Texas Alzheimer's Research & Care Consortium Longitudinal Data Set (LDS)

Form A1: Subject Demographics

Center: _____ TARCC Subject ID: _____ _____ _____ _____ _____ _____ Visit Date: __ __/ __ __/ __ __ __ __
m m d d y y y y

TARCC Visit #: __ __

Examiner's initials: __ __ __

BIRTHYR

1. Subject's year of birth: _____ y y y

SEX

2. Subject's sex: ☐ 1 Male ☐ 2 Female

If follow-up visit, skip to item #8.

HISPANIC

3a. Does the subject report being of Hispanic/Latino ethnicity (i.e., having origins from a mainly Spanish-speaking Latin American country), regardless of race?
☐ 1 Yes
☐ 0 No
☐ 9 Unknown

HISPOR

3b. If yes, what are the subject's reported origins?
☐ 1 Mexican/Chicano/ Mexican-American/
☐ 2 Puerto Rican
☐ 3 Cuban
☐ 4 Dominican
☐ 5 Central American
☐ 6 South American
☐ 50 Other (*specify*): _____
☐ 99 Unknown

HISPORX

RACE

4. What does subject report as his/her race?
☐ 1 White
☐ 2 Black or African American
☐ 3 American Indian or Alaska Native
☐ 4 Native Hawaiian or Other Pacific Islander
☐ 5 Asian
☐ 50 Other (*specify*): _____
☐ 99 Unknown

RACEX

RACESEC

5. What additional race does subject report?
☐ 1 White
☐ 2 Black or African American
☐ 3 American Indian or Alaska Native
☐ 4 Native Hawaiian or Other Pacific Islander
☐ 5 Asian
☐ 50 Other (*specify*): _____
☐ 88 None reported
☐ 99 Unknown

RACESECX

Center: _____ TARCC Subject ID: ____ ____ ____ ____ ____ ____ Visit Date: __ __/ __ __/ __ __ __ __
m m d d y y y y

TARCC Visit #: __ __
Examiner's initials: __ __ __

Check only one box per question.

RACETER

6. What additional race, beyond what was indicated above in questions 4 and 5, does subject report?	☐ 1 White ☐ 2 Black or African American ☐ 3 American Indian or Alaska Native ☐ 4 Native Hawaiian or Other Pacific Islander	☐ 5 Asian ☐ 50 Other (*specify*): _____ ☐ 88 None reported ☐ 99 Unknown

RACETERX

7. Subject's primary language:	☐ 1 English ☐ 2 Spanish ☐ 3 Mandarin ☐ 4 Cantonese ☐ 5 Russian	☐ 6 Japanese ☐ 8 Other primary language (*specify*): _____ ☐ 9 Unknown

PRIMLANG

PRIMLANGX

8. Subject's years of education (report achieved level using the codes below; if an attempted level is not completed, enter the number of years attended). High school/GED = 12; Bachelors degree = 16; Master's degree = 18; Doctorate = 20 years: __ (*99 = Unknown*)

EDUC

9. What is the subject's living situation?	☐ 1 Lives alone ☐ 2 Lives with spouse or partner ☐ 3 Lives with relative or friend	☐ 4 Lives with group ☐ 5 Other (*specify*): _____ ☐ 9 Unknown

LIVSIT

LIVSITX

10. What is the subject's level of independence?	☐ 1 Able to live independently ☐ 2 Requires some assistance with complex activities	☐ 3 Requires some assistance with basic activities ☐ 4 Completely dependent ☐ 9 Unknown

INDEPEND

11. What is the subject's type of residence?	☐ 1 Single family residence ☐ 2 Retirement community Entry Date: __/__/____ ☐ 3 Assisted living/ boarding home/adult family home Entry Date: __/__/____	☐ 4 Skilled nursing facility/ nursing home Entry Date: __/__/____ ☐ 5 Other (*specify*): _____ ☐ 9 Unknown

RESIDENC

RESID_ENT_DAT

RESIDENX

12. Subject's primary residence zip code (first 3 digits): __ __ __ (*leave blank if unknown*)

ZIP

Center: _____ TARCC Subject ID: ____ ____ ____ ____ ____ ____ Visit Date: __ __/ __ __/ __ __ __ __
m m d d y y y y

TARCC Visit #: __ __

Check only one box per question. Examiner's initials: __ __ __

13. Subject's current marital status: MARISTAT	☐ 1 Married ☐ 2 Widowed ☐ 3 Divorced ☐ 4 Separated	☐ 5 Never married ☐ 6 Living as married ☐ 8 Other (*specify*): _____ MARISTATX ☐ 9 Unknown
14. Is the subject left- or right-handed (for example, which hand would s/he normally use to write or throw a ball)? (Collect at baseline only) HANDED	☐ 1 Left-handed ☐ 2 Right-handed	☐ 3 Ambidextrous ☐ 9 Unknown

Texas Alzheimer's Research & Care Consortium Longitudinal Data Set (LDS)

Form A3: Subject Family History

Center: ____ TARCC Subject ID: ____ ____ ____ ____ ____ ____ Visit Date: __ __/__ __/__ __ __ __
m m d d y y y y

TARCC Visit #: __ __

Check only one box per question. Examiner's initials: __ __ __

For the following questions:

Dementia refers to progressive loss of memory and cognition, and is often described as senility, dementia, Alzheimer's Disease, hardening of the arteries, or other causes that compromised the subject's social or occupational functioning and from which they did not recover.

Please consider blood relatives only.

PARENTS:

MOMDEM

1. Did the subject's mother have dementia (as defined above), as indicted by symptoms, history or diagnosis? ☐ 1 Yes ☐ 0 No ☐ 9 Unknown

2. Did the subject's father have dementia (as defined above), as indicated by symptoms, history or diagnosis? ☐ 1 Yes ☐ 0 No ☐ 9 Unknown

DADDEM

SIBLINGS:

TWIN

3. Is the subject a twin? (Collect at baseline only) ☐ 1 Yes ☐ 0 No ☐ 9 Unknown

SIBS

4. How many full siblings did the subject have? *(99 = Unknown)* __ __

SIBSDEM

5. How many of these siblings had dementia (as defined above), as indicated by symptoms, history or diagnosis? *(99=Unknown; 88= N/A)* __ __

CHILDREN:

KIDS

6. How many biological children did the subject have? *(99 = Unknown)* __ __

KIDSDEM

7. How many of these children had dementia (as defined above), as indicated by symptoms, history or diagnosis? *(99=Unknown; 88= N/A)* __ __

Texas Alzheimer's Reasearch & Care Consortium Longitudinal Data Set (LDS)
Form A4: Subject Medications

Center: _____ TARCC Subject ID: ____ ____ ____ ____ Visit Date: __ __/__ __/__ __ __ __ (m m d d y y y y) TARCC Visit #: __ __

PMEDS

Instructions:
Record prescription and non-prescription non-steroidal anti-inflamma[illegible]y agents (NSAIDs), Vitamin E, Anti-dementia drugs, systemic steroids, chemotheraphy and other anti-inflammatories. For [illegible]h table (1 through 4), list all current drugs in that category. Complete all columns the first time the drug is recorded. At [illegible]bsequent visits, if the route, strength, frequency and start date have not changed, enter the drug name and check the box in column 1 (previously captured) only.

Exam[illegible] __ __ __

ADASTMO ADASTDA ADASTYR

1. Is the subject currently taking any NSAID medications? 1 Yes ○ 2 No ○

PMAF PMAFU

PMAPREV PMASU PMART PMAS PMA PMAP

List all curre[illegible] NSAIDs	(1) Check if columns (2) – (8) previously captured on an A4 form.	(2) Route	(3) Strength	(4) µg	mg	mL	IU	# D[illegible]ses	(5) D	W	M	(7) Start [illegible]ate	(8) Yes	No
[illegible]rescription NSAID [illegible]nedication name ([illegible]ease PRINT clearly)														
a)	☐			○1	○2	○3	○4		○1	○2	○3	___/___/_____	○1	○0
b)	☐			○1	○2	○3	○4		○1	○2	○3	___/___/_____	○1	○0
c)	☐			○1	○2	○3	○4		○1	○2	○3	___/___/_____	○1	○0
d)	☐			○1	○2	○3	○4		○1	○2	○3	___/___/_____	○1	○0
Non-prescription NSAID (please PRINT clearly)														
a)	☐			○1	○2	○3	○4		○1	○2	○3			
b)	☐			○1	○2	○3	○4		○1	○2	○3			
c)	☐			○1	○2	○3	○4		○1	○2	○3			
d)	☐			○1	○2	○3	○4		○1	○2	○3			

PMB, etc.
PMC, etc.
PMD, etc.

