Section 5

Treatment

Section 5: Experience of treatment

Main provider of treatment

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

The most common provider of treatment and care were General practitioner (GP)s (n=25,50.00 %), followed by Cardiologists (n=17, 34.00%).

Time to travel to main provider of treatment

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

There were 12 participants (40.00%) that travelled for less than 15 minutes, 8 participants (26.67%) that travelled between 15 and 30 minutes, 6 participants (20.00%) that travelled between 30 and 60 minutes, 1 participants (3.33%) that travelled between 60 and 90 minutes, and 2 participants (6.67%) that travelled more than 90 minutes.

Access to healthcare professionals

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

The majority of participants had access to a General Practitioner (GP) (n=43, 86.00%), and a Cardiologist (n=32, 64.00%). There were 11 participants (22.00%) that had a Specialist nurse, and 5 participants (10.00%) that had a Care coordinator, discharge planner or key worker.

Psychologist to care for their condition (n=13, 26.00%). There were 21 participants (42.00%) treated by a Dietitian/ nutritionist, 21 participants (42.00%) with a by a Pharmacist/ chemist, 13 participants (26.00%) cared for by a Psychologist, and 13 participants (26.00%) treated by a Exercise physiologist.

Respect shown

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

There were 28 participants (56.00%) that indicated that they had been treated with respect throughout their experience, and 16 participants (32.00%) that were treated with respect with the exception of one or two occasions. There were 6 participants (12.00%) that felt they had not been treated respectfully.

Health care system

In the online questionnaire, participants were asked questions about the healthcare system they used, about private insurance and about whether they were treated as a public or private patient.

The majority of participants had private health insurance (n=34, 68.00%). The majority of participants were not asked if they wanted to be treated as a public or private patient (n=32, 64.00%), however, they were asked if they had private health insurance (n=33, 66.00%).

Throughout their treatment, there were 19 participants (38.00%) that were treated as a private patient, 22 participants (44.00%) were mostly treated as a public patient, and there were 5 participants (10.00%) that were equally treated as a private and public patient.

Throughout their treatment, there were 15 participants (30.00%) that were treated mostly in the private hospital system, 28 participants (56.00%) were mostly treated in the public system, and there were 7 participants (14.00%) that were equally treated in the private and public systems.

Affordability of healthcare

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. The majority of participants never or rarely had to delay or cancel appointments due to affordability (n = 35, 70.00%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=43, 86.00%).

The third question was about the affordability of basic essentials such as such as food, housing and power. There were 37 participants (74.00%) that never or rarely had trouble paying for essentials, and 7 participants (14.00%) that sometimes found it difficult, and 6 participants (12.00%) 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 9 participants (18.00%) that paid for additional carers due to their condition.

Cost of condition

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

The most common amount was $100 or less (n=16, 32.00%), followed by between $101 to $250 (n=9, 18.00%). There were 3 participants (6.00%), that spent $1001 or more a month.

Burden of cost

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

The amount spent was an extremely significant or moderately significant burden for 13 participants (26.00%), somewhat significant for 15 participants (30.00%), and slightly or not at all significant for 22 participants (44.00%).

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 13 participants (26.00%) had not changed since diagnosis, and 6 participants (12.00%) were retired or did not have a job. There were 17 participants (34.00%) had to quit their job, 9 participants (18.00%) reduced the number of hours they worked, and 3 participants (6.00%) that accessed their superannuation early. There were 7 participants (14.00%) that took leave from work without pay, and 11 participants (22.00%) 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 16 participants (32.00%), without a main partner or carer. Most commonly, participants had partners or carers that did not change their work status due to their condition (n=26, 52.00%). There was 1 participant (2.00%) whose partner reduced the numbers of hours they worked, and 1 partner, (2.00%) that quit their job. The partners of 2 participants (4.00%) took leave without pay, and there were 3 partners (6.00%) that took leave with pay.

Reduced income due to condition

There were 20 participants (42.55%) that 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 in the table below.

Most commonly, participants were not sure about the amount their monthly income was reduced by $2000 to $5000 per month (n=7, 14.89%).

Burden of reduced income

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

For 11 of these participants (55.00%), the burden of this reduced income was extremely or moderately significant, for 5 participants (25.00%) the burden was somewhat significant, and for 4 participants (20.00%) the burden was slightly or not all significant.

Treatments overview

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

There were 17 participants (34.00%) that had surgical treatments, 40 participants (80.00%) that had drug treatments and 28 participants (56.00%) that used allied health services. The majority of participants had made lifestyle changes (n=42, 84%), and approximately a third used complementary therapies (n=42) (n=15, 35.71%).

Surgical treatments

Participants completed a series of questions about surgery, including type of surgery, quality of life, effectiveness of surgery, and side effects.
Details of quality of life and effectiveness are given for surgical interventions in 5 or more participants.

There were 6 participants (12.00%) that had coronary angioplasty, percutaneous coronary intervention or stents, 5 participants (10.00%) that had pacemaker or an implantable cardiac defibrillator (ICD) and 4 participants (8.00%) that had surgery for pacemaker or implantable cardioverter defibrillator. Other surgical interventions included Bypass surgery (n=2, 4.00%), and Heart valve surgery (n=1, 2.00%).

On average, quality of life from coronary angioplasty, percutaneous coronary intervention or stents was in the 'life was good' range (median=5.00, IQR = 2.25), and was found to be very effective (median=5.00 , IQR=0.00).

On average, quality of life from pacemaker or an implantable cardiac defibrillator (ICD) was in the 'life was average' range (median=4.00, IQR=1.00), and was found to be effective (median=4.00 , IQR=1.00).

Summary of drug treatments

In the online questionnaire, participants answered a series of questions about their treatment, including treatment given, quality of life from treatment, side effects from treatment and how effective they thought the treatment was. Details of quality of life and effectiveness are given for surgical interventions in 5 or more participants.

