

Section 5

Treatment

Section 5: Experience of treatment

Main provider of treatment

The most common providers of treatment and care were medical oncologists (n = 23, 52.27 %), followed by general practitioners (n = 9, 20.45%).

There were 16 participants (37.21%) that travelled for less than 15 minutes, 15 participants (34.88%) that travelled between 15 and 30 minutes, eight participants (18.60%) that travelled between 30 and 60 minutes, three participants (6.98%) that travelled between 60 and 90 minutes, and one participant (2.33%) that travelled more than 90 minutes

Access to healthcare professionals

All participants had access to a medical oncologist (n = 44, 100%), and almost all had a specialist surgeon (n = 42, 95.45%) and a general practitioner (n = 41, 93.18%). There were 38 participants (86.36%) that had an oncology/chemotherapy nurse and 37 participants (84.09%) that had a breast care nurse.

Almost half of the participants had a pharmacist to care for their condition (n = 18, 40.91%). There were 21 participants (47.73%) treated by a physiotherapist and, 11 participants (25.00%) treated by a dietitian/nutritionist.

Respect shown

There were 34 participants (77.27%) that indicated that they had been treated with respect throughout their experience, and nine participants (20.45%) who were treated with respect with the exception of one or two occasions. .

Health care system

The majority of participants had private health insurance (n = 33, 75.00%). The majority of participants were asked if they wanted to be treated as a public or private patient (n = 28, 63.64%), and, they were asked if they had private health insurance (n = 39, 88.64%).

Throughout their treatment, there were 20 participants (45.45%) who were treated as a private patient, 20 participants (45.45%) were mostly treated as a public patient, and there were four participants (9.09%) who were equally treated as a private and public patient.

Affordability of healthcare

The majority of participants never or rarely had to delay or cancel appointments due to affordability (n = 39, 88.64%).

Almost all of the participants never or rarely were unable to fill prescriptions (n = 40, 90.91%).

There were 34 participants (79.28%) that never or rarely had trouble paying for essentials, such as such as food, housing and power, and six participants (13.64%) that sometimes found it difficult, and four participants (9.09%) often or very often found it difficult to pay for basic essentials.

There were four participants (9.09%) that paid for additional carers due to their condition.

Cost of condition

Participants spent between \$50 and \$10,000 per month, most commonly between \$101 or less (n = 10, 22.73%), and \$101 to \$250 (n =10, 22.73%).

The amount spent was an extremely significant or moderately significant burden for 11 participants (25.00%), somewhat significant for nine participants (20.45%), and slightly or not at all significant for 24 participants (54.55%).

Changes to employment status

Work status for 12 participants (27.27%) had not changed since diagnosis, or were retired or did not have a job. There were four participants (9.09%) had to quit their job, 10 participants (22.73%) reduced the number of hours they worked, and four participants (9.09%) that accessed their superannuation early. There were 16 participants (36.36%) that took leave from work without pay, and 12 participants (27.27%) who took leave from work with pay.

There were 11 participants (25.00%), 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 = 22, 50.00%). There were four participants (9.09%) whose partners reduced the numbers of hours they worked, and no partners quit their job. The partners of five participants (11.36%) took leave without pay, and there were eight partners (18.18%) who took leave with pay.

Reduced income due to condition

Participants reported a reduced income from 500 to 10,000 per month, most commonly \$1501 to 2500 (n = 6, 13.64%).

For eight of these participants (42.11%), the burden of this reduced income was slightly or not at all significant, for five participants (26.32%) the burden was somewhat significant, and for 6 participants (31.58%) the burden was extremely or moderately significant.

Summary of surgery

There were 35 participants (79.55%) that had surgery for breast cancer (excluding biopsies). There were 15 participants (34.09%) that had one operation, 10 participants (22.73%) that had two operations, three participants (6.82%) that had three operations, and seven participants (15.91%) that had four or more operations.

There were 35 participants (79.55%) that had surgery for breast cancer (excluding biopsies). The most common types of surgeries were mastectomies (n=19, 43.18%), and lumpectomies (n=19, 43.18%). There were 13 participants (29.55%) had breast reconstruction, and seven participants (2.27%) had surgery to remove ovaries

Summary of drug treatments

There were 40 participants (90.91%) that had used drug treatments to treat their breast cancer. The most common treatment regimen was doxorubicin, cyclophosphamide, and paclitaxel (n=17, 38.64%), followed by single agent paclitaxel (n=11, 25.00%), Capecitabine (n=10, 22.73%), Doxorubicin and cyclophosphamide (n=8, 18.18%), Carboplatin paclitaxel (n=6, 13.64%), and Doxorubicin (n=5, 11.35%)

Summary of radiotherapy

There were 25 participants (56.82%) that had radiotherapy to the primary cancer site, and three participants (6.82%) that had radiotherapy to the secondary cancer site .

Allied health

Most participants used at least one type of allied health service (n = 34, 77.27%), and on average used 2 services (median = 2.00, IQR = 1.00).

The most common allied health service used was psychology services (n = 21, 47.73%), followed by physiotherapy (n = 20, 45.45%), and Dietician (n = 10, 22.73%). There were six participants (13.64%) who saw an occupational therapist, five participants (11.36%) who saw a podiatrist, and four participants (9.09%) who saw a social worker.

Lifestyle changes

Most participants used at made at least one lifestyle change (n = 38, 86.36%), and on average made 2 changes (median = 2.00, IQR = 2.00).

The most common lifestyle change used was exercise (n = 28, 63.64%), followed by diet changes (n = 23, 52.27%), and reducing or stopping alcohol if applicable (n = 24, 54.55%).

Complementary therapies

Most participants used at made at least one complementary therapy (n = 29, 65.91%), and on average used one therapy (median = 1.00, IQR = 2.00).

The most common complementary therapy used was mindfulness or relaxation techniques (n = 20, 45.45%), followed by massage therapy (n = 17, 38.64%), and taking supplements (n = 16, 36.36%) (Table 5.21, Figure 5.24).

Clinical trials

There was a total of 16 participants (36.36%) that had discussions about clinical trials, six participants (13.64%) had brought up the topic with their doctor, and the doctor of 10 participants (22.77%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n = 28, 63.64%).

There were four participants (9.09%) who had taken part in a clinical trial, 32 participants (72.73%) who would like to take part in a clinical trial if there was a suitable one, and eight participants, who have not participated in a clinical trial and do not want to (18.18%).

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 providers of treatment and care were medical oncologists (n = 23, 52.27%), followed by general practitioners (n = 9, 20.45%) (Table 5.1, Figure 5.1).

Table 5.1: Main provider of treatment

Main provider of treatment	Number (n=44)	Percent
General practitioner (GP)	9	20.45
Medical oncologist	23	52.27
Multidisciplinary team	3	6.82
Specialist surgeon	9	20.45

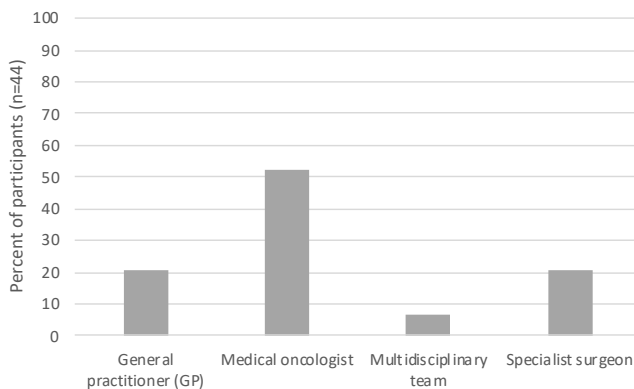


Figure 5.1: Main provider of treatment

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.

All participants had access to a medical oncologist (n = 44, 100%), and almost all had a specialist surgeon (n = 42, 95.45%) and a general practitioner (n = 41, 93.18%). There were 38 participants (86.36%) that had a

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 16 participants (37.21%) that travelled for less than 15 minutes, 15 participants (34.88%) that travelled between 15 and 30 minutes, eight participants (18.60%) that travelled between 30 and 60 minutes, three participants (6.98%) that travelled between 60 and 90 minutes, and one participant (2.33%) that travelled more than 90 minutes (Table 5.2, Figure 5.2).

Table 5.2: Time to travel to main provider of treatment

Time to travel to main provider of treatment	Number (n=43)	Percent
Less than 15 minutes	16	37.21
Between 15 and 30 minutes	15	34.88
Between 30 and 60 minutes	8	18.60
Between 60 and 90 minutes	3	6.98
More than 90 minutes	1	2.33

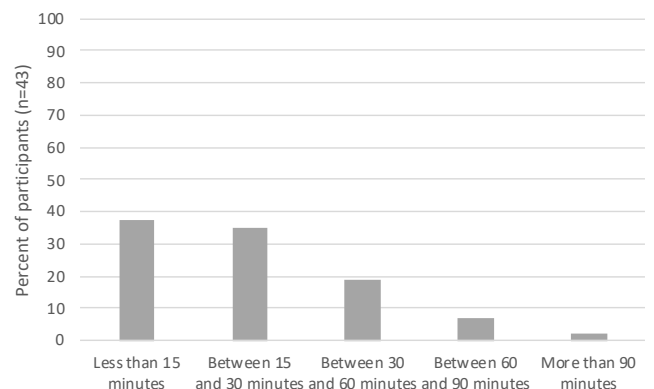


Figure 5.2: Time to travel to main provider of treatment

oncology/chemotherapy nurse and 37 participants (84.09%) that had a breast care nurse.

Almost half of the participants had a pharmacist to care for their condition (n = 18, 40.91%). There were 21 participants (47.73%) treated by a physiotherapist and, 11 participants (25.00%) treated by a dietitian/nutritionist (Table 5.3, Figure 5.3).

Table 5.3: Access to healthcare professionals

Healthcare professional	Number (n=44)	Percent
Medical oncologist	44	100.00
Radiation oncologist	31	70.45
Specialist surgeon	42	95.45
Palliative care specialist	2	4.55
Breast cancer care coordination discharge planner or key worker	14	31.82
Oncology/chemotherapy nurse	38	86.36
Breast care nurse	37	84.09
Lymphoedema practitioner	16	36.36
Speech therapist	0	0.00
Genetic counsellor	22	50.00
General practitioner	41	93.18
Physiotherapist	21	47.73
Weight loss specialist	0	0.00
Dietitian/nutritionist	11	25.00
Occupational therapist	4	9.09
Exercise physiologist	14	31.82
Pharmacist	18	40.91
Counsellor	9	20.45
Psychologist	20	45.45
Chiropractor	6	13.64
Osteopath	6	13.64
Social worker	2	4.55

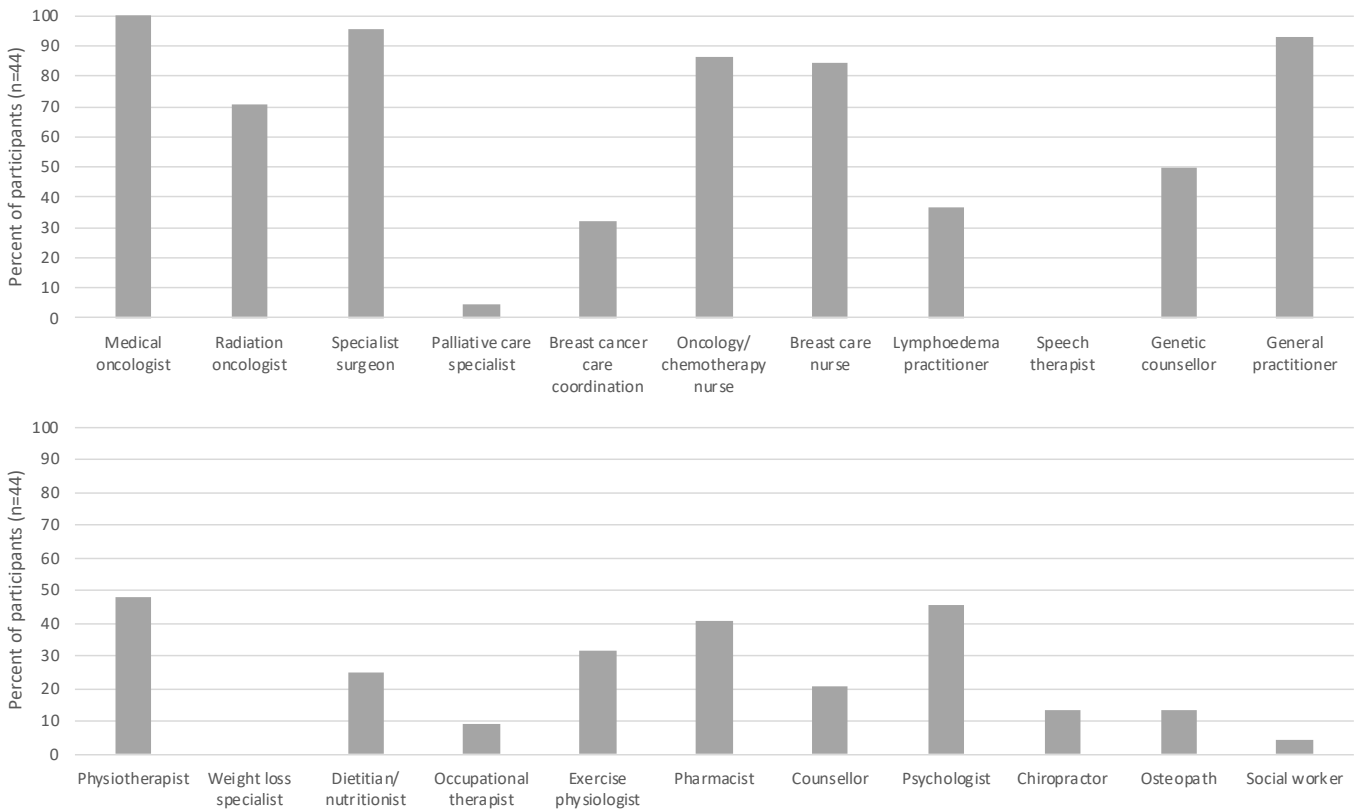


Figure 5.3: Access to healthcare professionals

Respect shown

Participants were asked to think about how respectfully they were treated throughout their experience, this question was asked in the online questionnaire.

Table 5.4: Respect shown

Respect shown	Number (n=44)	Percent
Respect shown	34	77.27
Respect shown, with the exception of one or two occasions	9	20.45
Respect not shown	1	2.27

There were 34 participants (77.27%) that indicated that they had been treated with respect throughout their experience, and nine participants (20.45%) who were treated with respect with the exception of one or two occasions (Table 5.4, Figure 5.4).

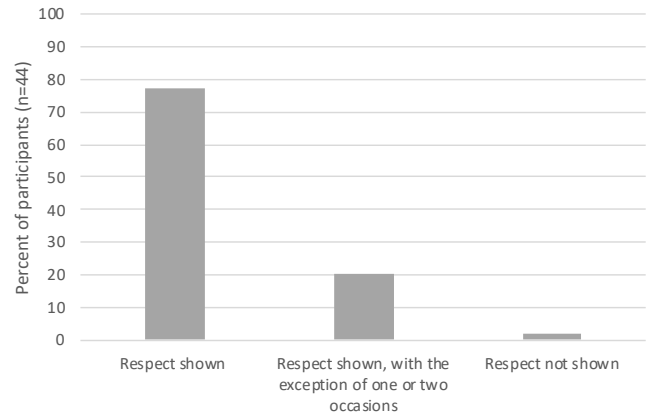


Figure 5.4: Respect shown

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 5.5, Figures 5.5 and 5.6).

The majority of participants had private health insurance (n = 33, 75.00%). The majority of participants were asked if they wanted to be treated as a public or

private patient (n = 28, 63.64%), and, they were asked if they had private health insurance (n = 39, 88.64%).

Throughout their treatment, there were 20 participants (45.45%) who were treated as a private patient, 20 participants (45.45%) were mostly treated as a public patient, and there were four participants (9.09%) who were equally treated as a private and public patient.

Table 5.5: Health care system

Health care services	Response	Number (n=44)	Percent
Private health insurance	No	11.00	25.00
	Yes	33.00	75.00
Asked whether you want to be treated as a public or private patient	No	16.00	36.36
	Yes	28.00	63.64
Asked whether you had private health insurance	No	5.00	11.36
	Yes	39.00	88.64
Throughout your treatment in hospital, have you most been treated as a public or a private patient	Equally as a public and private patient	4.00	9.09
	Private patient	20.00	45.45
	Public patient	20.00	45.45
Which hospital system have you primarily been treated in	Both public and private	4.00	9.09
	Private	20.00	45.45
	Public	20.00	45.45

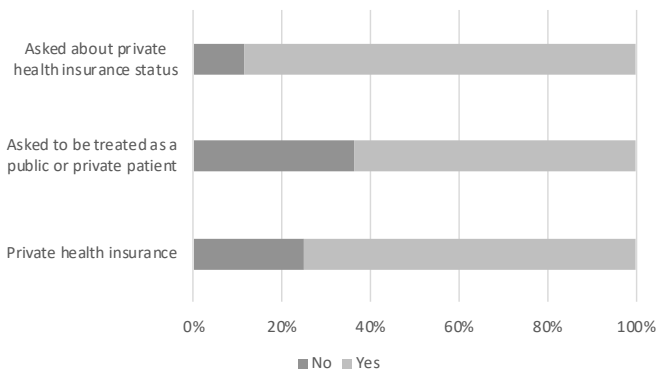


Figure 5.5: Health insurance

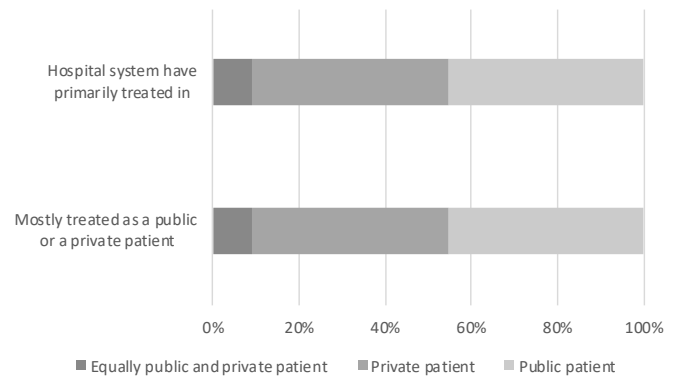


Figure 5.6: Hospital system

Affordability of healthcare

Participants were asked a series of questions about affordability of healthcare in the online questionnaire (Table 5.6, Figure 5.7).

