

Section 7

Care and support

Section 7: Experience of care and support

Care coordination

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 **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 this study had average communication with healthcare professionals.

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 this study had average navigation of the healthcare system.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. On average, participants in this study had average 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. On average, participants in this study rated their care coordination as average.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. On average, participants in this study 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 response was that they did not receive any formal support (30.77%), and some participants described that they did not need or seek help or support (19.23%). When participants got support, they most commonly received support from charities (30.77%) and from peer support or other patients (15.38%).

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 Table 7.1.

The overall scores for the cohort were in the second highest quintile for **Care coordination: Quality of care global measure** (median=8.00, IQR=4.50) indicating good quality of care

The overall scores for the cohort were in the middle quintile for **Care coordination: Communication** (mean=34.30, SD=11.06), **Care coordination: Navigation** (mean=23.37, SD=6.52), **Care coordination: Total score** (mean=57.67, SD=15.82), **Care coordination: Care coordination global measure** (median=6.00, IQR=6.00) 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. On average, participants in this study had average communication with healthcare professionals.

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 this study had average navigation of the healthcare system.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. On average, participants in this study had average 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. On average, participants in this study rated their care coordination as average.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. On average, participants in this study rated their rated their quality of care as good.

Table 7.1: Care coordination summary statistics

Care coordination scale (n=27)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	34.30	11.06	32.00	13.50	13 to 65	3
Navigation*	23.37	6.52	25.00	11.50	7 to 35	3
Total score*	57.67	15.82	56.00	22.50	20 to 100	3
Care coordination global measure	5.96	3.31	6.00	6.00	1 to 10	3
Quality of care global measure	6.81	3.00	8.00	4.50	1 to 10	4

*Normal distribution use mean and SD as measure of central tendency

Care coordination by participant type

There were 25 participants (92.59%) that had been diagnosed with lung cancer, and 2 participants (7.41%) that were family members or carers to people with lung

cancer. Comparisons were not made because there were too few family members and carers. Summary statistics are displayed in Table 7.x

Table 7.2: Care coordination by participant type summary statistics

Care coordination scale (n=27)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	34.30	11.06	32.00	13.50	13 to 65	3
Navigation*	23.37	6.52	25.00	11.50	7 to 35	3
Total score*	57.67	15.82	56.00	22.50	20 to 100	3
Care coordination global measure	5.96	3.31	6.00	6.00	1 to 10	3
Quality of care global measure	6.81	3.00	8.00	4.50	1 to 10	4

*Normal distribution use mean and SD as measure of central tendency

Care coordination by lung cancer stage

Comparisons were made by cancer stage, there were 11 participants (44.00%) with non-metastatic lung cancer and, 14 participants (56.00%) with metastatic lung cancer.

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.1).

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

Table 7.3: Care coordination by lung cancer stage summary statistics and T-test

Care coordination scale	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Communication	Non-metastatic	11	44.00	35.55	11.50	0.39	23	0.6984
	Metastatic	14	56.00	33.79	10.84			
Navigation	Non-metastatic	11	44.00	24.09	6.16	0.61	23	0.5486
	Metastatic	14	56.00	22.43	7.22			
Total score	Non-metastatic	11	44.00	59.64	16.33	0.53	23	0.6036
	Metastatic	14	56.00	56.21	15.98			
Care coordination global measure	Non-metastatic	11	44.00	6.00	3.07	-0.05	23	0.9577
	Metastatic	14	56.00	6.07	3.47			
Quality of care global measure	Non-metastatic	11	44.00	6.36	3.35	-0.92	23	0.3648
	Metastatic	14	56.00	7.43	2.41			

