Section 4

Decision-making

Section 4 summary

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about such options. The most common description was being presented with multiple treatment options, and this was described by 34 participants (69.39%). This was followed by being presented with one treatment option only (n=14, 28.57%).

Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, of the participants that were presented with multiple treatment options, 10 participants (20.41%) described taking part in the decision-making process, and the same number described not participating in the decision making process (n=10, 20.41%). There were 6 participants (12.24%) that described discussing multiple options, however they felt there was only one viable option. Of the participants presented with one option, they most commonly described being told what to do with out any discussion (n=5, 40.20%).

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most reported theme was taking the advice of their clinician, and this was described by 23 participants (46.94%). There were 15 participants (30.61%) that considered being cancer free, avoiding recurrence, or longevity, and 12 participants (24.49%) that described taking side effects into account. Other considerations included taking ease of administration into account (n=8, 16.33%), quality of life (n=7, 14.29%), costs (n=5, 10.20%), and impact on family and dependents (n=5, 10.20%).

Decision-making over time

Participants were asked if the way they made decisions had changed over time. There were 28 participants (57.14%) that felt the way they made decisions about treatment had not changed over time, and 20 participants (40.82%) that described decision making changing.

Where participants had not changed their decision making over time, this was because they have always taken the advice of clinicians (n=11, 22.45%), or had always been informed and assertive (n=7, 14.29%). Where participants had changed the way they make decisions, this was primarily in relation to becoming more informed or more assertive (n=13, 26.53%).

Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common response was wanting to be cancer free, avoid recurrence or increase longevity (n=20, 40.82%), and this was followed by wanting to improve their quality of life or return to normality (n=15, 30.61%). Other themes included wanting to minimise or avoid side effects (n=10, 20.41%), bladder preservation (n=8, 16.33%), wanting to be supported/reassured/informed by their healthcare team (n=6, 12.24%), and not having personal goals as they are guided by their doctor (n=5, 10.20%).

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about such options. The most common description was being presented with multiple treatment options, and this was described by 34 participants (69.39%). This was followed by being presented with one treatment option only (n=14, 28.57%).

Participant describes being presented with multiple options/approaches

I had the Dr. NAME neurologist here in LOCATION and he's awesome. He's set down this and he was straight up and down. My wife was with me and he said, It is stage two and it's hitting stage three. It's muscle invasive and it's high and that whatever it is, it's serious. And he said, ah, I don't think you're an option for BCG. So he said, What we'll have to do is take it completely and the prostate. And he said either have the stoma or have the neo bladder. But I, and I chose the stoma after discussion with him. And then. Yeah, okay. So my wife was in on it from day one. My, my, my, my partner.
Participant 038_2022AUBLC

PARTICIPANT Um, he told me that, um, when of course it was high grade. Um, it was a bit scary at the time when I had the TURBT and had been removed. He gave me the option of having treatment BCG or he said, you could get oh, I had to have a second TURBT. And he said if it came back that it was in the muscle. He said, you'll have to get your bladder removed like straight away. And if it's not, he basically said you can start your treatment of having the BCG treatment. And he said that was a bit scary, like only being diagnosed a month and then telling me I had to get my bladder removed. Well I didn't realise it was, I didn't think it was that serious, you know what I mean? Like 'cause you don't feel sick at the time, you know? I mean, there's except for having like the blood in urine, I felt okay, you know? I mean, like, I feel I didn't feel like I had cancer. Does that make sense?

INTERVIEWER Yeah. Yeah. Was definitely a shock.

PARTICIPANT It was, yeah. And then I had the, um, the second TURBT and he, he thought then because it hadn't invaded the, um, the wall of the bladder, he said we should go ahead with the, um, the BCG treatment and. Yeah. And, and he said, well, he did give me the option. He said, you can either go get your bladder removed or you could, or he suggested to go for the treatment of the BCG and see if that worked.
Participant 044_2022AUBLC

With the doctor? Yeah. Okay. We really didn't offer many different options. He said, okay, we need to do this and then we need to do that and then we need to do this. And there was no, no real options given. Oh, well, I guess before they removed the bladder, they did say we could choose to not remove it, but he wouldn't have a good prognosis for five years.
Carer 005_2022AUBLC

Participant describes being presented with one option/approach

Well, basically he just said that, well, get in and check it on a regular, you know, semi-regular basis sort of thing. And COVID was a disruptive force, I've got to say that, it didn't quite go to plan because of that. Pretty good. I've got to say that I didn't have too many issues with it did delay things at times but not to any great extent put it that way. It was only weeks, not months. And so, yeah, and I think that the discussion side of it probably. He spoke to me more as I, at the hospital rather than go back and see him. Whether I was 100% clear on everything. I would not say that I was. Normally when I go and see a specialist, I do take my wife with me, I mean she worked in the hospital system, which she can generally interpret something that I haven't quite picked up on as clearly. So I sort of yeah, I wouldn't say I was 100% clear of what was going to happen initially, but he spoke to me about the BCG and what should happen with that. And I didn't have any well, basically when I got down to that, that was another issue. But. Yeah. That's, that's basically what we spoke about.
Participant 011_2022AUBLC

Um, basically, I was diagnosed by I got referred to a urologist. He sent me for a couple of tests and come back with bladder cancer. Yeah. And then it was just cystoscopy and stuff like that at the start. And. Okay.
Participant 033_2022AUBLC

Okay. Well, I was in HOSPITAL when I was diagnosed, and when I woke up from the anaesthetic, the surgeon was trying to talk to me and I wasn't really around properly. So she, he, you know, broke the news and not a bit surprising, you know, totally surprised. And she also rang my wife. And Yeah. So that it was in a lot of discovery then of, of uh, they provide, they provide very good information to me, booklets etc. from the Cancer Foundation about it. And the pointed me towards a lot of reading. Now they were open to

discuss it as much as I wanted. And I also, when I stayed in hospital for a night, um, there was another surgeon that came around and talked about the, what had happened and what the process was likely to be from there on. They very good. I never went back to my, I didn't go back to my GP for probably quite a few weeks after and discussed with her what was happening. A new GP that was at this point. Participant 029_2022AUBLC

Table 4.1: Discussions about treatment

Discussions about treatments	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 presented with multiple options/approaches	34	69.39	13	65.00	7	70.00	10	71.43	30	68.18	4	80.00	9	52.94	25	78.13
Participant describes being presented with one option/approach	14	28.57	7	35.00	3	30.00	3	21.43	13	29.55	1	20.00	8	47.06	6	18.75
Other/no response	1	2.04	0	0.00	0	0.00	1	7.14	1	2.27	0	0.00	0	0.00	1	3.13

Discussions about treatments	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 presented with multiple options/approaches	34	69.39	22	75.86	11	57.89	11	73.33	22	66.67	13	65.00	20	71.43
Participant describes being presented with one option/approach	14	28.57	6	20.69	8	42.11	4	26.67	10	30.30	6	30.00	8	28.57
Other/no response	1	2.04	1	3.45	0	0.00	0	0.00	1	3.03	1	5.00	0	0.00

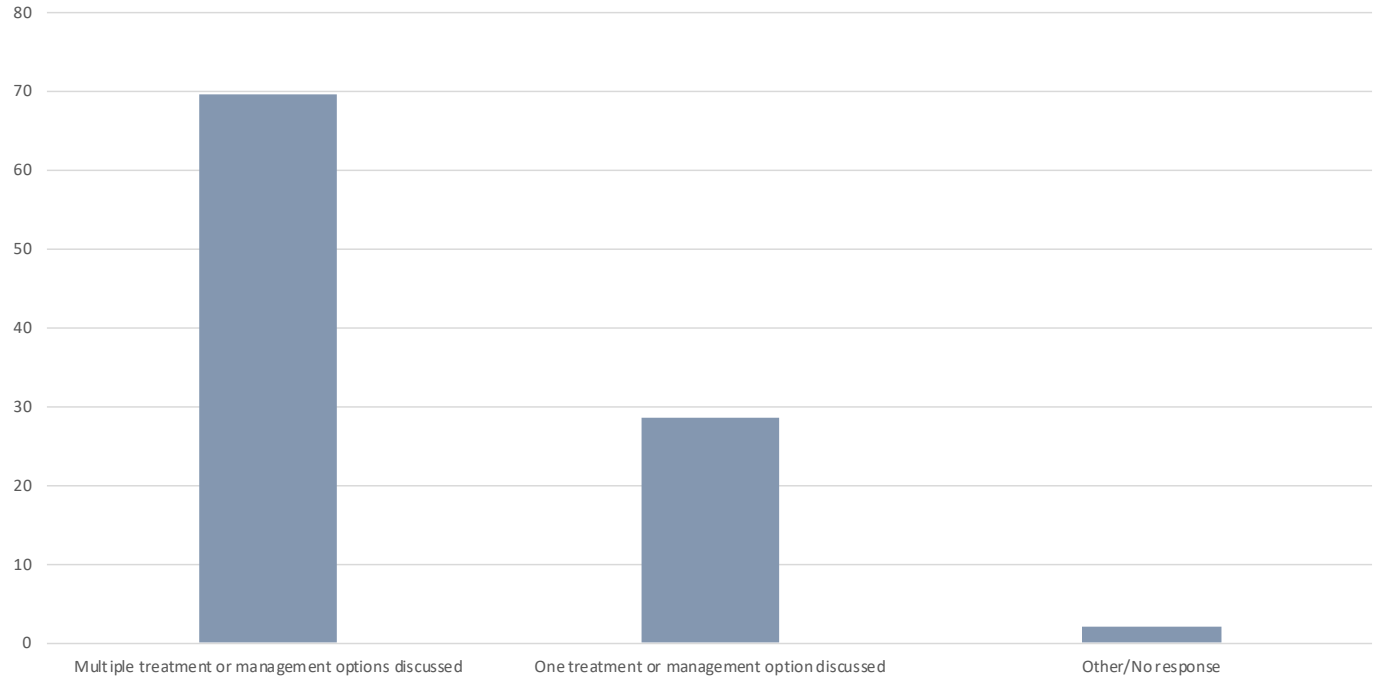

Figure 4.1: Discussions about treatment

Table 4.2: Discussions about treatment – subgroup variations

Discussions about treatments	Reported less frequently	Reported more frequently
Multiple treatment or management options discussed	Female University	Carer to someone with bladder cancer
One treatment or management option discussed	-	Female University

Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, of the participants that were presented with multiple treatment options, 10 participants (20.41%) described taking part in the decision-making process, and the same number described not participating in the decision making process (n=10, 20.41%). There were 6 participants (12.24%) that described discussing multiple options, however they felt there was only one viable option. Of the participants presented with one option, they most commonly described being told what to do with out any discussion (n=5, 40.20%).

Participant describes being presented with multiple options: Participated in the decision-making process

Okay. It's a beginning. When they find that tumour. Uh, yeah, they. They said, all right, I'm sure. I just wanna. It's a low, low grade. It was big, but low grade. And my urologist said it was so lucky. It was a low grade, and I'll see you next year. But I thought, yeah,

it is. He said it was a low grade, so don't worry. We'll do a check-up in 12 months time. But from my knowledge in COUNTRY there even there was low grade, they would do check up in like every three months for a while. Just make sure it's okay. So I thought a 12 month, leave it for 12 month is too long. And I ask the doctor if it's if you do that, you don't mind. For my peace of mind, can you do the analysis? This could be doing a check-up in like I. No, no, no. Actually the first time she said I would do the another cystoscopy in a six month time and okay I did another cystoscopy in September 2018 and it was come back clear okay so then he said okay then this year, next year, you don't need to do anything for 12 months. But I said for peace of mind, I can do it in a six month check-off and he did a cystoscopy check-up six months and actually, he find a high grade. So it was really lucky I did a six month check-up.

