

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 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			8074(0)			144501.00-145871.00
A2. Study visit	VISIT	0:Baseline	639(7.9)				
		1:Study Visit 1 (Month 6)	592(7.3)				
		2:Study Visit 2 (Month 12)	585(7.2)				
		3:Study Visit 3 (Month 24)	567(7.0)				
		4:Study Visit 4 (Month 36)	542(6.7)				
		7:Quarterly follow up call	4067(50.4)				
		8:Call from subject/family	252(3.1)				
		Missing	830(10.3)				
A2a. What number screening is this?	SCREEN_NUM		830(10.3)				
		1	578(7.2)				
		2	55(0.7)				
		3	6(0.1)				
		Skipped	6605(81.8)				
A3. Age at form completion	COMP_AGE			6712(1362)	12.47(6.27)	12.00(7.40,16.80)	0.50-29.00

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
A5. Source of information	SOURCE	Caregiver	4722(58.5)				
		<i>Missing</i>	830(10.3)				
		Subject	2522(31.2)				
B1a. How often: Dizziness upon standing	DIZ_OFT	<i>Unknown</i>	12(0.1)				
		<i>Missing</i>	830(10.3)				
		None/not at all	6147(76.1)				
		Often	124(1.5)				
		rarely	546(6.8)				
		Sometimes	415(5.1)				
B1b. How much bother: Dizziness upon standing	DIZ_BOT	<i>Missing</i>	12(0.1)				
		Disabling	4(<0.1)				
		Interfering with activities of daily living	21(0.3)				
		Interfering with function only	152(1.9)				
		<i>Missing</i>	830(10.3)				
		Skipped	6147(76.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Transient	908(11.2)				
B1c. Other cause: Dizziness upon standing	DIZ_CAU	-8:Unknown	10(0.1)				
		<i>Missing</i>	2(<0.1)				
		1:Yes	176(2.2)				
		2:No	909(11.3)				
		<i>Missing</i>	830(10.3)				
		Skipped	6147(76.1)				
B1c1. Specify other cause: Dizziness upon standing	DIZ_SP						
B2a. How often: Dizziness-other	OTHDIZ_OFT	<i>Unknown</i>	12(0.1)				
		<i>Missing</i>	830(10.3)				
		None/not at all	6688(82.8)				
		Often	47(0.6)				
		rarely	337(4.2)				
		Sometimes	160(2.0)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
B2b. How much bother: Dizziness-other	OTHDIZ_BOT	<i>Missing</i>	14(0.2)				
		Disabling	3(<0.1)				
		Interfering with activities of daily living	14(0.2)				
		Interfering with function only	145(1.8)				
		<i>Missing</i>	830(10.3)				
		Skipped	6688(82.8)				
		With head movements or nystagmus only	380(4.7)				
B2c. Other cause: Dizziness-other	OTHDIZ_CAU	-8:Unknown	10(0.1)				
		<i>Missing</i>	2(<0.1)				
		1:Yes	165(2.0)				
		2:No	379(4.7)				
		<i>Missing</i>	830(10.3)				
		Skipped	6688(82.8)				
B2c1. Specify other cause: Dizziness-other	OTHDIZ_SP						

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
B3a. How often: Fainting	FAINT_OFT	<i>Unknown</i>	10(0.1)				
		<i>Missing</i>	830(10.3)				
		None/not at all	7145(88.5)				
		Often	1(<0.1)				
		rarely	80(1.0)				
		Sometimes	8(0.1)				
B3b. How much bother: Fainting	FAINT_BOT	<i>Missing</i>	10(0.1)				
		<i>Missing</i>	830(10.3)				
		Present	89(1.1)				
		Skipped	7145(88.5)				
B3c. Other cause: Fainting	FAINT_CAU	-8:Unknown	9(0.1)				
		<i>Missing</i>	1(<0.1)				
		1:Yes	38(0.5)				
		2:No	51(0.6)				
		<i>Missing</i>	830(10.3)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Skipped	7145(88.5)				
B3c1. Specify other cause: Fainting	FAINT_SP						
B4a. How often: Shortness of breath	SOB_OFT	Unknown	12(0.1)				
		Missing	1(<0.1)				
		Missing	830(10.3)				
		None/not at all	6587(81.6)				
		Often	64(0.8)				
		rarely	306(3.8)				
		Sometimes	274(3.4)				
B4b. How much bother: Shortness of breath	SOB_BOT	Missing	14(0.2)				
		At rest, intubation/ventilator indicated	2(<0.1)				
		Missing	830(10.3)				
		On exertion, but can walk 1 flight of stairs without s	586(7.3)				