The first question was about having to delay or cancel healthcare appointments because they were unable to afford them. The majority of participants never or rarely had to delay or cancel appointments due to affordability (n = 39, 88.64%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n = 40, 90.91%).

The third question was about the affordability of basic essentials such as food, housing and power. There were 34 participants (79.28%) that never or rarely had trouble paying for essentials, and six participants (13.64%) that sometimes found it difficult, and four participants (9.09%) often or very often found it difficult to pay for basic essentials.

The final question was about paying for additional carers for themselves or for their family, there were four participants (9.09%) that paid for additional carers due to their condition.

Table 5.6: Affordability of healthcare

Affordability of healthcare	Response	Number (n=44)	Percent
Delay or cancel healthcare appointments due to affordability	Never	37.00	84.09
	Rarely	2.00	4.55
	Sometimes	2.00	4.55
	Often	1.00	2.27
	Very often	2.00	4.55
Did not fill prescriptions due to cost	Never	37.00	84.09
	Rarely	3.00	6.82
	Sometimes	4.00	9.09
	Often		0.00
	Very often		0.00
Difficult to pay for basic essentials	Never	28.00	63.64
	Rarely	6.00	13.64
	Sometimes	6.00	13.64
	Often	2.00	4.55
	Very often	2.00	4.55
Pay for additional carers for self or family	Yes	4.00	9.09
	No	40.00	90.91

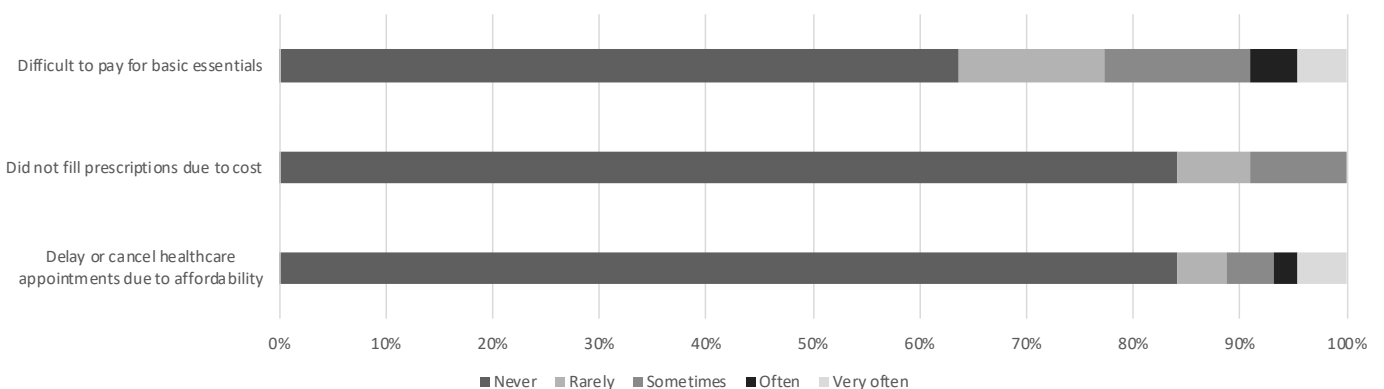


Figure 5.7: Affordability of healthcare

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 5.7, Figure 5.8).

Participants spent between \$50 and \$10,000 per month, most commonly between \$101 or less (n = 10, 22.73%), and \$101 to \$250 (n=10, 22.73%).

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

Estimated monthly out of pocket expenses	Number (n=44)	Percent
\$0	4	9.09
\$100 or less	10	22.73
\$101 to \$250	10	22.73
\$251 to \$500	7	15.91
\$501 to \$1000	5	11.36
\$1001 or more	4	9.09
Not sure of amount	4	9.09

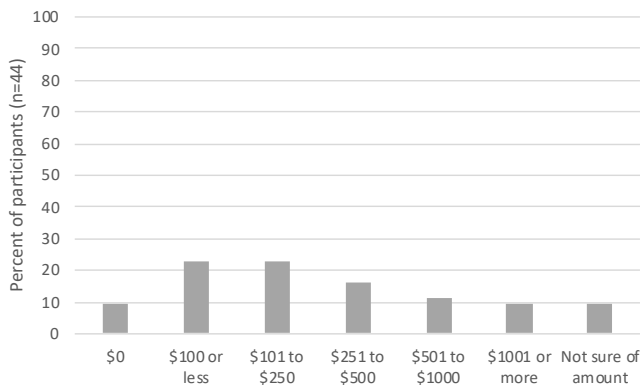


Figure 5.8: Estimated monthly out of pocket expenses due to condition

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 5.9, Figure 5.10).

Work status for 12 participants (27.27%) had not changed since diagnosis, or were retired or did not have a job. There were four participants (9.09%) had to quit their job, 10 participants (22.73%) reduced the number of hours they worked, and four participants (9.09%) that accessed their superannuation early. There were 16 participants (36.36%) that took leave from work without pay, and 12 participants (27.27%) who took leave from work with pay.

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 5.8, Figure 5.9).

The amount spent was an extremely significant or moderately significant burden for 11 participants (25.00%), somewhat significant for nine participants (20.45%), and slightly or not at all significant for 24 participants (54.55%).

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

Burden of out of pocket expenses	Number (n=44)	Percent
Extremely significant	5	11.36
Moderately significant	6	13.64
Somewhat significant	9	20.45
Slightly significant	15	34.09
Not at all significant	9	20.45

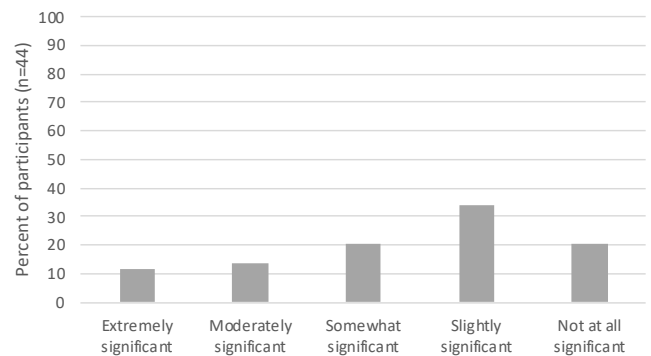


Figure 5.9: Burden of out-of-pocket expenses due to condition

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 5.10, Figure 5.11).

There were 11 participants (25.00%), 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 = 22, 50.00%). There were four participants (9.09%) whose partners reduced the numbers of hours they worked, and no partners quit their job. The partners of five participants (11.36%) took leave without pay, and there were eight partners (18.18%) who took leave with pay.

Table 5.9: Changes to employment status

Changes in employment status due to condition	Number (n=44)	Percent
Work status has not changed	11	25.00
Retired or did not have a job	1	2.27
Had to quit job	4	9.09
Reduced number of hours worked	10	22.73
Leave from work without pay	16	36.36
Leave from work with pay	12	27.27
Accessed Superannuation early due to condition	4	9.09

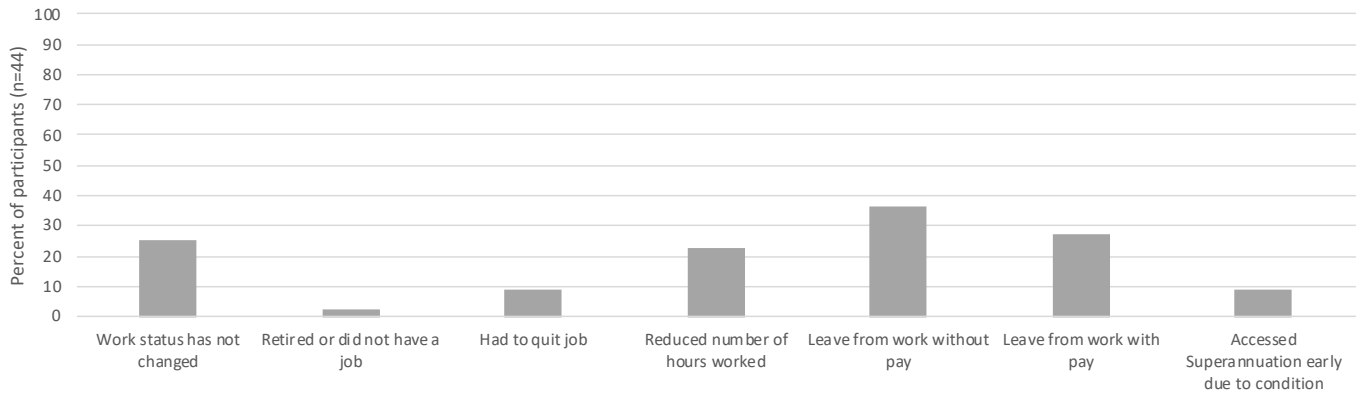


Figure 5.10: Changes to employment status

Table 5.10: Changes to care/partner employment status

Changes to care/partner employment status	Number (n=44)	Percent
Does not have a partner/main carer	11	25.00
Work status has not changed	22	50.00
Retired or did not have a job	0	0.00
Had to quit job	0	0.00
Reduced number of hours worked	4	9.09
Leave from work without pay	5	11.36
Leave from work with pay	8	18.18



Figure 5.11: Changes to care/partner employment status

Reduced income due to condition

Almost of the participants (n = 19, 43.18%) 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 5.11, Figure 5.12).

Participants reported a reduced income from 500 to 10,000 per month, most commonly \$1501 to 2500 (n = 6, 13.64%).

Burden of reduced income

Participants were then asked if this reduced family or household income was a burden.

For eight of these participants (42.11%), the burden of this reduced income was slightly or not at all significant, for five participants (26.32%) the burden was somewhat significant, and for 6 participants (31.58%) the burden was extremely or moderately significant (Table 5.12, Figure 5.13).

Table 5.11: Estimated monthly loss of income

Estimated monthly loss of income	Number (n=44)	Percent
\$0	25	56.82
\$500 to 1500	5	11.36
\$1501 to 2500	6	13.64
\$2501 to 5000	3	6.82
More than \$5000	3	6.82
Not sure/not specified	2	4.55

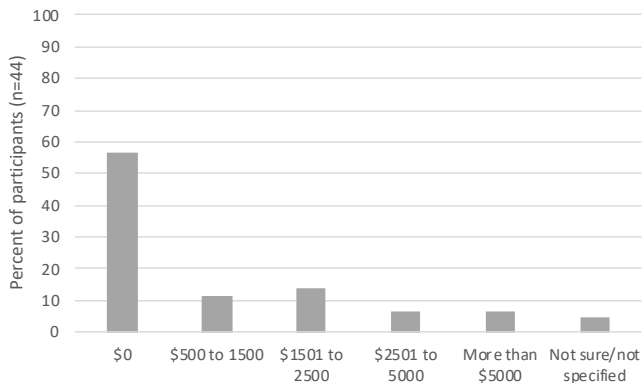


Figure 5.12: Estimated monthly loss of income

Table 5.12: Burden of reduced income

Burden of reduced income	Number (n=44)	Percent
Extremely significant	4	21.05
Moderately significant	2	10.53
Somewhat significant	5	26.32
Slightly significant	5	26.32
Not at all significant	3	15.79

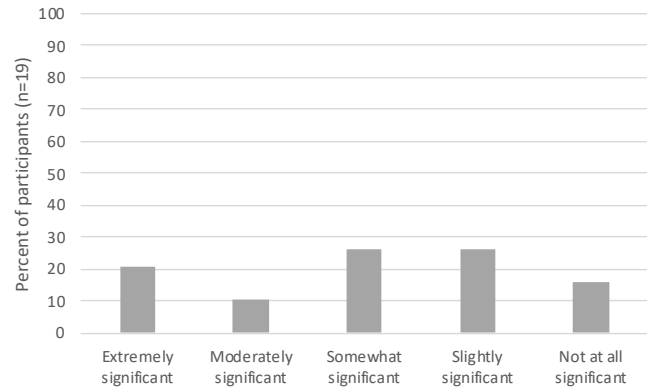


Figure 5.13: Burden of reduced income

Summary of surgery

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

There were 35 participants (79.55%) that had surgery for breast cancer (excluding biopsies). There were 15

participants (34.09%) that had one operation, 10 participants (22.73%) that had two operations, three participants (6.82%) that had three operations, and seven participants (15.91%) 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=44)	Percent
0	9	20.45
1	15	34.09
2	10	22.73
3	3	6.82
4 or more	7	15.91

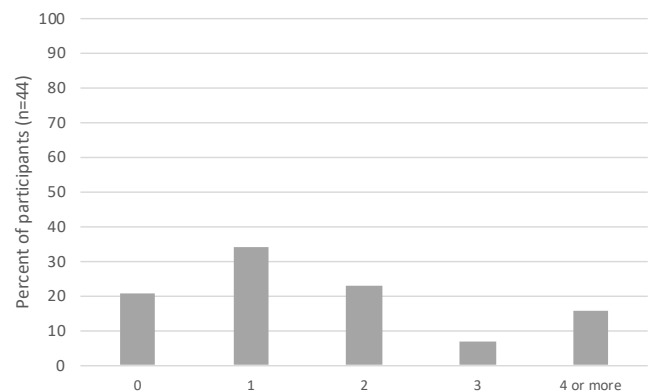


Figure 5.14: Number of surgeries

Surgical treatments

Participants completed a series of questions about surgery, including type of surgery, quality of life, effectiveness of surgery, and side effects. Details about year of surgery, side effects, quality of life and effectiveness are given in Table 5.14.

There were 35 participants (79.55%) that had surgery for breast cancer (excluding biopsies). The most common types of surgeries were mastectomies (n=19, 43.18%), and lumpectomies (n=19, 43.18%). There were 13 participants (29.55%) had breast reconstruction, and seven participants (2.27%) 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”. Values are calculated where there was adequate data available. Median quality of life from surgery ranged from 2.00 to 4.00, in the life was a distressing to life was average range. The lowest quality of life was reported from mastectomy (median = 2.00, IQR =1.00), and the highest quality of life from removal of ovaries (median = 4.00, IQR = 2.00) (Figure 5.16).

Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective. The median effectiveness of all surgery was between 4.00 and 5.00, in the effective to very effective range (Figure 5.17).