INTERVIEWER: Okay? Yeah. Okay. Yeah. Then what sort of discussions did you have about treating it.

PARTICIPANT: So that after that is okay? And he said, Oh, unfortunate, right? Um, how did that. Uh, the high grade. It was a high grade. It's no good. So she said a BCG is a standard of treatment for this tumour. Uh, thne he, he introduced me to BCG.
Participant 015_2022AUBLC

Where the main choices were to have either an ileal conduit like radical cystectomy and pelvic clearance with urostomy, I had to have a urostomy whatever way we went wasn't eligible to have a neo bladder because I had to take the urethra out. So that was easy choice. I didn't have to worry about that. And then the other option was a reservoir that sits in under the skin. You probably know that those and then you put a catheter in to empty them. And I thought, Oh yeah, I can probably manage that. That'd be right, because then everything's hidden. But then he told me that to make so you need to use a lot more bowel to make the capacity a reasonable size. And that means that that bit of bowel can then not absorb all the things that it used to when it was bowel. So you get quite low in magnesium and all sorts of electrolytes. And I remember having a patient coming in all the time who had had a similar piece of bowel taken out for something else, and we were forever topping up her magnesium and she just couldn't get electrolytes right. And I thought, I'm not doing that. So he said, look, the simplest is just a stoma. Ileal conduit stoma a bag. And you know, easy, so that was sort of decided in a way because of my knowledge in those areas, I guess. Yeah. So, you know, ideally I thought it'd be nice to have it hidden away and you could just empty it when you wanted to. But it sounded like there's too many medical issues with that. Yeah, just made it plain and simple. Just have a bag on, and you empty it and that's it.
Participant 018_2022AUBLC

So I don't have one doctor. I mean, I have a GP who sent me to the hospital for a cystoscopy. And the hospital told me that I have cancer. And they said that the treatment for me is surgery to remove the bladder. And I said, well, is there more other options for me? And they said, you can try radiation, but we do not recommend it for your age because you're not very old and you can handle the surgery. And with surgery that it cannot come back because you don't have a bladder, but with radiation that can come back and also with radiation, maybe not now, but maybe in few years, the radiation itself can cause cancer. So I said, okay, then I go for surgery, but I can I still talk to them, I still get some more information for radiation. So I was not given very clear information that in my case, radiation, radiation was equally successful. So then I told them, do you need more me to continue? … So I just wanted to be aware that, you know, the main difference was radiation versus surgery and both have pros and cons. And I really wanted to be completely, very clearly informed. But because both treatments have got risk, it's not that one is right or wrong. It's what you are prepared to pay, what risk you want to take.
Participant 028_2022AUBLC

Okay. So the options that are available to me, they strongly suggested having the bladder removed and a stoma put in. I yeah. I asked about, you know, the possibility of a neobladder right now at that time they said, look they, they basically said, they didn't do the neobladders all that much here in Australia and they weren't being able to, to give that is an option for me.
Participant 035_2022AUBLC

No, it was pretty, pretty quick, to be honest. It was it was just in there. I did I'm on the pension. So really a lot of this stuff has cost me a bit of money, but I couldn't afford to really go and see Dr. NAME in his private rooms there all the time because it's, you know, saying three times it cost me a fair bit of money, a couple of hundred bucks a visit. And so I saw he has these registrars work for him and you see them and that's free for pensioners. And they were fairly quick and to the point of pretty, you know, pretty good knowledge about it, you know, that it was really a fairly quick sort of summation of what had to be done. So that was basically, basically all I had I didn't or really the appointments only went for probably 5

minutes, maybe ten max. But you know, they were quite sympathetic it's something that we've got to do and we have to do is have a cystoscopy and worse comes to worse you lose your bladder, and I went, really? OK. That that hasn't come to fruition at this stage. Hopefully it doesn't in the future. So that's basically it for the treatment. It wasn't an hour interview or anything like that. It was just, tell me what I had, what had to be done, you don't have to have chemo. It's got to start next week. And that was it went in every day, every Wednesday for six weeks for the mitomycin. And that was basically it. So it wasn't anything not nothing like I had when I had both my knees replaced at that was a real, uh, consultations went forever. But that's about it. Just get in, have a look, see if we can get it and go from there. I suppose if I had to have a, I can't remember what they called a bladder replacement or was that a call that that would have been a bit more thorough or a bit more in-depth? That hasn't come to pass at this stage. I've got to say, Dr.. Excuse me. I've got to say Dr. NAME, it's been fantastic, really. He's a terrific bloke. The times I've seen him and we get along with him pretty well.
Participant 021_2022AUBLC

Participant describes being presented with multiple options: Did not participate in the decision-making process

Um, well, I had a phone call with a urologist after the cytology came back positive, and he said the treatment was going to be a trans urethral resection of the tumour. Um, after that, he said. When I was in hospital, I'd need another one in about four weeks time, which I had. And in the meantime, I was referred to an oncologist. And. Um. I guess my discussion with the oncologist is probably a bit sketchy because I couldn't have anyone with me when I went in. I'm trying to absorb it all. Basically, he just was going, because I had been on treatment for an autoimmune disease. He told me I wasn't suitable to have BCG, which was the treatment of choice. But even if I was suitable, there was a shortage so they couldn't have given it to me anyway. So the treatment was just gemcitabine at the end of his cycle treatment for six weeks. And then I would have, um, either he or the urologist said I'd have them cystoscopy after each a lot of treatment to see what the response was. Um, I, I believe in a letter to the GP and he said to the GP that we discussed having a cystectomy as a treatment of choice, but I don't believe that was the case.
Participant 002_2022AUBLC

So when we got, so the first, when I first went in and had tumours removed, obviously they were sent off for a biopsy. And it came back as non-muscle, a high grade non-muscle invasive bladder cancer. So. Um. Then I went in three weeks later and the next night it was non-muscle invasive at that point. It was a high grade tumour, cancer. Then when I went back in for another resection of the bladder. A trans urethral resection of the bladder. They then sent that off for a biopsy and that came back clear. So nothing the cancer cells hadn't metastasised into the muscle wall or anything like that. So after that the treatment option? Well, we didn't really, she said. But the treatment we would do is the BCG treatment, which was the tuberculosis vaccine, directly instilled into the bladder. Nothing else was really talked about other than. You know, she said, look, it's a 50% effective vaccine. If it doesn't work, it's potential bladder removal. But at this stage, this is just what happened, what the route that she thought would be best to go, because we got it sort of reasonably early, I guess it was classed a sT1. So even though there were three tumours about ten mil, it was still classed as an early, sort of finding. So I didn't feel the need to go down the radio or chemo route.
Participant 014_2022AUBLC

As soon as I was diagnosed with, um, sent straight to a urologist. And at this point was where he basically told me what it was. And he didn't really want to to mess around. So he didn't wan,t he didn't want me to go through chemo or radiotherapy. He thought the best option was to go straight to the operation to see what was going on.
Participant 027_2022AUBLC

Participant describes being presented with multiple options: They were told what to do without discussion

As I said, the first two, they cut out stuff. The next three were clear. Then I was on the BCG treatment and I got so sick from that that I had to, you know, I was in so much terrible pain from that that I had to I had to discontinue the BCG, which I know is a risk. But, but I couldn't. And, and he just kept saying that's the gold standard, that's the treatment for, you. And so there was no there was no discussion of other options or. Or. Or anything.
Participant 008_2022AUBLC

Just I can't really remember an actual discussion about the actual any treatments. They were just saying, oh, this is what we're going to do regarding this procedure. And then we'll then we'll go for the next procedure and we'll work out from there, from

there on. And it was just like they must have had steps that they had to follow, you know? I mean.
Participant 031_2022AUBLC

Very little, really. Dr. NAME is a highly skilled surgeon, urologist, and he, he just was pretty, matter of fact, and told me what the what it was and what would have to be done. He mentioned a neobladder, but he said he didn't think that that that would be the best option for me, probably because of my age and the fact that it grown into the muscle.
Participant 043_2022AUBLC

With the doctor? Yeah. Okay. We really didn't offer many different options. He said, okay, we need to do this and then we need to do that and then we need to do this. And there was no, no real options given. Oh, well, I guess before they removed the bladder, they did say we could choose to not remove it, but he wouldn't have a good prognosis for five years.
Carer 005_2022AUBLC

Participant describes being presented with multiple options: however, there was only one viable option

Um, so when I was first diagnosed and as I said, my GP told me that I had cancer and then my urologist followed up with a call and, mind you it was the middle of COVID. So all of my appointments were done via the phone, via phone. Um, but basically I didn't really have too many treatment options as far as I was aware. My urologist told me that chemotherapy or radiation or any of those forms of treatment would not be effective. The only way forward was to have part of my bladder removed.
Participant 009_2022AUBLC

All of these fundamentally tw,o two sources of conversation really in terms of surgery. And the first one was the cancer, which is the oncologist, the oncologist, who obviously was aware of the surgery. But he said that the cancer itself really had no other treatment. He said the only option was to not have it, not have to simply I couldn't have radio therapy because it was in the wrong places, too deep and too difficult. Anyway, so he said basically said, if you have it, you probably got, you know, up to another five years of life expectancy. If you don't have it, you'll probably get between six months and a year. If you're lucky. That was the oncologist saying those sentiments were basically reflected in the uro-surgeons sent to the, the primary resection the guy who actually removed the bladder. And he, he basically said that, I would say you can either take a punt and hope that you last six months or 12 months, he said, or you can have the operation and hopefully you can have up to another five years, he said. But apart from that, he said that this everything goes well, he said. But this operation is fraught with complications. And he said in many ways complications are more of a danger than the operation itself.
Participant 034_2022AUBLC

With the doctor? Yeah. Okay. We really didn't offer many different options. He said, okay, we need to do this and then we need to do that and then we need to do this. And there was no, no real options given. Oh, well, I guess before they removed the bladder, they did say we could choose to not remove it, but he wouldn't have a good prognosis for five years.
Carer 005_2022AUBLC

Participant describes being presented with multiple options: Changed clinician as they were not satisfied with discussion, lack of empathy and/or options presented

The first specialist I saw only talked about the gold standard is that we should rip everything out. And he wouldn't, he was immovable, but I'm also immovable, so I refused. … I will, I refused to cooperate with the surgery and insisted on a referral to an oncologist. So at that point they offered me what they call the tri modal option. So bladder salvage, which is what my main focus was on bladder salvage. So I didn't want to go down the road to surgery. … Okay. Well, once I got to the oncologists, they said that they felt that they could preserve my bladder and so they recommended it. And how does the chemotherapy dose dense? In fact, it was called. And I also saw a radio and oncology radiologist as well. And so the treatment that was recommended was the track to weekly for four sessions, followed by, I think it was 30 sessions of radiotherapy.
Participant 020_2022AUBLC

Well, I knew there was two types. All right. Bladder cancer. Okay. So basically. They talked a little bit about Neo. What they call it the one where you got the they make the bladder bag inside your body and they go to neo, whatever it's called. Then they talk about the one that's outside your body. Yeah, but I did my own research, mainly because the doctors they, they're very fast and they don't, don't spend much time explaining it. So you really because of I've had. As you know, I've told you already 4 cancers. So, you know, they're. I actually went to a private doctor to, to get my. And what was that one? That was a prostate. Yeah. So, you know, I paid a private

urologist to tell me about the prostate operation and stuff. And when he quoted me $25,000 for the operation, I said, I'll oh, I'll take the public one. He didn't want to know me after that because I went after I went through the public operation for the removal of the prostate. I want to talk to him again. And his secretary wouldn't let me talk to him. Oh, you just you chose the public operation, so sorry. No, our policy is we don't get involved after that. He was happy to take my money beforehand, and I would have paid money paid him again to afterwards. But he did want to know me, so I thought that was very lousy. But as far as bladder cancer, it's something that is, you know, you treat like a number.
Participant 042_2022AUBLC

No, I'm waiting. I could have started if I'd gone private. Probably in the next week or two. I'm hoping is to start in the next week or two. With public if the public takes too long, then I'll hand out my credit card and go back to the private sector. But again, it would probably be something after I believe I've entered a boy's club. Um, and therefore I just say I'm getting gouged every way I turn for out of pocket expenses. And I thought, no, I'm going for something that's fairly standard protocol, BCG. It's not rocket science. They rinse and repeat, you know, six times in a to do a three in a three and then spending what they say they should plateau or whatever. Um, so from my perspective, I've gone, I'll go public. If the wait list is too long, then yes, I'll jump back into the private queue and pay. But I just thought I can just say this is a bit of a boys club. So yeah.
Participant 017_2022AUBLC

Participant describes being presented with multiple options: Wanted more discussion/options

PARTICIPANT So there was no consideration of any assistance to help going to public systems. So if this is where you're angling or just the type of treatment that he was, I can I do private, I can help you privately. I can control the outcome privately and everything I do is private. And I said, what if I wanted to do public? He said, Yeah, you can go down that path. At no stage was there any option that he could assist me in that path that since come to light when I've gone and got an independent referral to public which circumvented back very, very quickly to him. And I don't quite know how that was done because it should not have happened. But anyway, he goes, Oh, well now I always said I could treat you as a public, a private patient, a public hospital, which was a direct lie because this guy.

