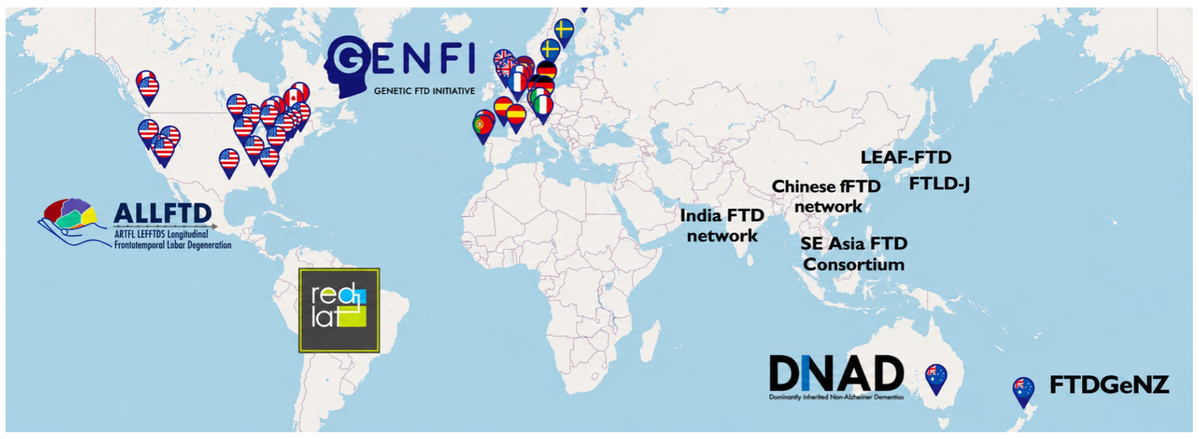
From an international cohort to clinical trials: the future for GENFI

Eva Cullen, Arabella Bouzigues, Jonathan Rohrer

Traditional cohort studies



GENFI
GENETIC FTD INITIATIVE

FPI
FTD Prevention Initiative

Largest study of genetic FTD

- Europe and Canada
- Annual visits
- >2000 participants
- >5000 visits
- >100 publications

International collaboration in genetic FTD

- 11 cohorts
- 6 continents

GENFI 4 ALL

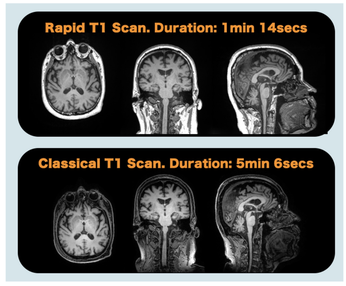
3 levels of participation

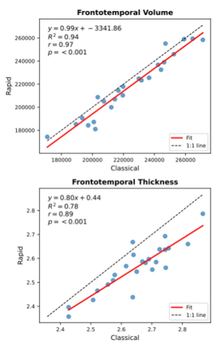
- Basic: registry-like (no in person visit)
- Remote: digital tests (brief in person visit)
- Detailed: tailored (in person visit)

Ongoing research

Novel MR brain imaging

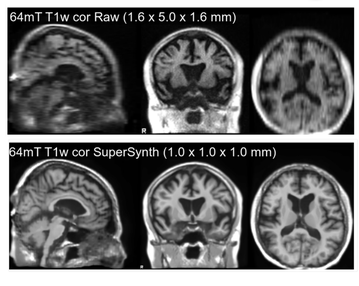
Rapid





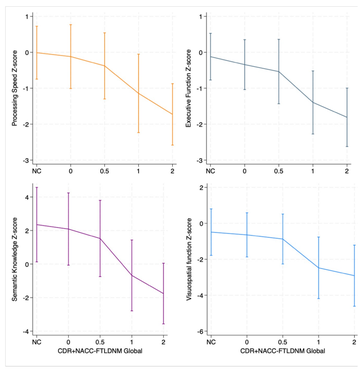
Hyperfine (portable)





