

Section 9

Expectations and messages to decision-makers

Section 9: Expectations of future treatment, care and support, information and communication

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common responses were that future treatment will be more affordable (26.92%), and will involve more clinical trials (including to access new technologies and treatments and funding) (26.92%). Other expectations of future treatments included treatments with fewer or less intense side effects and more discussion about side effects (23.08%), will include having choice and transparency in relation to treatment options (23.08%), future treatment will be more effective and/or targeted (15.38%), easier to administer or able to administer at home (11.54%), and future treatments will allow for a normal life/quality of life (11.54%).

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common responses were that future information will be more accessible and easy to find (19.23%), include the ability to talk to or access to a health professional (19.23%). Other expectations of future information included more details about disease trajectory and what to expect (11.54%), and more details about symptom and side effect control (11.54%). There were 5 participants (19.23 %) that were satisfied with the information they had received and had no particular comment.

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common expectations for future healthcare professional communication were that communication will be more empathetic (26.92%), and will include a multidisciplinary and coordinated approach (19.23%). Other expectations included that future communication will be more transparent and forthcoming (11.54%), and communication will include health professionals with a better knowledge of the condition (11.54%). There were 4 participants (15.38%) that were satisfied with the healthcare professional communication and had no particular comment.

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common expectation for future care and support was that it will include specialist clinics or services where they can talk to professionals either in person, phone, or online (38.46%). Other expectations if future care and support included practical support for example home care, transport, or financials support (15.38%), a multidisciplinary and coordinated approach to care and support (15.38%), long-term condition management and care planning (15.38%), and it will be more holistic that includes emotional health (11.54%). There were 5 participants (19.23%.) that were satisfied with their care and support and had no particular comment.

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common responses were that participants were grateful for low cost or free medical treatments through the government (46.15%), healthcare staff, including access to specialists (42.31%), for the entire health system (34.62 %), and Timely access to treatment (15.38%). There were 4 participants that expressed the need for lower treatment costs and extend Medicare coverage (15.38%).

Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it. The most important aspects reported were pain, nausea and vomiting and, tiredness and fatigue. The least important were mouth ulcers, loss of appetite and, hair loss.

Values in making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care. The most important aspects were “Ability to follow and stick to a treatment regime”, and “How personalised the treatment is for me”. The least important were “The severity of the side effects” and “Time impact of the treatment on my quality of life”.

Values for decision makers

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care. The most important values were “Quality of life for patients”, and “All patients being able to access all available treatments and services”. The least important was “Economic value to government and tax payers”.

Value to access treatments that reduce symptoms and improve quality of life

Participants were asked in the online questionnaire, if there was any value to access treatments that reduce symptoms and improve quality of life, even if it did not offer a cure. The majority of participants (n = 18, 72.00%) responded that this was of very significant value.

Time taking medication to improve quality of life

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure. The majority of participants (n = 14, 51.85%) would use a treatment for more than ten years for a good quality of life even if it didn't offer a cure.

Most effective form of medicine

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in. There were no participants (0.00%) that thought that medicine delivered by IV was most effective, 5 participants (18.52%) thought that pill form was most effective, and 11 participants (40.74%) that thought they were equally effective. There were 11 participants (40.74%) that were not sure.

Messages to decision-makers

Participants were asked, “If you were standing in front of the health minister, what would your message be in relation to your condition?” The most common messages to the health minister were to help raise community awareness (23.08%), that more clinical trials or new treatments are needed (23.08%), and they want more timely and equitable access to support, care and treatment (23.08 %). Other messages included to invest in health professionals to service the patient population (19.23%), Increase investment in general (11.54%), Invest in research, including to find new treatments (11.54%), and that treatments need to be affordable (11.54%). There were 3 participants whose message was that they were grateful for the healthcare system and the treatment that they received (11.54%).

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common responses were that future treatment will be more affordable (26.92%), and will involve more clinical trials (including to access new technologies and treatments and funding) (26.92%). Other expectations of future treatments included treatments with fewer or less intense side effects and more discussion about side effects (23.08%), will include having choice and transparency in relation to treatment options (23.08%), future treatment will be more effective and/or targeted (15.38%), easier to administer or able to administer at home (11.54%), and future treatments will allow for a normal life/quality of life (11.54%).

Future treatment will be more affordable

I think that radiation should be covered under private health. If you are a public patient, it gets covered, but if you are a private patient, you've got to pay for it. When you've sat in a waiting room where all these people, and some of them are a lot older than you, you know that they wouldn't have had super policies and things like that, which is a nightmare to get paid out on [unintelligible] They're spending their last cent to try and stay alive. This isn't necessarily lung cancer, this is just all radiation patients. That's ridiculous. Yet, it's considered outpatient, and yet, two stories above, I'm sitting in a chair, which is not a hospital, but that's for oncology and it's covered if you pay your excess, and yet radiation isn't. My treatment was \$32,000. Now, I don't know too many people who's got a lazy \$32,000 floating around to pay for. Of which, yes, you get some money back from Medicare, but somewhere in the mix, somebody's making-- To me, all this just reeks of a multimillion-dollar business, which is what cancer is, and it shouldn't be that way. That should be covered. My goal this year is to start writing letters to the health ministers and say, "Why? What the--" If they keep banging on about us having private health covers to take the pressure off the public system, of which is what I have done, and paid my whole way through my own life, and then I'm supposed to find a lazy \$32,000 to pay for my treatment?

Participant 018_2023AULUC

PARTICIPANT: The PBS scheme is really important because a lot of the new treatments wouldn't be available, including one I'm on right now wouldn't be available to people.

INTERVIEWER: Because of cost, yes?

PARTICIPANT: Yes.

...I'd like to see some new treatments. I don't know how they found a cure for COVID and they can't find one for cancer for so long.

Participant 026_2023AULUC

Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)

I would love to see Australia dovetail onto-- like America is approving these lung cancer medications so quickly and they're-- what do they call them? The FDA, they're approved fast tracking all these tablets every year. There's six, seven, eight tablets, but in Australia, we're still waiting approval. I would love Australia to just be able to approve some of these ones. If America has approved it, they can just put it in place so people have more options.

Participant 004_2023AULUC

PARTICIPANT: I think in America they have a lot more drugs available which are not available on PBS in Australia. The only ones we've got are, I think it's about three, four but as you progress sometimes the tumor mutates and you get new mutations which are accessible to other targeted therapy drugs, and those other mutations they aren't generally available in Australia. That would be a vast improvement if we could. I realized they're very expensive you're not talking about cures still. In America, they go from one to the other, to the other, the other and they do mutation studies and then...I think that would be an area that we can improve on.

Participant 024_2023AULUC

I would like clinical trials to be conducted on older people because the majority of people with lung cancer are old. Yes, it's 70% are over the age of 60, and I think it's 60% over the age of 80. I would like at least to have that. To have some clinical trials conducted on older people so that we have more guidance on what is the right treatment.

Participant 023_2023AULUC

Future treatments will have fewer or less intense side effects/more discussion about side effects

The thing that I would like to see improved is the toxicity on the body. I hear that the toxic side effects might actually be doing-- Might shorten my lifespan as well. Mainly the toxicity on the body. Other than that, I'm doing okay. Participant 007_2023AULUC

I suspect what we'll see and what I hope that we see quickly is just improvement in the targeted therapy, type of therapy that has less side effects, much more specific, maybe doesn't build up resistance. A lot of research in that area. It's huge isn't it that whole area of research and what's coming out all over the place? Participant 025_2023AULUC

Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)

There's so many aspects to this. One you go, cost can be a huge thing because new treatments come out and they're not on PBS and that means access is only if you can get special consideration or you have lots of dollars. It's important that it's accessible not just to me but to anyone. I think cost is a huge thing for people. I'm thinking globally here, in big terms of accessibility as in rural remote. I just feel for the people who have to go and in the mouth to get seen and get treated and don't have the services that we do in a big city, I think they get impacted terribly. For me personally, I think, what I would value in treatment is that still allows, it's not impacting on my day-to-day, but I can fit it into my life, if that makes sense.

Participant 020_2023AULUC

There are side effects but I don't really care. As long as it's accessible for every-- Yes, it's the access and that there's education around it, I don't care, I just want there to be treatment. Do you know what? I don't even have any expectations on it, I just want treatment so I can spend more quality time with my family.

Participant 027_2023AULUC

Future treatment will be more effective and/or targeted (personalised)

I'd like the new treatment to be personalized to the tumor markers and makeup. Where they're able to access information about the tumor and then have a

treatment that, say, they have a base treatment. Then based on your tumor makeup, they can add in a drop of this, a drop of that, a drop of something else, and then go into the-- Then that's what makes it up. I don't know, something a little bit more personalized. More personalized treatment, markers and makeup. Participant 015_2023AULUC

If we were to look for the imagined treatment, it would be something that was significantly effective, and perhaps, in my view of a different type, that may not have the sort of limited lifespan that the current thing that our treatments have because of our body's capacity to work around that. My wish is for a treatment but it's so pervasively effective then. It can be expected to be a very long-term, if not lifelong, effective treatment. I think that's just wishful thinking on my part, but one of the effects of this has been to think about what I want to do with the rest of my life, given that I can't control what I know is going to happen. All I can say is that I want to spend time doing things that I think are worthwhile, remain connected to the community, and treat my life as if it's going to go on similarly to what if I wasn't sick, but I'm ready to pull the plug on work and do other things if my health was going to go through a decline, I'm prepared for that, perhaps underprepared but nevertheless prepared.

Participant 022_2023AULUC

Future treatment will be easier to administer and/or able to administer at home and/or less invasive

Like the infusion, because someone new having an immunotherapy now, I figured they could do that. They could have a district nurse really do it or have someone who's used to cytotoxic, whatever. I think you could have it at home just as easy, that'd be a lot nicer.

Participant 001_2023AULUC

Definitely more targeted therapy, a lot easier to manage. You can get on with your daily tasks because it's a matter of taking the medication in the morning. It doesn't involve having to organize trips to hospital or clinic, taking time out for treatment. I've encountered a lot of people who are going through treatment, and then they'll go to work because they're able to actually continue working normally. Targeted therapy definitely there don't seem to be as many side effects as, say, chemotherapy. Not as debilitating, let's say, as radiotherapy and chemotherapy, but having said that, I've had SABR treatment, which is a lot more targeted type of radiotherapy compared to

your conventional. I didn't experience any sort of burning. I know my mum did when she had hers. She had some burning on her chest. Yes, so definitely targeted.

