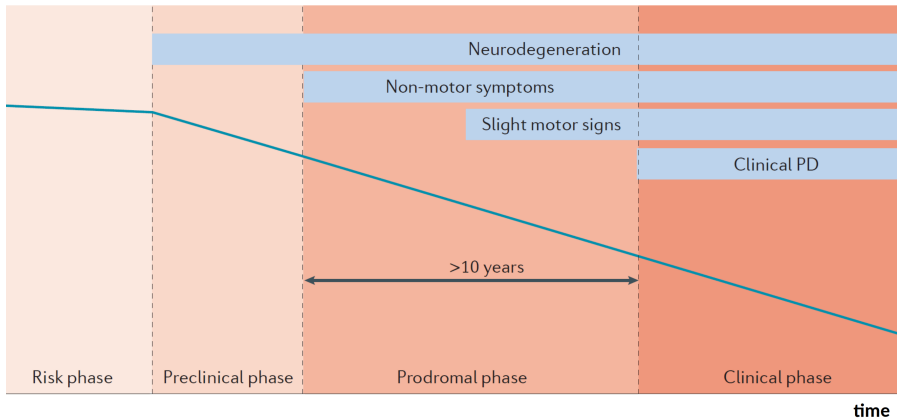# SHARE-CZ
neuroSHARE
What Others are Doing?
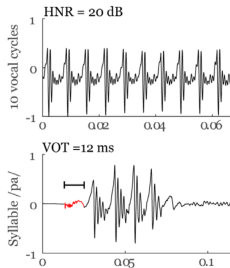
Radim Boháček

CERGE-EI

May 2025

neuroSHARE

- Early markers for neurodegenerative diseases: Prodromal phase
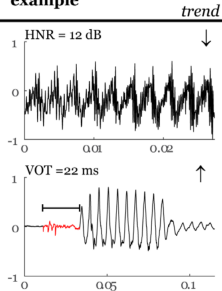- Parkinson's and Alzheimer's disease
- Dementia with Lewy bodies

neuroSHARE

▶ Clinics to Survey

▶ Three tests
  ▶ Speech test
  ▶ Standardized olfactory test
  ▶ Sleep test
    (REM behavior disorder)

▶ Power of combination

▶ Collected 2,097 tests

▶ Clinical validation (5%):
  consent 71%

Healthy speech example

Hypokinetic dysarthria example

trend

HNR = 20 dB

HNR = 12 dB   ↓

10 vocal cycles

VOT = 12 ms

VOT = 22 ms   ↑

Syllable /pa/

neuroSHARE in other countries

- ▶ Self-administered (remote) version
- ▶ Facial measures by phone or computer
- ▶ Hearing
- ▶ Vision
- ▶ Switzerland: CZ-CH funds in wave 11

SHARE-CZ Biomarkers and Exposomes

Biomarkers

▶ Venous blood samples

▶ Harmonized with HRS

▶ Markers for neurodegeneration

▶ Wave 11

Exposomes

▶ Internal and External

▶ Short- and long-term cumulative environmental exposure

▶ Relate outcome measures to heterogeneous environment

RECETOX Laboratories & EIRENE-ERIC

Link to administrative health data (wave 11)
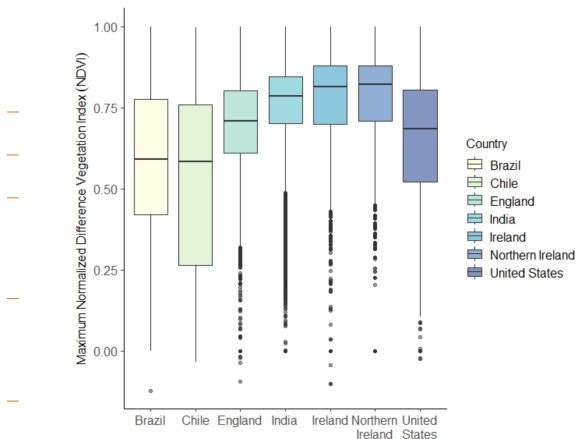
MAKE SHARE DATA GREAT AGAIN

What Others Are Doing?

HRS Biomarker Network Meeting

Exposomes

- Gateway
- EHEN and EIRENE-ERIC
- External = Just link geographic data
- Internal!