There were 23 participants (46.00%) that had antiplatelets, 18 participants (36.00%) that had beta blockers and 18 participants (36.00%) that had statins. Participants also took ACE inhibitors (n=10, 20%), ARBs (n=8, 16%), diurectics (n=6, 12%), cholesterol absorption inhibitors (n=5, 10.00%), calcium channel blockers (n=3, 6.00%), ARNIs (n=2, 4.00%), sinus node inhibitors (n=2, 4.00%), and glycosides (n=2, 4.00%).

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.

On average, quality of life from antiplatelets was in the 'life was average' range (median=4.00, IQR = 1.00), and was found to be effective (median=4.00 , IQR=0.50).

On average, quality of life from beta blockers was in the 'life was average to good' range (median=4.50, IQR=2.75), and was found to be effective (median=4.50 , IQR=1.00).

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

On average, quality of life from ACE inhibitors was in the 'life was average' range (median=4.00, IQR=1.50), and was found to be effective (median=4.00 , IQR=0.75).

On average, quality of life from ARBs e.g. candesartan, losartan, valsartan was in the 'life was average' range (median=4.00, IQR=2.25), and was found to be moderately effective to effective (median=3.50 , IQR=2.25).

On average, quality of life from anticoagulants was in the 'life was good to very good' range (median=5.50, IQR=3.25), and was found to be effective (median=4.00 , IQR=0.50).

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

On average, quality of life from cholesterol absorption inhibitors was in the 'life was average' range (median=5.00, IQR=0.00), and was found to be effective (median=4.00 , IQR=0.00).

Allied health

The most common allied health service used was seeing a dietician (n=14, 28.00%), followed by physiotherapy (n=13, 26.00%), and psychology or counselling (n=12, 24.00%). There were 9 participants (18.00%) that had occupational therapy, 9 participants (18.00%) that had speech therapy, and 5 participants (10.00%) that saw a social worker.

On average, quality of life from seeing a dietician was in the 'life was average' range (median=4.00, IQR = 2.75), and was found to be effective (median=4.00, IQR = 1.00).

On average, quality of life from physiotherapy 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=3.00).

On average, quality of life from psychology or counselling was in the 'life was distressing' range (median=2.00, IQR=2.25), and was found to be moderately effective (median=3.00, IQR=2.00).

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

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

Lifestyle changes

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

The majority of participants used at made at least one lifestyle change (n=42, 84.00%), and on average made 2 changes (median=2.00, IQR=1.75).

The most common lifestyle changes used were diet changes (n=29, 58.00%), and exercise (n=29, 58.00%), followed by and Quitting or cutting back on alcohol (n=19, 38.00%), and Quitting or cutting back on smoking (n=10, 20.00%).

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 effective (median=4.00, IQR=2.00).

On average, quality of life from exercise was in the 'life was good' range (median=5.00, IQR=2.00), and was found to be effective (median=4.00, IQR=1.00).

On average, quality of life from quitting or cutting back on alcohol was in the 'life was good' range (median=5.00, IQR=2.00), and was found to be effective (median=4.00, IQR=2.00).

On average, quality of life from quitting or cutting back on smoking was in the 'life was average' range (median=4.00, IQR=2.00), and was found to be effective (median=4.00, IQR=1.00).

Complementary therapies

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

Approximately a third of participants used at least one complementary therapy (n=15, 35.71%). The most common complementary therapy used was Mindfulness or relaxation techniques (n=11, 26.19%), followed by Massage therapy (n=7, 16.67%), Supplements (n=6, 14.29%), and acupuncture (n=5, 11.90%)

On average, quality of life from mindfulness or relaxation techniques was in the 'life was good' range (median=5.00, IQR=2.00), and was found to be effective (median=4.00, IQR=1.50).

On average, quality of life from massage therapy was in the 'life was distressing' range (median=2.00, IQR=2.50), and was found to be moderately effective (median=3.00, IQR=2.50).

On average, quality of life from supplements was in the 'life was average to good' range (median=4.50, IQR=2.50), and was found to be moderately effective to effective (median=3.50, IQR=1.00).

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

Clinical trials

Clinical trials discussions

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

There was a total of 4 participants (8%) that had discussions about clinical trials, 3 participants (6.00%) had brought up the topic with their doctor, and the doctor of 1 participant (2.00%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=46, 92.00%).

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 was 1 participant (2.00%) that had taken part in a clinical trial, 36 participants (72.00%) that would like to take part in a clinical trial if there was a suitable one, and 13 participants, that have not participated in a clinical trial and do not want to (26.00%).

Treatment and management following lipoprotein a test

Lipoprotein a testing

In the online questionnaire, participants noted if they had a Lipoprotein a test. There were 24 participants (43.64%) that had a Lipoprotein a test.

Lipoprotein a test results

As a follow up question, participants were asked if they knew the result of their Lipoprotein a test. There were 9 participants (16.36%) that did not know their result, 9 participants (16.36%) that knew result and gave a numerical value, and 6 participants (10.91%) that were not sure of exact result but that it was high.

Changes in treatment and management following Lipoprotein a testing

Participants noted in the online questionnaire any changes their doctor made to the treatment or management of their condition following lipoprotein a testing.

Most commonly, changes were made to medication (n=10, 41.67%), followed by recommendations for diet and lifestyle changes (n=6, 25.00%). There were 5 participants (20.83%) that were had additional monitoring, and 2 participants (8.33%), that had no made changes to treatment or management.

Participant-made changes following lipoprotein a/Lp(a) results

In the online questionnaire, participants noted the changes that they had made following getting their lipoprotein a/Lp(a) results.

The majority of participants made diet changes (n=18, 75.00%), and half the participants (50.00%) tried to exercise more. There were 8 participants (33.33%) that tried to drink less alcohol, and 8 participants (33.33%) that tried to lose weight. Other changes included tried to give up smoking (20.83%), became more careful about taking medicatins (16.67%) and became more caredful about making and attending medical appointments (12.50%). There were 2 participants (12.50%) that made no changes following thier lipoprotein a test result.

