

Section 9

Expectations and messages to decision-makers

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

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common theme was that future treatments will be accompanied by more information about available treatments and treatment pathways (n=13,26.53%), and this was followed by future treatment will be more accessible particularly equitable, timely and includes access in rural locations (n=12,24.49%).

Other participants would like future treatments to have less cost burden (n=10, 20.41%), to have more options, and/or will be targeted (n=9, 18.37%), to have fewer or less intense side effects (n=7, 14.29%), to be more effective (n=5, 10.20%), to prevent loss of bladder or will improve bladder replacements (n=5, 10.20%), to be administered in a less invasive and more dignified way (n=5, 10.20%), and to include emotional and mental support (n=5, 10.20%)

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common theme was that participants have no recommendations or they are satisfied with the information currently available (n=13, 26.53%). There were 9 participants (18.37%) that described that future information should be more accessible/easy to find, and 9 participants (18.37%) that described that future information should include all treatment options available to them.

Other participants described that future information will provide more details about mental health and emotional support (n=6, 12.24%), will help to inform the community and decision-makers about their condition (raise awareness) (n=6, 12.24%), will describe what to expect, especially with respect to side effects and treatment outcomes (n=6, 12.24%), will provide more details about where to find available services (n=5, 10.20%), and will be more targeted to specific types or stages (n=5, 10.20%).

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common theme was that participants expected future information will be more transparent and information more forthcoming (n=14, 28.57%). Other themes about expectations of future communication included that future communication will be more empathetic (n=11, 22.45%), will allow people more time to meet with their clinician to talk about all that they need to talk about (n=9, 18.37%), will include better communication between healthcare professionals, and better coordination of appointments (n=7, 14.29%), and will include discussions about mental and emotional health (n=6, 12.24%).

There were 7 participants (14.29%) that had no recommendations or that they experienced good communication.

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common theme was that participants had no recommendations or were satisfied with care received (n=15, 30.61%), and this was followed by 13 participants (26.53%) that described the expectation that future care and support will include more access to support services. Other expectations include, future care and support will include being able to connect with other patients through peer support (support groups, online forums) (n=9, 18.37%), will include more information and awareness of the condition (n=8, 16.33%), and will include mental health or emotional support (n=7, 14.29%).

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common theme was that participants were grateful for healthcare staff (n=22, 44.90%), and this was followed by 14 participants (28.57%) that described that participants were grateful for low cost or free medical treatments through the government, and 13 participants (26.53%) were grateful for timely access to treatment. Other participants were grateful for access to private healthcare or private insurance (n=10, 20.41%), and grateful for the entire health system (n=7, 14.29%).

Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, where 1 is the most important and 11 is the least important. The most important aspects reported were pain, nausea and vomiting and, diarrhoea. The least important were hair loss and, mouth ulcers.

Values in making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care, where 1 is the most important and 8 is the least important. The most important aspects were "How safe the medication is and weighing up the risks and benefits", and "The severity of the side effects". The least important were "Ability to follow and stick to a treatment regime" and "The financial costs to me and my family".

Values for decision makers

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care, where 1 is the most important and 5 is the least important. The most important values were "Quality of life for patients", and "All patients being able to access all available treatments and services". The least important was "Economic value to government and tax payers".

Time taking medication to improve quality of life

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

The most commonly participants would use a treatment for more than 10 years for a good quality of life even if it didn't offer a cure (n = 17, 36.17%), followed by less than a year (n=14, 29.79%), and between 1 and 5 years (n=12, 25.53%).

Messages to decision-makers

Participants were asked, "If you were standing in front of the health minister, what would your message be in relation to your condition?" The most common message was to help raise community awareness (n=16, 32.65%). This was followed by that they are grateful for the healthcare system and the treatment that they received (n=11, 22.45%), to invest in screening or early detection (n=7, 14.29%), to improve access to support and care (n=7, 14.29%), and to be compassionate and empathetic (n=6, 12.24%).

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common theme was that future treatments will be accompanied by more information about available treatments and treatment pathways (n=13,26.53%), and this was followed by future treatment will be more accessible particularly equitable, timely and includes access in rural locations (n=12,24.49%).

Other participants would like future treatments to have less cost burden (n=10, 20.41%), to have more options, and/or will be targeted (n=9, 18.37%), to have fewer or less intense side effects (n=7, 14.29%), to be more effective (n=5, 10.20%), to prevent loss of bladder or will improve bladder replacements (n=5, 10.20%), to be administered in a less invasive and more dignified way (n=5, 10.20%), and to include emotional and mental support (n=5, 10.20%)

Participant describes the expectation that future treatment will be accompanied by more information about available treatments and treatment pathways

And goodness me, it would be nice to see more actually more research into bladder transplants for those people that haven't got them any more. It would be nice if there was a less confusing amount of information about immuno therapy and about trials, because looking for trials is is very complicated. So some an easier access to that. I still see an oncologist. I'm sure that they would be very helpful, but without actually going and taking their time up just for questions, it would be good to have something that I could get clear, information that I could trust. To find potential trials, look at new research coming out.
Participant 020_2022AUBL

Well, I guess in an ideal world, you'd like someone to sit down and spend a lot of time going through what was available, what the risks were, and minimal costs and just really, really time spent making you fully aware of every choice you could have and what it would mean. I think I think that we I as I said to you earlier, if I this happened to me second time around, I would be almost demanding that I think of the cost, obviously, I can't demand that the information and the ability to discuss choices and to get information about choices would be would be really an advantage.
Participant 036_2022AUBL

PARTICIPANT: From any new treatments, I'd like to see clearer communication as to the benefits and the

potential side effects then. Yeah, I think that's number one. Number one. Okay.

INTERVIEWER: Is there anything else you'd like to add on?

PARTICIPANT: Well, hopefully the you know, the costs would be, you know, lower. You know, I'm really I'm realistic that that that's not going to happen.
Participant 008_2022AUBL

Participant describes the expectation that future treatments will be more accessible particularly equitable, timely and includes access in rural locations

Honestly, that everything flowed pretty well from me um. And I know from a lot of people it's more the time frame, you know. People want it fixed tomorrow, but it's just that they've got to deal with the system that's, you know, they're not the number one priority. But they are. But, you know, I guess from my point of view I just, you know, if there is a 40 year old with the same problem, to me, he would have a priority over me. You know, someone with a younger family or whatever. Like I said, I've a lot of got very, very good response and and yeah. Not no problems at all with anyone, you know. Hmm. I can't think of a thing that I would actually change. You know, the people were very, very good. You know.
Participant 011_2022AUBL

Oh. With the BCG? Mm hmm. I think it should be available when, you know, when you're ready to when you need it. Because, you know, when I first was eligible for I think I had to wait six months, and it was probably COVID things, but. And then when I did get it, the treatment was interrupted by that month because I got three weeks into it and then I couldn't get any more. Stop for a month and then go back on it.
Participant 016_2022AUBL

I suppose for me it's probably the way they're rolled out because if we talk bladder cancer, I'm at the pointy end where I've had everything removed it's but there's a lot of new treatments that should be available for somebody that's just been diagnosed that might be able to or should be able to have access to new treatments that way. Um, I think how bladder cancer patients have access to new treatments that, that sort of publicised. Um, yeah, I don't know how it could be publicised more widely through the medical profession. Yeah. But so that the patients that are

kept in the loop as we've actually got something that that is going to help with this particular type of bladder cancer.

Participant 035_2022AUBLC

Um, well, there was a shortage with the BCG and, you know, like, um, I found it really disappointing that, um, a lot of the people only get half treatment, half doses of, you know, half doses of the BCG. And I think, um, you know, disappointing that they, they told me that, and you wonder that if you actually got the full doses would it have worked? And I might not have had to have the radical cystectomy. I feel a little bit let down by, I don't know if its the medical and I know that there is a worldwide shortage is the BCG but um. Yeah let down by the medical pharmacies or whoever produces it that okay you know, why isn't there a supply of the BCG for bladder cancer patients. It just feels like that's a bit disheartening. Yeah. And I mean, it just feels like, you know, the didn't seem to be, um, they highlighted, you know, with a, with it, you know, like with it was a shortage of, of the BCG, which is, you know, like the help, you know, let people save lives really.

Participant 044_2022AUBLC

Participant describes the expectation that future treatment will have less cost burden

PARTICIPANT: Um. For me the costs, well, in an ideal world, I think that, we'd have no gap cover. For surgeons fees for cancer or some form of taxation benefits for people that are paying out large out-of-pocket amounts of money for medical treatment.

INTERVIEWER: Yeah. It's going to be extremely hard.

PARTICIPANT: Some sort of tax breaks that people do. I know they used to have. So the out-of-pocket expenses of Medicare like when that when it weren't covered after a certain amount, you could count on your tax. But that sort of I think it has gone, yes it has gone, my accountant said

Participant 001_2022AUBLC

PARTICIPANT: From any new treatments. I'd like to see clearer communication as to the benefits and the potential side effects then. Yeah, I think that's number one. Number one. Okay.

INTERVIEWER: Is there anything else you'd like to add on?

PARTICIPANT: Well, hopefully the you know, the costs would be, you know, lower. You know, I'm really I'm realistic that that that's not going to happen.

Participant 008_2022AUBLC

Probably just more if there was something that was going to be released, just maybe, probably more the, uh, the cost of things just to make it more easier for people to actually receive. Because I was lucky that most of mine was covered in, um, under my health care as well as Medicare. But I have had sleepless nights worrying about the potential financial impact of what future treatment would look like

Participant 009_2022AUBLC

Participant describes the expectation that future treatment will have more options, and/or will be targeted

Suppose what we'd like to see with regard to bladder cancer is that the bladder doesn't have to be removed because you don't have another one. And so therefore it's fairly alarming that there's been no progress really in terms of treatments to try to cure bladder cancer. I mean, everyone wants to cure every cancer, but this particular cancer can't even be cured by removing the tumour because it's a field cancer and new tumours will pop up. So it has that high recurrence rate. So there's that. And then also of course, because of that and because of the as I'm experiencing the ramifications of six years of treatment and biopsies, I need to have it removed. And there has been very little and I'm quoting in a YouTube PowerPoint I watched last night, I'm quoting an American, a sort of from America that there's been no progress in the last three decades in regard to how to how to create creating a bladder substitute and still using a piece of small bowel must not be many. So I would say some sort of I was thinking this morning, some sort of biomedical engineering kind of advance to to create to be able to install a new device that is not going to be rejected is something that will will be a good bladder substitute that you can connect to your utreters above and your urethra below. And that would help people progress on with a fairly normal life. It's not impacted by catherisation and and, you know, intermittent catheterisation and bags and, you know, loss of dignity and and etc., you know.

Participant 010_2022AUBLC

Well, I would have I would have liked to had some other options. Except for one. Yeah. Other than the one I have got. That's the main thing. But I haven't. I haven't talked to anyone else about that.

Participant 012_2022AUBLC

Oh, I'd like to see the development of them. Something to not be in BCG. I just don't think that. That it's such a chemical, even though it's a bacteria. Which by rights is natural. It's been a, you know, it's a, um, a lab grown bacteria sort of thing. I don't know. And natural it really is. But there's got to be something more stable. Not necessarily natural, but just something that's more targeted to addressing or solving the problem that is bladder cancer or cancer in general. BCG was found that was a tuberculosis vaccine and still is yet its use in bladder cancer like it's really strange and also can help with, no, not like skin cancers. That's where it was first recognised as skin cancer probably. I think maybe that was it that people who had TB at least weren't susceptible to skin cancer. But there was some very strange correlation made. And its purpose is not to fix bladder cancer. It just so happens that it does so in a perfect world that actually have something it target bladder cancer. With minimal side effects. I mean, that's a perfect world and very difficult to find, but something that was actually fit for purpose, not just an accidental accident.

Participant 030_2022AUBLC

Participant describes the expectation that future treatments will have fewer or less intense side effects

Well, I think immunotherapy. I think we have pembrolizumab, KEYTRUDA, which is the the immunotherapy that we use for bladder cancer. And from the people I know that have been on it, the side effects are much better than, say, chemotherapy. So I would like to see more immunotherapy, more personalised immunotherapy. So I'm really looking at the the individual's tumour and what drug is best going to work for them so that they're not subjected to take drugs that, you know, will have no impact on that type of tumour and therefore they experience side effects for no reason.

Participant 032_2022AUBLC

Oh, I'd like to see the development of them. Something to not be in BCG. I just don't think that. That it's such a chemical, even though it's a bacteria. Which by rights is natural. It's been a, you know, it's a, um, a lab grown bacteria sort of thing. I don't know. And natural it really is. But there's got to be something more stable. Not necessarily natural, but just something that's more targeted to addressing or solving the problem that is bladder cancer or cancer in general. BCG was found that was a tuberculosis vaccine and still is yet its use in bladder cancer like it's really strange and also can help with, no, not like skin cancers. That's where it was first recognised as skin

cancer probably. I think maybe that was it that people who had TB at least weren't susceptible to skin cancer. But there was some very strange correlation made. And its purpose is not to fix bladder cancer. It just so happens that it does so in a perfect world that actually have something it target bladder cancer. With minimal side effects. I mean, that's a perfect world and very difficult to find, but something that was actually fit for purpose, not just an accidental accident.

Participant 030_2022AUBLC

Participant describes the expectation that future treatment will be more effective

I really don't know. Obviously more success in stopping recurrence of it. But, you know, that's I think that's a very hard thing for the doctors or for surgical procedures to control. And that's a lot of to do with just genetics and what's going on inside your body, in your cells. So maybe something.

Participant 024_2022AUBLC

I'd just really like something to work to get to stop the cancer's growing. So yeah, I don't have any issue with the treatments or how they've been administered, but it's just that they obviously haven't worked that well.

Participant 025_2022AUBLC

Um. Yeah, I, I it just seems there seems to be the trial that I did may lead in the future to some sort of new way of treating bladder cancer. But at at the moment, the BCG is I mean, it's been they've been doing it for 40 years or so. You know, like it seems that there hasn't really been any any great outcomes or any great changes in the way in which the the cancer is dealt with. It would be nice to see see some I don't know whether it's lack of research or maybe it's just the fact that BCG is is pretty effective. Um, I don't know.

Participant 029_2022AUBLC

Participant describes the expectation that future treatment will prevent loss of bladder or will improve bladder replacements

So I would like to see see that, you know, it would be great if they could make, you know, and I mean, I don't know how futuristic I'm allowed to be, but, you know, when you lose your bladder and I have the neobladder, which is made out of a piece of my bowel, but, you know, if I could do something where you can have a bladder, that really is the muscle that you had before. So you know that you don't have to learn how to to make it work. It would just work like a normal

bladder. That would be great. And also then, you know, not having to cut your bowel. Um. To make your bladder. They can open that like. Like a lab grown, cloned bladder made out of your cells or something. Um, you know, that would be. That would be wonderful, because then it would be a muscle and it would work in the same way that your, you know, your bladder did. And, you know, when they cut you about it's a major part of the operation and your bowel like being cut and it causes you know, it makes you not well for quite a few days until it all starts working again. And, you know, I'm not complaining. I have to say my surgery, thank goodness, went really, really smoothly. But I was still in hospital for 11 days. So, you know, if they could improve that and it's also a major operation that was, you know, eight and a half hours of surgery. So know it's a long time. So. So. Yeah, but I think, you know, if we could really start analysing tumours and finding treatments that work for the particular tumour, you had that personalised to you. That would be great. And then then the artificial bladder, because, you know, it's nice to know that the bladder is that that the cancer is out of your body and, you know, not just using a drug to treat it in the in the non-muscle invasively. They can just cut all the tumour out and it hasn't gone into the muscle. I think the drug immunotherapy is fine, but, you know, in the more serious cases, it's nice to know that the cancer is out.

Participant 032_2022AUBLC

What would you like to see from new treatment? Yeah. Well, be nice to be able to keep be nice to be able to keep your real bladder. Um, yeah. Look, um. Obviously. A cure would be nice. But, you know, I guess I'd like to see more empathy from doctors and specialists because a lot of that is lacking in the, um, particularly in the public system. And, and there's a bit of resentment, as I said earlier, when I went to a private doctor, and I chose the public operation. The private doctor didn't want to know me anymore. Even though I was prepared, even though I was prepared to pay out of my self funding, you know, he didn't want to receive me anymore, so I thought that was pretty lousy.

