

Section 5

Treatment

Section 5: Experience of treatment

Main provider of treatment

The most common provider of treatment and care were medical oncologists (n = 26, 50.00 %), followed by specialist surgeons (n = 15, 28.85%).

There were 13 participants (25.49%) that travelled for less than 15 minutes, 23 participants (45.10%) that travelled between 15 and 30 minutes, nine participants (17.65%) that travelled between 30 and 60 minutes, two participants (3.92%) that travelled between 60 and 90 minutes, and four participants (7.84%) that travelled more than 90 minutes.

Access to healthcare professionals

Almost all participants had access to a medical oncologist (n = 49, 94.232%), and a specialist surgeon (n = 49, 94.23%) for the treatment and management of breast cancer. There were 43 participants (82.69%) that had a radiation oncologist, 43 participants (82.69%) that had a general practitioner (GP), and 42 participants (80.77%) had a breast care nurse, and 30 participants (57.69%).

There were 30 participants (57.69%) cared for by a oncology or chemotherapy nurse, 28 participants (53.85%) treated by a physiotherapist and, 25 participants (48.08%) with a pharmacist. Almost half of the participants had a lymphoedema practitioner to care for their condition (n = 24, 46.15%).

Health care system

The majority of participants had private health insurance (n = 41, 80.39%). The majority of participants were not asked if they wanted to be treated as a public or private patient (n = 31, 60.78%), however, they were asked if they had private health insurance (n = 44, 86.27%).

Throughout their treatment, there were 29 participants (56.86%) who were treated as a private patient, 13 participants (25.49%) were mostly treated as a public patient, and there were nine participants (17.65%) who were equally treated as a private and public patient.

Throughout their treatment, there were 25 participants (49.02%) who were treated mostly in the private hospital system, 11 participants (21.57%) were mostly treated in the public system, and there were 15 participants (29.41%) who were equally treated in the private and public systems.

Affordability of healthcare

Almost all the participants never or rarely had to delay or cancel appointments due to affordability (n = 48, 94.12%).

Almost all of the participants never or rarely were unable to fill prescriptions (n = 47, 92.16%).

There were 45 participants (88.24%) that never or rarely had trouble paying for essentials such as such as food, housing and power., and four participants (7.84%) that sometimes found it difficult.

There were 8 participants (15.69%) that paid for additional carers carers for themselves or for their family due to their condition.

Cost of condition

Participants estimated the amount they spend per month due to their condition, including doctors' fees, transport, carers, health insurance gaps and complementary therapies. The most common amount was between \$101 to \$250 (n = 15, 29.41%), followed by between \$251 to \$500 (n = 8, 15.69%). There were four participants (7.84%), who spent \$1001 or more a month.

The amount spent was an extremely significant or moderately significant burden for 12 participants (23.53%), somewhat significant for 12 participants (23.53%), and slightly or not at all significant for 27 participants (52.94%).

Changes to employment status

Work status for 10 participants (19.61%) had not changed since diagnosis, and eight participants (15.69%) were retired or did not have a job. There were eight participants (15.69%) that had to quit their job, 15 participants (29.41%) reduced the number of hours they worked, and three participants (5.88%) that accessed their superannuation early. There were 11 participants (21.57%) that took leave from work without pay, and 10 participants (19.61%) who took leave from work with pay.

Changes to carer/partner employment status

There were 11 participants (21.57%), without a main partner or carer. Most commonly, participants had partners or carers that did not change their work status due to their condition (n = 24, 47.06%). There were four participants (7.84%) whose partners reduced the numbers of hours they worked, and no partners of participants had to quit their job. The partners of two participants (3.92%) took leave without pay, and there were 10 partners (19.61%) who took leave with pay.

Reduced income due to condition

More than half of the participants (n = 27, 52.94%) indicated in the online questionnaire that they had a reduced family income due to their condition.

Most commonly, participants were not sure about the amount their monthly income was reduced by (n = 8, 15.69%), or reduced by between \$1001 to 2500 per month (n = 8, 15.69%).

For nine of these participants (33.33%) (40.74%), the burden of this reduced income was extremely or moderately significant, for 7 participants (25.93%) the burden was somewhat significant, and for seven participants (40.74%), the burden was slightly or not all significant .

Treatments overview

There were 46 participants (88.46%) that had surgery, 48 participants (92.31%) that had drug treatments, and 42 participants (80.77%) that had radiotherapy. The majority of participants had used allied health (n=40, 76.92%), complementary therapies (n=40, 76.92%), and, made lifestyle changes(n=45, 86.54%).

Surgical treatments

There were 46 participants (88.46%) that had surgery for breast cancer. The most common type of surgery was lumpectomy (n=30, 57.69%), followed by mastectomy (n=19, 36.54%). There were 14 participants (26.92%) that had breast reconstruction, 10 participants (19.23%) had re-excision following lumpectomy, and nine participants (17.31%) had surgery to remove ovaries.

Drug treatments

There were 48 participants (92.31%) that had drug treatments. The most common types of drug treatments were tamoxifen (n=23, (45.1%), letrozole n=18, (35.29%) and, anastrozole (n=8, 15.69%).

Radiotherapy

There were 40 participants (76.92%) that had radiotherapy to the primary cancer site, and four participants (7.69%) that had radiotherapy to a secondary cancer site.

Allied health

The most common allied health service used was physiotherapy (n = 31, 60.78%), followed by psychology (n = 18, 35.29%), and occupational therapist (n = 7, 13.73%). There were six participants (11.76%) that saw a dietician, and six participants (11.76%) that saw a social worker.

Lifestyle changes

The most common lifestyle change used was exercise (n = 43, 84.31%), followed by diet changes (n = 28, 54.90%), and quit or cut back on alcohol (n = 27, 52.94%).

Complementary therapies

The most common complementary therapies used were supplements (n = 25, 49.02%), and mindfulness or relaxation techniques (n = 25, 49.02%), and massage therapy.

Clinical trials

There was a total of 17 participants (33.33%) that had discussions about clinical trials, 4 participants (7.84%) had brought up the topic with their doctor, and the doctor of 13 participants (25.49%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n = 34, 66.67%).

There were seven participants (13.73%) that had taken part in a clinical trial, 32 participants (62.75%) that would like to take part in a clinical trial if there was a suitable one, and 12 participants, who have not participated in a clinical trial and do not want to (23.53%).

Description of mild side effects

In the structured interview, participants were asked how they would describe the term 'mild side effects'. The most common description of 'mild side effects' was to describe them with specific examples (n=27, 51.92%). There were 25 participants (48.08%) that described mild side effects as those that do not interfere with daily life, and 19 participants (36.54%) that described mild side effects as those that can be self-managed.

Of those who described a specific side effect, the most commonly described side effects were fatigue (n=7, 13.46%), mild pain or aches (n=6, 11.54%), and hair loss.

Description of severe side effects

In the structured interview, participants were asked how they would describe the term 'severe side effects'. The most common description of 'severe side effects' was a specific side effect as an example (n=30, 57.69%). Other descriptions of 'severe side effects' included those that impact everyday life/ability to conduct activities of daily living (n=26, 50.00%), those that require medical intervention (n=5, 9.62%).

Of those who described a specific side effect, the most commonly described side effects were pain (n=11, 21.15%), the emotional and mental impact (n=7, 13.46%), those that impact on sleep (n=5, 9.62%), and nausea (n=5, 9.62%).

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime. The most common themes described were adhering to treatment for a specific amount of time (n=20, 38.46%), and as per the advice of their specialist/as long as prescribed (n=19, 36.54%). Other participants described adhering to treatment as long as side effects are tolerable (n=15, 28.85%), and not giving up on any treatment (n=15, 28.85%).

What needs to change to feel like treatment is working

Participants were asked to describe what needs to change to feel like treatment is effective. The most common response from 24 participants (46.15%) was needing to see an improvement in specific symptoms, and this was followed by 19 participants (36.54%) that reported needing to experience an improvement in side effects in general, and needing evidence of stable disease or no disease progression (n= 12, 23.08%). There were 12 participants (23.08%) that described needing to have a balance between benefits and potential side effects, and 11 participants (21.15%), that reported that it was difficult to know if the treatment was working and that they needed evidence.

Where participants need to see improvements in specific side effects, the most noted side effects were aches and pain, and hot flushes.

What it would mean if treatment worked

Participants were asked to describe what it would mean to them, if their treatment worked. The most common response from 25 participants (48.08%) was allowing them to return to everyday activities or return to normal life. Other participants described that it would have a positive impact on their mental health (n=13, 25.00%), that it would allow them to work (n=9, 17.31%), get enough sleep (n=6, 11.54%), and do more exercise (n=5, 9.62%).

Main provider of treatment

Participants were asked in the online questionnaire who was the main healthcare professional that provided treatment and management of their condition.

The most common provider of treatment and care were medical oncologists (n = 26, 50.00 %), followed by specialist surgeons (n = 15, 28.85%) (Table 5.1, Figure 5.1).

Time to travel to main provider of treatment

Participants were asked in the online questionnaire how long they had to travel for to get to their appointments with their main treatment provider.

There were 13 participants (25.49%) that travelled for less than 15 minutes, 23 participants (45.10%) that travelled between 15 and 30 minutes, nine participants (17.65%) that travelled between 30 and 60 minutes, two participants (3.92%) that travelled between 60 and 90 minutes, and four participants (7.84%) that travelled more than 90 minutes (Table 5.2, Figure 5.2).

Table 5.1: Main provider of treatment

Main provider of treatment	Number (n=52)	Percent
Medical oncologist	26	50.00
Specialist surgeon	15	28.85
General practitioner (GP)	10	19.23
Other	3	5.77

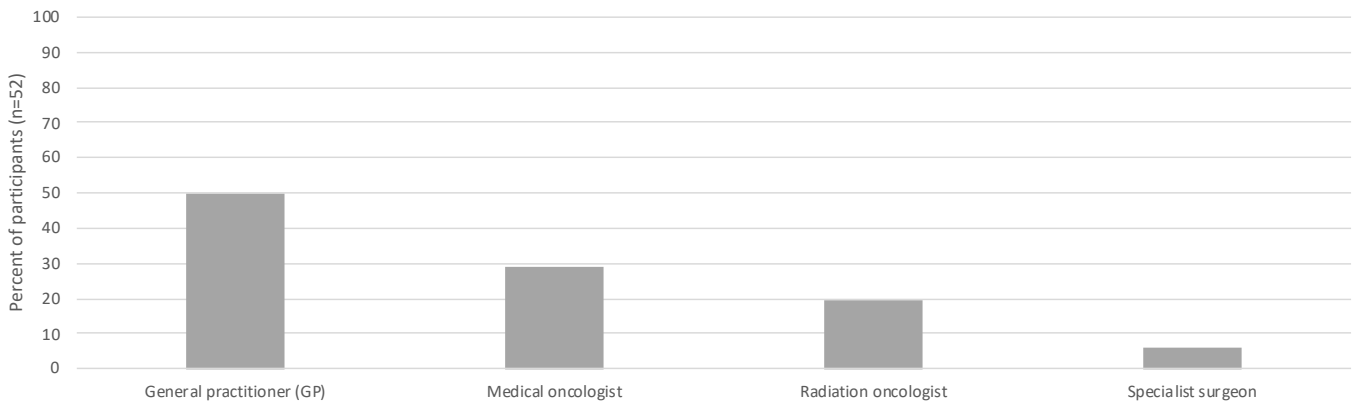


Figure 5.1: Main provider of treatment

Table 5.2: Time to travel to main provider of treatment

Main provider of treatment	Number (n=52)	Percent
Less than 15 minutes	13	25.49
Between 15 and 30 minutes	23	45.10
Between 30 and 60 minutes	9	17.65
Between 60 and 90 minutes	2	3.92
More than 90 minutes	4	7.84
Not applicable	1	

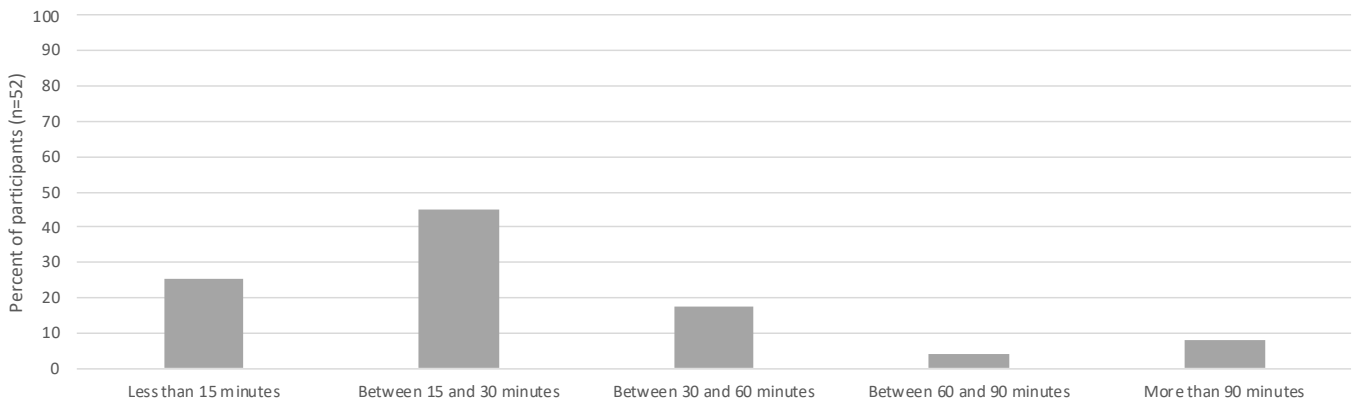


Figure 5.2: Time to travel to main provider of treatment

Access to healthcare professionals

Participants noted in the online questionnaire the healthcare professionals they had access to for the treatment and management of their condition.

Almost all participants had access to a medical oncologist (n = 49, 94.232%), and a specialist surgeon (n = 49, 94.23%) for the treatment and management of breast cancer. There were 43 participants (82.69%) that had a radiation oncologist, 43 participants (82.69%) that had a general practitioner (GP), and 42

participants (80.77%) had a breast care nurse, and 30 participants (57.69%).

There were 30 participants (57.69%) cared for by an oncology or chemotherapy nurse, 28 participants (53.85%) treated by a physiotherapist and, 25 participants (48.08%) with a pharmacist. Almost half of the participants had a lymphoedema practitioner to care for their condition (n = 24, 46.15%). (Table 5.3, Figure 5.3).

Table 5.3: Access to healthcare professionals

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

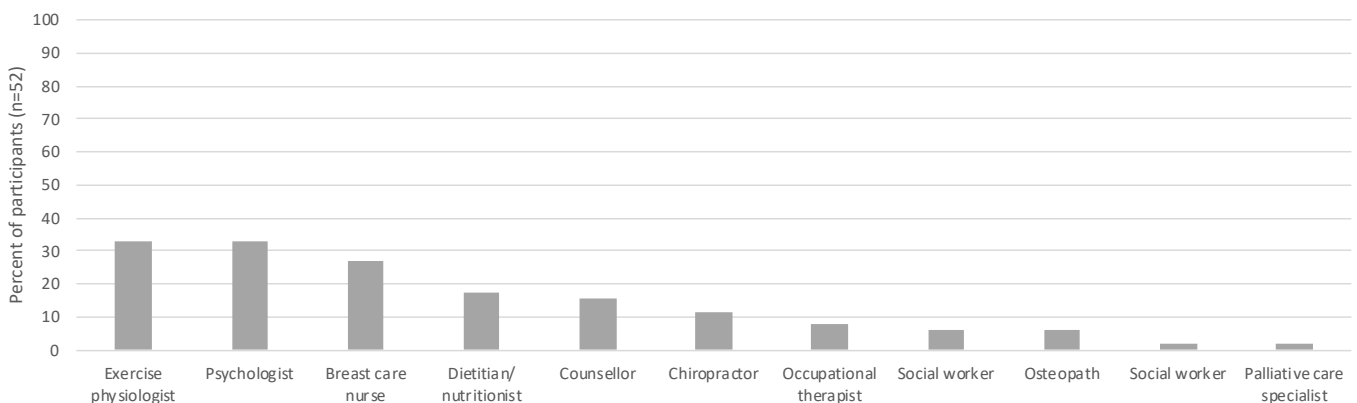


Figure 5.3: Access to healthcare professionals

Health care system

In the online questionnaire, participants were asked questions about the healthcare system they used, about private insurance and about whether they were treated as a public or private patient (Table 5.4, Figures 5.5 and 5.6).

The majority of participants had private health insurance (n = 41, 80.39%). The majority of participants were not asked if they wanted to be treated as a public or private patient (n = 31, 60.78%), however, they were asked if they had private health insurance (n = 44, 86.27%).

Throughout their treatment, there were 29 participants (56.86%) who were treated as a private patient, 13 participants (25.49%) were mostly treated as a public patient, and there were nine participants (17.65%) who were equally treated as a private and public patient.

Throughout their treatment, there were 25 participants (49.02%) who were treated mostly in the private hospital system, 11 participants (21.57%) were mostly treated in the public system, and there were 15 participants (29.41%) who were equally treated in the private and public systems.

Table 5.4: Health care system

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

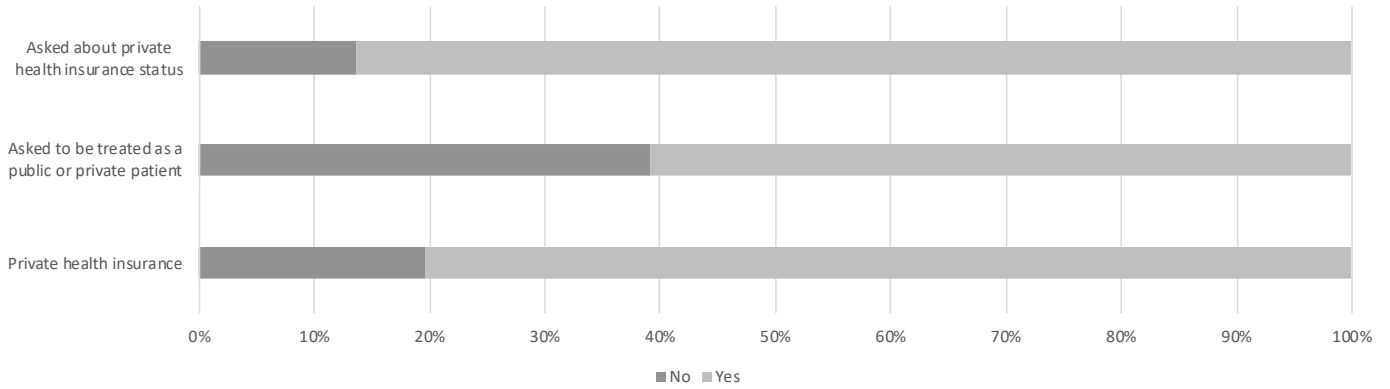


Figure 5.4: Health insurance

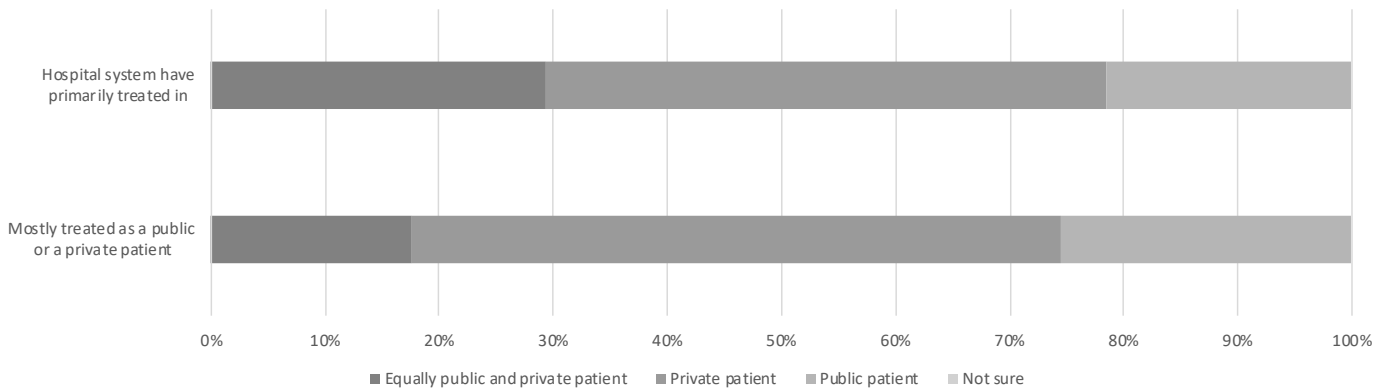


Figure 5.5: Hospital system

Affordability of healthcare

Participants were asked a series of questions about affordability of healthcare in the online questionnaire (Table 5.5, Figure 5.6).