After getting Lipoprotein a/Lp(a) results, activities to learn more about it

Participants noted the activities they had done to learn more about lipoprotein a.

More than half of the participants looked for information about it (n=13, 54.17%), and a third asked their doctor about it (n=8, 33.33%). There were 3 participants (12.50%) that joined a heart management program, and 3 participants (12.50%) that joined a patient group. There were 9 participants (37.50%) that did not do anything to find out more about Lp(a).

Did other members of family have a Lipoprotein a /Lp(a) test because of test result

Participants were asked if family members had a lipoprotein a /Lp(a) test because of test result. There were 6 participants (25.00%) that noted other family members had this test due to their result.

Description of mild side effects

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 described using a specific example (57.45%), and those that do not interfere with life (36.17%). Other themes included side effects that have a short duration (10.64%), and that they had only experienced or only described severe side effects (8.51%).

When a specific side effect was described, the most common side effects were aches and pain (23.40%), fatigue/lethargy (23.40%), headaches (6.38%), and nausea, vomiting,or loss of appetite (6.38%).

Description of severe side effects

In the structured interview, participants were asked how they would describe the term 'severe side effects'. The most common description of severe side effects were described using a specific example (57.45%), and those that impact everyday life or ability to conduct activities of daily living (34.04%). Other themes included those that are life threatening or result in hospitalisation (6.38%), those that cause long-term damage to their body (6.38%), those that requires medical intervention (6.38%), and those that cause a need to change or stop using medication (6.38%).

When a specific side effect was described, the most common examples were aches and pain (21.28%), cognitive difficulties, including brain fog and difficulty communicating (14.89%), the emotional or mental impact (10.64%). Other side effects included fatigue or lethargy (10.64%), nausea, vomiting,or loss of appetite (6.38%), reduced mobility or loss of independence (6.38%), and shortness of breath (6.38%).

Adherence to treatment

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 for a specific amount of time (46.81%), adhering to treatment according to the advice of their specialist or as long as prescribed (27.66%), and adhering to treatment as long as side effects are tolerable (25.53 %). Other themes included never giving up on any treatment (21.28%), and adhering to treatment as long as treatment is working (21.28%).

When participants stated a specific amount of time to adhere to a treatment, the most common amount of time was two to three months (14.89%), and six to twelve months (8.51%).

What needs to change to feel like treatment is working

Participants were asked to describe what needs to change to feel like treatment is effective. The most common responses were needing to see a specific symptom reduction (44.68%), and needing to see physical signs and symptoms disappear or reduce side effects (27.66%). Other themes included needing to see test results (14.89%), needing to see a return to day-to-day functionality (12.77%), and needing to have a balance between benefits and potential side effects (8.51%).

When a specific side effect or symptom was described, the most common examples were fatigue or lethargy (17.02%), heart rate or regular heart beat (8.51%), aches or pain (6.38 %), and the emotional, or mental impact (6.38%).

What it would mean if treatment worked

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 responses were that it would allow them to do everyday activities or return to normal life (17.02%), and it would lead to a reduction in symptoms or side effects (14.89%). This was followed by it would have positive impact on their mental health (12.77 %), and allow them to engage more with social activities and family life (8.51%).

Main provider of treatment

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

The most common provider of treatment and care were General practitioner (GP)s (n=25,50.00 %), followed by Cardiologists (n=17, 34.00%).

Time to travel to main provider of treatment

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

There were 12 participants (40.00%) that travelled for less than 15 minutes, 8 participants (26.67%) that travelled between 15 and 30 minutes, 6 participants (20.00%) that travelled between 30 and 60 minutes, 1 participants (3.33%) that travelled between 60 and 90 minutes, and 2 participants (6.67%) that travelled more than 90 minutes.

Table 5.1: Main provider of treatment

Main provider of treatment	Number (n=50)	Percent
General practitioner (GP)	25	50.00
Cardiologist	17	34.00
Neurologist	4	8.00
Multi-disciplinary	3	6.00
No main provider	1	2.00

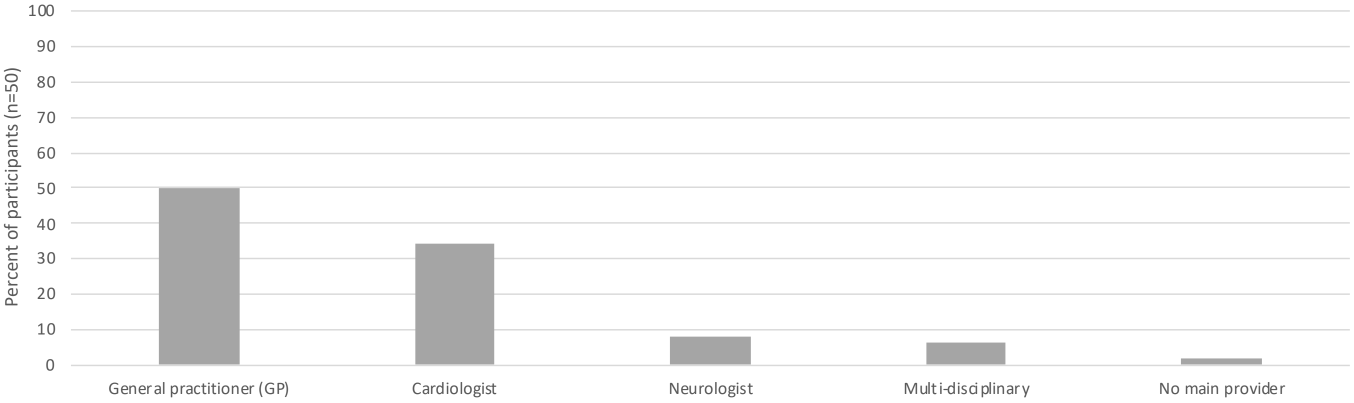

Figure 5.1: Main provider of treatment

Table 5.2: Time to travel to main provider of treatment

Main provider of treatment	Number (n=30)	Percent
Less than 15 minutes	12	40.00
Between 15 and 30 minutes	8	26.67
Between 30 and 60 minutes	6	20.00
Between 60 and 90 minutes	1	3.33
More than 90 minutes	2	6.67
No main provider	1	3.33