INTERVIEWER: Was specific to let your say BCG told the truth.

PARTICIPANT Yeah. So that kind of stuff. So he pretty much said Explain what BCG was and said, you know, it's immunotherapy. You have six treatments a couple of hours in the bladder. You go into a into a facility. It happens to be the same building he's in. They do it under like a day, not a day surgery, but like a clinical sort of thing. Nurse put it in, you get it in, you sit there and you go and you do that for six weeks. So that was all fairly well explained. He was very, very hesitant to talk about any sexual side effects of any type of thing, including, you know, what would happen if you lose your bladder. Urologist don't tend to want to talk too much about that upfront because it does impact your treatments and what you may or may not want to have done and how long you pursue with one treatment or another. Because I've since joined a bladder beat bladder support group. Um, so, you know, I've been to a couple of meetings, including one last night, which was all about BCG. Why do I say this? Because I'm now well informed and my wife has been miraculous at doing lots of online research to kind of go. Most of my intelligence has come from my wife and her research or the beat bladder website, BEAT cancer website or their support group and certainly not my urologist. He has given me the bare basics necessary to take you to the next step with a provider of his choice.
Participant 017_2022AUBLC

The urologist really just went through that they would have a look and confirm it was cancer. And that I would have probably BCG treatment. Mm yes. And he gave me a bit of information, but I didn't realise at that time how much or what to expect totally. You know, at that time I was hoping that. It would be, for want of a better term cured. Treated and I could just carry on as normal. It did indicate that if the BCG worked, I could have a follow up cystoscopy as I think it was. But I'm not sure if it's every six months or every three months for a while, and then it would go to six months. And so that was pretty much the discussion at that time. Um, yes. And then as I say I had the cystoscopy that doctor did that cystoscopy it removed tumours and it was high grade non-invasive.
Participant 003_2022AUBLC

Participant describes being presented with multiple options: No reason provided

It was a radical cystectomy, and an ileal conduit to that was what was offered. So chemotherapy was offered. First, you have to do chemotherapy first for

three, four cycles, and then a radical cystectomy would be would be ordered within after four weeks of chemo finishing. Okay. And what was it?
Carer 004_2022AUBLC

And really wasn't at diagnosis with the urologist. It was probably after confirmation. So he went in and had a scope done. It was see that I found a about a 5 cm centimetre tumour in the bladder wall which they removed and it went off for testing. It was when that test results come back that we then discussed a treatment plan which was initially with the urologist, but then we were referred on to an oncologist because to tackle my husband's bladder cancer, they were going to do a combination of chemotherapy and bladder removal. So, yeah, the oncologist was the one that discussed the treatment options with
Carer 002_2022AUBLC

Participant describes being presented with one option/approach: They were told what to do without discussion

Um, well, I was told that I would have BCG and nothing else, wasn't told about anything.
Participant 007_2022AUBLC

And really, it was only that I have BCG therapy. So and that that that has a I wasn't really aware that it had a sort of set Schedule. But yeah, I was told that BCG is the gold standard treatment source for my high grade non-muscle invasive bladder cancer. And so that's, you know, it wasn't really any of the discussion. I don't recall there being a discussion about cystectomy unless I blocked that out. Well, but I think I think it's fair that most urologists would recommend BCG before going straight to it cystectomy with, with Non-Muscle invasive.
Participant 010_2022AUBLC

And basically, I'll still remember, he said, you have to have your bladder out. If you don't, you've got six months. Not very um, yeah. And I basically said, no way you're not taking my bladder out.
Participant 023_2022AUBLC

Participant describes being presented with one option/approach: Participated in the decision-making process

And like, you know, like they I felt that they discussed, you know, whatever questions we had. I mean, I think I was in a bit of denial at some stage. Um, whatever questions my kids had, they, you know, went through it all and reassured. And so I was really quite pleased with, see, um. With the preparation. Yeah.
Participant 039_2022AUBLC

When I was first diagnosed, he didn't I wasn't really you know, I think I had already done research. So I kind of knew what, what might be discussed with me. But they decided that, that I didn't have to have any other treatment at that time, that they would just remove the cancer and do regular cystoscopy. So I think I had a cystoscopy every three months, just so.
Participant 026_2022AUBLC

Table 4.3: Discussions about treatment (Participation in discussions)

Discussions about treatment (Participation in discussions)	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 presented with multiple options: Participated in the decision-making process	10	20.41	5	25.00	2	20.00	3	21.43	10	22.73	0	0.00	2	11.76	8	25.00
Participant describes being presented with multiple options: Did not participate in the decision-making process	10	20.41	4	20.00	1	10.00	5	35.71	10	22.73	0	0.00	2	11.76	8	25.00
Participant describes being presented with multiple options: They were told what to do without discussion	8	16.33	4	20.00	1	10.00	2	14.29	7	15.91	1	20.00	3	17.65	5	15.63
Participant describes being presented with multiple options: however, there was only one viable option	6	12.24	3	15.00	1	10.00	1	7.14	5	11.36	1	20.00	2	11.76	4	12.50
Participant describes being presented with multiple options: Changed clinician as they were not satisfied with discussion, lack of empathy and/or options presented	3	6.12	1	5.00	1	10.00	1	7.14	3	6.82	0	0.00	0	0.00	3	9.38
Participant describes being presented with multiple options: Wanted more discussion/options	3	6.12	1	5.00	2	20.00	0	0.00	3	6.82	0	0.00	2	11.76	1	3.13
Participant describes being presented with multiple options: No reason provided	3	6.12	1	5.00	0	0.00	0	0.00	1	2.27	2	40.00	1	5.88	2	6.25
Participant describes being presented with one option/approach: They were told what to do without discussion	5	10.20	3	15.00	1	10.00	0	0.00	4	9.09	1	20.00	3	17.65	2	6.25
Participant describes being presented with one option/approach: Participated in the decision-making process	3	6.12	0	0.00	1	10.00	2	14.29	3	6.82	0	0.00	2	11.76	1	3.13

Discussions about treatment (Participation in discussions)	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 presented with multiple options: Participated in the decision-making process	10	20.41	5	17.24	4	21.05	3	20.00	6	18.18	2	10.00	7	25.00
Participant describes being presented with multiple options: Did not participate in the decision-making process	10	20.41	8	27.59	2	10.53	2	13.33	8	24.24	4	20.00	6	21.43
Participant describes being presented with multiple options: They were told what to do without discussion	8	16.33	3	10.34	5	26.32	2	13.33	6	18.18	3	15.00	5	17.86
Participant describes being presented with multiple options: however, there was only one viable option	6	12.24	5	17.24	1	5.26	2	13.33	4	12.12	3	15.00	3	10.71
Participant describes being presented with multiple options: Changed clinician as they were not satisfied with discussion, lack of empathy and/or options presented	3	6.12	2	6.90	1	5.26	1	6.67	2	6.06	1	5.00	2	7.14
Participant describes being presented with multiple options: Wanted more discussion/options	3	6.12	2	6.90	1	5.26	2	13.33	1	3.03	2	10.00	1	3.57
Participant describes being presented with multiple options: No reason provided	3	6.12	2	6.90	1	5.26	0	0.00	3	9.09	1	5.00	2	7.14
Participant describes being presented with one option/approach: They were told what to do without discussion	5	10.20	3	10.34	2	10.53	0	0.00	5	15.15	1	5.00	4	14.29
Participant describes being presented with one option/approach: Participated in the decision-making process	3	6.12	1	3.45	2	10.53	2	13.33	1	3.03	2	10.00	1	3.57

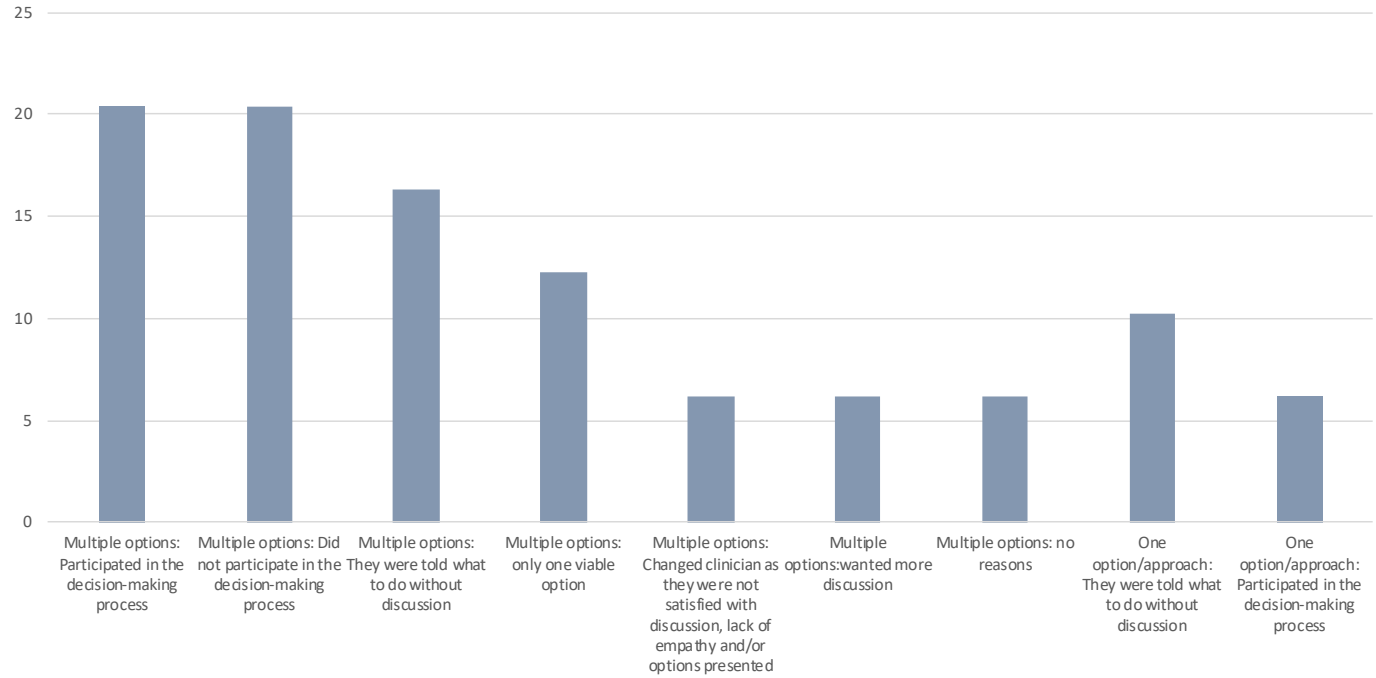

Figure 4.2: Discussions about treatment (Participation in discussions)

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

Discussions about treatment (Participation in discussions)	Reported less frequently	Reported more frequently
Participant describes being presented with multiple options: Participated in the decision-making process	Carer to someone with bladder cancer Mid to low status	-
Participant describes being presented with multiple options: Did not participate in the decision-making process	Invasive (Stage III) Carer to someone with bladder cancer	Advanced (Stage IV)

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most reported theme was taking the advice of their clinician, and this was described by 23 participants (46.94%). There were 15 participants (30.61%) that considered being cancer free, avoiding recurrence, or longevity, and 12 participants (24.49%) that described taking side effects into account. Other considerations included taking ease of administration into account (n=8, 16.33%), quality of life (n=7, 14.29%), costs (n=5, 10.20%), and impact on family and dependents (n=5, 10.20%).

Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)

I just mainly do what the urologist tells me to. Oh. Because it. Because I've had no one. No. No one's ever spoken to me about it. So if I'm, you know, I've got to take faith that he knows what he's doing and he can get rid of it. Well, I don't know whether you'll ever get rid of it, but. Yeah. Put it in remission.
Participant 007_2022AUBLC

But then I just do what they tell me. Okay. You know, I haven't played the role. It's even. I just do it. So they

set up the surgery, I just fill out the form and go to the hospital.
Participant 013_2022AUBLC

It was, I guess, trust in my medical team, my brainiacs I called them, my brainiacs, and just the logic behind it. Like everything they explain to me made sense.
Participant 022_2022AUBLC

Participant describes taking being cancer free, avoiding recurrence, or longevity into account when making decisions about treatment (Total)

Um. I suppose the treatment you're hoping that you'll get it, well a cure. Really hope that you will get a cure so that life can continue on. So my treatment really pretty much I've done whatever the doctors have told me, I've been fairly careful to follow through with all my appointments and all the check-ups. I was hoping that I wouldn't have to have the bladder removal. I got a second opinion on that. Oh my daughter in law works for an insurance company who have a scheme where family members can have a second opinion from a group called Best Doctors. So before I actually went through the bladder removal operation, I was in touch with them and was eligible for this service. And they went through. They speak to your doctors, all your treatment people, and agreed that radical cystectomy was my best option. Not what you want to hear. So I, I don't want to die yet.
Participant 003_2022AUBLC

Life expectancy. Yes. Um. The pros and cons of undergoing surgery. And how it's going to impact on my life. The recovery time. Mainly life expectancy. By having it go down, however. And I take the advice of the doctor.
Participant 038_2022AUBLC

Um, you know, just, um, DOCTOR came up to me and he said, you could have more treatment or you can get your bladder removed. And of course, I had been it had reoccurred. I think it was three or four times. Three times, I think over the three years. But two and a half years. I so well, if he offered me more treatment of that, I'll be sitting here in six months time and we could be having this discussion again. And I didn't want to, um, I didn't want the cancer to become invasive and then, you know, for the rest of my body. So I made the decision of going ahead and get me bladder removed.
Participant 044_2022AUBLC

Participant describes taking side effects into account when making decisions about treatment (Total)

The main one is the is the side effects. A lesser one, but still relevant is, is the finances the cost? And I suppose the third one less important is the distance to travel. I mean, that doesn't worry me because I don't, I, I only do a bit of casual work now so it doesn't affect me. I can, you know, I'm going to a different hospital in CITY now, which is not anywhere near where I live, but that doesn't worry me. The main one is the side effects and the second one would be the finances.
Participant 008_2022AUBLC

Um, what the treatments I need, I, I'm a PROFESSION. I tend to want to know what the treatment actually is and what, what the benefits and side effects of the treatment are, particularly to lifestyle. And initially when I looked at the, the big decision was not, not to do BCG because it's pretty much standard treatment and um, you know, you do that. But the trial was another issue. Whether I do the trial or do it became a major thing to consider how much of my time and how much I'd actually go through in doing the trial. Because the, the trial has three pages of side effects, possible side effects starting at one in one in ten, which is, you know, nausea and, and all that sort of thing. And going through to one in a thousand of you dying and things like that. So it's things to be to be heart issues or lung issues or all those sort of things. So you have to really weigh those up. So I was very I was pleased to get a lot of support from my son in, in looking at that with me and then also with my doctor. And I was able to go back to the, the professor who was leading the trial. And he's a very down to earth sort of guy as well. And discuss, you know, in real terms, what does that mean when they say you got to 100, one, 100 chance of having issues with lung and the fact that the, the drug can actually attack many or the side effects to any tissues in your body that now what does that actually mean and how likely are those sorts of things. And it I was very supportive of all that.
Participant 029_2022AUBLC

Side effects. The big one. Yeah. And then the effect it will have on the cancer. Long term, long term prognosis, I guess.
Carer 005_2022AUBLC

Participant describes taking ease of administration into account when making decisions about treatment (Total)

Well location. We wanted it because I wasn't able to go with him again. There was only one person in the day room, the treatment room. So location was really

important for us. That was a big factor, that he didn't have to go too far to have chemotherapy. We did ask the question about having chemotherapy at home, but because we were public patients, that wasn't an option for us.
Carer 002_2022AUBLC

Well, the main the main one is the treatment I had is very invasive. I'm a little bit apprehensive about it. As I said, I'm facing it again now. So, yeah, I would say that my mind is the same. I'm still. It's very invasive and then, and it's sometimes painful.
Participant 012_2022AUBLC

Look, I guess what I was told, what I was going to have to get done. And how are we going to be administered. It was a bit daunting in the beginning. You know, obviously, you know, it's all administered through a catheter. So which is, you know. So I was a bit worried. But then after a couple of sessions, it was fine. And I just thought, you know, whatever is, you know, I'm not the specialist, my urologist is the specialist. So I'm just really relying on their advice and, you know, for them to tell me what needs to be done.
Participant 024_2022AUBLC

Participant describes taking cost into account when making decisions about treatment (Total)

Um, cost to a point. We can afford it. Do we need to spend? I've got top private health, pay a fortune in Medicare, Medicare levies. So I'm going, why do I need to keep digging into my pocket for cancer? So that's a consideration. It's not a deal breaker. The other thing I was going to say was second opinion. We're getting a second opinion at this stage on the 10th of May from a very respectable urologist just to kind of. And it might also be another way to get into the public system to him, given that he also operates in the public system. And we do lots of research. Well, considering you know what my options are.
Participant 017_2022AUBLC

Yeah. You know, and so I walked out of there thinking, I never want to see him again. I'm saying to my husband, Did you not find him? You know, that he had no empathy for you. Did you not find that he you know, and then he talked about money as if it was almost guilting us into you should not even be thinking because I asked the question about, well, what are out-of-pocket pockets going to be because we've got private health insurance. And it was like, oh, you don't ask me that. You have to talk to my secretary about it. I said, But you must know what you are. I said, Yes, I'll talk to your secretary about it. But you must know what you're out of pocket. And it was like verbatim, I'm telling you. Well, if you want to give less to your children in their will, for your husband's health, that would be a good idea. So that's why I totally disliked him. Oh, yeah, that's.
Carer 004_2022AUBLC

Um. The cost. Mm hmm. The risk? The risk of having it done or not having it done, time off work.
Participant 016_2022AUBLC

Participant describes taking quality of life into account when making decisions about treatments (Total)

Probably earlier. When I first started, it was about lifestyle. All my lifestyle is, is active. I'm actually a skydiver. If I had surgery, I would have probably had to stop that. If you have a if you have a bag hanging off you, you can't really jump out of a plane and not have problems. So that was my primary focus, was to maintain my lifestyle as it was.
Participant 020_2022AUBLC

Um, to, to get the cancer out of me. You get to get it. Get back to where I was.
Participant 033_2022AUBLC

Um, what the treatments I need, I, I'm a PROFESSION. I tend to want to know what the treatment actually is and what, what the benefits and side effects of the treatment are, particularly to lifestyle. And initially when I looked at the, the big decision was not, not to do BCG because it's pretty much standard treatment and um, you know, you do that. But the trial was another issue. Whether I do the trial or do it became a major thing to consider how much of my time and how much I'd actually go through in doing the trial. Because the, the trial has three pages of side effects, possible side effects starting at one in one in ten, which is, you know, nausea and, and all that sort of thing. And going through to one in a thousand of you dying and things like that. So it's things to be to be heart issues or lung issues or all those sort of things. So you have to really weigh those up. So I was very I was pleased to get a lot of support from my son in, in looking at that with me and then also with my doctor. And I was able to go back to the, the professor who was leading the trial. And he's a very down to earth sort of guy as well. And discuss, you know, in real terms, what does that mean when they say you got to 100, one, 100 chance of having issues with lung and the fact that the, the drug can actually attack many or the side effects to any tissues in your body that now what does that actually mean and how likely are

those sorts of things. And it I was very supportive of all that.
Participant 029_2022AUBLC

Participant describes taking the potential impact on their family or dependents into account when making decisions about treatment (Total)

Well, how really it was going to affect the rest of my life. Um, what was the best option for both myself and my family?
Participant 027_2022AUBLC

Well, the first thing was, what do I need to do to give me the best chance of living? So that was number one. And basically my decision was have this surgery and, you know, hopefully everything's contained and you will live or not have this surgery. And the prognosis was not good. So that was my number one thought. I also had school age children. One of them was doing their final year of school. So that was sort of a consideration as well. I selected or elected to have a neobladder, one, because I was young and a good candidate for a neobladder, two, because, you know, if everything went well and worked well, it gave me just that little bit more normality. Because while I don't have a bladder, my neobladder is inside of me. It's made out of a piece of my bowel. I operate it just like a regular person operates their bladder. So that was you know, that was that was an important decision for me that, you know, I don't have anything external. If you were to look at me, you would not know I've had this surgery.
Participant 032_2022AUBLC

The things, I suppose. Firstly, yeah, it's myself and my family. The things that I think of first and foremost, how it impacts me and how it can have whatever potential treatment is going to impact my family going forward.
Participant 035_2022AUBLC

Participant describes taking the advice of family and friends into account when making decisions about treatment (Total)

Oh, look, I really just have to go with what? You know, they tell me what they what they recommend. I discuss it with m,y I mean, discuss it with the family and my husband. But we all go. We. Just think we have to go with what they're recommending, which I don't know enough about it, you know?
Participant 004_2022AUBLC

Probably the main thing was that I'm in a men's shed. I've got a couple of guys out there that have had cancer that has actually gone to their lungs. So I knew by discussion with them on these issues, if it didn't get rid of the cancer at the right time. So I sort of you know by reading and researching and actually being able to talk to people that are in that situation. I knew that probably better out sooner rather than later I didn't postpone anything I did it as soon as practical, mainly because I, you know, I, my, my main mantra is I've got my youngest grandson is nine. And I'd like to be here when they grow up, you know, not in the adults, but as long as I can, if they're old enough to realise what's happened, you know, I would like to be there for that to.
Participant 011_2022AUBLC

Participant describes taking bladder preservation into account when making decisions about treatment (Total)

