PERSONAL EXPERIENCE EXPECTATIONS KNOWLEDGE

PEEK

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HORMONE POSITIVE BREAST CANCER

AUSTRALIAN STUDY 2021

Section 1

Introduction
&
Methodology

This is where you can read about the PEEK methodology, information about the recruitment period and approach.

There is also a review of other mixed methodology studies in the field to identify the position of the PEEK study in the context of other literature. PEEK studies are often the largest of their kind in depth and participant numbers.

Full Report
Summary of Results
Infographic
Slide Set
Introduction & Methodology
Demographics
Symptoms & Diagnosis
Decision-making
Treatment
Communication & Information
Care & Support
Quality of Life
Expectations & Messages to Decision-Makers
Advice from current patients to patients in the future
Discussion
Where to from here?

The Centre for Community-Driven Research team for this study included:

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Thank you to each and every person that participated in this PEEK study.

This study was generously sponsored by Gilead Australia.

Gilead Australia provided arm's length sponsorship for the Centre for Community-Driven Research to report on the PEEK protocol data for people who have been diagnosed with hormone positive breast cancer. The sponsor had no input into the methodology, data collection, data analysis or reporting.

Position of this PEEK study

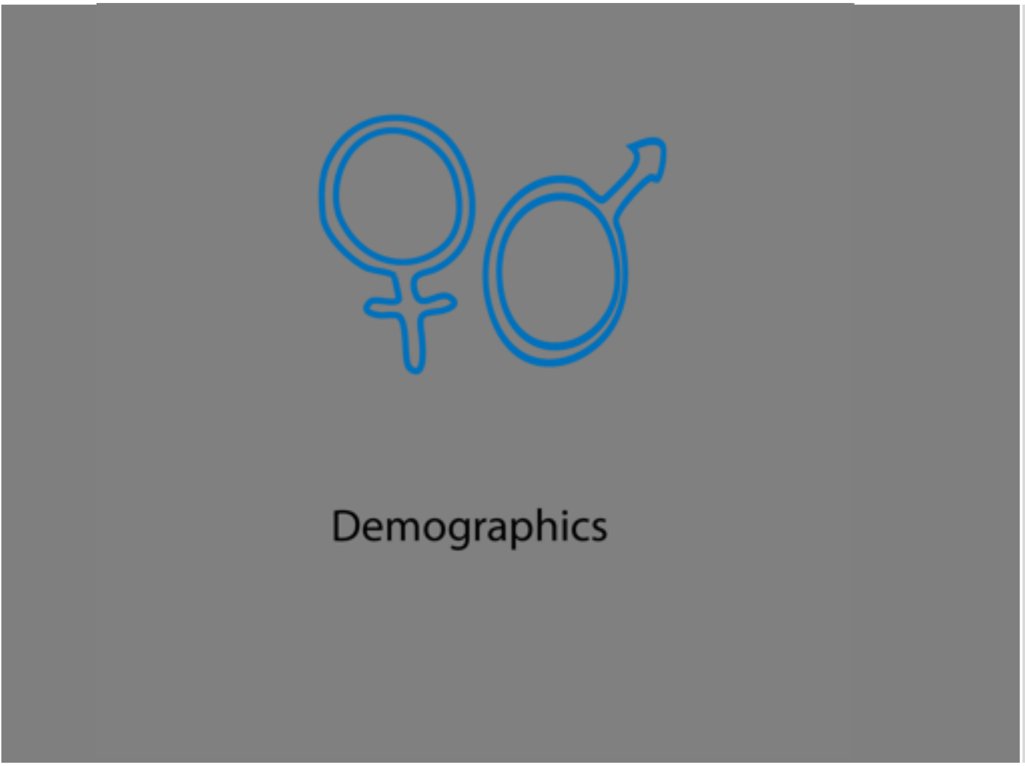
There were 12 studies identified of between six and 902 participants. There was only one study identified that interviewed participants or used qualitative methods, this study was focused on African Americans diagnosed with triple negative breast cancer (Bollinger).

A comparison of studies is available in Section 1.

A PubMed search was conducted on 4 October 2021 to identify studies reporting patient experience, patient reported outcomes, and quality of life studies in the Australian hormone-receptor positive breast cancer community. Studies conducted more than five years ago were excluded, and studies that included multiple types of breast cancers that did not report hormone-receptor positive breast cancers separately (as a subgroup) were excluded. There were 12 studies identified of between 26 and 4891 participants. There was only one study identified that interviewed participants or used qualitative methods, this study was focused on endocrine therapy.

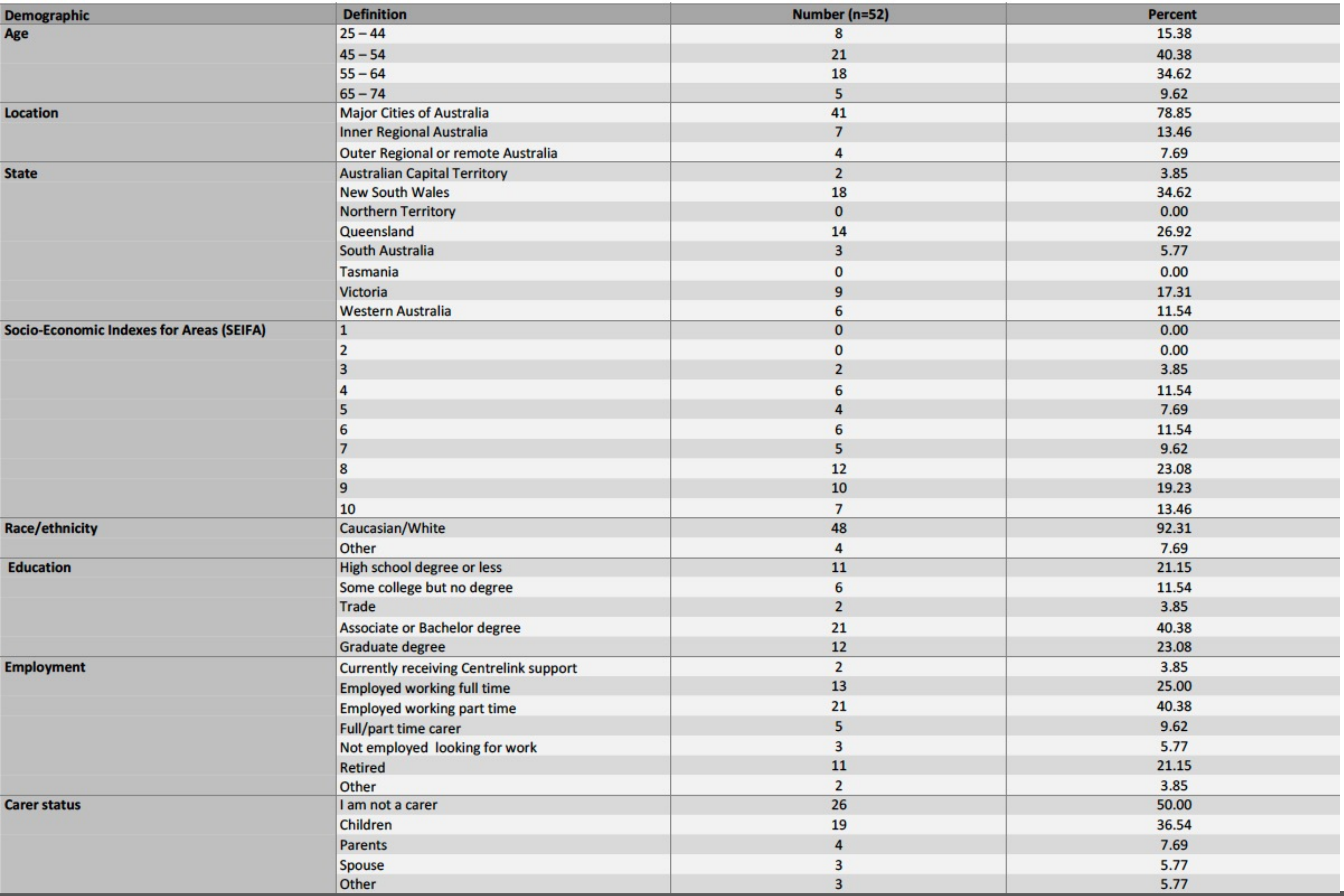
This PEEK study includes 52 people diagnosed with hormone-receptor positive breast cancer throughout Australia, including a qualitative structured interview and quantitative questionnaire. This study in hormone-receptor positive breast cancer is therefore the largest mixed method study reported in an Australian population. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Section 2



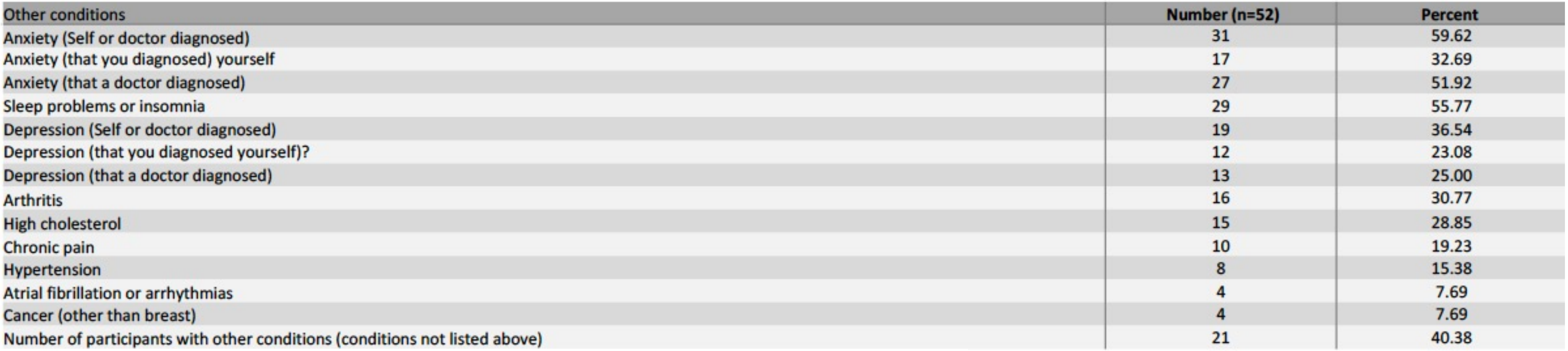
The demographic section is where you can find information about the study cohort. This is also where the sub-groups used throughout the study are described and where the baseline health of the cohort is described, using the SF36 questionnaire.

Demographics



Demographic	Definition	Number (n=52)	Percent
Age	25 – 44	8	15.38
	45 – 54	21	40.38
	55 – 64	18	34.62
	65 – 74	5	9.62
Location	Major Cities of Australia	41	78.85
	Inner Regional Australia	7	13.46
	Outer Regional or remote Australia	4	7.69
State	Australian Capital Territory	2	3.85
	New South Wales	18	34.62
	Northern Territory	0	0.00
	Queensland	14	26.92
	South Australia	3	5.77
	Tasmania	0	0.00
	Victoria	9	17.31
	Western Australia	6	11.54
Socio-Economic Indexes for Areas (SEIFA)	1	0	0.00
	2	0	0.00
	3	2	3.85
	4	6	11.54
	5	4	7.69
	6	6	11.54
	7	5	9.62
	8	12	23.08
	9	10	19.23
	10	7	13.46
Race/ethnicity	Caucasian/White	48	92.31
	Other	4	7.69
Education	High school degree or less	11	21.15
	Some college but no degree	6	11.54
	Trade	2	3.85
	Associate or Bachelor degree	21	40.38
	Graduate degree	12	23.08
Employment	Currently receiving Centrelink support	2	3.85
	Employed working full time	13	25.00
	Employed working part time	21	40.38
	Full/part time carer	5	9.62
	Not employed looking for work	3	5.77
	Retired	11	21.15
	Other	2	3.85
Carer status	I am not a carer	26	50.00
	Children	19	36.54
	Parents	4	7.69
	Spouse	3	5.77
	Other	3	5.77

Comorbidities



Other conditions	Number (n=52)	Percent
Anxiety (Self or doctor diagnosed)	31	59.62
Anxiety (that you diagnosed) yourself	17	32.69
Anxiety (that a doctor diagnosed)	27	51.92
Sleep problems or insomnia	29	55.77
Depression (Self or doctor diagnosed)	19	36.54
Depression (that you diagnosed yourself)?	12	23.08
Depression (that a doctor diagnosed)	13	25.00
Arthritis	16	30.77
High cholesterol	15	28.85
Chronic pain	10	19.23
Hypertension	8	15.38
Atrial fibrillation or arrhythmias	4	7.69
Cancer (other than breast)	4	7.69
Number of participants with other conditions (conditions not listed above)	21	40.38

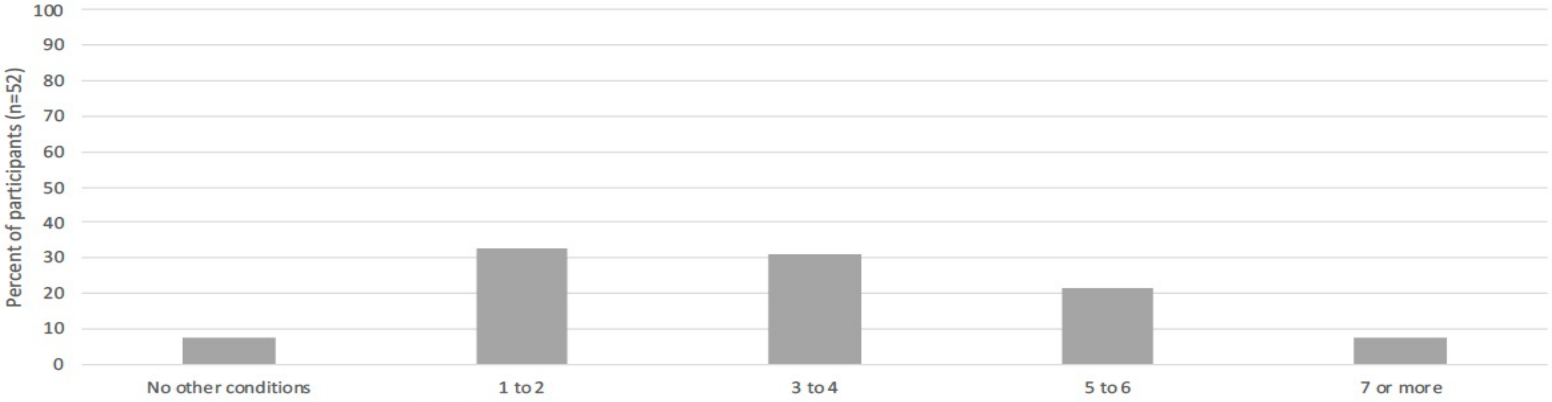
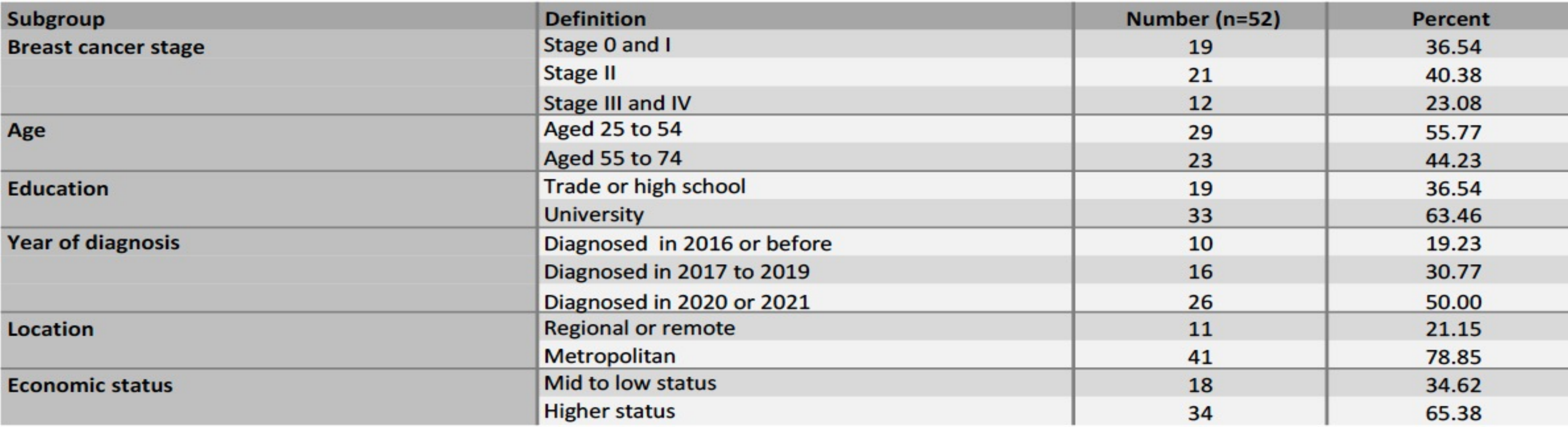


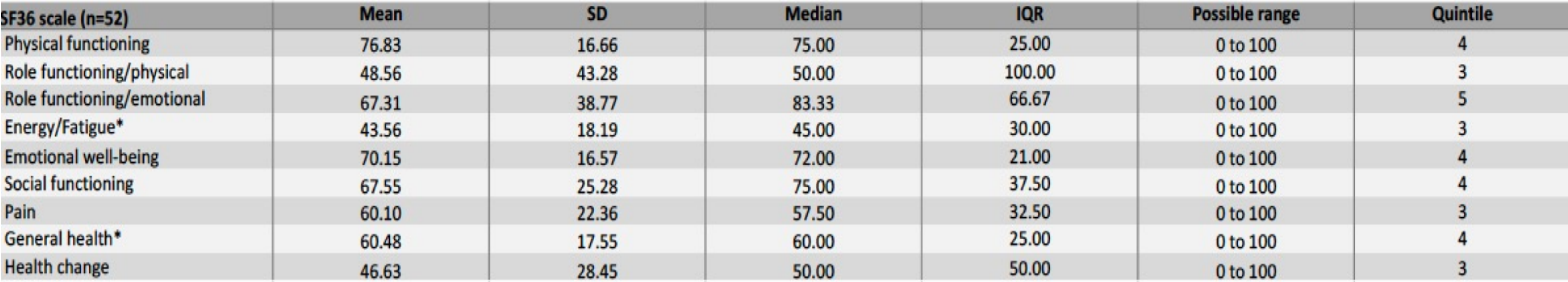
Figure 2.2: Number of other conditions

Subgroups



Subgroup	Definition	Number (n=52)	Percent
Breast cancer stage	Stage 0 and I	19	36.54
	Stage II	21	40.38
	Stage III and IV	12	23.08
Age	Aged 25 to 54	29	55.77
	Aged 55 to 74	23	44.23
Education	Trade or high school	19	36.54
	University	33	63.46
Year of diagnosis	Diagnosed in 2016 or before	10	19.23
	Diagnosed in 2017 to 2019	16	30.77
	Diagnosed in 2020 or 2021	26	50.00
Location	Regional or remote	11	21.15
	Metropolitan	41	78.85
Economic status	Mid to low status	18	34.62
	Higher status	34	65.38

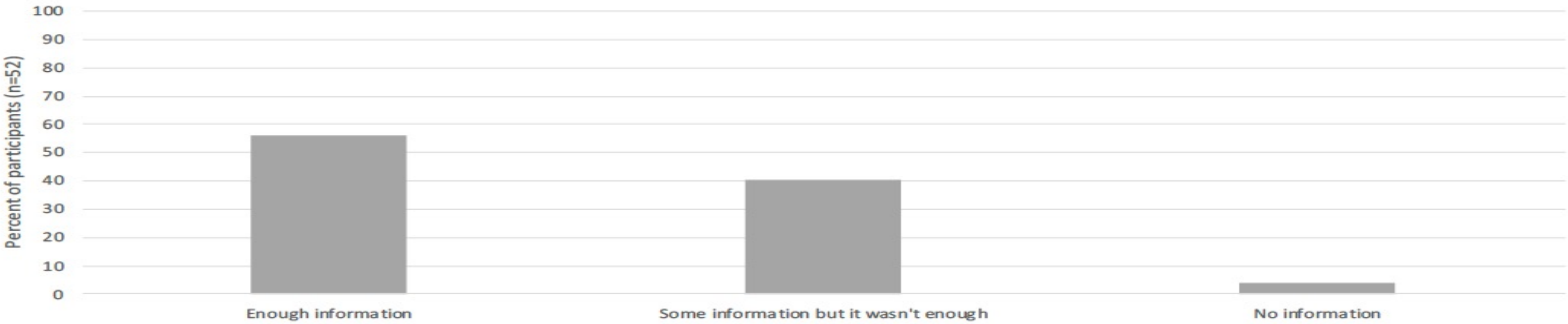
Baseline health

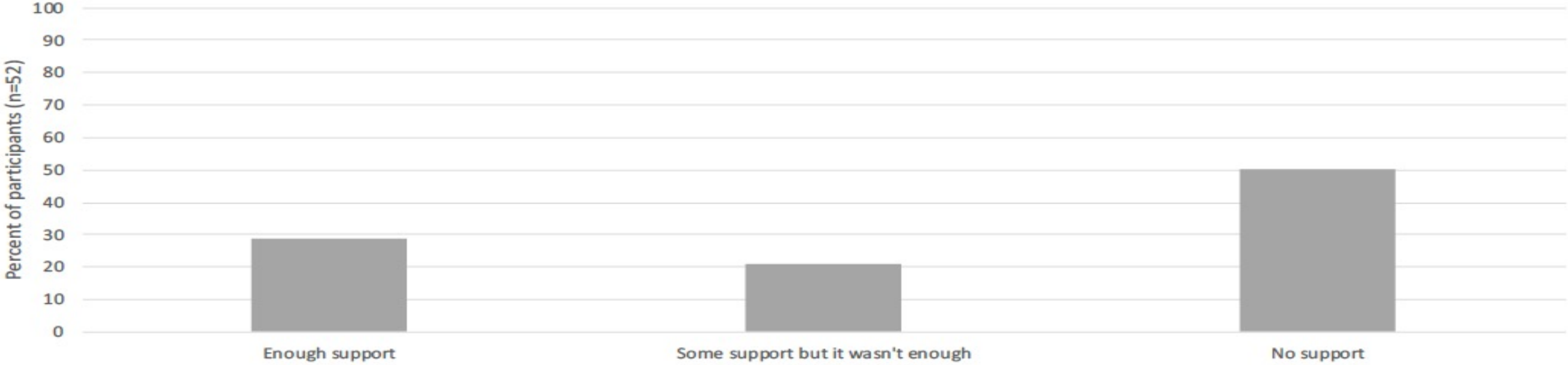


SF36 scale (n=52)	Mean	SD	Median	IQR	Possible range	Quintile
Physical functioning	76.83	16.66	75.00	25.00	0 to 100	4
Role functioning/physical	48.56	43.28	50.00	100.00	0 to 100	3
Role functioning/emotional	67.31	38.77	83.33	66.67	0 to 100	5
Energy/Fatigue*	43.56	18.19	45.00	30.00	0 to 100	3
Emotional well-being	70.15	16.57	72.00	21.00	0 to 100	4
Social functioning	67.55	25.28	75.00	37.50	0 to 100	4
Pain	60.10	22.36	57.50	32.50	0 to 100	3
General health*	60.48	17.55	60.00	25.00	0 to 100	4
Health change	46.63	28.45	50.00	50.00	0 to 100	3

Section 3

The symptoms and diagnosis section is where you can find information about experience of symptoms before diagnosis, as well as the symptoms that led to the diagnosis. There is information about the diagnostic tests that were performed, where the tests were conducted and the time from tests to diagnosis. In this section, there is also information about the participant's understanding of their condition and their understanding of their prognosis.





Information + support at diagnosis

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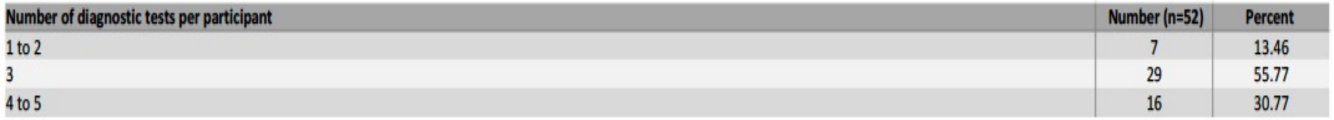
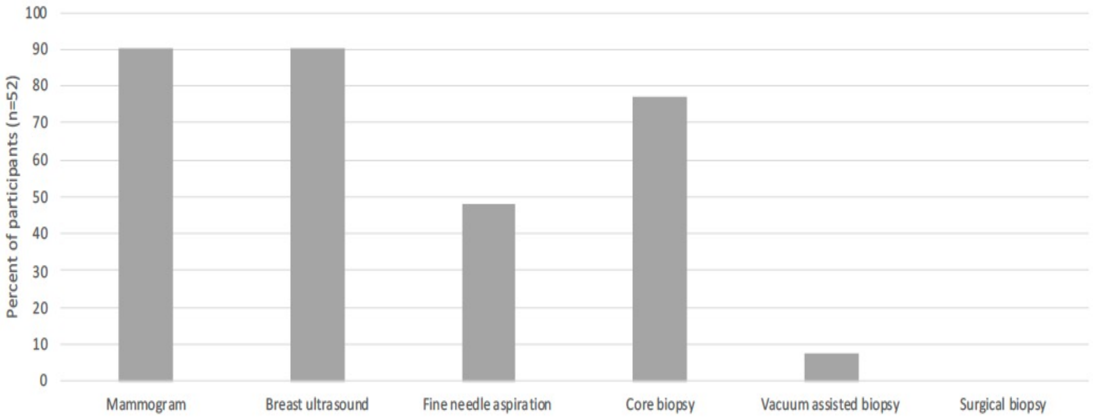
Diagnosis

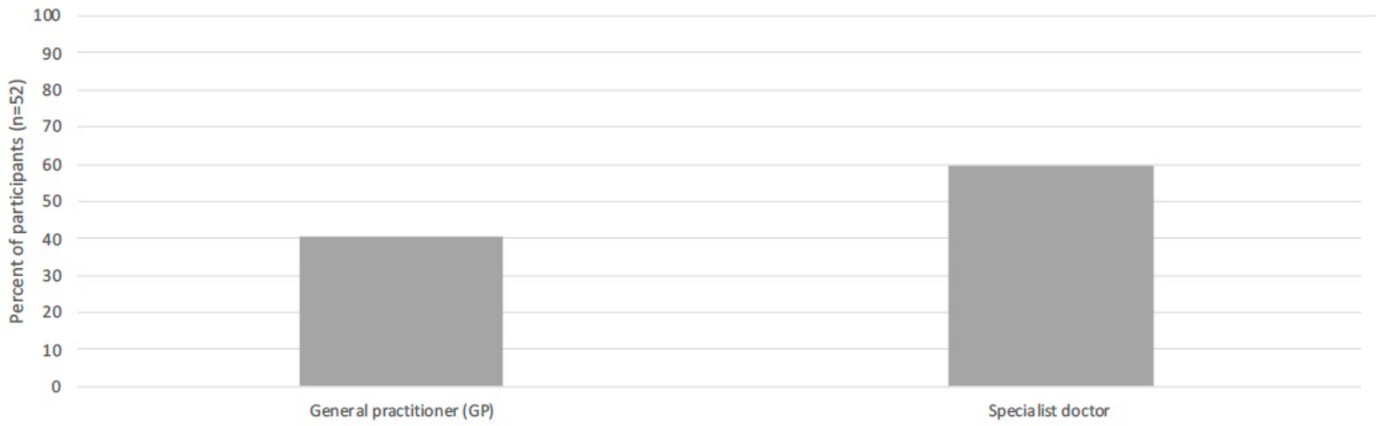


Number of diagnostic tests per participant	Number (n=52)	Percent
1 to 2	7	13.46
3	29	55.77
4 to 5	16	30.77

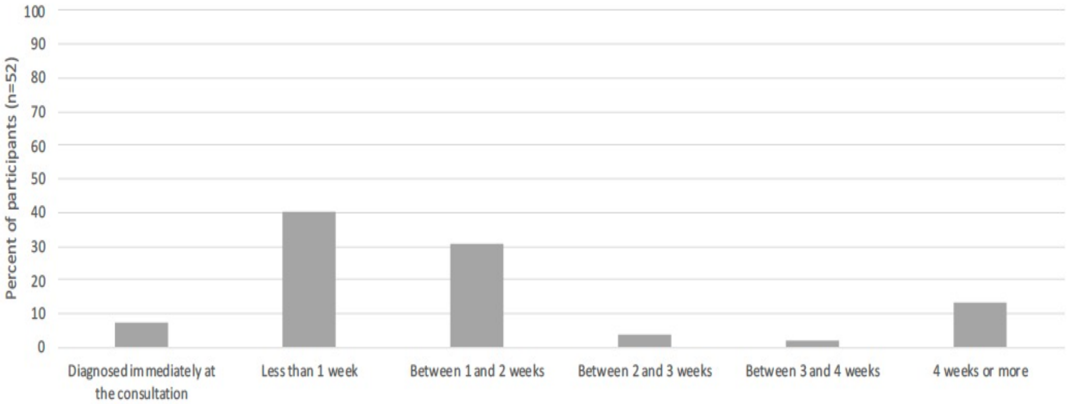
Diagnostic tests



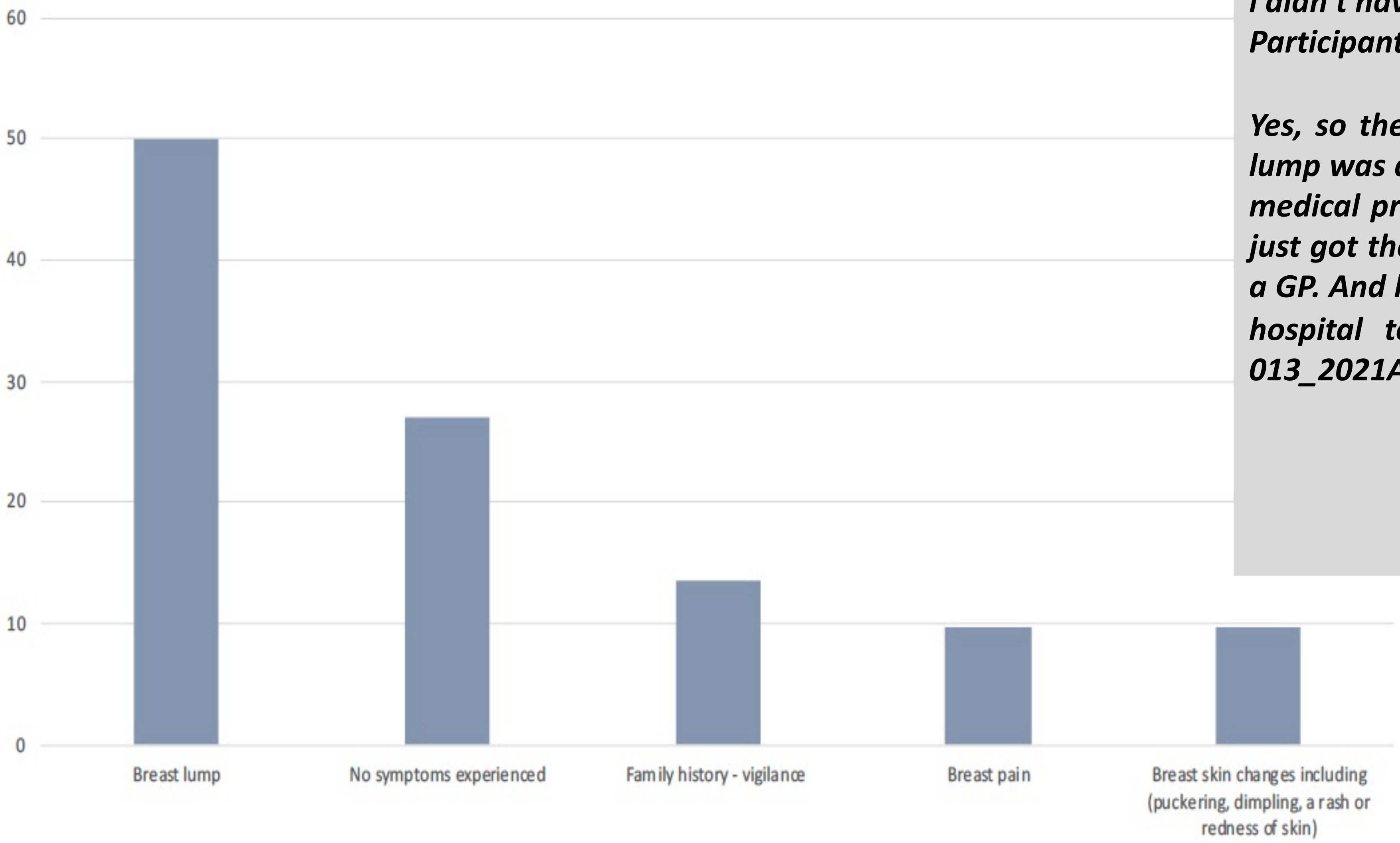
Who gave the diagnosis



Time from test to diagnosis

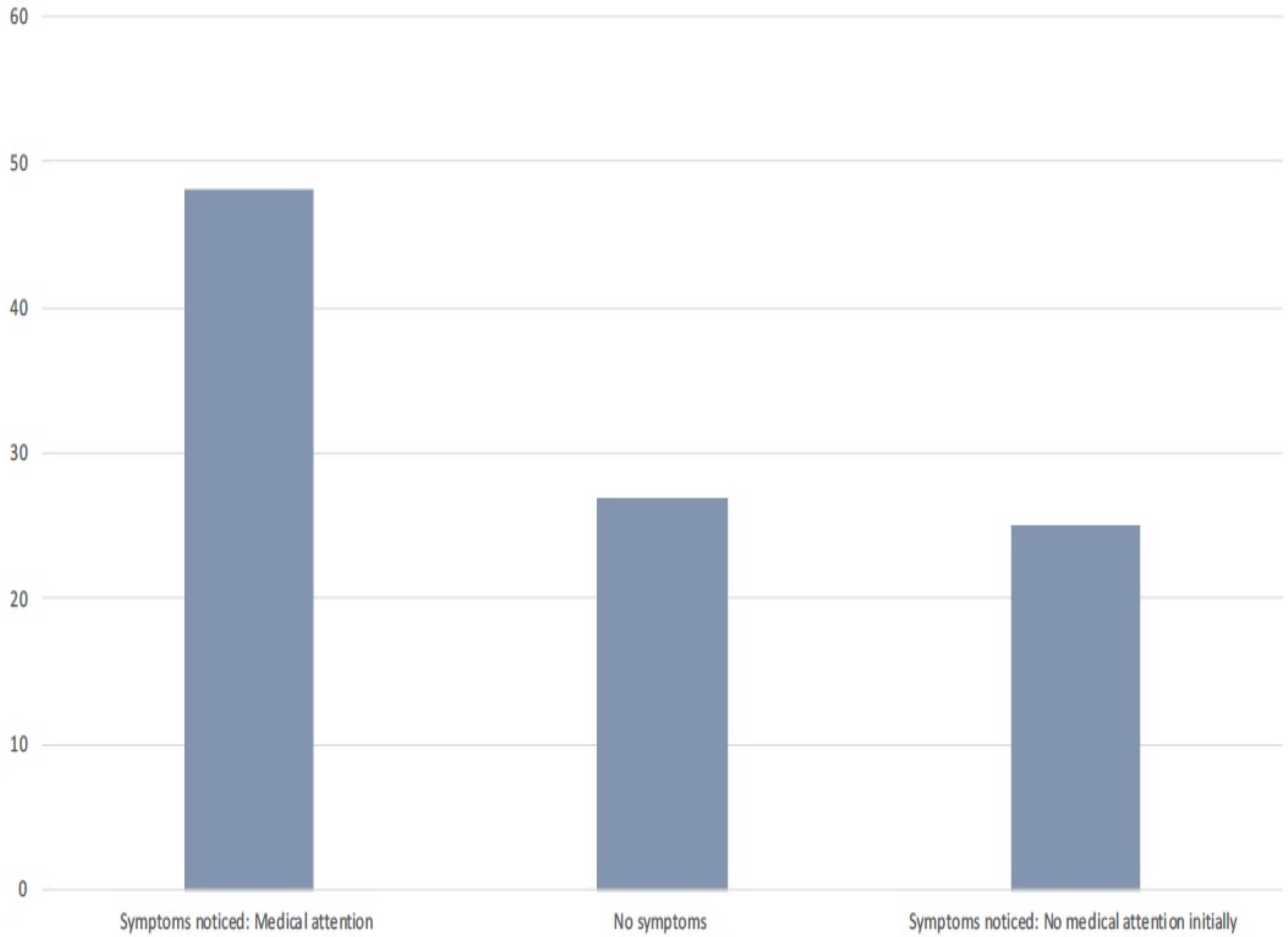


Symptoms leading to diagnosis (% of all participants)



