Section 7 Care and support

Section 7: Experience of care and support

Care coordination

- The care coordination scores for the entire cohort for navigation, total score, care coordination global measure and quality of care global measure were all in the middle of the scale, indicating moderate outcomes. The communication score was in the second lowest quintile indicating poor communication.

Care coordination – by general health

- There were no differences observed in any care coordination scales between those with higher general health and those with lower general health

Care coordination – by physical functioning

- There were no differences observed in any care coordination scales between those with higher physical functioning and those with lower physical functioning

Care coordination – by emotional well-being

- There were no differences observed in any care coordination scales between those with higher emotional well-being and those with lower emotional well-being

Care coordination– by social functioning

- Participants with higher social functioning had a significantly better outcome compared to those with lower social functioning for the Care coordination: Navigation scale. No other statistically significant differences were observed between these two groups for any Care Coordination scores

Care coordination – by hearing problems

- There were no differences observed in any care coordination scales between those with hearing problems and those with no hearing problems

Care coordination – by eye problems

- There were no differences observed in any care coordination scales between those with eye problems and those with no eye problems

Care coordination – by location

- There were no differences observed in any care coordination scales between participants that live in metropolitan areas and those that live in regional or rural areas.

Care coordination – by education

- There were no differences observed in any care coordination scales between participants with university qualifications and those with high school or trade qualifications

Care coordination – by SEIFA

- There were no differences observed in any care coordination scales between participants that live in areas with higher SEIFA scores and those that live in areas with lower SEIFA scores.

Care and support

- Participants were asked what care and support they had received throughout their experience. This question aims to investigate what services patients consider to be support and care services. The most common description of care and support was in the form of domestic and home care support from government services and NDIS (n=14, 28.00%), this was followed by participants describing that they did not receive any care and support in general (n =9, 18.00%) and not receiving significant support and care from the clinical setting (n=9, 18.00%). There were also seven participants (14.00%) that described receiving support from family and friends.
- In relation to sub-group variations, participants with high social functioning (30.00%) describes not receiving any care and support more frequently than the general population (18.00%)

Experience of coordination of care

A Care Coordination questionnaire was completed. The Care Coordination questionnaire comprises a total score, 2 sub 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 Table 7.1. Overall the entire cohort had a median care received score of 9.0, which is in the highest quintile, indicating very good care received. The scores for navigation (mean = 22.28, sd = 5.27), total score (mean = 55.68, sd=13.52), care coordination global measure (median = 5.00, IQR = 2) and quality of care global measure (median = 6.0, IQR =1.00) were in the middle of the scale. The communication scale (median = 33.40, IQR = 9.77) was in the second lowest quintile indicating poor communication.

Comparisons of care coordination have been made based on general health (Figures 7.1 to 7.5, Tables 7.2 to 7.3), physical functioning (Figures 7.6 to 7.10, Tables 7.4 to 7.5), emotional well-being (Figures 7.11 to 7.15, Tables 7.6 to 7.7), social functioning, (Figures 7.16 to 7.20, Tables 7.8 to 7.9), hearing problems (Figures 7.21 to 7.25, Tables 7.10 to 7.11), eye problems (Figures 7.26 to 7.30, Tables 7.12 to 7.13), location (Figures 7.31 to 7.35, Tables 7.14 to 7.15), education (Figures 7.36 to 7.40, Table 7.16), and SEIFA (Figures 7.41 to 7.45, Tables 7.17 to 7.18).

Table 7.1: Summary statistics Total score - Communication and Navigation

Care coordination scale	Mean	SD	Median	IQR	Possible range
Communication*	33.40	9.77	36.00	4.00	13-65
Navigation*	22.28	5.27	21.50	4.50	7-35
Total score*	55.68	13.52	57.00	7.75	20-100
Care coordination global measure	4.76	2.36	5.00	2.00	1-10
Quality of care global measure	5.52	2.34	6.00	1.00	1-10

*Normal distribution, use mean and sd as central measure

Comparisons of Care Coordination scores by general health

Comparisons of Care Coordination scores were made between those that have higher general health and those that have lower general health. Boxplots for each of the care coordination scales are displayed in Figures 7.1 to 7.5. A two-sample t-test was used when assumptions for normality and variance were met (Table 7.2), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.3). There were no statistically significant differences observed between groups for any Care Coordination scores.

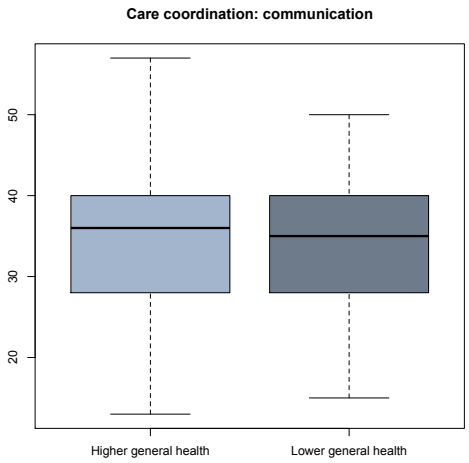

Figure 7.1: Boxplot of Care coordination: communication by general health

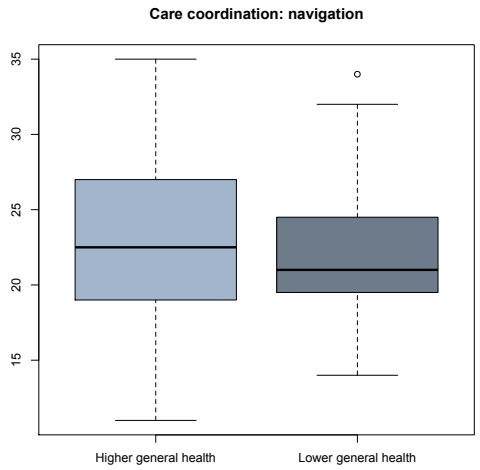

Figure 7.2: Boxplot of Care coordination: navigation by general health

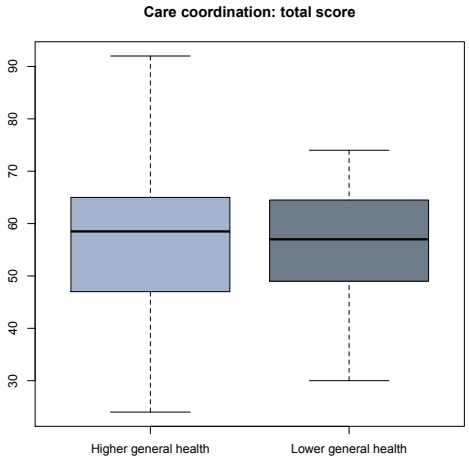

Figure 7.3: Boxplot of Care coordination: total score by general health

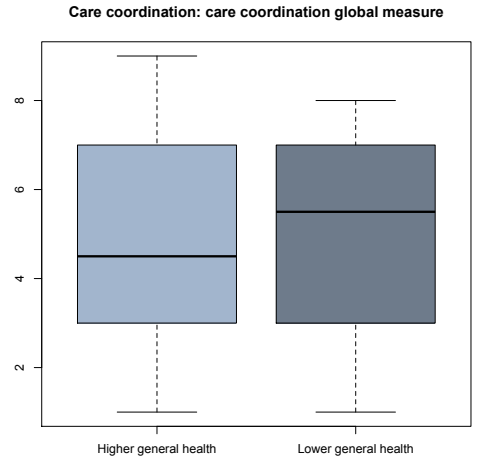

Figure 7.4: Boxplot of Care coordination: care coordination global measure by general health

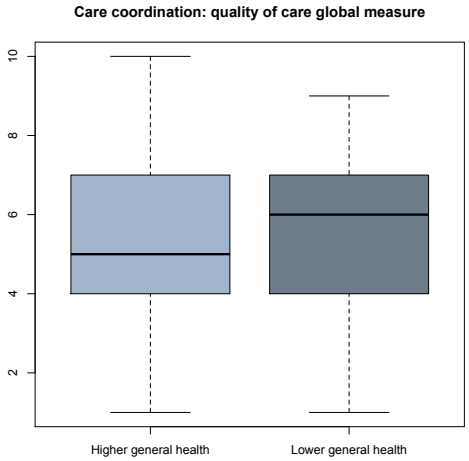

Figure 7.5: Boxplot of Care coordination: quality of care global measure by general health

