

Section 5

Treatment

Section 5: Experience of treatment

Main provider of treatment

The most common provider of treatment and care were medical oncologists (n=21, 72.41 %), followed by radiation oncologists (n=4, 13.79%) (

Access to healthcare professionals

The majority of participants had access to a medical Oncologist (n=23, 85.19%), a respiratory physician (n=21, 77.78%) and a General Practitioner (n=22, 81.48%). Less than a third (n=8, 29.63%) had access to a lung cancer nurse. A third of participants (n=9, 33.33%) had counselling or psychological support.

Respect shown

There were 14 participants (51.85%) that indicated that they had been treated with respect throughout their experience, and 9 participants (33.33%) that were treated with respect with the exception of one or two occasions. There were 4 participants (14.81%) that felt they had not been treated respectfully (Table 5.3, Figure 5.3).

Health care system

The majority of participants had private health insurance (n=16, 59.26%). Throughout their treatment, there were 11 participants (40.74%) that were treated as a private patient, 14 participants (51.85%) were mostly treated as a public patient, and there were 2 participants (7.41%) that were equally treated as a private and public patient.

Throughout their treatment, there were 10 participants (37.04%) that were treated mostly in the private hospital system, 12 participants (44.44%) were mostly treated in the public system, and there were 5 participants (18.52%) that were equally treated in the private and public systems.

Affordability of healthcare

The first question was about having to delay or cancel cancer healthcare appointments because they were unable to afford them. Almost all the participants never or rarely had to delay or cancel appointments due to affordability (n = 22, 81.48%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=25, 92.59%).

The third question was about the affordability of basic essentials such as food, housing and power. There were 22 participants (81.48%) that never or rarely had trouble paying for essentials, and 2 participants (7.41%) that sometimes found it difficult, and 3 participants (11.11%) often or very often found it difficult to pay for basic essentials.

The final question was about paying for additional carers for themselves or for their family, there were 4 participants (14.81%) that paid for additional carers due to their condition.

Cost of condition

Participants estimated the amount they spend per month due to their condition, including doctors' fees, transport, carers, health insurance gaps and complementary therapies. The most common amount was between \$1 to 100 (n=7, 25.93%), followed by between \$251 to 500 (n=5, 18.52%). There were 3 participants (11.11%), that spent More than \$1000 a month.

Changes to employment status

Work status for 3 participants (11.11%) had not changed since diagnosis, and 5 participants (18.52%) were retired or did not have a job. There were 8 participants (29.63%) had to quit their job, 9 participants (33.33%) reduced the number of hours they worked, and 3 participants (11.11%) that accessed their superannuation early. There were 2 participants (7.41%) that took leave from work without pay, and 5 participants (18.52%) that took leave from work with pay.

Changes to carer/partner employment status

Most commonly, participants had partners or carers that did not change their work status due to their condition (n=14, 51.85%), and there were 8 partners (29.63%) or carers that were retired or did not have a job. There were 4 participants (14.81%) whose partners reduced the numbers of hours they worked, and 1 partner (3.70%) that quit their job. The partners of 2 participants (7.41%) took leave without pay, and there were 4 partners (14.81%) that took leave with pay.

Reduced income due to condition

More than half of the participants (n=13, 48.15%) indicated in the online questionnaire that they had a reduced family income due to their condition. Most commonly, participants were not sure about the amount their monthly income was reduced by (n=5, 29.41%), or reduced by between More than \$5000 per month (n=5, 29.41%).

Summary of treatments

There were 12 participants (41.38%) that had surgery, 12 participants (44.44%) that had chemotherapy, 15 participants (55.56%) that had immunotherapy, 10 participants (37.04%) that had radiotherapy, 2 participants (7.41%) that had taken part in clinical trials, and 2 participants (7.41%) that had no treatment. There were 12 participants (41.38%) that had surgery for their condition (excluding biopsies). There were 9 participants (31.03%) that had one operation, 3 participants (10.34%) that had two operations

Quality of life was rated on a Likert scale from one to seven, where one is "Life was very distressing" and seven is "Life was great". Quality of life ranged between 2.00 and 5.00 for all treatments, in the life was distressing to life was good range. Quality of life was in the life was distressing range for surgery to remove lymph nodes, and for cisplatin (Median =2.00). Quality of life was in the life was distressing to a little distressing range for radiotherapy, and was in the life was a little distressing (Median =3.00) range for lobectomy and Wedge resection, Segmentectomy or Sleeve resection. Quality of life for both immunological treatments, Tagrisso and Alectinib was in the life was good range (median=5.0).

Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective. Participants on average found all types of surgery (lobectomy, Wedge resection, Segmentectomy or Sleeve resection, and lymph node resection) to be very effective (median =5.00), and all types of immunotherapy (Tagrisso and Alectinib) to be very effective (median = 5.00). Cisplatin was found to be moderately effective (median =3.00), and radiotherapy somewhat to moderately effective (median = 2.75).

Clinical trials discussions

There was a total of 11 participants (40.74%) that had discussions about clinical trials, 5 participants (18.52%) had brought up the topic with their doctor, and the doctor of 6 participants (22.22%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=16, 59.26%).

Clinical trial participation

There were 2 participants (7.41%) that had taken part in a clinical trial, 22 participants (81.48%) that would like to take part in a clinical trial if there was a suitable one, and 3 participants, that have not participated in a clinical trial and do not want to (11.11%).

Description of mild side effects

In the structured interview, participants were asked how they would describe the term 'mild side effects'. The most common response was using a specific example to describe mild side effects (69.23%). Other descriptions of mild side effects were those that do not interfere with life (46.15%), and those that can be managed with self-medication or self-management (Over-the-counter) (30.77 %).

When a specific side effect was described, the most common responses were aches/pain (general) (23.08%), skin rash or itch (23.08%), and gastrointestinal distress (19.23 %). Other examples included fatigue/lethargy (11.54%), and being short of breath (11.54%)

Description of severe side effects

In the structured interview, participants were asked how they would describe the term 'severe side effects'. The most common response was using a specific example to describe severe side effects (61.54%), followed by side effects that impact everyday life/ability to conduct activities of daily living (38.46%).

When a specific side effect was described, the most

The most common examples were being short of breath (15.38%), having general aches and pains (11.54%), and the emotional or mental impact (11.54 %).

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime. The most common responses were that they did not give up on any treatment (34.62%), and as long as side effects are tolerable (23.08%). Other themes included the advice of their specialist, or as long as prescribed (19.23%), adhering to treatment for a specific amount of time (19.23%), and being unable to answer as they had not had treatment or cannot answer hypothetical question (11.54%).

When participants stated a specific amount of time to adhere to a treatment, the most common amount of time was two to three months.

What needs to change to feel like treatment is working

Participants were asked to describe what needs to change to feel like treatment is effective. The most common responses were seeing evidence of stable disease or no disease progression (57.69%), and seeing reduction of physical signs and symptoms (19.23%).

As a follow up question, participants were asked what it would mean to them if the treatment worked in the way they described. The most common responses were allowing them to do everyday activities and return to normal life (23.08%), leading to a reduction in symptoms or side effects (19.23%), and allowing them to engage more with social activities and family life (15.38 %). Other themes included allowing them to return to work (11.54%), allowing them to do domestic tasks (11.54%), allowing them to do more exercise (11.54%), and that it would have a positive impact on their mental health (11.54%).

Main provider of treatment

Participants were asked in the online questionnaire who was the main healthcare professional that provided treatment and management of their condition.

The most common provider of treatment and care were medical oncologists (n=21, 72.41%), followed by radiation oncologists (n=4, 13.79%) (Table 5.1, Figure 5.1).

Table 5.1: Main provider of treatment

Main provider of treatment	Number (n=29)	Percent
Medical oncologist	21	72.41
Radiation oncologist	4	13.79
Respiratory specialist	2	6.90
Surgeon	2	6.90
General practitioner	1	3.45

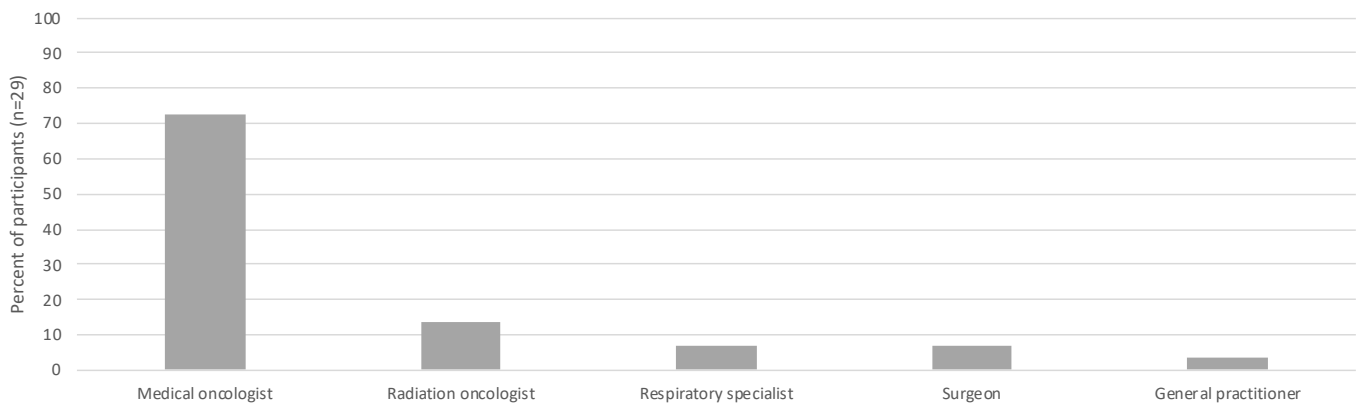


Figure 5.1: Main provider of treatment

Access to healthcare professionals

Participants noted in the online questionnaire the healthcare professionals they had access to for the treatment and management of their condition.

The majority of participants had access to a medical Oncologist (n=23, 85.19%), a respiratory physician

(n=21, 77.78%) and a General Practitioner (n=22, 81.48%). Less than a third (n=8, 29.63%) had access to a lung cancer nurse. A third of participants (n=9, 33.33%) had counselling or psychological support. (Table 5.2, Figure 5.2)

Table 5.2: Access to healthcare professionals

Healthcare professional	Number (n=27)	Percent
Medical Oncologist	23	85.19
Respiratory physician	21	77.78
Surgeon	15	55.56
Radiation oncologist	10	37.04
Psychiatrist	1	3.70
General Practitioner	22	81.48
Lung cancer nurse	8	29.63
Registered Nurse	8	29.63
Counselling or psychological support	9	33.33
Dietitian	6	22.22
Physiotherapy	6	22.22
Podiatrist	1	3.70
Genetic counsellor	1	3.70
Occupational therapy	1	3.70
Other	4	14.81

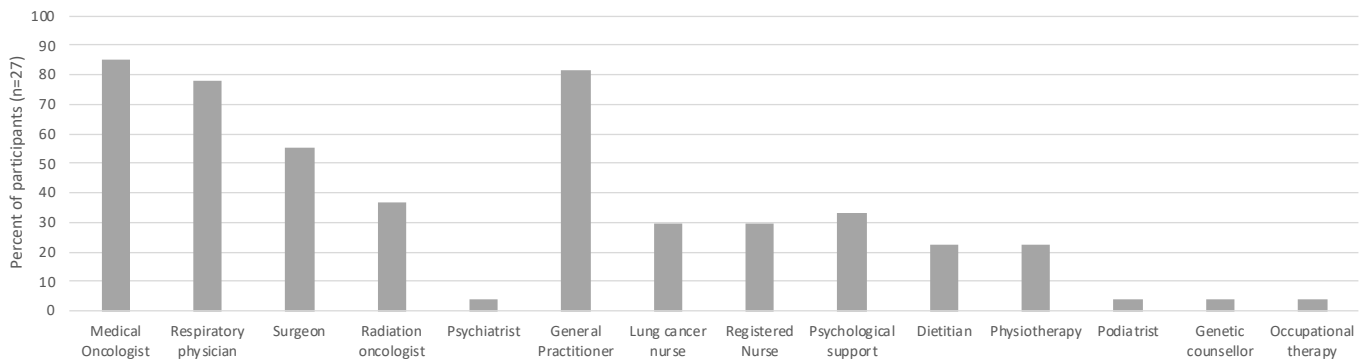


Figure 5.2: Access to healthcare professionals

Respect shown

Participants were asked to think about how respectfully they were treated throughout their experience, this question was asked in the online questionnaire.

There were 14 participants (51.85%) that indicated that they had been treated with respect throughout their

experience, and 9 participants (33.33%) that were treated with respect with the exception of one or two occasions. There were 4 participants (14.81%) that felt they had not been treated respectfully (Table 5.3, Figure 5.3).

