Section 6

Information and communication

Section 6: Information and communication

Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common type of information accessed by 41 participants (83.67%) was the internet in general, this was followed by accessing information through a bladder cancer charity (n=32, 65.31%), and through other patient's experience (n=24, 48.98%). Other participants described accessing information from books, pamphlets and newsletters (n=16, 32.65%), through treating clinician (n=13, 26.53%), through international sources (n=13, 26.53%), through Facebook and/or social media (n=9, 18.37%), and through journals (research articles) (n=8, 16.33%).

Where participants mentioned specific health charities, these were most commonly BEAT Bladder Cancer Australia (n=19, 38.78%), Cancer Council (n=18, 36.73%), and Bladder Cancer Awareness Australia (n=5, 10.20%).

Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be *most* helpful. The most common type of information found to be helpful by 16 participants (32.65%) was information from health charities. There were 14 participants (28.57%) that described information from other people's experiences as helpful, and 14 participants (28.57%) that described hearing what to expect (e.g. from disease, side effects, treatment) as being helpful. Other types of information described as being helpful included treatment options (n=10, 20.41%), talking to their doctor or specialist (n=8, 16.33%), information specific to their condition (n=8, 16.33%), and information about stoma management or from their stoma nurse (n=7, 14.29%).

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. There were 22 participants (44.90%) that responded that no information was not helpful, and 7 participants (14.29%) that were confident in deciding if something is not helpful (or not credible). The most common type of information found to be unhelpful by 9 participants (18.37%) was from their GP or specialist, this was followed by worse case scenarios (n=5, 10.20%), and a lack of information in general, and lack of community awareness as not helpful (n=5, 10.20%).

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. Overall, the most common theme was talking to someone plus online information (n=17, 34.69%), followed by talking to someone (n=14, 28.57%), online (n=14, 28.57%), and written information preference (n=11, 22.45%).

The main reasons for a preference for online information were accessibility, being able to digest information at their own pace, and finding personalised or relevant information. The main reasons for talking to someone as a preference were being able to ask questions, get personalised or relevant information, and feeling supported. The main reason for written material as a preference was being able to refer back to it.

Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common time that participants described being receptive to receiving information after the shock of diagnosis (n=18, 36.73%), this was followed by participants describing being receptive to information from the beginning when diagnosed (n=13, 26.53%), after the start of treatment (n=9, 18.37%), and continuously throughout their experience or bit-by-bit so that it is digestible (n=9, 18.37%). Other participants described being receptive to information after they have had time to learn about condition/thought about questions to ask their healthcare professional (n=7, 14.29%), and a month after diagnosis (n=5, 10.20%).

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having an overall positive experience (n=22, 44.90%). There were 13 participants (26.53%) that described an overall positive experience, with the exception of one or two occasions, 9 participants (18.37%) that had an overall negative experience and 4 participants (8.16%) that had an overall negative experience.

Healthcare professional communication (Rationale for response)

Participants described reasons for positive or negative communication with healthcare professionals.

Participants that had positive communication, described the reason for this was because of holistic, two-way, supportive and comprehensive conversations (n=18, 36.73%), and this was followed by participant describing good communication with no particular reason given (n=17, 34.69%).

The main reasons for negative communication was limited communication that was not supportive, or empathetic (n=10, 20.41%), that information about treatment being withheld or given too late (n=8, 16.33%), and was limited in relation to their understanding of the condition (n=6, 12.24%)

Partners in health

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 scales; knowledge, coping, recognition and treatment of symptoms, adherence to treatment and total score. A higher score denotes a better understanding and knowledge of disease.

The **Partners in Health questionnaire (PIH)** measures an individual's knowledge and confidence for managing their own health.

The **Partners in health: knowledge** scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. On average, participants in this study had very good knowledge about their condition and treatments.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in this study had a good ability to manage the effects of their health condition.

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average participants in this study had a very good ability to adhere to treatments and communicate with healthcare professionals.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average participants in this study had very good recognition and management of symptoms.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average participants in this study had a good overall knowledge, coping and confidence for managing their own health.

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options (n=38, 80.85%), disease management (n=23, 48.94%), disease cause (n=22, 46.81%), and physical activity (n=16, 34.04%) were most frequently given to participants by healthcare professionals, and, information about complementary therapies (n=3, 6.38%), how to interpret test results (n=3, 6.38%) and, hereditary considerations (n=0, 0.00%) were given least often.

Information searched independently

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. The topics participants most often searched for were treatment options (n=28, 59.57%), disease cause (n=26, 55.32%), disease management (n=21, 44.68%) and, how interpret test results (n=18, 38.30%) were most frequently searched for independently and, information about physical activity (n=13, 27.66%), clinical trials (n=10, 21.28%), and hereditary considerations (n=7, 14.89%) were searched for least often.

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were hereditary considerations (n=40, 85.11%) and clinical trials (n=33, 70.21%).

The topics that participants did not search for independently after receiving information from healthcare professionals were treatment options (n=22, 46.81%) and disease Cause (n=12, 25.53%).

The topics that participants were given most information from both healthcare professionals and searching independently for were treatment options (n=16, 34.04%) and disease management (n=12, 25.53%).

The topics that participants searched for independently after not receiving information from healthcare professionals were how to interpret test results (n=17, 36.17%), and disease cause (n=14, 29.79%).

Most accessed information

Participants were asked to rank which information source that they accessed most often, where 1 is the most trusted and 4 is the least trusted. Across all participants, information from Non-profit organisations, charity or patient organisations and the hospital or clinic where treated. Information from Pharmaceutical companies were least accessed.

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 16 participants (33.33%) had accessed My Health Record.

Of those that had accessed My Health Record, there were 11 participants (68.75%) who found it to be poor or very poor, 4 participants (25.00%) who found it acceptable, and 1 participant (6.25%) who found it to be good or very good.

Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common type of information accessed by 41 participants (83.67%) was the internet in general, this was followed by accessing information through a bladder cancer charity (n=32, 65.31%), and through other patient's experience (n=24, 48.98%). Other participants described accessing information from books, pamphlets and newsletters (n=16, 32.65%), through treating clinician (n=13, 26.53%), through international sources (n=13, 26.53%), through Facebook and/or social media (n=9, 18.37%), and through journals (research articles) (n=8, 16.33%).

Where participants mentioned specific health charities, these were most commonly BEAT Bladder Cancer Australia (n=19, 38.78%), Cancer Council (n=18, 36.73%), and Bladder Cancer Awareness Australia (n=5, 10.20%).

Participant describes accessing information through the internet in general

Um, I've unfortunately been best friends with Dr. Google. I do a lot of research on my own, um, because, honestly, I don't get much information from my care providers. Um, but basically I was just more looking for information on my type of cancer. Um, what? You know, the life expectancy after five years and, you know, all those kind of questions that you need to know to ease the mind.
Participant 009_2022AUBLC

Um, yeah. When I was first diagnosed, I just googled and went from there. Found a support group on social media, spoke to the Cancer, Cancer Council, and it just went from there.
Participant 033_2022AUBLC

Yeah. Yeah. I think that, you know, they, you know, they're always saying, you know, don't don't go searching information, you'll get wrong information and stuff. But I think that. I think that you have to do that anyway. I think that I think it's good to do that because at least, you know, you look at the worst case scenarios, you look at options, and you do learn a lot by just searching. Um. You know, because doctors don't tell you that much. And you know, they might give you a couple of pamphlets still, still don't answer your questions. So if you didn't do a bit of research yourself and I like to do the research and get my head around what the problem is and. But yeah, I know lots of people that don't like to do that. So so I think we just all do what we need to do.
Participant 026_2022AUBLC

Participant describes accessing information from a specific health charity

So my wife very quickly found this BEAT bladder cancer dot org website. I think it's an association that has been my primary source. They have everything laid out. They've got videos from urologists that explains all the things. Great online resources. Cancer Council STATE, which seems just a broader part of Cancer Council, have got great documents, really simple to read 50 page booklets on what it means to have bladder cancer, all the different types dealing with telling your kids, dealing with the sexual side or the impact on the sex life around those sort of things. We've also joined this support group that I've talked about, which is, again, an extension of the BEAT Bladder Cancer Association. And I've also joined a couple of different Facebook groups that are support groups where people post how they're going or challenges they're having or just what are people have done when this fork in the road, you know, getting that sort of again, that peer feedback from other people.
Participant 017_2022AUBLC

Mostly from the Internet. Um, mostly I'm answering this in reverse, mostly from Cancer Council literature, both here and, and some of the American stuff and the British stuff. So it's yeah, it's usually the internet that I find out information from.
Participant 006_2022AUBLC

PARTICIPANT: Yeah, I, I sought all sorts of information. I did find fairly early on them BCAN forum, which is, which is um, in America. But they they get people from all over the world sort of asking questions and and contributing. And that's reasonably good. Then at the end of 2019, I found the BEAT bladder cancer group and also the bladder Cancer Australia with another organisation. I think it's more based in Melbourne and the BEAT especially has been wonderful because they have, you know, much about BEAT?.

INTERVIEWER: No, I don't. Sorry.

PARTICIPANT: Okay. So BEAT is an organisation that was strung out as a family's losses. Their 45 year old mother died of bladder cancer. They she had two

young children, very similar. Very similar, although the children are a bit older. And I think she was a bit older than Jane McGrath, but certainly a similar scenario. And her husband then started a charitable organisation in her memory to to sponsor the recognition of bladder cancer because it's such an unknown cancer. And BEAT stands for bladder cancer Education, Awareness and Treatment. So and they started off with meetings at Macquarie University Hospital once a month. So I went to a couple of those and then of course COVID hit. So yeah, they changed to having Zoom meetings. And the good thing about that is, of course, once they spread, tried to spread, that the awareness of the existence of this group and people from all over Australia tuned in and joined and it's been very, very beneficial to all these people. They are, they're very, become a very cohesive, supportive group in every way it should be here.
Participant 010_2022AUBLC

Participant describes primarily accessing information through other patient's experience

Yeah. It's actually quite a lot. I suppose. When you have a medical condition, you tend to get close minded about it and the whole universe sort of circles around your own condition. But I imagine that that applies to every condition that you can think or, you know, some that from an itchy nose to a stubbed foot. The um, I don't think there's any real. Just try to think of that. Well. There is a tremendous wealth of knowledge that I have found in and my wife, found through the relevant associations of this condition. And I imagine all conditions having an association somewhere. It's usually buried as part of the council. The Cancer Council umbrella. There's a lot of different types of cancers and different types of associations with them, of course, and there's really so much information out there that you just can't handle it, or even if it's there, if you need it. And it has proved very useful. Particularly useful at the outset when you first, when you first contemplating whether to have the operation or not. Getting online to people that have had it is a big plus. It really does give you some inspiration. Both for then and later. And I think something that probably applies to all forms of cancer, you know, it's like bonding, I guess, and bonding that other people go through.
Participant 034_2022AUBLC

Mainly the bladder council. There was some information on that. The BEAT support group where they have as I said to you, they have guest speakers, in fact, just on Tuesday night was a fantastic guest speaker. It was a urologist from Macquarie University Hospital, I think, and he spoke for 40 minutes about BCG and I learnt so much about BCG, this far down the track. And then after. they've had a guest speaker, they've had a physiotherapist come that was also good that had the histologist come, a whole lot of things. And then they have a roundtable conversation where. Perhaps somebody that's new and they're on the Zoom meeting for the first time and are being told that they need to have their bladder removed and they want to ask who here has, had the bladder removed, and they'll get feedback from various members that have been through that experience. So that's been really good. But as I say, also really scary because you see the worst case scenarios and then, just Google. I've had, no I think I got given a bit of a one page leaflet from the urologist on bladder cancer that just talked about the treatment for BCG. But that's been it really it. The nurses were too busy to really talk to you at great length.
Participant 036_2022AUBLC

Well, we actually funny enough, my daughter came to me and she said, Mum, I found these girls in Melbourne whose father passed away from bladder cancer and they'd really like to talk to you. So, anyhow, long story short, they run a support service of Bladder Cancer Australia. And so we join that support group, and we have been out on a few functions with them and met quite a few different members. And we just came back from a retreat in February with them all. And it was really nice to hear everybody's stories and meet them. And their quality of life and what kind of treatments they've had and everyone was just so different.
Carer 001_2022AUBLC

Participant describes receiving information from books, pamphlets and newsletters

Really, the only information I mean, as I said, I was given pamphlets before the BCG treatment about what to expect. Um, but really the only information I've had is from looking on the internet . And I also am part of the Facebook group Bladder Cancer Awareness Group. So I joined up so pretty early, this about six months after I was diagnosed. So I haven't had any other information.
Participant 025_2022AUBLC

So my wife very quickly found this BEAT bladder cancer dot org website. I think it's an association that has been my primary source. They have everything laid out. They've got videos from urologists that explains all the things. Great online resources. Cancer Council STATE, which seems just a broader part of

Cancer Council, have got great documents, really simple to read 50 page booklets on what it means to have bladder cancer, all the different types dealing with telling your kids, dealing with the sexual side or the impact on the sex life around those sort of things. We've also joined this support group that I've talked about, which is, again, an extension of the BEAT Bladder Cancer Association. And I've also joined a couple of different Facebook groups that are support groups where people post how they're going or challenges they're having or just what are people have done when this fork in the road, you know, getting that sort of again, that peer feedback from other people.
Participant 017_2022AUBLC

The Cancer Council of course, I got a , which you'll know about, you know, the booklet they've got, which is very good. Um, there's a lot of stuff online, I believe, from reputable sources that, that I, uh, I read a lot of that stuff. They tell you the same sort of thing. So, and it doesn't, it doesn't say anything about, you, it says something about, you know, what the cancer is about and what stages and that sort of thing. So it doesn't really give you an answer for you how long, you know, you're going to be around. Yeah. The other thing which was important was I got an invite to join BEAT, B.E.A.T, bladder something I can't remember what it is called which is run by clinical and uh, other people. And it's a sort of self-help talk. Zoom. Zoom meetings.
Participant 029_2022AUBLC

Participant describes primarily accessing information through treating clinician

Um, basically the internet. But, um, you know, she just looking at what a stoma actually was. Um, we found out a lot of information from the actual specialist regarding the neobladder, because that is what he specialises in. More so than removal, than the stoma. But just looking at side effects and what the what the possibility. If I had to have radio radiotherapy or chemotherapy.
Participant 027_2022AUBLC

Uh, we got a whole heap of information. Um, but we did a bit of research on the net. Um. As far, as muscular invasive bladder cancer, when our urologist gave us a couple of pamphlets to read up on to start with. Um. And, uh. And then when we had our interview. With one of the nurses at the renal unit in the HOSPITAL, she gave us a lot more information abou. bladder cancer, and neo bladder and all that kind of stuff. So, we were, we were pretty sure at that point roughly about what was what was coming up.
Participant 040_2022AUBLC

Well, the information, the information that I received was from Doctor NAME, he gave me papers 2 papers, a few sheets of paper to explain what would happen and what the options were for this operation. Um, I didn't look on Google, but lots and lots of people do apparently, because I think that can be can probably cause more anxiety than it's worth, but then hopes. And he explained to me the options or what would have to happen.
Participant 043_2022AUBLC

PARTICIPANT In general, it just would have been the health professionals that gave us booklets, bladder cancer booklets. I sourced a lot of my information from my bladder cancer support group.

INTERVIEWER Online.

PARTICIPANT Online yes. That was the main thing, really. And asking the questions like I guess with the professionals when we're at appointments, I'd always write things down, put them in a book, write them down and take notes and. Yeah.
Carer 002_2022AUBLC

Participant describes accessing information primarily through international sources

Okay. So so basically the information I sought out since diagnosis was the Understanding Bladder Cancer booklet, which is a Cancer Council booklet. There really wasn't a lot of rest for bladder cancer for Australians. So, you know, there was no Australian website to go to. So we looked at the overseas websites. I mean I'm not sure when I, you know, in the few weeks I had to make this decision, I was up to joining a support group. But I mean, that's that's a fabulous resource. And looking back on it now, it would have been good if I'd known that there was one. Well, not not not face to face one, but it would have been good to have been able to think about asking some questions there. So basically the information I have sought out is, you know, information on neobladders and what other people do and how they manage with them.
Participant 032_2022AUBLC

I've got. I guess sort of a science background. So I would just look for medical journals and use those as the point of reference, and basic government stuff. And that's okay. And the American stuff. The British stuff for bladder of cancer is probably better than the American, and recommended by the urologist as well,

so that was good. Recommended such confirmed. And, generally speaking, there's only a few good reports, or journal articles on BCG in the last probably five years or ten years or whatever. Most of them are quite specific, but just general ones about the efficacy of BCG and stuff like that. There's some good ones, so I'd read those, understand what it was about as best I could, not getting too scientific about it, but just understanding likely success on how it works as best people can describe it.
Participant 030_2022AUBLC

Participant describes accessing information primarily through Facebook and/or social media

Um, yeah. When I was first diagnosed, I just googled and went from there. Found a support group on social media, spoke to the Cancer, Cancer Council, and it just went from there.
Participant 033_2022AUBLC

Just what's on Google and what's been on Facebook. My surgeon doesn't want me to use Facebook. He wants me to be on the bladder cancer sites. He said to me, they make people depressed and they make them more worried. And he's, that's your opinion. You know, he's just sort of against social media, but he's worried about it for me to hear everyone's negative stories about losing their bladders and things. And he said it's in his opinion, it's not good for your emotional well-being.
Participant 001_2022AUBLC

Mainly government. So it's just to try and get a bit of independence as opposed to, you know, I know the pharmaceutical companies develop the products and things, but this tends to make it more of a sales pitch. So I've gone to mainly independent organisations, cancer councils and things like that and government sponsored websites just to try and get a bit more of a, an independent view of it. And then yeah, as I say, a couple of the support groups that, that I'm on. One support group on the on Facebook, there's a sort of Australia-New Zealand bladder cancer support group just sort of saying, yeah, what other people have done and are doing and all of that.
Participant 014_2022AUBLC

Participant describes accessing information primarily through journals (research articles)

Um, well, I got very little from the hospital. I got all the information, that's true, Googling through medical journals, through the BEAT bladder cancer website and support group. Um. That's probably where I've got most of my information. The bladder, called BCAN , which is American based. Web site for this sort of thing. I've done a lot of, I am a HEALTHCARE PROFESSIONAL, so I do it to different medical journals to try and get urology journals to try and get whatever information is available.
Participant 002_2022AUBLC

Well, I like looking at them. Well, general searches on the Internet at the Mayo Clinic in America. Find the, their information is very good. I didn't know that they existed until I actually had a blood test. And the person who gave me a blood test, the pathology collector, had bladder cancer herself. She was the one who gave me the information about it. So then I looked up that group that the like the Bladder Cancer Society or whatever they are, what comes under the Cancer Council, whoever they are. Yeah. Um, uh, I've got access to some databases, so I've looked at some academic articles about BCG treatment and you know, because that gave me reassurance that a lot of people, not a lot, but quite a few people find it too difficult to continue BCG
Participant 008_2022AUBLC

I've got. I guess sort of a science background. So I would just look for medical journals and use those as the point of reference, and basic government stuff. And that's okay. And the American stuff. The British stuff for bladder of cancer is probably better than the American, and recommended by the urologist as well, so that was good. Recommended such confirmed. And, generally speaking, there's only a few good reports, or journal articles on BCG in the last probably five years or ten years or whatever. Most of them are quite specific, but just general ones about the efficacy of BCG and stuff like that. There's some good ones, so I'd read those, understand what it was about as best I could, not getting too scientific about it, but just understanding likely success on how it works as best people can describe it.
Participant 030_2022AUBLC

Table 6.1: Access to information.