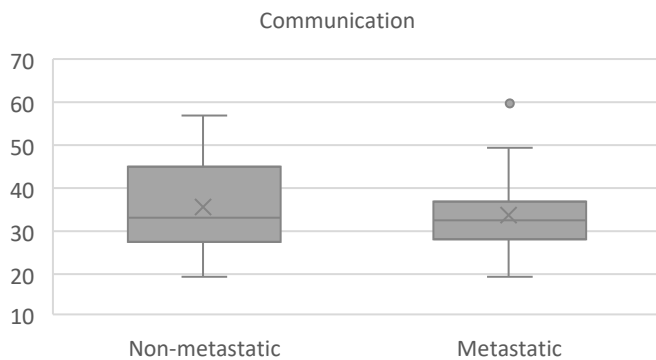


Figure 7.1: Boxplot of Care coordination: Communication by lung cancer stage

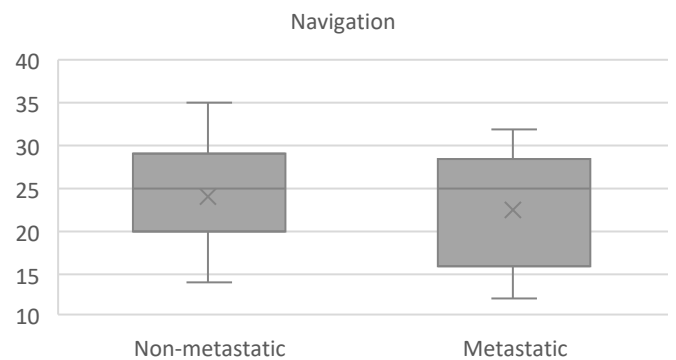


Figure 7.2: Boxplot of Care coordination: Navigation by lung cancer stage

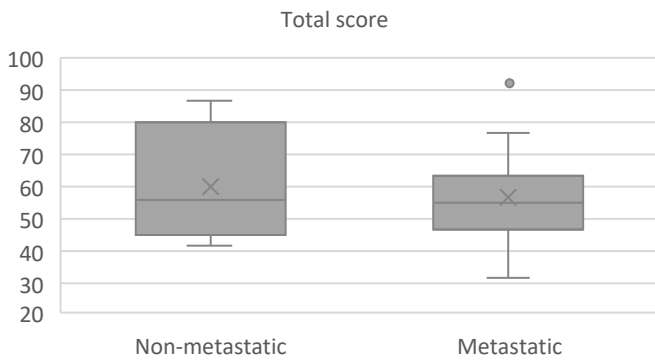


Figure 7.3: Boxplot of Care coordination: Total score by lung cancer stage

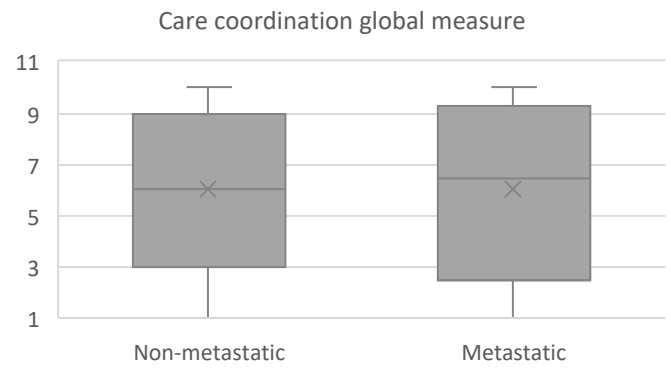


Figure 7.4: Boxplot of Care coordination: Care coordination global measure by lung cancer stage

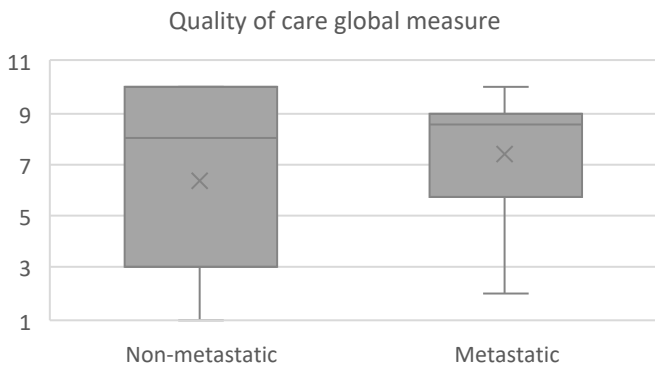


Figure 7.5: Boxplot of Care coordination: Quality of care global measure by lung cancer stage

Care coordination by gender

Comparisons were made by gender, there were 20 female participants (74.07%), and 8 male participants (25.93%).

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).

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

Table 7.4: Care coordination by gender summary statistics and T-test

Care coordination scale	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Navigation	Female	20	74.07	23.30	6.30	-0.09	25	0.9267
	Male	7	25.93	23.57	7.66			
Total score	Female	20	74.07	56.80	16.07	-0.47	25	0.6397
	Male	7	25.93	60.14	16.06			

Table 7.5: Care coordination by gender summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=27)	Percent	Median	IQR	W	p-value
Communication	Female	20	74.07	31.50	7.25	53.50	0.3751
	Male	7	25.93	39.00	13.00		
Care coordination global measure	Female	20	74.07	5.50	6.00	63.00	0.7166
	Male	7	25.93	7.00	4.50		
Quality of care global measure	Female	20	74.07	7.50	5.00	62.00	0.6749
	Male	7	25.93	8.00	2.00		