I didn't have any. It was just a mammogram. Participant 024_2021AUHRP

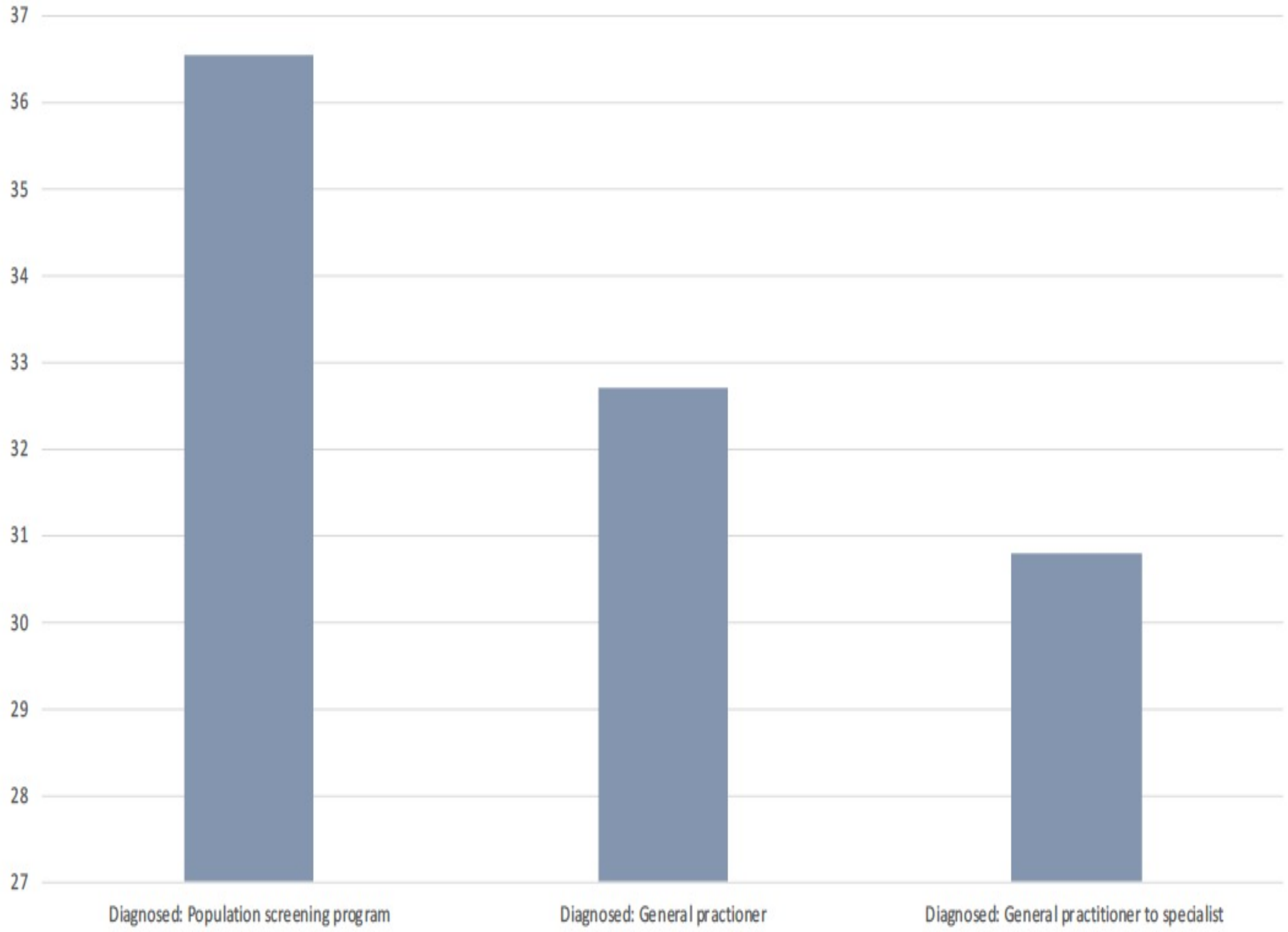
Yes, so then. So it was pretty scary, because the lump was quite big. So I went straight into a GP, a medical practice the next morning and saw a GP just got their first thing for when they opened for a GP. And he then was it gave me a referral to the hospital to get some scans done. Participant 013_2021AUHRP



Well, that's not how it happened. And for me, I was just having a routine mammogram. I had no symptoms. Because it was my routine, biannual mammogram, so I booked it. My GP is fairly proactive here. He will, he will remind me when I'm due. Participant 001_2021AUHRP

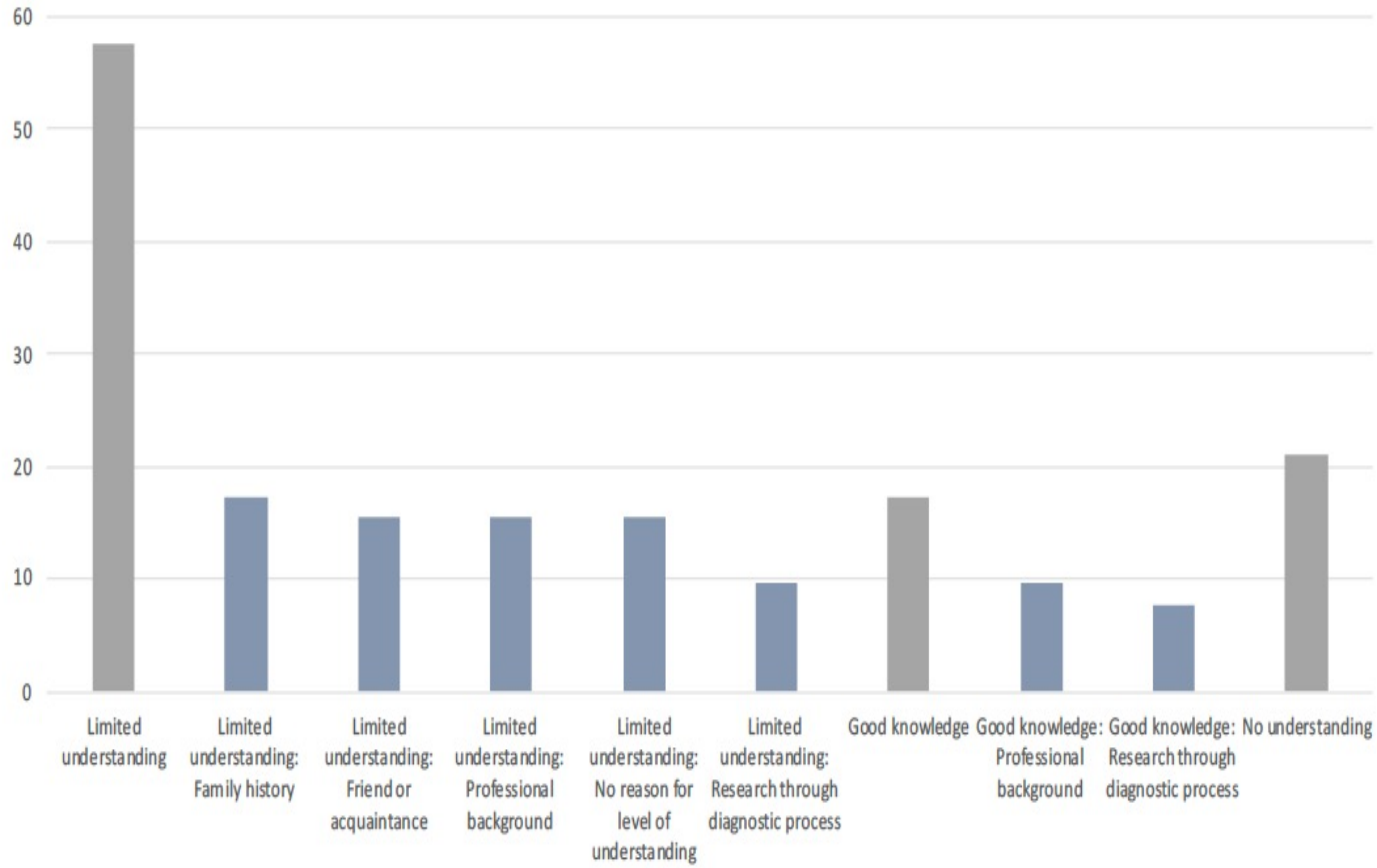
I went to the doctor initially, and she put me on a course of antibiotics but also ordered a scan for that week. While I was still on my antibiotics, I went for a mammogram first off, and in the mammogram, she said, "Oh, it's just a bit of mastitis and some fibroids, because I already have fibroids in the other breast. 052_2021AUHRP

Seeking medical attention (% of all participants)



Yep, so my GP just did a breast exam. And she felt the lump as well. I was then referred to get an ultrasound. And then, when the results of that came back, I was referred to HOSPITAL, which was two and a half hours away from where I lived for a biopsy. And I had that at around 11:30 one day by 12:30. Lunchtime the next day, the doctor had rung me and given me the results. Participant 020_2021AUHRP

Diagnostic pathways (% of all participants)



Not a lot, to be honest with you. For me, because of my age, not many people had spoken about it before. I've never really been educated on it, so nothing. Now I know everything about it, but yes, nothing at all really. Participant 008_2021AUHRP

Relatively literate but not really up to date, that would be my summary. Obviously it's not something I'd done a lot of reading about in the last 10 years because it really hadn't been on my radar, but I had a reasonable understanding of most of the basics. Participant 005_2021AUHRP

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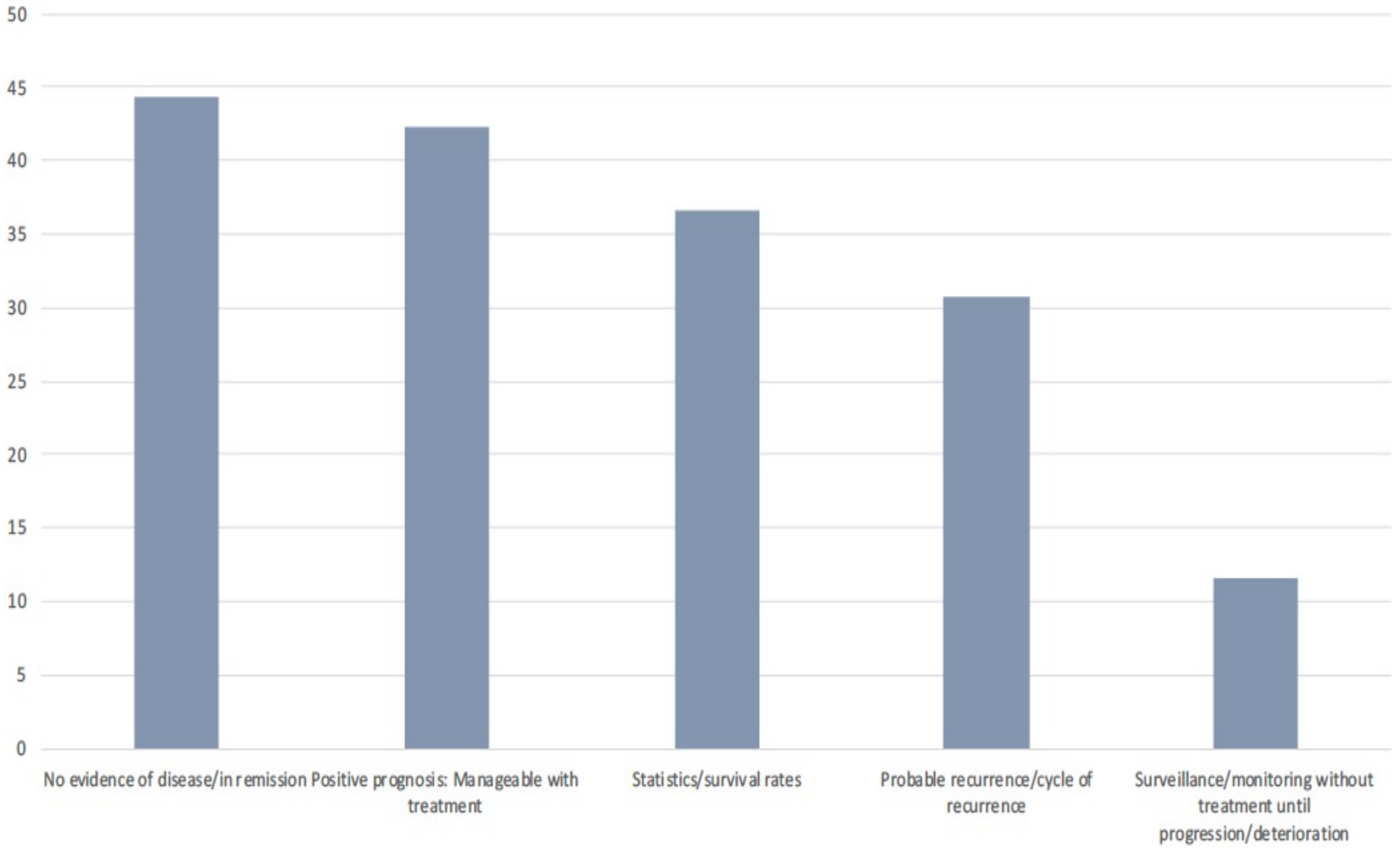
Understanding of disease at diagnosis

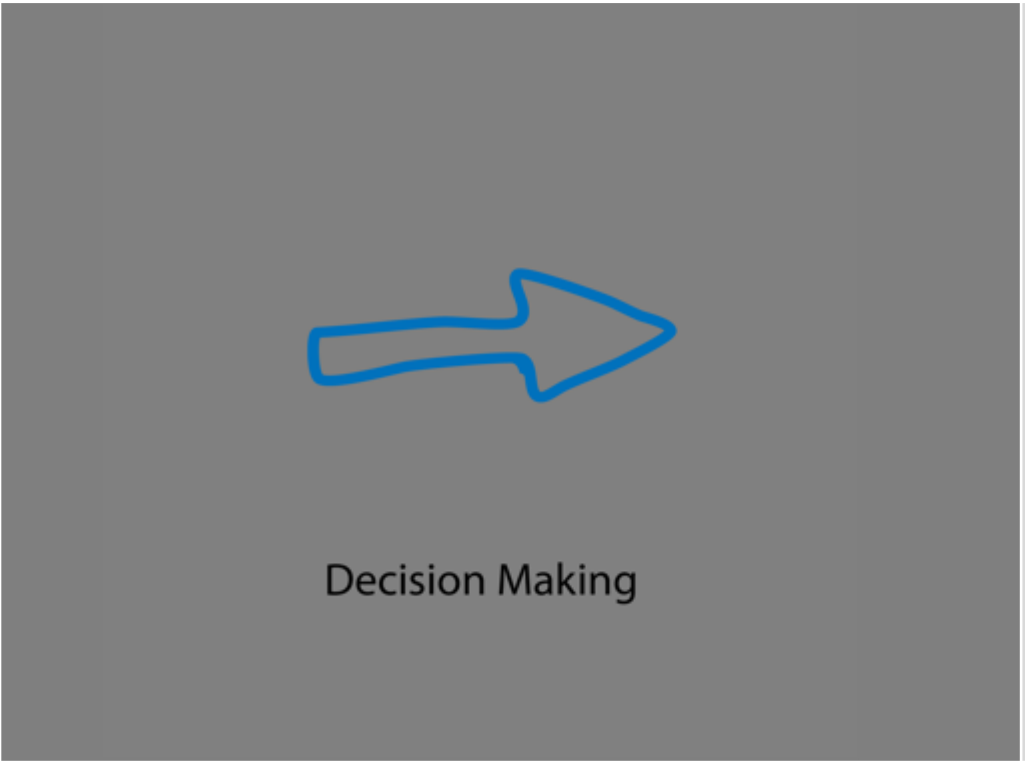
Understanding of prognosis



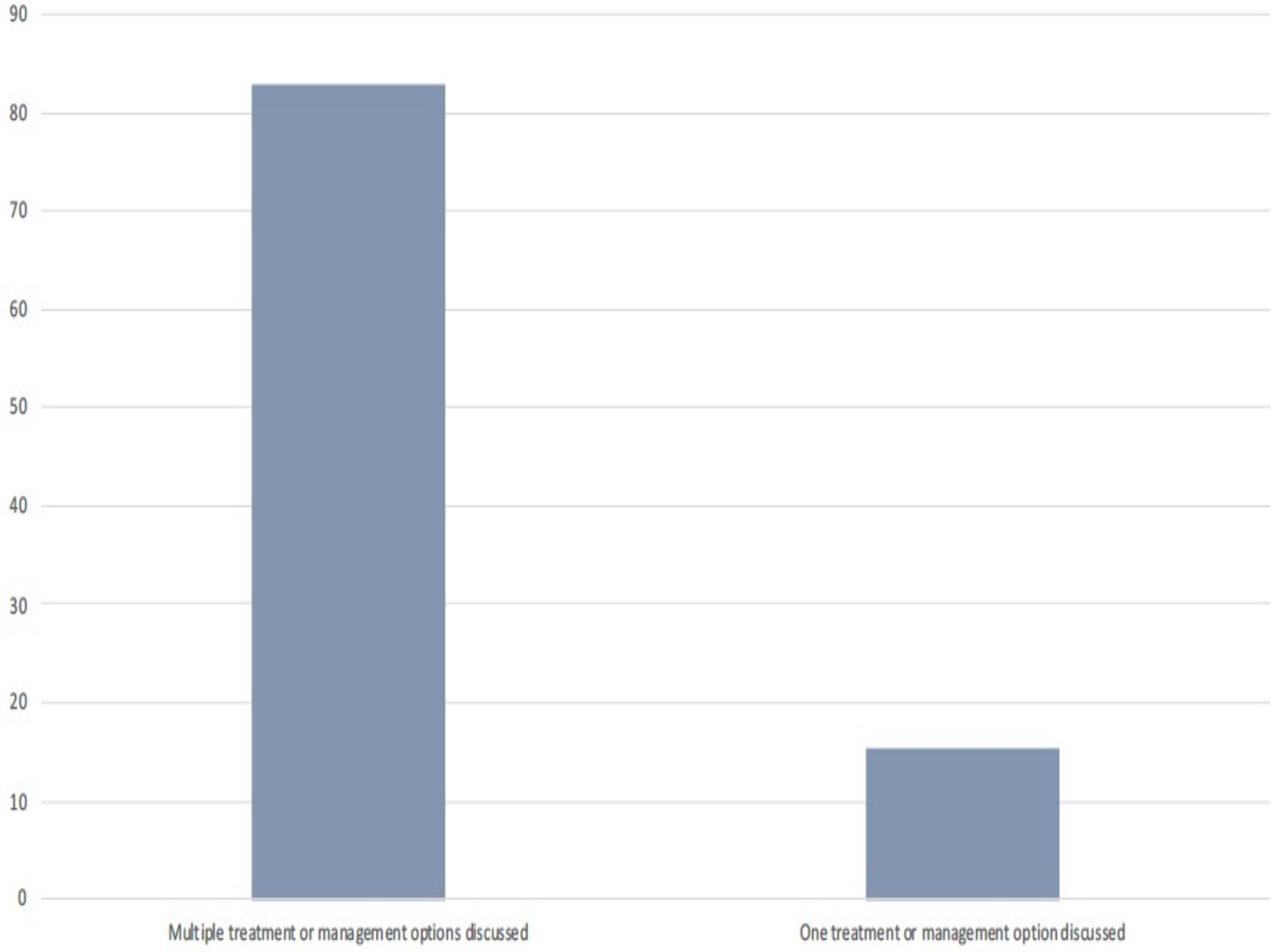
Yes, so I am technically free of cancer now, thankfully. I have finished my treatments six weeks ago now, end of radiation. Now it's just all the follow-ups. I've just literally started my hormone blockers yesterday. Participant 008_2021AUHRP

would say it's pretty good. Mine was a low stage tumor so it's only a 1A but it was high grade, grade three, and it was treated with wide local excision and radiotherapy which means the risk of recurrence in the same site at five years is about 10%. Because it's a hormone-positive tumor, total risk of recurrence per year is 2%, and that doesn't seem to diminish after 20 years, which is the longest trial that's been done so far. Participant 005_2021AUHRP

Section 4



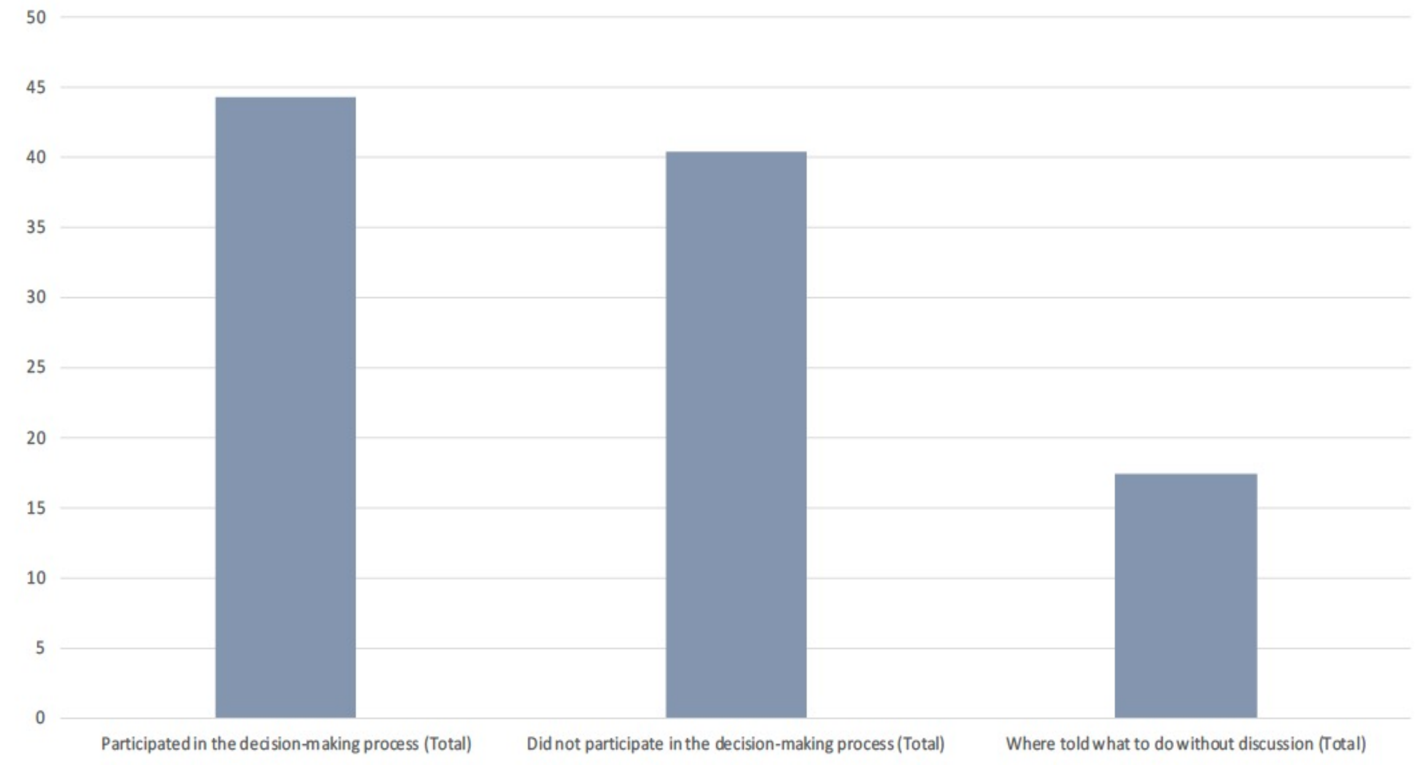
In the decision-making section, you can find information about the conversations that were had about treatment options at diagnosis, what is important to people when they make decisions about treatment, and whether decision-making changes over time.



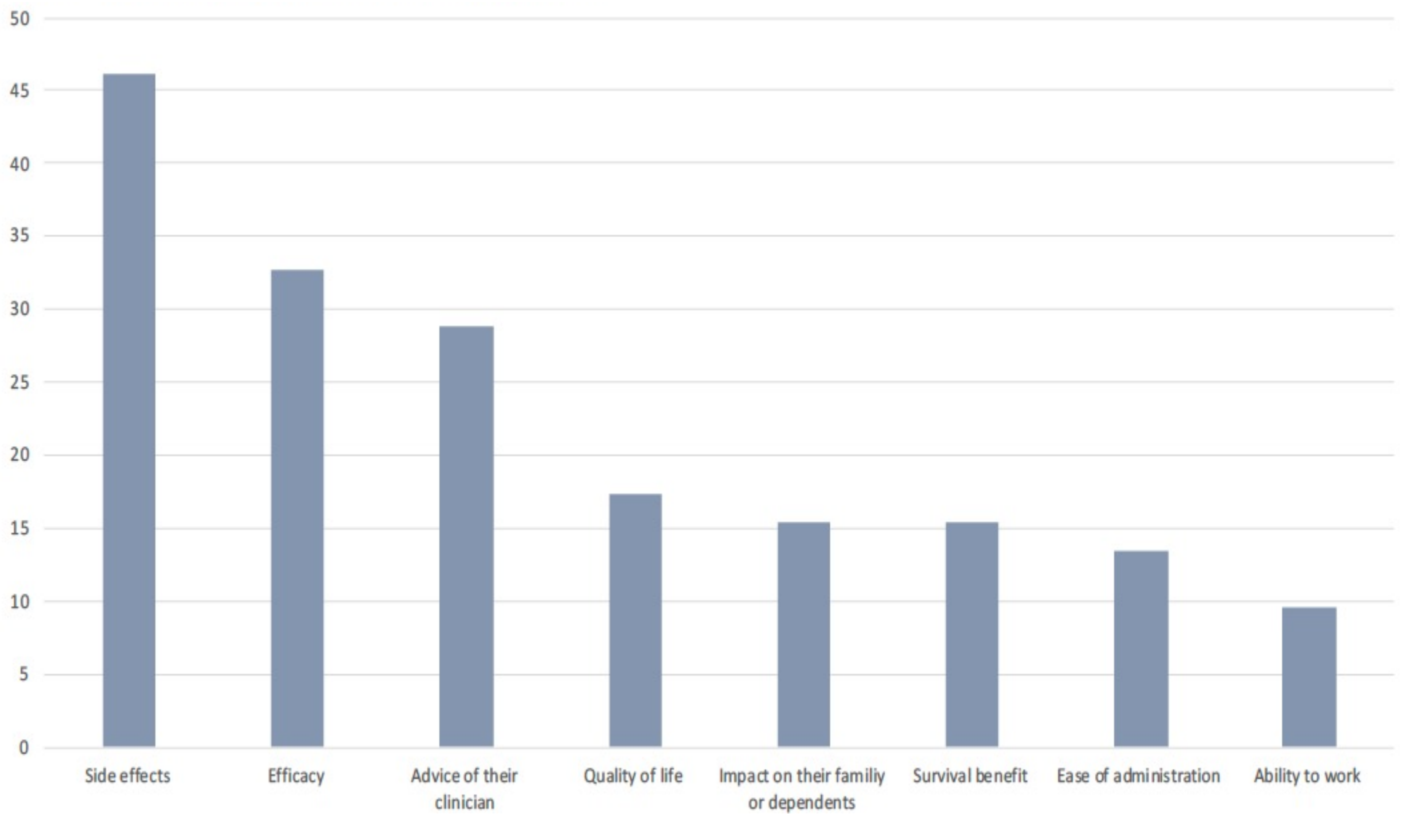
We had with the surgeon, the specialist, it was quite a long consultation for probably a good hour-and-a-half. My husband and I were in there and had lots of-- I had lots of questions written down. He was very patient and agreed to everything. For me, I think my initial-- I went in there. I think like lots of women do, they say, "Just take my breasts, take both the breasts and take them off." He, in the nicest possible way didn't say, "No, we're not doing that," but I think he-- I needed more information from him to make a decision that worked for my type of breast cancer, which he did. I felt like he gave me all the options and was quite clear about it, too. Made me feel that why-- Yes, I don't need to remove this part of my body right now. Participant 009_2021AUHRP

Discussions about treatment (% of all participants)

Discussions about treatment (Participation in discussions) (% of all participants)



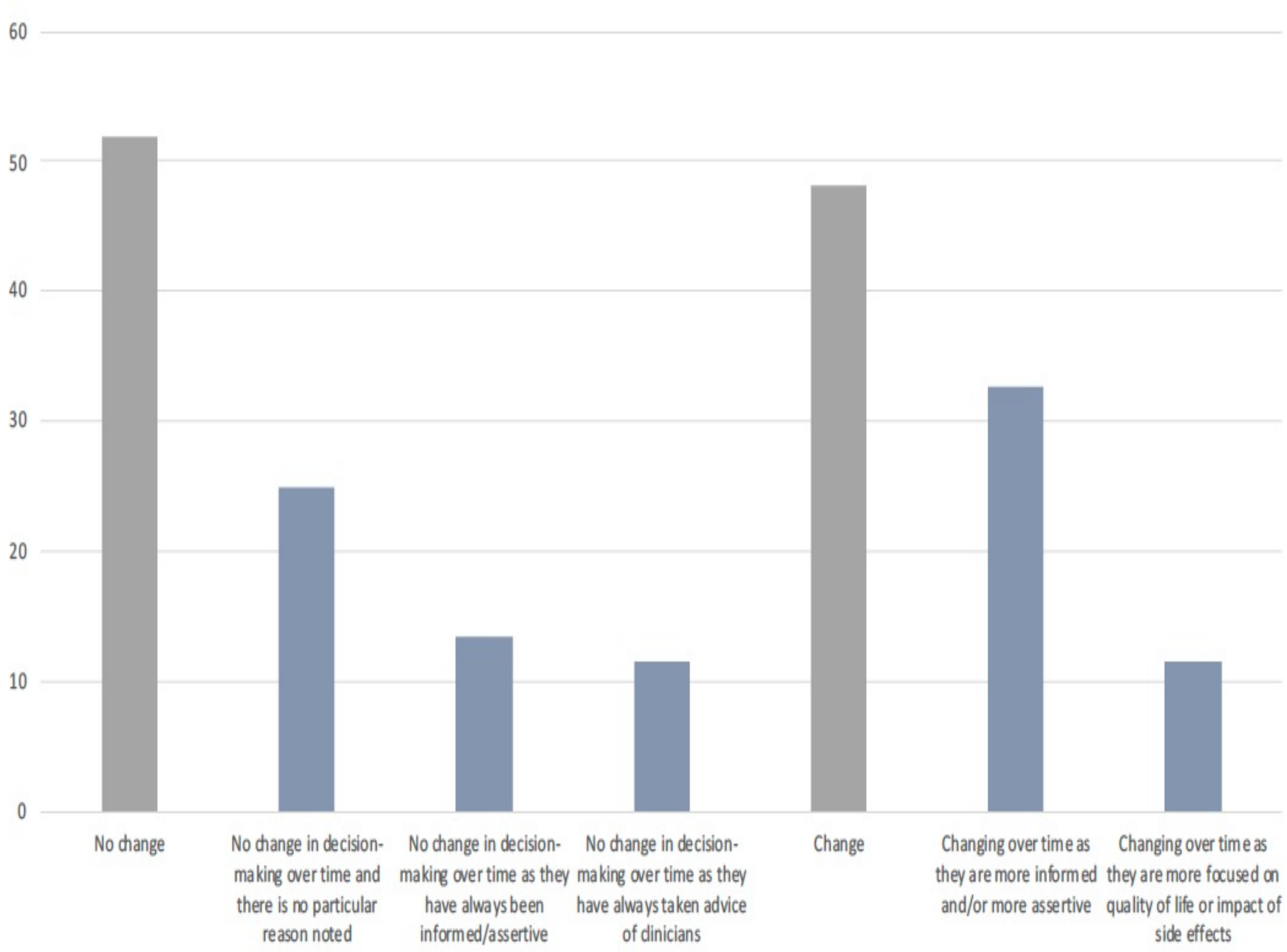
It was definitely not a conversation, more of a this is what we're, this is what we're doing. You know, there was I wasn't really given any options. As far as treatment options, I was basically just told you will be coming in in two days for mastectomy and the lymph nodes. And then when I saw the oncologist, she was like, and we will be starting chemo on this date. And please don't have any more children was basically the conversation. Yeah. Yeah. Participant 033_2021AUHRP



