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Cohort Profile

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Cohort Profile Update: The Harmonised Cognitive Assessment Protocol Sub-study of The Irish Longitudinal Study on Ageing (TILDA-HCAP)

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Key Features

- The Irish Longitudinal Study on Ageing—Harmonised Cognitive Assessment Protocol (TILDA-HCAP) is closely harmonized with the original Health and Retirement Study (HRS), The Northern Ireland Cohort longitudinal study of Ageing- and The English Longitudinal Study of Ageing HCAPs.
- TILDA-HCAP was carried out between 2021 and 2024, and included 1344 respondents and 982 informants.
- Detailed cognitive assessments were carried out in randomly selected respondents aged ≥65 years from The Irish Longitudinal Study on Ageing (TILDA) to provide a composite cognitive assessment that was appropriate for a research diagnosis of dementia and cognitive impairment.
- TILDA is unique among the HRS family of studies in its collection of objective cardiovascular, autonomic, neuropsychological, and sensory data. Linking HCAP to these data will enhance the understanding of risk factors and biomarkers of cognitive impairment and dementia.
- Pseudonymized TILDA data sets are available in public data archives, with TILDA-HCAP data forthcoming. All queries about data access should be addressed to tilda@tcd.ie.

The original cohort

The Irish Longitudinal Study on Ageing (TILDA) is a longitudinal study of a nationally representative sample of individuals who are aged ≥50 years and living in Ireland [1, 2]. The sampling and study design have been described previously [3]. Briefly, community-dwelling adults who are aged ≥50 years and their spouses (of any age) who were cognitively normal and able to provide informed consent were eligible to participate. The study started in 2009 and participants are reassessed every 2 years. The study has three components: a computer-assisted personal interview, a self-completion questionnaire, and a health assessment carried out by trained nurses, every two waves. Biomedical assessments include blood samples, anthropological measures, and detailed cardiovascular assessments. Blood and hair samples are analysed for biomarkers that are associated with a range of conditions such as age-related diseases, cardiovascular health, vision and nutritional deficiencies, epigenetics, genome-wide association studies, inflammation, allostatic load, immunity, neurocardiovascular instability, and frailty. The data currently span 12 years and Wave 6 took place in 2022/2023. The first four waves of TILDA were funded by the Irish Government, The Atlantic Philanthropies, and Irish Life Plc. Continued funding (Waves 5–9) was received from the Irish Government, managed through the Health Research Board.

The primary goal of TILDA is to provide evidence for understanding the physical, social, and economic circumstances that influence the aging process. Its objective is to investigate and determine the underlying causal pathways, and to contribute to the broader scientific understanding of aging. At Wave 6, a refreshment sample of new participants aged 45–64 years was also recruited to ensure that the overall sample remained representative of the Irish population who were aged ≥50 years and to better investigate the impact of mid-life characteristics on later-life outcomes. For up-to-date

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information about TILDA, see the study website (www.tilda.ie).

What is the reason for the new data collection?

Europe's population is rapidly aging—an unprecedented phenomenon that will increase the health, social, and economic burden of dementia and brain disorders [4]. In 2010, the annual direct and indirect cost of brain disorders to the European Union was €798 million, of which dementia disorders accounted for ∼€130 million or 17% of that cost [5]. The prospective aging of the Irish population will lead to similar increases in the number of people with dementia in Ireland [6].

Accurately capturing the prevalence and burden of dementia coupled with an understanding of risk factors is an important aim of many longitudinal studies of aging and in particular the Health and Retirement Study (HRS) family of longitudinal studies [7]. Such representative longitudinal studies are important to facilitate robust epidemiological and health economic projections [8]. Currently, there are insufficient data available to examine comparative dementia data internationally and to determine prevalence estimates from population-based studies that use similar diagnostic and research methods [9]. Furthermore, participant attrition can be associated with cognitive decline as such studies can be cognitively challenging [10]. To accommodate this, HRS and TILDA incorporate proxy interviews for participants who are unable to complete a self-interview and work to ensure that representation of these participants is retained, thus reducing bias due to cognitive abilities associated with nonresponse [10].