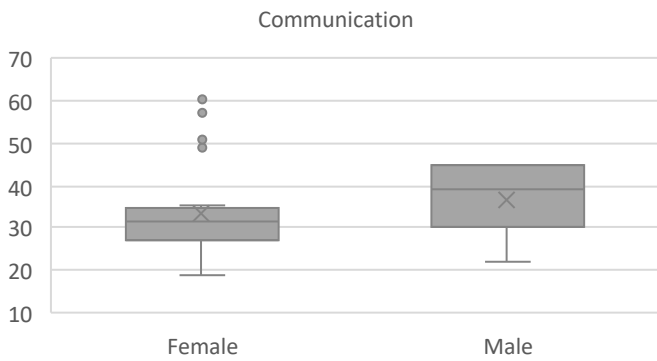


Figure 7.6: Boxplot of Care coordination: Communication by gender

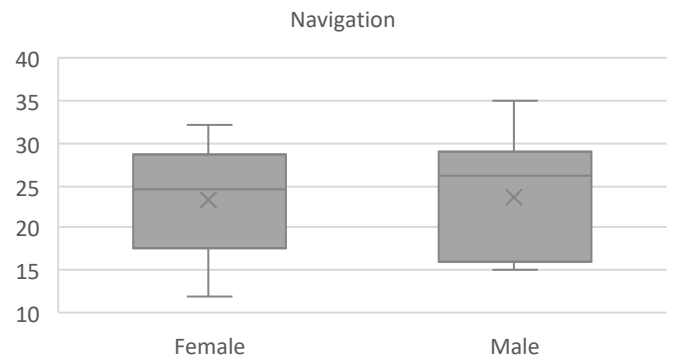


Figure 7.7: Boxplot of Care coordination: Navigation by gender

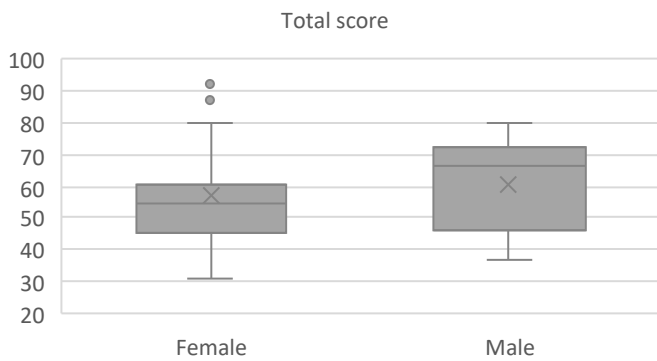


Figure 7.8: Boxplot of Care coordination: Total score by gender

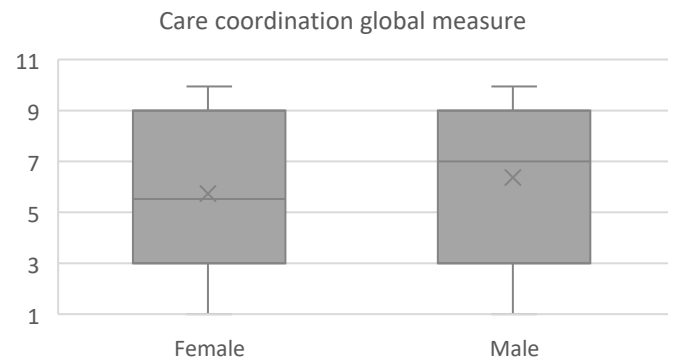


Figure 7.9: Boxplot of Care coordination: Care coordination global measure by gender

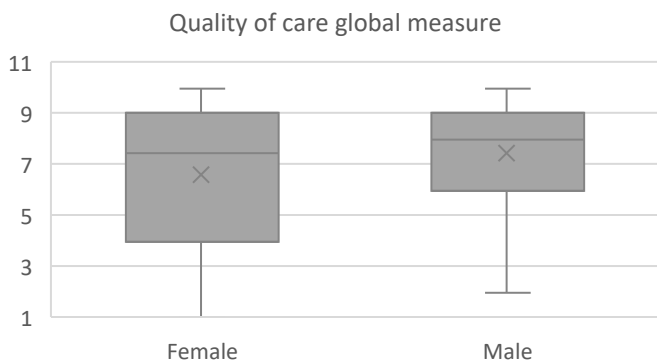


Figure 7.10: Boxplot of Care coordination: Quality of care global measure by gender

Care coordination by age

Participants were grouped according to age, with comparisons made between participants aged 35 to 64 (n=15, 55.56%), and participants aged 65 or older (n=12, 44.44%).

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).

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

Table 7.6: Care coordination by age summary statistics and T-test

Care coordination scale	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Navigation	Aged 35 to 64	15	55.56	23.20	6.70	-0.15	25	0.8829
	Aged 65 or older	12	44.44	23.58	6.58			
Total score	Aged 35 to 64	15	55.56	55.07	15.57	-0.95	25	0.3498
	Aged 65 or older	12	44.44	60.92	16.21			

Table 7.7: Care coordination by age summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=27)	Percent	Median	IQR	W	p-value
Communication	Aged 35 to 64	15	55.56	29.00	6.50	61.50	0.1711
	Aged 65 or older	12	44.44	34.00	14.25		
Care coordination global measure	Aged 35 to 64	15	55.56	7.00	6.50	76.00	0.5061
	Aged 65 or older	12	44.44	6.00	4.75		
Quality of care global measure	Aged 35 to 64	15	55.56	8.00	5.00	79.50	0.6218
	Aged 65 or older	12	44.44	8.00	3.50		