Table 5.14: Details of surgeries

Surgery		Lumpectomy		Re-excision following lumpectomy		Mastectomy		Breast reconstruction		Surgery to remove ovaries		Surgery to relieve symptoms	
		n=19	%	n=2	%	n=19	%	n=13	%	n=7	%	n=1	%
Number		19	43.18	2	4.55	19	43.18	13	29.55	7	15.91	1	2.27
Year of surgery	2020 to 2021	9	47.37	0	0.00	9	47.37	6	46.15	2	28.57	0	0.00
	2017 to 2019	6	31.58	1	50.00	8	42.11	6	46.15	3	42.86	1	100.00
	2016 or before	4	21.05	1	50.00	2	10.53	1	7.69	2	28.57	0	0.00
Side effects	No side effects	8	42.11	1	50.00	1	5.26	1	7.69	1	14.29	0	0.00
	A high temperature	1	5.26	0	0.00	0	0.00	1	7.69		0.00	0	0.00
	Feeling generally unwell	3	15.79	1	50.00	4	21.05	2	15.38	2	28.57	0	0.00
	Feeling hot and cold	0	0.00	0	0.00	1	5.26	2	15.38		0.00	0	0.00
	Feeling sick	1	5.26	0	0.00	1	5.26	2	15.38	1	14.29	0	0.00
	Pain	0	0.00	1	50.00	17	89.47	11	84.62	3	42.86	1	100.00
	Shivering	10	52.63	0	0.00	1	5.26	2	15.38		0.00	0	0.00
	Swelling/redness around wound	3	15.79	0	0.00	5	26.32	6	46.15		0.00	0	0.00
	Other	1	5.26	0	0.00	4	21.05	2	15.38	1	14.29	0	0.00
		Median	IQR	Median	IQR	Median	IQR	Median	IQR	Median	IQR	Median	IQR
Quality of life		3	1.00	-	-	2	1.00	3	2.00	4	2.00	-	-
Effectiveness		5	1.00	-	-	5	1.00	4	1.00	5	1	-	-

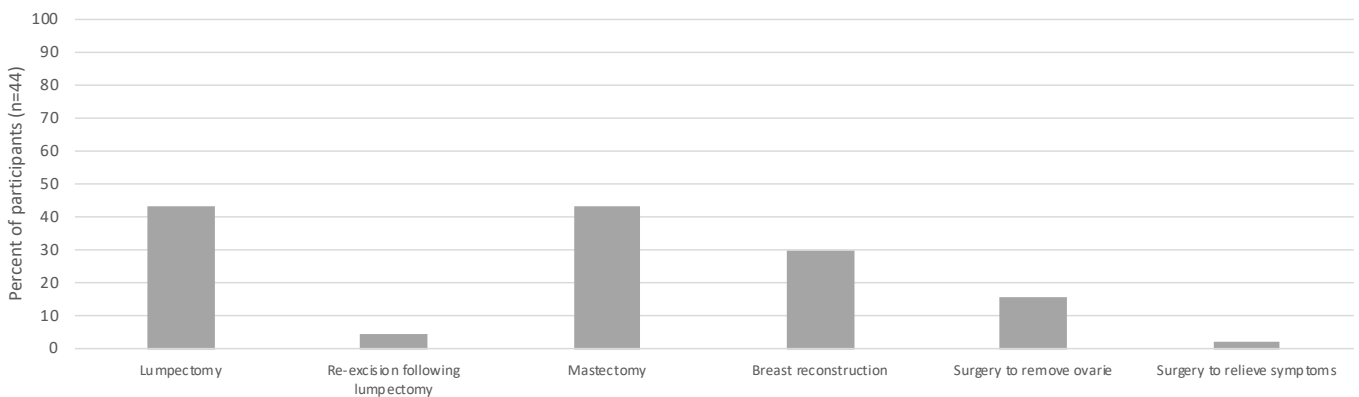


Table 5.15: Type of surgery

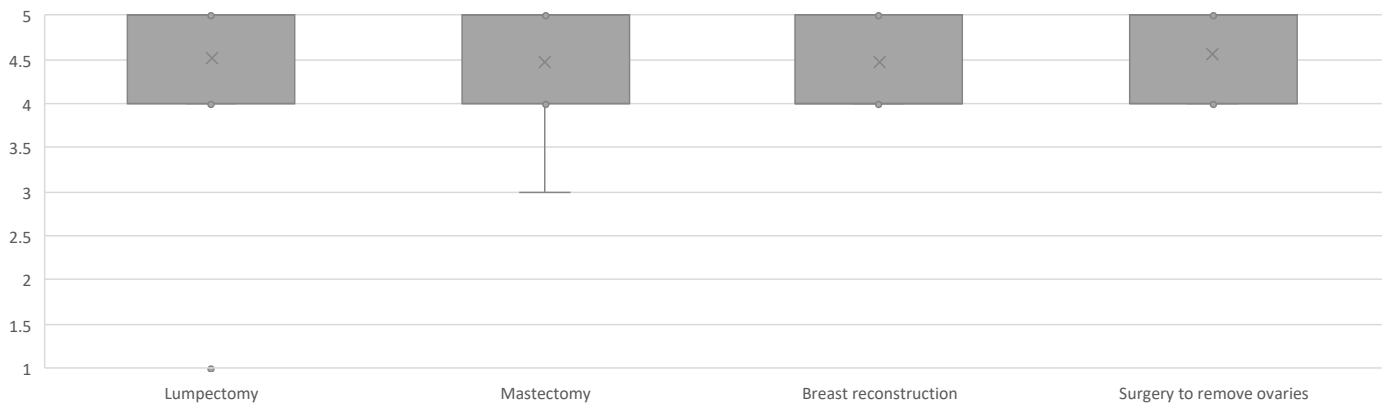


Figure 5.16: Quality of life from surgery

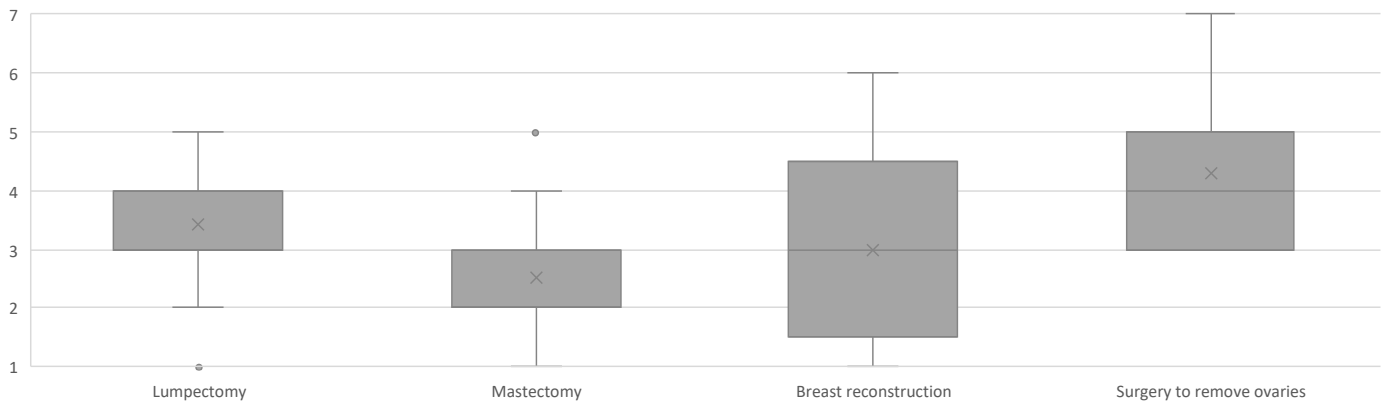


Figure 5.17: Effectiveness of surgery

Summary of drug treatments

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

A review was then conducted to compare the results of the online questionnaire and the structured interview responses to a question asked about the treatments that participants had experienced. Where treatments were mentioned in the structured interview but not marked by participants in the online questionnaire, these were added manually, but do not include a quality of life and effectiveness rating.

Where participants were unsure of names of treatments, these were also cross validated with interview transcripts. Where it was clear that an error had been made in the online questionnaire, these were removed. In this study, there were two occasions where the participant had entered a treatment in error that was later removed.

There were 40 participants (90.91%) that had used drug treatments to treat their breast cancer. The most common treatment regimen was doxorubicin,

cyclophosphamide, and paclitaxel (n=17, 38.64%), followed by single agent paclitaxel (n=11, 25.00%), Capecitabine (n=10, 22.73%), Doxorubicin and cyclophosphamide (n=8, 18.18%), Carboplatin paclitaxel (n=6, 13.64%), and Doxorubicin (n=5, 11.35%) (Table 5.15, 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". Values are calculated where there was adequate data available. Median quality of life from treatments ranged from 2.00 to 3.00, in the life was distressing to life was a little distressing range (Table 5.16, Figure 5.19).

Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective. Median effectiveness from treatments ranged from 2.00 to 5.00, in the somewhat to very effective range. (Table 5.16, Figure 5.10)

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

On average, quality of life from paclitaxel was in the 'life was a little distressing' range (median = 3.00, IQR = 2.00), and was found to be very effective (median = 5.00, IQR = 4.00).

On average, quality of life from Capecitabine was in the 'life was a little distressing' range (median = 3.00, IQR = 1.00), and was found to be effective (median = 4.00, IQR = 0.00).

On average, quality of life from Doxorubicin and cyclophosphamide was in the 'life was a distressing' range (median = 2.00, IQR = 1.00), and was found to be very effective (median = 5.00, IQR = 1.00).

On average, quality of life from Carboplatin paclitaxel was in the 'life was a distressing' range (median = 2.00, IQR = 1.50), and was found to be effective (median = 4.00, IQR = 0.75).

On average, quality of life from Doxorubicin was in the 'life was a distressing' range (median = 2.00, IQR = 1.00), and was found to be very effective (median = 5.00, IQR = 1.00).

Table 5.15: Summary of drug treatments

Drug treatments	Number (n=44)	Percent
Doxorubicin, cyclophosphamide, and paclitaxel	17	38.64
Paclitaxel	11	25.00
Capecitabine	10	22.73
Doxorubicin and cyclophosphamide	8	18.18
Carboplatin paclitaxel	6	13.64
Doxorubicin	5	11.36
Carboplatin	3	6.82
Docetaxel	3	6.82
Docetaxel and cyclophosphamide	3	6.82
Fluorouracil, epirubicin, and cyclophosphamide	3	6.82
Cyclophosphamide and methotrexate	2	4.55
Denosumab	1	2.27
Zoledronic acid	1	2.27

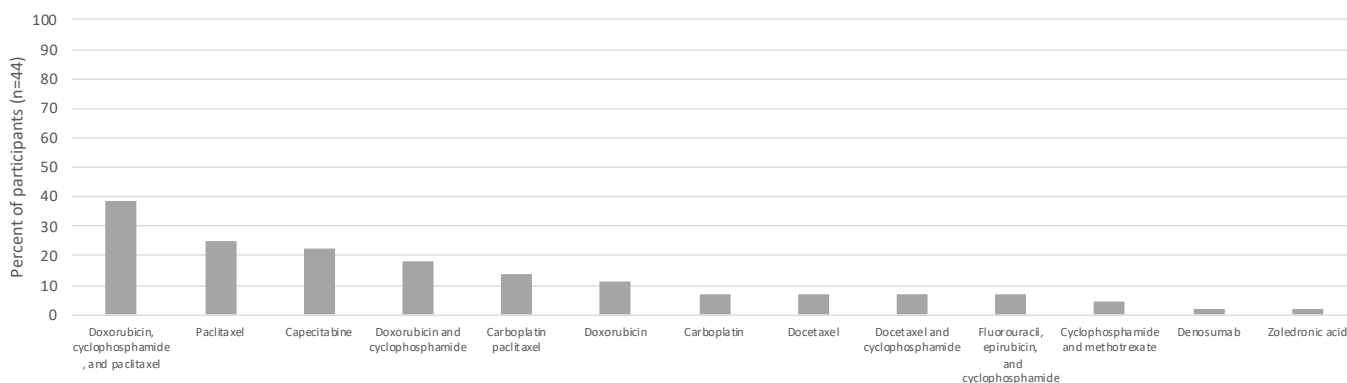


Figure 5.18: Type of drug treatments

Table 5.16: Summary of drug treatments taken by more than five participants

Drug treatments		Doxorubicin and cyclophosphamide, and paclitaxel		Capecitabine		Paclitaxel		Doxorubicin and cyclophosphamide		Carboplatin paclitaxel		Doxorubicin	
		n=17	%	n=10	%	n=11	%	n=8	%	n=6	%	n=5	%
Number		17	38.64	10	22.73	11	25.00	8	18.18	6	13.64	5	11.36
Year of treatment	2020 to 2021	8	47.06	6	60.00	6	54.55	4	50.00	2	33.33	2	40.00
	2017 to 2019	7	41.18	3	30.00	4	36.36	4	50.00	4	66.67	3	60.00
	2016 or before	2	11.76	1	10.00	1	9.09	0	0.00	0	0.00	0	0.00
Status	Finished treatment as planned	13	76.47	6	60.00	8	72.73	8	100.00	6	100.00	5	100.00
	Finished due to side effects or ineffectiveness	3	17.65	1	10.00	1	9.09	0	0.00	0	0.00	0	0.00
	Currently taking	1	5.88	3	30.00	1	9.09	0	0.00	0	0.00	0	0.00
Side effects	No side effects	4	23.53	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
	Appetite loss	0	0.00	3	30.00	0	0.00	0	0.00	0	0.00	0	0.00
	Bone pain	13	76.47	0	0.00	0	0.00	0	0.00	2	33.33	0	0.00
	Chemo brain	15	88.24	0	0.00	0	0.00	7	87.50	4	66.67	0	0.00
	Diarrhoea	7	41.18	5	50.00	6	54.55	3	37.50	1	16.67	0	0.00
	Flu-like symptoms	1	5.88	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
	Hair loss	17	100.00	0	0.00	9	81.82	8	100.00	4	66.67	5	100.00
	Hand-foot syndrome	0	0.00	9	90.00	0	0.00	0	0.00	0	0.00	0	0.00
	Heart problems	0	0.00	1	10.00	0	0.00	0	0.00	0	0.00	2	40.00
	High blood bilirubin levels	0	0.00	1	10.00	0	0.00	0	0.00	0	0.00	0	0.00
	Infection risk (neutropenia)	14	82.35	1	10.00	1	9.09	4	50.00	4	66.67	3	60.00
	Injection-site reaction or pain	2	11.76	0	0.00	0	0.00	1	12.50	0	0.00	1	20.00
	Joint and muscle pain / stiffness	1	5.88	0	0.00	0	0.00	0	0.00	4	66.67	0	0.00
	Low platelets	5	29.41	0	0.00	1	9.09	1	12.50	2	33.33	3	60.00
	Low red blood cells (anaemia)	4	23.53	0	0.00	2	18.18	0	0.00	2	33.33	2	40.00
	Menopausal symptoms	13	76.47	1	10.00	7	63.64	6	75.00	0	0.00	0	0.00
	Mouth pain and soreness	8	47.06	2	20.00	3	27.27	5	62.50	3	50.00	2	40.00
	Nail changes	12	70.59	0	0.00	7	63.64	2	25.00	4	66.67	3	60.00
	Nausea and or vomiting	8	47.06	2	20.00	5	45.45	6	75.00	2	33.33	1	20.00
	Nerve damage	11	64.71	0	0.00	6	54.55	0	0.00	5	83.33	0	0.00
	Redness and itching along vein	2	11.76	0	0.00	0	0.00	2	25.00	0	0.00	1	20.00
	Skin colour changes	0	0.00	0	0.00	0	0.00	2	25.00	0	0.00	1	20.00
	Skin rash	2	11.76	0	0.00	2	18.18	0	0.00	0	0.00	0	0.00
	Radiation recall	1	5.88	0	0.00	0	0.00	0	0.00	0	0.00	1	20.00
	Photosensitivity	5	29.41	4	40.00	0	0.00	0	0.00	0	0.00	1	20.00
	Stomach pain	0	0.00	2	20.00	0	0.00	0	0.00	0	0.00	0	0.00
	Taste and smell changes	13	76.47	3	30.00	7	63.64	3	37.50	5	83.33	3	60.00
Tiredness and lack of energy	17	100.00	10	100.00	9	81.82	8	100.00	5	83.33	4	80.00	
Urine turning orange or red	15	88.24	0	0.00	0	0.00	7	87.50	0	0.00	4	80.00	
Other	0	0.00	3	30.00	3	27.27	1	12.50	1	16.67	0	0.00	
		Median	IQR	Median	IQR	Median	IQR	Median	IQR	Median	IQR	Median	IQR
Quality of life		2.00	4.00	3.00	1.00	3.00	2.00	2.00	1.00	2.00	1.50	2.00	1.00
Effectiveness		2.00	1.00	4.00	0.00	5.00	4.00	5.00	1.00	4.00	0.75	5.00	1.00

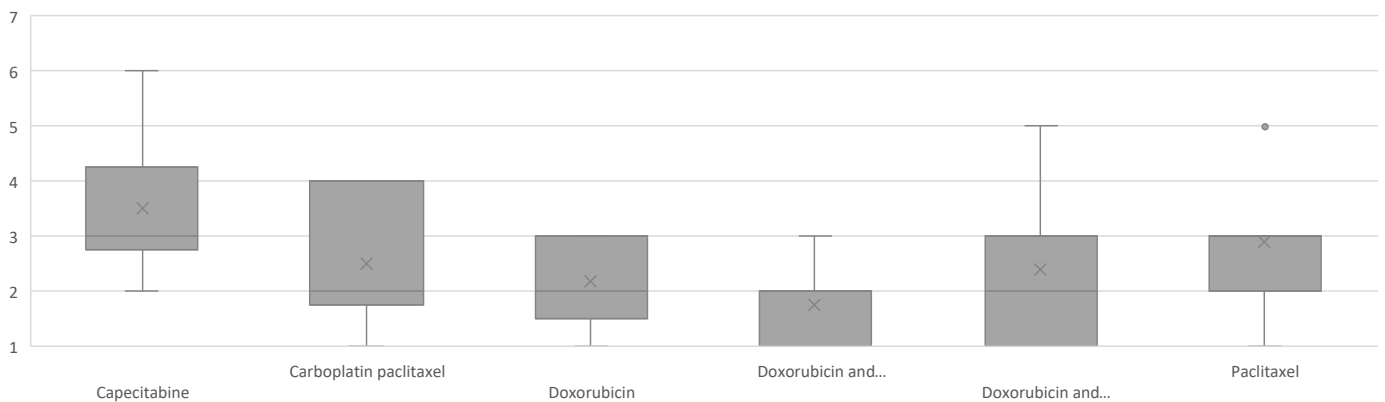


Figure 5. 19: Quality of life from drug treatments

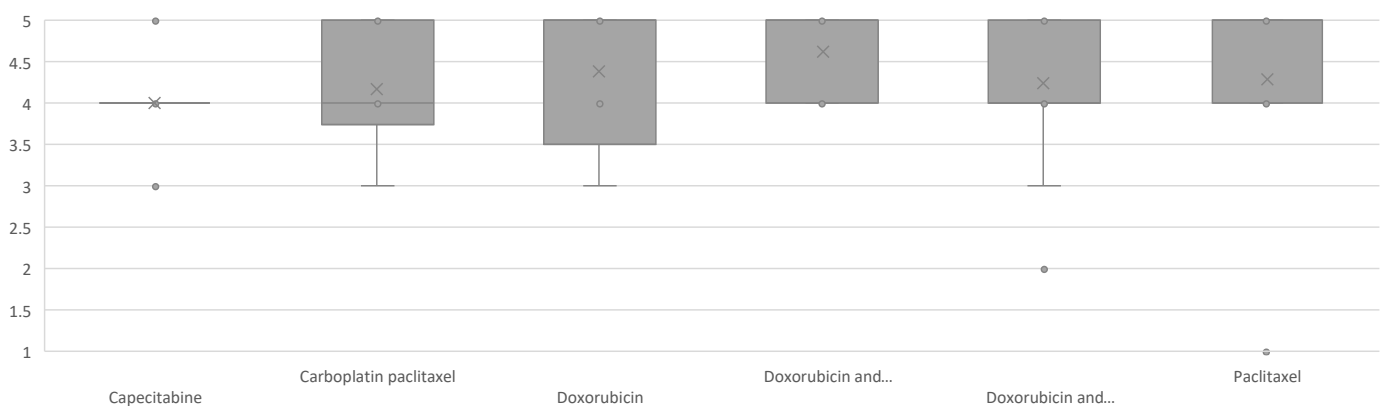


Figure 5.20: Effectiveness of drug treatments

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, more details about side effects are given in Table 5.17.

