

Section 6

Information and communication

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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 responses were the internet (including health charities) (57.69%), specific health charities (57.69%), and Facebook and/or social media (42.31 %). Other information sources included other patient's experience (including support groups) (19.23%), journals (research articles) (15.38%), books, pamphlets and newsletters (11.54%), and conferences or webinars (11.54%).

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 response was other people's experiences (peer-to-peer) (42.31%). Other helpful information included talking to a doctor or specialist or healthcare team (19.23%), hearing what to expect (e.g. from disease, side effects, treatment) (19.23 %), medical journals and scientific information (19.23%), and health charities (11.54%)

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. The most common responses were sources that are not credible (not evidence-based) (26.92%), worse case scenarios (23.08 %), and some information given by their GP or specialist (15.38%) were not helpful. Other participants described that no information was not helpful (23.08%), or that they were confident in deciding themselves (11.54%)

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. The most common responses were talking to someone plus online information (38.46%), online information (30.77%), and written information (23.08 %). Other preferences included talking to someone (11.54%), and all forms (11.54%).

The main reasons for a preference for online information were accessibility (38.46%), and being able to digest information at their own pace (19.23%). The main reason for talking to someone as a preference was being able to ask questions, get clarifications, and feeling supported (23.08 %). Participants described that written information, online information and talking to someone was preferred because it was relevant or personalised (30.77%).

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 times were at the beginning (diagnosis) (26.92%), and after results from treatment, follow up scans, or when disease progressed (26.92%). Other times included after treatment (19.23%), continuously (19.23%), and after the shock of diagnosis (11.54%).

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=26, 52.00%). The most common responses that they had overall positive communication (38.46%), and overall negative communication (30.77%). Other participants described that communication was overall positive, with the exception of one or two occasions (19.23%).

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 (19.23%). The main reason for negative communication was that it was dismissive, that they had one way conversations (15.38 %).

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: 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 were good at coping with their condition.

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: 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 very good treatment adherence.

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 very good overall knowledge, coping and confidence for managing their own health.

Ability to take medicine as prescribed

Participants were asked about their ability to take medicines as prescribed. The majority of the participants responded that they took medicine as prescribed all the time (n=15, 60.00%), and 10 participants (40.00%) responded that they took medicines as prescribed most of the time.

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options (n=17, 62.96%), disease cause (n=8, 29.63%), physical activity (n=8, 29.63%) and, disease management (n=7, 25.93%) were most frequently given to participants by healthcare professionals, and, information about clinical trials (n=3, 11.11%), how to interpret test results (n=2, 7.41%) and, hereditary considerations (n=2, 7.41%) 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 disease management (n=22, 81.48%), disease cause (n=19, 70.37%), treatment options (n=19, 70.37%) and, interpret test results (n=16, 59.26%) were most frequently searched for independently by participants, and, information about physical activity (n=13, 48.15%), diet (n=11, 40.74%) and, psychological/ social support (n=11, 40.74%) were searched for least often.

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were clinical trials (n=13, 48.15%) and diet (n=12, 44.44%).

The topics that participants did not search for independently after not receiving information from healthcare professionals were treatment options (n=6, 22.22%) and physical activity (n=6, 22.22%).

The topics that participants were given most information from both healthcare professionals and searching independently for were treatment options (n=11, 40.74%) and disease management (n=6, 22.22%).

The topics that participants searched for independently after not receiving information from healthcare professionals were disease management (n=16, 59.26%) and interpret test results (n=16, 59.26%).

Most accessed information

Participants were asked to rank which information source that they accessed most often. Across all participants, information from Non-profit organisations, charity or patient organisations was most accessed followed by information from the Government. Information from Pharmaceutical companies and from 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 11 participants (35.48%) had accessed My Health Record, 20 participants (64.52%) had not.

Of those that had accessed My Health Record, there were 5 participants (45.45%) who found it to be poor or very poor, 2 participants (18.18%) who found it acceptable, and 4 participants (36.36%) 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 responses were the internet (Including health charities) (57.69%), specific health charities (57.69%), and Facebook and/or social media (42.31 %). Other information sources included other patient's experience (including support groups) (19.23%), journals (research articles) (15.38%), books, pamphlets and newsletters (11.54%), and conferences or webinars (11.54%).

Participant describes accessing information through the internet in general

Everything on the internet that I can read. Everything. I'll probably read too much.
Participant 003_2023AULUC

PARTICIPANT: Well, I would say one word, Google. I went there straight away soon as I came home from the hospital and I was diagnosed, I Googled it. Even all my family Googled it. Participant 013_2023AULUC

Well, the hospital's given me far more than I don't even need and the rest of it I just googled. Participant 017_2023AULUC

Participant describes accessing information from a specific health charity

Well, I've Googled online and they say never Google, but I have. I've looked up medical things because I've got a medical background. None of it is good news. I've looked at the Cancer Council of Victoria and then I got onto the Lung Cancer Society in Queensland. I've been looking at all that stuff, reading up on it. Participant 001_2023AULUC

Since I was diagnosed there was nothing available in Australia. There was like one lung cancer foundation nurse in Brisbane. That's the only kind of information that was available. Since then it's improved slightly. I just went to all the American support websites and the Lung Cancer Foundation of America just to seek out-- just to have that hope. Just to have that hope that people can actually live with this. I think the American sites were really quite positive and hopeful. Participant 004_2023AULUC

Internet obviously, a cancer council, with their information guides and facts, but Dr. Google with everything else, any questions I've had actually, I would Google. Any research or everything.
Participant 026_2023AULUC

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

In I went and there's all the trials that are going on around the world and all different. I've just got in my saved area of my Facebook, I've got hundreds and hundreds and hundreds and hundreds of studies and all the information I need. If something happens, then I just go into that and I can look it up and say, okay, this is what you do, because, in the end, the oncologists here do not know how to deal with my type of lung cancer. Because it's so rare, they just don't have the capacity to do it, and I understand that, and I know they don't have time to read all the stuff that I'm reading, so I'm doing that job for them. Anyway, this page has been fantastic. There's so many doctors in there. The people that have ALK lung cancer, there's, [inaudible] and they're all really smart people. Really, really smart people.
Participant 002_2023AULUC

Yes, Dr. Google and I joined a couple of Facebook pages that talk about lung cancer. One is exclusively Australian. Another one isn't so it's a bit different and I like to look for-- A lot of the people on the Facebook pages, a lot of them are going through horrendous times with radiotherapy and chemotherapy so it's not applicable to me. I seek out those who've had something similar to me to see what sort of experience it was for them and their recovery periods. Participant 010_2023AULUC

Most of mine has been via a Facebook group, which is an ALK-positive, so it's specific to my genetic mutation that I have, and it's a global group, and it's extremely good. It is within the group or a number of health professionals globally who specialize in this particular type of cancer. Plus, also there's a wealth of people globally who are suffering from it currently, and there's so much information that comes after that unbelievably useful. It primarily comes from there, and also just from searching around on the internet, but I haven't really had anything that was relevant from my medical team.
Participant 021_2023AULUC

Participant describes primarily accessing information through other patient's experience

Yes, and connecting with other people. That is the way you find your information and navigate your care because people have that knowledge, they've been through it before. You can always learn from someone who's gone ahead of you. That was my biggest thing, we've got to have more people to connect with, so that we can learn from the people in front of us. That's one thing. That was a face-to-face support group. Then I came across an online support group specifically for ALK-positive lung cancer, that was amazing. They were trying to advocate and do all those things which was fantastic. I learnt heaps from them. Then we all build off each other. Through connecting with each other, we had so much to share, so much we could do. I learnt about Gamma Knife radiation so I knew how to navigate that.
Participant 015_2023AULUC

Oh gosh. Did lots of Googling, until I actually stopped myself, because you go down a rabbit hole of looking at statistics and [unintelligible] accumulation, not a person. The other thing I've done is got in touch with the Lung Foundation Australia and I guess sought support as in becoming a peer connect member. I've joined a group through our Peter MacCallum Hospital that meet monthly and those connections. You get to talk about the things that perhaps you want an answer to and that's easy there because you don't need a specialist to tell you. I've joined the Facebook EGRF cancer group and they're all good. They're all good avenues to ask simple things such as my toes playing up with this drug, anyone got any ideas, the best way to tackle it and it's great. The little things where I don't want to go running off to a medical specialist. If I think it's serious, I will see a doctor. If it's these minor things, they're often a great source.
Participant 020_2023AULUC

Participant describes accessing information primarily through journals (research articles)

I've purposely avoided lung organizations, patient organizations, and I've gone straight to reading the papers of people who presented at conferences. I started with the World Conference in Barcelona, which I think was four years ago. I read absolutely all the papers of the different people who presented at this conference. For each person who presented at the World Conference on lung cancer, often get published 50 papers each or more, so I read. I only go to that.
Participant 023_2023AULUC

I've looked up some journals on some of the studies that are done. In fact, I found one that looked at brain radiation, let's say in Spain and on metastases in the brain, and it found that this compound had a favorable overall survival advantage over not having it.

Participant 024_2023AULUC

Participant describes receiving information from books, pamphlets and newsletters

Everywhere I can find it. I actually ... I look at research articles on a weekly basis. I get a lot of newsletters from different lung cancer organizations and foundations. They inform me of trials and new treatments and patients stories and all that type of thing. Much of my information I get through lung cancer foundations.

Participant 007_2023AULUC

As soon as the diagnosis came through, they give you a large package that has everything from what lung cancer is right through the treatments, et cetera. It's a bit of heavy reading.

Participant 012_2023AULUC

Participant describes accessing information from conferences and webinars

Through the Lung Foundation and I actually speak regularly to one of the lung cancer nurses there. I remember calling the Cancer Council, speaking to one of the nurses there. Then just various articles that come through email, social media. I'm aware that there's-- Is it in Melbourne? They had a conference in May. The Thoracic Surgeon's Association.

Participant 005_2023AULUC

PARTICIPANT: I've tried to, every single bit of information about how positive, I've tried to research. I've been fortunate that website-- there's an American group and that's on a website and they've got oncologists that really specialize in [unintelligible], they do webinars. I've watched them and I join-- They do two days of speaking about the different drugs. I make sure I'm familiar with everything. I know there's a new trial in America, [crosstalk] Australia at the moment. I follow all of that. I feel it's good and bad because I feel like I'm very knowledgeable about everything to do without. I don't know other stuff but I feel like I've looked at everything, even complicated threads. What people do with vitamins and things like that. Not that I've done a lot of that. I take my medication.

Participant 027_2023AULUC

Table 6.1: Access to information.

Access to information	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes accessing information through the internet in general	15	57.69	14	56.00	1	100.00	7	70.00	8	50.00	11	68.75	4	40.00
Participant describes accessing information from a specific health charity	15	57.69	14	56.00	1	100.00	4	40.00	11	68.75	12	75.00	3	30.00
Participant describes accessing information primarily through Facebook and/or social media	11	42.31	11	44.00	0	0.00	5	50.00	6	37.50	9	56.25	2	20.00
Participant describes primarily accessing information through other patient's experience	5	19.23	5	20.00	0	0.00	1	10.00	4	25.00	4	25.00	1	10.00
Participant describes accessing information primarily through journals (research articles)	4	15.38	4	16.00	0	0.00	1	10.00	3	18.75	2	12.50	2	20.00
Participant describes receiving information from books, pamphlets and newsletters	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	2	12.50	1	10.00
Participant describes accessing information from conferences and webinars	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00

Access to information	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes accessing information through the internet in general	15	57.69	9	52.94	6	66.67	8	61.54	7	53.85	2	100.00	13	54.17	8	88.89	7	41.18
Participant describes accessing information from a specific health charity	15	57.69	12	70.59	3	33.33	5	38.46	10	76.92	1	50.00	14	58.33	4	44.44	11	64.71
Participant describes accessing information primarily through Facebook and/or social media	11	42.31	10	58.82	1	11.11	3	23.08	8	61.54	1	50.00	10	41.67	2	22.22	9	52.94
Participant describes primarily accessing information through other patient's experience	5	19.23	5	29.41	0	0.00	1	7.69	4	30.77	0	0.00	5	20.83	0	0.00	5	29.41
Participant describes accessing information primarily through journals (research articles)	4	15.38	1	5.88	3	33.33	3	23.08	1	7.69	0	0.00	4	16.67	0	0.00	4	23.53
Participant describes receiving information from books, pamphlets and newsletters	3	11.54	2	11.76	1	11.11	2	15.38	1	7.69	0	0.00	3	12.50	0	0.00	3	17.65
Participant describes accessing information from conferences and webinars	3	11.54	3	17.65	0	0.00	2	15.38	1	7.69	0	0.00	3	12.50	2	22.22	1	5.88

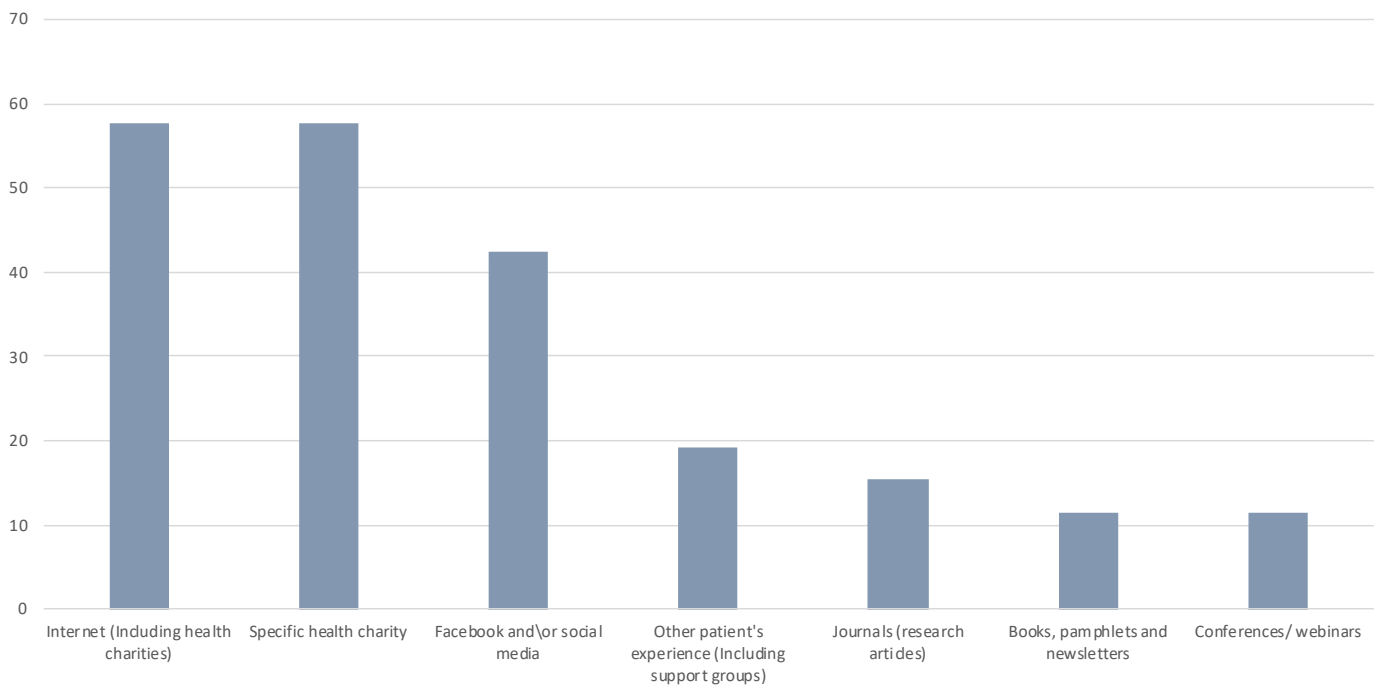


Figure 6.1: Access to information

Table 6.2: Access to information – subgroup variations

Theme	Less frequently	More frequently
Participant describes accessing information through the internet in general	Male Higher status	Non-metastatic Female Mid to low status
Participant describes accessing information from a specific health charity	Non-metastatic Male Aged 65 or older Trade or high school Mid to low status	Metastatic Female Aged 35 to 64 University
Participant describes accessing information primarily through Facebook and/or social media	Male Aged 65 or older Trade or high school Mid to low status	Female Aged 35 to 64 University Higher status
Participant describes primarily accessing information through other patient's experience	Aged 65 or older Trade or high school Mid to low status	Aged 35 to 64 University Higher status
Participant describes accessing information primarily through journals (research articles)	Mid to low status	Aged 65 or older
Participant describes receiving information from books, pamphlets and newsletters	Mid to low status	-
Participant describes accessing information from conferences and webinars	Male Aged 65 or older	Mid to low status

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 response was other people's experiences (peer-to-peer) (42.31%). Other helpful information included talking to a doctor or specialist or healthcare team (19.23%), hearing what to expect (e.g. from disease, side effects, treatment) (19.23 %), medical journals and scientific information (19.23%), and health charities (11.54%)

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

I think from a psychological perspective-- when you get diagnosed you're not going, "Okay, let me see what this treatment will do," and that. You're kind of more going-- you google it, says you'll be dead within a year, and you're literally trying to find information that says, "No, you won't be dead in a year." That's the information when you've got lung cancer stage 4, you're looking for that kind of information, the information that will give you hope, "That these people here, they've lived for X number of years," and that gets you back on a normal track of feeling like, "Well, I've got this thing, but I can actually maybe live with it." Participant 004_2023AULUC

With the social media pages, I guess other people who are on exactly the same drug with exactly the same type of cancer is nice because it's a fairly rare one, so people say you'll get better and there'll be a new drug, but I know there's not going to be. It's nice to have other people who are just happy to be symptom-free, I guess. Participant 006_2023AULUC

What I've just said the Facebook page, the Australian Lung Cancer Support Group it's called. I just found that they don't talk in medical terms, they talk in lay terms.