The first question was about having to delay or cancel healthcare appointments because they were unable to afford them. Almost all the participants never or rarely had to delay or cancel appointments due to affordability (n = 48, 94.12%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n = 47, 92.16%).

The third question was about the affordability of basic essentials such as food, housing and power. There were 45 participants (88.24%) that never or rarely had trouble paying for essentials, and four participants (7.84%) that sometimes found it difficult.

The final question was about paying for additional carers for themselves or for their family, there were 8 participants (15.69%) that paid for additional carers due to their condition.

Table 5.5: Affordability of healthcare

Affordability of healthcare	Response	Number (n=51)	Percent
Delay or cancel healthcare appointments due to affordability	Never	44	86.27
	Rarely	4	7.84
	Sometimes	1	1.96
	Often	1	1.96
	Very often	1	1.96
Did not fill prescriptions due to cost	Never	46	90.20
	Rarely	1	1.96
	Sometimes	4	7.84
	Often	0	0.00
	Very often	0	0.00
Difficult to pay for basic essentials	Never	35	68.63
	Rarely	10	19.61
	Sometimes	4	7.84
	Often	1	1.96
	Very often	1	1.96
Pay for additional carers for self or family	Yes	8	15.69
	No	43	84.31

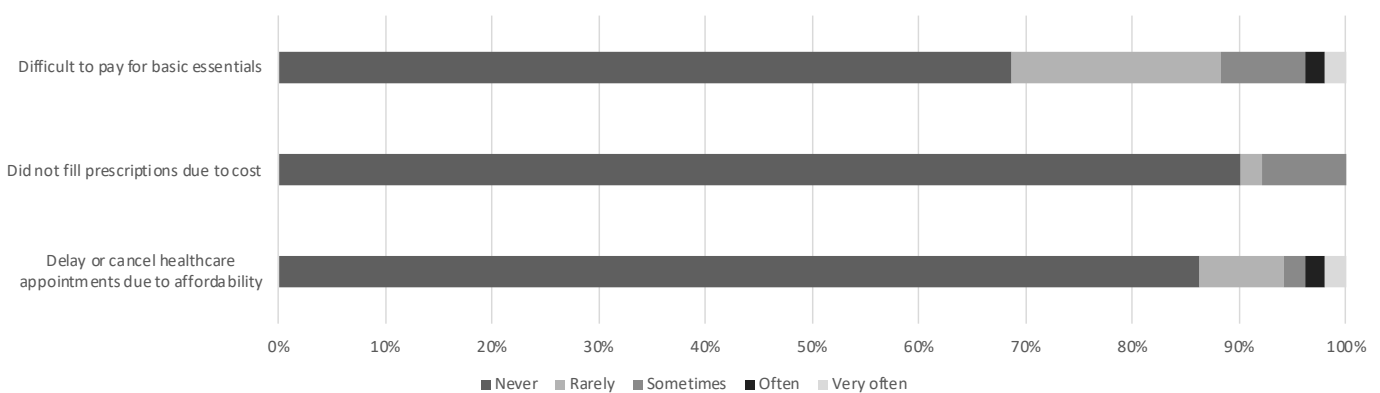


Figure 5.6: Affordability of healthcare

Cost of condition

In the online questionnaire, participants estimated the amount they spend per month due to their condition, including doctors' fees, transport, carers, health insurance gaps and complementary therapies. Where the response was given in a dollar amount, it is listed below (Table 5.6, Figure 5.7).

The most common amount was between \$101 to \$250 (n = 15, 29.41%), followed by between \$251 to \$500 (n = 8, 15.69%). There were four participants (7.84%), who spent \$1001 or more a month.

Burden of cost

As a follow up question, for participants who had monthly expenses due to their condition, participants were asked if the amount spent was a burden (Table 5.7, Figure 5.8).

The amount spent was an extremely significant or moderately significant burden for 12 participants (23.53%), somewhat significant for 12 participants (23.53%), and slightly or not at all significant for 27 participants (52.94%).

Table 5.6: Estimated monthly out of pocket expenses due to condition

Estimated monthly out of pocket expenses	Number (n=51)	Percent
\$0	3	5.88
\$100 or less	7	13.73
\$101 to \$250	15	29.41
\$251 to \$500	8	15.69
\$501 to \$1000	4	7.84
\$1001 or more	4	7.84
Not sure of amount	10	19.61

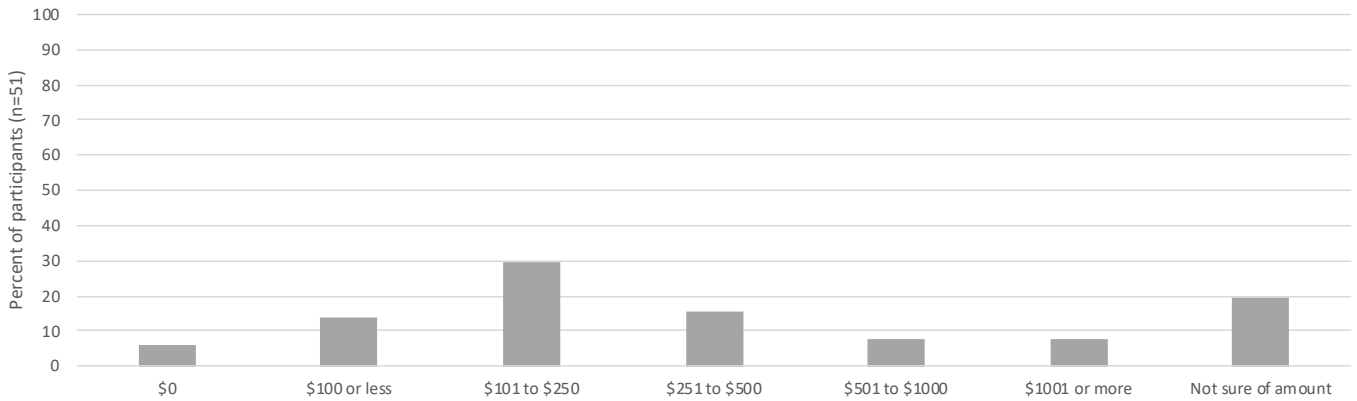


Figure 5.7: Estimated monthly out of pocket expenses due to condition

Table 5.7: Burden of out-of-pocket expenses due to condition

Burden of out of pocket expenses	Number (n=51)	Percent
Extremely significant	4	7.84
Moderately significant	8	15.69
Somewhat significant	12	23.53
Slightly significant	16	31.37
Not at all significant	11	21.57

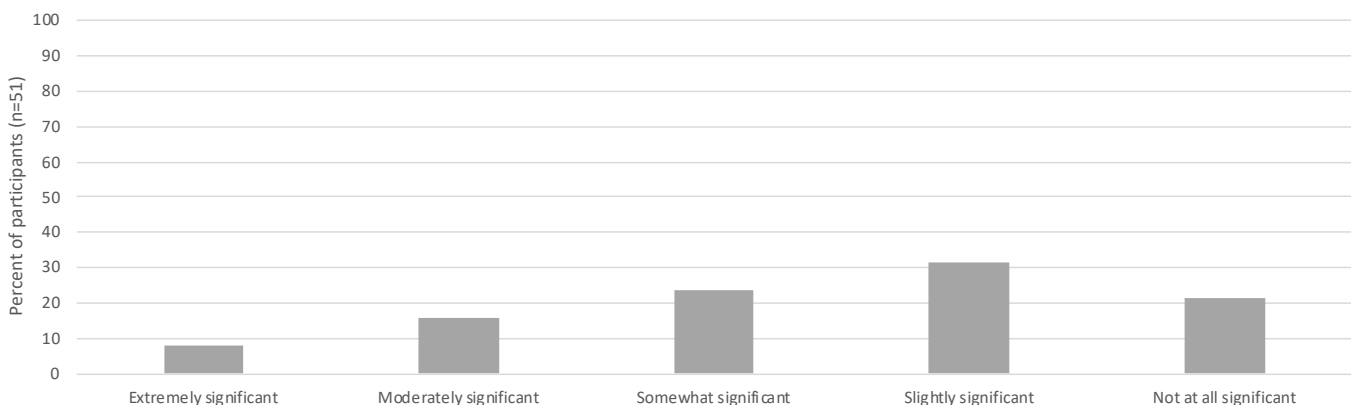


Figure 5.8: Burden of out-of-pocket expenses due to condition

Changes to employment status

Participants were asked, in the online questionnaire, if they had any changes to their employment status due to their condition. Participants were able to choose multiple changes to employment (Table 5.8, Figure 5.9).

Work status for 10 participants (19.61%) had not changed since diagnosis, and eight participants (15.69%) were retired or did not have a job. There were eight participants (15.69%) that had to quit their job, 15 participants (29.41%) reduced the number of hours they worked, and three participants (5.88%) that

accessed their superannuation early. There were 11 participants (21.57%) that took leave from work without pay, and 10 participants (19.61%) who took leave from work with pay.

Changes to carer/partner employment status

Participants were asked, in the online questionnaire, if they had any changes to the employment status of their care or partner due to their condition. Participants were able to choose multiple changes to employment. (Table 5.9, Figure 5.10).

There were 11 participants (21.57%), without a main partner or carer. Most commonly, participants had partners or carers that did not change their work status due to their condition (n = 24, 47.06%). There were

four participants (7.84%) whose partners reduced the numbers of hours they worked, and no partners of participants had to quit their job. The partners of two participants (3.92%) took leave without pay, and there were 10 partners (19.61%) who took leave with pay.

Table 5.8: Changes to 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

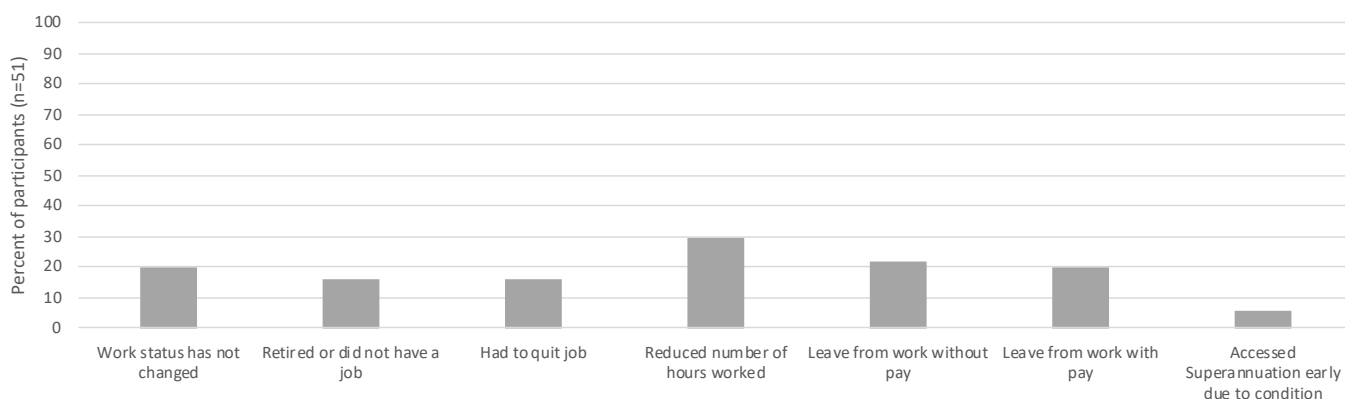


Figure 5.9: Changes to employment status

Table 5.9: Changes to carer/partner employment status

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

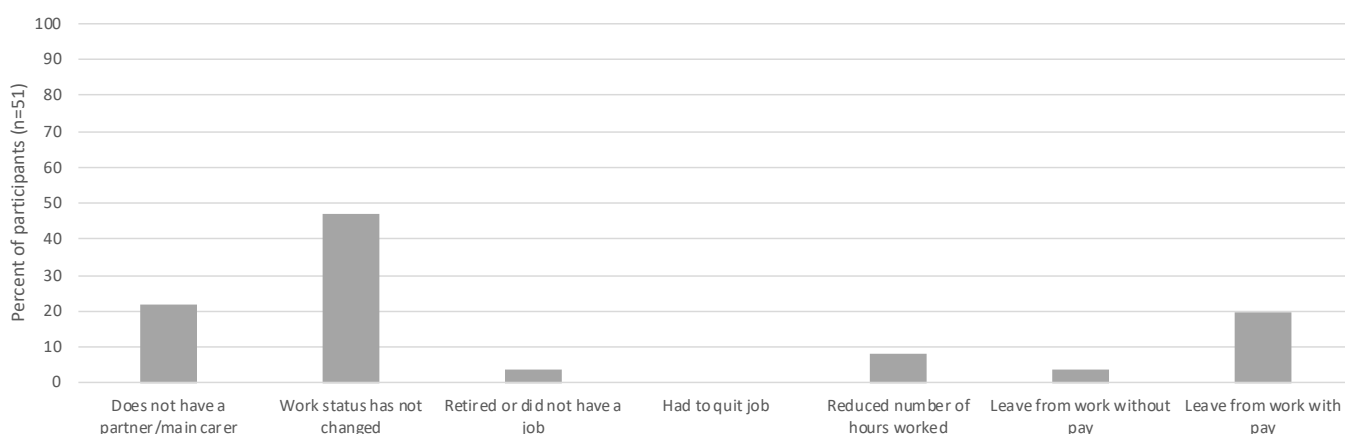


Figure 5.10: Changes to carer/partner employment status

Reduced income due to condition

More than half of the participants (n = 27, 52.94%) indicated in the online questionnaire that they had a reduced family income due to their condition.

Estimated reduction monthly income

As a follow up question, participants were asked if their family or household income had reduced due to their condition. Where a dollar amount was given, it is listed below (Table 5.10, Figure 5.11).

Most commonly, participants were not sure about the amount their monthly income was reduced by (n = 8, 15.69%), or reduced by between \$1001 to 2500 per month (n = 8, 15.69%).

Table 5.10: Estimated monthly loss of income

Estimated monthly loss of income	Number (n=51)	Percent
\$0	24	47.06
Less than \$1000	3	5.88
\$1001 to 2500	8	15.69
\$2501 to 5000	8	15.69
More than \$5000	2	3.92
Not sure/not specified	6	11.76

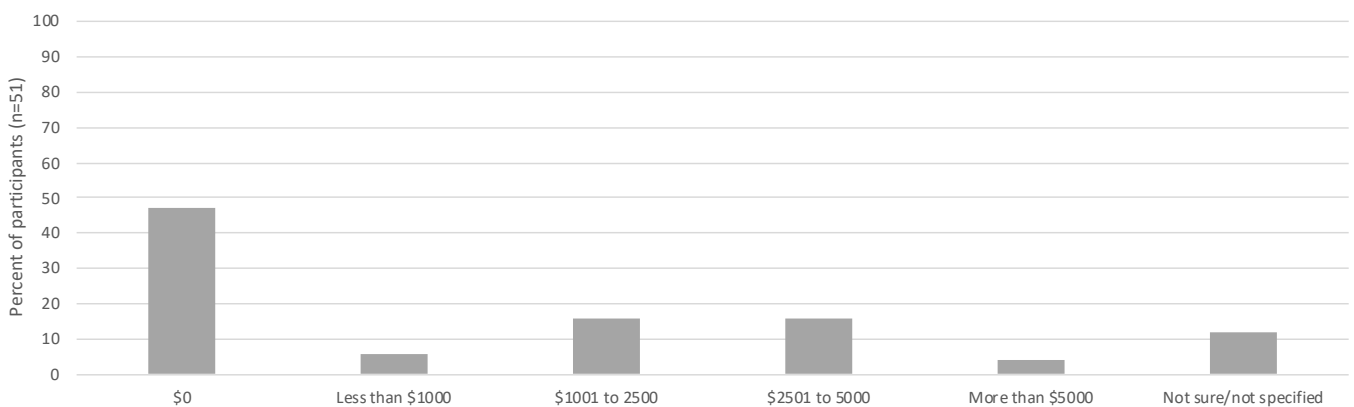


Figure 5.11: Estimated monthly loss of income

Table 5.11: Burden of reduced income

Burden of reduced income	Number (n=27)	Percent
Extremely significant	3	11.11
Moderately significant	6	22.22
Somewhat significant	7	25.93
Slightly significant	9	33.33
Not at all significant	2	7.41

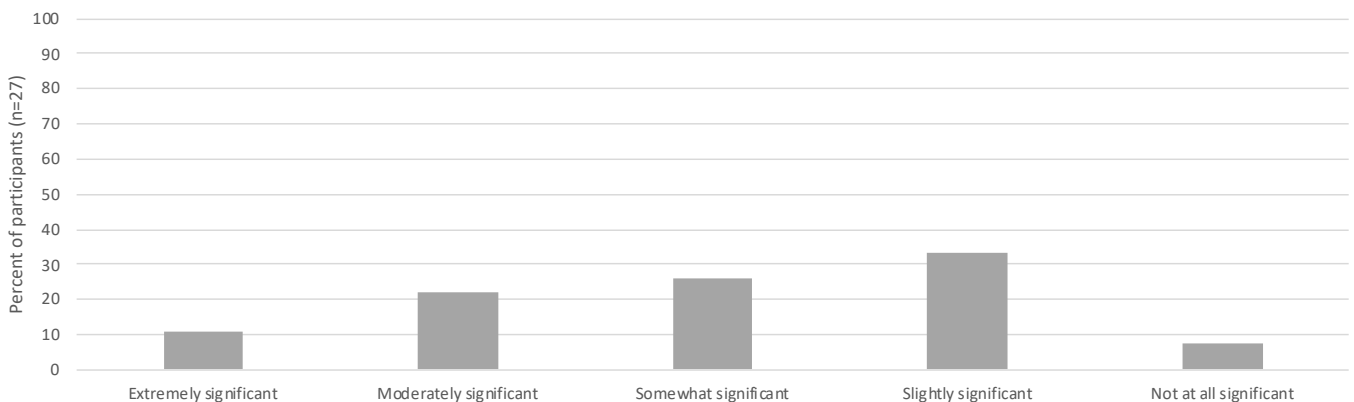


Figure 5.12: Burden of reduced income

Burden of reduced income

Participants were then asked if this reduced family or household income was a burden. (Table 5.11, Figure 5.12).

For nine of these participants (33.33%) (40.74%), the burden of this reduced income was extremely or moderately significant, for 7 participants (25.93%) the burden was somewhat significant, and for seven participants (40.74%), the burden was slightly or not all significant.

