Section 3

Symptoms and diagnosis

Section 3: Symptoms and diagnosis

Symptoms before diagnosis

Participants were asked in the questionnaire which symptoms they had before diagnosis, they could choose from a set list of symptoms and could then specify other symptoms not listed. There were 6 participants (20.69%) that had no symptoms before diagnosis. Participants had a maximum of 8 symptoms, and a median of 3.00 (IQR=3.00)

The most common symptoms before diagnosis were feeling tired or having lower energy levels than usual (n=19, 65.52%), shortness of breath and wheezing (n=13, 44.83%), and coughing or spitting up blood (n=13, 44.83%). The median quality of life was between 2.00 and 5.00, for all of the symptoms listed in the questionnaire, this is in the "Life was very distressing" to "Life was good" range. The symptoms with the worst quality of life were feeling tired or having lower energy levels than usual, shortness of breath and wheezing, coughing or spitting up blood, and shoulder or back pain

Symptoms leading to diagnosis

In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually led to their diagnosis. Almost all participants (92.31%) strongly recalled their symptoms or how they came to be diagnosed. The most common symptom leading to diagnosis was having shortness of breath (30.77%), persistent cough or chest infection (26.92%), and there were 5 participants (19.23%). who experienced no symptoms before diagnosis. Other symptoms included fatigue (15.38%), blood in phlegm (11.54%), flu-like symptoms (11.54%), and rib or lung pain (11.54%).

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. The most common responses were seeking medical attention relatively soon (53.85%), followed by not seeking medical attention initially (26.92%). There were 5 participants that described having no symptoms (19.23 %)

Symptoms leading to diagnosis: Description of diagnostic pathway

In the structured interview, participants described their diagnostic pathway in the healthcare system. The most common responses were that they were diagnosed by a specialist from their general practitioner (34.62%), and having multiple specialists needed before diagnosis (26.92%). Other pathways included being diagnosed in an emergency department (23.08%), and being diagnosed by their general practitioner during a routine check-up that was not related to symptoms (15.38%)

Timing of diagnosis

Participants were asked to give the approximate date of when they first noticed symptoms of lung cancer and the approximate date of diagnosis with lung cancer. Where enough information was given, an approximate duration from first noticing symptoms to diagnosis was calculated. Duration was calculated for 29 participants (9 participants had no symptoms before diagnosis), there were 7 participants (24.14%) that were diagnosed less than 1 month of noticing symptoms, 4 participants (13.79%) diagnosed between 2 and 3 months from noticing symptoms, 5 participants (17.24%) that were diagnosed between 6 months and 1 year of noticing symptoms, and 4 participants (13.79%) that were diagnosed more than 1 year of noticing symptoms.

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis. There were 7 participants (24.14%) that were diagnosed less than 1 week after testing, 8 participants (27.59%) diagnosed between 1 and 2 weeks after testing, 8 participants (27.59%) that were diagnosed between 2 and 3 weeks after testing, and 6 participants (20.69%) that were diagnosed 4 weeks or after testing.

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with lung cancer. They could choose from a set list of diagnostic tests and could then specify other tests not listed. The number of tests per participant were counted using both tests from the set list and other tests specified.

Participants reported between 0 to 5 diagnostic tests (median=3.00 , IQR=1.00). The most common tests were PET scan (n=23, 79.31%), Biopsy (n=20, 68.97%), CT scan (n=25, 86.21%), and Chest x-ray (n=15, 51.72%).

Diagnosis provider and location

Participants were asked in the online questionnaire, which healthcare professional gave them their diagnosis, and where they were given the diagnosis. Almost half of the participants were given their diagnosis by a respiratory specialist (n=14, 48.28%), and there were 5 participants (17.24%) given the diagnosis by a general practitioner, 3 participants (10.34%) diagnosed by an oncologist, and 3 participants (10.34%) by an emergency doctor or ambulance paramedic. Participants were most commonly given their diagnosis in the hospital (n=15, 51.72%), this was followed by the specialist clinic (n=6, 20.69%), and the general practice.

Year of diagnosis

Participants were diagnosed between 2012 to 2022. There were 24 participants (82.76%) that were diagnosed in the last five years.

Lung cancer diagnosis, stage and spread

The majority of participants were diagnosed with Non-small cell lung cancer. There were 4 participants (12.50%), with Stage 1 lung cancer, 3 participants (9.38%) with Stage 2, 4 participants (12.50%) with Stage 3, and 18 participants (56.25%), with Stage 4 lung cancer. . There were 13 participants (44.83%) that noted that the cancer had spread. The most common sites of spread were the brain (n=6, 20.69%), lymph nodes (n=4, 13.79%) and bones (n=4, 13.79%). There were 8 participants (27.59%) that reported having had a lung cancer recurrence.

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. The most common responses were having no or little knowledge at diagnosis(61.54%), having knowledge because of family history of the condition or knowing someone who has the condition (15.38%), and having knowledge from a professional background (11.54 %).

Emotional support at diagnosis

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis. There were 6 participants (20.69%) who had enough support, 3 participants (10.34%) that had some support but it wasn't enough, and 20 participants (68.97%) had no support.

Costs at diagnosis

Participants noted in the online questionnaire the amount of out-of-pocket expenses they had at diagnosis, for example doctors' fees, and diagnostic tests. There were 16 participants (55.17%) who had no out of pocket expenses, and 3 participants (10.34%) who did not know or could not recall. There were 5 participants (17.24%) that spent between $400 and $800, and 5 participants (17.24%) that spent more than $1000

For 22 participants (75.86%) the cost was slightly or not at all significant. For 5 participants (17.24%) the out-of-pocket expenses were somewhat significant, and for 2 participants (6.90%), the burden of out-of-pocket expenses were moderately or extremely significant.

Genetic tests and biomarkers

Participants answered questions in the online questionnaire about if they had any discussions with their doctor about biomarkers, genomic and gene testing that might be relevant to treatment. If they did have a discussion, they were asked if they brought up the topic or if their doctor did. Most commonly, participants had never had a conversation about biomarkers, genomic, or gene testing that might be relevant to treatment, (n=16, 55.17%). There were 3 participants (10.34%) who brought up the topic with their doctor, and 10 participants (34.48%) whose doctor brought up the topic with them

Participants were then asked if they had had any biomarker, genomic or gene testing. If they had testing, they were asked if they had it as part of a clinical trial, paid for it themselves or if they did not have to pay for it. Those that did not have the test were asked if they were interested in this type of test. Participants most commonly did not have any genetic or biomarker tests but would like to (n=13, 44.83%). There were 2 participants (6.90%) who did not have these tests and were not interested in them, and a total of 14 participants (48.28%) that had biomarker tests.

More than half status for at least one biomarker (n=16, 55.17%). Most commonly, participants knew their EGFR status (n=9, 31.03%), followed by ALK status (n=7, 24.14%)

Understanding of prognosis

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. The most common responses were uncertainty around prognosis (61.54%), and that they had a poor prognosis or a terminal condition (15.38%). Other themes included having no evidence of disease or that they are in remission (11.54%), and describing a specific timeframe that they are expected to live (7.69%).

Experience of symptoms before diagnosis

Participants were asked in the questionnaire which symptoms they had before diagnosis, they could choose from a set list of symptoms and could then specify other symptoms not listed.

There were 6 participants (20.69%) that had no symptoms before diagnosis. Participants had a maximum of 8 symptoms, and a median of 3.00 (IQR=3.00) (Table 3.1, Figure 3.1).

Table 3.1: Number of symptoms per participant

Number of symptoms per participant	Number (n=29)	Percent
No symptoms	6	20.69
1 to 2	7	24.14
3 to 4	10	34.48
5 to 6	3	10.34
7 to 8	3	10.34

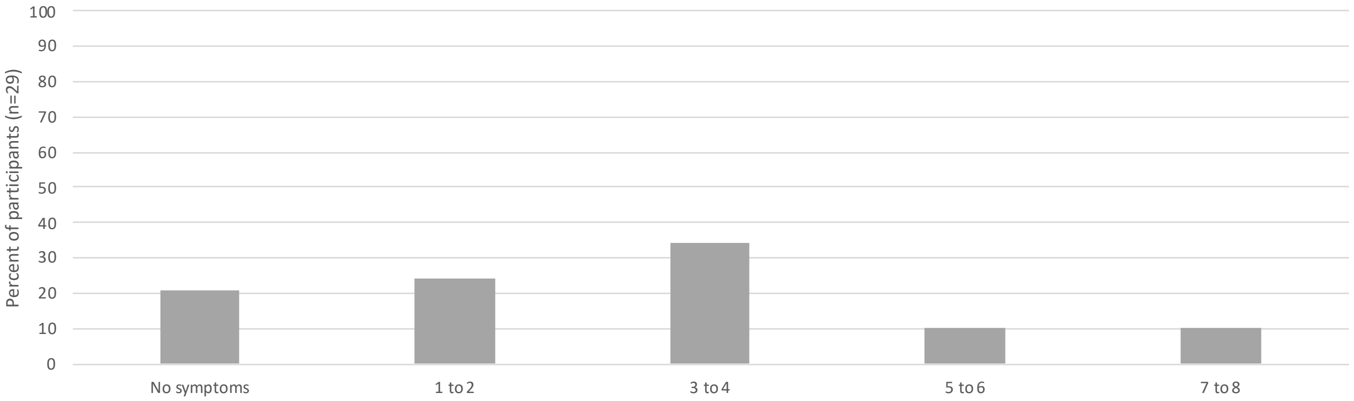

Figure 3.1: Number of symptoms per participant

Symptoms before diagnosis

The most common symptoms before diagnosis were feeling tired or having lower energy levels than usual (n=19, 65.52%), shortness of breath and wheezing (n=13, 44.83%), and coughing or spitting up blood (n=13, 44.83%) (Table 3.2, Figure 3.2).

Participants were asked a follow up question about their quality of life while experiencing these symptoms. Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Median quality of life is presented where five or more participants reported the symptom.

The median quality of life was between 2.00 and 5.00, for all of the symptoms listed in the questionnaire, this is in the “Life was very distressing” to “Life was good” range. The symptoms with the worst quality of life were feeling tired or having lower energy levels than usual, shortness of breath and wheezing, coughing or spitting up blood, and shoulder or back pain (Table 3.2, Figure 3.3).

Table 3.2: Symptoms before diagnosis

Symptom	Number (n=29)	Percent	Quality of life	
			Median	IQR
Feel tired/lower energy levels than usual	19	65.52	3.00	3.50
Shortness of breath and wheezing	13	44.83	3.00	2.00
Coughing or spitting up blood	13	44.83	3.00	3.00
Shoulder or back pain	11	37.93	3.00	1.50
A new persistant cough	11	37.93	5.00	2.50
Chest pain	5	17.24	2.00	4.00
Recurring bronchitis or pneumonia	4	13.79	NA	NA
Hoarseness (scratchy voice)	3	10.34	NA	NA
Loss of appetite	2	6.90	NA	NA
Unexplained weight loss	2	6.90	NA	NA
No symptoms	6	20.69	NA	NA

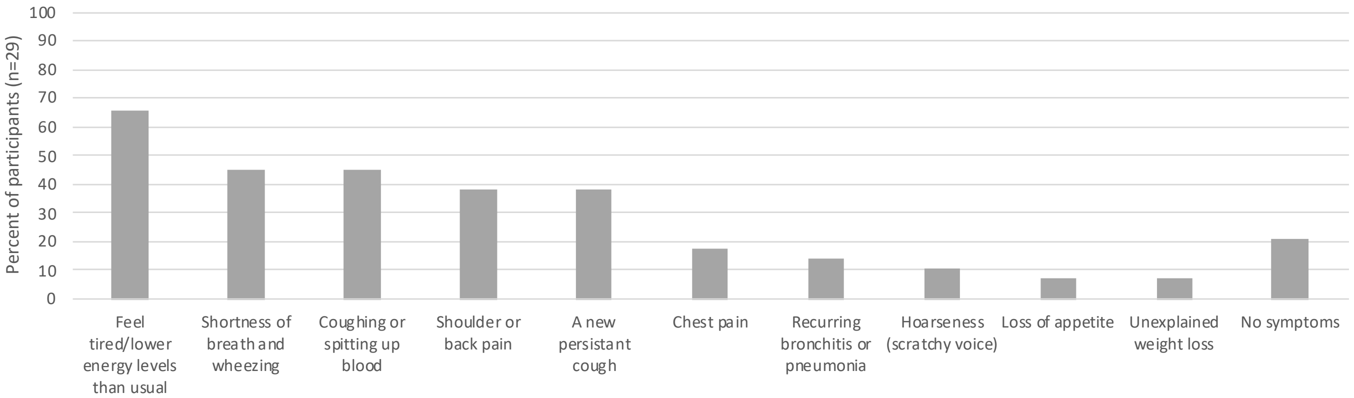

Figure 3.2: Symptoms before diagnosis

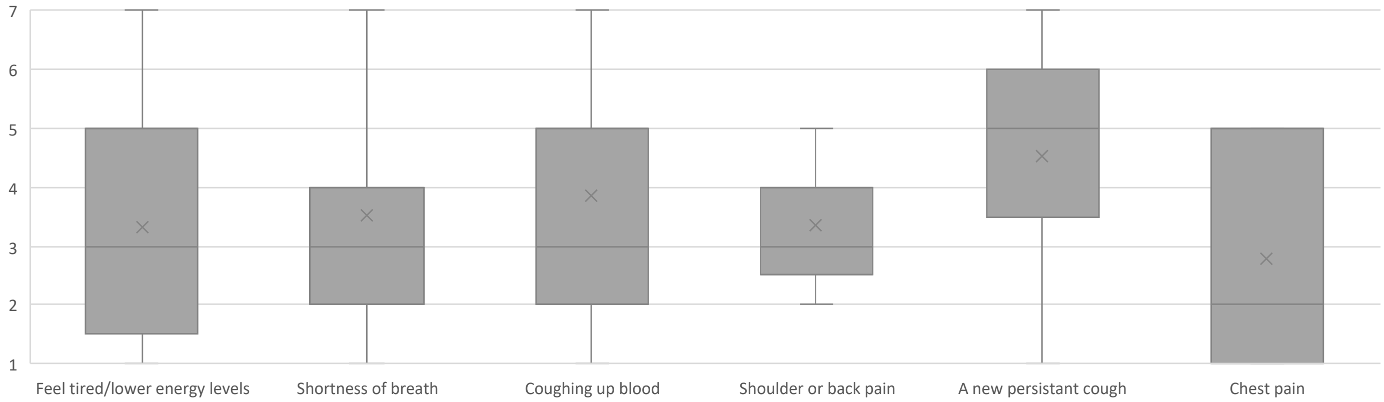

Figure 3.3: Quality of life from symptoms before diagnosis

Symptoms leading to diagnosis

In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis.

