CENTRE FOR COMMUNITY-DRIVEN RESEARCH

Personal Experience, Expectations and Knowledge (PEEK) SPECIAL REPORT

People diagnosed with:

Metastatic triple negative + hormone positive breast cancer

Volume 6 (2023), Special Issue

Summary of results

Executive summary

Stage III & IV

There were 39 participants with triple negative or hormone receptor positive breast cancer in the study from across Australia. The majority of participants lived in major cities, they lived in all levels of economic advantage, aged mostly between 35 and 54. More than half of the participants had completed some university, and most were employed either full time or part time.

Physical health and interfered with work and other activities for participants in this stud, they were often fatigues, and had health that was somewhat worse than a year ago.

Half of the participants described no common symptoms of breast cancer when they were diagnosed. For those with symptoms, the most common symptom was having a breast lump or lumps. The majority did not currently have any symptoms of breast cancer, for those with symptoms, anxiety, fatigue, and concentration problems were most common.

This is a group that had health conditions other than breast cancer to deal with, most often anxiety, sleep problems, and depression.

This is a patient population that sought medical attention after noticing symptoms and were diagnosed after their general practitioner referred them to a specialist. Participants were also commonly diagnosed through breast cancer screening.

This is a cohort that were commonly diagnosed with breast cancer without experiencing symptoms. On average, this group had three diagnostic tests for breast cancer, they were diagnosed by a general practitioner in a general practice. The cost of diagnosis was not a burden to them and their families. This is a group that did not have enough emotional support at the time of diagnosis, half of the participants had enough information. This is a cohort that had conversations about biomarker/genomic/gene testing, and had knowledge of their biomarker status.

This is a study cohort that had limited knowledge of breast cancer before they were diagnosed. This patient population described prognosis in terms of no evidence of disease or in remission, using statistics or in relation to likeliness of recurrence.

This is a patient population that had discussions about multiple treatment options, and less than half felt they had participated in the decision-making process.

This is a study cohort that took into account the advice of their clinician as part of many considerations when making decisions about treatment.

Within this patient population, participants had not changed decision making over time, this was linked to being informed and assertive.

When asked about their personal goals of treatment or care participants most commonly described wanting to control side effects and to treat the disease.

This is a group that were cared for by a medical oncologist, and it usually took less than an 30 minutes to travel to medical appointments.

Almost three-quarters of this cohort had private health insurance, more than half were private patients treated in the private hospital system. This is a group that did not have trouble paying for healthcare appointments, prescriptions, and paying for basic essentials. Their monthly expenses due to breast cancer were moderately or somewhat of a burden.

Participants in this study had to reduce hours, or take leave from work. Carers and family did not have to change employment status. The loss of family income was a burden.

All participants with stage III & IV breast cancer had treatment, the majority had surgery and radiotherapy.

Almost half had conversations about clinical trials, and the majority would take part in a clinical trial if there was a suitable one for them.

This is a patient population that described mild side effects as those which can be self-managed and do not interfere with daily life.

This is a study cohort that described severe side effects as symptoms such as those that impact everyday life and the ability to conduct activities of daily living.

This is a patient population which that they would adhere to treatment according to the advice of their doctor, or would not give up on any treatment. This is a study cohort that needed to see physical signs to feel that treatment is working as well, as seeing positive scan or test results.

Participants in this study had very good knowledge about their condition, were good at coping with their condition, were very good at recognizing and managing symptoms, and were very good at adhering to treatment.

Participants were given information about treatment options, hereditary considerations, disease management physical activity from health care professionals, and searched for d interpret test results, disease management, treatment options, complementary therapies most often. This is a group who accessed information from non-profit, charity or patient organisations most often.

This is a patient population that access information primarily through the internet, or their treating.

This is a study cohort that found information about other people's experiences and about what to expect from the disease, side effects and treatments as being most helpful.

Participants commonly found no information unhelpful, and information that was not credible as unhelpful.

This is a group that preferred online information, or online information plus talking to someone. This is a study cohort that generally felt most receptive to information from the beginning, or after the shock of diagnosis.

Most participants described receiving an overall positive experience with health professional communication (some with a few exceptions) which was holistic, two way and comprehensive. For those that had a negative experience it was mostly communication was dismissive.

The participants in this study experienced very good quality of care, and good coordination of care. They had a good ability to navigate the healthcare system, and experienced good communication from healthcare professionals.

This is a patient population did not receive any formal support, or found support from charities.

This is a patient population that experienced a negative impact on quality of life largely due to emotional strain on themselves, and their family. Life was a little distressing for this group, due to having breast cancer.

This is a study cohort that experienced at least some impact on their mental health and to maintain their mental health they used coping strategies such as seeking help from a mental health professional or doing exercise.

Within this patient population, participants described being physically active, and the importance of self-care, in order to maintain their general health.

Participants in this study had felt vulnerable especially during or after treatments. To manage vulnerability, they relied on self-help for example resilience, acceptance, and staying positive.

This cohort most commonly felt there was a mix of positive and negative impacts on their relationships, with some relationships strengthened, and others withdrawing from relationships.

Participants felt they were a burden on their family, due to the extra household duties and responsibilities, and the emotional strain.

Most participants felt there was some cost burden which was from the costs of treatments, tests and scans, and also from having to take time off work.

The participants in this PEEK study had moderate levels of anxiety in relation to their condition.

Participants would like future treatments to be more affordable, with fewer or less intense side effects.

This is a study cohort that would like more information to be easier to find, and include information about available services.

Participants in this study would like future communication to be more forthcoming and transparent. Many participants were happy with their communication with healthcare professionals.

Participants would like future treatments to include access to appropriate real-world support services.

This patient population was grateful timely access to treatment and their healthcare staff.

It was important for this cohort to control fatigue, pain, fertility, and heart problems. Participants in this study would consider taking a treatment for more than ten years if quality of life is improved with no cure.

Participants' message to decision-makers was that timely and equitable access to treatment is important, and to understand the financial impactions.

This is a patient population that wished they had known what to expect from their condition especially the disease trajectory and disease biology. They also wished they had known more about the treatment options and available support.

The aspect of care or treatment that participants in this study would most like to change is to have changed the kind of treatment they had, however, many wouldn't change any aspect of their treatment or care.

Section 1

Introduction and methods

Introduction

This special report combines data from two PEEK studies conducted in 2021: The PEEK Study in Triple negative breast cancer and PEEK Study in Hormone receptor-positive breast cancer. A total of 102 participants with breast cancer took part, 39 of these participants had advanced breast cancer, 27 with triple negative breast cancer and 12 with hormone-receptor positive breast cancer.

This special report is focused on the participants with advanced breast cancer, the results in each section describes the results of the 39 participants with advanced breast cancer. In addition, data is tabulated for:

- All participants from both studies (n=102)
- All participants with advanced breast cancer (n=39)
- All participants with early breast cancer (n=63)
- Triple negative and advanced breast cancer
- (n=27)
- Hormone receptor positive and advanced breast cancer (n=12)
- All participants with triple negative breast cancer (n=50)
- All participants with hormone receptor positive breast cancer (n=52)
- Triple negative and early breast cancer
- (n=23)
- Hormone receptor positive and early breast cancer (n=40)

Where the Stage III & IV groups differ by 10% from the combined “All participants” (n=102), these are listed in a Stage III & IV variations table.

Figures in this study display results for all participants with advanced breast cancer (n=39), and as a comparator all participants with early breast cancer (n=63)

Background

Triple negative breast cancers are defined by the lack of progesterone and oestrogen receptors, and HER2 proteins[1,2]. Triple negative breast cancers are an aggressive form of breast cancer that typically affects younger women, has a poor prognosis, and lack of targeted therapies[3,4].

In 2019, there were 19,371 new cases of breast cancer reported in Australia[5]. Approximately 12 to 17% of all breast cancers are triple negative[3], that is an estimated 3000 new cases of triple negative breast cancer in Australia 2019.
Hormone-receptor positive breast cancers are sensitive to oestrogen or progesterone, approximately 70% of breast cancers are hormone-receptor positive[6]. Adjuvant treatment with tamoxifen is recommended, followed by an addition five years for pre or peri-menopausal women, and an additional five years with tamoxifen or an aromatase inhibitor for post-menopausal women[6].

Hormone therapy increases overall survival, decreases risk recurrence, and decreases risk of contralateral breast cancer[6,7]. However, risks from hormone treatment include menopausal symptoms, additional risks from tamoxifen included endometrial cancer, deep vein thrombosis or pulmonary embolism, and uterine cancer, additional risks from aromatase inhibitors include heart disease, and osteoporosis[6,8]

Personal Experience, Expectations and Knowledge (PEEK)

Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.

The research protocol used in PEEK studies is independently driven by CCDR. PEEK studies include a quantitative and qualitative component. The quantitative component is based on a series of validated tools. The qualitative component is the result of two years of protocol testing by CCDR to develop a structured interview that solicits patient experience data and provides patients with the opportunity to provide advice on what they would like to see in relation to future treatment, information and care. The structured interview has also been designed so that the outcomes of PEEK studies can inform policy, research, care, information, supportive care services and advocacy efforts.

Participants

To be eligible for the study, participants needed to have been diagnosed with breast cancer (either triple negative or hormone receptor positive), have experienced the healthcare system in Australia, be 18 years of age or older, be able to speak English, and be able to give consent to participate in the study. Participants were recruited in 2021.

Ethics

Ethics approval for this study was granted (as a low or negligible risk research study) by the Centre for Community-Driven Research Ethics Committee (Reference CS_Q4_03).

Data collection

Data for the online questionnaire was collected using Zoho Survey (Zoho Corporation Pvt. Ltd. Pleasanton, California, USA, www.zoho.com/survey). Participants completed the survey from in 2021.

There were five researchers who conducted telephone interviews and used standardised prompts throughout the interview. The interviews were recorded and transcribed verbatim. Identifying names and locations were not included in the transcript. All transcripts were checked against the original recording for quality assurance. Interview data was collected in 2021.

Online questionnaire (quantitative)

The online questionnaire consisted of the 36-Item Short Form Health Survey (SF36) (RAND Health)[9], a modified Cancer Care Coordination Questionnaire for Patients (CCCQ)[10], the Short Fear of Progression Questionnaire (FOP12)[11], and the Partners in Health version 2 (PIH)[12]. In addition, investigator derived questions about demographics, diagnosis, treatment received and future treatment decisions making were included.

Structured Interview (qualitative)

Interviews were conducted via telephone by registered nurses who were trained in qualitative research. The first set of interview questions guided the patient through their whole experience from when symptoms were noticed up to the present day.

Questionnaire analysis

Statistical analysis was conducted using R included in the packages "car", "dplyr" and "ggplot2" (R 3.3.3 GUI 1.69 Mavericks build (7328). The aim of the statistical analysis of the SF36, CCCQ, FOP12, and PIH responses was to identify variations by breast cancer stage. Scales and subscales were calculated according to reported instructions[9-12].

The Location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics[13].

The level of socio-economic status of participants was evaluated by postcode using the Socio-economic Indexes for Areas (SEIFA) accessed from the Australian Bureau of Statistics[14].

For comparisons by breast cancer stage, a two-sample t-test was used when assumptions for normality and variance were met, or when assumptions were not met, a Wilcoxon rank sum test with continuity correction was used. Questions where participants were asked to rank preferences were analysed using weighted averages. Weights were applied in reverse, the most preferred option was given the largest weight equal to the number of options, the least preferred option was given the lowest weight of 1.

Structured interviews analysis

A content analysis was conducted using conventional analysis to identify major themes from structured interviews. Text from the interviews were read line-by-line by the lead researcher and then imported into NVivo 8 (QSR International)/MaxQDA. Each question within the interview was individually analysed. Initial categories and definitions were identified and registered in NVivo 8 (QSR International)/MaxQDA. The minimum coded unit was a sentence with paragraphs and phrases coded as a unit.

A second researcher verified the codes and definitions, and the text was coded until full agreement was reached using the process of consensual validation. Where a theme occurred less than 5 times it was not included in the study results, unless this result demonstrated a significant gap or unexpected result.

Data analysis and final reporting was completed in June 2021.

Abbreviations and terminology

ASGS	The Australian Statistical Geography Standard from the Australian Bureau of Statistics, defines remoteness and urban/rural definitions in Australia
CCDR	Centre for Community-Driven Research
dF	Degrees of Freedom. The number of values in the final calculation of a statistic that are free to vary.
f	The F ratio is the ratio of two mean square values, used in an ANOVA comparison. A large F ratio means that the variation among group means is more than you'd expect to see by chance.
FOP	Fear of Progression. Tool to measure anxiety related to progression
IQR	Interquartile range. A measure of statistical dispersion, being equal to the difference between 75th and 25th percentiles, or between upper and lower quartiles.
p	Probability value. A small *p*-value (typically ≤ 0.05) indicates strong. A large *p*-value (> 0.05) indicates weak evidence.
PEEK	Patient Experience, Expectations and Knowledge
PIH	Partners in Health
SD	Standard deviation. A quantity expressing by how much the members of a group digger from the mean value for the group/
SEIFA	Socio-Economic Indexes for Areas (SEIFA) ranks areas in Australia according to relative socio-economic advantage and disadvantage. This is developed by the Australian Bureau of Statistics.
SF36	Short Form Health Survey 36
t	t-Statistic. Size of the difference relative to the variation in your sample data.
Tukey HSD	Tukey's honestly significant difference test. It is used in this study to find 3significantly different means following an ANOVA test.
W	The W statistic is the test value from the Wilcoxon Rank sum test. The theoretical range of W is between 0 and (number in group one) x (number in group 2). When W=0, the two groups are exactly the same.
X^2	Chi-squared. Kruskal-Wallis test statistic approximates a chi-square distribution. The Chi-square test is intended to test how likely it is that an observed distribution is due to chance.

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Section 2

Demographics

Section 2 Demographics: Stage III & IV

There were 39 people with stage III or IV breast cancer that took part in this study. Participants were aged from 18 to 74 years of age, most were aged between 45 to 54 years (n=17, 43.59%).

Participants were most commonly from New South Wales (n=18, 34.62%), Queensland (n=14, 26.92%), and Victoria (n=9, 17.31%). Most participants were from major cities (n=41, 78.85%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 34 participants (65.39%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 18 participants (34.62%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

There were 33 participants (63.46%) that had completed university to at least an associate degree. There were 15 participants who were employed full time (38.46%), and 14 participants employed part time (35.90%).

Other health conditions: Stage III & IV

Participants were asked about health conditions, other than breast cancer that they had to manage. Participants could choose from a list of common health conditions and could specify other conditions.

The majority of participants had at least one other condition that they had to manage (n=47, 87.18%), the maximum number reported was 9 other conditions, with a median of 3.00 other conditions (Table 2.3, Figure 2.2). The most commonly reported health condition was sleep problems or insomnia (n=29, 55.77%), followed by anxiety (n=31, 59.62%), depression (n=19, 36.54%), and arthritis (n=16, 30.77%) (Table 2.4, Figure 2.3).

Baseline health: Stage III & IV

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were slightly limited for participants in this study.

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, physical health often interfered with work or other activities for participants in this study.

SF36 Role functioning/emotional scale measures how emotional problems interfere with work or other activities. On average, emotional problems never interfered with work or other activities for participants in this study.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants were often fatigued.

The **SF36 Emotional well-being** scale measures how a person feels, for example happy, calm, depressed or anxious. On average, participants had good emotional well-being.

The **SF36 Social functioning** scale measures limitations on social activities due to physical or emotional problems. On average, social activities were slightly limited for participants in this study.

The **SF36 Pain** scale measures how much pain, and how pain interferes with work and other activities. On average, participants had moderate pain.

The **SF36 General health** scale measures perception of health. On average, participants reported average health.

The **SF36 Health change** scale measures health compared to a year ago. On average, participants reported that their health is somewhat worse now compared to a year ago.

Demographics: Stage III & IV

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There were 33 participants (63.46%) that had completed university to at least an associate degree. There were 15 participants who were employed full time (38.46%), and 14 participants employed part time (35.90%).

Table 2.1: Demographics

Demographics	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
State										
Australian Capital Territory	2	1.96	0	0.00	2	3.85	0	0.00	0	0.00
New South Wales	32	31.37	14	28.00	18	34.62	7	25.93	4	33.33
Queensland	28	27.45	14	28.00	14	26.92	6	22.22	**2**	**16.67**
South Australia	4	3.92	1	2.00	3	5.77	0	0.00	**2**	**16.67**
Tasmania	1	0.98	1	2.00	0	0.00	1	3.70	0	0.00
Victoria	20	19.61	11	22.00	9	17.31	**8**	**29.63**	3	25.00
Western Australia	15	14.71	9	18.00	6	11.54	5	18.52	1	8.33
Socioeconomic status										
1	2	1.96	2	4.00	0	0.00	2	7.41	0	0.00
2	6	5.88	6	12.00	0	0.00	2	7.41	0	0.00
3	5	4.90	3	6.00	2	3.85	3	11.11	0	0.00
4	8	7.84	2	4.00	6	11.54	2	7.41	1	8.33
5	9	8.82	5	10.00	4	7.69	1	3.70	0	0.00
6	8	7.84	2	4.00	6	11.54	1	3.70	1	8.33
7	11	10.78	6	12.00	5	9.62	3	11.11	2	16.67
8	16	15.69	4	8.00	12	23.08	3	11.11	**5**	**41.67**
9	19	18.63	9	18.00	10	19.23	5	18.52	**1**	**8.33**
10	18	17.65	11	22.00	7	13.46	5	18.52	2	16.67
Location										
Major Cities of Australia	75	73.53	34	68.00	41	78.85	19	70.37	**11**	**91.67**
Inner Regional Australia	20	19.61	13	26.00	7	13.46	**8**	**29.63**	**0**	**0.00**
Outer Regional Australia	5	4.90	2	4.00	3	5.77	0	0.00	0	0.00
Remote Australia	2	1.96	1	2.00	1	1.92	0	0.00	1	8.33
Education										
Trade or high school	43	42.16	24	48.00	19	36.54	**15**	**55.56**	4	33.33
University	59	57.84	26	52.00	33	63.46	**12**	**44.44**	8	66.67
Employment status										
Currently receiving Centrelink support	4	3.92	2	3.17	2	5.13	2	7.41	0	0.00
Disabled, not able to work	2	1.96	2	3.17	0	0.00	0	0.00	0	0.00
Employed, working full time	39	38.24	24	38.10	15	38.46	12	44.44	**3**	**25.00**
Employed, working part time	36	35.29	22	34.92	14	35.90	9	33.33	5	41.67
Full/part time carer	7	6.86	5	7.94	2	5.13	1	3.70	1	8.33
Full/part time study	2	1.96	1	1.59	1	2.56	1	3.70	0	0.00
Not employed, looking for work	2	1.96	2	3.17	0	0.00	0	0.00	0	0.00
Not employed, not looking for work	6	5.88	3	4.76	3	7.69	1	3.70	**2**	**16.67**
Retired	10	9.80	8	12.70	2	5.13	1	3.70	1	8.33
Age										
25 – 34	5	4.90	3	4.76	2	5.13	1	3.70	1	8.33
35 – 44	22	21.57	11	17.46	11	28.21	**9**	**33.33**	2	16.67
45 – 54	43	42.16	26	41.27	17	43.59	11	40.74	6	50.00
55 – 64	26	25.49	18	28.57	8	20.51	5	18.52	3	25.00
65 – 74	6	5.88	5	7.94	1	2.56	1	3.70	0	0.00

Demographics	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
State										
Australian Capital Territory	2	1.96	2	3.17	0	0.00	0	0.00	2	5.00
New South Wales	32	31.37	21	33.33	11	28.21	7	30.43	14	35.00
Queensland	28	27.45	20	31.75	8	20.51	8	34.78	12	30.00
South Australia	4	3.92	2	3.17	2	5.13	1	4.35	1	2.50
Tasmania	1	0.98	0	0.00	1	2.56	0	0.00	0	0.00
Victoria	20	19.61	9	14.29	11	28.21	3	13.04	6	15.00
Western Australia	15	14.71	9	14.29	6	15.38	4	17.39	5	12.50
Socioeconomic status										
1	2	1.96	0	0.00	2	5.13	0	0.00	0	0.00
2	6	5.88	4	6.35	2	5.13	**4**	**17.39**	0	0.00
3	5	4.90	2	3.17	3	7.69	0	0.00	2	5.00
4	8	7.84	5	7.94	3	7.69	0	0.00	5	12.50
5	9	8.82	8	12.70	1	2.56	4	17.39	4	10.00
6	8	7.84	6	9.52	2	5.13	1	4.35	5	12.50
7	11	10.78	6	9.52	5	12.82	3	13.04	3	7.50
8	16	15.69	8	12.70	8	20.51	**1**	**4.35**	7	17.50
9	19	18.63	13	20.63	6	15.38	4	17.39	9	22.50
10	18	17.65	11	17.46	7	17.95	6	26.09	5	12.50
Location										
Major Cities of Australia	75	73.53	45	71.43	30	76.92	15	65.22	30	75.00
Inner Regional Australia	20	19.61	12	19.05	8	20.51	5	21.74	7	17.50
Outer Regional Australia	5	4.90	5	7.94	0	0.00	2	8.70	3	7.50
Remote Australia	2	1.96	1	1.59	1	2.56	1	4.35	0	0.00
Education										
Trade or high school	43	42.16	24	38.10	19	48.72	9	39.13	15	37.50
University	59	57.84	39	61.90	20	51.28	14	60.87	25	62.50
Employment status										
Currently receiving Centrelink support	4	3.92	2	2.00	2	3.85	0	0.00	2	5.00
Disabled, not able to work	2	1.96	**1**	**52.00**	1	1.92	1	4.35	1	2.50
Employed, working full time	39	38.24	26	30.00	**13**	**25.00**	**14**	**60.87**	**10**	**25.00**
Employed, working part time	36	35.29	**15**	**4.00**	21	40.38	6	26.09	16	40.00
Full/part time carer	7	6.86	2	2.00	5	9.62	1	4.35	4	10.00
Full/part time study	2	1.96	1	2.00	1	1.92	0	0.00	1	2.50
Not employed, looking for work	2	1.96	1	2.00	1	1.92	1	4.35	1	2.50
Not employed, not looking for work	6	5.88	1	4.00	5	9.62	0	0.00	3	7.50
Retired	10	9.80	2	0.00	8	15.38	1	4.35	7	17.50
Age										
25 – 34	5	4.90	**4**	**30.00**	1	1.92	3	13.04		0.00
35 – 44	22	21.57	**15**	**44.00**	7	13.46	6	26.09	5	12.50
45 – 54	43	42.16	**22**	**16.00**	21	40.38	11	47.83	15	37.50
55 – 64	26	25.49	**8**	**2.00**	18	34.62	**3**	**13.04**	**15**	**37.50**
65 – 74	6	5.88	1	0.00	5	9.62		0.00	5	12.50

Table 2.2: Demographics – Stage III & IV variations

Demographics	Reported less frequently	Reported more frequently
State		
Queensland	Hormone receptor Stage III & IV	-
South Australia	-	Hormone receptor Stage III & IV
Victoria	-	Triple negative Stage III & IV
Socioeconomic status		
8	-	Hormone receptor Stage III & IV
9	Hormone receptor Stage III & IV	-
Location		
Major Cities of Australia	-	Hormone receptor Stage III & IV
Inner Regional Australia	Hormone receptor Stage III & IV	Triple negative Stage III & IV
Education		
Trade or high school	-	Triple negative Stage III & IV
University	Triple negative Stage III & IV	-
Employment		
Employed, working full time	Hormone receptor Stage III & IV	-
Not employed, not looking for work	-	Hormone receptor Stage III & IV
Age		
35 – 44	-	Triple negative Stage III & IV

Other health conditions: Stage III & IV

Participants were asked about health conditions, other than breast cancer that they had to manage. Participants could choose from a list of common health conditions and could specify other conditions.

The majority of participants had at least one other condition that they had to manage (n=47, 87.18%), the maximum number reported was 9 other conditions, with a median of 3.00 other conditions (Table 2.3, Figure 2.1). The most commonly reported health condition was sleep problems or insomnia (n=29, 55.77%), followed by anxiety (n=31, 59.62%), depression (n=19, 36.54%), and arthritis (n=16, 30.77%) (Table 2.5, Figure 2.2).

Table 2.3: Number of other health conditions

Number of other conditions	All participants n=102	%	All Stage 0 to II n=63	%	All Stage III & IV n=39	%	Triple negative Stage III & IV n=27	%	Hormone receptor Stage III & IV n=12	%
No other conditions	12	11.76	7	14.00	5	9.62	4	14.81	1	8.33
1 to 2	35	34.31	19	38.00	16	30.77	12	44.44	2	16.67
3to 4	29	28.43	12	24.00	17	32.69	5	18.52	6	50.00
5 to 6	22	21.57	11	22.00	11	21.15	5	18.52	2	16.67
7 or more	4	3.92	1	2.00	3	5.77	1	3.70	1	8.33

Number of other conditions	All participants n=102	%	All Triple negative n=50	%	All Hormone receptor n=52	%	Triple negative Stage 0 to II n=23	%	Hormone receptor Stage 0 to II n=40	%
No other conditions	12	11.76	7	11.11	5	12.82	3	13.04	4	10.00
1 to 2	35	34.31	21	33.33	14	35.90	7	30.43	14	35.00
3to 4	29	28.43	18	28.57	11	28.21	7	30.43	11	27.50
5 to 6	22	21.57	15	23.81	7	17.95	6	26.09	9	22.50
7 or more	4	3.92	2	3.17	2	5.13	0	0.00	2	5.00

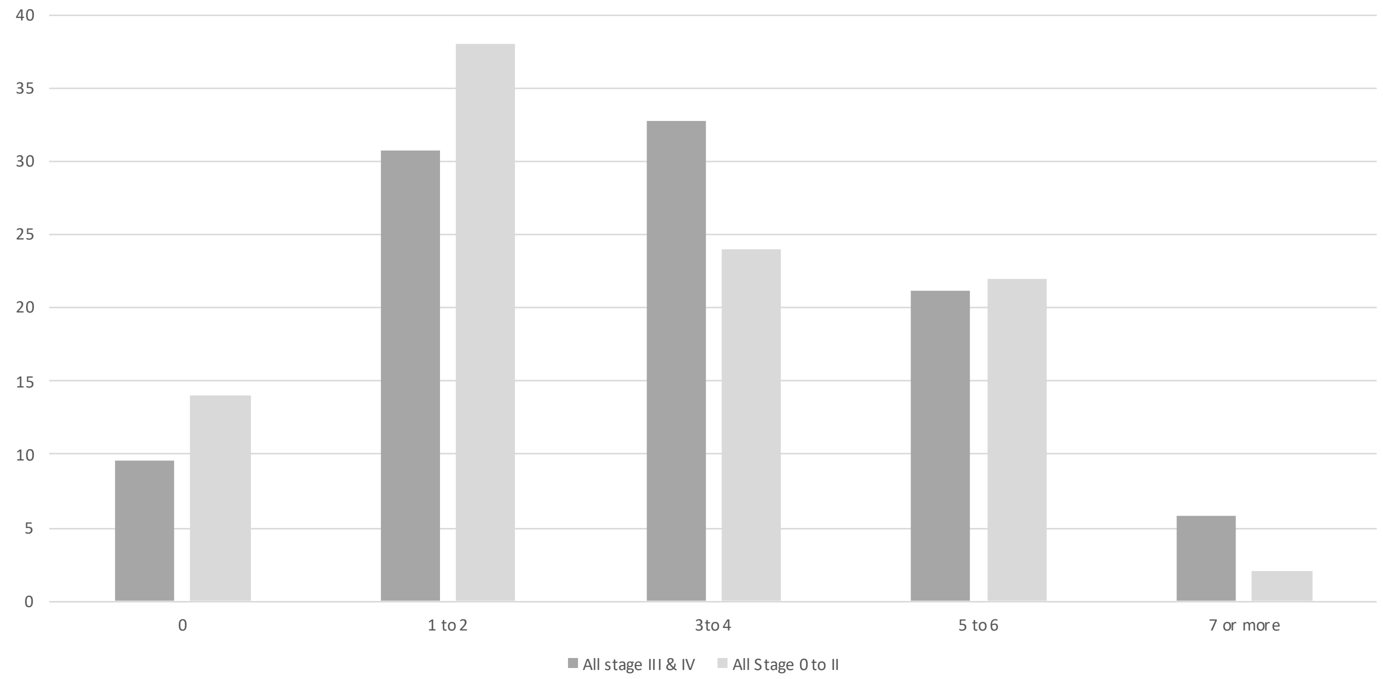


Figure 2.1: Number of other health conditions (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 2.4: Number of other health conditions– Stage III & IV variations

Theme	Reported less frequently	Reported more frequently
1 to 2	Hormone receptor Stage III & IV	Triple negative Stage III & IV
3to 4		Hormone receptor Stage III & IV

Table 2.5: Other health conditions

Other health conditions	All participants n=102	%	All Stage 0 to II n=63	%	All Stage III & IV n=39	%	Triple negative Stage III & IV n=27	%	Hormone receptor Stage III & IV n=12	%
Sleep problems or insomnia	51	50.00	22	44.00	29	55.77	12	44.44	7	58.33
Anxiety (self diagnosed)	43	42.16	25	50.00	18	34.62	13	48.15	5	41.67
Anxiety (that a doctor diagnosed)	37	36.27	11	22.00	26	50.00	3	11.11	7	58.33
Anxiety (Total)	58	56.86	27	54.00	31	59.62	13	48.15	9	75.00
Depression (self diagnosed yourself)	26	25.49	14	28.00	12	23.08	6	22.22	3	25.00
Depression (that a doctor diagnosed)	23	22.55	10	20.00	13	25.00	4	14.81	6	50.00
Depression (Total)	38	37.25	19	38.00	19	36.54	8	29.63	6	50.00
Arthritis	25	24.51	9	18.00	16	30.77	5	18.52	3	25.00
High cholesterol	22	21.57	7	14.00	15	28.85	4	14.81	3	25.00
Chronic pain	22	21.57	13	26.00	9	17.31	6	22.22	4	33.33
Hypertension	12	11.76	4	8.00	8	15.38	1	3.70	0	0.00
Atrial fibrillation or arrhythmias	8	7.84	4	8.00	4	7.69	2	7.41	0	0.00
Other cancer	6	5.88	2	4.00	4	7.69	1	3.70	3	25.00
Stroke	2	1.96	1	2.00	1	1.92	1	3.70	0	0.00
COPD (Chronic obstructive pulmonary disease	1	0.98	1	2.00	0	0.00	1	3.70	3	25.00
Diabetes type I	1	0.98	1	2.00	0	0.00	0	0.00	0	0.00
Diabetes type II	2	1.96	2	4.00	0	0.00	1	3.70	0	0.00

Other health conditions	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Sleep problems or insomnia	51	50.00	32	50.79	19	48.72	10	43.48	22	55.00
Anxiety (self diagnosed)	43	42.16	25	39.68	18	46.15	**12**	**52.17**	13	32.50
Anxiety (that a doctor diagnosed)	37	36.27	27	42.86	**10**	**25.64**	8	34.78	**19**	**47.50**
Anxiety (Total)	58	56.86	36	57.14	22	56.41	14	60.87	22	55.00
Depression (self diagnosed yourself)	26	25.49	17	26.98	9	23.08	8	34.78	9	22.50
Depression (that a doctor diagnosed)	23	22.55	13	20.63	10	25.64	6	26.09	7	17.50
Depression (Total)	38	37.25	24	38.10	14	35.90	**11**	**47.83**	13	32.50
Arthritis	25	24.51	17	26.98	8	20.51	4	17.39	13	32.50
High cholesterol	22	21.57	15	23.81	7	17.95	3	13.04	12	30.00
Chronic pain	22	21.57	12	19.05	10	25.64	7	30.43	5	12.50
Hypertension	12	11.76	11	17.46	1	2.56	3	13.04	8	20.00
Atrial fibrillation or arrhythmias	8	7.84	6	9.52	2	5.13	2	8.70	4	10.00
Other cancer	6	5.88	2	3.17	4	10.26	1	4.35	1	2.50
Stroke	2	1.96	1	1.59	1	2.56	0	0.00	1	2.50
COPD (Chronic obstructive pulmonary disease	1	0.98	0	0.00	1	2.56	1	4.35	1	2.50
Diabetes type I	1	0.98	1	1.59	0	0.00	1	4.35	0	0.00
Diabetes type II	2	1.96	1	1.59	1	2.56	1	4.35	0	0.00

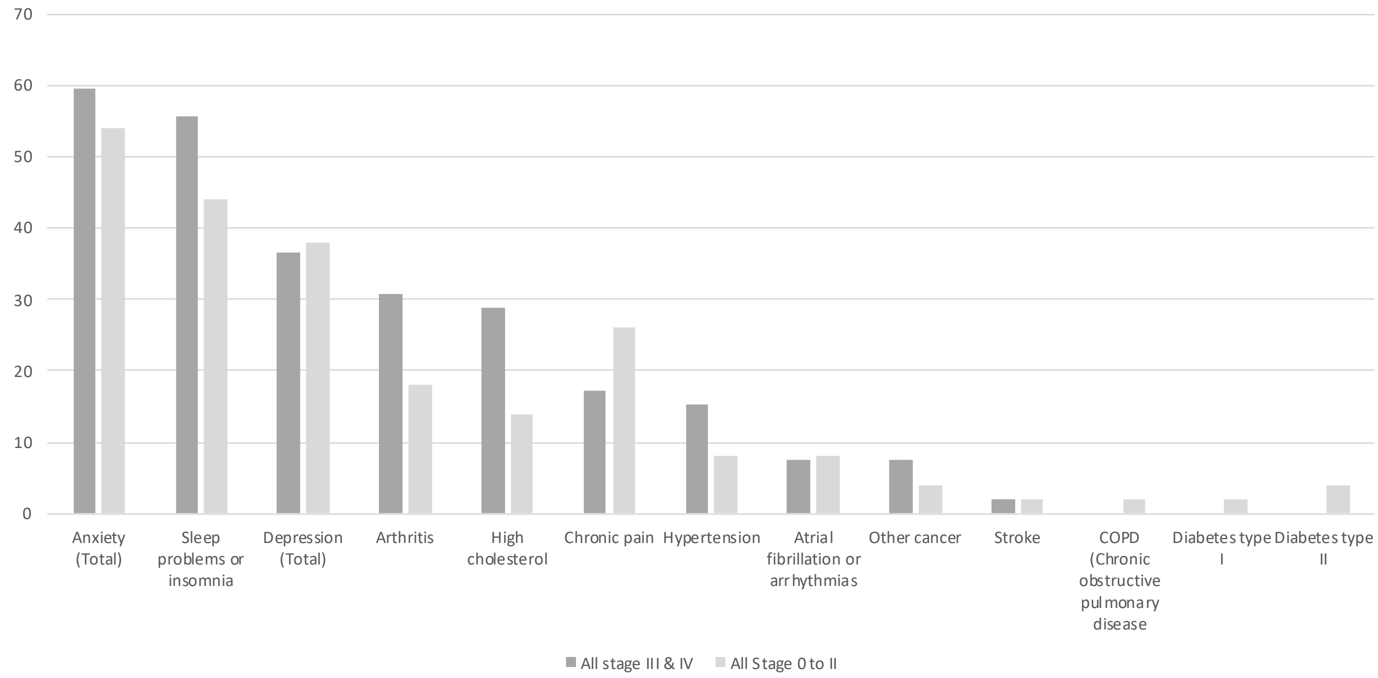


Figure 2.2: Other health conditions (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 2.6: Other health conditions – Stage III & IV variations

Other health conditions	Reported less frequently	Reported more frequently
Anxiety (that a doctor diagnosed)	Triple negative Stage III & IV	All Stage III & IV Hormone receptor Stage III & IV
Anxiety (Total)	-	Hormone receptor Stage III & IV
Depression (that a doctor diagnosed)	-	Hormone receptor Stage III & IV
Depression (Total)	-	Hormone receptor Stage III & IV
Chronic pain	-	Hormone receptor Stage III & IV
Hypertension	Hormone receptor Stage III & IV	-
Other cancer	-	Hormone receptor Stage III & IV
COPD (Chronic obstructive pulmonary disease	-	Hormone receptor Stage III & IV

Baseline health: Stage III to IV

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function.

Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 2.7, for scales with a normal distribution, the mean and SD should be used as a central measure, and median and IQR for scales that do not have a normal distribution.

The overall scores for the cohort were in the highest quintile for Role functioning/emotional (median=83.33, IQR=66.67), indicating very good emotional role functioning.

The overall scores for the cohort were in the second highest quintile for SF36 Physical functioning (median=72.50, IQR=26.25), SF36 Emotional well-being (median=72.00, IQR=24.00), and SF36 Social functioning (median=62.50, IQR=25.00), indicating good physical functioning, good emotional well-being, and good social functioning.

The overall scores for the cohort were in the middle quintile for SF36 Pain (mean=58.96, SD=23.86), and SF36 General health (mean=53.47, SD=17.64), indicating moderate pain, and moderate general health.

The overall scores for the cohort were in the second lowest quintile for SF36 Role functioning/physical (median=37.50, IQR=75.00), SF36 Energy/Fatigue (mean=39.58, SD=18.45), and SF36 Health change (median=37.50, IQR=31.25), indicating poor physical role functioning, poor energy, and health that was somewhat worse than a year ago

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were slightly limited for participants in this study.

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, physical health often interfered with work or other activities for participants in this study.

SF36 Role functioning/emotional scale measures how emotional problems interfere with work or other activities. On average, emotional problems never interfered with work or other activities for participants in this study.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants were often fatigued.

The SF36 Emotional well-being scale measures how a person feels, for example happy, calm, depressed or anxious. On average, participants had good emotional well-being.

The **SF36 Social functioning** scale measures limitations on social activities due to physical or emotional problems. On average, social activities were slightly limited for participants in this study.

The **SF36 Pain** scale measures how much pain, and how pain interferes with work and other activities. On average, participants had moderate pain.

The **SF36 General health** scale measures perception of health. On average, participants reported average health.

The **SF36 Health change** scale measures health compared to a year ago. On average, participants reported that their health is somewhat worse now compared to a year ago.

Table 2.6: SF36 summary statistics - Stage III to IV

SF36 scale (n=36)	Mean	SD	Median	IQR	Possible range	Quintile
Physical functioning	69.86	21.63	72.50	26.25	0 to 100	4
Role functioning/physical	45.14	41.33	37.50	75.00	0 to 100	2
Role functioning/emotional	62.96	42.00	83.33	66.67	0 to 100	5
Energy/Fatigue*	39.58	18.45	45.00	35.00	0 to 100	2
Emotional well-being	67.67	15.19	72.00	24.00	0 to 100	4
Social functioning	62.50	25.88	62.50	25.00	0 to 100	4
Pain*	58.96	23.86	57.50	36.25	0 to 100	3
General health*	53.47	17.64	52.50	26.25	0 to 100	3
Health change	46.53	31.71	37.50	31.25	0 to 100	2

*Normal distribution, use mean and SD as central measure. Possible range 0-100

SF36 by Stage

Participants with stage 0 to II breast cancer (n=60, 62.50%) were compared to participants with stage II and IV breast cancer (n=36,37.50)

A two-sample t-test was used when assumptions for normality and variance were met (Table 2.8), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.9).

No significant differences were observed between participants by breast cancer stage for any of the SF36 scales.

Table 2.7: SF36 by breast cancer stage summary statistics and T-test

SF36 scale	Group	Number (n=96)	Percent	Mean	SD	T	dF	p-value
Energy/Fatigue	All stage 0 to II	60	62.50	44.75	18.67	1.32	94	0.1906
	All stage III & IV	36	37.50	39.58	18.45			
Pain	All stage 0 to II	60	62.50	63.58	24.37	0.91	94	0.3666
	All stage III & IV	36	37.50	58.96	23.86			
General health	All stage 0 to II	60	62.50	58.42	18.40	1.29	94	0.1987
	All stage III & IV	36	37.50	53.47	17.64			

Table 2.8: SF36 by breast cancer stage summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=96)	Percent	Median	IQR	W	p-value
Physical functioning	All stage 0 to II	60	62.50	80.00	30.00	1296.00	0.1008
	All stage III & IV	36	37.50	72.50	26.25		
Role functioning/physical	All stage 0 to II	60	62.50	62.50	100.00	1255.00	0.1698
	All stage III & IV	36	37.50	37.50	75.00		
Role functioning/emotional	All stage 0 to II	60	62.50	100.00	33.33	1261.00	0.1297
	All stage III & IV	36	37.50	83.33	66.67		
Emotional well-being	All stage 0 to II	60	62.50	76.00	20.00	1279.00	0.1310
	All stage III & IV	36	37.50	72.00	24.00		
Social functioning	All stage 0 to II	60	62.50	75.00	31.25	1326.00	0.0595
	All stage III & IV	36	37.50	62.50	25.00		
Health change	All stage 0 to II	60	62.50	50.00	50.00	1164.50	0.5131
	All stage III & IV	36	37.50	37.50	31.25		

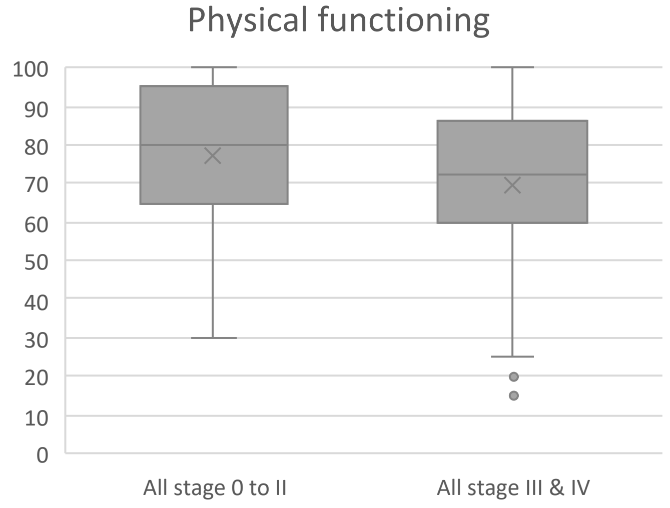


Figure 2.3: Boxplot of SF36 Physical functioning by breast cancer stage

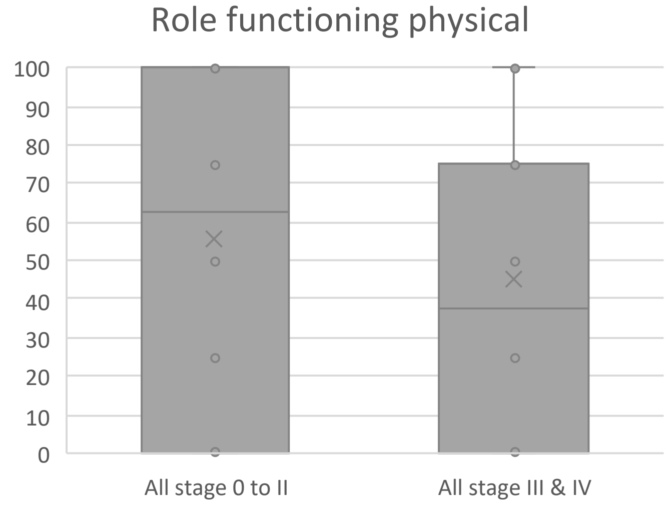


Figure 2.4: Boxplot of SF36 Role functioning/physical by breast cancer stage

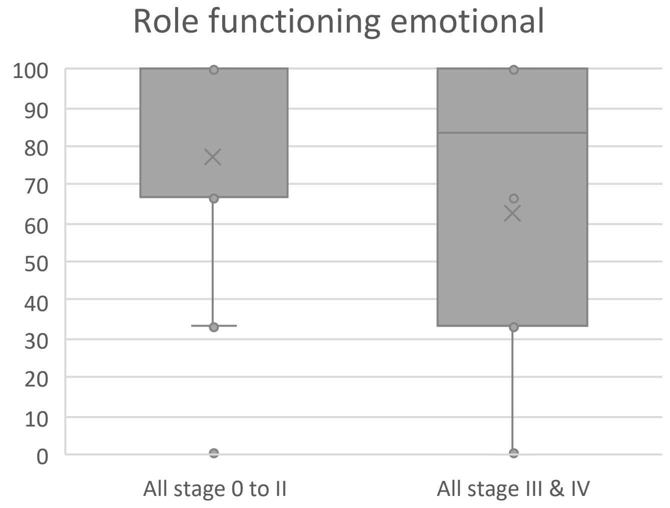


Figure 2.5: Boxplot of SF36 Role functioning/emotional by breast cancer stage

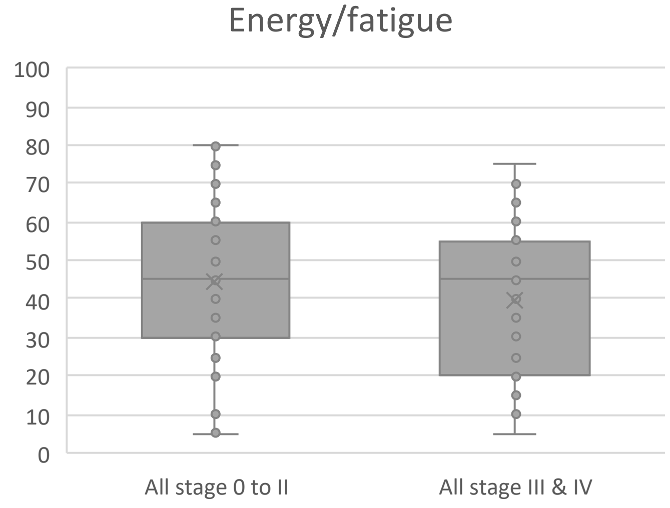


Figure 2.6: Boxplot of SF36 Energy/fatigue by breast cancer stage

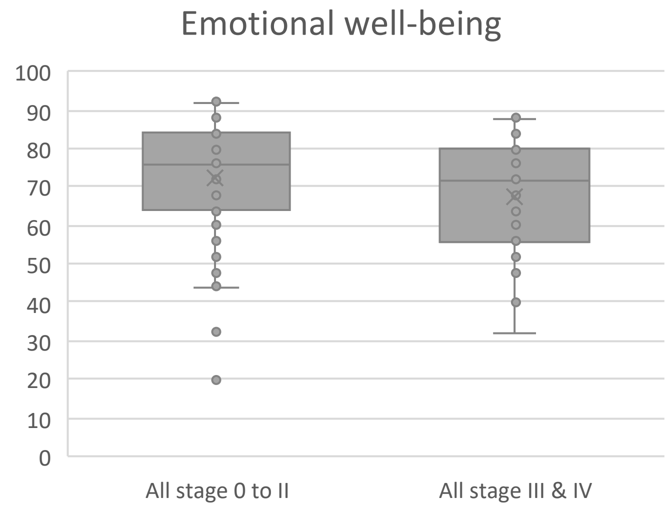


Figure 2.7: Boxplot of SF36 Emotional well-being by breast cancer stage

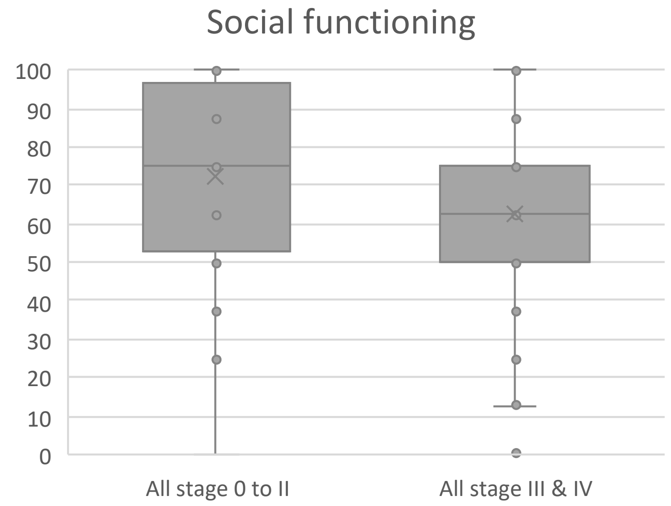


Figure 2.8: Boxplot of SF36 Social functioning by breast cancer stage

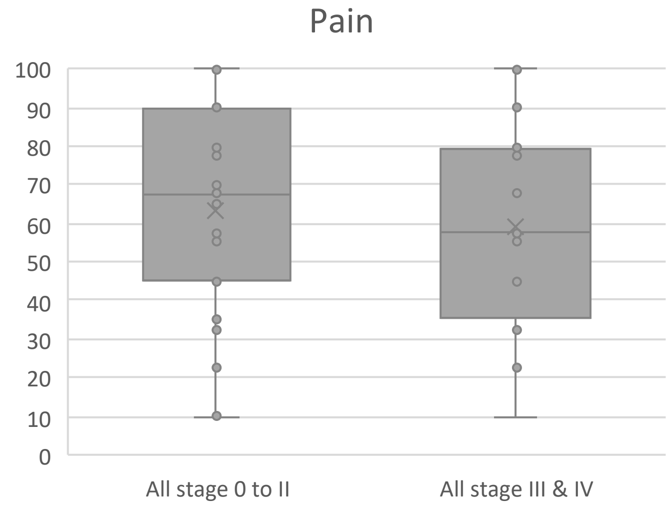


Figure 2.9: Boxplot of SF36 Pain by a breast cancer stage

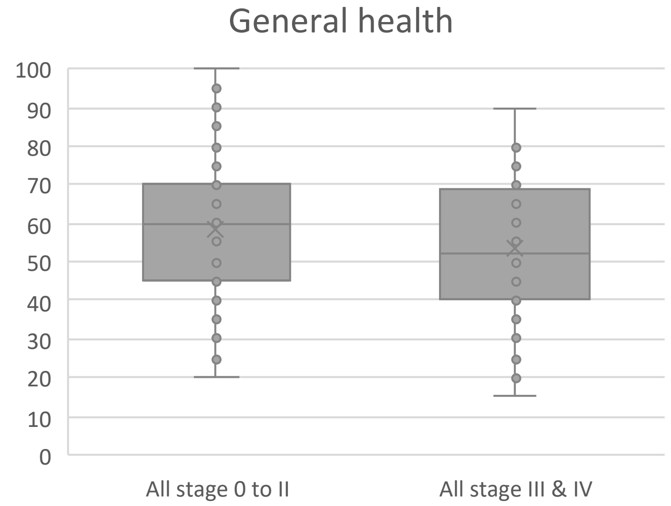


Figure 2.10: Boxplot of SF36 General health by breast cancer stage

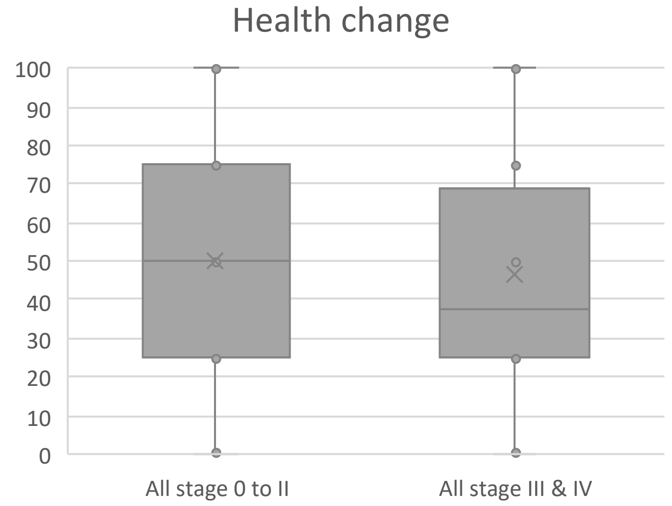


Figure 2.11: Boxplot of SF36 Health change by breast cancer stage

Section 3

Symptoms and diagnosis

Section 3: Symptoms and diagnosis

Experience of symptoms before diagnosis: Stage III to IV

There were 19 participants (50.00%) that had no symptoms before diagnosis. Participants had a maximum of 8 symptoms, and a median of 0.50. The most common symptoms before diagnosis were anxiety/anxious mood (n=18, 47.37%), fatigue (n=18, 47.37%), thinking and memory problem (n=17, 44.74%), and, weight and muscle changes (n=16, 42.11%)

Symptoms leading to diagnosis: Stage III to IV

In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis.

Most commonly participants strongly recalled their symptoms or how they came to be diagnosed (87.18%). Others had no symptoms (5.13%), or being incapacitated at the time and cannot remember the but recalls what their family members or other sources have told them (2.56%).

The most common symptoms leading to diagnosis were having a breast lump or lumps (66.67%), and fatigue (10.26 %). Other themes included breast pain (5.13%), breast skin changes including puckering, dimpling, a rash, or redness of skin (5.13%), a family history and being vigilant about breast health (2.56%), and breast changes (size shape and feel) (2.56%). There were 2 participants (5.13%) that described not noticing any symptoms.

Symptoms leading to diagnosis: Seeking medical attention: Stage III to IV

Participants described when they sought medical attention after noticing symptoms. The most common responses were having symptoms and seeking medical attention relatively soon (71.79%), having no symptoms or not noticing any symptoms before diagnosis, diagnosis was through routine screening(10.26%), and having symptoms and not seeking medical attention initially (12.82 %).

Symptoms leading to diagnosis: Description of diagnostic pathway : Stage III to IV

In the structured interview, participants described their diagnostic pathway in the healthcare system. The most common descriptions were diagnosed by their general practitioner due to concerns about symptoms (following imaging studies) (48.72%), a linear diagnosis after being referred to a specialist from their general practitioner (28.21%), and (17.95 %).

Timing of diagnosis: Stage III to IV

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis.

Participants were most commonly diagnosed immediately at the consultation (n = 2, 5.26%). There were 19 participants (50.00%) that were diagnosed less than one week after diagnostic tests, 12 participants (31.58%) diagnosed between 1 and 2 weeks, 2 participants (5.26%) diagnosed between 2 and 3 weeks, 0 participants (0.00%) diagnosed between 3 and 4 weeks, and 2 participants (5.26%) diagnosed more than four weeks after diagnostic testing.

Diagnostic tests: Stage III to IV

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with stage III and IV breast cancer. They could choose from a set list of diagnostic tests, and could then specify other tests not listed. The number of tests per participant were counted using both tests from the set list and other tests specified.

Participants reported between 1 and 5 diagnostic tests (median=3.00). The most common tests were Breast ultrasound (n=33, 84.62%), Core biopsy (A wider needle is used to remove a piece of tissue (n=32, 82.05%), Mammogram (n=29, 74.36%), and Fine needle aspiration (A thin needle is used to take tissue from the breast lump (n=12, 30.77%).

Diagnosis provider and location: Stage III to IV

Participants were asked in the online questionnaire, which healthcare professional gave them their diagnosis, and where they were given the diagnosis.

Almost half of the participants were given their diagnosis by a General practitioner (GP (n=18, 47.37%), and there were 13 participants (34.21%) given the diagnosis by a Breast specialist, and 5 participants (13.16%) diagnosed by Surgeon.

Participants were most commonly given their diagnosis in the General practice (n=16, 42.11%), this was followed by the Specialist clinic (n=12, 31.58%), and at Breast screening (n=4, 10.53%).

Understanding of disease at diagnosis: Stage III to IV

Participants were asked in the structured interview how much they knew about their condition at diagnosis. The most common response was knowing nothing or very little about the condition at diagnosis (41.03%).

Where participants had a little knowledge about their condition at diagnosis, the most common reasons were were knowing a little about the condition due to having a friend or acquaintance with the condition (10.26%), and knowing a little about the condition from having general knowledge or awareness of it (7.69%). Other themes included knowing a little about the condition from having a professional background (5.13%), knowing a little about the condition without giving a reason (5.13%), knowing a little about the condition because they have a family history (2.56%), and knowing a little about the condition by learning about it before or during the diagnostic process (2.56%).

Where participants had a good knowledge about their condition at diagnosis, the most common reasons were knowing about the condition by learning about it before or during the diagnostic process (10.26%), and knowing about the condition due to information given to them by healthcare professionals (7.69%). Other themes included knowing about the condition due to professional background (5.13%), knowing about the condition due to having a friend or acquaintance with the condition (5.13%),knowing about the condition due to public awareness (2.56%), and knowing about the condition at diagnosis because they have a family history (2.56%).

Emotional support at diagnosis: Stage III to IV

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis.

There were 7 participants (18.42%) who had enough support, 10 participants (26.32%) that had some support, but it wasn’t enough, and 21 participants (55.26%) had no support.

Information at diagnosis: Stage III to IV

Participants were asked in the online questionnaire how much information they or their family received at diagnosis.

There were 19 participants (50.00%) who had enough information, 16 participants (42.11%) that had some information, but it wasn’t enough, and 3 participants (7.89%) had no information.

Costs at diagnosis: Stage III to IV

Participants noted in the online questionnaire the amount of out-of-pocket expenses they had at diagnosis, for example doctors' fees, and diagnostic tests.

There were 10 participants (26.32%) who had no out of pocket expenses, and 10 participants (26.32%) who did not know or could not recall. There were 9 participants (23.68%) that spent Less than $500, 6 participants (15.79%) that spent between $500 to $1000, and 3 participants (7.89%) that spent More than $1000.

In the follow-up question about the burden of costs at diagnosis, for 30 participants who had out of pocket expenses.

For 15 participants (53.57%) the cost was slightly or not at all significant. For 6 participants (21.43%) the out-of-pocket expenses were somewhat significant, and for 7 participants (25.00%), the burden of out-of-pocket expenses were moderately or extremely significant.

Genetic tests and biomarkers: Stage III to IV

Participants answered questions in the online questionnaire about if they had any discussions with their doctor about biomarkers, genomic and gene testing that might be relevant to treatment. If they did have a discussion, they were asked if they brought up the topic or if their doctor did.

Most commonly, participants had never had a conversation about biomarkers, genomic, or gene testing that might be relevant to treatment, (n=11, 28.95%). There were 5 participants (13.16%) who brought up the topic with their doctor, and 22 participants (57.89%) whose doctor brought up the topic with them.

Participants were then asked if they had had any biomarker, genomic or gene testing. If they had testing, they were asked if they had it as part of a clinical trial, paid for it themselves or if they did not have to pay for it. Those that did not have the test were asked if they were interested in this type of test.

The majority of participants did not have any genetic or biomarker tests but would like to (n=12, 31.58%). There were 1 participants (2.63%) who did not have these tests and were not interested in them, and a total of 25 participants (65.79%) that had biomarker tests.

Current symptoms: Stage III to IV

Almost half of the participants had symptoms to deal with at the time of completing the questionnaire (n=18, 47.37%). Participants had between 2 to 11 symptoms. The most common current symptoms, were fatigue (n=18, 47.37%), thinking and memory problem (n=17, 44.74%), weight and muscle changes (n=16, 42.11%), Pain (n=16, 42.11%), depression/depressed mood (n=15, 39.47%), and sleep problems (n=14, 36.84%).

Understanding of prognosis: Stage III to IV

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. The most common responses were that there was no evidence of disease or that they are in remission (48.72%), and in relation to statistics or survival rates (28.21%). Other themes included that they would likely have a recurrence, or were in a cycle of recurrence (28.21%), that their prognosis was positive, that their condition is manageable (23.08%), and that they were monitoring their condition until there is an exacerbation or progression (20.51%).

Experience of symptoms before diagnosis: Stage III & IV

Participants were asked in the questionnaire which symptoms they had before diagnosis, they could choose from a set list of symptoms and could then specify other symptoms not listed.

There were 19 participants (50.00%) that had no symptoms before diagnosis. Participants had a maximum of 8 symptoms, and a median of 0.50 (Table 3.1, Figure 3.1).

Table 3.1: Number of symptoms per participant

Number of symptoms per participant	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=101	%	n=63	%	n=38	%	n=27	0.00	n=11	0.00
0	56	55.45	37	58.73	19	50.00	13	48.15	6	54.55
1 to 2	24	23.76	14	22.22	10	26.32	8	29.63	2	18.18
3 to 4	10	9.90	5	7.94	5	13.16	5	18.52	0	0.00
5 to 6	7	6.93	4	6.35	3	7.89	1	3.70	2	18.18
7 or more	4	3.96	3	4.76	1	2.63	0	0.00	1	9.09

Number of symptoms per participant	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=101	%	n=50	%	n=51	%	n=23	0.00	n=40	0.00
0	56	55.45	26	52.00	30	58.82	13	56.52	24	60.00
1 to 2	24	23.76	15	30.00	9	17.65	7	30.43	7	17.50
3 to 4	10	9.90	7	14.00	3	5.88	2	8.70	3	7.50
5 to 6	7	6.93	1	2.00	6	11.76	0	0.00	4	10.00
7 or more	4	3.96	1	2.00	3	5.88	1	4.35	2	5.00

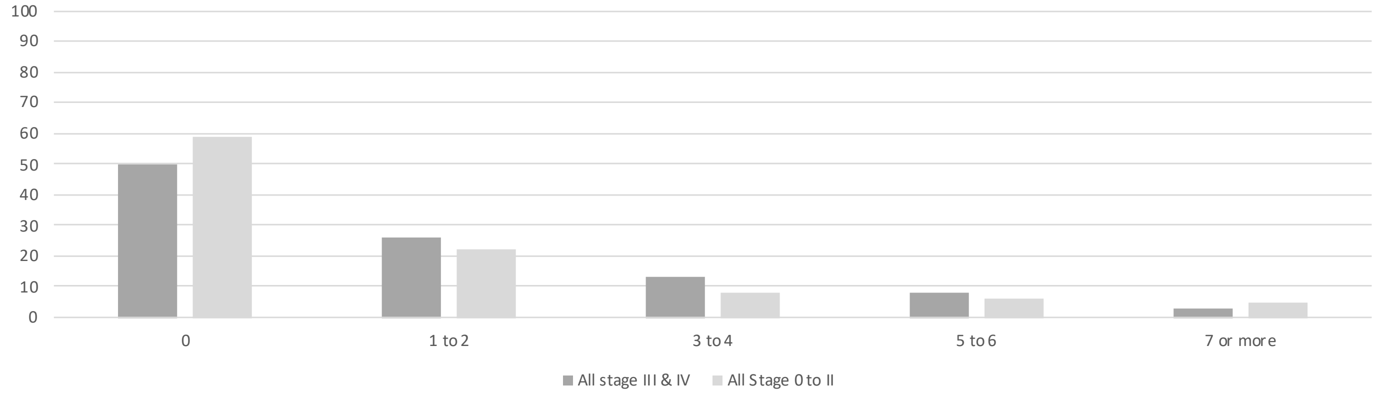


Figure 3.1: Number of symptoms per participant (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 3.2: Number of symptoms per participant – Stage III & IV variations

Number of symptoms per participant	Reported less frequently	Reported more frequently
5 to 6	-	Hormone receptor Stage III & IV

Symptoms before diagnosis: Stage III & IV

The most common symptoms before diagnosis were anxiety/anxious mood (n=18, 47.37%), fatigue (n=18, 47.37%), thinking and memory problem (n=17, 44.74%), and, weight and muscle changes (n=16, 42.11%) (Table 3.3, Figure 3.2).

Table 3.3: Symptoms before diagnosis

Symptoms before diagnosis	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=101	%	n=63	%	n=38	%	n=27	0.00	n=11	0.00
Breast lump	33	32.67	17	26.98	16	42.11	11	40.74	5	45.45
Breast pain	22	21.78	13	20.63	9	23.68	7	25.93	2	18.18
Breast changes (size, shape, feel	18	17.82	10	15.87	8	21.05	6	22.22	2	18.18
Fatigue	20	19.80	12	19.05	8	21.05	5	18.52	3	27.27
Lump in armpit	9	8.91	4	6.35	5	13.16	2	7.41	3	27.27
Breast skin changes	11	10.89	6	9.52	5	13.16	2	7.41	3	27.27
Change in the position of nipple	6	5.94	4	6.35	2	5.26	1	3.70	1	9.09
Bone pain	4	3.96	2	3.17	2	5.26	0	0.00	2	18.18
Appetite loss	6	5.94	4	6.35	2	5.26	1	3.70	1	9.09
Fluid leaking from nipple red or inflamed breast(s	2	1.98	1	1.59	1	2.63	0	0.00	1	9.09
Persistent cough or chest infection	3	2.97	2	3.17	1	2.63	0	0.00	1	9.09

Symptoms before diagnosis	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=101	%	n=50	%	n=51	%	n=23	0.00	n=40	0.00
Breast lump	33	32.67	19	38.00	14	27.45	8	34.78	9	22.50
Breast pain	22	21.78	13	26.00	9	17.65	6	26.09	7	17.50
Breast changes (size, shape, feel	18	17.82	9	18.00	9	17.65	3	13.04	7	17.50
Fatigue	20	19.80	8	16.00	12	23.53	3	13.04	9	22.50
Lump in armpit	9	8.91	3	6.00	6	11.76	1	4.35	3	7.50
Breast skin changes	11	10.89	3	6.00	8	15.69	1	4.35	5	12.50
Change in the position of nipple	6	5.94	2	4.00	4	7.84	1	4.35	3	7.50
Bone pain	4	3.96	1	2.00	3	5.88	1	4.35	1	2.50
Appetite loss	6	5.94	3	6.00	3	5.88	2	8.70	2	5.00
Fluid leaking from nipple red or inflamed breast(s	2	1.98	1	2.00	1	1.96	1	4.35	0	0.00
Persistent cough or chest infection	3	2.97	1	2.00	2	3.92	1	4.35	1	2.50

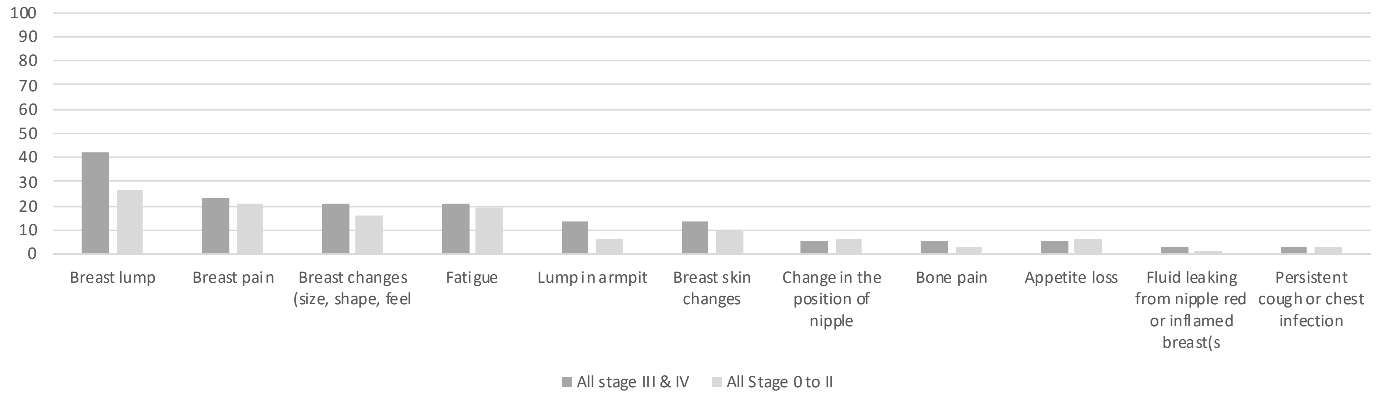


Figure 3.2: Symptoms before diagnosis (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 3.4: Symptoms before diagnosis – Stage III & IV variations

Symptoms before diagnosis	Reported less frequently	Reported more frequently
Breast lump	-	Hormone receptor Stage III & IV
Lump in armpit	-	Hormone receptor Stage III & IV
Breast skin changes	-	Hormone receptor Stage III & IV
Change in the position of nipple	-	
Bone pain	-	Hormone receptor Stage III & IV

Symptoms leading to diagnosis: Stage III & IV

In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis.

Most commonly participants strongly recalled their symptoms or how they came to be diagnosed (87.18%). Others had no symptoms (5.13%), or being incapacitated at the time and cannot remember the but recalls what their family members or other sources have told them (2.56%).

The most common symptoms leading to diagnosis were having a breast lump or lumps (66.67%), and fatigue (10.26 %). Other themes included breast pain (5.13%), breast skin changes including puckering, dimpling, a rash, or redness of skin (5.13%), a family history and being vigilant about breast health (2.56%), and breast changes (size shape and feel) (2.56%). There were 2 participants (5.13%) that described not noticing any symptoms.

Participant describes having a breast lump or lumps which led to their diagnosis

No. I don't really recall any signs or symptoms. I know one of my friends told me that it was getting harder to wake me up, so maybe I was a bit more tired than usual. Actually, I found the lump on my breast. I was in pain. My breast was sore, and I felt a lump there. Then when I looked at myself in the mirror, I don't know whether I was imagining or not, I swear I saw bruising, so I thought I'd injured myself at the time. That's pretty much what happened with me. Participant_028TNG

Okay. It was actually on a Wednesday. I was getting ready for work. I noticed a large lump under my left arm, and I just thought that's a bit unusual. I went to work and mentioned it to a few people. What I actually did was I thought I'll ring up and make an appointment for the doctor on Friday. If the lump is still there on Friday, I'll go to the doctor. If it's not there, I'll cancel it. It was there on Friday, so I went to the doctor. Participant_046TNG

Participant describes having no symptoms

I have a history of breast cysts, so I used to be monitored yearly for any changes in my breast. That got changed to two-yearly, literally two years prior to my diagnosis. I was diagnosed from mammograms. I'm a country patient. I live in LOCATION. I was sent to LOCATION to have a mammogram. Prior to the mammogram, on the day, I was given an ultrasound, and I knew myself from the ultrasound what we were looking at, even though no one said anything. By the time I got home, I was already in panic mode without having a diagnosis from anyone. I just knew myself what was going on. I'd done my own research to find a surgeon who I wanted to see, which was NAME at HOSPITAL. When my doctor phoned me the following day after my mammogram and ultrasound, he said, "How you going?" I said, "I know." He goes, "Right. What do you want to do?" I said, "This is who I want to see. Send me to LOCATION." That's how it went. Participant_034TNG

Yes. I did a mammogram and they called me back and said that they wanted to do a follow-up screening. They didn't say anything at the time. I had to go and do a further ultrasound and biopsy. Then they said to me that they would call me in a week's time with the results. They called me two days later and asked me to come in and I suspected then that it wasn't good. I met the breast surgeon or the surgeon that I go to the BreastScreen. He went through my diagnosis with me in LOCATION at the centre there and told me the results of the biopsy and the further ultrasound. Participant_029TNG

I just went for a routine mammogram. Then got recalled when they noticed some changes on that one. Went then to Breast Screen in town and had a repeat mammogram and then a biopsy, ultrasound. When they then discovered yes, I had a tumour. Then I went to see the surgeon, and he on looking at the mammogram, then sent me for an MRI, and they subsequently found a second tumour. Participant 050_2021AUHRP

Participant describes having fatigue which led to their diagnosis

Yes. I don't think I actually had any signs, actually. Maybe tiredness was one but, basically, I found the breast cancer myself, funny enough, by dislocating my shoulder and then finding the lump at the same time. Participant_024TNG

No. I don't really recall any signs or symptoms. I know one of my friends told me that it was getting harder to wake me up, so maybe I was a bit more tired than usual. Actually, I found the lump on my breast. I was in pain. My breast was sore, and I felt a lump there. Then when I looked at myself in the mirror, I don't know whether I was imagining or not, I swear I saw bruising, so I thought I'd injured myself at the time. That's pretty much what happened with me. Participant_028TNG

Table 3.5: Symptom recall

Symptom recall	**All participants**		**All Stage 0 to II**		**All Stage III & IV**		**Triple negative Stage III & IV**		**Hormone receptor Stage III & IV**	
	n=102	**%**	**n=63**	**%**	**n=39**	**%**	**n=27**	**%**	**n=12**	**%**
Symptom recall strong	84	82.35	50	79.37	34	87.18	24	88.89	10	83.33
No Symptoms	14	13.73	12	19.05	2	5.13	**0**	**0.00**	2	16.67
Symptom recall unclear	1	0.98	0	0.00	1	2.56	1	3.70	0	0.00
Other	3	2.94	1	1.59	2	5.13	2	7.41	0	0.00

Symptom recall	**All participants**		**All Triple negative**		**All Hormone receptor**		**Triple negative Stage 0 to II**		**Hormone receptor Stage 0 to II**	
	n=102	**%**	**n=50**	**%**	**n=52**	**%**	**n=23**	**%**	**n=40**	**%**
Symptom recall strong	84	82.35	46	92.00	38	73.08	**22**	**95.65**	**28**	**70.00**
No Symptoms	14	13.73	**0**	**0.00**	**14**	**26.92**	**0**	**0.00**	**12**	**30.00**
Symptom recall unclear	1	0.98	1	2.00	0	0.00	0	0.00	0	0.00
Other	3	2.94	3	6.00	0	0.00	1	4.35	0	0.00

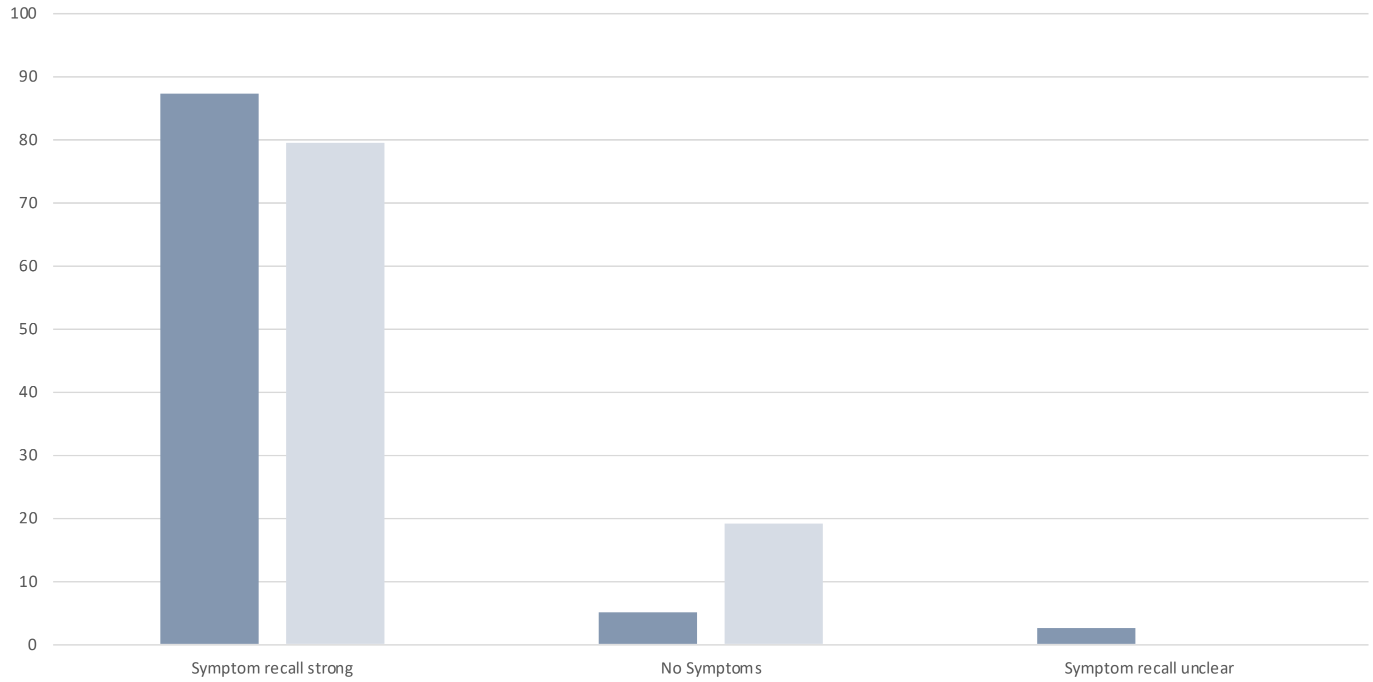


Figure 3.3: Symptom recall (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 3.6: Symptoms leading to diagnosis

Symptoms leading to diagnosis	**All participants**		**All Stage 0 to II**		**All Stage III & IV**		**Triple negative Stage III & IV**		**Hormone receptor Stage III & IV**	
	n=102	**%**	**n=63**	**%**	**n=39**	**%**	**n=27**	**%**	**n=12**	**%**
Participant describes having a breast lump or lumps which led to their diagnosis	58	56.86	32	50.79	26	66.67	**20**	**74.07**	6	50.00
Participant describes having fatigue which led to their diagnosis	7	6.86	3	4.76	4	10.26	4	14.81	0	0.00
Participant describes having breast pain which led to their diagnosis	5	4.90	3	4.76	2	5.13	0	0.00	**2**	**16.67**
Participant describes having breast skin changes including (puckering, dimpling, a rash or redness of skin) which led to their diagnosis	5	4.90	3	4.76	2	5.13	0	0.00	**2**	**16.67**
Participant describes having a family history and being vigilant about breast health which led to their diagnosis	7	6.86	6	9.52	1	2.56	0	0.00	1	8.33
Participant describes having breast changes (size, shap and feel) which led to their diagnosis	1	0.98	0	0.00	1	2.56	0	0.00	1	8.33
Participant describes having changes in the position of the nipple	2	1.96	2	3.17	0	0.00	0	0.00	0	0.00

Symptoms leading to diagnosis	**All participants**		**All Triple negative**		**All Hormone receptor**		**Triple negative Stage 0 to II**		**Hormone receptor Stage 0 to II**	
	n=102	**%**	**n=50**	**%**	**n=52**	**%**	**n=23**	**%**	**n=40**	**%**
Participant describes having a breast lump or lumps which led to their diagnosis	58	56.86	32	64.00	26	50.00	12	52.17	20	50.00
Participant describes having fatigue which led to their diagnosis	7	6.86	7	14.00	0	0.00	3	13.04	0	0.00
Participant describes having breast pain which led to their diagnosis	5	4.90	0	0.00	5	9.62	0	0.00	3	7.50
Participant describes having breast skin changes including (puckering, dimpling, a rash or redness of skin) which led to their diagnosis	5	4.90	0	0.00	5	9.62	0	0.00	3	7.50
Participant describes having a family history and being vigilant about breast health which led to their diagnosis	7	6.86	0	0.00	7	13.46	0	0.00	6	15.00
Participant describes having breast changes (size, shap and feel) which led to their diagnosis	1	0.98	0	0.00	1	1.92	0	0.00	0	0.00
Participant describes having changes in the position of the nipple	2	1.96	0	0.00	2	3.85	0	0.00	2	5.00

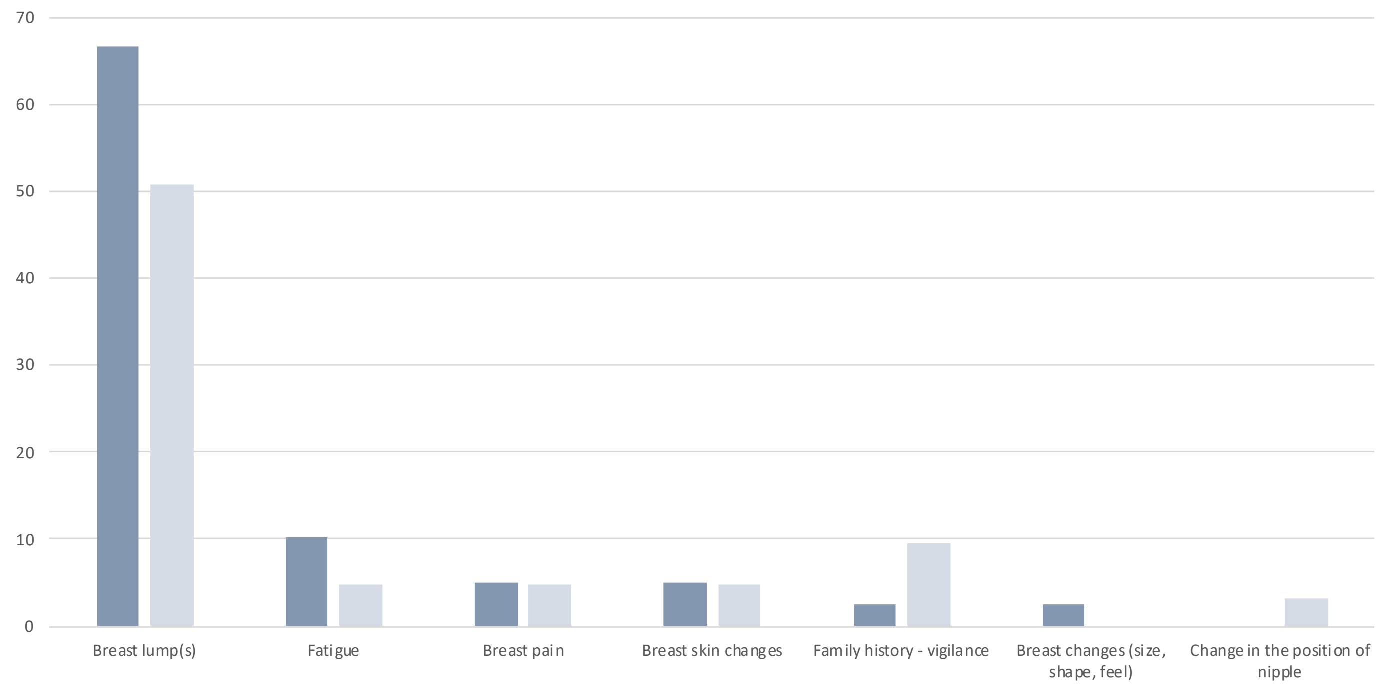


Figure 3.4: Symptoms leading to diagnosis (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 3.7: Symptoms leading to diagnosis – Stage III & IV variations

Symptoms leading to diagnosis	Reported less frequently	Reported more frequently
Participant describes having a breast lump or lumps which led to their diagnosis	-	Triple negative Stage III & IV
Participant describes having breast pain which led to their diagnosis	-	Hormone receptor Stage III & IV
Participant describes having breast skin changes including (puckering, dimpling, a rash or redness of skin) which led to their diagnosis	-	Hormone receptor Stage III & IV

Symptoms leading to diagnosis: Seeking medical attention: Stage III & IV

Participants described when they sought medical attention after noticing symptoms. The most common responses were having symptoms and seeking medical attention relatively soon (71.79%), having no symptoms or not noticing any symptoms before diagnosis, diagnosis was through routine screening(10.26%), and having symptoms and not seeking medical attention initially (12.82 %).

Participant describes having symptoms and seeking medical attention relatively soon

Okay, well, I wasn't under any surveillance because there's no history of cancer in my family. When I went to the doctor when I first noticed the lump, she sent me off to get a mammogram and an ultrasound done. Based on the ultrasound images, she then sent me to get a fine needle biopsy done. That was what showed us that it was a cancerous mass. Participant_027TNG

I was very, very healthy at the time, hardly went to the doctor. I found the lump. I made an appointment within a day or two to see-- I knew that it was not supposed to be there, so I went and saw my GP. He straight away felt it and was quite concerned. Sent me straight away for a mammogram, got in the next day for a mammogram and an ultrasound. The results came back, I think, the next day. I had to go there. There is definitely something there. They made me an appointment with a surgeon and I saw the surgeon within two days, basically. From that point on the surgeon sort of looked at it, felt it, realized that he thought it would be something. Sent me for a biopsy, I think. Some sort of scan, I can't exactly remember what it was but I do know I went for a biopsy. While having the biopsy, they basically told me that it was cancer. They didn't come out and say, "You have cancer" but they spoke about, "It looks like cancer" so you know, I've got five sisters, so I went back to the surgeon, he confirmed that, yes, it was. Put me in touch with an oncologist. Because of the triple-

negative, they decided that I would do chemo first. Participant_035TNG

Participant describes having no symptoms or not noticing any symptoms before diagnosis, diagnosis was through routine screening

Yes. I did a mammogram and they called me back and said that they wanted to do a follow-up screening. They didn't say anything at the time. I had to go and do a further ultrasound and biopsy. Then they said to me that they would call me in a week's time with the results. They called me two days later and asked me to come in and I suspected then that it wasn't good. I met the breast surgeon or the surgeon that I go to the BreastScreen. He went through my diagnosis with me in LOCATION at the centre there and told me the results of the biopsy and the further ultrasound. Participant_029TNG

I just went for a routine mammogram. Then got recalled when they noticed some changes on that one. Went then to Breast Screen in town and had a repeat mammogram and then a biopsy, ultrasound. When they then discovered yes, I had a tumour. Then I went to see the surgeon, and he on looking at the mammogram, then sent me for an MRI, and they subsequently found a second tumour. Participant 050_2021AUHRP

Participant describes having symptoms and not seeking medical attention initially

PARTICIPANT: Yes, so I was pregnant. It was in about May last year, 2020. I noticed a lump that had started, but I put that down to hormonal prepping for birth and breastfeeding and all that stuff, I didn't really think much of it. Then, it gradually grew bigger and bigger. Once I birthed my baby and when she was about four months old, I actually went and got it checked out.
INTERVIEWER: PARTICIPANT, can you describe how you came to be diagnosed? Now, for this, you can talk about any tests that were ordered and who ordered them for you if you can remember that. This might also include any ongoing management or surveillance that you might have been under before you were diagnosed.
PARTICIPANT: I went to my GP and had a referral for an ultrasound. Then, from that ultrasound, my GP referred me to a specialist, which was of my choosing because background-wise, I've got family history. I'd already been linked in with HOSPITAL previously and all the family history. My mother and my grandmother all went through HOSPITAL, so I requested for the referral to go to HOSPITAL. Then I had a sited biopsy and from that is when they did the diagnosis. Participant_030TNG

Table 3.8: Seeking medical attention

Seeking medical attention	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes having symptoms and seeking medical attention relatively soon	56	54.90	28	44.44	28	71.79	20	74.07	8	66.67
Participant describes having no symptoms or not noticing any symptoms before diagnosis, diagnosis was through routine screening	20	19.61	16	25.40	4	10.26	2	7.41	2	16.67
Participant describes having symptoms and not seeking medical attention initially	19	18.63	15	23.81	4	10.26	2	7.41	2	16.67
Participant describes having symptoms and not seeking medical attention initially, but recognising the importance of those symptoms in hindsight	4	3.92	3	4.76	1	2.56	1	3.70	0	0.00
Other	3	2.94	1	1.59	2	5.13	2	7.41	0	0.00

Seeking medical attention	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes having symptoms and seeking medical attention relatively soon	56	54.90	28	44.44	28	71.79	20	74.07	8	66.67
Participant describes having no symptoms or not noticing any symptoms before diagnosis, diagnosis was through routine screening	20	19.61	16	25.40	4	10.26	2	7.41	2	16.67
Participant describes having symptoms and not seeking medical attention initially	19	18.63	15	23.81	4	10.26	2	7.41	2	16.67
Participant describes having symptoms and not seeking medical attention initially, but recognising the importance of those symptoms in hindsight	4	3.92	3	4.76	1	2.56	1	3.70	0	0.00
Other	3	2.94	1	1.59	2	5.13	2	7.41	0	0.00

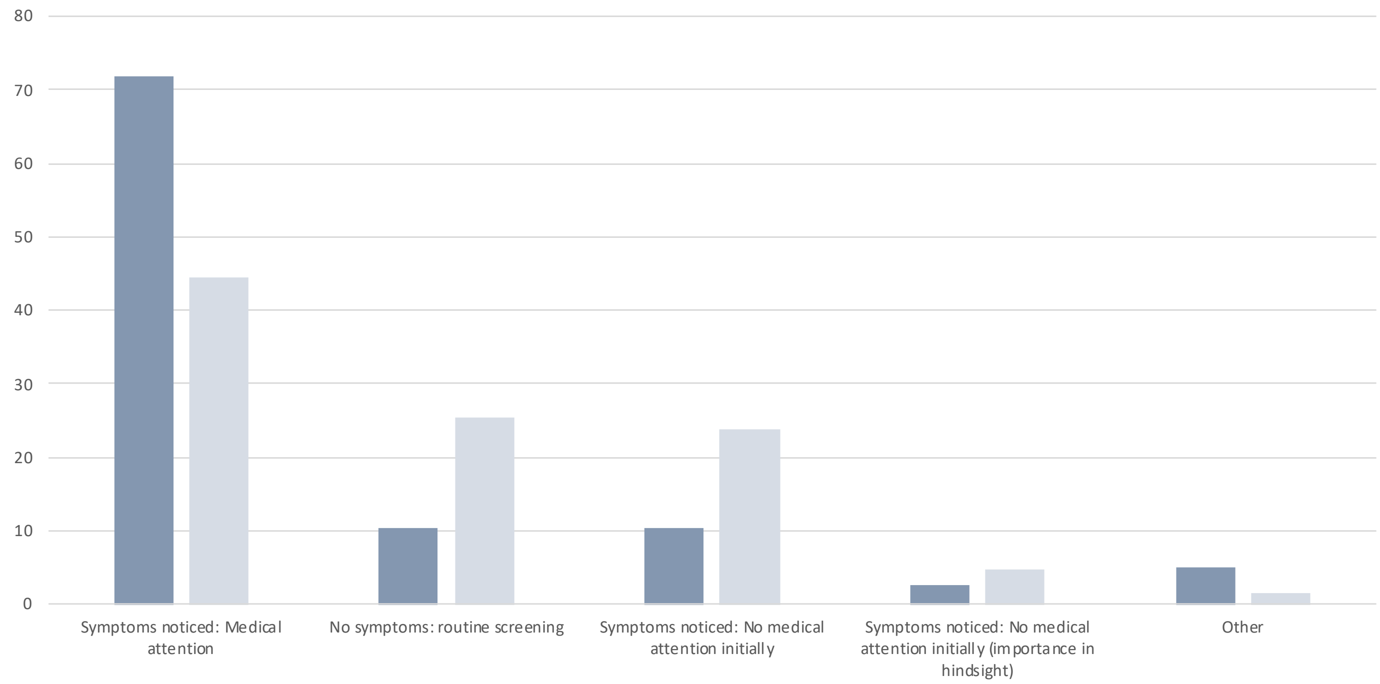


Figure 3.5: Seeking medical attention – (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 3.9: Seeking medical attention – Stage III & IV variations

Theme	Reported less frequently	Reported more frequently
Participant describes having symptoms and seeking medical attention relatively soon	-	All Stage III & IV Triple negative Stage III & IV Hormone receptor Stage III & IV
Participant describes having no symptoms or not noticing any symptoms before diagnosis, diagnosis was through routine screening	Triple negative Stage III & IV	-
Participant describes having symptoms and not seeking medical attention initially	Triple negative Stage III & IV	-

Symptoms leading to diagnosis: Description of diagnostic pathway : Stage III & IV

In the structured interview, participants described their diagnostic pathway in the healthcare system. The most common descriptions were diagnosed by their general practitioner due to concerns about symptoms (following imaging studies) (48.72%), a linear diagnosis after being referred to a specialist from their general practitioner (28.21%), and (17.95 %).

Participant describes being diagnosed by their general practitioner due to concerns about symptoms (following imaging studies)

When I went to the doctor, he felt the lump. He was concerned. He sent me off for a mammogram and then ultrasound on my breast, and also sent me to get blood tests. I had the mammogram and the ultrasound that afternoon. When I was having that done, I was very lucky I had the head of the place there doing my ultrasound. I said to him, "It's cancer that's gone to my lymph nodes, hasn't it?" Because my dad had cancer before, and I knew about the lymph nodes side of things. He said, "Yes, it has." He said, "You're going to have to have a biopsy. The doctor will order that for you," but he said, "If you want me to, I can do that now for you." I said, "Yes, go ahead. Do it now," so I had the biopsy done then and there. I had the blood tests done the next day. Then I had an appointment with the doctor on the Wednesday to get all the results. That's when he informed me that I had breast cancer. It was all very quick. Participant_046TNG

OK, now I just after feeling the lump, I got up the courage three days later to go see my GP and he had a feel for it and they said, Oh, I'm going to send you for an ultrasound and biopsy for biopsy. I think it was. And I like, oh, OK. So what are you thinking? And he said, well, I need to check that it's not breast cancer. But he said that I had a feeling I knew it was. I remember feeling, you know, that he knows something here. And so a few days later, I got into the whole biopsy and the ultrasound and I knew from then I had trouble doing the biopsy, very painful. And then when I went back to the GP, he said to me, I just have to confirm you've got cancer in your breast. And I'm very sorry if you are, but I have breast cancer. And he *said, yes, you have. And oh. Oh, hang on. I was expecting him to say that. And then he just basically said, well, now, but I refer you to a surgeon to have a lumpectomy and to see how we go from there. And then it all started. Participant_049TNG*

I went to the doctor initially, and she put me on a course of antibiotics but also ordered a scan for that week. While I was still on my antibiotics, I went for a mammogram first off, and in the mammogram, she said, "Oh, it's just a bit of mastitis and some fibroids, because I already have fibroids in the other breast. When I had the ultrasound I think that's when she found it. She didn't say anything to me during that, but she was a bit quiet. I was called in the next day, to my GP, and she said that since she told me that it's highly likely that it is breast cancer. Participant 052_2021AUHRP

Participant describes a linear diagnosis after being referred to a specialist from their general practitioner

was very, very healthy at the time, hardly went to the doctor. I found the lump. I made an appointment within a day or two to see-- I knew that it was not supposed to be there, so I went and saw my GP. He straight away felt it and was quite concerned. Sent me straight away for a mammogram, got in the next day for a mammogram and an ultrasound. The results came back, I think, the next day. I had to go there. There is definitely something there. They made me an appointment with a surgeon and I saw the surgeon within two days, basically. From that point on the surgeon sort of looked at it, felt it, realized that he thought it would be something. Sent me for a biopsy, I think. Some sort of scan, I can't exactly remember what it was but I do know I went for a biopsy. While having the biopsy, they basically told me that it was cancer. They didn't come out and say, "You have cancer" but they spoke about, "It looks like cancer" so you know, I've got five sisters, so I went back to the surgeon, he confirmed that, yes, it was. Put me in touch with an oncologist. Because of the triple-negative, they decided that I would do chemo first. Participant_035TNG

I had my first mammogram in 2014, I think, because a friend of mine had breast cancer. I was only 46 at the time, I guess. A friend of mine had had breast cancer, so she said, "Oh, we should all--" The rest of us all went and had mammograms, and then I didn't have another one until 2019, I guess it was. Then, I found the lump myself just a few days before Christmas, and I went to see my GP. I called and got in to see her immediately that afternoon. She did a manual examination and sent me straight to CLINIC in LOCATION for a scan. Then the scan came back and she let me know that there was something that she felt needed some attention, so she organized a meeting to DOCTOR. Participant_041TNG

The doctor, I saw the same GP that I'd seen for the original lump, same lump, two months earlier. I think he and I both agreed that the lumps were of concern. He sent me off for an ultrasound, and he also suggested that maybe it'd be worth looking in to see a breast specialist surgeon. Because if again we didn't see anything on the investigations, then at least she could explain why this kept on happening. In hindsight, I think he knew better. He knew more than he was giving away. The ultrasound definitely showed breast cancer or very suspicious stuff. I saw the breast specialist literally within a day after getting the ultrasound. She pretty much diagnosed me on the spot, seeing the ultrasound and examining me. Participant 051_2021AUHRP

Participant describes being diagnosed through a population screening program

Yes. I did a mammogram and they called me back and said that they wanted to do a follow-up screening. They didn't say anything at the time. I had to go and do a further ultrasound and biopsy. Then they said to me that they would call me in a week's time with the results. They called me two days later and asked me to come in and I suspected then that it wasn't good. I met the breast surgeon or the surgeon that I go to the BreastScreen. He went through my diagnosis with me in Southport at the centre there and told me the results of the biopsy and the further ultrasound. Participant_029TNG

Table 3.10: Diagnostic pathway

Diagnostic pathway	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes being diagnosed by their general practitioner due to concerns about symptoms (following imaging studies)	46	45.10	**29**	**58.00**	**17**	**32.69**	**14**	**60.87**	**13**	**32.50**
Participant describes being referred directly to a specialist from their general practioner which led to their diagnosis	27	26.47	11	22.00	16	30.77	**2**	**8.70**	14	35.00
Participant describes being diagnosed through a population screening program	24	23.53	**5**	**10.00**	**19**	**36.54**	4	17.39	13	32.50
Other	5	4.90	3	4.76	2	5.13	2	7.41	0	0.00

Diagnostic pathway	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes being diagnosed by their general practitioner due to concerns about symptoms (following imaging studies)	46	45.10	29	58.00	17	32.69	14	60.87	13	32.50
Participant describes being referred directly to a specialist from their general practioner which led to their diagnosis	27	26.47	11	22.00	16	30.77	2	8.70	14	35.00
Participant describes being diagnosed through a population screening program	24	23.53	5	10.00	19	36.54	4	17.39	13	32.50
Other	5	4.90	5	10.00	0	0.00	3	13.04	0	0.00

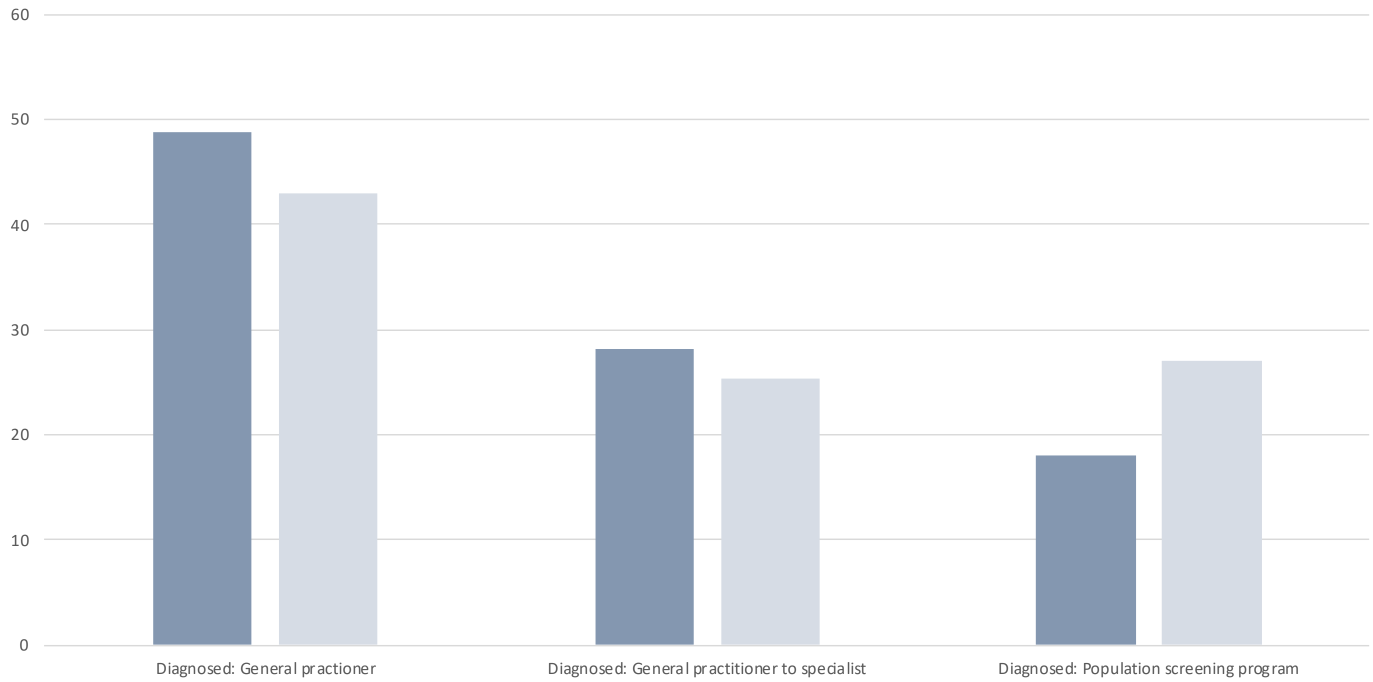


Figure 3.6: Diagnostic pathway (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 3.11: Diagnostic pathway – Stage III & IV variations

Diagnostic pathway	Reported less frequently	Reported more frequently
Participant describes being diagnosed by their general practitioner due to concerns about symptoms (following imaging studies)	Hormone receptor Stage III & IV Triple negative Stage 0 to II	Triple negative Stage III & IV All Hormone receptor Hormone receptor Stage 0 to II
Participant describes being referred directly to a specialist from their general practioner which led to their diagnosis	Hormone receptor Stage 0 to II	-
Participant describes being diagnosed through a population screening program	Triple negative Stage III & IV All Hormone receptor	Hormone receptor Stage III & IV Triple negative Stage 0 to II

Timing of diagnosis: Stage III & IV

Time from diagnostic test to receiving a diagnosis

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis.

Participants were most commonly diagnosed immediately at the consultation (n = 2, 5.26%). There were 19 participants (50.00%) that were diagnosed less than one week after diagnostic tests, 12 participants (31.58%) diagnosed between 1 and 2 weeks, 2 participants (5.26%) diagnosed between 2 and 3 weeks, 0 participants (0.00%) diagnosed between 3 and 4 weeks, and 2 participants (5.26%) diagnosed more than four weeks after diagnostic testing (Table 3.12, Figure 3.7).

Table 3.12: Time from diagnostic test to diagnosis

Number of diagnostic tests per participant	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	0.00	n=12	0.00
1	7	6.86	3	4.76	4	10.26	3	11.11	1	8.33
2	10	9.80	6	9.52	4	10.26	3	11.11	1	8.33
3	58	56.86	35	55.56	23	58.97	16	59.26	7	58.33
4	25	24.51	18	28.57	7	17.95	4	14.81	3	25.00
5	2	1.96	1	1.59	1	2.56	1	3.70	0	0.00

Number of diagnostic tests per participant	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	0.00	n=40	0.00
1	7	6.86	4	8.00	3	5.77	1	4.35	2	5.00
2	10	9.80	6	12.00	4	7.69	3	13.04	3	7.50
3	58	56.86	29	58.00	29	55.77	13	56.52	22	55.00
4	25	24.51	10	20.00	15	28.85	6	26.09	12	30.00
5	2	1.96	1	2.00	1	1.92	0	0.00	1	2.50

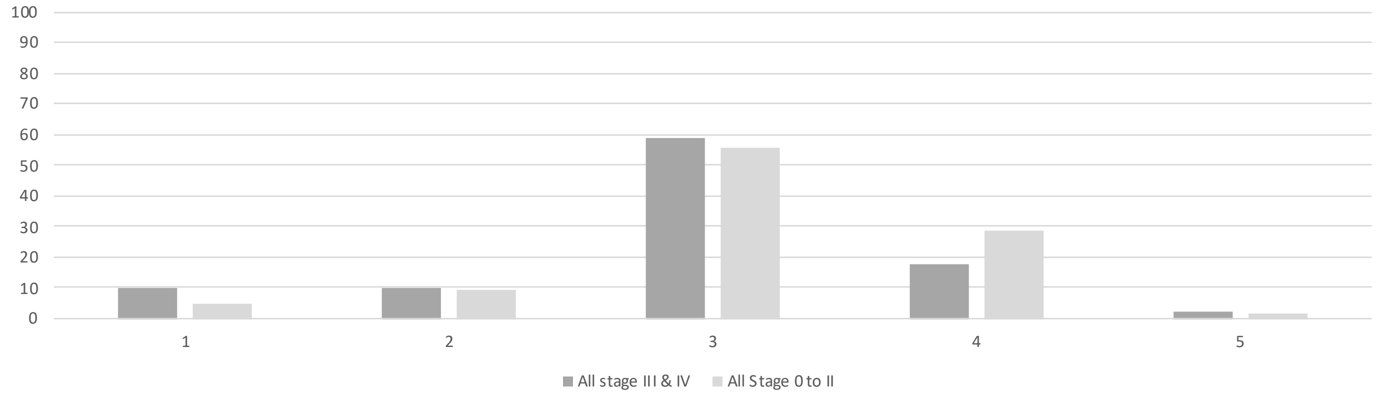


Figure 3.7: Time from diagnostic test to diagnosis (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Diagnostic tests: Stage III & IV

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with stage III and IV breast cancer. They could choose from a set list of diagnostic tests, and could then specify other tests not listed. The number of tests per participant were counted using both tests from the set list and other tests specified.

Participants reported between 1 and 5 diagnostic tests (median=3.00) (Table 3.13, Figure 3.8). The most common tests were Breast ultrasound (n=33, 84.62%), Core biopsy (A wider needle is used to remove a piece of tissue (n=32, 82.05%), Mammogram (n=29, 74.36%), and Fine needle aspiration (A thin needle is used to take tissue from the breast lump (n=12, 30.77%) (Table 3.15, Figure 3.9).

Table 3.13: Number of diagnostic tests

Time from diagnosis test to diagnosis	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=99	%	n=61	%	n=38	%	n=26	%	n=12	%
Diagnosed immediately at the consultation	4	4.04	2	3.28	2	5.26	0	0.00	2	16.67
Less than 1 week	48	48.48	29	47.54	19	50.00	15	57.69	4	33.33
Between 1 and 2 weeks	28	28.28	16	26.23	12	31.58	9	34.62	3	25.00
Between 2 and 3 weeks	5	5.05	3	4.92	2	5.26	1	3.85	1	8.33
Between 3 and 4 weeks	3	3.03	3	4.92	0	0.00	0	0.00	0	0.00
4 weeks or more	8	8.08	6	9.84	2	5.26	0	0.00	2	16.67
Not specified	3	3.03	2	3.28	1	2.63	1	3.85	0	0.00

Time from diagnosis test to diagnosis	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=99	%	n=47	%	n=52	%	n=21	0.00	n=40	0.00
Diagnosed immediately at the consultation	4	4.04	0	0.00	4	7.69	0	0.00	2	5.00
Less than 1 week	48	48.48	27	54.00	21	40.38	12	57.14	17	42.50
Between 1 and 2 weeks	28	28.28	12	24.00	16	30.77	3	14.29	13	32.50
Between 2 and 3 weeks	5	5.05	3	6.00	2	3.85	2	9.52	1	2.50
Between 3 and 4 weeks	3	3.03	2	4.00	1	1.92	2	9.52	1	2.50
4 weeks or more	8	8.08	1	2.00	7	13.46	1	4.76	5	12.50
Not specified	3	3.03	2	4.00	1	1.92	1	4.76	1	2.50

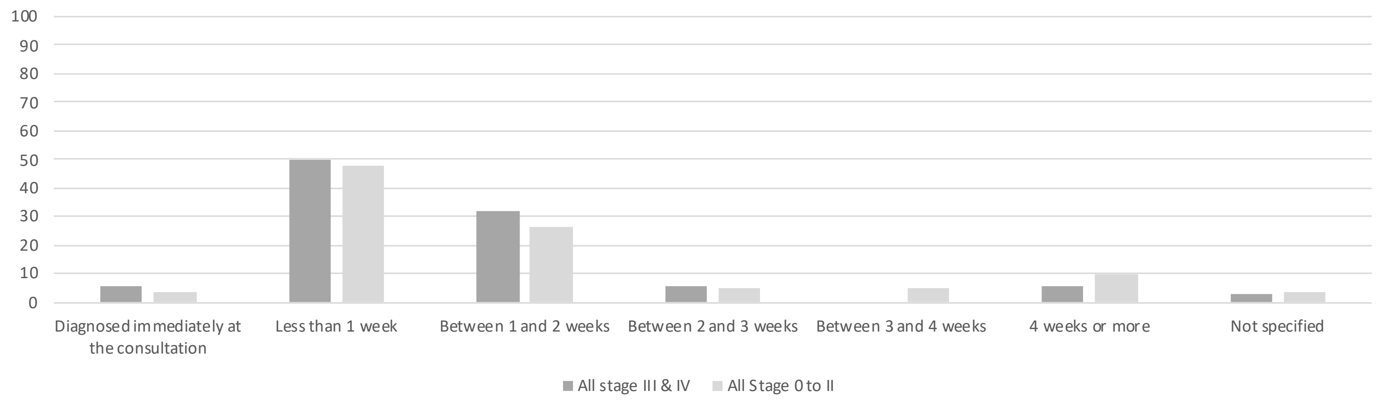


Figure 3.8: Number of diagnostic tests (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 3.14: Number of diagnostic tests– Stage III & IV variations

Time from diagnosis test to diagnosis	Reported less frequently	Reported more frequently
Diagnosed immediately at the consultation	-	Hormone receptor Stage III & IV
Less than 1 week	Hormone receptor Stage III & IV	

Table 3.15: Diagnostic tests

Diagnostic tests	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	0.00	n=12	0.00
Breast ultrasound	89	87.25	56	88.89	33	84.62	**19**	**70.37**	10	83.33
Core biopsy (A wider needle is used to remove a piece of tissue	81	79.41	49	77.78	32	82.05	22	81.48	**11**	**91.67**
Mammogram	86	84.31	57	90.48	29	74.36	22	81.48	10	83.33
Fine needle aspiration (A thin needle is used to take tissue from the breast lump	42	41.18	30	47.62	**12**	**30.77**	**8**	**29.63**	4	33.33
Vacuum assisted biopsy Surgical biopsy	2	1.96	1	1.59	1	2.56	1	3.70	0	0.00

Diagnostic tests	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Breast ultrasound	89	87.25	42	84.00	47	90.38	20	86.96	37	92.50
Core biopsy (A wider needle is used to remove a piece of tissue	81	79.41	41	82.00	40	76.92	20	86.96	**36**	**90.00**
Mammogram	86	84.31	39	78.00	47	90.38	19	82.61	30	75.00
Fine needle aspiration (A thin needle is used to take tissue from the breast lump	42	41.18	17	34.00	25	48.08	9	39.13	**21**	**52.50**
Vacuum assisted biopsy Surgical biopsy	2	1.96	1	2.00	1	1.92	0	0.00	1	2.50

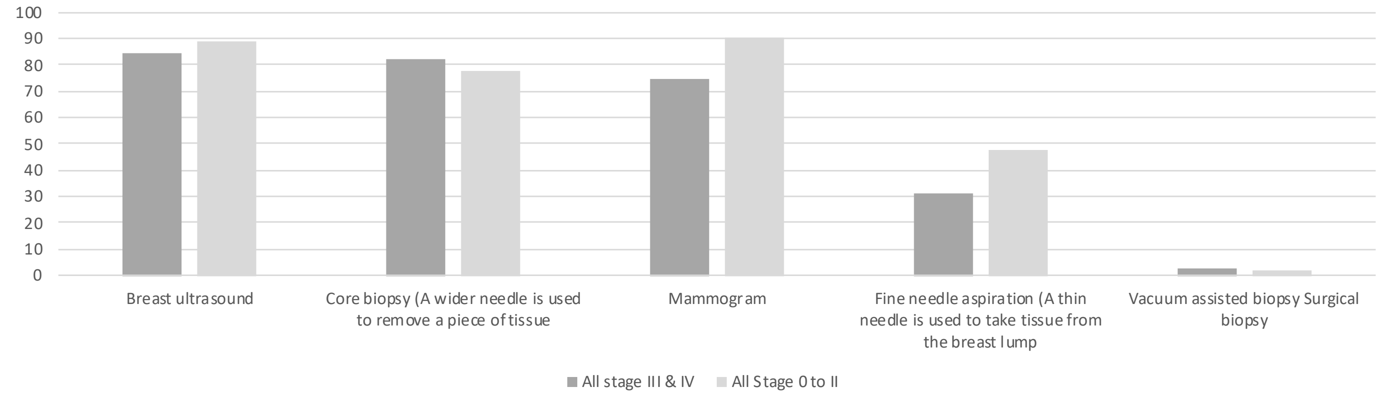


Figure 3.9: Diagnostic tests (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 3.16: Diagnostic tests– Stage III & IV variations

Diagnostic tests	Reported less frequently	Reported more frequently
Breast ultrasound	Triple negative Stage III & IV	-
Core biopsy (A wider needle is used to remove a piece of tissue	-	Hormone receptor Stage III & IV
Fine needle aspiration (A thin needle is used to take tissue from the breast lump	All Stage III & IV Triple negative Stage III & IV	-

Diagnosis provider and location: Stage III & IV

Participants were asked in the online questionnaire, which healthcare professional gave them their diagnosis, and where they were given the diagnosis.