Treatments overview

Participants noted in the online questionnaire the different treatments, allied health services, complementary therapies, and lifestyle changes they had since diagnosis with their condition (Table 5.12, Figure 5.13).

There were 46 participants (88.46%) that had surgery, 48 participants (92.31%) that had drug treatments, and 42 participants (80.77%) that had radiotherapy. The majority of participants had used allied health (n=40, 76.92%), complementary therapies (n=40, 76.92%), and, made lifestyle changes(n=45, 86.54%).

Table 5.12: Treatments overview

Treatments overview	Number (n=52)	Percent
No treatment	1	1.92
Surgery	46	88.46
Drug treatments	48	92.31
Radiotherapy	42	80.77
Allied health	40	76.92
Complementary therapies	40	76.92
Lifestyle Changes	45	86.54

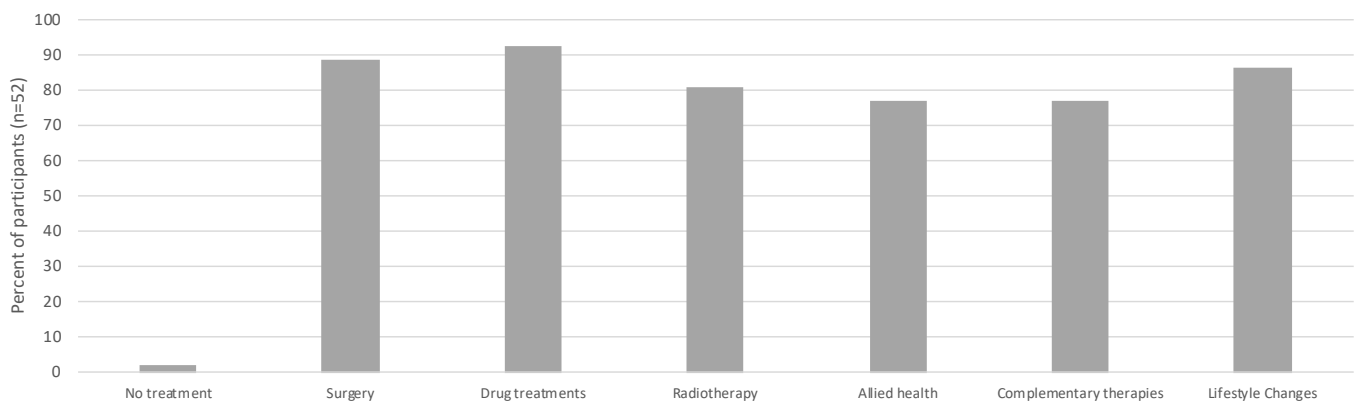


Figure 5.13: Treatments overview

Summary of surgery

In the online questionnaire, participants noted the number of operations (excluding biopsies) that they had for breast cancer.

There were 46 participants (88.46%) that had surgery for breast cancer (excluding biopsies). There were 17

participants (32.69%) that had one operation, 12 participants (23.08%) that had two operations, eight participants (15.38%) that had three operations, and nine participants (17.31%) that had four or more operations (Table 5.13, Figure 5.14).

Table 5.13: Number of surgeries

Number of operations (excluding biopsy)	Number (n=52)	Percent
0	6	11.54
1	17	32.69
2	12	23.08
3	8	15.38
4 or more	9	17.31

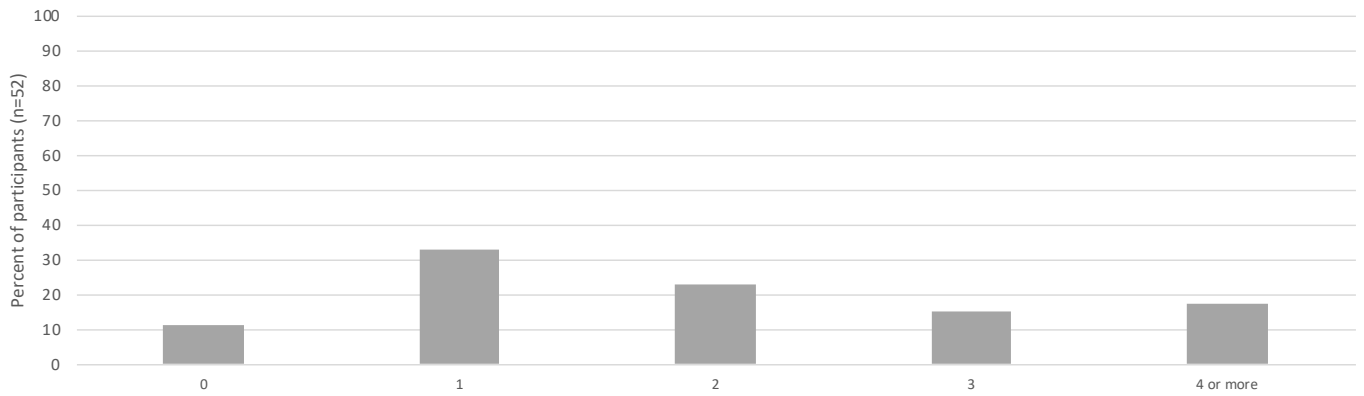


Figure 5.14: Number of surgeries

Surgical treatments

Participants completed a series of questions about surgery, including type of surgery, quality of life, effectiveness of surgery, and side effects. A summary of the surgery, quality of life and effectiveness is presented in Table 5.14.

There were 46 participants (88.46%) that had surgery for breast cancer. The most common type of surgery was lumpectomy (n=30, 57.69%), followed by mastectomy (n=19, 36.54%). There were 14 participants (26.92%) that had breast reconstruction, 10 participants (19.23%) had re-excision following lumpectomy, and nine participants (17.31%) had surgery to remove ovaries (Figure 5.15).

Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective. Values are calculated where there was adequate data available (five or more participants).

Median quality of life from surgery ranged from 4.00 to 5.00, in the life was average to life was good range (Figure 5.16). The median effectiveness of all surgery was between 4.00 and 5.00, in the effective to very effective range (Figure 5.17).

On average, quality of life from lumpectomy was in the 'life was average' range (median = 4.00, IQR = 1.00), and was found to be effective to very effective (median = 4.50, IQR = 1.00).

On average, quality of life from re-excision following lumpectomy was in the 'life was a little distressing' range (median = 3.00, IQR = 1.50), and was found to be effective (median = 4.00, IQR = 0.00).

On average, quality of life from mastectomy was in the 'life was a little distressing' range (median = 3.00, IQR = 2.50), and was found to be effective (median = 4.00, IQR = 1.00).

On average, quality of life from breast reconstruction was in the 'life was distressing to a little distressing' range (median = 2.50, IQR = 1.75), and was found to be effective (median = 4.00, IQR = 1.75).

On average, quality of life from surgery to remove ovaries was in the 'life was average' range (median = 4.00, IQR = 0.00), and was found to be very effective (median = 5.00, IQR = 1.00).

Table 5.14 Summary of surgeries

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	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

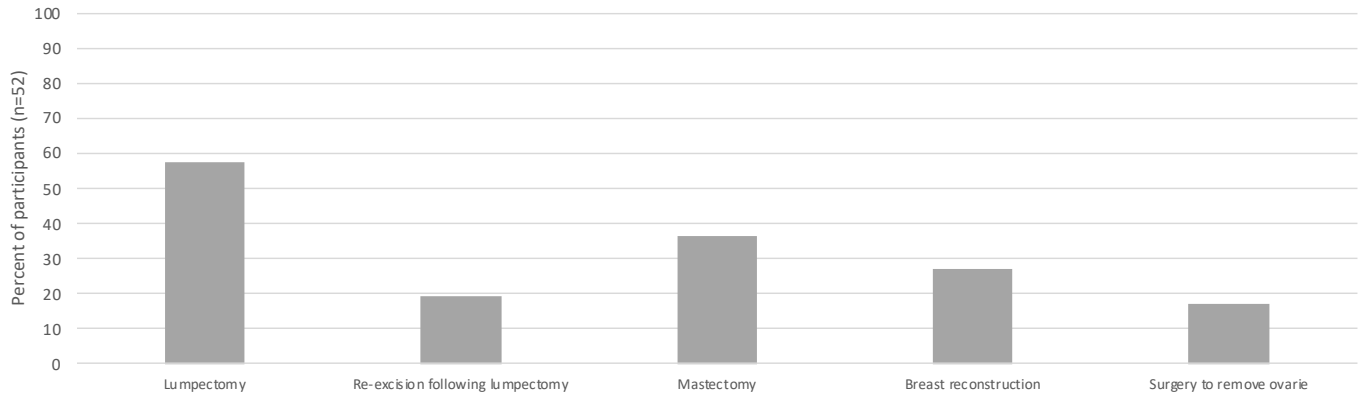


Figure 5.15: Summary of surgeries

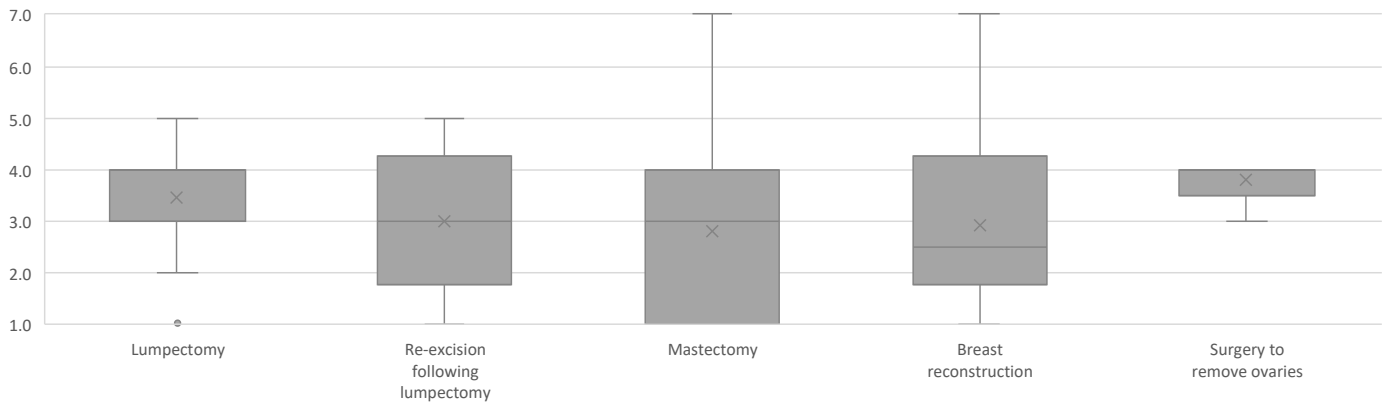


Figure 5.16: Quality of life from surgery

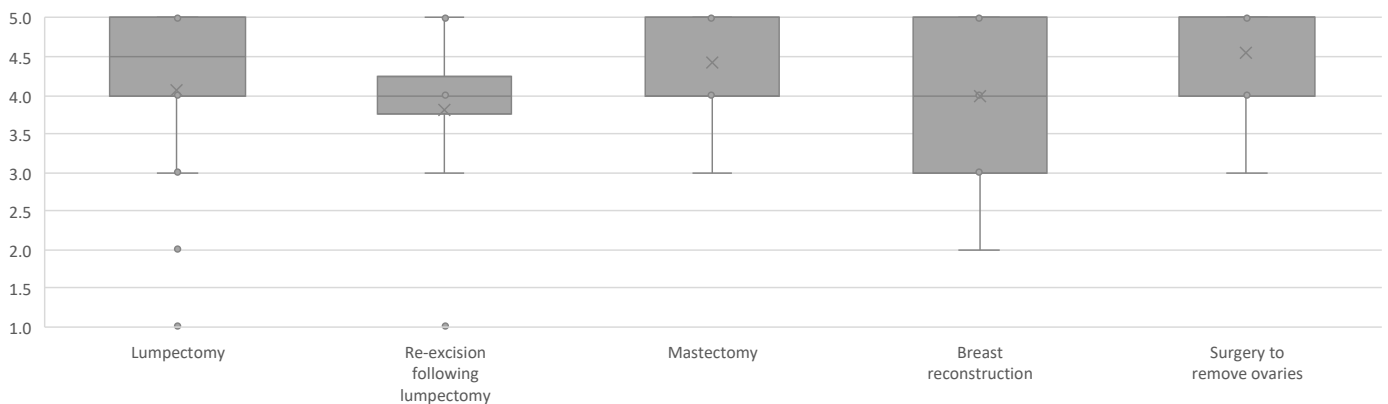


Figure 5.17: Effectiveness of surgery

Summary of drug treatments

Participants completed a series of questions about surgery, including type of surgery, quality of life, effectiveness of surgery, and side effects. A summary of the surgery, quality of life and effectiveness is presented in Table 5.15, and more detailed information including side effects is given in Table 5.16.

There were 48 participants (92.31%) that had drug treatments. The most common types of drug treatments were tamoxifen (n=23, (45.1%), letrozole n=18, (35.29%) and, anastrozole (n=8, 15.69%) (Figure 5.18).

Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great” (Figure 5.19). Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective (Figure 5.20). Values are calculated where there was adequate data available (five or more participants).

Median quality of life from treatments ranged from 3.00 to 4.00, in the life was a little distressing to average range. Median effectiveness from treatments ranged from 3.00 to 5.00 in the moderately effective to very effective range.

On average, quality of life from tamoxifen was in the 'life was a little distressing' range (median = 3.00, IQR = 2.00), and was found to be effective (median = 4.00, IQR = 1.00).

On average, quality of life from letrozole was in the 'life was average' range (median = 4.00, IQR = 3.00), and was found to be effective (median = 4.00, IQR = 1.00).

On average, quality of life from anastrozole was in the 'life was average' range (median = 4.00, IQR = 1.50), and was found to be effective (median = 4.00, IQR = 0.00).

On average, quality of life from fluorouracil, epirubicin, cyclophosphamide and docetaxel was in the 'life was a little distressing' range (median = 3.00, IQR = 0.75), and was found to be effective (median = 4.00, IQR = 0.00).

On average, quality of life from doxorubicin, cyclophosphamide, and paclitaxel was in the 'life was a little distressing' range (median = 3.00, IQR = 0.00), and was found to be very effective (median = 5.00, IQR = 1.00).

On average, quality of life from exemestane was in the 'life was average' range (median = 4.00, IQR = 3.00), and was found to be moderately effective (median = 3.00, IQR = 2.50).

On average, quality of life from paclitaxel was in the 'life was average' range (median = 4.00, IQR = 1.00), and was found to be effective to very effective (median = 4.50, IQR = 1.25).

Table 5.15: Summary of 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

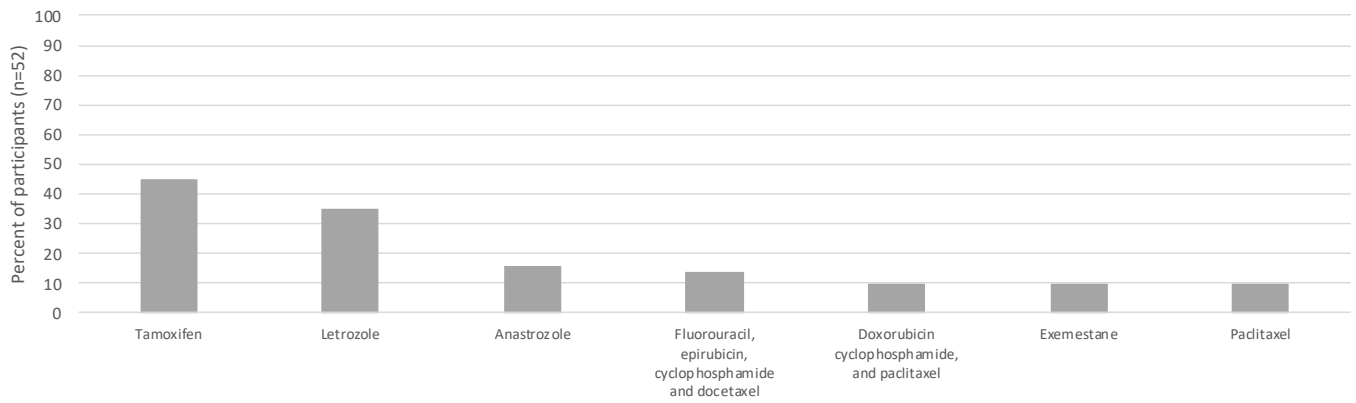


Figure 5.18: Summary of drug treatments

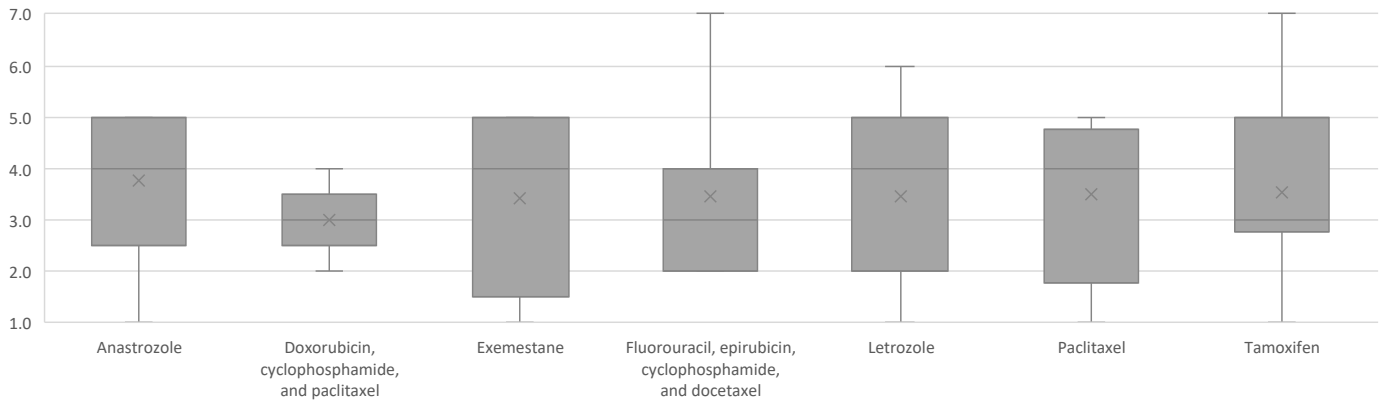


Figure 5.19: Quality of life from drug treatments (where complete data was available)

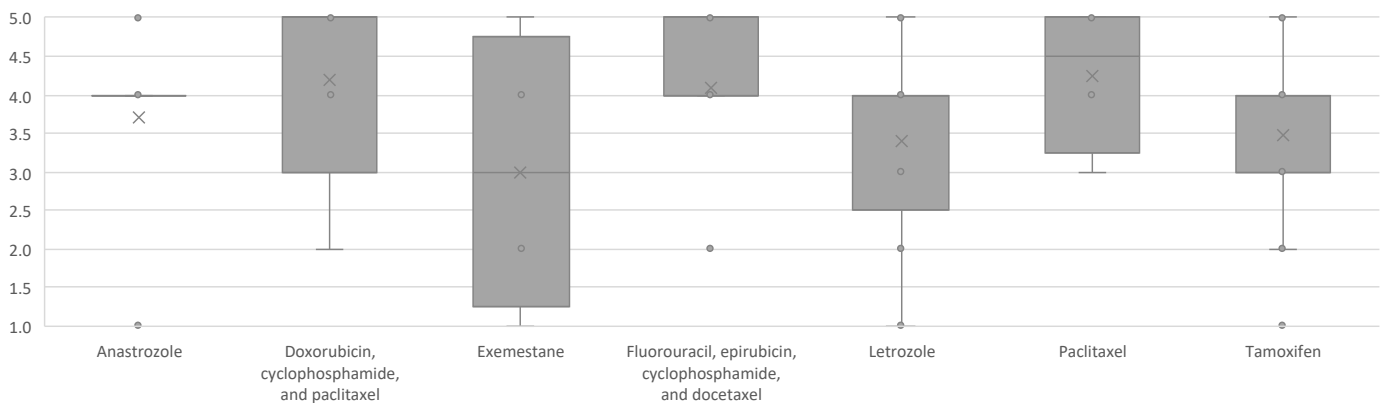


Figure 5.20: Effectiveness of drug treatments (where complete data was available)

