

# Decision-Making in Epilepsy Care - Are Digital Services Underutilised?

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# Rationale

- The study was built on
  - digitalisation of healthcare has enhanced clinical decision-making (DM) and patient engagement in chronic disease management, including epilepsy.
  - DM has shifted toward patient-centred shared decision-making (SDM), involving mutual information exchange between healthcare professionals (HCP) and patients (Hansson & Fröding 2021)
- The role of information management is vital in supporting treatment planning and continuity of care (Min et al. 2021)



# Rationale

- Research shows that people with epilepsy experience unmet needs regarding accessible and comprehensive information (Baker et al. 2025, Henning et al. 2019, Rusten et al. 2025)
- HCPs play a key role in supporting patients and in meeting patient's information needs (Tian et al. 2025, Kälviäinen et al 2025)
  - Nurses have a key role in supporting epilepsy management (Higgins et al. 2018)
  - Neurologists mainly lead assessment and treatment planning (Stern et al. 2018)
- Digital services may offer opportunities for information management (Shagog et al. 2020, Kuusisto et al. 2025)



# Objective

- This study aimed to explore
  - how HCPs use digital services to share information and
  - examined neurologists' and nurses' perceptions of their own and each other's roles in DM,
    - with particular attention to how digitalisation may support information sharing.



# Study Design

- Two focus groups November & December 2022
  - neurologists (n=3) and nurses specialised in neurology (n=4)
  - participants worked in Finnish wellbeing services counties, which are responsible for organising public social and healthcare services.
- Sample (N = 287) of Finnish people with multiple sclerosis and epilepsy (pwMS/E)
- The interviews were conducted via Teams Meeting App in Finnish by two interviewers and one technical support person
- The participants were asked about their practices of information sharing for patients as part of their roles in clinical DM.
- The discussions were audio recorded, and anonymity was considered in the transcription. The data were uploaded in Atlas.ti software (version 23.0.7) and analysed using deductive content analysis based on coding that identified the different themes.



# Results

- Neurologists

- predominantly approached DM and information sharing from a clinical expert perspective, and emphasised the medical and evidence-based reasoning.
- Only one neurologist reported utilising digital tools, i.e. external virtual hubs and websites (e.g. HealthVillage.fi, EURAP) in sharing information with patients and considering the language skills of the patient.
- Another neurologist considered digital information sharing to be a nurse's duty.

*“The epilepsy nurse goes through the medication information, what epilepsy means and what kinds of things affect the success of the treatment, providing basic information about epilepsy and introducing the Epilepsy Association's website.” (Neurologist)*