So, like side effects and then the short term effects as well as the long term effects there whether it whether the doctor thought it was necessary or not and why. What else? How it was sort of going to affect my lifestyle at the time. And the kind of support I could get to go through that. Treatment I suppos. Participant 020_2021AUHRP

Well, I guess a lot of it is how it's going to make me feel really. I've had a lot of crises in my life, a lot of grief, and a lot of crises, so I'm very…for want of a better-- I suppose fragile. I've just got to be really careful of my care. I have no compunction of changing doctors, for example, like the one I just told you. You can't go and see a doctor and come out crying every time, it's ridiculous. Participant 038_2021AUHRP

Considerations when making decisions about treatment



No, I think the same way. I think I'm a pretty common sense sort of person. My husband and I have got a good relationship and we talk about lots of things and we chat about-- Bounce it off each other and see. I think I'm pretty calculated how I make deci-- Yes, I think I'm the same. Participant 009_2021AUHRP

I want to know more detail. I ask more questions these days. That would be about the only thing that I've changed. I want to know, what's that? Why is that? Yes, so it's to why, what, where, when type questions, yes. Participant 012_2021AUHRP

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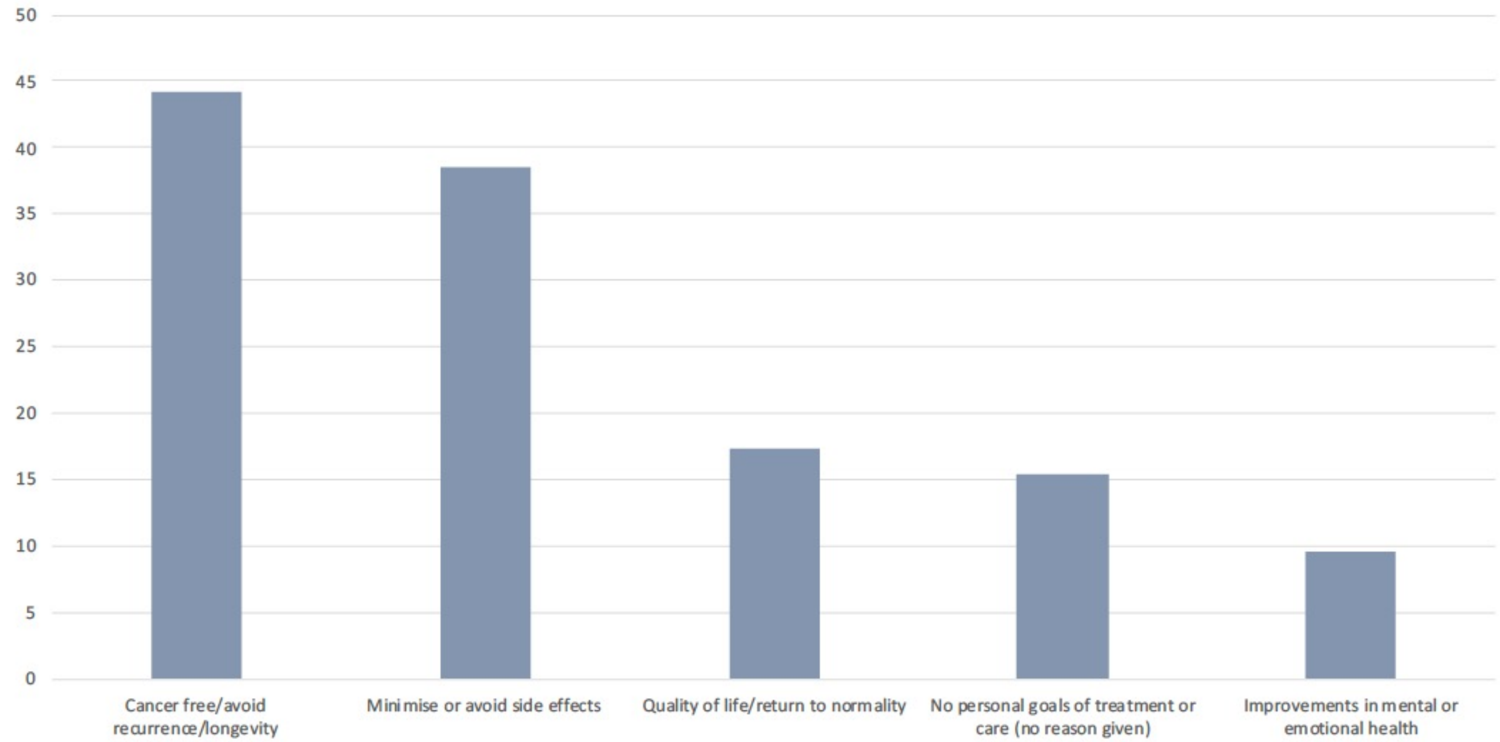
Decision-making over time



My goals are to reduce actually the side effects because I'm still experiencing, which is my lung function, to get my lung function back to normal or as best I can, and the swelling and tenderness in my breast, to reduce that as much as possible. Also, in my left arm to get a full range of movement and strength back in my left arm. Participant 047_2021AUHRP

I just want to be back to normal. I know it sounds silly because that's probably what you get from everybody. I just want to be able to function better. I have terrible memory loss. I'm in constant pain all the time. I get terrible side effects from most of the medications I take. It's just wanting to get back. I'm slowly getting there, but it's just having that normality, the way I look, it's the way I function every day. It's sometimes a hard task. Participant 008_2021AUHRP

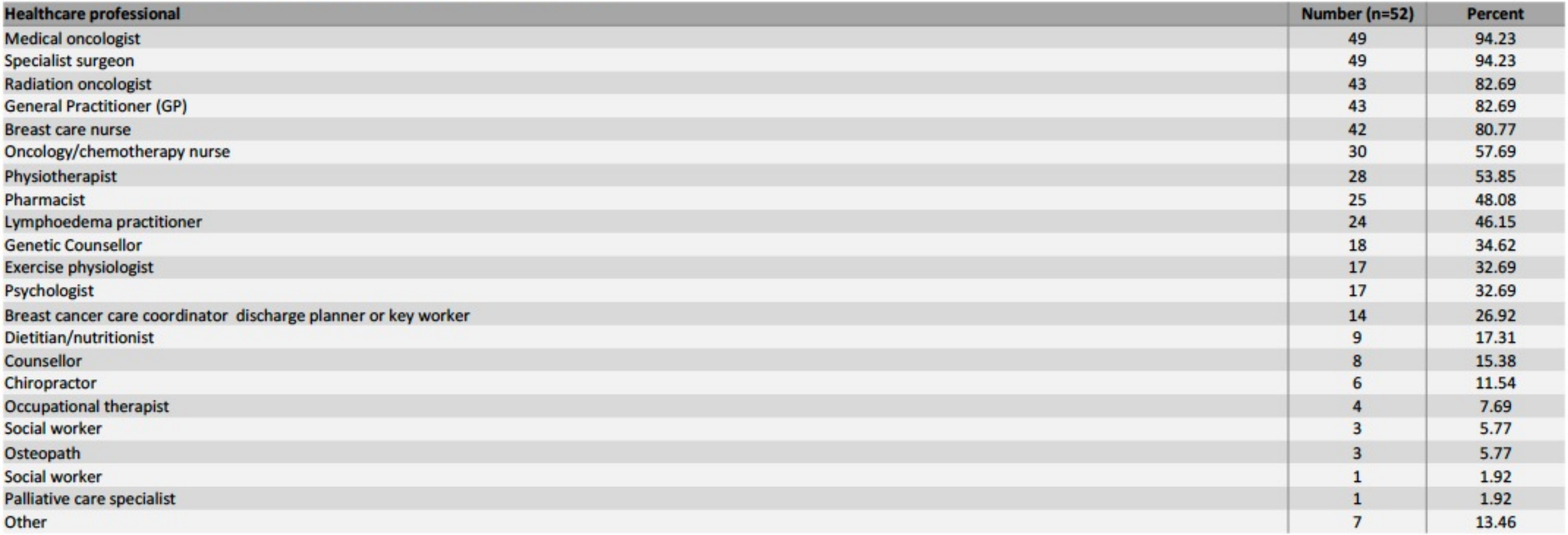
Personal goals of treatment (% of all participants)

Section 5

Treatment

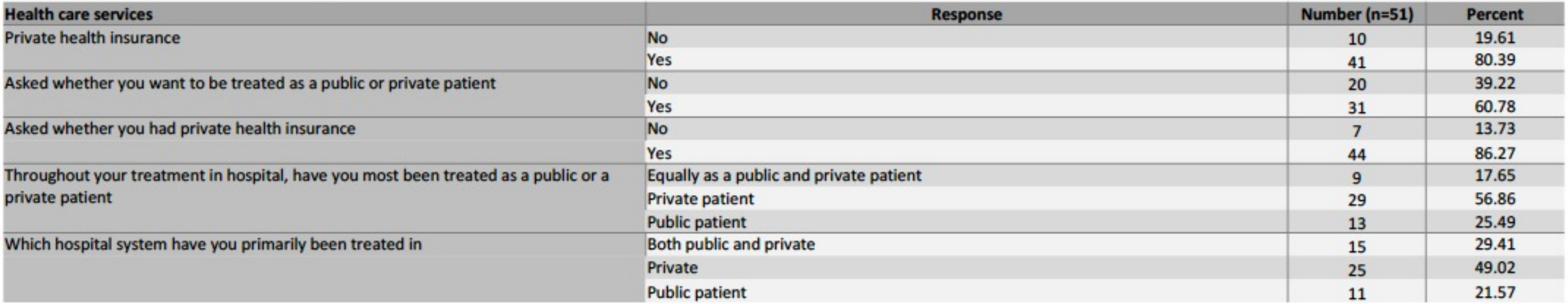
The treatment section is one of the largest sections in each study. Information is available in relation to the types of treatments people have experienced as well as rating quality of life and effectiveness for each treatment. There is information about the main providers of treatment, access to health professionals and information about which part of the health system participants were treated in. There is information about affordability of healthcare, any reduced income for the patient or their family, an additional costs or changes to employment. There is then also detailed information about the treatments that the participants have experienced, whether they had any side effects, their description of mild side effects and severe side effects, and any complementary therapies that they may have used. Information in relation to access to allied health is also available. Information about what needs to change to feel like treatment is effective, and adherence to treatment is also presented. In this section, there is also information on whether discussions about clinical trials were held with clinicians, and for those who have been on a trial, what their experience was like.

Health professionals accessed

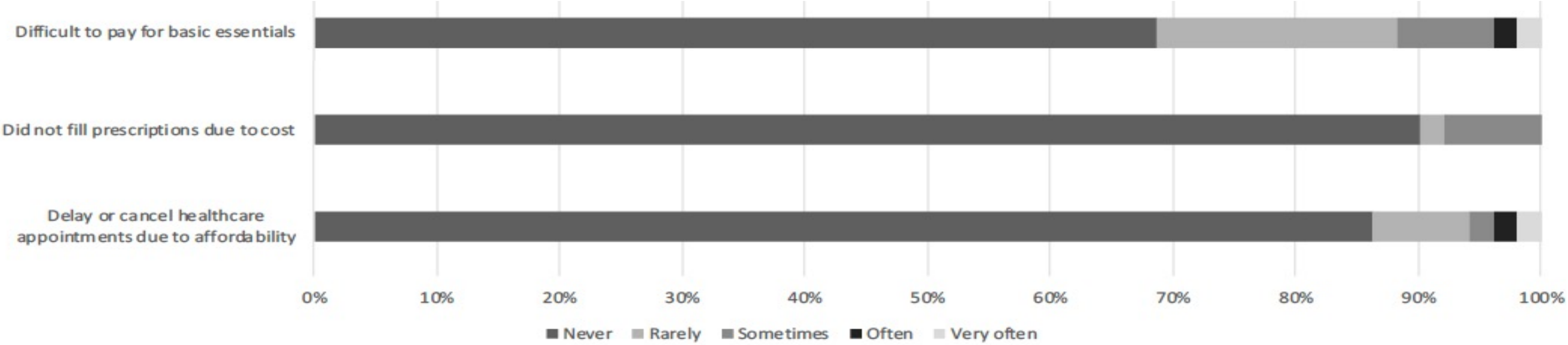


Healthcare professional	Number (n=52)	Percent
Medical oncologist	49	94.23
Specialist surgeon	49	94.23
Radiation oncologist	43	82.69
General Practitioner (GP)	43	82.69
Breast care nurse	42	80.77
Oncology/chemotherapy nurse	30	57.69
Physiotherapist	28	53.85
Pharmacist	25	48.08
Lymphoedema practitioner	24	46.15
Genetic Counsellor	18	34.62
Exercise physiologist	17	32.69
Psychologist	17	32.69
Breast cancer care coordinator discharge planner or key worker	14	26.92
Dietitian/nutritionist	9	17.31
Counsellor	8	15.38
Chiropractor	6	11.54
Occupational therapist	4	7.69
Social worker	3	5.77
Osteopath	3	5.77
Social worker	1	1.92
Palliative care specialist	1	1.92
Other	7	13.46

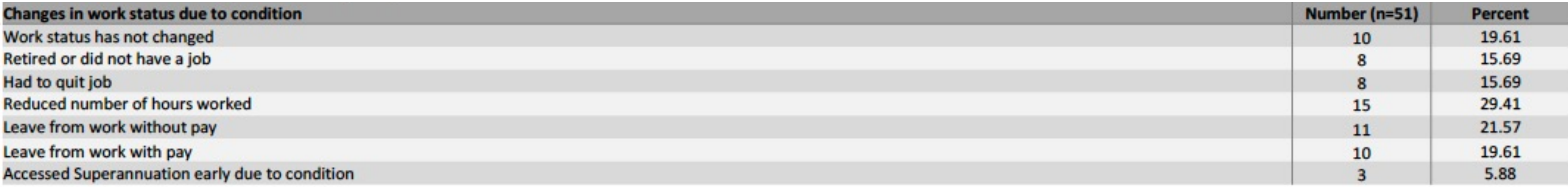
Access to healthcare



Health care services	Response	Number (n=51)	Percent
Private health insurance	No	10	19.61
	Yes	41	80.39
Asked whether you want to be treated as a public or private patient	No	20	39.22
	Yes	31	60.78
Asked whether you had private health insurance	No	7	13.73
	Yes	44	86.27
Throughout your treatment in hospital, have you most been treated as a public or a private patient	Equally as a public and private patient	9	17.65
	Private patient	29	56.86
	Public patient	13	25.49
Which hospital system have you primarily been treated in	Both public and private	15	29.41
	Private	25	49.02
	Public patient	11	21.57

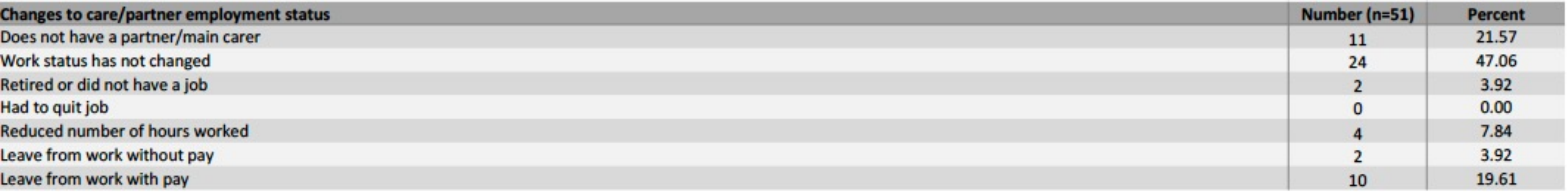


Employment status



Changes in work status due to condition	Number (n=51)	Percent
Work status has not changed	10	19.61
Retired or did not have a job	8	15.69
Had to quit job	8	15.69
Reduced number of hours worked	15	29.41
Leave from work without pay	11	21.57
Leave from work with pay	10	19.61
Accessed Superannuation early due to condition	3	5.88

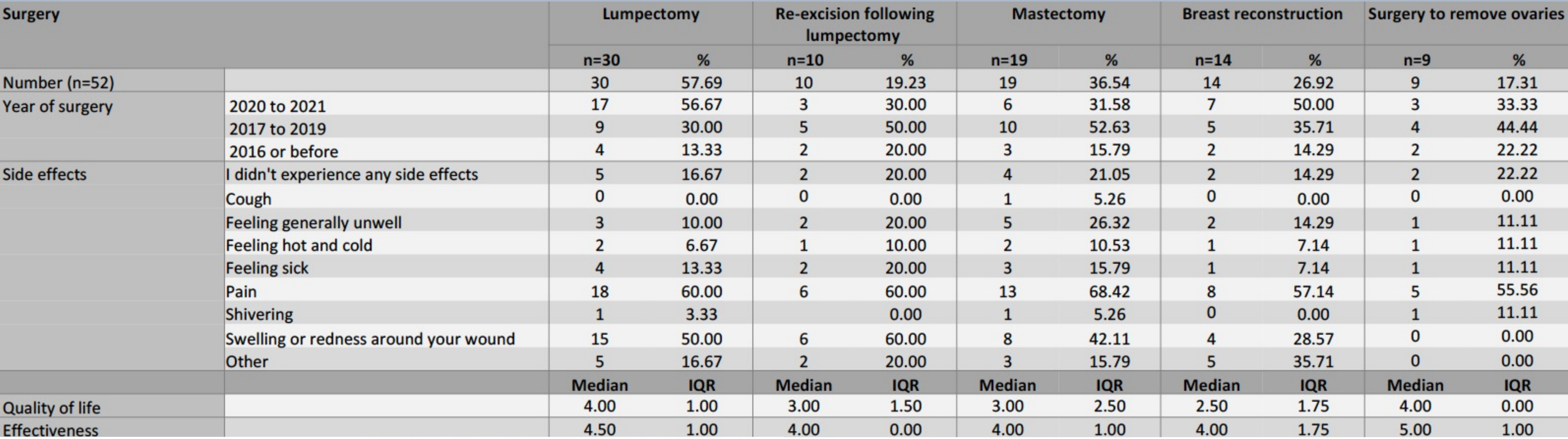
Participant’s employment



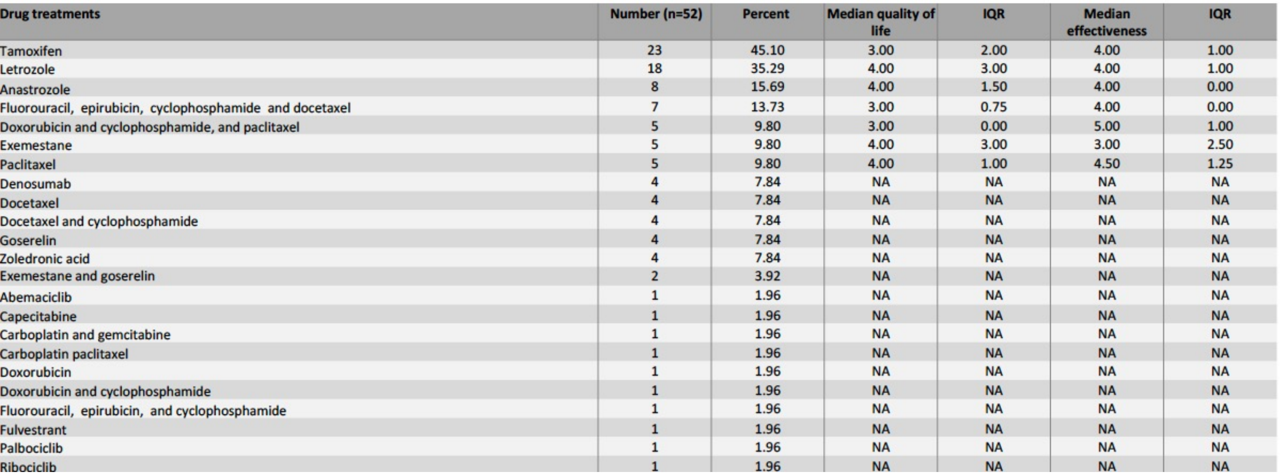
Changes to care/partner employment status	Number (n=51)	Percent
Does not have a partner/main carer	11	21.57
Work status has not changed	24	47.06
Retired or did not have a job	2	3.92
Had to quit job	0	0.00
Reduced number of hours worked	4	7.84
Leave from work without pay	2	3.92
Leave from work with pay	10	19.61

Main carer/partner’s employment

Surgery

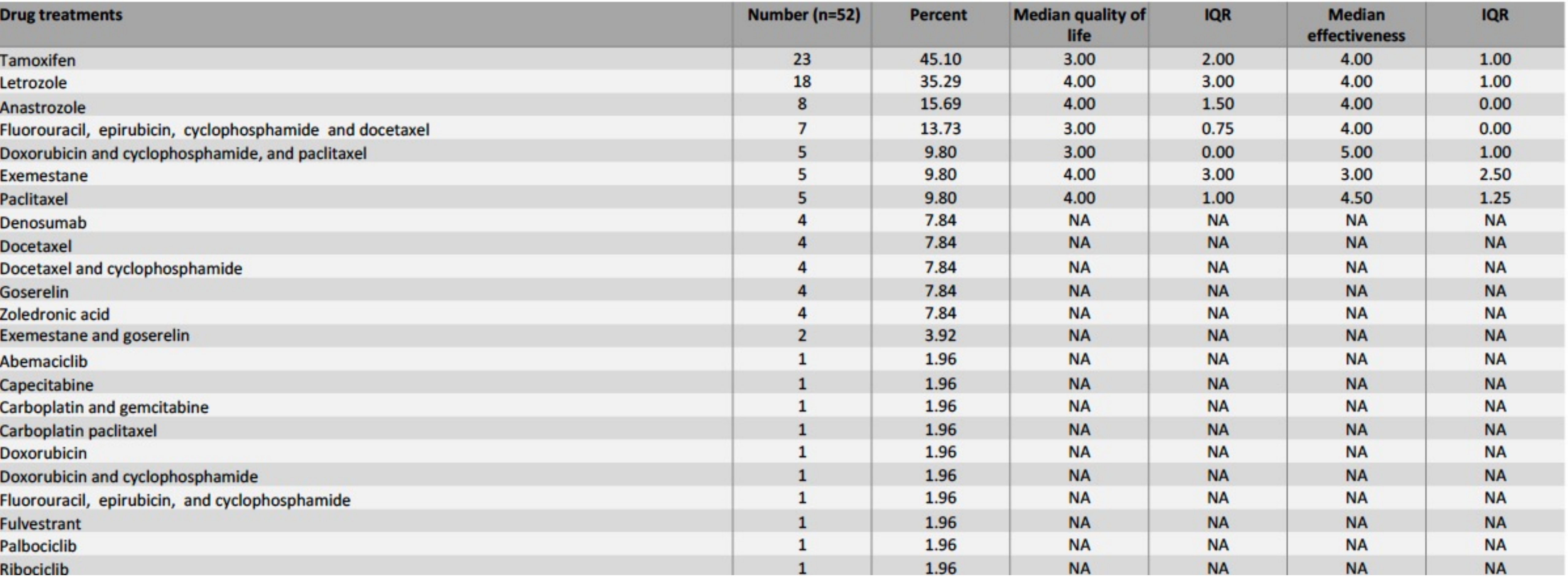


Surgery		Lumpectomy		Re-excision following lumpectomy		Mastectomy		Breast reconstruction		Surgery to remove ovaries	
		n=30	%	n=10	%	n=19	%	n=14	%	n=9	%
Number (n=52)		30	57.69	10	19.23	19	36.54	14	26.92	9	17.31
Year of surgery	2020 to 2021	17	56.67	3	30.00	6	31.58	7	50.00	3	33.33
	2017 to 2019	9	30.00	5	50.00	10	52.63	5	35.71	4	44.44
	2016 or before	4	13.33	2	20.00	3	15.79	2	14.29	2	22.22
Side effects	I didn't experience any side effects	5	16.67	2	20.00	4	21.05	2	14.29	2	22.22
	Cough	0	0.00	0	0.00	1	5.26	0	0.00	0	0.00
	Feeling generally unwell	3	10.00	2	20.00	5	26.32	2	14.29	1	11.11
	Feeling hot and cold	2	6.67	1	10.00	2	10.53	1	7.14	1	11.11
	Feeling sick	4	13.33	2	20.00	3	15.79	1	7.14	1	11.11
	Pain	18	60.00	6	60.00	13	68.42	8	57.14	5	55.56
	Shivering	1	3.33		0.00	1	5.26	0	0.00	1	11.11
	Swelling or redness around your wound	15	50.00	6	60.00	8	42.11	4	28.57	0	0.00
	Other	5	16.67	2	20.00	3	15.79	5	35.71	0	0.00
		Median	IQR	Median	IQR	Median	IQR	Median	IQR	Median	IQR
Quality of life		4.00	1.00	3.00	1.50	3.00	2.50	2.50	1.75	4.00	0.00
Effectiveness		4.50	1.00	4.00	0.00	4.00	1.00	4.00	1.75	5.00	1.00

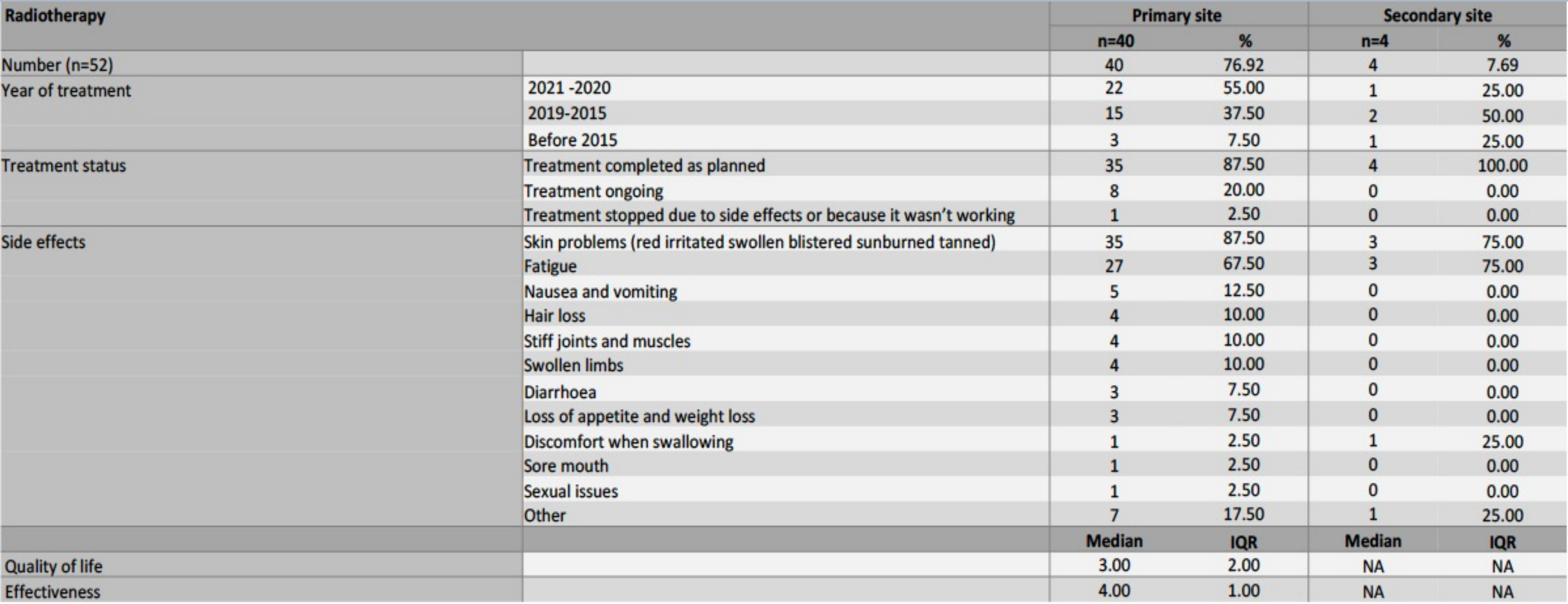


Drug treatments	Number (n=52)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Tamoxifen	23	45.10	3.00	2.00	4.00	1.00
Letrozole	18	35.29	4.00	3.00	4.00	1.00
Anastrozole	8	15.69	4.00	1.50	4.00	0.00
Fluorouracil, epirubicin, cyclophosphamide and docetaxel	7	13.73	3.00	0.75	4.00	0.00
Doxorubicin and cyclophosphamide, and paclitaxel	5	9.80	3.00	0.00	5.00	1.00
Exemestane	5	9.80	4.00	3.00	3.00	2.50
Paclitaxel	5	9.80	4.00	1.00	4.50	1.25
Denosumab	4	7.84	NA	NA	NA	NA
Docetaxel	4	7.84	NA	NA	NA	NA
Docetaxel and cyclophosphamide	4	7.84	NA	NA	NA	NA
Goserelin	4	7.84	NA	NA	NA	NA
Zoledronic acid	4	7.84	NA	NA	NA	NA
Exemestane and goserelin	2	3.92	NA	NA	NA	NA
Abemaciclib	1	1.96	NA	NA	NA	NA
Capecitabine	1	1.96	NA	NA	NA	NA
Carboplatin and gemcitabine	1	1.96	NA	NA	NA	NA
Carboplatin paclitaxel	1	1.96	NA	NA	NA	NA
Doxorubicin	1	1.96	NA	NA	NA	NA
Doxorubicin and cyclophosphamide	1	1.96	NA	NA	NA	NA
Fluorouracil, epirubicin, and cyclophosphamide	1	1.96	NA	NA	NA	NA
Fulvestrant	1	1.96	NA	NA	NA	NA
Palbociclib	1	1.96	NA	NA	NA	NA
Ribociclib	1	1.96	NA	NA	NA	NA

Drug treatments



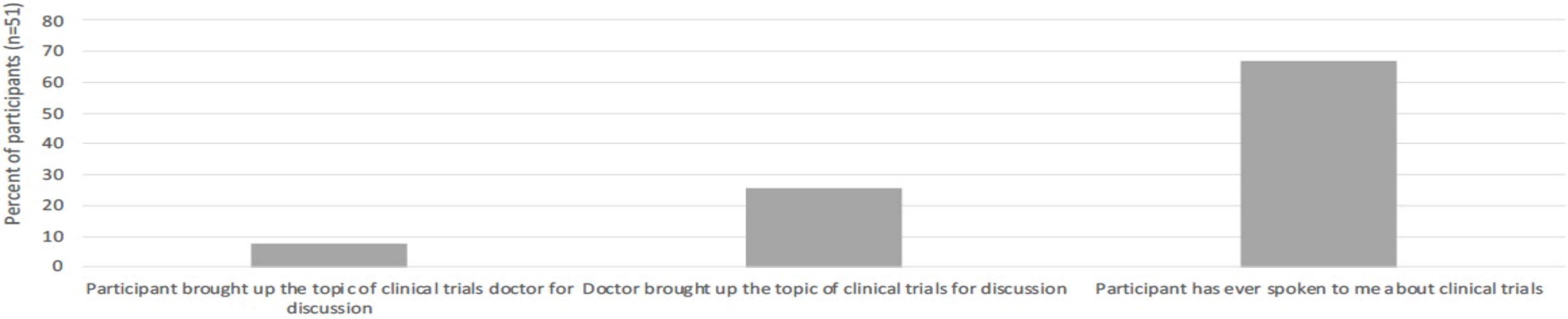
Drug treatments	Number (n=52)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Tamoxifen	23	45.10	3.00	2.00	4.00	1.00
Letrozole	18	35.29	4.00	3.00	4.00	1.00
Anastrozole	8	15.69	4.00	1.50	4.00	0.00
Fluorouracil, epirubicin, cyclophosphamide and docetaxel	7	13.73	3.00	0.75	4.00	0.00
Doxorubicin and cyclophosphamide, and paclitaxel	5	9.80	3.00	0.00	5.00	1.00
Exemestane	5	9.80	4.00	3.00	3.00	2.50
Paclitaxel	5	9.80	4.00	1.00	4.50	1.25
Denosumab	4	7.84	NA	NA	NA	NA
Docetaxel	4	7.84	NA	NA	NA	NA
Docetaxel and cyclophosphamide	4	7.84	NA	NA	NA	NA
Goserelin	4	7.84	NA	NA	NA	NA
Zoledronic acid	4	7.84	NA	NA	NA	NA
Exemestane and goserelin	2	3.92	NA	NA	NA	NA
Abemaciclib	1	1.96	NA	NA	NA	NA
Capecitabine	1	1.96	NA	NA	NA	NA
Carboplatin and gemcitabine	1	1.96	NA	NA	NA	NA
Carboplatin paclitaxel	1	1.96	NA	NA	NA	NA
Doxorubicin	1	1.96	NA	NA	NA	NA
Doxorubicin and cyclophosphamide	1	1.96	NA	NA	NA	NA
Fluorouracil, epirubicin, and cyclophosphamide	1	1.96	NA	NA	NA	NA
Fulvestrant	1	1.96	NA	NA	NA	NA
Palbociclib	1	1.96	NA	NA	NA	NA
Ribociclib	1	1.96	NA	NA	NA	NA