Table 7.2: Summary statistics and Two sample t test by general health

Care coordination scale by general health	Group	Count	Mean	SD	t	dF	p
Communication	Higher general health	22	33.36	10.93	-0.02	48	0.9817
	Lower general health	28	33.43	8.96			
Navigation	Higher general health	22	22.86	6.13	0.69	48	0.4931
	Lower general health	28	21.82	4.55			
Total score	Higher general health	22	56.23	15.84	0.25	48	0.8026
	Lower general health	28	55.25	11.66			

Table 7.3: Summary statistics Wilcoxon rank sum test with continuity correction by general health

Care coordination scale by general health	Group	Count	Median	IQR	W	p
Care coordination global score	Higher general health	22	4.50	3.75	293	0.7746
	Lower general health	28	5.50	4.00		
Quality of care global score	Higher general health	22	5.00	3.00	290	0.7295
	Lower general health	28	6.00	2.50		

Comparisons of Care Coordination scores by physical functioning

Comparisons of Care Coordination scores were made between participants with higher physical functioning and those with lower physical functioning. Boxplots for each of the care coordination scales are displayed in Figures 7.6 to 7.10. A two-sample t-test was used when assumptions for normality and variance were met (Table 7.4), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.5). There were no statistically significant differences observed between groups for any Care Coordination scores

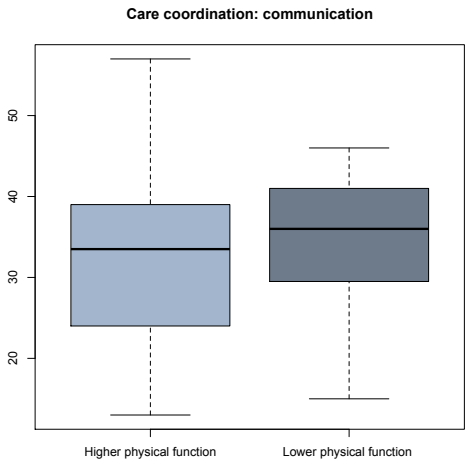

Figure 7.6: Boxplot of Care coordination: communication by physical functioning

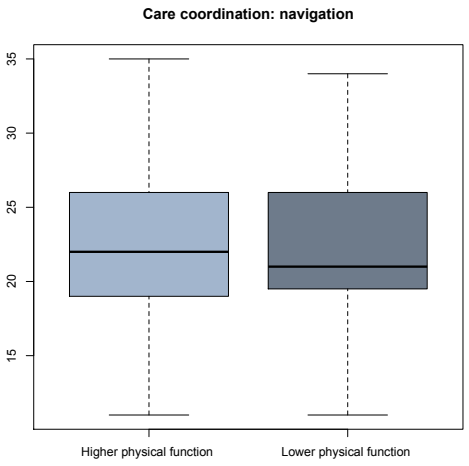

Figure 7.7: Boxplot of Care coordination: navigation by physical functioning

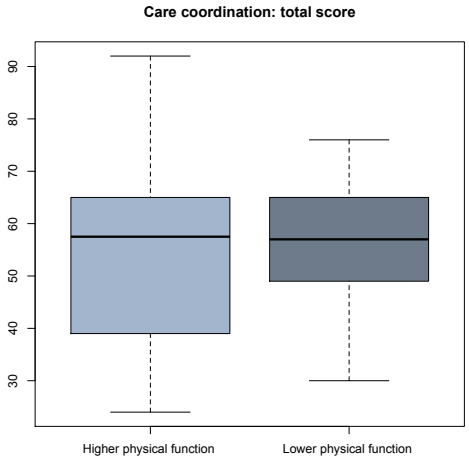

Figure 7.8: Boxplot of Care coordination: total score by physical functioning

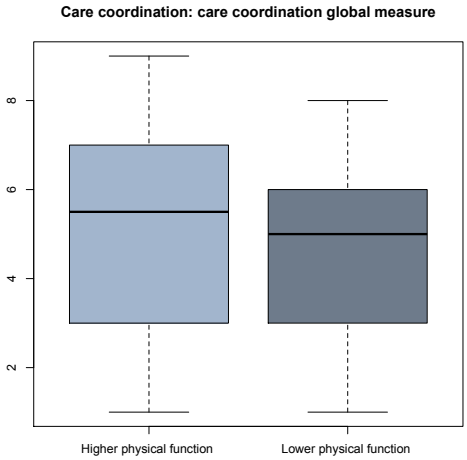

Figure 7.9: Boxplot of Care coordination: care coordination global measure by physical functioning

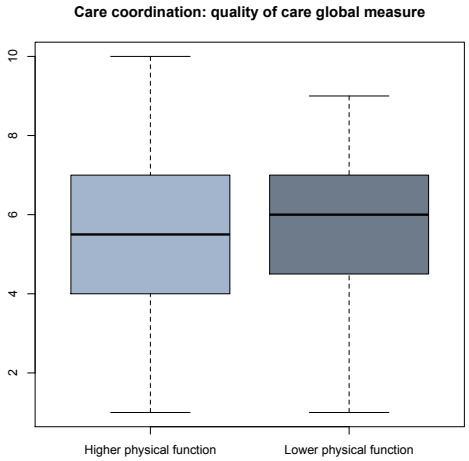

Figure 7.10: Boxplot of Care coordination: quality of care global measure by physical functioning

Table 7.4: Summary statistics and Two sample t test by physical functioning

Care coordination scale by physical functioning	Group	Count	Mean	SD	t	dF	p
Communication	Higher physical functioning	22	32.64	11.31	-0.49	48	0.6291
	Lower physical functioning	28	34.00	8.53			
Navigation	Higher physical functioning	22	22.27	5.19	-0.01	48	0.9932
	Lower physical functioning	28	22.29	5.42			
Total Score	Higher physical functioning	22	54.91	15.51	-0.35	48	0.7247
	Lower physical functioning	28	56.29	11.98			

Table 7.5: Summary statistics Wilcoxon rank sum test with continuity correction by physical functioning

Care coordination scale by physical functioning	Group	Count	Median	IQR	W	p
Care coordination global measure	Higher physical functioning	22	5.50	4.00	337.50	0.5668
	Lower physical functioning	28	5.00	3.00		
Care coordination quality of care global measure	Higher physical functioning	22	5.50	3.00	330.00	0.6709
	Lower physical functioning	28	6.00	2.25		

Comparisons of Care Coordination scores by emotional well-being

Comparisons of Care Coordination scores were made between those that have higher emotional well-being compared to those with lower emotional well-being. Boxplots for each of the care coordination scales are displayed in Figures 7.11 to 7.15. A two-sample t-test was used when assumptions for normality and variance were met (Table 7.6), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.7). No statistically significant differences were observed between these two groups for any Care Coordination scores (Tables 7.11 and 7.12).