Almost half of the participants were given their diagnosis by a General practitioner (GP (n=18, 47.37%), and there were 13 participants (34.21%) given the diagnosis by a Breast specialist, and 5 participants (13.16%) diagnosed by Surgeon (Table 3.17, Figure 3.10).

Participants were most commonly given their diagnosis in the General practice (n=16, 42.11%), this was followed by the Specialist clinic (n=12, 31.58%), and at Breast screening (n=4, 10.53%) (Table 3.19, Figure 3.11).

Table 3.17: Healthcare professional that gave diagnosis

Healthcare professional that gave diagnosis	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=99	%	n=61	%	n=38	%	n=26	0.00	n=12	0.00
General practitioner (GP	48	48.48	30	49.18	18	47.37	15	57.69	3	25.00
Breast specialist	32	32.32	19	31.15	13	34.21	5	19.23	7	58.33
Surgeon	14	14.14	9	14.75	5	13.16	5	19.23	0	0.00
Other	5	5.05	3	4.92	2	5.26	1	3.85	2	16.67

Healthcare professional that gave diagnosis	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=99	%	n=47	%	n=52	%	n=21	0.00	n=40	0.00
General practitioner (GP	48	48.48	27	54.00	21	40.38	12	57.14	18	45.00
Breast specialist	32	32.32	11	22.00	21	40.38	6	28.57	14	35.00
Surgeon	14	14.14	7	14.00	7	13.46	2	9.52	7	17.50
Other	5	5.05	2	4.00	3	5.77	1	4.76	1	2.50

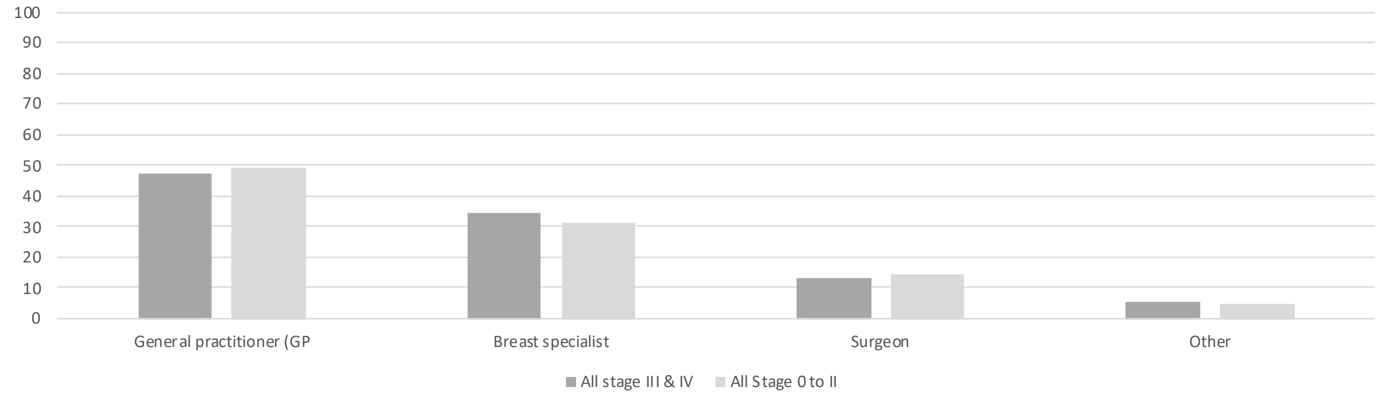


Figure 3.10: Healthcare professional that gave diagnosis (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 3.18: Healthcare professional that gave diagnosis– Stage III & IV variations

Healthcare professional that gave diagnosis	Reported less frequently	Reported more frequently
General practitioner (GP	Hormone receptor Stage III & IV	-
Breast specialist	Triple negative Stage III & IV	Hormone receptor Stage III & IV
Surgeon	Hormone receptor Stage III & IV	-
Other	-	Hormone receptor Stage III & IV

Table 3.19: Diagnosis location

Diagnosis location	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=99	%	n=61	%	n=38	%	n=26	%	n=12	%
General practice (GP)	41	41.41	25	40.98	16	42.11	13	50.00	3	25.00
Specialist clinic	29	29.29	17	27.87	12	31.58	8	30.77	5	41.67
Breast screening	9	9.09	5	8.20	4	10.53	1	3.85	2	16.67
Phone or telehealth	11	11.11	7	11.48	4	10.53	4	15.38	0	0.00
Hospital	9	9.09	7	11.48	2	5.26	0	0.00	2	16.67

Diagnosis location	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=99	%	n=47	%	n=52	%	n=21	%	n=40	%
General practice (GP)	41	41.41	24	48.00	17	32.69	11	52.38	14	35.00
Specialist clinic	29	29.29	14	28.00	15	28.85	6	28.57	10	25.00
Breast screening	9	9.09	1	2.00	8	15.38	0	0.00	5	12.50
Phone or telehealth	11	11.11	7	14.00	4	7.69	3	14.29	5	12.50
Hospital	9	9.09	1	2.00	8	15.38	1	4.76	6	15.00

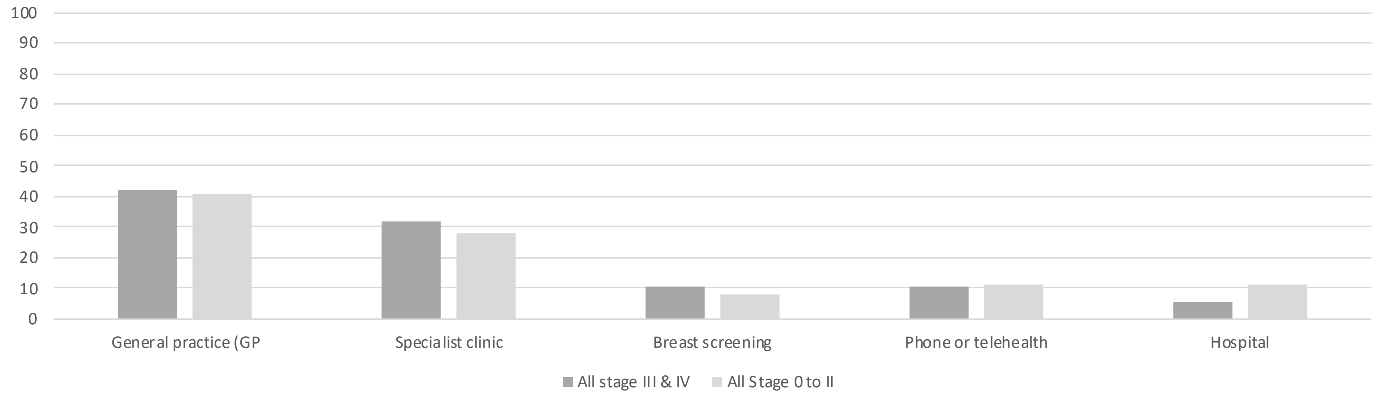


Figure 3.11: Diagnosis location (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 3.20: Diagnosis location– Stage III & IV variations

Diagnosis location	Reported less frequently	Reported more frequently
General practice (GP)	Hormone receptor Stage III & IV	-
Specialist clinic	-	Hormone receptor Stage III & IV
Phone or telehealth	Hormone receptor Stage III & IV	-

Understanding of disease at diagnosis: Stage III & IV

Participants were asked in the structured interview how much they knew about their condition at diagnosis. The most common response was knowing nothing or very little about the condition at diagnosis (41.03%).

Where participants had a little knowledge about their condition at diagnosis, the most common reasons were were knowing a little about the condition due to having a friend or acquaintance with the condition (10.26%), and knowing a little about the condition from having general knowledge or awareness of it (7.69%). Other themes included knowing a little about the condition from having a professional background (5.13%), knowing a little about the condition without giving a reason (5.13%), knowing a little about the condition because they have a family history (2.56%), and knowing a little about the condition by learning about it before or during the diagnostic process (2.56%).

Where participants had a good knowledge about their condition at diagnosis, the most common reasons were knowing about the condition by learning about it before or during the diagnostic process (10.26%), and knowing about the condition due to information given to them by healthcare professionals (7.69%). Other themes included knowing about the condition due to professional background (5.13%), knowing about the condition due to having a friend or acquaintance with the condition (5.13%),knowing about the condition due to public awareness (2.56%), and knowing about the condition at diagnosis because they have a family history (2.56%).

Limited understanding: Friend or acquaintance

PARTICIPANT: I wasn't diagnosed until after surgery, when they found out it was triple-negative.
INTERVIEWER: When they told you what your diagnosis was and that it was triple-negative, did you know much about breast cancer, in general, at that time?
PARTICIPANT: I only knew about hormone breast cancer. I just knew that ladies would be on Tamoxifen. I'd had a few friends over the years that had been on Tamoxifen, but I had no idea that there was all the different subgroups and subtypes. Participant_040TNG

I'm a naturopath by trade. I [unintelligible 00:09:31], well, probably more than the general layperson.
I have a colleague who also has breast cancer and had been going through treatment. I've known some people and I've treated, given people supportive treatment, who've had breast cancer, so I knew a bit, but not a lot about metastatic breast cancer. Participant_050TNG

Limited understanding: general awareness/knowledge

Not a lot. I just knew that I had breast cancer and that I would have to have a lumpectomy and then possibly I'd have to have chemotherapy, which was a total shock to me. Participant_049TNG

Good knowledge: Research through diagnostic process

No. My mum had actually passed away from bowel cancer, so I knew of bowel cancer. No one in my family had ever had breast cancer. They ascertained very quickly that it was triple-negative and they sort of gave me a bit of a rundown on triple-negative. I did a lot of research myself after that, but they sort of gave me the understanding that that was why I was doing chemo first and that, you know, because of it, they could-- If it shrunk enough, I wouldn't have to have a mastectomy. They never really explained to me probably how triple-negative can come back. It was sort of, "This is triple-negative. This is what we're doing." and I probably shouldn't have Googled, but I actually Googled and realized that it's probably not one of the better types of breast cancer. Participant_035TNG

Good knowledge: given by healthcare professional

The minute the GP receptionist called me, I knew it was going to be something. I knew it was breast cancer. My GP had mentioned it was triple-negative. She had said to me, as I left, "Don't Google and stay off the forums." I actually, funnily enough, had obliged. I did at one point look up triple-negative because I had no idea what that meant. I ended up just looking at the Breast Cancer Network page, I think it was, which doesn't really give you too much scary information, which is good.

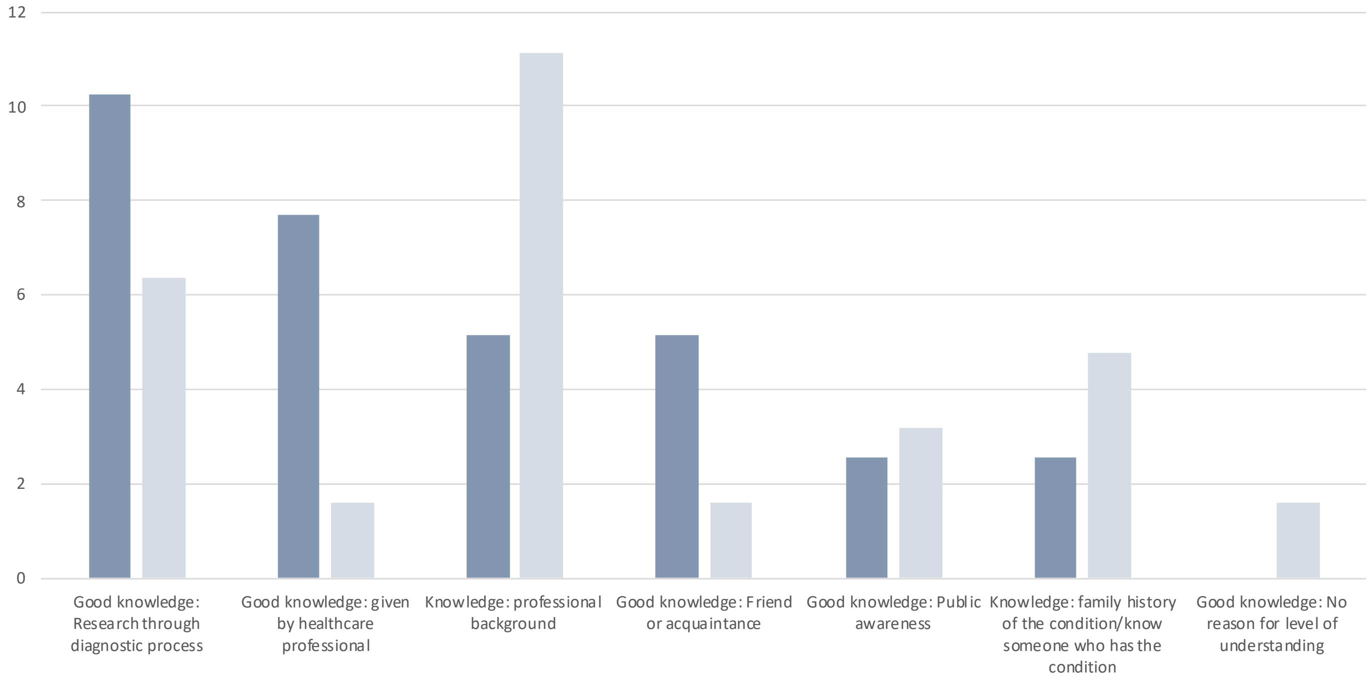
We also, after seeing the breast surgeon on the Thursday, we had been going through infertility and IVF, and we obviously on the Thursday, after our breast surgeon's appointment, we had called our fertility specialists to chat to him about what that would mean for us and what options we had for fertility preservation, things like that. I remember him saying to me, because it wasn't hormonally driven, that-- My breast surgeon explained to me that it wasn't responsive to hormones, and it didn't come back with a HER2. He was the one who explained a little bit more about what triple-negative was, but at no point did I actually grasp how scary triple-negative is. I remember our fertility specialist telling us, because it wasn't hormonally driven, he was happy for us to do another round of IVF with fertility preservation. My husband and I thought we'd got the good breast cancer. Not that there's any good or bad breast cancer, but we were like, "Cool, we get to still do something. We're lucky that we got this version and hadn't got a hormonally driven version.

It wasn't until pretty much I'd finished chemotherapy that I actually fully understood what triple-negative meant, and the statistics around triple-negatives, the statistics around survival rate. I remember my surgeon saying to me at the beginning that we needed to make some decisions within the first four weeks because they'd like to do something within the first week, but it was never because it's triple-negative. As far as we were concerned, we've got some good breast cancer and that was what it was. Participant_025TNG

Table 3.20: Understanding of disease at diagnosis

Understanding of disease at diagnosis	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes knowing nothing or very little about the condition at diagnosis	32	31.37	16	25.40	16	41.03	**14**	**51.85**	**2**	**16.67**
Participant describes knowing a little about the condition due to having a friend or aquantaince with the condition	10	9.80	6	9.52	4	10.26	0	0.00	**4**	**33.33**
Participant describes knowing a little about the condition from having general knowledge or awareness of it	10	9.80	7	11.11	3	7.69	2	7.41	1	8.33
Participant describes knowing a little about the condition from having a professional background	8	7.84	6	9.52	2	5.13	0	0.00	2	16.67
Participant describes knowing a little about the condition without giving a reason	8	7.84	6	9.52	2	5.13	0	0.00	2	16.67
Participant describes knowing a little about the condition because they have a family history	12	11.76	11	17.46	1	2.56	1	3.70	**0**	**0.00**
Participant describes knowing a little about the condition by learning about it before or during the diagnositic process	5	4.90	4	6.35	1	2.56	0	0.00	1	8.33
Participant describes knowing about the condition by learning about it before or during the diagnositic process	8	7.84	4	6.35	4	10.26	2	7.41	2	16.67
Participant describes knowing about the condition due to information given to them by healthcare professionals	4	3.92	1	1.59	3	7.69	3	11.11	0	0.00
Participant describes knowing about the condition due to professional background	9	8.82	7	11.11	2	5.13	2	7.41	0	0.00
Participant describes knowing about the condition due to having a friend or acquaintance with the condition	3	2.94	1	1.59	2	5.13	2	7.41	0	0.00
Participant describes knowing about the condition due to public awareness	3	2.94	2	3.17	1	2.56	1	3.70	0	0.00
Participant describes knowing about the condition at diagnosis because they have a family history	4	3.92	3	4.76	1	2.56	1	3.70	0	0.00
Participant describes knowing about the condition at diagnosis without giving a reason for level of knowledge	1	0.98	1	1.59	0	0.00	0	0.00	0	0.00

Understanding of disease at diagnosis	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes knowing nothing or very little about the condition at diagnosis	32	31.37	21	42.00	11	21.15	7	30.43	9	22.50
Participant describes knowing a little about the condition due to having a friend or aquantaince with the condition	10	9.80	2	4.00	8	15.38	2	8.70	4	10.00
Participant describes knowing a little about the condition from having general knowledge or awareness of it	10	9.80	7	14.00	3	5.77	5	21.74	2	5.00
Participant describes knowing a little about the condition from having a professional background	8	7.84	0	0.00	8	15.38	0	0.00	6	15.00
Participant describes knowing a little about the condition without giving a reason	8	7.84	0	0.00	8	15.38	0	0.00	6	15.00
Participant describes knowing a little about the condition because they have a family history	12	11.76	3	6.00	9	17.31	2	8.70	9	22.50
Participant describes knowing a little about the condition by learning about it before or during the diagnositic process	5	4.90	0	0.00	5	9.62	0	0.00	4	10.00
Participant describes knowing about the condition by learning about it before or during the diagnositic process	8	7.84	4	8.00	4	7.69	2	8.70	2	5.00
Participant describes knowing about the condition due to information given to them by healthcare professionals	4	3.92	4	8.00	0	0.00	1	4.35	0	0.00
Participant describes knowing about the condition due to professional background	9	8.82	4	8.00	5	9.62	2	8.70	5	12.50
Participant describes knowing about the condition due to having a friend or acquaintance with the condition	3	2.94	2	4.00	1	1.92	0	0.00	1	2.50
Participant describes knowing about the condition due to public awareness	3	2.94	3	6.00	0	0.00	2	8.70	0	0.00
Participant describes knowing about the condition at diagnosis because they have a family history	4	3.92	2	4.00	2	3.85	1	4.35	2	5.00
Participant describes knowing about the condition at diagnosis without giving a reason for level of knowledge	1	0.98	0	0.00	1	1.92	0	0.00	1	2.50



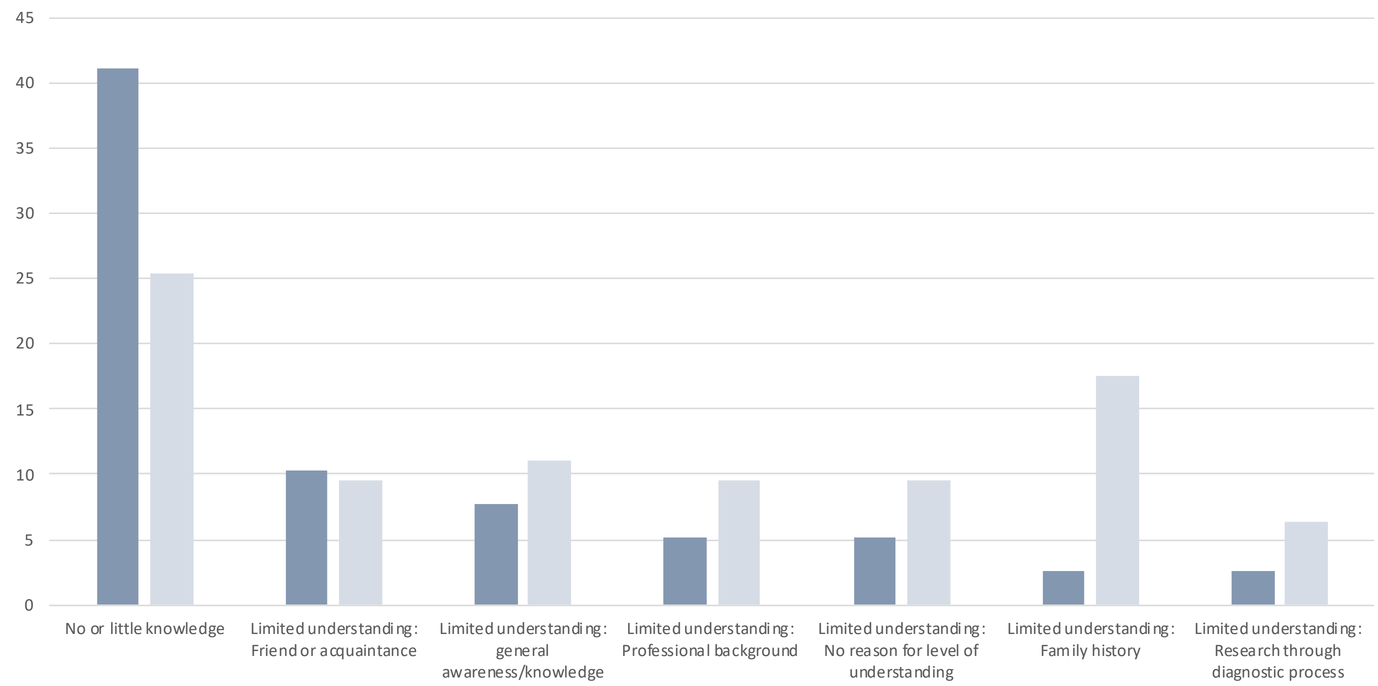


Figure 3.12 Understanding of disease at diagnosis (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 3.21: Understanding of disease at diagnosis – Stage III & IV variations

Understanding of disease at diagnosis	Reported less frequently	Reported more frequently
Participant describes knowing nothing or very little about the condition at diagnosis	Hormone receptor Stage III & IV	Triple negative Stage III & IV
Participant describes knowing a little about the condition due to having a friend or acquaintance with the condition	-	Hormone receptor Stage III & IV
Participant describes knowing a little about the condition because they have a family history	Hormone receptor Stage III & IV	

Emotional support at diagnosis: Stage III & IV

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis.

There were 7 participants (18.42%) who had enough support, 10 participants (26.32%) that had some support, but it wasn't enough, and 21 participants (55.26%) had no support (Table 3.22, Figure 3.13).

Table 3.22: Emotional support at diagnosis

Emotional support at diagnosis	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=99	%	n=61	%	n=38	%	n=26	%	n=12	%
Enough support	26	26.26	19	31.15	7	18.42	3	11.54	4	33.33
Some support but it wasn't enough	20	20.20	10	16.39	10	26.32	8	30.77	2	16.67
No support	53	53.54	32	52.46	21	55.26	15	57.69	6	50.00

Emotional support at diagnosis	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=99	%	n=47	%	n=52	%	n=21	%	n=40	%
Enough support	26	26.26	11	22.00	15	28.85	8	38.10	11	27.50
Some support but it wasn't enough	20	20.20	9	18.00	11	21.15	1	4.76	9	22.50
No support	53	53.54	27	54.00	26	50.00	12	57.14	20	50.00

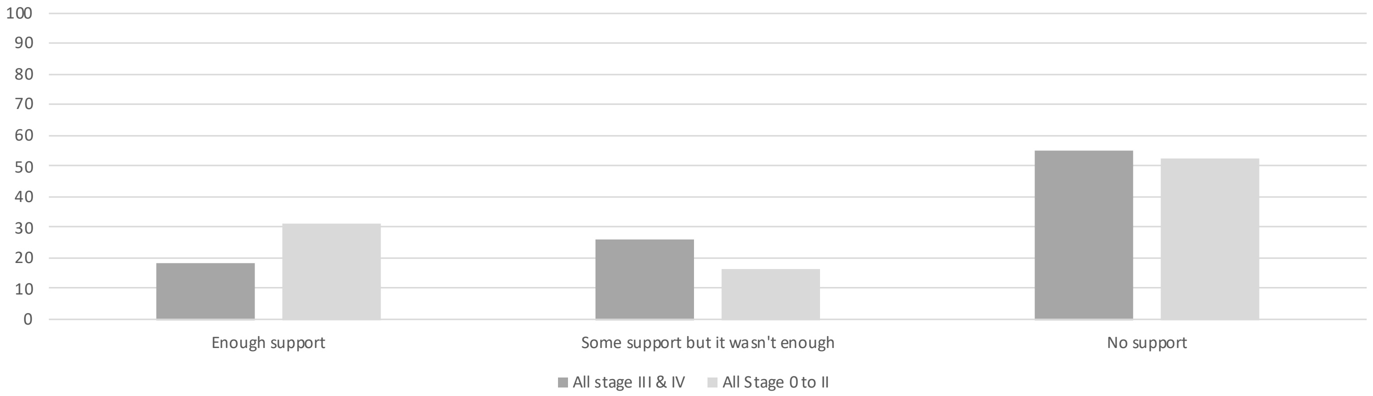


Figure 3.13: Emotional support at diagnosis (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 3.23: Emotional support at diagnosis – Stage III & IV variations

Emotional support at diagnosis	Reported less frequently	Reported more frequently
Enough support	Triple negative Stage III & IV	-
Some support but it wasn't enough	-	Triple negative Stage III & IV

Information at diagnosis: Stage III & IV

Participants were asked in the online questionnaire how much information they or their family received at diagnosis.

There were 19 participants (50.00%) who had enough information, 16 participants (42.11%) that had some information, but it wasn't enough, and 3 participants (7.89%) had no information (Table 3.24, Figure 3.14).

Table 3.24: Information at diagnosis

Information at diagnosis	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=99	%	n=61	%	n=38	%	n=26	%	n=12	%
Enough information	50	50.51	31	50.82	19	50.00	10	38.46	9	75.00
Some information but it wasn't enough	41	41.41	25	40.98	16	42.11	13	50.00	3	25.00
No information	8	8.08	5	8.20	3	7.89	3	11.54	0	0.00

Information at diagnosis	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=99	%	n=47	%	n=52	%	n=21	%	n=40	%
Enough information	50	50.51	21	42.00	29	55.77	11	52.38	20	50.00
Some information but it wasn't enough	41	41.41	20	40.00	21	40.38	7	33.33	18	45.00
No information	8	8.08	6	12.00	2	3.85	3	14.29	2	5.00

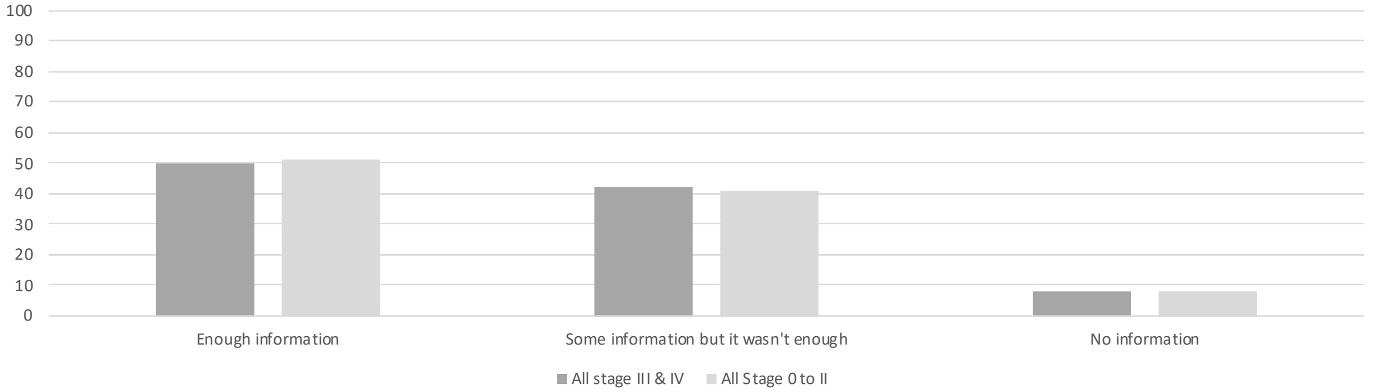


Figure 3.14: Information at diagnosis (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 3.25: Information at diagnosis – Stage III & IV variations

Information at diagnosis	Reported less frequently	Reported more frequently
Enough information	Triple negative Stage III & IV	Hormone receptor Stage III & IV
Some information but it wasn't enough	Hormone receptor Stage III & IV	-

Costs at diagnosis: Stage III & IV

Out of pocket expenses at diagnosis

Participants noted in the online questionnaire the amount of out-of-pocket expenses they had at diagnosis, for example doctors' fees, and diagnostic tests.

There were 10 participants (26.32%) who had no out of pocket expenses, and 10 participants (26.32%) who did not know or could not recall. There were 9 participants (23.68%) that spent Less than $500, 6 participants (15.79%) that spent between $500 to $1000, and 3 participants (7.89%) that spent More than $1000 (Table 3.26, Figure 3.15).

Burden of diagnostic costs

In the follow-up question about the burden of costs at diagnosis, for 30 participants who had out of pocket expenses.

For 15 participants (53.57%) the cost was slightly or not at all significant. For 6 participants (21.43%) the out-of-pocket expenses were somewhat significant, and for 7 participants (25.00%), the burden of out-of-pocket expenses were moderately or extremely significant (Table 3.28, Figure 3.16)

Table 3.26: Out of pocket expenses at diagnosis

Out of pocket expenses for diagnostic tests	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=99	%	n=61	%	n=38	%	n=26	0.00	n=12	%
$0	32	32.32	22	36.07	10	26.32	5	19.23	5	41.67
Less than $500	17	17.17	8	13.11	9	23.68	7	26.92	2	16.67
$500 to $1000	12	12.12	6	9.84	6	15.79	8	30.77	1	8.33
More than $1000	17	17.17	14	22.95	3	7.89	2	7.69	0	0.00
Not sure	21	21.21	11	18.03	10	26.32	4	15.38	4	33.33

Out of pocket expenses for diagnostic tests	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=99	%	n=47	%	n=52	%	n=21	%	n=40	%
$0	32	32.32	13	26.00	19	36.54	8	38.10	14	35.00
Less than $500	17	17.17	10	20.00	7	13.46	3	14.29	5	12.50
$500 to $1000	12	12.12	11	22.00	1	1.92	5	23.81	2	5.00
More than $1000	17	17.17	4	8.00	13	25.00	2	9.52	13	32.50
Not sure	21	21.21	9	18.00	12	23.08	3	14.29	6	15.00

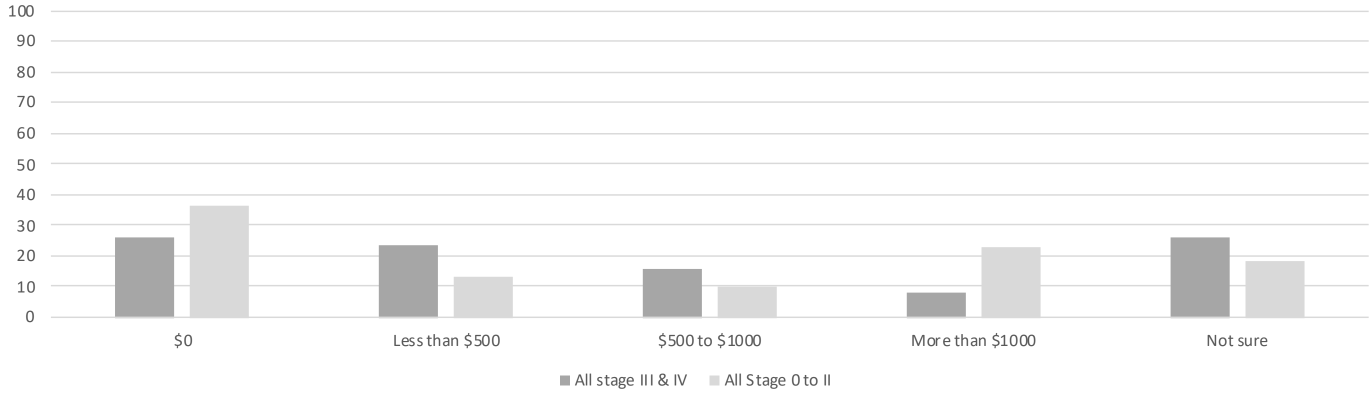


Figure 3.15: Out of pocket expenses at diagnosis (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 3.27: Out of pocket expenses at diagnosis– Stage III & IV variations

Out of pocket expenses for diagnostic tests	Reported less frequently	Reported more frequently
$0	Triple negative Stage III & IV	-
$500 to $1000	--	Triple negative Stage III & IV
More than $1000	Hormone receptor Stage III & IV	-

Table 3.28: Burden of diagnostic costs

Burden of diagnostic costs	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=67	%	n=39	%	n=28	%	n=21	%	n=7	%
Not at all significant	11	16.42	3	7.69	8	28.57	5	23.81	3	42.86
Slightly significant	22	32.84	15	38.46	7	25.00	6	28.57	1	14.29
Somewhat significant	19	28.36	13	33.33	6	21.43	4	19.05	2	28.57
Moderately significant	9	13.43	5	12.82	4	14.29	4	19.05	0	0.00
Extremely significant	6	8.96	3	7.69	3	10.71	2	9.52	1	14.29

Burden of diagnostic costs	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=67	%	n=34	%	n=33	%	n=13	%	n=26	%
Not at all significant	11	16.42	8	23.53	3	9.09	3	23.08	0	0.00
Slightly significant	22	32.84	12	35.29	10	30.30	6	46.15	9	34.62
Somewhat significant	19	28.36	7	20.59	12	36.36	3	23.08	10	38.46
Moderately significant	9	13.43	5	14.71	4	12.12	1	7.69	4	15.38
Extremely significant	6	8.96	2	5.88	4	12.12	0	0.00	3	11.54

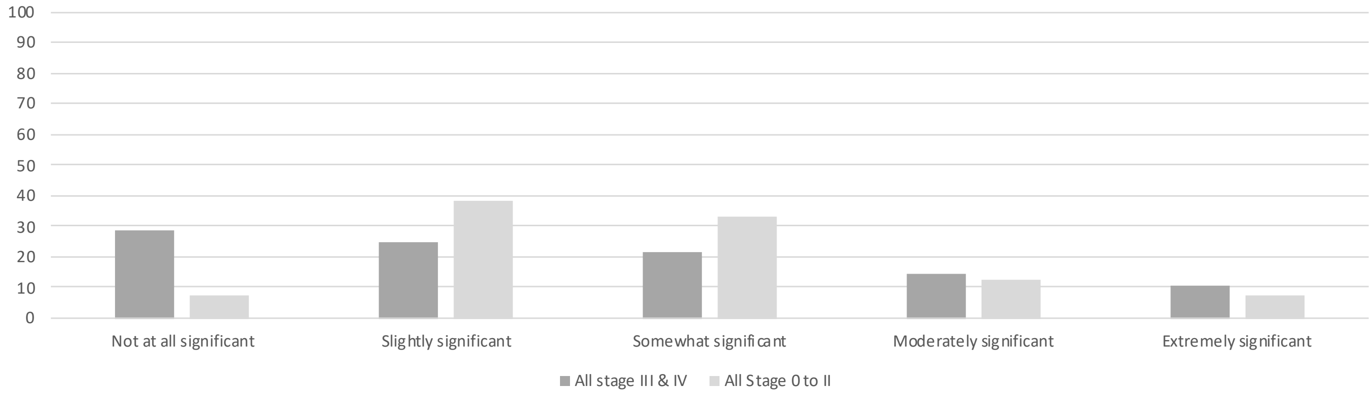


Figure 3.16: Burden of diagnostic costs

Table 3.29: Burden of diagnostic costs– Stage III & IV variations (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Theme	Reported less frequently	Reported more frequently
Not at all significant	-	All Stage III & IV Hormone receptor Stage III & IV
Slightly significant	Hormone receptor Stage III & IV	-
Moderately significant	Hormone receptor Stage III & IV	-

Genetic tests and biomarkers: Stage III & IV

Participants answered questions in the online questionnaire about if they had any discussions with their doctor about biomarkers, genomic and gene testing that might be relevant to treatment. If they did have a discussion, they were asked if they brought up the topic or if their doctor did.

Most commonly, participants had never had a conversation about biomarkers, genomic, or gene testing that might be relevant to treatment, (n=11, 28.95%). There were 5 participants (13.16%) who brought up the topic with their doctor, and 22 participants (57.89%) whose doctor brought up the topic with them (Table 3.30, Figure 3.17).

Participants were then asked if they had had any biomarker, genomic or gene testing. If they had testing, they were asked if they had it as part of a clinical trial, paid for it themselves or if they did not have to pay for it. Those that did not have the test were asked if they were interested in this type of test.

The majority of participants did not have any genetic or biomarker tests but would like to (n=12, 31.58%). There was one participant (2.63%) who did not have these tests and was not interested in them, and a total of 25 participants (65.79%) that had biomarker tests (Table 3.32, Figure 3.18).

Table 3.30: Discussions about biomarkers

Discussions about biomarkers	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=99	%	n=61	%	n=38	%	n=26	%	n=12	%
Participant brought up the topic with doctor for discussion	21	21.21	16	26.23	5	13.16	3	11.54	2	16.67
Doctor brought up the topic with participant for discussion	49	49.49	27	44.26	22	57.89	13	50.00	9	75.00
Participant had no discussion about this type of test	29	29.29	18	29.51	11	28.95	10	38.46	1	8.33

Discussions about biomarkers	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=99	%	n=47	%	n=52	%	n=21	%	n=40	%
Participant brought up the topic with doctor for discussion	21	21.21	7	14.00	14	26.92	4	19.05	12	30.00
Doctor brought up the topic with participant for discussion	49	49.49	27	54.00	22	42.31	14	66.67	13	32.50
Participant had no discussion about this type of test	29	29.29	13	26.00	16	30.77	3	14.29	15	37.50

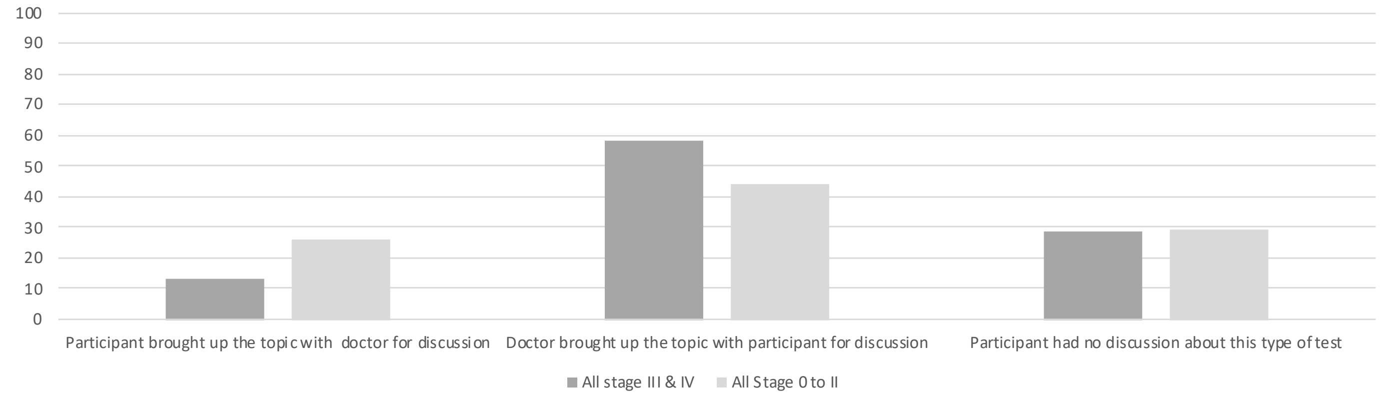


Figure 3.17: Discussions about biomarkers (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 3.31: Discussions about biomarkers– Stage III & IV variations

Discussions about biomarkers	Reported less frequently	Reported more frequently
Doctor brought up the topic with participant for discussion	-	Hormone receptor Stage III & IV
Participant had no discussion about this type of test	Hormone receptor Stage III & IV	-

Table 3.32: Experience of genetic tests and biomarkers

Experience of genetic tests and biomarkers	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=99	%	n=61	%	n=38	%	n=26	%	n=12	%
Participant had this test and did not have to pay out of pocket for it	42	42.42	23	37.70	19	50.00	12	46.15	7	58.33
Participant had this test athrough a clinical trial	3	3.03	0	0.00	3	7.89	0	0.00	3	25.00
Participant had this type of test and paid for it	8	8.08	5	8.20	3	7.89	3	11.54	0	0.00
Participant did not have this test and is not interested in it	6	6.06	5	8.20	1	2.63	1	3.85	0	0.00
Participant did not have this test but would like to	40	40.40	28	45.90	12	31.58	10	38.46	2	16.67

Experience of genetic tests and biomarkers	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=99	%	n=47	%	n=52	%	n=21	%	n=40	%
Participant had this test and did not have to pay out of pocket for it	42	42.42	28	56.00	14	26.92	16	76.19	7	17.50
Participant had this test athrough a clinical trial	3	3.03	0	0.00	3	5.77	0	0.00	0	0.00
Participant had this type of test and paid for it	8	8.08	4	8.00	4	7.69	1	4.76	4	10.00
Participant did not have this test and is not interested in it	6	6.06	1	2.00	5	9.62	0	0.00	5	12.50
Participant did not have this test but would like to	40	40.40	14	28.00	26	50.00	4	19.05	24	60.00

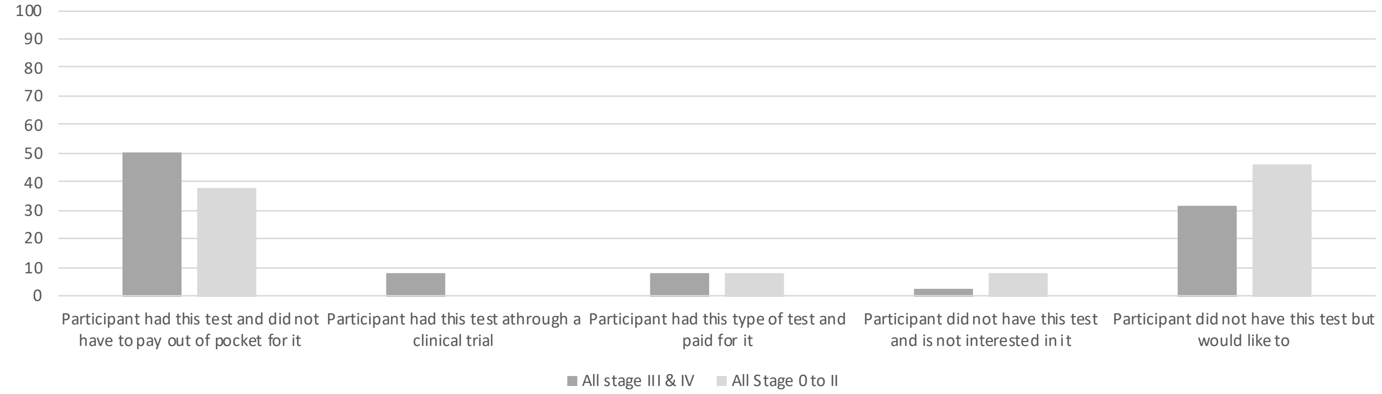


Figure 3.18: Experience of genetic tests and biomarkers (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 3.33: Experience of genetic tests and biomarkers – Stage III & IV variations

Experience of genetic tests and biomarkers	Reported less frequently	Reported more frequently
Participant had this test and did not have to pay out of pocket for it	-	Hormone receptor Stage III & IV
Participant had this test athrough a clinical trial	-	Hormone receptor Stage III & IV
Participant did not have this test but would like to	Hormone receptor Stage III & IV	-

Current symptoms: Stage III & IV

Number of current symptoms

Almost half of the participants had symptoms to deal with at the time of completing the questionnaire (n=18, 47.37%). Participants had between 3 to 11 symptoms (Table 3.34, Figure 3.19).

Type of current symptoms

The most common current symptoms, were fatigue (n=18, 47.37%), thinking and memory problem (n=17, 44.74%), weight and muscle changes (n=16, 42.11%), Pain (n=16, 42.11%), depression/depressed mood (n=15, 39.47%), and sleep problems (n=14, 36.84%) (Table 3.36, Figure 3.20).

Table 3.34: Number of current symptoms

Number of current symptoms	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=101	%	n=63	%	n=38	%	n=27	%	n=11	%
No symptoms	56	55.45	36	57.14	20	52.63	15	55.56	5	45.45
1 to 2	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
3 to 4	1	0.99	1	1.59	0	0.00	0	0.00	0	0.00
5 to 6	6	5.94	3	4.76	3	7.89	3	11.11	0	0.00
7 to 8	11	10.89	5	7.94	6	15.79	5	18.52	1	9.09
9 to 10	17	16.83	13	20.63	4	10.53	1	3.70	3	27.27
11 or more	10	9.90	5	7.94	5	13.16	3	11.11	2	18.18

Number of current symptoms	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=101	%	n=50	%	n=51	%	n=23	%	n=40	%
No symptoms	56	55.45	29	58.00	27	52.94	14	60.87	22	55.00
1 to 2	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
3 to 4	1	0.99	0	0.00	1	1.96	0	0.00	1	2.50
5 to 6	6	5.94	4	8.00	2	3.92	1	4.35	2	5.00
7 to 8	11	10.89	7	14.00	4	7.84	2	8.70	3	7.50
9 to 10	17	16.83	6	12.00	11	21.57	5	21.74	8	20.00
	10	9.90	4	8.00	6	11.76	1	4.35	4	10.00

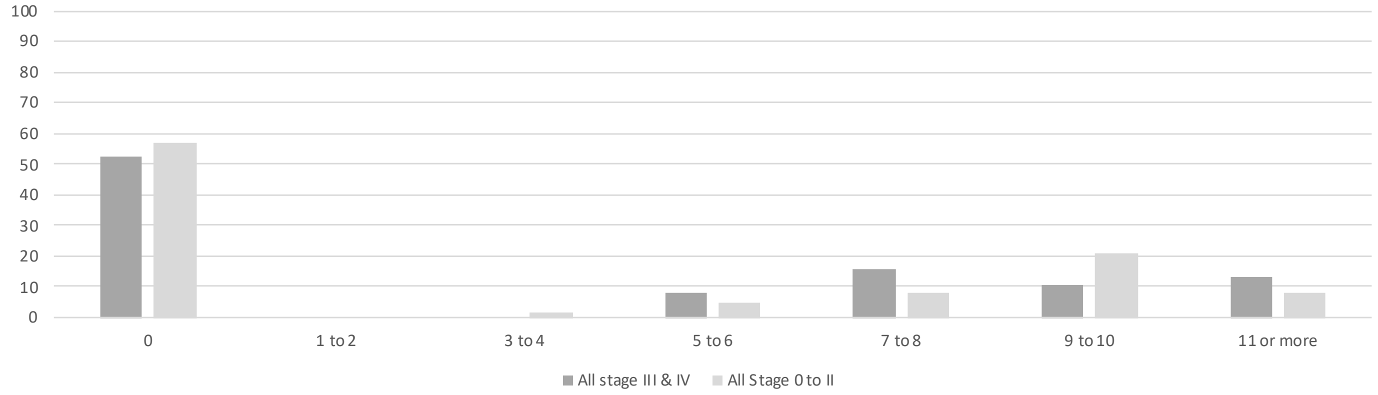


Figure 3.19: Number of current symptoms (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 3.35: Number of current symptoms– Stage III & IV variations

Number of current symptoms	Reported less frequently	Reported more frequently
9 to 10	Triple negative Stage III & IV	Hormone receptor Stage III & IV

Table 3.36: Type of current symptoms

Type of current symptoms	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=101	%	n=63	%	n=38	%	n=27	%	n=11	%
Anxiety	42	41.58	24	38.10	18	47.37	12	44.44	6	54.55
Fatigue	44	43.56	26	41.27	18	47.37	12	44.44	6	54.55
Thinking and memory problem	42	41.58	25	39.68	17	44.74	11	40.74	6	54.55
Weight and muscle changes	41	40.59	25	39.68	16	42.11	10	37.04	6	54.55
Pain	41	40.59	25	39.68	16	42.11	10	37.04	6	54.55
Depression	38	37.62	23	36.51	15	39.47	10	37.04	5	45.45
Sleep problems	40	39.60	26	41.27	14	36.84	9	33.33	5	45.45
Sexual function	34	33.66	21	33.33	13	34.21	8	29.63	5	45.45
Bone problems	32	31.68	20	31.75	12	31.58	7	25.93	5	45.45
Bladder problems	12	11.88	7	11.11	5	13.16	4	14.81	1	9.09

Type of current symptoms	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=101	%	n=50	%	n=51	%	n=23	%	n=40	%
Anxiety	42	41.58	21	42.00	21	41.18	9	39.13	15	37.50
Fatigue	44	43.56	21	42.00	23	45.10	9	39.13	17	42.50
Thinking and memory problem	42	41.58	20	40.00	22	43.14	9	39.13	16	40.00
Weight and muscle changes	41	40.59	18	36.00	23	45.10	8	34.78	17	42.50
Pain	41	40.59	18	36.00	23	45.10	8	34.78	17	42.50
Depression	38	37.62	19	38.00	19	37.25	9	39.13	14	35.00
Sleep problems	40	39.60	17	34.00	23	45.10	8	34.78	18	45.00
Sexual function	34	33.66	14	28.00	20	39.22	6	26.09	15	37.50
Bone problems	32	31.68	14	28.00	18	35.29	7	30.43	13	32.50
Bladder problems	12	11.88	6	12.00	6	11.76	2	8.70	5	12.50

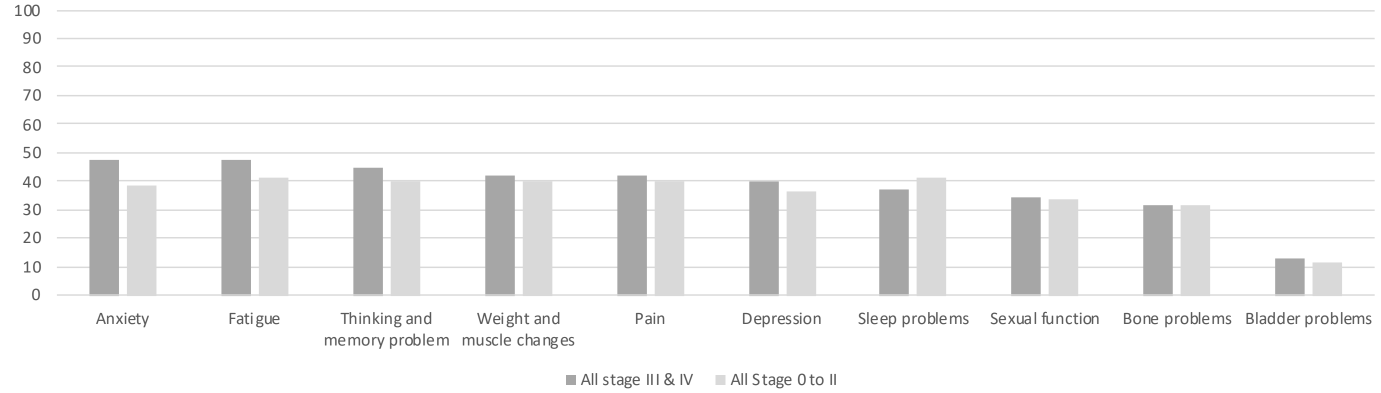


Figure 3.20: Type of current symptoms (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 3.37: Type of current symptoms– Stage III & IV variations

Type of current symptoms	Reported less frequently	Reported more frequently
Anxiety/anxious mood	-	Hormone receptor Stage III & IV
Fatigue	-	Hormone receptor Stage III & IV
Thinking and memory problem	-	Hormone receptor Stage III & IV
Weight and muscle changes	-	Hormone receptor Stage III & IV
Pain	-	Hormone receptor Stage III & IV
Sexual function/ability to have intimate relationships	-	Hormone receptor Stage III & IV
Bone problems	-	Hormone receptor Stage III & IV

Understanding of prognosis: Stage III & IV

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. The most common responses were that there was no evidence of disease or that they are in remission (48.72%), and in relation to statistics or survival rates (28.21%). Other themes included that they would likely have a recurrence, or were in a cycle of recurrence (28.21%), that their prognosis was positive, that their condition is manageable (23.08%), and that they were monitoring their condition until there is an exacerbation or progression (20.51%).

Participant describes prognosis in relation to there being no evidence of disease or that they are in remission

Well, I am cancer-free at the moment. I have triple-negative breast cancer. My understanding is that the first two years are the most critical, and then after that, you get to the five-year mark and then hopefully not going to come back. Participant_027TNG

Look, I think in the scheme of things, I'm doing really well on treatment. At my last two PET scans, which were in April this year and October, November last year, my spinal lesions had completely resolved, all my bone lesions have resolved, and my lymph nodes lesions, well, the swollen lymph nodes, there's no evidence of any active disease anywhere in my body, and my cancer markers are back down to the normal range. Participant_050TNG

Yes, they're really good. I'm cancer-free my oncologist says as far as they can say that. Participant_043TNG

Participant describes prognosis in relation to statistics or survival rates

Well, since then I have been diagnosed with the PALB2 gene, once, I got that diagnosis, the specialist told me that it was more likely that the cancer would return because I had the gene. I had a double mastectomy and reconstruction. Later on, the risk for the PALB2 gene of ovarian cancer increased. Last year I had a hysterectomy and my ovaries removed. Now I've got *less risk than the general population of getting breast cancer again because of both procedures. Participant_037TNG*

I'm six years since diagnosis, so I'm the same risk as the rest of the population. Participant_040TNG

Yes. I have triple-negative breast cancer, which I thought I was going to be clear after five years, but they did say that triple-negative can take up to 10 years before you can actually say you're in the clear. I've still got another three years of that to go. Participant_024TNG

Participant describes prognosis in relation to probable recurrence, or cycle of recurrence

Yes. At the moment, I've had really good reactions to all of my treatments. I have apparently, like a 15% chance of it coming back. I'm now officially two years since my diagnosis. I've got another three years to go before I'm technically, go back to the same percentage of getting cancer, go back to the same percentage as someone else in the general population of having cancer. Participant_025TNG

Yes. I'm currently undergoing an oral chemo now just to clean up if there's any residual. I will undergo monitoring for the next few years really and because of the type that I have, which is triple-negative, the chances of reoccurrence is extremely high, so I need to have that monitoring. Then, as the years go on, the chances decrease of it recurring. Participant_030TNG

Favorable. I think when the oncologist explained it to me, he said that they are getting it down to probably in the realm of potential 15% chance of recurrence. Participant 050_2021AUHRP

Participant describes prognosis in a positive way, that their condition is manageable

Yes. I'm currently undergoing an oral chemo now just to clean up if there's any residual. I will undergo monitoring for the next few years really and because of the type that I have, which is triple-negative, the chances of reoccurrence is extremely high, so I need to have that monitoring. Then, as the years go on, the chances decrease of it recurring. Participant_030TNG

It's very positive. After chemo and then surgery, I had a PCR, a pathological complete response to chemo, which there were no signs of the cancer afterwards, which resulted in doing 16 radiation sessions instead of further. They didn't even do radiation under my arm because there was no node involvement. Nobody will tell you what your outlook is, they can't but it is all very positive. Participant_029TNG

At the moment, I'm pretty good. I've got a few secondaries, but nothing that they can't control at the moment. Participant_032TNG

Participant describes prognosis in relation to monitoring their condition until there is an exacerbation or progression

Yes. I've had pathological complete results, so no evidence of disease anymore. All being clear. I've had a double mastectomy and do a reconstruction at the same time. At the moment, it's just three monthly checkups with oncologists and my breast surgeon. I have had lots of nerve issues from having that done. I've got an ongoing treatment for that. Participant_036TNG

Yes, so I can, I've finished all of the testings, and I'm now on surveillance. I have three months check-in with either a medical oncologist or radiation oncologist, or my surgeon. I'm not what they call a complete pathological response, like a negative, to say you absolutely got no cancer. Some distance surveillance to say, "Look, we've treated it, technically, we don't know if it's going to come back or not. It shouldn't come back because you've had all the treatments, but you are at risk." Participant_047TNG

Well, if I follow the statistics of triple negative breast cancer, I'm still not to my five year my five year clearance. So I'm still being monitored for recurrence. But if you don't look at the statistics and you go by my general health and wellbeing and my prognosis for the future is very good because I'm very healthy, I'm very active, I feel good. We don't have any sort of concerns other than ongoing issues from chemotherapy, not you get achy joints and all that sort of stuff that every time you get a bit of a bike or something, you think, oh, my God, is that cancer. Participant_044TNG

Table 3.38: Understanding of prognosis

Understanding of prognosis	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes prognosis in relation to there being no evidence of disease or that they are in remission	49	48.04	30	47.62	19	48.72	11	40.74	8	66.67
Participant describes prognosis in relation to statistics or survival rates	37	36.27	26	41.27	11	28.21	9	33.33	2	16.67
Participant describes prognosis in relation to probable recurrence, or cycle of recurrence	30	29.41	19	30.16	11	28.21	8	29.63	3	25.00
Participant describes prognosis in a positive way, that their condition is manageable	31	30.39	22	34.92	9	23.08	3	11.11	6	50.00
Participant describes prognosis in relation to monitoring their condition until there is an exacerbation or progression	17	16.67	9	14.29	8	20.51	7	25.93	1	8.33
Participant describes prognosis in relation to specific timeframe that they are expected to live	2	1.96	2	3.17	0	0.00	0	0.00	0	0.00
Participant describes prognosis in relation to poor outcomes, or terminal condition	2	1.96	2	3.17	0	0.00	0	0.00	0	0.00
Participant describes prognosis in a positive way, that it is curable with treatment	1	0.98	1	1.59	0	0.00	0	0.00	0	0.00

Understanding of prognosis	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes prognosis in relation to there being no evidence of disease or that they are in remission	49	48.04	26	52.00	23	44.23	15	65.22	15	37.50
Participant describes prognosis in relation to statistics or survival rates	37	36.27	18	36.00	19	36.54	9	39.13	17	42.50
Participant describes prognosis in relation to probable recurrence, or cycle of recurrence	30	29.41	14	28.00	16	30.77	6	26.09	13	32.50
Participant describes prognosis in a positive way, that their condition is manageable	31	30.39	7	14.00	24	46.15	4	17.39	18	45.00
Participant describes prognosis in relation to monitoring their condition until there is an exacerbation or progression	17	16.67	11	22.00	6	11.54	4	17.39	5	12.50
Participant describes prognosis in relation to specific timeframe that they are expected to live	2	1.96	0	0.00	2	3.85	0	0.00	2	5.00
Participant describes prognosis in relation to poor outcomes, or terminal condition	2	1.96	0	0.00	2	3.85	0	0.00	2	5.00
Participant describes prognosis in a positive way, that it is curable with treatment	1	0.98	0	0.00	1	1.92	0	0.00	1	2.50

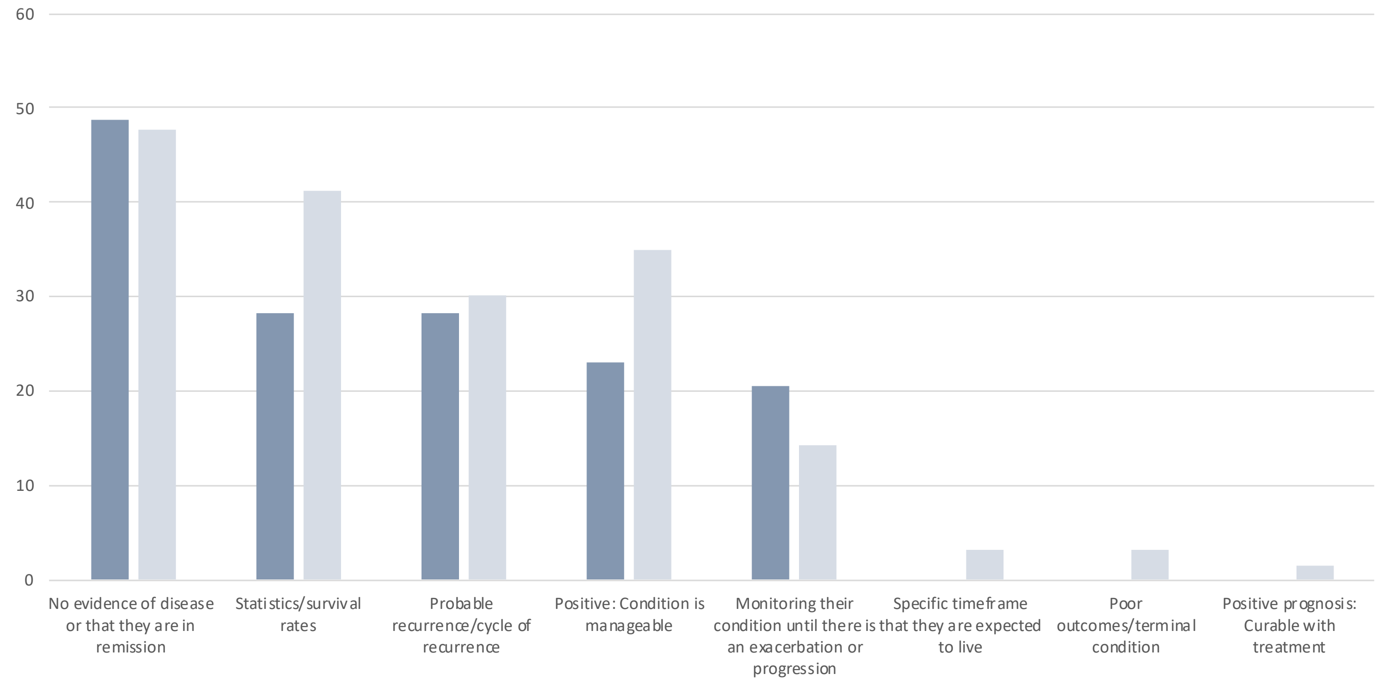


Figure 3.21: Understanding of prognosis (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 3.39: Understanding of prognosis – Stage III & IV variations

Understanding of prognosis	Reported less frequently	Reported more frequently
Participant describes prognosis in relation to there being no evidence of disease or that they are in remission	-	Hormone receptor Stage III & IV
Participant describes prognosis in relation to statistics or survival rates	Hormone receptor Stage III & IV	-
Participant describes prognosis in a positive way, that their condition is manageable	Triple negative Stage III & IV	Hormone receptor Stage III & IV

Section 4

Decision-making

Section 4 summary

Discussions about treatment: Stage III & IV

Participants were asked to recall what treatment options they were presented with and how they felt about the options. Participants most commonly were presented with multiple options (74.36%), and one treatment option (17.95%). This was followed by no discussions about treatment (2.56 %).

Discussions about treatment (Participation in discussions): Stage III & IV

For those with a single treatment option, most commonly they were told what to do without discussion (15.38%), did not participate in the decision-making process (5.13%), and felt rushed and/or overwhelmed in the decision-making process (2.56 %). Other themes included had a medical emergency/urgent treatment required (2.56%), and changed clinician as they were not satisfied with discussion, lack of empathy and/or options presented (2.56%).

For those presented with multiple treatment options, most commonly they participated in the decision-making process (28.21%), they did not participate in the decision-making process (28.21%), and they were told what to do without discussion (20.51 %). Other themes included they were comfortable deferring to doctor/accept recommended approach (10.26%), and they felt rushed and/or overwhelmed in the decision-making process (5.13%).

Considerations when making decisions: Stage III & IV: Stage III & IV

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were advice of their clinician (33.33%), side effects (23.08%), and efficacy (20.51 %). Other themes included quality of life (15.38%), survival benefit (10.26%), cost (10.26%), statistics or treatment outcomes (7.69%), impact on their family or dependents (7.69%), and ease of treatment administration (2.56%).

Decision-making over time: Stage III & IV

Participants were asked if the way they made decisions had changed over time. The most common responses were that they had changed the way they make decisions (41.03%), and not changed the way they make decisions (51.28%).

Where participants had changed the way they make decisions, the most common reasons were that they were more informed and/or more assertive (25.64%), more proactive (2.56%), and more focused on quality of life (2.56 %).

Where participants had changed the way they make decisions, the most common reasons were that they were does not mention any reason (15.38%), always been informed/assertive (15.38%), and always taken advice of clinicians (5.13 %).

Personal goals of treatment or care: Stage III & IV

Participants were asked what their own personal goals of treatment or care were. The most common responses were to minimise or avoid side effects (28.21%), treat the disease and get better (17.95%), and be cancer free, avoid recurrence, increase longevity (15.38 %). Other themes included get through medical treatment (12.82%), live independently (10.26%), improvements in mental and emotional health (10.26%), have physical improvements in their condition (5.13%), survival (5.13%), and have quality of life/return to normality (2.56%).

Others described that they had no personal goals of treatment or care as they weren't aware of anything they could do to improve their condition (7.69%), and they had no personal goals of treatment or care (no reason given) (5.13 %).

Discussions about treatment: Stage III & IV

Participants were asked to recall what treatment options they were presented with and how they felt about the options. Participants most commonly were presented with multiple options (74.36%), and one treatment option (17.95%). This was followed by no discussions about treatment (2.56 %).

Participant describes multiple options being presented

When I first saw the surgeon and he booked me in pretty much straight away for surgery, and there wasn't really a discussion around other options it was a case of, "You will need surgery, you will need chemo, and you will need radiation for this type of cancer and this is what we do." I was booked in for surgery, and then while doing a little bit of investigating I found a triple-negative trial that was taking place at our local hospital. I followed that up to see if I'd be a participant for the trial. I met with the trial's team and the oncologist because I wanted to see if that was my only option. The trial was for neoadjuvant chemo and immunotherapy. Sadly, I wasn't eligible because the cancer was too far advanced for what they needed. However, those discussions led me to choose to do the chemo first before surgery, but I hadn't known that was an option at the beginning. It was just, "This is what we'll do. It will be surgery, chemo, radiation." Participant_033TNG

I did go to my-- Well, I was referred to a specialist, obviously, my breast surgeon, and he discussed the options with chemoradiation. Basically, preserving, I guess it was, so it wasn't like the mastectomy or anything but to do the lumpectomy and then decide on the treatment after those results have come back Participant_024TNG

My GP didn't really talk about treatment plans because she was basically like, "That's what your breast surgeon and your team will talk to you about." It was really my breast surgeon that spoke to me about it and explained that I would need surgery, I would need chemotherapy because of the type of cancer it was, and then there was a high likelihood that we would need radiation. Participant_025TNG

Participant describes one option being presented

The only one conversation I had was removal. They had to remove both breasts. That's all. They didn't suggest anything else, not a thing. Participant_032TNG

Basically that I had to start chemo as soon as possible. I didn't really have a choice because my cancer was very aggressive and it was very large. It had already travelled to the lymph nodes. They just basically said the smaller they can get it, the safer it would be to have surgery. They really didn't give me an option, in the sense that it was too big and it was growing too fast. They believed that that was the safest and best option for me. Participant_046TNG

Table 4.1: Discussions about treatment

Discussions about treatment	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes multiple options being presented	81	79.41	52	82.54	29	74.36	20	74.07	9	75.00
Participant describes one option being presented	16	15.69	9	14.29	7	17.95	4	14.81	3	25.00
Participant describes no treatments being discussed	1	0.98	0	0.00	1	2.56	1	3.70	0	0.00
Other	2	1.96	1	1.59	1	2.56	1	3.70	0	0.00

Discussions about treatment	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes multiple options being presented	81	79.41	38	76.00	43	82.69	18	78.26	34	85.00
Participant describes one option being presented	16	15.69	8	16.00	8	15.38	4	17.39	5	12.50
Participant describes no treatments being discussed	1	0.98	1	2.00	0	0.00	0	0.00	0	0.00
Other	2	1.96	2	4.00	0	0.00	1	4.35	0	0.00

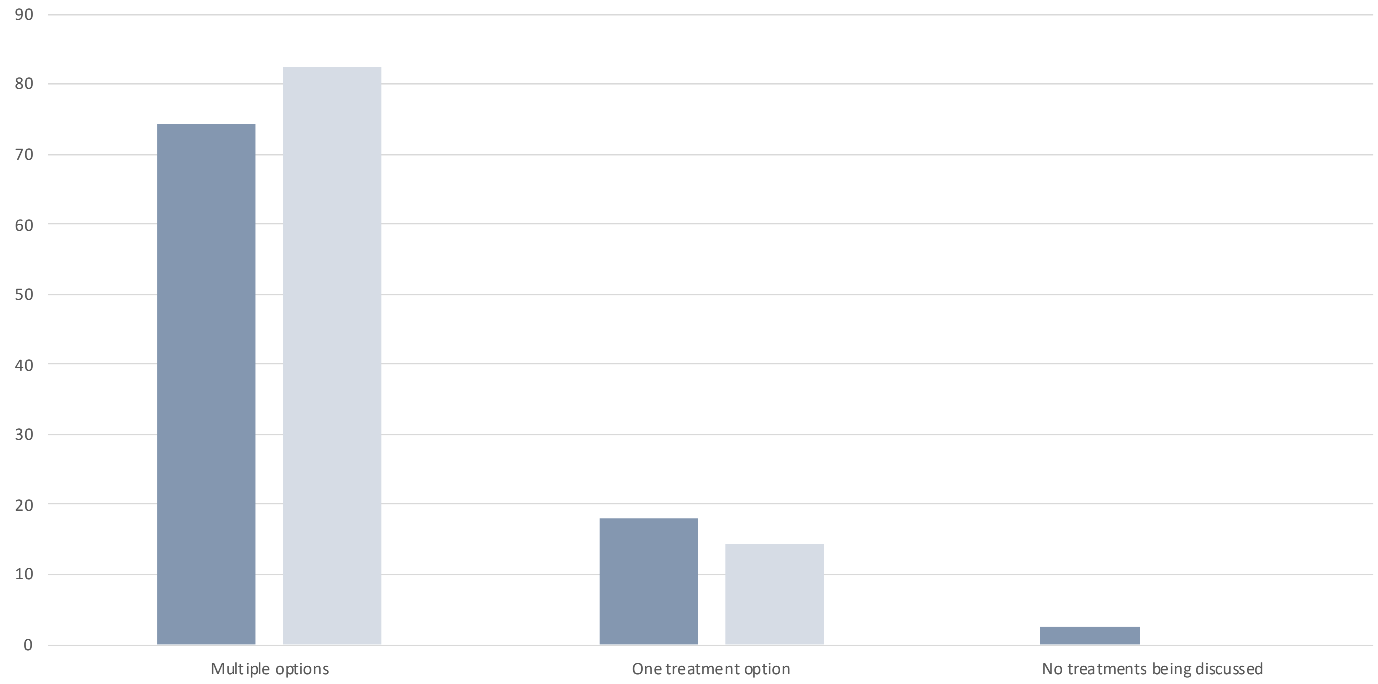


Figure 4.1: Discussions about treatment (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Discussions about treatment (Participation in discussions): Stage III & IV

For those with a single treatment option, most commonly they were told what to do without discussion (15.38%), did not participate in the decision-making process (5.13%), and felt rushed and/or overwhelmed in the decision-making process (2.56 %). Other themes included had a medical emergency/urgent treatment required (2.56%), and changed clinician as they were not satisfied with discussion, lack of empathy and/or options presented (2.56%).

For those presented with multiple treatment options, most commonly they participated in the decision-making process (28.21%), they did not participate in the decision-making process (28.21%), and they were told what to do without discussion (20.51 %). Other themes included they were comfortable deferring to doctor/accept recommended approach (10.26%), and they felt rushed and/or overwhelmed in the decision-making process (5.13%).

Participant describes being presented with multiple options and participated in the decision-making process

Well, the other thing I forgot to tell you is that I have a triple-negative tumour. DOCTOR explained to me that because that is the type of tumour that's most likely to recur and it was Stage 3, Grade 3, so fast-growing, aggressive. She explained that it was going to need quite aggressive treatment as well. She was very, very good at explaining what I would need and why. It was very clear to me the reasons why I was going to need six months of chemo, and mastectomy, and radiation, because of the type and how much the tumour had progressed. Participant_041TNG

First diagnosed, I was driving to the surgeon's office that night booking surgery for five days time. He gave me the option of whether I wanted a lumpectomy, which would be followed up with radiation or mastectomy in which case radiation would not be required for my diagnosis. He gave statistics that differed by 1%, between the two options. At that point, I still thought I had what mum had. Mum had had a lumpectomy and mum had had radiation and she was perfectly fine 13 years later. I, at that point, chose the lumpectomy, followed by radiation being the less invasive option being that I was still young, I'd still keep my boob and I wasn't at all concerned about the radiation.
Some people are terrified of radiation, but I actually work with it, so that was not a bother at all. For me, it was justified to treat what was needed. After that, I was told that I needed chemo. I was not aware up front that I would need chemo. It wasn't until after the surgery and I got the results of the surgery, but I understand that a triple negative diagnosis under the

age of 40, chemo is given. It was always on the cards, but it was not mentioned. Participant_048TNG

The surgeon said sent me straight off to the oncologist said, there was nothing for him to treat, so he sent me up to my oncologist who went through all of the-- He was a very good communicator, and he went through all of the tests results with me in detail and showed me the scan and then talked about treatment options, and he recommended that through the treatment that I have been following is the best option for me at the time, but talked a little bit around other things I could do, but said he strongly recommend going down the particular path that I did. Participant_050TNG

Participant describes being presented with multiple options but did not participate in the decision-making process

When I was given the diagnosis, my specialist had already spoken to an oncologist that was based in my hometown and they actually had a working relationship previously. She had already discussed with him what the options will be, so I knew ahead of time what was going to happen. I didn't really have options as such. I was just told what it would need to be and due to the nature and the size of it, it just had to get done. I didn't have time to look at the scope of it and what other options were there. Participant_030TNG

When I first saw the surgeon and he booked me in pretty much straight away for surgery, and there wasn't really a discussion around other options it was a case of, "You will need surgery, you will need chemo, and you will need radiation for this type of cancer and this is what we do." Participant_033TNG

There wasn't any options. I was just told what treatments I was having. I think because I was in shock, I did what they told me to do. I probably didn't ask enough questions about other treatments. I just thought, "Well, they're the experts. I'll do what I'm being told to do." Participant_045TNG

Participant describes being presented with multiple options, however, they were told what to do without discussion

I was just basically told by the oncologists that these were the treatments I had to have. There wasn't really that much of a discussion. It was like, "We have a medical team and they all get together and they decide what sort of treatment is best for you, blah, blah, blah." When I went in to see the oncologist the first time, they had already mapped out a treatment plan for me, basically. Participant_028TNG

I don't actually think I was given an option. I was told because it was triple-negative the best option was to have chemo first. They told me that it was chemo and then a lumpectomy and that was it. Participant_035TNG

Participant describes being presented with multiple options, and were comfortable deferring to doctor/accept recommended approach

There wasn't any options. I was just told what treatments I was having. I think because I was in shock, I did what they told me to do. I probably didn't ask enough questions about other treatments. I just thought, "Well, they're the experts. I'll do what I'm being told to do. Participant_045TNG

The only conversation I had was just with the after being referred to an oncologist or first off, the breast surgeon decided that if the lumpectomy was okay, there would be a sign of having to have a mastectomy. But then I got referred to the oncologist and then basically I just got told that with my type of breast cancer, the best treatment would be chemotherapy and radiation. And I knew nothing else. So I just went with what he said. Participant_049TNG

Participant describes being presented with one option/approach, that they were told what to do without discussion

We went just bang, bang, bang. This is what we're doing. We didn't even discuss like a full mastectomy or anything. He just said partial, and I trusted him completely. Participant 027_2021AUHRP

The only one conversation I had was removal. They had to remove both breasts. That's all. They didn't suggest anything else, not a thing. Participant 032_2021AUHRP

Table 4.3: Discussions about treatment (Participation in discussions)

Discussions about treatment (Participation in discussions)	**All participants**		**All Stage 0 to II**		**All Stage III & IV**		**Triple negative Stage III & IV**		**Hormone receptor Stage III & IV**	
	n=102	**%**	**n=63**	**%**	**n=39**	**%**	**n=27**	**%**	**n=12**	**%**
Participant describes being presented with multiple options and participated in the decision-making process	38	37.25	27	42.86	11	28.21	**7**	**25.93**	4	33.33
Participant describes being presented with multiple options but did not participate in the decision-making process	30	29.41	19	30.16	11	28.21	7	25.93	4	33.33
Participant describes being presented with multiple options, however, they were told what to do without discussion	18	17.65	10	15.87	8	20.51	7	25.93	1	8.33
Participant describes being presented with multiple options, and were comfortable deferring to doctor/accept recommended approach	5	4.90	1	1.59	4	10.26	4	14.81	0	0.00
Participant describes being presented with multiple options, however felt rushed and/or overwhelmed in the decision-making process	4	3.92	2	3.17	2	5.13	2	7.41	0	0.00
Participant describes being presented with multiple options, however changed clinician as they were not satisfied with discussion, lack of empathy and/or options presented	1	0.98	1	1.59	0	0.00	0	0.00	0	0.00
Participant describes being presented with one option/approach, that they were told what to do without discussion	11	10.78	5	7.94	6	15.38	4	14.81	2	16.67
Participant describes being presented with one option/approach and did not participate in the decision-making process	4	3.92	2	3.17	2	5.13	0	0.00	**2**	**16.67**
Participant describes being presented with one option/approach, and felt rushed and/or overwhelmed in the decision-making process	1	0.98	0	0.00	1	2.56	1	3.70	0	0.00
Participant describes being presented with one option/approach because it was a medical emergency/urgent treatment required	1	0.98	0	0.00	1	2.56	1	3.70	0	0.00
Participant describes being presented with one option, however changed clinician as they were not satisfied with discussion, lack of empathy and/or options presented	1	0.98	0	0.00	1	2.56	1	3.70	0	0.00
Participant describes being presented with one option/approach, and had some but very little discussion	2	1.96	2	3.17	0	0.00	0	0.00	0	0.00
Participant describes being presented with one option/approach and that they participated in the decision-making process	3	2.94	3	4.76	0	0.00	0	0.00	0	0.00
Participant describes being presented with one option/approach, and that they wanted more discussion or options	1	0.98	1	1.59	0	0.00	0	0.00	0	0.00

Discussions about treatment (Participation in discussions)	**All participants**		**All Triple negative**		**All Hormone receptor**		**Triple negative Stage 0 to II**		**Hormone receptor Stage 0 to II**	
	n=102	**%**	**n=50**	**%**	**n=52**	**%**	**n=23**	**%**	**n=40**	**%**
Participant describes being presented with multiple options and participated in the decision-making process	38	37.25	17	34.00	21	40.38	10	43.48	17	42.50
Participant describes being presented with multiple options but did not participate in the decision-making process	30	29.41	13	26.00	17	32.69	6	26.09	13	32.50
Participant describes being presented with multiple options, however, they were told what to do without discussion	18	17.65	13	26.00	5	9.62	6	26.09	4	10.00
Participant describes being presented with multiple options, and were comfortable deferring to doctor/accept recommended approach	5	4.90	5	10.00	0	0.00	1	4.35	0	0.00
Participant describes being presented with multiple options, however felt rushed and/or overwhelmed in the decision-making process	4	3.92	4	8.00	0	0.00	2	8.70	0	0.00
Participant describes being presented with multiple options, however changed clinician as they were not satisfied with discussion, lack of empathy and/or options presented	1	0.98	1	2.00	0	0.00	1	4.35	0	0.00
Participant describes being presented with one option/approach, that they were told what to do without discussion	11	10.78	7	14.00	4	7.69	3	13.04	2	5.00
Participant describes being presented with one option/approach and did not participate in the decision-making process	4	3.92	0	0.00	4	7.69	0	0.00	2	5.00
Participant describes being presented with one option/approach, and felt rushed and/or overwhelmed in the decision-making process	1	0.98	1	2.00	0	0.00	0	0.00	0	0.00
Participant describes being presented with one option/approach because it was a medical emergency/urgent treatment required	1	0.98	1	2.00	0	0.00	0	0.00	0	0.00
Participant describes being presented with one option, however changed clinician as they were not satisfied with discussion, lack of empathy and/or options presented	1	0.98	1	2.00	0	0.00	0	0.00	0	0.00
Participant describes being presented with one option/approach, and had some but very little discussion	2	1.96	2	4.00	0	0.00	2	8.70	0	0.00
Participant describes being presented with one option/approach and that they participated in the decision-making process	3	2.94	1	2.00	2	3.85	1	4.35	2	5.00
Participant describes being presented with one option/approach, and that they wanted more discussion or options	1	0.98	1	2.00	0	0.00	1	4.35	0	0.00

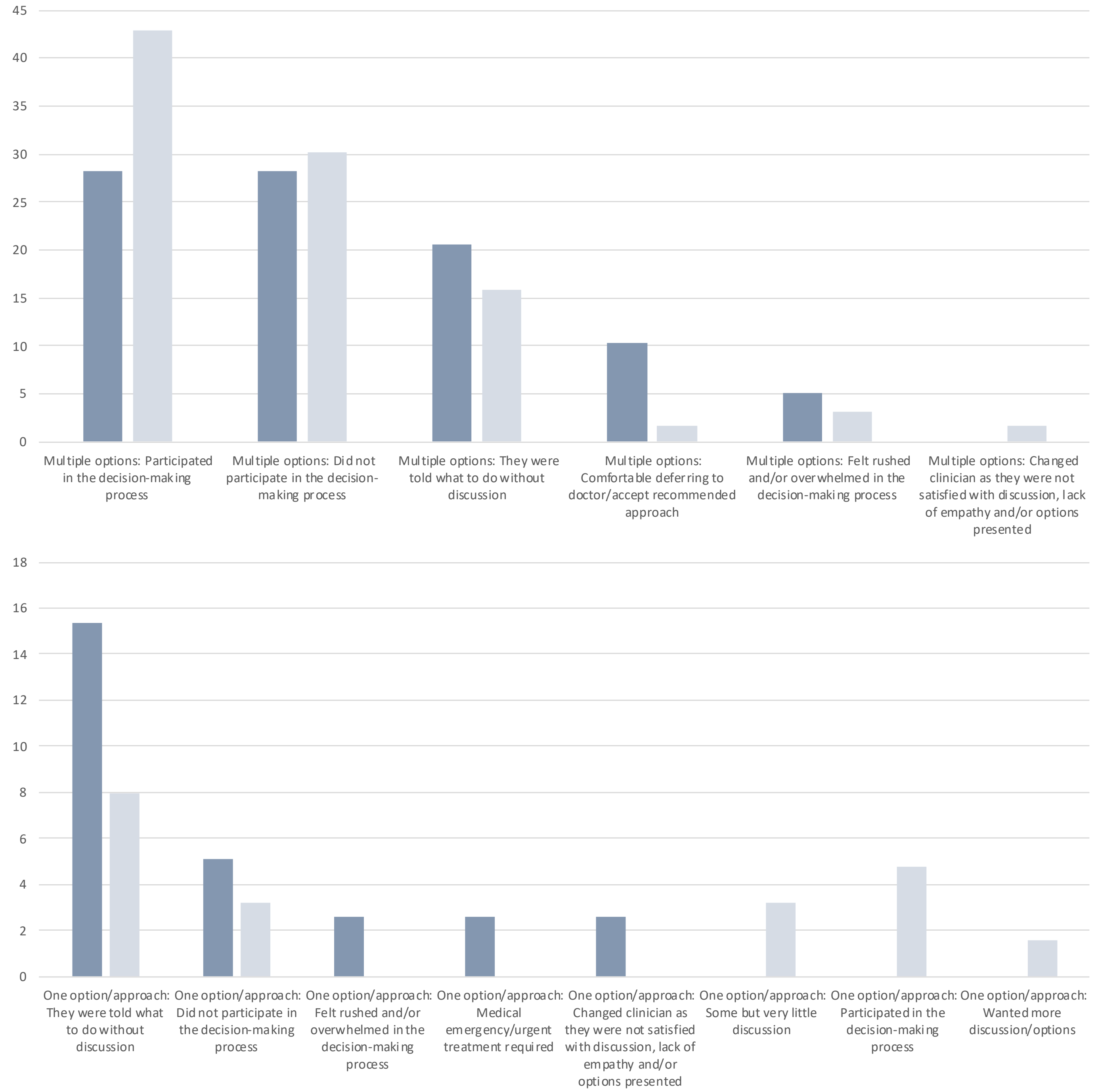


Figure 4.2: Discussions about treatment (Participation in discussions) – (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 4.4: Discussions about treatment (Participation in discussions) – Stage III & IV variations

Discussions about treatment (Participation in discussions)	Reported less frequently	Reported more frequently
Participant describes being presented with multiple options and participated in the decision-making process	Triple negative Stage III & IV	-
Participant describes being presented with one option/approach and did not participate in the decision-making process	-	Hormone receptor Stage III & IV

Considerations when making decisions: Stage III & IV: Stage III & IV

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were advice of their clinician (33.33%), side effects (23.08%), and efficacy (20.51 %). Other themes included quality of life (15.38%), survival benefit (10.26%), cost (10.26%), statistics or treatment outcomes (7.69%), impact on their family or dependents (7.69%), and ease of treatment administration (2.56%).

Participant describes taking the advice of their clinician into account when making decisions about treatments

I probably was a little stunned at the time. Like I said, my mum has been five years with cancer. I think I just trusted what they were saying to me. I felt like I needed to trust the options they were giving me. I was only ever really given one option and that was to do the chemo first. I don't feel like I really had any options there. I think it was, "This is triple-negative. This is the best course." I think if I'd jumped up and down and said I want to know the other stuff maybe they would have given it to me, but I was quite happy to take under consideration what they were suggesting. Participant_035TNG

I very much followed my-- I guess what I did is I followed the lead of my specialists. My specialists would recommend the course of action of treatment and then I'd go off and do some research and I pretty much felt comfortable with my team and what they were recommending. Participant 043_2021AUHRP

Participant describes taking side effects into account when making decisions about treatments

As far as the cancer, I was never given any options. If I had, I guess the side effects and how they were going to impact my life, would have been my main concern. Participant_027TNG

The success rate, the side effects, has it been used before for these cases, and, the convenience of it, I guess, like how much it's going to affect my day to day life? Participant_044TNG

Certainly, what are the benefits of the treatment? How much benefit I'm I likely to get from the treatment? Then on the other hand what are the side effects? The side effects and what they might do to my body. Participant 047_2021AUHRP

Participant describes taking quality of life into account when making decisions about treatments

As far as the cancer, I was never given any options. If I had, I guess the side effects and how they were going to impact my life, would have been my main concern. Participant_027TNG

Obviously, quality of life. I think that maybe want you to do certain things in life, how much does that have an impact on you in daily living and is it worth it? Because at the moment, I've just started my hormone suppressing therapy. I'm struggling with-- I've just gone back to work and my bones, joint pain, and all that stuff is really impacting on me. I'm in that mindset of really researching a lot at the moment to determine is this really going to help me or is it going to impede on my life so much that I'm not going to enjoy life anymore? Participant 048_2021AUHRP

Participant describes taking the survival benefit into account when making decisions about treatment

I guess the first priority is staying alive and making sure that I'm not just saying no to something because I don't want to do it, when I know that really, it's the only option, I've got to do it. The first priority is always being alive and planning on being alive for not just three years, but 70 more years kind of thing. Obviously not 70, but like another 30 plus years. Participant_025TNG

Basically, what the results are. Basically, what the chances are of survival. What's the chances with that form of treatment, and what were the side effects involved. Participant_046TNG

Just survival rates. I mean I just do whatever is possible to be able to get a good outcome. Participant 046_2021AUHRP

Participant describes taking cost into account when making decisions about treatments

Children, finances, physical mobility, probably emotional as well, and that's about it. Participant_024TNG

Cost sometimes comes into it a little bit. I've definitely learned that I just ask now, do I have to pay for this? Can you bulk bill me? Because nobody tells you that getting cancer is actually expensive so that's definitely something, yes. Participant_043TNG

Participant describes taking statistics/outcome of treatment into account when making decisions about treatment

I didn't consider anything. I considered that my oncologist was making all the right decisions for me. It wasn't till the end that I realized I should have taken more charge of my body, and ask more questions, and ask the success statistics. I didn't do any of that. That's what I would do now. If I was to go back in time or I have to start any treatment again, I'd be asking what are all my alternatives? Why do I have to just have that one? I'd want more options this time, because I was in shock, I just did what they told me to do. Participant_046TNG

Obviously, what's going to be best practice. I think you just have to go with the research as to what has worked for the majority of patients which have got your condition. I know with triple-negative breast cancer, it's a little bit rarer than some of the others, and there's probably not as much data out there as what there is for the hormone receptive cancers. You can only really go with what they know, and for us it's just chemotherapy, which is mainly targeting it. I think there was a paper which came out today, actually, or it might have been this week, on triple-negative which I think might have been with HOSPITAL. Participant_034TNG

Participant describes taking the impact on their family or dependents into account when making decisions about treatments

Children, finances, physical mobility, probably emotional as well, and that's about it. Participant_024TNG

I haven't really made decisions about treatment, I've just done what I've been told, but my biggest consideration is my family life. I've got two young daughters, that has been a bit of a factor in terms of how to work around it. Participant_030TNG

At most? For me personally, when I was deciding my treatment had more to do with my life, then, you know, more with more how important it was to me to live long opposed to just having, you know, keeping things more conservative because I didn't want to go through life. So I didn't want to have my breasts removed or if I didn't want to have treatment because the side effects were worse than the outcome. Like, I, I was more I really fear that any of that was it was more I've got three young children. Participant_044TNG

Table 4.5 Considerations when making decisions

Considerations when making decisions	**All participants**		**All Stage 0 to II**		**All Stage III & IV**		**Triple negative Stage III & IV**		**Hormone receptor Stage III & IV**	
	n=102	**%**	**n=63**	**%**	**n=39**	**%**	**n=27**	**%**	**n=12**	**%**
Participant describes taking the advice of their clinician into account when making decisions about treatments (Total)	33	32.35	20	31.75	13	33.33	9	33.33	4	33.33
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	23	22.55	11	17.46	12	30.77	8	29.63	**4**	**33.33**
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	10	9.80	9	14.29	1	2.56	1	3.70	0	0.00
Participant describes taking side effects into account when making decisions about treatments (Total)	35	34.31	26	41.27	**9**	**23.08**	7	25.93	**2**	**16.67**
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	6	5.88	4	6.35	2	5.13	2	7.41	0	0.00
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	29	28.43	22	34.92	**7**	**17.95**	5	18.52	**2**	**16.67**
Participant describes taking efficacy into account when making decisions about treatments (Total)	24	23.53	16	25.40	8	20.51	4	14.81	4	33.33
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	3	2.94	1	1.59	2	5.13	1	3.70	1	8.33
Participant describes taking efficacy into account as the only thing that they consider when making decisions about treatment	21	20.59	15	23.81	6	15.38	3	11.11	3	25.00
Participant describes taking quality of life into account when making decisions about treatments (Total)	15	14.71	9	14.29	6	15.38	4	14.81	2	16.67
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	2	1.96	1	1.59	1	2.56	1	3.70	0	0.00
Participant describes taking quality of life into account as the only thing that they consider when making decisions about treatment	13	12.75	8	12.70	5	12.82	3	11.11	2	16.67
Participant describes taking the survival benefit into account when making decisions about treatment (Total)	15	14.71	11	17.46	4	10.26	2	7.41	2	16.67
Participant describes taking the survival benefit into account as the only thing that they consider when making decisions about treatment	5	4.90	3	4.76	2	5.13	1	3.70	1	8.33
Participant describes taking the survival benefit into account as part of multiple aspects that they consider when making decisions about treatment	10	9.80	8	12.70	2	5.13	1	3.70	1	8.33
Participant describes taking cost into account when making decisions about treatments (Total)	6	5.88	2	3.17	4	10.26	4	14.81	0	0.00
Participant describes taking cost into account as part of multiple aspects that they consider when making decisions about treatment	1	0.98	0	0.00	1	2.56	1	3.70	0	0.00
Participant describes taking cost into account as the only thing that they consider when making decisions about treatment	5	4.90	2	3.17	3	7.69	3	11.11	0	0.00
Participant describes taking statistics/outcome of treatment into account when making decisions about treatment (Total)	7	6.86	4	6.35	3	7.69	3	11.11	0	0.00
Participant describes taking statistics/outcome of treatment into account as the only thing that they consider when making decisions about treatment	3	2.94	1	1.59	2	5.13	2	7.41	0	0.00
Participant describes taking statistics/outcome of treatment into account as part of multiple aspects that they consider when making decisions about treatment	4	3.92	3	4.76	1	2.56	1	3.70	0	0.00
Participant describes taking the impact on their family or dependents into account when making decisions about treatments (Total)	8	7.84	5	7.94	3	7.69	0	0.00	**3**	**25.00**
Participant describes taking the potential impact on their family or dependents into account as part of multiple aspects that they consider when making decisions about treatment	2	1.96	0	0.00	2	5.13	0	0.00	**2**	**16.67**
Participant describes taking the potential impact on their family or dependents into account as the only thing that they consider when making decisions about treatment	6	5.88	5	7.94	1	2.56	0	0.00	1	8.33
Participant describes taking the ease of administration into account when making decisions about treatment (Total)	7	6.86	6	9.52	1	2.56	0	0.00	1	8.33
Participant describes taking ease of administration into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking ease of administration into account as part of multiple aspects that they consider when making decisions about treatment	7	6.86	6	9.52	1	2.56	0	0.00	1	8.33
Participant describes taking the ability to work into account when making decisions about treatments (Total)	5	4.90	5	7.94	0	0.00	0	0.00	0	0.00
Participant describes taking their ability to work into account as part of multiple aspects that they consider when making decisions about treatment	4	3.92	4	6.35	0	0.00	0	0.00	0	0.00
Participant describes taking their ability to work into account as the only thing that they consider when making decisions about treatment	1	0.98	1	1.59	0	0.00	0	0.00	0	0.00

Considerations when making decisions	**All participants**		**All Triple negative**		**All Hormone receptor**		**Triple negative Stage 0 to II**		**Hormone receptor Stage 0 to II**	
	n=102	**%**	**n=50**	**%**	**n=52**	**%**	**n=23**	**%**	**n=40**	**%**
Participant describes taking the advice of their clinician into account when making decisions about treatments (Total)	33	32.35	18	36.00	15	28.85	9	39.13	11	27.50
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	23	22.55	15	30.00	8	15.38	7	30.43	**4**	**10.00**
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	10	9.80	3	6.00	7	13.46	2	8.70	7	17.50
Participant describes taking side effects into account when making decisions about treatments (Total)	35	34.31	**11**	**22.00**	**24**	**46.15**	**4**	**17.39**	**22**	**55.00**
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	6	5.88	2	4.00	4	7.69	0	0.00	4	10.00
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	29	28.43	**9**	**18.00**	**20**	**38.46**	**4**	**17.39**	**18**	**45.00**
Participant describes taking efficacy into account when making decisions about treatments (Total)	24	23.53	7	14.00	17	32.69	**3**	**13.04**	13	32.50
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	3	2.94	1	2.00	2	3.85	0	0.00	1	2.50
Participant describes taking efficacy into account as the only thing that they consider when making decisions about treatment	21	20.59	6	12.00	15	28.85	3	13.04	12	30.00
Participant describes taking quality of life into account when making decisions about treatments (Total)	15	14.71	6	12.00	9	17.31	2	8.70	7	17.50
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	2	1.96	1	2.00	1	1.92	0	0.00	1	2.50
Participant describes taking quality of life into account as the only thing that they consider when making decisions about treatment	13	12.75	5	10.00	8	15.38	2	8.70	6	15.00
Participant describes taking the survival benefit into account when making decisions about treatment (Total)	15	14.71	7	14.00	8	15.38	5	21.74	6	15.00
Participant describes taking the survival benefit into account as the only thing that they consider when making decisions about treatment	5	4.90	3	6.00	2	3.85	2	8.70	1	2.50
Participant describes taking the survival benefit into account as part of multiple aspects that they consider when making decisions about treatment	10	9.80	4	8.00	6	11.54	3	13.04	5	12.50
Participant describes taking cost into account when making decisions about treatments (Total)	6	5.88	6	12.00	0	0.00	2	8.70	0	0.00
Participant describes taking cost into account as part of multiple aspects that they consider when making decisions about treatment	1	0.98	1	2.00	0	0.00	0	0.00	0	0.00
Participant describes taking cost into account as the only thing that they consider when making decisions about treatment	5	4.90	5	10.00	0	0.00	2	8.70	0	0.00
Participant describes taking statistics/outcome of treatment into account when making decisions about treatment (Total)	7	6.86	7	14.00	0	0.00	**4**	**17.39**	0	0.00
Participant describes taking statistics/outcome of treatment into account as the only thing that they consider when making decisions about treatment	3	2.94	3	6.00	0	0.00	1	4.35	0	0.00
Participant describes taking statistics/outcome of treatment into account as part of multiple aspects that they consider when making decisions about treatment	4	3.92	4	8.00	0	0.00	3	13.04	0	0.00
Participant describes taking the impact on their family or dependents into account when making decisions about treatments (Total)	8	7.84	0	0.00	8	15.38	0	0.00	5	12.50
Participant describes taking the potential impact on their family or dependents into account as part of multiple aspects that they consider when making decisions about treatment	2	1.96	0	0.00	2	3.85	0	0.00	0	0.00
Participant describes taking the potential impact on their family or dependents into account as the only thing that they consider when making decisions about treatment	6	5.88	0	0.00	6	11.54	0	0.00	5	12.50
Participant describes taking the ease of administration into account when making decisions about treatment (Total)	7	6.86	0	0.00	7	13.46	0	0.00	6	15.00
Participant describes taking ease of administration into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking ease of administration into account as part of multiple aspects that they consider when making decisions about treatment	7	6.86	0	0.00	7	13.46	0	0.00	6	15.00
Participant describes taking the ability to work into account when making decisions about treatments (Total)	5	4.90	0	0.00	5	9.62	0	0.00	5	12.50
Participant describes taking their ability to work into account as part of multiple aspects that they consider when making decisions about treatment	4	3.92	0	0.00	4	7.69	0	0.00	4	10.00
Participant describes taking their ability to work into account as the only thing that they consider when making decisions about treatment	1	0.98	0	0.00	1	1.92	0	0.00	1	2.50

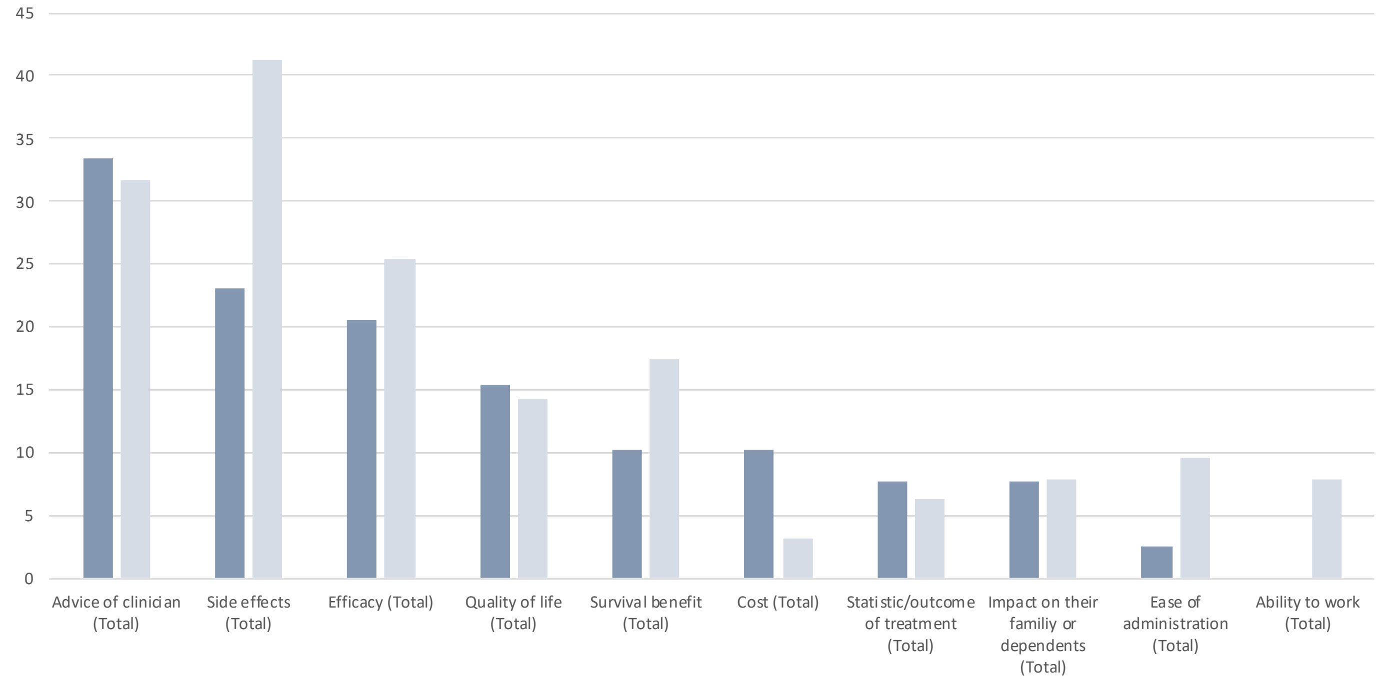


Figure 4.3 Considerations when making decisions – (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 4.6: Considerations when making decisions – Stage III & IV variations

Considerations when making decisions	Reported less frequently	Reported more frequently
Participant describes taking side effects into account when making decisions about treatment (Total)	All Stage III & IV Hormone receptor Stage III & IV	-
Impact on their family or dependents	-	Hormone receptor Stage III & IV

Decision-making over time: Stage III & IV

Participants were asked if the way they made decisions had changed over time. The most common responses were that they had changed the way they make decisions (41.03%), and not changed the way they make decisions (51.28%).

Where participants had changed the way they make decisions, the most common reasons were that they were more informed and/or more assertive (25.64%), more proactive (2.56%), and more focused on quality of life (2.56 %).

Where participants had not changed the way they make decisions, the most common reasons were that they were does not mention any reason (15.38%), always been informed/assertive (15.38%), and always taken advice of clinicians (5.13 %).

Participant describes decision-making changing over time as they are more informed and/or more assertive

I've learned to go with my gut instinct and to be my own advocate. If I don't get the answer I want, I'll now keep asking. Whereas before, I would have been like, "Oh, okay. Well, you're the doctor, you know best." Participant _027TNG

PARTICIPANT: I think I evolved as I went along. At first, I couldn't. You're in such deep shock with that diagnosis. I don't care what anybody says, I was so shocked. There's no history of breast cancer or anything in my family, I was not expecting that. In the end, I would take along my list of questions, write down my list of questions, and I would sit there. [chuckles] Like, "I'm going to list the questions I really want them answered." Every time I went somewhere, I had a list of questions so that I could get answers to stuff.
INTERVIEWER: Did it help to write them down?
PARTICIPANT: Yes.
Participant _029TNG

I just look at the big picture and the end result now, not just the immediate-- Initially, I used to just make a decision on, "Okay, what's the right thing to do right now?" Moving forward now, I ask a lot more questions about why did they say this? Why are they suggesting this for me? Even just my surgery, I was like, "Why am I only having a lumpectomy? Why aren't I having a breast removal? Then she talked to me through that and I was like, "Okay, I'll just have a lumpectomy then." I didn't ask a question. I just went with what she was saying. Participant _045

Participant describes no change in decision-making over time as they have always been informed/assertive

I think the same way. I'm a very, fact and research-driven person about anything health-related. Participant _050TNG

For me, we pretty much approached the decisions in the same way, but that's because prior to breast cancer, as I mentioned, we had already gone through infertility treatment. For me, breast cancer wasn't the end of my world, I'd already had the bad news. My world had already fallen apart, pretty much, so by the time I got told I had cancer, it was more of a reaction, "Of course it is, why wouldn't it be?" Every decision we've ever made for any medical purpose has always been made with us acknowledging that this is the decision we're making now, based off the information we currently have. We might in 10 months' time, know more information that may have changed the decision we would have made, but right now, this is the reason we're making this decision and that's what we accept. From a medical perspective, it hasn't changed the way that we make decisions. Participant _025TNG

I think with health-based things, I've always been pretty good with making decisions. I've tried to implement that into my personal and normal life [chuckles] because I'm much more factual and logical about it all. Whereas I've become quite emotional with my personal life so I'm trying to take that really big positive and bring it into [chuckles] the other elements of my life. Participant 042_2021AUHRP

Table 4.7: Decision-making over time

Decision-making over time	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes decision-making changing over time	52	50.98	36	57.14	16	41.03	**11**	**40.74**	5	41.67
Participant describes decision-making changing over time as they are more informed and/or more assertive	30	29.41	20	31.75	10	25.64	8	29.63	**2**	**16.67**
Participant describes decision-making changing over time as they are more proactive	6	5.88	5	7.94	1	2.56	1	3.70	0	0.00
Participant describes decision-making changing over time as they are more focused on quality of life or impact of side effects	6	5.88	5	7.94	1	2.56	0	0.00	1	8.33
Participant describes decision-making changing over time as they are more cautious and considered	5	4.90	5	7.94	0	0.00	0	0.00	0	0.00
Participant describes no change in decision-making over time	45	44.12	25	39.68	20	51.28	13	48.15	**7**	**58.33**
Participant describes no change in decision-making over time and there is no particular reason noted	20	19.61	14	22.22	6	15.38	5	18.52	**1**	**8.33**
Participant describes no change in decision-making over time as they have always been informed/assertive	11	10.78	5	7.94	6	15.38	2	7.41	**4**	**33.33**
Participant describes no change in decision-making over time as they have always taken advice of clinicians	6	5.88	4	6.35	2	5.13	0	0.00	**2**	**16.67**

Decision-making over time	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes decision-making changing over time	52	50.98	27	54.00	25	48.08	**16**	**69.57**	20	50.00
Participant describes decision-making changing over time as they are more informed and/or more assertive	30	29.41	13	26.00	17	32.69	5	21.74	15	37.50
Participant describes decision-making changing over time as they are more proactive	6	5.88	6	12.00	0	0.00	**5**	**21.74**	0	0.00
Participant describes decision-making changing over time as they are more focused on quality of life or impact of side effects	6	5.88	0	0.00	6	11.54	0	0.00	5	12.50
Participant describes decision-making changing over time as they are more cautious and considered	5	4.90	5	10.00	0	0.00	**5**	**21.74**	0	0.00
Participant describes no change in decision-making over time	45	44.12	18	36.00	27	51.92	**5**	**21.74**	20	50.00
Participant describes no change in decision-making over time and there is no particular reason noted	20	19.61	7	14.00	13	25.00	**2**	**8.70**	**12**	**30.00**
Participant describes no change in decision-making over time as they have always been informed/assertive	11	10.78	4	8.00	7	13.46	2	8.70	3	7.50
Participant describes no change in decision-making over time as they have always taken advice of clinicians	6	5.88	0	0.00	6	11.54	0	0.00	4	10.00

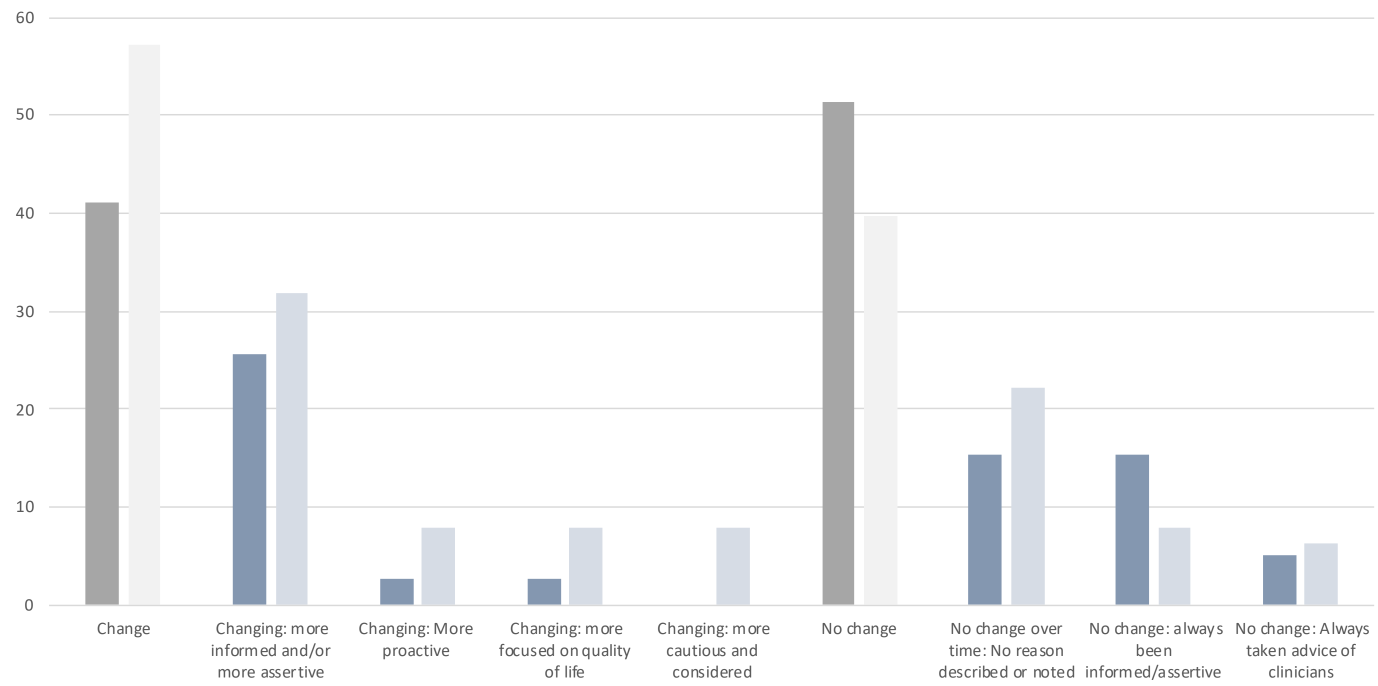


Figure 4.4: Decision-making over time – (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 4.8: Decision-making over time – Stage III & IV variations

Decision-making over time	Reported less frequently	Reported more frequently
Participant describes decision-making changing over time	Triple negative Stage III & IV	-
Participant describes no change in decision-making over time	-	Hormone receptor Stage III & IV

Personal goals of treatment or care: Stage III & IV

Participants were asked what their own personal goals of treatment or care were. The most common responses were to minimise or avoid side effects (28.21%), treat the disease and get better (17.95%), and be cancer free, avoid recurrence, increase longevity (15.38 %). Other themes included get through medical treatment (12.82%), live independently (10.26%), improvements in mental and emotional health (10.26%), have physical improvements in their condition (5.13%), survival (5.13%), and have quality of life/return to normality (2.56%).

Others described that they had no personal goals of treatment or care as they weren't aware of anything they could do to improve their condition (7.69%), and they had no personal goals of treatment or care (no reason given) (5.13 %).