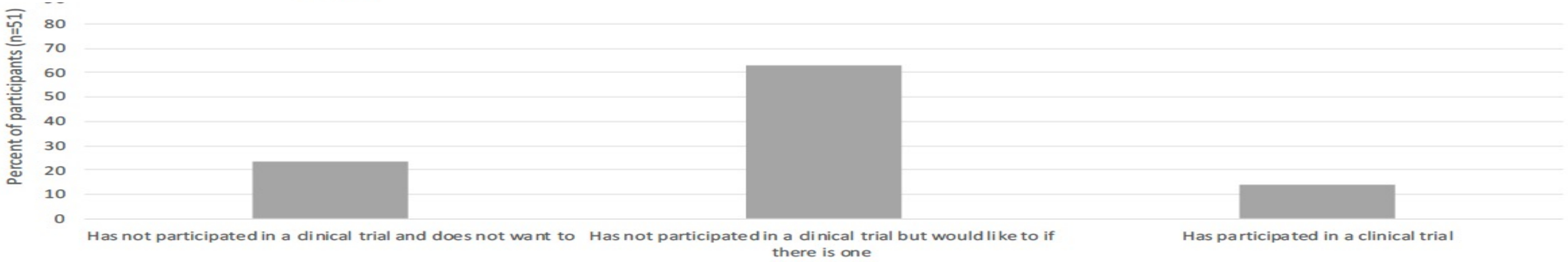


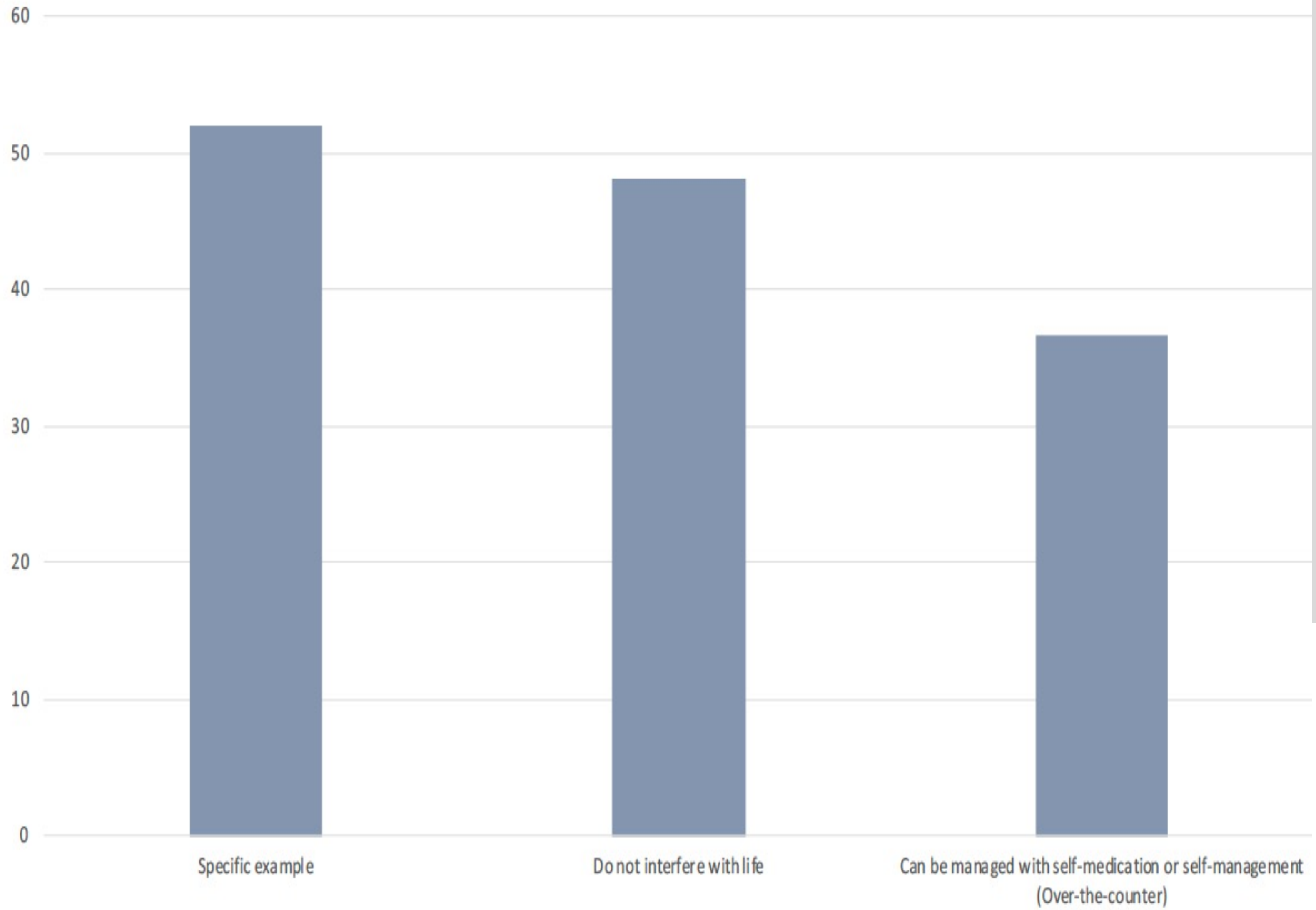
Radiotherapy		Primary site		Secondary site	
		n=40	%	n=4	%
Number (n=52)		40	76.92	4	7.69
Year of treatment	2021 -2020	22	55.00	1	25.00
	2019-2015	15	37.50	2	50.00
	Before 2015	3	7.50	1	25.00
Treatment status	Treatment completed as planned	35	87.50	4	100.00
	Treatment ongoing	8	20.00	0	0.00
	Treatment stopped due to side effects or because it wasn't working	1	2.50	0	0.00
Side effects	Skin problems (red irritated swollen blistered sunburned tanned)	35	87.50	3	75.00
	Fatigue	27	67.50	3	75.00
	Nausea and vomiting	5	12.50	0	0.00
	Hair loss	4	10.00	0	0.00
	Stiff joints and muscles	4	10.00	0	0.00
	Swollen limbs	4	10.00	0	0.00
	Diarrhoea	3	7.50	0	0.00
	Loss of appetite and weight loss	3	7.50	0	0.00
	Discomfort when swallowing	1	2.50	1	25.00
	Sore mouth	1	2.50	0	0.00
	Sexual issues	1	2.50	0	0.00
	Other	7	17.50	1	25.00
		Median	IQR	Median	IQR
Quality of life		3.00	2.00	NA	NA
Effectiveness		4.00	1.00	NA	NA

Radiation therapy

Clinical trials



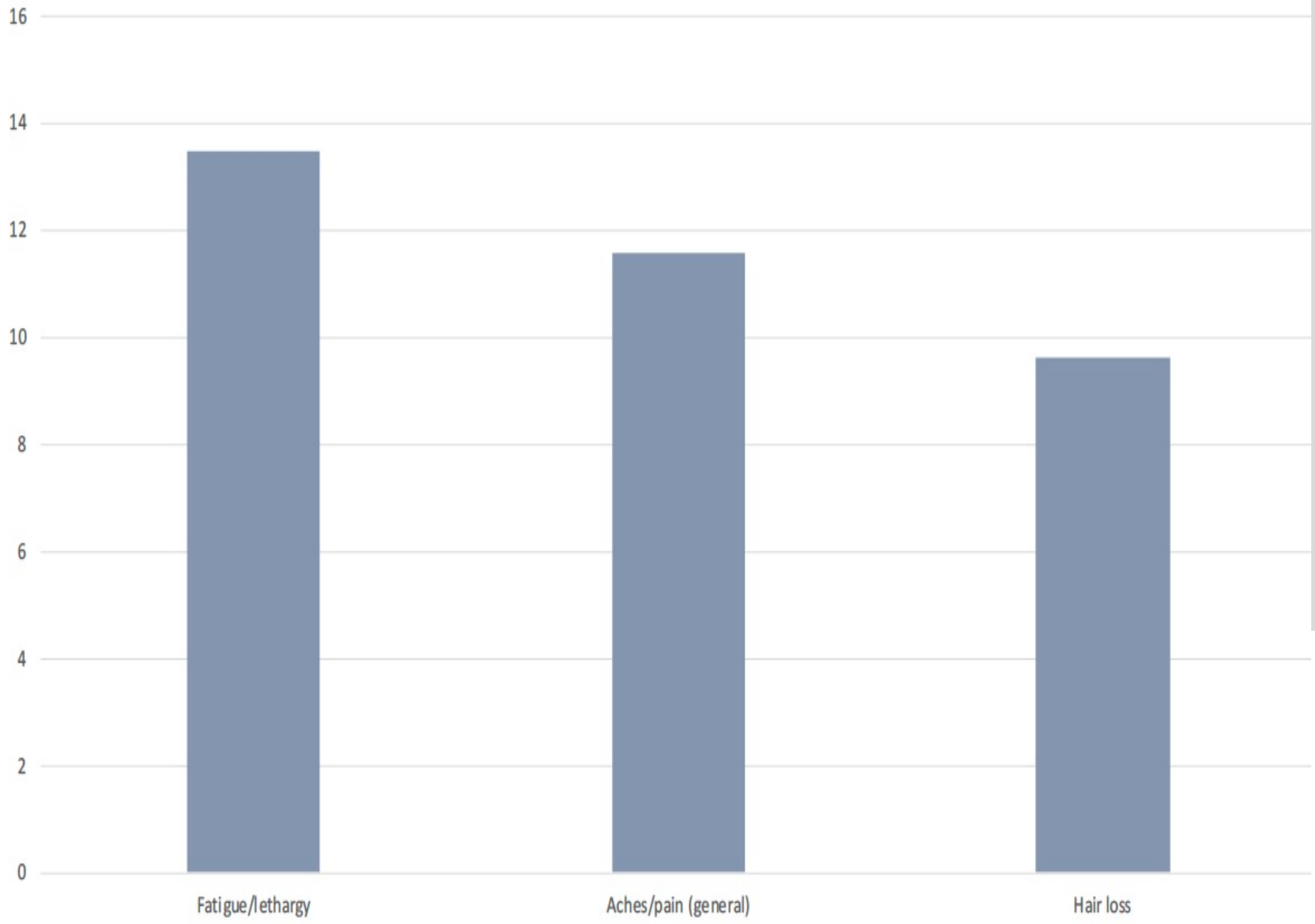




Mild side effects would be neuropathy, nerve pain. Yes, dealing with the seroma. They're all fairly mild. You know, it's nothing that, sort of, really, really bad. Participant 003_2021AUHRP

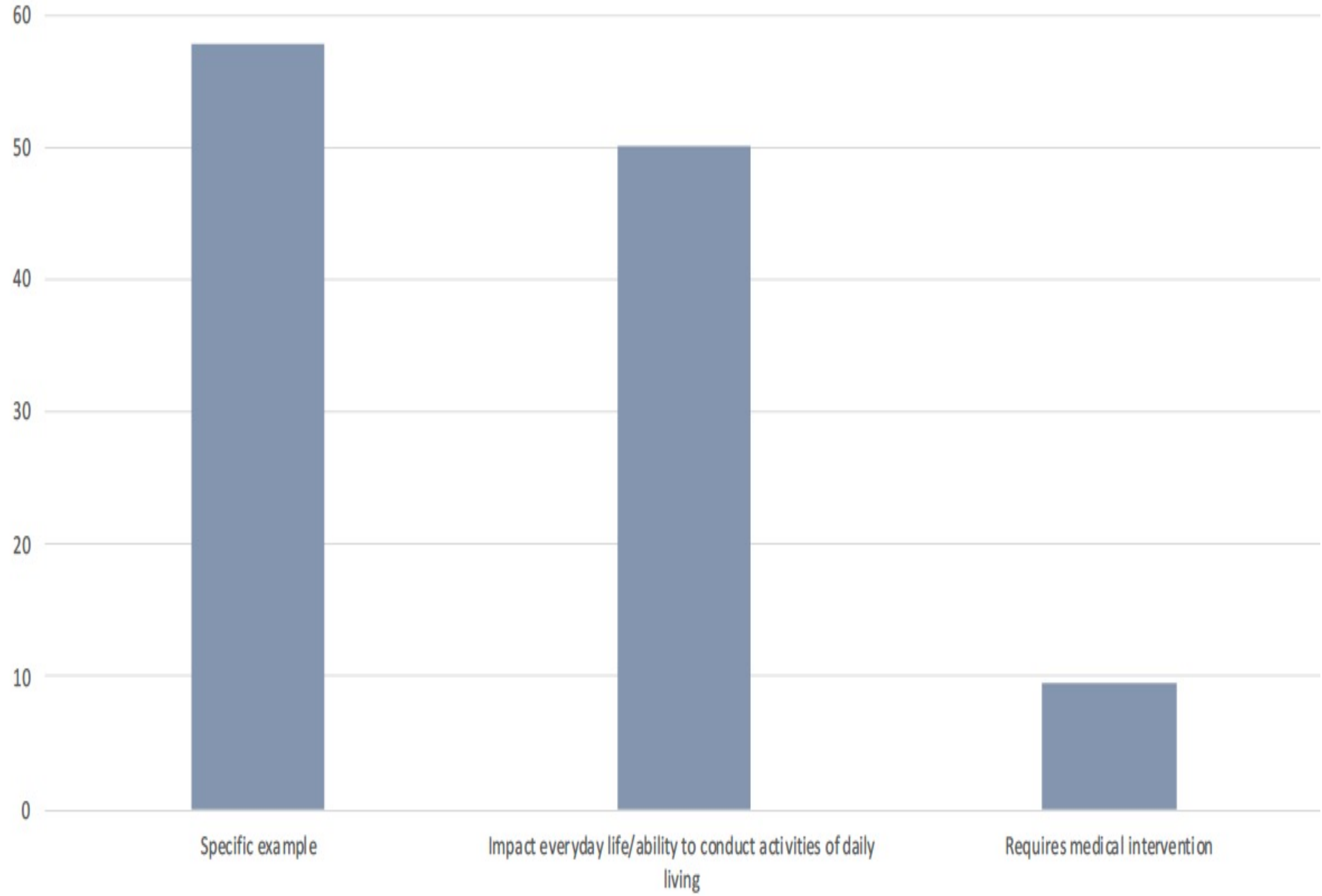
They're all manageable because even, I guess, some people would consider hair loss as being significant but it didn't really bother me that much. I think it bothered my vacuum cleaner far more than it bothered me. The only one that's really adjusted how I function, which I would say is the definition of something that's not mild would be the hot flashes. Participant 005_2021AUHRP

Description of mild side effects (% of all participants)



Just a general annoyance, like something that you can fix. Does that make sense? You know, like, you know, the side effect of constipation is a mild side effects. And it's frustrating at the time, but you know, it's fleeting, and it goes away. Yes. Whereas, you know, your more in depth side effects for the ones that doesn't matter what you do, like the weight gain, you know, I could live on freaking lettuce leaves for ever and still not lose any weight. Participant 033_2021AUHRP

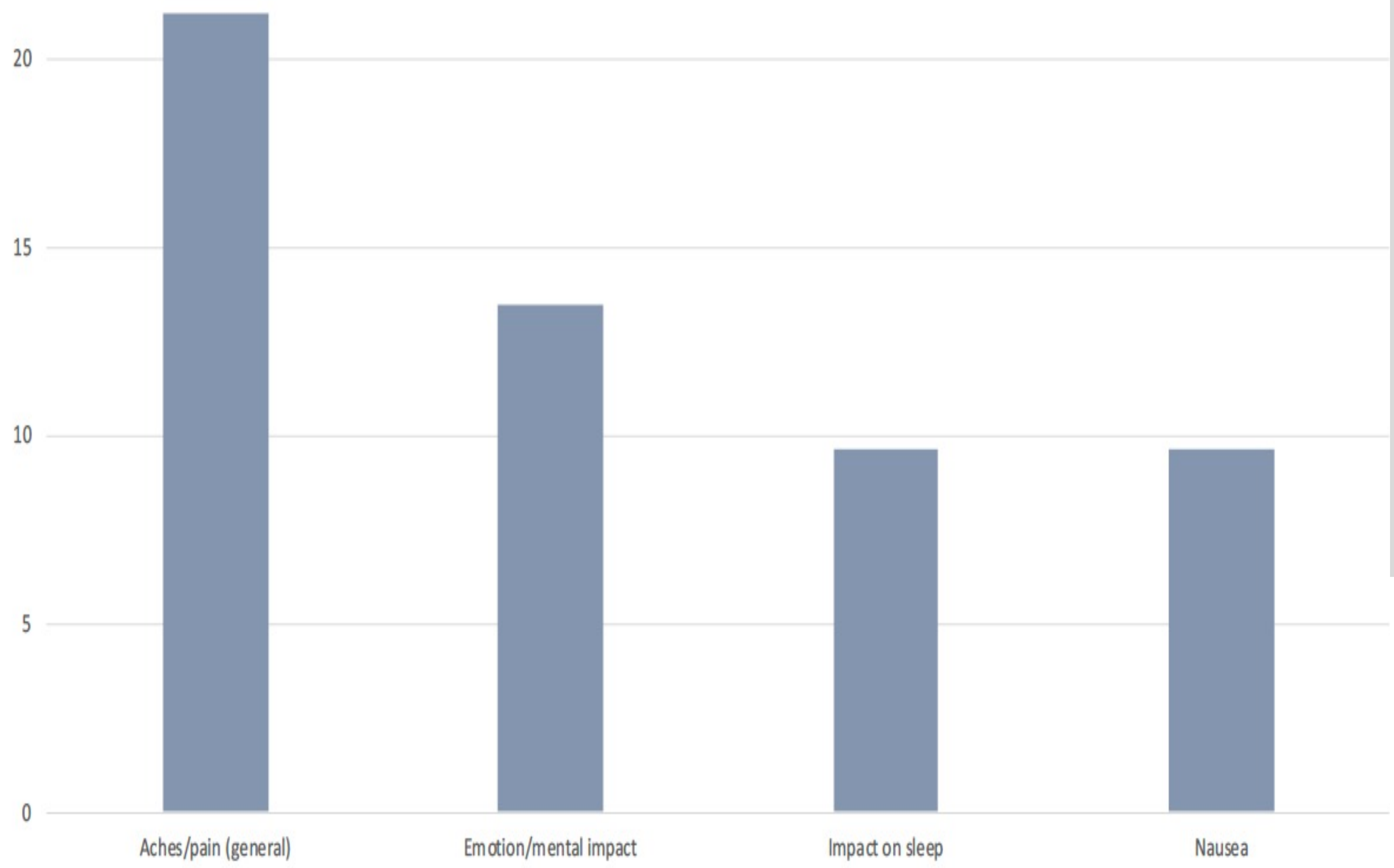
Description of mild side effects: Specific example (% of all participants)



Severe to me would be it would inhibit my daily living or my life as far as I wouldn't be able to go to work, and I wouldn't be able to go out to do the shopping, or it would interfere with my life, would be what I would class as severe. Participant 017_2021AUHRP

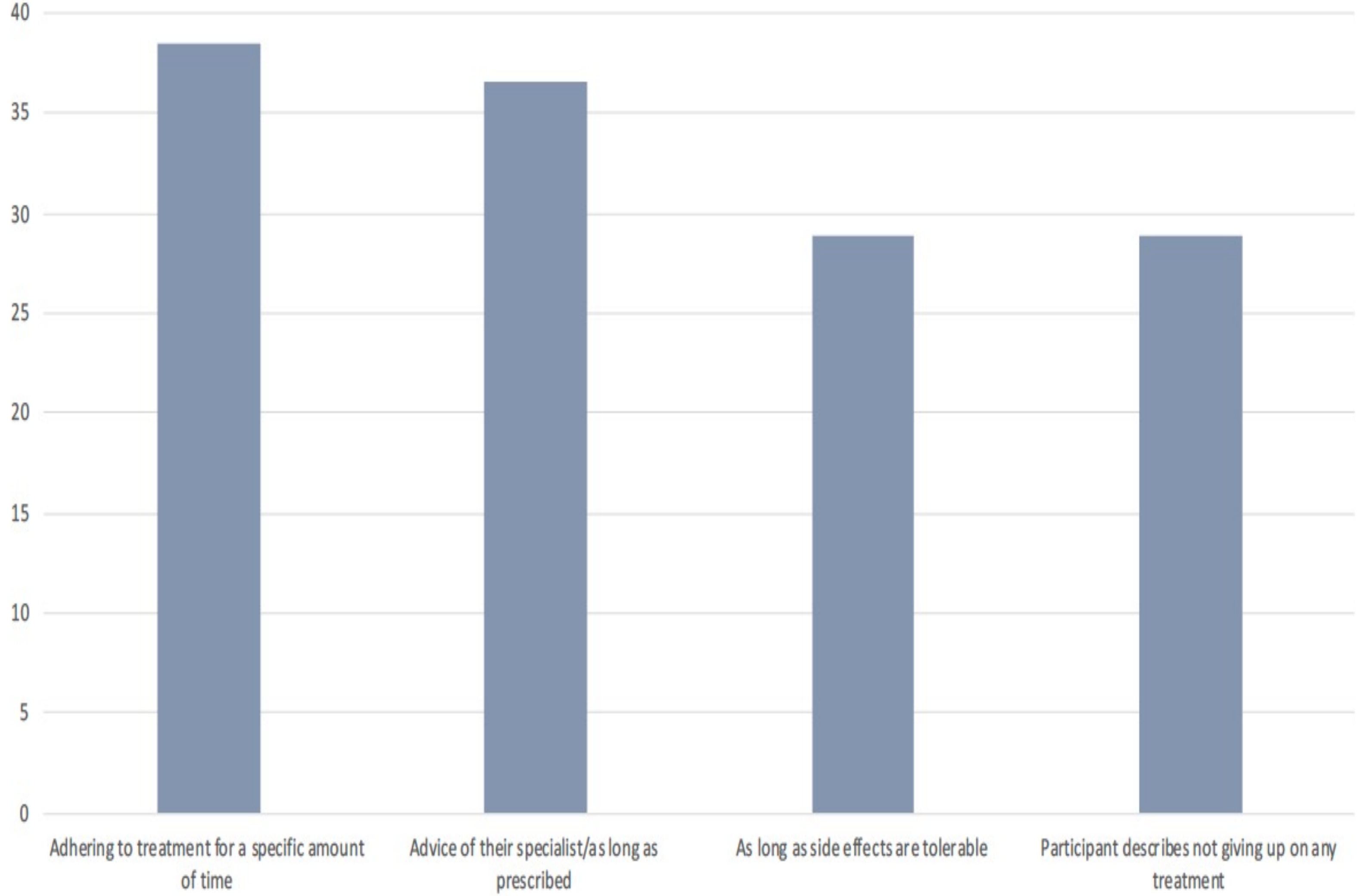
When you feel so down and you cry because you're so fed up with feeling sore and in pain all the time. Participant 012_2021AUHRP

Description of severe side effects (% of all participants)



Severe side effects, I guess where it is having much more impact on your daily life. It does have you thinking about changing or stopping the treatment. It takes a lot more care to manage. A lot more treatment to manage and it has an effect physically and emotionally on how you feel about A, if it's a physical pain type side effects, ongoing pain has an effect on your mood and mental health. Severe side effects can affect body image. Again, the amount of treatments that you need to manage those side effects. Participant 023_2021AUHRP

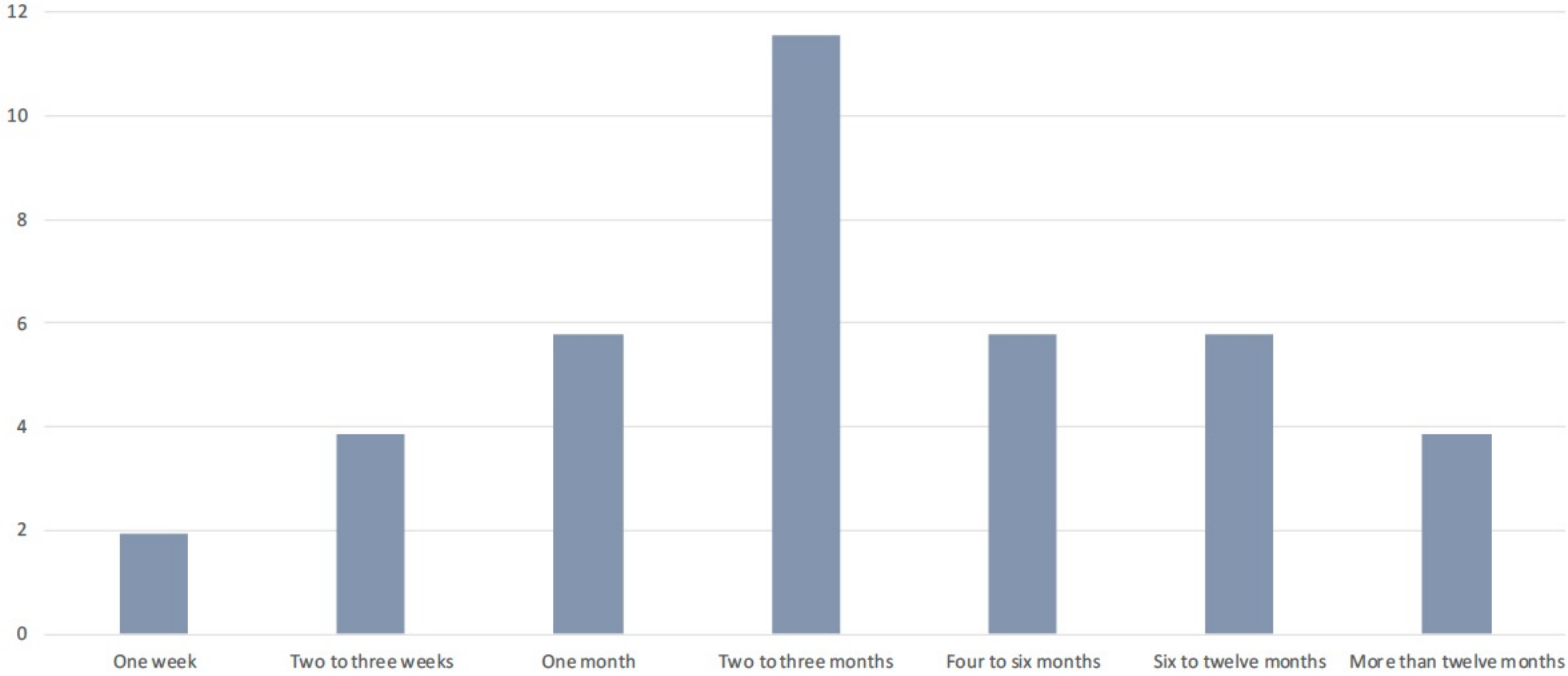
Description of severe side effects: Specific side effect examples (% of all participants)



Yes. I think that depends on what you're trying because I think you need to really understand the nature of treatment and what's going on behind it. There's not much point trying it for less than two weeks. I think that depends on the treatment really. Based on whether it's going to be something that should fix things quickly, or it takes a couple of weeks to work. Participant 005_2021AUHRP

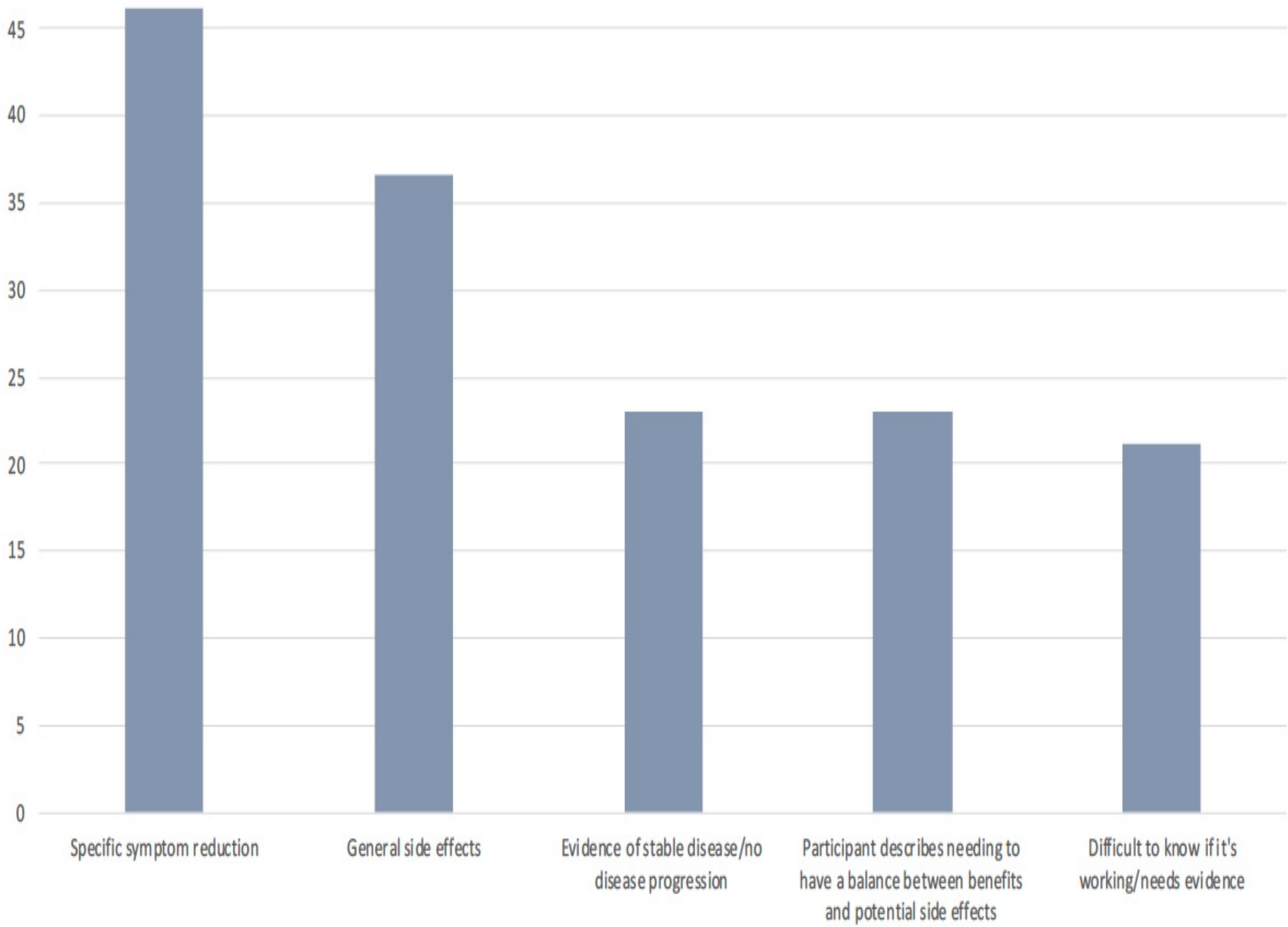
Yeah, I stick with it. I follow the protocols. If it says, you know, you're going to have nausea, take this stuff to stop it. Yes, I will take it. And you know, if I'm going to go off something, it's going to be because I've discussed it with the doctor. Participant 003_2021AUHRP

Adherence to treatment (% of all participants)



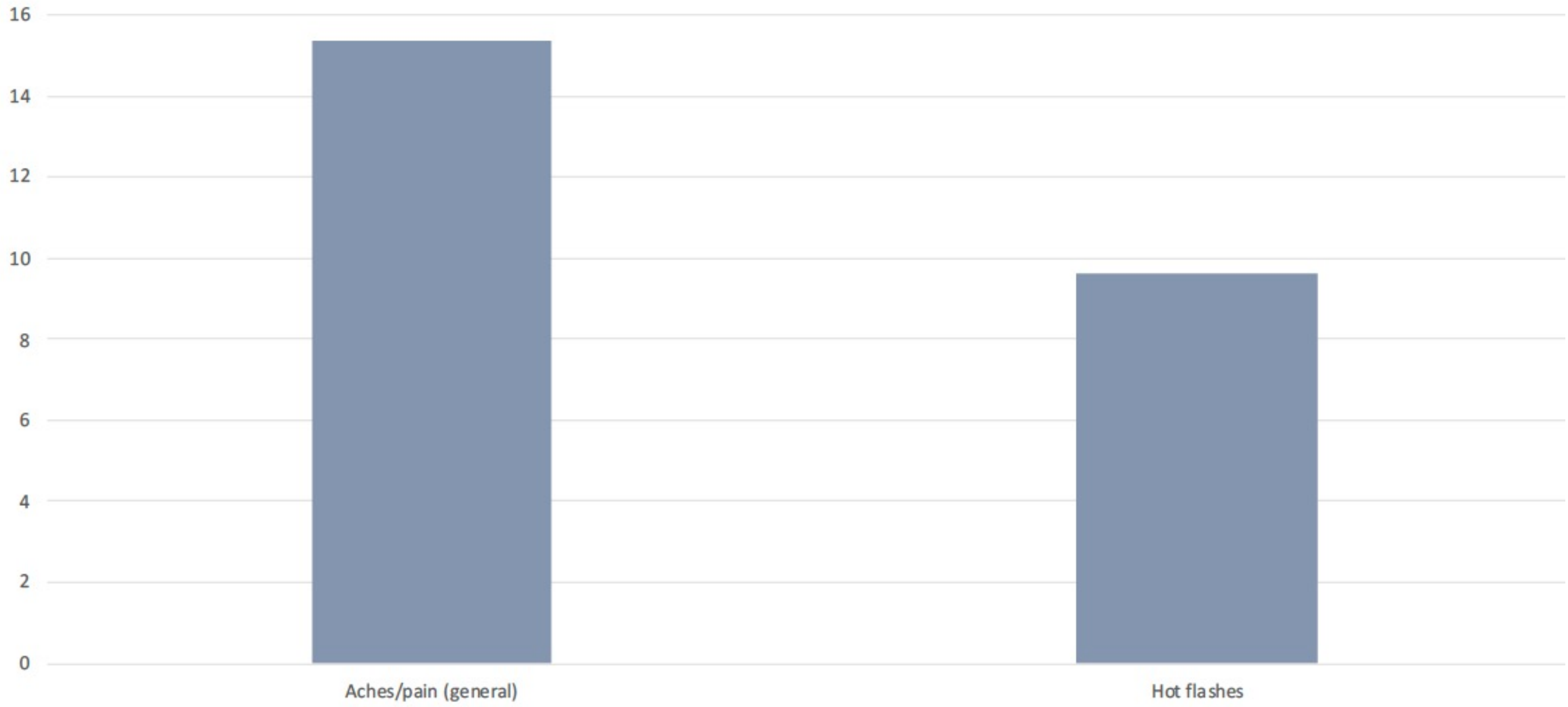
Adherence to treatment: specific amount of time (% of all participants)