The diagnosis of dementia can be clinically challenging and is currently determined by consensus from medical experts who are informed by a combination of cognitive, physical, and disability tests coupled with neuroimaging and detailed neurological function tests. This approach is not practical in longitudinal population surveys. Consequently, HRS has developed and validated a new composite cognitive assessment that is appropriate for a research diagnosis of dementia and cognitive impairment (i.e. for population research and not clinical use) in large population surveys; it includes pertinent informant information and targeted cognitive tests [11]. The Harmonised Cognitive Assessment Protocol (HCAP), which has already been carried out by a number of HRS family studies including the English Longitudinal Study on Ageing (ELSA) [12], the China Health and Retirement Study [13], and the Longitudinal Aging Study India [14], will allow the global harmonization and validation of the protocol and provide global prevalence, incidence, predictors, and associations of dementia. The TILDA-HCAP assessment is identical to that of the HRS-HCAP and comprises ∼1 hour of face-to-face neuropsychological testing with the respondent and a further 20-minute interview with a knowledgeable informant. TILDA is one of the HRS family of studies but is unique in its collection of additional objective measures of cardiovascular, autonomic, and neuropsychological data, and measures of the senses. This additional information, which is harmonized to HCAP measures, will enhance the understanding of risk factors and cognitive biomarkers for future survey waves in the HRS family of studies that are participating in HCAP.

What will be the new areas of research?

To date, longitudinal data analyses of TILDA have investigated determinants for changing health, including cognitive decline. Cognitive decline was associated with several factors, including age-related cardiovascular changes [15, 16], mobility and health characteristics [17–19], nutrition [20], sleep [21], stress [22–24], allostatic load [23], social characteristics [25–27], and perceptions of aging [28]. Further details on all TILDA publications are available at https://tilda.tcd.ie/publications/. Future work will develop diagnostic criteria for dementia and mild cognitive impairment (MCI) by using HCAP. This will be harmonized across the HRS studies and then will be used to develop a national prevalence estimate for dementia. A further wave of TILDA-HCAP is planned in the future to allow incident impairment to be determined. Objective measures of brain health that are collected in the core study include neuroimaging, cerebral oxygenation using near-infrared spectroscopy, cortisol and other biological stress indicators, and multisensory integration. The unique objective health measures offer an opportunity to investigate the potential causal physiological, biological, and social pathways through cardiovascular disease, stress, and resilience to incident MCI and dementia. Examining progression rates from normal cognitive function to MCI and from MCI to dementia, along with the identification of associated risk factors, is of considerable public health relevance. To accomplish this, it is imperative to have closely harmonized, richly characterized, nationally representative data sets with sizable sample sizes and multiple waves of health measurements preceding the diagnosis. By interpreting these data at time points before and after cognitive decline, the impact of decline on social and community factors can be assessed. This will aid progress towards fulfilling the top priorities in dementia research and prevention as highlighted by the World Health Organization [29] to develop international collaborative research with open access to research data that will inform effective prevention or care strategies worldwide.

Who is in the cohort?

Figure 1 shows how participants were selected for the HCAP study. Participants were eligible for recruitment into the HCAP sub-study if they were members of the original TILDA cohort, aged ≥65 years, and had completed a computer-assisted telephone interview at Wave 6 of TILDA ($n = 3708$). Of these individuals, 50% were allocated to the HCAP study and the other 50% were allocated to a core Wave 6 health assessment ($n = 1830$). Fifty percent of the HCAP sample were selected at random from participants who were living alone and 50% from those who were living in couples. Core TILDA members who were living in nursing homes were eligible provided they had given a self-interview at Wave 6. Participants who were interviewed by proxy at Wave 6 were not eligible for recruitment into HCAP.

There was some evidence of an educational gradient in the TILDA-HCAP participation rates. Of the individuals who completed HCAP, 44% had tertiary-level education compared with 33% of those who were eligible but were unwilling to participate. Among the rest of the TILDA cohort at the baseline wave, 28% had tertiary-level education. HCAP respondents were also more likely to be in the highest quintile for household income (15%) compared with eligible individuals who were unwilling to participate.

