

## Section 7

### Care and support

## Section 7: Experience of care and support

### Care coordination

A Care Coordination questionnaire was completed by participants within the online questionnaire. The Care Coordination questionnaire comprises a total score, two scales (communication and navigation), and a single question for each relating to care-coordination and care received. A higher score denotes better care outcome.

The overall scores for the cohort were in the highest quintile for **Care coordination: Quality of care** global measure (median=7.00, IQR=3.00) indicating good quality of care. The overall scores for the cohort were in the highest quintile for **Care coordination: Communication** (median=36.00, IQR=13.00), **Care coordination: Navigation** (median=23.00, IQR=8.00), **Care coordination: Total score** (mean=58.51, SD=14.77), **Care coordination: Care coordination global measure** (median=6.00, IQR=4.00) indicating moderate communication, moderate communication, moderate care coordination, moderate care coordination.

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. The average score indicates that participants had moderate communication with healthcare professionals.

The **Care coordination: navigation** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. The average score indicates that participants had moderate navigation of the healthcare system.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. The average score indicates that participants had moderate communication, navigation and overall experience of care coordination.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. The average score indicates that participants scored rated their care coordination as moderate.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. The average score indicates that participants rated their quality of care as good.

### Experience of care and support

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common responses were that they did not receive formal support (25.12%), found support and care from hospital or clinical setting (23.38%), family and friends (20.65%), and charities (17.41%). Other themes included peer support or other patients (13.93%), and challenges accessing support (12.44%).

## Care coordination

A Care Coordination questionnaire was completed by participants within the online questionnaire. The Care Coordination questionnaire comprises a total score, two scales (communication and navigation), and a single question for each relating to care-coordination and care received. A higher score denotes better care outcome. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in the table below.

The overall scores for the cohort were in the highest quintile for **Care coordination: Quality of care** global measure (median=7.00, IQR=3.00) indicating good quality of care.

The overall scores for the cohort were in the highest quintile for **Care coordination: Communication** (median=36.00, IQR=13.00), **Care coordination: Navigation** (median=23.00, IQR=8.00), **Care coordination: Total score** (mean=58.51, SD=14.77), **Care coordination: Care coordination global measure** (median=6.00, IQR=4.00) indicating moderate communication, moderate communication, moderate care coordination, moderate care coordination.

Comparisons of Care co-ordination have been made based on condition, participant type, gender, age, education, location and socioeconomic status.

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects

of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. The average score indicates that participants had moderate communication with healthcare professionals.

The **Care coordination: navigation** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. The average score indicates that participants had moderate navigation of the healthcare system.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. The average score indicates that participants had moderate communication, navigation and overall experience of care coordination.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. The average score indicates that participants scored rated their care coordination as moderate.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. The average score indicates that participants rated their quality of care as good.

**Table 7.1: Care coordination summary statistics**

Care coordination scale (n=368)	Mean	SD	Median	IQR	Possible range	Quintile
Communication	35.55	10.34	36.00	13.00	13 to 65	3
Navigation	22.96	6.07	23.00	8.00	7 to 35	3
Total score*	58.51	14.77	60.00	19.00	20 to 100	3
Care coordination global measure	5.79	2.60	6.00	4.00	1 to 10	3
Quality of care global measure	6.59	2.43	7.00	3.00	1 to 10	4

Normal distribution use mean and SD as measure of central tendency

## Care coordination by condition

Comparisons were made by **condition**. There were 58 participants (15.89%) with developmental anomalies , 74 participants (20.27%) with diseases of the immune system , 92 participants (25.21%) with diseases of the nervous system , 27 participants (7.40%) with diseases of the skin , 92 participants (25.21%) with endocrine, nutritional or metabolic diseases , and 22 participants (6.03%) with other rare condition.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal. A Tukey HSD test was used post hoc to identify the source of any differences identified in the one-way ANOVA test.

When 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 one way ANOVA test indicated a statistically significant difference in the Care coordination: Communication scale between groups,  $F(5, 362) = 3.80$   $p = 0.0023$ . The largest significant difference was between participants in the Developmental anomalies subgroup (median = 36.12, IQR = 10.27), and participants in the Endocrine, nutritional or metabolic diseases subgroup (median = 37.28, IQR = 9.81,  $p < 0.0000$ ).

A one way ANOVA test indicated a statistically significant difference in the Care coordination: Navigation scale between groups,  $F(5, 362) = 7.06$   $p = < 0.0001$ . The largest significant difference was between participants in the Other rare condition subgroup (median = 23.44, IQR = 7.08), and participants in the Endocrine, nutritional or metabolic diseases subgroup (median = 24.38, IQR = 5.34,  $p < 0.0000$ ).

A one way ANOVA test indicated a statistically significant difference in the Care coordination: Total score scale between groups,  $F(5, 362) = 5.95$   $p = < 0.0001$ . The largest significant difference was between participants in the Other rare condition subgroup (median = 58.56, IQR = 16.34), and participants in the Endocrine, nutritional or metabolic diseases subgroup (median = 61.66, IQR = 13.75,  $p < 0.0000$ ).

A Kruskal-Wallis test indicated a statistically significant difference in the Care coordination: Care coordination global measure scale between groups,  $\chi^2(5) = 18.46$   $p = 0.0024$ . The largest significant difference was between participants in the Diseases of the nervous system subgroup (median = 7.00, IQR = 3.00), and participants in the Diseases of the skin subgroup (median = 4.00, IQR = 2.50,  $p = 0.0019$ ).

A Kruskal-Wallis test indicated a statistically significant difference in the Care coordination: Quality of care global measure scale between groups,  $\chi^2(5) = 27.73$   $p = < 0.0001$ . The largest significant difference was between participants in the Developmental anomalies subgroup (median = 8.00, IQR = 3.00), and participants in the Diseases of the skin subgroup (median = 5.00, IQR = 3.00,  $p = < 0.0001$ ).

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects

of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. On average, participants in the Diseases of the nervous system subgroup scored higher than participants in the Diseases of the immune system subgroup. This indicates that healthcare communication was average for participants in the Diseases of the nervous system subgroup, and poor for participants in the Diseases of the immune system subgroup.

The **Care coordination: navigation** scale measures the ability of a patient to navigate the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. On average, participants in the Developmental anomalies subgroup scored higher than participants in the Diseases of the immune system subgroup. This indicates that healthcare navigation was good for participants in the Developmental anomalies subgroup, and average for participants in the Diseases of the immune system subgroup.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. On average, participants in the Developmental anomalies subgroup had a higher total score for navigation compared to Diseases of the immune system, however communication, navigation and overall experience of care coordination was average for both groups.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. On average, participants in the Diseases of the nervous system subgroup scored higher than participants in the Diseases of the skin subgroup. This indicates that, overall care coordination was good for participants in the Diseases of the nervous system subgroup, and poor for participants in the Diseases of the skin subgroup.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. On average, participants in the Developmental anomalies subgroup scored higher than participants in the Diseases of the skin subgroup. This indicates that, quality of care was good for participants in the Developmental anomalies subgroup, and average for participants in the Diseases of the skin subgroup.

**Table 7.2: Care coordination by condition summary statistics and one-way ANOVA**

Partners in health scale	Group	Number (n=368)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Communication	Developmental anomalies	58	15.89	36.12	10.27	Between groups	1954.00	5	390.90	3.80	0.0023*
	Diseases of the immune system	74	20.27	32.21	9.07	Within groups	37246.00	362	102.90		
	Diseases of the nervous system	92	25.21	37.44	10.28	Total	39200.00	367			
	Diseases of the skin	27	7.40	31.19	11.64						
	Endocrine, nutritional or metabolic diseases	92	25.21	37.28	9.81						
	Other rare condition	22	6.03	35.12	11.74						
Navigation	Developmental anomalies	58	15.89	22.25	5.78	Between groups	1201.00	5	240.14	7.06	<0.0001*
	Diseases of the immune system	74	20.27	20.75	5.97	Within groups	12316.00	362	34.02		
	Diseases of the nervous system	92	25.21	24.61	5.70	Total	13517.00	367			
	Diseases of the skin	27	7.40	19.26	6.43						
	Endocrine, nutritional or metabolic diseases	92	25.21	24.38	5.34						
	Other rare condition	22	6.03	23.44	7.08						
Total score	Developmental anomalies	58	15.89	58.37	15.12	Between groups	6077.00	5	1215.40	5.95	<0.0001*
	Diseases of the immune system	74	20.27	52.96	13.13	Within groups	73947.00	362	204.30		
	Diseases of the nervous system	92	25.21	62.05	14.37	Total	80024.00	367			
	Diseases of the skin	27	7.40	50.44	15.08						
	Endocrine, nutritional or metabolic diseases	92	25.21	61.66	13.75						
	Other rare condition	22	6.03	58.56	16.34						