Table 5.3: Respect shown

Respect shown	Number (n=27)	Percent
Respect shown	14	51.85
Respect shown, with the exception of one or two occasions	9	33.33
Respect not shown	4	14.81

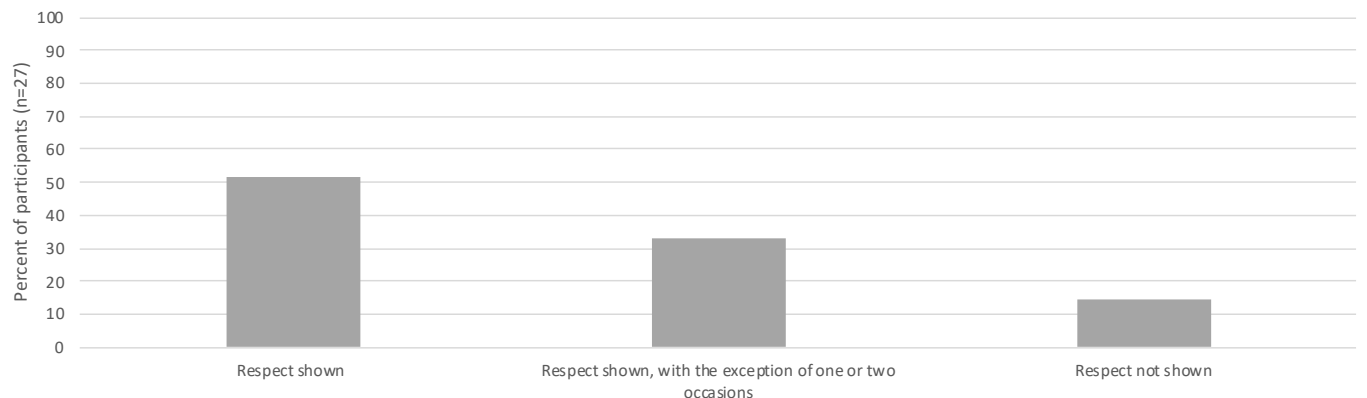


Figure 5.3: Respect shown

Health care system

In the online questionnaire, participants were asked questions about the healthcare system they used, about private insurance and about whether they were treated as a public or private patient (Table 5.4, Figures 5.4 and 5.5).

The majority of participants had private health insurance (n=16, 59.26%). Throughout their treatment, there were 11 participants (40.74%) that were treated as a private patient, 14 participants (51.85%) were mostly treated as a public patient, and

there were 2 participants (7.41%) that were equally treated as a private and public patient.

Throughout their treatment, there were 10 participants (37.04%) that were treated mostly in the private hospital system, 12 participants (44.44%) were mostly treated in the public system, and there were 5 participants (18.52%) that were equally treated in the private and public systems.

Table 5.4: Health care system

Health care services	Response	Number (n=27)	Percent
Private health insurance	No	11	40.74
	Yes	16	59.26
Throughout your treatment in hospital, have you most been treated as a public or a private patient	Equally as a public and private patient	2	7.41
	Private patient	11	40.74
	Public patient	14	51.85
Which hospital system have you primarily been treated in	Both public and private	5	18.52
	Private	10	37.04
	Public	12	44.44



Figure 5.4: Health insurance

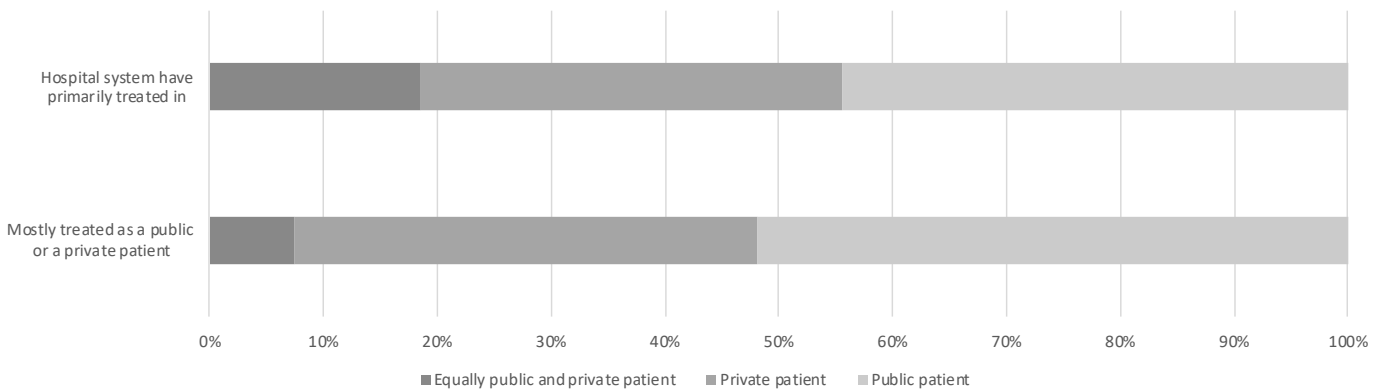


Figure 5.5: Hospital system

Affordability of healthcare

Participants were asked a series of questions about affordability of healthcare in the online questionnaire (Table 5.5, Figure 5.6).

The first question was about having to delay or cancel healthcare appointments because they were unable to afford them. Almost all the participants never or rarely had to delay or cancel appointments due to affordability (n = 22, 81.48%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=25, 92.59%).

The third question was about the affordability of basic essentials such as food, housing and power. There were 22 participants (81.48%) that never or rarely had trouble paying for essentials, and 2 participants (7.41%) that sometimes found it difficult, and 3 participants (11.11%) often or very often found it difficult to pay for basic essentials.

The final question was about paying for additional carers for themselves or for their family, there were 4 participants (14.81%) that paid for additional carers due to their condition.

Table 5.5: Affordability of healthcare

Health services and insurance	Response	Number (n=27)	Percent
Delay or cancel healthcare appointments due to affordability	Never	20	74.07
	Rarely	2	7.41
	Sometimes	4	14.81
	Often	1	3.70
	Very often	0	0.00
Did not fill prescriptions due to cost	Never	25	92.59
	Rarely	0	0.00
	Sometimes	1	3.70
	Often	1	3.70
	Very often	0	0.00
Difficult to pay for basic essentials	Never	15	55.56
	Rarely	7	25.93
	Sometimes	2	7.41
	Often	1	3.70
	Very often	2	7.41
Pay for additional carers for self or family	Yes	4	14.81
	No	23	85.19

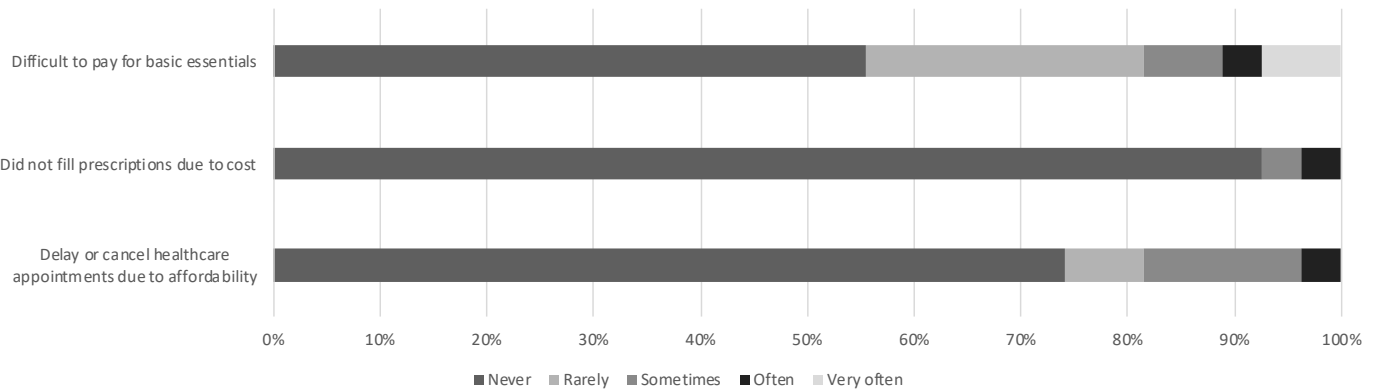


Figure 5.6: Affordability of healthcare

Cost of condition

In the online questionnaire, participants estimated the amount they spend per month due to their condition, including doctors’ fees, transport, carers, health insurance gaps and complementary therapies. Where the response was given in a dollar amount, it is listed below (Table 5.6, Figure 5.7).

The most common amount was between \$1 to 100 (n=7, 25.93%), followed by between \$251 to 500 (n=5, 18.52%). There were 3 participants (11.11%), that spent More than \$1000 a month.

Table 5.6: Estimated monthly out of pocket expenses due to condition

Estimated monthly out of pocket expenses	Number (n=27)	Percent
\$0	4	14.81
\$1 to 100	7	25.93
\$101 to 250	3	11.11
\$251 to 500	5	18.52
\$501 to 1000	3	11.11
More than \$1000	3	11.11
Not sure	2	7.41

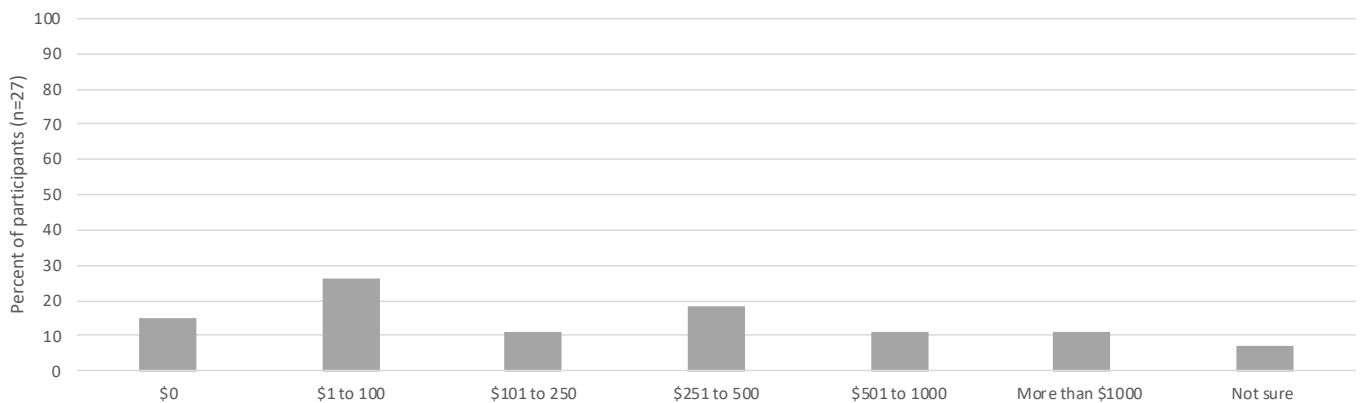


Figure 5.7: Estimated monthly out of pocket expenses due to condition

Changes to employment status

Participants were asked, in the online questionnaire, if they had any changes to their employment status due to their condition. Participants were able to choose multiple changes to employment (Table 5.7, Figure 5.8).

Work status for 3 participants (11.11%) had not changed since diagnosis, and 5 participants (18.52%) were retired or did not have a job. There were 8 participants (29.63%) had to quit their job, 9 participants (33.33%) reduced the number of hours they worked, and 3 participants (11.11%) that accessed their superannuation early. There were 2 participants (7.41%) that took leave from work without pay, and 5 participants (18.52%) that took leave from work with pay.

Changes to carer/partner employment status

Participants were asked, in the online questionnaire, if they had any changes to the employment status of their care or partner due to their condition. Participants were able to choose multiple changes to employment. (Table 5.8, Figure 5.9).

Most commonly, participants had partners or carers that did not change their work status due to their condition (n=14, 51.85%), and there were 8 partners (29.63%) or carers that were retired or did not have a job. There were 4 participants (14.81%) whose partners reduced the numbers of hours they worked, and 1 partner (3.70%) that quit their job. The partners of 2 participants (7.41%) took leave without pay, and there were 4 partners (14.81%) that took leave with pay.