People ask questions that sometimes they don't want to ask their doctors or whatever.

Participant 010_2023AULUC

I think the most helpful because it's also a lot to do with getting the head around it all has been the Facebook group. I just, oh, both and the HOSPITAL, the actual group, Oh God, we're not consumers. I hate that word. People with lived experience. Meeting up with other people with lived experience has been the biggest help to me in getting my head around having this diagnosis, which has been very important to do. Participant 020_2023AULUC

Participant describes talking to their doctor or specialist as helpful

The most helpful information was Doctors NAME and NAME, the information that they imparted to me, my specialists. Just the information they imparted. Once again, it goes back to you've got a problem, they're going to try and help you and fix you. Participant 012_2023AULUC

I think the initial beautiful diagram I got from the first oncologist, it was fantastic. I remember going to her initially and then she did tests, and then she couldn't see me. I think it was 10 days later, and I just rang her up on day seven, and I said, "I'm really sorry." I said, "I cannot wait another day." She said, "Come in and see me tomorrow." She saw me and wrote down the results, and then she said, "Look, I haven't got all the tests back, however, this is where we're going." Participant 019_2023AULUC

The most helpful information obviously, comes from the oncologist because it's factual and based on [crosstalk] It's just basically about, the prognosis for a start, but also about the treatment.

Participant 026_2023AULUC

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

Given that I've gone on this one treatment that's been very effective, knowing what to expect from this drug treatment, observing that I'm consistent with the good end of that, that's all very encouraging. I have a friend who's a doctor. My GP is very approachable. My lung cancer nurse answers any questions I have or tells me who to go to. Just no lack of information about anything I want to know about.

Participant 022_2023AULUC

Treatments available, prognosis, general outcomes. Different options because when you do initially hear the word cancer let alone lung cancer, initially have just one thought in mind, that there's only one path that you can go down. Then you realize there's new treatments, like the targeted therapy. I've told people along the way when I-- You've talked about it. I always think that had this happened 10 years ago, I might not be here today, but because we've made advancements in this new type of treatment, we're able to live with it a lot longer.

Participant 005_2023AULUC

Participant describes information from research journals or scientific sources

PARTICIPANT: Journal articles. They're up-to-date information and they are normally cutting-edge information. Participant 007_2023AULUC

It depends because it changes according to where I am in the journey and what kind of information I seek. For instance, what has been the most helpful recently to me has been on YouTube looking at surgery of lymph nodes on people who had previously received immunotherapy and how it actually impacts on the texture of the tissues of the lymph node. That's quite

interesting. That was useful for me because I had received no information on the impact of immunotherapy on the tissue of lymph nodes. Receiving images of surgery of ablation of lymph nodes after immunotherapy or before and the difference in the tissue of the body and the lymph nodes, which is part of the immune system, that was helpful. Because for me, what is helpful is knowledge. Anything which increases my scientific knowledge is helpful. Because it will help me manage and drive my care if I try and gain as much knowledge as possible. It's scientific knowledge.

Participant 023_2023AULUC

I'm following the trials on the targeted therapy. I find that really interesting because I suspect that's where I'm heading. If I do get a recurrence and I perhaps can't take the [unintelligible] biomarkers [unintelligible] change, then the targeted therapy is what's going to help me because I don't know if I could go down a chemo line again.

Participant 025_2023AULUC

Participant describes health charities information as helpful

For me, it's verbal, not written. I'm more of a verbal person. Them just going through with me, like the Lung Foundation just chatting over the phone going this is what usually happens or whatever, and then we can follow that. I'm more of a verbal person. Participant 030_2023AULUC

The most helpful I think is I joined a Facebook group, Lung Cancer Australia. I can't quite remember the name of it. I read their stories. The people who belong to that group, I read their stories, the posts they put up. I read what they go through, what they've been through. I think that I'm quite lucky compared to what some other people are going through. Honestly, that's been the most helpful because that just makes me feel grateful that I'm not as unwell as what they are, or some of those people that have been battling this disease for years.

Participant 003_2023AULUC

Table 6.3: Information that was helpful

Information that has been helpful	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes other people's experiences as helpful (Peer-to-peer)	11	42.31	11	44.00	0	0.00	6	60.00	5	31.25	8	50.00	3	30.00
Participant describes talking to their doctor or specialist as helpful	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	3	18.75	2	20.00
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	5	19.23	5	20.00	0	0.00	1	10.00	4	25.00	3	18.75	2	20.00
Participant describes information from research journals or scientific sources	5	19.23	5	20.00	0	0.00	1	10.00	4	25.00	5	31.25	0	0.00
Participant describes health charities information as helpful	3	11.54	2	8.00	1	100.00	2	20.00	1	6.25	2	12.50	1	10.00

Information that has been helpful	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes other people's experiences as helpful (Peer-to-peer)	11	42.31	8	47.06	3	33.33	4	30.77	7	53.85	2	100.00	9	37.50	4	44.44	7	41.18
Participant describes talking to their doctor or specialist as helpful	5	19.23	4	23.53	1	11.11	2	15.38	3	23.08	0	0.00	5	20.83	2	22.22	3	17.65
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	5	19.23	4	23.53	1	11.11	3	23.08	2	15.38	0	0.00	5	20.83	2	22.22	3	17.65
Participant describes information from research journals or scientific sources	5	19.23	4	23.53	1	11.11	3	23.08	2	15.38	0	0.00	5	20.83	1	11.11	4	23.53
Participant describes health charities information as helpful	3	11.54	2	11.76	1	11.11	1	7.69	2	15.38	1	50.00	2	8.33	1	11.11	2	11.76

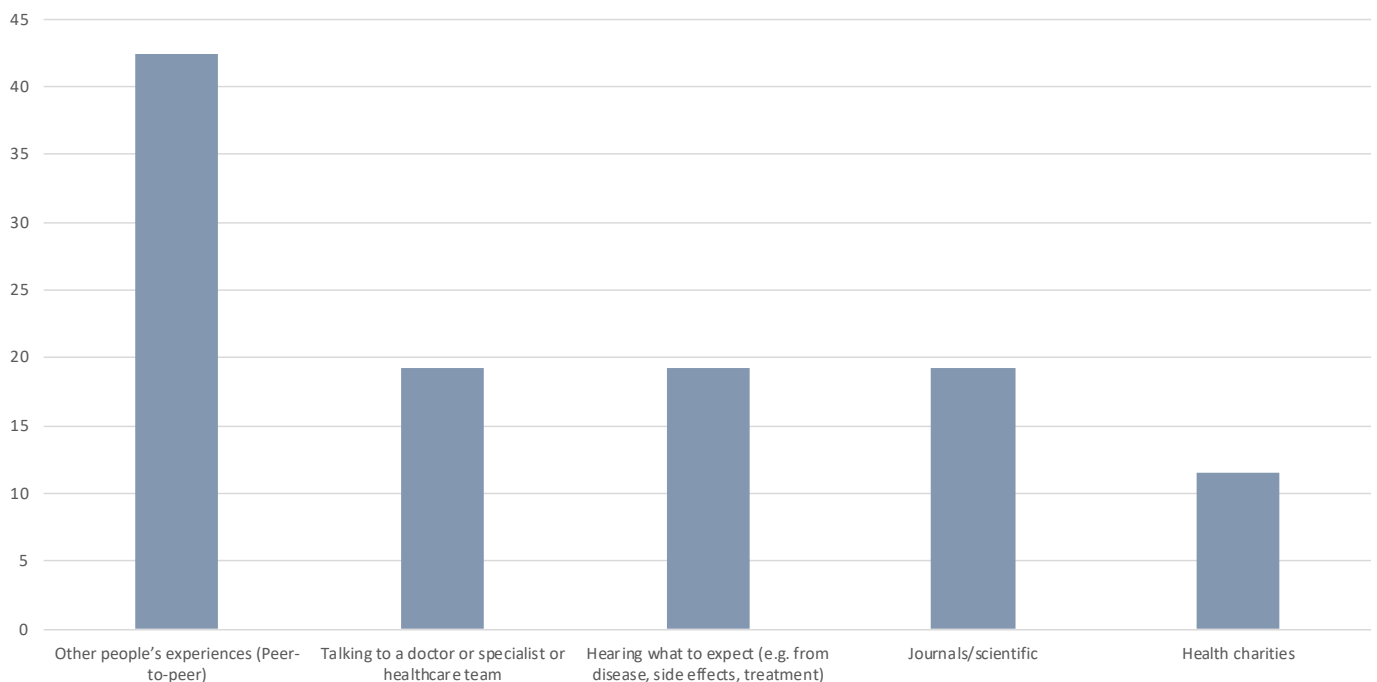


Figure 6.2: Information that was helpful

Table 6.4: Information that was helpful – subgroup variations

Theme	Less frequently	More frequently
Participant describes other people's experiences as helpful (Peer-to-peer)	Metastatic Male Trade or high school	Non-metastatic University
Participant describes information from research journals or scientific sources	Male	Female

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. The most common responses were sources that are not credible (not evidence-based) (26.92%), worse case scenarios (23.08 %), and some information given by their GP or specialist (15.38%) were not helpful. Other participants described that no information was not helpful (23.08%), or that they were confident in deciding themselves (11.54%)

Participant describes information from sources that are not credible as not helpful (Not evidence-based)

Yes. As I said, lots of pages that are telling me that if I pray, [laughs] enough that everything will be fine. Probably more of that just social media stuff. Participant 006_2023AULUC

Mostly social media posts from uneducated people who think they have some weird and wacky thing they think you should do to cure your cancer. Mainly social media is very unhelpful in my opinion. Sometimes there are helpful, but that's [unintelligible] unhelpful information. Participant 007_2023AULUC

No, only from listening to other people who don't know what they're talking about. Participant 017_2023AULUC

Yes, it's all the crap about if don't eat sugar or if you don't eat that. Friendly advice from every single person. I don't even tell them now. I feel comfortable not listening to it. I also sometimes feel comfortable ignoring my GP. I have really worked out that they have no clue. This sounds bad, I suppose, [unintelligible] but I wish I could speak with people that know what I'm going through, the medical people that actually get it in a way. Participant 027_2023AULUC

Participant describes no information being not helpful

No, I don't think there's a-- Knowledge is power. Participant 019_2023AULUC

No, every bit of information is useful. I've tried to go on sites that's Mayo Clinic or proper medical sites, not crazy crackpot sort of science, and also just listening to what people who've gone through cancer. A few of the people commented on my condition. One of the things I came to a conclusion that everyone's cancer is slightly different so we can't necessarily draw solid conclusions. Participant 028_2023AULUC

No, I can't think of anything. Participant 010_2023AULUC

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

Just from Google Search, just soon as you type "lung cancer prognosis stage 4," it says that 3% or something of people will be alive in 5 years and most people will be getting a year. That's not helpful information. Participant 004_2023AULUC

Absolutely. Every time I saw a statistic, every time I saw something about smoking or non-smoking, it was really not helpful. The stigma, [crosstalk], the statistics, especially early on, are really confronting for someone newly diagnosed. It was like your death sentence. Every research article you read started with,

"Lung cancer is the leading cause cancer, morbidity, and mortality in Australia." Participant 015_2023AULUC

I'm very selective about what I read on the internet because I know I'll only read peer-reviewed stuff. I guess some of the internet delving I did was unhelpful because the statistics are so miserable for metastatic lung cancer that I had myself dead in no time anyway. Then you start meeting people who are on the same drug as you, who are actually living longer than the statistics say they should. I think some of the internet stuff, even if it's peer-reviewed, et cetera, it can be unhelpful for your mental state. Participant 020_2023AULUC

Participant describes the GP/specialist as being not helpful

No, nothing. I've not found anything unhelpful, apart from my GP, he's unhelpful. Participant 003_2023AULUC

Just the lack of conversation from the oncologist, to be honest, as a carer it's really frustrating. You turn up there for your regular three-weekly or six-weekly appointment and she goes, "How's everything going? Good. See you later. I'll see you in six weeks." There's no discussion around the ins and outs. She won't dig a bit further for dad and dad doesn't [inaudible] Participant 030_2023AULUC

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

I'd say no. I determine what I think is helpful to know. There's information out there which is, in my view, very unregulated. I just don't choose to explore that. I'm aware of source of information that I would regard with some skepticism, but I don't feel affected by that because I just choose what I want to pay attention to. Participant 022_2023AULUC

I'm very selective about what I read on the internet because I know I'll only read peer-reviewed stuff. I guess some of the internet delving I did was unhelpful because the statistics are so miserable for metastatic lung cancer that I had myself dead in no time anyway. Then you start meeting people who are on the same drug as you, who are actually living longer than the statistics say they should. I think some of the internet stuff, even if it's peer-reviewed, et cetera, it can be unhelpful for your mental state. Participant 020_2023AULUC

Table 6.5: Information that was not helpful

Information that has not been helpful	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	7	26.92	7	28.00	0	0.00	3	30.00	4	25.00	6	37.50	1	10.00
Participant describes no information being not helpful	6	23.08	6	24.00	0	0.00	3	30.00	3	18.75	4	25.00	2	20.00
Participant describes information about worse case scenarios and negative information as being not helpful	6	23.08	6	24.00	0	0.00	2	20.00	4	25.00	5	31.25	1	10.00
Participant describes the GP/specialist as being not helpful	4	15.38	3	12.00	1	100.00	2	20.00	2	12.50	3	18.75	1	10.00
Participant describes feeling confident in deciding if something is not helpful (or not credible)	3	11.54	3	12.00	0	0.00	0	0.00	3	18.75	2	12.50	1	10.00