**Table 7.3: Care coordination by condition one-way post hoc Tukey HSD test**

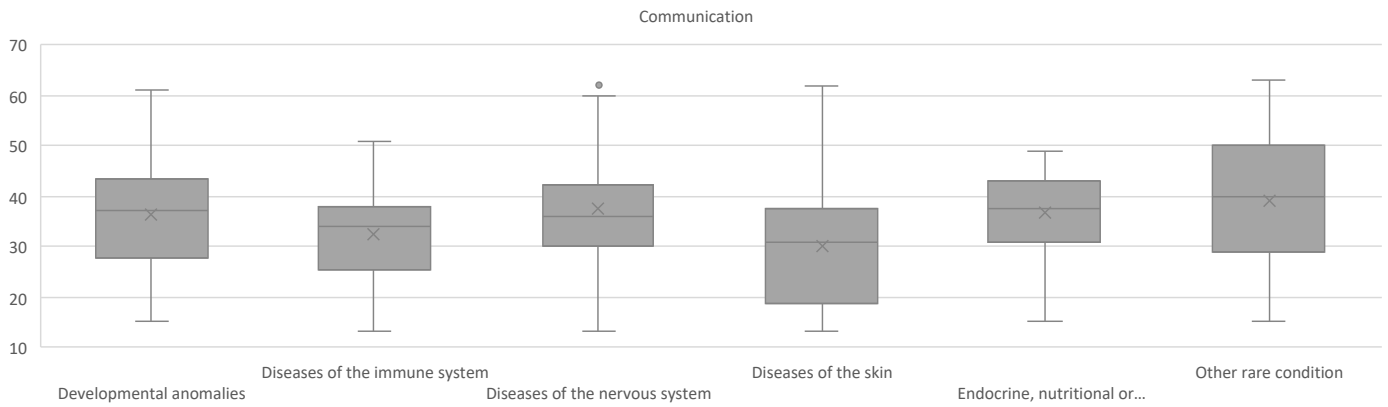
Care coordination scale	Group	Difference	Upper	Lower	p adjusted
Communication	Diseases of the immune system - Developmental anomalies	-3.91	-9.07	1.24	0.2512
	Diseases of the nervous system - Developmental anomalies	1.32	-3.57	6.21	0.9720
	Diseases of the skin - Developmental anomalies	-4.94	-11.73	1.85	0.2982
	Endocrine, nutritional or metabolic diseases - Developmental anomalies	1.15	-3.72	6.03	0.9843
	Other rare condition - Developmental anomalies	-1.00	-7.97	5.97	0.9985
	Diseases of the nervous system - Diseases of the immune system	5.23	0.67	9.79	0.0141*
	Diseases of the skin - Diseases of the immune system	-1.02	-7.58	5.54	0.9977
	Endocrine, nutritional or metabolic diseases - Diseases of the immune system	5.07	0.52	9.62	0.0191*
	Other rare condition - Diseases of the immune system	2.91	-3.83	9.66	0.8186
	Diseases of the skin - Diseases of the nervous system	-6.26	-12.61	0.10	0.0564
	Endocrine, nutritional or metabolic diseases - Diseases of the nervous system	-0.16	-4.41	4.09	1.0000
	Other rare condition - Diseases of the nervous system	-2.32	-8.87	4.23	0.9126
	Endocrine, nutritional or metabolic diseases - Diseases of the skin	6.09	-0.25	12.44	0.0682
	Other rare condition - Diseases of the skin	3.93	-4.13	12.00	0.7285
	Navigation	Other rare condition - Endocrine, nutritional or metabolic diseases	-2.16	-8.70	4.38
Diseases of the immune system - Developmental anomalies		-1.50	-4.46	1.47	0.6986
Diseases of the nervous system - Developmental anomalies		2.37	-0.44	5.18	0.1545
Diseases of the skin - Developmental anomalies		-2.99	-6.89	0.92	0.2442
Endocrine, nutritional or metabolic diseases - Developmental anomalies		2.14	-0.67	4.94	0.2483
Other rare condition - Developmental anomalies		1.19	-2.81	5.20	0.9570
Diseases of the nervous system - Diseases of the immune system		3.86	1.24	6.49	0.0004*
Diseases of the skin - Diseases of the immune system		-1.49	-5.26	2.28	0.8676
Endocrine, nutritional or metabolic diseases - Diseases of the immune system		3.63	1.02	6.25	0.0012*
Other rare condition - Diseases of the immune system		2.69	-1.19	6.57	0.3520
Diseases of the skin - Diseases of the nervous system		-5.35	-9.01	-1.70	0.0005*
Endocrine, nutritional or metabolic diseases - Diseases of the nervous system		-0.23	-2.67	2.21	0.9998
Other rare condition - Diseases of the nervous system		-1.17	-4.94	2.59	0.9481
Endocrine, nutritional or metabolic diseases - Diseases of the skin		5.12	1.47	8.77	0.0010*
Other rare condition - Diseases of the skin		4.18	-0.46	8.82	0.1042
Total score	Other rare condition - Endocrine, nutritional or metabolic diseases	-0.94	-4.70	2.82	0.9796
	Diseases of the immune system - Developmental anomalies	-5.41	-12.67	1.85	0.2716
	Diseases of the nervous system - Developmental anomalies	3.69	-3.20	10.57	0.6432
	Diseases of the skin - Developmental anomalies	-7.92	-17.49	1.64	0.1685
	Endocrine, nutritional or metabolic diseases - Developmental anomalies	3.29	-3.58	10.17	0.7440
	Other rare condition - Developmental anomalies	0.19	-9.63	10.01	1.0000
	Diseases of the nervous system - Diseases of the immune system	9.10	2.67	15.52	0.0009*
	Diseases of the skin - Diseases of the immune system	-2.51	-11.75	6.73	0.9709
	Endocrine, nutritional or metabolic diseases - Diseases of the immune system	8.70	2.29	15.11	0.0017*
	Other rare condition - Diseases of the immune system	5.60	-3.90	15.11	0.5404
	Diseases of the skin - Diseases of the nervous system	-11.61	-20.56	-2.66	0.0032*
	Endocrine, nutritional or metabolic diseases - Diseases of the nervous system	-0.39	-6.38	5.59	1.0000
	Other rare condition - Diseases of the nervous system	-3.49	-12.72	5.73	0.8872
	Endocrine, nutritional or metabolic diseases - Diseases of the skin	11.22	2.27	20.16	0.0050*
	Other rare condition - Diseases of the skin	8.12	-3.25	19.48	0.3186
Other rare condition - Endocrine, nutritional or metabolic diseases	-3.10	-12.31	6.12	0.9290	

**Table 7.4: Care coordination by condition summary statistics and Kruskal Wallis test**

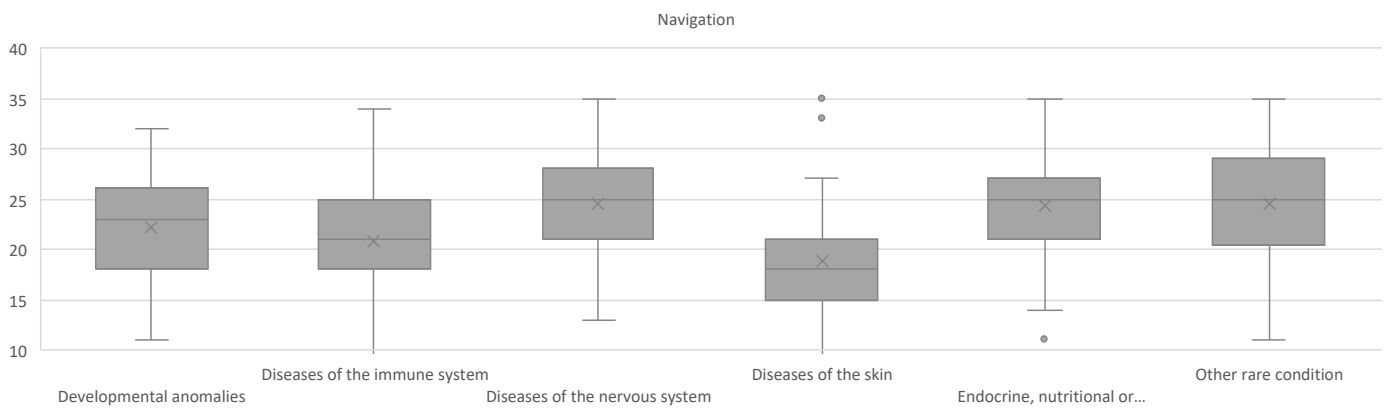
SF36 scale	Group	Number (n=368)	Percent	Median	IQR	C <sup>2</sup>	dF	p-value
Care coordination global measure	Developmental anomalies	58	15.89	6.00	5.00	18.46	5	0.0024
	Diseases of the immune system	74	20.27	5.00	3.00			
	Diseases of the nervous system	92	25.21	7.00	3.00			
	Diseases of the skin	27	7.40	4.00	2.50			
	Endocrine, nutritional or metabolic diseases	92	25.21	7.00	3.75			
	Other rare condition	22	6.03	5.00	6.00			
Quality of care global measure	Developmental anomalies	58	15.89	8.00	3.00	27.73	5	<0.0001*
	Diseases of the immune system	74	20.27	7.00	3.25			
	Diseases of the nervous system	92	25.21	8.00	2.00			
	Diseases of the skin	27	7.40	5.00	3.00			
	Endocrine, nutritional or metabolic diseases	92	25.21	7.00	4.00			
	Other rare condition	22	6.03	7.00	4.00			

**Table 7.5: Care coordination by condition one-way post hoc Wilcoxon rank sum test**

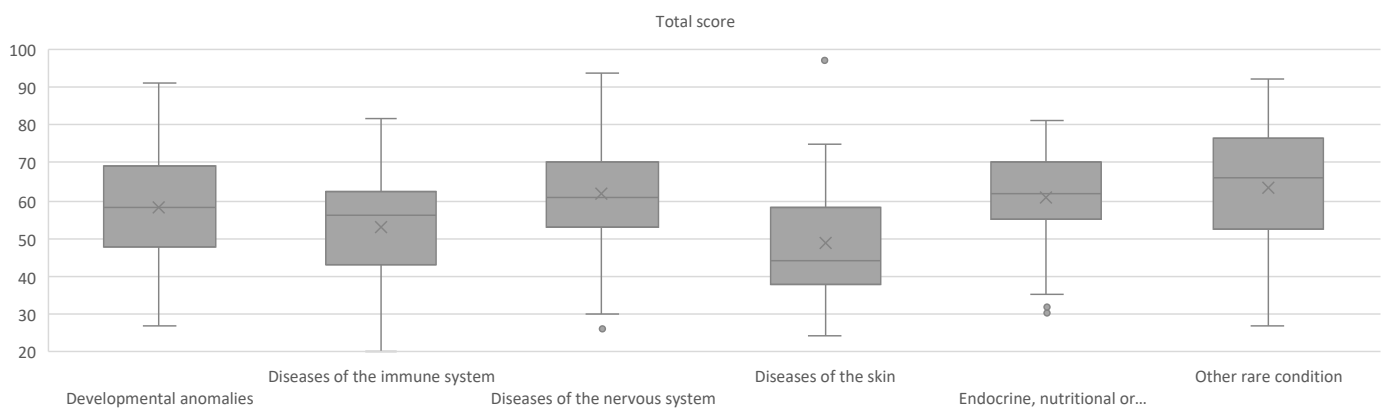
SF36 scale		Developmental anomalies	Diseases of the immune system	Diseases of the nervous system	Diseases of the skin	Endocrine, nutritional or metabolic diseases
<b>Coping</b>	Diseases of the immune system	0.3338	-	-	-	-
	Diseases of the nervous system	0.7507	0.0400*	-	-	-
	Diseases of the skin	0.0400*	0.0720	0.0019*	-	-
	Endocrine, nutritional or metabolic diseases	0.8317	0.0743	0.8317	0.0049*	-
	Other rare condition	0.7789	0.9404	0.3338	0.3338	0.5369
<b>Adherence to treatment</b>	Diseases of the immune system	0.0442	-	-	-	-
	Diseases of the nervous system	0.4700	0.1470	-	-	-
	Diseases of the skin	<0.0001*	0.0038*	<0.0001*	-	-
	Endocrine, nutritional or metabolic diseases	0.4700	0.1470	0.9836	0.0001*	-
	Other rare condition	0.3781	0.9192	0.4700	0.0309*	0.4700



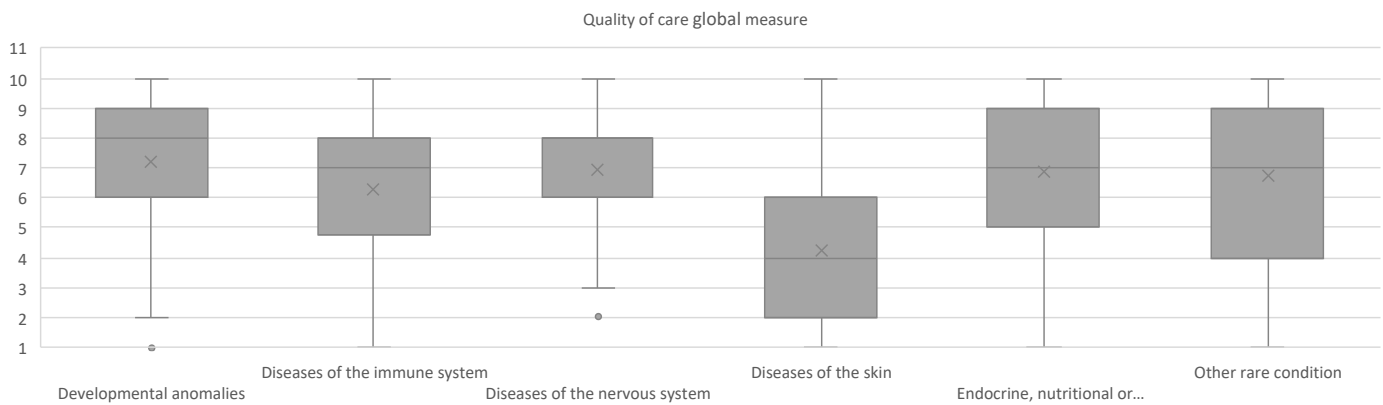
**Figure 7.1: Boxplot of Care coordination: Communication by condition**



