ITHS | Institute of Translational Health Sciences
Accelerating Research. Improving Health.

University of Washington Seattle
Institute of Translational Health Science (ITHS)

PBH-LD

📖 Codebook ▾

<div align="center">

📖 **Data Dictionary Codebook**

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01/24/2019 9:26am

	#	Variable / Field Name	Field Label *Field Note*	Field Attributes (Field Type, Validation, Choices, Calculations, etc.)
Instrument: **Patient Id** (patient_id)				
	1	id	ID	text
	2	patient_id_complete	Section Header: *Form Status* Complete?	dropdown 0 Incomplete 1 Unverified 2 Complete
Instrument: **Subject Info** (subject_info)				
	3	myow_scrnid	Screening Number (assigned prior to Enrollment number = PID)	text
	4	interview_date	Date of Interview	text (date_ymd), Required
	5	longdist	Long-distance interview protocol was used with this subject.	radio 1 Yes 0 No 99 missing

Instrument: **Values** (values)

	615	values_calmselfcare	How would you rate your overall self-care from day-to-day when life is calm?	radio

5	5 Excellent
4.75	4.75
4.5	4.5
4.25	4.25
4	4
3.75	3.75
3.5	3.5
3.25	3.25
3	3
2.75	2.75
2.5	2.5
2.25	2.25
2	2
1.75	1.75
1.5	1.5
1.25	1.25
1	1 Very poor
99	Missing

	616	values_illselfcare	How would you rate your overall self-care when your loved one is very ill?	radio

5	5 Excellent
4.75	4.75
4.5	4.5
4.25	4.25
4	4
3.75	3.75
3.5	3.5
3.25	3.25
3	3
2.75	2.75
2.5	2.5
2.25	2.25
2	2
1.75	1.75
1.5	1.5
1.25	1.25
1	1 Very poor
99	Missing

	617	values_complete	Section Header: *Form Status* Complete?	dropdown

0	Incomplete
1	Unverified
2	Complete

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	639			
	640		:	

Instrument: **BRS** (brs)

	642	brs1_bounce	Section Header: *Brief Resilience Scale (BRS)* I tend to bounce back quickly after hard times.	radio 1 · Strongly Disagree (1) 2 · Disagree (2) 3 · Neutral (3) 4 · Agree (4) 5 · Strongly Agree (5) 99 · missing Custom alignment: LH
	643	brs2_makethrough	I have a hard time making it through stressful events.	radio 5 · Strongly Disagree (5) 4 · Disagree (4) 3 · Neutral (3) 2 · Agree (2) 1 · Strongly Agree (1) 99 · missing Custom alignment: LH

644	brs3_recover	It does not take me long to recover from a stressful event.	radio

radio

1	Strongly Disagree (1)
2	Disagree (2)
3	Neutral (3)
4	Agree (4)
5	Strongly Agree (5)
99	missing

Custom alignment: LH

645	brs4_snapback	It is hard for me to snap back when something bad happens.	radio

radio

5	Strongly Disagree (5)
4	Disagree (4)
3	Neutral (3)
2	Agree (2)
1	Strongly Agree (1)
99	missing

Custom alignment: LH

646	brs5_comethrough	I usually come through difficult times with little trouble.	radio

radio

1	Strongly Disagree (1)
2	Disagree (2)
3	Neutral (3)
4	Agree (4)
5	Strongly Agree (5)
99	missing

Custom alignment: LH

647	brs6_getover	I tend to take a long time to get over set-backs in my life.	radio

radio

5	Strongly Disagree (5)
4	Disagree (4)
3	Neutral (3)
2	Agree (2)
1	Strongly Agree (1)
99	missing

Custom alignment: LH

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648 brs_total

Show the field ONLY if:
[brs1_bounce] <> 99 and [brs2_makethrough] <> 99 and [brs3_recover] <> 99 and [brs4_snapback] <> 99 and [brs5_comethrough] <> 99 and [brs6_getover] <> 99

BRS total:

calc
Calculation: if([brs1_bounce] < 88, [brs1_bounce], 0)+ if([brs2_makethrough] < 88, [brs2_makethrough], 0)+ if([brs3_recover] < 88, [brs3_recover], 0)+ if([brs4_snapback] < 88, [brs4_snapback], 0)+ if([brs5_comethrough] < 88, [brs5_comethrough], 0)+ if([brs6_getover] < 88, [brs6_getover], 0)
Custom alignment: RH

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649 brs_average

Show the field ONLY if:
[brs1_bounce] <> 99 and [brs2_makethrough] <> 99 and [brs3_recover] <> 99 and [brs4_snapback] <> 99 and [brs5_comethrough] <> 99 and [brs6_getover] <> 99

BRS Average Score:
(Average BRS = Item total / 6)

calc
Calculation: [brs_total]/6
Custom alignment: RH

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650 brs_complete

Section Header: *Form Status*
Complete?

dropdown

0	Incomplete
1	Unverified
2	Complete

Instrument: **MYLOH Demog** (myloh_demog)