Table 5.7: Changes to employment status

Changes in work status due to condition	Number (n=27)	Percent
Work status has not changed	3	11.11
Retired or did not have a job	5	18.52
Had to quit job	8	29.63
Reduced number of hours worked	9	33.33
Leave from work without pay	2	7.41
Leave from work with pay	5	18.52
Accessed Superannuation early due to condition	3	11.11

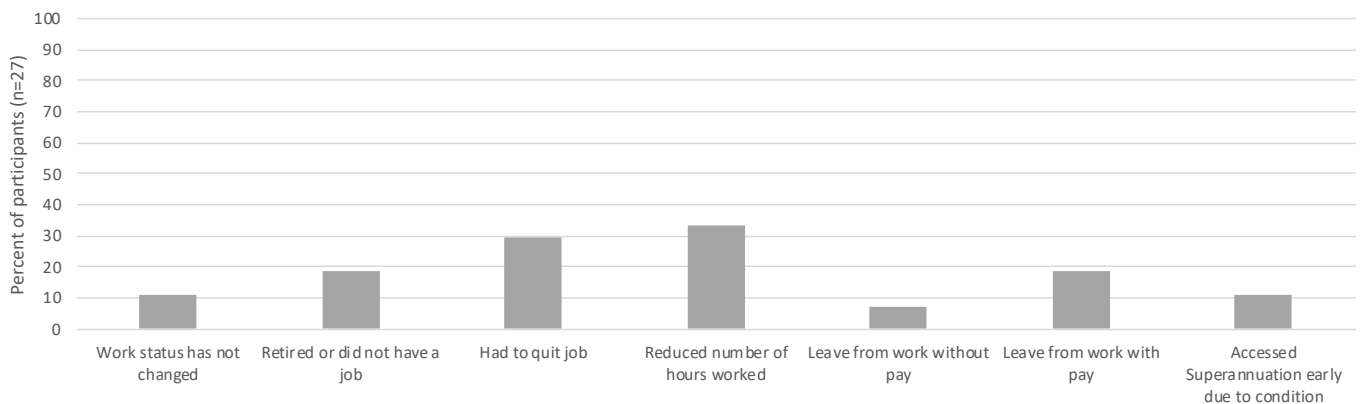


Figure 5.8: Changes to employment status

Table 5.8: Changes to care/partner employment status

Changes to care/partner employment status	Number (n=27)	Percent
Work status has not changed	14	51.85
Retired or did not have a job	8	29.63
Had to quit job	1	3.70
Reduced number of hours worked	4	14.81
Leave from work without pay	2	7.41
Leave from work with pay	4	14.81

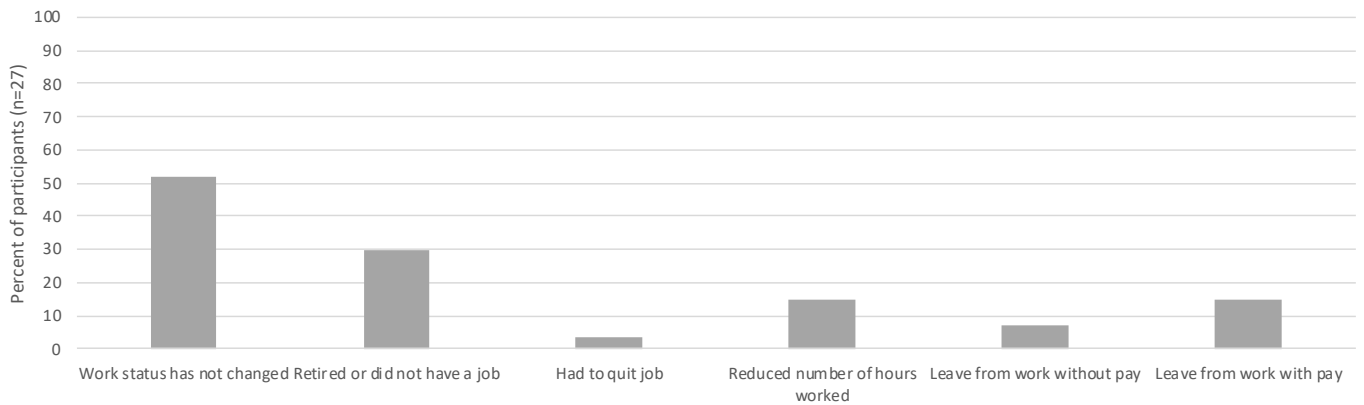


Figure 5.9: Changes to care/partner employment status

Reduced income due to condition

More than half of the participants (n=13, 48.15%) indicated in the online questionnaire that they had a reduced family income due to their condition.

Estimated reduction monthly income

As a follow up question, participants were asked if their family or household income had reduced due to their

condition. Where a dollar amount was given, it is listed below (Table 5.9, Figure 5.10).

Most commonly, participants were not sure about the amount their monthly income was reduced by (n=5, 29.41%), or reduced by between More than \$5000 per month (n=5, 29.41%).

Table 5.9: Estimated monthly loss of income

Estimated monthly loss of income	Number (n=17)	Percent
\$0	4	23.53
\$3000 to 5000	3	17.65
More than \$5000	5	29.41
Not sure	5	29.41

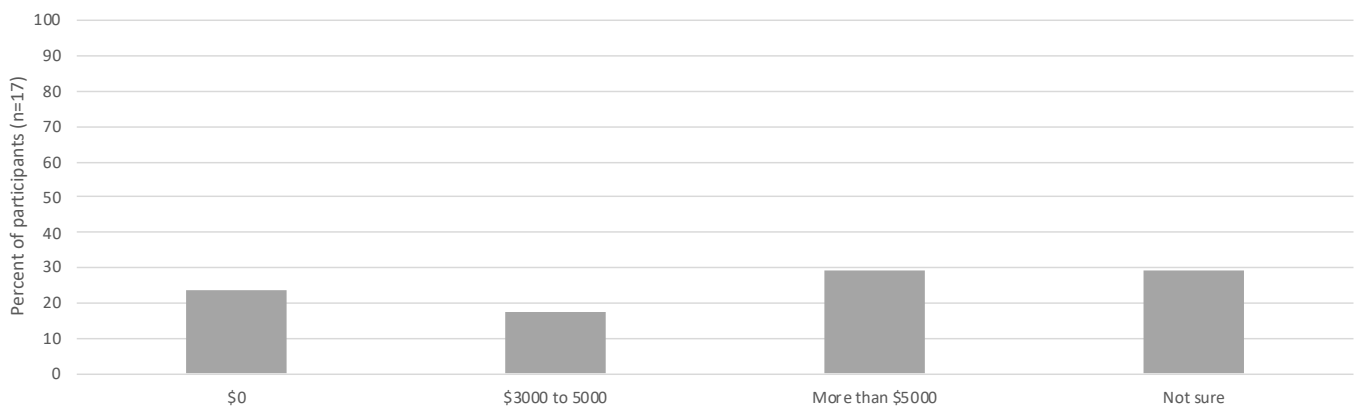


Figure 5.10: Estimated monthly loss of income

Summary of treatments

In the online questionnaire, participants noted the types of treatment they had for lung cancer, the side effects, their quality of life during treatment and rated how effective they found the treatments. All of the treatments noted in the online questionnaire are listed in Table 5.10 and Figure 5.11) Additional details about side effects, quality of life, and effectiveness are listed for treatments were more than 5 participants had used the treatment (Tables 5.10 to 5.14, Figures 5.12 and 5.13)

There were 12 participants (41.38%) that had surgery, 12 participants (44.44%) that had chemotherapy, 15 participants (55.56%) that had immunotherapy, 10 participants (37.04%) that had radiotherapy, 2 participants (7.41%) that had taken part in clinical trials, and 2 participants (7.41%) that had no treatment.

There were 12 participants (41.38%) that had surgery for their condition (excluding biopsies). There were 9 participants (31.03%) that had one operation, 3

participants (10.34%) that had two operations (Table 5.11, Figure 5.14).

Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Quality of life ranged between 2.00 and 5.00 for all treatments, in the life was distressing to life was good range.

Quality of life was in the life was distressing range for surgery to remove lymph nodes, and for cisplatin (Median =2.00). Quality of life was in the life was distressing to a little distressing range for radiotherapy, and was in the life was a little distressing (Median =3.00) range for lobectomy and Wedge resection, Segmentectomy or Sleeve resection. Quality of life for

both immunological treatments, Tagrisso and Alectinib was in the life was good range (median=5.0).

Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective. Participants on average found all types of surgery (lobectomy, Wedge resection, Segmentectomy or Sleeve resection, and lymph node resection) to be very effective (median =5.00), and all types of immunotherapy (Tagrisso and Alectinib) to be very effective (median = 5.00). Cisplatin was found to be moderately effective (median =3.00), and radiotherapy somewhat to moderately effective (median = 2.75).

Side effects from treatments are listed in Tables 5.12. to 5.14.

Table 5.10: Summary of treatments

Treatments overview	Number	Percent	Type of treatment	Number	Percent	Quality of life		Effectiveness	
						Median	IQR	Median	IQR
No treatment (n=27)	2	7.41	-	-	-	-	-	-	-
Surgery (n=29)	12	41.38	Lobectomy	10	34.48	3.00	1.00	5.00	0.75
			Wedge resection, Segmentectomy or Sleeve resection	5	17.24	3.00	1.00	5.00	2.00
			Surgery to remove lymph nodes	5	17.24	2.00	1.00	5.00	2.00
Chemotherapy (n=27)	12	44.44	Cisplatin	8	29.63	2.00	0.75	3.00	2.00
			Carboplatin	4	14.81	-	-	-	-
			Vinorelbine	3	11.11	-	-	-	-
			Paclitaxel	3	11.11	-	-	-	-
			Pemetrexed	3	11.11	-	-	-	-
			Etoposide and cisplatin	2	7.41	-	-	-	-
			Carboplatin and etoposide	2	7.41	-	-	-	-
			Pemetrexed and cisplatin	2	7.41	-	-	-	-
			Gemcitabine	1	3.70	-	-	-	-
Immunotherapy (n=27)	15	55.56	Tagrisso	7	25.93	5.00	0.50	5.00	0.25
			Alectinib	6	22.22	5.00	1.50	5.00	0.00
			Tarceva	3	11.11	-	-	-	-
			Crizotinib	2	7.41	-	-	-	-
			Certinib	1	3.70	-	-	-	-
			Lorlatinib	1	3.70	-	-	-	-
Radiotherapy (n=27)	10	37.04	-	-	-	2.50	2.00	2.75	3.00
Clinical trials (n=27)	2	7.41	-	-	-	-	-	-	-