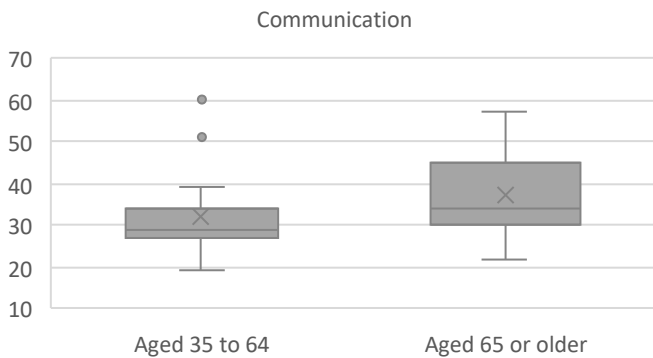


Figure 7.11: Boxplot of Care coordination: Communication by age

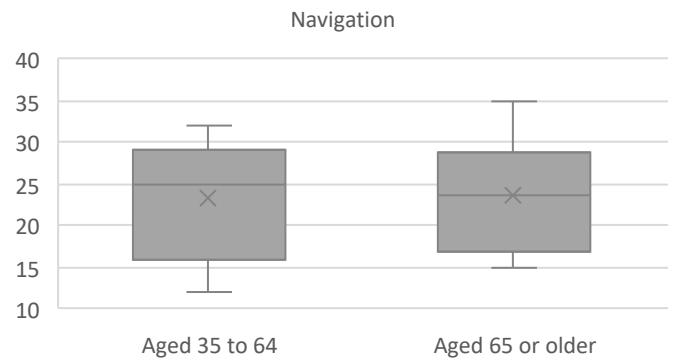


Figure 7.12: Boxplot of Care coordination: Navigation by age

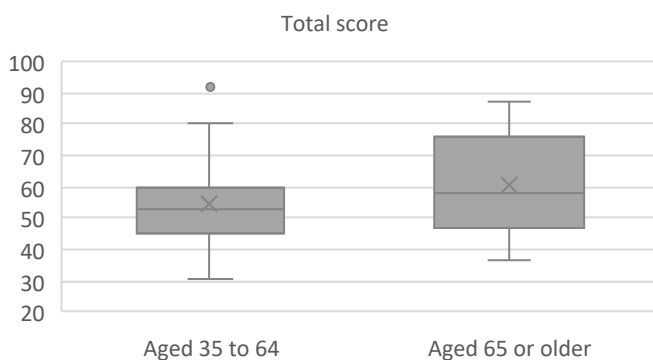


Figure 7.13: Boxplot of Care coordination: Total score by age

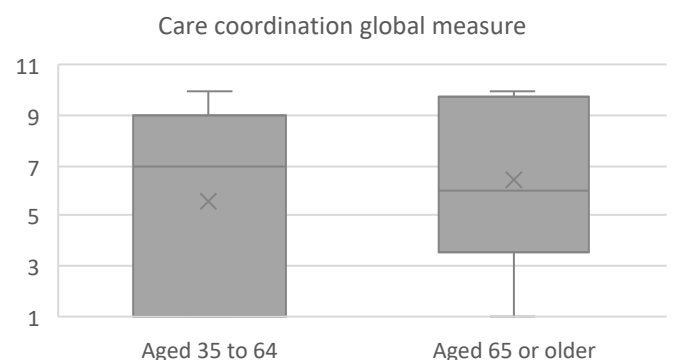


Figure 7.14: Boxplot of Care coordination: Care coordination global measure by age

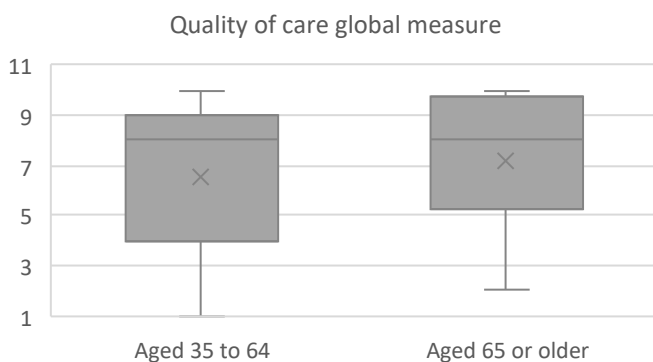


Figure 7.15: Boxplot of Care coordination: Quality of care global measure by age

Care coordination by education

Comparisons were made by education status, between those with trade or high school qualifications (n=15, 55.56%), and those with a university qualification (n=12, 44.44%).

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 significant differences were observed between participants by **education** for any of the Care coordination scales.