		Skipped	6587(81.6)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Unable to walk 1 flight of stairs or 1 city block with	38(0.5)				
		With activities of daily living	17(0.2)				
B4c. Other cause: Shortness of breath	SOB_CAU	-8:Unknown	10(0.1)				
		<i>Missing</i>	4(<0.1)				
		1:Yes	213(2.6)				
		2:No	430(5.3)				
		<i>Missing</i>	830(10.3)				
		Skipped	6587(81.6)				
B4c1. Specify other cause: Shortness of breath	SOB_SP						
B5a. How often: Wheezing (bronchospasm)	WHEEZE_OFT	<i>Unknown</i>	11(0.1)				
		<i>Missing</i>	3(<0.1)				
		<i>Missing</i>	830(10.3)				
		None/not at all	6992(86.6)				
		Often	17(0.2)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		rarely	150(1.9)				
		Sometimes	71(0.9)				
B5b. How much bother: Wheezing (bronchospasm)	WHEEZE_BOT	<i>Missing</i>	14(0.2)				
		Asymptomatic	132(1.6)				
		Interfering with function	21(0.3)				
		<i>Missing</i>	830(10.3)				
		Skipped	6992(86.6)				
		Symptomatic, not interfering with function	85(1.1)				
B6a. How often: Palpitations (cardiac arrhythmia)	PALP_OFT	<i>Unknown</i>	1(<0.1)				
		<i>Missing</i>	830(10.3)				
		None/not at all	2412(29.9)				
		Often	36(0.4)				
		rarely	309(3.8)				
		Skipped	4319(53.5)				
		Sometimes	167(2.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
B6b. How much bother: Palpitations (cardiac arrhythmia)	PALP_BOT	Missing	1(<0.1)				
		Missing	830(10.3)				
		Present	467(5.8)				
		Present with associated symptoms	45(0.6)				
		Skipped	6731(83.4)				
B7a. How often: Headache	HEAD_OFT	Missing	830(10.3)				
		None/not at all	1593(19.7)				
		Often	208(2.6)				
		rarely	642(8.0)				
		Skipped	4319(53.5)				
B7b. How much bother: Headache	HEAD_BOT	Sometimes	482(6.0)				
		Disabling	7(0.1)				
		Mild, not interfering with function	859(10.6)				
		Missing	830(10.3)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Moderate, interfering with function only	377(4.7)				
		Severe, interfering with activities of daily living	89(1.1)				
		Skipped	5912(73.2)				
B8a. How often: Nasal congestion, head cold	NASAL_OFT	<i>Missing</i>	830(10.3)				
		None/not at all	1764(21.8)				
		Often	156(1.9)				
		rarely	663(8.2)				
		Skipped	4319(53.5)				
		Sometimes	342(4.2)				
B8b. How much bother: Nasal congestion, head cold	NASAL_BOT	Mild	899(11.1)				
		<i>Missing</i>	830(10.3)				
		Moderate	253(3.1)				
		Severe	9(0.1)				
		Skipped	6083(75.3)				
B9a. How often: Cough	COUGH_OFT	<i>Missing</i>	830(10.3)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		None/not at all	2364(29.3)				
		Often	47(0.6)				
		rarely	352(4.4)				
		Skipped	4319(53.5)				
		Sometimes	162(2.0)				
B9b. How much bother: Cough	COUGH_BOT	<i>Missing</i>	830(10.3)				
		Significantly interfering with sleep or daily living	3(<0.1)				
		Skipped	6683(82.8)				
		Symptomatic, narcotic medication indicated	17(0.2)				
		Symptomatic, non-narcotic medication only indicated	541(6.7)				
B10a. How often: Chest pain	CHEST_OFT	<i>Missing</i>	830(10.3)				
		None/not at all	2367(29.3)				
		Often	26(0.3)				
		rarely	348(4.3)				
		Skipped	4319(53.5)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Sometimes	184(2.3)				
B10b. How much bother: Chest pain	CHEST_BOT	Disabling	2(<0.1)				
		Mild, not interfering with function	384(4.8)				
		<i>Missing</i>	830(10.3)				
		Moderate, interfering with function only	149(1.8)				
		Severe, interfering with activities of daily living	23(0.3)				
		Skipped	6686(82.8)				
B11a. How often: Change in how food tastes	TASTE_OFT	<i>Missing</i>	830(10.3)				
		None/not at all	2836(35.1)				
		Often	23(0.3)				
		rarely	36(0.4)				
		Skipped	4319(53.5)				
		Sometimes	30(0.4)				