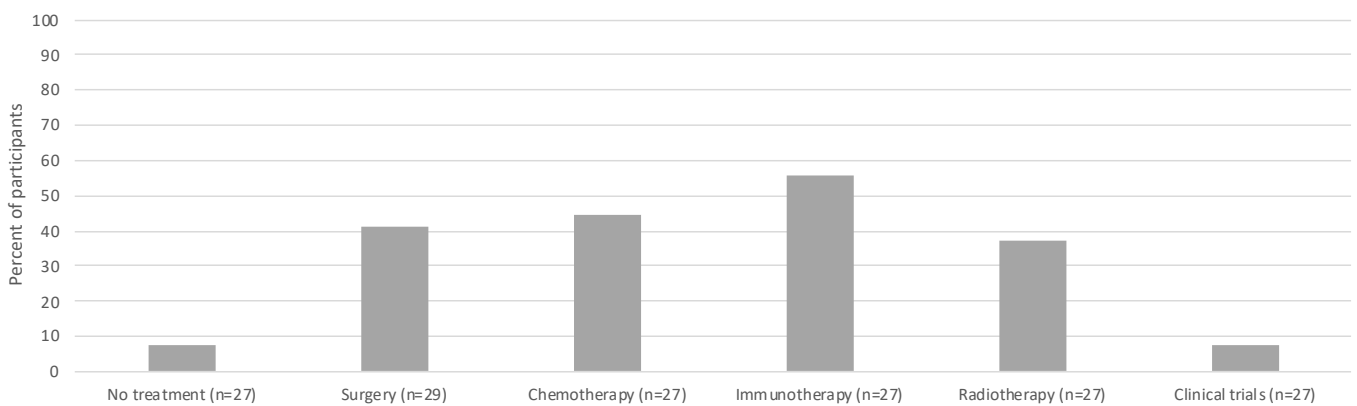


Figure 5.11: Summary of treatments

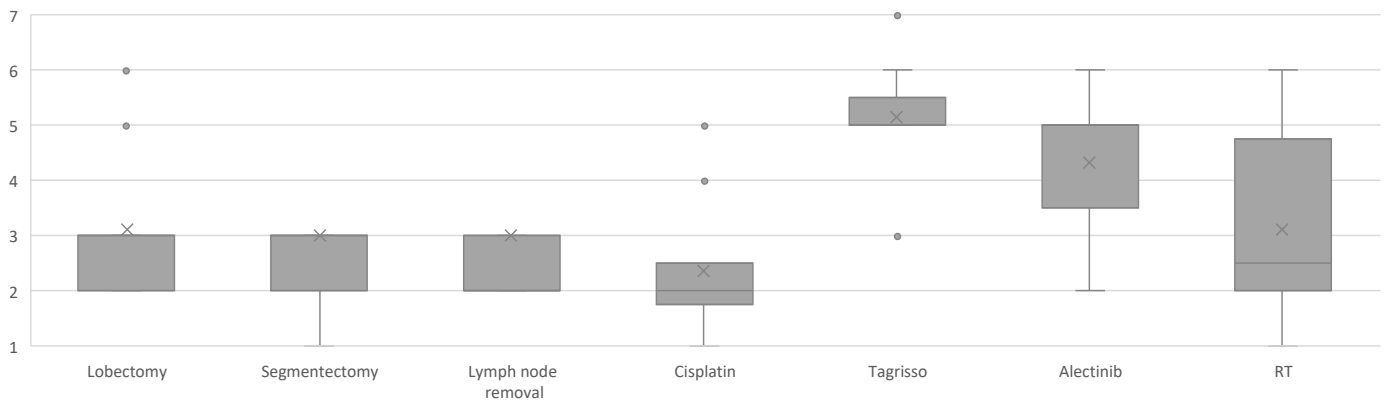


Figure 5.12: Quality of life from treatments

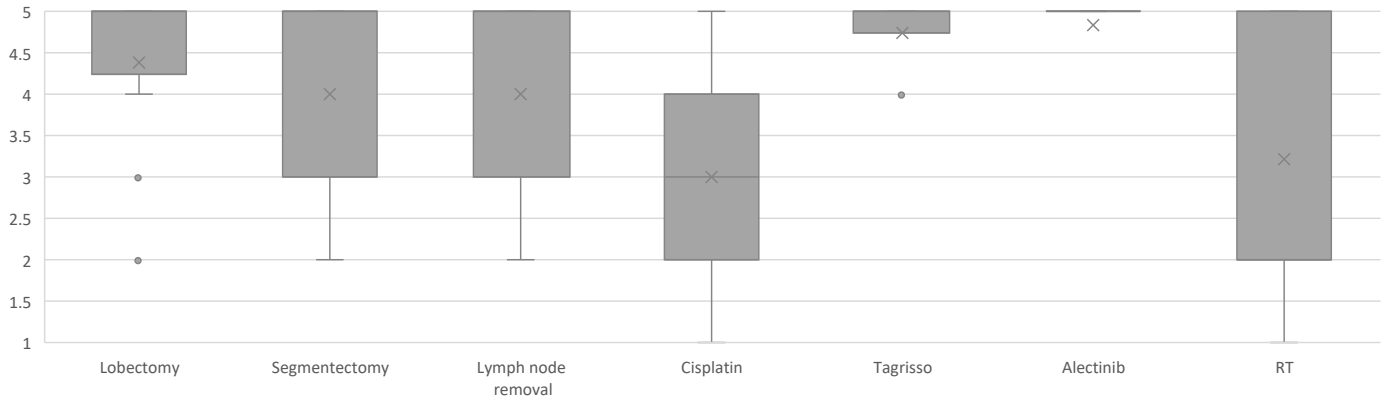


Figure 5.13: Effectiveness of treatments

Table 5.11: Number of surgeries

Number of operations (excluding biopsy)	Number (n=29)	Percent
0	17	58.62
1	9	31.03
2	3	10.34

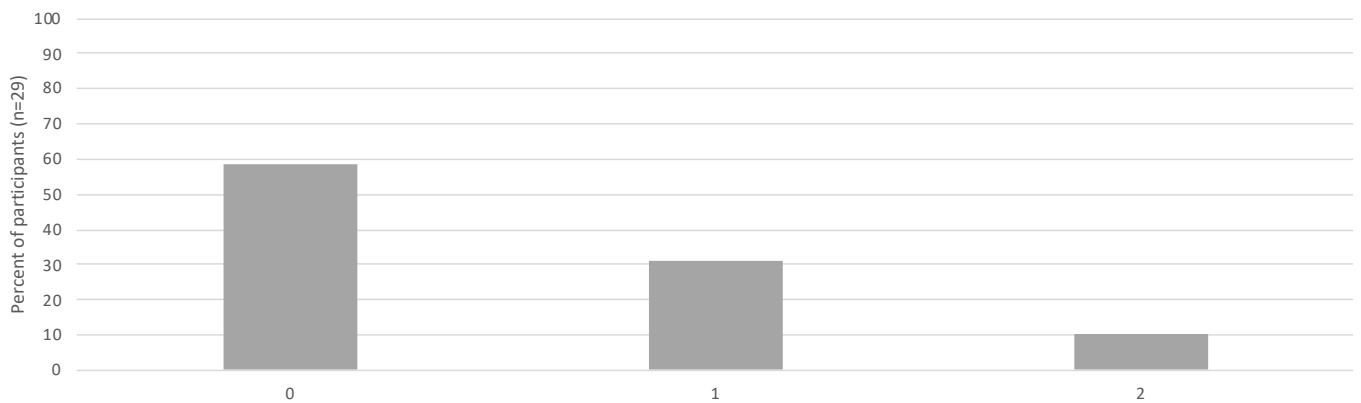


Figure 5.14: Number of surgeries

Table 5.12: Side effects from surgery

Side effects from surgery	Lobectomy		Wedge resection, Segmentectomy or Sleeve resection		Surgery to remove lymph nodes	
	n=10	Percent	n=5	Percent	n=5	Percent
No side effects	0	0.00	0	0.00	0	0.00
Pain	9	90.00	5	100.00	4	80.00
Breathlessness	5	50.00	2	40.00	3	60.00
Fatigue	5	50.00	3	60.00	3	60.00
Feeling generally unwell	2	20.00	1	20.00	0	0.00
Long term side effects	2	20.00	1	20.00	2	40.00
Swelling or redness around wound	2	20.00	2	40.00	3	60.00
Cough	1	10.00	0	0.00	1	20.00

Table 5.13: Side effects from drug treatments

Side effects from drug treatments	Cisplatin		Count of Tagrisso		Count of Alectinib	
	n=8		n=7		n=6	
No side effects	0	0.00	0	0.00	0	0.00
Anemia (low red blood cell counts)	4	50.00	0	0.00	1	16.67
Appetite changes	4	50.00	1	14.29	2	33.33
Changes in libido and sexual function	6	75.00	0	0.00	5	83.33
Chemo brain	5	62.50	2	28.57	4	66.67
Constipation	5	62.50	1	14.29	5	83.33
Diarrhoea	3	37.50	3	42.86	2	33.33
Easy bruising and bleeding	1	12.50	0	0.00	1	16.67
Fatigue	7	87.50	6	85.71	6	100.00
Hair loss	4	50.00	0	0.00	2	33.33
Infection	1	12.50	1	14.29	0	0.00
Mood changes	4	50.00	0	0.00	2	33.33
Mouth, tongue and throat problems	6	75.00	0	0.00	2	33.33
Nausea and vomiting	4	50.00	1	14.29	0	0.00
Nerve and muscle problems	4	50.00	2	28.57	4	66.67
Skin and nail changes	2	25.00	5	71.43	3	50.00
Urine and bladder changes and kidney problems	2	25.00	1	14.29	3	50.00
Weight changes	6	75.00	1	14.29	3	50.00

Table 5.14: Side effects from radiotherapy

Side effects from radiotherapy	Number (n=10)	Percent
No side effects	1	10.00
A type of swelling called lymphedema	1	10.00
Cough, fever and fullness of the chest	2	20.00
Dental problems	1	10.00
Difficulty swallowing	3	30.00
Dry mouth	2	20.00
Fatigue	7	70.00
Mouth and gum sores	2	20.00
Nausea and vomiting	1	10.00
Radiation fibrosis which is permanent scarring of the lungs	1	10.00
Shortness of breath	3	30.00
Shoulder stiffness	1	10.00
Skin blistering or peeling	3	30.00
Skin dryness or itching	3	30.00

Clinical trials

Clinical trials discussions

In the online questionnaire, participants were asked if they had discussions with their doctor about clinical trials, and if they did, who initiated the discussion (Table 5.15, Figure 5.15).

There was a total of 11 participants (40.74%) that had discussions about clinical trials, 5 participants (18.52%) had brought up the topic with their doctor, and the doctor of 6 participants (22.22%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=16, 59.26%).

Table 5.15: Clinical trial discussions

Clinical trial discussions	Number (n=27)	Percent
Participant brought up the topic of clinical trials doctor for discussion	5	18.52
Doctor brought up the topic of clinical trials for discussion	6	22.22
Participant has ever spoken to me about clinical trials	16	59.26

Clinical trial participation

As a follow up question, participants were asked if they had taken part in a clinical trial, and if they had not taken part if they were interested in taking part (Table 5.16, Figure 5.16).

There were 2 participants (7.41%) that had taken part in a clinical trial, 22 participants (81.48%) that would like to take part in a clinical trial if there was a suitable one, and 3 participants, that have not participated in a clinical trial and do not want to (11.11%).

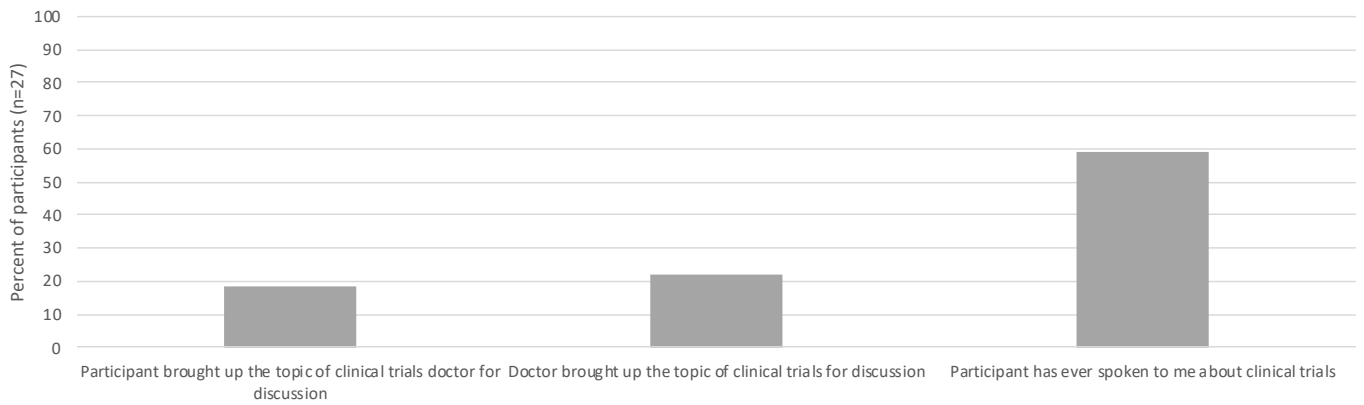


Figure 5.15: Clinical trial discussions

Table 5.16: Clinical trial participation

Clinical trial participation	Number (n=27)	Percent
Has not participated in a clinical trial and does not want to	3	11.11
Has not participated in a clinical trial but would like to if there is one	22	81.48
Has participated in a clinical trial	2	7.41

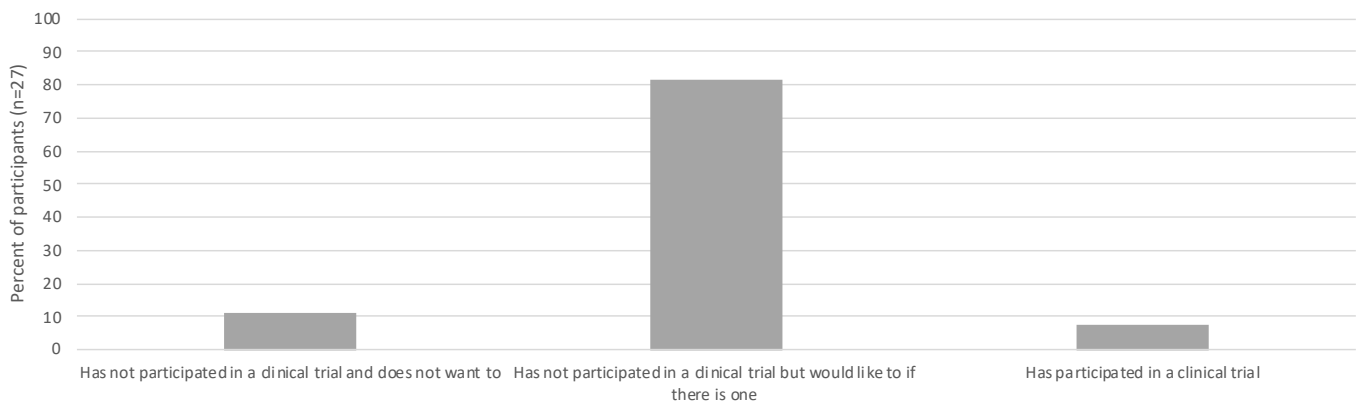


Figure 5.16: Clinical trial participation

Description of mild side effects

In the structured interview, participants were asked how they would describe the term 'mild side effects'. The most common response was using a specific example to describe mild side effects (69.23%). Other descriptions of mild side effects were those that do not interfere with life (46.15%), and those that can be managed with self-medication or self-management (Over-the-counter) (30.77 %).

When a specific side effect was described, the most common responses were aches/pain (general) (23.08%), skin rash or itch (23.08%), and gastrointestinal distress (19.23 %). Other examples included fatigue/lethargy (11.54%), and being short of breath (11.54%)

Participant describes mild side effects as those that do not interfere with daily life

I think the mild side effects still allow you to have that quality of life and do things, where you're not lying in bed feeling bad and stuff like that.

Participant 004_2023AULUC

Mild side effect is something you can go about your daily life with and it doesn't have an impact, doesn't have too much of an impact on your quality of life. You can still dress yourself, you can still get to move yourself around. You don't actually need a carer.

Participant 007_2023AULUC

I think mild side effects are things that might cause some pain or some annoyance, general annoyance, but don't prevent you from doing anything in your normal day.