THE EUROPEAN HUMAN EXPOSOME NETWORK (EHEN)

EHEN is the world's largest project network studying the impact of environmental exposure on health

Venous Blood

- ▶ HRS, ELSA, NICOLA, TILDA, MHAS, CHARLS

- ▶ Columbia (COSA) Brazil

- ▶ India (LASI-DAD) Sri Lanka (SLHAS)

- ▶ Lebanon (LSAHA)

- ▶ Kenya (LOSHAK)

- ▶ Costa Rica (CRELES): Telomeres length

- ▶ BCS70 Cohort, HS&B

Venous Blood Samples

▶ Hallmarks of Aging:
Mitochondrial function, cellular senescence, cell exhaustion

▶ Biomarkers for neurodegeneration

▶ Ageing biomarkers

▶ Epigenetic age

▶ DNA

▶ GWAS

▶ Storage for future analysis
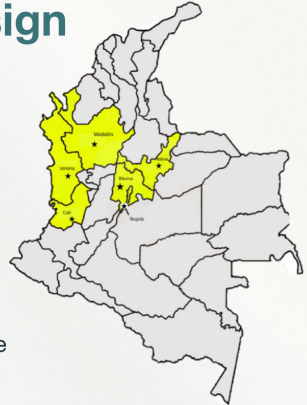
COSA Pilot Design

6 cities (municipios), 3 urban/3 rural

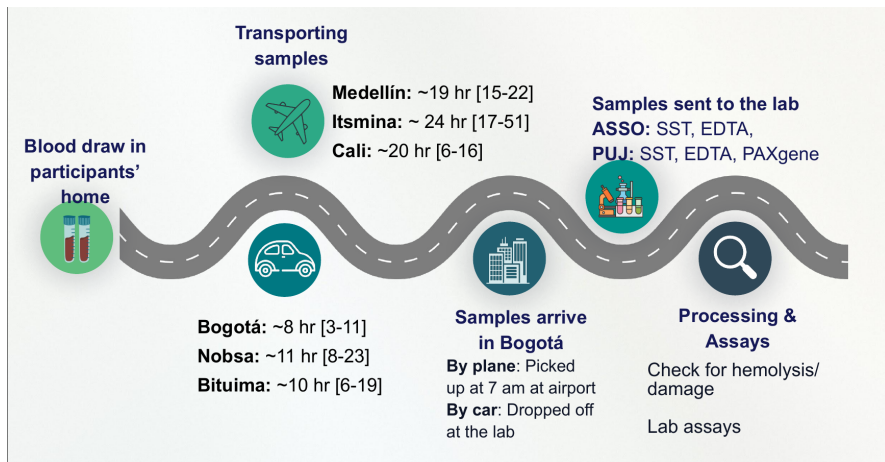Face-to-face interviews with adults 50+ and their spouses N=740 (36 proxies)

Subsample selected for performance-based assessment and whole blood collection
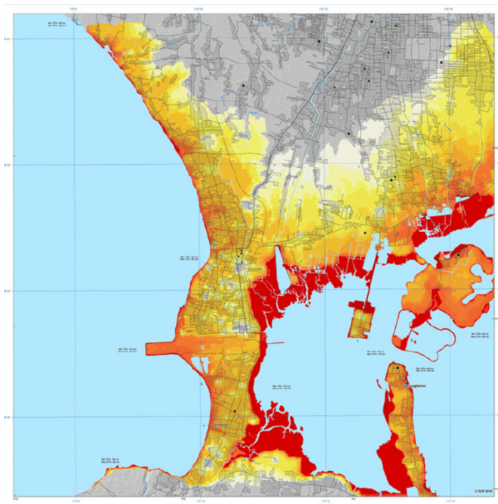
https://cosaweb.org

▶ COSA (Columbia)

▶ Venous blood

▶ Blood transfer from Medellin to Bogota

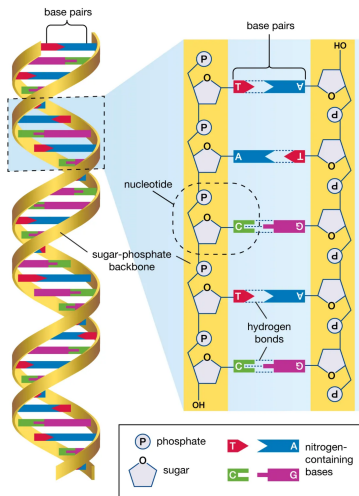# What Others Are Doing: STAR

Study of Tsunami
Aftermath & Recovery

- ▶ Blood samples
- ▶ Dried plasma spots
- ▶ Hair
- ▶ Cognition
- ▶ Research on trauma effects

