

Marfan Data Codebook
A115: Family Update Form
(raw data)

DATE CREATED 13SEP18

Number of Observations: 542

Number of Variables: 114

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			542(0)			144511.00-145867.00
A2. Study visit	VISIT	STUDY VISIT 4 (MONTH 36)	542(100.0)				
A5. Age at visit	VISIT_AGE			542(0)	13.81(6.19)	13.20(8.80,18.20)	3.50-29.00
A6. Previously reported relatives with Marfan syndrome	RELATIVE	NO	219(40.4)				
		YES	323(59.6)				
B1. Number of relatives reported at Baseline	REL_NUM			323(219)	1.94(0.86)	2.00(1.00,2.00)	1.00-5.00
B1.a1.Code	RELCODE_0	Brother	21(3.9)				
		Father	157(29.0)				
		Maternal Grandmother	6(1.1)				
		<i>Missing</i>	219(40.4)				
		Mother	119(22.0)				
		Paternal Grandfather	6(1.1)				
		Sister	13(2.4)				
		Son	1(0.2)				
B1.a2.Code	RELCODE_1	Brother	60(11.1)				

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		Father	10(1.8)				
		Maternal Grandmother	26(4.8)				
		<i>Missing</i>	326(60.1)				
		Mother	15(2.8)				
		Paternal Grandfather	37(6.8)				
		Paternal Grandmother	20(3.7)				
		Sister	48(8.9)				
B1.a3.Code	RELCODE_2	Brother	20(3.7)				
		Maternal Grandmother	6(1.1)				
		<i>Missing</i>	471(86.9)				
		Mother	2(0.4)				
		Paternal Grandfather	16(3.0)				
		Paternal Grandmother	10(1.8)				
		Sister	17(3.1)				
B1.a3.Code	RELCODE_3	Brother	4(0.7)				
		Daughter	1(0.2)				

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		Father	1(0.2)				
		Maternal Grandmother	1(0.2)				
		<i>Missing</i>	527(97.2)				
		Paternal Grandfather	3(0.6)				
		Sister	4(0.7)				
		Son	1(0.2)				
B1.a5.Code	RELCODE_4	Father	1(0.2)				
		Maternal Grandmother	1(0.2)				
		<i>Missing</i>	539(99.4)				
		Paternal Grandfather	1(0.2)				
B1.a11.reported as a deceased at the baseline(A111)	DECEASED_0	<i>Missing</i>	229(42.3)				
		NO	247(45.6)				
		<i>Version</i>	29(5.4)				
		YES	37(6.8)				
B1.a12.reported as a deceased at the baseline(A111)	DECEASED_1	<i>Missing</i>	323(59.6)				
		NO	145(26.8)				

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		<i>Version</i>	29(5.4)				
		YES	45(8.3)				
B1.a13.reported as a deceased at the baseline(A111)	DECEASED_2	<i>Missing</i>	453(83.6)				
		NO	47(8.7)				
		<i>Version</i>	29(5.4)				
		YES	13(2.4)				
B1.a14.reported as a deceased at the baseline(A111)	DECEASED_3	<i>Missing</i>	501(92.4)				
		NO	9(1.7)				
		<i>Version</i>	29(5.4)				
		YES	3(0.6)				
B1.a15.reported as a deceased at the baseline(A111)	DECEASED_4	<i>Missing</i>	511(94.3)				
		NO	1(0.2)				
		<i>Version</i>	29(5.4)				
		YES	1(0.2)				

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Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
B1.b1.New Aortic aneurysm since baseline	AORANEUR_0	<i>Missing</i>	219(40.4)				
		No	268(49.4)				
		Skipped	37(6.8)				
		Unknown	12(2.2)				
		Yes	6(1.1)				
B1.b2.New Aortic aneurysm since baseline	AORANEUR_1	<i>Missing</i>	326(60.1)				
		No	159(29.3)				
		Skipped	45(8.3)				
		Unknown	10(1.8)				
		Yes	2(0.4)				
B1.b3.New Aortic aneurysm since baseline	AORANEUR_2	<i>Missing</i>	471(86.9)				
		No	52(9.6)				
		Skipped	13(2.4)				
		Unknown	4(0.7)				
		Yes	2(0.4)				