Participant describes wanting to minimise or avoid side effects

I was told I would have chemotherapy, there'd be no question of that. I was just terrified of vomiting, to be honest. I didn't really care about losing my hair or anything like that, it was more just being sick. Participant_040TNG

Look, it's a hard one. I'm extremely fortunate with side effects from the treatments I've had have been minimal and not ongoing as such. Once that treatment's finished, the side effects stopped, I've been really lucky in that sense. I just probably want--and I will probably do is once the treatments even finished is, I just want more education for people on how to handle the side effects as opposed to just being told what to do and not actually have that support there. Participant_030TNG

Participant describes wanting to treat the disease/get better

Pretty much the goal was to get rid of the cancer, and get through this part of my life, and get back to normal life. Pretty much the goal was to get rid of the cancer, and get through this part of my life, and get back to normal life. Participant_025TNG

I was hoping that the tumour would completely disappear. That was number one or it would reduce, but I was hoping it'd disappear. I wanted to be better quickly. Participant_035TNG

PARTICIPANT: Initially it was a matter of just attack it with whatever it needs and kill it so I can continue my life, and now there is that balance between what'd you call it? Sorry, I've gone blank, but--
INTERVIEWER: Is it quality of life?
PARTICIPANT: Quality of life, yes. That's exactly it. Quality of life versus successful treatment. Participant_048TNG

Participants describe wanting to be cancer free, avoid recurrence or increase longevity

My main goal was basically to just still be here. I didn't really go beyond that. I didn't think about, whether there was going to be any limitations or any of that sort of stuff. Just basically survival
Participant 050_2021AUHRP

Yes. To survive it. [chuckles] I was terrified of chemo. Participant_041TNG

Participant describes wanting to follow/get through treatment

My goals are really just to get through the treatment cycles and then go on to live a full life. That's my ultimate goal. Obviously, managing the side effects and the treatment things has been okay, I'm getting through that quite well. My goal at the moment is just to get through each step as I come to it. For chemo, I just focused on getting through chemo and now that's finished. Now, I'm focusing on the surgery and what comes next and things like the lymphedema and what might happen. Then when I've done that, I'm sure I'll focus on the radiation, but it's just been I like to do it in stages. Participant_033TNG

No, I basically was taking their advice because obviously, I haven't had to deal with anything like this before, so I was taking what their advice was. The first lot of chemo, I thought, well, I'm going to do this. I'm going to keep working full-time as long as I can. I didn't know whether I could or not. I spoke to my bosses and they were great because I said I don't know-- They said, I'm I going to need time off? I said I don't know. I may not know until the day of. I really don't know. I just want to keep going as long as I can, and that's what I did. Participant_046TNG

Participant describes wanting to live independently

My goals are really just to get through the treatment cycles and then go on to live a full life. That's my ultimate goal. Obviously, managing the side effects and the treatment things has been okay, I'm getting through that quite well. My goal at the moment is just to get through each step as I come to it. For chemo, I just focused on getting through chemo and now that's finished. Now, I'm focusing on the surgery and what comes next and things like the lymphedema and what might happen. Then when I've done that, I'm sure I'll focus on the radiation, but it's just been I like to do it in stages. Participant_033TNG

I'm not having active treatment anymore because I'm out the other side, I'm having reconstruction and surgeries and stuff like that. My thing is just to try and get back to normal really, I want to feel normal again. Participant_043TNG

Participant described wanting to see mental/emotional improvements

Well, I don't know. I had to actually stop my Taxol treatment early because I got neuropathy and they were worried that if they kept treating me that it'd become permanent. I had to stop that early. Going through chemo has been really, really hard for me. I've had a lot of very bad side effects. I've been very sick. I'm glad I finished chemo. The only thing that I've really done, I haven't even done it yet. I would like to participate in this return to wellness exercise program, et cetera that they're running at LOCATION Health. It's a Paula program. I'm basically waiting to see how I feel. I would like to do that and just like to do more exercise and obviously talk to a psychologist, because this is really bad for mental health as well. I haven't really, really made any plans yet. I just want to get through all this. Participant_028TNG

Yeah, I, I was diagnosed right at the start of it when everything just shut down. So I had very little support from allied health. So for me that was a big thing. And I don't know what normally happens because it obviously was different than covid. But I didn't say if I had five and a half months had treatment and the dietitian saw me on my second last chemo. So I didn't say anyone about my diet or anything. It was just information. And I looked at myself and I I really felt that exercise is so important and I was so sick and getting my chemo and I have to keep going. And I didn't go for a walk every day. And I really feel like if I had if I knew the importance of that, I probably would have done it. But that was something, you know, it's something that I know now afterwards. But in the *end, I still got I've got peripheral neuropathy in my hands and feet and I've still got a lot of pain and back pain. And six months after I finished treatment, I went to the oncologist and this is my new normal. And she said, well, why don't we do six months of rehab? So that's when I went to I exercise physiologist and I've been doing a bit of strength training and hydrotherapy and things like that. And it is improving, but it's still very and I feel like I would like to see that as an opt out type of thing, so I would love to. And so that has been my past five and six months ahead in my recovery, because when I finished chemo, it was just, OK, that's it. You know, we don't need to see you for a few months. And I was just left on my own and I feel like I still needed that support with exercise and your diet and those sorts of things and the mental health as well, because it doesn't just end when you have your last. I have a lot of stuff still going on, and unless I had a about it, you know, I would still be in the same boat. And when I did talk to the doctors about it, they just kept wanting to give me something, tablets and pain relief. And I you know, I don't like that because I get really sick from it. So and even at all, I needed was someone to say, you need to go. And do you know, the next is just stuff so that for that help, which, you know, I really feel like that should just be part of your normal course of treatment. You have to have those people involved. Participant_038TNG*

Participant describes no personal goals of treatment or care as they weren't aware of anything they could do to improve their condition

Yeah. I just I had no I mean all I knew was I had breast cancer, I had no friends, I had no knowledge of anyone having to have had done any of this. I was totally shocked because I was I take you and I look at things that I kept asking me then when your family had breast cancer, as your mother was saying, answer those questions. But I didn't know anything. I was so naive. Probably the worst. And it's just, you know, so many years, ten years now down the track, it makes me angry to think that we're not given enough information at the start. Participant_049TNG

I'm not sure. For my age, I'm 64, I just figure I will just plod along as I'm going. I'm having surgery for something else in the next month or so, but no, I have no real plans for anything else. I basically do what my oncologist tells me to do. Participant_032TNG

Table 4.9: Personal goals of treatment or care

Personal goals of treatment or care	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes wanting to minimise or avoid side effects of treatment for their condition	25	24.51	14	22.22	11	28.21	5	18.52	**6**	**50.00**
Participant describes wanting to treat the disease/get better	14	13.73	7	11.11	7	17.95	**7**	**25.93**	**0**	**0.00**
Participants describe wanting to be cancer free, avoid recurrence or increase longevity	23	22.55	17	26.98	6	15.38	**0**	**0.00**	**6**	**50.00**
Participant describes wanting to follow/get through treatment	12	11.76	7	11.11	5	12.82	5	18.52	**0**	**0.00**
Participant describes wanting to live independently	8	7.84	4	6.35	4	10.26	4	14.81	0	0.00
Participant described wanting to see mental/emotional improvements	11	10.78	7	11.11	4	10.26	3	11.11	1	8.33
Participant describes no personal goals of treatment or care as they weren't aware of anything they could do to improve their condition	3	2.94	0	0.00	3	7.69	3	11.11	0	0.00
Participants describe wanting to see physical improvements in their condition	5	4.90	3	4.76	2	5.13	2	7.41	0	0.00
Participant describes wanting to survive	4	3.92	2	3.17	2	5.13	2	7.41	0	0.00
Participant describes no personal goals of treatment or care (no reason given)	9	8.82	7	11.11	2	5.13	0	0.00	2	16.67
Participant describes wanting to improve their quality of life or return to normality	9	8.82	8	12.70	1	2.56	0	0.00	1	8.33
Participant describes wanting to returning to work	5	4.90	5	7.94	0	0.00	0	0.00	0	0.00
Participant describes wanting to stay healthy	4	3.92	4	6.35	0	0.00	0	0.00	0	0.00

Personal goals of treatment or care	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes wanting to minimise or avoid side effects of treatment for their condition	25	24.51	**5**	**10.00**	**20**	**38.46**	**0**	**0.00**	**14**	**35.00**
Participant describes wanting to treat the disease/get better	14	13.73	**14**	**28.00**	**0**	**0.00**	**7**	**30.43**	**0**	**0.00**
Participants describe wanting to be cancer free, avoid recurrence or increase longevity	23	22.55	**0**	**0.00**	**23**	**44.23**	**0**	**0.00**	**17**	**42.50**
Participant describes wanting to follow/get through treatment	12	11.76	**12**	**24.00**	**0**	**0.00**	**7**	**30.43**	**0**	**0.00**
Participant describes wanting to live independently	8	7.84	8	16.00	0	0.00	4	17.39	0	0.00
Participant described wanting to see mental/emotional improvements	11	10.78	6	12.00	5	9.62	3	13.04	4	10.00
Participant describes no personal goals of treatment or care as they weren't aware of anything they could do to improve their condition	3	2.94	3	6.00	0	0.00	0	0.00	0	0.00
Participants describe wanting to see physical improvements in their condition	5	4.90	5	10.00	0	0.00	3	13.04	0	0.00
Participant describes wanting to survive	4	3.92	4	8.00	0	0.00	2	8.70	0	0.00
Participant describes no personal goals of treatment or care (no reason given)	9	8.82	1	2.00	8	15.38	1	4.35	6	15.00
Participant describes wanting to improve their quality of life or return to normality	9	8.82	0	0.00	9	17.31	0	0.00	**8**	**20.00**
Participant describes wanting to returning to work	5	4.90	5	10.00	0	0.00	**5**	**21.74**	0	0.00
Participant describes wanting to stay healthy	4	3.92	4	8.00	0	0.00	**4**	**17.39**	0	0.00

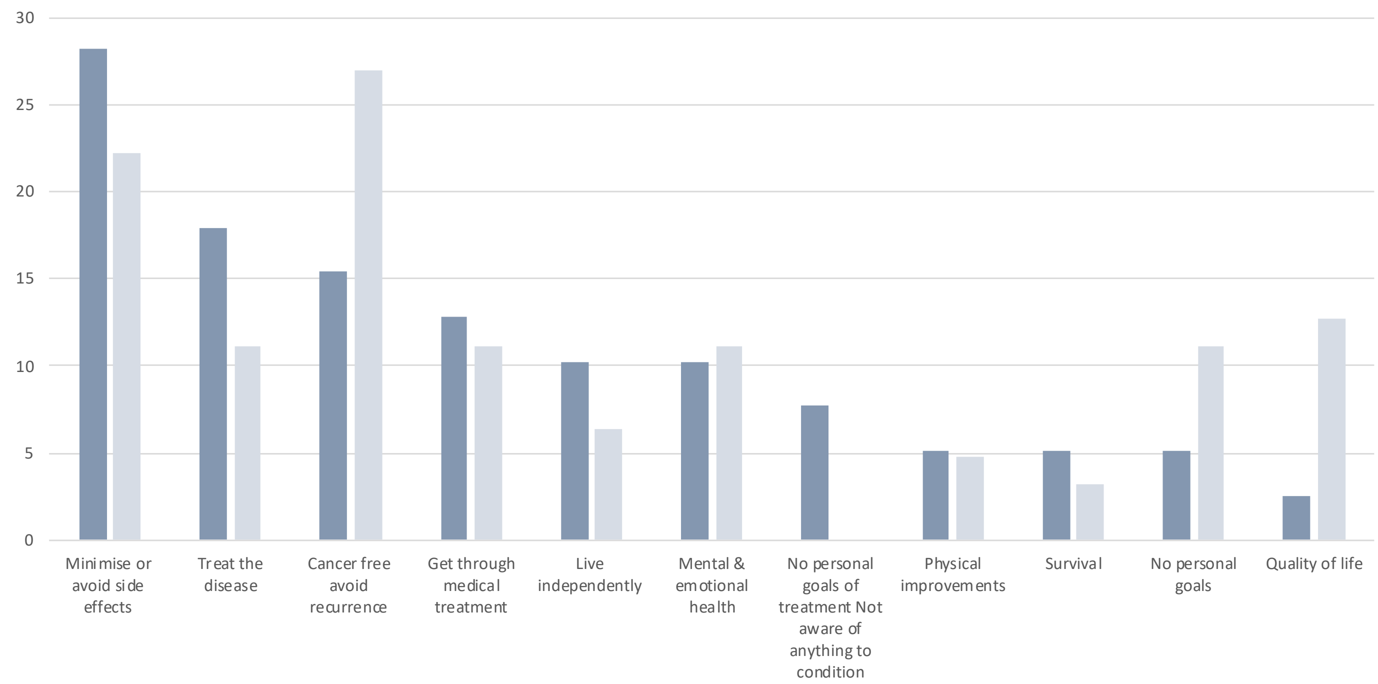


Figure 4.5: Personal goals of treatment or care – (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 4.10: Personal goals of treatment or care – Stage III & IV variations

Personal goals of treatment or care	Reported less frequently	Reported more frequently
Participant describes wanting to minimise or avoid side effects of treatment for their condition	-	Hormone receptor Stage III & IV
Participant describes wanting to treat the disease/get better	Hormone receptor Stage III & IV	Triple negative Stage III & IV
Participants describe wanting to be cancer free, avoid recurrence or increase longevity	Triple negative Stage III & IV	Hormone receptor Stage III & IV
Participant describes wanting to follow/get through treatment	Hormone receptor Stage III & IV	-

Section 5

Treatment

Section 5: Experience of treatment

Main provider of treatment: Stage III & IV

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

The most common provider of treatment and care were Medical oncologists (n=24,66.67 %), followed by Specialist surgeons (n=8, 22.22%) .

Time to travel to main provider of treatment: Stage III & IV

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

There were 13 participants (36.11%) that travelled for less than 15 minutes, 13 participants (36.11%) that travelled between 15 and 30 minutes, 7 participants (19.44%) that travelled between 30 and 60 minutes, 2 participants (5.56%) that travelled between 60 and 90 minutes, and 1 participants (2.78%) that travelled more than 90 minutes.

Access to healthcare professionals: Stage III & IV

Almost all participants had access to a Medical oncologist (n=36, 100.00%), a Specialist surgeon (n=33, 91.67%) and a Radiation oncologist (n=30, 83.33%). There were 33 participants (91.67%) that had a General Practitioner (GP).

There were 31 participants (86.11%) that had a Breast care nurse, 31 participants (86.11%) that had a Oncology/chemotherapy nurse and 10 participants (27.78%) that had a Breast cancer care coordinator.

There were 21 participants (58.33%) treated by a Physiotherapist, 18 participants (50.00%) treated by a Genetic Counsellor, and 18 participants (50.00%) treated by a Pharmacist, 17 participants (47.22%) treated by a Lymphoedema practitioner, and 17 participants (47.22%) treated by a Psychologist .

Health care system: Stage III & IV

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 .

The majority of participants had private health insurance (n=26, 72.22%). The majority of participants were not asked if they wanted to be treated as a public or private patient (n=13, 36.11%), however, they were asked if they had private health insurance (n=33, 91.67%).

Throughout their treatment, there were 16 participants (44.44%) that were treated as a private patient, 15 participants (41.67%) were mostly treated as a public patient, and there were 5 participants (13.89%) that were equally treated as a private and public patient.

Throughout their treatment, there were 17 participants (47.22%) that were treated mostly in the private hospital system, 13 participants (36.11%) were mostly treated in the public system, and there were 6 participants (16.67%) that were equally treated in the private and public systems.

Affordability of healthcare: Stage III & IV

Participants were asked a series of questions about affordability of healthcare in the online questionnaire.

The first question was about having to delay or cancer healthcare appointments because they were unable to afford them. Almost all the participants never or rarely had to delay or cancel appointments due to affordability (n = 33, 91.67%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=34, 94.44%).

The third question was about the affordability of basic essentials such as such as food, housing and power. There were 27 participants (75.00%) that never or rarely had trouble paying for essentials, and 7 participants (19.44%) that sometimes found it difficult, and 2 participants (5.56%) 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 32 participants (88.89%) that paid for additional carers due to their condition.

Cost of condition: Stage III & IV

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.

The most common amount was between $1001 to 2500 (n=5, 13.89%), followed by between $2501 to 5000 (n=8, 22.22%). There were 5 participants (13.89%), that spent Not sure/not specified a month.

Burden of cost

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

The amount spent was an extremely significant or moderately significant burden for 11 participants (50.00%), somewhat significant for 5 participants (22.73%), and slightly or not at all significant for 6 participants (27.27%).

Changes to employment status: Stage III & IV

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 .

Work status for 5 participants (13.89%) had not changed since diagnosis, and 1 participants (2.78%) were retired or did not have a job. There were 5 participants (13.89%) had to quit their job, 11 participants (30.56%) reduced the number of hours they worked, and 3 participants (8.33%) that accessed their superannuation early. There were 15 participants (41.67%) that took leave from work without pay, and 10 participants (27.78%) that took leave from work with pay.

Changes to carer/partner employment status

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

There were 10 participants (27.78%), 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=16, 44.44%). There were 3 participants (8.33%) whose partners reduced the numbers of hours they worked, and 0 partners, (0.00%) that quit their job. The partners of 3 participants (8.33%) took leave without pay, and there were 6 partners (16.67%) that took leave with pay.

Reduced income due to condition

Almost all of the participants (n=35, 97.22%) 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.

Most commonly, participants were not sure about the amount their monthly income was reduced by (n=5, 13.89%), or reduced by between $101 to $250 per month (n=10, 27.78%).

Burden of reduced income

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

For 12 of these participants (33.33%), the burden of this reduced income was extremely or moderately significant, for 12 participants (33.33%) the burden was somewhat significant, and for 12 participants (33.33%) the burden was slightly or not all significant.

Summary of surgery: Stage III & IV

There were 2 participants (7.14%) that had Re-excision following lumpectomy, 19 participants (67.86%) that had Mastectomy and 11 participants (39.29%) that had Breast reconstruction. Five participants (17.86%) had surgery to remove ovaries, and one participant had (3.57%) surgery to relieve symptoms.

Summary of treatments: Stage III & IV

Treatments are listed in the table below. All participants with stage II & IV breast cancer received treatment, 28 participants (77.78%) had surgery, and 26 participants (72.22%) had radiotherapy.

Allied health: Stage III & IV

The most common allied health service used was Physiotherapy (n=19, 52.78%), followed by Psychologist (n=19, 52.78%), and Dietician (n=7, 19.44%). There were 5 participants (13.89%) that saw a Podiatrist, 4 participants (11.11%) that saw a Occupational therapist, and 2 participants (5.56%) that saw a Social worker.

Lifestyle changes: Stage III & IV

The most common lifestyle change used was Exercise (n=26, 72.22%), followed by Reduce or quit alcohol (n=21, 58.33%), and Diet changes (n=18, 50.00%).

Complementary therapies: Stage III & IV

The most common complementary therapy used was Mindfulness or relaxation techniques (n=18, 50.00%), followed by Massage therapy (n=15, 41.67%), and Supplements (n=15, 41.67%).

Clinical trials: Stage III & IV

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.

There was a total of 17 participants (47.22%) that had discussions about clinical trials, 4 participants (11.11%) had brought up the topic with their doctor, and the doctor of 13 participants (36.11%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=19, 52.78%).

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 .

There were 4 participants (11.11%) that had taken part in a clinical trial, 28 participants (77.78%) that would like to take part in a clinical trial if there was a suitable one, and 4 participants, that have not participated in a clinical trial and do not want to (11.11%).

Description of mild side effects: Stage III & IV

In the structured interview, participants were asked how they would describe the term 'mild side effects'. The most common descriptions of mild side effects were those that do not interfere with life (61.54%), and described using a specific example (43.59%). This was followed by those that can be managed with self-medication or self-management (23.08 %), and those that are irritating/frustrating (5.13%).

When a specific side effect was described, the most common responses were nausea (15.38%), and tiredness (15.38%). Other themes included feeling of discomfort (5.13%), headache (5.13%), mild pain (5.13%), bowel problems (e.g. diarrhea) (5.13%), stomach ache (2.56%), burning (2.56%), and fogginess (2.56410256410256%).

Description of severe side effects: Stage III & IV

In the structured interview, participants were asked how they would describe the term 'severe side effects'. The most common description of severe side effects were those that impact everyday life or ability to conduct activities of daily living (58.97%), and described using a specific example (51.28%). Other themes included those that are life threatening or result in hospitalisation (7.69%), those that impact their everyday life by being bed ridden (7.69%), and those that are difficult to cope with/go through (5.13%).

When a specific side effect was described, the most common examples were extreme/chronic pain (20.51%), emotional/mental struggle (20.51%), and nausea/vomiting (12.82 %). Other themes included neuropathy (10.26%), hair, eyebrows, eyelashes loss (7.69%), lack of appetite (5.13%), impact on sleep (5.13%), and aches/pain (general) (5.13%).

Adherence to treatment: Stage III & IV

Participants were asked in the structured interview what influences their decision to continue with a treatment regime. The most common responses were adhering to treatment according to the advice of their specialist/as long as prescribed (43.59%), never giving up on any treatment(33.33%), and adhering to treatment for a specific amount of time (25.64 %). Other themes included needing to see test results/no evidence or reduction of disease (15.38%), and adhering to treatment as long as side effects are tolerable (12.82%).

When participants stated a specific amount of time to adhere to a treatment, the most common amount of time was one week (10.26%), followed by four to six weeks(5.13%), and two to three months (5.13 %).

What needs to change to feel like treatment is working: Stage III & IV

Participants were asked to describe what needs to change to feel like treatment is effective. The most common responses were needing to see physical signs and symptoms disappear/reduce side effects (28.21%), needing to see positive results of tests/or scan showing disease reduction (23.08%), and needing to see evidence of stable disease/no disease progression (17.95 %). Other themes included needing to have side effects (12.82%), needing to experience an improvement in a specific symptom (12.82%), that it is difficult to know that it is working/needs evidence (10.26%), needing to see a return to day-to-day functionality (7.69%), needing to see improvements in general wellbeing (quality of life) (7.69%), and needing to have a balance between benefit and side effects (5.13%).

When a specific side effect or symptom was described, the most common examples were in pain levels (23.08%), in nausea(12.82%), and in menopause side effects (5.13 %).

What it would mean if treatment worked: Stage III & IV

As a follow up question, participants were asked what it would mean to them if the treatment worked in the way they described. The most common response was that it would allow them to do everyday activities/return to normal life (61.54%), this was followed by allowing them to engage more with social activities and family life (15.38%), lead to a reduction in symptoms/side effects (15.38 %), and have a positive impact on their mental health (15.38%). Other themes included allowing them to return to work (12.82%), allowing them to do domestic tasks (7.69%), and allowing them to do more exercise (7.69%).

Main provider of treatment: Stage III & IV

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

The most common provider of treatment and care were Medical oncologists (n=24,66.67 %), followed by Specialist surgeons (n=8, 22.22%) .

Time to travel to main provider of treatment: Stage III & IV

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

There were 13 participants (36.11%) that travelled for less than 15 minutes, 13 participants (36.11%) that travelled between 15 and 30 minutes, 7 participants (19.44%) that travelled between 30 and 60 minutes, 2 participants (5.56%) that travelled between 60 and 90 minutes, and 1 participants (2.78%) that travelled more than 90 minutes.

Table 5.1: Main provider of treatment

Main provider of treatment	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=96	%	n=60	%	n=36	%	n=24	%	n=12	%
General practitioner (GP)	18	18.75	15	25.00	**3**	**8.33**	3	12.50	**0**	**0.00**
Medical oncologist	47	48.96	**23**	**38.33**	**24**	**66.67**	**17**	**70.83**	7	58.33
Radiation oncologist	1	1.04	1	1.67		0.00	0	0.00	0	0.00
Specialist surgeon	23	23.96	15	25.00	8	22.22	**3**	**12.50**	**5**	**41.67**
Multi-disciplinary team	5	5.21	4	6.67	1	2.78	1	4.17	0	0.00
Other	2	2.08	2	3.33	0	0.00	0	0.00	0	0.00

Main provider of treatment	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=96	%	n=44	%	n=52	%	n=20	%	n=40	%
General practitioner (GP)	18	18.75	9	20.45	9	17.31	**6**	**30.00**	9	22.50
Medical oncologist	47	48.96	23	52.27	24	46.15	**6**	**30.00**	17	42.50
Radiation oncologist	1	1.04		0.00	1	1.92	0	0.00	1	2.50
Specialist surgeon	23	23.96	9	20.45	14	26.92	6	30.00	9	22.50
Multi-disciplinary team	5	5.21	3	6.82	2	3.85	2	10.00	2	5.00
Other	2	2.08	0	0.00	2	3.85	0	0.00	2	5.00

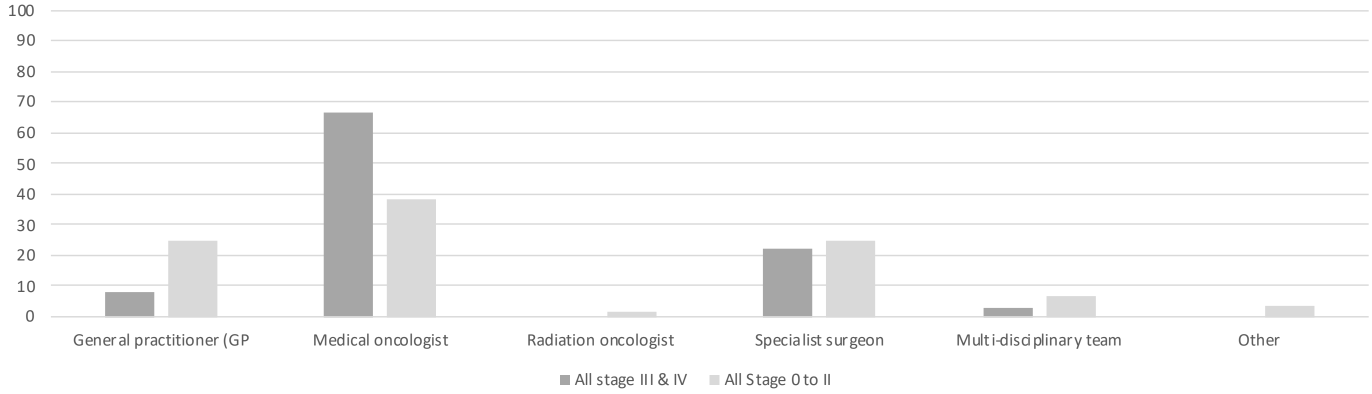


Figure 5.1: Main provider of treatment(% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 5.2: Main provider of treatment– Stage III & IV variations

Main provider of treatment	Reported less frequently	Reported more frequently
General practitioner (GP)	All Stage III & IV Hormone receptor Stage III & IV	-
Medical oncologist	-	All Stage III & IV Triple negative Stage III & IV
Specialist surgeon	Triple negative Stage III & IV	Hormone receptor Stage III & IV

Table 5.3: Time to travel to main provider of treatment

Time to travel to main provider of treatment	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=96	%	n=60	%	n=36	%	n=24	%	n=12	%
Less than 15 minutes	29	30.21	16	26.67	13	36.11	9	37.50	4	33.33
Between 15 and 30 minutes	38	39.58	25	41.67	13	36.11	9	37.50	4	33.33
Between 30 and 60 minutes	17	17.71	10	16.67	7	19.44	4	16.67	3	25.00
Between 60 and 90 minutes	5	5.21	3	5.00	2	5.56	2	8.33	0	0.00
More than 90 minutes	6	6.25	5	8.33	1	2.78	0	0.00	1	8.33
Not specified	1	1.04	1	1.67	0	0.00	0	0.00	0	0.00

Time to travel to main provider of treatment	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=96	%	n=44	%	n=52	%	n=20	%	n=40	%
Less than 15 minutes	29	30.21	16	36.36	13	25.00	7	35.00	9	22.50
Between 15 and 30 minutes	38	39.58	15	34.09	23	44.23	6	30.00	19	47.50
Between 30 and 60 minutes	17	17.71	8	18.18	9	17.31	4	20.00	6	15.00
Between 60 and 90 minutes	5	5.21	3	6.82	2	3.85	1	5.00	2	5.00
More than 90 minutes	6	6.25	2	4.55	4	7.69	2	10.00	3	7.50
Not specified	1	1.04		0.00	1	1.92	0	0.00	1	2.50

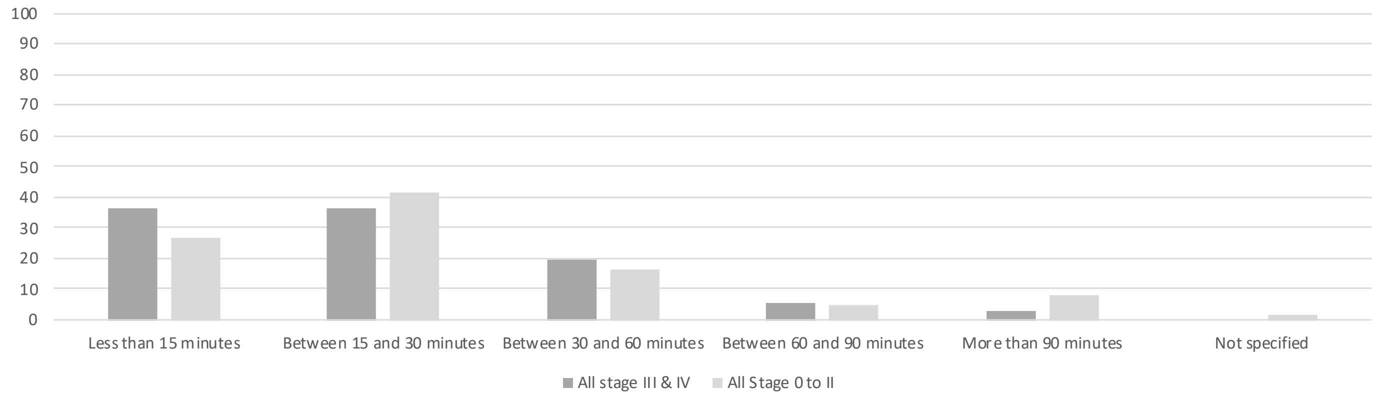


Figure 5.2: Time to travel to main provider of treatment(% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Access to healthcare professionals: Stage III & IV

Almost all participants had access to a Medical oncologist (n=36, 100.00%), a Specialist surgeon (n=33, 91.67%) and a Radiation oncologist (n=30, 83.33%). There were 33 participants (91.67%) that had a General Practitioner (GP).

There were 31 participants (86.11%) that had a Breast care nurse, 31 participants (86.11%) that had a Oncology/chemotherapy nurse and 10 participants (27.78%) that had a Breast cancer care coordinator.

There were 21 participants (58.33%) treated by a Physiotherapist, 18 participants (50.00%) treated by a Genetic Counsellor, and 18 participants (50.00%) treated by a Pharmacist, 17 participants (47.22%) treated by a Lymphoedema practitioner, and 17 participants (47.22%) treated by a Psychologist .

Table 5.4: Access to healthcare professionals

Access to healthcare professionals	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=96	%	n=60	%	n=36	%	n=24	%	n=12	%
Medical oncologist	93	96.88	57	95.00	36	100.00	24	100.00	12	100.00
Specialist surgeon	91	94.79	58	96.67	33	91.67	23	95.83	10	83.33
Radiation oncologist	74	77.08	44	73.33	30	83.33	21	87.50	9	75.00
Palliative care specialist	3	3.13		0.00	3	8.33	2	8.33	1	8.33
General Practitioner (GP)	84	87.50	51	85.00	33	91.67	23	95.83	10	83.33
Breast care nurse	79	82.29	48	80.00	31	86.11	21	87.50	10	83.33
Oncology/chemotherapy nurse	68	70.83	37	61.67	31	86.11	22	91.67	9	75.00
Breast cancer care coordinator	28	29.17	18	30.00	10	27.78	7	29.17	3	25.00
Physiotherapist	49	51.04	28	46.67	21	58.33	15	62.50	6	50.00
Genetic Counsellor	40	41.67	22	36.67	18	50.00	10	41.67	8	66.67
Pharmacist	43	44.79	25	41.67	18	50.00	11	45.83	7	58.33
Lymphoedema practitioner	40	41.67	23	38.33	17	47.22	10	41.67	7	58.33
Psychologist	37	38.54	20	33.33	17	47.22	12	50.00	5	41.67
Exercise physiologist	31	32.29	21	35.00	10	27.78	6	25.00	4	33.33
Counsellor	17	17.71	8	13.33	9	25.00	5	20.83	4	33.33
Dietitian/nutritionist	20	20.83	12	20.00	8	22.22	6	25.00	2	16.67
Chiropractor	12	12.50	7	11.67	5	13.89	5	20.83	0	0.00
Osteopath	9	9.38	4	6.67	5	13.89	4	16.67	1	8.33
Occupational therapist	8	8.33	4	6.67	4	11.11	3	12.50	1	8.33
Social worker	6	6.25	3	5.00	3	8.33	1	4.17	2	16.67

Access to healthcare professionals	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=96	%	n=44	%	n=52	%	n=20	%	n=40	%
Medical oncologist	93	96.88	44	100.00	49	94.23	20	100.00	37	92.50
Specialist surgeon	91	94.79	42	95.45	49	94.23	19	95.00	39	97.50
Radiation oncologist	74	77.08	31	70.45	43	82.69	10	50.00	34	85.00
Palliative care specialist	3	3.13	2	4.55	1	1.92	0	0.00	0	0.00
General Practitioner (GP)	84	87.50	41	93.18	43	82.69	18	90.00	33	82.50
Breast care nurse	79	82.29	37	84.09	42	80.77	16	80.00	32	80.00
Oncology/chemotherapy nurse	68	70.83	38	86.36	30	57.69	16	80.00	21	52.50
Breast cancer care coordinator	28	29.17	14	31.82	14	26.92	7	35.00	11	27.50
Physiotherapist	49	51.04	21	47.73	28	53.85	6	30.00	22	55.00
Genetic Counsellor	40	41.67	22	50.00	18	34.62	12	60.00	10	25.00
Pharmacist	43	44.79	18	40.91	25	48.08	7	35.00	18	45.00
Lymphoedema practitioner	40	41.67	16	36.36	24	46.15	6	30.00	17	42.50
Psychologist	37	38.54	20	45.45	17	32.69	8	40.00	12	30.00
Exercise physiologist	31	32.29	14	31.82	17	32.69	8	40.00	13	32.50
Counsellor	17	17.71	9	20.45	8	15.38	4	20.00	4	10.00
Dietitian/nutritionist	20	20.83	11	25.00	9	17.31	5	25.00	7	17.50
Chiropractor	12	12.50	6	13.64	6	11.54	1	5.00	6	15.00
Osteopath	9	9.38	6	13.64	3	5.77	2	10.00	2	5.00
Occupational therapist	8	8.33	4	9.09	4	7.69	1	5.00	3	7.50
Social worker	6	6.25	2	4.55	4	7.69	1	5.00	2	5.00

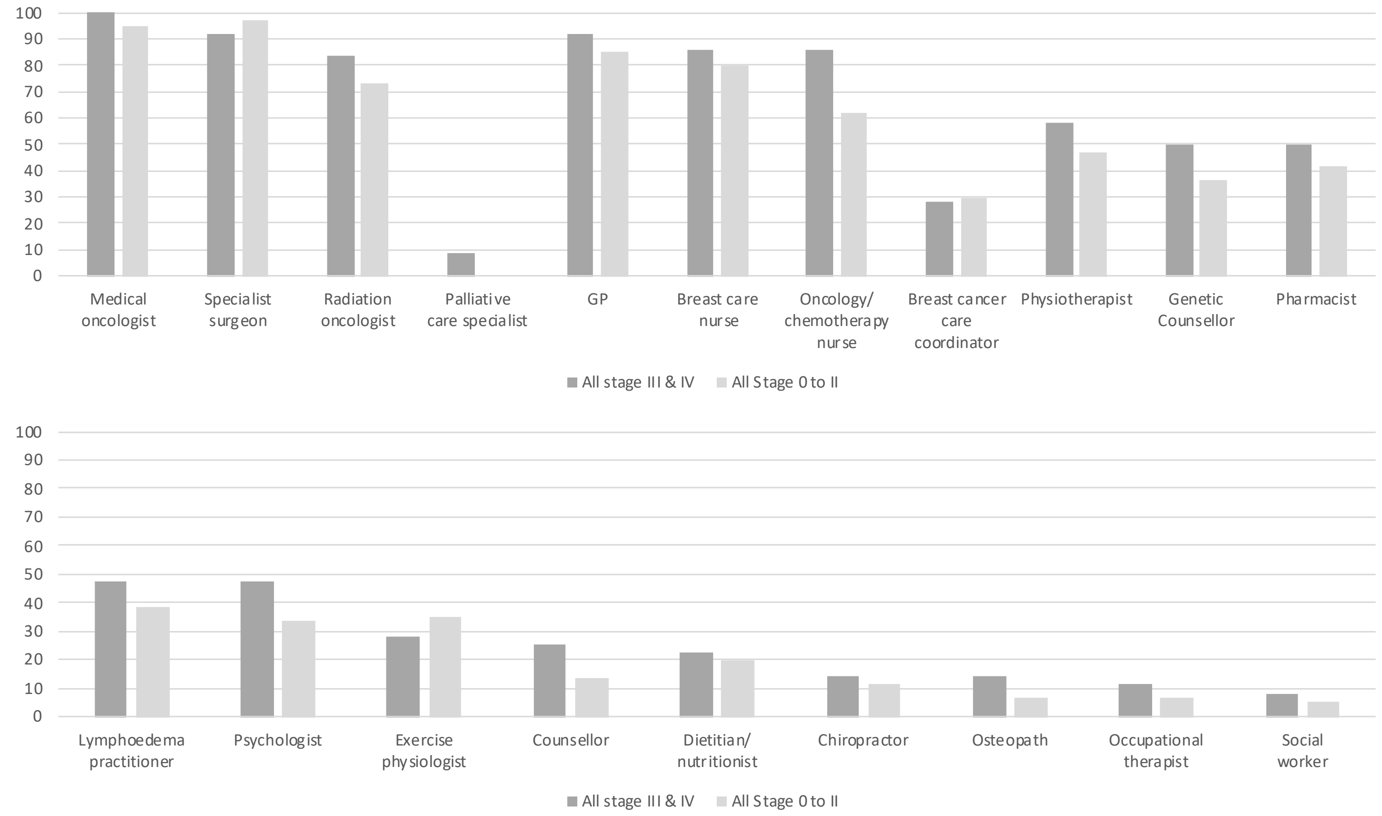


Figure 5.3: Access to healthcare professionals(% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 5.5: Access to healthcare professionals – Stage III & IV variations

Access to healthcare professionals	Reported less frequently	Reported more frequently
Specialist surgeon	Hormone receptor Stage III & IV	-
Radiation oncologist	-	Triple negative Stage III & IV
Oncology/chemotherapy nurse	-	All Stage III & IV Triple negative Stage III & IV
Physiotherapist	-	Triple negative Stage III & IV
Genetic Counsellor	-	Hormone receptor Stage III & IV
Pharmacist	-	Hormone receptor Stage III & IV
Lymphoedema practitioner	-	Hormone receptor Stage III & IV
Psychologist	-	Triple negative Stage III & IV
Counsellor	-	Hormone receptor Stage III & IV
Chiropractor	Hormone receptor Stage III & IV	-
Social worker	-	Hormone receptor Stage III & IV

Health care system: Stage III & IV

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 .

The majority of participants had private health insurance (n=26, 72.22%). The majority of participants were not asked if they wanted to be treated as a public or private patient (n=13, 36.11%), however, they were asked if they had private health insurance (n=33, 91.67%).

Throughout their treatment, there were 16 participants (44.44%) that were treated as a private patient, 15 participants (41.67%) were mostly treated as a public patient, and there were 5 participants (13.89%) that were equally treated as a private and public patient.

Throughout their treatment, there were 17 participants (47.22%) that were treated mostly in the private hospital system, 13 participants (36.11%) were mostly treated in the public system, and there were 6 participants (16.67%) that were equally treated in the private and public systems.

Table 5.6: Health care system

Health care system	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=95	%	n=59	%	n=36	%	n=24	24.00	n=12	12.00
Private health insurance										
No	21	22.11	11	18.64	10	27.78	6	25.00	4	33.33
Yes	74	77.89	48	81.36	26	72.22	18	75.00	8	66.67
Asked if you wanted to be treated as public or private patient										
No	36	37.89	23	38.98	13	36.11	7	29.17	6	50.00
Yes	59	62.11	36	61.02	23	63.89	17	70.83	6	50.00
Asked if you had private insurance										
No	12	12.63	9	15.25	3	8.33	1	4.17	2	16.67
Yes	83	87.37	50	84.75	33	91.67	23	95.83	10	83.33
Mostly public or private patient										
Equally as a public and private patient	13	13.68	8	13.56	5	13.89	1	4.17	4	33.33
Private patient	49	51.58	33	55.93	16	44.44	13	54.17	3	25.00
Public patient	33	37.74	18	30.51	15	41.67	10	41.67	5	41.67
Which hospital system										
Both public and private	19	20.00	13	22.03	6	16.67	1	4.17	5	41.67
Private	45	47.37	28	47.46	17	47.22	14	58.33	3	25.00
Public	31	32.63	18	30.51	13	36.11	9	37.50	4	33.33

Health care system	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=95	%	n=44	%	n=51	%	n=20	20.00	n=39	39.00
Private health insurance										
No	21	22.11	11	25.00	10	19.61	5	25.00	6	15.38
Yes	74	77.89	33	75.00	41	80.39	15	75.00	33	84.62
Asked if you wanted to be treated as public or private patient										
No	36	37.89	16	36.36	20	39.22	9	45.00	14	35.90
Yes	59	62.11	28	63.64	31	60.78	11	55.00	25	64.10
Asked if you had private insurance										
No	12	12.63	5	11.36	7	13.73	4	20.00	5	12.82
Yes	83	87.37	39	88.64	44	86.27	16	80.00	34	87.18
Mostly public or private patient										
Equally as a public and private patient	13	13.68	4	9.09	9	17.65	3	15.00	5	12.82
Private patient	49	51.58	20	45.45	29	56.86	7	35.00	26	66.67
Public patient	33	34.74	20	45.45	13	25.49	10	50.00	8	20.51
Which hospital system										
Both public and private	19	20.00	4	9.09	15	29.41	3	15.00	10	25.64
Private	45	47.37	20	45.45	25	49.02	6	30.00	22	56.41
Public	31	32.63	20	45.45	11	21.57	11	55.00	7	17.95

Table 5.7: Health care system – Stage III & IV variations

Health care system	Reported less frequently	Reported more frequently
Private health insurance		
No		Hormone receptor Stage III & IV
Yes	Hormone receptor Stage III & IV	
Asked if you wanted to be treated as public or private patient		
No		Hormone receptor Stage III & IV
Yes	Hormone receptor Stage III & IV	
Asked if you had private insurance		
No		
Yes		
Mostly public or private patient		
Equally as a public and private patient		Hormone receptor Stage III & IV
Private patient	Hormone receptor Stage III & IV	
Public patient		
Which hospital system		
Both public and private	Triple negative Stage III & IV	Hormone receptor Stage III & IV
Private	Hormone receptor Stage III & IV	Triple negative Stage III & IV

Affordability of healthcare: Stage III & IV

Participants were asked a series of questions about affordability of healthcare in the online questionnaire.

The first question was about having to delay or cancer healthcare appointments because they were unable to afford them. Almost all the participants never or rarely had to delay or cancel appointments due to affordability (n = 33, 91.67%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=34, 94.44%).

The third question was about the affordability of basic essentials such as such as food, housing and power. There were 27 participants (75.00%) that never or rarely had trouble paying for essentials, and 7 participants (19.44%) that sometimes found it difficult, and 2 participants (5.56%) 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 32 participants (88.89%) that paid for additional carers due to their condition.

Table 5.8: Affordability of healthcare

Affordability of healthcare	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=95	%	n=59	%	n=36	%	n=24	24.00	n=12	12.00
Cancel appointments										
Never	81	85.26	52	88.14	29	80.56	19	79.17	10	83.33
Rarely	6	6.32	2	3.39	4	11.11	2	8.33	**2**	**16.67**
Sometimes	3	3.16	1	1.69	2	5.56	2	8.33	0	0.00
Often	2	2.11	2	3.39	0	0.00	0	0.00	0	0.00
Very often	3	3.16	2	3.39	1	2.78	1	4.17	0	0.00
Did not fill prescriuptions										
Never	83	87.37	52	88.14	31	86.11	20	83.33	11	91.67
Rarely	4	4.21	1	1.69	3	8.33	2	8.33	1	8.33
Sometimes	8	8.42	6	10.17	2	5.56	2	8.33	0	0.00
Difficult to pay for basic necessities										
Never	63	66.32	41	69.49	22	61.11	15	62.50	7	58.33
Rarely	16	16.84	11	18.64	5	13.89	**1**	**4.17**	**4**	**33.33**
Sometimes	10	10.53	3	5.08	7	19.44	**6**	**25.00**	1	8.33
Often	3	3.16	2	3.39	1	2.78	1	4.17	0	0.00
Very often	3	3.16	2	3.39	1	2.78	1	4.17	0	0.00
Additional carers										
No	83	87.37	51	86.44	32	88.89	21	87.50	11	91.67
Yes	12	12.63	8	13.56	4	11.11	3	12.50	1	8.33

Affordability of healthcare	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=95	%	n=44	%	n=51	%	n=20	20.00	n=39	39.00
Cancel appointments										
Never	81	85.26	37	84.09	44	86.27	18	90.00	34	87.18
Rarely	6	6.32	2	4.55	4	7.84	0	0.00	2	5.13
Sometimes	3	3.16	2	4.55	1	1.96	0	0.00	1	2.56
Often	2	2.11	1	2.27	1	1.96	1	5.00	1	2.56
Very often	3	3.16	2	4.55	1	1.96	1	5.00	1	2.56
Did not fill prescriuptions										
Never	83	87.37	37	84.09	46	90.20	17	85.00	35	89.74
Rarely	4	4.21	3	6.82	1	1.96	1	5.00		0.00
Sometimes	8	8.42	4	9.09	4	7.84	2	10.00	4	10.26
Difficult to pay for basic necessities										
Never	63	66.32	28	63.64	35	68.63	13	65.00	28	71.79
Rarely	16	16.84	6	13.64	10	19.61	5	25.00	6	15.38
Sometimes	10	10.53	6	13.64	4	7.84	0	0.00	3	7.69
Often	3	3.16	2	4.55	1	1.96	1	5.00	1	2.56
Very often	3	3.16	2	4.55	1	1.96	1	5.00	1	2.56
Additional carers										
No	83	87.37	40	90.91	43	84.31	19	95.00	32	82.05
Yes	12	12.63	4	9.09	8	15.69	1	5.00	7	17.95

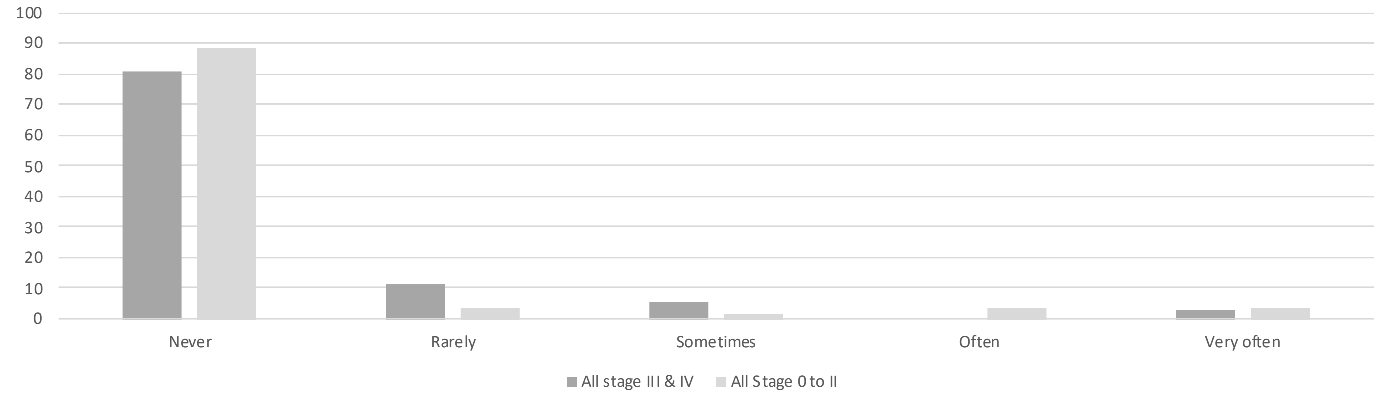


Figure 5.4: Cancel appointments (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

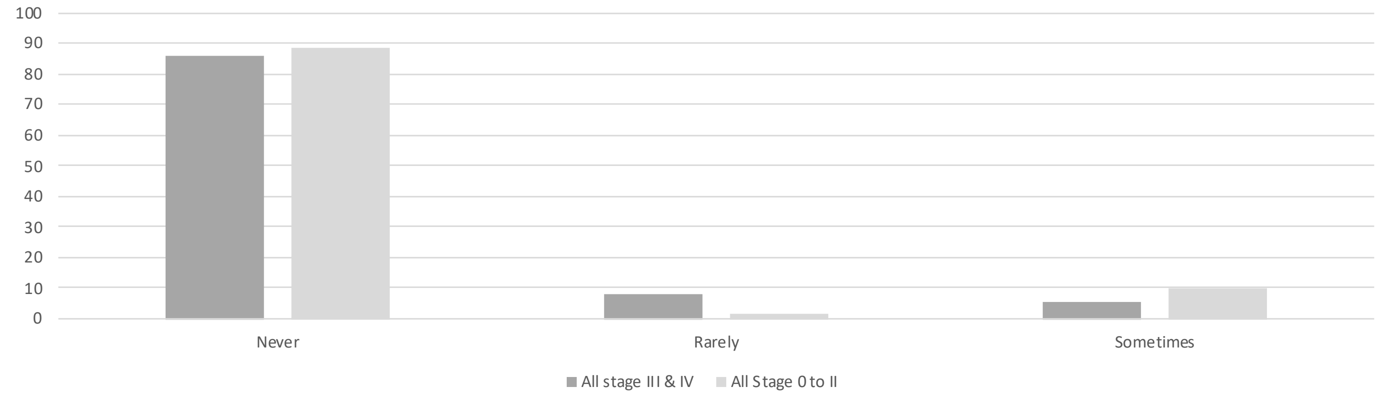


Figure 5.5: Did not fill prescriptions (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

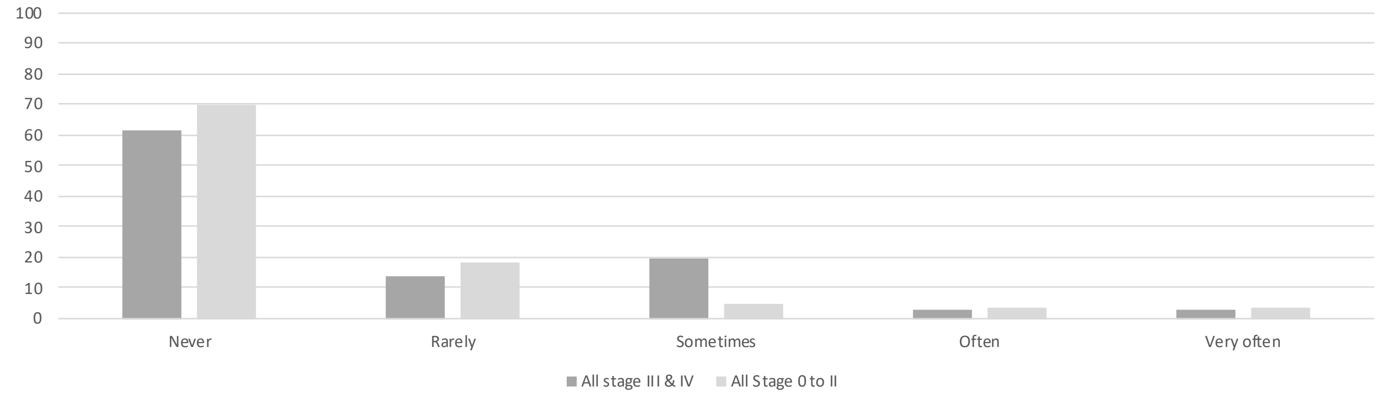


Figure 5.6: Pay for basic essentials (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 5.9: Affordability of healthcare – Stage III & IV variations

Affordability of healthcare	Reported less frequently	Reported more frequently
Cancel appointments		
Rarely	-	Hormone receptor Stage III & IV
Difficult to pay for basic necessities		
Rarely	Triple negative Stage III & IV	Hormone receptor Stage III & IV
Sometimes	-	Triple negative Stage III & IV

Cost of condition: Stage III & IV

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.

The most common amount was between $1001 to 2500 (n=5, 13.89%), followed by between $2501 to 5000 (n=8, 22.22%). There were 5 participants (13.89%), that spent Not sure/not specified a month.

Burden of cost

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

The amount spent was an extremely significant or moderately significant burden for 11 participants (50.00%), somewhat significant for 5 participants (22.73%), and slightly or not at all significant for 6 participants (27.27%).

Table 5.10: Estimated monthly out of pocket expenses due to condition

Estimated monthly out of pocket expenses due to condition	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=95	%	n=59	%	n=36	%	n=24	24.00	n=12	12.00
$0	49	51.58	35	59.32	14	38.89	11	45.83	3	25.00
$100 to 1000	7	7.37	5	8.47	2	5.56	1	4.17	1	8.33
$1001 to 2500	10	10.53	5	8.47	5	13.89	3	12.50	2	16.67
$2501 to 5000	15	15.79	7	11.86	8	22.22	5	20.83	3	25.00
More than $5000	4	4.21	2	3.39	2	5.56	2	8.33	0	0.00
Not sure/not specified	10	10.53	5	8.47	5	13.89	2	8.33	3	25.00

Estimated monthly out of pocket expenses due to condition	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=95	%	n=44	%	n=51	%	n=20	20.00	n=39	39.00
$0	49	51.58	25	56.82	24	47.06	14	70.00	21	53.85
$100 to 1000	7	7.37	4	9.09	3	5.88	3	15.00	2	5.13
$1001 to 2500	10	10.53	5	11.36	5	9.80	2	10.00	3	7.69
$2501 to 5000	15	15.79	5	11.36	10	19.61	0	0.00	7	17.95
More than $5000	4	4.21	2	4.55	2	3.92	0	0.00	2	5.13
Not sure/not specified	10	10.53	3	6.82	7	13.73	1	5.00	4	10.26

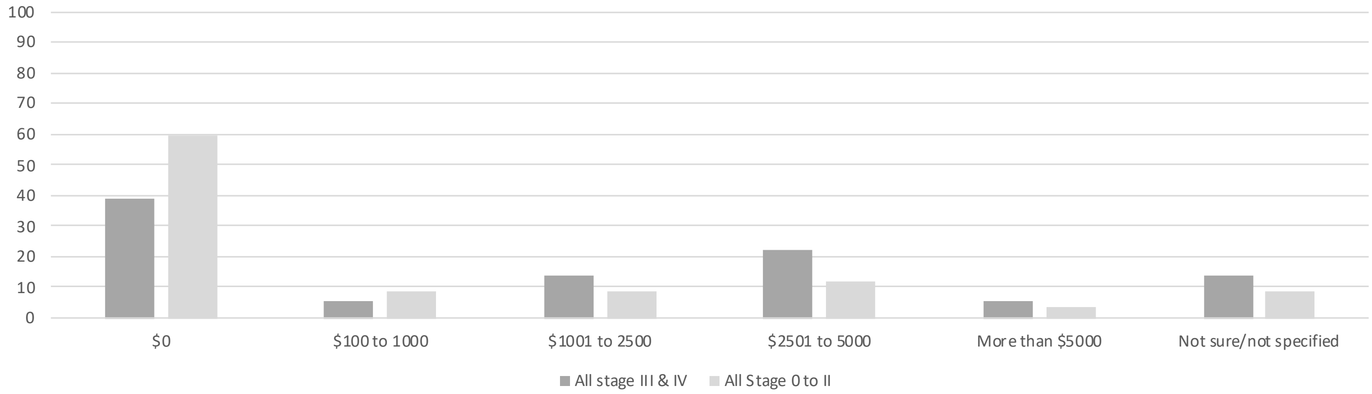


Figure 5.7: Estimated monthly out of pocket expenses due to condition (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 5.11: Estimated monthly out of pocket expenses due to condition– Stage III & IV variations

Estimated monthly out of pocket expenses due to condition	Reported less frequently	Reported more frequently
$0	All Stage III & IV Hormone receptor Stage III & IV	-
Not sure/not specified	-	Hormone receptor Stage III & IV

Table 5.12: Burden of out-of-pocket expenses due to condition

Burden of out-of-pocket expenses due to condition	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=46	%	n=24	%	n=22	%	n=13	13.00	n=9	9.00
Extremely significant	7	15.22	2	8.33	5	22.73	3	23.08	2	22.22
Moderately significant	8	17.39	2	8.33	6	27.27	1	7.69	5	55.56
Somewhat significant	12	26.09	7	29.17	5	22.73	4	30.77	1	11.11
Slightly significant	14	30.43	10	41.67	4	18.18	3	23.08	1	11.11
Not at all significant	5	10.87	3	12.50	2	9.09	2	15.38	0	0.00

Burden of out-of-pocket expenses due to condition	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=46	%	n=19	%	n=27	%	n=6	6.00	n=18	18.00
Extremely significant	7	15.22	4	21.05	3	11.11	1	16.67	1	5.56
Moderately significant	8	17.39	2	10.53	6	22.22	1	16.67	1	5.56
Somewhat significant	12	26.09	5	26.32	7	25.93	1	16.67	6	33.33
Slightly significant	14	30.43	5	26.32	9	33.33	2	33.33	8	44.44
Not at all significant	5	10.87	3	15.79	2	7.41	1	16.67	2	11.11

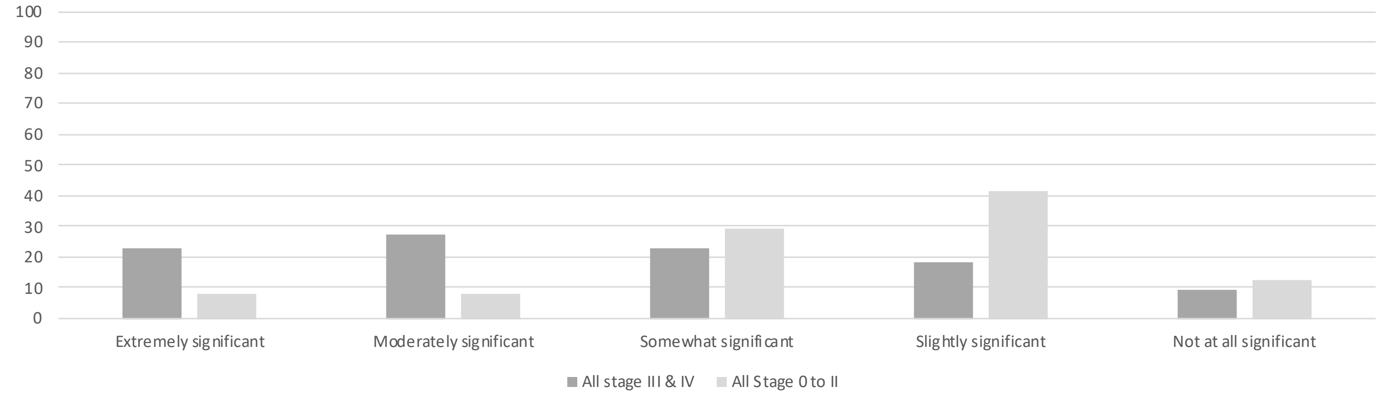


Figure 5.8: Burden of out-of-pocket expenses due to condition (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 5.13: Burden of out-of-pocket expenses due to condition– Stage III & IV variations

Burden of out-of-pocket expenses due to condition	Reported less frequently	Reported more frequently
Moderately significant	-	Hormone receptor Stage III & IV
Somewhat significant	Hormone receptor Stage III & IV	
Slightly significant	All Stage III & IV Hormone receptor Stage III & IV	-
Not at all significant	Hormone receptor Stage III & IV	-

Changes to employment status: Stage III & IV

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 .

Work status for 5 participants (13.89%) had not changed since diagnosis, and 1 participants (2.78%) were retired or did not have a job. There were 5 participants (13.89%) had to quit their job, 11 participants (30.56%) reduced the number of hours they worked, and 3 participants (8.33%) that accessed their superannuation early. There were 15 participants (41.67%) that took leave from work without pay, and 10 participants (27.78%) that took leave from work with pay.

Changes to carer/partner employment status

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

There were 10 participants (27.78%), 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=16, 44.44%). There were 3 participants (8.33%) whose partners reduced the numbers of hours they worked, and 0 partners, (0.00%) that quit their job. The partners of 3 participants (8.33%) took leave without pay, and there were 6 partners (16.67%) that took leave with pay.

Table 5.14: Changes in employment status due to condition

Changes in employment status due to condition	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=95	%	n=59	%	n=36	%	n=24	24.00	n=12	12.00
Work status has not changed	21	22.11	16	27.12	5	13.89	4	16.67	1	8.33
Retired or did not have a job	9	9.47	8	13.56	1	2.78	1	4.17	0	0.00
Had to quit job	12	12.63	7	11.86	5	13.89	2	8.33	3	25.00
Reduced number of hours worked	25	26.32	14	23.73	11	30.56	6	25.00	5	41.67
Leave from work without pay	27	28.42	12	20.34	15	41.67	11	45.83	4	33.33
Leave from work with pay	22	23.16	12	20.34	10	27.78	5	20.83	5	41.67
Accessed Superannuation early due to condition	7	7.37	4	6.78	3	8.33	3	12.50	0	0.00

Changes in employment status due to condition	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=95	%	n=44	%	n=51	%	n=20	20.00	n=39	39.00
Work status has not changed	21	22.11	11	25.00	10	19.61	7	35.00	9	23.08
Retired or did not have a job	9	9.47	1	2.27	8	15.69	0	0.00	8	20.51
Had to quit job	12	12.63	4	9.09	8	15.69	2	10.00	5	12.82
Reduced number of hours worked	25	26.32	10	22.73	15	29.41	4	20.00	10	25.64
Leave from work without pay	27	28.42	16	36.36	11	21.57	5	25.00	7	17.95
Leave from work with pay	22	23.16	12	27.27	10	19.61	7	35.00	5	12.82
Accessed Superannuation early due to condition	7	7.37	4	9.09	3	5.88	1	5.00	3	7.69

Figure 5.9: Changes in employment status due to condition (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 5.15: Changes in employment status due to condition– Stage III & IV variations

Estimated monthly out of pocket expenses due to condition	Reported less frequently	Reported more frequently
Work status has not changed	Hormone receptor Stage III & IV	-
Had to quit job	-	Hormone receptor Stage III & IV
Reduced number of hours worked	-	Hormone receptor Stage III & IV
Leave from work without pay	-	All Stage III & IV Triple negative Stage III & IV
Leave from work with pay	-	Hormone receptor Stage III & IV

Figure 5.10: Changes in employment status due to condition

Table 5.16: Changes to carer/partner employment status

Changes to carer/partner employment status	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=95	%	n=59	%	n=36	%	n=24	%	n=12	%
Does not have a partner/main carer	22	23.16	12	20.34	10	27.78	6	25.00	4	33.33
Work status has not changed	46	48.42	30	50.85	16	44.44	12	50.00	4	33.33
Retired or did not have a job	2	2.11	2	3.39	0	0.00	0	0.00	0	0.00
Had to quit job	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Reduced number of hours worked	8	8.42	5	8.47	3	8.33	2	8.33	1	8.33
Leave from work without pay	7	7.37	4	6.78	3	8.33	3	12.50	0	0.00
Leave from work with pay	18	18.95	12	20.34	6	16.67	2	8.33	4	33.33

Changes to carer/partner employment status	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=95	%	n=44	%	n=51	%	n=20	%	n=39	%
Does not have a partner/main carer	22	23.16	11	25.00	11	21.57	5	25.00	7	17.95
Work status has not changed	46	48.42	22	50.00	24	47.06	10	50.00	20	51.28
Retired or did not have a job	2	2.11	0	0.00	2	3.92		0.00	2	5.13
Had to quit job	0	0.00	0	0.00	0	0.00		0.00		0.00
Reduced number of hours worked	8	8.42	4	9.09	4	7.84	2	10.00	3	7.69
Leave from work without pay	7	7.37	5	11.36	2	3.92	2	10.00	2	5.13
Leave from work with pay	18	18.95	8	18.18	10	19.61	6	30.00	6	15.38

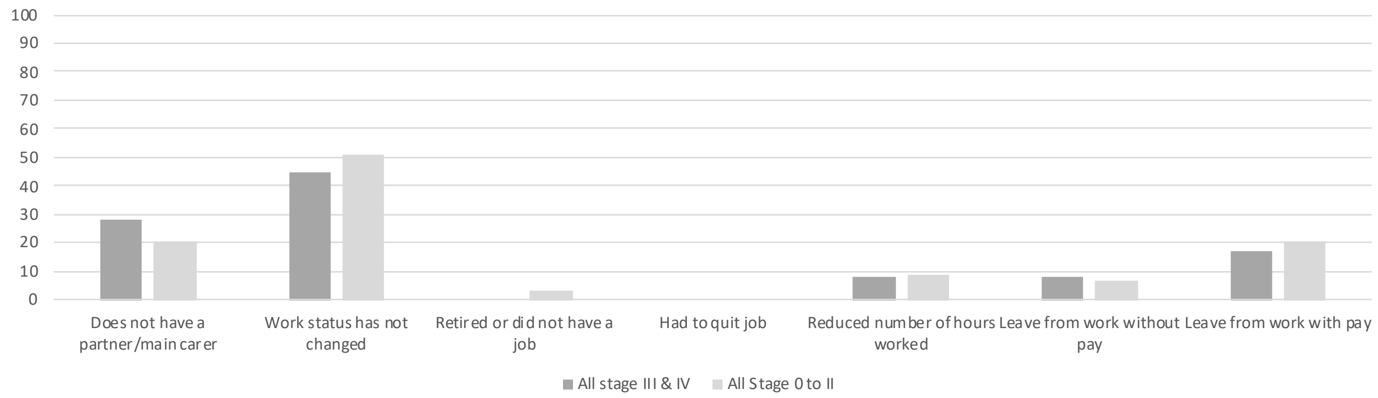


Figure 5.10: Changes to carer/partner employment status (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 5.17: Changes to carer/partner employment status– Stage III & IV variations

Changes to carer/partner employment status	Reported less frequently	Reported more frequently
Does not have a partner/main carer	-	Hormone receptor Stage III & IV
Work status has not changed	Hormone receptor Stage III & IV	-
Leave from work with pay	Triple negative Stage III & IV	Hormone receptor Stage III & IV

Reduced income due to condition

Almost all of the participants (n=35, 97.22%) 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.

Most commonly, participants were not sure about the amount their monthly income was reduced by (n=5, 13.89%), or reduced by between $101 to $250 per month (n=10, 27.78%).

Burden of reduced income

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

For 12 of these participants (33.33%), the burden of this reduced income was extremely or moderately significant, for 12 participants (33.33%) the burden was somewhat significant, and for 12 participants (33.33%) the burden was slightly or not all significant.

Table 5.18: Estimated monthly loss of income

Estimated monthly loss of income	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=95	%	n=59	%	n=36	%	n=24	24.00	n=12	12.00
$0	6	6.32	5	8.47	1	2.78	0	0.00	1	8.33
$100 or less	18	18.95	13	22.03	5	13.89	3	12.50	2	16.67
$101 to $250	29	30.53	19	32.20	10	27.78	6	25.00	4	33.33
$251 to $500	12	12.63	5	8.47	7	19.44	5	20.83	2	16.67
$501 to $1000	10	10.53	6	10.17	4	11.11	3	12.50	1	8.33
$1001 or more	10	10.53	5	8.47	5	13.89	4	16.67	1	8.33
Not sure of amount	10	10.53	6	10.17	4	11.11	3	12.50	1	8.33

Estimated monthly loss of income	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=95	**%**	**n=44**	**%**	**n=51**	**%**	**n=20**	**20.00**	**n=39**	**39.00**
$0	6	6.32	3	6.82	3	5.88	3	15.00	2	5.13
$100 or less	18	18.95	9	20.45	9	17.65	6	**30.00**	7	17.95
$101 to $250	29	30.53	12	27.27	17	33.33	6	30.00	13	33.33
$251 to $500	12	12.63	6	13.64	6	11.76	1	5.00	4	10.26
$501 to $1000	10	10.53	6	13.64	4	7.84	3	15.00	3	7.69
$1001 or more	10	10.53	4	9.09	6	11.76	0	**0.00**	5	12.82
Not sure of amount	10	10.53	4	9.09	6	11.76	1	5.00	5	12.82

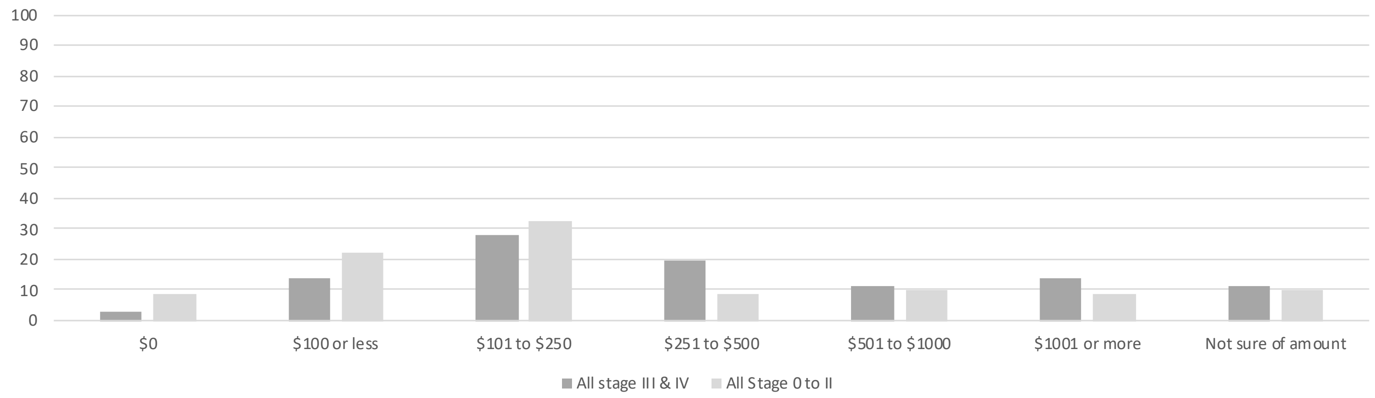


Figure 5.11: Estimated monthly loss of income (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 5.19: Burden of reduced income

Burden of reduced income	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=95	%	n=59	%	n=36	%	n=24	24.00	n=12	12.00
Extremely significant	9	9.47	4	6.78	5	13.89	3	12.50	2	16.67
Moderately significant	14	14.74	7	11.86	7	19.44	4	16.67	3	25.00
Somewhat significant	21	22.11	9	15.25	12	33.33	8	33.33	4	33.33
Slightly significant	31	32.63	28	47.46	3	8.33	3	12.50	0	0.00
Not at all significant	20	21.05	11	18.64	9	25.00	6	25.00	3	25.00

Burden of reduced income	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=95	%	n=44	%	n=51	%	n=20	20.00	n=39	39.00
Extremely significant	9	9.47	5	11.36	4	7.84	2	10.00	2	5.13
Moderately significant	14	14.74	6	13.64	8	15.69	2	10.00	5	12.82
Somewhat significant	21	22.11	9	20.45	12	23.53	1	5.00	8	20.51
Slightly significant	31	32.63	15	34.09	16	31.37	12	60.00	16	41.03
Not at all significant	20	21.05	9	20.45	11	21.57	3	15.00	8	20.51

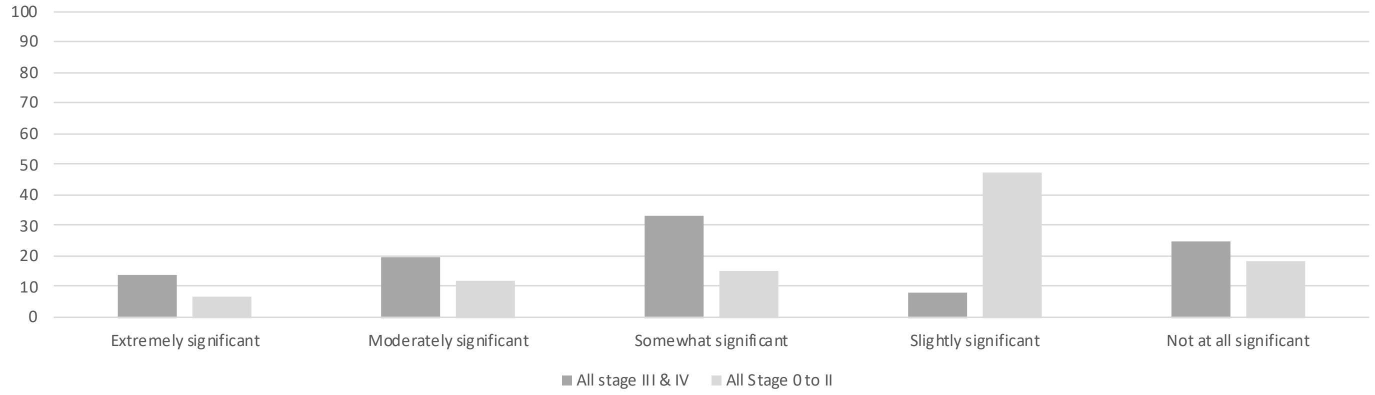


Figure 5.12: Burden of reduced income (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 5.20: Burden of reduced income– Stage III & IV variations

Burden of reduced income	Reported less frequently	Reported more frequently
Moderately significant	-	Hormone receptor Stage III & IV
Somewhat significant	-	All Stage III & IV Triple negative Stage III & IV Hormone receptor Stage III & IV
Slightly significant	All Stage III & IV Triple negative Stage III & IV Hormone receptor Stage III & IV	-

Summary of surgery: Stage III & IV

There were 2 participants (7.14%) that had Re-excision following lumpectomy, 19 participants (67.86%) that had Mastectomy and 11 participants (39.29%) that had Breast reconstruction. Five participants (17.86%) had surgery to remove ovaries, and one participant had (3.57%) surgery to relieve symptoms.

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

Median quality of life from surgery ranged from 2 to 5, in the life was distressing to good range. The median effectiveness of all surgery was between 4 and 5, in the effective to very effective range.

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

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

On average, quality of life from Breast reconstruction was in the 'life was distressing' range (median=2.00, IQR=1.50), and was found to be effective (median=4.00 , IQR=1.00).

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

Table 5.21 Summary of surgeries

Surgery	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=81	%	n=53	%	n=28	%	n=20	%	n=8	%
Lumpectomy	51	62.96	37	69.81	14	50.00	10	50.00	4	50.00
Re-excision following lumpectomy	12	14.81	10	18.87	2	7.14	2	10.00	0	0.00
Mastectomy	40	49.38	21	39.62	19	67.86	13	65.00	6	75.00
Breast reconstruction	27	33.33	16	30.19	11	39.29	9	45.00	2	25.00
Surgery to remove ovaries	16	19.75	11	20.75	5	17.86	3	15.00	2	25.00
Surgery to relieve symptoms	1	1.23	0	0.00	1	3.57	1	5.00	0	0.00

Surgery	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=81	%	n=35	%	n=46	%	n=15	%	n=38	%
Lumpectomy	51	62.96	19	54.29	32	69.57	9	60.00	28	73.68
Re-excision following lumpectomy	12	14.81	2	5.71	10	21.74	0	0.00	10	26.32
Mastectomy	40	49.38	20	57.14	20	43.48	7	46.67	14	36.84
Breast reconstruction	27	33.33	13	37.14	14	30.43	4	26.67	12	31.58
Surgery to remove ovaries	16	19.75	7	20.00	9	19.57	4	26.67	7	18.42
Surgery to relieve symptoms	1	1.23	1	2.86	0	0.00	0	0.00	0	0.00

Surgery	All Stage III & IV		Quality of life		Effectiveness	
	n=36	%	Median	IQR	Median	IQR
Mastectomy	18	50.00	2.00	1.00	4.50	1.00
Lumpectomy	13	36.11	3.00	1.00	5.00	1.00
Breast reconstruction	11	30.56	2.00	1.50	4.00	1.00
Surgery to remove ovaries	5	13.89	5.00	1.00	5.00	0.00

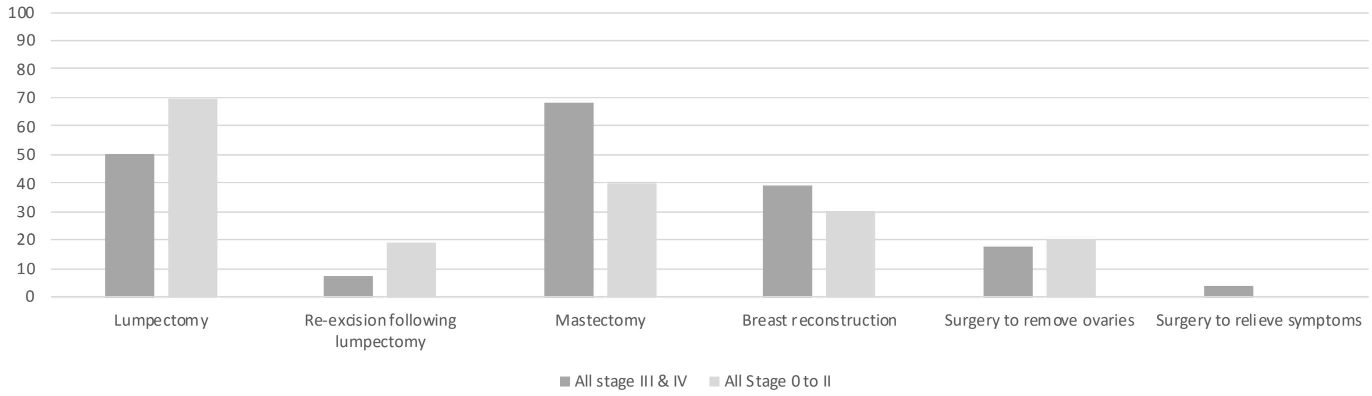


Figure 5.13: Summary of surgeries (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

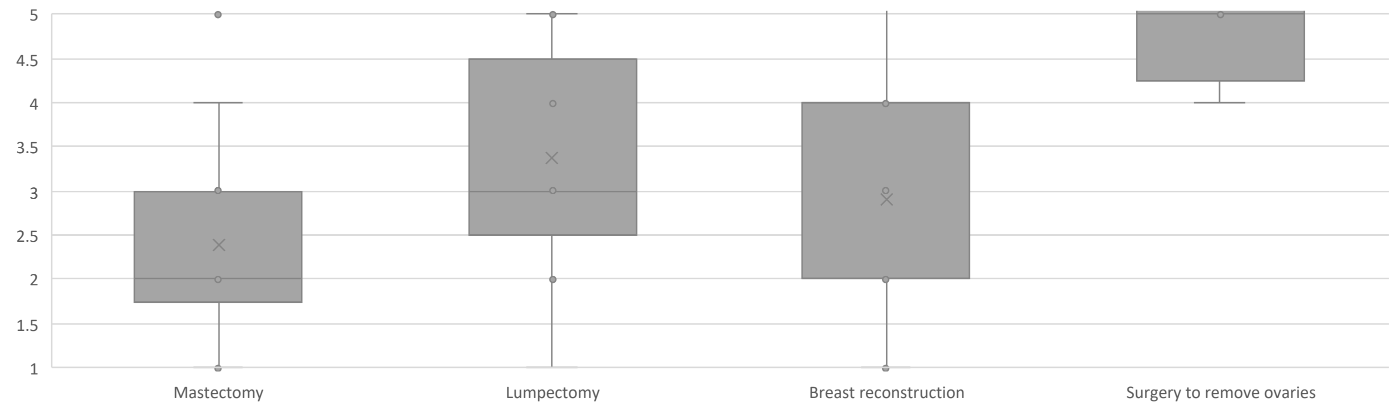


Figure 5.14: Quality of life from surgery: Stage III & IV

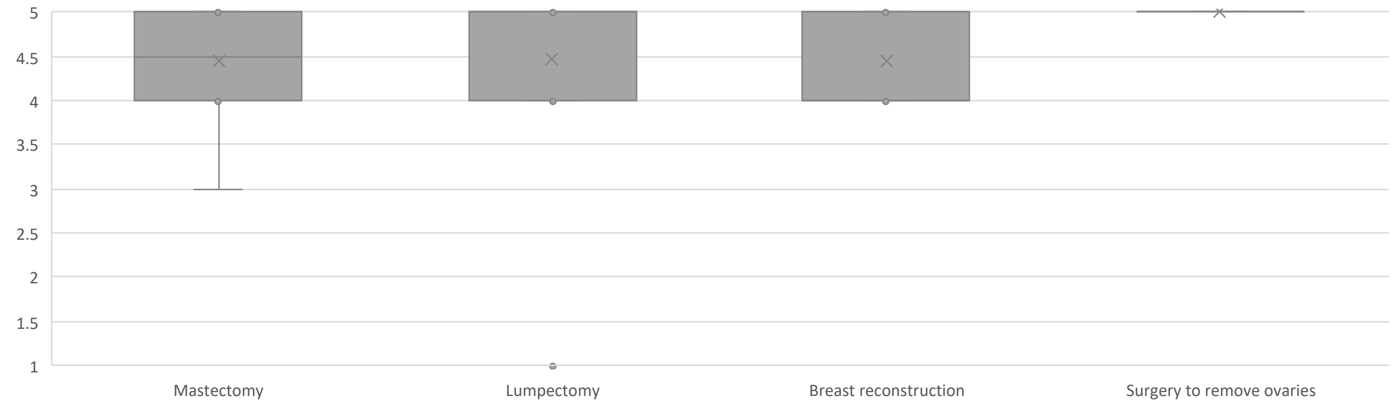


Figure 5.15: Effectiveness of surgery: Stage III & IV

Table 5.22 Summary of surgeries– Stage III & IV variations

Surgery	Reported less frequently	Reported more frequently
Lumpectomy	All Stage III & IV Triple negative Stage III & IV Hormone receptor Stage III & IV	-
Re-excision following lumpectomy	Hormone receptor Stage III & IV	-
Mastectomy	-	All Stage III & IV Triple negative Stage III & IV Hormone receptor Stage III & IV
Breast reconstruction	-	Triple negative Stage III & IV

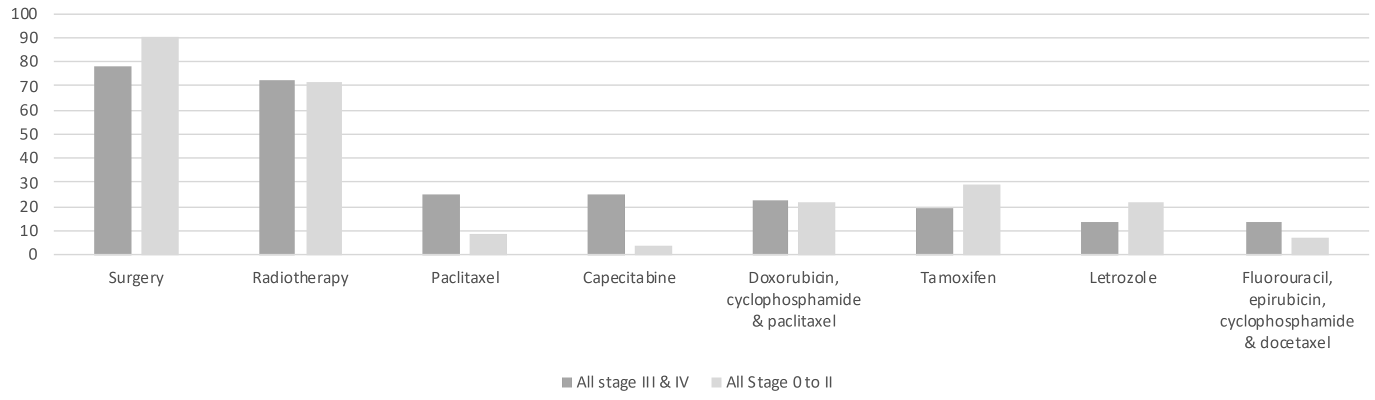
Summary of treatments: Stage III & IV

Treatments are listed in the table below. All participants with stage II & IV breast cancer received treatment, 28 participants (77.78%) had surgery, and 26 participants (72.22%) had radiotherapy.

Table 5.23: Overview of treatments reported

Summary of treatments	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=95	%	n=59	%	n=36	%	n=24	%	n=12	%
No treatment	1	1.05	1	1.69	0	0.00	0	0.00	0	0.00
Surgery	81	85.26	53	89.83	28	77.78	20	83.33	8	66.67
Radiotherapy	68	71.58	42	71.19	26	72.22	18	75.00	8	66.67
Paclitaxel	14	14.74	5	8.47	9	25.00	7	29.17	2	16.67
Capecitabine	11	11.58	2	3.39	9	25.00	8	33.33	1	8.33
Doxorubicin and cyclophosphamide and paclitaxel	21	22.11	13	22.03	8	22.22	7	29.17	1	8.33
Tamoxifen	24	25.26	17	28.81	7	19.44	1	4.17	6	50.00
Letrozole	18	18.95	13	22.03	5	13.89	1	4.17	4	33.33
Fluorouracil epirubicin cyclophosphamide and docetaxel	9	9.47	4	6.78	5	13.89	3	12.50	2	16.67
Doxorubicin	6	6.32	1	1.69	5	13.89	4	16.67	1	8.33
Doxorubicin and cyclophosphamide	9	9.47	4	6.78	5	13.89	5	20.83	0	0.00
Docetaxel and cyclophosphamide	7	7.37	3	5.08	4	11.11	2	8.33	2	16.67
Goserelin	7	7.37	3	5.08	4	11.11	2	8.33	2	16.67
Carboplatin paclitaxel	7	7.37	3	5.08	4	11.11	4	16.67	0	0.00
Denosumab	5	5.26	2	3.39	3	8.33	1	4.17	2	16.67
Docetaxel	7	7.37	4	6.78	3	8.33	1	4.17	2	16.67
Palbociclib	2	2.11	0	0.00	2	5.56	1	4.17	1	8.33
Anastrozole	8	8.42	7	11.86	1	2.78	0	0.00	1	8.33
Carboplatin and gemcitabine	1	1.05	0	0.00	1	2.78	0	0.00	1	8.33
Exemestane	5	5.26	4	6.78	1	2.78	0	0.00	1	8.33
Exemestane and goserelin	2	2.11	1	1.69	1	2.78	0	0.00	1	8.33
Fulvestrant	1	1.05	0	0.00	1	2.78	0	0.00	1	8.33
Ribociclib	1	1.05	0	0.00	1	2.78	0	0.00	1	8.33
Zoledronic acid	5	5.26	4	6.78	1	2.78	0	0.00	1	8.33
Carboplatin	3	3.16	2	3.39	1	2.78	1	4.17	0	0.00
Cyclophosphamide and methotrexate	2	2.11	1	1.69	1	2.78	1	4.17	0	0.00
Doxorubicin cyclophosphamide paclitaxel and trastuzumab	1	1.05	0	0.00	1	2.78	1	4.17	0	0.00
Paclitaxel pertuzumab and trastuzumab	1	1.05	0	0.00	1	2.78	1	4.17	0	0.00
Abemaciclib	1	1.05	1	1.69	0	0.00	0	0.00	0	0.00
Fluorouracil epirubicin and cyclophosphamide	1	1.05	1	1.69	0	0.00	0	0.00	0	0.00

Summary of treatments	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=95	%	n=44	%	n=51	%	n=20	%	n=39	%
No treatment	1	1.05	0	0.00	1	1.96	0	0.00	1	2.56
Surgery	81	85.26	35	77.27	46	90.20	15	75.00	38	97.44
Radiotherapy	68	71.58	26	59.09	42	82.35	8	40.00	34	87.18
Paclitaxel	14	14.74	10	22.73	4	7.84	3	15.00	2	5.13
Capecitabine	11	11.58	10	22.73	1	1.96	2	10.00	0	0.00
Doxorubicin and cyclophosphamide and paclitaxel	21	22.11	16	36.36	5	9.80	9	45.00	4	10.26
Tamoxifen	24	25.26	1	2.27	23	45.10	0	0.00	17	43.59
Letrozole	18	18.95	1	2.27	17	33.33	0	0.00	13	33.33
Fluorouracil epirubicin cyclophosphamide and docetaxel	9	9.47	3	6.82	6	11.76	0	0.00	4	10.26
Doxorubicin	6	6.32	5	11.36	1	1.96	1	5.00	0	0.00
Doxorubicin and cyclophosphamide	9	9.47	8	18.18	1	1.96	3	15.00	1	2.56
Docetaxel and cyclophosphamide	7	7.37	3	6.82	4	7.84	1	5.00	2	5.13
Goserelin	7	7.37	2	4.55	5	9.80	0	0.00	3	7.69
Carboplatin paclitaxel	7	7.37	6	13.64	1	1.96	2	10.00	1	2.56
Denosumab	5	5.26	1	2.27	4	7.84	0	0.00	2	5.13
Docetaxel	7	7.37	3	6.82	4	7.84	2	10.00	2	5.13
Palbociclib	2	2.11	1	2.27	1	1.96	0	0.00	0	0.00
Anastrozole	8	8.42	0	0.00	8	15.69	0	0.00	7	17.95
Carboplatin and gemcitabine	1	1.05	0	0.00	1	1.96	0	0.00	0	0.00
Exemestane	5	5.26	0	0.00	5	9.80	0	0.00	4	10.26
Exemestane and goserelin	2	2.11	0	0.00	2	3.92	0	0.00	1	2.56
Fulvestrant	1	1.05	0	0.00	1	1.96	0	0.00	0	0.00
Ribociclib	1	1.05	0	0.00	1	1.96	0	0.00	0	0.00
Zoledronic acid	5	5.26	0	0.00	5	9.80	0	0.00	4	10.26
Carboplatin	3	3.16	3	6.82	0	0.00	2	10.00	0	0.00
Cyclophosphamide and methotrexate	2	2.11	2	4.55	0	0.00	1	5.00	0	0.00
Doxorubicin cyclophosphamide paclitaxel and trastuzumab	1	1.05	1	2.27	0	0.00	0	0.00	0	0.00
Paclitaxel pertuzumab and trastuzumab	1	1.05	1	2.27	0	0.00	0	0.00	0	0.00
Abemaciclib	1	1.05	0	0.00	1	1.96	0	0.00	1	2.56
Fluorouracil epirubicin and cyclophosphamide	1	1.05	0	0.00	1	1.96	0	0.00	1	2.56



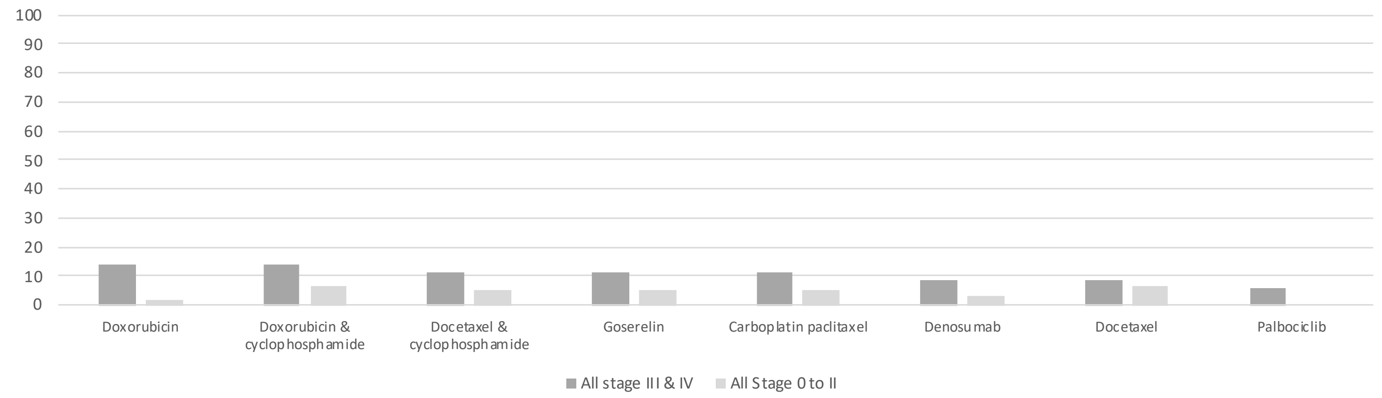


Figure 5.16: Overview of treatments reported in combinations (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Drug treatments

The most common types of drug treatments were Paclitaxel, (n=9, 25.00%), Capecitabine (n=9,25.00%), and Doxorubicin and cyclophosphamide, and paclitaxel (n=8,22.22%).

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

Median quality of life from drug treatments ranged from 1 to 4, in the life was very distressing to average range.The median effectiveness of drug treatments was between 4 and 5, in the effective to very effective range.

On average, quality of life from Paclitaxel was in the 'life was a little distressing' range (median=3.00, IQR=5.00), and was found to be very effective (median=5.00 , IQR=9.00).

On average, quality of life from Capecitabine was in the 'life was a little distressing' range (median=3.00, IQR=7.00), and was found to be effective (median=4.00 , IQR=7.75).

On average, quality of life from Doxorubicin and cyclophosphamide, and paclitaxel was in the 'life was a little distressing' range (median=3.00, IQR=6.00), and was found to be effective (median=4.00 , IQR=9.00).

On average, quality of life from Tamoxifen was in the 'life was a little distressing' range (median=3.00, IQR=7.00), and was found to be very effective (median=4.50 , IQR=9.00).

On average, quality of life from Letrozole was in the 'life was average' range (median=4.00, IQR=8.00), and was found to be effective (median=4.00 , IQR=8.00).

On average, quality of life from Fluorouracil, epirubicin, cyclophosphamide, and docetaxel was in the 'life was a little distressing' range (median=3.00, IQR=6.00), and was found to be very effective (median=5.00 , IQR=9.75).

On average, quality of life from Doxorubicin was in the 'life was distressing' range (median=2.00, IQR=5.00), and was found to be effective (median=4.00 , IQR=8.00).

On average, quality of life from Doxorubicin and cyclophosphamide was in the 'life was very distressing' range (median=1.00, IQR=3.00), and was found to be very effective (median=5.00 , IQR=9.00).

Table 5.24: Drug treatments quality of life and effectiveness: Stage III & IV

Drug treatments	All Stage III & IV		Quality of life		Effectiveness		Stopped treatment due to side effects	
	n=36	%	Median	IQR	Median	IQR	Median	IQR
Paclitaxel	9	25.00	3.00	5.00	5.00	9.00	1	11.11
Capecitabine	9	25.00	3.00	7.00	4.00	7.75	2	22.22
Doxorubicin and cyclophosphamide, and paclitaxel	8	22.22	3.00	6.00	4.00	9.00	1	12.50
Tamoxifen	8	22.22	3.00	7.00	4.50	9.00	2	25.00
Letrozole	5	13.89	4.00	8.00	4.00	8.00	2	40.00
Fluorouracil, epirubicin, cyclophosphamide, and docetaxel	5	13.89	3.00	6.00	5.00	9.75	0	0.00
Doxorubicin	6	16.67	2.00	5.00	4.00	8.00	0	0.00
Doxorubicin and cyclophosphamide	6	16.67	1.00	3.00	5.00	9.00	0	0.00

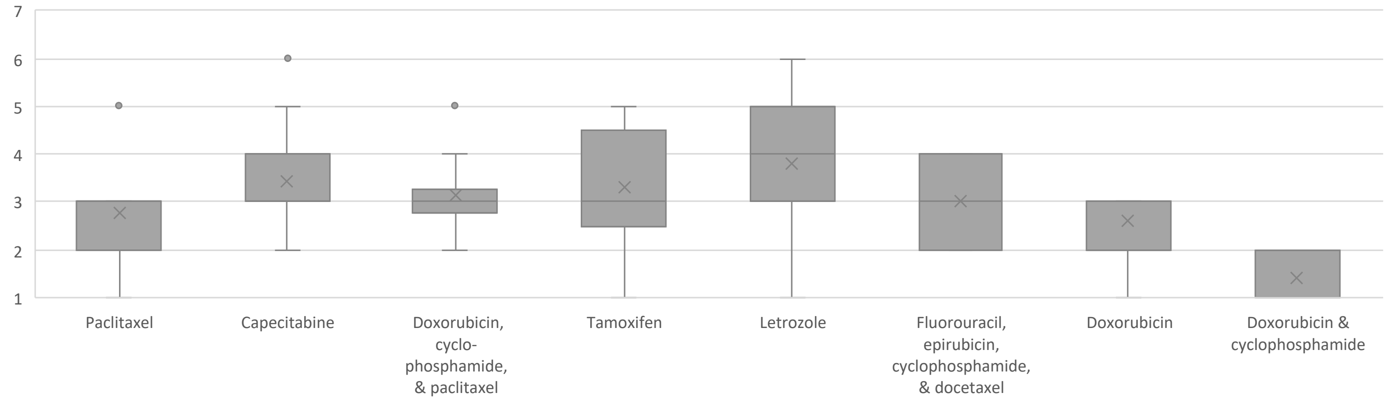


Figure 5.17: Drug treatments quality of life: Stage III & IV

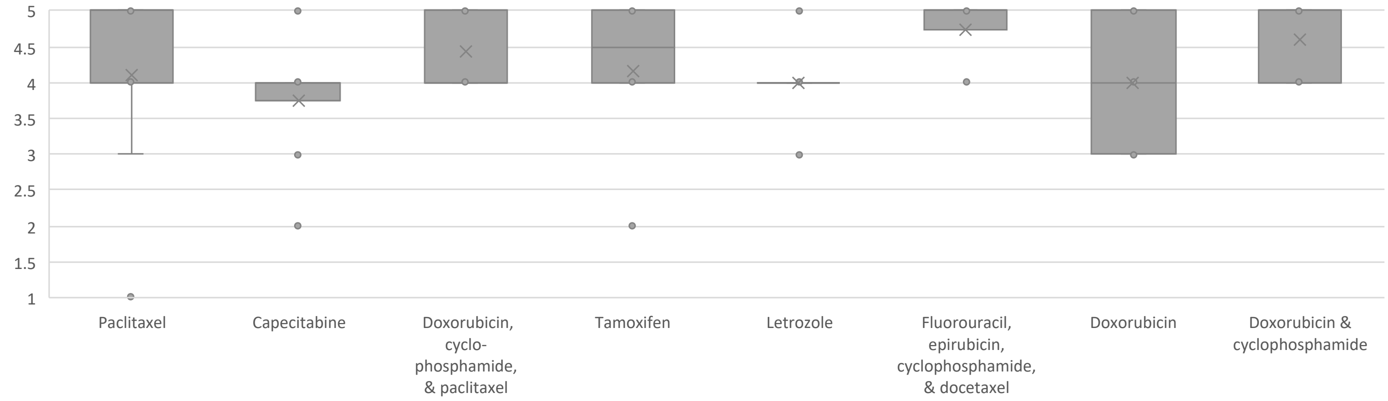


Figure 5.18: Drug treatments effectiveness: Stage III & IV

Allied health: Stage III & IV

The most common allied health service used was Physiotherapy (n=19, 52.78%), followed by Psychologist (n=19, 52.78%), and Dietician (n=7, 19.44%). There were 5 participants (13.89%) that saw a Podiatrist, 4 participants (11.11%) that saw a Occupational therapist, and 2 participants (5.56%) that saw a Social worker.

On average, quality of life from Physiotherapy 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 Psychology 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=2.50).

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

On average, quality of life from Podiatry was in the 'life was good' range (median=5.00, IQR=1.00), and was found to be effective (median=4.00, IQR=3.00).

Table 5.25: Allied health

Allied health	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=96	%	n=60	%	n=36	%	n=24	24.00	n=12	12.00
Physiotherapy	51	53.13	32	53.33	19	52.78	12	50.00	2	16.67
Occupational therapist	13	13.54	9	15.00	4	11.11	3	12.50	1	8.33
Psychologist	39	40.63	20	33.33	19	52.78	12	50.00	7	58.33
Dietician	16	16.67	9	15.00	7	19.44	5	20.83	1	8.33
Social worker	10	10.42	8	13.33	2	5.56	1	4.17	7	58.33
Podiatrist	8	8.33	3	5.00	5	13.89	4	16.67	1	8.33

Allied health	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=96	%	n=44	%	n=52	%	n=20	20.00	n=39	39.00
Physiotherapy	51	53.13	20	45.45	31	59.62	8	40.00	24	61.54
Occupational therapist	13	13.54	6	13.64	7	13.46	3	15.00	6	15.38
Psychologist	39	40.63	21	47.73	18	34.62	9	45.00	11	28.21
Dietician	16	16.67	10	22.73	6	11.54	5	25.00	4	10.26
Social worker	10	10.42	4	9.09	6	11.54	3	15.00	5	12.82
Podiatrist	8	8.33	5	11.36	3	5.77	1	5.00	2	5.13

Allied health	All Stage III & IV		Quality of life		Effectiveness	
	n=36	%	Median	IQR	Median	IQR
Physiotherapy	19	52.78	3	2	4	2
Psychologist	19	52.78	3	2	4	2.5
Dietician	7	19.44	3	3	4	1.5
Podiatrist	5	13.89	5	1	4	3

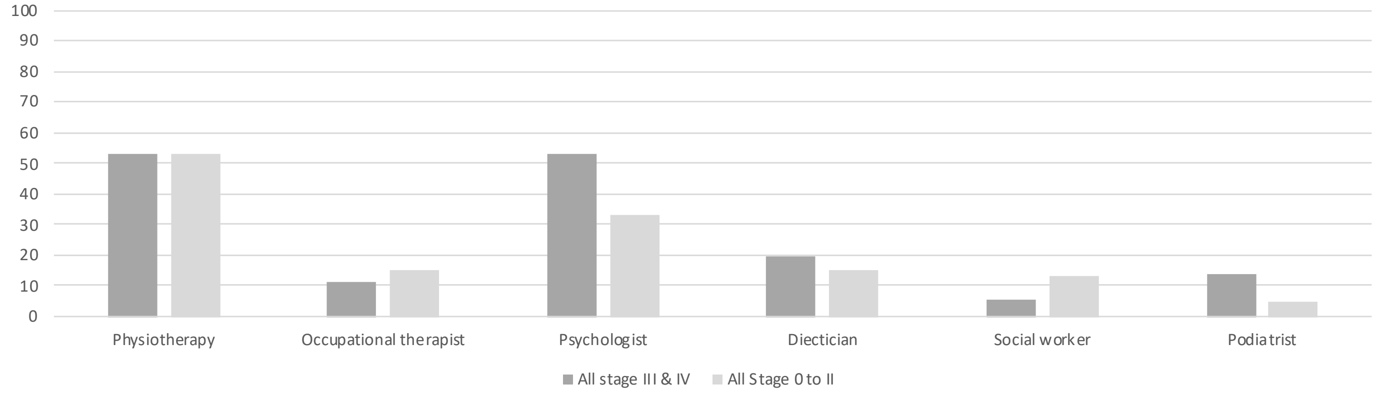


Figure 5.19: Allied health (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

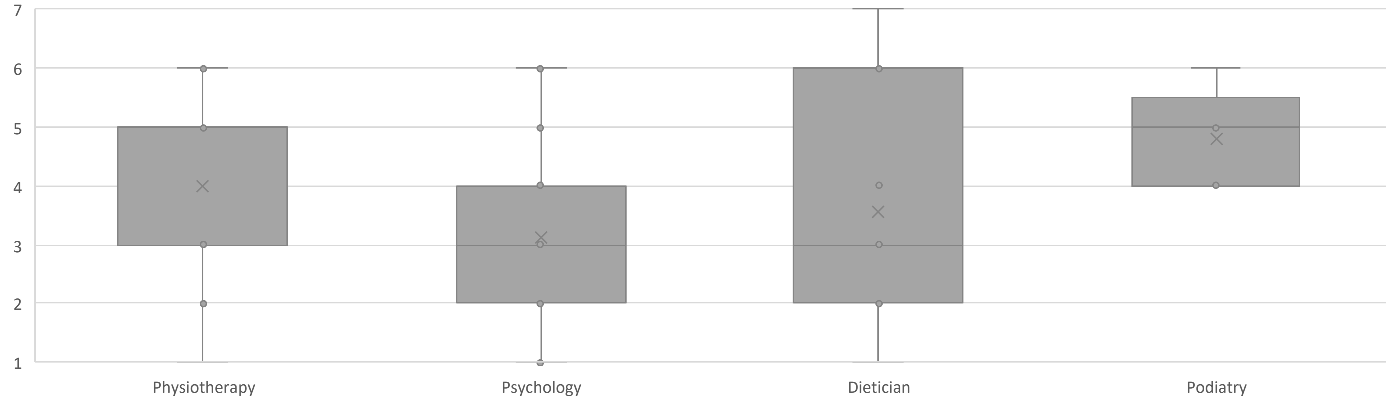


Figure 5.19: Quality of life from allied health: Stage III & IV

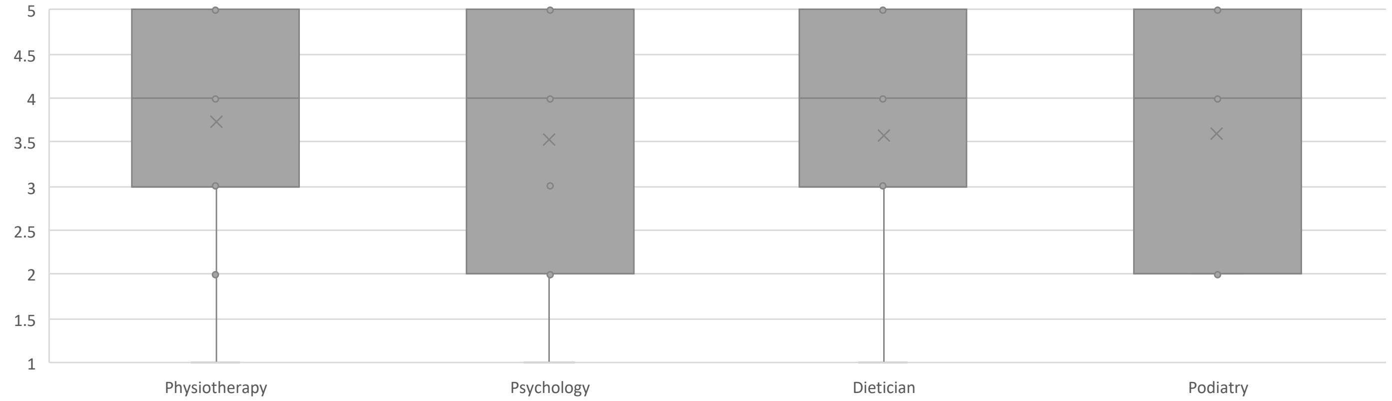


Figure 5.20: Effectiveness of allied health: Stage III & IV

Table 5.26: Allied health– Stage III & IV variations

Allied health	Reported less frequently	Reported more frequently
Physiotherapy	Hormone receptor Stage III & IV	-
Psychologist	-	All Stage III & IV Hormone receptor Stage III & IV
Social worker	-	Hormone receptor Stage III & IV

Lifestyle changes: Stage III & IV

The most common lifestyle change used was Exercise (n=26, 72.22%), followed by Reduce or quit alcohol (n=21, 58.33%), and Diet changes (n=18, 50.00%).

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

On average, quality of life from Exercise 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 Reduce alcohol was in the 'life was average' range (median=4.00, IQR=2.00), and was found to be effective (median=4.00, IQR=2.00).

Table 5.27: Lifestyle changes

Lifestyle changes	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=95	%	n=59	%	n=36	%	n=24	24.00	n=12	12.00
Exercise	71	74.74	45	76.27	26	72.22	16	66.67	10	83.33
Reduce or quit alcohol	51	53.68	30	50.85	21	58.33	13	54.17	8	66.67
Diet changes	51	53.68	33	55.93	18	50.00	10	41.67	8	66.67

Lifestyle changes	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=95	%	n=44	%	n=51	%	n=20	20.00	n=39	39.00
Exercise	71	74.74	28	63.64	43	84.31	12	60.00	33	84.62
Reduce or quit alcohol	51	53.68	24	54.55	27	52.94	11	55.00	19	48.72
Diet changes	51	53.68	23	52.27	28	54.90	13	65.00	20	51.28

Lifestyle changes	All Stage III & IV		Quality of life		Effectiveness	
	n=36	%	Median	IQR	Median	IQR
Exercise	26	72.22	4	2	3	2
Reduce or quit alcohol	21	58.33	3	2	4	1
Diet changes	18	50.00	4	2	4	2

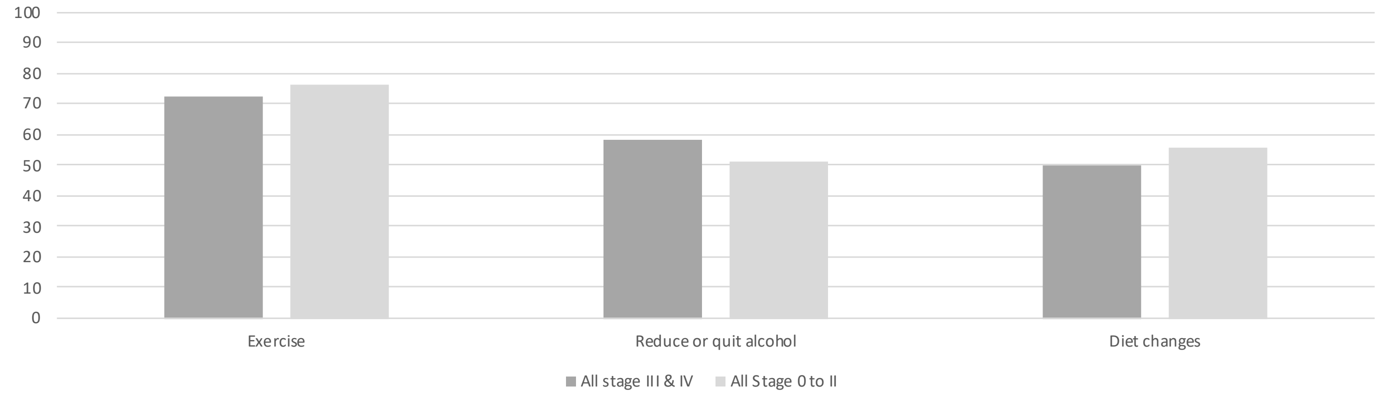


Figure 5.21: Lifestyle changes (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Figure 5.22: Quality of life from lifestyle changes: Stage III & IV

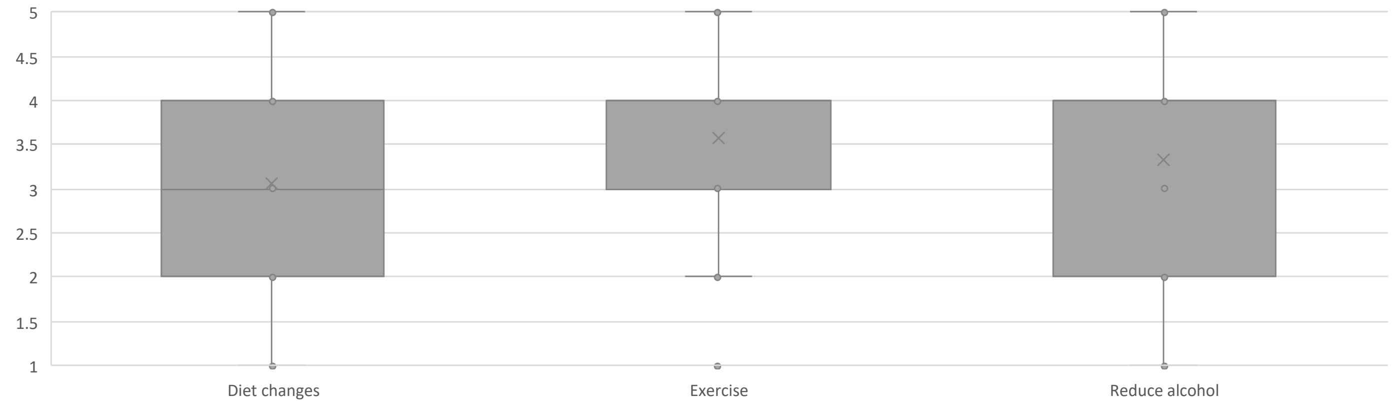


Figure 5.23: Effectiveness of lifestyle changes: Stage III & IV

Table 5.28: Lifestyle changes– Stage III & IV variations

Lifestyle changes	Reported less frequently	Reported more frequently
Reduce or quit alcohol	-	Hormone receptor Stage III & IV
Diet changes	Triple negative Stage III & IV	Hormone receptor Stage III & IV

Complementary therapies: Stage III & IV

The most common complementary therapy used was Mindfulness or relaxation techniques (n=18, 50.00%), followed by Massage therapy (n=15, 41.67%), and Supplements (n=15, 41.67%).

