

## **Section 3**

### **Symptoms and diagnosis**

## Section 3: Symptoms and diagnosis

### 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 3 participants (6.98%) that had no symptoms before diagnosis. Participants had a maximum of 6 symptoms, and a median of 2.00 (IQR=2.00).

### Symptoms before diagnosis

The most common symptoms before diagnosis were blood in urine (n=33, 76.74%), needing to pass urine often (n=16, 37.21%), lower abdominal/stomach or back pain (n=14, 32.56%), and burning feeling when passing urine (n=12, 27.91%).

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 3.00 and 4.50, for all of the symptoms listed in the questionnaire, this is in the “Life was a little distressing” to “Life was average to good” range. The symptoms with the worst quality of life were needing to pass urine often, and a burning feeling when passing urine.

### 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.

The majority participants described symptoms leading to a diagnosis in a clear way (n=43, 87.76%). There were 4 participants (8.16%) that described symptoms leading to diagnosis but not with a clear recollection, and there were 2 participants (4.08%) that described having no symptoms.

The most common symptom leading to diagnosis was having blood in urine (n=35, 71.43%), this was followed by pain in the bladder region (n=4, 8.16%), and having frequent or prolonged urinary tract infections (n=3, 6.12%). There were 7 participants (14.29%) that described changes in urinary habits which did not lead to diagnosis, however recognised the importance in hindsight.

### Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. There were 37 participants (75.51%) that described having symptoms and seeking medical attention relatively soon. There were 8 participants (16.33%) that described having symptoms and not seeking medical attention initially, and 4 participants (8.16%) that described not having any symptoms before diagnosis

### Symptoms leading to diagnosis: Description of diagnostic pathway

Participants were most commonly referred directly to a specialist from their general practitioner which led to their diagnosis (n=30, 61.22%), and this was followed by being diagnosed by their general practitioner due to concerns about symptoms (n=10, 20.41%). There were 6 participants (12.24%) that described being diagnosed after being admitted into the emergency department or hospital, and 3 participants (6.12%) that were diagnosed by their general practitioner following routine check-up or incidental finding.

### **Time from symptoms to diagnosis**

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

Duration was calculated for 42 participants. There were 12 participants (28.57%) that were diagnosed less than 1 month of noticing symptoms, 13 participants (30.95%) diagnosed 1 to 3 months from noticing symptoms, 6 participants (14.29%) that were diagnosed 3 to 6 months of noticing symptoms, and 11 participants (26.19%) that were diagnosed 6 months or more after noticing symptoms.

### **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.

Participants were most commonly diagnosed less than a week after diagnostic tests (n = 12, 27.91%). There were 11 participants (25.58%) that were diagnosed less than between 1 and 2 weeks after diagnostic tests, 10 participants (23.26%) diagnosed between 2 and 3 weeks, 10 participants (23.26%) diagnosed more than four weeks after diagnostic testing.

### **Diagnostic tests**

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with bladder 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 1 to 6 diagnostic tests (median=4.00, IQR=2.00). The most common tests were cystoscopy and biopsy (n=37, 86.05%), urine tests (n=32, 74.42%), ultrasound scans (n=29, 67.44%), and CT scans (n=27, 62.79%).

### **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.

The majority of participants received their diagnosis by a urologist (n=33, 76.74%). There were 8 participants (18.60%) that received their diagnosis from a general practitioner.

Participants were most commonly given their diagnosis in the specialist clinic (n=19, 44.19%), this was followed by the hospital (n=14, 32.56%), and the general practice (GP) (n=7, 16.28%).

### **Year of diagnosis**

Participants were diagnosed between 2004 to 2022. There were 18 participants (42.86%) that were diagnosed in the last three years.

### **Bladder cancer diagnosis**

The majority of participants were diagnosed with urothelial carcinoma (n=25, 58.14%), followed by squamous cell carcinoma (n=4, 9.30%). There were 3 participants (6.98%) that were diagnosed with adenocarcinoma, and 3 participants (6.98%), diagnosed with transitional cell carcinoma. There were 9 participants (20.93%) who were not sure about the type they were diagnosed with.

## **Bladder cancer stage**

There were 43 people with bladder cancer who took part in this study. There were 5 participants (11.63%) with Stage 0, 14 participants (32.56%) with Stage I, 10 participants (23.26%) with Stage II, 10 participants (23.26%) with Stage III and 4 participants (9.30%) with stage IV bladder cancer.

## **Bladder cancer spread**

Participants noted in the online questionnaire if the cancer had spread, and where it had spread to. There were 7 participants (16.28%) that noted that the cancer had spread. The most common site of spread were lymph nodes (n=4, 9.30%).

## **Bladder cancer recurrence**

Almost half of the participants noted that they had a bladder cancer recurrence (n=21, 48.84%), there were 17 participants (39.53%) that had not had a recurrence and there were 5 participants that were not sure (11.63%).

## **Understanding of disease at diagnosis**

Participants were asked in the structured interview how much they knew about their condition at diagnosis. Most participants described having no understanding about the condition at diagnosis (n=32, 65.31%), this was followed by knowing very little about the condition (n=13, 26.53%), and having a good understanding (n=3, 6.12%). The most common reason for having limited knowledge was from doing research through the diagnostic process (n=7, 14.29%).

## **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 10 participants (23.26%) who had enough support, 5 participants (11.63%) that had some support but it wasn't enough, and 28 participants (65.12%) had no support.

## **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 14 participants (32.56%) who had no out of pocket expenses, and 15 participants (34.88%) who did not know or could not recall. There were 3 participants (6.98%) that spent \$1 to \$250, 3 participants (6.98%) that spent between \$251 to \$500, 2 participants (4.65%) that spent \$501 to \$1000, and 6 participants (13.95%) that spent more than \$1000.

## **Burden of diagnostic costs**

In the follow-up question about the burden of costs at diagnosis, for 30 participants who had out of pocket expenses.

For 28 participants (73.68%) the cost was slightly or not at all significant. For 6 participants (15.79%) the out-of-pocket expenses were somewhat significant, and for 4 participants (10.53%), 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=39, 90.70%). There were 3 participants (6.98%) who brought up the topic with their doctor, and a single participant (2.33%) 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.

The majority of participants did not have any genetic or biomarker tests but would like to (n=32, 74.42%). There were 9 participants (20.93%) who did not have these tests and were not interested in them, and a single participant (2.33%) that had biomarker tests.

## **Biomarker status**

All participants (n=43, 100%) were not sure about any markers that they have in relation to bladder cancer.

## **Understanding of prognosis**

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. Participants most commonly described their prognosis in relation to having no evidence of disease or that they are in remission (n=28, 57.14%), and in relation to monitoring their condition with tests, scans, or regular follow up appointments (n=28, 57.14%). There were 12 participants (24.49%) that described prognosis in relation to probable recurrence/cycle of recurrence, 10 participants (20.41%) that described prognosis in relation to tumour grade or stage, and 7 participants (14.29%) described prognosis in relation to a specific timeframe that they have been disease free.

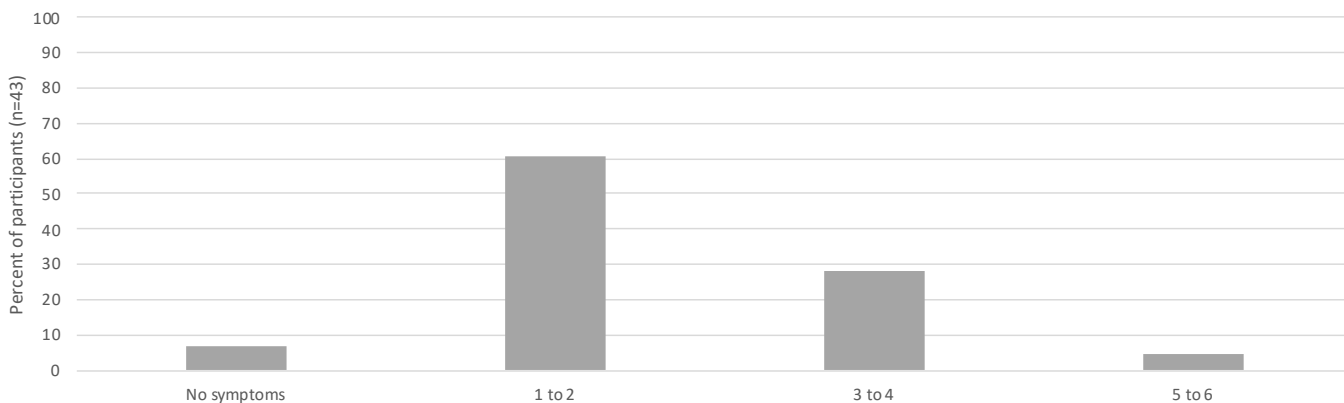
## Experience of symptoms before diagnosis

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 3 participants (6.98%) that had no symptoms before diagnosis. Participants had a maximum of 6 symptoms, and a median of 2.00 (IQR=2.00) (Table 3.1, Figure 3.1).

**Table 3.1: Number of symptoms per participant**

Number of symptoms per participant	Number (n=43)	Percent
No symptoms	3	6.98
1 to 2	26	60.47
3 to 4	12	27.91
5 to 6	2	4.65



**Figure 3.1: Number of symptoms per participant**

## Symptoms before diagnosis

The most common symptoms before diagnosis were blood in urine (n=33, 76.74%), needing to pass urine often (n=16, 37.21%), lower abdominal/stomach or back pain (n=14, 32.56%), and burning feeling when passing urine (n=12, 27.91%) (Table 3.2, Figure 3.2).

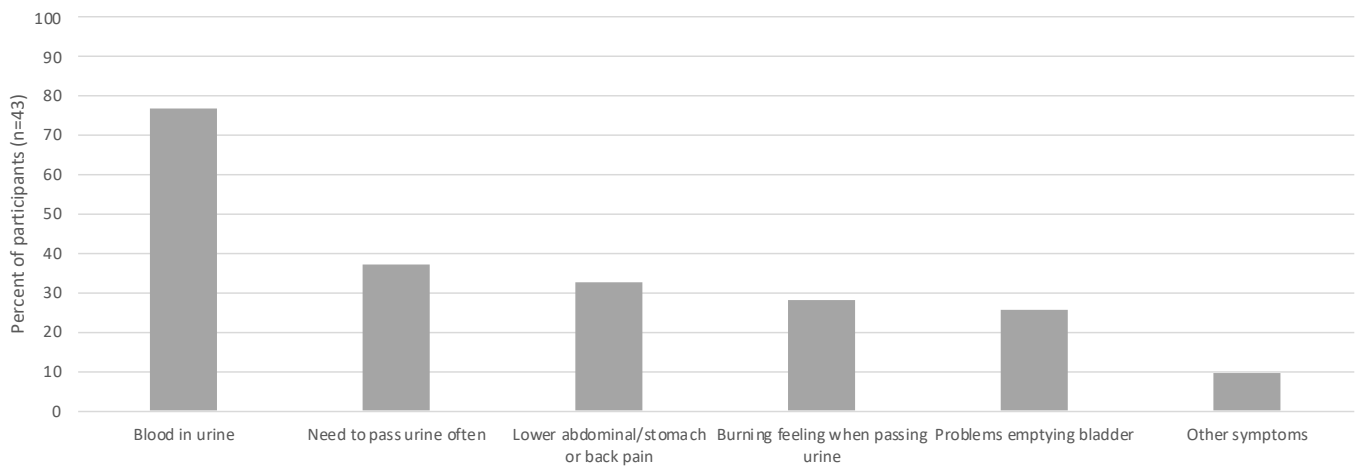
Participants were asked a follow up question about their quality of life while experiencing these symptoms. Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Median quality of life is

presented where five or more participants reported the symptom.

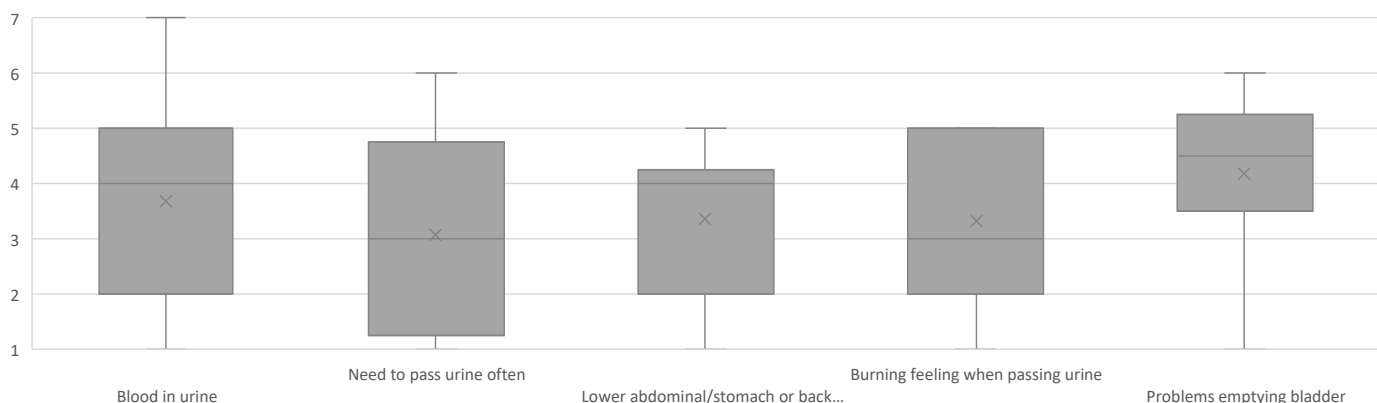
The median quality of life was between 3.00 and 4.50, for all of the symptoms listed in the questionnaire, this is in the “Life was a little distressing” to “Life was average to good” range. The symptoms with the worst quality of life were needing to pass urine often, and a burning feeling when passing urine (Table 3.2, Figure 3.3).

**Table 3.2: Symptoms before diagnosis**

Symptom	Number (n=43)	Percent	Quality of life	
			Mean	SD
No symptoms	3	6.98	NA	NA
Blood in urine	33	76.74	4.00	3.00
Need to pass urine often	16	37.21	3.00	2.50
Lower abdominal/stomach or back pain	14	32.56	4.00	1.75
Burning feeling when passing urine	12	27.91	3.00	3.00
Problems emptying bladder	11	25.58	4.50	1.00
Other symptoms	4	9.30	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.

The majority participants described symptoms leading to a diagnosis in a clear way (n=43, 87.76%). There were 4 participants (8.16%) that described symptoms leading to diagnosis but not with a clear recollection, and there were 2 participants (4.08%) that described having no symptoms.

The most common symptom leading to diagnosis was having blood in urine (n=35, 71.43%), this was followed by pain in the bladder region (n=4, 8.16%), and having frequent or prolonged urinary tract infections (n=3, 6.12%). There were 7 participants (14.29%) that described changes in urinary habits which did not lead to diagnosis, however recognised the importance in hindsight.