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B1.b4.New Aortic aneurysm since baseline	AORANEUR_3	<i>Missing</i>	527(97.2)				
		No	11(2.0)				
		Skipped	3(0.6)				
		Unknown	1(0.2)				
B1.b5.New Aortic aneurysm since baseline	AORANEUR_4	<i>Missing</i>	539(99.4)				
		No	1(0.2)				
		Skipped	1(0.2)				
		Unknown	1(0.2)				
B1.b11.Location of aneurysm	ANEURLOC_0	Aortic Root/Ascending aorta	2(0.4)				
		Descending aorta/Abnominal	3(0.6)				
		<i>Missing</i>	219(40.4)				
		Skipped	317(58.5)				
		Unknown	1(0.2)				
B1.b12.Location of aneurysm	ANEURLOC_1	Aortic Root/Ascending aorta	1(0.2)				
		Descending aorta/Abnominal	1(0.2)				
		<i>Missing</i>	326(60.1)				

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Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Skipped	214(39.5)				
B1.b13.Location of aneurysm	ANEURLOC_2	Aortic Root/Ascending aorta	2(0.4)				
		Missing	471(86.9)				
		Skipped	69(12.7)				
B1.b14.Location of aneurysm	ANEURLOC_3	Missing	527(97.2)				
		Skipped	15(2.8)				
B1.b15.Location of aneurysm	ANEURLOC_4	Missing	539(99.4)				
		Missing	219(40.4)				
		No	269(49.6)				
		Skipped	3(0.6)				
		Skipped	37(6.8)				
		Unknown	9(1.7)				
		Yes	8(1.5)				
B1.c2.New Aortic dissection since baseline	AORDISS_1	Missing	326(60.1)				
		No	161(29.7)				
		Skipped	45(8.3)				

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Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Unknown	7(1.3)				
		Yes	3(0.6)				
B1.c3.New Aortic dissection since baseline	AORDISS_2	<i>Missing</i>	471(86.9)				
		No	56(10.3)				
		Skipped	13(2.4)				
		Unknown	2(0.4)				
B1.c4.New Aortic dissection since baseline	AORDISS_3	<i>Missing</i>	527(97.2)				
		No	11(2.0)				
		Skipped	3(0.6)				
		Unknown	1(0.2)				
B1.c5.New Aortic dissection since baseline	AORDISS_4	<i>Missing</i>	539(99.4)				
		No	1(0.2)				
		Skipped	1(0.2)				
		Unknown	1(0.2)				
B1.c11.Location of dissection	DISSLOC_0	Aortic Root/Ascending aorta	2(0.4)				

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Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Descending aorta/Abnominal	1(0.2)				
		<i>Missing</i>	219(40.4)				
		Skipped	315(58.1)				
		Unknown	5(0.9)				
B1.c12.Location of dissection	DISSLOC_1	Aortic Root/Ascending aorta	1(0.2)				
		Both	1(0.2)				
		<i>Missing</i>	326(60.1)				
		Skipped	213(39.3)				
		Unknown	1(0.2)				
B1.c13.Location of dissection	DISSLOC_2	<i>Missing</i>	471(86.9)				
		Skipped	71(13.1)				
B1.c14.Location of dissection	DISSLOC_3	<i>Missing</i>	527(97.2)				
		Skipped	15(2.8)				
B1.c15.Location of dissection	DISSLOC_4	<i>Missing</i>	539(99.4)				
		Skipped	3(0.6)				
B1.d1.New Aortic surgery since baseline	AORSURG_0	<i>Missing</i>	219(40.4)				

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Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		No	256(47.2)				
		Skipped	37(6.8)				
		Unknown	9(1.7)				
		Yes	21(3.9)				
B1.d2.New Aortic surgery since baseline	AORSURG_1	<i>Missing</i>	326(60.1)				
		No	159(29.3)				
		Skipped	45(8.3)				
		Unknown	6(1.1)				
		Yes	6(1.1)				
B1.d3.New Aortic surgery since baseline	AORSURG_2	<i>Missing</i>	471(86.9)				
		No	55(10.1)				
		Skipped	13(2.4)				
		Unknown	2(0.4)				
		Yes	1(0.2)				
B1.d4.New Aortic surgery since baseline	AORSURG_3	<i>Missing</i>	527(97.2)				

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Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		No	11(2.0)				
		Skipped	3(0.6)				
		Unknown	1(0.2)				
B1.d5.New Aortic surgery since baseline	AORSURG_4	<i>Missing</i>	539(99.4)				
		Skipped	1(0.2)				
		Unknown	1(0.2)				
		Yes	1(0.2)				
B1.d11.Location of surgery	SURGLOC_0	<i>Missing</i>	1(0.2)				
		Aortic Root/Ascending aorta	9(1.7)				
		Both	2(0.4)				
		Descending aorta/Abnominal	3(0.6)				
		<i>Missing</i>	219(40.4)				
		Skipped	302(55.7)				
		Unknown	6(1.1)				
B1.d12.Location of surgery	SURGLOC_1	Aortic Root/Ascending aorta	2(0.4)				
		Descending aorta/Abnominal	1(0.2)				

