

The Horizon 21 European Down Syndrome Consortium

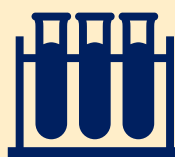
Investigating Alzheimer’s Disease linked to Trisomy 21

Ivain P, Benejam B, Loosli SV, Sandkühler K, Levin J, Martet D, Rebillat AS, Khoo WM, Zaman S, Fortea J, Larsen FK, Medbøen IT, Langballe EM, Baldimtsi E, Tsolaki M, McGlinchey E, McCarron M, Real De Azua D, Öhman F, Zetterberg H, Strydom A

**10** European clinical sites

**250** Adults with Down syndrome recruited

**Longitudinal follow-ups at 12-, and 24-months**

**Blood plasma and clinical markers collected at each visit**

**Evidence to support future clinical trials**

About

Horizon 21 is a European multicentre consortium established to improve the diagnostic, monitoring, and prevention of Alzheimer’s disease in people with Down syndrome.

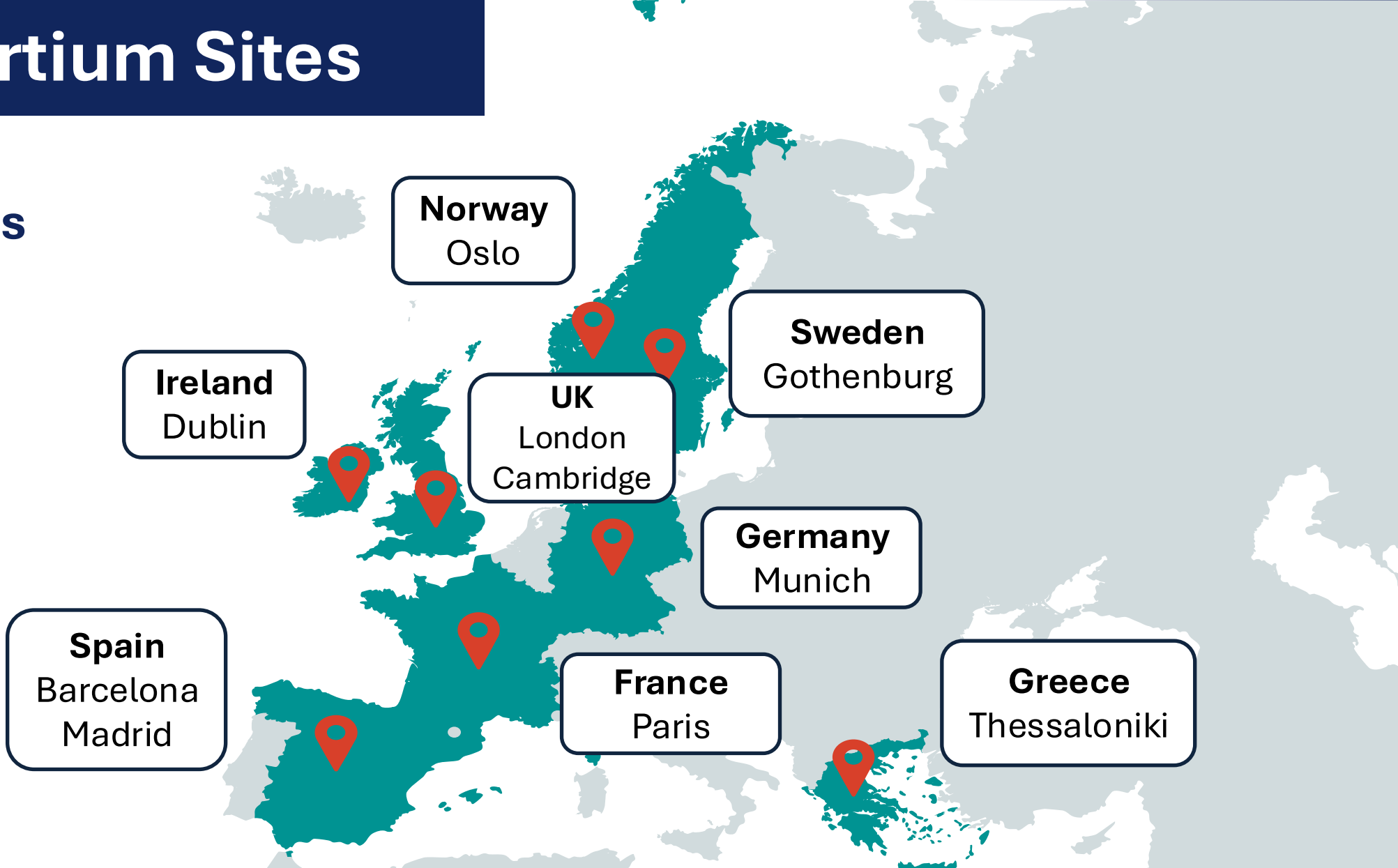
We develop harmonised clinical assessments, create longitudinal datasets, establish a plasma biobank and generate evidence to support future international prevention and treatment trials.

