

Section 2

Demographics

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Participants

In this PEEK study, a total of 407 participants with rare diseases or carers to people with rare diseases were recruited into the study. There were 5 that completed or partially completed online questionnaires only and 10 participants that completed the interview only. There were 96 participants (23.59%) with diseases of the nervous system, 96 participants (23.59%) with endocrine, nutritional or metabolic diseases, 81 participants (16.71%) with diseases of the immune system, 68 participants (16.71%) with developmental anomalies, 34 participants (7.86%) with other rare condition, and 32 participants (7.86%) with diseases of the skin.

Demographics

There were 407 people with that took part in this study, 299 were females (73.83%). Participants were aged from infant to over 75 years of age, most were aged between 35 to 64 years (n=232, 64.09%).

Participants were most commonly from New South Wales (n=124, 30.47%), Queensland (n=92, 22.60%), and Victoria (n=91, 22.36%). Most participants were from major cities (n=295, 72.48%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 204 participants (49.88%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 203 participants (50.12%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

There were 201 participants (50.38%) that had completed university to at least an associate degree. There were 163 participants who were employed either full time (24.56%), or part time (23.10%). Almost half of the participants were carers to family members or spouses (n=192, 53.04%), and just under half of the participants carers to children (n=155, 42.82%).

Other health conditions

Participants were asked about health conditions, other than their rare disease that they had to manage. Participants could choose from a list of common health conditions and could specify other conditions.

The majority of participants had at least one other condition that they had to manage (n=287, 93.79%), the maximum number reported was 16 other conditions, with a median of 4.00 other conditions (IQR = 5.00). The most commonly reported health condition was anxiety (n=173, 56.54%), followed by sleep problems or insomnia (n=169, 55.23%), chronic pain (n=154, 50.33%), and depression (n=132, 43.14%).

Subgroup analysis

Comparisons were made by condition. There were 67 participants (16.46%) with developmental anomalies, 82 participants (20.15%) with diseases of the immune system, 99 participants (24.32%) with diseases of the nervous system, 32 participants (7.86%) with diseases of the skin, 95 participants (23.34%) with endocrine, nutritional or metabolic diseases, and 32 participants (7.86%) with other rare condition.

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function.

The overall scores for the cohort were in the second highest quintile for **SF36 Role functioning/emotional** (median=66.67, IQR=100.00), **SF36 Emotional well-being** (median=68.00, IQR=27.00), indicating good emotional role functioning, good emotional well-being.

The overall scores for the cohort were in the middle quintile for **SF36 Physical functioning** (median=55.00, IQR=60.00), **SF36 Social functioning** (median=50.00, IQR=50.00), **SF36 Pain** (median=55.00, IQR=45.00), **SF36 Health change** (median=50.00, IQR=25.00), indicating moderate physical functioning, moderate social functioning, moderate pain, about the same as a year ago.

The overall scores for the cohort were in the second lowest quintile for **SF36 Role functioning/physical** (median=25.00, IQR=100.00), **SF36 Energy/Fatigue** (median=30.00, IQR=35.00), **SF36 General health** (median=40.00, IQR=35.00), indicating poor physical role functioning, poor energy, poor general health.

Comparisons of SF36 have been made based on condition, participant type, gender, age, education, location and socioeconomic status.

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were moderately limited for participants in this study.

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, physical health often interfered with work or other activities for participants in this study.

SF36 Role functioning/emotional scale measures how emotional problems interfere with work or other activities. On average, emotional problems sometimes interfered with work or other activities for participants in this study.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants were often fatigued.

The **SF36 Emotional well-being** scale measures how a person feels, for example happy, calm, depressed or anxious. On average, participants had good emotional well-being.

The **SF36 Social functioning** scale measures limitations on social activities due to physical or emotional problems. On average, social activities were moderately limited for participants in this study.

The **SF36 Pain** scale measures how much pain, and how pain interferes with work and other activities. On average, participants had moderate pain.

The **SF36 General health** scale measures perception of health. On average, participants reported poor health.

The **SF36 Health change** scale measures health compared to a year ago. On average, participants reported that their health is about the same as a year ago.

Participants

In this PEEK study, a total of 402 participants with rare diseases or carers to people with rare diseases were recruited into the study. There were 5 that completed or partially completed online questionnaires only and 10 participants that completed the interview only.

There were 96 participants (23.59%) with diseases of the nervous system, 96 participants (23.59%) with

endocrine, nutritional or metabolic diseases, 81 participants (16.71%) with diseases of the immune system, 68 participants (16.71%) with developmental anomalies, 34 participants (7.86%) with other rare condition, and 32 participants (7.86%) with diseases of the skin.

Table 2.1: Participants

Participants and diagnosis	Number (n=407)	Percent
Diseases of the nervous system	96	23.59
Endocrine, nutritional or metabolic diseases	96	23.59
Diseases of the immune system	81	19.90
Developmental anomalies	68	16.71
Other rare condition	34	8.35
Diseases of the skin	32	7.86

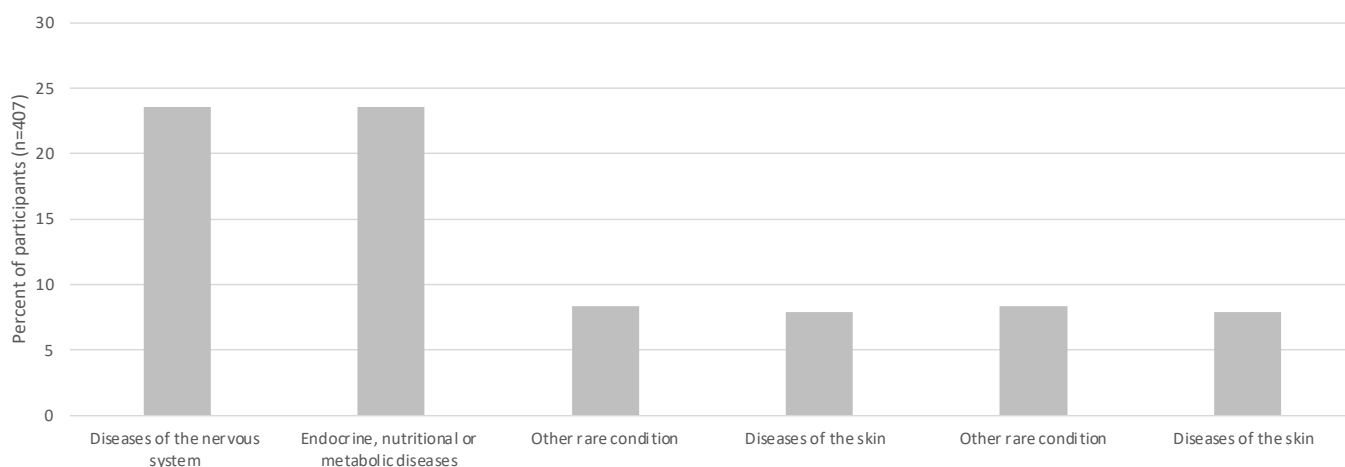


Figure 2.1: Participants

Demographics

There were 407 people with rare diseases that took part in this study, 299 were females (73.83%). Participants were aged from infant to over 75 years of age, most were aged between 35 to 64 years (n=232, 64.09%).

Participants were most commonly from New South Wales (n=124, 30.47%), Queensland (n=92, 22.60%), and Victoria (n=91, 22.36%). Most participants were from major cities (n=295, 72.48%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 204 participants (49.88%) from an area with a high SEIFA

score of 7 to 10 (more advantage), and 203 participants (50.12%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

There were 201 participants (50.38%) that had completed university to at least an associate degree. There were 163 participants who were employed either full time (24.56%), or part time (23.10%).

Almost half of the participants were carers to family members or spouses (n=192, 53.04%), most commonly carers to Children (n=155, 42.82%). The demographics of participants are listed in Table 2.2.

Table 2.2: Demographics

Demographic	Definition	Number	Percent
Gender (n=405)	Female	299	73.83
	Male	106	26.17
Age of person with condition (n=407)	Aged under 18	98	24.08
	18 to 24	14	3.44
	25 to 34	61	14.99
	35 to 44	58	14.25
	45 to 54	55	13.51
	55 to 64	61	14.99
	65 to 74	43	10.57
	75+	17	4.18
Location (n=407)	Major Cities of Australia	295	72.48
	Inner Regional Australia	77	18.92
	Outer Regional Australia	30	7.37
	Remote and very remote Australia	5	1.23
State (n=407)	Australian Capital Territory	14	3.44
	New South Wales	124	30.47
	Northern Territory	1	0.25
	Queensland	92	22.60
	South Australia	33	8.11
	Tasmania	10	2.46
	Victoria	91	22.36
	Western Australia	42	10.32
Socio-Economic Indexes for Areas (SEIFA) (n=407)	1	31	7.62
	2	27	6.63
	3	24	5.90
	4	29	7.13
	5	36	8.85
	6	56	13.76
	7	28	6.88
	8	49	12.04
	9	65	15.97
	10	62	15.23
Race/ethnicity (n=387)	Caucasian/White	350	90.44
	Asian	9	2.33
	Indigenous Australian/Torres Strait Islander	8	2.07
	Mixed race	6	1.55
	Pacific Islander	4	1.03
	Other	10	2.58
Education (n=399)	Less than high school degree	22	5.51
	High school degree or equivalent	70	17.54
	Some college but no degree	66	16.54
	Trade	34	8.52
	Trade or high school (Not specified)	6	1.50
	Associate degree	17	4.26
	Bachelor degree	97	24.31
	Graduate degree	78	19.55
	University (not specified)	9	2.26
Employment (n=342)	Currently receiving Centrelink support	44	12.87
	Disabled, unable to work	56	16.37
	Employed, working full time	84	24.56
	Employed, working part time	79	23.10
	Self employed	5	1.46
	Work in casual employment	10	2.92
	Engage in voluntary work	13	3.80
	Full/part time carer	34	9.94
	Full/part time study	16	4.68
	Not employed, looking for work	10	2.92
	Not employed, not looking for work	8	2.34
	Retired	63	18.42
Carer status (n=362)	I am not a carer	170	46.96
	Children	155	42.82
	Parents	20	5.52
	Spouse/Partner	19	5.25
	Grandchildren	14	3.87
	Other	6	1.66

Other health conditions

Participants were asked about health conditions, other than their primary rare disease that they had to manage. Participants could choose from a list of common health conditions and could specify other conditions.

The majority of participants had at least one other condition that they had to manage (n=287, 93.79%),

the maximum number reported was 16 other conditions, with a median of 4.00 other conditions (IQR = 5.00). The most commonly reported health condition was anxiety (n=173, 56.54%), followed by sleep problems or insomnia (n=169, 55.23%), chronic pain (n=154, 50.33%), and depression (n=132, 43.14%).

Table 2.3: Number of other health conditions

Number of other conditions	Number (n=306)	Percent
No other conditions	19	6.21
1 to 2	56	18.30
3 to 4	62	20.26
5 to 6	65	21.24
7 to 8	48	15.69
9 to 10	28	9.15
11 or more	28	9.15

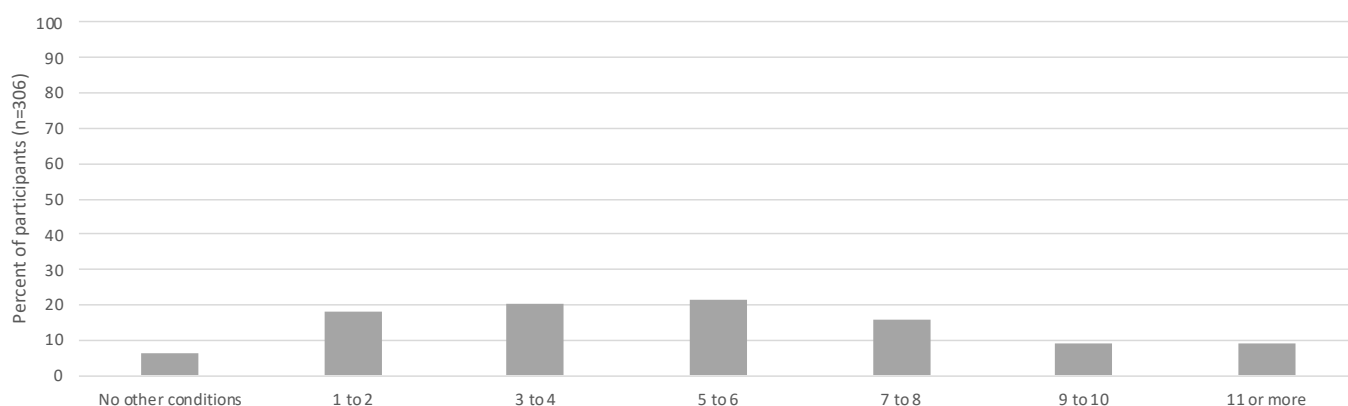


Figure 2.2: Number of other health conditions

Table 2.4: Other health conditions

Other conditions	Number (n=306)	Percent
Anxiety (Total)	173	56.54
Do you have anxiety (self diagnosed)	113	36.93
Do you have anxiety (diagnosed by a doctor)	106	34.64
Sleep problems or insomnia	169	55.23
Chronic pain	154	50.33
Depression (Total)	132	43.14
Depression (Self diagnosed)	74	24.18
Depression (Diagnosed by a doctor)	83	27.12
Arthritis	100	32.68
Hypertension	68	22.22
Asthma	49	16.01
High cholesterol	39	12.75
Atrial fibrillation	38	12.42
CODP (Chronic obstructive pulmonary disease)	22	7.19
Diabetes	22	7.19
Cancer	22	7.19
Stroke	16	5.23
Arrhythmias	15	4.90
Angina	14	4.58
Chronic heart failure	11	3.59
Chronic kidney disease	5	1.63

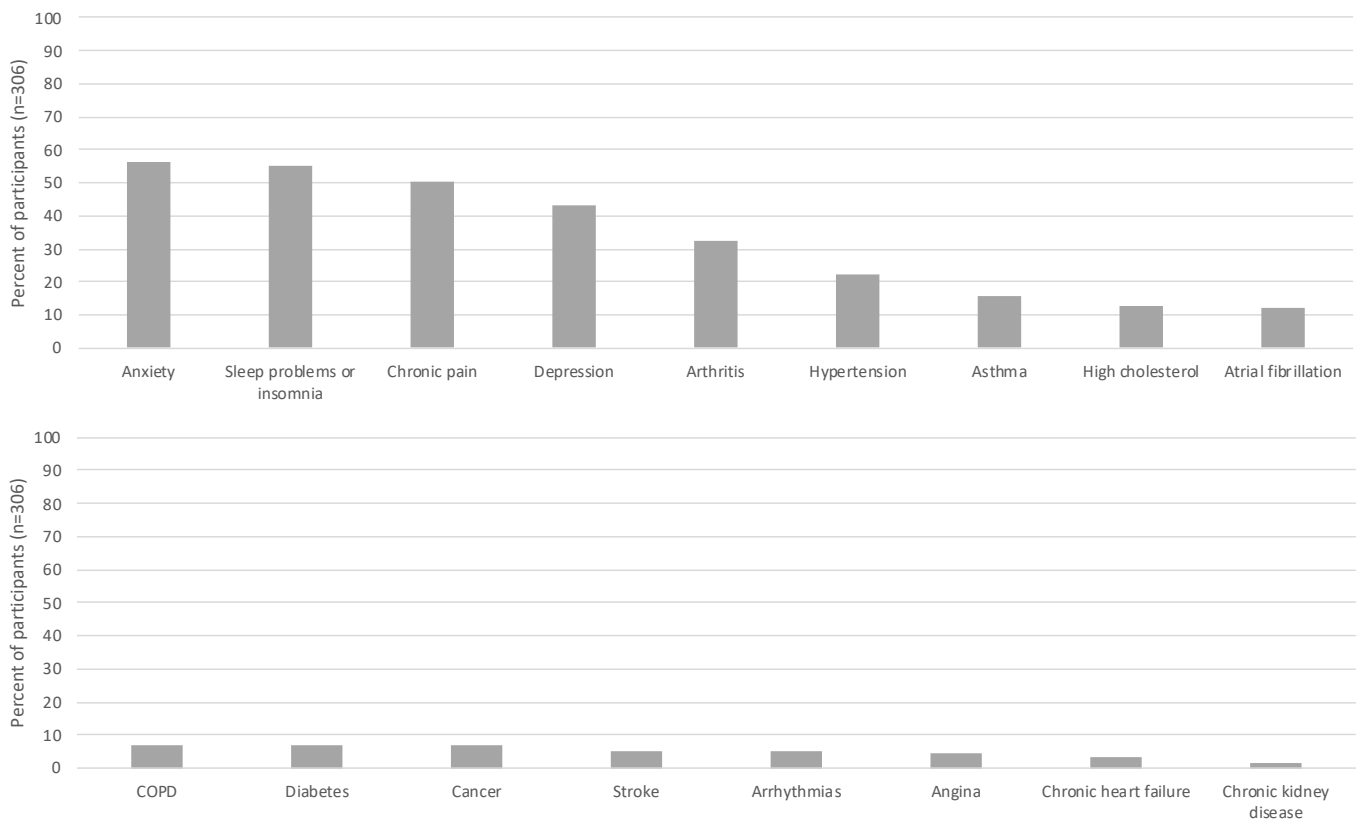


Figure 2.3: Other health conditions (% of all participants)

Subgroup analysis

Subgroup analysis are included throughout the study and the subgroups are listed in Table 2.5.