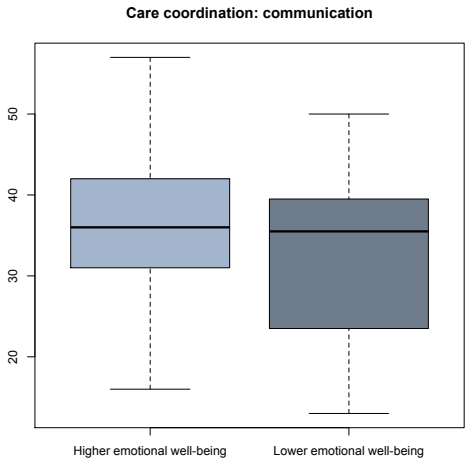

Figure 7.11: Boxplot of Care coordination: communication by social functioning

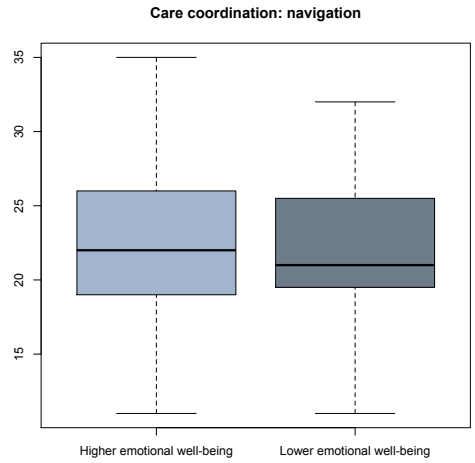

Figure 7.12: Boxplot of Care coordination: navigation by social functioning

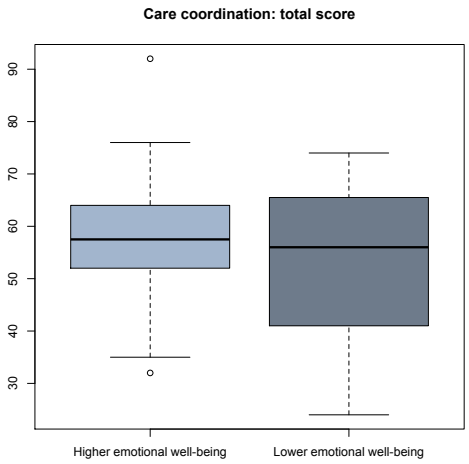

Figure 7.13: Boxplot of Care coordination: total score by emotional well-being

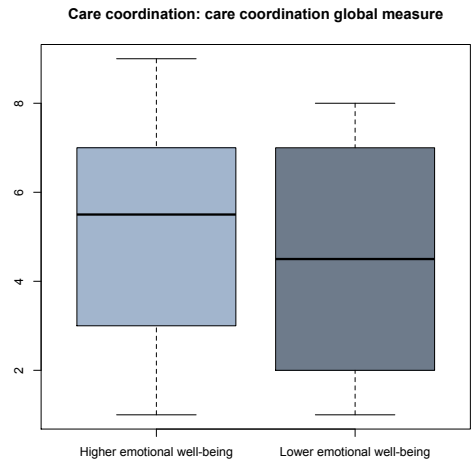

Figure 7.14: Boxplot of Care coordination: care coordination global measure by emotional well-being

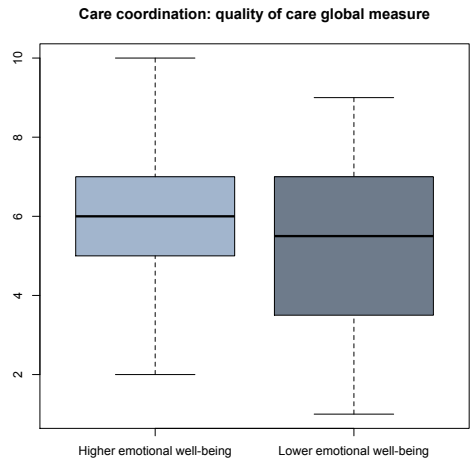

Figure 7.15: Boxplot of Care coordination: quality of care global measure by emotional well-being

Table 7.6: Summary statistics and Two sample t test by emotional well-being

Care coordination scale by emotional well-being	Group	Count	Mean	SD	t	dF	p
Communication	Higher emotional well-being	26	35.08	9.15	1.27	48	0.2097
	Lower emotional well-being	24	31.58	10.28			
Navigation	Higher emotional well-being	26	22.88	5.50	0.84	48	0.4039
	Lower emotional well-being	24	21.63	5.04			
Total score	Higher emotional well-being	26	57.96	12.54	1.25	48	0.2175
	Lower emotional well-being	24	53.21	14.36			

* Statistically significant at p<0.05

Table 7.7: Summary statistics Wilcoxon rank sum test with continuity correction by emotional well-being

Care coordination scale by emotional well-being	Group	Count	Median	IQR	W	p
Care coordination global measure	Higher emotional well-being	26	5.50	3.50	360.50	0.3462
	Lower emotional well-being	24	4.50	4.50		
Quality of care global measure	Higher emotional well-being	26	6.00	2.00	343.00	0.5493
	Lower emotional well-being	24	5.50	3.25		

Comparisons of Care Coordination scores by social functioning

Comparisons of Care Coordination scores were made between those that have higher social functioning compared to those with lower social functioning. Boxplots for each of the care coordination scales are displayed in Figures 7.16 to 7.20. A two-sample t-test was used when assumptions for normality and variance were met (Table 7.8), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.9). A Wilcoxon rank sum test with continuity correction indicated a those with higher social functioning (Median = 25.00, IQR =5.25) had a significantly better outcome compared to those with lower social functioning (Median = 20.00, IQR = 3.00) for the Care coordination: Navigation scale [W=438.00, p=0.0063]. No other statistically significant differences were observed between these two groups for any Care Coordination scores.

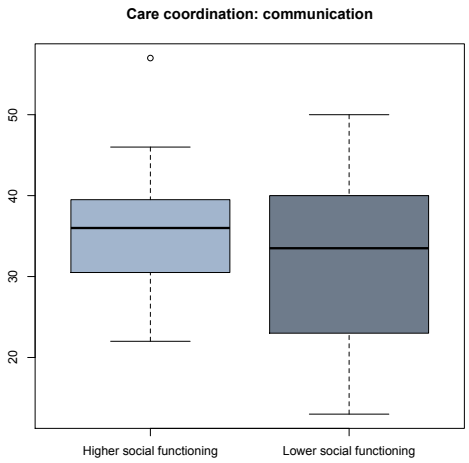

Figure 7.16: Boxplot of Care coordination: communication by social functioning

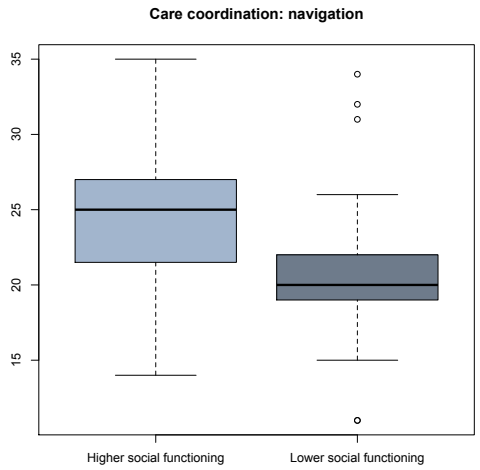

Figure 7.17: Boxplot of Care coordination: navigation by social functioning

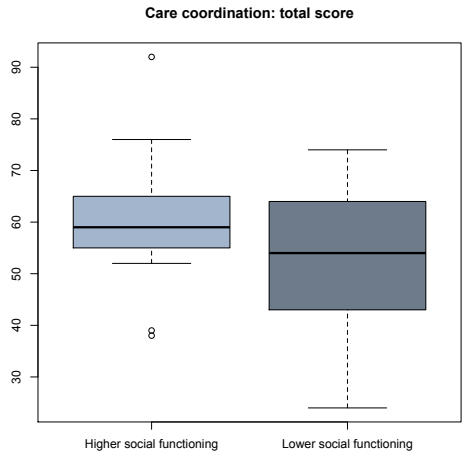

Figure 7.18: Boxplot of Care coordination: total score by social functioning

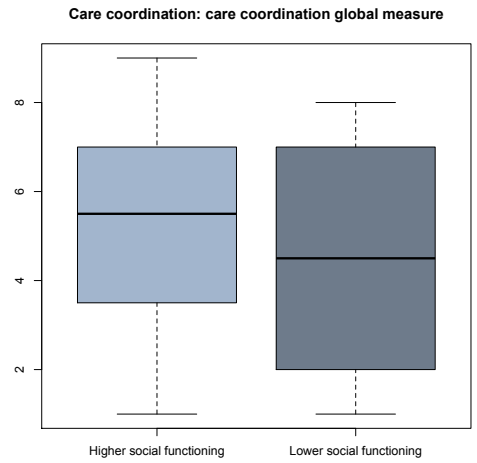

Figure 7.19: Boxplot of Care coordination: care coordination global measure by social functioning

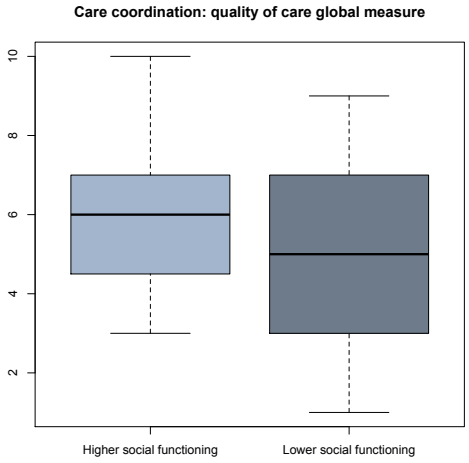

Figure 7.20: Boxplot of Care coordination: quality of care global measure by social functioning