B11b. How much bother: Change in how food tastes	TASTE_BOT	Altered taste but no change in diet	67(0.8)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Altered taste with change in diet	22(0.3)				
		<i>Missing</i>	830(10.3)				
		Skipped	7155(88.6)				
B12a. How often: Stomach pain or indigestion	STOM_OFT	<i>Missing</i>	830(10.3)				
		None/not at all	2340(29.0)				
		Often	75(0.9)				
		rarely	327(4.1)				
		Skipped	4319(53.5)				
		Sometimes	183(2.3)				
B12b. How much bother: Stomach pain or indigestion	STOM_BOT	Disabling	1(<0.1)				
		Mild, not interfering with function	440(5.4)				
		<i>Missing</i>	830(10.3)				
		Moderate, interfering with function only	128(1.6)				
		Severe, interfering with activities of daily living	16(0.2)				
		Skipped	6659(82.5)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
B13a. How often: Nausea	NAUSEA_OFT	<i>Missing</i>	830(10.3)				
		None/not at all	2528(31.3)				
		Often	21(0.3)				
		rarely	272(3.4)				
		Skipped	4319(53.5)				
		Sometimes	104(1.3)				
B13b. How much bother: Nausea	NAUSEA_BOT	Inadequate oral caloric or fluid intake, in fluids, tu	1(<0.1)				
		Loss of appetite without alteration in eating habits	320(4.0)				
		<i>Missing</i>	830(10.3)				
		Oral intake decreased without significant weight loss	76(0.9)				
		Skipped	6847(84.8)				
B14a. How often: Vomiting	VOMIT_OFT	<i>Missing</i>	830(10.3)				
		None/not at all	2599(32.2)				
		Often	11(0.1)				
		rarely	275(3.4)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Skipped	4319(53.5)				
		Sometimes	40(0.5)				
B14b. How much bother: Vomiting	VOMIT_BOT	>=6 episodes/24hr, IV fluids indicated >=24 hrs	3(<0.1)				
		1 episode/24hrs	294(3.6)				
		2-5 episodes/24hr, IV fluids indicated <24 hrs	29(0.4)				
		<i>Missing</i>	830(10.3)				
		Skipped	6918(85.7)				
B15a. How often: Diarrhea	DIAR_OFT	<i>Missing</i>	830(10.3)				
		None/not at all	2475(30.7)				
		Often	19(0.2)				
		rarely	352(4.4)				
		Skipped	4319(53.5)				
		Sometimes	79(1.0)				
B15b. How much bother: Diarrhea	DIAR_BOT	Increase of <4 stools/day over baseline	398(4.9)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Increase of >=7 stools/day over baseline,interfering w	8(0.1)				
		Increase of 4-6 stools/day over baseline	44(0.5)				
		<i>Missing</i>	830(10.3)				
		Skipped	6794(84.1)				
B16a. How often: Constipation	CONST_OFT	<i>Missing</i>	830(10.3)				
		None/not at all	2552(31.6)				
		Often	62(0.8)				
		rarely	182(2.3)				
		Skipped	4319(53.5)				
		Sometimes	129(1.6)				
B16b. How much bother: Constipation	CONST_BOT	Interfering with activities of daily living	2(<0.1)				
		<i>Missing</i>	830(10.3)				
		Occasional or intermittent symptoms	318(3.9)				
		Persistent symptoms, regular use of laxatives	53(0.7)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Skipped	6871(85.1)				
B17a. How often: Hands or feet becoming cold	COLD_OFT	Missing	830(10.3)				
		None/not at all	2559(31.7)				
		Often	121(1.5)				
		rarely	116(1.4)				
		Skipped	4319(53.5)				
		Sometimes	129(1.6)				
B17b. How much bother: Hands or feet becoming cold	COLD_BOT	Mild	319(4.0)				
		Missing	830(10.3)				
		Moderate	45(0.6)				
		Severe	2(<0.1)				
		Skipped	6878(85.2)				
B18a. How often: Muscle pain or cramps	MUSCLE_OFT	Missing	830(10.3)				
		None/not at all	2213(27.4)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Often	93(1.2)				
		rarely	347(4.3)				
		Skipped	4319(53.5)				
		Sometimes	272(3.4)				
B18b. How much bother: Muscle pain or cramps	MUSCLE_BOT	Disabling	1(<0.1)				
		Mild, not interfering with function	486(6.0)				
		<i>Missing</i>	830(10.3)				
		Moderate, interfering with function only	201(2.5)				
