PLM-PVA Data Dictionary v1

Field	Description	Type, format/units/values
call_timestamp	Date and time IVR voice call initiated	string, YYYY/MM/DD HH:MM:SS UTC +0000
recording_duration	Length of recording captured by IVR system	integer, seconds
callref	Unique reference number for voice recording	integer
audio_duration	Length of audio captured by IVR system during call	real, seconds
voice_indexstart	Starting audio sample index at which voicing is detected, if at all	integer, samples
voice_indexend	Ending audio sample index at which voicing is detected, it at all	integer, samples
voice_code	Quality of voice recording: 'ok' – (part of) recording usable, 'bad' – recording unusable (no features extracted)	string, 'ok'/'bad'
voice_usable_duration	Length of usable voicing detected	real, seconds
feature01	Median F0	real, Hz
feature02	Mean absolute F0 time derivative	real, Hz^2
feature03	Median absolute F0 time derivative	real, Hz^2
feature04	Mean absolute value of time derivative of RMS power	real, Hz
feature05	Median absolute value of time derivative of RMS power	real, Hz
feature06-feature19	Median cepstral coefficients 0-12 for entire voice recording	13 x real
feature20-feature32	Mean absolute time derivative of cepstral coefficients 0-12 across entire voice recording	13 x real
feature33	Recurrence period density entropy (RPDE) Hnorm	real
feature34	Detrended fluctuation analysis (DFA) scaling parameter alpha	real
feature35	Modified pitch period entropy (PPE)	real
feature36	Relative spectral power 0-500Hz	real
feature37	Relative spectral power 500-1kHz	real
feature38	Relative spectral power 1kHz-2kHz	real
feature39	Relative spectral power 2kHz-4kHz	real
user_id_hashed	Hashed PatientsLikeMe user ID	string
pvi_created_at	Date and time at which unique reference number for call was	string, YYYY-MM-DD HH:MM:SS.d

	collected by PatientsLikeMe	
current_age	Age of participant when call was recorded	integer, years
sex	Sex of participant	string, 'M'/'F'/empty
years_since_first_symptom	Years since first Parkinson's symptoms detected by participant	integer, years
pdrs_date	Reference date at which PDRS applies	string, YYYY-MM-DD
pdrs_reported_at	Date and time at which PDRS was collected by PatientsLikeMe	string, YYYY-MM-DD HH:MM:SS.d
days_from_pvi_to_pdrs	Number of days elapsed between PDRS reference date (pdrs_date) and unique call reference number collected (pvi_created_at)	integer, days
pdrs_score	Scaled sum of all PDRS entries Q1-Q17 below	integer, 0-100
memory	PDRS Q1	integer, 0-4
hallucinations	PDRS Q2	integer, 0-4
mood	PDRS Q3	integer, 0-4
motivation	PDRS Q4	integer, 0-4
speech	PDRS Q5	integer, 0-4
saliva	PDRS Q6	integer, 0-4
swallowing	PDRS Q7	integer, 0-4
handwriting	PDRS Q8	integer, 0-4
cutting_food	PDRS Q9	integer, 0-4
dressing	PDRS Q10	integer, 0-4
hygiene	PDRS Q11	integer, 0-4
turning_in_bed	PDRS Q12	integer, 0-4
falling	PDRS Q13	integer, 0-4
freezing	PDRS Q14	integer, 0-4
walking	PDRS Q15	integer, 0-4
tremors	PDRS Q16	integer, 0-4
numbness	PDRS Q17	integer, 0-4
hoehn_yahr	Hoehn and Yahr stage at time of reporting PDRS	integer, 1-5
on_treatment_id	Whether participant was 'on' vs. 'off' medication when PDRS was reported	string, 'true'/'false'
calls_per_user	Number of calls made by this user	integer

PLM-PVA PDRS/Hoehn and Yahr Questions

Field	Value	Descriptive Value
memory	0, 1, 2, 3, 4	0 - 'No memory problems' 1 - 'Mild memory problems; I am often forgetful and can only partially remember some events.' 2 - 'Moderate memory problems that mean I get disoriented sometimes and can sometimes get confused easily.' 3 - 'Severe memory problems which mean I have difficulty remembering what day it is or where I am and often get confused.' 4 - 'Very severe memory problems; I sometimes forget where I am and what day it is; I have great difficulty making decisions or solving problems.'
hallucinations	0, 1, 2, 3, 4	0 - 'I never see things which are invisible to other people ('hallucinations').' 1 - 'I experience very vivid dreams.' 2 - 'Sometimes I see things which are invisible to other people but I know they are not real.' 3 - ' Sometimes I see things which are invisible to other people and I believe they are real.' 4 - 'I see things which are invisible to other people most of the time and I believe they are real.'
mood	0, 1, 2, 3, 4	0 - 'I do not get sad for long periods.' 1 - 'I sometimes get sad for longer than normal; i.e. more than a few days or a week.' 2 - 'I sometimes get sad for greater than a week at a time.' 3 - 'I get sad for extended periods during which I lose weight - can not sleep - and have poor appetite.' 4 - 'I get sad for extended periods and have thoughts about suicide.'
motivation	0, 1, 2, 3, 4	0 - 'My levels of motivation are about normal.' 1 - 'I have become less assertive and more passive.' 2 - 'I have lost some of my initiative and am less interested in hobbies.' 3 - 'I have lost some of my initiative and am uninterested in my daily routine.' 4 - 'I am withdrawn and initiate very little activity.'
speech	0, 1, 2, 3, 4	0 - 'No; the way I speak has not changed.' 1 - 'Yes; the way I speak has changed but other people understand me without any problem.' 2 - 'Yes; the way I speak has changed somewhat and sometimes I have to repeat to make myself understood.' 3 - 'Yes; the way I speak has changed enough and

