

## Section 4

### Decision-making

## **Section 4 summary**

### **Discussions about treatment**

Participants were asked to recall what treatment options they were presented with and how they felt about the options. Participants most commonly were presented with multiple options (61.54%), followed by one treatment option (34.62%).

#### **Discussions about treatment (Participation in discussions)**

Participants described their participation in discussions about treatments. The most common responses were participants presented with multiple options were that they participated in the decision-making process (34.62%), they were told what to do without discussion (19.23 %), and that they were presented with multiple option but did not give a reason or a description of participation in discussions (19.23%). For those with a single treatment option, most commonly they were told what to do without discussion (11.54%).

#### **Considerations when making decisions**

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were efficacy (50.00%), advice of their clinician (26.92%), and side effects (23.08 %). Other considerations included their own research (19.23%), quality of life (15.38%), cost (11.54%), and that they were not given options so considerations not taken into account (11.54%).

#### **Decision-making over time**

Participants were asked if the way they made decisions had changed over time. The most common responses were that they had not changed the way they made decisions (42.31%), followed by not changing the way they made decisions (38.46%).

Where participants had changed the way they make decisions, the most common reason was that they had become more informed and/or more assertive (30.77%). Where participants had not changed the way they make decisions, the most common reason was that they had always taken advice of clinicians (11.54%).

#### **Personal goals of treatment or care**

Participants were asked what their own personal goals of treatment or care were. The most common response was to be cancer free, to avoid recurrence, or increase longevity (38.46%).

Other themes treatment goals included minimising or avoiding side effects (26.92%), quality of life, or return to normality (23.08%), and some wanted improvements in the communication and information about treatment they received from their doctor (15.38%)

## Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about the options. Participants most commonly were presented with multiple options (61.54%), followed by one treatment option (34.62%).

Participants described their participation in discussions about treatments. The most common responses were participants presented with multiple options were that they participated in the decision-making process (34.62%), they were told what to do without discussion (19.23%), and that they were presented with multiple option but did not give a reason or a description of participation in discussions (19.23%). For those with a single treatment option, most commonly they were told what to do without discussion (11.54%).

### **Participant describes multiple options being presented and participating in the decision-making process**

*Before they found out it was ALK, they said they'd get me started on chemo. Then from chemo, they would go to immunotherapy and possibly radiate too. After I was diagnosed ALK, obviously, I'm going to go on these tablets and at the end of the tablets, when they stop working, then we'll go through chemo. That took immunotherapy, but that won't be happening because it doesn't work on ALK. I think the biggest problem we've got in Australia is the oncologists really don't know a lot about ALK. Immuno just speeds it up and makes it more aggressive. He and I had an argument about that one day. [chuckles] I've run out of the target therapy. I'll just be on chemo until that stops working. Then that'll be it.*  
Participant 002\_2023AULUC

*Look, the respiratory specialist recommended that I have surgery because it was quite small the lesion but it was growing. He did say that obviously, I didn't have to have it done. If opted to, I could just have regular scans to monitor it for a while, but that wasn't his recommendation.*  
Participant 010\_2023AULUC

*Well, he initially, the specialist, said that-- Well, I asked him, as I said, what the prognosis was and he said, well, it's 20%. Then I said, well, I don't know if it's worth going ahead with those odds and he said, "There a lot of people are still around, that were diagnosed the same as you, and they're still around a few years later," but he said, "What happens is, at the hospital, all the specialists get together, I think there's*

*about five of them, every Tuesday and they discuss all the new cases for the week and decide what their best course of action is for each patient." He said that to me, and then he said, "I'll ring you when we've decided, and then it's up to you whether you want to proceed or not." He rang me back and told me on a Tuesday that they had decided to go ahead with both radium and chemo consecutively for a six-week period and did I want to proceed, and I had been arrested by everybody by then and said, "Yes, I suppose so."*  
Participant 017\_2023AULUC

*Basically, of course, they held off, except I have a lot of brain metastasis. On the cards is eventually whole brain radiation. At the moment, as soon as we got the EGFR diagnosis, I was started on the tablet. When they stop working, they have talked about the types of chemo and immunotherapy. One question that's come up is they're cautious about immunotherapy with me because I have had some major autoimmune disease. That will be a discussion we have when we get there. What I can see on the cards is when this drug stops working optimally, that I am looking at some brain radiation and looking down a path of some chemo question immunotherapy.*  
Participant 020\_2023AULUC

### **Participant describes multiple options being presented and being told what to do without discussion**

*Well, he didn't give me any option. He just said, "We're giving you chemo and immunotherapy." I went right on, that was it.*  
Participant 001\_2023AULUC

*I've had one appointment with the respiratory specialist on the 4th of March at my local base hospital. I was told that I would probably have to go to LOCATION for resection, for surgery to remove the nodule. I've also been back to my GP every Friday for the last month, and that's it. They can't give me any answers. They're not communicating with him. He's requested my information and he hasn't gotten anything. That's it.*  
Participant 003\_2023AULUC

*Initially, I suppose I have to say I was first diagnosed over the phone. They told me the news that I had lung cancer via a telehealth, which I didn't necessarily agree with, but anyway, that's what happened to me. They said, "We'll be choosing your team of doctors for you." Then he said, "I want you to go and speak to the*

*radiation oncologist. I want you to speak to a medical oncologist. I want you to speak to the surgeon. Then we'll come back and discuss from there." I hurried around and tried to make those appointments to go and speak to these people. The medical oncologist said, "We're going to do one more bronchoscopy, and if all your lymph nodes are clear, then we'll start you on chemo." I wasn't asked or even told these are your options. It was just like, this is what we're going to do. We're going to do this, we're going to do that, we're going to do this. I was a private patient. I'd never been diagnosed with lung cancer. I just figured that was what happened. You just went, "Okay, righto." You went with it, basically.*

*Participant 018\_2023AULUC*

*No, I don't know. They haven't told me much at all. They said there's a few types of treatment, but they did not elaborate. It was more a chemo treatment. They said if a chemo fails, they'll do the radio type.*

*Participant 029\_2023AULUC*

**Participant describes one option being presented and being told what to do without discussion**

*When I was in respiratory, I was seeing a doctor in respiratory, this is the early stages of diagnosis, and a surgeon, I think a lady surgeon came in and she sat in. She went away, and she's coming back and she said, "Are you free to stay for an extra hour?" I said, "Yes, of course, I am." Immediately, when I was finished with the respiratory doctor, she said, "Come with me." Immediately, took me to radiation.*

