

Section 10

Advice to others in the future: The benefit of hindsight

Section 10: Advice to others in the future

Anything participants wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common things that participants had wished they'd known earlier were to communicate and increase understanding of lung cancer (23.08%), that they had known the early signs and symptoms (19.23 %), and to be assertive, an advocate, informed, and ask questions (15.38%).

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common themes were that they would not change any aspect and were satisfied with their care or treatment (38.46%). Others would access appropriate specialist or treatment sooner (11.54%), and some participants described a single negative experience that they would like to have changed (11.54 %).

Anything participants wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common things that participants had wished they'd known earlier were to communicate and increase understanding of lung cancer (23.08%), that they had known the early signs and symptoms (19.23%), and to be assertive, an advocate, informed, and ask questions (15.38%).

Participant wishes they had known to communicate/increase understanding

Like I said, I'd like to have known, I suppose, just more information gently and comprehensively explained to me, as opposed to "Hey, go read this. The second chemo, I said, "Oh, my gum is doing what have you," and this nurse said, "Aren't you doing--" or "Are you following your dental protocol?" What's dental protocol? It was in the notes, and she grabbed them off me, went to page seven, circled it with a red pen, with a big attitude and says, "It's right there." I went, "Yes, I'm sorry, I was probably a little bit preoccupied and hadn't got to reading that," so things like that need to change, things like that. I felt like I was suddenly 8 years old or 12 years old, and I just failed my maths exam. It was like, "What's that?" I'm the same age as woman, like, "Why am I getting treated like this? Things like that, I would like to have had explained to me. I'd like someone to have said to me-- It'd be nice to have a coordinator who said, "This is how your treatment plan, we feel, is best for you to go, and this is probably the best routine. this is how things will flow, to give me-- and you had some of that to some degree, but not enough for my liking.

Participant 018_2023AULUC

One of the questions I have is why I wasn't given some treatment to shrink the tumour first before I had the surgery, because I noticed they do that a lot in the UK and in America. Would that have allowed me to keep my lobe of my lung? I haven't dared ask the guys [unintelligible] they'll job me off. That's not standard treatment. I've got questions like that. Then of course, like I said before, is the [unintelligible] going to save my life or is it actually going to give me something else, is it going to mess up some other organs in my body? It's all a bit hazy.

Participant 025_2023AULUC

Probably not from a lung cancer perspective because I have lung cancer primarily, I believe because of my genetic condition. I think in terms of that genetic condition, there's a lot of stuff that could have been

[unintelligible] but scanning early which I think now they've got a screening process for adults, but they never historically did. I think that is part of the issue occurring.

Participant 026_2023AULUC

Participant described that they were satisfied with their experience and have no particular comment

Not that I can think of. No. Everyone's different, aren't they? It took time to process. I don't know. I thought I was going to die a lot quicker, and then I had a lot more time, which is nice because now I've had time to sort a lot more things out, whereas before, I was in a bit of a haze of medication and treatments and I was unwell for a good seven months, and then I felt better. Life changed.

Participant 006_2023AULUC

No, not really. It would've been lovely to pick this up before it was metastatic, but I understand even when I think, "Oh I had a funny little cough at times." There's no way you would've thought I was going to develop one cancer. I was not sitting there as a prime candidate. To be forewarned of what can happen, not until you're thrown in the big pool, do you need to know the ins and outs of everything because there's so much that can happen in your life. No, there's not really anything. I don't think I missed anything in my symptoms. I don't think anyone would've acted any earlier, and I don't think there's anything I needed to be forewarned because lung cancer is not one disease. It's a bazillion different little diseases and so you couldn't be forewarned about all the pathways, so not really.

Participant 020_2023AULUC

Participant wishes they had known the early signs and symptoms

I would like that commercial about lung cancer being a cancer that can happen to anyone, not just smokers, because you never think, "Oh, I'd better look out for these symptoms because it could be the lung cancer." Because you just think, "No, it won't happen to me."