Participant 005_2023AULUC

Future treatments will allow for a normal life/quality of life

There are side effects but I don't really care. As long as it's accessible for every-- Yes, it's the access and that there's education around it, I don't care, I just want there to be treatment. Do you know what? I don't

even have any expectations on it, I just want treatment so I can spend more quality time with my family. Participant 027_2023AULUC

For dad, right now things are working, so why change the wheel when it's actually working? If it wasn't working, the side effects are a big thing. Seeing other people having treatments as well, they have lots of side effects. Maybe having less side effects for them and quality of life. That's about it really. Participant 030_1_2023AULUC

Table 9.1: Expectations of future treatment

Expectations of future treatments	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	%
Future treatment will be more affordable	7	26.92	7	28.00	0	0.00	3	30.00	4	25.00	5	31.25	2	20.00
Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)	7	26.92	7	28.00	0	0.00	2	20.00	5	31.25	6	37.50	1	10.00
Future treatments will have fewer or less intense side effects/more discussion about side effects	6	23.08	5	20.00	1	100.00	1	10.00	5	31.25	4	25.00	2	20.00
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	6	23.08	6	24.00	0	0.00	3	30.00	3	18.75	6	37.50	0	0.00
Future treatment will be more effective and/or targeted (personalised)	4	15.38	4	16.00	0	0.00	1	10.00	3	18.75	3	18.75	1	10.00
Future treatment will be easier to administer and/or able to administer at home and/or less invasive	3	11.54	3	12.00	0	0.00	0	0.00	3	18.75	3	18.75	0	0.00
Future treatments will allow for a normal life/quality of life	3	11.54	2	8.00	1	100.00	0	0.00	3	18.75	1	6.25	2	20.00

Expectations of future treatments	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	%
Future treatment will be more affordable	7	26.92	5	29.41	2	22.22	2	15.38	5	38.46	1	50.00	6	25.00	2	22.22	5	29.41
Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)	7	26.92	5	29.41	2	22.22	1	7.69	6	46.15	1	50.00	6	25.00	3	33.33	4	23.53
Future treatments will have fewer or less intense side effects/more discussion about side effects	6	23.08	5	29.41	1	11.11	4	30.77	2	15.38	0	0.00	6	25.00	2	22.22	4	23.53
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	6	23.08	5	29.41	1	11.11	3	23.08	3	23.08	1	50.00	5	20.83	2	22.22	4	23.53
Future treatment will be more effective and/or targeted (personalised)	4	15.38	4	23.53	0	0.00	1	7.69	3	23.08	0	0.00	4	16.67	1	11.11	3	17.65
Future treatment will be easier to administer and/or able to administer at home and/or less invasive	3	11.54	2	11.76	1	11.11	1	7.69	2	15.38	0	0.00	3	12.50	1	11.11	2	11.76
Future treatments will allow for a normal life/quality of life	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

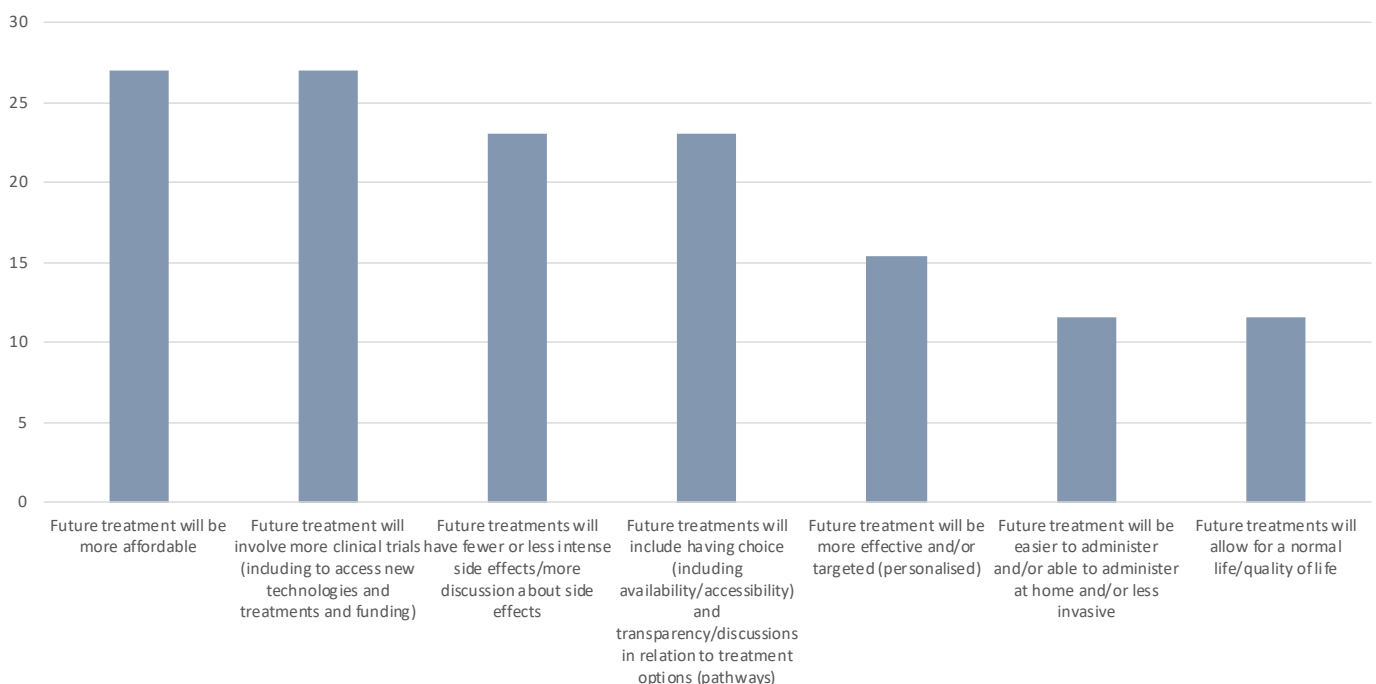


Figure 9.1: Expectations of future treatment

Table 9.2: Expectations of future treatment – subgroup variations

Theme	Less frequently	More frequently
Future treatment will be more affordable	Trade or high school	University
Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)	Male Trade or high school	Female University
Future treatments will have fewer or less intense side effects/more discussion about side effects	Non-metastatic Aged 65 or older	
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	Male Aged 65 or older	Female
Future treatment will be more effective and/or targeted (personalised)	Aged 65 or older	
Future treatment will be easier to administer and/or able to administer at home and/or less invasive	Non-metastatic Male	
Future treatments will allow for a normal life/quality of life	Non-metastatic	

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common responses were that future information will be more accessible and easy to find (19.23%), include the ability to talk to or access to a health professional (19.23%). Other expectations of future information included more details about disease trajectory and what to expect (11.54%), and more details about symptom and side effect control (11.54%). There were 5 participants (19.23 %) that were satisfied with the information they had received and had no particular comment.

Future information will be more accessible/easy to find

I think that it's the opposite. There's a lot of information out there and I think that's what threw me initially, that there was information overload for me just trying to deal with it all. There's plenty of information out there, it's whether you want to access it. I know there's people out there that don't access all the resources that we've actually got available here, such as exercise clinics. Even the Look Good Feel Good workshops. I feel like as cancer patients, we've got quite a bit of support out there, it's just finding it. I did get quite a bit of information while I was in the hospital the first time, and then I've accessed information at the excise clinic. They've got information there and there's even some at the treatment center I go to. Then I come across other groups via social media, like there's Cancer Australia, I think it's called. I came across that and I wasn't aware of that, but I have noticed that on a lot of these booklets, especially the ones that cancer puts out that quite often will put links to other resources. Participant 005_2023AULUC

I wasn't given that much information. It's like you're given a diagnosis and the treatment option and then off you go. No. I could have gotten in contact with the Cancer Council and probably they could have given me information and things. Would it be nice if there was a little package to give out or something full of how to access...I thought Cancer Council was all that sunscreens, to tell you the truth. [chuckles] It never crossed my mind that they deal with cancer. Isn't that hilarious? [laughs] I don't know. A specific lung cancer information pack, wouldn't that be nice?

Participant 006_2023AULUC

Future information will include the ability to talk to/access to a health professional

I think the doctor should spend a bit more time with you in the beginning and give you the paperwork, but explain what you've got to go through and how it's going to work. It was just a muddle at the beginning. I didn't know what I was doing.

Participant 001_2023AULUC

Yes. I just wish that someone could spend time explaining it. I feel like I'm in a different position now because I've done my own research. There's really a lot of really difficult nights reading, researching, questioning, and I just wish...Now, I've just made three years, [inaudible]. I guess maybe-- I just wish there was more support.

Participant 027_2023AULUC

PARTICIPANT: I think it could be presented in the way of information for any type of cancer to have a pack ready for the family. We were given two sheets on it and that was about it and some lung, sorry, Cancer Council information about what they can offer but it'd be nice to have the charities like Lung Foundation have some information in there where you can go and have a look at their website, but also have some reading material for when the carers are ready to read

it because at that stage they're not ready, they're grieving for their loved one or if they're not terminal, they're trying to get them through the next couple of months while they have some intensive treatment...Yes, more information and a professional pack that you can refer back to later on when you're ready to read it. More support from the nurses. In the initial stages, we had a lung-- I know that this is a privilege because there's not a lot around, but a lung cancer nurse that supported us, but they attended one appointment, and then you can't get them on the phone because they're so bogged down with that many patients. That's never been a real service that we could utilize because there have been so many other people that they're supporting.

Participant 030_2023AULUC

Future information will provide more details about disease trajectory and what to expect

I don't know whether it's not available because people don't like to hear it. I would like to know what is going to happen. I know that's a hard question because things probably are different, but there's got to be an average of what happened, what can happen, or what happens next.

Participant 013_2023AULUC

They need a group. They need a support group. They need somewhere we can go to ask questions on a regular basis that we can discuss between patients what our own journeys have been like. I just think that that would be so beneficial, and to have a group where we can talk about end-of-life decisions and what we need to do to get ourselves in order for that. There's nothing out there, nothing

Participant 014_2023AULUC

Future information will provide more details about symptom and side effect control

I think I would've liked more information on the limitations post-surgery of what you should and shouldn't be doing at home, at work, et cetera, and what sort of timeframe you could be looking at to start recommencing activities. The hospital didn't supply anything, and the surgeon just said, don't lift anything over 5 kilos.