*Participant 012\_2023AULUC*

*I'm racking my brains. I think it was pretty much presented to me that there was really only one course of action which was surgery to remove it, which was probably-- No. Yes, I think the facts of the matter of that without my interpretation of the facts were just that, yes, that was the only course of action, was to take a lobectomy, undertake a lobectomy, and remove the associated lymph nodes as well.*

*Participant 021\_2023AULUC*

*Nobody ever spoke to me about what the treatment would be post. There was talk about seeing an oncologist but, at that point in time nothing had been discussed or decided. That all came post-surgery.*

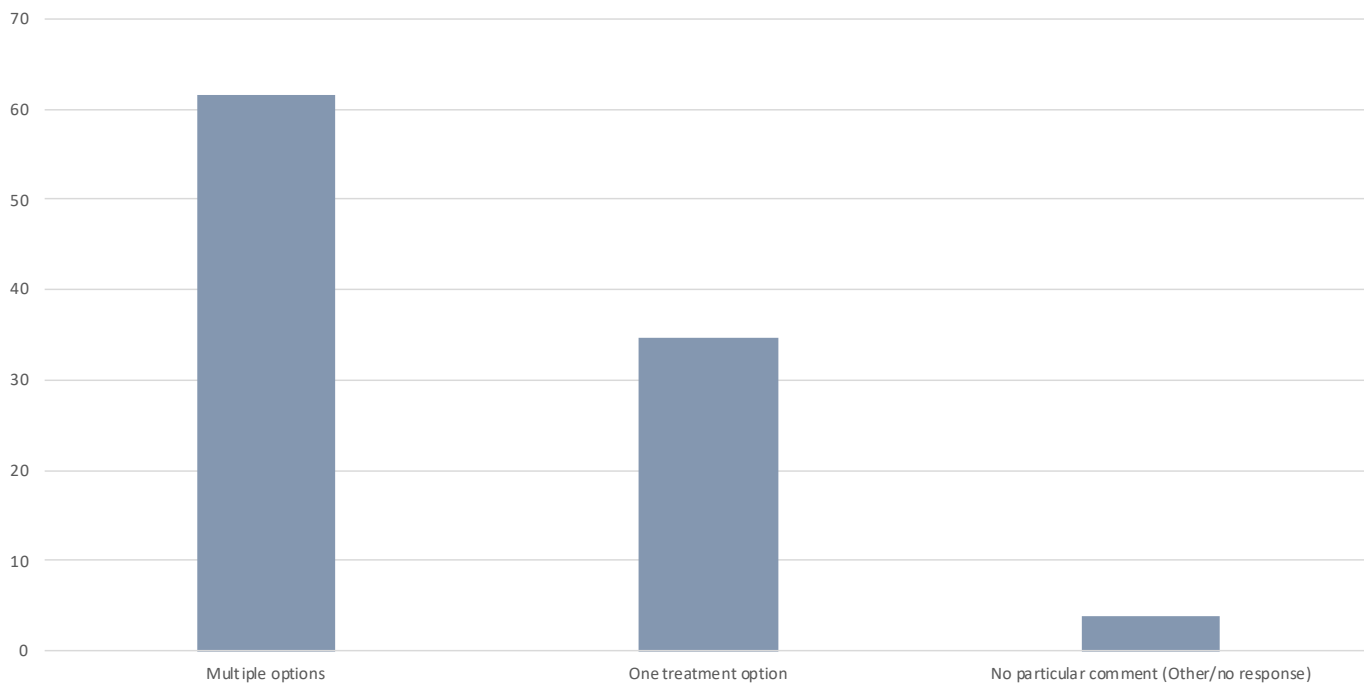
*Participant 025\_2023AULUC*

**Table 4.1: Discussions about treatment**

Discussions about 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 multiple treatment options being discussed	16	61.54	15	60.00	1	100.00	4	40.00	12	75.00	13	81.25	3	30.00
Participant describes one treatment option being discussed	9	34.62	9	36.00	0	0.00	5	50.00	4	25.00	5	31.25	4	40.00
No particular comment (Other/no response)	1	3.85	1	4.00	0	0.00	1	10.00	0	0.00	1	6.25	0	0.00

Discussions about 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 multiple treatment options being discussed	16	61.54	9	52.94	7	77.78	9	69.23	7	53.85	1	50.00	15	62.50	5	55.56	11	64.71
Participant describes one treatment option being discussed	9	34.62	6	35.29	3	33.33	4	30.77	5	38.46	1	50.00	8	33.33	4	44.44	5	29.41
No particular comment (Other/no response)	1	3.85	1	5.88	0	0.00	0	0.00	1	7.69	0	0.00	1	4.17	0	0.00	1	5.88



**Figure 4.1: Discussions about treatment**

**Table 4.2: Discussions about treatment – subgroup variations**

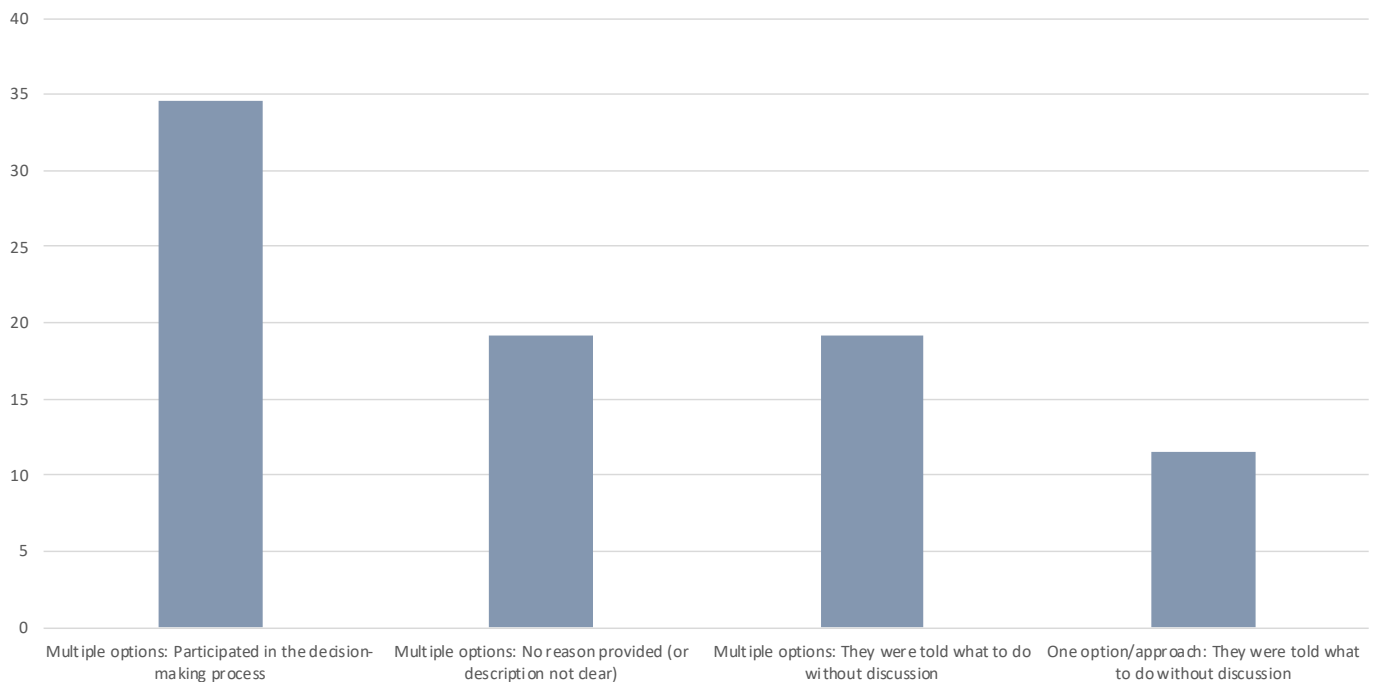
Theme	Less frequently	More frequently
Participant describes multiple treatment options being discussed	Non-metastatic Male	Metastatic Female Aged 65 or older
Participant describes one treatment option being discussed	-	Non-metastatic