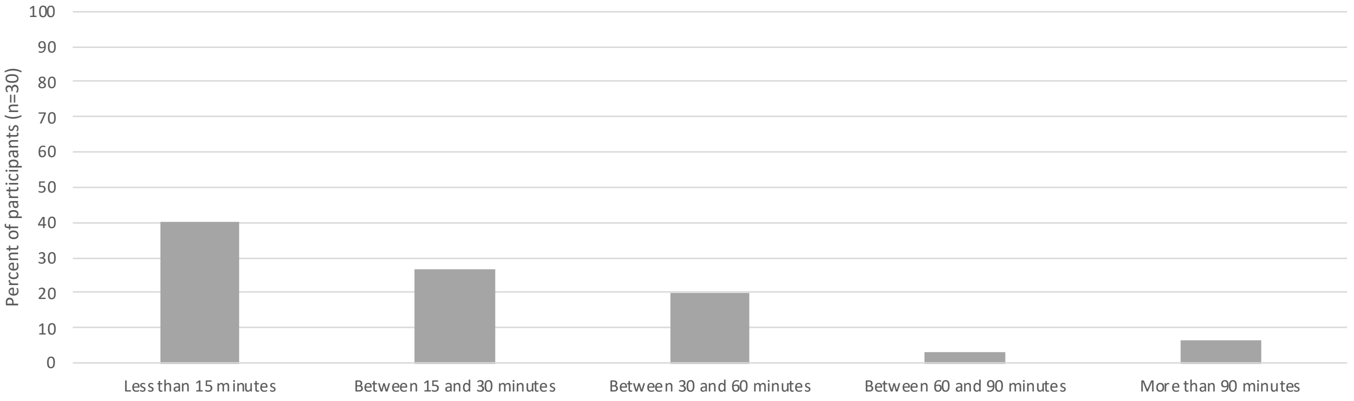

Figure 5.2: Time to travel to main provider of treatment

Access to healthcare professionals

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

The majority of participants had access to a General Practitioner (GP) (n=43, 86.00%), and a Cardiologist (n=32, 64.00%). There were 11 participants (22.00%) that had a Specialist nurse, and 5 participants (10.00%) that had a Care coordinator, discharge planner or key worker.

Psychologist to care for their condition (n=13, 26.00%). There were 21 participants (42.00%) treated by a Dietitian/ nutritionist, 21 participants (42.00%) with a by a Pharmacist/ chemist, 13 participants (26.00%) cared for by a Psychologist, and 13 participants (26.00%) treated by a Exercise physiologist.

Table 5.3: Access to healthcare professionals

Healthcare professional	Number (n=50)	Percent
Cardiologist	32	64.00
Emergency doctor	14	28.00
Neurologist	12	24.00
Physiotherapist	11	22.00
Rehabilitation physician	7	14.00
Surgeon	7	14.00
General Practitioner (GP)	43	86.00
Specialist nurse	11	22.00
Care coordinator, discharge planner or key worker	5	10.00
Registered Nurse	4	8.00
Community nurse	1	2.00
Dietitian/ nutritionist	21	42.00
Pharmacist/ chemist	21	42.00
Exercise physiologist	13	26.00
Psychologist	13	26.00
Occupational therapist	10	20.00
Cardiac rehabilitation	8	16.00
Speech pathologist	6	12.00
Ophthalmologist/ orthopedist	5	10.00
Social worker	5	10.00
Neuropsychologist	4	8.00
Chiropractor	3	6.00
Counsellor	3	6.00

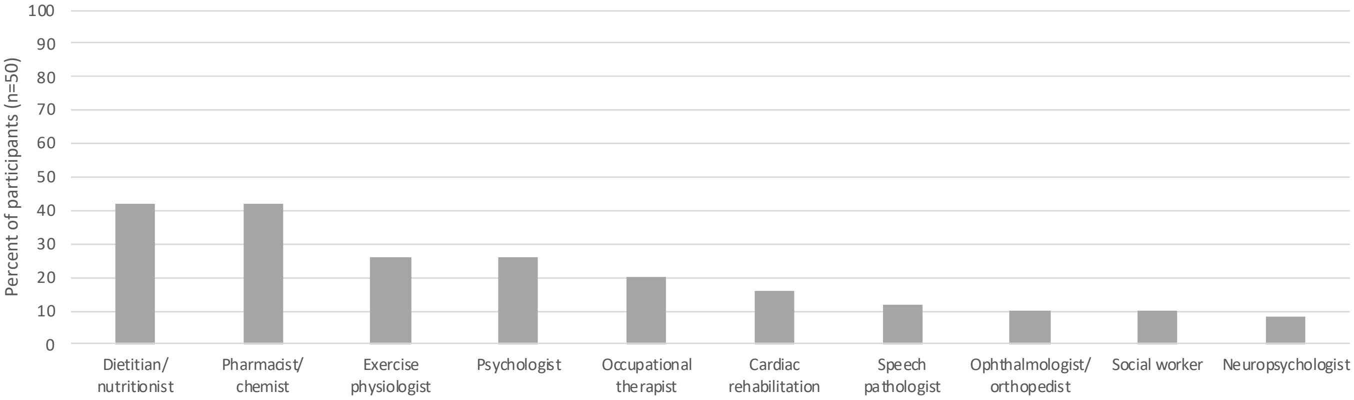

Figure 5.3: Access to healthcare professionals

Respect shown

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

There were 28 participants (56.00%) that indicated that they had been treated with respect throughout their experience, and 16 participants (32.00%) that were treated with respect with the exception of one or two occasions. There were 6 participants (12.00%) that felt they had not been treated respectfully.