There were 25 participants (56.82%) that had radiotherapy to the primary cancer site, and three participants (6.82%) that had radiotherapy to the secondary cancer site .

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”. Median quality of life from radiotherapy for the primary cancer site was 4.00, in the life was a average range .

Effectiveness of treatment was rated on a five point scale where one is ineffective, and five is very effective. Median effectiveness from radiotherapy for primary cancer site was 4.50 in the effective to very effective range.

Table 5.17: Radiotherapy quality of life and effectiveness

Radiotherapy		Primary site		Secondary site	
		n=25	%	n=3	%
Number		25	56.82	3	6.82
Year of treatment	2020 to 2021	12	27.27	1	33.33
	2017 to 2019	9	20.45	1	33.33
	2016 or before	4	9.09	1	33.33
Treatment status	Treatment completed	22	88.00	0	0.00
	Treatment ongoing	1	4.00	0	0.00
	No response	2	8.00	0	0.00
Side effects	No side effects	2	8.00	0	0.00
	Discomfort when swallowing	3	12.00	0	0.00
	Fatigue	18	72.00	3	100.00
	Loss of appetite and weight loss	2	8.00	1	33.33
	Nausea and vomiting	2	8.00	1	33.33
	Sexual issues	2	8.00	0	0.00
	Skin problems (red, irritated, swollen, blistered, sunburned, tanned)	19	76.00	3	100.00
	Sore mouth	2	8.00	0	0.00
	Stiff joints and muscles	5	20.00	1	33.33
	Swollen limbs	0	0.00	1	33.33
		Median	IQR	Median	IQR
Quality of life		4	2	-	-
Effectiveness		4.5	1	-	-

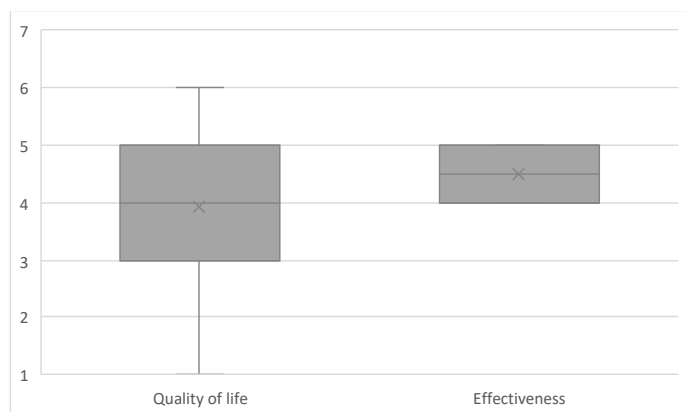


Figure 5.21: Quality of life and effectiveness

Allied health

Participants were asked about allied health services they used, the quality of life from these therapies, and how effective they found them (Table 5.18, Figures 5.22 to 5.24).

Most participants used at least one type of allied health service (n = 34, 77.27%), and on average used 2 services (median = 2.00, IQR = 1.00).

The most common allied health service used was psychology services (n = 21, 47.73%), followed by physiotherapy (n = 20, 45.45%), and Dietician (n = 10, 22.73%). There were six participants (13.64%) who saw an occupational therapist, five participants (11.36%) who saw a podiatrist, and four participants (9.09%) who saw a social worker.

On average, quality of life from psychology services 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 = 2.00).

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 = 1.25).

On average, quality of life from dietary services was in the 'life was distressing to a little distressing' range (median = 3.50, IQR = 2.00), and was found to be moderately effective to effective (median = 3.00, IQR = 2.25).

Table 5.18: Allied health

Allied health	Number (n=44)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Psychologist	21	47.73	3.00	2.00	4.00	2.00
Physiotherapist	20	45.45	4.00	2.00	4.00	1.25
Dietician	10	22.73	3.50	2.00	3.00	2.25
Occupational therapist	6	13.64	4.00	1.50	3.50	1.00
Podiatrist	5	11.36	4.00	1.00	4.00	1.00
Social worker	4	9.09	-	-	-	-

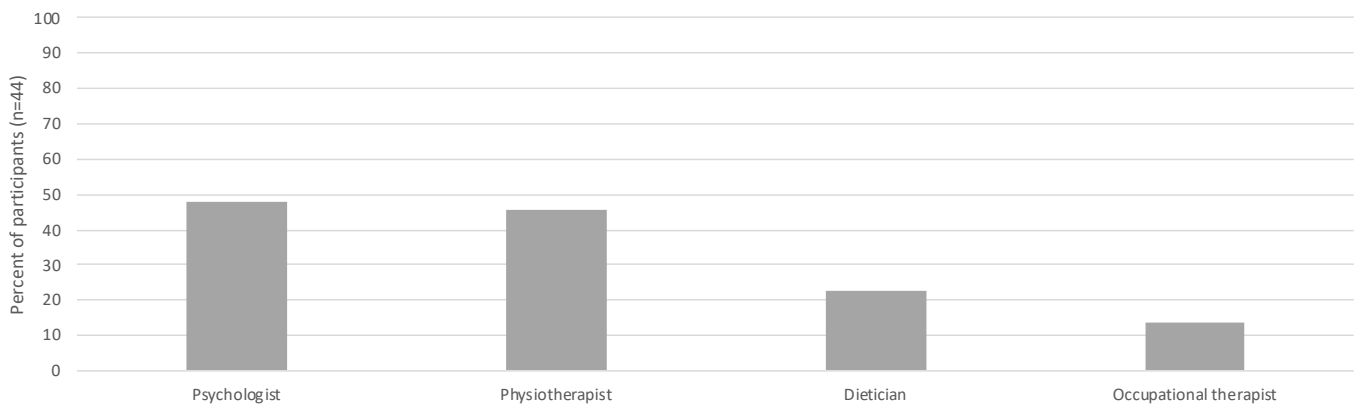


Figure 5.22: Allied health

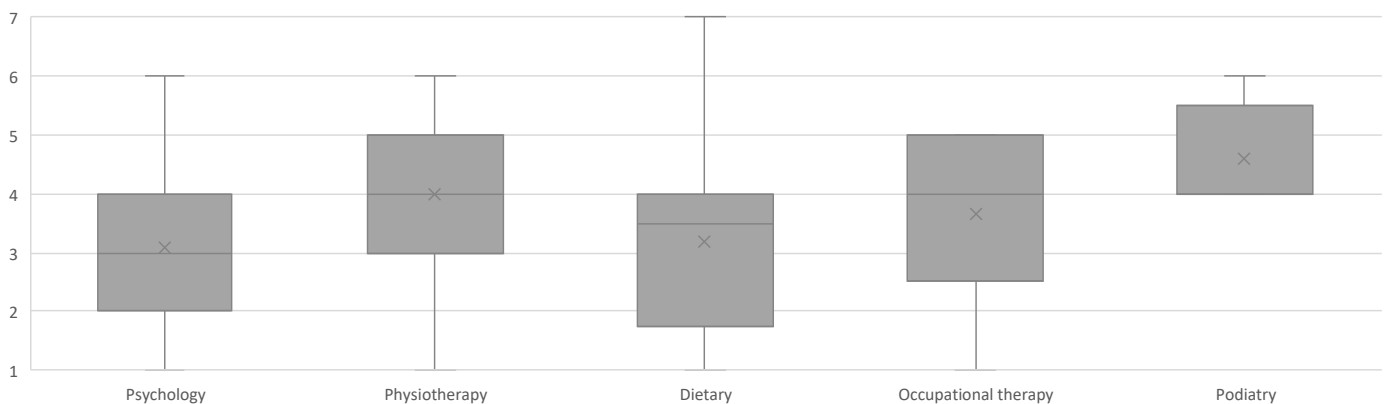


Figure 5.23: Quality of life from allied health

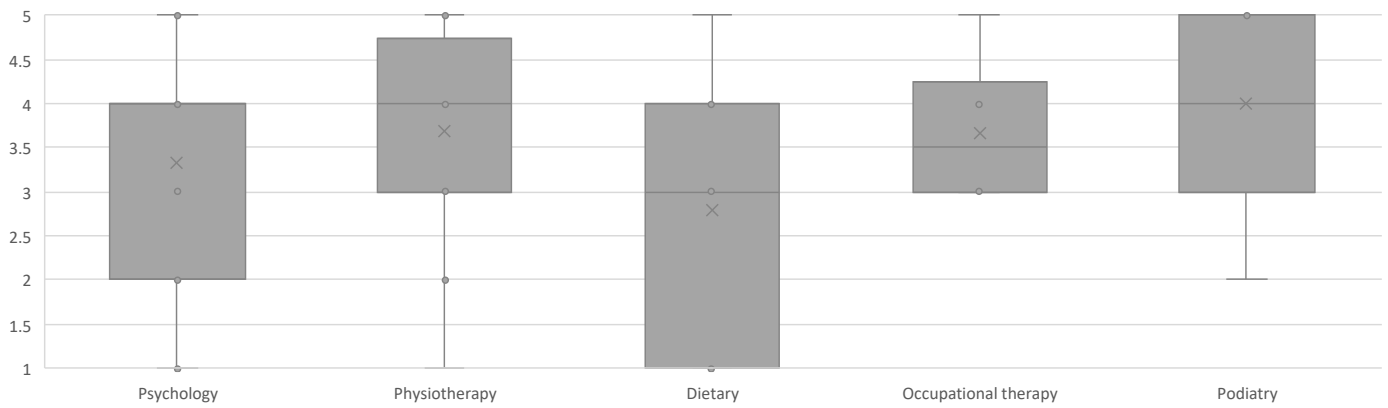


Figure 5.24: Effectiveness of allied health

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, Figures 5.25 to 5.27).

Most participants used at made at least one lifestyle change (n = 38, 86.36%), and on average made 2 changes (median = 2.00, IQR = 2.00).

The most common lifestyle change used was exercise (n = 28, 63.64%), followed by diet changes (n = 23, 52.27%), and reducing or stopping alcohol if applicable (n = 24, 54.55%) (Table 5.21, Figure 5.24).

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 = 4.00, IQR = 1.00).

On average, quality of life from exercise was in the 'life was average' range (median = 4.00, IQR = 1.50), and was found to be effective (median = 3.00, IQR = 1.00).

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

Table 5.19: Lifestyle changes

Lifestyle changes	Number (n=44)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Exercise	28	63.64	4.00	2.00	4.00	1.00
Diet changes	23	52.27	4.00	1.50	3.00	1.00
Reduce alcohol (n=30)	24	54.55	4.00	4.00	5.00	4.00
Quit smoking (n=6)	2	4.55				

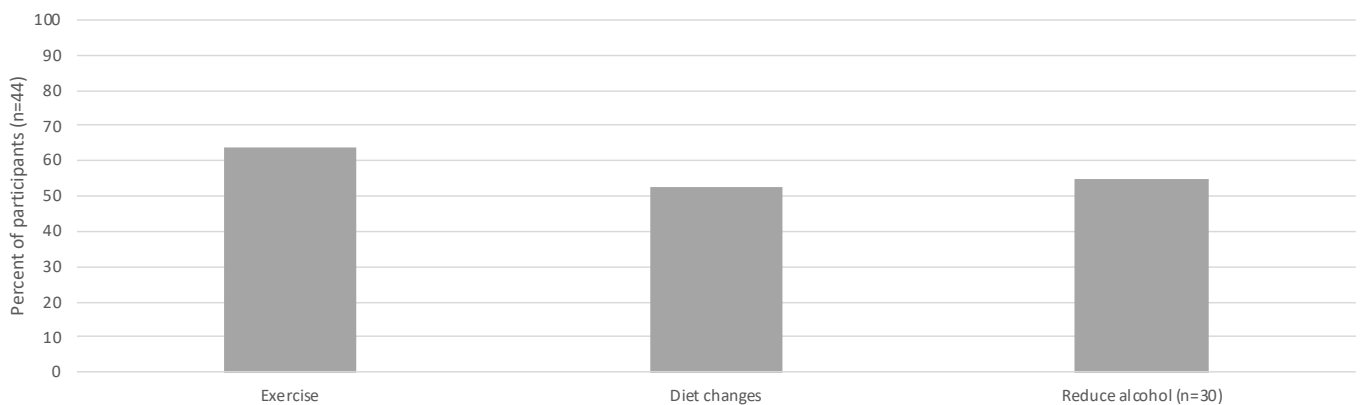


Figure 5.25: Lifestyle changes

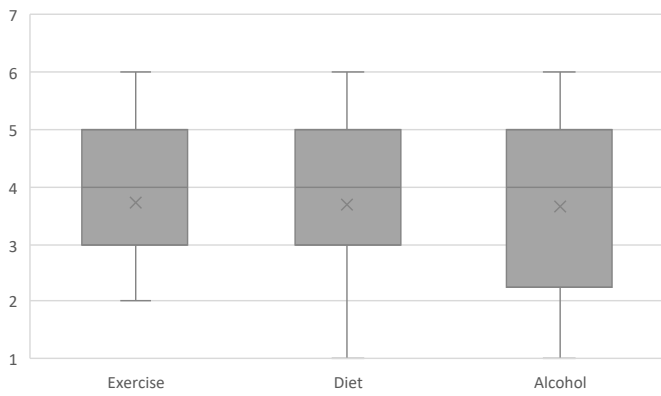


Figure 5.26: Quality of life from lifestyle changes

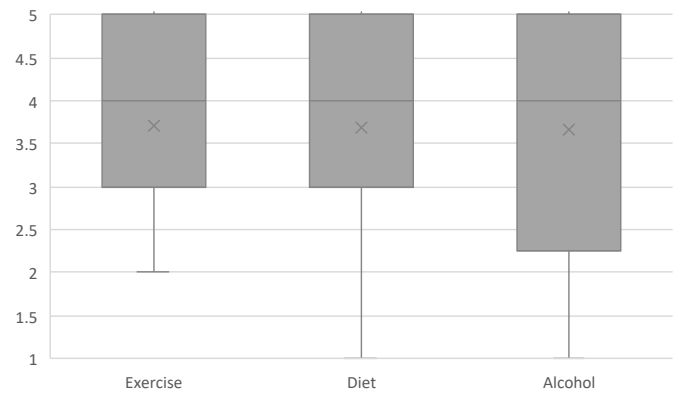


Figure 5.27: Effectiveness from lifestyle changes

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, Figures 5.28 to 5.30).

Most participants used at made at least one complementary therapy (n = 29, 65.91%), and on average used one therapy (median = 1.00, IQR = 2.00).

The most common complementary therapy used was mindfulness or relaxation techniques (n = 20, 45.45 %), followed by massage therapy (n = 17, 38.64%), and taking supplements (n = 16, 36.36%) (Table 5.21, Figure 5.24).

On average, quality of life from mindfulness or relaxation 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 massage therapy was in the 'life was average' range (median = 4.00, IQR = 1.00), and was found to be effective (median = 4.00, IQR = 2.00).

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 = 1.25).