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		<i>Missing</i>	326(60.1)				
		Skipped	210(38.7)				
		Unknown	3(0.6)				
B1.d13.Location of surgery	SURGLOC_2	Aortic Root/Ascending aorta	1(0.2)				
		<i>Missing</i>	471(86.9)				
		Skipped	70(12.9)				
B1.d14.Location of surgery	SURGLOC_3	<i>Missing</i>	527(97.2)				
		Skipped	15(2.8)				
B1.d15.Location of surgery	SURGLOC_4	Aortic Root/Ascending aorta	1(0.2)				
		<i>Missing</i>	539(99.4)				
		Skipped	2(0.4)				
B1.d21.Age at new surgery	SURGAGE_0			13(529)	34.69(14.13)	41.00(26.00,44.00)	2.00-47.00
B1.d22.Age at new surgery	SURGAGE_1			4(538)	20.75(7.14)	18.50(16.00,25.50)	15.00-31.00
B1.d23.Age at new surgery	SURGAGE_2			1(541)	24.00()	24.00(24.00,24.00)	24.00-24.00
B1.d24.Age at new surgery	SURGAGE_3						
B1.d25.Age at new surgery	SURGAGE_4			1(541)	44.00()	44.00(44.00,44.00)	44.00-44.00

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B1.e1.New Mitral valve surgery since baseline	MVSURG_0	<i>Missing</i>	219(40.4)				
		No	270(49.8)				
		Skipped	37(6.8)				
		Unknown	11(2.0)				
		Yes	5(0.9)				
B1.e2.New Mitral valve surgery since baseline	MVSURG_1	<i>Missing</i>	326(60.1)				
		No	160(29.5)				
		Skipped	45(8.3)				
		Unknown	8(1.5)				
		Yes	3(0.6)				
B1.e3.New Mitral valve surgery since baseline	MVSURG_2	<i>Missing</i>	471(86.9)				
		No	56(10.3)				
		Skipped	13(2.4)				
		Unknown	2(0.4)				
B1.e4.New Mitral valve surgery since baseline	MVSURG_3	<i>Missing</i>	527(97.2)				

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		No	11(2.0)				
		Skipped	3(0.6)				
		Unknown	1(0.2)				
B1.e5.New Mitral valve surgery since baseline	MVSURG_4	<i>Missing</i>	539(99.4)				
		Skipped	1(0.2)				
		Unknown	2(0.4)				
B1.f1.New Ectopia lentis since baseline	ECTLENTIS_0	<i>Missing</i>	219(40.4)				
		No	263(48.5)				
		Skipped	37(6.8)				
		Unknown	15(2.8)				
		Yes	8(1.5)				
B1.f2.New Ectopia lentis since baseline	ECTLENTIS_1	<i>Missing</i>	326(60.1)				
		No	154(28.4)				
		Skipped	45(8.3)				
		Unknown	12(2.2)				

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		Yes	5(0.9)				
B1.f3.New Ectopia lentis since baseline	ECTLENTIS_2	<i>Missing</i>	471(86.9)				
		No	54(10.0)				
		Skipped	13(2.4)				
		Unknown	3(0.6)				
		Yes	1(0.2)				
B1.f4.New Ectopia lentis since baseline	ECTLENTIS_3	<i>Missing</i>	527(97.2)				
		No	9(1.7)				
		Skipped	3(0.6)				
		Unknown	3(0.6)				
B1.f5.New Ectopia lentis since baseline	ECTLENTIS_4	<i>Missing</i>	539(99.4)				
		Skipped	1(0.2)				
		Unknown	2(0.4)				
B1.g1.Is this relative alive today	VITALSTAT_0	<i>Missing</i>	219(40.4)				
		No	11(2.0)				

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		Skipped	37(6.8)				
		Unknown	2(0.4)				
		Yes	273(50.4)				
B1.g2.Is this relative alive today	VITALSTAT_1	<i>Missing</i>	326(60.1)				
		No	9(1.7)				
		Skipped	45(8.3)				
		Unknown	3(0.6)				
		Yes	159(29.3)				
B1.g3.Is this relative alive today	VITALSTAT_2	<i>Missing</i>	471(86.9)				
		No	6(1.1)				
		Skipped	13(2.4)				
		Unknown	1(0.2)				
		Yes	51(9.4)				
B1.g4.Is this relative alive today	VITALSTAT_3	<i>Missing</i>	527(97.2)				
		Skipped	3(0.6)				
		Yes	12(2.2)				