NMA, etc.
NMB, etc.
NMC, etc.
NMD, etc.

Do not record PRN non-prescription NSAIDs

Route: PO = Oral IM = Intramuscular IV = Intravenous SC = Subcutaneous TOP = Topical ID = Intradermal SL = Sublingual IN = Intranasal

Texas Alzheimer's Research & Care Consortium Longitudinal Data Set (LDS)
Form A4: Subject Medications

Center: _____ TARCC Subject ID: ____ ____ ____ ____ ____ ____ Visit Date: __ __/__ __/__ __ __ __ (m m d d y y y y) TARCC Visit #: __ __

...er's initials: __ __ __

2. Vitamin E History: a) Is the patient currently taking Vitamin E? 1 Yes ○ 2 No ○
b) Has the patient ever taken Vitamin E? 1 Yes ○ 2 No ○

VITENOW VITEEVER VEAPREV VEART VEA VEAS VEASU VEAF VEAFU VEASTMO VEASTDA VEASTYR

List all current vitamin E drugs.

(1) Vitamin E (please PRINT clearly)	(2) Check if columns (3) – (8) previously captured on an A4 form.	(3) Route	(4) Strength	(5) µg	mg	mL	IU	(6) # Doses	(7) D	W	M	(8) Start date
	☐			○1	○2	○3	○4		○1	○2	○3	___/___/_____
	☐			○1	○2	○3	○4		○1	○2	○3	___/___/_____
	☐			○1	○2	○3	○4		○1	○2	○3	___/___/_____
	☐			○1	○2	○3	○4		○1	○2	○3	___/___/_____

VEB, etc. VEC, etc. VED, etc.

ADMEDNOW ADMEDEVER

3. Anti-Dementia Drug History: a) Is the patient currently taking anti-dementia medication? 1 Yes ○ 2 No ○
b) Has the patient ever taken anti-dementia medication? 1 Yes ○ 2 No ○

List all current anti-dementia drugs. (See instructions below)

(1) Anti-dementia Drugs (See code list)	(2) Check if columns (3) – (8) previously captured on an A4 form.	(3) Route	(4) Strength	(5) µg	mg	mL	IU	(6) # Doses	(7) D	W	M	(8) Start date
a)	☐			○1	○2	○3	○4		○1	○2	○3	___/___/_____
b)	☐			○1	○2	○3	○4		○1	○2	○3	___/___/_____
c)	☐			○1	○2	○3	○4		○1	○2	○3	___/___/_____
d)	☐			○1	○2	○3	○4		○1	○2	○3	___/___/_____
e)	☐			○1	○2	○3	○4		○1	○2	○3	___/___/_____
f)	☐			○1	○2	○3	○4		○1	○2	○3	___/___/_____

ADA, etc. ADB, etc. ADC, etc. ADD, etc. ADE, etc. ADF, etc.

(1): A = Donepezil (Aricept) B = Galantamine (Reminyl) C = Rivastigmine (Exelon) D = Tacrine E = Memantine (Namenda) F = Other (Please print name of drug.) G = Capriylidene (Axona)

Route: PO = Oral IM = Intramuscular IV = Intravenous SC = Subcutaneous TOP = Topical ID = Intradermal SL = Sublingual IN = Intranasal

Texas Alzheimer's Research & Care Consortium Longitudinal Data Set (LDS)
Form A4: Subject Medications

Center: _____ TARCC Subject ID: ____ ____ ____ ____ ____ ____ Visit Date: __ __/__ __/__ __ __ __ TARCC Visit #: __ __
m m d d y y y y

Examiner's initials: __ __ __

4. Use of systemic steroids, chemotherapy and anti-inflammatories (except NSAIDs) at baseline is exclusionary. If these treatments are initiated after baseline, please record below.

SSAPREV SSART SSASTMO SSASTDA SSASTYR SSA SSAS SSASU SSAF SSAFU

List all current systemic steroids, chemotherapy drugs and anti-inflammatories (except NSAIDs)	(2) Check if columns (3) – (8) previously captured on an A4 form.	(3) Route	Medication strength: Enter numeric value for strength, then indicate the appropriate unit of measure (µg, mg, mL, IU). Code 99999 for unknown. (4) Strength	(5) µg	mg	mL	IU	Frequency: Enter numeric value for total number of doses taken per Day, Week, or Month. Code 99 for unknown. (6) # Doses	(7) D	W	M	Enter complete date where possible. Code 9 for unknown month, day. Code 99 for unknown year. (8) Start date
a)	☐			○1	○2	○3	○4		○1	○2	○3	___/___/_____
b)	☐			○1	○2	○3	○4		○1	○2	○3	___/___/_____
c)	☐			○1	○2	○3	○4		○1	○2	○3	___/___/_____
d)	☐			○1	○2	○3	○4		○1	○2	○3	___/___/_____
e)	☐			○1	○2	○3	○4		○1	○2	○3	___/___/_____
f)	☐			○1	○2	○3	○4		○1	○2	○3	___/___/_____

SSB, etc.
SSC, etc.
SSD, etc.
SSE, etc.
SSF, etc.

Route: PO = Oral IM = Intramuscular IV = Intravenous SC = Subcutaneous TOP = Topical ID = Intradermal SL = Sublingual IN = Intranasal

DRG_TRIAL

5. Is the subject in an investigational anti-dementia drug trial? ₁**Yes** ○ ₂**No** ○

If yes, indicate drug(s) being studied: _____

DRG_TRIALX

Texas Alzheimer's Research & Care Consortium Longitudinal Data Set (LDS)
Form A5: Subject Health History

Center: ____ TARCC Subject ID: ____ ____ ____ ____ ____ ____ Visit Date: __ __/__ __/__ __ __ __
m m d d y y y y

TARCC Visit #: __ __

Check only one box per question. Examiner's initials: __ __ __

Record the presence or absence of a **history** of these conditions at this visit as determined by the clinician's best judgment, based on informant report, medical records, and/or observation.

- A condition should be considered "Absent: if it is not indicated by information obtained from informant report, medical records and/or observation.
- A condition should be considered "Recent/Active: if it happened within the last year or still requires active management, and is consistent with information obtained from informant report, medical records and/or observation.
- A condition should be considered "Remote/Inactive" if it existed or occurred in the past (greater than one year ago) but was resolved or there is no current treatment underway.
- A condition should be considered "Unknown" if there is insufficient information available from informant report, medical records and/or observation.

1. **Cardiovascular disease**	Absent	Active	Inactive	Unknown
a. Heart attack/cardiac arrest (CVHATT)	☐ 0	☐ 1	☐ 2	☐ 9
b. Atrial fibrillation (CVAFIB)	☐ 0	☐ 1	☐ 2	☐ 9
c. Angioplasty/endarterectomy/stent (CVANGIO)	☐ 0	☐ 1	☐ 2	☐ 9
d. Cardiac bypass procedure (CVBYPASS)	☐ 0	☐ 1	☐ 2	☐ 9
e. Pacemaker (CVPACE)	☐ 0	☐ 1	☐ 2	☐ 9
f. Congestive heart failure (CVCHF)	☐ 0	☐ 1	☐ 2	☐ 9
g. Other (*specify*): _____ (CVOTHR, CVOTHRX)	☐ 0	☐ 1	☐ 2	☐ 9

2. **Cerebrovascular disease**	Absent	Active	Inactive	Unknown
a. Stroke (CBSTROKE)	☐ 0		☐ 2	☐ 9
If active, indicate year(s) in which this occurred: (*9999 = Year unknown*)		1) ____ (STROK1YR) 2) ____ (STROK2YR, etc.) 3) ____		
		4) ____ 5) ____ 6) ____		
b. Transient ischemic attack (CBTIA)	☐ 0	☐ 1		☐ 9
If active, indicate year(s) in which this occurred: (*9999 = Year unknown*)		1) ____ (TIA1YR) 2) ____ (TIA2YR, etc.) 3) ____		
		4) ____ 5) ____ 6) ____		
c. Other (*specify*): _____ (CBOTHR, CBOTHRX)	☐ 0	☐ 1	☐ 2	☐ 9