What needs to change to feel like treatment is working (% of all participants)

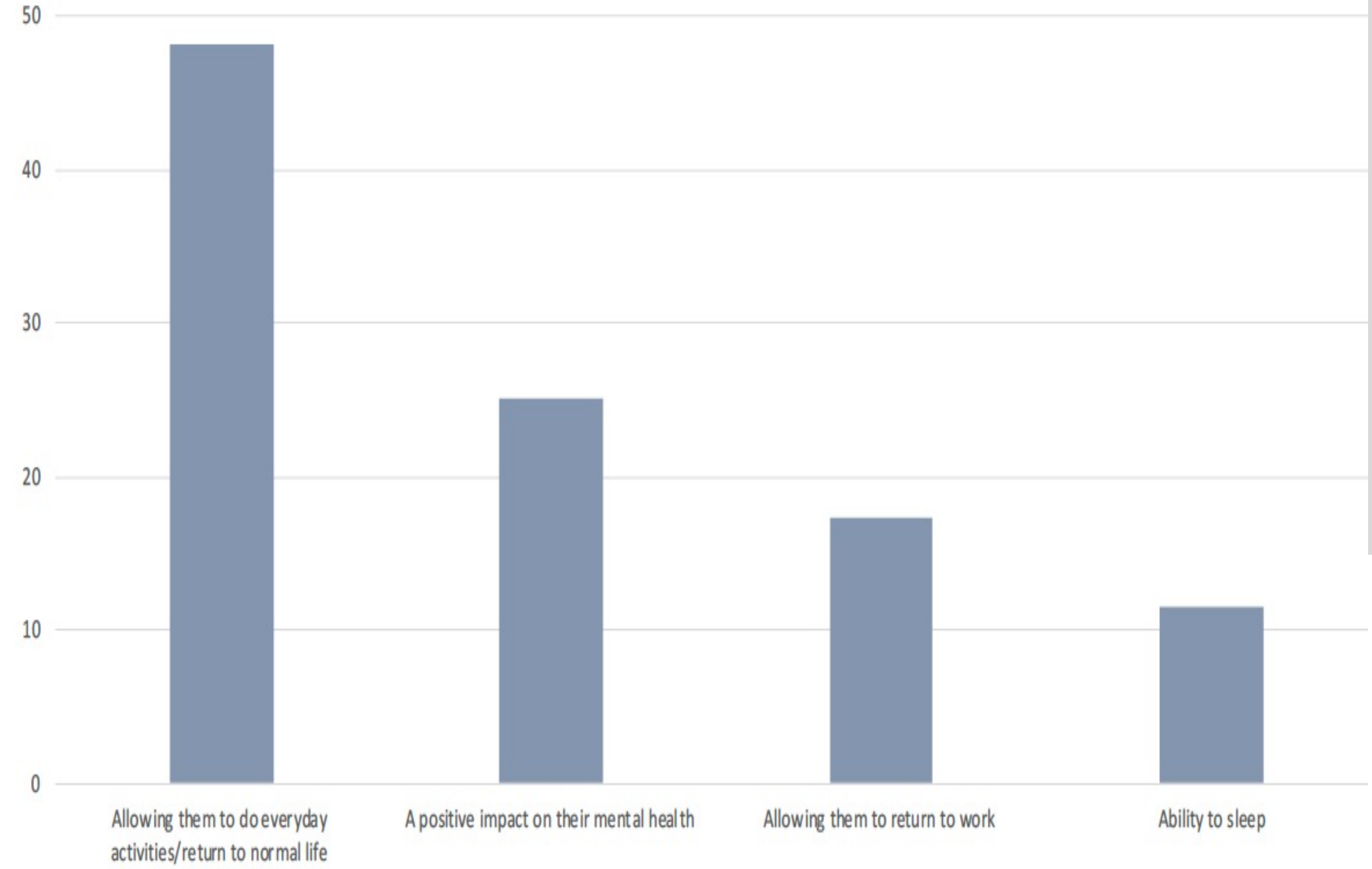


If there was a treatment to reduce the side effects and that'd be good depends how much it really impacts on quality of life because 4% doesn't sound like enough to make life unbearable, we'll see which one's most worthwhile. Yeah. Participant 018_2021AUHRP

I think when it comes to things like the hormone blockers, I think the reduction in side effects would be, for me, what really needs to change to make me happy to stay on the things. Participant 014_2021AUHRP



What needs to change to feel like treatment is working: specific symptoms (% of all participants)



I can go on living, get to work, I can travel, I can be active in sports, but if I had really bad side effects, I wouldn't be able to do that, or if the cancer comes back, I have to change my life to a deal with it. Participant 007_2021AUHRP

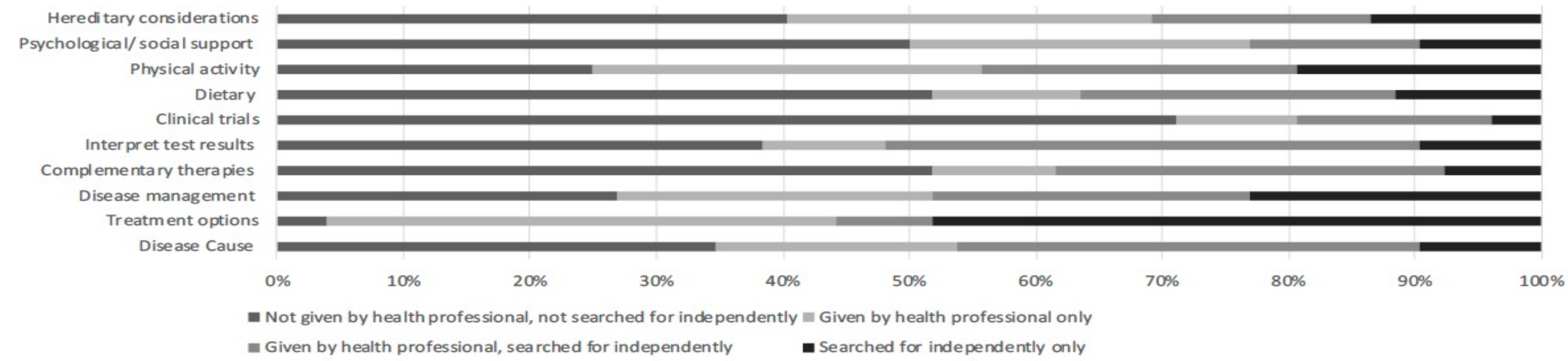
I guess just day-to-day living, cooking dinner, doing a little bit of housework, reading the newspaper, just get on with the basic things, being able to shower unassisted. For the first couple of days after each lot of chemo, I could've had a chair in the shower because I just felt so wobbly. Participant 039_2021AUHRP

What would it mean if treatment worked (% of all participants)

Section 6

Communication
&
Information

This section report access to information, information that was helpful and information that was not helpful, when participants feel they were most receptive to receiving information, information preferences, information topics for which information was received or searched for, as well as when it was received and additional information was required. This is also where there is information about healthcare professional communication and participant’s knowledge and confidence in managing their own health using the Partners in Health tool.



The largest gaps in information, where information was neither given to patients nor searched for independently were clinical trials (n = 37, 71.15%), dietary information (n = 27, 51.92%), complementary therapies (n = 27, 51.92%) and psychological and social support (n = 26, 50.00%).

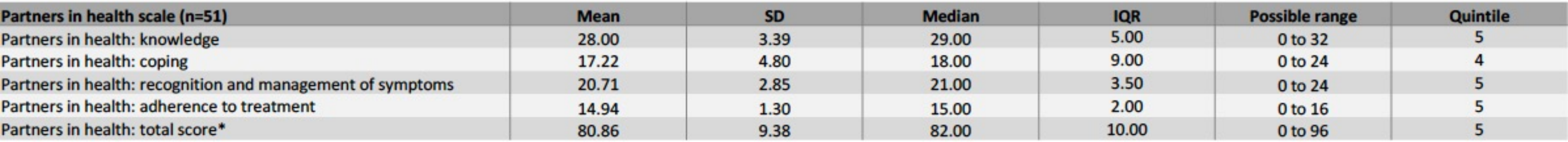
The topics that participants most commonly did not search for independently after not receiving information from healthcare professionals were treatment options (n = 21, 40.38%) and physical activity (n = 16, 30.77%).

The topics that participants were given most information from both healthcare professionals and searching independently for were how to interpret test results (n = 22, 42.31%), and disease Cause (n = 19, 36.54%).

The topics that participants most commonly searched for independently after not receiving information from healthcare professionals were treatment options (n = 25, 48.08%) and disease management (n = 12, 23.08%).

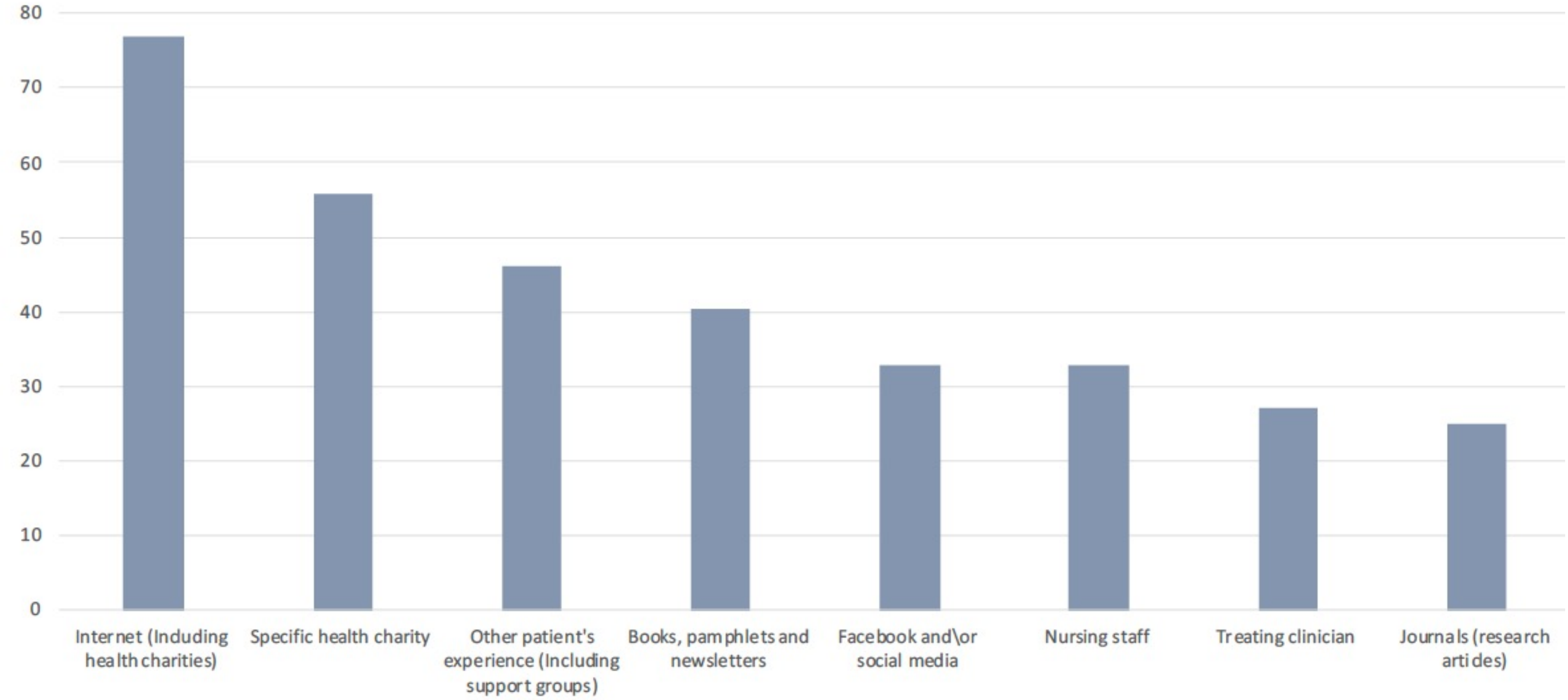
Information gaps

Partners in Health



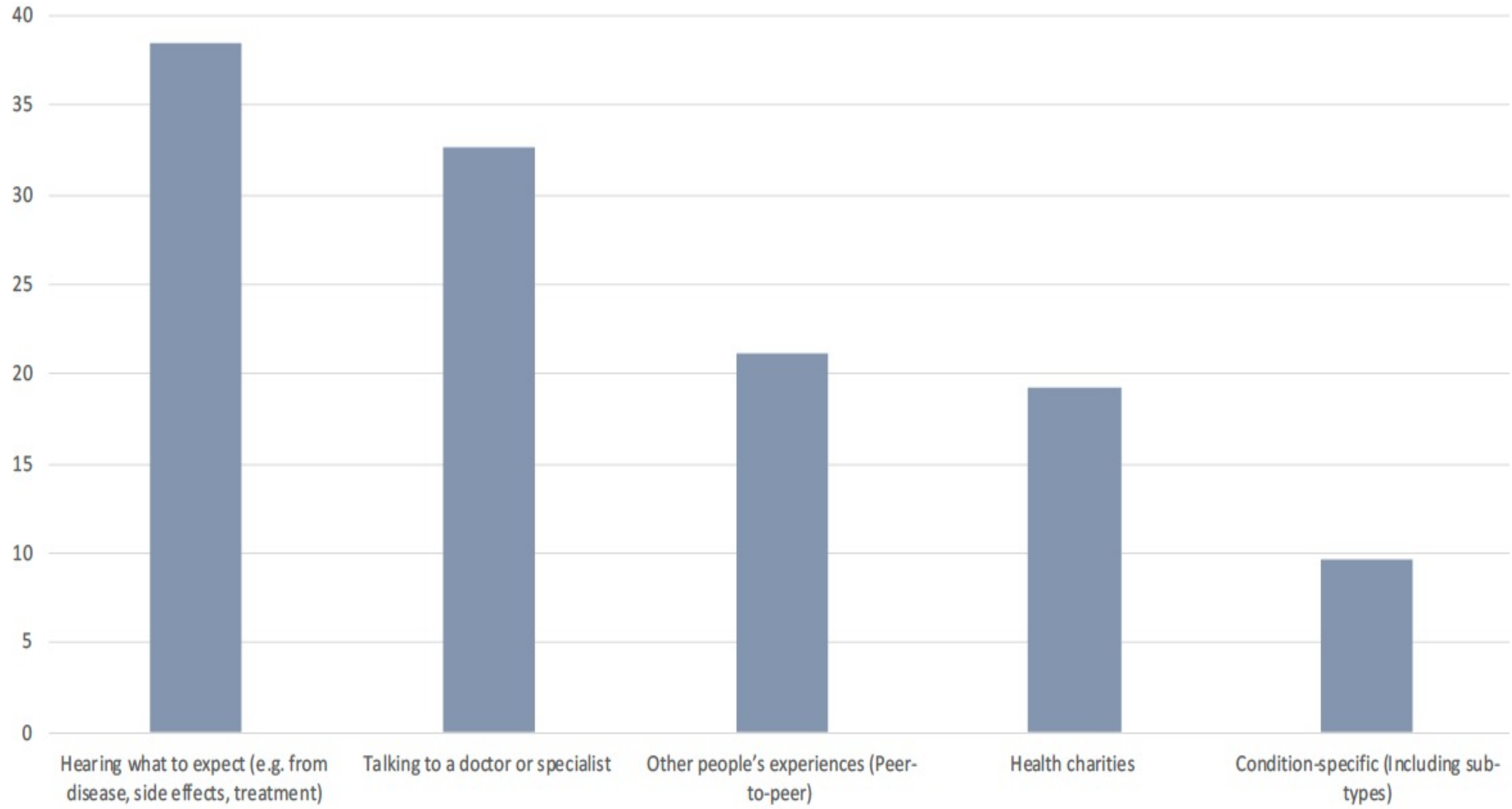
Partners in health scale (n=51)	Mean	SD	Median	IQR	Possible range	Quintile
Partners in health: knowledge	28.00	3.39	29.00	5.00	0 to 32	5
Partners in health: coping	17.22	4.80	18.00	9.00	0 to 24	4
Partners in health: recognition and management of symptoms	20.71	2.85	21.00	3.50	0 to 24	5
Partners in health: adherence to treatment	14.94	1.30	15.00	2.00	0 to 16	5
Partners in health: total score*	80.86	9.38	82.00	10.00	0 to 96	5

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



Centre for Community-Driven Research

Information accessed (% of all participants)

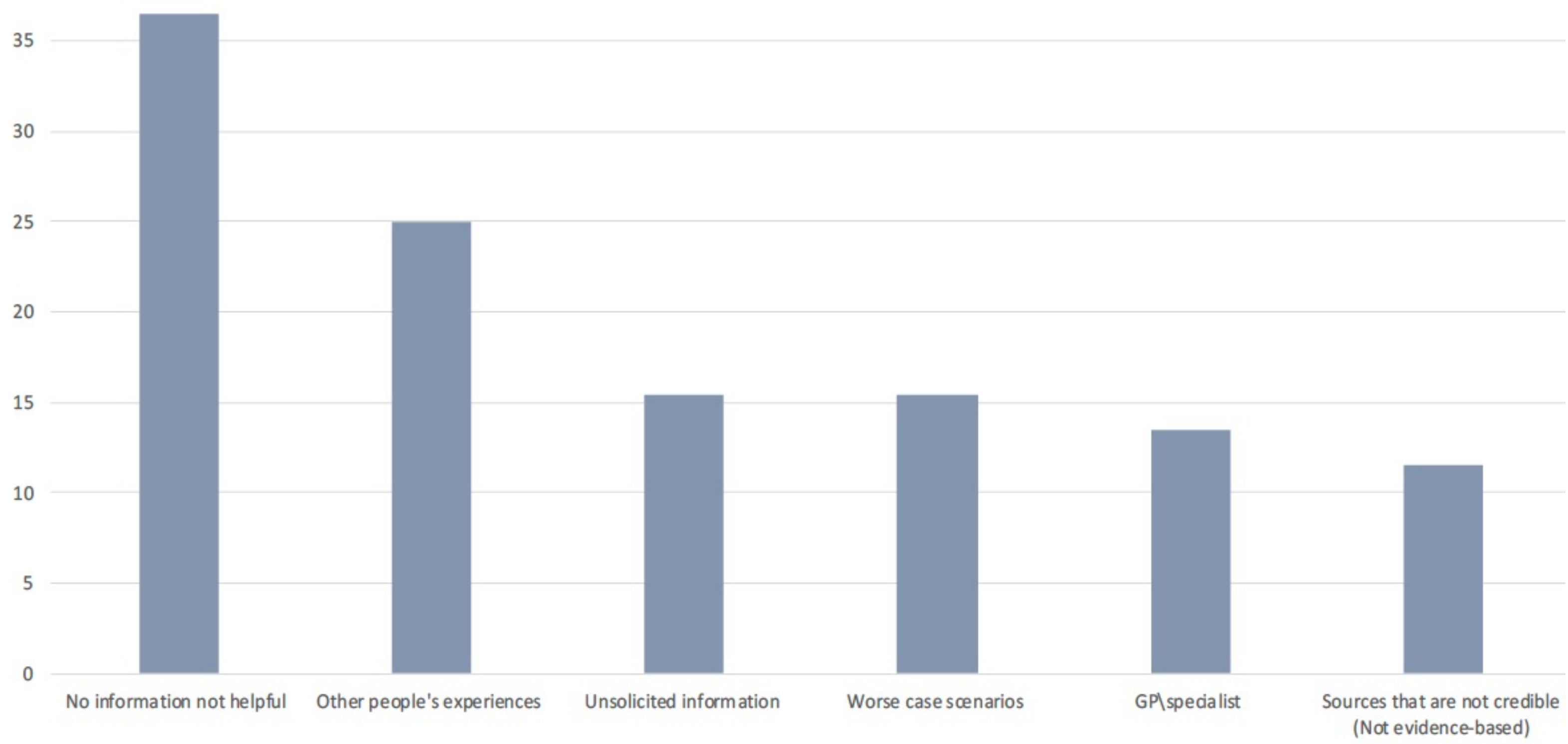


I guess knowing what's going to happen to me as I went through chemo and then radiation. Knowing what to expect. Participant 039_2021AUHRP

A lot of it was just kind of more under like, you know, the information that gave us an understanding of what to expect and what the process was, you know, from, from where you were, what was the next step? And the step after that so far, so you knew where you're heading and that sort of stuff? Participant 020_2021AUHRP

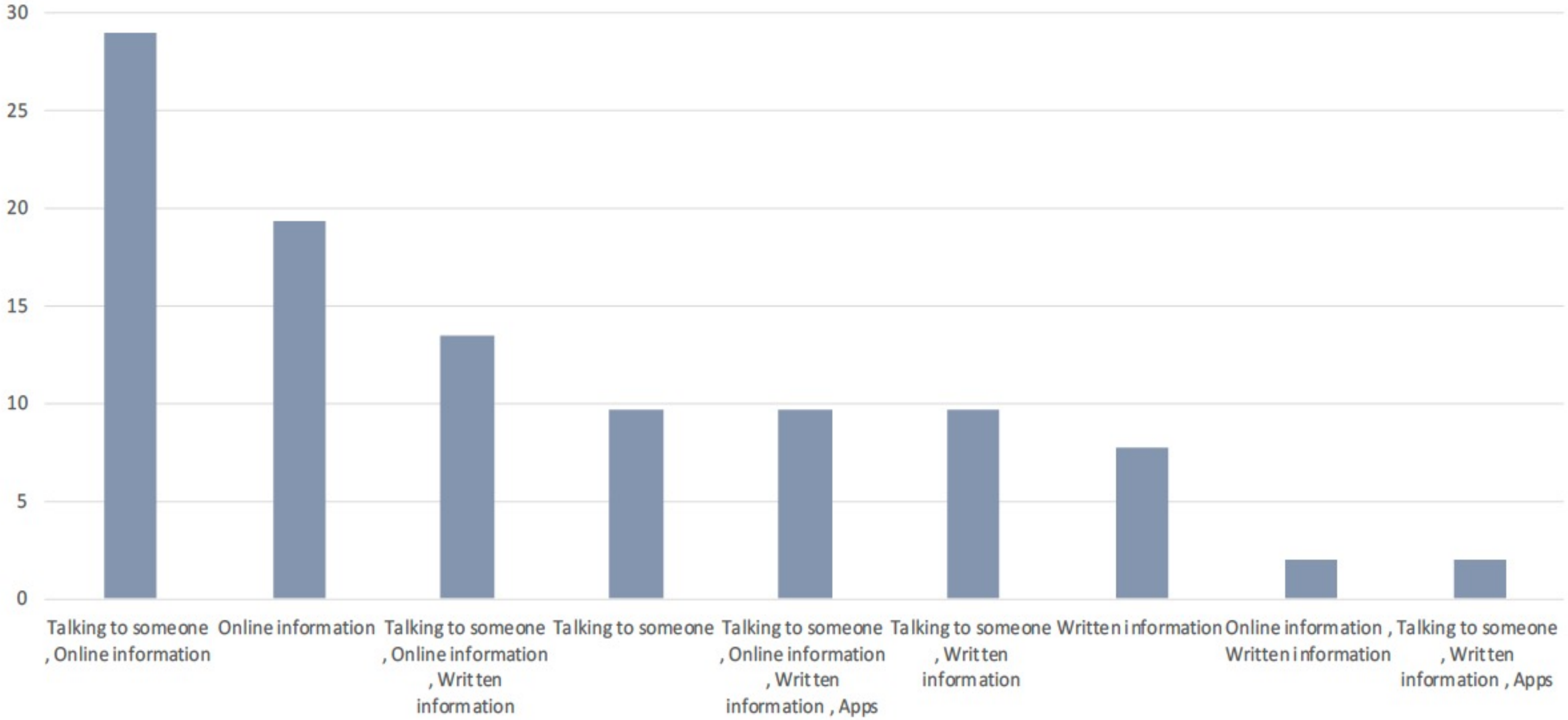
Information that has been helpful (% of all participants)

Information that has not been helpful (% of all participants)



I will say, like some of the Facebook pages, some of them have been really helpful. Some of them have been very unhelpful as well, just because the people that you get on there, you obviously get some people who are less than helpful. Generally, I'd stay away from undocumented and unsupported sites. It's just not the sort of place that I would go to, to look for information. Participant 037_2021AUHRP

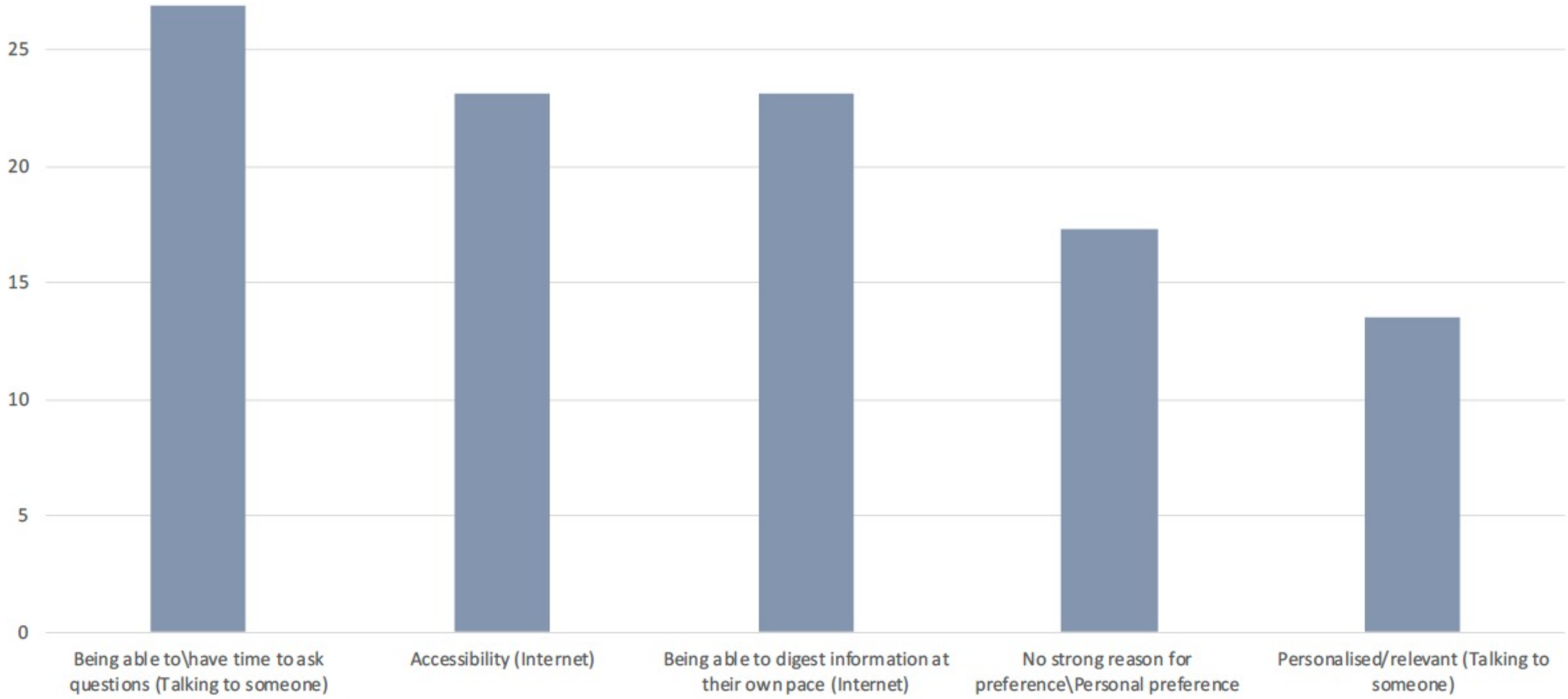
Not really, like I mean, we were we were given a lot of information at appointments and stuff like that. It was relevant to what was being discussed, but it wasn't necessarily something that I research further on or something like that. Participant 020_2021AUHRP



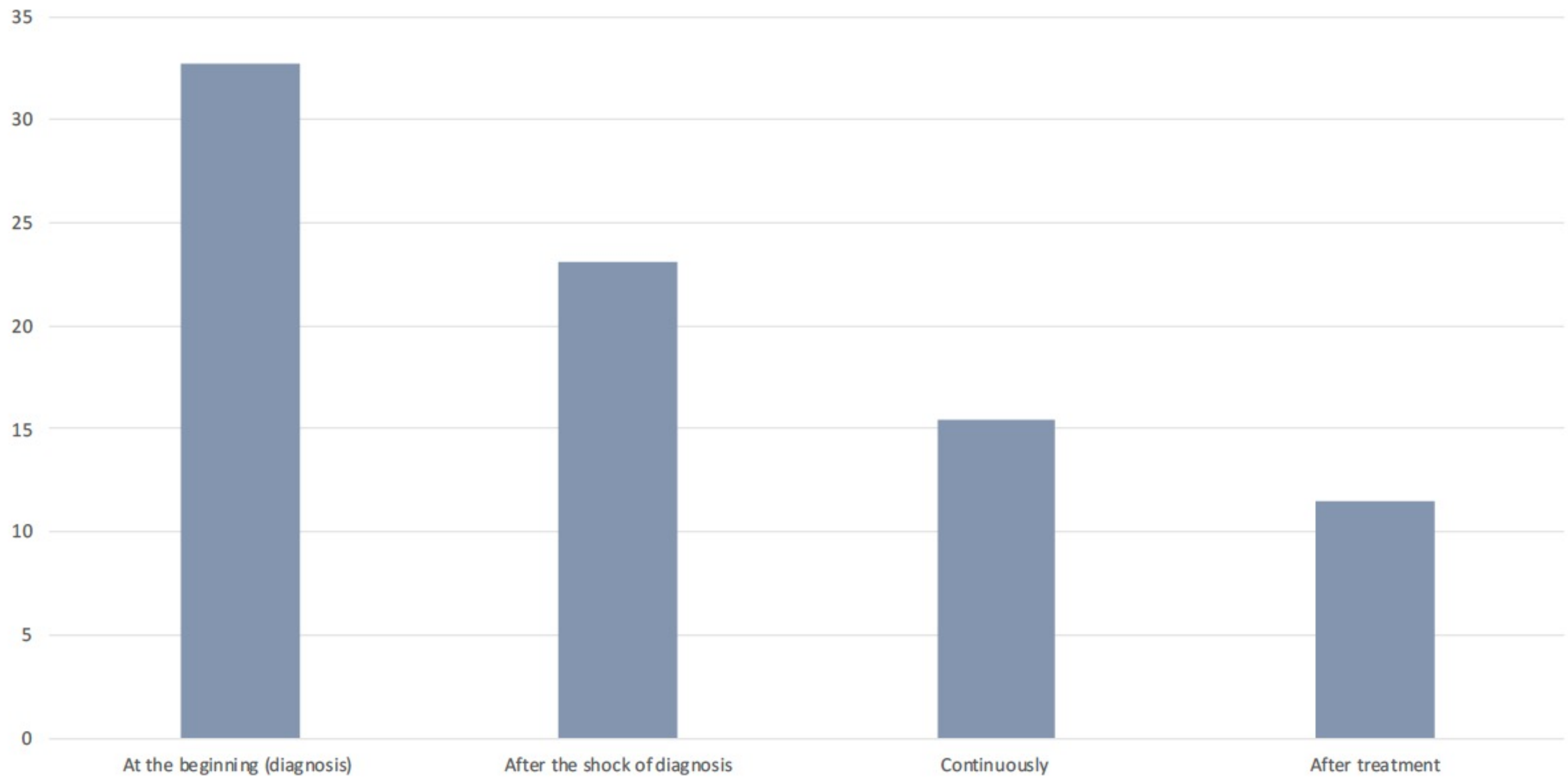
Certainly, talking to the specialist and the information they gave. Then I did find the network good for some general information. Participant 011_2021AUHRP

I prefer when it comes to my own treatment anyways, face to face. So that when you're processing it, you can ask a question directly and get a response. That's just my personal, and I think that's a generational thing. Participant 018_2021AUHRP

Information preferences (% of all participants)