Um. I suppose the treatment you're hoping that you'll get it, well a cure. Really hope that you will get a cure so that life can continue on. So my treatment really pretty much I've done whatever the doctors have told me, I've been fairly careful to follow through with all my appointments and all the check-ups. I was hoping that I wouldn't have to have the bladder removal. I got a second opinion on that. Oh my daughter in law works for an insurance company who have a scheme where family members can have a second opinion from a group called Best Doctors. So before I actually went through the bladder removal operation, I was in touch with them and was eligible for this service. And they went through. They speak to your doctors, all your treatment people, and agreed that radical cystectomy was my best option. Not what you want to hear. So I, I don't want to die yet.
Participant 003_2022AUBLC

Probably earlier. When I first started, it was about lifestyle. All my lifestyle is, is active. I'm actually a skydiver. If I had surgery, I would have probably had to stop that. If you have a if you have a bag hanging off you, you can't really jump out of a plane and not have problems. So that was my primary focus, was to maintain my lifestyle as it was.
Participant 020_2022AUBLC

Participant describes being given only one treatment option, they could have treatment or risk progression or death (Total)

Well, there seemed to be in the literature suggested that there was only one immunotherapy treatment

because it wasn't chemotherapy, it was immunotherapy. And there's really only one tried and tested. Apart from clinical trials, it's not really anything else currently available. So there wasn't an option. It was either BCG or nothing, really. Participant 030_2022AUBLC

Look, we haven't really had to make too many decisions about treatment because we've always had BCG available. I know that isn't the same for everybody, and he hasn't needed to go to a different type of treatment. So really, that was just always the obvious choice and the only choice we've had to make. Carer 003_2022AUBLC

Table 4.5 Considerations when making decisions

Considerations when making treatment decisions	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 taking the advice of their clinician into account when making decisions about treatment (Total)	23	46.94	7	35.00	6	60.00	9	64.29	22	50.00	1	20.00	9	52.94	14	43.75
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	10	20.41	3	15.00	2	20.00	5	35.71	10	22.73	0	0.00	3	17.65	7	21.88
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	13	26.53	4	20.00	4	40.00	4	28.57	12	27.27	1	20.00	6	35.29	7	21.88
Participant describes taking being cancer free, avoiding recurrence, or longevity into account when making decisions about treatment (Total)	15	30.61	6	30.00	2	20.00	6	42.86	14	31.82	1	20.00	3	17.65	12	37.50
Participant describes taking being cancer free, avoiding recurrence, or longevity into account as part of multiple considerations when making decisions about treatment	11	22.45	3	15.00	1	10.00	6	42.86	10	22.73	1	20.00	2	11.76	9	28.13
Participant describes taking being cancer free, avoiding recurrence, or longevity into account as the only thing that they consider when making decisions about treatment	4	8.16	3	15.00	1	10.00	0	0.00	4	9.09	0	0.00	1	5.88	3	9.38
Participant describes taking side effects into account when making decisions about treatment (Total)	12	24.49	3	15.00	2	20.00	4	28.57	9	20.45	3	60.00	2	11.76	10	31.25
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	11	22.45	3	15.00	1	10.00	4	28.57	8	18.18	3	60.00	1	5.88	10	31.25
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	1	2.04	0	0.00	1	10.00	0	0.00	1	2.27	0	0.00	1	5.88	0	0.00
Participant describes taking ease of administration into account when making decisions about treatment (Total)	8	16.33	3	15.00	1	10.00	2	14.29	6	13.64	2	40.00	1	5.88	7	21.88
Participant describes taking ease of administration into account as part of multiple aspects that they consider when making decisions about treatment	6	12.24	3	15.00	1	10.00	1	7.14	5	11.36	1	20.00	1	5.88	5	15.63
Participant describes taking ease of administration into account as the only thing that they consider when making decisions about treatment	2	4.08	0	0.00	0	0.00	1	7.14	1	2.27	1	20.00	0	0.00	2	6.25
Participant describes taking quality of life into account when making decisions about treatments (Total)	7	14.29	1	5.00	1	10.00	5	35.71	7	15.91	0	0.00	1	5.88	6	18.75
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	7	14.29	1	5.00	1	10.00	5	35.71	7	15.91	0	0.00	1	5.88	6	18.75
Participant describes taking quality of life into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking cost into account when making decisions about treatment (Total)	5	10.20	3	15.00	1	10.00	0	0.00	4	9.09	1	20.00	1	5.88	4	12.50
Participant describes taking cost into account as part of multiple aspects that they consider when making decisions about treatment	5	10.20	3	15.00	1	10.00	0	0.00	4	9.09	1	20.00	1	5.88	4	12.50
Participant describes taking cost into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking the potential impact on their family or dependents into account when making decisions about treatment (Total)	5	10.20	1	5.00	1	10.00	2	14.29	4	9.09	1	20.00	1	5.88	4	12.50
Participant describes taking the potential impact on their family or dependents into account as part of multiple aspects that they consider when making decisions about treatment	5	10.20	1	5.00	1	10.00	2	14.29	4	9.09	1	20.00	1	5.88	4	12.50
Participant describes taking the potential impact on their family or dependents into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking the advice of family and friends into account when making decisions about treatment (Total)	3	6.12	2	10.00	0	0.00	1	7.14	3	6.82	0	0.00	1	5.88	2	6.25
Participant describes taking the advice of family and friends into account as part of multiple aspects that they consider when making decisions about treatment	3	6.12	2	10.00	0	0.00	1	7.14	3	6.82	0	0.00	1	5.88	2	6.25
Participant describes taking the advice of family and friends into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking bladder preservation into account when making decisions about treatment (Total)	3	6.12	2	10.00	0	0.00	0	0.00	2	4.55	1	20.00	1	5.88	2	6.25
Participant describes taking bladder preservation into account as part of multiple aspects that they consider when making decisions about treatment	3	6.12	2	10.00	0	0.00	0	0.00	2	4.55	1	20.00	1	5.88	2	6.25
Participant describes taking bladder preservation into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes being given only one treatment option, they could have treatment or risk progression or death (Total)	3	6.12	0	0.00	1	10.00	1	7.14	2	4.55	1	20.00	0	0.00	3	9.38
Participant describes being given only one treatment option, they could have treatment or risk progression or death	3	6.12	0	0.00	1	10.00	1	7.14	2	4.55	1	20.00	0	0.00	3	9.38

Considerations when making treatment decisions	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 taking the advice of their clinician into account when making decisions about treatment (Total)	23	46.94	16	55.17	7	36.84	7	46.67	16	48.48	10	50.00	13	46.43
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	10	20.41	9	31.03	1	5.26	4	26.67	6	18.18	7	35.00	3	10.71
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	13	26.53	7	24.14	6	31.58	3	20.00	10	30.30	3	15.00	10	35.71
Participant describes taking being cancer free, avoiding recurrence, or longevity into account when making decisions about treatment (Total)	15	30.61	11	37.93	3	15.79	5	33.33	9	27.27	9	45.00	5	17.86
Participant describes taking being cancer free, avoiding recurrence, or longevity into account as part of multiple considerations when making decisions about treatment	11	22.45	10	34.48	1	5.26	5	33.33	6	18.18	9	45.00	2	7.14
Participant describes taking being cancer free, avoiding recurrence, or longevity into account as the only thing that they consider when making decisions about treatment	4	8.16	1	3.45	2	10.53	0	0.00	3	9.09	0	0.00	3	10.71
Participant describes taking side effects into account when making decisions about treatment (Total)	12	24.49	9	31.03	3	15.79	7	46.67	5	15.15	9	45.00	3	10.71
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	11	22.45	9	31.03	2	10.53	6	40.00	5	15.15	8	40.00	3	10.71
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	1	2.04	0	0.00	1	5.26	1	6.67	0	0.00	1	5.00	0	0.00
Participant describes taking ease of administration into account when making decisions about treatment (Total)	8	16.33	6	20.69	2	10.53	4	26.67	4	12.12	4	20.00	4	14.29
Participant describes taking ease of administration into account as part of multiple aspects that they consider when making decisions about treatment	6	12.24	4	13.79	2	10.53	4	26.67	2	6.06	4	20.00	2	7.14
Participant describes taking ease of administration into account as the only thing that they consider when making decisions about treatment	2	4.08	2	6.90	0	0.00	0	0.00	2	6.06	0	0.00	2	7.14
Participant describes taking quality of life into account when making decisions about treatments (Total)	7	14.29	5	17.24	2	10.53	3	20.00	4	12.12	4	20.00	3	10.71
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	7	14.29	5	17.24	2	10.53	3	20.00	4	12.12	4	20.00	3	10.71
Participant describes taking quality of life into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking cost into account when making decisions about treatment (Total)	5	10.20	2	6.90	3	15.79	3	20.00	2	6.06	4	20.00	1	3.57
Participant describes taking cost into account as part of multiple aspects that they consider when making decisions about treatment	5	10.20	2	6.90	3	15.79	3	20.00	2	6.06	4	20.00	1	3.57
Participant describes taking cost into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking the potential impact on their family or dependents into account when making decisions about treatment (Total)	5	10.20	4	13.79	1	5.26	2	13.33	3	9.09	4	20.00	1	3.57
Participant describes taking the potential impact on their family or dependents into account as part of multiple aspects that they consider when making decisions about treatment	5	10.20	4	13.79	1	5.26	2	13.33	3	9.09	4	20.00	1	3.57
Participant describes taking the potential impact on their family or dependents into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking the advice of family and friends into account when making decisions about treatment (Total)	3	6.12	3	10.34	0	0.00	1	6.67	2	6.06	2	10.00	1	3.57
Participant describes taking the advice of family and friends into account as part of multiple aspects that they consider when making decisions about treatment	3	6.12	3	10.34	0	0.00	1	6.67	2	6.06	2	10.00	1	3.57
Participant describes taking the advice of family and friends into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking bladder preservation into account when making decisions about treatment (Total)	3	6.12	2	6.90	1	5.26	0	0.00	3	9.09	2	10.00	1	3.57
Participant describes taking bladder preservation into account as part of multiple aspects that they consider when making decisions about treatment	3	6.12	2	6.90	1	5.26	0	0.00	3	9.09	2	10.00	1	3.57
Participant describes taking bladder preservation into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes being given only one treatment option, they could have treatment or risk progression or death (Total)	3	6.12	1	3.45	2	10.53	0	0.00	3	9.09	0	0.00	3	10.71
Participant describes being given only one treatment option, they could have treatment or risk progression or death	3	6.12	1	3.45	2	10.53	0	0.00	3	9.09	0	0.00	3	10.71

