Stanford University School of Medicine
Research IT

BMT313- 11/29/18

 Project Home   **Project Setup**   **Codebook**

📖 Data Dictionary Codebook

05/08/2019 8:08pm

⌃ Collapse all instruments

	#	Variable / Field Name	Field Label *Field Note*	Field Attributes (Field Type, Validation, Choices, Calculations, etc.)
Instrument: **Letter Study** (letter_study)				⌃ Collapse
	1	record_id	Record ID:	text (integer, Min: 0, Max: 1127)
	2	packet_number	Packet Number:	text (integer)
	3	study_arm	Study Arm:	radio 1 control (AD) 2 intervention (letter)
	4	spn	SPN:	text (number)
	5	screen_date	Screen date:	text (date_mdy, Min: 2017-03-20)
	6	eligibility	Eligibile?	yesno 1 Yes 0 No
	7	reason_not_eligible	Reason not eligible:	notes
	8	enrolled	Enrolled?	yesno 1 Yes 0 No
	9	reason_not_enrolled	Reason not enrolled:	checkbox 1 reason_not_enrolled___1 stressful/overwhelmed 2 reason_not_enrolled___2 already have AD 3 reason_not_enrolled___3 want to stay positive/don't want to think about it 99 reason_not_enrolled___99 other
	10	consent_date	Consent Date:	text (date_mdy, Min: 2017-03-20)
	11	collected	Collected *Was the packet returned/collected?*	yesno 1 Yes 0 No
	12	collection_prior_to_infusion	Collection Prior to Infusion: *Was the packet collected before BMT?*	yesno 1 Yes 0 No
	13	background	Section Header: *Sociodemographics* What is your background?	checkbox, Identifier 1 background___1 Non-Hispanic White 2 background___2 Hispanic

				3	background___3	Black or African American
				4	background___4	Asian
				99	background___99	Other

14	background_other Show the field ONLY if: [background(99)] = '1'	Other	text		
15	religiousspiritual_affiliation	What is your religious/spiritual affiliation?	text		
16	current_relationship_status	What is your current relationship status?	radio		
				1	Married
				2	Single
				3	Divorced
				4	Widowed
				5	In a committed relationship but not married
17	highest_level_of_education	What is your highest level of education?	radio		
				1	No formal education
				2	Elementary school
				3	High School
				4	College
				5	Graduate/Professional
18	how_well_do_you_understand	How well do you understand the medical situations/scenarios involved in end-of-life care (e.g. cardiac resuscitation, mechanical ventilation, feeding tubes, etc.)?	radio		
				1	Do not understand
				2	Understand a little
				3	Understood most of it
				4	Understand very well
19	have_you_completed_an_adva	Have you completed an advanced directive document in the past (this may also be called a living will)?	radio		
				0	No
				1	Yes
20	pain	Section Header: *ESAS Please circle the number that best describes how you feel NOW:* No Pain	radio (Matrix)		
				0	0
				1	1
				2	2
				3	3
				4	4
				5	5
				6	6
				7	7
				8	8
				9	9
				10	10
21	tiredness	No Tiredness	radio (Matrix)		
				0	0
				1	1
				2	2
				3	3

				4 | 4
				5 | 5
				6 | 6
				7 | 7
				8 | 8
				9 | 9
				10 | 10
	22	drowsiness	No Drowsiness	radio (Matrix)
				0 | 0
				1 | 1
				2 | 2
				3 | 3
				4 | 4
				5 | 5
				6 | 6
				7 | 7
				8 | 8
				9 | 9
				10 | 10
	23	nausea	No Nausea	radio (Matrix)
				0 | 0
				1 | 1
				2 | 2
				3 | 3
				4 | 4
				5 | 5
				6 | 6
				7 | 7
				8 | 8
				9 | 9
				10 | 10
	24	lack_of_appetite	No Lack of Appetite	radio (Matrix)
				0 | 0
				1 | 1
				2 | 2
				3 | 3
				4 | 4
				5 | 5
				6 | 6
				7 | 7
				8 | 8
				9 | 9
				10 | 10

25	shortness_of_breath	No Shortness of Breath	radio (Matrix)
			0 0
			1 1
			2 2
			3 3
			4 4
			5 5
			6 6
			7 7
			8 8
			9 9
			10 10
26	depression	No Depression	radio (Matrix)
			0 0
			1 1
			2 2
			3 3
			4 4
			5 5
			6 6
			7 7
			8 8
			9 9
			10 10
27	anxiety	No Anxiety	radio (Matrix)
			0 0
			1 1
			2 2
			3 3
			4 4
			5 5
			6 6
			7 7
			8 8
			9 9
			10 10
28	wellbeing	Best Wellbeing	radio (Matrix)
			0 0
			1 1
			2 2
			3 3
			4 4
			5 5