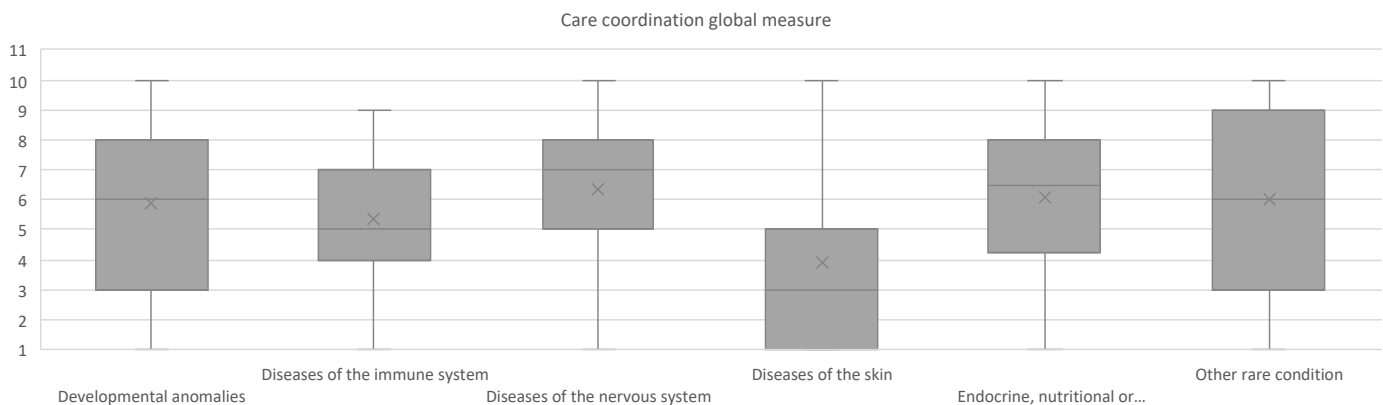
**Figure 7.2: Boxplot of Care coordination: Navigation by condition**



**Figure 7.3: Boxplot of Care coordination: Total score by condition**



**Figure 7.4: Boxplot of Care coordination: Care coordination global measure by condition**



**Figure 7.5: Boxplot of Care coordination: Quality of care global measure by condition**

### Care coordination by type of participant

Comparisons were made by **type of participant** there were 246 participants (66.85%) with person with condition and, 122 participants (33.15%) with carer.

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

A two sample t-test indicated that the mean score for the Care coordination Communication scale [ $t(366) = -3.77$ ,  $p = 0.0002$ ] was significantly lower for participants in the Person with condition subgroup (Mean = 34.15, SD = 9.89) compared to participants in the Carer subgroup (Mean = 38.39, SD = 10.67.)

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Care coordination Navigation scale [ $W = 11900.00$ ,  $p = 0.0012$ ] was significantly lower for participants in the Person with condition subgroup (Median = 22.00, IQR = 7.75) compared to participants in the Carer subgroup (Median = 25.00, IQR = 7.00).

A two sample t-test indicated that the mean score for the Care coordination Total score scale [ $t(366) = -3.91$ ,  $p = 0.0001$ ] was significantly lower for participants in the Person with condition subgroup (Mean = 56.43, SD = 14.22) compared to participants in the Carer subgroup (Mean = 62.70, SD = 15.02.)

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Care coordination Care coordination global measure scale [ $W = 11419.00$ ,  $p = 0.0002$ ] was significantly lower for participants in the Person with condition subgroup (Median = 6.00, IQR = 4.00) compared to participants in the Carer subgroup (Median = 7.00, IQR = 3.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Care coordination Quality of care global measure scale [ $W = 10360.00$ ,  $p < 0.0000$ ] was significantly lower for participants in the Person with condition subgroup (Median = 7.00, IQR = 4.00) compared to participants in the Carer subgroup (Median = 8.00, IQR = 2.00).



The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. On average, participants in the Carer subgroup had a higher score for communication compared to Person with condition, however, healthcare communication was average for both groups.

The **Care coordination: navigation** scale measures the ability of a patient to navigate the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. On average, participants in the Carer subgroup scored higher than participants in the Person with condition subgroup. This indicates that healthcare navigation was good for participants in the Carer subgroup, and average for participants in the Person with condition subgroup.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. On average, participants in the Carer subgroup had a higher total score for navigation compared to Person with condition, however communication, navigation and overall experience of care coordination was average for both groups.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. On average, participants in the Carer subgroup scored higher than participants in the Person with condition subgroup. This indicates that, overall care coordination was good for participants in the Carer subgroup, and average for participants in the Person with condition subgroup.

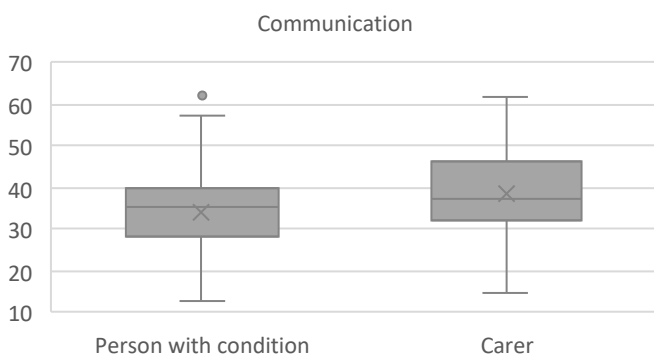
The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. On average, participants in the Carer subgroup had a higher score for quality of care compared to Person with condition, however, quality of care was good for both groups.

**Table 7.6: Care coordination by type of participant summary statistics and T-test**

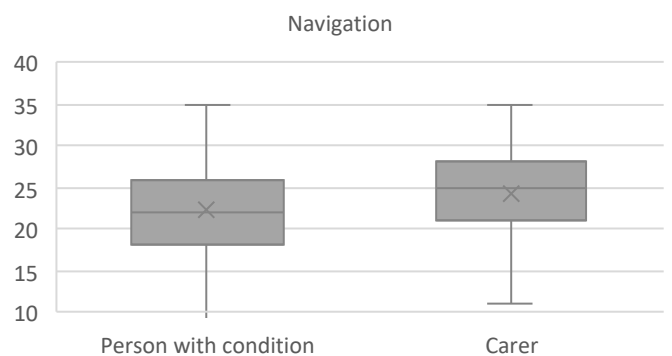
Care coordination scale	Group	Number (n=368)	Percent	Mean	SD	T	dF	p-value
Communication	Person with condition	246	66.85	34.15	9.89	-3.77	366.00	0.0002*
	Carer	122	33.15	38.39	10.67			
Total score	Person with condition	246	66.85	56.43	14.22	-3.91	366.00	0.0001*
	Carer	122	33.15	62.70	15.02			

**Table 7.7: Care coordination by type of participant summary statistics and Wilcoxon test**

Care coordination scale	Group	Number (n=368)	Percent	Median	IQR	W	p-value
Navigation	Person with condition	246	66.85	22.00	7.75	11900.00	0.0012*
	Carer	122	33.15	25.00	7.00		
Care coordination global measure	Person with condition	246	66.85	6.00	4.00	11419.00	0.0002*
	Carer	122	33.15	7.00	3.00		
Quality of care global measure	Person with condition	246	66.85	7.00	4.00	10360.00	0.0000*
	Carer	122	33.15	8.00	2.00		

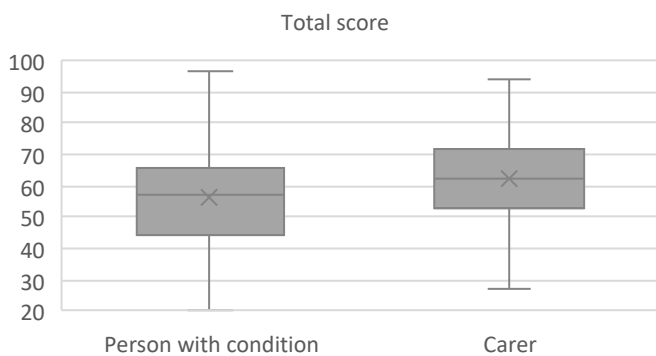


**Figure 7.6: Boxplot of Care coordination: Communication by type of participant**

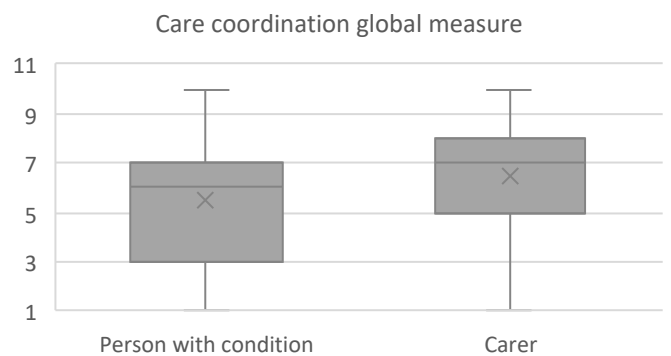


**Figure 7.7: Boxplot of Care coordination: Navigation by type of participant**

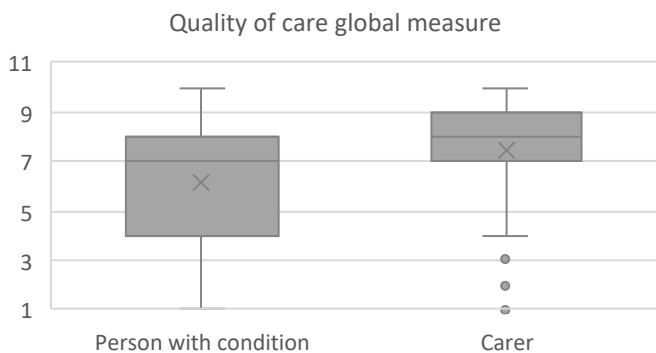




**Figure 7.8: Boxplot of Care coordination: Total score by type of participant**



**Figure 7.9: Boxplot of Care coordination: Care coordination global measure by type of participant**



**Figure 7.10: Boxplot of Care coordination: Quality of care global measure by type of participant**

### Care coordination by gender

Comparisons were made by **gender**, there were 274 female participants (74.86%) and 92 male participants (25.14%).

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

A two sample t-test indicated that the mean score for the Care coordination Navigation scale [ $t(364) = -3.31$ ,  $p = 0.0010$ ] was significantly lower for participants in the Female subgroup (Mean = 22.37, SD = 6.09) compared to participants in the Male subgroup (Mean = 24.76, SD = 5.70.)

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Care coordination Communication scale [ $W = 10164.00$ ,  $p = 0.0054$ ] was significantly lower for participants in the Female subgroup (Median = 35.00, IQR = 13.00) compared to participants in the Male subgroup (Median = 38.00, IQR = 12.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Care coordination Total score scale [ $W = 9613.00$ ,  $p = 0.0007$ ] was significantly lower for participants in the Female subgroup (Median = 57.00, IQR = 20.00) compared to participants in the Male subgroup (Median = 64.00, IQR = 16.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Care coordination Care coordination global measure scale [ $W = 10117.00$ ,  $p = 0.0044$ ] was significantly lower for participants in the Female subgroup (Median = 6.00, IQR = 4.00) compared to participants in the Male subgroup (Median = 7.00, IQR = 4.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Care coordination Quality of care global measure scale [ $W = 9653.00$ ,  $p = 0.0007$ ] was significantly lower for participants in the Female subgroup (Median = 7.00, IQR = 3.00) compared to participants in the Male subgroup (Median = 8.00, IQR = 3.00).

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. On average, participants in the Male subgroup had a higher score for communication compared to Female, however, healthcare communication was average for both groups.

The **Care coordination: navigation** scale measures the ability of a patient to navigate the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. On average, participants in the Male subgroup scored higher than participants in the Female subgroup. This indicates that healthcare navigation was good for participants in the Male subgroup, and average for participants in the Female subgroup.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. On average, participants in the Male subgroup had a higher total score for navigation compared to Female, however communication, navigation and overall experience of care coordination was average for both groups.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. On average, participants in the Male subgroup scored higher than participants in the Female subgroup. This indicates that, overall care coordination was good for participants in the Male subgroup, and average for participants in the Female subgroup.

