Summary Variables

2020 ILIAD Summary Variables

OVERVIEW for all of ILIAD 2020

With funds from the National Institute on Aging the WLS partnered with UW Madison's Alzheimer Disease Research Center (ADRC) to conduct a new round of interviews starting in 2019. ILIAD 2020 (Initial Lifetime's Impact on Alzheimer's Disease and Related Dementias) includes either one or two interviews for each participant for whom we had a prior measure of cognition or another criterium.

First, we conducted a "short" interview that took 30 to 40 minutes. The focus was on memory and thinking and we repeated activities used in prior rounds of the study and for the first time, we administered the Telephone Interview for Cognitive Status-modified (TICS-M). We also updated some family and health measures. Next, we recruited participants who scored below a cutoff on the TICS-M to participate in a "long" interview with both a trained survey interviewer (IV) and an Advanced Practive Provider (APP) also known as a nurse practitioner. We planned for the long interview to be an in-person interview with both the IV and APP present. Because of the Covid-19 pandemic we stopped in-person interviews shortly after we started. We restarted the long interviews after developing a comporable phone instrument. As vaccines and testing became available we were able to return to in-person visits. By the end of our fielding period for the long follow-up interview, participants who completed the 2020 long instrument did so in one of four ways. See measure o1a942re for the four different combination of modes for the long interview.

If we learned that the intended participant died or was too ill to be interviewed, we recruited an informant to answer questions about the participant's cognitive health. These informant interviews used the Dementia Questionnaire (DQ) which was scored for dementia. See measure stat20DQ for the number and type of interviews we completed using the DQ

The information gathered by the IV and APP was presented to a group of clinicians at a consensus conference. Taking into account other medical conditions and symptoms, the clinicians assigned each participant a level of impairment (o1a951re) and accompanying primary, contributing and non-contributing factors. Along with level of impairment we include MCI Subtype (o1a952re) and whether the consensus panel determined that Alzheimer's Disease was primary, contributing or not present. Along with Alzheimer's disease the consensus committee also noted additional etiologies of impairment. These other etiologies do not include enough cases to make available on the public release of the data. Researchers needing these additional measures should contact wls@ssc.wisc.edu.

The information collected on the DQ was first processed using an algorithim to approximate a dementia diagnosis. Next a clinician looked at the outcome of the algorithim as well as the detailed notes that the interviewers captured during their conversations. The clinician confirmed the diagnosis and also assigned a level of confidence to the diagnosis based on the DQ. See measures o1a954re and o1a955re.

Finally for the ease of researchers wishing to combine cases that completed the long interview with cases for which we only have proxy data we create two versions of a combined diagnosis measure (o1a956re and o1a957re)

Researchers wanting a precise measure that minimizes false positives (aka type 1 error) should consider o1a956re which we labeled "Positive Predictive Value (PPV) Summary Score." Conceptually PPV=(True Positives/(True Positives + False Positives). For this measure we were more conservative in who we designated as meeting the criteria for a research diagnosis of dementia, MCI, or other impairment. The cost of using this measure is that you might miss some cases (i.e. have more false negatives).

Researchers wanting a broader measure that minimizes false negatives (aka type 2 error) should consider o1a957re which we labeled "Negative Predictive Value (NPV) Summary Score." Conceptually NPV=(True Negatives)/(True Negatives + False Negatives). For this measure any indication of poor cognitive performance at any point (for any reason) was used to move cases from the "cognitively normal" category into the "impaired" category. This is important from a population health perspective because it's more likely to capture any signal of potential cognitive problems. While it results in less precision for identifying cases, it allows for the most comprehensive estimate of potential *needs* associated with poorer cognitive performance.

Researchers wanting more details on how we created a resesarch diagnosis can learn more by reading cor 1029 in Appendix X.

Appendix X

We are currently repeating the same protocol with the same participants for ILIAD 2023.