Table 7.8: Summary statistics and Two sample t test by social functioning

Care coordination scale by emotional well-being	Group	Count	Median	IQR	W	p
Care coordination global measure	Higher emotional well-being	26	5.50	3.50	360.50	0.3462
	Lower emotional well-being	24	4.50	4.50		
Quality of care global measure	Higher emotional well-being	26	6.00	2.00	343.00	0.5493
	Lower emotional well-being	24	5.50	3.25		

Table 7.9: Summary statistics Wilcoxon rank sum test with continuity correction by metastatic status

Care coordination scale by social functioning	Group	Count	Median	IQR	W	p
Communication	Higher social functioning	20	36.00	8.50	349.00	0.3363
	Lower social functioning	30	33.50	16.25		
Navigation	Higher social functioning	20	25.00	5.25	438.00	0.0063*
	Lower social functioning	30	20.00	3.00		
Care coordination global measure	Higher social functioning	20	5.50	3.25	350.50	0.3170
	Lower social functioning	30	4.50	4.50		
Quality of care global measure	Higher social functioning	20	6.00	2.25	351.50	0.3072
	Lower social functioning	30	5.00	3.75		

* Statistically significant at $p<0.05$

Comparisons of Care Coordination scores by hearing problems

Comparisons of Care Coordination scores were made between those that have hearing problems and those that do not. Boxplots for each of the care coordination scales are displayed in Figures 7.21 to 7.25 A two-sample t-test was used when assumptions for normality and variance were met (Table 7.10), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.11). No statistically significant differences were observed between these two groups for any Care Coordination scores.

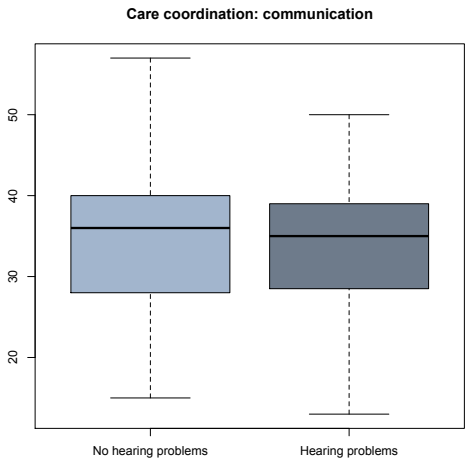

Figure 7.21: Boxplot of Care coordination: communication by hearing problems

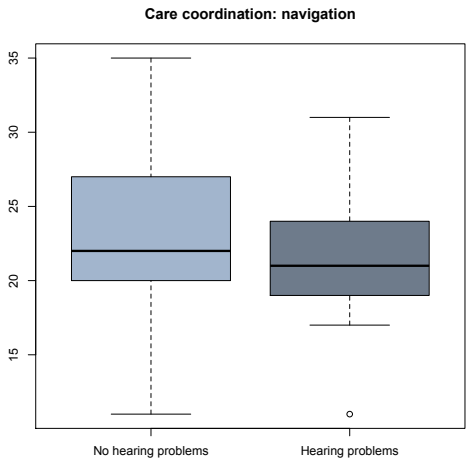

Figure 7.22: Boxplot of Care coordination: navigation by hearing problems

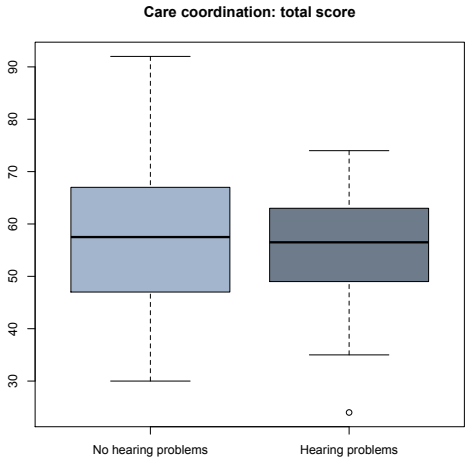

Figure 7.23: Boxplot of Care coordination: total score by hearing problems

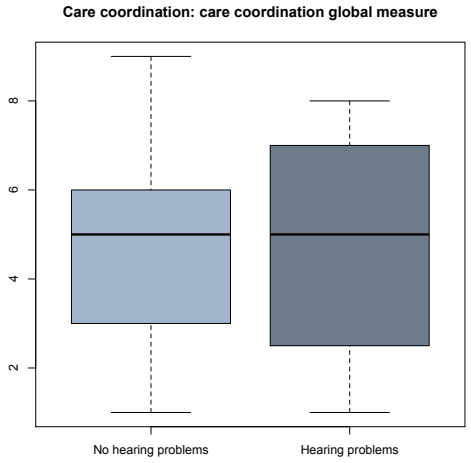

Figure 7.24: Boxplot of Care coordination: care coordination global measure by hearing problems

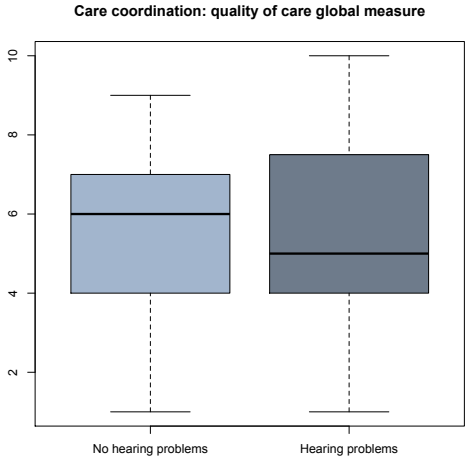

Figure 7.25: Boxplot of Care coordination: quality of care global measure by hearing problems

Table 7.10: Summary statistics and Two sample t test by hearing problems

Care coordination scales by hearing problems	Group	Count	Mean	SD	t	dF	p
Communication	No hearing problems	26	34.00	10.28	0.45	48	0.6559
	Hearing problems	24	32.75	9.36			
Total score	No hearing problems	26	56.88	14.79	0.65	48	0.5174
	Hearing problems	24	54.38	12.17			
Quality of care global measure	No hearing problems	26	5.50	2.21	-0.06	48	0.9506
	Hearing problems	24	5.54	2.52			

Table 7.11: Summary statistics Wilcoxon rank sum test with continuity correction by hearing problems

Care coordination scales by hearing problems	Group	Count	Median	IQR	W	p
Navigation	No hearing problems	26	22.00	6.75	354.00	0.4184
	Hearing problems	24	21.00	5.00		
Care coordination global measure	No hearing problems	26	5.00	2.75	333.50	0.6803
	Hearing problems	24	5.00	4.25		

Comparisons of Care Coordination scores by eye problems

Comparisons of Care Coordination scores were made between those that have eye problems and those that do not. Boxplots for each of the care coordination scales are displayed in Figures 7.26 to 7.30 A two-sample t-test was used when assumptions for normality and variance were met (Table 7.12), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.13). No statistically significant differences were observed between these two groups for any Care Coordination scores.