**Table 4.3: Discussions about treatment (Participation in discussions)**

Participation in decision making	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 multiple options being presented and participating in the decision-making process	9	34.62	9	36.00	0	0.00	4	40.00	5	31.25	8	50.00	1	10.00
Participant describes multiple options being presented and there is no particular reason noted	5	19.23	4	16.00	1	100.00	0	0.00	5	31.25	4	25.00	1	10.00
Participant describes multiple options being presented and being told what to do without discussion	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	4	25.00	1	10.00
Participant describes one option being presented and being told what to do without discussion	3	11.54	3	12.00	0	0.00	3	30.00	0	0.00	1	6.25	2	20.00

Participation in decision making	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 multiple options being presented and participating in the decision-making process	9	34.62	5	29.41	4	44.44	6	46.15	3	23.08	0	0.00	9	37.50	2	22.22	7	41.18
Participant describes multiple options being presented and there is no particular reason noted	5	19.23	4	23.53	1	11.11	2	15.38	3	23.08	1	50.00	4	16.67	3	33.33	2	11.76
Participant describes multiple options being presented and being told what to do without discussion	5	19.23	2	11.76	3	33.33	2	15.38	3	23.08	1	50.00	4	16.67	2	22.22	3	17.65
Participant describes one option being presented and being told what to do without discussion	3	11.54	2	11.76	1	11.11	2	15.38	1	7.69	0	0.00	3	12.50	0	0.00	3	17.65



**Figure 4.2: Discussions about treatment (Participation in discussions)**

**Table 4.4: Discussions about treatment (Participation in discussions) – subgroup variations**

Theme	Less frequently	More frequently
Participant describes multiple options being presented and participating in the decision-making process	Male University Mid to low status	Female Trade or high school
Participant describes multiple options being presented and there is no particular reason noted	Non-metastatic	Metastatic
Participant describes multiple options being presented and being told what to do without discussion	-	Mid to low status Aged 65 or older
Participant describes one option being presented and being told what to do without discussion	Metastatic Mid to low status	Non-metastatic

### Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were efficacy (50.00%), advice of their clinician (26.92%), and side effects (23.08%). Other considerations included their own research (19.23%), quality of life (15.38%), cost (11.54%), and that they were not given options so considerations not taken into account (11.54%).

#### Participant describes taking efficacy into account when making decisions about treatment

*I suppose the effectiveness, the side effects, and I suppose this time around because I really didn't have any other choice, I had to go with the chemotherapy. There was no other choice in terms of targeted therapy. This was my next option and immunotherapy.*  
Participant 005\_\_2023AULUC

*How effective they're going to be, and the side effects I'm going to have.*  
Participant 024\_\_2023AULUC

*The main thing I take into consideration is living as long as physically possible because I've got a child, but I guess, I like to maintain well as long as possible, and I just do whatever's necessary at the time, while this medication works. [crosstalk] but when it stops working, I'll look at something else.*  
Participant 026\_\_2023AULUC

#### Participant describes taking the advice of their clinician into account when making decisions about treatment

*I took whatever they offered me.*  
Participant 019\_\_2023AULUC

*To be honest, we haven't been involved in those decisions. The oncologist makes those decisions and just says what you're going to do. Dad's been happy to follow with that but as a daughter, I've been there every step of the way, every appointment. We'll chat about it later on and dad's put his trust in this oncologist, so he just trusts what they've actually said and what they've laid out. There really hasn't been*

any options or given options. It's been dictated what your treatment route's going to be.

Participant 030\_2023AULUC

Well, right from the beginning we were sold the osimertinib, the targeted therapy. The oncologist at the beginning was very big on pushing that. When I spoke just privately to the cardiothoracic surgeon, he backed it. I just wanted to check with him and make sure or see what he thought and he thought it was a worthwhile path to go down.

Participant 025\_2023AULUC

#### Participant describes taking side effects into account when making decisions about treatment

I look at how long is it while it has to be administered. I look at the results of the trial and I want to have an idea of the demographics on which the drugs have been tested. That's quite a complex thing because I basically now look at research papers and how long it's been conducted, and then I decide if the treatment is going to be worse than the cancer itself. More destructive. If the treatment is going to do more harm than the cancer.

Participant 023\_2023AULUC

How effective they're going to be, and the side effects I'm going to have.

Participant 024\_2023AULUC

I suppose the effectiveness, the side effects, and I suppose this time around because I really didn't have any other choice, I had to go with the chemotherapy. There was no other choice in terms of targeted therapy. This was my next option and immunotherapy.

Participant 005\_2023AULUC

#### Participant describes taking their own research into account when making decisions about treatment

That I was put on a second generation, not a first generation when I started. I've been doing a lot of research on when the third generation, which is the last one runs out, can I go back and get on the first generation one? I've been doing a bit of study on that sort of thing so that I can present it to my oncologist. Also, my second generation, there were two of them in the second generation. Can I go up sideways once this one stops working? Can I go to its-- I don't know if they're exactly the same. If they're exactly the same, it's not going to work. My oncologist is given me free-range. He said if I pick something, he'll just do it. As

long as it's on the PBS, he'll just do it. That's what we are going to do.