Comparisons were made by **condition**. There were 67 participants (16.46%) with developmental anomalies, 82 participants (20.15%) with diseases of the immune system, 99 participants (24.32%) with diseases of the nervous system, 32 participants (7.86%) with diseases of the skin, 95 participants (23.34%) with endocrine, nutritional or metabolic diseases, and 32 participants (7.86%) with other rare conditions.

Comparisons were made by **type of participant** there were 272 participants (66.83%) people with the condition themselves and 135 participants (33.17%) that were carers.

Comparisons were made by **gender**, there were 299 female participants (73.83%), and 106 male participants (26.17%).

Comparisons were made by **age** of person with condition. There were 99 participants (24.32%) aged

under 18, 132 participants (32.43%) aged 18 to 44, 116 participants (28.50%) aged 45 to 64, and 60 participants (14.74%) aged 65 or older.

Comparisons were made by **education** status, between those with trade or high school qualifications (n=198, 49.62%), and those with a university qualification (n=201, 50.38%).

The **location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional or remote areas (n=112, 27.52%) were compared to those living in a metropolitan area (n=295, 72.48%).

Comparisons were made by **socioeconomic status**, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6 (n=203, 49.88%) compared to those with a higher SEIFA score of 7-10 (n=204, 50.12%).

Table 2.5: Subgroups

Subgroup	Definition	Number	Percent
Condition (n=407)	Developmental anomalies	67	16.46
	Diseases of the immune system	82	20.15
	Diseases of the nervous system	99	24.32
	Diseases of the skin	32	7.86
	Endocrine, nutritional or metabolic diseases	95	23.34
	Other rare condition	32	7.86
	Participant type (n=407)	Person with condition	272
	Carer	135	33.17
Gender (n=405)	Female	299	73.83
	Male	106	26.17
Age of person with condition (n=407)	Aged under 18	99	24.32
	Aged 18 to 44	132	32.43
	Aged 45 to 64	116	28.50
	Aged 65 or older	60	14.74
Education (n=399)	Trade or high school	198	49.62
	University	201	50.38
Location (n=404)	Regional or remote	112	27.52
	Metropolitan	295	72.48
Socioeconomic status (n=404)	Mid to low status	203	49.88
	Higher status	204	50.12

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function.

Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 2.6, for scales with a normal distribution, the mean and SD should be used as a central measure, and median and IQR for scales that do not have a normal distribution.

The overall scores for the cohort were in the second highest quintile for **SF36 Role functioning/emotional** (median=66.67, IQR=100.00), **SF36 Emotional well-being** (median=68.00, IQR=27.00), indicating good emotional role functioning, good emotional well-being.

The overall scores for the cohort were in the middle quintile for **SF36 Physical functioning** (median=55.00, IQR=60.00), **SF36 Social functioning** (median=50.00, IQR=50.00), **SF36 Pain** (median=55.00, IQR=45.00), **SF36 Health change** (median=50.00, IQR=25.00), indicating moderate physical functioning, moderate social functioning, moderate pain, about the same as a year ago.

The overall scores for the cohort were in the second lowest quintile for **SF36 Role functioning/physical** (median=25.00, IQR=100.00), **SF36 Energy/Fatigue** (median=30.00, IQR=35.00), **SF36 General health** (median=40.00, IQR=35.00), indicating poor physical role functioning, poor energy, poor general health.

Comparisons of SF36 have been made based on condition, participant type, gender, age, education, location and socioeconomic status.

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were moderately limited for participants in this study.

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, physical health often interfered with work or other activities for participants in this study.

SF36 Role functioning/emotional scale measures how emotional problems interfere with work or other activities. On average, emotional problems sometimes interfered with work or other activities for participants in this study.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants were often fatigued.

The **SF36 Emotional well-being** scale measures how a person feels, for example happy, calm, depressed or anxious. On average, participants had good emotional well-being.

The **SF36 Social functioning** scale measures limitations on social activities due to physical or emotional problems. On average, social activities were moderately limited for participants in this study.

The **SF36 Pain** scale measures how much pain, and how pain interferes with work and other activities. On average, participants had moderate pain.

The **SF36 General health** scale measures perception of health. On average, participants reported poor health.

The **SF36 Health change** scale measures health compared to a year ago. On average, participants reported that their health is about the same as a year ago.

Table 2.6: SF36 summary statistics

SF36 scale (n=383)	Mean	SD	Median	IQR	Possible range	Quintile
Physical functioning	54.32	32.69	55.00	60.00	0 to 100	3
Role functioning/physical	37.24	42.78	25.00	100.00	0 to 100	2
Role functioning/emotional	51.22	44.24	66.67	100.00	0 to 100	4
Energy/Fatigue	33.69	22.61	30.00	35.00	0 to 100	2
Emotional well-being	64.09	20.06	68.00	27.00	0 to 100	4
Social functioning	53.08	28.79	50.00	50.00	0 to 100	3
Pain	55.69	30.00	55.00	45.00	0 to 100	3
General health	41.64	24.02	40.00	35.00	0 to 100	2
Health change	44.76	24.74	50.00	25.00	0 to 100	3

Skewed distribution, use median and IQR as central measure. Possible range 0-100

SF36 by condition

Comparisons were made by **condition**. There were 59 participants (15.45%) with developmental anomalies, 77 participants (20.16%) with diseases of the immune system, 93 participants (24.35%) with diseases of the nervous system, 30 participants (7.85%) with diseases of the skin, 95 participants (24.87%) with endocrine, nutritional or metabolic diseases, and 28 participants (7.33%) with other rare condition.

Where the assumptions for normality of residuals were not met, a Kruskal-Wallis test was used. Post hoc pairwise comparisons using Wilcoxon rank sum test was used to identify the source of any differences identified in the Kruskal -Wallis test.

A Kruskal-Wallis test indicated a statistically significant difference in the SF36 Physical functioningscale between groups, $\chi^2(5) = 41.62$ $p < 0.0001$. The largest significant difference was between Developmental anomalies (median = 80, IQR = 37.5), and Endocrine, nutritional or metabolic diseases (median = 45, IQR = 60, $p < 0.0001$).

A Kruskal-Wallis test indicated a statistically significant difference in the SF36 Role functioning physicalscale between groups, $\chi^2(5) = 40.98$ $p < 0.0001$. The largest significant difference was between Developmental anomalies (median = 75, IQR = 75), and Endocrine, nutritional or metabolic diseases (median = 0, IQR = 50, $p < 0.0001$).

A Kruskal-Wallis test indicated a statistically significant difference in the SF36 Energy/fatiguescale between groups, $\chi^2(5) = 27.73$ $p < 0.0001$. The largest significant difference was between Developmental anomalies (median = 40, IQR = 27.5), and Diseases of the immune system (median = 20, IQR = 30, $p = 0.0008$).

A Kruskal-Wallis test indicated a statistically significant difference in the SF36 Social functioningscale between groups, $\chi^2(5) = 16.89$ $P = 0.0047$. The largest significant difference was between Developmental anomalies (median = 62.5, IQR = 31.25), and Diseases of the immune system (median = 37.5, IQR = 37.5, $p = 0.0085$).

A Kruskal-Wallis test indicated a statistically significant difference in the SF36 Painscale between groups, $\chi^2(5) = 51.6$ $p < 0.0001$. The largest significant difference was between Other rare condition (median = 85, IQR = 30.63), and Diseases of the immune system (median = 45, IQR = 32.5, $p < 0.0001$).

A Kruskal-Wallis test indicated a statistically significant difference in the SF36 General healthscale between groups, $\chi^2(5) = 63.85$ $p < 0.0001$. The largest significant difference was between Developmental anomalies (median = 55, IQR = 35), and Diseases of the immune system (median = 25, IQR = 30, $p < 0.0001$).

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, participants in the Developmental anomalies subgroup scored higher than participants in the Endocrine, nutritional or metabolic diseases subgroup. This indicates that physical activities were slightly limited for participants in the Developmental anomalies subgroup, and were moderately limited for participants in the Endocrine, nutritional or metabolic diseases subgroup.

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, participants in the Developmental anomalies subgroup scored higher than participants in

the Endocrine, nutritional or metabolic diseases subgroup. This indicates that physical health seldom interfered with work or other activities for participants in the Developmental anomalies subgroup, and almost always interfered for participants in the Endocrine, nutritional or metabolic diseases subgroup.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants in the Developmental anomalies subgroup scored higher than participants in the Diseases of the immune system subgroup. This indicates that participants in the Developmental anomalies subgroup were often fatigued, and participants in the Diseases of the immune system subgroup were almost always fatigued.

SF36 Social functioning scale measures limitations on social activities due to physical or emotional problems. On average, participants in the Developmental anomalies subgroup scored higher than participants in the Diseases of the immune system subgroup. This indicates that social activities were moderately limited for participants in the Developmental anomalies subgroup, and limited for participants in the Diseases of the immune system subgroup.

SF36 Pain scale measures how much pain, and how pain interferes with work and other activities. On average, participants in the Other rare condition subgroup scored higher than participants in the Diseases of the immune system subgroup. This indicates that participants in the Other rare condition subgroup had no pain, and participants in the Diseases of the immune system subgroup had moderate pain.

SF36 General health scale measures perception of health. On average, participants in the Developmental anomalies subgroup scored higher than participants in the Diseases of the immune system subgroup. This indicates that participants in the Developmental anomalies subgroup had average health, and participants in the Diseases of the immune system subgroup had poor health.

SF36 Health change scale measures health compared to a year ago. On average, participants in the Developmental anomalies subgroup scored higher than participants in the Endocrine, nutritional or metabolic diseases subgroup. This indicates that participants in the Developmental anomalies subgroup reported that their health was about the same as it was a year ago, and participants in the Endocrine, nutritional or metabolic diseases subgroup reported somewhat worse health.

Table 2.7: SF36 by condition summary statistics and Kruskal Wallis test

SF36 scale	Group	Number (n=379)	Percent	Median	IQR	C ²	dF	p-value
Physical functioning	Developmental anomalies	59	15.45	80.00	37.50	41.62	5	<0.0001*
	Diseases of the immune system	77	20.16	50.00	35.00			
	Diseases of the nervous system	93	24.35	65.00	80.00			
	Diseases of the skin	30	7.85	62.50	50.00			
	Endocrine, nutritional or metabolic diseases	95	24.87	45.00	60.00			
	Other rare condition	28	7.33	80.00	53.75			
Role functioning physical	Developmental anomalies	59	15.45	75.00	75.00	40.98	5	<0.0001*
	Diseases of the immune system	77	20.16	0.00	25.00			
	Diseases of the nervous system	93	24.35	25.00	100.00			
	Diseases of the skin	30	7.85	25.00	50.00			
	Endocrine, nutritional or metabolic diseases	95	24.87	0.00	50.00			
	Other rare condition	28	7.33	62.50	100.00			
Role functioning emotional	Developmental anomalies	59	15.45	66.67	100.00	5.46	5	0.3619
	Diseases of the immune system	77	20.16	33.33	100.00			
	Diseases of the nervous system	93	24.35	66.67	100.00			
	Diseases of the skin	30	7.85	50.00	100.00			
	Endocrine, nutritional or metabolic diseases	95	24.87	33.33	100.00			
	Other rare condition	28	7.33	50.00	100.00			
Energy/fatigue	Developmental anomalies	59	15.45	40.00	27.50	27.73	5	<0.0001*
	Diseases of the immune system	77	20.16	20.00	30.00			
	Diseases of the nervous system	93	24.35	35.00	30.00			
	Diseases of the skin	30	7.85	25.00	33.75			
	Endocrine, nutritional or metabolic diseases	95	24.87	30.00	32.50			
	Other rare condition	28	7.33	47.50	36.25			
Emotional well-being	Developmental anomalies	59	15.45	64.00	20.00	10.79	5	0.0558
	Diseases of the immune system	77	20.16	68.00	24.00			
	Diseases of the nervous system	93	24.35	72.00	28.00			
	Diseases of the skin	30	7.85	56.00	27.00			
	Endocrine, nutritional or metabolic diseases	95	24.87	72.00	20.00			
	Other rare condition	28	7.33	64.00	29.00			
Social functioning	Developmental anomalies	59	15.45	62.50	31.25	16.89	5	0.0047*
	Diseases of the immune system	77	20.16	37.50	37.50			
	Diseases of the nervous system	93	24.35	62.50	37.50			
	Diseases of the skin	30	7.85	50.00	46.88			
	Endocrine, nutritional or metabolic diseases	95	24.87	50.00	50.00			
	Other rare condition	28	7.33	62.50	40.63			
Pain	Developmental anomalies	59	15.45	77.50	35.00	51.60	5	<0.0001*
	Diseases of the immune system	77	20.16	45.00	32.50			
	Diseases of the nervous system	93	24.35	57.50	45.00			
	Diseases of the skin	30	7.85	45.00	35.00			
	Endocrine, nutritional or metabolic diseases	95	24.87	55.00	45.00			
	Other rare condition	28	7.33	85.00	30.63			
General health	Developmental anomalies	59	15.45	55.00	35.00	63.85	5	<0.0001*
	Diseases of the immune system	77	20.16	25.00	30.00			
	Diseases of the nervous system	93	24.35	50.00	25.00			
	Diseases of the skin	30	7.85	30.00	23.75			
	Endocrine, nutritional or metabolic diseases	95	24.87	35.00	32.50			
	Other rare condition	28	7.33	55.00	30.00			
Health change	Developmental anomalies	59	15.45	50.00	0.00	18.62	5	0.0023*
	Diseases of the immune system	77	20.16	50.00	50.00			
	Diseases of the nervous system	93	24.35	50.00	25.00			
	Diseases of the skin	30	7.85	50.00	0.00			
	Endocrine, nutritional or metabolic diseases	95	24.87	25.00	25.00			
	Other rare condition	28	7.33	50.00	0.00			