Table 7.8: Care coordination by education summary statistics and T-test

Care coordination scale	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Communication	Trade or high school	15	55.56	34.53	10.40	0.12	25	0.9038
	University	12	44.44	34.00	12.30			
Navigation	Trade or high school	15	55.56	23.07	6.90	-0.27	25	0.7927
	University	12	44.44	23.75	6.30			
Total score	Trade or high school	15	55.56	57.60	16.19	-0.02	25	0.9810
	University	12	44.44	57.75	16.07			

Table 7.9: Care coordination by education summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=27)	Percent	Median	IQR	W	p-value
Care coordination global measure	Trade or high school	15	55.56	5.00	5.00	72.00	0.3887
	University	12	44.44	8.00	4.25		
Quality of care global measure	Trade or high school	15	55.56	8.00	4.50	90.00	1.0000
	University	12	44.44	8.00	3.50		

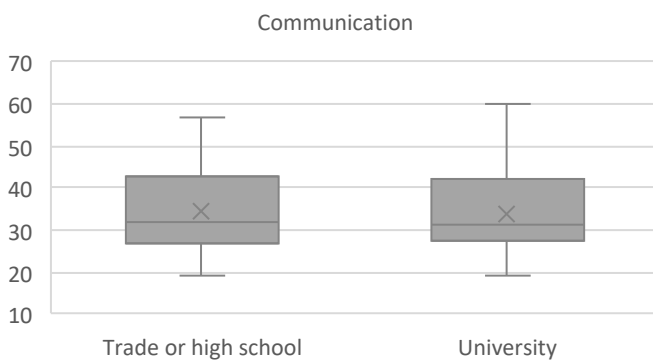


Figure 7.16: Boxplot of Care coordination: Communication by education

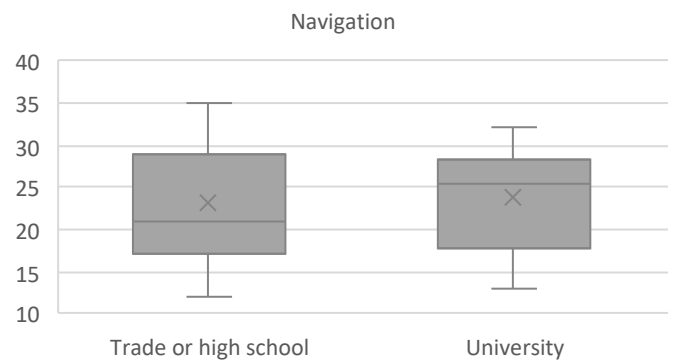


Figure 7.17: Boxplot of Care coordination: Navigation by education

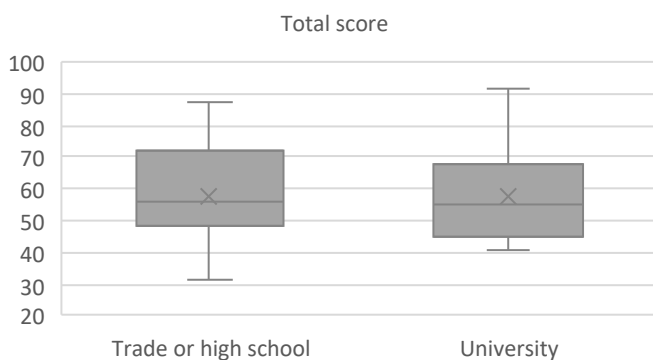


Figure 7.18: Boxplot of Care coordination: Total score by education

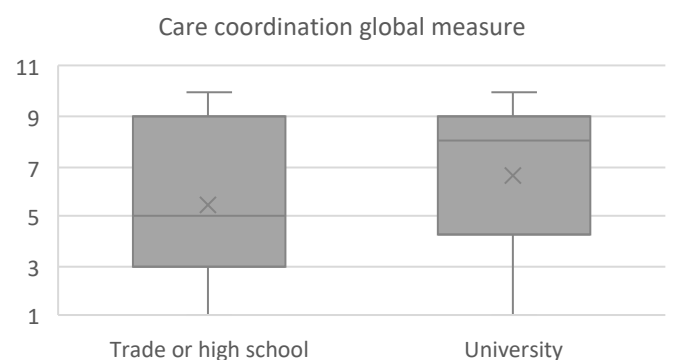


Figure 7.19: Boxplot of Care coordination: Care coordination global measure by education

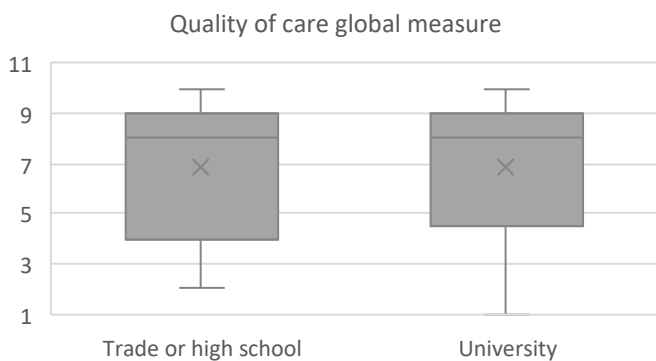


Figure 7.20: Boxplot of Care coordination: Quality of care global measure by education

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. There were 2 participants (7.41%) living in regional or remote areas and 25 participants

(92.59%) living in metropolitan areas. Comparisons were not made because there were too few participants lived in regional or remote areas. Summary statistics are displayed in Table 7.10.