Participant 002\_2023AULUC

Well, right from the beginning we were sold the osimertinib, the targeted therapy. The oncologist at the beginning was very big on pushing that. When I spoke just privately to the cardiothoracic surgeon, he backed it. I just wanted to check with him and make sure or see what he thought and he thought it was a worthwhile path to go down. Fortunately, we are in a position where we can afford it, albeit being a little bit difficult, but [inaudible] afford it. I'm taking that for three years. I haven't really been given a lot of information about it. I've researched it all myself because there is a lot about it online, of course, as there is with everything. I've pretty much done most of the research about the drug myself and decided myself that I would pursue this for a while, providing I didn't have too many adverse side effects. To date, I haven't.

Participant 025\_2023AULUC

#### Participant describes taking quality of life into account when making decisions about treatment

Look, I do a bit of research, but I just want quality of life. That's my big thing. I know I'm never going to get better, but I want a good quality of life for as long as I can. I guess that would be my main decision-maker. My darling sister does a lot of research stuff. She's currently doing a thesis on—Anyway, but she does a lot of research for me into things. Family are good support and look, I've got a lot of friends in the medical field, so often I'll run things by them as well.

Participant 006\_2023AULUC

At the beginning, I needed the best possible treatment so that my kids had a mum. I needed a treatment that was going to keep me alive. I didn't care what the side effects were, if it meant I could live another day, to live and breathe and touch my child, my newborn baby, that was my priority. I actually was willing to take and tolerate a lot in that first three years, even though that treatment was so harsh, I was willing to do that, that sort of considerations for me then. Then, as we've moved along, it's been more about quality of life, how can I maximize my quality of life so that I can be a mom, so that I can kick a football with my son, so that I can watch a movie with my daughter and take her out for a milkshake, on a ride on their bike [unintelligible] Being able to do things and have a good quality of life that enabled me to not only live but to live well.

Participant 015\_2023AULUC



*Look, there's a few. Very much my relationship, the impact it's going to have on the adult, but my adult children and my partner. It's got to be manageable for them and not distressing for them what I do as well. Very much my cognitive functioning. That is one thing I'm very scared of losing, and quality of life. Quality of life is to me more important to be enjoying life and participating in a way that I want to, even if it's limited, but in a way that I find comfortable rather than just being alive for being alive sake.*  
*Participant 020\_2023AULUC*

**Participant describes taking cost into account when making decisions about treatment**

*Quality of life, how long the treatment will last, how much the treatment will cost and whether I can have it locally or if I have to travel. Those type of decisions.*  
*Participant 007\_2023AULUC*

*It's a little bit hypothetical because I've only had one treatment, but I have talked about future treatments. I look at, in particular the updated website, which PROFESSOR is a co-contributor to, and that gathers all of the latest information on, in my case ALK. I would look at what performances had, what clinical trials have tested for, what the limitations of their conclusions might be, and what the cost of the treatment might be because we're very fortunate in Australia that in the tyrosine kinase inhibitor area, the key drugs that are already covered by PBS.*

*It's a serious concern to me that I could end up thinking, "Well, the next treatment for me is something that's not on the PBS, and it's going to cost me and my family a huge amount." Just have my fingers crossed, that that doesn't occur. That's why being actively involved in sources of clinical trial information, that's TOGA especially, and connected to other things, it is useful to make me as fit a patient as I can be, for those discussions.*  
*Participant 022\_2023AULUC*

**Participant described that they were not given options and that their considerations not taken into account**

*I think the easiest way to answer that is I wasn't really given a decision about treatment. It was do you want surgery or do you not want surgery, so it's not really a decision is it? Do you want surgery? Do you want it out? [chuckles] There wasn't a choice between--*  
*Participant 021\_2023AULUC*

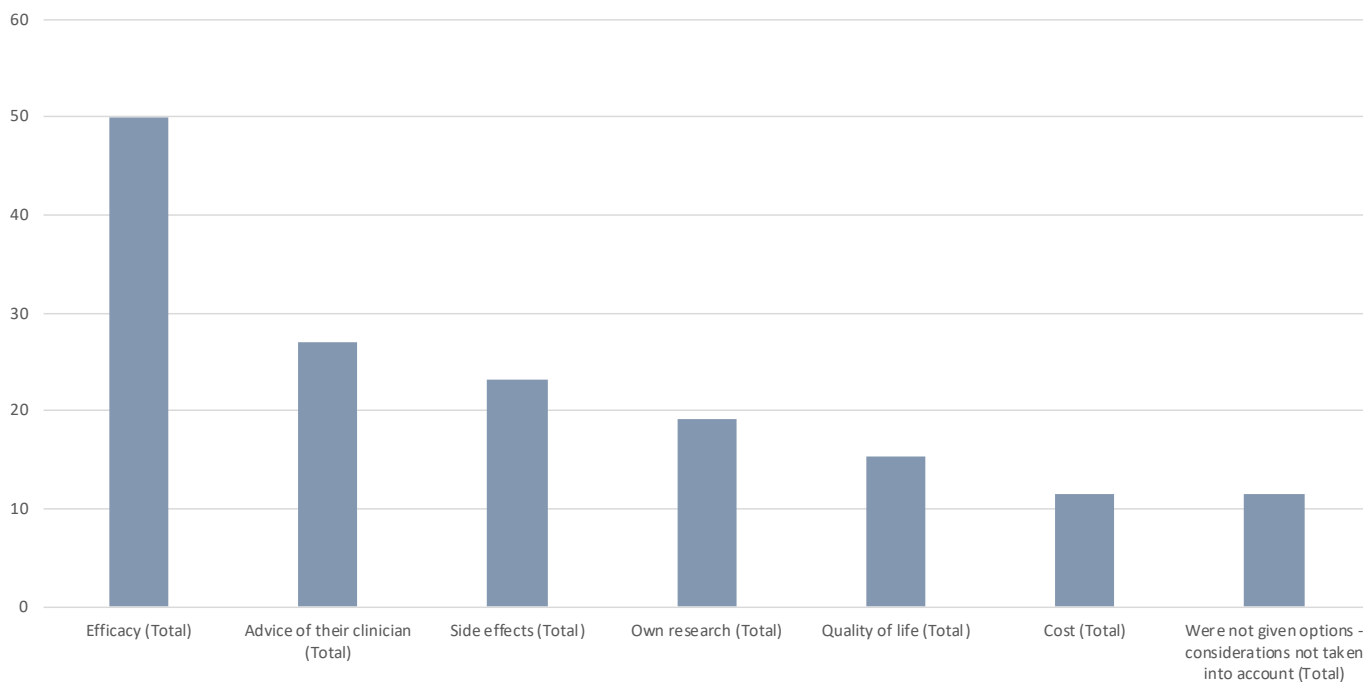
*Well, as I said, with this one I've got, my treatment options have been limited, so my choices have also been limited, but I guess for this drug side effects, but then if I don't take it, then I die, if I take it, I get a little bit sick. I guess—*  
*Participant 006\_2023AULUC*