Participant 042_2022AUBLC

And goodness me, it would be nice to see more actually more research into bladder transplants for those people that haven't got them any more.
020_2022AUBLC

Participant describes the expectation that future BCG treatment will be administered in a less invasive and more dignified way

Uh, well, if we didn't have to, if the treatment didn't have to be shoved down my penis. So I'd think that'd be great. But I guess it's probably the best way because it's it's not a it's not a broad spectrum chemotherapy where it rattles your whole body or anything like that. Even with the chemo, they do a direct installation as well. So, you know, that's an uncomfortable feeling, having something going up the wrong way. And it has to be said, and you certainly leave your dignity at the door when you walk in. It's all on show. But, they've been doing this treatment for us for a fair while and it's probably one of the even now it's only 50% effective, the BCG. When it's effective, it's effective. It's either going to work on you or it's not. So I haven't had to have the radio or the chemotherapy. So if there was an easy way to put it in there. Yeah, but there's not because it's got good direct to it and it doesn't affect any other part of my body. I'm not getting an intravenous sort of injection or something that's coursing through my veins or, or a shot of radiation. So. I think for this method, it's probably the only way that I can do it. And, you know, look, the nurses are they're very good. They're not fumbling around. They know what they're doing, they do this a lot. So not not just with BCG, but they do these catheters and things all the time. So they're very practised and they're very the hygiene is second to none. They're oh, yeah. Each time they do it, the whole regime is very routine. Rather, the whole routine is, is second to none.

Participant 014_2022AUBLC

Right. Um, look, it would be great to, I guess, it would be great to have a more time efficient one as well as a treatment would be, because you know, every time you someone has a BCG, they have to be in there for a minimum of 2 to 3 hours. So, yeah, I guess that would be amazing if it just a little less time effective. And, um, yeah, with side effects would definitely be more amazing and. Like you mentioned before, if it was just like a pill or a tablet or injection, that would be fantastic.

Carer 003_2022AUBLC

Participant describes the expectation that future treatment will include emotional and mental support

I think I thought when you're having treatments, I think. You know, I don't I don't think I felt emotional support and and really that's what you need I reckon, to deal with treatment is support. And so I think more

needs to go into. Into that just, improving the experience, I guess. And. So that you don't feel like a number or you don't just you know, you don't feel like you don't really matter. It's, you know, it's called process.

Participant 026_2022AUBLIC

On treatments. Yeah. Yeah, I suspect the availability of the robotic surgery. Mm hmm. Without the high cost overhead. Because I think if you don't have private insurance, you have to pay for it. Um. That would be handy for patients. What else? I think. I think and this is regarding patients that have already been diagnosed with cancer that right? So they may be the knowledge around support groups and where to get help.

Participant 022_2022AUBLIC

When I was actually diagnosed like with the thing you sort of, you come out of the surgery and says, Oh, you've got bladder cancer. I felt there was no actual support, not unless you rang up yourself and followed up. I think there should, um, urologist or whoever is dealing with it should give you some numbers or, you know, support like that. I just feel like you're on your own after they sort of give you the diagnosis.

Participant 044_2022AUBLIC

Participant describes the expectation that future treatment will be accompanied by more community awareness and early detection

New treatments. Yeah. Oh, yeah. I couldn't. I couldn't really say, um, it's catch it a lot earlier and, you know, not remove it would be so much better. And I just so much cheaper. Yeah. An early diagnosis.

Participant 031_2022AUBLIC

It's the number one thing I think. I think more awareness of of of of the cancer. And like I say, May is bladder cancer month. So we're doing a couple of things. Different markets in public areas, I think. It's not, the treatment is there. And this is changing. Every, every time I look, it's changing. You know, like 20 years ago, I wouldn't have survived and here I am, it hasn't metastasised, I underwent chemo, so really I think the only thing I can think of that that sticks in my mind more than anything else I've brought up is GPs

have to know that there's blood in your pee, check it, not just for don't just assume that it is a UTI to me that's the most education is. Because my GP, my new GP, the other one didn't know about BEAT cancer Australia. So. And I'm only using patients more. We're covering patients more to inform new patients are starting their journey that not to worry. There is no one where I could talk to them at the beginning. Now that I've been there. I believe there's a lot of us have got something to offer those who are just beginning the journey. Even if it's going to be a terminal result, you know, it's it's good to be able to talk to someone who's been there rather than a doctor or a nurse that. Does that make sense

Participant 038_2022AUBLIC

Look, I think there's studies going on all the time. My my oncologist was over in America giving. And actually, I meant to ask him exactly what the new treatment is he's working on. Um, I do believe that there's studies going on and new drugs will all the time. I truly believe that. And as I said, my oncologist was in America giving a talk on what he's actually. Yeah. Yeah. So I guess just funding to to I'm, I think like there's not a lot of. A lot of there's not a lot of talk about bladder cancer.

Participant 039_2022AUBLIC

Participant describes being uncertain about what to expect from future treatments/would defer to medical advice

PARTICIPANT I don't know. I don't know about that.

INTERVIEWER That's okay.

PARTICIPANT I never thought about that. No. I'm sorry. I don't know. I don't know.

Participant 007_2022AUBLIC

Oh, I don't know.

Participant 013_2022AUBLIC

PARTICIPANT: Well, almost. Okay. One treatment. I'm not on any. I'm not on any, uh, radiation, or chemo type therapy. So I can't really answer that question.

Participant 037_2022AUBLIC

Table 9.1: Expectations of future treatment

Expectations of future 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 the expectation that future treatment will be accompanied by more information about available treatments and treatment pathways	13	26.53	6	30.00	3	30.00	4	28.57	13	29.55	0	0.00	4	23.53	9	28.13
Participant describes the expectation that future treatments will be more accessible particularly equitable, timely and includes access in rural locations	12	24.49	5	25.00	3	30.00	3	21.43	11	25.00	1	20.00	4	23.53	8	25.00
Participant describes the expectation that future treatment will have less cost burden	10	20.41	5	25.00	1	10.00	2	14.29	8	18.18	2	40.00	4	23.53	6	18.75
Participant describes the expectation that future treatment will have more options, and/or will be targeted	9	18.37	3	15.00	1	10.00	5	35.71	9	20.45	0	0.00	4	23.53	5	15.63
Participant describes the expectation that future treatments will have fewer or less intense side effects	7	14.29	2	10.00	1	10.00	3	21.43	6	13.64	1	20.00	2	11.76	5	15.63
Participant describes the expectation that future treatment will be more effective	5	10.20	0	0.00	3	30.00	0	0.00	3	6.82	2	40.00	1	5.88	4	12.50
Participant describes the expectation that future treatment will prevent loss of bladder or will improve bladder replacements	5	10.20	1	5.00	1	10.00	3	21.43	5	11.36	0	0.00	3	17.65	2	6.25
Participant describes the expectation that future BCG treatment will be administered in a less invasive and more dignified way	5	10.20	3	15.00	0	0.00	1	7.14	4	9.09	1	20.00	1	5.88	4	12.50
Participant describes the expectation that future treatment will include emotional and mental support	5	10.20	2	10.00	2	20.00	1	7.14	5	11.36	0	0.00	3	17.65	2	6.25
Participant describes the expectation that future treatment will be accompanied by more community awareness and early detection	4	8.16	0	0.00	1	10.00	3	21.43	4	9.09	0	0.00	1	5.88	3	9.38
Participant describes being uncertain about what to expect from future treatments/would defer to medical advice	3	6.12	2	10.00	0	0.00	1	7.14	3	6.82	0	0.00	1	5.88	2	6.25

Expectations of future 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 the expectation that future treatment will be accompanied by more information about available treatments and treatment pathways	13	26.53	8	27.59	5	26.32	5	33.33	8	24.24	7	35.00	6	21.43
Participant describes the expectation that future treatments will be more accessible particularly equitable, timely and includes access in rural locations	12	24.49	9	31.03	2	10.53	4	26.67	7	21.21	6	30.00	5	17.86
Participant describes the expectation that future treatment will have less cost burden	10	20.41	6	20.69	4	21.05	4	26.67	6	18.18	5	25.00	5	17.86
Participant describes the expectation that future treatment will have more options, and/or will be targeted	9	18.37	5	17.24	4	21.05	2	13.33	7	21.21	3	15.00	6	21.43
Participant describes the expectation that future treatments will have fewer or less intense side effects	7	14.29	6	20.69	1	5.26	4	26.67	3	9.09	3	15.00	4	14.29
Participant describes the expectation that future treatment will be more effective	5	10.20	2	6.90	3	15.79	2	13.33	3	9.09	1	5.00	4	14.29
Participant describes the expectation that future treatment will prevent loss of bladder or will improve bladder replacements	5	10.20	3	10.34	2	10.53	1	6.67	4	12.12	1	5.00	4	14.29
Participant describes the expectation that future BCG treatment will be administered in a less invasive and more dignified way	5	10.20	3	10.34	2	10.53	2	13.33	3	9.09	1	5.00	4	14.29
Participant describes the expectation that future treatment will include emotional and mental support	5	10.20	3	10.34	1	5.26	1	6.67	3	9.09	3	15.00	1	3.57
Participant describes the expectation that future treatment will be accompanied by more community awareness and early detection	4	8.16	3	10.34	1	5.26	1	6.67	3	9.09	3	15.00	1	3.57
Participant describes being uncertain about what to expect from future treatments/would defer to medical advice	3	6.12	2	6.90	1	5.26	0	0.00	3	9.09	1	5.00	2	7.14

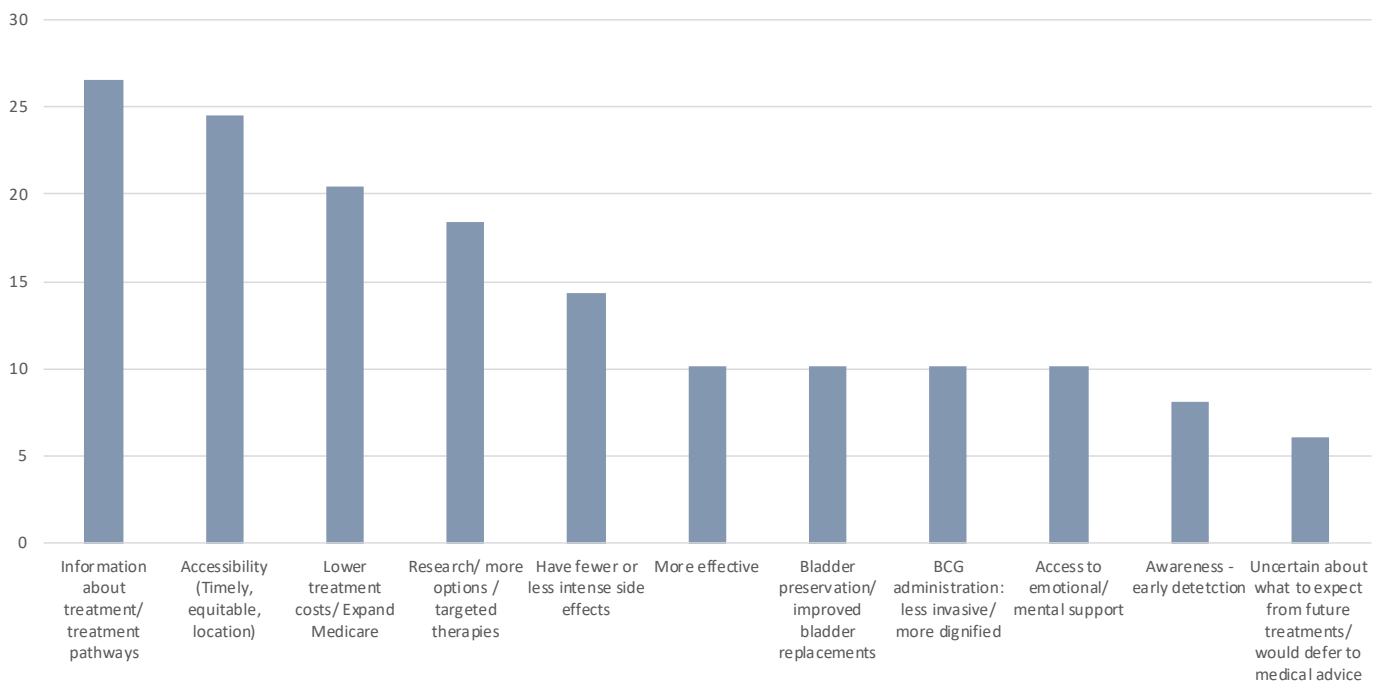


Figure 9.1: Expectations of future treatment

Table 9.2: Expectations of future treatment – subgroup variations

Expectations of future treatments	Reported less frequently	Reported more frequently
Participant describes the expectation that future treatment will be accompanied by more information about available treatments and treatment pathways	Carer to someone with bladder cancer	-
Participant describes the expectation that future treatments will be more accessible particularly equitable, timely and includes access in rural locations	University	-
Participant describes the expectation that future treatment will have less cost burden	Invasive (Stage III)	Carer to someone with bladder cancer
Participant describes the expectation that future treatment will have more options, and/or will be targeted	Carer to someone with bladder cancer	Advanced (Stage IV)
Participant describes the expectation that future treatments will have fewer or less intense side effects		Regional or remote
Participant describes the expectation that future treatment will be more effective	Early (Stages 0 and I) Advanced (Stage IV)	Invasive (Stage III) Carer to someone with bladder cancer
Participant describes the expectation that future treatment will prevent loss of bladder or will improve bladder replacements	Carer to someone with bladder cancer	Advanced (Stage IV)
Participant describes the expectation that future BCG treatment will be administered in a less invasive and more dignified way	Invasive (Stage III)	-
Participant describes the expectation that future treatment will include emotional and mental support	Carer to someone with bladder cancer	-

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common theme was that participants have no recommendations or they are satisfied with the information currently available (n=13, 26.53%). There were 9 participants (18.37%) that described that future information should be more accessible/easy to find, and 9 participants (18.37%) that described that future information should include all treatment options available to them.

Other participants described that future information will provide more details about mental health and emotional support (n=6, 12.24%), will help to inform the community and decision-makers about their condition (raise awareness) (n=6, 12.24%), will describe what to expect, especially with respect to side effects and treatment outcomes (n=6, 12.24%), will provide more details about where to find available services (n=5, 10.20%), and will be more targeted to specific types or stages (n=5, 10.20%).

Participant has no recommendations/is satisfied with the information currently available

Well, that's an interesting question because I go back to BEAT Bladder Cancer Australia each month. We have a guest speaker. It's been on BCG treatment, it's been on sexual relationships, speaking on health. So nutrition, exercise, that type of topic is very helpful. And physiotherapist uh. When I had NAME in my case was absolutely awesome. She helped me afterwards and followed on from that as well.
Participant 038_2022AUBL

No. I think, again, I went through the Cancer Council booklet and it's it's all good. It's all pretty. It's got everything, you know, it's got all the options. It's all very well written, you know, and like somebody who knows zero about bladder cancer, they can know everything, you know, how to see their symptoms, what treatment options, what type of cancer, what support is there, what afterwards? You know, I think the Cancer Council is doing a brilliant job. Yeah. That that's such a good and helpful information booklet.
Participant 028_2022AUBL

I think when you're going on this journey, I think. I think my urologist got it right. We just deal with things as presented and we try things. And I think we started on mitomycin because it wasn't as strong the BCG And so therefore that's what we started with as a first step and we just worked through the steps and more serious treatment as things don't work.
Participant 024_2022AUBL

Participant describes the expectation that future information will be more accessible/easy to find

I think we could just go, but it is a bit of an overlap. We go back to that first two weeks when I'm in shock. It would have been nice to. Be made aware that all this information is available and not forced down my throat, that, you know, you're going to need to read all this. When you feel able to sit down and concentrate and here it is. And if you have any questions, this is where you can get the answers from.
Participant 020_2022AUBL

I had to ask people, do I had to dig a bit. You have to dig a little bit deep to find some of this information.

But. I just again, everything's sort of around BCG just because that's how it is and that's what it is. I know there are trials out there and I don't know if there's much information on. It probably is, and I just haven't found it. I was hungry for information. When I first got diagnosed and I'm less so now, I just sort of become part of life. And it's not quite like this anymore. But I think more information on alternatives would be really good alternative treatments.

Participant 030_2022AUBLC

I think a bomb needs to get put under the communication and information. You know, the it was just as a registered nurse who was a strong advocate for patients and, you know, providing information. I have found the whole thing has been really scarily missing. There just isn't that information available. There's no support. As I said, you in the cancer service, you don't even feel like a person. So yeah, I do. I think the whole thing needs to be re looked at. The main support I've had in through the BEAT Bladder Cancer Support Group, which is online and sending emails, I've sent a couple of times to try and get some information and I found that been really helpful. But in terms of the information that I've been offered voluntarily through and support through the hospital, there's there's really none.

Participant 002_2022AUBLC

Participant describes the expectation that future information will include all treatment options available to them

No the format doesn't really worry me. It can be black and white with headings or whatever it's, it's a clearer discussion of the treatment options at each stage or, or the different stages of the disease. And that's what I haven't. I mean, for example, the current urologist has difficulties, his communication style problems. He's doing, as I said, a flexible cystoscopy that was never, ever mentioned to me by the previous urologist. You know, you had to have the full cystoscopy every time. Yeah. So I mean, that's that's a that's that's a different that's a different treatment option, which the first I heard about it was when I went to the new urologist. I didn't go to him because of that. I just found that out from they gave me the option.

