

No	Variable Name	Level	Label	Explanation
1	record_id			Record id from redcap
2	Redcap_event_name	pre_discharge_arm_1	Base	Time points of data taken
		baseline_1week_arm_1	W1	Base – baseline (demographic) W1 – week 1
		1month_arm_1	M1	M1 – month 1
		2month_arm_1	M2	M2 – month 2
		3month_arm_1	M3	M3 – month 3 M4 – month 4
				W1–M4 – time from patient discharge, until data/response taken
				Note: using interview duration may give finer detail (in days, weeks, or months) – refer variable no 38 for ZBI and 66 for CAFU
3	pt_id			Patient's id, Patient identifications were de-identification and replaced with new id One patient may have several caregivers, in which pt_id can be used to match the caregivers with correspond patient
4	pt_gender	0	Female	Patient's gender
		1	Male	
5	pt_age			Patient's age, Calculated from patient's date of birth to discharge date
6	pt_hosp	0	Hospital A	Hospital. The hospitals were anonymised.
		1	Hospital B	
		2	Hospital C	
7	pt_mrs	0	No symptoms	Patient's modified Rankin scale mRS score upon patient's discharge, which measure degree of disability or dependence of daily activities, with higher score indicating higher disability p/s: 6 – dead (not included in this study) p/s: label score is optional
		1	Symptoms but no disability	
		2	Mild disability	
		3	Moderate disability	
		4	Moderate Severe disability	
		5	Severe disability / bedridden	
8	pt_bi_phyg	0	0	Patient's Barthel Index Score, by each item – Personal hygiene, Bathing, Feeding, Toilet, Stair climbing, Dressing, Bowel control, Body transfer (chair/bed) Ambulation (or wheelchair) Measuring patient's performance in ADLs. Higher score indicating higher performance.
9	pt_bi_bath	1	phyg, bath, wcha 1	
10	pt_bi_feed		feed, toil, stair, dres, bowel, blad 2	
11	pt_bi_toil		tran, ambu 3	
12	pt_bi_stair	2	phyg, bath, wcha 3	
13	pt_bi_dres		feed, toil, stair, dres, bowel, blad 5	
14	pt_bi_bowel		tran, ambu 8	
15	pt_bi_blad	3	phyg, bath, wcha 4	
16	pt_bi_tran		feed, toil, stair, dres, bowel, blad 5	
17	pt_bi_ambu		tran, ambu 12	
18	pt_bi_wcha	4	phyg, bath, wcha 5	
			feed, toil, stair, dres, bowel, blad 8	
			tran, ambu 15	

No	Variable Name	Level	Label	Explanation
19	pt_bi_ambu_stat	0	Ambulate (Walk)	Patient's ambulation status. If patient able to ambulate, pt_bi_ambu (variable no 20) will be recorded, or if patient on wheelchair, pt_bi_whca (variable no 21) will be recorded
		1	Wheelchair	
20	pt_bi_score			Patient's Total Barthel Index Score Measuring patient's performance in ADLs. Higher score indicating higher performance. Range of total score 0 – total disability / dependence 100 – total independence
21	stroke_episode	0	No	Patient previous stroke history
		1	Yes	
22	stroke_firsthx_yr			Year of first stroke attack
23	stroke_lasthx_yr			Year of the most recent stroke attack (before current episode)
24	pt_nocg			Number of caregivers for the stroke patients Patient may have several caregivers. Note: not all caregivers may agree to participate in this study
25	pt_nohh			Number of household members of the stroke patient

No	Variable Name	Level	Label	Explanation
26	cg_id			Caregiver's id, Caregiver identifications were de-identification and replaced with new id
27	cg_gender	0	Female	Caregiver's gender
		1	Male	
28	cg_age			Caregiver's age (year)
29	cg_livept	0	No	Does the caregiver lives with patient?
		1	Yes	
30	cg_relation	0	Spouse	Caregiver's relationship with patient
		1	Children	
		2	Child-in-law	
		3	Grandchildren	
		4	Sibling	
		5	Parent	
31	cg_marital	0	Single	Caregiver's marital status
		1	Married	
32	cg_edulvl	0	Didn't go to school	Caregiver's education levels Primary – primary school (Standard 1 – 6) Secondary – secondary school (Form 1 – 5) Tertiary – diploma, degree, master, doctorate etc
		1	Primary School	
		2	Secondary School	
		3	College / University	
33	cg_occupation	0	Unemployed	Caregiver's occupational status
		1	Student	
		2	Employed	
34	cg_typeoccu			Caregiver's occupation, Open ended question. Not applicable for unemployed or student
35	cg_personalincome	0	No income	Caregiver's income level
		1	< RM 1,000	
		2	RM 1,000 – 2,999	
		3	RM 3,000 – 4,999	
		4	> RM 5,000	
36	cg_hhincome	0	< RM 1,000	Caregiver's total household income
		1	RM 1,000 – 2,999	
		2	RM 3,000 – 4,999	
		3	RM 5,000 – 7,999	
		4	> RM 8,000	
37	cg_othercr	0	No	Caregiver other dependence Is there any other dependence (other than stroke patient) that caregiver taking care off? – may include other stroke patients, children etc
		1	Yes	
38	cg_nocr			Number of caregiver's dependence, Not applicable if the caregiver didn't have other dependence
39	cg_paidcg	0	No	Does the patient had paid caregiver (maid, nurses etc)
		1	Yes	