Information that has not been helpful	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	7	26.92	5	29.41	2	22.22	4	30.77	3	23.08	1	50.00	6	25.00	3	33.33	4	23.53
Participant describes no information being not helpful	6	23.08	2	11.76	4	44.44	2	15.38	4	30.77	1	50.00	5	20.83	1	11.11	5	29.41
Participant describes information about worse case scenarios and negative information as being not helpful	6	23.08	6	35.29	0	0.00	3	23.08	3	23.08	0	0.00	6	25.00	3	33.33	3	17.65
Participant describes the GP/specialist as being not helpful	4	15.38	3	17.65	1	11.11	2	15.38	2	15.38	1	50.00	3	12.50	3	33.33	1	5.88
Participant describes feeling confident in deciding if something is not helpful (or not credible)	3	11.54	2	11.76	1	11.11	2	15.38	1	7.69	0	0.00	3	12.50	1	11.11	2	11.76

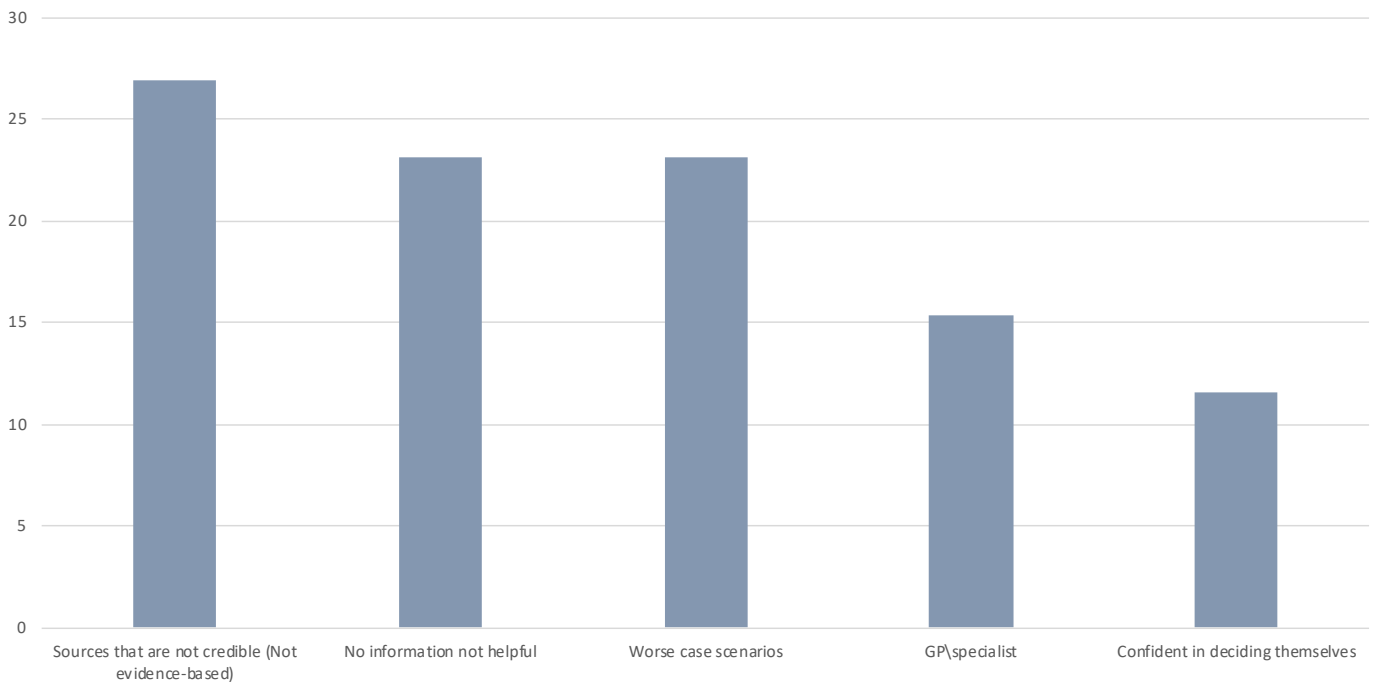


Figure 6.3: Information that was not helpful

Table 6.6: Information that was not helpful – subgroup variations

Theme	Less frequently	More frequently
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	Male	Female
Participant describes no information being not helpful	Aged 35 to 64 Mid to low status	Aged 65 or older
Participant describes information about worse case scenarios and negative information as being not helpful	Male Aged 65 or older	Aged 35 to 64 Mid to low status
Participant describes the GP/specialist as being not helpful	-	Mid to low status
Participant describes feeling confident in deciding if something is not helpful (or not credible)	Non-metastatic	-

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. The most common responses were talking to someone plus online information (38.46%), online information (30.77%), and written information (23.08 %). Other preferences included talking to someone (11.54%), and all forms (11.54%).

The main reasons for a preference for online information were accessibility (38.46%), and being able to digest information at their own pace (19.23%). The main reason for talking to someone as a preference was being able to ask questions, get clarifications, and feeling supported (23.08 %). Participants described that written information, online information and talking to someone was preferred because it was relevant or personalised (30.77%).

Talking to someone plus online information as main preference

Probably a bit of a mixture, but online, via email or the Alpha Group, which is the lung cancer group with the Lung Foundation, that's an online forum. That's all good. That kind of stuff is good, but having online where I'm able to print something if I want to read through it at my own pace would be ideal. Person to person. I think there should be a little bit more person-to-person if possible. Sometimes you need to feel like someone actually has some compassion and care.
Participant 018_2023AULUC

I actually like to talk to the oncologist to get a general overview and then I love being referred to something online because it's always there. I don't want to find that bit of paper that they handed me with it on and I can always refer back to it because you don't take everything in at a consultation. It's great to have a reliable source that they will say, go and get this information here that I can refer back to. Online for me is really handy.
Participant 020_2023AULUC

I spend a lot of my time online so I'm quite comfortable with-- I've been using computers for more than 40 years or whatever, so I'm not like some my people of my age who don't know how to use a computer, so I'm fairly comfortable. I've got a research background, so I know how to do research properly, but it was interesting to talk to some of the doctors and nurses who have got current and day-to-day experience.
Participant 028_2023AULUC

Online information as main preference

Definitely online because I can read it over and over again until I get it right and I can save, that in the end, that's all I need. I don't go on the internet, but when I'm reading a proper studies that have been done on real patients and so on.
Participant 002_2023AULUC

Probably online just because it's easier. As I said, I'm from a fairly smaller country town. It's not like I have big groups or people to talk about it with. Of course, COVID has prevented any type of groups. I'm happy with online information.
Participant 006_2023AULUC

Only online information because I can come and go to that point and I can read it at my leisure and I can critique at my leisure and actually try and work out

how viable and accurate the information is.
Participant 007_2023AULUC

Look, it is easier just to look online and the information is readily available. Sorry, I've just remembered something else. I have been looking at the Cancer Council as well online and that's been quite good as well.

Participant 010_2023AULUC

Written information as main preference

PARTICIPANT: I would've loved it if Australia had like breast cancer, but had pamphlets. You just go and grab the pamphlet from your doctor's surgery and there you have it. It tells you about the new types of treatment, and that it's not all doom and gloom anymore. That's what I would love. They didn't have anything, it's so underfunded in lung cancer. There's literally nothing out there. All your oncologist says to you is, "Don't google it," but you've got to get your information from somewhere...I think when it happens and you get the CT scan results and you go to your GP and they go, oh, they think they found the lung cancer. At that point, you need to have that booklet so that you can have knowing the facts of the matter, sort of thing. You go through so much mental turmoil going, "I didn't smoke, how did I get this thing?" You go through a lot. It would be nice to have that booklet that explains everything and that they've got these new treatments, et cetera.

Participant 004_2023AULUC

PARTICIPANT: Look, if I can access it online, great. I'm still not opposed to written. I have lots of books and lots of things here.

Participant 015_2023AULUC

Talking to someone as main preference

I don't think you can-- You need to speak to your oncologist. Your oncologist is the only one that really knows. You can't compare your journey with someone else's journey. You've just got to hope that you've got a good oncologist, whether they're-- I did an interview the other day with someone and I think they were talking about the lack of information. It's funny, that's the one thing I will say is, you know how the Cancer Council have all the books on all the different cancers? When you go to a Guard Chemo, they'll have every cancer and those yellow books, and they're very good. However, I could not bring myself to go and get the lung cancer one because I was so mortified that I had it, and because of the general attitude, no one's survived. I couldn't even go and get the book, I was just

not ready to face it. I'll just deal with the oncologist and the nurse, the fantastic nurse I had for the trial. They were positive. Not positive, positive, but they told you what-- Just their communication was brilliant. The people who can't deal with not having a yes or a no, they're not going to find the journey good, because no one really knows. A lot of people-- One of my friends has rung me up because her mother was diagnosed with it last year, and she didn't want to have any treatment. He said, "Could you speak to her?" I did. I did manage to talk her into having the treatment. However, she's going to die. You're dealing with all that as well. It's just everyone is individually on this journey next to each other. It's not like other cancers.

Participant 019_2023AULUC

I like to get information from a mixed range of sources. My preference is to get the factual

information from the specialist, and then, to have material to take away that you can read that he's given all his referred to because then, you know it's accurate information but, I do like to read it later because obviously the appointments are quite quick and you forget stuff when you get bombarded.

Participant 026_2023AULUC

All forms

No. You can ring me. You can email me. You can fax me. You can do whatever you want.

Participant 014_2023AULUC

No, it doesn't matter.

Participant 017_2023AULUC

Table 6.7: Information preferences

Information preferences	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Talking to someone plus online information as main preference	10	38.46	9	36.00	1	100.00	4	40.00	6	37.50	6	37.50	4	40.00
Online information as main preference	8	30.77	8	32.00	0	0.00	2	20.00	6	37.50	7	43.75	1	10.00
Written information as main preference	6	23.08	6	24.00	0	0.00	1	10.00	5	31.25	5	31.25	1	10.00
Talking to someone as main preference	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	2	12.50	1	10.00
All forms	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	3	18.75	0	0.00

Information preferences	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Talking to someone plus online information as main preference	10	38.46	7	41.18	3	33.33	5	38.46	5	38.46	0	0.00	10	41.67	1	11.11	9	52.94
Online information as main preference	8	30.77	5	29.41	3	33.33	4	30.77	4	30.77	2	100.00	6	25.00	3	33.33	5	29.41
Written information as main preference	6	23.08	3	17.65	3	33.33	1	7.69	5	38.46	0	0.00	6	25.00	2	22.22	4	23.53
Talking to someone as main preference	3	11.54	2	11.76	1	11.11	1	7.69	2	15.38	0	0.00	3	12.50	1	11.11	2	11.76
All forms	3	11.54	1	5.88	2	22.22	2	15.38	1	7.69	0	0.00	3	12.50	3	33.33	0	0.00

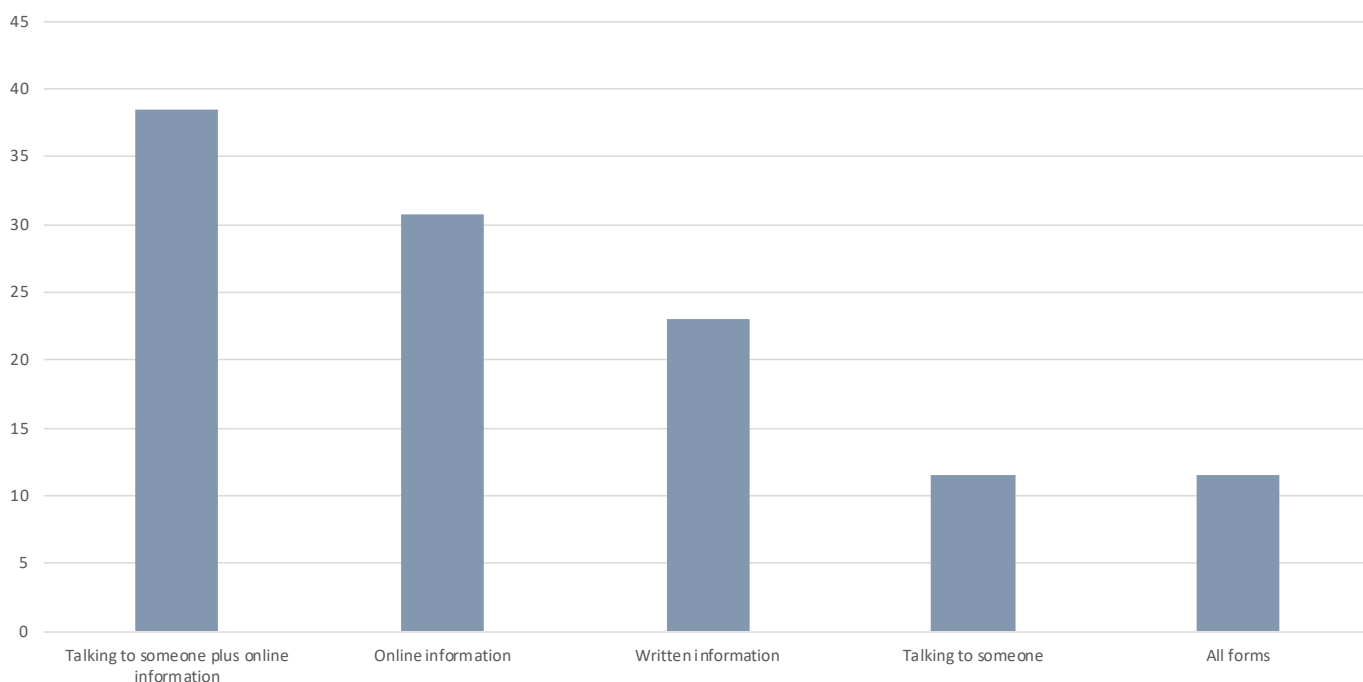


Figure 6.4: Information preferences

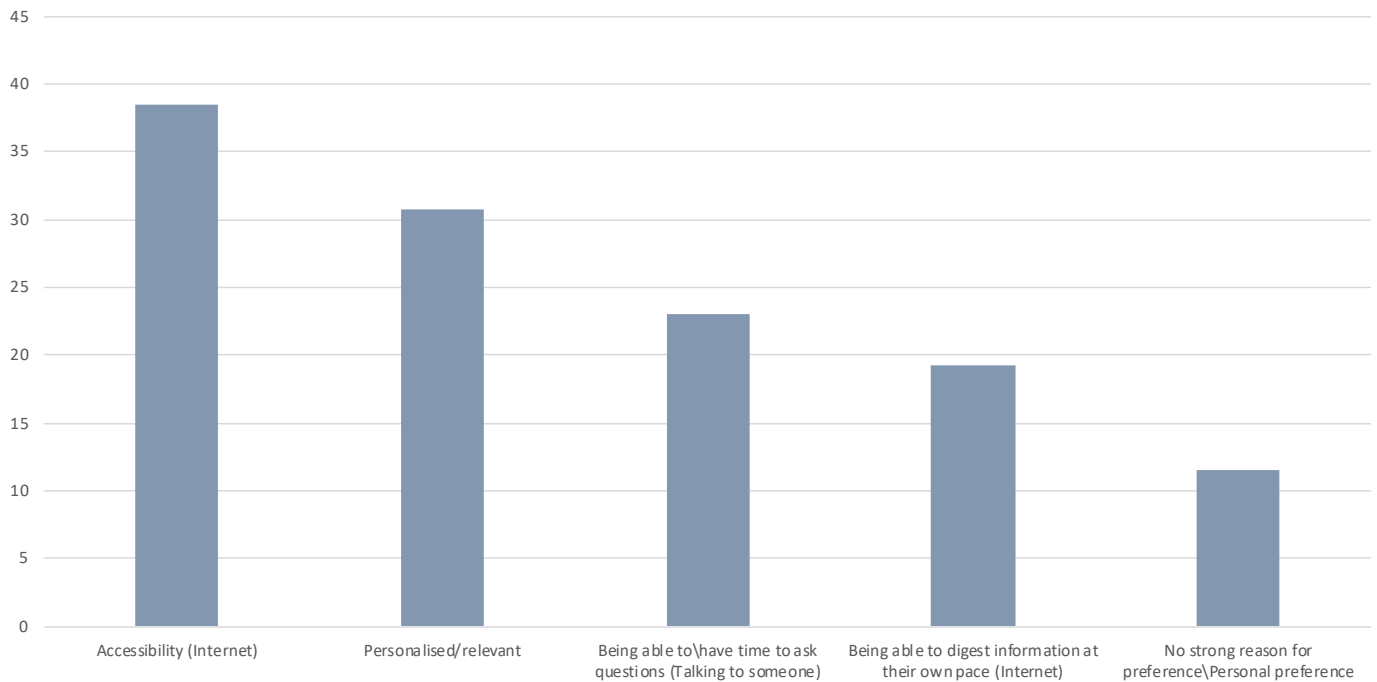


Figure 6.5: Reasons for information preferences by format

Table 6.8: Information preferences – subgroup variations

Theme	Less frequently	More frequently
Talking to someone plus online information as main preference	Mid to low status	Higher status
Online information as main preference	Non-metastatic Male	Female
Written information as main preference	Non-metastatic Male Trade or high school	Aged 65 or older University
All forms	Male Higher status	Aged 65 or older Mid to low status

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 times were at the beginning (diagnosis) (26.92%), and after results from treatment, follow up scans, or when disease progressed (26.92%). Other times included after treatment (19.23%), continuously (19.23%), and after the shock of diagnosis (11.54%).