Participant 008_2022AUBLC

Well, going to the initial diagnosis, I'm like, a bit more, um. I mean, all I had was you got bladder cancer. Bladder is going to come out. Um, and then the ins and outs of the operation, you know, there was no options, you know, I mean, I wanted to explore more the, the

BCG or or what ever it's called treatment, but that was, that wasn't on the table. Um, I mean, basically what I'm saying is if I could have kept my bladder, yeah, yeah, I would have, but I didn't have that option. The fact that that surgeon didn't give me that option, so was like going to have a second opinion or third opinion as you do

Participant 023_2022AUBLC

Yeah. So there was never any options presented. But I guess there was also there was never any discussion or presentation of what current research there was or even if there was like, you know, are there any clinical trials? What kind of procedures have either historically been used and are still used or what is new or what is. Yeah. And maybe that's seen as too overwhelming and confusing for the patient.

Participant 041_2022AUBLC

Participant describes the expectation that future information will provide more details about mental health and emotional support

Uh uh, I think more support groups, more personal care and mental support. That's the part I totally missed.

Participant 005_2022AUBLC

Well, we didn't know about any support groups. We didn't know anything about where you could get help for for financial reasons. We didn't know mental health. I think that should have been. You know people could say he was really depressed, but no one did anything about it.

Carer 001_2022AUBLC

I think a bomb needs to get put under the communication and information. You know, the it was just as a registered nurse who was a strong advocate for patients and, you know, providing information. I have found the whole thing has been really scarily missing. There just isn't that information available. There's no support. As I said, you in the cancer service, you don't even feel like a person. So yeah, I do. I think the whole thing needs to be re looked at. The main support I've had in through the BEAT Bladder Cancer Support Group, which is online and sending emails, I've sent a couple of times to try and get some information and I found that been really helpful. But in terms of the information that I've been offered voluntarily through and support through the hospital, there's there's really none. I think the one to get is breast cancer. Not that I wish that on anybody, but I believe it's so much more help and and services available for people with breast cancer. I don't I don't

know why, but the, I rang the Cancer Society to try and get some help and information and they couldn't even help me.

Participant 002_2022AUBLC

Participant describes the expectation that future information will help to inform the community and decision-makers about their condition (raise awareness)

No, look, As I said earlier, it's not one of those cancers that you don't hear much about. Yes. So anything would be would be some improvement. I did coincidentally hear a radio programme, I think about this time last year where they talked about it must have been Bladder Cancer Awareness Week. And I heard a few people, I stumbled on it. I didn't know it was going to happen. It was on the ABC and they were talking about it and you know, that sort of information was fantastic. I really listened to it and I was like, Wow, that's good to know that. And that's the sort of information that needs to come out. I think with all of these with these cancers, people are always feeling they're a bit in the dark. But there is information there with with the lesser known cancers, I find it's harder to dig out that information without getting into the really bad. You know what? This what happens.

Participant 006_2022AUBLC

Probably just, I think that I think BEAT bladder cancer has kind of already started it, but maybe because I didn't actually see them originally, but maybe like on bigger pages like the Cancer Council, I would really like to see more information about like maybe some prompts about questions to ask urologist and GP use and those kind of things. Just more tips and tricks of like what we could be asking rather than being overwhelmed with all this information and not being able to connect the dots or anything. So yeah, maybe just some of yeah. And just some every day. So I didn't actually know. I know this sounds stupid, but I didn't even know bladder cancer was a real thing. Like, I knew it was a thing, but like, I didn't know anyone that it affected. So maybe just trying to put it out to the world that we do need to be aware of other types of cancer. Um. Because I've been looked at differently, like I've lost half my bladder, but I still have both my boobs. Like I don't have breast cancer, but if I had breast cancer, I think people would look at me differently because it's more commonly known.

Participant 009_2022AUBLC

I think it's definitely not highlighted enough on, say, like TV adverts or radio adverts or newspaper adverts.

It's not out there a lot. You don't know about it until you've got it. And it's not like breast cancer is front and centre at the moment for a lot of Australians and bowel cancer is front and centre for a lot of Australians. But bladder cancer, you never hear anything on it.

Participant 031_2022AUBLC

PARTICIPANT I'd love to walk into a toilet one day and see a sign on the door when we're talking about urine and blood in the urine. Those kind of signs need to be in toilets. Toilet cubicles. Not to say more awareness. More promoting it on. Yeah. Screening. Why can't we do screening? If there is any such thing, can we screen for bladder cancer? Like we do for bowel cancer and breast cancer.

INTERVIEWER Yeah. That's a good question.

PARTICIPANT And why haven't we got that up and running? Well, there's that. Anything, I guess, that can just. Allow us to have an early diagnosis, because I know if my husband was, you know, diagnosed early, it might have been a very different outcome. So it may not have been, but, you know it could have been.

Carer 002_2022AUBLC

Participant describes the expectation that future information will describe what to expect, especially with respect to side effects and treatment outcomes

I suppose the one thing that stands out that is not discussed is. Like with any area that that might affect your, your sexual life. That's one thing that is so often a no go zone. And yet, you know, it's a big part of our lives and it's not something you want to give up. So you shouldn't have to bring that subject up. And like I, you know, I have with all my specialist, because I'm an out there kind of woman, I have a bit of a medical background on my husband and I still, you know, certainly enjoy our sex life. So it's not something we before are happy to just, uh, of course, you know, my life and longevity is more important, but at the same time, if it can be spared and accommodated, then you, you want that to be considered and taken into account and sensitivity and all the rest. So that's something that is, as per usual, the last thing that people feel comfortable talking about. So the elephant in the room.

Participant 010_2022AUBLC

PARTICIPANT: There was very little information about recovery and things after recovery.

INTERVIEWER: You mean after the bladder removal?

PARTICIPANT: Yes, I had I had side effects in my body. And that's when my treatment really fell apart. To be honest, no one wanted to own the problem or to really help me out.

Participant 016_2022AUBLC

I think a break down in the post-operative, so again, part of the cancer, part of it the post-operative stages, what the impacts of the surgery can mean both and separated maybe for some male and female. And from my perspective, um, like, there was a vaginal leakage, and I didn't know what that was. And when I went to, I went back to the urologist, and he said, oh, yeah, that can happen. That's, why wasn't something that I was told about? What does it mean, and how long is it going to last?

And for men and also women as well. Um, from a, um, from a sexuality perspective and, you know, intimate relationships and things like that, I think there needs to be more awareness around what the impacts of the operation, um, will preclude you from being able to do. But also tell you what you can continue to do. ... And the how, you know, I think online again is good, but, um, it should be certainly something that's either if it's not offered by the urologist, then they should be directing to, you know, an appropriate sort of forum or group that can discuss.

Participant 022_2022AUBLC

Participant describes the expectation that future information will provide more details about where to find available services

And I think sometimes even a list with what, a list of what is there and how to contact them would be useful. Not everybody is able to sort of will access it if they don't have the facilities and symptoms, they don't know what it is knowing what's there sometimes. And knowing like a slide. And you know, it's easy to say, oh, go and speak to so-and-so. But you need to know what they provide. Is that what you're after? So I think some kind of list would be a start. And I do think the hospital is busy enough, I suppose, but wouldn't it would be nice if there was some way where you could, you could go easily call to get your information. Or a meeting place where you could be with people who have the same problems as you. So you can get how do they manage. Often a lot of the stuff I find out is by the group on Facebook, you know,

all different things that are available. And yeah, I did go to a few of the sessions of the urostomy group where I got information there. But then, of course COVID shut everything down, and now that they've opened up again I think to this, every one of them, they only do it once every two months. And if I've got something else on, I can't go. I haven't been yet. Probably about two and a half years since I went to a meeting of them.

Participant 003_2022AUBLC

I suppose clinical trials is one thing that would be good to be better presented. You know, it's quite tricky to find that information out at the moment. And you know. Also, I suppose one thing that would be good to know is, you know, where you know is the best place to go that do a lot of radical cystectomy. You know, because you don't want to be in a hospital that does, you know, once a year or even worse, you want to be somewhere where they're doing them often.

Participant 032_2022AUBLC

I guess like the emotional support is sorely lacking. And like, as I said before, like if you when you get diagnosed, be handed like a brochure. And on bladder cancer and also, um, you know, where to get support, whether it be emotionally, financially, anything. You know, here's a phone number that you can call. Um. You know, that would be. That would be amazing. Like I said, we were lucky that we had a family member who's an oncologist that we were able to call and talk to. But I imagine most people don't have that. So, yeah, I think written information in a hardcopy at the time of diagnosis where you can take away and actually read it and process it later. It would be would be something that definitely should happen.

Carer 003_2022AUBLC

Participant describes the expectation that future information will be more targeted to specific types or stages

No, the format doesn't really worry me. It can be black and white with headings or whatever it it's. It's a clearer discussion of the treatment options at each stage or, or the different stages of the disease. And that's what I haven't. I mean, for example, the current urologist has difficulties, his communication style problems. He's doing, as I said, a flexible cystoscopy that was never, ever mentioned to me by the previous urologist. You know, you had to have the full cystoscopy every time. Yeah. So I mean, that's that's a that's that's a different that's a different treatment option, which the first I heard about it was when I went to the new urologist. I didn't go to him because

of that. I just found that out from they gave me the option.

Participant 008_2022AUBLC

Um, I felt like that because as NAME was in a muscular, that I thought it was well, the information was about the other sort, you know, so it wasn't relevant. I think it should have been divided into two groups

Carer 005_2022AUBLC

You know, I would love to be able to click on, you know. Click on. You know, what I love about the support group is that we, you know, this week, next week, next. So there's this month last month they did a you know, a specialist came on and talked about must non-muscle invasive bladder cancer. And I sat and listened to the whole thing and it wasn't relevant to me. But the fact that when I said to them, is it possible to have the next talk be about muscle invasive? And they put it on. So this next week, I'm going to hear all about, you know, and that would be so wonderful that someone could video that. And that I could click on to that that link so that I can say to anybody else who comes on and says, Listen, my husband just got diagnosed with muscle invasive bladder cancer, you know, instead of reading, can we listen to someone talking about it and what the options are for treatment and all that? That would be fantastic. Yeah, like that would have been so good for me if if there was, you know, not everyone. You know, I'm I'm a I'm a researcher, right? Like so I'm a person that will go on and read and all that. But my husband isn't. Whereas if I could have said to my husband, All you have to do is click on this person. This person is talking about muscle invasive bladder cancer. And this

person's not only telling you about muscle invasive bladder cancer, but it's also telling you about the most recent research into your options of preservation, or surgical removal and gives you all this information there and and you can make your decision. And it doesn't need me to have to research it to give you the option, you know.

Carer 004_2022AUBLC

Participant describes the expectation that in future there will be enough time to discuss information with their healthcare professionals

I think. I think it's kind of like. When when they give you mass information, it's like they need to follow up in a few days time and and and care enough to go through it again. And answer your questions. Yeah. You know, the times that you're getting lots of information, you can't ask questions because you're just trying to grab. What's going on. And then you don't really feel like you can ring back and bother them and ask questions later.

Participant 026_2022AUBLC

It's a big game and it's a big question really, isn't it. I guess I think we could just go, but it is a bit of an overlap. We go back to that first two weeks when I'm in shock. It would have been nice to. Be made aware that all this information is available and not forced down my throat, that, you know, you're going to need to read all this. When you feel able to sit down and concentrate and and here it is. And if you have any questions, this is where you can get the answers from.

Participant 020_2022AUBLC

Table 9.3: Expectations of future information

Expectations of future information	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 has no recommendations/is satisfied with the information currently available	13	26.53	4	20.00	5	50.00	4	28.57	13	29.55	0	0.00	2	11.76	11	34.38
Participant describes the expectation that future information will be more accessible/easy to find	9	18.37	4	20.00	2	20.00	3	21.43	9	20.45	0	0.00	6	35.29	3	9.38
Participant describes the expectation that future information will include all treatment options available to them	9	18.37	3	15.00	1	10.00	4	28.57	8	18.18	1	20.00	4	23.53	5	15.63
Participant describes the expectation that future information will provide more details about mental health and emotional support	6	12.24	4	20.00	0	0.00	0	0.00	4	9.09	2	40.00	4	23.53	2	6.25
Participant describes the expectation that future information will help to inform the community and decision-makers about their condition (raise awareness)	6	12.24	2	10.00	0	0.00	3	21.43	5	11.36	1	20.00	2	11.76	4	12.50
Participant describes the expectation that future information will describe what to expect, especially with respect to side effects and treatment outcomes	6	12.24	4	20.00	2	20.00	0	0.00	6	13.64	0	0.00	5	29.41	1	3.13
Participant describes the expectation that future information will provide more details about where to find available services	5	10.20	2	10.00	0	0.00	1	7.14	3	6.82	2	40.00	3	17.65	2	6.25
Participant describes the expectation that future information will be more targeted to specific types or stages	5	10.20	3	15.00	0	0.00	0	0.00	3	6.82	2	40.00	0	0.00	5	15.63
Participant describes the expectation that in future there will be enough time to discuss information with their healthcare professionals	3	6.12	0	0.00	2	20.00	1	7.14	3	6.82	0	0.00	1	5.88	2	6.25

Expectations of future information	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 has no recommendations/is satisfied with the information currently available	13	26.53	8	27.59	5	26.32	2	13.33	11	33.33	4	20.00	9	32.14
Participant describes the expectation that future information will be more accessible/easy to find	9	18.37	5	17.24	4	21.05	3	20.00	6	18.18	3	15.00	6	21.43
Participant describes the expectation that future information will include all treatment options available to them	9	18.37	4	13.79	5	26.32	3	20.00	6	18.18	4	20.00	5	17.86
Participant describes the expectation that future information will provide more details about mental health and emotional support	6	12.24	2	6.90	4	21.05	1	6.67	5	15.15	2	10.00	4	14.29
Participant describes the expectation that future information will help to inform the community and decision-makers about their condition (raise awareness)	6	12.24	5	17.24	1	5.26	2	13.33	4	12.12	3	15.00	3	10.71
Participant describes the expectation that future information will describe what to expect, especially with respect to side effects and treatment outcomes	6	12.24	3	10.34	3	15.79	2	13.33	4	12.12	1	5.00	5	17.86
Participant describes the expectation that future information will provide more details about where to find available services	5	10.20	2	6.90	3	15.79	1	6.67	4	12.12	2	10.00	3	10.71
Participant describes the expectation that future information will be more targeted to specific types or stages	5	10.20	4	13.79	1	5.26	4	26.67	1	3.03	4	20.00	1	3.57
Participant describes the expectation that in future there will be enough time to discuss information with their healthcare professionals	3	6.12	2	6.90	1	5.26	3	20.00	0	0.00	3	15.00	0	0.00

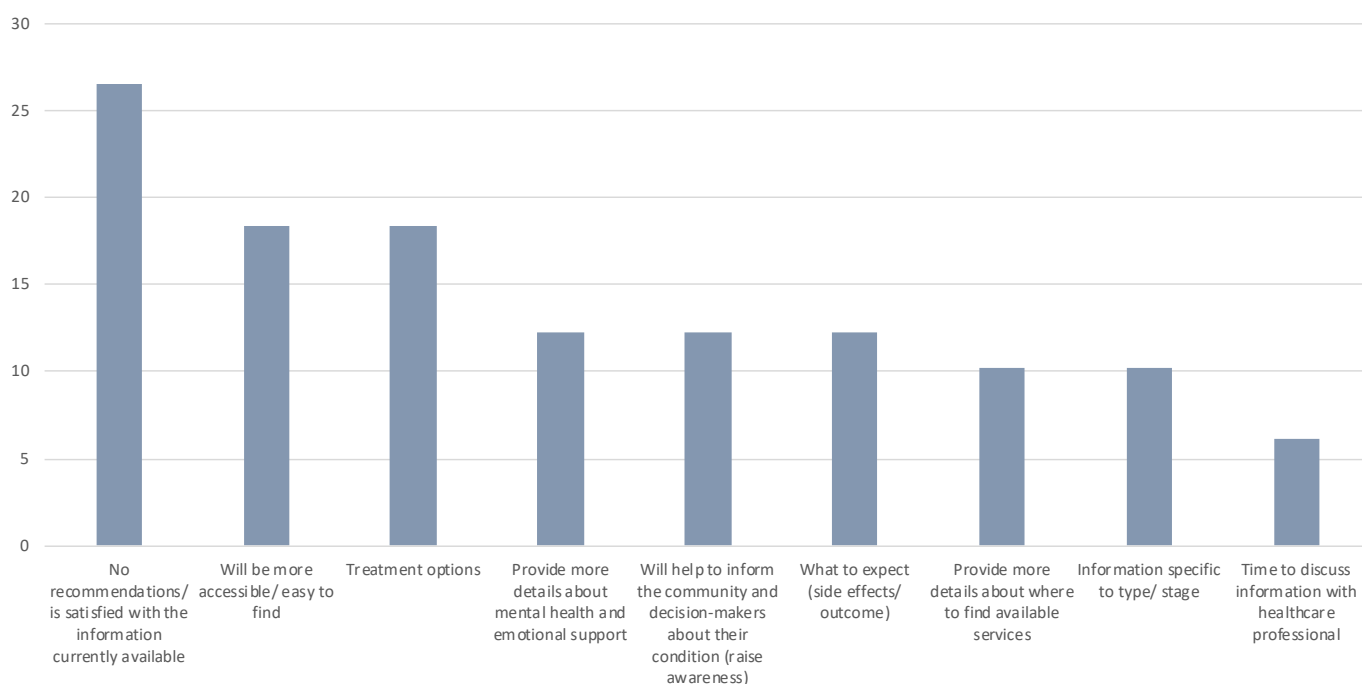


Figure 9.2: Expectations of future information

Table 9.4: Expectations of future information – subgroup variations

Expectations of future information	Reported less frequently	Reported more frequently
Participant has no recommendations/is satisfied with the information currently available	Carer to someone with bladder cancer Female Regional or remote	Invasive (Stage III)
Participant describes the expectation that future information will be more accessible/easy to find	Carer to someone with bladder cancer	Female
Participant describes the expectation that future information will include all treatment options available to them	-	Advanced (Stage IV)
Participant describes the expectation that future information will provide more details about mental health and emotional support	Invasive (Stage III) Advanced (Stage IV)	Carer to someone with bladder cancer Female
Participant describes the expectation that future information will help to inform the community and decision-makers about their condition (raise awareness)	Invasive (Stage III)	-
Participant describes the expectation that future information will describe what to expect, especially with respect to side effects and treatment outcomes	Advanced (Stage IV) Carer to someone with bladder cancer	Female
Participant describes the expectation that future information will provide more details about where to find available services	Invasive (Stage III)	Carer to someone with bladder cancer
Participant describes the expectation that future information will be more targeted to specific types or stages	Invasive (Stage III) Advanced (Stage IV) Female	Carer to someone with bladder cancer Regional or remote

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common theme was that participants expected future information will be more transparent and information more forthcoming (n=14, 28.57%). Other themes about expectations of future communication included that future communication will be more empathetic (n=11, 22.45%), will allow people more time to meet with their clinician to talk about all that they need to talk about (n=9, 18.37%), will include better communication between healthcare professionals, and better coordination of appointments (n=7, 14.29%), and will include discussions about mental and emotional health (n=6, 12.24%).