Center: _____ TARCC Subject ID: ____ ____ ____ ____ ____ ____ Visit Date: __ __/__ __/__ __ __ __
m m d d y y y y

TARCC Visit #: ___

Check only one box per question. Examiner's initials: ___

3. Parkinsonian features (PD)	Absent	Active	Unknown
a. Parkinson's disease	☐ 0	☐ 1	☐ 9
If active, indicate year of diagnosis: (*9999 = Year unknown*) ____ (PDYR)			
b. Other Parkinsonism disorder (PDOTHR)	☐ 0	☐ 1	☐ 9
If active, indicate year of diagnosis: (*9999 = Year unknown*) ____ (PDOTHRYR)			

4. Other neurologic conditions	Absent	Active	Inactive	Unknown
a. Seizures (SEIZURES)	☐ 0	☐ 1	☐ 2	☐ 9
b. Traumatic brain injury				
1) with brief loss of consciousness (< 5 minutes) (TRAUMBRF)	☐ 0		☐ 2	☐ 9
2) with extended loss of consciousness (≥ 5 minutes) (TRAUMEXT)	☐ 0	☐ 1	☐ 2	☐ 9
3) with chronic deficit or dysfunction (TRAUMCHR)	☐ 0	☐ 1	☐ 2	☐ 9
c. Other (*specify*): _____ (NCOTHR)	☐ 0	☐ 1	☐ 2	☐ 9
_____ (NCOTHRX)				

5. Medical/metabolic conditions	Absent	Active	Inactive	Unknown
a. Hypertension (HYPERTEN)	☐ 0	☐ 1	☐ 2	☐ 9
b. Hypercholesterolemia (HYPERCHO)	☐ 0	☐ 1	☐ 2	☐ 9
c. Diabetes (DIABETES)	☐ 0	☐ 1	☐ 2	☐ 9
d. B12 deficiency (B12DEF)	☐ 0	☐ 1	☐ 2	☐ 9
e. Thyroid disease (THYROID)	☐ 0	☐ 1	☐ 2	☐ 9
f. Incontinence – urinary (INCONTU)	☐ 0	☐ 1	☐ 2	☐ 9
g. Incontinence – bowel (INCONTF)	☐ 0	☐ 1	☐ 2	☐ 9
h. Cancer (other than non-melanoma skin cancer and chronic non-metastatic prostate cancer) (CANCER)	☐ 0	☐ 1	☐ 2	☐ 9

6. Depression	No	Yes	Unknown
a. Active within past 2 years (DEP2YRS)	☐ 0	☐ 1	☐ 9
b. Other episodes (prior to 2 years) (DEPOTHR)	☐ 0	☐ 1	☐ 9

Center: _____ TARCC Subject ID: ____ ____ ____ ____ ____ ____ Visit Date: __ __/__ __/__ __ __ __
m m d d y y y y

TARCC Visit #: __ __

Examiner's initials: __ __ __

Check only one box per question.

ALCOHOL

7. Substance abuse and psychiatric disorders	Absent	Active	Inactive	Unknown
a. Substance abuse – alcohol				
1) Clinically significant impairment occurring over a 12-month period manifested in one of the following: work, driving, legal or social.	☐ 0	☐ 1	☐ 2	☐ 9

7. b. Cigarette smoking history *If baseline, omit question 0) and begin with 1).*	No	Yes	Unknown
TOBACLSTYR 0) Has subject smoked cigarettes during the last year? *If no, skip to item 7c.*	☐ 0	☐ 1	☐ 9
TOBAC30 1) Has subject smoked cigarettes within last 30 days?	☐ 0	☐ 1	☐ 9
TOBAC100 2) Has subject smoked more than 100 cigarettes in his/her life?	☐ 0	☐ 1	☐ 9

(If no, indicate "N/A" for questions 3), 4), and 5) below.)

SMOKYRS

3) Total years smoked: (*88 = N/A; 99 = Unknown*) __ __

PACKSPER

4) Average number of packs/day smoked:

☐ 1 1 cigarette – < ½ pack ☐ 4 1½ – < 2 packs ☐ 9 Unknown

☐ 2 ½ – < 1 pack ☐ 5 ≥ 2 packs

☐ 3 1 – < 1½ pack ☐ 8 N/A

QUITSMOK

5) If subject quit smoking, specify age when last smoked (i.e., quit):
(*888 = N/A; 999 = Unknown*) __ __ __

7. c. Other abused substances	Absent	Active	Inactive	Unknown
ABUSOTHR 1) Clinically significant impairment occurring over a 12-month period manifested in one of the following: work, driving, legal or social.	☐ 0	☐ 1	☐ 2	☐ 9

ABUSX

If active or inactive, specify abused substance(s): _____

7. d. Psychiatric disorders	☐ 0	☐ 1	☐ 2	☐ 9

If active or inactive, specify disorder(s): _____

PSYCDIS

PSYCDISX

Center: _____ TARCC Subject ID: ____ ____ ____ ____ ____ ____ Visit Date: __ __/ __ __/ __ __ __ __
m m d d y y y y

TARCC Visit #: __ __

Examiner's initials: __ __ __

Check only one box per question.

8. Chronic Inflammatory or Autoimmune Conditions:	Absent	Active	Inactive	Unknown
a. Inflammatory bowel disease (IBD)	☐ 0	☐ 1	☐ 2	☐ 9
b. Arthritic conditions (ARTHRITIC)	☐ 0	☐ 1	☐ 2	☐ 9
c. Autoimmune disorders (AUTOIMM)		☐ 1	☐ 2	☐ 9
d. Other, specify (CHRON_OTH)	☐ 0	☐ 1	☐ 2	☐ 9

_____ (CHRON_OTHX)

Texas Alzheimer's Research & Care Consortium Longitudinal Data Set (LDS)
Form B1: Evaluation Form – Physical

Center: _____ TARCC Subject ID: _ _ _ _ _ _ _ _ _ Visit Date: _ _/_ _/_ _ _ _
m m d d y y y y

TARCC Visit #: _ _
Examiner's initials: _ _ _

SUBJECT PHYSICAL MEASUREMENTS		
1. Subject height (inches):	*(99.9 = unknown)*	HEIGHT _ _ . _
2. Subject weight (lbs.):	*(999 = unknown)*	WEIGHT _ _ _
3. Subject blood pressure (sitting)	*(999/999 = unknown)*	BPSYS _ _ _/BPDIAS _ _ _
4. Subject resting heart rate (pulse)	*(999 = unknown)*	HRATE _ _ _

ADDITIONAL PHYSICAL OBSERVATIONS	Yes	No	Unknown
5. Without corrective lenses, is the subject's vision functionally normal? (VISION)	☐ 1	☐ 0	☐ 9
6. Does the subject usually wear corrective lenses? (VISCORR)	☐ 1	☐ 0	☐ 9
6a. If yes, is the subject's vision functionally normal <u>with</u> corrective lenses? (VISWCORR)	☐ 1	☐ 0	☐ 9
7. Without a hearing aid(s), is the subject's hearing functionally normal? (HEARING)	☐ 1	☐ 0	☐ 9
8. Does the subject usually wear a hearing aid(s)? (HEARAID)	☐ 1	☐ 0	☐ 9
8a. If yes, is the subject's hearing functionally normal <u>with</u> a hearing aid(s)? (HEARWAID)	☐ 1	☐ 0	☐ 9

Texas Alzheimer's Research & Care Consortium Longitudinal Data Set (LDS)
Form B5: Behavioral Assessment – Neuropsychiatric Inventory Questionnaire (NPI-Q)

Center: _____ TARCC Subject ID: _____ _____ _____ _____ _____ _____ Visit Date: __ __/__ __/__ __ __ __
m m d d y y y y

TARCC Visit #: __ __
Examiner's initials: __ __ __

Please ask the following questions based upon changes. Indicate "yes" only if the symptom has been present in the past month; otherwise, indicate "no". For each item marked "yes", rate the SEVERITY of the symptom (how it affects the patient):
1 = Mild (noticeable, but not a singnificant change)
2 = Moderate (significant, but not a dramatic change)
3 = Severe (very marked or prominent; a dramatic change)