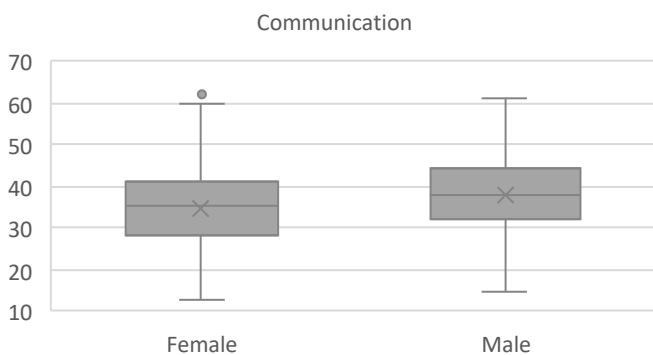
The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. On average, participants in the Male subgroup had a higher score for quality of care compared to Female, however, quality of care was good for both groups.

**Table 7.8: Care coordination by gender summary statistics and two-sample t-test**

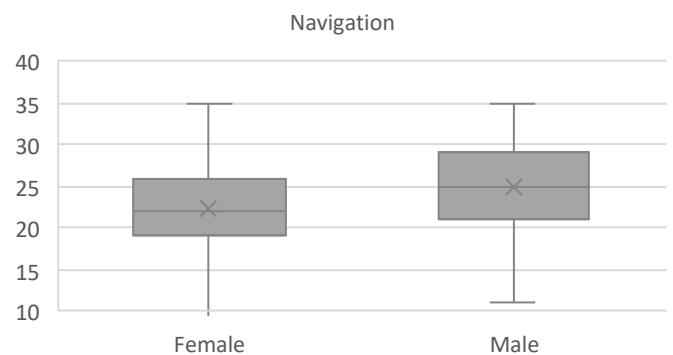
Care coordination scale	Group	Number (n=366)	Percent	Mean	SD	T	dF	p-value
Navigation	Female	274	74.86	22.37	6.09	-3.31	364.00	0.0010*
	Male	92	25.14	24.76	5.70			

**Table 7.8: Care coordination by gender summary statistics and Wilcoxon test**

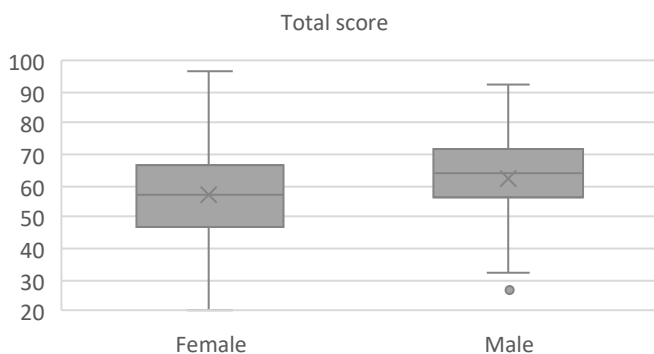
Care coordination scale	Group	Number (n=366)	Percent	Median	IQR	W	p-value
Communication	Female	274	74.86	35.00	13.00	10164.00	0.0054*
	Male	92	25.14	38.00	12.00		
Total score	Female	274	74.86	57.00	20.00	9613.00	0.0007*
	Male	92	25.14	64.00	16.00		
Care coordination global measure	Female	274	74.86	6.00	4.00	10117.00	0.0044*
	Male	92	25.14	7.00	4.00		
Quality of care global measure	Female	274	74.86	7.00	3.00	9653.00	0.0007*
	Male	92	25.14	8.00	3.00		



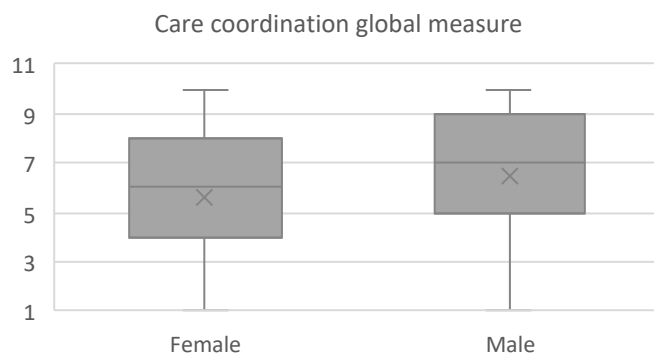
**Figure 7.11: Boxplot of Care coordination: Communication by gender**



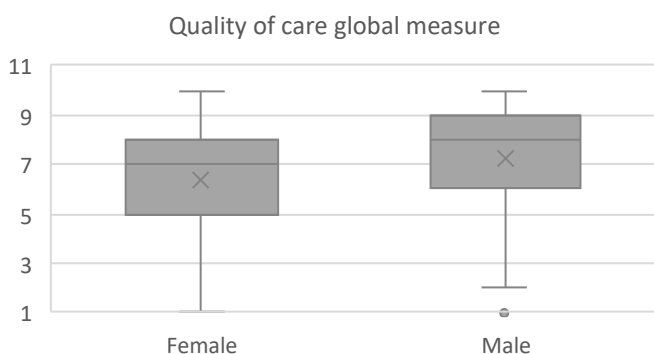
**Figure 7.12: Boxplot of Care coordination: Navigation by gender**



**Figure 7.13: Boxplot of Care coordination: Total score by gender**



**Figure 7.14: Boxplot of Care coordination: Care coordination global measure by gender**



**Figure 7.15: Boxplot of Care coordination: Quality of care global measure by gender**

### Care coordination by age

Comparisons were made by **age** of person with condition. There were 88 participants (23.91%) with aged under 18, 117 participants (31.79%) with aged 18 to 44, 105 participants (28.53%) with aged 45 to 64, and 58 participants (15.76%) with aged 65 or older.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal. A Tukey HSD test was used post hoc to identify the source of any differences identified in the one-way ANOVA test.

When 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 one way ANOVA test indicated a statistically significant difference in the Care coordination: Communication scale between groups,  $F(3, 364) = 13.90$   $p < 0.0001$ . The largest significant difference was between participants in the Aged 45 to 64 subgroup (median = 33.43, IQR = 9.02), and participants in the Aged 65 or older subgroup (median = 39.34, IQR = 9.79,  $p < 0.0000$ ).

A one way ANOVA test indicated a statistically significant difference in the Care coordination: Navigation scale between groups,  $F(3, 364) = 9.89$   $p < 0.0001$ . The largest significant difference was between participants in the Aged 45 to 64 subgroup (median = 22.37, IQR = 6.25), and participants in the Aged 65 or older subgroup (median = 24.83, IQR = 5.51,  $p < 0.0001$ ).

A one way ANOVA test indicated a statistically significant difference in the Care coordination: Total score scale between groups,  $F(3, 364) = 15.43$   $p < 0.0001$ . The largest significant difference was between participants in the Aged 45 to 64 subgroup (median = 55.80, IQR = 13.73), and participants in the Aged 65 or older subgroup (median = 64.17, IQR = 13.48,  $p < 0.0000$ ).

A Kruskal-Wallis test indicated a statistically significant difference in the Care coordination: Care coordination global measure scale between groups,  $\chi^2(3) = 26.24$   $P = <0.0001$ . The largest significant difference was between Aged under 18 (median = 7.5, IQR = 3), and Aged 18 to 44 (median = 5, IQR = 4,  $p = 0.0002$ ).

A Kruskal-Wallis test indicated a statistically significant difference in the Care coordination: Quality of care global measure scale between groups,  $\chi^2(3) = 41.88$   $P = <0.0001$ . The largest significant difference was between Aged under 18 (median = 8, IQR = 2), and Aged 18 to 44 (median = 6, IQR = 4,  $p = <0.0001$ ).

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. On average, participants in the Aged under 18 subgroup scored higher than participants in the Aged 18 to 44 subgroup. This indicates that healthcare communication was average for participants in the Aged under 18 subgroup, and poor for participants in the Aged 18 to 44 subgroup.

The **Care coordination: navigation** scale measures the ability of a patient to navigate the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. On

average, participants in the Aged under 18 subgroup scored higher than participants in the Aged 18 to 44 subgroup. This indicates that healthcare navigation was good for participants in the Aged under 18 subgroup, and average for participants in the Aged 18 to 44 subgroup.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. On average, participants in the Aged under 18 subgroup had a higher total score for navigation compared to Aged 18 to 44, however communication, navigation and overall experience of care coordination was average for both groups.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. On average, participants in the Aged under 18 subgroup scored higher than participants in the Aged 18 to 44 subgroup. This indicates that, overall care coordination was good for participants in the Aged under 18 subgroup, and average for participants in the Aged 18 to 44 subgroup.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. On average, participants in the Aged under 18 subgroup scored higher than participants in the Aged 18 to 44 subgroup. This indicates that, quality of care was good for participants in the Aged under 18 subgroup, and average for participants in the Aged 18 to 44 subgroup.

**Table 7.9: Care coordination by age summary statistics and one-way ANOVA**

Care coordination scale	Group	Number (n=368)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Communication	Aged under 18	88	23.91	39.77	11.15	Between groups	4030.00	3	1343.40	13.90	<0.0001*
	Aged 18 to 44	117	31.79	32.41	9.48	Within groups	35171.00	364	96.60		
	Aged 45 to 64	105	28.53	33.43	9.02	Total	39201.00	367			
	Aged 65 or older	58	15.76	39.34	9.79						
Navigation	Aged under 18	88	23.91	24.97	5.12	Between groups	1019.00	3	339.70	9.89	<0.0001*
	Aged 18 to 44	117	31.79	21.05	6.18	Within groups	12497.00	364	34.30		
	Aged 45 to 64	105	28.53	22.37	6.25	Total	13516.00	367			
	Aged 65 or older	58	15.76	24.83	5.51						
Total score	Aged under 18	88	23.91	64.74	15.30	Between groups	9027.00	3	3009.00	15.43	<0.0001*
	Aged 18 to 44	117	31.79	53.46	13.35	Within groups	70997.00	364	195.00		
	Aged 45 to 64	105	28.53	55.80	13.73	Total	80024.00	367			
	Aged 65 or older	58	15.76	64.17	13.48						

**Table 7.10: Care coordination by age one-way post hoc Tukey HSD test**

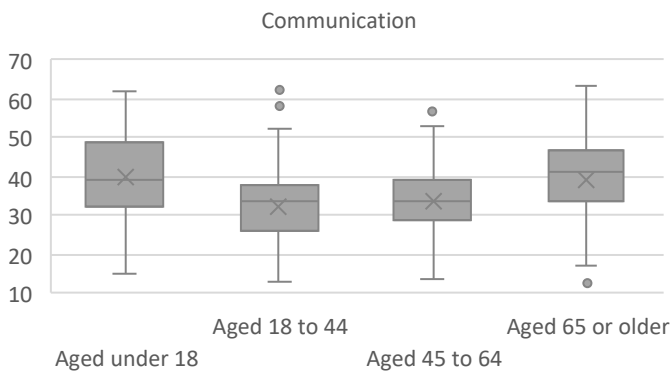
Care coordination scale	Group	Difference	Upper	Lower	p adjusted
Communication	Aged 18 to 44 - Aged under 18	-7.36	-10.94	-3.78	<0.0001*
	Aged 45 to 64 - Aged under 18	-6.34	-10.01	-2.68	0.0001*
	Aged 65 or older - Aged under 18	-0.43	-4.72	3.86	0.9940
	Aged 45 to 64 - Aged 18 to 44	1.02	-2.39	4.43	0.8677
	Aged 65 or older - Aged 18 to 44	6.93	2.86	11.01	0.0001*
	Aged 65 or older - Aged 45 to 64	5.92	1.77	10.07	0.0015*
Navigation	Aged 18 to 44 - Aged under 18	-3.91	-6.05	-1.78	<0.0001*
	Aged 45 to 64 - Aged under 18	-2.59	-4.78	-0.41	0.0125*
	Aged 65 or older - Aged under 18	-0.14	-2.70	2.42	0.9990
	Aged 45 to 64 - Aged 18 to 44	1.32	-0.71	3.35	0.3379
	Aged 65 or older - Aged 18 to 44	3.78	1.35	6.20	0.0004*
	Aged 65 or older - Aged 45 to 64	2.46	-0.02	4.93	0.0525
Total score	Aged 18 to 44 - Aged under 18	-11.28	-16.36	-6.19	<0.0001*
	Aged 45 to 64 - Aged under 18	-8.94	-14.15	-3.73	0.0001*
	Aged 65 or older - Aged under 18	-0.57	-6.66	5.53	0.9951
	Aged 45 to 64 - Aged 18 to 44	2.34	-2.51	7.18	0.5982
	Aged 65 or older - Aged 18 to 44	10.71	4.92	16.50	<0.0001*
	Aged 65 or older - Aged 45 to 64	8.37	2.48	14.27	0.0016*