Access to 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 describes accessing information through the internet in general	41	83.67	17	85.00	9	90.00	12	85.71	38	86.36	3	60.00	14	82.35	27	84.38
Participant describes accessing information from a specific health charity	32	65.31	15	75.00	5	50.00	8	57.14	28	63.64	4	80.00	12	70.59	20	62.50
Participant describes primarily accessing information through other patient's experience	24	48.98	8	40.00	5	50.00	8	57.14	21	47.73	3	60.00	9	52.94	15	46.88
Participant describes receiving information from books, pamphlets and newsletters	16	32.65	4	20.00	3	30.00	7	50.00	14	31.82	2	40.00	7	41.18	9	28.13
Participant describes primarily accessing information through treating clinician	13	26.53	6	30.00	1	10.00	4	28.57	11	25.00	2	40.00	6	35.29	7	21.88
Participant describes accessing information primarily through international sources	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 accessing information primarily through Facebook and/or social media	9	18.37	7	35.00	0	0.00	2	14.29	9	20.45	0	0.00	5	29.41	4	12.50
Participant describes accessing information primarily through journals (research articles)	8	16.33	4	20.00	0	0.00	2	14.29	6	13.64	2	40.00	3	17.65	5	15.63

Access to 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 describes accessing information through the internet in general	41	83.67	25	86.21	16	84.21	13	86.67	28	84.85	18	90.00	23	82.14
Participant describes accessing information from a specific health charity	32	65.31	19	65.52	12	63.16	10	66.67	21	63.64	13	65.00	18	64.29
Participant describes primarily accessing information through other patient's experience	24	48.98	14	48.28	10	52.63	5	33.33	19	57.58	10	50.00	14	50.00
Participant describes receiving information from books, pamphlets and newsletters	16	32.65	8	27.59	8	42.11	5	33.33	11	33.33	4	20.00	12	42.86
Participant describes primarily accessing information through treating clinician	13	26.53	8	27.59	5	26.32	5	33.33	8	24.24	6	30.00	7	25.00
Participant describes accessing information primarily through international sources	13	26.53	9	31.03	3	15.79	3	20.00	9	27.27	5	25.00	7	25.00
Participant describes accessing information primarily through Facebook and/or social media	9	18.37	4	13.79	5	26.32	4	26.67	5	15.15	4	20.00	5	17.86
Participant describes accessing information primarily through journals (research articles)	8	16.33	3	10.34	5	26.32	3	20.00	5	15.15	4	20.00	4	14.29

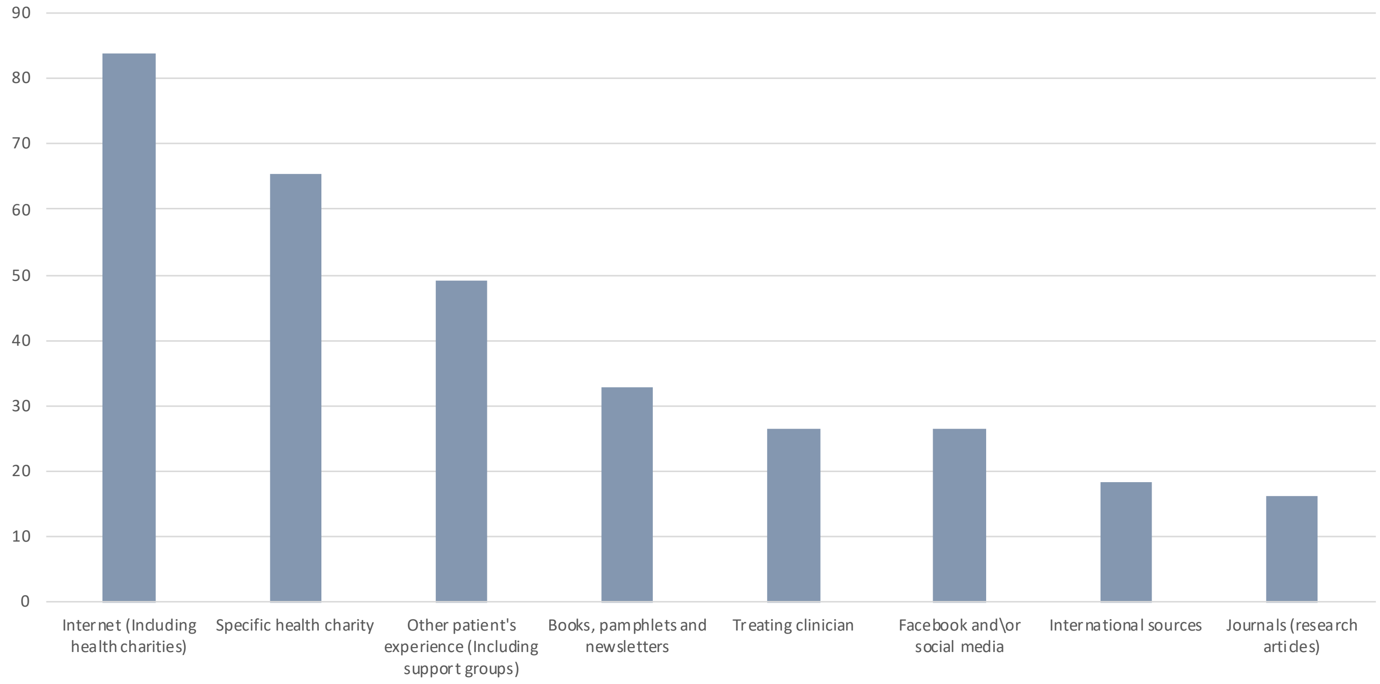

Figure 6.1: Access to information

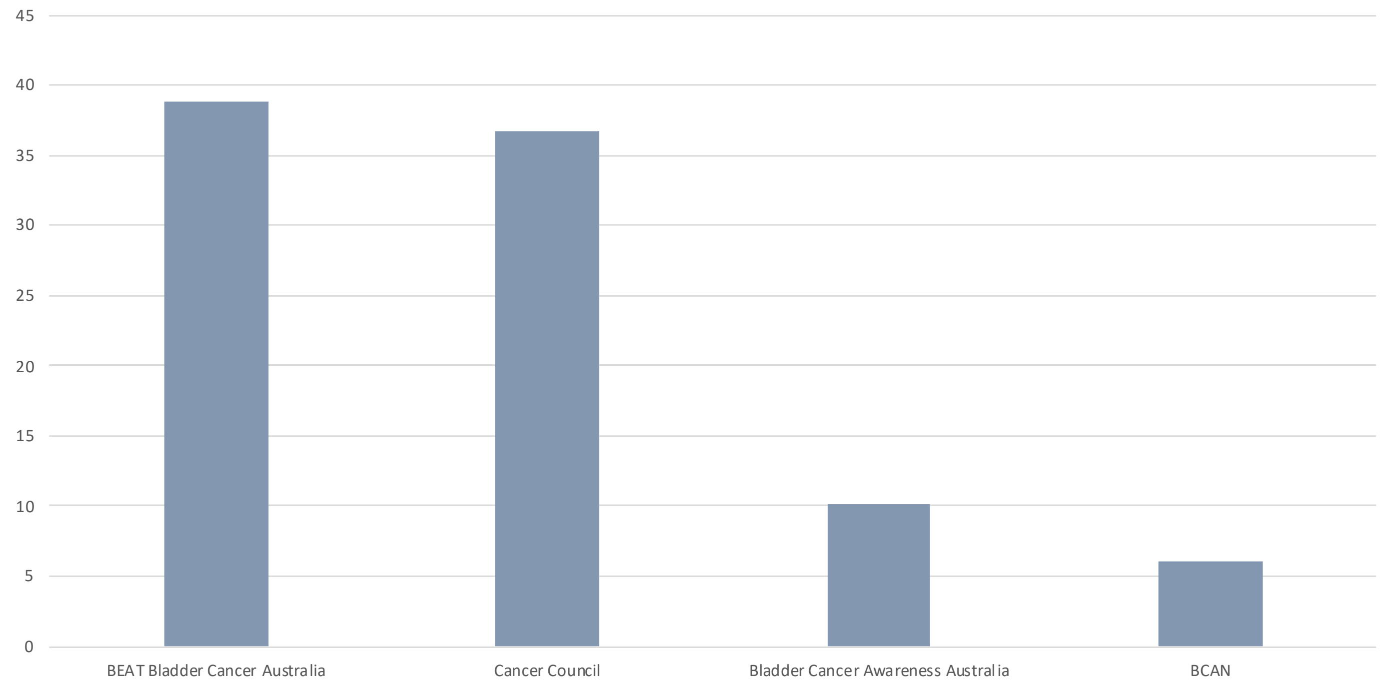

Figure 6.2: Specific charities

Table 6.2: Access to information – subgroup variations

Access to information	Reported less frequently	Reported more frequently
Participant describes accessing information through the internet in general	Carer to someone with bladder cancer	-
Participant describes accessing information from a specific health charity	Invasive (Stage III)	Carer to someone with bladder cancer
Participant describes primarily accessing information through other patient's experience	Regional or remote	Carer to someone with bladder cancer
Participant describes receiving information from books, pamphlets and newsletters	Early (Stages 0 and I) Mid to low status	Advanced (Stage IV) Higher status
Participant describes primarily accessing information through treating clinician	Invasive (Stage III)	Carer to someone with bladder cancer
Participant describes accessing information primarily through international sources	Carer to someone with bladder cancer University	-
Participant describes accessing information primarily through Facebook and/or social media	Invasive (Stage III) Carer to someone with bladder cancer	Early (Stages 0 and I) Female
Participant describes accessing information primarily through journals (research articles)	Invasive (Stage III)	Carer to someone with bladder cancer

Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be *most* helpful. The most common type of information found to be helpful by 16 participants (32.65%) was information from health charities. There were 14 participants (28.57%) that described information from other people's experiences as helpful, and 14 participants (28.57%) that described hearing what to expect (e.g. from disease, side effects, treatment) as being helpful. Other types of information described as being helpful included treatment options (n=10, 20.41%), talking to their doctor or specialist (n=8, 16.33%), information specific to their condition (n=8, 16.33%), and information about stoma management or from their stoma nurse (n=7, 14.29%).

Participant describes health charities information as helpful

> *Um, I've just found just the booklets from the Cancer Council. I've just found that they have been excellent information sources. Um, but because it just depends like every, night, like I have random thought and they kind of answer my questions like, you know what I mean? Like there's always an answer somewhere on the Cancer Council website.*
> *Participant 009_2022AUBLC*

> *PARTICIPANT: Ah, probably the information from the BEAT support group. Mm hmm. Yep. Yeah. Okay. It is formal and informal because they have like they have the monthly get togethers where they'll often have, you know, an expert, but they also have discussion with other patients and things like that. And so that's been very useful. Yeah.*

INTERVIEWER: So it's at the same time like for information but also for like support group, right?

PARTICIPANT: Correct. People who've been through what you've been through and can give you tips and encouragement. Support as well. Yep, yep, yep.
Participant 016_2022AUBLC

PARTICIPANT: Uh, I think BEAT bladder cancer, the support group has been. The most. I got the most information from and also from the people, the experience. I think that that's the most helpful one.

INTERVIEWER: So what type of information? Bladder cancer provide you? Yeah.

PARTICIPANT: Uh, it's more the mental side about it and how other people's journeys are.
Participant 005_2022AUBLC

Participant describes other people's experiences as helpful (Peer-to-peer)

Basically I think what I got from the forums from the Facebook pages. Hmm. And that's very helpful to me, to be honest. Putting your mind at rest and just sort of want to stay on top of it and understanding what's what's going to happen. You know what I'm going to go through
Participant 011_2022AUBLC

Well, I've received information. What has been the most helpful? Um. Well, I think, um. Well, I suppose back to the other question. So now I'm involved in the, in the support group. So, um, I mean, that's been very helpful to me, other people that, I mean, it's just been fabulous to meet other people that have, that no longer have their bladder and to meet other females that have neobladders. You know, and just be able and around my age. So that's been fabulous to to do that that's been incredibly helpful and to hear about their journey and and and discuss it, you know, compared to my journey. And so that's been that's been fabulous. Um. Um, you know, just reading some, you know, some more, some more information about bladder cancer and, and the different treatment has also been helpful. Even some of the information about clinical trials so that, you know, if it does recur, what's what's next, you know?
Participant 032_2022AUBLC

Possibly that I know that, you know, like, I rang a few people before I had my radical cystectomy and, you know, the guy said, you know, that they've, they've got through it, okay. And yeah, one guy goes climbing mountains and I know another guy ride motorbikes and he said that he got back on his bike, you know, like he's riding bikes. So after the, after the surgery, you can still yeah, I was worried about not being able to do a lot of the activities I used to do before, but yeah. So then I found that I've been able to do most of the things that I could do before my operation
Participant 044_2022AUBLC

Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful

Basically I think what I got from the forums from the facebook pages. Hmm. And that's very helpful to me, to be honest. Putting your mind at rest and just sort of want to stay on top of it and understanding what's what's going to happen. You know what I'm going to go through
Participant 011_2022AUBLC

The plain English way that these documents have been written to kind of go, this is what it means. This is this is, you know, really, really simple to read. Like, I gave it to my 76 year old mother and said, read this. This will tell you all about what I've got, you know, really simple, digestible guide. So, like, all information about like, you know, what does it mean to be high grade or non-invasive? And, you know, what is BCG, talks about what is BCG, how its administered, you know, just all of that sort of broken down into. And it's you can almost see that when you read all this stuff and then the doctor goes, will be doing this. I'm going, Yeah, you're just following the textbook, you know, because it seems to me, for me at this point, it's a very textbook protocol. You can almost second guess what the doctor's going to say next, and yet you are just ticking off the next thing on the on the court, as you said, the decision tree type thing. I'm sure it gets trickier once we go to BCG and, you know, potential implications. But but right now, it seems to be, you know, even the fact that it says, you know, you're going to go and get a CT scan or probably do an ultrasound start. Yeah, tick, tick, tick. So it's been it's been very easy to follow it. It's almost like paint with numbers know. But it's that type of thing where, you know, I guess you're kind of following a recipe here. And it's it's I guess it's comforting to kind of know, well, he's not off the reservation with what he's doing. It seems to be very simple in terms of, you know, what he's prescribing is the next thing. This is the urologist lines up with the literature that I've been provided, but he didn't provide any of that directly. I think he provided one document, a link to a document, but he was very dismissive of, you know, the support group type things or the opinions of those guys. Yeah. The

only people that go into those, the ones that got the problems right and it's couldn't be further from the truth. In general it is people inspiring others with their experiences. That may be good or otherwise, but it's very inspirational and very uplifting. His view was when I was going, if people are going well, no one talks about it online. It's only people that aren't going well. Well, that's not actually true. Maybe you need to spend 5 minutes in these forums and understand they're not quite what you think they are. So he was a bit dismissive of that. So again, done most of my own research. He probably hates it because we quite often will send him a link to kind of something and go.
Participant 017_2022AUBLC

I think the Cancer Council booklet and also the the beat the two initial meetings where I found out about, you know, people with bags and other other other issues, what that actually meant with their daily life and their journeys, journeys with cancer. Some of them weren't able to receive BCG treatment at all because they were in states where it was in short supply and they went on to other other sorts of drugs. So their journey was much more complicated than my mine, mine was very much routine. It was, you know, standard treatment except for the trial drug. So I did it whilst I still get information from BEAT and they still get invited to a meeting. I haven't been attending those, although they've also done a couple of very good videos as well. So they're very, very good. So background information is good.
Participant 029_2022AUBLC

Participant describes information about treatment options as helpful

I've got a lot of information on I wouldn't call them alternative therapies, but on other treatment options like the tri modal option um, about other forms of surgery, So there's neobladder and the ileal conduit. So I looked into all that and it was all use. It was useful information which just made me more determined to live a normal life.
Participant 020_2022AUBLC

Well, the the notes that he gave me, they were just a few sheets, I've still got them here, I was looking at them. They just explain what will happen during the operation and how there's a couple of options that are available. The removal of the bladder. If the cancer is grown into the wall of the bladder or this neobladder, they make and and replace or or repair your existing bladder. And the information he gave me also explained how they take a piece of the small intestine and bring it through the abdomen, and then you have to to the urine goes into a bag. So that's that information seemed to me it was easy to understand. Well, it was written in plain English, let's put it like that. And I mean, he he didn't he didn't. The consultations I had with him were quite brief because he doesn't he's not a man who sort of talks a lot, but he gave me the information very clearly.
Participant 043_2022AUBLC

The studies, I find the most recent studies, in fact, that have been been being trialled and tested. I've found that to be the most informative, even more. And then that's how we've gone down to actually getting in touch with the radiation oncologist like we never thought. We never even thought that radiation was an option.
Carer 004_2022AUBLC

Participant describes talking to their doctor or specialist as helpful

PARTICIPANT: Look, I think that you just like I've had the same urologist for 18 years, and then I saw the head urologist at HOSPITAL. And then I had to because I had to do an operation that nobody knew how to do on me. And so then I had to see the head urologist at LOCATION because she knew more than anybody else on this particular thing. Now, she was brilliant. Like, I think that I gleaned more information from her in one consultation than what I had. From all the others. So, so I think you just get lucky. Maybe occasionally, and somebody who's good with, because doctors and not traditionally good with people. They do their thing, but they often don't know how to relate.

INTERVIEWER: In specifically, what information you found helpful from him or was it just, you know, ?

PARTICIPANT: Well, and I now think I should change to her, even though it will cost me a lot more money because she just explained everything, and asked questions and sounded like she gave a shit.
Participant 026_2022AUBLC

Well, I myself, I took it from the doctor because I thought, well, he knows what he's talking about and he's the one that's going to be doing the surgery and the post-operative treatment.
Participant 027_2022AUBLC

From the probably the two two source of interactions is the urologist surgeon who who did the operation. His information has been particularly valuable and

also the specialist stoma nurse. Her information has been absolutely wonderful.
Participant 034_2022AUBLC

Participant describes information specific to their condition (and sub-types) as helpful

Probably the most helpful is that it's a different if, if it's maintained in the outer wall of the bladder. It is 95% curable. If it gets if it gets into the inner layer, or it spreads that it has, it gets worse the further it goes in. That's grade T1 or T2 or whatever its called, then Two, three and four. I think I was grade three. I think he said two or three anyway. He said it was what you call it, not advanced. I've got the I forgotton whatever it was, wasn't superficial. Anyway, I put it that way.
Participant 021_2022AUBLC

The pieces of information that are helpful to me is understanding the diagnosis initially. To be able to say, yeah, if somebody says to you, look, you've been diagnosed with bladder cancer, T1, and I say, if, if a medical person says, you've got bladder cancer, the first thing you start thinking of, you're going to die. Your gonna die. And you're so confused. You have no idea what, what, what they're saying that. But I think a lot of that material would actually all standard says, Well, hey, look, these are the four stages that you have and that it's possible to have. Yeah. And if you if you have one of the lowest tears, that's great. You've got a lot more treatment options that are available. I get that. That helps put somebodies mind at ease. Yeah. Especially somebody that's just coming in and then they have very little. But just to have very little cancer there at all to, to be concerned about. But at the same time, if you if you've been diagnosed, it say at T3 or T2 say, well, okay, what does that mean? Yeah, well, what are the options available? What can we do with that level, that change. Yeah. And. Yeah. To keep it in layman's terms for someone as well. Because everything's a lot of stuff that's either written from the medical side of you. I mean, I'm comfortable with some of it, but I don't understand everything. Yeah, right. So it's also the way that something's written.
Participant 035_2022AUBLC

Probably more. About. Not not so much the treatment for it because it was going to be fairly, fairly obvious to start with. Um, but more, more. about potential secondary infections and, and whether or not it was it was muscular, invasive. But and then because it got into the lymph system, then it was like researching. How much, you know, what, what possibilities that presented. Um. And then it was like, well, okay, well, let's not be an ostrich and stick our heads in the sand. Um. Let's face it, we're dealing with a five year lottery here.
Participant 040_2022AUBLC

Participant describes information about stoma management or from their stoma nurse as being helpful

I suppose, really, that was, not very mind blowing, was about the bag and you know, the appliance that you use. And it was probably the most helpful. I think it took that little unknown away. You can't, there's no way i you haven't had it done, you could imagine. You know, how it all works and what it's all about. And so that was probably most helpful. Yeah. I'm trying to think a lot of it was just basic stuff, whether it was helpful or not..
Participant 003_2022AUBLC

Probably the, the company ostomy books that the stoma nurse gave me initially, you go on their sites and they have little videos of other people who had been through it. Those sort of things were helpful. And their booklets and stuff about, you know, about adjusting to a different sort of life. Probably the most helpful thing.
Participant 018_2022AUBLC

I guess what I got from the doctors. Um, yeah. Like and the stoma nurse, like, towards when I was having about to have the surgery. I am so the stoma nurse and I actually got her to put a bag, an appliance on my tummy. Um, and then I filled it with water when I was at home just to see how it felt. Um, yeah, so I did that. And so, like, I kind of was thinking about clothes that kind of, um, I thought, oh, can I wear, you know, my normal clothes, jeans and, and, you know, sports things, which I found that I can, of course. Yeah. Nothing changes, really
Participant 039_2022AUBLC

Participant describes information from international sources as being helpful

I think it is basically that there are different levels of bladder cancer. And don't be afraid to ask questions. A theme of a few of the patient groups from the U.S. and Canada was, don't be afraid to ask too many questions of a surgeon.
Participant 019_2022AUBLC

Which information has been the most helpful? Most helpful? Most helpful. You mean. I mean, it's been on on on Internet only. It's the, it's the, you know, the the

hospital websites which publish the patient information. Not like Google thing, you know, but the the does the proper cancer hospital information. Like Australian Cancer Council, Australia, the USA. I think I don't remember the name of that website and the UK also. So all I could say that the information is very clear and. But I will just add that all these hospitals, they have information for patients and they have information for physicians also, which is a bit high level. And I do tend to read the physician information also. Then I wanted more detail so I didn't understand everything, but I did understand more than what they give to patients.
Participant 028_2022AUBLC

Participant describes all or any information as being helpful

Any information going from having no information at all and not knowing what a dealing with? Yeah. So any information I could get through my research. You know, was helpful.
Participant 002_2022AUBLC

I think just all of it, really, because I'm the person I want to know. So to me, I think it was just all of it from start to finish. Yeah, I don't think there's I don't think there's never too much. There's no such thing as never too much information. That's how I felt
Carer 002_2022AUBLC

Table 6.3: Information that was helpful

Information that has been helpful	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 health charities information as helpful	16	32.65	8	40.00	3	30.00	**3**	**21.43**	14	31.82	2	40.00	5	29.41	11	34.38
Participant describes other people's experiences as helpful (Peer-to-peer)	14	28.57	6	30.00	**1**	**10.00**	5	35.71	12	27.27	**2**	**40.00**	5	29.41	9	28.13
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	14	28.57	4	20.00	**4**	**40.00**	**6**	**42.86**	14	31.82	**0**	**0.00**	**7**	**41.18**	7	21.88
Participant describes information about treatment options as helpful	10	20.41	3	15.00	2	20.00	4	28.57	9	20.45	1	20.00	5	29.41	5	15.63
Participant describes talking to their doctor or specialist as helpful	8	16.33	3	15.00	2	20.00	3	21.43	8	18.18	**0**	**0.00**	4	23.53	4	12.50
Participant describes information specific to their condition (and sub-types) as helpful	8	16.33	3	15.00	2	20.00	3	21.43	8	18.18	**0**	**0.00**	2	11.76	6	18.75
Participant describes information about stoma management or from their stoma nurse as being helpful	7	14.29	2	10.00	**3**	**30.00**	2	14.29	7	15.91	**0**	**0.00**	4	23.53	3	9.38
Participant describes information from international sources as being helpful	3	6.12	2	10.00	1	10.00	0	0.00	3	6.82	0	0.00	0	0.00	3	9.38
Participant describes all or any information as being helpful	3	6.12	2	10.00	0	0.00	0	0.00	2	4.55	1	20.00	1	5.88	2	6.25

Information that has been helpful	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 health charities information as helpful	16	32.65	11	37.93	5	26.32	**7**	**46.67**	9	27.27	**10**	**50.00**	**6**	**21.43**
Participant describes other people's experiences as helpful (Peer-to-peer)	14	28.57	7	24.14	6	31.58	**2**	**13.33**	11	33.33	5	25.00	8	28.57
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	14	28.57	**5**	**17.24**	**9**	**47.37**	3	20.00	11	33.33	**3**	**15.00**	**11**	**39.29**
Participant describes information about treatment options as helpful	10	20.41	5	17.24	5	26.32	2	13.33	8	24.24	**2**	**10.00**	8	28.57
Participant describes talking to their doctor or specialist as helpful	8	16.33	5	17.24	3	15.79	**4**	**26.67**	4	12.12	4	20.00	4	14.29
Participant describes information specific to their condition (and sub-types) as helpful	8	16.33	4	13.79	4	21.05	1	6.67	7	21.21	**1**	**5.00**	7	25.00
Participant describes information about stoma management of from their stoma nurse as being helpful	7	14.29	4	13.79	3	15.79	1	6.67	6	18.18	3	15.00	4	14.29
Participant describes information from international sources as being helpful	3	6.12	1	3.45	2	10.53	1	6.67	2	6.06	1	5.00	2	7.14
Participant describes all or any information as being helpful	3	6.12	2	6.90	1	5.26	1	6.67	2	6.06	1	5.00	2	7.14