**Table 4.5 Considerations when making decisions**

Considerations when making decisions about 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 taking efficacy into account when making decisions about treatment (Total)	13	50.00	13	52.00	0	0.00	4	40.00	9	56.25	9	56.25	4	40.00
Participant describes taking efficacy into account as part of multiple aspects when making decisions about treatment	11	42.31	11	44.00	0	0.00	3	30.00	8	50.00	8	50.00	3	30.00
Participant describes taking efficacy into account as the only consideration when making treatment decisions	2	7.69	2	8.00	0	0.00	1	10.00	1	6.25	1	6.25	1	10.00
Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)	7	26.92	6	24.00	1	100.00	4	40.00	3	18.75	5	31.25	2	20.00
Participant describes taking the advice of their clinician into account as part of multiple aspects when making decisions about treatment	3	11.54	3	12.00	0	0.00	3	30.00	0	0.00	2	12.50	1	10.00
Participant describes taking the advice of their clinician into account as the only consideration when making treatment decisions	4	15.38	3	12.00	1	100.00	1	10.00	3	18.75	3	18.75	1	10.00
Participant describes taking side effects into account when making decisions about treatment (Total)	6	23.08	6	24.00	0	0.00	1	10.00	5	31.25	4	25.00	2	20.00
Participant describes taking side effects into account as part of multiple aspects when making decisions about treatment	6	23.08	6	24.00	0	0.00	1	10.00	5	31.25	4	25.00	2	20.00
Participant describes taking side effects into account as the only consideration when making treatment decisions	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking their own research into account when making decisions about treatment (Total)	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	4	25.00	1	10.00
Participant describes taking their own research into account as part of multiple aspects when making decisions about treatment	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	3	18.75	1	10.00
Participant describes taking their own research into account as the only consideration when making treatment decisions	1	3.85	1	4.00	0	0.00	0	0.00	1	6.25	1	6.25	0	0.00
Participant describes taking quality of life into account when making decisions about treatment (Total)	4	15.38	4	16.00	0	0.00	0	0.00	4	25.00	4	25.00	0	0.00
Participant describes taking quality of life into account as part of multiple aspects when making decisions about treatment	4	15.38	4	16.00	0	0.00	0	0.00	4	25.00	4	25.00	0	0.00
Participant describes taking quality of life into account as the only consideration when making treatment decisions	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking cost into account when making decisions about treatment (Total)	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	2	12.50	1	10.00
Participant describes taking cost into account as part of multiple aspects when making decisions about treatment	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	2	12.50	1	10.00
Participant describes taking cost into account as the only consideration when making treatment decisions	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes that they were not given options and that their considerations not taken into account (Total)	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	2	12.50	1	10.00
Participant describes that they were not given options and that their considerations not taken into account, but described other considerations that were important to them when making decisions about treatment	2	7.69	2	8.00	0	0.00	0	0.00	2	12.50	2	12.50	0	0.00
Participant describes that they were not given options and that their considerations not taken into account	1	3.85	1	4.00	0	0.00	1	10.00	0	0.00	0	0.00	1	10.00

Considerations when making decisions about 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 taking efficacy into account when making decisions about treatment (Total)	13	50.00	8	47.06	5	55.56	5	38.46	8	61.54	2	100.00	11	45.83	4	44.44	9	52.94
Participant describes taking efficacy into account as part of multiple aspects when making decisions about treatment	11	42.31	7	41.18	4	44.44	4	30.77	7	53.85	2	100.00	9	37.50	4	44.44	7	41.18
Participant describes taking efficacy into account as the only consideration when making treatment decisions	2	7.69	1	5.88	1	11.11	1	7.69	1	7.69	0	0.00	2	8.33	0	0.00	2	11.76
Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)	7	26.92	3	17.65	4	44.44	4	30.77	3	23.08	1	50.00	6	25.00	2	22.22	5	29.41
Participant describes taking the advice of their clinician into account as part of multiple aspects when making decisions about treatment	3	11.54	2	11.76	1	11.11	1	7.69	2	15.38	1	50.00	2	8.33	1	11.11	2	11.76
Participant describes taking the advice of their clinician into account as the only consideration when making treatment decisions	4	15.38	1	5.88	3	33.33	3	23.08	1	7.69	0	0.00	4	16.67	1	11.11	3	17.65
Participant describes taking side effects into account when making decisions about treatment (Total)	6	23.08	3	17.65	3	33.33	4	30.77	2	15.38	1	50.00	5	20.83	2	22.22	4	23.53
Participant describes taking side effects into account as part of multiple aspects when making decisions about treatment	6	23.08	3	17.65	3	33.33	4	30.77	2	15.38	1	50.00	5	20.83	2	22.22	4	23.53
Participant describes taking side effects into account as the only consideration when making treatment decisions	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking their own research into account when making decisions about treatment (Total)	5	19.23	4	23.53	1	11.11	2	15.38	3	23.08	1	50.00	4	16.67	2	22.22	3	17.65
Participant describes taking their own research into account as part of multiple aspects when making decisions about treatment	4	15.38	3	17.65	1	11.11	2	15.38	2	15.38	1	50.00	3	12.50	2	22.22	2	11.76
Participant describes taking their own research into account as the only consideration when making treatment decisions	1	3.85	1	5.88	0	0.00	0	0.00	1	7.69	0	0.00	1	4.17	0	0.00	1	5.88
Participant describes taking quality of life into account when making decisions about treatment (Total)	4	15.38	4	23.53	0	0.00	2	15.38	2	15.38	1	50.00	3	12.50	1	11.11	3	17.65
Participant describes taking quality of life into account as part of multiple aspects when making decisions about treatment	4	15.38	4	23.53	0	0.00	2	15.38	2	15.38	1	50.00	3	12.50	1	11.11	3	17.65
Participant describes taking quality of life into account as the only consideration when making treatment decisions	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking cost into account when making decisions about treatment (Total)	3	11.54	3	17.65	0	0.00	1	7.69	2	15.38	0	0.00	3	12.50	0	0.00	3	17.65
Participant describes taking cost into account as part of multiple aspects when making decisions about treatment	3	11.54	3	17.65	0	0.00	1	7.69	2	15.38	0	0.00	3	12.50	0	0.00	3	17.65
Participant describes taking cost into account as the only consideration when making treatment decisions	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes that they were not given options and that their considerations not taken into account (Total)	3	11.54	3	17.65	0	0.00	2	15.38	1	7.69	1	50.00	2	8.33	2	22.22	1	5.88
Participant describes that they were not given options and that their considerations not taken into account, but described other considerations that were important to them when making decisions about treatment	2	7.69	2	11.76	0	0.00	1	7.69	1	7.69	1	50.00	1	4.17	2	22.22	0	0.00
Participant describes that they were not given options and that their considerations not taken into account	1	3.85	1	5.88	0	0.00	1	7.69	0	0.00	0	0.00	1	4.17	0	0.00	1	5.88