Digital cognitive testing & composite measures

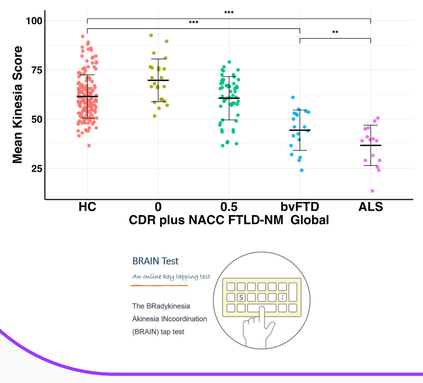
ignite

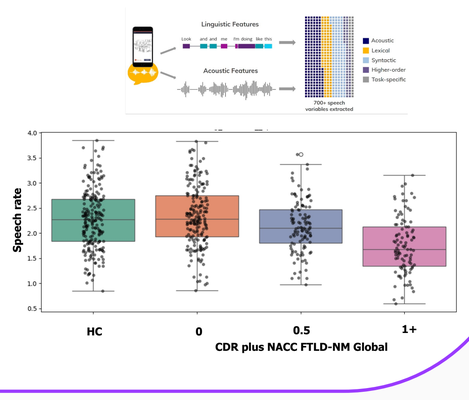


GENFI-Cog COMPOSITE SCORE

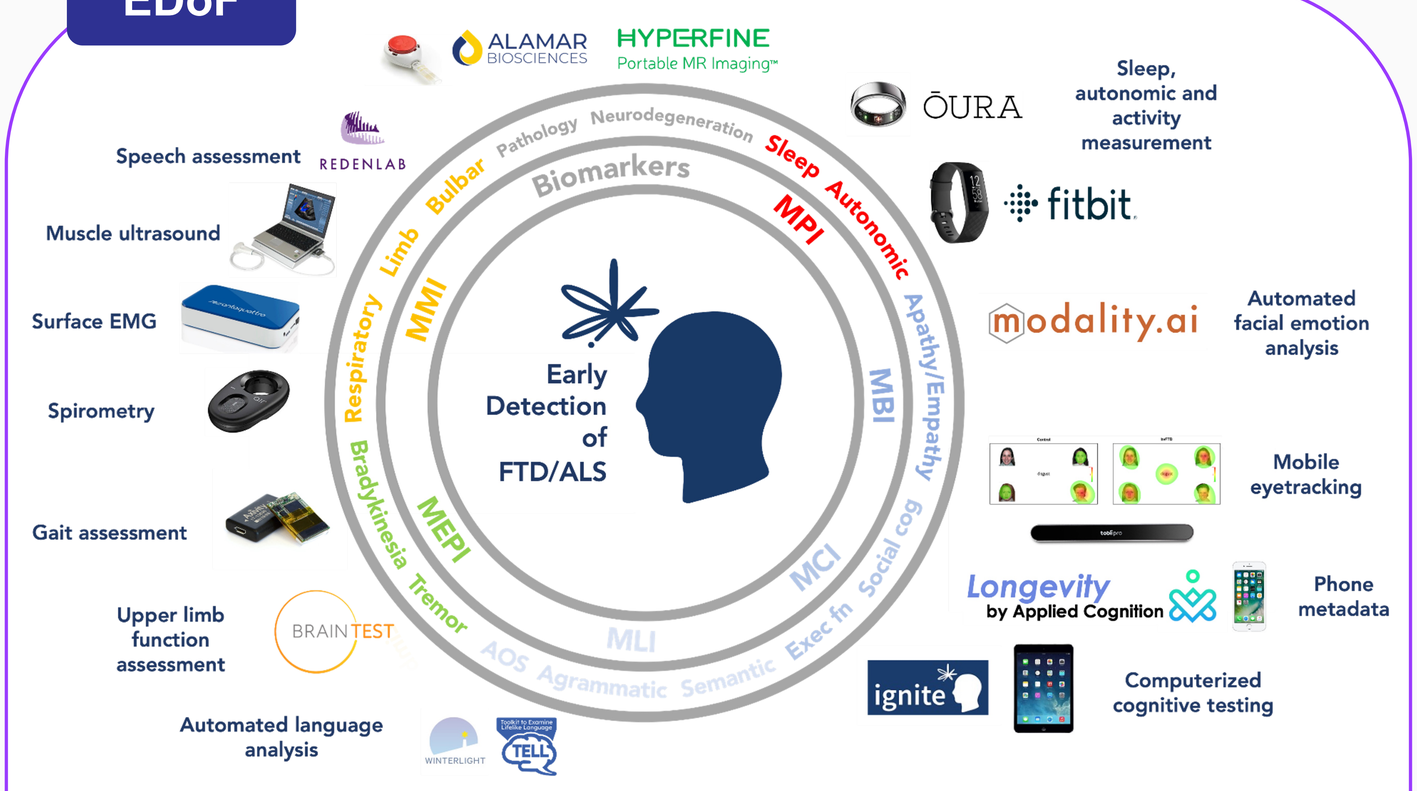
C9orf72	GRN	MAPT
Category fluency	Camel and Cactus Test	Camel and Cactus Test
Color Word Interference Test – color and word naming	Color Word Interference Test - ink naming	Boston Naming Test
Color Word Interference Test - ink naming	Trail Making Test - part B	Color Word Interference Test – color naming
Trail Making Test - part B	Benson Figure recall	Benson Figure recall
Benson Figure Copy	FCSRT immediate total recall and delayed free recall	FCSRT immediate free and total recall
FCSRT immediate free recall	Facial Emotional Recognition Test	Facial Emotional Recognition Test
Facial Emotional Recognition Test		