					6	6
					7	7
					8	8
					9	9
					10	10

29	other_problem Show the field ONLY if: [other_problem] = "0" or "1" or "2" or "3" or "4" or "5" or "6" or "7" or "8" or "9" or "10"	No Other Problem	radio (Matrix)

0	0
1	1
2	2
3	3
4	4
5	5
6	6
7	7
8	8
9	9
10	10

Field Annotation: next question for other problem

30	otherproblem Show the field ONLY if: [other_problem] = '0' or [other_problem] = '1' or [other_problem] = '2' or [other_problem] = '3' or [other_problem] = '4' or [other_problem] = '5' or [other_problem] = '6' or [other_problem] = '7' or [other_problem] = '8' or [other_problem] = '9' or [other_problem] = '10'	Other problem:	text
31	here_is_what_matters_most Show the field ONLY if: [study_arm] = '2'	Section Header: *What Matters Most Letter* Here is what matters most to me:	notes
32	here_are_my_important_futu Show the field ONLY if: [study_arm] = '2'	Here are my important future life milestones:	notes
33	here_is_how_we_prefer_to_h Show the field ONLY if: [study_arm] = '2'	Here is how we prefer to handle bad news in my family:	notes
34	here_is_how_we_make_medica Show the field ONLY if: [study_arm] = '2'	Here is how we make medical decisions in our family:	notes
35	here_is_what_i_do_not_want Show the field ONLY if: [study_arm] = '2'	Here is what I DO NOT WANT at the end of my life:	checkbox

1	here_is_what_i_do_not_want___1	If my heart were to stop, do not attempt to restart it
2	here_is_what_i_do_not_want___2	I do not

							want to be on a breathing machine
					3	here_is_what_i_do_not_want___3	I do not want artificial liquid feeding
					4	here_is_what_i_do_not_want___4	I do not want dialysis
					5	here_is_what_i_do_not_want___5	I do not want to spend my last days in a hospital
					6	here_is_what_i_do_not_want___6	I do not want to die at home
					99	here_is_what_i_do_not_want___99	Other
	36	donotwantother Show the field ONLY if: [here_is_what_i_do_not_want(99)] = '1'	Other	notes			
	37	here_is_what_i_do_want_at Show the field ONLY if: [study_arm] = '2'	Here is what I DO WANT at the end of my life:	checkbox			
					1	here_is_what_i_do_want_at___1	I want to be pain free
					2	here_is_what_i_do_want_at___2	I want to spend my last days in the hospital
					3	here_is_what_i_do_want_at___3	I want you to help me die gently and naturally
					4	here_is_what_i_do_want_at___4	I want to die at home
					5	here_is_what_i_do_want_at___5	I want hospice care
					99	here_is_what_i_do_want_at___99	Other
	38	dowantother Show the field ONLY if: [here_is_what_i_do_want_at(99)] = '1'	Other:	notes			
	39	if_my_pain_and_distress_ar Show the field ONLY if: [study_arm] = '2'	If my pain and distress are difficult to control, please sedate me even if this means that I may die sooner	yesno 1 Yes 0 No			
	40	here_is_what_i_want_to_do Show the field ONLY if: [study_arm] = '2'	Here is what I want to do when my family wants you to do something different than what I want for myself:	radio 1 I am asking you to show them this form and guide my family to follow my wishes 2 I want you to override my wishes as my family knows best			