Table 5.16: Details of drug treatments taken by more than five participants (where complete data was available)

Drug treatments (5 or more participants)		Tamoxifen		Letrozole		Anastrozole		Fluorouracil, epirubicin, cyclophosphamide and docetaxel		Doxorubicin and cyclophosphamide and paclitaxel		Exemestane		Paclitaxel	
		n=23	%	n=18	%	n=8	%	n=7	%	n=5	%	n=5	%	n=5	%
Year of treatment	2021 -2020	23	44.23	18	34.62	8	15.38	7	13.46	5	9.62	5	9.62	5	9.62
	2019-2015	8	34.78	9	50.00	4	50.00	1	14.29	2	40.00	2	40.00	2	40.00
	Before 2015	10	43.48	5	27.78	3	37.50	3	42.86	3	60.00	3	60.00	2	40.00
Treatment status	Participant is taking as needed/prescribed	5	21.74	2	11.11	1	12.50	2	28.57	0	0.00	0	0.00	0	0.00
	Participant doesn't need to take it any more	9	39.13	9	50.00	6	75.00	0	0.00	1	20.00	4	80.00	0	0.00
	Participants stopped due to side effects or not working	3	13.04	0	0.00	1	12.50	1	14.29	1	20.00	0	0.00	1	20.00
	Participants finished treatment as planned	7	30.43	7	38.89	1	12.50	0	0.00	0	0.00	1	20.00	3	60.00
Side effects	No side effects	2	8.70	2	11.11	1	12.50	0	0.00	0	0.00	1	20.00	0	0.00
	Allergic reaction	2	8.70	1	5.56	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
	Blood clots	0	0.00	0	0.00	0	0.00	1	14.29	0	0.00	0	0.00	0	0.00
	Bone pain	1	4.35	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
	Changes to the lining of the womb and risk of developing cancer of the uterus	0	0.00	0	0.00	0	0.00	0	0.00	2	40.00	4	80.00	0	0.00
	Chemo brain (chemotherapy-related cognitive impairment)	4	17.39	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
	Diarrhoea	0	0.00	0	0.00	0	0.00	6	85.71	5	100.00	0	0.00	0	0.00
	Extra fluid in the body (fluid retention)	0	0.00	0	0.00	0	0.00	2	28.57	3	60.00	0	0.00	1	20.00
	Eye problems	13	56.52	4	22.22	2	25.00	4	57.14	0	0.00	1	20.00	0	0.00
	Hair loss	0	0.00	0	0.00	0	0.00	2	28.57	0	0.00	0	0.00	0	0.00
	Hand-foot syndrome	0	0.00	0	0.00	0	0.00	6	85.71	5	100.00	0	0.00	4	80.00
	Headache	0	0.00	0	0.00	0	0.00	4	57.14	0	0.00	0	0.00	0	0.00
	Hot flushes	8	34.78	6	33.33	3	37.50	0	0.00	0	0.00	2	40.00	0	0.00
	High blood cholesterol levels	19	82.61	12	66.67	6	75.00	0	0.00	0	0.00	4	80.00	0	0.00
	Infection risk (neutropenia)	0	0.00	1	5.56	0	0.00	0	0.00	0	0.00	1	20.00	0	0.00
	Injection-site reaction or pain	0	0.00	0	0.00	0	0.00	4	57.14	3	60.00	0	0.00	2	40.00
	Joint and muscle pain and stiffness	0	0.00	0	0.00	0	0.00	0	0.00	2	40.00	0	0.00	0	0.00
	Low platelets (thrombocytopenia)	16	69.57	14	77.78	6	75.00	6	85.71	0	0.00	5	100.00	0	0.00
	Low red blood cells (anaemia)	0	0.00	0	0.00	0	0.00	1	14.29	1	20.00	0	0.00	0	0.00
	Menopausal symptoms	0	0.00	0	0.00	0	0.00	1	14.29	2	40.00	0	0.00	1	20.00
	Mouth pain and soreness (mucositis)	0	0.00	0	0.00	0	0.00	3	42.86	3	60.00	0	0.00	2	40.00
	Nail changes	0	0.00	0	0.00	0	0.00	3	42.86	1	20.00	0	0.00	2	40.00
	Nausea and or vomiting	0	0.00	0	0.00	0	0.00	5	71.43	2	40.00	0	0.00	3	60.00
	Nerve damage (peripheral neuropathy)	0	0.00	2	11.11	3	37.50	5	71.43	3	60.00	0	0.00	1	20.00
	Redness and itching along vein	0	0.00	0	0.00	0	0.00	6	85.71	4	80.00	0	0.00	4	80.00
	Skin rash	0	0.00	0	0.00	0	0.00	1	14.29	1	20.00	0	0.00	0	0.00
	Skin that is more sensitive to the sun (photosensitivity)	0	0.00	0	0.00	0	0.00	3	42.86	1	20.00	0	0.00	0	0.00
	Taste and smell changes	0	0.00	0	0.00	0	0.00	2	28.57	1	20.00	0	0.00	0	0.00
	Tiredness and lack of energy (fatigue)	0	0.00	0	0.00	0	0.00	4	57.14	5	100.00	0	0.00	2	40.00
	Urine turning orange or red	0	0.00	0	0.00	0	0.00	6	85.71	5	100.00	0	0.00	4	80.00
	Vaginal changes	0	0.00	0	0.00	0	0.00	5	71.43	5	100.00	0	0.00	0	0.00
	Weak and brittle bones (osteoporosis)	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	3	60.00	0	0.00
	Other	0	0.00	2	11.11	1	12.50	0	0.00	0	0.00	1	20.00	0	0.00

Summary of radiotherapy

In the online questionnaire, participants answered a series of questions about their radiotherapy treatment, including treatment given, quality of life from treatment, side effects from treatment and how effective they thought the treatment was. Median quality of life, and effectiveness, and side effects are given in Table 5.17.

There were 40 participants (76.92%) that had radiotherapy to the primary cancer site, and four participants (7.69%) that had radiotherapy to a secondary cancer site (Figure 5.21).

Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective. Values are calculated where there was adequate data available (five or more participants).

Median quality of life from radiotherapy to the primary cancer site was 3.00, in the life was a little distressing range (Figure 5.21). Median effectiveness of radiotherapy the primary cancer site was 4.00, in the effective range (Figure 5.22).

Table 5.17: Radiotherapy quality of life and effectiveness

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
Quality of life		3.00	2.00	NA	NA
Effectiveness		4.00	1.00	NA	NA

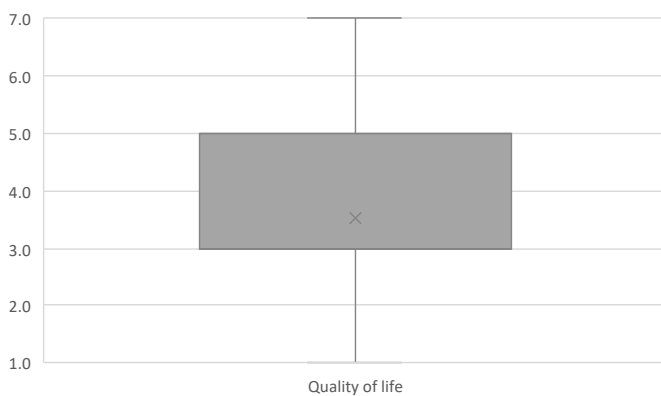


Figure 5.21: Quality of life from radiotherapy

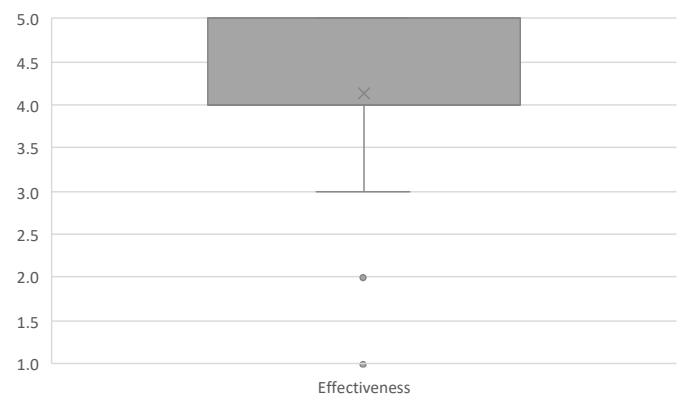


Figure 5.22: Effectiveness of radiotherapy

Allied health

Participants were asked about allied health services they used, the quality of life from these therapies, and how effective they found them.

Most participants used at least one type of allied health service (n = 40, 76.92%), and on average used one service (median = 1.00, IQR = 1.00).

The most common allied health service used was physiotherapy (n = 31, 60.78%), followed by psychology (n = 18, 35.29%), and occupational therapist (n = 7, 13.73%). There were six participants (11.76%) that saw a dietician, and six participants (11.76%) that saw a social worker (Table 5.18, Figure 5.23).

Quality of life was rated on a Likert scale from one to seven, where one is "Life was very distressing" and seven is "Life was great" (Figure 5.24). Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective (Figure 5.24). Values are calculated where there was adequate data available (five or more participants).

On average, quality of life from physiotherapy was in the 'life was average' range (median = 4.00, IQR = 2.00),

and was found to be effective (median = 4.00, IQR = 1.00).

On average, quality of life from psychology was in the 'life was a little distressing' range (median = 3.00, IQR = 3.00), and was found to be effective (median = 4.00, IQR = 2.00).

On average, quality of life from occupational therapy was in the 'life was a little distressing' range (median = 3.00, IQR = 0.50), and was found to be effective (median = 4.00, IQR = 1.50).

On average, quality of life from dieticians was in the 'life was good' range (median = 5.00, IQR = 1.50), and was found to be effective (median = 4.00, IQR = 2.25).

On average, quality of life from social work was in the 'life was distressing' range (median = 2.00, IQR = 1.50), and was found to be moderately effective to effective (median = 3.50, IQR = 1.75).

Table 5.18: Allied health

Allied health	Number (n=51)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Physiotherapist	31	60.78	4.00	2.00	4.00	1.00
Psychologist	18	35.29	3.00	3.00	4.00	2.00
Occupational therapist	7	13.73	3.00	0.50	4.00	1.50
Dietician	6	11.76	5.00	1.50	4.00	2.25
Social worker	6	11.76	2.00	1.50	3.50	1.75
Podiatrist	3	5.88	NA	NA	NA	NA
Speech pathologist or speech therapist	0	0.00	NA	NA	NA	NA
Neuropsychologist	0	0.00	NA	NA	NA	NA

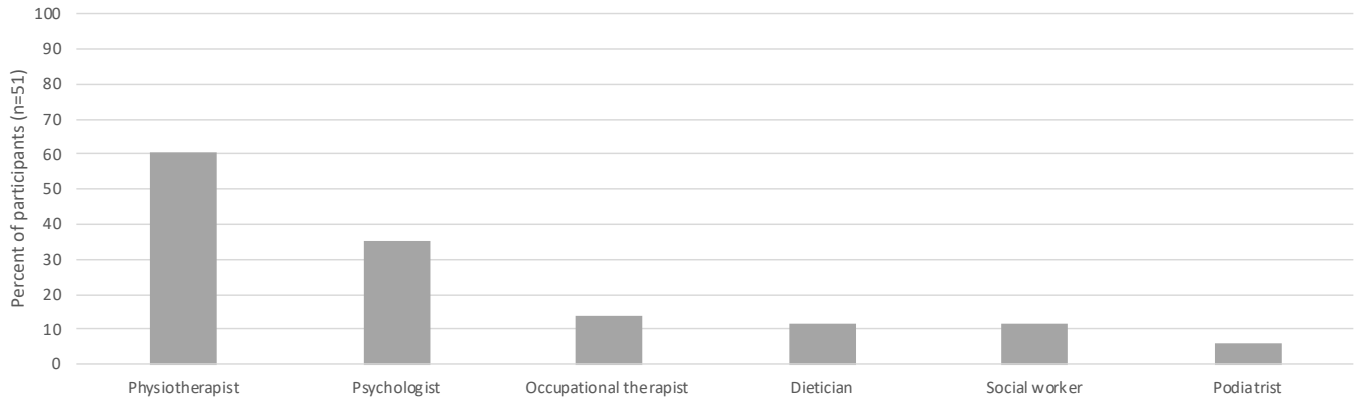


Figure 5.23: Allied health

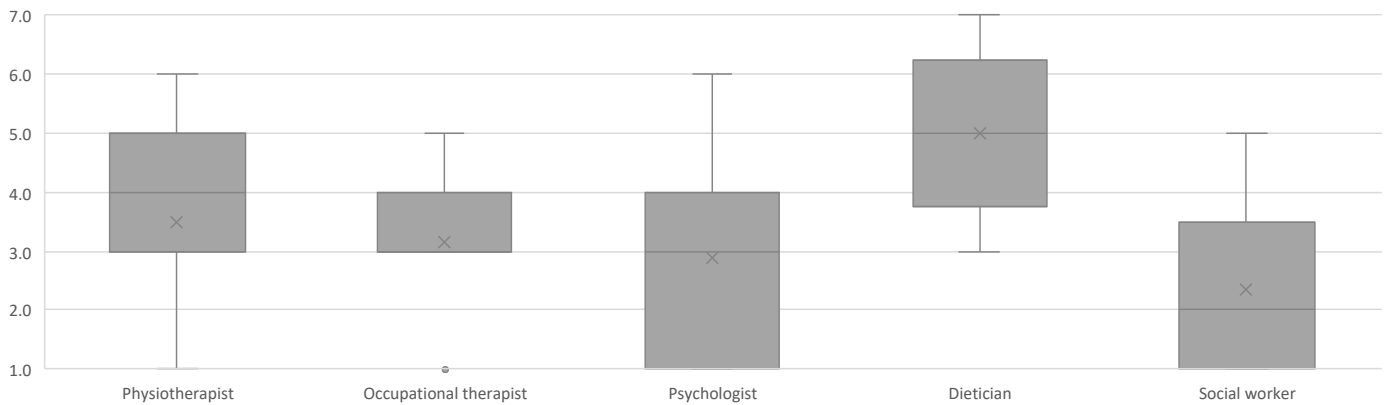


Figure 5.24: Quality of life from allied health

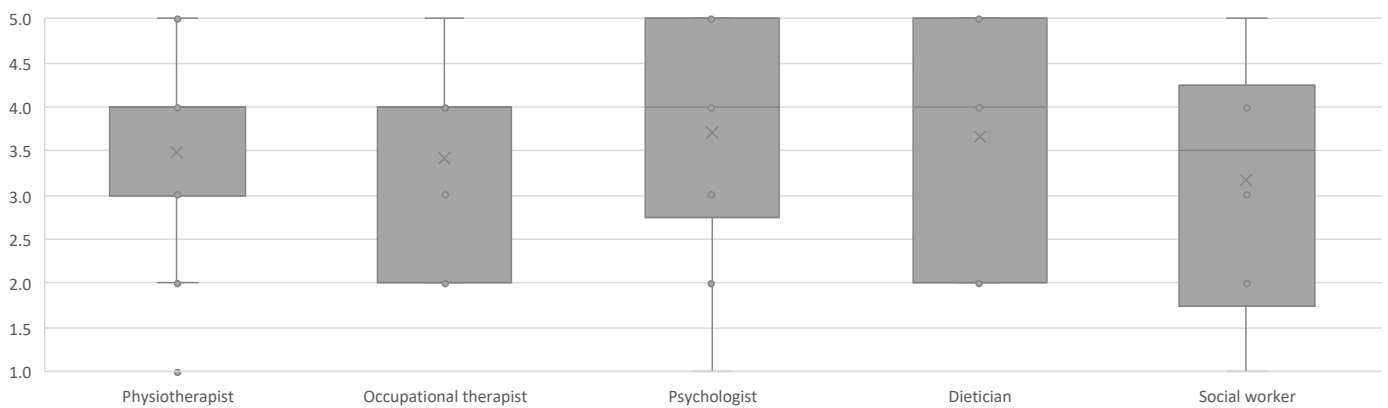


Figure 5.25: Effectiveness of allied health

Lifestyle changes

Participants were asked about any lifestyle changes they had made since diagnosis, the quality of life from these changes, and how effective they found them (Table 5.19).

Most participants used at made at least one lifestyle change (n = 45, 86.54%), and on average made two changes (median = 2.00, IQR = 2.00).

The most common lifestyle change used was exercise (n = 43, 84.31%), followed by diet changes (n = 28, 54.90%), and quit or cut back on alcohol (n = 27, 52.94%) (Figure 5.26).

Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great” (Figure 5.27). Effectiveness of

treatment was rated on a five-point scale where one is ineffective, and five is very effective (Figure 5.28). Values are calculated where there was adequate data available (five or more participants).

On average, quality of life from Exercise was in the 'life was good' range (median = 5.00, IQR = 1.00), and was found to be effective (median = 4.00, IQR = 1.50).

On average, quality of life from Diet changes was in the 'life was average' range (median = 4.00, IQR = 2.00), and was found to be moderately effective (median = 3.00, IQR = 2.00).

On average, quality of life from reducing alcohol was in the 'life was good' range (median = 5.00, IQR = 1.00), and was found to be effective (median = 4.00, IQR = 1.00).