NPIQINF

1. NPI information: ☐ 1 Spouse ☐ 2 Child ☐ 3 Other (*specify*): _____ NPIQINFX

	Yes No	Severity
2. DELUSIONS: Does the patient believe that others are stealing from him or her, or planning to harm him or her in some way? (DEL / DELSEV)	2a ☐ 1 ☐ 0	2b. ☐ 1 ☐ 2 ☐ 3
3. HALLUCINATIONS: Does the patient act as if he or she hears voices? Does he or she talk to people who are not there? (HALL / HALLSEV)	3a. ☐ 1 ☐ 0	3b. ☐ 1 ☐ 2 ☐ 3
4. AGITATION OR AGGRESSION: Is the patient stubborn and resistive to help from others? (AGIT / AGITSEV)	4a. ☐ 1 ☐ 0	4b. ☐ 1 ☐ 2 ☐ 3
5. DEPRESSION OR DYSPHORIA: Does the patient act as if he or she is sad or in low spirits? Does he or she cry? (DEPD / DEPDSEV)	5a. ☐ 1 ☐ 0	5b. ☐ 1 ☐ 2 ☐ 3
6. ANXIETY: Does the patient become upset when separated from you? Does he or she have any other signs of nervousness, such as shortness of breath, sighing, being unable to relax, or feeling excessively tense? (ANX / ANXSEV)	6a. ☐ 1 ☐ 0	6b. ☐ 1 ☐ 2 ☐ 3
7. ELATION OR EUPHORIA: Does the patient appear to feel too good or act excessively happy? (ELAT / ELATSEV)	7a. ☐ 1 ☐ 0	7b. ☐ 1 ☐ 2 ☐ 3
8. APATHY OR INDIFFERENCE: Does the patient seem less interested in his or her usual activities and in the activities and plans of others? (APA / APASEV)	8a. ☐ 1 ☐ 0	8b. ☐ 1 ☐ 2 ☐ 3

Center: _____ TARCC Subject ID: ____ ____ ____ ____ ____ ____ Visit Date: __ __/__ __/__ __ __ __
m m d d y y y y

TARCC Visit #: __ __
Examiner's initials: __ __ __

	Yes No	Severity
9. DISINHIBITION: Does the patient seem to act impulsively? For example, does the patient talk to strangers as if he or she knows them, or does the patient say things that may hurt people's feelings?	9a. ☐ 1 ☐ 0 DISN	9b. ☐ 1 ☐ 2 ☐ 3 DISNSEV
10. IRRITABILITY OR LABILITY: Is the patient impatient or cranky? Does he or she have difficulty coping with delays or waiting for planned activities?	10a. ☐ 1 ☐ 0 IRR	10b. ☐ 1 ☐ 2 ☐ 3 IRRSEV
11. MOTOR DISTURBANCE: Does the patient engage in repetitive activities, such as pacing around the house, handling buttons, wrapping string, or doing other things repeatedly?	11a. ☐ 1 ☐ 0 MOT	11b. ☐ 1 ☐ 2 ☐ 3 MOTSEV
12. NIGHTTIME BEHAVIORS: Does the patient awaken you during the night, rise too early in the morning, or take excessive naps during the day?	12a. ☐ 1 ☐ 0 NITE	12b. ☐ 1 ☐ 2 ☐ 3 NITESEV
13. APPETITE AND EATING: Has the patient lost or gained weight, or had a change in the food he or she likes?	13a. ☐ 1 ☐ 0 APP	13b. ☐ 1 ☐ 2 ☐ 3 APPSEV

Texas Alzheimer's Research & Care Consortium Longitudinal Data Set (LDS)
Form C1: Neuropsychological Core Battery for Cognitive Assessment

Center: _____ TARCC Subject ID: _____ _____ _____ _____ _____ _____ Visit Date: __ __/__ __/__ __ __ __
m m d d y y y y

C1DAT

TARCC Visit #: __ __
Examiner's initials: __ __ __

Date Neuropsychol[MMSE]e Battery administered: __ __/__ __/__ __ __ __
m m d d y y y y

1. Total MMSE: __ __ (0-30, 99)

CDRMEM CDROR CDRJU CDRHOB

2. CDR: (0, 0.5, 1-3) *9 = Missing*

LITPROB

2a. Memory: __.__ 2c. Judgment: __.__ 2e. Home/Hobbies: __.__
2b. Orientation: __.__ 2d. Comm. Affairs: __.__ 2f. Personal Care: __.__

CDRCA CDRPER

☐ Check here if patient has literacy difficulties.

☐ Check here if patient is too impaired and no further tests were given.
Leave the rest of the form blank. Otherwise, if the subject cannot complete all or part of any of the following exams, or a test is not administered at your site, you must fill in a missing code for all items (except where noted).

TOOIMPAIRED

Attention:

WAISR_DIGIF WAIS3_DIGIF WMSR_DIGIF WAIS3_DIGIB WMSR_DIGIB

3. Digit Span:
For the version of the test administered at your site, a score (or the missing data code, 99) where applicable must be entered. Versions not administered at your site should be left blank.

WAISR_DIGIB

	WAIS-R	WMS-III / WAIS-III	WMS-[illegible]
3a. Forward:	__ __ (0-14)	__ __ (0-16)	__ __ (0-12)
3b. Backward:	__ __ (0-14)	__ __ (0-14)	__ __ (0-12)
Longest Span:			
3c. Forward:	__ __ (0-9)	__ __ (0-9)	__ __ (0-8)
3d. Backward:	__ __ (0-8)	__ __ (0-8)	__ __ (0-7)
3e. Total Score:	__ __ (0-28)	__ __ (0-30)	__ __ (0-24)

WAISR_DIGILF WAIS3_DIGILF WAIS3_DIGILB WMSR_DIGILF
WAISR_DIGILB WMSR_DIGILB

4. Trail Making Test:
4a. Part A—total number of seconds to complete: __ __ __ (0-180) *999=Missing*
4b. Part A—total errors: __ __ (0-25, 99)

WAIS3_DIGTOT WMSR_DIGTOT
WAISR_DIGTOT TRAILA TRAILAERR

Center: _____ TARCC Subject ID: _____ _____ _____ _____ _____ _____ Visit Date: __ __/__ __/__ __ __ __
m m d d y y y y

TARCC Visit #: __ __
Examiner's initials: __ __ __

Executive Function:

Trail Making Test (cont.):

TRAILB

TRAILBERR

4c. Part B—total number of seconds to complete: __ __ __ (0-300) *999=Missing*

4d. Part B—total errors: __ __ (0-25, 99)

CLOX1

5a. CLOX (Executive Clock Drawing): CLOX 1: __ __ (0-15, 99)

CLOX2

TAPS

CLOX 2: __ __ (0-15, 99)

6b. TAPS: __ __ (0-75, 99)

Memory:

WMSR_LMEM1

WMSR_LMEM2

7. WMS Logical Memory

WMSR_STORY1A

WMSR_STORY2A

For the version of the test administered at your site, a score (or the missing code, if applicable) must be entered. The version not administered at your site should be left blank.
Note: Total scores and/or sub-scores are not allowed for WMS Logical Memory. If you are not providing all [illegible] leave un-provided fields blank.

WMSR_STORY1B1

	WMS-III	WMS-R
WMS3_LMEM1		
7a. WMS Logical Memory I:	(0-75, 99)	__ __ (0-50, 99)
WMS3_STORY1A		
7a-1. Story A:	__ __ (0-25)	__ __ (0-25)
WMS3_STORY1B1		
7a-2. Story B-1:		__ __ (0-25)
WMS3_STORY1B2		
7a-3. Story B-2:		
WMS3_LMEM2		
7b. WMS Logical Memory II:	__ __ (0-50, 99)	__ __ (0-50, 99)
WMS3_STORY2A		
7b-1. Story A:	__ __ (0-25)	__ __ (0-25)
7b-2. Story B:	__ __ (0-25)	__ __ (0-25)
WMS3_STORY2B		

WMSR_STORY2B

CERAD_LL_1

List Learning

7.1a	List Trial 1	__ __ (0-10, 99)
7.1b	List Trial 2	__ __ (0-10, 99)
7.1c	List Trial 3	__ __ (0-10, 99)
7.1d	Delayed Recall	__ __ (0-10, 99)

CERAD_LL_2

CERAD_LL_3

CERAD_LL_DELAY

7.2 CERAD Word List Recognition

7.2a	Recognition YES correct	__ __ (0-10, 99)
7.2b	Recognition NO correct	__ __ (0-10, 99)

CREAD_WR_NO

CERAD_WR_YES

Center: _____ TARCC Subject ID: _____ _____ _____ _____ _____ _____ Visit Date: __ __/ __ __/ __ __ __ __
m m d d y y y y

TARCC Visit #: __ __
Examiner's initials: __ __ __

Language:

8. Boston Naming Test:
For the version of the test administered at your site, a score or the missing data code (99) must be entered. The version not administered at your site should be left blank.

