DATA DICTIONARY FOR FOCIS VARIABLES CREATED AFTER RAW DATA CLEANING

This data dictionary also includes some variables also listed in REDCap code book that might be useful for data analyses (e.g. demographics)
See: FOCIS REDCap Codebook for all individual component variables
Note: Pilot subjects with record_id 501-522 do not have all the variables available for the rest of the subjects (record_id 1-118).

Blue highlight reflects variables of certain measures that are used in our published analyses

Variables	Description	Reference
Subject Identifier		
record_id	id	
Demographic and Clinical covariables		
age	Age in years at study entry *(code 999 for those 90 and older)*	
male	1 = male, 0 = female	
race	1 = White, 2 = Black, 3 = Other	
hispanic	1 = Hispanic ethnicity, 2 = non-Hispanic ethnicity	
education	1 = Elementary, 2 = Junior High, 3 = High School, 4 = Associates, 5 = College, 6 = Graduate School	
medicare	medicare = 1 if insstatus___1 == 1, medicare = 0 if insstatus___1 == 0	
medicaid	medicaid = 1 if insstatus___2 == 1, medicaid = 0 if insstatus___2 == 0	
private	private = 1 if insstatus___3 == 1, private = 0 if insstatus___3 == 0	
no_insurance	no_insurance = 1 if insstatus___4 == 1, no_insurance = 0 if insstatus___4 == 0	
height	Height Measured (cm)	
weight	Weight Measured (kg)	
pre_residence	1 = home, 2 = Assisted Living or Retirement Facility, 3 = Subacute Rehabilitation, 4 = Nursing Home Resident	
pre_residence1	1 = Home, 2 = Nursing Home Resident	
bmi	Body Mass Index in kg/m2	
charlsonCI	Charlson comorbidity index score	Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *J Chronic Dis* 1987; 40: 373-383.
mechanical_ventilation	1 = mechanical ventilation, 0 = BIPAP or high flow nasal cannula oxygen only	
iculos	ICU length of stay in days	

hosplos	Hospital length of stay in days	
code_dc	1 = Full Code, 2 = DNR or DNR/DNI	
dclocation	1 = Home, 2 = Acute Rehabilitation, 3 = Sub-Acute Rehabilitation, 4 = Skilled-Nursing Facility, 5 = Long Term Acute Care Facility, 6 = Hospice or Home Hospice	
dclocation1	1= Home, 2 = Skilled-Care Facility	
demented	1= cognitive dysfunction by mini-cog on initial assessment, 0 = no cogntive dysfunction per mini-cog	
delirium	1 = delirium by the CAM-ICU, 0 = no delirium	
cogimpair	1 = delirium or cognitive dysfunction by Mini-Cog (those with delirium did not have Mini-Cog), 0 = no delirium and no cognitive dysfunction by mini-cog	
cfs	Clinical Frailty Scale, 1-9	
cfsfrailty	1= Clinical Frailty Scale >= 5, 0 = Clinical Frailty Scale <= 4	
Apache-II score		
apache	Acute Physiology And Chronic Health Evalulation II score (continuous variable)	Knaus WA, Draper EA, Wagner DP, Zimmerman JE. APACHE II: a severity of disease classification system. Crit Care Med 1985; 13: 818-829.
Fried Frailty Score variables		Fried LP, Tangen CM, Walston J, Newman AB, Hirsch C, Gottdiener J, Seeman T, Tracy R, Kop WJ, Burke G, McBurnie MA. Frailty in older adults: evidence for a phenotype. *J Gerontol A Biol Sci Med Sci* 2001; 56: M146-156.
frailty_score	Fried frailty score (0-5) for those with complete data for all 5 measurements	
frailty_score1	Fried frailty score (0-5) with missing measurements set to '0'. Ok through record_id 119 since no one has more than 2 missing	
frail	1 = frailty score >= 3, 0 if frailty score 0-2 for those with complete Fried frailty measurements	
frail2	1 = frailty score >= 3, 0 if frailty score 0-2, with missing measurements set to '0'. Ok through record_id 119 since no one has more than 2 missing	
cat3frail2	0 = robust (score 0), 1 = pre-frail (score 1-2), 2 = frail (score >= 3) where missing measurements set to '0'	
frailty_score_dasi	Fried frailty score (0-5) for those with complete data for all 5 measurements, with DASI with lung transplant cutoff for low physical activity assessment	
frailty_score_dasi1	Fried frailty score (0-5) with missing measurements set to '0' and with DASI as low physical activity measurements.	