Table 5.19: Lifestyle changes

Lifestyle changes	Number (n=51)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Exercise	43	84.31	5.00	1.00	4.00	1.50
Diet changes	28	54.90	4.00	2.00	3.00	2.00
Quit or cut back on alcohol (n=39)	27	52.94	5.00	1.00	4.00	1.00
Quit smoking (n=8)	0	0.00	NA	NA	NA	NA

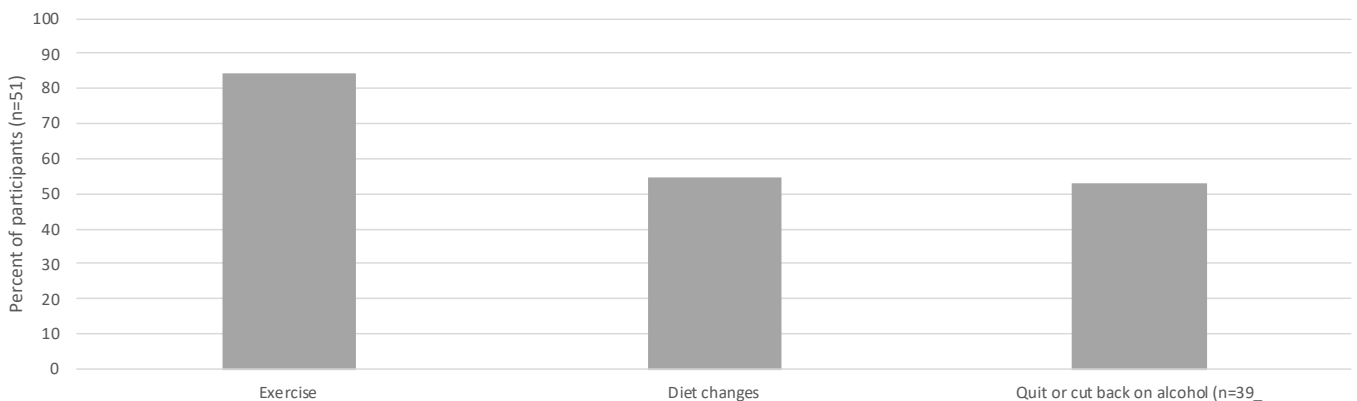


Figure 5.26: Lifestyle changes

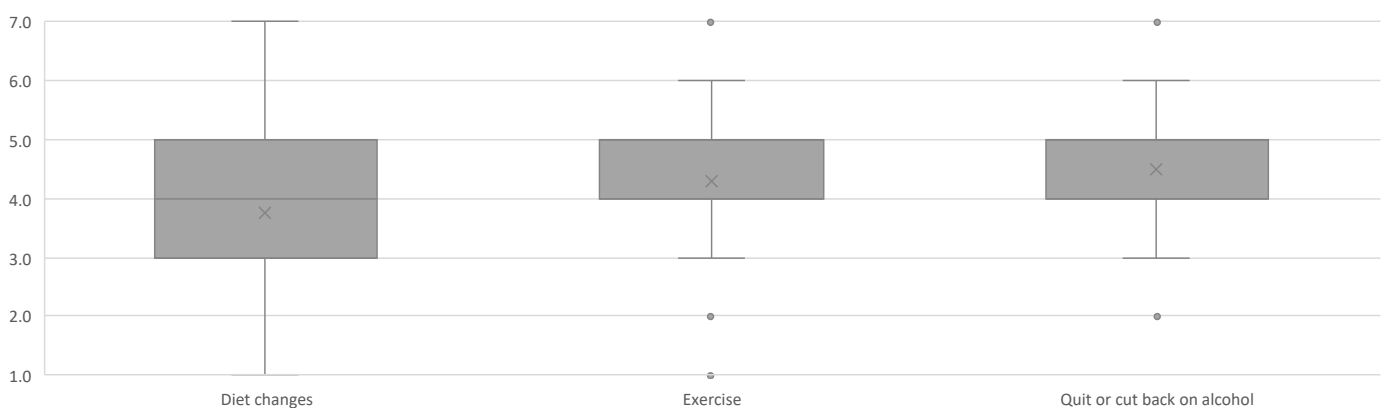


Figure 5.27: Quality of life from lifestyle changes

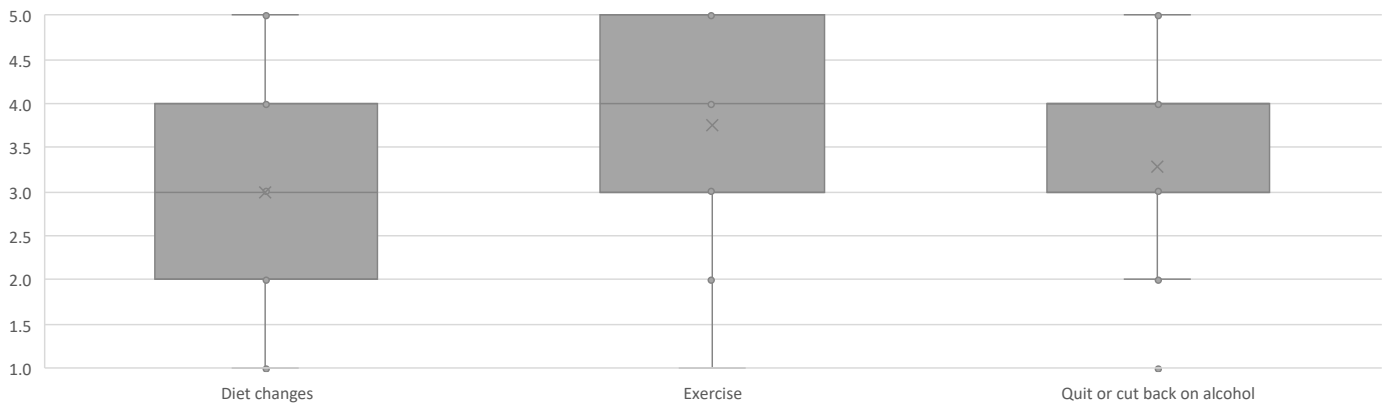


Figure 5.28: Effectiveness from lifestyle changes

Complementary therapies

Participants were asked about any complementary therapies they used to manage their condition, the quality of life from these changes, and how effective they found them (Table 5.20).

Most participants used at made at least one complementary therapy (n = 40, 76.92%), and on average used 1 therapies (median = 1.00, IQR = 1.00).

The most common complementary therapies used were supplements (n = 25, 49.02%), and mindfulness or relaxation techniques (n = 25, 49.02%), and massage therapy (n = 16, 31.37%) (Figure 5.29).

Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great” (Figure 5.30). Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective (Figure 5.31). Values are calculated where there was adequate data available (five or more participants).

On average, quality of life from supplements was in the 'life was average' range (median = 4.00, IQR = 2.00), and was found to be moderately effective (median = 3.00, IQR = 1.00).

On average, quality of life from mindfulness or relaxation techniques was in the 'life was average' range (median = 4.00, IQR = 2.00), and was found to be effective (median = 4.00, IQR = 3.00).

On average, quality of life from massage therapy was in the 'life was average to good' range (median = 4.50, IQR = 2.00), and was found to be effective to very effective (median = 4.50, IQR = 1.00).

On average, quality of life from naturotherapy was in the 'life was a little distressing range' (median = 3.00, IQR = 3.00), and was found to be effective (median = 4.00, IQR = 1.00).

Table 5.20: Complementary therapies

Complementary therapies	Number (n=51)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Supplements	25	49.02	4.00	2.00	3.00	1.00
Mindfulness or relaxation techniques	25	49.02	4.00	2.00	4.00	3.00
Massage therapy	16	31.37	4.50	2.00	4.50	1.00
Naturopath	5	9.80	3.00	3.00	4.00	1.00
Acupuncture	4	7.84	NA	NA	NA	NA
Homeopathy	1	1.96	NA	NA	NA	NA

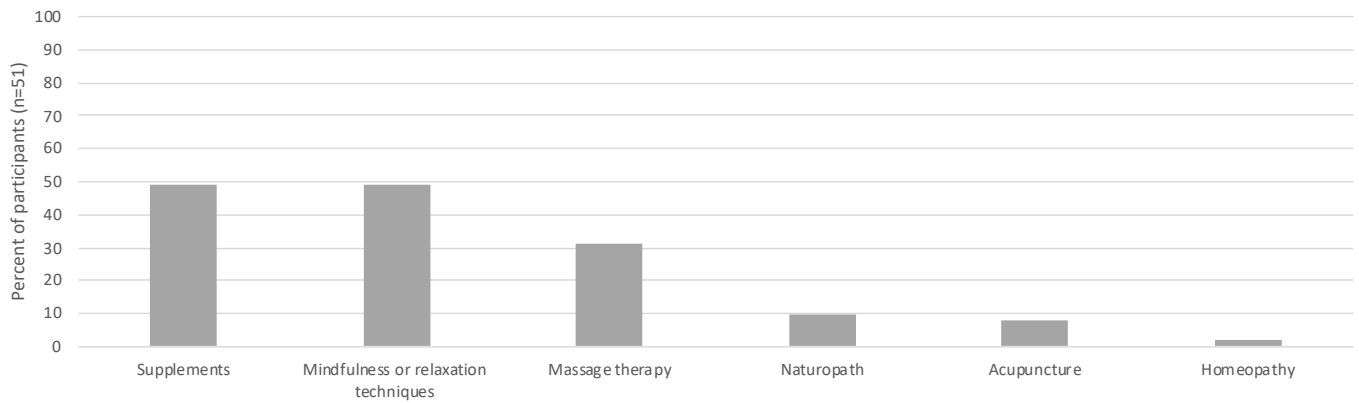


Figure 5.29: Complementary therapies

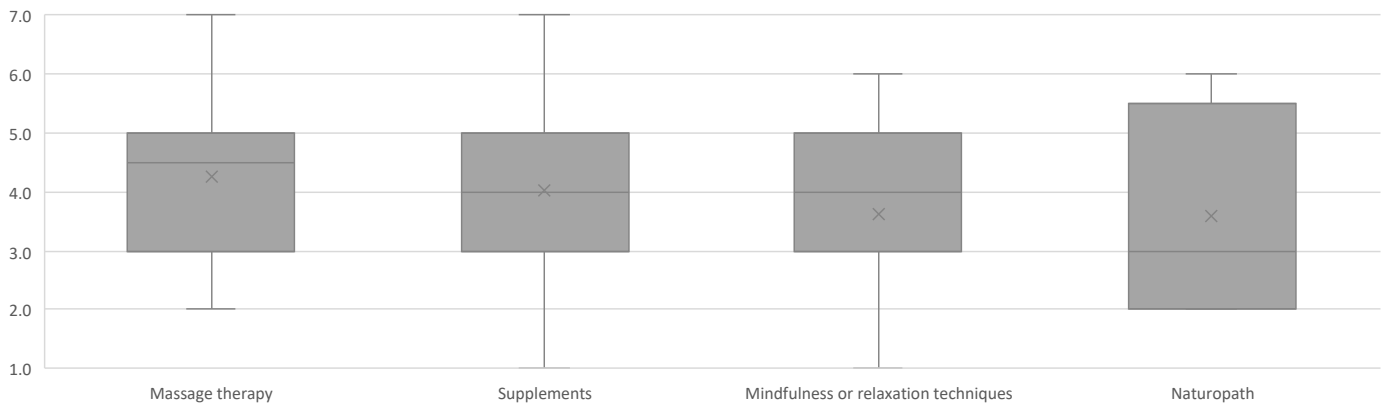


Figure 5.30: Quality of life from complementary therapies

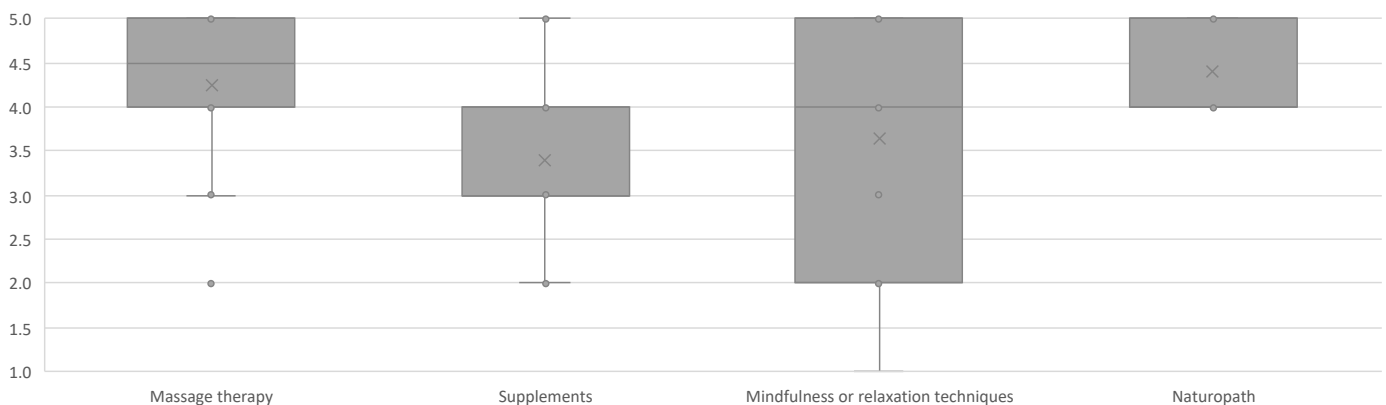


Figure 5.31: Effectiveness of complementary therapies

Clinical trials

Clinical trials discussions

In the online questionnaire, participants were asked if they had discussions with their doctor about clinical trials, and if they did, who initiated the discussion (Table 5.21, Figure 5.32).

There was a total of 17 participants (33.33%) that had discussions about clinical trials, 4 participants (7.84%) had brought up the topic with their doctor, and the doctor of 13 participants (25.49%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n = 34, 66.67%).

Clinical trial participation

As a follow up question, participants were asked if they had taken part in a clinical trial, and if they had not taken part if they were interested in taking part (Table 5.22, Figure 5.33).

There were seven participants (13.73%) that had taken part in a clinical trial, 32 participants (62.75%) that would like to take part in a clinical trial if there was a suitable one, and 12 participants, who have not participated in a clinical trial and do not want to (23.53%).

Table 5.21: Clinical trial discussions

Clinical trial discussions	Number (n=51)	Percent
Participant brought up the topic of clinical trials doctor for discussion	4	7.84
Doctor brought up the topic of clinical trials for discussion	13	25.49
Participant has ever spoken to me about clinical trials	34	66.67

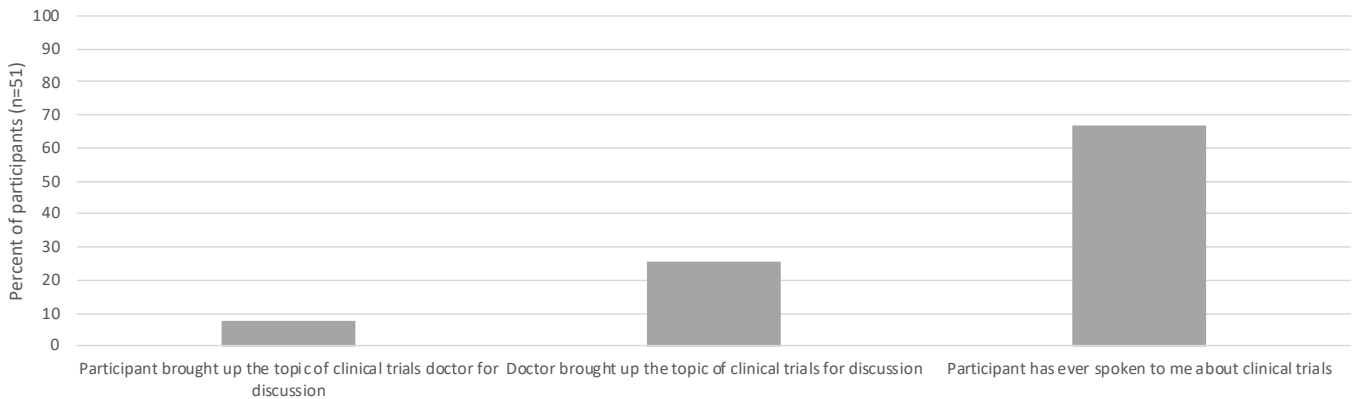


Figure 5.32: Clinical trial discussions

Table 5.22: Clinical trial participation

Clinical trial participation	Number (n=51)	Percent
Has not participated in a clinical trial and does not want to	12	23.53
Has not participated in a clinical trial but would like to if there is one	32	62.75
Has participated in a clinical trial	7	13.73

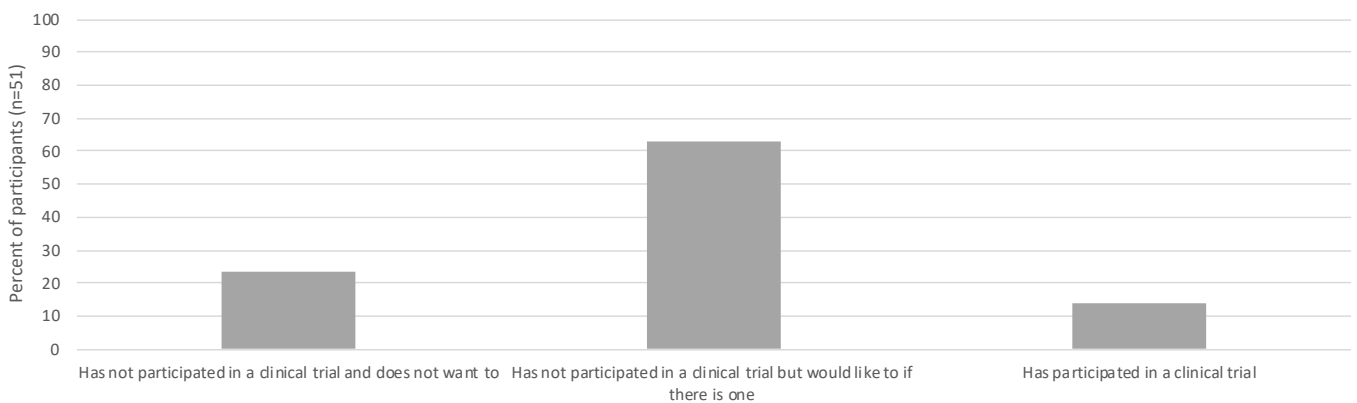


Figure 5.33: Clinical trial participation

Description of mild side effects

In the structured interview, participants were asked how they would describe the term ‘mild side effects’. The most common description of ‘mild side effects’ was to describe them with specific examples (n=27, 51.92%). There were 25 participants (48.08%) that described mild side effects as those that do not interfere with daily life, and 19 participants (36.54%) that described mild side effects as those that can be self-managed.

Of those who described a specific side effect, the most commonly described side effects were fatigue (n=7, 13.46%), mild pain or aches (n=6, 11.54%), and hair loss.