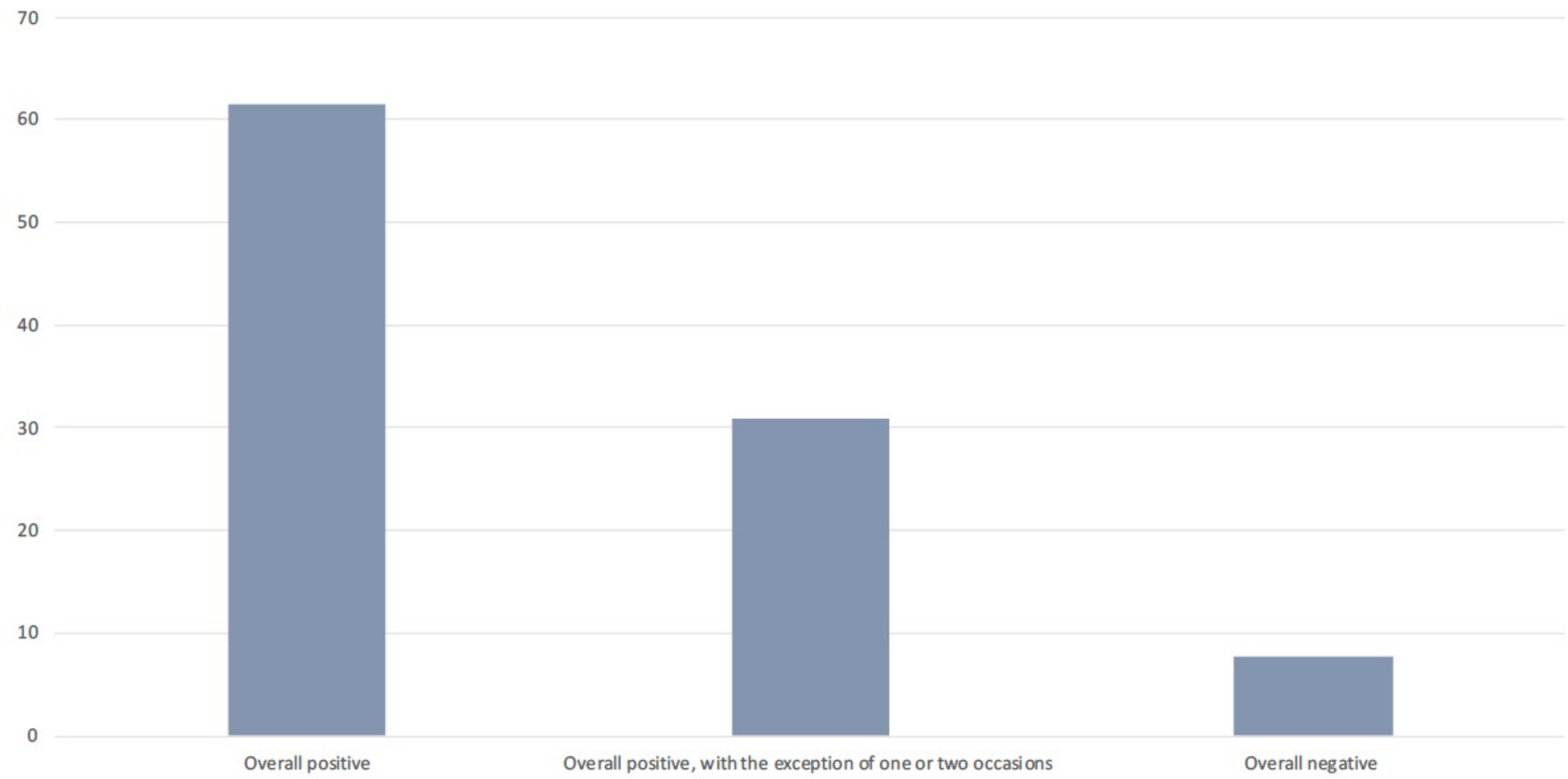


Information preference rationale (% of all participants)



> *I think when I was first diagnosed, I was just soaking up everything and reading everything. I couldn't think of anything else, so I was really reading everything and searching the net, doing all of this stuff. Well, probably I still could-- That's what I do anyway. Yes, so probably at the start for me, and then as things settled down and then I was a bit more selective and able to look at things with a bit more depth and trained a bit more is what I would say. Participant 036_2021AUHRP*

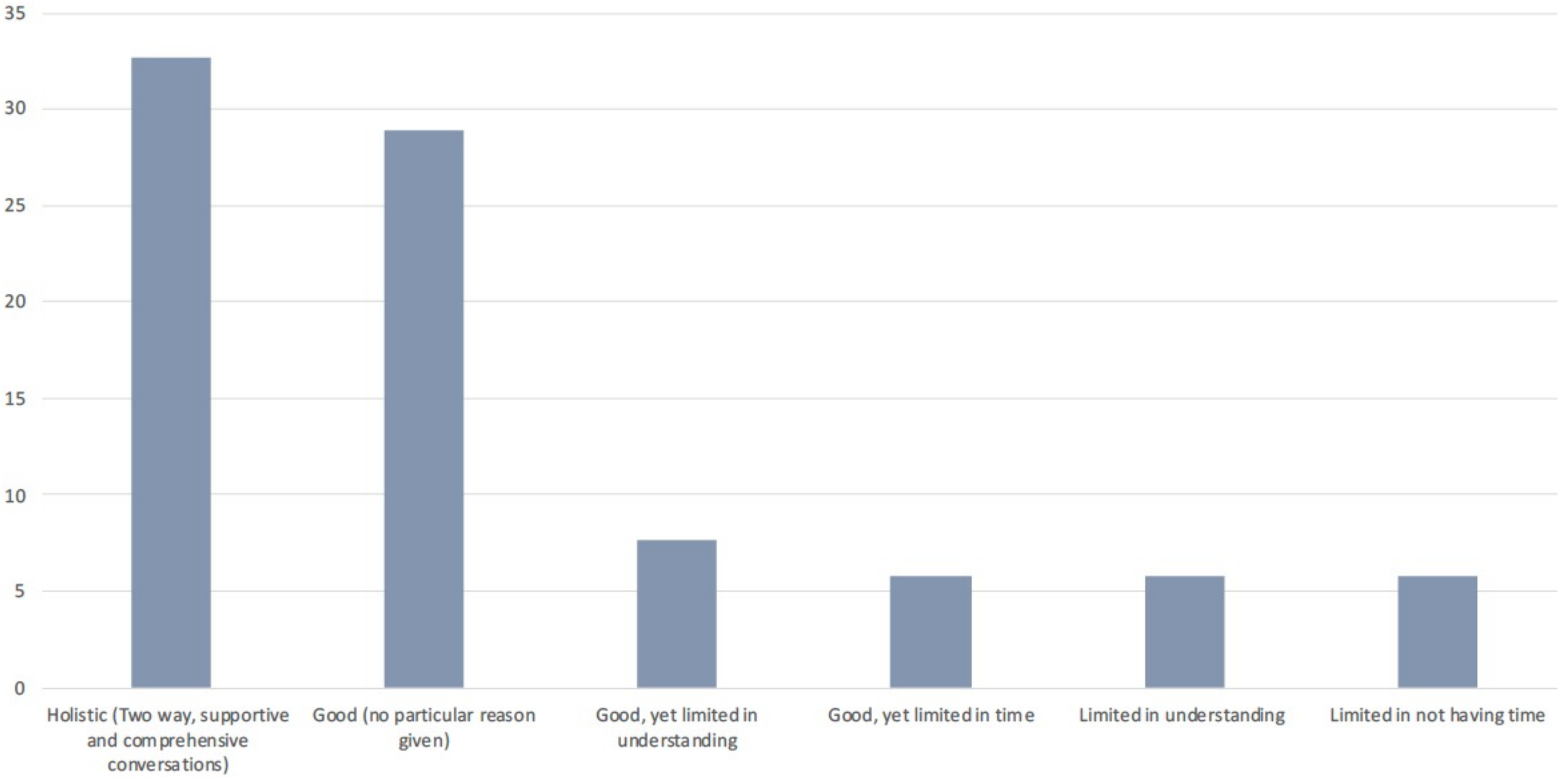
Timing of information (% of all participants)



It's been good. They've been really good. They've shared to me as much information as they can and, obviously, enlighten me to risk factors and possible side effects as best they can, and then they've, obviously, touch base with me and I've been able to share what's been happening. They've been able to help me with those issues as needed so that's been good. Participant 042_2021AUHRP

The surgeon was really good. The oncologist was really good. I wasn't so impressed with the radiation oncologist. I've only had one blip with the oncologist, and I think she was just having a bad day. Participant 030_2021AUHRP

Healthcare professional communication (% of all participants)



My surgeon has always been really open to discussions and answering questions and to a great degree, she has been a go-to and my medical oncologist is also fabulous, in a different way. He is very good at using statistics for and against things to help with decision making and doesn't push a decision overly in one direction. He'll gently encourage but he's not a you must-do-this person, it's, "I suggest this because the research shows." My GP, hit and miss. Participant 023_2021AUHRP

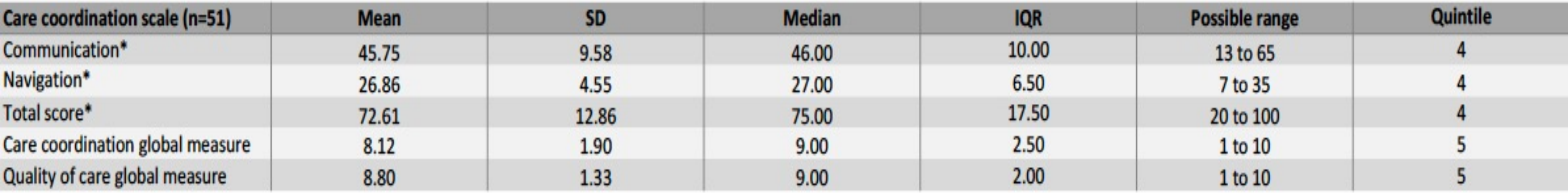
Healthcare professional communication: Rationale (% of all participants)

Section 7

Care
&
Support

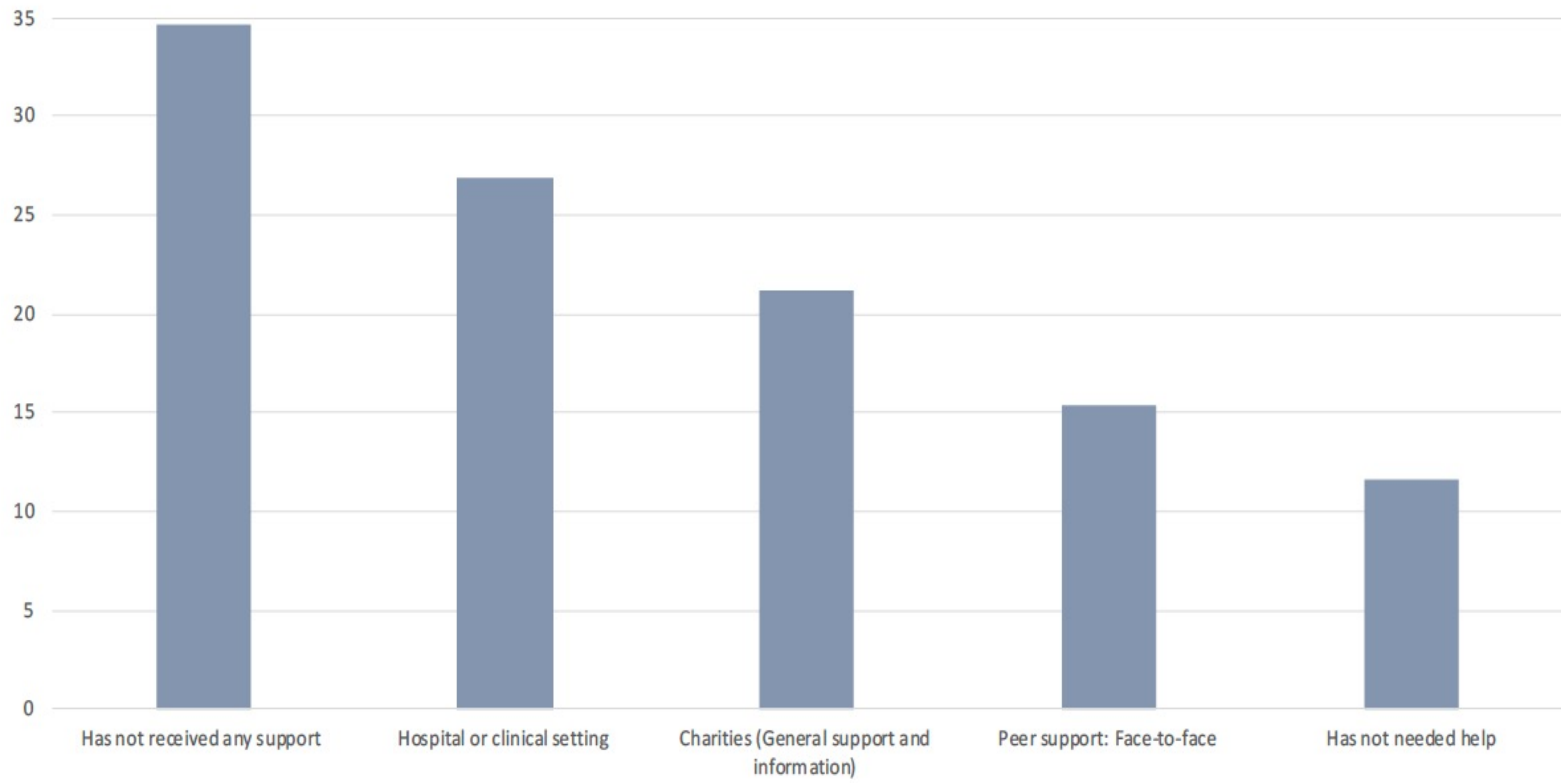
A Care Coordination questionnaire tool is used and reported in this section to demonstrate how people have been able to navigate the health system. There is also information about the care and support people have received, including from the charity sector.

Care coordination



Care coordination scale (n=51)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	45.75	9.58	46.00	10.00	13 to 65	4
Navigation*	26.86	4.55	27.00	6.50	7 to 35	4
Total score*	72.61	12.86	75.00	17.50	20 to 100	4
Care coordination global measure	8.12	1.90	9.00	2.50	1 to 10	5
Quality of care global measure	8.80	1.33	9.00	2.00	1 to 10	5

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



The breast cancer nurse at my oncology unit was amazing. She told me about all the charities that were available, all the support that was available. If I wanted counseling it was available. She was my main go-to if I needed something to help with something, she was just a breast care nurse. Participant 024_2021AUHRP

It was there if I needed it. I remember one day when I was having radiation, I was a complete mess and I was just lying there crying. When I finished, the social worker came and sat down and had a cup of tea with me. I think I just gave myself a good virtual kick in the pants and got back on track. If I needed help, I'm sure that could have been arranged. Participant 039_2021AUHRP

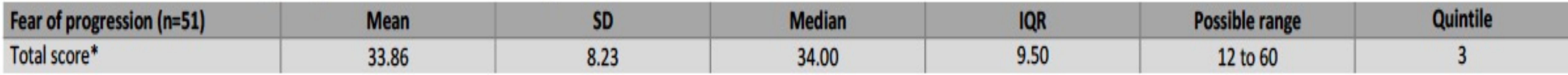
Care and support received (% of all participants)

Section 8

Quality of Life

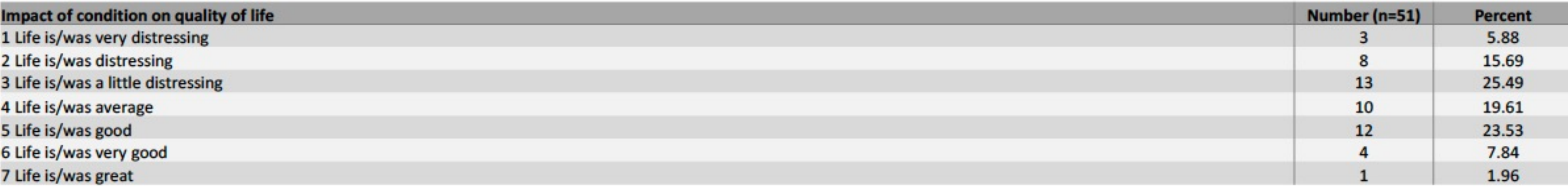
In this section, information is available in relation to the impact that the condition or disease has on quality of life, regular activities to maintain mental health, regular activities to maintain physical health, impact on relationships, impact on family and relationships, cost considerations. The Fear of Progression tool is used and reported here to describe the level of anxiety that participants may have in relation to their condition.

Anxiety (measured by FOP)
Overall quality of life

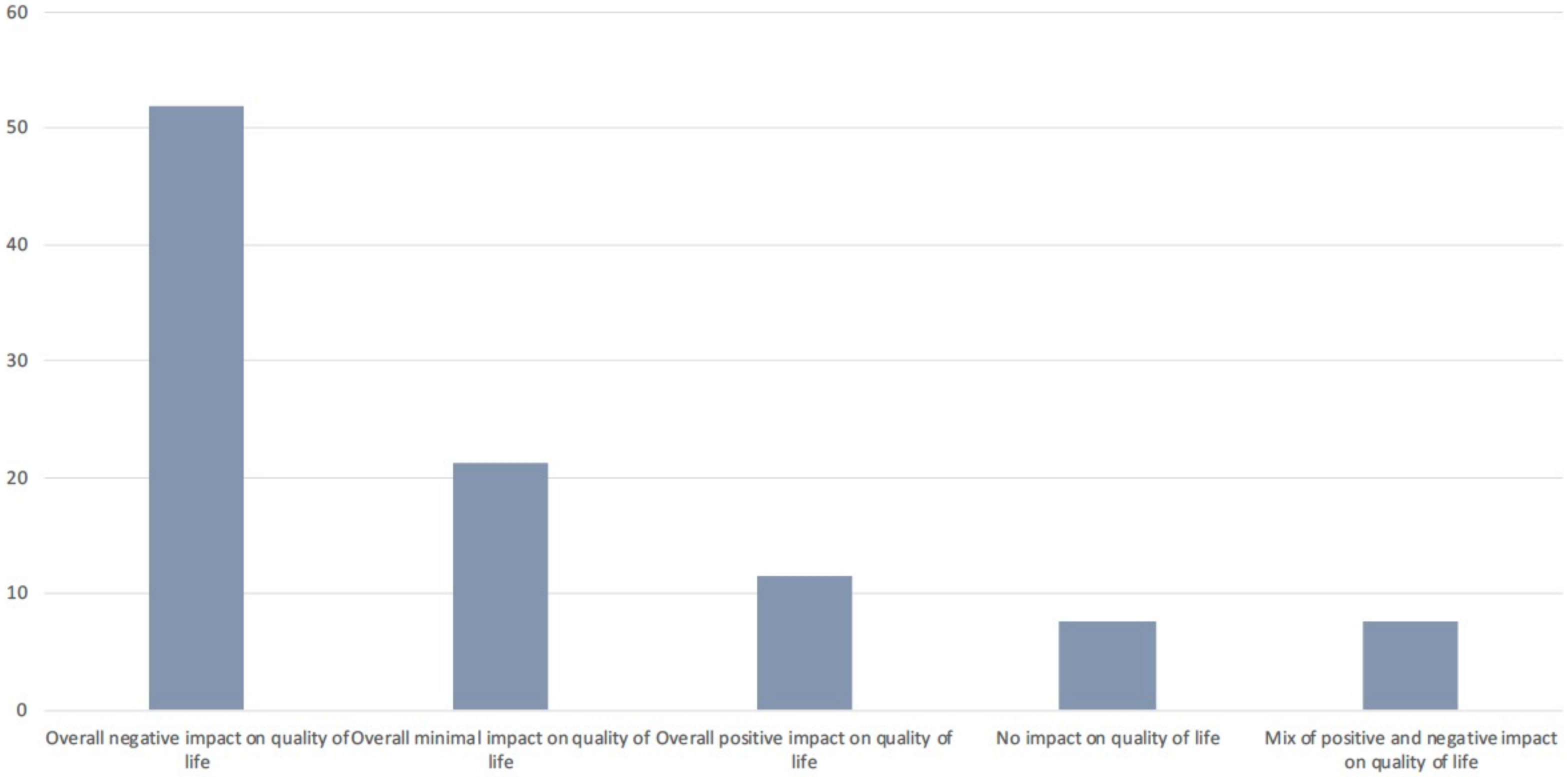


Fear of progression (n=51)	Mean	SD	Median	IQR	Possible range	Quintile
Total score*	33.86	8.23	34.00	9.50	12 to 60	3

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

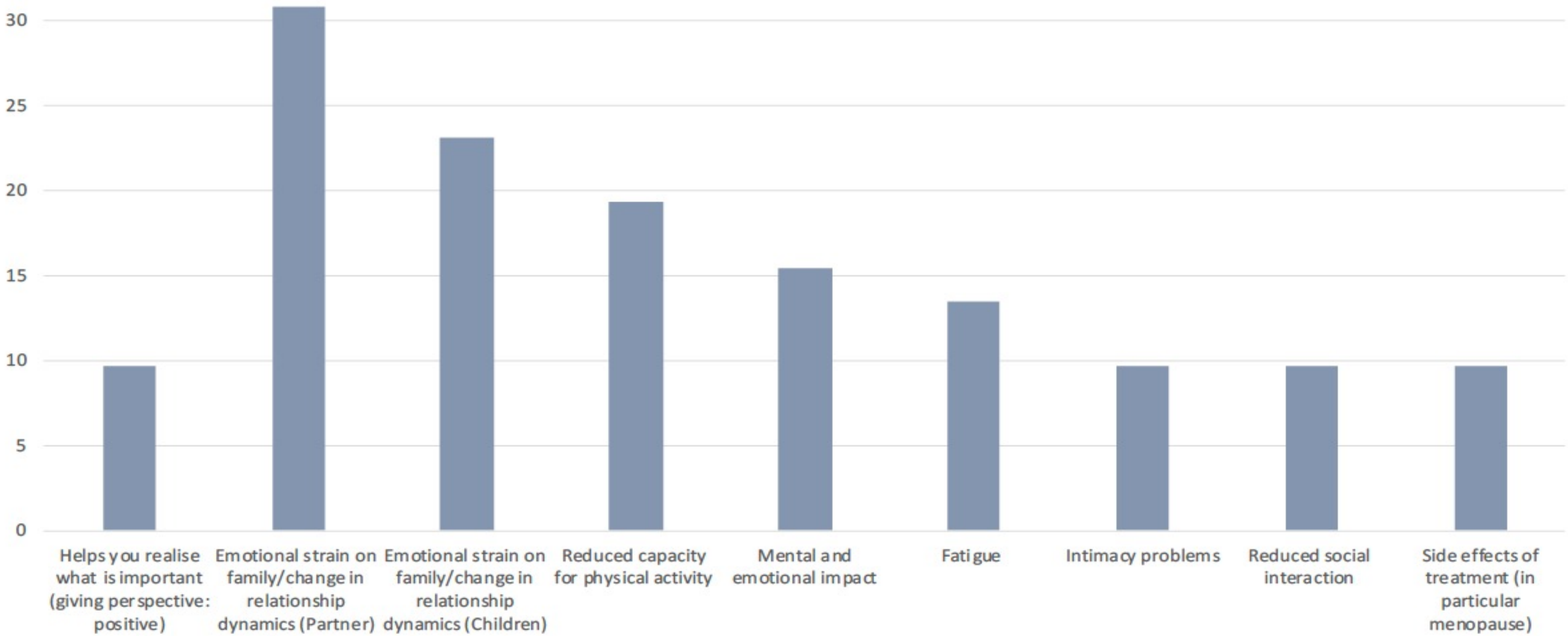


Impact of condition on quality of life	Number (n=51)	Percent
1 Life is/was very distressing	3	5.88
2 Life is/was distressing	8	15.69
3 Life is/was a little distressing	13	25.49
4 Life is/was average	10	19.61
5 Life is/was good	12	23.53
6 Life is/was very good	4	7.84
7 Life is/was great	1	1.96

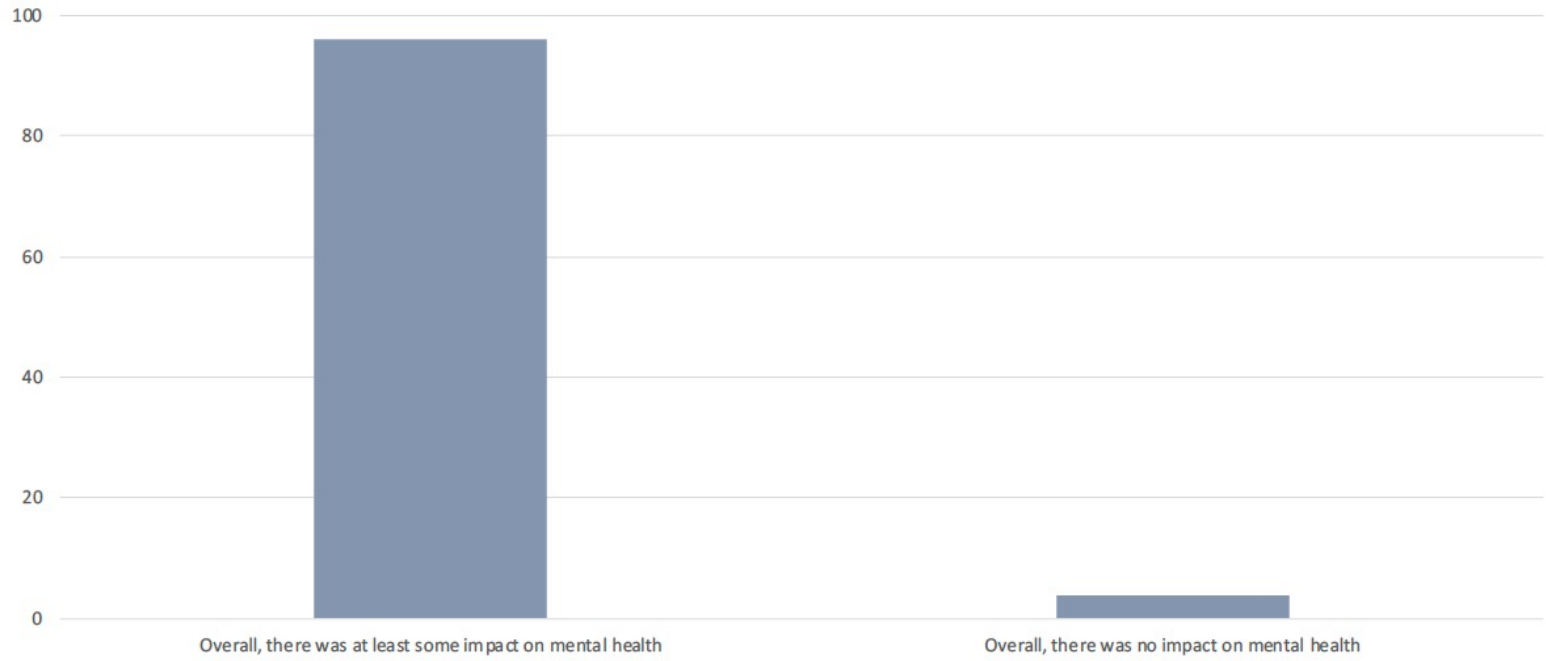


> ***Look, on the emotional side of things, that emotional strain, my husband is still struggling with that. He struggles physically with intimacy. He also struggles with the communication side of things. Just generally, if I get tired or if I have a conversation and halfway through the sentence, I forget what I'm talking about, or what that line of sentence is and such. Participant 031_2021AUHRP***
>
> ***I suppose there's still that element of vulnerability. Even though I've moved on, sometimes I go, "You've had cancer and cancer is a terminal illness. Whether I'm cancer free or not, it's irrelevant. At the end of the day, I have had a cancer diagnosis." That's the way I look at that. I don't dwell on it. I don't feel sorry for myself. I don't wallow. I don't whinge and whine but I've had cancer. Participant 027_2021AUHRP***

Impact on quality of life (% of all participants)

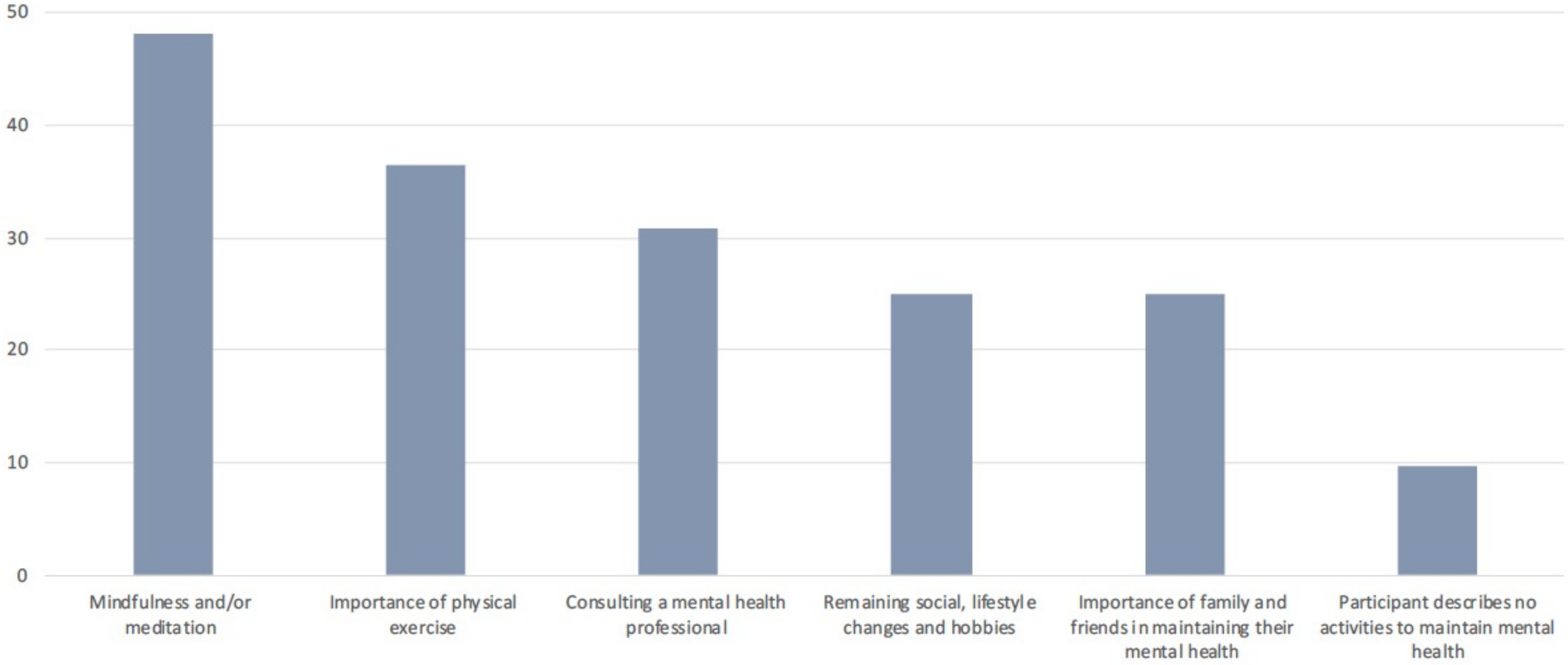


Impact on quality of life (reasons) (% of all participants)

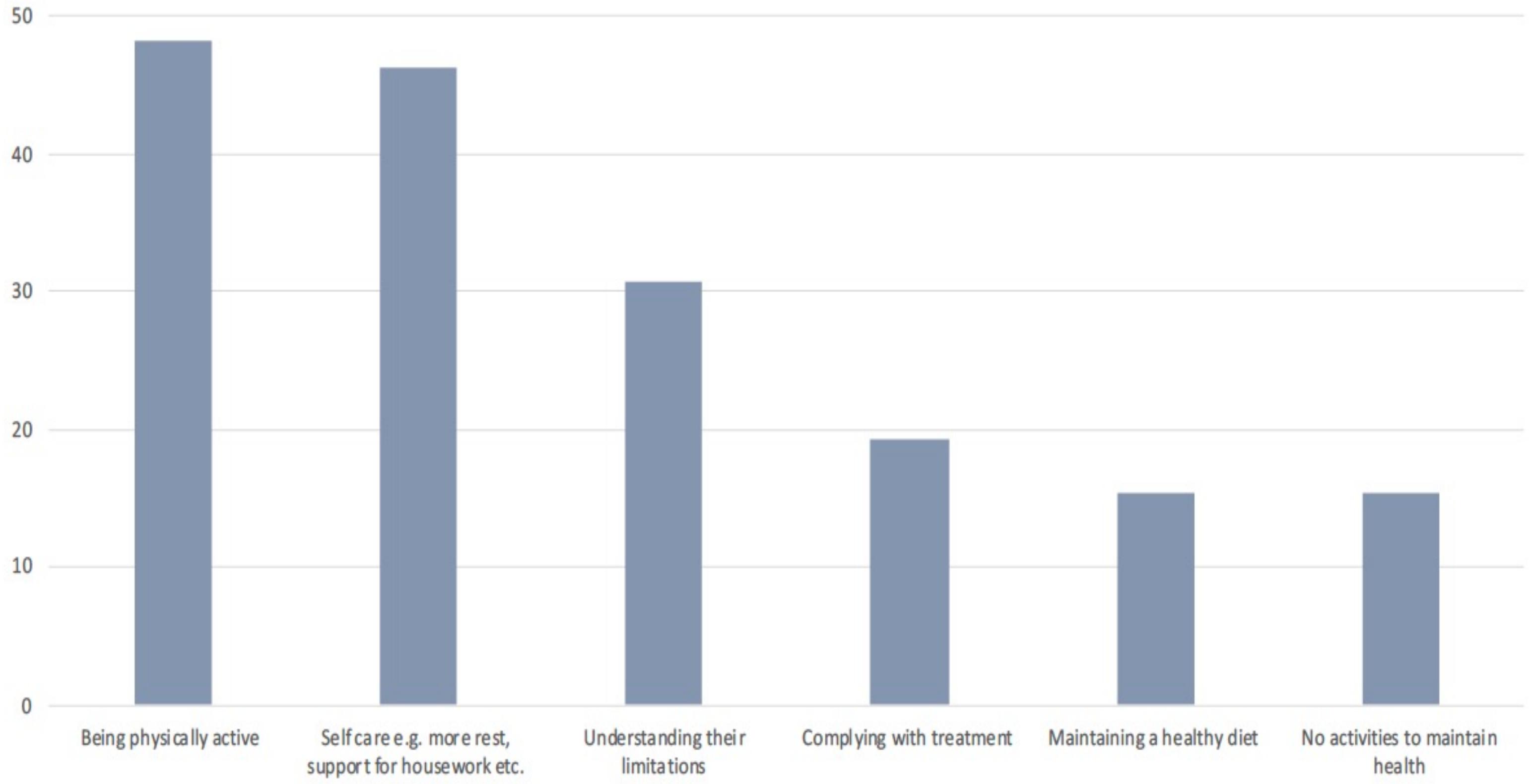


Yes. It has impacted it somewhat. I do yoga and that is not just physical, but mentally and emotionally a benefit. The focus on breathing throughout yoga practice makes a big difference to my mental state, and my emotional state is very calm. Anytime that I'm feeling like I'm struggling a bit and need some zen, [chuckles] that's what I rely on yoga for. Participant 044_2021AUHRP