Participant 010_2023AULUC

I'd like to see a little bit more discussion on side effects for a start and not just routine generic stuff. For example, I will give you dexamethasone for your nausea. What if that doesn't work? What happens or time frames of how long it's going to work? Because of my PROFESSION background, more information on what it's doing, when [unintelligible] and all that business, when it peaks and when you have the trough with your white cell counts and all that information, I would have found interesting. I sourced it to a degree, [unintelligible] that information. I know I would have liked to go on to see the beginning a physio or exercise physiologist. I'm probably changing questions here. I would have loved to have had access maybe to a lung cancer nurse. Someone who knows. I have these big [unintelligible] coming in all the time saying things to me like, "[unintelligible] do we take your blood pressure on?" Each time I'd have to say, "I haven't got breast cancer. I've got lung cancer." Just read my notes for God's sake. Oh, just staff a little bit more and tune to what's going on, but I think a lung cancer nurse-- I'm in CITY. I think we've got one or two here and there in the public sector. Being a private patient, I don't have access to any of that. I'd love to see more access to that. They'd be a great point of communication. Participant 025_2023AULUC

Table 9.3: Expectations of future information

Expectations of future information	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	%
Future information will be more accessible/easy to find	5	19.23	4	16.00	1	100.00	1	10.00	4	25.00	3	18.75	2	20.00
Future information will include the ability to talk to/access to a health professional	5	19.23	4	16.00	1	100.00	2	20.00	3	18.75	4	25.00	1	10.00
No particular comment - satisfied with experience	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	2	12.50	3	30.00
Future information will provide more details about disease trajectory and what to expect	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00
Future information will provide more details about symptom and side effect control	3	11.54	3	12.00	0	0.00	3	30.00	0	0.00	2	12.50	1	10.00

Expectations of future information	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	%
Future information will be more accessible/easy to find	5	19.23	4	23.53	1	11.11	3	23.08	2	15.38	1	50.00	4	16.67	2	22.22	3	17.65
Future information will include the ability to talk to/access to a health professional	5	19.23	3	17.65	2	22.22	2	15.38	3	23.08	1	50.00	4	16.67	2	22.22	3	17.65
No particular comment - satisfied with experience	5	19.23	2	11.76	3	33.33	3	23.08	2	15.38	0	0.00	5	20.83	1	11.11	4	23.53
Future information will provide more details about disease trajectory and what to expect	3	11.54	2	11.76	1	11.11	1	7.69	2	15.38	0	0.00	3	12.50	2	22.22	1	5.88
Future information will provide more details about symptom and side effect control	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

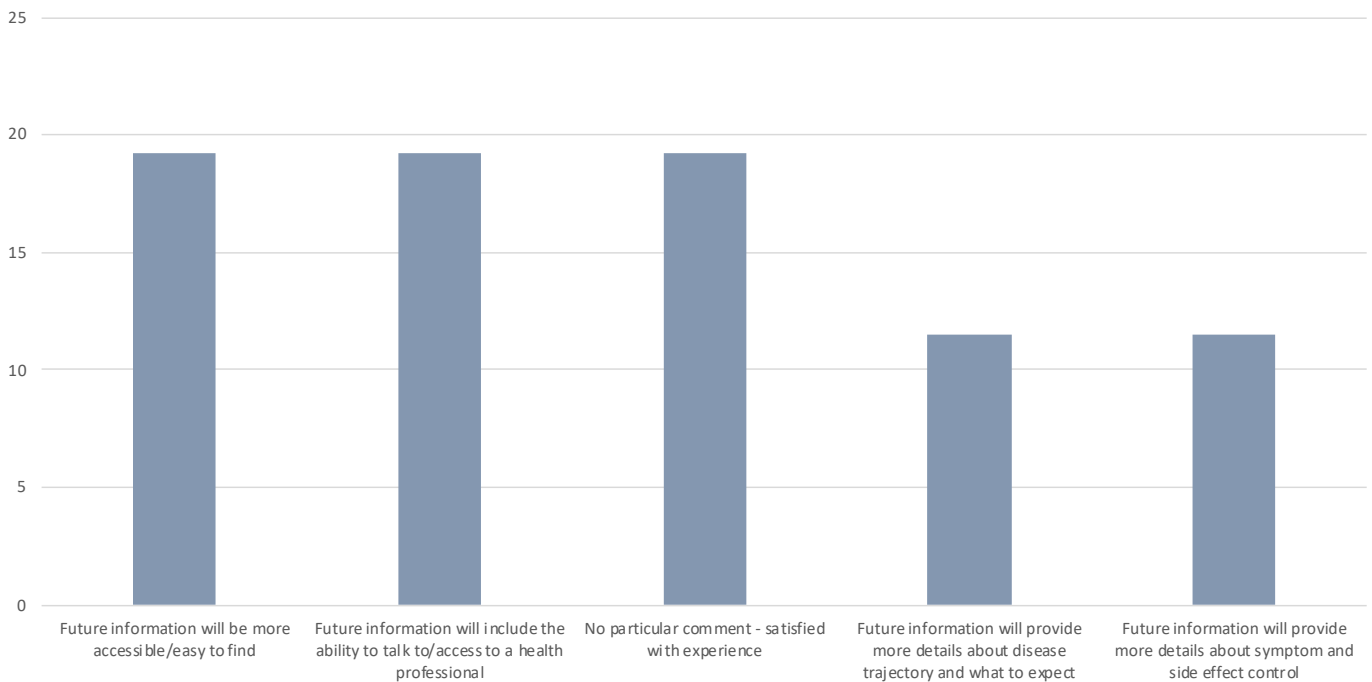


Figure 9.2: Expectations of future information

Table 9.4: Expectations of future information – subgroup variations

Theme	Less frequently	More frequently
No particular comment - satisfied with experience	-	Male Aged 65 or older Mid to low status
Future information will provide more details about disease trajectory and what to expect	Male	
Future information will provide more details about symptom and side effect control	Metastatic Mid to low status	Non-metastatic

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common expectations for future healthcare professional communication were that communication will be more empathetic (26.92%), and will include a multidisciplinary and coordinated approach (19.23%). Other expectations included that future communication will be more transparent and forthcoming (11.54%), and communication will include

health professionals with a better knowledge of the condition (11.54%). There were 4 participants (15.38%) that were satisfied with the healthcare professional communication and had no particular comment.

Future communication will be more empathetic

I think there's still a lot of change it needs to happen with health professionals and stigma. I think a lot of the health professionals carry the lung cancer stigma and it should start with them of removing the stigma. We shouldn't be treated any differently to a breast cancer patient because we've got lung cancer. Breast cancer patient get, "Oh, you've got breast cancer, you poor thing." Lung cancer, patient get, "Oh, well you must have smoked heavily before that." Health professionals I think need to be more compassionate for lung cancer patients, but also either be good to see more health professionals take up lung cancer as a professional. There's not very many lung cancer specialists, oncologists around, that would specialize in lung [unintelligible]. That would be really good if that would increase.

Participant 007_2023AULUC

Oh, my God. That just-- [laughs] I'd like to be treated with compassion and made to feel as if they, at least, care. The receptionist from the first surgeon, she was so rude to me, I actually said to her, "At no point have you made me feel of worth. At no point have you made me feel as if you care and that my life is worth anything." I had to pick myself up and move it to the other doctor. I said, "Because if you're that numb, you shouldn't be dealing with people in my condition." I would like to see that change. I understand they've got a job to do. I understand that they're protecting the doctor, I understand all of that. However, there are ways you can deliver news, and there are ways you can talk to people, and they need to learn that they-- Here's the thing, when you've got lung cancer, you're treated completely different to when if it's breast cancer. I know that because I've got friends who've had breast cancer, that "Oh, they were so lovely to me, and they're so supportive, and they're so this, and they're so that," and I'm going, "Really? Man, I feel like I'm just beating my way through obstacle after obstacle, to be heard. I actually said to someone, I feel that I've become someone who I'm really not because I have to jump up and down and I have to be...and have a meltdown almost so [unintelligible] to be heard and to be taken serious or dealt with compassionately. That's the biggest thing that needs to change. That shouldn't happen. But I always feel like I have to be something, someone I'm not and someone I don't like, because it's the only way that I get listened to.

Participant 018_2023AULUC

Future communication will include a multidisciplinary and coordinated approach

Absolutely. Yes. For sure. I had a pulmonary function test and an echocardiogram of my heart back on the 4th of March, and I asked my GP today whether he had those results and he said no. So the hospital cannot even send those results to my GP, and he's requested them twice. Why? What's the break there? What's gone wrong?

Participant 003_2023AULUC

I think it's important that they communicate with each other so that there's one unified plan and that each professional understands what the other professional is doing so that it's a combined effort. I've got a friend, she doesn't have cancer, but eight years ago, she got diagnosed with preleukemia, so she had a bone marrow transplant and she's encountered some issues in the public system with communication between the different professionals. I experienced a bit of that when I was in hospital the first time because I got a bit frustrated towards the end because I was trying to get my results to the suit of appropriate department to then start working on my treatment plan. There seem to be a gap in the communication between the departments and everything seem to have to be faxed. I was lucky because my daughter was working there. She would physically take the paperwork from her area to the other area. I got very frustrated just before I left because I just found there was a bit of a gap in how the departments were communicating with each other. Having said that, with my latest diagnosis, my ophthalmologist actually referred me to the MRI, to have the MRI, so I had the MRI, and then I discovered this mess. My oncologist had the results. They diagnosed the brain tumor, and within a couple of days, my oncologist is ringing me, and then the neurosurgeon, and the ophthalmologist. I could see there was real communication between them and they'd already worked out a plan for surgery and treatment, et cetera. Now everyone knows that they made a difference because they were also in the private system. I don't know if there's a difference between doctors in the public system and doctors in the private system. I don't know if that really is a factor. I did feel like the doctors had already worked everything out before they even told me, which is encouraging. Participant 005_2023AULUC

I would like to see the health system change in that, there's one central point hospital of care for a person as opposed to going everywhere. My experience at the main hospital I am engaged with is really positive,

but it's not the same in others. I think if people are required to reschedule a surgery or anything else, they should be communicating with you verbally, not just sending a letter out to say that you are no longer getting seen. Participant 026_2023AULUC

Future communication will be more transparent and forthcoming

In general, I'd say no, but in my experience in the hospital with the surgical team was that there was nowhere near enough communication. That was extremely stressful. Yes, that really didn't help. It was very stressful for me and very stressful for my wife. Participant 021_2023AULUC

Well, I think they've got to be totally honest and I think they should say to you, when they're booking you in for chemo that we'll give you something for the nausea we'll give you all the stuff for the side effects you might get and just explain to you why. When I got there, like the first time that they take [inaudible] what do I need that for? Even though I'm PROFESSION, I couldn't think why I needed it, what's that going to do. Supposedly that stops inflammation and help stop the nausea. They give you a [inaudible] you don't know what for. Participant 001_2023AULUC

Future communication will include health professionals with a better knowledge of the condition