Table 7.10: Care coordination by location summary statistics

Care coordination scale	Group	Number (n=27)	Percent	Mean	SD	Median	IQR	Quintile
Communication*	Regional or remote	2	7.41	39.50	28.99	39.50	20.50	3
	Metropolitan	25	92.59	33.88	9.75	32.00	11.00	-
Navigation*	Regional or remote	2	7.41	27.50	6.36	27.50	4.50	3
	Metropolitan	25	92.59	23.04	6.55	25.00	11.00	-
Total score*	Regional or remote	2	7.41	67.00	35.36	67.00	25.00	3
	Metropolitan	25	92.59	56.92	14.54	56.00	20.00	-
Care coordination global measure	Regional or remote	2	7.41	5.50	6.36	5.50	4.50	3
	Metropolitan	25	92.59	6.00	3.19	6.00	6.00	-
Quality of care global measure	Regional or remote	2	7.41	5.50	6.36	5.50	4.50	4
	Metropolitan	25	92.59	6.92	2.81	8.00	4.00	-

*Normal distribution use mean and SD as measure of central tendency

Care coordination by socioeconomic status

Comparisons were made by socioeconomic status, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6, Mid to low status (n=10, 37.04%) compared to those with a higher SEIFA score of 7-10, Higher status (n=17, 62.96%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.11), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.12).

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

Table 7.11: Care coordination by socioeconomic status summary statistics and T-test

Care coordination scale	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Navigation	Mid to low status	10	37.04	23.00	7.20	-0.22	25	0.8260
	Higher status	17	62.96	23.59	6.32			
Total score	Mid to low status	10	37.04	57.50	21.37	-0.04	25	0.9675
	Higher status	17	62.96	57.76	12.25			
Care coordination global measure	Mid to low status	10	37.04	4.80	3.68	-1.43	25	0.1658
	Higher status	17	62.96	6.65	2.98			

Table 7.12: Care coordination by socioeconomic status summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=27)	Percent	Median	IQR	W	p-value
Communication	Mid to low status	10	37.04	30.50	25.75	74.50	0.6150
	Higher status	17	62.96	32.00	10.00		
Quality of care global measure	Mid to low status	10	37.04	4.50	7.00	57.50	0.1706
	Higher status	17	62.96	8.00	2.00		