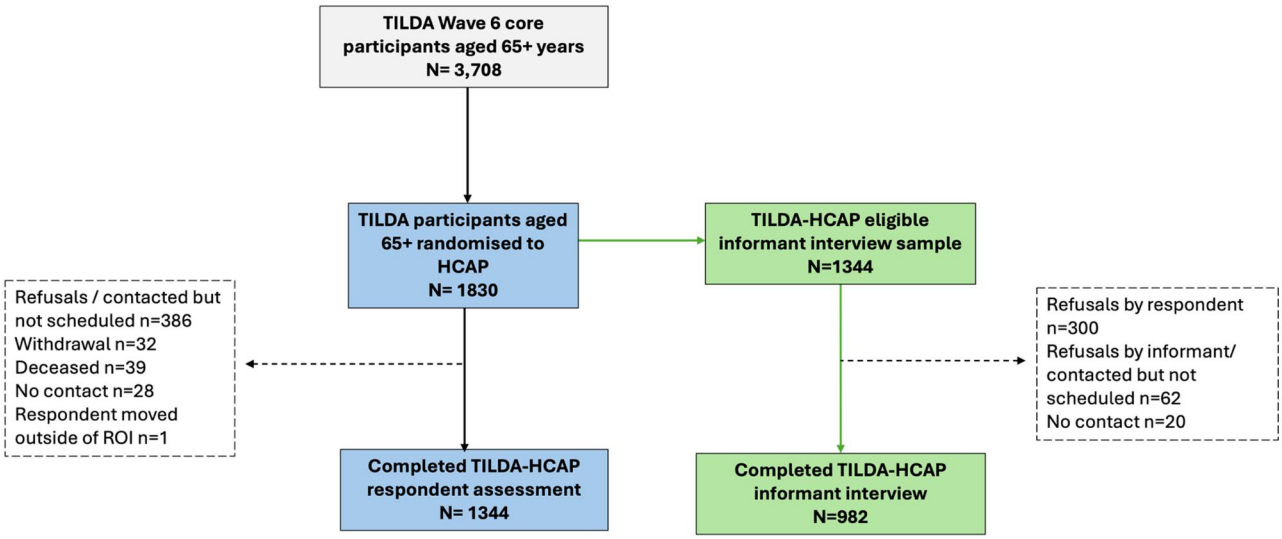

Figure 1. Flow diagram of respondent and informant selection through The Irish Longitudinal Study of Ageing Harmonised Cognitive Assessment Protocol. ROI, Republic of Ireland.

Training and fieldwork

Fieldwork took place between December 2021 and January 2024. University of Michigan personnel who were experienced in the administration of HCAP provided HCAP training and materials to the TILDA team. The TILDA-HCAP team also worked closely with the teams from sister studies that were conducted by the Northern Ireland Cohort for the Longitudinal Study of Ageing [30] and ELSA [12] to ensure cross-harmonization between the three studies.

Trained research nurses conducted the face-to-face assessment in the participants' own homes. Data were recorded by using computer-assisted personal interview techniques and specific health assessment software. Research nurse training focused particularly on the delivery of cognitive assessments to individuals who are cognitively impaired. HRS senior staff who were experienced in HCAP administration assisted TILDA in developing appropriate training protocols and delivering this training to TILDA research nurses. This ensured that the tests were delivered in a harmonized way with the HRS protocols. Tests were administered in the same order as in HRS-HCAP. Participants were assessed in their homes and verbal informed consent was obtained on the day.

Information from a knowledgeable informant is commonly used in both clinical and research assessments of cognitive impairment and dementia to assess any change in cognitive performance and limitation in activities. As part of HCAP, separate consent was obtained from the participant to seek an informant interview, after which the individual in question was approached with information, to seek consent and to conduct the interview. The informant interview is ideally conducted with someone who is in close and regular contact with the respondent, e.g. a spouse, family member, or carer, so that accurate information about any observed changes in function and cognition can be provided. Research assistants and nurses conducted informant interviews by phone.

TILDA-HCAP participant selection and response rates

Based on the eligible pool of participants, 1830 individuals were approached for recruitment into HCAP. As prospective respondents had taken part in Wave 6 of TILDA, they were familiar with the general procedures involved. Of the sample of 1830, 1344 interviews were obtained, giving a response rate of 73.4%. Table 1 shows the demographic characteristics of responders in terms of the proportion of individuals who were eligible for participation.

TILDA-HCAP informant selection and response rates

Interviews were also conducted with 982 informants, representing a response rate of 73.0% of the eligible sample ($n = 1344$). A large proportion of informants were children of the respondents (48.4%), with the remainder comprising spouses/partners (27.6%), siblings (10.4%), friends (8.2%), neighbors (0.3%), or other (5%). Informants other than children, siblings, or grandchildren reported knowing the respondent for an average of 43 years (SD = 13.6, range = 1–70).

Data quality

Quality-control (QC) checks were carried out by research staff. A protocol was devised and refined in the first few months of fieldwork. The final QC and scoring protocol consisted of tests that were difficult to score in real time during interviews and tasks that had a high error rate during the initial QC checks. The administration of certain cognitive tests was also audio recorded to aid in scoring and QC. The QC procedure took 15–20 minutes per respondent. After fieldwork completion, both the respondent and informant data sets were further checked for data-entry errors and any inappropriate assignment of response categories was corrected.

How often have they been followed up?