**Figure 4.3 Considerations when making decisions**

**Table 4.6: Considerations when making decisions – subgroup variations**

Theme	Less frequently	More frequently
Participant describes taking efficacy into account when making decisions about treatment (Total)	Trade or high school	University
Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)	-	Non-metastatic Aged 65 or older
Participant describes taking side effects into account when making decisions about treatment (Total)	Non-metastatic	Aged 65 or older
Participant describes taking quality of life into account when making decisions about treatment (Total)	Non-metastatic Male Aged 65 or older	-
Participant describes taking cost into account when making decisions about treatment (Total)	Aged 65 or older Mid to low status	-
Participant describes that they were not given options and that their considerations not taken into account (Total)	Aged 65 or older	Mid to low status

**Decision-making over time**

Participants were asked if the way they made decisions had changed over time. The most common responses were that they had not changed the way they made decisions (42.31%), followed by not changing the way they made decisions (38.46%).

Where participants had changed the way they make decisions, the most common reason was that they had become more informed and/or more assertive (30.77%). Where participants had not changed the way they make decisions, the most common reason was that they had always taken advice of clinicians (11.54%).

**Participant describes decision-making changing over time as they are more informed and/or more assertive**

*I'm more of an advocate. Like, I won't take, "No, nothing's wrong." I kind of go, "No, I will go to somebody who I can see immediately." I have changed. I'm a bit more determined to get answers.*  
Participant 004\_2023AULUC

*No, it's totally changed. The more [crosstalk] you have and the more knowledge you have, the more informed your decisions are.*  
Participant 007\_2023AULUC

*I've got more information now. I can ask more questions.*

Participant 010\_2023AULUC

*Basically, I was a bit in a state of panic where I didn't think very clearly. Plus, I have never dealt with health providers previously and I had this naive approach that they know best. I was not able to drive my care. I didn't have enough knowledge. Now I can.*

Participant 023\_2023AULUC

**Participant describes no change in decision-making over time as they have always taken advice of clinicians**

*Oh no, I approach it the same way. Like he picked the first one for me and I'm happy with that. That's going to change at some point. At some point, we're going to have to sit down and say, "Right, what's next?" We'll just wait and then we'll make those decisions.*  
Participant 002\_2023AULUC

*Not really. I've put my trust in my oncologist and I've had good results up until now. I've followed through what he suggested.*  
Participant 005\_2023AULUC

**Table 4.7: Decision-making over time**

Decision making over time	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 the way they make decisions not changing over time	11	42.31	11	44.00	0	0.00	5	50.00	6	37.50	8	50.00	3	30.00
Participant describes no change in decision-making over time as they have always taken advice of clinicians	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	2	12.50	1	10.00
Participant describes no change in decision-making but does not mention any reason	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	2	12.50	1	10.00
Participant describes the way they make decisions changing over time	10	38.46	9	36.00	1	100.00	2	20.00	8	50.00	8	50.00	2	20.00
Participant describes decision-making changing over time as they are more informed and/or more assertive	8	30.77	8	32.00	0	0.00	2	20.00	6	37.50	7	43.75	1	10.00
No particular comment (Other/no response)	5	19.23	5	20.00	0	0.00	3	30.00	2	12.50	3	18.75	2	20.00

Decision making over time	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 the way they make decisions not changing over time	11	42.31	7	41.18	4	44.44	7	53.85	4	30.77	1	50.00	10	41.67	5	55.56	6	35.29
Participant describes no change in decision-making over time as they have always taken advice of clinicians	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
Participant describes no change in decision-making but does not mention any reason	3	11.54	1	5.88	2	22.22	3	23.08	0	0.00	0	0.00	3	12.50	2	22.22	1	5.88
Participant describes the way they make decisions changing over time	10	38.46	5	29.41	5	55.56	5	38.46	5	38.46	0	0.00	10	41.67	2	22.22	8	47.06
Participant describes decision-making changing over time as they are more informed and/or more assertive	8	30.77	4	23.53	4	44.44	4	30.77	4	30.77	0	0.00	8	33.33	2	22.22	6	35.29
No particular comment (Other/no response)	5	19.23	4	23.53	1	11.11	1	7.69	4	30.77	1	50.00	4	16.67	2	22.22	3	17.65