Table 5.20: Complementary therapies

Complementary therapies	Number (n=44)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Mindfulness or relaxation	20	45.45	3.00	2.00	4.00	1.00
Massage therapy	17	38.64	4.00	1.00	4.00	2.00
Supplements	16	36.36	4.00	2.00	3.00	1.25
Acupuncture	6	13.64	4.50	1.75	3.50	1.00
Naturopathy	5	11.36	4.00	5.00	1.00	2.00
Homeopathy	2	4.55	3.50	1.50	4.00	1.00

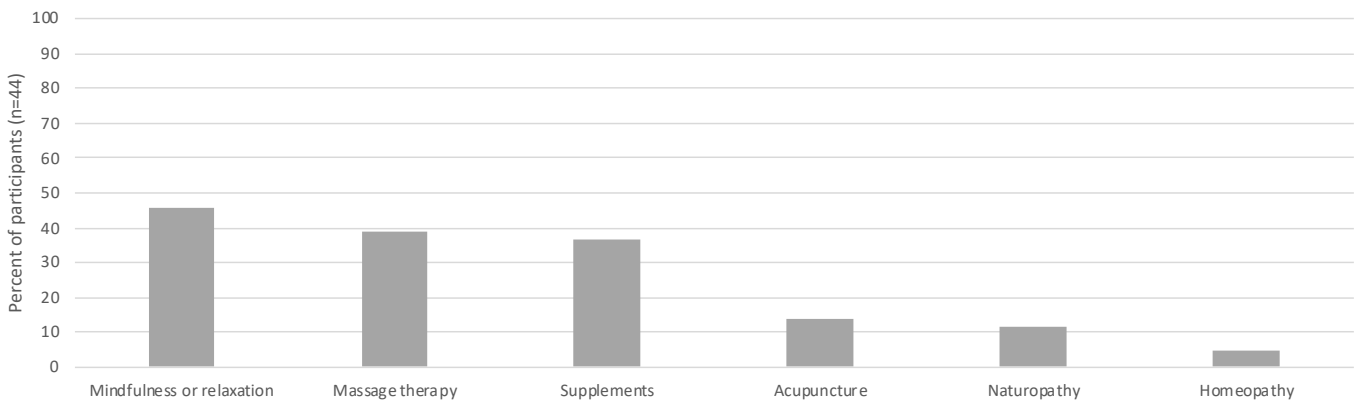


Figure 5.28: Complementary therapies

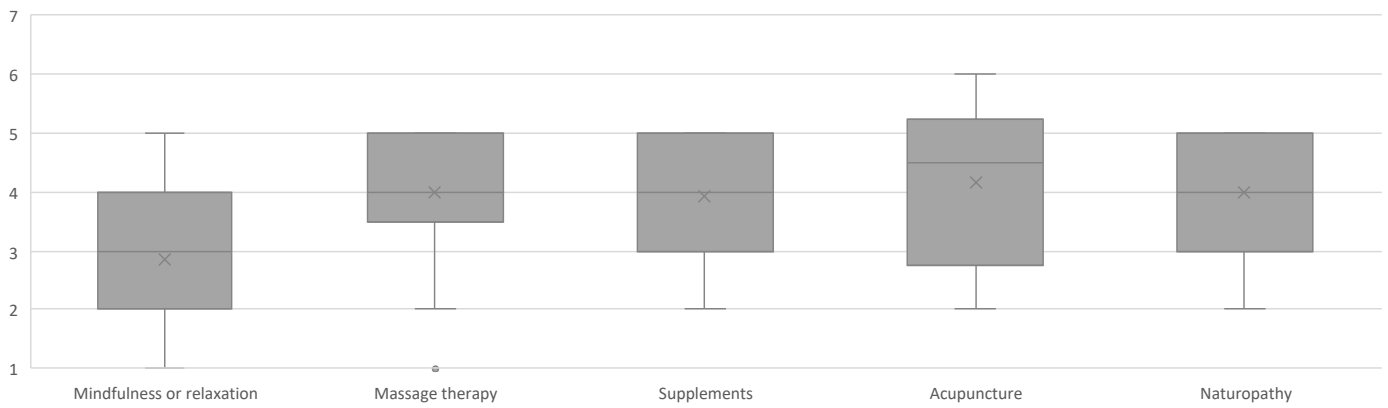


Figure 5.29: Quality of life from complementary therapies

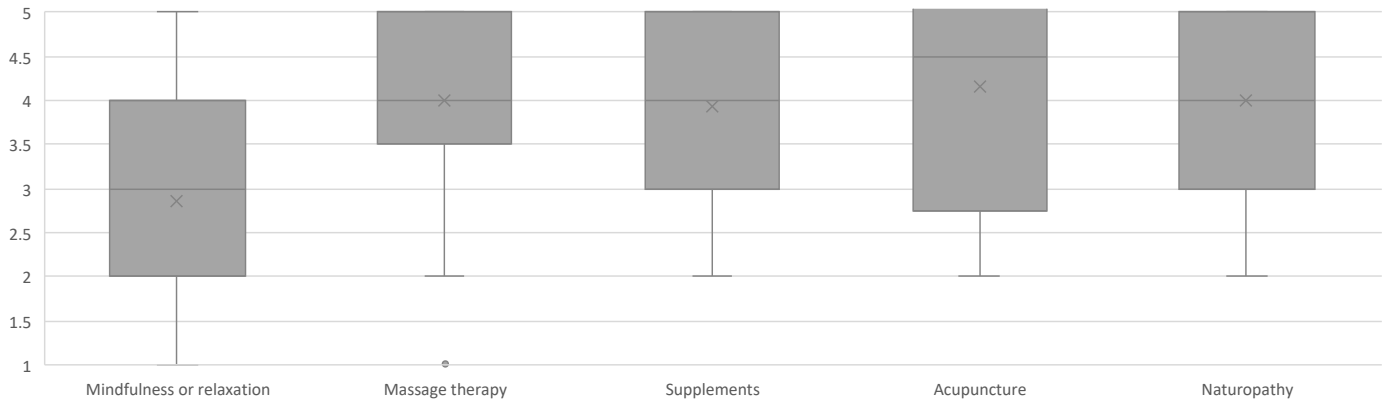


Figure 5.30: Effectiveness of complementary therapies

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 5.31).

There was a total of 16 participants (36.36%) that had discussions about clinical trials, six participants (13.64%) had brought up the topic with their doctor, and the doctor of 10 participants (22.77%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n = 28, 63.64%).

Table 5.21: Clinical trial discussions

Clinical trial discussions	Number (n=44)	Percent
Participant brought up the topic of clinical trials doctor for discussion	6	13.64
Doctor brought up the topic of clinical trials for discussion	10	22.73
Participant has ever spoken to me about clinical trials	28	63.64

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 5.32).

There were four participants (9.09%) who had taken part in a clinical trial, 32 participants (72.73%) who would like to take part in a clinical trial if there was a suitable one, and eight participants, who have not participated in a clinical trial and do not want to (18.18%).

Table 5.22: Clinical trial participation

Clinical trial participation	Number (n=44)	Percent
Has not participated in a clinical trial and does not want to	8	18.18
Has not participated in a clinical trial but would like to if there is one	32	72.73
Has participated in a clinical trial	4	9.09

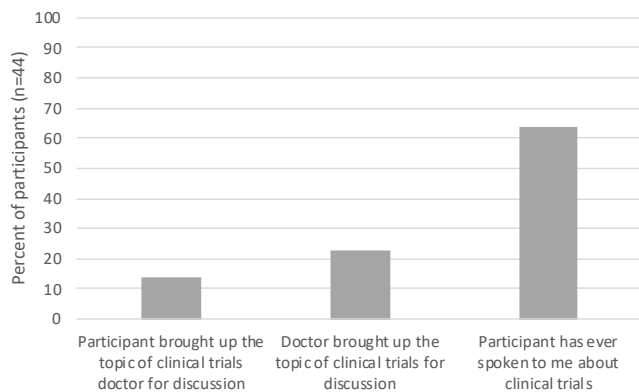


Figure 5.31: Clinical trial discussions

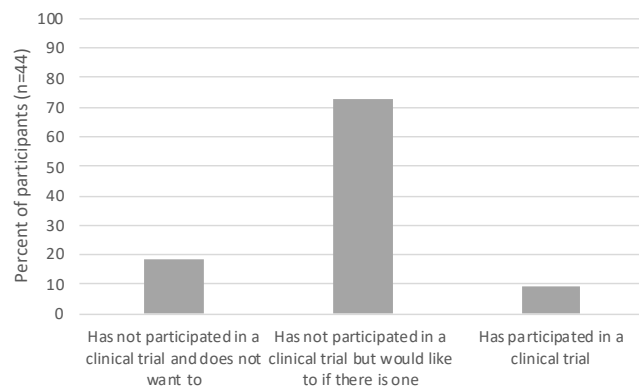


Figure 5.32: Clinical trial participation

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 those that are self managed or do not interfere with life (n=38, 76.00%), and others described mild side effects by using an example (n=21, 42.00%), or described them as side effects that could be managed with medications or treatment (n=5, 10.00%).

Where participants used an example to describe a mild side effect, this was most commonly nausea (n=10, 20.00%), followed by a feeling of discomfort (n=7, 10.00%).

Participant describes mild side effects as those that can be self-managed and do not interfere with daily life

Mild side effects...this is a good question. Mild side effects is an effect that you're aware of, that is impacting you, but it doesn't interfere with your day. You can still function, you can still get jobs done, you can still interact with people, but there's a background of discomfort. Participant_005

Oh, I guess it's hard because I got through it all. So it was all doable. And I guess you learn strategies that makes it more manageable. So they seem more mild. I guess things like the reflux, the nausea, the what else? Like losing your hair, I guess, in theory is a mild side effect. But if that had massive emotional and mental effects from it, I guess so. It's hard to try and categorise them separately. But I guess in theory that fits into both of the categories. Yeah, the fingernail changes. Yeah, I think they're more the mild ones, whereas the more severe ones, once again, I could say hair loss, but that was more to do with the emotional side of it. The fatigue was really hard and I had to manage that, especially being half naked. I was

precancer that was really mentally challenging as well. And I had to really manage that. And then the peripheral neuropathy and the pain, that was another side effect. Participant_010

I would say mild side effects is something that I could deal with at home, something that could be managed with over-the-counter drugs and which didn't affect my quality of life Participant_016

Participant describes mild side effects giving the specific example of nausea

Some mild side effect is something that would not really affect your everyday living or life. You would still be able to have something for it like mild nausea, mild bone pain. You might be able to take a tablet and it would come better. For me, that's mild side effects. Participant_018

I guess mild side effects-- seems like the nausea where you feel bad, but it's not stopping you from going on with your day. You can work through it. It doesn't impede you. Participant_020

Oh, well, just maybe a bit of nausea. Yes, a little aches and pains. I'm pretty tough. Pain, it takes a bit to get me down, but yes, things off-color and headaches and the usual things. They weren't enormous compared to from what I've heard other people have, it was not enormous. Participant_032

Participant describes mild side effects giving the specific example of feeling of discomfort

I suppose to me, mild side effects would be feeling slightly off-color, maybe to do radiation just nothing that impeded my going on with daily life. I think mild side effects would be. Participant_004

Mild side effects to me would be still being able to go about your daily business, but just at a slower pace, and maybe you're feeling a bit uncomfortable. Participant_037

My minor discomfort or. Yeah, like the city I consider very mild. OK, yeah, I didn't really have any. It's not like I can say, oh yeah, I had ulcers in my mouth and that was really horrible. Participant_003

Participant describes mild side effects as those that can be managed with medications/treatment

I would say mild side effects is something that I could deal with at home, something that could be managed with over-the-counter drugs and which didn't affect my quality of life. Participant_016

Reactions to your body that can be treated or dealt with, with medicines or alternative treatments that can not impact your life. Participant_036

I think all of the side effects I had were mild, other than the bone pain that came with Taxol, that was awful. Mild was just anything that didn't really mess up with my day. I could still do things. There was never a day I didn't get out of bed, showered, dressed, and go about my day, ever. If that's the case, I think they were all mild. There was nothing that I couldn't cope with or needed to take to my bed. There was certain events I would have to cancel. I didn't feel like going out in the evenings and things like that. The symptoms were mild. There was nothing that required hospital treatment. There was nothing that required GP treatment. It was all manageable at home with over-the-counter medications and a few cuddles. Participant_033

Table 5.23: Description of mild side effects

Description of mild side effects	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes mild side effects as those that can be self-managed and do not interfere with daily life	38	76.00	18	78.26	20	74.07	12	63.16	20	80.00	20	76.92	18	75.00	16	66.67	22	84.62
Participant provides a specific side effect as an example to describe mild side effects	21	42.00	11	47.83	10	37.04	7	36.84	11	44.00	11	42.31	10	41.67	12	50.00	9	34.62
Participant describes mild side effects as those that can be managed with medications/treatment	5	10.00	2	8.70	3	11.11	2	10.53	2	8.00	1	3.85	4	16.67	1	4.17	4	15.38

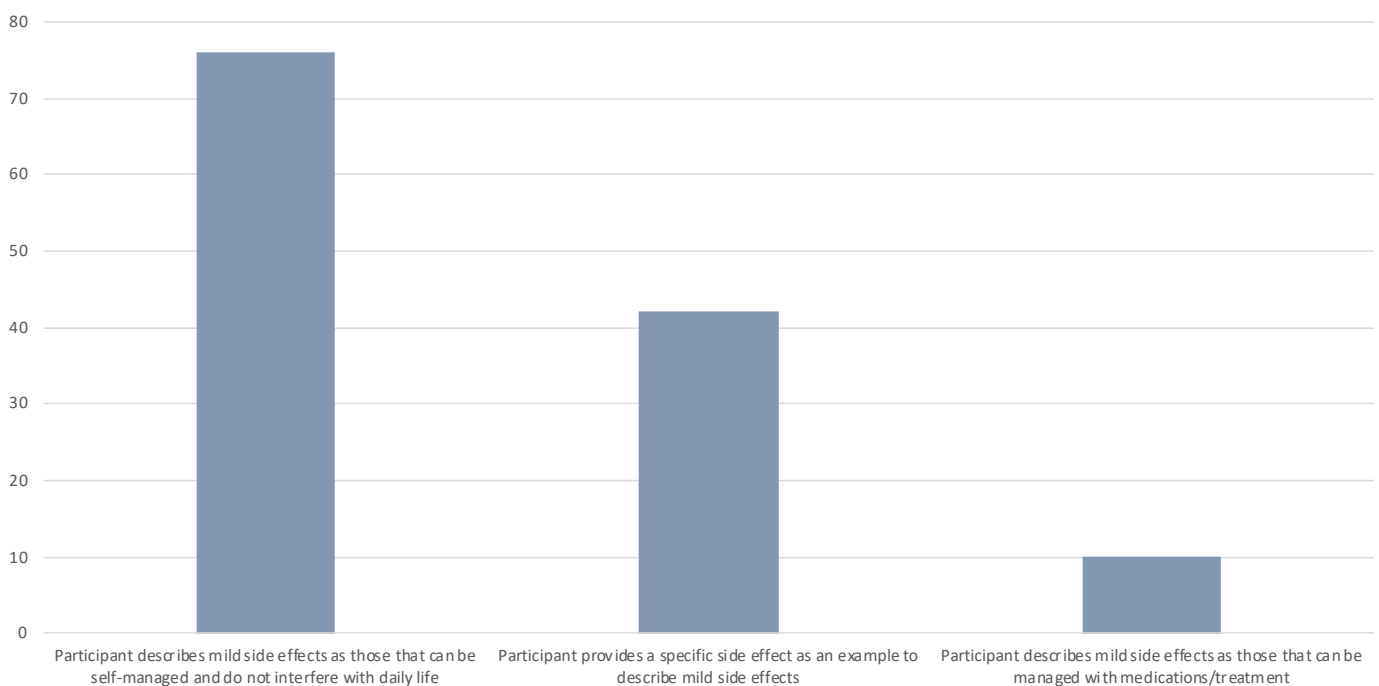


Figure 5.33: Description of mild side effects - percent of all participants

Table 5.24: Description of mild side effects - subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes mild side effects as those that can be self-managed and do not interfere with daily life	Poor physical function Aged 45 to 54	Aged 25 to 44 Aged 55 to 74
Participant provides a specific side effect as an example to describe mild side effects	Aged 25 to 44 Aged 55 to 74	Aged 45 to 54

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

Description of mild side effects (Specific side effects)	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes mild side effects giving the specific example of nausea	10	20.00	4	17.39	6	22.22	5	26.32	5	20.00	5	19.23	5	20.83	8	33.33	2	7.69
Participant describes mild side effects giving the specific example of feeling of discomfort	7	14.00	5	21.74	2	7.41	1	5.26	4	16.00	4	15.38	3	12.50	3	12.50	4	15.38

Description of mild side effects (Specific side effects)	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes mild side effects giving the specific example of nausea	10	20.00	4	17.39	8	23.53	5	25.00	5	16.67	2	10.53	6	27.27	2	22.22
Participant describes mild side effects giving the specific example of feeling of discomfort	7	14.00	5	21.74	4	11.76	2	10.00	5	16.67	2	10.53	4	18.18	1	11.11

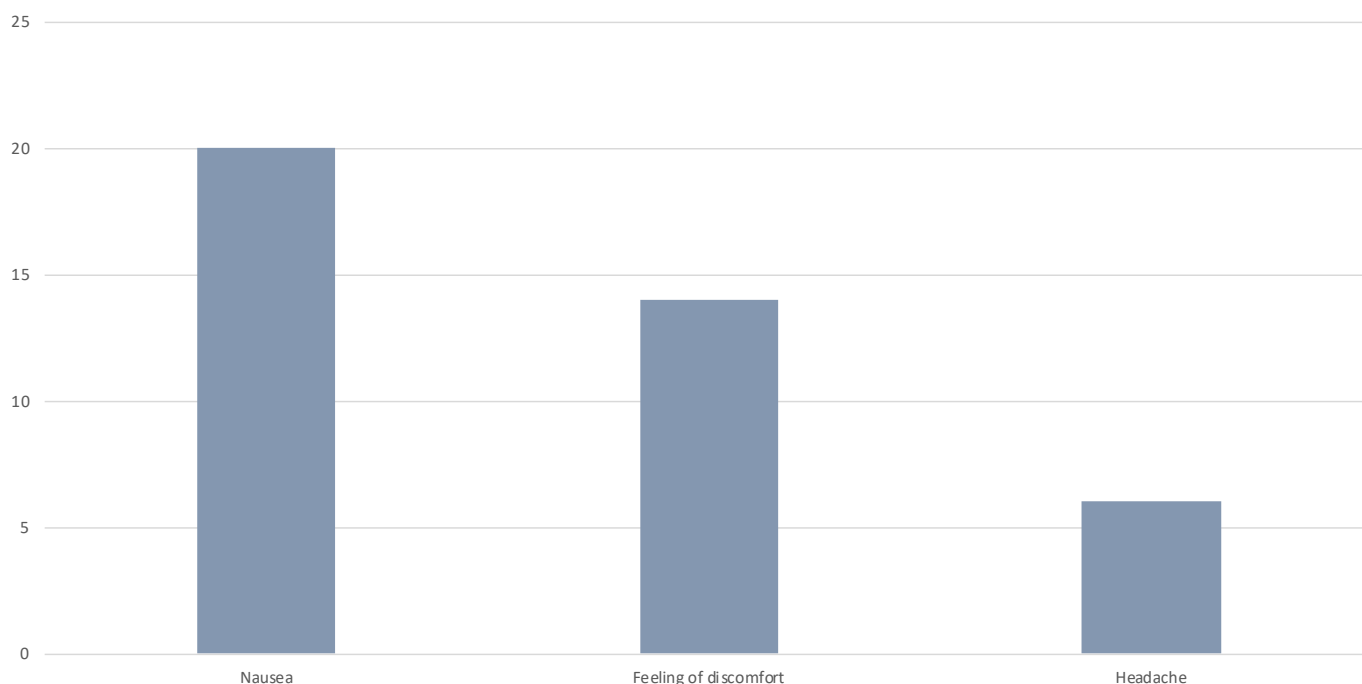


Figure 5.34: Description of mild side effects (Specific side effects) - percent of all participants

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

Theme	Reported less frequently	Reported more frequently
Participant describes mild side effects giving the specific example of nausea	University	Trade or high school

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 side effects that impact everyday life, or ability to conduct daily living (n=34, 68.00%). Other descriptions of ‘severe side effects’ included using an example to describe severe side effects (n=28, 56.00%), and side effects that are life threatening, or require hospitalisation (n=7, 14.00%).