661	myloh_ptage	Section Header: *Care Recipient Demographics (from medical record data)* PWD Age *999=missing*	text (integer, Min: 0, Max: 999) Custom alignment: RH
662	myloh_ptgender	PWD Gender	radio <table><tr><td>2</td><td>Male</td></tr><tr><td>1</td><td>Female</td></tr><tr><td>99</td><td>Missing</td></tr></table> Custom alignment: RH
663	myloh_ptethnicity	PWD Ethnicity	radio <table><tr><td>1</td><td>Hispanic or Latino</td></tr><tr><td>2</td><td>Not Hispanic or Latino</td></tr><tr><td>99</td><td>Missing</td></tr></table>
664	myloh_ptrace	PWD Race (check all that apply)	checkbox <table><tr><td>01</td><td>myloh_ptrace___01</td><td>Native Hawaiian or other Pacific Islander</td></tr><tr><td>05</td><td>myloh_ptrace___05</td><td>African American or Black</td></tr><tr><td>04</td><td>myloh_ptrace___04</td><td>Asian</td></tr><tr><td>06</td><td>myloh_ptrace___06</td><td>Caucasian or White</td></tr><tr><td>03</td><td>myloh_ptrace___03</td><td>American Indian or Alaska Native</td></tr><tr><td>99</td><td>myloh_ptrace___99</td><td>Missing</td></tr></table>
665	myloh_ptmedicare	Does PWD receive Medicare?	radio <table><tr><td>1</td><td>Yes</td></tr><tr><td>0</td><td>No</td></tr><tr><td>99</td><td>missing</td></tr></table> Custom alignment: RH

	666	myloh_ptmedicaid	Does PWD receive Medicaid?	radio
				<table><tr><td>1</td><td>Yes</td></tr><tr><td>0</td><td>No</td></tr><tr><td>99</td><td>missing</td></tr></table>
	667		Section Header: *Care Partner-Supplied Information (Paper MYLOH form)*	
	668	myloh_cgtype	What kind of Care Partner are you?	radio <table><tr><td>1</td><td>I am a primary person responsible for care</td></tr><tr><td>2</td><td>I am a helper person who assists with care</td></tr><tr><td>3</td><td>I assist with care from long-distance</td></tr><tr><td>99</td><td>missing</td></tr></table>
	669	myloh_cgage	CG Age *999=missing*	text (integer, Min: 0, Max: 999) Custom alignment: RH
	670	myloh_cggender	CG Gender	radio <table><tr><td>2</td><td>Male</td></tr><tr><td>1</td><td>Female</td></tr><tr><td>99</td><td>Missing</td></tr></table> Custom alignment: RH
	671	myloh_reside	Do you live with him/her?	radio <table><tr><td>1</td><td>Yes, I live with PWD.</td></tr><tr><td>0</td><td>No</td></tr><tr><td>99</td><td>Missing</td></tr></table> Custom alignment: RH
	672	myloh_reside_spec	(free text) Do you live with him/her?	text
	673	myloh_cgeduc	What is the highest level of education you have achieved? (CG education level)	radio <table><tr><td>1</td><td>some school (grade 1-12)</td></tr><tr><td>2</td><td>high school graduate</td></tr><tr><td>2.5</td><td>some college</td></tr><tr><td>3</td><td>college graduate</td></tr><tr><td>4</td><td>vocational training</td></tr><tr><td>5</td><td>post-graduate education</td></tr><tr><td>99</td><td>Missing</td></tr></table>
	674	myloh_cgeducgrade Show the field ONLY if: [myloh_cgeduc] = '1'	What grade (grade 1-12) CG completed? *99=missing OR -99=not applicable (if grade>12 or missing)*	text (number)
	675	myloh_cgwork	CG Work Status ("are you currently working a full or part-time job?")	radio <table><tr><td>1</td><td>full time</td></tr><tr><td>2</td><td>part time</td></tr><tr><td>3</td><td>not working</td></tr><tr><td>99</td><td>missing</td></tr></table>
	676	myloh_relation	Relationship to care recipient:	radio <table><tr><td>4</td><td>Spouse</td></tr><tr><td>5</td><td>Domestic Partner</td></tr><tr><td>3</td><td>Child</td></tr><tr><td>2</td><td>Other Relative</td></tr><tr><td>1</td><td>Friend</td></tr><tr><td>88</td><td>Other (none of the above)</td></tr><tr><td>99</td><td>Missing</td></tr></table>
	677	myloh_relation_other Show the field ONLY if: [myloh_relation] = '88'	Other relationship to care recipient (please specify)	text
	678	myloh_dementiayears	How many years has she/he had a dementia diagnosis? *99=missing*	text