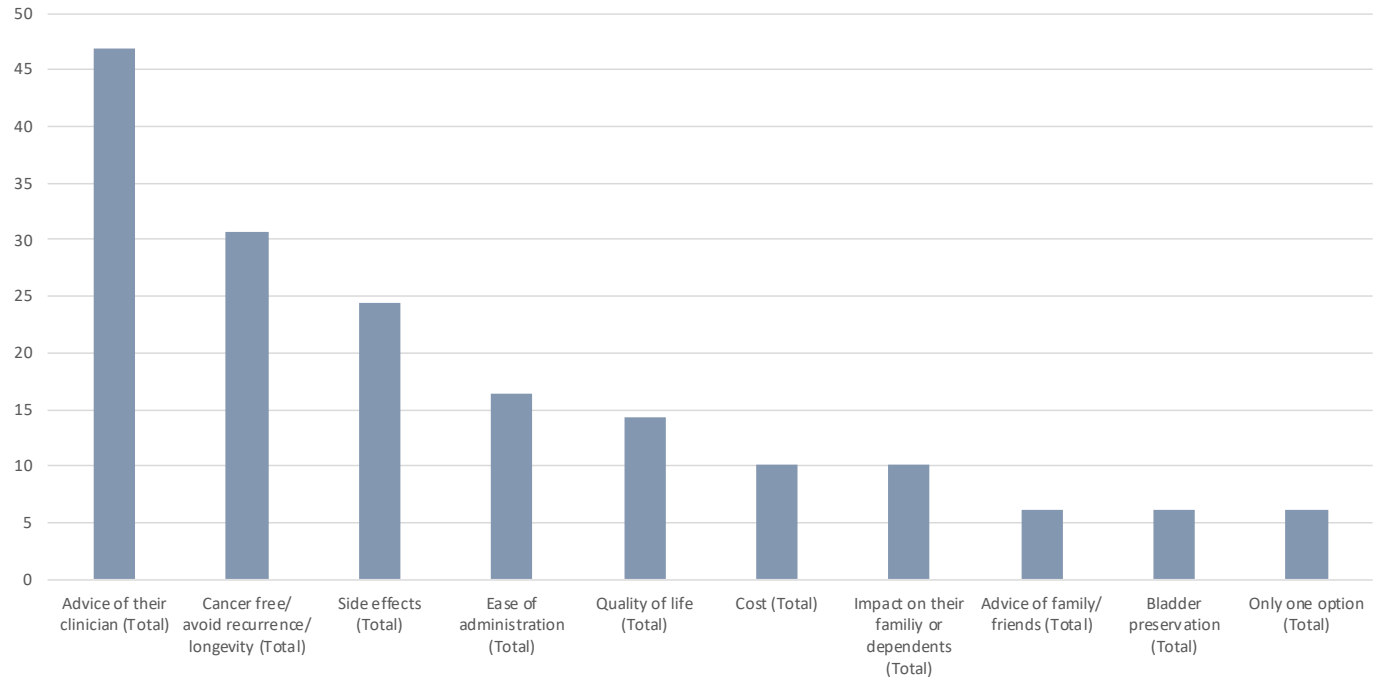

Figure 4.3 Considerations when making decisions

Table 4.6: Considerations when making decisions – subgroup variations

Considerations when making treatment decisions	Reported less frequently	Reported more frequently
Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)	Early (Stages 0 and I) Carer to someone with bladder cancer University	Invasive (Stage III) Advanced (Stage IV)
Participant describes taking being cancer free, avoiding recurrence, or longevity into account when making decisions about treatment (Total)	Invasive (Stage III) Carer to someone with bladder cancer Female University Higher status	Advanced (Stage IV) Mid to low status
Participant describes taking side effects into account when making decisions about treatment (Total)	Female Higher status	Carer to someone with bladder cancer Regional or remote Mid to low status
Participant describes taking ease of administration into account when making decisions about treatment (Total)	Female	Carer to someone with bladder cancer Regional or remote
Participant describes taking quality of life into account when making decisions about treatments (Total)	Carer to someone with bladder cancer	Advanced (Stage IV)
Participant describes taking cost into account when making decisions about treatment (Total)	Advanced (Stage IV)	-

Decision-making over time

Participants were asked if the way they made decisions had changed over time. There were 28 participants (57.14%) that felt the way they made decisions about treatment had not changed over time, and 20 participants (40.82%) that described decision making changing.

Where participants had not changed their decision making over time, this was because they have always taken the advice of clinicians (n=11, 22.45%), or had always been informed and assertive (n=7, 14.29%). Where participants had changed the way they make decisions, this was primarily in relation to becoming more informed or more assertive (n=13, 26.53%).

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

Look, no, because I didn't know anything about it and as I say it's I'm more than happy to be guided by those that know more than I do.
Participant 014_2022AUBLC

I think I approach in the same way. Yeah. I'd like to see an evidence base for whatever treatment I'm going to choose and like read up on the research and that sort of thing. But I've always done that, so I think it's probably similar. I think where the change in my problem solving abilities would have come when I did a master's of research. And then you start looking, you look at things a different way after that. So yeah, that's probably more influenced me than anything else.
Participant 018_2022AUBLC

In terms of my health, even actually strengthen my position in terms of listening to professionals because it's working? Yeah.

Participant 024_2022AUBLC

Participant describes no change in decision-making over time and there is no particular reason noted

Yeah. No, I don't think so. I don't think much has changed, to be honest.
Participant 009_2022AUBLC

Oh, I think I might them the same way.
Participant 012_2022AUBLC

In the same way. Yeah, I'm okay. I'm quite still quite happy with the decision that we made.
Participant 027_2022AUBLC

Participant describes no change in decision-making over time as they have always been informed/assertive

No, no, no, no, no, no, no. I did research when I was on Internet research. I don't just rely on Dr Google though, but I try and get onto the different sites and the you know, that I'm one of the American and English bladder cancer sites and there was the Australian ones and tried to see what was the up to date technology and what they were doing and everything else. So I thought I was pretty well on top of our discussion and I had a pretty good understanding of where I was going with. Hmm. It still doesn't prepare you for the operation or anything. But, you know, it gives you a bit better understanding. Put it that way. Hmm. I've always been a pretty healthy person I've only had a knee replacement ten years ago. But and I thought that was fairly healthy, like helping me know I used to run marathons and I and I've actually been back out kayaking since.
Participant 011_2022AUBLC

Uh, I. I don't think it has changed, because it's just my just my personality. I don't take a decision until I have all the information. So I would have rather postponed my decision if I was unsure. But I would first be very clear that what are available options and then take the decision. So nothing has changed once I decided on.
Participant 028_2022AUBLC

No, I I've, I've always it always approach things in the same way. I think if you weren't either technically or structured in your thinking, putting all these things together would be terribly hard for some. But it's hard enough on your own. It's hard enough with a group of, you know, two or three people deciding what's the best thing to do. But if you all just seek and or not seek, but just trying to weigh up what to do, I think it'd be terribly hard to have that, you know, ability to read and try and understand, digest what it was all about.
Participant 029_2022AUBLC

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

Possibly I would ask more questions. I would know the questions to ask now. What are the problems with this stuff as you don't know what questions to ask? I do believe that somewhere along the line it might be, you know, if you Google stuff, I do believe there is a sort of it could be a list. So when you go to a doctor, or when you go somewhere with something like this, you've got a list of questions. You know, what was the treatment? What if I don't have treatment? Do I need chemo? Do I need this? Knowing the questions to ask was probably one of the missing links kind of thing for me, I did ask questions. I took my partner with me whenever I was getting results yeah, I find that, it's trying to go into some mental lockdown, I didn't take issues in. And then when we'd come out, I'd remember some. And he would say, Oh, well, what about when he said this? Or What about when he said that? So that's the way to, to get your head around more information.
Participant 003_2022AUBLC

Now, I do a lot more research now. Yeah. Because I got a hell of a scare with the with the first diagnosis. So I did a lot more research and I take notes at the meetings, I go to, telephone calls or whatever, and then I do my own independent research. And if, if, if, if it's convenient, I go to the there's the bladder cancer support group meetings, which is where I how I came to hear your research project.
Participant 008_2022AUBLC

Yeah, I think I've probably found myself becoming more affirmative and more speaking out, being my own advocate, asking lots more questions. Yeah. I think are definitely.
Carer 002_2022AUBLC

Participant describes decision-making changing over time as they are more focused on quality of life or impact of side effects

PARTICIPANT: And I think just being more well-informed, I can consider more things before I make a decision. Like I took my sister with me to the consult I had a couple of weeks ago to, to the surgeon who's

going to do my cystectomy. And, of course, you know, at the end of it all, he says, well, if that is what I need to know, is whether or not you, you want me to do the operation for you. And by that point, I'd decided because, you know, you just want to feel the same similar thing about having a face to face consult. If you just want to get a good feel about whether or not you feel this is the person. Are you happy to do this for you? Um, yeah, but I, you know, I came to that decision fairly quickly and my sister commented later that I mean, she, I think she was on the same page, especially if it's easy for her to say that I should have it because not having as much of it is not having her. She had her reasons for saying have it because she she's looking at saving my life or as I'm sort of considering more things. But it's more simplistic to her that she did say. Um, for, for a family that doesn't make, make decisions quickly. You made that decision quickly. But yeah, I, I had made that decision probably several months beforehand because my bladder function has declined so much that it has impacted on my, my life to the point where if I go to CITY I have to make sure I have no fluid for, you know, don't drink anything for 12 hours beforehand, so that I don't have to stop. Um, so am I. I can barely hold 100 mLs in my bladder. Now.

INTERVIEWER: That sounds like it makes things a lot more complicated. Yeah.

PARTICIPANT: Yeah. So that's what sort of helped me come to the as well as time and also my life revolving around three monthly, um, anaesthetics. And um, and then between those three months is in intra-cystical therapy, which is becoming so my bladder has barely ever had the chance to, to feel normal again. And then when it didn't feel normal again, you think, well, okay, this is the rest of my life, so you got to make a decision. And so it was pretty. Yeah, I think I was. In a way, I've been fortunate that I've been able to ease my way into this decision, whereas some people who find they're muscle invasive, I said straight away, they don't have that luxury.
Participant 010_2022AUBLC

Well, we are more comfortable with it now, I guess. Like we've just gotten used to how it goes and know what we're in for. Unfortunately, the last one, though, was really it affected him much more than the first. Yeah. So that was a lot more severe. So I guess like the next one we'll be a little bit more, concerned, and worried about what's coming up, what sort of reaction he'll have
Carer 003_2022AUBLC

Participant describes decision-making changing over time as they base decisions more on their experience and judgement

Yes, I do. I don't trust my urologist. We're making more independent decisions of the urologist. And initially I trusted the GP, went to the you know, you got a look, you go to a GP and they refer you to a urologist. You don't kind of go, I don't know, you just go to who he said, right. And even he wanted feedback, so how have you found him? Because he said, you know, I refer people to him. And I said, well, this is you know, I don't think he's, I think he's loose with the truth. I don't like his bedside manner. I'm not saying he's not a great surgeon. He's probably a great surgeon. But I don't like his I don't like the way he talks to me and I don't like the way he communicates to me. And therefore, that's why I'm looking to go an alternate path. So it does change my decision making. Based upon those experiences, if I gelled with him, like if I had a, you know, if we had rapport. There's no rapport there. That's my point. Yeah. Because I don't trust him.
Participant 017_2022AUBLC

Well, I would, I would say in the same way. I've recently joined a couple of support groups over Zoom by the cancer support group. And I've heard other people talking about how they've done loads of research and they've got second and third opinions and they've had all sorts of treatment, but they're still got the cancer. And also, I've heard people on those calls talk about having a neobladder and, and how actually difficult that is to manage. So to be honest, I say it's not ideal to have this new sort of body, if you like, but I feel that it was certainly the best option for me and I haven't had to have any other treatment and hopefully I won't have to have any other treatment.
Participant 043_2022AUBLC

Participant describes decision-making changing over time and there is no particular reason noted
Oh, yeah. I've change the way I make decisions. In how I do things. And yes, I do change.
Participant 037_2022AUBLC

