

Marfan Data Codebook
A111: Family History Form
(raw data)

DATE CREATED 13SEP18

Number of Observations: 613

Number of Variables: 74

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			613(0)			144508.00-145870.00
A2. Study visit	VISIT	0:Baseline	613(100.0)				
A2a. What number screening is this?	SCREEN_NUM			613(0)	1.08(0.29)	1.00(1.00,1.00)	1.00-3.00
A5. Age at visit	VISIT_AGE			613(0)	11.23(6.32)	10.90(6.00,15.50)	0.50-26.00
A6. Any relatives with Marfan syndrome	RELATIVE	-8:Unknown	23(3.8)				
		1:Yes	364(59.4)				
		2:No	226(36.9)				
B1. How many relatives with known/suspected Marfan syndrome?	REL_NUM	1	127(20.7)				
		2	157(25.6)				
		3	61(10.0)				
		4	15(2.4)				
		5	4(0.7)				
		Skipped	249(40.6)				
B1a. Relative 1 code	RELCODE_0	Brother	25(4.1)				

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		Father	172(28.1)				
		Maternal Grandfather	3(0.5)				
		Maternal Grandmother	6(1.0)				
		<i>Missing</i>	249(40.6)				
		Mother	138(22.5)				
		Paternal Grandfather	3(0.5)				
		Sister	15(2.4)				
		Son	2(0.3)				
B1a. Relative 1 code	RELCODE_1	Brother	64(10.4)				
		Father	10(1.6)				
		Maternal Grandfather	22(3.6)				
		Maternal Grandmother	29(4.7)				
		<i>Missing</i>	376(61.3)				
		Mother	16(2.6)				
		Paternal Grandfather	20(3.3)				

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		Paternal Grandmother	22(3.6)				
		Sister	54(8.8)				
B1a. Relative 1 code	RELCODE_2	Brother	24(3.9)				
		Daughter	1(0.2)				
		Maternal Grandfather	7(1.1)				
		Maternal Grandmother	7(1.1)				
		<i>Missing</i>	533(86.9)				
		Mother	2(0.3)				
		Paternal Grandfather	10(1.6)				
		Paternal Grandmother	10(1.6)				
		Sister	19(3.1)				
B1a. Relative 1 code	RELCODE_3	Brother	4(0.7)				
		Daughter	1(0.2)				
		Father	1(0.2)				
		Maternal Grandfather	3(0.5)				
		Maternal Grandmother	2(0.3)				

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		<i>Missing</i>	594(96.9)				
		Paternal Grandfather	2(0.3)				
		Sister	5(0.8)				
		Son	1(0.2)				
B1a. Relative 1 code	RELCODE_4	Brother	1(0.2)				
		Father	1(0.2)				
		Maternal Grandfather	1(0.2)				
		Maternal Grandmother	1(0.2)				
		<i>Missing</i>	609(99.3)				
B1b. Aortic Aneurysm	AORANEUR_0	-8:Unknown	37(6.0)				
		1:Yes	160(26.1)				
		2:No	167(27.2)				
		<i>Missing</i>	249(40.6)				
B1b. Aortic Aneurysm	AORANEUR_1	-8:Unknown	38(6.2)				
		1:Yes	78(12.7)				

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		2:No	121(19.7)				
		<i>Missing</i>	376(61.3)				
B1b. Aortic Aneurysm	AORANEUR_2	-8:Unknown	12(2.0)				
		1:Yes	29(4.7)				
		2:No	39(6.4)				
		<i>Missing</i>	533(86.9)				
B1b. Aortic Aneurysm	AORANEUR_3	-8:Unknown	4(0.7)				
		1:Yes	6(1.0)				
		2:No	9(1.5)				
		<i>Missing</i>	594(96.9)				
B1b. Aortic Aneurysm	AORANEUR_4	-8:Unknown	1(0.2)				
		1:Yes	2(0.3)				
		2:No	1(0.2)				
		<i>Missing</i>	609(99.3)				
B1b1. Location of Aortic Aneurysm	ANEURLOC_0	<i>Unknown</i>	20(3.3)				