That's a good question. Look I don't care. You can't expect everything from an oncologist, everyone's different and it's just personality, different personalities, and everything. You just want them to know what they're doing. I don't care about the delivery. I always go to my oncologist, I always have someone with me and he just sits there and he just talks to me and that's how it should be. Every now and then my dad might ask something but it is between him and me and that's how it should be. He's the only one who knows anything about it, not all these people who have gone to Google stuff. What other things could have happened, they can do that but the

oncologists I think, are busy. Well, most doctors are apart from a psychologist, but you book an hour. Who knows? I can deal with-- I just want a good doctor, I don't care about their delivery and whether it's got Asperger's or, he's got my interest with him. I even think to a point that he may have put me on the trial, just to access me to good treatment. Everyone talks about manners and politeness and everything. Yes, it's good but if it's not there, and the doctors looking after you and, helping you. I don't know, INTERVIEWER. The nurses it will be good to have more nurses but the doctor, it doesn't really worry me that I'm getting kind of good results. I don't have a problem with the way I've been dealt with with my oncologist. As I said, I had an amazing trial nurse. The nurse support has gone down now that I'm not on the trial because whenever I'm on trial, they've got all the blood tests and everything has to be documented but there definitely needs to be more lung care nurses. Participant 019_2023AULUC

I don't have a huge expectation of the oncologist or the radiation specialists to support me emotionally because I think that's beyond their remit. What I do think they need to be able to do or no, not they, in particular, but what should be available, is there are breast care nurses when you have breast cancer, it's very easy to get in contact with that middle person who has medical knowledge, understands all the treatment pathways, can talk to you in general about things that you are concerned about, but which you don't want to go back to your oncologist and ask this. What might be a silly question? It's so hard to say, lung specialists. I think in the lung cancer space, we need lung cancer nurses. We need where there's very few of them and I think we need them more commonly available and we need them to know about them. Because I would've found that a fantastic resource in that person would've been in a way, a directory and said, "This is the pathway, this is the things you can access." You could ask the trivial question of where you are not going to make an appointment for an oncologist because it's not really that important, but you would like to get some help on something Participant 020_2023AULUC

Table 9.5: Expectations of future healthcare professional communication

Expectations of future communication	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	%
Future communication will be more empathetic	7	26.92	6	24.00	1	100.00	1	10.00	6	37.50	4	25.00	3	30.00
Future communication will include a multidisciplinary and coordinated approach	5	19.23	5	20.00	0	0.00	3	30.00	2	12.50	5	31.25	0	0.00
No particular comment - satisfied with experience	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	3	18.75	1	10.00
Future communication will be more transparent and forthcoming	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	2	12.50	1	10.00
Future communication will include health professionals with a better knowledge of the condition	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00

Expectations of future communication	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	%
Future communication will be more empathetic	7	26.92	5	29.41	2	22.22	3	23.08	4	30.77	0	0.00	7	29.17	1	11.11	6	35.29
Future communication will include a multidisciplinary and coordinated approach	5	19.23	5	29.41	0	0.00	2	15.38	3	23.08	1	50.00	4	16.67	4	44.44	1	5.88
No particular comment - satisfied with experience	4	15.38	1	5.88	3	33.33	3	23.08	1	7.69	0	0.00	4	16.67	2	22.22	2	11.76
Future communication will be more transparent and forthcoming	3	11.54	1	5.88	2	22.22	2	15.38	1	7.69	0	0.00	3	12.50	0	0.00	3	17.65
Future communication will include health professionals with a better knowledge of the condition	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

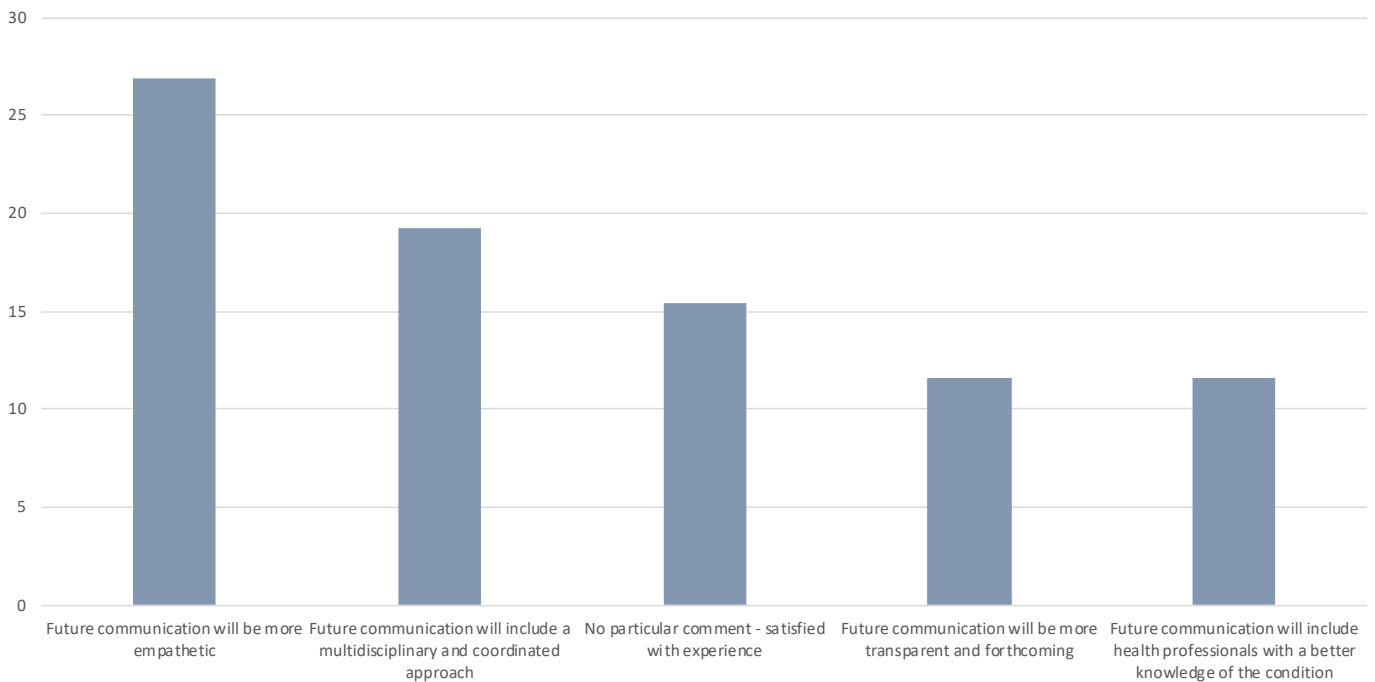


Figure 9.3: Expectations of future healthcare professional communication

Table 9.6: Expectations of future healthcare professional communication – subgroup variations

Theme	Less frequently	More frequently
Future communication will be more empathetic	Non-metastatic Mid to low status	Metastatic
Future communication will include a multidisciplinary and coordinated approach	Male Aged 65 or older Higher status	Non-metastatic Female Aged 35 to 64 Mid to low status
No particular comment - satisfied with experience	-	Aged 65 or older
Future communication will be more transparent and forthcoming	Mid to low status	Aged 65 or older
Future communication will include health professionals with a better knowledge of the condition	Male Aged 65 or older Mid to low status	-

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common expectation for future care and support was that it will include specialist clinics or services where they can talk to professionals either in person, phone,

or online (38.46%). Other expectations if future care and support included practical support for example home care, transport, or financials support (15.38%), a multidisciplinary and coordinated approach to care and support (15.38%), long-term condition management and care planning (15.38%), and it will be more holistic that includes emotional health (11.54%). There were 5

participants (19.23%.) that were satisfied with their care and support and had no particular comment.

Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)

I reckon a dedicated hospital for cancer where you can go to ER with any cancer. Because I'm sure the ERs are all filled with people having some kind of fever or reaction. If one in two people are getting cancer, then I would love to see a hospital devoted to cancer where you can just go to the emergency and get seen to. They know all about targeted therapy and they can just help you out. Because a lot of the time, I've been to ER a few times and no one knows anything. You say, "Targeted therapy," they say, "Oh, immunotherapy," and you're like, "No, this is a completely different thing." I think there needs to be a gap filled there.
Participant 004_2023AULUC

I think a lung cancer nurse and somebody that you can talk to about the medication. Some [unintelligible] pharmacist or whatever that knows about the drug because I get it from somewhere and they don't know about the drug. Even the oncologist just chuck's you the generic piece of paper that lists all the side effects. When you look at that on its own, it's horrific. Why anyone would take [unintelligible] but you do [laughs].
Participant 025_2023AULUC

Future care and support to include practical support (home care, transport, financial)

Anything to make our life easier, even the Cancer Council. They give you \$100 to have a cleaner, but only once which is fine. They were average, but some people they need that and why is it just one 100? It should be ongoing 100. I don't know maybe old people get more I think they might get more access to services. Yes, just help wherever we can get it. If someone has cancer, the other partner has to go to work and you need someone to get the kids off to school. I had friends coming in getting the kids off to school and yes, there are people who don't know people like that. Yes, there's a lot of room there where they can assist people. Really, anyone with lung cancer should be treated like an elderly person I think and they should access the same services. Participant 019_2023AULUC

Well. I think that perhaps even if they did a phone service to ring up and check on people, make sure they're right. I think down the track, I will need someone to help me at home because my husband's too old to do anything. I'm still doing all the shopping, cooking, everything, but anyway. [crosstalk]
Participant 001_2023AULUC

Future care and support will include a multidisciplinary and coordinated approach

No, I don't think so. I know I had a sister go in procedures [inaudible] and do you have follow-up phone calls with the hospital? It may be because of her particular operation that was warranted, but I didn't get any sort of follow-up, and I just don't know. Sometimes it would've been nice to say, "Oh, gee, I've still got this pain in my side, and is that normal?" There was no follow-up from the hospital.
Participant 010_2023AULUC

PARTICIPANT: It's definitely the idea of lung nurse someone, a nurse with that specialist knowledge who can be there. Yes. They become your point of contact. They can be that middle person between you and a specialist. They have a little bit more capacity because that's what they're there for, to steer you emotionally to where you might find resources, help, et cetera. I think that is solely lacking. The other thing I think is really lacking is public awareness. Again, having breast cancer, I saw what public awareness does. You can tell anyone, "Oh, I've got breast cancer," and they go, "Oh gosh, how are you going?" You tell them you've got lung cancer and they go, "Oh, how long did you smoke?" You go, "Oh, not a question to ask anyone." You do not bring about your own cancer deliberately. I think that's a public awareness thing. I don't know if that falls into arraignment, but that's what I think is poor in Australia. We don't understand it. Not a blame game. This can happen to anyone.
Participant 020_2023AULUC

Future care and support will include more long-term condition management (care planning)

The thing that we found is that when dad does decline and decline means that he would like to stay home. There is not enough support from My Aged Care to support him to stay dignified. His family is going to have to do it and that's something that he didn't want to do. There's not a lot of options for palliative care here in Queensland. Palliative care unit, it's like nearly an hour's drive or more in traffic. That's not something that he would like to utilize and then there's a

*Hopewell House, but they've always got so many patients in there that you pretty much wouldn't get in there anyway. It's really not enough support when it comes to end-of-life I feel for patients.
Participant 030_2023AULUC*