**Table 7.11: Care coordination by age summary statistics and Kruskal Wallis test**

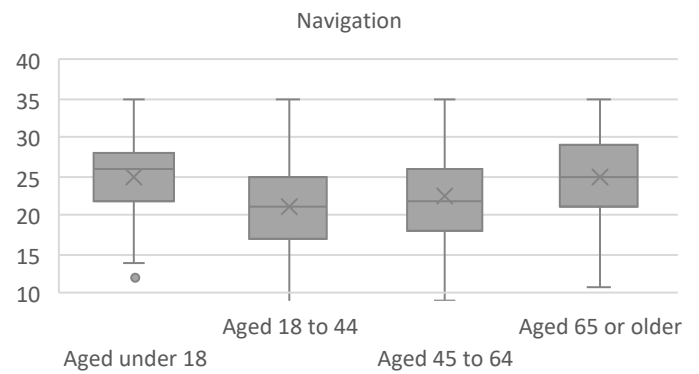
Care coordination scale	Group	Number (n=368)	Percent	Median	IQR	C <sup>2</sup>	dF	p-value
Care coordination global measure	Aged under 18	88	23.91	7.50	3.00	26.24	3	<0.0001*
	Aged 18 to 44	117	31.79	5.00	4.00			
	Aged 45 to 64	105	28.53	5.00	4.00			
	Aged 65 or older	58	15.76	7.00	4.00			
Quality of care global measure	Aged under 18	88	23.91	8.00	2.00	41.88	3	<0.0001*
	Aged 18 to 44	117	31.79	6.00	4.00			
	Aged 45 to 64	105	28.53	7.00	4.00			
	Aged 65 or older	58	15.76	8.00	2.75			

**Table 7.12: Care coordination by age one-way post hoc Wilcoxon rank sum test**

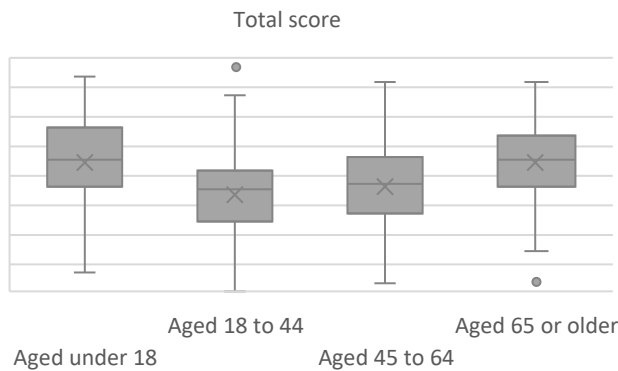
SF36 scale	Group	Aged under 18	Aged 18 to 44	Aged 45 to 64	Aged 65 or older
Care coordination global measure	Aged 18 to 44	0.0002*	-	-	-
	Aged 45 to 64	0.0011*	0.5084	-	-
	Aged 65 or older	0.8844	0.0011*	0.0034*	-
Quality of care global measure	Aged 18 to 44	<0.0001*	-	-	-
	Aged 45 to 64	<0.0001*	0.6775	-	-
	Aged 65 or older	0.7505	0.0002*	0.0010*	-



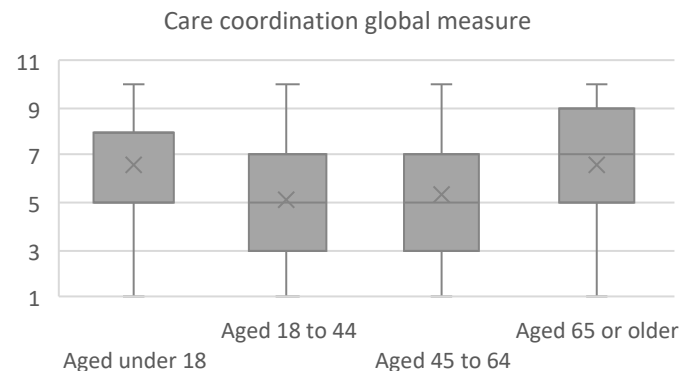
**Figure 7.16: Boxplot of Care coordination: Communication by age**



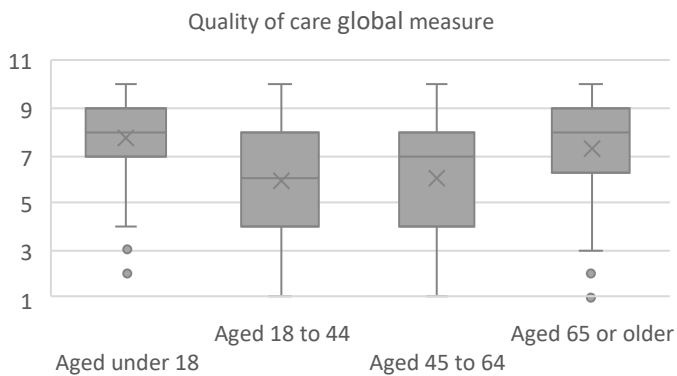
**Figure 7.17: Boxplot of Care coordination: Navigation by age**



**Figure 7.18: Boxplot of Care coordination: Total score by age**



**Figure 7.19: Boxplot of Care coordination: Care coordination global measure by age**



**Figure 7.20: Boxplot of Care coordination: Quality of care global measure by age**

### Care coordination by education

Comparisons were made by **education** status, between those with trade or high school qualifications (n=176, 48.89%), and those with a university qualification (n=184, 51.11%).

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

A two sample t-test indicated that the mean score for the Care coordination Navigation scale [t(358) = -2.37, p = 0.0185] was significantly lower for participants in the Trade or high school subgroup (Mean = 22.11, SD =

6.42) compared to participants in the University subgroup (Mean = 23.62, SD = 5.65.)

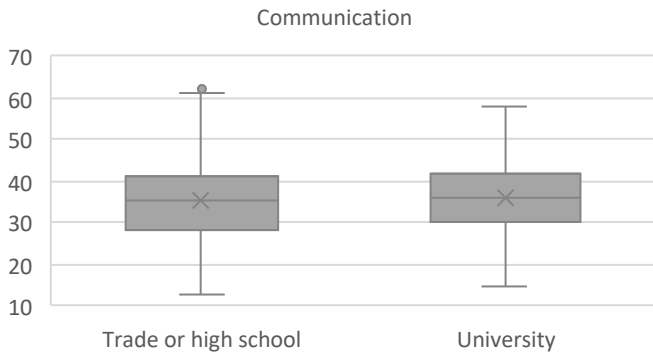
The **Care coordination: navigation** scale measures the ability of a patient to navigate the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. On average, participants in the University subgroup scored higher than participants in the Trade or high school subgroup, healthcare system navigation was average for both groups.

**Table 7.13: Care coordination by education summary statistics and T-test**

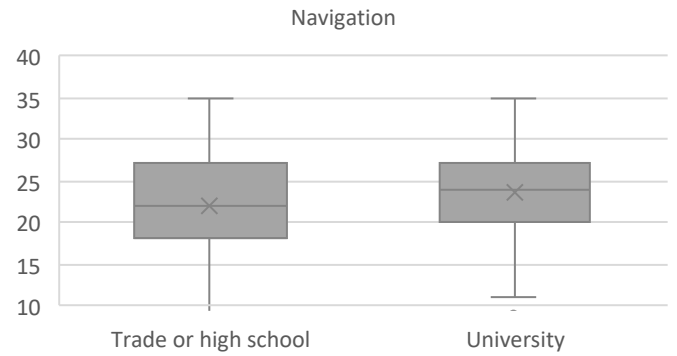
Care coordination scale	Group	Number (n=360)	Percent	Mean	SD	T	dF	p-value
Communication	Trade or high school	176	48.89	35.22	11.00	-0.52	358	0.6030
	University	184	51.11	35.79	9.84			
Navigation	Trade or high school	176	48.89	22.11	6.42	-2.37	358	0.0185*
	University	184	51.11	23.62	5.65			

**Table 7.14: Care coordination by education summary statistics and Wilcoxon test**

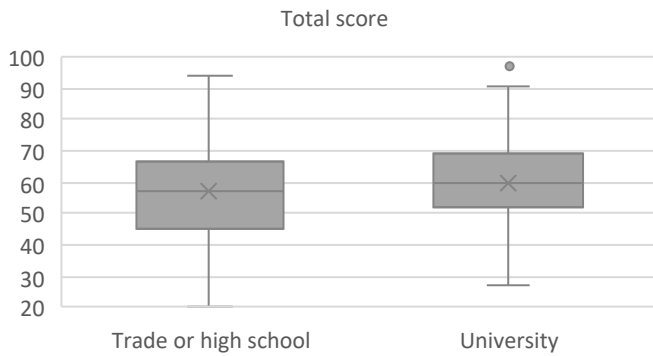
Care coordination scale	Group	Number (n=360)	Percent	Median	IQR	W	p-value
Total score	Trade or high school	176	48.89	57.00	22.00	14736.00	0.1402
	University	184	51.11	60.00	17.00		
Care coordination global measure	Trade or high school	176	48.89	6.00	5.00	15139.00	0.2833
	University	184	51.11	6.00	4.00		
Quality of care global measure	Trade or high school	176	48.89	7.00	3.25	14812.00	0.1579
	University	184	51.11	7.00	2.25		



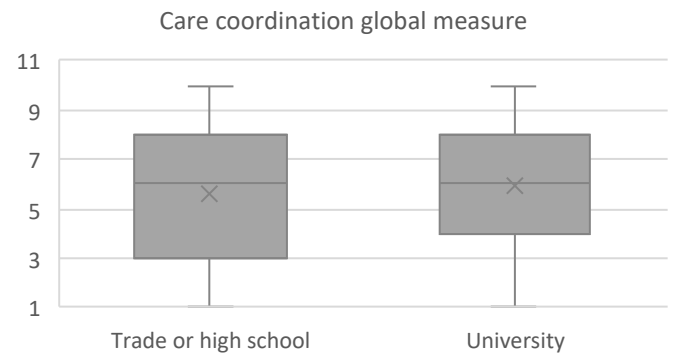
**Figure 7.21: Boxplot of Care coordination: Communication by education**



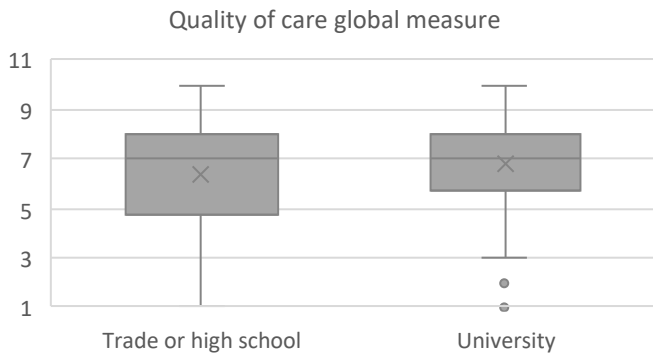
**Figure 7.22: Boxplot of Care coordination: Navigation by education**



**Figure 7.23: Boxplot of Care coordination: Total score by education**



**Figure 7.24: Boxplot of Care coordination: Care coordination global measure by education**



**Figure 7.25: Boxplot of Care coordination: Quality of care global measure by education**

### Care coordination 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=102, 27.72%) were compared to those living in a metropolitan area (n=266, 72.28%).