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		Aortic root/ascending aorta	111(18.1)				
		Both	15(2.4)				
		Descending aorta/abnomianl	14(2.3)				
		Missing	249(40.6)				
		Skipped	204(33.3)				
B1b1. Location of Aortic Aneurysm	ANEURLOC_1	Unknown	19(3.1)				
		Aortic root/ascending aorta	39(6.4)				
		Both	6(1.0)				
		Descending aorta/abnomianl	14(2.3)				
		Missing	376(61.3)				
		Skipped	159(25.9)				
B1b1. Location of Aortic Aneurysm	ANEURLOC_2	Unknown	8(1.3)				
		Aortic root/ascending aorta	20(3.3)				
		Descending aorta/abnomianl	1(0.2)				
		Missing	533(86.9)				

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		Skipped	51(8.3)				
B1b1. Location of Aortic Aneurysm	ANEURLOC_3	Unknown	3(0.5)				
		Aortic root/ascending aorta	3(0.5)				
		Missing	594(96.9)				
		Skipped	13(2.1)				
B1b1. Location of Aortic Aneurysm	ANEURLOC_4	Unknown	2(0.3)				
		Missing	609(99.3)				
		Skipped	2(0.3)				
B1c. Aortic dissection	AORDISS_0	-8:Unknown	38(6.2)				
		1:Yes	69(11.3)				
		2:No	257(41.9)				
		Missing	249(40.6)				
B1c. Aortic dissection	AORDISS_1	-8:Unknown	31(5.1)				
		1:Yes	39(6.4)				

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Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		2:No	167(27.2)				
		<i>Missing</i>	376(61.3)				
B1c. Aortic dissection	AORDISS_2	-8:Unknown	9(1.5)				
		1:Yes	7(1.1)				
		2:No	64(10.4)				
		<i>Missing</i>	533(86.9)				
B1c. Aortic dissection	AORDISS_3	-8:Unknown	4(0.7)				
		1:Yes	4(0.7)				
		2:No	11(1.8)				
		<i>Missing</i>	594(96.9)				
B1c. Aortic dissection	AORDISS_4	-8:Unknown	2(0.3)				
		2:No	2(0.3)				
		<i>Missing</i>	609(99.3)				
<created var>Relative(s) with aortic dissection	AORDISS			613(0)	1.82(0.38)	2.00(2.00,2.00)	1.00-2.00
B1c1. Location of Aortic dissection	DISSLOC_0	<i>Unknown</i>	11(1.8)				

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Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Aortic root/ascending aorta	37(6.0)				
		Both	5(0.8)				
		Descending aorta/abnomianl	16(2.6)				
		<i>Missing</i>	249(40.6)				
		Skipped	295(48.1)				
B1c1. Location of Aortic dissection	DISSLOC_1	<i>Unknown</i>	21(3.4)				
		Aortic root/ascending aorta	14(2.3)				
		Descending aorta/abnomianl	4(0.7)				
		<i>Missing</i>	376(61.3)				
		Skipped	198(32.3)				
B1c1. Location of Aortic dissection	DISSLOC_2	<i>Unknown</i>	4(0.7)				
		Aortic root/ascending aorta	3(0.5)				
		<i>Missing</i>	533(86.9)				
		Skipped	73(11.9)				

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Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
B1c1. Location of Aortic dissection	DISSLOC_3	Unknown	2(0.3)				
		Aortic root/ascending aorta	2(0.3)				
		Missing	594(96.9)				
		Skipped	15(2.4)				
B1c1. Location of Aortic dissection	DISSLOC_4	Missing	609(99.3)				
		Skipped	4(0.7)				
B1d. Aortic surgery	AORSURG_0	-8:Unknown	16(2.6)				
		1:Yes	156(25.4)				
		2:No	192(31.3)				
		Missing	249(40.6)				
B1d. Aortic surgery	AORSURG_1	-8:Unknown	16(2.6)				
		1:Yes	53(8.6)				
		2:No	168(27.4)				
		Missing	376(61.3)				
B1d. Aortic surgery	AORSURG_2	-8:Unknown	8(1.3)				