Participant describes being receptive from the beginning (diagnosis)

Definitely, in the beginning. In the beginning, you've got your adrenaline going through the roof and you're just inputting. Inputting, inputting the whole time, trying to find a way out of this. I know that sounds really silly, but it's like you're in a hole and you're trying to dig your way out. Definitely in the beginning. Then the adrenaline drops off after about six months, you can feel it dropping off, and you relax to this.
Participant 002_2023AULUC

Immediately once I was sent to the two specialists, they sat me down and they told me what going to occur, what was the problem, and the procedures were going to happen. Of course, I had to give my consent. That should do. I had to give my consent, but they were like, "There's a diagnosis, and this is what we can do, this is what we can't do, and this is how we're going to approach it." I think that's the greatest information you can get to make [crosstalk].
Participant 012_2023AULUC

I wish I had met someone that could have explained cancer to me when I was originally diagnosed. I still can't believe no one spoke to me about it or talked to me about it. All that they said to me was, "You're 1B," and it was something like the cancer was smaller or [inaudible] one. It's a B because-- I can't even remember it. Then, when I went on [unintelligible] my oncologist didn't even tell me that I was stage 4. I heard it on the phone. He rang up and had to get my prescription. I said to him, "Am I now stage 4 cancer?" He said, "Yes.". If I hadn't overheard his conversation when he rang up requesting my medication I wouldn't have known.
Participant 027_2023AULUC

Participant describes being receptive to information after results from treatment are known, or when getting results of follow up scans

Probably once I had my very first scan after my initial treatment and I saw positive results, then I was probably more receptive to all that information because I could see that the treatment was actually working. Since my latest diagnosis, I haven't really done much research. I think I've just been overwhelmed with taking in what I have to go through this time around. To be honest, the third time that you hear that the disease has progressed is the hardest compared to the first time. For a while, I was almost cruising along, living with this disease is stable to the point where the doctors could hardly see any tumour. Not that I was in remission, but it was very stable. Then to find that we've gone backwards quite a bit with this latest diagnosis and it's really been confronting mentally.

INTERVIEWER: Yes, that would be hard.

PARTICIPANT: We thought that's stable that we even bought a river cruise in Europe for May next year. We haven't cancelled that. We've got up to a month before if we need to. That's how confident we were. I was actually having issues getting travel insurance. That's why we hadn't been able to book the whole trip because my cancer wasn't going to be covered but we thought, we can work around that. Even my doctor given me a letter of recommendation stating that my disease was stable to help support my application for travel insurance.

Participant 005_2023AULUC

*Probably after I've kept getting good results.
Participant 013_2023AULUC*

*Yes. I think in the period after the major improvements from my drug treatment, that was when I was most available because prior to that, there was a degree of desperation, of desperately hoping that the direction I was going was going to lead to my recovery. Once the signs of that recovery were there, that was very reassuring and enabled me to access that information in a much more relaxed manner. That's how it is now. I just think about the time when my drug treatment ceases to be effective and that there's a very major likelihood that that will be the case. I won't be on this drug treatment forever or for the rest of my life. That's an anxiety in waiting. My preparation for that is to be well informed, to have my connections active, and to give it my attention and talk with relevant people about what my needs are.
Participant 022_2023AULUC*

Participant describes being receptive to information after treatment

I think probably post-treatment once because in terms of emergency, your brain is not, actually it's a flight or fight. It's this survival thing where you have this tunnel vision and the tunnel vision is, okay, you are the specialist. I've got that. What do I need? If you frame it into the perspective that I was trusting the medical system and the health system, which I've lost total trust in now, so at the time the last thing I wanted, it was just throw me a hand, save me from that, and do whatever you think. Once you do the first treatment, you finish the first treatment. After I think you've done something, at least it's action. Then in the time where you finished the treatment that you've been given, then the emergency has passed because you've done whatever you had to do at the time. That's when you start accumulating information and integrating information. I certainly don't need it at the beginning.

Participant 024_2023AULUC

Probably post-op but pre-op it was just such a shock because of my anxiety and catastrophizer as well. Post-op it's better to get information about the future, what happens now, what's the prognosis, what your outlook going to be.

Participant 010_2023AULUC

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

Okay, I'm going to give you an example here, you're probably going to [crosstalk]. Here's a great example of when not to give information, when a person has a - what it bronchoscopy or myelination? No, bronchoscopy. When a person has just had a bronchoscopy being put under sedation and I've come out and I said to the nurse, "Am I okay?" I was still waking up, she said, "Yes, yes, they got lots of blood clots out." I went, "Oh, great." I go in and been put in my room, and I think, "Great, it's a blood clot." Then a doctor comes into my room and starts wanting to talk to me and says, "Do you know why you're here?" I say, "Yes, I have a blood clot." He says, "No, you have lung cancer." "What do you mean? No, I have a blood clot." He said, "Doctor, blah, blah, blah, came in and spoke to you about you having lung cancer." I do not recall a single word that he-- Never tell someone who has just come out from sedation bad news, because it's bad enough that you're coming out from sedation, let alone being hit by the words. You know what? He

probably did tell me but do I remember a single word of it? No. Was my [crosstalk] my first experience, someone [crosstalk] me saying, "No, you do not have a blood clot, you have lung cancer." I think that little bits over time, for someone like me, I was in hospital for two weeks. There was no reason for anybody to not keep communicating with me along the way. To be honest, it did happen slowly over time, but it could have been better. I think that even over a course of a day, someone could have come in and started speaking to me about some things and assess the situation. I don't think anyone ever assesses the situation about where you're at, if I'm in hospital, someone needed to have assessed, "When is the right time to tell her?" I don't feel anyone did.

Participant 015_2023AULUC

PARTICIPANT: No because when they give you the diagnosis, they also give you-- I've got three big booklets and a whole heap of paper stuff and a whole heap of information to bring home and read. Then when you go up for treatment for the first time, they show you videos and all sorts of things. It's just incredible. I was just blown away by it all.

Participant 017_2023AULUC

I don't know about that. At the start, there was a lot going on. I took a nurse with me to the original appointment who took lots of notes so I could read through them later. I did put my head in the sand for a while. I guess I'm probably more receptive now, but only maybe because I've come to terms [laughs] a bit better.

Participant 006_2023AULUC

Yes and I remember the first couple of visits where you're getting told this is and I got told it was lung cancer from my breasts oncologist because we were all going down that path and then she got the results and she said to me, "I'm really sorry to tell you." That was like a big body blow. The first visit to the medical oncologist for my lung cancer was just a blur. I would say a couple of months in was when I had my head around enough that I could actually start to ask questions that were more relevant. I consider myself pretty good medically and understand a lot but I really think it takes a couple of months before you can go, oh my head's clear enough to ask some more pertinent questions, not to be just in this whirlwind of panic. Does that make sense?

Participant 020_2023AULUC

Participant describes being receptive to information after the shock of diagnosis

Table 6.9: Timing of information

Timing of information	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes being receptive from the beginning (diagnosis)	7	26.92	7	28.00	0	0.00	3	30.00	4	25.00	5	31.25	2	20.00
Participant describes being receptive to information after results from treatment are known, or when getting results of follow up scans	7	26.92	7	28.00	0	0.00	2	20.00	5	31.25	6	37.50	1	10.00
Participant describes being receptive to information after treatment	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	5	31.25	0	0.00
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	3	18.75	2	20.00
Participant describes being receptive to information after the shock of diagnosis	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00

Timing of information	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes being receptive from the beginning (diagnosis)	7	26.92	5	29.41	2	22.22	4	30.77	3	23.08	0	0.00	7	29.17	3	33.33	4	23.53
Participant describes being receptive to information after results from treatment are known, or when getting results of follow up scans	7	26.92	5	29.41	2	22.22	5	38.46	2	15.38	1	50.00	6	25.00	4	44.44	3	17.65
Participant describes being receptive to information after treatment	5	19.23	3	17.65	2	22.22	3	23.08	2	15.38	0	0.00	5	20.83	1	11.11	4	23.53
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	5	19.23	4	23.53	1	11.11	0	0.00	5	38.46	0	0.00	5	20.83	1	11.11	4	23.53
Participant describes being receptive to information after the shock of diagnosis	3	11.54	2	11.76	1	11.11	2	15.38	1	7.69	1	50.00	2	8.33	1	11.11	2	11.76

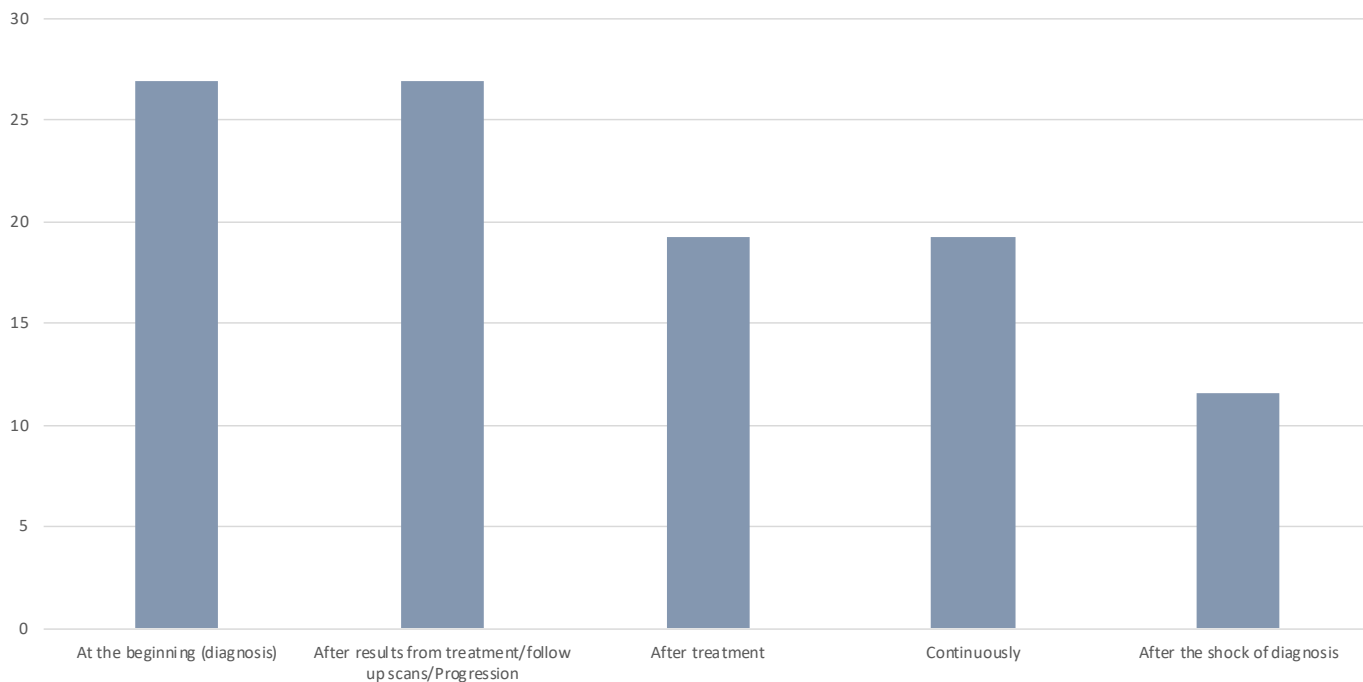


Figure 6.6: Timing of information

Table 6.10: Timing of information – subgroup variations

Theme	Less frequently	More frequently
Participant describes being receptive from the beginning (diagnosis)	-	-
Participant describes being receptive to information after results from treatment are known, or when getting results of follow up scans	Male University	Female Trade or high school Mid to low status
Participant describes being receptive to information after treatment	Male	Female
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	Trade or high school	University
Participant describes being receptive to information after the shock of diagnosis	Male	-

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=26, 52.00%). The most common responses that they had overall positive communication (38.46%), and overall negative communication (30.77%). Other participants described that communication was overall positive, with the exception of one or two occasions (19.23%).

Participants describes health professional communication as being overall positive

It's been good, especially with my oncologist because he seems to have a lot of empathy and I can tell when things are going well and when things aren't going well. I never actually asked him for a prognosis at the beginning and I don't think he believes in giving a prognosis either because everyone's different. Everyone's situation is

different in how they deal with treatment, that sort of thing. We never discussed prognosis and another lung cancer patient said to me, "No other human being should tell you how many months you've got left." I agree with that, just go with what you've got but this time around, when I had this latest diagnosis, I did ask him and he gave me a timeframe, I think maybe reluctantly, but I think I pressed it a bit more this time. He said, "You can go way past that."

Participant 005_2023AULUC

It's been good since I've been referred from the oncologist, the first part, I guess where they're trying to determine what stage you're at and because the PET showed up a few different hotspots, and unfortunately in CITY, different hospitals have different specialists, so I got referred to four different hospitals all around CITY for different treatment at different body parts, whereas it's easier just to be managed by one

hospital. Good, yet coordination could be better.
Participant 026_2023AULUC

Yes, it's been awesome. Top-notch.
Participant 006_2023AULUC

Participants describes health professional communication as being overall negative

DOCTOR said, "You've got lung cancer, you're going to die. This is what we can do now. That's it." They really don't know much enough about it. They put all lung cancers into the same box, I guess, too because that's what most people do. I share to people a lot about lung cancer. They, "Oh, did you smoke?" "No. It's nothing to do with smoking. It's a gene, but anyway." I think they're a bit the same, too. They know that if you've got stage 4 lung cancer, that you're going to be dead within 12 months. They don't tell me anything I don't already know. [crosstalk].

Participant 002_2023AULUC

Between 0 and 10, I would say 2.
Participant 023_2023AULUC

I'd say pretty woeful. It's been shocking. I thought I was going a bit nuts. [unintelligible] talked one night to my husband, and he said, "I was wondering when you're going to say something about this." because he's been coming to the appointments with the oncologist and he said, he can't believe how poor it is. I'm not nuts. It has been really-- It's just like a process and it's almost like they've got their hand on the door the minute you sit down to open up and chuck you out again. They're nice enough people. Whether they're just so busy, or whether because I'm 2A and they're dealing with much sicker people. I don't know what it is but anyway, still a paying client.

Participant 025_2023AULUC

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

Good. Mostly good. Sometimes, it's really good when you've got an appointment, and you're sitting in front of the person or you're on the phone with them. It's really hard to get that appointment sometimes. If you want information outside of your allotted appointment time that might really difficult.