### Participant describes having blood in urine, which led to their diagnosis

*Mine was so simple. There's only one day in the whole of my pre diagnosis prior to me seeing a doctor. It's a matter of hours from first noticing. I had never noticed any pain, any sensation, any thing whatsoever. I woke up one morning to help a friend in a business to drive a truck for them. And I'm a PROFESSION, but I have a heavy vehicle licence, and I want to do a pee when I woke up in the morning. And I went to urinate and I thought, Oh, it feels like I'm passing a lot of water, like a lot of fluids. And I looked down and I just saw a stream of what looked like pure blood flowing out of my body. And I absolutely freaked out.*

*Participant 001\_2022AUBLC*

*About 25 years ago, I had an autoimmune disease which was treated with steroids and the chemo drug cyclophosphamide, and I always knew that was a risk of cyclophosphamide. Bladder cancer. So I had some when I wasn't sure, I had some a little bit of blood loss. Well, it's just pink. And I thought, oh, that's not sure if that's from the bladder or not, so. But I thought, Oh, I better get that checked pretty quickly. But I'd had*

uterine polyps a couple of years before that. So first I went to the just spoke to the gynae and she said, Oh, we're going to have a pelvic ultrasound and that showed up the bladder tumours. So yeah, it was a haematuria that, that alerted me to it and I didn't really ignore it because I knew that it was a risk it already has.

Participant 019\_2022AUBLC

Basically, it was blood in my pee. And at the time I was doing quite a bit of race walking and competitive long distance walking, and I put it in as being just things shaking too much basically. And I did ignore the symptoms for about six months before I did talk with my GP.

Yeah. Yeah. Yeah. Yeah. I mean, the main symptoms were the blood in the urine and then it developed into clots. And it's that point that I knew something was wrong like that. So I didn't know whether it was kidney infection or whatever. So I waited about a week. I went to the GP and it was, you know, then he just put me through a lot of tests. He was okay then.

Participant 023\_2022AUBLC

Um, not really, because my first major symptom was blood in my urine, which I acted on immediately. So. So I didn't really have anything where, you know, I thought, oh, that could have been a problem. I was completely healthy, you know, I wasn't even feeling tired. So. So I didn't really. There wasn't anything that I ignored.

Participant 032\_2022AUBLC

Um, I had, um, blood in my urine. I had a AF heart condition and, um, I was put on blood thinners. And with that, the blood started showing up in me urine. I thought it was from the blood thinners cause in the, the blood and urine and um, I went and seen just me GP because, and after a couple of weeks and he, he sent me for my test and he sent me for a CT scan and he called me back the next day. Um, because we got the results of the scan and um, they found a four and a half centimetre tumour in me bladder. And from there, I went to the urologist. I think it was about a week later and. He organised me to have a two. TURBT. An incision to get the tumour removed.

Participant 044\_2022AUBLC

**Participant describes changes in urinary habits, which did not lead to diagnosis, however recognised the importance in hindsight**

Yes, mainly just slightly slight changes in, uh, voiding as in like, um, yeah, I really only noticed in retrospect. So I would say my bladder not quite emptying with the

first sort of empty and then I would kind of think, oh yeah, just, um, you know, use like my sphincter again. And a bit more would empty as if there was something holding back the rest of the urine. So that certainly but not to the point where it, it rang alarm bells. And I suppose that was really the only thing. Yeah. Until the morning that I had haematuria.

Participant 010\_2022AUBLC

Yeah, I'm 72 now from the age of about 35. I've had bladder problems. Well, I'd been going to the toilet regularly at night, three or four times, sometimes five times a night. And then it escalated about seven years ago. I was going all the time and I never saw anyone about it because it didn't cause me any pain, just the lack of sleep. And then I was playing golf six years ago, in May 2006, and I went to the toilet at the golf and I just started peeing blood. And I immediately went to HOSPITAL in CITY and they did a scan, a CT scan I think it was, and they said I had some sort of tumour there that there was, they weren't sure whether it was bladder cancer or whatever. So they booked me in for cystoscopy and straight away, which was done I think within about a week. And they came back and said tthe biopsy that said that I had high grade bladder cancer. Can't remember the size of the cancer. I think it was a couple of centimetres, maybe two.

Participant 021\_2022AUBLC

Yes. Let me have a look. What? My local doctor, my local GP. He had been monitoring my blood and urine from March last year. He didn't, he was a little bit concerned and mentioned there was a little blood in the urine and I didn't really think too much about it, but he just kept calling me back. And then I was also mention to him that I was needing to go to the toilet to urinate quite a lot in the night, and that had been probably going on for quite some years. And when he heard that, he referred me to get a pelvic ultrasound in LOCATION.

Participant 043\_2022AUBLC

My husband has been a frequent urinator for years. And we always thought that was, you know, prostate linked. And he's had he had all the checks, all the the scans and none of the time came on. And the last big last scans were two years ago before COVID. Yes. And the only other symptom then that we got him tested on was about a month before he got his diagnosis. He had some urine and some blood in his urine. Okay. Okay. And then he had it the second day, and he only told me on the second day, and I said to him, Well, you need to go and get checked. And within a week, he had the doctor's appointment. He had the ultrasound. Carer 004\_2022AUBLC



**Participant describes having pain in bladder region, which led to their diagnosis**

*PARTICIPANT Okay. I had absolutely no symptoms. But one morning, early December of 2017, I woke up with severe, right sided pain, which I thought was renal colic. So I kind of thought that I had renal stones and that was the only symptoms that I had. I had no blood in the urine or anything like that. So it came as quite a surprise*

*INTERVIEWER Okay. Anything else*

*PARTICIPANT No, just the pain. Just the pain. So I went to my local doctor and I had to seek a scan. And that's when they recommended that. I see a specialist. Participant 039\_2022AUBLC*

*So it started off fairly suddenly. So I was actually heading away for a weekend with friends and someone else was driving, us sitting in the backseat. And I had pains in my back just beneath my rib cage sort of kicks that are going to kidney location. And I did actually, it was it was of a, sort of severity where I actually called, you know, a nurse on call and asked for advice, you know, if I should do anything in particular or what kind of pain management or I should look at. Anyway, they suggested that I went and saw a GP, so I did that the following morning. It was Saturday morning, and they just prescribed a particular pain medication, which I can't remember at the time that the oncologist had actually, actually told me later that it was the completely wrong thing to be prescribing for someone with kidney pain. Anyway, I was only away for the weekend and as we were coming home by the Sunday. I was actually at school reunion anyway, and I avoided a couple of things because it seemed too much pain. And on the way, as we were driving. On the way home on a Sunday afternoon, I got the, I got my friend to just drop me at the hospital that emergency at the hospital, too, so we*

*could start having a look at that. Yeah. And so, so the cancer itself was in the ureter and it had occluded the ureter so. And so I was just getting kidney pain from pressure because of the occluded ureter.*

*Participant 041\_2022AUBLC*

*Just the frequent urination he never had never presented with any blood in the urine. And then probably about eight months after that had been going on, he then had very extreme pelvic pain that sent him kind of in a bowl on the ground, huddled in pain. And that was what escalated him to the emergency department*

*Carer 002\_2022AUBLC*

**Participant describes having frequent or prolonged urinary tract infections, which led to their diagnosis**

*Okay. The first the very first symptom, I realised what it was, was a very fine speck of blood on the toilet paper the size of a pinhead. And I just thought, oh. Women's problems. And I never saw it again for months. Then I started to have urinary tract infections. And I went to the Doctor several times and she gave me antibiotics. And really didn't seem to do much except clear it up.*

*Participant 003\_2022AUBLC*

*Yeah, it was August 20, 21, like late, like 2020. I started to get like what I thought were UTIs that, you know, that I could go to the toilet and that. But every time they did, a pathology, there was no bugs in it. Participant 004\_2022AUBLC*

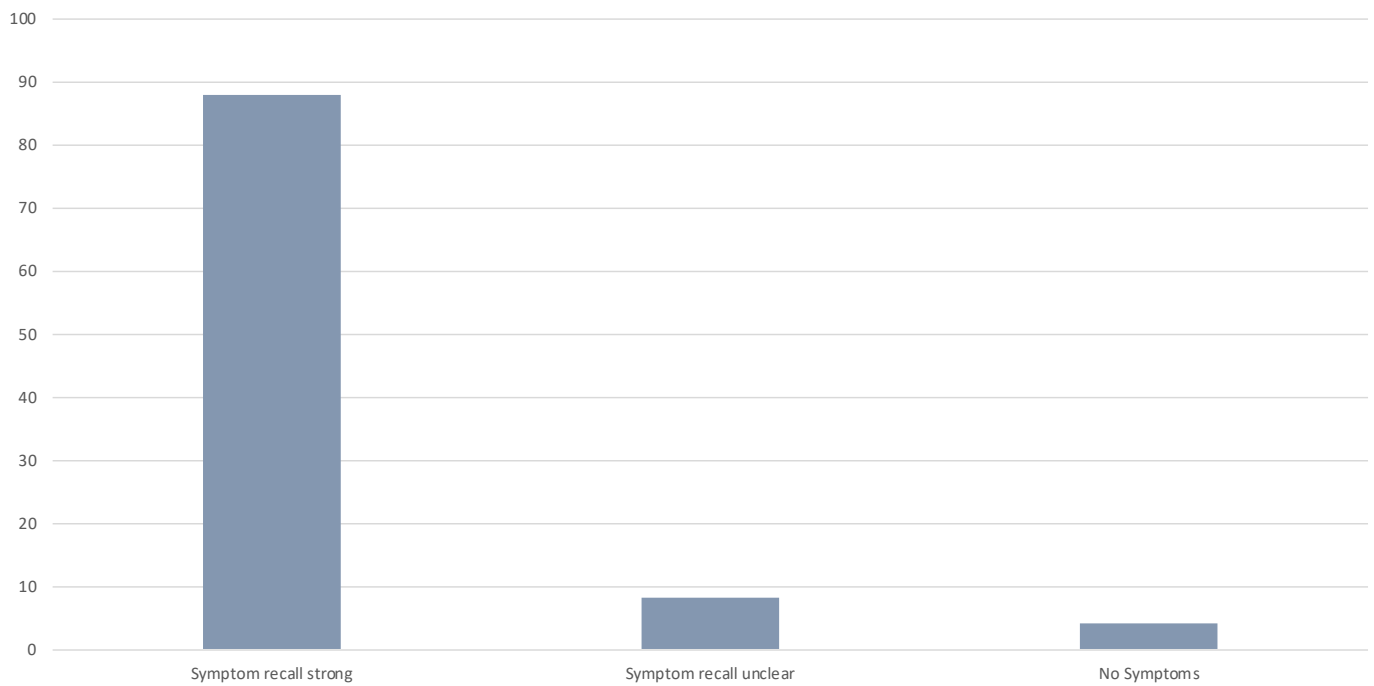
*Yes, certainly. I was seeing my GP about, uh, urinary tract infections. I had the typical sort of symptoms of that my GP started looking at that. In fact, he looked at it for many months and he never mentioned bladder cancer at all. But I found out later about that. Participant 029\_2022AUBLC*

**Table 3.3: Symptom recall**

Symptom recall	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes symptoms leading to diagnosis in a clear way (strong recall)	43	87.76	19	95.00	10	100.00	10	71.43	39	88.64	4	80.00	15	88.24	28	87.50
Participant describes symptoms leading to diagnosis but does not provide a clear recollection	4	8.16	1	5.00	0	0.00	2	14.29	3	6.82	1	20.00	2	11.76	2	6.25
Participant describes having no symptoms before diagnosis	2	4.08	0	0.00	0	0.00	2	14.29	2	4.55	0	0.00	0	0.00	2	6.25

Symptom recall	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes symptoms leading to diagnosis in a clear way (strong recall)	43	87.76	26	89.66	16	84.21	14	93.33	28	84.85	18	90.00	24	85.71
Participant describes symptoms leading to diagnosis but does not provide a clear recollection	4	8.16	1	3.45	3	15.79	1	6.67	3	9.09	1	5.00	3	10.71
Participant describes having no symptoms before diagnosis	2	4.08	2	6.90	0	0.00	0	0.00	2	6.06	1	5.00	1	3.57



**Figure 3.4: Symptom recall**

Symptom recall	Reported less frequently Advanced (Stage IV)	Reported more frequently Invasive (Stage III)
Participant describes symptoms leading to diagnosis in a clear way (strong recall)		
Participant describes symptoms leading to diagnosis but does not provide a clear recollection	-	Carer to someone with bladder cancer

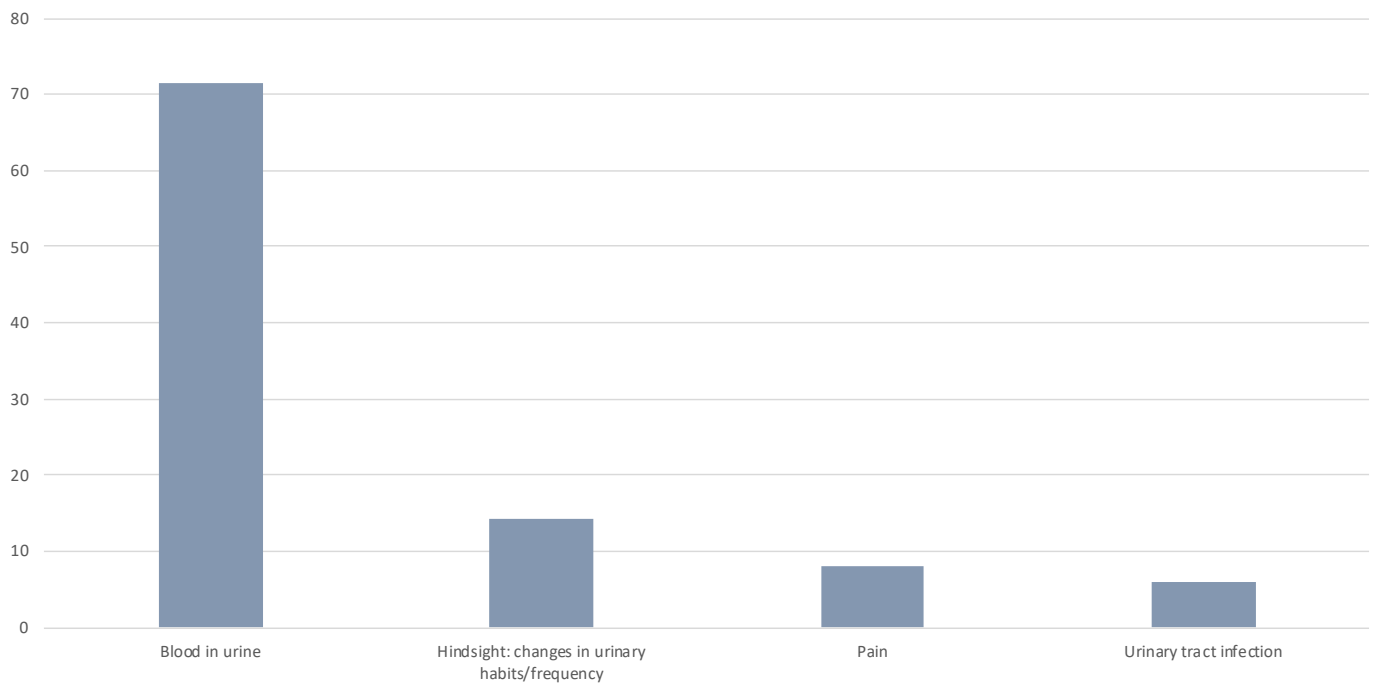
**Table 3.4: Symptom recall– subgroup variations**

**Table 3.5: Symptoms leading to diagnosis**

Symptoms leading to diagnosis	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes having blood in urine, which led to their diagnosis	35	71.43	17	85.00	8	80.00	7	50.00	32	72.73	3	60.00	12	70.59	23	71.88
Participant describes changes in urinary habits, which did not lead to diagnosis, however recognised the importance in hindsight	7	14.29	3	15.00	1	10.00	1	7.14	5	11.36	2	40.00	3	17.65	4	12.50
Participant describes having pain in bladder region, which led to their diagnosis	4	8.16	0	0.00	0	0.00	3	21.43	3	6.82	1	20.00	2	11.76	2	6.25
Participant describes having frequent or prolonged urinary tract infections, which led to their diagnosis	3	6.12	2	10.00	0	0.00	1	7.14	3	6.82	0	0.00	2	11.76	1	3.13

Symptoms leading to diagnosis	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes having blood in urine, which led to their diagnosis	35	71.43	21	72.41	13	68.42	11	73.33	23	69.70	15	75.00	19	67.86
Participant describes changes in urinary habits, which did not lead to diagnosis, however recognised the importance in hindsight	7	14.29	5	17.24	2	10.53	2	13.33	5	15.15	2	10.00	5	17.86
Participant describes having pain in bladder region, which led to their diagnosis	4	8.16	2	6.90	2	10.53	0	0.00	4	12.12	0	0.00	4	14.29
Participant describes having frequent or prolonged urinary tract infections, which led to their diagnosis	3	6.12	3	10.34	0	0.00	1	6.67	2	6.06	2	10.00	1	3.57



**Figure 3.5: Symptoms leading to diagnosis**

**Table 3.6: Symptoms leading to diagnosis – subgroup variations**

Symptoms leading to diagnosis	Reported less frequently	Reported more frequently
Participant describes having blood in urine, which led to their diagnosis	Advanced (Stage IV) Carer to someone with bladder cancer	Early (Stages 0 and I) Carer to someone with bladder cancer
Participant describes changes in urinary habits, which did not lead to diagnosis, however recognised the importance in hindsight	-	Carer to someone with bladder cancer

### Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. There were 37 participants (75.51%) that described having symptoms and seeking medical attention relatively soon. There were 8 participants (16.33%) that described having symptoms and not seeking medical attention initially, and 4 participants (8.16%) that described not having any symptoms before diagnosis.