What Others Are Doing: HRS

- Salivary DNA
  (once per person)

- DNA sequencing

- VBS
  (panel every 6 years)

- Metals and infection

- Neuropathological markers

What Others Are Doing: ELSA

- ▶ Nurse visit
- ▶ Venous blood (every 4y)
- ▶ Cardiometabolic profile
- ▶ DNAm, RNAseq
- ▶ Lung function
- ▶ Hair
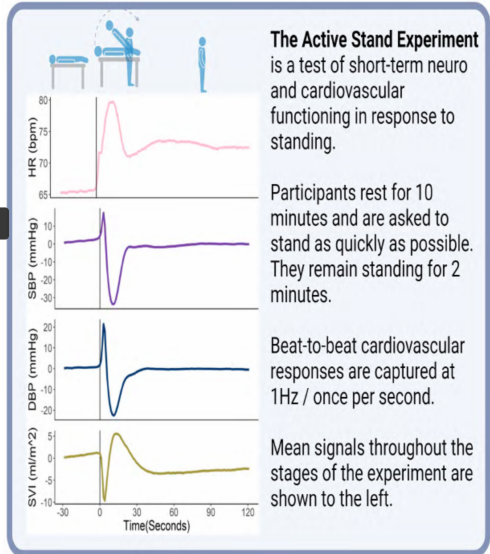- ▶ Nutrition
- ▶ Hearing
- ▶ HCAP2

What Others Are Doing: NICOLA

RESEARCH AREA	New measures
Cognition	• **Blood based markers of neueodegeneration** i.e. amyloid and phosphorylated tau proteins, NFL and GFAP • **Clinical validation of HCAP tool**
Eye health	• Novel imaging modalities incl. **widefield retinal OCT, OCT-angiography and anterior segment OCT** • **Epigenetic clock analyses** to define exposure associated methylation changes that influence aging, age-related ocular disease and retinal markers of brain health
Kidney disease	• Investigation of **genetic, epigenetic and proteomic basis of kidney disease** and contributing to largest genome-wide association study (GWAS) conducted to date • Identification of **genetic changes, DNA methylation profiles, telomere variation and mitochondrial dysfunction** as risk factors for renal outcomes
Molecular biomarkers	• **Long read sequencing** to identify mosaic loss of chromosome X and Y that occurs more frequently as people age
Microbiome	• Analysis of **stool samples** to explore the influence of medicines on the microbiome, the influence of gut microbiome on metabolism and effectiveness of medication and microbial taxa enrichment/depletion to inform personalised medicine • Analysis of saliva, oral examination in a subset
Nutrition	• Nutrient biomarkers and nutrient intake data for >50 nutrients based on FFQ • Impact of **food insecurity** and **diet quality** on aging
Environment	• **Linkage of >280 environment related variables** to Wave 1 and 2 data • Deriving harmonized environmental variables for international comparative analyses • Development of a publicly accessible **environmental data geoportal**

What Others Are Doing: TILDA

- VBS (wave 1, 3, 6)
- Hair (wave 3)
- Faecal (wave 6)
- Saliva
- Active stand: Blood pressure

The Active Stand Experiment is a test of short-term neuro and cardiovascular functioning in response to standing.

Participants rest for 10 minutes and are asked to stand as quickly as possible. They remain standing for 2 minutes.

Beat-to-beat cardiovascular responses are captured at 1Hz / once per second.

Mean signals throughout the stages of the experiment are shown to the left.

Cognition and neuropsychology

TMB cognitive assessments

TMB Digit Symbol Matching
Processing Speed

Reaction time -> milliseconds (ms)
Lower score= faster processing speed

Backward Digit Span
Working Memory

5 3 2

Then press the numbers on the **keyboard**
in **reverse** order.

Number string score
Higher score= better memory

▶ Digital cognition and neuropsychology

▶ Add Health: CAPS (Cognitive Assessment, Physical and Sensory Functions)

▶ Columbia University and NIH

Lessons

▶ Project-oriented collections

▶ Run by external experts:
  Whole survey (Costa Rica, Bali) or as special projects

▶ Institutional structure
  External researchers involved
  Project managers and accountability

▶ Strategy and planning

▶ Content is determined by expert research community

SHARE

- ▶ SHARE is behind
- ▶ Lack of expertise: internal or external
- ▶ Financing only for innovative research projects
- ▶ Money train has left
- ▶ Constraints in capacity
- ▶ External private financing
- ▶ Need to move fast and pilot new projects
- ▶ Connect to projects and experts