Participant 007_2023AULUC

I think the communication has been-- Okay. Look I think it'd be unfair to paint that brush, the negative brush to the clinician to have provided really superior care and support and communication. I think communication in general has been really good but there have been particular individuals where it has been horrible. I don't want to give an average score and go, "Oh, yes, this generally has been okay." Because it has either been really good or I've had really bad. I've had a clinician walk in again and say, "Do you why you're here today?" Because they all want to ask you why you're here today. You say, "Yes, I have lung cancer." He says, "Well, I have your results." I say, "Well, I don't want them." He said, "I'm sorry?" I said, "Well, have you got my pathology report?" He said, "No." I said, "Well, until you've got my report and you know exactly what you're going to do with me, don't give me anything. Don't come and talk to me." He said, "Well, that's not how we do things here." I said, "That's how we're going to do things here." I think, again, no understanding or consideration of where I was at. I said, "I feel like I've been bashed to the floor, and now they want to beat me over and over and over again." I was sick of people walking into my room, wanting to give me more information when I'm, "Enough already." I think communication when I-- Communication has been poor, because they hadn't recognized where I was at at the earlier stage. Then I did have one oncologist where his communication was horrible, and I hated that 12 months. The stress that that created for me was incredible. He was one of the reasons I wanted to leave and come off the trial. Then, I've had others where it's amazing.

Participant 015_2023AULUC

I've either had really good communication or I've had awful communication. Awful. In some respects, the awful people have actually accessed me and made it so I ended up with a better outcome, if that makes any sense. You don't get any more from doctors unless you ask. You don't get anymore unless you have it written down and you go in there and ask for it. Otherwise, you don't necessarily get told it. Then with different receptionists, some of them can be quite awful. One of them, who was booking my surgery, was just appalling, but, had she not been so appalling, I probably wouldn't have had -- Well, we had words and then [chuckles] I said, "Move me to another doctor," and she did, and I think I ended up with a better surgeon and a better outcome. As awful as it was, it probably gave me a better outcome, truth be known. My actual care of looking after me, I think, seemed quite

good, but some of the communication, like the finance person, in Genesis care for my radiation because, of course, that's not covered under your private healthcare and you had to pay for it. She

was completely rude and obnoxious. Anyway, you get through that.
Participant 018_2023AULUC

Table 6.11: Healthcare professional communication.

Healthcare professional communication	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participants describes health professional communication as being overall positive	10	38.46	10	40.00	0	0.00	6	60.00	4	25.00	6	37.50	4	40.00
Participants describes health professional communication as being overall negative	8	30.77	7	28.00	1	100.00	3	30.00	5	31.25	7	43.75	1	10.00
Participants describes health professional communication as being overall positive, with the exception of one or two occasions	5	19.23	5	20.00	0	0.00	1	10.00	4	25.00	4	25.00	1	10.00
No particular comment (Other/no response)	3	11.54	3	12.00	0	0.00	0	0.00	3	18.75	2	12.50	1	10.00

Healthcare professional communication	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participants describes health professional communication as being overall positive	10	38.46	6	35.29	4	44.44	7	53.85	3	23.08	1	50.00	9	37.50	4	44.44	6	35.29
Participants describes health professional communication as being overall negative	8	30.77	5	29.41	3	33.33	2	15.38	6	46.15	1	50.00	7	29.17	2	22.22	6	35.29
Participants describes health professional communication as being overall positive, with the exception of one or two occasions	5	19.23	4	23.53	1	11.11	1	7.69	4	30.77	0	0.00	5	20.83	1	11.11	4	23.53
No particular comment (Other/no response)	3	11.54	1	5.88	2	22.22	3	23.08	0	0.00	0	0.00	3	12.50	2	22.22	1	5.88

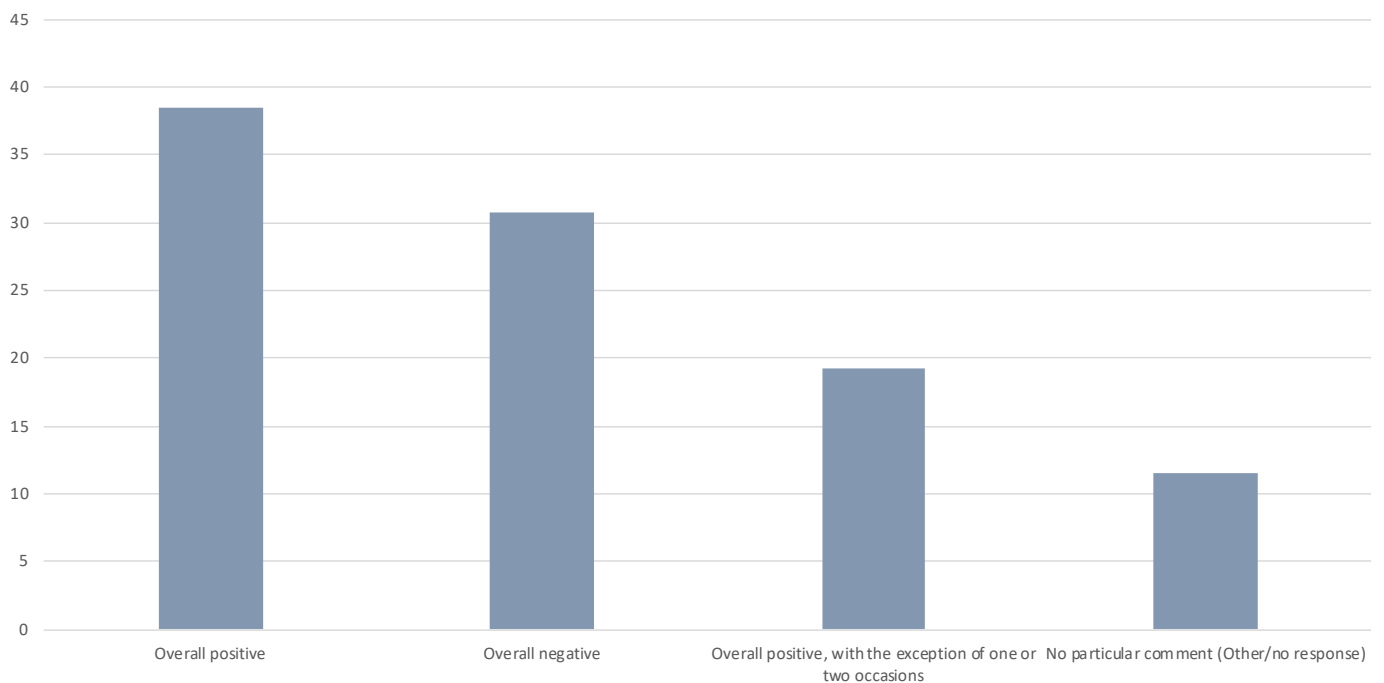


Figure 6.7: Healthcare professional communication

Table 6.12: Healthcare professional communication – subgroup variations

Theme	Less frequently	More frequently
Participants describes health professional communication as being overall positive	Metastatic University	Non-metastatic Trade or high school
Participants describes health professional communication as being overall negative	Male Trade or high school	Female University
Participants describes health professional communication as being overall positive, with the exception of one or two occasions	Trade or high school	University
No particular comment (Other/no response)	Non-metastatic University	Aged 65 or older Trade or high school Mid to low status

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

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comprehensive conversations (19.23%). The main reason for negative communication was that it was dismissive, that they had one way conversations (15.38 %).

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

Care coordination scale (n=27)	Mean	Median
Communication*	34.38	32.00
Navigation*	23.37	25.00
Total score*	57.67	56.00
Care coordination global measure	5.96	6.00
Quality of care global measure	6.81	8.00

I think the communication has been-- Okay. Look I think it'd be unfair to paint that brush, the negative brush to the clinician to have provided really superior care and support and communication. I think communication in general has been really good but there have been particular individuals where it has been horrible. I don't want to give an average score and go, "Oh, yes, this generally has been okay." Because it has either been really good or I've had really bad. Participant 015_2023AULUC

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

I think been pretty good. Although 18 years ago when I went off the trial and the trial nurse went

away, I think she's a general cancer nurse who works over two hospitals, it's diminished. She was the one who also said, "Oh, it's in your head. It's like, "How dare you?" You just shouldn't say that as a nurse. There are other ways to approach things like that. Anyway, it is what it is, isn't it? I think nursing's changed a lot as well in the last 20 years. There's not as much care over there. When they moved me from ICU to the ward, they knocked the tube that I had for my pain relief. It was an odd PSA button that you press. All night, I was calling the nurse and I kept on saying, I'm in pain. He said, just keep on clicking it. You can't overdose on it. I'm thinking, why? I've been clicking all night. I was in so much pain and I couldn't move. I had a drain coming out of the side. The day nurse came on and she took off the tube. It had been dismantled and there was a big lump and a bruise all over my arm from where it had just drained and hadn't gone into my blood. You're just thinking, oh my gosh. Like just shit, whose fault is it? Who is in the wrong here? NAME has it, it was the one who shut it down. Do I blame him or do I blame the nurse who wheels me from ICU into the ward, or do I blame the nurse who I kept on buzzing and he did nothing about it? You just think, well, thank God I'm still alive and I can walk out of here. It shouldn't have happened. Participant 019_2023AULUC

Table 6.13: Healthcare professional communication (Rationale for response)

Healthcare professional communication (rationale for response)	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes healthcare communication as good, with no particular reason given	6	23.08	6	24.00	0	0.00	3	30.00	3	18.75	4	25.00	2	20.00
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	5	19.23	5	20.00	0	0.00	1	10.00	4	25.00	3	18.75	2	20.00
Participant describes health professional communication as being dismissive (One way conversation)	4	15.38	4	16.00	0	0.00	1	10.00	3	18.75	3	18.75	1	10.00
Participant describes healthcare communication as limited, with no particular reason given	4	15.38	3	12.00	1	100.00	1	10.00	3	18.75	3	18.75	1	10.00

Healthcare professional communication (rationale for response)	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes healthcare communication as good, with no particular reason given	6	23.08	3	17.65	3	33.33	3	23.08	3	23.08	1	50.00	5	20.83	2	22.22	4	23.53
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	5	19.23	4	23.53	1	11.11	3	23.08	2	15.38	0	0.00	5	20.83	1	11.11	4	23.53
Participant describes health professional communication as being dismissive (One way conversation)	4	15.38	3	17.65	1	11.11	0	0.00	4	30.77	0	0.00	4	16.67	0	0.00	4	23.53
Participant describes healthcare communication as limited, with no particular reason given	4	15.38	1	5.88	3	33.33	2	15.38	2	15.38	0	0.00	4	16.67	1	11.11	3	17.65

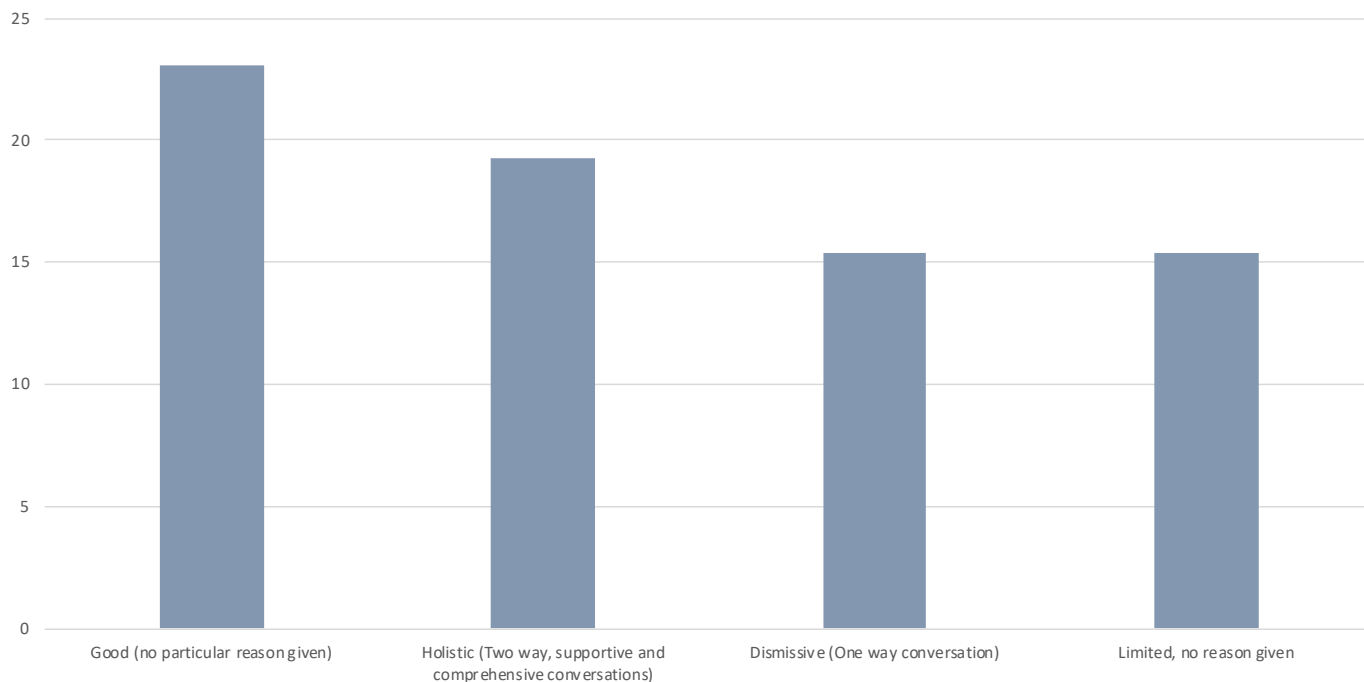


Figure 6.8: Healthcare professional communication (Rationale for response)

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

Theme	Less frequently	More frequently
Participant describes healthcare communication as good, with no particular reason given	-	Aged 65 or older
Participant describes health professional communication as being dismissive (One way conversation)	Trade or high school Mid to low status	University
Participant describes healthcare communication as limited, with no particular reason given	-	Aged 65 or older

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=28.00, IQR=7.50), **Partners in health: Recognition and management of symptoms** (mean=19.89, SD=3.39), **Partners in health: Adherence to treatment** (median=15.00, IQR=4.00), **Partners in health: Total score** (median=78.00, IQR=26.50) indicating very good knowledge, very good recognition and management of symptoms, very good adherence to treatment, very good overall ability to manage their health

The overall scores for the cohort were in the second highest quintile for **Partners in health: Coping** (mean=15.89, SD=5.96), indicating good coping.

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 were good at coping with their condition.

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: 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 very good treatment adherence.

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 very good overall knowledge, coping and confidence for managing their own health.

Table 6.15: Partners in health summary statistics

Partners in health scale (n=27)	Mean	SD	Median	IQR	Possible range	Quintile
Knowledge	25.15	6.70	28.00	7.50	0 to 32	5
Coping*	15.89	5.96	16.00	7.50	0 to 24	4
Recognition and management of symptoms*	19.89	3.39	20.00	4.50	0 to 24	5
Adherence to treatment	13.41	3.72	15.00	4.00	0 to 16	5
Total score	74.33	18.45	78.00	26.50	0 to 96	5

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

Partners in health by participant type

There were 25 participants (92.59%) that had been diagnosed with lung cancer, and 2 participants (7.41%) that were family members or carers to people with lung

cancer. Comparisons were not made because there were too few family members and carers. Summary statistics are displayed in Table 6.16.

Table 6.16: Partners in health by participant type summary

Partners in health scale	Group	Number (n=27)	Percent	Mean	SD	Median	IQR	Quintile
Knowledge	Person with lung cancer	25	92.59	25.40	6.76	28.00	7.00	5
	Family member or carer	2	7.41	22.00	7.07	22.00	5.00	-
Coping*	Person with lung cancer	25	92.59	16.08	6.14	16.00	7.00	4
	Family member or carer	2	7.41	13.50	2.12	13.50	1.50	-
Recognition and management of symptoms*	Person with lung cancer	25	92.59	19.88	3.53	20.00	5.00	5
	Family member or carer	2	7.41	20.00	0.00	20.00	0.00	-
Adherence to treatment	Person with lung cancer	25	92.59	13.44	3.86	16.00	4.00	5
	Family member or carer	2	7.41	13.00	1.41	13.00	1.00	-
Total score	Person with lung cancer	25	92.59	74.80	19.00	79.00	27.00	5
	Family member or carer	2	7.41	68.50	10.61	68.50	7.50	-

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

Partners in health by lung cancer stage

Comparisons were made by cancer stage, there were 11 participants (44.00%) with non-metastatic lung cancer and, 14 participants (56.00%) with metastatic lung cancer.