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BRIEF VARIABLE DESCRIPTIONS
      2020 ILIAD Participation
            xstat20short  2020 ILIAD Participation in Short Interview
            xstat20long   2020 ILIAD Participation in Long Interview
            xstat20DQ     2020 ILIAD Proxy Participation in Dementia Questionnaire

      Information about the 2020 ILIAD interviews
            o1a003re     Age at time of Short interview
            o1a020re     State of Residence
            o1a934re     2020 FIPS code for home address
            o1a935re     2020 Census Tract code of home address
            o1a936re     2020 Census Block code of home address
            o1a937re     2020 Place FIPS code of home address
            o1a938re     2020 Minor Civil Divison code of home address
            o1a016rem    Month Completed ILIAD 2020 Short Interview
            o1a016rey    Year Completed ILIAD 2020 Short Interview
            o1a026rem    Month Informant Completed ILIAD 2020 DQ
            o1a026rey    Year Informant Completed ILIAD 2020 DQ
            o1a940re     Mode of Short interview
            o1a941re     Months between Short and Long interviews
            o1a942re     Mode of Long Interviews

      Outcome of 2020 ILIAD Long Interviews
            o1a951re     Level of cognitive impairment via Consensus
            o1a952re     MCI Subtype
            o1a953re     Consensus outcome for Alzheimer's Disease

      Outcome of 2020 ILIAD Dementia Questionnaire (DQ)
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        o1a954re      Research Diagnosis Via Proxy
        o1a955re      Confidence of Proxy Diagnosis

Combined Outcome of DQ and Long Interview
        o1a956re      Positive Predictive Value Summary Score
        o1a957re      Negative Predictive Value Summary Score

Imputed Cognition
        o1a958re      Imputed Cognition for people who qualified for,
                      but did not complete, the Time 1 long Interview
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xstat20short: 2020 ILIAD Participation in Short Interview.

Data source: Sibling Respondent   Collected in: 2020   Mode: In person & telephone
Source variables: code

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
.	System missing - NR	3418	3104	6522
1	Complete	699	860	1559
2	Refused	100	124	224
3	Not Found	82	86	168
4	Deceased	104	95	199
5	Respondent Away/Unavailable	7	23	30
6	Unable	27	49	76

xstat20long: 2020 ILIAD Participation in long Interview.

Data source: Sibling Respondent   Collected in: 2020   Mode: In person & telephone
Source variables: code

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
.	System missing - NR	3418	3104	6522
-2	Inappropriate Inapplicable	301	337	638
1	Complete	164	159	323
2	Not Eligible above cut-off	518	682	1200
3	Eligible refused/non-contact	12	8	20
4	Eligible died before completing long	3	8	11
5	Physically or Mentally unable	21	43	64

xstat20dq: 2020 ILIAD Proxy Participation in Dementia Questionnaire.

Data source: Sibling Respondent   Collected in: 2020   Mode: In person & telephone
Source variables: code

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
.	System missing - NR	3418	3104	6522
1	Proxy Complete	19	34	53
2	Mortality complete	76	71	147
3	Not completed	924	1132	2056

o1a003re: Age at time of Short Interview.

Data source: Sibling Respondent   Collected in: 2020   Mode: In person & telephone
Source variables: cmpldate, birthdate

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
.	System missing - NR	3418	3104	6522
-2	Inappropriate Inap, (Did not complete the short interview)	320	377	697
49 - 72		148	167	315
73 - 76		159	199	358
77 - 79		150	175	325
80 - 84		143	179	322
85 - 97		99	140	239

Note: Bottom-coded at 64 and top-coded at 90 on the public release.

o1a020re: State of Residence

Data source: Sibling Respondent   Collected in: 2020   Mode: In person & telephone
Source variables: T1P1_STATE

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
.	System missing - NR	3418	3104	6522
-2	Inappropriate Inap, (Did not complete the short interview)	320	377	697
1	Alabama	4	2	6
2	Alaska	1	2	3
3	Arizona	17	21	38
4	Arkansas	5	1	6
5	California	22	31	53
6	Colorado	12	8	20
7	Connecticut	1	0	1
8	Delaware	0	1	1
9	Washington, D.C.	1	0	1

10	Florida	27	31	58
11	Georgia	6	6	12
12	Hawaii	0	1	1
13	Idaho	1	5	6
14	Illinois	25	18	43
15	Indiana	2	4	6
16	Iowa	1	1	2
17	Kansas	2	3	5
18	Kentucky	3	2	5
19	Louisiana	1	0	1
21	Maryland	4	4	8
22	Massachusetts	2	7	9
23	Michigan	8	9	17
24	Minnesota	34	28	62
25	Mississippi	1	2	3
26	Missouri	5	7	12
27	Montana	4	7	11
28	Nebraska	1	1	2
29	Nevada	4	1	5
31	New Jersey	2	3	5
32	New Mexico	2	7	9
33	New York	5	5	10
34	North Carolina	4	10	14
35	North Dakota	0	2	2
36	Ohio	4	6	10
37	Oklahoma	2	0	2
38	Oregon	5	5	10
39	Pennsylvania	7	5	12