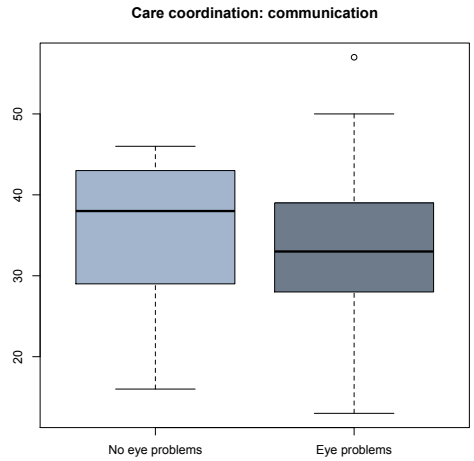

Figure 7.26: Boxplot of Care coordination: communication by eye problems

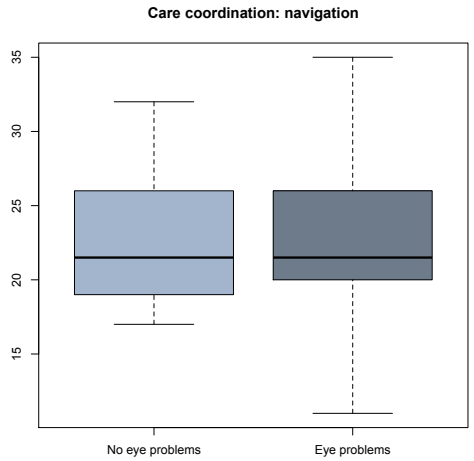

Figure 7.27: Boxplot of Care coordination: navigation by eye problems

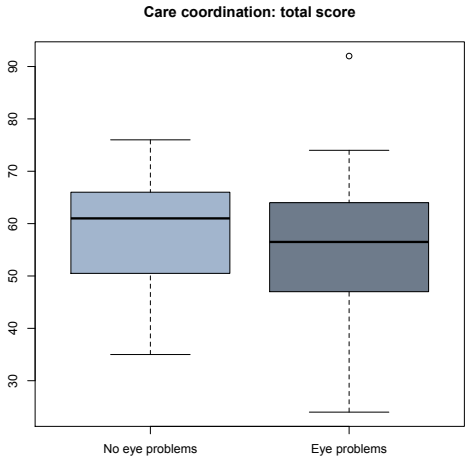

Figure 7.28: Boxplot of Care coordination: total score by eye problems

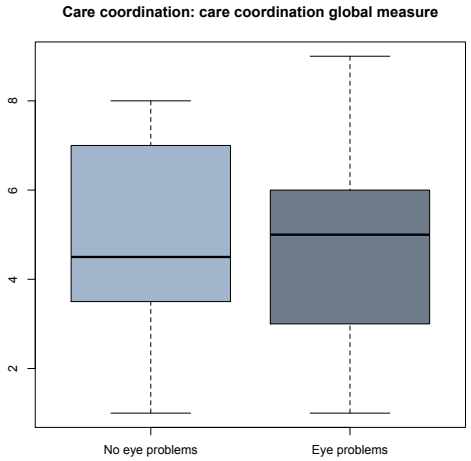

Figure 7.29: Boxplot of Care coordination: care coordination global measure by eye problems

Figure 7.30: Boxplot of Care coordination: quality of care global measure by eye problems

Table 7.12: Summary statistics and Two sample t test by eye problems

Care coordination scales by eye problems	Group	Count	Mean	SD	t	dF	p
Total score	No eye problems	16	57.94	12.34	0.81	48	0.4235
	Eye problems	34	54.62	14.08			
Quality of care global measure	No eye problems	16	5.88	2.16	0.73	48	0.4676
	Eye problems	34	5.35	2.44			

Table 7.3: Summary statistics Wilcoxon rank sum test with continuity correction by eye problems

Care coordination scales by eye problems	Group	Count	Median	IQR	W	p
Communication	No eye problems	16	38.00	13.50	338.00	0.1727
	Eye problems	34	33.00	10.50		
Navigation	No eye problems	16	21.50	7.00	277.50	0.9168
	Eye problems	34	21.50	6.00		
Care coordination global measure	No eye problems	16	4.50	3.25	290.50	0.7052
	Eye problems	34	5.00	3.00		

* Statistically significant at p<0.05

Comparisons of Care Coordination scores by location

Comparisons of Care Coordination scores were made between those that live in metropolitan areas compared to those that live in regional or rural areas. Boxplots for each of the care coordination scales are displayed in Figures 7.31 to 7.35 A two-sample t-test was used when assumptions for normality and variance were met (Table 7.14), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.15). No statistically significant differences were observed between these two groups for any Care Coordination scores.

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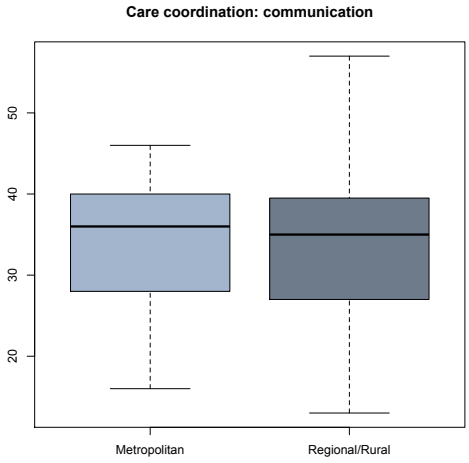


Figure 7.31: Boxplot of Care coordination: communication by location

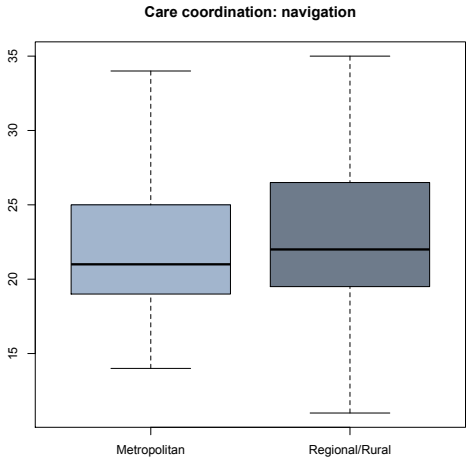


Figure 7.32: Boxplot of Care coordination: navigation by location

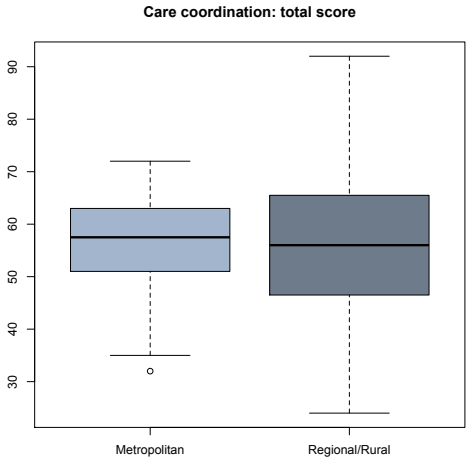


Figure 7.33: Boxplot of Care coordination: total score by location

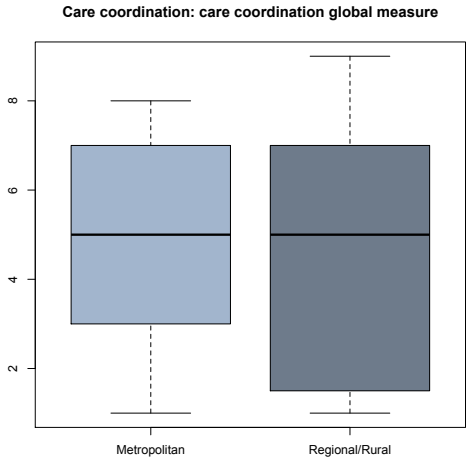


Figure 7.34: Boxplot of Care coordination: care coordination global measure by location

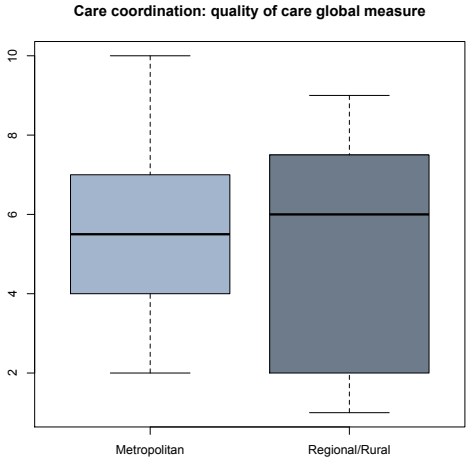


Figure 7.35: Boxplot of Care coordination: quality of care global measure by location

Table 7.14: Summary statistics and Two sample t test by location

Care coordination scales by location	Group	Count	Mean	SD	t	dF	p
Communication	Metropolitan	30	33.57	8.52	0.1463	48	0.8843
	Regional/Remote	20	33.15	11.63			
Navigation	Metropolitan	30	22.10	4.37	-0.293	48	0.7707
	Regional/Remote	20	22.55	6.51			

Table 7.15: Summary statistics Wilcoxon rank sum test with continuity correction by location

Care coordination scales by location	Group	Count	Median	IQR	W	p
Total score	Metropolitan	30	57.50	11.50	303.00	0.9605
	Regional/Remote	20	56.00	18.50		
Care coordination global measure	Metropolitan	30	5.00	3.50	333.00	0.5154
	Regional/Remote	20	5.00	5.25		
Quality of care global measure	Metropolitan	30	5.50	3.00	303.00	0.9601
	Regional/Remote	20	6.00	4.75		

Comparisons of Care Coordination scores by education

Comparisons of Care Coordination scores were made between those that have with university qualifications and those with high school or trade. Boxplots for each of the care coordination scales are displayed in Figures 7.36 to 7.40.