Impact on mental health (% of all participants)



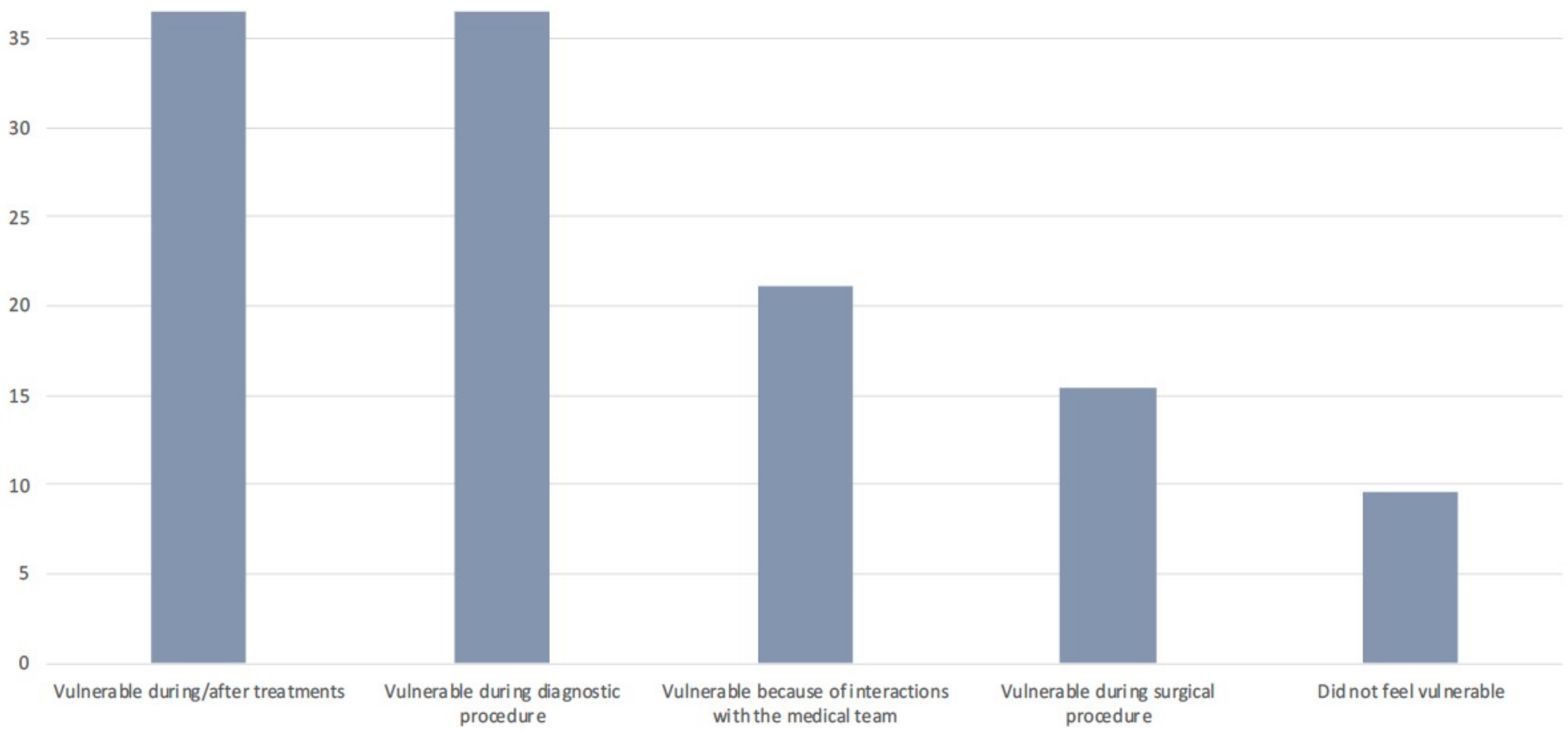
Regular activities to maintain mental health (% of all participants)



Making sure that you're doing everything possible to reduce the chances of it coming back. You're taking medication, getting your exercise, you're also going to really work on having a positive mindset. When those thoughts come into your mind, you've got to have people that you can talk to and things that you can do that can reduce that stress and reduce that. Just be able to talk through this with people and get that rational response. There's definitely a need to be able to talk to people and do things that are going to reduce that stress. Participant 037_2021AUHRP

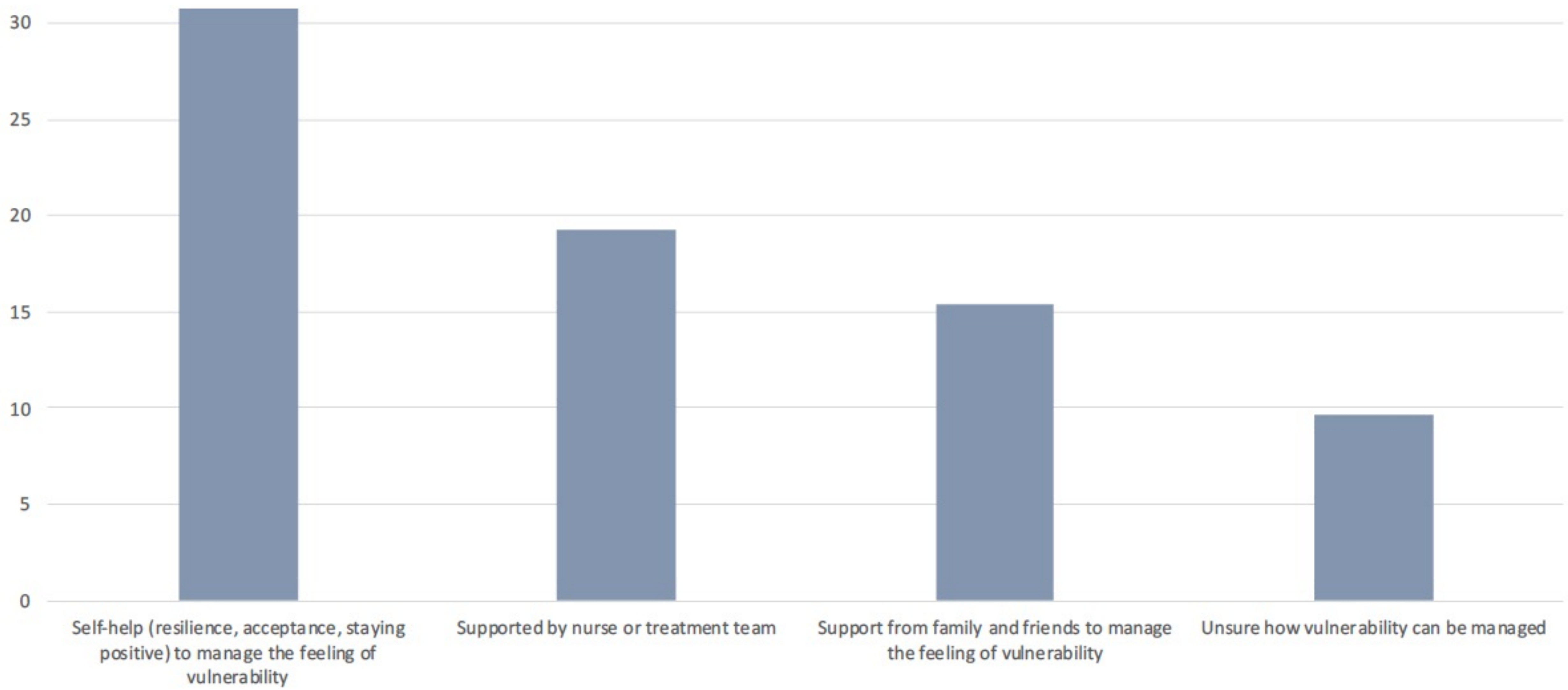
Regular activities to maintain general health (% of all participants)

Vulnerability
(% of all participants)



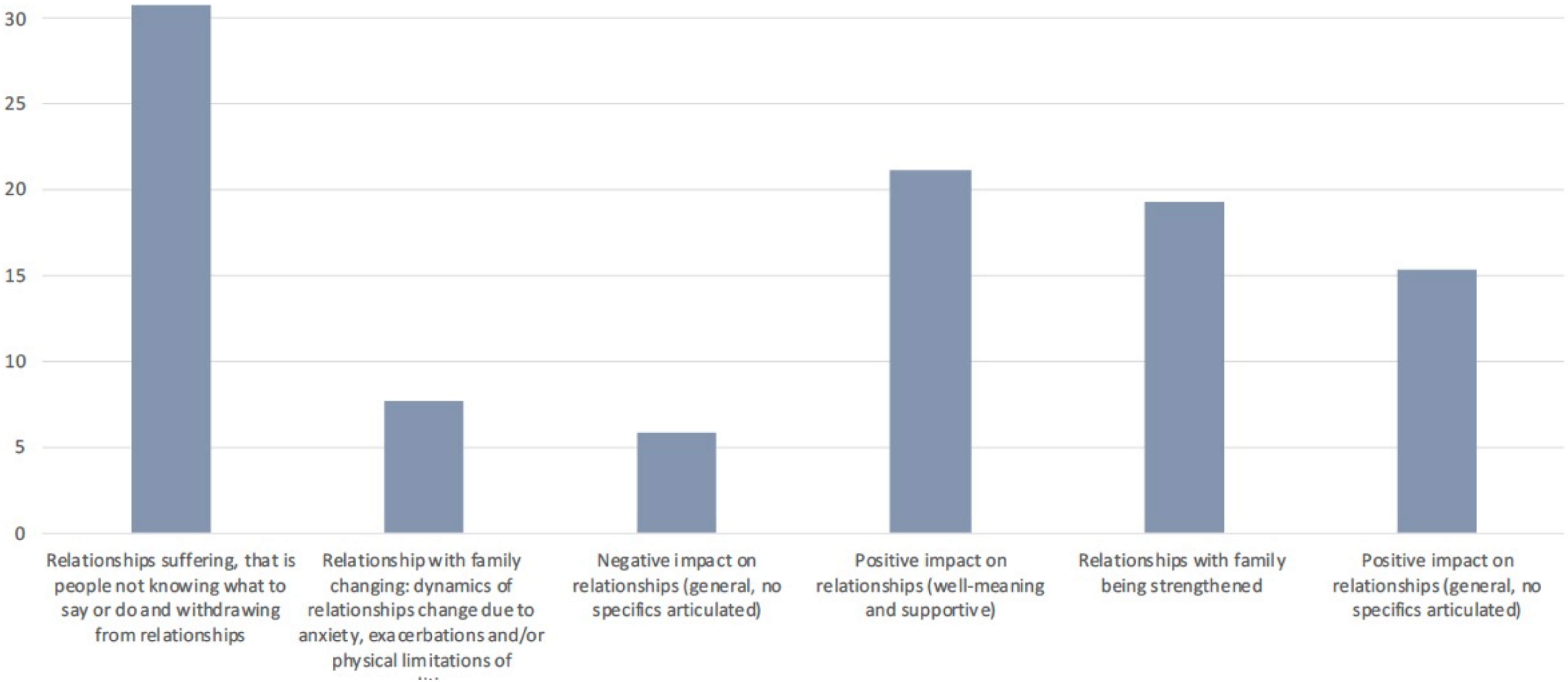
Yes. With the medical oncologist that I had. She was almost menacing. When I actually suggested that I didn't want to take medication, she went, "I knew it, should have just given you chemotherapy." I walked out, I burst into tears. I went, "Oh my God, so mean." Then being on the drugs, of course, your hormones are suppressed, you'll gain weight. You don't have a choice. I'm a size 12. I'm not a big, huge girl. She'd make comments and say, "Oh, you're getting fat." I'd be like, "Oh my God, you're so not helpful." Participant 038_2021AUHRP

Going to theatre. That sitting in a bed waiting to go to the theatre, just wanting to run and knowing that you can't. Participant 011_2021AUHRP

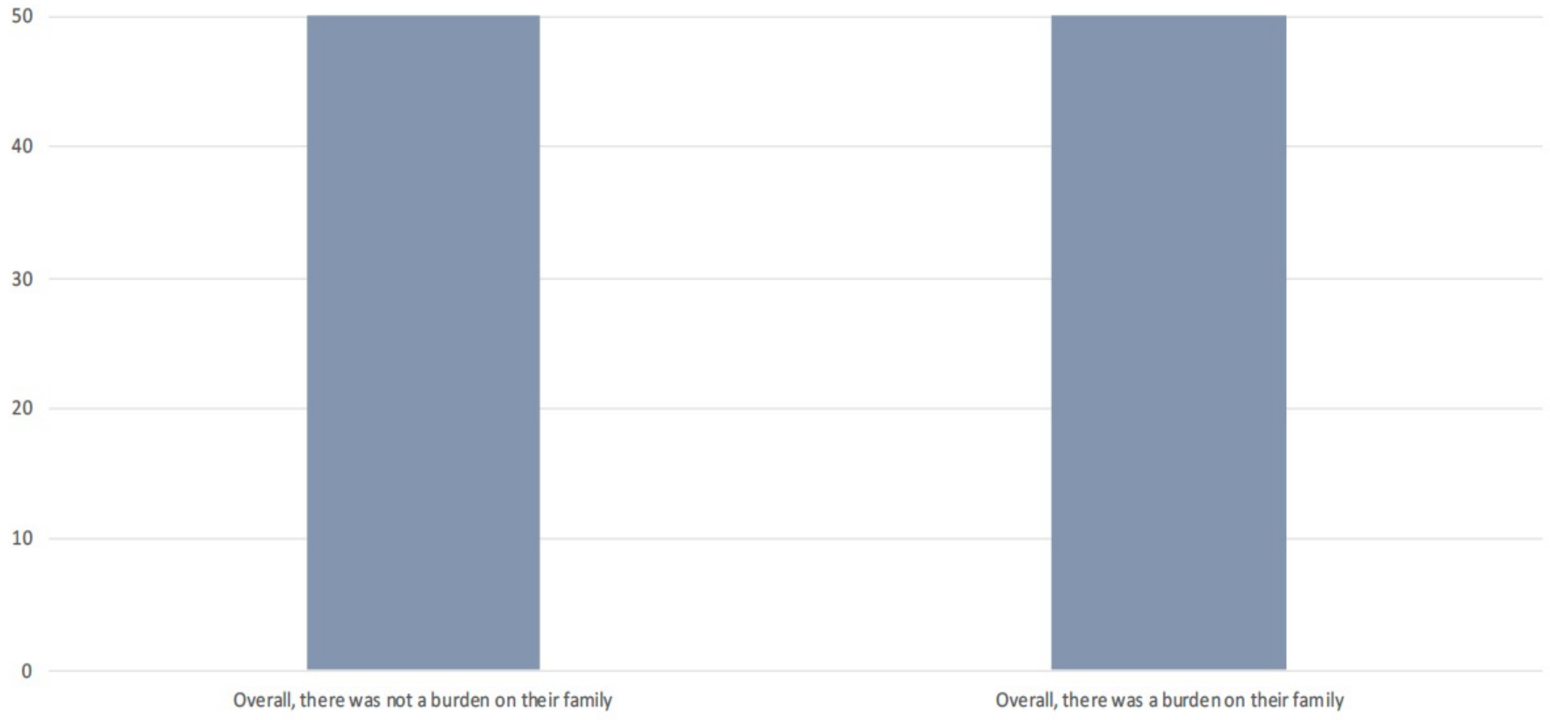


Methods to manage vulnerability

(% of all participants)



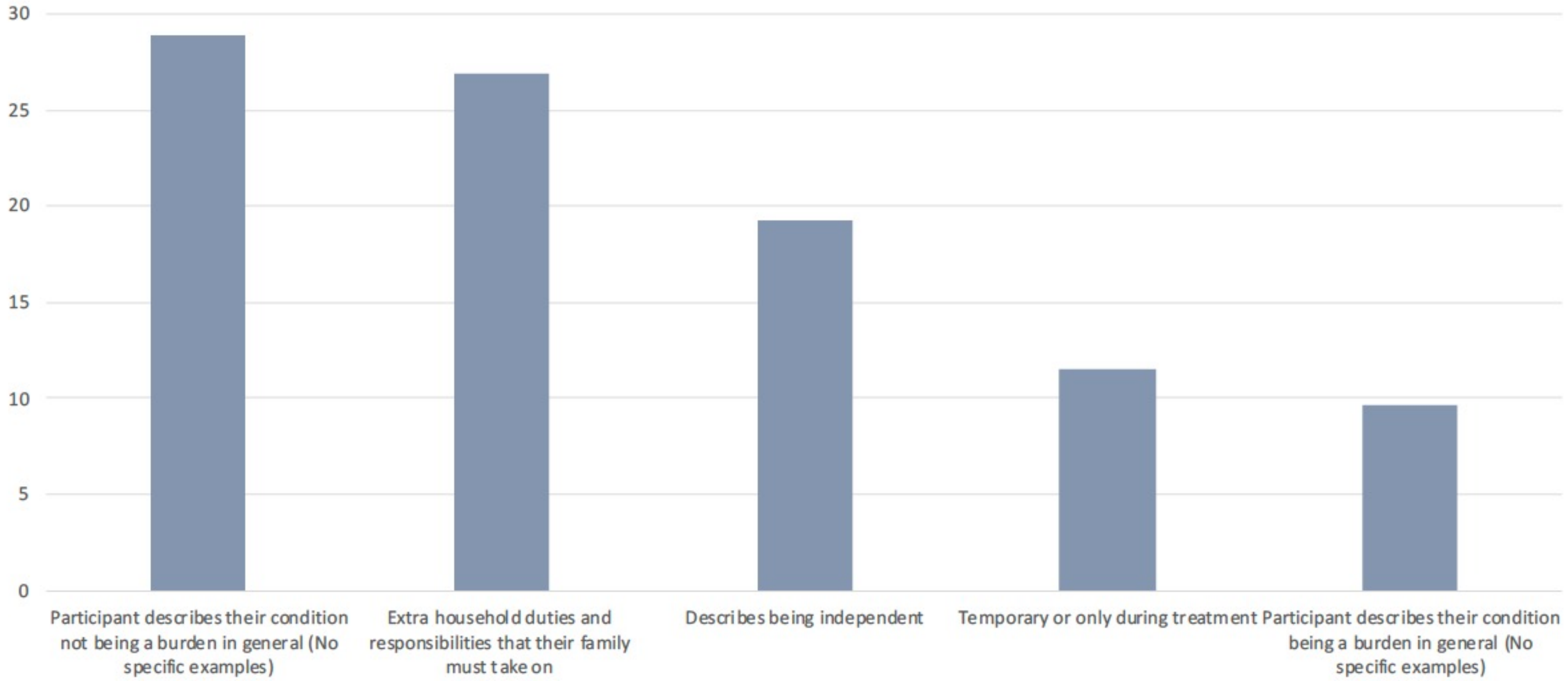
Impact on relationships (% of all participants)



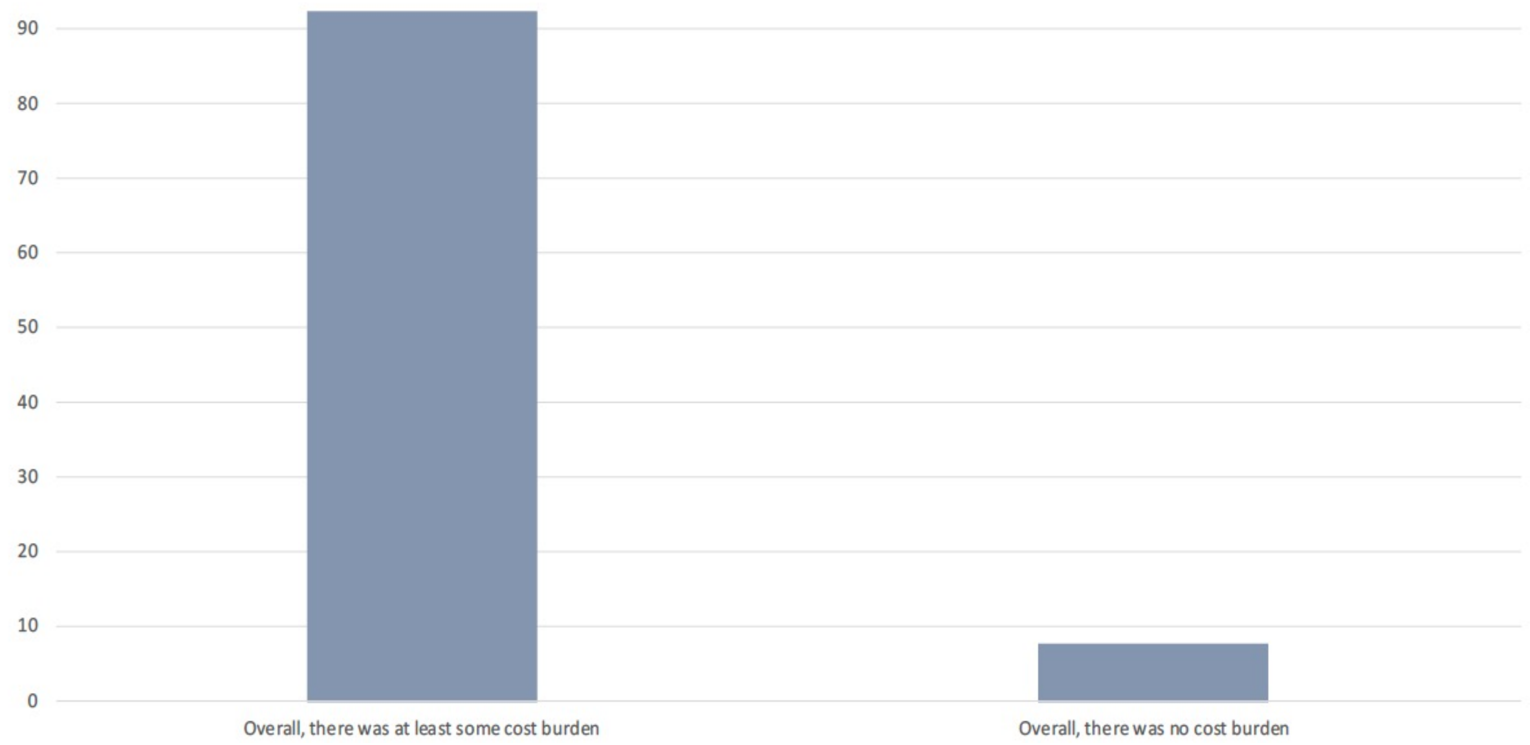
No, I think that I'm probably more likely now to ask my husband to carry the washing out the washing line for a meal or two things. But he's a man that's always wanted to do those things. But in the past, I've always felt able to do them. But no, I was trying to ask him to to give me a hand. Participant 019_2021AUHR

A little bit, but we've also been out of work, we've been able to get through it and we're coming to the end of it now. We've been okay. Participant 042_2021AUHRP

Burden on family
(% of all participants)

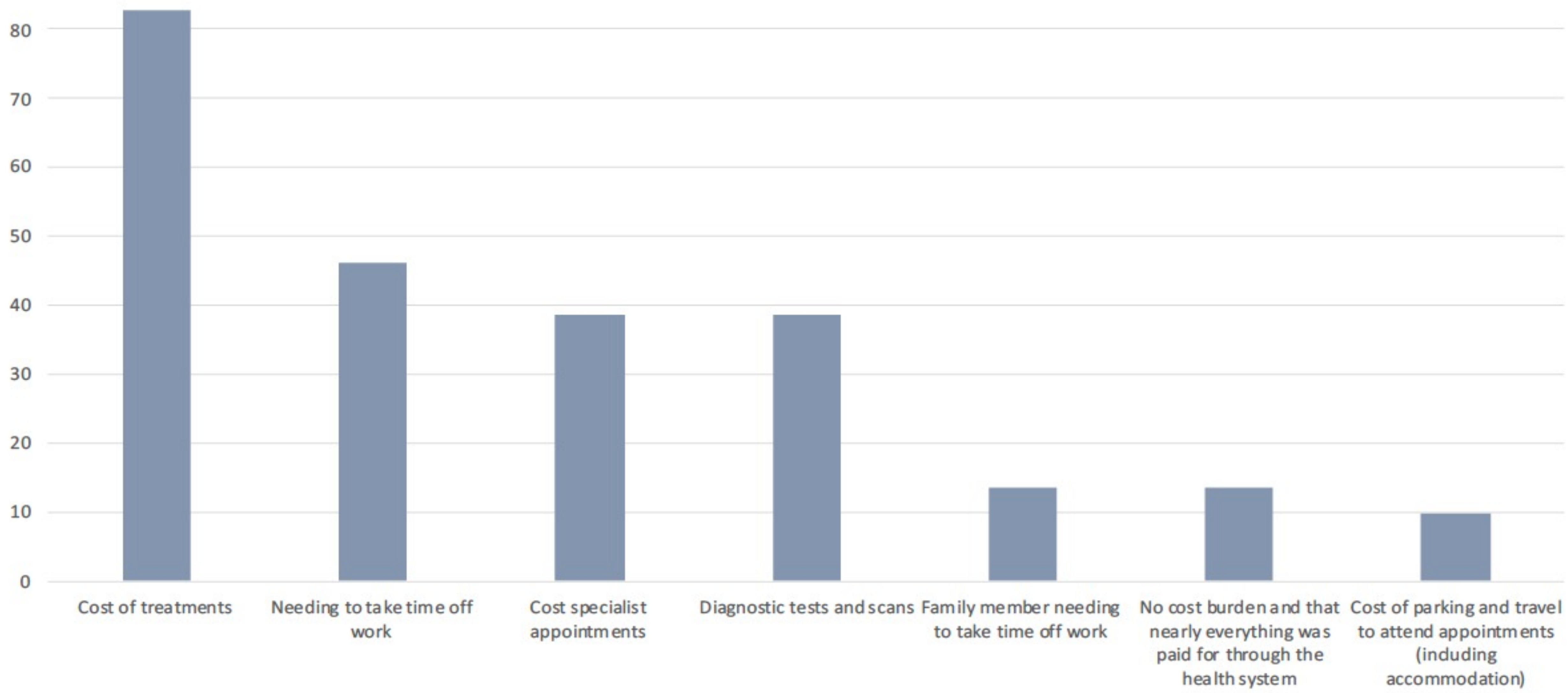


Burden on family (% of all participants)



I think that it's not cheap to get cancer, that's for sure. I was overwhelmed by the information that I had sent to me via the email from my breast surgeon after I saw him. So I received some of the possible figures of how much his fees would be, anaesthetic fees, the hospital, all of those things. And so they came hard and fast. And so I think coping with the unexpected diagnosis, coupled with having all of the cost, I was overwhelmed by it. You know, I was concerned by it. And I mean, I was reassured by my husband, who said, look, you know, we have to do this and don't think about it. But I'm the money manager in the house, so I was concerned. Having said that, I didn't, regardless of how much it was going to cost, I wasn't going to go through the public system because I wouldn't have had any form of control about my choices in the public system. Participant 019_2021AUHRP

Cost considerations
(% of all participants)



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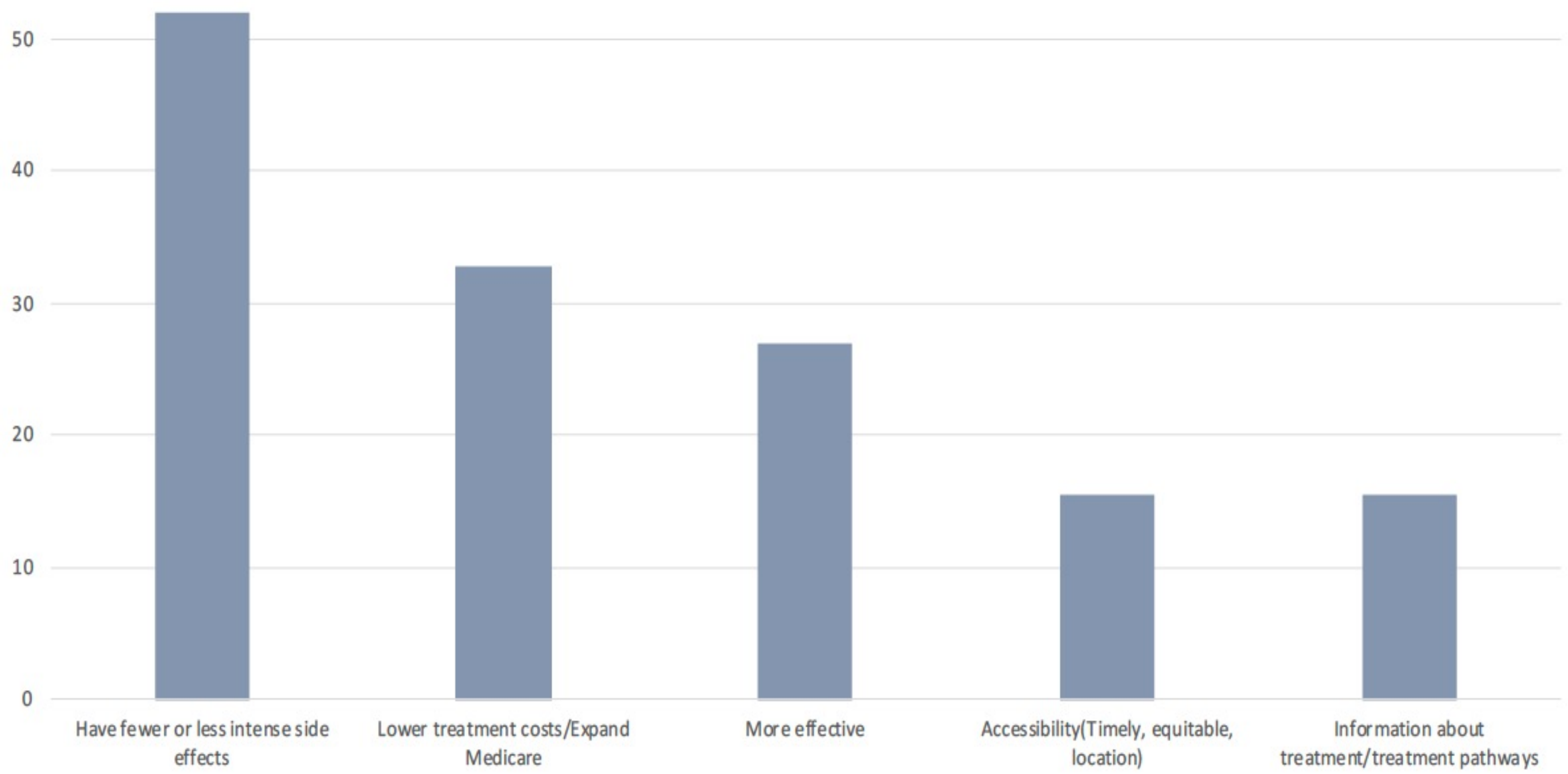
Cost burden (% of all participants)

Section 9

Expectations
&
Messages to Decision-Makers

By the time participants are asked questions about their expectations of the future, they have had the chance to talk about everything that they have been through. It means that they have been able to reflect on what worked for them and what was potentially not so great. In this section there is information about what participants would like to see from future treatments, information, care and communication. We present the cohorts message to decision-makers about their condition and the values that are important to them when they make decisions about treatment and care. In this section there is also information about what people have been grateful for.