Assumptions for normality and variance for a two-sample t-test were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.17).

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

Table 6.17: Partners in health by lung cancer stage summary statistics and T-test

Partners in health scale	Group	Number (n=27)	Percent	Median	IQR	W	p-value
Knowledge	Non-metastatic	11	44.00	24.00	12.00	42.00	0.0576
	Metastatic	14	56.00	28.50	3.75		
Coping	Non-metastatic	11	44.00	15.00	8.50	66.00	0.5632
	Metastatic	14	56.00	16.00	4.50		
Recognition and management of symptoms	Non-metastatic	11	44.00	18.00	6.50	51.50	0.1658
	Metastatic	14	56.00	20.00	2.00		
Adherence to treatment	Non-metastatic	11	44.00	13.00	6.50	50.50	0.1303
	Metastatic	14	56.00	16.00	2.75		
Total score	Non-metastatic	11	44.00	77.00	31.00	54.50	0.2281
	Metastatic	14	56.00	80.50	11.50		

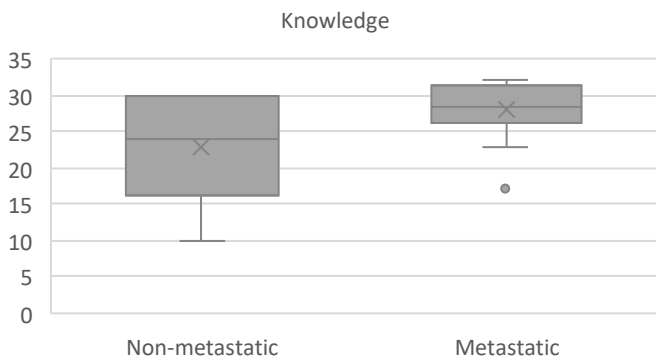


Figure 6.9: Boxplot of Partners in health: knowledge by lung cancer stage

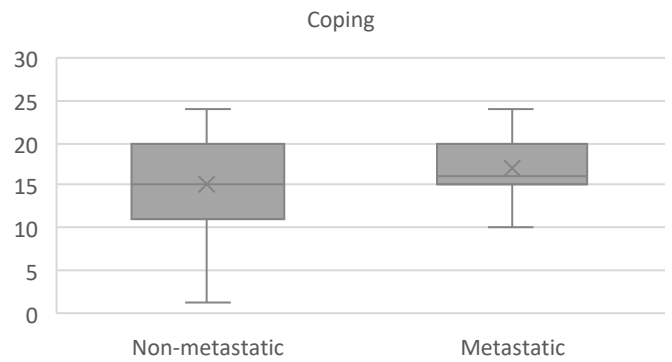


Figure 6.10: Boxplot of Partners in health: coping by lung cancer stage

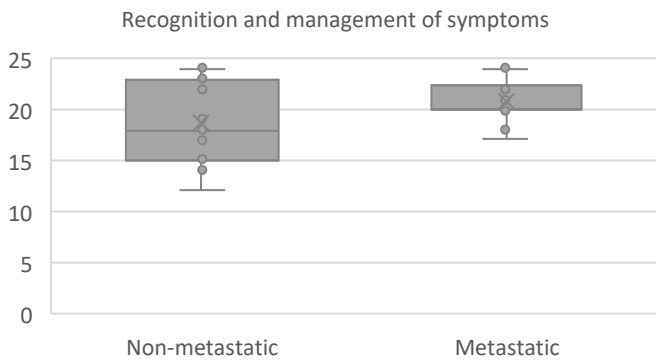


Figure 6.11: Boxplot of Partners in health: recognition and management of symptoms by lung cancer stage

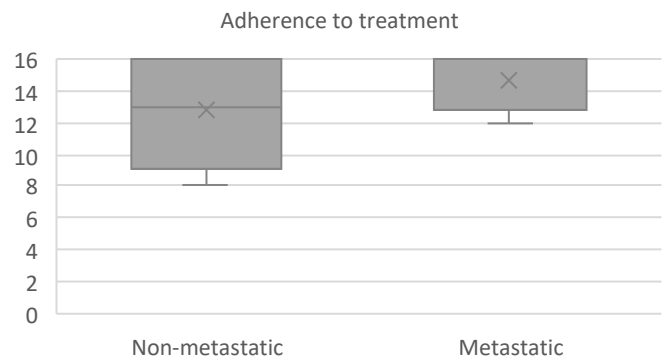


Figure 6.12: Boxplot of Partners in health: adherence to treatment by lung cancer stage

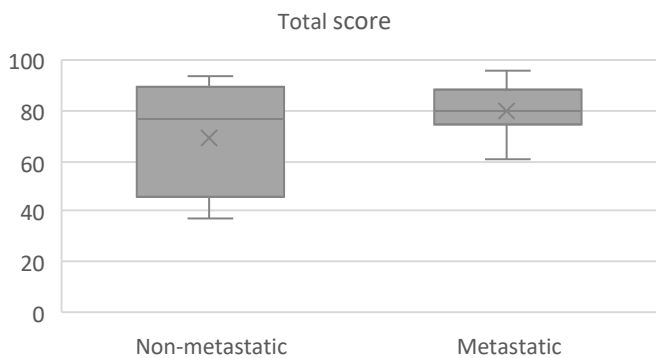


Figure 6.13: Boxplot of Partners in health Total score by lung cancer stage

Partners in health by gender

Comparisons were made by gender, there were 20 female participants (74.07%), and 8 male participants (25.93%).

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).

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

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

Partners in health scale	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Knowledge	Female	20	74.07	24.25	7.11	-1.19	25	0.2466
	Male	7	25.93	27.71	4.89			
Adherence to treatment	Female	20	74.07	12.80	4.09	-1.46	25	0.1557
	Male	7	25.93	15.14	1.57			

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

Partners in health scale	Group	Number (n=27)	Percent	Median	IQR	W	p-value
Coping	Female	20	74.07	16.00	8.25	60.50	0.6169
	Male	7	25.93	16.00	6.00		
Recognition and management of symptoms	Female	20	74.07	20.00	4.50	50.50	0.2872
	Male	7	25.93	21.00	3.00		
Total score	Female	20	74.07	77.50	25.00	51.50	0.3189
	Male	7	25.93	83.00	14.00		

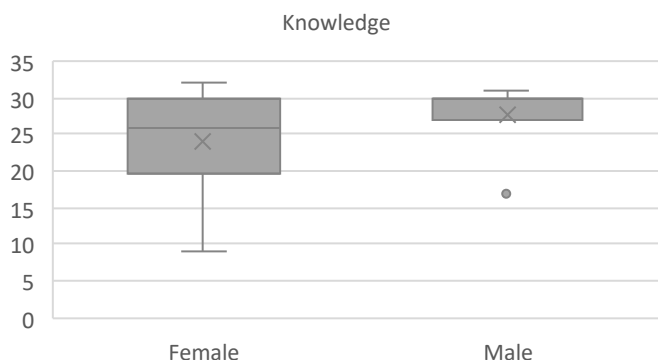


Figure 6.14: Boxplot of Partners in health: knowledge by gender

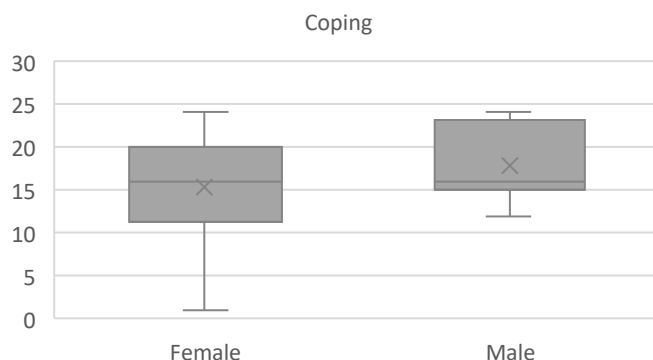


Figure 6.15: Boxplot of Partners in health: coping by gender

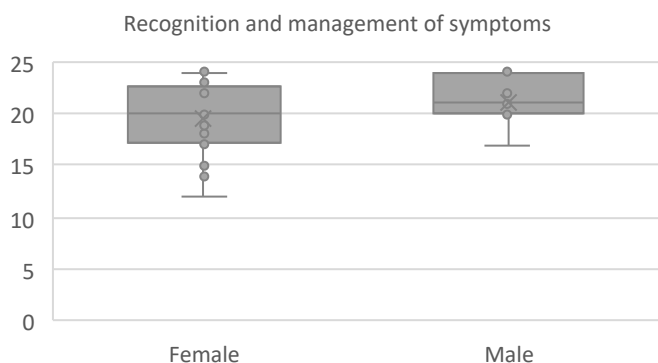


Figure 6.16: Boxplot of Partners in health: recognition and management of symptoms by gender

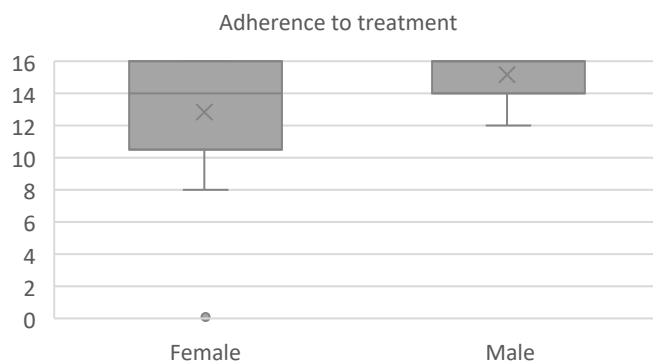


Figure 6.17: Boxplot of Partners in health: adherence to treatment by gender

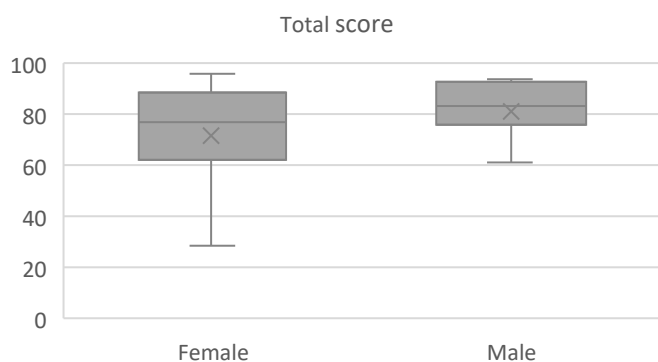


Figure 6.18: Boxplot of Partners in health Total score by gender

Partners in health by age

Participants were grouped according to age, with comparisons made between participants aged 35 to 64 (n=15, 55.56%), and participants aged 65 or older (n=12, 44.44%).

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 age for any of the Partners in health scales.

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

Partners in health scale	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Coping	Aged 35 to 64	15	55.56	15.87	5.79	-0.02	25	0.9832
	Aged 65 or older	12	44.44	15.92	6.42			
Total score	Aged 35 to 64	15	55.56	73.20	19.93	-0.35	25	0.7286
	Aged 65 or older	12	44.44	75.75	17.17			

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

Partners in health scale	Group	Number (n=27)	Percent	Median	IQR	W	p-value
Knowledge	Aged 35 to 64	15	55.56	28.00	6.00	85.50	0.8442
	Aged 65 or older	12	44.44	28.50	8.75		
Recognition and management of symptoms	Aged 35 to 64	15	55.56	20.00	6.50	81.00	0.6745
	Aged 65 or older	12	44.44	20.00	2.25		
Adherence to treatment	Aged 35 to 64	15	55.56	15.00	4.00	77.00	0.5167
	Aged 65 or older	12	44.44	16.00	4.00		

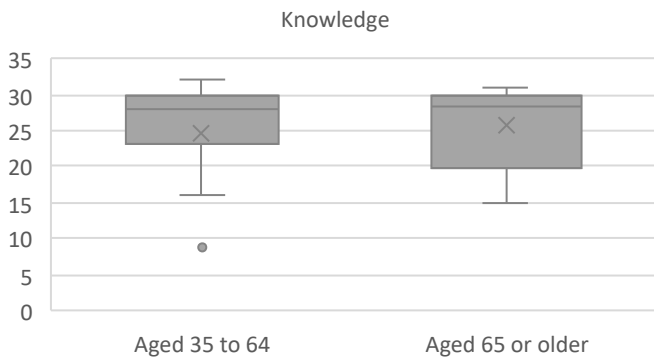


Figure 6.19: Boxplot of Partners in health: knowledge by age

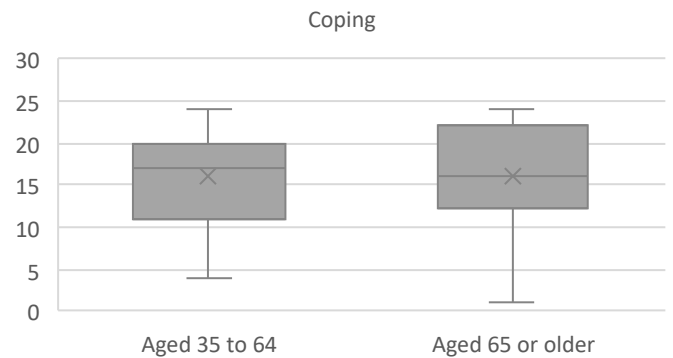


Figure 6.20: Boxplot of Partners in health: coping by age

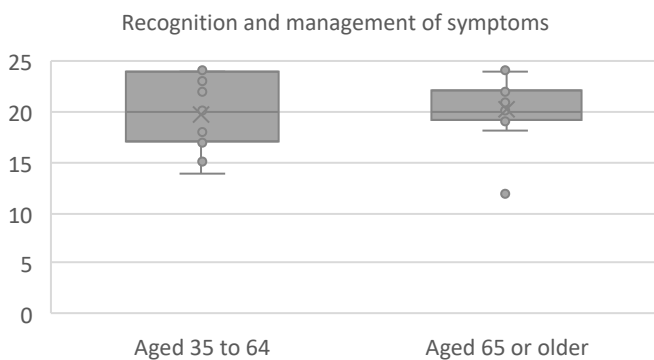


Figure 6.21: Boxplot of Partners in health: recognition and management of symptoms by age

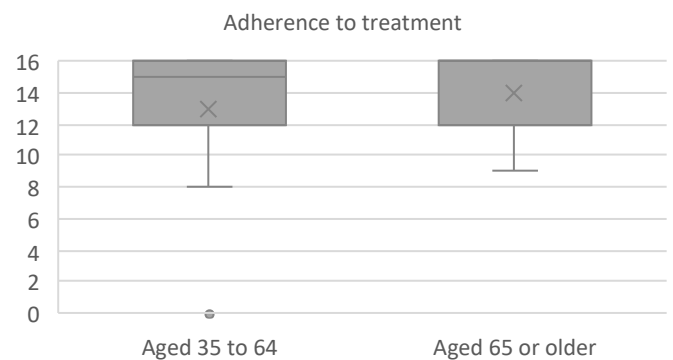


Figure 6.22: Boxplot of Partners in health: adherence to treatment by age

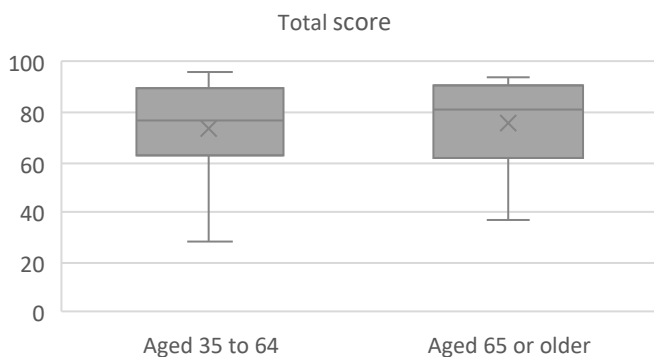


Figure 6.23: Boxplot of Partners in health Total score by age

Partners in health by education

Comparisons were made by education status, between those with trade or high school qualifications (n=15, 55.56%), and those with a university qualification (n=12, 44.44%).