Our Aims

- 1 Determine factors influencing age of onset and diagnosis of Alzheimer’s disease
- 2 Validate the CAMDEX & CAMCOG-DS-II
- 3 Link longitudinal cognition with blood biomarkers
- 4 Generate evidence to support the FINGER-ID Lifestyle Intervention Trial

Consortium Sites

10 clinical sites across Europe



Study Design

**Cognitive Assessments**

- CAMCOG-DS-II
- Modified Cued Recall Test
- CANTAB MOT & PAL
- Purdue Pegboard Test

**Informant Questionnaires**

- CAMDEX-DS-II
- Dementia Questionnaire for People with Learning Disabilities (DLD)
- Short ABS

**Clinical Assessments**

- Medical history
- Dementia diagnosis
- Demographics
- Lifestyle factors

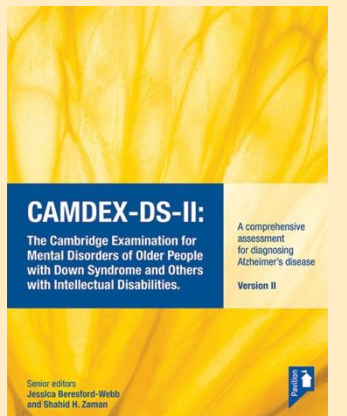
**Blood Collection**

- Aβ40/42
- pTau
- NfL
- GFAP
- APOE genotyping

**Longitudinal Follow-up**

- Baseline
- T2 12-months
- T3 24-months

CAMCOG-DS-II



The CAMCOG-DS-II is a neuropsychological test battery adapted for adults with Down syndrome to detect cognitive decline associated with Alzheimer’s disease.

- Validated in 223 participants across 7 countries & 6 languages
- Minimal floor/ceiling effects compared to other tools
- High reliability (inter-rater and test re-test)
- Strong construct and concurrent validation

PPI

- Multinational PPI group including adults with Down syndrome & families/carers
- Language-specific meetings and cross-country online meetings to share experiences and priorities
- PPI informed study delivery & design for FINGER-ID intervention

Characteristics	T1	T2	T3
Participants, n	250	169	94
Male, n (%)	130 (52.0 %)	88 (52%)	48 (51.1%)
Female, n (%)	120 (48.0 %)	81 (48%)	46 (48.9%)
Dementia, n (%)	41 (16.4%)	32 (19%)	11 (11.7%)
Prodromal, n (%)	17 (6.8%)	12 (7%)	6 (6.4%)
No dementia, n (%)	170 (68.0%)	113 (67%)	74 (78.7%)
Other cognitive decline, n (%)	22 (8.8%)	12 (7%)	4 (4.3%)
Aged 18-34 years, n (%)	94 (37.6%)	50 (30%)	20 (21.3%)
Aged 35-44 year, n (%)	69 (27.6%)	55 (33%)	37 (39.4%)
Aged 45-54 years, n (%)	53 (21.2%)	36 (21%)	22 (23.4%)
Age ≥55 years, n (%)	34 (13.6%)	28 (17%)	15 (16.0%)

Recent Outputs



McGlinchey, E. (2026). Lifestyle intervention and cognitive outcomes in Down syndrome: a horizon 21 European Down syndrome consortium scoping review. <https://doi.org/10.1186/s11689-026-09694-0>



Ivain, P., Baksh. (2025). Validation of the CAMCOG-DS-II, a neuropsychological test battery for Alzheimer’s disease in people with Down syndrome: A Horizon 21 European Down syndrome Consortium study. <https://doi.org/10.1002/alz.70071>



Larsen, F. K. (2024). Age of Alzheimer’s disease diagnosis in people with Down syndrome and associated factors: Results from the Horizon 21 European Down syndrome consortium. <https://doi.org/10.1002/alz.13779>



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