BOSTON30 BOSTON60

30-Item **60-Item**

__ __ (0-30, 99) __ __ (0-60, 99)

FAS_F FAS_A FAS_S

9. FAS Verbal Fluency: F __ __ A __ __ S __ __ (0-50, 99)

ANIMAL

9.1 Animal Fluency Total Score: __ __ (0-50, 99)

Premorbid IQ:
Complete one and only one at baseline.

AMNART WAT

10. AMNART (Total Errors): __ __ (0-50, 99) WAT (Total Correct): __ __ (0-30, 99)

WMS3_VR_A WMS3_VR_B WMS3_VR_C WMS3_VR_D WMS3_VR_E

WMS3_VR2_A WMS3_VR2_B WMS3_VR2_C WMS3_VR2_D WMS3_VR2_E

WMSR_VR_A WMSR_VR_B WMSR_VR_C WMSR_VR_D

WMSR_VR2_A WMSR_VR2_B WMSR_VR2_C WMSR_VR2_D

on:
of the test admin core code
t be entered. Ver at y blan

	IS-III(VRI)		**WM -R(VRI)**	**WM R(VRII)**
11a. Figure				
A	__ __ (0-10)	__ __ (0-10)	__ __ (0-7)	__ __ (0-7)
B	__ __ (0-10)	__ __ (0-10)	__ __ (0-7)	__ __ (0-7)
C	__ __ (0-18)	__ __ (0-18)	__ __ (0-9)	__ __ (0-9)
D	__ __ (0-34)	__ __ (0-34)	__ __ (0-18)	__ __ (0-18)
E	__ __ (0-32)	__ __ (0-32)		
11b. VRI	__ __ __ (0-104)		__ __ (0-41, 99)	
11c. VRII		__ __ __ (0-104)		__ (0-41, 99)

WMS3_VRI WMS3_VRII WMSR_VRI WMSR_VRII

Depression:

12. Geriatric Depression Scale (GDS) **30-Item:** __ __ (0-30, 99)

GDS30

Texas Alzheimer's Research & Care Consortium Longitudinal Data Set (LDS)

Form D1: Clinician Diagnosis – Cognitive Status and Dementia

Center: _____ TARCC Subject ID: _____ Visit Date: __/__/____
m m d d y y y y

TARCC Visit #: __
Examiner's initials: __

Check only one box per response category.

WHODIDDX NORMCOG DEMENTED

1. Responses are based on:		☐ 2 Consensus diagnosis (required)
2. Does the subject have normal cognition (no MCI or dementia)?	☐ 1 Yes *(If yes, skip to #14)*	☐ 0 No *(If no, continue to #3)*
3. Does the subject meet criteria for dementia (in accordance with standard criteria for dementia of the Alzheimer's type or for other non-Alzheimer's dementing disorders)?	☐ 1 Yes *(If yes, skip to #5)*	☐ 0 N *(If no, c*

MCIAPLAN MCIAPATT MCIAPEX MCIAVIS

4. If the subject does not have normal cognition and is not dement[illegible] the type of co[illegible] impairment (*choose only one [illegible] from items 4a thru 4[illegible] sent"; mark all othe[illegible] "absent"*) **and then design[illegible] ed cause(s) of the [illegible] completing item[illegible] 5–28:**

MCIAMEM MCIN1LAN MCIN1ATT MCIN1EX MCIN1VIS

	Present	Absent		Yes	No
4a. Amnestic MCI – memory impairment only	☐ 1	☐ 0			
4b. Amnestic MCI – memory impairment plus one or more other domains (*if present, check one or more domain boxes "yes" and check all other domain boxes "no"*)	☐ 1	☐ 0	1) Lang[illegible]age	☐ 1	☐ 0
			2) Attent[illegible]n	☐ 1	☐ 0
			3) Executi[illegible]e function	☐ 1	☐ 0
			4) Visuospat[illegible]al	☐ 1	☐ 0
4c. Non-amnestic MCI – single domain (*if present, check only one domain box "yes"; check all other domain boxes "no"*)	☐ 1	☐ 0	1) Language	☐ 1	☐ 0
			2) Attention	☐ 1	☐ 0
			3) Executive function	☐ 1	☐ 0
			4) Visuospatial	☐ 1	☐ 0
4d. Non-amnestic MCI – multiple domains (*if present, check two or more domain boxes "yes" and check all other domain boxes "no"*)	☐ 1	☐ 0	1) Language	☐ 1	☐ 0
			2) Attention	☐ 1	☐ 0
			3) Executive function	☐ 1	☐ 0
			4) Visuospatial	☐ 1	☐ 0
4e. Impaired, not MCI (after baseline).	☐ 1	☐ 0			

MCIAPLUS MCINON1 MCINON2 IMPNOMCI MCIN2LAN MCIN2ATT MCIN2EX MCIN2VIS

Center: _____ TARCC Subject ID: ____ ____ ____ ____ ____ ____ Visit Date: __ __/__ __/__ __ __ __
m m d d y y y y

TARCC Visit #: __ __
Examiner's initials: __ __ __

Check only one box per response category.

Please indicate if the following conditions are present or absent. If present, also indicate if the condition is primary or contributing to the observed cognitive impairment (reported in items 3 or 4), based on the clinician's best judgment. *

Mark only one condition as primary.	Present	Absent	If Present: Primary	If Present: Contributing
5. Probable AD (NINCDS/ADRDA) (*if present, skip to item #7*) PROBAD	☐ 1	☐ 0	5a. PROBADIF	2
6. Possible AD (NINCDS/ADRDA) (*if #5 is present, leave this blank*) POSSAD	☐ 1	☐ 0	6a. POSSADIF	
7. Dementia with Lewy bodies * DLB	☐ 1	☐ 0	7a. ☐ DLBIF	☐ 2
8. Probable Vascular dementia (NINDS/AIREN) (*if present, skip to item #10*) VASC		☐ 0	8a. ☐ 1 VASCIF	
9. Possible vascular dementia (NINDS/AIREN) ** (*If #8 present, leave this blank*) POS_VASC		0	POS_VASCIF	☐ 2
10. Alcohol-related dementia ALCDEM	☐ 1	☐ 0	10a.	ALCDEMIF
11. Dementia of undetermined etiology DEMUN	1	☐ 0	DEMUNIF	☐ 2
12. Frontotemporal dementia (behavioral/executive dementia) FTD	1	☐ 0	12a. ☐ 1	FTDIF
13. Primary progressive aphasia (aphasic dementia) PPAPH		☐ 0	13a.	PPAPHIF
(*If PPA is present, specify type by checking one box below "present" and all others "absent"*): PNAPH				
1) Progressive nonfluent aphasia	☐ 1	☐ 0		
2) Semantic dementia – anomia plus word comprehension SEMDEMAN	☐ 1	☐ 0		
3) Semantic dementia – agnostic variant SEMDEMAG	☐ 1	☐ 0		
4) Other (e.g., logopenic, anomic, transcortical, word deafness, syntactic comprehension, motor speech disorder) PPAOTHR	☐ 1	☐ 0		

*Note: Code Lewy Body variant of AD as probable AD primary(1) and Dementia with Lewy Bodies contributing(2) (these patients are eligible for study entry at baseline)

**Note: If Probable AD is primary(1) and 9 Posible Vascular Dementia is contributing(2) and all other inclusion/exclusion criteria are met at baseline, subject is eligible for study entry (for example, if they only have extensive white matter disease and no stroke or focal signs).

Center: _____ TARCC Subject ID: ___ ___ ___ ___ ___ ___ Visit Date: __ __/__ __/__ __ __ __
m m d d y y y y

TARCC Visit #: __ __
Examiner's initials: __ __ __

Check only one box per response category.