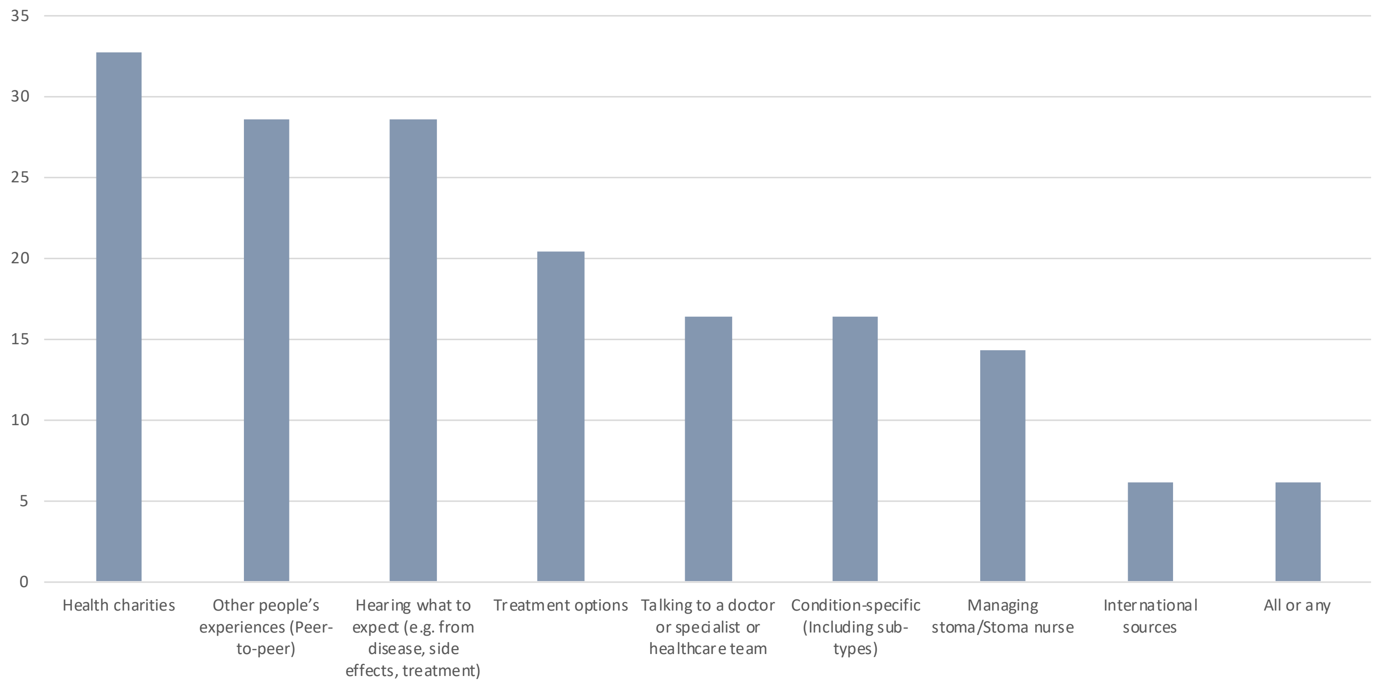

Figure 6.3: Information that was helpful

Table 6.4: Information that was helpful – subgroup variations

Information that has been helpful	Reported less frequently	Reported more frequently
Participant describes health charities information as helpful	Advanced (Stage IV) Higher status	Regional or remote Mid to low status
Participant describes other people's experiences as helpful (Peer-to-peer)	Invasive (Stage III) Regional or remote	Carer to someone with bladder cancer
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	Carer to someone with bladder cancer Trade or high school Mid to low status	Invasive (Stage III) Advanced (Stage IV) Female University Higher status
Participant describes information about treatment options as helpful	Mid to low status	-
Participant describes talking to their doctor or specialist as helpful	Carer to someone with bladder cancer	Regional or remote
Participant describes information specific to their condition (and sub-types) as helpful	Carer to someone with bladder cancer Mid to low status	-
Participant describes information about stoma management of from their stoma nurse as being helpful	Carer to someone with bladder cancer	Invasive (Stage III)
Participant describes all or any information as being helpful	-	Carer to someone with bladder cancer

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. There were 22 participants (44.90%) that responded that no information was not helpful, and 7 participants (14.29%) that were confident in deciding if something is not helpful (or not credible). The most common type of information found to be unhelpful by 9 participants (18.37%) was from their GP or specialist, this was followed by worse case scenarios (n=5, 10.20%), and a lack of information in general, and lack of community awareness as not helpful (n=5, 10.20%).

Participant describes no information being not helpful

No. No. Everyone I've encountered has been, has given me the right information. Nothing that's been useless. No, nothing.
Participant 022_2022AUBLC

No, not really. I mean, it is all helpful information and you need to know everything
Participant 024_2022AUBLC

Well, I think everybody everybody's tried to do their best and, and I do believe that my health is my responsibility. So I'm not just relying on them. And so, so I don't know that anybody hasn't been helpful.
Participant 026_2022AUBLC

Participant describes the GP/specialist as being not helpful

Well, the first urologist gave me pictures of my bladder, but didn't explain it at all very clearly to me. And then he gave me printouts, which is flat out, obviously in English, but it's written in a very technical

language. So I didn't find that really helpful at all. In fact, I found nothing helpful from both urologists. Most of my nearly all my information is from my own research.
Participant 008_2022AUBLC

No, not really. I think probably the nurses. Keen to really push me to have the treatment every month because that's what their, they were told that I had to have. So they're putting a little bit of pressure on me to come back every month. And I but they were lovely. They were really nice, lovely, lovely people. But they were busy. They had people day that they were on chemo as well that they were having to look after. So I couldn't expect too much from them. The urology practise, I don't think there was a lot of support there really. I think once or twice, as I said to you, I phoned the nurse and she was helpful. But I think I really felt like I was on my own and I think what would have been really nice is to actually have. Gone and have coffee with some other people that had bladder cancer and that we're on BCG and and just maybe had someone that coordinated it and talked about it rather than a Zoom meeting, which was quite, quite good. But because there's about 23, 30 people on the Zoom meeting, often you didn't really get a chance to ask a question or you felt a bit intimidated anyway because you were on Zoom. So something like that would have been nice.
Participant 036_2022AUBLC

Look, I don't know if it's been unhelpful, but it's definitely been confronting at times. Like, as I said, the oncologist that we first spoke to has the bedside manner of, I don't know what a bull. Um. Sorry. Yeah, like. Just the way he put he was just, you know, and in a very confronting manner, I guess.
Carer 003_2022AUBLC

But what he's directly contradicted himself is, again, this may not be an answer to your question, but couple of things we picked up early on was absolute contradiction in what the what he just said. And then when we next met in what he said, he backflipped on, you know, when we provided challenges, he goes, you know, we should do this. You know, the safest thing is to do this. And my wife goes, hang on a moment, if you do that, you receding or whatever, you know, it's the cancer and it could seed into the kidney, he goes, yeah, you're right. So if you actually want to do the safest thing, do the following. All right. And my wife goes, yes, that's the point I'm trying to get at. Four weeks later, when you meet him, he goes, and remember how I told you we should do this? I'm thinking, bullshit. You did, you, she told you something else. We corrected you and then you agreed with our position. And now you're you, now you're replaying that position as your own. That's those types of things to me. Whereas he lost integrity with me. I'm sorry the trust eroded very quickly between patient and practitioner. Not again. I can't say he's not a great surgeon. I'm not qualified to do know anything that he does when I'm under the, on the bed, on the operating table. But in the clinical setting, he backflips and is a bit loose with the truth and things like that. Whether he knows he's doing it, I don't know. But it doesn't. You know, my wife and I just both pick up and go, you know, that, you know, you kind of fact check, fact check,hang on fact check. That's not right. That's not what you said last time or whatever, you know.
Participant 017_2022AUBLC

Participant describes feeling confident in deciding if something is not helpful (or not credible)

Not really. No, no. I mean, there's been a bit of rubbish on there and things that I've just disregarded. Yeah. Things on the rubbish. There's no, I don't believe in instant cures. And you know what of that kind of stuff out of this life that's really not medical. That's just rubbish. I'm not going to look at that.
Participant 001_2022AUBLC

Um. Uh, yeah, there's probably a fair bit, um, but you know, um, there's a lot of websites that provide information that you don't necessarily trust, but I've actually, I tend to only look at Australian websites or I tend to only really look at Cancer Council websites if I'm being honest.
Participant 009_2022AUBLC

All the different, you get different information from certain people about it. And saying that, you know, if you get it, you know, you're in a bit of trouble for that sort of thing. The only the only things I take notice of is the medical doctors, you know, urologists, not from reviews of people writing in or things that you see on YouTube. So it's mainly mainly misinformation about how bad, how dire things are from people who are not medical practitioners and things like that.
Participant 021_2022AUBLC

Participant describes information about worse case scenarios and negative information as being not helpful

Yes. I have to say, this is my opinion on diagnosis. When I, you know, one of the first websites you come across will be the Cancer Council. And you know,

straight up, it gives you the fact that this about five year survival rate for bladder cancer is 50%. And that sent me into a spin, if you know what I mean. And, you know, it might be true, but it's just, you know, it depends on the type of, you know, that survival rate depends on many, many factors. Yes. And. I just don't necessarily think it's helpful to have that kind of information upfront. Does that make sense?
Participant 016_2022AUBLC

Some of the very old studies on the Internet that, you know, gives people very less hope and, you know, and, you know, talks about, you know, the prognosis hasn't been good. And then when I've looked at the study data, I thought, oh, okay, thank God that's been that's an old one. But definitely the bladder cancer. And can I tell you the I found actually my daughter in law found the bladder cancer support survivor support group. So yeah, so that has been really fantastic in terms of getting emotional and and psychological support for me as a carer. That's been my main source of, of help.
Carer 004_2022AUBLC

Possibly the ones that went into detail about the different levels, but you didn't know what level we were at, so you didn't know which one was appropriate. It was a bit scary.
Carer 005_2022AUBLC

Participant describes a lack of information in general, and lack of community awareness as not helpful

Not that I remember. I think it was just a surprise at the time. There was only one resource with Australian authorshship and that would have been the Cancer Council of New South Wales. It was a 1 or 2 pages. Yeah. That was my only sort of memory of the time. Yeah. There's always stuff that isn't helpful, but nothing really that stuck out as being quack, quack medicine or quack therapies. No. Not everything I was asked about and read about has been helpful.
Participant 019_2022AUBLC

Oh, look, just not. Really. I was looking at my own clinical trials to see if there were any clinical trials, just more more confidence about whether or not there were clinical trials available or a little bit of information about the fact that they exist. They are not common, but they do happen. And I'll let you know if somebody had said to me, I'll let you know if there's any opportunity for your demographic, your, your current situation. I'll let you know. As opposed to saying, yeah, there are some out there and okay going on and was kind of the attitude which might have been the same message. I just misinterpreted it, but it would have been good to be part of a and it still might be good to be part of a clinical trial. Because I just think BCG is, as I said, it's good, but it's just not it's not a healthy option. Okay. Yeah. So I guess. Yeah, probably good for that.
Participant 030_2022AUBLC

PARTICIPANT I don't like that bladder cancer doesn't get the spotlight that a lot of other cancers get, like bowel cancer and breast cancer and ovarian cancer because it kills many people annually every year. And yet it doesn't, it's not under the radar. It doesn't get the spotlight that some of the other cancers do. And I don't think there should be any comparison when we're dealing with something that's, you know, it's so it's deadly. Cancer is deadly if it's not caught early.

INTERVIEWER Yeah, it's quite insidious, but no. And not many people do. Know about it. Yeah. Because it hasn't been as marketed or out in the open. Let's talk about.

PARTICIPANT Yep. Yep. So, yeah, I think a big thing for bladder cancer that's missing is, um. You know, promoting it on promoting it, on making people. A lot of people that we spoke to said, oh, my God, I didn't even know it was a thing. You could get cancer in your bladder like here you can you can.

INTERVIEWER You can get it anywhere.

PARTICIPANT You can get cancer anywhere. It's all about the cells, you know, just growing, multiplying and dividing and, you know. So, yeah, it's, um, I think if there's anything that's lacking in regards to bladder cancer, it's that it's just not out there like the other cancers are. And it needs to be. It's just as important.
Carer 002_2022AUBLC

Participant describes other people's experiences as being not helpful

Oh, I don't think so. Not, not, not, not helpless. As I said, a few of the a couple of the groups, they're all a bit way past where I am. And I just had to go. I don't need I don't want to hear about that at this stage. I don't I don't need to be Thinking about That yet.
Participant 004_2022AUBLC

Oh. Oh, I don't think so. There was one patient who said to me, It's much easier for people to have surgery because they don't have to sit having, you know, cystoscopy every six months and worrying about things. And I thought, oh, that's a person who hasn't had surgery. But that was just an unhelpful comment.

Participant 018_2022AUBLC

I think it would be from most of my friends and family who try to tell about their own experience. You know, some friend has a friend going to say, look, this is what works for him. You know, you should try this. And that's the worst thing somebody can do. You know, I mean, they don't know my full condition, so people will try to be helpful then. I think that's the worst. I don't think people should try to help a cancer patient and leave it. They should leave it to the doctors and specialists, you know?
Participant 028_2022AUBLC

Participant describes information that is not comprehensive as being not helpful

What was not helpful? Yeah. The total support. Because a urologist, they do the treatments, but they don't think about the human body and the mind. So that's something I really missed.
Participant 005_2022AUBLC

Um, initial, initial GP, I suppose. I don't know about that. He didn't really tell me much at all. Yeah, I can get from hospital onwards yet that they'd be open and honest, which I also do anyway. I also like to call a spade a shovel. And they were, you know, they, they told me straight. All good after that.
Participant 023_2022AUBLC

Table 6.5: Information that was not helpful

Information that has not been helpful	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes no information being not helpful	22	44.90	6	30.00	5	50.00	11	78.57	22	50.00	0	0.00	8	47.06	14	43.75
Participant describes the GP/specialist as being not helpful	9	18.37	5	25.00	2	20.00	1	7.14	8	18.18	1	20.00	4	23.53	5	15.63
Participant describes feeling confident in deciding if something is not helpful (or not credible)	7	14.29	6	30.00	1	10.00	0	0.00	7	15.91	0	0.00	2	11.76	5	15.63
Participant describes information about worse case scenarios and negative information as being not helpful	5	10.20	2	10.00	1	10.00	0	0.00	3	6.82	2	40.00	3	17.65	2	6.25
Participant describes a lack of information in general, and lack of community awareness as not helpful	5	10.20	2	10.00	0	0.00	1	7.14	3	6.82	2	40.00	0	0.00	5	15.63
Participant describes other people's experiences as being not helpful	3	6.12	2	10.00	1	10.00	0	0.00	3	6.82	0	0.00	2	11.76	1	3.13
Participant describes information that is not comprehensive as being not helpful	3	6.12	1	5.00	2	20.00	0	0.00	3	6.82	0	0.00	1	5.88	2	6.25

Information that has not been helpful	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes no information being not helpful	22	44.90	13	44.83	8	42.11	3	20.00	18	54.55	7	35.00	14	50.00
Participant describes the GP/specialist as being not helpful	9	18.37	4	13.79	5	26.32	3	20.00	6	18.18	4	20.00	5	17.86
Participant describes feeling confident in deciding if something is not helpful (or not credible)	7	14.29	4	13.79	3	15.79	2	13.33	5	15.15	3	15.00	4	14.29
Participant describes information about worse case scenarios and negative information as being not helpful	5	10.20	3	10.34	2	10.53	3	20.00	2	6.06	3	15.00	2	7.14
Participant describes a lack of information in general, and lack of community awareness as not helpful	5	10.20	4	13.79	1	5.26	3	20.00	2	6.06	2	10.00	3	10.71
Participant describes other people's experiences as being not helpful	3	6.12	1	3.45	2	10.53	0	0.00	3	9.09	0	0.00	3	10.71
Participant describes information that is not comprehensive as being not helpful	3	6.12	2	6.90	1	5.26	2	13.33	1	3.03	2	10.00	1	3.57

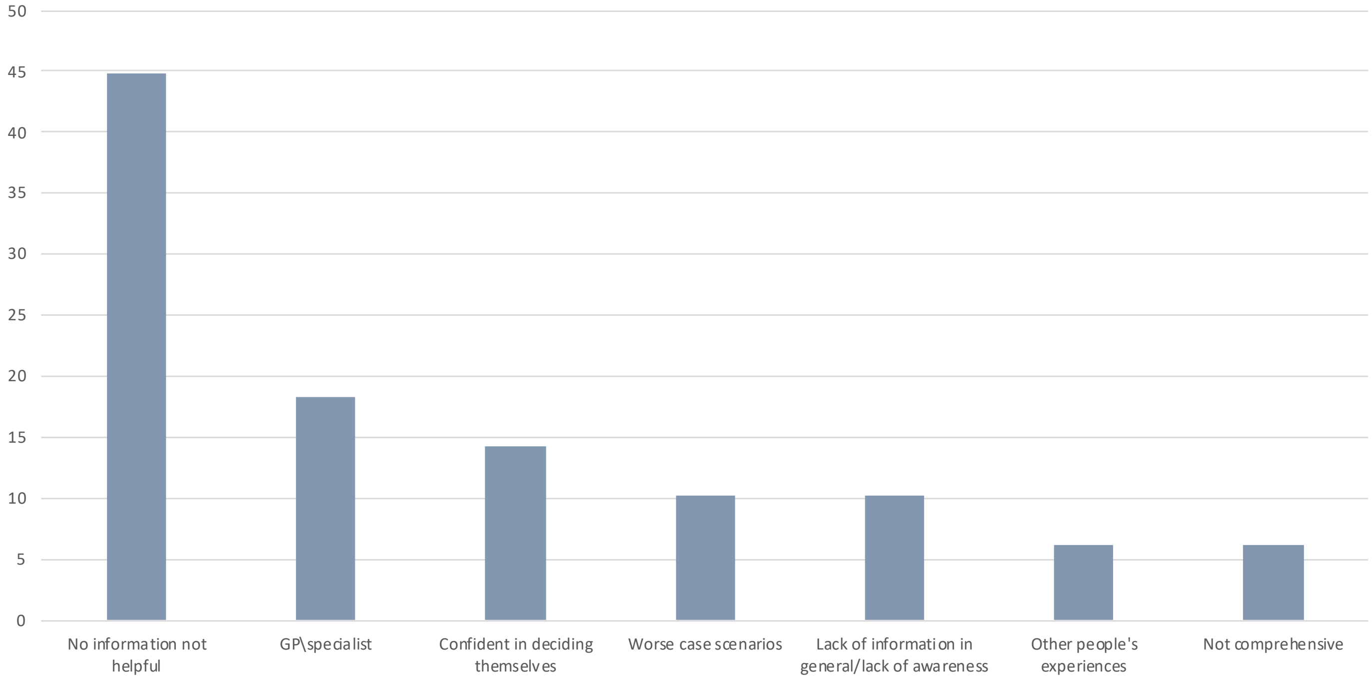

Figure 6.4: Information that was not helpful

Table 6.6: Information that was not helpful – subgroup variations

Information that has not been helpful	Reported less frequently	Reported more frequently
Participant describes no information being not helpful	Early (Stages 0 and I) Carer to someone with bladder cancer Regional or remote	Advanced (Stage IV)
Participant describes the GP/specialist as being not helpful	Advanced (Stage IV)	-
Participant describes feeling confident in deciding if something is not helpful (or not credible)	Advanced (Stage IV) Carer to someone with bladder cancer	Early (Stages 0 and I)
Participant describes information about worse case scenarios and negative information as being not helpful	Advanced (Stage IV)	Carer to someone with bladder cancer
Participant describes a lack of information in general, and lack of community awareness as not helpful	Invasive (Stage III) Female	Carer to someone with bladder cancer

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. Overall, the most common theme was talking to someone plus online information (n=17, 34.69%), followed by talking to someone (n=14, 28.57%), online (n=14, 28.57%), and written information preference (n=11, 22.45%).

The main reasons for a preference for online information were accessibility, being able to digest information at their own pace, and finding personalised or relevant information. The main reasons for talking to someone as a preference were being able to ask questions, get personalised or relevant information, and feeling supported. The main reason for written material as a preference was being able to refer back to it.