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

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=1.50).

On average, quality of life from Mindfullness was in the 'life was a little distressing' range (median=3.00, IQR=2.75), and was found to be effective (median=4.00, IQR=2.75).

On average, quality of life from Naturopathy was in the 'life was average' range (median=3.50, IQR=2.50), and was found to be very effective (median=5.00, IQR=0.75).

Table 5.29: Complementary therapies

Complementary therapies	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=96	%	n=60	%	n=36	%	n=24	%	n=12	%
Massage therapy	33	34.38	18	30.00	15	41.67	11	45.83	4	33.33
Acupuncture	10	10.42	6	10.00	4	11.11	3	12.50	1	8.33
Supplements	41	42.71	26	43.33	15	41.67	10	41.67	5	41.67
Mindfulness or relaxation techniques	45	46.88	27	45.00	18	50.00	10	41.67	8	66.67
Homeopathy	3	3.13	2	3.33	1	2.78	1	4.17		0.00
Naturopathy	10	10.42	4	6.67	6	16.67	4	16.67	2	16.67

Complementary therapies	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=96	%	n=44	%	n=52	%	n=20	%	n=39	%
Massage therapy	33	34.38	17	38.64	16	30.77	6	30.00	12	30.77
Acupuncture	10	10.42	6	13.64	4	7.69	3	15.00	3	7.69
Supplements	41	42.71	16	36.36	25	48.08	6	30.00	20	51.28
Mindfulness or relaxation techniques	45	46.88	20	45.45	25	48.08	10	50.00	17	43.59
Homeopathy	3	3.13	2	4.55	1	1.92	1	5.00	1	2.56
Naturopathy	10	10.42	5	11.36	5	9.62	1	5.00	3	7.69

Allied health	All Stage III & IV		Quality of life		Effectiveness	
	n=36	%	Median	IQR	Median	IQR
Massage therapy	15	41.67	4.00	1.50	4.00	1.50
Supplements	15	41.67	4.00	2.00	3.00	1.50
Mindfullness	18	50.00	3.00	2.75	4.00	2.75
Naturopathy	6	16.67	3.50	2.50	5.00	0.75

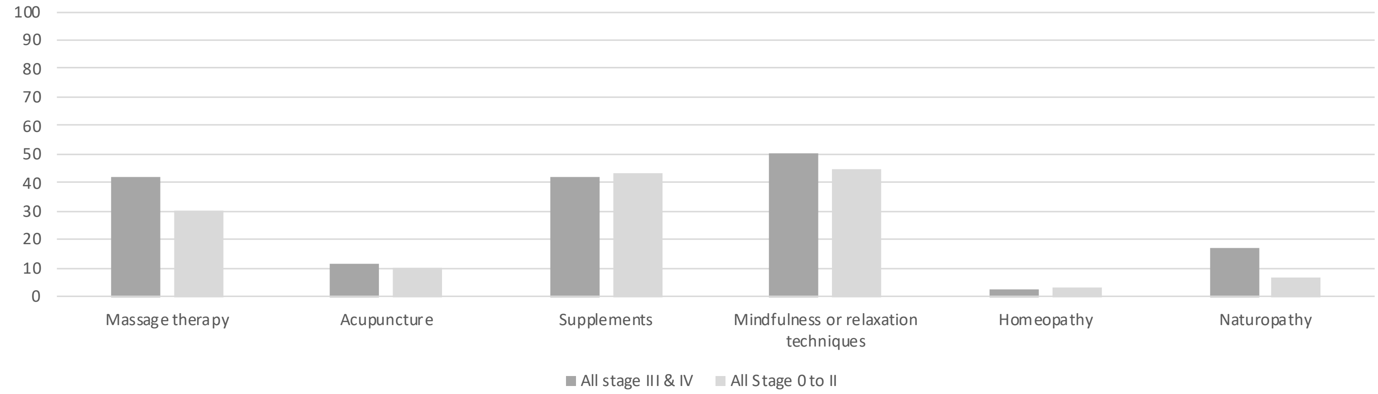


Figure 5.24: Complementary therapies (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

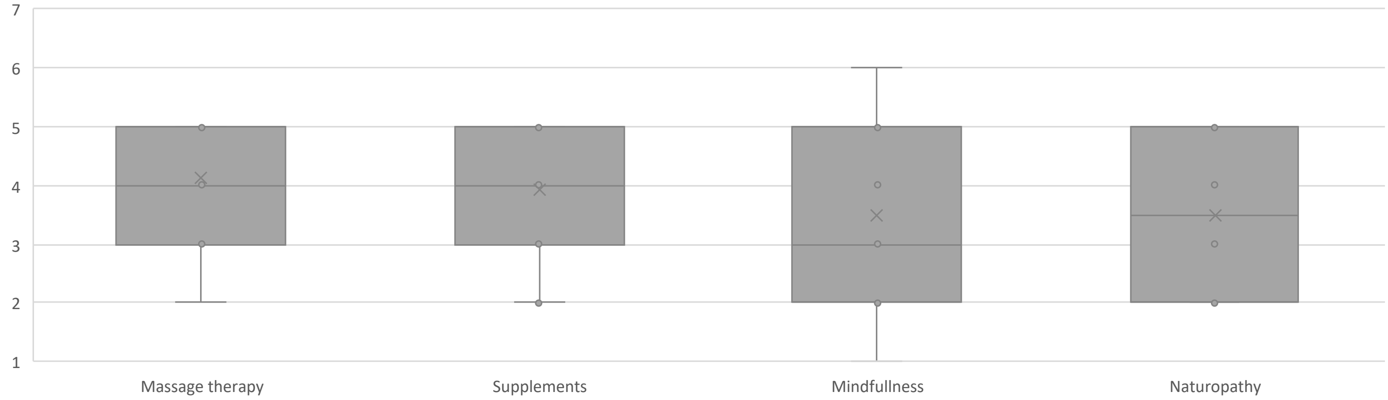


Figure 5.25: Quality of life from complementary therapies

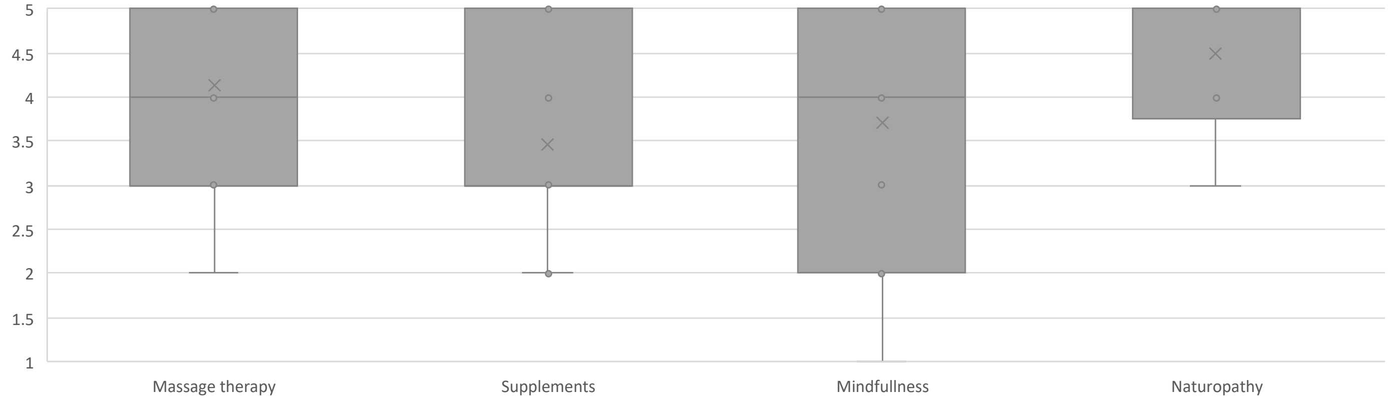


Figure 5.26: Effectiveness of complementary therapies

Table 5.30: Complementary therapies– Stage III & IV variations

Complementary therapies	Reported less frequently	Reported more frequently
Massage therapy	-	Triple negative Stage III & IV
Mindfulness or relaxation techniques	-	Hormone receptor Stage III & IV

Clinical trials: Stage III & IV

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.

There was a total of 17 participants (47.22%) that had discussions about clinical trials, 4 participants (11.11%) had brought up the topic with their doctor, and the doctor of 13 participants (36.11%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=19, 52.78%).

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 .

There were 4 participants (11.11%) that had taken part in a clinical trial, 28 participants (77.78%) that would like to take part in a clinical trial if there was a suitable one, and 4 participants, that have not participated in a clinical trial and do not want to (11.11%).

Table 5.31: Clinical trial discussions

Clinical trial discussions	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=95	%	n=59	%	n=36	%	n=24	%	n=12	%
Participant brought up the topic of clinical trials doctor for discussion	10	10.53	6	10.17	4	11.11	3	12.50	1	8.33
Doctor brought up the topic of clinical trials for discussion	23	24.21	10	16.95	13	36.11	7	29.17	6	50.00
Participant has ever spoken to me about clinical trials	62	65.26	43	72.88	19	52.78	14	58.33	5	41.67

Clinical trial discussions	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=95	%	n=44	%	n=51	%	n=20	%	n=39	%
Participant brought up the topic of clinical trials doctor for discussion	10	10.53	6	13.64	4	7.84	3	15.00	3	7.69
Doctor brought up the topic of clinical trials for discussion	23	24.21	10	22.73	13	25.49	3	15.00	7	17.95
Participant has ever spoken to me about clinical trials	62	65.26	28	63.64	34	66.67	14	70.00	29	74.36

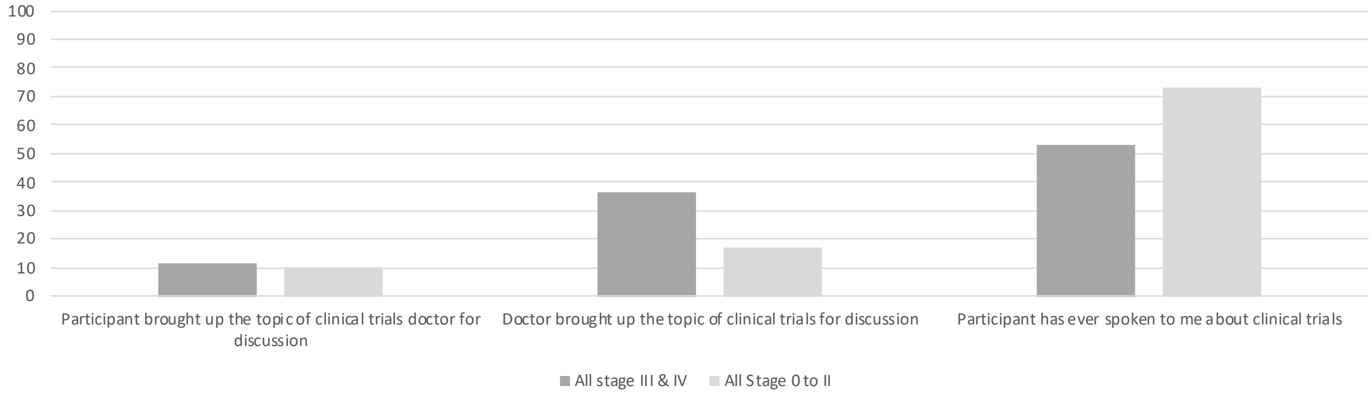


Figure 5.27: Clinical trial discussions (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 5.32: Clinical trial discussions– Stage III & IV variations

Clinical trial discussions	Reported less frequently	Reported more frequently
Doctor brought up the topic of clinical trials for discussion	-	All Stage III & IV Hormone receptor Stage III & IV
Participant has ever spoken to me about clinical trials	All Stage III & IV Hormone receptor Stage III & IV	-

Table 5.33: Clinical trial participation

Clinical trial participation	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=95	%	n=59	%	n=36	%	n=24	24.00	n=12	12.00
Has not participated in a clinical trial and does not want to	20	21.05	16	27.12	4	11.11	2	8.33	2	16.67
Has not participated in a clinical trial but would like to if there is one	64	67.37	36	61.02	28	77.78	21	87.50	7	58.33
Has participated in a clinical trial	11	11.58	7	11.86	4	11.11	1	4.17	3	25.00

Clinical trial participation	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=95	%	n=44	%	n=51	%	n=20	20.00	n=39	39.00
Has not participated in a clinical trial and does not want to	20	21.05	8	18.18	12	23.53	6	30.00	10	25.64
Has not participated in a clinical trial but would like to if there is one	64	67.37	32	72.73	32	62.75	11	55.00	25	64.10
Has participated in a clinical trial	11	11.58	4	9.09	7	13.73	3	15.00	4	10.26

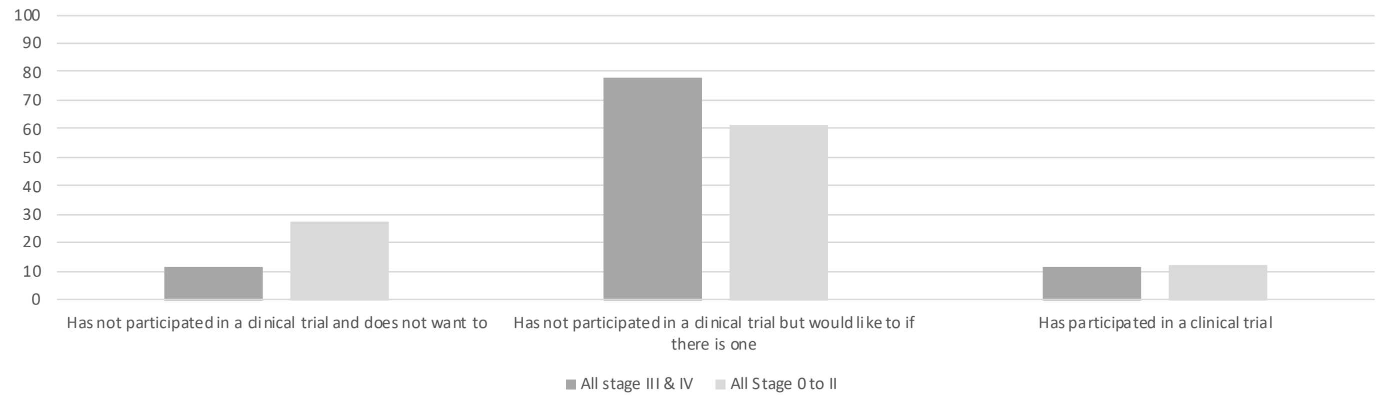


Figure 5.28: Clinical trial participation (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 5.34: Clinical trial participation– Stage III & IV variations

Clinical trial participation	Reported less frequently	Reported more frequently
Has not participated in a clinical trial and does not want to	Triple negative Stage III & IV	-
Has not participated in a clinical trial but would like to if there is one	-	All Stage III & IV Triple negative Stage III & IV
Has participated in a clinical trial	-	Hormone receptor Stage III & IV

Description of mild side effects: Stage III & IV

In the structured interview, participants were asked how they would describe the term ‘mild side effects’. The most common descriptions of mild side effects were those that do not interfere with life (61.54%), and described using a specific example (43.59%). This was followed by those that can be managed with self-medication or self-management (23.08 %), and those that are irritating/frustrating (5.13%).

When a specific side effect was described, the most common responses were nausea (15.38%), and tiredness (15.38%). Other themes included feeling of discomfort (5.13%), headache (5.13%), mild pain (5.13%), bowel problems (e.g. diarrhea) (5.13%), stomach ache (2.56%), burning (2.56%), and fogginess (2.56410256410256%).

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

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

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_037TNG

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

Participant provides a specific side effect as an example

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_032TNG

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

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. 032_2021AUHRP

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

Reactions to your body that can be treated or dealt with, with medicines or alternative treatments that can not impact your life. Participant_036TNG

Well, basically most of all my nausea and all that, because I slept through it, I found that only mild because I coped with it. I just learned-- I was told by everybody that if I start to get tired, I had to rest and sleep because my body was trying to fight everything and I needed to rest my body. I did that. Basically did everything I was told, so I coped with that. Participant_046TNG

Yes, I'd definitely say something I could cope with, that it wasn't dramatically affecting my life, or what I could do, or how I could live it. Or easily treated to overcome them. Participant_048TNG

Table 5.35: Description of mild side effects

Description of mild side effects	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes mild side effects as those that do not interfere with daily life	63	61.76	39	61.90	24	61.54	20	74.07	4	33.33
Participant provides a specific side effect as an example	48	47.06	31	49.21	17	43.59	10	37.04	7	58.33
Participant describes mild side effects as those that can be self-managed	24	23.53	15	23.81	9	23.08	3	11.11	6	50.00
Participant describes mild side effects as those that are irritating/frustrating	4	3.92	2	3.17	2	5.13	2	7.41	0	0.00

Description of mild side effects	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes mild side effects as those that do not interfere with daily life	63	61.76	38	76.00	25	48.08	18	78.26	21	52.50
Participant provides a specific side effect as an example	48	47.06	21	42.00	27	51.92	11	47.83	20	50.00
Participant describes mild side effects as those that can be self-managed	24	23.53	5	10.00	19	36.54	2	8.70	13	32.50
Participant describes mild side effects as those that are irritating/frustrating	4	3.92	4	8.00	0	0.00	2	8.70	0	0.00

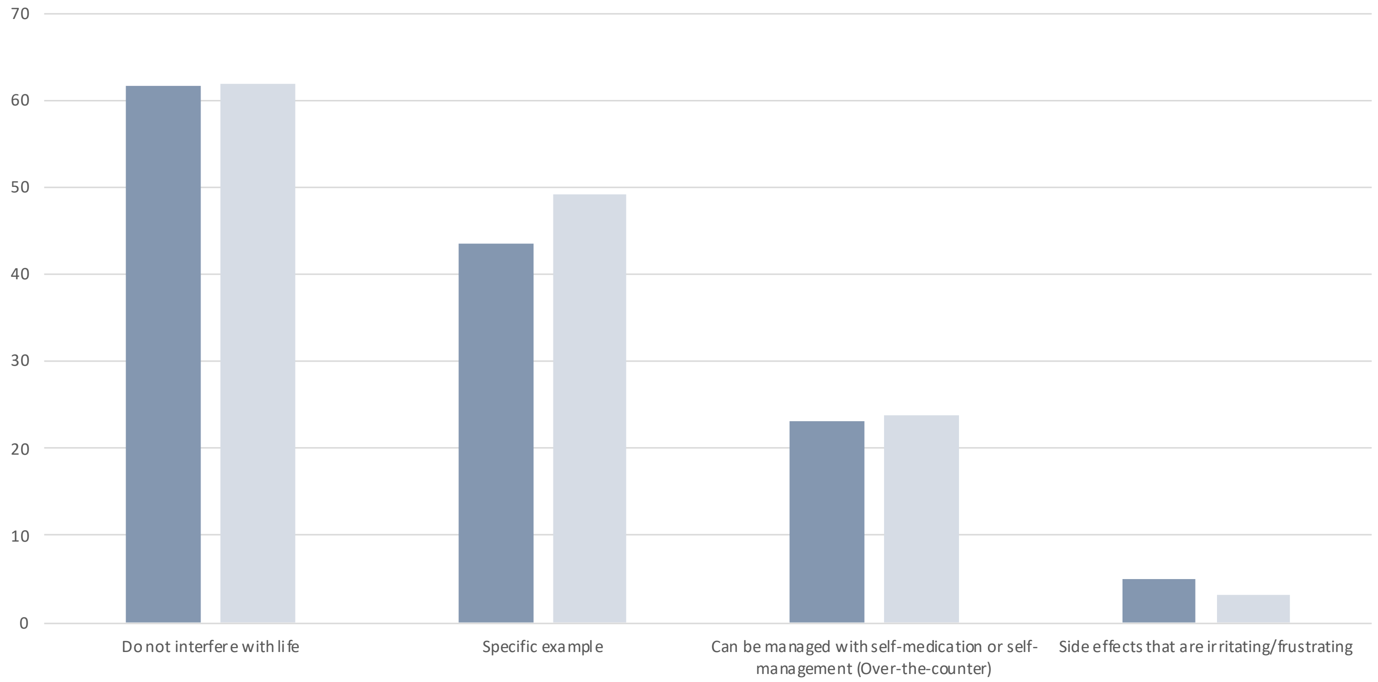


Figure 5.29: Description of mild side effects (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 5.36: Description of mild side effects – –Stage III & IV variations

Description of mild side effects	Reported less frequently	Reported more frequently
Participant describes mild side effects as those that do not interfere with daily life	Hormone receptor Stage III & IV	Triple negative Stage III & IV
Participant provides a specific side effect as an example	Triple negative Stage III & IV	Hormone receptor Stage III & IV
Participant describes mild side effects as those that can be self-managed	Triple negative Stage III & IV	Hormone receptor Stage III & IV

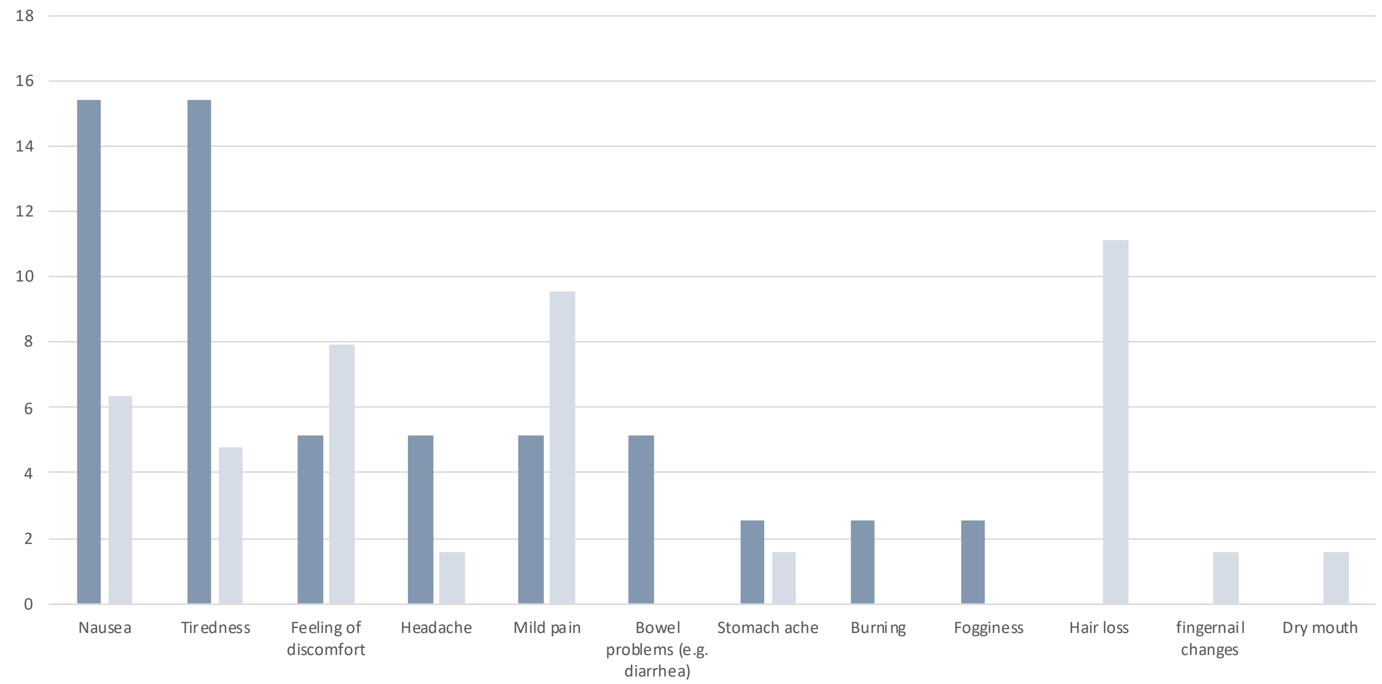


Figure 5.30: Description of mild side effects (Specific side effects) (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Description of severe side effects: Stage III & IV

In the structured interview, participants were asked how they would describe the term 'severe side effects'. The most common description of severe side effects were those that impact everyday life or ability to conduct activities of daily living (58.97%), and described using a specific example (51.28%). Other themes included those that are life threatening or result in hospitalisation (7.69%), those that impact their everyday life by being bed ridden (7.69%), and those that are difficult to cope with/go through (5.13%).

When a specific side effect was described, the most common examples were extreme/chronic pain (20.51%), emotional/mental struggle (20.51%), and nausea/vomiting (12.82 %). Other themes included neuropathy (10.26%), hair, eyebrows, eyelashes loss (7.69%), lack of appetite (5.13%), impact on sleep (5.13%), and aches/pain (general) (5.13%).

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

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

I think severe side effects are things that either you weren't expecting in a way or that as I've mentioned, the opposite to the mild ones is that things that stop you or prevent you from doing things. For me, I had severe side effects with all of my fingers. I wasn't actually able to do a lot of stuff with my hands because I just was in so much pain. Yes. Participant_025TNG

I'd describe it as a change that affected the way you lived your life. Losing your hair, some people might call that minor because your hair's going to grow back, but it really does affect every time you walk out the door or look in the mirror, or anything. It makes a big change mentally to you. Like if you were getting violently ill, or unable to eat, or anything, or bone pain stopping you from getting out of bed, or whatever, they'd be serious side effects. Participant_048TNG

Participant provides a specific side effect as an example

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_027TNG

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_042TNG

Like I just had the faecal 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_028TNG

Severe side effects to me would be uncontrolled nausea, uncontrolled pain, and immobility. Participant_037TNG

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

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_033TNG

I guess, yes, obviously, it's something which you can't cope with. For me, severe effects, I'd-- If they've generally been that severe, then I've been hospitalized. Participant_034TNG

Participant identifies severe side effects as impacting their everyday life by being bed ridden

Me not being able to move and get out of bed or function correctly. Walking was one, or concentrating on anything for too long. Participant_024TNG

Debilitating, I would be in bed, I'd just feel like a train had hit me and I just have to sleep. The best thing was just closing my eyes in a dark room and just trying to get through the day. Participant_040TNG

Table 5.37: Description of severe side effects

Description of severe side effects	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	60	58.82	37	58.73	23	58.97	17	62.96	6	50.00
Participant provides a specific side effect as an example	58	56.86	38	60.32	20	51.28	12	44.44	8	66.67
Participant describes severe side effects as those that are life threatening or result in hospitalisation	12	11.76	9	14.29	3	7.69	2	7.41	1	8.33
Participant identifies severe side effects as impacting their everyday life by being bed ridden	4	3.92	1	1.59	3	7.69	3	11.11	0	0.00
Participant describes severe side effects as those that are difficult to cope with/go through	3	2.94	1	1.59	2	5.13	2	7.41	0	0.00
Participant describes severe side effects as those with long-lasting side effects	4	3.92	4	6.35	0	0.00	0	0.00	0	0.00

Description of severe side effects	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	60	58.82	34	68.00	26	50.00	17	73.91	20	50.00
Participant provides a specific side effect as an example	58	56.86	28	56.00	30	57.69	16	69.57	22	55.00
Participant describes severe side effects as those that are life threatening or result in hospitalisation	12	11.76	7	14.00	5	9.62	5	21.74	4	10.00
Participant identifies severe side effects as impacting their everyday life by being bed ridden	4	3.92	4	8.00	0	0.00	1	4.35	0	0.00
Participant describes severe side effects as those that are difficult to cope with/go through	3	2.94	3	6.00	0	0.00	1	4.35	0	0.00
Participant describes severe side effects as those with long-lasting side effects	4	3.92	4	8.00	0	0.00	4	17.39	0	0.00

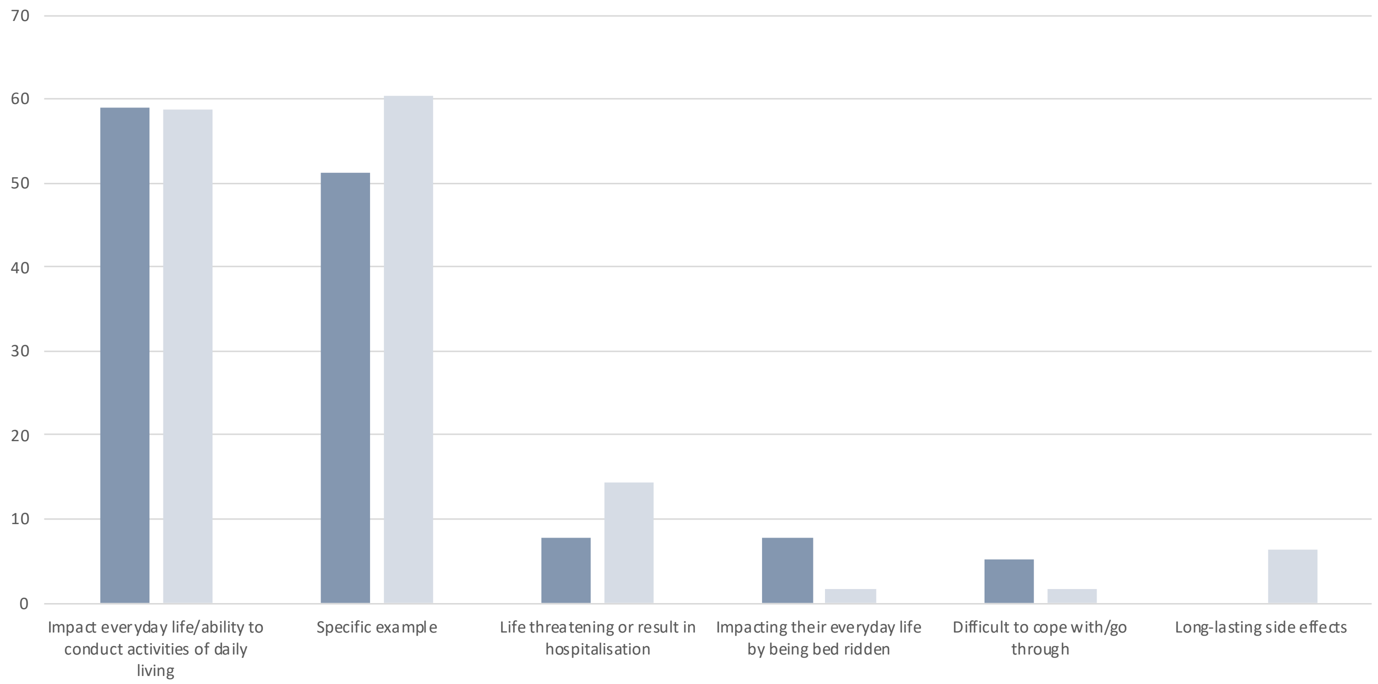


Figure 5.31: Description of severe side effects (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 5.38: Description of severe side effects – –Stage III & IV variations

Description of severe side effects	Reported less frequently	Reported more frequently
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	-	-
Participant provides a specific side effect as an example	Triple negative Stage III & IV	-

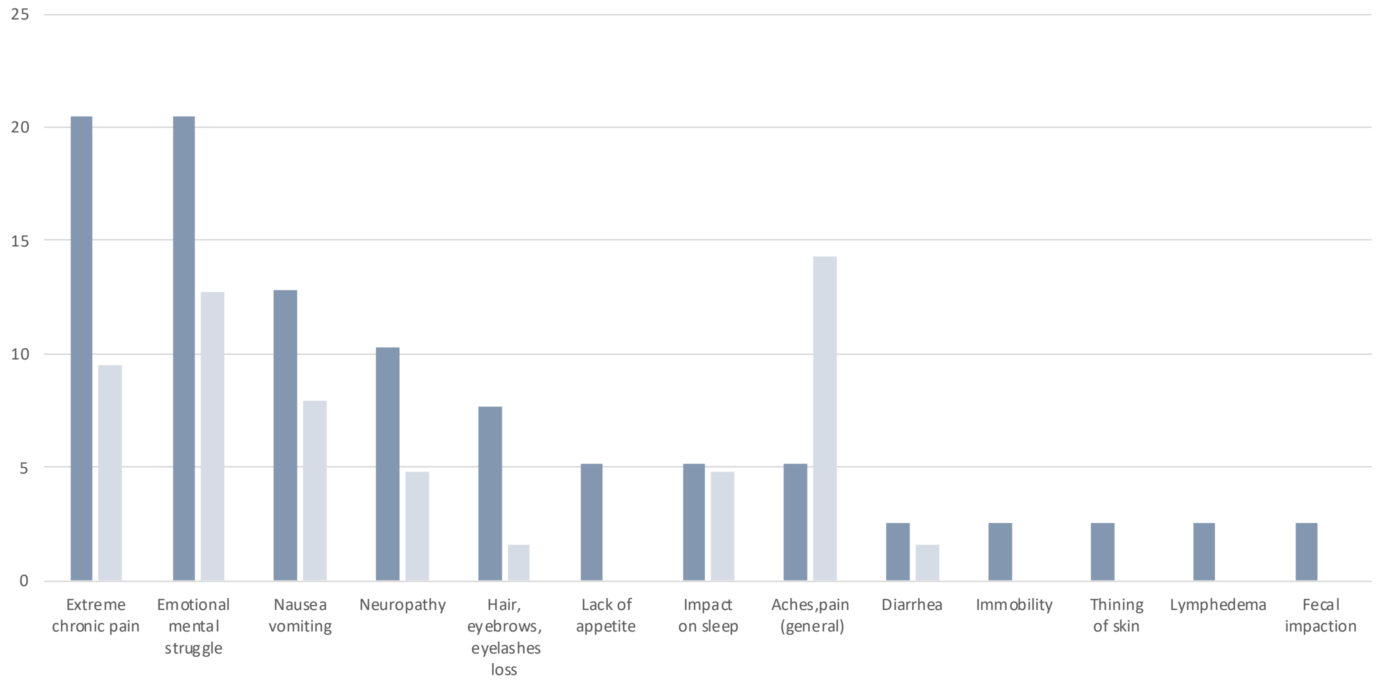


Figure 5.32: Description of severe side effects (Specific example) (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Adherence to treatment: Stage III & IV

Participants were asked in the structured interview what influences their decision to continue with a treatment regime. The most common responses were adhering to treatment according to the advice of their specialist/as long as prescribed (43.59%), never giving up on any treatment(33.33%), and adhering to treatment for a specific amount of time (25.64 %). Other themes included needing to see test results/no evidence or reduction of disease (15.38%), and adhering to treatment as long as side effects are tolerable (12.82%).

When participants stated a specific amount of time to adhere to a treatment, the most common amount of time was one week (10.26%), followed by four to six weeks(5.13%), and two to three months (5.13 %).

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

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

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

Participant describes not giving up on any treatment

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

I've never got to that point. I guess with tamoxifen I was getting side effects, but I always knew that I wanted to get onto an aromatase inhibitor because that was meant to be better for invasive lobular. I just cracked on through tamoxifen. I'm not at that point yet. Even if I stop my medication-- A lot of women talk about stopping tamoxifen or Aromasin because of the impact it's having on them being in menopause, but the fact is even if I stop taking those drugs now, I've had my gynae surgery. I have those side effects. I'm not at that stage. I think it's also difficult to try and differentiate. Is that side effect because I'm in menopause, is it because of the Aromasin, or is it because I'm getting older, or is it just because of the cancer or of all the treatment? Is it all of those things? It's really difficult to actually isolate what's what. Participant 043_2021AUHRP

Participant describes adhering to treatment for a specific amount of time

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_025TNG

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_044TNG

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_028TNG

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_038TNG

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

Table 5.39: Adherence to treatment

Adherence to treatment	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	46	45.10	29	46.03	17	43.59	15	55.56	2	16.67
Participant describes not giving up on any treatment	31	30.39	18	28.57	13	33.33	8	29.63	5	41.67
Participant describes adhering to treatment for a specific amount of time	33	32.35	23	36.51	10	25.64	6	22.22	4	33.33
Participant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	8	7.84	2	3.17	6	15.38	6	22.22	0	0.00
Participant describes adhering to treatment as long as side effects are tolerable	22	21.57	17	26.98	5	12.82	4	14.81	1	8.33

Adherence to treatment	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	46	45.10	27	54.00	19	36.54	12	52.17	17	42.50
Participant describes not giving up on any treatment	31	30.39	16	32.00	15	28.85	8	34.78	10	25.00
Participant describes adhering to treatment for a specific amount of time	33	32.35	13	26.00	20	38.46	7	30.43	16	40.00
Participant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	8	7.84	8	16.00	0	0.00	2	8.70	0	0.00
Participant describes adhering to treatment as long as side effects are tolerable	22	21.57	7	14.00	15	28.85	3	13.04	14	35.00

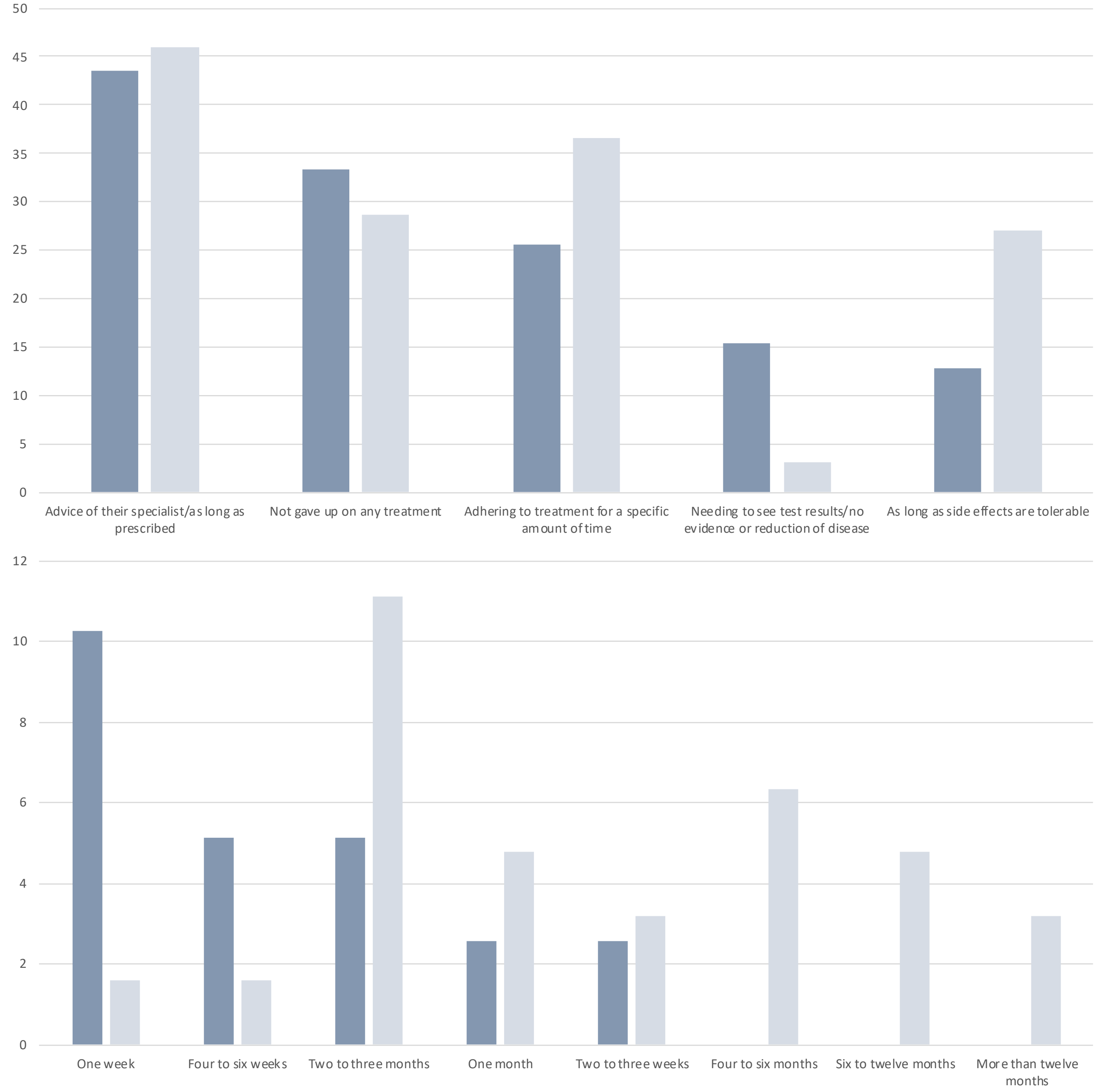


Figure 5.33: Adherence to treatment (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 5.40: Adherence to treatment (Time to adhere to treatment) – Stage III & IV variations

Adherence to treatment	Reported less frequently	Reported more frequently
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	Hormone receptor Stage III & IV	Triple negative Stage III & IV
Participant describes not giving up on any treatment		Hormone receptor Stage III & IV
Participant describes adhering to treatment for a specific amount of time	Triple negative Stage III & IV	-
Participant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	-	Triple negative Stage III & IV
Participant describes adhering to treatment as long as side effects are tolerable	Hormone receptor Stage III & IV	-

What needs to change to feel like treatment is working: Stage III & IV

Participants were asked to describe what needs to change to feel like treatment is effective. The most common responses were needing to see physical signs and symptoms disappear/reduce side effects (28.21%), needing to see positive results of tests/or scan showing disease reduction (23.08%), and needing to see evidence of stable disease/no disease progression (17.95 %). Other themes included needing to have side effects (12.82%), needing to experience an improvement in a specific symptom (12.82%), that it is difficult to know that it is working/needs evidence (10.26%), needing to see a return to day-to-day functionality (7.69%), needing to see improvements in general wellbeing (quality of life) (7.69%), and needing to have a balance between benefit and side effects (5.13%).

When a specific side effect or symptom was described, the most common examples were in pain levels (23.08%), in nausea(12.82%), and in menopause side effects (5.13 %).

Participants reported needing to see all physical signs and symptoms disappear

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_030TNG

Symptoms, so either less nausea or less rashes or less visible and physical symptoms Participant_036TNG

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_047TNG

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_050TNG

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

PARTICIPANT: Oh, that you're cancer free that you have a scan, of breast cancer patients don't unless they're symptomatic. They don't have scans, they just have mammography or ultrasounds they don't have CTs, like about cancer or pancreatic cancer, we don't have anything or you don't need any scans unless you symptomatic. And then I see so many women with breast cancer present with symptoms are yet sorry, it's gone to your bones Gone to your lungs. Okay. So that sort of is strange to me, but I guess there must be research that shows there's no need to unnecessary scan. For breast cancer patients
INTERVIEWER: So, if your not getting those scans, how do you know if the treatment's working?
PARTICIPANT: Exactly. I'm having a mammogram and ultrasound, so I'll know that it's not in my boob. Yeah, but unless you're a stage three or four, I doubt you're gonna have scans. Okay, right, I guess because it shouldn't really come back. But you know, there's

different types of breast cancers, some are more aggressive than others. It just depends on all your scores and all that stuff we go into. So I guess you're not going to know you're just going to have to trust that your mammogram and see a good boob and your ultrasound on your lymph nodes. And that shows up. Participant 041_2021AUHRP

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

Participants reported needing to experience side effects

Funny enough, the less side effects I got, the more I worried that it wasn't actually working. I think your blood counts tell you if it's working or not and if you're having problems with them, then maybe you need to talk to your team, but I trusted that they told me it was working. Participant_035TNG

Participants reported needing to experience an improvement in a specific symptom

For me, it either eases the pain in my legs and my feet and sleep. At one stage, I was not able to sleep so being able to have something to help me have a full night's sleep and also get some relief from the pain for a little while. Participant_027TNG

Symptoms, so either less nausea or less rashes or less visible and physical symptoms Participant_036TNG

Well, yes, it would be side effects of nausea and pain. Yeah. When I had had that needle, I think was cold during treatment, I knew that I had to have it, but it caused a lot of pain. But, you know, I knew that I needed that or I would be able to have my chemo. That was something that I would keep going with that pain medication. I would just stop taking if it was something. Participant_038TNG

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

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

Table 5.41: What needs to change to feel like treatment is working

What needs to change to feel like treatment is working	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participants reported needing to see all physical signs and symptoms disappear	21	20.59	10	15.87	11	28.21	**11**	**40.74**	**0**	**0.00**
Participants reported needing to see positive results of tests/or scan showing disease reduction	17	16.67	8	12.70	9	23.08	**9**	**33.33**	**0**	**0.00**
Participants reported needing to experience evidence of stable disease/no disease progression	20	19.61	13	20.63	7	17.95	4	14.81	3	25.00
Participants reported needing to experience side effects	21	20.59	16	25.40	5	12.82	**1**	**3.70**	**4**	**33.33**
Participants reported needing to experience an improvement in a specific symptom	24	23.53	19	30.16	**5**	**12.82**	**0**	**0.00**	**5**	**41.67**
Participant reports that it is difficult to know that it is working/needs evidence	11	10.78	7	11.11	4	10.26	**0**	**0.00**	**4**	**33.33**
Participants reported needing to experience a return to day-to-day functionality	6	5.88	3	4.76	3	7.69	3	11.11	0	0.00
Participants reported needing to experience an improvement in general wellbeing (quality of life)	4	3.92	1	1.59	3	7.69	3	11.11	0	0.00
Participant describes needing to have a balance between benefit and side effects	12	11.76	10	15.87	2	5.13	**0**	**0.00**	2	16.67
Participants reported needing to experience improved mobility	1	0.98	0	0.00	1	2.56	1	3.70	0	0.00
Participants reported needing to have treatment and results supported by research	1	0.98	1	1.59	0	0.00	0	0.00	0	0.00

What needs to change to feel like treatment is working	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participants reported needing to see all physical signs and symptoms disappear	21	20.59	21	42.00	0	0.00	10	43.48	0	0.00
Participants reported needing to see positive results of tests/or scan showing disease reduction	17	16.67	17	34.00	0	0.00	8	34.78	0	0.00
Participants reported needing to experience evidence of stable disease/no disease progression	20	19.61	8	16.00	12	23.08	4	17.39	9	22.50
Participants reported needing to experience side effects	21	20.59	2	4.00	19	36.54	1	4.35	15	37.50
Participants reported needing to experience an improvement in a specific symptom	24	23.53	0	0.00	24	46.15	0	0.00	19	47.50
Participant reports that it is difficult to know that it is working/needs evidence	11	10.78	0	0.00	11	21.15	0	0.00	7	17.50
Participants reported needing to experience a return to day-to-day functionality	6	5.88	6	12.00	0	0.00	3	13.04	0	0.00
Participants reported needing to experience an improvement in general wellbeing (quality of life)	4	3.92	4	8.00	0	0.00	1	4.35	0	0.00
Participant describes needing to have a balance between benefit and side effects	12	11.76	0	0.00	12	23.08	0	0.00	10	25.00
Participants reported needing to experience improved mobility	1	0.98	1	2.00	0	0.00	0	0.00	0	0.00
Participants reported needing to have treatment and results supported by research	1	0.98	1	2.00	0	0.00	1	4.35	0	0.00

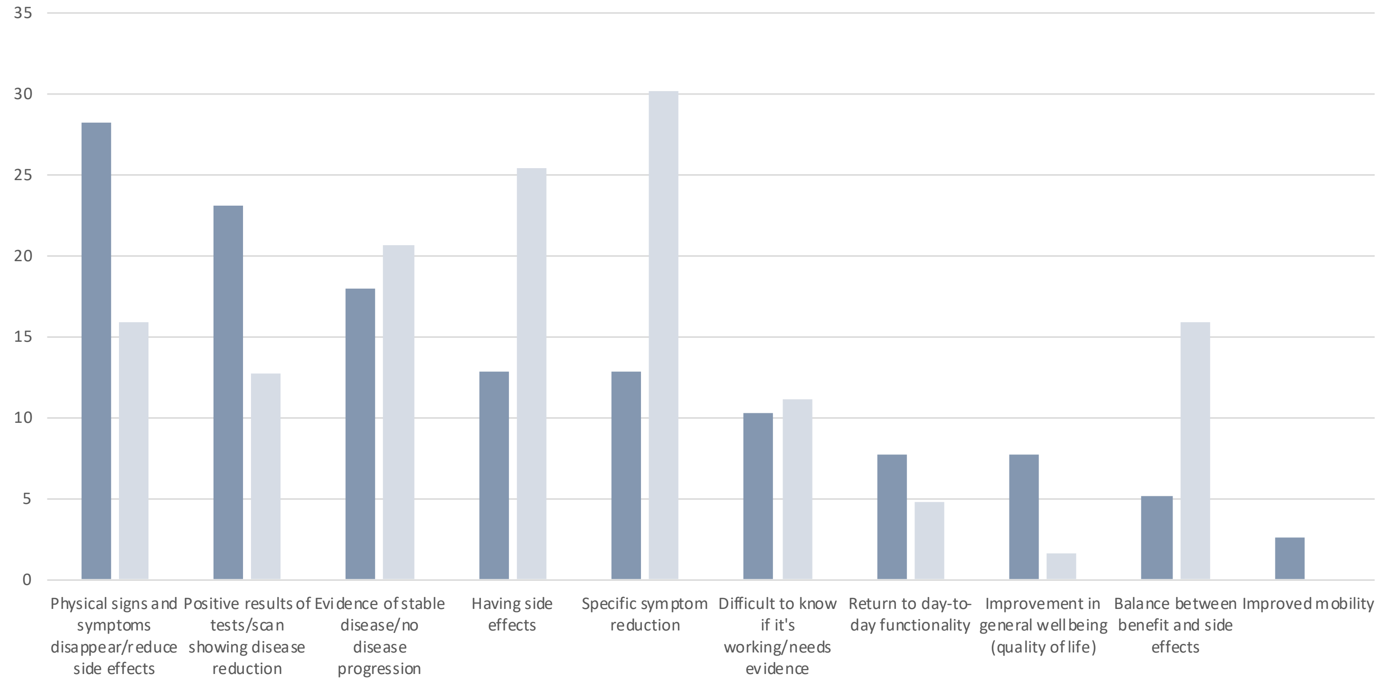


Figure 5.34: What needs to change to feel like treatment is working (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

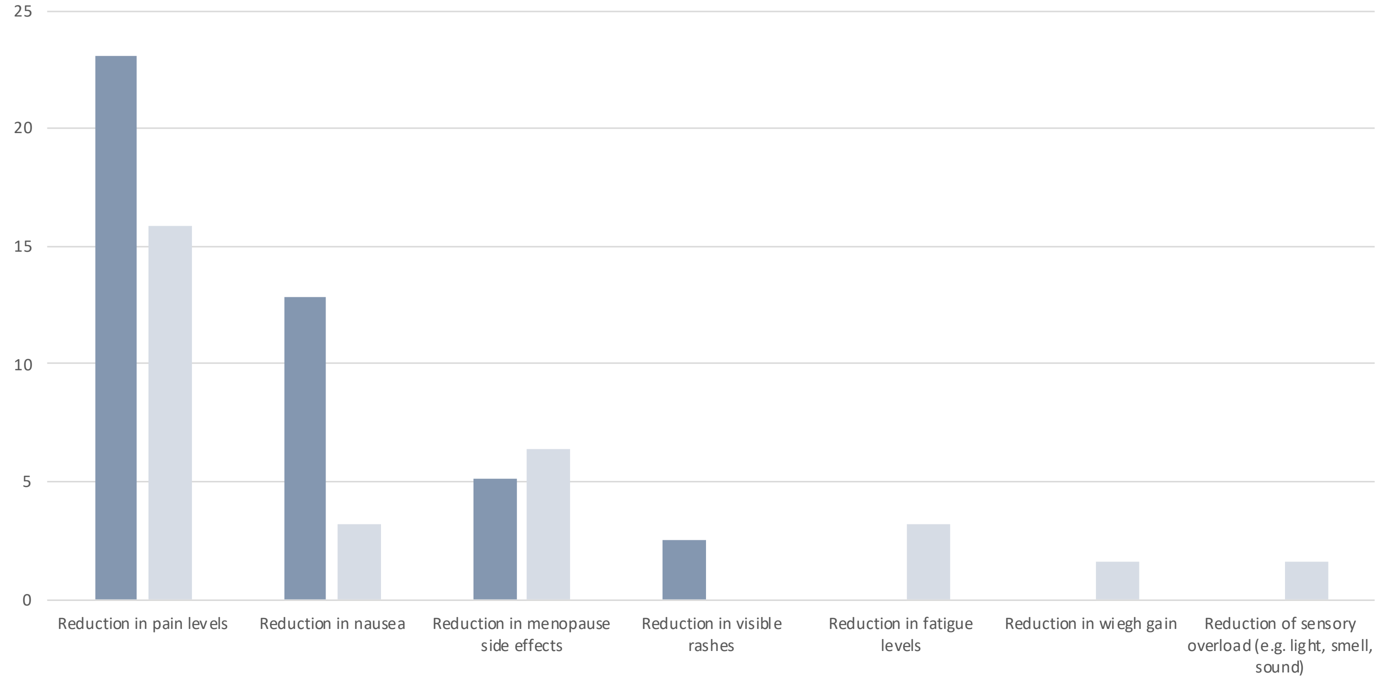


Figure 5.35: What needs to change to feel like treatment is working – specific symptoms (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 5.42: What needs to change to feel like treatment is working – Stage III & IV variations

What needs to change to feel like treatment is working	Reported less frequently	Reported more frequently
Participants reported needing to see all physical signs and symptoms disappear	Hormone receptor Stage III & IV	Triple negative Stage III & IV
Participants reported needing to see positive results of tests/or scan showing disease reduction	Hormone receptor Stage III & IV	Triple negative Stage III & IV
Participants reported needing to experience side effects	Triple negative Stage III & IV	Hormone receptor Stage III & IV
Participants reported needing to experience an improvement in a specific symptom	All Stage III & IV Triple negative Stage III & IV	Hormone receptor Stage III & IV
Participant reports that it is difficult to know that it is working/needs evidence	Triple negative Stage III & IV	Hormone receptor Stage III & IV
Participant describes needing to have a balance between benefit and side effects	Triple negative Stage III & IV	-

What it would mean if treatment worked: Stage III & IV

As a follow up question, participants were asked what it would mean to them if the treatment worked in the way they described. The most common response was that it would allow them to do everyday activities/return to normal life (61.54%), this was followed by allowing them to engage more with social activities and family life (15.38%), lead to a reduction in symptoms/side effects (15.38 %), and have a positive impact on their mental health (15.38%). Other themes included allowing them to return to work (12.82%), allowing them to do domestic tasks (7.69%), and allowing them to do more exercise (7.69%).

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

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

PARTICIPANT: That would be wonderful.
INTERVIEWER: Okay. What would you be able to do that you couldn't do if the treatment wasn't doing its job?
PARTICIPANT: Probably be more energetic. That's my only real problem. I eat well and I go out and I go shopping, it makes sense, and to that thing. Probably I'd like to be able to walk long distances or maybe go swimming more. Just, I'd like a bit more energy. Participant_032TNG

Well, it meant that I would be able to to go out and not have to worry about where toilets were located or what was going to happen next. You know, I mean, the unknown of when you're going to be sick or, you know, just driving if you're going to be sick. So to know that that would be eliminated from the start would be it would just be a godsend. Participant_049TNG

Participant described treatment allowing them to engage more with social activities and family life

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_037TNG

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_038TNG

I can live. As a fundamental point, I'm alive and I'm able to make plans and enjoy time with
my family and friends. Participant_050TNG

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

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_047TNG*

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

It would make life so much easier. It's really everything. It's being able to sit my desk all day at work, to go to the gym full time, and be able to do all the classes that I used to do and just be a happier person. Participant_027TNG

If that had worked and I would be able to do a whole lot more. My exercise was limited on the days when the bone pain was severe. My mood was reduced. I didn't have a good-- You're not feeling great because you can't get up and do things. I very much like to be preventative with health. I want to be out and keeping fit, and exercising, and keeping my mind healthy and my body healthy. On those days where the treatment I didn't feel was working or I was in so much pain, I didn't do those things. I think that's a vicious cycle really. It doesn't help you mentally or physically. I just became a couch potato for a few days each round and that's not-- I didn't like that mentally or physically. I'm not sure if I'm answering your questions or just rambling. [laughs] Participant_033TNG

Participant describes treatment allowing them to return to work

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_036TNG

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_038TNG

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

Participant describes treatment allowing them to do domestic tasks

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_048TNG

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_036TNG

Participant describes treatment allowing them to do more exercise

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

Table 5.43: What it would mean if treatment worked

What it would mean if treatment worked	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes treatment allowing them to do everyday activities/ return to normal life	60	58.82	36	57.14	24	61.54	18	66.67	6	50.00
Participant described treatment allowing them to engage more with social activites and family life	14	13.73	8	12.70	6	15.38	6	22.22	**0**	**0.00**
Participant describes treatment leading to a reduction in symptoms/side effects	11	10.78	5	7.94	6	15.38	**6**	**22.22**	**0**	**0.00**
Participant describes treatment working as having a positive impact on their mental health	16	15.69	10	15.87	6	15.38	3	11.11	3	25.00
Participant describes treatment allowing them to return to work	16	15.69	11	17.46	5	12.82	4	14.81	1	8.33
Participant describes treatment allowing them to do domestic tasks	6	5.88	3	4.76	3	7.69	3	11.11	0	0.00
Participant describes treatment allowing them to do more exercise	5	4.90	2	3.17	3	7.69	0	0.00	**3**	**25.00**
Participant describes treatment allowing them to get enough sleep	6	5.88	5	7.94	1	2.56	0	0.00	1	8.33

What it would mean if treatment worked	All participants n=102	 %	All Triple negative n=50	 %	All Hormone receptor n=52	 %	Triple negative Stage 0 to II n=23	 %	Hormone receptor Stage 0 to II n=40	 %
Participant describes treatment allowing them to do everyday activities/ return to normal life	60	58.82	**35**	**70.00**	**25**	**48.08**	**17**	**73.91**	**19**	**47.50**
Participant described treatment allowing them to engage more with social activites and family life	14	13.73	**14**	**28.00**	**0**	**0.00**	**8**	**34.78**	**0**	**0.00**
Participant describes treatment leading to a reduction in symptoms/side effects	11	10.78	**11**	**22.00**	**0**	**0.00**	**5**	**21.74**	**0**	**0.00**
Participant describes treatment working as having a positive impact on their mental health	16	15.69	3	6.00	13	25.00	**0**	**0.00**	10	25.00
Participant describes treatment allowing them to return to work	16	15.69	7	14.00	9	17.31	3	13.04	8	20.00
Participant describes treatment allowing them to do domestic tasks	6	5.88	6	12.00	0	0.00	3	13.04	0	0.00
Participant describes treatment allowing them to do more exercise	5	4.90	0	0.00	5	9.62	0	0.00	2	5.00
Participant describes treatment allowing them to get enough sleep	6	5.88	0	0.00	6	11.54	0	0.00	5	12.50

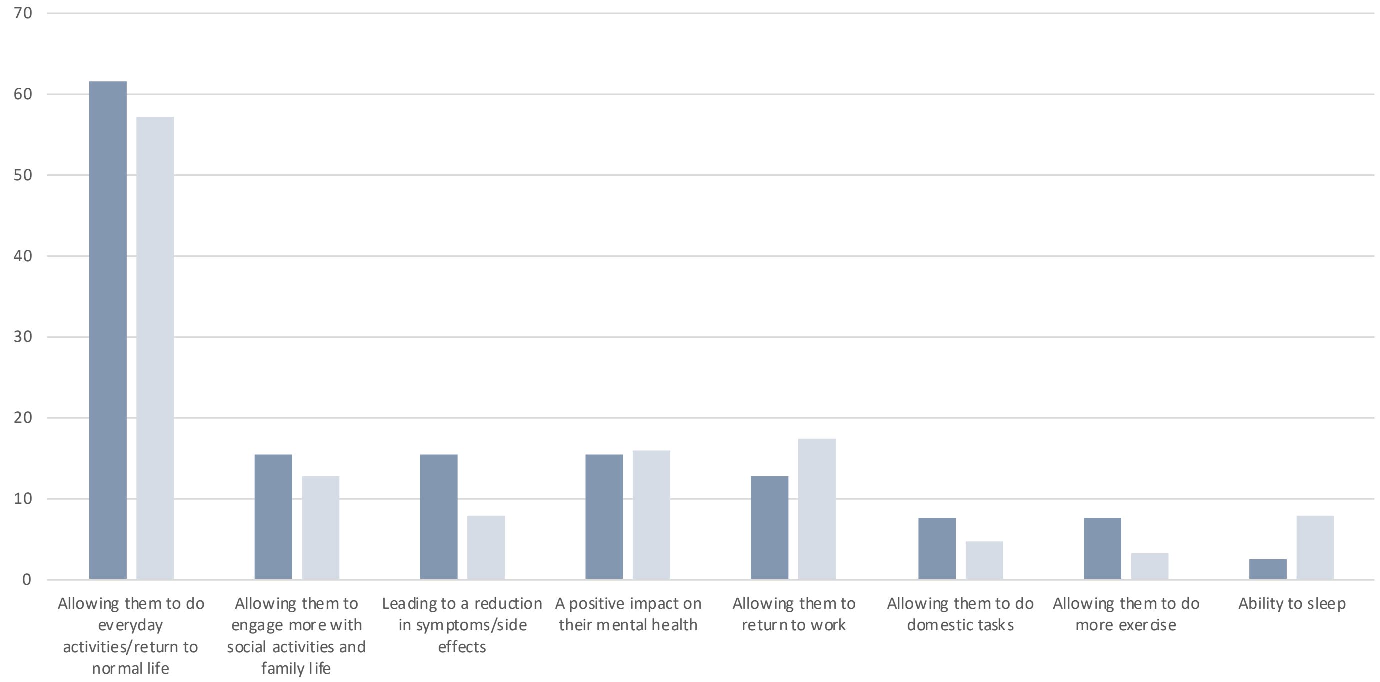


Figure 5.36: What it would mean if treatment worked (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 5.44: What it would mean if treatment worked– Stage III & IV variations

What it would mean if treatment worked	Reported less frequently	Reported more frequently
Participant described treatment allowing them to engage more with social activites and family life	Hormone receptor Stage III & IV	-
Participant describes treatment leading to a reduction in symptoms/side effects	Hormone receptor Stage III & IV	Triple negative Stage III & IV
Participant describes treatment allowing them to do more exercise		Hormone receptor Stage III & IV

Section 6

Information and communication

Section 6: Information and communication

Access to information: Stage III & IV

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common responses were the internet (Including health charities) (53.85%), their treating clinician (38.46%), and from Facebook and\or social media (35.90 %). Other themes included from other patient's experience (Including support groups) (35.90%), from books, pamphlets and newsletters (25.64%), from nursing staff (25.64%), from a specific health charity (15.38%), and from journals (research articles) (10.26%).

Information that was helpful: Stage III & IV

In the structured interview, participants were asked to describe what information they had found to be most helpful. The most common responses were other people’s experiences (33.33%), hearing what to expect (e.g. from disease, side effects, treatment) (33.33%), and condition-specific (Including sub-types) (23.08 %). Other themes included talking to a doctor or specialist or healthcare team (17.95%), information from health charities (12.82%), treatment options (10.26%), and triggers and managing exacerbations (5.13%).

Information that was not helpful: Stage III & IV

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common responses were no information not helpful (30.77%), sources that are not credible (Not evidence-based) (25.64%), and GP or specialist (20.51 %). Other themes included other people's experiences (15.38%), unsolicited information (12.82%), a lack of new information (7.69%), worse case scenarios (7.69%), and not type specific or too general (5.13%).

Information preferences: Stage III & IV

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. The most common responses were online information (30.77%), and talking to someone plus online information (28.21%). Other themes included written information (23.08%), talking to someone (17.95%), and all forms (10.26%).

The main reasons for a preference for online information were accessibility (20.51%), being able to digest information at own pace(15.38%), and convenient (7.69 %). Other themes included have a lot of information (7.69%), and have control/personal research (10.26%).

The main reasons for a preference for talking to someone were comfortable/convenient (7.69%), and time for interaction/ask questions (15.38%). Other themes included valuable/knowledgeable (10.26%), and personalised/relevant (10.26%).

Timing of information: Stage III & IV

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common times were at the beginning (diagnosis) (23.08%), after the shock of diagnosis (17.95%), and before starting treatment (17.95 %). Other themes included during treatment (15.38%), three weeks after diagnosis (10.26%),after treatment (10.26%), and continuously (7.69%).

Healthcare professional communication: Stage III & IV

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having an overall positive (53.85%), and overall positive, with the exception of one or two occasions (23.08%). Other themes included mix of positive and negative (10.26%), and overall negative (7.69%).

Healthcare professional communication (Rationale for response) : Stage III & IV

Participants described reasons for positive or negative communication with healthcare professionals. Participants that had positive communication, described the reason for this was because of holistic with two way, supportive and comprehensive conversations (38.46%), and good, with no particular reason given (17.95%).

Participants that had negative communication, described the reason for this was because of not forthcoming (5.13%), and dismissive (One way conversation) (5.13%).

Partners in health

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

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

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

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

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

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

Information given by health professionals: Stage III & IV

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options (n=34, 94.44%), hereditary considerations (n=26, 72.22%), disease management (n=21, 58.33%), and physical activity (n=19, 52.78%) were most frequently given to participants by healthcare professionals, and information about clinical trials (n=7, 19.44%), complementary therapies (n=6, 16.67%), and interpret test results (n=3, 8.33%) were given least often .

Information searched independently: Stage III & IV

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. The topics participants most often searched for were interpret test results (n=23, 63.89%), disease management (n=21, 58.33%), treatment options (n=18, 50.00%), and complementary therapies (n=17, 47.22%) were most frequently given to participants by healthcare professionals, and, information about clinical trials (n=11, 30.56%), dietary (n=10, 27.78%), and psychological/ social support (n=8, 22.22%) were searched for least often .

Information gaps: Stage III & IV

The largest gaps in information, where information was neither given to patients nor searched for independently were clinical trials (n=22, 61.11%) and dietary (n=20, 55.56%).

The topics that participants did not search for independently after not receiving information from healthcare professionals were treatment options (n=17, 47.22%) and disease management (n=11, 30.56%).

The topics that participants were given most information from both healthcare professionals and searching independently for were treatment options (n=17, 47.22%) and physical activity (n=15, 41.67%).

The topics that participants searched for independently after not receiving information from healthcare professionals were interpret test results (n=22, 61.11%) and complementary therapies (n=14, 38.89%).

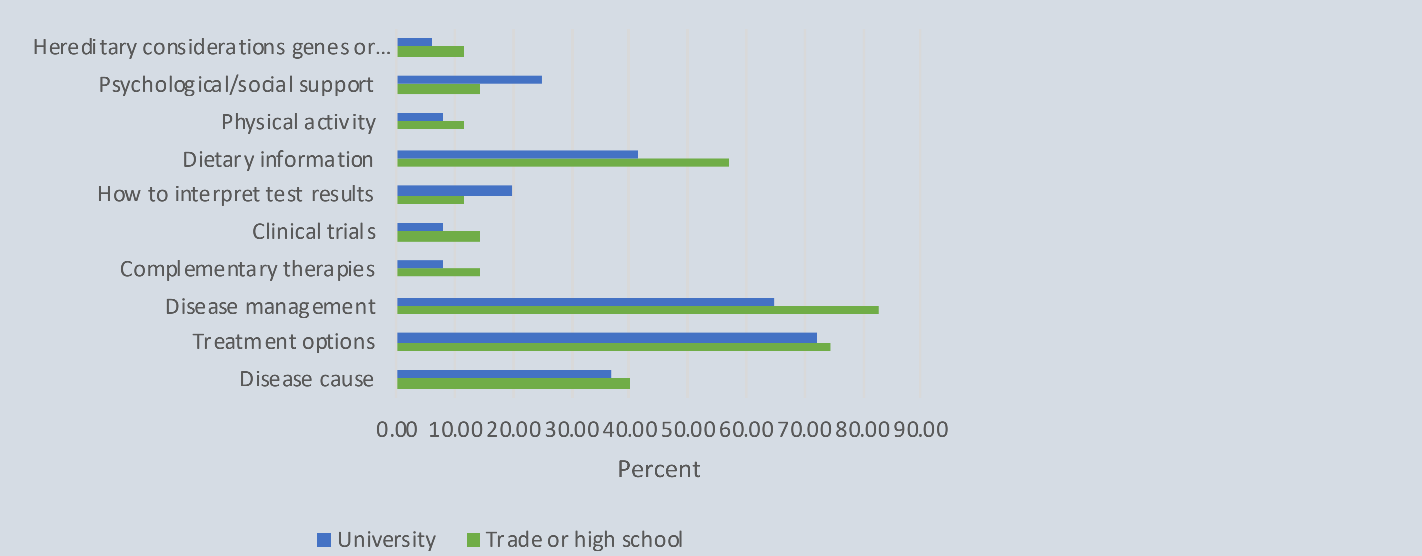
Most accessed information: Stage III & IV

Participants were asked to rank which information source that they accessed most often, where 1 is the most trusted and 5 is the least trusted. A weighted average is presented in Table 6.36 and Figure 6.48. With a weighted ranking, the higher the score, the more accessed the source of information.

My Health Record: Stage III & IV

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 12 participants (33.33%) had accessed My Health Record, 24 participants (66.67%) had not.

Of those that had accessed My Health Record, there were 3 participants (25.00%) who found it to be poor or very poor, 4 participants (33.33%) who found it acceptable, and 5 participants (41.67%) who found it to be good or very good.



Access to information: Stage III & IV

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common responses were the internet (Including health charities) (53.85%), their treating clinician (38.46%), and from Facebook and\or social media (35.90 %). Other themes included from other patient's experience (Including support groups) (35.90%), from books, pamphlets and newsletters (25.64%), from nursing staff (25.64%), from a specific health charity (15.38%), and from journals (research articles) (10.26%).

Participant describes accessing information through the internet in general

Mainly off the internet, like going on to the Cancer Australia. Is that what it's called? Cancer Australia website, National Breast Cancer Foundation website. On Facebook, I found that a group of women in Australia and New Zealand who have the same type of cancer that I had. A triple-negative and that was actually quite a good source of support. If you had questions like, "Oh, this happened to me, or this happened to anyone else. Should I go and see my doctor?" That was more moral support, but mostly on the internet from reliable sources. Participant_027TNG

I've got a lot of information from support groups, breast cancer support groups, but a lot of information just from a normal breast cancer research website. Yeah, the Cancer Council, website Breast Cancer website. Yeah, I've got a lot of information from over the years. Participant_031TNG

I have just Googled a lot of stuff, information. I have asked for information from the best chemists and the surgeons and they just all say, I've got a , a Facebook group. A lot of the questions that I have can be answered by people they've already been through, going through. Participant_038TNG

Participant describes primarily accessing information through treating clinician

From my doctors. I haven't really used the Internet to look stuff up because I just don't want to get misinformation. I've tried to be careful about that, or I've got friends that are nurses, so sometimes I've asked them to clarify something for me, or if I'm not sure about something, I have my breast care nurse. She was really good when I was having treatment at explaining stuff. Participant_043TNG

Oh, tons of it. [scoffs] My oncologist gave me some really good information from, I think it was Queensland or New South Wales. Anyway, with just good information about the drugs. I've just done heaps and heaps of Googling through PubMed and other sorts of-- not doctor Googling. I'm looking at reputable journal articles. I'm a member of a number of forums through Breast Cancer Australia, and also a couple of closed Facebook groups for people on the particular drugs and with the same sort of diagnosis that I have. I read a lot. I'm on alert for drug trials, and I read details. I do quite a bit of reading and research all the time. Participant_050TNG

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

Okay, I just sought out everything. I think I've had access to My Journey through Breast Care-- what's it? National Association which had then information groups, little blogs, and webinars, and things that you *could access. I found through Breast Cancer Care WA, they have had classes and courses like Look Good, Feel Good. Also, stress management, all sorts of, yes, lots. Lots on menopause. I've sought out a menopause specialist since finishing treatment. What else? Facebook triple-negative groups, go to my same cancer treatment and also, young peoples under-45's local support groups. They send the information. Yes, I probably surf the net and I try to find as much as I can that way talking to other people that have been through it. Participant_036TNG*

Dr. Google, a lot. [laughs] A lot. I've also, spent a lot of time on Facebook forums, specifically closed ones for stage four breast cancer patients. There's one that's Australia and New Zealand-based. There's one that's international. I've more recently joined one for the older patients and one that's for stage four liver mets-- Breast cancer with liver Mets. Mums with stage four breast cancer, so a fair few different forums. I've got a brain trust of real time experience. That's been really useful. Google's been good. I've been tapping into things like PubMed and the like. The breast care nurse is terrific as well. My oncologist has just wealth of knowledge, and she gives me a lot of times, but I obviously, you don't have them on tap. The breast care nurse has been really great in terms of filling out some information that I think of later on. Participant 051_2021AUHRP

Participant describes primarily accessing information through other patient's experience

I had a friend who put me in contact with the charity Pink Finss. They've given me a lot of support on a holistic level just with information, support packages, financial support, emotional support, support for the family, support group, just everything. They've really supported me a lot throughout the year. Then, I've also looked at all the support online from Breast Cancer Foundation, Cancer Council, McGraw Foundation, all that stuff. Obviously, looked at all the information from that. I only ever really looked at reputable sites and then just people's accounts of things, someone shared their experience, I didn't really go looking at random stuff that wasn't reputable. Then I just took people's experiences also with a grain of salt, knowing that everyone's different in how they respond and react. To me, knowledge is power. If I had the information there, then I could adapt it to fit me. Participant 042_2021AUHRP

Like I said, I'm in a support group, which has helped me immensely because most of these ladies are going through exactly the same thing or have been through it. I also joined the Breast Cancer National, what is it? Is it the National Breast Cancer- hey? Participant_028TNG

I've got a lot of information from support groups, breast cancer support groups, but a lot of information just from a normal breast cancer research website. Yeah, the Cancer Council, website Breast Cancer website. Yeah, I've got a lot of information from over the years. Participant_031TNG

Participant describes receiving information from books, pamphlets and newsletters

I've relied heavily on the Breast Cancer Network Associations information pages. My specialist, my breast surgeon on the first day that I saw him, gave me a book, called, Getting To Know Early Breast Cancer or You've Been Diagnosed With Early Breast Cancer. I actually really heavily relied on that book as my Bible. It actually travelled with me for the first three weeks of my diagnosis and I read things on the train and I treated that as the encyclopaedia of things. I really avoided going on and googling stuff or finding people's opinions that have been through my type of cancer. I had two friends, two family members not biological family members, but external family members who had gone through cancer, who I actually had them as a great support to kind of talk to about things but I never got them to tell me all the bad stuff or the…They never gave me the bad stories and it was only as things happen that I would call them and be like, "Oh, I had this happen," and they're like, "Yes, we had that too, it's completely normal." I didn't use a lot of the forums and I didn't use a lot of the Facebook pages until I was quite well far into my journey. It was probably almost done through chemotherapy before I even kind of joined any Facebook pages for support or any of the forums to support because I relied on making sure that I was getting the information from accurate breast cancer websites rather than some person who set up a breast cancer website. This book, which I think has now become My Journey tool with Breast Cancer Network Association, that really, for me was my-- if this is what it says in here, then this is what it says. Participant_025TNG

You go to the hospital and you get a lot of pamphlets and they give you a lot of information from there. Of course, you tend to get on the internet, but sometimes I think that can be a little harmful to your psyche. I joined a couple of Facebook support groups, but I found, probably three months into it, I left because it *can be very depressing. They were suggesting things that I think you have to find those things out for yourself anyway. The doctor would give you a whole heap of stuff and I found them probably the best rather than looking at the Internet. Participant_035TNG*

I had all the information, like the pamphlets and all of those things from Breast Screen. I also got given some more, when I went for the chemotherapy. Then I didn't actually really, like I said, I didn't Google anything, look online, or do any of that stuff. That was it. Participant 050_2021AUHRP

Participant describes receiving information through nursing staff

From my doctors. I haven't really used the Internet to look stuff up because I just don't want to get misinformation. I've tried to be careful about that, or I've got friends that are nurses, so sometimes I've asked them to clarify something for me, or if I'm not sure about something, I have my breast care nurse. She was really good when I was having treatment at explaining stuff. Participant_043TNG

OK, so I've had a bit of good stuff. Everyone Googles. I've had a try after joining a support group with breast cancer care WA, I learnt a lot through that with through the counsellor giving us information and also a breast nurse who was constantly updating me with anything that was on. And then my oncologist, he would give me information Participant_049TNG

Participant describes accessing information from a specific health charity

I've relied heavily on the Breast Cancer Network Associations information pages. My specialist, my breast surgeon on the first day that I saw him, gave me a book, called, Getting To Know Early Breast Cancer or You've Been Diagnosed With Early Breast Cancer. I actually really heavily relied on that book as my Bible. It actually traveled with me for the first three weeks of my diagnosis and I read things on the train and I treated that as the encyclopedia of things. I really avoided going on and googling stuff or finding people's opinions that have been through my type of cancer.
Participant_025TNG

PARTICIPANT: I've received lots of information. The Breast Cancer Nurse from the McGrath Foundation, she's been excellent and emailed me all sorts of information. I think it was her told me to go the breast cancer-- Is it BCNF? What's it called? Breast Cancer [unintelligible 00:23:02]
INTERVIEWER: BCNA.
PARTICIPANT: Yes, that one. To go there and use that as a source of information. I've being provided with lots of links and lots of information as to where I can go. I've had printouts given and emailed to me with other links to resources and sites that I can visit. That's what I've been using. Participant_033TNG

Participant describes accessing information primarily through journals (research articles)

For a lot of the information, I'll go onto PubMed or some of the journals which we can access through [unintelligible 00:31:06]. Access journal articles I guess, especially on triple-negative and for me, I also researched the likes of the Mediterranean Diet which actually does show improvement with triple-negative breast cancer patients as well. That's something which I've adapted as well with dietary. Anything that pops up, I'll research into, especially if it's in regards to triple-negative. Participant_034TNG

Oh, tons of it. [scoffs] My oncologist gave me some really good information from, I think it was Queensland or New South Wales. Anyway, with just good information about the drugs. I've just done heaps and heaps of Googling through PubMed and other sorts of-- not doctor Googling. I'm looking at reputable journal articles. I'm a member of a number of forums through Breast Cancer Australia, and also a couple of closed Facebook groups for people on the particular drugs and with the same sort of diagnosis that I have. I read a lot. I'm on alert for drug trials, and I read details. I do quite a bit of reading and research all the time. Participant_050TNG

Table 6.1: Access to information.

Access to information	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes accessing information through the internet in general	68	66.67	47	74.60	**21**	**53.85**	**12**	**44.44**	9	75.00
Participant describes primarily accessing information through treating clinician	31	30.39	16	25.40	15	38.46	**11**	**40.74**	4	33.33
Participant describes accessing information primarily through Facebook and/or social media	35	34.31	21	33.33	14	35.90	10	37.04	4	33.33
Participant describes primarily accessing information through other patient's experience	40	39.22	26	41.27	14	35.90	10	37.04	4	33.33
Participant describes receiving information from books, pamphlets and newsletters	32	31.37	22	34.92	10	25.64	6	22.22	4	33.33
Participant describes receiving information through nursing staff	27	26.47	17	26.98	10	25.64	5	18.52	**5**	**41.67**
Participant describes accessing information from a specific health charity	29	28.43	23	36.51	**6**	**15.38**	**0**	**0.00**	**6**	**50.00**
Participant describes accessing information primarily through journals (research articles)	15	14.71	11	17.46	4	10.26	2	7.41	2	16.67
Participant describes receiving information through allied health	2	1.96	1	1.59	1	2.56	1	3.70	0	0.00
Participant describes receiving information from chemist/pharmacist	1	0.98	0	0.00	1	2.56	1	3.70	0	0.00

Access to information	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes accessing information through the internet in general	68	66.67	**28**	**56.00**	**40**	**76.92**	16	69.57	**31**	**77.50**
Participant describes primarily accessing information through treating clinician	31	30.39	17	34.00	14	26.92	6	26.09	10	25.00
Participant describes accessing information primarily through Facebook and/or social media	35	34.31	18	36.00	17	32.69	8	34.78	13	32.50
Participant describes primarily accessing information through other patient's experience	40	39.22	16	32.00	24	46.15	**6**	**26.09**	**20**	**50.00**
Participant describes receiving information from books, pamphlets and newsletters	32	31.37	11	22.00	21	40.38	5	21.74	**17**	**42.50**
Participant describes receiving information through nursing staff	27	26.47	10	20.00	17	32.69	5	21.74	12	30.00
Participant describes accessing information from a specific health charity	29	28.43	**0**	**0.00**	**29**	**55.77**	**0**	**0.00**	**23**	**57.50**
Participant describes accessing information primarily through journals (research articles)	15	14.71	**2**	**4.00**	**13**	**25.00**	**0**	**0.00**	**11**	**27.50**
Participant describes receiving information through allied health	2	1.96	2	4.00	0	0.00	1	4.35	0	0.00
Participant describes receiving information from chemist/pharmacist	1	0.98	1	2.00	0	0.00	0	0.00	0	0.00

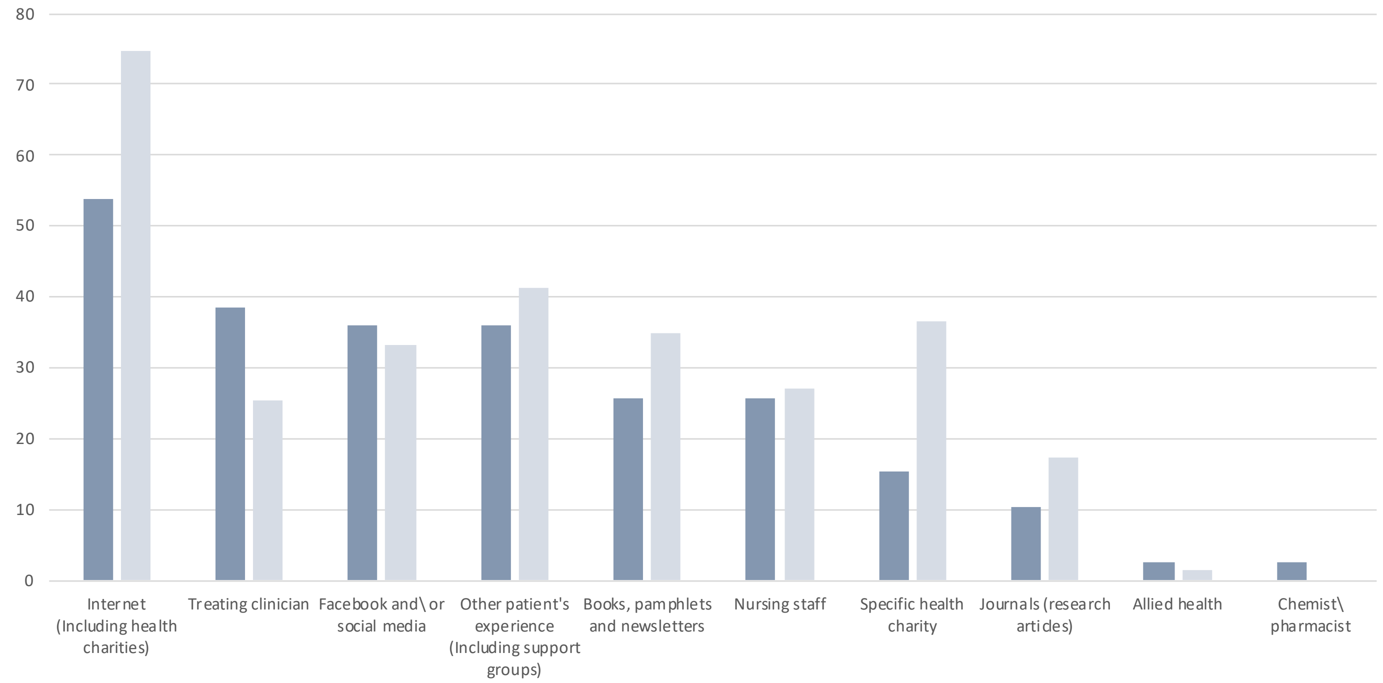


Figure 6.1: Access to information (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 6.2: Access to information – Stage III & IV variations

Access to information	Reported less frequently	Reported more frequently
Participant describes accessing information through the internet in general	All Stage III & IV Triple negative Stage III & IV	-
Participant describes primarily accessing information through treating clinician	-	Triple negative Stage III & IV
Participant describes receiving information through nursing staff	-	Hormone receptor Stage III & IV
Participant describes accessing information from a specific health charity	All Stage III & IV Triple negative Stage III & IV	Hormone receptor Stage III & IV

Information that was helpful: Stage III & IV

In the structured interview, participants were asked to describe what information they had found to be most helpful. The most common responses were other people's experiences (33.33%), hearing what to expect (e.g. from disease, side effects, treatment) (33.33%), and condition-specific (Including sub-types) (23.08 %). Other themes included talking to a doctor or specialist or healthcare team (17.95%), information from health charities (12.82%), treatment options (10.26%), and triggers and managing exacerbations (5.13%).

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

I think it's the experience of all the other women, what they've been through at the time of that particular [UNINTELLIGABLE] , having a chemotherapy without going through radiation. It's hearing true stories of what other women have have gone through. And for you to know what to expect or not expect to understand that not everyone has the same side effects over time, even if so, knowing in advance information. Participant_049TNG

I think the clinical information from that team was helpful, but for me. We see it with my with the Facebook group being able to, you know, say I've got this going on and lots of people say, yep, that happened to me, too. And knowing that that's normal. So I guess just having that support of other women who've been through what you're going through because, you know, a lot of the treating team haven't. They have a different understanding. Participant_038TNG

Yes. Probably access to the online network. Access to all of these people who have gone through or are going through what I am and to be able to share information and knowledge and get advice. That's been really fantastic. Participant_041TNG

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

I guess the most helpful has been finding out about the outcomes and the recurrence rate versus the survival rate. I guess that kind of thing about what the future potentially had in front of me. Participant_027TNG

I think from the nurses during chemo at the hospital, because they would go through the information on a piece of paper with you, but then they would also just talk to you in real life about, "It says here that you might get this and a lot of people actually get these." It made it like a real situation as opposed to just what a piece of paper was telling you. Participant_045TNG

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

I think the most helpful is knowing that it's okay and it's really normal and that the type of cancer I had is treatable. At the beginning, as I said, realistically, none of my specialists told me too much about triple-negative and the really negative connotations it has, but the really scary side effects or the scary prognosis that you can find on a lot of pages now when you start to do your research. It was nice to get information that was really necessarily necessary but wasn't too much information. For example, everyone talks about the stage of breast cancer they have. I remember asking my surgeon two appointments in what stage mine was. We knew it was grade three, which was really aggressive, but he said to me the stages-- He implied that the staging is really old school terminology, and they talk either early breast cancer or metastatic breast cancer. I've never done the, "Oh, I'm a stage 2B grade 4, whatever type of breast cancer." I just have always been early breast cancer. Having done my own research, I'm fortunate to know I was stage 1. I was pretty early stage. I think for me the benefit of getting information that was absolutely necessary, but not too much and not too scary, I suppose, the really positive information. Participant_025TNG

Probably the pamphlets and the sheets that they printed off from your chemo place, from your oncologist, from your breast cancer. Anything like that is the best thing. They give you a book, which I probably didn't read until two or three weeks, four weeks into my treatment because I just couldn't process what was going on. Going back, I found a lot of that was helpful as well. The information that they give you when at the time of your diagnosis mightn't help you right at the start because you're still trying to understand what's going on. Being able to go back and look at it, I think, is a good thing as well. Participant_035TNG

Being specific to my type of cancer because a lot of the time it's to do with hormonal cancer. Most people just presume that if you've got breast cancer, it's a hormonal type, having people understand there's different types of finding specific information for me has been helpful. Participant_036TNG

Participant describes talking to their doctor or specialist as helpful

The most helpful? I can't think of any one thing. Most helpful? Just being about to talk to somebody, as I said *just to confirm if…because with the triple-negative, you have this underlying fear of it returning, so any little ache and pain, is, "Is that cancer coming back?" Which I did ask the doctor yesterday. I said, "Is there anything I should really look out for, or worry about?" He said, "Well, the first thing you don't do, is you don't worry. " [chuckles] Which is really nice and positive. Participant_029TNG*

Probably the information that, as it's explained to me, either by the doctors or nursing staff, rather than reading it. They're able to provide it in a way that's more interactive, and I can ask follow up questions and things like that. Participant 050_2021AUHRP

Participant describes health charities information as helpful

I got provided a booklet at very beginning on breast cancer. I can't remember what it's called, but it basically walks you through each step-by-step, which is offered from [UNINTELLIGABLE] from the National Breast Cancer Council. That was my best resource. Participant_024TNG

I would say, I think, a printed booklet is helpful. I also was involved with the Cancer Council with their breast reconstruction. Actually, I might have seen this breast cancer booklet because I thought there wasn't enough information in there about triple-negative. Basically, a doctor wrote about the triple-negative details of diagnosis and they asked me just to put any or to have a look at it, to see if there's anything that I felt should be added to it. I think with a booklet, even though you can get things online, it's quite good to have something to hold and go back to as well, particularly for older ladies. You said anything else. I also I suppose, these days you can get things online. There was a diary offered, I think, that you could write your thoughts in, but I never bothered. Participant_040TNG

Participant describes information about treatment options as helpful

I guess at the outset, the research showing the effectiveness of the treatments that I'm on was encouraging, and more recently, I probably find some of the forums where people discuss side effects and things that occur when they're on the [unintelligible] treatments to me and also the same psychological issues that we deal with. I find that helpful, seeing that other people go through the same sorts of things and looking at how other people have dealt with some side effects. It's given me some ideas to pursue and follow and often reject, but [laughs] sometimes you could go on with [unintelligible] Participant_050 TNG

I got provided a booklet at very beginning on breast cancer. I can't remember what it's called, but it basically walks you through each step-by-step, which is offered from [unintelligible] from the National Breast Cancer Council. That was my best resource. Participant_024 TNG

Table 6.3: Information that was helpful

Information that was helpful	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes other people's experiences as helpful (Peer-to-peer)	30	29.41	17	26.98	13	33.33	10	37.04	3	25.00
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	34	33.33	21	33.33	13	33.33	7	25.93	**6**	**50.00**
Participant describes information specific to their condition (and sub-types) as helpful	18	17.65	9	14.29	9	23.08	**8**	**29.63**	1	8.33
Participant describes talking to their doctor or specialist as helpful	26	25.49	19	30.16	7	17.95	**3**	**11.11**	4	33.33
Participant describes health charities information as helpful	15	14.71	10	15.87	5	12.82	2	7.41	**3**	**25.00**
Participant describes information about treatment options as helpful	9	8.82	5	7.94	4	10.26	4	14.81	0	0.00
Participant describes information about triggers and managing or avoiding exacerbations	4	3.92	2	3.17	2	5.13	2	7.41	0	0.00
Participant describes no particular information being especially helpful	3	2.94	2	3.17	1	2.56	1	3.70	0	0.00
Participant describes all or any information as being helpful	2	1.96	1	1.59	1	2.56	1	3.70	0	0.00

Information that was helpful	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes other people's experiences as helpful (Peer-to-peer)	30	29.41	19	38.00	11	21.15	9	39.13	8	20.00
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	34	33.33	14	28.00	20	38.46	7	30.43	14	35.00
Participant describes information specific to their condition (and sub-types) as helpful	18	17.65	13	26.00	5	9.62	5	21.74	4	10.00
Participant describes talking to their doctor or specialist as helpful	26	25.49	9	18.00	17	32.69	6	26.09	13	32.50
Participant describes health charities information as helpful	15	14.71	5	10.00	10	19.23	3	13.04	7	17.50
Participant describes information about treatment options as helpful	9	8.82	9	18.00	0	0.00	**5**	**21.74**	0	0.00
Participant describes information about triggers and managing or avoiding exacerbations	4	3.92	4	8.00	0	0.00	2	8.70	0	0.00
Participant describes no particular information being especially helpful	3	2.94	3	6.00	0	0.00	2	8.70	0	0.00
Participant describes all or any information as being helpful	2	1.96	2	4.00	0	0.00	1	4.35	0	0.00

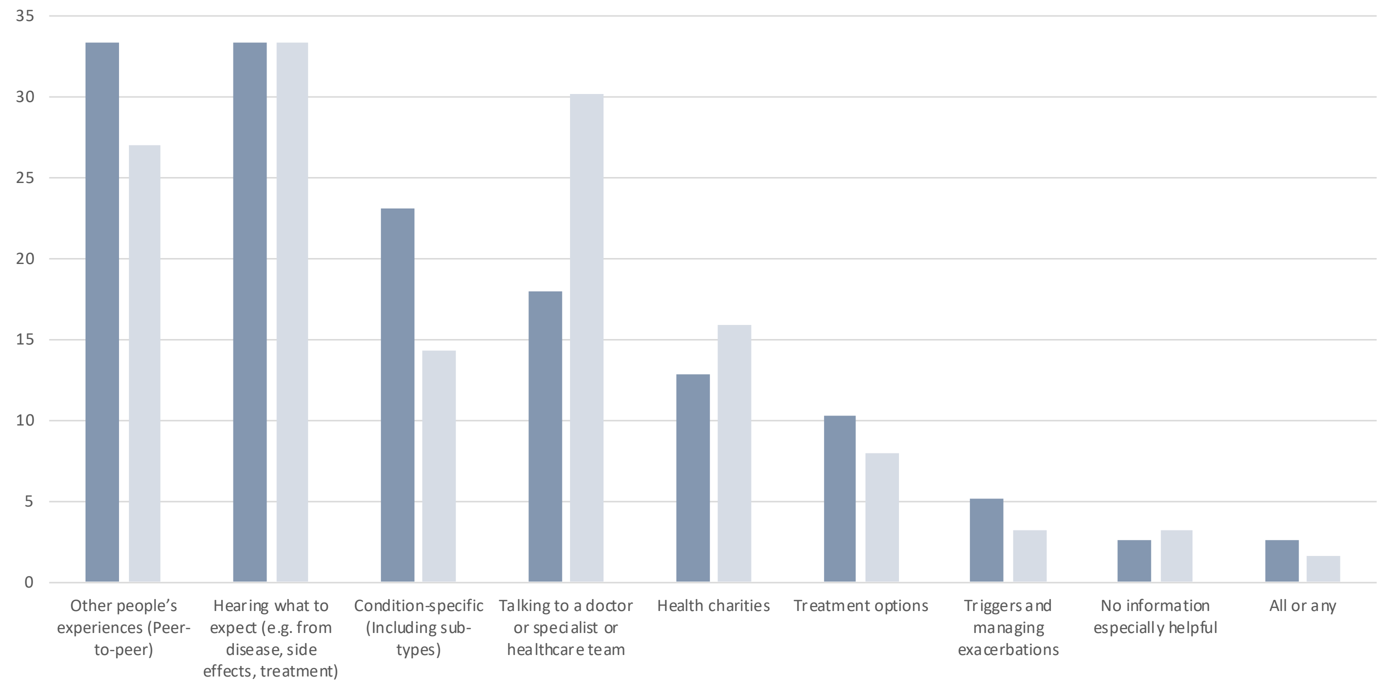


Figure 6.2: Information that was helpful (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 6.4: Information that was helpful – Stage III & IV variations

Information that was helpful	Reported less frequently	Reported more frequently
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	-	Hormone receptor Stage III & IV
Participant describes information specific to their condition (and sub-types) as helpful	-	Triple negative Stage III & IV
Participant describes talking to their doctor or specialist as helpful	Triple negative Stage III & IV	-
Participant describes health charities information as helpful	-	Hormone receptor Stage III & IV

Information that was not helpful: Stage III & IV

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common responses were no information not helpful (30.77%), sources that are not credible (Not evidence-based) (25.64%), and GP or specialist (20.51 %). Other themes included other people's experiences (15.38%), unsolicited information (12.82%), a lack of new information (7.69%), worse case scenarios (7.69%), and not type specific or too general (5.13%).

Participant describes no information being not helpful

No, I don't think there's anything. I think the more information you have, the better you are Participant_049 TNG

I don't think so. I think a lot of what I've come across has helped in some way. Obviously, it doesn't get rid of cancer but-- Participant_034 TNG

No, pretty accurate actually. Participant_032 TNG

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

Only the things that I found by myself on Google, they weren't helpful. I joined a Facebook group and left within 10 minutes, that wasn't helpful at all. Those sorts of blogs and stories, they haven't been helpful at all for me. Maybe they are for other people, but for me, that wasn't helpful at all. Just typing in triple-negative breast cancer into Google is probably the most unhelpful thing that you can do. I found that out the hard way. Participant_033 TNG

Online closed Facebook groups can be helpful as well, but the danger with those is it's just people's opinions and they not necessarily got anybody monitoring what people are saying. The danger with those as well is that people die, particularly with the triple-negative group and I think that can be very upsetting when it *comes on your face and you can see that they've mentioned somebody that has passed away. I think I've probably gone off subject here, but I find that a little bit dangerous, but there's nothing anyone can do about that. Participant_040 TNG*

Participant describes the GP/specialist as being not helpful

Not really. Probably it's my experience with my breast cancer nurse. More the fact that I, for the first month, thought breast cancer nurses were unicorns that they apparently existed but I never saw one. The treatment hospital that I had had three breast cancer nurses, but they're based around the treatment you're having. There's a breast cancer nurse for surgical, there's a breast cancer nurse for medical, and a breast cancer nurse for radiation oncology. They're not I guess, what a lot of people think of breast cancer nurses. They weren't my best buddy. They weren't there for me to sit with me and talk me through everything. I had my first surgery and still had never met the surgical breast care nurse. I had, as I mentioned, the medical oncologist, breast care nurses. I have a great relationship with her, but she wasn't sitting in on my appointments and hold my hand and guide me through the process, which is what it seems like a lot of McGrath nurses do, for example. She was the one who gave me my Zoladex injections, but for me, I think that and I know a lot of people at the hospital I went to, they all have the same reaction is that there's a breast care nurse but there's not a breast care nurse. Participant_025 TNG

If the hospital would have said to me at the time, "We can do the double mastectomy and the reconstruction," I would have gone with that. I don't know, in hindsight, whether that would have been the-- In hindsight, that wouldn't have been the right decision, but at the time, I thought that was pretty unhelpful, that whole scenario of, go and see the breast surgeon, then you've got to go and see a plastic surgeon. I found that whole experience the worst. Participant_029 TNG

Participant describes other people's experiences as being not helpful

Some things that I've come across as not being helpful, this is just in a normal breast cancer group, and it's not a specific type of cancer. People saying that they still went to work, they didn't have any side effects, blah, blah, blah, that sort of thing. I was just like, "I don't know what treatment you're getting, but it's obviously nothing like mine." That sort of thing. I was like, "How can anybody still work? Do they have servants at home?" I don't know. People going, "Oh, I didn't have any side effects, blah, blah, blah," that made me feel really bad. Participant_028 TNG

PARTICIPANT: Only the things that I found by myself on Google, they weren't helpful. I joined a Facebook group and left within 10 minutes, that wasn't helpful at all. Those sorts of blogs and stories, they haven't been helpful at all for me. Maybe they are for other people, but for me, that wasn't helpful at all. Just typing in triple-negative breast cancer into Google is probably the most unhelpful thing that you can do. I found that out the hard way. Participant_033 TNG

Participant describes other people giving their advice or opinions as being not helpful

People that think they can cure your cancer and tell you that, do you think you can take your loss and people that want to help but really not, you know, OK, medical practitioners come up and say, you know, really come on. Participant_044 TNG

No. Well, just well-meaning people who keep telling you, "Stay positive. Stay positive." [chuckles] Participant_041 TNG

Oh, God, yes. So many people's opinions in terms of telling you what to do, and lots of people going, "Oh, you should do this." So many people don't know, to be honest, I didn't know there were that many varieties of breast cancer that you could get. You don't know that till you get that pathway if you know what I mean. It would be confusing sometimes when people would talk about generically breast cancer, and then when they publish information and talk about breast cancer. Actually, you need to be a little bit more specific because I don't take any medication afterwards. I don't need to take hormone blockers. I don't need to do all those things. Lots of people go, "Oh, you're going to take that drug for 5 or 10 years." I'm like, "That's not me." They're like, "Oh." It would probably be, just sometimes they weren't specific enough for me, I know it's not right, but people would talk about having a complete pathological response and I'm negative. I'd go, "Well, I can't say that. I don't know how you know that. I don't know how you know, once you've finished all your treatment, how you know you don't have it, but you've just got to deal with that." Participant_047 TNG

Participant describes a lack of new information as not helpful

Not really. Probably it's my experience with my breast cancer nurse. More the fact that I, for the first month, thought breast cancer nurses were unicorns that they apparently existed but I never saw one. The treatment hospital that I had had three breast cancer nurses, but they're based around the treatment you're having. There's a breast cancer nurse for surgical, there's a breast cancer nurse for medical, and a breast cancer nurse for radiation oncology. They're not I guess, what a lot of people think of breast cancer nurses. They weren't my best buddy. They weren't there for me to sit with me and talk me through everything. I had my first surgery and still had never met the surgical breast care nurse. I had, as I mentioned, the medical oncologist, breast care nurses. I have a great relationship with her, but she wasn't sitting in on my appointments and hold my hand and guide me through the process, which is what it seems like a lot of McGrath nurses do, for example. She was the one who gave me my Zoladex injections, but for me, I think that and I know a lot of people at the hospital I went to, they all have the same reaction is that there's a breast care nurse but there's not a breast care nurse. Participant_025 TNG

If the hospital would have said to me at the time, "We can do the double mastectomy and the reconstruction," I would have gone with that. I don't know, in hindsight, whether that would have been the—in hindsight, that wouldn't have been the right decision, but at the time, I thought that was pretty unhelpful, that whole scenario of, go and see the breast surgeon, then you've got to go and see a plastic surgeon. I found that whole experience the worst…With breast cancer, nobody will tell you, "Have a lumpectomy," or, "Have a mastectomy," and then you have an oncologist tell me, "Oh, why wouldn't you just have a mastectomy?" Then you have somebody having a lumpectomy. Everybody just has an opinion one way or the other, really, you're torn about what you want to do about that. There's no clear guideline about which way to go. I found that the most distressing time for me. It wasn' t until I went and saw DOCTOR the second time and he said, "I don't think you need put yourself through that unless you have an underlying condition." It just seemed to be the right thing. He said the right thing at the right time, to me, anyway. Participant_029 TNG

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

I guess other people's horror stories. Participant 050_2021AUHRP

Apart from those support groups has been a little bit helpful when you needed things, but I also think you've just got to be a bit careful there because you're seeing people die, or you're seeing people who get a relapse and it can be quite hard to take that in. I know some support groups are really, really good, but I think you just need to be very careful of the support groups you join. 035_2021AUHRP

Table 6.5: Information that was not helpful

Information that was not helpful	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes no information being not helpful	32	31.37	20	31.75	12	30.77	8	29.63	4	33.33
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	23	22.55	13	20.63	10	25.64	8	29.63	2	16.67
Participant describes the GP/specialist as being not helpful	18	17.65	10	15.87	8	20.51	6	22.22	2	16.67
Participant describes other people's experiences as being not helpful	16	15.69	10	15.87	6	15.38	3	11.11	3	25.00
Participant describes other people giving their advice or opinions as being not helpful	12	11.76	7	11.11	5	12.82	3	11.11	2	16.67
Participant describes a lack of new information as not helpful	6	5.88	3	4.76	3	7.69	3	11.11	0	0.00
Participant describes information about worse case scenarios and negative information as being not helpful	10	9.80	7	11.11	3	7.69	1	3.70	2	16.67
Participant describes information that is not specific to their condition or sub-type as being not helpful (Too general)	3	2.94	1	1.59	2	5.13	2	7.41	0	0.00

Information that was not helpful	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes no information being not helpful	32	31.37	13	26.00	19	36.54	5	21.74	15	37.50
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	23	22.55	**17**	**34.00**	**6**	**11.54**	**9**	**39.13**	**4**	**10.00**
Participant describes the GP/specialist as being not helpful	18	17.65	11	22.00	7	13.46	5	21.74	5	12.50
Participant describes other people's experiences as being not helpful	16	15.69	3	6.00	13	25.00	**0**	**0.00**	10	25.00
Participant describes other people giving their advice or opinions as being not helpful	12	11.76	4	8.00	8	15.38	1	4.35	6	15.00
Participant describes a lack of new information as not helpful	6	5.88	6	12.00	0	0.00	3	13.04	0	0.00
Participant describes information about worse case scenarios and negative information as being not helpful	10	9.80	2	4.00	8	15.38	1	4.35	6	15.00
Participant describes information that is not specific to their condition or sub-type as being not helpful (Too general)	3	2.94	3	6.00	0	0.00	1	4.35	0	0.00

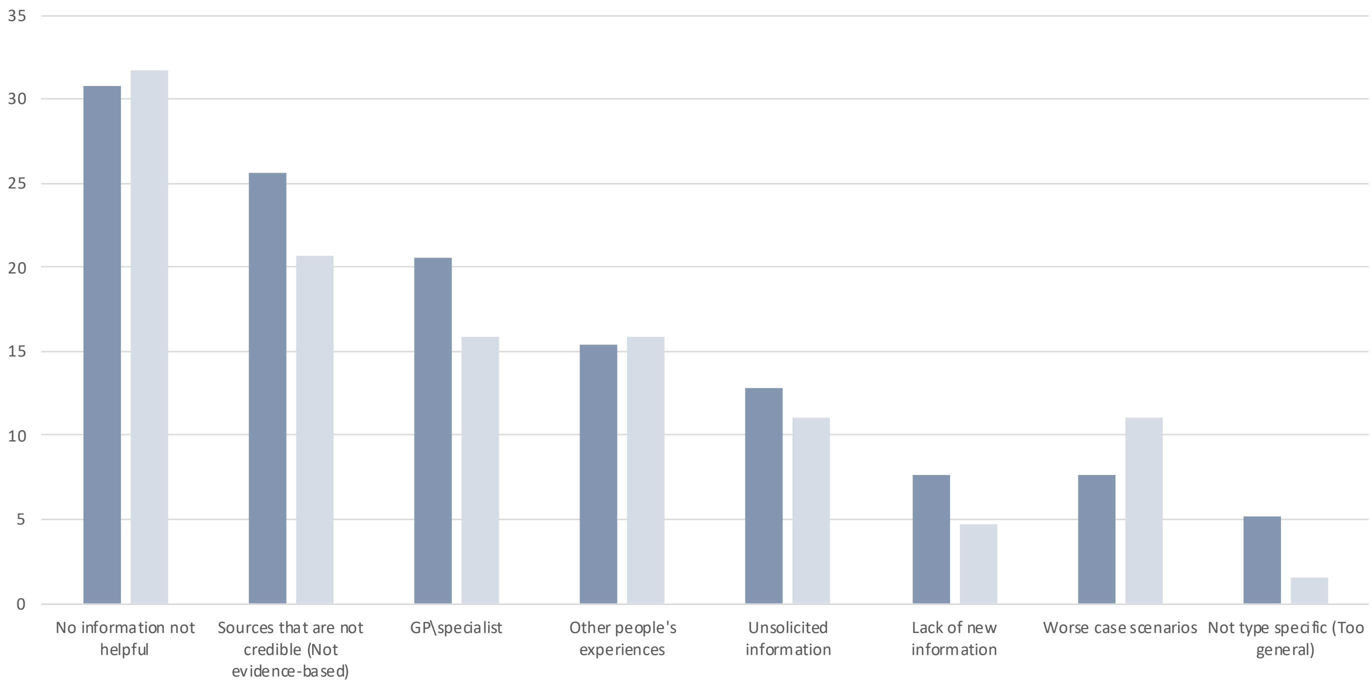


Figure 6.3: Information that was not helpful (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Information preferences: Stage III & IV

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. The most common responses were online information (30.77%), and talking to someone plus online information (28.21%). Other themes included written information (23.08%), talking to someone (17.95%), and all forms (10.26%).

The main reasons for a preference for online information were accessibility (20.51%), being able to digest information at own pace(15.38%), and convenient (7.69 %). Other themes included have a lot of information (7.69%), and have control/personal research (10.26%).

The main reasons for a preference for talking to someone were comfortable/convenient (7.69%), and time for interaction/ask questions (15.38%). Other themes included valuable/knowledgeable (10.26%), and personalised/relevant (10.26%).