41	South Carolina	1	4	5
43	Tennessee	5	8	13
44	Texas	11	14	25
45	Utah	2	0	2
47	Virginia	4	13	17
48	Washington	8	8	16
49	West Virginia	1	1	2
50	Wisconsin	442	565	1007
500	Not in USA	0	1	1

o1a934re: 2020 FIPS code for home address, coded by UW Applied Population Laboratory

Data source: Sibling Respondent   Collected in: 2020   Mode: In person & telephone
Source variables: T1P1_STATE
NOT AVAILABLE ON PUBLIC RELEASE

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
	System missing - NR	3418	3104	6522
"-2"	Inappropriate Inap, (Did not complete the short interview)	320	377	697
"-4"	Not Ascertained, (Not codeable or outside USA)	3	6	9
"06065"		1	1	2
"08059"		0	2	2
"12103"		2	6	8
"13067"		0	2	2
"27065"		1	0	1
"27139"		1	0	1
"34005"		1	0	1
"39129"		1	0	1
"42027"		1	1	2
"51173"		0	1	1

Note: Only 13 of 361 values are listed.

o1a935re: 2020 Census Tract code of home address, coded by UW Applied Population Laboratory

Data source: Sibling Respondent   Collected in: 2020   Mode: In person & telephone
Source variables: Tract20
NOT AVAILABLE ON PUBLIC RELEASE

Value	Label	Frequencies		
		Male	**Female**	**Total**
	System missing - NR	3418	3104	6522
"-2"	Inappropriate Inap, (Did not complete the short interview)	320	377	697
"-4"	Not Ascertained, (Not codeable or outside USA)	3	6	9
"17015960100"		1	0	1
"17031804109"		1	0	1
"24031700615"		1	0	1
"26071000500"		1	0	1
"27163070703"		1	0	1
"51013100700"		1	0	1
"55101001101"		1	0	1
"55121100400"		1	0	1
"55133200101"		0	1	1
"55139002402"		1	1	2

Note: Only 13 of 1211 values are listed.

o1a936re: 2020 Census Block code of home address, coded by UW Applied Population Laboratory

Data source: Sibling Respondent   Collected in: 2020   Mode: In person & telephone
Source variables: Block20
NOT AVAILABLE ON PUBLIC RELEASE

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
	System missing - NR	3418	3104	6522
"-2"	Inappropriate Inap, (Did not complete the short interview)	320	377	697
"-4"	Not Ascertained, (Not codeable or outside USA)	3	6	9
"040190047105000"		0	1	1
"050070208012022"		1	0	1
"120950178081000"		1	0	1
"130670304092000"		0	1	1
"170318001001004"		1	0	1
"420639608002045"		1	0	1
"511610312023011"		0	1	1
"550079601001064"		0	1	1
"550170107005046"		1	0	1
"551199604003033"		0	1	1

Note: Only 13 of 1532 values are listed.

o1a937re: 2020 Place FIPS code of home address, coded by UW Applied Population Laboratory

Data source: Sibling Respondent   Collected in: 2020   Mode: In person & telephone
Source variables: Place20
NOT AVAILABLE ON PUBLIC RELEASE

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
	System missing - NR	3418	3104	6522
"-2"	Inappropriate Inap, (Did not complete the short interview)	320	377	697
"-4"	Not Ascertained, (Not codeable or outside USA)	222	258	480
"0425300"		1	0	1
"0439370"		0	1	1
"0470320"		2	0	2
"0606000"		2	0	2
"0654848"		0	1	1
"0811810"		1	0	1
"1238250"		1	1	2
"3771460"		1	0	1
"5557100"		0	1	1

Note: Only 12 of 584 values are listed.

o1a938re: 2020 Minor Civil Divison code of home address, coded by UW Applied Population Laboratory

Data source: Sibling Respondent   Collected in: 2020   Mode: In person & telephone
Source variables: MCD
NOT AVAILABLE ON PUBLIC RELEASE

Value	Label	Frequencies		
		Male	**Female**	**Total**
	System missing - NR	3418	3104	6522
"-2"	Inappropriate Inap, (Did not complete the short interview)	320	377	697
"-4"	Not Ascertained, (Not codeable or outside USA)	3	6	9
"0600190200"		2	0	2
"1703132694"		1	0	1
"1703154898"		0	1	1
"1711983284"		0	1	1
"2710954880"		1	0	1
"3203194635"		0	1	1
"5106993663"		1	0	1
"5500931000"		4	3	7
"5512377075"		1	0	1
"5513955775"		1	1	2

Note: Only 13 of 912 values are listed.

o1a016rem: Month Completed ILIAD 2020 Short Interview.