Of those who described a specific side effect, the most commonly described side effects were extreme or

chronic pain (n=14, 28.00%), emotional or mental struggle (n=9, 18.00%), neuropathy (n=7, 14.00%), fatigue (n=6, 12.00%), and nausea and vomiting (n=5, 10.00%).

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

Severe would be not able to behave like your usual self. Irritable and tired and exhausted and not able to get the jobs done that you would need to get done.

*Yes, lots of resting, and avoiding life. [chuckles]
Participant_005*

*It's your new world so the side effects where you have to actually make changes to your life because you can't live your life as you used to before.
Participant_008*

*Side effects that stop me from being able to participate in daily activities. For example, the couple of times that I got admitted to hospital where I just, for example, the episode of colitis that I had started off with bouts of diarrhea that were sending me to the toilet 14, 15 times a day where I was so ill, I couldn't lift my head off the pillow and ended up in hospital. I could have-- I was pretty well totally out of it.
Participant_013*

*I would describe severe as, like you said, side effects that affected me, affected my ability to carry on daily activities, like brushing my teeth, going to the toilet, carrying on life as normal. Ones which gave me extremely severe fatigue. It was hard to even get out of the bed. Also, ones which had a more longer-term side effect.
Participant_016*

Participant describes severe side effects giving the specific example of extreme/chronic pain

*A severe side effect would be something that would affect your life greatly, whether it's through pain or whatever. Pain where you would not be able to perform your day-to-day life, and taking medication for it would not help at all.
Participant_018*

*The severe side effects were crippling. They messed with your mind in the sense that every part of your body ached from your toes to the top of your head and it was a [inaudible] pain. It was an internal pain and it was unbearable and as I said to several people, it's something I wouldn't wish on my worst enemy was to have to go through that kind of pain.
Participant_027*

*Well, the pins and needles that it must still get bad cramps in my veins as well because of the pain pangs. And you and your breast. Yeah, from the surgery and stitches in the bone, which makes it hard to move around sometimes. So, yeah, and there's probably a few other ones, but also the thinning of the skin from the chemotherapy I think can but also in the ear, in the bladder and the common area. Yet you became pretty quick
Participant_031*

*Severe side effects to me would be uncontrolled nausea, uncontrolled pain, and immobility.
Participant_037*

Participant describes severe side effects giving the specific example of emotional/mental struggle

*Oh, I guess it's hard because I got through it all. So it was all doable. And I guess you learn strategies that makes it more manageable. So they seem more mild. I guess things like the reflux, the nausea, the what else? Like losing your hair, I guess, in theory is a mild side effect. But if that had massive emotional and mental effects from it, I guess so. It's hard to try and categorise them separately. But I guess in theory that fits into both of the categories. Yeah, the fingernail changes. Yeah, I think they're more the mild ones, whereas the more severe ones, once again, I could say hair loss, but that was more to do with the emotional side of it. The fatigue was really hot and I had to manage that, especially being half naked. I was precancer that was really mentally challenging as well. And I had to really manage that. And then the peripheral neuropathy and the pain, that was another side effect.
Participant_010*

*Severe side effects weren't pretty at all for me. Obviously, I had some very strong reactions. They were very hard for me to cope with mentally because I felt that I was putting a strain on my family. Having the cancer diagnosis is a hard enough thing to cope with when you have young children and a partner. Not that my kids were that young, but they were young enough for me to be concerned because you still want to do things. Having no energy, and having the reactions that I did like with the pneumonia, and the herniated disks, and the nerve damage, it was quite debilitating for me. As a mother, you feel like a failure because you can't do the things that you wanted to do, or need to do to provide for your family.
Participant_022*

*There are two words in English, it was debilitating and another was, it sucks life out of you, you have no joy...You can't do anything, you're sad, yes, dark, sad, you can't do anything.
Participant_042*

Participant describes severe side effects as those that are life threatening or require hospitalisation

*I would say about sort of let's call an ambulance. You need to get extra medical assistance. And yeah, well, I guess that's really super severe. But then severe is also when are just in constant pain. Extreme discomfort. Yes.
Participant_001*

I think severe side effects, as you said, would be side effects that I couldn't cope with on my own and would need to get help with either extra medication or be admitted to the hospital, to me that would be severe that I would have to ask for help. Participant_004

Severe to me, is when I need other help. When I can't cope with it at home or I need some medical input. For me, that would be more severe. If I can cope with it at home, it's not. Severe would be when I have to go and get some outside help to deal with something. Participant_033

Participant describes severe side effects giving the specific example of neuropathy

Like I just had the fecal impaction, that was pretty stressful. I was freaking out on a Sunday. I managed to calm myself down though. That was really bad. [unintelligible]. Oh, my God. I haven't been able to-- you can't eat. It's just, yes, they were horrible and they're so painful. There's hardly anything you could do for them, so yes, that's really bad. The neuropathy as well. My fingers and my fingertips and my toes are numb. I was feeling like my right hand is being quite painful as well with the neuropathy. I've tried to handle it to the best my ability, but it still-- I mean you drop things, you can't open things, it's hard to walk. It's actually quite stressful. Participant_028

When I say life, your activities that you did prior to your diagnosis. With my neuropathy, I can't walk around for extended periods of time without my feet becoming so painful. I used to run and walk with friends all the time. I can't do any of that. Participant_029

The diarrhoea was definitely the worst. Never knowing where you when you would have to go to the toilet, having to keep, you know, change of clothes in my office at work, having to take change of clothes in my car, having to make sure that you're at a you go out to dinner, you know where the toilets are located. That was for the diarrhoea. But the neuropathy was really hard to cope with when you got no feelings in your fingers and toes, you couldn't I couldn't pick anything up off the table. You know, you couldn't hold a pen, things like that. That sounds quite severe. Participant_049

Participant describes severe side effects giving the specific example of fatigue

Severe would be not able to behave like your usual self. Irritable and tired and exhausted and not able to get the jobs done that you would need to get done. Yes, lots of resting, and avoiding life. [chuckles] Participant_005

Yes, I still have some. I still have the chronic pain and the fatigue that slides me right down and for someone with four children and a full-time job, I can't function. I can't do what I'm supposed to do. That's what I would call a severe side effect. Participant_012

I would describe severe as, like you said, side effects that affected me, affected my ability to carry on daily activities, like brushing my teeth, going to the toilet, carrying on life as normal. Ones which gave me extremely severe fatigue. It was hard to even get out of the bed. Also, ones which had a more longer-term side effect. Participant_016

Participant describes severe side effects giving the specific example of nausea/vomiting

Exactly what I had on AC, where I was nauseous and felt like I needed to vomit and I couldn't. I had a high temperature. I found it difficult to get out of bed. The mouth sores made it very difficult to eat, so it was very uncomfortable and painful. It hurt to speak. Sorry, I've blocked it out a bit, I think. The reflux was horrendous. Couldn't brush my teeth. It was difficult. You just feel it all the time, so uncomfortable. That's that. Participant_007

Severe side effects to me would be uncontrolled nausea, uncontrolled pain, and immobility. Participant_037

I think that would be like vomiting all the time and I didn't have any of that. I think I thought that that's what was going to happen when they said, "You might get sick and you might have really bad diarrhea." I thought it was going to be coming from both ends and you'd be green like they are on TV, whereas I didn't have that. Sorry. [laughs] Participant_045

Table 5.27: Description of severe side effects

Description of severe side effects	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	34	68.00	17	73.91	17	62.96	13	68.42	17	68.00	15	57.69	19	79.17	14	58.33	20	76.92
Participant provides a specific side effect as an example to describe severe side effects	28	56.00	16	69.57	12	44.44	13	68.42	12	48.00	12	46.15	16	66.67	14	58.33	14	53.85
Participant describes severe side effects as those that are life threatening or require hospitalisation	7	14.00	5	21.74	2	7.41	3	15.79	3	12.00	3	11.54	4	16.67	2	8.33	5	19.23

Description of severe side effects	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	34	68.00	13	81.25	21	61.76	12	60.00	22	73.33	14	73.68	14	63.64	6	66.67
Participant provides a specific side effect as an example to describe severe side effects	28	56.00	9	56.25	19	55.88	12	60.00	16	53.33	10	52.63	14	63.64	4	44.44
Participant describes severe side effects as those that are life threatening or require hospitalisation	7	14.00	4	25.00	3	8.82	4	20.00	3	10.00	0	0.00	5	22.73	2	22.22

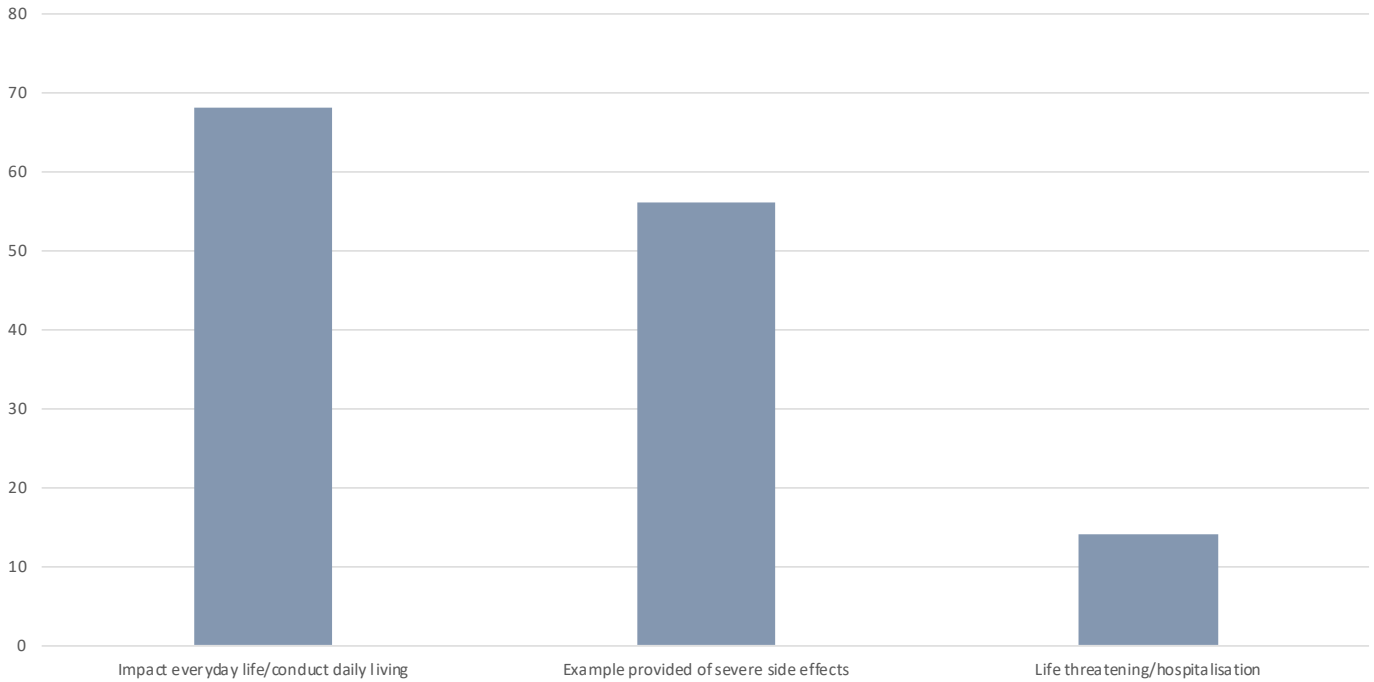


Figure 5.35: Description of severe side effects - percent of all participants

Table 5.28: Description of severe side effects – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	Diagnosed before 2020	Diagnosed in 2020 or 2021 Regional or remote
Participant provides a specific side effect as an example to describe severe side effects	Advanced breast cancer Aged 55 to 74	Early breast cancer Poor physical function Diagnosed in 2020 or 2021
Participant describes severe side effects as those that are life threatening or require hospitalisation	Aged 25 to 44	Regional or remote

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

Description of severe side effects (Specific example)	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes severe side effects giving the specific example of extreme/chronic pain	14	28.00	6	26.09	8	29.63	6	31.58	6	24.00	6	23.08	8	33.33	9	37.50	5	19.23
Participant describes severe side effects giving the specific example of emotional/mental struggle	9	18.00	3	13.04	6	22.22	3	15.79	6	24.00	5	19.23	4	16.67	2	8.33	7	26.92
Participant describes severe side effects giving the specific example of neuropathy	7	14.00	3	13.04	4	14.81	4	21.05	3	12.00	3	11.54	4	16.67	5	20.83	2	7.69
Participant describes severe side effects giving the specific example of fatigue	6	12.00	6	26.09	0	0.00	2	10.53	2	8.00	4	15.38	2	8.33	4	16.67	2	7.69
Participant describes severe side effects giving the specific example of nausea/vomiting	5	10.00	1	4.35	4	14.81	2	10.53	2	8.00	3	11.54	2	8.33	2	8.33	3	11.54

Description of severe side effects (Specific example)	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes severe side effects giving the specific example of extreme/chronic pain	14	28.00	4	25.00	10	29.41	4	20.00	10	33.33	5	26.32	7	31.82	2	22.22
Participant describes severe side effects giving the specific example of emotional/mental struggle	9	18.00	1	6.25	8	23.53	5	25.00	4	13.33	4	21.05	4	18.18	1	11.11
Participant describes severe side effects giving the specific example of neuropathy	7	14.00	0	0.00	7	20.59	1	5.00	6	20.00	0	0.00	4	18.18	3	33.33
Participant describes severe side effects giving the specific example of fatigue	6	12.00	3	18.75	3	8.82	4	20.00	2	6.67	3	15.79	3	13.64	0	0.00
Participant describes severe side effects giving the specific example of nausea/vomiting	5	10.00	0	0.00	5	14.71	1	5.00	4	13.33	1	5.26	4	18.18	0	0.00