Participant describes online information as main information preference

Probably online because you can access it any time and you're not filing a bookshelf full of books and pamphlets that you will probably never look at again, and definitely you've got an in-person thing too. Participant_030TNG

Online information probably, because I can read it and then reread it and I can print it out. I can give it to my partner to read and then we can discuss things and I can bounce ideas with him. Phone conversations, I think you don't retain all the detail from a phone conversation. I know you I don't. Participant_050TNG

I guess, probably the internet because then I can access the information when I want to or when I need to. If I wake up at three o'clock in the morning and think, "Oh, I wonder." I can immediately jump on it and try and source some kind of answer. Participant_027TNG

Participant describes talking to someone plus online information as main information preference

I'm probably online because it's small world wide, and you can get a wide range of outcomes, a wide range of knowledge. And I do like to talk to people as well just because, you know, you can get some really *interesting information from different people. So it's open to communication and knowledge. So if anybody has any information that they know that I can learn from that out and Participant_044 TNG*

I think I prefer talking to someone, but I do read a lot of online things with our support group. We have a pretty good network of ladies where we have our Facebook page and someone sees an article, they will forward it to everyone else to read and then sometimes we will then we'll discuss it as a group. So I think that has been the best source of information to me. Participant_049 TNG

Participant describes written information as main preference

I like written or online information. Talking to people is lovely, but I don't always-- I think when you're in a new diagnosis state, I know that I don't always remember what they've said or I remember incorrectly. I've found written information the most useful for me that I can go back to and look again, whether that be printed and handed out in booklet form, I don't mind, but online is great too. It's just knowing where to go and what to read, and not going rogue. Participant_033 TNG

I think the booklet. Online is easy, but I think you can get a lot of misinformation online. You've got to be very careful where you look in. I think there's a couple of good places that we were encouraged to join from the hospitals that have been quite good. I think a book that you can, every now and again, go back and have a look is also something that is quite good. Probably, I find book-type stuff rather than online because, like I said, online, you're just not too sure where it's coming from. Participant_035 TNG

Participant describes talking to someone as main information preference

I would prefer to talk face-to-face, if I can. Otherwise, booklets when you've got time to actually comprehend things. I also do like the resources of emails, works I contact or somebody that you can contact.
INTERVIEWER: What's your reason for preferring a face-to-face conversations?
PARTICIPANT: I think that face-to-face is easier to talk about it, instead of like with an email. You can certainly talk about it as well, but face-to-face, you have got that personal contact, so you feel like there's somebody on the other end that's listening. Participant_024TNG

PARTICIPANT: Probably talking to someone. One-on-one seems to be a lot easier these days.
INTERVIEWER: Are there other reasons why you prefer one-on-one?
PARTICIPANT: Not really, no. I think when you're actually sitting with somebody that you absorb more probably. Participant_032TNG

I think talking to someone is the best because you've got the interaction, that personal side of things, you can ask questions then and there, that sort of thing, yes. Participant_046TNG

Participant describes preferring all forms of information

There's benefits to all of those. I like online because it means that as I think of things in my own time, I have that access. I've really enjoyed also meeting women with breast cancer and talking to people who are having similar experiences to me. That's been really, really valuable. I haven't really read many booklets because pretty much all the information I find is either online or directly from someone else. Participant_036TNG

Table 6.6: Information preferences

Information preferences	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes online information as main information preference	26	25.49	14	22.22	12	30.77	9	33.33	3	25.00
Participant describes talking to someone plus online information as main information preference	22	21.57	11	17.46	11	28.21	**9**	**33.33**	2	16.67
Participant describes written information as main preference	21	20.59	12	19.05	9	23.08	6	22.22	3	25.00
Participant describes talking to someone as main information preference	26	25.49	19	30.16	7	17.95	**4**	**14.81**	3	25.00
Participant describes prefering all forms of information	17	16.67	13	20.63	4	10.26	**1**	**3.70**	3	25.00
Participant describes apps as main information preference	3	2.94	2	3.17	1	2.56	1	3.70	0	0.00
Participant describes podcast as main preference	2	1.96	1	1.59	1	2.56	1	3.70	0	0.00

Information preferences	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes online information as main information preference	26	25.49	15	30.00	11	21.15	6	26.09	8	20.00
Participant describes talking to someone plus online information as main information preference	22	21.57	12	24.00	10	19.23	3	13.04	8	20.00
Participant describes written information as main preference	21	20.59	11	22.00	10	19.23	5	21.74	7	17.50
Participant describes talking to someone as main information preference	26	25.49	11	22.00	15	28.85	7	30.43	12	30.00
Participant describes prefering all forms of information	17	16.67	4	8.00	13	25.00	3	13.04	10	25.00
Participant describes apps as main information preference	3	2.94	3	6.00	0	0.00	2	8.70	0	0.00
Participant describes podcast as main preference	2	1.96	2	4.00	0	0.00	1	4.35	0	0.00

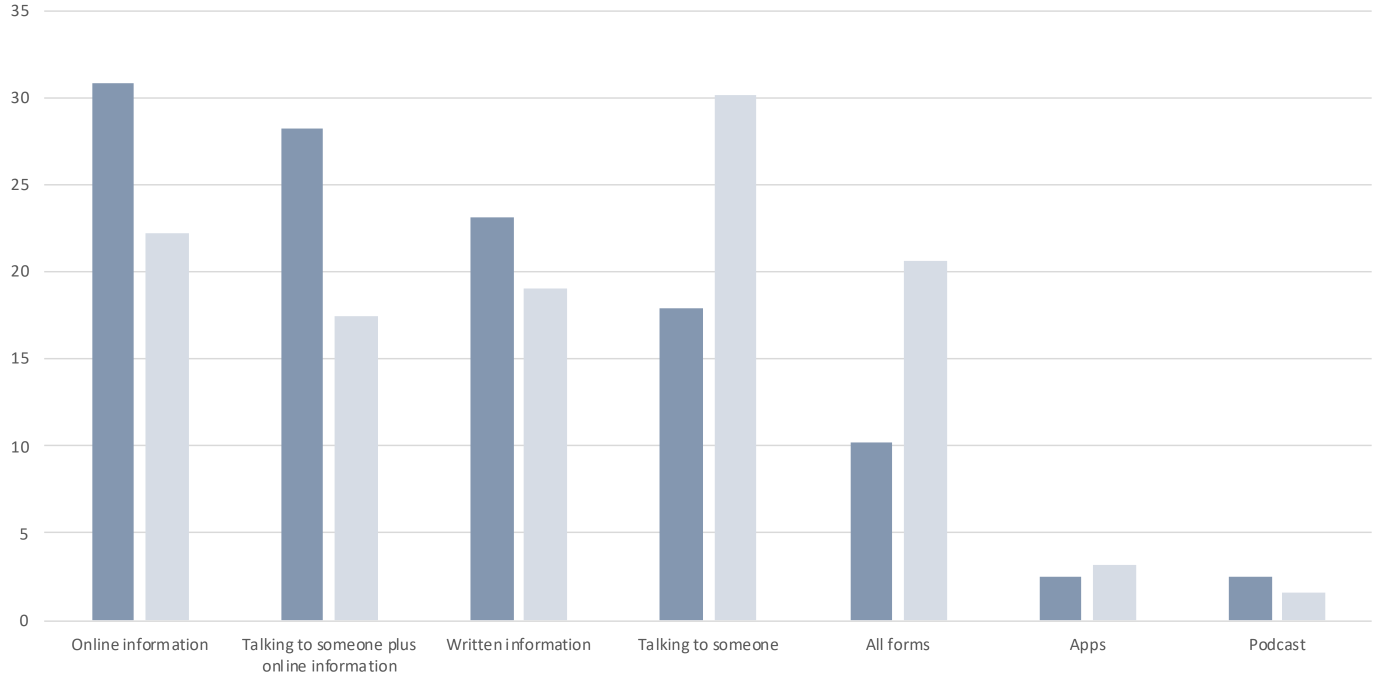


Figure 6.4: Information preferences (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

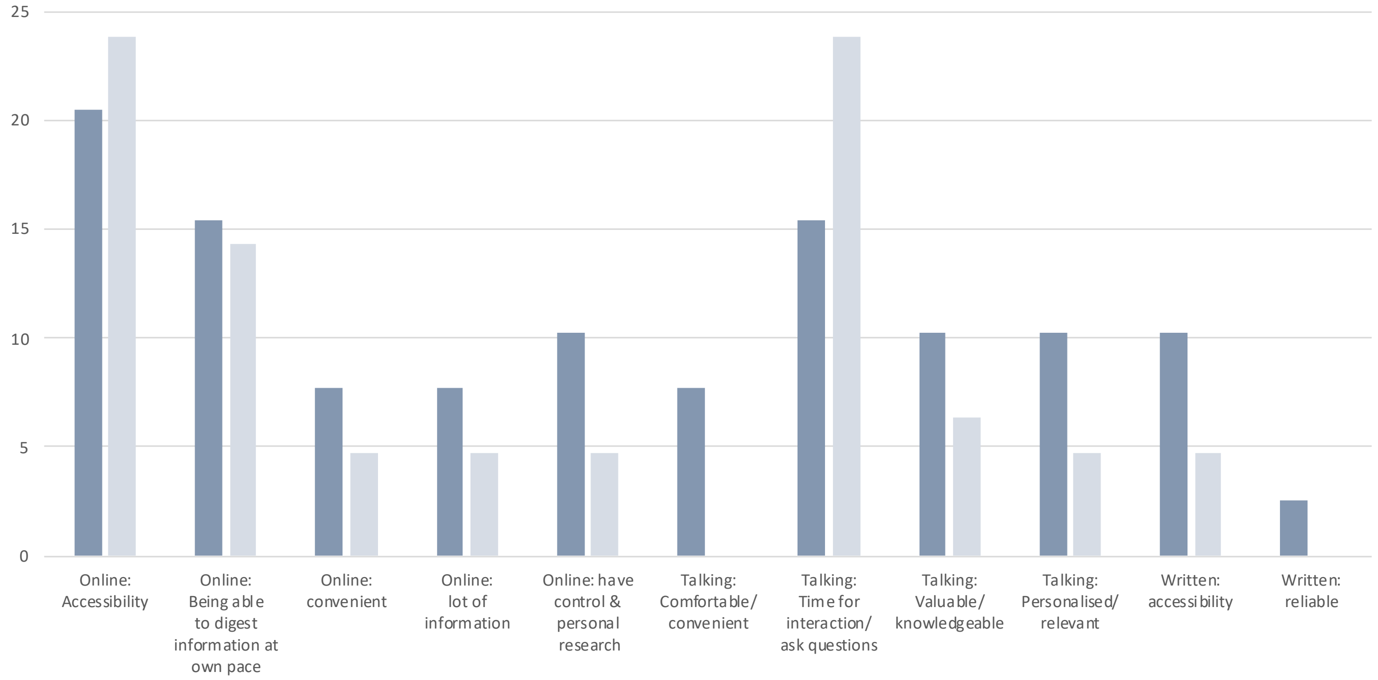


Figure 6.5: Reasons for information preferences by format (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 6.7: Information preferences – Stage III & IV variations

Information preferences	Reported less frequently	Reported more frequently
Participant describes talking to someone plus online information as main information preference		Triple negative Stage III & IV
Participant describes talking to someone as main information preference	Triple negative Stage III & IV	
Participant describes preferring all forms of information	Triple negative Stage III & IV	

Timing of information: Stage III & IV

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common times were at the beginning (diagnosis) (23.08%), after the shock of diagnosis (17.95%), and before starting treatment (17.95 %). Other themes included during treatment (15.38%), three weeks after diagnosis (10.26%),after treatment (10.26%), and continuously (7.69%).

Participant describes being receptive from the beginning (diagnosis)

Probably in the early days when I was first diagnosed. I I want to know as much as I could know, because I've never worked in the cancer area before and I didn't even know there was such a thing as triple negative. You know, I was very eager to find out as much as I could about it and what treatments were available. But in some ways that remained to. Right, because when you look at the statistics and you look at all the research around, it's not a positive outcome. Yeah. So very quickly to take what is good for you and say what's not good for you, because, you know, I just want to have a lot of information that wasn't good enough. And I knew that that wasn't good for my healing or my well-being. So I opted to seek the solution that I respect. Participant_044 TNG

I was ready to take information in at diagnosis, but finding the right information to take in took a couple of months if that makes sense. Even if I got diagnosed and I was told what type it was and what sort of treatments and surgeries and everything like that was ahead. It probably wasn't until I was in the middle of chemotherapy that I got the information that was right, and that was the main. Participant_030 TNG

Participant describes being receptive to information after the shock of diagnosis

I think, to begin with, you've got no ability to take information in, there's so many-- You're scared shitless and you don't know what to do. As soon as you have a plan, I think you can start to take information in. Once I went and got a plan from the medical oncologist. I knew what NAME had said, "Get the surgery, but there's going to be chemotherapy and radiation." I needed a plan. Until I had that plan, I just couldn't-- there's no point reading anything, you don't know what you're going to get. It's just too confusing. Once I got Gavin's plan and then I understood a little bit more about it-- everyone else was reading pathology results and I'm like, "I don't know what all that means. I don't know how to deal with that." For me, sometimes it was too much and so I just, I don't know, I just stepped away from it. When it was, I have to say halfway through, so when I talked to the genetic specialist, she was great. She gave me more-- when we were talking to her, I could prep up questions. That was really good because it made me think you had to focus on certain elements. Then when I came away from that, I did more research. That was halfway through the chemotherapy. I was in a better position to listen and not be so scared. Participant_047 TNG

I think the first appointment you have, it's very overwhelming because you're getting all of these things thrown at you. Being able to go home and digest it and having the support of this information book was really useful because you can start doing that. I probably, at the very beginning, found a lot of information overwhelming because you just didn't know.
Now that I know a lot of stuff more than I did at that point in time, I think too, there would've been a lot more I would have asked about, but I had every information. I don't at any point in time think that I didn't have enough information to make an informed decision. Probably more receptive to information once you've got the information and being able to think about it and then go back to someone to clarify what you understood it to be was actually correct. Participant_025 TNG

Participant describes being receptive to information before starting treatment

Before I started treatment. Participant_028 TNG

Probably before the operation. Yes, before she operated, I saw her a few times and she explained *things quite well and my new oncologist is very good. Participant_032 TNG*

Participant describes being receptive to information during treatment

Probably I didn't start fully taking the information until after I started chemo. I think, right up to the moment that the surgeon was drawing on for surgery, I was in that, "This isn't really happening mindset. Maybe at the point of surgery, and then again at the point of where chemo started because I guess until then, I didn't really know what was going to happen. They can tell you, "Okay, you you're going to get an IVA." Until you're actually in there and having the nurse explain, "This is what we're going to do. This is how long it's going to take. This is why we're doing it."' That's where it all becomes real. Participant_027 TNG

I think once you commence the treatment. I kind of wish, and again, because of COVID, I wasn't allowed to do that, but I wish I could bring my husband, not only to my first chemotherapy but also to my second. Because the first time seeing the nurse and seeing the oncologist and starting all of those IV chemos and everything, it's like you're in a big bubble house. You don't really understand everything. I feel like you should be allowed to either take notes or bring the person to two meetings, not just one. Participant_042 TNG

Participant describes being receptive to information three weeks after diagnosis

Three weeks after my diagnosis. For the first three weeks, I was going along and doing everything, but I literally was still reeling from the shock. Participant_045 TNG

I think in a couple of weeks after the diagnosis, when I'd accepted it and understood a little bit more, that was a good time to give information, but right at the beginning, I feel like there probably wasn't enough information given at the diagnosis time. Hence, why I Googled on my own because I had a lot of questions and they weren't necessarily answered and I didn't understand anything. I think at that point, more targeted information would have been really good, whether I'd read it there and then I don't know, but to have been given it and had it at hand so that when I was ready, I had something that was useful and helpful to look at. Rather than when I was ready, taking to Google because I didn't know stuff and thought that's what I needed to find out. The diagnosis day, I don't think enough information was given at all. It was really a case of, "This is what we're going to do. We're going to get you into surgery. You're booked in two weeks' time da da and this is what's happening." I hadn't even understood the different grades of cancer or stages or what triple-negative cancer was. I didn't know anything. It was really a lack of information at diagnosis I found. That would have been helpful. Whether I'd read it or not, I don't know, but it would have been good to have. Participant_033 TNG

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

I've probably been quite receptive to receiving information the whole way through being all that, knowledge is power. Any piece of information could be beneficial to me or, God forbid, I have contact with someone else, it could be beneficial to them. I just generally like to gather as much as I can from everywhere. Participant 042_2021AUHRP

Table 6.8: Timing of information

Timing of information	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes being receptive from the beginning (diagnosis)	32	31.37	23	36.51	9	23.08	5	18.52	4	33.33
Participant describes being receptive to information after the shock of diagnosis	21	20.59	14	22.22	7	17.95	3	11.11	4	33.33
Participant describes being receptive to information before starting treatment	8	7.84	1	1.59	7	17.95	7	25.93	0	0.00
Participant describes being receptive to information during treatment	11	10.78	5	7.94	6	15.38	6	22.22	0	0.00
Participant describes being receptive to information three weeks after diagnosis	5	4.90	1	1.59	4	10.26	4	14.81	0	0.00
Participant describes being receptive to information after treatment	9	8.82	5	7.94	4	10.26	1	3.70	3	25.00
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	9	8.82	6	9.52	3	7.69	0	0.00	3	25.00
Participant describes being receptive to information 12 months or more after diagnosis	2	1.96	1	1.59	1	2.56	1	3.70	0	0.00
Participant describes being receptive to information a month after diagnosis	1	0.98	0	0.00	1	2.56	1	3.70	0	0.00
Participant describes being receptive to information with a week after diagnosis	5	4.90	5	7.94	0	0.00	0	0.00	0	0.00
Participant describes being receptive to information two weeks after diagnosis	1	0.98	1	1.59	0	0.00	0	0.00	0	0.00
Participant describes being receptive to information six weeks after diagnosis	1	0.98	1	1.59	0	0.00	0	0.00	0	0.00
Participant describes being receptive to information two months after diagnosis	1	0.98	1	1.59	0	0.00	0	0.00	0	0.00

Timing of information	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes being receptive from the beginning (diagnosis)	32	31.37	12	24.00	20	38.46	7	30.43	16	40.00
Participant describes being receptive to information after the shock of diagnosis	21	20.59	8	16.00	13	25.00	5	21.74	9	22.50
Participant describes being receptive to information before starting treatment	8	7.84	8	16.00	0	0.00	1	4.35	0	0.00
Participant describes being receptive to information during treatment	11	10.78	11	22.00	0	0.00	5	21.74	0	0.00
Participant describes being receptive to information three weeks after diagnosis	5	4.90	5	10.00	0	0.00	1	4.35	0	0.00
Participant describes being receptive to information after treatment	9	8.82	2	4.00	7	13.46	1	4.35	4	10.00
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	9	8.82	0	0.00	9	17.31	0	0.00	6	15.00
Participant describes being receptive to information 12 months or more after diagnosis	2	1.96	2	4.00	0	0.00	1	4.35	0	0.00
Participant describes being receptive to information a month after diagnosis	1	0.98	1	2.00	0	0.00	0	0.00	0	0.00
Participant describes being receptive to information with a week after diagnosis	5	4.90	5	10.00	0	0.00	5	21.74	0	0.00
Participant describes being receptive to information two weeks after diagnosis	1	0.98	1	2.00	0	0.00	1	4.35	0	0.00
Participant describes being receptive to information six weeks after diagnosis	1	0.98	1	2.00	0	0.00	1	4.35	0	0.00
Participant describes being receptive to information two months after diagnosis	1	0.98	1	2.00	0	0.00	1	4.35	0	0.00

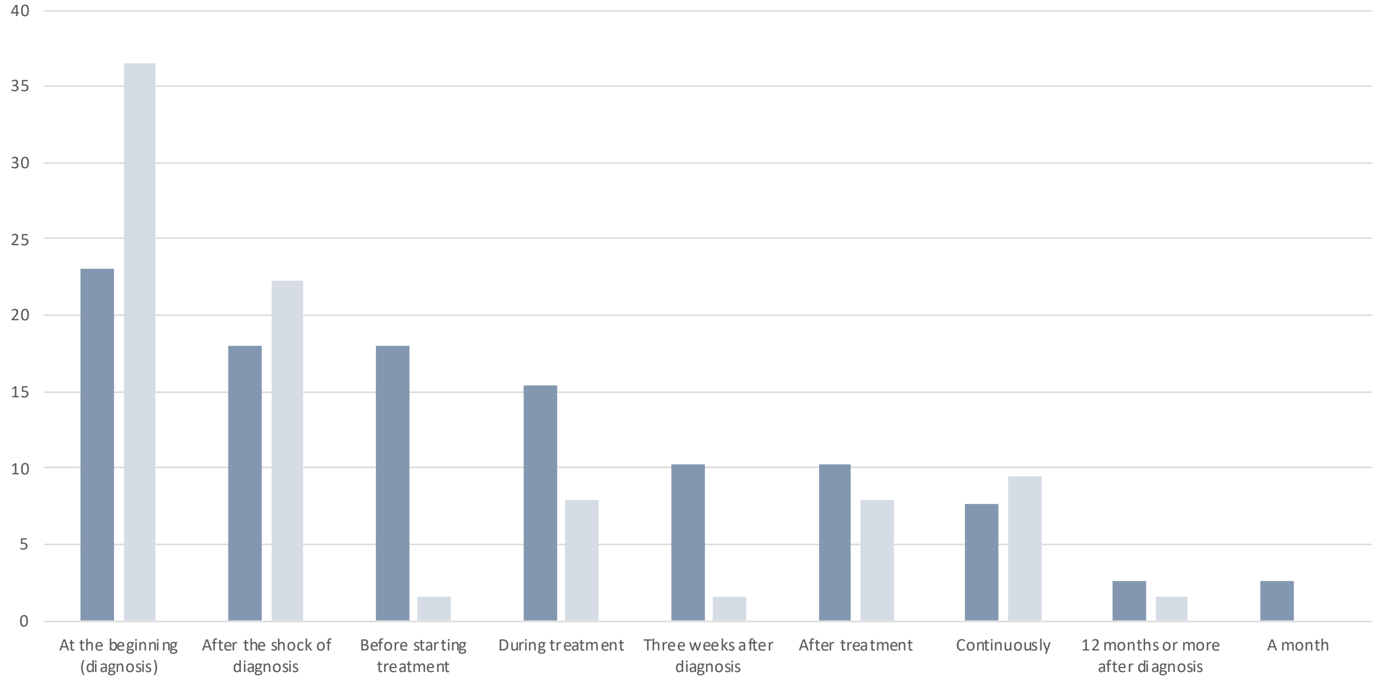


Figure 6.6: Timing of information (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 6.9: Timing of information – Stage III & IV variations

Timing of information	Reported less frequently	Reported more frequently
Participant describes being receptive from the beginning (diagnosis)	Triple negative Stage III & IV	-
Participant describes being receptive to information after the shock of diagnosis	-	Hormone receptor Stage III & IV
Participant describes being receptive to information before starting treatment	-	All Stage III & IV Triple negative Stage III & IV
Participant describes being receptive to information during treatment	Hormone receptor Stage III & IV	Triple negative Stage III & IV
Participant describes being receptive to information after treatment	-	Hormone receptor Stage III & IV
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	-	Hormone receptor Stage III & IV

Healthcare professional communication: Stage III & IV

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having an overall positive (53.85%), and overall positive, with the exception of one or two occasions (23.08%). Other themes included mix of positive and negative (10.26%), and overall negative (7.69%).

Participant describes communication with healthcare professionals as overall positive

The communication with all the healthcare professionals I've experienced with breast cancer has been phenomenal. I have such a great relationship with all of my medical professionals. I can ask them any question at any point in time and they will always answer me. I never have felt like because I wasn't *having an appointment with them that I couldn't ask the question. For me, I've had no issues with communication. My surgeon came in on a day off after he played tennis on a weekend to make sure that he'd heard that I'd had all of this nerve pain. He wanted to come and check I was okay. I've had really great communication with them. Participant_025 TNG*

It's been good. Regular check-ups, regular catch-ups, all that sort of thing, so I can ask any questions that I need to ask. I always write down things if I think of them before I go, so I can ask questions. Participant_046 TNG

I think it's been good. I've got a very open doctor who's happy to work with me and not just tell me what he thinks should happen and respect that I'm going to be talking to other people and is happy to sit and talk to me about any questions I have or we negotiate when I'll have restaging scans and how I'll manage appointment times around going on holidays and he's great from that point of view. Participant_050 TNG

Participant describes communication with healthcare professionals as overall positive, with the exception of one or two occasions

Look, every time I've seen a doctor or a nurse they've been fabulous. I could not complain about any of the health professionals that I saw apart from the plastic surgeon. I thought his bedside manner could have done with some improvement. They're all fabulous, but there was this underlying thing of that they're just so overworked that you feel for them. Participant_02 TNG 9

I would class it as good. Because I'm obviously going to a big hospital, sometimes you're not getting back the information that you need in a timely manner I guess, or what I consider a timely manner. I did butt heads with my surgeon. Don't get me wrong, she's a brilliant surgeon, but we did butt heads on a few occasions in regards to my treatment because I felt like I was being forced down a path without being given options. Participant_034 TNG

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

Participant describes health professional communication as a mix of positive and negative

It's hard to differentiate because it's been a year, a year-long journey. I would say I had two different practices that I was part of. The first one, it was really false hope, not giving me enough information. It was only telling me, "You're fine. Keep going. You're fine." Brushing it off, like not making appointments in person or through certain phone calls. Just really, really poor. Second time, unfortunately, I'm in a situation where I have to be taken quite seriously. My doctors have been very thorough and my oncologist saved my life because pretty much, I had days to live before they were going to affect my brain. Participant_042 TNG

Overall, I would say probably good with the immediate contact, but resources from the outside like the breast care nurse, and things like that was probably not so great. Participant_024 TNG

I think the medical staff has been have been very good, but overall, I feel like with all the side effects and things like that, they don't tell you until it happens and you say, oh, this is happening. And I can tell you that sitting on the side effects, I just feel like and I don't want to overwhelm you. I understand that. And because it doesn't happen to everybody, but when things happen to you at home and it scares you and, you know, it's just supposed to be happening, like when I had no blood in my stool, was that something that was that normal or my bleeding internally? And I need to get to the doctor, you know, that those things, because they tell you that right at the start what to expect if I just talk to you about it as it happens. Participant_038 TNG

Participant describes communication with healthcare professionals as overall negative

PARTICIPANT: Pretty poor.
INTERVIEWER: Do you have any examples that come to mind that you would like to share?
PARTICIPANT: My main problem with my oncologist who [chuckles] she made assumptions about my treatment rather than checking my file before she put me on different medications. She doesn't return phone calls, she doesn't return emails. Her lack of follow-up is very frustrating. The turning point for me was when she put me on medication and when I did my annual

research and contacted her and said, ''Should I really be on this?'' She was like, ''Well, this is why I put you on it.'' I'm like, ''That's not why I was taking that.'' She said, ''Oh, yes. I forgot.'' It was like I lost all confidence at that time. Participant_027 TNG

The thing is no one, actually, has come back to me and said, "All the guidelines have changed, maybe you should go and get genetically tested." None of my breast care providers did that. It was only that I had a, what do you call them, my gastroenterologist. I have ulcerative colitis and it's in remission, so every three years, I have a colonoscopy. Then one of my colonoscopies he found these flat hollowed. He said that I should look into getting genetically tested for breast cancer because there can be a link between bile cancer and breast cancer. He told me to go and get genetically tested. Then, when I got my results, I happened to seen him again and I'd been to the breast clinic and explained to them and I'd say, "We'll just monitor the condition." My gastroenterologist said, "No, no, no, you need to go and get a different opinion and see this breast specialist because she specializes in genetic conditions as well." I went and saw her. Whenever the guidelines changed for being able to be genetically tested, I think I should have been notified back then. Participant_037 TNG

Good question. Very good question. I have found that it's not always very clear. In fact, I learned to take a good friend with me who is quite skilled at note taking and it also helping me take notes. I don't wish to be disrespectful, but a lot of times things were not very clear. I think that's probably to do with, in terms of me and lots of other patients, our lack of understanding of what's going on and how it all goes together and the pathway and that. I guess there's so much maybe information. I don't feel the communication that's particularly good. Participant 047_2021AUHRP

Table 6.10: Healthcare professional communication.

Healthcare professional communication	**All participants**		**All Stage 0 to II**		**All Stage III & IV**		**Triple negative Stage III & IV**		**Hormone receptor Stage III & IV**	
	n=102	**%**	**n=63**	**%**	**n=39**	**%**	**n=27**	**%**	**n=12**	**%**
Participant describes communication with healthcare professionals as overall positive	58	56.86	37	58.73	21	53.85	15	55.56	6	50.00
Participant describes communication with healthcare professionals as overall positive, with the exception of one or two occasions	26	25.49	17	26.98	9	23.08	**4**	**14.81**	**5**	**41.67**
Participant describes health professional communication as a mix of positive and negative	8	7.84	4	6.35	4	10.26	4	14.81	0	0.00
Participant describes communication with healthcare professionals as overall negative	8	7.84	5	7.94	3	7.69	2	7.41	1	8.33
Other	2	1.96	0	0.00	2	5.13	2	7.41	0	0.00

Healthcare professional communication	**All participants**		**All Triple negative**		**All Hormone receptor**		**Triple negative Stage 0 to II**		**Hormone receptor Stage 0 to II**	
	n=102	**%**	**n=50**	**%**	**n=52**	**%**	**n=23**	**%**	**n=40**	**%**
Participant describes communication with healthcare professionals as overall positive	58	56.86	26	52.00	32	61.54	11	47.83	26	65.00
Participant describes communication with healthcare professionals as overall positive, with the exception of one or two occasions	26	25.49	10	20.00	16	30.77	6	26.09	11	27.50
Participant describes health professional communication as a mix of positive and negative	8	7.84	8	16.00	0	0.00	4	17.39	0	0.00
Participant describes communication with healthcare professionals as overall negative	8	7.84	4	8.00	4	7.69	2	8.70	3	7.50
Other	2	1.96	2	4.00	0	0.00	0	0.00	0	0.00

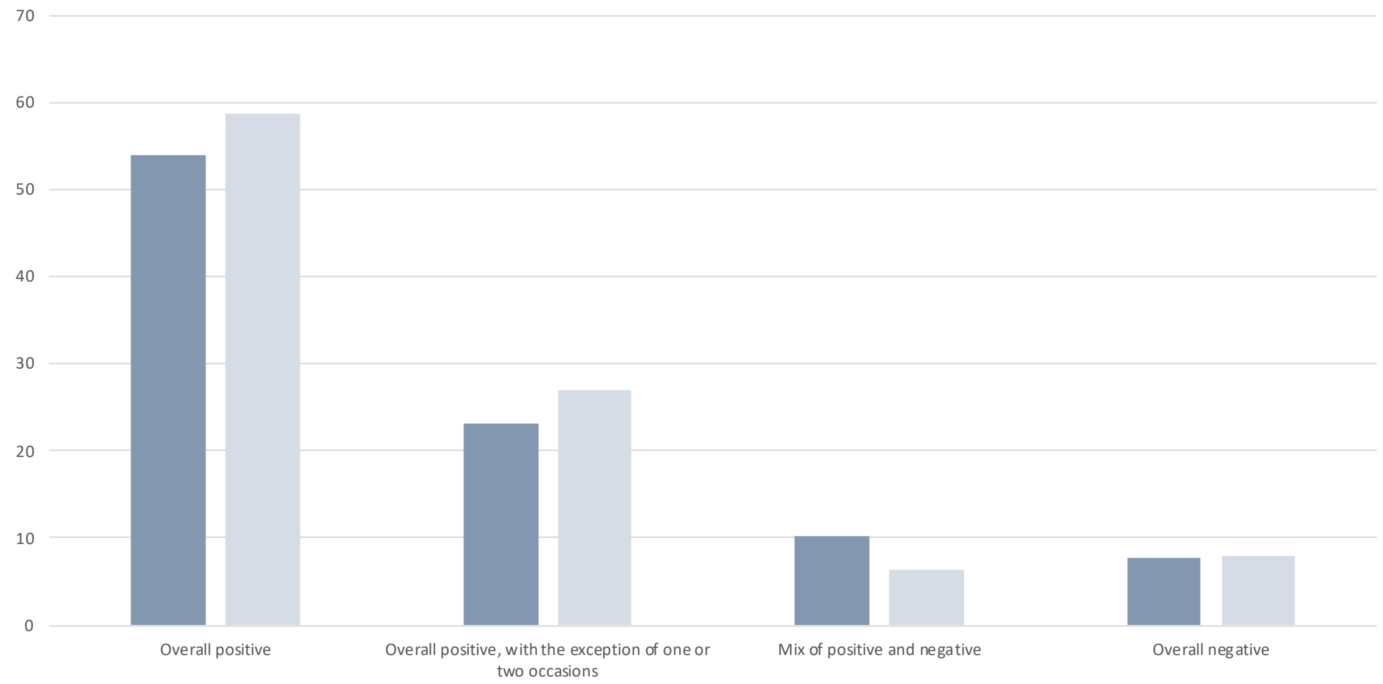


Figure 6.7: Healthcare professional communication (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 6.11: Healthcare professional communication – Stage III & IV variations

Healthcare professional communication	Reported less frequently	Reported more frequently
Participant describes communication with healthcare professionals as overall positive, with the exception of one or two occasions	Triple negative Stage III & IV	Hormone receptor Stage III & IV

Healthcare professional communication (Rationale for response) : Stage III & IV

Participants described reasons for positive or negative communication with healthcare professionals. Participants that had positive communication, described the reason for this was because of holistic with two way, supportive and comprehensive conversations (38.46%), and good, with no particular reason given (17.95%).

Participants that had negative communication, described the reason for this was because of not forthcoming (5.13%), and dismissive (One way conversation) (5.13%).

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

The communication with all the healthcare professionals I've experienced with breast cancer has been phenomenal. I have such a great relationship with all of my medical professionals. I can ask them any question at any point in time and they will always answer me. I never have felt like because I wasn't having an appointment with them that I couldn't ask the question. For me, I've had no issues with communication. My surgeon came in on a day off after he played tennis on a weekend to make sure that he'd heard that I'd had all of this nerve pain. He wanted to come and check I was okay. I've had really great communication with them. Participant_025 TNG

It's been good. Regular checkups, regular catch-ups, all that sort of thing, so I can ask any questions that I need to ask. I always write down things if I think of them before I go, so I can ask questions. Participant_046 TNG

Participant describes healthcare communication as limited (not forthcoming/lacking)

The thing is no one, actually, has come back to me and said, "All the guidelines have changed, maybe you should go and get genetically tested." None of my breast care providers did that. It was only that I had a, what do you call them, my gastroenterologist. I have ulcerative colitis and it's in remission, so every three years, I have a colonoscopy. Then one of my

colonoscopies he found these flat hollowed. He said that I should look into getting genetically tested for breast cancer because there can be a link between bile cancer and breast cancer. He told me to go and get genetically tested.
Then, when I got my results, I happened to seen him again and I'd been to the breast clinic and explained to them and I'd say, "We'll just monitor the condition." My gastroenterologist said, "No, no, no, you need to go and get a different opinion and see this breast specialist because she specializes in genetic conditions as well." I went and saw her. Whenever the guidelines changed for being able to be genetically tested, I think I should have been notified back then. Participant_03 TNG 7

The doctors have been good. In fact, oh, I had three very good doctors, but as I said previously, I never met a breast care nurse. I've had none of that helpfulness after the mastectomy and things like that. I mean I coped okay, but looking back, they should have insisted more that somebody called me, I think. Participant_040 TNG

Table 6.12: Healthcare professional communication (Rationale for response)

Healthcare professional communication (Rationale for response)	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	37	36.27	22	34.92	15	38.46	11	40.74	4	33.33
Participant describes no specific reason for healthcare communication	13	12.75	6	9.52	7	17.95	**7**	**25.93**	**0**	**0.00**
Participant describes healthcare communication as limited (not forthcoming/lacking)	11	10.78	5	7.94	6	15.38	**6**	**22.22**	**0**	**0.00**
Participant describes healthcare communication as good, with no particular reason given	15	14.71	12	19.05	3	7.69	**0**	**0.00**	**3**	**25.00**
Participant describes health professional communication as helpful	5	4.90	3	4.76	2	5.13	2	7.41	0	0.00
Participant describes health professional communication as being dismissive (One way conversation)	5	4.90	3	4.76	2	5.13	2	7.41	0	0.00
Participant describes health professional communication as limited in relation to their understanding of the condition	7	6.86	6	9.52	1	2.56	0	0.00	1	8.33
Participant describes health professional communication as limited in relation health professionals not having a lot of time	3	2.94	2	3.17	1	2.56	0	0.00	1	8.33
Participant describes healthcare communication as good, yet limited in relation to their understanding of the condition	4	3.92	4	6.35	0	0.00	0	0.00	0	0.00
Participant describes healthcare communication as good, yet limited in relation to health professionals not having a lot of time	3	2.94	3	4.76	0	0.00	0	0.00	0	0.00

Healthcare professional communication (Rationale for response)	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	37	36.27	20	40.00	17	32.69	9	39.13	13	32.50
Participant describes no specific reason for healthcare communication	13	12.75	**13**	**26.00**	**0**	**0.00**	**6**	**26.09**	**0**	**0.00**
Participant describes healthcare communication as limited (not forthcoming/lacking)	11	10.78	**11**	**22.00**	**0**	**0.00**	**5**	**21.74**	**0**	**0.00**
Participant describes healthcare communication as good, with no particular reason given	15	14.71	**0**	**0.00**	**15**	**28.85**	**0**	**0.00**	**12**	**30.00**
Participant describes health professional communication as helpful	5	4.90	5	10.00	0	0.00	3	13.04	0	0.00
Participant describes health professional communication as being dismissive (One way conversation)	5	4.90	5	10.00	0	0.00	3	13.04	0	0.00
Participant describes health professional communication as limited in relation to their understanding of the condition	7	6.86	4	8.00	3	5.77	**4**	**17.39**	2	5.00
Participant describes health professional communication as limited in relation health professionals not having a lot of time	3	2.94	0	0.00	3	5.77	0	0.00	2	5.00
Participant describes healthcare communication as good, yet limited in relation to their understanding of the condition	4	3.92	0	0.00	4	7.69	0	0.00	4	10.00
Participant describes healthcare communication as good, yet limited in relation to health professionals not having a lot of time	3	2.94	0	0.00	3	5.77	0	0.00	3	7.50

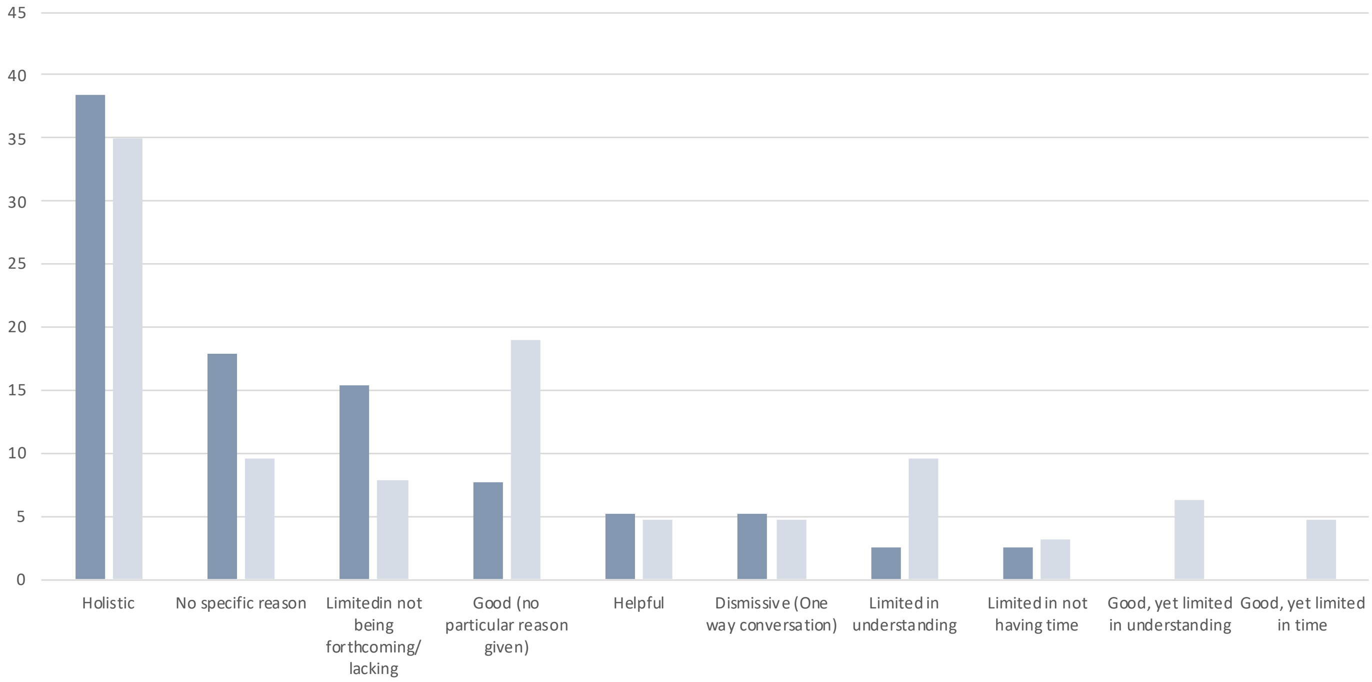


Figure 6.8: Healthcare professional communication (Rationale for response) (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 6.13: Healthcare professional communication (Rationale for response) – Stage III & IV variations

Healthcare professional communication (Rationale for response)	Reported less frequently	Reported more frequently
Participant describes no specific reason for healthcare communication	Hormone receptor Stage III & IV	Triple negative Stage III & IV
Participant describes healthcare communication as limited (not forthcoming/lacking)	Hormone receptor Stage III & IV	Triple negative Stage III & IV
Participant describes healthcare communication as good, with no particular reason given	Triple negative Stage III & IV	Hormone receptor Stage III & IV

Partners in health

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

The overall scores for the cohort were in the highest quintile for Partners in health:Knowledge (median=27.00, IQR=5.25), Partners in health:Recognition and management of symptoms (median=21.00, IQR=3.00), Partners in health:Adherence to treatment (median=15.00, IQR=2.00), Partners in health:Total score (mean=78.00, SD=7.87) indicating very good knowledge, very good recognition and management of symptoms, very good adherence to treatment, very good overall ability to manage their health

The overall scores for the cohort were in the second highest quintile for Partners in health:Coping (median=16.50, IQR=8.00), indicating good coping.

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

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

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

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

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

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

Table 6.15: Partners in health summary statistics

Partners in health scale (n=95)	Mean	SD	Median	IQR	Possible range	Quintile
Knowledge	26.53	3.56	27.00	5.25	0 to 32	5
Coping	16.50	4.07	16.50	8.00	0 to 24	4
Recognition and management of symptoms	20.31	2.28	21.00	3.00	0 to 24	5
Adherence to treatment	14.67	1.37	15.00	2.00	0 to 16	5
Total score*	78.00	7.87	79.50	9.00	0 to 96	5

*Skewed distribution use median and IQR as measure of central tendency

Partners in health by breast cancer stage

Participants with stage 0 to II breast cancer (n=59, 62.11%) were compared to participants with stage II and IV breast cancer (n=36, 37.89).

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

No significant differences were observed between participants by breast cancer stage for any of the Partners in Health scales.

Table 6.16: Partners in health by breast cancer stage summary statistics and T-test

Partners in health scale	Group	Number (n=95)	Percent	Mean	SD	T	dF	p-value
Total score	All stage 0 to II	59	62.11	79.15	10.28	0.58	93	0.5654
	All stage III & IV	36	37.89	78.00	7.87			

Partners in health scale	Group	Number (n=95)	Percent	Median	IQR	W	p-value
Knowledge	All stage 0 to II	59	62.11	28.00	5.00	1224.50	0.2119
	All stage III & IV	36	37.89	27.00	5.25		
Coping	All stage 0 to II	59	62.11	18.00	8.50	1125.00	0.6305
	All stage III & IV	36	37.89	16.50	8.00		
Recognition and management of symptoms	All stage 0 to II	59	62.11	20.00	3.00	1070.50	0.9506
	All stage III & IV	36	37.89	21.00	3.00		
Adherence to treatment	All stage 0 to II	59	62.11	15.00	2.00	1133.00	0.5694
	All stage III & IV	36	37.89	15.00	2.00		

Table 6.17: Partners in health by breast cancer stage summary statistics and and Wilcoxon test

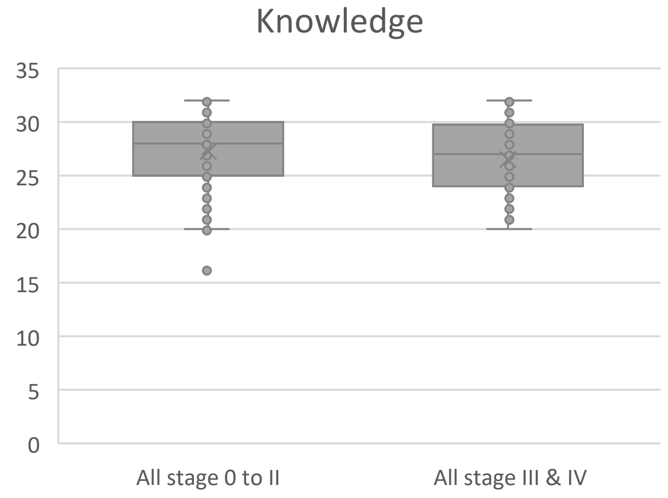


Figure 6.9: Boxplot of Partners in health: knowledge by breast cancer stage

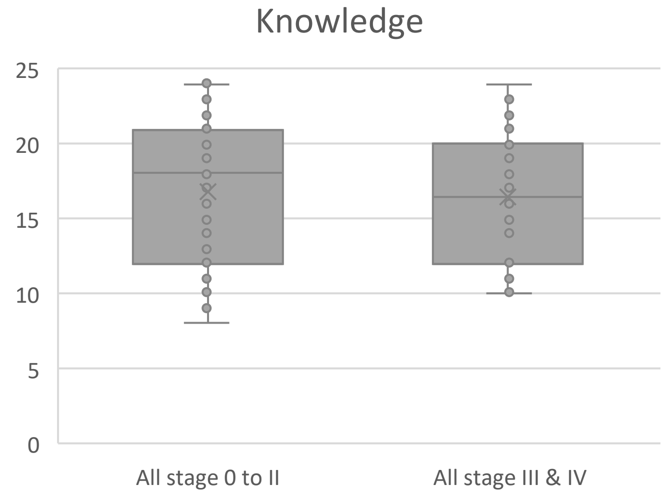
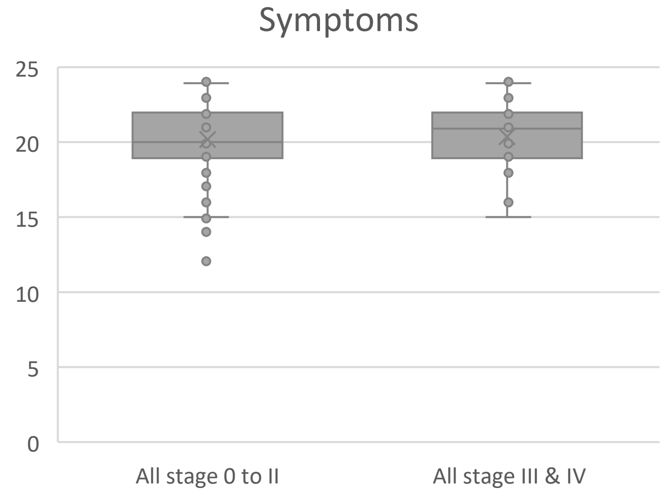


Figure 6.10: Boxplot of Partners in health: coping by breast cancer stage



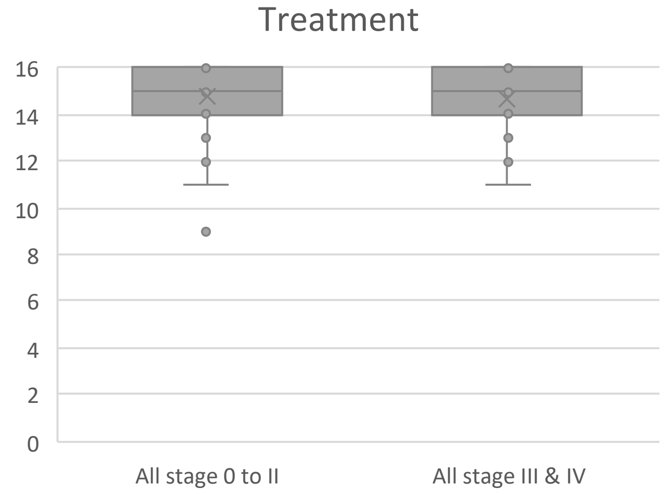


Figure 6.11: Boxplot of Partners in health: recognition and management of symptoms by breast cancer stage

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

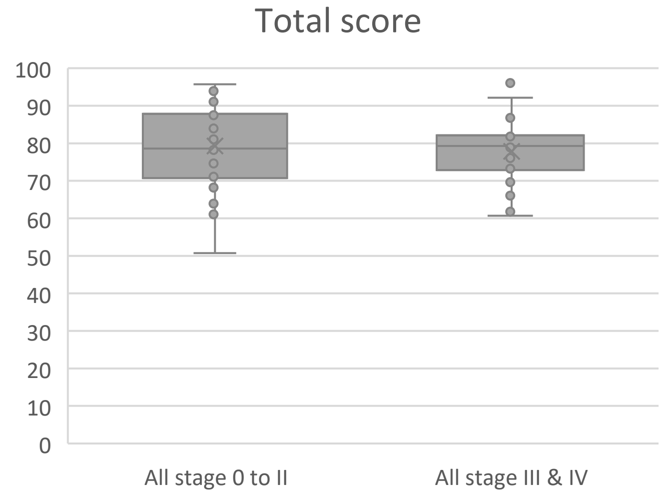


Figure 6.13: Boxplot of Partners in health Total score by breast cancer stage

Information given by health professionals: Stage III & IV

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options (n=34, 94.44%), hereditary considerations (n=26, 72.22%), disease management (n=21, 58.33%), and physical activity (n=19, 52.78%) were most frequently given to participants by healthcare professionals, and information about clinical trials (n=7, 19.44%), complementary therapies (n=6, 16.67%), and interpret test results (n=3, 8.33%) were given least often .

Table 6.14: Information given by health professionals

Information given by healthcare professionals	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=95	%	n=59	%	n=36	%	n=24	24.00	n=12	12.00
Disease cause	26	27.37	16	27.12	10	27.78	5	20.83	5	41.67
Treatment options	87	91.58	53	89.83	34	94.44	23	95.83	11	91.67
Disease management	51	53.68	30	50.85	21	58.33	17	70.83	4	33.33
Complementary therapies	15	15.79	9	15.25	6	16.67	4	16.67	2	16.67
How to interpret test results	16	16.84	13	22.03	3	8.33	3	12.50		0.00
Clinical trials	13	13.68	6	10.17	7	19.44	3	12.50	4	33.33
Dietary	23	24.21	12	20.34	11	30.56	8	33.33	3	25.00
Physical activity	46	48.42	27	45.76	19	52.78	14	58.33	5	41.67
Psychological/social support	39	41.05	23	38.98	16	44.44	11	45.83	5	41.67
Hereditary considerations, genes or genomic biomarker information	52	54.74	26	44.07	26	72.22	16	66.67	10	83.33

Information searched for independently	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=95	%	n=44	%	n=51	%	n=20	20.00	n=39	39.00
Disease cause	26	27.37	11	25.00	15	29.41	6	30.00	10	25.64
Treatment options	87	91.58	41	93.18	46	90.20	18	90.00	35	89.74
Disease management	51	53.68	26	59.09	25	49.02	9	45.00	21	53.85
Complementary therapies	15	15.79	6	13.64	9	17.65	2	10.00	7	17.95
How to interpret test results	16	16.84	6	13.64	10	19.61	3	15.00	10	25.64
Clinical trials	13	13.68	6	13.64	7	13.73	3	15.00	3	7.69
Dietary	23	24.21	11	25.00	12	23.53	3	15.00	9	23.08
Physical activity	46	48.42	20	45.45	26	50.98	6	30.00	21	53.85
Psychological/social support	39	41.05	20	45.45	19	37.25	9	45.00	14	35.90
Hereditary considerations, genes or genomic biomarker information	52	54.74	30	68.18	22	43.14	14	70.00	12	30.77

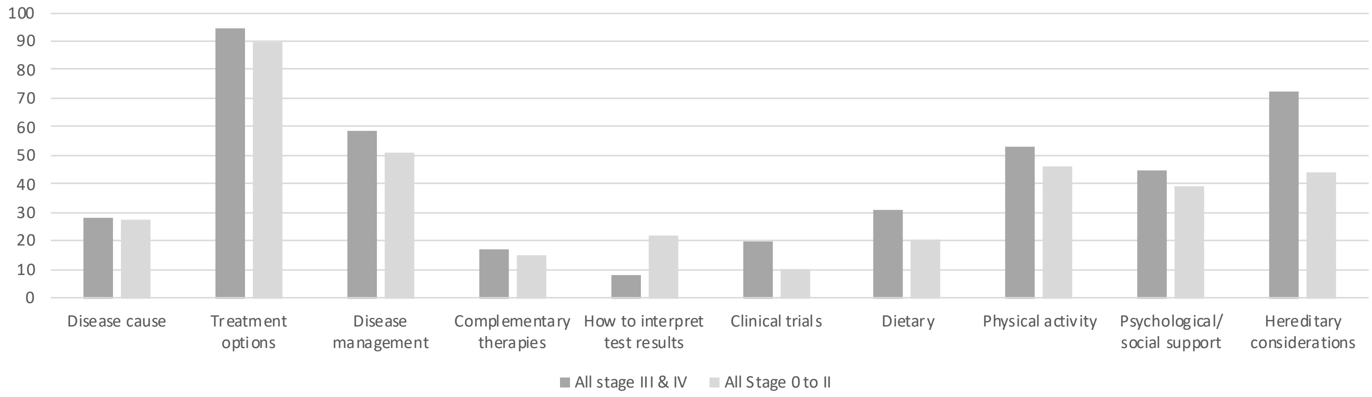


Figure 6.14: Information given by health professionals (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 6.15: Information given by health professionals – Stage III & IV variations

Information given by healthcare professionals	Reported less frequently	Reported more frequently
Disease cause	-	Hormone receptor Stage III & IV
Disease management	Hormone receptor Stage III & IV	Triple negative Stage III & IV
How to interpret test results	Hormone receptor Stage III & IV	-
Clinical trials	-	Hormone receptor Stage III & IV
Hereditary considerations, genes or genomic biomarker information	-	All Stage III & IV Triple negative Stage III & IV Hormone receptor Stage III & IV

Information searched independently: Stage III & IV

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. The topics participants most often searched for were interpret test results (n=23, 63.89%), disease management (n=21, 58.33%), treatment options (n=18, 50.00%), and complementary therapies (n=17, 47.22%) were most frequently given to participants by healthcare professionals, and, information about clinical trials (n=11, 30.56%), dietary (n=10, 27.78%), and psychological/ social support (n=8, 22.22%) were searched for least often .

Table 6.16: Information searched for independently

Information searched for independently	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=95	%	n=59	%	n=36	%	n=24	24.00	n=12	12.00
Disease cause	44	46.32	29	49.15	15	41.67	9	37.50	6	50.00
Treatment options	49	51.58	31	52.54	18	50.00	11	45.83	7	58.33
Disease management	45	47.37	24	40.68	21	58.33	14	58.33	7	58.33
Complementary therapies	42	44.21	25	42.37	17	47.22	12	50.00	5	41.67
How to interpret test results	54	56.84	31	52.54	23	63.89	15	62.50	8	66.67
Clinical trials	21	22.11	10	16.95	11	30.56	8	33.33	3	25.00
Dietary	35	36.84	25	42.37	10	27.78	4	16.67	6	50.00
Physical activity	41	43.16	29	49.15	12	33.33	8	33.33	4	33.33
Psychological/social support	24	25.26	16	27.12	8	22.22	5	20.83	3	25.00
Hereditary considerations, genes or genomic biomarker information	33	34.74	20	33.90	13	36.11	9	37.50	4	33.33

Information searched for independently	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=95	%	n=44	%	n=51	%	n=20	20.00	n=39	39.00
Disease cause	44	46.32	20	45.45	24	47.06	11	55.00	18	46.15
Treatment options	49	51.58	20	45.45	29	56.86	9	45.00	22	56.41
Disease management	45	47.37	20	45.45	25	49.02	6	30.00	18	46.15
Complementary therapies	42	44.21	22	50.00	20	39.22	10	50.00	15	38.46
How to interpret test results	54	56.84	27	61.36	27	52.94	12	60.00	19	48.72
Clinical trials	21	22.11	11	25.00	10	19.61	3	15.00	7	17.95
Dietary	35	36.84	16	36.36	19	37.25	12	60.00	13	33.33
Physical activity	41	43.16	18	40.91	23	45.10	10	50.00	19	48.72
Psychological/social support	24	25.26	12	27.27	12	23.53	7	35.00	9	23.08
Hereditary considerations, genes or genomic biomarker information	33	34.74	17	38.64	16	31.37	8	40.00	12	30.77

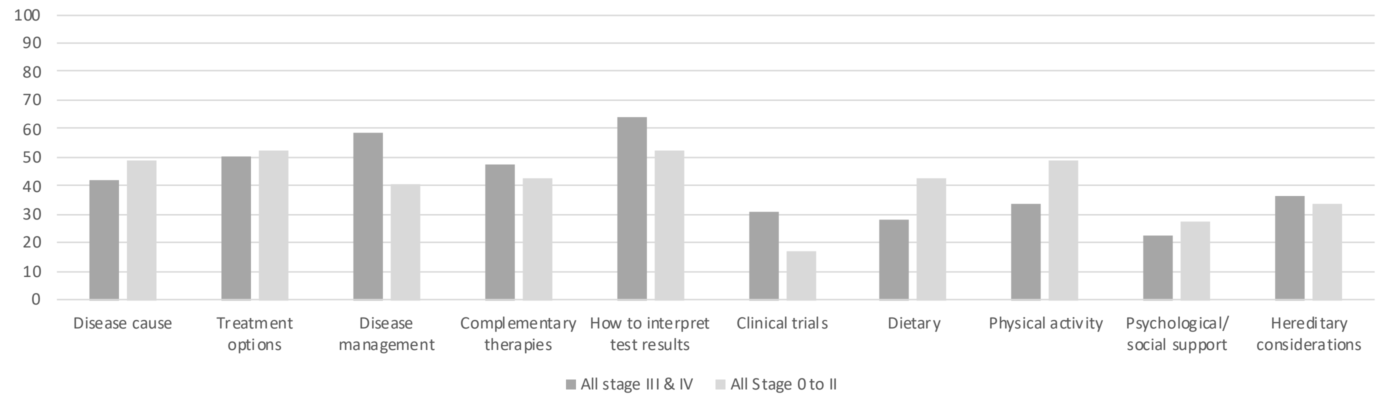


Figure 6.15: Information searched for independently (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 6.17: Information searched for independently – Stage III & IV variations

Information searched for independently	Reported less frequently	Reported more frequently
Disease management	-	All Stage III & IV Triple negative Stage III & IV Hormone receptor Stage III & IV
Clinical trials	-	Triple negative Stage III & IV
Dietary	Triple negative Stage III & IV	Hormone receptor Stage III & IV

Information gaps: Stage III & IV

The largest gaps in information, where information was neither given to patients nor searched for independently were clinical trials (n=22, 61.11%) and dietary (n=20, 55.56%).

The topics that participants did not search for independently after not receiving information from healthcare professionals were treatment options (n=17, 47.22%) and disease management (n=11, 30.56%).

The topics that participants were given most information from both healthcare professionals and searching independently for were treatment options (n=17, 47.22%) and Pphysical activity (n=15, 41.67%).

The topics that participants searched for independently after not receiving information from healthcare professionals were interpret test results (n=22, 61.11%) and complementary therapies (n=14, 38.89%).

Table 6.18: Information gaps

Information topic	Not given by health professional, not searched for independently		Given by health professional only		Given by health professional, searched for independently		Searched for independently only	
	n=36	%	n=36	%	n=36	%	n=36	%
Disease cause	18	50.00	6	16.67	4	11.11	11	30.56
Treatment options	4	11.11	17	47.22	17	47.22	1	2.78
Disease management	8	22.22	10	27.78	11	30.56	10	27.78
Complementary therapies	19	52.78	3	8.33	3	8.33	14	38.89
How to interpret test results	14	38.89	2	5.56	1	2.78	22	61.11
Clinical trials	22	61.11	6	16.67	1	2.78	10	27.78
Dietary information	20	55.56	9	25.00	2	5.56	8	22.22
Physical activity	12	33.33	15	41.67	4	11.11	8	22.22
Psychological/social support	18	50.00	13	36.11	3	8.33	5	13.89
Hereditary considerations	11	30.56	15	41.67	11	30.56	2	5.56

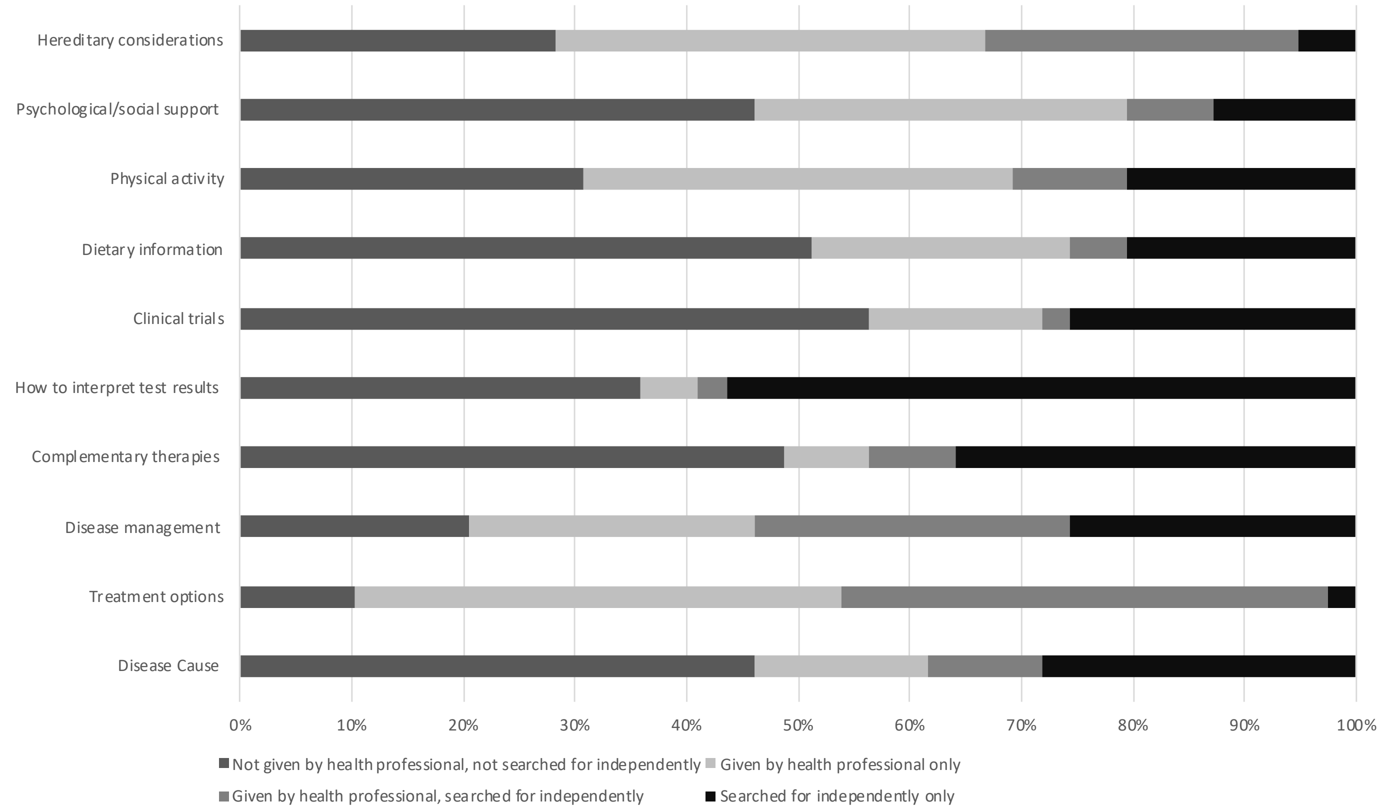


Figure 6.16: Information gaps (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Most accessed information : Stage III & IV

Participants were asked to rank which information source that they accessed most often, where 1 is the most trusted and 5 is the least trusted. A weighted average is presented in Table 6.36 and Figure 6.48. With a weighted ranking, the higher the score, the more accessed the source of information.

Across all participants, information from Non-profit organisations, charity or patient organisations was most accessed followed by information from the Hospital or clinic where being treated . Information from Medical journals and from Pharmaceutical companies were least accessed.

Table 6.19: Most accessed information

Most accessed information	All participants (n=95)	All stage 0 to II (n=59)	All stage III & IV (n=36)	Stage III & IV triple negative (n=24)	Stage III & IV hormone-receptor positive (n=12)	All Triple negative (n=44)	All hormone-receptor positive (n=51)	Stage 0 to II triple negative (n=20)	Stage 0 to II hormone-receptor positive (n=39)
Non-profit organisations, charity or patient organisations	4.11	3.98	4.31	4.46	4.00	4.36	3.88	4.25	3.85
Government	3.22	3.34	3.03	3.13	2.83	3.25	3.20	3.40	3.31
Pharmaceutical companies	1.95	1.92	2.00	1.88	2.25	1.95	1.94	2.05	1.85
Hospital or clinic where being treated	3.17	3.14	3.22	3.38	2.92	3.11	3.22	2.80	3.31
Medical journals	2.56	2.63	2.44	2.17	3.00	2.32	2.76	2.50	2.69

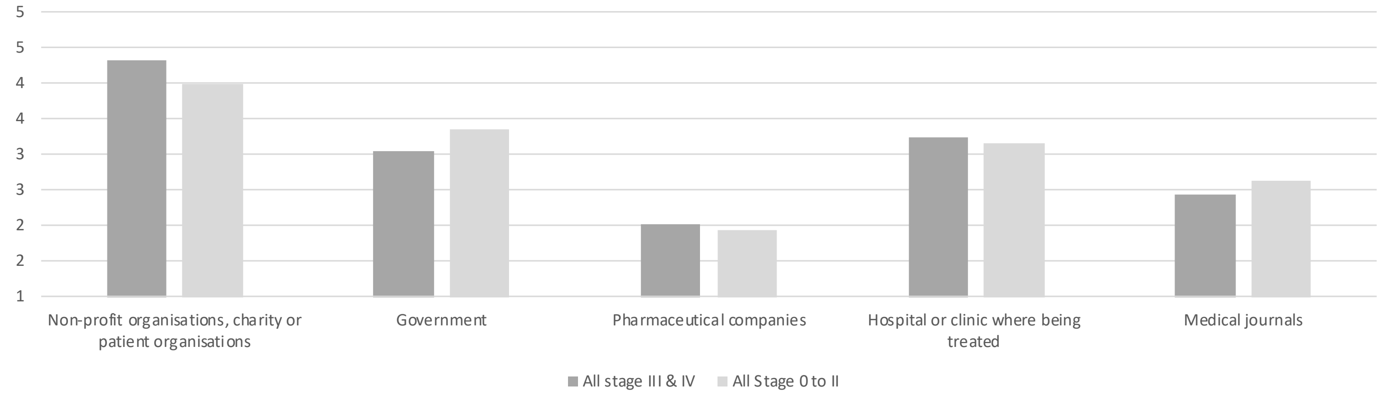


Figure 6.17: Most accessed information (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

My Health Record: Stage III & IV

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 12 participants (33.33%) had accessed My Health Record, 24 participants (66.67%) had not.

Of those that had accessed My Health Record, there were 3 participants (25.00%) who found it to be porr or very poor, 4 participants (33.33%) who found it acceptable, and 5 participants (41.67%) who found it to be good or very good.

Table 6.20: Accessed My Health Record

Accessed "My health record"	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=95	%	n=59	%	n=36	%	n=24	24.00	n=12	12.00
Yes	31	32.63	19	32.20	12	33.33	12	50.00	0	0.00
No	52	54.74	32	54.24	20	55.56	10	41.67	10	83.33
Not sure	8	8.42	5	8.47	3	8.33	1	4.17	2	16.67
Doesn't know what 'My Health Record' is	4	4.21	3	5.08	1	2.78	1	4.17	0	0.00

Accessed "My health record"	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=95	%	n=44	%	n=51	%	n=20	20.00	n=39	39.00
Yes	31	32.63	19	43.18	12	23.53	7	35.00	12	30.77
No	52	54.74	21	47.73	31	60.78	11	55.00	21	53.85
Not sure	8	8.42	2	4.55	6	11.76	1	5.00	4	10.26
Doesn't know what 'My Health Record' is	4	4.21	2	4.55	2	3.92	1	5.00	2	5.13

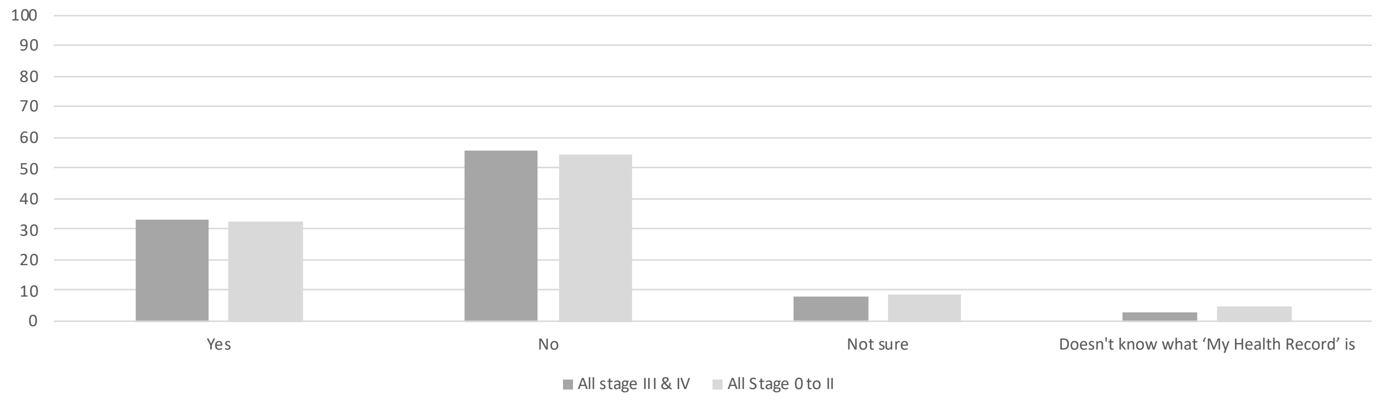


Figure 6.18: Accessed My Health Record (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 6.21: Accessed My Health Record– Stage III & IV variations

Theme	Reported less frequently	Reported more frequently
Yes	Hormone receptor Stage III & IV	Triple negative Stage III & IV
No	Triple negative Stage III & IV	Hormone receptor Stage III & IV

Table 6.22: How useful was My Health Record

How useful was "My health record"	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=31	%	n=19	%	n=12	%				
Very poor	8	25.81	6	31.58	2	16.67	2	8.33	0	0.00
Poor	7	22.58	6	31.58	1	8.33	1	4.17	0	0.00
Acceptable	9	29.03	5	26.32	4	33.33	4	16.67	0	0.00
Good	5	16.13	2	10.53	3	25.00	3	12.50	0	0.00
Very good	2	6.45	0	0.00	2	16.67	2	8.33	0	0.00

How useful was "My health record"	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=31	%	n=19	%	n=12	%				
Very poor	8	25.81	4	21.05	4	33.33	2	10.00	4	10.26
Poor	7	22.58	4	21.05	3	25.00	3	15.00	3	7.69
Acceptable	9	29.03	5	26.32	4	33.33	1	5.00	4	10.26
Good	5	16.13	4	21.05	1	8.33	1	5.00	1	2.56
Very good	2	6.45	2	10.53	0	0.00	0	0.00	0	0.00

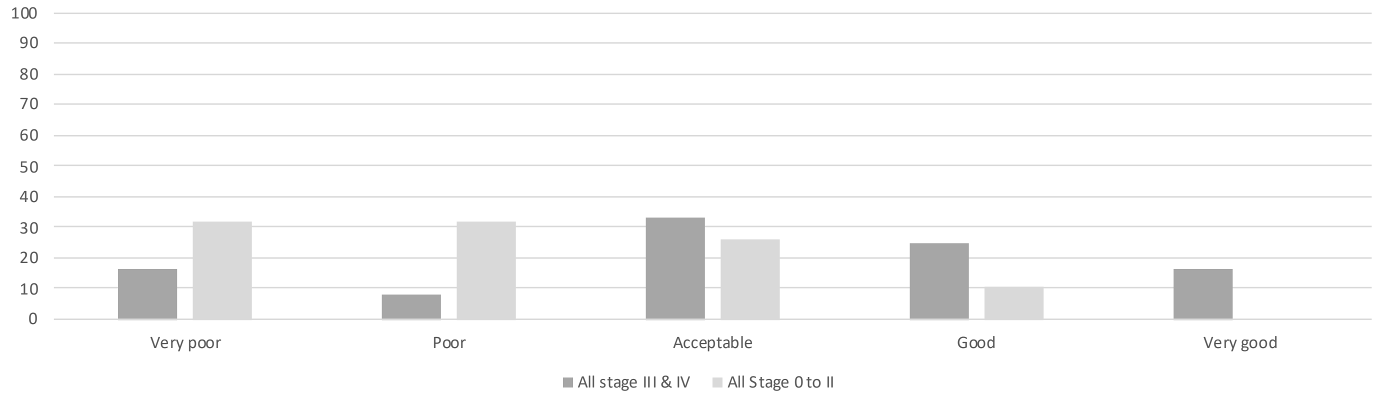


Figure 6.19: How useful was My Health Record (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 6.23: How useful was My Health Record – Stage III & IV variations

How useful was "My health record"	Reported less frequently	Reported more frequently
Very poor	Triple negative Stage III & IV Hormone receptor Stage III & IV	-
Poor	All Stage III & IV Triple negative Stage III & IV Hormone receptor Stage III & IV	-
Acceptable	Triple negative Stage III & IV Hormone receptor Stage III & IV	-
Good	Hormone receptor Stage III & IV	-
Very good	-	All Stage III & IV

Section 7

Care and support

Section 7: Experience of care and support

Care coordination: Stage III to IV

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. The average score indicates that participants had good communication with healthcare professionals.

The **Care coordination: navigation** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. The average score indicates that participants had good navigation of the healthcare system.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. The average score indicates that participants had good communication, navigation and overall experience of care coordination.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. The average score indicates that participants scored rated their care coordination as good.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. The average score indicates that participants rated their quality of care as very good.

Experience of care and support: Stage III to IV

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common responses were that they found support and care from did not receive any formal support (35.90%), charities (28.21%), and hospital or clinical setting (15.38 %). Other themes included peer support or other patients (15.38%), through a community service program (7.69%), psychologist or counselling service (7.69%), family and friends (7.69%), and allied health services (5.13%).

Care coordination scale	Mean	SD	Median	IQR
Care coordination: communication*	34.40	9.31	35.00	11.25
Care coordination: navigation*	24.72	4.76	25.00	6.00
Care coordination: total score*	59.12	12.54	60.00	16.00
Care coordination: care coordination global measure	6.46	2.27	7.00	3.00
Care coordination: quality of care global measure	7.31	1.91	8.00	1.25

Care coordination: Stage III to IV

A Care Coordination questionnaire was completed by participants within the online questionnaire. The Care Coordination questionnaire comprises a total score, two scales (communication and navigation), and a single question for each relating to care-coordination and care received. A higher score denotes better care outcome. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 7.1.

The overall scores for the cohort were in the highest quintile for Care coordination: Quality of care global measure (median=9.00, IQR=1.25) indicating very good quality of care

The overall scores for the cohort were in the second highest quintile for Care coordination: Communication (mean=45.78, SD=7.17), Care coordination: Navigation (mean=26.53, SD=4.26), Care coordination: Total score (mean=72.31, SD=9.37), Care coordination: Care coordination global measure (median=8.00, IQR=2.00), indicating good communication, good communication, good coordination, good care coordination.

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. The average score indicates that participants had good communication with healthcare professionals.

The **Care coordination: navigation** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. The average score indicates that participants had good navigation of the healthcare system.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. The average score indicates that participants had good communication, navigation and overall experience of care coordination.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. The average score indicates that participants scored rated their care coordination as good.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. The average score indicates that participants rated their quality of care as very good.

Table 7.1: Care coordination summary statistics- Stage III to IV

Care coordination scale (n=95)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	45.78	7.17	46.00	8.50	13 to 65	4
Navigation*	26.53	4.26	27.00	7.00	7 to 35	4
Total score*	72.31	9.37	74.50	14.25	20 to 100	4
Care coordination global measure	7.61	1.78	8.00	2.00	1 to 10	4
Quality of care global measure	8.64	1.25	9.00	1.25	1 to 10	5

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

Care coordination by stage: Stage III to IV

Participants with stage 0 to II breast cancer (n=59, 62.11%) were compared to participants with stage II and IV breast cancer (n=36, 37.89).

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

No significant differences were observed between participants by breast cancer stage for any of the Care Coordination scales.

Table 7.2: Care coordination by breast cancer stage summary statistics and T-test

Care coordination scale	Group	Number (n=95)	Percent	Mean	SD	T	dF	p-value
Communication	All stage 0 to II	59	62.11	44.90	9.69	-0.47	93	0.6388
	All stage III & IV	36	37.89	45.78	7.17			
Navigation	All stage 0 to II	59	62.11	26.83	4.24	0.34	93	0.7370
	All stage III & IV	36	37.89	26.53	4.26			

Table 7.3: Care coordination by breast cancer stage summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=95)	Percent	Median	IQR	W	p-value
Total score	All stage 0 to II	59	62.11	73.00	16.50	1054.50	0.9571
	All stage III & IV	36	37.89	74.50	14.25		
Care coordination global measure	All stage 0 to II	59	62.11	8.00	2.50	1252.00	0.1381
	All stage III & IV	36	37.89	8.00	2.00		
Quality of care global measure	All stage 0 to II	59	62.11	9.00	2.00	1077.50	0.9051
	All stage III & IV	36	37.89	9.00	1.25		

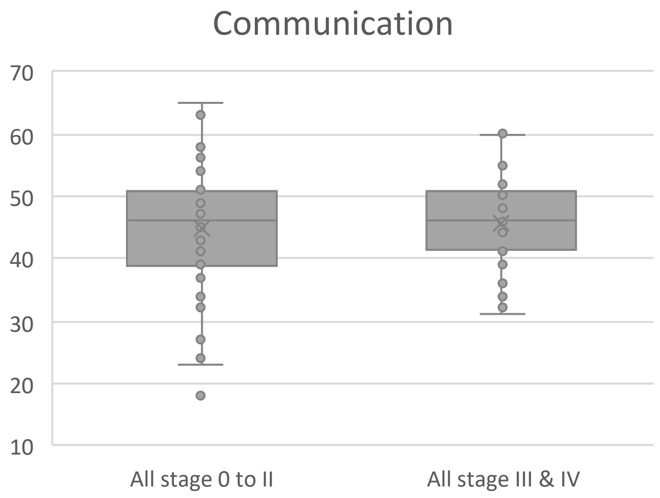


Figure 7.1: Boxplot of Care coordination: Communication by breast cancer stage

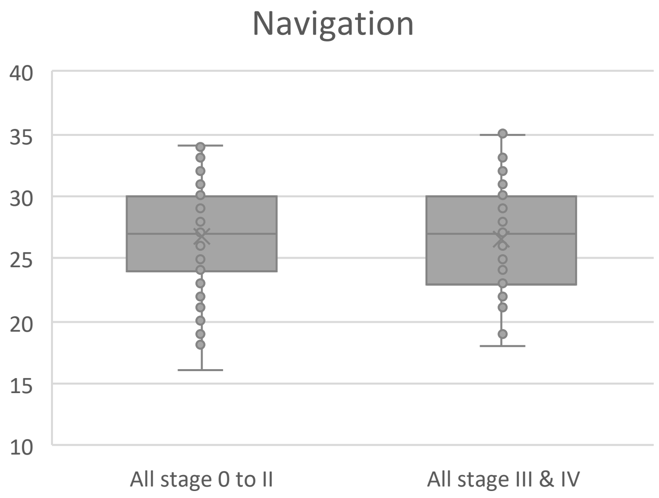


Figure 7.2: Boxplot of Care coordination: Navigation by breast cancer stage

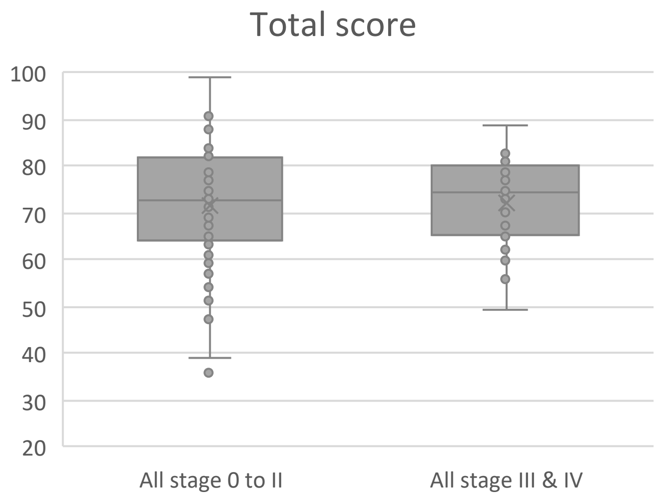


Figure 7.3: Boxplot of Care coordination: Total score by breast cancer stage

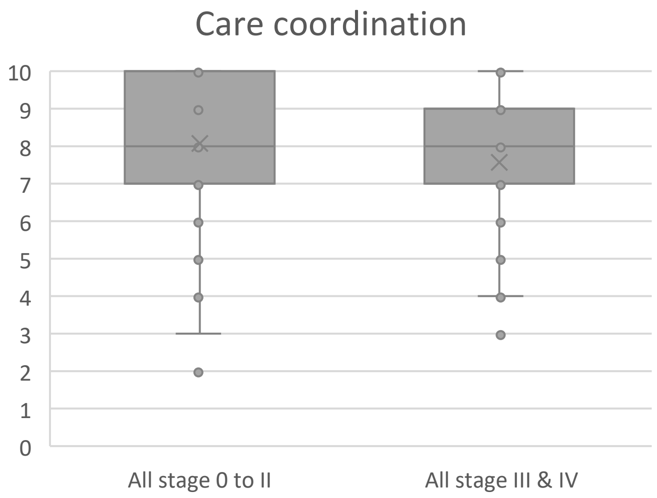


Figure 7.4: Boxplot of Care coordination: Care coordination global measure by breast cancer stage

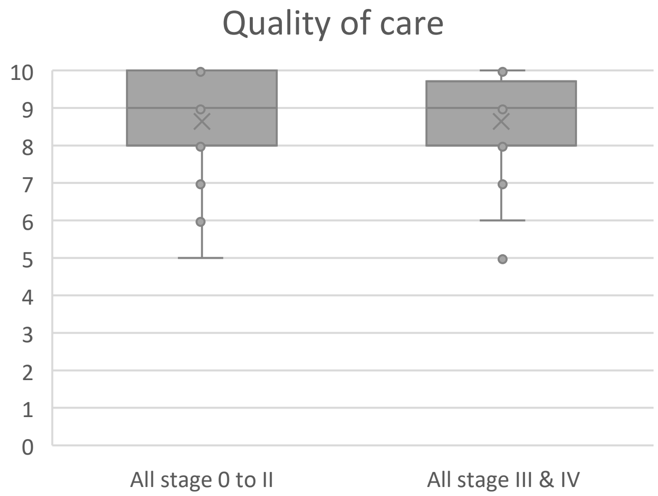


Figure 7.5: Boxplot of Care coordination: Quality of care global measure by breast cancer stage

Experience of care and support: Stage III to IV

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common responses were that they found support and care from did not receive any formal support (35.90%), charities (28.21%), and hospital or clinical setting (15.38 %). Other themes included peer support or other patients (15.38%), through a community service program (7.69%), psychologist or counselling service (7.69%), family and friends (7.69%), and allied health services (5.13%).

Participant describes that they did not receive any formal support

No. I haven't had any. Participant_035 TNG

No, I got no support from anywhere. Participant_025 TNG

No, what is this? I don't even know what these people are so I guess the answer is no. [laughs] Participant_042 TNG

Participant describes getting care and support from charities

I've received some support from a charity called Mummy's Wish. They gave me a grocery voucher, which was really lovely and just the materials and *things for my daughter. Look Good Feel Better Foundation. They sent me through that little pack that they sent your information. I know BCNA, one of the nurses just called me to check in and see how I was going. That was really good in terms of just mental health, particularly, at the beginning of things. That would be the three things. Participant 052_2021AUHRP*

Yes, had support through Breast Care WA for group support classes, I've been to that. They do offer a psychologist as well, but I didn't use them. I went somewhere else. Support in terms of community? Not as in an organization, but I've had a network of friends that have been there or communities that have delivered meals and helped that way. I've had that through the community. Participant_036 TNG

The support I've had from Cancer Council, once I had contacted them, they gave me some financial support at the beginning of the breast to me so she could be in contact with me at any time, or I could contact her at any time to talk through things. Also, I supplied a counsellor where we had monthly meetings and she would facilitate it. And then I'd seen her on a personal basis over the years. I then joined another support group, which was a group of ladies where we did activities together once every quarter sort of thing, and then we started doing monthly catch up and now we're doing catch up to talk to various professional. We had a person coming to talk to us about exercise therapy Participant_049 TNG

Participant describes getting care and support from hospital or clinical setting

I had the hospital group, which was good, the Cancer Council, the peer support group, our breast reconstruction group. It's just support from professionals, isn't it? Participant_040 TNG

I had two telephone counselling sessions with a psychologist who's specialized in breast cancer. After I was diagnosed with the gene, I had an in-person counselling session through the breast cancer organization, I can't remember which one. I had one in-person session. The biggest help, at the time, was the first cancer nurse. I could ring her. I met with her a few times, and I could call her any time. She totally understood what I was going through. Participant_037 TNG

The breast care nurses from the hospital, they would ring twice a week, where you're going through surgery and chemotherapy. For me, I just did six months of chemo, that was great. Community-wise, look, no, nothing in the community from that. Nothing from that perspective. My physiotherapist, she was great. I love her, she was amazing. Participant_047 TNG

Participant describes getting care and support from peer support or other patients

I had the hospital group, which was good, the Cancer Council, the peer support group, our breast reconstruction group. It's just support from professionals, isn't it? Participant_040 TNG

Yes, it was the early breast cancer group at the HOSPITAL. Even now, I'm a peer mentor. Peer mentors meet up regularly for coffee. We've become our own little support group as well. Participant 043_2021AUHRP

Participant describes receiving support through a community service program

Yes, I have. I suppose you call it community service, a breast care nurse has probably put me in touch with a few. I have reached out to what's called Mummy's Wish which has got some support components in there as well. What else is there? There's not much community-wise in that sense that isn't through our local cancer centre. There's a support network group that they've finally been able to get going again after all the COVID stuff. That's one we just started so that's something I'll actively participate in. Other than that, a lot of it's just online. Participant_030 TNG

Participant describes getting care and support from psychologist or counselling service

I had two telephone counselling sessions with a psychologist who's specialized in breast cancer. After I was diagnosed with the gene, I had an in-person counselling session through the breast cancer organization, I can't remember which one. I had one in-person session. The biggest help, at the time, was the first cancer nurse. I could ring her. I met with her a few times, and I could call her any time. She totally understood what I was going through. Participant_037 TNG

The support I've had from Cancer Council, once I had contacted them, they gave me some financial support *at the beginning of the breast to me so she could be in contact with me at any time, or I could contact her at any time to talk through things. Also, I supplied a counsellor where we had monthly meetings and she would facilitate it. And then I'd seen her on a personal basis over the years. I then joined another support group, which was a group of ladies where we did activities together once every quarter sort of thing, and then we started doing monthly catch up and now we're doing catch up to talk to various professional. We had a person coming to talk to us about exercise therapy. Participant_049 TNG*

Participant describes getting care and support from family and friends

Yes, had support through Breast Care WA for group support classes, I've been to that. They do offer a psychologist as well, but I didn't use them. I went somewhere else. Support in terms of community? Not as in an organization, but I've had a network of friends that have been there or communities that have delivered meals and helped that way. I've had that through the community. Participant_036 TNG

Not from any charities, no. It's just that group and my friends but nothing external. Participant_045 TNG

Table 7.14: Experience of care and support

Experience of care and support	**All participants**		**All Stage 0 to II**		**All Stage III & IV**		**Triple negative Stage III & IV**		**Hormone receptor Stage III & IV**	
	n=102	**%**	**n=63**	**%**	**n=39**	**%**	**n=27**	**%**	**n=12**	**%**
Participant describes that they did not receive any formal support	33	32.35	19	30.16	14	35.90	9	33.33	5	41.67
Participant describes getting care and support from charities	30	29.41	19	30.16	11	28.21	9	33.33	**2**	**16.67**
Participant describes getting care and support from hospital or clinical setting	25	24.51	19	30.16	6	15.38	5	18.52	**1**	**8.33**
Participant describes getting care and support from peer support or other patients	13	12.75	7	11.11	6	15.38	3	11.11	**3**	**25.00**
Participant describes receiving support through a community service program	12	11.76	9	14.29	3	7.69	3	11.11	**0**	**0.00**
Participant describes getting care and support from psychologist or counselling service	5	4.90	2	3.17	3	7.69	3	11.11	0	0.00
Participant describes getting care and support from family and friends	4	3.92	1	1.59	3	7.69	3	11.11	0	0.00
Participant describes receiving support through allied health services	4	3.92	2	3.17	2	5.13	2	7.41	0	0.00
Participant describes receiving support through home care	4	3.92	3	4.76	1	2.56	1	3.70	0	0.00
Participant describes receiving support through peer support (Online, online/phone groups or social media)	1	0.98	0	0.00	1	2.56	1	3.70	0	0.00
Participant describes that they did not need or seek help or support	6	5.88	5	7.94	1	2.56	0	0.00	1	8.33
Participant describes getting care and support from domestic services and/or home care	3	2.94	3	4.76	0	0.00	0	0.00	0	0.00
Participant describes receiving support through financial support	2	1.96	2	3.17	0	0.00	0	0.00	0	0.00
Participant describes receiving support through peer support (Face-to-face)	1	0.98	1	1.59	0	0.00	0	0.00	0	0.00

Experience of care and support	**All participants**		**All Triple negative**		**All Hormone receptor**		**Triple negative Stage 0 to II**		**Hormone receptor Stage 0 to II**	
	n=102	**%**	**n=50**	**%**	**n=52**	**%**	**n=23**	**%**	**n=40**	**%**
Participant describes that they did not receive any formal support	33	32.35	15	30.00	18	34.62	6	26.09	13	32.50
Participant describes getting care and support from charities	30	29.41	19	38.00	11	21.15	**10**	**43.48**	9	22.50
Participant describes getting care and support from hospital or clinical setting	25	24.51	11	22.00	14	26.92	6	26.09	13	32.50
Participant describes getting care and support from peer support or other patients	13	12.75	5	10.00	8	15.38	2	8.70	5	12.50
Participant describes receiving support through a community service program	12	11.76	**12**	**24.00**	**0**	**0.00**	**9**	**39.13**	**0**	**0.00**
Participant describes getting care and support from psychologist or counselling service	5	4.90	5	10.00	0	0.00	2	8.70	0	0.00
Participant describes getting care and support from family and friends	4	3.92	4	8.00	0	0.00	1	4.35	0	0.00
Participant describes receiving support through allied health services	4	3.92	4	8.00	0	0.00	2	8.70	0	0.00
Participant describes receiving support through home care	4	3.92	4	8.00	0	0.00	3	13.04	0	0.00
Participant describes receiving support through peer support (Online, online/phone groups or social media)	1	0.98	1	2.00	0	0.00	0	0.00	0	0.00
Participant describes that they did not need or seek help or support	6	5.88	0	0.00	6	11.54	0	0.00	5	12.50
Participant describes getting care and support from domestic services and/or home care	3	2.94	3	6.00	0	0.00	**3**	**13.04**	0	0.00
Participant describes receiving support through financial support	2	1.96	2	4.00	0	0.00	2	8.70	0	0.00
Participant describes receiving support through peer support (Face-to-face)	1	0.98	1	2.00	0	0.00	1	4.35	0	0.00

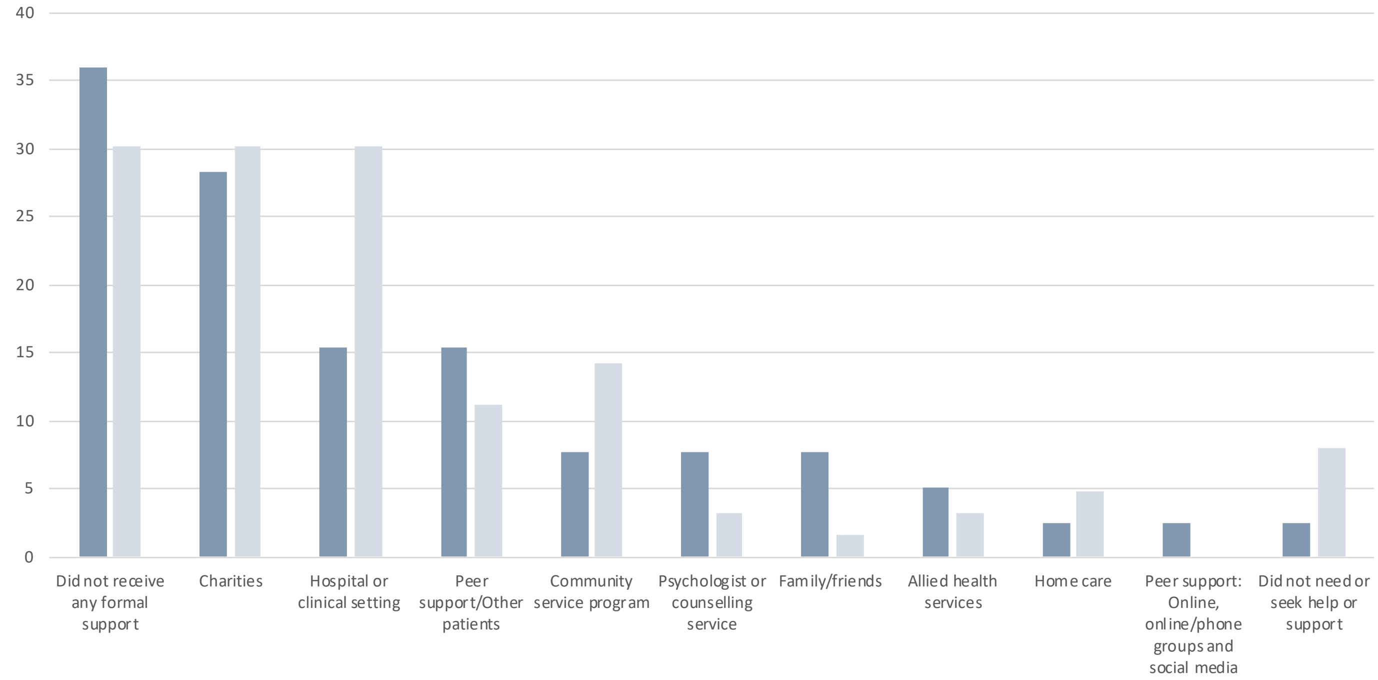


Figure 7.6: Experience of care and support(% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 7.5: Experience of care and support – subgroup variations – Stage III & IV variations

Experience of care and support	Reported less frequently	Reported more frequently
Participant describes getting care and support from charities	Hormone receptor Stage III & IV	-
Participant describes getting care and support from hospital or clinical setting	Hormone receptor Stage III & IV	-
Participant describes getting care and support from peer support or other patients	-	Hormone receptor Stage III & IV
Participant describes receiving support through a community service program	Hormone receptor Stage III & IV	-

Section 8

Quality of life

Section 8: Quality of life

Impact on quality of life: Stage III to IV

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Most commonly, the descriptions suggested that there was an overall negative impact on quality of life (51.28%), and overall positive impact on quality of life (17.95%). Other themes included a mix of positive and negative impact on quality of life (10.26%), overall no impact on quality of life (7.69%), and overall a minimal impact on quality of life (7.69%).

The most common themes in relation to a negative impact on quality of life were emotional strain (including family/change in relationship dynamics) (51.28%), and managing side effects and symptoms (15.38%). Other themes included reduced capacity for physical activity/needing to slow down (7.69%), and reduced social interaction (5.13%).

The most common themes in relation to a positive impact on quality of life were that it brings people together/highlights supportive relationships (10.26%), better self-care (5.13%), and strengthened relationships and shows you who really cares about you (5.13 %).

Impact on mental health: Stage III to IV

In the structured interview, participants were asked if there had been an impact on their mental health. Most commonly, the descriptions suggested that overall, there was at least some impact on mental health (87.18%), and overall, there was no impact on mental health (7.69%).

Regular activities to maintain mental health: Stage III to IV

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common response was consulting a mental health professional (30.77%), and the importance of physical exercise (28.21%). Other themes included coping strategies such as remaining social, lifestyle changes and hobbies (25.64%), the importance of family and friends in maintaining their mental health (25.64%), and mindfulness and/or meditation (20.51%).

Regular activities to maintain health: Stage III to IV

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health? The most common activities for general health were doing physical exercise/physically active (53.85%), self care e.g. more rest, accepting help, pacing (38.46%), and complying with treatment/management (20.51 %). Other themes included understanding their limitations (17.95%), maintaining a healthy diet (15.38%), socialising with friends and/or family (12.82%), maintaining a normal routine (10.26%), no activities to maintain health (10.26%), and medication to manage symptoms/side effects (7.69%).

Experience of vulnerability: Stage III to IV

In the structured interview, participants were asked if there had been times that they felt vulnerable. The most common responses were that they felt vulnerable during/after treatments (41.03%), when having negative thoughts (uncertainty, loneliness, worries) (15.38%), and when feeling sick/unwell (15.38 %). Other themes included during diagnostic procedure (15.38%), because of interactions with the medical team (12.82%),when having sensitive discussion (diagnosis, treatment decision) (10.26%), and during surgical procedure (10.26%).

Methods to manage vulnerability: Stage III to IV

In the structured interview, participants described ways that they managed feelings of vulnerability. The most common ways to manage vulnerability were using self-help methods (resilience, acceptance, staying positive) (28.21%), and support from nurse or treatment team (20.51%). Other themes included adapting (e.g, more proactive, assertive, put boundaries) to manage the feeling of vulnerability (7.69%), and getting support from family and friends (7.69%).

Impact on relationships: Stage III to IV

Most commonly, the descriptions suggested that overall, there was an impact on relationships that was both positive and negative (33.33%), overall, there was a negative impact on relationships (28.21%), and overall, there no impact on relationships (17.95 %). Other themes included overall, there was a positive impact on relationships (10.26%), and overall, there was an impact on relationships that was neither positive nor negative (5.13%).

The most common themes in relation to having a positive impact on relationships from family relationships being strengthened (12.82%), and from people being well-meaning and supportive (7.69%).

The most common themes in relation to having a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships (28.21%), and from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition (5.13%).

Burden on family: Stage III to IV

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Most commonly, the descriptions suggested that overall, there was a burden on their family (58.97%), and overall, there was not a burden on their family (35.90%).

The main reasons that participant described their condition being a burden were the extra household duties and responsibilities that their family must take on (15.38%), the mental/emotional strain placed on their family(7.69%), and the extra assistance needed getting to appointments (7.69 %). Other themes included the extra financial assistance needed (5.13%), and that the burden on family was temporary or only during treatment (7.69%).

The main reason that participant described their condition not being a burden were that they were independent and did not need any help from family (15.38%).

Cost considerations: Stage III to IV

In the structured interview, participants were asked about any significant costs associated with having their condition. The most common descriptions were that overall, there was at least some cost burden (76.92%), and overall, there was no cost burden (15.38%).

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments (including repeat scripts) (56.41%), diagnostic tests and scans (38.46%), and needing to take time off work (25.64 %). Other themes included the cost specialist appointments (17.95%), private care (12.82%), allied health care (10.26%), the cost of parking and travel to attend appointments (including accommodation) (5.13%), and a family member needing to take time off work (5.13%).

Where participants described no cost burden associated with their condition, it was most commonly in relation to nearly everything was paid for through the public health system (7.69%), and nearly everything was paid for through the private health system (5.13%).

Overall impact of condition on quality of life: Stage III to IV

In the online questionnaire, participants were asked to rate the overall impact their condition on quality of life. 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. The average score was in the Life was a little distressing range (median = 3.00).

Experience of anxiety related to disease progression: Stage III to IV

Fear of progression: Stage III to IV

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. The overall scores for the cohort were in the middle quintile for Fear of progression: Total score (mean=36.22, SD=6.82), indicating moderate levels of anxiety.

Fear of progression by breast cancer stage: Stage III to IV

Participants with stage 0 to II breast cancer (n=59, 62.11%) were compared to participants with stage II and IV breast cancer (n=36, 37.89).

A two-sample t-test was used when assumptions for normality and variance were met or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.nn).

Fear of progression individual questions Stage III to IV

On average, participants scored in the "Seldom" range for the following questions: "Afraid of pain" (median=2.00, IQR=1.00), "Is disturbed that they may have to rely on strangers for activities of daily living" (median=2.00, IQR=2.00), "If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped" (median=2.00, IQR=1.00), "Anxious if not experiencing any side effects think it doesn't work" (median=2.00, IQR=2.00).

On average, participants scored in the "Sometimes" range for the following questions: "Becomes anxious thinking that disease may progress" (median=3.00, IQR=1.00), "Has concerns about reaching professional and/or personal goals because of illness:" (median=3.00, IQR=1.25), "When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation" (median=3.00, IQR=2.00), "The possibility of relatives being diagnosed with this disease disturbs participant" (median=3.00, IQR=1.00), "Worried that at some point in time will no longer be able to pursue hobbies because of illness" (median=3.00, IQR=1.00), "Afraid of severe medical treatments during the course of illness" (median=3.00, IQR=1.00), "Worried that treatment could damage their body" (median=3.00, IQR=1.00), "The thought that they might not be able to work due to illness disturbs participant" (median=3.00, IQR=1.00).

On average, participants scored in the "Often" range for the following questions: "Is nervous prior to doctors appointments or periodic examinations" (median=3.50, IQR=1.00), "Worried about what will become of family if something should happen to participant" (median=4.00, IQR=1.00).

Impact on quality of life: Stage III to IV

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Most commonly, the descriptions suggested that there was an overall negative impact on quality of life (51.28%), and overall positive impact on quality of life (17.95%). Other themes included a mix of positive and negative impact on quality of life (10.26%), overall no impact on quality of life (7.69%), and overall a minimal impact on quality of life (7.69%).

The most common themes in relation to a negative impact on quality of life were emotional strain (including family/change in relationship dynamics) (51.28%), and managing side effects and symptoms (15.38%). Other themes included reduced capacity for physical activity/needing to slow down (7.69%), and reduced social interaction (5.13%).

The most common themes in relation to a positive impact on quality of life were that it brings people together/highlights supportive relationships (10.26%), better self-care (5.13%), and strengthened relationships and shows you who really cares about you (5.13 %).

Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)

Yes, it very much has affected my quality of life. I only have my daughter. It hasn't really affected her too much. She's had to help me out a few times, but I would imagine it's stressful for her because her mum has got cancer. I've tried very hard to not let her know everything that's going on. She's had to make meals for me and all that sort of stuff to put in the freezer, "Just come over and keep me company," or whatever, just to try and keep me sane. Like I said, I've tried not to involve her too much. Participant_028 TNG

Yes, I think it has. I think things have definitely changed and I think it definitely had an impact on my family but I think we're okay as well. We're getting through it, obviously, and, obviously, with COVID, it's made it a bit more difficult because I haven't been able to take the kids to the hospital. They haven't been able to visit me at any of them. They're dropping off. During lockdown and stuff for chemo, they weren't able to come in or they were able to visit me at the hospital when I had surgery. I think it has changed a lot for us, but I think we're also okay. Participant 042_2021AUHRP

Participant describes a negative impact on quality of life due to managing side effects and symptoms

Yeah, I still suffer from fatigue that affects my marriage as much as that the beginning he said he understood everything and he was quite careful with me and understood you know why I couldn't work as hard as I used to. But that changed and that would stand against me not being able to remember things and not being able to you know work seven days a week or whatever it was, caused quite a few problems. Participant 045_2021AUHRP

It definitely has affected my quality of life. For six months, I've been basically-- Most I can count on two hands the number of days where I felt okay in six months. That was really, really tough. It was lockdown in pandemic most of that time anyway, but I was not able to do much of what I normally would do that gives me pleasure. That's been difficult. Participant_041 TNG

Participant describes a negative impact on quality of life due to reduced capacity for physical activity/needing to slow down

I'm a single person. It hasn't really affected my family, but it has certainly affected the quality of my life, in terms of I was a very active person, bush-walking and kayaking. I am very limited in my ability to get back into that. It's affected that. I'd love to be out doing a lot more physical activities and things and I can't. I'm much reduced in that and I'm a lot more tired. I'm not back at work, so there is that aspect of purpose in life. I'm having to think about whether actually-- I'm left with a big choice of, "I'm I actually able to go back to work or should I retire and just try and enjoy the however many years that I have left?" There's certainly some big-- It certainly affected my outlook on life in terms of that and my life's pathway of where I'm going. Participant 047_2021AUHRP

Definitely. I try for it to not to. I've always been someone who's a bit of a weirdo. When it comes to exercise, I have low tolerance and stuff, I get sore easily. With all my chemo and the drugs that I've been on, I find it really hard. I went for a half and hour walk last night, it was so nice. I was nearly crippled by the time I got back. My legs were so sore. I'm so stiff in my joints. The last time when I was in bed, I was just in tears because my legs were in so much pain. Even during my chemo, probably up until the third

round, I was still on a treadmill. I was still able to go out, I was doing my exercises. Some days I'd feel the pain, but my body wasn't as sore. Now, all my joints are really bad. My bones ache really bad. I've obviously lost a lot of muscle strength. I'm finding it really hard to do any exercise. I've only just gone back to work the last three weeks and I'm only working two to three days a week and that's really physical. I'm just exhausted when I get home.
048_2021AUHRP

That's a tricky one. It's hard to just say yes or no. I feel my outlook has been better, I appreciate more. Quality of life through the different treatments has changed. When the trial was failing at the end of last year, quality of life was pretty poor. Xeloda wasn't fun because of the hand and foot, which really cut off or reduced my exercising opportunities because my feet were just really sensitive and hot and angry. I haven't been able to drive recently, so that's a bit tricky. Participant 051_2021AUHRP

Participant describes a positive impact on quality of life because it brings people together/highlights supportive relationships

I think it's probably improved my quality of life and my family life, as in my children. I'm sorry, I didn't have any family support really at the time. I faced that with my husband at the time. Yes, I think now it's just more about living for me and my children. Participant_024 TNG

I think it probably has, but only from the initial shock and the dealing with the, "Oh my gosh, what does this mean? How are we going to get through this? What does this mean for us? Am I going to survive?" those sorts of things, that affects your quality of life. Most days are really good days and know then that nothing's changed and we're still a very happy family unit. Yes, you are dealing with things that you've never thought you would as a family or not yet. Yes, it affects the quality of life in some regards, but for the most part, I'd say, no, we're pretty strong. Participant_033 TNG

Table 8.1: Impact on quality of life

Impact on quality of life	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Experience described suggests that there was an overall negative impact on quality of life	53	51.96	33	52.38	20	51.28	13	48.15	7	58.33
Experience described suggests that there was an overall positive impact on quality of life	12	11.76	5	7.94	7	17.95	4	14.81	**3**	**25.00**
Experience described suggests that there was a mix of positive and negaitve impact on quality of life	11	10.78	7	11.11	4	10.26	4	14.81	**0**	**0.00**
Experience described suggests that there was overall no impact on quality of life	9	8.82	6	9.52	3	7.69	3	11.11	0	0.00
Experience described suggests that there was overall a minimal impact on quality of life	14	13.73	11	17.46	3	7.69	**1**	**3.70**	2	16.67
Other	3	2.94	1	1.59	2	5.13	2	7.41	0	0.00

Impact on quality of life	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Experience described suggests that there was an overall negative impact on quality of life	53	51.96	26	52.00	27	51.92	13	56.52	20	50.00
Experience described suggests that there was an overall positive impact on quality of life	12	11.76	6	12.00	6	11.54	2	8.70	3	7.50
Experience described suggests that there was a mix of positive and negaitve impact on quality of life	11	10.78	7	14.00	4	7.69	3	13.04	4	10.00
Experience described suggests that there was overall no impact on quality of life	9	8.82	5	10.00	4	7.69	2	8.70	4	10.00
Experience described suggests that there was overall a minimal impact on quality of life	14	13.73	3	6.00	11	21.15	2	8.70	9	22.50
Other	3	2.94	3	6.00	0	0.00	1	4.35	0	0.00

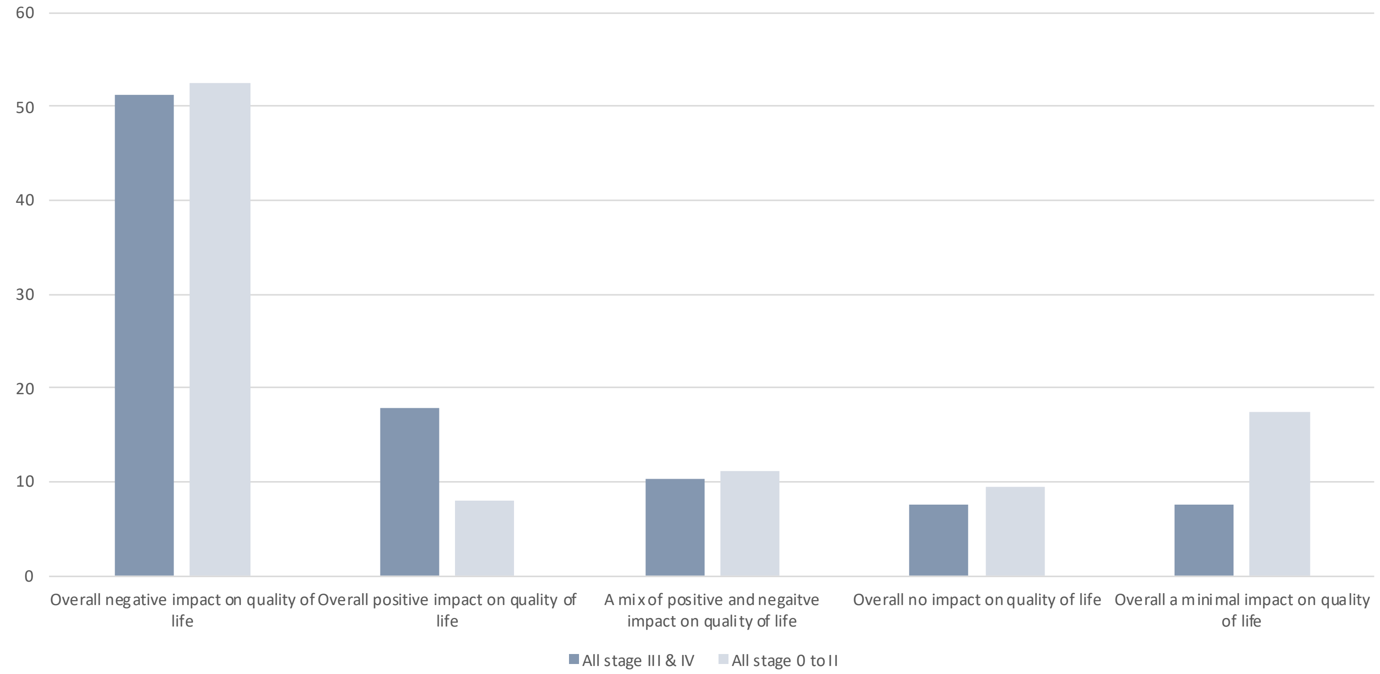


Figure 8.1: Impact on quality of life (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 8.2: Impact quality of life – Stage III & IV variations

Impact on quality of life	Reported less frequently	Reported more frequently
Experience described suggests that there was an overall positive impact on quality of life		Hormone receptor Stage III & IV
Experience described suggests that there was a mix of positive and negaitve impact on quality of life	Hormone receptor Stage III & IV	
Experience described suggests that there was overall a minimal impact on quality of life	Triple negative Stage III & IV	

Table 8.3: Impact on quality of life (Reasons)

Impact on quality of life (Reasons)	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)	53	51.96	33	52.38	20	51.28	14	51.85	6	50.00
Participant describes a negative impact on quality of life due to managing side effects and symptoms	20	19.61	14	22.22	6	15.38	5	18.52	**1**	**8.33**
Participant describes a negative impact on quality of life due to reduced capacity for physical activity/needing to slow down	18	17.65	15	23.81	3	7.69	**2**	**7.41**	1	8.33
Participant describes a negative impact on quality of life due to reduced social interaction	5	4.90	3	4.76	2	5.13	0	0.00	**2**	**16.67**
Participant describes a negative impact on quality of life due to inability to work/changes with their work	2	1.96	1	1.59	1	2.56	1	3.70	0	0.00
Participant describes a negative impact on quality of life due to being unable to travel/adapt significantly in order to travel	1	0.98	0	0.00	1	2.56	1	3.70	0	0.00
Participant describes a negative impact on quality of life due to fatigue	7	6.86	6	9.52	1	2.56	0	0.00	1	8.33
Participant describes a negative impact on quality of life due to intimacy challenges	5	4.90	5	7.94	0	0.00	0	0.00	0	0.00
Participant describes a negative impact on quality of life due to the emotional strain on self	8	7.84	8	12.70	0	0.00	0	0.00	0	0.00
Participant describes a positive impact on quality of life because it brings people together/highlights supportive relationships	10	9.80	6	9.52	4	10.26	2	7.41	2	16.67
Participant describes a positive impact on quality of life because it made them have better self-care	4	3.92	2	3.17	2	5.13	2	7.41	0	0.00
Participant describes positive impact as it strengthened relationships and shoes you who really cares about you	4	3.92	2	3.17	2	5.13	2	7.41	0	0.00

Impact on quality of life (Reasons)	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes a negative impact on quality of life due to the emotional strain (including family/change in relationship dynamics)	53	51.96	25	50.00	28	53.85	11	47.83	22	55.00
Participant describes a negative impact on quality of life due to managing side effects and symptoms	20	19.61	15	30.00	5	9.62	10	43.48	4	10.00
Participant describes a negative impact on quality of life due to reduced capacity for physical activity/needing to slow down	18	17.65	8	16.00	10	19.23	6	26.09	9	22.50
Participant describes a negative impact on quality of life due to reduced social interaction	5	4.90	0	0.00	5	9.62	0	0.00	3	7.50
Participant describes a negative impact on quality of life due to inability to work/changes with their work	2	1.96	2	4.00	0	0.00	1	4.35	0	0.00
Participant describes a negative impact on quality of life due to being unable to travel/adapt significantly in order to travel	1	0.98	1	2.00	0	0.00	0	0.00	0	0.00
Participant describes a negative impact on quality of life due to fatigue	7	6.86	0	0.00	7	13.46	0	0.00	6	15.00
Participant describes a negative impact on quality of life due to intimacy challenges	5	4.90	0	0.00	5	9.62	0	0.00	5	12.50
Participant describes a negative impact on quality of life due to the emotional strain on self	8	7.84	0	0.00	8	15.38	0	0.00	8	20.00
Participant describes a positive impact on quality of life because it brings people together/highlights supportive relationships	10	9.80	5	10.00	5	9.62	3	13.04	3	7.50
Participant describes a positive impact on quality of life because it made them have better self-care	4	3.92	4	8.00	0	0.00	2	8.70	0	0.00
Participant describes positive impact as it strengthened relationships and shoes you who really cares about you	4	3.92	4	8.00	0	0.00	2	8.70	0	0.00

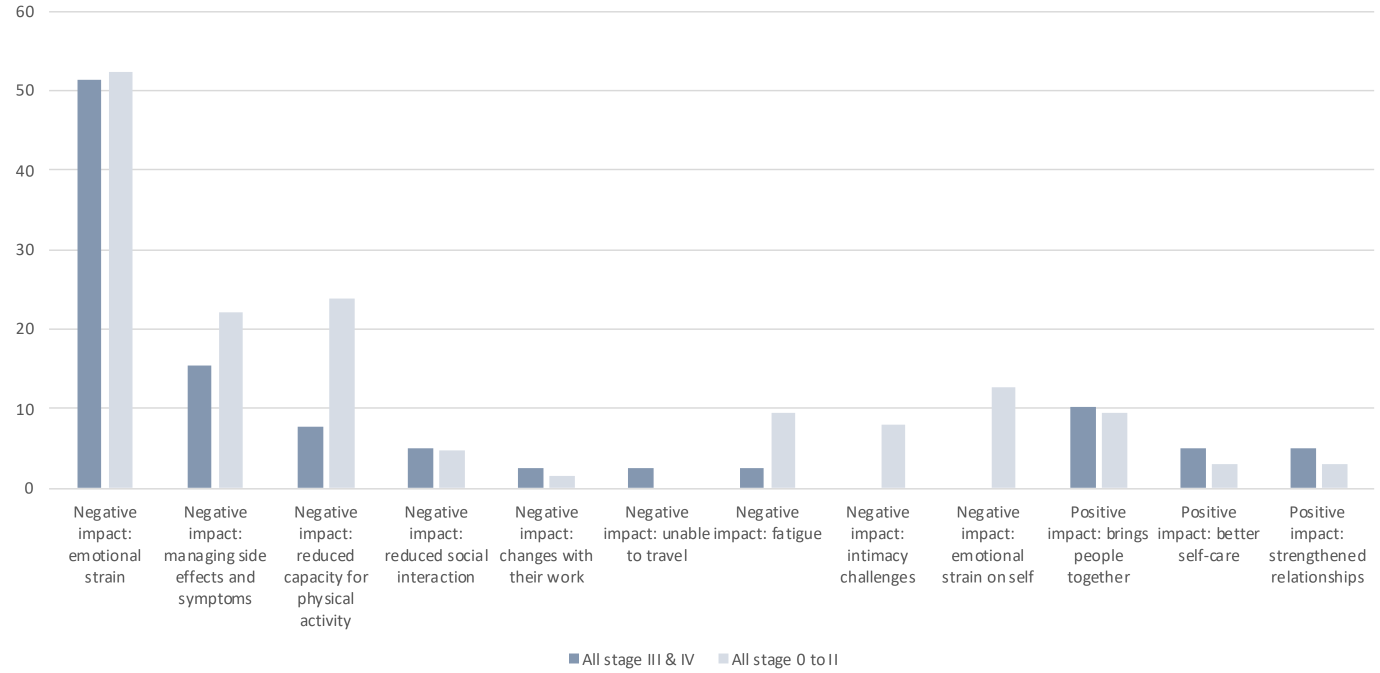


Figure 8.2: Impact on quality of life (Reasons) (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 8.4: Impact on quality of life (Reasons) – Stage III & IV variations

Impact on quality of life (Reasons)	Reported less frequently	Reported more frequently
Participant describes a negative impact on quality of life due to managing side effects and symptoms	Hormone receptor Stage III & IV	-
Participant describes a negative impact on quality of life due to reduced capacity for physical activity/needing to slow down	Triple negative Stage III & IV	-
Participant describes a negative impact on quality of life due to reduced social interaction	-	Hormone receptor Stage III & IV

Impact on mental health: Stage III to IV

In the structured interview, participants were asked if there had been an impact on their mental health. Most commonly, the descriptions suggested that overall, there was at least some impact on mental health (87.18%), and overall, there was no impact on mental health (7.69%).