Participant describes talking to someone plus online information as main preference

That's an interesting one. It depends on the type of information as to. How I'd like to receive it. If it's something that I'm looking for. Initially. I like to find it online. And the reason for that is. It's there, it's indelible and it's digestibility permanent. You can stare it for long as you like, and the words don't go away until you actually comprehend what you're looking at, which you don't get too much with talking because you can go in one ear and out the other by the next day, which it doesn't do online. But then having said that, there are other things where. A reaction to a question and answer can lead to another question which doesn't happen online. So in a case like that, it's better to have a personal conversation online. So it depends on the type of information that you're after. Sometimes, mostly. In fact, I think it's probably a combination of the two. For me anyway. It's best to look it up. Obviously online, get a broad, knowledge of what it is and then really talk to somebody about it on the same page swapping ideas. So that's good. The telephone is probably the last the last device, usually for expediency of time or distance. It serves the purpose providing what you need to know. This is fairly succinct. But it's no cause for index views is not really very useful or not useful as face to face chat or an online discussion.
Participant 034_2022AUBLC

And what I think I like to talk to people because I get the immediate opportunity to ask questions. But but I also don't mind online because I can do it at my own pace. Um, occasionally, like in appointments, whether someone is busy or whether you perceive that you don't want to take up too much of their time, that they might be busy but can sometimes affect. Yeah, that face to face. So it's going to be close, But probably as a main one, that face to face.
Participant 022_2022AUBLC

I don't have a preference, per se. I value listening to a professional, who has been working in the field for a number of ten, 20, 30 years and I would value whatever they say because I have a specialised knowledge, but so and I probably put more light on that than a lot of websites that you, although it might seem reputable you still doesn't know necessarily. So the trusted referral is always something that's, you know, the highest held in the highest regard by me but also online. Like there are so obviously sites I think it's a kind of what healthline or the cancer council or whatever they are. There are a few websites that you know are pretty reputable and it's also a very good source of diverse information, which is some you might not get necessarily from the people that you know. So it's is it hard. I value both equally, but I think you get different things out of them.
Participant 024_2022AUBLC

I think it's both because I mean, like the online information is not specific to your case. But when I talk to my radiation and chemotherapy doctors, they know my specific case and they can provide me information specific to me. So some level of information, general information on the Internet, but

specific information, I think it's better to talk to my treating doctor.
Participant 028_2022AUBLC

Participant describes talking to someone as main preference

Quite honestly, I think it would have been really good to be able to sit down and talk to somebody maybe over a cup of tea in a relaxed more and had a discussion. Have face to face with the urologists, have an oncologist that was more, um, had a better bedside manner maybe or more compassionate, um, or somebody that could coordinate it all. I had to do all the coordination myself between the urologists and oncologists, and that was really stressful when you're trying to deal with, you know, a condition like I, I was facing, um. While information online was helpful. I don't think there's anything that is better than having a conversation. A face to face conversation with somebody that actually understands and is compassionate and can answer your questions.
Participant 002_2022AUBLC

I think if you get information from talking to someone or from the, like from from the medical professionals. I think is probably the best because that's probably going to be the most accurate. And if you can go through with someone and had it and been through it and had their experiences, at least you know what you're up for. Uh, I think if I, if I could have my time again, I would have loved to have turned around and had a conversation with somebody about this. To know what I was going to be in store for. I would have still gone through the operation. But at least. You would have known what was coming. Up. What what the possible side effects were going to be, and what challenges were going to lie ahead. Hmm. You know, the fun stuff.
Participant 040_2022AUBLC

I'd much prefer to speak to people face to face. Just answer your question. Yes. Yeah, I'm I'm I'm not one for sitting on the Internet all day looking at stuff. I, I'd prefer to talk to someone face to face, like the doctor or the consultant and. Yeah. That's the way I like to to have things done. Like for example, there's a the LOCATION Stoma Association, they've got a support group. I met with them just a couple of weeks ago. They were able to have a face to face meeting the first time they've been able to have quite a long time. And I found that very helpful, just going along and talking to the nurses there and a couple of the patients as well. I found that really helpful and, you know, reassuring that, you know, on your own, the people that come out there to help
Participant 043_2022AUBLC

Participant describes online information as main preference

We've got yeah, we got you know, when the first time we went into the research in the rural urologists offices, obviously she gave us some some booklets and they generally give you a little bit of info and then point you. In the in the direction of various websites. I think I find that easy because you can sit down wherever you want, whether it's in your bed or on a lounge or in an office and. Go trawling through the Internet and finding what you can.
Participant 014_2022AUBLC

PARTICIPANT: Um. I like the online stuff because it's. They're readily accessible. I suppose if you got to talk to somebody, you got to ring them up. And then they gotta ring you back and god know what else. So it's a little bit of a little bit of.

INTERVIEWER: Yeah, I get that.

PARTICIPANT: We play phone tag for about three days and then you. Also.

INTERVIEWER: Get what you're aiming for.

PARTICIPANT: I think. But yeah, I prefer to go online because you can find the answer straight away.
Participant 037_2022AUBLC

PARTICIPANT: Probably online. My guess.

INTERVIEWER: Okay. Why is that?

PARTICIPANT: Because it's quick and easy to access. If you've got a question, you just go straight to it.

Carer 003_2022AUBLC

Participant describes written information as main preference

Probably written down information, whether it was, you know, on a piece of paper or we're on a flyer or on a website. Probably on a piece of paper would be better for my husband because just of his generation, first things written down and I think it's easy to take the mean if you can read it and reread it a few times.
Carer 005_2022AUBLC

I like the opportunity to talk to someone, but I like things written down. You know, sometimes you talk to someone, and you go away and you think, oh, did he say it was pink. Or did he say it was blue? Or did he say it was this? Or they said it was that. Whereas if it's written down, and then you can refer back to it. When your mind stops. Because your mind doesn't look the same when you're going through things like that at all. So it's almost a bit like it seizes up and can't absorb all the information that you would normally.
Participant 003_2022AUBLC

To grasp it to get a good understanding. So. So I think you do need everything. I think you need. You need to be able to talk to a doctor and you need to. Pamphlets are good. Like when? When I was. When I found out I had my bladder out. I needed the pamphlets because I needed to go back and relook at information to get my head around it and it can be good. And I still had to go online and look for information to understand more about it. But yes, I needed all three things I needed to be spoken to about it in the first place and have the pamphlets. And then I had to look further to find more information.
Participant 026_2022AUBLC

Table 6.7: Information preferences

Information preferences	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 talking to someone plus online information as main preference	17	34.69	**4**	**20.00**	**6**	**60.00**	**7**	**50.00**	17	38.64	**0**	**0.00**	7	41.18	10	31.25
Participant describes talking to someone as main preference	14	28.57	6	30.00	3	30.00	3	21.43	12	27.27	**2**	**40.00**	4	23.53	10	31.25
Participant describes online information as main preference	14	28.57	**9**	**45.00**	**1**	**10.00**	3	21.43	13	29.55	1	20.00	5	29.41	9	28.13
Participant describes written information as main preference	11	22.45	6	30.00	2	20.00	2	14.29	10	22.73	1	20.00	**6**	**35.29**	5	15.63

Information preferences	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 talking to someone plus online information as main preference	17	34.69	9	31.03	8	42.11	4	26.67	13	39.39	6	30.00	11	39.29
Participant describes talking to someone as main preference	14	28.57	9	31.03	4	21.05	5	33.33	8	24.24	7	35.00	6	21.43
Participant describes online information as main preference	14	28.57	8	27.59	6	31.58	5	33.33	9	27.27	5	25.00	9	32.14
Participant describes written information as main preference	11	22.45	**3**	**10.34**	**8**	**42.11**	4	26.67	7	21.21	5	25.00	6	21.43

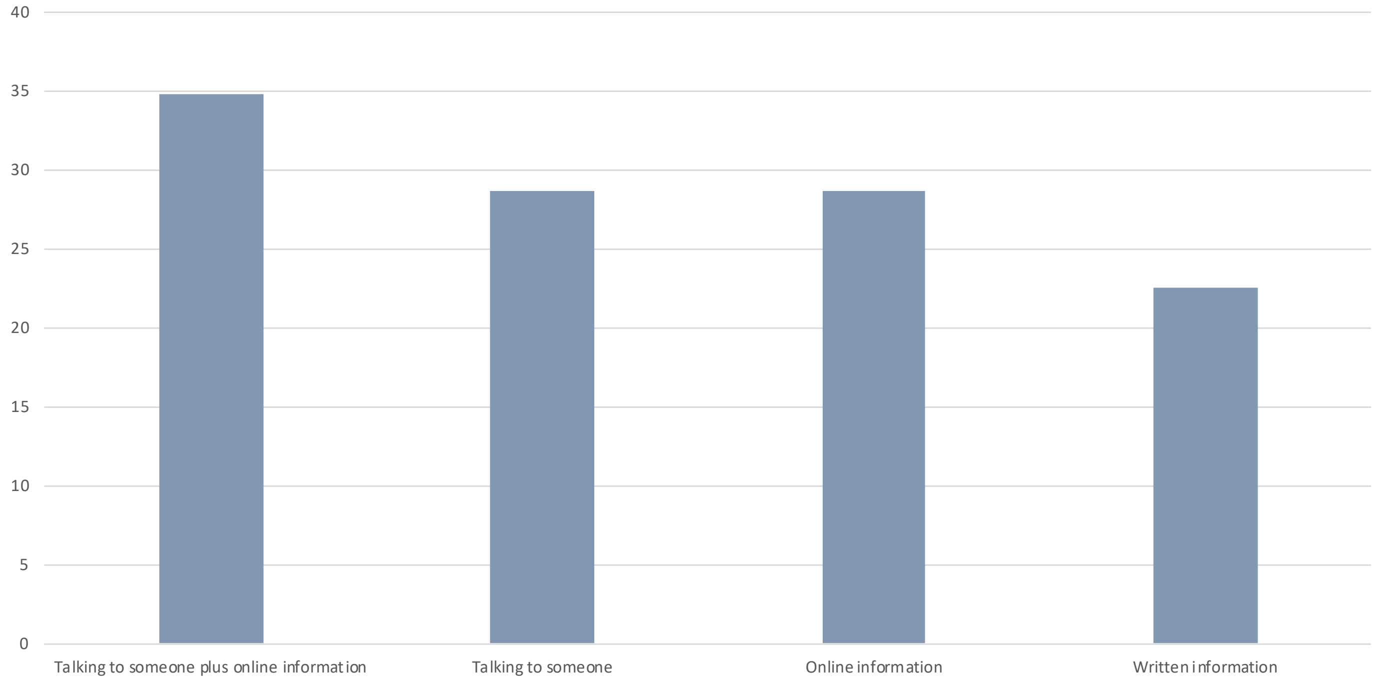

Figure 6.5: Information preferences

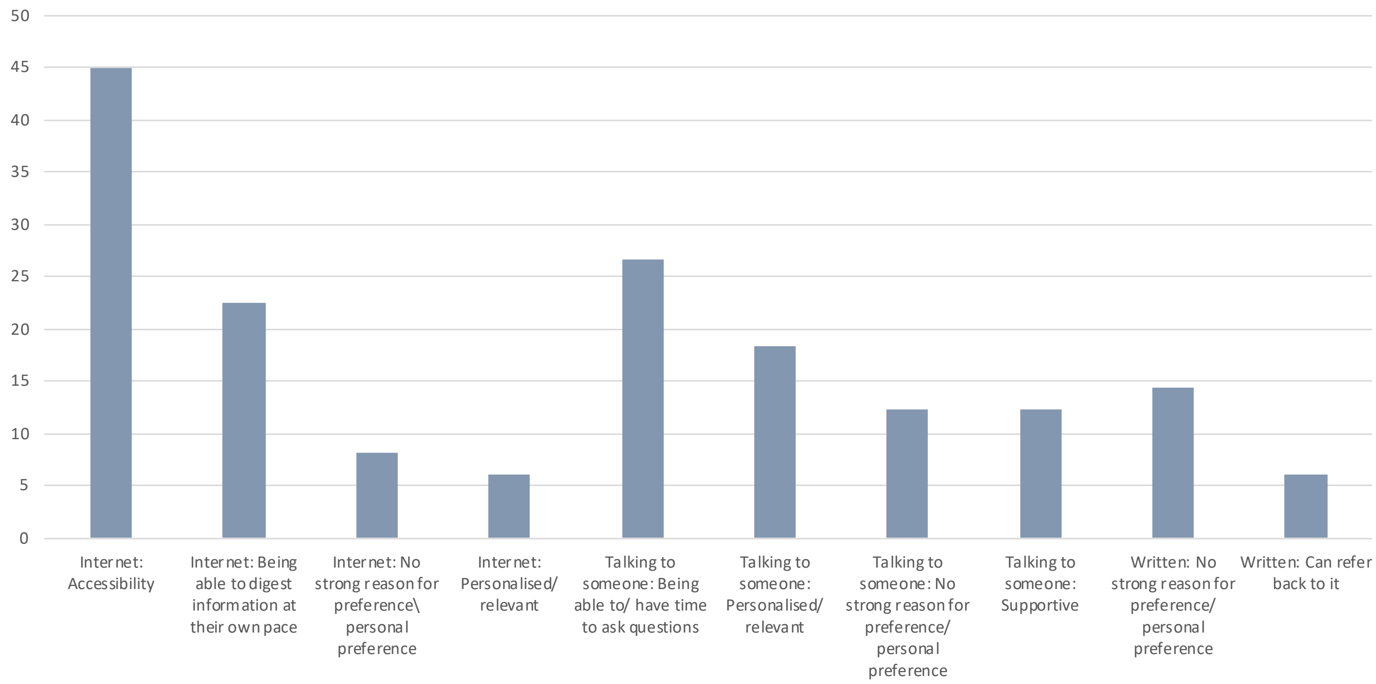

Figure 6.6: Reasons for information preferences by format

Table 6.8: Information preferences – subgroup variations

Information preferences	Reported less frequently	Reported more frequently
Participant describes talking to someone plus online information as main preference	Early (Stages 0 and I) Carer to someone with bladder cancer	Invasive (Stage III) Advanced (Stage IV)
Participant describes talking to someone as main preference	-	Carer to someone with bladder cancer
Participant describes online information as main preference	Invasive (Stage III)	Early (Stages 0 and I)
Participant describes written information as main preference	Trade or high school	Female University

Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common time that participants described being receptive to receiving information after the shock of diagnosis (n=18, 36.73%), this was followed by participants describing being receptive to information from the beginning when diagnosed (n=13, 26.53%), after the start of treatment (n=9, 18.37%), and continuously throughout their experience or bit-by-bit so that it is digestible (n=9, 18.37%). Other participants described being receptive to information after they have had time to learn about condition/thought about questions to ask their healthcare professional (n=7, 14.29%), and a month after diagnosis (n=5, 10.20%).

Participant describes being receptive to information after the shock of diagnosis

Probably around the time I, I think the sequence I think is I had my first cystoscopy to removed it and then I had another one and then he told me it was cancer. So have another look. And I think when he first spoke to me in the in his waiting rooms and told me it was cancer, I don't know how much I absorbed, to be honest. I was a bit, as you are, taken aback. It always happens to somebody else. But when he told when he sat down and talked to me after my second cystoscopy, when he sort of did a double check to make sure he had missed anything, I think that's when I started to take it in a bit more and think, okay, well, we can do this.

Participant 006_2022AUBLC

Um. Probably only just, excuse me, I'm loosing my voice a bit there. Well, after diagnosis initially it was just overwhelming. Yeah, you know, the mind just didn't function very well. And I've got to say, after the operation, more and more, I was in a definitely in a different zone with my mind, similar to what they say on COVID, I guess I was in a fog. I was treasurer, in my local men's shed and I had to end up resigning from that position. I just couldn't concentrate on it. No, I found it very, very difficult to, I could do things in short pieces, but I couldn't do it long term. I couldn't sit down and even reading, and I've been an avid reader all my life I would read ten pages or 20 pages. then I'd put the book down. Which, you know, I used

to read for hours once, was much more effective in that in that regard, you know, and that and that sort of thing. But I can I can read something for a while and do something else and then I can read something for a while again. Yeah. I can't concentrate on one thing for too long. Better, better now than what I was Christmas time sort of thing. Christmas time was a bit of a turning point for me with that I think.
Participant 011_2022AUBLC

PARTICIPANT: But when you first diagnosed with cancer, you can't take anything in because you can only hear the word cancer. And so you're not going to remember anything then. So, you know, on initial diagnosis you need, if they're going to give you all that information at that time, that's pointless because you're not going to you're not going to take it in. What did you ask me?

INTERVIEWER: Just when you are most receptive to receiving.

PARTICIPANT: Receiving the, receiving information. Yeah. Um. Well, you know, when you don't feel rushed like this, if you, if you in an appointment and you can sense that you're being rushed, they want to get you out, then you're not really taking anything in because you're feeling feeling rushed about it. Yeah. So, so I think it's important to, that they have the time, and I think it is important that they talk to you about it and give you information about it to take time to read because you're not going to remember what you get told.
Participant 026_2022AUBLC

Participant describes being receptive from the beginning (diagnosis)

I think, me, my process, because I'm a process person or list person or organised person. It all fell into context straight away. And I think there was a day of a day of tears, still tears in between. And during but a day of tears start with the first diagnosis. And that was onwards. Getting rid of this bastard. We're getting it fixed. There, it wasn't, it wasn't, oce or twice when sort of little tumours decided to regrow. Yes, we'd have tears in the day surgery area waiting to go home. But then we move on and do it.
Participant 019_2022AUBLC

Oh, gosh, it's hard to say. It's really hard to say because it feels like I've, even though it is all bladder cancer, it feels like I've had different cancers, if that makes sense. Because it's gone from low grade to, yeah, like even being a different type of bladder cancer. Going from the low grade to the high grade and the different treatment regimes and things. Oh. I don't know. I wanted more information at times than what I have given. But that's probably just me as well. You know I like to know what's going on
Participant 001_2022AUBLC

Yeah. I remember the anxious wait, getting the first biopsy. That was probably the hardest thing. I think were pretty receptive. And then there's that, you know, that four or five day wait to find out, you know, what type of cancer you've got because that when conjured up all sorts of things in that period, thought that four or five days that conjured up the worst case scenario that could happen. And, you know, anything from the best to the worst and probably. And I think once you've heard that diag that initial diagnosis of of what grade and muscle invasiveness or not you've got you probably. Well, to me that relaxed me considerably. Still got cancer. But that could be, you know, could be worse. Um, I was probably more receptive to take other things on board. Up until that point, my mind was just bothering with, Gee, you know, what does this mean? You know, because, you know, we just come back from a long holiday in COVID and we're planning the time it so our minds are spinning, going. Retirement looks like that's not going to happen. Am I going to make it to retirement? You know, I am. I see the kids hit their 21st , you know, that kind of crap that goes through your head, because we just didn't know enough about it initially. So, you know, we were bewildered, kind of lost, like going, how did I get here? And then you kind of get clarity as you start to read material and as you start to go to treatments. And it makes more sense. And then once you got your diagnosis. Okay, this may not be a death sentence. So if it is, it's not going to be in the next few years. Right. So.
Participant 017_2022AUBLC

Participant describes being receptive to information after treatment

I think in the beginning. You'll have the most eager. Your most eager to. To get the basic information. And I know your. When everything is under control, you have different needs of of information that it's more the long term. First, you go to short term, get the tumour out and then it's more information about the long term.
Participant 005_2022AUBLC

You know, probably after, after they removed the tumour, of the timing for reality, they removed the first tumour and they said that it was clear and it

hadn't spread. That was when I really started looking into it. I sort of didn't want to know that because I was scared before that. And then when I got the positive news after the first TURBT, and that's when I sort of feel more confident to understand more about what was going on.
Participant 024_2022AUBLC

Take in? Yeah. Not. Not really, no. My wife took a lot of notes and it pretty much. For me once I heard, you know, bladder removal was pretty much switched off. I didn't want to know at the time. I was very angry about it, though, and not to do with anybody else, but just me, and my wife took a lot of notes asked and most of the questions. And then afterwards we went back through it again. But being receptive to all, you know, eventually once everything was done. And like the doc. Once the doctors started giving you advice, you just followed their advice. And everything was fine, you know?
Participant 031_2022AUBLC

Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible

Uh, I think I'm always receptive to reading about it and any new treatments or strategies. I think I, I think I'm a lot calmer now with it because, you know, I haven't had I haven't had a, you know, procedure that's had to cut things out, etc., in the last 12 months. So, you know, suppose I'm in remission temporarily or whatever. Um. So, um. Um. Yeah. I don't know. Any time, I think.
Participant 008_2022AUBLC

Yeah, good question. That's, um, I suppose honestly, it's a gradual thing and I was very fortunate. I'm probably not a good one to ask this because I'm very fortunate in that I have a HEALTH PROFESSIONAL background, so I'm not quite as fazed by things as some people would be, and I'm very quick to look things up as well. I don't know if you don't know something, you google it, ASAP and um. Yeah, and I don't mind talking about anything medical reasons even if it if it is about myself. But certainly because I was as I said before, I didn't know anything about that. … . Um, so I would say. I probably learnt a lot in the first month and there and then from then on I'm mean I'm even learning things now because I'm still kind of looking through YouTube videos I haven't looked at before. And it's just there's a lot of information out there.
Participant 010_2022AUBLC

Participant describes being receptive to information after they have had time to learn about condition/thought about questions to ask their healthcare professional

Probably after the first appointment. I think the first appointment was a bit I don't want to say overwhelming because it wasn't that overwhelming, but it was probably the most confusing because it was the first time I'd heard lots of different terms that I didn't really understand.
Participant 022_2022AUBLC

PARTICIPANT: Um. I suppose now would be the best. Oh, yeah. Oh, I think so.

INTERVIEWER: Uh. Um. Okay. What's the reason? Why do you think you are more receptive to information now than in the past?

PARTICIPANT: Probably because I I've had more and more information, as you say, that more communication. More information. Give me a better view.
Participant 012_2022AUBLC

PARTICIPANT: Oh, well, you know, you don't really, because in those early days almost completely knocks you sideways. And I your, I mean, I had my son with me, or a friend, NAME, she's a friend . All I've for 25 years now. So. So. Yeah, see, it's basically you don't hear anything, and that's the trouble. You go to these appointments and most of it just goes flows out the window you know, so the problem with taking my son was that he was just as shocked as I was.. And you come out and you think. Well, yeah, well, what did he say?

INTERVIEWER: And if you ask your son to probably say something different than you.

PARTICIPANT: Yeah. And it's very hard because, I mean, sure, take a tape recorder in with you, you miss a lot of stuff, you know.

INTERVIEWER: That you know. So did it get any better? Now, now, when you sit down and talk to a medical professional, does it?