Only Wave 1 of the TILDA-HCAP sub-study has been carried out so far; however, respondents will continue to take part in the main study waves and will be followed up as part of that study. Future funding will be applied for to carry out repeat waves of HCAP.

What has been measured?

There are two components to the TILDA-HCAP data collection: the objective cognitive testing of the respondent,

Table 1. The response rate to TILDA-HCAP by demographic characteristics

Characteristic	Respondent interview		Informant interview	
	Eligible, *n*	Completed, *n* (% of eligible)	Eligible, *n*	Completed, *n* (% of eligible)
Age group, *n* (%)				
65–74 years	1040	790 (76.0%)	790	587 (74.3%)
75–84 years	617	441 (71.5%)	441	315 (71.4%)
85+ years	173	113 (65.3%)	113	80 (70.8%)
Sex, *n* (%)				
Male	796	581 (73.0%)	581	440 (75.7%)
Female	1034	763 (73.8%)	763	542 (71.0%)
Education, *n* (%)				
Primary	374	257 (68.7%)	257	161 (62.6%)
Secondary	711	500 (70.3%)	500	361 (72.2%)
Tertiary	745	587 (78.8%)	587	460 (78.4%)
Location				
Dublin city or county	431	332 (77.0%)	332	256 (77.1%)
Other town/city	520	369 (71.0%)	369	262 (71.0%)
Rural	879	643 (73.1%)	643	464 (72.2%)
Total	1830	1344	1344	982

Ages provided reflect the age at the beginning of HCAP fieldwork. Primary, secondary, and tertiary education correspond to ≤8, 9–13, and >13 years of education, respectively.
TILDA-HCAP, The Irish Longitudinal Study on Ageing Harmonised Cognitive Assessment Protocol.

Table 2. Battery of cognitive tests included in TILDA-HCAP respondent and informant interviews, and correspondence with the main waves of TILDA

Harmonized cognitive assessment	TILDA-HCAP	TILDA main waves
TILDA-HCAP respondent interview		
Mini-Mental State Examination (MMSE)	✔	✔ (CAPI)
HRS Telephone Interview for Cognitive Status (HRS-TICS)	✔	x
CERAD word-list recall—immediate	✔	✔ (CAPI)[a]
Retrieval fluency (animals)	✔	✔ (CAPI)
Letter cancellation	✔	X
Backward count	✔	X
10/66 Community Screening Instrument for Dementia (CSID)	✔	X
CERAD word-list recall—delayed	✔	✔ (CAPI)[a]
East Boston Memory Test—immediate	✔	X
Wechsler Memory Scale–IV—immediate	✔	X
CERAD word list—recognition	✔	X
Constructional praxis—immediate	✔	X
Symbol digit modalities test (SDMT)	✔	X
CERAD word list—recognition	✔	X
CERAD Constructional praxis—immediate	✔	X
SDMT	✔	X
Constructional praxis—delayed	✔	X
East Boston Memory Test—delayed	✔	X
Wechsler Memory Scale–IV—delayed	✔	X
Wechsler Memory Scale–IV—recognition	✔	X
Number series	✔	X
Raven's Matrices	✔	X
Trail Making Test A & B	✔	✔ (HA)[b]
TILDA-HCAP informant interview		
Jorm informant questionnaire on cognitive decline in the elderly (IQCODE)	✔	✔ (proxy interview)
Blessed dementia rating scale-part 2	✔	X
HRS activities questionnaire	✔	X
Community Screening Instrument for Dementia (CSI-D) cognitive activities questionnaire	✔	X
10/66 research group informant questionnaire	✔	X
Blessed dementia rating scale-part 1	✔	X

[a] Main waves include different word lists. [b]Main wave includes a different trail making test (Color Trails Test).
✔ indicates test was included; **X** indicates test was not included.
CAPI, computer-assisted personal interview; CERAD, Consortium to Establish a Registry for Alzheimer's Disease; EBMT, East Boston Memory Test; HA, health assessment; SDMT, Symbol Digit Modalities Test; TILDA-HCAP, The Irish Longitudinal Study on Ageing Harmonised Cognitive Assessment Protocol.

conducted face-to-face; and a telephone interview with their nominated informant. Table 2 lists the cognitive tests that were used in the respondent interview and the instruments that were included in the informant interview. The tests were designed to assess different domains of cognitive functioning, namely memory, executive function (including attention), language, orientation, and visuospatial ability. It was expected that a certain proportion of respondents would not complete all of the HCAP tests, so core cognitive measures [Mini-Mental State Examination, HRS Telephone Interview

for Cognitive Status, Consortium to Establish a Registry for Alzheimer's Disease (CERAD) word-list recall and recognition, retrieval fluency, letter cancellation, backward counting, East Boston Memory Test, and Wechsler Memory Scale–IV] were included in the first half of the assessment to maximize the chances that these would be completed.