# Results

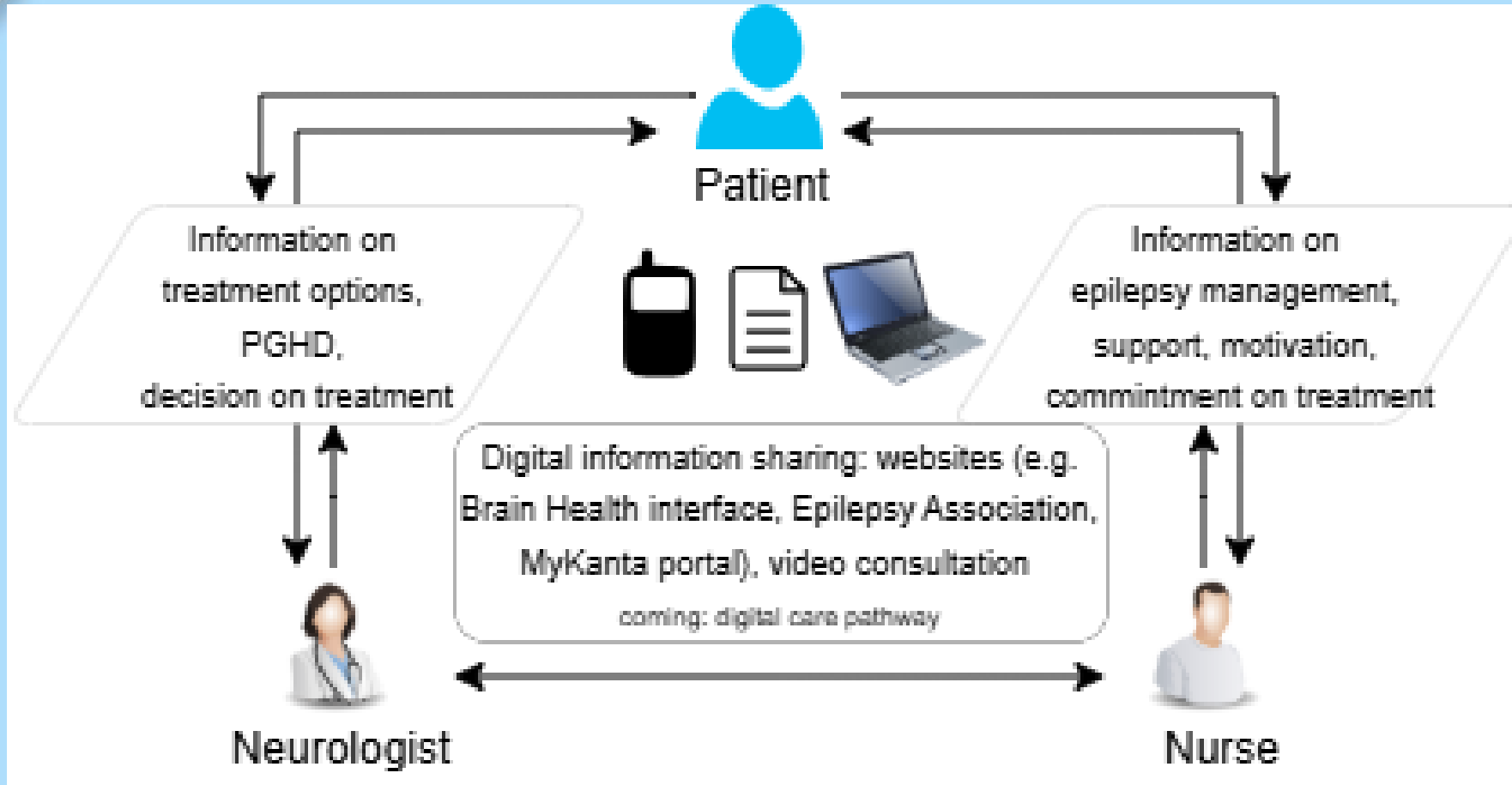
- Nurses

- considered neurologists as responsible for informing patients and making treatment decisions,
  - while neurologists viewed nurses as key mediators and follow-up contacts.
- identified themselves as intermediaries, highlighting the importance of accessible information alongside healthcare access and sufficient consultation time.
- Had a proactive role in sharing digital resources (e.g. the Finnish Epilepsy Association, Brain Health interface, and MyKanta, a nationwide portal, during in-person or video consultations.
  - Written material was accordingly in use, especially for older patients
- Considered there's urge for digital care pathway
  - Yet found patient's preferences for acquiring information important

*"I always make a summary of the issues and listen. To see if it's understood. If necessary, I write and give instructions to read My Kanta or contact us. The encouragement and effort often help. But also giving the opportunity for contact if needed."*  
(Nurse)



# Summary of the results



# Conclusions & Discussion

- Digital technologies were **underutilised in clinical decision-making (DM)**, especially for patient information sharing
- Information was still delivered **mainly in face-to-face appointments**
- **Nurses are more active** in using digital services than neurologists
- **Adequate, timely information is critical:**
  - Enables patients to evaluate treatment options and
  - Express preferences
  - Improves understanding of disease impact on daily life
- **Inadequate information:**
  - Weakens decision-making
  - Leads patients to seek **potentially unreliable external sources**



# Implications & Future Research

- **Digital care pathways** seen as a key solution:
  - Improve care coordination and information accessibility
  - Provide **reliable, patient-centred information**
- Combining **traditional counselling + digital tools**:
  - Supports self-management
  - Enhances patient engagement and SDM
- Emerging tools (e.g., **digital epilepsy registry**) enable:
  - Integration of patient-generated data into clinical DM
- **Future research needs to:**
  - Evaluate effectiveness, accessibility, and user experience of digital interventions
  - Understand how digital information sharing supports **interprofessional collaboration** across time and place



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## Acknowledgements and Contact Info

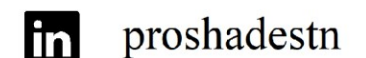
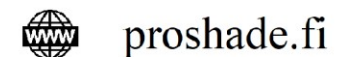
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# Thank you!