*Yes, I think there needs to be survivorship care for people in the absence of a cure. Survivorship care in the absence of a cure for patients particularly with terminal lung cancer.
Participant 015_2023AULUC*

Future care and support will be more holistic (including emotional health)

*More mental health services. Access to mental health services. It's crucial.
Participant 007_2023AULUC*

*The only thing that I can think of really there is, everything was geared very much to my physical health, but not mental health. Like I said previously, I'm quite robust mentally. I think I was four weeks into my hospital stay before anybody asked me how I was. That was an orderly-- What do you call them? that person that does the cleaning and what have you. He asked me how I was when I collapsed in a heap, basically [laughs]. It was completely absent, the mental side of it. I thought that was a shame, really, because if somebody wasn't as robust as me, they would've probably collapsed in the heap a lot quicker than I did. It was a very, very challenging time.
Participant 021_2023AULUC*

Table 9.7: Expectations of future care and support

Expectations of future care and support	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	%
Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	10	38.46	10	40.00	0	0.00	5	50.00	5	31.25	10	62.50	0	0.00
No particular comment - satisfied with experience	5	19.23	5	20.00	0	0.00	3	30.00	2	12.50	2	12.50	3	30.00
Future care and support to include practical support (home care, transport, financial)	4	15.38	3	12.00	1	100.00	0	0.00	4	25.00	3	18.75	1	10.00
Future care and support will include a multidisciplinary and coordinated approach	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	4	25.00	0	0.00
Future care and support will include more long-term condition management (care planning)	4	15.38	3	12.00	1	100.00	0	0.00	4	25.00	3	18.75	1	10.00
Future care and support will be more holistic (including emotional health)	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	2	12.50	1	10.00

Expectations of future care and support	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	%
Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	10	38.46	8	47.06	2	22.22	4	30.77	6	46.15	1	50.00	9	37.50	6	66.67	4	23.53
No particular comment - satisfied with experience	5	19.23	0	0.00	5	55.56	4	30.77	1	7.69	0	0.00	5	20.83	2	22.22	3	17.65
Future care and support to include practical support (home care, transport, financial)	4	15.38	2	11.76	2	22.22	1	7.69	3	23.08	0	0.00	4	16.67	0	0.00	4	23.53
Future care and support will include a multidisciplinary and coordinated approach	4	15.38	2	11.76	2	22.22	3	23.08	1	7.69	0	0.00	4	16.67	0	0.00	4	23.53
Future care and support will include more long-term condition management (care planning)	4	15.38	2	11.76	2	22.22	2	15.38	2	15.38	1	50.00	3	12.50	1	11.11	3	17.65
Future care and support will be more holistic (including emotional health)	3	11.54	3	17.65	0	0.00	2	15.38	1	7.69	0	0.00	3	12.50	0	0.00	3	17.65

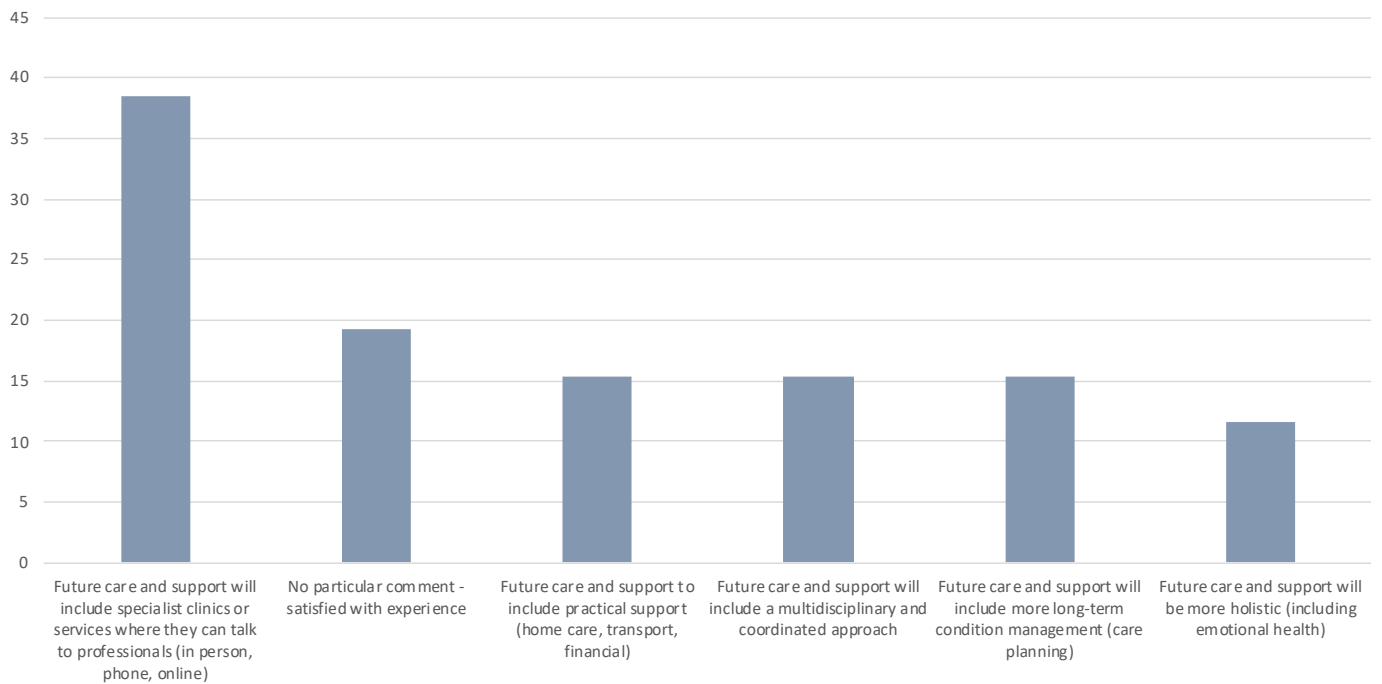


Figure 9.4: Expectations of future care and support

Table 9.8: Expectations of future care and support – subgroup variations

Theme	Less frequently	More frequently
Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	Male Aged 65 or older Higher status	Non-metastatic Female Mid to low status
No particular comment - satisfied with experience	Aged 35 to 64 University	Non-metastatic Male Aged 65 or older Trade or high school
Future care and support to include practical support (home care, transport, financial)	Non-metastatic Mid to low status	-
Future care and support will include a multidisciplinary and coordinated approach	Male Mid to low status	-
Future care and support will include more long-term condition management (care planning)	Non-metastatic	-
Future care and support will be more holistic (including emotional health)	Aged 65 or older Mid to low status	-

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common responses were that participants were grateful for low cost or free medical treatments through the government (46.15%), healthcare staff, including access to specialists (42.31%), for the entire health system (34.62 %), and Timely access to treatment (15.38%). There were 4 participants that expressed the need for lower treatment costs and extend Medicare coverage (15.38%).

Low cost/free medical treatments through the government

Oh look, the fact that these drugs are PBS is a life changer. I'm very grateful they are because 8,000 a month is not something you can stump up easily. If I had to pay for my own care, if I had to pay the whole lot of scans, et cetera, I would have to be keeping on

working, and that would be physically and mentally really difficult to do, so I am really grateful medication too, the ongoing that is covered.

Participant 020_2023AULUC

I don't know whether it's totally worldwide, but we are very lucky in Australia. We're so far ahead of many countries including Britain I believe, and America, that we have such a system whereby your doctor can send a letter to a specialist, which he did. That started my journey for treatment and it cost me nothing. I end up with these magic people that are highly trained. You can tell that they'd love their job, the work they're doing, and the dedication that they put in so much is. The same with Silverchain. Unbelievable, these people. The nurses, the dedication that they have, the girls and boys that bringing your meals, I'm not saying all of them, but a lot of them are there to help

Participant 012_2023AULUC

My God, absolutely everything, and I mean everything. I have told so many people this, how lucky we are to live here because for what I've been given, would cost hundreds of thousands of dollars overseas and they wouldn't have been able to afford that, so, they probably died. Absolutely everything, very, very grateful.

Participant 017_2023AULUC

Healthcare staff (including access to specialists)

Oh, massively [chuckles]. Right away from when I first went into the hospital with those arm pains and the identification of it through having a chest X-ray then a CT scan and the diligence of the people that assessed those scans to actually see that there was this small nodule that I had in my lung. I'm extremely grateful for that, of course. Despite all of the problems that I had in the hospital, the complications and everything, the surgical team and the overall care and the outcome have been excellent. The access to CT scans and all that sort of thing, I'm very grateful for that, because, of course, that gives me a sense of confidence that it's all been dealt with. With a few exceptions, overall, the Australian Health System has been enormously beneficial, and I'm extremely grateful.

Participant 021_2023AULUC

Oh, everything. I don't quite know where to start with that one. Great GP. Great oncology team. Excellent thoracic surgeon. Even my pharmacist would say there are two patients that get my treatment from him, that he knows us both individually and I go there and he recognizes me and knows. He knows why I'm there and all of that contributes to superb experience if you can say that. To be sick is a bad thing, but to be sick and well cared for.

Participant 022_2023AULUC

I think we're really lucky. I know there's people that spend \$10,000 a month for the medication that I'm on in other countries. I think PBS and even while I've said about the disjointedness of, I think the treat care teams are excellent, [unintelligible] and you've got options.

Participant 026_2023AULUC

Entire health system

I don't know whether it's totally worldwide, but we are very lucky in Australia. We're so far ahead of many countries including Britain I believe, and America, that we have such a system whereby your doctor can send

a letter to a specialist, which he did. That started my journey for treatment and it cost me nothing. I end up with these magic people that are highly trained. You can tell that they'd love their job, the work they're doing, and the dedication that they put in so much is. The same with NAME. Unbelievable, these people. The nurses, the dedication that they have, the girls and boys that bringing your meals, I'm not saying all of them, but a lot of them are there to help

Participant 012_2023AULUC

My God, absolutely everything, and I mean everything. I have told so many people this, how lucky we are to live here because for what I've been given, would cost hundreds of thousands of dollars overseas and they wouldn't have been able to afford that, so, they probably died. Absolutely everything, very, very grateful.

Participant 017_2023AULUC

I think we are extremely lucky because I think our quality of care is quite good. Like I said, the quality of care, I thought, was quite good. I think our hospitals are quite good. I'm extremely lucky because I feel like I had options, in the sense that I went private, and I had a good array of doctors and what have you. No, I think we are lucky, but I just think that there's, from an administration point of view and from a care and compassion point of view, and to simplify the system, which is so complicated when it doesn't need to be, is what we need to work on.

