

Marfan Data Codebook
A123: Study Drug Re-Uptitration During Maintenance Phase – Study Drugs A and B
(raw data)

DATE CREATED 13SEP18

Number of Observations: 109

Number of Variables: 26

Organization of file: Up to Six Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
A1. Random identification number	RANDOM_ID			109(0)			144515.00-145867.00
A2. Study drug assigned	STUDYDRUG123	Study Drug A	99(90.8)				
		Study Drug B	10(9.2)				
A3. Prescription number	RX_NUM123	4	4(3.7)				
		5	2(1.8)				
		6	11(10.1)				
		7	13(11.9)				
		8	15(13.8)				
		9	8(7.3)				
		10	9(8.3)				
		11	8(7.3)				
		12	2(1.8)				
		13	8(7.3)				
		14	7(6.4)				
		15	3(2.8)				

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		16	5(4.6)				
		17	1(0.9)				
		18	3(2.8)				
		19	2(1.8)				
		21	1(0.9)				
		22	1(0.9)				
		30	1(0.9)				
		31	2(1.8)				
		33	1(0.9)				
		36	2(1.8)				
B1.Age at check up call	CALL123_AGE			109(0)	11.33(5.64)	12.10(6.90,14.50)	1.50-26.80
B2. Study drug intolerances?	INTOL123	1:Yes	5(4.6)				
		2:No	104(95.4)				
B2a. Intolerances: Dizziness?	DIZZ123	2:No	5(4.6)				
		Skipped	104(95.4)				

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B2b. Intolerances: Fatigue?	FATIGUE123	1:Yes	2(1.8)				
		2:No	3(2.8)				
		Skipped	104(95.4)				
B2c. Intolerances: Syncope?	SYNCOPE123	2:No	5(4.6)				
		Skipped	104(95.4)				
B2d. Intolerances: Shortness of breath?	SOB123	2:No	5(4.6)				
		Skipped	104(95.4)				
B2e. Intolerances: Other symptoms	OTHSX123	1:Yes	4(3.7)				
		2:No	1(0.9)				
		Skipped	104(95.4)				
B3. Subject < 18 months?	AGE18MO	2:No	109(100.0)				
B3a. Systolic blood pressure	SBP_123						
B3b. Diastolic blood pressure	DBP_123						
B3c. Systolic blood pressure <2%tile for age?	SBP_PCT123	Skipped	109(100.0)				

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C0. Was an ECG done?	ECG_DONE	1:Yes	99(90.8)				
		2:No	10(9.2)				
C1. Age at ECG	ECG_AGE123			99(10)	11.02(5.44)	11.90(6.00,13.90)	1.60-24.70
C2. 24 hour average heart rate	AVG_HR123			99(10)	76.97(11.54)	77.00(70.00,84.00)	48.00-105.00
C2a. 24 hour average heart rate, above threshold?	THRESHOLD123	1:Yes	98(89.9)				
		2:No	1(0.9)				
		Skipped	10(9.2)				
C2b. Current heart rate below target?	CUR_HR123	1:Yes	22(20.2)				
		2:No	71(65.1)				
		Skipped	16(14.7)				
D1. Outcome of assessment	OUTCOME123	Adjust dose	80(73.4)				
		Continue reuptitration	29(26.6)				
E1. Age of uptitration	UPDOSE123_AGE			29(80)	12.38(5.22)	12.70(9.90,15.20)	4.30-23.20
E2. Uptitration: Dose prescribed	UP_RX123			29(80)	2.77(0.97)	2.90(2.10,3.60)	0.80-4.00

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E3. Uptitration: Frequency of administration	UP_FREQ123	Daily	20(18.3)				
		Skipped	80(73.4)				
		Twice a day	9(8.3)				
E4. Uptitration: Daily dose	UP_DAY123			29(80)	111.26(50.38)	100.00(75.00,125.00)	37.50-250.00
F1. Age maintenance dose reached	MAINT_AGE			80(29)	10.94(5.77)	11.55(6.10,13.90)	1.50-26.80
Form Version	VER_ID	A	109(100.0)				