Table 5.4: Respect shown

Respect shown	Number (n=50)	Percent
Respect shown	28	56.00
Respect shown, with the exception of one or two occasions	16	32.00
Respect not shown	6	12.00

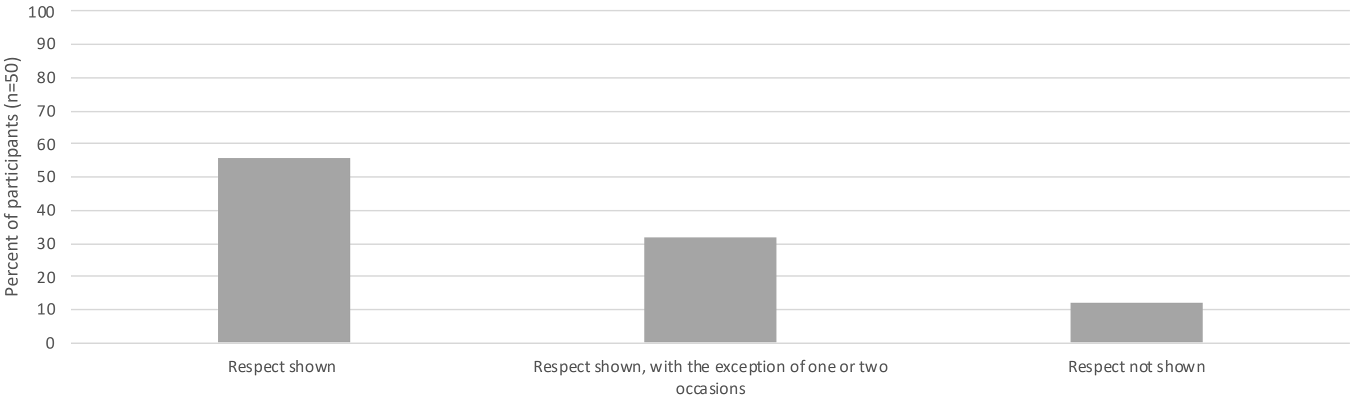

Figure 5.4: Respect shown

Health care system

In the online questionnaire, participants were asked questions about the healthcare system they used, about private insurance and about whether they were treated as a public or private patient.

The majority of participants had private health insurance (n=34, 68.00%). The majority of participants were not asked if they wanted to be treated as a public or private patient (n=32, 64.00%), however, they were asked if they had private health insurance (n=33, 66.00%).

Throughout their treatment, there were 19 participants (38.00%) that were treated as a private patient, 22 participants (44.00%) were mostly treated as a public patient, and there were 5 participants (10.00%) that were equally treated as a private and public patient.

Throughout their treatment, there were 15 participants (30.00%) that were treated mostly in the private hospital system, 28 participants (56.00%) were mostly treated in the public system, and there were 7 participants (14.00%) that were equally treated in the private and public systems.

Table 5.5: Health care system

Health care services	Response	Number (n=50)	Percent
Private health insurance	No	16	32.00
	Yes	34	68.00
Asked whether you want to be treated as a public or private patient	No	32	64.00
	Yes	18	36.00
Asked whether you had private health insurance	No	17	34.00
	Yes	33	66.00
Throughout your treatment in hospital, have you most been treated as a public or a private patient	Equally as a public and private patient	5	10.00
	Private patient	19	38.00
	Public patient	22	44.00
	Not sure	4	8.00
Which hospital system have you primarily been treated in	Both public and private	7	14.00
	Private	15	30.00
	Public patient	28	56.00
	Not sure	0	0.00

