Remote Assessment of Neurodegenerative Diseases in Population Surveys

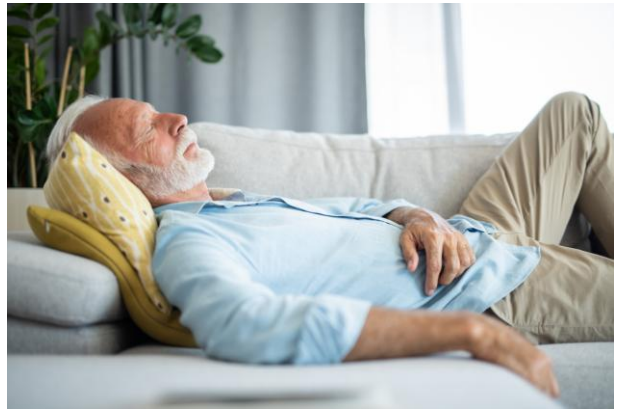
Vojtech Illner, PhD
Radim Bohacek, PhD
Jan Rusz, PhD
Petr Dusek, PhD

The NeuroSHARE module

- Part of 10th SHARE wave in Czech Republic
  - HCAP in wave 9

speech test
(set of speech tasks)

smell test
(olfactory testing kit)

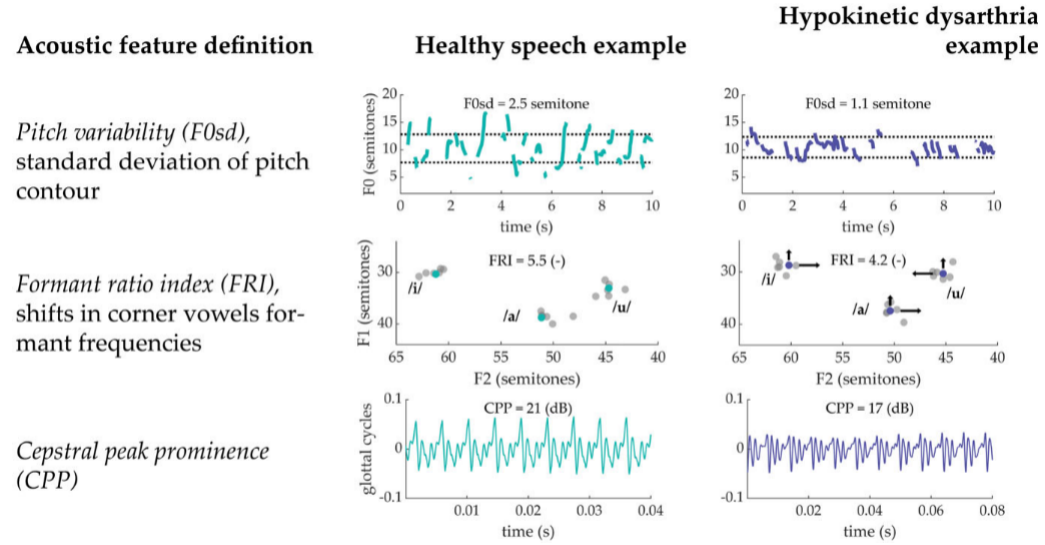


sleep test
(brief questionnaire)

- Tasks sensitive to the presence of *early* neurodegeneration
  - Evidence from clinical setting – first ever study in representative sample

Speech test (10 min)

- Vowel phonation, syllable repetition, reading passage, tale narration, monologue
- Motor (acoustic) perturbances *(articulation, monotonicity, loudness, rhythm, pauses…)*
- Linguistic (cognitive) decline *(vocabulary, phrasing, sentence, structure…)*
- 100% automatically computed and evaluated
- Requires microphone



Feature description	Healthy speech	Mild cognitive impairment	trend
Content words, reflect a tendency to prioritize or neglect content-bearing words	*Content words* = 0.55 (-) …*cats are definitely funny animals, and I love them*…	Content words = 0.67 (-) …*I like funny cats. I like dogs, horses too*…	↑
Function words, evaluate the tendency to use or neglect fuction words, representing the grammatical and syntactic role in a sentence.	Function words = 0.44 (-) …*cats are definitely funny animals, and I love them*…	Function words = 0.33 (-) …*I like funny cats. I like dogs, horses too*…	↓
Moving-average type-token ratio (MATTR), evaluates the richness of vocabulary by exploring unique and repeated words.	MATTR = 1 (-) …*cats are definitely funny animals, and I love them*…	MATTR = 0.78 (-) …*I like funny cats. I like dogs, horses too*…	↓

Smell test (8 min)