If the subject has normal cognition, indicate only if the following conditions are present or absent.
If the subject is **cognitively impaired**, indicate if the condition is present and also whether the condition is primary, contributing, or non-contributing to the observed cognitive impairment (reported in items 3 or 4), based on your best judgment.

Mark only one condition as primary.	Present	Absent	If Present: Primary	Contributing	Non-contrib.
14. Progressive supranuclear palsy PSP	☐ 1	☐ 0	14a. PSPIF	☐ 2	☐ 3
15. Corticobasal degeneration CORT	☐ 1	☐ 0	15a. ☐ 1	☐ 2 CORTIF	☐ 3
16. Huntington's disease HUNT	☐ 1	☐ 0	HUNTIF	☐ 2	☐ 3
17. Prion disease PRION	☐ 1	☐ 0	17a. ☐	PRIONIF	☐ 3
18. Cognitive dysfunction from medications MEDS	☐ 1	☐ 0	18a. MEDSIF		☐ 3
19. Cognitive dysfunction from medical illnesses DYSILL	☐ 1	☐ 0	19a. ☐	DYSILLIF	☐ 3
20. Depression (major according to DSM criteria) DEP	☐ 1	☐ 0	20a. DEPIF	2	☐ 3
21. Other major psychiatric illness OTHPSY	☐ 1	☐ 0	21a. ☐	OTHPSYIF	☐ 3
22. Down's syndrome DOWNS	☐ 1	☐ 0	22a. ☐ 1	☐ DOWNSIF	
23. Parkinson's disease PARK	☐ 1	☐ 0	23a PARKIF	☐ 2	☐ 3
24. Stroke STROKE	☐ 1	☐ 0	24a. ☐ 1	STROKEIF	3
25. Hydrocephalus HYCEPH	☐ 1	☐ 0	25a. HYCEPHIF	2	☐ 3
26. Traumatic brain injury BRNINJ	☐ 1	☐ 0	26a. ☐ 1	BRNINJIF	☐ 3
27. CNS neoplasm NEOP	☐ 1	☐ 0	NEOPIF	☐ 2	☐ 3
28. Other (*specify*): COGOTH _____ COGOTHX	☐ 1	☐ 0	28a. ☐ 1	☐ 2 COGOTHIF	☐ 3

Texas Alzheimer's Research & Care Consortium Longitudinal Data Set (LDS)
Form E1: Exit Form

Center: _____ TARCC Subject ID: ____ ____ ____ ____ ____ ____

EXITDATE

1. Date patient exited study..... __ __/__ __/__ __ __ __
(If patient died, enter date of death.) m m d d y y y y

WITHDREW

2. Reason for termination:

a) Patient withdrew from study..... 1 Yes ○ 2 No ○

DIED

b) Patient death..... 1 Yes ○ 2 No ○

LOST

c) Lost to follow-up..... 1 Yes ○ 2 No ○

WDOTHREAS

d) Other reason..... 1 Yes ○ 2 No ○

RESIDE_CARE

3. Does the subject currently reside (or at the time of death, if deceased) in a long-term care facility (assisted living, boarding home, adult family home, skilled nursing facility or nursing home)?..... 1 Yes ○ 2 No ○ 3 Unknown ○

RESIDE_DAT

If yes, record date of entry..... __ __/__ __/__ __ __ __
m m d d y y y y

4. Comments

WDOTHREASX

_____

_____

_____

Texas Alzheimer's Research & Care Consortium Longitudinal Data Set (LDS)
Form F1: Physical Self-Maintenance Scale (PSMS)

Center: _____ TARCC Subject ID: _ _ _ _ _ _ Visit Date: _ _/_ _/_ _ _ _
m m d d y y y y

TARCC Visit #: _ _
Examiner's initials: _ _ _

PSMS1

Directions
Check one statement in each category, 1 through 5, that applies to the subject.

1. TOILET

☐1 Cares for self at toilet completely, no incontinence.

☐2 Needs to be reminded or needs help in cleaning self, or has rare (weekly at most) accidents.

☐3 Soiling or wetting while asleep more than once a week.

☐4 Soiling or wetting while awake more than once a week.

PSMS2

☐5 No control of bladder.

2. FEEDING

☐1 Eats without assistance.

☐2 Eats with minor assistance at meal times and/or with special preparation of food (cutting up meat for example), or uses wrong utensils, or needs help in cleaning up after meals.

☐3 Feeds self with moderate assistance and is untidy.

☐4 Requires extensive assistance for all meals.

PSMS3

☐5 Does not feed self at all and resists efforts of others to feed him/her.

3. DRESSING

☐1 Dresses, undresses, and selects clothes from own wardrobe.

☐2 Dresses and undresses self if clothes are preselected by another or if needs to be reminded to change clothes or reminded to put on certain items (such as underwear).

☐3 Needs some minor physical assistance in dressing (with buttons, zippers, tying shoes, etc.) even if clothes are preselected.

☐4 Needs major assistance with dressing, but cooperates with efforts of others to help.

☐5 Completely unable to dress self and/or resists efforts of others to help.

Center: _____ TARCC Subject ID: _ _ _ _ _ _ Visit Date: _ _/_ _/_ _ _ _
m m d d y y y y

TARCC Visit #: _ _
Examiner's initials: _ _ _

PSMS4

4. GROOMING (neatness, personal hygiene)

☐1 Always neatly dressed, well-groomed, without assistance.

☐2 Grooms self adequately with occasional minor assistance (e.g., shaving, cutting of fingernails, etc.)

☐3 Needs moderate and regular assistance or supervision in grooming.

☐4 Needs total grooming care, but c[illegible] well-groomed after help from others.

PSMS5

☐5 Actively negates all efforts of o[illegible]s to maintain grooming.

5. PHYSICAL AMBULATION

☐1 Is capable of ambulating about the neighborhood or city (refers to person's physical ability to ambulate, not ability to navigate or find one's way around.)

☐2 Ambulates within residence or within about a one block radius.

☐3 Ambulates with assistance of another person, or using railing, wall, cane, walker, or wheelchair.

☐4 Sits unsuppo[illegible] or wheelchair, but cannot propel self without help.

PSMS6

☐5 Bedridden m[illegible] than half of the time.

6. BATHING

☐1 Bathes self (tub, shower, sponge bath) without help.

☐2 Bathes self with help in getting in and out of tub, or bathes self with verbal supervision or reminding.

☐3 Needs moderate (physical) assistance in bathing, (may be able to wash face and hands easily, but cannot bathe rest of body).

☐4 Does not wash self, but is cooperative with those who bathe him/her.

☐5 Does not try to wash self and/or resists efforts to keep him/her clean.

Texas Alzheimer's Research & Care Consortium Longitudinal Data Set (LDS)
Form F2: Instrumental Activities of Daily Living Scale (IADL) Form

Center: _____ TARCC Subject ID: _ _ _ _ _ _ _ Visit Date: _ _/_ _/_ _ _ _
m m d d y y y y

TARCC Visit #: _ _
Examiner's initials: _ _ _

IADL1

Check one statement in each category. Consider whether participant "could do" activity instead of "does do."

1. ABILITY TO USE TELEPHONE

- ☐ 1 Operates telephone on own initiative; looks up and dials numbers, etc.
- ☐ 2 Dials a few well-known numbers.
- ☐ 3 Answers telephone but does not dial.
- ☐ 4 Does not use telephone at all under own initiative, but may talk if put on line.
- ☐ 5 Incapable of using telephone.

IADL2

2. SHOPPING

- ☐ 1 Takes care of all shopping needs independently.
- ☐ 2 Shops independently for a limited number of purchases (3 or less).
- ☐ 3 Needs to be accompanied on every shopping trip.
- ☐ 4 Completely unable to shop.

IADL3

3. FOOD PREPARATION

- ☐ 0 Not Applicable: Never did prepare meals.
- ☐ 1 Plans, prepares, and serves adequate meals independently.
- ☐ 2 Prepares adequate meals if supplied with ingredients, or given supervision or reminding.
- ☐ 3 Heats and serves prepared meals, or prepares meals but does not maintain adequate diet.
- ☐ 4 Needs to have meals prepared and served.