#### Participant describes having symptoms and seeking medical attention relatively soon

*Yeah, sure. I had a frequency of of urination going to the toilet and and it was sudden onset. And I when this first happened, I was immediately concerned and I went to my general practitioner. And he started doing, you know, blood tests and all those sorts of things. And I said to him could it be cancer, and he laughed it off. Sadly, that's what it was. So. So my first comment is, my first comment is, well, certainly with this GP at the GP level, they had no he had no understanding. And he was an old he was not a young doctor, the GP. He had no understanding of looking for that, you know, the signs of potential bladder cancer. Participant 008\_2022AUBLC*

*Sure. I was very fortunate. Everything panned out is as good as you know, you'd want for for a quick diagnosis and until the, You know, that tumour removal, actually. So that morning I woke up, went a toilet and noticed that it was very evident. It certainly wasn't frank Haematuria was just a different bloodstain. And so I thought, hmm, that's interesting. Went and had something to drink and thought, I'll check, check the next time I go to the toilet. Of course. And the next void was also quite bloodstained. So I thought, this is not good. I'll ring my GP which I did. Or ring a GP, I just thought he gave he'll do so and get booked in to see the GP later that afternoon and. She checked my urine and said, okay, what we might do is. I get you an ultrasound. So in the same, I think. Yeah, that's right. So an ultrasound I booked for next day went and had that done. And I remember as I was having it done, I asked them. I asked the ultrasound-ographer. You know how it looked. And she said, Oh, you better check with your GP about that. So I knew something was up and I took the scans home. Participant 010\_2022AUBLC*

*Um. As soon as I had the bleed, I went into the doctors, um, he sent me for an ultrasound and a blood test.*

*And the results came back. That there was a lesion on my bladder.*

*Participant 027\_2022AUBLC*

*PARTICIPANT Okay. I had absolutely no symptoms. But one morning, early December of 2017, I woke up with severe, right sided pain, which I thought was renal colic. So I kind of thought that I had renal stones and that was the only symptoms that I had. I had no blood in the urine or anything like that. So it came as quite a surprise.*

*INTERVIEWER Okay. Anything else?*

*PARTICIPANT No, just the pain. Just the pain. So I went to my local doctor and I had to seek a scan. And that's when they recommended that. I see a specialist.*

*Participant 039\_2022AUBLC*

**Participant describes having symptoms and not seeking medical attention initially**

*Yes, I can. I can't put a date to it. Right. Let's say sometime in maybe late 2015, early 2016, I remember reporting to my GP that I had noticed a little bit of blood in my urine and he gave me a, you know, little bottle to take home and said, well, if it happens again, pee in to this to this sort of thing. And I think about 18 months elapsed before it got to the point where I went back again and said, I really do have a bit of blood.*

*Participant 006\_2022AUBLC*

*Basically, it was blood in my pee. And at the time I was doing quite a bit of race walking and competitive long distance walking, and I put it in as being just things shaking too much basically. And I did ignore the symptoms for about six months before I did talk with my GP.*

*Participant 019\_2022AUBLC*

*Yeah. Um, blood in urine. I think I was perimenopausal. Um, so I assumed it was spotting. Um, I didn't think it was anything unusual. Um, what. What took me to the doctor was the hot flushes and*

*the, um, uncontrolled emotion. So I was crying at the drop of a hat.*

*Participant 022\_2022AUBLC*

**Participant describes having no symptoms or not noticing any symptoms before diagnosis**

*I didn't have any symptoms. I went for my normal prostate blood tests and it showed an anomaly when I did an ultrasound, it showed up in an ultrasound. Okay. Participant 031\_2022AUBLC*

*Well, the interesting thing was that I was asymptomatic and I had had a bit of a history of urinary tract infections, but I had no blood in the urine or pain or anything to indicate that I was something was going on in my bladder. In fact, it was just purely by chance that I was diagnosed. I changed doctors and started up with a new doctor and she had a look at my history and the medications I was on, and she could see that I was using a particular gel that eventually it's vaginally applied and she was a bit concerned about the long term use of it. And so what she asked me to do was to go and have a abdominal ultrasound because she was a bit concerned about what was happening to the uterus and she wanted to get checked to make sure there was no adverse effects on the uterus. So I just went off to have an ultrasound of the abdominal area and that's when it was picked up. So I was actually a very lucky girl because if my doctor hadn't asked me to do that, it could have progressed for quite a while before symptoms developed.*

*Participant 036\_2022AUBLC*

*My local doctor, my local GP. He had been monitoring my blood and urine from March last year. He didn't, he was a little bit concerned and mentioned there was a little blood in the urine and I didn't really think too much about it, but he just kept calling me back. And then I was also mention to him that I was needing to go to the toilet to urinate quite a lot in the night, and that had been probably going on for quite some years. And when he heard that, he referred me to get a pelvic ultrasound in LOCATION.*

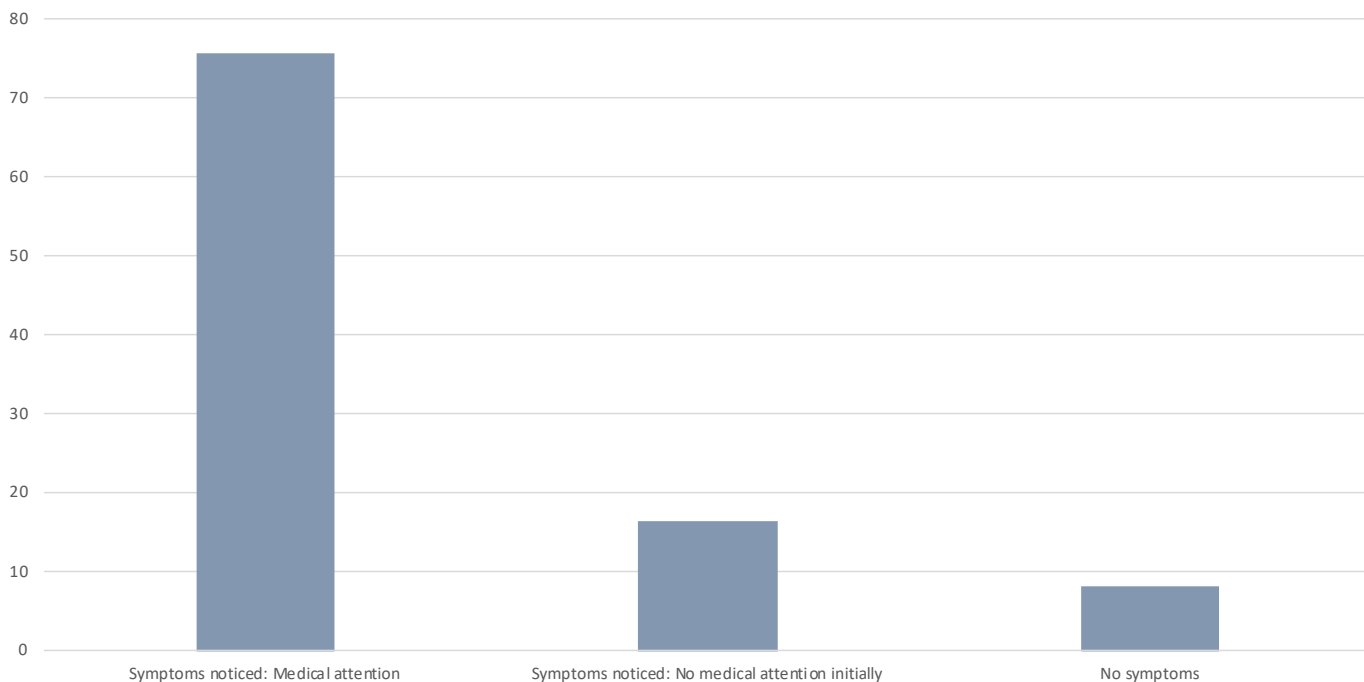
*Participant 043\_2022AUBLC*

**Table 3.7: Seeking medical attention**

Seeking medical attention	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes having symptoms and seeking medical attention relatively soon	37	75.51	15	75.00	8	80.00	11	78.57	34	77.27	3	60.00	13	76.47	24	75.00
Participant describes having symptoms and not seeking medical attention initially	8	16.33	4	20.00	2	20.00	0	0.00	6	13.64	2	40.00	2	11.76	6	18.75
Participant describes having no symptoms or not noticing any symptoms before diagnosis	4	8.16	1	5.00	0	0.00	3	21.43	4	9.09	0	0.00	2	11.76	2	6.25

Seeking medical attention	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes having symptoms and seeking medical attention relatively soon	37	75.51	20	68.97	16	84.21	11	73.33	25	75.76	15	75.00	21	75.00
Participant describes having symptoms and not seeking medical attention initially	8	16.33	6	20.69	2	10.53	3	20.00	5	15.15	3	15.00	5	17.86
Participant describes having no symptoms or not noticing any symptoms before diagnosis	4	8.16	3	10.34	1	5.26	1	6.67	3	9.09	2	10.00	2	7.14



**Figure 3.6: Seeking medical attention**

**Table 3.8: Seeking medical attention – subgroup variations**

Seeking medical attention	Reported less frequently	Reported more frequently
Participant describes having symptoms and seeking medical attention relatively soon	Carer to someone with bladder cancer	-
Participant describes having symptoms and not seeking medical attention initially	Advanced (Stage IV)	Carer to someone with bladder cancer

**Symptoms leading to diagnosis: Description of diagnostic pathway**

Participants were most commonly referred directly to a specialist from their general practitioner which led to their diagnosis (n=30, 61.22%), and this was followed by being diagnosed by their general practitioner due to concerns about symptoms (n=10, 20.41%). There were 6 participants (12.24%) that described being diagnosed after being admitted into the emergency department or hospital, and 3 participants (6.12%) that were diagnosed by their general practitioner following routine check-up or incidental finding.

**Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis**

*Um, I started having a show of, uh, you know, a little bit of blood. So I, over a period of time I went to the GP with samples and they had it tested and said, Oh yeah, there was a little bit, but it'll be alright, it's probably an infection and gave me some antibiotics and then it got a little bit worse. So I went back again and this time he said, I want you to go and have a MRI at oh no an ultrasound at the local X-ray place and also make an appointment with a urologist in your area. And yeah, so I made the appointment and I got the results back saying that I had a tumour and I went back to the doctor and the doctor rang straight away to the urologist and they got me seen to that day. And then a couple of weeks later I went back, I went in the hospital and they found two tumours and high grade*

cancer cells, but it was still only stage one, so I got it early. And so since then I've had 13 cystoscopy and one flexible. And then I've had, uh, 18 BCG.

Participant 007\_2022AUBLC

Oh, well, I went made an appointment for the doctor and got the I think the next day I took a sample and she looked at it and said, Oh, it's a infection. But then she sent it off and found it. It wasn't an infection. Mm hmm. And then I think I had to have an ultrasound. Yep. And then she referred me to a urologist.

Participant 013\_2022AUBLC

Okay. So I was. I had an ultrasound and then was quickly sent to a urologist. So the urologist then informed me that I had bladder cancer.

Participant 026\_2022AUBLC

Okay. Yeah. Well, the first thing I went to, I went to my GP and and explained the symptoms to him, which didn't really need much explanation because was sort of blood in the urine. And so the first, the first test was actually conducted. He sent me to he referred me to a urologist and urologist. Then he conducted a test with a camera. I don't know what it's called.

Participant 034\_2022AUBLC

### **Participant describes being diagnosed by their general practitioner due to concerns about symptoms**

So went to the GP. We started talking about how HRT. Like the help with the hot flushes. And I, um, through the conversation with the I happened to mention the spotting. Let's do a few tests before we talk about hormone replacement. And that led to me having a urine test, and they found gross hematuria. And then I was directed to have an ultrasound. And at that point, they found a, um, a four centimetre tumour at the top of my bladder.

Participant 022\_2022AUBLC

Well, I had it took me a while to be diagnosed because being a female and being young for blood, I was only 49. I had blood in my urine. I went to the GP, they said it was a UTI, gave me antibiotics, came back, the blood came back. About two weeks later it went back to the the GP. They tried a different set of antibiotics. Then the blood came back and went back to the GP and they tested my urine and she said, Oh, it's just microscopic blood, you know, it's nothing, don't worry about it, go home, you know, live your life, everything's okay. Then the blood came back again and went back to the GP and you know, I said, you know, this is, you know, pattern which is, you know, there's something wrong. So then I thought that it was

going to be a gynaecological problem and she wanted to send me for an ultrasound of the uterus. But then we decided to see if I could do the bladder at the same time. And when I had an ultrasound of the bladder, they saw the tumour straight away. So it did take a while. Frustrating process. It was very frustrating. So I have to say that the GP side of it was very poor and I'm lucky to be alive because it took so long to diagnose.

Participant 032\_2022AUBLC

**PARTICIPANT:** He actually got not his normal doctor. He got them because many doctors in that room. And he said, Oh, Phil, I never have you in he never ever have you in my office. And he. Said. You. Could have a UTI. You know what? I'm going to waste your money and I'm going to send you through all these tests.

**INTERVIEWER** Good on him, Okay, so what happened? Okay. So. Any. Any idea what those tests were off the top of your head?