Table 2.8: SF36 by condition one-way post hoc Wilcoxon rank sum test

SF36 scale		Developmental anomalies	Diseases of the immune system	Diseases of the nervous system	Diseases of the skin	Endocrine, nutritional or metabolic diseases
Physical functioning	Diseases of the immune system	<0.0001*	-	-	-	-
	Diseases of the nervous system	0.0020*	0.1020	-	-	-
	Diseases of the skin	0.0074*	0.1502	0.9606	-	-
	Endocrine, nutritional or metabolic diseases	<0.0001*	0.9606	0.1928	0.2457	-
	Other rare condition	0.6390	0.0020*	0.0520	0.0856	0.0042*
Role functioning/physical	Diseases of the immune system	<0.0001*	-	-	-	-
	Diseases of the nervous system	0.0041*	0.0426*	-	-	-
	Diseases of the skin	0.0041*	0.1454	0.6610	-	-
	Endocrine, nutritional or metabolic diseases	<0.0001*	0.6610	0.0757	0.2746	-
	Other rare condition	0.4843	0.0041*	0.1454	0.1178	0.0048*
Energy/Fatigue	Diseases of the immune system	0.0008*	-	-	-	-
	Diseases of the nervous system	0.2361	0.0037*	-	-	-
	Diseases of the skin	0.0286*	0.5163	0.0994	-	-
	Endocrine, nutritional or metabolic diseases	0.0305*	0.1134	0.1799	0.5407	-
	Other rare condition	0.4522	0.0019	0.0994	0.0286*	0.0286*
Social functioning	Diseases of the immune system	0.0085*	-	-	-	-
	Diseases of the nervous system	0.4338	0.0294	-	-	-
	Diseases of the skin	0.1573	0.5079	0.3404	-	-
	Endocrine, nutritional or metabolic diseases	0.0377*	0.4338	0.1775	0.9651	-
	Other rare condition	0.5079	0.2246	0.9651	0.5079	0.4542
Pain	Diseases of the immune system	<0.0001*	<0.0001*	-	-	-
	Diseases of the nervous system	0.1258	-	-	-	-
	Diseases of the skin	0.0002*	0.8722	0.0027*	-	-
	Endocrine, nutritional or metabolic diseases	0.0027*	0.0027	0.0829	0.0472*	-
	Other rare condition	0.4652	<0.0001*	0.0639	0.0002*	0.0027*
General health	Diseases of the immune system	<0.0001*	-	-	-	-
	Diseases of the nervous system	0.1687	0.0000*	-	-	-
	Diseases of the skin	0.0010*	0.1842	0.0025*	-	-
	Endocrine, nutritional or metabolic diseases	0.0004*	0.0066*	0.0018*	0.5193	-
	Other rare condition	0.8411	<0.0001*	0.1687	0.0011*	0.0011*
Health change	Diseases of the immune system	0.3359	-	-	-	-
	Diseases of the nervous system	0.2679	0.9669	-	-	-
	Diseases of the skin	0.9669	0.4694	0.3537	-	-
	Endocrine, nutritional or metabolic diseases	0.0045*	0.2998	0.1501	0.0261	-
	Other rare condition	0.4694	0.2679	0.1695	0.5049	0.0051*