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B1.g5.Is this relative alive today	VITALSTAT_4	<i>Missing</i>	539(99.4)				
		No	1(0.2)				
		Skipped	1(0.2)				
		Yes	1(0.2)				
B1.g11.Cause of death	DEATHCAUSE_0	Aortic Dissection	4(0.7)				
		<i>Missing</i>	219(40.4)				
		Non-cardiac	2(0.4)				
		Other Cardiac	2(0.4)				
		Skipped	312(57.6)				
		Sudden, Cause Unknown	3(0.6)				
B1.g12.Cause of death	DEATHCAUSE_1	Aortic Dissection	3(0.6)				
		<i>Missing</i>	326(60.1)				
		Non-cardiac	2(0.4)				
		Other Cardiac	3(0.6)				
		Skipped	207(38.2)				
		Sudden, Cause Unknown	1(0.2)				

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B1.g13.Cause of death	DEATHCAUSE_2	Aortic Dissection	1(0.2)				
		<i>Missing</i>	471(86.9)				
		Non-cardiac	1(0.2)				
		Other Cardiac	1(0.2)				
		Skipped	65(12.0)				
		Sudden, Cause Unknown	3(0.6)				
B1.g14.Cause of death	DEATHCAUSE_3	<i>Missing</i>	527(97.2)				
		Skipped	15(2.8)				
B1.g15.Cause of death	DEATHCAUSE_4	<i>Missing</i>	1(0.2)				
		<i>Missing</i>	539(99.4)				
		Skipped	2(0.4)				
B1.g21.Age at death	DEATHAGE_0			10(532)	44.20(9.10)	45.00(42.00,50.00)	25.00-56.00
B1.g22.Age at death	DEATHAGE_1			9(533)	59.44(10.43)	62.00(55.00,66.00)	41.00-75.00
B1.g23.Age at death	DEATHAGE_2			6(536)	47.00(15.28)	40.50(40.00,44.00)	39.00-78.00
B1.g24.Age at death	DEATHAGE_3						
B1.g25.Age at death	DEATHAGE_4						

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C1. How many relatives were newly diagnosed	REL_NUM_NEW			33(509)	1.12(0.33)	1.00(1.00,1.00)	1.00-2.00
C1.a1 code	RELCODE_NEW_0	Brother	10(1.8)				
		Father	1(0.2)				
		Maternal Grandmother	3(0.6)				
		<i>Missing</i>	509(93.9)				
		Mother	3(0.6)				
		Paternal Grandfather	2(0.4)				
		Sister	13(2.4)				
		Son	1(0.2)				
C1.a2 code	RELCODE_NEW_1	Brother	3(0.6)				
		<i>Missing</i>	538(99.3)				
		Mother	1(0.2)				
C1.b1.New Aortic aneurysm since baseline	AORANEUR_NEW_0	<i>Missing</i>	509(93.9)				
		No	28(5.2)				
		Unknown	2(0.4)				
		Yes	3(0.6)				

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C1.b2.New Aortic aneurysm since baseline	AORANEUR_NEW_1	<i>Missing</i>	538(99.3)				
		No	3(0.6)				
		Unknown	1(0.2)				
C1.b11.Location of aneurysm	ANEURLOC_NEW_0	Aortic Root/Ascending aorta	3(0.6)				
		<i>Missing</i>	509(93.9)				
		Skipped	30(5.5)				
C1.b12.Location of aneurysm	ANEURLOC_NEW_1	<i>Missing</i>	538(99.3)				
		Skipped	4(0.7)				
C1.c1.New Aortic dissection since baseline	AORDISS_NEW_0	<i>Missing</i>	509(93.9)				
		No	30(5.5)				
		Unknown	2(0.4)				
		Yes	1(0.2)				
C1.c2.New Aortic dissection since baseline	AORDISS_NEW_1	<i>Missing</i>	538(99.3)				
		No	3(0.6)				
		Unknown	1(0.2)				

Marfan Data Codebook
A115: Family Update Form
(raw data)