**PARTICIPANT:** He sent him for a CT scan, blood tests and urine tests.

Carer 001\_2022AUBLC

### **Participant describes being diagnosed after being admitted into the emergency department or hospital**

So it started off fairly suddenly. So I was actually heading away for a weekend with friends and someone else was driving, us sitting in the backseat. And I had pains in my back just beneath my rib cage sort of kicks that are going to kidney location. And I did actually, it was it was of a, sort of severity where I actually called, you know, a nurse on call and asked for advice, you know, if I should do anything in particular or what kind of pain management or I should look at. Anyway, they suggested that I went and saw a GP, so I did that the following morning. It was Saturday morning, and they just prescribed a particular pain medication, which I can't remember at the time that the oncologist had actually, actually told me later that it was the completely wrong thing to be prescribing for someone with kidney pain. Anyway, I was only away for the weekend and as we were coming home by the Sunday. I was actually at school reunion anyway, and I avoided a couple of things because it seemed too much pain. And on the way, as we were driving. On the way home on a Sunday afternoon, I got the, I got my friend to just drop me at the hospital that emergency at the hospital, too, so we could start having a look at that. Yeah. And so, so the cancer itself was in the ureter and it had occluded the

ureter so. And so I was just getting kidney pain from pressure because of the occluded ureter.  
Participant 041\_2022AUBLC

Yeah, I'm 72 now from the age of about 35. I've had bladder problems. Well, I'd been going to the toilet regularly at night, three or four times, sometimes five times a night. And then it escalated about seven years ago. I was going all the time and I never saw anyone about it because it didn't cause me any pain, just the lack of sleep. And then I was playing golf six years ago, in May 2016, and I went to the toilet at the golf and I just started peeing blood. And I immediately went to HOSPITAL in CITY and they did a scan, a CT scan I think it was, and they said I had some sort of tumour there that there was, they weren't sure whether it was bladder cancer or whatever. So they booked me in for cystoscopy and straight away, which was done I think within about a week. And they came back and said tthe biopsy that said that I had high grade bladder cancer. Can't remember the size of the cancer. I think it was a couple of centimetres, maybe two.  
Participant 021\_2022AUBLC

Well, I just said I had blood in my urine. Um, and then in 2016, I took the wife for a cruise and I noticed there was blood in my urine again. And this was first in November 2016. I went to a hospital emergency or whatever it was, and they said, Sorry, NAME, you got bladder cancer. And they said it's. Well, I had all three types adenocarcinoma, CIS and papillary. Three different cancers in the bladder.  
Participant 042\_2022AUBLC

Participant describes being diagnosed by their general practitioner following routine check-up or incidental finding

The PSA tests. I would have I would have had every year and the prostate and that all been negative above one. And that was the only one. And I said they sent me off to get my prostate ultrasound. And while she was rummaging around with the ultrasound, she found the anomalies in the bladder instead.  
Participant 031\_2022AUBLC

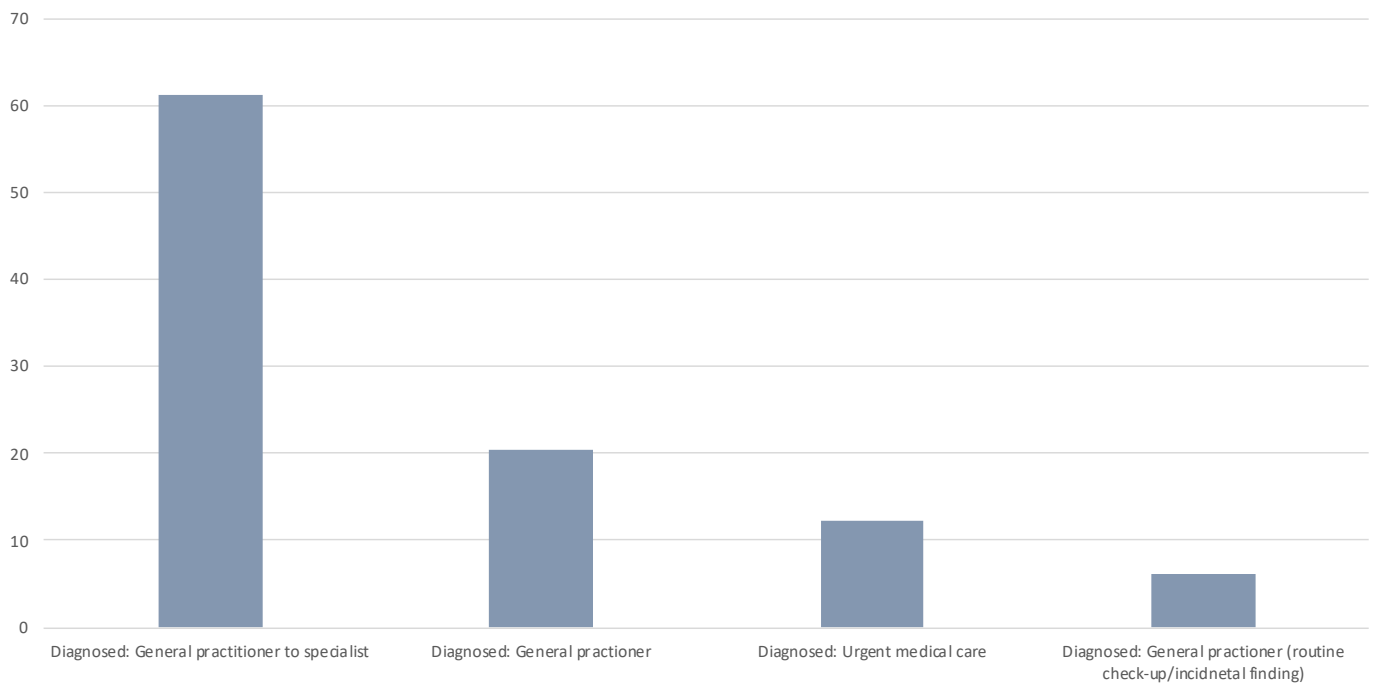
Well, the interesting thing was that I was asymptomatic and I had had a bit of a history of urinary tract infections, but I had no blood in the urine or pain or anything to indicate that I was something was going on in my bladder. In fact, it was just purely by chance that I was diagnosed. I changed doctors and started up with a new doctor and she had a look at my history and the medications I was on, and she could see that I was using a particular gel that eventually it's vaginally applied and she was a bit concerned about the long term use of it. And so what she asked me to do was to go and have a abdominal ultrasound because she was a bit concerned about what was happening to the uterus and she wanted to get checked to make sure there was no adverse effects on the uterus. So I just went off to have an ultrasound of the abdominal area and that's when it was picked up. So I was actually a very lucky girl because if my doctor hadn't asked me to do that, it could have progressed for quite a while before symptoms developed.  
Participant 036\_2022AUBLC

Table 3.9: Diagnostic pathway

Diagnostic pathway	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis	30	61.22	15	75.00	5	50.00	6	42.86	26	59.09	4	80.00	13	76.47	17	53.13
Participant describes being diagnosed by their general practitioner due to concerns about symptoms	10	20.41	3	15.00	4	40.00	2	14.29	9	20.45	1	20.00	2	11.76	8	25.00
Participant describes being diagnosed after being admitted into the emergency department or hospital	6	12.24	1	5.00	1	10.00	4	28.57	6	13.64	0	0.00	1	5.88	5	15.63
Participant describes being diagnosed by their general practitioner following routine check-up or incidental finding	3	6.12	1	5.00	0	0.00	2	14.29	3	6.82	0	0.00	1	5.88	2	6.25

Diagnostic pathway	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis	30	61.22	16	55.17	14	73.68	9	60.00	21	63.64	12	60.00	18	64.29
Participant describes being diagnosed by their general practitioner due to concerns about symptoms	10	20.41	6	20.69	3	15.79	3	20.00	6	18.18	4	20.00	5	17.86
Participant describes being diagnosed after being admitted into the emergency department or hospital	6	12.24	4	13.79	2	10.53	2	13.33	4	12.12	2	10.00	4	14.29
Participant describes being diagnosed by their general practitioner following routine check-up or incidental finding	3	6.12	3	10.34	0	0.00	1	6.67	2	6.06	2	10.00	1	3.57



**Figure 3.7: Diagnostic pathway**

**Table 3.10: Diagnostic pathway – subgroup variations**

Diagnostic pathway	Reported less frequently	Reported more frequently
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis	Invasive (Stage III) Advanced (Stage IV)	Early (Stages 0 and I) Carer to someone with bladder cancer Female University
Participant describes being diagnosed by their general practitioner due to concerns about symptoms	-	Invasive (Stage III)
Participant describes being diagnosed after being admitted into the emergency department or hospital	Carer to someone with bladder cancer	Advanced (Stage IV)

## Timing of diagnosis

### Time from symptoms to diagnosis

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

Duration was calculated for 42 participants. There were 12 participants (28.57%) that were diagnosed less than 1 month of noticing symptoms, 13 participants (30.95%) diagnosed 1 to 3 months from noticing symptoms, 6 participants (14.29%) that were diagnosed 3 to 6 months of noticing symptoms, and 11 participants (26.19%) that were diagnosed 6 months or more after noticing symptoms (Table 3.11, Figure 3.8).

### Time from diagnostic test to receiving a diagnosis

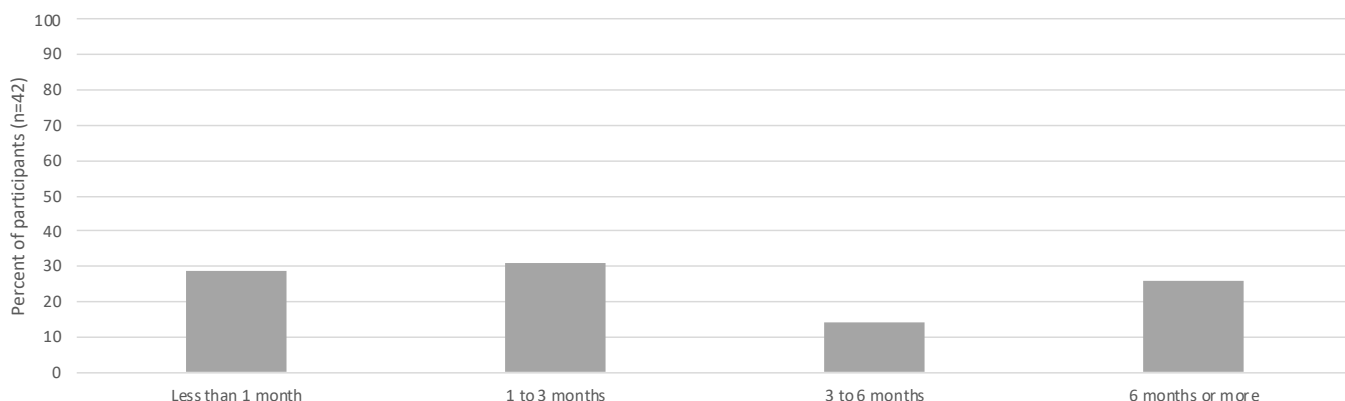
Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis.

Participants were most commonly diagnosed less than a week after diagnostic tests (n = 12, 27.91%). There were 11 participants (25.58%) that were diagnosed less than between 1 and 2 weeks after diagnostic tests, 10 participants (23.26%) diagnosed between 2 and 3 weeks, 10 participants (23.26%) diagnosed more than four weeks after diagnostic testing (Table 3.12, Figure 3.9).



**Table 3.11: Time from symptoms to diagnosis**

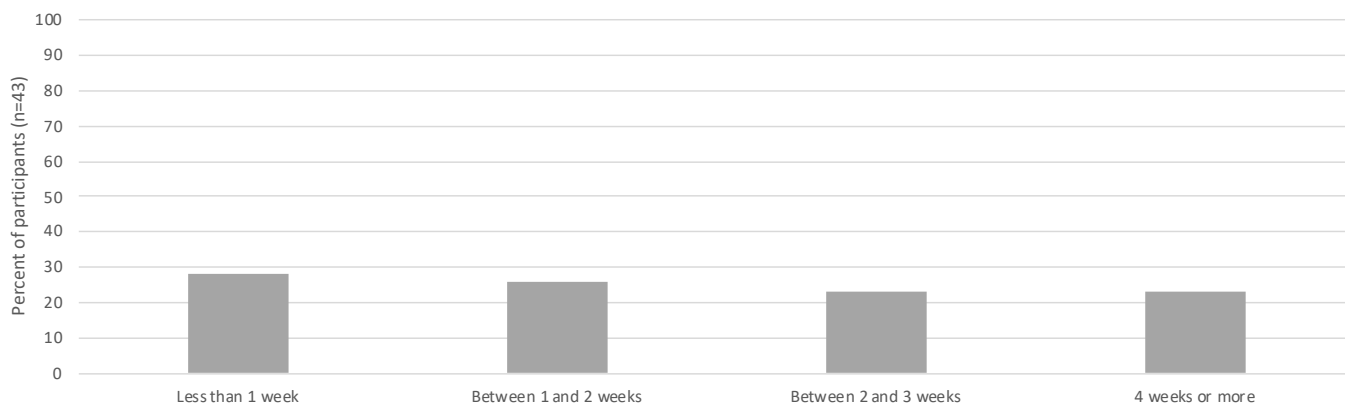
Time from symptoms to diagnosis	Number (n=42)	Percent
Less than 1 month	12	28.57
1 to 3 months	13	30.95
3 to 6 months	6	14.29
6 months or more	11	26.19



**Figure 3.8: Time from symptoms to diagnosis**

**Table 3.12: Time from diagnostic test to diagnosis**

Time from diagnosis test to diagnosis	Number (n=43)	Percent
Less than 1 week	12	27.91
Between 1 and 2 weeks	11	25.58
Between 2 and 3 weeks	10	23.26
4 weeks or more	10	23.26



**Figure 3.9: Time from diagnostic test to diagnosis**

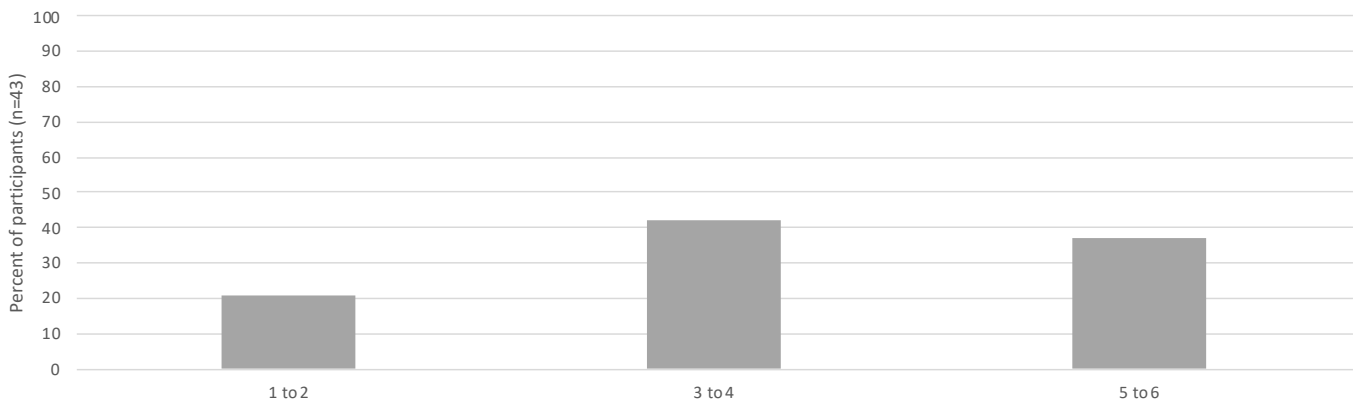
### Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with bladder 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 1 to 6 diagnostic tests (median=4.00, IQR=2.00) (Table 3.13, Figure 3.10). The most common tests were cystoscopy and biopsy (n=37, 86.05%), urine tests (n=32, 74.42%), ultrasound scans (n=29, 67.44%), and CT scans (n=27, 62.79%) (Table 3.14, Figure 3.11).