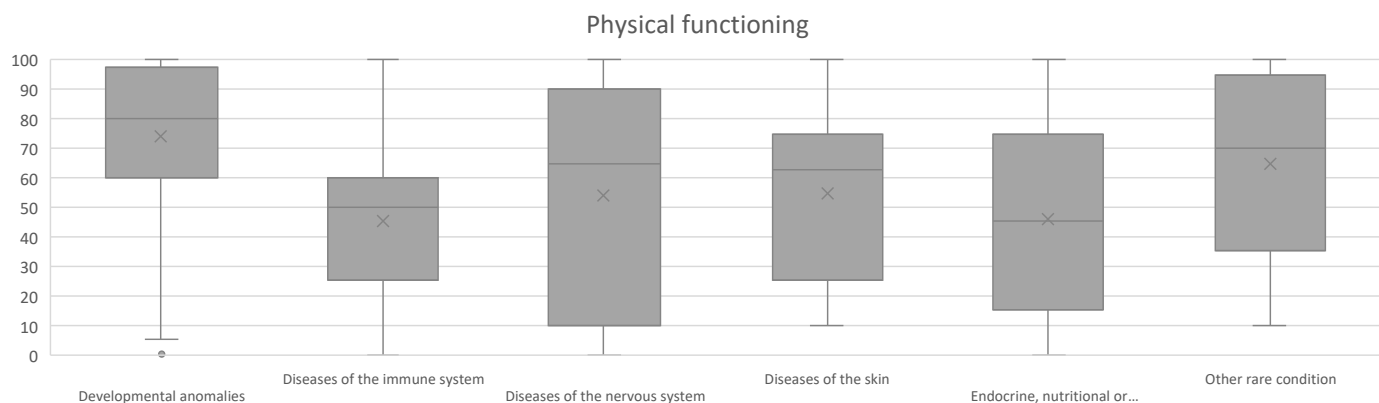


Figure 2.4: Boxplot of SF36 Physical functioning by condition

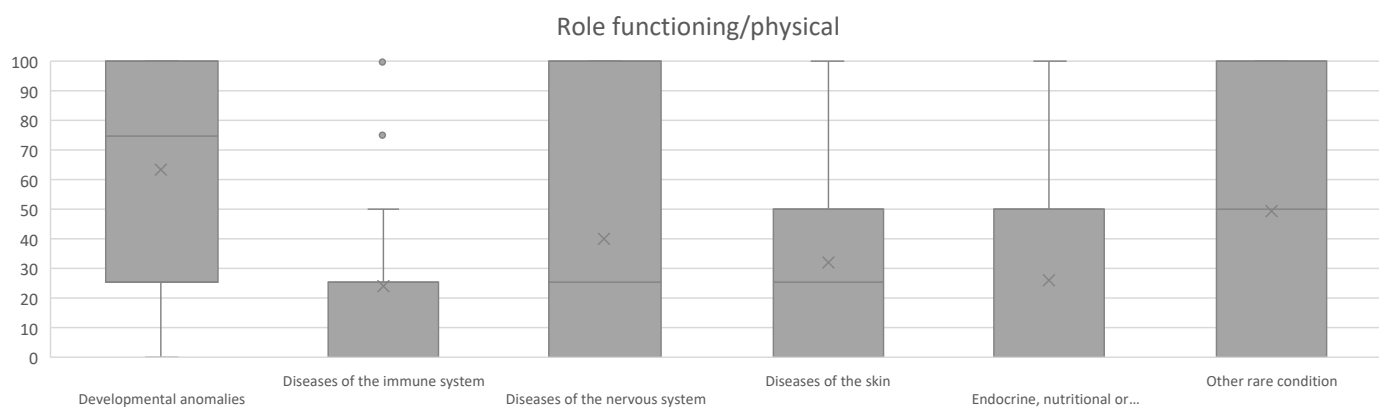


Figure 2.5: Boxplot of SF36 Role functioning/physical by condition

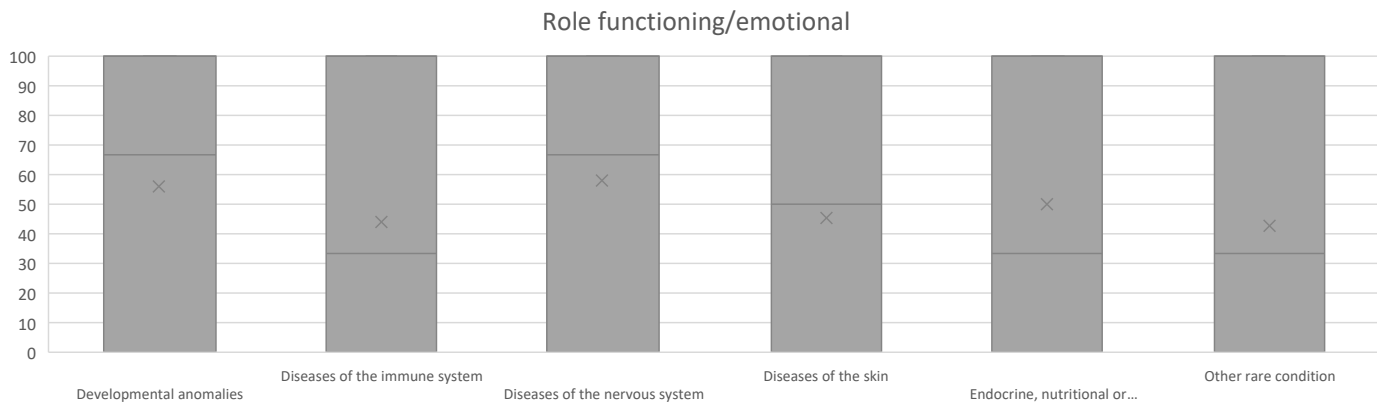


Figure 2.6: Boxplot of SF36 Role functioning/emotional by condition

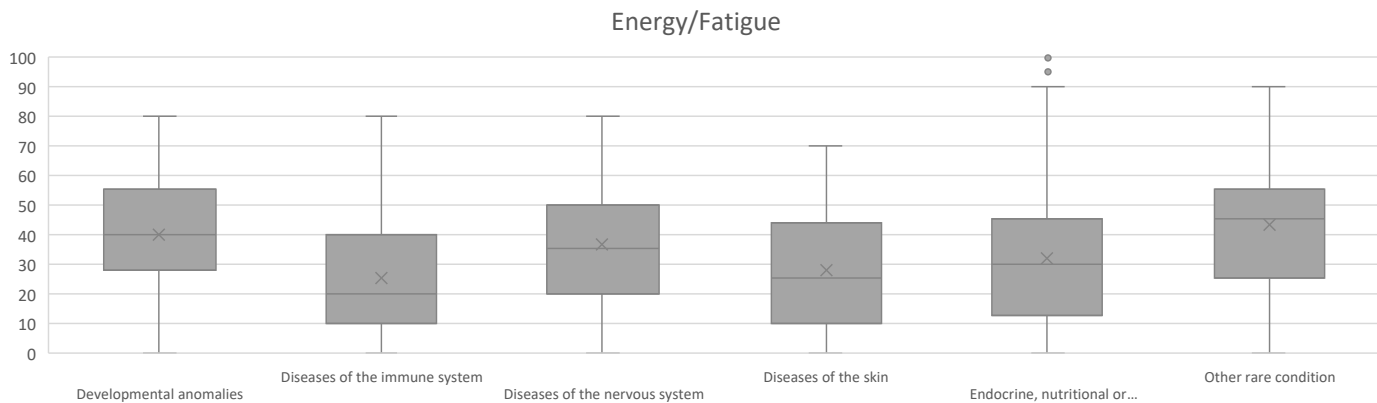


Figure 2.7: Boxplot of SF36 Energy/fatigue by condition

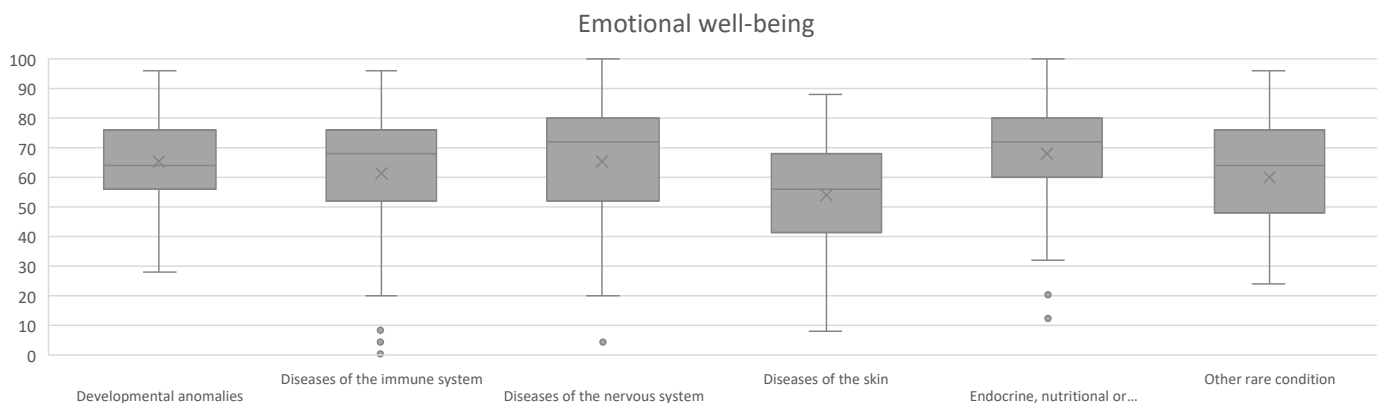


Figure 2.8: Boxplot of SF36 Emotional well-being by condition

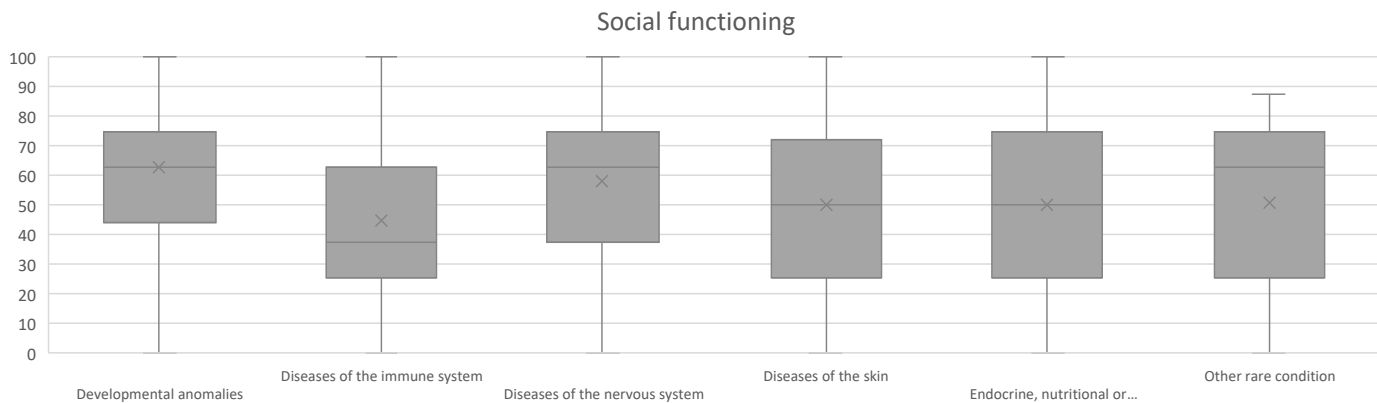


Figure 2.9: Boxplot of SF36 Social functioning by condition

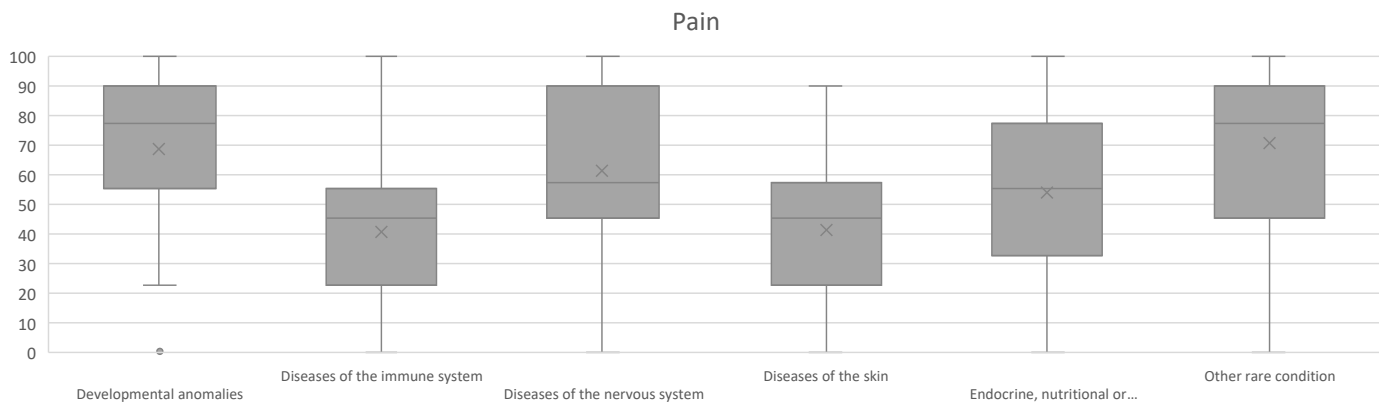


Figure 2.10: Boxplot of SF36 Pain by condition

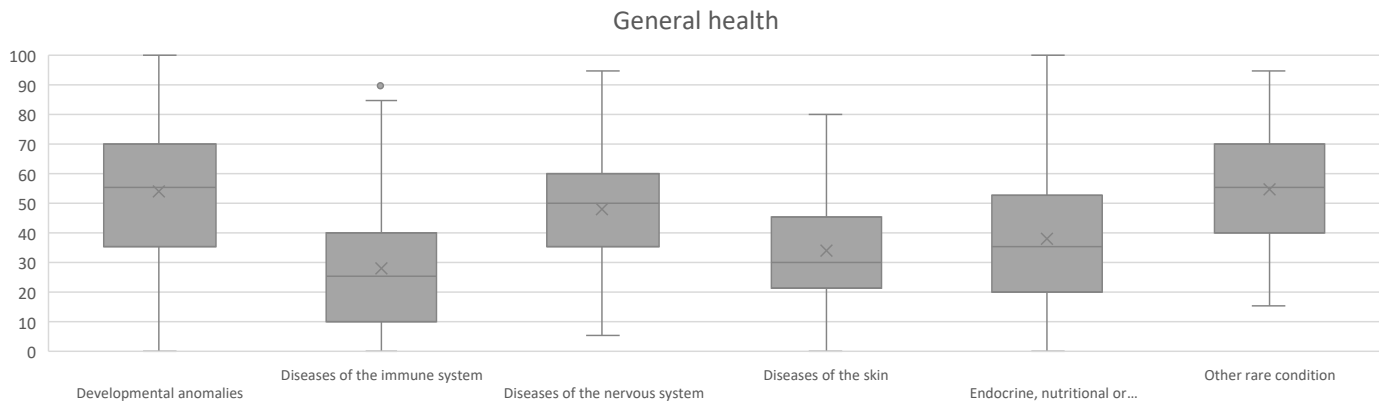


Figure 2.11: Boxplot of SF36 General health by condition

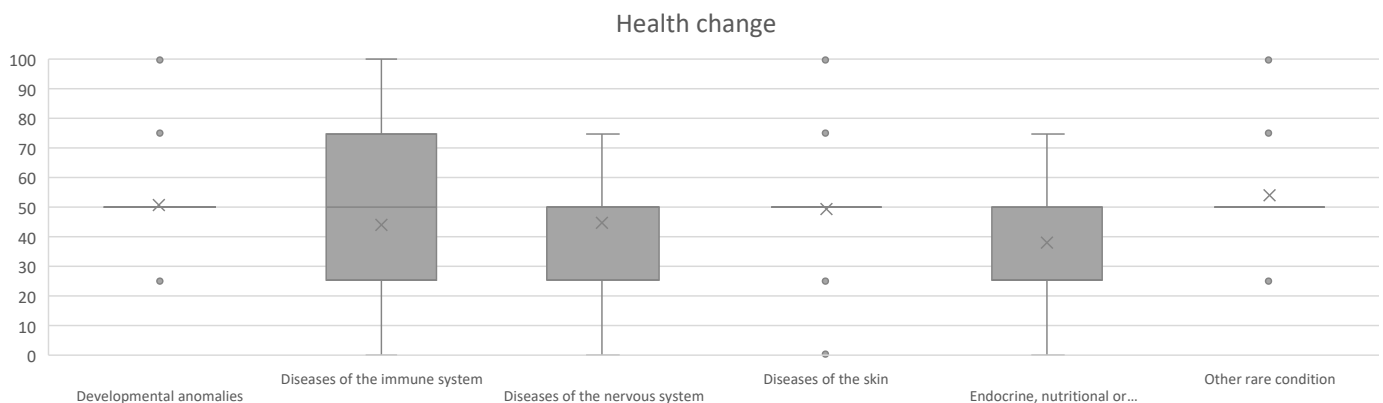


Figure 2.12: Boxplot of SF36 Health change by condition

SF36 by participant type

Comparisons were made by **type of participant** there were 256 participants (67.02%) with person with condition and, 126 participants (32.98%) with carer.

Assumptions for normality and variance for a two-sample t-test were not met, a Wilcoxon rank sum test with continuity correction was used.

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 Physical functioning** scale [$W = 9112.50$, $p < 0.0001$] was significantly lower for participants in the Person with condition subgroup (Median = 50.00, IQR = 50.00)

compared to participants in the Carer subgroup (Median = 82.50, IQR = 45.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 Role functioning physical** scale [$W = 10401.00$, $p < 0.0001$] was significantly lower for participants in the Person with condition subgroup (Median = 0.00, IQR = 50.00) compared to participants in the Carer subgroup (Median = 75.00, IQR = 100.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 Energy/fatigue** scale [$W = 12864.00$, $p = 0.001$] was

significantly lower for participants in the Person with condition subgroup (Median = 30.00, IQR = 30.00) compared to participants in the Carer subgroup (Median = 40.00, IQR = 28.75).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 Social functioning** scale [W = 12984.00, p = 0.002] was significantly lower for participants in the Person with condition subgroup (Median = 50.00, IQR = 50.00) compared to participants in the Carer subgroup (Median = 62.50, IQR = 37.50).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 Pain** scale [W = 10296.00, p<0.0001] was significantly lower for participants in the Person with condition subgroup (Median = 45.00, IQR = 45.00) compared to participants in the Carer subgroup (Median = 77.50, IQR = 45.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 General health** scale [W = 8901.00, p<0.0001] was significantly lower for participants in the Person with condition subgroup (Median = 32.50, IQR = 30.00) compared to participants in the Carer subgroup (Median = 55.00, IQR = 30.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 Health change** scale [W = 14486.00, p = 0.086] was significantly lower for participants in the Person with condition subgroup (Median = 50.00, IQR = 25.00) compared to participants in the Carer subgroup (Median = 50.00, IQR = 25.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 Physical functioning** scale [W = 9112.50, p<0.0001] was significantly lower for participants in the Person with condition subgroup (Median = 50.00, IQR = 50.00) compared to participants in the Carer subgroup (Median = 82.50, IQR = 45.00).

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On

average, participants in the Carer subgroup scored higher than participants in the Person with condition subgroup. This indicates that physical activities were not limited for participants in the Carer subgroup, and were slightly limited for participants in the Person with condition subgroup.

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, participants in the Carer subgroup scored higher than participants in the Person with condition subgroup. This indicates that physical health seldom interfered with work or other activities for participants in the Carer subgroup, and almost always interfered for participants in the Person with condition subgroup.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants in the Carer subgroup had a higher score for energy/fatigue compared to Person with condition, however, both groups were often fatigued.

SF36 Social functioning scale measures limitations on social activities due to physical or emotional problems. On average, participants in the Carer subgroup scored higher than participants in the Person with condition subgroup. This indicates that social activities were slightly limited for participants in the Carer subgroup, and moderately limited for participants in the Person with condition subgroup.

SF36 Pain scale measures how much pain, and how pain interferes with work and other activities. On average, participants in the Carer subgroup scored higher than participants in the Person with condition subgroup. This indicates that participants in the Carer subgroup had mild pain, and participants in the Person with condition subgroup had moderate pain.

SF36 General health scale measures perception of health. On average, participants in the Carer subgroup scored higher than participants in the Person with condition subgroup. This indicates that participants in the Carer subgroup had good health, and participants in the Person with condition subgroup had average health.

Table 2.9: SF36 by participant type summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=382)	Percent	Median	IQR	W	p-value
Physical functioning	Person with condition	256	67.02	50.00	50.00	9112.50	<0.0001*
	Carer	126	32.98	82.50	45.00		
Role functioning/physical	Person with condition	256	67.02	0.00	50.00	10401.00	<0.0001*
	Carer	126	32.98	75.00	100.00		
Role functioning/emotional	Person with condition	256	67.02	50.00	100.00	15462.00	0.4863
	Carer	126	32.98	66.67	100.00		
Energy/Fatigue	Person with condition	256	67.02	30.00	30.00	12864.00	0.0013*
	Carer	126	32.98	40.00	28.75		
Emotional well-being	Person with condition	256	67.02	68.00	25.00	15302.00	0.4145
	Carer	126	32.98	68.00	23.00		
Social functioning	Person with condition	256	67.02	50.00	50.00	12984.00	0.0018*
	Carer	126	32.98	62.50	37.50		
Pain	Person with condition	256	67.02	45.00	45.00	10296.00	<0.0001*
	Carer	126	32.98	77.50	45.00		
General health	Person with condition	256	67.02	32.50	30.00	8901.00	<0.0001*
	Carer	126	32.98	55.00	30.00		
Health change	Person with condition	256	67.02	50.00	25.00	14486.00	0.0864
	Carer	126	32.98	50.00	25.00		