Experience described suggests that overall, there was at least some impact on mental health

It does because especially as a female, you lose all your hair and it's debilitating or it was me. Some women say, "Well, I shaved my head before it started falling out myself. Fantastic and I had control." And I conceded off and said I cried the whole time I was sitting my head shaved and couldn't look in a mirror. When I had no hair. How did I look after it? I probably didn't, to be quite honest. I was just at this stage, I was just getting through each day as it came without looking too far ahead because I couldn't cope with it. Participant_027 TNG

I think the other day I thought I might actually look up someone to talk to about it, because I didn't really think about it throughout the process because I just wanted to get on with it and keep working so that I could just be focused. Now, you're at the end, it's like, "I actually survived something pretty amazing." It does get a bit overwhelming every now and then. Yes, I get like, "Oh, no." I just start crying like, "Whoa, that was good you know. Well done that you did that." but it might be beneficial for me to go talk to someone about it. That's probably where I'm at right now. Participant_045 TNG

Yes, it does affect, obviously. It does affect that side of things. I find I'm a lot more emotional now, just overall. I try to have time out for me all the time, like most days, have a little bit of time to do that. I love walking on the beach or something like that. Being around water helps me. The local cancer support groups, they do pamper days on the coast, so we go to those. They have massage and do different things like that just to treat you, so I try to do them when I can. Participant_046 TNG

Experience described suggests that overall, there was no impact on mental health

It has affected me not so much emotionally but mentally probably I'm quite strong-minded. I've been pretty good in that aspect, but it's because it's impacted me physically. I've got to rebuild my physical strength and wellbeing before I'm content in that mental capacity of it. Participant_030 TNG

Table 8.5: Impact on mental health

Impact on mental health	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Experience described suggests that overall, there was at least some impact on mental health	95	93.14	61	96.83	34	87.18	23	85.19	11	91.67
Experience described suggests that overall, there was no impact on mental health	5	4.90	2	3.17	3	7.69	2	7.41	1	8.33
Other or mixed experience	2	1.96	0	0.00	2	5.13	2	7.41	0	0.00

Impact on mental health	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Experience described suggests that overall, there was at least some impact on mental health	95	93.14	45	90.00	50	96.15	22	95.65	39	97.50
Experience described suggests that overall, there was no impact on mental health	5	4.90	3	6.00	2	3.85	1	4.35	1	2.50
Other or mixed experience	2	1.96	2	4.00	0	0.00	0	0.00	0	0.00

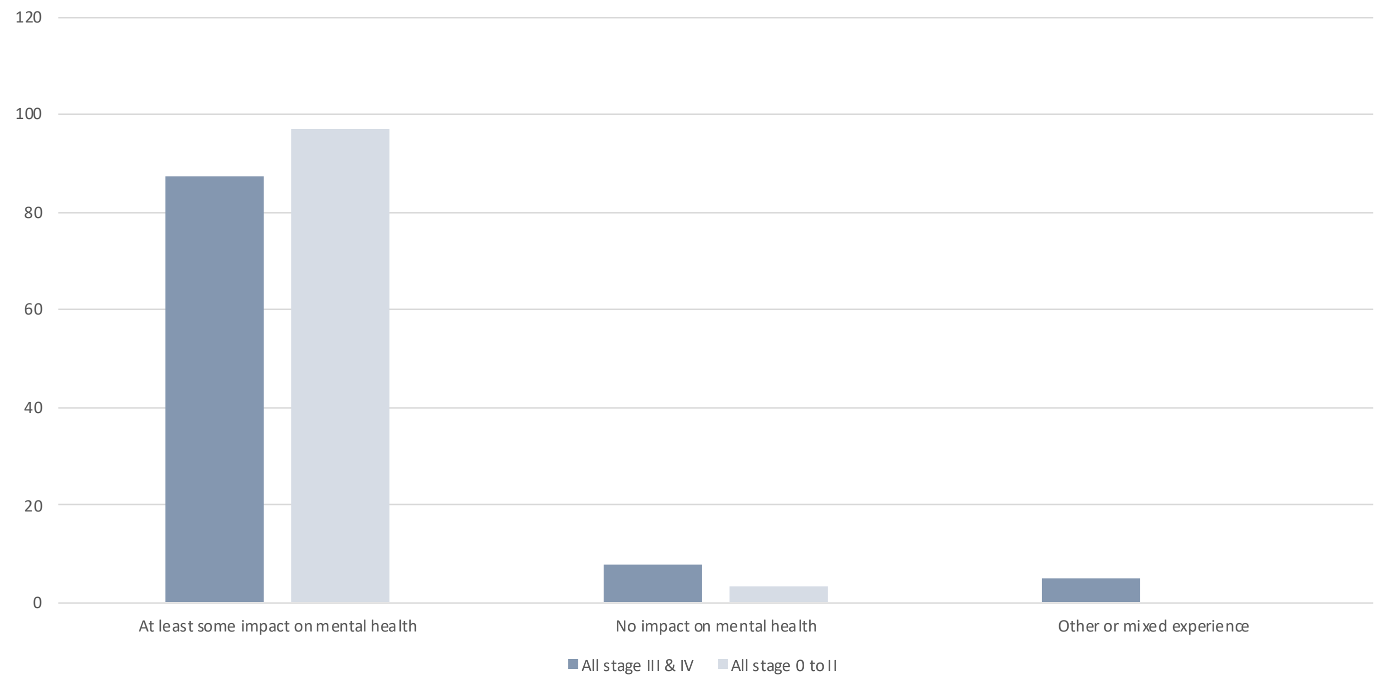


Figure 8.3: Impact on mental health (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Regular activities to maintain mental health: Stage III to IV

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common response was consulting a mental health professional (30.77%), and the importance of physical exercise (28.21%). Other themes included coping strategies such as remaining social, lifestyle changes and hobbies (25.64%), the importance of family and friends in maintaining their mental health (25.64%), and mindfulness and/or meditation (20.51%).

Participant describes consulting a mental health professional to maintain their mental health

Seeing a psychologist at the moment. During treatment, no, I didn't. Didn't have the time or that wellness to deal with it at the time. My treatment started so quickly there wasn't time to get in really beforehand, but now I am, yes. Participant_036 TNG

I do walk regularly. I do know that helps. There are certain days that are worse than others. I've just started just last week antidepressants, and I've accessed a psychologist again because I had stopped that for seven months, I was doing pretty well. It just comes and goes, and I think with every-- you do get a lot of anxiety when you have a new pain or it's just something new, or when you have a scan coming up. That will be ongoing, speaking with other people, that will be ongoing. Participant 049_2021AUHRP

Yes. I recognized that I needed to see a psychologist. I obviously went and got that all sorted straight away, but it just took months before it could happen. I've got mindfulness journals, I try and do exercise when I can. Sometimes I'm really unmotivated [chuckles]. Participant 048_2021AUHRP

Participant describes the importance of physical exercise to maintain their mental health

Yes, I'm back at work so I have the social aspect. I'm back at my gym three times a week. The physical activity is helping but it's also the social interaction, which helps the mental side because I've got so many friends there who are like, "You're looking so well. You're back at the gym already." and so that kind of thing has really helped me get through it. Participant_027 TNG

Yes, it certainly does affect your mental and emotional health. I think for me a few things, physical activity when I can do it, and I think to a degree that was certainly helpful for me keeping as active as possible, physically. I guess for me the spiritual component. I'm a spiritual person and just using my spiritual-- The word is there. My spirituality has *absolutely helped me to be centered and to not be anxious, or to be less anxious is probably a better word, and has given me some more peace and hope. Participant 047_2021AUHRP*

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

Participant describes coping strategies such as remaining social, lifestyle changes and hobbies to maintain their mental health

Yes, it does for everyone, I guess. I do have moments that that I do feel more afraid of it reoccurring or especially when close friends get cancer or have three goons. And I do have to really make myself think, no, no, no, this is not going to happen to you. She was a different case or him. They had different cancers or they had different outcomes. Yeah. So it makes it hard sometimes. Yeah. And I really have to remind myself about it and then. Just yeah, and then just released myself, so I'll have to talk to someone about it or also by listening to some music and start doing things, more things to enjoy myself, to least try to find relief and. Yeah, yeah. Participant_031 TNG

Yes, it does affect, obviously. It does affect that side of things. I find I'm a lot more emotional now, just overall. I try to have time out for me all the time, like most days, have a little bit of time to do that. I love walking on the beach or something like that. Being around water helps me. The local cancer support groups, they do pamper days on the coast, so we go to those. They have massage and do different things like that just to treat you, so I try to do them when I can. Participant_046 TNG

Participant describes the importance of family and friends in maintaining their mental health to maintain their mental health

Absolutely. When I was first diagnosed, it was terrifying. I have a long health history of not being very well with some pretty serious illnesses. In between that period of time from diagnosis to initial diagnosis to having a PET scan, I was terrified about what was my prognosis. Getting your head around having cancer is just an extraordinary thing to try to do. I couldn't even say the word out loud for a couple of weeks. It was so overwhelming, and just that thing where you wake up in the morning for that brief second, you forget what's really going on, and then it just hits you like a ton of bricks. I just be going about my day and it'd be like getting this reality slap every once in a while where it's just I'd go and I would just remember what was going on. It was like my whole body would just flood with this fear. I go for walks every day on the beach, I do a lot of meditation, guided meditations. I've got my psychologist. I do go for walks with friends most days when we're allowed to. I do try to talk to my partner once, if not twice a day. I just make sure that I'm keeping up those human connections, trying to have some enjoyable time, but also practicing well-being techniques that really helped me, and massage really helps a lot, too. Participant_041 TNG

Apart from seeing a psychologist and talking to my daughter endlessly, no I don't. I guess I do think it's affected me in some ways. I haven't got the patience I once did. Yes, talking to people helps. Participant_03 TNG 2

Participant describes mindfulness and/or meditation to maintain their mental health

I do personal development courses at different times and just general ones, not specifically related to cancer. I try to spend time doing meditation. I find that helps calm my mind. Participant_037 TNG

Absolutely. When I was first diagnosed, it was terrifying. I have a long health history of not being very well with some pretty serious illnesses. In between that period of time from diagnosis to initial diagnosis to having a PET scan, I was terrified about what was my prognosis. Getting your head around having cancer is just an extraordinary thing to try to do. I couldn't even say the word out loud for a couple of weeks. It was so overwhelming, and just that thing where you wake up in the morning for that brief second, you forget what's really going on, and then it just hits you like a ton of bricks. I just be going about my day and it'd be like getting this reality slap every once in a while where it's just I'd go and I would just remember what was going on. It was like my whole body would just flood with this fear. I go for walks every day on the beach, I do a lot of meditation, guided meditations. I've got my psychologist. I do go *for walks with friends most days when we're allowed to. I do try to talk to my partner once, if not twice a day. I just make sure that I'm keeping up those human connections, trying to have some enjoyable time, but also practicing well-being techniques that really helped me, and massage really helps a lot, too. Participant_041 TNG*

Table 8.6: Regular activities to maintain mental health

Regular activities to maintain mental health	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes consulting a mental health professional to maintain their mental health	33	32.35	21	33.33	12	30.77	8	29.63	4	33.33
Participant describes the importance of physical exercise to maintain their mental health	34	33.33	23	36.51	11	28.21	5	18.52	6	50.00
Participant describes coping strategies such as remaining social, lifestyle changes and hobbies to maintain their mental health	31	30.39	21	33.33	10	25.64	8	29.63	2	16.67
Participant describes the importance of family and friends in maintaining their mental health to maintain their mental health	21	20.59	11	17.46	10	25.64	6	22.22	4	33.33
Participant describes mindfulness and/or meditation to maintain their mental health	30	29.41	22	34.92	8	20.51	2	7.41	6	50.00
Participant describes the importance of accepting condition/positive outlook	8	7.84	6	9.52	2	5.13	2	7.41	0	0.00
Participant describes the importance of self care in maintaining their mental health	6	5.88	4	6.35	2	5.13	2	7.41	0	0.00
Participant describes support groups to maintain mental health to maintain their mental health	3	2.94	1	1.59	2	5.13	2	7.41	0	0.00
Participant describes no activities to maintain mental health to maintain their mental health	8	7.84	6	9.52	2	5.13	2	7.41	0	0.00
Participant describes support from medical team to maintain their mental health	3	2.94	2	3.17	1	2.56	1	3.70	0	0.00
Participant describes taking medication to maintain their mental health	2	1.96	1	1.59	1	2.56	1	3.70	0	0.00
Participant describes maintaining a healthy diet to maintain their mental health	4	3.92	3	4.76	1	2.56	0	0.00	1	8.33

Regular activities to maintain mental health	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes consulting a mental health professional to maintain their mental health	33	32.35	17	34.00	16	30.77	9	39.13	12	30.00
Participant describes the importance of physical exercise to maintain their mental health	34	33.33	15	30.00	19	36.54	10	43.48	13	32.50
Participant describes coping strategies such as remaining social, lifestyle changes and hobbies to maintain their mental health	31	30.39	18	36.00	13	25.00	10	43.48	11	27.50
Participant describes the importance of family and friends in maintaining their mental health to maintain their mental health	21	20.59	8	16.00	13	25.00	2	8.70	9	22.50
Participant describes mindfulness and/or meditation to maintain their mental health	30	29.41	5	10.00	25	48.08	3	13.04	19	47.50
Participant describes the importance of accepting condition/positive outlook	8	7.84	8	16.00	0	0.00	6	26.09	0	0.00
Participant describes the importance of self care in maintaining their mental health	6	5.88	6	12.00	0	0.00	4	17.39	0	0.00
Participant describes support groups to maintain mental health to maintain their mental health	3	2.94	3	6.00	0	0.00	1	4.35	0	0.00
Participant describes no activities to maintain mental health to maintain their mental health	8	7.84	3	6.00	5	9.62	1	4.35	5	12.50
Participant describes support from medical team to maintain their mental health	3	2.94	3	6.00	0	0.00	2	8.70	0	0.00
Participant describes taking medication to maintain their mental health	2	1.96	2	4.00	0	0.00	1	4.35	0	0.00
Participant describes maintaining a healthy diet to maintain their mental health	4	3.92	2	4.00	2	3.85	2	8.70	1	2.50

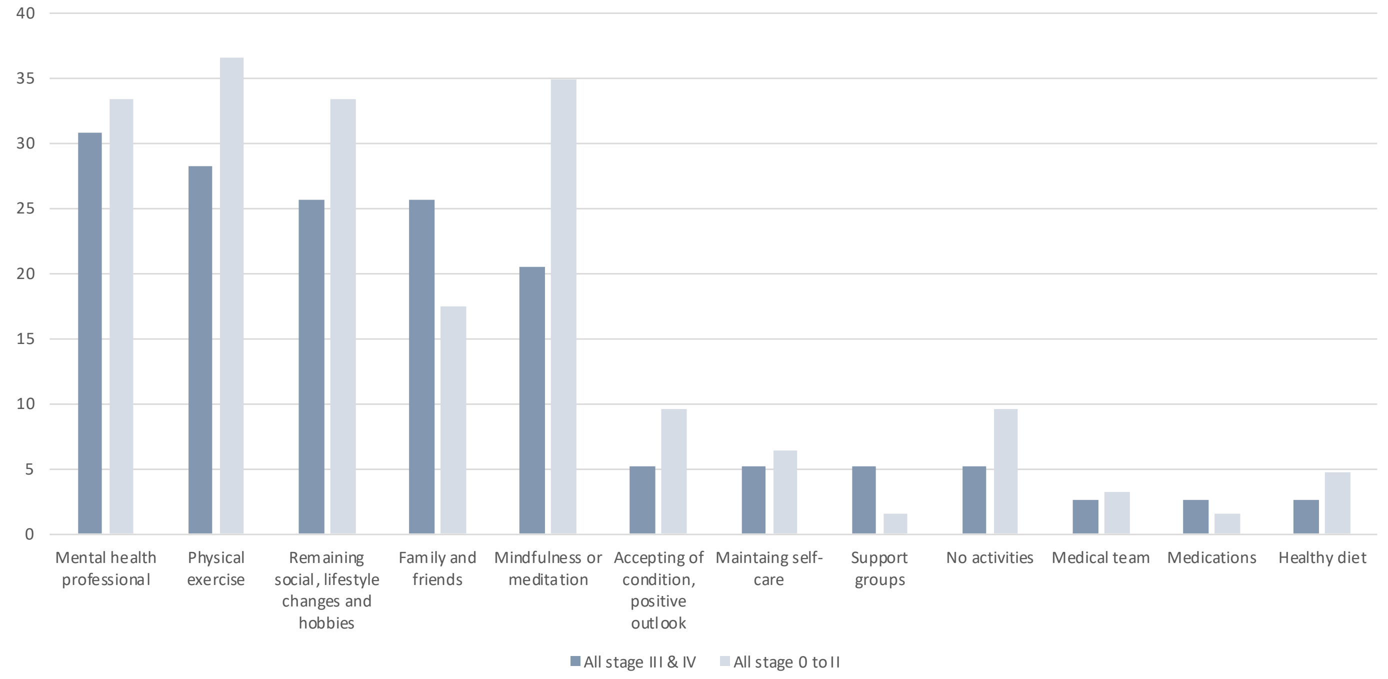


Table 8.7: Regular activities to maintain mental health – Stage III & IV variations

Regular activities to maintain mental health	Reported less frequently	Reported more frequently
Participant describes the importance of physical exercise to maintain their mental health	Triple negative Stage III & IV	Hormone receptor Stage III & IV
Participant describes coping strategies such as remaining social, lifestyle changes and hobbies to maintain their mental health	Hormone receptor Stage III & IV	
Participant describes the importance of family and friends in maintaining their mental health to maintain their mental health	-	Hormone receptor Stage III & IV
Participant describes mindfulness and/or meditation to maintain their mental health	Triple negative Stage III & IV	Hormone receptor Stage III & IV

Regular activities to maintain health: Stage III to IV

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health? The most common activities for general health were doing physical exercise/physically active (53.85%), self care e.g. more rest, accepting help, pacing (38.46%), and complying with treatment/management (20.51 %). Other themes included understanding their limitations (17.95%), maintaining a healthy diet (15.38%), socialising with friends and/or family (12.82%), maintaining a normal routine (10.26%), no activities to maintain health (10.26%), and medication to manage symptoms/side effects (7.69%).

Participant describes the importance of doing physical exercise/physically active in maintaining their general health

I just keep active. I need to keep my mind active. I need to keep my body active. I found throughout treatment if I kept my life as normal as possible and try to keep my routine, I got through things better. Even with my radiotherapy, I know people said they had terrible fatigue. I didn't notice that fatigue because I kept my day normal. I did my radiotherapy as the last thing I did during the day, got home, went from my daily walk, made dinner, had dinner, had my rest, and then go to sleep. I found that doing that all throughout treatment helped me because I wasn't being fatigued at the time of the day when I shouldn't be, sort of being fatigued when I should be. Participant_034 TNG

Well, activity is it sounds weird, but for fatigue and aches, actually, you've got to keep moving. Movements, exercise, connecting with others that might understand, and talking, not being afraid to actually just say, "This is good. This is not so good. This is shit. This is happening." It's always there. Participant 043_2021AUHRP

Participant describes the importance of self care e.g. more rest, accepting help, pacing in maintaining their general health

I do sleep. I do have naps now to recharge, I guess you could say. It can be anywhere between 20 minutes and three hours probably on a day that I do get to rest and not working with a basket wick. I guess, activity, so exercise and walking basically helps that thing, the [unintelligible] just have social relationships. Participant_024 TNG

You need to make sure you rest. You have to rest. I see a chiro once every probably I think every three weeks, whereas before I would be seeing him every three months, but I make sure I see him every three weeks at the moment. Other than that, drink lots of water and just be aware of what's hurting in your body and if that's normal, as well. Participant_035 TNG

Participant describes the importance of complying with treatment/management in maintaining their general health

I need to take multiple tablets [chuckles] for dealing with the pain and things like that and other associated issues. I go to a physio and hydrotherapy to try and just get some movement back and things like that, exercises. I see a support group of ladies which just gives me the reassurance of having someone else there to talk to and feed off if you need help or anything like that. Participant_036 TNG

All right. Just doctors, my regular doctor's appointments. What else do I do? Like I say, I can't exercise. I used to swim, but I can't at the moment, and that's just because it's too cold, and that's less good. Just the only thing I really do is see my doctors on a regular basis. I do spend a lot of time by myself at home, but I'm used to that now, plus probably with COVID it's safer to stay home. Participant_032 TNG

Participant describes the importance of understanding their limitations in maintaining their general health

Yes, okay. I certainly have slowed my day down in terms of I don't live my life at a fast pace. I've made sure that I am-- I have definitely slowed the pace of my days down and I don't rush. I give myself every day plenty of time and I don't push myself to try and accomplish too much in a day. In terms of even mentally planning things, I have to give myself plenty of time to just mentally plan what I'm doing. I try and exercise every day, get some form of physical exercise. My spiritual activity, I pray and meditate every day, first thing in the morning, to help me. Participant 047_2021AUHRP

PARTICIPANT: Well, I exercise today and hydrotherapy. And I really when I was when I had the hysterectomy and I couldn't do the exercise and everything, it's only been just this week that I could go back. I have really gone backwards with time and things like that because I haven't been able to do that. So that's something I've got to keep on top of. Otherwise it gets really. Sorry what was the question?
INTERVIEWER: what is some of the things you do every day to help set you up for a good day?
PARTICIPANT: Yeah, and I guess not trying to do too much in one day, then I can't do too much for a few days after that. So it's just doing a little bit at a time and building on that. Participant_038 TNG

Participant describes the importance of maintaining a healthy diet in maintaining their general health

Okay. Daily walking. I do meditation quite regularly. I try to eat as healthy as possible. Catching up with friends and seeing my mum who is doing really well. She's a bit of an inspiration. Catching up with our children. It's just the daily checking in with the closest friends and family, and walking, meditation is a big thing for me, and doing my lymphedema exercises. There's certain things that I do have to do daily. Participant 049_2021AUHRP

What I need to do is be more active and I haven't got there yet. Dr. de Viana said to me to keep the cancer away there's three things I have to do. Reach a healthy body weight, which I haven't done. Exercise for half an hour every day whether you get sweaty and red in the face or 45 minutes every second day, and stay away from processed sugar as much as possible. I have an agenda that I will meet that criteria but it's a way to go. I've got to lose about 12 kilos to get to a healthy body weight, I've got to start exercising, and I've got to cut sugar out. [chuckles] Participant_029 TNG

Participant describes the importance of socialising with friends and/or family in maintaining their general health

I need to take multiple tablets [chuckles] for dealing with the pain and things like that and other associated issues. I go to a physio and hydrotherapy to try and just get some movement back and things like that, exercises. I see a support group of ladies which just gives me the reassurance of having someone else there to talk to and feed off if you need help or anything like that. Participant_036 TNG

I do sleep. I do have naps now to recharge, I guess you could say. It can be anywhere between 20 minutes and three hours probably on a day that I do get to rest and not working with a basket wick. I guess, activity, so exercise and walking basically helps that thing, the [unintelligible] just have social relationships. Participant_024 TNG

Participant describes the importance of maintaining a normal routine in maintaining their general health

For me to function and to do most of the things I need to do, I need my life to be as close to what it was as possible. That's really important to me. I want to be able to go out and do things, and that's really important. I don't want to cancel things or not be able to do stuff because that affects my ability. I don't want to fall in that pattern of I've got cancer, I'm having chemo, I can't do this, this and this. For me, it's a mental battle, I think, to make sure that I don't allow myself to fall into that pattern of getting out of things or using it to not do things. I find that helpful for me. Obviously, I probably rest more than I did. I didn't use to stop very much. Now I probably do rest more and I allow myself to do that. That's a change, I guess, just going, "Actually, I need a break. I need to just put my feet up for an hour or do something, have a rest." That's different from how I used to be. Where you just power through all day long because that's what the days are for. Really, I don't think there's-- I think I answered your question. Participant_033 TNG

I just keep active. I need to keep my mind active. I need to keep my body active. I found throughout treatment if I kept my life as normal as possible and try to keep my routine, I got through things better. Even with my radiotherapy, I know people said they had terrible *fatigue. I didn't notice that fatigue because I kept my day normal. I did my radiotherapy as the last thing I did during the day, got home, went from my daily walk, made dinner, had dinner, had my rest, and then go to sleep. I found that doing that all throughout treatment helped me because I wasn't being fatigued at the time of the day when I shouldn't be, sort of being fatigued when I should be. Participant_034 TNG*

I walk every day. Even during the peak of chemo where I was like out of breath, I still made myself walk. I've got this thing about getting fresh air every single day, but my thing was, is just getting up and getting dressed and having a routine that I have to do it every day. I can't go, "I'm feeling crappy and I'm just going to stay in bed." I pushed myself to not do that because you're not going to achieve anything. I just kept pushing myself every day to get out of bed and get up, get a routine. Dropping my son off was really important to me, at school. Participant_045 TNG

Table 8.8: Regular activities to maintain health

Regular activities to maintain health	**All participants**		**All Stage 0 to II**		**All Stage III & IV**		**Triple negative Stage III & IV**		**Hormone receptor Stage III & IV**	
	n=102	**%**	**n=63**	**%**	**n=39**	**%**	**n=27**	**%**	**n=12**	**%**
Participant describes the importance of doing physical exercise/physically active in maintaining their general health	51	50.00	30	47.62	21	53.85	14	51.85	7	58.33
Participant describes the importance of self care e.g. more rest, accepting help, pacing in maintaining their general health	43	42.16	28	44.44	15	38.46	8	29.63	7	58.33
Participant describes the importance of complying with treatment/management in maintaining their general health	21	20.59	13	20.63	8	20.51	6	22.22	2	16.67
Participant describes the importance of understanding their limitations in maintaining their general health	29	28.43	22	34.92	7	17.95	5	18.52	2	16.67
Participant describes the importance of maintaining a healthy diet in maintaining their general health	20	19.61	14	22.22	6	15.38	6	22.22	0	0.00
Participant describes the importance of socialising with friends and/or family in maintaining their general health	9	8.82	4	6.35	5	12.82	3	11.11	2	16.67
Participant describes the importance of maintaining a normal routine in maintaining their general health	7	6.86	3	4.76	4	10.26	4	14.81	0	0.00
Participant describes the importance of no activities to maintain their general health	13	12.75	9	14.29	4	10.26	3	11.11	1	8.33
Participant describes the importance of medication to manage symptoms/side effects in maintaining their general health	4	3.92	1	1.59	3	7.69	3	11.11	0	0.00
Participant describes the importance of vitamins and supplements in maintaining their general health	3	2.94	1	1.59	2	5.13	2	7.41	0	0.00

Regular activities to maintain health	**All participants**		**All Triple negative**		**All Hormone receptor**		**Triple negative Stage 0 to II**		**Hormone receptor Stage 0 to II**	
	n=102	**%**	**n=50**	**%**	**n=52**	**%**	**n=23**	**%**	**n=40**	**%**
Participant describes the importance of doing physical exercise/physically active in maintaining their general health	51	50.00	26	52.00	25	48.08	12	52.17	18	45.00
Participant describes the importance of self care e.g. more rest, accepting help, pacing in maintaining their general health	43	42.16	19	38.00	24	46.15	11	47.83	17	42.50
Participant describes the importance of complying with treatment/management in maintaining their general health	21	20.59	11	22.00	10	19.23	5	21.74	8	20.00
Participant describes the importance of understanding their limitations in maintaining their general health	29	28.43	13	26.00	16	30.77	8	34.78	14	35.00
Participant describes the importance of maintaining a healthy diet in maintaining their general health	20	19.61	12	24.00	8	15.38	6	26.09	8	20.00
Participant describes the importance of socialising with friends and/or family in maintaining their general health	9	8.82	5	10.00	4	7.69	2	8.70	2	5.00
Participant describes the importance of maintaining a normal routine in maintaining their general health	7	6.86	7	14.00	0	0.00	3	13.04	0	0.00
Participant describes the importance of no activities to maintain their general health	13	12.75	5	10.00	8	15.38	2	8.70	7	17.50
Participant describes the importance of medication to manage symptoms/side effects in maintaining their general health	4	3.92	4	8.00	0	0.00	1	4.35	0	0.00
Participant describes the importance of vitamins and supplements in maintaining their general health	3	2.94	3	6.00	0	0.00	1	4.35	0	0.00

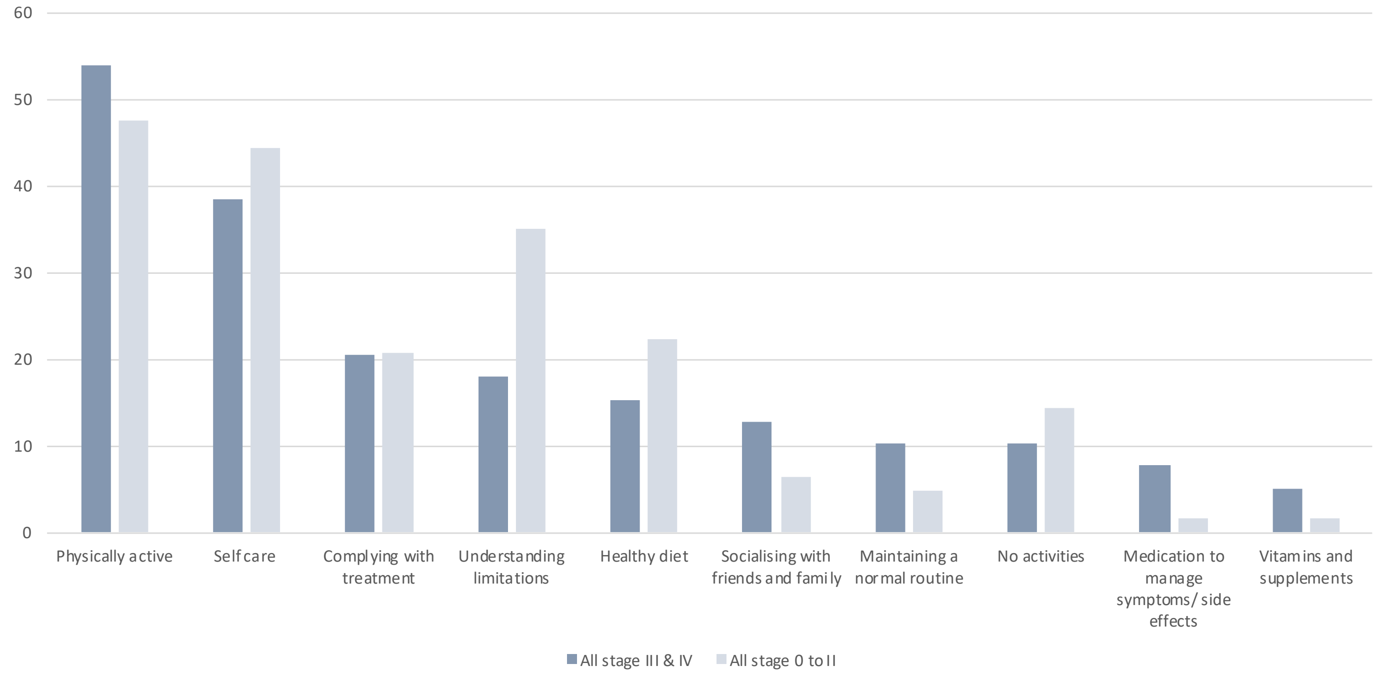


Figure 8.5: Regular activities to maintain health (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 8.9: Regular activities to maintain health – Stage III & IV variations

Regular activities to maintain health	Reported less frequently	Reported more frequently
Participant describes the importance of self care e.g. more rest, accepting help, pacing in maintaining their general health	Triple negative Stage III & IV	Hormone receptor Stage III & IV
Participant describes the importance of understanding their limitations in maintaining their general health	All Stage III & IV Hormone receptor Stage III & IV	-
Participant describes the importance of maintaining a healthy diet in maintaining their general health	Hormone receptor Stage III & IV	-

Experience of vulnerability: Stage III to IV

In the structured interview, participants were asked if there had been times that they felt vulnerable. The most common responses were that they felt vulnerable during/after treatments (41.03%), when having negative thoughts (uncertainty, loneliness, worries) (15.38%), and when feeling sick/unwell (15.38 %). Other themes included during diagnostic procedure (15.38%), because of interactions with the medical team (12.82%),when having sensitive discussion (diagnosis, treatment decision) (10.26%), and during surgical procedure (10.26%).

Participant describes feeling vulnerable during/after treatments

I think I felt pretty vulnerable that first day at the chemo unit. Just that day. Participant 044_2021AUHRP

Not really, I suppose. No, I don't think so. [chuckles] My attitude has always been like, things just need to happen because they need to happen to make me better. I've never gone-- Sorry. Probably the only time I've felt vulnerable, and I don't know if this is my right understanding of vulnerable, is when I had my port inserted because it was done under local anaesthetic. I think I cried more that day than I've cried the entire time with breast cancer combined. I really was just hoping to have it under general because I have a fear of needles and it for me, was probably, it was a lot worse than I thought it was going to be. The week after, it took me a really long time to adjust to having the port in. Six months later, by the time it was time to get it taken out. I didn't want it removed. I wanted to keep it. I'd have to say that was probably the worst day for me was the day we got the port inserted. I forgot. Sorry, going back as well, part of the reason why it was a terrible day was because I had really bad constipation and I had some fissures from chemo. I got anal fissures because of the constipation. I was dealing with all of that at the same time, which was probably not fun. I think it was just all of that *combined and they're being told it was happening under local, I was just-- I lost it. Which is fair enough. Like "You want to do what? You want me to be awake for this? What the heck. Just put me to sleep." Participant_025 TNG*

Participant describes feeling vulnerable when having negative thoughts (uncertainty, loneliness, worries)

I suppose a little bit, because you feels like it's all happening to you and you don't really have any control. I suppose there's a bit of vulnerability there and that you'll just need to put your life in the hands of these people who are telling you what to do, but you've only just met them, or guiding you as what to do. There is some vulnerability there. Also with the lack of knowledge and lack of understanding, that makes you quite vulnerable because I didn't have enough information to make decisions. I was floundering about, I guess, just trying to guess at what I should do next. That vulnerability, but I think as soon as I have knowledge and you can make some informed choices and informed decisions, that goes away. I feel in a much better place now to not challenge particularly, but at least to ask questions and to ask questions of my oncologist and the surgeon and say, "Is this the right thing? Do I need to do this? How about that?" and happy to have those conversations. Whereas to start with it felt very much, you just sit there and they tell you what it is that you need to do, and that does make me feel quite vulnerable. Participant_033 TNG

PARTICIPANT: Oh, yeah, I feel vulnerable quite often the fear.
INTERVIEWER: Is there a particular moment that comes to mind that you would like to share?
PARTICIPANT: It's when your family and friends don't understand and they don't you feel that? I don't want to understand that. But on that most vulnerable Participant_049 TNG

Participant describes feeling vulnerable when feeling sick/unwell

Yes, when I was going through chemo. I was not in a good space because I was so sick. As I said, I had to go and see the psychologist. Yes, I was in a particularly vulnerable space going through chemo. Participant_029 TNG

Yes, I must admit there was one time. It was the last week of radiation or the second last-- I was in the second last week of radiation treatment, and the nurse was really rude to me. It was the first time in the whole process, someone had ever just not been sensitive. She started to tell me off about taking Panadol and not managing my pain appropriately and I don't know this. It was the only time, and I had 10 months of going in and out of hospitals and that sort of stuff, it was this one single time I can say I didn't like it. Yes, this was the only time I can think of. Participant_047 TNG

Participant describes feeling vulnerable because of interactions with the medical team

Friends taking advantage of me money-wise, that sort of things. I thought of something else, but now I can't remember. I have actually felt quite vulnerable and taken advantage of a few times, even with medical professionals, but I'm actually pretty good at putting my foot down and saying, "I'm not putting up with this." Definitely, I have been vulnerable, and I had been taken advantage of. It's been quite hurtful Participant_028 TNG

Yes, I must admit there was one time. It was the last week of radiation or the second last-- I was in the second last week of radiation treatment, and the nurse was really rude to me. It was the first time in the whole process, someone had ever just not been sensitive. She started to tell me off about taking Panadol and not managing my pain appropriately and I don't know this. It was the only time, and I had 10 months of going in and out of hospitals and that sort of stuff, it was this one single time I can say I didn't like it. Yes, this was the only time I can think of. Participant_047 TNG

Participant describes feeling vulnerable when having sensitive discussion (diagnosis, treatment decision)

Yeah, I think after I had the biopsy and I didn't know what it was, I found those days between the Friday and that Tuesday when I got my diagnosis. That was pretty scary. And even after the diagnosis, I think all of that time up until I had the surgery and they removed the tissue and told me that there was no cancer cells. And, you know, I think that you're vulnerable right up until then. It's a very scary time. Yes. Yes. Participant_038 TNG

Yes. Obviously, right at the start of diagnosis I was petrified, and not knowing at that stage that there *can be good treatment options for triple-negative. Everything that you first look online, is it's the worst cancer to get. Everything's doom and gloom and then you sort of delve into it and go, well actually, no, just the recurrence rate is high, but if you get to this point, you're actually in a better position than some of the hormone receptor cancers. That was quite scary. I guess recurrence always plays on your mind with triple-negative, so that makes you quite vulnerable. Participant_034 TNG*

Table 8.10: Experience of vulnerability

Experience of vulnerability	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes feeling vulnerable during/after treatments	39	38.24	23	36.51	16	41.03	13	48.15	3	25.00
Participant describes feeling vulnerable when having negative thoughts (uncertainty, loneliness, worries)	15	14.71	9	14.29	6	15.38	6	22.22	0	0.00
Participant describes feeling vulnerable when feeling sick/unwell	9	8.82	3	4.76	6	15.38	6	22.22	0	0.00
Participant describes feeling vulnerable during diagnostic procedure	19	18.63	13	20.63	6	15.38	0	0.00	6	50.00
Participant describes feeling vulnerable because of interactions with the medical team	15	14.71	10	15.87	5	12.82	3	11.11	2	16.67
Participant describes feeling vulnerable when having sensitive discussion (diagnosis, treatment decision)	14	13.73	10	15.87	4	10.26	4	14.81	0	0.00
Participant describes feeling vulnerable during surgical procedure	8	7.84	4	6.35	4	10.26	0	0.00	4	33.33
Participant describes that they did not feel vulnerable	9	8.82	7	11.11	2	5.13	2	7.41	0	0.00
Participant describes feeling vulnerable when unaware of what is happening/lack information	3	2.94	1	1.59	2	5.13	2	7.41	0	0.00
Participant describes feeling vulnerable because of financial worries	2	1.96	0	0.00	2	5.13	2	7.41	0	0.00
Participant describes feeling vulnerable because of physical changes	2	1.96	1	1.59	1	2.56	1	3.70	0	0.00
Participant describes feeling vulnerable all the time	2	1.96	1	1.59	1	2.56	1	3.70	0	0.00
Participant describes feeling vulnerable felt vulnerable: no specifics	1	0.98	0	0.00	1	2.56	1	3.70	0	0.00

Experience of vulnerability	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes feeling vulnerable during/after treatments	39	38.24	20	40.00	19	36.54	7	30.43	16	40.00
Participant describes feeling vulnerable when having negative thoughts (uncertainty, loneliness, worries)	15	14.71	15	30.00	0	0.00	9	39.13	0	0.00
Participant describes feeling vulnerable when feeling sick/unwell	9	8.82	9	18.00	0	0.00	3	13.04	0	0.00
Participant describes feeling vulnerable during diagnostic procedure	19	18.63	0	0.00	19	36.54	0	0.00	13	32.50
Participant describes feeling vulnerable because of interactions with the medical team	15	14.71	4	8.00	11	21.15	1	4.35	9	22.50
Participant describes feeling vulnerable when having sensitive discussion (diagnosis, treatment decision)	14	13.73	14	28.00	0	0.00	10	43.48	0	0.00
Participant describes feeling vulnerable during surgical procedure	8	7.84	0	0.00	8	15.38	0	0.00	4	10.00
Participant describes that they did not feel vulnerable	9	8.82	4	8.00	5	9.62	2	8.70	5	12.50
Participant describes feeling vulnerable when unaware of what is happening/lack information	3	2.94	3	6.00	0	0.00	1	4.35	0	0.00
Participant describes feeling vulnerable because of financial worries	2	1.96	2	4.00	0	0.00	0	0.00	0	0.00
Participant describes feeling vulnerable because of physical changes	2	1.96	2	4.00	0	0.00	1	4.35	0	0.00
Participant describes feeling vulnerable all the time	2	1.96	2	4.00	0	0.00	1	4.35	0	0.00
Participant describes feeling vulnerable felt vulnerable: no specifics	1	0.98	1	2.00	0	0.00	0	0.00	0	0.00

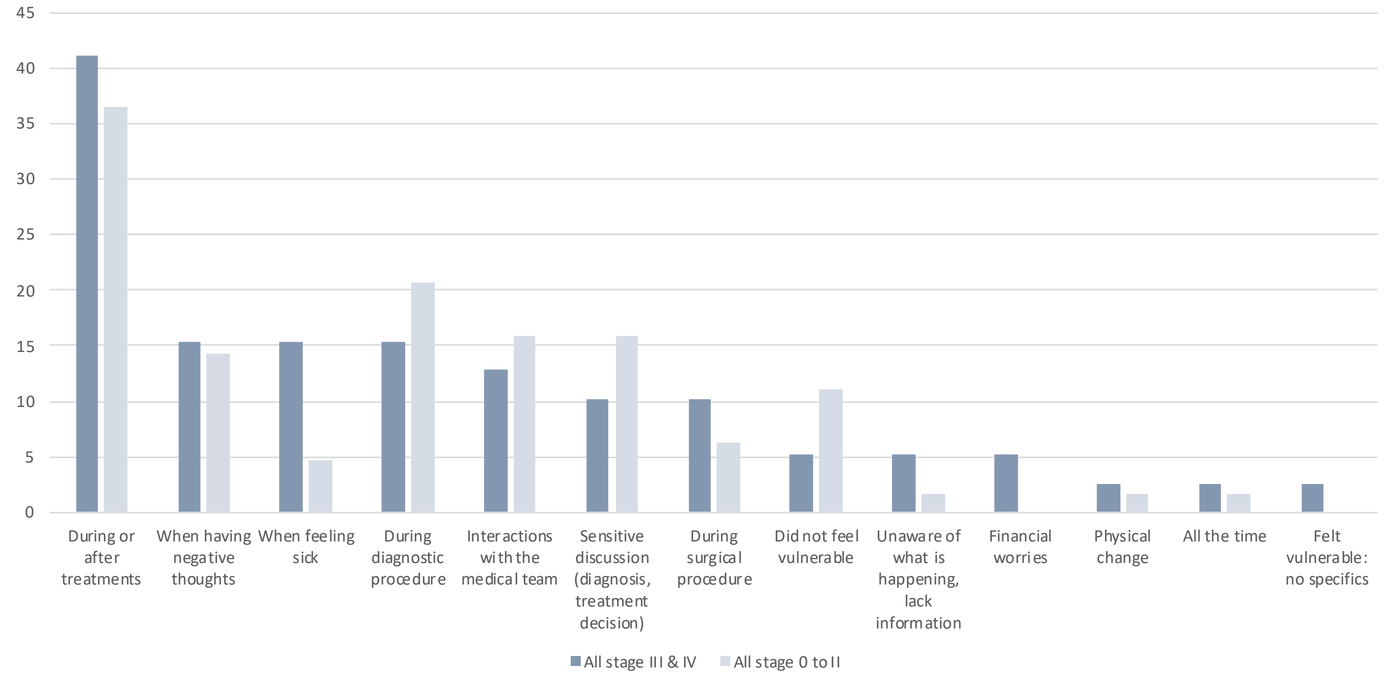


Figure 8.6: Experience of vulnerability (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 8.11: Experience of vulnerability – Stage III & IV variations

Experience of vulnerability	Reported less frequently	Reported more frequently
Participant describes feeling vulnerable during/after treatments	Hormone receptor Stage III & IV	-
Participant describes feeling vulnerable when having negative thoughts (uncertainty, loneliness, worries)	Hormone receptor Stage III & IV	-
Participant describes feeling vulnerable when feeling sick/unwell		Triple negative Stage III & IV
Participant describes feeling vulnerable during diagnostic procedure	Triple negative Stage III & IV	Hormone receptor Stage III & IV
Participant describes feeling vulnerable when having sensitive discussion (diagnosis, treatment decision)	Hormone receptor Stage III & IV	-
Participant describes feeling vulnerable during surgical procedure	-	Hormone receptor Stage III & IV

Methods to manage vulnerability: Stage III to IV

In the structured interview, participants described ways that they managed feelings of vulnerability. The most common ways to manage vulnerability were using self-help methods (resilience, acceptance, staying positive) (28.21%), and support from nurse or treatment team (20.51%). Other themes included adapting (e.g, more proactive, assertive, put boundaries) to manage the feeling of vulnerability (7.69%), and getting support from family and friends (7.69%).

Participant describes using self-help methods (resilience, acceptance, staying positive) to manage the feeling of vulnerability

I think everything was out of my hands, but I just had to do what I had to do, and keeping a positive attitude as much as I could helped me through it. It was like, okay, this has happened. We're going to deal with it and get on with life. You just had to push it away and do that. Participant_046

Aside from trying to schedule the appointments as close as I to each other? There's always a couple of days in between and just, I guess making sure that I tell my family that I'm anxious and I'm stressed and basically leave me alone until I get the results. I don't know. I haven't mentioned, I should have mentioned earlier when you were talking about complimentary things. I've been doing a lot of yoga, and I find that incredibly helpful. At those times when I'm feeling really anxious, the yoga is particularly good. It helps settle, helps me settle, and refocus. Participant_050

Participant describes support from nurse or treatment team to manage the feeling of vulnerability

I was because the nurses could see how nervous I was and they did take the time to explain the whole process to me, and then to explain how I might feel the next day and what I could do to alleviate that. The nurses in the day Ward area we're fabulous. Participant_027

I think more interaction with the medical staff would have helped, but I can't ever see that happening. Participant_029

It was funny, I spoke to one of the nurses when I was doing that. Nurses outside are not the same, but they're not the radiation therapists that you work with. I spoke to them, told them how bad she made me feel in terms of that sort of stuff, and they were great. The head of the center came and grabbed me, he said, "PARTICIPANT, I heard about yesterday, this is not all right. I want to talk to you." They made me not feel vulnerable as a result of that if you know what I mean? Participant_047

Participant describes adapting (e.g, more proactive, assertive, put boundaries) to manage the feeling of vulnerability

Oh, no, I stood up. I said something. The surgeon who was coming in to put it in, walked in with gloves on, rubber gloves, and I said to him, "Oh, can you change your gloves?" because what have you been doing? It was full COVID situation at that stage as well. Everyone that came into the room came in with no gloves and then put gloves on, but he walked in, opened the door with his hand, and then he was supposed to be cutting open my breasts and putting something in. He's like, "Well, I haven't touched anything." and I said, "I don't know that." I made him change his gloves. That's why I reckon I got such a badly bruised breast because he was very aggressive when he put it in. I did put in a report about him because I wasn't happy. That was the only time. I've had the best, best experiences. I can't fault any *practitioner or staff member or receptionist, everyone has been amazing. Participant_045*

Aside from trying to schedule the appointments as close as I to each other? There's always a couple of days in between and just, I guess making sure that I tell my family that I'm anxious and I'm stressed and basically leave me alone until I get the results. I don't know. I haven't mentioned, I should have mentioned earlier when you were talking about complimentary things. I've been doing a lot of yoga, and I find that incredibly helpful. At those times when I'm feeling really anxious, the yoga is particularly good. It helps settle, helps me settle, and refocus. Participant_050

Participant describes getting support from family and friends to manage the feeling of vulnerability

I did try to address certain things. Basically, with those finances because I didn't work for 18 months, so I was lucky that I could work from home with my job. Obviously, it wasn't every day so you only get paid for the hours that you do. I did have friends and neighbors at the time, not so much family. I really only had my resources that were in my current area, I guess. Participant_024

I felt like it was out of my control. I was really lucky that my husband was there and then a friend there who is a nurse that was there and he actually worked in the hospital and he actually stepped in and took my blood for me. Otherwise, I don't, yes. Participant_043

Table 8.12: Methods to manage vulnerability

Methods to manage vulnerability	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes using self-help methods (resilience, acceptance, staying positive) to manage the feeling of vulnerability	23	22.55	12	19.05	11	28.21	4	14.81	7	58.33
Participant describes support from nurse or treatment team to manage the feeling of vulnerability	19	18.63	11	17.46	8	20.51	5	18.52	3	25.00
Participant describes adapting (e.g, more proactive, assertive, put boundaries) to manage the feeling of vulnerability	6	5.88	3	4.76	3	7.69	3	11.11	0	0.00
Participant describes getting support from family and friends to manage the feeling of vulnerability	13	12.75	10	15.87	3	7.69	2	7.41	1	8.33
Participant describes no methods to manage vulnerability	8	7.84	6	9.52	2	5.13	2	7.41	0	0.00
Participant describes support from mental health professionals to manage the feeling of vulnerability	2	1.96	0	0.00	2	5.13	2	7.41	0	0.00
Participant describes getting informed to manage the feeling of vulnerability	4	3.92	3	4.76	1	2.56	1	3.70	0	0.00

Methods to manage vulnerability	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes using self-help methods (resilience, acceptance, staying positive) to manage the feeling of vulnerability	23	22.55	7	14.00	16	30.77	3	13.04	9	22.50
Participant describes support from nurse or treatment team to manage the feeling of vulnerability	19	18.63	9	18.00	10	19.23	4	17.39	7	17.50
Participant describes adapting (e.g, more proactive, assertive, put boundaries) to manage the feeling of vulnerability	6	5.88	6	12.00	0	0.00	3	13.04	0	0.00
Participant describes getting support from family and friends to manage the feeling of vulnerability	13	12.75	5	10.00	8	15.38	3	13.04	7	17.50
Participant describes no methods to manage vulnerability	8	7.84	3	6.00	5	9.62	1	4.35	5	12.50
Participant describes support from mental health professionals to manage the feeling of vulnerability	2	1.96	2	4.00	0	0.00	0	0.00	0	0.00
Participant describes getting informed to manage the feeling of vulnerability	4	3.92	4	8.00	0	0.00	3	13.04	0	0.00

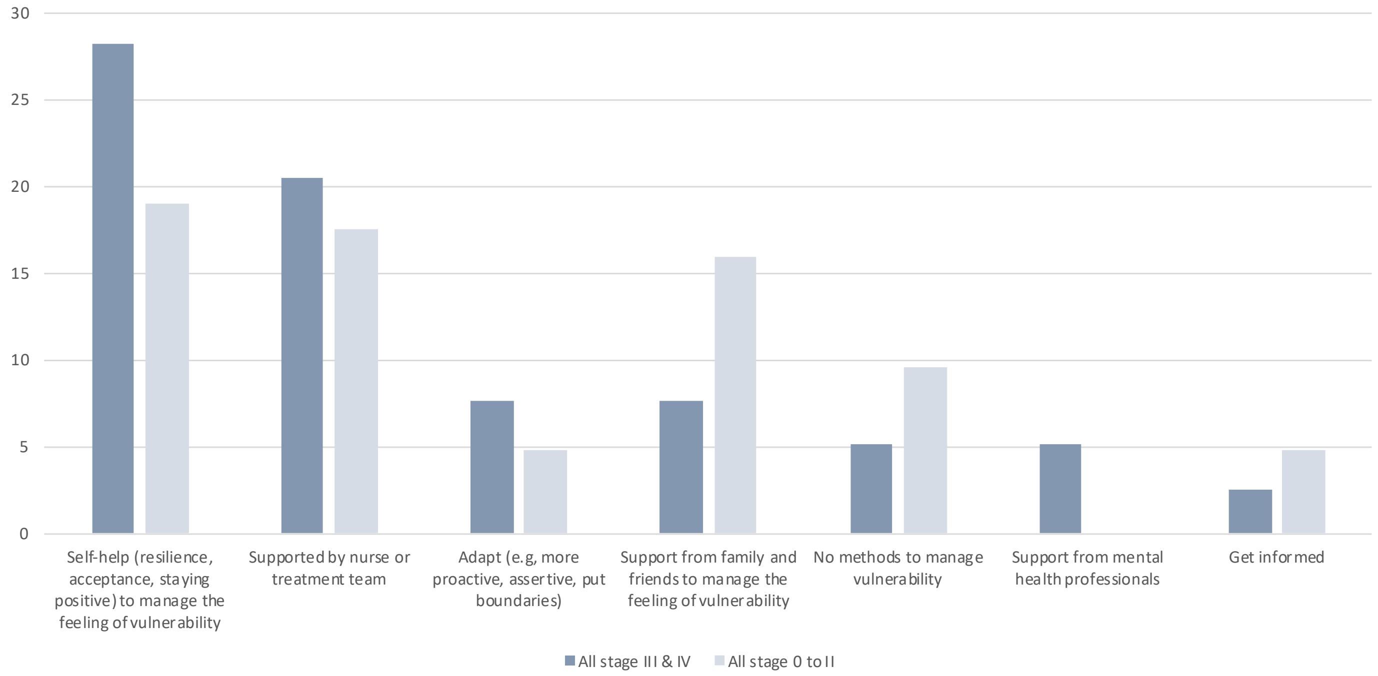


Figure 8.7: Methods to manage vulnerability (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 8.13: Methods to manage vulnerability – Stage III & IV variations

Methods to manage vulnerability	Reported less frequently	Reported more frequently
Participant describes using self-help methods (resilience, acceptance, staying positive) to manage the feeling of vulnerability	-	Hormone receptor Stage III & IV

Impact on relationships: Stage III to IV

Most commonly, the descriptions suggested that overall, there was an impact on relationships that was both positive and negative (33.33%), overall, there was a negative impact on relationships(28.21%), and overall, there no impact on relationships (17.95 %). Other themes included overall, there was a positive impact on relationships (10.26%), and overall, there was an impact on relationships that was neither positive nor negative (5.13%).

The most common themes in relation to having a positive impact on relationships from family relationships being strengthened (12.82%), and from people being well-meaning and supportive (7.69%).

The most common themes in relation to having a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships (28.21%), and from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition (5.13%).

Participant described a mixed impact on relationships, some strengthened, others disappeared

Some friends yes. We're no longer friends because they decided to make it all about them and share my story on social media, and talk about how it was affecting them. Yes, I've definitely moved on from some friendships, but my family, it's brought us closer. My mum, especially, weirdly, at first she was like, "Oh, you'll be alright; you'll get through this." and I think she realized how serious it was. She's just been really good and doing checks every day, whereas she never used to do any of that. My dad and I both got diagnosed cancer on the same day. Unfortunately, he was at the end of his journey. He passed in March this year. Participant_045

It's starting to sound a bit awful but you know who your real friends are, you know who your family members are. The people that weren't there at the time, I think we just don't talk to them anymore. Participant_024

So much, yes. I've become a lot close to my husband, which is great for family. Just emotional support and the physical and beautiful. [unintelligible] that part so much. I have become more close to my mother- in-law as well, because we have to rely on them with the kids. By the same token, some relationships have ceased to exist because some of my girlfriends can't have me being sick because I scare them. Participant_042

Participant describes a positive impact on relationships from family relationships being strengthened

Yeah, I think I think that it has more. In a positive way, I feel like I've got everyone just surrounded me when I was diagnosed and you like that, I guess I've got stronger relationships with, you know, a few of my friends because of it. Participant_038

I guess, yes, I've said earlier that it makes you focus on the things that are important. I think focusing on the relationships that are important and looking at whether when you have restrictions to your energy, the things that you do do have to be important and good things. There's no place to deal with toxic sorts of relationships. I had realized that, yes there were a couple that weren't serving me any good in the mix, so they're no longer in the mix. Participant_050

I've lost friends. I have strained relationships with family because of the way they've treated me during treatment, but then it's strengthened my relationship with my husband to like a real depth. I found out who true friends are. Participant 043_2021AUHRP

Participant describes a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships

With friends certainly, yes. I have lost a lot of friends when I was first diagnosed. Through no fault of my own, I've had people send me emails saying, "We can't handle being around you while you're sick, so you won't be seeing us while you're going through this." Another woman downstairs in our foyer, told me when I lost my hair that it offended her seeing me bald. That I wouldn't be seeing her. I felt like, yes, I have lost a few friends because of it but [unintelligible] yet and they won't [unintelligible]. Participant_032

Yes, it has. You have friends come out of the woodwork that you hadn't spoken to for ages, and then you have friends that you thought were very close friends that don't come near you. I think they think it's catching or they don't know what to say or don't know how to feel, what to feel or do around you. Participant_046

Table 8.14: Impact on relationships

Impact on relationships	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes that overall, there was an impact on relationships that was both positive and negative	32	31.37	19	30.16	13	33.33	10	37.04	3	25.00
Participant describes that overall, there was a negative impact on relationships	20	19.61	9	14.29	11	28.21	7	25.93	4	33.33
Participant describes that overall, there no impact on relationships	21	20.59	14	22.22	7	17.95	4	14.81	3	25.00
Participant describes that overall, there was a positive impact on relationships	19	18.63	15	23.81	4	10.26	3	11.11	1	8.33
Participant describes that overall, there was an impact on relationships that was neither positive nor negative	5	4.90	3	4.76	2	5.13	1	3.70	1	8.33
Participant gives a description suggesting that overall there is an impact on quality of life, but does not describe the impact	3	2.94	3	4.76	0	0.00	0	0.00	0	0.00

Impact on relationships	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes that overall, there was an impact on relationships that was both positive and negative	32	31.37	19	38.00	13	25.00	9	39.13	10	25.00
Participant describes that overall, there was a negative impact on relationships	20	19.61	11	22.00	9	17.31	4	17.39	5	12.50
Participant describes that overall, there no impact on relationships	21	20.59	8	16.00	13	25.00	4	17.39	10	25.00
Participant describes that overall, there was a positive impact on relationships	19	18.63	7	14.00	12	23.08	4	17.39	11	27.50
Participant describes that overall, there was an impact on relationships that was neither positive nor negative	5	4.90	3	6.00	2	3.85	2	8.70	1	2.50
Participant gives a description suggesting that overall there is an impact on quality of life, but does not describe the impact	3	2.94	0	0.00	3	5.77	0	0.00	3	7.50
Other	2	1.96	2	4.00	0	0.00	0	0.00	0	0.00

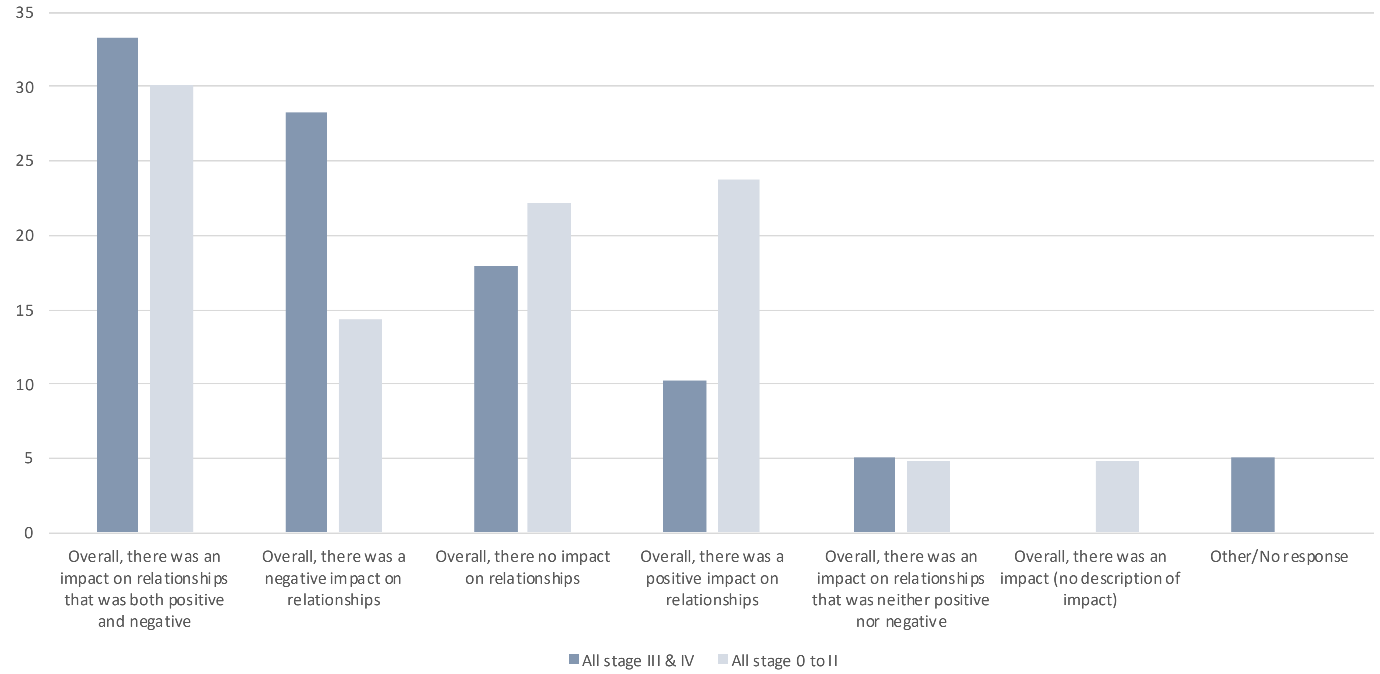


Figure 8.8: Impact on relationships (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 8.15: Impact on relationships – Stage III & IV variations

Impact on relationships	Reported less frequently	Reported more frequently
Participant describes that overall, there was a negative impact on relationships	-	Hormone receptor Stage III & IV
Participant describes that overall, there was a positive impact on relationships	Hormone receptor Stage III & IV	-

Table 8.16: Impact on relationships (Reason for impact)

Reasons for impact on relationships	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships	24	23.53	13	20.63	11	28.21	7	25.93	4	33.33
Participant described a mixed impact on relationships, some strengthened, others disappeared	14	13.73	8	12.70	6	15.38	6	22.22	0	0.00
Participant describes a positive impact on relationships from family relationships being strengthened	17	16.67	12	19.05	5	12.82	4	14.81	1	8.33
Participant describes a positive impact on relationships from people being well-meaning and supportive	11	10.78	8	12.70	3	7.69	0	0.00	3	25.00
Participant describes a negative impact on relationships from the dynamics of relationships chaning due to anxiety, exacerbations and/or physical limitations of condition	10	9.80	8	12.70	2	5.13	1	3.70	1	8.33
Participant describes a negative impact on relationships (general, no specifics articulated)	3	2.94	1	1.59	2	5.13	0	0.00	2	16.67
Participant describes a positive impact on relationships (general, no specifics articulated)	9	8.82	8	12.70	1	2.56	0	0.00	1	8.33

Reasons for impact on relationships	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships	24	23.53	8	16.00	16	30.77	1	4.35	12	30.00
Participant described a mixed impact on relationships, some strengthened, others disappeared	14	13.73	14	28.00	0	0.00	8	34.78	0	0.00
Participant describes a positive impact on relationships from family relationships being strengthened	17	16.67	7	14.00	10	19.23	3	13.04	9	22.50
Participant describes a positive impact on relationships from people being well-meaning and supportive	11	10.78	0	0.00	11	21.15	0	0.00	8	20.00
Participant describes a negative impact on relationships from the dynamics of relationships chaning due to anxiety, exacerbations and/or physical limitations of condition	10	9.80	6	12.00	4	7.69	5	21.74	3	7.50
Participant describes a negative impact on relationships (general, no specifics articulated)	3	2.94	0	0.00	3	5.77	0	0.00	1	2.50
Participant describes a positive impact on relationships (general, no specifics articulated)	9	8.82	1	2.00	8	15.38	1	4.35	7	17.50

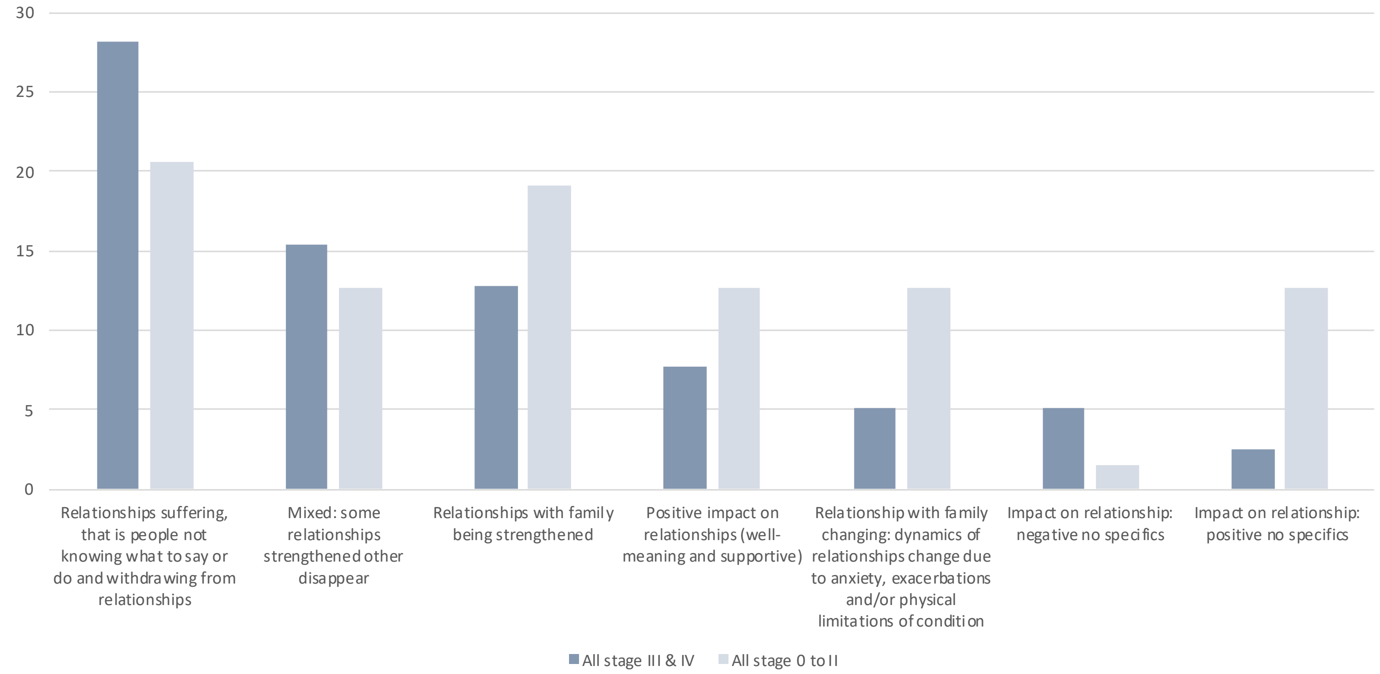


Figure 8.9: Impact on relationships (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 8.17: Impact on relationships: Reason for impact – Stage III & IV variations

Reasons for impact on relationships	Reported less frequently	Reported more frequently
Participant describes a positive impact on relationships from people being well-meaning and supportive	Triple negative Stage III & IV	Hormone receptor Stage III & IV
Participant describes a negative impact on relationships (general, no specifics articulated)		Hormone receptor Stage III & IV

Burden on family: Stage III to IV

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Most commonly, the descriptions suggested that overall, there was a burden on their family (58.97%), and overall, there was not a burden on their family (35.90%).

The main reasons that participant described their condition being a burden were the extra household duties and responsibilities that their family must take on (15.38%), the mental/emotional strain placed on their family(7.69%), and the extra assistance needed getting to appointments (7.69 %). Other themes included the extra financial assistance needed (5.13%), and that the burden on family was temporary or only during treatment (7.69%).

The main reason that participant described their condition not being a burden were that they were independent and did not need any help from family (15.38%).

Participant describes the extra household duties and responsibilities that their family must take on as a burden on their family

Oh, absolutely. My kids are just like-- It's quite funny. Because your kids somehow-- Like my kids at the time, they're 21 and 24 now, two years ago is 19, 22, there had to take on parenting, looking after things and driving me around, and that happened for a while afterwards. Memory-wise, you're not that good so they'd have to correct you, they'd go, "Mum, that's not right. You missed this," or, "we've forgotten that." They'd go, "Mum, mum, you can't do that," it's funny, they're definitely taken on a parent-- when they're older, they should take on a parenting role. I guess, other people in the family that you thought would be closer to help you do things, just didn't do any respite for the kids or for my husband. It's a quite funny thing that you look back on. Participant_047

I think probably more on my husband, because I'm going to do more stuff with the kids because I am able to do the physical stuff, because I'm always very active in sports. So those things he does more and that I *probably do less. And. The house is in this tidy, is what it used to be, that he probably doesn't do more, just do it when I can, not feeling well, I get up and stuff and when I'm done, then it just doesn't get them here. Participant_038*

Participant describes the mental/emotional strain placed on their family as a burden on their family

It was when I was going through my treatment, I felt like I was a burden. But they seem to think that they would happy. But I didn't want my kids to emotionally deal with them. I'm sick. And all that sort of stuff to me was the bit that the thought of us, which Participant_044

Well, within our little family, yes, extended family, no, and they do all still feel a bit more. Yeah, as soon as yeah. As they look at me and they can see the way I'm looking and see what's wrong. I do worry a bit more. And trying to find out what's going on. Are you alright and. Yeah they do. Yeah they do see quicker than anyone else if that there's something not right. Participant_031

Participant describes the extra assistance needed getting to appointments as a burden on their family

Yes. I think that-- I don't know. You sort of feel like you're a burden or you get made to feel like you're a burden because there's so many treatments or appointments to get to and whatever else it's like, "Oh, there's your cancer getting in the way again?" It's like, "Yes, well, I didn't ask for it." Participant_034

Yes. I do. That's definitely been a lot that's put on my husband because he's been my care I suppose when I haven't been well, and then he comes to all my appointments with me so he's a second set of ears. Participant_043

Participant describes being independent and not a burden on their family

It hasn't been yet. I've been really happy about that because I've managed to maintain all of the things I was doing before, but I was initially really worried about that, that I don't want to be cared for. I don't want people having to do my housework and my cooking and thankfully, that hasn't happened. That was a huge concern. I think it would be again. I don't know how post-surgery, what happens. I assume I may need a little bit more help after that. I don't want that. Yes, I don't want that to burden them. Again, because I just don't want to be a patient. I want to be the matriarch of the family getting on and doing what I do. I don't like that. Participant_033

PARTICIPANT: No, because nobody's had to provide any for me. [chuckles]
INTERVIEWER: Yes, you're living by yourself. You've mentioned.
PARTICIPANT: Yes. Participant_041

Table 8.18: Burden on family

Burden on family	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes that overall, there was a burden on their family	56	54.90	33	52.38	23	58.97	16	59.26	7	58.33
Participant describes that overall, there was not a burden on their family	44	43.14	30	47.62	14	35.90	9	33.33	5	41.67
Other	2	1.96	0	0.00	2	5.13	2	7.41	0	0.00

Burden on family	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes that overall, there was a burden on their family	56	54.90	30	60.00	26	50.00	14	60.87	19	47.50
Participant describes that overall, there was not a burden on their family	44	43.14	18	36.00	26	50.00	9	39.13	21	52.50
Other	2	1.96	2	4.00	0	0.00	0	0.00	0	0.00

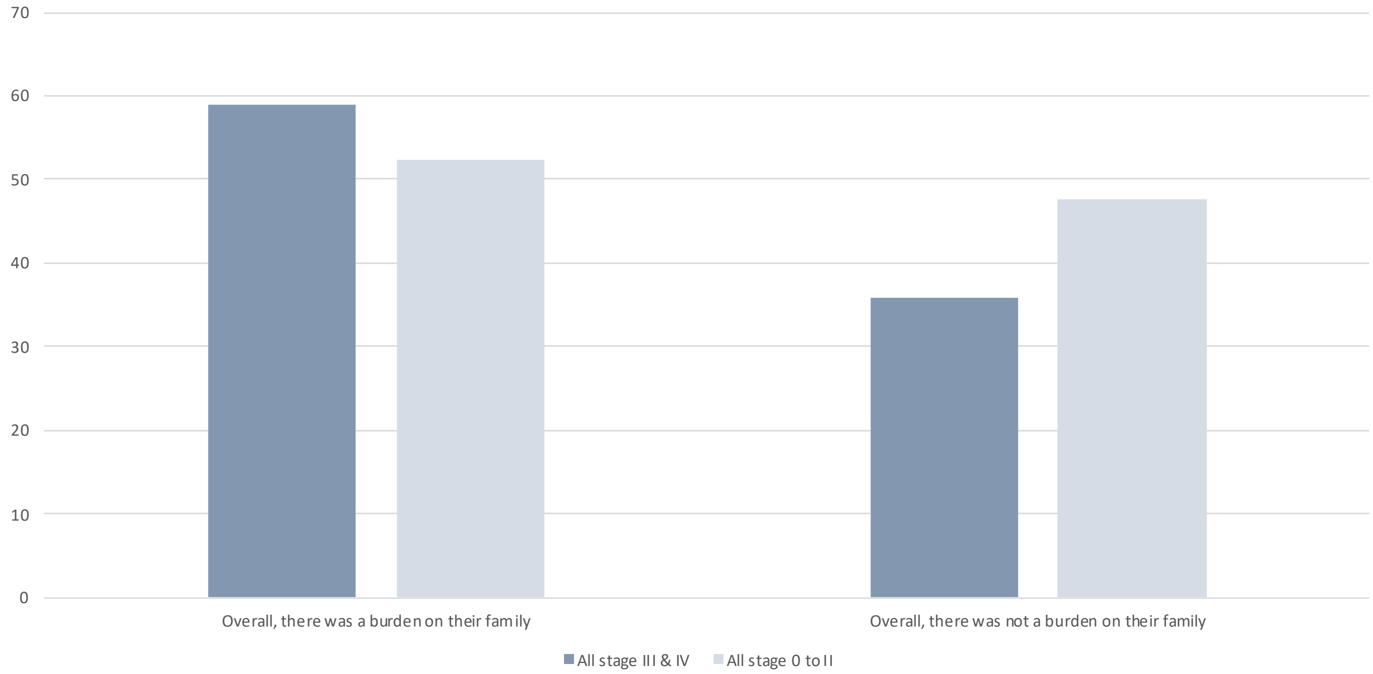


Figure 8.10: Burden on family (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 8.19: Burden on family (description)

Burden on family (description)	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes their condition being a burden in general (No specific examples) as a burden on their family	17	16.67	8	12.70	9	23.08	7	25.93	2	16.67
Participant describes the extra household duties and responsibilities that their family must take on as a burden on their family	24	23.53	18	28.57	6	15.38	3	11.11	3	25.00
Participant describes the mental/emotional strain placed on their family as a burden on their family	6	5.88	3	4.76	3	7.69	3	11.11	0	0.00
Participant describes the extra assistance needed getting to appointments as a burden on their family	4	3.92	1	1.59	3	7.69	3	11.11	0	0.00
Participant describes the extra financial assistance needed as a burden on their family	2	1.96	0	0.00	2	5.13	2	7.41	0	0.00
Participant describes that the burden on family was temporary or only during treatment	6	5.88	3	4.76	3	7.69	0	0.00	3	25.00
Participant describes their condition not being a burden in general (No specific examples) as a burden on their family	28	27.45	20	31.75	8	20.51	6	22.22	2	16.67
Participant describes being independent and not a burden on their family	15	14.71	9	14.29	6	15.38	3	11.11	3	25.00

Burden on family (description)	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes their condition being a burden in general (No specific examples) as a burden on their family	17	16.67	12	24.00	5	9.62	5	21.74	3	7.50
Participant describes the extra household duties and responsibilities that their family must take on as a burden on their family	24	23.53	10	20.00	14	26.92	7	30.43	11	27.50
Participant describes the mental/emotional strain placed on their family as a burden on their family	6	5.88	6	12.00	0	0.00	3	13.04	0	0.00
Participant describes the extra assistance needed getting to appointments as a burden on their family	4	3.92	4	8.00	0	0.00	1	4.35	0	0.00
Participant describes the extra financial assistance needed as a burden on their family	2	1.96	2	4.00	0	0.00	0	0.00	0	0.00
Participant describes that the burden on family was temporary or only during treatment	6	5.88	0	0.00	6	11.54	0	0.00	3	7.50
Participant describes their condition not being a burden in general (No specific examples) as a burden on their family	28	27.45	13	26.00	15	28.85	7	30.43	13	32.50
Participant describes being independent and not a burden on their family	15	14.71	5	10.00	10	19.23	2	8.70	7	17.50

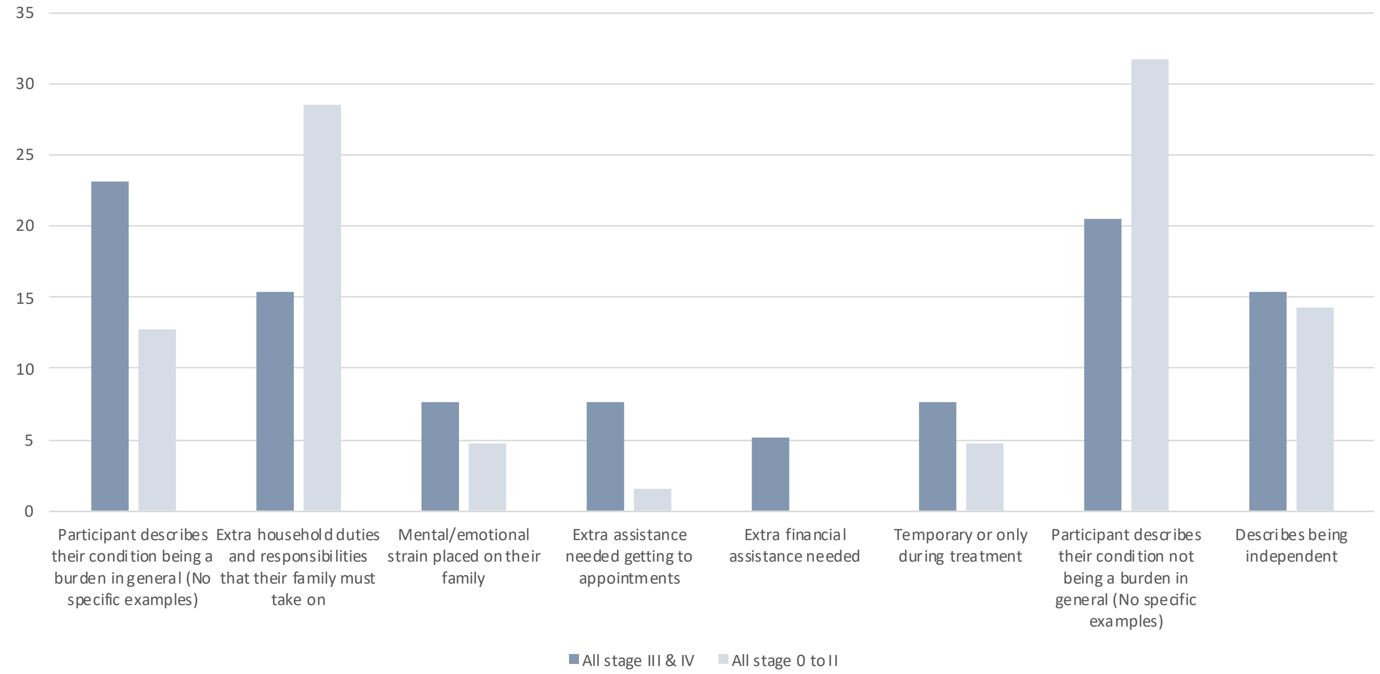


Figure 8.11: Burden on family (description) (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 8.20: Burden on family (description) – Stage III & IV variations

Burden on family (description)	Reported less frequently	Reported more frequently
Participant describes the extra household duties and responsibilities that their family must take on as a burden on their family	Triple negative Stage III & IV	
Participant describes that the burden on family was temporary or only during treatment		Hormone receptor Stage III & IV
Participant describes their condition not being a burden in general (No specific examples) as a burden on their family	Hormone receptor Stage III & IV	
Participant describes being independent and not a burden on their family		Hormone receptor Stage III & IV

Cost considerations: Stage III to IV

In the structured interview, participants were asked about any significant costs associated with having their condition. The most common descriptions were that overall, there was at least some cost burden (76.92%), and overall, there was no cost burden (15.38%).

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments (including repeat scripts) (56.41%), diagnostic tests and scans (38.46%), and needing to take time off work (25.64 %). Other themes included the cost specialist appointments (17.95%), private care (12.82%), allied health care (10.26%), the cost of parking and travel to attend appointments (including accommodation) (5.13%), and a family member needing to take time off work (5.13%).

Where participants described no cost burden associated with their condition, it was most commonly in relation to nearly everything was paid for through the public health system (7.69%), and nearly everything was paid for through the private health system (5.13%).

Cost burden in relation to the cost of treatments (including repeat scripts)

Well, for me, the biggest cost was the surgery. That nearly killed me on its own but other than that, I've really haven't had through the process of the actual treatment, I haven't had any out of profit. The only things that I've paid for would be when I went to see the physio or a massage. Participant_027

It's a huge financial burden. Particularly, we own our own business, so time off work, luckily for me wasn't an issue, but for others, it is. The medical bills aside. Yes. I'd say we probably spent close to $30,000. My surgery alone was $20,000, $21,000. and then ongoing pharmacy deals and medical -the follow-up physio bills and things that. Yes. It's significant. I don't

know how you would deal with it if you weren't as financially secure. You'd have to go into the public system I guess. I feel as though being a private patient, I didn't expect there to be so many additional costs. Participant_036

Cost burden in relation to diagnostic tests and scans

The costs have been a huge shock. Actually, I had no idea how much cost would be involved in a breast cancer diagnosis. It's been quite an eye-opener. It hasn't affected us too much financially. Luckily we're in a position that we can cope with that. I worry for people who can't, and it also makes me quite angry that we are so massively out of pocket. Things like all the testing, the PET scans, the mammograms, and they want to do them repeatedly, and then another scan and then there's this, and then there's that, and it's costing hundreds of dollars each time with minimal back from Medicare. Those costs are huge. My biggest annoyance with costs, I suppose, was not being asked at the beginning if I wanted to be a public or private patient, that was never mentioned, it was just assumed. Have you got a private health card? Yes, I do. Here you go. That means now that I've had to pay gap fees for the surgeon, and gap fees for the hospital, and additional fees that the person sitting next to me, who's in the public system isn't having to pay and is getting the same treatment. I find that that was a shock. The costs have been huge, obviously, I've given up work now for a short time just while I go through surgery. I don't know, I might work part-time after that. The loss of income has been obviously a challenge, and the costs continue to mount up. Each week there's something else. Participant_033

Yes, diagnosis, that cost us a lot of money. That was a real shock. When I went and had an ultrasound and a biopsy, I was not expecting to be told that it'll be $500. Me and my husband just about had a heart attack. [chuckles] We've had lots of costs on it. It's cost us money, we've had to travel. My husband had to take time off work. My medication, different medications that I've had to take. I'm trying to think what else, and just different tests. Even doctors, you get rebates back on some of them and some of them you don't. Every time I go see my oncologist, that costs money. Every time I see my surgeon, it costs money. Participant_043

I chose to go private with my surgery, so I had to pay for the hospital. I had to pay for the surgeon. I had to pay for the anesthetist. I had to pay for the assistance surgeon. There'd been substantial costs there. Not a lot in terms of medication. When I had to go back and- - I had to go back and have more mammograms, ultrasounds and core biopsies. I had to pay for that. I've had to pay for the one physiotherapy, the one that I found the physiotherapist. I've had to pay for her. Participant 047_2021AUHRP

Cost burden in relation to needing to take time off work

Yes, basically, time off work was one. Accessing income support was terrible. Bills, a few, like we've the scans and things that you've still got to go through, so the mammograms and all that you have to pay for afterwards, the ultrasounds. Pretty much all the regular testing. Medication, I didn't have any, so I was lucky there. Paying out for bills and things like that was probably my biggest one. Participant_024

Well, for the surgery, I was very lucky. I spoke to the specialist, and they did it all out-of-pocket on Gov Private Health fund, and there was going to be a large out-of-pocket, but I got that all covered. Scans are very expensive. All your PET scans and all that stuff, that's costly there. Radiation is a ridiculous cost, but I spoke to someone in my cancer support group here and they told me that I should be able to get it all bulk-billed and not have to pay, so I ended up not having to pay. That was going to be something like $10,000. That was hard. I got that. Well, I'm still on long-term sick leave since surgery, and I haven't felt that I'm ready to go back to work yet. I did try to go back a couple of months ago and I lasted a day and I had to come home and lie down. I couldn't even stand in the shower. I was physically and mentally exhausted. I have been off work for nearly 12 months. I had holidays and long service and everything like that, which took me until February, but I haven't been paid anything since then because I've got some money in the bank put away. I'm not entitled to any Centrelink payments or anything like that. Financially, yes, it's been really tough. There's no form of income. Yes, mentally, it's pretty tough on the family as well as yourself. [crosstalk] It has been [unintelligible] financially and mentally. Participant_046

Cost burden in relation to the cost specialist appointments

That's probably been one of the very challenging parts as well. My surgery is going to be $6,000 out of pocket. The specialists, the scans, every biopsy, and I had to go to emergency three times during chemo. One time when I called my oncologist, he was away and the one standing in for him suggested I went to a *private hospital. I didn't realize what financial implication that had until the bills came. Even though I have private health insurance, I still had $800 out of pocket for the pathology tests. It's cost thousands and thousands of thousands out of pocket, and I'm a single mother. I wasn't able to take time off. I've continued working almost full-time through this whole thing, and that's been horrendous. Thank God I'm working from home because a lot of days I work on the sofa, [chuckles] and I was fortunate that I had six weeks of leave that I'd saved up for holidays with my parents in Canada because otherwise, I wouldn't have had enough leave to get me through it. The financial side of it is terrible. Participant_041*

Yes, diagnosis, that cost us a lot of money. That was a real shock. When I went and had an ultrasound and a biopsy, I was not expecting to be told that it'll be $500. Me and my husband just about had a heart attack. [chuckles] We've had lots of costs on it. It's cost us money, we've had to travel. My husband had to take time off work. My medication, different medications that I've had to take. I'm trying to think what else, and just different tests. Even doctors, you get rebates back on some of them and some of them you don't. Every time I go see my oncologist, that costs money. Every time I see my surgeon, it costs money. Participant_043

I've had to pay for the respiratory physician. I've had to pay for scans and X-rays related to the respiratory physician. I guess the other cost in a sense is that I haven't been able to work. My income has been reduced. I'm on income protection. I do have that, but it has meant that my wage has decreased. Participant 047_2021AUHRP

Cost burden in relation to private care

While we were out on the farm, we were farming, we got a housekeeper in because we were busy on the farm and I had a child to look after. We paid for a housekeeper, a live-in housekeeper. Then, there was out-of- pocket costs because I went private for surgery and for chemotherapy therapy. Radiotherapy, there was no out-of- pocket because I went public. Then, there was the ongoing costs of the surveillance, like every time I had a mammogram and ultrasound. That was always out-of-pocket. Participant_037

I went privately and say, you know, there was a lot of gaps in everything, particularly the surgery. But yeah, so and I'm still not back at work yet. So that's obviously financially hard on us. And then, you know, it's quite frustrating because when if you go through the public system, you get all the physios, it's for free. And I asked if I could join that group and I said no, because you're a private patient. But just because I pay private health covid doesn't mean I'm rich and I can't afford all the other treatments, you know? So, yeah, that's been a bit frustrating. That's how I do it, because I want to get back to work and I have to get back to work, but I've just got to pay for it. You know that part. I have covered some of that. Participant_038

Cost burden in relation to allied health care

Well, for me, the biggest cost was the surgery. That nearly killed me on its own but other than that, I've really haven't had through the process of the actual treatment, I haven't had any out of profit. The only things that I've paid for would be when I went to see the physio or a massage. Participant_027

It's a huge financial burden. Particularly, we own our own business, so time off work, luckily for me wasn't an issue, but for others, it is. The medical bills aside. Yes. I'd say we probably spent close to $30,000. My surgery alone was $20,000, $21,000. and then ongoing pharmacy deals and medical - the follow-up physio bills and things that. Yes. It's significant. I don't know how you would deal with it if you weren't as financially secure. You'd have to go into the public system I guess. I feel as though being a private patient, I didn't expect there to be so many additional costs. Participant_036

I went privately and say, you know, there was a lot of gaps in everything, particularly the surgery. But yeah, so and I'm still not back at work yet. So that's obviously financially hard on us. And then, you know, it's quite frustrating because when if you go through the public system, you get all the physios, it's for free. And I asked if I could join that group and I said no, because you're a private patient. But just because I pay private health covid doesn't mean I'm rich and I can't afford all the other treatments, you know? So, yeah, that's been a bit frustrating. That's how I do it, because I want to get back to work and I have to get back to work, but I've just got to pay for it. You know that part. I have covered some of that. Participant_038

Table 8.21: Cost considerations

Cost considerations	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes that overall, there was at least some cost burden	84	82.35	54	85.71	30	76.92	**19**	**70.37**	11	91.67
Participant describes that overall, there was no cost burden	15	14.71	9	14.29	6	15.38	5	18.52	1	8.33
Other/No response	2	1.96	0	0.00	2	5.13	2	7.41	0	0.00

Cost considerations	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes that overall, there was at least some cost burden	84	82.35	**36**	**72.00**	48	92.31	17	73.91	**37**	**92.50**
Participant describes that overall, there was no cost burden	15	14.71	11	22.00	4	7.69	**6**	**26.09**	3	7.50
Other/No response	2	1.96	2	4.00	0	0.00	0	0.00	0	0.00

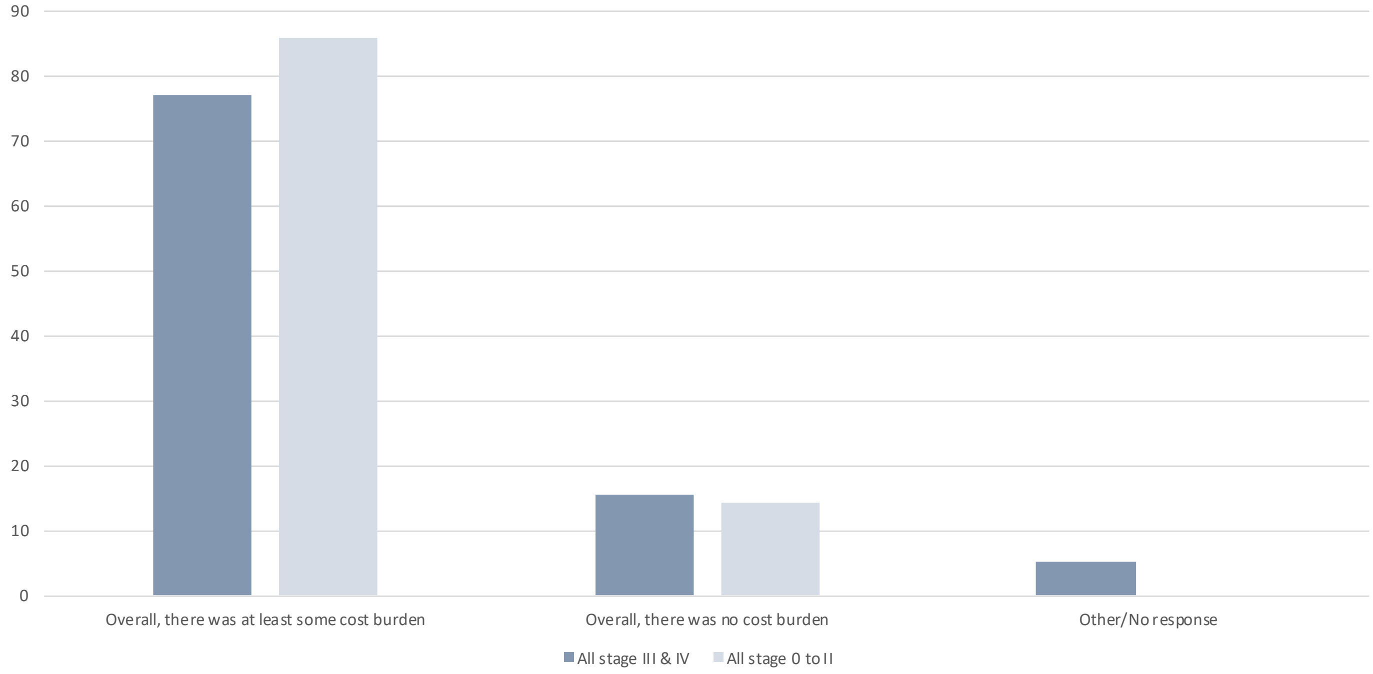


Figure 8.12: Cost considerations (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 8.22: Cost considerations – Stage III & IV variations

Cost considerations	Reported less frequently	Reported more frequently
Participant describes that overall, there was at least some cost burden	Triple negative Stage III & IV	-

Table 8.23: Cost considerations (Reasons for cost)

Cost considerations (Reasons for cost)	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Cost burden in relation to the cost of treatments (including repeat scripts)	68	66.67	46	73.02	**22**	**56.41**	**12**	**44.44**	**10**	**83.33**
Cost burden in relation to diagnostic tests and scans	35	34.31	20	31.75	15	38.46	10	37.04	5	
Cost burden in relation to needing to take time off work	33	32.35	23	36.51	10	25.64	**5**	**18.52**	5	41.67
Cost burden in relation to the cost specialist appointments	26	25.49	19	30.16	7	17.95	**3**	**11.11**	4	41.67
Cost burden in relation to private care	7	6.86	2	3.17	5	12.82	**5**	**18.52**	0	33.33
Cost burden in relation to allied health care	6	5.88	2	3.17	4	10.26	4	14.81	0	0.00
Cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	11	10.78	9	14.29	2	5.13	2	7.41	**0**	0.00
Cost burden in relation to a family member needing to take time off work	9	8.82	7	11.11	2	5.13	1	3.70	1	**0.00**
No cost burden and that nearly everything was paid for through the public health system	13	12.75	10	15.87	3	7.69	1	3.70	2	8.33
No cost burden and that nearly everything was paid for through the private health system	3	2.94	1	1.59	2	5.13	2	7.41	0	16.67
No cost burden no specific reason given	2	1.96	0	0.00	2	5.13	2	7.41	0	0.00

Cost considerations (Reasons for cost)	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Cost burden in relation to the cost of treatments (including repeat scripts)	68	66.67	**25**	**50.00**	**43**	**82.69**	**13**	**56.52**	**33**	**82.50**
Cost burden in relation to diagnostic tests and scans	35	34.31	15	30.00	20	38.46	**5**	**21.74**	15	37.50
Cost burden in relation to needing to take time off work	33	32.35	**9**	**18.00**	**24**	**46.15**	**4**	**17.39**	**19**	**47.50**
Cost burden in relation to the cost specialist appointments	26	25.49	**6**	**12.00**	**20**	**38.46**	**3**	**13.04**	**16**	**40.00**
Cost burden in relation to private care	7	6.86	7	14.00	0	0.00	2	8.70	0	0.00
Cost burden in relation to allied health care	6	5.88	6	12.00	0	0.00	2	8.70	0	0.00
Cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	11	10.78	6	12.00	5	9.62	4	17.39	5	12.50
Cost burden in relation to a family member needing to take time off work	9	8.82	2	4.00	7	13.46	1	4.35	6	15.00
No cost burden and that nearly everything was paid for through the public health system	13	12.75	6	12.00	7	13.46	5	21.74	5	12.50
No cost burden and that nearly everything was paid for through the private health system	3	2.94	3	6.00	0	0.00	1	4.35	0	0.00
No cost burden no specific reason given	2	1.96	2	4.00	0	0.00	0	0.00	0	0.00

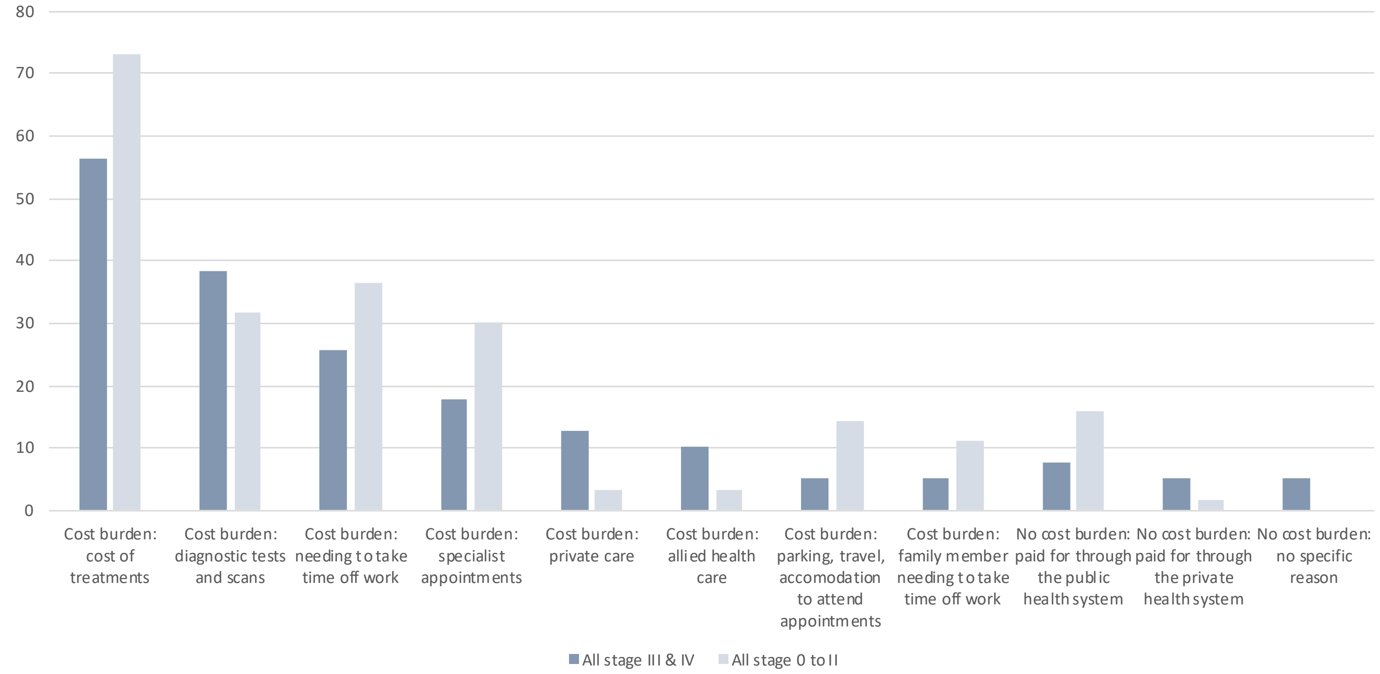


Figure 8.13: Cost considerations (Reasons for cost) (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 8.24: Cost considerations (Reasons for cost) – Stage III & IV variations

Cost considerations (Reasons for cost)	Reported less frequently	Reported more frequently
Cost burden in relation to the cost of treatments (including repeat scripts)	All Stage III & IV Triple negative Stage III & IV	Hormone receptor Stage III & IV Triple negative Stage 0 to II
Cost burden in relation to needing to take time off work	Triple negative Stage III & IV	
Cost burden in relation to the cost specialist appointments	Triple negative Stage III & IV	-
Cost burden in relation to private care	-	Triple negative Stage III & IV
Cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	Hormone receptor Stage III & IV	-

Overall impact of condition on quality of life: Stage III to IV

In the online questionnaire, participants were asked to rate the overall impact their condition on quality of life. 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. The average score was in the Life was a little distressing range (median = 3.00) .

Table 8.25: Overall impact of condition on quality of life

Overall impact of condition on quality of life	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=95	%	n=59	%	n=36	%	n=24	%	n=12	%
1 Life is/was very distressing	9	9.47	6	10.17	3	8.33	3	12.50		0.00
2 Life is/was distressing	17	17.89	9	15.25	8	22.22	3	12.50	5	41.67
3 Life is/was a little distressing	22	23.16	12	20.34	10	27.78	6	25.00	4	33.33
4 Life is/was average	14	14.74	12	20.34	2	5.56	1	4.17	1	8.33
5 Life is/was good	22	23.16	13	22.03	9	25.00	7	29.17	2	16.67
6 Life is/was very good	9	9.47	5	8.47	4	11.11	4	16.67	0	0.00
7 Life is/was great	2	2.11	2	3.39	0	0.00	0	0.00	0	0.00

Overall impact of condition on quality of life	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=95	%	n=44	%	n=51	%	n=20	%	n=39	%
1 Life is/was very distressing	9	9.47	6	13.64	3	5.88	3	15.00	3	7.69
2 Life is/was distressing	17	17.89	9	20.45	8	15.69	6	30.00	3	7.69
3 Life is/was a little distressing	22	23.16	9	20.45	13	25.49	3	15.00	9	23.08
4 Life is/was average	14	14.74	4	9.09	10	19.61	3	15.00	9	23.08
5 Life is/was good	22	23.16	10	22.73	12	23.53	3	15.00	10	25.64
6 Life is/was very good	9	9.47	5	11.36	4	7.84	1	5.00	4	10.26
7 Life is/was great	2	2.11	1	2.27	1	1.96	1	5.00	1	2.56

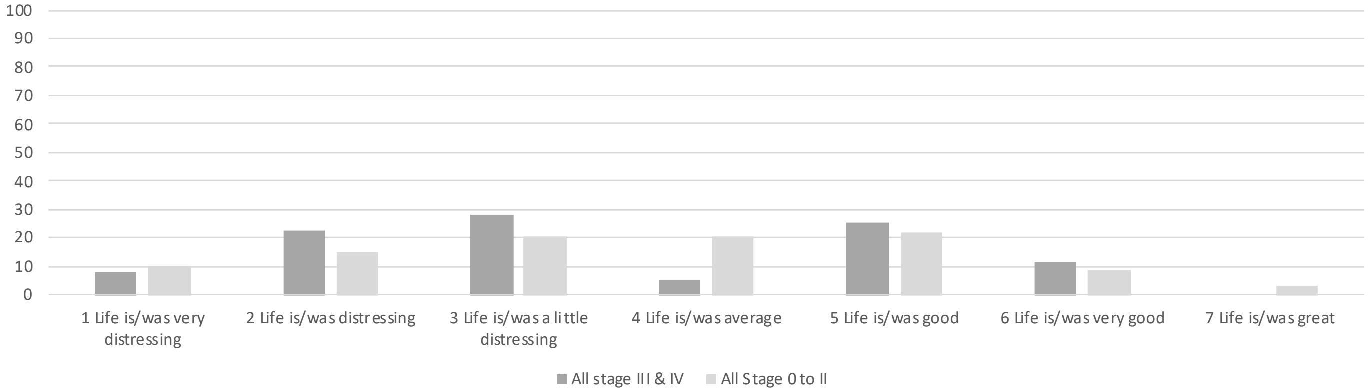


Figure 8.14: Overall impact of condition on quality of life (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 8.26: Overall impact of condition on quality of life – Stage III & IV variations

Overall impact of condition on quality of life	Reported less frequently	Reported more frequently
2 Life is/was distressing		Hormone receptor Stage III & IV
3 Life is/was a little distressing		Hormone receptor Stage III & IV
4 Life is/was average	Triple negative Stage III & IV	

Experience of anxiety related to disease progression: Stage III to IV

Fear of progression: Stage III to IV

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. Summary statistics for the entire cohort are displayed in Table 8.27. The overall scores for the cohort were in the middle quintile for Fear of progression: Total score (mean=36.22, SD=6.82), indicating moderate levels of anxiety.