Participant 018_2023AULUC

Need for lower treatment costs and extend Medicare coverage

Other than it's gotten very expensive. That's the only. Considering what's my insurance company paid and the government subsidizes, the huge amount of money that I still had out of pocket extra to paying the surgeon and things like this. Every time you go to a doctor, you out of pocket, \$90 whatever, \$100 whatever. I can afford it. It's not an issue but considering how much, years ago you were never out of pocket.

Participant 028_2023AULUC

Yes. I put it on the PBS, the drugs on the-- Oh at the moment-- Yes, the health system's great. It's just you've got to get the right doctors to get you in there. Well privately, as you know, every time I have a scan it costs me AUD200 out of my own pocket, and if I was public, I wouldn't be paying that. Every time I go and see the doctors, 200, I don't know. I lose track. Have a

lung function test that's AUD300, that all starts to add up. But yes, I could always go public and do that. I do think Medicare provides a lot. I just wish they put these drugs on the PBS.

Participant 025_2023AULUC

Timely access to treatment

We have got a good health system and I appreciate the timely manner that everything was done and that I didn't have to wait. Everything was done really efficiently. I don't know what it's like in other

countries, but it makes such a difference for a patient. That was my experience.

Participant 010_2023AULUC

I think dad's just as blessed to be able to utilize immunotherapy. We know not so long ago it wasn't free. People had to pay a lot of money for each round of treatment, which is not cheap and we see that as a blessing and we don't take it for granted. In terms of that treatment, not a lot of people can access treatment like that in any other country for free.

Participant 030_2023AULUC

Table 9.9: What participants are grateful for in the health system

What participants are grateful for in the health system	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	%
Low cost/free medical treatments through the government	12	46.15	11	44.00	1	100.00	4	40.00	8	50.00	10	62.50	2	20.00
Healthcare staff (including access to specialists)	11	42.31	11	44.00	0	0.00	6	60.00	5	31.25	7	43.75	4	40.00
Entire health system	9	34.62	9	36.00	0	0.00	6	60.00	3	18.75	6	37.50	3	30.00
Need for lower treatment costs and extend Medicare coverage	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	3	18.75	1	10.00
Timely access to treatment	4	15.38	3	12.00	1	100.00	1	10.00	3	18.75	3	18.75	1	10.00

What participants are grateful for in the health system	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	%
Low cost/free medical treatments through the government	12	46.15	9	52.94	3	33.33	6	46.15	6	46.15	1	50.00	11	45.83	6	66.67	6	35.29
Healthcare staff (including access to specialists)	11	42.31	9	52.94	2	22.22	3	23.08	8	61.54	1	50.00	10	41.67	3	33.33	8	47.06
Entire health system	9	34.62	6	35.29	3	33.33	5	38.46	4	30.77	1	50.00	8	33.33	3	33.33	6	35.29
Need for lower treatment costs and extend Medicare coverage	4	15.38	3	17.65	1	11.11	1	7.69	3	23.08	0	0.00	4	16.67	1	11.11	3	17.65
Timely access to treatment	4	15.38	2	11.76	2	22.22	3	23.08	1	7.69	1	50.00	3	12.50	2	22.22	2	11.76

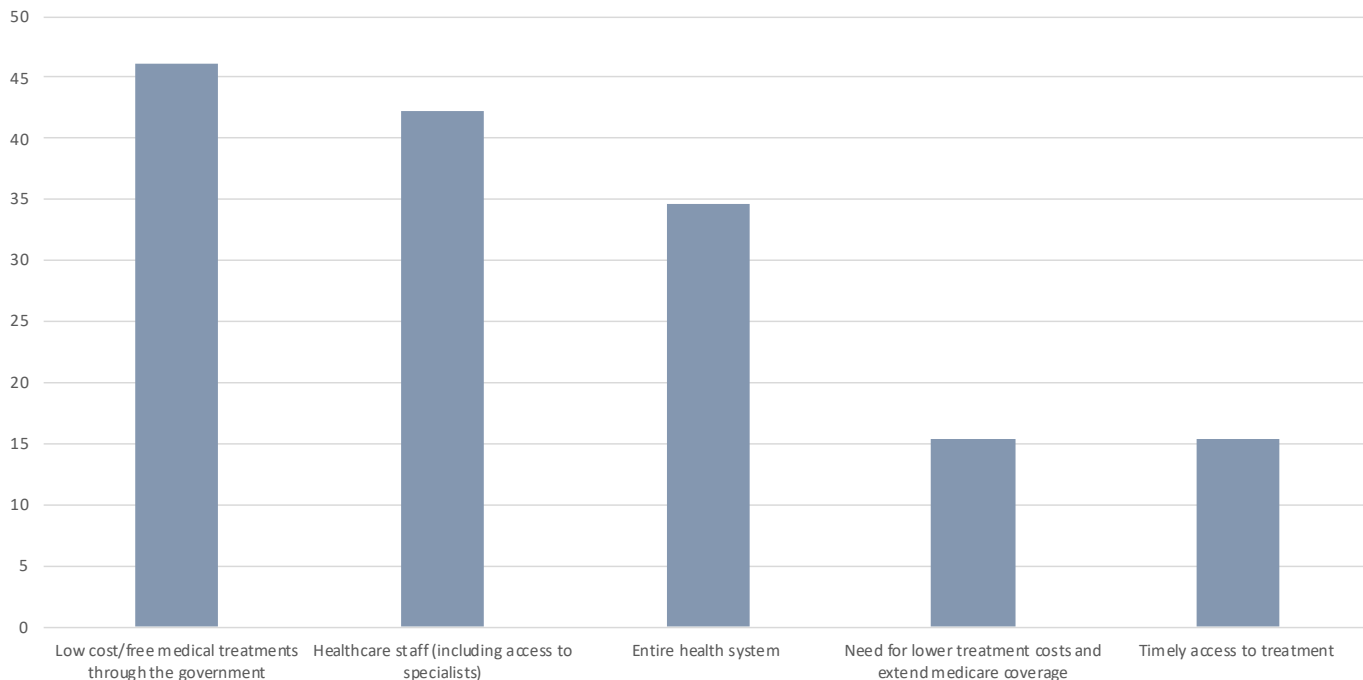


Figure 9.5: What participants are grateful for in the health system

Table 9.10: What participants are grateful for in the health system – subgroup variations

Theme	Less frequently	More frequently
Low cost/free medical treatments through the government	Male Aged 65 or older Higher status	Female Mid to low status
Healthcare staff (including access to specialists)	Metastatic Aged 65 or older Trade or high school	Non-metastatic Aged 35 to 64 University
Entire health system	Metastatic	Non-metastatic

Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, where 1 is the most important and 8 is the least important. A weighted average is presented in Table 9.6, Figure 9.6. With a weighted ranking, the higher the

score, the greater value it is to participants. The most important aspects reported were pain, nausea and vomiting and, tiredness and fatigue. The least important were mouth ulcers, loss of appetite and, hair loss.

Table 9.11: Symptoms and aspects of quality of life

Symptoms and aspects of quality of life	Weighted average (n=25)
Nausea and vomiting	6.2
Pain	6.72
Tiredness and Fatigue	5.52
Diarrhoea	4.32
Constipation	3.96
Mouth ulcers	3.52
Loss of appetite	3.32
Hair loss	2.44

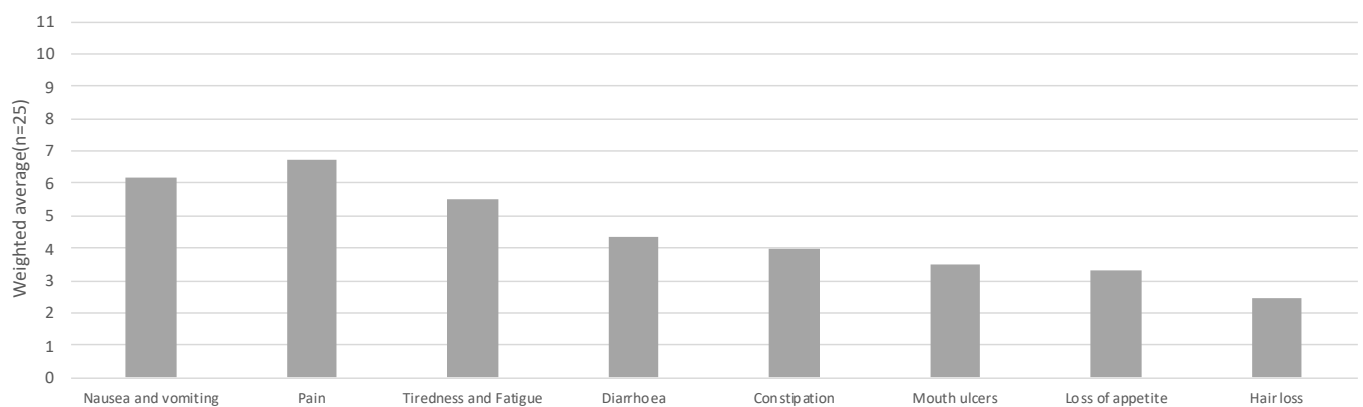


Figure 9.6: Symptoms and aspects of quality of life

Values in making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care, where 1 is the most important and 8 is the least important. A weighted average is presented in Figure 9.7. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important aspects were “Ability to follow and stick to a treatment regime”, and “How personalised the treatment is for me”. The least important were “The severity of the side effects” and “Time impact of the treatment on my quality of life”.

Table 9.12: Values in making decisions

Symptom	Weighted average (n=27)
How safe the medication is and weighing up the risks and benefits	6.33
The severity of the side effects	6.30
Time impact of the treatment on my quality of life	5.11
How the treatment is administered	3.85
How personalised the treatment is for me	4.26
The ability to include my family in making treatment decisions	2.63
Ability to follow and stick to a treatment regime	3.89
The financial costs to me and my family	3.63

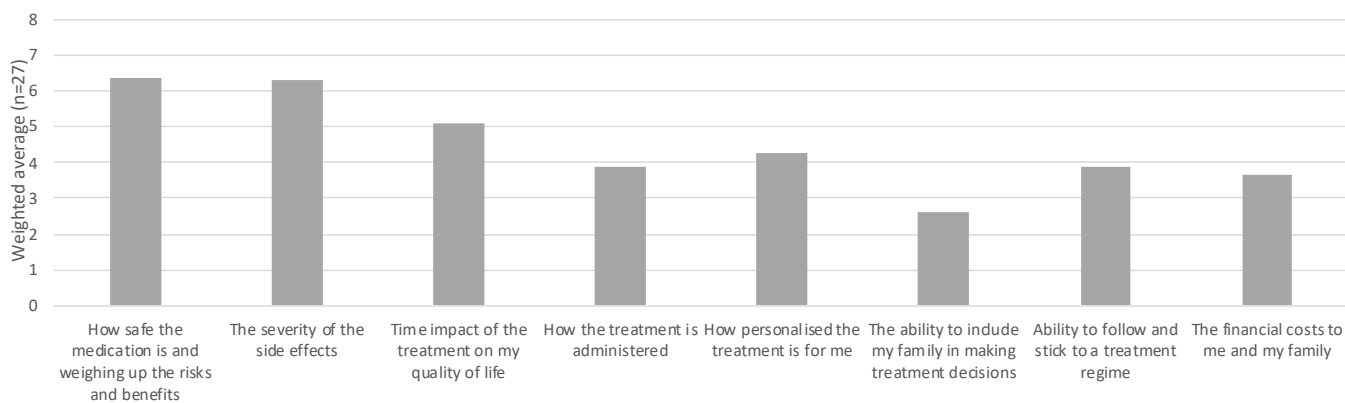


Figure 9.7: Values in making decisions

Values for decision makers

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care, where 1 is the most important and 5 is the least important. A weighted average is presented in Figure 9.8. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important values were “Quality of life for patients”, and “All patients being able to access all available treatments and services”. The least important was “Economic value to government and tax payers”.