		Severe, interfering with activities of daily living	24(0.3)				
		Skipped	6532(80.9)				
B19a. How often: Back pain	BACK_OFT	<i>Missing</i>	830(10.3)				
		None/not at all	2189(27.1)				
		Often	174(2.2)				
		rarely	293(3.6)				
		Skipped	4319(53.5)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Sometimes	269(3.3)				
B19b. How much bother: Back pain	BACK_BOT	Mild, not interfering with function	500(6.2)				
		<i>Missing</i>	830(10.3)				
		Moderate, interfering with function only	206(2.6)				
		Severe, interfering with activities of daily living	30(0.4)				
		Skipped	6508(80.6)				
B20a. How often: Swelling around the eyes	EYES_OFT	<i>Missing</i>	830(10.3)				
		None/not at all	2791(34.6)				
		Often	22(0.3)				
		rarely	67(0.8)				
		Skipped	4319(53.5)				
		Sometimes	45(0.6)				
B20b. How much bother: Swelling around the eyes	EYES_BOT	Generalized facial or neck edema with functional impai	1(<0.1)				
		Localized facial or neck edema with functional impairm	3(<0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Localized to dependent areas, no impariment	130(1.6)				
		<i>Missing</i>	830(10.3)				
		Skipped	7110(88.1)				
B21a. How often: Swelling around the feet	FEET_OFT	<i>Missing</i>	830(10.3)				
		None/not at all	2899(35.9)				
		Often	3(<0.1)				
		rarely	12(0.1)				
		Skipped	4319(53.5)				
		Sometimes	11(0.1)				
B21b. How much bother: Swelling around the feet	FEET_BOT	5-10% inter-limb discrepancy in volume or circumferenc	26(0.3)				
		<i>Missing</i>	830(10.3)				
		Skipped	7218(89.4)				
B22a. How often: Mood changes	MOOD_OFT	<i>Missing</i>	830(10.3)				
		None/not at all	2402(29.7)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Often	147(1.8)				
		rarely	140(1.7)				
		Skipped	4319(53.5)				
		Sometimes	236(2.9)				
B22b. How much bother: Mood changes	MOOD_BOT	mild mood alteration not interfering with function	308(3.8)				
		<i>Missing</i>	830(10.3)				
		Moderate mood alteration interfering with function	162(2.0)				
		Severe mood alteration, interfering with activiteis of	48(0.6)				
		Skipped	6721(83.2)				
		Sucidal ideation, danger to self or others	5(0.1)				
B22c. Specify the mood change (use CTCAE short name)	MOOD_SP						
B23a. How often: Behavior changes	BEHAVE_OFT	<i>Missing</i>	830(10.3)				
		None/not at all	2669(33.1)				
		Often	73(0.9)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		rarely	80(1.0)				
		Skipped	4319(53.5)				
		Sometimes	103(1.3)				
B23b. How much bother: Behavior changes	BEHAVE_BOT	Change harmful to other or self, hospitalizaiton indic	3(<0.1)				
		Change, adversely affecting subject or family	90(1.1)				
		Change, but not adversely affecting subject or family	142(1.8)				
		Mental health intervention indicated	21(0.3)				
		<i>Missing</i>	830(10.3)				
		Skipped	6988(86.5)				
B24a. How often: Trouble sleeping	SLEEP_OFT	<i>Missing</i>	830(10.3)				
		None/not at all	2315(28.7)				
		Often	189(2.3)				
		rarely	198(2.5)				
		Skipped	4319(53.5)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Sometimes	223(2.8)				
B24b. How much bother: Trouble sleeping	SLEEP_BOT	<i>Missing</i>	1(<0.1)				
		Difficulty sleeping, interfering with function but not	185(2.3)				
		Frequent difficulty sleeping, interfering with activity	22(0.3)				
		<i>Missing</i>	830(10.3)				
		Occasional difficulty with sleeping	402(5.0)				
		Skipped	6634(82.2)				
B25a. How often: Nightmares	NIGHT_OFT	<i>Missing</i>	830(10.3)				
		None/not at all	2361(29.2)				
		Often	67(0.8)				
		rarely	327(4.1)				
		Skipped	4319(53.5)				
		Sometimes	170(2.1)				