Assumptions for normality and variance were met (Table 7.16), a two-sample t-test was used to compare mean scores. No statistically significant differences were observed between these two groups for any Care Coordination scores.

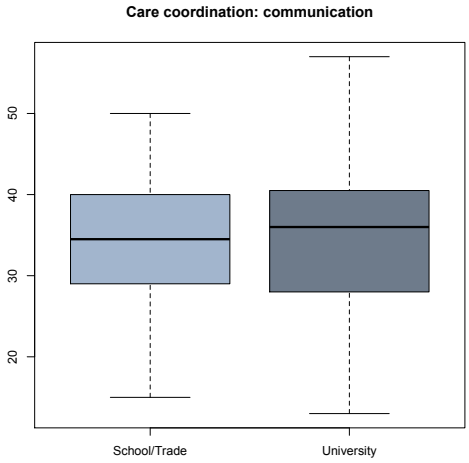


Figure 7.36: Boxplot of Care coordination: communication by education

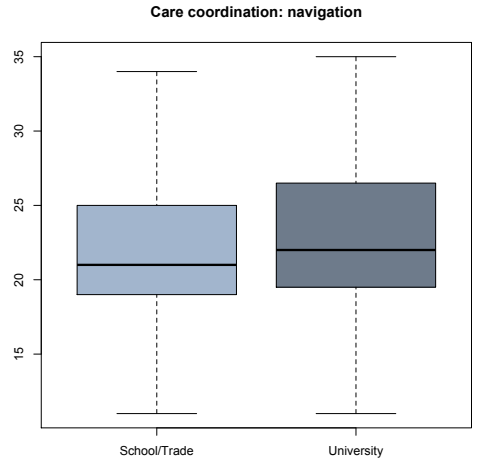
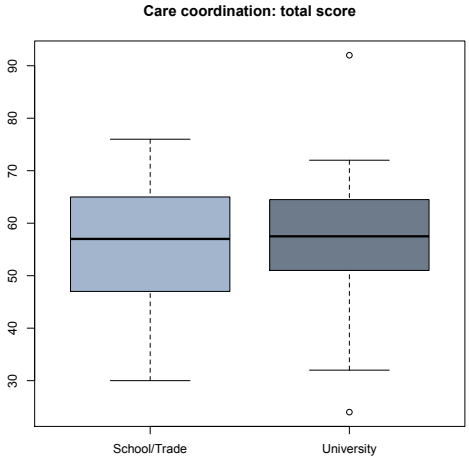


Figure 7.37: Boxplot of Care coordination: navigation by education



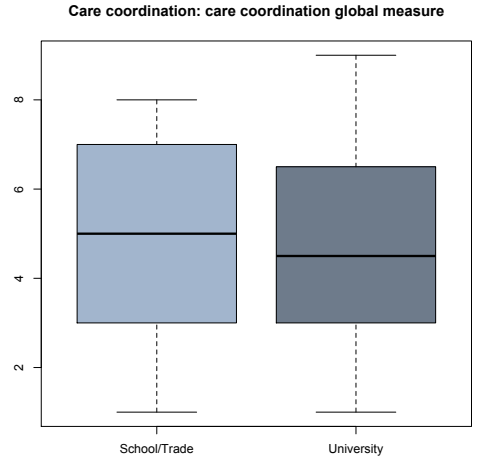


Figure 7.38: Boxplot of Care coordination: total score by education

Figure 7.39: Boxplot of Care coordination: care coordination global measure by education

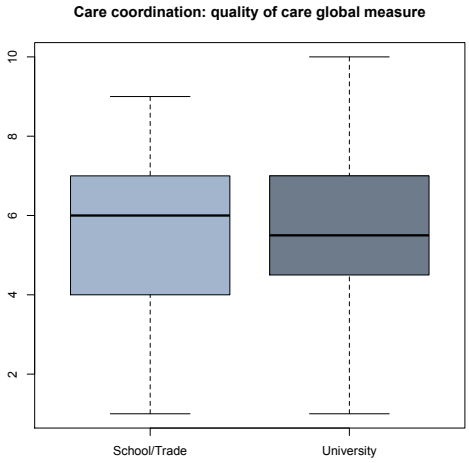


Figure 7.40: Boxplot of Care coordination: quality of care global measure by education

Table 7.16: Summary statistics and Two sample t test by education

Care coordination scales by education	Group	Count	Mean	SD	t	dF	p
Communication	School/Trade	14	33.38	9.14	-0.01	48	0.9909
	University	12	33.42	10.61			
Navigation	School	10	21.65	5.15	-0.87	48	0.3872
	University	8	22.96	5.42			
Total score	School	18	55.04	12.44	-0.35	48	0.7307
	University	16	56.38	14.83			
Care coordination global measure	School	26	4.92	2.17	0.50	48	0.6162
	University	24	4.58	2.59			
Quality of care global measure	School	22	5.38	2.40	-0.42	48	0.6748
	University	20	5.67	2.32			

Comparisons of Care Coordination scores by SEIFA

Comparisons of Care Coordination scores were made between those that have with higher SEIFA and those with lower SEIFA Boxplots for each of the care coordination scales are displayed in Figures 7.41 to 7.45. A two-sample t-test was used when assumptions for normality and variance were met (Table 7.17), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.18). No statistically significant differences were observed between these two groups for any Care Coordination scores.

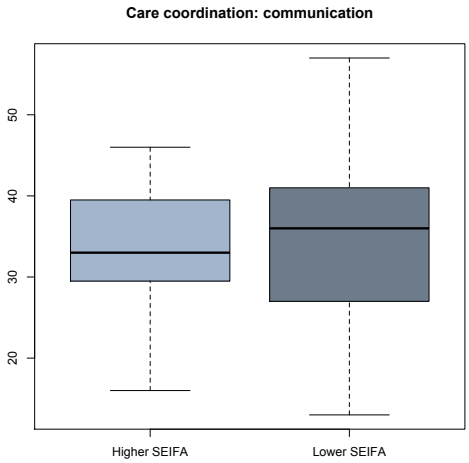


Figure 7.41: Boxplot of Care coordination: communication by SEIFA

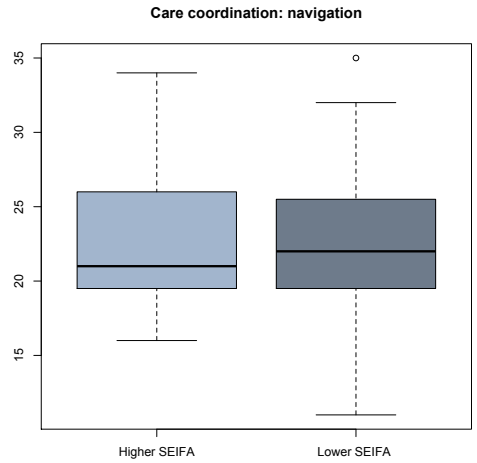


Figure 7.42: Boxplot of Care coordination: navigation by SEIFA

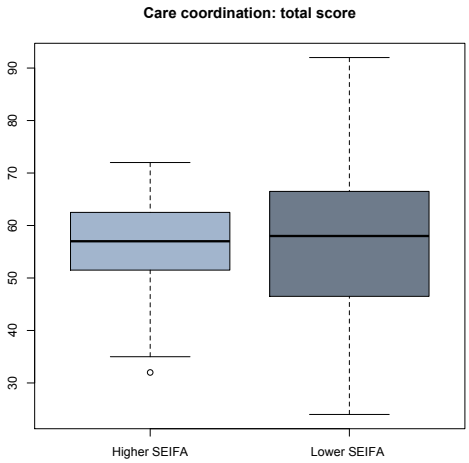


Figure 7.43: Boxplot of Care coordination: total score by SEIFA

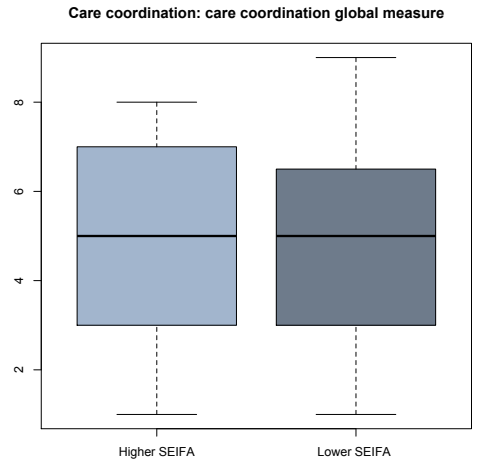


Figure 7.44: Boxplot of Care coordination: care coordination global measure by SEIFA