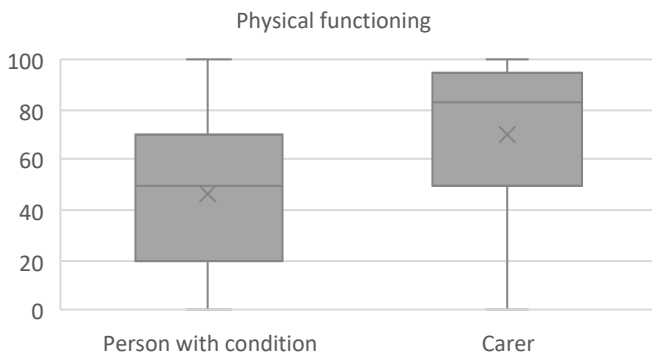


Figure 2.13: Boxplot of SF36 Physical functioning by participant type

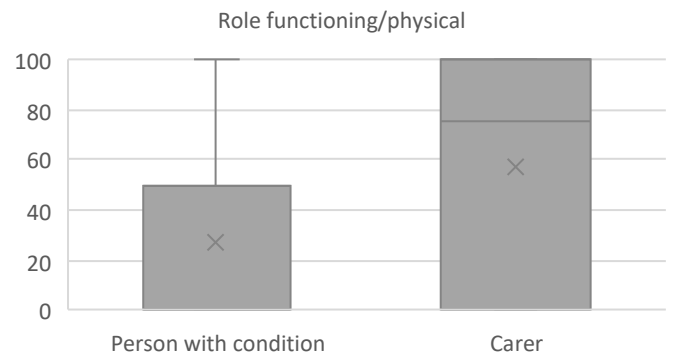


Figure 2.14: Boxplot of SF36 Role functioning/physical by participant type

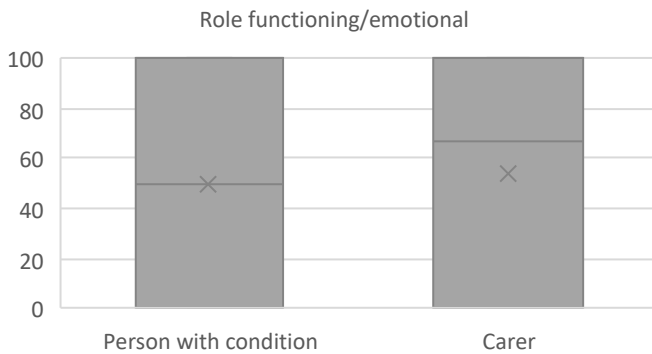


Figure 2.15: Boxplot of SF36 Role functioning/emotional by participant type

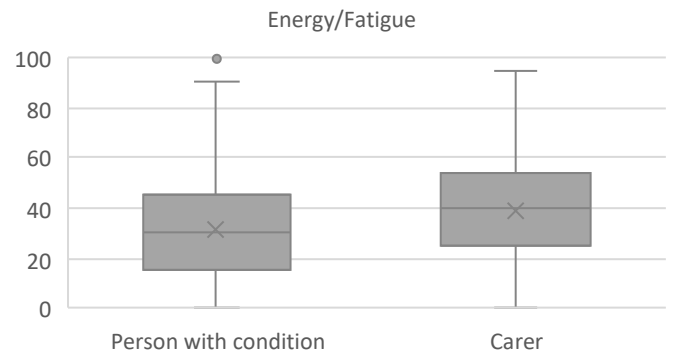


Figure 2.16: Boxplot of SF36 Energy/fatigue by participant type

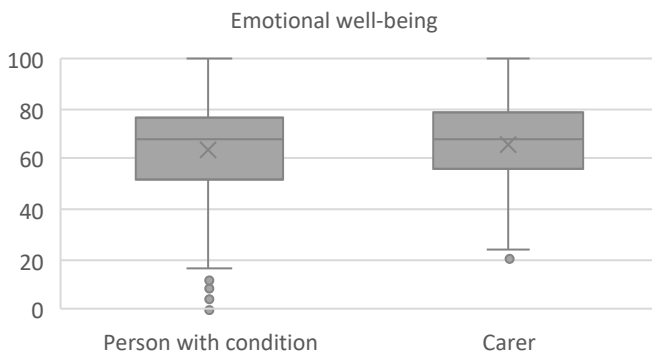


Figure 2.17: Boxplot of SF36 Emotional well-being by participant type

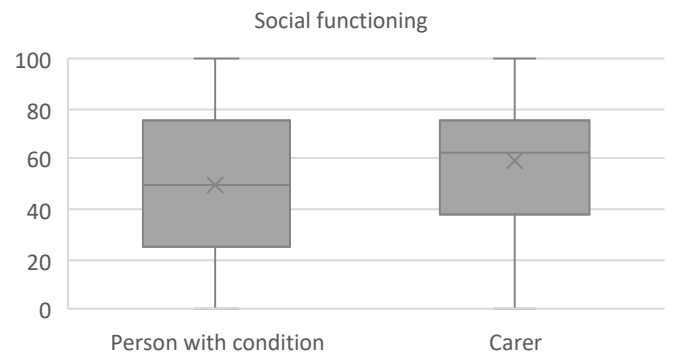


Figure 2.18: Boxplot of SF36 Social functioning by participant type

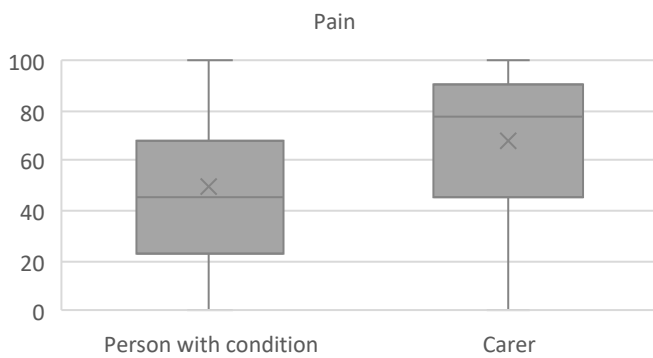


Figure 2.19: Boxplot of SF36 Pain by participant type

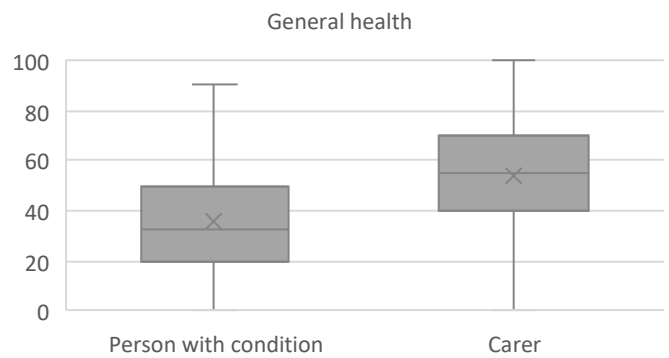


Figure 2.20: Boxplot of SF36 General health by participant type

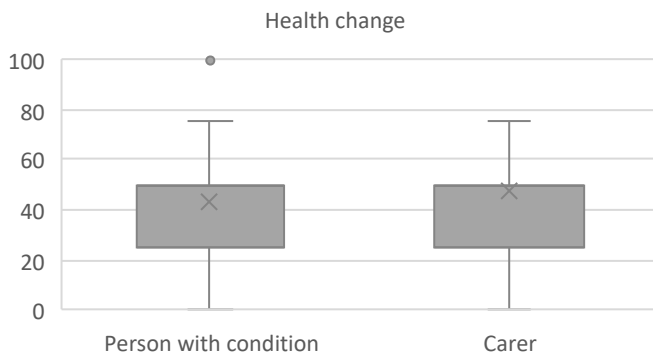


Figure 2.21: Boxplot of SF36 Health change by participant type

SF36 by gender

Comparisons were made by **gender**, there were 285 female participants (75.00%), and 95 male participants (25.00%).

Assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used.

Wilcoxon rank sum tests with continuity correction indicated that the median score for the SF36 Physical functioning scale [W = 10896.00, p = 0.004] was significantly lower for participants in the Female subgroup (Median = 55.00, IQR = 60.00) compared to participants in the Male subgroup (Median = 65.00, IQR = 65.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the SF36 Role functioning physical scale [W = 11180.00, p = 0.006] was significantly lower for participants in the Female subgroup (Median = 0.00, IQR = 75.00) compared to participants in the Male subgroup (Median = 50.00, IQR = 100.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the SF36

Energy/fatigue scale [W = 10618.00, p = 0.002] was significantly lower for participants in the Female subgroup (Median = 30.00, IQR = 30.00) compared to participants in the Male subgroup (Median = 40.00, IQR = 32.50).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the SF36 Social functioning scale [W = 10658.00, p = 0.002] was significantly lower for participants in the Female subgroup (Median = 50.00, IQR = 50.00) compared to participants in the Male subgroup (Median = 62.50, IQR = 50.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the SF36 Pain scale [W = 9887.00, p < 0.0001] was significantly lower for participants in the Female subgroup (Median = 45.00, IQR = 45.00) compared to participants in the Male subgroup (Median = 67.50, IQR = 45.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the SF36 General health scale [W = 10317.00, p = 0.001] was significantly lower for participants in the Female subgroup (Median

= 35.00, IQR = 35.00) compared to participants in the Male subgroup (Median = 50.00, IQR = 40.00).

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, participants in the Male subgroup scored higher than participants in the Female subgroup. This indicates that physical activities were slightly limited for participants in the Male subgroup, and were moderately limited for participants in the Female subgroup.

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, participants in the Male subgroup scored higher than participants in the Female subgroup. This indicates that physical health sometimes interfered with work or other activities for participants in the Male subgroup, and almost always interfered for participants in the Female subgroup.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants in the Male subgroup had a higher score

for energy/fatigue compared to Female, however, both groups were often fatigued.

SF36 Social functioning scale measures limitations on social activities due to physical or emotional problems. On average, participants in the Male subgroup scored higher than participants in the Female subgroup. This indicates that social activities were slightly limited for participants in the Male subgroup, and moderately limited for participants in the Female subgroup.

SF36 Pain scale measures how much pain, and how pain interferes with work and other activities. On average, participants in the Male subgroup scored higher than participants in the Female subgroup. This indicates that participants in the Male subgroup had mild pain, and participants in the Female subgroup had moderate pain.

SF36 General health scale measures perception of health. On average, participants in the Male subgroup scored higher than participants in the Female subgroup. This indicates that participants in the Male subgroup had average health, and participants in the Female subgroup had poor health.

Table 2.10: SF36 by gender summary statistics and T-test

SF36 scale	Group	Number (n=380)	Percent	Median	IQR	W	p-value
Physical functioning	Female	285	75.00	55.00	60.00	10896.00	0.0043*
	Male	95	25.00	65.00	65.00		
Role functioning/physical	Female	285	75.00	0.00	75.00	11180.00	0.0061*
	Male	95	25.00	50.00	100.00		
Role functioning/emotional	Female	285	75.00	66.67	100.00	12814.00	0.4083
	Male	95	25.00	66.67	100.00		
Energy/Fatigue	Female	285	75.00	30.00	30.00	10618.00	0.0016*
	Male	95	25.00	40.00	32.50		
Emotional well-being	Female	285	75.00	68.00	24.00	12124.00	0.1266
	Male	95	25.00	72.00	24.00		
Social functioning	Female	285	75.00	50.00	50.00	10658.00	0.0017*
	Male	95	25.00	62.50	50.00		
Pain	Female	285	75.00	45.00	45.00	9887.00	0.0001*
	Male	95	25.00	67.50	45.00		
General health	Female	285	75.00	35.00	35.00	10317.00	0.0005*
	Male	95	25.00	50.00	40.00		
Health change	Female	285	75.00	50.00	25.00	12593.00	0.2808
	Male	95	25.00	50.00	25.00		

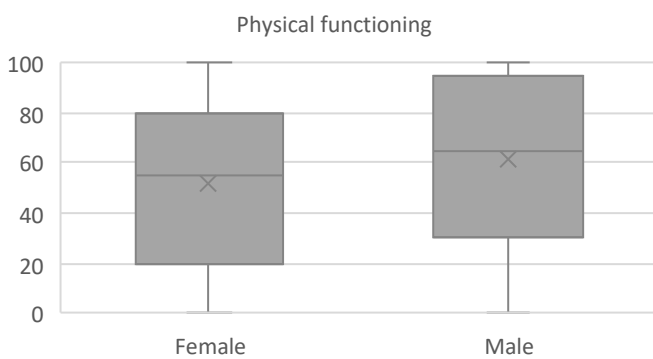


Figure 2.22: Boxplot of SF36 Physical functioning by gender

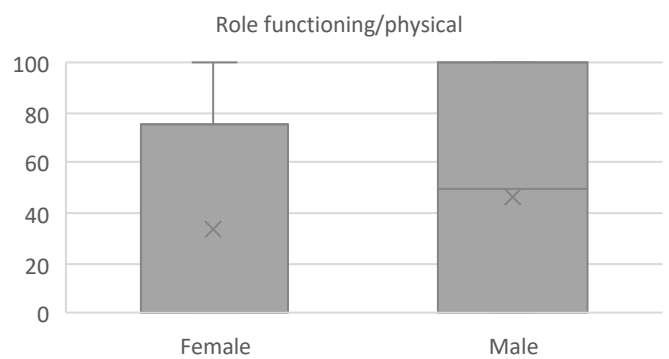


Figure 2.23: Boxplot of SF36 Role functioning/physical by gender

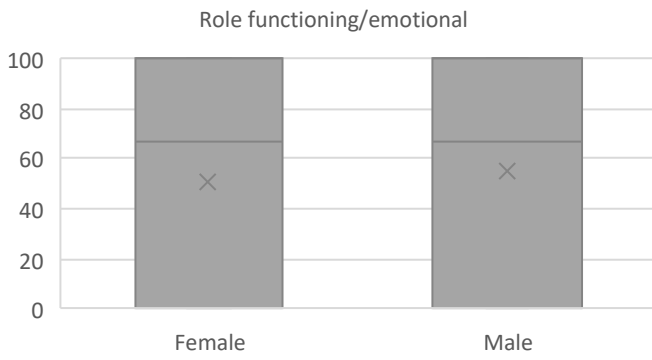


Figure 2.24: Boxplot of SF36 Role functioning/emotional by gender

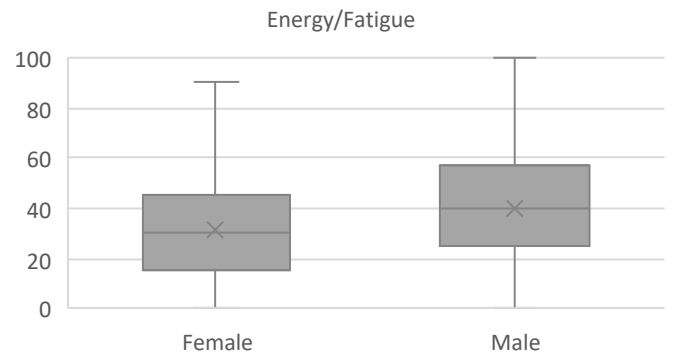


Figure 2.25: Boxplot of SF36 Energy/fatigue by gender



Figure 2.26: Boxplot of SF36 Emotional well-being by gender

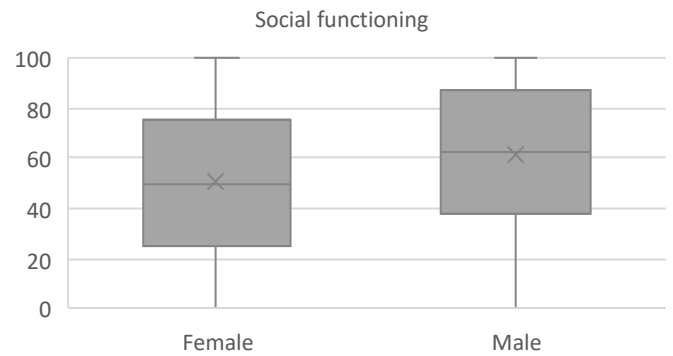


Figure 2.27: Boxplot of SF36 Social functioning by gender

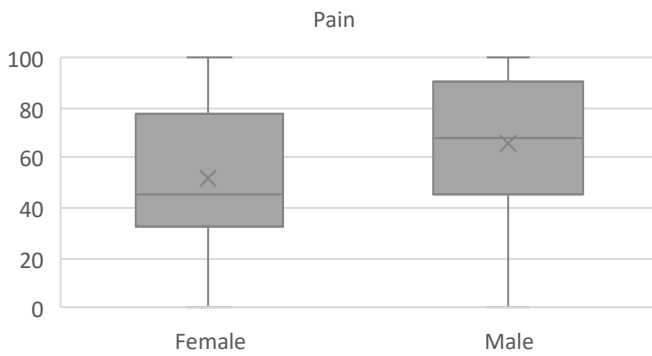


Figure 2.28: Boxplot of SF36 Pain by gender

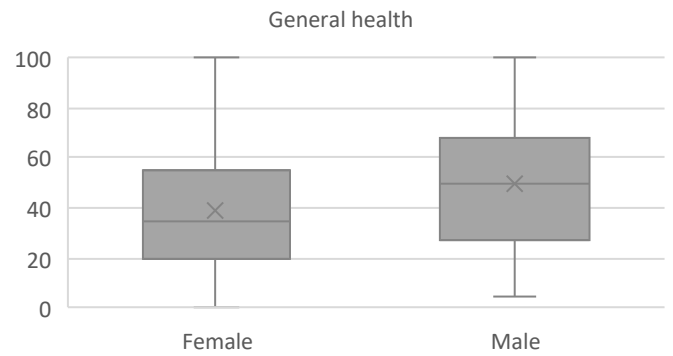


Figure 2.29: Boxplot of SF36 General health by gender

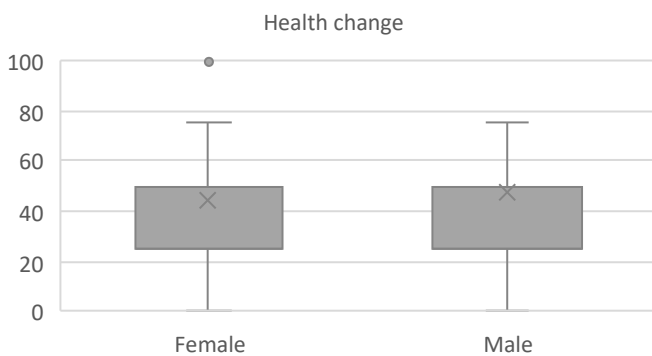


Figure 2.30: Boxplot of SF36 Health change by gender

SF36 by age

Comparisons were made by **age** of person with condition. There were 90 participants (23.56%) with aged under 18, 125 participants (32.72%) with aged 18 to 44, 109 participants (28.53%) with aged 45 to 64, and 58 participants (15.18%) with aged 65 or older.

The assumptions for normality of residuals was not met, a Kruskal-Wallis test was used. Post hoc pairwise comparisons using Wilcoxon rank sum test was used to identify the source of any differences identified in the Kruskal -Wallis test.