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. On average fear of progression score for participants in this study indicated moderate levels of anxiety.

Table 8.27: Fear of progression summary statistics

Fear of progression (n=95)	Mean	SD	Median	IQR	Possible range	Quintile
Total score*	36.22	6.82	36.00	8.00	12 to 60	3

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

Fear of progression by breast cancer stage: Stage III to IV

Participants with stage 0 to II breast cancer (n=59, 62.11%) were compared to participants with stage II and IV breast cancer (n=36, 37.89).

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

No significant differences were observed between participants by breast cancer stage for the fear of progression score.

Table 8.28: Fear of progression total score by breast cancer stage summary statistics and T-test

Fear of progression	Group	Number (n=95)	Percent	Mean	SD	T	dF	p-value
Total score	All stage 0 to II	59	62.11	33.93	8.46	-1.37	93	0.1730
	All stage III & IV	36	37.89	36.22	6.82			

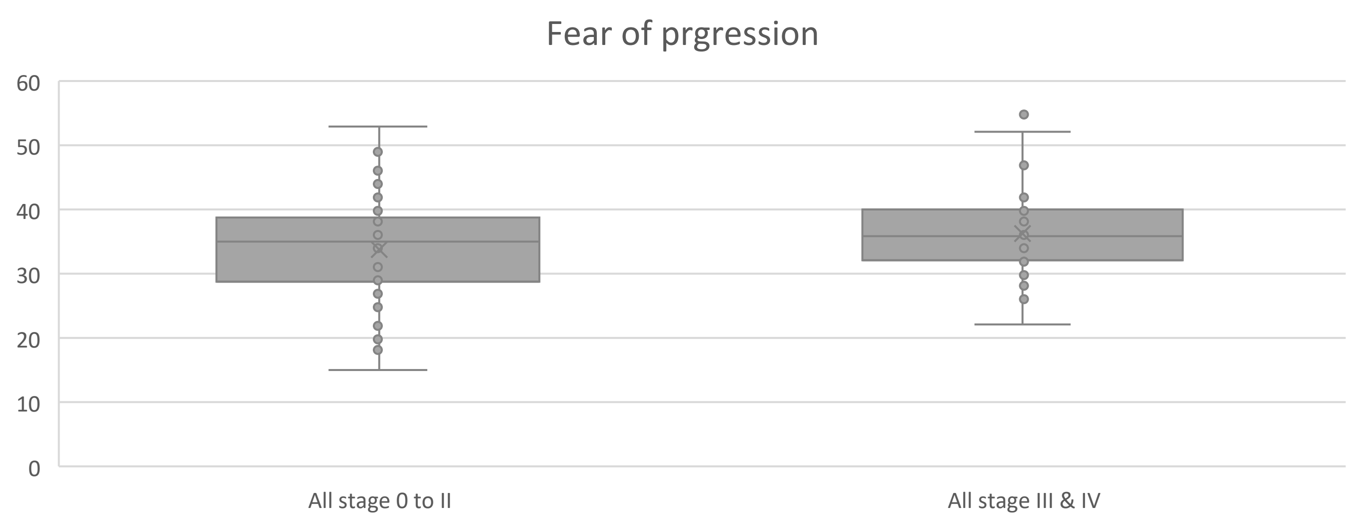


Figure 8.15: Boxplot of Fear of progression total score by breast cancer stage

Anxiety about treatment: Stage III to IV

Fear of progression individual questions Stage III to IV

An overview of responses to individual fear of progression questions is given in the table below.

On average, participants scored in the "Seldom" range for the following questions: "Afraid of pain" (median=2.00, IQR=1.00), "Is disturbed that they may have to rely on strangers for activities of daily living" (median=2.00, IQR=2.00), "If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped" (median=2.00, IQR=1.00), "Anxious if not experiencing any side effects think it doesn't work" (median=2.00, IQR=2.00).

On average, participants scored in the "Sometimes" range for the following questions: "Becomes anxious thinking that disease may progress" (median=3.00, IQR=1.00), "Has concerns about reaching professional and/or personal goals because of illness:" (median=3.00, IQR=1.25), "When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation" (median=3.00, IQR=2.00), "The possibility of relatives being diagnosed with this disease disturbs participant" (median=3.00, IQR=1.00), "Worried that at some point in time will no longer be able to pursue hobbies because of illness" (median=3.00, IQR=1.00), "Afraid of severe medical treatments during the course of illness" (median=3.00, IQR=1.00), "Worried that treatment could damage their body" (median=3.00, IQR=1.00), "The thought that they might not be able to work due to illness disturbs participant" (median=3.00, IQR=1.00).

On average, participants scored in the "Often" range for the following questions: "Is nervous prior to doctors appointments or periodic examinations" (median=3.50, IQR=1.00), "Worried about what will become of family if something should happen to participant" (median=4.00, IQR=1.00).

Table 8.29: Fear of progression individual questions: Stage III to IV

Fear of progression (n=95)	Median	IQR	Average response
Becomes anxious thinking that disease may progress	3.00	1.00	Sometimes
Is nervous prior to doctors appointments or periodic examinations	3.50	1.00	Often
Afraid of pain	2.00	1.00	Seldom
Has concerns about reaching professional and/or personal goals because of illness:	3.00	1.25	Sometimes
When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation	3.00	2.00	Sometimes
The possibility of relatives being diagnosed with this disease disturbs participant	3.00	1.00	Sometimes
Is disturbed that they may have to rely on strangers for activities of daily living	2.00	2.00	Seldom
Worried that at some point in time will no longer be able to pursue hobbies because of illness	3.00	1.00	Sometimes
Afraid of severe medical treatments during the course of illness	3.00	1.00	Sometimes
Worried that treatment could damage their body	3.00	1.00	Sometimes
Worried about what will become of family if something should happen to participant	4.00	1.00	Often
The thought that they might not be able to work due to illness disturbs participant	3.00	1.00	Sometimes
If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped	2.00	1.00	Seldom
Anxious if not experiencing any side effects think it doesn't work	2.00	2.00	Seldom

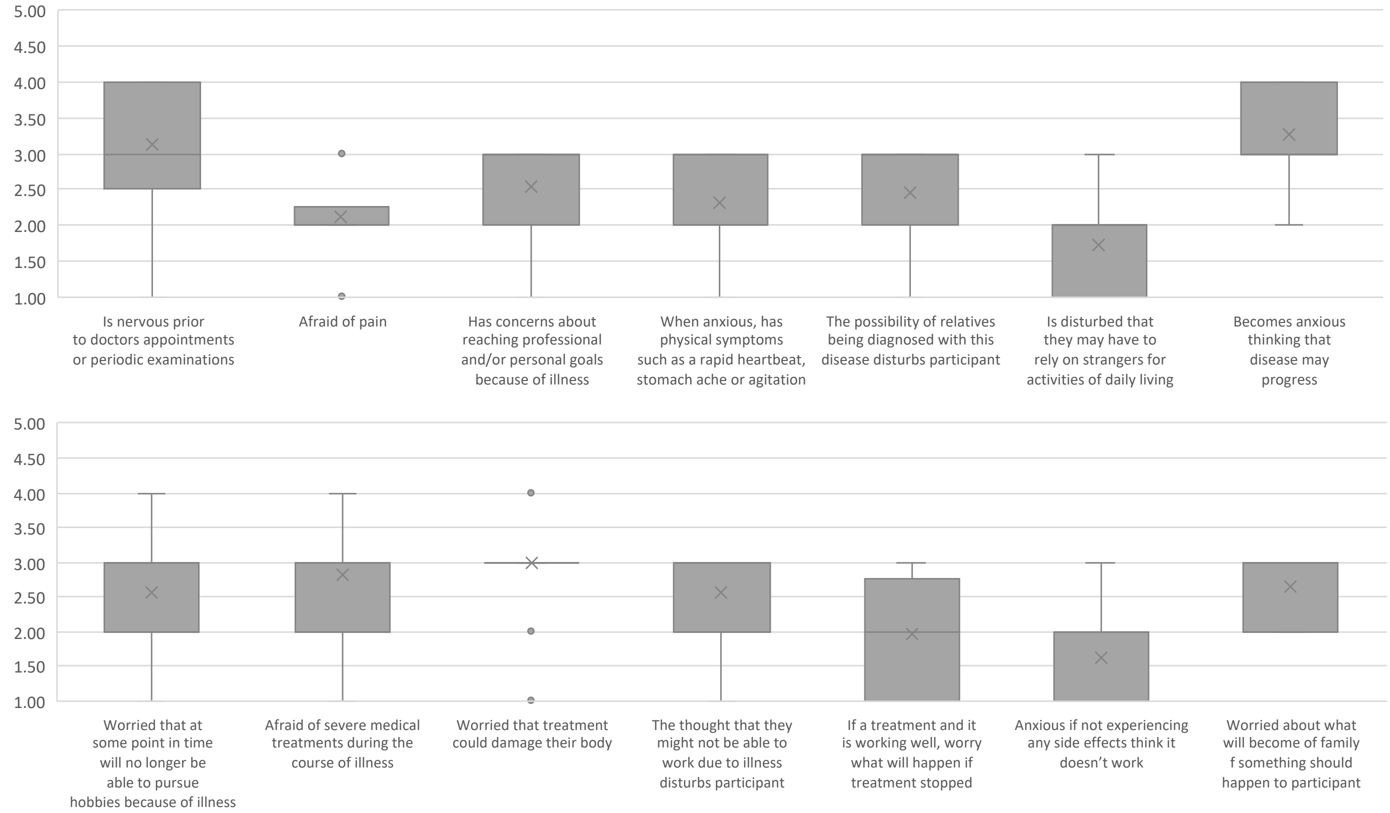


Figure 8.16: Fear of progression individual questions: Stage III & IV

Section 9

Expectations and messages to decision-makers

Section 9: Expectations of future treatment, care and support, information and communication

Expectations of future treatment: Stage III and IV

Participants were asked in the structured interview what their expectations of future treatments are. The most common responses were that future treatment will be more affordable (38.46%), and have fewer or less intense side effects/more discussion about side effects (30.77%). Other themes included be more effective and/or targeted (personalised) (17.95%), have more research/advances for treatment (10.26%),be easier to administer and/or able to administer at home and/or less invasive (10.26%), and be accessible (timely, equitable, location) (7.69%).

Expectations of future information: Stage III and IV

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common responses were that future information will be more accessible/easy to find (20.51%), provide more details about where to find available services (12.82 %), and provide more details about symptom and side effect control (12.82 %). Other themes included be more holistic (including emotional health) (10.26%),provide more general information about the condition (10.26%),help to inform the community and decision-makers about their condition (raise awareness) (10.26%), and provide more details about how to manage personal and intimate problems (7.69%).
There were 4 participants (12.82%) that had no recommendations and were satisfied with the information currently available.

Expectations of future healthcare professional communication: Stage III and IV

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common expectations for future healthcare professional communication were that communication will be more transparent and forthcoming (23.08%), include listening to the patient(17.95%), and be more empathetic (15.38 %).

There were 12 participants (30.77%) that had no recommendations and were satisfied with the healthcare communication they had.

Expectations of future care and support: Stage III and IV

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common expectation for future care and support was that it will include more access to support services (51.28%), and will include specialist clinics or services where they can talk to professionals (in person, phone, online) (30.77%). Other themes included will include being able to connect with other patients through peer support (support groups, online forums) (12.82%), will include more long-term condition management (care planning) (12.82%), and will be more holistic (including emotional health) (10.26%).
There were 5 participants (12.82%) that had no recommendations and were satisfied with the care and support they received.

What participants are grateful for in the health system: Stage III and IV

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common responses were that participants were grateful for timely access to treatment (28.21%), healthcare staff (including access to specialists)(28.21%), and the entire health system (20.51 %). Other themes included access to private healthcare/private insurance (17.95%), low cost or free medical care through the government (15.38%), and low cost or free medical treatments through the government (12.82%).

Symptoms and aspects of quality of life: Stage III and IV

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, where 1 is the most important and 11 is the least important. The most important aspects reported were Fatigue Pain, Fertility, and Heart problems. The least important were Lymphoedema, Menopause and menopausal symptoms, and Body image.

Values in making decisions: Stage III and IV

Participants were asked to rank what is important for them overall when they make decisions about treatment and care, where 1 is the most important and 8 is the least important.

The most important aspects were "How safe the medication is and weighing up the risks and benefits", and "The severity of the side effects". The least important were "Ability to follow and stick to a treatment regime" and "How the treatment is administered".

Values for decision makers: Stage III and IV

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care, where 1 is the most important and 5 is the least important.

The most important values were “Quality of life for patients”, and “All patients being able to access all available treatments and services”. The least important was “Economic value to government and tax payers”.

Time taking medication to improve quality of life: Stage III and IV

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn’t offer a cure. The majority of participants (n = 20, 55.56%) would use a treatment for more than ten years for a good quality of life even if it didn’t offer a cure.

Most effective form of medicine: Stage III and IV

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in.

There were 15 participants (41.67%) that thought that medicine delivered by IV was most effective, no participants (0.00%) thought that pill form was most effective, and 11 participants (30.56%) that thought they were equally effective. There were 10 participants (27.78%) that were not sure.

Messages to decision-makers: Stage III and IV

Participants were asked, “If you were standing in front of the health minister, what would your message be in relation to your condition?” The most common messages to the health minister were the need for timely and equitable access to support, care and treatment (46.15%), to understand the financial implications (and provide financial support) (28.21%), and the need for a tailored care plan (15.38 %). Other themes included to increase investment (general) (12.82%), to invest in professional development so that clinicians understand the condition (10.26%),to have a holistic approach to the condition (including emotional support) (7.69%), and to improve wait times (7.69%).

Expectations of future treatment: Stage III and IV

Participants were asked in the structured interview what their expectations of future treatments are. The most common responses were that future treatment will be more affordable (38.46%), and have fewer or less intense side effects/more discussion about side effects (30.77%). Other themes included be more effective and/or targeted (personalised) (17.95%), have more research/advances for treatment (10.26%),be easier to administer and/or able to administer at home and/or less invasive (10.26%), and be accessible (timely, equitable, location) (7.69%).

Future treatment will be more affordable

Obviously because I was triple-negative, I'd like to see a proper targeted treatment for triple-negative, so that it's not just a case of, "Well, let's just throw everything at it and hope for the best." Definitely, for me, that's a really big thing is finding the reason for triple-negative and why triple-negative happens when it's not a genetic mutation, and having a proper targeted treatment for it. Obviously, having access to the current drugs that we have, that may not necessarily have been created for breast cancer, but now they're finding work on particularly triple-negative, having them added to the PBS and not paying a ridiculous amount out of pocket, and making it within people's financial reach would be really important. Participant_025TNG

I personally think that you shouldn't have to pay for anything. I don't know why some stuff is charged for, and some stuff isn't. I wish the government just funded it. That was something that we found really difficult. We just didn't know if we went if we were going to get a bill for something or not. I wish chemo didn't make them sick, but I don't really think there's anything anybody can tell about that. Participant_043TNG

Cost is a big one. There was a clinical trial that I could've had the immunotherapy for free, but the doctor said it was too risky to wait. It boggles my mind to think about the poor people that couldn't afford to have it and therefore the positive effects that I won't be having for them just because they weren't in a good financial position or have somebody either that could fund it for them or to gather the funding to cover it. I know it can't be offered everywhere, but I've got a friend, she has to travel well over an hour to get treatment for a different kind of cancer from where she lives. Participant_048TNG

Future treatments will have fewer or less intense side effects/more discussion about side effects

I don't think anyone should have to pay in Australia for health care of that nature. Because I think it puts a value on people's lives, that is unrealistic because you know you can't do that assess that someone's life is more valuable than someone else's or someone else's can afford it more than someone else. I think it should all be free or you know covered like with Medicare. As far as treatment something other than chemo would be fantastic that doesn't mush your brain and puts you in a perpetual state of old ladyness. No offense to old ladies but I would have liked to go up there naturally and then um you know if there are side effects you know what work harder on getting treatments for it not to say well you know suck it up because like like like I have realized recently that we are living longer which means they're living longer with the side effects. I you know, you need to have a good quality of life not just enough just to live because you might last five years or whatever. I'm gonna live a long life hopefully. Participant 045_2021AUHRP

And I'd like to see my side effects, obviously, from chemo, but I think it would be nice to have it has the chemo administered at home. But you've still got to see the doctor anyway, say, you know, and I think that a lot of the time you could be that video game or something like that, you could be with the doctor. So I think that that would be helpful so that you don't have to leave the house and especially in the uncertainty when you're immunocompromised. It's really scary to go into a hospital because you don't know, you know, who everybody is or where they've been. Participant_038TNG

Future treatment will be more effective and/or targeted (personalised)

I'd just like to see new treatments that are more successful with less side effects, more targeted, I guess. More targeted treatments, rather than your whole body getting sick. Participant_037TNG

Now I consider that not only the fact that I have fought breast cancer, but now it's all these other things that are going to go along with it. I think that that needs to improve in more understanding and more, I don't know, surely there is something that they can do to that is going to target better or I don't know. You try to get through one thing, but now you *have just jeopardized a whole lot of other body systems. Participant 048_2021AUHRP*

Participant describes the expectation that future treatment will informed by more research/advances in treatments

For regional Australia. I would like to see more possibilities, yes. More different treatments if more choices given even for trial things and stuff. Participant_031

Me personally, I think they need to stop using these particular chemo drugs, they're barbaric. They've been around since the 1940s. I even read an article about how, I can't remember which one of the chemo drugs it is, it can affect your heart. I think the article was saying that they could do something to improve the chemo medication, but they won't. I was just like, "Okay." It's like they're basically injecting poison into our bodies, that obviously gives us really bad side effects because of what it is to cure our cancer. Then, with the whole, as well, having to have your breasts removed, where you might have a lump, I don't know what I'm going to do yet, but just say, for example, I had to have a double mastectomy. I know they're doing some clinical trials in Texas, where they're just doing the chemotherapy or whatever, they're not actually doing the surgery. I think I get really annoyed when I see, always, ads or whatever, they come up on my feed on Facebook or Instagram to say, "Oh, we're trying to find a cure for cancer." It's like, "Well, we've been donating money to these causes for years and years and years, you still haven't found a cure for cancer. You're still using all these barbaric treatments." Something has to change. I know that I have a rare and aggressive form of cancer. I also know that one of the ladies in my group, she's terminal because she was chemo-resistant, but she actually started a petition, so we can have access to molecular testing and different types of chemo. She actually went to Canberra to speak to Greg Hans about it. Funding will come through, I think it's in November, for testing and treatment. They just have to go through PBS, so people like myself, people that don't have a lot of money can access that sort of treatment. Sorry, I know I'm going on and on. Participant_028TNG

Future treatment will be easier to administer and/or able to administer at home and/or less invasive

And I'd like to see my side effects, obviously, from chemo, but I think it would be nice to have it has the chemo administered at home. But you've still got to see the doctor anyway, say, you know, and I think that a lot of the time you could be that video game or something like that, you could be with the doctor. So I think that that would be helpful so that you don't have to leave the house and especially in the uncertainty when you're immunocompromised. It's really scary to go into a hospital because you don't know, you know, who everybody is or where they've been. Participant_038TNG

Oh, gosh, if there could be a treatment that has no side effects, that would be a miracle. Obviously, if you weren't having cell, you're having IV That would be great because I have come out of treatment at times looking like the walking wounded where they've tried three or four times to hit a vein. Yes, avoiding that would be great. It's really anything that can lessen side effects, and then is more easily administered would be wonderful. Participant_027TNG

I think it would be good if we were given the option to be tested prior to starting a treatment. I didn't know about that test until after I finished my treatment. It would've been good to have that initially. I would have paid for it had I known, but I didn't even know about it. Participant_045TNG

Participant describes the expectation that future treatments will more accessible (Timely, equitable, location)

Could I have none of that stuff, no cost, no side effects? That'd be awesome. It's interesting that where it's been administered does impact. I feel like an absolute winger to say that the trial just being in LOCATION went on both in LOCATION, that was-- I wouldn't say problematic, but it was more impactful than the ones at my closer hospital, which is only within 10, 15 minutes, as different to half an hour, 45 minutes drive. Having to wait six weeks for a specialist appointment rather than get in in a timely fashion, when you know things are hanging in the balance, that's really a relief when that stuff comes through. Obviously, it'd be nice if things were reasonably priced, but I think just having availability is the first and most important thing. Sure, I don't want side effects, but damn I want availability of stuff if it's going to make a difference. Participant 051_2021AUHRP

Table 9.1: Expectations of future treatment

Expectations of future treatment	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Future treatment will be more affordable	28	27.45	13	20.63	15	38.46	10	37.04	5	41.67
Future treatments will have fewer or less intense side effects/more discussion about side effects	39	38.24	27	42.86	12	30.77	7	25.93	5	41.67
Future treatment will be more effective and/or targeted (personalised)	25	24.51	18	28.57	7	17.95	4	14.81	3	25.00
Participant describes the expectation that future treatment will informed by more research/advances in treatments	8	7.84	4	6.35	4	10.26	4	14.81	0	0.00
Future treatment will be easier to administer and/or able to administer at home and/or less invasive	7	6.86	3	4.76	4	10.26	4	14.81	0	0.00
Participant describes the expectation that future treatments will more accessible (Timely, equitable, location)	8	7.84	5	7.94	3	7.69	0	0.00	3	25.00
Future treatment will involve a more holistic approach	7	6.86	5	7.94	2	5.13	2	7.41	0	0.00
Future treatment will be the same as it is now	5	4.90	3	4.76	2	5.13	2	7.41	0	0.00
Future treatments are important but we cannot ignore prevention, awareness and education	5	4.90	3	4.76	2	5.13	2	7.41	0	0.00
Participant describes the expectation that future treatment will be accompanied with more support and care planning, particularly post treatment	4	3.92	2	3.17	2	5.13	2	7.41	0	0.00
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	8	7.84	6	9.52	2	5.13	0	0.00	2	16.67

Expectations of future treatment	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Future treatment will be more affordable	28	27.45	11	22.00	17	32.69	1	4.35	12	30.00
Future treatments will have fewer or less intense side effects/more discussion about side effects	39	38.24	12	24.00	27	51.92	5	21.74	22	55.00
Future treatment will be more effective and/or targeted (personalised)	25	24.51	11	22.00	14	26.92	7	30.43	11	27.50
Participant describes the expectation that future treatment will informed by more research/advances in treatments	8	7.84	8	16.00	0	0.00	4	17.39	0	0.00
Future treatment will be easier to administer and/or able to administer at home and/or less invasive	7	6.86	7	14.00	0	0.00	3	13.04	0	0.00
Participant describes the expectation that future treatments will more accessible (Timely, equitable, location)	8	7.84	0	0.00	8	15.38	0	0.00	5	12.50
Future treatment will involve a more holistic approach	7	6.86	7	14.00	0	0.00	5	21.74	0	0.00
Future treatment will be the same as it is now	5	4.90	5	10.00	0	0.00	3	13.04	0	0.00
Future treatments are important but we cannot ignore prevention, awareness and education	5	4.90	5	10.00	0	0.00	3	13.04	0	0.00
Participant describes the expectation that future treatment will be accompanied with more support and care planning, particularly post treatment	4	3.92	4	8.00	0	0.00	2	8.70	0	0.00
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	8	7.84	0	0.00	8	15.38	0	0.00	6	15.00

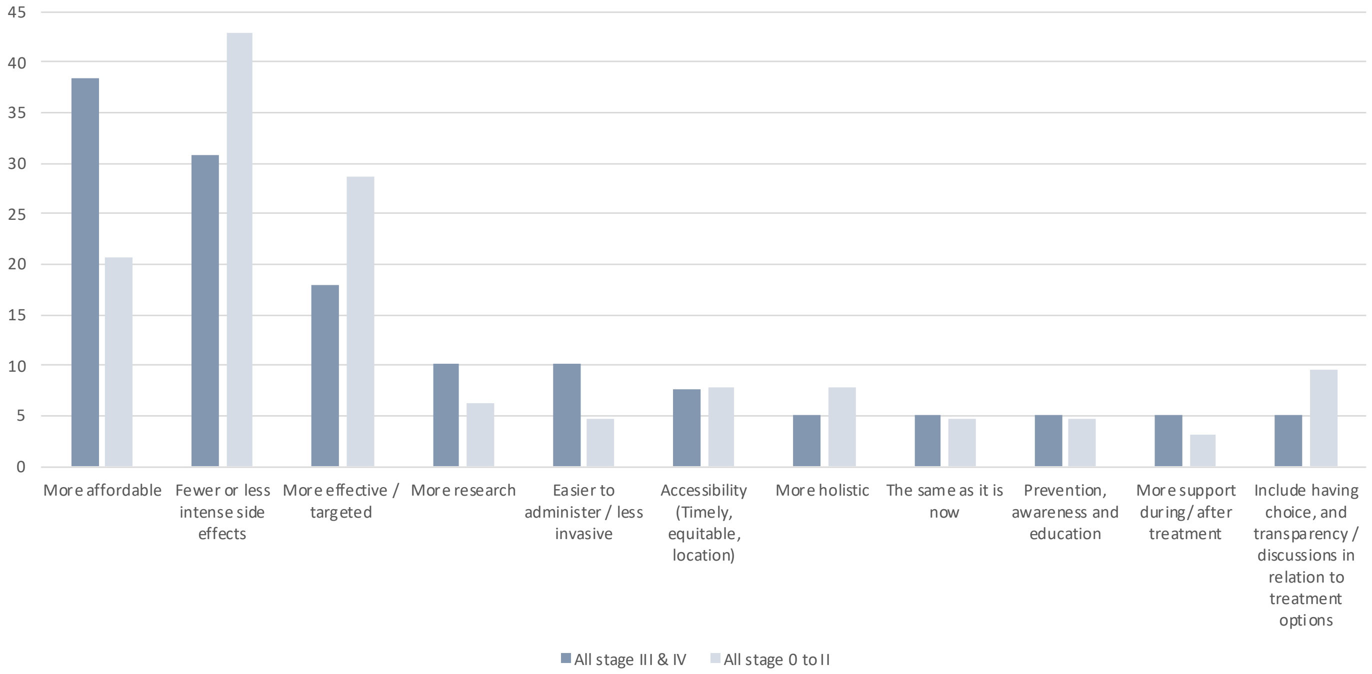


Figure 9.1: Expectations of future treatment (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 9.2: Expectations of future treatment – Stage III & IV variations

Expectations of future treatment	Reported less frequently	Reported more frequently
Future treatment will be more affordable	All Stage III & IV Hormone receptor Stage III & IV	
Future treatments will have fewer or less intense side effects/more discussion about side effects	Triple negative Stage III & IV	
Participant describes the expectation that future treatments will more accessible (Timely, equitable, location)		Hormone receptor Stage III & IV

Expectations of future information: Stage III and IV

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common responses were that future information will be more accessible/easy to find (20.51%), rovide more details about where to find available services (12.82 %), and provide more details about symptom and side effect control (12.82 %). Other themes included be more holistic (including emotional health) (10.26%),provide more general information about the condition (10.26%),help to inform the community and decision-makers about their condition (raise awareness) (10.26%), and provide more details about how to manage personal and intimate problems (7.69%).
There were 4 participants (12.82%) that had no recommendations and were satisfied with the information currently available.

Future information will be more accessible/easy to find

I think COVID made it extremely difficult for a lot of this because the face-to-faces just aren't there. The information that is given to you is either a booklet or a piece of paper. I'd like to be able to see more in-person stuff. Time is so important to this, whereas when you're in an appointment and there's 500 people waiting to see the same specialist that day, it's all time-poor. That's probably more time, I suppose. Participant_030TNG

It's very hard to get things online I find and that's not blaming anyone else. Maybe I'm just incompetent when it comes to computers.
INTERVIEWER: You found it difficult looking for things online?
PARTICIPANT: I did.
INTERVIEWER: Okay.
PARTICIPANT: Yes. My husband's a computer whiz so he does everything for me. Participant_032TNG

I do think that those drug information sheets should be rewritten. Realistically they're for the doctors, not the patients, but if they are going to be using them for the patients then they need to be different, or they need to develop something else that is more for the patients. Participant_048TNG

Participant describes the expectation that future information will provide more details about where to find available services

I don't know whether it was because I walked into my first appointment with my specialists and I walked into my first appointment with my medical oncologist, and I talked to them about my infertility that we'd been through that it was just assumed, but I felt like at no point did anyone kind of talk to me too much about the infertility side of what chemotherapy can do things to fertility. It was never really talked to me about fertility preservation options because I think it was just assumed I already had a specialist, so I had all of that under control, and I could deal with that myself. I was 37 at the time, and so I think there was that-- I felt like I was too old to be the young patient but too young to be the old patient. I said, given this, I didn't fit in the mode, I suppose, of certain people. I definitely think more inflammation around fertility and the side effects of that would be really good. I also think more information, it was really helpful to see people who've been out of cancer and who were 15 years, 20 years down the track from having their cancer diagnosis. Having information provided to you in the first appointment about…Do you know what? This is really hard One of my biggest pet peeves is that everyone talks about how amazing the National Breast Cancer Foundation is and how amazing the Breast Cancer Network Australia is. I still have actually no idea what they do to help with cancer patients. Having a bit more information about the services that they offer and what they can do for you, I think would be really useful. If you go into their website, I can find 10 different ways of how I can donate money to them but I can't find what they…They say they support breast cancer patients, but what do they actually do to support breast cancer patients. I think it's really important too to have a local area, information pack.

You're having a...You live in LOCATION because there's all of these amazing charities that exist, that you don't know about until someone tells you about them. There's a thing called the OTIS foundation that provides holiday accommodation to breast cancer patients. I think there's a company called Pink Things which is in the LOCATION, there's all of these things. I found and felt that if I had children, there would be way more support information given to me in the first instance. Because I didn't have children, and I had a husband who worked from home, I didn't really get a lot of information about support resources that were available, which is probably why I didn't access any of them because I didn't know they existed. The other thing that would have been really useful to me was actually knowing about...like getting some information on where to go to get a wig, or where to go to get nice scarves. Again, there's all these amazing organizations like Bravery, sews the scarves and real French headbands for some hair things, and all of these things that exist for cancer patients that you really almost need to be in the cancer world and have a secret connection to someone who goes, "Oh, by the way, this exists." When you're first diagnosed with that you don't know about that. Six months down the track, I now know where to go to find a wig, I now know where to go to do this and it's really hard to get those level of-- not the everyday 17 support but then where do I go for a headband? Or where do I go for a headscarf? That level of information would be really good. As I said, I think if it was like a local by region by region thing that was even just a website that had links to all these companies, it would be really good. Interviewer: Yes, that would be fantastic. A lot of these little charities who don't have a big platform people don't know about it and I think a lot of people find out about these little charities through Facebook pages or by word of mouth or things like that. I think if there was some online service to know what you can access in your area...I know it's a huge, big thing to do, and there's probably no money for it and that's probably what prevented a lot of people from doing it because they cost money but it's like, for instance, the cancer council's website, and they have that on their website or just something that you can be told, "This is what you do. This is who you go to," it would be great. Participant_025TNG

I think that's support. The direct link of this is what you need to fill out. This is how you're going to get that financial support and someone directly there to help you and take out all that time. I spent I don't even know how long on hold, waiting for letters, waiting for support, getting turned around from person to person. Like a ridiculous RSM. I spent a good 20 hours on the phone for them trying to get the support to then fill out all the documents and be told no because we've done something wrong, and then to resubmit it. Then by the time we resubmit it, we had to get the accountant involved, just that sort of thing. That really needs to change. Participant 042_2021AUHRP

Future information will provide more details about symptom and side effect control

I think the I would like more information on what happens after the chemotherapy as far as side effects and what people are left with afterwards. And I'd like to see more follow up from the teams around that to make sure that you are doing OK. Sorry. Have I answer the question that I. Yeah. Participant_038TNG

Menopause 100%. Never pain, nerve damage, chemo side effects afterwards Participant_036TNG

My oncologist just gave me a piece of paper with all the symptoms that I would experience. That could have been a bit prettier, if what I mean, like a little bit less or sear, but he was giving me the most up-to-date information. Participant_040TNG

Future information will be more holistic (including emotional health)

If I ruled the world and I could have it how I wanted, I guess maybe to have someone like a counselor that you would speak to before you start your treatment just to see where your head's at and make sure the information you're hearing is accurate information. I guess, to have that reassurance at the start that you're on the right plan or whatever. Maybe something like that when you walk in and you know nothing, you have someone to talk you through the process in a non-clinical way. Participant_027TNG

I think for me personally, I'd like to see the medical profession, maybe be a little bit more open to alternative options and not so cut and dried about no, don't go there. Participant 047_2021AUHRP

Participant describes the expectation that future information will provide more general information about the condition

Yes. When I was first diagnosed, there probably wasn't a lot on triple-negative and outside of being told don't Google I wasn't given much insight, so I did Google, so I could find my own insight. I think that *there needs to be more printed information given to a patient so that they know exactly what they're dealing with and exactly what it is. Participant_034*

PARTICIPANT: When you're doing your grading and staging, and-- that was really difficult to-- I know it was on the Cancer Council website and clicking through that, but you don't understand it. For me, I couldn't understand it. I got really obsessed with it to begin with, and then going, "I'm Stage 3. What does that mean? What does that mean? I don't know." For me, having statistics to tell you by stage and grade what the occurrence is would be great, particularly, by the type of breast cancer. No one keeps that, if you know what I mean?
INTERVIEWER: Yes.
PARTICIPANT: I don't know whether they'll-- maybe they do, they just don't tell you. You can't find that because it's probably the thing at the beginning is like, "Is this going to reoccur?" and, "Is it going to kill me?" That would have to be, for me, the thing that I still research it now. Participant_047TNG

Future information will help to inform the community and decision-makers about their condition (raise awareness)

I'm not 100% sure if this would work, but I think that when they-- I know I've seen a woman coming in that's been recently diagnosed and she's being given a tour of the center. I was sitting in a treatment chair once and I was listening to the ones next door and they were telling them all about the treatment and all this, and they make it sound like-- Yes, it's hard, but they don't really go into full detail about how bad it can be. I don't know, maybe they could have a volunteer or someone that's been through it, that can help them out. Not to scare them off or anything like that, just to sit them down and say, "Well, these are all the things that can happen. It's really hard." Do you know what I mean? I think that yes they do, they need to give people more information. I don't know if this is ever going to happen, I think it would also be awesome to educate the public. Like I said, I had no idea really. You just think, "Oh, you're going to lose your hair, your eyebrows, your eyelashes, you might be tired, you might be sick," but it's so much more than that. I just think people need to be educated. That's just my opinion. Participant_028TNG

I just like to say I'd like to see more information in GP's offices. And I still don't believe that our general practitioners know enough about breast cancer and and what should be offered to women who are diagnosed and information out to the public public who have got no idea if I just hear or she's got breast cancer, but I got no idea. And so it's all about education for me. Participant_049TNG

Satisfied with experience

I remember the first thing is giving me information and stuff, so I think it was pretty much readily available and in an easier to read format. Participant_037TNG

No, I've had access to terrific information. Participant_041TNG

Table 9.3: Expectations of future information

Expectations of future information	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Future information will be more accessible/easy to find	16	15.69	8	12.70	8	20.51	5	18.52	3	25.00
Participant describes the expectation that future information will provide more details about where to find available services	21	20.59	16	25.40	5	12.82	3	11.11	2	16.67
No particular comment - satisfied with experience	14	13.73	9	14.29	5	12.82	4	14.81	1	8.33
Future information will provide more details about symptom and side effect control	21	20.59	16	25.40	5	12.82	3	11.11	2	16.67
Future information will be more holistic (including emotional health)	7	6.86	3	4.76	4	10.26	4	14.81	0	0.00
Participant describes the expectation that future information will provide more general information about the condition	6	5.88	2	3.17	4	10.26	4	14.81	0	0.00
Future information will help to inform the community and decision-makers about their condition (raise awareness)	4	3.92	1	1.59	3	7.69	3	11.11	0	0.00
Participant describes the expectation that future information will provide more details about how to manage personal and intimate problems	6	5.88	4	6.35	2	5.13	2	7.41	0	0.00
Future information will provide more details on subgroups and specific classifications of their condition	6	5.88	4	6.35	2	5.13	0	0.00	**2**	**16.67**
Future information will allow for patient record keeping	6	5.88	4	6.35	2	5.13	0	0.00	**2**	**16.67**
Participant describes the expectation that future information will provide more details about treatments	7	6.86	6	9.52	1	2.56	1	3.70	0	0.00
Participant describes the expectation that future information will provide more details about holistic treatments	9	8.82	8	12.70	1	2.56	0	0.00	1	8.33
Future information will provide more details about exacerbation of disease (including recurrence)	2	1.96	2	3.17	0	0.00	0	0.00	0	0.00
Participant describes the expectation that future information will be more targeted to a specific age group	5	4.90	5	7.94	0	0.00	0	0.00	0	0.00

Expectations of future information	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Future information will be more accessible/easy to find	16	15.69	5	10.00	11	21.15	0	0.00	8	20.00
Participant describes the expectation that future information will provide more details about where to find available services	21	20.59	8	16.00	13	25.00	5	21.74	11	27.50
No particular comment - satisfied with experience	14	13.73	7	14.00	7	13.46	3	13.04	6	15.00
Future information will provide more details about symptom and side effect control	21	20.59	5	10.00	16	30.77	2	8.70	14	35.00
Future information will be more holistic (including emotional health)	7	6.86	7	14.00	0	0.00	3	13.04	0	0.00
Participant describes the expectation that future information will provide more general information about the condition	6	5.88	6	12.00	0	0.00	2	8.70	0	0.00
Future information will help to inform the community and decision-makers about their condition (raise awareness)	4	3.92	4	8.00	0	0.00	1	4.35	0	0.00
Participant describes the expectation that future information will provide more details about how to manage personal and intimate problems	6	5.88	6	12.00	0	0.00	4	17.39	0	0.00
Future information will provide more details on subgroups and specific classifications of their condition	6	5.88	0	0.00	6	11.54	0	0.00	4	10.00
Future information will allow for patient record keeping	6	5.88	0	0.00	6	11.54	0	0.00	4	10.00
Participant describes the expectation that future information will provide more details about treatments	7	6.86	7	14.00	0	0.00	6	26.09	0	0.00
Participant describes the expectation that future information will provide more details about holistic treatments	9	8.82	3	6.00	6	11.54	3	13.04	5	12.50
Future information will provide more details about exacerbation of disease (including recurrence)	2	1.96	2	4.00	0	0.00	2	8.70	0	0.00
Participant describes the expectation that future information will be more targeted to a specific age group	5	4.90	0	0.00	5	9.62	0	0.00	5	12.50

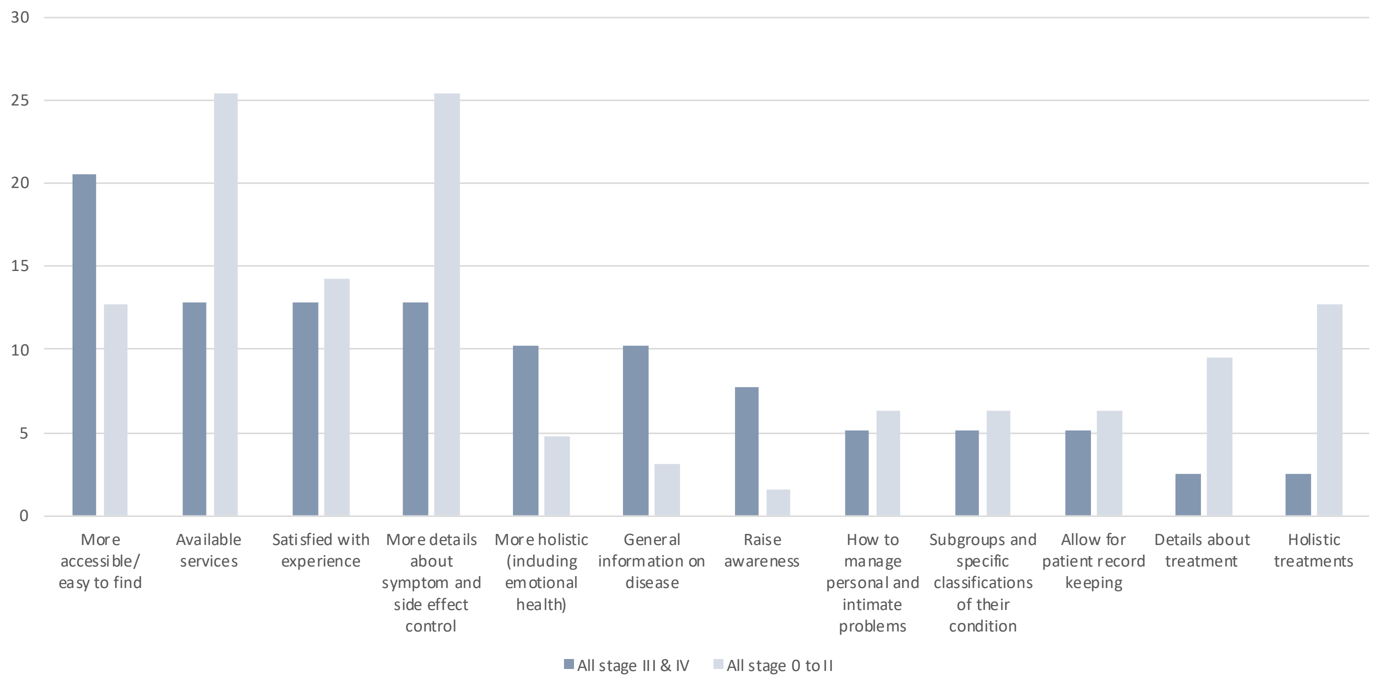


Figure 9.2: Expectations of future information. (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 9.4: Expectations of future information – Stage III & IV variations

Expectations of future information	Reported less frequently	Reported more frequently
Future information will provide more details on subgroups and specific classifications of their condition	-	Hormone receptor Stage III & IV
Future information will allow for patient record keeping	-	Hormone receptor Stage III & IV

Expectations of future healthcare professional communication: Stage III and IV

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common expectations for future healthcare professional communication were that communication will be more transparent and forthcoming (23.08%), include listening to the patient(17.95%), and be more empathetic (15.38 %).

There were 12 participants (30.77%) that had no recommendations and were satisfied with the healthcare communication they had.

Satisfied with communication

No. I had a very good medical professional who looked after me. I don't have any issues there. Participant_024TNG

No, I think that I've been very lucky with my health professionals along the way. They've been very supportive and informative and that sort of thing. Participant_046TNG

No. As I said, my team were great. Gavin was like, "Just ring me anytime. Just do what you need to do." Participant_047TNG

Future communication will be more transparent and forthcoming

They've actually been really good. There's massive gaps I think, in the communication in general, but I don't know if that's in relation to that question. I might answer that and you'll tell me it's not what you're looking for, is not the right time to say that. What I've noticed with the whole journey is how much coordination and organizing you have to do yourself as a cancer patient. There's an expectation that you'll know what to do and where to go and who to talk to and how to do that. Things like contacting surgeons yourself, finding a surgeon, making an arrangement to go there, trying to get scans organized, you have to do all that yourself. Following up things that haven't been done, contacting the oncology rooms because they haven't got back to you about something where you don't know when the next appointment date is. There seems to be an awful lot of things that you need to do yourself to coordinate your own treatment, that I didn't think would be that way. I thought it would be more scheduled, "This is what happened, this is your journey, you need to see this person, this person, and this person." but I felt like that information wasn't given, that wasn't communicated and it's been trying to find out for myself, "Who do I see? Who do I need to see? Where do I go next? Where do I go for scans? Where do I go?" Then you need a heart ultrasound, well, you need to get that done before your chemo next Monday. Where do I go to get that done? Then you find everywhere is booked. You're trying to look at traveling two hours away to try and get an appointment for a scan that you've just been told that you need in the next four days without any information on where to go. That sort of stuff is just not communicated, and that's being really challenging. Participant_033

You have to read the patient. Some of us want to know all the truth, doesn't matter how grim it is, whereas others should be protected from the truth and the partner should be should be made aware. Sorry, I'm such a such a chatterbox. If it wasn't for the PET scan, I would have never known that I had the disease in my bones. Now I know it so now I'm just checking in all the time, so I have extra anxiety. Read your patient, provide all the resources, provide various places where you can go to without judgment. Without judging, yes. Participant_042TNG

Future communication will include listening to the patient

I don't think so, because I've actually had-- I think I, fortunately, had a really incredible and supportive experience going through my breast cancer with all of my medical professionals and their communication. I don't think there's really anything that I felt I've missed out on that they could improve on. Sorry, I'd say that. I think for me, the biggest thing that made my communication with my specialists really good was that I didn't go in and go, "Oh, I read this on a forum and this is what you need to be doing," and I never questioned by specialists. Also, I, from the very beginning, because I knew my surgeon had one treatment plan option and my oncologist had a different view, I knew that they were all talking and they were talking to each other about me. I never felt like one person didn't know something about me that the other did. I think as long as people know that they're being supported and that their specialists are communicating with each other and the decisions are being made as a whole not just by one person. I think that would be really important for other people. I had that experience. Participant_025TNG

Whenever I've spoken to anyone, they say they only tell you this much because if they told you everything, perhaps wouldn't go through with it or wouldn't go down the path that they suggest is the best way I feel as though that's a very blanketed statement for some people. Myself, I would have dealt better if I knew upfront what I was dealing with. I think it needs to be more individualized to the person. I feel as though that needs to be a discussion with your breast care nurse or your oncologist of how much information you really want to know, do you want to know, like from here to the end of the process, or do you want to know just what you're dealing with now? I think that would be better dealt with, and explanation of cost would be another one, as what you're in for, for the whole *journey, that would be the two things. Participant_036TNG*

Future communication will be more empathetic

I don't know. I think that I've had fairly good communication with most of my health professionals. As I said, the only one which I've butted heads with has been my surgeon, NAME. I don't know if it's just her as a person. I think it is. She's quite abrupt. The last thing you want is someone who's abrupt dealing with you when you got breast cancer and you tried to make heads and tails of what's going on in your life and being told, this is what you're doing, whether you like it or not, doesn't really sit well with some people. It's like, "How about you give us some options? How about you [unintelligible] yourself a little bit because you're not advocating for me?". Participant_034

Yes, and I actually said this to them one day. I think they'd need to remember that the people they're treating are people and that while for the person administering the treatment, it might be the one they stabbed that day. The person receiving the treatment it might be the first time they've ever done this, so you just need to explain what's being done and why it's being done. Participant_027TNG

She was absolutely couldn't believe it. If that's what's happening with somebody who has a lot of contact with breast cancer patients, we've got a lot of work to do. Similarly with the fellow who said to me, "As long as your MRI doesn't come up with like a Christmas tree, then you'll go and have them done any other." That's like no, that is not acceptable. Participant 043_2021AUHRP

Table 9.5: Expectations of future healthcare professional communication

Expectations of future healthcare professional communication	**All participants**		**All Stage 0 to II**		**All Stage III & IV**		**Triple negative Stage III & IV**		**Hormone receptor Stage III & IV**	
	n=102	**%**	**n=63**	**%**	**n=39**	**%**	**n=27**	**%**	**n=12**	**%**
No particular comment - satisfied with experience	42	41.18	30	47.62	**12**	**30.77**	**6**	**22.22**	6	50.00
Future communication will be more transparent and forthcoming	29	28.43	20	31.75	9	23.08	7	25.93	**2**	**16.67**
Future communication will include listening to the patient	10	9.80	3	4.76	7	17.95	**7**	**25.93**	0	0.00
Future communication will be more empathetic	20	19.61	14	22.22	6	15.38	3	11.11	3	25.00
Participant describes the expectation that future communication will be more accurate and detailed (including more scientific)	10	9.80	8	12.70	2	5.13	2	7.41	0	0.00
Future communication will include developing a care plan with follow-up	5	4.90	3	4.76	2	5.13	2	7.41	0	0.00
Participant describes the expectation that future communication will acknowledge that the condition is serious and cannot be ignored	2	1.96	0	0.00	2	5.13	2	7.41	0	0.00
Participant describes the expectation that future communication will be more consistent across healthcare staff	3	2.94	2	3.17	1	2.56	1	3.70	0	0.00
Future communication will allow people more time to meet with their clinician	2	1.96	1	1.59	1	2.56	1	3.70	0	0.00
Future communication will be more holistic (including emotional health)	3	2.94	3	4.76	0	0.00	0	0.00	0	0.00

Expectations of future healthcare professional communication	**All participants**		**All Triple negative**		**All Hormone receptor**		**Triple negative Stage 0 to II**		**Hormone receptor Stage 0 to II**	
	n=102	**%**	**n=50**	**%**	**n=52**	**%**	**n=23**	**%**	**n=40**	**%**
No particular comment - satisfied with experience	42	41.18	**13**	**26.00**	**29**	**55.77**	**7**	**30.43**	**23**	**57.50**
Future communication will be more transparent and forthcoming	29	28.43	13	26.00	16	30.77	6	26.09	14	35.00
Future communication will include listening to the patient	10	9.80	**10**	**20.00**	0	0.00	3	13.04	0	0.00
Future communication will be more empathetic	20	19.61	9	18.00	11	21.15	6	26.09	8	20.00
Participant describes the expectation that future communication will be more accurate and detailed (including more scientific)	10	9.80	**10**	**20.00**	0	0.00	**8**	**34.78**	0	0.00
Future communication will include developing a care plan with follow-up	5	4.90	5	10.00	0	0.00	3	13.04	0	0.00
Participant describes the expectation that future communication will acknowledge that the condition is serious and cannot be ignored	2	1.96	2	4.00	0	0.00	0	0.00	0	0.00
Participant describes the expectation that future communication will be more consistent across healthcare staff	3	2.94	3	6.00	0	0.00	2	8.70	0	0.00
Future communication will allow people more time to meet with their clinician	2	1.96	2	4.00	0	0.00	1	4.35	0	0.00
Future communication will be more holistic (including emotional health)	3	2.94	3	6.00	0	0.00	**3**	**13.04**	0	0.00

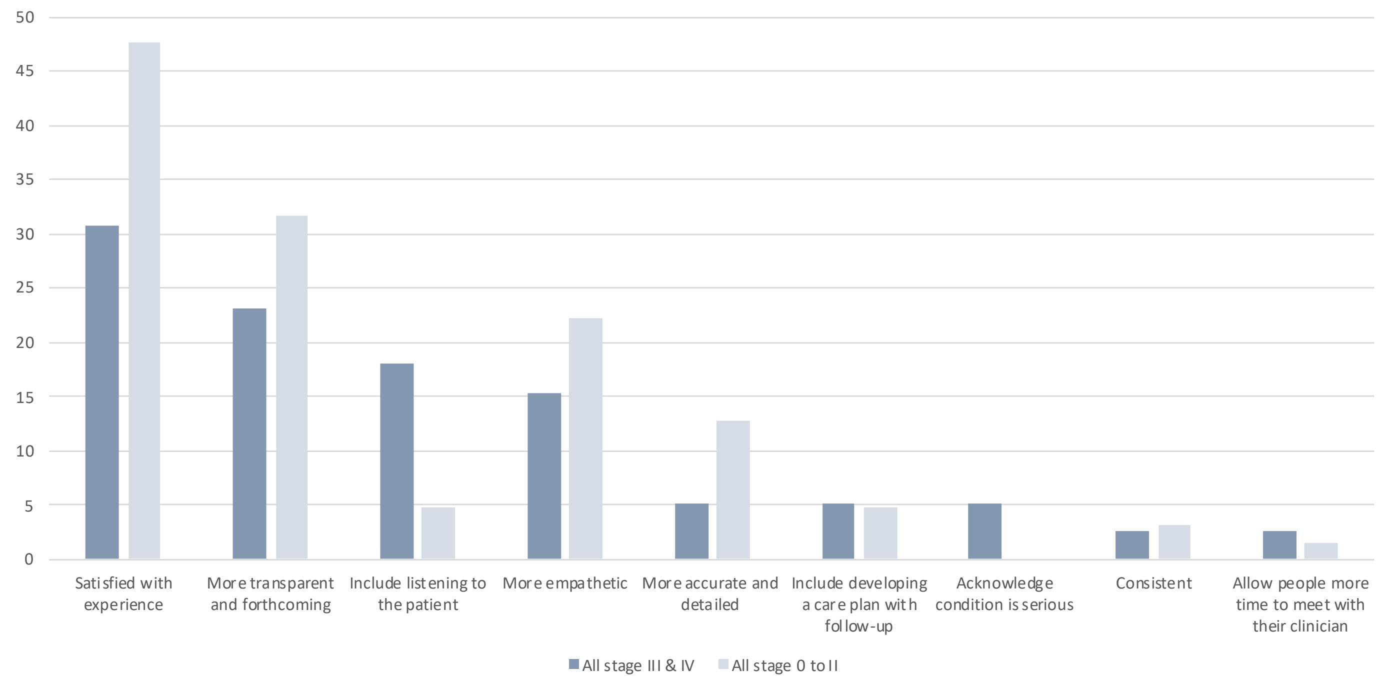


Figure 9.3: Expectations of future healthcare professional communication (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 9.6: Expectations of future healthcare professional communication – Stage III & IV variations

Expectations of future healthcare professional communication	Reported less frequently	Reported more frequently
No particular comment - satisfied with experience	All Stage III & IV Triple negative Stage III & IV	-
Future communication will be more transparent and forthcoming	Hormone receptor Stage III & IV	-
Future communication will include listening to the patient	-	Triple negative Stage III & IV

Expectations of future care and support: Stage III and IV

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common expectation for future care and support was that it will include more access to support services (51.28%), and will include specialist clinics or services where they can talk to professionals (in person, phone, online) (30.77%). Other themes included will include being able to connect with other patients through peer support (support groups, online forums) (12.82%), will include more long-term condition management (care planning) (12.82%), and will be more holistic (including emotional health) (10.26%).

There were 5 participants (12.82%) that had no recommendations and were satisfied with the care and support they received.

Future care and support will include more access to support services

I don't know. I'd probably get support with doing my housework and all that sort of stuff. I think if there are people like myself who I'm very independent, and God, I hate asking for help. I think if they could maybe have more-- I don't know, maybe sit down and talk to people about their situation more. I could have probably done with, maybe, some help around the house, that sort of stuff. I know, like I said, I got the transport, which is awesome. Participant_02TNG 8

I would have loved, absolutely loved the day I was diagnosed to be given the name of someone to go and speak to about the practical stuff. As in what that journey is going to be like, the sorts of people you're going to need to come into contact with, what their roles are, what they do, where you find them, how you contact them. That real step-by-step guide, and I feel like that was the crucial thing that was missing. For *me, I think the diagnosis was just walking out of the doctor's office, not having a clue where to go or who to talk to or what to do, or where I needed to go, and if they say, "Oh, you need this, you need an oncologist, you need to do this, you need these scans." but no guidance as to where to go. I feel like the key thing for me would be a person that you are put in contact with whether it's a breast care nurse, or whether it's another role completely. Someone that you speak to immediately on diagnosis, that we'll be able to answer all of the questions you have about the practical stuff and the treatment. Things around who's involved in the care and what your team is going to look like, and what those people do because when you're new to the journey you have no idea, you have absolutely no clue who these people are and what their roles- Participant_033TNG*

I think it'd be really helpful to somebody just to talk to you more about diet and exercise. I think especially the exercise stuff just to give you some information, I have certain exercises the can help you with the side effects, I think, or what you can actually do. Or how to modify what exercise you're doing. I think stuff like that could be really important. Participant 052_2021AUHRP

Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)

I would have loved, absolutely loved the day I was diagnosed to be given the name of someone to go and speak to about the practical stuff. As in what that journey is going to be like, the sorts of people you're going to need to come into contact with, what their roles are, what they do, where you find them, how you contact them. That real step-by-step guide, and I feel like that was the crucial thing that was missing. For me, I think the diagnosis was just walking out of the doctor's office, not having a clue where to go or who to talk to or what to do, or where I needed to go, and if they say, "Oh, you need this, you need an oncologist, you need to do this, you need these scans." but no guidance as to where to go. I feel like the key thing for me would be a person that you are put in contact with whether it's a breast care nurse, or whether it's another role completely. Someone that you speak to immediately on diagnosis, that we'll be able to answer all of the questions you have about the practical stuff and the treatment. Things around who's involved in the care and what your team is going to look like, and what those people do because when you're new to the journey you have no idea, you have absolutely no clue who these people are and what their roles-. Participant_033TNG

I would love there to be a one-stop-shop so that you go and somebody is there for your physio, your chiropractic, all the breast care, questions that you have. Yes, just a whole umbrella where it's so hard to-- like lymphedema, side effects from chemo, or whatever. Just someone that would deal with all of it. You don't have to run around to so many different professionals and you're constantly-- it's hard to get into appointments as well. Somewhere that just dealt with everything.. Yes. Like a hub for everything. Like you could have your own oncologist in different paths, but this is where you went for everything else. Participant_036TNG

Future care and support will include being able to connect with other patients through peer support (support groups, online forums)

I would like to see support groups or people with similar types of cancer that you have say that you're able to meet other people and talk about your experience with them, because I feel like they understand more like that to me is more beneficial than seeing a psychologist and. So can you repeat the question? Yes, there was something else I had in my head. Participant_038TNG

I believe that the cancer support group, that's just an organization of people going through cancer, that has been very helpful for me. What they're trying to do with the group is to get to people when they're diagnosed because they supply a lot of information that we don't know. You don't know about options about breast surgeons. My GP, who recommended a breast surgeon, he said if his wife had it, he wouldn't send her anywhere else, so I took that as my recommendation, but you've got to make all those decisions and you don't know. Us, as a group together, a list of the surgeons in the area and all that sort of thing and costings and everything like that, but when you're first diagnosed, you're not part of that group because you don't know. It's something that those support groups of people that have gone through it, I think help you more than anything, and getting the information to them. They're putting brochures in the hospitals and things like that to help people. That's the big thing is when you're first diagnosed, you've got so much going on and you don't know. They're saying, "Okay, you got to go and see an oncologist. Who would you like to see?" It's like you never look at-

- No one doesn't know who an oncologist in the area is if you haven't had to deal with anything like that. It's that information in that crucial time when you're first diagnosed that needs to get to people because you don't know. It's even like, I would have been out-of-pocket $10,000 for my radiation if I hadn't have gone to the morning tea that the cancer group had and mentioned it to one of the ladies there, and she told me how to get out of paying it. Things like that. It's that crucial time, right at the beginning when you're up in the air, not knowing where you're coming or going, and you're in such a shock and you've got to make all those decisions. Participant_046TNG

Future care and support will include more long-term condition management (care planning)

Absolutely. Yes, a nutritionist and an exercise program that was monitored. Not somebody telling you, "Oh go home and do situps or walk around the block." Something that's monitored so that you've got accountability so that it helps you to achieve those things. There's no point in people telling you something unless there's a guideline and somebody's helping you along the way. Everybody can tell you you need to lose weight, "Go ahead and lose weight." [chuckles] It's not that easy. Participant_029TNG

Look, I definitely think exercise. I definitely think there needs to be something about-- you finish your chemotherapy and come back in three weeks, you need something in between. They know resistance exercise, like doing something from that point of view helps in terms of prognosis and things like that. I didn't want to do group therapy or anything like that, that wasn't for me, but doing exercise classes and getting a way to keep you moving and stuff like that. I just don't think there's enough of it, and it wasn't highly promoted in the hospital to go and do it. If they say, "Go and move," you go and do these things. I think having a breast care exercise class that I went to, I was one of a few new patients, we only had one or two new patients, there were a lot of older patients in it that were still going. For me, I reckon those exercise classes have to be something to keep people moving. Participant_047TNG

Future care and support will be more holistic (including emotional health)

Psychologists. Cancer psychologists. Participant_042

I think that the program that I had at my hospital that helps with distance and management, I think that is a fantastic thing they've done. I just don't think it's funded enough and there's not enough hours there. I think that, potentially, would be something that's perfect that even the best [unintelligible] can get involved on. You have a hotline that you can ring up and use, whether it be your symptoms and stuff, because you can have physical symptoms, but then you can also have things that you're struggling with. It could be mentally troubling you.
Participant 048_2021AUHRP

Satisfied with care and support

And I think I've been very lucky with the breast nurses and counsellors that I've had, the access I've had to different activities at different hospitals where I support women and men with cancer. It's just getting that information out. But I think I've been very lucky with that sort of thing. Participant_049TNG

Yes, I think the model that is used by the martyr the early breast cancer program. Whenever I've mentioned it to anybody, whether they live in Australia or they live in the UK, they have been blown away by what is singularly one of the best things I've ever did. It quells the panic that I had. It quells the overwhelm of information because I have this one point. I've done it via Zoom as a mentor with them. It works via Zoom. I think that should be looked at as a model and should be replicated as a model. Then the other thing is there needs to be something that may be similar or such is really looking at this post-treatment. It's not just relying on Facebook groups because there's a lot of misinformation that comes from people that mean to what is coming from a good place, but it's not helping. Participant 043_2021AUHRP

Nothing I can think of. I've had access to everything I need. Participant 044_2021AUHRP

Table 9.7: Expectations of future care and support

Expectations of future care and support	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Future care and support will include more access to support services	58	56.86	38	60.32	20	51.28	15	55.56	5	41.67
Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	19	18.63	7	11.11	12	30.77	9	33.33	3	25.00
Future care and support will include being able to connect with other patients through peer support (support groups, online forums)	12	11.76	7	11.11	5	12.82	2	7.41	3	25.00
No particular comment - satisfied with experience	16	15.69	11	17.46	5	12.82	2	7.41	3	25.00
Future care and support will include more long-term condition management (care planning)	11	10.78	6	9.52	5	12.82	2	7.41	3	25.00
Future care and support will be more holistic (including emotional health)	13	12.75	9	14.29	4	10.26	3	11.11	1	8.33
Participant describes the expectation that future care and support will include more access to specialist nurses	4	3.92	2	3.17	2	5.13	2	7.41	0	0.00

Expectations of future care and support	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Future care and support will include more access to support services	58	56.86	24	48.00	34	65.38	9	39.13	29	72.50
Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	19	18.63	10	20.00	9	17.31	1	4.35	6	15.00
Future care and support will include being able to connect with other patients through peer support (support groups, online forums)	12	11.76	6	12.00	6	11.54	4	17.39	3	7.50
No particular comment - satisfied with experience	16	15.69	5	10.00	11	21.15	3	13.04	8	20.00
Future care and support will include more long-term condition management (care planning)	11	10.78	4	8.00	7	13.46	2	8.70	4	10.00
Future care and support will be more holistic (including emotional health)	13	12.75	7	14.00	6	11.54	4	17.39	5	12.50
Participant describes the expectation that future care and support will include more access to specialist nurses	4	3.92	4	8.00	0	0.00	2	8.70	0	0.00

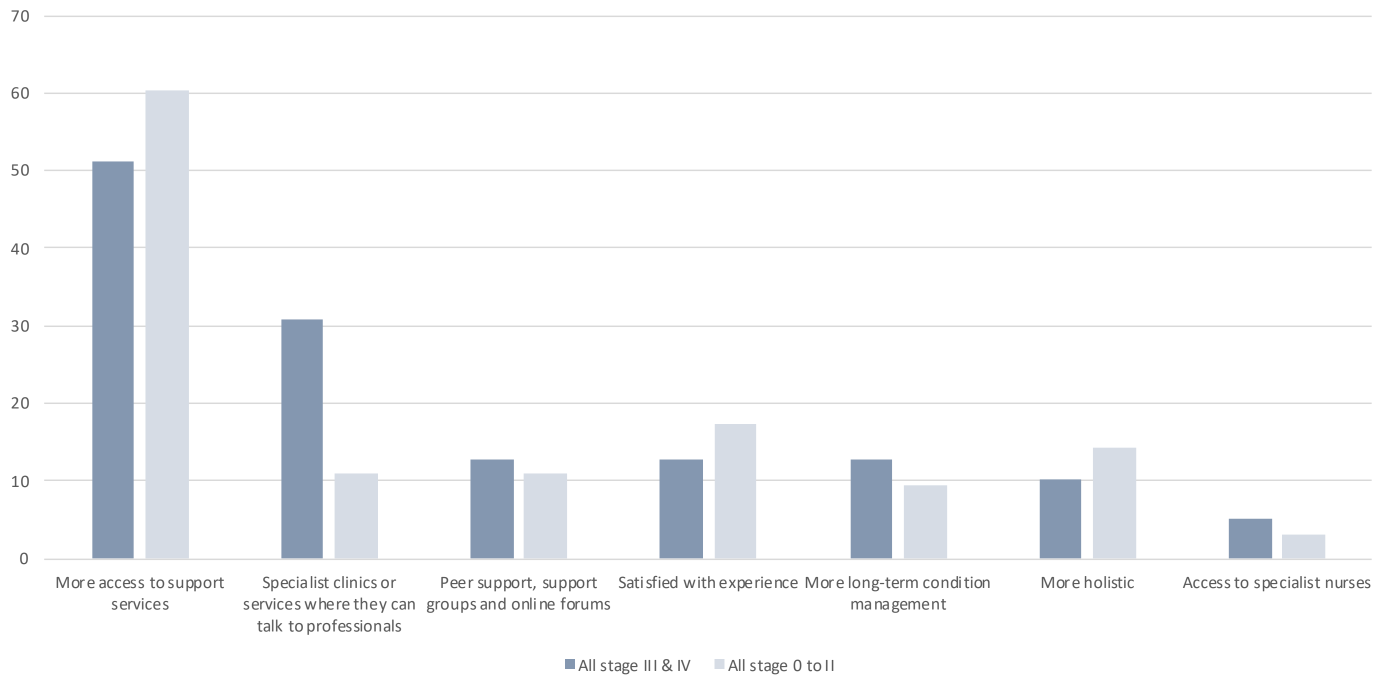


Figure 9.4: Expectations of future care and support (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 9.8: Expectations of future care and support – Stage III & IV variations

Expectations of future care and support	Reported less frequently	Reported more frequently
Future care and support will include more access to support services	Hormone receptor Stage III & IV	-
Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	-	All Stage III & IV Triple negative Stage III & IV
Future care and support will include being able to connect with other patients through peer support (support groups, online forums)	-	Hormone receptor Stage III & IV
Future care and support will include more long-term condition management (care planning)	-	Hormone receptor Stage III & IV

What participants are grateful for in the health system: Stage III and IV

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common responses were that participants were grateful for timely access to treatment (28.21%), healthcare staff (including access to specialists)(28.21%), and the entire health system (20.51 %). Other themes included access to private healthcare/private insurance (17.95%), low cost or free medical care through the government (15.38%), and low cost or free medical treatments through the government (12.82%).

Participant describes being grateful for timely access to treatment

Yes, all of it has been really good. The speed from diagnosis to getting treatment was really quick. It didn't feel it at the time, but I think it was only five weeks from diagnosis to starting chemo. It was quite a quick turnaround. I was able to get appointments with the people I needed to see. The oncologist has been amazing, the breast care nurse has been amazing, the treatment team of the hospital are fantastic. It's all been excellent. There's been no issues at all with the treatment that I've been given. No. Participant_033TNG

Everything. Everything. I've got relatives in England and I know sometimes they have to wait weeks until they can access stuff. Everything happened within a week. The chemo facilities were lovely. The radiation people were marvellous. Like I said, I was lucky to have the Mepitel for nothing. Even the chemo, the oral chemo was easy to get and all that kind of stuff. The lumpectomy was very, very smooth, and they make sure everything is good. I think everything in Australia is very, very good, and we're very lucky. Participant_035TNG

I think having access to all of it has been a blessing and the speed of which I've been able to access has been terrific. I can't fault it. Participant 051_2021AUHRP

Participant describes being grateful for healthcare staff (including access to specialists)

Yes, I guess my particular team has just been outstanding. Participant_041TNG

The fantastic doctors. We've got some of the best breast care nurses in the world, and very lucky to have gotten into here and had an exceptional result. I feel as though the team of nurses and everything are all very caring and very loving. The staff, they do amazing things. Participant_036TNG

Participant describes being grateful for the entire health system

I am eternally grateful I live in Australia and we have the health care system we have. The fact that I could go through the treatment I had to go through and not the out-of-pocket other than the surgery, I will be eternally grateful for. My ex-husband who is American and he has often said to me, "If we were living in America, we couldn't afford to be treated." Yes. I feel that we're truly blessed to have the healthcare system we have in this country. Participant_027TNG

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

Participant describes being grateful for access to private healthcare/private insurance

I had private health care. All my treatment has been through private. This is all in relation to that. Thank God it wasn't an American private health care model. The two-tier that we have, I was really fortunate and it worked for me, I guess that. Thank goodness. It was the two-tier private model. We have not the ridiculous American model. Participant 043_2021AUHRP

I think it was that I did have the choice because I had private health. Other than that, I couldn't really say what the public system was like, but yes, no, I think it was all pretty good. Again, it would just be cost. Participant_024TNG

Participant describes being grateful for low cost/free medical care through the government (Public health system in general)

I'm just very thankful of that our town rallied for a cancer center down here, so I didn't have to travel to get my treatment. The only thing I went through is surgery, so chemo and radiation was all done in my *hometown, which is 10 minutes away. I'm probably thankful for the fact that it costs minimal. That we're not having to pay and remortgage houses for the treatment. [laughs] That's probably the biggest thing I've had with it. Participant_030TNG*

Pretty much grateful for everything because we are lucky where we are. Despite having to wait for things, once you are diagnosed, it is pretty much taken, everything sort of flows, and it is quick to access. The cost is, like I said, I haven't had to pay for anything of my medical treatment at all. Participant 049_2021AUHRP

Participant describes being grateful for low cost/free medical treatments through the government

Well, when I was going through chemo and radiation and it was completely free, I was so grateful that the level of care was there. I must say, even though those doctors-- when I'm saying the doctors, anything that I've said is not against the doctors or the nurses that I dealt with because they've all been amazing, the level of care, caring people, but they're busy and that's not their fault. I would never say that it's their fault because they've all been very caring and concerned, and lovely people. No, I felt grateful that I lived in Australia [chuckles] and had that level of hospital care. Participant_029TNG

The fact that I can receive Palbociclib, the CDK4/6 inhibitor on the PBS for $40 a month is absolutely life-changing because I would be much, much sicker without it. I strongly believe it's responsible for my metastasis disappearing. I know that it's not available in many countries, not accessible and hugely expensive in others. Participant_050TNG

Table 9.9: What participants are grateful for in the health system

What participants are grateful for in the health system	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes being grateful for timely access to treatment	30	29.41	19	30.16	11	28.21	9	33.33	**2**	**16.67**
Participant describes being grateful for healthcare staff (including access to specialists)	33	32.35	22	34.92	11	28.21	8	29.63	3	25.00
Participant describes being grateful for the entire health system	26	25.49	18	28.57	8	20.51	5	18.52	3	25.00
Participant describes being grateful for access to private healthcare/private insurance	18	17.65	11	17.46	7	17.95	**1**	**3.70**	**6**	**50.00**
Participant describes being grateful for low cost/free medical care through the government (Public health system in general)	21	20.59	15	23.81	6	15.38	3	11.11	3	25.00
Participant describes being grateful for low cost/free medical treatments through the government	12	11.76	7	11.11	5	12.82	5	18.52	**0**	**0.00**
Participant describes being grateful for timely access to diagnostics	10	9.80	8	12.70	2	5.13	1	3.70	1	8.33

What participants are grateful for in the health system	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes being grateful for timely access to treatment	30	29.41	17	34.00	13	25.00	8	34.78	11	27.50
Participant describes being grateful for healthcare staff (including access to specialists)	33	32.35	16	32.00	17	32.69	8	34.78	14	35.00
Participant describes being grateful for the entire health system	26	25.49	10	20.00	16	30.77	5	21.74	13	32.50
Participant describes being grateful for access to private healthcare/private insurance	18	17.65	**3**	**6.00**	**15**	**28.85**	2	8.70	9	22.50
Participant describes being grateful for low cost/free medical care through the government (Public health system in general)	21	20.59	9	18.00	12	23.08	6	26.09	9	22.50
Participant describes being grateful for low cost/free medical treatments through the government	12	11.76	**12**	**24.00**	**0**	**0.00**	**7**	**30.43**	**0**	**0.00**
Participant describes being grateful for timely access to diagnostics	10	9.80	4	8.00	6	11.54	3	13.04	5	12.50

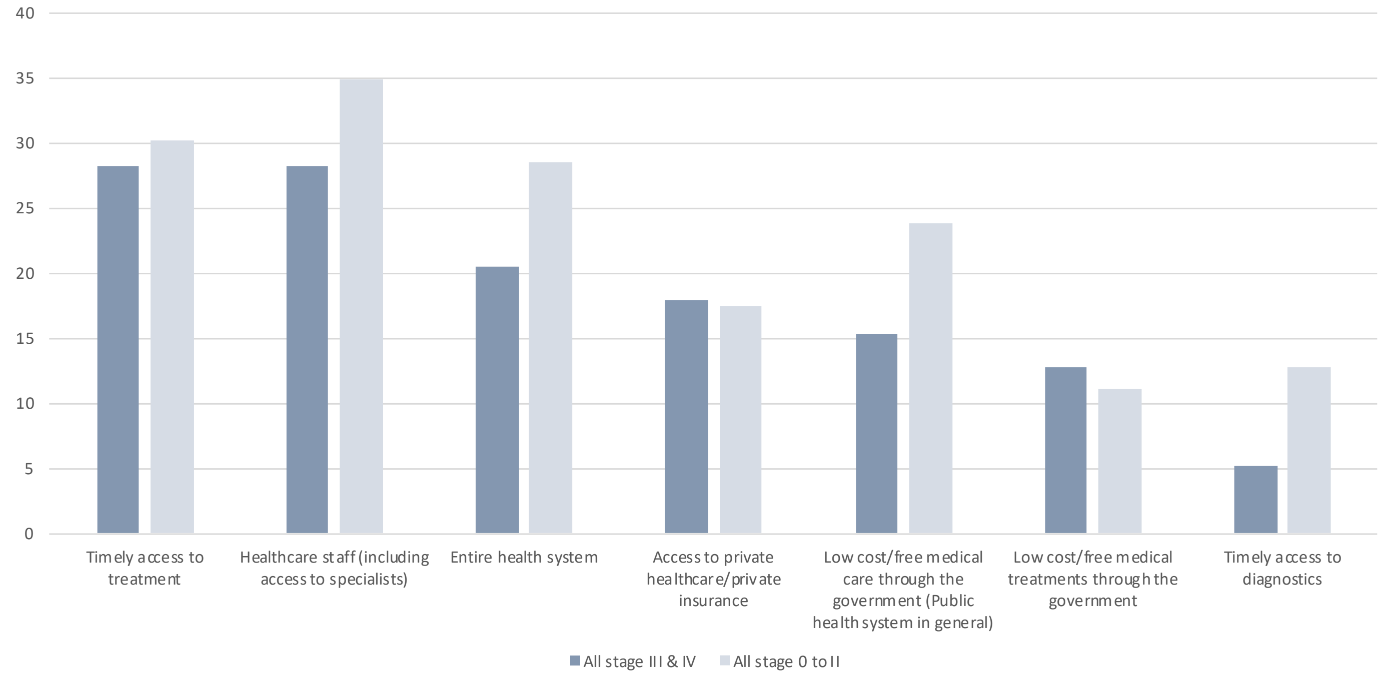


Figure 9.5: What participants are grateful for in the health system (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 9.10: What participants are grateful for in the health system – Stage III & IV variations

What participants are grateful for in the health system	Reported less frequently	Reported more frequently
Participant describes being grateful for timely access to treatment	Hormone receptor Stage III & IV	-
Participant describes being grateful for access to private healthcare/private insurance	Triple negative Stage III & IV	Hormone receptor Stage III & IV
Participant describes being grateful for low cost/free medical treatments through the government	Hormone receptor Stage III & IV	-

Symptoms and aspects of quality of life: Stage III and IV

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, where 1 is the most important and 11 is the least important. A weighted average is presented in Table 9.6, Figure 9.6. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important aspects reported were Fatigue Pain, Fertility, and Heart problems. The least important were Lymphoedema, Menopause and menopausal symptoms, and Body image.

Table 9.11: Symptoms and aspects of quality of life (weighted average)

Symptoms and aspects of quality of life	All participants (n=95)	All stage 0 to II (n=59)	All stage III & IV (n=36)	Stage III & IV triple negative (n=24)	Stage III & IV hormone-receptor positive (n=12)	All Triple negative (n=44)	All hormone-receptor positive (n=51)	Stage 0 to II triple negative (n=20)	Stage 0 to II hormone-receptor positive (n=39)
Fatigue Pain	5.50	5.37	5.73	5.45	6.27	5.66	5.37	5.89	4.77
Lymphoedema	3.21	3.10	3.39	3.73	2.56	3.17	3.25	2.55	3.56
Fertility	4.85	4.25	5.80	7.33	3.50	5.38	4.00	4.20	3.00
Menopause and menopausal symptoms	3.67	4.03	3.13	3.00	3.43	3.04	4.22	3.09	4.36
Anxiety and depression	4.91	5.24	4.44	4.59	4.10	4.82	5.00	5.13	4.89
Body image	3.51	4.00	2.67	2.75	2.57	3.86	3.33	5.33	3.38
Sexual difficulties	3.29	3.18	3.50	2.92	4.67	3.14	3.41	3.40	3.08
Problems with movement and strength	4.85	4.76	4.97	4.90	5.08	5.11	4.65	5.40	4.77
Heart problems	4.95	4.61	5.62	5.81	5.13	5.44	4.50	5.05	5.14
Memory loss and cognitive function (“chemo brain”)	5.04	5.13	4.92	4.50	5.75	4.62	5.42	4.78	5.50
Effects on bones and joints	4.68	4.69	4.66	4.90	4.25	4.60	4.74	4.30	4.50

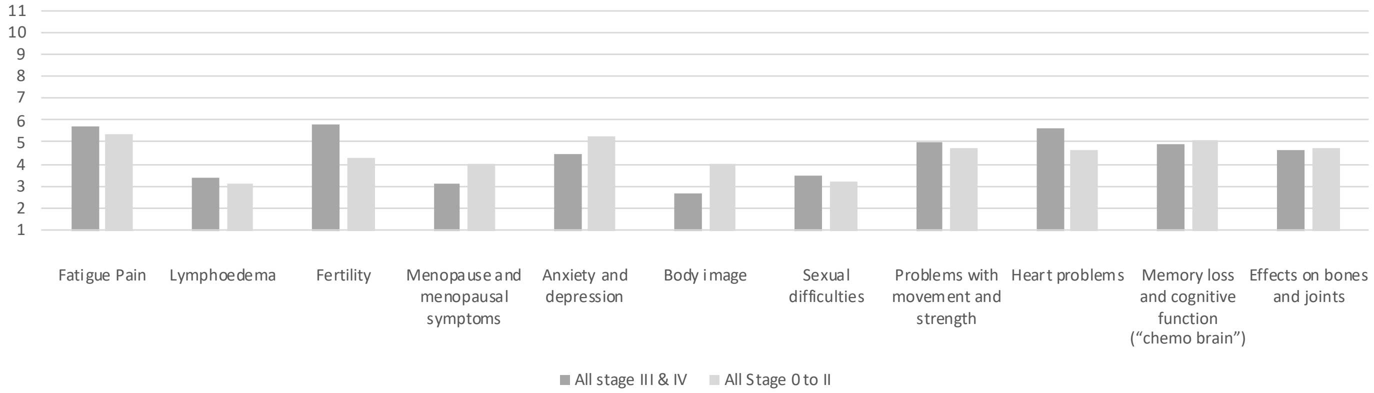


Figure 9.6: Symptoms and aspects of quality of life (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Values in making decisions: Stage III and IV

Participants were asked to rank what is important for them overall when they make decisions about treatment and care, where 1 is the most important and 8 is the least important. A weighted average is presented in Figure 9.7. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important aspects were "How safe the medication is and weighing up the risks and benefits", and "The severity of the side effects". The least important were "Ability to follow and stick to a treatment regime" and "How the treatment is administered".

Table 9.12: Values in making decisions

Values in making decisions	All participants (n=95)	All stage 0 to II (n=59)	All stage III & IV (n=36)	Stage III & IV triple negative (n=24)	Stage III & IV hormone-receptor positive (n=12)	All Triple negative (n=44)	All hormone-receptor positive (n=51)	Stage 0 to II triple negative (n=20)	Stage 0 to II hormone-receptor positive (n=39)
How safe the medication is and weighing up the risks and benefits	6.39	6.49	6.22	5.92	6.83	6.25	6.51	6.65	6.43
The severity of the side effects	5.66	5.59	5.78	5.58	6.17	5.55	5.76	5.50	5.91
Time impact of the treatment on my quality of life	5.01	5.00	5.03	4.58	5.92	4.84	5.16	5.15	5.22
How the treatment is administered	3.39	3.51	3.19	2.96	3.67	3.25	3.51	3.60	3.26
How personalised the treatment is for me	5.47	5.42	5.56	6.08	4.50	5.61	5.35	5.05	5.52
The ability to include my family in making treatment decisions	3.27	3.20	3.39	4.13	1.92	3.82	2.80	3.45	3.30
Ability to follow and stick to a treatment regime	3.56	3.66	3.39	3.29	3.58	3.11	3.94	2.90	4.17
The financial costs to me and my family	3.24	3.12	3.44	3.46	3.42	3.57	2.96	3.70	2.17

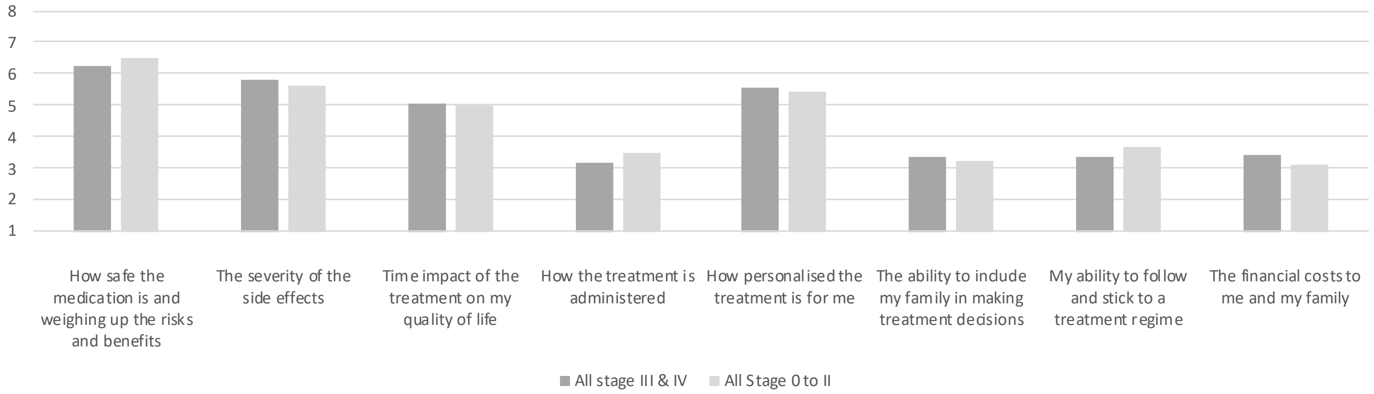


Figure 9.7: Values in making decisions (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Values for decision makers: Stage III and IV

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care, where 1 is the most important and 5 is the least important. A weighted average is presented in Figure 9.8. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important values were “Quality of life for patients”, and “All patients being able to access all available treatments and services”. The least important was “Economic value to government and tax payers”.

Table 9.13: Values for decision makers

Values for decision makers	All participants (n=95)	All stage 0 to II (n=59)	All stage III & IV (n=36)	Stage III & IV triple negative (n=24)	Stage III & IV hormone-receptor positive (n=12)	All Triple negative (n=44)	All hormone-receptor positive (n=51)	Stage 0 to II triple negative (n=20)	Stage 0 to II hormone-receptor positive (n=39)
Economic value to government and tax payers	4.24	4.29	4.17	4.17	4.17	4.27	4.22	4.40	4.39
Economic value to patients and their families	5.61	5.66	5.53	5.63	5.33	5.68	5.55	5.75	5.83
Quality of life for patients	6.97	7.08	6.78	6.75	6.83	6.80	7.12	6.85	7.30
Compassion	6.07	5.97	6.25	6.17	6.42	6.16	6.00	6.15	5.74
All patients being able to access all available treatments and services	7.11	7.00	7.28	7.29	7.25	7.09	7.12	6.85	6.74

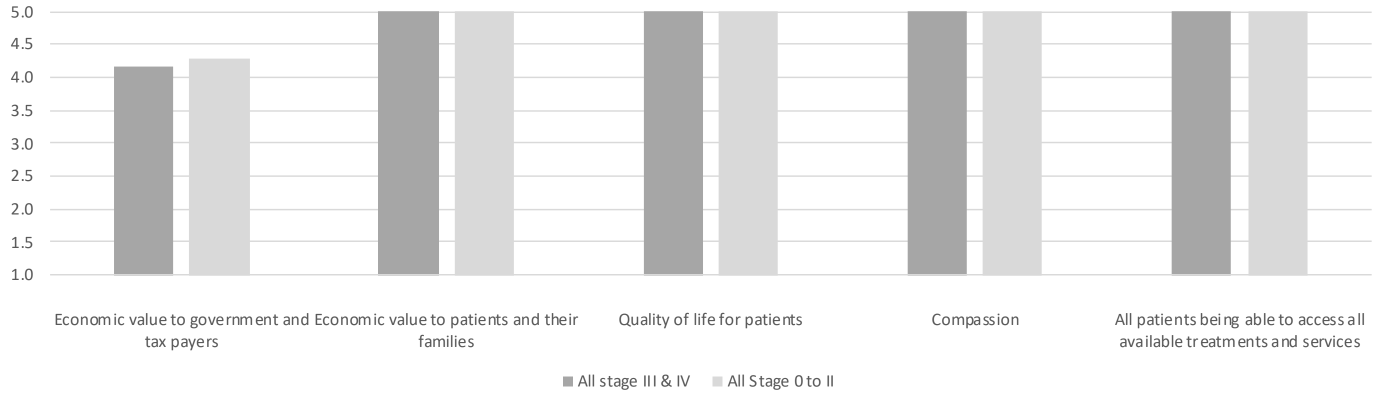


Figure 9.8: Values for decision makers (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Time taking medication to improve quality of life: Stage III and IV

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn’t offer a cure.

The majority of participants (n = 20, 55.56%) would use a treatment for more than ten years for a good quality of life even if it didn’t offer a cure (Table 9.14, Figure 9.9).

Table 9.14: Time taking treatment to improve quality of life

Time taking medication to improve quality of life	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	(n=95)	%	(n=59)	%	(n=36)	%	(n=24)	%	(n=12)	%
Less than 1 year	1	1.05	0	0.00	1	2.78	1	4.17	0	0.00
1 to 5 years	38	40.00	25	42.37	13	36.11	8	33.33	5	41.67
5 to 10 years	3	3.16	1	1.69	2	5.56	1	4.17	1	8.33
More than 10 years	53	55.79	33	55.93	20	55.56	14	58.33	6	50.00

Time taking medication to improve quality of life	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=95	%	(n=44)	%	(n=51)	%	(n=20)	%	(n=39)	%
Less than 1 year	1	1.05	1	2.27	0	0.00	0	0.00	0	0.00
1 to 5 years	**20**	**21.05**	14	31.82	24	47.06	6	30.00	19	48.72
5 to 10 years	**20**	**21.05**	1	2.27	2	3.92	0	0.00	1	2.56
More than 10 years	53	55.79	28	63.64	25	49.02	**14**	**70.00**	19	48.72

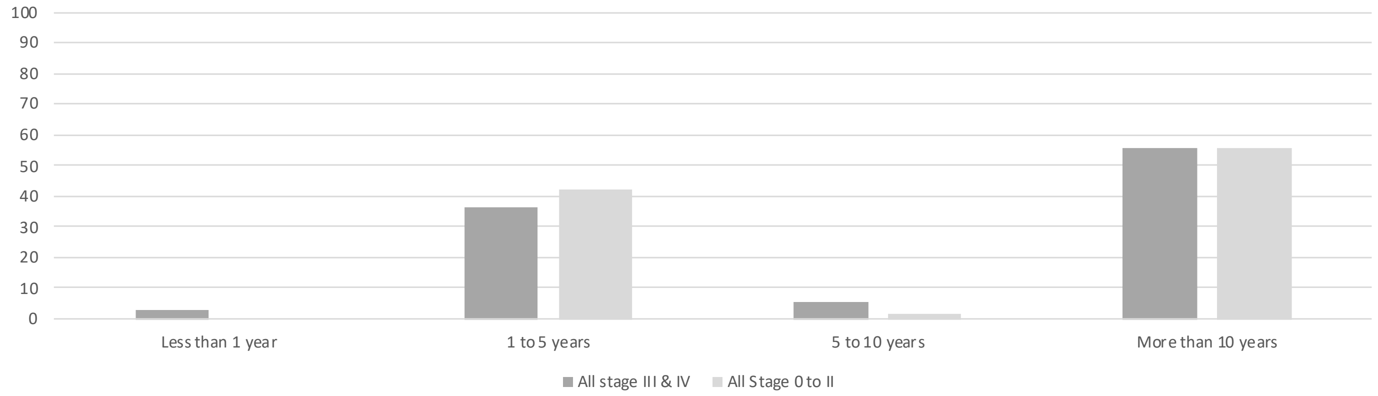


Figure 9.9: Time taking treatment to improve quality of life (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Most effective form of medicine: Stage III and IV

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in (Table 9.15, Figure 9.10).

There were 15 participants (41.67%) that thought that medicine delivered by IV was most effective, no participants (0.00%) thought that pill form was most effective, and 11 participants (30.56%) that thought they were equally effective. There were 10 participants (27.78%) that were not sure.

Table 9.15: Most effective form of medicine

Most effective form of medicine	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	(n=95)	%	(n=59)	%	(n=36)	%	(n=24)	%	(n=12)	%
Equally effective	37	38.95	22	37.29	15	41.67	10	41.67	5	41.67
In a pill form that I can take at home	6	6.32	6	10.17	0	0.00	0	0.00	0	0.00
IV form (through a drip in hospital	20	21.05	9	15.25	11	30.56	8	33.33	3	25.00
Not sure	32	33.68	22	37.29	10	27.78	6	25.00	4	33.33

Most effective form of medicine	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=95	**%**	**(n=44)**	**%**	**(n=51)**	**%**	**(n=20)**	**%**	**(n=39)**	**%**
Equally effective	37	38.95	16	36.36	21	41.18	6	30.00	16	41.03
In a pill form that I can take at home	6	6.32		0.00	6	11.76	0	0.00	6	15.38
IV form (through a drip in hospital	20	21.05	15	34.09	5	9.80	7	35.00	2	5.13
Not sure	32	33.68	13	29.55	19	37.25	7	35.00	15	38.46

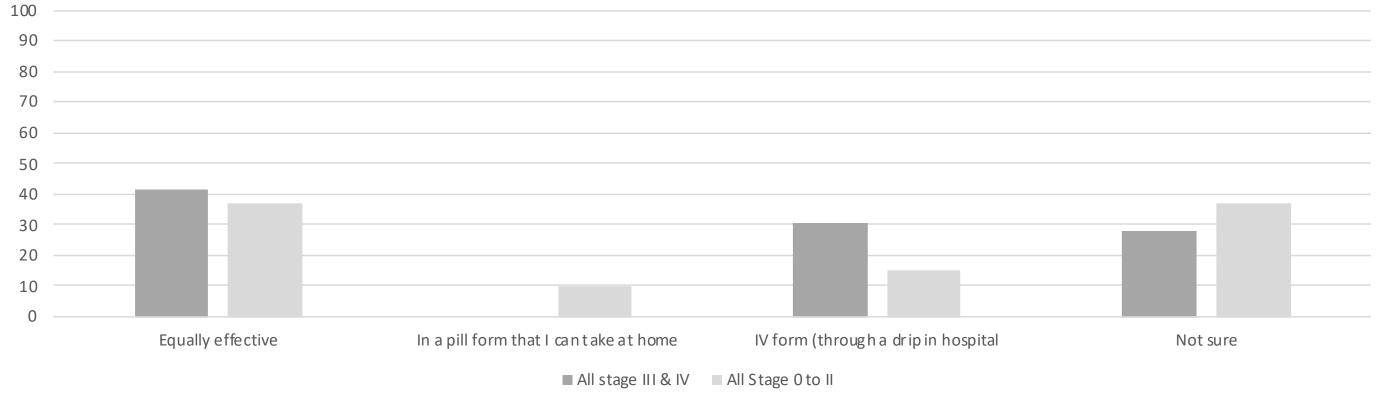


Figure 9.10: Most effective form of medicine (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 9.16: Most effective form of medicine – Stage III & IV variations

Most effective form of medicine	Reported less frequently	Reported more frequently
IV form (through a drip in hospital	-	Triple negative Stage III & IV

Messages to decision-makers: Stage III and IV

Participants were asked, “If you were standing in front of the health minister, what would your message be in relation to your condition?” The most common messages to the health minister were the need for timely and equitable access to support, care and treatment (46.15%), to understand the financial implications (and provide financial support) (28.21%), and the need for a tailored care plan (15.38 %). Other themes included to increase investment (general) (12.82%), to invest in professional development so that clinicians understand the condition (10.26%),to have a holistic approach to the condition (including emotional support) (7.69%), and to improve wait times (7.69%).

Timely and equitable access to support, care and treatment

Probably I think people think once you've had treatment and you've had the chemo when your so called cancer free and that's it. I think psychologically afterwards I think women would be good if there was follow up and some sort of psychological or mental health check or Yeah, I think it all happens while you're having treatment and the breast care nurse comes out and all that and then once you're done, that's it, you don't hear from anyone. Except for this study. It's like your treatment's done, but you're better now you're good, off you go. You're on your own, and I still don't have a boob. Participant 041_2021AUHRP

I would definitely say that people should have equal access to everything. I said before about having surgery paid publicly, so it shouldn't matter. It should all be the same for everybody regardless of whether you're through a private health fund or you have none at all. I feel as though you're actually worse off being through the private system yet our whole tax system says that you need to be part of a private health fund over 30 so it feels very contradictory to me. It'd be one thing I'll definitely say you need to look at. Participant_036TNG

Understand the financial implications (and provide financial support)

I think the radiation, it's a big thing for treatment, the costings and all that sort of thing. Even though I go Private Health, the out-of-pocket is ridiculous. If you pay into a health fund, you shouldn't have to pay any out-of- pocket for anything, I believe. With the radiation, I would have had to travel an hour there and an hour back each day, if I wanted to go somewhere where I had bulk-billed radiation. Anyone in this area, it's an hour travel there and back, and you'd have to get someone to take you because you don't feel like driving afterwards. It's something that's a bit tough if you can't get to the public radiation places. They should be able to provide some assistance through the others, but like I said, you can, and you don't know those things unless you have people that will tell you those things beforehand. Participant_046TNG

I guess just that the out-of-pocket costs are really hard to manage Participant_041TNG

Participant's message is that tailored care plans are needed

Look, I would say that it’s pretty good. The one thing I would say and what I have noticed through my own research and I’ve asked questions on the triple-negative page which I’m on, is that there's women who are younger and younger being diagnosed with breast cancer and I think there needs to be more targeting to younger women. Participant_034TNG

Making sure that all new chemotherapies are viable for metastatic breast cancer? Unfortunately, a lot of these drugs that are coming out that approved there aren't a primary. They should be more thought go into women with metastatic breast cancer and being able to access chemotherapy at CBS process. Women with breast cancer can be cured. They're not going to die of metastatic, we are going to die. But if you can prolong someone's life with a drug that is being put on the PB's and not having to pay, say, forty thousand dollars for three months of treatment, that would be a huge help with that. Participant_049TNG

Increase investment (general)

Fund more Stage 4. One in three women potentially will move on to be metastatic. I think it's underfunded. Actually, could I change that? Get more support for stage 4, but particularly research around the recurrence of stage 4. The fact that we don't actually know is outrageous. The fact that they don't actually track and have any statistics about stage 4. More funding and research around stage 4. Participant 043_2021AUHRP

Please keep funding a variety of research into breast cancer. A variety of research. Participant 047_2021AUHRP

Invest in professional development so that clinicians understand the condition

Breast care nurses. We need more breast care nurses, 24 hours, 7 days a week. We need that resource. I was going through treatment and one of the nurses was telling me that they had their hours cut at the hospital. I just thought, "How can they cut their hours? It's just crazy." I go to Gold Coast Uni and there was hundreds of cancer patients through there at the time. I think they did a bit of a petition too. I was telling somebody in one of the Facebook groups, and I think they all petitioned to see if we can get more hours for the breast care nurses. They're so underrated and their assistance is amazing. Participant_029TNG

I haven't really thought of something like that. I know that there's a lot of courses out there that are pushing more money, obviously is one and that's generally to support. If we could have a couple of extra breast care nurses in our hometown, I think the things that I've got concerns about would be answered. It's getting more bodies in there to then create that access. Yes, and just generally pour more money to research, get it done. The amount of money going into cancer research and stuff like that and to not have, we can get a COVID vaccine for crying out loud. [crosstalk] We can't get something to cancer why? But, anyway. Participant_030TNG

Holistic approach to the condition (including emotional support)

They also need to make treatment more affordable, that sort of thing. That has to change. Just because you don't have a lot of money and, say, can't afford to pay hundreds of thousands of dollars for treatment, doesn't mean you should be punished for it. We should all be able to access the treatment, especially if we can see that it's working. Basically more, unfortunately, more money needs to be spent on curing cancer or cancer treatments. I don't know if that's ever going to happen. I don't know how much they're going to be able to perfect it, but I can see that it is starting to happen. They also need to do something with regards to the impact that it has on a person's mental health as well. It's still a lot that needs to be done. Participant_038TNG

I would definitely say that people should have equal access to everything. I said before about having surgery paid publicly, so it shouldn't matter. It should all be the same for everybody regardless of whether you're through a private health fund or you have none at all. I feel as though you're actually worse off being through the private system yet our whole tax system says that you need to be part of a private health fund over 30 so it feels very contradictory to me. It'd be one thing I'll definitely say you need to look at. I also think I would be telling him that there needs to be more care given in terms of, I guess if you said holistic. There needs to be more access to physios and psychologists and things like that as part of a government rollout. Participant_036TNG

It's such a huge thing now, such a big population of people have breast cancer so I think that all hospitals-- I think they are starting to have it now should have specialty areas for that demographic of people. I think that has access through a lot of different services to help people mentally, physically get through this and rehabilitate because it is something that you'll--especially after a double mastectomy or anything. If I had my legs chopped off, I'd be sent to rehab to get a new, and they'll have services available to help me walk again and to do all the things and they'll probably address my mental health and all that stuff more than when you get your breasts cut off. I think that's not recognized. I think that there needs to be some form of rehabilitation after that to help people get through because breast cancer diagnosis isn't something that you can just then get well from, I think it's something that you live with for the rest of your life, and you're mentally going to be always worried that it's going to come back again. I think there needs to be more fully into improving the quality of life and helping people get through this situation. Participant 048_2021AUHRP

Table 9.16 Messages to decision-makers

Message to decision-makers	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Timely and equitable access to support, care and treatment	48	47.06	30	47.62	18	46.15	11	40.74	7	58.33
Understand the financial implications (and provide financial support)	24	23.53	13	20.63	11	28.21	8	29.63	3	25.00
Participant's message is that tailored care plans are needed	11	10.78	5	7.94	6	15.38	6	22.22	0	0.00
Increase investment (general)	16	15.69	11	17.46	5	12.82	3	11.11	2	16.67
Invest in professional development so that clinicians understand the condition	7	6.86	3	4.76	4	10.26	4	14.81	0	0.00
Holistic approach to the condition (including emotional support)	11	10.78	8	12.70	3	7.69	3	11.11	0	0.00
Improve wait times	9	8.82	6	9.52	3	7.69	0	0.00	3	25.00
Compassionate and empathetic	6	5.88	4	6.35	2	5.13	0	0.00	2	16.67
Invest in screening/early detection	6	5.88	4	6.35	2	5.13	0	0.00	2	16.67
Improve rural services	6	5.88	4	6.35	2	5.13	0	0.00	2	16.67
No particular comment - satisfied with experience	5	4.90	4	6.35	1	2.56	1	3.70	0	0.00
Help raise community awareness	2	1.96	1	1.59	1	2.56	1	3.70	0	0.00
Participant's message is that it it is life-long that needs to be managed	1	0.98	0	0.00	1	2.56	1	3.70	0	0.00
Participant's message is that there needs to be support for side effects and symptoms, including long term follow up and support	6	5.88	5	7.94	1	2.56	0	0.00	1	8.33
Treatments need to be affordable	13	12.75	13	20.63	0	0.00	0	0.00	0	0.00

Message to decision-makers	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Timely and equitable access to support, care and treatment	48	47.06	22	44.00	26	50.00	11	47.83	19	47.50
Understand the financial implications (and provide financial support)	24	23.53	16	32.00	8	15.38	8	34.78	5	12.50
Participant's message is that tailored care plans are needed	11	10.78	11	22.00	0	0.00	5	21.74	0	0.00
Increase investment (general)	16	15.69	7	14.00	9	17.31	4	17.39	7	17.50
Invest in professional development so that clinicians understand the condition	7	6.86	7	14.00	0	0.00	3	13.04	0	0.00
Holistic approach to the condition (including emotional support)	11	10.78	5	10.00	6	11.54	2	8.70	6	15.00
Improve wait times	9	8.82	0	0.00	9	17.31	0	0.00	6	15.00
Compassionate and empathetic	6	5.88	0	0.00	6	11.54	0	0.00	4	10.00
Invest in screening/early detection	6	5.88	0	0.00	6	11.54	0	0.00	4	10.00
Improve rural services	6	5.88	0	0.00	6	11.54	0	0.00	4	10.00
No particular comment - satisfied with experience	5	4.90	5	10.00	0	0.00	4	17.39	0	0.00
Help raise community awareness	2	1.96	2	4.00	0	0.00	1	4.35	0	0.00
Participant's message is that it it is life-long that needs to be managed	1	0.98	1	2.00	0	0.00	0	0.00	0	0.00
Participant's message is that there needs to be support for side effects and symptoms, including long term follow up and support	6	5.88	0	0.00	6	11.54	0	0.00	5	12.50
Treatments need to be affordable	13	12.75	0	0.00	13	25.00	0	0.00	13	32.50

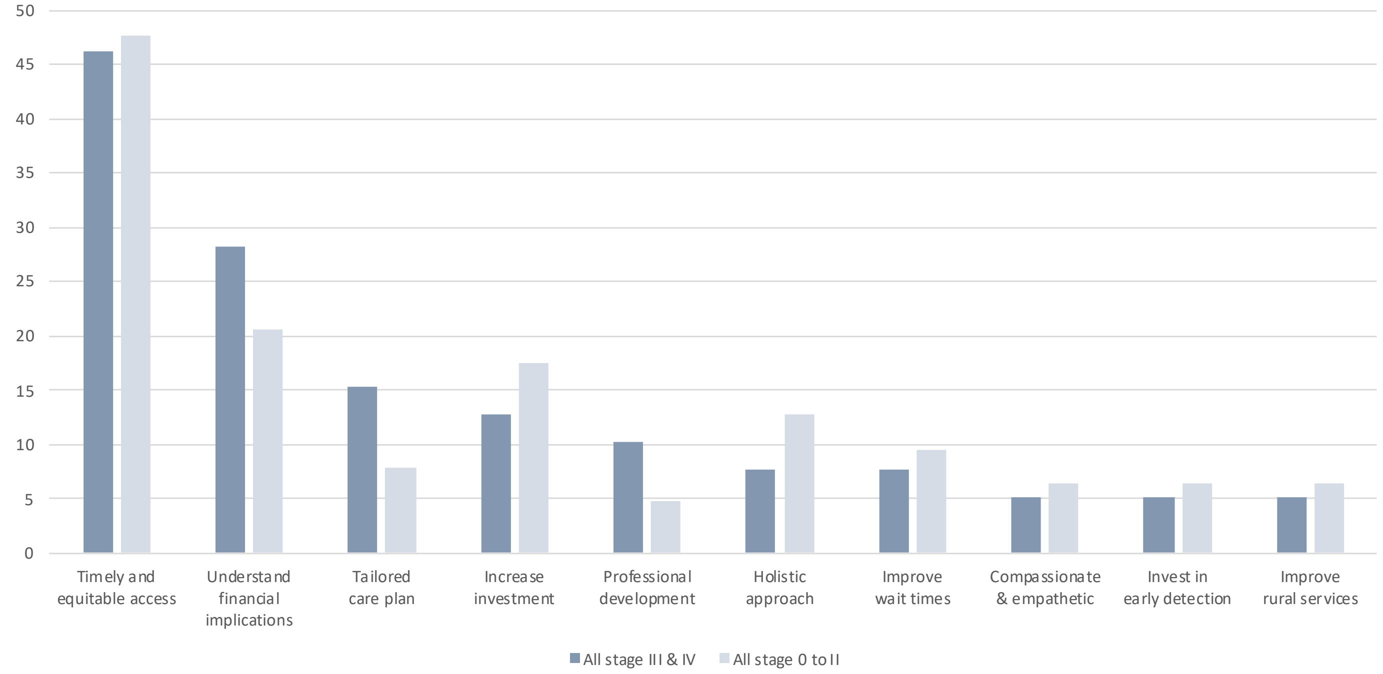


Figure 9.11: Messages to decision-makers (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 9.18: Messages to decision-makers – Stage III & IV variations

Message to decision-makers	Reported less frequently	Reported more frequently
Timely and equitable access to support, care and treatment	-	Hormone receptor Stage III & IV
Participant's message is that tailored care plans are needed	Hormone receptor Stage III & IV	Triple negative Stage III & IV
Holistic approach to the condition (including emotional support)	Hormone receptor Stage III & IV	-
Improve wait times	-	Hormone receptor Stage III & IV
Compassionate and empathetic	-	Hormone receptor Stage III & IV
Invest in screening/early detection	-	Hormone receptor Stage III & IV
Improve rural services	-	Hormone receptor Stage III & IV
Treatments need to be affordable	All Stage III & IV Triple negative Stage III & IV Hormone receptor Stage III & IV	-

Section 10

Advice to others in the future: The benefit of hindsight

Section 10: Advice to others in the future

Anything participants wish they had known earlier: Stage III & IV

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common things that participants had wished they'd known earlier were what to expect from their condition, particularly disease trajectory and understanding of disease biology (28.21%), more about the pros and cons of treatment options (15.38%), and more about what support was available to them (15.38 %). Other themes included the early signs and symptoms of the condition (12.82%), more about side effects of treatments (10.26%), and to sought seek medical attention sooner, or had population screening sooner (7.69%).

Other participants described that there was nothing they wished they had known earlier, some gave no reasons for this no (15.38%), and others did not describe anything they wish they'd known earlier as they are learning progressively/continuously (7.69%).

Aspect of care or treatment they would change: Stage III & IV

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common themes were that they would change or stop the kind of treatment they received (12.82%), and would have liked more information/discussion from healthcare staff (7.69%).

Others described that they would not change any aspect of their care or treatment without giving a reason (23.08%), and would not change any aspect of their care or treatment/satisfied with care and treatment received (17.95%).

Expectations of future treatment: Stage III and IV

Participants were asked in the structured interview what their expectations of future treatments are. The most common responses were that future treatment will be more affordable (38.46%), and have fewer or less intense side effects/more discussion about side effects (30.77%). Other themes included be more effective and/or targeted (personalised) (17.95%), have more research/advances for treatment (10.26%),be easier to administer and/or able to administer at home and/or less invasive (10.26%), and be accessible (timely, equitable, location) (7.69%).