Participant 026_2023AULUC

Participant describes mild side effects as those that can be self-managed

They weren't mild. A mild side effect is having to take a Panadol. Actually, I'll tell you what, the Tagrisso I'm on, that had my, well, mildish side effects.
Participant 019_2023AULUC

Cope with? The rashes he can cope with usually we medicate for that. Breathing is a major side effect. Like I said, that's a huge impact on his life. The coughing up of blood is a mild side effect. The reflux is a mild one. The major one is the breathing.
Participant 030_2023AULUC

If it's skin eruptions, you can put cream on it.
Participant 024_2023AULUC

Participant describes mild side effects giving the specific example of Aches/pain (general)

Just some discomfort and limited movement. Not sleeping well, but they're all mild side effects. I don't think I had significant side effects.
Participant 010_2023AULUC

Oh, most of them aren't that mild really. They're probably a bit more significant than that. Pain, I suppose. If I breathe in deeply now I can still feel pain in my chest. When I lay on my side in bed, it's still sore, when I lean back on one side in my chair, it's very uncomfortable where one of the surgical insertions was. I suppose it's probably the mild things would be pain. Moving towards the more moderate stuff, it's probably really my-- the side effects are really just in terms of my breathing, my aerobic capacity, which is understandable
Participant 021_2023AULUC

Participant describes mild side effects giving the specific example of a skin rash or an itch

From my point of view my mild side effects are things that don't impact my daily life so much. They don't impact me doing my daily life. At the moment, I have skin rashes from the medication, that's become a mild side effect. It's when they negatively impact my function and how I perform in the day.
Participant 027_2023AULUC

Mild side effects would be tiredness, a rash from the radiation. That's mild. You can expect that. That's about mild as you can get.
Participant 014_2023AULUC

Participant describes mild side effects giving the specific example of Gastrointestinal distress

Mild side effects I would say nausea or diarrhea and loss of appetite. Yes, that's just mild.
Participant 023_2023AULUC

PARTICIPANT: Side effects that are noticeable but don't have a significant impact on my daily life.
INTERVIEWER: Could you list a few examples?
PARTICIPANT: Like the constipation. It's annoying but it doesn't stop me doing anything. It's just unpleasant. That's all. It's just unpleasant. I don't think it's causing me any effects beyond what I'm observing.
Participant 022_2023AULUC

Participant describes mild side effects giving the specific example of Fatigue/lethargy

Just feeling a little bit sick. Feeling tired. It was okay. All my side effects are mild I'd say. I wasn't really sick or anything.
Participant 001_2023AULUC

Fatigue. I have that every day. I go to bed early. I sleep like [unintelligible] and what else? That's probably the only mild one I have, but the major one.
Participant 002_2023AULUC

Participant describes mild side effects giving the specific example of shortness of breath

Okay, so I've probably got mild side effects now because I know it's just going to get worse. Mild side effects would be shortness of breath. I don't know. There's a lot to take into account with that. I have a lot of inflammation in my lungs. I cough up blood. I get dizzy when I cough. I have nausea. I get headaches. That sort of thing.
Participant 003_2023AULUC

Maybe just a slight shortness of breath, that I can cope with. What else? I don't know.
Participant 013_2023AULUC

Table 5.17: Description of mild side effects

Description of mild side effects	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 provides a specific side effect as an example	18	69.23	17	68.00	1	100.00	7	70.00	11	68.75	12	75.00	6	60.00
Participant describes mild side effects as those that do not interfere with daily life	12	46.15	12	48.00	0	0.00	4	40.00	8	50.00	10	62.50	2	20.00
Participant describes mild side effects as those that can be self-managed	8	30.77	7	28.00	1	100.00	3	30.00	5	31.25	5	31.25	3	30.00

Description of mild side effects	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 provides a specific side effect as an example	18	69.23	10	58.82	8	88.89	10	76.92	8	61.54	2	100.00	16	66.67	6	66.67	12	70.59
Participant describes mild side effects as those that do not interfere with daily life	12	46.15	9	52.94	3	33.33	5	38.46	7	53.85	0	0.00	12	50.00	5	55.56	7	41.18
Participant describes mild side effects as those that can be self-managed	8	30.77	5	29.41	3	33.33	4	30.77	4	30.77	0	0.00	8	33.33	1	11.11	7	41.18

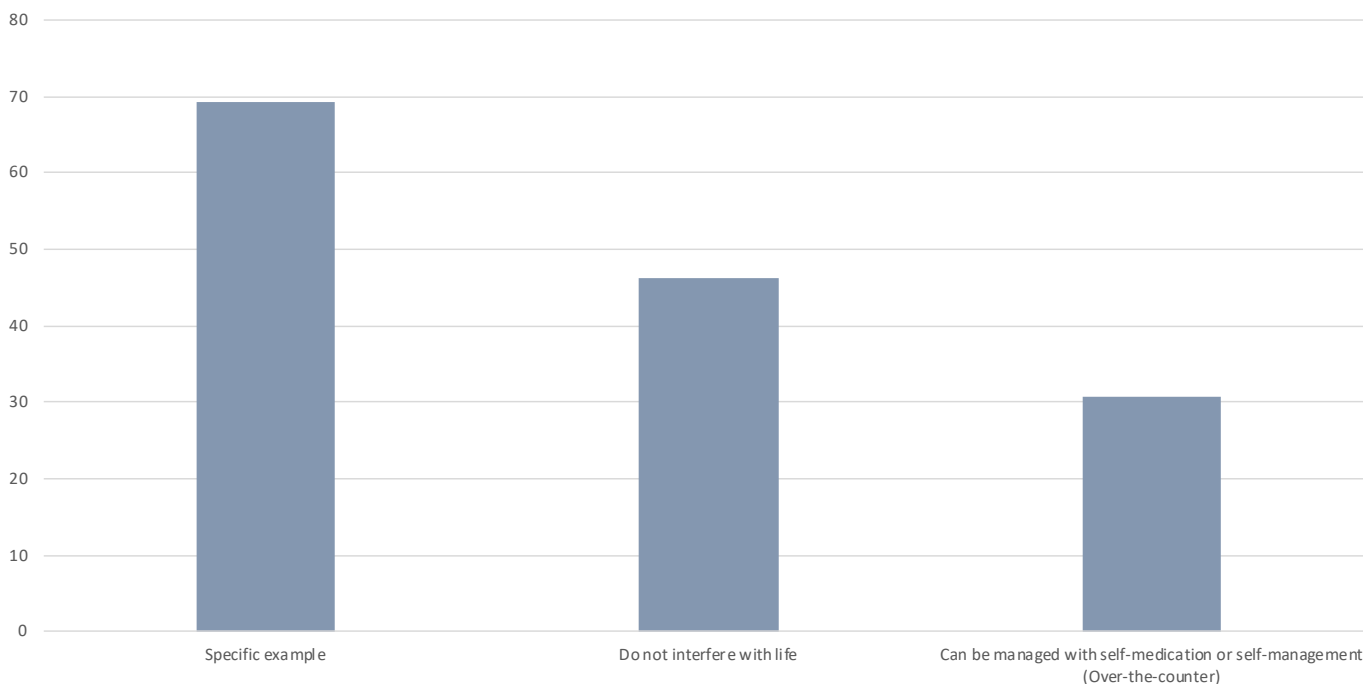


Figure 5.17: Description of mild side effects

Table 5.18: Description of mild side effects – subgroup variations

Theme	Less frequently	More frequently
Participant provides a specific side effect as an example	Aged 35 to 64	Aged 65 or older
Participant describes mild side effects as those that do not interfere with daily life	Male	Female
Participant describes mild side effects as those that can be self-managed	Aged 65 or older	Higher status
	Mid to low status	

Table 5.19: Description of mild side effects (Specific side effects)

Description of mild side effects (specific example)	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 mild side effects giving the specific example of Aches/pain (general)	6	23.08	6	24.00	0	0.00	4	40.00	2	12.50	4	25.00	2	20.00
Participant describes mild side effects giving the specific example of a skin rash or an itch	6	23.08	6	24.00	0	0.00	2	20.00	4	25.00	4	25.00	2	20.00
Participant describes mild side effects giving the specific example of Gastrointestinal distress	5	19.23	4	16.00	1	100.00	1	10.00	4	25.00	2	12.50	3	30.00
Participant describes mild side effects giving the specific example of Fatigue/lethargy	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00
Participant describes mild side effects giving the specific example of shortness of breath	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	2	12.50	1	10.00

Description of mild side effects (specific example)	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 mild side effects giving the specific example of Aches/pain (general)	6	23.08	4	23.53	2	22.22	5	38.46	1	7.69	0	0.00	6	25.00	1	11.11	5	29.41
Participant describes mild side effects giving the specific example of a skin rash or an itch	6	23.08	4	23.53	2	22.22	3	23.08	3	23.08	1	50.00	5	20.83	4	44.44	2	11.76
Participant describes mild side effects giving the specific example of Gastrointestinal distress	5	19.23	2	11.76	3	33.33	4	30.77	1	7.69	0	0.00	5	20.83	0	0.00	5	29.41
Participant describes mild side effects giving the specific example of Fatigue/lethargy	3	11.54	2	11.76	1	11.11	0	0.00	3	23.08	0	0.00	3	12.50	1	11.11	2	11.76
Participant describes mild side effects giving the specific example of shortness of breath	3	11.54	2	11.76	1	11.11	2	15.38	1	7.69	1	50.00	2	8.33	2	22.22	1	5.88

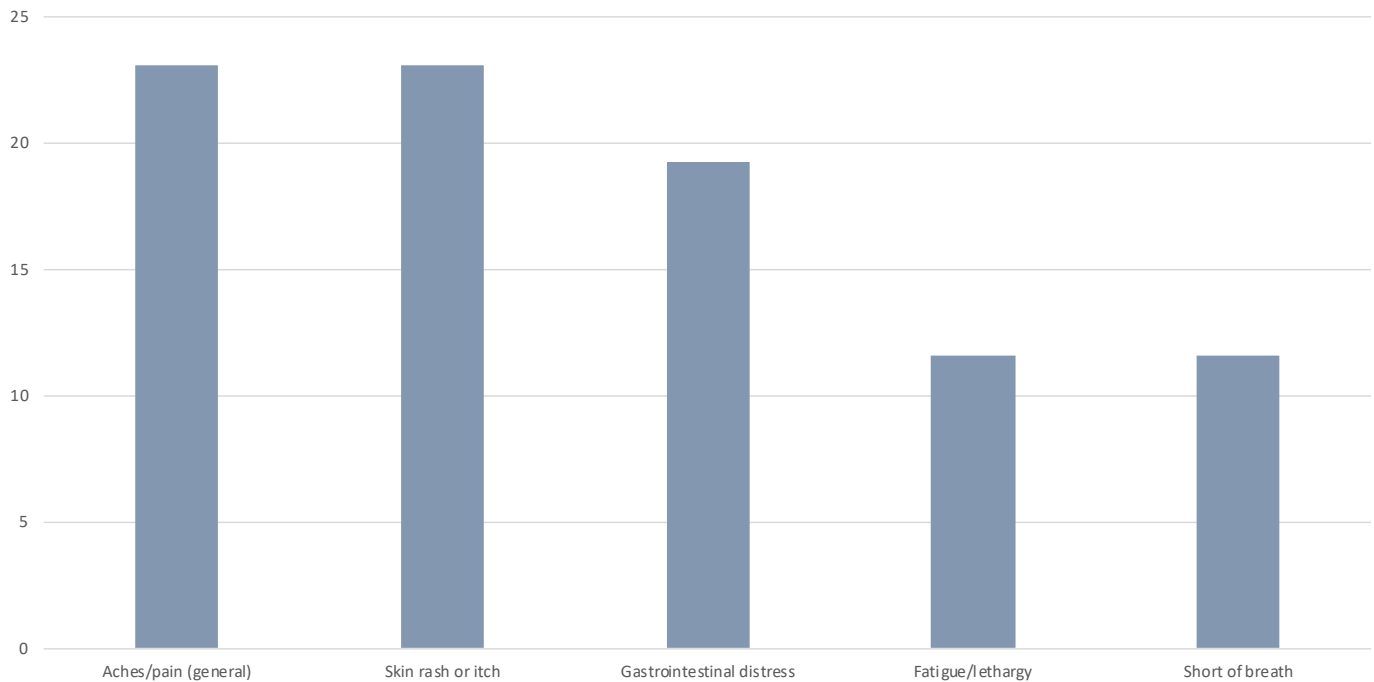


Figure 5.18: Description of mild side effects (Specific side effects)

Table 5.20: Description of mild side effects (Specific side effects) – subgroup variations

Theme	Less frequently	More frequently
Participant describes mild side effects giving the specific example of Aches/pain (general)	Metastatic University Mid to low status	Non-metastatic Trade or high school
Participant describes mild side effects giving the specific example of a skin rash or an itch	Higher status	Mid to low status
Participant describes mild side effects giving the specific example of Gastrointestinal distress	University Mid to low status	Male Aged 65 or older Trade or high school Higher status
Participant describes mild side effects giving the specific example of Fatigue/lethargy	Male Trade or high school	University
Participant describes mild side effects giving the specific example of shortness of breath	-	Mid to low status

Description of severe side effects

In the structured interview, participants were asked how they would describe the term ‘severe side effects’. The most common response was using a specific example to describe severe side effects (61.54%), followed by side effects that impact everyday life/ability to conduct activities of daily living (38.46%)

The most common examples were being short of breath (15.38%), having general aches and pains (11.54%), and the emotional or mental impact (11.54%).

Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living

A severe side effect. Wow, probably when you can't breathe or pain that stops me from just generally moving freely and doing things.
Participant 006_2023AULUC

Where it's just so debilitating you can't actually function.

Participant 020_2023AULUC

Severe is when you can't get out of bed, or when you have a shower and you have to lay on the floor for 30 minutes before you can get up. That's severe.

Participant 025_2023AULUC

Participant describes severe side effects giving the specific example of shortness of breath

Vomiting, nausea, I heard of those, and not being able to breathe properly, maybe being put on oxygen.

Participant 014_2023AULUC

Cope with? The rashes he can cope with usually we medicate for that. Breathing is a major side effect. Like I said, that's a huge impact on his life. The coughing up of blood is a mild side effect. The reflux is a mild one. The major one is the breathing.

Participant 030_2023AULUC

Participant describes severe side effects giving the specific example of Aches/pain (general)

You know what, I am coping so just my hip joints, they're extremely painful. My back, I have a lot of problems with my back now. Just my spine and my ribcage. Everything hurts but you just get on with it.
Participant 002_2023AULUC

Severe vomiting, severe nausea, severe diarrhea, all-over body rash, and just uncontrollable pain.
Participant 005_2023AULUC

Participant describes severe side effects giving the specific example of Emotion/mental impact

Those were extremely severe. Post all of that, I don't really think there were any severe. I would say there were moderate effects, probably because I'm pretty physically fit, as I said. I think my aerobic capacity has been affected moderately, I don't think it's been

affected severely. Mentally, I would say, it's probably quite severe in terms of the overall effect it's had on me. Even saying that I'm feeling a bit emotional now.
Participant 021_2023AULUC

PARTICIPANT: Oh, I think depression and severe nausea and weight loss. Yes. I had anxiety, overeating. Severe. Other than that, the mental side of it. Yes.
Participant 024_2023AULUC

Severe is fatigue where I can't even lift my arms up. Or I'm on the couch and I fall asleep, that's severe for me. Things like, I have insomnia and you could put this down to stress, or I think it's got something to do-- like weight gain with the medication, that can impact-- That's there and it's bad that obviously impacts my daily function because my self-esteem but the fatigue and the cognition, that's impacting how I function every day.
Participant 027_2023AULUC

Table 5. 21: Description of severe side effects

Description of severe side effects	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 provides a specific side effect as an example	16	61.54	15	60.00	1	100.00	5	50.00	11	68.75	10	62.50	6	60.00
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	10	38.46	9	36.00	1	100.00	4	40.00	6	37.50	8	50.00	2	20.00

Description of severe side effects	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 provides a specific side effect as an example	16	61.54	8	47.06	8	88.89	9	69.23	7	53.85	0	0.00	16	66.67	5	55.56	11	64.71
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	10	38.46	8	47.06	2	22.22	4	30.77	6	46.15	1	50.00	9	37.50	4	44.44	6	35.29

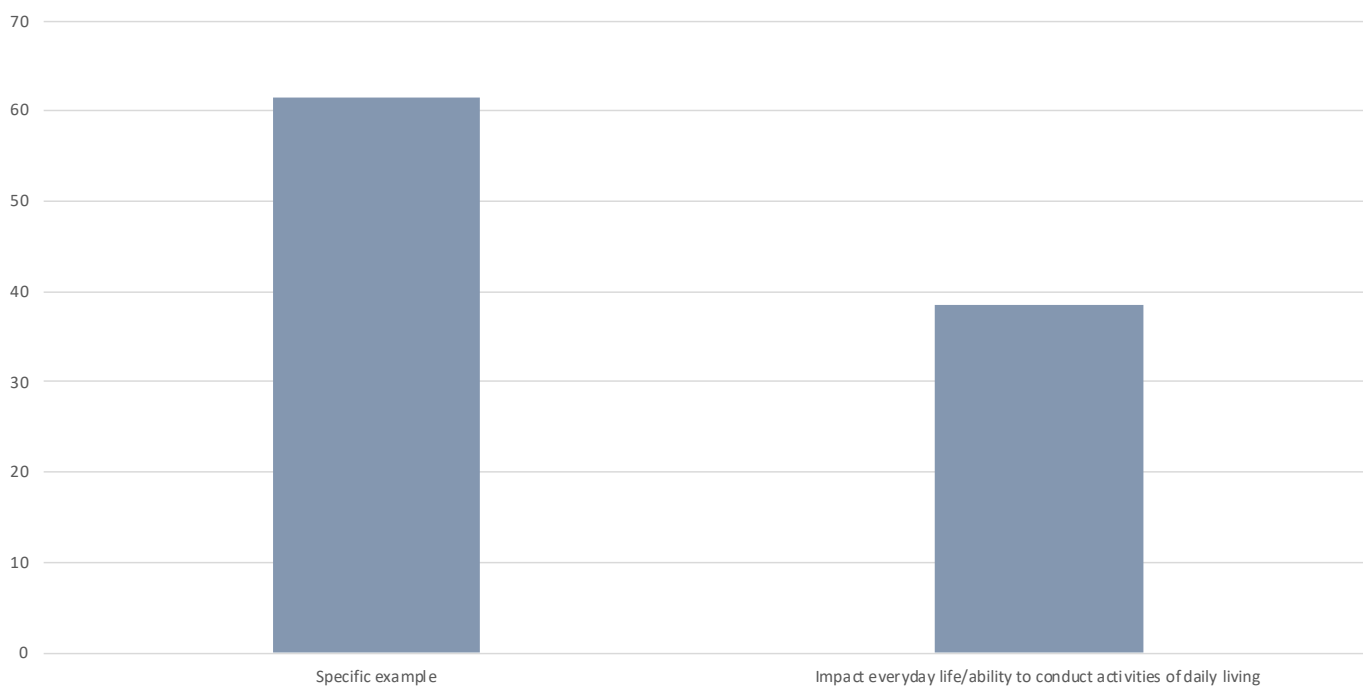


Figure 5.19: Description of severe side effects

Table 5. 22: Description of severe side effects – subgroup variations

Theme	Less frequently	More frequently
Participant provides a specific side effect as an example	Non-metastatic Aged 35 to 64	Aged 65 or older
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	Male Aged 65 or older	Female

Table 5. 23: Description of severe side effects (Specific example)

Description of severe side effects (specific examples)	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 severe side effects giving the specific example of shortness of breath	4	15.38	3	12.00	1	100.00	1	10.00	3	18.75	3	18.75	1	10.00
Participant describes severe side effects giving the specific example of Aches/pain (general)	3	11.54	3	12.00	0	0.00	0	0.00	3	18.75	3	18.75	0	0.00
Participant describes severe side effects giving the specific example of Emotion/mental impact	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	1	6.25	2	20.00

Description of severe side effects (specific examples)	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 severe side effects giving the specific example of shortness of breath	4	15.38	2	11.76	2	22.22	2	15.38	2	15.38	1	50.00	3	12.50	3	33.33	1	5.88
Participant describes severe side effects giving the specific example of Aches/pain (general)	3	11.54	3	17.65	0	0.00	1	7.69	2	15.38	1	50.00	2	8.33	2	22.22	1	5.88
Participant describes severe side effects giving the specific example of Emotion/mental impact	3	11.54	2	11.76	1	11.11	2	15.38	1	7.69	0	0.00	3	12.50	1	11.11	2	11.76

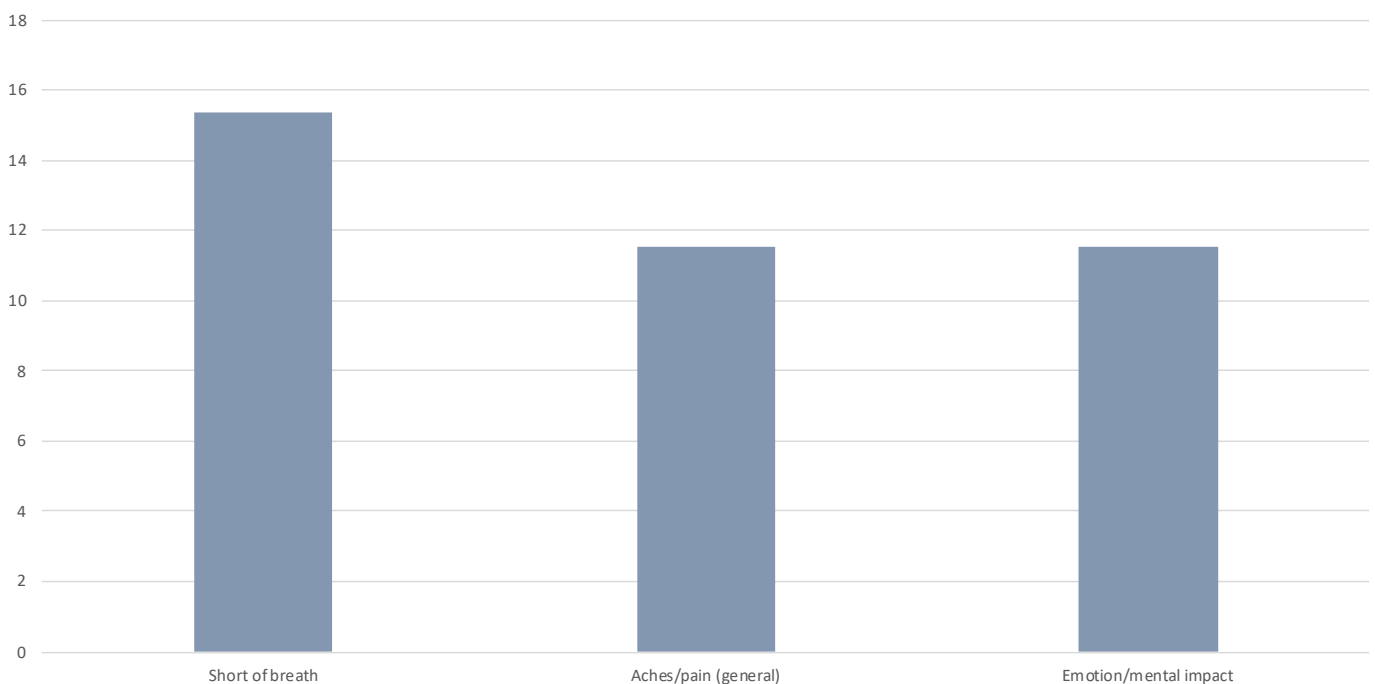


Figure 5.20: Description of severe side effects (Specific example)

Table 5. 24: Description of severe side effects (Specific side effects)– subgroup variations

Theme	Less frequently	More frequently
Participant describes severe side effects giving the specific example of shortness of breath		Mid to low status
Participant describes severe side effects giving the specific example of Aches/pain (general)	Non-metastatic Male Aged 65 or older	Mid to low status

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime.

The most common responses were that they did not give up on any treatment (34.62%), and as long as side effects are tolerable (23.08%). Other themes included the advice of their specialist, or as long as prescribed (19.23%), adhering to treatment for a

specific amount of time (19.23%), and being unable to answer as they had not had treatment or cannot answer hypothetical question (11.54%).

When participants stated a specific amount of time to adhere to a treatment, the most common amount of time was two to three months.

Participant describes not giving up on any treatment

I'd keep going with it just, hopefully it works. They did give me dexamethasone to stop me being sick while I was having chemo. That was something different they gave me and that did a good job.

Participant 001_2023AULUC

I think with this EGFR lung cancer you just put up with anything because the alternative is you're going to die. You just go, "Well, that's the tablet that I'm on," and that's the way it is.

Participant 004_2023AULUC

I've never given up a treatment.

Participant 007_2023AULUC

PARTICIPANT: I think that's probably not applicable in my case because I haven't had any other treatments post-surgery.

INTERVIEWER: Understand, yes. We can skip it.

PARTICIPANT: Yes, if I did have one I would stick to absolutely because it's just too important not to.

Participant 021_2023AULUC

Participant describes adhering to treatment as long as side effects are tolerable

That's a good question. You're saying if I'm having chemotherapy now and I don't think it's working, I suppose again, I would rely on my doctor's advice because I want to persevere with it to obviously get a positive outcome. At the same time, how much pain and severe side further effects can you deal with as well? The hair loss doesn't bother me. I lost a fair bit of hair when I had the radiotherapy. Something like that doesn't bother me because you can deal with that. It's just dealing with, say, vomiting, which I didn't experience at all this time. I suppose pain more than anything. Participant 005_2023AULUC

I would say about two months. If I've got the mild side effects of diarrhea or of the skin rash, but it's not with high temperature and no pus, what I do is I reduce what they give me. I just do it because I think, well, I'll have to manage it myself, and then when I have the appointment, I say, "I've taken half of what you gave me because I can't live like that." That's all.