There were 7 participants (14.29%) that had no recommendations or that they experienced good communication.

Participant describes the expectation that future communication will be more transparent and information more forthcoming

PARTICIPANT: I guess I like to know. The facts, I like to be told the facts. Even if they're not great, I've just got to know. Yeah. And, um. I guess just more disclosure, maybe. Um, I know I said I like to access information online, but maybe something in at the same time in writing when you actually physically see a doctor. But when you reach that clinic, when I left the clinic for the first time of bladder cancer or suspected may have bladder cancer. After I first saw my surgeon, I left with no information. Does that make sense? Nothing in writing.

INTERVIEWER: Nothing to go back to or anything.

PARTICIPANT: Nothing to refer back to or nothing to explain that you're going to have a T U R B T. All I remember was I sat in the surgeon's room. And he had this model of, like, a male torso or not to full torso, but just a urological system and that sort of male part. And he had the cystoscopy tube, and I said, oh whereabouts will you be cutting me? Like to get the to get into the bladder? You go through my side or under my belly or whereabouts to go, and all of a sudden you get to sort of model thing out and starts showing, oh I put a tube through your penis and I put this camera up there and I'm just like, I remember I swore when he showed me this, I'm like you've got to be bleeping joking or something like that. And then I realised,

oops, you know, oops what am I saying, I'm swearing at his doctor because I was in shock, you know? And it's just like there was nothing to sort of, um, I had if I hadn't asked that, if I hadn't said something, I wouldn't have known what I was having done. And yeah, so I guess to something to say, this is what you're going to have done. You might feel this way or it won't be painful. It may seem painful, but you'll be asleep or or something of that nature without having to ask for, you know, without asking it.

INTERVIEWER: Like you're not going to be expected to know.

PARTICIPANT: It's like I had weight loss surgery, which has been very successful as a whole, which I with the top surgeon in his field and you come out sort of with it, you know with a folder full of information about this is what you're going to have done and this is how it works and blah, blah, blah. These are the different options available and you know, you're fully armed with information and that's not something that generally is going to kill you or not like it's cancer, you know. So yeah, it's a bit different.

Participant 001_2022AUBLC

No. It just comes back to two reliable information sources. And I think easier access, easier access, more logical access to information about trials that would be important and treatment options.

Participant 020_2022AUBLC

Um, well, we've got to go back to the initial GP. I mean, I'm sorry, it sounds like an old echo, but yeah, the initial diagnosis, well, it wasn't diagnosed at the GP. He probably knew, but he passed me over to the urology. So I would have liked him to still come clean earlier with the a bit more warning. In a way, I knew in my head that something was wrong. So then would you think something like that, you, you, you, you basically go into or what if what that. It's you know, without knowing the facts. You know. I would have liked a clearer, a clearer timeline.

Participant 023_2022AUBLC

Yes. That look, you know, you've got non-invasive muscle bladder cancer. Click on this site and they're going to tell you this side is going to say, tell you what it is, what the treatments are. How many people have, you know, all the studies that have been done on it? This is what the studies have found. And. These are you know, these studies are telling you that this is the best way to go. All this is the studies are telling you

that there's multiple options. And. Any of these options have similar risks and benefits.

Carer 004_2022AUBL

Participant describes the expectation that future communication will be more empathetic

I guess that health professionals can become a bit destigmatised, desensitised rather to it. And so for them, it's very matter of fact. And although, you know, we are friendly with my urologist, it's her job and she talks as very matter of fact, there's not a huge amount of compassion and warmth. And that's certainly no judgement. I mean, also some people don't have that. But, you know, she's a well, she's a leader in a field, there's no question about it, urology, but, she, you know she didn't deal with it very well. When I broke down and cried, I suppose she was like, oh, I don't have any tissues. She felt a bit uncomfortable. So I guess and that's been a thing in the medical industry. Is is compassion, I suppose. I mean, she is. But, you know, the desensitised to something that you just do day in day out in your routine. It, you know, she'll tell you all the facts and everything like that that doesn't have the, um the warmth, I suppose. I guess that they just need that training in to deal with, with compassion and humanity side of it.

Participant 014_2022AUBL

Oh, yeah. Um, get rid of the pedestal if, in my case, urologist, get rid of your pedestal, you know, stand next to me, be in the trenches with me, you know, show some empathy. Um. Be balanced and be open and transparent.

Participant 017_2022AUBL

PARTICIPANT: *No, it's 90% of it. Excellent.*

INTERVIEWER: *Yeah. And that 10% though.*

PARTICIPANT: *Yeah. Yeah. Nurses. Reception staff. Yeah. Registrar's. All good Yeah.*

INTERVIEWER: *Okay.*

PARTICIPANT: *For one day when I did come back after a few months we were in day surgery and we were both having a cup of tea in our cubicle, routine would be, anaesthetists and surgeon walk past in a hurry and then registrar walk will past, but he stopped and turned and came back. And said, I saw you guys were a bit upset. Do you guys want to talk about it? Yeah, that was good. I hope that guy. It's almost eight years*

ago. Hopefully he hasn't lost that if he's a qualified surgeon somewhere now.

Participant 019_2022AUBL

Participant describes the expectation that future communication will allow people more time to meet with their clinician to talk about all that they need to talk about

Oh, yeah. They need to sit down and explain the diagnosis as soon as possible. Just explain and make sure you understand it and not have to find out for yourself... They assumed I knew what was going on... I had to wait for 3 hours in the out patients, and they just see you for 5 minutes...To be treated with respect I suppose...3 hours for nothing.

Participant 013_2022AUBL

As I said before, just a little bit of a little bit of a consultation after after any procedure. You know I can't fault Dr NAME, I can't fault him at all for what he what he's told me and the lengths and explanations that he's given me and the consultations I've had with him. There's just a little bit of that. And as I said before, just after after any sort of treatment. Just be told what may or may not happen if everything's clear. So, you know, the first four or five cystoscopies I had, the doctors, the doctors, one doctor, they're all different. The doctor came and said to me, fine, it's all clear. You know, you can, go home. When you when you come out of the anaesthetic, you know, when you when you're okay and that just you breathe easy, you know. But when they don't when they don't get any information after the procedure, that's when you go home with thinking, what if? you know? So that's the only thing I can think of about. Little bit of the information that should be given to you.

Participant 021_2022AUBL

No, I was very lucky. You know, I had my urologist texting me when I got home and check in and see how I was going. I was really I had a really good relationship with my oncologist and urologist. So, but from others I hear of, you know, the empathy is just sometimes not there at all. And that's what people want. They want a little bit of empathy and they want someone that doesn't make them feel rushed and makes them feel like they can ask questions. Or if they can't, if they haven't got the time, you know, give them an avenue to ask the questions, whether it's through them still or via someone else.

Participant 022_2022AUBL

Participant has no recommendations/experienced good communication

*No, my communication has been very good.
Participant 012_2022AUBLC*

*I had a great I had a great experience the journey.
Participant 024_2022AUBLC*

*No, not really. I think the urologist, he is very approachable, my GP is good. Um. The nursing staff? Yeah. I don't think I could change anything.
Participant 027_2022AUBLC*

Participant describes the expectation that future communication will include better communication between healthcare professionals, and better coordination of appointments

*So I think it also needs to be coordinated. I think, you know, they talk about a multidisciplinary team that discusses your case. I think as a patient, you've got a right to be at that. So you can get a holistic view about what the what the thoughts are of the treating health professionals are and you become you need to be central to
Participant 002_2022AUBLC*

*I think. Yeah. Okay. So once it's established that you are. In a situation that will require continuing. Or. Potentially continuing care and visits and appointments. I guess. If there was some point of contact, some stuff, some single point of contact rather than the reception desk and asking to be put through urology. Or. Or, you know, put through a oncology. Well, you put through to the cancer centre, which I didn't know existed until sort of 5 years in. Yeah. A point of contact, but not just emergency, or asking to speak to a urology registrar because you don't think something's quite right after you've been sent home.
Participant 041_2022AUBLC*

Oh, no, no. I'm happy with that. All, good, doctors. So. But. Yeah. Um. Yeah, it's actually in between oncologist and the urologist, if, well, I can talk with them in at one time. Same here. I could put it on the same table and I can talk with two doctors that together. It's much easier sometimes, I got to see separate. You know, sometimes the information they are not sharing, and I'm in the middle, and I have to ask them or so I have to have a cystoscopy before treatment. After treatment or you know, it depends on the on the sometimes the doctors, the oncologist after your utilisation. You're just asking me to ask the

*oncologists So, you know, I'm in the middle sometimes. He's like, if I we can see together, it's much easier. But yeah, yeah, yeah, yeah. Maybe difficult. You know, I understand that.
Participant 015_2022AUBLC*

Participant describes the expectation that future communication will include discussions about mental and emotional health

PARTICIPANT: I think. Everybody looks at their own little territory. They don't look at the full person.

INTERVIEWER: Okay. Anything else?

*PARTICIPANT: They are more on the mental side because everybody that's, I think, a nurse changes dressing. A surgeon does the cutting and the camera work, but. They don't see the human being and the impact it has on the human being.
Participant 005_2022AUBLC*

*Well, yes, I think they just need to be much more empathetic when they don't have to, you know, they don't know us, they don't have to cry or anything, but they could at least sit down and talk to you. As a human being. And I think they should refer you to Allied Health. You know, your social worker or psychologist or counsellor or whatever you want to call them. You know, it just seems to be a very one on one relationship. That is, there's no there's no cross disciplinary consideration. I mean, I even looked in the first I looked in his waiting room, there are no brochures there for any other health care. Allied Health? Nothing. The only brochures for the hospitals where he where he where he performs the surgeries and procedures.
Participant 008_2022AUBLC*

PARTICIPANT Yeah, probably would be, as I said, day. Like, um, I don't know, they could direct you to, um.

INTERVIEWER Like support groups.

PARTICIPANT Or group or social, you know, like a social worker or someone, you know, like, and you could to actually, um, I don't know if they've changed the system. I actually spoke to his nurse after, after he had given me the diagnosis, I went into, like he told me the diagnosis and then his nurse they had a nurse there at the time after that and she sort of explained the situation, you know, where it was going to happen next after that. And I felt that that was really good that she actually I know he's busy with all these other patients and stuff like that. So I found it really helpful

that he had someone that was there to explain what was going to happen. But what she did, she explained to, you know, what was going to happen, you know, like where it was going to go from there. Okay. You know, and you know.

Participant 044_2022AUBLC

Participant describes the expectation that future communication will include better ability to make appointments with specialists and contact them between appointments

Yes. Because sometimes you can't actually get to speak to your urologists or anyone on the urology team except through at the time of an appointment. Yes. I'm not sure. Like the three monthly scheduled appointment. If you've got a problem outside of that time and you don't get to it's not easy to get to speak to anybody without making a lot of fuss.

Participant 016_2022AUBLC

Perhaps just a bit more information. Yeah. That's I don't have very long with the doctor when. After I've had the operations or anything sort of 5 minutes or something. So. Yeah. I don't know whether I should have a second opinion, but then trying to get into a different specialist would take another six months or something, or even more. So that's why I just think I'm lucky that I've got someone that is treating me.

Participant 025_2022AUBLC

Not really, no. I don't know. Once you do get hold of a doctor, the information is free flowing and they're not afraid to tell you they are. You know what you want

to hear or what you need to hear. Sorry. Yeah. Getting a hold of them is the hardest part because they are a busy, busy bunch of people.

Participant 031_2022AUBLC

Participant describes the expectation that future communication will include developing a care plan with follow-up

I think the this probably like finding aftercare, the support. It was something that, you know, I had to do by myself or actually through the help of my daughter. In hospital, they give you you they show you have to you try to change the bag and put you into signing up for the STATE Stoma Association. But I don't recall that there was any, any clues on or any sort of information given as to, to mental health afterwards and support groups that wasn't mentioned.

Participant 043_2022AUBLC

I think. Yeah. Okay. So once it's established that you are. In a situation that will require continuing. Or. Potentially continuing care and visits and appointments. I guess. If there was some point of contact, some stuff, some single point of contact rather than the reception desk and asking to be put through urology. Or. Or, you know, put through a oncology. Well, you put through to the cancer centre, which I didn't know existed until sort of 5 years in. Yeah. A point of contact, but not just emergency, or asking to speak to a urology registrar because you don't think something's quite right after you've been sent home.

Participant 041_2022AUBLC

Table 9.5: Expectations of future healthcare professional communication

Expectations of future communication	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 the expectation that future communication will be more transparent and information more forthcoming	14	28.57	7	35.00	3	30.00	2	14.29	12	27.27	2	40.00	4	23.53	10	31.25
Participant describes the expectation that future communication will be more empathetic	11	22.45	4	20.00	1	10.00	4	28.57	9	20.45	2	40.00	1	5.88	10	31.25
Participant describes the expectation that future communication will allow people more time to meet with their clinician to talk about all that they need to talk about	9	18.37	6	30.00	3	30.00	0	0.00	9	20.45	0	0.00	7	41.18	2	6.25
Participant has no recommendations/experienced good communication	7	14.29	1	5.00	3	30.00	2	14.29	6	13.64	1	20.00	0	0.00	7	21.88
Participant describes the expectation that future communication will include better communication between healthcare professionals, and better coordination of appointments	7	14.29	5	25.00	1	10.00	1	7.14	7	15.91	0	0.00	4	23.53	3	9.38
Participant describes the expectation that future communication will include discussions about mental and emotional health	6	12.24	3	15.00	1	10.00	2	14.29	6	13.64	0	0.00	4	23.53	2	6.25
Participant describes the expectation that future communication will include better ability to make appointments with specialists and contact them between appointments	5	10.20	3	15.00	0	0.00	1	7.14	4	9.09	1	20.00	2	11.76	3	9.38
Participant describes the expectation that future communication will include developing a care plan with follow-up	3	6.12	0	0.00	1	10.00	2	14.29	3	6.82	0	0.00	2	11.76	1	3.13

Expectations of future communication	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 the expectation that future communication will be more transparent and information more forthcoming	14	28.57	11	37.93	3	15.79	7	46.67	7	21.21	9	45.00	5	17.86
Participant describes the expectation that future communication will be more empathetic	11	22.45	8	27.59	3	15.79	3	20.00	8	24.24	4	20.00	7	25.00
Participant describes the expectation that future communication will allow people more time to meet with their clinician to talk about all that they need to talk about	9	18.37	4	13.79	4	21.05	2	13.33	6	18.18	2	10.00	6	21.43
Participant has no recommendations/experienced good communication	7	14.29	5	17.24	2	10.53	4	26.67	3	9.09	4	20.00	3	10.71
Participant describes the expectation that future communication will include better communication between healthcare professionals, and better coordination of appointments	7	14.29	2	6.90	5	26.32	1	6.67	6	18.18	2	10.00	5	17.86
Participant describes the expectation that future communication will include discussions about mental and emotional health	6	12.24	4	13.79	2	10.53	2	13.33	4	12.12	4	20.00	2	7.14
Participant describes the expectation that future communication will include better ability to make appointments with specialists and contact them between appointments	5	10.20	0	0.00	4	21.05	1	6.67	3	9.09	1	5.00	3	10.71
Participant describes the expectation that future communication will include developing a care plan with follow-up	3	6.12	1	3.45	2	10.53	1	6.67	2	6.06	1	5.00	2	7.14