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Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		1:Yes	12(2.0)				
		2:No	60(9.8)				
		<i>Missing</i>	533(86.9)				
B1d. Aortic surgery	AORSURG_3	-8:Unknown	3(0.5)				
		1:Yes	3(0.5)				
		2:No	13(2.1)				
		<i>Missing</i>	594(96.9)				
B1d. Aortic surgery	AORSURG_4	-8:Unknown	1(0.2)				
		1:Yes	1(0.2)				
		2:No	2(0.3)				
		<i>Missing</i>	609(99.3)				
<created var>Relative(s) with aortic surgery	AORSURG			613(0)	1.68(0.47)	2.00(1.00,2.00)	1.00-2.00
B1d1. Location of Aortic surgery	SURGLOC_0	<i>Unknown</i>	25(4.1)				
		Aortic root/ascending aorta	110(17.9)				

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Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Both	16(2.6)				
		Descending aorta/abnomianl	5(0.8)				
		<i>Missing</i>	249(40.6)				
		Skipped	208(33.9)				
B1d1. Location of Aortic surgery	SURGLOC_1	<i>Unknown</i>	21(3.4)				
		Aortic root/ascending aorta	24(3.9)				
		Both	4(0.7)				
		Descending aorta/abnomianl	4(0.7)				
		<i>Missing</i>	376(61.3)				
		Skipped	184(30.0)				
B1d1. Location of Aortic surgery	SURGLOC_2	<i>Unknown</i>	3(0.5)				
		Aortic root/ascending aorta	9(1.5)				
		<i>Missing</i>	533(86.9)				
		Skipped	68(11.1)				

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Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
B1d1. Location of Aortic surgery	SURGLOC_3	Unknown	1(0.2)				
		Aortic root/ascending aorta	2(0.3)				
		Missing	594(96.9)				
		Skipped	16(2.6)				
B1d1. Location of Aortic surgery	SURGLOC_4	Unknown	1(0.2)				
		Missing	609(99.3)				
		Skipped	3(0.5)				
B1d2. Age at first surgery	SURGAGE_0			133(480)	31.61(8.60)	30.00(25.00,37.00)	1.00-60.00
B1d2. Age at first surgery	SURGAGE_1			43(570)	37.60(13.52)	38.00(28.00,45.00)	2.00-65.00
B1d2. Age at first surgery	SURGAGE_2			7(606)	34.29(16.73)	41.00(18.00,50.00)	15.00-56.00
B1d2. Age at first surgery	SURGAGE_3			2(611)	41.00(0.00)	41.00(41.00,41.00)	41.00-41.00
B1d2. Age at first surgery	SURGAGE_4						
B1e. Mitral valve surgery	MVSURG_0	-8:Unknown	43(7.0)				
		1:Yes	57(9.3)				
		2:No	264(43.1)				

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		<i>Missing</i>	249(40.6)				
B1e. Mitral valve surgery	MVSURG_1	-8:Unknown	37(6.0)				
		1:Yes	20(3.3)				
		2:No	180(29.4)				
		<i>Missing</i>	376(61.3)				
B1e. Mitral valve surgery	MVSURG_2	-8:Unknown	10(1.6)				
		1:Yes	8(1.3)				
		2:No	62(10.1)				
		<i>Missing</i>	533(86.9)				
B1e. Mitral valve surgery	MVSURG_3	-8:Unknown	5(0.8)				
		2:No	14(2.3)				
		<i>Missing</i>	594(96.9)				
B1e. Mitral valve surgery	MVSURG_4	-8:Unknown	2(0.3)				
		2:No	2(0.3)				
		<i>Missing</i>	609(99.3)				
B1f. Ectopia lentis	ECTLENTIS_0	-8:Unknown	66(10.8)				