Participant 004_2023AULUC

Yes, lung screening, definitely. Being more aware of what this issue was in my chest at the time and taking it further. I would occasionally get what seemed like bad indigestion six years ago. I would have felt the strong pains coming across my back. I saw my GP about it and it was treated as indigestion and she

*gave me some medication, it seemed to go away, but there was never any discussion outside of that. One night, the pain got really strong and my husband decided to take me to a private hospital and focus was on my heart. I stayed overnight in ECG, kept me overnight for observation, my heart was fine.
Participant 005_2023AULUC*

*Probably, it would've been nice if we could have diagnosed it earlier, because by the time, we've got it at stage 3, that's pretty devastating to get that even for me. I didn't let it affect me, but still, it did knock me a bit. Probably, an earlier diagnosis would've been better. I've been looking at that because I've already become aware of it at the signs and symptoms of lung cancer, a bit long before diagnosis, but they generally say that, by the time that you are diagnosed, you're at that stage because it's funny then that it becomes apparent that that's what the problem is.
Participant 017_2023AULUC*

*I wish I knew what to look for. I wish I knew dad could have-- In hindsight, dad has had the symptoms for at least six months and I wish there was more education to the general public about what lung cancer looks like because there's not enough [inaudible] We could have probably had six months off the tumor growing, whether that would've made any difference, I don't know, but something that you live with and you go, I could have but didn't.
Participant 030_2023AULUC*

Participant wishes they had known to be assertive, an advocate, informed, & ask questions

*Oh, so much. Firstly I wish I had known that a non-smoker could get lung cancer and I think more people should be told that. I wish I had known that I could stand up for myself and advocate for myself to my oncologist or any health professional rather than what they say is what needs to be done. Now I know that I can do my own research and I can say to him, what do you think of this and he's like, oh yes, I'll have a look at this. I think this, that, and the other and he's very open to it, whereas initially he's the professional and he knows what needs to be done. Right now I wish for everybody on diagnosis to know that they can have an impact on their treatment plans.
Participant 007_2023AULUC*

*Yes. Advocate more. Advocate and question more, ask for details. Don't feel like-- I just wish I was more knowledgeable about cancer. I just don't think as a society we talk about it openly enough. I don't know. The other thing is, can I just say, I don't even know what to do. I think I have to prepare a will and [crosstalk] I don't even know if it is that. No one had told me. I haven't thought, and probably I haven't gone looking for it, but [crosstalk] moment, the things that I should be doing because things could turn around really quickly.
Participant 027_2023AULUC*