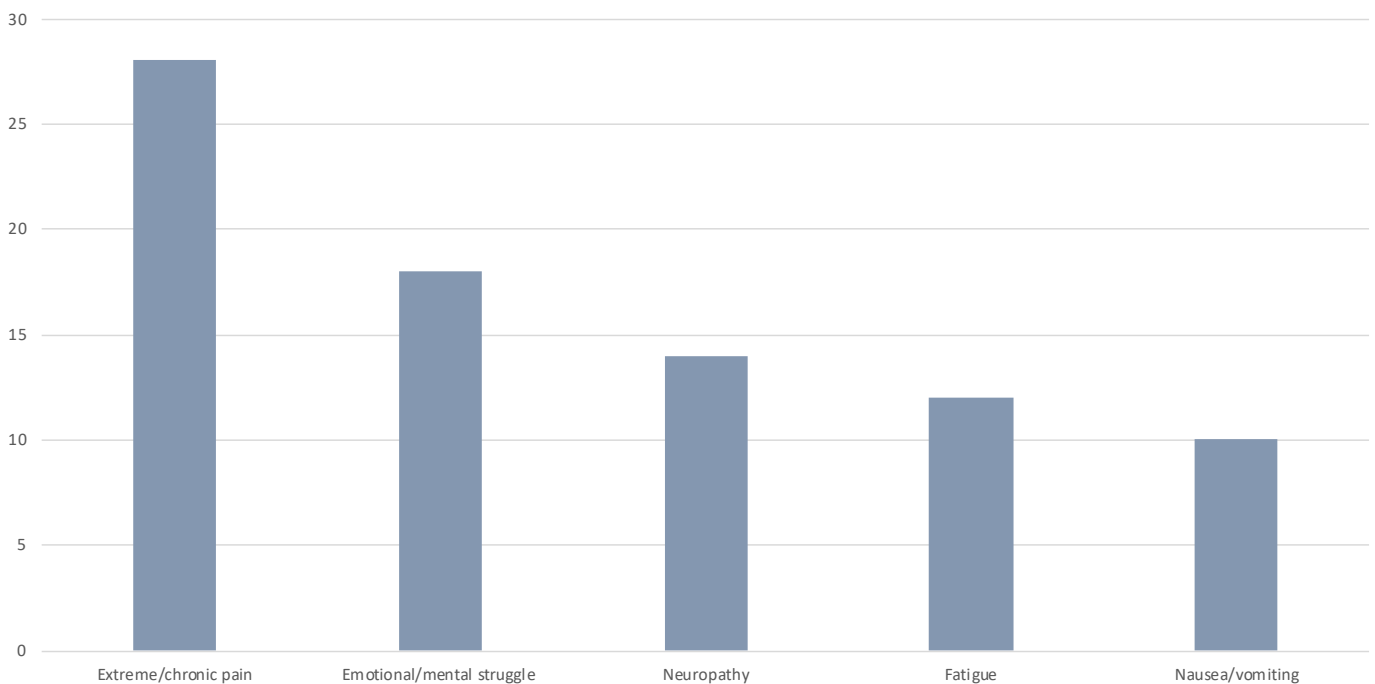


Figure 5.36: Description of severe side effects (Specific example) - percent of all participants

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

Theme	Reported less frequently	Reported more frequently
Participant describes severe side effects giving the specific example of emotional/mental struggle	Regional or remote	-
Participant describes severe side effects giving the specific example of neuropathy	Regional or remote Aged 25 to 44	Aged 55 to 74
Participant describes severe side effects giving the specific example of fatigue	Advanced breast cancer Aged 55 to 74	Early breast cancer

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime. The most common theme described were taking the advice of specialist, or taking it as prescribed (n=27, 54.00%). This was followed by participants describing not giving up on any treatment (n=16, 32.00%), taking treatments for a specific amount of time (n=13, 26.00%), seeing test results with no evidence of disease or reduction of disease (n=8, 16.00%), and as long as side effects tolerable (n=7, 14.00%).

Where participants stated a specific amount of time to adhere to a treatment, the most common amount of time was one week.

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

If I don't think it's working, I don't know. I would keep going with it because I wouldn't, I wouldn't assume that I knew if it was working or not. OK, so I think I would stick with it, although I did refuse some medication they would of after my surgery. So I was being offered drugs for pain relief, but I researched side effects and so I just didn't want to take it. So I refused drugs. But pain relief, I wouldn't. I would. I trusted my oncologist. Participant_001

Would depend on the medication and what they what the medical advice was about, how long it takes to work. For example, if I said it takes three months to work on what if it wasn't working the way it was, like if you were hoping that it came to spread after three months and that's not what we need. Participant_002

If it's something that I can order in bulk, I normally order bulk, so I can try it. I've got a very close relationship with my GP. Anything that I've tried, I've discussed with him about, how long I should take it and to give that a try. It's usually at least three or four months that I've done something for. Participant_008

Participant describes not giving up on any treatment

My treatment, I was never going to quit it. I was never going to say after round three of chemo, this is too much or I don't think it's working. And I was not I wouldn't never would never have considered stopping. Participant_003

I'm not going to give up on it because I have a 10-year-old daughter, so we were just going to persevere. Participant_007

I've been lucky that everything that I've been given has not really been an issue, so I haven't had to give up on it as such. I've known there's an end date or whatever with chemo, in particular. Everything else, I haven't really gone, "I can't do this anymore Participant_021

Participant describes adhering to treatment for a specific amount of time

Would depend on the medication and what they what the medical advice was about, how long it takes to work. For example, if I said it takes three months to work on what if it wasn't working the way it was, like if you were hoping that it came to spread after three months and that's not what we need. Participant_002

Oh. I try really hard not to give up on it. Because mine was triple-negative, I haven't had to do any of the hormone replacement side of things, like long term, so I'm not currently on any medications for cancer. I think it would really need to be some severe side effects, but I would have those discussions with my specialist and see what other medications they can prescribe to help with those side effects so that you can continue doing it. I think at the end of the day, the decisions all need to be based off of if they give me the best chance of living. Participant_025

Probably a few weeks, depending on what it is like. You've got to look at what you take and why you're taking it and how long your fixes to take it anymore. But, you know, when you should see an improvement or whether you should say that it's making some sort of benefit. So you've got to go through all of that size before you can, that this isn't for me. Participant_044

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

I don't really given up on anything, I don't think, except for maybe the Taxol, the Paclitaxel, because I was getting neuropathy so they had to stop that. I still take Endone occasionally if I'm in a lot of pain. Participant_028

I feel like I manage pain better than nausea. So whenever I'm given pain medication and I take antiemetic with it, but if it still makes me sick, I want the animatics off in my sleep. And I don't like that feeling and I don't like the feeling of sleeping tablets and I don't sleep well. But I think that that's just that's my choice. I don't like I feel like I'm hung over the next day if I take some medication Participant_038

Table 5.31: Adherence to treatment

Adherence to treatment	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	27	54.00	12	52.17	15	55.56	10	52.63	15	60.00	15	57.69	12	50.00	10	41.67	17	65.38
Participant describes not giving up on any treatment	16	32.00	8	34.78	8	29.63	7	36.84	8	32.00	8	30.77	8	33.33	8	33.33	8	30.77
Participant describes adhering to treatment for a specific amount of time	13	26.00	7	30.43	6	22.22	7	36.84	5	20.00	7	26.92	6	25.00	7	29.17	6	23.08
Participant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	8	16.00	2	8.70	6	22.22	2	10.53	4	16.00	4	15.38	4	16.67	1	4.17	7	26.92
Participant describes adhering to treatment as long as side effects are tolerable	7	14.00	3	13.04	4	14.81	3	15.79	3	12.00	5	19.23	2	8.33	3	12.50	4	15.38

Adherence to treatment	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	27	54.00	8	50.00	19	55.88	9	45.00	18	60.00	11	57.89	9	40.91	7	77.78
Participant describes not giving up on any treatment	16	32.00	5	31.25	11	32.35	4	20.00	12	40.00	7	36.84	3	13.64	6	66.67
Participant describes adhering to treatment for a specific amount of time	13	26.00	4	25.00	9	26.47	6	30.00	7	23.33	5	26.32	7	31.82	1	11.11
Participant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	8	16.00	4	25.00	4	11.76	4	20.00	4	13.33	2	10.53	6	27.27	0	0.00
Participant describes adhering to treatment as long as side effects are tolerable	7	14.00	2	12.50	5	14.71	4	20.00	3	10.00	3	15.79	2	9.09	2	22.22

Figure 5.37: Adherence to treatment - percent of all participants

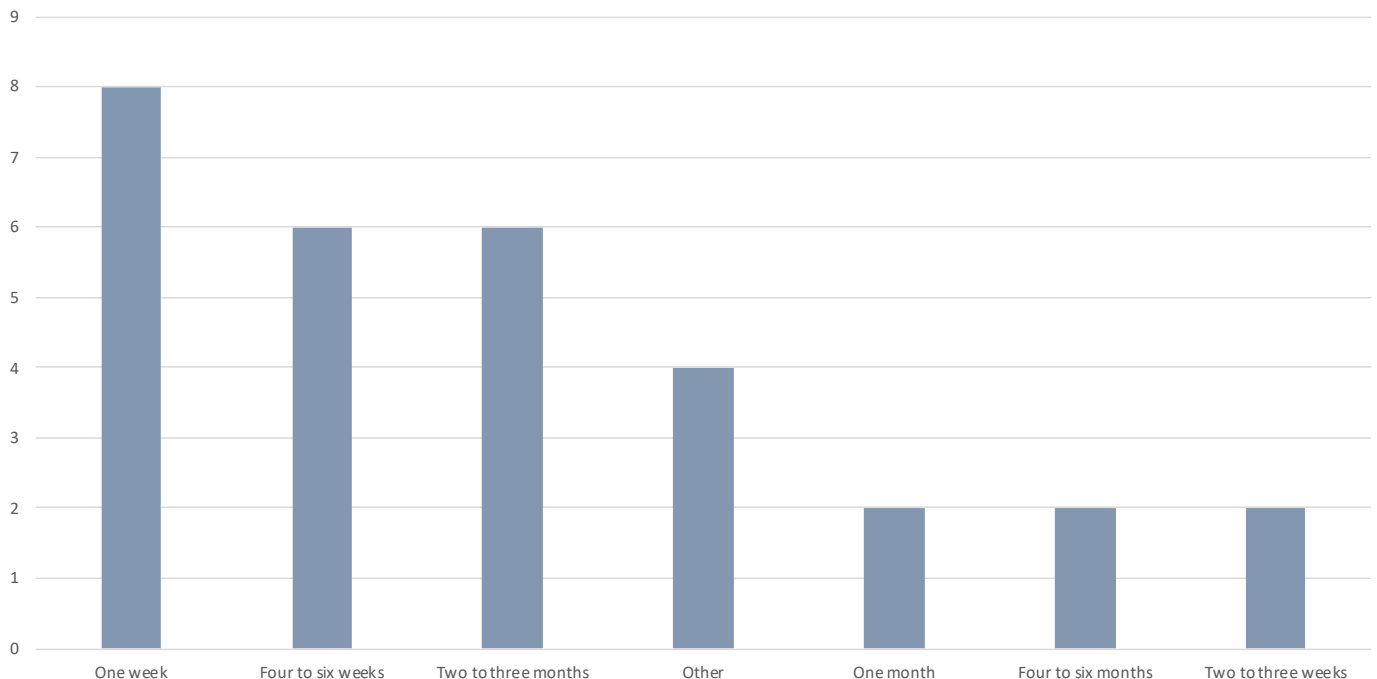


Figure 5.38: Adherence to treatment (Time to adhere to treatment)

Table 5.32: Adherence to treatment – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	Trade or high school Aged 45 to 54	University Aged 55 to 74
Participant describes not giving up on any treatment	Mid to low status Aged 45 to 54	Aged 55 to 74
Participant describes adhering to treatment for a specific amount of time	Aged 55 to 74	Poor physical function
Participant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	Trade or high school Aged 55 to 74	University Aged 45 to 54

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 21 participants (42%) who described the reduction or disappearance of physical signs and symptoms. There were 17 participants (34%) who described seeing positive results of tests, or scans showing disease reduction, eight participants (16%) who described seeing evidence of stable disease, or no disease progression, and six participants (12.00%) who described needing to return to day-to-day functionality.

Where participants described seeing reduction in specific signs and symptoms, this was most commonly a reduction in pain levels (n=10, 20.00%), and a reduction in nausea (n=7, 14.00%).

Participants reported needing to see physical signs and symptoms disappear/reduced

I generally just observe over time my symptoms and how I'm feeling. Then if I don't feel like it's changing, then I probably speak to my GP and even speak to my psychologist or what have you. They've helped me realize sometimes that it's actually not working. There's some things I've taken that I hadn't really realized that, of course, they're not working, but they aren't. Participant_008

Yes, so reduction in pain, visually reduction in, for example, the tumor when they did ultrasounds, reduction in size of it. Also, a palpable time is when I couldn't feel the lump anymore physically myself, or if my doctor said, "Good job, we can't feel the lumps anymore." Those things, so clinical markers, physically feeling better, absence of pain and inflammation. Participant_016

It's hard. For me, I need facts to know that it's working. I need scans, I need reports, that thing, whereas you just don't know. That's probably the hardest thing about this whole thing, is you just don't know that it's worked unless there's been a physical change. Participant_030

Symptoms, so either less nausea or less rashes or less visible and physical symptoms Participant_036

Participants reported needing to see positive results of tests/or scan showing disease reduction

PARTICIPANT: Surgery is you go in and you have it and you're out. Decision on which surgery has it be cool.

INTERVIEWER: When you take any medication, what is it that you're looking for that helps you indicate if it's working or not? Is it reduction in why you're taking it? What treatment are you looking for? Changes in your blood results or imaging?

PARTICIPANT: Yes. I guess from that point of view, your [unintelligible] changes in your blood results, the [unintelligible] was making sure you had the white blood cells to make sure I had enough ready to go to the next one. See, I didn't take much treatment. I took the supplements, and anti-nausea, those tablets I took them then that they had to stop the nausea. I just took them as much as I could. The constipation, the tablets that you took for that, you were trying to make sure that your bowels were operating. That was having a physical effect on you. The only other medication I took was the reflux medication, and that was to relieve the pain. There was a physical response to that as well. Participant_047

I'd look at the scan results, or I'd look at the blood test results and any other ways that they were for measuring its effectiveness. Participant_050

Yes, so reduction in pain, visually reduction in, for example, the tumor when they did ultrasounds, reduction in size of it. Also, a palpable time is when I couldn't feel the lump anymore physically myself, or if my doctor said, "Good job, we can't feel the lumps anymore." Those things, so clinical markers, physically feeling better, absence of pain and inflammation. Participant_016

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

I guess evidence of disease progression, that would be my primary thing, I wouldn't just judge if it was working or not buy side effects or symptoms. Participant_001

Well, I have no visibility of whether somethings working because they got all the lump out and I just had to have faith that it's doing something to make sure that there's no more cancer growing. Participant_007

Well, it's one for me. I never knew throughout the journey whether it was working or not, what they could test, anything to say it's working, the cancer's shrunk or anything like that, because I had a lumpectomy and then it was just let's just kill your body, fill it with poison to get any stragglers. I knew after my lumpectomy and sentinel node was removed that it hadn't spread to any other nodes. So that was a good thing. Participant_003

Participants reported needing to experience a return to day-to-day functionality

That would've been amazing. I would have been able to, I think, eat better, and just generally, I don't know, be part of my family better if you know what I mean. Take part in family life. Participant_004

It would. Being able to take that medication helped my quality of life. It allowed me to get out of the house and socialise with friends. It allowed me to go for walks on the beach on really good days. It meant that I could exercise to the point of going for a run or going for a swim during treatment. I had my 30th birthday, so it meant that I was able to still go out to dinner with friends and enjoy those kinds of things. It also meant that I wasn't sleeping all day, every day, and I was able to do activities to distract myself or to find joy in my every day during treatment. Participant_010

It means I can live normally. It means I can get in my car and drive, I can go to work and do my job properly. It means I can exercise to a similar level to what I was doing before. It means I can live my life how I did before I got cancer. Participant_020

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		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participants reported needing to see physical signs and symptoms disappear/reduced	21	42.00	10	43.48	11	40.74	9	47.37	7	28.00	9	34.62	12	50.00	9	37.50	12	46.15
Participants reported needing to see positive results of tests/or scan showing disease reduction	17	34.00	8	34.78	9	33.33	8	42.11	7	28.00	8	30.77	9	37.50	5	20.83	12	46.15
Participants reported needing to experience evidence of stable disease/no disease progression	8	16.00	4	17.39	4	14.81	4	21.05	3	12.00	5	19.23	3	12.50	2	8.33	6	23.08
Participants reported needing to experience a return to day-to-day functionality	6	12.00	3	13.04	3	11.11	2	10.53	4	16.00	2	7.69	4	16.67	6	25.00	0	0.00

What needs to change to feel like treatment is working	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participants reported needing to see physical signs and symptoms disappear/reduced	21	42.00	10	62.50	11	32.35	8	40.00	13	43.33	10	52.63	10	45.45	1	11.11
Participants reported needing to see positive results of tests/or scan showing disease reduction	17	34.00	5	31.25	12	35.29	4	20.00	13	43.33	8	42.11	5	22.73	4	44.44
Participants reported needing to experience evidence of stable disease/no disease progression	8	16.00	4	25.00	4	11.76	4	20.00	4	13.33	1	5.26	5	22.73	2	22.22
Participants reported needing to experience a return to day-to-day functionality	6	12.00	1	6.25	5	14.71	1	5.00	5	16.67	2	10.53	1	4.55	3	33.33