frail_dasi	1 = frailty score >= 3, 0 if frailty score 0-2 for those with complete Fried frailty measurements (where DASI is the assessment of low physical activity)
frail_dasi2	1 = frailty score >= 3, 0 if frailty score 0-2, with missing measurements set to '0'
cat3frail_dasi2	0 = robust (score 0), 1 = pre-frail (score 1-2), 2 = frail (score >= 3) where missing measurements set to '0' and DASI as low physical activity measurement

Fried Frailty components dichotomized with missing measurements set to "0"

exhausted_frailty1	exhausted_frailty1 = exhausted_frailty, exhausted_frailty1 = 0 if exhausted_frailty missing
wtloss10_1	wtloss10_1 = wtloss10, wtloss10_1 = 0 if wtloss10 missing
low_phys_activity1	low_phys_activity1 = low_phys_activity, low_phys_activity1 = 0 if low_phys_activity missing
dasi_low_phys_act1	dasi_low_phys_act1 = dasi_low_phys_act, dasi_low_phys_act1 = 0 if dasi_low_phys_act missing (score <= 12.5 men, score <= 10 in women)
slow_walk1	slow_walk1 = slow_walk, slow_walk1 = 0 if slow_walk missing
weak_grip1	weak_grip1 = weak_grip, weak_grip1 = 0 if weak_grip missing

Baldwin MR, Singer JP, Huang D, et al. Refining Low Physical Activity Measurement Improves Frailty Assessment in Advanced Lung Disease and Survivors of Critical Illness. *Annals of the American Thoracic Society.* 2017;14(8):1270-1279.

Minnesota Leisure time kcal/wk for Fried frailty low activity measure

kcalwt	kilocalories expended per week assessed by the Minnesota Leisure Activities Index

DASI Duke Activity Status Index) for modified Fried frailty low activity measure

dasisum*	Duke Activities Status Index (DASI) score (a unitless measurement 0-58.2)

Alonso J, Permanyer-Miralda G, Cascant P, Brotons C, Prieto L, Soler-Soler J. Measuring functional status of chronic coronary patients. Reliability, validity and responsiveness to clinical change of the reduced version of the Duke Activity Status Index (DASI). *Eur Heart J* 1997; 18: 414-419.

Death Variables

death	1 = died within 6 months (183 days) of hospital discharge, 0 = alive at 6-months

death_date	Date of death if died during the first 6 months (183 days) after hospital discharge	
death_location	1 = Home, 2 = Hospital, 3 = Skilled-care facility, 4 = Hospice or Home Hospice	
dnr_death	1 = DNR at the time of death per surrogate, 0 = Full Code at the time of death per surrogate	
Measurements of disability		
Katz Score		Ahasic AM, Van Ness PH, Murphy TE, Araujo KL, Pisani MA. Functional status after critical illness: agreement between patient and proxy assessments. *Age and ageing* 2015; 44: 506-510.
pre_katz_score	Number of independent basic Katz ADLs one month prior to hospitalization for critical illness (0-6)	
katz_score_Ini	Number of independent basic Katz ADLs during initial study assessment during the week prior to anticipated discharge (0-6)	
katz_score_1mo	Katz basic ADLS with independence at 1-month after hospital discharge (0-6)	
katz_score_3mo	Katz basic ADLS with independence at 3-months after hospital discharge (0-6)	
katz_score_6mo	Katz basic ADLS with independence at 6-months after hospital discharge (0-6)	
pre_dependencies	Katz basic ADL dependencies prior to hospitalization (6-katz score)	
dependencies_Ini	Katz basic ADL dependencies prior to hospital discharge (6-katz score)	
dependencies_1mo	Katz basic ADL dependencies at 1 month (6-katz score)	
dependencies_3mo	Katz basic ADL dependencies at 3 months (6-katz score)	
dependencies_6mo	Katz basic ADL dependencies at 6 months (6-katz score)	
Barthel Score		Shah S, Vanclay F, Cooper B. Improving the sensitivity of the Barthel Index for stroke rehabilitation. *Journal of clinical epidemiology* 1989; 42: 703-709.
pre_barthel_score	Barthel score 1-month prior to hospitalization for critical illness (0-100)	
barthel_score_Ini	Barthel score during initial study assessment during the week prior to anticipated hospital discharge (0-100)	
barthel_score_1mo	Barthel score at 1-month after hospital discharge (0-100)	
barthel_score_3mo	Barthel score at 3-months after hospital discharge (0-100)	
barthel_score_6mo	Barthel score at 6-months after hospital discharge (0-100)	