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=27)	Percent	Mean	SD	T	dF	p-value
Coping	Trade or high school	15	55.56	15.13	6.51	-0.73	25	0.4721
	University	12	44.44	16.83	5.31			
Recognition and management of symptoms	Trade or high school	15	55.56	19.40	3.40	-0.83	25	0.4127
	University	12	44.44	20.50	3.42			

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

Partners in health scale	Group	Number (n=27)	Percent	Median	IQR	W	p-value
Knowledge	Trade or high school	15	55.56	28.00	9.50	80.50	0.6584
	University	12	44.44	27.50	6.75		
Adherence to treatment	Trade or high school	15	55.56	15.00	4.00	79.50	0.6040
	University	12	44.44	15.50	3.00		
Total score	Trade or high school	15	55.56	77.00	25.00	78.00	0.5744
	University	12	44.44	79.00	15.50		

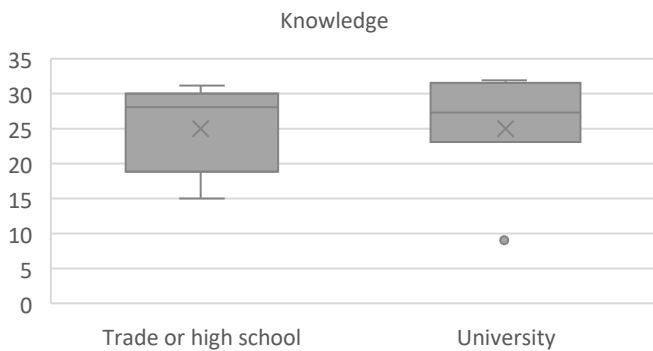


Figure 6.24: Boxplot of Partners in health: knowledge by education

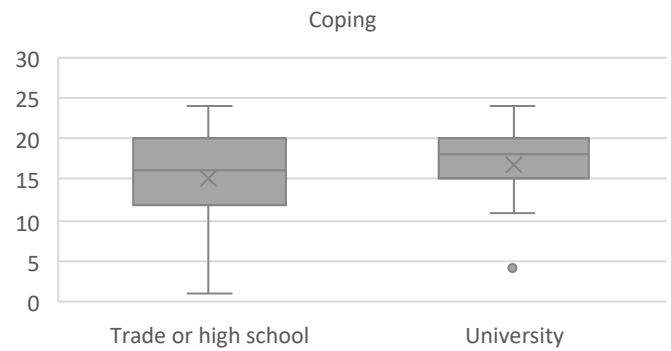


Figure 6.25: Boxplot of Partners in health: coping by education

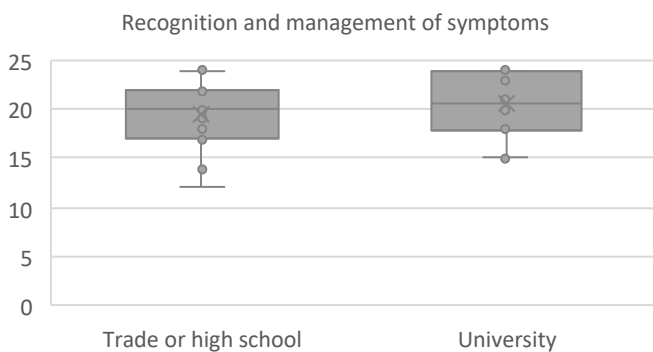


Figure 6.26: Boxplot of Partners in health: recognition and management of symptoms by education

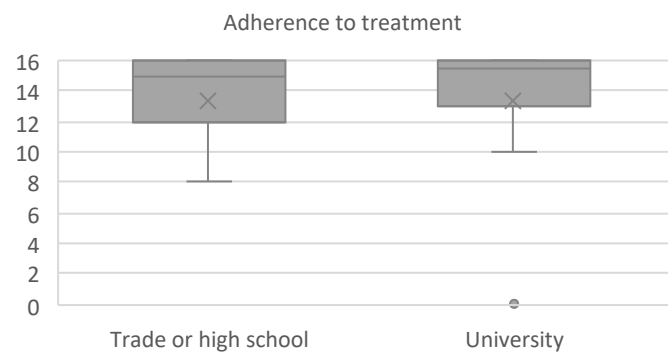


Figure 6.27: Boxplot of Partners in health: adherence to treatment by education

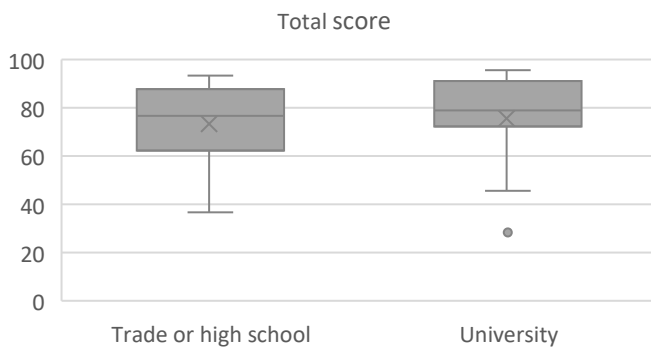


Figure 6.28: Boxplot of Partners in health Total score by education

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. There were 2 participants (7.41%) living in regional or remote areas and 25 participants

(92.59%) living in metropolitan areas. Comparisons were not made because there were too few participants lived in regional or remote areas. Summary statistics are displayed in Table 6.24.

Table 6.24: Partners in health by location summary statistics

Partners in health scale	Group	Number (n=27)	Percent	Mean	SD	Median	IQR	Quintile
Knowledge	Regional or remote	2	7.41	20.50	16.26	20.50	11.50	5
	Metropolitan	25	92.59	25.52	5.97	28.00	7.00	-
Coping	Regional or remote	2	7.41	14.00	14.14	14.00	10.00	4
	Metropolitan	25	92.59	16.04	5.46	16.00	7.00	-
Recognition and management of symptoms	Regional or remote	2	7.41	19.50	6.36	19.50	4.50	5
	Metropolitan	25	92.59	19.92	3.28	20.00	4.00	-
Adherence to treatment	Regional or remote	2	7.41	8.00	11.31	8.00	8.00	5
	Metropolitan	25	92.59	13.84	2.66	15.00	4.00	-
Total score	Regional or remote	2	7.41	62.00	48.08	62.00	34.00	5
	Metropolitan	25	92.59	75.32	16.08	78.00	25.00	-

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

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, Mid to low status (n=10, 37.04%) compared to those with a higher SEIFA score of 7-10, Higher status (n=17, 62.96%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.25), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.26).

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

Table 6.25: Partners in health by socioeconomic status summary statistics and T-test

Partners in health scale	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Recognition and management of symptoms	Mid to low status	10	37.04	17.70	3.80	-0.04	25	0.9675
	Higher status	17	62.96	21.18	2.40			

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

Partners in health scale	Group	Number (n=27)	Percent	Median	IQR	W	p-value
Knowledge	Mid to low status	10	37.04	24.50	12.50	74.50	0.6150
	Higher status	17	62.96	29.00	6.00		
Coping	Mid to low status	10	37.04	13.50	11.50	83.00	0.9399
	Higher status	17	62.96	16.00	5.00		
Adherence to treatment	Mid to low status	10	37.04	12.50	6.50	60.50	0.2238
	Higher status	17	62.96	16.00	3.00		
Total score	Mid to low status	10	37.04	70.00	34.25	57.50	0.1706
	Higher status	17	62.96	82.00	14.00		

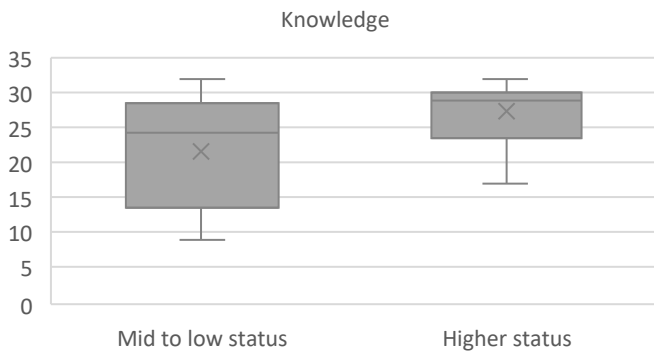


Figure 6.29: Boxplot of Partners in health: knowledge by socioeconomic status

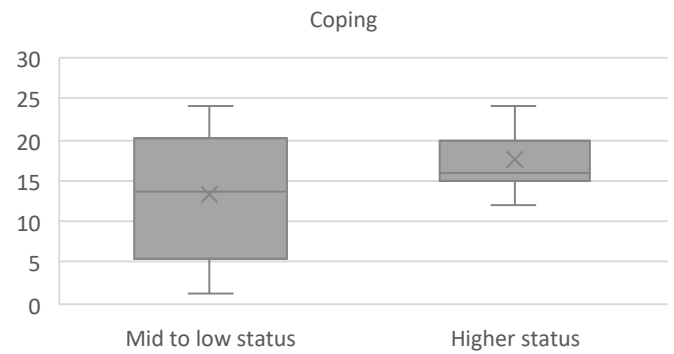


Figure 6.30: Boxplot of Partners in health: coping by socioeconomic status

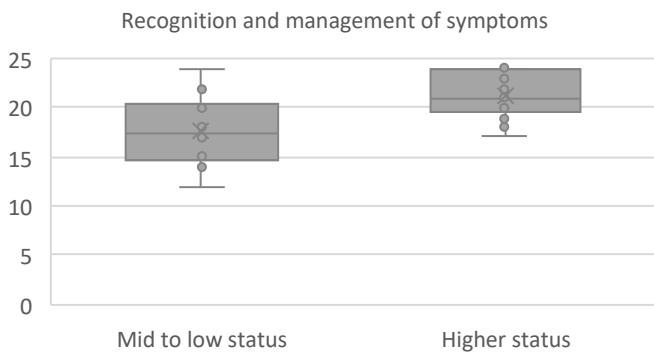


Figure 6.31: Boxplot of Partners in health: recognition and management of symptoms by socioeconomic status

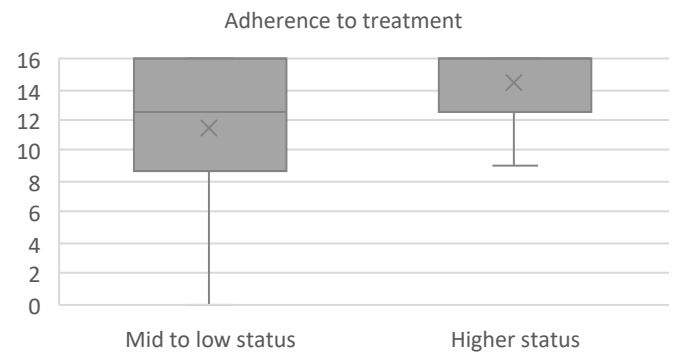


Figure 6.32: Boxplot of Partners in health: adherence to treatment by socioeconomic status

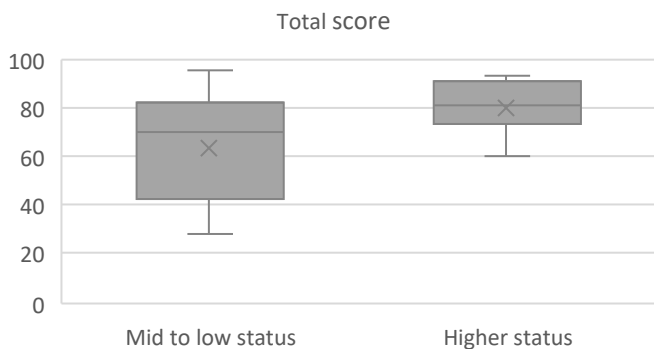


Figure 6.33: Boxplot of Partners in health Total score by socioeconomic status

Ability to take medicine as prescribed

Participants were asked about their ability to take medicines as prescribed. The majority of the participants responded that they took medicine as prescribed all the time (n=15, 60.00%), and 10

participants (40.00%) responded that they took medicines as prescribed most of the time. (Table 6.27, Figure 6.34).

Table 6.27: Ability to take medicine as prescribed

Ability to take medicine and stick to prescription	Number (n=25)	Percent
All of the time	15	60.00
Most of the time	10	40.00
Sometimes	0	0.00
Rarely	0	0.00

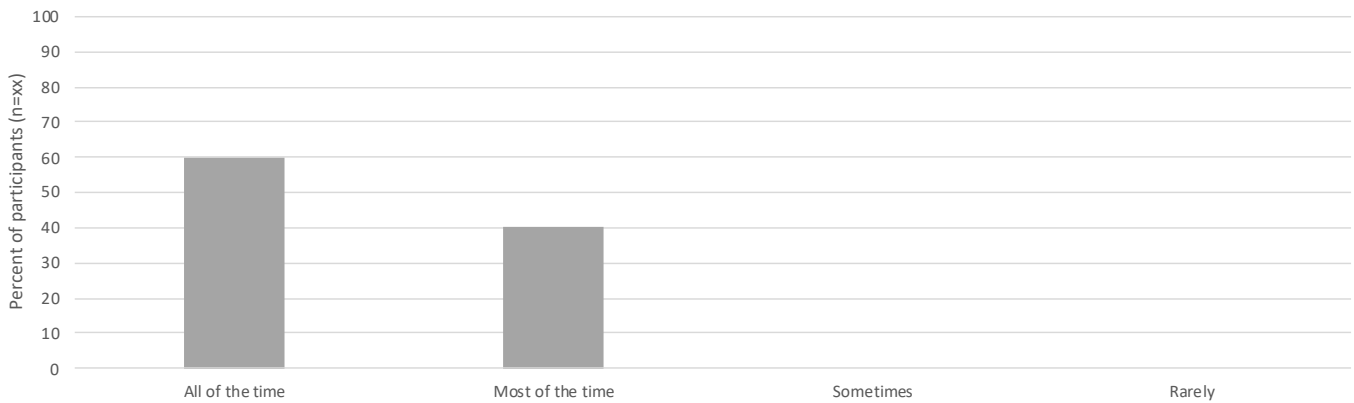


Figure 6.34: Ability to take medicine as prescribed

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options (n=17, 62.96%), disease cause (n=8, 29.63%), physical activity (n=8, 29.63%) and, disease management (n=7, 25.93%) were most frequently

given to participants by healthcare professionals, and, information about clinical trials (n=3, 11.11%), how to interpret test results (n=2, 7.41%) and, hereditary considerations (n=2, 7.41%) were given least often (Table 6.28, Figure 6.35).