Almost all participants (92.31%) strongly recalled their symptoms or how they came to be diagnosed.

The most common symptom leading to diagnosis was having shortness of breath (30.77%), persistent cough or chest infection (26.92%), and there were 5 participants (19.23%). who experienced no symptoms before diagnosis. Other symptoms included fatigue (15.38%), blood in phlegm (11.54%), flu-like symptoms (11.54%), and rib or lung pain (11.54%).

Participant describes having shortness of breath which led to their diagnosis

Yes. I was away during COVID. We were up north with friends. We were in LOCATION, but there was no COVID. Every day, we used to walk about 10 kilometers which I didn't have a problem with. Then on this walk, there was one part of it where we had to climb over a big hill to get to the other side. I just couldn't climb up a hill. My friends were older than me said, "That's not right." I just thought, well, perhaps that's just normal for me. I'm fine on the flat, but I can't do hills. Anyway, and then I got home, say in late September, early October. I always walk every day and I started going for walks and I was getting more and more short of breath. Went to my local doctor and told them and he listened.
Participant 001_2023AULUC

Yes. At work, it was becoming extremely difficult to breathe while I was working. I was becoming more and more short of breath, and that probably happened six months before they found the nodule in my lung.
Participant 003_2023AULUC

Yes. I had only one symptom and that was what I thought was getting progressively and significantly unfit. What I realized now was that I was getting restless because of a significant pleural effusion. I was aware of this through December and January. December 2020 to January 2021, thinking my fitness was going backwards very, very fast. Then I decided now there's something seriously going wrong here, maybe I have a lung infection or something, I thought.

Shall I go into this detail? Is this appropriate? It would have been something like the 27th or 28th of January 2021 and I thought, there's seriously wrong here. I've got to find out what's going on so I called a telehealth number and I opted to speak to a nurse and she asked me typical sorts of questions and I reported really severe breathlessness on exertion and she, I think, had the view that it was likely I had some heart condition. Anyway, it ended in her saying, "Well, on the basis of everything you've told me, I think this is a medical emergency, would you like me to call an ambulance?" I was completely shocked by that response, but I said, "Well, no, no need to call an ambulance, I'll get my wife to take me up to the hospital." 022_2023AULUC

Participant describes having persistent cough or chest infection which led to their diagnosis

Probably had a bit of a cough for ages. [crosstalk] Yes, maybe a year or so. I had a chest infection that I'd been on some antibiotics, and then I went back to the doctor because I still had the cough and they sent me for a CT. Participant 026_2023AULUC

I think the most prominent one is I had a cough, but then a few people around me in my friendship group had this same cough. I almost felt like I was getting a cold because I just felt very fatigued and like I was coming down with a virus or something. I ended up going to the doctor just to get antibiotics for the cough. Just on the off chance he happened to say, "Well, you're 50 years old. I think we'll do a CT scan just to be--" the famous last words, "it'll probably be nothing but just do the CT scan." That's when it came back as, yes, lung cancer stage 4, kind of thing.
Participant 004_2023AULUC

Participant describes having not experiencing symptoms before diagnosis

No, I didn't have any symptoms at all, INTERVIEWER. It was found by mistake
14_2023AULUC

Yes. I actually had no symptoms to offer because it was incidentally found at a very early stage, so I was extremely fortunate.
21_2023AULUC

Participant describes having fatigue which led to their diagnosis

Yes. For five years prior to diagnosis, I presented to the GP with extreme fatigue, cough, a lot of cough, breathlessness. 023_2023AULUC

There was definitely shortness of breath, fatigue and then a wheeze on exertion that then progressively developed and all those symptoms got worse until eventually I coughed up blood.
Participant 015_2023AULUC

Participant describes having blood in phlegm which led to their diagnosis

Yes. I had a persistent cough and chest infections for two and a half years. Yes, before I was diagnosed. I kept going back to the doctor and he kept doing x-rays and sputum tests and nothing shows as wrong with me until then I started getting pain up under my rib. I started coughing just a tiny little bit of blood in my phlegm. Then he sent me for a nose and throat specialist and they did a CT.
Participant 007_2023AULUC

Participant describes having flu-like symptoms which led to their diagnosis

I didn't know any symptoms. I wasn't aware of what lung cancer looks like or any of the symptoms, but thinking back now, dad had said that he had the flu, he had something on his chest. He thought it was a chest infection so he kept visiting GPs in the area because we'd only just moved to the area. Participant 030_2023AULUC

Participant describes having pain (Ribs/lungs) which led to their diagnosis

Yes. I had fatigue. I found it difficult to walk up the stairs without having a rest halfway up, which was just not like me. That's probably the biggest problem I had. I didn't have anything else up until I got pain. I had pain under my right arm in my ribcage. It was quite bad. I couldn't sleep on that side. That's when I went to the doctor.
Participant 002_2023AULUC

Table 3.3: Symptom recall

Symptom recall	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	%
Symptom recall strong	24	92.31	23	92.00	1	100.00	9	90.00	15	93.75	18	112.50	6	60.00
No Symptoms	1	3.85	1	4.00	0	0.00	1	10.00	0	0.00	0	0.00	1	10.00

Symptom recall	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	%
Symptom recall strong	24	92.31	15	88.24	9	100.00	12	92.31	12	92.31	2	100.00	22	91.67	9	100.00	15	88.24
No Symptoms	1	3.85	0	0.00	1	11.11	1	7.69	0	0.00	0	0.00	1	4.17	0	0.00	1	5.88

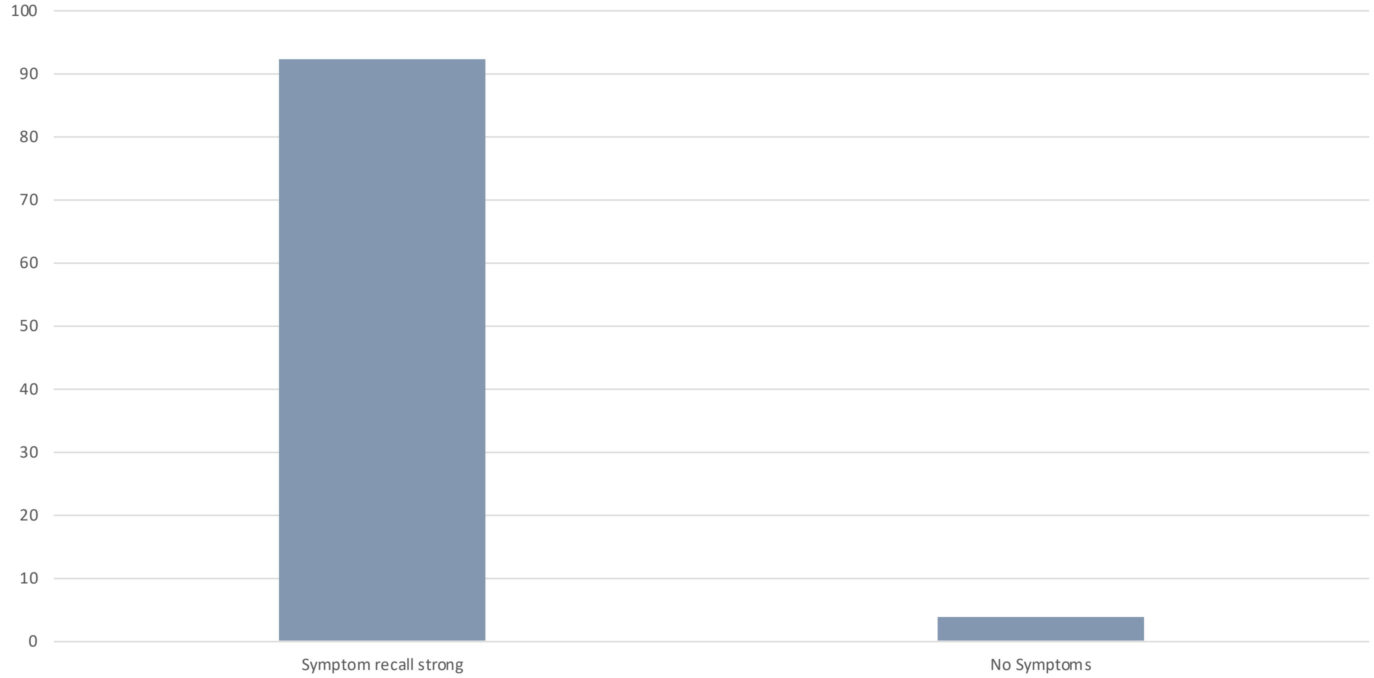

Figure 3.4: Symptom recall

Table 3.4: Symptoms leading to diagnosis

Symptoms leading to diagnosis	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes having shortness of breath which led to their diagnosis	8	30.77	8	32.00	0	0.00	1	10.00	7	43.75	7	43.75	1	10.00
Participant describes having persistent cough or chest infection which led to their diagnosis	7	26.92	6	24.00	1	100.00	3	30.00	4	25.00	5	31.25	2	20.00
Participant describes having not experiencing symptoms before diagnosis	5	19.23	5	20.00	0	0.00	3	30.00	2	12.50	3	18.75	2	20.00
Participant describes having fatigue which led to their diagnosis	4	15.38	4	16.00	0	0.00	0	0.00	4	25.00	4	25.00	0	0.00
Participant describes having blood in phlegm which led to their diagnosis	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	2	12.50	1	10.00
Participant describes having flu-like symptoms which led to their diagnosis	3	11.54	2	8.00	1	100.00	0	0.00	3	18.75	2	12.50	1	10.00
Participant describes having pain (Ribs/lungs) which led to their diagnosis	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00

Symptoms leading to diagnosis	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes having shortness of breath which led to their diagnosis	8	30.77	5	29.41	3	33.33	3	23.08	5	38.46	1	50.00	7	29.17	3	33.33	5	29.41
Participant describes having persistent cough or chest infection which led to their diagnosis	7	26.92	4	23.53	3	33.33	4	30.77	3	23.08	0	0.00	7	29.17	2	22.22	5	29.41
Participant describes having not experiencing symptoms before diagnosis	5	19.23	2	11.76	3	33.33	3	23.08	2	15.38	0	0.00	5	20.83	2	22.22	3	17.65
Participant describes having fatigue which led to their diagnosis	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
Participant describes having blood in phlegm which led to their diagnosis	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
Participant describes having flu-like symptoms which led to their diagnosis	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
Participant describes having pain (Ribs/lungs) which led to their diagnosis	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