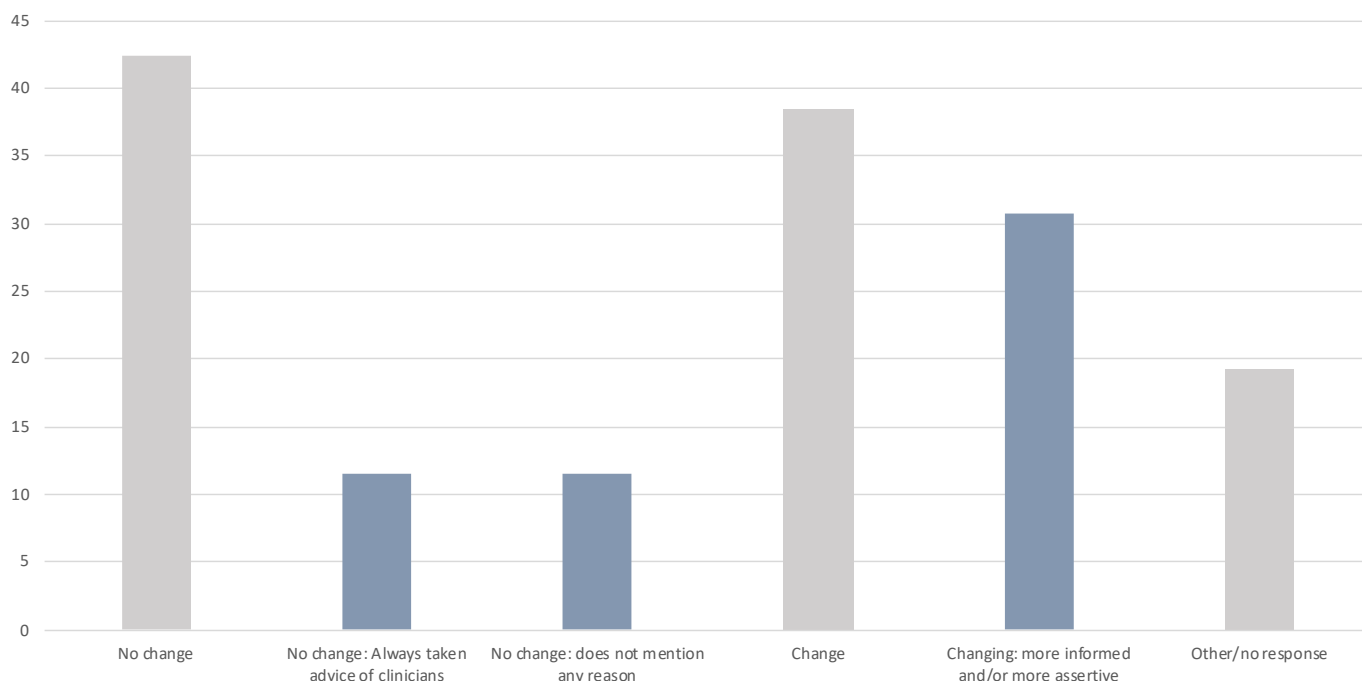


Figure 4.4: Decision-making over time

Table 4.8: Decision-making over time – subgroup variations

Theme	Less frequently	More frequently
Participant describes the way they make decisions not changing over time	Male University	Trade or high school Mid to low status
Participant describes the way they make decisions changing over time	Non-metastatic Male Mid to low status	Metastatic Female Aged 65 or older

## Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common response was to be cancer free, to avoid recurrence, or increase longevity (38.46%).

Other themes treatment goals included minimising or avoiding side effects (26.92%), quality of life, or return to normality (23.08%), and some wanted improvements in the communication and information about treatment they received from their doctor (15.38%)

**Participants describe wanting to be cancer free, avoid recurrence or increase longevity**

*I want to stay alive. I want the best treatment that would keep me alive.*

*Participant 007\_2023AULUC*

*Yes, definitely-- Obviously, I want to live longer. I want to live as long as I possibly can and that was one of the treatment decisions that we made. We switched for that reason, that would then also help to promote better quality of life, potentially. When I say potentially, it's a bit of a convoluted way of answering because I was on a targeted therapy, and was starting to show signs of progression over a 12-month period. We treated a lesion and I continued on the treatment, we treated another lesion, and I wanted to continue*

on that treatment. My doctor said to me, I would rather switch treatments now and give you the best possible coverage we can versus you stay on this treatment, potentially progress again, that we don't know what physical limitations it may then lead to long term. So it's living long with a good quality of life. The side effects were also a plus to this type of treatment, so I was initially not keen to it but we've switched because of that.

Participant 015\_2023AULUC

My own goal? To get better. To be cancer free. To do everything I could within my power to improve how I was living my life. If there was any steps I could take to change things and to end up with a cancer-free diagnosis. I viewed every stage of my treatment, as hard as it was, I just went, "I'm one step closer to being cancer-free." That's all I kept saying in my head. I'm one step closer to cancer free. I worked in small increment but incremental goals of getting myself cancer free.

Participant 018\_2023AULUC

#### **Participant describes wanting to minimise or avoid side effects of treatment for their condition**

For me to be pain-free. That's one of the goals and to try and avoid progression in the central nervous system. That's the second goal. Pain-free is one, and then central nervous system is the second goal.

Participant 023\_2023AULUC

**PARTICIPANT:** Oh, yes. I have, yes. I had to avoid, especially during the chemo, I had to avoid the nausea because I used to get terrible nausea with [crosstalk]. I really don't like chemo. I don't think I'd ever have it again. Nausea, and also sent me into a mental spiral where I got very depressed. I lost a lot of weight. I lost the will to live especially.

Participant 024\_2023AULUC

**PARTICIPANT:** I don't mind, I can tell you. My first thing is I try and reduce the side effects of the medication I'm on. I try to start-- The situation is that my oncologist has not ever treated anyone with my cancer and the medication is new. It's new medication and he doesn't really understand it. He's like, "If the side effects are too much, I'll put you on a lower dose." I don't want to go on a lower dose, but as he says to me, "I'm here for your cancer. Anything else that's going on, you have to see your GP." I go to my GP and my GP is like, "I've never even heard of this treatment, it's all very new and I don't know what you can do."

Participant 027\_2023AULUC

#### **Participant describes wanting to improve their quality of life or return to normality**

I don't know. Look, I'm just living. I'm not thinking about it too much. In the first, probably, year because I'm only 15 months, 16 months in. First-year, you wake up every morning it's the first thing you'd think about and it was the last thing you thought about when you went to bed. That's not happening now. It's a part of me and it's part of our life, so we're just getting on with it.

Participant 002\_2023AULUC

**PARTICIPANT:** It's hard to say because I don't know if it's realistic to want to be back to normal because I don't know anybody in this situation. I don't know if that is a realistic goal. At the moment, I'm post eight weeks up. Whilst the operation was good and so was the post-recovery, I have had quite a bit of soreness. It's made me reluctant to do certain things like picking up my grandkids. The surgeon said to me at the postoperative interview, don't lift anything over five kilos. He intimated that was for six to eight weeks after the op. I'm only just now starting to feel confident that I could maybe do that and maybe get back into some gardening and maybe pull my weight in around the house with the housework. Is that the sort of things you meant? The one thing that I did do straight away, we always walked for exercise. When I got back home from the hospital, we got back into that straight away. Obviously, it was slower to start with, but I do think that helped me with my recovery that I was active and moving.

Participant 010\_2023AULUC

My own personal goal is to maximize my quality of life, not the quantity. I'm not a person who will go for any treatment just for the sake of a few more weeks or months if it's going to mean those weeks and months don't give me quality of life. For me, that is maintaining relationships with my family. I'm willing to lose a little bit of independence. Absolutely autonomous at the moment, but they will become-- Cognitively, it's very important that I'm cognitively okay. I wouldn't do treatment if I thought it meant a huge cognitive decline and that would affect my relationships. I don't want to do treatment which means my family are seeing me so incapacitated that it's distressing to them even though I'm alive because that's not life for me.