It's changed.
Carer 005_2022AUBLC

Table 4.7: Decision-making over time

Decision-making over time	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 no change in decision-making over time (Total)	28	57.14	12	60.00	6	60.00	9	64.29	27	61.36	1	20.00	7	41.18	21	65.63
Participant describes no change in decision-making over time as they have always taken advice of clinicians	11	22.45	4	20.00	3	30.00	4	28.57	11	25.00	0	0.00	4	23.53	7	21.88
Participant describes no change in decision-making over time and there is no particular reason noted	7	14.29	3	15.00	1	10.00	2	14.29	6	13.64	1	20.00	1	5.88	6	18.75
Participant describes no change in decision-making over time as they have always been informed/assertive	7	14.29	3	15.00	2	20.00	2	14.29	7	15.91	0	0.00	1	5.88	6	18.75
Participant describes decision-making changing over time (Total)	20	40.82	7	35.00	4	40.00	5	35.71	16	36.36	4	80.00	9	52.94	11	34.38
Participant describes decision-making changing over time as they are more informed and/or more assertive	13	26.53	6	30.00	1	10.00	4	28.57	11	25.00	2	40.00	5	29.41	8	25.00
Participant describes decision-making changing over time as they are more focused on quality of life or impact of side effects	3	6.12	2	10.00	0	0.00	0	0.00	2	4.55	1	20.00	2	11.76	1	3.13
Participant describes decision-making changing over time as they base decisions more on their experience and judgement	3	6.12	0	0.00	1	10.00	2	14.29	3	6.82	0	0.00	1	5.88	2	6.25
Participant describes decision-making changing over time and there is no particular reason noted	3	6.12	0	0.00	1	10.00	1	7.14	2	4.55	1	20.00	1	5.88	2	6.25
Other/no response	1	2.04	1	5.00	0	0.00	0	0.00	1	2.27	0	0.00	1	5.88	0	0.00

Decision-making over time	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 no change in decision-making over time (Total)	28	57.14	19	65.52	8	42.11	10	66.67	17	51.52	13	65.00	14	50.00
Participant describes no change in decision-making over time as they have always taken advice of clinicians	11	22.45	7	24.14	4	21.05	3	20.00	8	24.24	4	20.00	7	25.00
Participant describes no change in decision-making over time and there is no particular reason noted	7	14.29	6	20.69	0	0.00	4	26.67	2	6.06	4	20.00	2	7.14
Participant describes no change in decision-making over time as they have always been informed/assertive	7	14.29	5	17.24	2	10.53	4	26.67	3	9.09	4	20.00	3	10.71
Participant describes decision-making changing over time (Total)	20	40.82	10	34.48	10	52.63	5	33.33	15	45.45	7	35.00	13	46.43
Participant describes decision-making changing over time as they are more informed and/or more assertive	13	26.53	10	34.48	3	15.79	2	13.33	11	33.33	6	30.00	7	25.00
Participant describes decision-making changing over time as they are more focused on quality of life or impact of side effects	3	6.12	1	3.45	2	10.53	1	6.67	2	6.06	1	5.00	2	7.14
Participant describes decision-making changing over time as they base decisions more on their experience and judgement	3	6.12	2	6.90	1	5.26	1	6.67	2	6.06	1	5.00	2	7.14
Participant describes decision-making changing over time and there is no particular reason noted	3	6.12	1	3.45	2	10.53	1	6.67	2	6.06	1	5.00	2	7.14
Other/no response	1	2.04	0	0.00	1	5.26	0	0.00	1	3.03	0	0.00	1	3.57

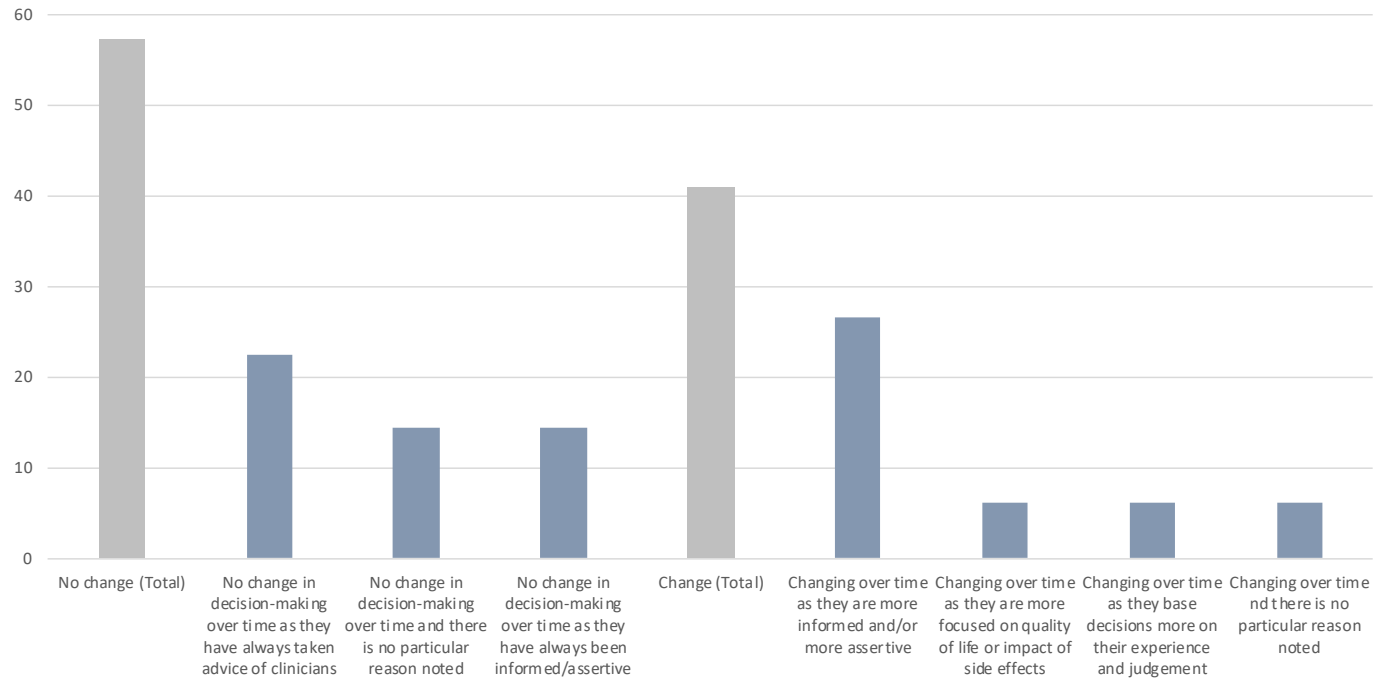

Figure 4.4: Decision-making over time

Table 4.8: Decision-making over time – subgroup variations

Decision-making over time	Reported less frequently	Reported more frequently
Participant describes no change in decision-making over time (Total)	Carer to someone with bladder cancer Female University	-
Participant describes decision-making changing over time (Total)	-	Carer to someone with bladder cancer Female University

Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common response was wanting to be cancer free, avoid recurrence or increase longevity (n=20, 40.82%), and this was

followed by wanting to improve their quality of life or return to normality (n=15, 30.61%). Other themes included wanting to minimise or avoid side effects (n=10, 20.41%), bladder preservation (n=8, 16.33%), wanting to be supported/reassured/informed by their healthcare team (n=6, 12.24%), and not having personal goals as they are guided by their doctor (n=5, 10.20%).

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

My girls. Well. Uh, main one was just obviously try and keep my, keep my bladder. But the ultimate goal was to stay alive. I'm only 49, so I was. Whatever it takes. Um, you know, the fact that we, you know, because I've only got young children, I wanted to. Yeah, I want to see them finish school and achieve things. So that was my main goal was to stay alive. But then secondary to that was to keep my bladder. Um. I didn't really want to. Yeah. Have a, a bag or anything like that. So that was mainly it.
Participant 014_2022AUBLC

Oh, my goal was just to get rid of the cancer and those like, you know, not um, you know, if it's going to hurt, it's going to hurt. If it's going to be required for me to do things, I'll do it. It has to be done. So he had a very he had a very willing and accommodating patient. I'm also relatively young. For someone to have this. And so I think that made it, you know, I just you know, it was scary for me given how young I am, and just the not quite in common. And just so I was pretty, you know, the goal is simple. Just get rid of it, whatever it takes to do so.
Participant 024_2022AUBLC

Ah, well, of course the goal was to rid myself of the cancer for as long as possible. Obviously, the diagnosis, the prognosis is variable person to person. And depending on the type of cancer and the individuals that my expectation was that I could have a normal sort of life and, and somehow outlived the possibility of dying of bladder cancer.
029_2022AUBLC

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

I think I just have been through the whole thing, hoping and expecting to come out of it pretty much as I was before I went in, minus a couple of years of your life.
Participant 006_2022AUBLC

And what was my goal or the treatment? Yes, first firstly, my first the first and foremost was, was to be able to live and. Yeah. And to live a, aquiet life with some, some sort of quality attached to it, you know. Yeah. That was that was that never, ever going to be at the stage where we could turn and say, look, life is going to be normal again after this this happened. Um, but yeah, I was hoping that I would be able to lead a normal, active life.
Participant 035_2022AUBLC

PARTICIPANT: All I'd like to do is get, like I say, get back to about 80% of where I was, where I can actually do things without, without running out of breath. I realise with the operation there comes life changing elements, but at the end of the day it's a lot to be able to do stuff. With it without sort of having to rest every 20 minutes or so.
Participant 040_2022AUBLC

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

Okay. Well, I suppose my, my main goal at that point was to just keep my bladder. And, yeah, um, the further I got into the, um, this BCG therapy, the more you have, the more impact it has. Um, side effects wise. Um, so, yes. Then I. When it when it became, I think you maintenance dose is usually three. Your first induction is six. Six weekly doses. And then you have a break. And then when you have it again, it's three. So I got to the point with I can't remember how many along the line, but the third, the second or third dose, it has an a cumulative effect on your bladder up with those three weeks. And that was once when I just rang them up and say, look, I've still got haematuria and a lot of discomfort and I'm wondering whether I should be having the next dose. And they said, just leave it. And then I got to another point, which was, I think my very last go at BCG. It was unbearable. And I'm just. Yes. Very, very, very distressing to have it like it got 20 times to the toilet in the space of an hour. It's just so irritating. And I think at that point, too, I'd already had a recurrent so high grade. So it was obviously I'd become. Well, I'm assuming they use the word resistant to it, or it wasn't working for me anyway.
Participant 010_2022AUBLC

And the occupational therapist was really good too. She said to me, Are you just expecting to go back four days a week? I said, Oh, well, that was a plan. And she said, Well, that's really stupid, but you know, you're your own worst enemy. You need to go back one day a week and see how you go, and then two days a week, maybe for a couple of weeks and then build up

slowly and just see how you are. And, and I also, because I'd had 23 lymph nodes taken out, I went to see a lymphedema physio because I just wanted to get a baseline and make sure that if I got any leg swelling that she'd already seen me and to give me some exercises to make sure I didn't get lymphedema. And she said the same thing. She said, you're stupid, just going back straight away and, and you need to just grade it. So that was really helpful. And then it built up over a couple of months back to four days a week again. And so my goals were just getting back to work and managing to get through the day here was, you know, learning how to manage the bag and when to empty that sort of stuff and not have a leak. And, and then at home also done swimming and playing tennis this not that often but and walk the dogs all the time so and it's a bit scary start doing lifting, because the literature says you can get a hernia quite easily so I've done that slowly but now I come back to pretty much full strength again. I'm just a bit more careful now.
Participant 018_2022AUBLC

My personal goals is probably not to have treatment. Yeah, I don't. My body doesn't like. My body doesn't like. Artificial chemical stuff. So, so I react to a lot of things. I react to a lot of medications. And so it's a nightmare for me to be. To be trying to deal this way. It's bad enough if I have to go into hospital and what they want to give me and I argue because I'm going to react to it and know. Yes. So, so my goal is not is to monitor it and hopefully not to have to have treatment.
Participant 026_2022AUBLC

Participant describes wanting to preserve their bladder

Just to stay alive suppose at that time, just to stay alive. The main thing that I kept, well my main goal, my main goal is to retain my bladder. To not have a bag. That's my main goal.
Participant 001_2022AUBLC

I refused to cooperate with the surgery and insisted on a referral to an oncologist. So at that point they offered me what they call the tri modal option. So bladder salvage, which is what my main focus was on bladder salvage.
Participant 020_2022AUBLC

Um. Look, I think just the goals of going ahead was to stop the cancer from recurring really. And to avoid the need to have a radical cystectomy. I guess that was really the main. The main objective.
Participant 002_2022AUBLC

Participant describes no personal goals of treatment or care (no reason given)

There's been no. None.
Participant 008_2022AUBLC

PARTICIPANT: There's no it hasn't affected me at all. So I'm just, just planning for the next operation the rest of the year and then see what happens.

