



**European
Reference
Network**

for rare or low prevalence
complex diseases

⚙️ **Network**
Epilepsies (ERN EpiCARE)

● **Member**
Universitätsklinikum
Bonn — Deutschland



ERN EpiCARE :

A network for rare and low prevalence complex epilepsies

WP5: Neuropsychology

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WP5: objectives, deliverables



Objectives:

- Further update to E-neuropsych website with functional platform available by end of month 12
- Web address: 131.220.26.124

Update: E-NEUROPSYCH



content-related changes:

- clinical data match registry provided by the network
- individual neuropsychological test batteries possible
 - greater individualism, loss of comparability, retrospective analysis possible
 - excludes collection of common normative data for use by all centers

Update: E-NEUROPSYCH



content of the database/app:

Patient data entry: in accordance with the eCRF from the registry

STEP 2: CRF

GENERAL INFORMATION | **EPILEPSY & SEIZURES** | CURRENT TREATMENT | SURGERY

Predominant current seizure type

Seizure frequency

Specify

seizure frequency last 6 months

Etiology

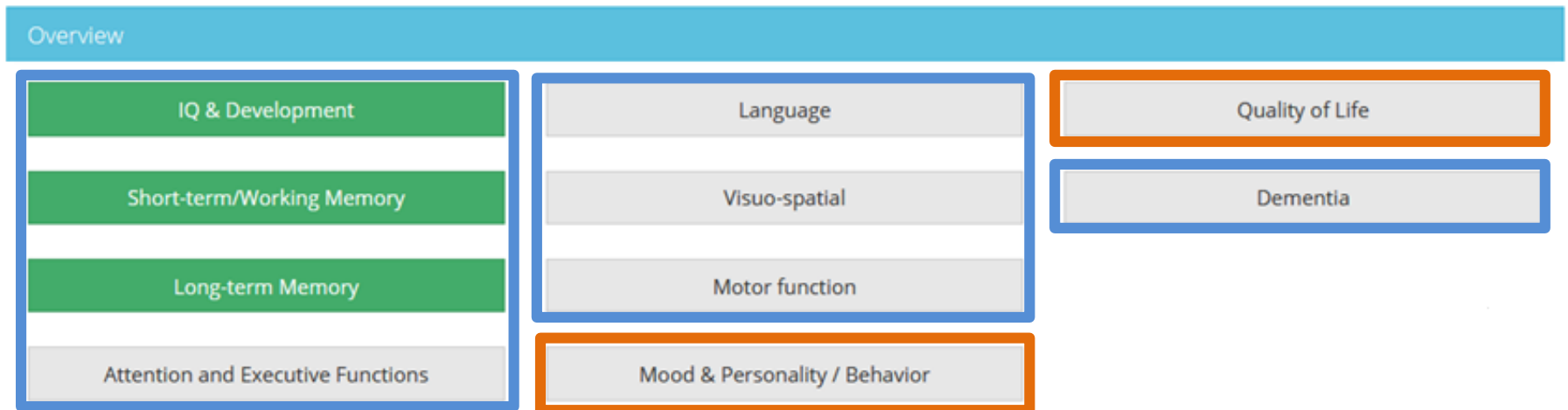
Epilepsy syndrome

Update: E-NEUROPSYCH



content of the database/app:

Objective cognitive & subjective domains:



Update: E-NEUROPSYCH



content of the database/app:

Entering data:

Tests Patient: 9 Test Menu ?

Long-term Memory

Test used:

2 selected ▾

VLMT (Verbaler Lern- und Merkfähigkeitstest)
1-impaired ▾

DCS II (Diagnosticum für Cerebralschädigung)
2-borderline ▾

Summary: Long-term Memory

1-impaired ▾

free recall impaired, loss of 5 word after retention

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content of the database/app:

SINGER scale: assessment of severely intellectually impaired patients

I Eating/drinking

| | 0 | 1 | 2 | 3 | 4 | 5 | 6 |
|-------------------------------|---|--|---|--|---|--|----------------|
| I Eating/drinking | Fed by trained medical staff, (IV, PEG tube, swallow training), no cooperation 0* | Fed by trained medical staff, safe swallowing only during therapy, beginning cooperation 0 | safe swallowing of adapted food beyond therapy, PEG tube only for liquids 0 | independent eating under supervision and help with food preparation, PEG managed by patient if necessary 0 | independent eating of adapted food, potentially with reduced speed and use of tools 5 | independent without limitations to diet / food consistency and without aids 10 | not applicable |
| II Dressing/Undressing | completely dependent on professional help 0 | beginning cooperation in the upper body part, otherwise active professional help 0 | independent dressing of the upper body, active help needed for lower body 5 | independent supervision, active help only for preparation, shoes and fastenings 5 | independent with use of auxiliary devices, help with orthosis 10 | independent without aids 10 | not applicable |

...