The informant interview was a structured interview that comprised questions about the health of the respondent, their functional and cognitive abilities, and any changes over time. Informants were asked questions about the respondent's ability to carry out activities of daily living and their engagement in social and leisure activities. Informants were also asked whether the respondent had ever received any diagnosis of stroke, dementia, or Parkinson's disease. The instruments and question sets included are described in Table 2.

What has it found? Key findings and publications

The TILDA-HCAP sub-study provides a detailed neuropsychological and clinical assessment of a random sample of individuals aged ≥65 years that can be extrapolated to the rest of the TILDA population and, by extension, to those who are living in the community in Ireland. Table 3 shows the sociodemographic and health characteristics of the sample as a whole and divided by gender. Men were more likely than women to be married or living with a partner and have a higher household income. They were also more likely to smoke and drink alcohol frequently, to be more physically active, and to rate their health as excellent or very good. On the other hand, women were more likely to be lonely and to be impaired in at least one instrumental activity of daily living. Table 4 shows the mean (unweighted) scores from each of the tests for the sample and by age group. Analyses to assign a classification of no cognitive impairment, MCI, or dementia are underway, with the goal of estimating the prevalence of dementia and MCI in the older adult population in Ireland. TILDA-HCAP preliminary data are also being used for several small pilot projects focused on refining the HCAP methodology.

What are the main strengths and weaknesses?

The main strengths of this study are the robust sampling procedures, study design, and harmonization with other HRS-HCAP studies. The close harmonization of the study protocol with other international HCAP studies will allow investigations of global prevalence, incidence, predictors, and associations of dementia. Because TILDA-HCAP is embedded within a nationally representative longitudinal study with large numbers of objective physical measures, cognitive measures, and genomics, it provides rich phenotyping by dementia status and the necessary data to facilitate the extrapolation of results to the Irish population.

Several limitations of the study should be acknowledged. The HCAP study sample differs somewhat, particularly by educational attainment, from the main TILDA cohort. However, the availability of the linked TILDA study data set will allow the development of weights based on prior TILDA participation, which will provide an opportunity to correct

Table 3. Sociodemographic and health characteristics of TILDA-HCAP respondents

Characteristic	Overall HCAP sample, mean (SD)/%	Men, mean (SD)/%	Women, mean SD)/%	*P*-value
Age	75.059 (6.59)	75.47 (6.45)	75.68 (6.69)	0.563
Educational attainment				
Primary/none	257 (19.12)	123 (21.17)	134 (17.56)	
Secondary	500 (37.20)	213 (36.66)	287 (37.61)	
Third/higher	587 (43.68)	245 (42.17)	342 (44.82)	0.240
Geographical region				
Dublin city or county	332 (24.70)	140 (24.10)	192 (25.16)	
Other town/city	369 (27.46)	152 (26.16)	217 (28.44)	
Rural	643 (47.84)	289 (49.74)	354 (46.40)	0.461
Married/living with partner	782 (58.18)	398 (68.50)	384 (50.33)	0.000
Socioeconomic group (quintiles)				
Lowest	214 (20.68)	78 (17.07)	136 (23.53)	
2nd	196 (18.94)	85 (18.60)	111 (19.20)	
3rd	218 (21.06)	98 (21.44)	120 (20.76)	
4th	194 (18.74)	82 (17.94)	112 (19.38)	
Highest	213 (20.58)	114 (24.95)	99 (17.13)	0.011
Excellent/very good self-reported health	734 (54.61)	335 (57.66)	399 (52.29)	0.050
Depressive symptoms[a]	18 (1.38)	4 (0.71)	14 (1.88)	0.073
Lonely (often/sometimes)[b]	391 (33.53)	123 (25.05)	268 (39.70)	0.000
Physical activity				
Low	390 (29.08)	138 (23.79)	252 (33.11)	
Moderate	588 (43.85)	221 (38.10)	367 (48.23)	
High	363 (27.07)	221 (38.10)	142 (18.66)	0.000
Smoking				
Never	652 (48.51)	238 (40.96)	414 (54.26)	
Past	602 (44.79)	302 (51.98)	300 (39.32)	
Current	90 (6.70)	41 (7.06)	49 (6.42)	0.000
Daily alcohol consumption	72 (6.12)	47 (9.40)	25 (3.70)	0.000
Impaired on at least one instrumental activities of daily living (IADLs)	91 (6.77)	27 (4.65)	64 (8.39)	0.007
Impaired on at least one activities of daily living (ADLs)	134 (9.97)	56 (9.64)	78 (10.22)	0.723

Age corresponds to age on the date of interview.
[a] Depressive symptoms established by using a threshold of 9 on an 11-item version of the Centre for Epidemiological Studies Depression Scale (CES-D).
[b] Loneliness ascertained by using Item 5 of the University of California Los Angeles (UCLA) Loneliness scale: 'How often do you feel lonely?'
TILDA-HCAP, The Irish Longitudinal Study on Ageing Harmonised Cognitive Assessment Protocol.

