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 q1a942re 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 (q1a951re) and accompanying primary, contributing and non-contributing factors. Along with level of impairment we include MCI Subtype (q1a952re) 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 q1a954re and q1a955re.

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 (q1a956re and q1a957re)

Researchers wanting a precise measure that minimizes false positives (aka type 1 error) should consider q1a956re 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 q1a957re 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.

BRIEF VARIABLE DESCRIPTIONS

2020 ILIAD Participation

stat20short	2020 ILIAD Participation in Short Interview
stat20long	2020 ILIAD Participation in Long Interview
stat20DQ	2020 ILIAD Proxy Participation in Dementia Questionnaire

Information about the 2020 ILIAD interviews

q1a003re	Age at time of Short interview
q1a020re	State of Residence
q1a934re	2020 FIPS code for home address
q1a935re	2020 Census Tract code of home address
q1a936re	2020 Census Block code of home address
q1a937re	2020 Place FIPS code of home address
q1a938re	2020 Minor Civil Divison code of home address
q1a016rem	Month Completed ILIAD 2020 Short Interview
q1a016rey	Year Completed ILIAD 2020 Short Interview
q1a026rem	Month Informant Completed ILIAD 2020 DQ
q1a026rey	Year Informant Completed ILIAD 2020 DQ
q1a940re	Mode of Short interview
q1a941re	Months between Short and Long interviews
q1a942re	Mode of Long Interviews

Outcome of 2020 ILIAD Long Interviews

q1a951re	Level of cognitive impairment via Consensus
q1a952re	MCI Subtype
q1a953re	Consensus outcome for Alzheimer's Disease

Outcome of 2020 ILIAD Dementia Questionnaire (DQ)

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        q1a954re     Research Diagnosis Via Proxy
        q1a955re     Confidence of Proxy Diagnosis

Combined Outcome of DQ and Long Interview
        q1a956re     Positive Predictive Value Summary Score
        q1a957re     Negative Predictive Value Summary Score

Imputed Cognition
        q1a958re     Imputed Cognition for people who qualified for,
                     but did not complete, the Time 1 long Interview
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stat20short: 2020 ILIAD Participation in Short Interview.

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

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
.	System missing - NR	2880	2735	5615
1	Complete	1471	1877	3348
2	Refused	119	190	309
3	Not Found	102	151	253
4	Deceased	328	263	591
5	Respondent Away/Unavailable	26	26	52
6	Unable	65	84	149

stat20long: 2020 ILIAD Participation in Long Interview.

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

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
.	System missing - NR	2880	2735	5615
-2	Inappropriate Inapplicable	590	642	1232
1	Complete	404	400	804
2	Not Eligible above cut-off	1011	1419	2430
3	Eligible refused/non-contact	26	34	60
4	Eligible died before completing long	19	18	37
5	Physically or Mentally unable	61	78	139

Note: We administered the long interview to two participants who were not eligible based on the corrected results of the TICSm. Both of these participants completed the long interview and we include the outcome of the long interview in the data

stat20dq: 2020 ILIAD Proxy Participation in Dementia Questionnaire.

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

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
.	System missing - NR	2880	2735	5615
1	Proxy Complete	55	60	115
2	Mortality complete	210	153	363
3	Not completed	1846	2378	4224

q1a003re: Age at time of Short Interview.

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

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
.	System missing - NR	2880	2735	5615
-2	Inappropriate Inap, (Did not complete the short interview)	640	714	1354
78		0	1	1
79		13	45	58
80		304	462	766
81		822	1039	1861
82		289	285	574
83		40	43	83
84		2	2	4
85		1	0	1

Note: Bottom-coded at 79 and top-coded at 83 on the public release.

q1a020re: State of Residence

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

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
.	System missing - NR	2880	2735	5615
-2	Inappropriate Inap, (Did not complete the short interview)	640	714	1354
1	Alabama	5	6	11
2	Alaska	6	2	8
3	Arizona	48	68	116
4	Arkansas	9	6	15
5	California	59	67	126
6	Colorado	22	25	47

7	Connecticut	1	6	7
8	Delaware	0	3	3
9	Washington, D.C.	1	1	2
10	Florida	77	94	171
11	Georgia	11	10	21
12	Hawaii	0	1	1
13	Idaho	4	4	8
14	Illinois	35	57	92
15	Indiana	13	13	26
16	Iowa	7	12	19
17	Kansas	7	2	9
18	Kentucky	2	4	6
19	Louisiana	1	2	3
20	Maine	2	0	2
21	Maryland	5	6	11
22	Massachusetts	4	10	14
23	Michigan	15	17	32
24	Minnesota	60	52	112
25	Mississippi	0	1	1
26	Missouri	8	6	14
27	Montana	5	6	11
28	Nebraska	3	3	6
29	Nevada	7	7	14
30	New Hampshire	3	1	4
31	New Jersey	3	6	9
32	New Mexico	6	9	15
33	New York	2	10	12
34	North Carolina	10	14	24