DATE CREATED 13SEP18

Number of Observations: 542

Number of Variables: 114

Organization of file: One Record per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
C1.c11.Location of dissection	DISSLOC_NEW_0	Aortic Root/Ascending aorta	1(0.2)				
		Missing	509(93.9)				
		Skipped	32(5.9)				
C1.c12.Location of dissection	DISSLOC_NEW_1	Missing	538(99.3)				
		Skipped	4(0.7)				
C1.d1.New Aortic surgery since baseline	AORSURG_NEW_0	Missing	509(93.9)				
		No	27(5.0)				
		Unknown	1(0.2)				
		Yes	5(0.9)				
C1.d1.New Aortic surgery since baseline	AORSURG_NEW_1	Missing	538(99.3)				
		No	3(0.6)				
		Unknown	1(0.2)				
C1.d11.Location of surgery	SURGLOC_NEW_0	Aortic Root/Ascending aorta	5(0.9)				
		Missing	509(93.9)				
		Skipped	28(5.2)				

Marfan Data Codebook
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Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
C1.d12.Location of surgery	SURGLOC_NEW_1	<i>Missing</i>	538(99.3)				
		Skipped	4(0.7)				
C1.d21.Age at new surgery	SURGAGE_NEW_0			5(537)	52.40(31.57)	52.00(24.00,84.00)	18.00-84.00
C1.d22.Age at new surgery	SURGAGE_NEW_1						
C1.e1.New Mitral valve surgery since baseline	MVSURG_NEW_0	<i>Missing</i>	509(93.9)				
		No	31(5.7)				
		Unknown	2(0.4)				
C1.e2.New Mitral valve surgery since baseline	MVSURG_NEW_1	<i>Missing</i>	538(99.3)				
		No	3(0.6)				
		Unknown	1(0.2)				
C1.f1.New Ectopia lentis since baseline	ECTLENT_NEW_0	<i>Missing</i>	509(93.9)				
		No	25(4.6)				
		Unknown	1(0.2)				
		Yes	7(1.3)				
C1.f2.New Ectopia lentis since baseline	ECTLENT_NEW_1	<i>Missing</i>	538(99.3)				

Marfan Data Codebook
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Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		No	3(0.6)				
		Unknown	1(0.2)				
C1.g1.Is this relative alive today	VITALSTAT_NE_0	Missing	509(93.9)				
		Yes	33(6.1)				
C1.g2.Is this relative alive today	VITALSTAT_NE_1	Missing	538(99.3)				
		Yes	4(0.7)				
C1.g11.Cause of death	DEATHCAUSE_N_0	Missing	509(93.9)				
		Skipped	33(6.1)				
C1.g12.Cause of death	DEATHCAUSE_N_1	Missing	538(99.3)				
		Skipped	4(0.7)				
C1.g21.Age at death	DEATHAGE_NEW_0						
C1.g22.Age at death	DEATHAGE_NEW_1						
C1. Any relatives newly diagnosed with Marfan syndrome?	RELATIVE_NEW	NO	509(93.9)				
		YES	33(6.1)				
D1. Relatives screened for the Marfan Trial	SCREENED_REL	NO	419(77.3)				

Marfan Data Codebook
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Organization of file: One Record per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		YES	123(22.7)				
D2. How many relatives were screened for the Marfan Trial	SCREENED_NUM			123(419)	1.23(0.54)	1.00(1.00,1.00)	1.00-4.00
D2.11 Random study ID number	RANDOMSCREENID_0			123(419)			144503.00-145870.00
D2.12 Random study ID number	RANDOMSCREENID_1			22(520)			144626.00-145812.00
D2.13 Random study ID number	RANDOMSCREENID_2			5(537)			144713.00-145525.00
D2.14 Random study ID number	RANDOMSCREENID_3			1(541)			145075.00-145075.00
D2.21.Relationship	SCREENED_COD_0	Brother	67(12.4)				
		Daughter	1(0.2)				
		Father	1(0.2)				
		<i>Missing</i>	419(77.3)				
		Mother	2(0.4)				
		Sister	51(9.4)				
		Son	1(0.2)				
D2.22.Relationship	SCREENED_COD_1	Brother	13(2.4)				
		<i>Missing</i>	520(95.9)				
		Sister	9(1.7)				

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Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
D2.23.Relationship	SCREENED_COD_2	Brother	1(0.2)				
		<i>Missing</i>	537(99.1)				
		Sister	4(0.7)				
D2.24.Relationship	SCREENED_COD_3	<i>Missing</i>	541(99.8)				
		Son	1(0.2)				
Form Version	VER_ID	A	68(12.5)				
		B	474(87.5)				