**Table 3.13: Number of diagnostic tests**

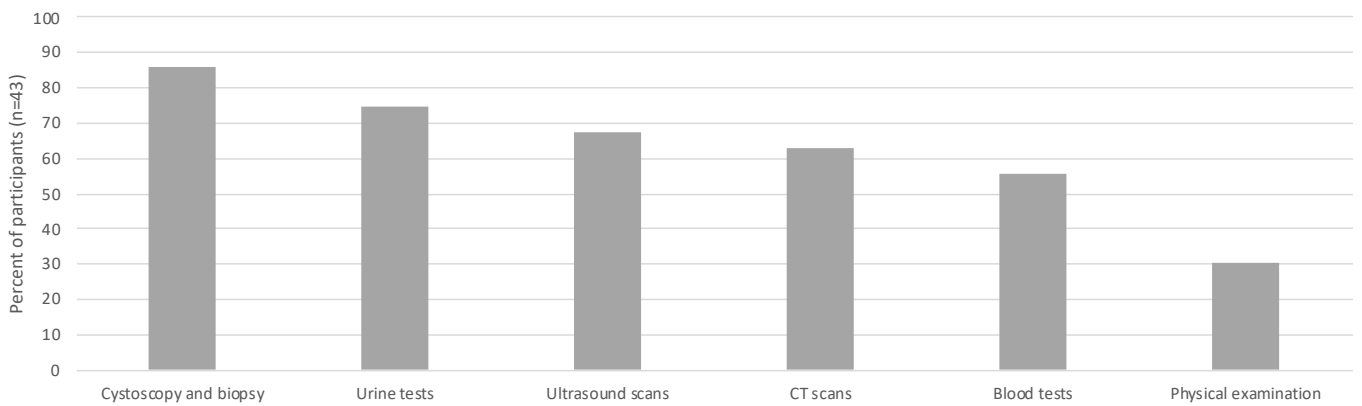
Number of diagnostic tests per participant	Number (n=43)	Percent
1 to 2	9	20.93
3 to 4	18	41.86
5 to 6	16	37.21



**Figure 3.10: Number of diagnostic tests**

**Table 3.14: Diagnostic tests**

Diagnostic tests	Number (n=43)	Percent
Cystoscopy and biopsy	37	86.05
Urine tests	32	74.42
Ultrasound scans	29	67.44
CT scans	27	62.79
Blood tests	24	55.81
Physical examination	13	30.23



**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.

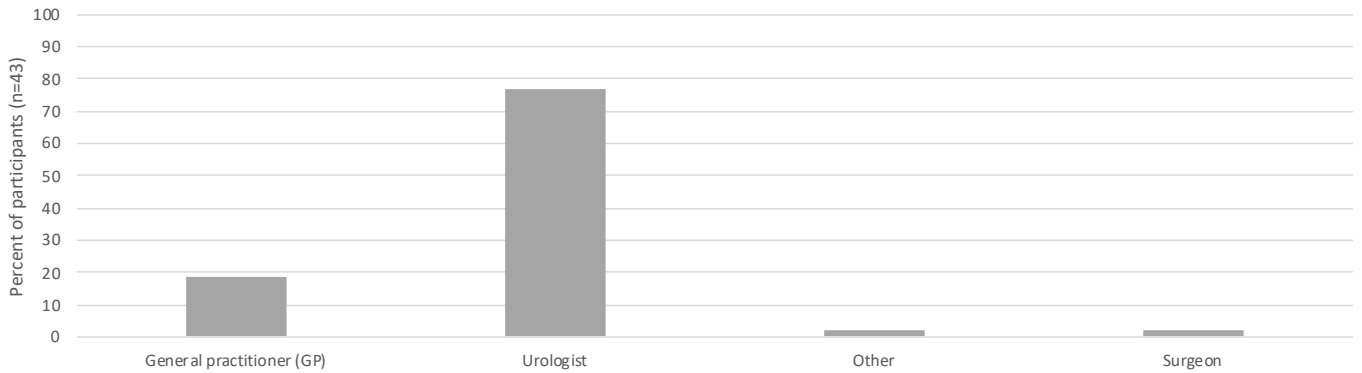
The majority of participants received their diagnosis by a urologist (n=33, 76.74%). There were 8 participants

(18.60%) that received their diagnosis from a general practitioner (Table 3.15, Figure 3.12).

Participants were most commonly given their diagnosis in the specialist clinic (n=19, 44.19%), this was followed by the hospital (n=14, 32.56%), and the general practice (GP) (n=7, 16.28%) (Table 3.16, Figure 3.13).

**Table 3.15: Diagnosis provider**

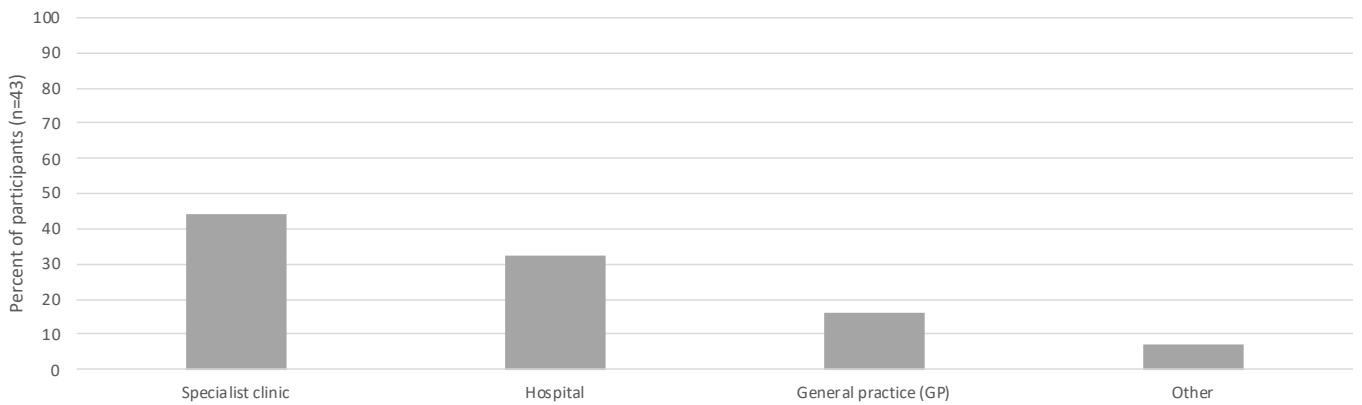
Health professional gave diagnosis	Number (n=43)	Percent
General practitioner (GP)	8	18.60
Urologist	33	76.74
Other	1	2.33
Surgeon	1	2.33



**Figure 3.12: Diagnosis provider**

**Table 3.16: Diagnosis location**

Location of diagnosis	Number (n=43)	Percent
Specialist clinic	19	44.19
Hospital	14	32.56
General practice (GP)	7	16.28
Other	3	6.98



**Figure 3.13: Diagnosis location**

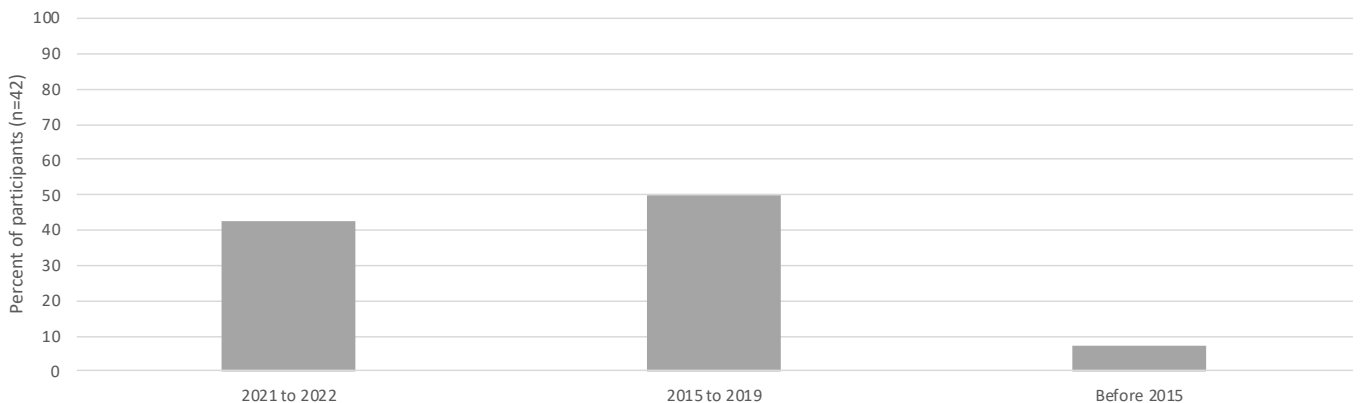
### Year of diagnosis

In the online questionnaire, participants noted the approximate date of diagnosis, the year of diagnosis is presented in Table 3.17, Figure 3.14.

Participants were diagnosed between 2004 to 2022. There were 18 participants (42.86%) that were diagnosed in the last three years.

**Table 3.17: Year of diagnosis**

Year of diagnosis	Number (n=42)	Percent
2021 to 2022	18	42.86
2015 to 2019	21	50.00
Before 2015	3	7.14



**Figure 3.14: Year of diagnosis**

## Bladder cancer diagnosis, stage and spread

### Bladder cancer diagnosis

The majority of participants were diagnosed with urothelial carcinoma (n=25, 58.14%), followed by squamous cell carcinoma (n=4, 9.30%). There were 3 participants (6.98%) that were diagnosed with adenocarcinoma, and 3 participants (6.98%), diagnosed with transitional cell carcinoma. There were 9 participants (20.93%) who were not sure about the type they were diagnosed with (Table 3.18, Figure 3.15).

### Bladder cancer stage

There were 43 people with bladder cancer who took part in this study. There were 5 participants (11.63%) with Stage 0, 14 participants (32.56%) with Stage I, 10 participants (23.26%) with Stage II, 10 participants

(23.26%) with Stage III and 4 participants (9.30%) with stage IV bladder cancer (Table 3.19, Figure 3.16).

### Bladder cancer spread

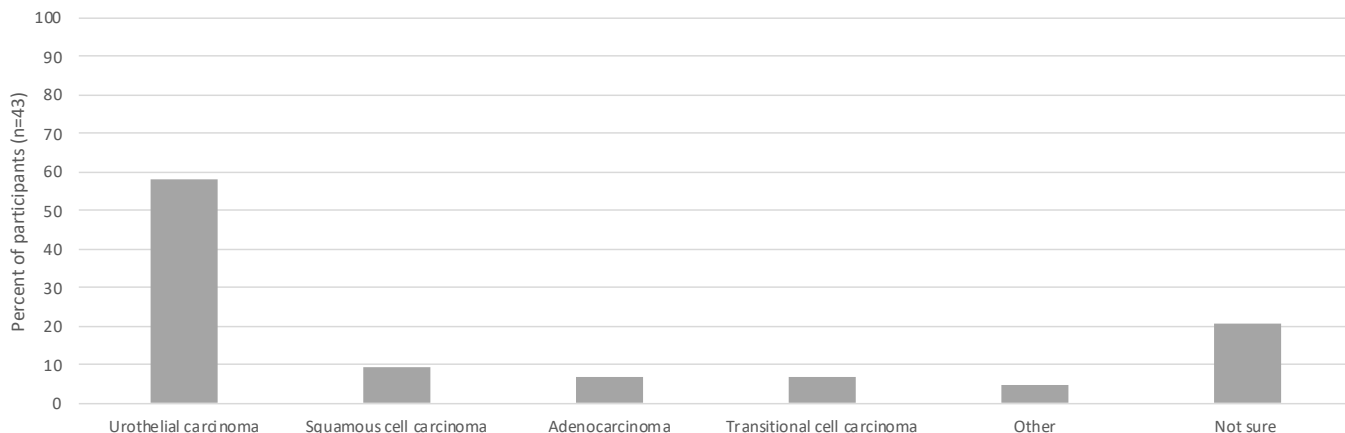
Participants noted in the online questionnaire if the cancer had spread, and where it had spread to. There were 7 participants (16.28%) that noted that the cancer had spread. The most common site of spread were lymph nodes (n=4, 9.30%) (Table 3.20, Figure 3.17).

### Bladder cancer recurrence

Almost half of the participants noted that they had a bladder cancer recurrence (n=21, 48.84%), there were 17 participants (39.53%) that had not had a recurrence and there were 5 participants that were not sure (11.63%) (Table 3.21, Figure 3.18).