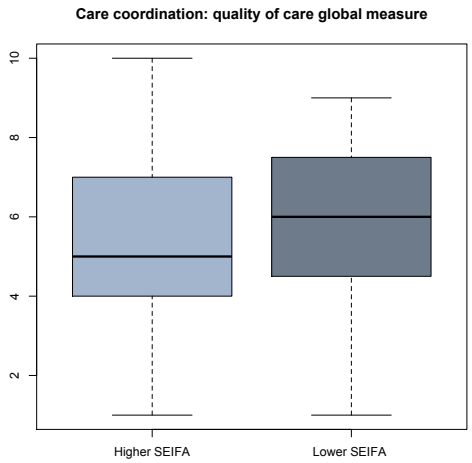


Figure 7.45: Boxplot of Care coordination: quality of care global measure by SEIFA

Table 7.17: Summary statistics and Two sample t test by SEIFA

Care coordination scales by SEIFA	Group	Count	Mean	SD	t	dF	P
Communication	Higher SEIFA	27	33.00	8.28	-0.31	48	0.7573
	Lower SEIFA	23	33.87	11.45			

Table 7.18: Summary statistics Wilcoxon rank sum test with continuity correction by SEIFA

Care coordination scales by SEIFA	Group	Count	Median	IQR	W	p
Navigation	Higher SEIFA	27	21.00	6.50	308	0.9688
	Lower SEIFA	23	22.00	6.00		
Total score	Higher SEIFA	27	57.00	11.00	297.5	0.8076
	Lower SEIFA	23	58.00	20.00		
Care coordination global measure	Higher SEIFA	27	5.00	4.00	326.5	0.7604
	Lower SEIFA	23	5.00	3.50		
Quality of care global measure	Higher SEIFA	27	5.00	3.00	261.5	0.3398
	Lower SEIFA	23	6.00	3.00		

Experience of care and support

Participants were asked what care and support they had received throughout their experience. This question aims to investigate what services patients consider to be support and care services. The most common description of care and support was in the form of domestic and home care support from government services and NDIS (n=14, 28.00%), this was followed by participants describing that they did not receive any care and support in general (n =9, 18.00%) and not receiving significant support and care from the clinical setting (n=9, 18.00%). There were also seven participants (14.00%) that described receiving support from family and friends.

Participant describes support and care in the form of domestic and home care support from government services and NDIS

Other than that, because of my actual condition or my condition, I have NDIS, so I have somebody who comes in twice a week, so it's things like going grocery shopping, because I find that quite difficult, so that to me is care and support. Pretty much that's it, but I think that covers me for what I need. Participant 7

We started a while ago having paying someone to clean house. Just recently, I've gone on to the NDIS which there are a few hiccups, but I'm being given, supposedly given funding for a lot more of that sort of thing. It's still just starting but it's not really happened yet, but it's progressing hopefully, so that's good. Participant 34

I've got NDIS funding which I've been trying to utilize. They tell you off for not using enough money then when you may need to use it, they won't let you use it. Participant 38

Participant describes not receiving any care and support

Not a bit, nothing. Participant 3

No. None. Participant 10

Nothing. Not that I can think. I can't really think of the time. Participant 11

Participant describes not receiving significant support and care from the clinical setting

I'm supposed to have, what do you call it? Occupational therapy. It had never happened since I've been out of hospital. I'm supposed to do that. A lot of things supposed to happen didn't happen. Participant 1

I just see the doctor on a regular basis but just there are no other real support. Participant 19

Sure, easy. Zero…I do think that the system could be a little better when it does come to remote people. When we do head to LOCATION or somewhere maybe they could be, I don't know, maybe there could be a better way of dealing with particularly young adolescent people transferring to the adult system. That they don't fall through the holes that we have, that their appointments are possibly grouped together with the number of specialists that are not available to us in this area. Because they don't see them all the time. NAME can present very well in the half hour or hour appointment that she's there for by getting through there and getting from there and then at the end of that day, oh my gosh, she doesn't do well at all. Participant 49

In relation to sub-group variations, participants with high social functioning (30.00%) describes not receiving any care and support more frequently than the general population (18.00%)

Table 7.19: Perceptions of care and support received

Care and support received	All participants		Metropolitan		Rural		SEIFA (High)		SEIFA (Low)	
	n=50	%	n=30	%	n=20	%	n=27	%	n=23	%
Participant describes support and care in the form of domestic and home care support from government services and NDIS	14	28.00	8	26.67	6	30.00	8	29.63	6	26.09
Participant describes not receiving any care and support	9	18.00	7	23.33	2	10.00	6	22.22	3	13.04
Participant describes not receiving significant support and care from the clinical setting	9	18.00	4	13.33	5	25.00	4	14.81	5	21.74
Participant describes support and care from family friends (general)	7	14.00	4	13.33	3	15.00	3	11.11	4	17.39
Participant describes support and care in the form of community health services (Neurological service)	6	12.00	4	13.33	2	10.00	3	11.11	3	13.04
Participant describes receiving additional care and support for allied health services	6	12.00	5	16.67	2	10.00	4	14.81	3	13.04
Participant describes support and care in the form of family or friends to help with transport(to appointments and everyday activties)	5	10.00	4	13.33	1	5.00	3	11.11	2	8.70
Participant describes support and care in the form of help with visual impairment (Vision Australia)	5	10.00	2	6.67	3	15.00	2	7.41	3	13.04
Participant describes satisfaction with accessing support and assistance from the AMDF	5	10.00	3	10.00	2	10.00	4	14.81	1	4.35
Participant describes support and care in the form of connecting with other patients and sharing their experience	4	8.00	3	10.00	1	5.00	2	7.41	2	8.70
Participant describes support and care in the form of family and friends helping with domestic help	4	8.00	2	6.67	3	15.00	2	7.41	3	13.04

Care and support received	All participants		High school or trade		University		Hearing impairment		Eye or visual impairment	
	n=50	%	n=26	%	n=24	%	n=24	%	n=34	%
Participant describes support and care in the form of domestic and home care support from government services and NDIS	14	28.00	7	26.92	7	29.17	7	29.17	9	26.47
Participant describes not receiving any care and support	9	18.00	7	26.92	2	8.33	3	12.50	9	26.47
Participant describes not receiving significant support and care from the clinical setting	9	18.00	5	19.23	4	16.67	6	25.00	7	20.59
Participant describes support and care from family friends (general)	7	14.00	3	11.54	4	16.67	3	12.50	5	14.71
Participant describes support and care in the form of community health services (Neurological service)	6	12.00	3	11.54	3	12.50	4	16.67	4	11.76
Participant describes receiving additional care and support for allied health services	6	12.00	3	11.54	4	16.67	3	12.50	4	11.76
Participant describes support and care in the form of family or friends to help with transport(to appointments and everyday activties)	5	10.00	1	3.85	4	16.67	3	12.50	2	5.88
Participant describes support and care in the form of help with visual impairment (Vision Australia)	5	10.00	2	7.69	3	12.50	3	12.50	3	8.82
Participant describes satisfaction with accessing support and assistance from the AMDF	5	10.00	2	7.69	3	12.50	4	16.67	4	11.76
Participant describes support and care in the form of connecting with other patients and sharing their experience	4	8.00	2	7.69	2	8.33	1	4.17	4	11.76
Participant describes support and care in the form of family and friends helping with domestic help	4	8.00	3	11.54	2	8.33	2	8.33	2	5.88