Table 10.1: Anything participants wish they had known earlier

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

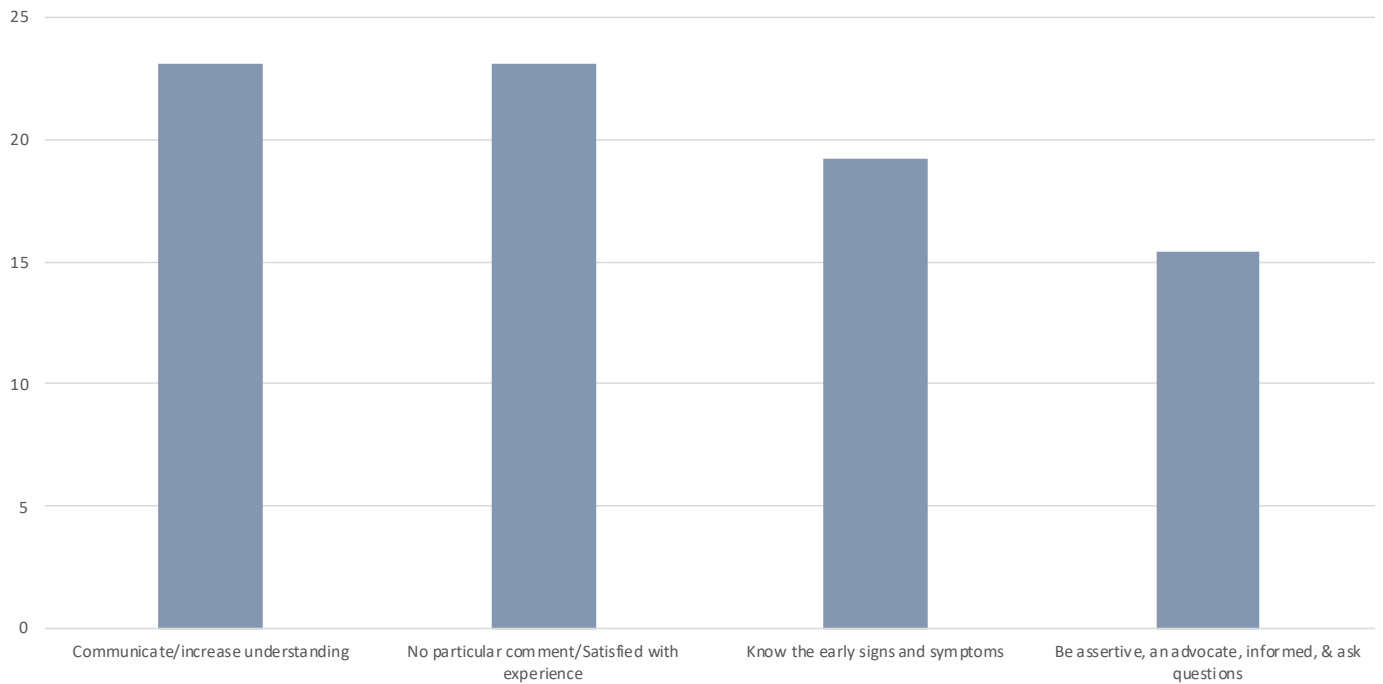


Figure 10.1: Anything participants wish they had known earlier

Table 10.2: Anything participants wish they had known earlier – 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	-

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common themes were that they would not change any aspect and were satisfied with their care or treatment (38.46%). Others would access appropriate specialist or treatment sooner (11.54%), and some participants described a single negative experience that they would like to have changed (11.54 %).

Participant would not change any aspect of their care or treatment/satisfied with care and treatment received

No, because I feel that this is the best treatment I could get. I can't knock any of it.

Participant 001_2023AULUC

No. Everything from my pharmacist to my nurse, that's very, very good.

Participant 022_2023AULUC

All the medical staff were excellent. The nurses were great. Excellent. That's what I found. Nurses are the backbone of the hospital.

Participant 024_2023AULUC

No. The care has been good from the nurses. Like I said, the oncologist not so much, but the nurses have been amazing. Each time he goes for treatment, they're very informative. They're comfortable, they're good in checking him with his mental health as well. They've just been supportive. Like I said, we've really had good experiences other than the lack of information from the oncologist.

Participant 030_2023AULUC

Participant would have liked to have access to a specialist in their condition, and treatment sooner

Yes [laughs]. I would never have gone for that respiratory physician if I'd known. Normal practice for that would have been to have the biopsy within a couple of weeks and I would have had surgery within four to five weeks. It would have been stage 1B or 1A - No, it would have been 1B, it's bigger. It would have been 1B and I might have avoided some of this treatment. Definitely, it's out there. I was happy with the surgeon. I think I would get a second opinion of an oncologist now.

Participant 025_2023AULUC

Yes. I wouldn't have gone to that respiratory specialist. I want an oncologist. I should've questioned everything right from the start. They talk about that genomic testing, whatever, and the gene testing, someone should have sat and explained it to me. I'm just thankful that the thoracic surgeon center for

testing, because, like he said, the respiratory specialist didn't even want to tell me I was out positive, [inaudible].

Participant 027_2023AULUC

Participant described a single negative experience that they would like to have changed

No, no, it was all good. Just the hospital stay was pretty diabolical. That was hideous.

Participant 019_2023AULUC

That's a hard one to answer. My hospital experience post when I had the complications, most of that was very traumatic and made worse by the way that I was treated. I've been through a lot of that. That really needed to change because it wasn't handled very well at all.