INTERVIEWER: And like any personal goals or treatment, like what you hope can achieve after the operation.

PARTICIPANT: No.
Participant 013_2022AUBLC

Participant describes wanting to be supported/reassured/informed by their healthcare team

Not. Certainly not. No, none of that. Certainly. I've talked about that with my wife. And, you know, what point would we give up BCG and just go for bladder removal? You know, if, if you know, if you're, you know, 12, 15 rounds of, you know, courses of BCG or whatever, you might go, are we kidding ourselves here? Because, you know, if you're two years into it and you still trying to solve this, maybe a bladder out would be a better outcome. But that has side effects. And we've talked about, you know, nerves, nerve saving surgery, if we had to get to that. Again, this has all been our own research, not really coming from the clinician himself, looked at, you know, blue light therapy for cystoscopy to have looked at. Are there any clinical trials have, you know, looked at all the various options. And again, that's all been my wife's work not really coming from the clinician himself he's very much of, well the next stage is BCG go off here, go see Dr. X and you know, they'll make that happen. And then I'll come back every three months and have a look and see in resect or whatever you need to do. And you know, it's all been very short term focussed, very like, let's just get past the next month, let's just get past the next month. You know, long term strategy, no long term options, no ever talk about survival options, that kind of stuff. Oh, he did explain, to be fair, he did explain, the difference is if I had muscle invasive what that meant in terms of immediate bladder loss, you know, those kind of things, the fact that, you know, he was going this is good news. You've got yes, you've got high grade between the two resections. He said it had come back and he had to, you know, go deeper and that's the

stuff. But he said it's still second histology came back as the same diagnosis, which was high grade non-muscle invasive. So he had explained what the other types could have been and what that would have meant for treatment. But in terms of mine he goes BCG is your next step.
Participant 017_2022AUBLC

That was that was that was six years ago. And all the cystoscopies have been then have been clear since then. They found, they did find something different. I should be about to say that they found and what I call it, that red my red marks on the bladder which they scraped. And set off the biopsy. But one thing they didn't tell me in in the March, in March when I had the urgent cystoscopy, they didn't tell me that the scab forms and once the scab falls off you can you can start peeing blood again, which happened about two weeks later after the cystoscopy happened in early April this year. And I just sort of I have got to come back. And I went to emergency. I spent 10 hours in emergency. They put a bloody catheter in me, which was agony. I had to have it taken out and, I just went home. I went home. I just said, I've got to go. I rang Dr NAME, and I saw Dr NAME. And he said, oh, that's the, that's the scab that forms. That happens quite regularly, quite often and you'll see blood for about a day or two. If they had to tell me that, you know, six, six weeks, two weeks prior, I wouldn't have spent 10 hours in emergency and had catheters put in me and all that sort of thing. So that's one thing he should, should have told me. Should have told me at the point when I had this could be a large issue. They definitely should have told me, you may, you may have some bleeding in a couple of weeks when we did the biopsy of the scab may cause you to bleed. So I just frankly, I just thought this is it that's going to come back. Could have come back. So my wife, she drove me to emergency 10 hours later. Because the doctors down there, they're only kids. You know, as I didn't like to say no, because I have this time we got to do this, we're going to see someone, all this sort of thing. And in the end, I just walked out. I spend so much time telling them, I just got to get going and I'll speak to my urologist tomorrow.
Participant 021_2022AUBLC

PARTICIPANT: My own goal is, was that I wanted the, the, the most appropriate treatment for my case because I that I somehow felt that the doctors there they want to influence you and that the. They would like to you to go to a particular have a particular treatment. But it may be best for you, but, sometimes, you know, the treatment, which is best for you, may not be so. You know what you want. So I just wanted to be aware that, you know, the main difference was radiation versus surgery and both have pros and cons. And I really wanted to be completely, very clearly informed. But because both treatments have got risk, it's not that one is right or wrong. It's what you are prepared to pay, what risk you want to take.
Participant 028_2022AUBLC

Participant describes no personal goals as they are guided by their doctor

Well, it was always I know the BCG is the standard of treatment and I wasn't any issue about it. And I would say that I was a scare already a little bit scared of the side effect. But anyway, well, doctor said if I need it and yeah. So I accepted the BCG treatment.
Participant 015_2022AUBLC

Well, not being aware of anything. I just was guided by the doctor.
Participant 027_2022AUBLC

Look, I, I actually probably didn't. I think I just put my trust into the urologist. Um, I knew there was neo bladders and things like that, but he kind of just said no. Um, you know, like, because it was muscle invasive, there was the bladder had to, there was no the ileal conduit was the correct way to go.
Participant 039_2022AUBLC

Table 4.9: Personal goals of treatment or care

Personal goals of treatment	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	%
Participants describe wanting to be cancer free, avoid recurrence or increase longevity	20	40.82	7	35.00	6	60.00	5	35.71	18	40.91	2	40.00	5	29.41	15	46.88
Participant describes wanting to improve their quality of life or return to normality	15	30.61	6	30.00	2	20.00	6	42.86	14	31.82	1	20.00	6	35.29	9	28.13
Participant describes wanting to minimise or avoid side effects of treatment for their condition	10	20.41	3	15.00	3	30.00	1	7.14	7	15.91	3	60.00	2	11.76	8	25.00
Participant describes wanting to preserve their bladder	8	16.33	6	30.00	1	10.00	1	7.14	8	18.18	0	0.00	3	17.65	5	15.63
Participant describes no personal goals of treatment or care (no reason given)	6	12.24	3	15.00	1	10.00	2	14.29	6	13.64	0	0.00	2	11.76	4	12.50
Participant describes wanting to be supported/reassured/informed by their healthcare team	6	12.24	1	5.00	4	40.00	1	7.14	6	13.64	0	0.00	2	11.76	4	12.50
Participant describes no personal goals as they are guided by their doctor	5	10.20	1	5.00	1	10.00	2	14.29	4	9.09	1	20.00	3	17.65	2	6.25

Personal goals of treatment	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	%
Participants describe wanting to be cancer free, avoid recurrence or increase longevity	20	40.82	13	44.83	6	31.58	9	60.00	10	30.30	9	45.00	10	35.71
Participant describes wanting to improve their quality of life or return to normality	15	30.61	9	31.03	6	31.58	5	33.33	10	30.30	8	40.00	7	25.00
Participant describes wanting to minimise or avoid side effects of treatment for their condition	10	20.41	8	27.59	2	10.53	3	20.00	7	21.21	5	25.00	5	17.86
Participant describes wanting to preserve their bladder	8	16.33	4	13.79	4	21.05	1	6.67	7	21.21	1	5.00	7	25.00
Participant describes no personal goals of treatment or care (no reason given)	6	12.24	2	6.90	4	21.05	1	6.67	5	15.15	2	10.00	4	14.29
Participant describes wanting to be supported/reassured/informed by their healthcare team	6	12.24	3	10.34	3	15.79	4	26.67	2	6.06	3	15.00	3	10.71
Participant describes no personal goals as they are guided by their doctor	5	10.20	2	6.90	3	15.79	1	6.67	4	12.12	0	0.00	5	17.86

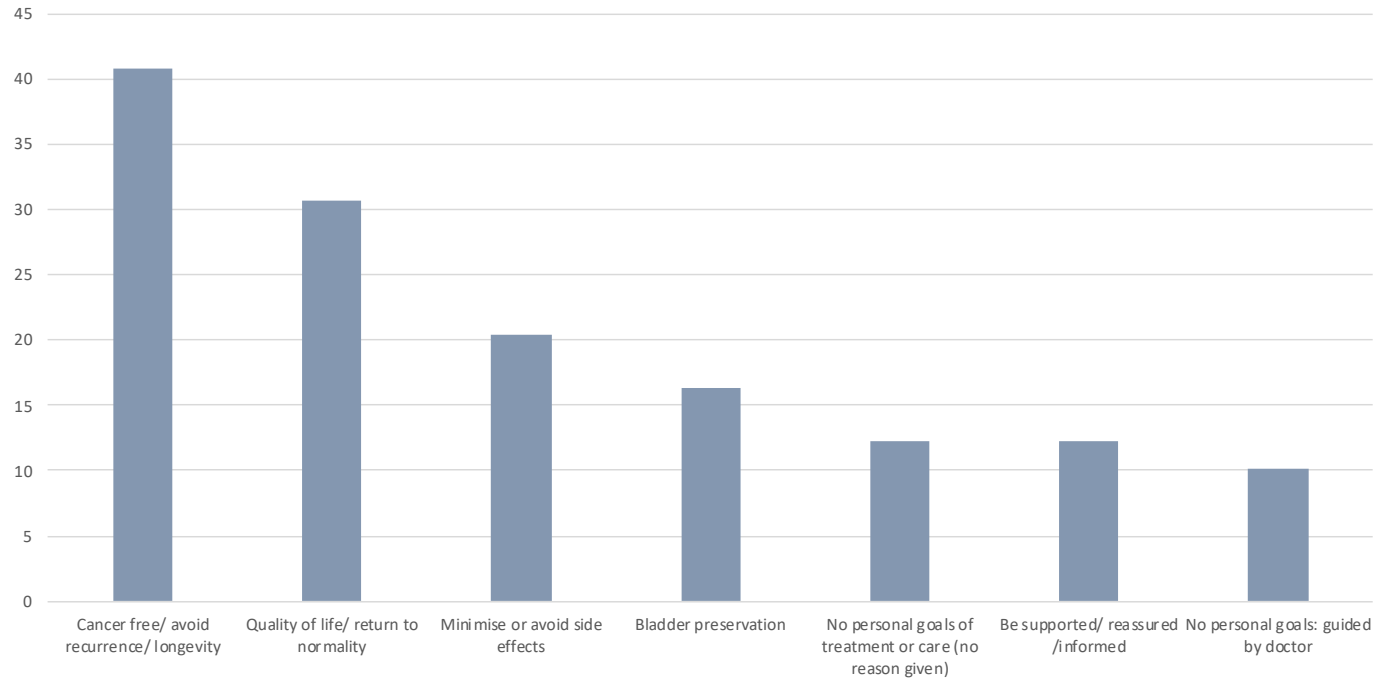

Figure 4.5: Personal goals of treatment or care

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

Personal goals of treatment	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	%
Participants describe wanting to be cancer free, avoid recurrence or increase longevity	20	40.82	13	44.83	6	31.58	9	60.00	10	30.30	9	45.00	10	35.71
Participant describes wanting to improve their quality of life or return to normality	15	30.61	9	31.03	6	31.58	5	33.33	10	30.30	8	40.00	7	25.00
Participant describes wanting to minimise or avoid side effects of treatment for their condition	10	20.41	8	27.59	2	10.53	3	20.00	7	21.21	5	25.00	5	17.86
Participant describes wanting to preserve their bladder	8	16.33	4	13.79	4	21.05	1	6.67	7	21.21	1	5.00	7	25.00
Participant describes no personal goals of treatment or care (no reason given)	6	12.24	2	6.90	4	21.05	1	6.67	5	15.15	2	10.00	4	14.29
Participant describes wanting to be supported/reassured/informed by their healthcare team	6	12.24	3	10.34	3	15.79	4	26.67	2	6.06	3	15.00	3	10.71
Participant describes no personal goals as they are guided by their doctor	5	10.20	2	6.90	3	15.79	1	6.67	4	12.12	0	0.00	5	17.86