35	North Dakota	0	3	3
36	Ohio	11	17	28
37	Oklahoma	2	5	7
38	Oregon	9	11	20
39	Pennsylvania	8	6	14
40	Rhode Island	1	0	1
41	South Carolina	9	4	13
42	South Dakota	4	1	5
43	Tennessee	8	10	18
44	Texas	23	32	55
45	Utah	3	3	6
47	Virginia	8	16	24
48	Washington	14	13	27
49	West Virginia	0	1	1
50	Wisconsin	925	1218	2143
51	Wyoming	1	3	4
500	Not in USA	4	3	7

Note: On the public release, all codes other than Wisconsin (50) have been collapsed into a non-Wisconsin "other" category (0). The private data includes codes for states and foreign countries.

q1a934re: 2020 FIPS code for home address, coded by UW Applied Population Laboratory

Data source: Graduate 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	2880	2735	5615
"-2"	Inappropriate Inap, (Did not complete the short interview)	640	714	1354
"-4"	Not Ascertained, (Not codeable or outside USA)	17	19	36
"06013"		3	2	5
"09001"		1	2	3
"18105"		0	1	1
"18141"		1	1	2
"24013"		0	1	1
"36077"		0	1	1
"39041"		1	0	1
"46037"		1	0	1
"54105"		0	1	1
"55105"		27	34	61

Note: Only 13 of 542 values are listed.

q1a935re: 2020 Census Tract code of home address, coded by UW Applied Population Laboratory

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

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
	System missing - NR	2880	2735	5615
"-2"	Inappropriate Inap, (Did not complete the short interview)	640	714	1354
"-4"	Not Ascertained, (Not codeable or outside USA)	17	19	36
"06037480500"		0	1	1
"17195001700"		0	1	1
"26041971100"		1	0	1
"27003050222"		0	1	1
"39095007002"		1	0	1
"39169003000"		0	1	1
"55033970300"		0	2	2
"55073000300"		2	2	4
"55079019200"		1	1	2
"55131420105"		2	1	3

Note: Only 13 of 2114 values are listed.

q1a936re: 2020 Census Block code of home address, coded by UW Applied Population Laboratory

Data source: Graduate 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	2880	2735	5615
"-2"	Inappropriate Inap, (Did not complete the short interview)	640	714	1354
"-4"	Not Ascertained, (Not codeable or outside USA)	17	19	36
"060730097045005"		1	0	1
"270190907033011"		0	1	1
"270530276013007"		1	0	1
"410670317081012"		0	1	1
"550619604011025"		0	1	1
"550710052001001"		1	1	2
"550790010002001"		1	0	1
"551170114001013"		0	1	1
"551314201041048"		1	0	1
"551332017031007"		1	0	1

Note: Only 13 of 3202 values are listed.

q1a937re: 2020 Place FIPS code of home address, coded by UW Applied Population Laboratory

Data source: Graduate 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	2880	2735	5615
"-2"	Inappropriate Inap, (Did not complete the short interview)	640	714	1354
"-4"	Not Ascertained, (Not codeable or outside USA)	450	502	952
"0611390"		0	1	1
"0612930"		1	0	1
"0644000"		4	5	9
"1234132"		1	0	1
"1267887"		1	0	1
"2148006"		1	0	1
"2655100"		0	1	1
"2732498"		1	0	1
"2744476"		1	0	1
"5577875"		3	3	6

Note: Only 13 of 1004 values are listed.

q1a938re: 2020 Minor Civil Divison code of home address, coded by UW Applied Population Laboratory

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

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
	System missing - NR	2880	2735	5615
"-2"	Inappropriate Inap, (Did not complete the short interview)	640	714	1354
"-4"	Not Ascertained, (Not codeable or outside USA)	17	19	36
"1210393042"		2	2	4
"1719744238"		1	1	2
"1809742444"		1	0	1
"2610953020"		2	0	2
"2712358000"		3	0	3
"5500513500"		0	1	1
"5501153850"		1	0	1
"5501184325"		0	1	1
"5507377150"		0	1	1
"5513133000"		3	7	10

Note: Only 13 of 1507 values are listed.

q1a016rem: Month Completed ILIAD 2020 Short Interview.

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

Frequencies

Value	Label	Male	Female	Total
.	System missing - NR	3520	3449	6969
1	January	149	153	302
2	February	129	173	302
3	March	94	131	225
4	April	76	84	160
5	May	101	143	244
6	June	101	130	231
7	July	94	151	245
8	August	164	221	385
9	September	174	225	399
10	October	156	156	312
11	November	96	104	200
12	December	137	206	343

q1a016rey: Year Completed ILIAD 2020 Short Interview.