41	organdonation Show the field ONLY if: [study_arm] = '2'	After a person passes away, their organs and tissues (eyes, kidneys, liver, heart, skin, etc) can be donated to help other people who are ill. Please choose one of the following:	radio 	1	I will donate any of my organs and tissues after I pass away.
2	I will donate the following organs, tissues only
3	I do NOT want to donate my organs or tissues after I pass away.
4	I do NOT want to decide now. My proxy can decide after I pass away.	
42	donateonly Show the field ONLY if: [organdonation] = '2'	I will donate the following organs, tissues only	notes
43	here_is_other_information Show the field ONLY if: [study_arm] = '2'	Here is other information to convey:	notes
44	agent_s_authority_my_agent Show the field ONLY if: [study_arm] = '1'	Section Header: *Traditional Advance Directive PART 1- POWER OF ATTORNEY FOR HEALTH CARE DESIGNATION OF AGENT I designate the following individual as my agent to make health care decisions for me:* AGENT'S AUTHORITY: My agent is authorized to make all health care decisions for me, including decisions to provide, withhold, or withdraw artificial nutrition and hydration and all other forms of health care to keep me alive, except as I state here:	notes
45	when_agent_s_authority_bec Show the field ONLY if: [study_arm] = '1'	WHEN AGENT'S AUTHORITY BECOMES EFFECTIVE:	radio | 1	My agent's authority becomes effective when my primary physician determines that I am unable to make my own health care decisions.
2	My agent's authority to make health care decisions for me takes effect immediately.	
46	agent_s_postdeath_authorit Show the field ONLY if: [study_arm] = '1'	AGENT'S POSTDEATH AUTHORITY: My agent is authorized to make anatomical gifts, authorize an autopsy and direct disposition of my remains, except as I state here or in Part 3 of this form:	notes
47	end_of_life_decisions_i_di Show the field ONLY if: [study_arm] = '1'	Section Header: *PART 2 - INSTRUCTIONS FOR HEALTH CARE If you fill out this part of the form, you may strike any wording you do not want.* END OF LIFE DECISIONS: I direct that my health care providers and others involved in my care provide, withhold, or withdraw treatment in accordance with the choice I have marked below:	radio | 1	Choice Not To Prolong Life: I do not want my life to be prolonged if (1) I have an incurable and irreversible condition that will result in my death within a relatively short time, (2) I become unconscious and, to a reasonable degree of medical certainty, I will not regain consciousness, or (3) the likely risks and burdens of treatment would outweigh the expected benefits
2	Choice To Prolong Life: I want my life to be prolonged as long as possible within the limits of generally accepted health care standards.	
48	relief_from_pain_except_as Show the field ONLY if: [study_arm] = '1'	RELIEF FROM PAIN: Except as I state in the following space, I direct that treatment for alleviation of pain or discomfort be provided at all times, even if it hastens my death:	notes
49	other_wishes_if_you_do_not Show the field ONLY if: [study_arm] = '1'	OTHER WISHES: (If you do not agree with any of the optional choices above and wish to write your own, or if you wish to add to the instructions you have given above, you may do so here.) I direct that:	notes

50	i_upon_my_death Show the field ONLY if: [study_arm] = '1'	Section Header: *PART 3 - DONATION OF ORGANS AT DEATH (OPTIONAL)* I. Upon my death:	radio 1 | I give any needed organs, tissues, or parts. 2 | I do not authorize the donation of any organs, tissues or parts. 3 | I give the following organs, tissues, or parts only:
51	i_give_the_following_organ Show the field ONLY if: [study_arm] = '1'	I give the following organs, tissues, or parts only:	text
52	my_gift_is_for_the_followi Show the field ONLY if: [study_arm] = '1'	Section Header: *II. If you wish to donate organs, tissues, or parts, you must complete II. and III.* My gift is for the following purposes:	checkbox 1 | my_gift_is_for_the_followi___1 | Transplant 2 | my_gift_is_for_the_followi___2 | Therapy 3 | my_gift_is_for_the_followi___3 | Research 4 | my_gift_is_for_the_followi___4 | Education
53	my_donated_skin_may_be_use Show the field ONLY if: [study_arm] = '1'	Section Header: *III. I understand that tissue banks work with both nonprofit and for-profit tissue processors and distributors. It is possible that donated skin may be used for cosmetic or reconstructive surgery purposes. It is possible that donated tissue may be used for transplants outside of the United States.* 1. My donated skin may be used for cosmetic surgery purposes.	yesno 1 | Yes 0 | No
54	my_donated_tissue_may_be_u Show the field ONLY if: [study_arm] = '1'	2. My donated tissue may be used for applications outside of the United States.	yesno 1 | Yes 0 | No
55	donated_tissue_may_be_used Show the field ONLY if: [study_arm] = '1'	3. My donated tissue may be used by for-profit tissue processors and distributors.	yesno 1 | Yes 0 | No
56	easy_to_read_and_understan	Section Header: *Post-form Questionnaire Please check the box for each question to evaluate the advance directive form you just completed. The advance directive I just completed:* Easy to read and understand.	radio (Matrix) 1 | Strongly agree 2 | Agree 3 | Neither Agree nor Disagree 4 | Disagree 5 | Strongly Disagree
57	helped_me_reflect_on_what	Helped me reflect on what matters most to me, and my important future milestones.Helped me reflect on what matters most to me, and my important future milestones.	radio (Matrix) 1 | Strongly agree 2 | Agree 3 | Neither Agree nor Disagree 4 | Disagree 5 | Strongly Disagree
58	helped_me_describe_how_we	Helped me describe how we make medical decisions in my family.	radio (Matrix) 1 | Strongly agree 2 | Agree 3 | Neither Agree nor Disagree 4 | Disagree 5 | Strongly Disagree
59	stimulated_my_own_thinking	Stimulated my own thinking about the types of treatment and care I want at the end of life.	radio (Matrix) 1 | Strongly agree