- Standard HCAP olfactory test (HRS, ELSA)
  - Not part of SHARE
- Recognition of scents
- Smell sensitivity
- Requires sniffing sticks set

Sleep test (5 min)

- A validated questionnaire (RBDSQ) for assessment of abnormal behavior in REM phase (RBD) during sleep
- Up to 80% RBD patiens develop PD or DLB

NeuroSHARE (tests combination)

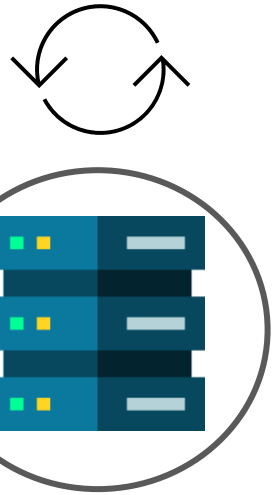
- The combination of these clinically validated tests offer superior sensitivity & robustness
- Objective, short, low-cost
- Language/culture independent
- Self-administration

The current setup

Face to face CAPI interview

Questionnaire with recording booklet, microphone, sniffing sticks

The data is periodically sent to a secured server



Automated data processing

& biomarkers evaluation

Respondents with estimated high risk are invited to a clinic

Clinical validation

The current validation setup

- Directed towards synucleinopathies – early PD, DLB, RBD, MSA,…

SERVER – NeuroSHARE model

Speech model of early PD

Adjusted smell test score

Adjusted sleep test score

+ relevant respondent info

Upon a high-risk score

Entry clinical interview

CLINICAL VALIDATION

Subjected to assessment

MRI, DaT scan, biopsy, polysomnography, further screening Diagnosis

Not subjected to assessment

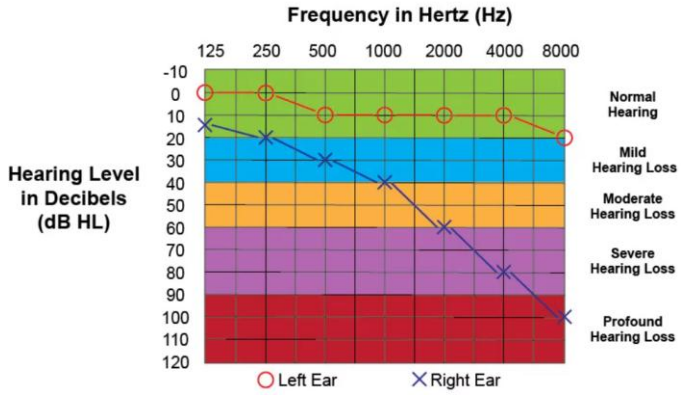
The respondent refused or provided previously unstated exclusion criteria

The current state of study

- Sample n=4000, consent rate 90%
- Clinical validation 5% (200+)
- Current state:
  - ~ 1000 respondents
  - Low willingness (~20%) to clinic visit, higher in females
  - All participants at the visit demonstrated a neurodegenerative condition or are being suspected of one
- When finished:
  - Validation of the NeuroSHARE module
  - Joint evaluation of:
    - NeuroSHARE
    - Standard SHARE cognition module
    - SHARE HCAP

Future progress & challenges

- Incorporating additional sensitive, objective tasks
  - Facial expression
  - Hearing ability
  - Vision ability



Cheeks			
Cheek Surface Variability	Surface Left/Right	The standard deviation of the image entropy of difference between cheek areas of two consecutive video frames. Describes changes in the cheek area during cheek raising and relaxation.	
Mouth			
Upper Lip Elevation/ Depression	Euclidean Central	The standard deviation of the distance between the upper lip and the nose tip normalized by the distance between medial eye corners. Represents movement of the upper lip.	
Lower Lip Elevation/ Depression	Euclidean Central	The standard deviation of the distance between the lower lip and the nose tip normalized by the distance between medial eye corners. Represents movement of the lower lip.	
Mouth Corner Adduction/Abduction	Euclidean Left/Right	The standard deviation of the distance between the mouth corner and the nose tip normalized by the distance between medial eye corners. Represents changes of the mouth shape.	
Jaw			
Jaw Elevation/ Depression	Euclidean Central	The standard deviation of the distance between the chin and the nose tip normalized by the distance between medial eye corners. Represents movement of the mandible.	

- Transformation to 100% remote setup, smartphone-, or computer-based.
  - Pilot test in 2026, CZ
  - SHARE Fieldwork wave 11 in CZ/CH

Summary & goals

- Validated, low-cost, short, objective, non-invasive, scalable, automatically evaluated method
- Extensions to a broader spectrum of neurodegenerative conditions, i.e., dementia
- Self-administered mode in 2026
- Open for collaboration