

Barriers and opportunities opened by regenerative medicine: when the research meets the people

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**.



FOCUS GROUP

21 people, was divided in **3 groups** to perform facilitated focus groups. Each group had a moderator, and was composed by people with high familiarity with the disease, being patients or caregivers

DISCUSSION

Questions have been prepared to allow HERMES's researcher to understand **how patients and caregivers perceive the framework proposed by HERMES**: 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 COLLECTION & ANALYSIS

Data were collected recording the conversations, these have been then transcribed. Transcription have been **analysed and aggregated performing thematic analysis**. This last step allowed to aggregate results from the three different tables, selecting more recurring topics of discussions and defining main conclusions and recommendations

RESULTS

- **The worse is the situation of the patient, the higher is the readiness to explore new treatments:** being very much affected by the disease pushes the patients to be more prompt in testing a new approach
- **Artificial Intelligence is a topic that make people feel scared and less secure:** the main fear is that the implant operation could be too invasive and irreversible, highlighting the fear that a chip could be manipulated from the outside, being hacked, collecting data or exposed to errors in coding and programming
- **Participants need to check information on trusted sources:** the big part of the acceptance of a new treatment passes through the surgeon and the hospital that is taking care of the patient



RECOMMENDATIONS

- **Innovation takes time**, to be ready to test a new solutions in 5-10 years, it is important to start talking about the innovation now with patients
- Patients need **more information and reassurance** about the functioning of the new technology proposed
- **Education of the public at large** is crucial to increase awareness and improve acceptability of a new paradigm,
- **Policy makers and regulators need to define specific and updated framework** for the adoption of new techniques and standards in the cure of epilepsy being ethically and regulatory compliant.
- **Researchers and scientists should focus on the research and on the sharing of findings**
- **Meetings** to discuss similar issues and compare experiences and opinions are welcome

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

In collaboration with:

EpilepsieNL
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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