B25b. How much bother: Nightmares	NIGHT_BOT	Mild	405(5.0)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		<i>Missing</i>	830(10.3)				
		Moderate	137(1.7)				
		Severe	22(0.3)				
		Skipped	6680(82.7)				
B26a. How often: Tiredness or lack of energy	TIRED_OFT	<i>Missing</i>	830(10.3)				
		None/not at all	1999(24.8)				
		Often	231(2.9)				
		rarely	291(3.6)				
		Skipped	4319(53.5)				
		Sometimes	404(5.0)				
B26b. How much bother: Tiredness or lack of energy	TIRED_BOT	Disabling	1(<0.1)				
		Mild fatigue over baseline	690(8.5)				
		<i>Missing</i>	830(10.3)				
		Moderate or causing difficulty performing some activit	220(2.7)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Severe fatigue interfering with activiteis of daily li	15(0.2)				
		Skipped	6318(78.3)				
B27. How many other symptoms to report?	OTHSX_NUM		830(10.3)				
		0	5681(70.4)				
		1	1138(14.1)				
		2	287(3.6)				
		3	82(1.0)				
		4	31(0.4)				
		5	15(0.2)				
		6	4(<0.1)				
		7	3(<0.1)				
		8	3(<0.1)				
B27b1.Other symptom code	OTHSX_CODE_0		6511(80.6)				
		10000085	20(0.2)				
		10000510	7(0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
	10001497		11(0.1)				
	10001760		5(0.1)				
	10002646		7(0.1)				
	10002855		16(0.2)				
	10003239		51(0.6)				
	10003815		1(<0.1)				
	10003988		37(0.5)				
	10005063		1(<0.1)				
	10006461		1(<0.1)				
	10006485		3(<0.1)				
	10006487		1(<0.1)				
	10008479		58(0.7)				
	10008496		21(0.3)				
	10008796		1(<0.1)				
	10010741		1(<0.1)				
	10010774		10(0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
	10010922		1(<0.1)				
	10011224		25(0.3)				
	10011985		1(<0.1)				
	10012174		2(<0.1)				
	10012378		21(0.3)				
	10012457		7(0.1)				
	10012745		9(0.1)				
	10013573		1(<0.1)				
	10013775		1(<0.1)				
	10013786		1(<0.1)				
	10013911		2(<0.1)				
	10013946		7(0.1)				
	10013950		1(<0.1)				
	10013968		1(<0.1)				
	10014012		2(<0.1)				
	10014020		1(<0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
	10014080		2(<0.1)				
	10015090		61(0.8)				
	10015218		1(<0.1)				
	10015832		7(0.1)				
	10015958		6(0.1)				
	10016256		92(1.1)				
	10016766		2(<0.1)				
	10016825		4(<0.1)				
	10017089		11(0.1)				
	10017574		7(0.1)				
	10017636		1(<0.1)				
	10017869		2(<0.1)				
	10018000		4(<0.1)				
	10018800		1(<0.1)				
	10018854		1(<0.1)				
	10019022		1(<0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
	10019211		198(2.5)				
	10019245		2(<0.1)				
	10020413		4(<0.1)				
	10020755		3(<0.1)				
	10020782		2(<0.1)				
	10020996		1(<0.1)				
	10021099		1(<0.1)				
	10021113		2(<0.1)				
	10021143		1(<0.1)				
	10021930		2(<0.1)				
	10022004		15(0.2)				
	10022437		18(0.2)				
	10023212		8(0.1)				
	10023215		1(<0.1)				
	10023879		1(<0.1)				
	10027175		2(<0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
	10027339		1(<0.1)				
	10028351		2(<0.1)				
	10028411		16(0.2)				
	10028813		12(0.1)				
	10028836		7(0.1)				
	10029226		1(<0.1)				
	10033091		1(<0.1)				
	10033314		1(<0.1)				
	10033425		33(0.4)				
	10033470		3(<0.1)				
	10033557		50(0.6)				
	10034264		2(<0.1)				
	10034310		1(<0.1)				
	10034537		1(<0.1)				
	10034620		2(<0.1)				
	10034719		7(0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
	10034754		1(<0.1)				
	10034835		2(<0.1)				
	10034844		6(0.1)				
	10034962		2(<0.1)				
	10035725		1(<0.1)				
	10035755		1(<0.1)				
	10035762		2(<0.1)				
	10036018		5(0.1)				
	10036520		1(<0.1)				
	10037087		8(0.1)				
	10037660		20(0.2)				
	10038848		2(<0.1)				
	10039087		16(0.2)				
	10039722		5(0.1)				
	10040752		1(<0.1)				
	10040756		7(0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
	10040865		1(<0.1)				