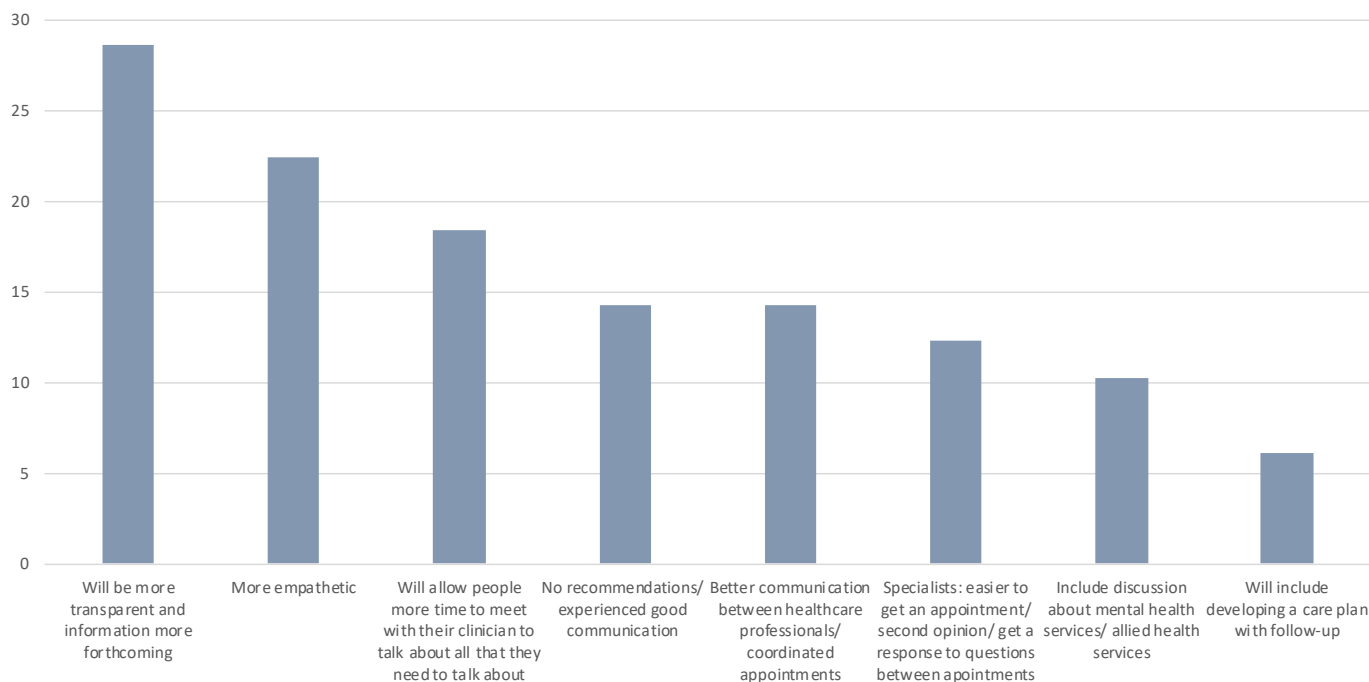


Figure 9.3: Expectations of future healthcare professional communication

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

Expectations of future communication	Reported less frequently	Reported more frequently
Participant describes the expectation that future communication will be more transparent and information more forthcoming	Advanced (Stage IV) University Higher status	Carer to someone with bladder cancer Regional or remote Mid to low status
Participant describes the expectation that future communication will be more empathetic	Invasive (Stage III) Female	Carer to someone with bladder cancer
Participant describes the expectation that future communication will allow people more time to meet with their clinician to talk about all that they need to talk about	Advanced (Stage IV) Carer to someone with bladder cancer Male	Early (Stages 0 and I) Invasive (Stage III) Female
Participant has no recommendations/experienced good communication	Female	Invasive (Stage III) Regional or remote
Participant describes the expectation that future communication will include better communication between healthcare professionals, and better coordination of appointments	Carer to someone with bladder cancer	Early (Stages 0 and I) University
Participant describes the expectation that future communication will include discussions about mental and emotional health	Carer to someone with bladder cancer	Female
Participant describes the expectation that future communication will include better ability to make appointments with specialists and contact them between appointments	Invasive (Stage III) Trade or high school	University

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common theme was that participants had no recommendations or were satisfied with care received (n=15, 30.61%), and this was followed by 13 participants (26.53%) that described the expectation that future care and support will include more access to support services. Other expectations include, future care and support will include being able to connect with other patients through peer support (support groups, online forums) (n=9, 18.37%), will include more information and awareness of the condition (n=8, 16.33%), and will include mental health or emotional support (n=7, 14.29%).

Participant has no recommendations/is satisfied with care received

I think my group of people that have this condition of are as, well targeted for is any particular group. So I don't think in our case there's much it can be done, should be going to make life very much better. Apart from not having to have that kind of drastic operation in the first place. But if you've got to have it, it really is done quite well at the moment.

Participant 034_2022AUBLC

I think it's at the right place now there is information available. I know those charities are communicating with most health systems around Australia. And yes, I think the information is a lot easier to pass on and communicate.

Participant 019_2022AUBLC

Participant describes the expectation that future care and support will include more access to support services

What more can be done? I really appreciated the Cancer Council was their lawn mowing guy that came out. That was really nice. Um, yeah. So it's, you know, the country. I feel sorry for the country people because they, you know, they got three hour drive or four hour drive to come into the city for treatment. And then, you know, they got the Cancer Council, got a special, special lodge for the country people so they can, you know, stay there for the treatment, cancer treatment, which is nice. I feel sorry for the children when I was getting my radiation.

Participant 042_2022AUBLC

Well, I know, like there's some charities that support people with young patients, with families, you know, with meals and those kind of things. But for bladder cancer patients, I don't think there is anything specific like that, I'm not really sure what's available because it's not easy to find out. But, um. And I just, just in the public system. I think there's probably more things that are offered that might already exist, but I just don't know about them. But for me, I'm quite happy back at work and I don't think I need more things. And maybe, funneling into lymphedema services. If patients don't know about it so that if they've had a lot of lymph nodes out, that just for, you know prevention down the track, you know.

Participant 018_2022AUBLC

Um, I'd like to see a, some sort of a list of all the appliances and things available to people with a stoma. I mean, I do my order from this stoma society or whatever they called, and I have to do the research to find out what the hell is out there. I think there should be a list of what what is good and what it's good for. We just just found a belt that has a little protective cover in it because he could never get comfortable with a seatbelt. Now, why we didn't get offered that from day one? I don't know, because it's brilliant.

Carer 005_2022AUBLC

Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums)

Okay, well, that's an interest. Yeah. What I'd like it's been rattling around in my brain for a couple of weeks now. What I would like to see a, probably a volunteer service where where people who have actually gone through the treatments can visit hospital, people who who've either had the operation or are going to have the operation. And we can all get together and talk and they can hear basically from the horse's mouth. What what treatment is like? Put their fears at ease. You can talk to a doctor. You can talk to any professionals. But to be honest, if you haven't actually go through it yourself, um, it doesn't really mean much to be. You know, I would love to see, you know, I would put my hand up in an instant to actually talk to someone about stoma treatment. I had a lovely stoma nurse. Yes. I didn't know what the hell this thing. Suddenly was going on the stomach and what the hell it was, you know? Yes. How to manage it, you know? You know, if I could go in and talk to someone,

say, well, it's not as bad as you think. Yeah. I've been doing this for a year. Yeah. What would you go. You talk to a crisis manager all the phone. You know, do you feel that they understand you feel depressed or whatever? Yeah. So if there was some sort of service that I could give back to someone who's going to do this if I can help someone. Yeah. Which is obviously why I'm talking to you as well.

Participant 023_2022AUBLC

I think again, this Facebook group was very good, so they organised a get togethers. We think that's what you need. You know, sometimes you need to meet face to face also.

Participant 028_2022AUBLC

Um, well, you know, I think it helps people to talk about it in a, you know, like a closed group of people on Facebook or one of these Inspire sites, you know? I think that helps a lot to talk about things. And there's one where there's men only, you know, they talk about sexual problems, this stuff, you know. Yeah. It's you know, it's. Yeah, I mean, that sort of thing is good. Um. I know we had a, you know, a session with the hospital where they spoke about chemotherapy and, you know, wigs and all that sort of stuff, you know, and using cosmetics to hide the skin rashes or whatever, you know, that was helpful to a certain extent.

Participant 042_2022AUBLC

Participant describes the expectation that future care and support will include more information and awareness of the condition

I would absolutely love some more charities around bladder cancer. Obviously, my cancer is relatively rare form of cancer of the cancer as well. So no one knew about it. So I think, again, just charities just to raise money for people that are going through everything, but also just to raise awareness of what it actually is and what the side effects of what the effects are. And yeah, because people don't understand that just something so simple can have such a major impact on your life.

Participant 009_2022AUBLC

I think maybe a little bit more, I think. Yeah. A bit more information earlier on. Might might have been a bit more beneficial. Yep. Um. So, like. Uh. From the, from the cancer centre. Because even to this point, there's a lot of people that have bladder cancer, but it's it for, for whatever reason, it's not widely known. I think it just needs to be more aware. More awareness out of and, you know, maybe GPs push, push it a little bit

further because I mean, basically, what's that the the detection side of it. It's. Um. Just it's an ultrasound. I mean, it's nothing invasive about it. So there's no need for people to, to um cringe from it. So. Yeah. So maybe maybe a bit more maybe a bit more awareness that that bladder cancer actually exists?

Participant 040_2022AUBLC

I there's there's definitely not enough information out there on bladder cancer because I had no idea. How, how, how how is it that I know so much about without having without having had it or anyone had it? But how is it that I know so much about breast cancer and, you know, the pink ribbon? How is it that I know so much about prostate cancer? How is it that I know so much about Movember and mental health? You know how I'm. And how is it that I mean, nothing. Nothing, nothing, nothing. Zero. How is it that I know about prostate? I know no one in my family that have had it. But how is it that I knew nothing about bladder cancer? How I how that everything that I've had to find out has been through my own sourcing of information groups. How is it that you know. Well, that everything that I've had to find. Yeah. And now that I know that. So now I know that this month, May is Bladder Cancer Awareness Month. But I had to find that out until my husband found it, you know?

Carer 004_2022AUBLC

Participant describes the expectation that future care and support will include mental health/emotional support

I think mental support it should be in the in the package. Yeah. Like I have a nurse, a urologist, oncologist, mental support, a social worker or whatever.

Participant 005_2022AUBLC

Possibly. You know, when you get your diagnosis. A recommendation to go and talk to someone straight away would probably be very helpful. Not everyone wants to do it. You know, you people try and sort of tough it out or whatever. And I think that if if you had someone to talk to straight away, they can set some methods of dealing with such shock. Because, you know, you get this diagnosis and then you're just in a bit of a, a world of oblivion, almost. You just, really, I remember being quite vacant and just staring off into space. So I think as soon as you get a diagnosis or recommendation from, from the health professional and with direct links, go and speak to this person. Let's make a booking for you to go and see a counsellor straight away so you can start to deal with this and get some strategies in place.

Participant 014_2022AUBLC

Well, I think there should be more on the counselling or support side or even somebody just giving you a call. You know, when people are first diagnosed, maybe someone just to give them a call to say, you know, are you okay? Do you understand what it is.

Participant 010_2022AUBLC

Participant describes the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)

Yeah, I didn't really have any problems in my care. I imagine a lot of other people would have problems with attending appointments. Um, so. But then I know that I didn't avail at any stage, but I know that the LOCATION Hospital to have all sorts of support systems where you can, you know, they have a bus that will pick you up and take you for appointments, etc.. Um, I didn't, did, didn't have to avail myself of that because I either drove myself or my wife was able to and then my son was a back up on top of that again. So, um, I think those services are terribly important for some people, but that weren't for me. And then there was, there was the issue for me and for others was the issue, well, what happens if something goes wrong on Saturday night at 11:00? You know what, what, what, what what would other people do? Not me or what would I do? Um, so they. They also have a LOCATION hospital have a system there for dealing with that as well. Yeah. Um, I think that that's just so terribly important. Someone to ring and say. I'm, I'm cancer. I'm a, I'm a, I'm a bladder cancer patient, and I've got bleeding or whatever it might do. What should I do? They've got those services. They're terribly important. I didn't have to use any of them, but they did. Terribly important.

Participant 029_2022AUBLC

Um. I don't, I don't think. And maybe I, further on if my cancer recurs and and progresses may maybe I will need most I probably will need support of some sort but I just really think that. They need, I just said it just needs to be a look at the way that. a person diagnosed with cancer is treated right from the beginning. And about what? Communication and about having support. It's not even I don't even know what sort of support that someone that is prepared to talk to you, that has information and knowledge right from the beginning, rather than you just left in the dark, floundering into secretive, find your own information. And to coordinate your own care. I think all the as I have said in all the other times, that's the thing that's

missing. Even, you know, to be, you know, when when I'm at the hospital there for most of the day, some days, you're not even offered a meal or something to eat. Um. You know, just just to have had that available would be really helpful. You know, the nurse would usually get me a cup of tea afterwards, but they're running to do that. And we feel really bad that when it's been so long since you've had any fluids. Yeah. You know, you're hanging out for a drink. You know, I think it'd be really good just to have that as part of the normal type, normal part of treatment, rather than then having to do it as a special request.

Participant 002_2022AUBLC

Participant describes the expectation that future care and support will include support for side effects of treatment

Um. No, the supply and all. That's pretty good. Probably because it's, I think, based on a. It's a semi-professional sort of thing. They've got, they've got paid workers and whatever in these organisations, but you know, that's a dollar thing as well because the Government subsidises it. You basically you've only got paid postage and it's probably people who can't afford the postage, you know, it's 15 bucks a month for most people in Australia. I think it's around that price. Yeah, some people probably struggle with that little bit of extra money. I'm very, very, very pleased that the government support them because I think if you bought it, I don't know the cost but buying as an individual would be, I know with the Americans struggle a lot because they've got to and they've got their supplies where I can abide by medical advice and do the changes and all the stuff as I should do them just they live probably a little bit more professionalism in that side of. Your not 100% in some cases, some people will explain, don't seem to be very confident what they're allowed to have and what they're not. They put a magazine out, but it's not it's not spelt out. If you're a newcomer coming in, it's not there in black and white for you or as clear as it probably could be, you know.

I know. I know. I can go back to a stoma nurse, but I don't believe I should be wasting her time on that sort of, you know, it's an admin thing, you know? Yeah. Not a Nursing thing, you know?

Participant 011_2022AUBLC

Yeah, definitely. More support. More, more talk about that. More awareness and being able to, you know, bring it out in the open and, and let people know that, you know, this life is going to be different. Post bladder removal, you know, knowing what to expect,

knowing how to deal with it, you know, even maybe support groups for something like that where people can go and they can talk about it. Because I know for us personally that being affected didn't affect their marriage, but it did affect intimacy and that affects the intimacy. If it's not there, that's how you relate to one another as well. Yeah, because it then starts to affect your mental attitude and how you're feeling about yourself as a person. So I feel like there's a whopping big hole there.

2_2022AUBL

Um. No, the supply and all. That's pretty good. Probably because it's, I think, based on a. It's a semi-professional sort of thing. They've got, they've got paid workers and whatever in these organisations, but you know, that's a dollar thing as well because the Government subsidises it. You basically you've only got paid postage and it's probably people who can't afford the postage, you know, it's 15 bucks a month for most people in Australia. I think it's around that price. Yeah, some people probably struggle with that

little bit of extra money. I'm very, very, very pleased that the government support them because I think if you bought it, I don't know the cost but buying as an individual would be, I know with the Americans struggle a lot because they've got to and they've got their supplies where I can abide by medical advice and do the changes and all the stuff as I should do them just they live probably a little bit more professionalism in that side of. Your not 100% in some cases, some people will explain, don't seem to be very confident what they're allowed to have and what they're not. They put a magazine out, but it's not it's not spelt out. If you're a newcomer coming in, it's not there in black and white for you or as clear as it probably could be, you know.

I know. I know. I can go back to a stoma nurse, but I don't believe I should be wasting her time on that sort of, you know, it's an admin thing, you know? Yeah. Not a Nursing thing, you know?