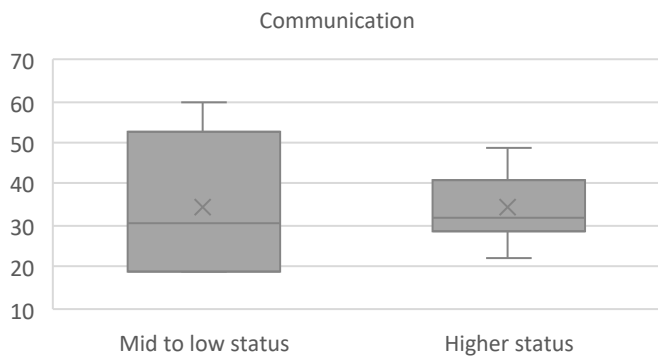


Figure 7.21: Boxplot of Care coordination: Communication by socioeconomic

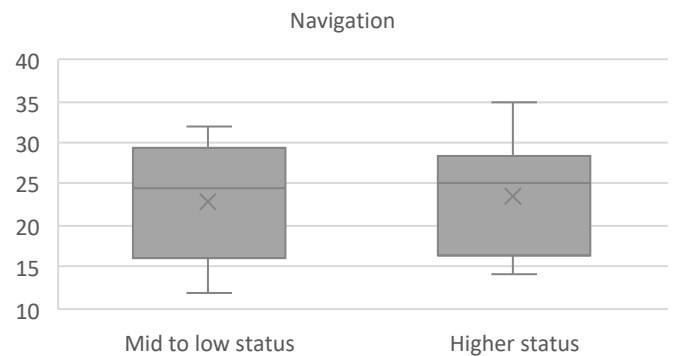


Figure 7.22: Boxplot of Care coordination: Navigation by socioeconomic

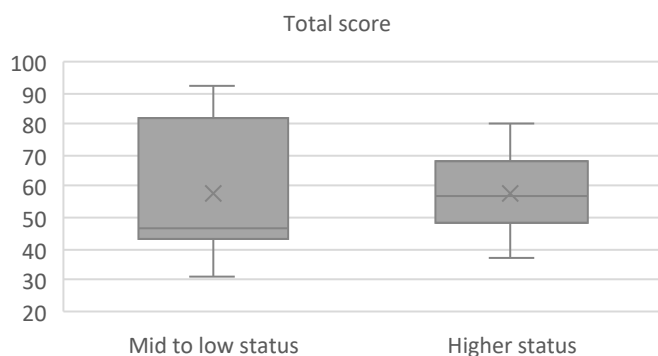


Figure 7.23: Boxplot of Care coordination: Total score by socioeconomic

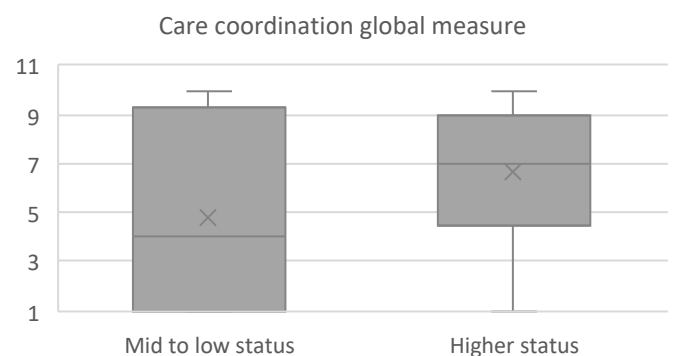


Figure 7.24: Boxplot of Care coordination: Care coordination global measure by socioeconomic

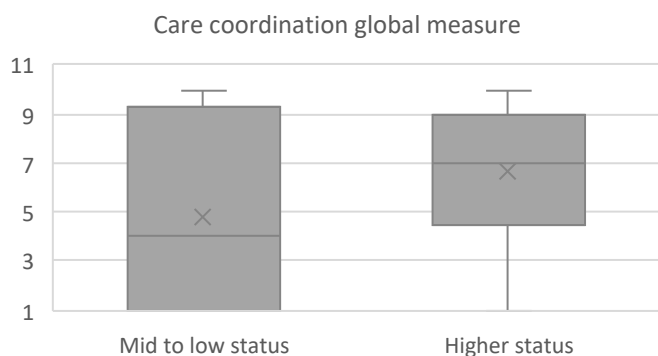


Figure 7.25: Boxplot of Care coordination: Quality of care global measure by socioeconomic

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 response was that they did not receive any formal support (30.77%), and some participants described that they did not need or seek help or support (19.23%). When participants got support, they most commonly received support from charities (30.77%) and from peer support or other patients (15.38%).

Participant describes that they did not receive any formal support

INTERVIEWER: My question is, have you received any support from Health and Community Services to help you manage the impact of your condition?

PARTICIPANT: No.

INTERVIEWER: Not at all.

PARTICIPANT: Australia are not very good at that.
Participant 002_2023AULUC

No, there's nothing there. I was never offered anything.

Participant 019_2023AULUC

Participant describes getting support from charities

Only the Lung Cancer Foundation, the nurse rings me every now and then to have a chat and she's lovely. I haven't got any home help, nothing like that.

Participant 001_2023AULUC

PARTICIPANT: Help that I've asked for, I did receive some help from an organization. There was Mummy's Wish. I reached out to them to get some comfort bears for my children where I could pre-record a message. I got that from them. There was another foundation, but I have a feeling both the people have passed away who had it. They provided a one-off financial support for when I was going to fly to CITY for Gamma Knife. They were called-- I could tell you, but I can't remember.

Participant 015_2023AULUC

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

Yes, but I haven't wanted to either. They're available, but I haven't needed them.

Participant 006_2023AULUC

I was given the opportunity through the Cancer Care Services at the hospital, but no, I didn't take advantage of any of them. I didn't need them, and even with the counseling, I didn't need that either, but I was offered everything, offered all those.

Participant 017_2023AULUC

I'd say, no, because I haven't sorted. I'm not feeling it, in any way, under cared for.

Participant 022_2023AULUC

No, but then I've probably haven't really needed it.

Participant 025_2023AULUC

Participant describes having peer support, or getting support from other patients

Yes. Definitely I feel supported by the people in the groups, the online, the Facebook one, and the HOSPITAL group. People will reach out if they think you're not doing well. Yes, definitely supported there. The Peer Connect program through Lung Foundation Australia. I am a primary peer there, so I will contact people, but it works both ways, even though I do the primary calling and it works both ways. That back and forth with someone who's got the same lived experience is supportive.

Participant 020_2023AULUC

When I was first diagnosed, through the Cancer Council, yes, and then outside of that I'm on a couple of Facebook groups also.

Participant 026_2023AULUC

My lung cancer coffee club we actually created, we're called The Grateful. I thought that would be a good title for us. It's all because of this smoking, smoking, smoking narrative. There's a lot of people that are getting diagnosed with this at younger ages that have never smoked because not that many people in Australia do actually smoke, or smoke a lot. Who would? and it's expensive.