Motor & speech assessments





EDoF



Goals

- Multimodal biomarker development and validation
- Trial design optimisation

Within a common infrastructure

Future perspectives

Short-duration high-frequency longitudinal studies

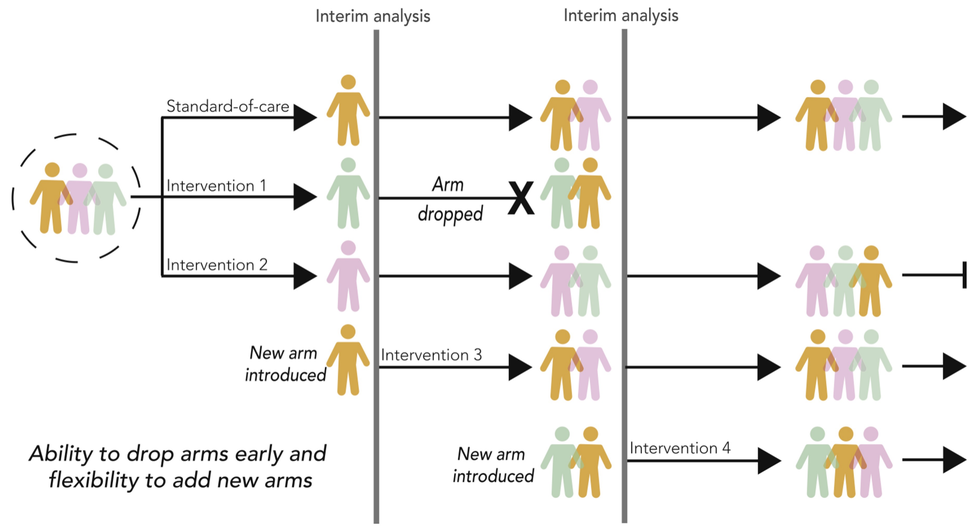
MAPLE
MAPT-FTD Longitudinal Evaluation of key endpoints

- Collecting run-in data for future platform trials
- 10 MAPT GENFI sites in Europe and Canada
- Recruitment ongoing

CEDAR
C9orf72 Endpoints Determination in ALS/FTD Research

- Aiming to develop within each subgroup

Platform trial



Growing collaborations

UK FTD NETWORK

GENFI ALS SUBSTUDY

KISSICK FAMILY FOUNDATION

cure MAPT FTD

CureGRN

BLUEFIELD PROJECT Curing FTD

CURE VCP DISEASE, INC.

UCL University College London

FTDtalk