Data source: Sibling Respondent   Collected in: 2020   Mode: In person & telephone
Source variables: cmpldate

Frequencies

Value	Label	Male	Female	Total
.	System missing - NR	3738	3481	7219
1	January	24	38	62
2	February	17	36	53
3	March	20	38	58
4	April	63	65	128
5	May	82	90	172
6	June	81	83	164
7	July	83	103	186
8	August	127	160	287
9	September	69	98	167
10	October	58	89	147
11	November	41	38	79
12	December	34	22	56

o1a016rey: Year Completed ILIAD 2020 Short Interview.

Data source: Sibling Respondent   Collected in: 2020   Mode: In person & telephone
Source variables: cmpldate

Frequencies

Value	Label	Male	Female	Total
.	System missing - NR	3738	3481	7219
2019		104	125	229
2020		403	494	897
2021		182	227	409
2022		10	14	24

o1a026rem: Month Proxy Completed ILIAD 2020 DQ.

Data source: Proxy   Collected in: 2020   Mode: In person & telephone
Source variables: pmcc_cmpldate

		Frequencies		
Value	Label	Male	Female	Total
.	System missing - NR	4342	4236	8578
1	January	10	12	22
2	February	6	11	17
3	March	6	7	13
4	April	18	14	32
5	May	8	4	12
6	June	4	4	8
7	July	11	12	23
8	August	6	7	13
9	September	6	14	20
10	October	9	8	17
11	November	6	5	11
12	December	5	7	12

o1a026rey: Year Proxy Completed ILIAD 2020 DQ.

Data source: Proxy   Collected in: 2020   Mode: In person & telephone
Source variables: pmcc_cmpldate

		Frequencies		
Value	Label	Male	Female	Total
.	System missing - NR	4342	4236	8578
2020		47	43	90
2021		39	53	92
2022		9	9	18

o1a940re: Mode of Short interview.

Data source: Sibling Respondent   Collected in: 2020   Mode: In person & telephone
Source variables: ivmode

Frequencies

Value	Label	Male	Female	Total
.	System missing - NR	20	29	49
-2	Inappropriate Inapplicable	3718	3452	7170
1	Telephone	691	848	1539
2	In-Person	8	12	20

o1a941re: Months between Short and Long interviews.

Data source: Sibling Respondent   Collected in: 2020   Mode: In person & telephone
Source variables: cmpldate, p2rdate

Frequencies

Value	Label	Male	Female	Total
.	System missing - NR	4273	4182	8455
1 - 3		46	36	82
4 - 5		45	50	95
6 - 8		36	34	70
9 - 17		33	31	64
18 - 33		4	8	12

Note: As shown in o1a942re the Long Interview is in practice two seperate interviews. The lag between the two long interviews (one conducted by an Interviewer and one by a Nurase Practitioner) is primarily less than one month.

o1a942re: Mode of Long interviews.

Data source: Sibling Respondent   Collected in: 2020   Mode: In person & telephone
Source variables: casetype

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
.	System missing - NR	321	366	687
-2	Inappropriate Inapplicable	3952	3816	7768
1	Standard (IV & APP In-person)	17	17	34
2	No Nurse (IV In-person)	2	0	2
3	Hybrid (IV In-person followed by APP Call)	0	2	2
4	Both Phone (IV & APP)	145	140	285

Note: IV is an abbreviation for an Interviewer and APP is an abbreviation for Advanced Practice Provider sometimes known as a Nurse Practitioner.

o1a951re: Level of cognitive impairment via Consensus.

Data source: Sibling Respondent   Collected in: 2020   Mode: In person & telephone
Source variables: REDCap data

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
.	System missing - NR	3719	3441	7160
-2	Inappropriate Inap, (Did not complete the long interview)	554	741	1295
1	Normal Cognition	59	59	118
2	MCI	77	62	139
3	Dementia	28	38	66

o1a952re: MCI Subtype.