Care and support received	All participants		Physical function (High)		Physical function (Low)		Emotional well-being (High)		Emotional well-being (Low)	
	n=50	%	n=22	%	n=28	%	n=26	%	n=24	%
Participant describes support and care in the form of domestic and home care support from government services and NDIS	14	28.00	4	18.18	10	35.71	7	26.92	7	29.17
Participant describes not receiving any care and support	9	18.00	6	27.27	3	10.71	4	15.38	5	20.83
Participant describes not receiving significant support and care from the clinical setting	9	18.00	6	27.27	3	10.71	5	19.23	4	16.67
Participant describes support and care from family friends (general)	7	14.00	4	18.18	3	10.71	2	7.69	5	20.83
Participant describes support and care in the form of community health services (Neurological service)	6	12.00	3	13.64	3	10.71	3	11.54	3	12.50
Participant describes receiving additional care and support for allied health services	6	12.00	2	9.09	5	17.86	4	15.38	3	12.50
Participant describes support and care in the form of family or friends to help with transport(to appointments and everyday activties)	5	10.00	1	4.55	4	14.29	2	7.69	3	12.50
Participant describes support and care in the form of help with visual impairment (Vision Australia)	5	10.00	2	9.09	3	10.71	3	11.54	2	8.33
Participant describes satisfaction with accessing support and assistance from the AMDF	5	10.00	4	18.18	1	3.57	2	7.69	3	12.50
Participant describes support and care in the form of connecting with other patients and sharing their experience	4	8.00	2	9.09	2	7.14	4	15.38	0	0.00
Participant describes support and care in the form of family and friends helping with domestic help	4	8.00	2	9.09	3	10.71	1	3.85	4	16.67

Care and support received	All participants		Social functioning (High)		Social functioning (Low)		General health (High)		General health (Low)	
	n=50	%	n=20	%	n=30	%	n=22	%	n=28	%
Participant describes support and care in the form of domestic and home care support from government services and NDIS	14	28.00	5	25.00	9	30.00	5	22.73	9	32.14
Participant describes not receiving any care and support	9	18.00	6	30.00	3	10.00	3	13.64	6	21.43
Participant describes not receiving significant support and care from the clinical setting	9	18.00	3	15.00	6	20.00	6	27.27	3	10.71
Participant describes support and care from family friends (general)	7	14.00	2	10.00	5	16.67	3	13.64	4	14.29
Participant describes support and care in the form of community health services (Neurological service)	6	12.00	1	5.00	5	16.67	3	13.64	3	10.71
Participant describes receiving additional care and support for allied health services	6	12.00	3	15.00	4	13.33	3	13.64	4	14.29
Participant describes support and care in the form of family or friends to help with transport(to appointments and everyday activties)	5	10.00	0	0.00	5	16.67	3	13.64	2	7.14
Participant describes support and care in the form of help with visual impairment (Vision Australia)	5	10.00	1	5.00	4	13.33	1	4.55	4	14.29
Participant describes satisfaction with accessing support and assistance from the AMDF	5	10.00	4	20.00	1	3.33	2	9.09	3	10.71
Participant describes support and care in the form of connecting with other patients and sharing their experience	4	8.00	3	15.00	1	3.33	2	9.09	2	7.14
Participant describes support and care in the form of family and friends helping with domestic help	4	8.00	2	10.00	3	10.00	2	9.09	3	10.71

Care and support received	All participants		Under 18		24-44		45-54		55-64		65-74+	
	n=50	%	n=6	%	n=14	%	n=9	%	n=11	%	n=10	%
Participant describes support and care in the form of domestic and home care support from government services and NDIS	14	28.00	0	0.00	2	14.29	3	33.33	4	36.36	5	50.00
Participant describes not receiving any care and support	9	18.00	0	0.00	3	21.43	2	22.22	3	27.27	1	10.00
Participant describes not receiving significant support and care from the clinical setting	9	18.00	1	16.67	2	14.29	3	33.33	1	9.09	2	20.00
Participant describes support and care from family friends (general)	7	14.00	1	16.67	1	7.14	1	11.11	2	18.18	2	20.00
Participant describes support and care in the form of community health services (Neurological service)	6	12.00	2	33.33	1	7.14	1	11.11	1	9.09	1	10.00
Participant describes receiving additional care and support for allied health services	6	12.00	3	50.00	2	14.29	0	0.00	1	9.09	1	10.00
Participant describes support and care in the form of family or friends to help with transport(to appointments and everyday activties)	5	10.00	0	0.00	2	14.29	0	0.00	1	9.09	2	20.00
Participant describes support and care in the form of help with visual impairment (Vision Australia)	5	10.00	0	0.00	1	7.14	3	33.33	1	9.09	0	0.00
Participant describes satisfaction with accessing support and assistance from the AMDF	5	10.00	0	0.00	2	14.29	1	11.11	1	9.09	1	10.00
Participant describes support and care in the form of connecting with other patients and sharing their experience	4	8.00	1	16.67	1	7.14	2	22.22	0	0.00	0	0.00
Participant describes support and care in the form of family and friends helping with domestic help	4	8.00	1	16.67	1	7.14	1	11.11	1	9.09	1	10.00

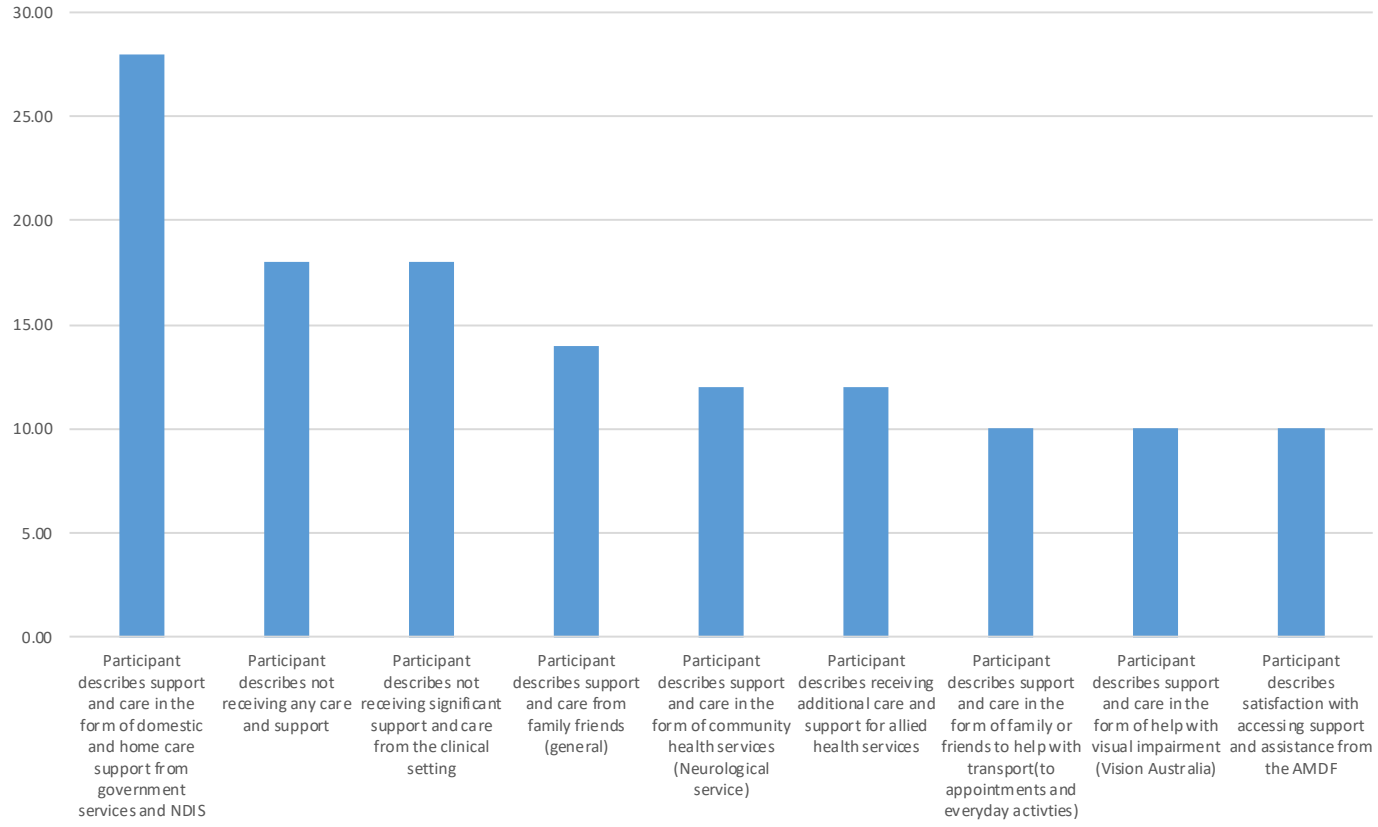


Figure 7.46: Perceptions of care and support received (% of all participants)