Participant provides a specific side effect as an example

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

The hair loss and stuff like that. I've been quite lucky to not have had too many side effects. I've actually been okay [chuckles] with that. Participant 042_2021AUHRP

Participant describes mild side effects as those that do not interfere with daily life

Okay. Mild side effects to me would be something that doesn't really interfere with my daily living, and I don't need to take any medication as far as Panadol or anything like that. That, to me, is a mild side effect. It's something that you know you can feel it, but it doesn't stop you doing anything. Participant 017_2021AUHRP

Well, I would say mild side effect is something that is perhaps a bit annoying but you're still functioning and able to operate as normal and do everything as normal. Participant 044_2021AUHRP

If it was mild, I could still carry out my daily activities maybe slightly reduced, but my self-care, my daily activities, and be able to continue the work, my work activities. Maybe some limitations, but still do most of the things I was doing previously in daily activities, social activities, and I guess, physically exercise and sports. Participant 047_2021AUHRP

Participant describes mild side effects as those that can be self-managed

Mild is the indigestion. Severe is the skin burn I'd say and fatigue is right up there, it's a shocker. I didn't realize the difference between fatigue and just being dead tired. Yeah. Oh, mild you can go and take Gaviscon and it fixes pain you can take Panadol and pretty much fix it. Burning skin it doesn't, you know, putting cream on does not stop that burning or itching. Participant 014_2021AUHRP

Oh, that's the minor things that you can go and take some Panadol and feel better from. Participant 030_2021AUHRP

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

Table 5.23: Description of mild side effects

Description of mild side effects	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant provides a specific side effect as an example	27	51.92	10	52.63	10	47.62	7	58.33	17	58.62	10	43.48	7	36.84	20	60.61
Participant describes mild side effects as those that do not interfere with daily life	25	48.08	9	47.37	12	57.14	4	33.33	12	41.38	13	56.52	10	52.63	15	45.45
Participant describes mild side effects as those that can be self-managed	19	36.54	7	36.84	6	28.57	6	50.00	8	27.59	11	47.83	10	52.63	9	27.27
Description of mild side effects	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant provides a specific side effect as an example	27	51.92	4	40.00	12	75.00	11	42.31	2	18.18	25	60.98	6	33.33	21	61.76
Participant describes mild side effects as those that do not interfere with daily life	25	48.08	4	40.00	8	50.00	13	50.00	6	54.55	19	46.34	11	61.11	14	41.18
Participant describes mild side effects as those that can be self-managed	19	36.54	4	40.00	2	12.50	13	50.00	6	54.55	13	31.71	5	27.78	14	41.18

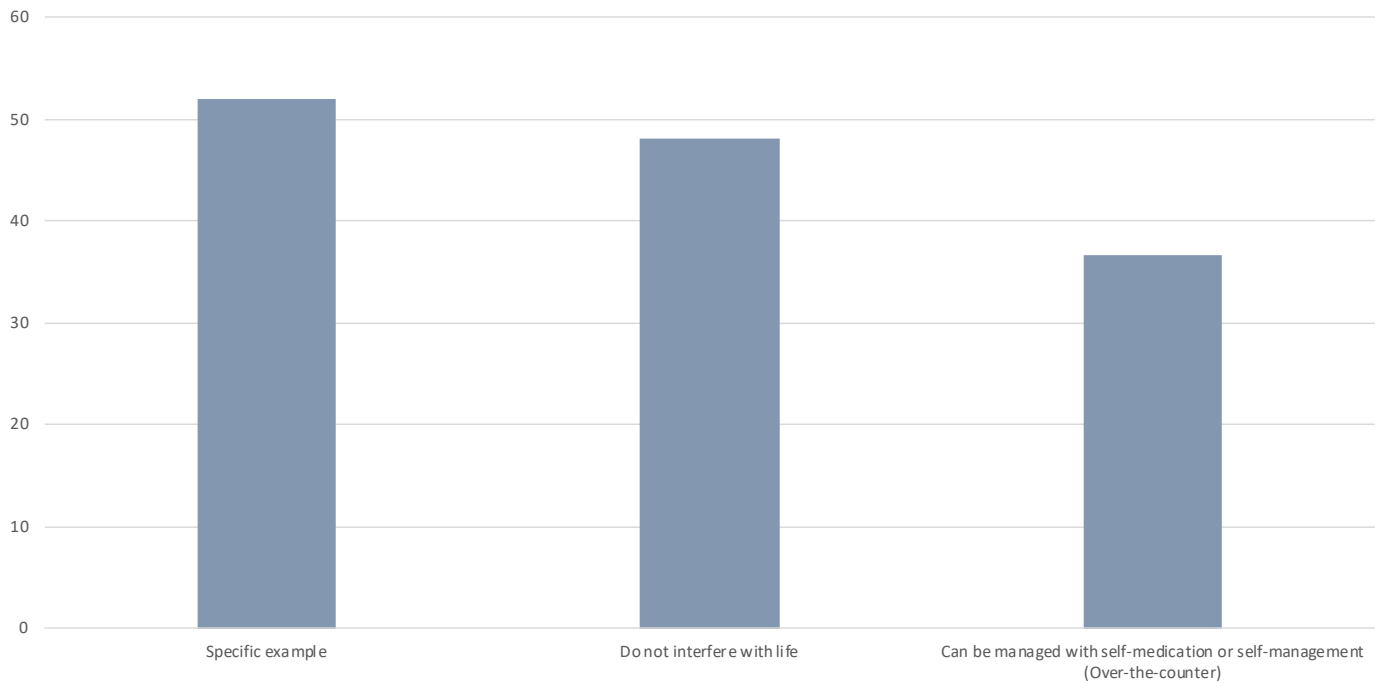


Figure 5.34: Description of mild side effects (percent of all participants)

Table 5.24: Description of mild side effects – subgroup variations

Description of mild side effects	Reported less frequently	Reported more frequently
Participant provides a specific side effect as an example	Trade or high school Diagnosed in 2016 or before Regional or remote Mid to low status	Diagnosed in 2017 to 2019
Participant describes mild side effects as those that do not interfere with daily life	Stage III and IV	Mid to low status
Participant describes mild side effects as those that can be self-managed	Diagnosed in 2017 to 2019	Stage III and IV Aged 55 to 74 Trade or high school Diagnosed in 2020 or 2021 Regional or remote

Table 5.25: Description of mild side effects (Specific side effects)

Description of mild side effects (Specific side effects)	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes mild side effects giving the specific example of Fatigue/lethargy	7	13.46	1	5.26	2	9.52	4	33.33	6	20.69	1	4.35	1	5.26	6	18.18
Participant describes mild side effects giving the specific example of aches/pain (general)	6	11.54	4	21.05	1	4.76	1	8.33	4	13.79	2	8.70	1	5.26	5	15.15
Participant describes mild side effects giving the specific example of hair loss	5	9.62	4	21.05	1	4.76	0	0.00	3	10.34	2	8.70	2	10.53	3	9.09

Description of mild side effects (Specific side effects)	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes mild side effects giving the specific example of Fatigue/lethargy	7	13.46	1	10.00	4	25.00	2	7.69	0	0.00	7	17.07	2	11.11	5	14.71
Participant describes mild side effects giving the specific example of aches/pain (general)	6	11.54	1	10.00	1	6.25	4	15.38	0	0.00	6	14.63	1	5.56	5	14.71
Participant describes mild side effects giving the specific example of hair loss	5	9.62	0	0.00	3	18.75	2	7.69	0	0.00	5	12.20	2	11.11	3	8.82

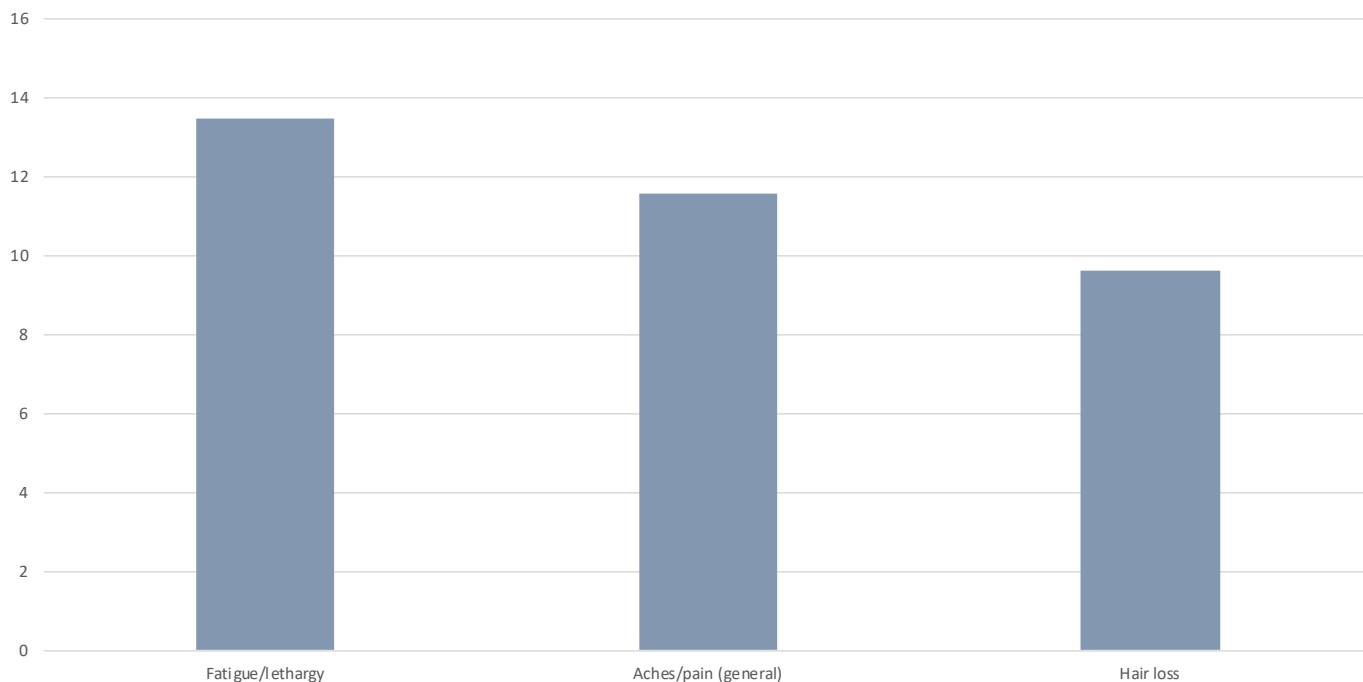


Figure 5.35: Description of mild side effects (Specific side effects) (percent of all participants)

Table 5.26: Description of mild side effects (Specific side effects) – subgroup variations

Description of mild side effects (Specific side effects)	Reported less frequently	Reported more frequently
Participant describes mild side effects giving the specific example of Fatigue/lethargy	Regional or remote	Stage III and IV Diagnosed in 2017 to 2019
Participant describes mild side effects giving the specific example of aches/pain (general)	Regional or remote	-
Participant describes mild side effects giving the specific example of hair loss	-	Stage 0 and I

Description of severe side effects

In the structured interview, participants were asked how they would describe the term ‘severe side effects’. The most common description of ‘severe side effects’ was a specific side effect as an example (n=30, 57.69%). Other descriptions of ‘severe side effects’ included those that impact everyday life/ability to conduct activities of daily living (n=26, 50.00%), those that require medical intervention (n=5, 9.62%).

Of those who described a specific side effect, the most commonly described side effects were pain (n=11, 21.15%), the emotional and mental impact (n=7, 13.46%), those that impact on sleep (n=5, 9.62%), and nausea (n=5, 9.62%).

Participant provides a specific side effect as an example of a severe side effect

The fluid accumulation post-surgery was uncomfortable and frustrating because I just wanted to get back to normal. That was probably what I found the toughest. Participant 011_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

Severe is more to do with the upset stomach for me, the nausea. It was hard to handle. That would be my thing, and the uncomfortableness behind your arm and pins, sharp pins and needles all down the back, which has now gone. It's gone, but it took a good about five months to go. Participant 032_2021AUHRP

Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living

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

Severe side effects is where you basically couldn't do what you would normally do. Participant 020_2021AUHRP

They're the activities that stop, would really stop me from doing my daily living tasks, and stopped me from working, and socializing, not being able to do social activities. It's really impacting on those and I guess my physical activities. Participant 047_2021AUHRP

Participant describes severe side effects as those that require medical intervention

Severe side effects, something that really limits me being able to function or puts me in a situation where I need other medical intervention? Yes, that would be my idea of severe side effects. 003_2021AUHRP

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

Yes, it's probably when you have to take the Endone that they prescribe for you. Participant 026_2021AUHRP

Table 5.27: Description of severe side effects

Description of severe side effects	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant provides a specific side effect as an example of a severe side effect	30	57.69	12	63.16	10	47.62	8	66.67	17	58.62	13	56.52	9	47.37	21	63.64
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	26	50.00	8	42.11	12	57.14	6	50.00	13	44.83	13	56.52	11	57.89	15	45.45
Participant describes severe side effects as those that require medical intervention	5	9.62	0	0.00	4	19.05	1	8.33	3	10.34	2	8.70	1	5.26	4	12.12

Description of severe side effects	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant provides a specific side effect as an example of a severe side effect	30	57.69	3	30.00	13	81.25	14	53.85	5	45.45	25	60.98	9	50.00	21	61.76
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	26	50.00	5	50.00	7	43.75	14	53.85	7	63.64	19	46.34	10	55.56	16	47.06
Participant describes severe side effects as those that require medical intervention	5	9.62	1	10.00	1	6.25	3	11.54	1	9.09	4	9.76	1	5.56	4	11.76

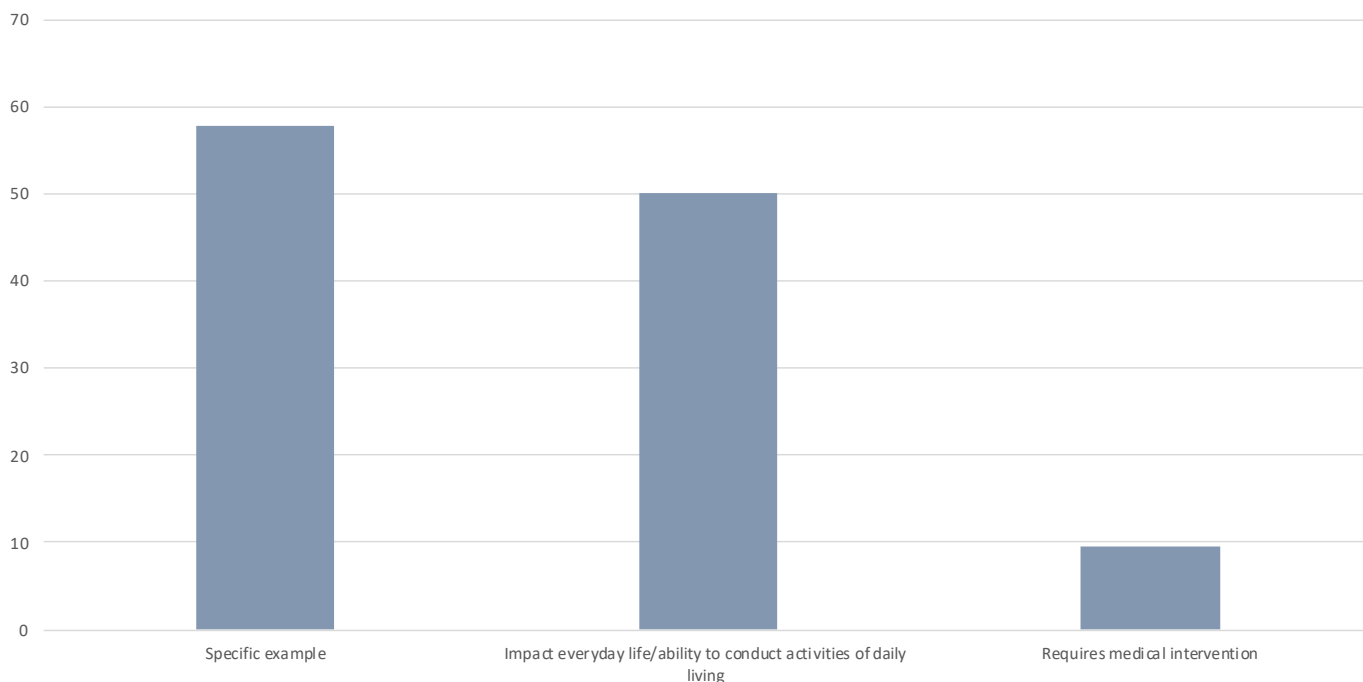


Figure 5.36: Description of severe side effects (percent of all participants)

Table 5.28: Description of severe side effects – subgroup variations

Description of severe side effects	Reported less frequently	Reported more frequently
Participant provides a specific side effect as an example of a severe side effect	Stage II Trade or high school Diagnosed in 2016 or before Regional or remote	Diagnosed in 2017 to 2019
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	-	Regional or remote

Table 5.29: Description of severe side effects (Specific example)

Description of severe side effects (Specific example)	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes severe side effects giving the specific example of aches/pain (general)	11	21.15	5	26.32	4	19.05	2	16.67	4	13.79	7	30.43	2	10.53	9	27.27
Participant describes severe side effects giving the specific example of the emotion/mental impact	7	13.46	1	5.26	4	19.05	2	16.67	3	10.34	4	17.39	3	15.79	4	12.12
Participant describes severe side effects giving the specific example of the impact on sleep	5	9.62	3	15.79	0	0.00	2	16.67	4	13.79	1	4.35	0	0.00	5	15.15
Participant describes severe side effects giving the specific example of nausea	5	9.62	2	10.53	2	9.52	1	8.33	4	13.79	1	4.35	4	21.05	1	3.03

Description of severe side effects (Specific example)	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes severe side effects giving the specific example of aches/pain (general)	11	21.15	1	10.00	4	25.00	6	23.08	2	18.18	9	21.95	6	33.33	5	14.71
Participant describes severe side effects giving the specific example of the emotion/mental impact	7	13.46	0	0.00	4	25.00	3	11.54	1	9.09	6	14.63	3	16.67	4	11.76
Participant describes severe side effects giving the specific example of the impact on sleep	5	9.62	1	10.00	2	12.50	2	7.69	1	9.09	4	9.76	0	0.00	5	14.71
Participant describes severe side effects giving the specific example of nausea	5	9.62	0	0.00	2	12.50	3	11.54	1	9.09	4	9.76	1	5.56	4	11.76

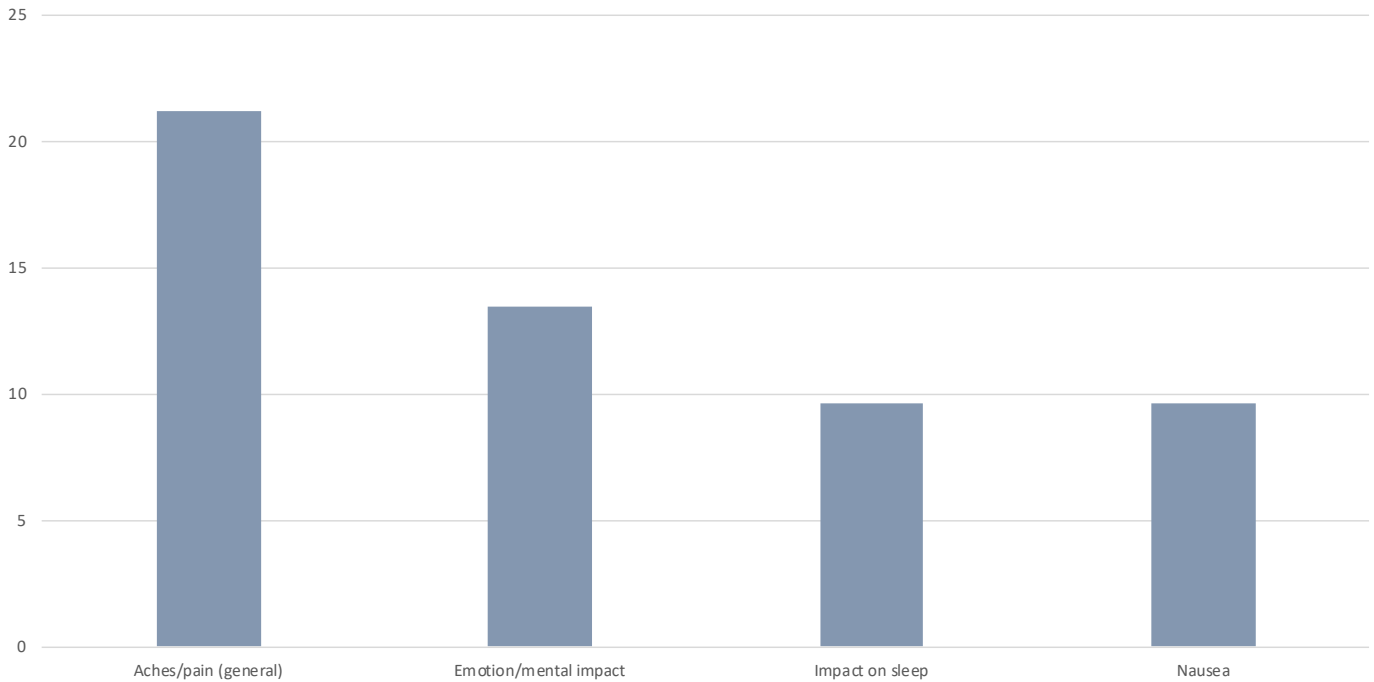


Figure 5.37: Description of severe side effects (Specific example) (percent of all participants)

Table 5.30: Description of severe side effects (Specific side effects)– subgroup variations

Description of severe side effects (Specific example)	Reported less frequently	Reported more frequently
Participant describes severe side effects giving the specific example of aches/pain (general)	Trade or high school Diagnosed in 2016 or before	Mid to low status
Participant describes severe side effects giving the specific example of the emotion/mental impact	Diagnosed in 2016 or before	Diagnosed in 2017 to 2019
Participant describes severe side effects giving the specific example of nausea	-	Trade or high school

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime. The most common themes described were adhering to treatment for a specific amount of time (n=20, 38.46%), and as per the advice of their specialist/as long as prescribed (n=19, 36.54%). Other participants described adhering to treatment as long as side effects are tolerable (n=15, 28.85%), and not giving up on any treatment (n=15, 28.85%).