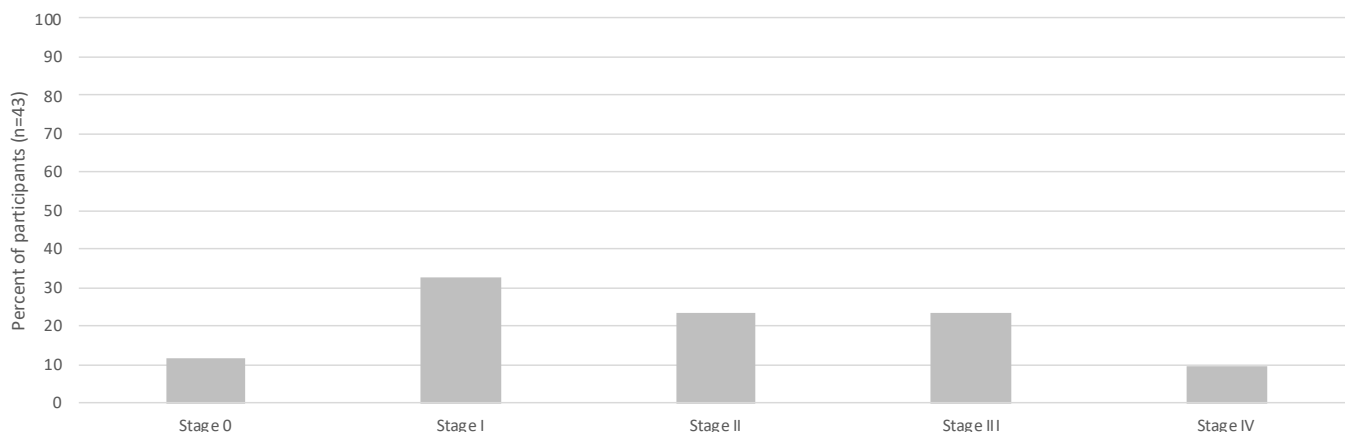
**Table 3.18: Type of bladder cancer**

Diagnosis	Number (n=43)	Percent
Urothelial carcinoma	25	58.14
Squamous cell carcinoma	4	9.30
Adenocarcinoma	3	6.98
Transitional cell carcinoma	3	6.98
Other	2	4.65
Not sure	9	20.93



**Figure 3.15: Type of bladder cancer**

**Table 3.19: Bladder cancer stage**

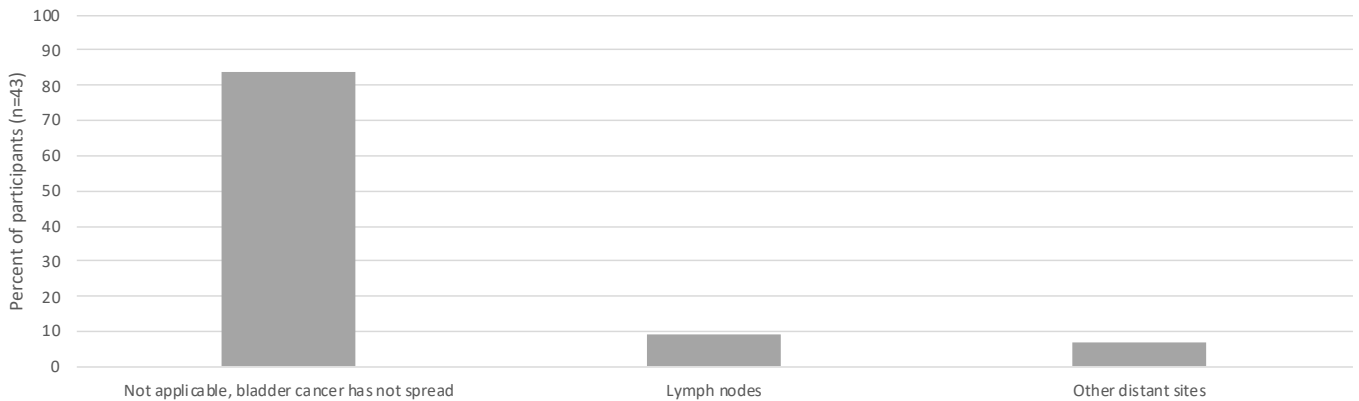


**Figure 3.16: Bladder cancer stage**

Bladder cancer stage	Number (n=48)	Percent
Stage 0	5	11.63
Stage I	14	32.56
Stage II	10	23.26
Stage III	10	23.26
Stage IV	4	9.30

**Table 3.20: Bladder cancer spread**

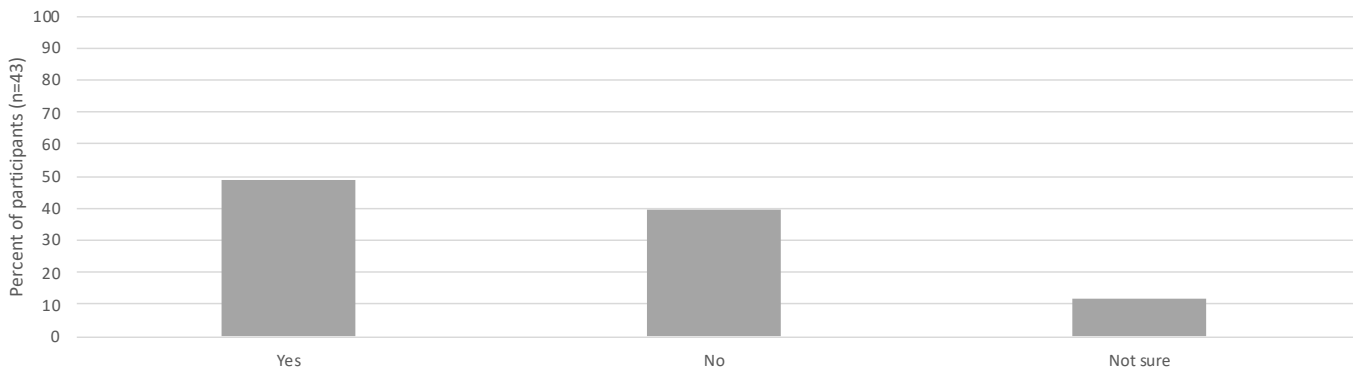
Cancer spread	n=43	%
Not applicable, bladder cancer has not spread	36	83.72
Lymph nodes	4	9.30
Other distant sites	3	6.98



**Figure 3.17: Bladder cancer spread**

**Table 3.21: Bladder cancer recurrence**

Recurrence since diagnosis	N=43	%
Yes	21	48.84
No	17	39.53
Not sure	5	11.63



**Figure 3.18: Bladder cancer recurrence**

### Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. Most participants described having no understanding about the condition at diagnosis (n=32, 65.31%), this was followed by knowing very little about the condition (n=13, 26.53%), and having a good understanding (n=3, 6.12%). The most common reason for having limited knowledge was from doing research through the diagnostic process (n=7, 14.29%).

#### Participant describes having no understanding of condition at diagnosis

*Nothing. To be honest, I didn't even, like a lot of people, realise there was such a thing. It's not one of the common talked about cancers like bowel or breast or anything like that.*

*Participant 014\_2022AUBLC*

*I'd never heard of it and never heard of bladder cancers, never heard of bladder cancer in my life. My wife is a registered nurse and has been in aged care for 25 years. Goes, what the hell are you doing with bladder cancer? Cause that's an old man's disease. And, you know, everybody said, you know, everyone queried me along the way. Were you a smoker and did you work in heavy industry or with chemicals or toxins*

*and that kind of stuff? I said, No, no, no, no, no. I sit behind a desk all day and have and have for 30 years. I'm a pen pusher or keyboard person. So that was a bit bizarre that I didn't fit the archetype for that thing, being 52 and non-smoker and an office worker. I don't sort of fit the demographic for this.*

*Participant 017\_2022AUBLC*

*I never heard of it. Didn't even know it existed. All I know is that when I went to the toilet playing golf, I just saw the blood coming out and went, This is something wrong? That's what I thought, because I remember playing football when I was in my twenties and a couple of blokes started peeing blood. It was because I got hit in the kidneys. I thought immediately I had a kidney problem or something, or the kidney infection or something. And they told me that there's a, there's a tumour on your bladder when they did the C.T. scan. I'd never heard of it, to be honest. Heard nothing about it. Okay. But I've done a bit of research since then, obviously, from the on the Internet, as most people do.*

*Participant 021\_2022AUBLC*

*Dead set nothing. Didn't know. Didn't even know you could get bladder cancer. And, and even, even then the word, the word cancer in any form whatsoever didn't exist. It was, it was not talked about. Um. The wording was possible carcinoma and that was it.*

*Participant 040\_2022AUBLC*

**Participant describes knowing very little about the condition at diagnosis**

*Well, firstly, nothing. And it didn't hit. There was no it it without being impolite. It was just like, you know, going to a shop and buying something, you know, the doctors said, no, this is what will happen to you. There was no I did ask because I did some research on the Internet. I did ask should there be a multi-disciplinary approach? And he didn't take kindly to that suggestion, which I believe is what, you know, the bladder cancer, bladder cancer support groups suggest, etc.. So I didn't I well, just on the job, the shock was this, you know, that I think the two main causes are smoking and, and working with paints, industrial factories, etc.. Yeah. And I've never done either. Yeah. I never you know, I'm not I'm not 100% healthy, but I've never smoked in my life and I've never worked in factories. So it was a great it was a great shock to me. And I think it was a surprise to the to the urologist.*

*Participant 008\_2022AUBLC*

*Absolutely nothing. I found myself getting online and stumbled across the Bladder Cancer Awareness Support Group, which I joined really quickly. And I reached out to the founders of that group, one of which is a doctor and her sister. They had lost their dad to bladder cancer nine years previously and they channelled their grief into setting up a support group in Melbourne. And it was there that I asked a lot of my questions because there were people that were much further into their bladder cancer journey than what we were. So that was my area I went to to ask questions and get more information, get support from people.*

*Carer 002\_2022AUBLC*

*When I was diagnosed. Okay. So. I suppose it all came to late 2019 oh. I knew it was serious at that. At that stage it was given the actual category I'd been diagnosed at. Yeah. There was every Yeah. That something had to be done very quickly to ensure that it wasn't spreading elsewhere to, to the body. And at that time, they turned around and said, look, we would suggest having the bladder resected and prostate resected. And yeah. And along with any other lymph nodes that are around there. To see exactly how far gone. So it's there was no chance for me to have any immunotherapy or any other type of treatment. And it had basically advanced so quickly and I suppose four or five months to to the time. Yeah. And they said, well we need to take your bladder out.*

*Participant 035\_2022AUBLC*

**Participant describes knowing about the condition at diagnosis**

*PARTICIPANT: My knowledge? Yeah, well, my background is nurse. So, like so, I knew about it.*

*INTERVIEWER: Okay.*

*PARTICIPANT: But yet. Yeah the things I knew about it's nasty one and deliberately peed on and a fostering think about it a lot. I had a bladder cancer, and said, my god, that is old mans disease. You know, I never smoked . I'm female. Why bladder cancer? Anyway, that's what I thought.*

*Participant 015\_2022AUBLC*

*Um. I was. Fairly well informed in terms of the nature of the cancer, how serious it was. The everybody stressed how dangerous and the operation is, but essentially was to have it. So that was that really. So I don't think it was there was no doubt about what I had to do. So none of it was a surprise.*

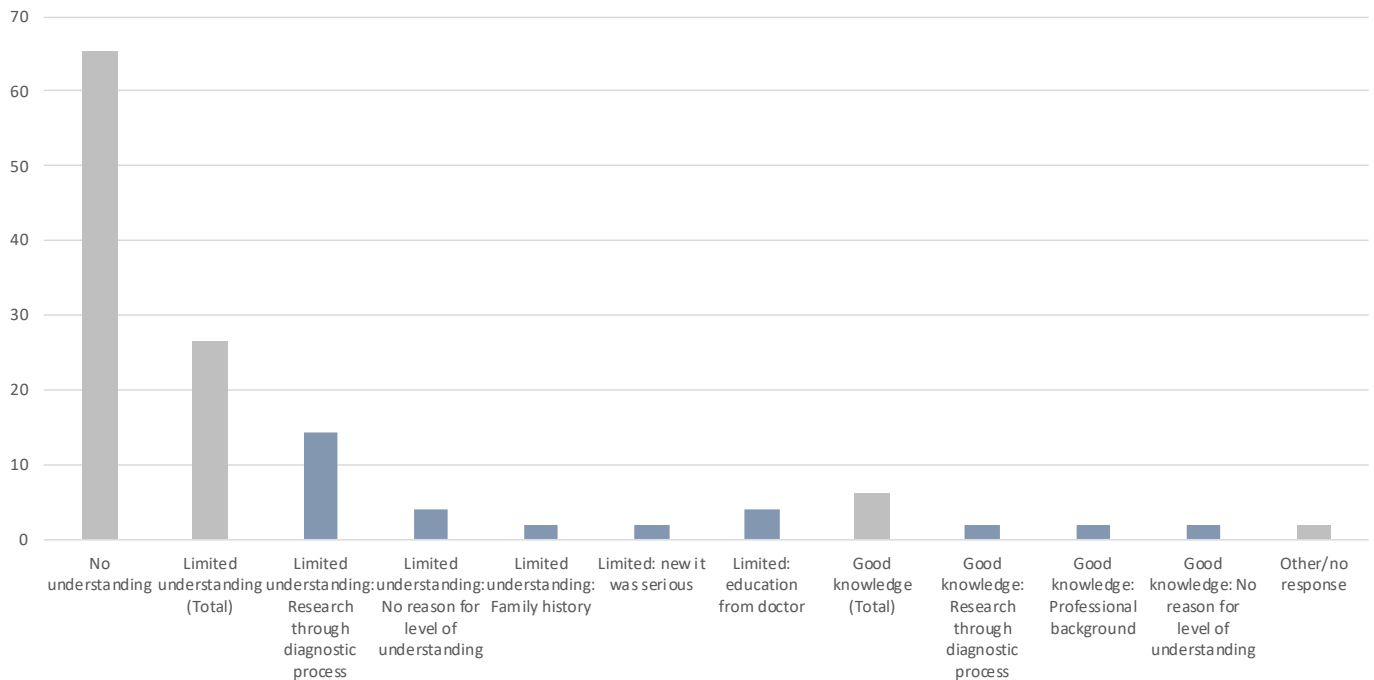
*Participant 034\_2022AUBLC*

**Table 3.22: Understanding of disease at diagnosis**

Understanding of disease at diagnosis	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes having no understanding of condition at diagnosis	32	65.31	12	60.00	10	100.00	6	42.86	28	63.64	4	80.00	10	58.82	22	68.75
Participant describes knowing very little about the condition at diagnosis	13	26.53	7	35.00	0	0.00	5	35.71	12	27.27	1	20.00	5	29.41	8	25.00
Participant describes knowing very little about the condition at diagnosis but notes they began researching the condition before or throughout the diagnostic process	7	14.29	5	25.00	0	0.00	1	7.14	6	13.64	1	20.00	3	17.65	4	12.50
Participant describes knowing very little about the condition at diagnosis but no specific reason for the level of knowledge	2	4.08	0	0.00	0	0.00	2	14.29	2	4.55	0	0.00	1	5.88	1	3.13
Participant describes knowing very little about the condition at diagnosis but notes they have a family history of the condition	1	2.04	0	0.00	0	0.00	1	7.14	1	2.27	0	0.00	0	0.00	1	3.13
Participant describes knowing very little about the condition at diagnosis but knew that it was serious	1	2.04	0	0.00	0	0.00	1	7.14	1	2.27	0	0.00	0	0.00	1	3.13
Participant describes knowing very little about the condition at diagnosis but notes that doctor explained it to them during the diagnostic process	2	4.08	2	10.00	0	0.00	0	0.00	2	4.55	0	0.00	1	5.88	1	3.13
Participant describes knowing about the condition at diagnosis	3	6.12	1	5.00	0	0.00	2	14.29	3	6.82	0	0.00	1	5.88	2	6.25
Participant describes knowing about the condition at diagnosis as they have begun researching the condition before or throughout the diagnostic process	1	2.04	0	0.00	0	0.00	1	7.14	1	2.27	0	0.00	0	0.00	1	3.13
Participant describes knowing about the condition as they have a medical, research or relevant professional background	1	2.04	1	5.00	0	0.00	0	0.00	1	2.27	0	0.00	1	5.88	0	0.00
Participant describes knowing/not knowing about the condition but no specific reason for the level of knowledge	1	2.04	0	0.00	0	0.00	1	7.14	1	2.27	0	0.00	0	0.00	1	3.13
Other/no response	1	2.04	0	0.00	0	0.00	1	7.14	1	2.27	0	0.00	1	5.88	0	0.00