	10040904		1(<0.1)				
	10042101		10(0.1)				
	10042667		6(0.1)				
	10043882		1(<0.1)				
	10044035		7(0.1)				
	10044055		1(<0.1)				
	10044565		6(0.1)				
	10044684		1(<0.1)				
	10046528		1(<0.1)				
	10046543		7(0.1)				
	10046574		2(<0.1)				
	10046749		8(0.1)				
	10046901		1(<0.1)				
	10047513		1(<0.1)				
	10047706		18(0.2)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
	10047895		3(<0.1)				
	10048038		1(<0.1)				
	10048294		3(<0.1)				
	10049083		1(<0.1)				
	10051077		1(<0.1)				
	10052558		2(<0.1)				
	10057668		8(0.1)				
	10058802		1(<0.1)				
	90004000		2(<0.1)				
	90004002		2(<0.1)				
	90004028		16(0.2)				
	90004038		37(0.5)				
	90004042		15(0.2)				
	90004050		30(0.4)				
	90004058		3(<0.1)				
	90004068		37(0.5)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
	90004076		26(0.3)				
	90004078		27(0.3)				
	90004080		23(0.3)				
	90004082		20(0.2)				
	90004084		32(0.4)				
	90004086		7(0.1)				
	90004092		2(<0.1)				
	90004094		1(<0.1)				
	90030124		1(<0.1)				
	90030148		1(<0.1)				
	90030150		1(<0.1)				
	90030164		1(<0.1)				
	90030172		1(<0.1)				
	90030186		1(<0.1)				
	90030192		1(<0.1)				
	90030220		1(<0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
	90030266		1(<0.1)				
	90030288		1(<0.1)				
	90030328		2(<0.1)				
	90030338		1(<0.1)				
	90030370		3(<0.1)				
	90030388		1(<0.1)				
	90030392		4(<0.1)				
	90030410		1(<0.1)				
	90030418		1(<0.1)				
	90030426		10(0.1)				
	90030436		1(<0.1)				
	90030454		6(0.1)				
	90030466		6(0.1)				
	90030468		1(<0.1)				
	90030486		68(0.8)				
	90030492		6(0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		90030506	5(0.1)				
		90030508	4(<0.1)				
		90030526	1(<0.1)				
		90030530	2(<0.1)				
		90030532	1(<0.1)				
		90030566	2(<0.1)				
		90030582	20(0.2)				
		90030714	1(<0.1)				
		90030952	1(<0.1)				
		90030982	14(0.2)				
B27b2.Other symptom code	OTHSX_CODE_1		7649(94.7)				
		10000085	10(0.1)				
		10000510	2(<0.1)				
		10001497	2(<0.1)				
		10002646	3(<0.1)				
		10002855	3(<0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
	10003127		1(<0.1)				
	10003239		3(<0.1)				
	10003263		1(<0.1)				
	10003988		10(0.1)				
	10006002		4(<0.1)				
	10008479		14(0.2)				
	10008496		2(<0.1)				
	10010305		2(<0.1)				
	10010741		1(<0.1)				
	10010774		2(<0.1)				
	10011224		24(0.3)				
	10012174		1(<0.1)				
	10012378		7(0.1)				
	10012457		1(<0.1)				
	10012745		4(<0.1)				
	10013786		1(<0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
	10014080		2(<0.1)				
	10015090		8(0.1)				
	10015535		2(<0.1)				
	10015832		1(<0.1)				
	10015936		1(<0.1)				
	10015958		3(<0.1)				
	10016256		18(0.2)				
	10016288		2(<0.1)				
	10016766		1(<0.1)				
	10017089		5(0.1)				
	10017574		1(<0.1)				
	10018876		3(<0.1)				
	10019211		23(0.3)				
	10020603		1(<0.1)				
	10021099		1(<0.1)				
	10021113		2(<0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
	10022004		1(<0.1)				
	10022437		5(0.1)				
	10023332		1(<0.1)				
	10028411		3(<0.1)				
	10028813		12(0.1)				
	10028836		2(<0.1)				
	10030180		1(<0.1)				
	10031009		1(<0.1)				
	10033091		1(<0.1)				
	10033425		17(0.2)				
	10033470		2(<0.1)				
	10033557		6(0.1)				
	10033656		1(<0.1)				
	10034264		1(<0.1)				
	10034580		1(<0.1)				
	10034719		2(<0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
	10034835		1(<0.1)				
	10034844		3(<0.1)				
	10036520		1(<0.1)				
	10037032		1(<0.1)				
	10037087		2(<0.1)				
	10037660		12(0.1)				
	10039087		4(<0.1)				
	10039722		1(<0.1)				
	10040752		2(<0.1)				
	10040756		3(<0.1)				
	10042101		5(0.1)				
	10042667		4(<0.1)				
	10044035		5(0.1)				