PARTICIPANT: Yes, because, again, when you when you get that diagnosis, you go home, you're thinking it over. Mm. You go to the Dr Google and and you can pre-arm yourself with questions you need to answer. And the Cancer Council helped me as well. And you need to ask, this that and the other. That's after the

fact, if you like. You know, I wish I'd asked that but it's too late. You know, you got your 20 minute window and that's it.
Participant 023_2022AUBLC

When I was trying to decide whether to go for surgery because the surgeon said, look, you've got those articles to read, and now you want to be you know, you want a surgical cure if you can. But I'm going to take the pathology to the surgical MDT and get all the opinions there of what would be recommended. Given the background of cyclophosphamide, because he hadn't come across it very often. And so he said, why don't we both make our own, you know, investigations? And then in bring me back after the MDT and that that's probably when I was the most clear of really researching and trying to work out which, which way to go. And then when he rang back and said, give overall opinion was radical cystectomy. I said, yeah, well, that's what I think too. So it was good that we both lined up on that because he recommended watching it, but, you know, would have been too nervous to go with that option.
Participant 018_2022AUBLC

Oh, from the moment, from the moment I knew that I had to decide whether I'm going to have an operation, this particular operation or not. That's the moment I knew I needed to find out about it. And I knew that was the moment I discovered how much information actually was out there. There is no shortage of information.
Participant 034_2022AUBLC

Participant describes being receptive to information a month after diagnosis

Yeah. I'm sorry. I'm just thinking. When I first got diagnosed. Absolutely. No, I cannot remember things. It was just lucky that I had a notepad and a pen and just literally wrote everything down that the specialist told me, because I would not have retained any information whatsoever. Um, I would probably say maybe about, I think it was about a month or two months after the diagnosis that I found that I was really retaining information better than what I first had and probably best during still since diagnosis.
Participant 009_2022AUBLC

Yeah, probably. You know what? I didn't do a lot of research at first because I was in shock and possibly a bit of denial. So, everyone else, like I know my sister was looking at stuff and probably my wife and probably some of the friends that I spoke to, but I myself was not even looking at stuff initially. You know, we got a booklet and. And I had a little bit of a look on the Internet, and I just sort of didn't want it because I was pretty worried, pretty scared and, when I saw that the 50% sort of margins or factors I was. Yeah. Had a pretty negative outlook on outlook initially of thinking. Well yeah, I'm probably going to be in that 50% where it doesn't, it doesn't work, which means I'd have to get my bladder out. Or worse still, I don't make it. So I reckon it took me about a month before I started delving in and doing a bit more reading and research and becoming bit more comfortable with it.
Participant 014_2022AUBLC

Table 6.9: Timing of information

Timing of 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 describes being receptive to information after the shock of diagnosis	18	36.73	**5**	**25.00**	**5**	**50.00**	6	42.86	16	36.36	2	40.00	5	29.41	13	40.63
Participant describes being receptive from the beginning (diagnosis)	13	26.53	**8**	**40.00**	**1**	**10.00**	**2**	**14.29**	11	25.00	**2**	**40.00**	5	29.41	8	25.00
Participant describes being receptive to information after treatment	9	18.37	4	20.00	2	20.00	3	21.43	9	20.45	**0**	**0.00**	4	23.53	5	15.63
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	9	18.37	4	20.00	**0**	**0.00**	**4**	**28.57**	8	18.18	1	20.00	2	11.76	7	21.88
Participant describes being receptive to information after they have had time to learn about condition/thought about questions to ask their healthcare professional	7	14.29	4	20.00	2	20.00	1	7.14	7	15.91	**0**	**0.00**	3	17.65	4	12.50
Participant describes being receptive to information a month after diagnosis	5	10.20	2	10.00	**0**	**0.00**	1	7.14	3	6.82	**2**	**40.00**	1	5.88	4	12.50

Timing of 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 describes being receptive to information after the shock of diagnosis	18	36.73	**14**	**48.28**	**4**	**21.05**	**9**	**60.00**	9	27.27	**10**	**50.00**	8	28.57
Participant describes being receptive from the beginning (diagnosis)	13	26.53	6	20.69	**7**	**36.84**	**2**	**13.33**	11	33.33	**3**	**15.00**	10	35.71
Participant describes being receptive to information after treatment	9	18.37	3	10.34	5	26.32	**1**	**6.67**	7	21.21	2	10.00	6	21.43
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	9	18.37	6	20.69	3	15.79	3	20.00	6	18.18	5	25.00	4	14.29
Participant describes being receptive to information after they have had time to learn about condition/thought about questions to ask their healthcare professional	7	14.29	6	20.69	1	5.26	2	13.33	5	15.15	4	20.00	3	10.71
Participant describes being receptive to information a month after diagnosis	5	10.20	5	17.24	**0**	**0.00**	**4**	**26.67**	1	3.03	4	20.00	1	3.57

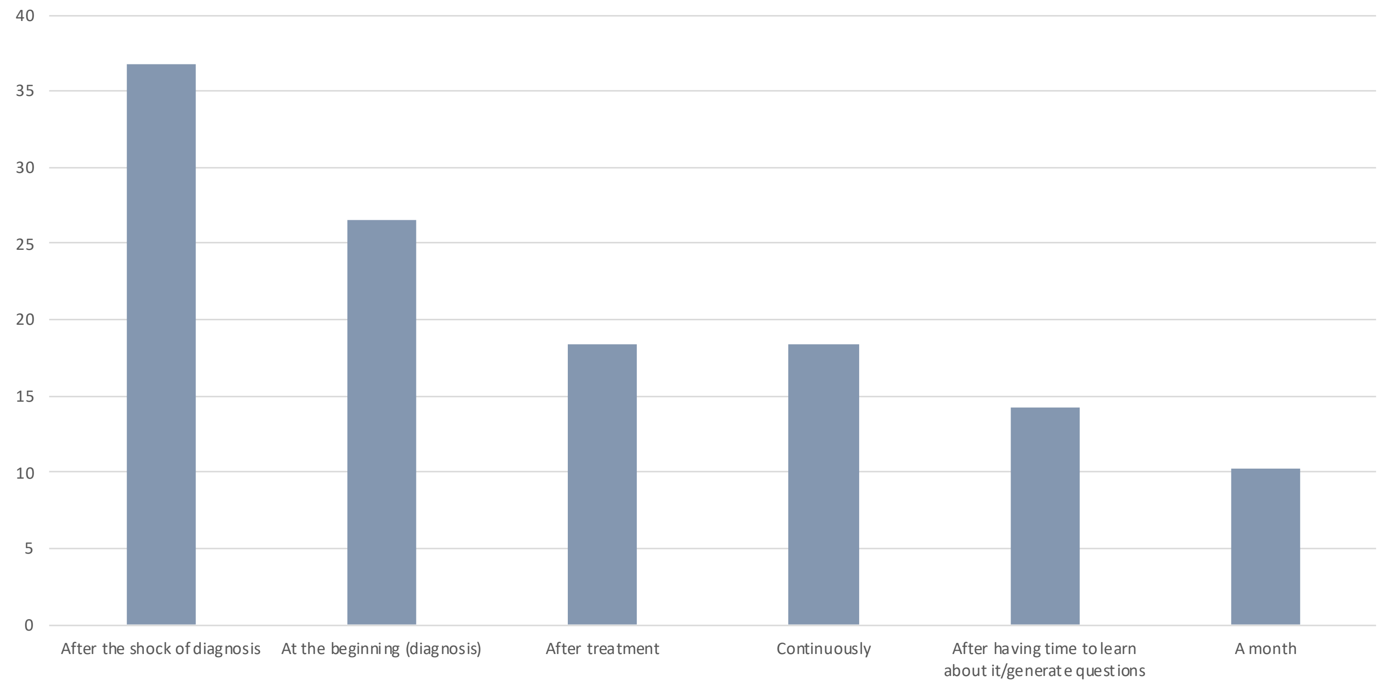

Figure 6.7: Timing of information

Table 6.10: Timing of information – subgroup variations

Timing of information	Reported less frequently	Reported more frequently
Participant describes being receptive to information after the shock of diagnosis	Early (Stages 0 and I) University	Invasive (Stage III) Trade or high school Regional or remote Mid to low status
Participant describes being receptive from the beginning (diagnosis)	Invasive (Stage III) Advanced (Stage IV) Regional or remote Mid to low status	Early (Stages 0 and I) Carer to someone with bladder cancer University
Participant describes being receptive to information after treatment	Carer to someone with bladder cancer Regional or remote	-
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	Invasive (Stage III)	Advanced (Stage IV)
Participant describes being receptive to information after they have had time to learn about condition/thought about questions to ask their healthcare professional	Carer to someone with bladder cancer	-
Participant describes being receptive to information a month after diagnosis	Invasive (Stage III) University	Carer to someone with bladder cancer Regional or remote

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having an overall positive experience (n=22, 44.90%). There were 13 participants (26.53%) that described an overall positive experience, with the exception of one or two occasions, 9 participants (18.37%) that had an overall negative experience and 4 participants (8.16%) that had an overall negative experience.

Participants describes health professional communication as being overall positive

You know, I'm more than happy they have kept in touch with me. I've got a brilliant GP, you know, he'll ring me up and talk to me if he's got any issues. Well, if something comes up. The doctor down there, they've been very straightforward. He lists what, what's gotta to be done, and why it's got to be done. The guy that did the operation. So I feel I'm in pretty, pretty good hands. There's nothing hidden.
Participant 011_2022AUBLC

Yeah, it's really fantastic. They're followed me up often. It was a period of time where I wasn't doing my check-ups as often as I should, and they were calling me and making sure that they were getting me back on track, it has been fantastic.
Participant 024_2022AUBLC

Well, both the specialist and the GP were pretty informative. So. My specialist is available by email

or by phone if I need him. So yeah, they're pretty accessible.
Participant 027_2022AUBLC

Participants describes health professional communication as being overall positive, with the exception of one or two occasions

Yeah. Look, it was pretty good. I think the only letdown for NAME was, like I said to you, we did a lot of telehealth consultations and. To me, I just feel like. I don't know what I feel like. I feel like I feel let down that. Erm. That something so serious was treated medically over the phone. Yes, that's how I feel. I feel something like that. You need to be face to face. I think the patient needs to be seen physically by the doctor. I mean, I'm even talking after having his bladder removed, you know, like, how do you assess how someone is managing a stoma or wound care and all that kind of thing when you're doing it via telehealth? I'm not saying there weren't times we didn't go. We did, but not often enough.
Carer 002_2022AUBLC

It's been varied. GP Yeah, as I said, lucky to be alive. Um, my surgeon, absolutely fabulous. Uh, and the urology nurse and the hospital, absolutely fabulous. I can't fault them in any way. They're the reason that I'm alive and so well today and managing so well today. And I know if I had a problem, I could pick up the phone to any of them. And I would be taken seriously. And they would seem.
Participant 032_2022AUBLC

Oh, in the most part. Very good. I think I had one bad experience. That wasn't very difficult. I just got rid of him.
Participant 020_2022AUBLC

Participants describes health professional communication as being overall negative

Um. Well, the conversation. I actually like the urologist, but the conversations with him were pretty hit and miss because they took place over the phone at a time when I didn't know when to expect the call. I didn't have my questions ready or when I did have questions ready, we had children in the car, so it wasn't really appropriate conversation. So I think that that could have been better. The oncologist, he was in the private sector. The oncologist was in the public sector. He he has the manner where he doesn't make eye contact with you. So it's very hard to feel validated or understood. He told me that, you know, if I what was my problem? About having my bladder removed because if I had breast cancer, I would have lost the breast by now. So I found that really difficult. That was a real conversation stopper from my my part when I had went out with the nurse that was supposed to be the coordinator. She and another person sat with their backs to me and with the computer just after I'd had my first appointment sorting out appointments. But I may as well would not have been there. I felt really very much like in an inanimate part of the procedure. So that's been pretty ordinary. Arriving in the four appointments I rarely get greeted with hello, it's sort of name Medicaid card sort of, and it's all so regimented. It's a horrible experience.
Participant 002_2022AUBLC

Not very well at first. I just had to find it out myself. Just read the discharge instructions or the pathology report. They hardly tell you anything. They just expected that I knew. I didn't, actually. When I went, after the surgery, they didn't explain at all.
Participant 013_2022AUBLC

Well, as I said, it's very poor. I think that I think both urologists have different personalities, but very poor in their communication. And I feel like it's visiting a factory. You know, you're going in there and you meet them, you pay the bill and you go. And it's there's not, as I say, and the current urologist has a practise nurse and and she just keeps saying, you know, doctors are very busy. Doctors very busy is very important. And I don't think that's really appropriate. When you're a patient and particularly a private patient, you're paying a tremendous amount of money. Yeah, because even though I've got top private health funding, you get very little back. Um, so I think communication is the biggest, it's the biggest concern I have.
Participant 008_2022AUBLC

Participants describes health professional communication as being a mix of positive and negative

With my GP. Brilliant. Mm hmm. Um. But some of the other professionals could be better work.
Participant 040_2022AUBLC

Hmm. Boy, that's, that's hard because we see so many people during, to try and sort of say, well, okay, the last two years, have you put an overall thing on communication? Some people have, some people some areas are excellent, either in other areas that are hopeless. And again, then even gets down to the individuals. You know, and I've had surgeons that, uh, excellent communicators and they see you as a, as a person, not just not just a problem or a yeah or, or an up or an operation that they need to. Um, but that, that runs that whole gamut. Whenever you have you human interaction, you get the good, you get the bad. Um, overall, look, the majority of communication we're talking about? I would say. 60% good. Yeah. Yeah. Yeah.
Participant 035_2022AUBLC

Table 6.11: Healthcare professional communication.

Healthcare professional 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	%
Participants describes health professional communication as being overall positive	22	44.90	7	35.00	6	60.00	8	57.14	21	47.73	1	20.00	6	35.29	16	50.0
Participants describes health professional communication as being overall positive, with the exception of one or two occasions	13	26.53	6	30.00	3	30.00	3	21.43	12	27.27	1	20.00	5	29.41	8	25.0
Participants describes health professional communication as being overall negative	9	18.37	6	30.00	1	10.00	1	7.14	8	18.18	1	20.00	6	35.29	3	9.38
Participants describes health professional communication as being a mix of positive and negative	4	8.16	1	5.00	0	0.00	2	14.29	3	6.82	1	20.00	0	0.00	4	12.5
Other/No response	5	10.20	1	5.00	0	0.00	2	14.29	3	6.82	2	40.00	0	0.00	5	15.6

Healthcare professional 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	%
Participants describes health professional communication as being overall positive	22	44.90	14	48.28	7	36.84	6	40.00	15	45.45	10	50.00	11	39.2
Participants describes health professional communication as being overall positive, with the exception of one or two occasions	13	26.53	7	24.14	6	31.58	3	20.00	10	30.30	4	20.00	9	32.1
Participants describes health professional communication as being overall negative	9	18.37	4	13.79	5	26.32	4	26.67	5	15.15	4	20.00	5	17.8
Participants describes health professional communication as being a mix of positive and negative	4	8.16	3	10.34	1	5.26	1	6.67	3	9.09	1	5.00	3	10.7
Other/No response	5	10.20	4	13.79	1	5.26	2	13.33	3	9.09	2	10.00	3	10.7

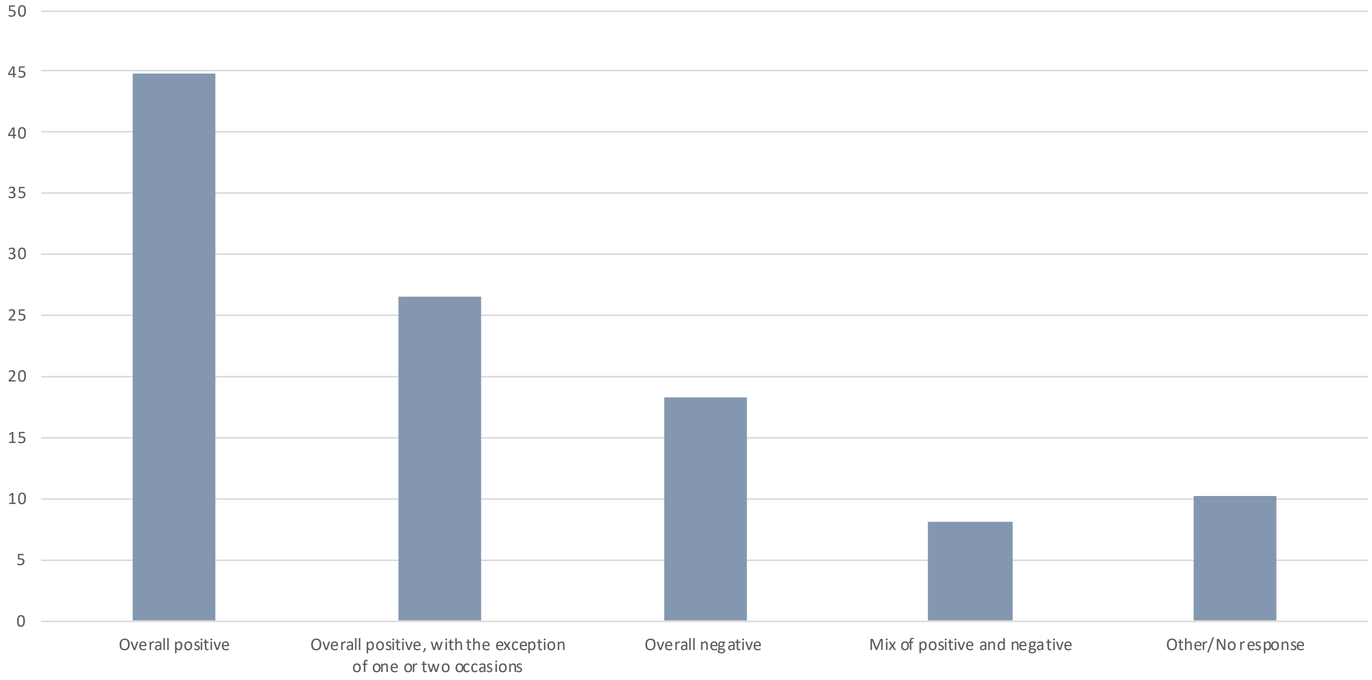

Figure 6.8: Healthcare professional communication

Table 6.12: Healthcare professional communication – subgroup variations

Healthcare professional communication	Reported less frequently	Reported more frequently
Participants describes health professional communication as being overall positive	Carer to someone with bladder cancer	Invasive (Stage III) Advanced (Stage IV)
Participants describes health professional communication as being overall negative	Advanced (Stage IV)	Early (Stages 0 and I) Female

Healthcare professional communication (Rationale for response)

Participants described reasons for positive or negative communication with healthcare professionals.

Participants that had positive communication, described the reason for this was because of holistic, two-way, supportive and comprehensive conversations (n=18, 36.73%), and this was followed by participant describing good communication with no particular reason given (n=17, 34.69%).

The main reasons for negative communication was limited communication that was not supportive, or empathetic (n=10, 20.41%), that information about treatment being withheld or given too late (n=8, 16.33%), and was limited in relation to their understanding of the condition (n=6, 12.24%)

Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)

You know, I'm more than happy they have kept in touch with me. I've got a brilliant GP, you know, he'll ring me up and talk to me if he's got any issues. Well, if something comes up. Um. Yeah, and. Yeah. The doctor down there, they've been very straightforward. He lists. What? What's gotta to be done? And why it's got to be done. The guy that did the operation. So I feel I'm in pretty, pretty good hands. There's nothing hidden. It's also the ups and downs of doing
Participant 011_2022AUBLC

There's been really good despite the speciaists that I had were really honest and they told me that yeah he always told me that this time that doesn't work this time you know what will be considering you have to have your radical cystectomy. And he took it to a board. He said, I've got a panel of specialists. He said, like the the time before I had the gemcitabine. He said, Well, I took it to the board and because it hasn't become invasive yet, he said, that we'll try this gemcitabine. And he said, this is your last chance. He said, because if it keeps on, yeah. Like he was pretty honest. He said that they're worried about it spread like going through the wall your bladder and he said if it keeps coming back, you know, he said it is more highly likely because it's high grade that it will go through all of your bladder. So he was really honest about the treatment. Then he suggested, that I go and see the the other specialist who does the the operation. And he sort of referred me on to him, you know, really honest. And it was really good. You know, it was the first two years of the treatment I was with him.
Participant 044_2022AUBLC

Oh, wonderful. Absolutely wonderful. Look at the oncologist. He. He just told me to ring him if I've got any problems. That was when I was going through surgery and things like that. And he would say, don't wait to ring his room. So I had his pager number as well. And I could I knew I could ring. And also the cancer, where I was having the chemo, the charge nurse, I guess she was the one that ran the unit. She was always available. If you had any queries or questions, you could bring them up and then they would contact the oncologist for you.
Participant 039_2022AUBLC

Participant describes healthcare communication as good, with no particular reason given

Overall, probably. Good. I say not great. Not satisfactory, but good.
Participant 016_2022AUBLC

I'm so lucky. So all the way through the people I was put on to were fantastic, post-operative care, you know, just fantastic.
Participant 022_2022AUBLC

PARTICIPANT: 90% good. Yep.

INTERVIEWER: Okay. That's good.

PARTICIPANT: Because the God surgeon lost 10% or it'd be a 100%
Participant 019_2022AUBLC

Participant describes healthcare communication as good, yet hard to access or make appointments with healthcare professionals

Well, I've got a great GP so I can openly talk to her. And, yeah, my urologist is a super busy man. He's the he's not easy to. You know, I have found that I could have make appointments. He's easy to talk but, yeah, but it's a communication. It's good. If I got a question. Mainly I've talked to them, my GP, and she can see she can help me to get to the answer if I need to. She said like, um, you know, if

it takes a long time to get an appointment with urologists and she said she's going to talk to him directly and it's very helpful. So yeah, I've got a very good quality in communication at the moment. I think the specialist they are nice, but it is hard to communicate with them.
Participant 015_2022AUBLC

Pretty good. Once you do get a hold of the doctor, it's been pretty good. They're very helpful. I've still got the contact numbers for the nurse specialist at the urology and she's always been really helpful. I've still got the contact numbers for the stoma therapy nurses and I can pick up the phone any time and speak to them if I have any issues. But other than that, yeah, everything's pretty fine as long as you get to speak to a doctor. They're not easy to get hold of either.
Participant 031_2022AUBLC

Once you can get hold of them. Good. Getting hold of them isn't always easy. And I think if there's ever a weak link in the chain, that's it. The professionals are, surgeons particularly and are very difficult to get hold of.
Participant 034_2022AUBLC

Participant describes health professional communication as being dismissive (One way conversation)

PARTICIPANT I've only spoken to the urologist. I've only spoken to the urologist.

INTERVIEWER Yeah. And what's that been like, do you think, in terms of communication?