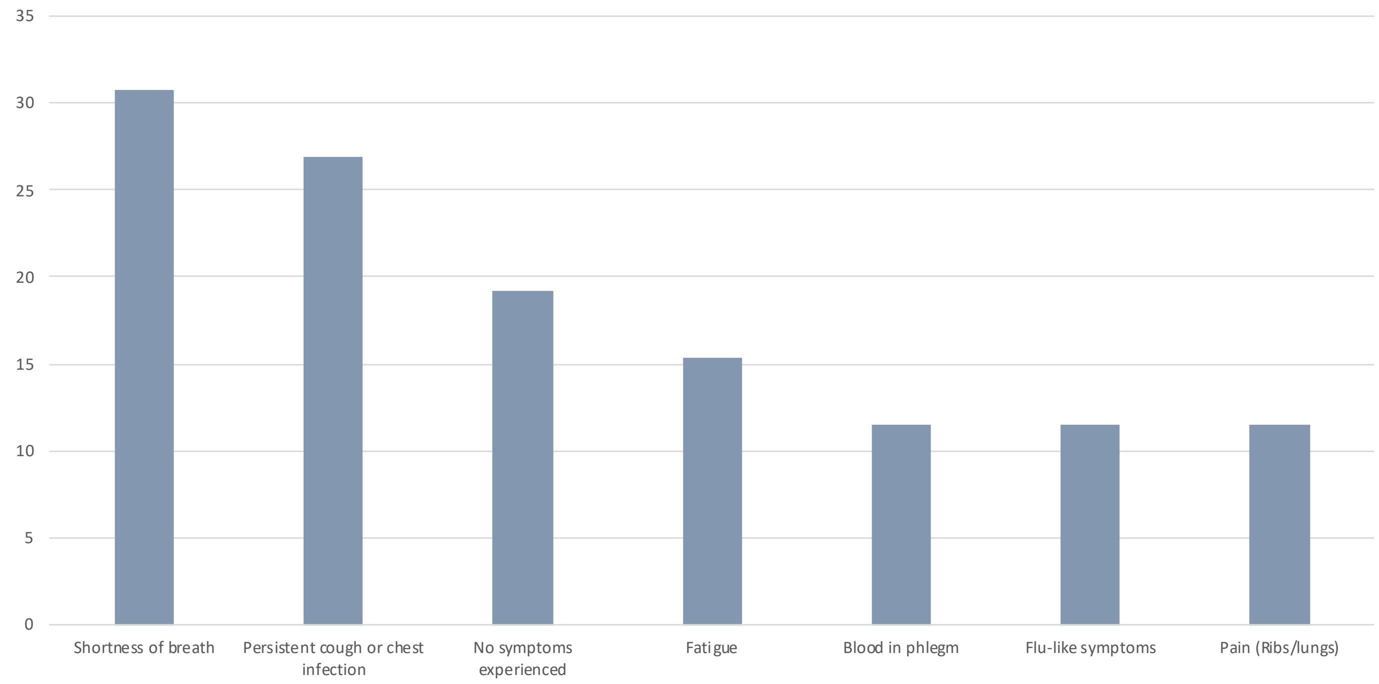

Figure 3.5: Symptoms leading to diagnosis

Table 3.5: Symptoms leading to diagnosis – subgroup variations

Symptoms leading to diagnosis	Less frequently	More frequently
Participant describes having shortness of breath which led to their diagnosis	Non-metastatic Male	Metastatic Female
Participant describes having not experiencing symptoms before diagnosis	-	Non-metastatic Aged 65 or older
Participant describes having fatigue which led to their diagnosis	Non-metastatic Male	-
Participant describes having blood in phlegm which led to their diagnosis	Mid to low status	-
Participant describes having flu-like symptoms which led to their diagnosis	Non-metastatic	-
Participant describes having pain (Ribs/lungs) which led to their diagnosis	Male	-

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. The most common responses were seeking medical attention relatively soon (53.85%), followed by not seeking medical attention initially (26.92%). There were 5 participants that described having no symptoms (19.23 %)

Having symptoms and seeking medical attention relatively soon

Yes. I had fatigue. I found it difficult to walk up the stairs without having a rest halfway up, which was just not like me. That's probably the biggest problem I had. I didn't have anything else up until I got pain. I had pain under my right arm in my ribcage. It was quite bad. I couldn't sleep on that side. That's when I went to the doctor. No, there was no surveillance. I'd been going to my doctor for about six months saying, "I'm really tired." He just kept checking my blood and saying, "Your blood work's fine." He didn't know what else to do. I lost a lot of weight. I thought maybe it was because I was overweight. I got down to 60 kilos, and I still didn't feel any better. When I had this pain, I actually didn't go to my doctor. I went to another just a random doctor. I said, "I think I've broken my rib." That's what it felt like. She sent me for a chest x-ray to check my ribs.
Participant 001_2023AULUC

I think the most prominent one is I had a cough, but then a few people around me in my friendship group had this same cough. I almost felt like I was getting a cold because I just felt very fatigued and like I was coming down with a virus or something. I ended up going to the doctor just to get antibiotics for the cough. Just on the off chance he happened to say, "Well, you're 50 years old. I think we'll do a CT scan just to be--" the famous last words, "it'll probably be nothing but just do the CT scan." That's when it came back as, yes, lung cancer stage 4, kind of thing.
Participant 004_2023AULUC

Yes. I had a persistent cough and chest infections for two and a half years. Yes, before I was diagnosed. I kept going back to the doctor and he kept doing x-rays and sputum tests and nothing shows as wrong with me until then I started getting pain up under my rib. I started coughing just a tiny little bit of blood in my phlegm. Then he sent me for a nose and throat specialist and they did a CT.
Participant 007_2023AULUC

Yes. For five years prior to diagnosis, I presented to the GP with extreme fatigue, cough, a lot of cough, breathlessness. They did some X-rays, and some lung function tests, and said that I was suffering from asthma, while in fact, I've never had asthma. That's it.
Participant 023_2023AULUC

He thought it was a chest infection so he kept visiting GPs in the area because we'd only just moved to the area. Through that, that's when they misdiagnosed, basically sitting home with Panadol. Then it got to the point that dad, he was doing some gardening work and I said, "Look, I think it's time we go to the hospital." The hospital's done the scan and found a mast in his lungs. Participant 030_2023AULUC

Having symptoms and not seeking medical attention initially

Yes. It started with a sore back and I just thought it was a muscular problem, I guess. It was probably a good six months before I went to a doctor. [chuckles] I went to massage, went to physios, did all that and it didn't work, and then went to a GP. Looking back, I probably also had some other symptoms. I'm a OCCUPATION, so lots of things I ignored, but had a bit of tachycardia, night sweats that I thought were maybe menopausal, maybe not. A few things that probably could have been signs.
Participant 006_2023AULUC

Probably had a bit of a cough for ages. [crosstalk] Yes, maybe a year or so. I had a chest infection that I'd been on some antibiotics, and then I went back to the doctor because I still had the cough and they sent me for a CT.
Participant 026_2023AULUC

I think I noticed, because I've got INFORMATION REMOVED background, I would notice that I had more of a restricted capacity. I would put it down to aging too because I know that changes as you get a go along. I didn't really think much more of it. Then probably the month before I noticed I was getting headaches a lot more frequently and would take, excuse me, I've got hiccups, take a few bouts of Panadol, but I was also going through menopause. I would get to treatment at my physio thinking that maybe it was also tension in my shoulders and neck, and they seemed to relieve it for a bit. Even two weeks before, we had a wedding and we were dancing and I felt like I was very puffed out. Again, I just put it down to getting older and didn't really think much more of it. Then it all came to head when I had a seizure. I collapsed at home and from the seizure, they determined that I had secondary brain tumors and the primary tumor was in my lungs. That's when it all happened.
Participant 005_2023AULUC

Having no symptoms or not noticing any symptoms before diagnosis

I didn't have symptoms. My diagnosis was picked up by a CT calcium score.
Participant 010_2023AULUC

PARTICIPANT: No.
INTERVIEWER: No? Didn't have anything?
PARTICIPANT: None.
Participant 027_2023AULUC

Table 3.6: Seeking medical attention

Seeking medical attention	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	%
Having symptoms and seeking medical attention relatively soon	14	53.85	13	52.00	1	100.00	4	40.00	10	62.50	9	56.25	5	50.00
Having symptoms and not seeking medical attention initially	7	26.92	7	28.00	0	0.00	3	30.00	4	25.00	7	43.75	0	0.00
Having no symptoms or not noticing any symptoms before diagnosis	5	19.23	5	20.00	0	0.00	3	30.00	2	12.50	3	18.75	2	20.00

Seeking medical attention	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	%
Having symptoms and seeking medical attention relatively soon	14	53.85	8	47.06	6	66.67	7	53.85	7	53.85	0	0.00	14	58.33	2	22.22	12	70.59
Having symptoms and not seeking medical attention initially	7	26.92	6	35.29	1	11.11	3	23.08	4	30.77	2	100.00	5	20.83	5	55.56	2	11.76
Having no symptoms or not noticing any symptoms before diagnosis	5	19.23	2	11.76	3	33.33	3	23.08	2	15.38	0	0.00	5	20.83	2	22.22	3	17.65

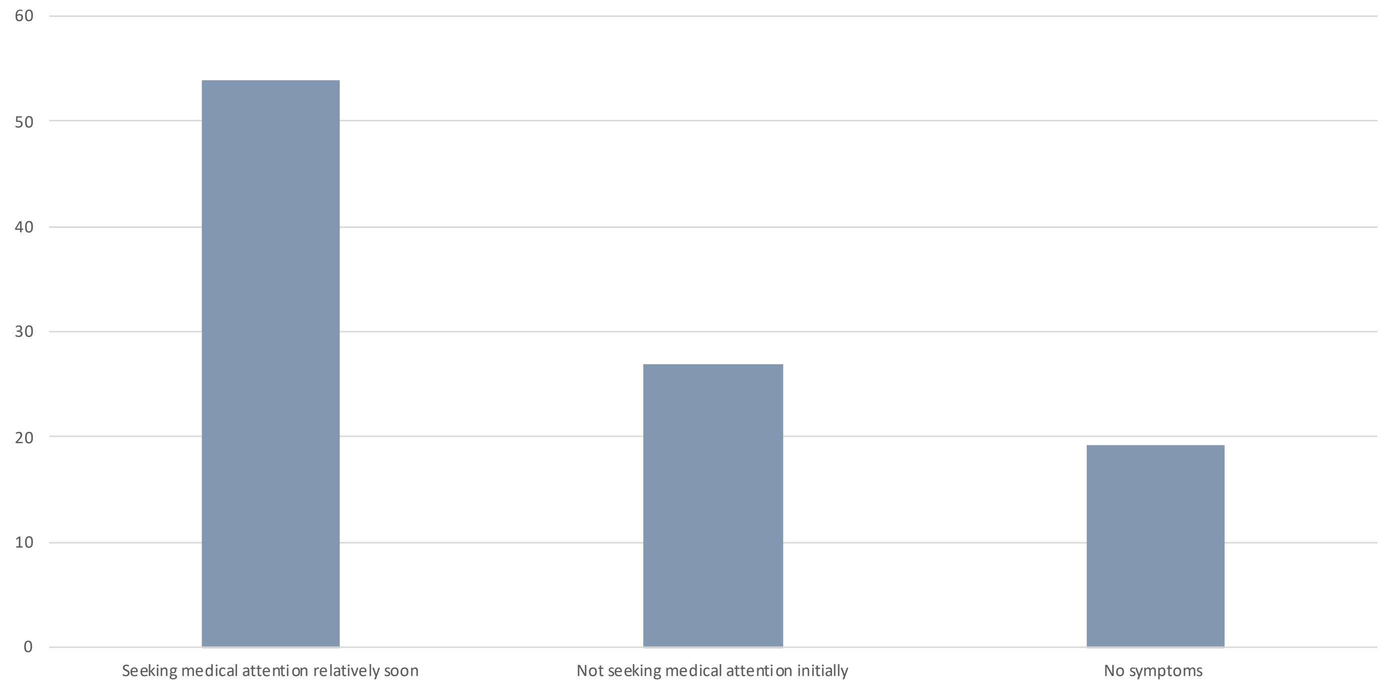

Figure 3.6: Seeking medical attention

Table 3.7: Seeking medical attention – subgroup variations

Seeking medical attention	Less frequently	More frequently
Having symptoms and seeking medical attention relatively soon	Non-metastatic Mid to low status	Aged 65 or older Higher status
Having symptoms and not seeking medical attention initially	Male Aged 65 or older Higher status	Female Mid to low status
Having no symptoms or not noticing any symptoms before diagnosis	-	Non-metastatic Aged 65 or older

Symptoms leading to diagnosis: Description of diagnostic pathway

In the structured interview, participants described their diagnostic pathway in the healthcare system. The most common responses were that they were diagnosed by a specialist from their general practioner (34.62%), and having multiple specialists needed before diagnosis (26.92%). Other pathways included being diagnosed in an emergency department (23.08%), and being diagnosed by their general practitioner during a routine check-up that was not related to symptoms (15.38%)

Specialist from their general practitioner (Linear)

I'd been going to my doctor for about six months saying, "I'm really tired." He just kept checking my blood and saying, "Your blood work's fine." He didn't know what else to do. I lost a lot of weight. I thought maybe it was because I was overweight. I got down to 60 kilos, and I still didn't feel any better. When I had this pain, I actually didn't go to my doctor. I went to another just a random doctor. I said, "I think I've broken my rib." That's what it felt like. She sent me for a chest x-ray to check my ribs. I got the results back before she did. I could see what was there. It was pretty obvious from there what was going on. When I walked in there, I knew. Then she said, "There's a mass in the right lung which just looked like a golf ball on the x-ray." She sent me for a CT, which I had the next day. Then the day after that, I went back to her and she hadn't read it. I watched her read it, and I could see by her face that it wasn't good. She did not hide. [laughs] She said, "This blood." Then she just kept shaking her head and saying, "This is very, very bad." I said, "Can I read it?" I had a read of it and I said, "Okay."
Participant 002_2023AULUC