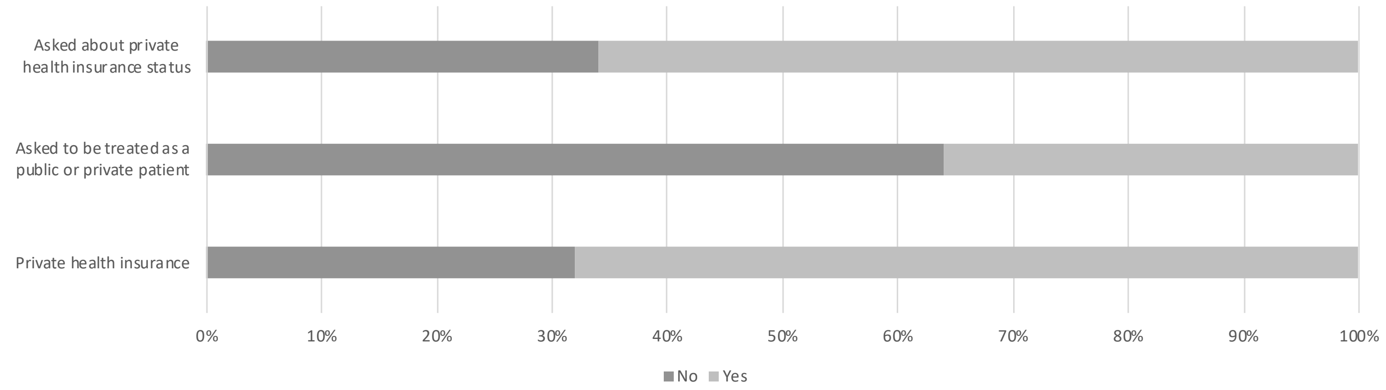

Figure 5.5: Health insurance

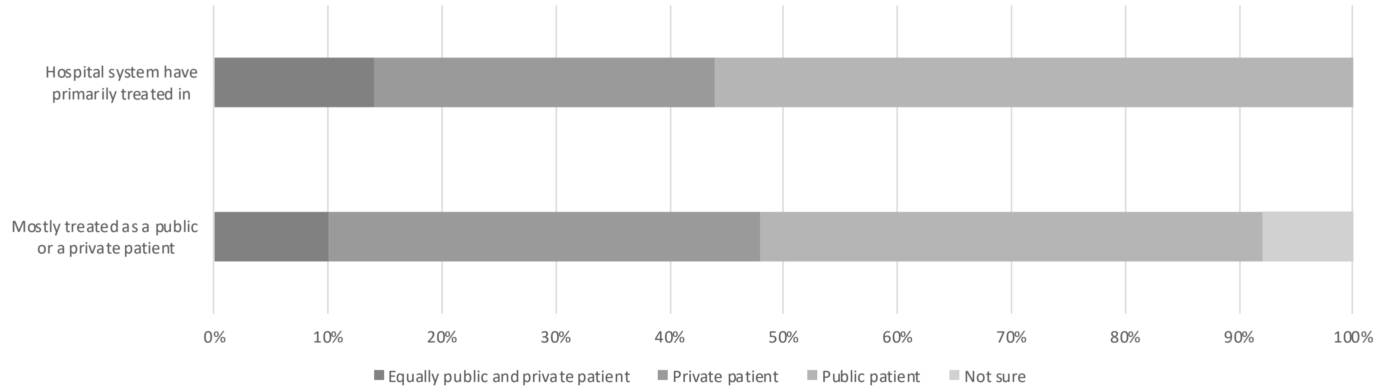

Figure 5.6: Hospital system

Affordability of healthcare

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

The first question was about having to delay or cancer healthcare appointments because they were unable to afford them. The majority of participants never or rarely had to delay or cancel appointments due to affordability (n = 35, 70.00%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=43, 86.00%).

The third question was about the affordability of basic essentials such as such as food, housing and power. There were 37 participants (74.00%) that never or rarely had trouble paying for essentials, and 7 participants (14.00%) that sometimes found it difficult, and 6 participants (12.00%) 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 9 participants (18.00%) that paid for additional carers due to their condition.

Table 5.6: Affordability of healthcare

Affordability of healthcare	Response	Number (n=50)	Percent
Delay or cancel healthcare appointments due to affordability	Never	31	62.00
	Rarely	4	8.00
	Sometimes	10	20.00
	Often	3	6.00
	Very often	2	4.00
Did not fill prescriptions due to cost	Never	36	72.00
	Rarely	7	14.00
	Sometimes	4	8.00
	Often	0	0.00
	Very often	3	6.00
Difficult to pay for basic essentials	Never	30	60.00
	Rarely	7	14.00
	Sometimes	7	14.00
	Often	2	4.00
	Very often	4	8.00
Pay for additional carers for self or family	Yes	9	18.00
	No	41	82.00

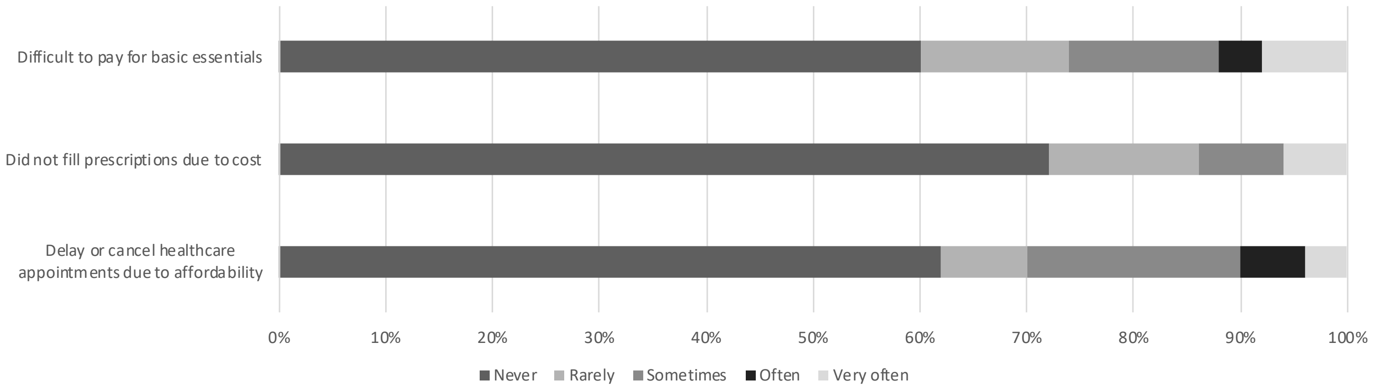

Figure 5.7: Affordability of healthcare

Cost of condition

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

The most common amount was $100 or less (n=16, 32.00%), followed by between $101 to $250 (n=9, 18.00%). There were 3 participants (6.00%), that spent $1001 or more a month.

Burden of cost

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

The amount spent was an extremely significant or moderately significant burden for 13 participants (26.00%), somewhat significant for 15 participants (30.00%), and slightly or not at all significant for 22 participants (44.00%).