Participant 020\_2023AULUC

**Participant describes wanting better communication and information from their doctor about their treatment and disease status**

*I just want something done. I'd be happy if I knew what their plan was, if they had a plan. I want to get back to work. I can't work at the moment because of the symptoms. I would just be happy if I knew what was happening.*

**Participant 003\_2023AULUC**

*Long-term is to be given information which I think is very hard to extract from people. Approachability, to be able to actually have access to-- I went private, which I'm not too sure is such the best thing to do. To have access to somebody when you need them when things are going pear-shaped. I'm on targeted therapy now, which I'm having to pay for myself, which is I*

*don't know if you know how much it costs, but it's a freaking arm and a leg. I think there should be some campaign or some interest in having the treatment put on the PBS. I don't understand why people who don't have the metastases are not able to access the treatment that will prevent me from getting metastases. I don't get that, and I don't understand why there isn't any campaigning for it.*

**Participant 025\_2023AULUC**

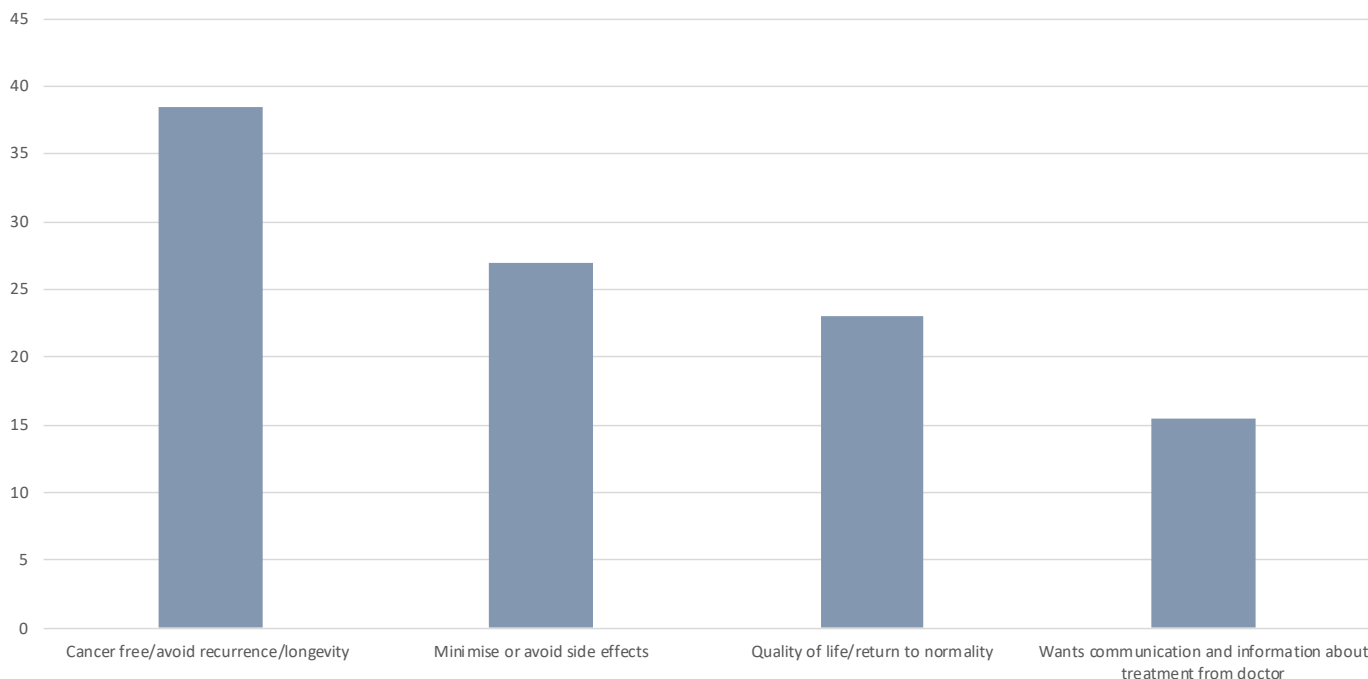
*It's not a goal, but I found that the oncologist that he sees is way too brief, does not explain things. I find myself looking to Google, which is not a good thing, to try and research what things mean, but apparently, that's a common occurrence with certain oncologists and dad doesn't want to change.*

**Participant 030\_2023AULUC**

**Table 4.9: Personal goals of treatment or care**

Personal goals of 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	%
Participants describe wanting to be cancer free, avoid recurrence or increase longevity	10	38.46	10	40.00	0	0.00	6	60.00	4	25.00	7	43.75	3	30.00
Participant describes wanting to minimise or avoid side effects of treatment for their condition	7	26.92	7	28.00	0	0.00	1	10.00	6	37.50	4	25.00	3	30.00
Participant describes wanting to improve their quality of life or return to normality	6	23.08	6	24.00	0	0.00	2	20.00	4	25.00	5	31.25	1	10.00
Participant describes wanting better communication and information from their doctor about their treatment and disease status	4	15.38	3	12.00	1	100.00	2	20.00	2	12.50	2	12.50	2	20.00

Personal goals of 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	%
Participants describe wanting to be cancer free, avoid recurrence or increase longevity	10	38.46	9	52.94	1	11.11	3	23.08	7	53.85	0	0.00	10	41.67	2	22.22	8	47.06
Participant describes wanting to minimise or avoid side effects of treatment for their condition	7	26.92	3	17.65	4	44.44	5	38.46	2	15.38	0	0.00	7	29.17	1	11.11	6	35.29
Participant describes wanting to improve their quality of life or return to normality	6	23.08	4	23.53	2	22.22	3	23.08	3	23.08	0	0.00	6	25.00	0	0.00	6	35.29
Participant describes wanting better communication and information from their doctor about their treatment and disease status	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



## Figure 4.5: Personal goals of treatment or care

**Table 4.10: Personal goals of treatment or care – subgroup variations**

Theme	Less frequently	More frequently
Participants describe wanting to be cancer free, avoid recurrence or increase longevity	Metastatic Aged 65 or older Trade or high school Mid to low status	Non-metastatic Aged 35 to 64 University
Participant describes wanting to minimise or avoid side effects of treatment for their condition	Non-metastatic University Mid to low status	Metastatic Aged 65 or older Trade or high school
Participant describes wanting to improve their quality of life or return to normality	Male Mid to low status	Higher status