Yes. At work, it was becoming extremely difficult to breathe while I was working. I was becoming more and more short of breath, and that probably happened six months before they found the nodule in my lung.
Participant 003_2023AULUC

One day I think I blew my nose and there may have been blood in it or something. I went back down to my GP for something completely-- I think it was the iron, and I said, "Oh, actually, also, I did cough up and there was a bit of blood, but I've got a cold, so I'm not worried about it." She said, "Oh, okay." She said, "Can you just go next door to the X-ray people, the radiologist, and just have a chest X-ray?"I went straight next door and got straight in, and the radiologist said to me, "Go straight back to your doctor."
Participant 019_2023AULUC

Multiple specialists needed before diagnosis (Complex)

She said it's an infection, so she put me on a double course of Rulide and Augmentin. I did that. I had a pre-chest x-ray as well, to see if the antibiotics has changed, then went back and had a post-x-ray. There was no change. She said to me, "I think you need a bronchoscopy." I'll give you a timeline. I saw her on 1st of September. By the 25th of October, I had a bronchoscopy, which I was really worried about. She came out and said, "No. All clear. You've just got garden variety pneumonia." I think I said to her, "What the hell's garden variety pneumonia?" But anyway. She then put me on three months of long-term antibiotics. Which I took for three months. I think I finished them in the end of January. Went back for a CT. I work in a hospital so the CT-- I could feel something is in my back by then, in my upper chest. The radiologist said to me-- I said to him, "It's still there." and he went, "Yes, it's still there." Anyway, I didn't have an appointment with her for a couple of weeks, so I didn't see her for a while. Then she rang me. I couldn't go in because there was a lot of COVID. I don't know if I had COVID going on or whatever. She said, "It's still there." At that point, I hadn't seen the results. She was still going down the line of, "Oh, have you been in contact with TB? It could be a fungal. Blah, blah, blah." Which is completely different to what the CT said. The CT said quite clear it was a cancer. Anyway, I had to wait another nine days or so for the lung biopsy. Had that. She got the results on the day. Still had to wait another nine or ten days to see her, which I actually brought forward because I was so stressed. I walked in and she said, "Oh, you've got an adenocarcinoma." That's how my diagnosis came about. She said stage 1B. Turned out to be 2A.
Participant 025_2023AULUC

The first week of August, I went in and I said, "I want a scan. This is ridiculous. There is something else going on." I booked in for a CT. On August 8th, I was told that my wrists were fine, but there was something in my lung, but not to worry. Then I went to the doctors and they said, "Oh, don't worry." I've not been a smoker before. "You're fit and healthy." The GP said, "Oh, we'll send you to our-- I think you should go for a PET scan." "What do you mean? I haven't been diagnosed at this stage. All right? So I get sent to a respiratory specialist. He tells me, "It can't be lung cancer." I'm a little bit stressed. It's probably me seeing-- when you have to have medications [inaudible]. You have to go into a nuclear scan which can only be done at the HOSPITAL. We've got to be there. So that...I have to wait two weeks. I have the assessment. I've got to wait another appointment to go see the respiratory specialist. The respiratory specialist said, "Oh, yes. It's come back. It doesn't look like it's a carcinoid, but there's other thing that it could be. I think we should just wait and see."
Participant 027_2023AULUC

Diagnosed in emergency department

Then it all came to head when I had a seizure. I collapsed at home and from the seizure, they determined that I had secondary brain tumors and the primary tumor was in my lungs. That's when it all happened.
Participant 005_2023AULUC

Right, now I went to the hospital because I had been puffy, like out of breath, and I had swollen legs so they put me into hospital. [crosstalk] Actually, they did a lung x-ray, is in the casualty department, and that's when they must have seen some spots, but didn't tell me.
Participant 013_2023AULUC

Diagnosed by their general practitioner during a routine check-up (not related to symptoms)

I didn't have symptoms. My diagnosis was picked up by a CT calcium score. My GP sent me off for the CT calcium score I think it was November last year because she wanted to check for plaque in my arteries and the lesions showed up then. After that, she sent me for another CT scan just specifically for the lungs. They reconfirmed what the CT calcium score had said. No symptoms. Participant 010_2023AULUC

Table 3.8: Diagnostic pathway

Diagnostic pathway	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	%
Specialist from their general practitioner (Linear)	9	34.62	9	36.00	0	0.00	3	30.00	6	37.50	7	43.75	2	20.00
Multiple specialists needed before diagnosis (Complex)	7	26.92	7	28.00	0	0.00	2	20.00	5	31.25	6	37.50	1	10.00
Diagnosed in emergency department	6	23.08	5	20.00	1	100.00	2	20.00	4	25.00	3	18.75	3	30.00
Diagnosed by their general practitioner during a routine check-up (not related to symptoms)	4	15.38	4	16.00	0	0.00	3	30.00	1	6.25	3	18.75	1	10.00

Diagnostic pathway	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	%
Specialist from their general practitioner (Linear)	9	34.62	7	41.18	2	22.22	3	23.08	6	46.15	2	100.00	7	29.17	4	44.44	5	29.41
Multiple specialists needed before diagnosis (Complex)	7	26.92	5	29.41	2	22.22	3	23.08	4	30.77	0	0.00	7	29.17	2	22.22	5	29.41
Diagnosed in emergency department	6	23.08	2	11.76	4	44.44	6	46.15	0	0.00	0	0.00	6	25.00	2	22.22	4	23.53
Diagnosed by their general practitioner during a routine check-up (not related to symptoms)	4	15.38	2	11.76	2	22.22	1	7.69	3	23.08	0	0.00	4	16.67	1	11.11	3	17.65

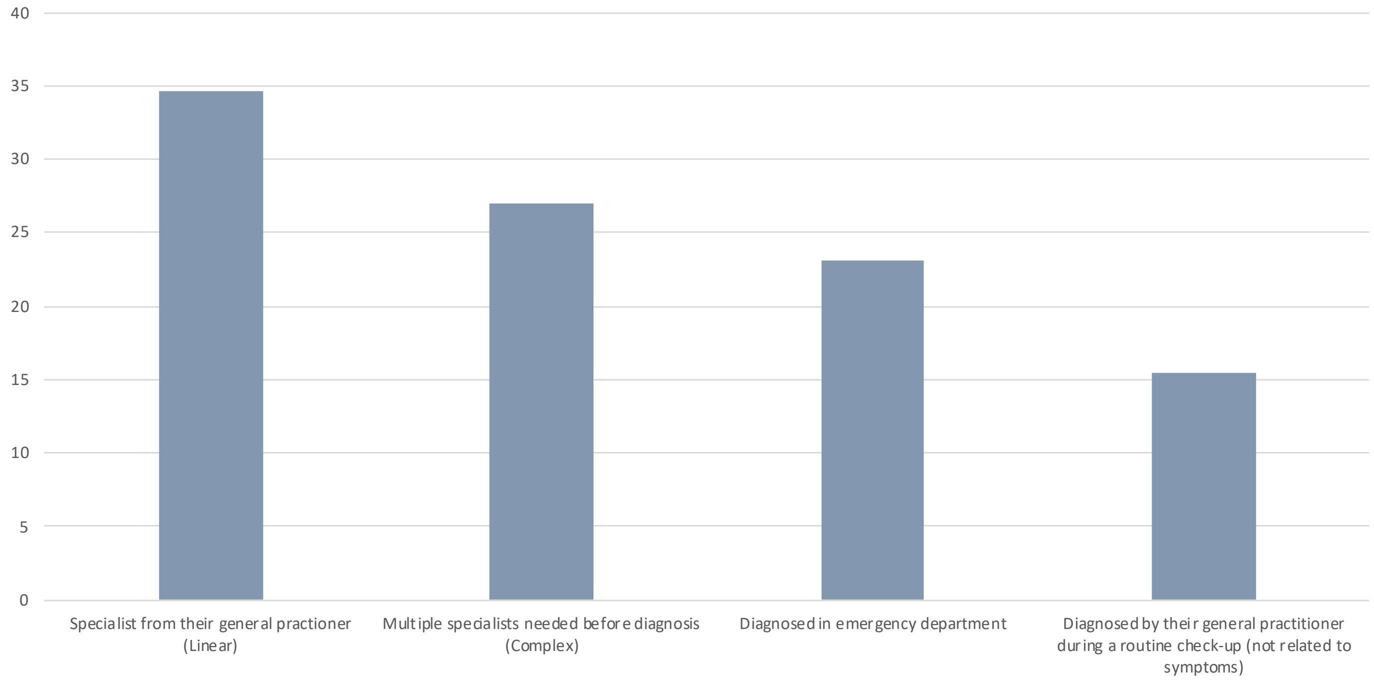

Figure 3.7: Diagnostic pathway

Table 3.9: Diagnostic pathway – subgroup variations

Diagnostic pathway	Less frequently	More frequently
Specialist from their general practitioner (Linear)	Male Aged 65 or older Trade or high school	University
Multiple specialists needed before diagnosis (Complex)	Male	Female
Diagnosed in emergency department	Aged 35 to 64 University	Aged 65 or older Trade or high school
Diagnosed by their general practitioner during a routine check-up (not related to symptoms)	-	Non-metastatic

Timing of diagnosis

Time from symptoms to diagnosis

Participants were asked to give the approximate date of when they first noticed symptoms of lung cancer and the approximate date of diagnosis with lung cancer. Where enough information was given, an approximate duration from first noticing symptoms to diagnosis was calculated.

Duration was calculated for 29 participants (9 participants had no symptoms before diagnosis), there were 7 participants (24.14%) that were diagnosed less than 1 month of noticing symptoms, 4 participants (13.79%) diagnosed between 2 and 3 months from noticing symptoms, 5 participants (17.24%) that were diagnosed between 6 months and 1 year of noticing symptoms, and 4 participants (13.79%) that were diagnosed more than 1 year of noticing symptoms (Table 3.10, Figure 3.8).

Time from diagnostic test to receiving a diagnosis

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis.

There were 7 participants (24.14%) that were diagnosed less than 1 week after testing, 8 participants

(27.59%) diagnosed between 1 and 2 weeks after testing, 8 participants (27.59%) that were diagnosed between 2 and 3 weeks after testing, and 6 participants (20.69%) that were diagnosed 4 weeks or after testing (Table 3.11, Figure 3.9).

Table 3.10: Time from symptoms to diagnosis

Time from symptoms to diagnosis	Number (n=29)	Percent
Less than 1 month	7	24.14
Between 2 and 3 months	4	13.79
Between 6 months and 1 year	5	17.24
More than 1 year	4	13.79
No symptoms	9	31.03

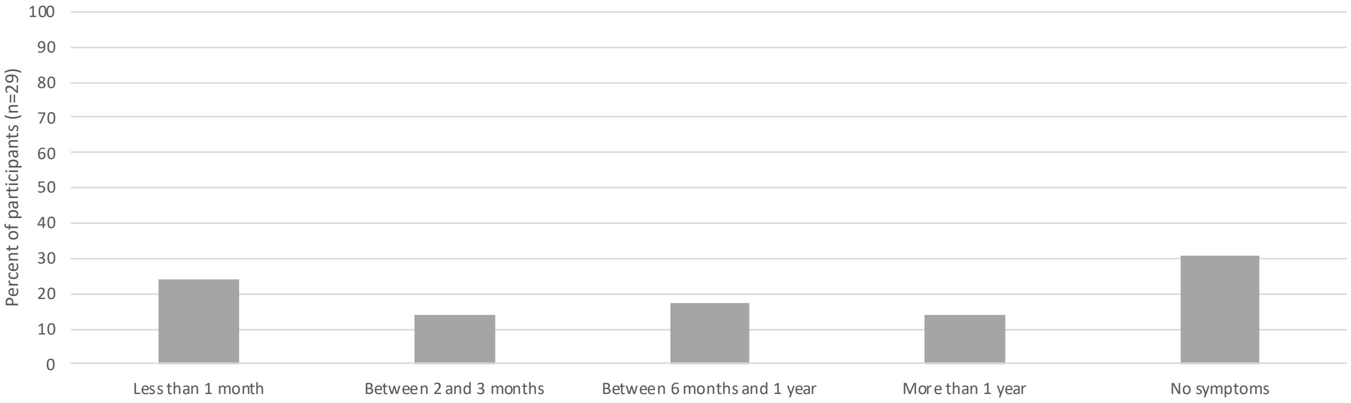

Figure 3.8: Time from symptoms to diagnosis

Table 3.11: Time from diagnostic test to diagnosis

Time from diagnosis test to diagnosis	Number (n=29)	Percent
Less than 1 week	7	24.14
Between 1 and 2 weeks	8	27.59
Between 2 and 3 weeks	8	27.59
4 weeks or more	6	20.69

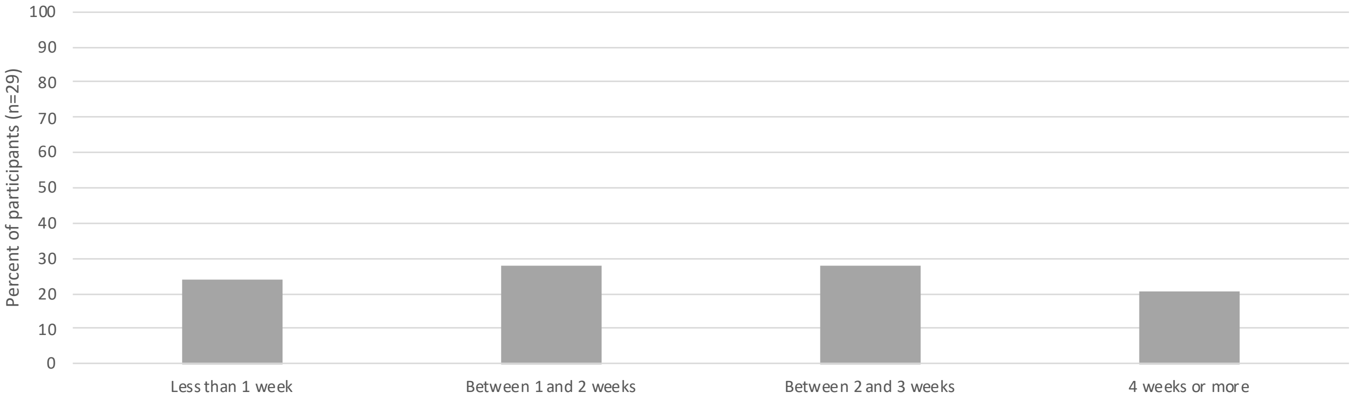

Figure 3.9: Time from diagnostic test to diagnosis

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with lung cancer. They could choose from a set list of diagnostic tests, and could then specify other tests not listed. The number of tests per participant were counted using both tests from the set list and other tests specified.

