

Marfan Data Codebook
A214: Subject Transfer Form
(raw data)

DATE CREATED 13SEP18

Number of Observations: 28

Number of Variables: 20

Organization of file: Up to Four Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
A214:A1. Random identification number	RANDOM_ID			28(0)			144558.00-145838.00
A214: A4. Reason for form completion	FORM_REASON	Subject beginning study follow-up at this site	14(50.0)				
		Subject ending study follow-up at this site	14(50.0)				
A214: B1. Study drug assigned	STUDYDRUG_B	<i>Skipped</i>	14(50.0)				
		STUDY DRUG A	8(28.6)				
		STUDY DRUG B	6(21.4)				
A214: B2. Study Drug Phase	DRUGPHASE_B	MAINTENANCE	14(50.0)				
		<i>Skipped</i>	14(50.0)				
A214:B3. Age when most recent prescription made	RX_AGE_214			14(14)	13.17(5.31)	12.40(10.70,15.80)	5.00-27.00
A214: B4. Originating site number-Randomized	ORIG_SITE		14(50.0)				
		1	4(14.3)				
		13	2(7.1)				
		17	2(7.1)				
		36	1(3.6)				

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		52	1(3.6)				
		65	1(3.6)				
		71	1(3.6)				
		83	1(3.6)				
		96	1(3.6)				
A214:B5. Age of last seen at the original site	LASTSEEN_AGE			14(14)	12.68(5.51)	12.10(9.70,15.80)	4.30-27.00
A214: B6. Transfer site number-Randomized	TRANS_SITE_B		14(50.0)				
		4	1(3.6)				
		15	1(3.6)				
		36	2(7.1)				
		52	1(3.6)				
		54	2(7.1)				
		65	1(3.6)				
		83	4(14.3)				
		96	2(7.1)				

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Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
A214: B8. Musculoskeletal Ancillary Study consent	MAS_CONSENT	<i>Missing</i>	4(14.3)				
		NO	9(32.1)				
		<i>Skipped</i>	14(50.0)				
		YES	1(3.6)				
A214: B9. Genetics Ancillary Study consent	GEN_CONSENT	<i>Missing</i>	2(7.1)				
		NO	8(28.6)				
		<i>Skipped</i>	14(50.0)				
		YES	4(14.3)				
A214: B9a. Was a blood sample drawn	BLOODDRAWN	<i>Skipped</i>	24(85.7)				
		YES	4(14.3)				
A214: C1. Study drug assigned	STUDYDRUG_C	<i>Skipped</i>	14(50.0)				
		STUDY DRUG A	8(28.6)				
		STUDY DRUG B	6(21.4)				
A214: C2. Study Drug Phase	DRUGPHASE_C	MAINTENANCE	14(50.0)				

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Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		<i>Skipped</i>	14(50.0)				
A214: C3. Transfer site number-Randomized	TRANS_SITE_C		14(50.0)				
		4	1(3.6)				
		15	1(3.6)				
		36	2(7.1)				
		52	1(3.6)				
		54	2(7.1)				
		65	1(3.6)				
		83	4(14.3)				
		96	2(7.1)				
A214:C4. Age when consent signed at transfer site	TRANS_CONS_AGE			14(14)	13.45(5.36)	12.55(10.80,16.60)	5.30-27.20
A214: C7. Musculoskeletal Ancillary Study participation	MAS_PARTICIP	<i>Missing</i>	8(28.6)				
		NO	6(21.4)				
		<i>Skipped</i>	14(50.0)				

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Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
A214:C7a. Age when MAS consent signed at transfer site	MAS_CONS_AGE						
A214: C8. Genetics Ancillary Study participation	GEN_PARTICIP	Missing	8(28.6)				
		NO	4(14.3)				
		Skipped	14(50.0)				
		YES	2(7.1)				
A214:C8a. Age when genetics consent signed at trnsfer site	GEN_CONS_AGE			2(26)	12.70(1.84)	12.70(11.40,14.00)	11.40-14.00
Form version	VER_ID	A	28(100.0)				