No	Variable Name	Level	Label	Explanation
40	zbi_dcdurday			Duration between ZBI interview date and patient's discharge date in days, weeks, or months
41	zbi_dcdurweek			
42	zbi_dcdurmonth			
43	zbi_cgnum			Number of caregivers taking care of the stroke patient during interview date. the number of caregivers taking care of patient may fluctuate.
44 – 64	zbi_q1 – zbi_q21	0	Never	ZBI score for each question Zarit Burden Interview use to assess caregiving burden. Higher scores indicate higher burden Q1 – Q22 specific question Q22 – overall feeling
		1	Rarely	
		2	Sometimes	
		3	Quite Frequently	
		4	Nearly Always	
65	zbi_q22	0	Not at all	p/s: label score is optional
		1	A little	
		2	Moderately	
		3	Quite a bit	
		4	Extremely	
66	zbi_total_score			Total ZBI score Range of total score 0 – no burden 88 – total burden

No	Variable Name	Level	Label	Explanation
67	cafu_dcdurday			Duration between CAFU interview date and patient's discharge date in days, weeks, or months
68	cafu_dcdurweek			
69	cafu_dcdurmonth			
70	cafu_cgnum			Number of caregivers taking care of the stroke patient during interview date, the number of caregivers taking care of patient may fluctuate.
71 - 100	cafu_q1_f – cafu_q8_f	0	Pt didn't require help	Patient's functional level (1) for IADL
		1	Pt require help	Does patient require help?
	cafu_q1_f_score - cafu_q8_f_score	1	Pt Need Help >75%	Patient's functional level (2) for IADL
		2	Pt Need Help 75%	If patient doesn't require help – does he need modification to do activity?
		3	Pt Need Help 50%	If patient require help – how much help the patient require?
		4	Pt Need Help 25%	f_score is patient's functional level assessed by the caregiver, with higher score correspond to higher functional level.
		5	Pt Need Help <25%	
		6	Pt Didn't Need Help, Require Modification	
		7	Pt Didn't Need Help, No Modification	Q1-Q8 correspond to IADL functions – telephone, shopping, food preparation, housework, laundry, travel, medicine, finances. p/s: label score is optional
	cafu_q1_d_score - cafu_q8_d_score	1	Pt Didn't Need Help, No Modification	Patient dependence level for IADL
		2	Pt Didn't Need Help, Require Modification	d_score is patient's dependence level assessed by the caregiver, with higher score correspond to higher dependence.
		3	Pt Need Help <25%	
		4	Pt Need Help 25%	Note: f_score and d_score is corresponded with each other, but in reverse scoring. 1 in d_score correspond to 7 in f_score, progressively, until 7 in d_score correspond to 1 in f_score
		5	Pt Need Help 50%	
		6	Pt Need Help 75%	
		7	Pt Need Help >75%	Q1-Q8 correspond to IADL functions – telephone, shopping, food preparation, housework, laundry, travel, medicine, finances. p/s: label score is optional
	cafu_q1_u – cafu_q8_u	0	Cg didn't help this activity	Caregivers help status for IADL
		1	Cg help this activity	Only available if cafu_qx_f = 1
	cafu_q1_u_score – cafu_q8_u_score	0	Not at all	Caregiver's upset level for IADL
		1	A little	Only available if cafu_qx_f = 1 and cafu_qx_u = 1
2		Moderately		
3		Very much	p/s: label score is optional	
4		Extremely		

No	Variable Name	Level	Label	Explanation
101	cafu_q9			Total hour of duration for caregiver to assist for IADL activities
102	cafu_iadl_f_avescore			Average f_score for IADL (Q1 – Q8) Range of average score 1 – total disability 7 – full function
103	cafu_iadl_d_avescore			Average d_score for IADL (Q1 – Q8) Range of average score 1 – total independence 7 – total dependence
104	cafu_iadl_u_totscore			Total u_score for IADL (Q1 – Q8) Range of total score 0 – no upset/burden 32 – total upset/burden
105	cafu_iadl_u_numyes			Total u for IADL (Q1 – Q8): Number of activities that caregiver giving the patient assistance Range of total score 0 – no assistance 8 – assistance to all 8 IADL activities
106	cafu_iadl_u_meanscore			IADL's mean upset score: Average upset score per total activities that require assistance. e.g. Cg A might only help in 1 activity, but very upset with the assistance, with u_score for the activity of max 4. The u_totscore is 4 and the average upset score for this particular caregiver is 4. Cg B give help in 4 activities, but very upset with the assistance, with u_score for the all the 4 activies of max 4. The u_totscore is 16 but the average upset score for this particular caregiver is 4. Cg C give help in 4 activities, but not so upset with the assistance, with u_score for the all the 4 activies of only 1 each. The total u_score is 4 and the average upset score for this particular caregiver is 1. Cg D give help in 4 activities, but very upset with the assistance for one of the activity, with u_score for the activity of max 4, while the other 3 activity didn't have upset at all (u_score 0). The total u_score is 4 and the average upset score for this particular caregiver is 1. Range of total score 0 – average no upset 4 – average total upset