I guess, the holy grail would be the hormone blocker that didn't cause menopause in the rest of the body. The true breast specific hormone blocker would be fantastic because it would just reduce the side effects and not leave you with that decision to make between maintaining your future health and given your cancer. Participant 005_2021AUHRP

They probably do need to look at the medication that they want you on for the next five years and how to make that much better for women. I feel sorry for some of the younger women though they got to be pushed into early menopause and all of that stuff at least I don't have to do that. Really been there done that sort of thing. Participant 030_2021AUHRP

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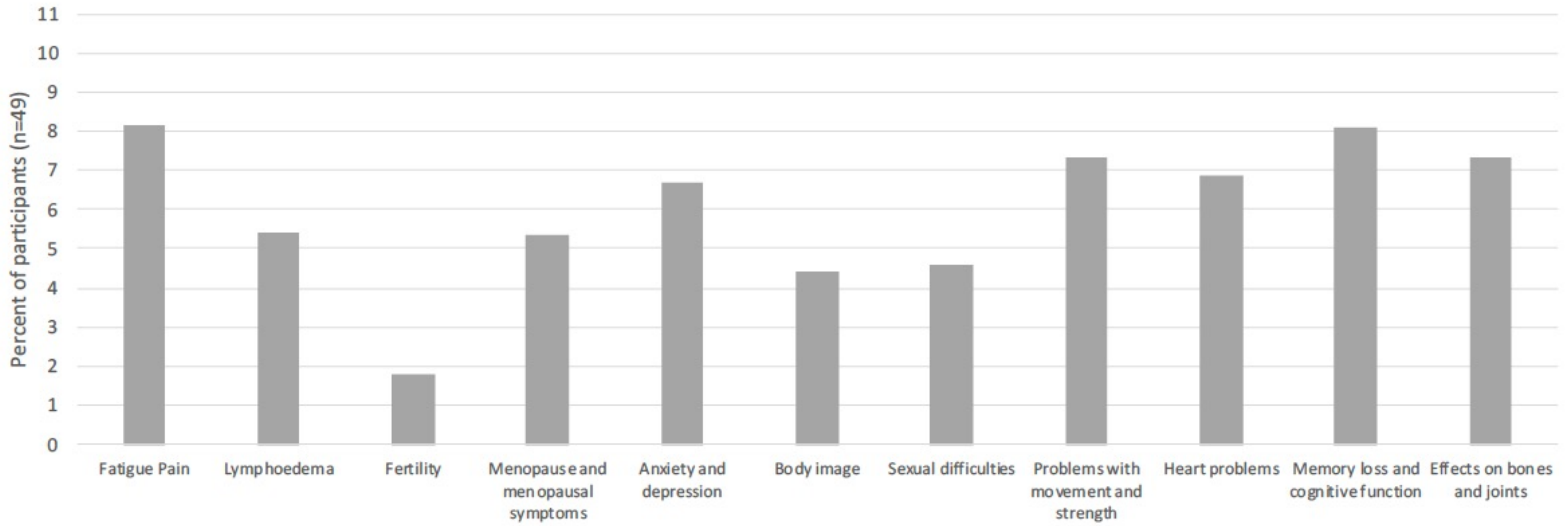
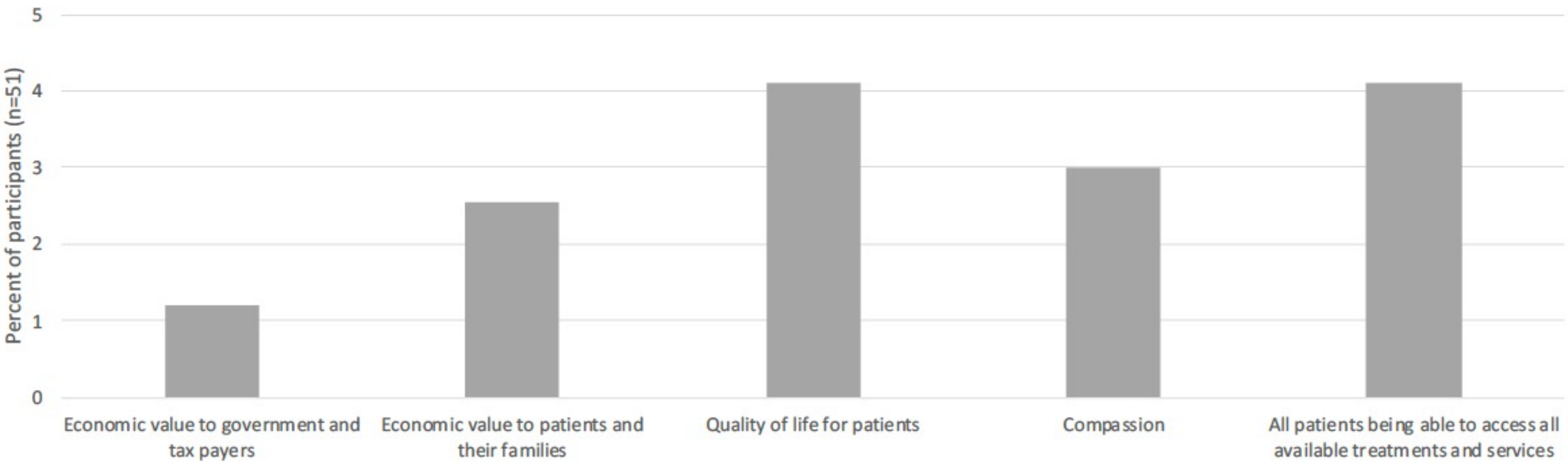
Expectations of future treatments (% of all participants)



Symptoms and aspects of quality of life



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

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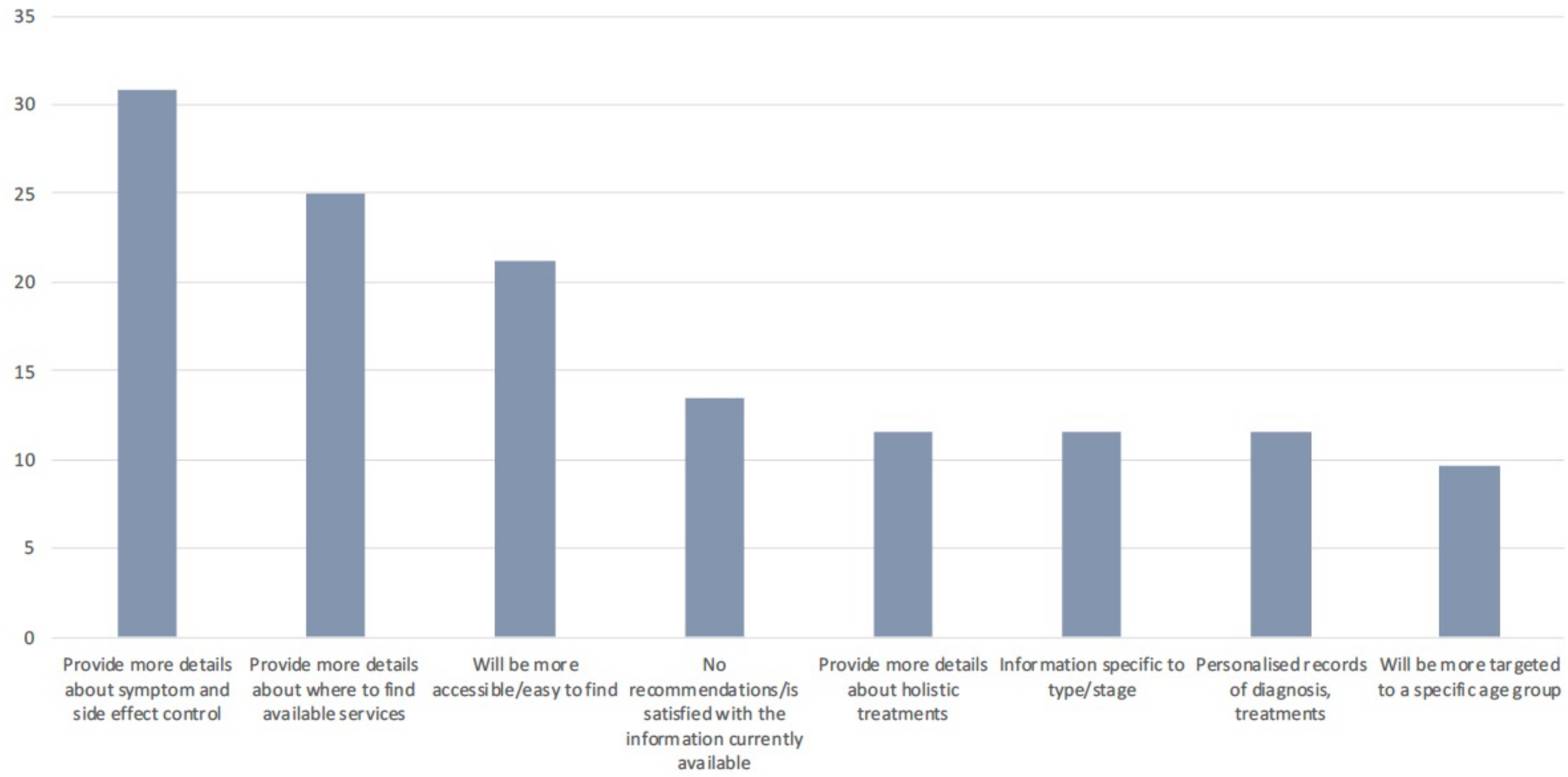
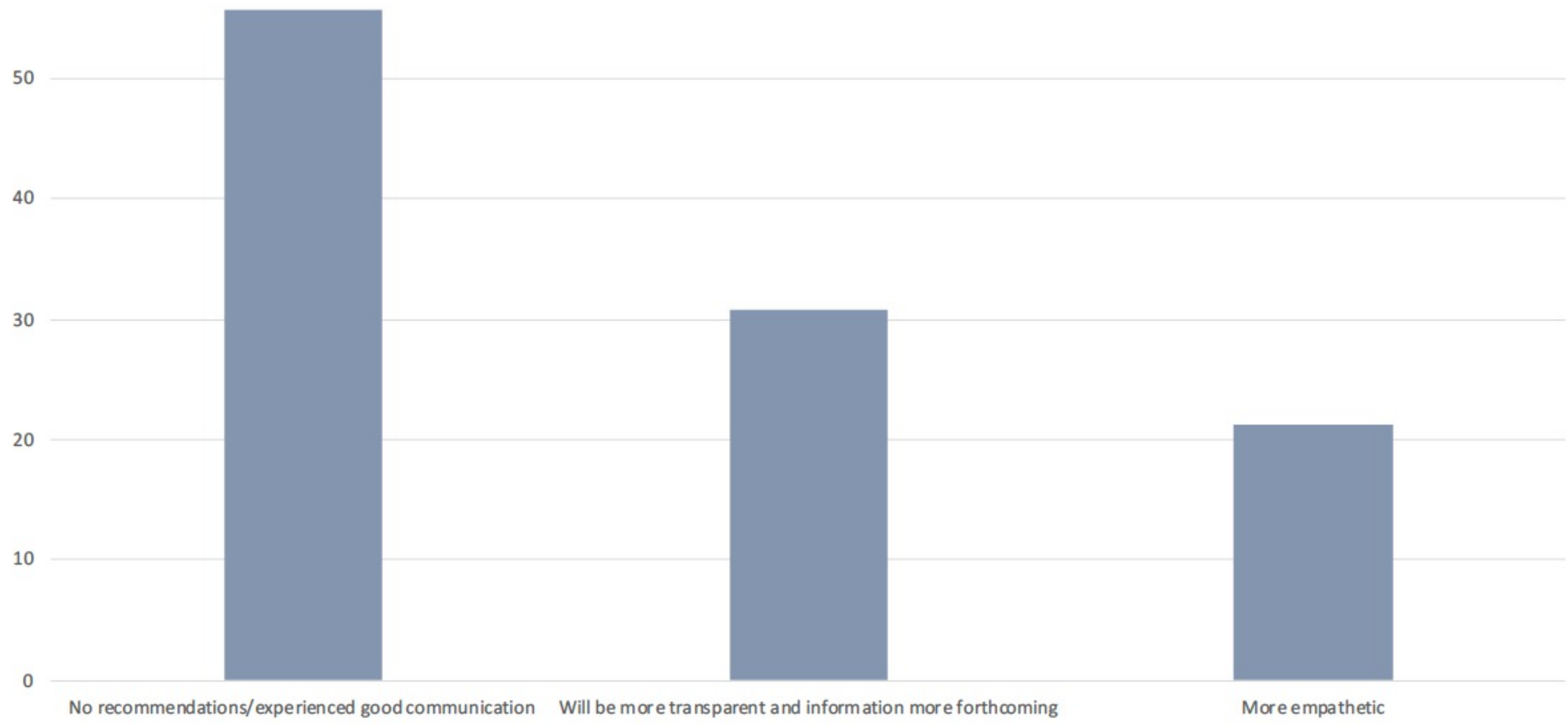
Values for decision to consider



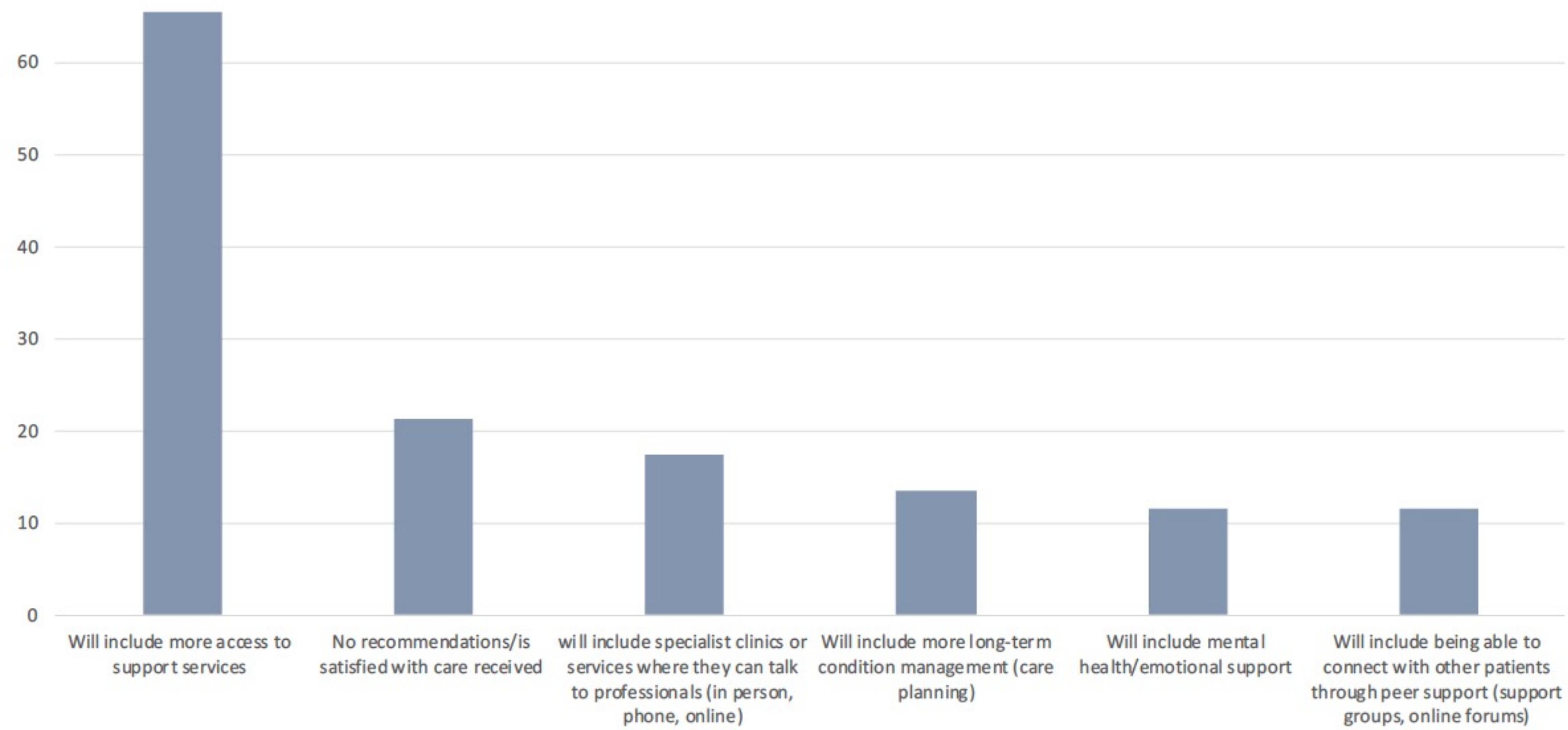
> *I think probably the issue with the nerve. The nerve pain that you actually get, but not everybody gets. That's something I had no idea about. Even with all my 40 years nursing experience, I had never heard anybody say anything about the nerve pain, and maybe that's because mostly it doesn't happen until you actually leave hospital. It wasn't actually until I'd got home and been home for a day or two that it started. That may be because of the local anesthetics and all that that are put in when you have the surgery maybe, and you don't feel it. That's probably something that people should be told about and given ways to deal with it, rather than-- It was a week later before I actually-- When I went and saw the breast care nurse a week later, and she told me what had to be done to relieve it, which was basically massaging it, which was excruciating. Participant 017_2021AUHRP*

Expectations of future information (% of all participants)



I think the only really negative experience was when the receptionist called me. It was literally a one-minute conversation of your tumours are not benign, you need to see a surgeon. In my mind, benign means non-cancer but not non-cancerous, and this call came at six o'clock on a Thursday night. Again, it was a receptionist. I could not marry that up in my mind. Now, I had an appointment with my GP the next morning at 11:00. When I got her on the phone, it seemed very disconnected because she was like, "Hello, how can I help you today?" I'm like, "Well, I got a call last night and I wanted to get my results." Participant 007_2021AUHRP

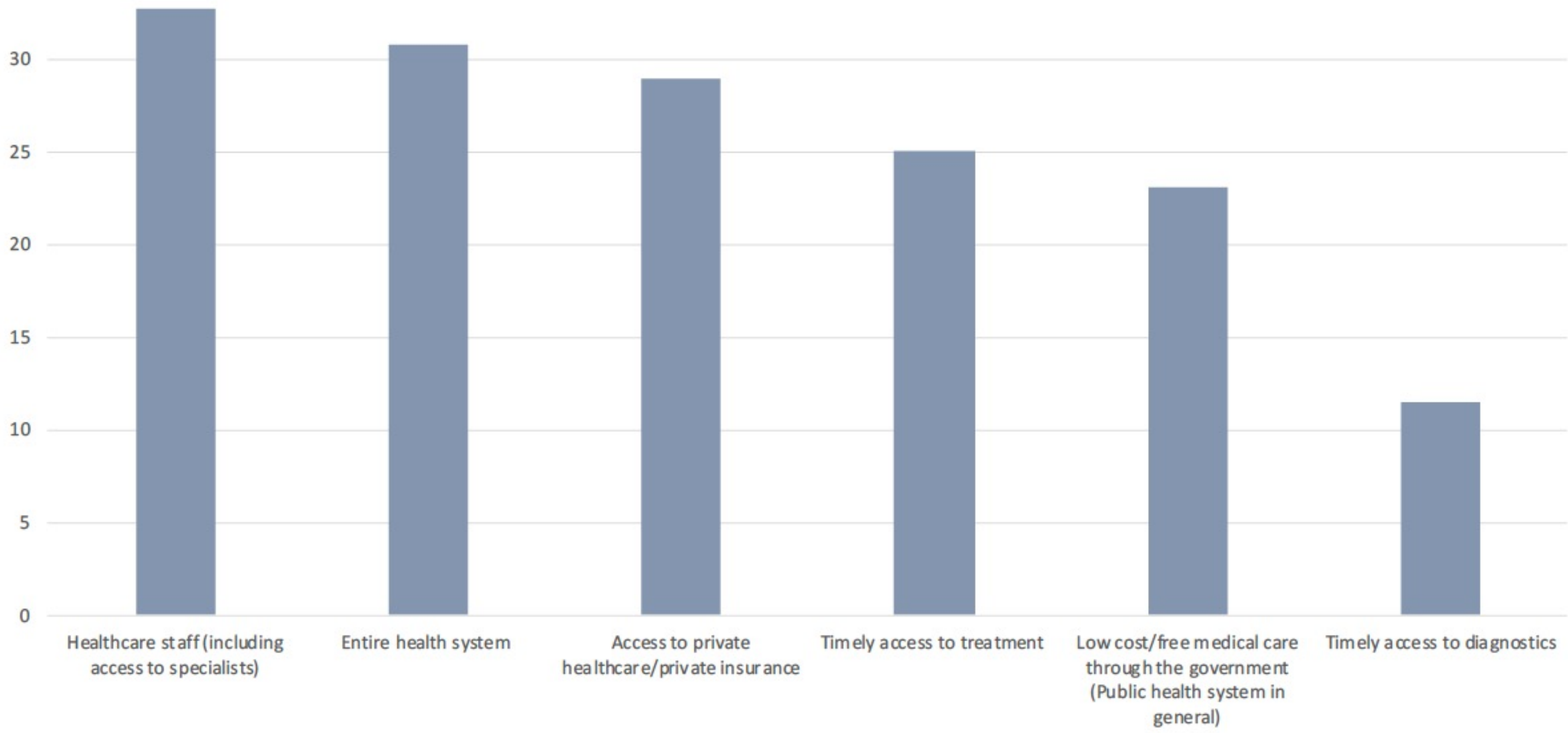
Expectations of future communication (% of all participants)



Just probably more calls just to check up on people. Some kind of liaison service so people just know that someone's thinking of them just, "Oh, how did your treatment go today? How are you feeling today?" It doesn't have to be a lot, but just someone touching base every now and then. Participant 038_2021AUHRP

Yes. As I said, the financial assistance is very tough on people. I wouldn't even know where to start with all of that, but everything was always there apart from-- Everything was always at your fingertips, I think, in the sense of, if you needed help with something, you could still speak to someone. The oncologists are really, really good where if you were struggling with something, they would pass you on to someone. Like I said, I was quite happy. Participant 008_2021AUHRP

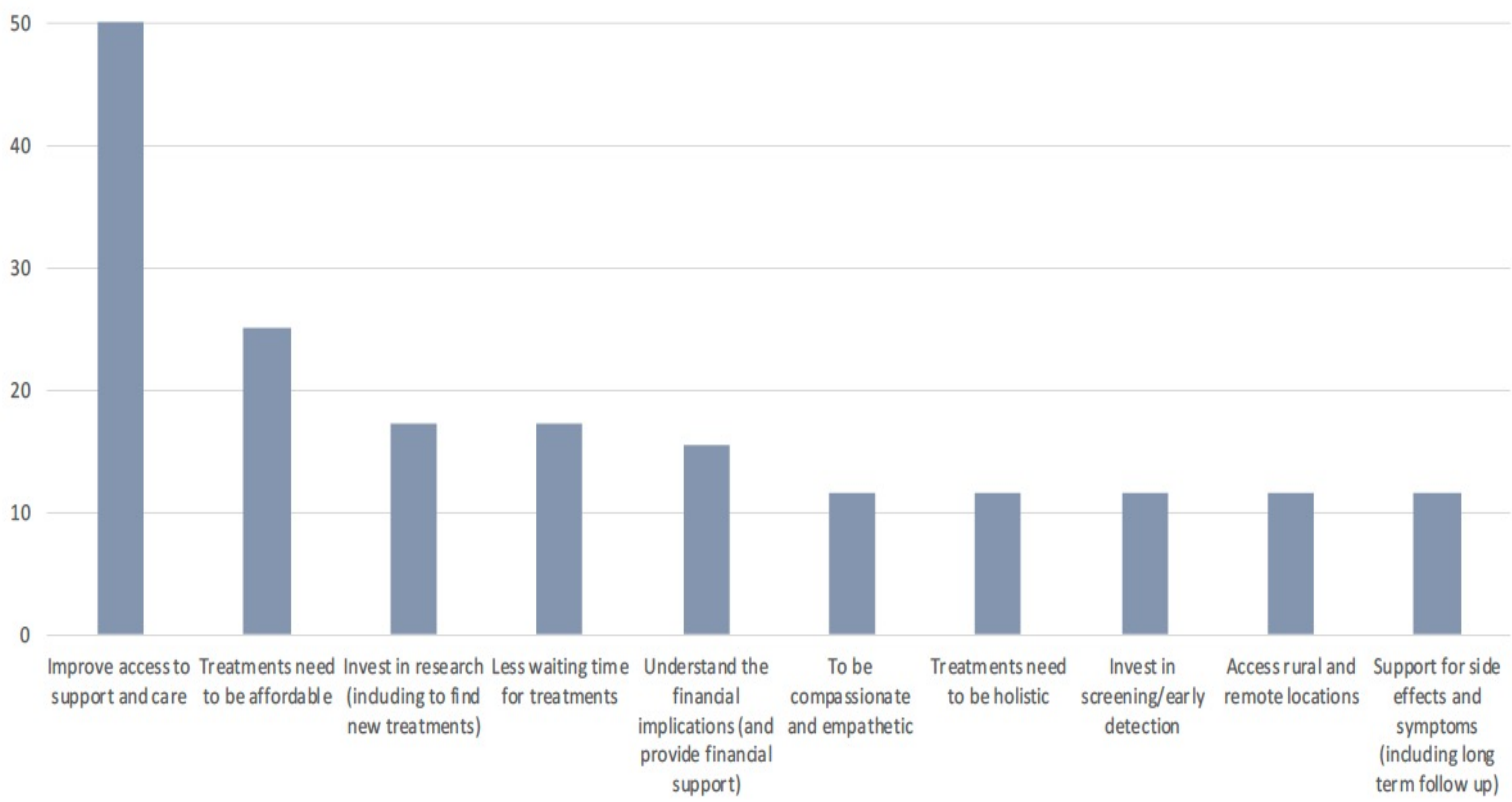
Expectations of future care and support (% of all participants)



The people, particularly the experts, with the specialists. The good treatment that I've had, that I've had access to. The patience that they had with me in terms of-- I think it's not easy being a doctor because a doctor-patient for other doctors because you know stuff. My GP is brilliant in that regard at giving me information at the right level. Treating me like a patient who has some knowledge. I've just been really grateful for the people whose care I've been under. Participant 011_2021AUHRP

All of it. Absolutely all of it. From my GP, getting an appointment for me the next day at the hospital with the surgeon that I need to see to have all this done. All of it, I'm grateful for all of it. I had no idea that our public system was as good as this, but it is a really good system. When you really need it, it does the job. Participant 044_2021AUHRP

What participants are grateful for in the health system (% of all participants)



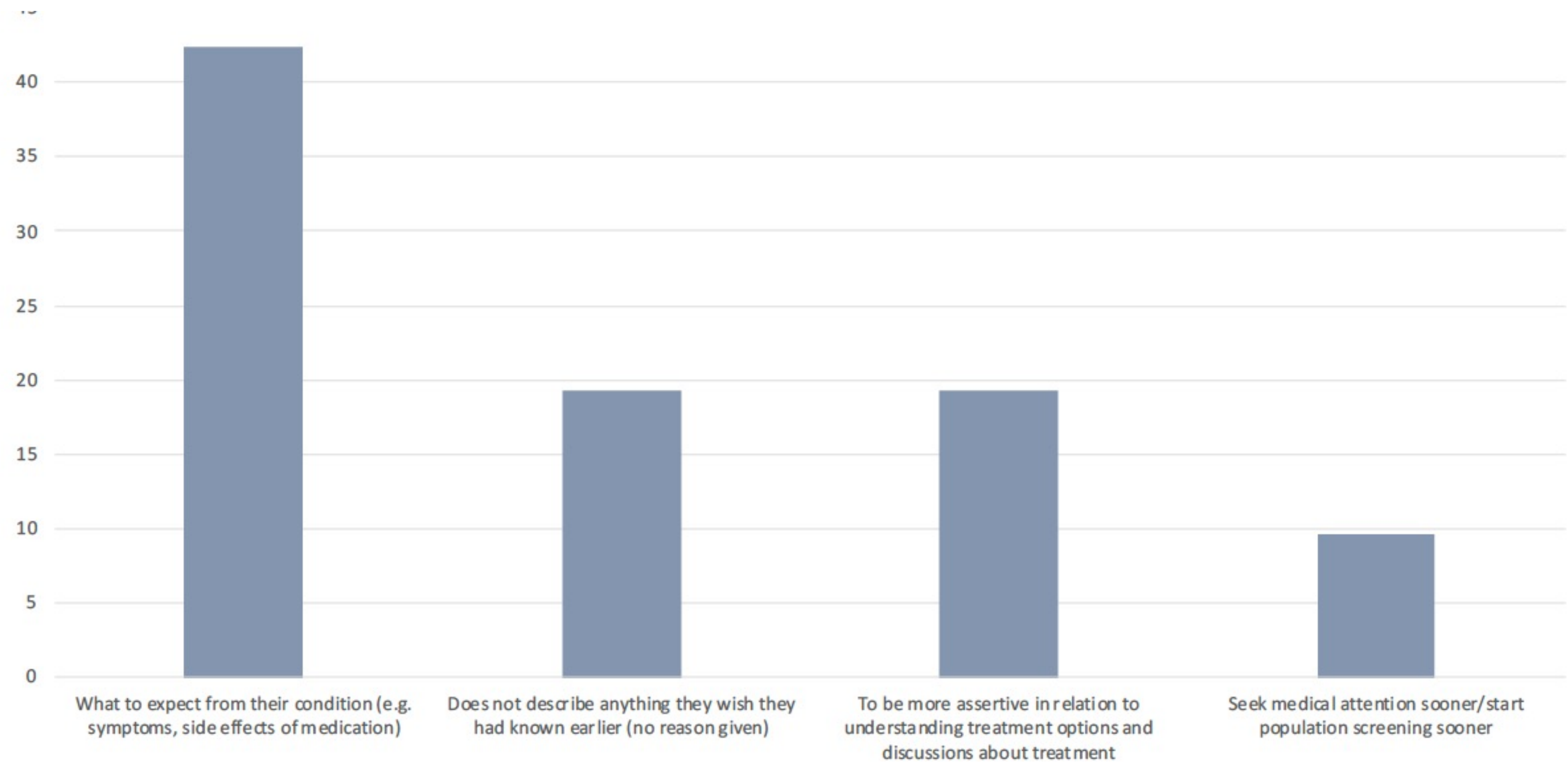
I would just implore them to think about it as if it was their loved one going through the treatment, what would they want for their loved one? Would they want easy access, do they want financially, are they able to afford it or they have to go through the public system, and if they go through the public system, do they have to wait? Is that wait going to impact on the prognosis? Pretty much just-- Imagine that it was you going through it, what would you want? Participant 025_2021AUHRP

Message to decision-makers (% of all participants)

Section 10

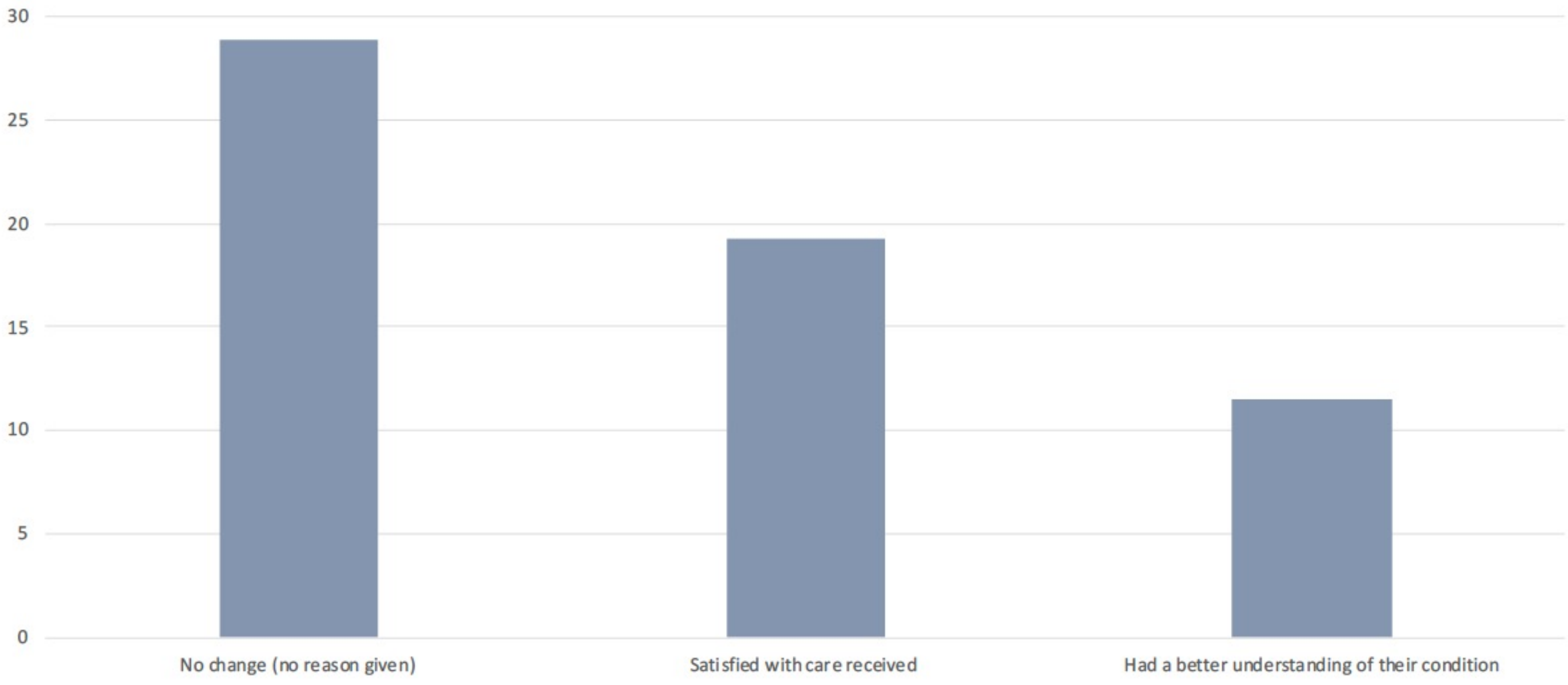
Advice from current patients
to
patients in the future

In this section we present the response to the question 'what is your advice to other people who are diagnosed in the future?' This gives participants the chance to impart knowledge and for patients to feel connected with others in the community.



I guess the thing that dawned on me the slowest of all is how long the journey is. When you're first diagnosed, it's sort of this is the problem that I've got to work out how to tackle it, and then you're like, "Well, okay, you can deal with it and I'll be back to normal in a month," it's like no. Three months? No. Six months? No. Actually, it's 15 years. It will be 15 years from diagnosis when I finally stop treatment. I think the thing that I probably know now that I think it would've been-- I don't know it would've been good to know then, but perhaps the thing that I was really thinking at first was that this is a chronic slow treatment process. It's going to go on a long time. Participant 005_2021AUHRP

Wish they had known earlier (% of all participants)



Probably it's the way sometimes they speak as I think I mentioned earlier and sometimes you're not quite a person that can be a bit frustrating angering to get angry but I did find I really had to push to get all the information I wanted. So they kept trying I think to protect me from overwhelming me but when I'm asking for it, yeah. I because I'm ready it's because it's what I want I think again, that's not treating everyone the same. Participant 045_2021AUHRP

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Anything to change about treatment or care (% of all participants)