Table 4. Descriptive statistics presenting raw means and standard deviation of the cognitive tests included in TILDA-HCAP respondent interview by age group

	Overall		65–74 years		75–84 years		≥85 years	
Test	*n*	Mean (SD)	*n*	Mean (SD)	*n*	Mean (SD)	*n*	Mean (SD)
MMSE	1294	28.38 (1.95)	648	28.87 (1.51)	499	28.11 (2.18)	99	27.23 (2.17)
HRS-TICS	1341	2.88 (0.34)	662	2.92 (0.27)	518	2.86 (0.35)	161	2.73 (0.47)
CERAD word list								
Immediate	1339	19.57 (4.46)	664	20.91 (3.95)	516	18.92 (4.38)	159	16.11 (4.43)
Delayed	1341	5.94 (2.41)	664	6.64 (2.17)	517	5.60 (2.31)	160	4.12 (2.53)
Recognition	1290	19.16 (1.45)	635	19.46 (1.04)	497	19.09 (1.47)	158	18.15 (2.14)
Retrieval fluency	1343	18.05 (5.96)	664	19.27 (5.66)	518	17.43 (6.02)	161	14.98 (5.60)
Letter cancellation	1325	15.54 (4.41)	660	16.70 (4.13)	512	14.89 (4.23)	153	12.78 (4.45)
Backwards count	1320	32.47 (11.70)	655	34.71 (11.73)	507	30.36 (9.91)	158	29.94 (14.81)
CSID	1340	3.95 (0.24)	663	3.96 (0.19)	515	3.97 (0.16)	162	3.86 (0.47)
EBMT								
Immediate	1335	2.74 (1.16)	661	2.91 (1.20)	515	2.68 (1.10)	159	2.21 (1.04)
Delayed	1328	1.43 (1.11)	661	1.61 (1.15)	512	1.30 (1.05)	155	1.09 (0.98)
Wechsler–IV								
Immediate	1330	9.01 (4.13)	658	9.94 (4.05)	515	8.48 (3.89)	157	6.81 (4.13)
Delayed	1315	6.33 (3.99)	657	7.26 (3.98)	508	5.77 (3.76)	150	4.12 (3.56)
Recognition	1260	10.58 (2.28)	641	11.05 (2.18)	486	10.21 (2.28)	133	9.61 (2.20)
Constructional praxis								
Copy	1323	8.99 (1.79)	655	9.26 (1.67)	512	8.82 (1.82)	156	8.49 (2.00)
Delayed recall	1198	7.00 (2.83)	612	7.75 (2.49)	457	6.47 (2.80)	129	5.36 (3.30)
SDMT	1316	31.99 (10.81)	657	36.24 (9.87)	507	29.47 (9.72)	153	22.05 (8.84)
Number series	1219	527.24 (32.01)	613	533.59 (28.68)	469	523.45 (33.08)	137	511.84 (35.21)
Ravens Matrices	1292	12.94 (3.02)	645	13.67 (2.77)	498	12.46 (3.06)	149	11.41 (3.05)
TMT A	1310	50.36 (25.05)	653	42.48 (17.76)	507	54.82 (25.46)	150	69.59 (34.95)
TMT B	1235	123.66 (56.06)	638	106.71 (45.21)	468	134.36 (57.11)	129	168.68 (68.82)

CERAD, Consortium to Establish a Registry for Alzheimer's Disease; CSID, Community Screening Instrument for Dementia; EBMT, East Boston Memory Test; HRS-TICS, Health and Retirement Study Telephone Interview for Cognitive Status; MMSE, Mini-Mental State Examination; SDMT, Symbol Digit Modalities Test; TILDA-HCAP, The Irish Longitudinal Study on Ageing Harmonised Cognitive Assessment Protocol; TMT A, Trail Making Test part A; TMT B, Trail Making Test part B.

for this potential bias. The TILDA sample was originally drawn from community-dwelling participants and includes only a limited number of proxy and nursing-home respondents, whom we were unable to recruit into TILDA-HCAP. A future wave of TILDA-HCAP would include proxy-only respondent interviews to improve our assessment of dementia in those who are too ill or frail to take part in the sub-study.