	10047513		1(<0.1)				
	10047706		7(0.1)				
	10051077		1(<0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
	10057668		1(<0.1)				
	90004000		1(<0.1)				
	90004002		2(<0.1)				
	90004028		1(<0.1)				
	90004038		16(0.2)				
	90004042		7(0.1)				
	90004050		10(0.1)				
	90004058		3(<0.1)				
	90004068		6(0.1)				
	90004076		3(<0.1)				
	90004078		8(0.1)				
	90004080		8(0.1)				
	90004082		6(0.1)				
	90004084		17(0.2)				
	90004092		1(<0.1)				
	90030228		1(<0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
	90030288		1(<0.1)				
	90030370		1(<0.1)				
	90030392		1(<0.1)				
	90030410		1(<0.1)				
	90030418		1(<0.1)				
	90030426		9(0.1)				
	90030440		1(<0.1)				
	90030454		3(<0.1)				
	90030466		2(<0.1)				
	90030468		1(<0.1)				
	90030486		17(0.2)				
	90030492		1(<0.1)				
	90030506		1(<0.1)				
	90030510		1(<0.1)				
	90030582		7(0.1)				
	90030982		4(<0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
B27b3.Other symptom code	OTHSX_CODE_2		7936(98.3)				
	10000085		2(<0.1)				
	10001497		1(<0.1)				
	10001760		1(<0.1)				
	10002646		1(<0.1)				
	10003988		3(<0.1)				
	10006002		1(<0.1)				
	10008496		2(<0.1)				
	10010774		2(<0.1)				
	10011224		13(0.2)				
	10012174		1(<0.1)				
	10012378		2(<0.1)				
	10012745		2(<0.1)				
	10013036		1(<0.1)				
	10013573		1(<0.1)				
	10013911		1(<0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
	10016256		6(0.1)				
	10017574		1(<0.1)				
	10017822		1(<0.1)				
	10018000		1(<0.1)				
	10018876		2(<0.1)				
	10019211		6(0.1)				
	10020603		1(<0.1)				
	10020782		1(<0.1)				
	10021113		1(<0.1)				
	10022437		1(<0.1)				
	10028411		2(<0.1)				
	10028813		4(<0.1)				
	10028836		1(<0.1)				
	10030180		1(<0.1)				
	10033425		4(<0.1)				
	10033470		1(<0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
	10033557		1(<0.1)				
	10033656		1(<0.1)				
	10034719		1(<0.1)				
	10034844		2(<0.1)				
	10037660		1(<0.1)				
	10040739		1(<0.1)				
	10042101		1(<0.1)				
	10042667		2(<0.1)				
	10043882		1(<0.1)				
	10044035		1(<0.1)				
	10047513		3(<0.1)				
	10047706		4(<0.1)				
	10047895		2(<0.1)				
	10048294		1(<0.1)				
	10057668		1(<0.1)				
	90004002		2(<0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
	90004028		1(<0.1)				
	90004038		2(<0.1)				
	90004042		3(<0.1)				
	90004068		3(<0.1)				
	90004078		4(<0.1)				
	90004080		4(<0.1)				
	90004084		4(<0.1)				
	90004094		1(<0.1)				
	90030006		1(<0.1)				
	90030370		1(<0.1)				
	90030418		1(<0.1)				
	90030426		1(<0.1)				
	90030454		4(<0.1)				
	90030468		1(<0.1)				
	90030486		9(0.1)				
	90030582		5(0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
B27b4.Other symptom code	OTHSX_CODE_3		8018(99.3)				
	10001497		1(<0.1)				
	10002855		4(<0.1)				
	10003239		2(<0.1)				
	10003988		1(<0.1)				
	10008479		1(<0.1)				
	10010774		2(<0.1)				
	10011224		2(<0.1)				
	10012174		1(<0.1)				
	10012378		1(<0.1)				
	10012745		1(<0.1)				
	10015958		1(<0.1)				
	10016256		2(<0.1)				
	10017089		1(<0.1)				
	10019211		3(<0.1)				
	10020755		1(<0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
	10022998		1(<0.1)				
	10023879		2(<0.1)				
	10028411		2(<0.1)				
	10028813		2(<0.1)				
	10034844		1(<0.1)				
	10039087		1(<0.1)				
	10040752		1(<0.1)				
	10042101		1(<0.1)				
	10046543		3(<0.1)				
	10046910		1(<0.1)				
	10047706		2(<0.1)				
	10048294		1(<0.1)				
	90004002		1(<0.1)				
	90004028		1(<0.1)				
	90004042		3(<0.1)				
	90004078		1(<0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		90004086	1(<0.1)				
		90030454	1(<0.1)				
		90030468	1(<0.1)				
		90030486	2(<0.1)				
		90030582	3(<0.1)				
B27b5.Other symptom code	OTHSX_CODE_4		8049(99.7)				