A Kruskal-Wallis test indicated a statistically significant difference in the SF36 Physical functioningscale between groups, $\chi^2(3) = 52.29$ $p < 0.0001$

The largest significant difference was between Aged under 18 (median = 85, IQR = 35), and Aged 45 to 64 (median = 40, IQR = 55, $p < 0.0001$). A Kruskal-Wallis test indicated a statistically significant difference in the SF36 Role functioning physicalscale between groups, $\chi^2(3) = 48.891$ $p < 0.0001$

The largest significant difference was between Aged under 18 (median = 75, IQR = 75), and Aged 65 or older (median = 0, IQR = 50, $p < 0.0001$). A Kruskal-Wallis test indicated a statistically significant difference in the SF36 Energy/fatiguescale between groups, $\chi^2(3) = 9.2464$ $P = 0.0262$

The largest significant difference was between Aged under 18 (median = 40, IQR = 33.75), and Aged 18 to 44 (median = 30, IQR = 30, $p = 0.012$). A Kruskal-Wallis test indicated a statistically significant difference in the SF36 Emotional well-beingscale between groups, $\chi^2(3) = 12.741$ $P = 0.0052$

The largest significant difference was between Aged under 18 (median = 72, IQR = 24), and Aged 18 to 44 (median = 64, IQR = 28, $p = 0.014$). A Kruskal-Wallis test indicated a statistically significant difference in the SF36 Social functioningscale between groups, $\chi^2(3) = 10.418$ $P = 0.0153$

The largest significant difference was between Aged under 18 (median = 62.5, IQR = 50), and Aged 18 to 44 (median = 50, IQR = 50, $p = 0.0091$). A Kruskal-Wallis test indicated a statistically significant difference in the SF36 Painscale between groups, $\chi^2(3) = 33.501$ $p < 0.0001$.

The largest significant difference was between Aged under 18 (median = 77.5, IQR = 55), and Aged 18 to 44 (median = 55, IQR = 45, $p < 0.0001$). A Kruskal-Wallis test indicated a statistically significant difference in the SF36 General healthscale between groups, $\chi^2(3) = 58.747$ $p < 0.0001$. The largest significant difference was between Aged under 18 (median = 60, IQR = 30), and Aged 45 to 64 (median = 30, IQR = 30, $p < 0.0001$).

A Kruskal-Wallis test indicated a statistically significant difference in the SF36 Health changescale between groups, $\chi^2(3) = 11.104$ $P = 0.0112$. The largest significant difference was between Aged under 18 (median = 50, IQR = 0), and Aged 65 or older (median = 25, IQR = 25, $p = 0.0046$).

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, participants in the Aged under 18 subgroup scored higher than participants in the Aged 45 to 64 subgroup. This indicates that physical activities were not limited for participants in the Aged under 18 subgroup, and were slightly limited for participants in the Aged 45 to 64 subgroup.

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, participants in the Aged under 18 subgroup scored higher than participants in the Aged 65 or older subgroup. This indicates that physical health sometimes interfered with work or other activities for participants in the Aged under 18 subgroup, and almost always interfered for participants in the Aged 45 to 64 subgroup.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants in the Aged under 18 subgroup had a higher score for energy/fatigue compared to Aged 18 to 44, however, both groups were often fatigued.

SF36 Emotional well-being scale measures how a person feels, for example happy, calm, depressed or anxious. On average, participants in the Aged under 18 subgroup had a higher score for emotional well-being compared to Aged 18 to 44, however, both groups had good emotional well-being.

SF36 Social functioning scale measures limitations on social activities due to physical or emotional problems. On average, participants in the Aged under 18 subgroup scored higher than participants in the Aged 18 to 44 subgroup. This indicates that social activities were slightly limited for participants in the Aged under 18 subgroup, and moderately limited for participants in the Aged 18 to 44 subgroup.

SF36 Pain scale measures how much pain, and how pain interferes with work and other activities. On average, participants in the Aged under 18 subgroup scored higher than participants in the Aged 18 to 44 subgroup. This indicates that participants in the Aged under 18 subgroup had mild pain, and participants in the Aged 18 to 44 subgroup had moderate pain.

SF36 General health scale measures perception of health. On average, participants in the Aged under 18 subgroup scored higher than participants in the Aged 45 to 64 subgroup. This indicates that participants in the Aged under 18 subgroup had average health, and participants in the Aged 45 to 64 subgroup had poor health.

SF36 Health change scale measures health compared to a year ago. On average, participants in the Aged under 18 subgroup scored higher than participants in the Aged 65 or older subgroup. This indicates that participants in the Aged under 18 subgroup reported that their health was about the same as it was a year ago, and participants in the Aged 65 or older subgroup reported somewhat worse health.

Table 2.11: SF36 by age summary statistics and Kruskal Wallis test

SF36 scale	Group	Number (n=382)	Percent	Median	IQR	C ²	dF	p-value
Physical functioning	Aged under 18	90	23.56	85.00	35.00	52.29	3	<0.0001*
	Aged 18 to 44	125	32.72	50.00	60.00			
	Aged 45 to 64	109	28.53	40.00	55.00			
	Aged 65 or older	58	15.18	42.50	53.75			
Role functioning physical	Aged under 18	90	23.56	75.00	75.00	48.891	3	<0.0001*
	Aged 18 to 44	125	32.72	0.00	75.00			
	Aged 45 to 64	109	28.53	0.00	50.00			
	Aged 65 or older	58	15.18	0.00	50.00			
Role functioning emotional	Aged under 18	90	23.56	66.67	100.00	1.4131	3	0.7025
	Aged 18 to 44	125	32.72	33.33	100.00			
	Aged 45 to 64	109	28.53	66.67	100.00			
	Aged 65 or older	58	15.18	66.67	100.00			
Energy/fatigue	Aged under 18	90	23.56	40.00	33.75	9.2464	3	0.0262*
	Aged 18 to 44	125	32.72	30.00	30.00			
	Aged 45 to 64	109	28.53	30.00	35.00			
	Aged 65 or older	58	15.18	35.00	38.75			
Emotional well-being	Aged under 18	90	23.56	72.00	24.00	12.741	3	0.0052*
	Aged 18 to 44	125	32.72	64.00	28.00			
	Aged 45 to 64	109	28.53	68.00	28.00			
	Aged 65 or older	58	15.18	72.00	20.00			
Social functioning	Aged under 18	90	23.56	62.50	50.00	10.418	3	0.0153*
	Aged 18 to 44	125	32.72	50.00	50.00			
	Aged 45 to 64	109	28.53	50.00	50.00			
	Aged 65 or older	58	15.18	50.00	50.00			
Pain	Aged under 18	90	23.56	77.50	55.00	33.501	3	<0.0001*
	Aged 18 to 44	125	32.72	55.00	45.00			
	Aged 45 to 64	109	28.53	45.00	45.00			
	Aged 65 or older	58	15.18	55.00	55.00			
General health	Aged under 18	90	23.56	60.00	30.00	58.747	3	<0.0001*
	Aged 18 to 44	125	32.72	35.00	35.00			
	Aged 45 to 64	109	28.53	30.00	30.00			
	Aged 65 or older	58	15.18	35.00	38.75			
Health change	Aged under 18	90	23.56	50.00	0.00	11.104	3	0.0112*
	Aged 18 to 44	125	32.72	50.00	25.00			
	Aged 45 to 64	109	28.53	50.00	25.00			
	Aged 65 or older	58	15.18	25.00	25.00			

Table 2.12: SF36 by age one-way post hoc Wilcoxon rank sum test

SF36 scale		Aged under 18	Aged 18 to 44	Aged 45 to 64
Physical functioning	Aged 18 to 44	<0.0001*	-	-
	Aged 45 to 64	<0.0001*	0.1300	-
	Aged 65 or older	<0.0001*	0.5800	0.5900
Role functioning/physical	Aged 18 to 44	<0.0001*	-	-
	Aged 45 to 64	<0.0001*	0.1200	-
	Aged 65 or older	<0.0001*	0.5900	0.4900
Energy/Fatigue	Aged 18 to 44	0.0120*	-	-
	Aged 45 to 64	0.1880	0.3930	-
	Aged 65 or older	0.3980	0.3590	0.6860
Emotional well-being	Aged 18 to 44	0.1130	-	-
	Aged 45 to 64	0.3090	0.0140*	-
	Aged 65 or older	0.3090	0.0140*	0.8750
Social functioning	Aged 18 to 44	0.0091*	-	-
	Aged 45 to 64	0.0682	0.6163	-
	Aged 65 or older	0.0682	0.7714	0.7714
Pain	Aged 18 to 44	<0.0001*	-	-
	Aged 45 to 64	<0.0001*	0.1340	-
	Aged 65 or older	0.0006*	0.7703	0.4042
General health	Aged 18 to 44	<0.0001*	-	-
	Aged 45 to 64	<0.0001*	0.2600	-
	Aged 65 or older	<0.0001*	0.6900	0.2600
Health change	Aged 18 to 44	0.3059	-	-
	Aged 45 to 64	0.0574	0.3059	-
	Aged 65 or older	0.0046*	0.0754	0.3102

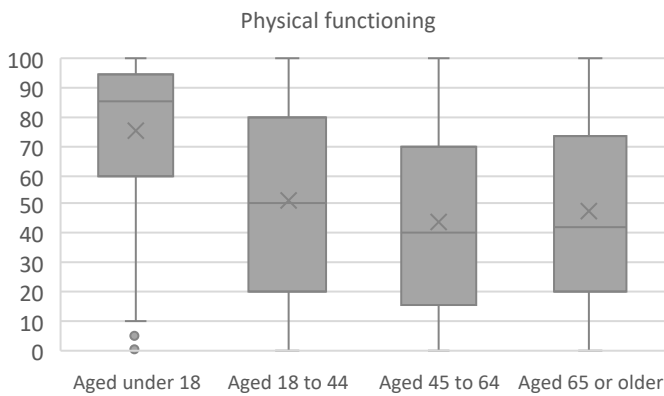


Figure 2.31: Boxplot of SF36 Physical functioning by age

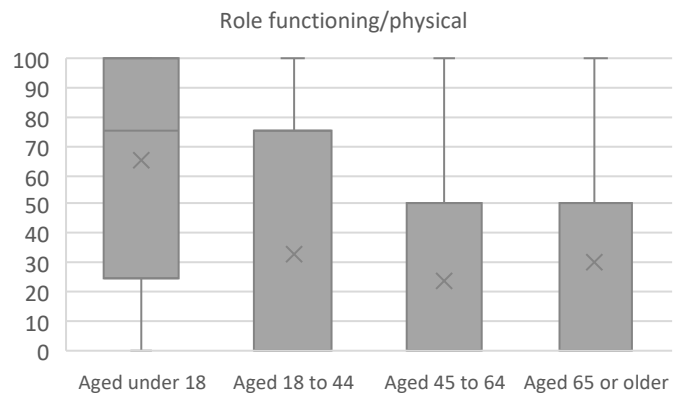


Figure 2.32: Boxplot of SF36 Role functioning/physical by age

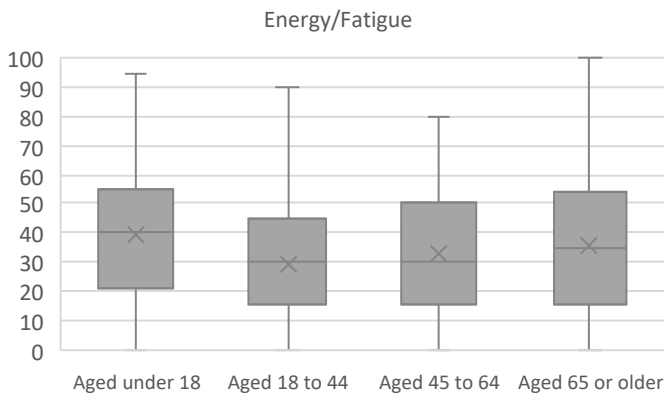


Figure 2.33: Boxplot of SF36 Role functioning/emotional by age

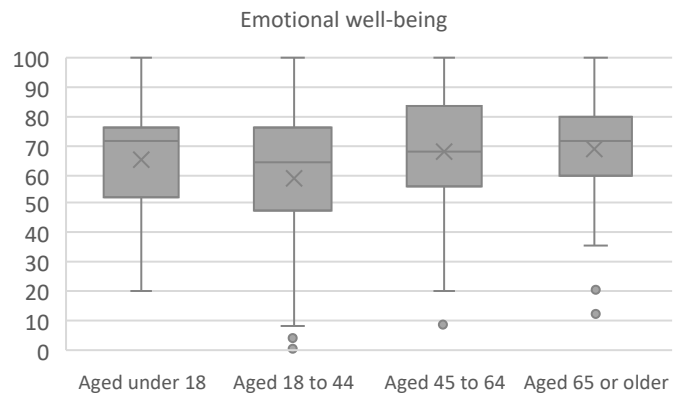


Figure 2.34: Boxplot of SF36 Energy/fatigue by age



Figure 2.35: Boxplot of SF36 Emotional well-being by age

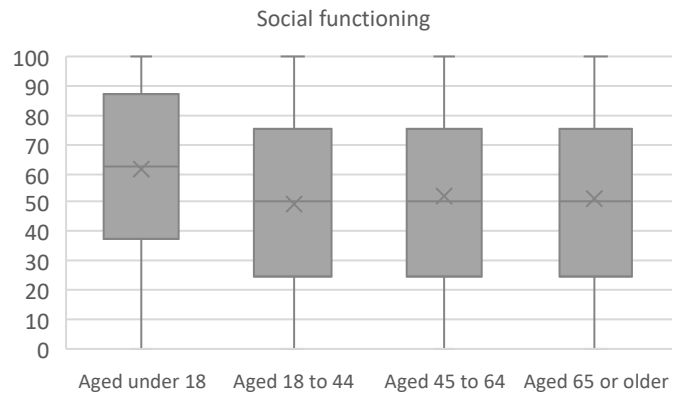


Figure 2.36: Boxplot of SF36 Social functioning by age



Figure 2.37: Boxplot of SF36 Pain by age

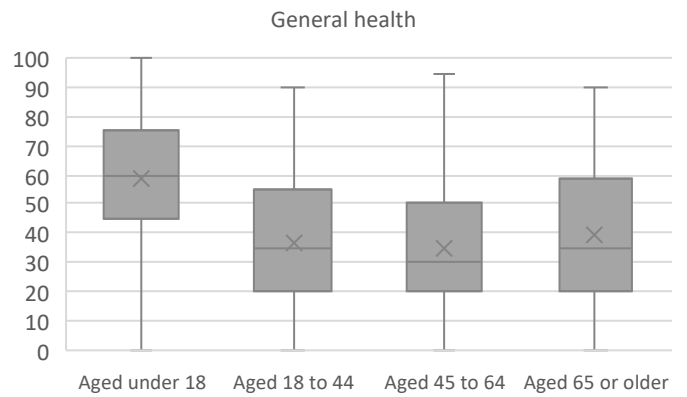


Figure 2.38: Boxplot of SF36 General health by age

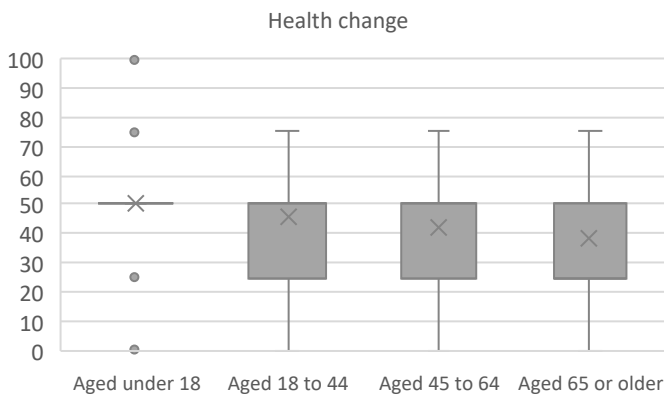


Figure 2.39: Boxplot of SF36 Health change by age

SF36 by education

Comparisons were made by **education** status, between those with trade or high school qualifications (n=185, 49.47%), and those with a university qualification (n=189, 50.53%).