Can I get hold of the data? Where can I find out more?

Currently, researchers can apply to access TILDA data through the Irish Social Science Data Archive (ISSDA) at University College Dublin (https://www.ucd.ie/issda/data/tilda/), with TILDA-HCAP data forthcoming. TILDA-HCAP data are currently in the process of being archived on the Gateway to Global Aging Data Enclave. The Gateway to Global Aging also offers a digital library of survey questions and identically defined variables, allowing comparison of TILDA data to population survey data on aging that were obtained from several other countries (https://g2aging.org/?section=homepage).

Ethics approval

THE TILDA-HCAP received ethical approval from the Faculty of Health Sciences Research Ethics Committee at Trinity College Dublin.

Use of artificial intelligence (AI) tools

No AI tools were used in the collection and/or analysis of the data, or in producing images or graphical elements of the paper.

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Author contributions

J.F. and C.M.G. prepared the manuscript. D.W., R.A.K., C. M.G. A.M., and B.L. contributed to the study concept and design. J.F., S.M.L., C.D.L., and G.O. carried out the analysis and interpretation of the data. All authors contributed to and revised the draft for final approval.

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Data availability

See "Can I get hold of the data?" above. Any other queries about data access should be forwarded to tilda@tcd.ie. General enquiries can be submitted to Dr Ann Monaghan, at ann.monaghan@tcd.ie.