Participant 011_2022AUBL

Table 9.7: Expectations of future care and support

Expectations of future care and support	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 has no recommendations/is satisfied with care received	15	30.61	7	35.00	4	40.00	3	21.43	14	31.82	1	20.00	5	29.41	10	31.25
Participant describes the expectation that future care and support will include more access to support services	13	26.53	4	20.00	2	20.00	5	35.71	11	25.00	2	40.00	3	17.65	10	31.25
Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums)	9	18.37	1	5.00	4	40.00	3	21.43	8	18.18	1	20.00	4	23.53	5	15.63
Participant describes the expectation that future care and support will include more information and awareness of the condition	8	16.33	4	20.00	0	0.00	2	14.29	6	13.64	2	40.00	3	17.65	5	15.63
Participant describes the expectation that future care and support will include mental health/emotional support	7	14.29	5	25.00	0	0.00	0	0.00	5	11.36	2	40.00	2	11.76	5	15.63
Participant describes the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	3	6.12	1	5.00	2	20.00	0	0.00	3	6.82	0	0.00	1	5.88	2	6.25
Participant describes the expectation that future care and support will include support for side effects of treatment	3	6.12	1	5.00	0	0.00	0	0.00	1	2.27	2	40.00	0	0.00	3	9.38

Expectations of future care and support	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 has no recommendations/is satisfied with care received	15	30.61	7	24.14	8	42.11	4	26.67	11	33.33	4	20.00	11	39.29
Participant describes the expectation that future care and support will include more access to support services	13	26.53	9	31.03	4	21.05	3	20.00	10	30.30	4	20.00	9	32.14
Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums)	9	18.37	4	13.79	5	26.32	4	26.67	5	15.15	4	20.00	5	17.86
Participant describes the expectation that future care and support will include more information and awareness of the condition	8	16.33	6	20.69	2	10.53	2	13.33	6	18.18	3	15.00	5	17.86
Participant describes the expectation that future care and support will include mental health/emotional support	7	14.29	5	17.24	2	10.53	4	26.67	3	9.09	3	15.00	4	14.29
Participant describes the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	3	6.12	1	3.45	2	10.53	1	6.67	2	6.06	1	5.00	2	7.14
Participant describes the expectation that future care and support will include support for side effects of treatment	3	6.12	3	10.34	0	0.00	1	6.67	2	6.06	2	10.00	1	3.57

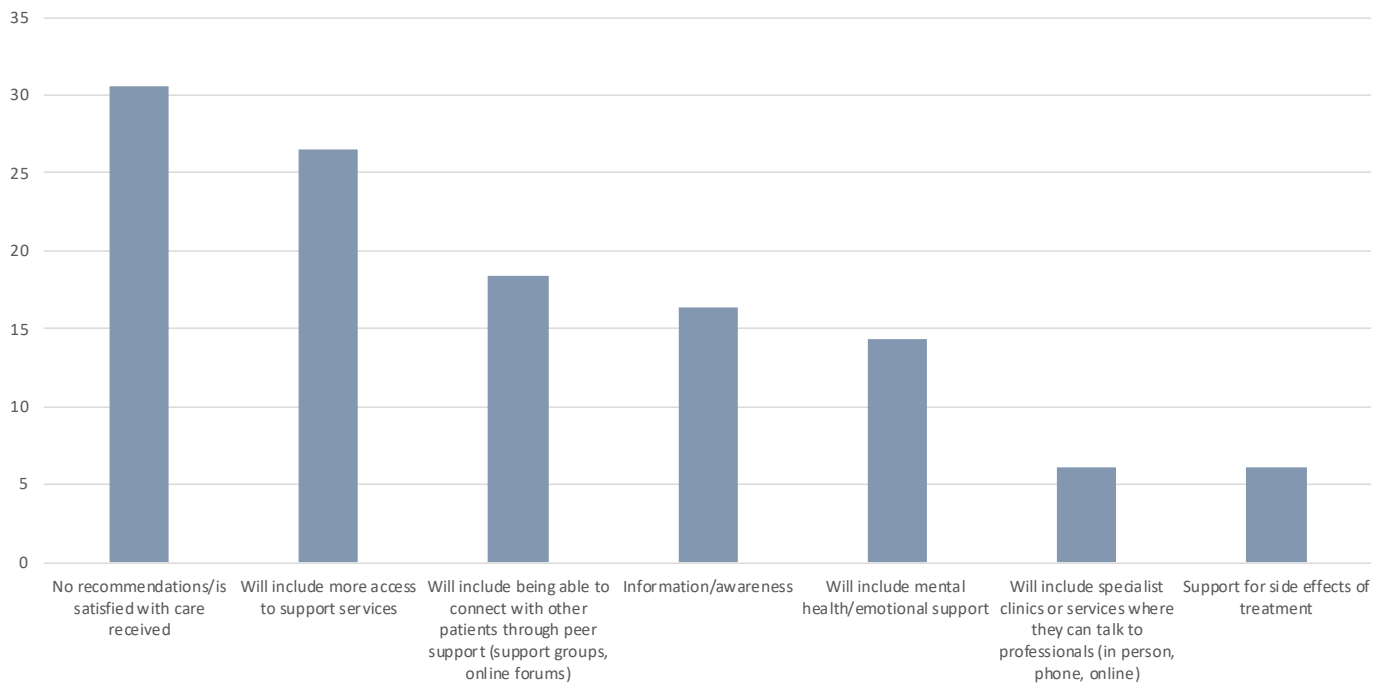


Figure 9.4: Expectations of future care and support

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

Expectations of future care and support	Reported less frequently	Reported more frequently
Participant has no recommendations/is satisfied with care received	Carer to someone with bladder cancer Mid to low status	University
Participant describes the expectation that future care and support will include more access to support services	-	Carer to someone with bladder cancer
Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums)	Early (Stages 0 and I)	Invasive (Stage III)
Participant describes the expectation that future care and support will include more information and awareness of the condition	Invasive (Stage III)	Carer to someone with bladder cancer
Participant describes the expectation that future care and support will include mental health/emotional support	Invasive (Stage III) Advanced (Stage IV)	Early (Stages 0 and I) Carer to someone with bladder cancer Regional or remote

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common theme was that participants were grateful for healthcare staff (n=22, 44.90%), and this was followed by 14 participants (28.57%) that described that participants were grateful for low cost or free medical treatments through the government, and 13 participants (26.53%) were grateful for timely access to treatment. Other participants were grateful for access to private healthcare or private insurance (n=10, 20.41%), and grateful for the entire health system (n=7, 14.29%).

Participant is grateful for healthcare staff

Well, I guess, um, I'm grateful that I haven't had to pay for the medications and the chemo and the immunotherapy drugs. I'm not sure what they cost, but I'm sure they wouldn't have been cheap. I guess I was lucky to get in as quickly as I did. So, you know,

I'm really grateful for that. And I am grateful for the nurses that are compassionate and kind and treat you like a person.

Participant 002_2022AUBLC

I'm just having. Oh, gee, I think. Yeah, I guess in the most part, having really empathic or empathetic specialists who are willing to answer questions and give clarity. Yeah. So I'm incredibly grateful to all of them.

Participant 020_2022AUBLC

I've been able to get access to some great medical specialists along the way, medical professionals, health professionals along the whole range, nursing staff all the way through the top up clinicians. So I feel grateful that I know there's other places that you can go to, don't have access to it.

Participant 035_2022AUBLC

Yeah, the oncology nurse at the HOSIPTAL. She was awesome. She was she like spoke to me two or three times before the operation. What was going to happen? Like explain the whole how long will it be in hospital for how long the operation was going to be for. And, you know, she found, I think her name was NAME. I found her really good. She explained everything like two or three times. So you knew what what procedure you were going to be happening to. You go to hospital. I think it was the day before the operation and she came in. I was having operation on Tuesday morning and she came up to me Monday afternoon and she explained, well, I went and seen her like I think it was two or three weeks before, a week beforehand I had had the pre-op and I went and had an interview with NURSES NAME and she explained the whole system what was going to happen, you know, like this will happen. You got to have a pick line and you'll stay overnight, you have a drip and then you have the operation would be 7 or 8 hours. And she said, you could end up in intensive care, but you said 9 times out of 10 you won't. But yeah, she she was really good. I found it. She explained the whole whole procedure

Participant 044_2022AUBLC

Participant is grateful for low cost/free medical treatments through the government

Oh yes, definitely. And I think yeah, I totally agree with that. The clinic that I go to, my local public hospital, which is a big one. Um to have that, the all the chemotherapy treatments have been wonderful. All I've had to pay for there is the medication which everyone should be able to afford. It was not prohibitive. And so, yeah, that's the main thing, I think. And, you know, there was no there's I like the fact that this I mean, I've paid to a health fund, but I like the fact that there's no demarcation between, you know, the rich and the poor there. It's just everyone. That's where you go for your chemotherapy. Yeah. Whereas things like radiotherapy, you know, there are private places you can have it sooner because you've got the money to pay for it. And that's what we all like to see our health system that treats people fairly no matter what the financial circumstances.

Participant 010_2022AUBLC

The hospital care. It was just incredible, really. Okay, like, I again had never experienced being hospitalised and it was a massive operation. Um, you know, um, just their care was incredible, like out of this world stuff out and nothing was ever too difficult. So, yeah, I found that to be really, really great. Um, I think the

bulk billing, um, through my GP and for my CT scans and things like that, that's been really good. Um, yeah, I think they, they really help in that, um, you know, financial sense.

Participant 022_2022AUBLC

The main thing is the cost to you know and I know people, they lose their life savings in other countries. Once you have it, it's not a cheap treatment, you know, and if I had to pay I would be, you know, I have no more, you know, I don't know how to pay it. I don't have that money.

Participant 028_2022AUBLC

Participant is grateful for timely access to treatment

Oh, okay. Well, that's that's a no brainer because, after having come back from COUNTRY to be honest, if I'd have been there. And I'm not the I'm not the downtreading in my my country of origin, but I'd probably still be bloody waiting for the operation.

Participant 023_2022AUBLC

Yeah just the level of care and the speed that they've go me into surgeries and there are multiple times the nurses the doctors everyone's been amazing in the fact that I haven't paid for it. It's just, you know, it's it's unbelievable. So no, I wouldn't anything. Everything's been a fantastic.

Participant 024_2022AUBLC

Yeah, so I guess what I've been grateful for is because I know like during COVID and as I'm on this Facebook group in Australia even that there was limited access to BCG and we never experienced that. We were lucky. So if, if I'm aware that if you can't get access to BCG and it's chemo which comes with a whole other bunch of side effects. So I'm very grateful for that. But he does hope has always going to have access to BCG.

Carer 003_2022AUBLC

The fact that we have private medical insurance, I think I'm very grateful that that we have that ability to have it and we can get treated immediately. Immediately. Yes. That's incredible. Right. And and having a second opinion, you know, being able to go to HOSPITAL and have a relatively, you know, a reasonable timeframe to get a second opinion. I think that's been fantastic finding, you know, having. I think that there should be a patient database. This should be a patient influenced database of doctors. So, you know. So I should be able to go on my. Go on. Get on to saying that, you know, 3000 patients have have recommended this specialist or. You know, I said there

should be a database of of doctors and specialists and that that patients have actually rated.

Carer 004_2022AUBLC

Participant is grateful for access to private healthcare/private insurance

Oh, just all of it. God, you know. I think we're right. We're very, very lucky. And I mean, I am I am also fortunate enough that I can have private health care as well. I can afford private healthcare. For how much longer? I'm not sure of it

Participant 004_2022AUBLC

Oh, I'm very grateful to my GP and how quick she dealt with. I'm grateful for my urologist, very patient with me and very clearly explaining things. The nurses so far are very caring and supportive and. And yeah, there's an advantage of private health system you're in there with in no time, because on a Tuesday I went to my GP Wednesday ultrasound. The next Tuesday I was with my urologist and on Friday it was in theatre. So yeah. Yeah. You don't have much time to think. And two weeks later I was back again. Because there was a bit of cancer found in my ureter. Also, I have to go back again. Okay. And in hindsight, they should have put a stent in there, but that's always in hindsight then it wouldn't have. That's a lot of drama that came after that. But, uh, yeah. It's but the. The thing with the cancer, I, um. They can treat it, but not cure it. And that's my eye opener. And. Yeah. That's the hardest thing, I think.

Participant 005_2022AUBLC

I think I was very fortunate to be able to continue on with BCG because I understand that there were shortages and the powers that be within the hospital system made sure that there was always some for me, which was because I got quite anxious. I mean, even though I hated it, I knew that I had to have it and they were talking about shortages. And then at one point my urologist said, she said, Oh, we might stop you

now. And I was like, No, that's not that's too soon. I don't want to stop now. And he said, Oh, well, that's up to you then. And he made sure that there was BCG available. So I think in other countries that may not have been the case, but I think the big thing was I am very, very lucky that I had private health insurance because I think to have gone to a general hospital might have been quite a different situation. I probably would have got a different nurse every time, probably got male nurses and maybe been told that the BCG was unavailable for me with. Whereas, I had the same people who were, you know, reliably in place every time I went, which was reassuring and the BCG was available. So yeah, I think Australia, it wasn't Medicare, it was my private insurance that gave me that support really. But living in Australia certainly helped.

Participant 036_2022AUBLC

Participant is grateful for the entire health system

Yeah just the level of care and the speed that they've go me into surgeries and there are multiple times the nurses the doctors everyone's been amazing in the fact that I haven't paid for it. It's just, you know, it's it's unbelievable. So no, I wouldn't anything. Everything's been a fantastic.

Participant 024_2022AUBLC

All, all of it. Yeah. I think we're very, very lucky here. M,y you look at America. Very different there. Yeah, we're very lucky, very, very fortunate here. And, um. Yeah. Looking back, I was grateful for all of that. I just wish that all of what he went through could have saved his life. That's all.

2_2022AUBLC

Oh, being grateful for it all, to be honest, it saved his life. So that's fine with me and some of the I mean, the chemotherapy nurses were just outstanding, they were just so empathetic and lovely.

Carer 005_2022AUBLC

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

What participants are grateful in the health system	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 is grateful for healthcare staff	22	44.90	8	40.00	6	60.00	6	42.86	20	45.45	2	40.00	9	52.94	13	40.63
Participant is grateful for low cost/free medical treatments through the government	14	28.57	6	30.00	5	50.00	3	21.43	14	31.82	0	0.00	5	29.41	9	28.13
Participant is grateful for timely access to treatment	13	26.53	7	35.00	2	20.00	2	14.29	11	25.00	2	40.00	5	29.41	8	25.00
Participant is grateful for access to private healthcare/private insurance	10	20.41	3	15.00	2	20.00	4	28.57	9	20.45	1	20.00	7	41.18	3	9.38
Participant is grateful for the entire health system	7	14.29	3	15.00	1	10.00	1	7.14	5	11.36	2	40.00	1	5.88	6	18.75

What participants are grateful in the health system	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 is grateful for healthcare staff	22	44.90	12	41.38	9	47.37	7	46.67	14	42.42	9	45.00	12	42.86
Participant is grateful for low cost/free medical treatments through the government	14	28.57	8	27.59	6	31.58	4	26.67	10	30.30	4	20.00	10	35.71
Participant is grateful for timely access to treatment	13	26.53	7	24.14	6	31.58	5	33.33	8	24.24	6	30.00	7	25.00
Participant is grateful for access to private healthcare/private insurance	10	20.41	4	13.79	6	31.58	2	13.33	8	24.24	2	10.00	8	28.57
Participant is grateful for the entire health system	7	14.29	6	20.69	1	5.26	3	20.00	4	12.12	4	20.00	3	10.71

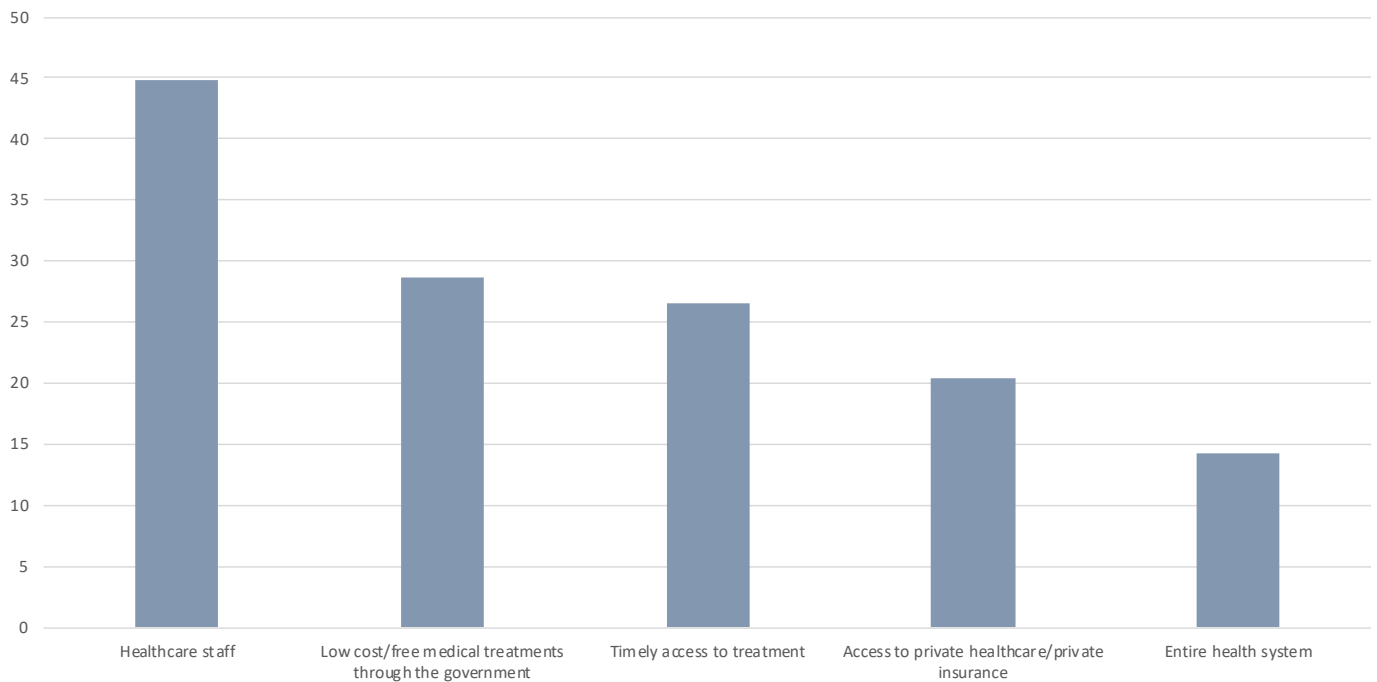


Figure 9.5: What participants are grateful for in the health system

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

What participants are grateful in the health system	Reported less frequently	Reported more frequently
Participant is grateful for healthcare staff	-	Invasive (Stage III)
Participant is grateful for low cost/free medical treatments through the government	Carer to someone with bladder cancer	Invasive (Stage III)
Participant is grateful for timely access to treatment	Advanced (Stage IV)	Carer to someone with bladder cancer
Participant is grateful for access to private healthcare/private insurance	Male	Female
Participant is grateful for the entire health system	Mid to low status	University
Participant is grateful for the entire health system	-	Carer to someone with bladder cancer

Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, where 1 is the most important and 11 is the least important. A weighted average is presented in Table

9.11, Figure 9.6. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important aspects reported were pain, nausea and vomiting and, diarrhoea. The least important were hair loss and, mouth ulcers.