Calculated Measurements of Incident Disability/Death

new_katz_disability3	1 = incident katz ADL disability or death at 3-month followup (katz ADL dependencies at 3 months > katz ADL dependencies pre-hospitalization), 0 = no new disability
new_katz_disability6	1 = incident katz ADL disability or death at 6-month followup (katz ADL dependencies at 3 months > katz ADL dependencies pre-hospitalization), 0 = no new disability
new_barthel_disability3	1 = incident barthel disability or death at 3-month followup (barthel score at 3months < barthel score pre-hospitalization), 0 = no new disability
new_barthel_disability6	1 = incident barthel disability or death at 6-month followup (barthel score at 6months < barthel score pre-hospitalization), 0 = no new disability

Measurements of Strength

MRC Score and Components

Hough CL, Lieu BK, Caldwell ES. Manual muscle strength testing of critically ill patients: feasibility and interobserver agreement. Critical care (London, England) 2011; 15: R43.

mrc_score	Sum score of limb strength during initial assessment (0-60)
shouldabd_r	MRC Right Shoulder Abduction (0-5, integer score)
abd_r	MRC Left Shoulder Abduction (0-5, integer score)
elbflex_r	MRC Right Elbow Flexion (0-5, integer score)
elbflexl_r	MRC Left Elbow Flexion (0-5, integer score)
wristext_r	MRC Right Wrist Extension (0-5, integer score)
wristextl_r	MRC Left Wrist Extension (0-5, integer score)
hipflex_r	MRC Right Hip Flexion (0-5, integer score)
hipflexl_r	MRC Left Hip Flexion (0-5, integer score)
kneeext_r	MRC Right Knee Flexion (0-5, integer score)
kneeextl_r	MRC Left Knee Flexion (0-5, integer score)
footdorsi_r	MRC Right Foot Dorsiflexion (0-5, integer score)
dorsiflexl_r	MRC Left Foot Dorsiflexion (0-5, integer score)
ICU-Acquired Weakness by MRC score	
icuaw	1 = mrc_score < 48, 0 = mrc_score >= 48

Maximal sniff nasal inspiratory pressure

snifftest_max	measurement of diaphragmatic strength (strongest of 10 tries, excludes anyone with a trach)

Gaitspeed (meters/second)

gaitspeed2	4.57m (15 foot gait speed) with 0 gaitspeed for those who could not walk

Re-hospitalizations

followupnote1	text notes by staff regarding the followup intervew
rehosptime	Count of acute care rehospitalizations in the first 183 days after hospital discharge
rehosp_1mo	1 = yes, rehospitalized since d/c, 0 = not rehospitalized
rehosptime_1mo	Number of times rehospitalized between discharge and date of 1 month followup interview
rehospnotes_1mo	*Location and reason for rehopitalization at 1-month (removed due to PHI)*
rehosp_3mo	1 = yes, rehospitalized since 1-month follow-up, 0 = not rehospitalized
rehosptime_3mo	Number of times rehospitalized between 1 and 3 month followup interview
rehospnotes_3mo	*Location and reason for rehopitalization at 3-months (removed due to PHI)*
rehosp_6mo	1 = yes, rehospitalized since 3-month follow-up, 0 = not rehospitalized
rehosptime_6mo	nNumber of times rehospitalized between 3 and 6 month followup interview
rehospnotes_6mo	*Location and reason for rehopitalization at 6-months (removed due to PHI)*
readmitcount	Total rehospitalization count over all followups