PARTICIPANT Uh. Oh, well, I don't I don't think it's that good because they just tell you, you know, with me, they just say, well, you know, we're going to do this, we're going to do that, and this is when we're going to do it.
Participant 007_2022AUBLC

Well, as I said, it's very poor. I think that I think both urologists have different personalities, but very poor in their communication. And I feel like it's visiting a factory. You know, you're going in there and you meet them, you pay the bill and you go. And it's there's not, as I say, and the current urologist has a practise nurse and and she just keeps saying, you know, doctors are very busy. Doctors very busy is very important. And I don't think that's really appropriate. When you're a patient and particularly a private patient, you're paying a tremendous amount of money. Yeah, because even though I've got top private health funding, you get very little back. Um, so I think communication is the biggest, it's the biggest concern I have. Yeah. With the health care treatment?
Participant 008_2022AUBLC

Um, very factual and uh, but not really giving options. It's just showing you what is the next step if you want to get rid of it.
Carer 005_2022AUBLC

Participant describes health professional communication as limited in relation to information about treatment being withheld or given too late

Well, I guess because it's gone on so long. I probably haven't had a lot of information. I don't seem to have got any further with knowing why or how, other than I have read that it's really hard to cure. They do recur. You know, sometimes it's really hard to get rid of so bladder cancer. So that's all I assume is the fact that I haven't got sick or anything is good is a bonus. And probably if I was feeling sick or anything, I would want to have more. Information, I guess.
Participant 025_2022AUBLC

Um, very factual and uh, but not really giving options. It's just showing you what is the next step if you want to get rid of it.
Carer 005_2022AUBLC

Um. With the the oncologist. I have Professor NAME. He's been fantastic. He's explained things. Very, very clearly. And he's giving me answers to questions that I trust. Um, I guess, um, in that he's sort of giving me a lot of hope for a successful treatment and so forth. And he's backed it up with reasons. If, for example, you know, you have non-muscle invasive cancer and it's this and it's that, you respond well to the BCG and blah, blah, blah, blah, blah, that sort of thing. So he's put me up into the high nineties at been successful in keeping my bladder and so forth, you know, those sorts of things. Um, so. Um. Yeah. Yeah. The, um. Yeah, I do trust what he's told me, I think above, you know, I like my surgeon, nd he's actually a really nice bloke and he's quite a funny guy. Yeah, but, um, at times I've wanted more answers and we've argued about things like, okay, part of my treatment is I had to get circumcised right, I know that sounds weird, but I, I wasn't circumcised when I was a child and the

nurses at the hospital actually said to me, Hey, um, the catheter is really were painful. And they said, I think you need to be, um, is there any reason you're not circumcised like these? You know, blah, blah, blah, blah. I should not just it wasn't done when I was a child they weren't doing at that time. It wasn't done routinely. And why the nurses said, yeah, it's, it's hard with the catheters, you know, maybe you should talk to your urologist about it. And I did, and he's like, no, I don't believe in it. I'm a conscientious objector, you know, I don't believe in doing these things. And I'm like, well, the nurses suggested it and it took a nurse to actually ring him up and give him a blast. You know, honestly, that's just me, you gutsy powerhouse. You, you know, she rang up and blasted him. Oh, really nurse, and you've made that diagnosis have you? And she's like, yes, I have. Yes, I have. I mean, he's come down to see me in the recovery and said, I don't like to admit it but she was right.
Participant 001_2022AUBLC

Participant describes health professional communication as limited in relation to their understanding of the condition

Um. I guess it's been I guess it's been good luck. It's hard. Like even when you were in hospital after major surgery, it's hard. It's hard to get information and it's hard to, to feel supported and, and living in the country. It's hard because you, you know, you can't get to help very quickly. Yes. And that you can't get to the hospital and the doctor that did the operation. So if you go to LOCAL HOSPITAL, nobody's going to have a clue and you just going to be worse off. So you'd rather not talk anymore. Well, damage can be caused by people who don't know anything. And and so, you know, I think that at the times that I've had, had things go wrong. It's been horrible to have to go to local hospitals because they've just got no clue of my actual problem. Whereas if I was in CITY obviously I'd be going to the hospital that the specialist was at and you'd be getting looked after by people who knew what was happening.
Participant 026_2022AUBLC

But, you know, the consultations are not all that long. But I've got to say, Doctor, in these consultations, the consultations with these registrars are very short, and sharp, because it'd be more people seeing him and seeing him. And that was a ten minute consultations. But the last consultation I had with Dr. NAME went for nearly an hour, sat me down and got me right through it, told me everything, and told me what to do to stopgoing to the toilet so much, if not all that sort of thing. So he's been a fantastic doctor and he's been brilliant. He's actually phoned me, as I said before, at home a few times to give me a progress on what, on what he thinks, And that everything's okay. The registrars have been okay, but the people are lining up to see them, left right and centre and my GP's they don't really, I have spoken to the GP a couple of times about it and they don't really know much about bladder cancer. They're not specialists, said that specialist Dr. NAME. The he's been pretty bloody good. I've seen him three times. As I said, it's very expensive. To see him for me. But he's good.
Participant 021_2022AUBLC

When you go to the nurse to change the dressing and the nurse says. Oh, I don't know what to do. Yeah. So you end up in theatre where you end up a theatre with your backpack still on your back, on your bed, when you're required to have some antibiotics before you go into surgery and they can't find your antibiotics.
Participant 005_2022AUBLC

Participant describes health professional communication as limited, with no particular reason given

The urologist now is really good that we have but yeah, the first urologist we had and the oncologist definitely not. I'd say it's been pretty poor
Carer 003_2022AUBLC

With my GP. Brilliant. Mm hmm. Um. But some of the other professionals could be better work.
Participant 040_2022AUBLC

Participant describes health professional communication as limited in relation to care coordination and conflicting information between healthcare professionals.

Well, the conversation. I actually like the urologist, but the conversations with him were pretty hit and miss because they took place over the phone at a time when I didn't know when to expect the call. I didn't have my questions ready or when I did have questions ready, we had children in the car, so it wasn't really appropriate conversation. So I think that that could have been better. The oncologist, he was in the private sector. The oncologist was in the public sector. He he has the manner where he doesn't make eye contact with you. So it's very hard

to feel validated or understood. He told me that, you know, if I what was my problem? About having my bladder removed because if I had breast cancer, I would have lost the breast by now. So I found that really difficult. That was a real conversation stopper from my my part when I had went out with the nurse that was supposed to be the coordinator. She and another person sat with their backs to me and with the computer just after I'd had my first appointment sorting out appointments. But I may as well would not have been there. I felt really very much like in an inanimate part of the procedure. So that's been pretty ordinary. Arriving in the four appointments I rarely get greeted with. Hello, it's sort of name Medicaid card sort of, and it's all so regimented. It's a horrible experience. Are the nurses very generally that give the treatment are empathetic, but they don't have the information and they can't get it to me because the specialist is not around when you have treatment. So when there was issues, all that information was coming third hand and there was a problem at one stage because the stent I had in was causing problems and impacting my bit, their ability to give me that treatment because of bleeding. And that was really difficult. And when I was in hospital, I was told was going to do theatre one minute, next minute. The other team was saying, no, you're not, and they couldn't agree on it. And then I was told I had to coordinate the conversation. So it was really, really, really difficult. So yeah, teh communication was what I thought was awful. I think it'd be really helpful to have somebody there that was like a case manager that could help you. My my GP tried to do that, but her all the communication she got was, you know, a week or two later in the form of the letter which didn't really answer the question.
Participant 002_2022AUBLC

Table 6.13: Healthcare professional communication (Rationale for response)

Healthcare professional communication (Rationale for response)	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 health professional communication as holistic (Two way, supportive and comprehensive conversations)	18	36.73	7	35.00	4	40.00	7	50.00	18	40.91	0	0.00	5	29.41	13	40.63
Participant describes healthcare communication as good, with no particular reason given	17	34.69	6	30.00	4	40.00	4	28.57	14	31.82	3	60.00	5	29.41	12	37.50
Participant describes healthcare communication as good, yet hard to access or make appointments with healthcare professionals	3	6.12	1	5.00	0	0.00	2	14.29	3	6.82	0	0.00	1	5.88	2	6.25
Participant describes health professional communication as being dismissive (One way conversation)	10	20.41	6	30.00	0	0.00	3	21.43	9	20.45	1	20.00	4	23.53	6	18.75
Participant describes health professional communication as limited in relation to information about treatment being withheld or given too late	8	16.33	6	30.00	1	10.00	0	0.00	7	15.91	1	20.00	5	29.41	3	9.38
Participant describes health professional communication as limited in relation to their understanding of the condition	6	12.24	3	15.00	2	20.00	1	7.14	6	13.64	0	0.00	4	23.53	2	6.25
Participant describes health professional communication as limited, with no particular reason given	4	8.16	0	0.00	1	10.00	2	14.29	3	6.82	1	20.00	0	0.00	4	12.50
Participant describes health professional communication as limited in relation to care coordination and conflicting information between healthcare professionals.	3	6.12	3	15.00	0	0.00	0	0.00	3	6.82	0	0.00	3	17.65	0	0.00

Healthcare professional communication (Rationale for response)	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 health professional communication as holistic (Two way, supportive and comprehensive conversations)	18	36.73	9	31.03	8	42.11	3	20.00	14	42.42	5	25.00	12	42.86
Participant describes healthcare communication as good, with no particular reason given	17	34.69	12	41.38	5	26.32	7	46.67	10	30.30	8	40.00	9	32.14
Participant describes healthcare communication as good, yet hard to access or make appointments with healthcare professionals	3	6.12	2	6.90	1	5.26	0	0.00	3	9.09	2	10.00	1	3.57
Participant describes health professional communication as being dismissive (One way conversation)	10	20.41	4	13.79	6	31.58	2	13.33	8	24.24	3	15.00	7	25.00
Participant describes health professional communication as limited in relation to information about treatment being withheld or given too late	8	16.33	5	17.24	3	15.79	3	20.00	5	15.15	3	15.00	5	17.86
Participant describes health professional communication as limited in relation to their understanding of the condition	6	12.24	3	10.34	3	15.79	1	6.67	5	15.15	3	15.00	3	10.71
Participant describes health professional communication as limited, with no particular reason given	4	8.16	3	10.34	1	5.26	2	13.33	2	6.06	2	10.00	2	7.14
Participant describes health professional communication as limited in relation to care coordination and conflicting information between healthcare professionals.	3	6.12	1	3.45	2	10.53	1	6.67	2	6.06	1	5.00	2	7.14

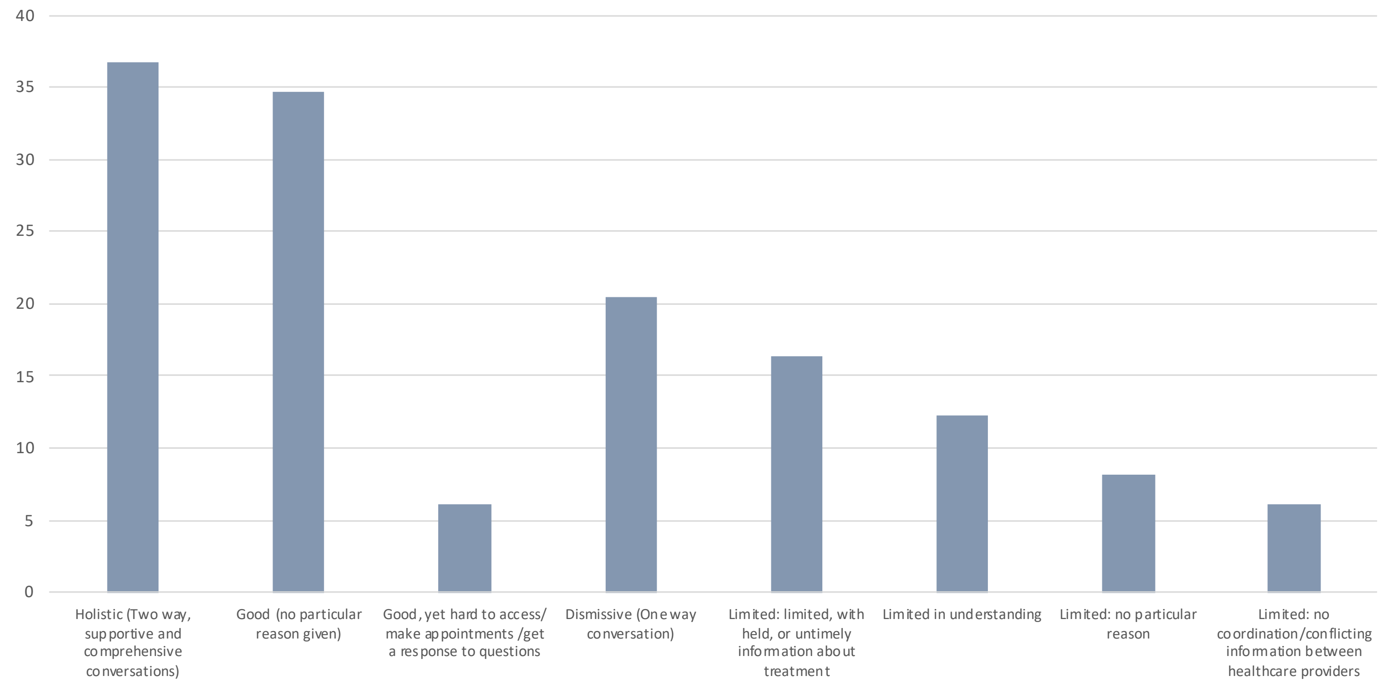

Figure 6.9: Healthcare professional communication (Rationale for response)

Table 6.14: Healthcare professional communication (Rationale for response) – subgroup variations

Healthcare professional communication (Rationale for response)	Reported less frequently	Reported more frequently
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	Carer to someone with bladder cancer Regional or remote Mid to low status	Advanced (Stage IV)
Participant describes healthcare communication as good, with no particular reason given	-	Carer to someone with bladder cancer Regional or remote
Participant describes healthcare communication as good, yet hard to access or make appointments with healthcare professionals	-	
Participant describes health professional communication as being dismissive (One way conversation)	Invasive (Stage III)	University
Participant describes health professional communication as limited in relation to information about treatment being withheld or given too late	Advanced (Stage IV)	Early (Stages 0 and I) Female
Participant describes health professional communication as limited in relation to their understanding of the condition	Carer to someone with bladder cancer	Female

Partners in health

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 scales; knowledge, coping, recognition and treatment of symptoms, adherence to treatment and total score. A higher score denotes a better understanding and knowledge of disease. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 6.15.

The overall scores for the cohort were in the highest quintile for **Partners in health: Knowledge** (median=27.00, IQR=5.00), **Partners in health: Recognition and management of symptoms** (median=21.00, IQR=4.50), **Partners in health: Adherence to treatment** (median=14.00, IQR=4.00), indicating very good knowledge, very good recognition and management of symptoms, and very good adherence to treatment.

The overall scores for the cohort were in the second highest quintile for **Partners in health: Coping** (mean=16.32, SD=4.86), **Partners in health: Total score** (mean=75.15, SD=13.51) indicating good coping, and good overall ability to manage their health

The **Partners in Health questionnaire (PIH)** measures an individual's knowledge and confidence for managing their own health.

The **Partners in health: knowledge** scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. On average, participants in this study had very good knowledge about their condition and treatments.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in this study had a good ability to manage the effects of their health condition.

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average participants in this study had a very good ability to adhere to treatments and communicate with healthcare professionals.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average participants in this study had very good recognition and management of symptoms.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average participants in this study had a good overall knowledge, coping and confidence for managing their own health.

Table 6.15: Partners in health summary statistics

Partners in health scale (n=47)	Mean	SD	Median	IQR	Possible range	Quintile
Knowledge	25.62	5.08	27.00	5.00	0 to 32	5
Coping*	16.32	4.86	16.00	8.00	0 to 24	4
Recognition and management of symptoms	19.87	3.58	21.00	4.50	0 to 24	5
Adherence to treatment	13.34	3.60	14.00	4.00	0 to 16	5
Total score*	75.15	13.51	76.00	15.50	0 to 96	4

*Normal distribution use mean and SD as measure of central tendency

Partners in health by bladder cancer stage

Comparisons were made by Stage. There were 18 participants (42.86%) with early bladder cancer (Stages 0 and I), 10 participants (23.81%) with invasive bladder cancer (Stage III), and 14 participants (33.33%) with advanced bladder cancer (Stage IV).

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 6.16). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 6.17).

No significant differences were observed between participants by **bladder cancer stage** for any of the Partners in health scales.

Table 6.16: Partners in health by bladder cancer stage summary statistics and one-way ANOVA

Partners in health scale	Group	Number (n=42)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Coping	Early	18	42.86	16.22	4.91	Between groups	7.80	2	3.883	0.15	0.8620
	Invasive	10	23.81	17.30	5.68	Within groups	1012.60	39	25.965		
	Advanced	14	33.33	16.43	4.91	Total	1020.40	41	29.848		

Table 6.17: Partners in health by bladder cancer stage summary statistics and Kruskal-Wallis test

Partners in health scale	Group	Number (n=42)	Percent	Median	IQR	C^2	dF	p-value
Knowledge	Early	18	42.86	25.50	7.75	3.04	2	0.2183
	Invasive	10	23.81	28.00	2.75			
	Advanced	14	33.33	27.00	2.75			
Recognition and management of symptoms	Early	18	42.86	21.00	4.25	0.54	2	0.7634
	Invasive	10	23.81	22.00	3.00			
	Advanced	14	33.33	20.50	3.75			
Adherence to treatment	Early	18	42.86	14.00	3.75	3.86	2	0.1453
	Invasive	10	23.81	16.00	0.75			
	Advanced	14	33.33	14.50	2.75			
Total score	Early	18	42.86	76.00	12.25	2.04	2	0.3615
	Invasive	10	23.81	84.00	12.75			
	Advanced	14	33.33	78.00	18.00			

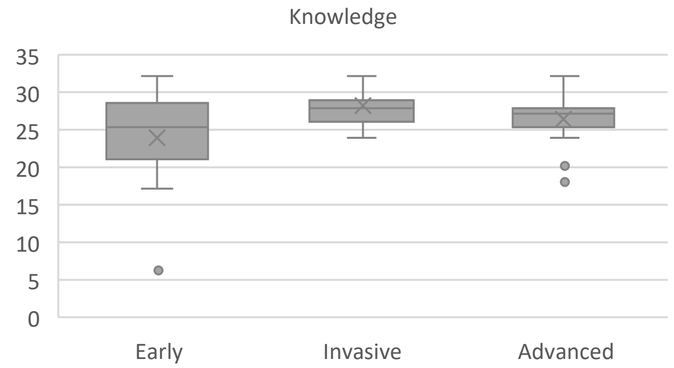

Figure 6.10: Boxplot of Partners in health: knowledge by bladder cancer stage

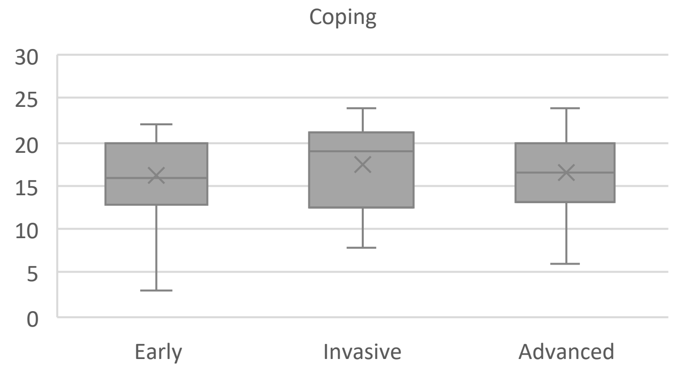

Figure 6.11: Boxplot of Partners in health: coping by bladder cancer stage

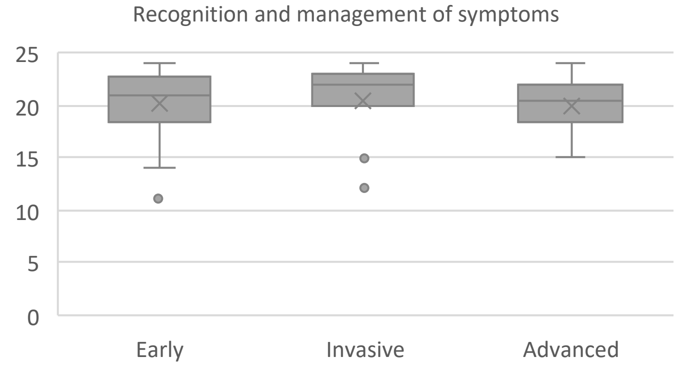

Figure 6.12: Boxplot of Partners in health: recognition and management of symptoms by bladder cancer stage

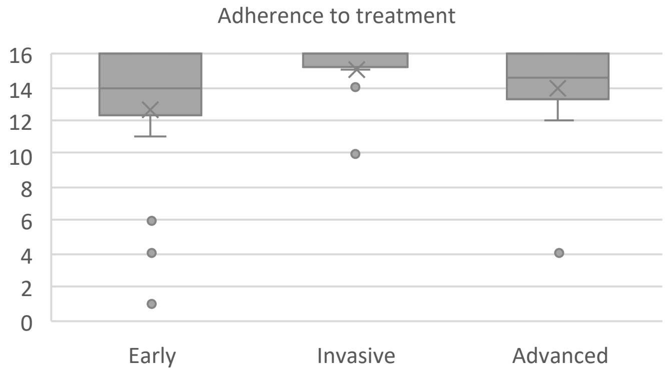

Figure 6.13: Boxplot of Partners in health: adherence to treatment by bladder cancer stage

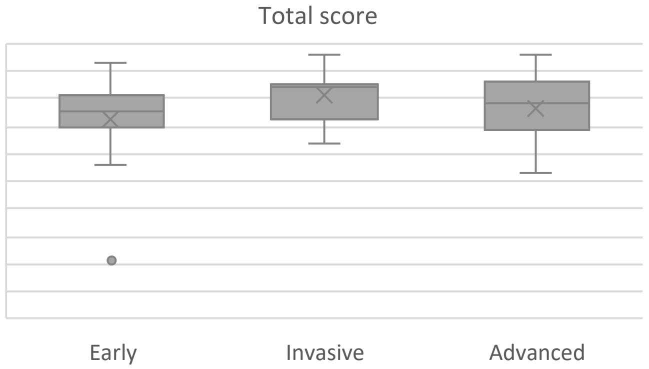

Figure 6.14: Boxplot of Partners in health Total score by bladder cancer stage

Partners in health by participant type

Comparisons were made by type of participant, there were 42 participants (89.36%) with bladder cancer and, 5 participants (10.64%) that were a carer to someone with bladder cancer.