Update: E-NEUROPSYCH



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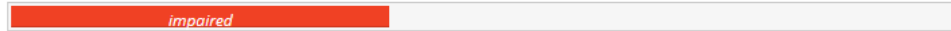
unique patient identifier: 10
Sex: male
Name: Florian, Schieder
Date of birth: 24-11-1989

Hand dominance: right-handed
Test date: 31.01.2019
Test-Id: 9
Test-No: 1

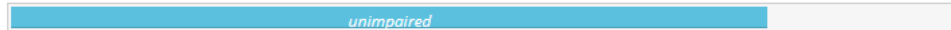
Categories:

(0-severely impaired: red, 1-impaired: red, 2-borderline: orange, 3-unimpaired: blue, 4-above average: green)

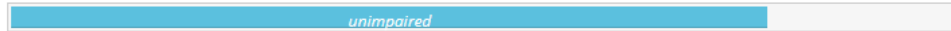
IQ & Development



Short-term Memory



Long-term Memory



Evaluation:

hghghghghg

EpiCARE

Future activities



- **E-NEUROPSYCH:**
 - Collection of adult patients who deteriorate over time and of patients with inflammatory and autoimmunological epilepsies , NORSE / FIRES
 - adaptation of SINGER scale for pediatric assessment
- **Neuropsychological Practical Training Course 2020**

Neuropsychological Practical Training Course 2020



- April 2020
- 42 participants interested from 24 centers across Europe
- 5 days
- Focus: homogenization of practice, practical knowledge, establish cooperations between centers
- neuropsychological AND medical experts

Neuropsychological Practical Training Course 2020



- Cheapest offer from: chateauform.com



- Château de Rosay (near Paris)
- 1.200 € p.p.
- includes: accomodation, food, conference rooms & materials

- travel to/from Paris: 200.00 € p.p.
- Since we are the reference centers, no external speakers will be required

Neuropsychological Practical Training Course 2020

- topics: diagnostics

general considerations & common pitfalls in neuropsychological assessment
domains, tools & interpretation
homogenization of protocols (core test battery for assessing cognitive, behavioral and affective domains)
specificity of neuropsychological tools
neuropsychological profile in patients with different epileptic syndromes
cognitive profile for daily functioning

- topics: surgery

risk evaluation, predictive value of neuropsychological assessment
Surgical approaches, new surgical treatments
Short-term / long-term outcome of epilepsy surgery
psychiatric outcomes
presurgical neuropsychological assessment, adjustments to assessment protocol (depending on the suspected localization of the epileptic focus)
Stimulation procedures

Neuropsychological Practical Training Course 2020

- topics: treatment

effect of neuropsychology/cognitive rehabilitation after surgery in adult
intervention for neuropsychological rehabilitation; neurorehabilitation
psychosocial intervention in pediatric epilepsy and care of family
psychological precursors of seizures and psychological strategies to self-control
Biofeedback
counselling

- topics: behavioral comorbidities

social cognition
affective processes
comorbidities and behavioral problems
early right temporal epilepsy and pseudo autism symptomatology

Neuropsychological Practical Training Course 2020



- further topics:

assessment of very low achievement children & interpretation of the profiles in cases of intellectual disability

long term development of cognitive functioning

cognitive deterioration in drug-resistant epilepsy

MRI & EEG

language assessment / lateralization: fMRI, Wada test, TCDS, dichotic listening) and its validity (especially regarding surgical planning, calculation of laterality indexes etc.)

AED side effects (side effects, add ons, detox, first seizure)

neuropsychology in neuroscience

PNES (diagnosis, counselling)



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Thank you for your attention