Table 9.11: Symptoms and aspects of quality of life

Symptoms and aspects of quality of life	Weighted average (n=42)
Pain	7.10
Nausea and vomiting	6.62
Diarrhoea	4.55
Tiredness and Fatigue	4.17
Loss of appetite	3.93
Constipation	3.40
Hair loss	3.24
Mouth ulcers	3.00

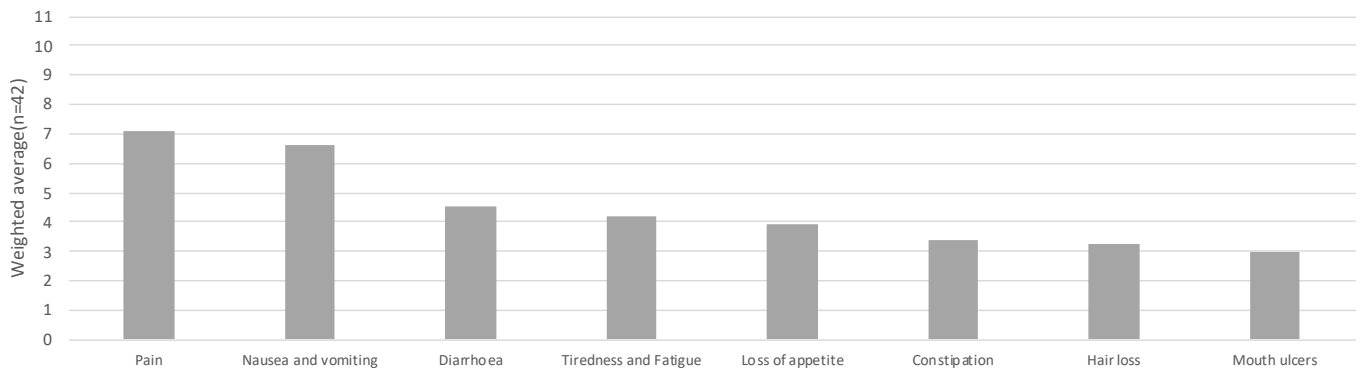


Figure 9.6: Symptoms and aspects of quality of life

Values in making decisions

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

The most important aspects were “How safe the medication is and weighing up the risks and benefits”, and “The severity of the side effects”. The least important were “Ability to follow and stick to a treatment regime” and “The financial costs to me and my family”.

Table 9.12: Values in making decisions

Symptom	Weighted average (n=47)
How safe the medication is and weighing up the risks and benefits	7.00
The severity of the side effects	6.83
Time impact of the treatment on my quality of life	5.70
How the treatment is administered	3.55
How personalised the treatment is for me	4.19
The ability to include my family in making treatment decisions	3.53
Ability to follow and stick to a treatment regime	2.62
The financial costs to me and my family	2.57

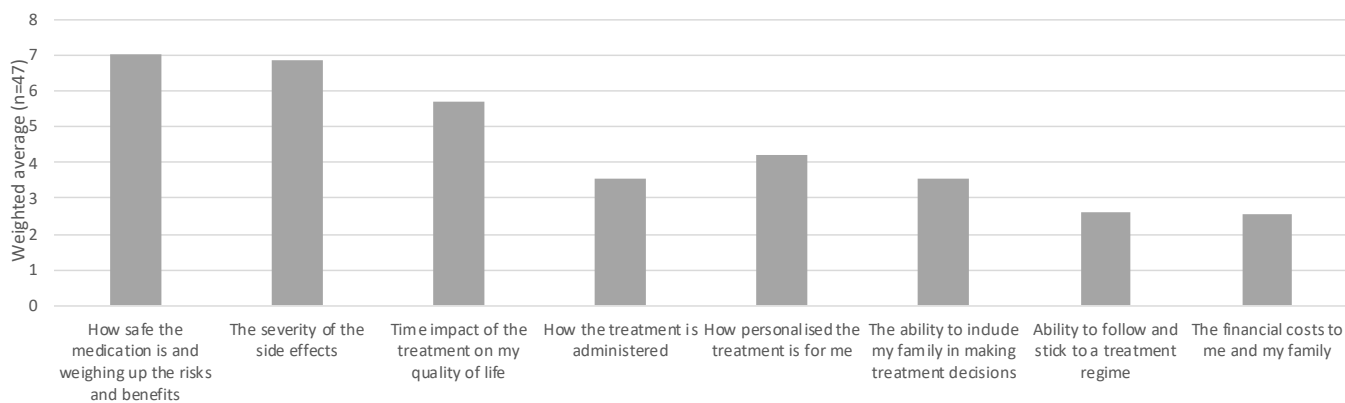


Figure 9.7: Values in making decisions

Values for decision makers

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

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

Table 9.13: Values for decision makers

Values for decision makers	Weighted average (n=47)
Economic value to government and tax payers	1.36
Economic value to patients and their families	2.57
Quality of life for patients	4.40
Compassion	2.91
All patients being able to access all available treatments and services	3.74

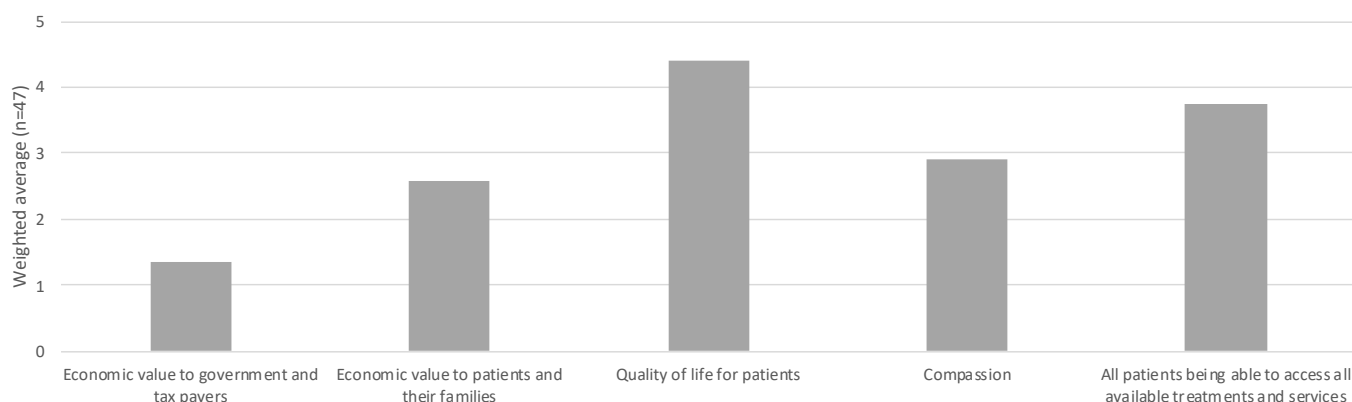


Figure 9.8: Values for decision makers

Time taking medication to improve quality of life

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

The most commonly participants would use a treatment for more than 10 years for a good quality of life even if it didn't offer a cure (n = 17, 36.17%), followed by less than a year (n=14, 29.79%), and between 1 and 5 years (n=12, 25.53%) (Table 9.14, Figure 9.9).

Table 9.14: Time taking treatment to improve quality of life

Time taking medication to improve quality of life	Number (n=47)	Percent
Less than 1 year	14	29.79
1 to 5 years	12	25.53
5 to 10 years	4	8.51
More than 10 years	17	36.17

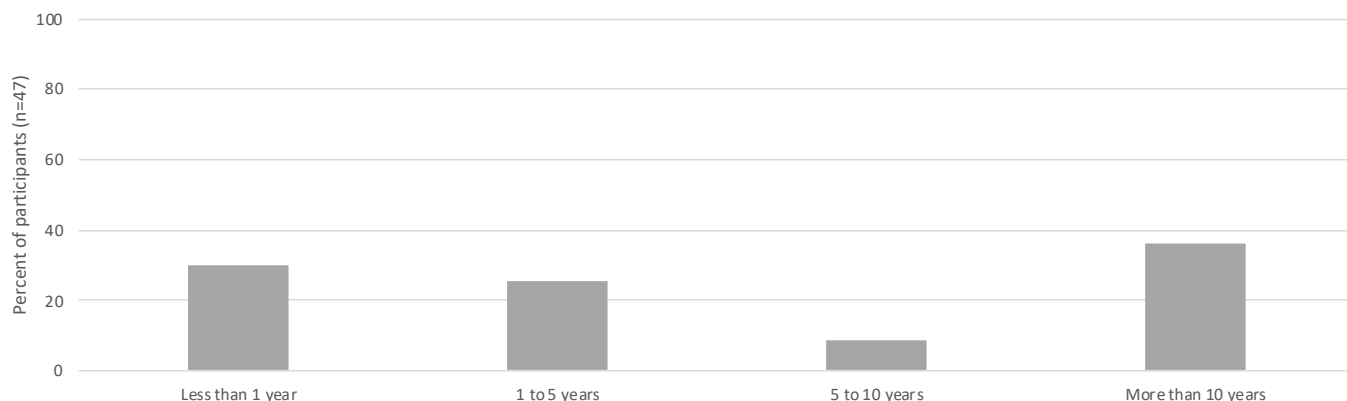


Figure 9.9: Time taking treatment to improve quality of life

Messages to decision-makers

Participants were asked, “If you were standing in front of the health minister, what would your message be in relation to your condition?” The most common message was to help raise community awareness (n=16, 32.65%). This was followed by that they are grateful for the healthcare system and the treatment that they received (n=11, 22.45%), to invest in screening or early detection (n=7, 14.29%), to improve access to support and care (n=7, 14.29%), and to be compassionate and empathetic (n=6, 12.24%).

Participant's message is to help raise community awareness

Oh, I would say. So I'm very thankful for all the treatment and care I've had. It's not, bladder cancer it's not massively common, but it's not uncommon, I think this 3000 cases a year. And I think an awareness campaign needs to be almost like a bowel cancer thing where. You know, you do a routine check or something like that just to see. Um. Because, you know, I got onto it early and I'm probably very lucky. Other people have probably thought, yeah, a bit of blood in urine will go away. And it did, you know, I had it for one day and then there's nothing I could have left it and thought nothing of it. Thought that my body had fixed itself. So if I was to talk to the Health Minister, I would decide an awareness. Not just of, you know, breast cancer and bowel cancer, but. You know, and heart disease. But of. Yeah. Are they all cancers, really? Yeah. I mean, I didn't even know about bladder cancer till I had it.
Participant 014_2022AUBLC

I think there needs to be more stoma nurses available, and I think that they need to be available 24/7. So whether there's a hotline or that sort of thing, and it probably doesn't warrant at the numbers of patients, but in comparison to other cancers and that sort of thing. But I think it's important to people that have experienced it to have easy access to a stoma nurse. I would probably. Now the Ostomy Association's pretty good. The fact that all of our supplies are covered by Medicare is excellent. Forgot to mention that, your supplies are really, really good. I pay something like \$60 a year membership for the Ostomy Association. Then pay for delivery. And that's it. So very lucky in that respect. Hmm. Yeah. I think that's about that's what I you know, this stoma nurses the availability of stoma nurses. And the other thing is awareness. I mean, okay, I know that's not really relevant to the question of if I was standing in front of the health minister, that's what I'd be pushing for, for awareness. Like, it's Bladder Cancer Awareness Month and the only things I see coming out from bladder cancer organisations or charities.
Participant 022_2022AUBLC

Excuse me. To, um I guess they put more funding. You know, there's a lot of talk about funding certain kinds of cancers. So I suppose the message would be to, fund bladder cancer. I'm not sure how how it's not really talked about. We hear about lung cancer. We hear about breast cancer. But there's not so much awareness of bladder cancer. So of us want him to do something to increase the awareness and also to, um, excuse me, to, to alert people to the symptoms of of

bladder cancer because they kind of creep up on you, you know, the obvious.

Participant 043_2022AUBLC

Participant's message is that they are grateful for the healthcare system and the treatment that they received

I'd have to shake his hand and say, well, pretty good at the moment. Yeah. Yeah. I certainly as I said this morning, a couple of negatives. But I think, you know, enables knowing that things are only minor irritation and more than you know you know, there's 5% of problems and 95% positivity. You know, you don't do much better than that most things in life

Participant 011_2022AUBLC

Oh, I have to tell you that I've been extremely satisfied with the system and with how I have been treated at HOSPITAL and I've been in other hospitals, which I regard to HOSPITAL as probably the best hospital I've ever been in, and I've been in a lot of hospitals with various injuries playing sport and that sort of thing. So. Yeah, I would have to say the treatment, I can't fault, except I have had a couple of minor things which I've already mentioned about the aftercare. When you are in a procedure in a bit of consultations after your procedure, it would would help that apart from that. You know, it's not a drama. When I've been in there and waited for seven or 8 hours to be done, I spent a day with people who have gone off their heads, about have to wait so long to get my head around it and that I've just got to sit there and wait, read the paper or something of it. Some people do have short tempers. I've seen medical staff go up to them and say, do you realise you have all this treatments for nothing. And that sort of shut them up pretty quick. So anyway, that treatment no dramas, it's been no problems at all really.

Participant 021_2022AUBLC

I'd say it's perfect, to be honest. That's just the way the system is designed. I mean, again, just based on my experience. Yes. Just everything's done methodical way. And the fact is, I didn't have to pay for pretty much any of it is just phenomenal. So I wouldn't change a thing. I think it's perfect.

Participant 024_2022AUBLC

Participant's message is to invest in research (including to find new treatments)

I think I would just go right to the root, which is to me, okay, it's not a sexy cancer, but you need to give it more funding. It's just it's just not it's not good enough that certain cancers that celebrities have are given far more money and far more airtime. It's it's got to be more funded and as in more research and just also picked up on at an earlier stage those things. I mean, especially with men, they tend to although men tend to ignore things like that. And unfortunately, as women, much as they might not ignore it, it tends to be more aggressive in women.

Participant 010_2022AUBLC

Okay. For the bladder cancer? Yeah. Yeah, please. Spend more money for research. We need a cure.

Participant 015_2022AUBLC

They created this specific bladder cancer centre and all research is being done with that. Also, they have a massive database, so all kinds of that kind of research and and do with that because lots of research is only short term. But if you have a big database, you can have data over 20 years or whatever. But they, they keep all the samples. Yeah. And you can study it for, for all kinds of things. And now you have to go for everything, everywhere and everybody. It would be handy if you have one stop. It's also there. When you enter there it's one stop and that's the end of the day. You know everything and make your plan and treatment.

Participant 005_2022AUBLC

Participant's message is to invest in screening/early detection

I don't know. I think I only what I'd said earlier that the the detection, early detection would be paramount. And that could save a lot of costs in the health system further down the line. And possibly also that Australia should look at um switching the market for BCG because um it nearly got wiped out. Uh, one of the years I was having it the whole, the. It's a, it's, it's grown from, I think from potato or something. It's the thing they treat tuberculosis with regularity.