Where participants stated a specific amount of time to adhere to a treatment, the most common amount of time was two to three months.

Participant describes adhering to treatment for a specific amount of time

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

I give something at least three months before I ask a question as to why isn't it doing what it's supposed to do. Participant 018_2021AUHRP

With the tablets, the first one I stuck with it for about three months. Then they put me on to the second one. I think I was on that for two months. Then they put me on the third one. Then by about two months when it was still giving me grief, that's when we had the conversation about long-term prognosis before I stopped taking them. I kept taking them. ...hen it was only in the last couple of months that I stopped. I pulled the sheets and I stopped taking them full stop. Participant 025_2021AUHRP

Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed

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

I didn't, I never did that. So I was five years on the Tamoxifen. And because I said five years, I didn't want to go the extra time because that was all new too. By the end of my five years, I'm just playing with trying for 10 years. And I've had enough I think I had that five year goal in my head that they said I could stop, and I think I mentioned the Zoladex I got after speaking with the surgeon and how I was feeling it was decided that it was better not to take it anymore. Participant 045_2021AUHRP

I probably the required length, in consultation with the medical person I continued. After discussing with them, I continued for the recommended time. Participant 047_2021AUHRP

Participant describes adhering to treatment as long as side effects are tolerable

Me personally, probably a good couple of months I'll do it. Depends how bad the side effects were. If it made you throw up and feel like that, I think two months is a long time. Participant 009_2021AUHRP

Usually, I'll just keep sticking with it forever until I see the doctor again. Unless it's causing really bad side effects or something. Participant 036_2021AUHRP

I'd say I'd like to give it a good chance. I know sometimes too, when you're starting a new medicine you can have the side effects then they can sort of die down or you get used to it as well. I tend to stick with it. The only thing would be if the side effects outweigh the benefits. Yes, I do like to stick with some things. Participant 052_2021AUHRP

Participant describes not giving up on any treatment

I haven't really been in that position. I have surgery, radiotherapy. That's done. I started on tamoxifen and then that's been fine. I'll stick with that. I think the tough thing will be when someone suggests I don't need to take it anymore. At this point, I would be very anxious about stopping it. Participant 011_2021AUHRP

Right. And I've been on this letrozole for a while now, nearly a year. So yeah, I haven't given up I thought, I know I mean, a Facebook group where a lot of women go oh stuff this, I'm not doing it because any, when you look at the percentages, it's only a couple of percents that increases but I said she's going to take all the percent you can get on top of everything you know, to survive. Participant 041_2021AUHRP

I've never got to that point. I guess with tamoxifen I was getting side effects, but I always knew that I wanted to get onto an aromatase inhibitor because that was meant to be better for invasive lobular. I just cracked on through tamoxifen. I'm not at that point yet. Even if I stop my medication-- A lot of women talk about stopping tamoxifen or Aromasin because of the impact it's having on them being in menopause, but the fact is even if I stop taking those drugs now, I've

had my gynae surgery. I have those side effects. I'm not at that stage. I think it's also difficult to try and differentiate. Is that side effect because I'm in menopause, is it because of the Aromasin, or is it because I'm getting older, or is it just because of the cancer or of all the treatment? Is it all of those things? It's really difficult to actually isolate what's what. Participant 043_2021AUHRP

Table 5.31: Adherence to treatment

Adherence to treatment	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes adhering to treatment for a specific amount of time	20	38.46	7	36.84	9	42.86	4	33.33	12	41.38	8	34.78	10	52.63	10	30.30
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	19	36.54	6	31.58	11	52.38	2	16.67	10	34.48	9	39.13	8	42.11	11	33.33
Participant describes adhering to treatment as long as side effects are tolerable	15	28.85	8	42.11	6	28.57	1	8.33	5	17.24	10	43.48	6	31.58	9	27.27
Participant describes not giving up on any treatment	15	28.85	3	15.79	7	33.33	5	41.67	10	34.48	5	21.74	2	10.53	13	39.39

Adherence to treatment	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes adhering to treatment for a specific amount of time	20	38.46	3	30.00	8	50.00	9	34.62	3	27.27	17	41.46	8	44.44	12	35.29
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	19	36.54	7	70.00	3	18.75	9	34.62	6	54.55	13	31.71	7	38.89	12	35.29
Participant describes adhering to treatment as long as side effects are tolerable	15	28.85	4	40.00	4	25.00	7	26.92	4	36.36	11	26.83	6	33.33	9	26.47
Participant describes not giving up on any treatment	15	28.85	1	10.00	7	43.75	7	26.92	4	36.36	11	26.83	8	44.44	7	20.59

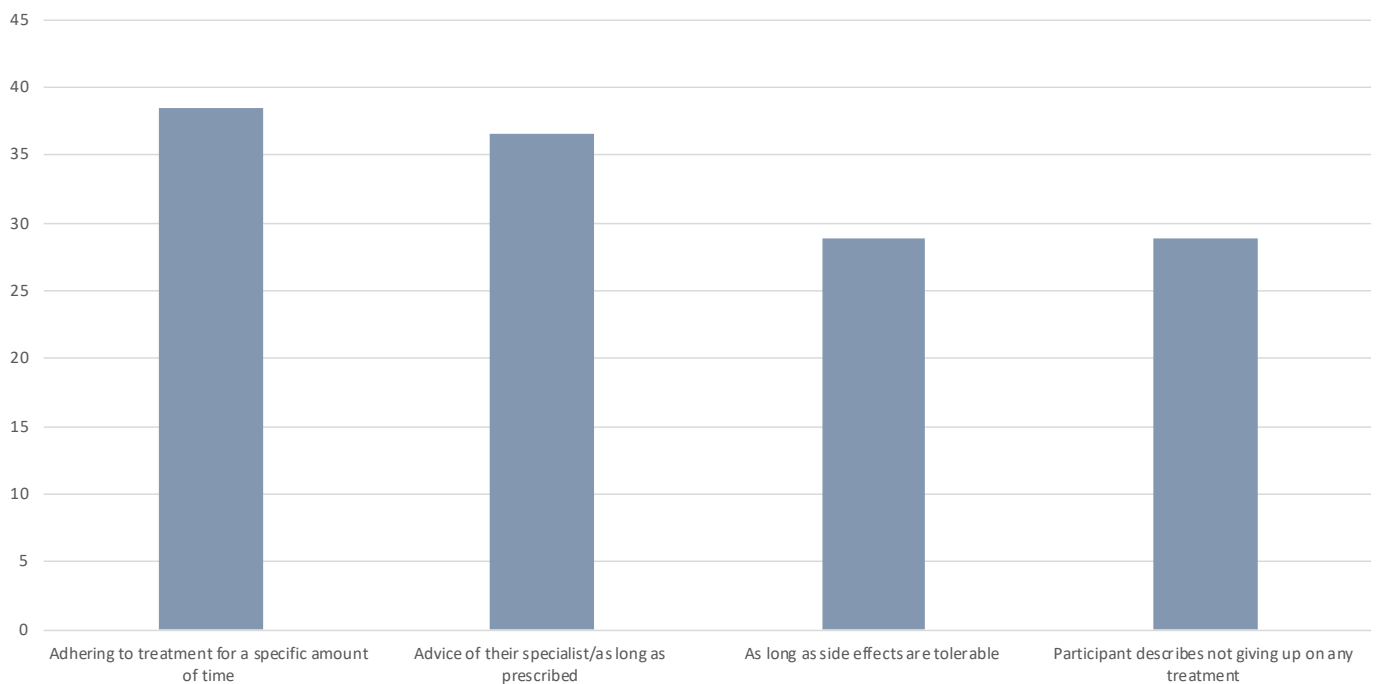


Figure 5.38: Adherence to treatment (percent of all participants)

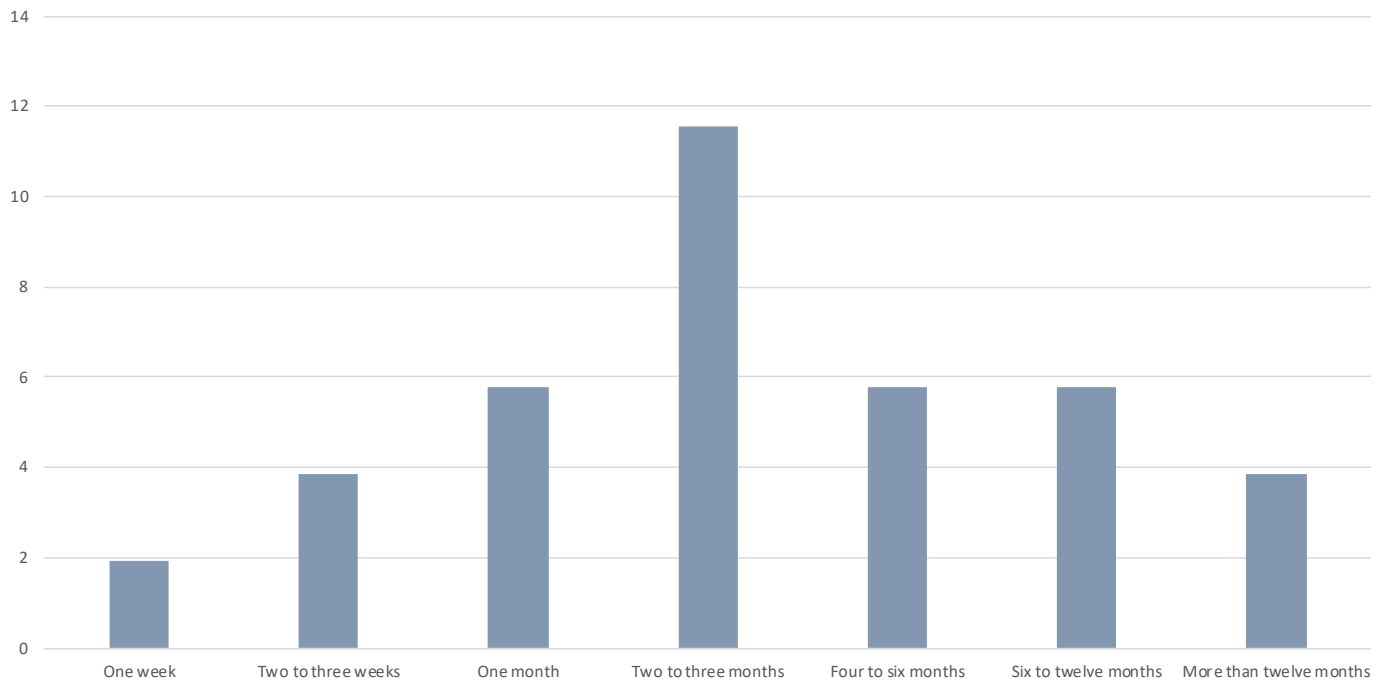


Figure 5.39: Adherence to treatment (Time to adhere to treatment) (percent of all participants)

Table 5.32: Adherence to treatment – subgroup variations

Adherence to treatment	Reported less frequently	Reported more frequently
Participant describes adhering to treatment for a specific amount of time	Regional or remote	Trade or high school Diagnosed in 2017 to 2019
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	Stage III and IV Diagnosed in 2017 to 2019	Stage II Diagnosed in 2016 or before Regional or remote
Participant describes adhering to treatment as long as side effects are tolerable	Stage III and IV Aged 25 to 54	Stage 0 and I Aged 55 to 74 Diagnosed in 2016 or before
Participant describes not giving up on any treatment	Stage 0 and I Trade or high school Diagnosed in 2016 or before	Stage III and IV University Diagnosed in 2017 to 2019 Mid to low status

What needs to change to feel like treatment is working

Participants were asked to describe what needs to change to feel like treatment is effective. The most common response from 24 participants (46.15%) was needing to see an improvement in specific symptoms, and this was followed by 19 participants (36.54%) that reported needing to experience an improvement in side effects in general, and needing evidence of stable disease or no disease progression (n= 12, 23.08%). There were 12 participants (23.08%) that described needing to have a balance between benefits and potential side effects, and 11 participants (21.15%), that reported that it was difficult to know if the treatment was working and that they needed evidence.

Where participants need to see improvements in specific side effects, the most noted side effects were aches and pain, and hot flushes.

Participants reported needing to experience an improvement in a specific symptom

Yeah, I guess Yeah, I guess certainly being less stressful, which is probably a direct result of possibly feeling better, having more energy. For me, because of the weight gain, it would possibly be losing weight, but feeling good, not losing weight for the wrong reasons, like or through stress or something like that, but genuinely losing it, because maybe you are more, have more energy. So you're doing more active, you know, you're doing more walking or exercising more than what you have. I guess if you've got swelling in things reduce swelling, if there's any, you know, healing of scars, that's all things that that that are working, you know that your skin is not dry and flaky or or. Whats the word is when it's sort of cold and clammy. Like your hair is in good condition. Like it's not dried, it's not falling out. And healthy for skin in terms of feeds moisturizer, like retains the moisture. So all those combination of things, I think. And I think you know, your stress is directly related to how you're feeling. So I think if you're feeling better, and things are looking better, then you tend to not stress as much you're more calm. Yeah. Participant 013_2021AUHRP

Yes, a reduction in the side effects. The reduced number of hot flushes I experience in a 24-hour period. Or the management of pain. If I'm taking something for the management of pain I would expect the pain to reduce. Participant 027_2021AUHRP

My foot, I used to support stuff, sometimes my feet are feeling really good today, I won't go with the support stuff and I might be able to go two or three days without it and then it will come back, it'll get worse and, "Okay, I've got to put the support stuff on again." It just gives me a little break from it sometimes or not doing at all but it comes back and I know what I've got to do to start off again. Participant 004_2021AUHRP

Participants reported needing to experience an improvement in side effects in general

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

So it'd be a reduction in side effects, or I guess it would be something that I would go through if there was a, you know, an in an increased chance of a better lifestyle outcome at the end of it. So, that bone pain that you get from the treatment, does that prevent you from doing anything in your day to day. Participant 020_2021AUHRP

Participants reported needing to experience evidence of stable disease/no disease progression

Probably I'd like to see maybe with the radiation especially, a bit of a X-ray or a scan before and after and what it's done. Visually I can't see that. I don't see that. I don't know. I didn't ask to see that either. Whether they would have showed me that, I don't know. It's something visual. I'm a visual person. I know it's probably make you feel more paranoid about it coming back, but I think to when I go back in December and see the surgeon, I know he's probably not going to allow me to do it. I could ask for it. I'd like to have another MRI done of my breast and see something visual that it's not there. Participant 009_2021AUHRP

PARTICIPANT: Oh, that you're cancer free that you have a scan, of breast cancer patients don't unless they're symptomatic. They don't have scans, they just have mammography or ultrasounds they don't have CTs, like about cancer or pancreatic cancer, we don't have anything or you don't need any scans unless you symptomatic. And then I see so many women with breast cancer present with symptoms are yet sorry, it's gone to your bones Gone to your lungs. Okay. So that sort of is strange to me, but I guess there must be research that shows there's no need to unnecessary scan. For breast cancer patients

INTERVIEWER: So, if your not getting those scans, how do you know if the treatment's working?

PARTICIPANT: Exactly. I'm having a mammogram and ultrasound, so I'll know that it's not in my boob. Yeah, but unless you're a stage three or four, I doubt you're gonna have scans. Okay, right, I guess because it shouldn't really come back. But you know, there's different types of breast cancers, some are more aggressive than others. It just depends on all your scores and all that stuff we go into. So I guess you're not going to know you're just going to have to trust that your mammogram and see a good boob and your ultrasound on your lymph nodes. And that shows up. Participant 041_2021AUHRP

Well, for me, it's just knowing that the tumor is responding to it. The side effects are all manageable if I know that it's working. The side effects, a lot of them are great so I'll put up with it if I know that the tumour is shrinking. Participant 044_2021AUHRP

Participant describes needing to have a balance between benefits and potential side effects

Definitely a reduction in side effects. It does—In the groups that I'm in, the support groups that I'm in the women some women just refuse, they just think it's about quality of life, not quantity. I mean I haven't got to that stage fortunately but there's a lot of women out there that just, "No, I want quality of life." They won't and look I'm one of the lucky ones. I don't consider that I've got bad side effects from this medication at this stage. There are a lot of women that have atrocious side effects and I don't know how they freaking get up and function every day. Participant 010_2021AUHRP

A reduction in side effects would be good and knowing that what I'm taking is keeping or is helping me. I don't know. They say that taking this hormone therapy, I think my oncologist told me it was only 8%,

but with chemo, it was 6%; this is 8%. It doesn't seem like a lot, but I'd rather put up with five years of mild symptoms if it's going to give me an 8% greater chance. If it's going to be severe like the first lot was, then I'd have to think about that again. I don't know if I'm going to continue it if the symptoms that I had from this last medication come again. Participant 035_2021AUHRP

I guess I'm not really going to know unless it worked. The only reason you know it hasn't worked is when you get the cancer back. I guess for me one of the key things I ask myself is, "If I stop doing this and my cancer came back, how would I feel?" That's one of the things that I try and think about. Is it too much? Is it too debilitating? Is it affecting my life to the point where it's just too much? I guess I'm not there at the moment. Participant 043_2021AUHRP

Participant reports that it is difficult to know that it is working/needs evidence

Yes, that's a hard one because I guess I couldn't understand why I needed to have chemo. I thought that that was a bit strange when I had a double mastectomy, my lymph nodes with CR, I didn't understand that. To me, you've gone through all this trauma of your body changing, and now you want me to do chemo and I lose my hair and all that stuff, and basically, I'm going to be off work. I think they need to sell it a bit better, I think, why? You need to have full disclosure and an understanding of why are they doing this, not because, "We just do this, because everyone that's in this category that has it." I think it needs to be really explained, research, evidence-based, and that's what we will do. When you have that cancer diagnosis, you start looking at research, you start hearing what other people are doing, what's out there, so they need to probably speak a little bit more like that as well. This is going to increase your probability or chances and whatever, but just, I don't know, having that more understanding. Participant 048_2021AUHRP

I don't know because with the cancer, I guess you can't tell if it's working or not. Sorry, I don't know. For the side effects, yes. When I was going to chemo, then anti-nausea tablets and stuff like yes that would work. Definitely that. I don't know whether the hormonal replacement therapy that I'm taking, is it working? I won't know. There are no markers that shows you that. There's no blood test I can take. I see that's the hard part of it. You don't know whether it's working or it's not. Until it comes back and you say, "Yes." I think that's the hard part. Participant 040_2021AUHRP

Well, with the cancer one you can't really tell, but with the side effects one, it's usually whether you get a significant improvement, or a mild improvement, or no improvement. Participant 036_2021AUHRP

Well, you don't really know, do you? I guess it's a bit of a hidden thing. You just got to hope that it's working. Participant 016_2021AUHRP