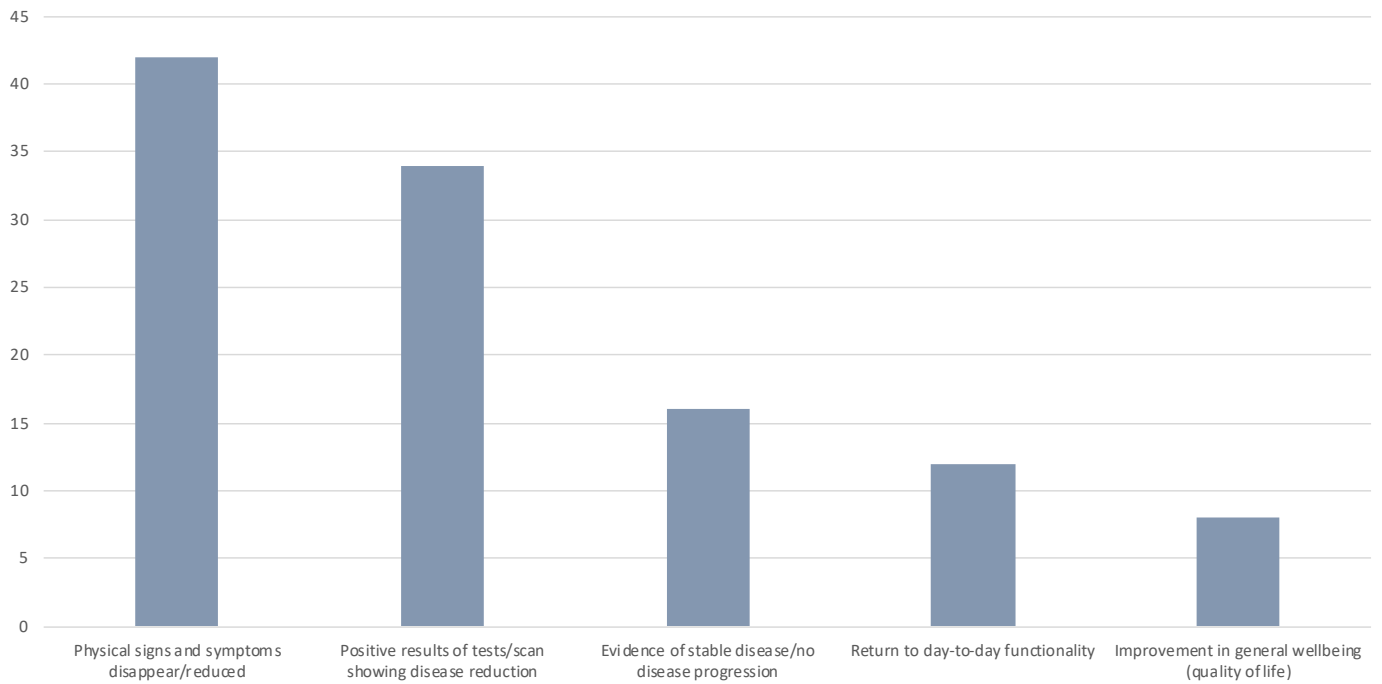


Figure 5.39: What needs to change to feel like treatment is working - percent of all participants

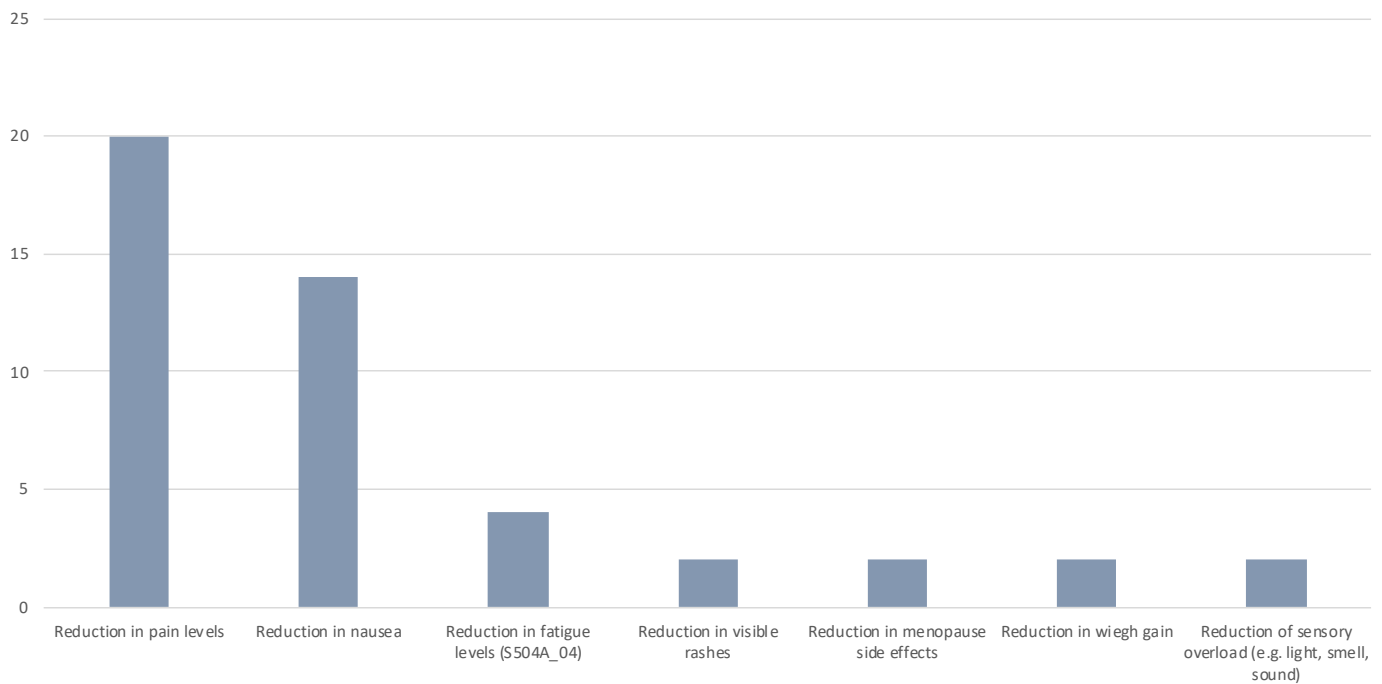


Figure 5.40: What needs to change to feel like treatment is working (specific symptoms) - percent of all participants

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

Theme	Reported less frequently	Reported more frequently
Participants reported needing to see physical signs and symptoms disappear/reduced	Good physical function Aged 55 to 74	Regional or remote Aged 25 to 44
Participants reported needing to see positive results of tests/or scan showing disease reduction	Trade or high school Mid to low status Aged 45 to 54	University Aged 55 to 74
Participants reported needing to experience evidence of stable disease/no disease progression	Aged 25 to 44	-
Participants reported needing to experience a return to day-to-day functionality	University	Trade or high school Aged 55 to 74

What it would mean if treatment worked

Participants were asked what it would mean for them in their everyday life if treatment worked. The most common response from 35 participants (70.00%) was that it would allow them to do everyday activities, or return to normal life. Other responses included being able to engage more with social activities and family life (n=14, 28.00%), a reduction in symptoms and side effects (n=11, 22.00%), the ability to return to work (n=7, 14.00%), and allowing them to do domestic tasks (n=6, 12.00%).

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

That would've been amazing. I would have been able to, I think, eat better, and just generally, I don't know, be part of my family better if you know what I mean. Take part in family life. Participant_004

It would. Being able to take that medication helped my quality of life. It allowed me to get out of the house and socialise with friends. It allowed me to go for walks on the beach on really good days. It meant that I could exercise to the point of going for a run or going for a swim during treatment. I had my 30th birthday, so it meant that I was able to still go out to dinner with friends and enjoy those kinds of things. It also meant that I wasn't sleeping all day, every day, and I was able to do activities to distract myself or to find joy in my every day during treatment. Participant_010

It means I can live normally. It means I can get in my car and drive, I can go to work and do my job properly. It means I can exercise to a similar level to what I was doing before. It means I can live my life how I did before I got cancer. Participant_020

Allowing them to engage more with social activities and family life

It would. Being able to take that medication helped my quality of life. It allowed me to get out of the house and socialise with friends. It allowed me to go for walks on the beach on really good days. It meant that I could exercise to the point of going for a run or going for a swim during treatment. I had my 30th birthday, so it meant that I was able to still go out to dinner with friends and enjoy those kinds of things. It also meant that I wasn't sleeping all day, every day, and I was able to do activities to distract myself or to find joy in my every day during treatment. Participant_010

Yes, obviously, if I was out of pain and not nauseous, I could eat and drink as normal, which would help my recovery, I believe. Also, just being able to spend time with my child, because that was my priority, because he needed me last year more than now. Basically, even be able to just eat, drink, have a shower myself without relying on anyone. Yes, just daily house chores. Participant_016

I would have been able to [unintelligible] get up and actually do things and continue on with life, and have less impact on myself and my family's life. Participant_018

It would mean I would be able to participate more in daily activities. My youngest daughter, I think she was seven, and I was trying to brush her hair, and get her ready for school, and I was vomiting. If I've been able to control my nausea, that would've been easier. Participant_037

Participant describes treatment leading to a reduction in symptoms/side effects

I took tablets for the nausea, and that meant that I could go out. Go to the shops and function. What else did I take? I didn't take much else. I might have taken Panadol to reduce some of the joint pain, and Nurofen. That one just allowed me to relax and not be in pain. That's about it. Participant_017

That would be if I could take something for that AC, in particular. If you can minimize just the overall effects of that, that would be amazing because that really made you feel like you had cancer. You knew that it was doing something to your body. The paclitaxel not so much. Like I said, I'd have it on the Friday and I'd be a bit high on the weekend but I went to work like nothing happened on the Monday. It was a big difference between the two, to me, so if there's something that makes you feel-- Because I always said I wasn't sick. There was nothing other than that pain. I'm not sick, don't make me feel like I'm sick. I was a bit horrible. Don't ask me how I am because I'm not sick. That was probably the difference where like going through AC, you do definitely feel sorry for yourself because you're like, "Now I feel sick." [chuckles] "Now I feel like crap," whereas if paclitaxel was an absolute walk in the park compared to it. Participant_021

Oh, if you take nausea, for example, the fact that you can actually concentrate, and you're not worried that you're going to vomit somewhere. It's quite just distressing in terms of just that feeling that you just think you're going to vomit, and you just need to keep walking. You can't sit still, you can't concentrate, but when you try to stop yourself from vomiting. On the [unintelligible] I have no idea but it's good anyway, whatever he told me I took it. Participant_047

Participant describes treatment allowing them to return to work

It'd be very different. My life would be very different because it's changed everything this fatigue. I'd be able to work again. I'd be able to participate more in social events. I still exercise, but I can't do it to the same extent I used to. Then family life would be a lot easier as well. Participant_008

Yes, correct. It means that you could function and do the tasks that you need to do in the household or work or whatever. Participant_036

If I could take pain medication, that would allow me to be on to stand for long periods of time, then I would be able to go back to work. So it would change a lot and it would allow me to be able to be more physically active with my kids, which is very. Important to me, but not being able to do that. Participant_038

Participant describes treatment allowing them to do domestic tasks

Drive my daughter to school. Make meals. I wasn't really able to get up to do any of that while I was on AC. Participant_007

Everything's harder to cope with when you're exhausted. Stress at work gets harder to deal with. Everything gets harder to deal with when you don't have energy. For example, I've just had a week off work. I'm off this week so it's the first time in ages that I've been able to do some of the deep cleaning in my house that's been neglected. I can't deal with that when I'm working five days and only got the weekend to recover kind of thing. That's the sort of thing that makes a difference. I can just get more life admin done. Participant_011

At the moment, I can barely look after my four-year-old. I'm actually going to have him tonight by myself to see if I can handle that. I can't bend from the hips, so bending over to try to change him or dress him or-- I cannot pick him up. He used to go to sleep in my bed and I'd carry him into his, I can't do that. I can't up and down off the floor to play with him when he wants. It's really affecting what I can do with him. I'm not able to do a lot of housework. I've had to move my microwave that was an under bench one up on top of the bench so I can actually bend over and use it and get things out. There's a lot that's affected at the moment. Participant_048

Table 5.35: What it would mean if treatment worked

What it would mean if treatment worked	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes treatment allowing them to do everyday activities/ return to normal life	35	70.00	17	73.91	18	66.67	14	73.68	17	68.00	17	65.38	18	75.00	18	75.00	17	65.38
Participant described treatment allowing them to engage more with social activities and family life	14	28.00	8	34.78	6	22.22	3	15.79	7	28.00	7	26.92	7	29.17	6	25.00	8	30.77
Participant describes treatment leading to a reduction in symptoms/side effects	11	22.00	5	21.74	6	22.22	5	26.32	4	16.00	6	23.08	5	20.83	3	12.50	8	30.77
Participant describes treatment allowing them to return to work	7	14.00	3	13.04	4	14.81	3	15.79	2	8.00	3	11.54	4	16.67	3	12.50	4	15.38
Participant describes treatment allowing them to do domestic tasks	6	12.00	3	13.04	3	11.11	3	15.79	3	12.00	2	7.69	4	16.67	1	4.17	5	19.23

What it would mean if treatment worked	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes treatment allowing them to do everyday activities/ return to normal life	35	70.00	12	75.00	23	67.65	14	70.00	21	70.00	8	42.11	18	81.82	9	100.00
Participant described treatment allowing them to engage more with social activities and family life	14	28.00	6	37.50	8	23.53	3	15.00	11	36.67	9	47.37	3	13.64	2	22.22
Participant describes treatment leading to a reduction in symptoms/side effects	11	22.00	5	31.25	6	17.65	5	25.00	6	20.00	5	26.32	5	22.73	1	11.11
Participant describes treatment allowing them to return to work	7	14.00	1	6.25	6	17.65	3	15.00	4	13.33	3	15.79	4	18.18	0	0.00
Participant describes treatment allowing them to do domestic tasks	6	12.00	3	18.75	3	8.82	1	5.00	5	16.67	4	21.05	2	9.09	0	0.00

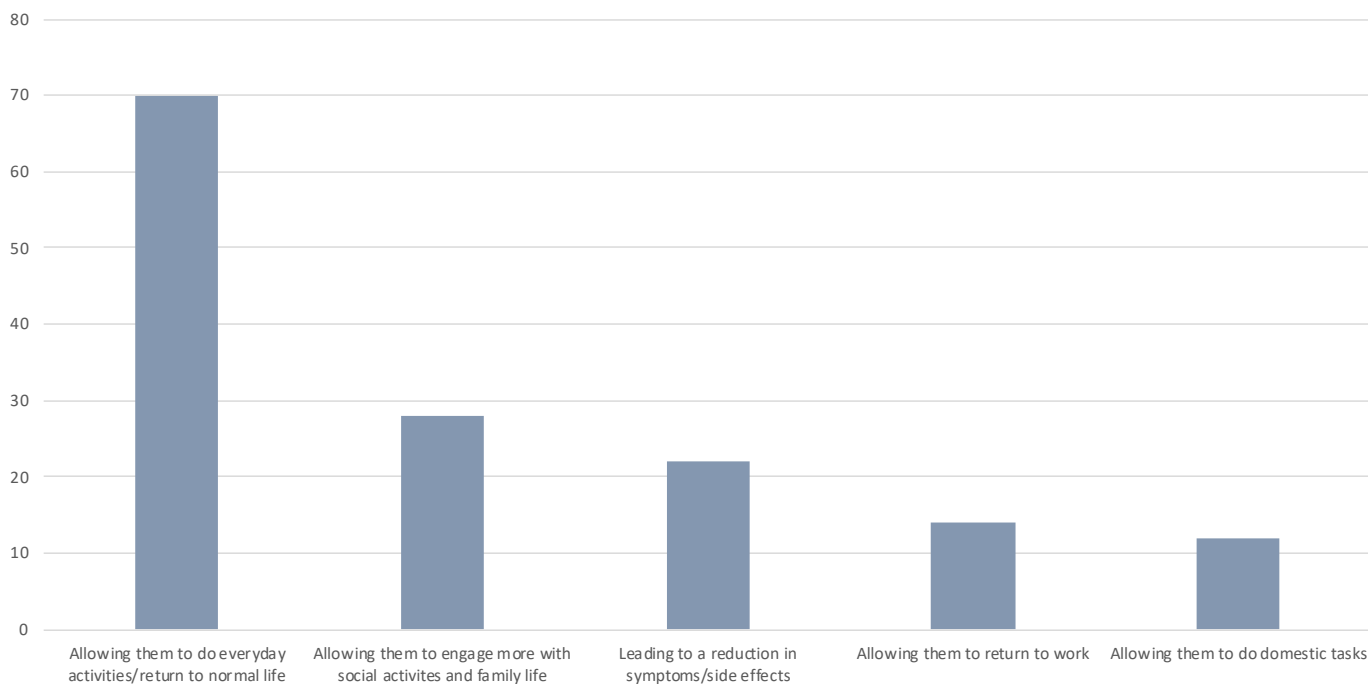


Figure 5.41: What it would mean if treatment worked - percent of all participants

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

Theme	Reported less frequently	Reported more frequently
Participant describes treatment allowing them to do everyday activities/ return to normal life	Aged 25 to 44	Aged 45 to 54 Aged 55 to 74
Participant described treatment allowing them to engage more with social activities and family life	Poor physical function Mid to low status Aged 45 to 54	Aged 25 to 44
Participant describes treatment leading to a reduction in symptoms/side effects	Aged 55 to 74	-
Participant describes treatment allowing them to return to work	Aged 55 to 74	-
Participant describes treatment allowing them to do domestic tasks	Aged 55 to 74	-