Participant 021_2023AULUC

Table 10.3: Aspect of care or treatment they would change

Anything they would change about treatment or care	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 would not change any aspect of their care or treatment/satisfied with care and treatment received	10	38.46	9	36.00	1	100.00	2	20.00	8	50.00	6	37.50	4	40.00
Participant would have liked to have access to a specialist in their condition, and treatment sooner	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00
Participant described a single negative experience that they would like to have changed	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	2	12.50	1	10.00

Anything they would change about treatment or care	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 would not change any aspect of their care or treatment/satisfied with care and treatment received	10	38.46	5	29.41	5	55.56	5	38.46	5	38.46	0	0.00	10	41.67	4	44.44	6	35.29
Participant would have liked to have access to a specialist in their condition, and treatment sooner	3	11.54	3	17.65	0	0.00	1	7.69	2	15.38	1	50.00	2	8.33	2	22.22	1	5.88
Participant described a single negative experience that they would like to have changed	3	11.54	3	17.65	0	0.00	1	7.69	2	15.38	1	50.00	2	8.33	1	11.11	2	11.76

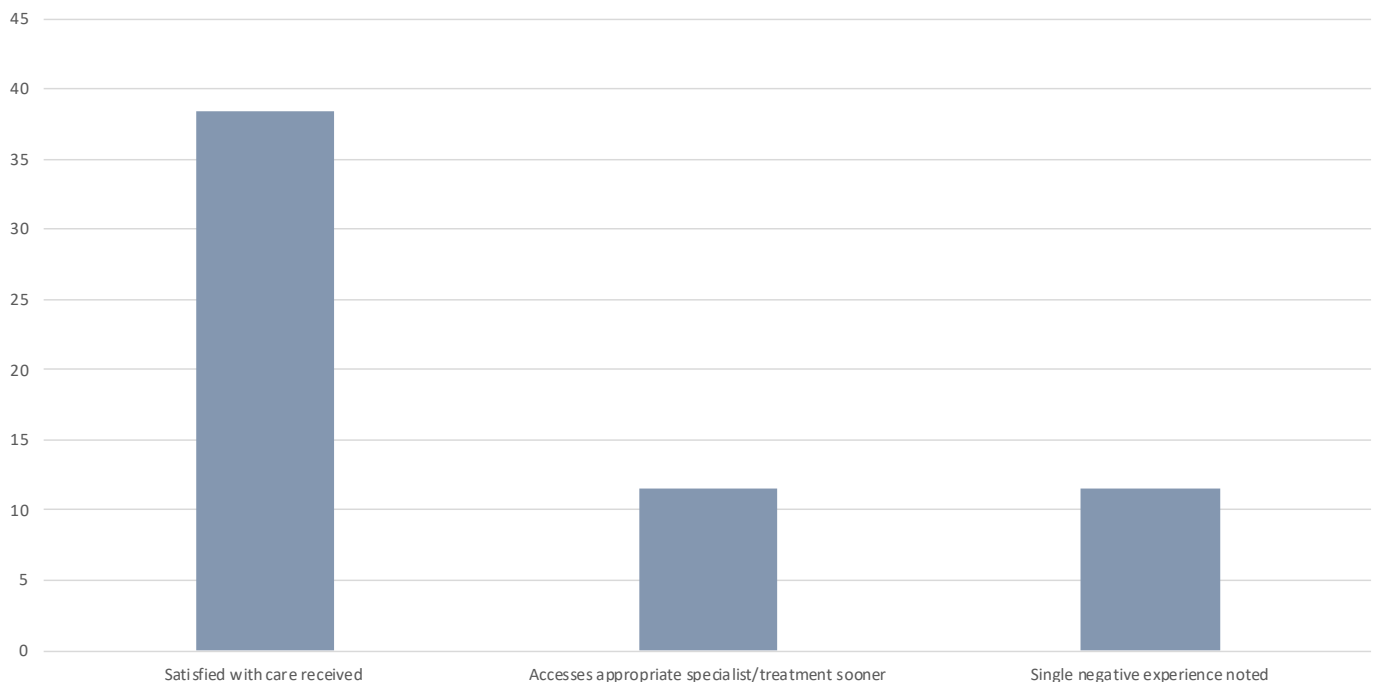


Figure 10.2: Aspect of care or treatment they would change

Table 10.4: Anything participants wish they had known earlier – subgroup variations

Theme	Less frequently	More frequently
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	Non-metastatic	Metastatic
Participant would have liked to have access to a specialist in their condition, and treatment sooner	Male Aged 65 or older	Aged 65 or older Mid to low status
Participant described a single negative experience that they would like to have changed	Aged 65 or older	-