Participants reported between 0 to 5 diagnostic tests (median=3.00 , IQR=1.00) (Table 3.12, Figure 3.10). The most common tests were PET scan (n=23, 79.31%), Biopsy (n=20, 68.97%), CT scan (n=25, 86.21%), and Chest x-ray (n=15, 51.72%) (Table 3.13, Figure 3.11).

Table 3.12: Number of diagnostic tests

Number of diagnostic tests per participant	Number (n=29)	Percent
0	1	3.45
1	2	6.90
2	3	10.34
3	13	44.83
4	9	31.03
5	1	3.45

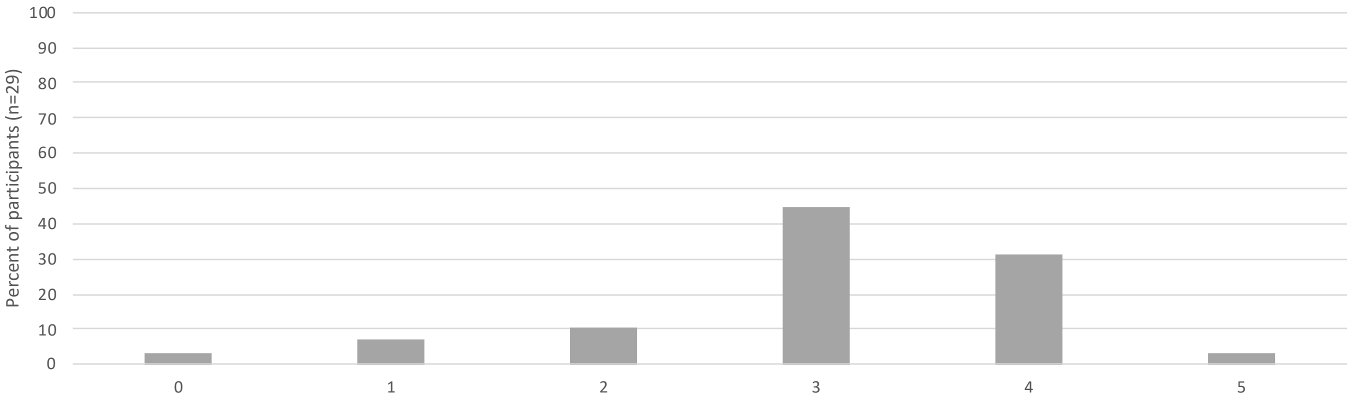

Figure 3.10: Number of diagnostic tests

Table 3.13: Diagnostic tests

Diagnostic tests	Number (n=29)	Percent
PET scan	23	79.31
Biopsy	20	68.97
CT scan	25	86.21
Chest x-ray	15	51.72
Sputum cytology (mucus from your lungs examined under a microscope)	2	6.90
Other	3	10.34
None	1	3.45

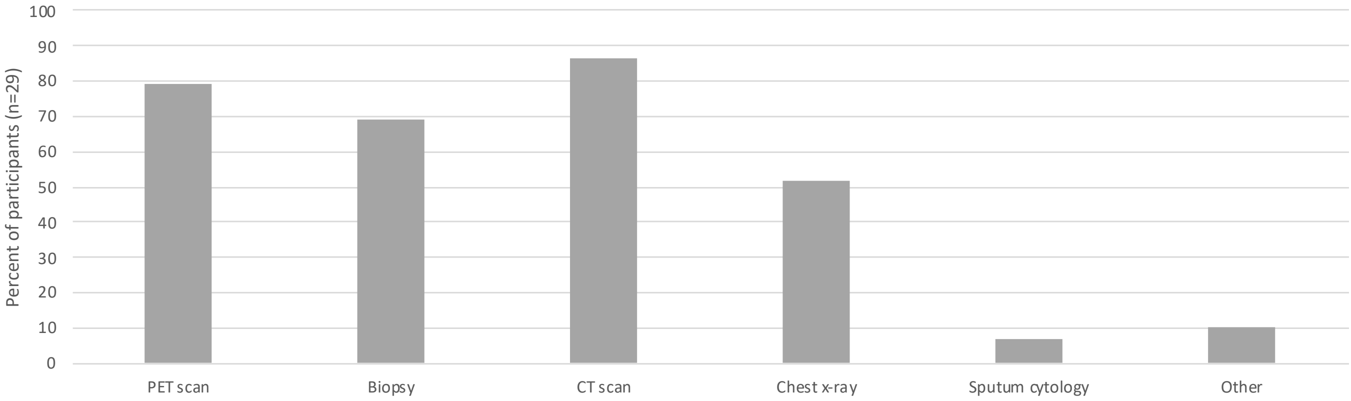

Figure 3.11: Diagnostic tests

Diagnosis provider and location

Participants were asked in the online questionnaire, which healthcare professional gave them their diagnosis, and where they were given the diagnosis.

Almost half of the participants were given their diagnosis by a respiratory specialist (n=14, 48.28%), and there were 5 participants (17.24%) given the diagnosis by a general practitioner, 3 participants (10.34%) diagnosed by an oncologist, and 3 participants (10.34%) by an emergency doctor or ambulance paramedic (Table 3.14, Figure 3.12).

Participants were most commonly given their diagnosis in the hospital (n=15, 51.72%), this was followed by the specialist clinic (n=6, 20.69%), and the general practice (n=4, 13.79%) (Table 3.15, Figure 3.13).

Table 3.14: Diagnosis provider

Health professional gave diagnosis	Number (n=29)	Percent
Respiratory specialist	14	48.28
General practitioner	5	17.24
Oncologist	3	10.34
Emergency department or ambulance	3	10.34
Surgeon	2	6.90
Other	2	6.90

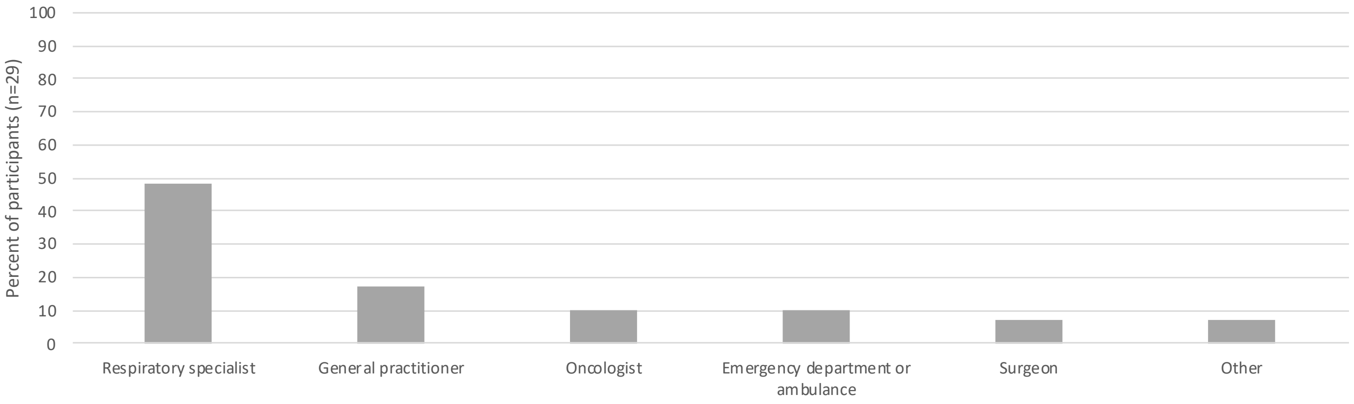

Figure 3.12: Diagnosis provider

Table 3.15: Diagnosis location

Location of diagnosis	Number (n=29)	Percent
Hospital	15	51.72
Specialist clinic	6	20.69
General practice	4	13.79
Over the phone	3	10.34
Other	1	3.45

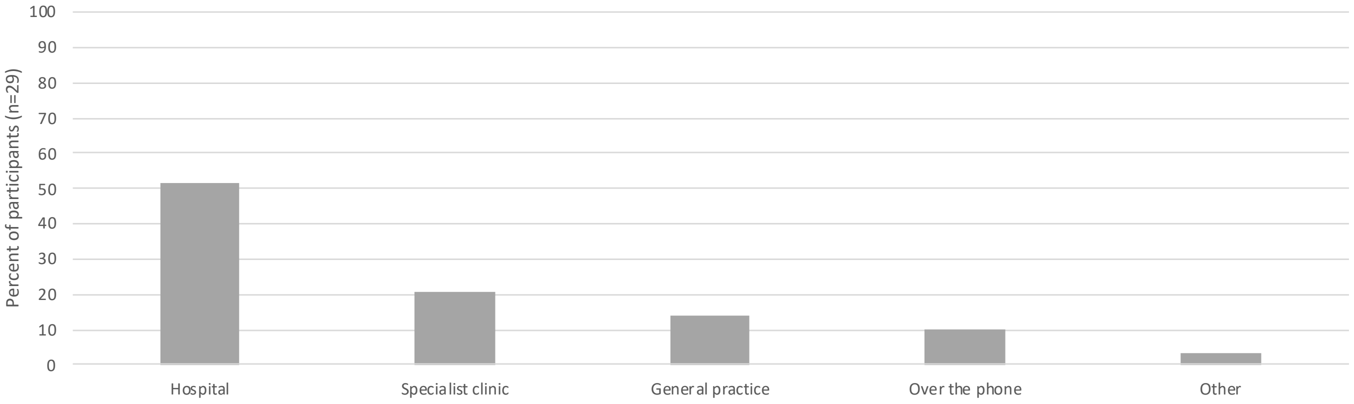

Figure 3.13: Diagnosis location

Year of diagnosis

In the online questionnaire, participants noted the approximate date of diagnosis, the year of diagnosis is presented in Table 3.16, Figure 3.14.

Participants were diagnosed between 2012 to 2022. There were 24 participants (82.76%) that were diagnosed in the last five years.

Table 3.16: Year of diagnosis

Year of diagnosis	Number (n=29)	Percent
2014 or before	3	10.34
2015 to 2019	5	17.24
2020 to 2022	21	72.41

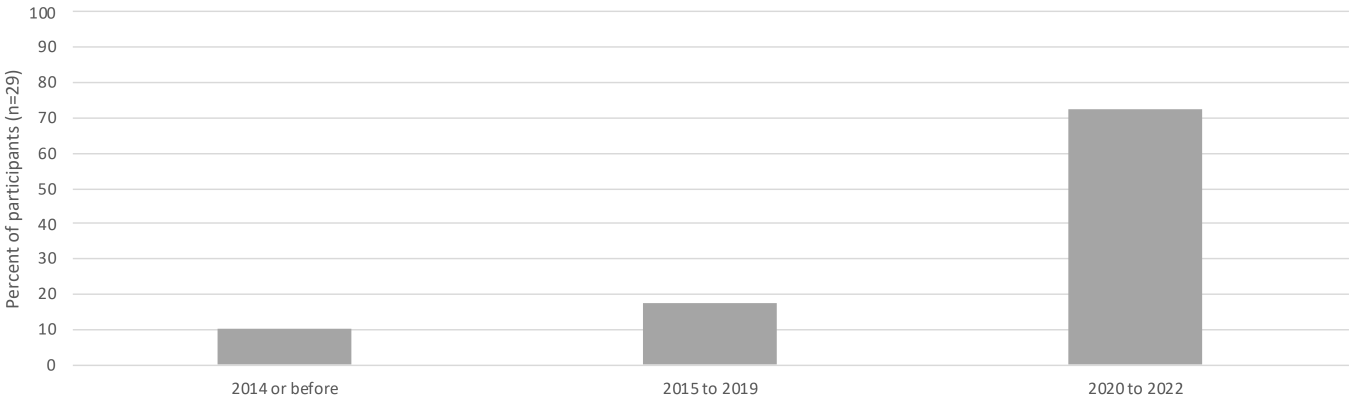

Figure 3.14: Year of diagnosis

Lung cancer diagnosis, stage and spread

Lung cancer diagnosis

The majority of participants were diagnosed with Non-small cell lung cancer (n=29, 90.63%) (Table 3.17, Figure 3.15).