			2	Agree
			3	Neither Agree nor Disagree
			4	Disagree
			5	Strongly Disagree
60	can_help_my_doctor_s_under	Can help my doctor(s) understand what treatments I want and do not want at the end of life.	radio (Matrix)	
			1	Strongly agree
			2	Agree
			3	Neither Agree nor Disagree
			4	Disagree
			5	Strongly Disagree
61	in_the_future_if_i_cannot	In the future, if I cannot make decisions for myself, this advance directive will help my family and friends understand exactly what treatments I want (and do not want) so they can make medical decisions on my behalf.	radio (Matrix)	
			1	Strongly agree
			2	Agree
			3	Neither Agree nor Disagree
			4	Disagree
			5	Strongly Disagree
62	i_feel_comfortable_using_t	I feel comfortable using this advance directive form	radio (Matrix)	
			1	Strongly agree
			2	Agree
			3	Neither Agree nor Disagree
			4	Disagree
			5	Strongly Disagree
63	i_am_clear_about_the_best	I am clear about the best choice for me.	radio (Matrix)	
			1	Strongly agree
			2	Agree
			3	Neither Agree nor Disagree
			4	Disagree
			5	Strongly Disagree
64	i_feel_sure_about_what_to	I feel sure about what to choose.	radio (Matrix)	
			1	Strongly agree
			2	Agree
			3	Neither Agree nor Disagree
			4	Disagree
			5	Strongly Disagree
65	this_decision_is_easy_for	This decision is easy for me to make.	radio (Matrix)	
			1	Strongly agree
			2	Agree
			3	Neither Agree nor Disagree
			4	Disagree
			5	Strongly Disagree
66	i_feel_i_have_made_an_info	I feel I have made an informed choice.	radio (Matrix)	
			1	Strongly agree
			2	Agree

				3	Neither Agree nor Disagree
				4	Disagree
				5	Strongly Disagree
67	my_decision_s_shows_what_i	My decision(s) shows what is important to me.	radio (Matrix)		
				1	Strongly agree
				2	Agree
				3	Neither Agree nor Disagree
				4	Disagree
				5	Strongly Disagree
68	i_expect_to_stick_with_my	I expect to stick with my decision(s).	radio (Matrix)		
				1	Strongly agree
				2	Agree
				3	Neither Agree nor Disagree
				4	Disagree
				5	Strongly Disagree
69	i_am_satisfied_with_my_dec	I am satisfied with my decision(s).	radio (Matrix)		
				1	Strongly agree
				2	Agree
				3	Neither Agree nor Disagree
				4	Disagree
				5	Strongly Disagree
70	ask_someone_to_be_your_med	Section Header: *Please answer the following questions about how CONFIDENT you are today that you could do the following:* Ask someone to be your medical decision maker	radio (Matrix)		
				1	Not at All
				2	A Little
				3	Somewhat
				4	Fairly
				5	Extremely
71	talk_with_your_doctors_abo	Talk with your doctors about who you want to your medical decision maker to be	radio (Matrix)		
				1	Not at All
				2	A Little
				3	Somewhat
				4	Fairly
				5	Extremely
72	talk_to_your_decision_make	Talk to your decision maker about how much flexibility you want to give them?	radio (Matrix)		
				1	Not at All
				2	A Little
				3	Somewhat
				4	Fairly
				5	Extremely
73	ask_the_right_questions_of	Ask the right questions of your doctors to help make good medical decisions?	radio (Matrix)		
				1	Not at All
				2	A Little
				3	Somewhat

			4	Fairly
			5	Extremely
74	asksomeonetobeyourmed	Section Header: *Please answer the following questions about how READY you are today to do the following:* Ask someone to be your medical decision maker	radio (Matrix)	
			1	Not at All
			2	A Little
			3	Somewhat
			4	Fairly
			5	Extremely
75	talkwithyourdrsabo	Talk with your doctors about who you want to your medical decision maker to be	radio (Matrix)	
			1	Not at All
			2	A Little
			3	Somewhat
			4	Fairly
			5	Extremely
76	talktoyourdecisionmake	Talk to your decision maker about how much flexibility you want to give them?	radio (Matrix)	
			1	Not at All
			2	A Little
			3	Somewhat
			4	Fairly
			5	Extremely
77	asktherightquestionsof	Ask the right questions of your doctors to help make good medical decisions?	radio (Matrix)	
			1	Not at All
			2	A Little
			3	Somewhat
			4	Fairly
			5	Extremely
78	letter_study_complete	Section Header: *Form Status* Complete?	dropdown	
			0	Incomplete
			1	Unverified
			2	Complete