Participant 004_2023AULUC

Table 7.13: Experience of care and support

Care and support received	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes that they did not receive any formal support	8	30.77	8	32.00	0	0.00	3	30.00	5	31.25	5	31.25	3	30.00
Participant describes getting support from charities	8	30.77	7	28.00	1	100.00	2	20.00	6	37.50	6	37.50	2	20.00
Participant describes that they did not need or seek help or support	5	19.23	5	20.00	0	0.00	3	30.00	2	12.50	3	18.75	2	20.00
Participant describes having peer support, or getting support from other patients	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	4	25.00	0	0.00

Care and support received	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes that they did not receive any formal support	8	30.77	3	17.65	5	55.56	7	53.85	1	7.69	1	50.00	7	29.17	3	33.33	5	29.41
Participant describes getting support from charities	8	30.77	4	23.53	4	44.44	7	53.85	1	7.69	0	0.00	8	33.33	2	22.22	6	35.29
Participant describes that they did not need or seek help or support	5	19.23	2	11.76	3	33.33	3	23.08	2	15.38	1	50.00	4	16.67	2	22.22	3	17.65
Participant describes having peer support, or getting support from other patients	4	15.38	1	5.88	3	33.33	4	30.77	0	0.00	0	0.00	4	16.67	2	22.22	2	11.76

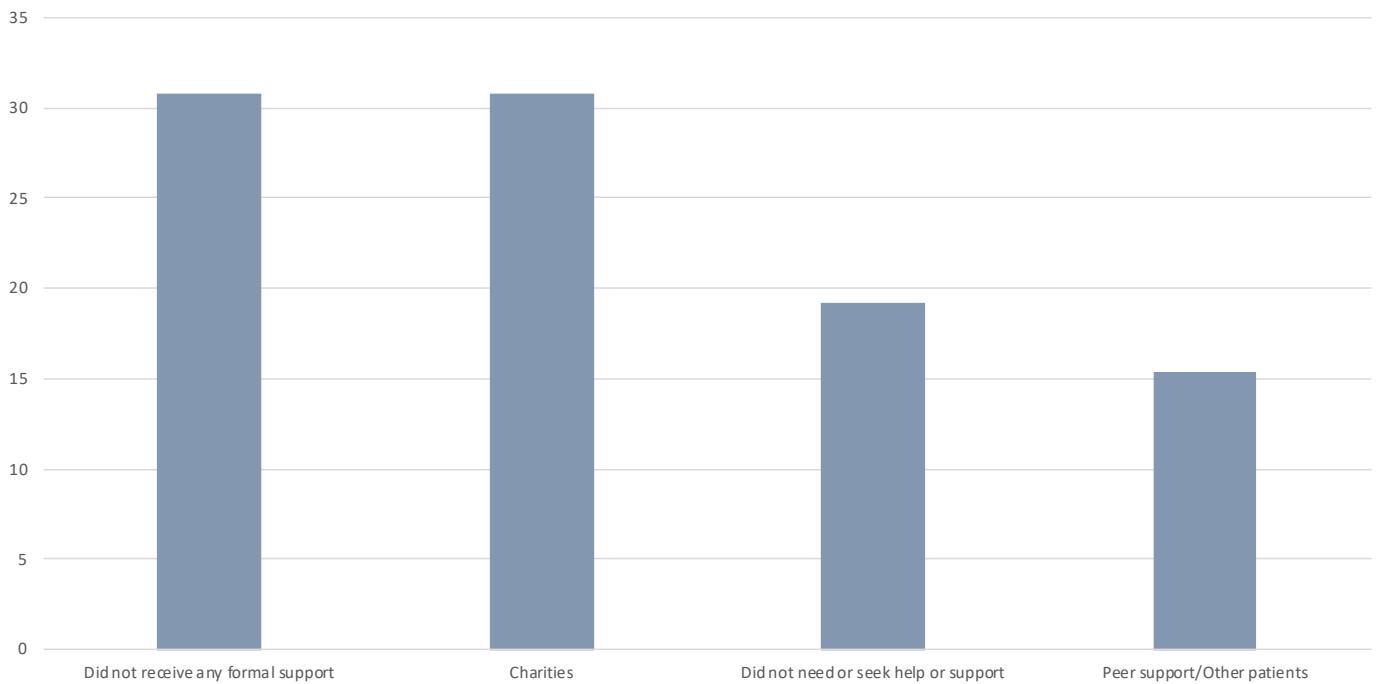


Figure 7.6: Experience of care and support

Table 7.14: Experience of care and support – subgroup variations

Theme	Less frequently	More frequently
Did not receive any formal support	Aged 35 to 64 University	Aged 65 or older Trade or high school
Charities	Non-metastatic Male University	Aged 65 or older Trade or high school
Did not need or seek help or support	-	Non-metastatic Aged 65 or older
Peer support/Other patients	Male University	Aged 65 or older Trade or high school