Lung cancer stage

There were 4 participants (12.50%), with Stage 1 lung cancer, 3 participants (9.38%) with Stage 2, 4 participants (12.50%) with Stage 3, and 18 participants (56.25%), with Stage 4 lung cancer.
(Table 3.18, Figure 3.16).

Lung cancer spread

Participants noted in the online questionnaire if the cancer had spread, and where it had spread to. There were 13 participants (44.83%) that noted that the cancer had spread. The most common sites of spread were the brain (n=6, 20.69%), lymph nodes (n=4, 13.79%) and bones (n=4, 13.79%) (Table 3.19, Figure 3.17).

Lung cancer recurrence

There were 8 participants (27.59%) that reported having had a lung cancer recurrence.

Table 3.17: Type of lung cancer

Diagnosis	Number (n=32)	Percent
Non-small cell lung cancer	29	90.63
Other/not sure	3	9.38

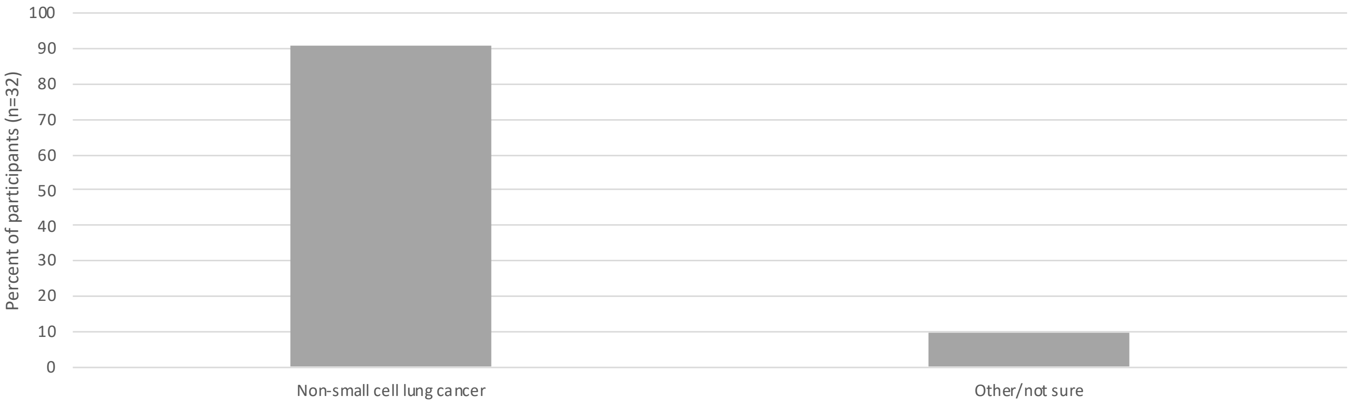

Figure 3.15: Type of lung cancer

Table 3.18: Lung cancer stage

Lung cancer stage	Number (n=32)	Percent
Stage 1	4	12.50
Stage 2	3	9.38
Stage 3	4	12.50
Stage 4	18	56.25
Not known	3	9.38

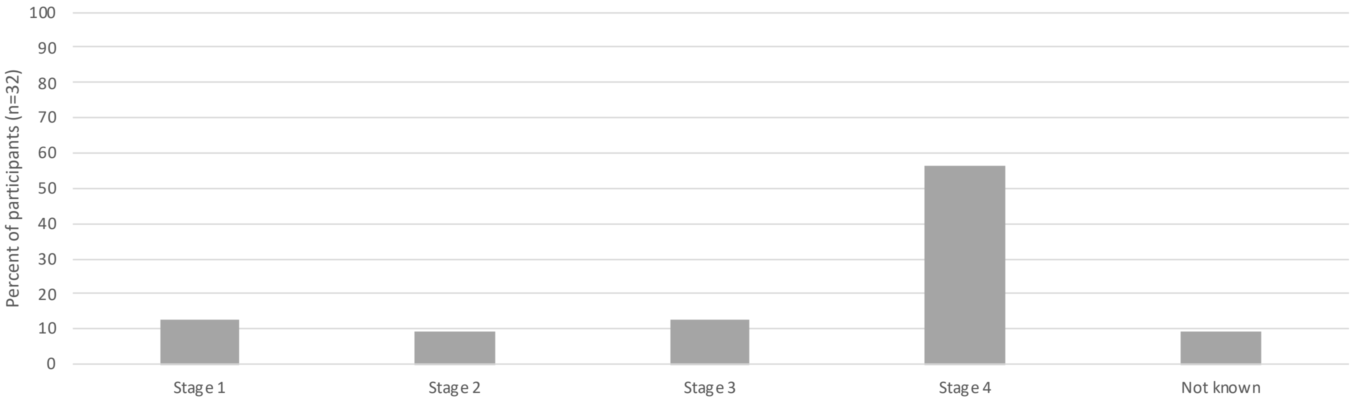

Figure 3.16: Lung cancer stage

Table 3.19: Lung cancer spread

Cancer spread	Number (n=29)	Percent
Brain	6	20.69
Lymph nodes	4	13.79
Bone	4	13.79
Lymph nodes	4	13.79
Liver	3	10.34
Esophagus	1	3.45
Adrenal glands	1	3.45
No spread/not sure	16	55.17

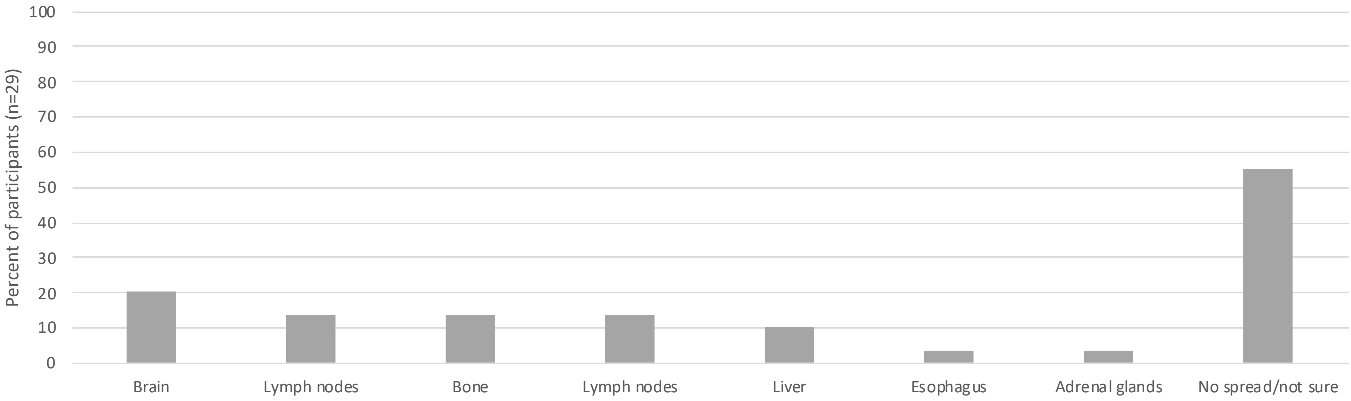

Figure 3.17: Lung cancer spread

Table 3. 20: Lung cancer recurrence

Lung cancer recurrence	Number (n=29)	Percent
No	21	72.41
Yes	8	27.59

Figure 3.18: Lung cancer recurrence

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. The most common responses were having no or little knowledge at diagnosis(61.54%), having knowledge because of family history of the condition or knowing someone who has the condition (15.38%), and having knowledge from a professional background (11.54 %).

Knowing nothing or very little about the condition at diagnosis

Not a lot, to be honest. There is a public perception that is related to smoking and I've never been a smoker. I know non-smokers would get it too. I really didn't have much information about lung cancer and would've never considered that that was a possibility for me. I couldn't understand how it could be at my age with my level of fitness at the time. It wouldn't have been comprehensible to consider lung cancer as a diagnosis.
Participant 005_2023AULUC

Nothing. Absolutely nothing at all. Participant 007_2023AULUC

Not a lot really. To be honest, I was in denial because a couple of years ago I'd had a very bad chest infection and I thought, "Oh, it's probably just scarring from that because that's not unusual." Of course, I follow all this up. I didn't not do anything about it, but until the respiratory specialist said it was lung cancer, I didn't think much of it. As I said, I had no symptoms. I felt well.
Participant 010_2023AULUC

Not a lot at all. I didn't even know your lungs started underneath your collarbone. I knew very, very little. I guess I was as ignorant as most of the public are thinking that I'm going to die, because you just hear that everyone who gets lung cancer dies. I had been a previous smoker, so I figured it was my own fault. That was basically all I knew.
Participant 018_2023AULUC

Very little, really. Of course, I jumped onto Google and freaked myself out completely about if it was a-- I was told that it was a spiculated nodule. Then having looked up to see what a spiculated module was and what the likelihood that that was cancerous, I was obviously extremely concerned at that point in time. 021_2023AULUC

Relatively little. I would say no specialist knowledge. Participant 022_2023AULUC

All I knew is that it was a bad cancer to have. Participant 023_2023AULUC

Very little. We've not got cancer in the family. Look, I smoked a tiny bit when I was way young, like 40 years earlier. I'm a HEALTH PROFESSIONAL but not in the area, oncology, and lung cancers as such is not an area I've ever worked in. I probably knew enough, but not enough, if that makes sense. 025_2023AULUC

Knowing about the condition at diagnosis because they have a family history of the condition/know someone who has the condition

I knew that it had killed my father. I knew that it was in most cases fairly dire diagnosis. I didn't think it was a good diagnosis. I thought it was a terminal diagnosis. 014_2023AULUC

Oh gosh. My only real knowledge of lung cancer is I knew through my work that it metastasizes to the brain and the eye. That was part of what I knew. I knew it went to bones. The only experience I'd had is that my father died of it about 20 years ago. That was pretty horrific because, of course, I came with that preconceived idea of I've really only got about six months to go.
Participant 020_2023AULUC

Knowing about the condition due to professional background

I'm a HEALTH PROFESSION. I probably have a little bit more knowledge about it than the average person, but I'm also a smoker. Yes. I'm not a professional in that field, but may be a little bit more than the average person. Participant 003_2023AULUC

Only what I'd learned at uni, because I have a health background, so I expected it to happen to smokers. I knew that lung cancer wasn't a great cancer to get, but I wasn't quite sure of the exact statistics until after I was diagnosed. That was about-- I knew there were different types of lung cancer. I knew there was non-small cell and small cell, but again, I didn't know specific details, certainly didn't know there was any mutations because of the [unintelligible 00:08:02] study that I had done was 8 or 9 or 10 years prior, even longer actually, maybe. Participant 015_2023AULUC

Table 3.21: Understanding of disease at diagnosis

Understanding of disease at diagnosis	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	%
Knowing nothing or very little about the condition at diagnosis	16	61.54	15	60.00	1	100.00	5	50.00	11	68.75	11	68.75	5	50.00
Knowing about the condition at diagnosis because they have a family history of the condition/know someone who has the condition	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	3	18.75	1	10.00
Knowing about the condition due to professional background	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00

Understanding of disease at diagnosis	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	%
Knowing nothing or very little about the condition at diagnosis	16	61.54	8	47.06	8	88.89	10	76.92	6	46.15	1	50.00	15	62.50	5	55.56	11	64.71
Knowing about the condition at diagnosis because they have a family history of the condition/know someone who has the condition	4	15.38	3	17.65	1	11.11	2	15.38	2	15.38	0	0.00	4	16.67	1	11.11	3	17.65
Knowing about the condition due to professional background	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