Future treatment will be more affordable

Obviously because I was triple-negative, I'd like to see a proper targeted treatment for triple-negative, so that it's not just a case of, "Well, let's just throw everything at it and hope for the best." Definitely, for me, that's a really big thing is finding the reason for triple-negative and why triple-negative happens when it's not a genetic mutation, and having a proper targeted treatment for it. Obviously, having access to the current drugs that we have, that may not necessarily have been created for breast cancer, but now they're finding work on particularly triple-negative, having them added to the PBS and not paying a ridiculous amount out of pocket, and making it within people's financial reach would be really important. Participant_025TNG

I personally think that you shouldn't have to pay for anything. I don't know why some stuff is charged for, and some stuff isn't. I wish the government just funded it. That was something that we found really difficult. We just didn't know if we went if we were going to get a bill for something or not. I wish chemo didn't make them sick, but I don't really think there's anything anybody can tell about that. Participant_043TNG

Cost is a big one. There was a clinical trial that I could've had the immunotherapy for free, but the doctor said it was too risky to wait. It boggles my mind to think about the poor people that couldn't afford to have it and therefore the positive effects that I won't be having for them just because they weren't in a good financial position or have somebody either that could fund it for them or to gather the funding to cover it. I know it can't be offered everywhere, but I've got a friend, she has to travel well over an hour to get treatment for a different kind of cancer from where she lives. Participant_048TNG

Future treatments will have fewer or less intense side effects/more discussion about side effects

I don't think anyone should have to pay in Australia for health care of that nature. Because I think it puts a value on people's lives, that is unrealistic because you know you can't do that assess that someone's life is more valuable than someone else's or someone else's can afford it more than someone else. I think it should all be free or you know covered like with Medicare. As far as treatment something other than chemo would be fantastic that doesn't mush your brain and puts you in a perpetual state of old ladyness. No offense to old ladies but I would have liked to go up there naturally and then um you know if there are side effects you know what work harder on getting treatments for it not to say well you know suck it up because like like like I have realized recently that we are living longer which means they're living longer with the side effects. I you know, you need to have a good quality of life not just enough just to live because you might last five years or whatever. I'm gonna live a long life hopefully. Participant 045_2021AUHRP

And I'd like to see my side effects, obviously, from chemo, but I think it would be nice to have it has the chemo administered at home. But you've still got to see the doctor anyway, say, you know, and I think that a lot of the time you could be that video game or something like that, you could be with the doctor. So I think that that would be helpful so that you don't have to leave the house and especially in the uncertainty when you're immunocompromised. It's really scary to go into a hospital because you don't know, you know, who everybody is or where they've been. Participant_038TNG

Future treatment will be more effective and/or targeted (personalised)

I'd just like to see new treatments that are more successful with less side effects, more targeted, I guess. More targeted treatments, rather than your whole body getting sick. Participant_037TNG

Now I consider that not only the fact that I have fought breast cancer, but now it's all these other things that are going to go along with it. I think that that needs to improve in more understanding and more, I don't know, surely there is something that they can do to that is going to target better or I don't know. You try to get through one thing, but now you *have just jeopardized a whole lot of other body systems. Participant 048_2021AUHRP*

Participant describes the expectation that future treatment will informed by more research/advances in treatments

For regional Australia. I would like to see more possibilities, yes. More different treatments if more choices given even for trial things and stuff. Participant_031

Me personally, I think they need to stop using these particular chemo drugs, they're barbaric. They've been around since the 1940s. I even read an article about how, I can't remember which one of the chemo drugs it is, it can affect your heart. I think the article was saying that they could do something to improve the chemo medication, but they won't. I was just like, "Okay." It's like they're basically injecting poison into our bodies, that obviously gives us really bad side effects because of what it is to cure our cancer. Then, with the whole, as well, having to have your breasts removed, where you might have a lump, I don't know what I'm going to do yet, but just say, for example, I had to have a double mastectomy. I know they're doing some clinical trials in Texas, where they're just doing the chemotherapy or whatever, they're not actually doing the surgery. I think I get really annoyed when I see, always, ads or whatever, they come up on my feed on Facebook or Instagram to say, "Oh, we're trying to find a cure for cancer." It's like, "Well, we've been donating money to these causes for years and years and years, you still haven't found a cure for cancer. You're still using all these barbaric treatments." Something has to change. I know that I have a rare and aggressive form of cancer. I also know that one of the ladies in my group, she's terminal because she was chemo-resistant, but she actually started a petition, so we can have access to molecular testing and different types of chemo. She actually went to Canberra to speak to Greg Hans about it. Funding will come through, I think it's in November, for testing and treatment. They just have to go through PBS, so people like myself, people that don't have a lot of money can access that sort of treatment. Sorry, I know I'm going on and on. Participant_028TNG

Future treatment will be easier to administer and/or able to administer at home and/or less invasive

And I'd like to see my side effects, obviously, from chemo, but I think it would be nice to have it has the chemo administered at home. But you've still got to see the doctor anyway, say, you know, and I think that a lot of the time you could be that video game or something like that, you could be with the doctor. So I think that that would be helpful so that you don't have to leave the house and especially in the uncertainty when you're immunocompromised. It's really scary to go into a hospital because you don't know, you know, who everybody is or where they've been. Participant_038TNG

Oh, gosh, if there could be a treatment that has no side effects, that would be a miracle. Obviously, if you weren't having cell, you're having IV That would be great because I have come out of treatment at times looking like the walking wounded where they've tried three or four times to hit a vein. Yes, avoiding that would be great. It's really anything that can lessen side effects, and then is more easily administered would be wonderful. Participant_027TNG

I think it would be good if we were given the option to be tested prior to starting a treatment. I didn't know about that test until after I finished my treatment. It would've been good to have that initially. I would have paid for it had I known, but I didn't even know about it. Participant_045TNG

Participant describes the expectation that future treatments will more accessible (Timely, equitable, location)

Could I have none of that stuff, no cost, no side effects? That'd be awesome. It's interesting that where it's been administered does impact. I feel like an absolute winger to say that the trial just being in LOCATION went on both in LOCATION, that was-- I wouldn't say problematic, but it was more impactful than the ones at my closer hospital, which is only within 10, 15 minutes, as different to half an hour, 45 minutes drive. Having to wait six weeks for a specialist appointment rather than get in in a timely fashion, when you know things are hanging in the balance, that's really a relief when that stuff comes through. Obviously, it'd be nice if things were reasonably priced, but I think just having availability is the first and most important thing. Sure, I don't want side effects, but damn I want availability of stuff if it's going to make a difference. Participant 051_2021AUHRP

Table 9.1: Expectations of future treatment

Expectations of future treatment	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Future treatment will be more affordable	28	27.45	13	20.63	15	38.46	10	37.04	5	41.67
Future treatments will have fewer or less intense side effects/more discussion about side effects	39	38.24	27	42.86	12	30.77	7	25.93	5	41.67
Future treatment will be more effective and/or targeted (personalised)	25	24.51	18	28.57	7	17.95	4	14.81	3	25.00
Participant describes the expectation that future treatment will informed by more research/advances in treatments	8	7.84	4	6.35	4	10.26	4	14.81	0	0.00
Future treatment will be easier to administer and/or able to administer at home and/or less invasive	7	6.86	3	4.76	4	10.26	4	14.81	0	0.00
Participant describes the expectation that future treatments will more accessible (Timely, equitable, location)	8	7.84	5	7.94	3	7.69	0	0.00	3	25.00
Future treatment will involve a more holistic approach	7	6.86	5	7.94	2	5.13	2	7.41	0	0.00
Future treatment will be the same as it is now	5	4.90	3	4.76	2	5.13	2	7.41	0	0.00
Future treatments are important but we cannot ignore prevention, awareness and education	5	4.90	3	4.76	2	5.13	2	7.41	0	0.00
Participant describes the expectation that future treatment will be accompanied with more support and care planning, particularly post treatment	4	3.92	2	3.17	2	5.13	2	7.41	0	0.00
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	8	7.84	6	9.52	2	5.13	0	0.00	2	16.67

Expectations of future treatment	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Future treatment will be more affordable	28	27.45	11	22.00	17	32.69	1	4.35	12	30.00
Future treatments will have fewer or less intense side effects/more discussion about side effects	39	38.24	12	24.00	27	51.92	5	21.74	22	55.00
Future treatment will be more effective and/or targeted (personalised)	25	24.51	11	22.00	14	26.92	7	30.43	11	27.50
Participant describes the expectation that future treatment will informed by more research/advances in treatments	8	7.84	8	16.00	0	0.00	4	17.39	0	0.00
Future treatment will be easier to administer and/or able to administer at home and/or less invasive	7	6.86	7	14.00	0	0.00	3	13.04	0	0.00
Participant describes the expectation that future treatments will more accessible (Timely, equitable, location)	8	7.84	0	0.00	8	15.38	0	0.00	5	12.50
Future treatment will involve a more holistic approach	7	6.86	7	14.00	0	0.00	5	21.74	0	0.00
Future treatment will be the same as it is now	5	4.90	5	10.00	0	0.00	3	13.04	0	0.00
Future treatments are important but we cannot ignore prevention, awareness and education	5	4.90	5	10.00	0	0.00	3	13.04	0	0.00
Participant describes the expectation that future treatment will be accompanied with more support and care planning, particularly post treatment	4	3.92	4	8.00	0	0.00	2	8.70	0	0.00
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	8	7.84	0	0.00	8	15.38	0	0.00	6	15.00

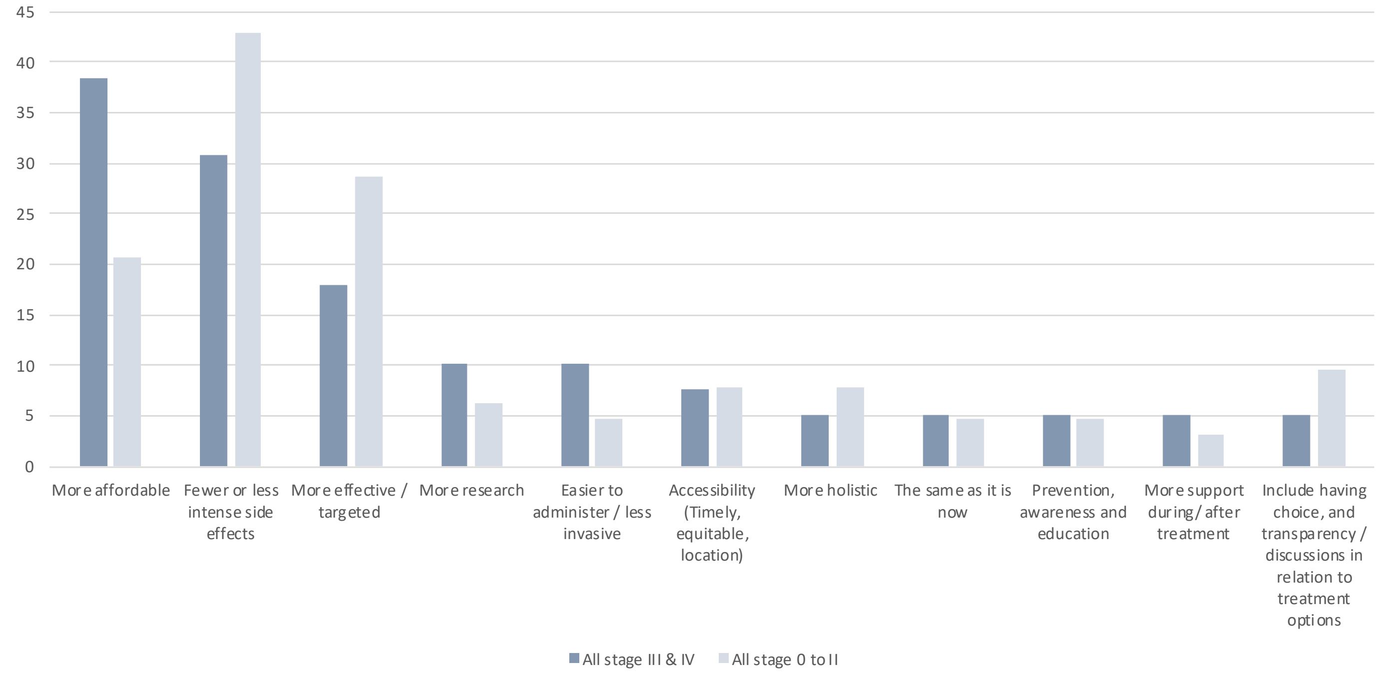


Figure 9.1: Expectations of future treatment (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 9.2: Expectations of future treatment – Stage III & IV variations

Expectations of future treatment	Reported less frequently	Reported more frequently
Future treatment will be more affordable	All Stage III & IV Hormone receptor Stage III & IV	
Future treatments will have fewer or less intense side effects/more discussion about side effects	Triple negative Stage III & IV	
Participant describes the expectation that future treatments will more accessible (Timely, equitable, location)		Hormone receptor Stage III & IV

Expectations of future information: Stage III and IV

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common responses were that future information will be more accessible/easy to find (20.51%), rovide more details about where to find available services (12.82 %), and provide more details about symptom and side effect control (12.82 %). Other themes included be more holistic (including emotional health) (10.26%),provide more general information about the condition (10.26%),help to inform the community and decision-makers about their condition (raise awareness) (10.26%), and provide more details about how to manage personal and intimate problems (7.69%).
There were 4 participants (12.82%) that had no recommendations and were satisfied with the information currently available.

Future information will be more accessible/easy to find

I think COVID made it extremely difficult for a lot of this because the face-to-faces just aren't there. The information that is given to you is either a booklet or a piece of paper. I'd like to be able to see more in-person stuff. Time is so important to this, whereas when you're in an appointment and there's 500 people waiting to see the same specialist that day, it's all time-poor. That's probably more time, I suppose. Participant_030TNG

It's very hard to get things online I find and that's not blaming anyone else. Maybe I'm just incompetent when it comes to computers.
INTERVIEWER: You found it difficult looking for things online?
PARTICIPANT: I did.
INTERVIEWER: Okay.
PARTICIPANT: Yes. My husband's a computer whiz so he does everything for me. Participant_032TNG

I do think that those drug information sheets should be rewritten. Realistically they're for the doctors, not the patients, but if they are going to be using them for the patients then they need to be different, or they need to develop something else that is more for the patients. Participant_048TNG

Participant describes the expectation that future information will provide more details about where to find available services

I don't know whether it was because I walked into my first appointment with my specialists and I walked into my first appointment with my medical oncologist, and I talked to them about my infertility that we'd been through that it was just assumed, but I felt like at no point did anyone kind of talk to me too much about the infertility side of what chemotherapy can do things to fertility. It was never really talked to me about fertility preservation options because I think it was just assumed I already had a specialist, so I had all of that under control, and I could deal with that myself. I was 37 at the time, and so I think there was that-- I felt like I was too old to be the young patient but too young to be the old patient. I said, given this, I didn't fit in the mode, I suppose, of certain people. I definitely think more inflammation around fertility and the side effects of that would be really good. I also think more information, it was really helpful to see people who've been out of cancer and who were 15 years, 20 years down the track from having their cancer diagnosis. Having information provided to you in the first appointment about…Do you know what? This is really hard One of my biggest pet peeves is that everyone talks about how amazing the National Breast Cancer Foundation is and how amazing the Breast Cancer Network Australia is. I still have actually no idea what they do to help with cancer patients. Having a bit more information about the services that they offer and what they can do for you, I think would be really useful. If you go into their website, I can find 10 different ways of how I can donate money to them but I can't find what they…They say they support breast cancer patients, but what do they actually do to support breast cancer patients. I think it's really important too to have a local area, information pack.

You're having a…You live in LOCATION because there's all of these amazing charities that exist, that you don't know about until someone tells you about them. There's a thing called the OTIS foundation that provides holiday accommodation to breast cancer patients. I think there's a company called Pink Things which is in the LOCATION, there's all of these things. I found and felt that if I had children, there would be way more support information given to me in the first instance. Because I didn't have children, and I had a husband who worked from home, I didn't really get a lot of information about support resources that were available, which is probably why I didn't access any of them because I didn't know they existed. The other thing that would have been really useful to me was actually knowing about…like getting some information on where to go to get a wig, or where to go to get nice scarves. Again, there's all these amazing organizations like Bravery, sews the scarves and real French headbands for some hair things, and all of these things that exist for cancer patients that you really almost need to be in the cancer world and have a secret connection to someone who goes, "Oh, by the way, this exists." When you're first diagnosed with that you don't know about that. Six months down the track, I now know where to go to find a wig, I now know where to go to do this and it's really hard to get those level of-- not the everyday 17 support but then where do I go for a headband? Or where do I go for a headscarf? That level of information would be really good. As I said, I think if it was like a local by region by region thing that was even just a website that had links to all these companies, it would be really good. Interviewer: Yes, that would be fantastic. A lot of these little charities who don't have a big platform people don't know about it and I think a lot of people find out about these little charities through Facebook pages or by word of mouth or things like that. I think if there was some online service to know what you can access in your area…I know it's a huge, big thing to do, and there's probably no money for it and that's probably what prevented a lot of people from doing it because they cost money but it's like, for instance, the cancer council's website, and they have that on their website or just something that you can be told, "This is what you do. This is who you go to," it would be great. Participant_025TNG

I think that's support. The direct link of this is what you need to fill out. This is how you're going to get that financial support and someone directly there to help you and take out all that time. I spent I don't even know how long on hold, waiting for letters, waiting for support, getting turned around from person to person. Like a ridiculous RSM. I spent a good 20 hours on the phone for them trying to get the support to then fill out all the documents and be told no because we've done something wrong, and then to resubmit it. Then by the time we resubmit it, we had to get the accountant involved, just that sort of thing. That really needs to change. Participant 042_2021AUHRP

Future information will provide more details about symptom and side effect control

I think the I would like more information on what happens after the chemotherapy as far as side effects and what people are left with afterwards. And I'd like to see more follow up from the teams around that to make sure that you are doing OK. Sorry. Have I answer the question that I. Yeah. Participant_038TNG

Menopause 100%. Never pain, nerve damage, chemo side effects afterwards Participant_036TNG

My oncologist just gave me a piece of paper with all the symptoms that I would experience. That could have been a bit prettier, if what I mean, like a little bit less or sear, but he was giving me the most up-to-date information. Participant_040TNG

Future information will be more holistic (including emotional health)

If I ruled the world and I could have it how I wanted, I guess maybe to have someone like a counselor that you would speak to before you start your treatment just to see where your head's at and make sure the information you're hearing is accurate information. I guess, to have that reassurance at the start that you're on the right plan or whatever. Maybe something like that when you walk in and you know nothing, you have someone to talk you through the process in a non-clinical way. Participant_027TNG

I think for me personally, I'd like to see the medical profession, maybe be a little bit more open to alternative options and not so cut and dried about no, don't go there. Participant 047_2021AUHRP

Participant describes the expectation that future information will provide more general information about the condition

Yes. When I was first diagnosed, there probably wasn't a lot on triple-negative and outside of being told don't Google I wasn't given much insight, so I did Google, so I could find my own insight. I think that *there needs to be more printed information given to a patient so that they know exactly what they're dealing with and exactly what it is. Participant_034*

PARTICIPANT: When you're doing your grading and staging, and-- that was really difficult to-- I know it was on the Cancer Council website and clicking through that, but you don't understand it. For me, I couldn't understand it. I got really obsessed with it to begin with, and then going, "I'm Stage 3. What does that mean? What does that mean? I don't know." For me, having statistics to tell you by stage and grade what the occurrence is would be great, particularly, by the type of breast cancer. No one keeps that, if you know what I mean?
INTERVIEWER: Yes.
PARTICIPANT: I don't know whether they'll-- maybe they do, they just don't tell you. You can't find that because it's probably the thing at the beginning is like, "Is this going to reoccur?" and, "Is it going to kill me?" That would have to be, for me, the thing that I still research it now. Participant_047TNG

Future information will help to inform the community and decision-makers about their condition (raise awareness)

I'm not 100% sure if this would work, but I think that when they-- I know I've seen a woman coming in that's been recently diagnosed and she's being given a tour of the center. I was sitting in a treatment chair once and I was listening to the ones next door and they were telling them all about the treatment and all this, and they make it sound like-- Yes, it's hard, but they don't really go into full detail about how bad it can be. I don't know, maybe they could have a volunteer or someone that's been through it, that can help them out. Not to scare them off or anything like that, just to sit them down and say, "Well, these are all the things that can happen. It's really hard." Do you know what I mean? I think that yes they do, they need to give people more information. I don't know if this is ever going to happen, I think it would also be awesome to educate the public. Like I said, I had no idea really. You just think, "Oh, you're going to lose your hair, your eyebrows, your eyelashes, you might be tired, you might be sick," but it's so much more than that. I just think people need to be educated. That's just my opinion. Participant_028TNG

I just like to say I'd like to see more information in GP's offices. And I still don't believe that our general practitioners know enough about breast cancer and and what should be offered to women who are diagnosed and information out to the public public who have got no idea if I just hear or she's got breast cancer, but I got no idea. And so it's all about education for me. Participant_049TNG

Satisfied with experience

I remember the first thing is giving me information and stuff, so I think it was pretty much readily available and in an easier to read format. Participant_037TNG

No, I've had access to terrific information. Participant_041TNG

Table 9.3: Expectations of future information

Expectations of future information	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Future information will be more accessible/easy to find	16	15.69	8	12.70	8	20.51	5	18.52	3	25.00
Participant describes the expectation that future information will provide more details about where to find available services	21	20.59	16	25.40	5	12.82	3	11.11	2	16.67
No particular comment - satisfied with experience	14	13.73	9	14.29	5	12.82	4	14.81	1	8.33
Future information will provide more details about symptom and side effect control	21	20.59	16	25.40	5	12.82	3	11.11	2	16.67
Future information will be more holistic (including emotional health)	7	6.86	3	4.76	4	10.26	4	14.81	0	0.00
Participant describes the expectation that future information will provide more general information about the condition	6	5.88	2	3.17	4	10.26	4	14.81	0	0.00
Future information will help to inform the community and decision-makers about their condition (raise awareness)	4	3.92	1	1.59	3	7.69	3	11.11	0	0.00
Participant describes the expectation that future information will provide more details about how to manage personal and intimate problems	6	5.88	4	6.35	2	5.13	2	7.41	0	0.00
Future information will provide more details on subgroups and specific classifications of their condition	6	5.88	4	6.35	2	5.13	0	0.00	**2**	**16.67**
Future information will allow for patient record keeping	6	5.88	4	6.35	2	5.13	0	0.00	**2**	**16.67**
Participant describes the expectation that future information will provide more details about treatments	7	6.86	6	9.52	1	2.56	1	3.70	0	0.00
Participant describes the expectation that future information will provide more details about holistic treatments	9	8.82	8	12.70	1	2.56	0	0.00	1	8.33
Future information will provide more details about exacerbation of disease (including recurrence)	2	1.96	2	3.17	0	0.00	0	0.00	0	0.00
Participant describes the expectation that future information will be more targeted to a specific age group	5	4.90	5	7.94	0	0.00	0	0.00	0	0.00

Expectations of future information	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Future information will be more accessible/easy to find	16	15.69	5	10.00	11	21.15	0	0.00	8	20.00
Participant describes the expectation that future information will provide more details about where to find available services	21	20.59	8	16.00	13	25.00	5	21.74	11	27.50
No particular comment - satisfied with experience	14	13.73	7	14.00	7	13.46	3	13.04	6	15.00
Future information will provide more details about symptom and side effect control	21	20.59	5	10.00	16	30.77	2	8.70	14	35.00
Future information will be more holistic (including emotional health)	7	6.86	7	14.00	0	0.00	3	13.04	0	0.00
Participant describes the expectation that future information will provide more general information about the condition	6	5.88	6	12.00	0	0.00	2	8.70	0	0.00
Future information will help to inform the community and decision-makers about their condition (raise awareness)	4	3.92	4	8.00	0	0.00	1	4.35	0	0.00
Participant describes the expectation that future information will provide more details about how to manage personal and intimate problems	6	5.88	6	12.00	0	0.00	4	17.39	0	0.00
Future information will provide more details on subgroups and specific classifications of their condition	6	5.88	0	0.00	6	11.54	0	0.00	4	10.00
Future information will allow for patient record keeping	6	5.88	0	0.00	6	11.54	0	0.00	4	10.00
Participant describes the expectation that future information will provide more details about treatments	7	6.86	7	14.00	0	0.00	6	26.09	0	0.00
Participant describes the expectation that future information will provide more details about holistic treatments	9	8.82	3	6.00	6	11.54	3	13.04	5	12.50
Future information will provide more details about exacerbation of disease (including recurrence)	2	1.96	2	4.00	0	0.00	2	8.70	0	0.00
Participant describes the expectation that future information will be more targeted to a specific age group	5	4.90	0	0.00	5	9.62	0	0.00	5	12.50

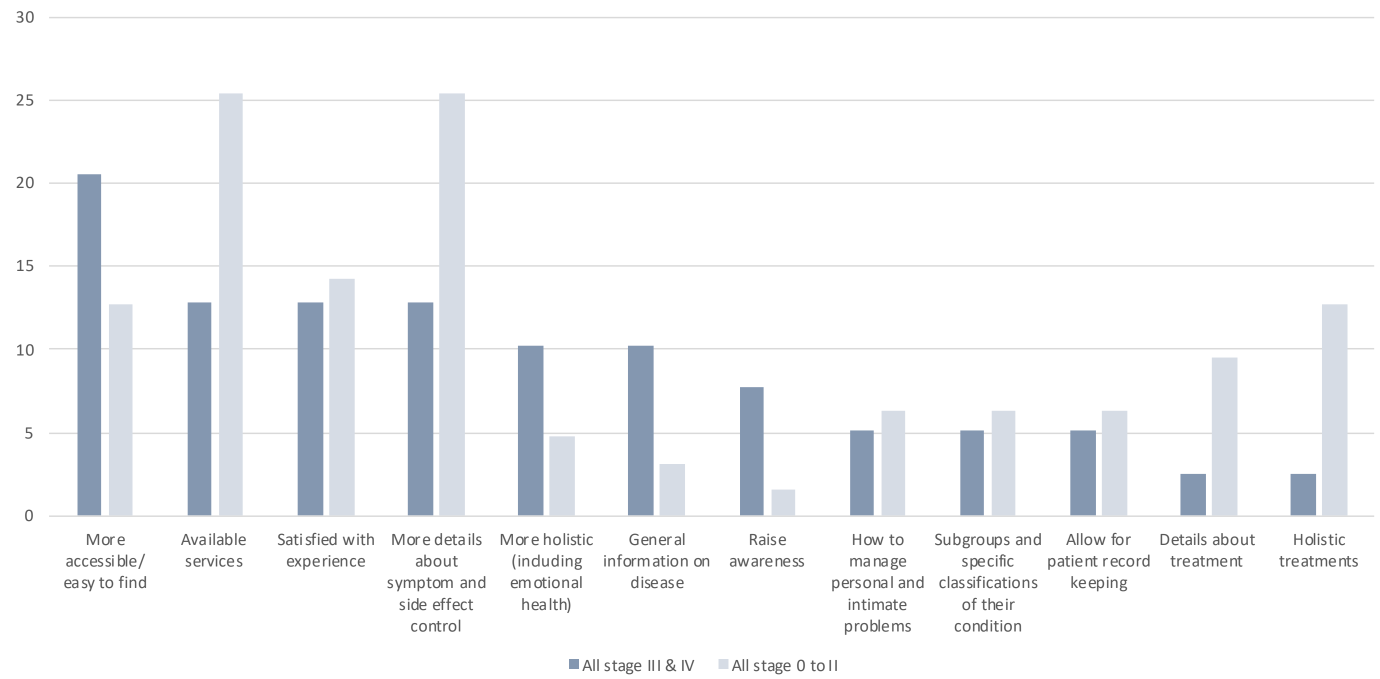


Figure 9.2: Expectations of future information. (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 9.4: Expectations of future information – Stage III & IV variations

Expectations of future information	Reported less frequently	Reported more frequently
Future information will provide more details on subgroups and specific classifications of their condition	-	Hormone receptor Stage III & IV
Future information will allow for patient record keeping	-	Hormone receptor Stage III & IV

Expectations of future healthcare professional communication: Stage III and IV

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common expectations for future healthcare professional communication were that communication will be more transparent and forthcoming (23.08%), include listening to the patient(17.95%), and be more empathetic (15.38 %).

There were 12 participants (30.77%) that had no recommendations and were satisfied with the healthcare communication they had.

Satisfied with communication

No. I had a very good medical professional who looked after me. I don't have any issues there. Participant_024TNG

No, I think that I've been very lucky with my health professionals along the way. They've been very supportive and informative and that sort of thing. Participant_046TNG

No. As I said, my team were great. Gavin was like, "Just ring me anytime. Just do what you need to do." Participant_047TNG

Future communication will be more transparent and forthcoming

They've actually been really good. There's massive gaps I think, in the communication in general, but I don't know if that's in relation to that question. I might answer that and you'll tell me it's not what you're looking for, is not the right time to say that. What I've noticed with the whole journey is how much coordination and organizing you have to do yourself as a cancer patient. There's an expectation that you'll know what to do and where to go and who to talk to and how to do that. Things like contacting surgeons yourself, finding a surgeon, making an arrangement to go there, trying to get scans organized, you have to do all that yourself. Following up things that haven't been done, contacting the oncology rooms because they haven't got back to you about something where you don't know when the next appointment date is. There seems to be an awful lot of things that you need to do yourself to coordinate your own treatment, that I didn't think would be that way. I thought it would be more scheduled, "This is what happened, this is your journey, you need to see this person, this person, and this person." but I felt like that information wasn't given, that wasn't communicated and it's been trying to find out for myself, "Who do I see? Who do I need to see? Where do I go next? Where do I go for scans? Where do I go?" Then you need a heart ultrasound, well, you need to get that done before your chemo next Monday. Where do I go to get that done? Then you find everywhere is booked. You're trying to look at traveling two hours away to try and get an appointment for a scan that you've just been told that you need in the next four days without any information on where to go. That sort of stuff is just not communicated, and that's being really challenging. Participant_033

You have to read the patient. Some of us want to know all the truth, doesn't matter how grim it is, whereas others should be protected from the truth and the partner should be should be made aware. Sorry, I'm such a such a chatterbox. If it wasn't for the PET scan, I would have never known that I had the disease in my bones. Now I know it so now I'm just checking in all the time, so I have extra anxiety. Read your patient, provide all the resources, provide various places where you can go to without judgment. Without judging, yes. Participant_042TNG

Future communication will include listening to the patient

I don't think so, because I've actually had-- I think I, fortunately, had a really incredible and supportive experience going through my breast cancer with all of my medical professionals and their communication. I don't think there's really anything that I felt I've missed out on that they could improve on. Sorry, I'd say that. I think for me, the biggest thing that made my communication with my specialists really good was that I didn't go in and go, "Oh, I read this on a forum and this is what you need to be doing," and I never questioned by specialists. Also, I, from the very beginning, because I knew my surgeon had one treatment plan option and my oncologist had a different view, I knew that they were all talking and they were talking to each other about me. I never felt like one person didn't know something about me that the other did. I think as long as people know that they're being supported and that their specialists are communicating with each other and the decisions are being made as a whole not just by one person. I think that would be really important for other people. I had that experience. Participant_025TNG

Whenever I've spoken to anyone, they say they only tell you this much because if they told you everything, perhaps wouldn't go through with it or wouldn't go down the path that they suggest is the best way I feel as though that's a very blanketed statement for some people. Myself, I would have dealt better if I knew upfront what I was dealing with. I think it needs to be more individualized to the person. I feel as though that needs to be a discussion with your breast care nurse or your oncologist of how much information you really want to know, do you want to know, like from here to the end of the process, or do you want to know just what you're dealing with now? I think that would be better dealt with, and explanation of cost would be another one, as what you're in for, for the whole *journey, that would be the two things. Participant_036TNG*

Future communication will be more empathetic

I don't know. I think that I've had fairly good communication with most of my health professionals. As I said, the only one which I've butted heads with has been my surgeon, NAME. I don't know if it's just her as a person. I think it is. She's quite abrupt. The last thing you want is someone who's abrupt dealing with you when you got breast cancer and you tried to make heads and tails of what's going on in your life and being told, this is what you're doing, whether you like it or not, doesn't really sit well with some people. It's like, "How about you give us some options? How about you [unintelligible] yourself a little bit because you're not advocating for me?". Participant_034

Yes, and I actually said this to them one day. I think they'd need to remember that the people they're treating are people and that while for the person administering the treatment, it might be the one they stabbed that day. The person receiving the treatment it might be the first time they've ever done this, so you just need to explain what's being done and why it's being done. Participant_027TNG

She was absolutely couldn't believe it. If that's what's happening with somebody who has a lot of contact with breast cancer patients, we've got a lot of work to do. Similarly with the fellow who said to me, "As long as your MRI doesn't come up with like a Christmas tree, then you'll go and have them done any other." That's like no, that is not acceptable. Participant 043_2021AUHRP

Table 9.5: Expectations of future healthcare professional communication

Expectations of future healthcare professional communication	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
No particular comment - satisfied with experience	42	41.18	30	47.62	12	30.77	6	22.22	6	50.00
Future communication will be more transparent and forthcoming	29	28.43	20	31.75	9	23.08	7	25.93	2	16.67
Future communication will include listening to the patient	10	9.80	3	4.76	7	17.95	7	25.93	0	0.00
Future communication will be more empathetic	20	19.61	14	22.22	6	15.38	3	11.11	3	25.00
Participant describes the expectation that future communication will be more accurate and detailed (including more scientific)	10	9.80	8	12.70	2	5.13	2	7.41	0	0.00
Future communication will include developing a care plan with follow-up	5	4.90	3	4.76	2	5.13	2	7.41	0	0.00
Participant describes the expectation that future communication will acknowledge that the condition is serious and cannot be ignored	2	1.96	0	0.00	2	5.13	2	7.41	0	0.00
Participant describes the expectation that future communication will be more consistent across healthcare staff	3	2.94	2	3.17	1	2.56	1	3.70	0	0.00
Future communication will allow people more time to meet with their clinician	2	1.96	1	1.59	1	2.56	1	3.70	0	0.00
Future communication will be more holistic (including emotional health)	3	2.94	3	4.76	0	0.00	0	0.00	0	0.00

Expectations of future healthcare professional communication	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
No particular comment - satisfied with experience	42	41.18	13	26.00	29	55.77	7	30.43	23	57.50
Future communication will be more transparent and forthcoming	29	28.43	13	26.00	16	30.77	6	26.09	14	35.00
Future communication will include listening to the patient	10	9.80	10	20.00	0	0.00	3	13.04	0	0.00
Future communication will be more empathetic	20	19.61	9	18.00	11	21.15	6	26.09	8	20.00
Participant describes the expectation that future communication will be more accurate and detailed (including more scientific)	10	9.80	10	20.00	0	0.00	8	34.78	0	0.00
Future communication will include developing a care plan with follow-up	5	4.90	5	10.00	0	0.00	3	13.04	0	0.00
Participant describes the expectation that future communication will acknowledge that the condition is serious and cannot be ignored	2	1.96	2	4.00	0	0.00	0	0.00	0	0.00
Participant describes the expectation that future communication will be more consistent across healthcare staff	3	2.94	3	6.00	0	0.00	2	8.70	0	0.00
Future communication will allow people more time to meet with their clinician	2	1.96	2	4.00	0	0.00	1	4.35	0	0.00
Future communication will be more holistic (including emotional health)	3	2.94	3	6.00	0	0.00	3	13.04	0	0.00

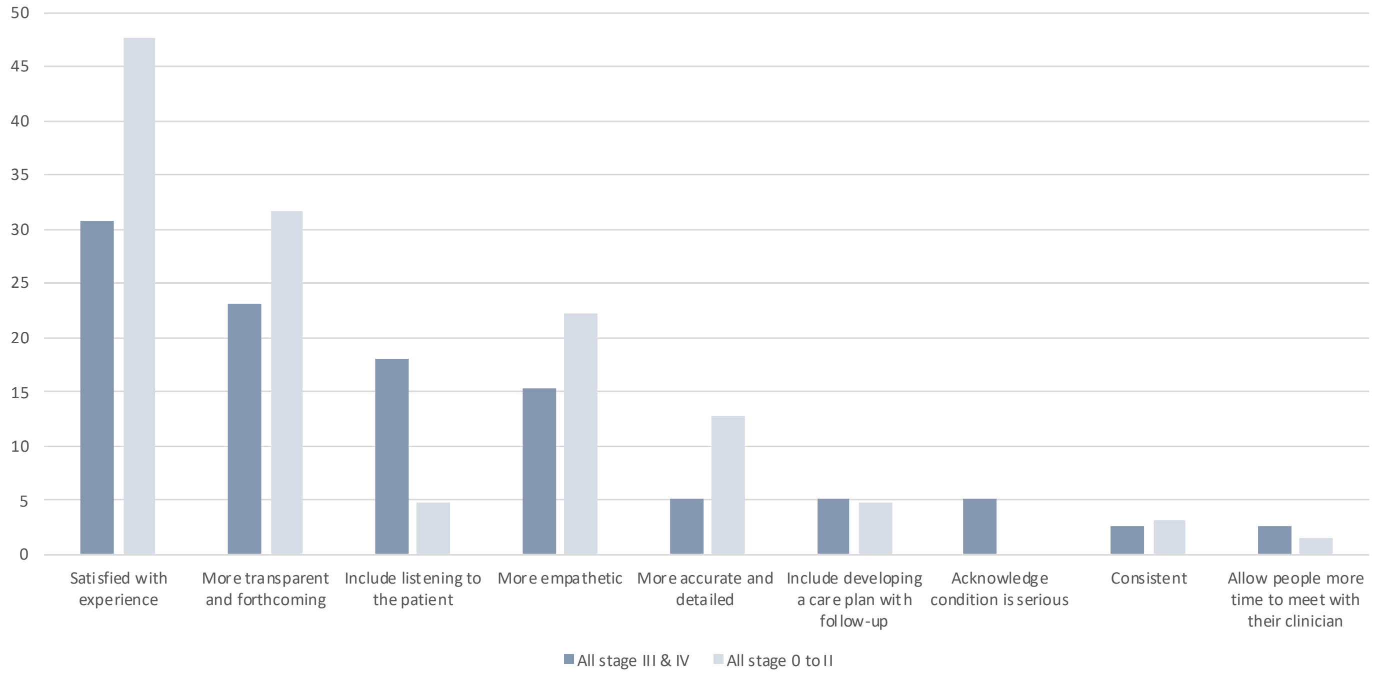


Figure 9.3: Expectations of future healthcare professional communication (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 9.6: Expectations of future healthcare professional communication – Stage III & IV variations

Expectations of future healthcare professional communication	Reported less frequently	Reported more frequently
No particular comment - satisfied with experience	All Stage III & IV Triple negative Stage III & IV	-
Future communication will be more transparent and forthcoming	Hormone receptor Stage III & IV	-
Future communication will include listening to the patient	-	Triple negative Stage III & IV

Expectations of future care and support: Stage III and IV

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common expectation for future care and support was that it will include more access to support services (51.28%), and will include specialist clinics or services where they can talk to professionals (in person, phone, online) (30.77%). Other themes included will include being able to connect with other patients through peer support (support groups, online forums) (12.82%), will include more long-term condition management (care planning) (12.82%), and will be more holistic (including emotional health) (10.26%).

There were 5 participants (12.82%) that had no recommendations and were satisfied with the care and support they received.

Future care and support will include more access to support services

I don't know. I'd probably get support with doing my housework and all that sort of stuff. I think if there are people like myself who I'm very independent, and God, I hate asking for help. I think if they could maybe have more-- I don't know, maybe sit down and talk to people about their situation more. I could have probably done with, maybe, some help around the house, that sort of stuff. I know, like I said, I got the transport, which is awesome. Participant_02TNG 8

I would have loved, absolutely loved the day I was diagnosed to be given the name of someone to go and speak to about the practical stuff. As in what that journey is going to be like, the sorts of people you're going to need to come into contact with, what their roles are, what they do, where you find them, how you contact them. That real step-by-step guide, and I feel like that was the crucial thing that was missing. For *me, I think the diagnosis was just walking out of the doctor's office, not having a clue where to go or who to talk to or what to do, or where I needed to go, and if they say, "Oh, you need this, you need an oncologist, you need to do this, you need these scans." but no guidance as to where to go. I feel like the key thing for me would be a person that you are put in contact with whether it's a breast care nurse, or whether it's another role completely. Someone that you speak to immediately on diagnosis, that we'll be able to answer all of the questions you have about the practical stuff and the treatment. Things around who's involved in the care and what your team is going to look like, and what those people do because when you're new to the journey you have no idea, you have absolutely no clue who these people are and what their roles- Participant_033TNG*

I think it'd be really helpful to somebody just to talk to you more about diet and exercise. I think especially the exercise stuff just to give you some information, I have certain exercises the can help you with the side effects, I think, or what you can actually do. Or how to modify what exercise you're doing. I think stuff like that could be really important. Participant 052_2021AUHRP

Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)

I would have loved, absolutely loved the day I was diagnosed to be given the name of someone to go and speak to about the practical stuff. As in what that journey is going to be like, the sorts of people you're going to need to come into contact with, what their roles are, what they do, where you find them, how you contact them. That real step-by-step guide, and I feel like that was the crucial thing that was missing. For me, I think the diagnosis was just walking out of the doctor's office, not having a clue where to go or who to talk to or what to do, or where I needed to go, and if they say, "Oh, you need this, you need an oncologist, you need to do this, you need these scans." but no guidance as to where to go. I feel like the key thing for me would be a person that you are put in contact with whether it's a breast care nurse, or whether it's another role completely. Someone that you speak to immediately on diagnosis, that we'll be able to answer all of the questions you have about the practical stuff and the treatment. Things around who's involved in the care and what your team is going to look like, and what those people do because when you're new to the journey you have no idea, you have absolutely no clue who these people are and what their roles-. Participant_033TNG

I would love there to be a one-stop-shop so that you go and somebody is there for your physio, your chiropractic, all the breast care, questions that you have. Yes, just a whole umbrella where it's so hard to-- like lymphedema, side effects from chemo, or whatever. Just someone that would deal with all of it. You don't have to run around to so many different professionals and you're constantly-- it's hard to get into appointments as well. Somewhere that just dealt with everything.. Yes. Like a hub for everything. Like you could have your own oncologist in different paths, but this is where you went for everything else. Participant_036TNG

Future care and support will include being able to connect with other patients through peer support (support groups, online forums)

I would like to see support groups or people with similar types of cancer that you have say that you're able to meet other people and talk about your experience with them, because I feel like they understand more like that to me is more beneficial than seeing a psychologist and. So can you repeat the question? Yes, there was something else I had in my head. Participant_038TNG

I believe that the cancer support group, that's just an organization of people going through cancer, that has been very helpful for me. What they're trying to do with the group is to get to people when they're diagnosed because they supply a lot of information that we don't know. You don't know about options about breast surgeons. My GP, who recommended a breast surgeon, he said if his wife had it, he wouldn't send her anywhere else, so I took that as my recommendation, but you've got to make all those decisions and you don't know. Us, as a group together, a list of the surgeons in the area and all that sort of thing and costings and everything like that, but when you're first diagnosed, you're not part of that group because you don't know. It's something that those support groups of people that have gone through it, I think help you more than anything, and getting the information to them. They're putting brochures in the hospitals and things like that to help people. That's the big thing is when you're first diagnosed, you've got so much going on and you don't know. They're saying, "Okay, you got to go and see an oncologist. Who would you like to see?" It's like you never look at-

- No one doesn't know who an oncologist in the area is if you haven't had to deal with anything like that. It's that information in that crucial time when you're first diagnosed that needs to get to people because you don't know. It's even like, I would have been out-of-pocket $10,000 for my radiation if I hadn't have gone to the morning tea that the cancer group had and mentioned it to one of the ladies there, and she told me how to get out of paying it. Things like that. It's that crucial time, right at the beginning when you're up in the air, not knowing where you're coming or going, and you're in such a shock and you've got to make all those decisions. Participant_046TNG

Future care and support will include more long-term condition management (care planning)

Absolutely. Yes, a nutritionist and an exercise program that was monitored. Not somebody telling you, "Oh go home and do situps or walk around the block." Something that's monitored so that you've got accountability so that it helps you to achieve those things. There's no point in people telling you something unless there's a guideline and somebody's helping you along the way. Everybody can tell you you need to lose weight, "Go ahead and lose weight." [chuckles] It's not that easy. Participant_029TNG

Look, I definitely think exercise. I definitely think there needs to be something about-- you finish your chemotherapy and come back in three weeks, you need something in between. They know resistance exercise, like doing something from that point of view helps in terms of prognosis and things like that. I didn't want to do group therapy or anything like that, that wasn't for me, but doing exercise classes and getting a way to keep you moving and stuff like that. I just don't think there's enough of it, and it wasn't highly promoted in the hospital to go and do it. If they say, "Go and move," you go and do these things. I think having a breast care exercise class that I went to, I was one of a few new patients, we only had one or two new patients, there were a lot of older patients in it that were still going. For me, I reckon those exercise classes have to be something to keep people moving. Participant_047TNG

Future care and support will be more holistic (including emotional health)

Psychologists. Cancer psychologists. Participant_042

I think that the program that I had at my hospital that helps with distance and management, I think that is a fantastic thing they've done. I just don't think it's funded enough and there's not enough hours there. I think that, potentially, would be something that's perfect that even the best [unintelligible] can get involved on. You have a hotline that you can ring up and use, whether it be your symptoms and stuff, because you can have physical symptoms, but then you can also have things that you're struggling with. It could be mentally troubling you.
Participant 048_2021AUHRP

Satisfied with care and support

And I think I've been very lucky with the breast nurses and counsellors that I've had, the access I've had to different activities at different hospitals where I support women and men with cancer. It's just getting that information out. But I think I've been very lucky with that sort of thing. Participant_049TNG

Yes, I think the model that is used by the martyr the early breast cancer program. Whenever I've mentioned it to anybody, whether they live in Australia or they live in the UK, they have been blown away by what is singularly one of the best things I've ever did. It quells the panic that I had. It quells the overwhelm of information because I have this one point. I've done it via Zoom as a mentor with them. It works via Zoom. I think that should be looked at as a model and should be replicated as a model. Then the other thing is there needs to be something that may be similar or such is really looking at this post-treatment. It's not just relying on Facebook groups because there's a lot of misinformation that comes from people that mean to what is coming from a good place, but it's not helping. Participant 043_2021AUHRP

Nothing I can think of. I've had access to everything I need. Participant 044_2021AUHRP

Table 9.7: Expectations of future care and support

Expectations of future care and support	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Future care and support will include more access to support services	58	56.86	38	60.32	20	51.28	15	55.56	5	41.67
Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	19	18.63	7	11.11	12	30.77	9	33.33	3	25.00
Future care and support will include being able to connect with other patients through peer support (support groups, online forums)	12	11.76	7	11.11	5	12.82	2	7.41	3	25.00
No particular comment - satisfied with experience	16	15.69	11	17.46	5	12.82	2	7.41	3	25.00
Future care and support will include more long-term condition management (care planning)	11	10.78	6	9.52	5	12.82	2	7.41	3	25.00
Future care and support will be more holistic (including emotional health)	13	12.75	9	14.29	4	10.26	3	11.11	1	8.33
Participant describes the expectation that future care and support will include more access to specialist nurses	4	3.92	2	3.17	2	5.13	2	7.41	0	0.00

Expectations of future care and support	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Future care and support will include more access to support services	58	56.86	24	48.00	34	65.38	9	39.13	29	72.50
Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	19	18.63	10	20.00	9	17.31	1	4.35	6	15.00
Future care and support will include being able to connect with other patients through peer support (support groups, online forums)	12	11.76	6	12.00	6	11.54	4	17.39	3	7.50
No particular comment - satisfied with experience	16	15.69	5	10.00	11	21.15	3	13.04	8	20.00
Future care and support will include more long-term condition management (care planning)	11	10.78	4	8.00	7	13.46	2	8.70	4	10.00
Future care and support will be more holistic (including emotional health)	13	12.75	7	14.00	6	11.54	4	17.39	5	12.50
Participant describes the expectation that future care and support will include more access to specialist nurses	4	3.92	4	8.00	0	0.00	2	8.70	0	0.00

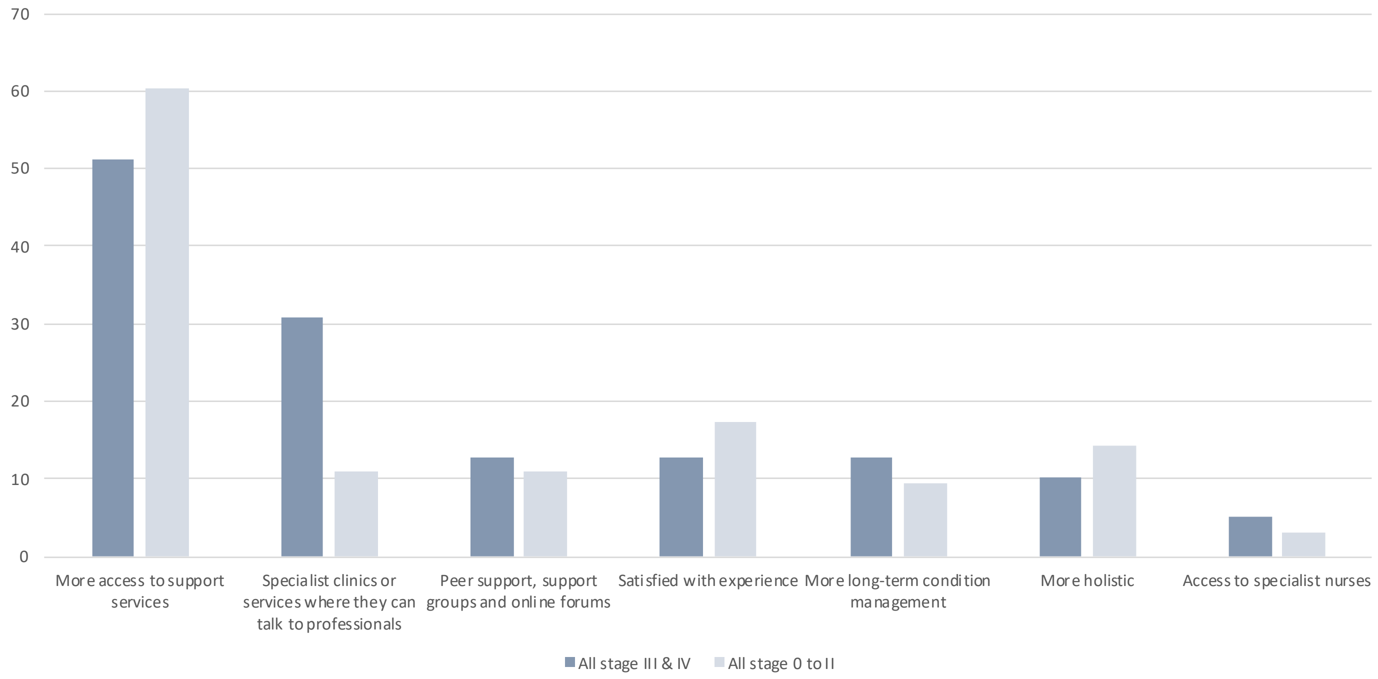


Figure 9.4: Expectations of future care and support (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 9.8: Expectations of future care and support – Stage III & IV variations

Expectations of future care and support	Reported less frequently	Reported more frequently
Future care and support will include more access to support services	Hormone receptor Stage III & IV	-
Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	-	All Stage III & IV Triple negative Stage III & IV
Future care and support will include being able to connect with other patients through peer support (support groups, online forums)	-	Hormone receptor Stage III & IV
Future care and support will include more long-term condition management (care planning)	-	Hormone receptor Stage III & IV

What participants are grateful for in the health system: Stage III and IV

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common responses were that participants were grateful for timely access to treatment (28.21%), healthcare staff (including access to specialists)(28.21%), and the entire health system (20.51 %). Other themes included access to private healthcare/private insurance (17.95%), low cost or free medical care through the government (15.38%), and low cost or free medical treatments through the government (12.82%).

Participant describes being grateful for timely access to treatment

Yes, all of it has been really good. The speed from diagnosis to getting treatment was really quick. It didn't feel it at the time, but I think it was only five weeks from diagnosis to starting chemo. It was quite a quick turnaround. I was able to get appointments with the people I needed to see. The oncologist has been amazing, the breast care nurse has been amazing, the treatment team of the hospital are fantastic. It's all been excellent. There's been no issues at all with the treatment that I've been given. No. Participant_033TNG

Everything. Everything. I've got relatives in England and I know sometimes they have to wait weeks until they can access stuff. Everything happened within a week. The chemo facilities were lovely. The radiation people were marvellous. Like I said, I was lucky to have the Mepitel for nothing. Even the chemo, the oral chemo was easy to get and all that kind of stuff. The lumpectomy was very, very smooth, and they make sure everything is good. I think everything in Australia is very, very good, and we're very lucky. Participant_035TNG

I think having access to all of it has been a blessing and the speed of which I've been able to access has been terrific. I can't fault it. Participant 051_2021AUHRP

Participant describes being grateful for healthcare staff (including access to specialists)

Yes, I guess my particular team has just been outstanding. Participant_041TNG

The fantastic doctors. We've got some of the best breast care nurses in the world, and very lucky to have gotten into here and had an exceptional result. I feel as though the team of nurses and everything are all very caring and very loving. The staff, they do amazing things. Participant_036TNG

Participant describes being grateful for the entire health system

I am eternally grateful I live in Australia and we have the health care system we have. The fact that I could go through the treatment I had to go through and not the out-of-pocket other than the surgery, I will be eternally grateful for. My ex-husband who is American and he has often said to me, "If we were living in America, we couldn't afford to be treated." Yes. I feel that we're truly blessed to have the healthcare system we have in this country. Participant_027TNG

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

Participant describes being grateful for access to private healthcare/private insurance

I had private health care. All my treatment has been through private. This is all in relation to that. Thank God it wasn't an American private health care model. The two-tier that we have, I was really fortunate and it worked for me, I guess that. Thank goodness. It was the two-tier private model. We have not the ridiculous American model. Participant 043_2021AUHRP

I think it was that I did have the choice because I had private health. Other than that, I couldn't really say what the public system was like, but yes, no, I think it was all pretty good. Again, it would just be cost. Participant_024TNG

Participant describes being grateful for low cost/free medical care through the government (Public health system in general)

I'm just very thankful of that our town rallied for a cancer center down here, so I didn't have to travel to get my treatment. The only thing I went through is surgery, so chemo and radiation was all done in my *hometown, which is 10 minutes away. I'm probably thankful for the fact that it costs minimal. That we're not having to pay and remortgage houses for the treatment. [laughs] That's probably the biggest thing I've had with it. Participant_030TNG*

Pretty much grateful for everything because we are lucky where we are. Despite having to wait for things, once you are diagnosed, it is pretty much taken, everything sort of flows, and it is quick to access. The cost is, like I said, I haven't had to pay for anything of my medical treatment at all. Participant 049_2021AUHRP

Participant describes being grateful for low cost/free medical treatments through the government

Well, when I was going through chemo and radiation and it was completely free, I was so grateful that the level of care was there. I must say, even though those doctors-- when I'm saying the doctors, anything that I've said is not against the doctors or the nurses that I dealt with because they've all been amazing, the level of care, caring people, but they're busy and that's not their fault. I would never say that it's their fault because they've all been very caring and concerned, and lovely people. No, I felt grateful that I lived in Australia [chuckles] and had that level of hospital care. Participant_029TNG

The fact that I can receive Palbociclib, the CDK4/6 inhibitor on the PBS for $40 a month is absolutely life-changing because I would be much, much sicker without it. I strongly believe it's responsible for my metastasis disappearing. I know that it's not available in many countries, not accessible and hugely expensive in others. Participant_050TNG

Table 9.9: What participants are grateful for in the health system

What participants are grateful for in the health system	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant describes being grateful for timely access to treatment	30	29.41	19	30.16	11	28.21	9	33.33	**2**	**16.67**
Participant describes being grateful for healthcare staff (including access to specialists)	33	32.35	22	34.92	11	28.21	8	29.63	3	25.00
Participant describes being grateful for the entire health system	26	25.49	18	28.57	8	20.51	5	18.52	3	25.00
Participant describes being grateful for access to private healthcare/private insurance	18	17.65	11	17.46	7	17.95	**1**	**3.70**	**6**	**50.00**
Participant describes being grateful for low cost/free medical care through the government (Public health system in general)	21	20.59	15	23.81	6	15.38	3	11.11	3	25.00
Participant describes being grateful for low cost/free medical treatments through the government	12	11.76	7	11.11	5	12.82	5	18.52	**0**	**0.00**
Participant describes being grateful for timely access to diagnostics	10	9.80	8	12.70	2	5.13	1	3.70	1	8.33

What participants are grateful for in the health system	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant describes being grateful for timely access to treatment	30	29.41	17	34.00	13	25.00	8	34.78	11	27.50
Participant describes being grateful for healthcare staff (including access to specialists)	33	32.35	16	32.00	17	32.69	8	34.78	14	35.00
Participant describes being grateful for the entire health system	26	25.49	10	20.00	16	30.77	5	21.74	13	32.50
Participant describes being grateful for access to private healthcare/private insurance	18	17.65	**3**	**6.00**	**15**	**28.85**	2	8.70	9	22.50
Participant describes being grateful for low cost/free medical care through the government (Public health system in general)	21	20.59	9	18.00	12	23.08	6	26.09	9	22.50
Participant describes being grateful for low cost/free medical treatments through the government	12	11.76	**12**	**24.00**	**0**	**0.00**	**7**	**30.43**	**0**	**0.00**
Participant describes being grateful for timely access to diagnostics	10	9.80	4	8.00	6	11.54	3	13.04	5	12.50

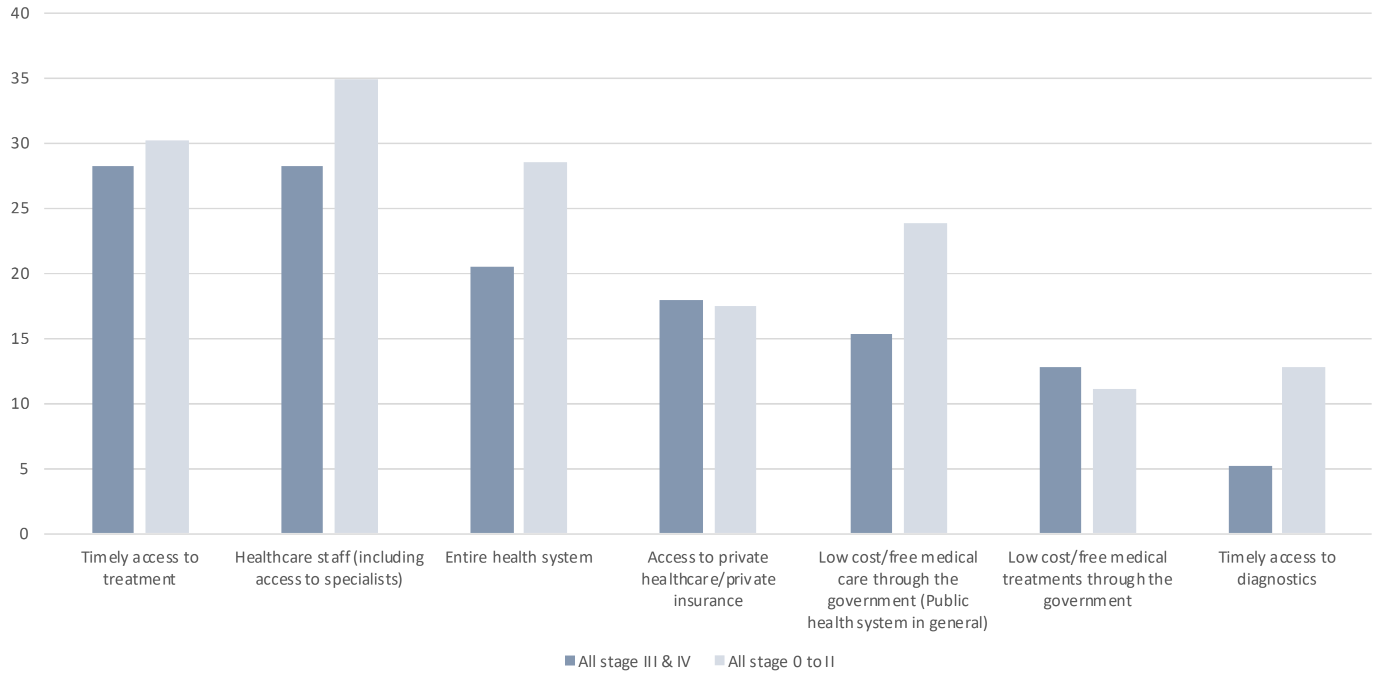


Figure 9.5: What participants are grateful for in the health system (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 9.10: What participants are grateful for in the health system – Stage III & IV variations

What participants are grateful for in the health system	Reported less frequently	Reported more frequently
Participant describes being grateful for timely access to treatment	Hormone receptor Stage III & IV	-
Participant describes being grateful for access to private healthcare/private insurance	Triple negative Stage III & IV	Hormone receptor Stage III & IV
Participant describes being grateful for low cost/free medical treatments through the government	Hormone receptor Stage III & IV	-

Symptoms and aspects of quality of life: Stage III and IV

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, where 1 is the most important and 11 is the least important. A weighted average is presented in Table 9.6, Figure 9.6. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important aspects reported were Fatigue Pain, Fertility, and Heart problems. The least important were Lymphoedema, Menopause and menopausal symptoms, and Body image.

Table 9.11: Symptoms and aspects of quality of life (weighted average)

Symptoms and aspects of quality of life	All participants (n=95)	All stage 0 to II (n=59)	All stage III & IV (n=36)	Stage III & IV triple negative (n=24)	Stage III & IV hormone-receptor positive (n=12)	All Triple negative (n=44)	All hormone-receptor positive (n=51)	Stage 0 to II triple negative (n=20)	Stage 0 to II hormone-receptor positive (n=39)
Fatigue Pain	5.50	5.37	5.73	5.45	6.27	5.66	5.37	5.89	4.77
Lymphoedema	3.21	3.10	3.39	3.73	2.56	3.17	3.25	2.55	3.56
Fertility	4.85	4.25	5.80	7.33	3.50	5.38	4.00	4.20	3.00
Menopause and menopausal symptoms	3.67	4.03	3.13	3.00	3.43	3.04	4.22	3.09	4.36
Anxiety and depression	4.91	5.24	4.44	4.59	4.10	4.82	5.00	5.13	4.89
Body image	3.51	4.00	2.67	2.75	2.57	3.86	3.33	5.33	3.38
Sexual difficulties	3.29	3.18	3.50	2.92	4.67	3.14	3.41	3.40	3.08
Problems with movement and strength	4.85	4.76	4.97	4.90	5.08	5.11	4.65	5.40	4.77
Heart problems	4.95	4.61	5.62	5.81	5.13	5.44	4.50	5.05	5.14
Memory loss and cognitive function ("chemo brain")	5.04	5.13	4.92	4.50	5.75	4.62	5.42	4.78	5.50
Effects on bones and joints	4.68	4.69	4.66	4.90	4.25	4.60	4.74	4.30	4.50

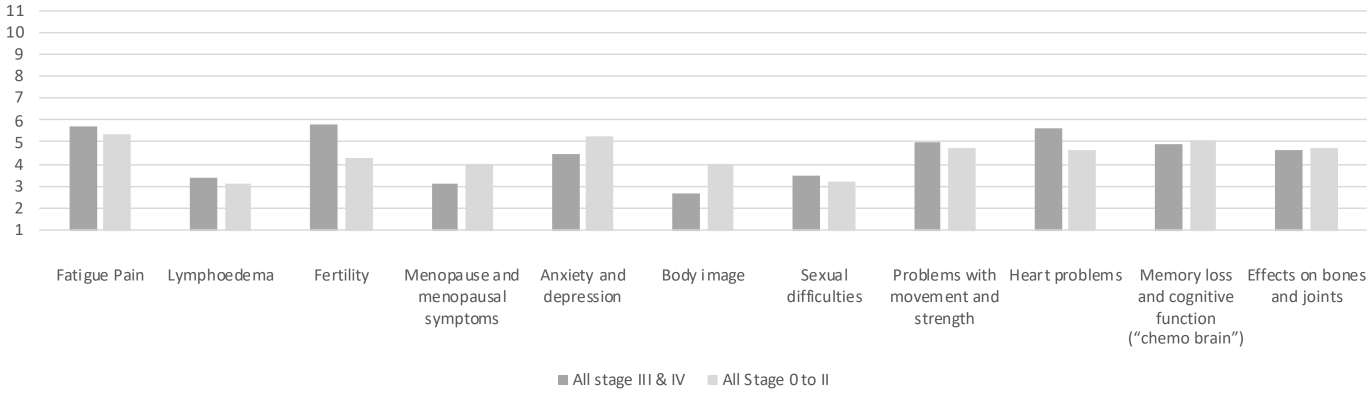


Figure 9.6: Symptoms and aspects of quality of life (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Values in making decisions: Stage III and IV

Participants were asked to rank what is important for them overall when they make decisions about treatment and care, where 1 is the most important and 8 is the least important. A weighted average is presented in Figure 9.7. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important aspects were "How safe the medication is and weighing up the risks and benefits", and "The severity of the side effects". The least important were "Ability to follow and stick to a treatment regime" and "How the treatment is administered".

Table 9.12: Values in making decisions

Values in making decisions	All participants (n=95)	All stage 0 to II (n=59)	All stage III & IV (n=36)	Stage III & IV triple negative (n=24)	Stage III & IV hormone-receptor positive (n=12)	All Triple negative (n=44)	All hormone-receptor positive (n=51)	Stage 0 to II triple negative (n=20)	Stage 0 to II hormone-receptor positive (n=39)
How safe the medication is and weighing up the risks and benefits	6.39	6.49	6.22	5.92	6.83	6.25	6.51	6.65	6.43
The severity of the side effects	5.66	5.59	5.78	5.58	6.17	5.55	5.76	5.50	5.91
Time impact of the treatment on my quality of life	5.01	5.00	5.03	4.58	5.92	4.84	5.16	5.15	5.22
How the treatment is administered	3.39	3.51	3.19	2.96	3.67	3.25	3.51	3.60	3.26
How personalised the treatment is for me	5.47	5.42	5.56	6.08	4.50	5.61	5.35	5.05	5.52
The ability to include my family in making treatment decisions	3.27	3.20	3.39	4.13	1.92	3.82	2.80	3.45	3.30
Ability to follow and stick to a treatment regime	3.56	3.66	3.39	3.29	3.58	3.11	3.94	2.90	4.17
The financial costs to me and my family	3.24	3.12	3.44	3.46	3.42	3.57	2.96	3.70	2.17

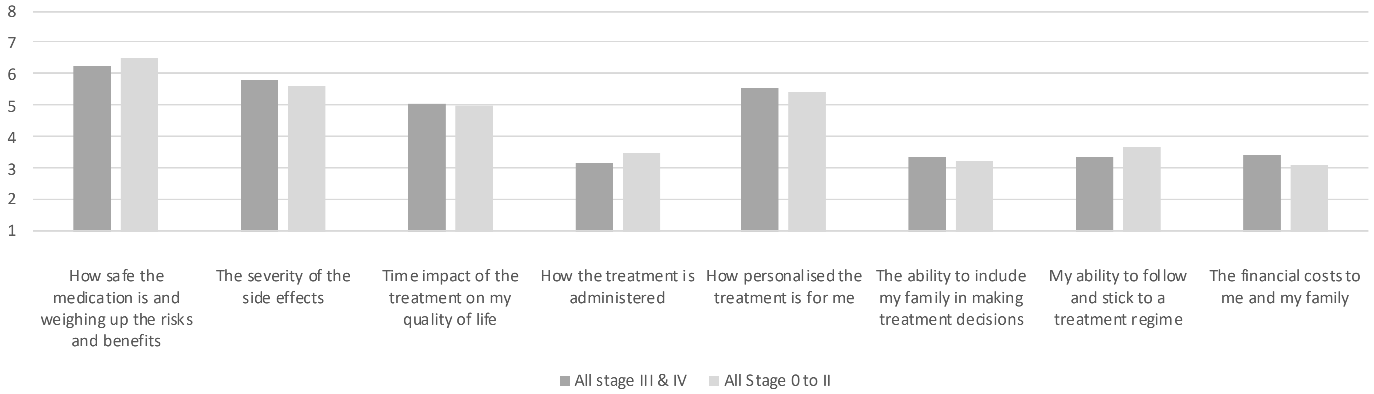


Figure 9.7: Values in making decisions (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Values for decision makers: Stage III and IV

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care, where 1 is the most important and 5 is the least important. A weighted average is presented in Figure 9.8. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important values were "Quality of life for patients", and "All patients being able to access all available treatments and services". The least important was "Economic value to government and tax payers".

Table 9.13: Values for decision makers

Values for decision makers	All participants (n=95)	All stage 0 to II (n=59)	All stage III & IV (n=36)	Stage III & IV triple negative (n=24)	Stage III & IV hormone-receptor positive (n=12)	All Triple negative (n=44)	All hormone-receptor positive (n=51)	Stage 0 to II triple negative (n=20)	Stage 0 to II hormone-receptor positive (n=39)
Economic value to government and tax payers	4.24	4.29	4.17	4.17	4.17	4.27	4.22	4.40	4.39
Economic value to patients and their families	5.61	5.66	5.53	5.63	5.33	5.68	5.55	5.75	5.83
Quality of life for patients	6.97	7.08	6.78	6.75	6.83	6.80	7.12	6.85	7.30
Compassion	6.07	5.97	6.25	6.17	6.42	6.16	6.00	6.15	5.74
All patients being able to access all available treatments and services	7.11	7.00	7.28	7.29	7.25	7.09	7.12	6.85	6.74

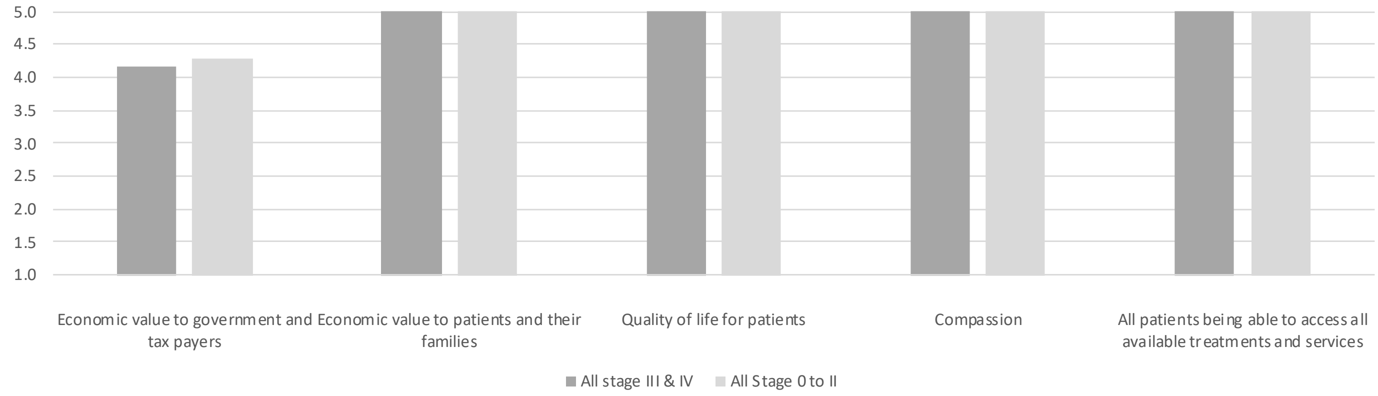


Figure 9.8: Values for decision makers (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Time taking medication to improve quality of life: Stage III and IV

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure.

The majority of participants (n = 20, 55.56%) would use a treatment for more than ten years for a good quality of life even if it didn't offer a cure (Table 9.14, Figure 9.9).

Table 9.14: Time taking treatment to improve quality of life

Time taking medication to improve quality of life	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	(n=95)	%	(n=59)	%	(n=36)	%	(n=24)	%	(n=12)	%
Less than 1 year	1	1.05	0	0.00	1	2.78	1	4.17	0	0.00
1 to 5 years	38	40.00	25	42.37	13	36.11	8	33.33	5	41.67
5 to 10 years	3	3.16	1	1.69	2	5.56	1	4.17	1	8.33
More than 10 years	53	55.79	33	55.93	20	55.56	14	58.33	6	50.00

Time taking medication to improve quality of life	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=95	%	(n=44)	%	(n=51)	%	(n=20)	%	(n=39)	%
Less than 1 year	1	1.05	1	2.27	0	0.00	0	0.00	0	0.00
1 to 5 years	**20**	**21.05**	14	31.82	24	47.06	6	30.00	19	48.72
5 to 10 years	**20**	**21.05**	1	2.27	2	3.92	0	0.00	1	2.56
More than 10 years	53	55.79	28	63.64	25	49.02	**14**	**70.00**	19	48.72

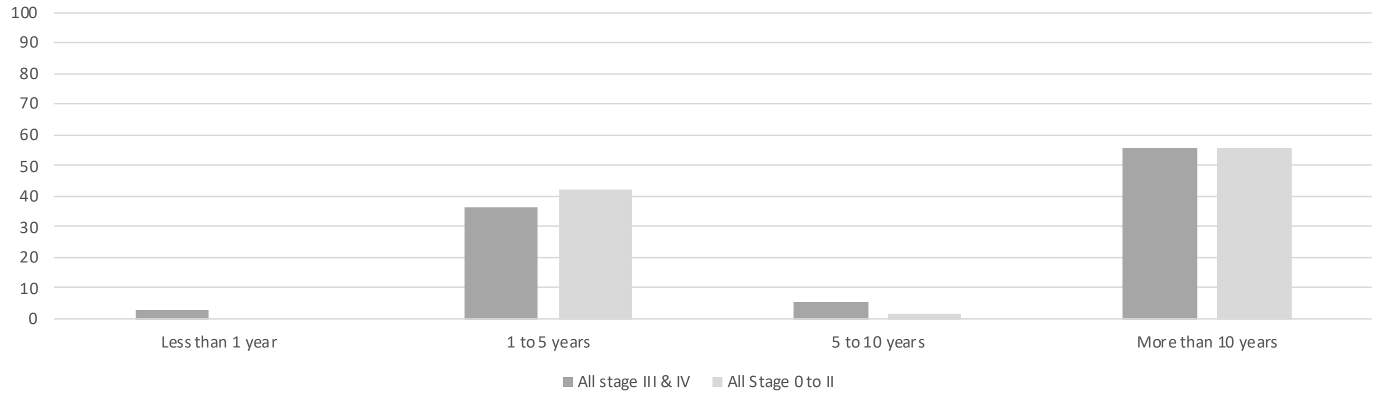


Figure 9.9: Time taking treatment to improve quality of life (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Most effective form of medicine: Stage III and IV

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in (Table 9.15, Figure 9.10).

There were 15 participants (41.67%) that thought that medicine delivered by IV was most effective, no participants (0.00%) thought that pill form was most effective, and 11 participants (30.56%) that thought they were equally effective. There were 10 participants (27.78%) that were not sure.

Table 9.15: Most effective form of medicine

Most effective form of medicine	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	(n=95)	%	(n=59)	%	(n=36)	%	(n=24)	%	(n=12)	%
Equally effective	37	38.95	22	37.29	15	41.67	10	41.67	5	41.67
In a pill form that I can take at home	6	6.32	6	10.17	0	0.00	0	0.00	0	0.00
IV form (through a drip in hospital	20	21.05	9	15.25	11	30.56	**8**	**33.33**	3	25.00
Not sure	32	33.68	22	37.29	10	27.78	6	25.00	4	33.33

Most effective form of medicine	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=95	%	(n=44)	%	(n=51)	%	(n=20)	%	(n=39)	%
Equally effective	37	38.95	16	36.36	21	41.18	6	30.00	16	41.03
In a pill form that I can take at home	6	6.32		0.00	6	11.76	0	0.00	6	15.38
IV form (through a drip in hospital	20	21.05	**15**	**34.09**	**5**	**9.80**	**7**	**35.00**	**2**	**5.13**
Not sure	32	33.68	13	29.55	19	37.25	7	35.00	15	38.46

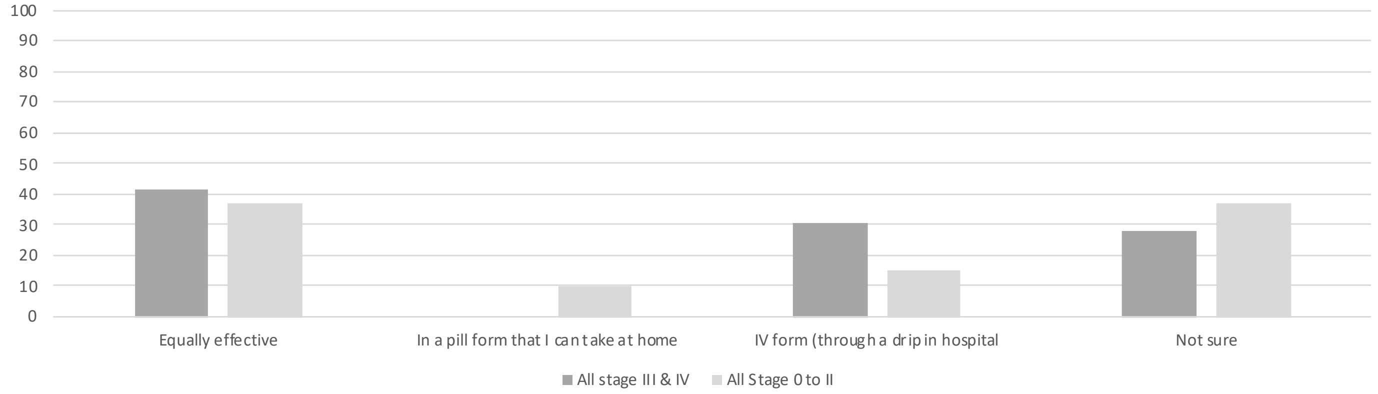


Figure 9.10: Most effective form of medicine (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 9.16: Most effective form of medicine – Stage III & IV variations

Most effective form of medicine	Reported less frequently	Reported more frequently
IV form (through a drip in hospital	-	Triple negative Stage III & IV

Messages to decision-makers: Stage III and IV

Participants were asked, "If you were standing in front of the health minister, what would your message be in relation to your condition?" The most common messages to the health minister were the need for timely and equitable access to support, care and treatment (46.15%), to understand the financial implications (and provide financial support) (28.21%), and the need for a tailored care plan (15.38 %). Other themes included to increase investment (general) (12.82%), to invest in professional development so that clinicians understand the condition (10.26%),to have a holistic approach to the condition (including emotional support) (7.69%), and to improve wait times (7.69%).

Timely and equitable access to support, care and treatment

Probably I think people think once you've had treatment and you've had the chemo when your so called cancer free and that's it. I think psychologically afterwards I think women would be good if there was follow up and some sort of psychological or mental health check or Yeah, I think it all happens while you're having treatment and the breast care nurse comes out and all that and then once you're done, that's it, you don't hear from anyone. Except for this study. It's like your treatment's done, but you're better now you're good, off you go. You're on your own, and I still don't have a boob. Participant 041_2021AUHRP

I would definitely say that people should have equal access to everything. I said before about having surgery paid publicly, so it shouldn't matter. It should all be the same for everybody regardless of whether you're through a private health fund or you have none at all. I feel as though you're actually worse off being through the private system yet our whole tax system says that you need to be part of a private health fund over 30 so it feels very contradictory to me. It'd be one thing I'll definitely say you need to look at. Participant_036TNG

Understand the financial implications (and provide financial support)

I think the radiation, it's a big thing for treatment, the costings and all that sort of thing. Even though I go Private Health, the out-of-pocket is ridiculous. If you pay into a health fund, you shouldn't have to pay any out-of- pocket for anything, I believe. With the radiation, I would have had to travel an hour there and an hour back each day, if I wanted to go somewhere where I had bulk-billed radiation. Anyone in this area, it's an hour travel there and back, and you'd have to get someone to take you because you don't feel like driving afterwards. It's something that's a bit tough if you can't get to the public radiation places. They should be able to provide some assistance through the others, but like I said, you can, and you don't know those things unless you have people that will tell you those things beforehand. Participant_046TNG

I guess just that the out-of-pocket costs are really hard to manage Participant_041TNG

Participant's message is that tailored care plans are needed

Look, I would say that it's pretty good. The one thing I would say and what I have noticed through my own research and I've asked questions on the triple-negative page which I'm on, is that there's women who are younger and younger being diagnosed with breast cancer and I think there needs to be more targeting to younger women. Participant_034TNG

Making sure that all new chemotherapies are viable for metastatic breast cancer? Unfortunately, a lot of these drugs that are coming out that approved there aren't a primary. They should be more thought go into women with metastatic breast cancer and being able to access chemotherapy at CBS process. Women with breast cancer can be cured. They're not going to die of metastatic, we are going to die. But if you can prolong someone's life with a drug that is being put on the PB's and not having to pay, say, forty thousand dollars for three months of treatment, that would be a huge help with that. Participant_049TNG

Increase investment (general)

Fund more Stage 4. One in three women potentially will move on to be metastatic. I think it's underfunded. Actually, could I change that? Get more support for stage 4, but particularly research around the recurrence of stage 4. The fact that we don't actually know is outrageous. The fact that they don't actually track and have any statistics about stage 4. More funding and research around stage 4. Participant 043_2021AUHRP

Please keep funding a variety of research into breast cancer. A variety of research. Participant 047_2021AUHRP

Invest in professional development so that clinicians understand the condition

Breast care nurses. We need more breast care nurses, 24 hours, 7 days a week. We need that resource. I was going through treatment and one of the nurses was telling me that they had their hours cut at the hospital. I just thought, "How can they cut their hours? It's just crazy." I go to Gold Coast Uni and there was hundreds of cancer patients through there at the time. I think they did a bit of a petition too. I was telling somebody in one of the Facebook groups, and I think they all petitioned to see if we can get more hours for the breast care nurses. They're so underrated and their assistance is amazing. Participant_029TNG

I haven't really thought of something like that. I know that there's a lot of courses out there that are pushing more money, obviously is one and that's generally to support. If we could have a couple of extra breast care nurses in our hometown, I think the things that I've got concerns about would be answered. It's getting more bodies in there to then create that access. Yes, and just generally pour more money to research, get it done. The amount of money going into cancer research and stuff like that and to not have, we can get a COVID vaccine for crying out loud. [crosstalk] We can't get something to cancer why? But, anyway. Participant_030TNG

Holistic approach to the condition (including emotional support)

They also need to make treatment more affordable, that sort of thing. That has to change. Just because you don't have a lot of money and, say, can't afford to pay hundreds of thousands of dollars for treatment, doesn't mean you should be punished for it. We should all be able to access the treatment, especially if we can see that it's working. Basically more, unfortunately, more money needs to be spent on curing cancer or cancer treatments. I don't know if that's ever going to happen. I don't know how much they're going to be able to perfect it, but I can see that it is starting to happen. They also need to do something with regards to the impact that it has on a person's mental health as well. It's still a lot that needs to be done. Participant_038TNG

I would definitely say that people should have equal access to everything. I said before about having surgery paid publicly, so it shouldn't matter. It should all be the same for everybody regardless of whether you're through a private health fund or you have none at all. I feel as though you're actually worse off being through the private system yet our whole tax system says that you need to be part of a private health fund over 30 so it feels very contradictory to me. It'd be one thing I'll definitely say you need to look at. I also think I would be telling him that there needs to be more care given in terms of, I guess if you said holistic. There needs to be more access to physios and psychologists and things like that as part of a government rollout. Participant_036TNG

It's such a huge thing now, such a big population of people have breast cancer so I think that all hospitals-- I think they are starting to have it now should have specialty areas for that demographic of people. I think that has access through a lot of different services to help people mentally, physically get through this and rehabilitate because it is something that you'll--especially after a double mastectomy or anything. If I had my legs chopped off, I'd be sent to rehab to get a new, and they'll have services available to help me walk again and to do all the things and they'll probably address my mental health and all that stuff more than when you get your breasts cut off. I think that's not recognized. I think that there needs to be some form of rehabilitation after that to help people get through because breast cancer diagnosis isn't something that you can just then get well from, I think it's something that you live with for the rest of your life, and you're mentally going to be always worried that it's going to come back again. I think there needs to be more fully into improving the quality of life and helping people get through this situation. Participant 048_2021AUHRP

Table 9.16 Messages to decision-makers

Message to decision-makers	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Timely and equitable access to support, care and treatment	48	47.06	30	47.62	18	46.15	11	40.74	7	58.33
Understand the financial implications (and provide financial support)	24	23.53	13	20.63	11	28.21	8	29.63	3	25.00
Participant's message is that tailored care plans are needed	11	10.78	5	7.94	6	15.38	6	22.22	0	0.00
Increase investment (general)	16	15.69	11	17.46	5	12.82	3	11.11	2	16.67
Invest in professional development so that clinicians understand the condition	7	6.86	3	4.76	4	10.26	4	14.81	0	0.00
Holistic approach to the condition (including emotional support)	11	10.78	8	12.70	3	7.69	3	11.11	0	0.00
Improve wait times	9	8.82	6	9.52	3	7.69	0	0.00	3	25.00
Compassionate and empathetic	6	5.88	4	6.35	2	5.13	0	0.00	2	16.67
Invest in screening/early detection	6	5.88	4	6.35	2	5.13	0	0.00	2	16.67
Improve rural services	6	5.88	4	6.35	2	5.13	0	0.00	2	16.67
No particular comment - satisfied with experience	5	4.90	4	6.35	1	2.56	1	3.70	0	0.00
Help raise community awareness	2	1.96	1	1.59	1	2.56	1	3.70	0	0.00
Participant's message is that it it is life-long that needs to be managed	1	0.98	0	0.00	1	2.56	1	3.70	0	0.00
Participant's message is that there needs to be support for side effects and symptoms, including long term follow up and support	6	5.88	5	7.94	1	2.56	0	0.00	1	8.33
Treatments need to be affordable	13	12.75	13	20.63	0	0.00	0	0.00	0	0.00

Message to decision-makers	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Timely and equitable access to support, care and treatment	48	47.06	22	44.00	26	50.00	11	47.83	19	47.50
Understand the financial implications (and provide financial support)	24	23.53	16	32.00	8	15.38	8	34.78	5	12.50
Participant's message is that tailored care plans are needed	11	10.78	11	22.00	0	0.00	5	21.74	0	0.00
Increase investment (general)	16	15.69	7	14.00	9	17.31	4	17.39	7	17.50
Invest in professional development so that clinicians understand the condition	7	6.86	7	14.00	0	0.00	3	13.04	0	0.00
Holistic approach to the condition (including emotional support)	11	10.78	5	10.00	6	11.54	2	8.70	6	15.00
Improve wait times	9	8.82	0	0.00	9	17.31	0	0.00	6	15.00
Compassionate and empathetic	6	5.88	0	0.00	6	11.54	0	0.00	4	10.00
Invest in screening/early detection	6	5.88	0	0.00	6	11.54	0	0.00	4	10.00
Improve rural services	6	5.88	0	0.00	6	11.54	0	0.00	4	10.00
No particular comment - satisfied with experience	5	4.90	5	10.00	0	0.00	4	17.39	0	0.00
Help raise community awareness	2	1.96	2	4.00	0	0.00	1	4.35	0	0.00
Participant's message is that it it is life-long that needs to be managed	1	0.98	1	2.00	0	0.00	0	0.00	0	0.00
Participant's message is that there needs to be support for side effects and symptoms, including long term follow up and support	6	5.88	0	0.00	6	11.54	0	0.00	5	12.50
Treatments need to be affordable	13	12.75	0	0.00	13	25.00	0	0.00	13	32.50

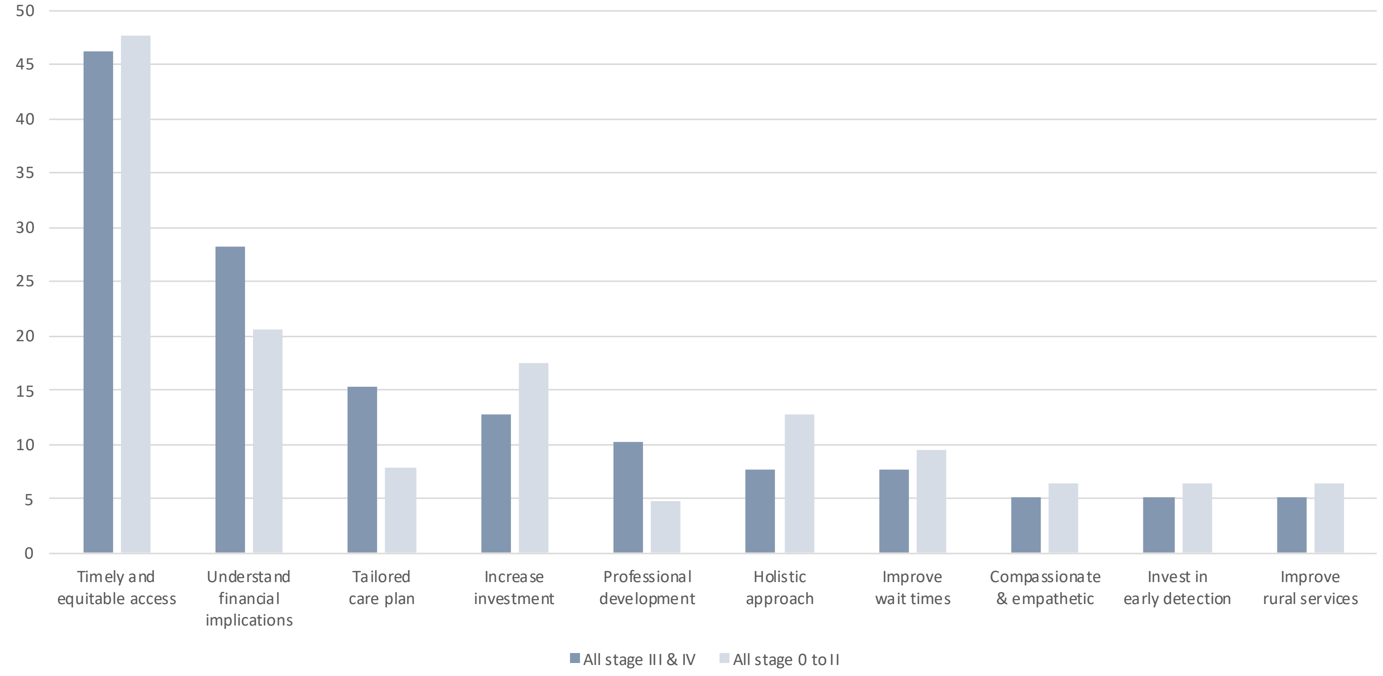


Figure 9.11: Messages to decision-makers (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 9.18: Messages to decision-makers – Stage III & IV variations

Message to decision-makers	Reported less frequently	Reported more frequently
Timely and equitable access to support, care and treatment	-	Hormone receptor Stage III & IV
Participant's message is that tailored care plans are needed	Hormone receptor Stage III & IV	Triple negative Stage III & IV
Holistic approach to the condition (including emotional support)	Hormone receptor Stage III & IV	-
Improve wait times	-	Hormone receptor Stage III & IV
Compassionate and empathetic	-	Hormone receptor Stage III & IV
Invest in screening/early detection	-	Hormone receptor Stage III & IV
Improve rural services	-	Hormone receptor Stage III & IV
Treatments need to be affordable	All Stage III & IV Triple negative Stage III & IV Hormone receptor Stage III & IV	-

Section 10

Advice to others in the future: The benefit of hindsight

Section 10: Advice to others in the future

Anything participants wish they had known earlier: Stage III & IV

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common things that participants had wished they'd known earlier were what to expect from their condition, particularly disease trajectory and understanding of disease biology (28.21%), more about the pros and cons of treatment options (15.38%), and more about what support was available to them (15.38 %). Other themes included the early signs and symptoms of the condition (12.82%), more about side effects of treatments (10.26%), and to sought seek medical attention sooner, or had population screening sooner (7.69%).

Other participants described that there was nothing they wished they had known earlier, some gave no reasons for this no (15.38%), and others did not describe anything they wish they'd known earlier as they are learning progressively/continuously (7.69%).

Aspect of care or treatment they would change: Stage III & IV

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common themes were that they would change or stop the kind of treatment they received (12.82%), and would have liked more information/discussion from healthcare staff (7.69%).

Others described that they would not change any aspect of their care or treatment without giving a reason (23.08%), and would not change any aspect of their care or treatment/satisfied with care and treatment received (17.95%).

Anything participants wish they had known earlier: Stage III & IV

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common things that participants had wished they'd known earlier were what to expect from their condition, particularly disease trajectory and understanding of disease biology (28.21%), more about the pros and cons of treatment options (15.38%), and more about what support was available to them (15.38 %). Other themes included the early signs and symptoms of the condition (12.82%), more about side effects of treatments (10.26%), and to sought seek medical attention sooner, or had population screening sooner (7.69%).

Other participants described that there was nothing they wished they had known earlier, some gave no reasons for this no (15.38%), and others
did not describe anything they wish they'd known earlier as they are learning progressively/continuously (7.69%).

Participant wishes they had known what to expect from their condition, particularly disease trajectory and understanding of disease biology

Yes, just how hard it was going to be. I have stressed what was going to be, not a walk in the park. Participant_028TNG

They don't talk about scans and things at the end. I wish I'd known at diagnosis that they don't scan you at the end of your treatment and things. There's no closure from that point of view. There's no, "I'm getting a PET scan or other scan to make sure it hasn't got anywhere in my body." That seems to be something common that a lot of my friends are all talking about. There's no end-of-treatment scan to say it's all gone. That plays on your mind. I'd like to see that talked about and told that that's the way it's going to be. Also, as I said, the ongoing medical menopause, that side of things afterwards, or how it affects your relationship. I had no idea that at the end of this you wouldn't be-- I knew you'd be not yourself, but I didn't realize that this is still another however many months before you feel well again. All those sort of fud things. Nobody talks about sex either. Nobody tells you that you're not going to have sex the whole time because if you're so sick and then you've got menopause. That's not going to happen either, you need to talk-- I feel as though your partners need to be told that. Your partner is a big part of your life, and that's a big part of most young people's cancer journey. That is just not even discussed, it's a big taboo subject. Participant_036TNG

Participant wishes they had known more about the pros and cons of treatment options

How the system works. This is pretty tricky. I think it would have been nice if they'd maybe been a bit of a flow diagram of, "This is how it could go" and this is, as I said, would be, "and if you need help or if you need from the side effects from anything else, this is who you contact". Participant 047_2021AUHRP

Yes, I wish when my oncologist had said "You've done Taxol. We can stop now." I wish I had stopped and I wish she'd actually said to me, "We need to stop because if we keep going, your neurons feed could potentially get worse. Rather than giving me an uneducated option, but to be told potential risks Participant_027TNG

Yes, the things I've mentioned before. Second opinion, seeking second opinion, asking questions and questioning. Not to be scared to ask questions why. Why are you getting this treatment? What is the purpose of the treatment? Is it going to work for me? Participant_042TNG

Participant wishes they had known more about what support was available to them

Definitely the nutrition to start with, the side effects of the chemo, and the neuropathy. If I could have found out there was a way to mitigate that a little bit more. Participant_029TNG

I don't think so. Probably just said access to other services. The broader may be some lists of people that you might consider contacting, and then the track, once you get your head around what's going on for you. In terms of social supports, and physical support at home. Yes. Participant_050TNG

Participant wishes they had known more about side effects of treatments

Yes. Probably wish I had of have known more about the gastrointestinal effect and how that can-- That really does alter your life when you're running to and from a room for months on end. That is the biggest pain in the ass. Knowing more about those sort of things. This is really what you have to look out for. If *you're going out for a walk, make sure you got a toilet nearby. Those sort of things. Participant_034TNG*

Definitely the nutrition to start with, the side effects of the chemo, and the neuropathy. If I could have found out there was a way to mitigate that a little bit more. Participant_029TNG

Participant wishes they had sought medical attention sooner, or had population screening sooner

That oh, definitely. Well, I always thought it was just like the ball came so that you have some 50 on and should be more promoted, that you can have mammograms for free from 40 years, because I was forty six when I got diagnosed and I never had a mammogram. Never, ever. I did. I didn't know that from 40 on. And yet it was for free as well. So yeah, that should be promoted definitely way better and better explained. Participant_031TNG

Participant does not describe anything they wish they'd known earlier as they are learning progressively/continuously

I think we always say that we wish we knew everything about more at the site about taking any these medications or these chemotherapy. I think it's nice to have known back then what I know now, but I don't think that's always possible in. Participant_049TNG

Not overly. I think a lot of this stuff was just a process, I do remember being like-- I couldn't even imagine myself being where I am now. They just didn't seem like there was-- but that's just something I think over time as you just get better and just you look back now and-- I do look back and think, "How the fuck did manage to do that?" Participant_043TNG

Table 10.1: Anything participants wish they had known earlier

Anything participants wish they had known earlier	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant wishes they had known what to expect from their condition, particularly disease trajectory and understanding of disease biology	32	31.37	21	33.33	11	28.21	6	22.22	5	41.67
Participant wishes they had known more about the pros and cons of treatment options	11	10.78	5	7.94	6	15.38	6	22.22	0	0.00
Participant wishes they had known more about what support was available to them	10	9.80	4	6.35	6	15.38	6	22.22	0	0.00
Participant does not describe anything they wish they had known earlier (no reason given)	20	19.61	14	22.22	6	15.38	4	14.81	2	16.67
Participant wishes they had know the early signs and symptoms of the condition	7	6.86	2	3.17	5	12.82	5	18.52	0	0.00
Participant wishes they had known more about side effects of treatments	9	8.82	5	7.94	4	10.26	4	14.81	0	0.00
Participant does not describe anything they wish they'd known earlier as they are learning progressively/continuously	6	5.88	3	4.76	3	7.69	3	11.11	0	0.00
Participant wishes they had sought medical attention sooner, or had population screening sooner	5	4.90	2	3.17	3	7.69	0	0.00	3	25.00
Participant wishes they had known the long term prognosis	2	1.96	0	0.00	2	5.13	2	7.41	0	0.00
Participant wishes they had known to be more assertive in relation to understanding treatment options and discussions about treatment	10	9.80	8	12.70	2	5.13	0	0.00	2	16.67
Participant does not describe anything they wish they'd known earlier as they had knowledge from family history	1	0.98	1	1.59	0	0.00	0	0.00	0	0.00
Participant wishes they had known the difference between private and public care	1	0.98	1	1.59	0	0.00	0	0.00	0	0.00

Anything participants wish they had known earlier	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant wishes they had known what to expect from their condition, particularly disease trajectory and understanding of disease biology	32	31.37	10	20.00	22	42.31	4	17.39	17	42.50
Participant wishes they had known more about the pros and cons of treatment options	11	10.78	11	22.00	0	0.00	5	21.74	0	0.00
Participant wishes they had known more about what support was available to them	10	9.80	10	20.00	0	0.00	4	17.39	0	0.00
Participant does not describe anything they wish they had known earlier (no reason given)	20	19.61	10	20.00	10	19.23	6	26.09	8	20.00
Participant wishes they had know the early signs and symptoms of the condition	7	6.86	7	14.00	0	0.00	2	8.70	0	0.00
Participant wishes they had known more about side effects of treatments	9	8.82	9	18.00	0	0.00	5	21.74	0	0.00
Participant does not describe anything they wish they'd known earlier as they are learning progressively/continuously	6	5.88	6	12.00	0	0.00	3	13.04	0	0.00
Participant wishes they had sought medical attention sooner, or had population screening sooner	5	4.90	0	0.00	5	9.62	0	0.00	2	5.00
Participant wishes they had known the long term prognosis	2	1.96	2	4.00	0	0.00	0	0.00	0	0.00
Participant wishes they had known to be more assertive in relation to understanding treatment options and discussions about treatment	10	9.80	0	0.00	10	19.23	0	0.00	8	20.00
Participant does not describe anything they wish they'd known earlier as they had knowledge from family history	1	0.98	1	2.00	0	0.00	1	4.35	0	0.00
Participant wishes they had known the difference between private and public care	1	0.98	1	2.00	0	0.00	1	4.35	0	0.00

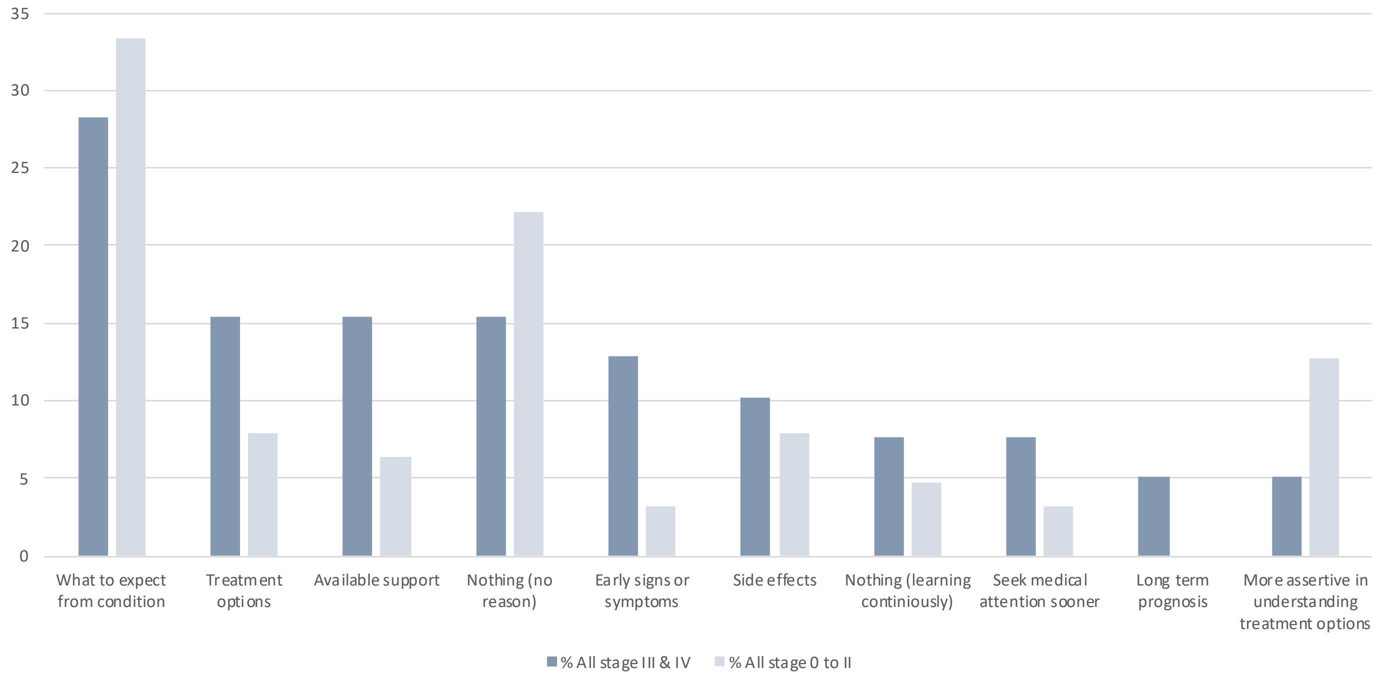


Figure 10.1: Anything participants wish they had known earlier (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 10.2: Anything participants wish they had known earlier – Stage III & IV variations

Anything participants wish they had known earlier	Reported less frequently	Reported more frequently
Participant wishes they had known what to expect from their condition, particularly disease trajectory and understanding of disease biology	-	Hormone receptor Stage III & IV
Participant wishes they had known more about the pros and cons of treatment options	Hormone receptor Stage III & IV	Triple negative Stage III & IV
Participant wishes they had known more about what support was available to them	-	Triple negative Stage III & IV
Participant wishes they had know the early signs and symptoms of the condition	-	Triple negative Stage III & IV
Participant wishes they had sought medical attention sooner, or had population screening sooner	-	Hormone receptor Stage III & IV

Aspect of care or treatment they would change: Stage III & IV

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common themes were that they would change or stop the kind of treatment they received (12.82%), and would have liked more information/discussion from healthcare staff (7.69%).

Others described that they would not change any aspect of their care or treatment without giving a reason (23.08%), and would not change any aspect of their care or treatment/satisfied with care and treatment received (17.95%).

Participant would change or stop the kind of treatment they received

I think if at the time I wasn't so rushed, I understand a lot of ladies now have chemo before surgery and if that has worked, where that's good psychologically is that you know the chemo has started destroying the tumor and it's shrinking or pitted. In my case, it would've made it smaller, so possibly I wouldn't have had to have some of the muscle in the ribs taken out, which is a little bit painful and possibly, it wouldn't have been such a big lump. Even now, and I say to a lot of people, if I had to have my time again, I would have had the double DIEP reconstruction, to take the anxiety out of having still have mammograms or ultrasounds on the other breast. I would always would have done that. I haven't mentioned that I've had a hysterectomy before and I've also had a new neurectomy from anxiety of being worried about my ovary, that I still had left after a hysterectomy 10 years before.
INTERVIEWER: Okay. You went ahead with that preventatively?
PARTICIPANT: Yes, I did. With the DIEP you can't feel your stomach. When I'd had an ovarian cyst 10 years before, which was a little bit large, I did get flight backache from it and I was worried. Even though the

doctors told me it wouldn't happen, I just didn't want to have this ovary sitting in there and never knowing anything about what's going on there. Of course, that's the one cancer that they've got no symptoms. Participant_040TNG

I didn't want to do radiation, and I still don't…I'm not a 100% sure if I did the right thing in having it because obviously, that forced me to have a full surgery rather than have a breast implant put in which is major surgery where he's putting a breast implant and it's not as big a deal. Participant_043TNG

If I'd known I had the gene, I would've had a double mastectomy, instead of a lumpectomy. Other than that, no. Participant_037TNG

Participant would have liked more information/discussion from healthcare staff

I think just the timing of giving them information and I understood the CI a. hey, did that education before I started my my is really busy and I said maybe they need more resources for people to be able to do that. And I know that it's important to tell people before I start all of these things, but for me personally, I didn't take in that information. So there's a lot of stuff that I did that I still don't remember. I remember that she said something about it. But I would about tell you what the vision that there was no follow up, you know, I that she talked about mask, that I couldn't remember what I had to do when I actually had something wrong with my. And so I that's when I Googled. And when I went to my Facebook group, it so did my mouth, you know, what's the best thing for it? And people gauge their opinions. And I tried things and I said, I think that it's just that repeating that information is like giving people the option, like what works for you. Participant_038TNG

ARTICIPANT: Yes. Having a second person there asking questions would be the big one. Just do research. My oncologist before would encourage me not to research, not to find out, not to know. This is the absolutely opposite. It should be absolutely opposite. You have to research, you are your advocate. You are the advocate of your health and your body. It's in your best interest to act and to ask questions. Participant_042TNG

Participant would not change any aspect of their care or treatment/satisfied with care and treatment received

I would change-- no. I don't believe so, I have the utmost respect for everybody that has been part of my treatment, and I'm forever grateful, the doctors and nurses that have helped me, so no. Participant_029TNG

Not from the care and treatment. The care and the treatment have been excellent. That has been really, really good. Once I was with the right people, it's been great. Participant_033TNG

Table 10.3: Aspect of care or treatment they would change

Aspect of care or treatment they would change	All participants		All Stage 0 to II		All Stage III & IV		Triple negative Stage III & IV		Hormone receptor Stage III & IV	
	n=102	%	n=63	%	n=39	%	n=27	%	n=12	%
Participant would not change any aspect of their care or treatment (no reason given)	24	23.53	15	23.81	9	23.08	6	22.22	3	25.00
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	22	21.57	15	23.81	7	17.95	**3**	**11.11**	**4**	**33.33**
Participant would change or stop the kind of treatment they received	7	6.86	2	3.17	5	12.82	**5**	**18.52**	0	0.00
Participant would have liked more information/discussion from healthcare staff	4	3.92	1	1.59	3	7.69	3	11.11	0	0.00
Participant would have liked more time and personalised attention with specialists	4	3.92	2	3.17	2	5.13	2	7.41	0	0.00
Treatment or care: More time and personlised attention (nurses)	3	2.94	1	1.59	2	5.13	2	7.41	0	0.00
Participant would have liked to have had a better understanding of their condition	10	9.80	8	12.70	2	5.13	0	0.00	2	16.67
Treatment or care: Switched health professionals	3	2.94	2	3.17	1	2.56	1	3.70	0	0.00
Treatment or care: Accesses appropriate specialist sooner	3	2.94	2	3.17	1	2.56	1	3.70	0	0.00
Treatment or care:Been more assertive	1	0.98	0	0.00	1	2.56	1	3.70	0	0.00
Treatment or care: fertility considerations	1	0.98	1	1.59	0	0.00	0	0.00	0	0.00
Treatment or care: switched to private	1	0.98	1	1.59	0	0.00	0	0.00	0	0.00
Treatment or care:Access to allied health	1	0.98	1	1.59	0	0.00	0	0.00	0	0.00
Treatment or care:Had a better understanding of their condition	1	0.98	1	1.59	0	0.00	0	0.00	0	0.00

Aspect of care or treatment they would change	All participants		All Triple negative		All Hormone receptor		Triple negative Stage 0 to II		Hormone receptor Stage 0 to II	
	n=102	%	n=50	%	n=52	%	n=23	%	n=40	%
Participant would not change any aspect of their care or treatment (no reason given)	24	23.53	9	18.00	15	28.85	**3**	**13.04**	12	30.00
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	22	21.57	12	24.00	10	19.23	**9**	**39.13**	6	15.00
Participant would change or stop the kind of treatment they received	7	6.86	7	14.00	0	0.00	2	8.70	0	0.00
Participant would have liked more information/discussion from healthcare staff	4	3.92	4	8.00	0	0.00	1	4.35	0	0.00
Participant would have liked more time and personalised attention with specialists	4	3.92	4	8.00	0	0.00	2	8.70	0	0.00
Treatment or care: More time and personlised attention (nurses)	3	2.94	3	6.00	0	0.00	1	4.35	0	0.00
Participant would have liked to have had a better understanding of their condition	10	9.80	0	0.00	10	19.23	0	0.00	**8**	**20.00**
Treatment or care: Switched health professionals	3	2.94	3	6.00	0	0.00	2	8.70	0	0.00
Treatment or care: Accesses appropriate specialist sooner	3	2.94	3	6.00	0	0.00	2	8.70	0	0.00
Treatment or care:Been more assertive	1	0.98	1	2.00	0	0.00	0	0.00	0	0.00
Treatment or care: fertility considerations	1	0.98	1	2.00	0	0.00	1	4.35	0	0.00
Treatment or care: switched to private	1	0.98	1	2.00	0	0.00	1	4.35	0	0.00
Treatment or care:Access to allied health	1	0.98	1	2.00	0	0.00	1	4.35	0	0.00
Treatment or care:Had a better understanding of their condition	1	0.98	1	2.00	0	0.00	1	4.35	0	0.00

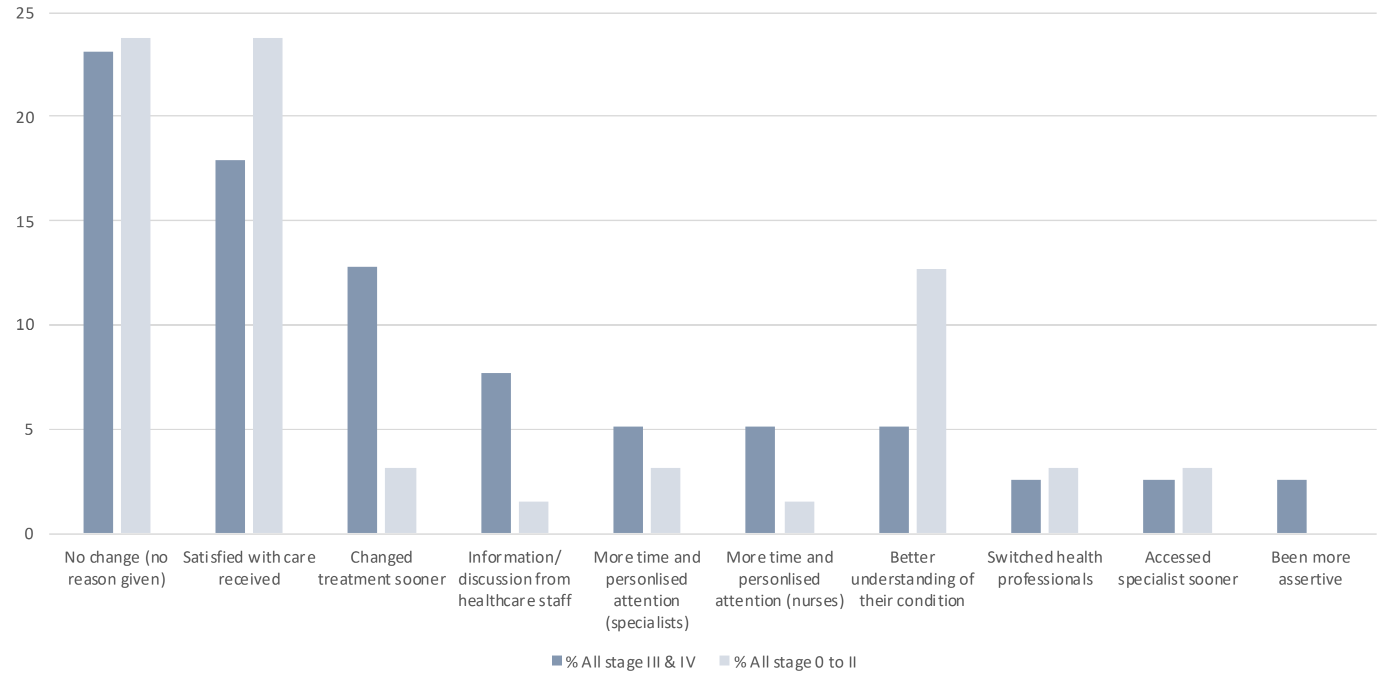


Figure 10.2: Aspect of care or treatment they would change (% of participants by stage) – Comparison of Stage III & IV with Stage 0 to II

Table 10.4: Anything participants wish they had known earlier – Stage III & IV variations

Aspect of care or treatment they would change	Reported less frequently	Reported more frequently
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	Triple negative Stage III & IV	Hormone receptor Stage III & IV
Participant would change or stop the kind of treatment they received		Triple negative Stage III & IV