679	myloh_cgtime	How long have you been his/her caregiver? (Provide number of months or years.) *99=missing*	text (number, Min: 0)
680	myloh_cgtimeunits Show the field ONLY if: [myloh_cgtime] <> ''	...time units for length of caregiving time:	dropdown, Required 	1	Years
2	Months
99	missing	
681	myloh_ethnicity	CG Ethnicity	radio 	1	Hispanic or Latino
2	Not Hispanic or Latino
99	Missing	
682	myloh_cgrace	CG Race (check all that apply)	checkbox | 01	myloh_cgrace___01	Native Hawaiian or other Pacific Islander
05	myloh_cgrace___05	African American or Black
04	myloh_cgrace___04	Asian
06	myloh_cgrace___06	Caucasian or White
03	myloh_cgrace___03	American Indian or Alaska Native
99	myloh_cgrace___99	Missing	
683	myloh_ptliving	Where does he/she live?	radio 	4	Home (house/apartment)
3	Assisted Living
2	Long Term Care/Nursing Home
1	Dementia (Memory) Care Facility
5	Adult Family Home
88	Other (none of the above)
99	Missing	
684	myloh_ptliving_other Show the field ONLY if: [myloh_ptliving] = '88'	Other living situation (please specify):	text
685	myloh_difficultypay	How difficult is it for you to pay for all of the basic needs (ex. food, medical & other supplies, medications) for the person with dementia?	radio 	1	1 Not Difficult
2	2
3	3
4	4
5	5 Extremely Difficult
99	Missing	
686	myloh_cghealth	Would you consider your general health to be: (CG health self-assessment)	radio 	1	poor
2	fair
3	good
4	very good
99	missing	
687	myloh_othercaregiving	Do you have caregiving responsibilities besides this person?	radio 	1	Yes
0	No
99	missing	 Custom alignment: RH
688	myloh_othercaregivingchild Show the field ONLY if: [myloh_othercaregiving] = '1'	How many children do you care for? *99=missing*	text (number, Min: 0)
689	myloh_othercaregivingadult Show the field ONLY if: [myloh_othercaregiving] = '1'	How many adults do you care for? *99=missing*	text (number, Min: 0)

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Instrument: MYOW Interview (myow_interview)

	819	int_housecall	Section Header: *House Call* Would you use a house call doctor?	radio (Matrix) 1 Yes 0 No 88 I don't know 99 missing
	820	int_decision	Section Header: *Palliative Care Questions* Did you feel like you were involved with the process of making a decision about care plan or care options for PWD?	radio (Matrix) 1 Yes 0 No 88 I don't know 99 missing
	821	int_priorities	Did the doctor ask you questions on priorities of care for PWD?	radio (Matrix) 1 Yes 0 No 88 I don't know 99 missing
	822	int_questions	Did you feel that all of your questions were answered?	radio (Matrix) 1 Yes 0 No 88 I don't know 99 missing
	823	int_procon	Did the provider discuss pros and cons of hospitalization?	radio (Matrix) 1 Yes 0 No 88 I don't know 99 missing
	824	int_choice	Did you feel that you had a choice in what to do?	radio (Matrix) 1 Yes 0 No 88 I don't know 99 missing
	825	int_palliativereferral	Were you referred to any Palliative or Geriatric Specialty Care?	radio (Matrix) 1 Yes 0 No 88 I don't know 99 missing

826	int_preventablehosp	Do you believe hospitalization could have been prevented?	radio (Matrix)
			1 Yes
			0 No
			88 I don't know
			99 missing
827	int_fup	Did the provider/PCP follow up with you while PWD was in the hospital?	radio (Matrix)
			1 Yes
			0 No
			88 I don't know
			99 missing
828	int_consult	Did the provider/PCP consult with hospital doctors?	radio (Matrix)
			1 Yes
			0 No
			88 I don't know
			99 missing
829	int_pcpknow	Section Header: *For PWD still in hospital,* For PWD still in hospital, does the provider/PCP know that he/she is in the hospital?	radio (Matrix)
			1 Yes
			0 No
			88 I don't know
			77 N/A
			99 missing
830	int_dementiacgreport	Section Header: *CG reported of Dementia* Does PWD have dementia (per CG report)?	radio
			1 Yes
			0 No
			99 missing
831	int_dementiapcpdx	Has a health care provider ever given PWD a diagnosis of dementia? (Select "Yes" if CG reported the doctor mentioned to them.)	radio
			1 Yes
			0 No
			99 missing
832	int_dementiacgknow_type Show the field ONLY if: [int_dementiacgreport] = '1'	Do you know what TYPE of dementia PWD has?	radio
			1 Yes
			0 No
			88 I don't know
			99 missing
833	int_dementiacgreport_type Show the field ONLY if: [int_dementiacgknow_type] = '1'	If CG knows about PWD's dementia, specify the TYPE of dementia PWD has. *Specify the Type of dementia.*	text
834	int_dementiacgknow_stage Show the field ONLY if: [int_dementiacgreport] = '1'	Do you know what STAGE of dementia PWD has?	radio
			1 Yes
			0 No
			88 I don't know
			99 missing
835	int_dementiacgreport_stage Show the field ONLY if: [int_dementiacgknow_stage] = '1'	If CG knows about PWD's dementia, specify the STAGE of dementia PWD has. *Specify the STAGE of dementia.*	text
836	int_dementiacgreport_progr	Did any provider explain the normal progression of dementia?	radio
			1 Yes
			0 No
			88 I don't know
			99 missing
837	myow_interview_complete	Section Header: *Form Status* Complete?	dropdown
			0 Incomplete
			1 Unverified
			2 Complete