Table 9.13: Values for decision makers

Values for decision makers	Weighted average (n=27)
Economic value to government and tax payers	1.52
Economic value to patients and their families	2.74
Quality of life for patients	4.19
Compassion	2.67
All patients being able to access all available treatments and services	3.89

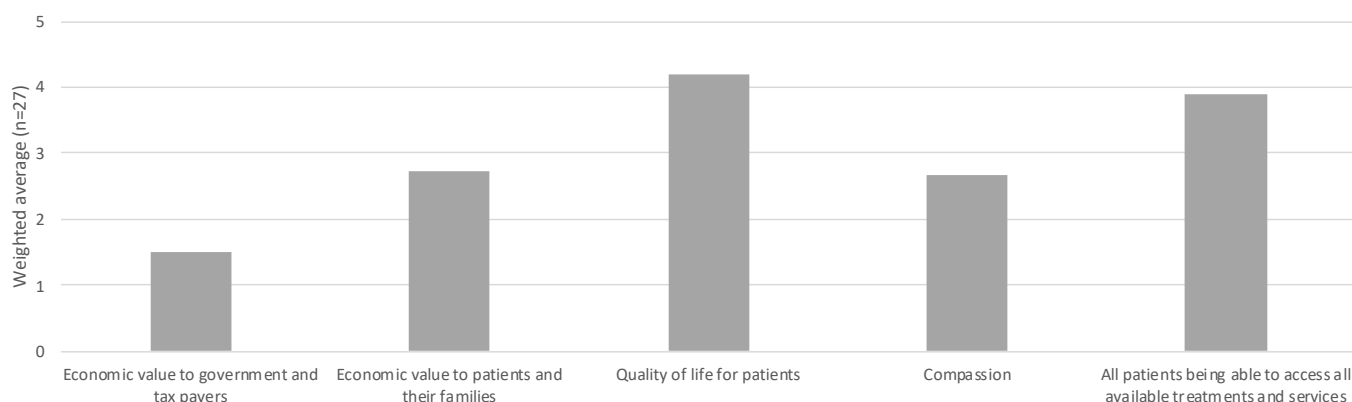


Figure 9.8: Values for decision makers

Value to access treatments that reduce symptoms and improve quality of life

Participants were asked in the online questionnaire, if there was any value to access treatments that reduce symptoms and improve quality of life, even if it did not offer a cure.

The majority of participants (n = 18, 72.00%) responded that this was of very significant value (Table 9.14, Figure 9.9).

Table 9.14: Value to access treatments that reduce symptoms and improve quality of life

Value to access treatments that reduce symptoms and improve quality of life, even if they don't offer a cure	Number (n=25)	Percent
Very significant value to me	18	72.00
Significant value to me	5	20.00
Moderate value to me	1	4.00
Some value to me	1	4.00

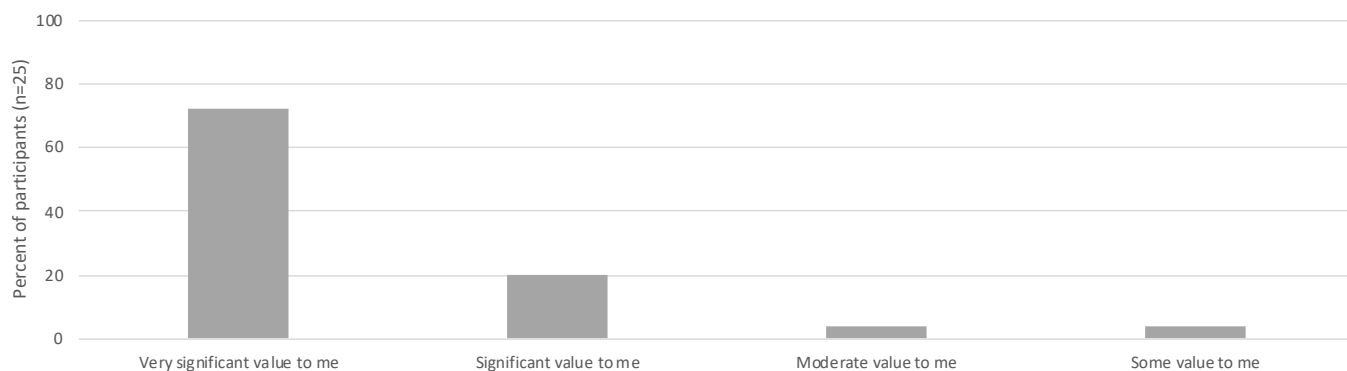


Figure 9.9: Value to access treatments that reduce symptoms and improve quality of life

Time taking medication to improve quality of life

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure.

The majority of participants (n = 14, 51.85%) would use a treatment for more than ten years for a good quality of life even if it didn't offer a cure (Table 9.14, Figure 9.9).

Table 9.14: Time taking treatment to improve quality of life

Time taking medication to improve quality of life	Number (n=27)	Percent
Less than 1 year	3	11.11
1 to 5 years	14	51.85
5 to 10 years	4	14.81
More than 10 years	6	22.22

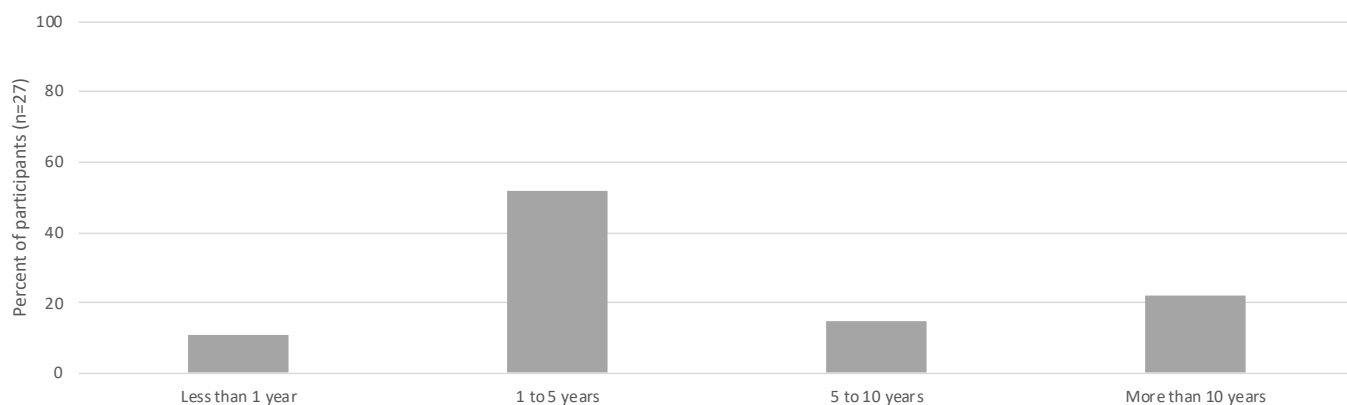


Figure 9.9: Time taking treatment to improve quality of life

Most effective form of medicine

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in. There were no participants (0.00%) that thought that medicine delivered by IV was most effective, 5 participants (18.52%) thought that pill form was most

effective, and 11 participants (40.74%) that thought they were equally effective. There were 11 participants (40.74%) that were not sure. (Table 9.15, Figure 9.10).

Table 9.15: Most effective form of medicine

Treatment most effective in what form	Number (n=27)	Percent
IV form (through a drip in hospital)	0	0.00
In a pill form that can be taken at home	5	18.52
Equally effective	11	40.74
Not sure	11	40.74

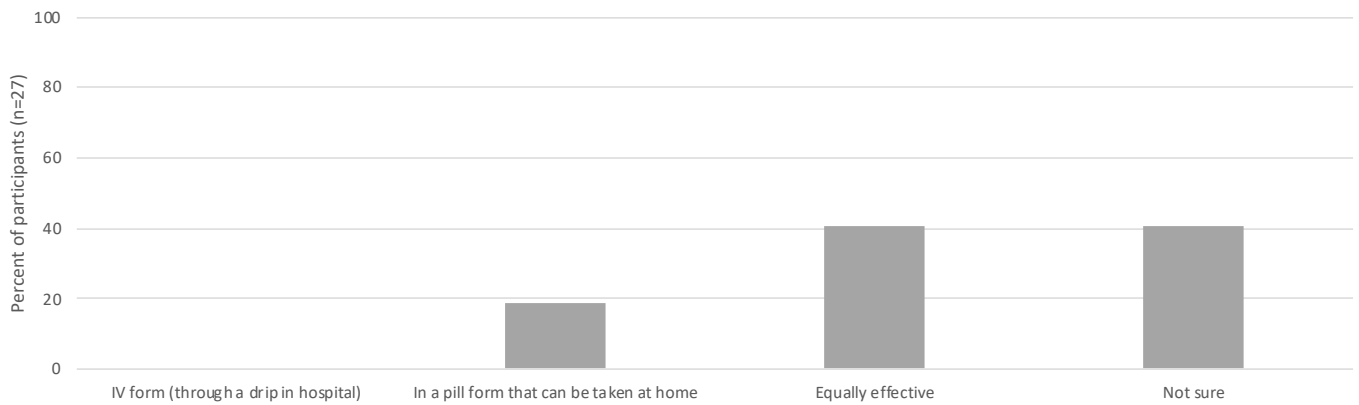


Figure 9.10: Most effective form of medicine

Messages to decision-makers

Participants were asked, “If you were standing in front of the health minister, what would your message be in relation to your condition?” The most common messages to the health minister were to help raise community awareness (23.08%), that more clinical trials or new treatments are needed (23.08%), and they want more timely and equitable access to support, care and treatment (23.08 %). Other messages included to invest in health professionals to service the patient population (19.23%), Increase investment in general (11.54%), Invest in research, including to find new treatments (11.54%), and that treatments need to be affordable (11.54%). There were 3 participants whose message was that they were grateful for the healthcare system and the treatment that they received (11.54%).