EuroQol Data

euroqol_surr_Ini	1 = surrogate assisted or answered questions for the subject, 0 = subject reported
euroqol_surr_1mo	1 = surrogate assisted or answered questions for the subject, 0 = subject reported
euroqol_surr_3mo	1 = surrogate assisted or answered questions for the subject, 0 = subject reported
euroqol_surr_6mo	1 = surrogate assisted or answered questions for the subject, 0 = subject reported
EQ_index_Ini*	EQ5D at initial assessment (i.e. hospital discharge) (see RedCap codebook for how these EQ5D component variables are operationalized)
EQ_index_1mo*	EQ5D at 1-month
EQ_index_3mo	EQ5D at 3-months
EQ_index_6mo	EQ5D at 6-months
euro_mob_Ini*	baseline assessment
euro_mob_1mo*	1-month assessment
euro_mob_3mo	3-month assessment
euro_mob_6mo	6-month assessment
euro_selfcare_Ini*	baseline assessment
euro_selfcare_1mo*	1-month assessment
euro_selfcare_3mo	3-month assessment
euro_selfcare_6mo	6-month assessment
euro_act_Ini*	baseline assessment
euro_act_1mo*	1-month assessment
euro_act_3mo	3-month assessment
euro_act_6mo	6-month assessment
euro_pain_Ini*	baseline assessment

euro_pain_1mo*	1-month assessment
euro_pain_3mo	3-month assessment
euro_pain_6mo	6-month assessment
euro_anxdep_Ini*	baseline assessment
euro_anxdep_1mo*	1-month assessment
euro_anxdep_3mo	3-month assessment
euro_anxdep_6mo	6-month assessment

ESAS Symptom Scores at hospital discharge & 1-month (approximate 40 subjects had 1-month follow-up between the pilot cohort and main FOCIS cohort)

Hui D, Shamieh O, Paiva CE, Khamash O, Perez-Cruz PE, Kwon JH, Muckaden MA, Park M, Arthur J, Bruera E. Minimal Clinically Important Difference in the Physical, Emotional, and Total Symptom Distress Scores of the Edmonton Symptom Assessment System. *Journal of pain and symptom management* 2016; 51: 262-269.

edsym___1_Ini	Indicator for whether ESAS completed by patient, surrogate or both before discharge
edsym___2_Ini	Indicator for whether ESAS completed by patient, surrogate or both before discharge
edsym___3_Ini	Indicator for whether ESAS completed by patient, surrogate or both before discharge
edsym___1_1mo	Indicator for whether ESAS completed by patient, surrogate or both at 1-month
edsym___2_1mo	Indicator for whether ESAS completed by patient, surrogate or both at 1-month
edsym___3_1mo	Indicator for whether ESAS completed by patient, surrogate or both at 1-month
pained_Ini	pain 0-10 (prior to hospital discharge)
pained_1mo	1-month assessment
tired_Ini	fatigue 0-10 (prior to hospital discharge)
tired_1mo	1-month assessment
nauseated _Ini	nausea 0-10 (prior to hospital discharge)
nauseated_1mo	1-month assessment
depressed_Ini	depressed 0-10
depressed_1mo	1-month assessment
anxious_Ini	anxiety 0-10
anxious_1mo	1-month assessment
drowsy_Ini	drowsiness 0-10
drowsy_1mo	1-month assessment
appetite_Ini	appetite 0-10

appetite_1mo	1-month assessment	
wellness_Ini	well-being 0-10	
wellness_1mo	1-month assessment	
shortbreath_Ini	shortness of breath 0-10	
shortbreath_1mo	1-month assessment	
Palliative Care Consults and End-of-Life Care Questions		
pallcare	1 = received a palliative care consultation during hospitalization, 0 = no	
eolq1	"Do you prefer your goal of care to be made comfortable": 1 = Yes, 2 = No, 3 = Unsure, 4 =We did not ask	Casarett D, Karlawish J, Morales K, Crowley R, Mirsch T, Asch DA. Improving the use of hospice services in nursing homes: a randomized controlled trial. *JAMA.* 2005;294(2):211-217.
eolq2	"Do you desire chest compressions or mechanical ventilation": 1 = yes, 2 = No, 3 = Unsure, 4 = We did not ask regarding	Casarett D, Karlawish J, Morales K, Crowley R, Mirsch T, Asch DA. Improving the use of hospice services in nursing homes: a randomized controlled trial. *JAMA.* 2005;294(2):211-217.
code_dc	Code status at hospital discharge. 1 = Full Code, 2 = DNR or DNR/DNI	
Brief Fatigue Inventory		Shuman-Paretsky MJ, Belser-Ehrlich J, Holtzer R. Psychometric properties of the Brief Fatigue Inventory in community-dwelling older adults. *Archives of physical medicine and rehabilitation.* 2014;95(8):1533-1539.
See REDCap codebook		
PHQ-9 Depression survey		Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. *Journal of General Internal*