References

1. Kearney PM, Cronin H, O'Regan C *et al.* Cohort Profile: The Irish Longitudinal Study on Ageing. *Int J Epidemiol* 2011;**40**:877–84.
2. Donoghue OA, McGarrigle CA, Foley M, Fagan A, Meaney J, Kenny RA. Cohort Profile Update: The Irish Longitudinal Study on Ageing (TILDA). *Int J Epidemiol* 2018;**47**:1398–l.
3. Whelan BJ, Savva GM. Design and methodology of the Irish Longitudinal Study on Ageing. *J Am Geriatr Soc* 2013;**61 Suppl 2**:S265–8.
4. Misiak B, Cialkowska-Kuzminska M, Frydecka D, Chladzinska-Kiejna S, Kiejna A. European studies on the prevalence of dementia in the elderly: time for a step towards a methodological consensus. *Int J Geriatr Psychiatry* 2013;**28**:1211–21.
5. Gustavsson A, Svensson M, Jacobi F *et al.*; CDBE2010Study Group. Cost of disorders of the brain in Europe 2010. *Eur Neuropsychopharmacol* 2011;**21**:718–79.
6. Connolly S, Gillespie P, O'Shea E, Cahill S, Pierce M. Estimating the economic and social costs of dementia in Ireland. *Dementia (London)* 2014;**13**:5–22.
7. Sonnega A, Faul JD, Ofstedal MB, Langa KM, Phillips JW, Weir DR. Cohort Profile: the Health and Retirement Study (HRS). *Int J Epidemiol* 2014;**43**:576–85.
8. World Health Organization. *Optimizing Brain Health across the Life Course: WHO Position Paper*. Geneva; 2022. https://iris.who.int/bitstream/handle/10665/361251/9789240054561-eng.pdf (9 August 2022, date last accessed).
9. Wu YT, Beiser AS, Breteler MMB *et al.* The changing prevalence and incidence of dementia over time—current evidence. *Nat Rev Neurol* 2017;**13**:327–39.
10. Weir D, Faul J, Langa K. Proxy interviews and bias in the distribution of cognitive abilities due to non-response in longitudinal studies: a comparison of HRS and ELSA. *Longit Life Course Stud* 2011;**2**:170–84.
11. Langa KM, Ryan LH, McCammon RJ *et al.* The health and retirement study harmonized cognitive assessment protocol project: study design and methods. *Neuroepidemiology* 2020;**54**:64–74.
12. Cadar D, Abell J, Matthews FE *et al.* Cohort Profile Update: The Harmonised Cognitive Assessment Protocol Sub-study of the English Longitudinal Study of Ageing (ELSA-HCAP). *Int J Epidemiol* 2021;**50**:725–726i.
13. Meng Q, Wang H, Strauss J *et al.* Validation of neuropsychological tests for the China Health and Retirement Longitudinal Study Harmonized Cognitive Assessment Protocol. *Int Psychogeriatr* 2019;**31**:1709–19.
14. Banerjee J, Jain U, Khobragade P *et al.* Methodological considerations in designing and implementing the harmonized diagnostic assessment of dementia for longitudinal aging study in India (LASI-DAD). *Biodemography Soc Biol* 2020;**65**:189–213.
15. McNicholas T, Tobin K, Carey D, O'Callaghan S, Kenny RA. Is Baseline Orthostatic Hypotension Associated With a Decline in Global Cognitive Performance at 4-Year Follow-Up? Data From TILDA (The Irish Longitudinal Study on Ageing). *J Am Heart Assoc* 2018;**7**:e008976.
16. Knight SP, Newman L, Scarlett S *et al.* Associations between cardiovascular signal entropy and cognitive performance over eight years. *Entropy (Basel)* 2021;**23**:1337.
17. De Looze C, Williamson W, Demnitz N, O'Connor D, Hernández B, Kenny RA. Physical function, an adjunct to brain health score for phenotyping cognitive function trajectories in older age: findings from The Irish Longitudinal Study on Ageing (TILDA). *J Gerontol A Biol Sci Med Sci* 2022;**77**:1593–602.
18. Hartley P, Monaghan A, Donoghue OA, Kenny RA, Romero-Ortuno R. Exploring bi-directional temporal associations between timed-up-and-go and cognitive domains in the Irish longitudinal study on ageing (TILDA). *Arch Gerontol Geriatr* 2022;**99**:104611.
19. Maasakkers CM, Claassen J, Scarlett S *et al.* Is there a bidirectional association between sedentary behaviour and cognitive decline in older adults? Findings from the Irish Longitudinal Study on Ageing. *Prev Med Rep* 2021;**23**:101423.
20. O'Connor DMA, Scarlett S, De Looze C *et al.* Low folate predicts accelerated cognitive decline: 8-year follow-up of 3140 older adults in Ireland. *Eur J Clin Nutr* 2022;**76**:950–7.
21. Ryan DJ, De Looze C, McGarrigle CA, Scarlett S, Kenny RA. Examining mental health and autonomic function as putative mediators of the relationship between sleep and trajectories of cognitive function: findings from the Irish longitudinal study on ageing (TILDA). *Aging Ment Health* 2024;**28**:1634–41.
22. Feeney JC, O'Halloran AM, Kenny RA. The Association Between Hair Cortisol, Hair Cortisone, and Cognitive Function in a Population-Based Cohort of Older Adults: Results From The Irish Longitudinal Study on Ageing. *J Gerontol A Biol Sci Med Sci* 2020;**75**:257–65.
23. De Looze C, McCrory C, O'Halloran A, Polidoro S, Anne Kenny R, Feeney J. Mind versus body: Perceived stress and biological stress are independently related to cognitive decline. *Brain Behav Immun* 2024;**115**:696–704.
24. Feeney J, O'Sullivan M, Kenny RA, Robertson IH. Change in perceived stress and 2-year change in cognitive function among older adults: The Irish Longitudinal Study on Ageing. *Stress Health* 2018;**34**:403–10.
25. Orr J, Ward M, Kenny RA, McGarrigle CA. Mini-mental state examination trajectories after age 50 by religious affiliation and practice in Ireland. *Eur J Ageing* 2021;**18**:565–74.
26. Loughrey DG, Feeney J, Kee F *et al.* Social factors may mediate the relationship between subjective age-related hearing loss and episodic memory. *Aging Ment Health* 2021;**25**:824–31.
27. McHugh Power J, Tang J, Kenny RA, Lawlor BA, Kee F. Mediating the relationship between loneliness and cognitive function: the role of depressive and anxiety symptoms. *Aging Ment Health* 2020;**24**:1071–8.
28. McGarrigle CA, Ward M, Kenny RA. Negative aging perceptions and cognitive and functional decline: Are you as old as you feel? *J Am Geriatr Soc* 2022;**70**:777–88.
29. World Health Organization. *Global Action Plan on the Public Health Response to Dementia 2017–2025*. Geneva: World Health Organization; 2017. Report No.: Licence: CC BY-NC-SA 3.0 IGO. https://iris.who.int/bitstream/handle/10665/259615/9789241513487-eng.pdf? (7 December 2017, date last accessed).
30. O'Hara L, Neville C, Marr C *et al.* Investigating the prevalence of cognitive impairment and dementia in the Northern Ireland Cohort for the Longitudinal Study of Ageing (NICOLA): the Harmonised Cognitive Assessment Protocol (HCAP) cross-sectional substudy. *BMJ Open* 2024;**14**:e075672.

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Cohort Profile