

Marfan Data Codebook
A121: Study Drug Initiation – Study Drugs A and B
(raw data)

DATE CREATED 07NOV18

Number of Observations: 605

Number of Variables: 25

Organization of file: One Record 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			605(0)			144508.00-145870.00
A2. Study drug assigned	STUDYDRUG121	STUDY DRUG A	301(49.8)				
		STUDY DRUG B	304(50.2)				
A3. Prescription number	RX_NUM121			605(0)	1.00(0.00)	1.00(1.00,1.00)	1.00-1.00
B1.Age at intial dose prescribed	INIT121_AGE			605(0)	11.27(6.32)	10.90(6.10,15.50)	0.50-26.00
B2. Initiation: Dose prescribed	INIT_RX121			605(0)	0.47(0.08)	0.50(0.40,0.50)	0.30-1.00
B3. Initiation: Frequency of administration	INIT_FREQ121	DAILY	605(100.0)				
B4. Initiation: Daily dose	INIT_DAY121			605(0)	19.33(11.36)	12.50(12.50,25.00)	2.00-75.00
C1.AGE at check-up call	CALL121_AGE			301(304)	11.57(6.44)	11.40(6.60,15.90)	0.60-26.00
C2. Study drug intolerances?	INTOL121	NO	292(48.3)				
		SKIPPED	304(50.2)				
		YES	9(1.5)				
C2a. Intolerances: Dizziness?	DIZZ121	NO	6(1.0)				

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		SKIPPED	596(98.5)				
		YES	3(0.5)				
C2b. Intolerances: Fatigue?	FATIGUE121	NO	6(1.0)				
		SKIPPED	596(98.5)				
		YES	3(0.5)				
C2c. Intolerances: Syncope?	SYNCOPE121	NO	9(1.5)				
		SKIPPED	596(98.5)				
C2d. Intolerances: Shortness of breath?	SOB121	NO	8(1.3)				
		SKIPPED	596(98.5)				
		YES	1(0.2)				
C2e. Intolerances: Other symptoms	OTHSX121	NO	6(1.0)				
		SKIPPED	596(98.5)				
		YES	3(0.5)				
C2f. Intolerances: Other reason?	OTHR121	NO	7(1.2)				

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		SKIPPED	596(98.5)				
		YES	2(0.3)				
D1. Outcome of assessment	OUTCOME121	ADJUST DOSE	4(0.7)				
		CONTINUE UPTITRATION	297(49.1)				
		SKIPPED	304(50.2)				
E1. Age at uptitration	UPDOSE121_AGE			297(308)	11.60(6.45)	11.40(6.60,16.20)	0.60-26.00
E2. Uptitration: Dose prescribed	UP_RX121			297(308)	1.00(0.12)	1.00(0.90,1.10)	0.50-2.00
E3. Uptitration: Frequency of administration	UP_FREQ121	DAILY	297(49.1)				
		SKIPPED	308(50.9)				
E4. Uptitration: Daily dose	UP_DAY121			297(308)	40.94(22.01)	37.50(25.00,50.00)	1.00-150.00
F1. Age at adjustment	ADJUST121_AGE			4(601)	9.75(6.10)	12.20(6.20,13.30)	0.70-13.90
F2. Adjustment: Action taken	ACTION121	CHANGED TO NIGHT-TIME ADMINISTRATION	1(0.2)				
		MAINTAIN CURRENT DOSE	1(0.2)				
		OTHER	2(0.3)				

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		SKIPPED	601(99.3)				
F3. Adjustment: Dose prescribed	ADJ_RX121			3(602)	0.57(0.06)	0.60(0.50,0.60)	0.50-0.60
F4. Adjustment: Daily dose	ADJ_DAY121			3(602)	30.50(23.79)	37.50(4.00,50.00)	4.00-50.00
Form Version	VER_ID	A	605(100.0)				