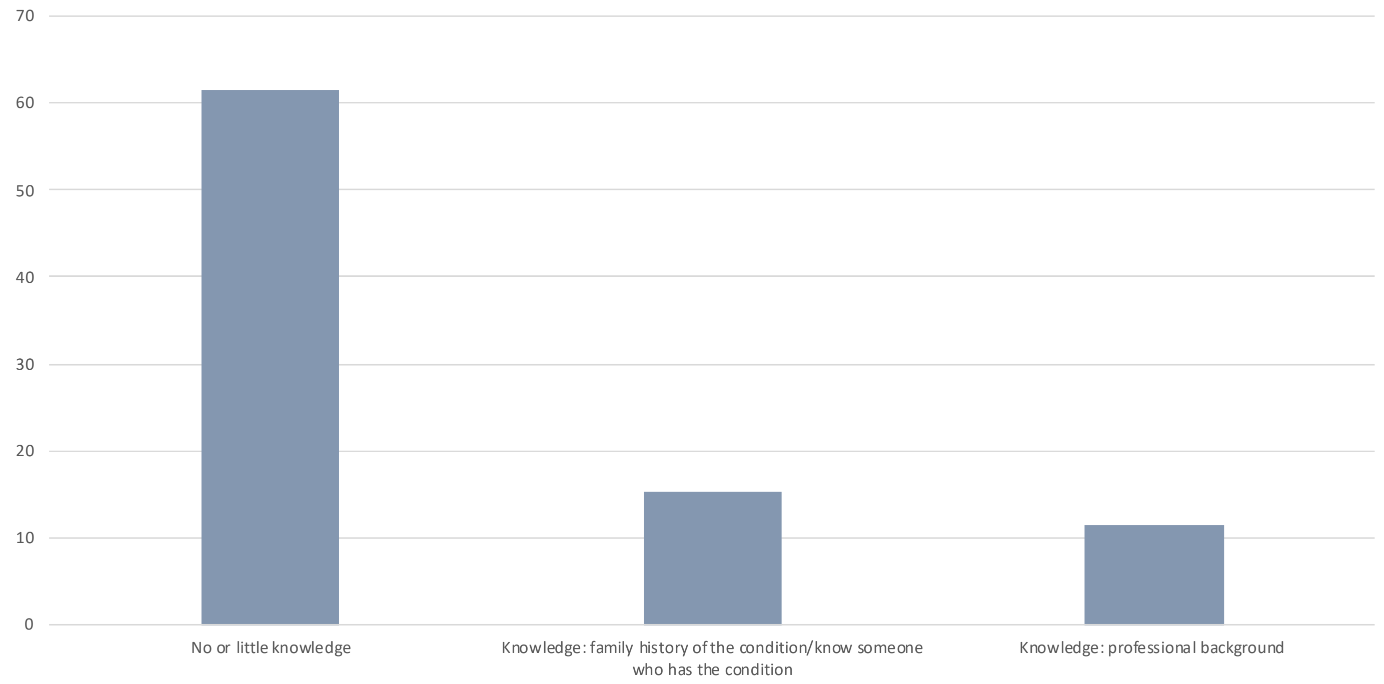

Figure 3.19 Understanding of disease at diagnosis

Table 3.22: Understanding of disease at diagnosis – subgroup variations

Understanding of disease at diagnosis	Less frequently	More frequently
Knowing nothing or very little about the condition at diagnosis	Non-metastatic Male Aged 35 to 64 University	Aged 65 or older Trade or high school
Knowing about the condition due to professional background	Male Aged 65 or older	-

Emotional support at diagnosis

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis.

There were 6 participants (20.69%) who had enough support, 3 participants (10.34%) that had some support but it wasn't enough, and 20 participants (68.97%) had no support (Table 3.23, Figure 3.20).

Table 3.23: Emotional support at diagnosis

Emotional support at diagnosis	n=29	%
Enough support	6	20.69
Some support but it wasn't enough	3	10.34
No support	20	68.97

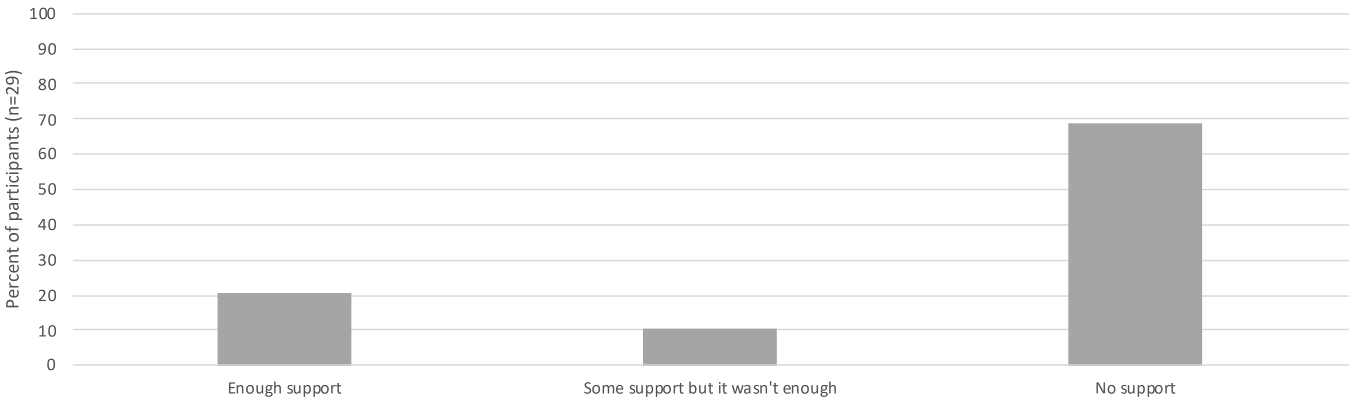

Figure 3.20: Emotional support at diagnosis

Costs at diagnosis

Out of pocket expenses at diagnosis

Participants noted in the online questionnaire the amount of out-of-pocket expenses they had at diagnosis, for example doctors' fees, and diagnostic tests.

There were 16 participants (55.17%) who had no out of pocket expenses, and 3 participants (10.34%) who did not know or could not recall. There were 5 participants (17.24%) that spent between $400 and $800, and 5 participants (17.24%) that spent more than $1000 (Table 3.24, Figure 3.21).

Burden of diagnostic costs

For 22 participants (75.86%) the cost was slightly or not at all significant. For 5 participants (17.24%) the out-of-pocket expenses were somewhat significant, and for 2 participants (6.90%), the burden of out-of-pocket expenses were moderately or extremely significant (Table 3.25, Figure 3.22)

Table 3.24: Out of pocket expenses at diagnosis

Out of pocket expenses for diagnostic tests	Number (n=29)	Percent
$0	16	55.17
$400 to 800	5	17.24
>$1000	5	17.24
Not sure	3	10.34

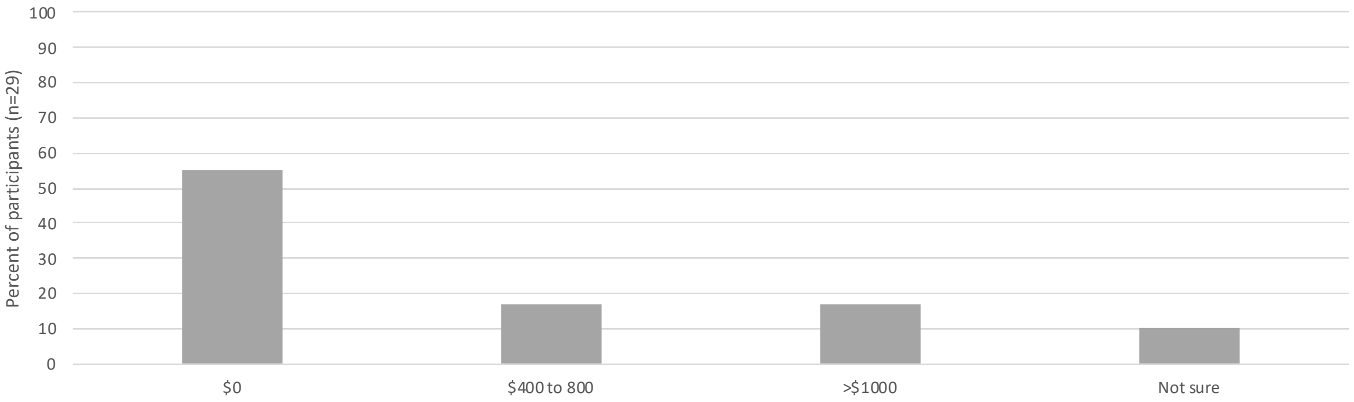

Figure 3.21: Out of pocket expenses at diagnosis

Table 3.25: Burden of diagnostic costs

Burden of diagnostic costs	Number (n=29)	Percent
Not at all significant	15	51.72
Slightly significant	7	24.14
Somewhat significant	5	17.24
Moderately significant	0	0.00
Extremely significant	2	6.90

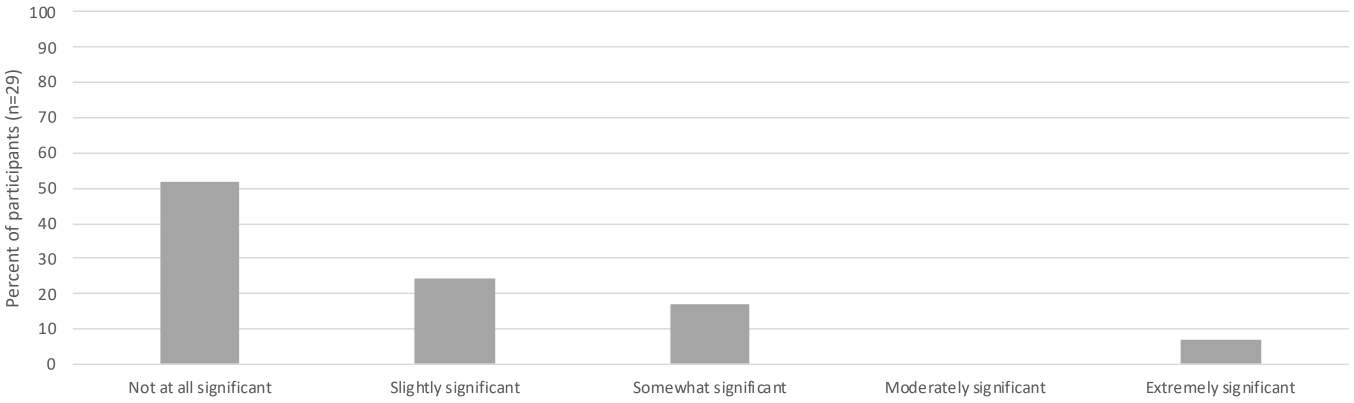

Figure 3.22: Burden of diagnostic costs

Genetic tests and biomarkers

Participants answered questions in the online questionnaire about if they had any discussions with their doctor about biomarkers, genomic and gene testing that might be relevant to treatment. If they did have a discussion, they were asked if they brought up the topic or if their doctor did.

Most commonly, participants had never had a conversation about biomarkers, genomic, or gene testing that might be relevant to treatment, (n=16, 55.17%). There were 3 participants (10.34%) who brought up the topic with their doctor, and 10 participants (34.48%) whose doctor brought up the topic with them (Table 3.26, Figure 3.23).

Participants were then asked if they had had any biomarker, genomic or gene testing. If they had testing, they were asked if they had it as part of a clinical trial, paid for it themselves or if they did not have to pay for it. Those that did not have the test were asked if they were interested in this type of test.

Participants most commonly did not have any genetic or biomarker tests but would like to (n=13, 44.83%). There were 2 participants (6.90%) who did not have these tests and were not interested in them, and a total of 14 participants (48.28%) that had biomarker tests (Table 3.27, Figure 3.24).

Table 3.26: Discussions about biomarkers

Discussions about biomarkers	Number (n=29)	Percent
Participant brought up the topic with doctor for discussion	3	10.34
Doctor brought up the topic with participant for discussion	10	34.48
Participant had no discussion about this type of test	16	55.17

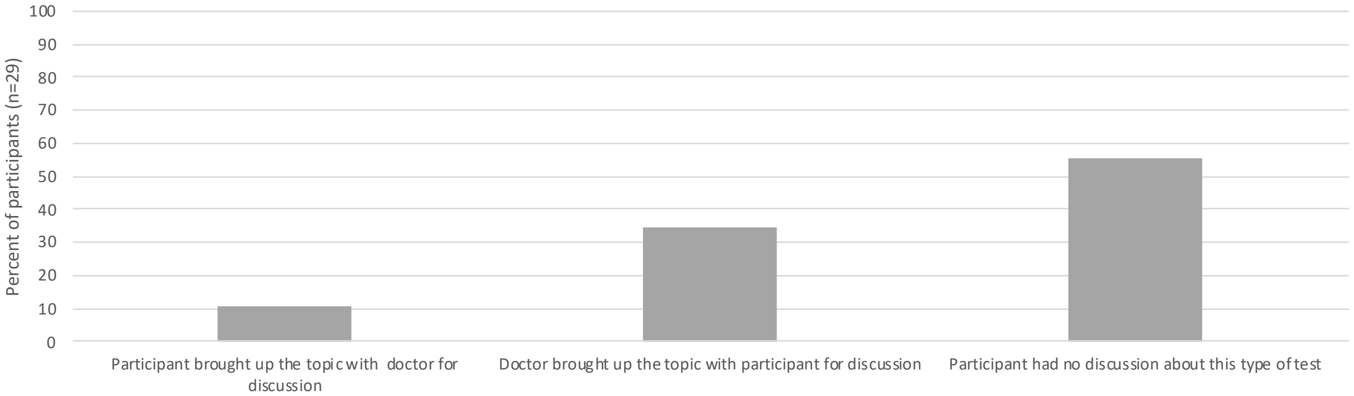

Figure 3.23: Discussions about biomarkers

Table 3.27: Experience of genetic tests and biomarkers

Experience of genetic tests and biomarkers	Number (n=29)	Percent
Participant had this test and did not have to pay out of pocket for it	9	31.03
Participant had this test athrough a clinical trial	0	0.00
Participant had this type of test and paid for it	5	17.24
Participant did not have this test and is not interested in it	2	6.90
Participant did not have this test but would like to	13	44.83

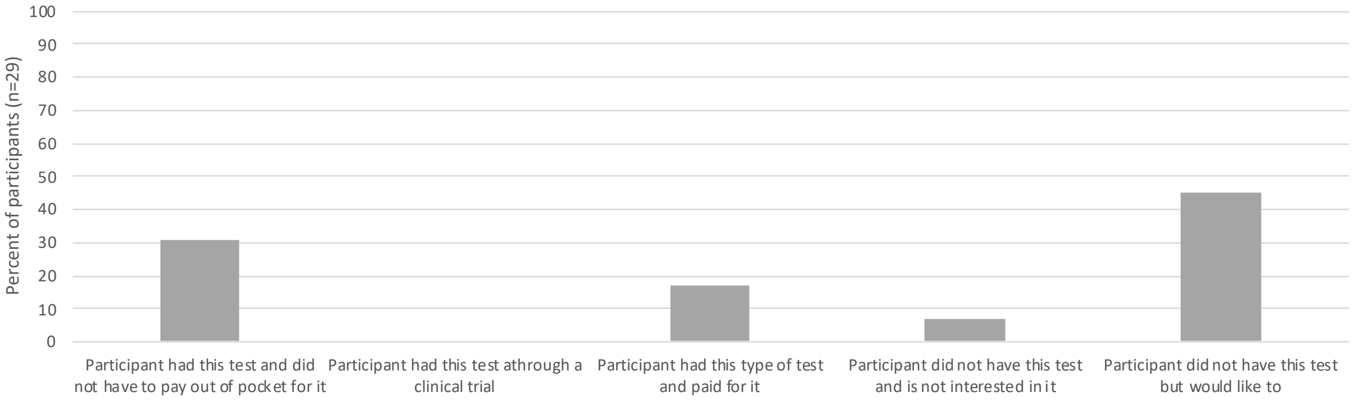

Figure 3.24: Experience of genetic tests and biomarkers

Biomarker status

More than half status for at least one biomarker (n=16, 55.17%). Most commonly, participants knew their EGFR status (n=9, 31.03%), followed by ALK status (n=7, 24.14%) (Table 3.28, Figure 3.25).