Table 6.28: Information given by health professionals

Accessed "My health record"	Number (n=27)	Percent
Disease cause	8	29.63
Treatment options	17	62.96
Disease management	7	25.93
Complementary therapies	3	11.11
How to interpret test results	2	7.41
Clinical trials	3	11.11
Dietary	5	18.52
Physical activity	8	29.63
Psychological/social support	5	18.52
Hereditary considerations	2	7.41
No information	5	18.52

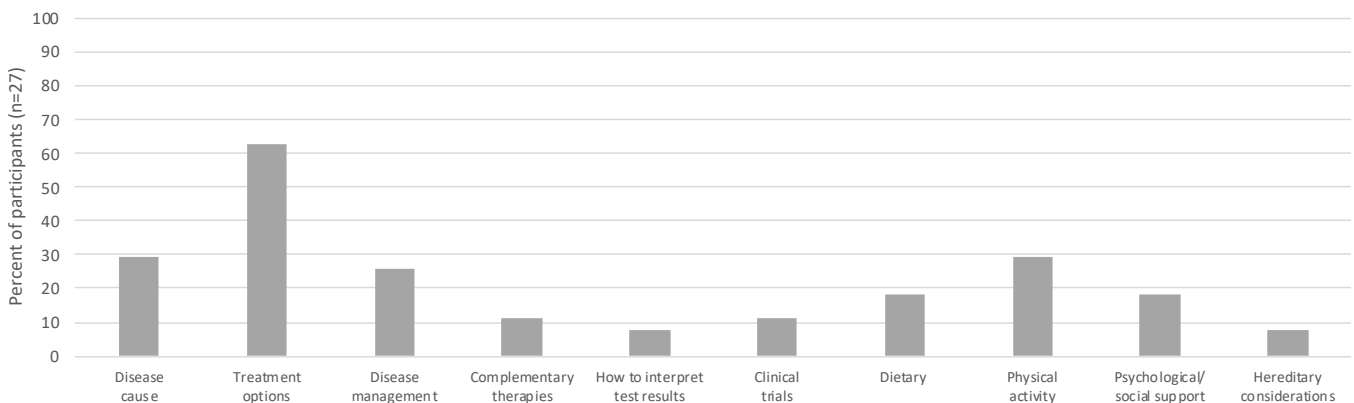


Figure 6.35: Information given by health professionals

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 disease management (n=22, 81.48%), disease cause (n=19, 70.37%), treatment options (n=19, 70.37%) and,

interpret test results (n=16, 59.26%) were most frequently searched for independently by participants, and, information about physical activity (n=13, 48.15%), diet (n=11, 40.74%) and, psychological/ social support (n=11, 40.74%) were searched for least often (Table 6.29, Figure 6.36).

Table 6.29: Information searched for independently

Accessed "My health record"	Number (n=27)	Percent
Disease cause	19	70.37
Treatment options	19	70.37
Disease management	22	81.48
Complementary therapies	15	55.56
How to interpret test results	16	59.26
Clinical trials	13	48.15
Dietary	11	40.74
Physical activity	13	48.15
Psychological/social support	11	40.74
Hereditary considerations	15	55.56
No information	0	0.00

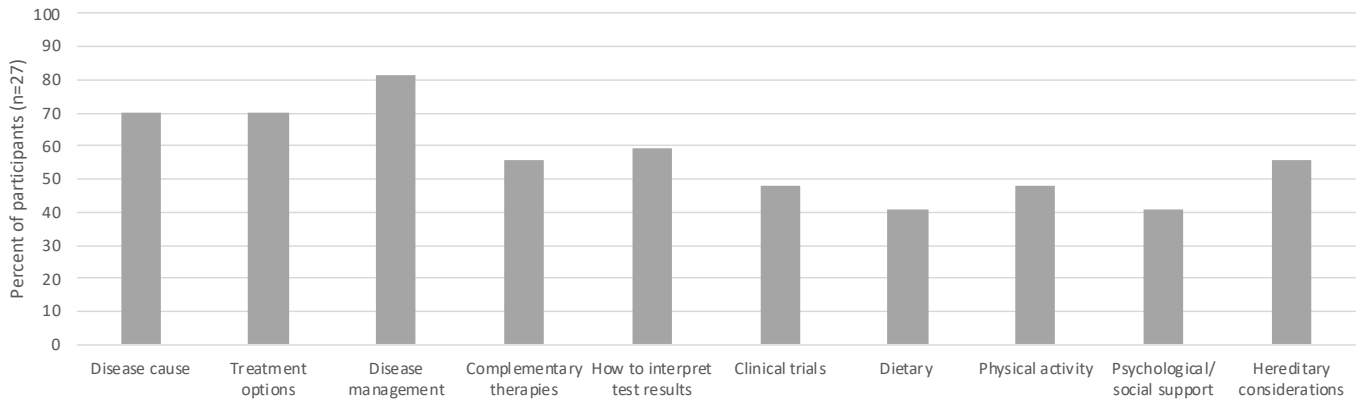


Figure 6.36: Information searched for independently

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were clinical trials (n=13, 48.15%) and diet(n=12, 44.44%).

The topics that participants did not search for independently after not receiving information from healthcare professionals were treatment options (n=6, 22.22%) and physical activity (n=6, 22.22%).

The topics that participants were given most information from both healthcare professionals and

searching independently for were treatment options (n=11, 40.74%) and disease management (n=6, 22.22%).

The topics that participants searched for independently after not receiving information from healthcare professionals were disease management (n=16, 59.26%) and interpret test results (n=16, 59.26%) (Table 6.30, Figure 6.37).

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=27	%	n=27	%	n=27	%	n=27	%
Disease Cause	5	18.52	3	11.11	5	18.52	14	51.85
Treatment options	2	7.41	6	22.22	11	40.74	8	29.63
Disease management	4	14.81	1	3.70	6	22.22	16	59.26
Complementary therapies	10	37.04	2	7.41	1	3.70	14	51.85
How to interpret test results	9	33.33	2	7.41	0	0.00	16	59.26
Clinical trials	13	48.15	1	3.70	2	7.41	11	40.74
Dietary information	12	44.44	4	14.81	1	3.70	10	37.04
Physical activity	8	29.63	6	22.22	2	7.41	11	40.74
Psychological/social support	12	44.44	4	14.81	1	3.70	10	37.04
Hereditary considerations	12	44.44	0	0.00	2	7.41	13	48.15

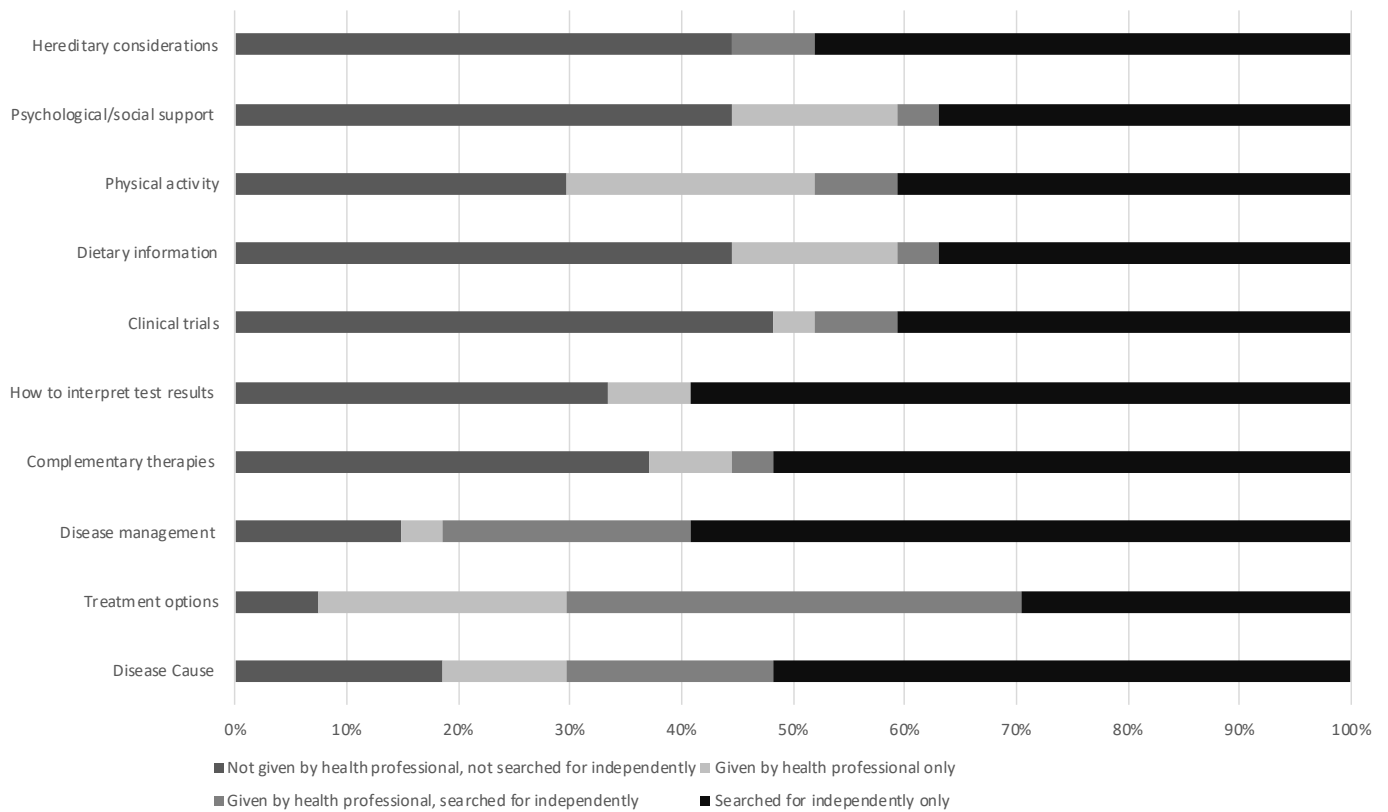


Figure 6.37: Information gaps

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 6.31 and Figure 6.38. 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 was most accessed followed by information from the Government. Information from Pharmaceutical companies and from were least accessed.

Table 6.31: Most accessed information

Information source	Weighted average (n=27)
Non-profit organisations, charity or patient organisations	3.04
Government	2.74
Hospital or clinic I am being treated in	2.59
Pharmaceutical companies	1.63

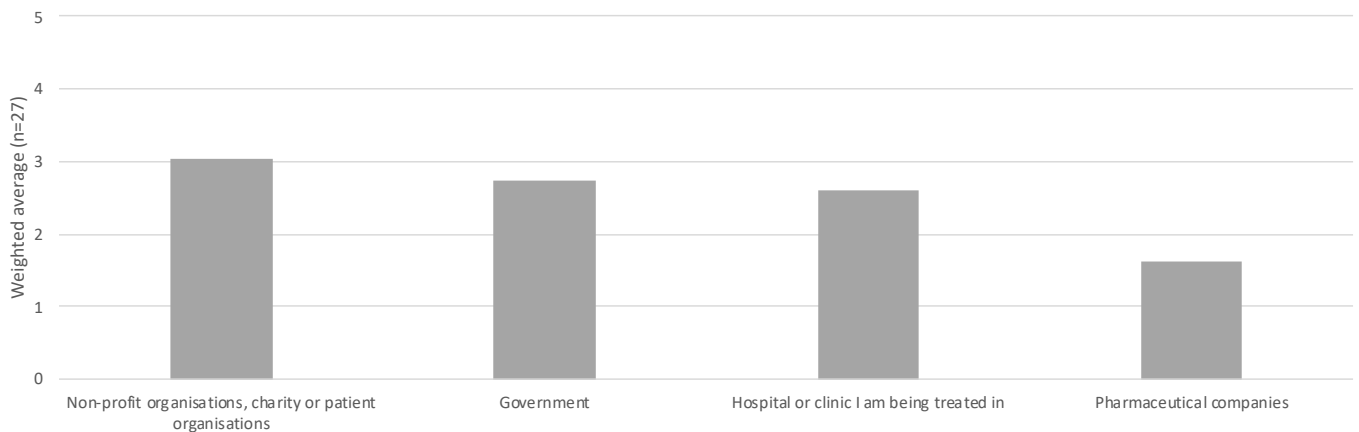


Figure 6.38: Most accessed information

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 11 participants (35.48%) had accessed My Health Record, 20 participants (64.52%) had not (Table 6.32, Figure 6.39).

Of those that had accessed My Health Record, there were 5 participants (45.45%) who found it to be poor or very poor, 2 participants (18.18%) who found it acceptable, and 4 participants (36.36%) who found it to be good or very good (Table 6.33, Figure 6.40).

Table 6.32: Accessed My Health Record

Accessed "My health record"	Number (n=31)	Percent
Yes	11	35.48
No	16	51.61
Not sure	1	3.23
Doesn't know what 'My Health Record' is	3	9.68

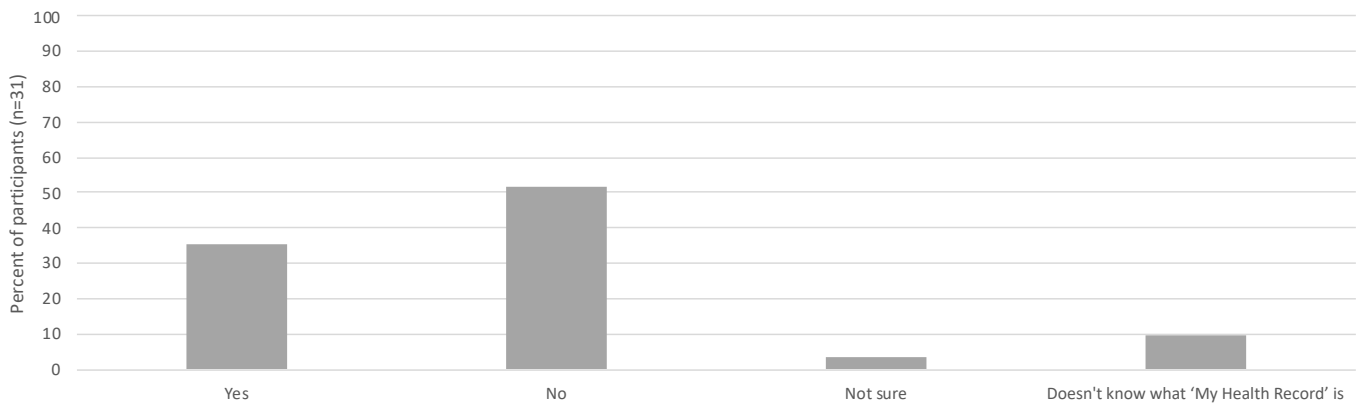


Figure 6.39: Accessed My Health Record

Table 6.33: How useful was My Health Record

How useful was "My health record"	Number (n=11)	Percent
Very poor	1	9.09
Poor	4	36.36
Acceptable	2	18.18
Good	4	36.36
Very good	0	0.00

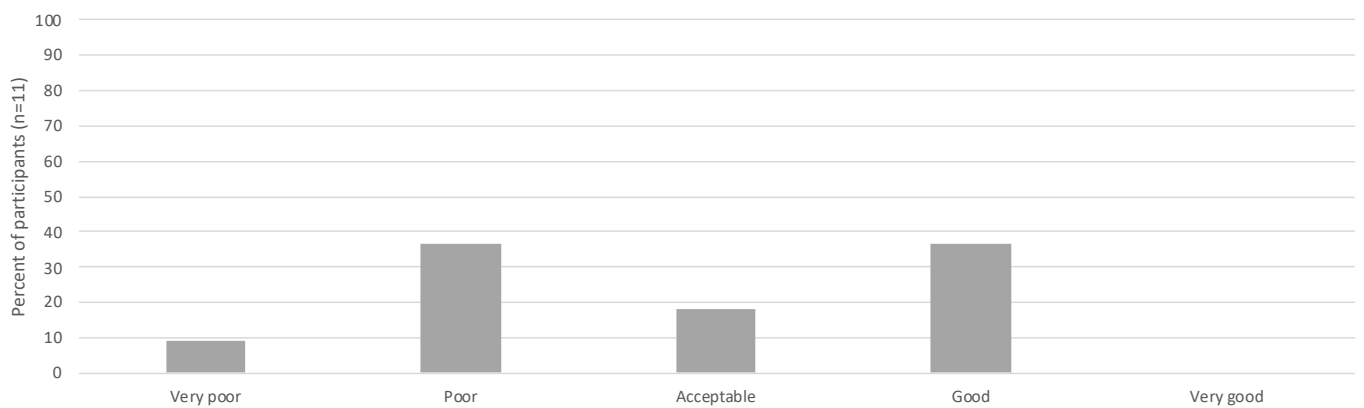


Figure 6.40: How useful was My Health Record