Data source: Sibling Respondent   Collected in: 2020   Mode: In person & telephone
Source variables: REDCap data

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
.	System missing - NR	3719	3441	7160
-2	Inappropriate Inap, (No MCI determination o1a951re != 3)	641	838	1479
1	Single Domain Amnestic	22	10	32
2	Single Domain Non-Amnestic	20	22	42
3	Multi Domain Amnestic	25	21	46
4	Multi Domain Non-Amnestic	10	9	19

Note: Five cognitive domains were considered: attention, executive functioning, language, memory, and visuospatial abilities

o1a953re: Consensus outcome for Alzheimer's Disease.

Data source: Sibling Respondent   Collected in: 2020   Mode: In person & telephone
Source variables: REDCap data

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
.	System missing - NR	4273	4182	8455
0	Not Present	75	81	156
1	1 Primary	80	77	157
2	2 Contributing	9	1	10

Note: Along with Alzheimer's disease the consensus committee also noted additional etiologies of impairment. These other etiologies do not include enough cases to make available on the public release of the data. Researchers needing these additional measures should contact wls@ssc.wisc.edu.

o1a954re: Research Diagnosis via Proxy.

Data source: Proxy   Collected in: 2020   Mode: In person & telephone
Source variables: DQ Instrument

Frequencies

Value	Label	Male	Female	Total
.	System missing - NR	4342	4236	8578
0	No Dementia	59	40	99
1	Non-Alzheimer's Dementia	20	11	31
2	Alzheimer's Dementia	16	54	70

Note: See stat20DQ to differentiate between cases where the proxy was reporting on a living participant or a deceased participant.

o1a955re: Confidence of Proxy Diagnosis.

Data source: Proxy   Collected in: 2020   Mode: In person & telephone
Source variables: DQ Instrument

Frequencies

Value	Label	Male	Female	Total
.	System missing - NR	4342	4236	8578
1	High	10	7	17
2	Moderate	16	31	47
3	Low	22	27	49
4	Not reviewed	47	40	87

o1a956re: Positive Predictive Value Summary Outcome

Data source: Sibling Participant or Proxy   Collected in: 2020   Mode: In person & telephone
Source variables: xstat20long, o1a951re, DQ Instrument, REDCap data, o1a952re, o1a953re, o1a954re

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
.	System missing - NR	3651	3382	7033
1	Assumed Normal Cognition TICSm above cutoff	515	682	1197
2	Normal Cognition, Consensus	59	59	118
3	Normal Cognition, Proxy	58	40	98
4	MCI AD, Consensus	63	41	104
5	MCI Non-AD, Consensus	14	21	35
6	Dementia AD, Consensus	26	37	63
7	Dementia Non-AD, Consensus	2	1	3
8	Dementia AD, Proxy	16	53	69
9	Dementia Non-AD, Proxy	20	11	31
11	TICSm < 29 Died before or refused long interview	13	14	27

Note: Please read the overview above to learn more about this measure.

o1a957re: Negative Predictive Value Summary Outcome

Data source: Sibling Participant or Proxy   Collected in: 2020   Mode: In person & telephone
Source variables: o1a916re, o1a951re, DQ Instrument, REDCap data, o1a952re, o1a953re, o1a954re

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
.	System missing - NR	3648	3373	7021
1	Normal	571	720	1291
2	Impaired	164	169	333
3	Dementia	54	79	133

Note: Please read the overview above to learn more about this measure.

o1a958re: Imputed Cognition for people who qualified for but did not complete the Time 1 long interview

Data source: Sibling Respondent   Collected in: 2020   Mode: In person & telephone
Source variables: Imputation algorithim

Frequencies

Value	Label	Male	Female	Total
.	System missing - NR	3651	3382	7033
-2	Inappropriate Inap, (o1a956re != 11)	773	945	1718
1	Normal Cognition	8	7	15
2	MCI	4	6	10
3	Dementia	1	1	2

Note: The imputation was performed using IVEware based on the following variables:
respondent type, sex, age, ancestry, parental education, IQ, highest educational degree, income and net worth in 2011, marital status, area deprivation index, TICS factors, letter fluency, digit ordering, number series, change in immediate and delayed recall from 2011, self-rated health and chronic health conditions, and hearing problems. We would like to stress that the imputation is probabilistic and recommend using the imputed measure in statistical models based on the entire ILIAD sample.

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