A two-sample t-test was used when assumptions for normality and variance were met, or when

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

No significant differences were observed between participants by **location** for any of the Care coordination scales.

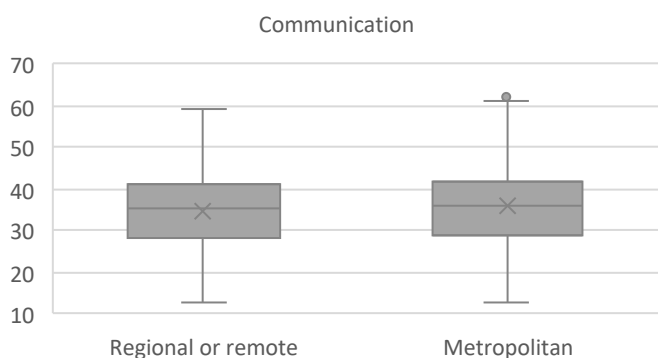


**Table 7.15: Care coordination by location summary statistics and T-test**

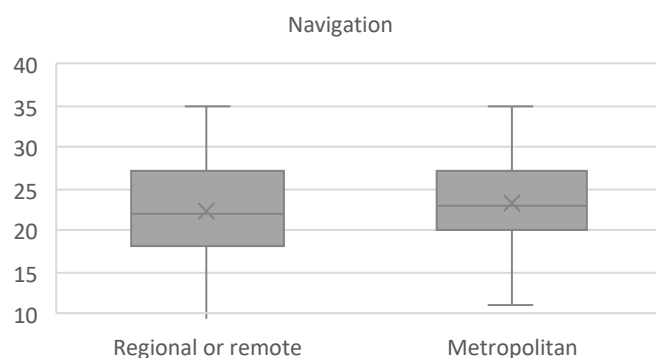
Care coordination scale	Group	Number (n=368)	Percent	Mean	SD	T	dF	p-value
Communication	Regional or remote	102	27.72	34.81	10.31	-0.85	366	0.3954
	Metropolitan	266	72.28	35.84	10.35			
Total score	Regional or remote	102	27.72	57.13	15.30	-1.12	366	0.2654
	Metropolitan	266	72.28	59.05	14.55			

**Table 7.16: Care coordination by location summary statistics and Wilcoxon test**

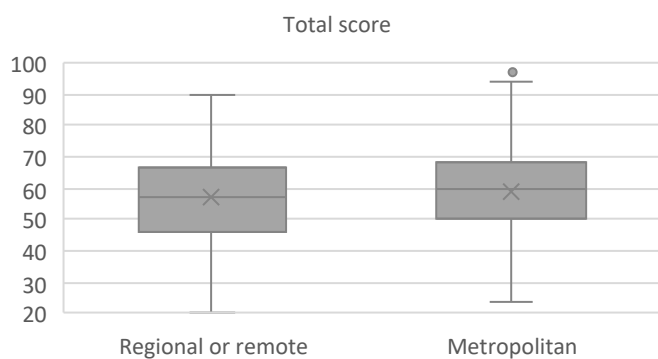
Care coordination scale	Group	Number (n=368)	Percent	Median	IQR	W	p-value
Navigation	Regional or remote	102	27.72	22.00	9.00	12548.00	0.2644
	Metropolitan	266	72.28	23.00	7.00		
Care coordination global measure	Regional or remote	102	27.72	6.00	4.75	13222.00	0.7047
	Metropolitan	266	72.28	6.00	4.00		
Quality of care global measure	Regional or remote	102	27.72	7.00	2.75	13300.00	0.7694
	Metropolitan	266	72.28	7.00	3.00		



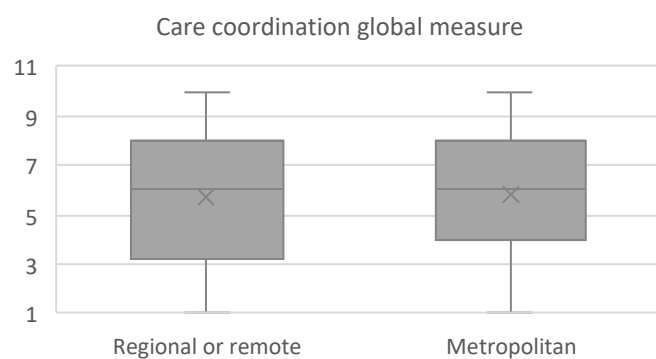
**Figure 7.26: Boxplot of Care coordination: Communication by location**



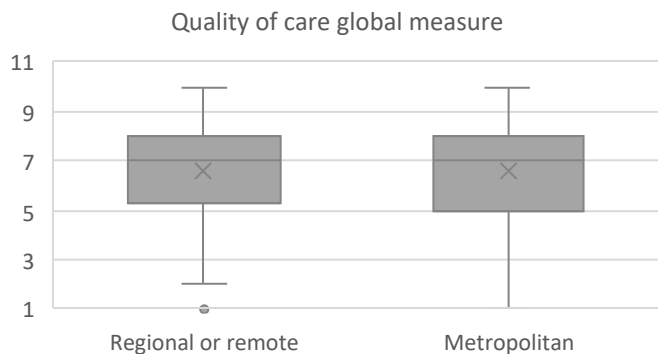
**Figure 7.27: Boxplot of Care coordination: Navigation by location**



**Figure 7.28: Boxplot of Care coordination: Total score by location**



**Figure 7.29: Boxplot of Care coordination: Care coordination global measure by location**



**Figure 7.30: Boxplot of Care coordination: Quality of care global measure by location**

## Care coordination by socioeconomic status

Comparisons were made by **socioeconomic status**, using the Socio-economic Indexes for Areas (SEIFA) ([www.abs.gov.au](http://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=182, 49.46%) compared to those with a higher SEIFA score of 7-10 (n=186, 50.54%).

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

A two sample t-test indicated that the mean score for the Care coordination Communication scale [t(366) = -2.71, p = 0.0071] was significantly lower for participants in the Mid to low status subgroup (Mean = 34.09, SD = 10.43) compared to participants in the Higher status subgroup (Mean = 36.98, SD = 10.07.)

A two sample t-test indicated that the mean score for the Care coordination Total score scale [t(366) = -3.78, p = 0.0002] was significantly lower for participants in the Mid to low status subgroup (Mean = 55.63, SD = 15.02) compared to participants in the Higher status subgroup (Mean = 61.34, SD = 13.99.)

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Care coordination Navigation scale [W = 12262.00, p = <0.0001] was significantly lower for participants in the Mid to low status subgroup (Median = 21.00, IQR = 8.00) compared to participants in the Higher status subgroup (Median = 25.00, IQR = 7.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Care coordination Care coordination global measure scale [W = 13780.00, p = 0.002] was significantly lower for participants in the Mid to low status subgroup (Median = 5.00, IQR = 5.00) compared to participants in the Higher status subgroup (Median = 7.00, IQR = 3.75).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Care coordination Quality of care global measure scale [W = 13838.00, p = 0.0022] was significantly lower for participants in the Mid to low status subgroup (Median = 7.00, IQR = 3.00) compared to participants in the Higher status subgroup (Median = 8.00, IQR = 3.00).

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. On average, participants in the Higher status subgroup had a higher score for communication compared to Mid to low status, however, healthcare communication was average for both groups.

The **Care coordination: navigation** scale measures the ability of a patient to navigate the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. On average, participants in the Higher status subgroup scored higher than participants in the Mid to low status subgroup. This indicates that healthcare navigation was good for participants in the Higher status subgroup, and average for participants in the Mid to low status subgroup.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. On average, participants in the Higher status subgroup scored higher than participants in the Mid to low status subgroup. This indicates that communication, navigation and overall experience of care coordination was average for participants in the Higher status subgroup, and poor for participants in the Mid to low status subgroup.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. On average, participants in the Higher status subgroup scored higher than participants in the Mid to low status subgroup. This indicates that, overall care coordination was good for participants in the Higher status subgroup, and average for participants in the Mid to low status subgroup.

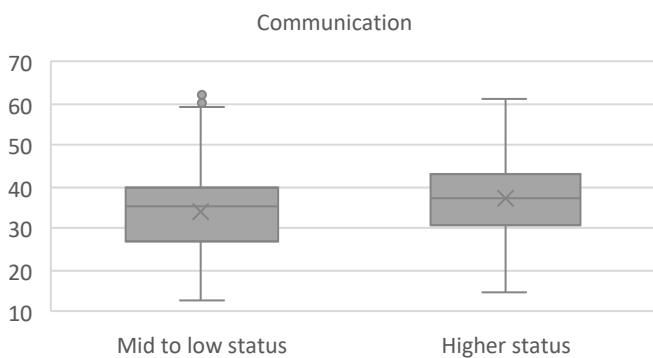
The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. On average, participants in the Higher status subgroup had a higher score for quality of compared to Mid to low status, however, quality of care was good for both groups.

**Table 7.17: Care coordination by socioeconomic status summary statistics and T-test**

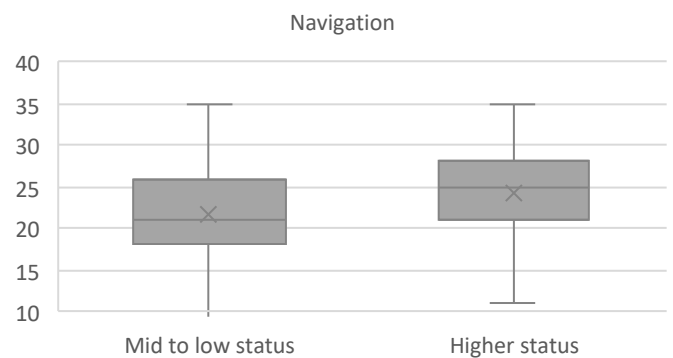
Care coordination scale	Group	Number (n=368)	Percent	Mean	SD	T	dF	p-value
Communication	Mid to low status	182	49.46	34.09	10.43	-2.71	366	0.0071*
	Higher status	186	50.54	36.98	10.07			
Total score	Mid to low status	182	49.46	55.63	15.02	-3.78	366	0.0002*
	Higher status	186	50.54	61.34	13.99			

**Table 7.18: Care coordination by socioeconomic status summary statistics and Wilcoxon test**

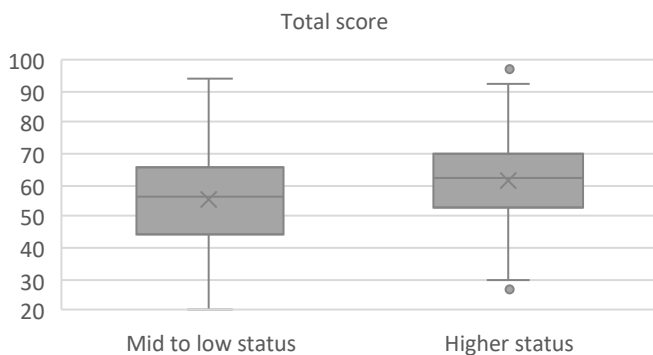
Care coordination scale	Group	Number (n=368)	Percent	Median	IQR	W	p-value
Navigation	Mid to low status	182	49.46	21.00	8.00	12262.00	<0.0001*
	Higher status	186	50.54	25.00	7.00		
Care coordination global measure	Higher status	182	49.46	5.00	5.00	13780.00	0.002*
	Mid to low status	186	50.54	7.00	3.75		
Quality of care global measure	Higher status	182	49.46	7.00	3.00	13838.00	0.0022*
	Mid to low status	186	50.54	8.00	3.00		