Understanding of disease at diagnosis	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes having no understanding of condition at diagnosis	32	65.31	20	68.97	11	57.89	12	80.00	19	57.58	13	65.00	18	64.29
Participant describes knowing very little about the condition at diagnosis	13	26.53	7	24.14	6	31.58	3	20.00	10	30.30	6	30.00	7	25.00
Participant describes knowing very little about the condition at diagnosis but notes they began researching the condition before or throughout the diagnostic process	7	14.29	3	10.34	4	21.05	2	13.33	5	15.15	2	10.00	5	17.86
Participant describes knowing very little about the condition at diagnosis but no specific reason for the level of knowledge	2	4.08	1	3.45	1	5.26	0	0.00	2	6.06	1	5.00	1	3.57
Participant describes knowing very little about the condition at diagnosis but notes they have a family history of the condition	1	2.04	1	3.45	0	0.00	0	0.00	1	3.03	1	5.00	0	0.00
Participant describes knowing very little about the condition at diagnosis but knew that it was serious	1	2.04	1	3.45	0	0.00	0	0.00	1	3.03	1	5.00	0	0.00
Participant describes knowing very little about the condition at diagnosis but notes that doctor explained it to them during the diagnostic process	2	4.08	1	3.45	1	5.26	1	6.67	1	3.03	1	5.00	1	3.57
Participant describes knowing about the condition at diagnosis	3	6.12	2	6.90	1	5.26	0	0.00	3	9.09	1	5.00	2	7.14
Participant describes knowing about the condition at diagnosis as they have begun researching the condition before or throughout the diagnostic process	1	2.04	1	3.45	0	0.00	0	0.00	1	3.03	0	0.00	1	3.57
Participant describes knowing about the condition as they have a medical, research or relevant professional background	1	2.04	0	0.00	1	5.26	0	0.00	1	3.03	0	0.00	1	3.57
Participant describes knowing/not knowing about the condition but no specific reason for the level of knowledge	1	2.04	1	3.45	0	0.00	0	0.00	1	3.03	1	5.00	0	0.00
Other/no response	1	2.04	0	0.00	1	5.26	0	0.00	1	3.03	0	0.00	1	3.57



**Figure 3.19 Understanding of disease at diagnosis**

**Table 3.23: Understanding of disease at diagnosis – subgroup variations**

Understanding of disease at diagnosis	Reported less frequently	Reported more frequently
Participant describes having no understanding of condition at diagnosis	Advanced (Stage IV)	Invasive (Stage III) Carer to someone with bladder cancer Regional or remote
Participant describes knowing very little about the condition at diagnosis	Invasive (Stage III)	

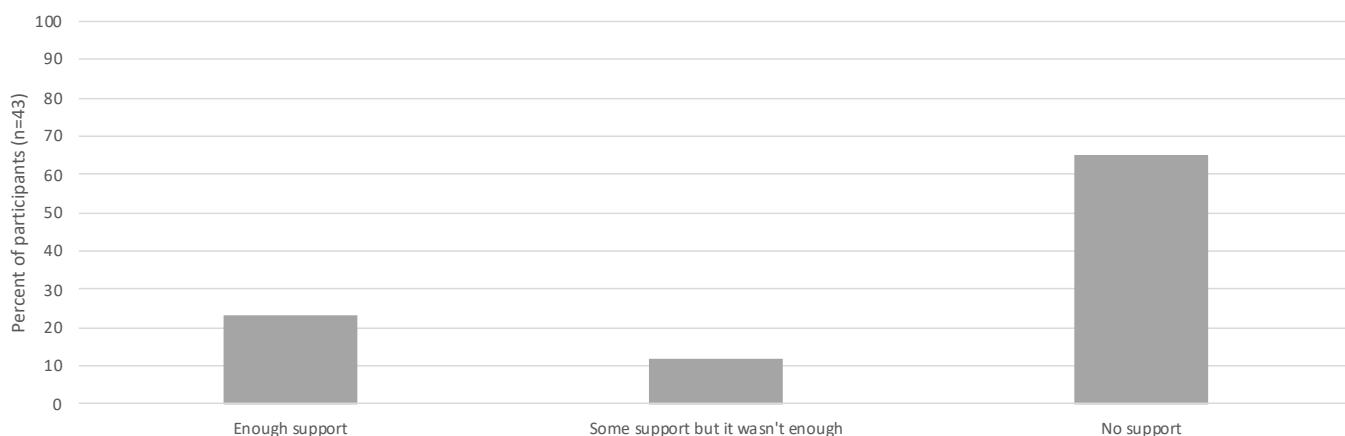
### Emotional support at diagnosis

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

There were 10 participants (23.26%) who had enough support, 5 participants (11.63%) that had some support but it wasn't enough, and 28 participants (65.12%) had no support (Table 3.24, Figure 3.20).

**Table 3.24: Emotional support at diagnosis**

Emotional support at diagnosis	Number (n=43)	Percent
Enough support	10	23.26
Some support but it wasn't enough	5	11.63
No support	28	65.12



**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 14 participants (32.56%) who had no out of pocket expenses, and 15 participants (34.88%) who did not know or could not recall. There were 3 participants (6.98%) that spent \$1 to \$250, 3 participants (6.98%) that spent between \$251 to \$500, 2 participants (4.65%) that spent \$501 to \$1000, and 6 participants (13.95%) that spent more than \$1000 (Table 3.25, Figure 3.21).

#### Burden of diagnostic costs

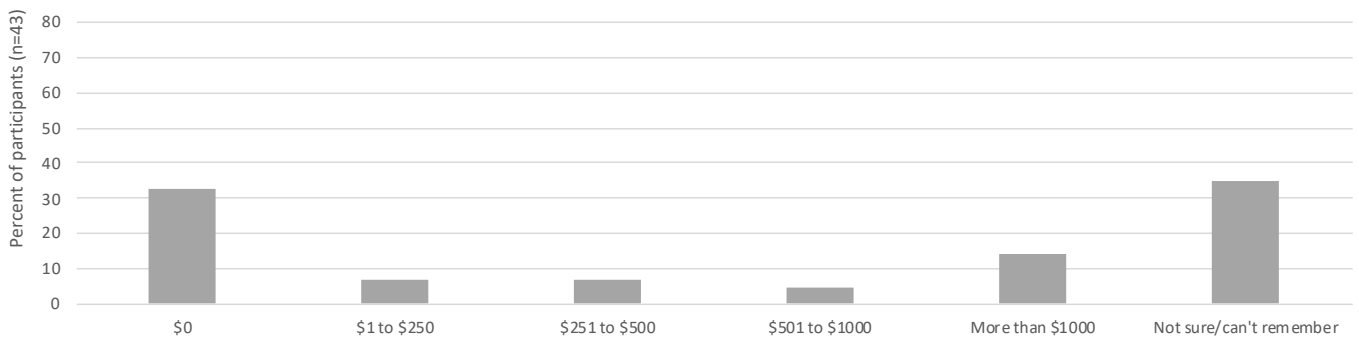
In the follow-up question about the burden of costs at diagnosis, for 30 participants who had out of pocket expenses.

For 28 participants (73.68%) the cost was slightly or not at all significant. For 6 participants (15.79%) the out-of-pocket expenses were somewhat significant, and for 4 participants (10.53%), the burden of out-of-pocket expenses were moderately or extremely significant (Table 3.26, Figure 3.22)



**Table 3.25: Out of pocket expenses at diagnosis**

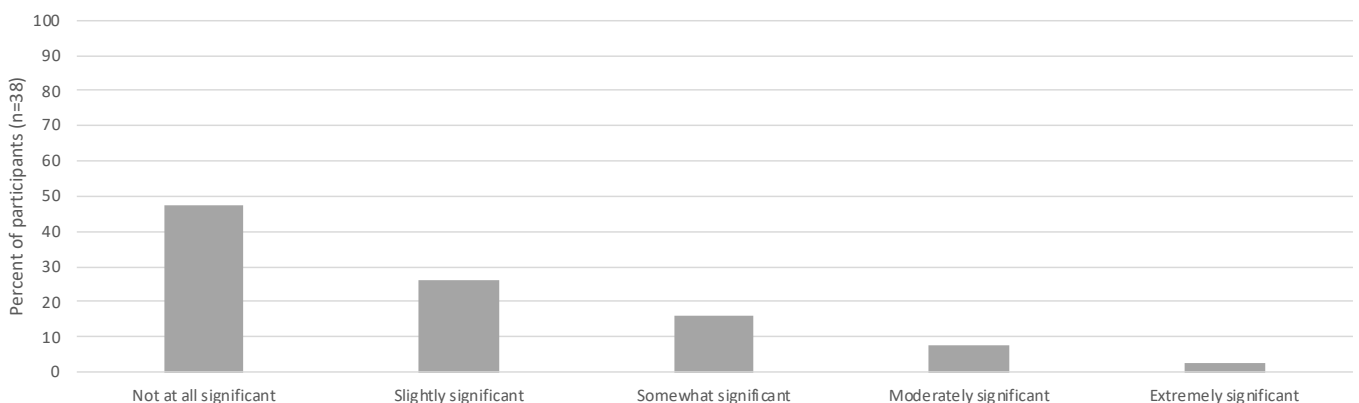
Out of pocket expenses for diagnostic tests	Number (n=43)	Percent
\$0	14	32.56
\$1 to \$250	3	6.98
\$251 to \$500	3	6.98
\$501 to \$1000	2	4.65
More than \$1000	6	13.95
Not sure/can't remember	15	34.88



**Figure 3.21: Out of pocket expenses at diagnosis**

**Table 3.26: Burden of diagnostic costs**

Burden of diagnostic costs	Number (n=38)	Percent
Not at all significant	18	47.37
Slightly significant	10	26.32
Somewhat significant	6	15.79
Moderately significant	3	7.89
Extremely significant	1	2.63



**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=39, 90.70%). There were 3 participants (6.98%) who brought up the topic with their doctor, and a single participant (2.33%) whose doctor brought up the topic with them (Table 3.27, 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.

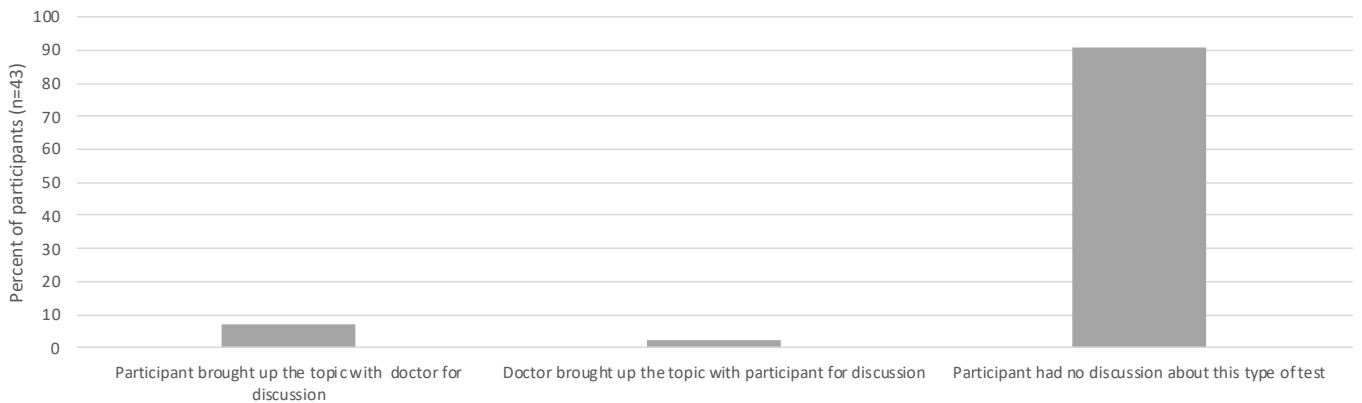
The majority of participants did not have any genetic or biomarker tests but would like to (n=32, 74.42%). There were 9 participants (20.93%) who did not have these tests and were not interested in them, and a single participant (2.33%) that had biomarker tests (Table 3.28, Figure 3.24).

#### Biomarker status

All participants (n=43, 100%) were not sure about any markers that they have in relation to bladder cancer.

**Table 3.27: Discussions about biomarkers**

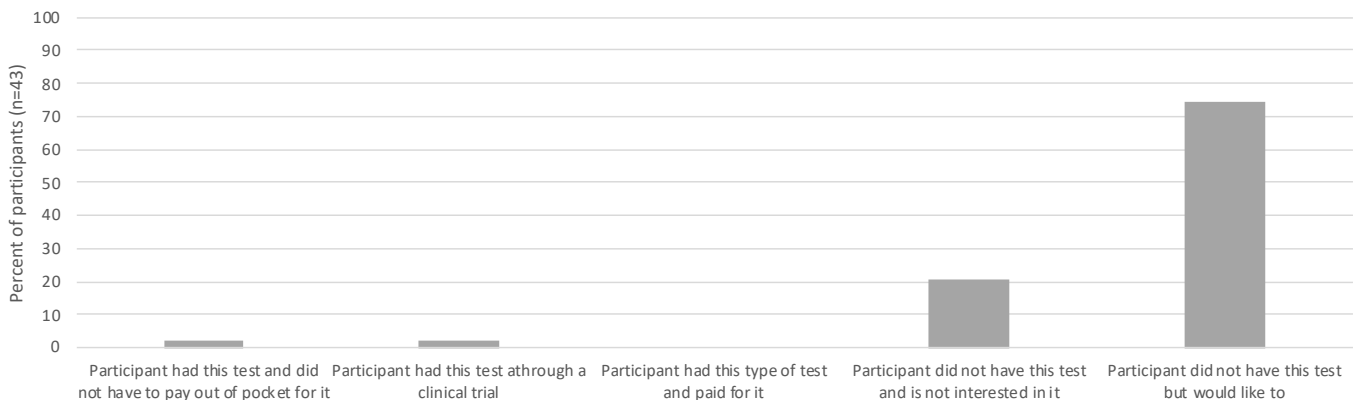
Discussions about biomarkers	Number (n=43)	Percent
Participant brought up the topic with doctor for discussion	3	6.98
Doctor brought up the topic with participant for discussion	1	2.33
Participant had no discussion about this type of test	39	90.70



**Figure 3.23: Discussions about biomarkers**

**Table 3.28: Experience of genetic tests and biomarkers**

Experience of genetic tests and biomarkers	Number (n=43)	Percent
Participant had this test and did not have to pay out of pocket for it	1	2.33
Participant had this test through a clinical trial	1	2.33
Participant had this type of test and paid for it	0	0.00
Participant did not have this test and is not interested in it	9	20.93
Participant did not have this test but would like to	32	74.42



**Figure 3.24: Experience of genetic tests and biomarkers**

### Understanding of prognosis

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. Participants most commonly described their prognosis in relation to having no evidence of disease or that they are in remission (n=28, 57.14%), and in relation to monitoring their condition with tests, scans, or regular follow up appointments (n=28, 57.14%). There were 12 participants (24.49%) that described prognosis in relation to probable recurrence/cycle of recurrence, 10 participants (20.41%) that described prognosis in relation to tumour grade or stage, and 7 participants (14.29%) described prognosis in relation to a specific timeframe that they have been disease free.

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

*Okay. Um. Medically, I don't know. At the moment I've been given an all clear and certainly the specialist that treated me fairly confident that I've had a result as good as I can expect and as good as they can expect. Um, so we're sort of basically we're happy about that. Um, so from that point of view, I'm not really too concerned about whether I get a return of the cancer or not. Um, so my primary concern has been really just learning to live with the results of the operation, which is, you know, nearly lost me back. Hmm.*  
Participant 034\_2022AUBLC

Well, the last prognosis is that, um, they did a cystoscopy and biopsies, they did a fair few biopsies. And, uh, the surgeon came in and seen me and said that he couldn't see any cells, so any cancer cells. So that was good. And then I've been to my urologist since, and he says that the bladder itself is all clear, but he's worried about, he's worried about the, the tubes and the kidneys.

Participant 007\_2022AUBLC

Um, well, I finished our BCG in January this year. I had a cystoscopy a couple of months later, cystoscopy, and everything was clear at the moment. I'll have another test probably in about three months time. And, yeah, I think at the moment it's it's I'm in remission, but at the moment there are no signs of the cancer, which is okay.