Assumptions for normality and variance for a two-sample t-test were not met, a Wilcoxon rank sum test with continuity correction was used.

No significant differences were observed between participants by **education** for any of the SF36 scales.

Table 2.13: SF36 by education summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=374)	Percent	Median	IQR	W	p-value
Physical functioning	Trade or high school	185	49.47	55.00	55.00	16016.00	0.1601
	University	189	50.53	60.00	60.00		
Role functioning/physical	Trade or high school	185	49.47	0.00	75.00	16742.00	0.4467
	University	189	50.53	25.00	100.00		
Role functioning/emotional	Trade or high school	185	49.47	33.33	100.00	16774.00	0.4728
	University	189	50.53	66.67	100.00		
Energy/Fatigue	Trade or high school	185	49.47	30.00	30.00	15916.00	0.1332
	University	189	50.53	35.00	35.00		
Emotional well-being	Trade or high school	185	49.47	64.00	24.00	16718.00	0.4638
	University	189	50.53	68.00	28.00		
Social functioning	Trade or high school	185	49.47	50.00	50.00	16817.00	0.5214
	University	189	50.53	50.00	37.50		
Pain	Trade or high school	185	49.47	55.00	55.00	16110.00	0.1870
	University	189	50.53	57.50	35.00		
General health	Trade or high school	185	49.47	40.00	35.00	15653.00	0.0796
	University	189	50.53	45.00	35.00		
Health change	Trade or high school	185	49.47	50.00	25.00	16794.00	0.4850
	University	189	50.53	50.00	25.00		

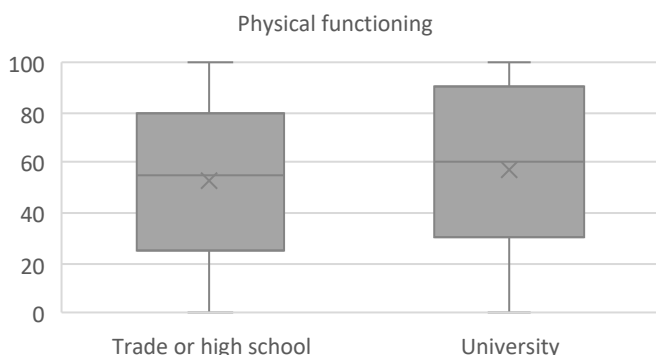


Figure 2.40: Boxplot of SF36 Physical functioning by education

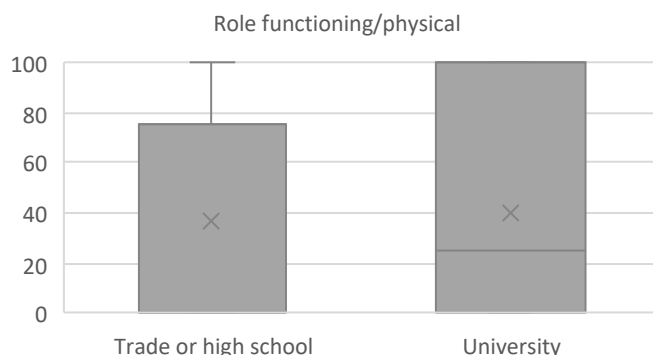


Figure 2.41: Boxplot of SF36 Role functioning/physical by education

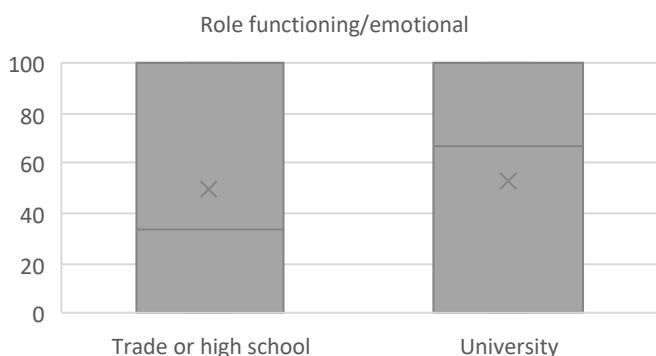


Figure 2.42: Boxplot of SF36 Role functioning/emotional by education

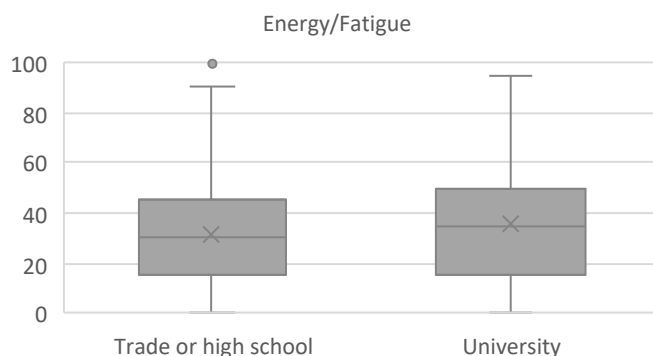


Figure 2.43: Boxplot of SF36 Energy/fatigue by education

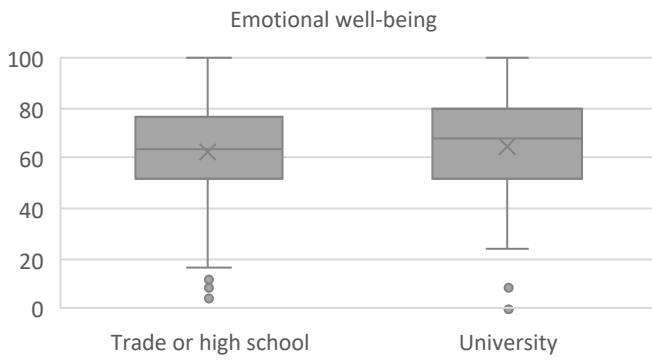


Figure 2.44: Boxplot of SF36 Emotional well-being by education

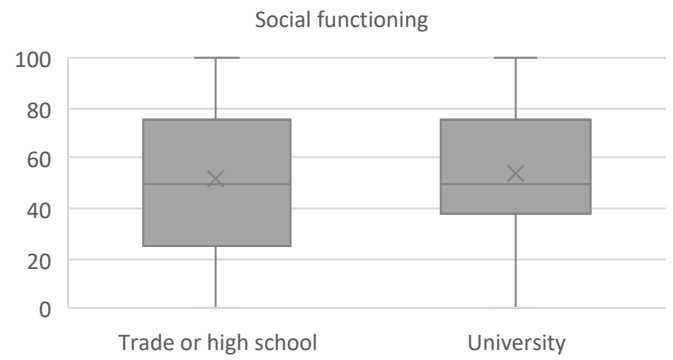


Figure 2.45: Boxplot of SF36 Social functioning by education

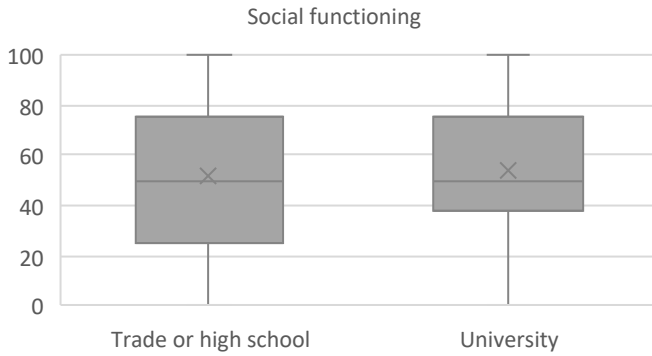


Figure 2.46: Boxplot of SF36 Pain by education

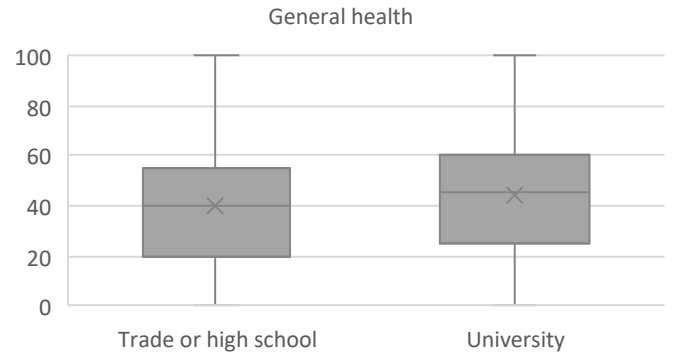


Figure 2.47: Boxplot of SF36 General health by education

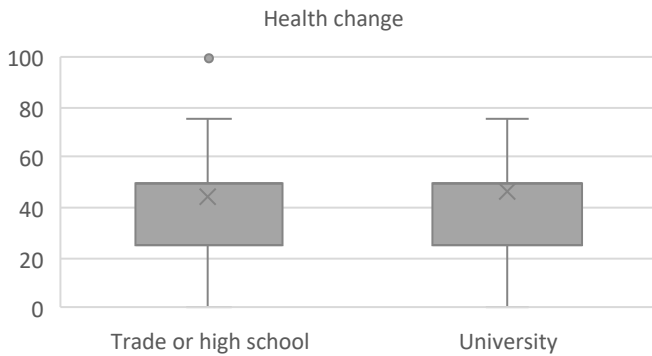


Figure 2.48: Boxplot of SF36 Health change by education

SF36 by location

The **location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional or remote areas (n=107, 28.01%) were compared to those living in a metropolitan area (n=275, 71.99%).

Assumptions for normality and variance for a two-sample t-test were not met, a Wilcoxon rank sum test with continuity correction was used.

Wilcoxon rank sum tests with continuity correction indicated that the median score for the SF36 Pain scale

[W = 12476.00, p = 0.020] was significantly lower for participants in the Regional or remote subgroup (Median = 55.00, IQR = 55.00) compared to participants in the Metropolitan subgroup (Median = 57.50, IQR = 56.25).

SF36 Pain scale measures how much pain, and how pain interferes with work and other activities. On average, participants in the Metropolitan subgroup had a higher score for Pain compared to Rural or remote, however, both groups had moderate pain.

Table 2.14: SF36 by location summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=382)	Percent	Median	IQR	W	p-value
Physical functioning	Rural or remote	107	28.01	50.00	57.50	14163.00	0.5704
	Metropolitan	275	71.99	60.00	60.00		
Role functioning/physical	Rural or remote	107	28.01	0.00	75.00	13616.00	0.2229
	Metropolitan	275	71.99	25.00	100.00		
Role functioning/emotional	Rural or remote	107	28.01	33.33	100.00	14465.00	0.7869
	Metropolitan	275	71.99	66.67	100.00		
Energy/Fatigue	Rural or remote	107	28.01	35.00	32.50	14793.00	0.9340
	Metropolitan	275	71.99	30.00	35.00		
Emotional well-being	Rural or remote	107	28.01	68.00	24.00	14854.00	0.8841
	Metropolitan	275	71.99	68.00	28.00		
Social functioning	Rural or remote	107	28.01	50.00	50.00	14225.00	0.6125
	Metropolitan	275	71.99	50.00	37.50		
Pain	Rural or remote	107	28.01	55.00	55.00	12476.00	0.0205*
	Metropolitan	275	71.99	57.50	56.25		
General health	Rural or remote	107	28.01	35.00	35.00	13952.00	0.4320
	Metropolitan	275	71.99	40.00	35.00		
Health change	Rural or remote	107	28.01	50.00	25.00	13416.00	0.1563
	Metropolitan	275	71.99	50.00	25.00		