Participant 023_2023AULUC

Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed

It's a bit of a hypothetical, but my approach would be to discuss that very point with my treatment team and say, "How often are you expecting to see me and what should I do if I have some concerns between those sessions?" That's the discussion I had with my first treatment. I'll start this, what should I expect and what do I do if something unexpected happens? That's part of why I like the team.

Participant 022_2023AULUC

I would not give up on anything until a doctor said that it doesn't work.

Participant 026_2023AULUC

Participant describes adhering to treatment for a specific amount of time

Probably a couple of months.

Participant 014_2023AULUC

Really when it comes to these sort of medications, it would be getting back test results that really show you having no impact. If you're talking generally about other medications I've been on, I would give them several weeks because things can take a long time to click in and work, but with the Osimertinib, it was really that scan results showed a change.

Participant 020_2023AULUC

PARTICIPANT: Well, I can tell you that because they've put me on Lyrica for some pain. I'd ask for three days and I went, "You can dump this one. I'm not doing it." Two to three days, and I would just get it out of my system. I wouldn't take it. I had severe nightmares and sweats. It was like honestly like I was having some sort of hallucinogenic drug. It was just awful. I just refused to take it. I said, "Find me something else. That's not working."

Participant 018_2023AULUC

Participant describes being unable to answer as they have not had treatment and/or cannot answer hypothetical question

Well, that's a hard question because with the problem that I've got, how do you know if it's working? You don't know. It's not as if you've got an ulcer or something on your leg and you take something for it and you can watch it heal or not heal. You can't see this. I find it quite a difficult question to answer.

Participant 017_2023AULUC

I haven't really been in that situation.

Participant 024_2023AULUC

Table 5. 25: Adherence to treatment

Adherence to treatment	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 not giving up on any treatment	9	34.62	9	36.00	0	0.00	2	20.00	7	43.75	7	43.75	2	20.00
Participant describes adhering to treatment as long as side effects are tolerable	6	23.08	6	24.00	0	0.00	3	30.00	3	18.75	5	31.25	1	10.00
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	4	25.00	1	10.00
Participant describes adhering to treatment for a specific amount of time	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	5	31.25	0	0.00
Participant describes being unable to answer as they have not had treatment and/or cannot answer hypothetical question	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	2	12.50	1	10.00

Adherence to treatment	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 not giving up on any treatment	9	34.62	6	35.29	3	33.33	4	30.77	5	38.46	1	50.00	8	33.33	3	33.33	6	35.29
Participant describes adhering to treatment as long as side effects are tolerable	6	23.08	4	23.53	2	22.22	4	30.77	2	15.38	0	0.00	6	25.00	2	22.22	4	23.53
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	5	19.23	5	29.41	0	0.00	1	7.69	4	30.77	1	50.00	4	16.67	3	33.33	2	11.76
Participant describes adhering to treatment for a specific amount of time	5	19.23	4	23.53	1	11.11	3	23.08	2	15.38	0	0.00	5	20.83	2	22.22	3	17.65
Participant describes being unable to answer as they have not had treatment and/or cannot answer hypothetical question	3	11.54	0	0.00	3	33.33	2	15.38	1	7.69	0	0.00	3	12.50	1	11.11	2	11.76

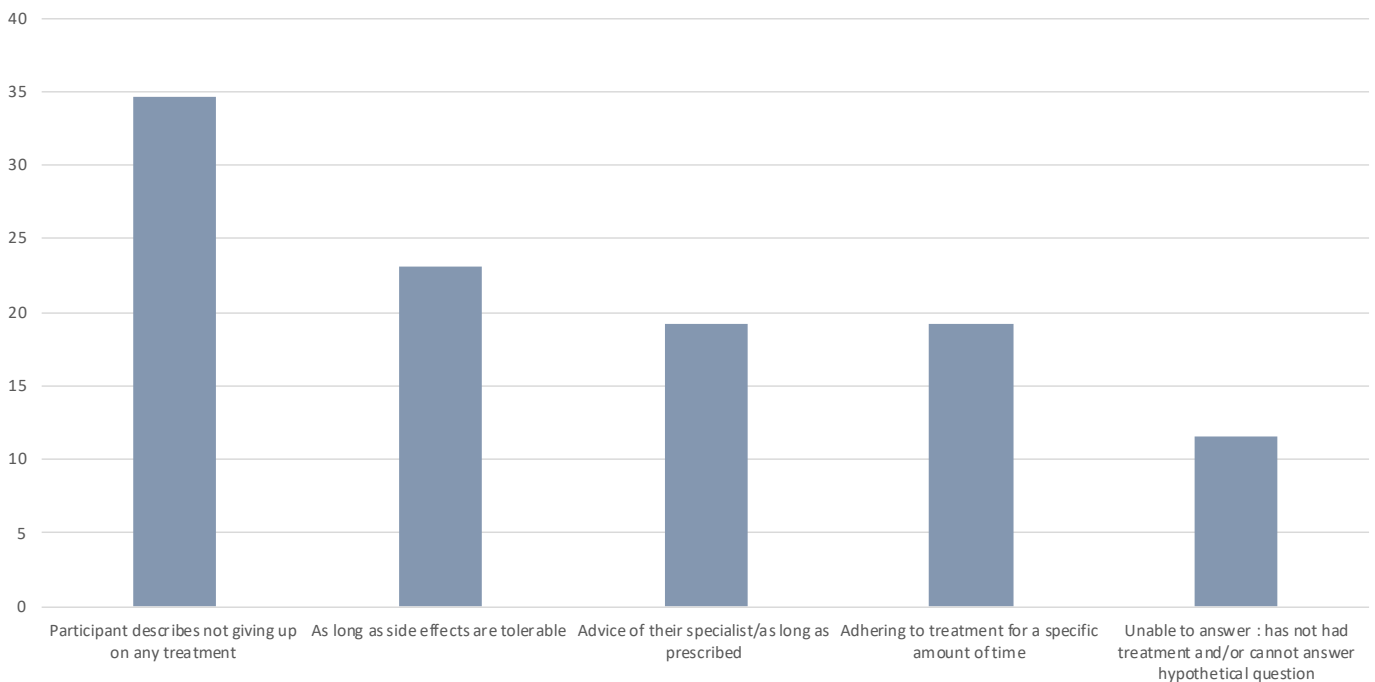


Figure 5.21: Adherence to treatment

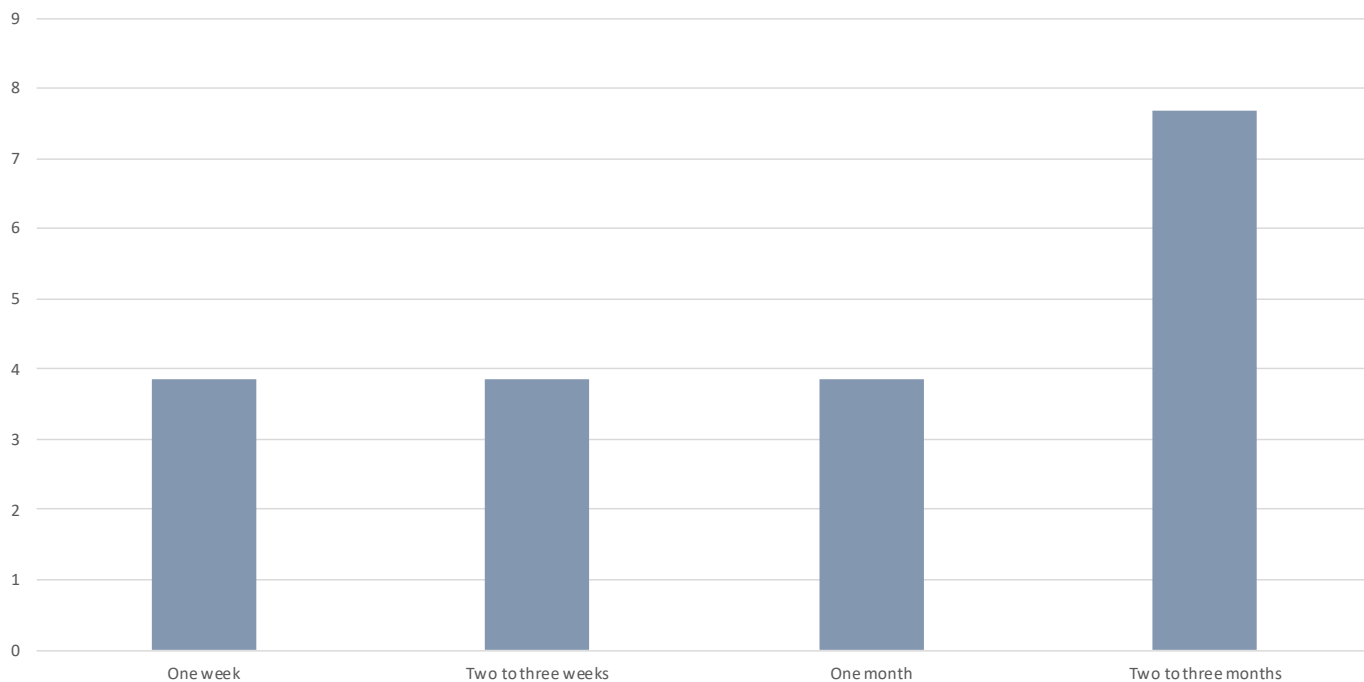


Figure 5.22: Adherence to treatment: specific time

Table 5.27: Adherence to treatment – subgroup variations

Theme	Less frequently	More frequently
Participant describes not giving up on any treatment	Non-metastatic Male	-
Participant describes adhering to treatment as long as side effects are tolerable	Male	-
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	Aged 65 or older Trade or high school	Aged 35 to 64 University Mid to low status
Participant describes adhering to treatment for a specific amount of time	Male	Female
Participant describes being unable to answer as they have not had treatment and/or cannot answer hypothetical question	Aged 35 to 64	Aged 65 or older

What needs to change to feel like treatment is working

Participants were asked to describe what needs to change to feel like treatment is effective. The most common responses were seeing evidence of stable disease or no disease progression (57.69%), and seeing reduction of physical signs and symptoms (19.23%).

Participants reported needing to experience evidence of stable disease/no disease progression

Oh, it means it's keeping it at bay, or reducing the tumors.

Participant 004_2023AULUC

What needs to improve, I suppose just getting accurate scan results, test results once the treatment's finished, evidence that it has done something.

Participant 005_2023AULUC

Oh, seeing the data. I see that the blood tests aren't showing any out-of-control blood features. The CT scan shows that the main tumor is reduced and stable and that there's no evidence and that there's no

evidence of any other metastatic activities. That's everything. That's I guess the triumvirate there of no pathology, no metastasis, and no progression. That's it.

Participant 022_2023AULUC

Participants reported needing to experience a reduction in physical signs and symptoms disappear/reduce side effects

It comes back to that quality of daily living, doesn't it? If I have improved symptom management, if the symptom control is better than the side effects if that makes sense.

Participant 006_2023AULUC

I actually need to feel or see some improvement. I need to feel that my symptoms are slightly better than what they were. Not worse. Does that make sense?

Participant 018_2023AULUC

When I started the Osimertinib, it was a few weeks in and I actually did get relief from some symptoms that I hadn't realized were lung cancer, like a really minor cough that I hadn't even thought about until I got the diagnosis and went, "Oh, that does come." It totally went and I actually thought then it was working a few weeks in. Physical things, I think that was it. I didn't have many physical symptoms really, so I wasn't expecting to feel much, I was more expecting to see it on a scan.

Participant 020_2023AULUC

What would it mean if treatment worked

As a follow up question, participants were asked what it would mean to them if the treatment worked in the way they described.

The most common responses were allowing them to do everyday activities and return to normal life (23.08%), leading to a reduction in symptoms or side effects (19.23%), and allowing them to engage more with social activities and family life (15.38%). Other themes included allowing them to return to work (11.54%), allowing them to do domestic tasks (11.54%), allowing them to do more exercise (11.54%), and that it would have a positive impact on their mental health (11.54%).

Participant describes treatment allowing them to do everyday activities/ return to normal life

It means I could probably live 80% like a normal person, and just do normal things like go shopping and just do normal things, basically. Maybe even have a job, I don't know.

Participant 004_2023AULUC

I guess with the first drug, the side effects were that bad that I couldn't work. Sometimes I couldn't leave the house. Even shaving was an issue because my skin would fall off, so that was terrible. This new drug means I was able to go back to work for a short amount of time once the side effect is still down. With this new drug, no, I feel great. I can go out, I can do things. I don't even know that I'm taking it.