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.18), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.19).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **Partners in health Adherence to treatment** scale [W = 182.00 , p = 0.0064] was significantly higher for participants in the patient subgroup (Median = 15.00, IQR = 2.75) compared to participants in the carer subgroup (Median = 11.00, IQR = 2.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **Partners in health Total score** scale [W = 165.50 , p = 0.0383] was significantly higher for participants in the patient subgroup (Median = 78.00, IQR = 15.50) compared to participants in the carer subgroup (Median = 68.00, IQR = 4.00).

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average, participants in the patient subgroup scored higher than participants in the carer subgroup. This indicates that, treatment adherence was very good for participants in the patient subgroup, and good for participants in the carer subgroup.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average, participants in the patient subgroup scored higher than participants in the carer subgroup. This indicates that overall knowledge, coping and confidence for managing their own health was very good for participants in the patient subgroup, and good for participants in the carer subgroup.

Table 6.18: Partners in health by participant type summary statistics and T-test

Partners in health scale	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Coping	Patient	42	89.36	16.55	4.99	0.93	45	0.3559
	Carer	5	10.64	14.40	3.36			

Table 6.19: Partners in health by participant type summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=47)	Percent	Median	IQR	W	p-value
Knowledge	Patient	42	89.36	27.00	5.00	134.00	0.3231
	Carer	5	10.64	25.00	4.00		
Recognition and management of symptoms	Patient	42	89.36	21.00	4.75	159.00	0.0632
	Carer	5	10.64	18.00	2.00		
Adherence to treatment	Patient	42	89.36	15.00	2.75	182.00	0.0064*
	Carer	5	10.64	11.00	2.00		
Total score	Patient	42	89.36	78.00	15.50	165.50	0.0383*
	Carer	5	10.64	68.00	4.00		

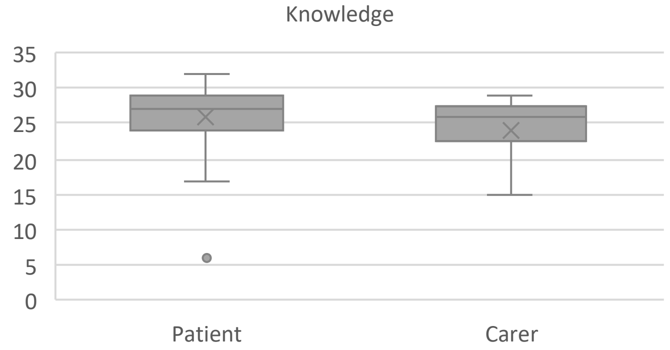

Figure 6.15: Boxplot of Partners in health: knowledge by participant type

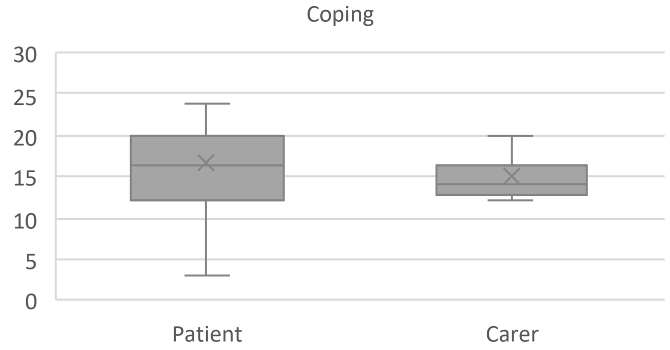

Figure 6.16: Boxplot of Partners in health: coping by participant type

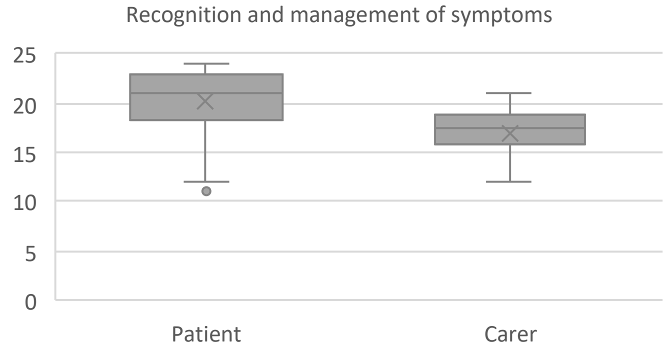

Figure 6.17: Boxplot of Partners in health: recognition and management of symptoms by participant type

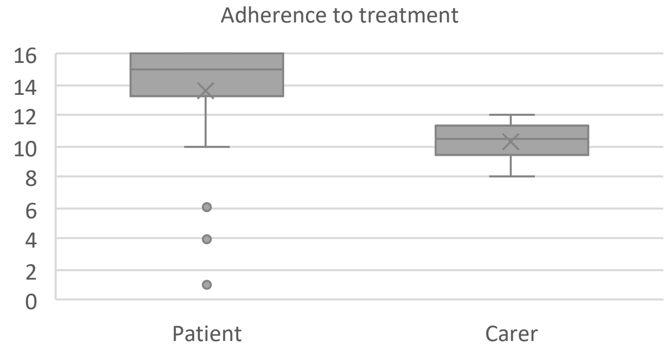

Figure 6.18: Boxplot of Partners in health: adherence to treatment by participant type

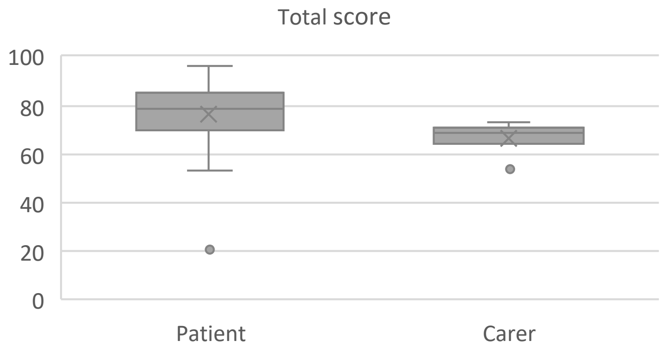

Figure 6.19: Boxplot of Partners in health Total score by participant type

Partners in health by gender

Comparisons were made by gender, there were 16 female participants (34.04%), and 31 male participants (65.96%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.20), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.21).

No significant differences were observed between participants by **gender** for any of the Partners in health scales.

Table 6.20: Partners in health by gender summary statistics and T-test

Partners in health scale	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Coping	Female	16	34.04	17.69	4.77	1.40	45	0.1680
	Male	31	65.96	15.61	4.83			

Table 6.21: Partners in health by gender summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=47)	Percent	Median	IQR	W	p-value
Knowledge	Female	16	34.04	28.00	3.50	300.50	0.2407
	Male	31	65.96	27.00	5.00		
Recognition and management of symptoms	Female	16	34.04	21.50	2.75	288.50	0.3661
	Male	31	65.96	20.00	5.00		
Adherence to treatment	Female	16	34.04	15.00	2.00	293.00	0.3020
	Male	31	65.96	14.00	4.50		
Total score	Female	16	34.04	81.00	14.00	314.00	0.1411
	Male	31	65.96	73.00	14.00		

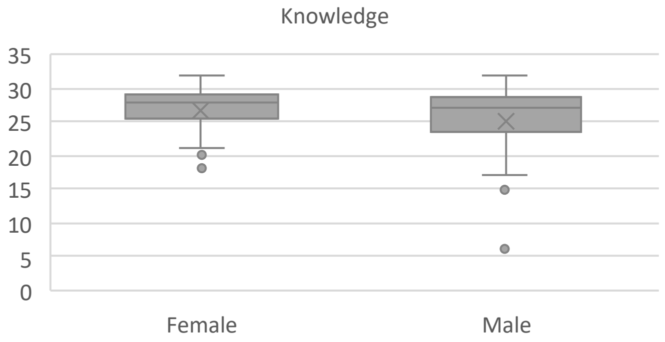

Figure 6.20: Boxplot of Partners in health: knowledge by gender

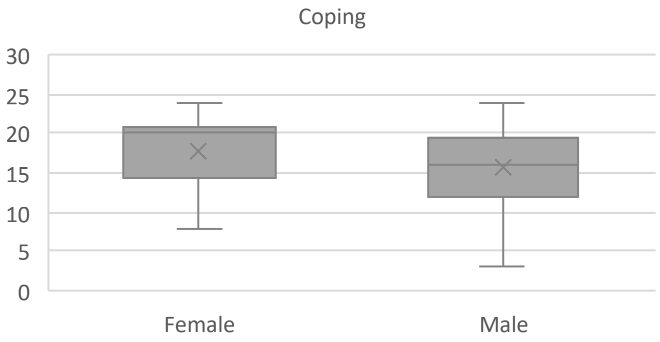

Figure 6.21: Boxplot of Partners in health: coping by gender

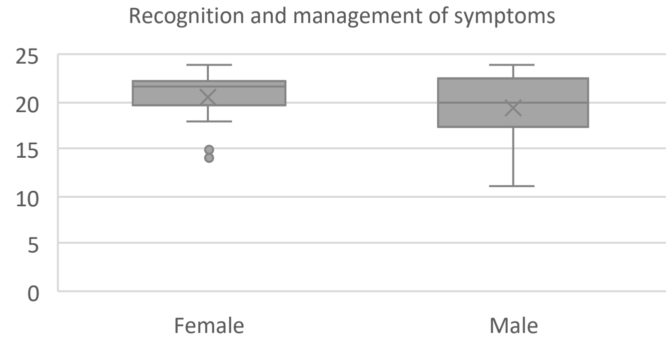

Figure 6.22: Boxplot of Partners in health: recognition and management of symptoms by gender

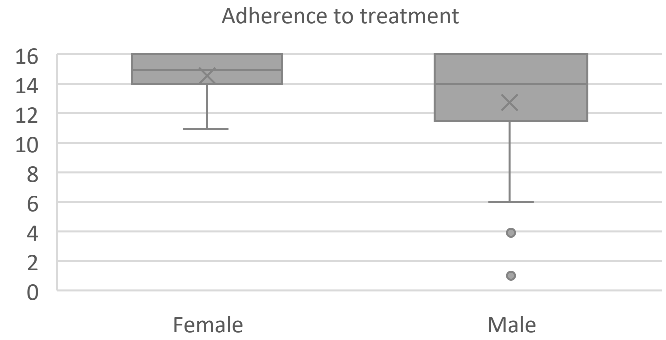

Figure 6.23: Boxplot of Partners in health: adherence to treatment by gender

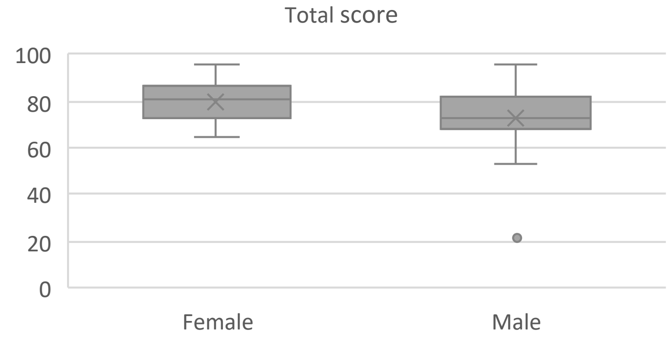

Figure 6.24: Boxplot of Partners in health Total score by gender

Partners in health by education

Comparisons were made by education status, between those with trade or high school qualifications (n=29, 61.70%), and those with a university qualification (n=18, 38.30%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.22), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.23).

No significant differences were observed between participants by **education** for any of the Partners in health scales.

Table 6.22: Partners in health by education summary statistics and T-test

Partners in health scale	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Coping	Trade or high school	29	61.70	16.10	4.10	-0.38	45	0.7038
	University	18	38.30	16.67	6.00			

Table 6.23: Partners in health by education summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=47)	Percent	Median	IQR	W	p-value
Knowledge	Trade or high school	29	61.70	27.00	4.00	196.50	0.1593
	University	18	38.30	28.50	6.00		
Recognition and management of symptoms	Trade or high school	29	61.70	20.00	4.00	222.50	0.4026
	University	18	38.30	21.50	5.75		
Adherence to treatment	Trade or high school	29	61.70	14.00	4.00	228.00	0.4625
	University	18	38.30	15.00	2.75		
Total score	Trade or high school	29	61.70	76.00	14.00	222.50	0.4052
	University	18	38.30	79.50	19.00		

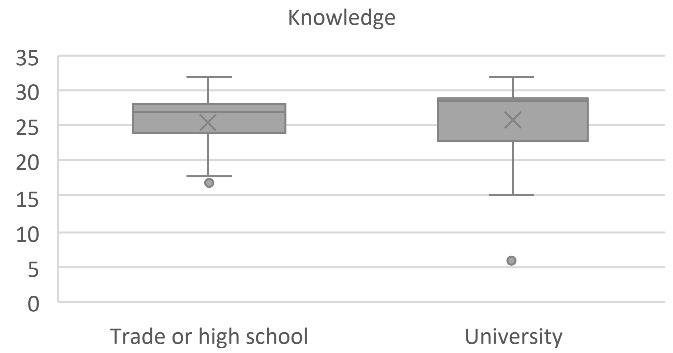

Figure 6.25: Boxplot of Partners in health: knowledge by education

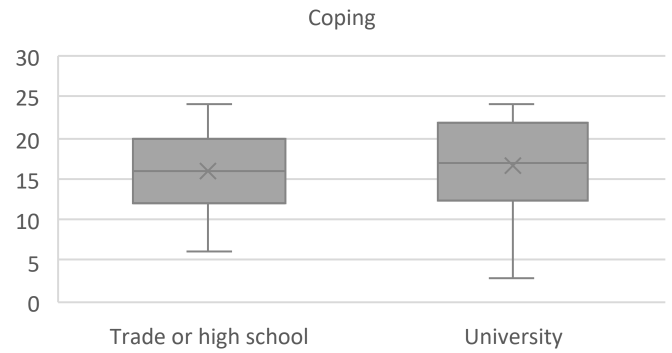

Figure 6.26: Boxplot of Partners in health: coping by education

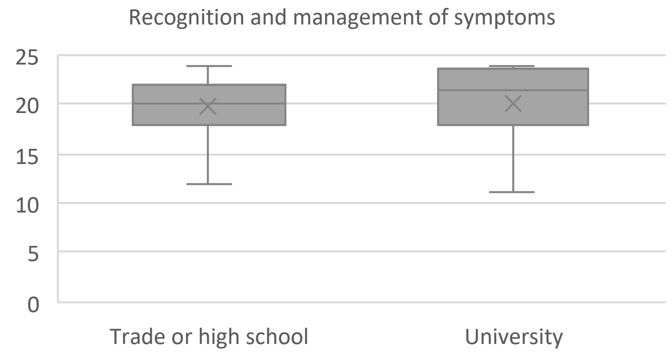

Figure 6.27: Boxplot of Partners in health: recognition and management of symptoms by education

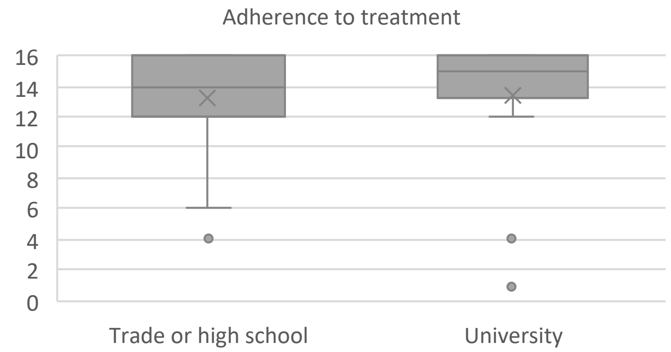

Figure 6.28: Boxplot of Partners in health: adherence to treatment by education

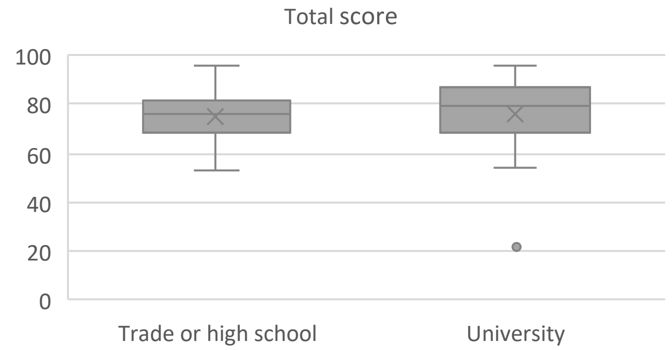

Figure 6.29: Boxplot of Partners in health Total score by education

Partners in health by location

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional or remote area (n=15, 31.91%) were compared to those living in a metropolitan area (n=32, 68.09%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.24), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.25).

No significant differences were observed between participants by **location** for any of the Partners in health scales.

Table 6.24: Partners in health by location summary statistics and T-test

Partners in health scale	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Coping	Regional or remote	15	31.91	15.33	5.59	-0.95	45	0.3466
	Metropolitan	32	68.09	16.78	4.50			

Table 6.25: Partners in health by location summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=47)	Percent	Median	IQR	W	p-value
Knowledge	Regional or remote	15	31.91	26.00	5.00	208.00	0.4700
	Metropolitan	32	68.09	27.00	5.00		
Recognition and management of symptoms	Regional or remote	15	31.91	20.00	6.50	209.00	0.4836
	Metropolitan	32	68.09	21.00	4.00		
Adherence to treatment	Regional or remote	15	31.91	15.00	3.00	273.50	0.4365
	Metropolitan	32	68.09	14.00	4.00		
Total score	Regional or remote	15	31.91	71.00	17.50	211.50	0.5224
	Metropolitan	32	68.09	76.50	12.50		

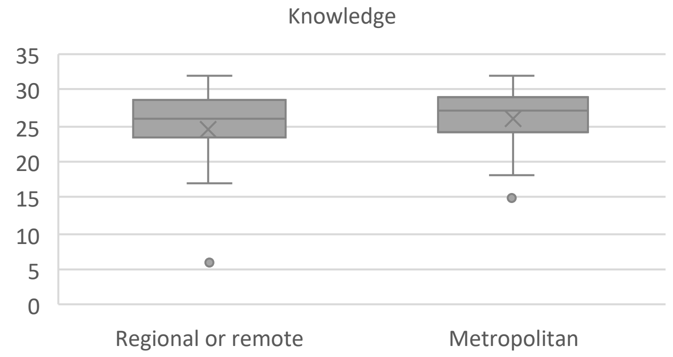

Figure 6.30: Boxplot of Partners in health: knowledge by location

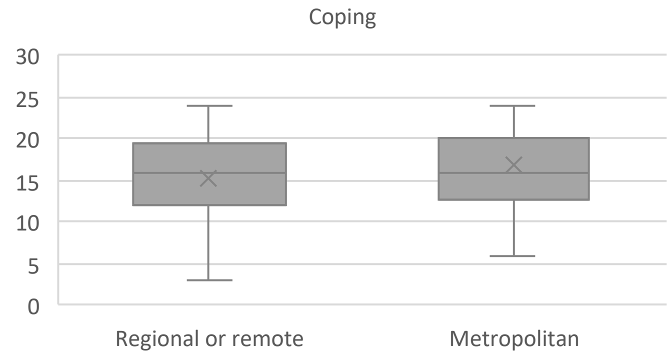

Figure 6.31: Boxplot of Partners in health: coping by location

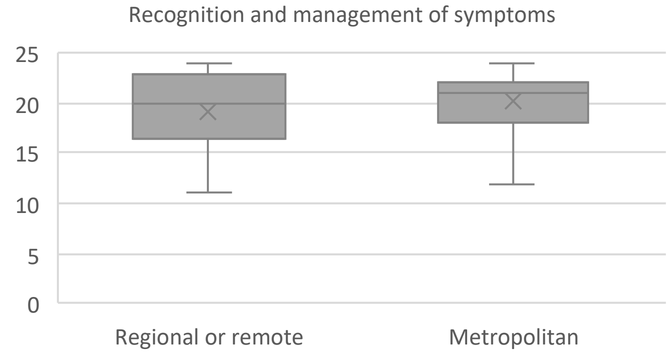

Figure 6.32: Boxplot of Partners in health: recognition and management of symptoms by location

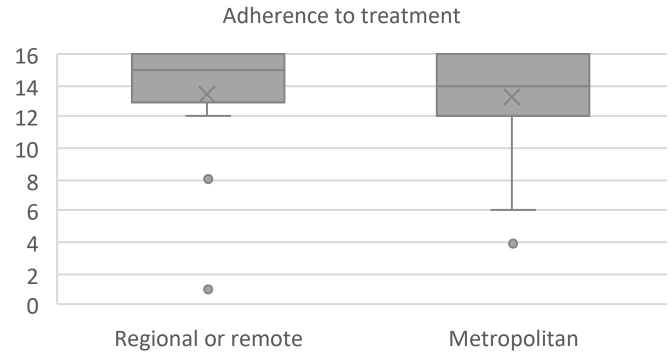

Figure 6.33: Boxplot of Partners in health: adherence to treatment by location

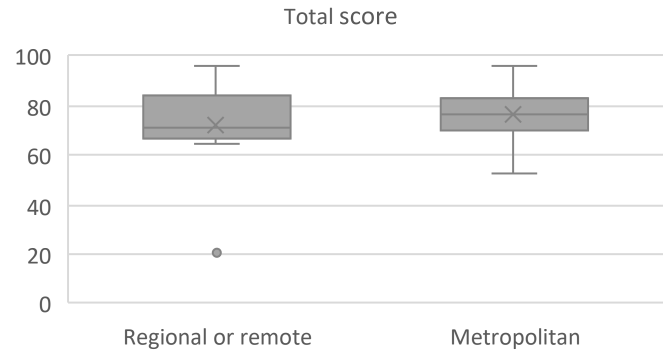

Figure 6.34: Boxplot of Partners in health Total score by location

Partners in health by socioeconomic status

Comparisons were made by socioeconomic status, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6 (n=20, 42.55%) compared to those with a higher SEIFA score of 7-10 (n=27, 57.45%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.26), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.27).

No significant differences were observed between participants by **socioeconomic status** for any of the Partners in health scales.