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

Frequencies

Value	Label	Male	Female	Total
.	System missing - NR	3520	3449	6969
2019		124	150	274
2020		797	1008	1805
2021		526	679	1205
2022		24	40	64

q1a026rem: 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	4726	5113	9839
1	January	22	30	52
2	February	17	16	33
3	March	16	19	35
4	April	27	21	48
5	May	7	7	14
6	June	19	15	34
7	July	21	12	33
8	August	38	25	63
9	September	47	18	65
10	October	21	32	53
11	November	14	14	28
12	December	16	4	20

q1a026rey: 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	4726	5113	9839
2020		115	71	186
2021		121	116	237
2022		29	26	55

q1a940re: Mode of Short interview.

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

Frequencies

Value	Label	Male	Female	Total
-2	Inappropriate Inapplicable	3520	3449	6969
1	Telephone	1454	1843	3297
2	In-Person	17	34	51

q1a941re: Months between Short and Long interviews.

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

Frequencies

Value	Label	Male	Female	Total
.	System missing - NR	4586	4927	9513
1 - 3		97	133	230
4 - 5		163	126	289
6 - 7		86	76	162
8 - 35		59	64	123

Note: As shown in q1a942re 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.

q1a942re: Mode of Long interviews.

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

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
.	System missing - NR	590	642	1232
-2	Inappropriate Inapplicable	3997	4284	8281
1	Standard (IV & APP In-person)	25	29	54
2	No Nurse (IV In-person)	3	0	3
3	Hybrid (IV In-person followed by APP Call)	1	3	4
4	Both Phone (IV & APP)	375	368	743

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

q1a951re: Level of cognitive impairment via Consensus.

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

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
.	System missing - NR	3470	3377	6847
-2	Inappropriate Inap, (Did not complete the long interview)	1117	1549	2666
1	Normal Cognition	172	170	342
2	MCI	175	154	329
3	Dementia	56	75	131
4	No Diagnosis	1	1	2

q1a952re: MCI Subtype.

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

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
.	System missing - NR	3470	3377	6847
-2	Inappropriate Inap, (No MCI determination q1a951re != 3)	1346	1795	3141
1	Single Domain Amnestic	37	23	60
2	Single Domain Non-Amnestic	61	55	116
3	Multi Domain Amnestic	58	43	101
4	Multi Domain Non-Amnestic	19	33	52

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

q1a953re: Consensus outcome for Alzheimer's Disease.

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

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
.	System missing - NR	4587	4926	9513
0	Not Present	217	214	431
1	1 Primary	174	183	357
2	2 Contributing	13	3	16

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.

q1a954re: 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	4726	5113	9839
0	No Dementia	163	117	280
1	Non-Alzheimer's Dementia	33	22	55
2	Alzheimer's Dementia	69	74	143

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

q1a955re: 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	4726	5113	9839
1	High	26	22	48
2	Moderate	52	48	100
3	Low	45	47	92
4	Not reviewed	142	96	238

q1a956re: Positive Predictive Value Summary Outcome

Data source: Graduate Participant or Proxy Collected in: 2020 Mode: In person & telephone
Source variables: stat20long, q1a951re, DQ Instrument, REDCap data, q1a952re, q1a953re, q1a954re

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
.	System missing - NR	3283	3253	6536
1	Assumed Normal Cognition TICSm above cutoff	1005	1416	2421
2	Normal Cognition, Consensus	172	170	342
3	Normal Cognition, Proxy	161	116	277
4	MCI AD, Consensus	139	119	258
5	MCI Non-AD, Consensus	36	35	71
6	Dementia AD, Consensus	48	67	115
7	Dementia Non-AD, Consensus	8	8	16
8	Dementia AD, Proxy	69	72	141
9	Dementia Non-AD, Proxy	33	22	55
11	TICSm < 29 Died before or refused long interview	37	48	85

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

q1a957re: Negative Predictive Value Summary Outcome

Data source: Graduate Participant or Proxy Collected in: 2020 Mode: In person & telephone
Source variables: q1a916re, q1a951re, DQ Instrument, REDCap data, q1a952re, q1a953re, q1a954re

		Frequencies		
Value	**Label**	**Male**	**Female**	**Total**
.	System missing - NR	3273	3236	6509
1	Normal	1151	1527	2678
2	Impaired	442	435	877
3	Dementia	125	128	253

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

q1a958re: Imputed Cognition for people who qualified for but did not complete the Time 1 long interview

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

Frequencies

Value	Label	Male	Female	Total
.	System missing - NR	3283	3253	6536
-2	Inappropriate Inap, (q1a956re != 11)	1671	2025	3696
1	Normal Cognition	16	23	39
2	MCI	20	16	36
3	Dementia	1	9	10

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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