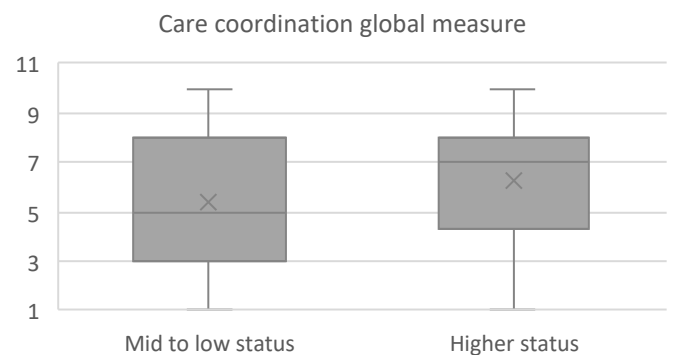
**Figure 7.31: Boxplot of Care coordination: Communication by socioeconomic status**



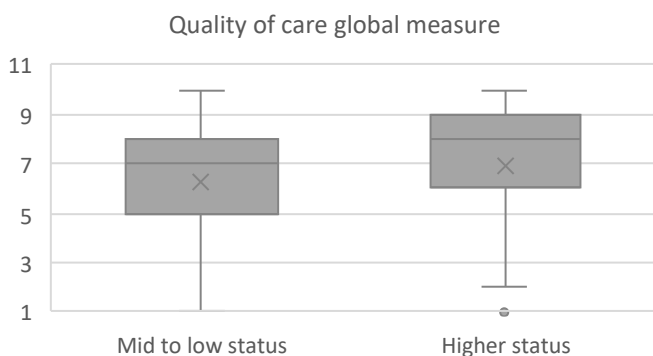
**Figure 7.32: Boxplot of Care coordination: Navigation by socioeconomic status**



**Figure 7.33: Boxplot of Care coordination: Total score by socioeconomic status**



**Figure 7.34: Boxplot of Care coordination: Care coordination global measure by socioeconomic status**



**Figure 7.35: Boxplot of Care coordination: Quality of care global measure by socioeconomic status**

## Experience of care and support

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common responses were that they did not receive formal support (25.12%), found support and care from hospital or clinical setting (23.38%), family and friends (20.65%), and charities (17.41%). Other themes included peer support or other patients (13.93%), and challenges accessing support (12.44%).

### Participant describes getting care and support from hospital or clinical setting

*The most support, probably the only support I've really received has been from my GP and my clinicians, my GP especially, he has been really good at trying to help me manage my pain. He's been really good at trying to...he tries to get me dressings and supplies and where he can he'll bulk on my appointments even though he's a private practice so that I can use the money I would have used on the appointment to go get medications or dressing.*

*Participant 012\_2023AUDSK*

*PARTICIPANT: Yes, I've received support from the hospital when she was first born. They helped a lot. They helped us with hostel in the hospital so we could stay there. They helped. They gave us a grant. They helped us with the cost of the milk, they helped us with the cost of the machine, so it was cheaper.*

*INTERVIEWER: They, the hospital helped quite a lot when she was just born and I think any other support groups, patient groups.*

*PARTICIPANT: Oh well, yeah. Like the support groups like the Heart Kids and the 22 Q support groups, they have helped in like emotional support and just...*

*Participant 013\_2023AUDPA*

*Yes. Well we've had a lot of support in terms of what the health system has provided us, like I've said with NAME NEUROLOGIST, and a lot of support from the local hospital who were very good when she used to come in with her seizures. We've had a lot support from the ECDP in the school there, I found them to be quite helpful. And the kindy have been really good because they have an extra person on staff to just have CHILD'S NAME at kindy, which is unbelievable experience for her.*

*Participant 057\_2023AUDPA*

### Participant describes that they did not receive any formal support

*No, not really. Yeah. I mean, when I had the interferon treatment, it was all through the hospital. So no, I wasn't aware of any other community support services that were available and none, none was made was, they didn't tell me about anything else was available. So, no, not not throughout.*

*Participant 011\_2023AUORC*

*No, because it's not a recognized condition. Nobody knows about it. It's not on any of their lists at any of their foundations or their centers. Never heard of it. So it's not something they'll come and help out with. It's not on the list. All these joints are run by the government and the government gives them a list and if it's not on the list then you know and I feel like that's. You know that one of the things with this too, it's just like nobody knows about it hurt. No one's heard of it.*

*Participant 006\_2023AUDSK*

*Not a bit, nothing.*

*067\_2023AUENM*

*None, from nowhere.*

*Participant 061\_2023AUDNS*

### Participant describes getting care and support from family and friends

*Not really much. It's all just informal support from family and friends and just asking for help when we need it. Yes, that's really been it.*

*Participant 053\_2023AUDPA*

*We definitely had that support there, which was very reassuring I guess to know you're in the hands of experts, and then also family looking after the other kids is an emotional support.*

*Participant 058\_2023AUDPA*

*Again, my family just stepped up and were just a huge help. They were our number one support. The hospital has been fantastic. All his therapists are amazing. I know I can email or call anyone at any time, and they will help. It's never too much of an effort for them to shoot an email back or give me a call to say, "Maybe you should try this or give this a go." We've been just lucky with support, medical, and family wise.*

*Participant 060\_2023AUDPA*

**Participant describes that they did not need or seek help or support**

*No, but like I was saying, thinking, I think I've been thinking. I think maybe in another year or so, I would. I think I will need somebody to clean. Yeah.*  
Participant 005\_2023AUDIS

*I can say that I haven't, because I have never asked for it, and I don't think anyone is particularly aware of it. I have had help and offers of what I can do in terms simply of age. Over 85 or whatever it is, there are various meetings at my local council. I've been given numbers to ring if I need help in the house and all sorts of things like that. That has nothing to do with the scleroderma, that's just to do with the age. As far as I am aware, as far as I can remember and think, I don't have any special treatment because of that. I don't think a lot of people are even aware of it.*  
Participant 012\_2023AUDIS

*No, but I guess I haven't reached out either*  
Participant 015\_2023AUDIS

**Participant describes getting care and support from charities**

*Community health, outreach programs which was the kids team in the early days. I did get Cerebral Palsy Alliance when it was called the testing centre. Each program we were able to get into. All the way searching for programs and outside support. Really, that's about it. We had two close friends in the room that helped a little bit. They had their own issues. They didn't value the kids informally, more than likely have mental illness themselves. You got to be very careful who you bring into the home. Friends and family were just too far away.*  
Participant 045\_2023AUDPA

*The support from the helpline when I rang the Tuberos Sclerosis Association, TSA Australia helpline, a helpline or-- Then obviously friends and family support has been huge. One thing that practical support has been really at the time, the meals, people coming and just picking up the vacuum cleaner and doing that. That's what I found amazingly helpful and looking at the other two, like taking NAME and NAME for play dates and doing stuff for them. That really helped so much. The practical stuff is really helpful. Not asking me what can I do to help you but actually initiating and doing something blew me away. You don't really realise what you're needing until someone actually does it. [laughs].*  
Participant 048\_2023AUDPA

**Participant describes the challenges of finding or accessing support**

*No, I don't think so. I don't know I'm eligible for anything. I did briefly look into the NDIS while I was still recovering after my second pregnancy. I also needed to start the NDIS for my son. I did that and I know it's such a nightmare system and I just did not have the mental space at the time. I haven't looked into anything like that or assumed I wasn't eligible.*  
Participant 004\_2023AUDPA

*No, I couldn't. The hardest thing is I couldn't get any support because I had no diagnosis. You know, and that's like I spoke to the NDIS the other day. And they don't even have Paget's on their thing because it's for older people so, and because I'm only 51, they put me under osteoarthritis or something like that. So I've got some stuff I've got a doctor to fill out, and I've got some stuff I've got to fill out and everything like that to actually send it off to them. But until I got diagnosed, I couldn't get any help from anybody.*  
Participant 014\_2023AUORC

*No. I've tried to seek it out, but I haven't got any.*  
Participant 014\_2023AUDIS

*We haven't really had any. The doctor told us to apply for even the healthcare card for her. That's been taking a while. He said to apply for NDIS. Never heard back from them. There's otherwise no support for her. Otherwise, it's paediatrician support. We haven't received anything.*  
Participant 052\_2023AUDPA

**Participant describes getting care and support from psychologist or counselling service**

*No, except for. I don't know what they call themselves now, but veterans and veterans families counselling service through the Department of Veterans Affairs, they provided quite a bit of counselling for free. Actually, a lot of what we discussed was not HS related, but family related. You know how my family is and how I fit within it, but I think that was helpful. It's been many years since I did that part, okay.*  
Participant 008\_2023AUDSK

*We've received support and care from psychologists over the years, especially ones who've been specialists in autism spectrum disorder. That's been very important for all of us, to understand what we were doing where we were trying to go, what we were trying to achieve. That's probably been it for us. We've*



*not really had any support workers or other people involved.*

*Participant 044\_2023AUDPA*

**Participant describes getting care and support from domestic services and/or home care**

*PARTICIPANT: Yes, I have. So with my local council I get home help. Which is supposed to be a fortnight. That's because of shortage of stuff is only once a month where they come in and they sweep my floors and then mop the floors and they clean the bathroom, so the handbags and the toilet and the shower.*

*INTERVIEWER: That's lovely. That's really helpful, isn't it?*

*PARTICIPANT: It is massively helpful. Yeah.*

*Participant 010\_2023AUDIS*

*No, only when he needed dressings. Like I, I was a community nurse, a local community nurse. And when he needed the the dressings for the pilot of the sinus, you had to attend the dressing clinic once a week and they would give you supplies for six days. And then I could do the dressings at home sort of thing. But yes, we would go, I don't think community health ever came here. I think we were taking PATIENT to to the community Health Center. So I might have. I might have had one of the girlfriends. He had a couple of ingrown toenails that I think he had two operations on. And we were doing it at the clinic, but PATIENT was screaming the place down and the room we were doing it into was next to the the magistrate and the and they were saying you need to do it somewhere else. So I think NAME used to come and do the dressings here at home so he could scream and set off in it. I mean she you're doing the very best thing.*

*Participant 040\_2023AUDPA*

*Apart from household help, no, I don't actually need anything else. There's a man from church comes to mow my lawn, which is tiny, but he does a much better job on the edges than I ever could. So I and I...a couple years ago I paid somebody to do some weeding, simply because it arranged so much like I normally no, I don't have any other care.*

*Participant 003\_2023AUDNS*

**Participant describes getting care and support from peer support or other patients**

*PARTICIPANT: Not really. I am in a support group on Facebook, so I'm not sure if that counts.*

*INTERVIEWER: Well, you've mentioned it, so that's good that you've got support. So is there anything else you want to add? What kind of support is that?*

*PARTICIPANT: It's just people sharing their experience with HS. It's just something that makes me feel like, you know, I'm not alone with what I'm dealing with. I don't know anyone in my personal life who has this. So I joined a group where other people have it and we all kind of share our thoughts and experience and inspirational quotes and stuff like that to make sure that we're all okay, I guess.*

*Participant 010\_2023AUDSK*

*Well, apart from all the specialists we've had, I can't remember if the OT and the speech, he I don't know if they came from the council or where they came from originally, but we haven't had a anybody assisting us as pointing us in the right direction or anything like that. We've just done it ourselves. And as I mentioned, we're part of the support group and we touch base with them from time to time.*

*Participant 093\_2023AUENM*

*The most support came from when I first joined the support group, the patient support group, because I found people on a similar journey going through the same things where we could share information and and and give and given advice on who to see, what to see, things like that. The rest of it's a bit hard because I've now been running the organization for over 15 years, so I'm supporting myself really. It's funny but yeah but no, the the support group is probably I would say my, my biggest place for to gather support. The next one would be from international professionals who I have now formed friendships and alliances with as well. So again I'm very fortunate in that area because of the connections I've made. Most families don't have that connection, but the support group and and and also passionate doctors. Now that we've got a couple of those here that we as a family have connected to and they've gone out there and learned about the condition and how it affects families and also looked at it more holistically than just a number.*

*Participant 025\_2023AUDPA*

**Participant describes getting care and support from respite care**

*But we came home on hospital in the home and that transitioned to some sort of funding package that allowed us to have a respite. Carers come into the home on a regular basis in those first few years and they then had to be trained in suction and and oxygen*

control and feeding, the tube feeding. And so they were really really useful to have other services and we didn't access any Council services. That was just wasn't worth it for us. You know, like cleaning the house and stuff. No was that respite care was the main services. He, he then had you know learning assistance at school he had. Now he's got this communication guide, which is like a support worker, the orientation, mobility, that's sort of like a service that we still use today, which helps him orientate in any situation he's in. So it's part of that planning to a transition. No, I think that's it.

