, as policy makers and regulators, is also crucial to improve the awareness of the topic. Of course, it emerged clearly that the final decision to be undergone to an AI implant depends on the success and documentation of human trials.

The main recommendations

According to the findings, it seems that **people with well knowledge of the disease can detect very clearly which are their concerns and the potential issues opened by a new framework**, as the one proposed by HERMES. However, it should be considered that **being very much affected by the disease pushes the patients to be more prompt in testing a new approach**. The others remain a bit more skeptical and ready to adopt more traditional procedures.

Nevertheless, **patients definitely need more information and reassurance about the functioning of the new technology proposed** (e.g. clarification about the fact that the AI chip is not pre programmed, it is not possible to be abused from the outside and it is safe in the way in which it is created). The fact that the proposed solution has a direct effect on the brain creates a high level of fear, because participants seem to immediately connect it to a possible abuse of emotions and personality.

Another element to be discussed is that innovation takes time to be understood and accepted. Most of the concerns that arose during the workshop were related to the fact that AI is a complex topic and not a very clear term; these reasons induce people to adopt a more defensive approach, and people need to become confident with the topic slowly absorbing information and data. **To increase awareness and improve acceptability of a new paradigm, participants suggested several actions**. It seems that the lower level to start is to work on education of the public at large, even if they could find the topic irrelevant and difficult. However, working on the public opinion could have a good effect on policy makers, and then regulators. Indeed, policy makers and regulators have been mentioned several times to take care to define specific and updated framework for the adoption of new techniques and standards in the cure of epilepsy being ethically and regulatory compliant. In parallel, researchers and scientists should focus on the research and on the sharing of their findings, also taking care to do some lobby activities toward policy makers and institutions, as they could be perceived by high level stakeholders as more entitled to talk about the disease and new solutions.

From research projects, such as Hermes, and associations working in the field, as EpilepsyNL, **participants expect continuous work of sharing knowledge, updating information that is trusted and scientifically based. Also, participants welcome the opportunity to have some meetings to discuss similar issues and compare experiences and opinions**. Such meetings help patients in feeling less isolated in the disease and to clarify aspects through the sharing of others' experiences.

We thank department of Functional neurosurgery and epilepsy UMC Utrecht for their aid in organizing the event.

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