No	Variable Name	Level	Label	Explanation
107 - 136	cafu_q10_f – cafu_q16_f	0	Pt didn't require help	Patient's functional level (1) for ADL
		1	Pt require help	Does patient require help?
	cafu_q10_f_score - cafu_q16_f_score	1	Pt Need Help >75%	Patient's functional level (2) for ADL
		2	Pt Need Help 75%	If patient doesn't require help – does he need modification to do activity?
		3	Pt Need Help 50%	If patient require help – how much help the patient require?
		4	Pt Need Help 25%	
		5	Pt Need Help <25%	f_score is patient's functional level assessed by the caregiver, with higher score correspond to higher functional level.
		6	Pt Didn't Need Help, Require Modification	Q10-Q16 correspond to ADL functions – body transfer, eating, bathing, upper body dressing, lower body dressing, toilet, grooming.
		7	Pt Didn't Need Help, No Modification	p/s: label score is optional
	cafu_q10_d_score - cafu_q16_d_score	1	Pt Didn't Need Help, No Modification	Patient dependence level for ADL
		2	Pt Didn't Need Help, Require Modification	d_score is patient's dependence level assessed by the caregiver, with higher score correspond to higher dependence.
		3	Pt Need Help <25%	
		4	Pt Need Help 25%	Note: f_score and d_score is corresponded with each other, but in reverse scoring. 1 in d_score correspond to 7 in f_score, progressively, until 7 in d_score correspond to 1 in f_score
		5	Pt Need Help 50%	
		6	Pt Need Help 75%	Q10-Q16 correspond to ADL functions – body transfer, eating, bathing, upper body dressing, lower body dressing, toilet, grooming.
		7	Pt Need Help >75%	p/s: label score is optional
	cafu_q10_u – cafu_q16_u	0	Cg didn't help this activity	Caregivers help status for ADL
		1	Cg help this activity	Only available if cafu_qx_f = 1
	cafu_q10_u_score – cafu_q16_u_score	0	Not at all	Caregiver's upset level for ADL
		1	A little	
2		Moderately	Only available if cafu_qx_f = 1 and cafu_qx_u = 1	
3		Very much		
4		Extremely	p/s: label score is optional	
137	cafu_q17			Total hour of duration for caregiver to assist for ADL activities

No	Variable Name	Level	Label	Explanation
138	cafu_adl_f_avescore			<p>Average f_score for ADL (Q10 – Q16)</p> <p>Range of average score 1 – total disability 7 – full function</p>
139	cafu_adl_d_avescore			<p>Average d_score for ADL (Q10 – Q16)</p> <p>Range of average score 1 – total independence 7 – total dependence</p>
140	cafu_adl_u_totscore			<p>Total u_score for ADL (Q10 – Q16)</p> <p>Range of total score 0 – no upset/burden 28 – total upset/burden</p>
141	cafu_adl_u_numyes			<p>Total u for ADL (Q10 – Q16): Number of activities that caregiver giving the patient assistance</p> <p>Range of total score 0 – no assistance 7 – assistance to all 8 IADL activities</p>
142	cafu_adl_u_meanscore			<p>ADL's mean upset score: Average upset score per total activities that require assistance.</p> <p>e.g.</p> <p>Cg A might only help in 1 activity, but very upset with the assistance, with u_score for the activity of max 4. The u_totscore is 4 and the average upset score for this particular caregiver is 4.</p> <p>Cg B give help in 4 activities, but very upset with the assistance, with u_score for the all the 4 activies of max 4. The u_totscore is 16 but the average upset score for this particular caregiver is 4.</p> <p>Cg C give help in 4 activities, but not so upset with the assistance, with u_score for the all the 4 activies of only 1 each. The total u_score is 4 and the average upset score for this particular caregiver is 1.</p> <p>Cg D give help in 4 activities, but very upset with the assistance for one of the activity, with u_score for the activity of max 4, while the other 3 activity didn't have upset at all (u_score 0). The total u_score is 4 and the average upset score for this particular caregiver is 1.</p> <p>Range of total score 0 – average no upset 4 – average total upset</p>