Table 5.33: What needs to change to feel like treatment is working

What needs to change to feel like treatment is working	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participants reported needing to experience an improvement in a specific symptom	24	46.15	8	42.11	11	52.38	5	41.67	10	34.48	14	60.87	8	42.11	16	48.48
Participants reported needing to experience an improvement in side effects in general	19	36.54	7	36.84	8	38.10	4	33.33	11	37.93	8	34.78	8	42.11	11	33.33
Participants reported needing to experience evidence of stable disease/no disease progression	12	23.08	5	26.32	4	19.05	3	25.00	7	24.14	5	21.74	3	15.79	9	27.27
Participant describes needing to have a balance between benefits and potential side effects	12	23.08	4	21.05	6	28.57	2	16.67	6	20.69	6	26.09	5	26.32	7	21.21
Participant reports that it is difficult to know that it is working/needs evidence	11	21.15	5	26.32	2	9.52	4	33.33	6	20.69	5	21.74	4	21.05	7	21.21

What needs to change to feel like treatment is working	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participants reported needing to experience an improvement in a specific symptom	24	46.15	6	60.00	8	50.00	10	38.46	5	45.45	19	46.34	5	27.78	19	55.88
Participants reported needing to experience an improvement in side effects in general	19	36.54	4	40.00	5	31.25	10	38.46	2	18.18	17	41.46	7	38.89	12	35.29
Participants reported needing to experience evidence of stable disease/no disease progression	12	23.08	1	10.00	5	31.25	6	23.08	4	36.36	8	19.51	6	33.33	6	17.65
Participant describes needing to have a balance between benefits and potential side effects	12	23.08	3	30.00	4	25.00	5	19.23	2	18.18	10	24.39	4	22.22	8	23.53
Participant reports that it is difficult to know that it is working/needs evidence	11	21.15	2	20.00	4	25.00	5	19.23	1	9.09	10	24.39	7	38.89	4	11.76

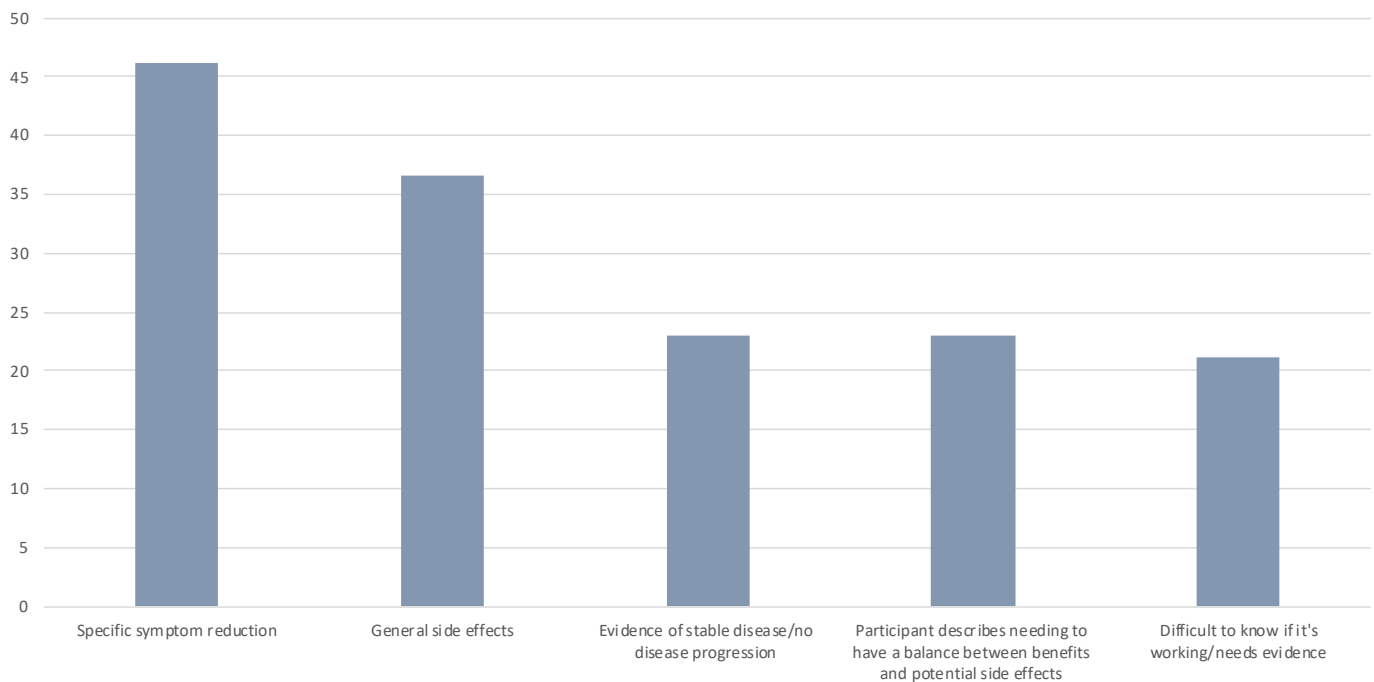


Figure 5.40: What needs to change to feel like treatment is working (percent of all participants)

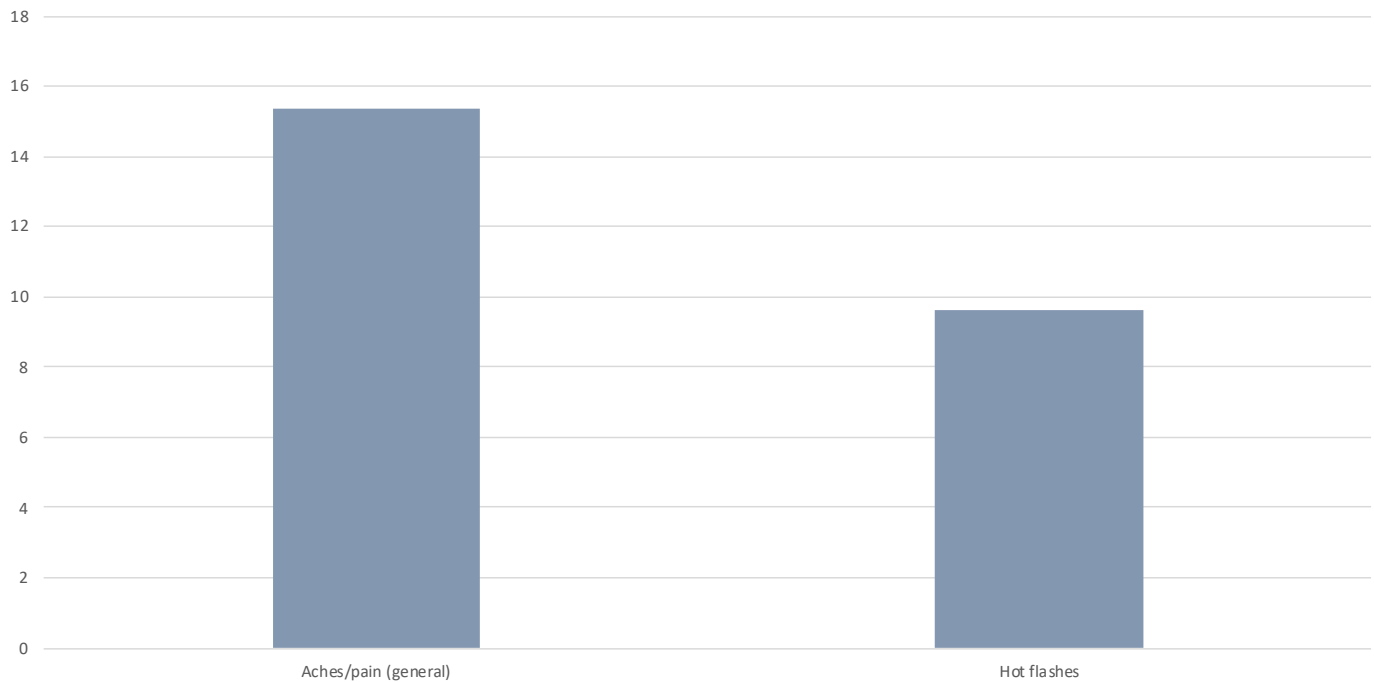


Figure 5.41: What needs to change to feel like treatment is working (specific symptoms) (percent of all participants)

Table 5.34: What needs to change to feel like treatment is working – subgroup variations

What needs to change to feel like treatment is working	Reported less frequently	Reported more frequently
Participants reported needing to experience an improvement in a specific symptom	Aged 25 to 54 Mid to low status	Aged 55 to 74 Diagnosed in 2016 or before
Participants reported needing to experience an improvement in side effects in general	Regional or remote	-
Participants reported needing to experience evidence of stable disease/no disease progression	Diagnosed in 2016 or before	Regional or remote Mid to low status
Participant reports that it is difficult to know that it is working/needs evidence	Stage II Regional or remote	Stage III and IV Mid to low status

What it would mean if treatment worked

Participants were asked to describe what it would mean to them, if their treatment worked. The most common response from 25 participants (48.08%) was allowing them to return to everyday activities or return to normal life. Other participants described that it would have a positive impact on their mental health (n=13, 25.00%), that it would allow them to work (n=9, 17.31%), get enough sleep (n=6, 11.54%), and do more exercise (n=5, 9.62%).

Participant describes treatment allowing them to do everyday activities/ return to normal life

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

I think being 41 years old, and every time I stand up, I feel like I'm 80, it's really hard. That would mean a lot to me to just feel normal again, I'm going to cry just thinking of it. Yes, because it really, you feel like that once the chemo is over, that you can start living again and get back to normal life, but you realize that your life's never going to be like that again. That's why I think I've struggled with the whole hormone therapy stuff and then they want to take out my ovaries and all that, I'm just refusing to do that, because there's a lot of research, you remove all those hormones totally, then you're already reducing someone's life sentence already, because your body made some of those hormones to function correctly to keep your organs and all that healthy, I do struggle with that a lot. Participant 048_2021AUHRP

Participant describes treatment working as having a positive impact on their mental health

For me, it's the impact and me emotionally, the chronic ongoing pain just get me down at times. I would say that compared to other people, my pain isn't really severe, but it's always there. It's things that I don't do that I used to really enjoy doing, cross stitching, that sort of thing, that my wrist doesn't really tolerate these days. My writing was never overly neat. These days, it's atrocious and ended actually. I can't for more than a few lines before my wrist starts getting really uncomfortable. Having never learned to touch stuff, I'm actually more comfortable typing than writing. [chuckles] The lymphedema for me has actually meant that I've had to change what I do work-wise. Of course, that is something that isn't ever going to go away. I just had to learn to live with that. Then alternative work that I've been really lucky to find. That's been a big side effect of it all. I forget that one sometimes. Participant 023_2021AUHRP

Probably, I think for mental support, I think often that's probably missed because it can be-- you do question how many chemicals you keep pumping and pumping into your body and it's like the tamoxifen, I know it's working even though my cancer count goes up and down. I feel that it is still working but sometimes, because I live in a warm part of Victoria, once full summer, late spring, summer, and autumn come along, I just perspire all the time. That sort of does impact what you then do and when you do things day to day, this sort of thing, it does change my routine quite a bit like I'll get up earlier and be outside early then come inside. I'll probably have a rest for a couple of hours around midday because then in the evening it's a lot cooler so I'm back outside. So you're outside for a lot longer but I think the mental support is probably a big one. Participant 031_2021AUHRP

If I had reduced side effects I'd probably more consistent in taking my medication. In that sense, I would actually then also, it would alleviate the feeling of worry and guilt. Even though you're making a decision to say, "I'm not going to take this medication," then you worry because you're not taking it. I think if the side effects were less, more patients would be inclined to take and deal with treatment. That's generally why most people stop any treatment whether it's radiation, chemotherapy, because the side effects are just not worth it. Participant 038_2021AUHRP

Participant describes treatment allowing them to return to work

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

If you're on a treatment which makes you nauseous, yes, you can take something to help alleviate the nausea, but that to me just means another pill to mask the problem. I'd prefer them to try and find a solution with a medication that doesn't create those things in the first place. Having said that, yes, if you can take something that alleviates it so you can-- in my case I can't work full time because I can't stand on my feet for more than a short period of time. I just lost a job because my wrist doesn't work properly so because I can't do what needs to be done at a speed that needs to be done, I can't hold that job. It impacts on your ability to better your life. I don't have answers for that because I don't know. Participant 018_2021AUHRP

I guess, if it wasn't causing this fatigue and some of the major issues, then I probably wouldn't miss as much work and probably wouldn't need to ask as much assistance from people but as it is, I'm coping pretty well. I don't know. When I was having AC chemo, I missed a fair bit of work in the days afterward. For a few days afterward, immediately after I was stuck. If I didn't have that side effect, I wouldn't have missed work. Participant 044_2021AUHRP

Participant describes treatment allowing them to get enough sleep

Well, most of the stuff I'm taking at the moment is just for the menopause thing. I think all that would happen is I would sleep better. Otherwise, they don't stop me doing things that this is uncomfortable, something that's disgusting and gross. If that stops happening, I'll have to do a lot less that would be better. Participant 036_2021AUHRP

I think if we talk about the hot flashes, for one of them, [unintelligible 00:16:26] talk about, increasing my body heat means that I shouldn't be exercising in the heat of the day. I can't overheat because then that increases the hot flashes and that increases the side effects of those which can be quite uncomfortable. Obviously, at night time, too many of those can keep you awake, they wake you up, they make it very difficult to sleep. Obviously, sleep deprivation then impacts the rest of your day. If I was to see a reduction even by half of those symptoms, then I'd simply be taking the medication because it would definitely lead to obviously a better night's sleep and you're going to be [unintelligible] the next day. Participant 037_2021AUHRP

Sleep, that's easy. [laughs] Sleep through the night. I think that would be the main thing. Participant 005_2021AUHRP

Participant describes treatment allowing them to do more exercise

It just means I could be more mobile. I could hit my 10,000 steps a day. Well, not quite. Having the antidepressant didn't take the pain away. It just made it easier to push through. By four-five o'clock, I was still in agony. If I could get rid of the side effects, I'd still be taking the tablets. Participant 025_2021AUHRP

Oh, I almost couldn't look after myself. In terms of, I couldn't carry out my daily living tasks, so I couldn't really go shopping. I couldn't go out socially. I certainly couldn't do any physical activity like sport or exercise. Couldn't do any of that. Participant 047_2021AUHRP

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

Table 5.35: What it would mean if treatment worked

What it would mean if treatment worked	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes treatment allowing them to do everyday activities/ return to normal life	25	48.08	9	47.37	10	47.62	6	50.00	11	37.93	14	60.87	9	47.37	16	48.48
Participant describes treatment working as having a positive impact on their mental health	13	25.00	3	15.79	7	33.33	3	25.00	8	27.59	5	21.74	4	21.05	9	27.27
Participant describes treatment allowing them to return to work	9	17.31	5	26.32	3	14.29	1	8.33	6	20.69	3	13.04	2	10.53	7	21.21
Participant describes treatment allowing them to get enough sleep	6	11.54	4	21.05	1	4.76	1	8.33	3	10.34	3	13.04	0	0.00	6	18.18
Participant describes treatment allowing them to do more exercise	5	9.62	1	5.26	1	4.76	3	25.00	3	10.34	2	8.70	1	5.26	4	12.12

What it would mean if treatment worked	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes treatment allowing them to do everyday activities/ return to normal life	25	48.08	7	70.00	6	37.50	12	46.15	6	54.55	19	46.34	11	61.11	14	41.18
Participant describes treatment working as having a positive impact on their mental health	13	25.00	2	20.00	7	43.75	4	15.38	2	18.18	11	26.83	3	16.67	10	29.41
Participant describes treatment allowing them to return to work	9	17.31	1	10.00	3	18.75	5	19.23	1	9.09	8	19.51	2	11.11	7	20.59
Participant describes treatment allowing them to get enough sleep	6	11.54	3	30.00	2	12.50	1	3.85	1	9.09	5	12.20	4	22.22	2	5.88
Participant describes treatment allowing them to do more exercise	5	9.62	2	20.00	2	12.50	1	3.85	1	9.09	4	9.76	3	16.67	2	5.88

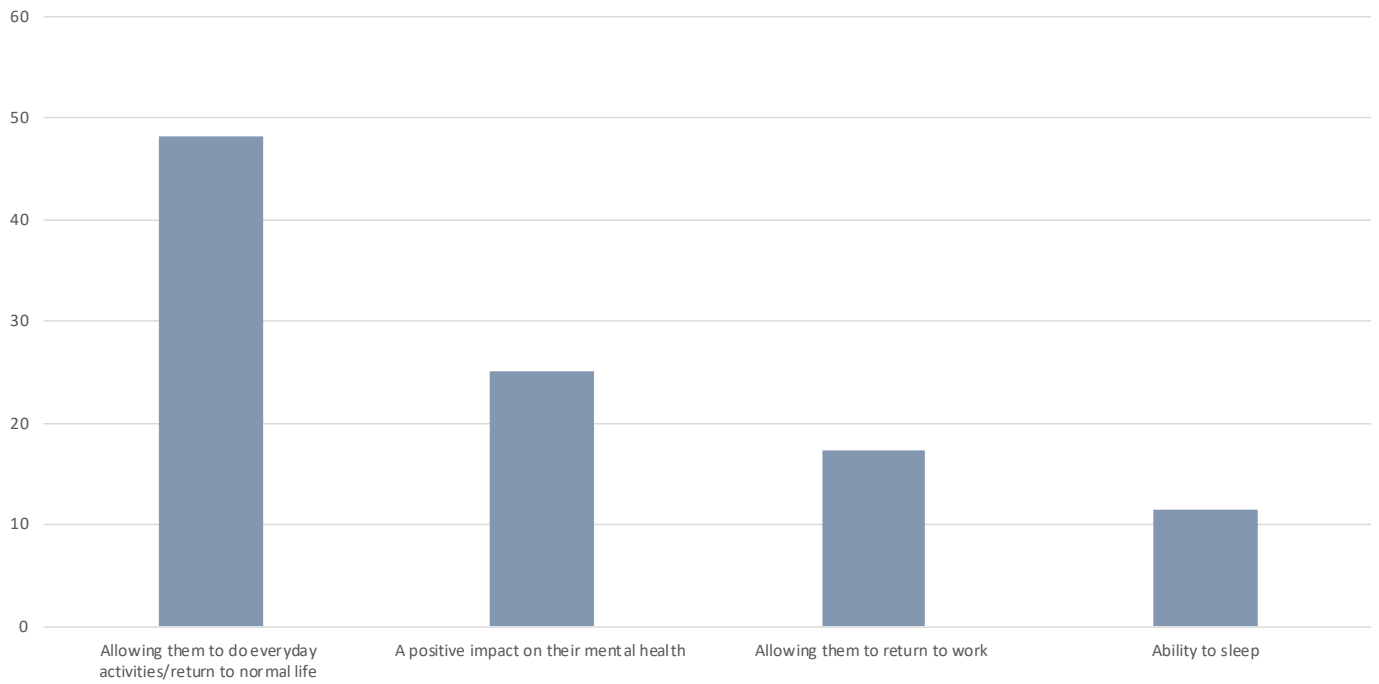


Figure 5.42: What it would mean if treatment worked (percent of all participants)

Table 5.36: What it would mean if treatment worked – subgroup variations

What it would mean if treatment worked	Reported less frequently	Reported more frequently
Participant describes treatment allowing them to do everyday activities/ return to normal life	Aged 25 to 54 Diagnosed in 2017 to 2019	Aged 55 to 74 Diagnosed in 2016 or before Mid to low status
Participant describes treatment working as having a positive impact on their mental health	-	Diagnosed in 2017 to 2019
Participant describes treatment allowing them to get enough sleep	Trade or high school	Diagnosed in 2016 or before Mid to low status
Participant describes treatment allowing them to do more exercise	-	Stage III and IV Diagnosed in 2016 or before