

**Marfan Data Codebook**  
**A104: Consent**  
**(raw data)**

**DATE CREATED 13SEP18**

**Number of Observations: 718**

**Number of Variables: 13**

**Organization of file: Up to three 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			718(0)			144502.00-145870.00
A2. Study visit	VISIT	0:Baseline	718(100.0)				
A2a. What number screening is this?	SCREEN_NUM	1	655(91.2)				
		2	59(8.2)				
		3	4(0.6)				
B1. Eligibility appeal outcome	ELIGAPPEAL	Approved	24(3.3)				
		Denied	1(0.1)				
		Not applicable	693(96.5)				
B2. Diagnosis of Marfan syndrome by Ghent criteria	DIAGMARFAN	1:Yes	670(93.3)				
		2:No	47(6.5)				
		Skipped	1(0.1)				
C1. Did subject or guardian consent?	CONSENT	1:Yes	640(89.1)				
		2:No	30(4.2)				
		Skipped	48(6.7)				

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C1a. Consent age	CONSENT_AGE			640(78)	11.18(6.30)	10.90(6.00,15.50)	0.50-26.00
C2. Why did subject/guardian refuse consent?	NOCONSENT	1:Subject/Family unwilling to participate in research	17(2.4)				
		2:Primary caretaker/cardiologist/geneticist did not wa	1(0.1)				
		22:Other	9(1.3)				
		Skipped	688(95.8)				
		Subject unwilling to be randomized	3(0.4)				
C2a. Reason subject/guardian unwilling to participate	UNWILLING	1:Because of time commitment	3(0.4)				
		2:Because of distance from center	3(0.4)				
		3:Insurance will ot cover echocardiogramsat a study ce	1(0.1)				
		4:No reason given	2(0.3)				
		99:Other	8(1.1)				
		Skipped	701(97.6)				
D1. Eligible to proceed w/ screening	ELIGIBLE104	1:Yes	640(89.1)				
		2:No	78(10.9)				

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D2. Does subject require prophylactic taper?	TAPER	1:Yes	254(35.4)				
		2:No	386(53.8)				
		Skipped	78(10.9)				
D2a. Age when prophylactic taper begun	TAPER_AGE			254(464)	12.30(5.82)	11.70(8.20,16.40)	0.60-25.80
Form Version	VER_ID	A	718(100.0)				