Participant 006_2022AUBLC

Um. Hmm. If we were able to have more choices for types of treatment. Let's get them here. Let's have them here. Make them available. It's important and the other thing is, like I said to you earlier on, is um making bladder cancer one of the cancers is up there

with all the others. And I just, you know, screening. Can we get screening? Is there any available screening for early diagnosis of bladder cancer? If there is, why can't that be? You know, rolled out like the bowel cancer screening and the breast cancer screening. That's important. I think that's a big one. That's important if it is a possibility. Let's make it a possibility. Let's have bladder cancer screening if that's what it takes. Urine tests. I mean, urine test from a certain age. I don't know. Yeah. So those. Yeah, I think just. Just the. Anything that would help promote awareness and early diagnosis. Yes.
Carer 002_2022AUBLC

What would be my message to him? My message to him would be that, you know, make be educated and aware of the warning signs and and react. Because early diagnosis saves lives. So that would be my first message to him. And you know, the GP shouldn't be so hesitant. You know, when, when you keep getting blood to send you for an initial scan. And my second message would be that I've been really lucky that I've been able to afford my the cost of my treatment. But robotic surgery is, you know, said that treatment I had had had was really wonderful in speeding up my recovery. And, you know, we should look at making that available to all, not just the ones that can afford to pay the additional costs associated with it. Okay.
Participant 032_2022AUBLC

Participant's message is to improve access to support and care

I think they need more like, more information, more support, more access to doctors, and more access outside the regular scheduled appointments or to the whole team, the urology team.
Participant 016_2022AUBLC

Oh, that's a big one. Um, I think, that probably there needs to be more support because people with bladder cancer, what goes on in their homes when they're trying to deal with it is huge. And I think once, especially if they get into the situation where they have muscle invasive cancer, bladder cancer, which I was fortunate that I didn't, what goes on with that? As with any cancer, it's the needs to be more care offered, more in-home treatments and definitely more financial support to people in that situation. But I'm a little bit remote from all that because, my was all handled okay. But I would push for definitely more support in home, you know, because if you're on your own and you had muscle invasive and you were being

on chemotherapy, I think it would be absolutely awful to have to try and cope with it on your own.
Participant 036_2022AUBLC

Participant's message is to be compassionate and empathetic

The staff in general. Thank you very much for doing an excellent job. Keep showing empathy and keep treating your patients as family members and friends and, surgeons, watch Patch Adams, read about Patch Adams.
Participant 019_2022AUBLC

PARTICIPANT: Well, now that's an interesting one. Firstly, I'd be really a I feel quite angry towards the authorities because they only take on the popular cancers, the popular ones that attract the funding. And so for the politicians to be popular, they give all the funding of research to things like brain cancer, breast cancer, cervical cancer, bowel cancer. And so I was really quite shocked when I found out that bladder cancer even existed. And even more shocked when I found that I really aren't very interested in it because it's not politically expedient for them to pay attention to it. So I'd probably tell him off.

INTERVIEWER: Hmm. I'm guess this is why the CCCR are doing this and why you're like this thing in to, like, the government know more about this, like the cancer they are not aware of.

PARTICIPANT: Yes. Yes. Because of end of day cancer's, cancer, when somebody gets it, they don't want to be either a group that feels cared for, a group that feels ostracised. They just want to know what's the best thing. And I think the way it's presented and through the press too, it's not presented very well at all. It's it's almost like bladder cancer. Is that the it's the the black sheep that you shouldn't talk about. I Mean, it's not obviously, but that's how we seem to present it.
Participant 020_2022AUBLC

No just that the system needs to have compassion and consideration for the people, that they're not numbers and as much as possible the systems support support them during their journey. To some people, that would be a daunting journey, understanding what's happening to them. So having having health professionals that can explain things in a layman's terms and set things out. I mean, I, I've had so many tests and things like that, I can understand where people would be completely bamboozled by, you

know, what they're got to do next week and whether they got it passed or whether they've got to, you know, psychologies or whatever, they've got to do that. The horrible thing for them and know it, you know, they need to have somebody following them. And if they get sick and they don't follow the you know, they they need to take a whole range of medicine and things like that. It's even worse.
Participant 029_2022AUBLC

Participant's message is to invest in professional development so that clinicians understand the condition

Uh, I guess mine would be more of that health education that patients need to go to tertiary centres to, you know, real experts in the field. And perhaps they need to train more of them because there's not that many. I don't actually know how many urology oncologists there are in Australia, but they're certainly concentrated in the big cities and your outcomes very much depend on who does your surgery. So I guess my message would be train more, more experts and educate people about signs and symptoms and perhaps have more comprehensive, holistic management within the hospitals. But I think really they do a pretty good job now. With what they do. Yeah. And he's sort of far removed from it probably doesn't really take much notice of the little plebs like us, but I guess more training of specialist surgeons. I guess we were lucky. Yeah. And it's a rare cancer, so they'd probably think it was a waste of money to put money into a rare cancer. I don't know.
Participant 018_2022AUBLC

I'd be saying to make sure that everybody is provided with the full information. I mean, I can only talk about my case ,and my case. In the end it was non-muscle invasive. It hasn't metastasised. So it is quite different to those other people. So for me it was a much more straightforward situation. And I suppose the other thing that I would try and get someone to to look at is to ensure that doctors follow up properly. I went through probably a couple of months to a doctor who was so busy, so busy turning over the patients that she, I think, was neglectful in providing me with the treatment or the information I needed. I was horrified when I discovered that I had bladder cancer after being going to her week after week after week and never got sent for any tests. Take take antibiotics and you know, blood in the urine. That is not normal and it wouldn't have hurt her to send me somewhere to get it checked, which is what the second doctor did. So I think the health professionals, doctors should be I'm

assuming, they should be more aware of what what to, what to do for people who present with those symptoms. Not treat them like a hypochondriac.
Participant 003_2022AUBLC

Participant's message is to improve healthcare professional communication and information given to patients

No discrimination. There should be a lack of discrimination on services that are available to people with bladder cancer as opposed to any other cancer. That would be number one. Number two, get a training package together that would assist patients who have been diagnosed with bladder cancer to get the information from a not just a you know, there has to be an auditory as well as a visual presentation of what's happening to them. And what they should be expecting from, you know, depending on what their diagnosis is, they say they should be a they should be a visual and auditory presentation, not something that just to be read, to get all the best information and it needs to be regularly updated. And so that people have can make informed decisions about their choices of treatment, not to neglect alternate therapies, because right now, alternative therapies get no mention because there's no studies being done on who survives these alternative treatments.
Carer 004_2022AUBLC

I think they need more like, more information, more support, more access to doctors, and more access outside the regular scheduled appointments or to the whole team, the urology team.
Participant 016_2022AUBLC

Participant's message is to employ more healthcare professionals, especially specialists and nurses

Well, I think it would be to spend a lot less money on football stadiums and a lot more money on hospital equipment. I mean, that seems to be one of the weaknesses. Is that we seem to be short of doctors, nurses and medical equipment, for the size of the the population that we have, but it's still one of the best in the world and we're still some of the luckiest people. Minister, get rid of some of those useless people that you got in there costing a fortune and start spending some money on where it counts.
Participant 034_2022AUBLC

PARTICIPANT: Yep. We need more doctors in the outpatients, cause they were just run off their feet.

INTERVIEWER: Right a wait for 3 hours.

PARTICIPANT: And get your operation. All right. As a follow up, you have to wait and hang around. So if he had I think it's more doctors or better care after just for the follow up

Participant 013_2022AUBLCL

Participant's message is that treatments need to be affordable

I think the fact that it's got to see, you know cancer full stop. Why why are people in this country with the healthcare system we have. Why are people required to to dig into their pocket? To solve cancer treatment in this country. Yeah. Yeah. That was the whole inequity thing, you know, the massive differences between public and private. Why is that the case in this country? When you talk about cancer, you're not talking about some discretional operation.

Participant 017_2022AUBLCL

What would be my message to him? My message to him would be that, you know, make be educated and aware of the warning signs and and react. Because early diagnosis saves lives. So that would be my first message to him. And you know, the GP shouldn't be so hesitant. You know, when, when you keep getting blood to send you for an initial scan. And my second message would be that I've been really lucky that I've been able to afford my the cost of my treatment. But robotic surgery is, you know, said that treatment I had had had was really wonderful in speeding up my recovery. And, you know, we should look at making that available to all, not just the ones that can afford to pay the additional costs associated with it. Okay.

Participant 032_2022AUBLCL

Participant's message is that they need to increase funding for specialist nurses

I think there needs to be more stoma nurses available, and I think that they need to be available 24/7. So whether there's a hotline or that sort of thing, and it probably doesn't warrant at the numbers of patients, but in comparison to other cancers and that sort of thing. But I think it's important to people that have experienced it to have easy access to a stoma nurse. I would probably. Now the Ostomy Association's pretty good. The fact that all of our supplies are covered by Medicare is excellent. Forgot to mention that, your supplies are really, really good. I pay something like \$60 a year membership for the Ostomy Association. Then pay for delivery. And that's it. So very lucky in that respect. Hmm. Yeah. I think that's about that's what I you know, this stoma nurses the availability of stoma nurses. And the other thing is awareness. I mean, okay, I know that's not really relevant to the question of if I was standing in front of the health minister, that's what I'd be pushing for, for awareness. Like, it's Bladder Cancer Awareness Month and the only things I see coming out from bladder cancer organisations or charities.

Participant 022_2022AUBLCL

Well, I'd say make it more aware. Mm hmm. And have an ostomy nurse: Sorry. Sorry. A stoma nurse. In every private hospital and public hospital in the state of STATE. Because I walk. If I were to walk from here. If I go from here to, let's say, to LOCTION, the treatment I get from a stoma nurse in LOCATION is not going to be the same as I get from a stoma nurse in this urban situation.

Participant 037_2022AUBLCL

Table 9.15: Messages to decision-makers

Message to decision-makers	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's message is to help raise community awareness	16	32.65	6	30.00	2	20.00	6	42.86	14	31.82	2	40.00	6	35.29	10	31.25
Participant's message is that they are grateful for the healthcare system and the treatment that they received	11	22.45	4	20.00	5	50.00	2	14.29	11	25.00	0	0.00	2	11.76	9	28.13
Participant's message is to invest in research (including to find new treatments)	10	20.41	4	20.00	2	20.00	3	21.43	9	20.45	1	20.00	5	29.41	5	15.63
Participant's message is to invest in screening/early detection	7	14.29	3	15.00	0	0.00	2	14.29	5	11.36	2	40.00	3	17.65	4	12.50
Participant's message is to improve access to support and care	7	14.29	2	10.00	1	10.00	3	21.43	6	13.64	1	20.00	4	23.53	3	9.38
Participant's message is to be compassionate and empathetic	6	12.24	2	10.00	2	20.00	2	14.29	6	13.64	0	0.00	0	0.00	6	18.75
Participant's message is to invest in professional development so that clinicians understand the condition	4	8.16	2	10.00	1	10.00	1	7.14	4	9.09	0	0.00	3	17.65	1	3.13
Participant's message is to improve healthcare professional communication and information given to patients	4	8.16	3	15.00	0	0.00	0	0.00	3	6.82	1	20.00	2	11.76	2	6.25
Participant's message is to employ more healthcare professionals, especially specialists and nurses	4	8.16	2	10.00	0	0.00	1	7.14	3	6.82	1	20.00	2	11.76	2	6.25
Participant's message is that treatments need to be affordable	3	6.12	1	5.00	0	0.00	2	14.29	3	6.82	0	0.00	2	11.76	1	3.13
Participant's message is that they need to increase funding for specialist nurses	3	6.12	0	0.00	1	10.00	2	14.29	3	6.82	0	0.00	1	5.88	2	6.25

Message to decision-makers	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's message is to help raise community awareness	16	32.65	11	37.93	4	21.05	6	40.00	9	27.27	8	40.00	7	25.00
Participant's message is that they are grateful for the healthcare system and the treatment that they received	11	22.45	7	24.14	4	21.05	3	20.00	8	24.24	5	25.00	6	21.43
Participant's message is to invest in research (including to find new treatments)	10	20.41	5	17.24	5	26.32	3	20.00	7	21.21	2	10.00	8	28.57
Participant's message is to invest in screening/early detection	7	14.29	5	17.24	2	10.53	3	20.00	4	12.12	2	10.00	5	17.86
Participant's message is to improve access to support and care	7	14.29	3	10.34	4	21.05	2	13.33	5	15.15	4	20.00	3	10.71
Participant's message is to be compassionate and empathetic	6	12.24	4	13.79	2	10.53	1	6.67	5	15.15	3	15.00	3	10.71
Participant's message is to invest in professional development so that clinicians understand the condition	4	8.16	1	3.45	3	15.79	0	0.00	4	12.12	1	5.00	3	10.71
Participant's message is to improve healthcare professional communication and information given to patients	4	8.16	2	6.90	2	10.53	2	13.33	2	6.06	4	20.00	0	0.00
Participant's message is to employ more healthcare professionals, especially specialists and nurses	4	8.16	2	6.90	2	10.53	1	6.67	3	9.09	2	10.00	2	7.14
Participant's message is that treatments need to be affordable	3	6.12	1	3.45	2	10.53	0	0.00	3	9.09	0	0.00	3	10.71
Participant's message is that they need to increase funding for specialist nurses	3	6.12	3	10.34	0	0.00	1	6.67	2	6.06	1	5.00	2	7.14

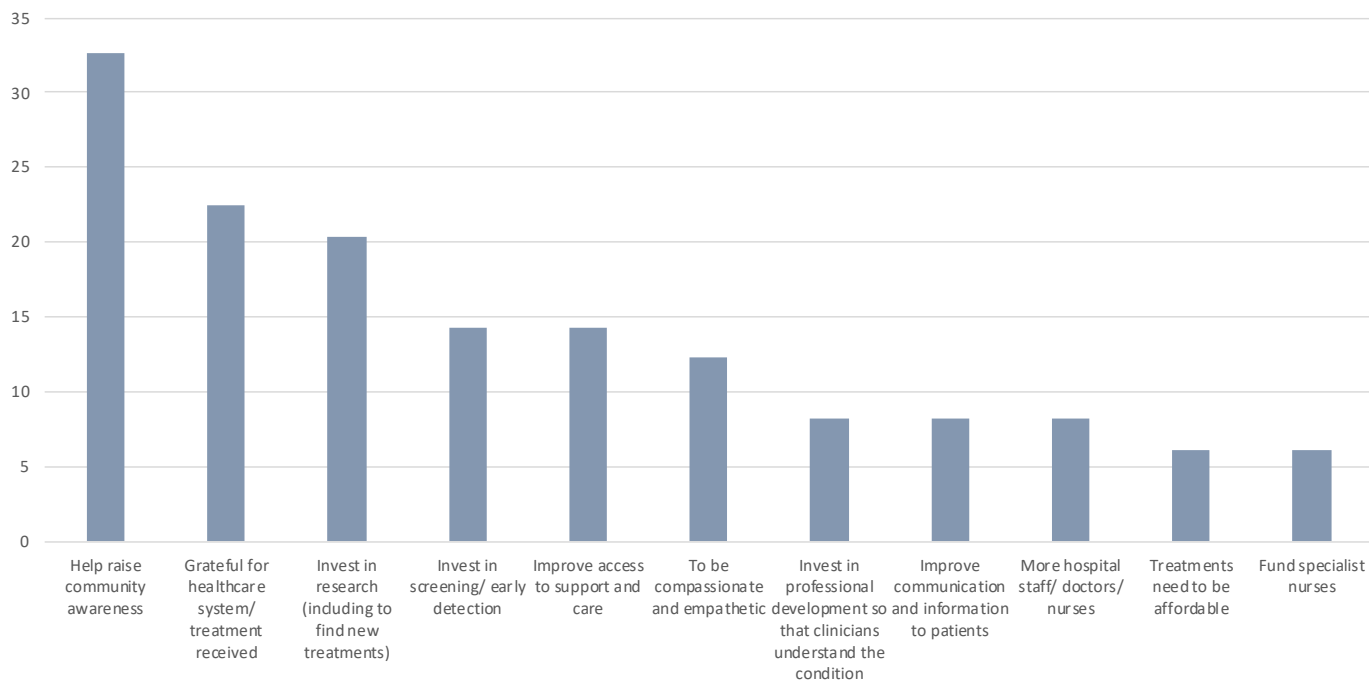


Figure 9.10: Messages to decision-makers

Table 9.16: Messages to decision-makers – subgroup variations

Message to decision-makers	Reported less frequently	Reported more frequently
Participant's message is to help raise community awareness	Invasive (Stage III) University	Advanced (Stage IV)
Participant's message is that they are grateful for the healthcare system and the treatment that they received	Carer to someone with bladder cancer Female	Invasive (Stage III)
Participant's message is to invest in research (including to find new treatments)	Mid to low status	-
Participant's message is to invest in screening/early detection	Invasive (Stage III)	Carer to someone with bladder cancer
Participant's message is to improve access to support and care	-	-
Participant's message is to be compassionate and empathetic	Carer to someone with bladder cancer Female	-