Table 6.26: Partners in health by socioeconomic status summary statistics and T-test

Partners in health scale	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Coping	Mid to low status	20	42.55	15.25	4.83	-1.31	45	0.1974
	Higher status	27	57.45	17.11	4.81			

Table 6.27: Partners in health by socioeconomic status summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=47)	Percent	Median	IQR	W	p-value
Knowledge	Mid to low status	20	42.55	25.50	3.50	182.00	0.0585
	Higher status	27	57.45	28.00	4.00		
Recognition and management of symptoms	Mid to low status	20	42.55	19.50	5.25	186.00	0.0706
	Higher status	27	57.45	21.00	3.00		
Adherence to treatment	Mid to low status	20	42.55	14.00	4.25	232.50	0.4108
	Higher status	27	57.45	15.00	3.00		
Total score	Mid to low status	20	42.55	72.00	13.75	187.50	0.0774
	Higher status	27	57.45	80.00	15.00		

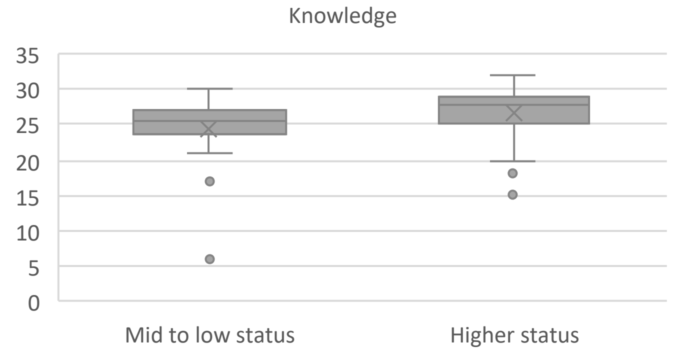

Figure 6.35: Boxplot of Partners in health: knowledge by socioeconomic status

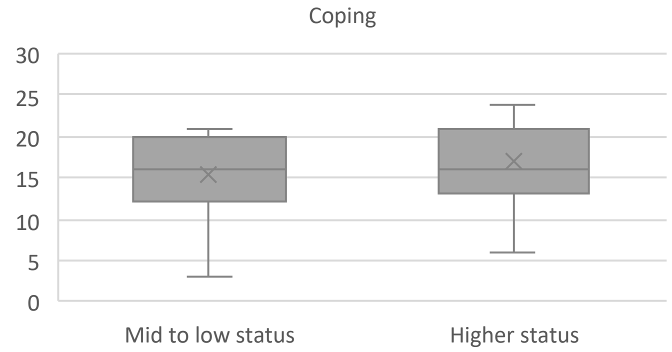

Figure 6.36: Boxplot of Partners in health: coping by socioeconomic status

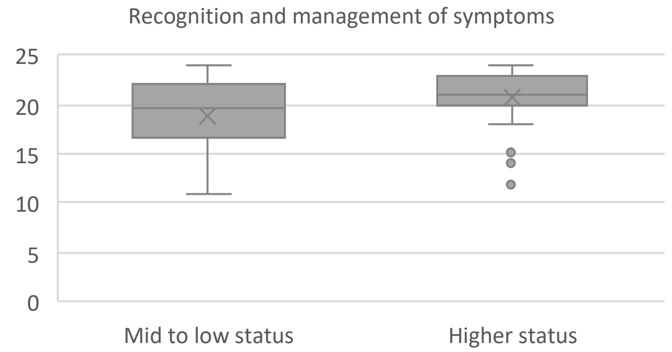

Figure 6.37: Boxplot of Partners in health: recognition and management of symptoms by socioeconomic status

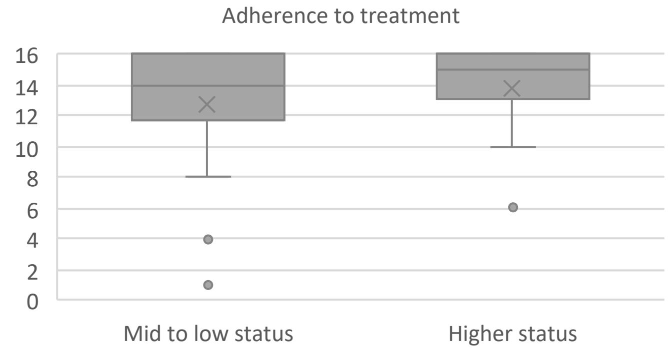

Figure 6.38: Boxplot of Partners in health: adherence to treatment by socioeconomic status

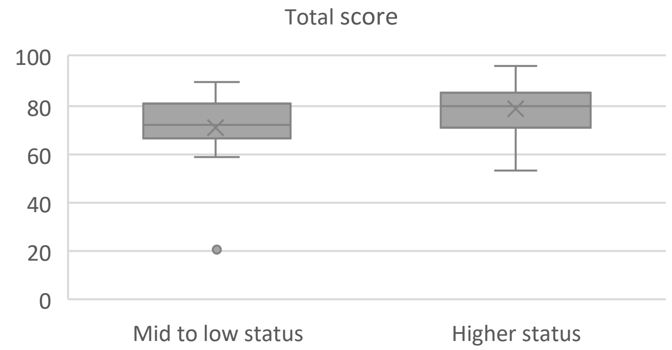

Figure 6.39: Boxplot of Partners in health Total score by socioeconomic status

Information given by health professionals

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options (n=38, 80.85%), disease management (n=23, 48.94%), disease cause (n=22, 46.81%), and physical activity (n=16, 34.04%) were most frequently given to participants by healthcare professionals, and, information about complementary therapies (n=3, 6.38%), how to interpret test results (n=3, 6.38%) and, hereditary considerations (n=0, 0.00%) were given least often (Table 6.28, Figure 6.40).

Table 6.28: Information given by health professionals

Information given by health professionals	n=47	Percent
Disease cause	22	46.81
Treatment options	38	80.85
Disease management	23	48.94
Complementary therapies	3	6.38
How to interpret test results	3	6.38
Clinical trials	5	10.64
Dietary information	12	25.53
Physical activity	16	34.04
Psychological/social support	8	17.02
Hereditary considerations, genes or genomic biomarker information	0	0.00
No information	0	0.00

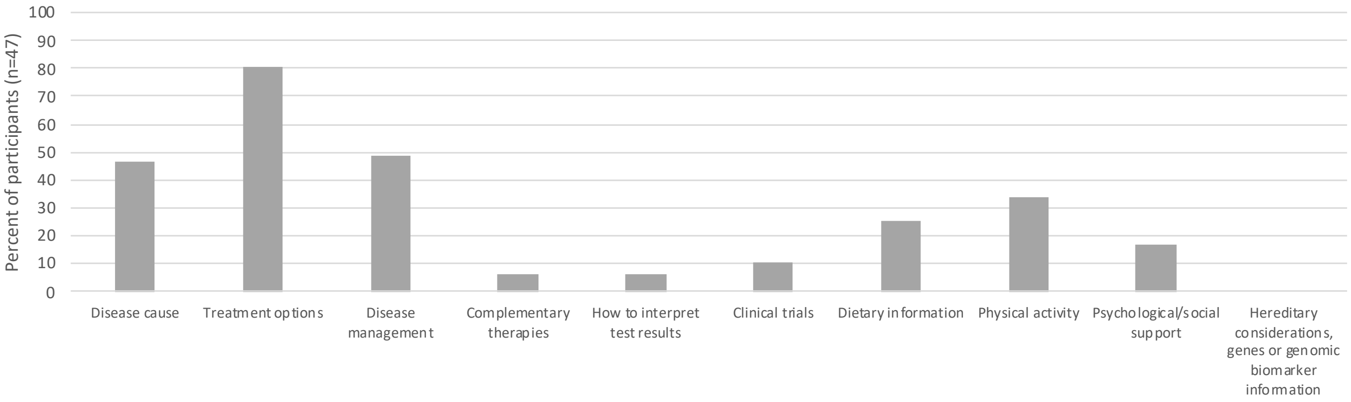

Figure 6.40: Information given by health professionals

Information searched independently

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. The topics participants most often searched for were treatment options (n=28, 59.57%), disease cause (n=26, 55.32%), disease management (n=21, 44.68%) and, how interpret test results (n=18, 38.30%) were most frequently searched for independently and, information about physical activity (n=13, 27.66%), clinical trials (n=10, 21.28%), and hereditary considerations (n=7, 14.89%) were searched for least often (Table 6.29, Figure 6.41).

Table 6.29: Information searched for independently

Information searched independently	n=47	Percent
Disease Cause	26	55.32
Treatment options	28	59.57
Disease management	21	44.68
Complementary therapies	14	29.79
Interpret test results	18	38.30
Clinical trials	10	21.28
Dietary	14	29.79
Physical activity	13	27.66
Psychological/ social support	14	29.79
Hereditary considerations	7	14.89
No information		

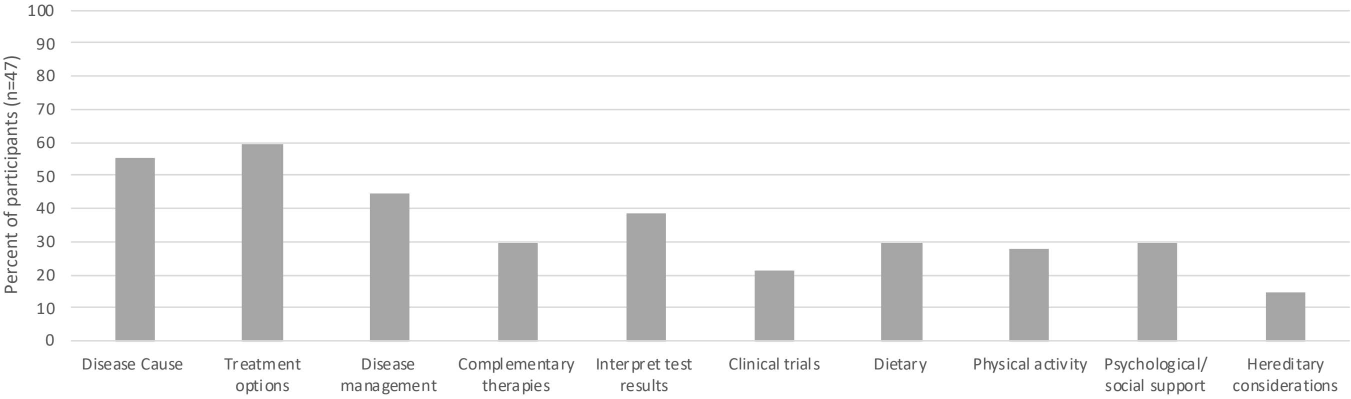

Figure 6.41: Information searched for independently

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were hereditary considerations (n=40, 85.11%) and clinical trials (n=33, 70.21%).

The topics that participants did not search for independently after receiving information from healthcare professionals were treatment options (n=22, 46.81%) and disease Cause (n=12, 25.53%).

The topics that participants were given most information from both healthcare professionals and searching independently for were treatment options (n=16, 34.04%) and disease management (n=12, 25.53%).

The topics that participants searched for independently after not receiving information from healthcare professionals were how to interpret test results (n=17, 36.17%), and disease Cause (n=14, 29.79%) (Table 6.30, Figure 6.42).

Table 6.30: Information gaps

Information topic	Not given by health professional, not searched for independently		Given by health professional only		Given by health professional, searched for independently		Searched for independently only	
	n=47	%	n=47	%	n=47	%	n=47	%
Disease Cause	11	23.40	10	21.28	12	25.53	14	29.79
Treatment options	3	6.38	16	34.04	22	46.81	6	12.77
Disease management	14	29.79	12	25.53	11	23.40	10	21.28
Complementary therapies	31	65.96	2	4.26	1	2.13	13	27.66
How to interpret test results	27	57.45	2	4.26	1	2.13	17	36.17
Clinical trials	33	70.21	4	8.51	1	2.13	9	19.15
Dietary information	24	51.06	9	19.15	3	6.38	11	23.40
Physical activity	22	46.81	12	25.53	4	8.51	9	19.15
Psychological/social support	27	57.45	6	12.77	2	4.26	12	25.53
Hereditary considerations	40	85.11	0	0.00	0	0.00	7	14.89

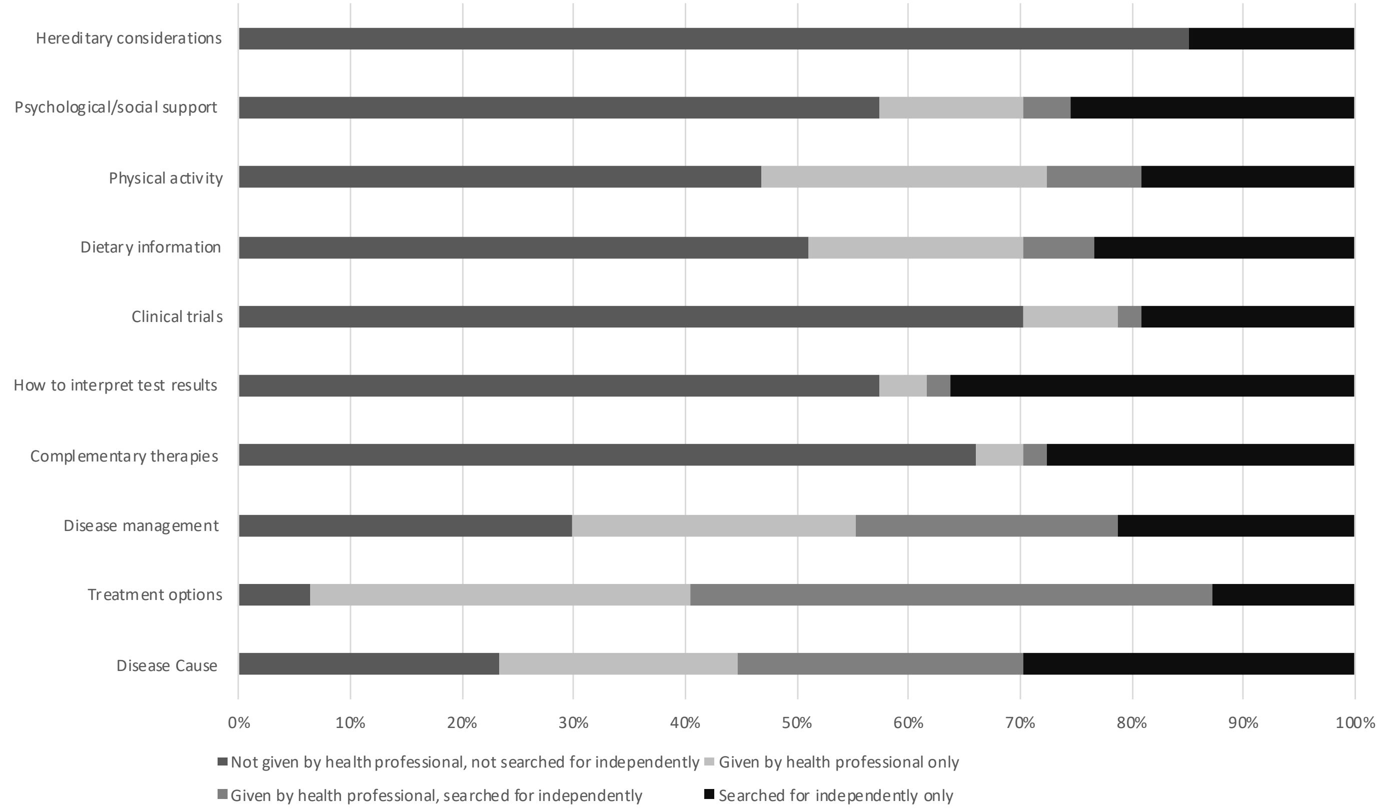

Figure 6.472: Information gaps

Most accessed information

Participants were asked to rank which information source that they accessed most often, where 1 is the most trusted and 4 is the least trusted. A weighted average is presented in Table 6.36 and Figure 6.48. With a weighted ranking, the higher the score, the more accessed the source of information.

Across all participants, information from Non-profit organisations, charity or patient organisations and the hospital or clinic where treated. Information from Pharmaceutical companies were least accessed.

Table 6.31: Most accessed information

Information source	Weighted average (n=47)
Non-profit organisations, charity or patient organisations	3.13
Government	2.57
Pharmaceutical companies	1.23
Hospital or clinic where being treated	3.06

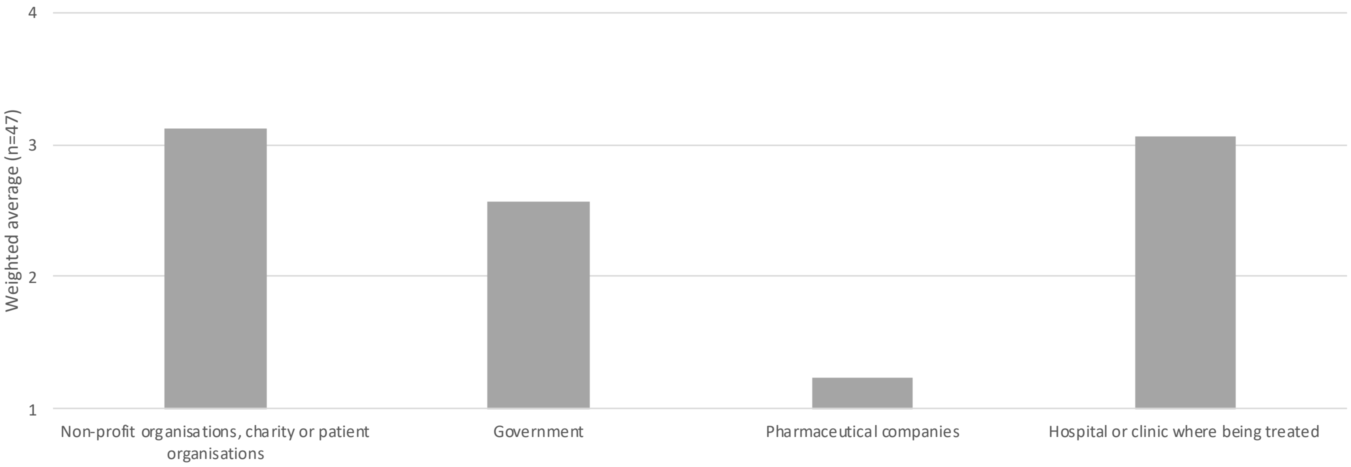

Figure 6.43: Most accessed information

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 16 participants (33.33%) had accessed My Health Record (Table 6.32. Figure 6.44).

Of those that had accessed My Health Record, there were 11 participants (68.75%) who found it to be poor or very poor, 4 participants (25.00%) who found it acceptable, and 1 participant (6.25%) who found it to be good or very good (Table 6.33, Figure 6.45).

Table 6.32: Accessed My Health Record

Accessed "My health record"	Number (n=48)	Percent
Yes	16	33.33
No	20	41.67
Not sure	8	16.67
Doesn't know what 'My Health Record' is	4	8.33

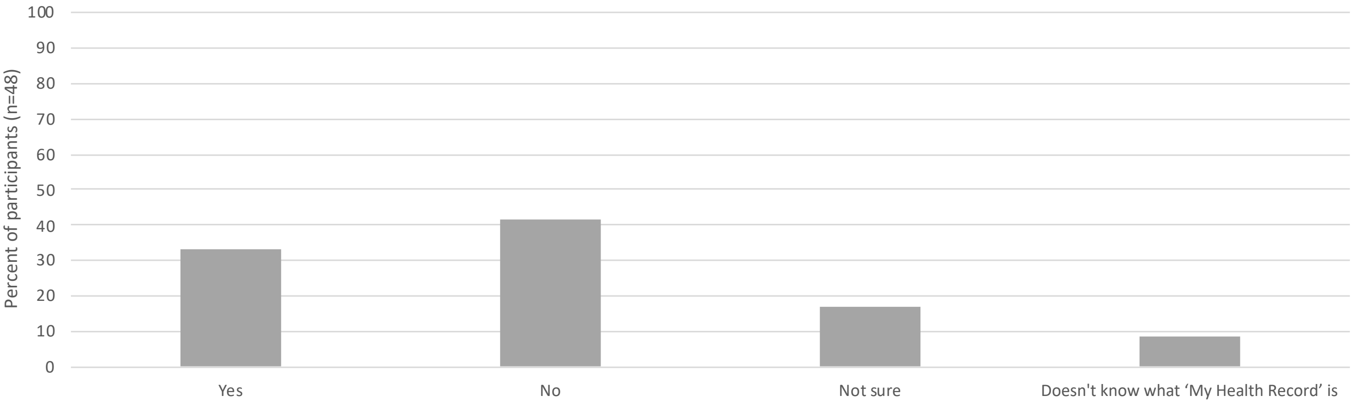

Figure 6.44: Accessed My Health Record

Table 6.33: How useful was My Health Record

How useful was "My health record"	Number (n=16)	Percent
Very poor	1	6.25
Poor	10	62.50
Acceptable	4	25.00
Good	0	0.00
Very good	1	6.25

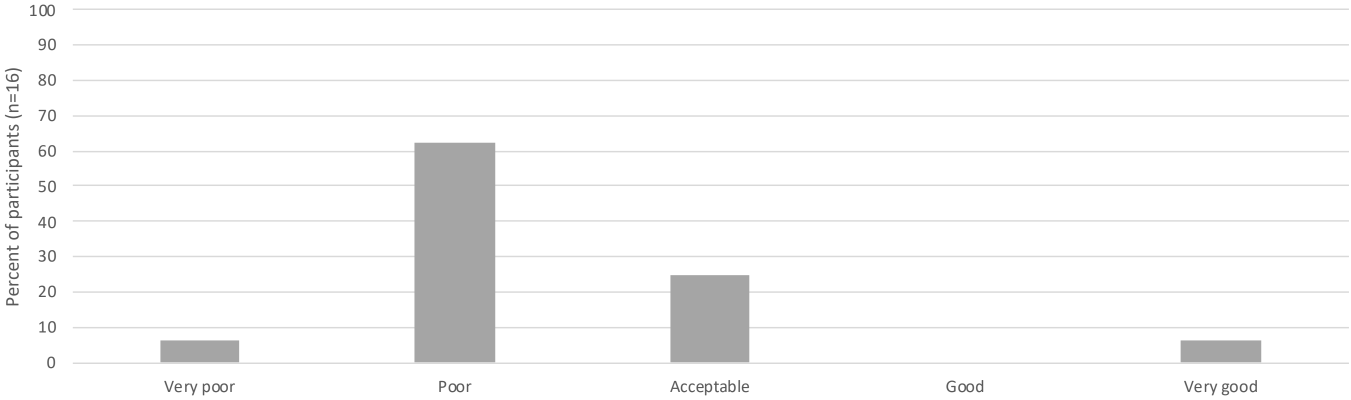

Figure 6.45: How useful was My Health Record