		Medicine. 2001;16(9):606-613.
ph9q_score_Ini	PH9Q sum score at initial assessment	
ph9q_score_1mo	PH9Q sum score at 1-month	
ph9q_depressed_Ini	1 = PH9Q survey score >= 10 (which is suggestive of depression), 0 = PH9Q score < 10 at initial assessment	
ph9q_depressed_1mo	1 = PH9Q survey score >= 10 (which is suggestive of depression), 0 = PH9Q score < 10 at 1-month follow-up	
Insomnia Severity Index (ISI)		Morin CM, Belleville G, Belanger L, Ivers H. The Insomnia Severity Index: psychometric indicators to detect insomnia cases and evaluate treatment response. *Sleep.* 2011;34(5):601-608.
isi_score_Ini	Insomnia severity index score initial assessment	
isi_score_1mo	Insomnia severity index score 1-month follow-up	
haveinsomnia_Ini	Insomnia severity index score >= 10 = 1, score < 10 = 0 at initial assessment	Bastien CH, Vallieres A, Morin CM. Validation of the Insomnia Severity Index as an outcome measure for insomnia research. *Sleep medicine.* 2001;2(4):297-307.
haveinomnia_1mo	Insomnia severity index score >= 10 = 1, score < 10 = 0 at 1-month follow-up	
FATE-S Survey		Casarett D, Shreve S, Luhrs C, et al. Measuring families' perceptions of care across a health care system: preliminary experience with the Family Assessment of Treatment at End of Life Short form (FATE-S). *Journal of pain and symptom management.* 2010;40(6):801-809.
fate_score	Fate-S survey score based on Casarrett calculation	
Variables for Survival and Recovery Time-to-Event Analyses		
ptime*	Duration of follow-up in days from date of hospital discharge to deathdate or last date of follow-up	

pstatus*	1 = dead at last follow-up time, 0 = alive at last follow-up time,
ptime2*	Duration of followup in days from date of hospital discharge right-censored at 183 days for those who survived
Variables for Survival Analysis	
ptime*	duration of follow-up in days from date of hospital discharge to deathdate or last date of follow-up
pstatus*	1 = dead at last follow-up time, 0 = alive at last follow-up time,
ptime2*	duration of followup in days from date of hospital discharge right-censored at 183 days for those who survived
recovery	1 = recovery to katz ADL score >= pre-hospitalization katz ADL score by 6 months, 0 = death or non-recovery
ptimerecovery	time from hospital discharge to first followup date when Katz recovery achieved, or time from hospital discharge to death, or time from hospital discharge to last follow-up date where recovery has still not yet occurred
recovery2	1 = recovery to Barthel Index score >= pre-hosptialization barthel score by 6-months, 0 = death or non-recovery
ptimerecovery2	time from hospital discharge until first followup date when Barthel recovery achieved, time from hospital discharge to death, or time from hospital discharge to last followup date where recovery has still not occurred.
lastdate	accounts for the recent of the two ICU discharge dates if both present, otherwise equals the one discharge date present
ptimerecoverycensored	time from hospital discharge to first followup date when KATZ recovery achieved, or time from hospital discharge to death, or time from hospital discharge to last follow-up date where recovery has still not yet occurred, with right-censoring for 6-month follow-up at 183 days for anyone with 6-month follow-up beyond 183 days
ptimerecovery2censored	time from hospital discharge to first followup date when BARTHEL recovery achieved, or time from hospital discharge to death, or time from hospital discharge to last follow-up date where recovery has still not yet occurred, with right-censoring for 6-month follow-up at 183 days for anyone with 6-month follow-up beyond 183 days
ptimerecovery3	ptimerecovery with decedents ptime imputed as 183 days
ptimerecovery4	ptimerecovery2 with decedents ptime imputed as 183 days
ptimerecoverycensored3	ptimerecoverycensored with decedents recovery time imputed as 183 days
ptimerecovery2censored4	ptimerecovery2censored with decents recovery time imputed as 183 days
Multiple Categorical Outcomes	
outcome3	0 = death, 1 = incident Katz ADL disability,2 = recovery
outcome4	0 = death, 1 = incident Barthel ADL disability, 2 = recovery
Biomarkers	
serum	1 = cryopreserved sample, 0 = none
plasma	1 = cryopreserved sample, 0 = none

*we have made several biomarker measurements (see FOCIS research protocol handbook for details), data available upon request.