IADL4

4. HOUSEKEEPING

- ☐ 0 Not Applicable: never did housekeeping.
- ☐ 1 Maintains house alone or with occasional assistance.
- ☐ 2 Performs light daily tasks such as dishwashing and bed-making
- ☐ 3 Performs light daily tasks but cannot maintain acceptable level of cleanliness.
- ☐ 4 Needs help with all home maintenance tasks.
- ☐ 5 Is unable to participate in any housekeeping tasks.

Center: _____ TARCC Subject ID: _ _ _ _ _ _ Visit Date: _ _/_ _/_ _ _ _
m m d d y y y y

TARCC Visit #: _ _
Examiner's initials: _ _ _

IADL5

5. LAUNDRY

- ☐ 0 Not Applicable: never did laundry.
- ☐ 1 Does personal laundry completely
- ☐ 2 Launders small items; rinses socks, some items, etc.
- ☐ 3 All laundry must be done by others.

IADL6

6. MODE OF TRANSPORTATION

- ☐ 1 Travels independently on public transportation or drives own car.
- ☐ 2 Arranges own travel via taxi/bus, but does not drive own car.
- ☐ 3 Travels on public transportation when a accompanied by another.
- ☐ 4 Travel limited to taxi or automobile wit ce of another.

IADL7

7. ABILITY TO HANDLE FINANCES

- ☐ 0 Not Applicable: Never handled finances.
- ☐ 1 Manages financial matters independently (budgets, writes checks, pays rent/bills, goes to bank, balances checkbook), collects and keeps track of income.
- ☐ 2 Manages day-to-day purchases, but needs help w g, major purchases, etc.
- ☐ 3 Incapable of handling money.

IADL8

8. RESPONSIBLE FOR OWN MEDICATIONS

- ☐ 0 Not Applicable: Not taking any medication.
- ☐ 1 Is responsible for taking medication in correct dosages at correct time.
- ☐ 2 Takes responsibility if medication is prepared in advance in separate dosages, or if reminded.
- ☐ 3 Is not capable of dispensing own medication.

Texas Alzheimer's Research & Care Consortium Longitudinal Data Set (LDS) – Visit Packet
Form I1: Informant Contact Form

Center: _____ TARCC Subject ID: _ _ _ _ _ _ _ _ Subject Visit Date: _ _/_ _/_ _ _ _

TARCC Visit #: _ _
Examiner's initials: _ _ _

1. How contacted? ..... INHOWCONTACT ○ 1 In-Person ○ 2 Phone

2. Date of informant contact ..... INDTECONT _ _/_ _/_ _ _ _

3. Informant's year of birth ..... INBIRYR _ _ _ _

4. Informant's sex ..... INSEX ○ 1 Male ○ 2 Female

4a. Is this a new informant? ..... ISNEWINFORM ○ 1 Yes ○ 0 No
If no, skip to item #9.

5. Does the informant report being of Hispanic/Latino ethnicity (i.e., having origins from a mainly Spanish-speaking Latin American Country), regardless of race? INHISP ○ 1 Yes ○ 0 No

5a. If yes, what are the informant's reported origins? INHISPOR

○ 1 Mexican/Chicano/ Mexican-American
○ 2 Puerto Rican
○ 3 Cuban
○ 4 Dominican
○ 5 Central American
○ 6 South American
○ 50 Other (specify): _____ INHISPOX
○ 99 Unknown

6. What does informant report as his/her race? INRACE

○ 1 White
○ 2 Black or African American
○ 3 American Indian or Alaska Native
○ 4 Native Hawaiian or Other Pacific Islander
○ 5 Asian
○ 50 Other (specify): _____ INRACEX
○ 99 Unknown

Texas Alzheimer's Research & Care Consortium Longitudinal Data Set (LDS) – Visit Packet
Form I1: Informant Contact Form

Center: _____ TARCC Subject ID: ___ ___ ___ ___ ___ ___ Subject Visit Date: __ __/__ __/__ __

TARCC Visit #: __ __
Examiner's initials: __ __ __

7. What additional race does informant report? INRASEC

- ○ 1 White
- ○ 2 Black or African American
- ○ 3 American Indian or Alaska
- ○ 4 Native Hawaiian or Other Pacific Islander
- ○ 5 Asian
- ○ 50 Other (specify): _____ INRASECX
- ○ 88 None reported
- ○ 99 Unknown

8. What additional race, beyond what was indicated above in questions 6 and 7, does informant report? INRATER

- ○ 1 White
- ○ 2 Black or African American
- ○ 3 American Indian or Alaska Native
- ○ 4 Native Hawaiian or Other Pacific Islander
- ○ 5 Asian
- ○ 50 Other (specify): _____ INRATERX
- ○ 88 None reported
- ○ 99 Unknown

9. Informant's years of education (report achieved level using the codes below; if an attempted level is not completed, enter the number of years attended). High school/GED = 12; Bachelors degree = 16; Master's degree = 18; Doctorate = 20 years: INEDUC

__ __ (99 = unknown)

10. What is informant's relationship to subject? INRELTO

- ○ 1 Spouse/partner
- ○ 2 Child
- ○ 3 Sibling
- ○ 4 Other relative
- ○ 5 Friend/neighbor
- ○ 6 Paid caregiver/ provider
- ○ 7 Other (specify): _____ INRELTOX

Texas Alzheimer's Research & Care Consortium Longitudinal Data Set (LDS) – Visit Packet
Form I1: Informant Contact Form

Center: _____ TARCC Subject ID: __ __ __ __ __ __ Subject Visit Date: __ __/ __ __/ __ __

TARCC Visit #: __ __
Examiner's initials: __ __ __

INLIVWITH

11.	Does the informant live with the subject ?	○ 1 Yes (if yes, skip to #12)	○ 0 No
	11a. If no, approximate frequency of in-person visits:	○ 1 Daily	○ 4 At least 3x/month
		○ 2 At least 3x/week	○ 5 Monthly
		○ 3 Weekly	○ 6 Less than 1x a month
	11b. If no, approximate frequency of telephone contact:	○ 1 Daily	○ 4 At least 3x/month
		○ 2 At least 3x/week	○ 5 Monthly
		○ 3 Weekly	○ 6 Less than 1x a month

INVISITS

INCALLS

12.	Is there a question about the informant's reliability?	○ 1 Yes	○ 0 No

INRELY

Texas Alzheimer's Research & Care Consortium Longitudinal Data Set (LDS)
Form P1: Protocol Contact Form

Center: _____ TARCC Subject ID: ____ ____ ____ ____ ____ ____ Visit Date: __ __/ __ __/ __ __ __ __
m m d d y y y y

TARCC Visit #: __ __
Examiner's initials: __ __ __

PT_TYPE

1. Patient type at this visit …. ○ 1 AD Patient (possible/probable) ○ 2 Control ○ 4 MCI ○ 3 Other

PT_TYPE_OTHX

If other, please specify: _____

Collection of Blood Samples:

A blood sample is required at baseline for planned assays and banking. At follow-up visits, subjects will be asked but not required to provide blood samples. Draw all serum tubes before drawing any plasma tubes. Blood draw must be done immediately after fingerstick..