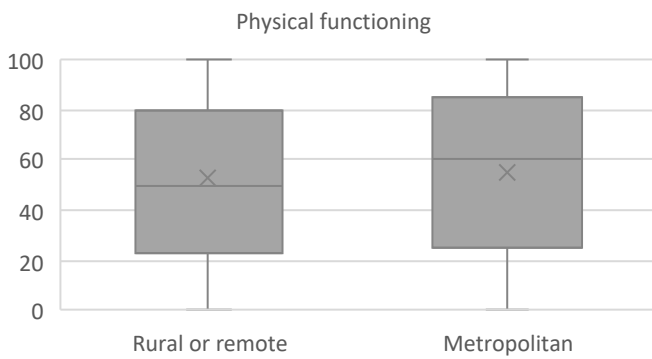


Figure 2.49: Boxplot of SF36 Physical functioning by location

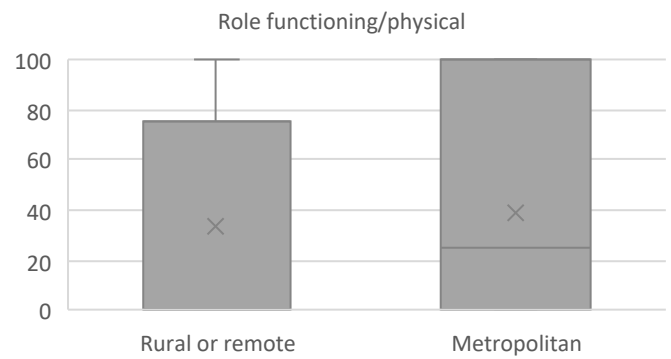


Figure 2.50: Boxplot of SF36 Role functioning/physical by location

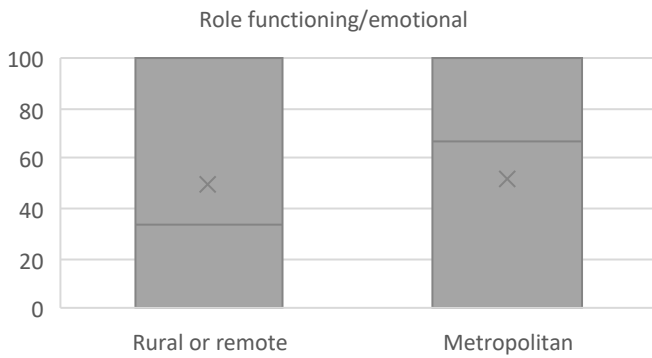


Figure 2.51: Boxplot of SF36 Role functioning/emotional by location

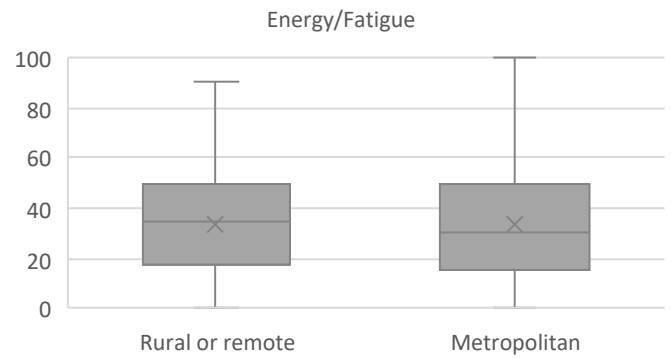


Figure 2.52: Boxplot of SF36 Energy/fatigue by location

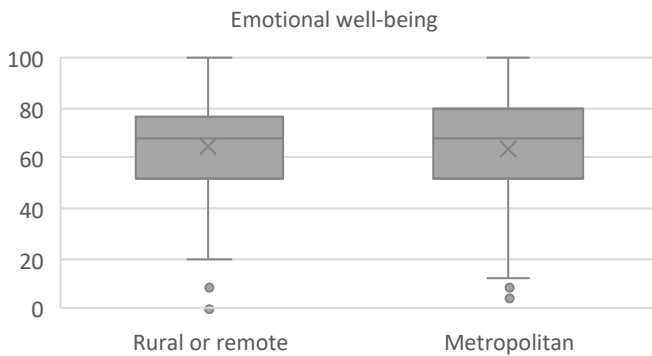


Figure 2.53: Boxplot of SF36 Emotional well-being by location

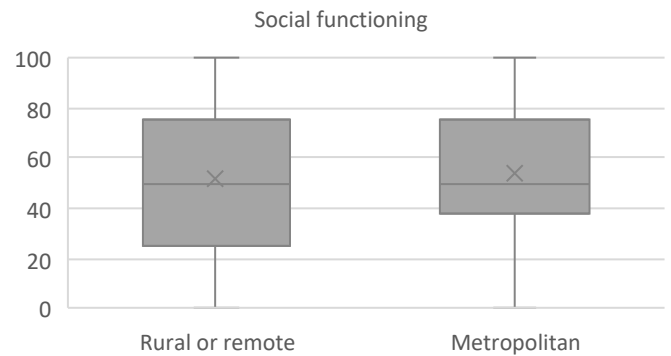


Figure 2.54: Boxplot of SF36 Social functioning by location

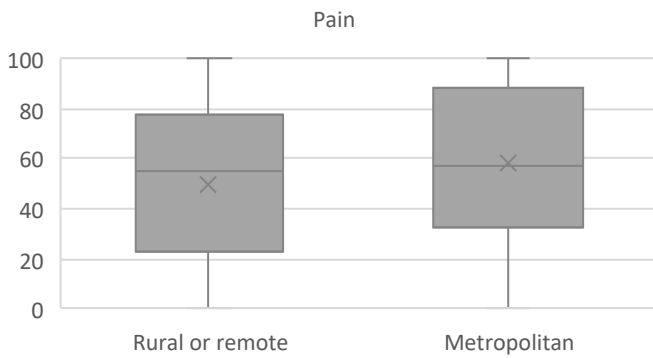


Figure 2.55: Boxplot of SF36 Pain by location

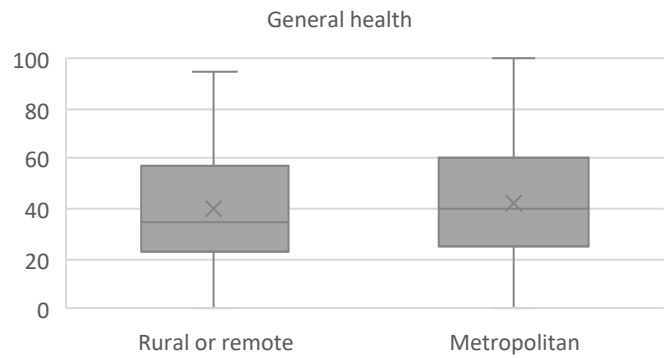


Figure 2.56: Boxplot of SF36 General health by location

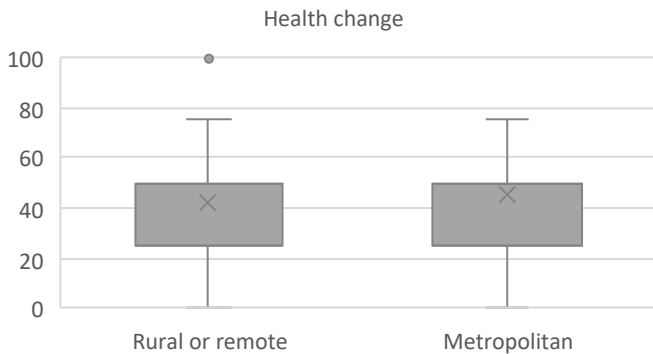


Figure 2.57: Boxplot of SF36 Health change by location

SF36 by socioeconomic status

Comparisons were made by **socioeconomic status**, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6 (n=191, 50.00%) compared to those with a higher SEIFA score of 7-10 (n=191, 50.00%).

Assumptions for normality and variance for a two-sample t-test were not met, a Wilcoxon rank sum test with continuity correction was used.

Wilcoxon rank sum tests with continuity correction indicated that the median score for the SF36 Physical functioning scale [W = 15642.00, p = 0.016] was significantly lower for participants in the Mid to low status subgroup (Median = 50.00, IQR = 57.50) compared to participants in the Higher status subgroup (Median = 65.00, IQR = 55.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the SF36 Role functioning emotional scale [W = 16174.00, p = 0.042] was significantly lower for participants in the Mid to low status subgroup (Median = 33.33, IQR = 100.00) compared to participants in the Higher status subgroup (Median = 66.67, IQR = 100.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the SF36 Emotional well-being scale [W = 15882.00, p = 0.029] was significantly lower for participants in the Mid to low status subgroup (Median = 64.00, IQR = 26.00) compared to participants in the Higher status subgroup (Median = 72.00, IQR = 24.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the SF36 Social functioning scale [W = 15784.00, p = 0.022] was significantly lower for participants in the Mid to low status subgroup (Median = 50.00, IQR = 50.00) compared to participants in the Higher status subgroup (Median = 62.50, IQR = 37.50).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the SF36 Pain scale [W = 15808.00, p = 0.024] was significantly lower for participants in the Mid to low status subgroup (Median = 45.00, IQR = 55.00) compared to participants in the Higher status subgroup (Median = 57.50, IQR = 55.00).

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, participants in the Higher status subgroup scored higher than participants in the Mid to low status

subgroup. This indicates that physical activities were slightly limited for participants in the Higher status subgroup, and were moderately limited for participants in the Mid to low status subgroup.

SF36 Role functioning/emotional scale measures how emotional problems interfere with work or other activities. On average, participants in the Higher status subgroup scored higher than participants in the Mid to low status subgroup. This indicates that emotional health seldom interfered with work or other activities for participants in the Higher status subgroup, and often interfered for participants in the Mid to low status subgroup.

SF36 Emotional well-being scale measures how a person feels, for example happy, calm, depressed or anxious. On average, participants in the Higher status subgroup had a higher score for emotional well-being compared to Mid to low status, however, both groups had good emotional well-being.

SF36 Social functioning scale measures limitations on social activities due to physical or emotional problems. On average, participants in the Higher status subgroup scored higher than participants in the Mid to low status subgroup. This indicates that social activities were slightly limited for participants in the Higher status subgroup, and moderately limited for participants in the Mid to low status subgroup.

SF36 Pain scale measures how much pain, and how pain interferes with work and other activities. On average, participants in the Higher status subgroup had a higher score for Pain compared to Mid to low status, however, both groups had moderate pain.

SF36 General health scale measures perception of health. On average, participants in the Higher status subgroup had a higher score for general health compared to Mid to low status, however, both groups had poor health.

Table 2.15: SF36 by socioeconomic status summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=382)	Percent	Median	IQR	W	p-value
Physical functioning	Mid to low status	191	50.00	50.00	57.50	15642.00	0.0159*
	Higher status	191	50.00	65.00	55.00		
Role functioning/physical	Mid to low status	191	50.00	0.00	75.00	16988.00	0.2111
	Higher status	191	50.00	25.00	100.00		
Role functioning/emotional	Mid to low status	191	50.00	33.33	100.00	16174.00	0.0423*
	Higher status	191	50.00	66.67	100.00		
Energy/Fatigue	Mid to low status	191	50.00	30.00	30.00	16513.00	0.1086
	Higher status	191	50.00	35.00	30.00		
Emotional well-being	Mid to low status	191	50.00	64.00	26.00	15882.00	0.0285*
	Higher status	191	50.00	72.00	24.00		
Social functioning	Mid to low status	191	50.00	50.00	50.00	15784.00	0.0218*
	Higher status	191	50.00	62.50	37.50		
Pain	Mid to low status	191	50.00	45.00	55.00	15808.00	0.0235*
	Higher status	191	50.00	57.50	55.00		
General health	Mid to low status	191	50.00	35.00	35.00	15757.00	0.0211*
	Higher status	191	50.00	40.00	35.00		
Health change	Mid to low status	191	50.00	50.00	25.00	17602.00	0.5305
	Higher status	191	50.00	50.00	25.00		

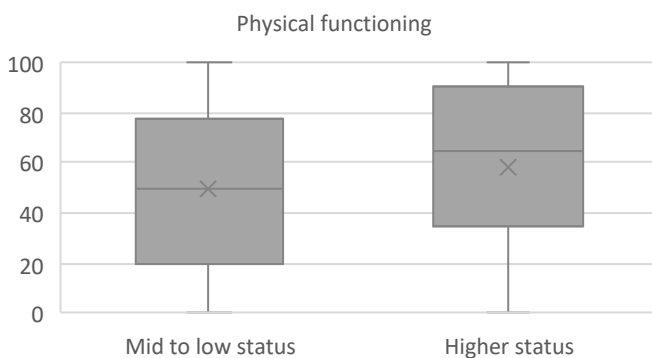


Figure 2.58: Boxplot of SF36 Physical functioning by socioeconomic status

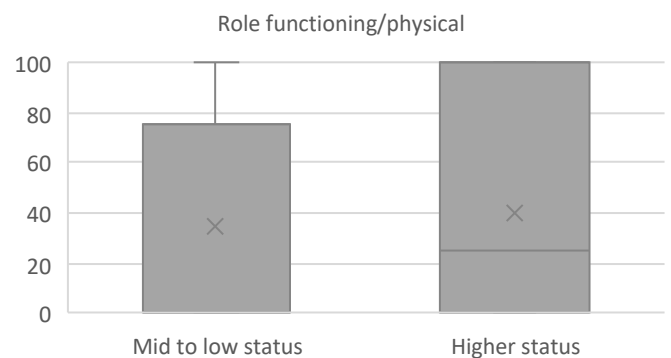


Figure 2.59: Boxplot of SF36 Role functioning/physical by socioeconomic status

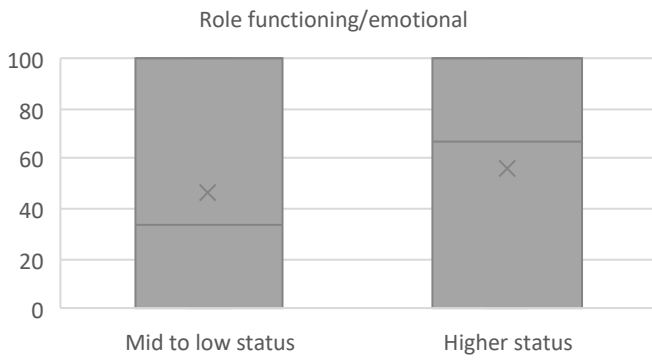


Figure 2.60: Boxplot of SF36 Role functioning/emotional by socioeconomic status

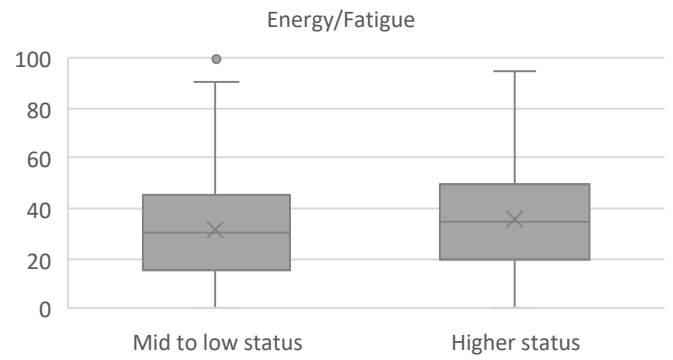


Figure 2.61: Boxplot of SF36 Energy/fatigue by socioeconomic status



Figure 2.62: Boxplot of SF36 Emotional well-being by socioeconomic status

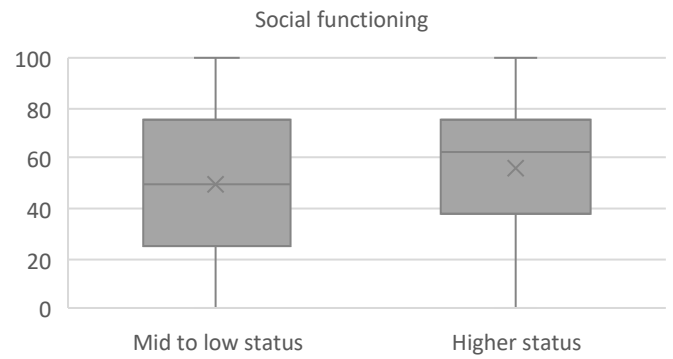


Figure 2.63: Boxplot of SF36 Social functioning by socioeconomic status

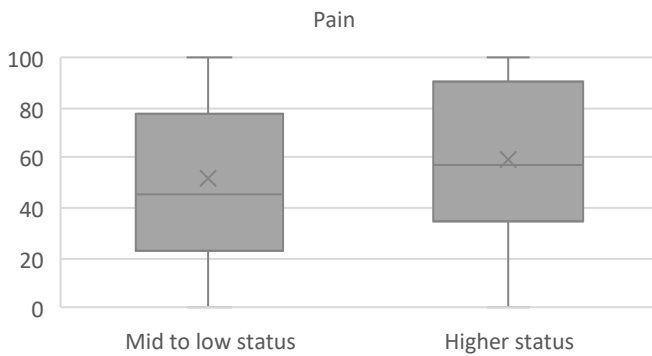


Figure 2.64: Boxplot of SF36 Pain by socioeconomic status

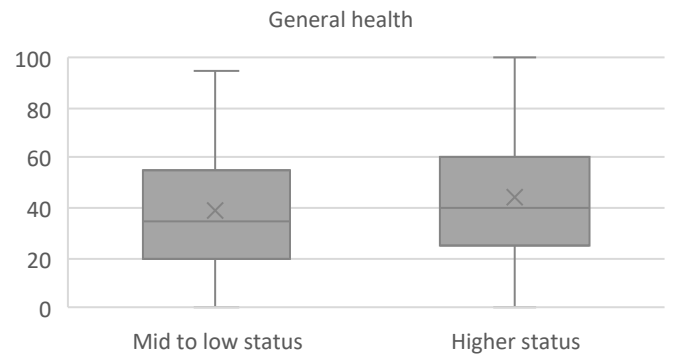


Figure 2.65: Boxplot of SF36 General health by socioeconomic status

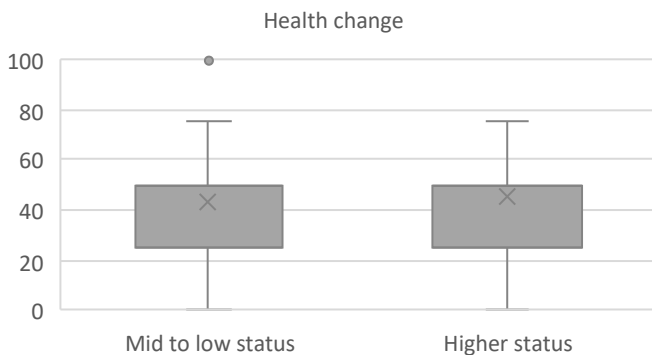


Figure 2.66: Boxplot of SF36 Health change by socioeconomic status