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		1:Yes	127(20.7)				
		2:No	171(27.9)				
		<i>Missing</i>	249(40.6)				
B1f. Ectopia lentis	ECTLENTIS_1	-8:Unknown	71(11.6)				
		1:Yes	63(10.3)				
		2:No	103(16.8)				
		<i>Missing</i>	376(61.3)				
B1f. Ectopia lentis	ECTLENTIS_2	-8:Unknown	23(3.8)				
		1:Yes	29(4.7)				
		2:No	28(4.6)				
		<i>Missing</i>	533(86.9)				
B1f. Ectopia lentis	ECTLENTIS_3	-8:Unknown	7(1.1)				
		1:Yes	7(1.1)				
		2:No	5(0.8)				
		<i>Missing</i>	594(96.9)				

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B1f. Ectopia lentis	ECTLENTIS_4	-8:Unknown	2(0.3)				
		1:Yes	1(0.2)				
		2:No	1(0.2)				
		<i>Missing</i>	609(99.3)				
B1g. Is this relative alive today	VITALSTAT_0	-8:Unknown	3(0.5)				
		1:Yes	311(50.7)				
		2:No	50(8.2)				
		<i>Missing</i>	249(40.6)				
B1g. Is this relative alive today	VITALSTAT_1	-8:Unknown	3(0.5)				
		1:Yes	177(28.9)				
		2:No	57(9.3)				
		<i>Missing</i>	376(61.3)				
B1g. Is this relative alive today	VITALSTAT_2	-8:Unknown	2(0.3)				
		1:Yes	57(9.3)				

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		2:No	21(3.4)				
		<i>Missing</i>	533(86.9)				
B1g. Is this relative alive today	VITALSTAT_3	1:Yes	14(2.3)				
		2:No	5(0.8)				
		<i>Missing</i>	594(96.9)				
B1g. Is this relative alive today	VITALSTAT_4	1:Yes	2(0.3)				
		2:No	2(0.3)				
		<i>Missing</i>	609(99.3)				
B1g1. Cause of death	DEATHCAUSE_0	Aortic dissection	15(2.4)				
		<i>Missing</i>	249(40.6)				
		Non-cardiac	11(1.8)				
		Other cardiac	13(2.1)				
		Skipped	314(51.2)				
		Sudden, cause unknown	11(1.8)				
B1g1. Cause of death	DEATHCAUSE_1	Aortic dissection	30(4.9)				

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		Missing	376(61.3)				
		Non-cardiac	8(1.3)				
		Other cardiac	7(1.1)				
		Skipped	180(29.4)				
		Sudden, cause unknown	12(2.0)				
B1g1. Cause of death	DEATHCAUSE_2	Aortic dissection	5(0.8)				
		Missing	533(86.9)				
		Non-cardiac	7(1.1)				
		Other cardiac	5(0.8)				
		Skipped	59(9.6)				
		Sudden, cause unknown	4(0.7)				
B1g1. Cause of death	DEATHCAUSE_3	Aortic dissection	1(0.2)				
		Missing	594(96.9)				
		Other cardiac	1(0.2)				
		Skipped	14(2.3)				

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		Sudden, cause unknown	3(0.5)				
B1g1. Cause of death	DEATHCAUSE_4	Missing	610(99.5)				
		Other cardiac	1(0.2)				
		Skipped	2(0.3)				
B1g2. Age at death, yrs	DEATHAGE_0			45(568)	42.24(11.47)	42.00(34.00,47.00)	22.00-77.00
B1g2. Age at death, yrs	DEATHAGE_1			52(561)	44.08(13.60)	43.00(32.50,56.00)	19.00-69.00
B1g2. Age at death, yrs	DEATHAGE_2			19(594)	46.05(18.02)	41.00(33.00,58.00)	22.00-78.00
B1g2. Age at death, yrs	DEATHAGE_3			3(610)	46.00(10.39)	52.00(34.00,52.00)	34.00-52.00
B1g2. Age at death, yrs	DEATHAGE_4			1(612)	52.00()	52.00(52.00,52.00)	52.00-52.00
Form Version	VER_ID	A	613(100.0)				