*Participant 028\_2023AUORC*

Yes, we were part of very special kids and the Starlight Foundation. So very special kids provide a family support worker for us and also they provide my oldest daughter with a, a friend to play with an adult young adult friend to take to the park and do those sorts of things. Also did respite care for maze and organized short notice respite care when we had our son recently. So that takes a lot of pressure off us knowing. That she could have. She was taken care of and we didn't have to worry about care arrangements for her.

*Participant 090\_2023AUENM*

*PARTICIPANT: So that's true, We have respite.*

*INTERVIEWER: Oh, yes, excellent.*

*PARTICIPANT: And that's been through the with the NDIS just and that's twice a week we have that.*

*INTERVIEWER: Excellent. Excellent.*

*PARTICIPANT: Just trying to think of anything else. No, I think that's about it.*

*Participant 015\_2023AUDPA*

**Participant describes getting care and support from NDIS**

Yes. Well, NDIS then would be the only one, but that was such a battle and it was rejected and my doctor said, "You have to do it again," so we had to do it again. That means thousands of doctors going to get the specialist report to get waiting for reports. Since it's been in place, it's only that I found fabulous carers that it's worked. Then nobody seems to be able to tell you do this with NDIS and you do that and they say things, "You've got to find a course person." Well, who's a course person? Right. It's not easy. Now that I have the support of NDIS and the care that I do, but if I ever have to move back to where I came from, it's going to be a nightmare because I have to get, well, it's an hour away, so maybe some of the carers might come, some possibly can't.

*Participant 001\_2023AUDNS*

*PARTICIPANT: No, I haven't applied for anything other than the NDIS.*

*INTERVIEWER: Yeah, Okay.*

*PARTICIPANT: Mainly because I know this is permanent and it's getting worse. So yeah, Participant 002\_2023AUDNS*

*Our only real support has been prior to the NDIS we had, I think, allocation of around \$8,000 a year. It's only happened very recently before the NDIS. Prior to that, I think we had an allocation of about \$2,000 a year which we couldn't really spend. We used to save it right until the last month or six weeks, and then spend it, get carers around, and blah, blah, this and that. Go to the beaches or do something for ourselves. Go for a meal or go to the beaches or something.*

*Participant 050\_2023AUDPA*

**Participant describes getting care and support in the form of financial support including financial counselling**

*I pay, I think it's \$15 a year to fibrosis QLD and they have like you pay that \$15 and I think you get. Like \$100 of your hospital parking covered for the year, you get \$150.00 towards physical subsidy kind of thing. So like if you go to the gym or if you need choose for the gym or something like that, then they pay for \$150.00 worth of that for the year. And also they cover \$100 of medications or medical things that you need and they do have a thing that they can grant. A free physio implement. So something like if we needed something to like a nebulizer, I haven't used that myself, but but no, it's also an option. I think that's what they cover for and that's about it. I haven't really reached out to anybody else for any support. I tried to get a healthcare card but that was about it.*

*Participant 013\_2023AUORC*

*Yeah, we receive cystic fibrosis QLD, sometimes do not for ages, but sometimes do like information for parents nights. We've been to some of those. They also provide us with financial assistance of, I think it's, what is it, \$100 a year for sport, \$50 a year for hospital parking, and every couple of years they help us with nebulizers of up to about \$500.00. So we get that and we get family. He gets the carer allowance. Which is 120 fortnight from Centrelink. I get support online from families and people living with CF. That's the biggest support and the friendships are made from other mums.*

*Participant 023\_2023AUORC*



So while I was probably when he was about a year old, I thought I guess financial counselling, I don't know if that that's part of that because I couldn't work as much as I was intending to. So just help managing

debt. I don't think, I don't think we've really thought any other sort of community support. Not that I can think of.  
Participant 089\_2023AUENM

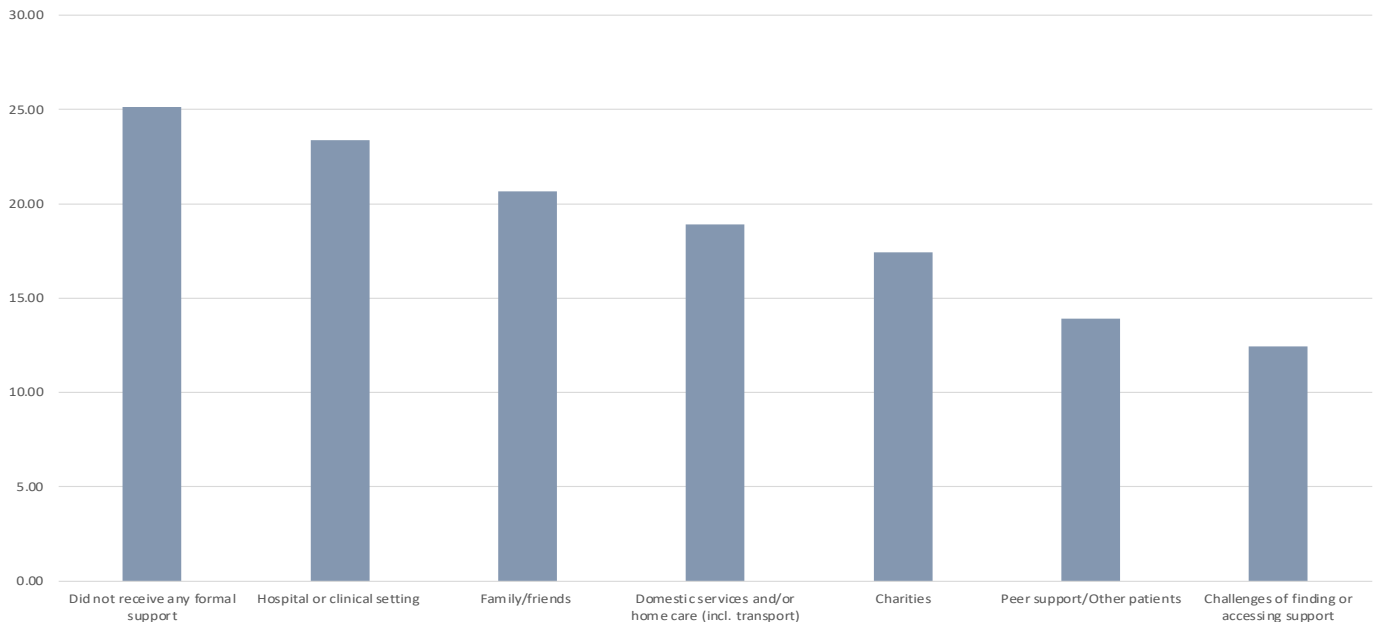
**Table 7.17: Experience of care and support**

Experience of care and support	All participants		Developmental anomalies		Diseases of the immune system		Diseases of the nervous system		Diseases of the skin		Endocrine, nutritional or metabolic diseases		Other rare condition		Person with condition		Family or carer		Female		Male	
	n=402	%	n=67	%	n=81	%	n=95	%	n=32	%	n=95	%	n=32	%	n=268	%	n=134	%	n=264	%	n=106	%
Did not receive any formal support	101	25.12	9	13.43	33	40.74	16	16.84	14	43.75	21	22.11	8	25.00	85	31.72	16	11.94	84	28.57	17	16.04
Hospital or clinical setting	94	23.38	26	38.81	15	18.52	14	14.74	6	18.75	25	26.32	8	25.00	52	19.40	42	31.34	61	20.75	33	31.13
Family/friends	83	20.65	16	23.88	7	8.64	20	21.05	0	0.00	37	38.95	3	9.38	51	19.03	32	23.88	52	17.69	31	29.25
Domestic services and/or home care (incl. transport)	76	18.91	5	7.46	16	19.75	32	33.68	0	0.00	19	20.00	4	12.50	56	20.90	20	14.93	61	20.75	15	14.15
Charities	70	17.41	15	22.39	3	3.70	13	13.68	0	0.00	29	30.53	10	31.25	31	11.57	39	29.10	40	13.61	30	28.30
Peer support/Other patients	56	13.93	9	13.43	11	13.58	10	10.53	5	15.63	18	18.95	3	9.38	36	13.43	20	14.93	41	13.95	15	14.15
Challenges of finding or accessing support	50	12.44	11	16.42	7	8.64	17	17.89	0	0.00	12	12.63	3	9.38	25	9.33	25	18.66	34	11.56	15	14.15

Care and support received	All participants		Aged under 18		Aged 18 to 44		Aged 45 to 64		Aged 65 plus		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=402	%	n=97	%	n=131	%	n=114	%	n=60	%	n=198	%	n=196	%	n=111	%	n=291	%	n=200	%	n=202	%
Did not receive any formal support	101	25.12	10	10.31	44	33.59	42	36.84	5	8.33	55	27.78	42	21.43	28	25.23	73	25.09	63	31.50	38	18.81
Hospital or clinical setting	94	23.38	33	34.02	22	16.79	19	16.67	20	33.33	44	22.22	47	23.98	28	25.23	66	22.68	42	21.00	52	25.74
Family/friends	83	20.65	23	23.71	20	15.27	22	19.30	18	30.00	37	18.69	39	19.90	19	17.12	64	21.99	39	19.50	44	21.78
Domestic services and/or home care (incl. transport)	76	18.91	13	13.40	26	19.85	26	22.81	11	18.33	43	21.72	39	19.90	17	15.32	59	20.27	38	19.00	38	18.81
Charities	70	17.41	29	29.90	14	10.69	14	12.28	13	21.67	33	16.67	31	15.82	23	20.72	47	16.15	24	12.00	46	22.77
Peer support/Other patients	56	13.93	11	11.34	18	13.74	13	11.40	14	23.33	26	13.13	30	15.31	13	11.71	43	14.78	21	10.50	35	17.33
Challenges of finding or accessing support	101	25.12	17	17.53	16	12.21	7	6.14	10	16.67	28	14.14	29	14.80	13	11.71	37	12.71	19	9.50	31	15.35

**Figure 7.36: Experience of care and support**



**Table 7.18: Experience of care and support – subgroup variations**

Care and support received	Reported less frequently	Reported more frequently
Did not receive any formal support	Developmental anomalies Aged under 18 Aged 65 plus	Diseases of the immune system Diseases of the skin Aged 45 to 64
Hospital or clinical setting		Developmental anomalies Aged under 18
Family/friends	Diseases of the immune system Diseases of the skin Other rare condition	Endocrine, nutritional or metabolic diseases
Domestic services and/or home care (incl. transport)	Developmental anomalies Diseases of the skin	Diseases of the nervous system
Charities	Diseases of the skin	Endocrine, nutritional or metabolic diseases Other rare condition Family or carer Male Aged under 18
Peer support/Other patients		
Challenges of finding or accessing support	Diseases of the skin Aged 18 to 44 Aged 45 to 64 Trade or high school University Regional or remote Metropolitan Mid to low status	