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

Estimated monthly out of pocket expenses	Number (n=50)	Percent
$0	1	2.00
$100 or less	16	32.00
$101 to $250	9	18.00
$251 to $500	6	12.00
$501 to $1000	7	14.00
$1001 or more	3	6.00
Not sure of amount	8	16.00

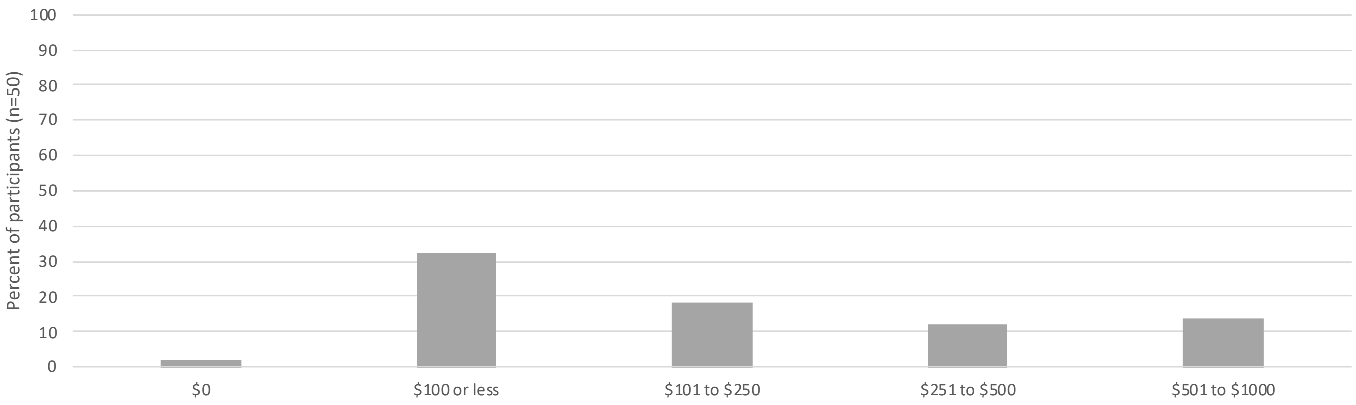

Figure 5.8: Estimated monthly out of pocket expenses due to condition

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

Burden of out of pocket expenses	Number (n=50)	Percent
Extremely significant	8	16.00
Moderately significant	5	10.00
Somewhat significant	15	30.00
Slightly significant	8	16.00
Not at all significant	14	28.00

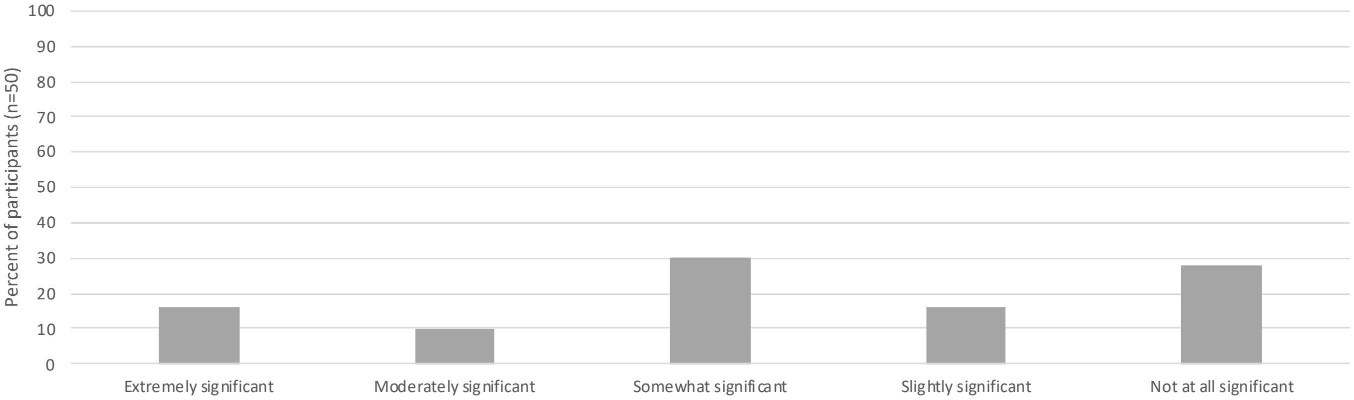

Figure 5.9: Burden of out-of-pocket expenses due to condition

Changes to employment status

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

Work status for 13 participants (26.00%) had not changed since diagnosis, and 6 participants (12.00%) were retired or did not have a job. There were 17 participants (34.00%) had to quit their job, 9 participants (18.00%) reduced the number of hours they worked, and 3 participants (6.00%) that accessed their superannuation early. There were 7 participants (14.00%) that took leave from work without pay, and 11 participants (22.00%) 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 16 participants (32.00%), without a main partner or carer. Most commonly, participants had partners or carers that did not change their work status due to their condition (n=26, 52.00%). There was 1 participant (2.00%) whose partner reduced the numbers of hours they worked, and 1 partner, (2.00%) that quit their job. The partners of 2 participants (4.00%) took leave without pay, and there were 3 partners (6.00%) that took leave with pay.

Table 5.9: Changes to employment status

Changes in work status due to condition	Number (n=50)	Percent
Work status has not changed	13	26.00
Retired or did not have a job	6	12.00
Had to quit job	17	34.00
Reduced number of hours worked	9	18.00
Leave from work without pay	7	14.00
Leave from work with pay	11	22.00
Accessed Superannuation early due to condition	3	6.00