		frequently I have to repeat to make myself understood.' 4 - 'Yes; the way I speak has changed so much that other people has difficulty understanding me or do not understand me at all.'
saliva	0, 1, 2, 3, 4	0 - 'No; I have not noticed that I have excessive saliva and I do not drool.' 1 - 'Yes; I have noticed a slight increase in the amount of saliva and on occasion I drool at night on my pillow.' 2 - 'Yes; I have moderate excess of saliva and occasionally I drool during the day.' 3 - 'Yes; I have a marked excess of saliva and frequently drool during the day.' 4 - 'Yes; I drool so much that I have to carry a handkerchief at all times.'
swallowing	0, 1, 2, 3, 4	0 - 'No; I do not have difficulty swallowing and I do not choke.' 1 - 'Yes; I do have difficulty swallowing but I rarely choke.' 2 - 'Yes; I do have difficulty swallowing and occasionally choke.' 3 - 'Yes; I do have difficulty swallowing and I need soft food to be able to eat.' 4 - 'Yes; I am incapable of swallowing and I need nasogastric intubation or I have had a gastrostomy.'
handwriting	0, 1, 2, 3, 4	0 - 'No; I have not noticed changes in the way I write.' 1 - 'Yes; my handwriting is somewhat slower or my letter formation is smaller.' 2 - 'Yes; now my handwriting is moderately slower and my letter formation is smaller; but everything I write can be understood.' 3 - 'Yes; my handwriting is very altered and there are some words that can not be understood.' 4 - 'Yes; my handwriting is deteriorated and most of the words can not be understood.'
cutting_food	0, 1, 2, 3, 4	0 - 'No; I do not cut food more slowly and I have no difficulty managing my utensils.' 1 - 'Yes; I am somewhat slower and more clumsy than before but I am still capable of eating without help.' 2 - 'Yes; I am slower and clumsier than before and I need help cutting some foods.' 3 - 'Yes; someone has to cut my food but I can still eat on my own.' 4 - 'I have to be fed because I can not do it on my own.'
dressing	0, 1, 2, 3, 4	0 - 'No; I do not find it difficult to get dressed nor am I slower than before.' 1 - 'Yes; I get dressed more slowly - but need little help.'

		2 - 'Yes; I get dressed slower and sometimes need help buttoning my clothes - tying my shoes or getting my arm in the sleeves.' 3 - 'Yes; I need substantial help to get dressed - but I can still do some things on my own.' 4 - 'I have to be dressed by someone else.'
hygiene	0, 1, 2, 3, 4	0 - 'No; I have not slowed down when performing these activities.' 1 - 'Yes; I am a little slower dealing with my hygiene - but I do not need help.' 2 - 'Yes; I am slower and need help bathing and using the facilities.' 3 - 'Yes; I am slower and need help bathing - brushing my teeth - fixing my hair - and going to the bathroom.' 4 - 'I need help with everything and I wear a Foley catheter.'
turning_in_bed	0, 1, 2, 3, 4	0 - 'No I do not have difficulty turning in bed or fixing the blankets.' 1 - 'Yes; I am somewhat clumsy or slower turning in bed or fixing the blankets.' 2 - 'Yes; I am capable of turning in bed or fixing the blankets but with great difficulty.' 3 - 'Yes; I am capable of turning in bed but I need help to complete the task.' 4 - 'I am incapable of turning in bed or fixing the blankets without help.'
falling	0, 1, 2, 3, 4	0 - 'No; I have not fallen.' 1 - 'Yes; I have fallen - but rarely.' 2 - 'Yes; occasionally I have fallen but it happens less than once a day.' 3 - 'Yes; I fall on average once a day.' 4 - 'Yes; I fall every day and more than once.'
freezing	0, 1, 2, 3, 4	0 - 'No; I have not experienced freezing.' 1 - 'Yes; I have experienced freezing when I walk but on rare occasions. Or sometimes when I start walking I experience freezing.' 2 - 'Yes; occasionally I experience freezing.' 3 - 'Yes; frequently I experience freezing while walking and occasionally I have fallen because of it.' 4 - 'Yes; frequently I experience freezing while walking and frequently; I have fallen because of it.'
walking	0, 1, 2, 3, 4	0 - 'No; the way I walk and my arm movement has not changed.' 1 - 'Yes; the way I walk has changed but it is not a problem.' 2 - 'Yes; I have moderate difficulty while walking - but I do not need help.'

		3 - 'Yes; I have great difficulty walking and need help.' 4 - 'I can not walk alone or with help.'
tremors	0, 1, 2, 3, 4	0 - 'No; I do not have visible tremors.' 1 - 'Yes; occasionally I do have visible tremors.' 2 - 'Yes; I have moderate tremors that bother me.' 3 - 'Yes; I have intense tremors that interfere with some activities.' 4 - 'Yes; I have intense tremors that interfere with the majority of my activities.'
numbness	0, 1, 2, 3, 4	0 - 'No; I do not feel numbness tingling or discrete pain - that I can attribute to my Parkinson's disease.' 1 - 'Yes; on occasion; I do feel numbness - tingling - or discrete pain - that I can attribute to my Parkinson's disease.' 2 - 'Yes; frequently; I do feel numbness - tingling - or pain - that I can attribute to my Parkinson's disease.' 3 - 'Yes; frequently I feel painful sensations attributable to my Parkinson's disease.' 4 - 'Yes; I feel extreme pain attributable to my Parkinson's disease.'
hoehn_yahr	1, 2, 3, 4, 5	1 - Symptoms on one side 2 - Symptoms on both sides 3 - Problems with balance and walking 4 - Stand and walk with difficulty 5 - Cannot stand or walk independently