WHOLEBLOOD

2. Whole Blood sample collected at this visit? ○ 1 Yes ○ 0 No

PLASMA

3. Plasma sample collected at this visit? ○ 1 Yes ○ 0 No

BUFFY

4. Buffy Coat collected at this visit? ○ 1 Yes ○ 0 No

SERUM

5. Serum sample collected at this visit? ○ 1 Yes ○ 0 No

WHYNOTALL

5a. If all of the above blood samples were not obtained at this visit, give reason:

○ 1 Patient refusal ○ 2 Venipuncture problem ○ 3 Other _____

WHYNOTALLX

DATEFOOD TIMEFOOD

6. Date/time of last meal or snack: __ __/ __ __/ __ __ __ __ __ __:__ __ AM ☐ or PM ☐

DATEDRAW TIMEDRAW

7. Date/time of blood draw: __ __/ __ __/ __ __ __ __ __ __:__ __ AM ☐ or PM ☐

DATESTICK TIMESTICK

8. Date/time of fingerstick: __ __/ __ __/ __ __ __ __ __ __:__ __ AM ☐ or PM ☐

BGRESULT

9. Fingerstick blood glucose result: __ __ __ mg/dL

SHARE_AGREE

10. Agrees to share blood and genetic code with non-TARCC researchers: ○ 1 Yes ○ 0 No

SHARE_DATE

Date __ __/ __ __/__ __ __ __

Texas Alzheimer's Research & Care Consortium Longitudinal Data Set (LDS)
Form X2: Physicians Estimate of Duration
(Required once per patient; Not applicable for Normal Controls)

IDURY

IDURM

Center: _____ TARCC Subject ID: _ _ _ _ _ _ Visit Date: _ _/_ _/_ _ _ _ Visit #: _ _

Examiner's Initials: _ _ _

Question	Yes	No	Unknown	Duration	
				Years	Months
1. Informant's general estimate of symptoms duration (unprompted)?					
2. Estimated duration of symptoms (review of medical records)? (99=unk)					
3. Does the patient:					
a. Forget where he/she has left things					
b. Forget known phone numbers					
c. Become confused as to:					
the time					
the place he/she is in					
his/her correct age or other personal information					
d. Have trouble making decisions or solving problems					
e. Repeat himself/herself					
4. Does the patient:					
a. Have trouble expressing himself/herself in words					
b. Say one word when he/she means another					
c. Use incomplete sentences, hesitates, stops while talking					
d. Have trouble finding words					
e. Have trouble understanding others					
f. Have trouble writing					
g. Have trouble understanding reading					
5. Does the patient:					
a. Have trouble balancing his/her checkbook					
b. Have difficulty operating a television set					
c. No longer drive a car because of memory/thinking problems					
d. Have trouble dialing the telephone					
e. Have difficulty traveling alone					
f. Get lost in his/her own home					
6. Does the patient:					
a. Have mood changes (anger, disinterest, sadness)					
b. Appear anxious/nervous (express worry, fear)					
c. Exhibit antisocial behavior (aggression, irritability)					
d. Behave in a paranoid (suspicious) manner					
e. Hear something that is not actually there					
f. See something that is not actually there					
g. Smell something that is not actually there					
h. Other (specify:)					
If present, are these symptoms disturbing to the patient?					
7. Does the patient:					
a. Confuse one person with another or misidentify common objects					
b. Express thoughts that things have happened which haven't happened (e.g. people rearranging things, someone in the house, someone trying to do them harm, etc.)					
c. Show changes in physical activity such:					
hyperactivity (pacing)					
underactivity (sleeps a lot, just sits)					
repeating activities (packing/unpacking, folding)					
Hypothesized Physicians Estimate of Duration (to nearest 0.5 years):					.
Physician's estimate confirmed by relationship to life events (to nearest 0.5 years):					.

MRDURY

MRDURM

PHYEST

PHYESTFIRM

Texas Alzheimer's Consortium Longitudinal Data Set (LDS) – Initial Visit Packet
Form X1: Clinical Information Form

Center: _____ ADC Subject ID: __ __ __ __ __ __ __ __ __ __ Visit Date: __ __/ __ __/ __ __

Note: This form is to be completed by the clinician.

ADC Visit #: __ __ __
Examiner's initials: __ __ __

Memory Complaint/Age of Onset:		**1 Yes**	**0 No**
1.	Does the subject report a decline in memory? ……	○	○
2a.	Does the clinician believe that there has been a current meaningful decline in the subject's memory, non-memory cognitive abilities, behavior, or ability to manage his/her affairs? ……..	○	○
2b.	At what age did the decline begin (based upon the clinician's assessment)? ……	__ __ __ (*999=Unknown*)	

Cardiovascular disease and related risk factors (based on current assessment):		**1 Yes**	**0 No**	**9 Unk**
3.	**Hyperlipidemia?** ……	○	○	○
	If yes, defined by: *(one or more of the following must be YES)*			
3a.	Self-report?…….……..	○	○	
3b.	Use of cholesterol-lowering agents?…….…….....	○	○	
3c.	Total serum cholesterol > 220mg/dL? ……	○	○	
	If yes, Total serum cholesterol: __ __ __ (mg/dL)			
3d.	LDL > 140mg/dL? …….…….	○	○	
	If yes, LDL value: __ __ __ (mg/dL)			
4.	**Diabetes mellitus?** …….	○	○	○
	If yes, defined by: *(one or more of the following must be YES)*			
4a.	Self-report? ……	○	○	
4b.	History of treatment for diabetes with insulin/oral hypoglycemic agents?...	○	○	
4c.	Fasting glucose of > 126mg/dL? ……...	○	○	
	If yes, Glucose value: __ __ __ (mg/dL)			
5.	**Hypertension?** ……	○	○	○
	If yes, defined by: *(one or more of the following must be YES)*			
5a.	Self-report? …….……	○	○	
5b.	Use of anti-hypertensive medications? ……..…..	○	○	
5c.	Systolic blood pressure > 140mmHg? ……	○	○	
	If yes, Systolic blood pressure value: __ __ __ (mm/Hg)			
5d.	Diastolic blood pressure > 90mmHg? ……..……...	○	○	
	If yes, Diastolic blood pressure value: __ __ __ (mm/Hg)			
6.	**Obesity?** ……..	○	○	○
	If yes, calculated through: *(one or more of the following must be YES)*			
6a.	Abdominal obesity? ……	○	○	
	(waist circumference > 102cm for men and > 88cm for women)			
	If yes, Waist circumference value: __ __ __ (cm)			
6b.	Body mass index (BMI) > 30? …….	○	○	
	If yes, BMI value: __ __ __ (kg/m^2)			

Texas Alzheimer's Consortium Longitudinal Data Set (LDS)
Form X1: Clinical Information Form

Center: _____ TARC Subject ID: __ __ __ __ __ __ Visit Date: __ __/ __ __/ __ __ __ __ Visit #: __ __
m m d d y y y y

Examiner's initials: __ __ __

Memory Complaint/Age of Onset:		**1 Yes**	**0 No**	
1.	Does the subject report a decline in memory? ……	○	○	
2a.	Does the clinician believe that there has been a current meaningful decline in the subject's memory, non-memory cognitive abilities, behavior, or ability to manage his/her affairs? ……..	○	○	
2b.	At what age did the decline begin (based upon the caregiver's assessment)? …..	__ __ __ (*999=Unknown*)		
2c.	Physician's estimate of duration (years) now captured on X2.			

Cardiovascular disease and related risk factors (based on current assessment):		**1 Yes**	**0 No**	**9 Unk**
3.	**Hyperlipidemia?** ……	○	○	○
	If yes, defined by:			
	3a. Self-report? ……..…	○	○	
	3b. Use of cholesterol-lowering agents? ……..……..……	○	○	
	3c. Other _____			
4.	**Diabetes mellitus?** …….	○	○	○
	If yes, defined by:			
	4a. Self-report? ……..…	○	○	
	4b. History of treatment for diabetes with insulin/oral hypoglycemic agents?	○	○	
	4c. Other _____			
5.	**Hypertension?** ……	○	○	○
	If yes, defined by:			
	5a. Self-report? ……..……..…	○	○	
	5b. Use of anti-hypertensive medications? ……..……..…….	○	○	
	5c. Other _____			
6.	**Obesity?** ……..	○	○	○
	If yes, calculated through:			
	6a. Abdominal obesity? …… (Waist circumference > 102cm for men and > 88cm for women)	○	○	
	6b. Body mass index (BMI) > 30? ……..……..…….	○	○	
	6c. Other _____			

Texas Alzheimer's Consortium Longitudinal Data Set (LDS) – Initial Visit Packet
Form X1: Clinical Information Form

Center: _____ ADC Subject ID: __ __ __ __ __ __ __ __ __ __ Visit Date: __ __/ __ __/ __ __

Note: This form is to be completed by the clinician.

ADC Visit #: __ __ __
Examiner's initials: __ __ __

Cardiovascular disease and related risk factors (cont.):		**1 Yes**	**0 No**	**9 Unk**
7. **Smoking**				
7a.	"Ever"? ……...	○	○	○
7b.	"Current"? ……...	○	○	○
8. **Other Information**				
	Self-reported history of:			
8a.	Atrial fibrillation? ……..……..	○	○	○
8b.	Other arrhythmias? ……..……	○	○	○
8c.	Myocardial infarction? ……..……..	○	○	○
8d.	Congestive heart failure? ……. ……...	○	○	○
8e.	Angina pectoris? ……..……	○	○	○