Participant 024\_2022AUBLC

**Participant describes prognosis in relation to monitoring their condition with tests, scans, or regular follow up appointments**

Well, I just get monitored with a CAT scan every six months and blood tests. And to all intents and purposes, he's got it all. It's cured at the moment. So it's just monitoring to make sure it doesn't come back. But given that everything is taken, the urethra, uh, top part of the ureters, bottom part sorry. And full radical hysterectomy and everything. And I think 23 lymph nodes were negative, which was that's all we took out. So it looks pretty clear and it's meant to have over 80% cure rate if you get it that early. So, yeah, I'm hopeful that it's cured.

Participant 018\_2022AUBLC

Yeah, basically a blood blood test and urine test once a year to see for any markers.

Participant 019\_2022AUBLC

Mine is very, very good. I think the bladder cancer was non-invasive and I've been on a number of treatments, including a trial drug, and I'm now over two years past the original remove or removal of the tumour and undergoing sort of routine and follow ups.

Participant 029\_2022AUBLC

My current outlook. Now, I am now on six monthly reviews with my oncologist, uh, my surgeon still just, uh, that I've gone to doing a phone check-up with me every three months just to see how things are going. But that pretty well handed it over to the oncologist, um, there's been no, no change as far as anything in,

uh, yeah, there's no other tumours visible or my blood are all coming back at this stage. Yeah, yeah, yeah.

Participant 035\_2022AUBLC

Yeah, well, what my current outlook is. I mean, the when I'd had the operation I had the operation on the 17th of September. Doctor NAME came in the following day or the day after to say that as far as they were concerned, the cancer, they'd got rid of it by removing the bladder of the cancer and cancer free, were his words. And I would have to, I didn't have to have any radiation or chemotherapy or anything at all. It was all really done quite quickly. But I have to have C.T. scans every six months for five years. And in fact, I'll have my first one in a couple of weeks time in May.

Participant 043\_2022AUBLC

**Participant describes prognosis in relation to probable recurrence/cycle of recurrence**

Yeah. Yeah. So I had another cystoscopy a few weeks back and that was the second one. So I was diagnosed about June last year. And so this was the second cystoscopy that I'd had. And it came back all clear. And in fact, the oncologist remarked that it was odd that they didn't even take a biopsy of just some tissue that might have looked a bit suspect. He said if I didn't even do a biopsy, it means you're very, very clear. So that was good to hear and, oh look, it's once it's happened, it can happen any time. So it's just a matter of having to live with the knowledge that it could happen again because it happened the first time. So it's not like I'm cured.

Participant 030\_2022AUBLC

**PARTICIPANT:** Oh, yes. Um, I, I had BCG, um, basically for the last couple of years, and then I got to the point where I just couldn't handle the BCG any longer. The side effects seem to be getting worse and worse. And my urologist was obviously checking, doing, cystoscopy every three months and every six months. And in the end, his recommendation was that I'd done well to stick it out as long as I had and basically to stop the BCG, which is what I did.

**INTERVIEWER:** So is the current outlook reasonable yet?

**PARTICIPANT:** Quite, quite reasonable. I belong to a group that's called Beat, B E A T, and it's run by a urologist that's based in Sydney. And I am aware through going, ther'e a Zoom meeting once a month, I'm aware with that that there's definitely the possibility of the cancer coming back and. At the

*moment I am cancer free. I had a cystoscopy in December and nothing was there, but I am aware that potentially it could come back. And my urologist has said just to have a cystoscopy once a year. But given that the initial one was a high grade, I discussed it with him and said, could I make it more often? And he said, that's entirely up to me. So I was elected at this point to have a cystoscopy every nine months. And I would have to say I get very anxious before each one because I am. Aware that it can just come back and and can also it can be that the kidneys become affected and what have you. And I don't want it to get out of control before I find out about it.*  
Participant 036\_2022AUBLC

*Yeah, sorry. Definitely. So it's pretty good at the moment because he's had some treatment and the last cystoscopy showed nothing has going back. And however when we went to the oncologist. He said that because it's high grade cancer, it's just a matter of when it comes back because it will come back. So it's just a matter of now just catching it early and preserving his bladder.*  
Carer 003\_2022AUBLC

#### **Participant describes prognosis in relation to tumour grade or stage**

*Well they sort of thinking that it it's okay the prognosis because it's still just sitting on the lining of of the bladder. So it's not invasive at this stage. I'm just trying to get rid of it.*  
Participant 004\_2022AUBLC

*Mine is very, very good. I think the bladder cancer was non-invasive and I've been on a number of treatments, including a trial drug, and I'm now over two years past the original remove or removal of the tumour and undergoing sort of routine and follow ups.*  
Participant 029\_2022AUBLC

*My prognosis is good. I had a radical cystectomy in 2017. Once I went, once I got referred to the urologist and they found the tumour. They even then still thought that this would be one of the low grade cases. But once they did the TURBT and had pathology done on the tumour, they realised that it was very aggressive and high grade and muscle invasive. So everything moved really quickly. I think I had the TURBT on the 10th of May and waited a week for the results and then I had a radical cystectomy already in June where they removed my bladder and I now have a neo bladder. So everything went really quickly. Like*

*no time to think, no time to act. Let's just get this out and hope that it hasn't spread.*  
Participant 032\_2022AUBLC

#### **Participant describes prognosis in relation to a specific timeframe that they have been disease free**

*My outlook. Oh, yeah, yeah, yeah. Okay. My current is, uh, is clear for two years.*  
Participant 016\_2022AUBLC

**PARTICIPANT:** Very good now.

**INTERVIEWER:** What does very good mean?

**PARTICIPANT:** So I should say excellent. I mean, I've been told repeatedly by my urologist that this. If my type of cancer was going to come back. It's generally within the first 12 months.

**INTERVIEWER:** And how long? When were you diagnosed?

**PARTICIPANT:** I was diagnosed in late, early, early 2016, January 2016. And I had the operation and everything out in March 2016.  
Participant 022\_2022AUBLC

#### **Participant describes prognosis in relation to the specific medical interventions they need to manage their condition**

*Or he said to me, Oh, it's just a low grade bladder cancer. We just have to keep an eye on. Okay. Take them off as they come up. And I actually spoke with a friend of my sister's who's a physician, and she's a good friend. And I said and she kept on saying to me, Have you had BCG? Have you had BCG? And I started to ask my surgeon, am I gonna have BCG. And he just said one day, why do you have this obsession about BCG? I said I'm not actually, I'm not. I don't know anything about this, but this doctor just said to me, she keeps on asking me if I had BCG and he said, no, no, BCG isn't for your sort of bladder cancer.*  
Participant 001\_2022AUBLC

*I just have another operation and that five months time or in July or by July, I suppose to have another operation.*  
Participant 013\_2022AUBLC

*Well, I had a series of BCG treatments in January and February, and I went back at the end of March to have a flexible cystoscopy and they found the third he found is still some tumours there. So I need to go back*

*in July and have an operation to have them removed. And he didn't say what the next step was, but I'm assuming I'll have more BCG treatment.*  
Participant 023\_2022AUBLC

**Participant describes prognosis in relation to statistics such as five year survival rates**

*Well, I just get monitored with a CAT scan every six months and blood tests. And to all intents and purposes, he's got it all. It's cured at the moment. So it's just monitoring to make sure it doesn't come back. But given that everything is taken, the urethra, uh, top part of the ureters, bottom part sorry. And full radical hysterectomy and everything. And I think 23 lymph nodes were negative, which was that's all we took out. So it looks pretty clear and it's meant to have over 80% cure rate if you get it that early. So, yeah, I'm hopeful that it's cured.*  
Participant 018\_2022AUBLC

*Very not much. All I know from my readings because. Once I got diagnosed, I started reading a lot all the research articles from Universities and Cancer Council, Victoria and America and UK. And with my treatment, it's actually there are two types of treatments surgery or radiation, and it's almost the same. There's about*

*67% survival, five year survival rate. Okay. And my my radiation doctor also said, yeah, it's around this much. Okay. 65 to 70%. But he says, I mean, my outlook looks good.*  
Participant 028\_2022AUBLC

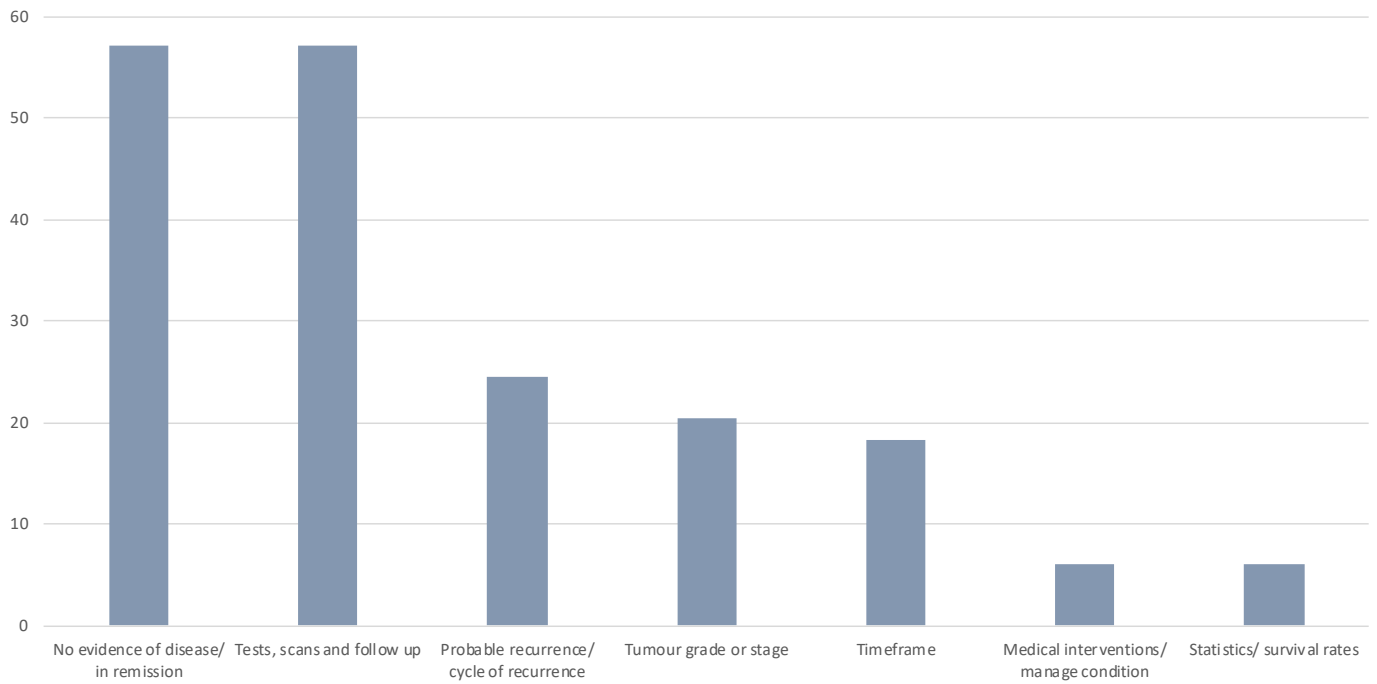
*PARTICIPANT: It's unusual. I'm talking to the urologist. They say it's unusual for a for a bladder cancer to metastasise and then slow down. So I had my secondaries in the lung and I had surgery done on my right lung it to remove part of the lower lobe. And there are two spots there looking at or two growths their looking at about know about a centimetre in diameter in my left lung, but, they're very static. They're just sitting there doing nothing and they're in a position that's awkward to biopsy. They assume that it's the metastasised bladder cancer. But they're just sitting there doing nothing which which they say is unusual. Of course, when I found out I had a metastasised bladder cancer, I went and googled, you know that. What is it, a, which which put it had something like 5% chance of survival. So after five years of prep. Which left me psychologically kind of screwed up for a little while, I mean. I'm not sure what you're supposed to how you're supposed to process that information.*  
Participant 041\_2022AUBLC

**Table 3.29: Understanding of prognosis**

Understanding of prognosis	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes prognosis in relation to no evidence of disease or that they are in remission	28	57.14	11	55.00	5	50.00	9	64.29	25	56.82	3	60.00	10	58.82	18	56.25
Participant describes prognosis in relation to monitoring their condition with tests, scans, or regular follow up appointments	28	57.14	14	70.00	5	50.00	7	50.00	26	59.09	2	40.00	9	52.94	19	59.38
Participant describes prognosis in relation to probable recurrence/cycle of recurrence	12	24.49	4	20.00	3	30.00	4	28.57	11	25.00	1	20.00	4	23.53	8	25.00
Participant describes prognosis in relation to tumour grade or stage	10	20.41	4	20.00	0	0.00	5	35.71	9	20.45	1	20.00	4	23.53	6	18.75
Participant describes prognosis in relation to a specific timeframe that they have been disease free	7	14.29	3	15.00	2	20.00	0	0.00	5	11.36	2	40.00	2	11.76	5	15.63
Participant describes prognosis in relation to the specific medical interventions they need to manage their condition	3	6.12	2	10.00	1	10.00	0	0.00	3	6.82	0	0.00	1	5.88	2	6.25
Participant describes prognosis in relation to statistics such as five year survival rates	3	6.12	1	5.00	1	10.00	1	7.14	3	6.82	0	0.00	0	0.00	3	9.38

Understanding of prognosis	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes prognosis in relation to no evidence of disease or that they are in remission	28	57.14	18	62.07	9	47.37	10	66.67	17	51.52	12	60.00	15	53.57
Participant describes prognosis in relation to monitoring their condition with tests, scans, or regular follow up appointments	28	57.14	15	51.72	12	63.16	10	66.67	17	51.52	11	55.00	16	57.14
Participant describes prognosis in relation to probable recurrence/cycle of recurrence	12	24.49	5	17.24	7	36.84	2	13.33	10	30.30	4	20.00	8	28.57
Participant describes prognosis in relation to tumour grade or stage	10	20.41	6	20.69	4	21.05	2	13.33	8	24.24	3	15.00	7	25.00
Participant describes prognosis in relation to a specific timeframe that they have been disease free	7	14.29	4	13.79	3	15.79	4	26.67	3	9.09	3	15.00	4	14.29
Participant describes prognosis in relation to the specific medical interventions they need to manage their condition	3	6.12	0	0.00	3	15.79	0	0.00	3	9.09	0	0.00	3	10.71
Participant describes prognosis in relation to statistics such as five year survival rates	3	6.12	2	6.90	1	5.26	0	0.00	3	9.09	0	0.00	3	10.71



**Figure 3.25: Understanding of prognosis**

**Table 3.30: Understanding of prognosis – subgroup variations**

Understanding of prognosis	Reported less frequently	Reported more frequently
Participant describes prognosis in relation to monitoring their condition with tests, scans, or regular follow up appointments	Carer to someone with bladder cancer	Early (Stages 0 and I)
Participant describes prognosis in relation to probable recurrence/cycle of recurrence	Regional or remote	University
Participant describes prognosis in relation to tumour grade or stage	Invasive (Stage III)	Advanced (Stage IV)
Participant describes prognosis in relation to a specific timeframe that they are expected to live	Advanced (Stage IV)	Invasive (Stage III) Carer to someone with bladder cancer