Help raise community awareness

PARTICIPANT: *Lung cancer, there needs to be education that anybody-- you know, the normal stuff. Anybody with lungs can get lung cancer. They need to change the focus from it not just being a smoking disease because there's so much guilt, no one deserves to get cancer. It needs to be a focus and a shift to know that it's a deadly-- it's the leading cause of death. People put it down to smoking. Whenever anyone hears I've got lung cancer, they always...I say to them, "Have you got lungs? You might get lung cancer too."*
Participant 027_2023AULUC

PARTICIPANT: *Also, why does lung cancer only attract, what is it 3% of the research dollar? Why is there not more research and also point out that it is not necessary just a smoker's illness, and a lot more younger people are getting afflicted by it now, aren't they?*
Participant 025_2023AULUC

More clinical trials and/or new treatments

I think I would ask him to expedite the approval of lung cancer medicines and get that advertising campaign on lung cancer that can affect anyone, not just smokers ASAP. Participant 004_2023AULUC

I've actually sent the health minister my feedback on the poor care from when I had surgeries [unintelligible] I think really it's just about making sure that hospitals remember that they're talking to people not just a number and it's difficult for families. Well, it's difficult for people to manage. Personalized care is important. That's my main thing. PBS is important. New treatments are important and personalized care. Participant 026_2023AULUC

Timely and equitable access to support, care and treatment

Well, anybody that's got lung cancer should never have to wait after they're diagnosed for treatment. They've got to get on to that straight away. I was lucky, but some people aren't lucky.
Participant 013_2023AULUC

PARTICIPANT: *I've already sat in front of the health minister. My message at that time was, you shouldn't have to be lucky or rich to have lung cancer.*
Participant 015_2023AULUC

Invest in health professionals to service the patient population

More support in hospitals, more beds, more education programs around lung cancer and I would request that-- More support, more beds, more cancer nurses, there's a huge need for it, better support around mental health for people that are going through cancer. I find that's a big loop gets left behind. That's really all that I'd probably say to the health minister. [chuckles]

Participant 030_2023AULUC

Oh, no, no. Hang on. Lung cancer nurses I haven't even mentioned them. We desperately need funding for lung cancer nurses. That goes back to the mental health and I can't believe I'd left out lung cancer nurses through this whole thing. The amount of lung cancer nurses compared to percentage-wise of people with lung cancer compared to the other cancers is just ridiculous. We have the equivalent of 12 full-time lung cancer nurses around Australia. There's [unintelligible] lung cancer patients that get diagnosed every year, you just can't find a lung cancer nurse anywhere. I've never ever met a lung cancer nurse in clinical practice. I've met them through the foundation, but I've never met them actually in a clinic.

Participant 007_2023AULUC

Grateful for the healthcare system and the treatment that they received

Thank you. That would be my answer.

Participant 022_2023AULUC

Well, I suppose he's got to be a downer, so I'd have to give him a 9 out of 10, I've got to take one off for the ramping. [laughter]

Participant 017_2023AULUC

Increase investment (general)

More funding. More funding, please.

Participant 014_2023AULUC

I would say the public hospital that I went to was absolutely horrendous. The whole experience was hideous and that he needs to put his hand in his pocket and put a little more money into lung health nurses, specific nurses. Why not? Because anyone can get lung cancer and it's just the right thing to do.

Participant 019_2023AULUC

Invest in research (including to find new treatments)

My message would be to him that we need access to more funds for research because at the moment it's not fair how inequitable the funding is distributed across cancer topics so if I had him in front of me, I would ask for the money to be shared more equitably over the different treatments over the different types of cancer. Lung cancer needs more money to research.

Participant 007_2023AULUC

PARTICIPANT: Also, why does lung cancer only attract, what is it 3% of the research dollar? Why is there not more research and also point out that it is not necessary just a smoker's illness, and a lot more younger people are getting afflicted by it now, aren't they?

Participant 025_2023AULUC

Treatments need to be affordable

For starters, I would be begging him to allow those that are at high risk to enable them to have a CT scan on a yearly system because that would save 12,500 lives. The problem is lung cancer is never diagnosed until it's too late in lots of cases, which is why only 15% of people make it past five years. That would be my first thing. The second thing I'd be saying is "You need to put radiation care under private health so we can claim that as well."

Participant 018_2023AULUC

I feel at the moment I've got treatment and care I need. My thing would be to talk about the disparities no, hang on, it's not really disparity. I'm trying to say there's a public and a private system. The private system is fine. The public system's very good, but being privately insured and yet it's still cost few thousands upon thousands makes it really very difficult at times. Again, I say I'm lucky I can afford it, but there are plenty of privately insured people who are stuck in a cycle of scraping together the dollars for their care just because they're privately insured, and that to me is very wrong. To me, I'd say to a health minister, I think we shouldn't have a private public system. It should be public and well-funded.

Participant 020_2023AULUC

Table 9.16 Messages to decision-makers

Message to decision-makers	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	%
Help raise community awareness	6	23.08	5	20.00	1	100.00	2	20.00	4	25.00	5	31.25	1	10.00
More clinical trials and/or new treatments	6	23.08	6	24.00	0	0.00	2	20.00	4	25.00	6	37.50	0	0.00
Timely and equitable access to support, care and treatment	6	23.08	6	24.00	0	0.00	1	10.00	5	31.25	6	37.50	0	0.00
Invest in health professionals to service the patient population	5	19.23	4	16.00	1	100.00	1	10.00	4	25.00	2	12.50	3	30.00
Grateful for the healthcare system and the treatment that they received	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	1	6.25	2	20.00
Increase investment (general)	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	2	12.50	1	10.00
Invest in research (including to find new treatments)	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00
Treatments need to be affordable	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	2	12.50	1	10.00

Message to decision-makers	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	%
Help raise community awareness	6	23.08	4	23.53	2	22.22	3	23.08	3	23.08	1	50.00	5	20.83	3	33.33	3	17.65
More clinical trials and/or new treatments	6	23.08	6	35.29	0	0.00	0	0.00	6	46.15	1	50.00	5	20.83	3	33.33	3	17.65
Timely and equitable access to support, care and treatment	6	23.08	4	23.53	2	22.22	3	23.08	3	23.08	2	100.00	4	16.67	3	33.33	3	17.65
Invest in health professionals to service the patient population	5	19.23	2	11.76	3	33.33	3	23.08	2	15.38	0	0.00	5	20.83	0	0.00	5	29.41
Grateful for the healthcare system and the treatment that they received	3	11.54	1	5.88	2	22.22	2	15.38	1	7.69	0	0.00	3	12.50	1	11.11	2	11.76
Increase investment (general)	3	11.54	2	11.76	1	11.11	1	7.69	2	15.38	0	0.00	3	12.50	1	11.11	2	11.76
Invest in research (including to find new treatments)	3	11.54	3	17.65	0	0.00	2	15.38	1	7.69	0	0.00	3	12.50	1	11.11	2	11.76
Treatments need to be affordable	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

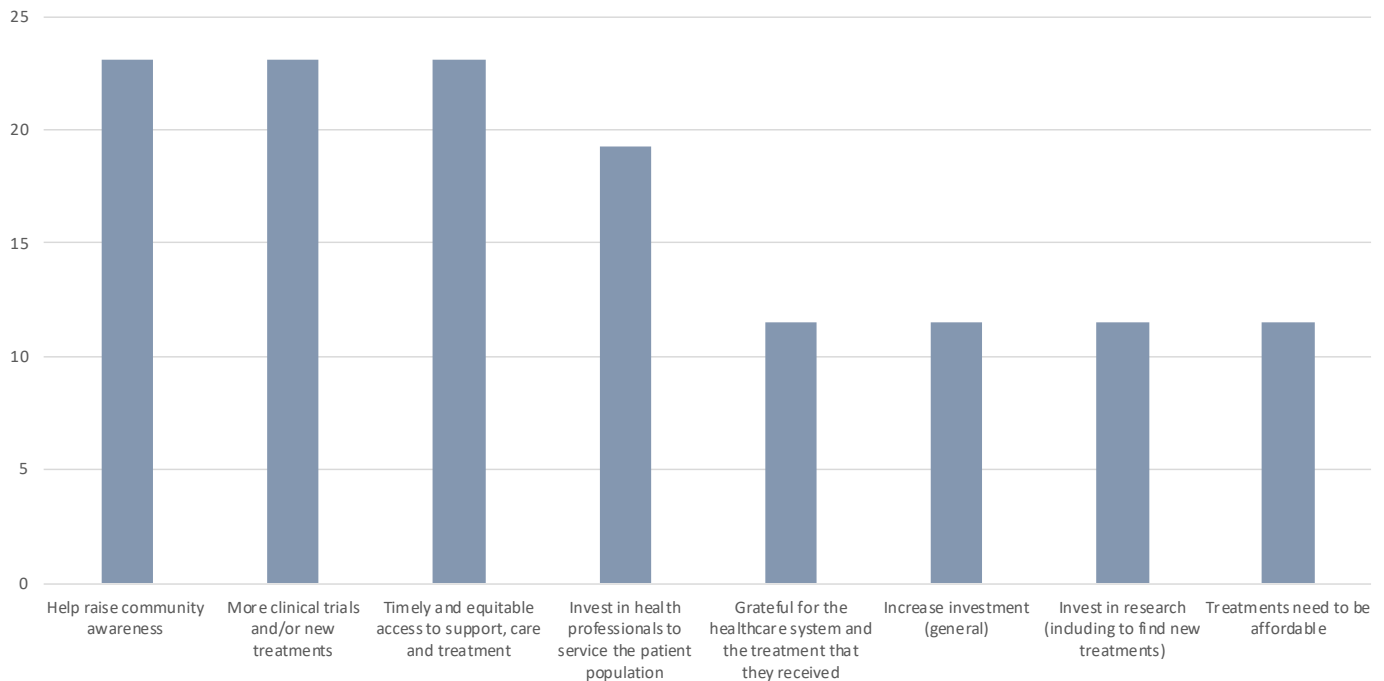


Figure 9.11: Messages to decision-makers

Table 9.17: Messages to decision-makers – subgroup variations

Theme	Less frequently	More frequently
Help raise community awareness	Male	Mid to low status
More clinical trials and/or new treatments	Male Aged 65 or older Trade or high school	Female Aged 35 to 64 University Mid to low status
Timely and equitable access to support, care and treatment	Non-metastatic Male	Female Mid to low status
Invest in health professionals to service the patient population	Mid to low status	Male Aged 65 or older Higher status
Grateful for the healthcare system and the treatment that they received	-	Aged 65 or older
Invest in research (including to find new treatments)	Male Aged 65 or older	-
Treatments need to be affordable	Mid to low status	-