Participant 006_2023AULUC

Participant describes treatment leading to a reduction in symptoms/side effects

Oh, it would be bliss. It's like this drug I'm taking at the moment for my neuropathy. This is week three, week four. It is making a mild difference, which I've been able to stand up longer and I'm not as pins and needles and that sort of thing. That to me, it's showing

some signs of success. That's what it needs to be. If I'm not seeing that, then I'm not putting another foreign thing into my body just for the sake of it.

Participant 018_2023AULUC

Like now, well, they usually make you very tired. You don't have as much energy. The tablets are, yes, they're fatiguing and just like my appetite's gone. I've lost weight.

Participant 019_2023AULUC

Participant described treatment allowing them to engage more with social activities and family life

Well, the treatment I got for the nausea never worked for me. Yes, and because of that, your whole life was changed. I didn't go out much. We got very insulated.

Participant 024_2023AULUC

Participant describes treatment allowing them to return to work

Huge. I would be able to get back to work, I'm hoping, and continue on with a reasonably functional life. Right now, I can't.

Participant 003_2023AULUC

It means I could probably live 80% like a normal person, and just do normal things like go shopping and just do normal things, basically. Maybe even have a job, I don't know.

Participant 004_2023AULUC

Participant describes treatment allowing them to do domestic tasks

It means I could probably live 80% like a normal person, and just do normal things like go shopping and just do normal things, basically. Maybe even have a job, I don't know.

Participant 004_2023AULUC

Participant describes treatment allowing them to do more exercise

I could take the dog for a walk and I could get to do some exercise and lose some weight. I wouldn't be washing the dishes and then I do half of them because I'm too tired to do the other half.

Participant 002_2023AULUC

Okay. All right. I feel like I would be able to engage more socially within my community, with family and friends. I would be able to exercise and have a regular exercise routine that would be inclusive within the

community. Right now, I don't know if I'm too scared or not confident enough to, but exercising in the community is something I'm not able to do. What else would I be able to do? I'd probably be more productive around the house.

Participant 015__2023AULUC

Participant describes treatment working as having a positive impact on their mental health

I think it just gave me the fact that I yes, once I knew that treatment was working, it stopped me dwelling

on death and made me dwell on life and go, "Now you've got an opportunity to keep moving forward." It took that weight of preparing to die off my shoulders and I went, "No, you're living for a while longer." It made me get up and go again, rather than sitting in that little mire of despair. I think psychologically it was huge and we don't know how long it's going to last, no one does, but it gave me that thing of get up and make the most of what you've got.

Participant 020_2023AULUC

Table 5. 28: What needs to change to feel like treatment is working

What needs to change to feel like treatment is working	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	%
Participants reported needing to experience evidence of stable disease/no disease progression	15	57.69	14	56.00	1	100.00	5	50.00	10	62.50	12	75.00	3	30.00
Participants reported needing to experience a reduction in physical signs and symptoms disappear/reduce side effects	5	19.23	5	20.00	0	0.00	1	10.00	4	25.00	5	31.25	0	0.00

What needs to change to feel like treatment is working	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	%
Participants reported needing to experience evidence of stable disease/no disease progression	15	57.69	10	58.82	5	55.56	6	46.15	9	69.23	0	0.00	15	62.50	5	55.56	10	58.82
Participants reported needing to experience a reduction in physical signs and symptoms disappear/reduce side effects	5	19.23	5	29.41	0	0.00	2	15.38	3	23.08	1	50.00	4	16.67	2	22.22	3	17.65

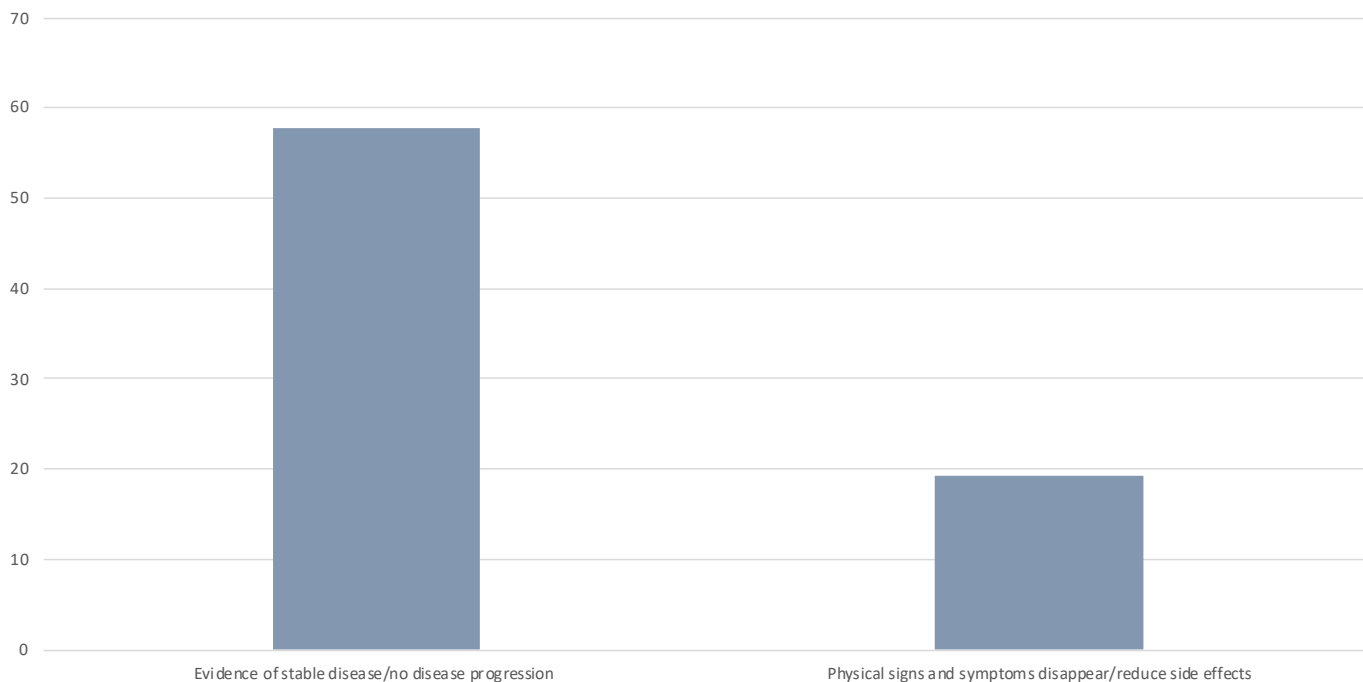


Figure 5.23: What needs to change to feel like treatment is working

Table 5. 29: What needs to change to feel like treatment is working – subgroup variations

Theme	Less frequently	More frequently
Participants reported needing to experience evidence of stable disease/no disease progression	Male Trade or high school	Female University
Participants reported needing to experience a reduction in physical signs and symptoms disappear/reduce side effects	Male Aged 65 or older	Female Aged 35 to 64

Table 5.30: What would it mean if treatment worked

What it would mean if treatment worked	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 treatment allowing them to do everyday activities/ return to normal life	6	23.08	5	20.00	1	100.00	3	30.00	3	18.75	4	25.00	2	20.00
Participant describes treatment leading to a reduction in symptoms/side effects	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	5	31.25	0	0.00
Participant described treatment allowing them to engage more with social activities and family life	4	15.38	3	12.00	1	100.00	0	0.00	4	25.00	2	12.50	2	20.00
Participant describes treatment allowing them to return to work	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00
Participant describes treatment allowing them to do domestic tasks	3	11.54	3	12.00	0	0.00	0	0.00	3	18.75	3	18.75	0	0.00
Participant describes treatment allowing them to do more exercise	3	11.54	3	12.00	0	0.00	0	0.00	3	18.75	3	18.75	0	0.00
Participant describes treatment working as having a positive impact on their mental health	3	11.54	3	12.00	0	0.00	0	0.00	3	18.75	3	18.75	0	0.00

What it would mean if treatment worked	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 treatment allowing them to do everyday activities/ return to normal life	6	23.08	5	29.41	1	11.11	2	15.38	4	30.77	2	100.00	4	16.67	4	44.44	2	11.76
Participant describes treatment leading to a reduction in symptoms/side effects	5	19.23	4	23.53	1	11.11	1	7.69	4	30.77	0	0.00	5	20.83	2	22.22	3	17.65
Participant described treatment allowing them to engage more with social activities and family life	4	15.38	2	11.76	2	22.22	1	7.69	3	23.08	1	50.00	3	12.50	1	11.11	3	17.65
Participant describes treatment allowing them to return to work	3	11.54	3	17.65	0	0.00	0	0.00	3	23.08	2	100.00	1	4.17	3	33.33	0	0.00
Participant describes treatment allowing them to do domestic tasks	3	11.54	3	17.65	0	0.00	0	0.00	3	23.08	0	0.00	3	12.50	1	11.11	2	11.76
Participant describes treatment allowing them to do more exercise	3	11.54	2	11.76	1	11.11	0	0.00	3	23.08	0	0.00	3	12.50	0	0.00	3	17.65
Participant describes treatment working as having a positive impact on their mental health	3	11.54	3	17.65	0	0.00	3	23.08	0	0.00	0	0.00	3	12.50	1	11.11	2	11.76

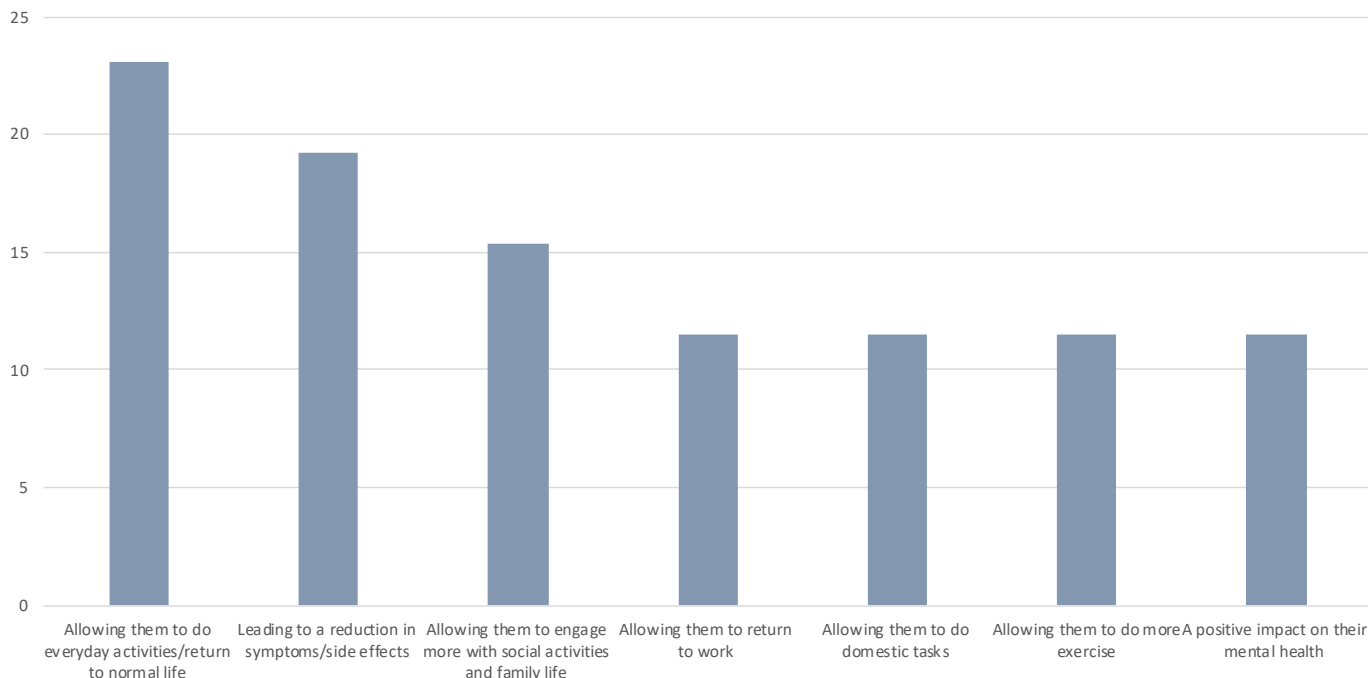


Figure 5.24: What would it mean if treatment worked

Table 5.31: What would it mean if treatment worked– subgroup variations

Theme	Less frequently	More frequently
Participant describes treatment allowing them to do everyday activities/ return to normal life	Aged 65 or older Higher status	Mid to low status
Participant describes treatment leading to a reduction in symptoms/side effects	Male Trade or high school	Female University
Participant described treatment allowing them to engage more with social activities and family life	Non-metastatic	-
Participant describes treatment allowing them to return to work	Male Aged 65 or older Trade or high school Higher status	University Mid to low status
Participant describes treatment allowing them to do domestic tasks	Non-metastatic Male Aged 65 or older Trade or high school	University
Participant describes treatment allowing them to do more exercise	Non-metastatic Male Trade or high school Mid to low status	University
Participant describes treatment working as having a positive impact on their mental health	Non-metastatic Male Aged 65 or older University	Trade or high school