Table 3. 28: Biomarker status

Biomarkers	Number (n=29)	Percent
EGFR	9	31.03
ALK	7	24.14
TP53	1	3.45
Not sure	13	44.83

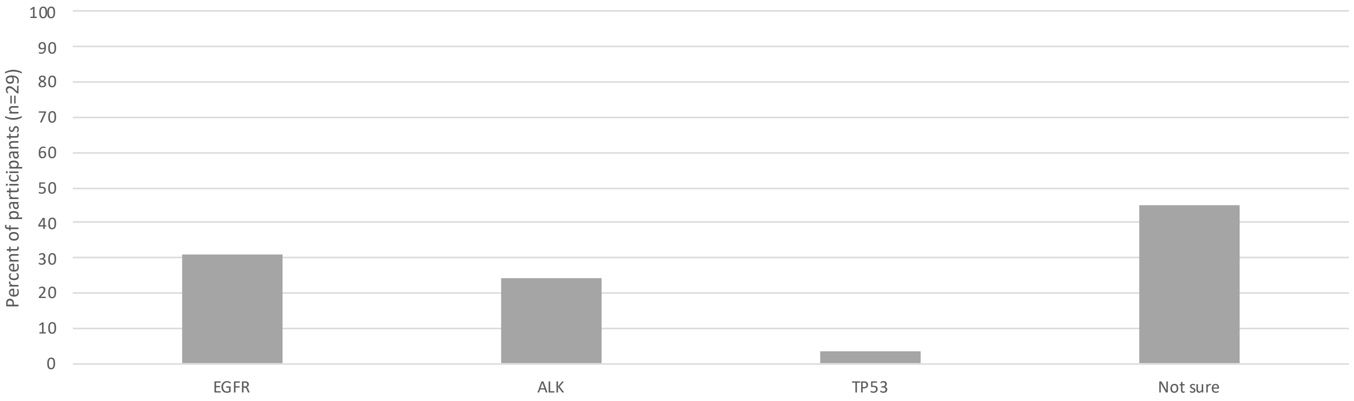

Figure 3.25: Biomarker status

Understanding of prognosis

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. The most common responses were uncertainty around prognosis (61.54%), and that they had a poor prognois or a terminal condition (15.38%). Other themes included having no evidence of disease or that they are in remission (11.54%), and describing a specific timeframe that they are expected to live (7.69%).

Participant describes prognosis in relation to uncertainty around prognosis

I don't have one. Participant 003_2023AULUC

It's a stage 4. They don't really give you a timeline. My oncologist said, "You can live the years and hopefully, there'll be new drugs coming out all the time." I think the prognosis there was a bit overhyped because I don't think there's that many clinical trials or good tablets for EGFR at the moment, but he didn't give me any timeframe. He just said, Years; I can keep you well for years." Participant 004_2023AULUC

No, I don't know what it is. Participant 007_2023AULUC

Well, I don't know. I was diagnosed in August, not last year, the year before. Participant 013_2023AULUC

At the time they did, but certainly not since because nobody knows how long anyone has to live at this point. I've had a lot of ups and downs in my treatment and I'm still alive. Participant 015_2023AULUC

Participant describes prognosis in relation to poor outcomes, or terminal condition

There's no cure for what I've got. Participant 001_2023AULUC

I don't like talking about survivors of lung cancer because there aren't many. For three and a half years, it's been, "You're going to die, you're not going to die, you're going--" to living with lung cancer. I look at it now and I hope that this is where it's going. It is like having blood pressure. We're taking a tablet each day, but we know the tablets stop working. We're just hoping that they come up with more tablets to stop the cancer developing. Participant 019_2023AULUC

For me, I'm realistic that this is a terminal disease. I am doing really well on my treatment and feeling like I don't have anything wrong with me. The side effects from my treatment are manageable. I tend to go, I don't want to think about them because I'm enjoying life as I did before and I will keep going that way until this stops working, and then we'll face the next thing. I'm cautiously optimistic. I know I can't live a long life, but what I'm living is a very good life. Participant 020_2023AULUC

Yes, it's good. It has progressed. Basically, they just don't talk about prognosis, really. They said, from the time when I was diagnosed, it was not curable, so I knew that as well. It's just-- For every day that you have, every week, every month, you're grateful, and that's it. It's just prolonging it, and making the best of it. 023_2023AULUC

Yes. Well, I'm considered terminal at the moment. Participant 024_2023AULUC

Participant describes prognosis in relation to there being no evidence of disease or that they are in remission

Well, I'm sort of in between scans. I'm halfway through before my next scan. I have been no evidence of disease within four weeks of taking the pills. That's continued, knock on wood, till my next scan. I'm in a lot of pain, but the chemo tablets are just horrific. I have a lot of problems, my joints, my muscles hurt. It's hard. It's affected my heart...No, it's poison in the end. Participant 002_2023AULUC

The surgeon said that they got all the cancer-- I had a lobectomy in the right lung, and he said that they got all the cancer that was there. There is no chemotherapy or radiotherapy. At the moment, I think I'm diagnosed as NED, no evidence of disease. I have to have a CT scan every six months and see the surgeon for the next five years. Participant 010_2023AULUC

I've just had my last scan about a month ago, and I'm cancer free. That was my 12-month scan. I've been 12 months since treatment. I've had 12 months and 3 monthly scans, and I'm clear at this stage. Participant 018_2023AULUC

At the moment, I'm officially cancer free. Participant 021_2023AULUC

Participant describes prognosis in relation to specific timeframe that they are expected to live

Yes. When I was diagnosed it was 2020, so what's that? Two years? That's pretty good. The prognosis was about seven months, I think, but I'm on targeted therapy, which has been working. I've just changed over to the new Osimertinib, but that will last less time than the first one did. I think my guess is end of the year would be a good-- If I can make it to the end of the year, so what's that? Another 6, 7 months maybe? Participant 006_2023AULUC

I got a 2 to 10-year prognosis. Participant 026_2023AULUC

No one will tell me that, but by the research, the progression pre-survival is between, they say it's up to seven years now, but there's some other people that it really depends on its targeted treatment. Participant 027_2023AULUC

Table 3. 29: Understanding of prognosis

Understanding of prognosis	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes prognosis in relation to uncertainty around prognosis	9	34.62	9	36.00	0	0.00	2	20.00	7	43.75	8	50.00	1	10.00
Participant describes prognosis in relation to poor outcomes, or terminal condition	7	26.92	6	24.00	1	100.00	0	0.00	7	43.75	5	31.25	2	20.00
Participant describes prognosis in relation to there being no evidence of disease or that they are in remission	5	19.23	5	20.00	0	0.00	4	40.00	1	6.25	3	18.75	2	20.00
Participant describes prognosis in relation to specific timeframe that they are expected to live	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00

Understanding of prognosis	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes prognosis in relation to uncertainty around prognosis	9	34.62	6	35.29	3	33.33	6	46.15	3	23.08	1	50.00	8	33.33	6	66.67	3	17.65
Participant describes prognosis in relation to poor outcomes, or terminal condition	7	26.92	3	17.65	4	44.44	3	23.08	4	30.77	1	50.00	6	25.00	1	11.11	6	35.29
Participant describes prognosis in relation to there being no evidence of disease or that they are in remission	5	19.23	3	17.65	2	22.22	3	23.08	2	15.38	0	0.00	5	20.83	0	0.00	5	29.41
Participant describes prognosis in relation to specific timeframe that they are expected to live	3	11.54	3	17.65	0	0.00	1	7.69	2	15.38	1	50.00	2	8.33	3	33.33	0	0.00

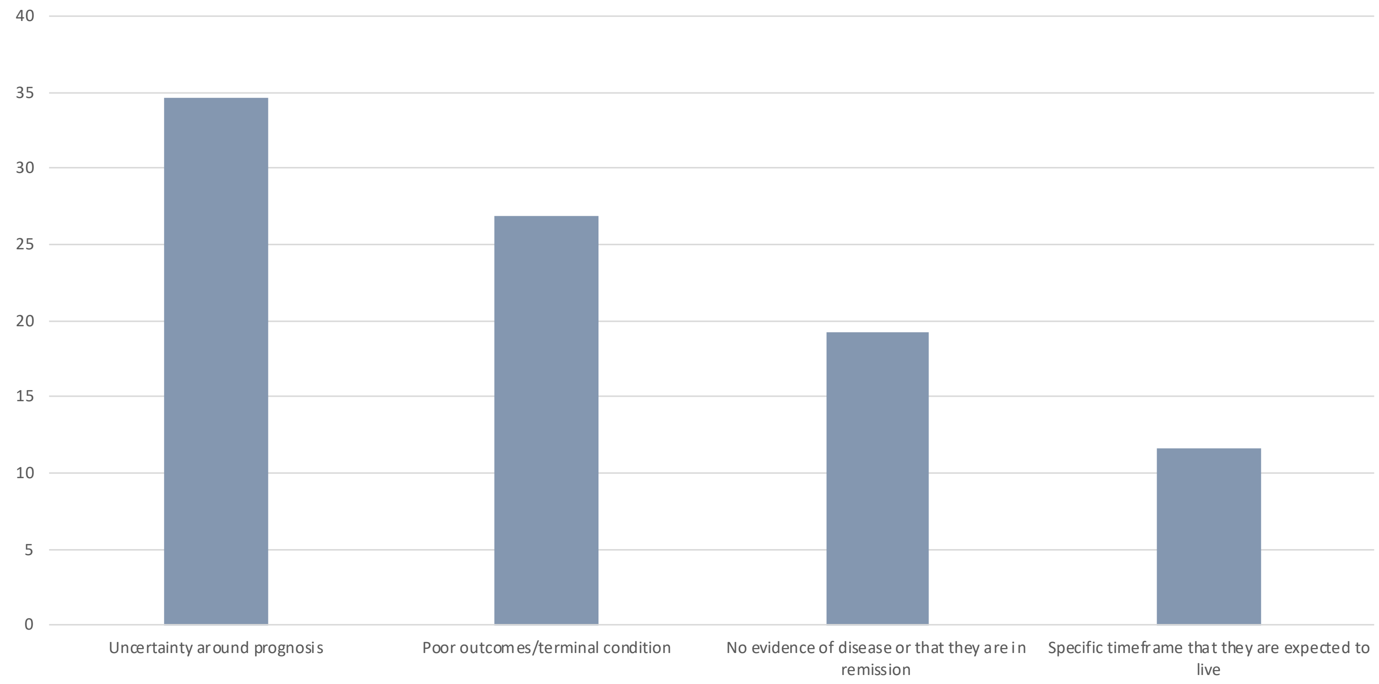

Figure 3.29: Understanding of prognosis

Table 3.26: Understanding of prognosis – subgroup variations

Understanding of prognosis	Less frequently	More frequently
Participant describes prognosis in relation to uncertainty around prognosis	Non-metastatic Male University Higher status	Female Trade or high school Mid to low status
Participant describes prognosis in relation to poor outcomes, or terminal condition	Non-metastatic Mid to low status	Metastatic Aged 65 or older
Participant describes prognosis in relation to there being no evidence of disease or that they are in remission	Metastatic Mid to low status	Non-metastatic Higher status
Participant describes prognosis in relation to specific timeframe that they are expected to live	Male Aged 65 or older Higher status	Mid to low status