		10000510	1(<0.1)				
		10002855	1(<0.1)				
		10003988	2(<0.1)				
		10012457	1(<0.1)				
		10012745	1(<0.1)				
		10016256	1(<0.1)				
		10022437	1(<0.1)				
		10028411	2(<0.1)				
		10028813	1(<0.1)				
		10037660	1(<0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		10039087	1(<0.1)				
		10042101	2(<0.1)				
		10047706	3(<0.1)				
		90004002	1(<0.1)				
		90004050	3(<0.1)				
		90004080	1(<0.1)				
		90030426	1(<0.1)				
		90030486	1(<0.1)				
B27b6.Other symptom code	OTHSX_CODE_5		8064(99.9)				
		10012457	1(<0.1)				
		10016256	4(<0.1)				
		10019211	1(<0.1)				
		10037660	1(<0.1)				
		90004082	1(<0.1)				
		90030486	2(<0.1)				
B27b7.Other symptom code	OTHSX_CODE_6		8068(99.9)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		10003239	1(<0.1)				
		10019211	1(<0.1)				
		10022004	1(<0.1)				
		10033091	1(<0.1)				
		10042667	1(<0.1)				
		90004084	1(<0.1)				
B27b8.Other symptom code	OTHSX_CODE_7		8071(100.0)				
		10014020	1(<0.1)				
		10019211	1(<0.1)				
		90030582	1(<0.1)				
B27c1.How often have you had	OTHSX_OFT_0	Unknown	1(<0.1)				
		Missing	1(<0.1)				
		Missing	6511(80.6)				
		Often	391(4.8)				
		rarely	627(7.8)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Sometimes	543(6.7)				
B27c2.How often have you had	OTHSX_OFT_1	Missing	7649(94.7)				
		Often	98(1.2)				
		rarely	176(2.2)				
		Sometimes	151(1.9)				
B27c3.How often have you had	OTHSX_OFT_2	Missing	7936(98.3)				
		Often	32(0.4)				
		rarely	59(0.7)				
		Sometimes	47(0.6)				
B27c4.How often have you had	OTHSX_OFT_3	Missing	8018(99.3)				
		Often	25(0.3)				
		rarely	20(0.2)				
		Sometimes	11(0.1)				
B27c5.How often have you had	OTHSX_OFT_4	Missing	8049(99.7)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		Often	3(<0.1)				
		rarely	12(0.1)				
		Sometimes	10(0.1)				
B27c6.How often have you had	OTHSX_OFT_5	Missing	8064(99.9)				
		Often	2(<0.1)				
		rarely	5(0.1)				
		Sometimes	3(<0.1)				
B27c7.How often have you had	OTHSX_OFT_6	Missing	8068(99.9)				
		rarely	3(<0.1)				
		Sometimes	3(<0.1)				
B27c8.How often have you had	OTHSX_OFT_7	Missing	8071(100.0)				
		rarely	2(<0.1)				
		Sometimes	1(<0.1)				
B27d1. Grade	OTHSX_BOT_0	GRADE 1	814(10.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		GRADE 2	603(7.5)				
		GRADE 3	133(1.6)				
		GRADE 4	11(0.1)				
		<i>Missing</i>	6512(80.7)				
		UNKNOWN	1(<0.1)				
B27d2. Grade	OTHSX_BOT_1	GRADE 1	240(3.0)				
		GRADE 2	154(1.9)				
		GRADE 3	25(0.3)				
		GRADE 4	6(0.1)				
		<i>Missing</i>	7649(94.7)				
B27d3. Grade	OTHSX_BOT_2	GRADE 1	82(1.0)				
		GRADE 2	48(0.6)				
		GRADE 3	6(0.1)				
		GRADE 4	2(<0.1)				
		<i>Missing</i>	7936(98.3)				
B27d4. Grade	OTHSX_BOT_3	GRADE 1	28(0.3)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		GRADE 2	24(0.3)				
		GRADE 3	3(<0.1)				
		GRADE 4	1(<0.1)				
		<i>Missing</i>	8018(99.3)				
B27d5. Grade	OTHSX_BOT_4	GRADE 1	17(0.2)				
		GRADE 2	8(0.1)				
		<i>Missing</i>	8049(99.7)				
B27d6. Grade	OTHSX_BOT_5	GRADE 1	6(0.1)				
		GRADE 2	4(<0.1)				
		<i>Missing</i>	8064(99.9)				
B27d7. Grade	OTHSX_BOT_6	GRADE 1	3(<0.1)				
		GRADE 2	3(<0.1)				
		<i>Missing</i>	8068(99.9)				
B27d8. Grade	OTHSX_BOT_7	GRADE 1	1(<0.1)				
		GRADE 2	2(<0.1)				

Marfan Data Codebook
A116: Adverse Drug Reaction Questionnaire
(raw data)

DATE CREATED 13SEP18

Number of Observations: 8074

Number of Variables: 92

Organization of file: Up to 21 Records per Patient

Variable Label (VAR)	Variable Name	Category	N(%)	N(Missing)	Mean(SD)	Median(Q1,Q3)	Range of Values
		<i>Missing</i>	8071(100.0)				
Form Version	VER_ID		830(10.3)				
		A	7244(89.7)				