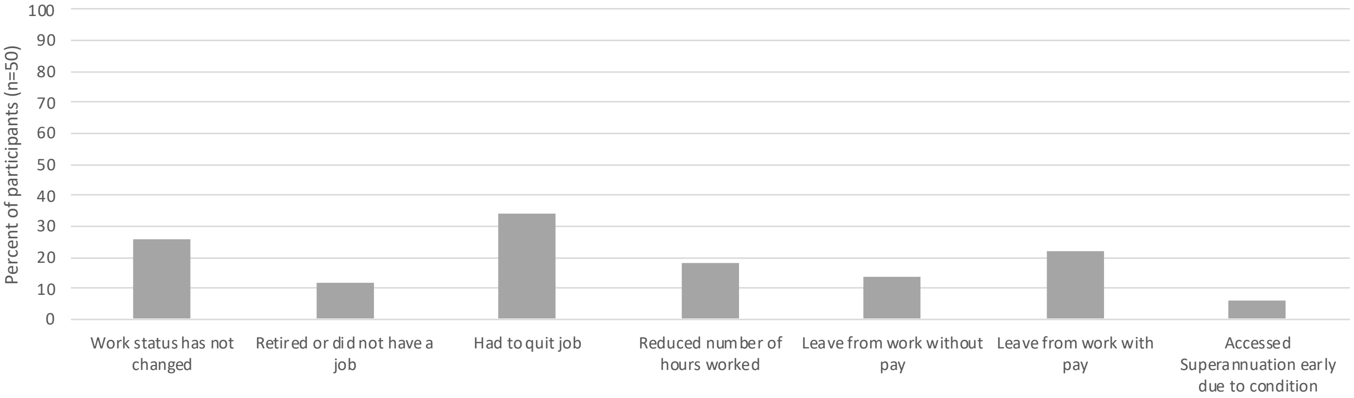

Figure 5.10: Changes to employment status

Table 5.10: Changes to care/partner employment status

Changes in partner or main carer work status due to condition	Number (n=50)	Percent
Does not have a partner/main carer	16	32.00
Work status has not changed	26	52.00
Retired or did not have a job	1	2.00
Had to quit job	1	2.00
Reduced number of hours worked	1	2.00
Leave from work without pay	2	4.00
Leave from work with pay	3	6.00

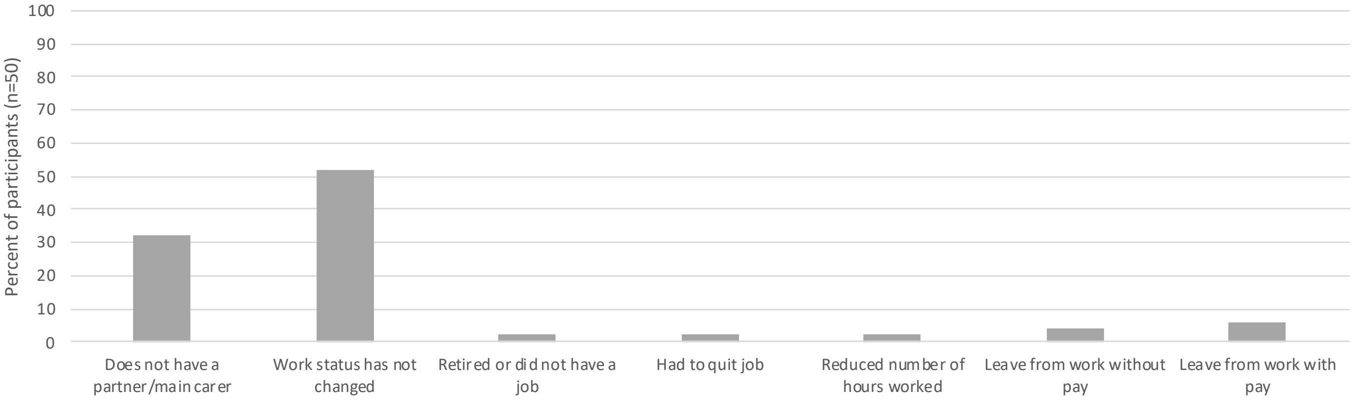

Figure 5.11: Changes to care/partner employment status

Reduced income due to condition

There were 20 participants (42.55%) that 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 in the table below.

Most commonly, participants were not sure about the amount their monthly income was reduced by $2000 to $5000 per month (n=7, 14.89%).

Burden of reduced income

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

For 11 of these participants (55.00%), the burden of this reduced income was extremely or moderately significant, for 5 participants (25.00%) the burden was somewhat significant, and for 4 participants (20.00%) the burden was slightly or not all significant.

Table 5.11: Estimated monthly loss of income

Estimated monthly loss of income	Number (n=47)	Percent
$0	27	57.45
$800 to $1000	4	8.51
$2000 to $5000	7	14.89
More than $5000	3	6.38
Not sure/not specifed	6	12.77

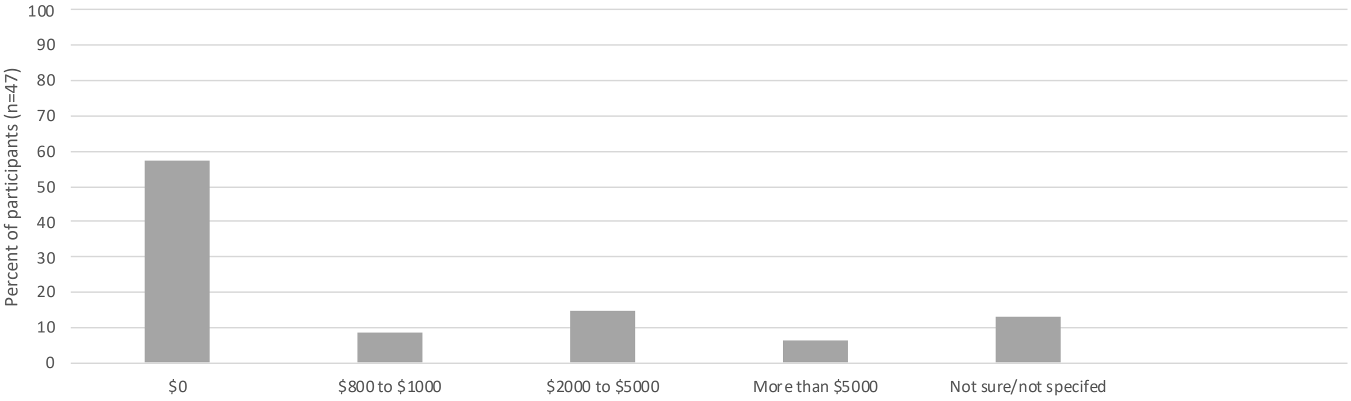

Figure 5.12: Estimated monthly loss of income

Table 5.12: Burden of reduced income

Burden of reduced income	Number (n=20)	Percent
Extremely significant	11	55.00
Moderately significant	0	0.00
Somewhat significant	5	25.00
Slightly significant	4	20.00
Not at all significant	0	0.00

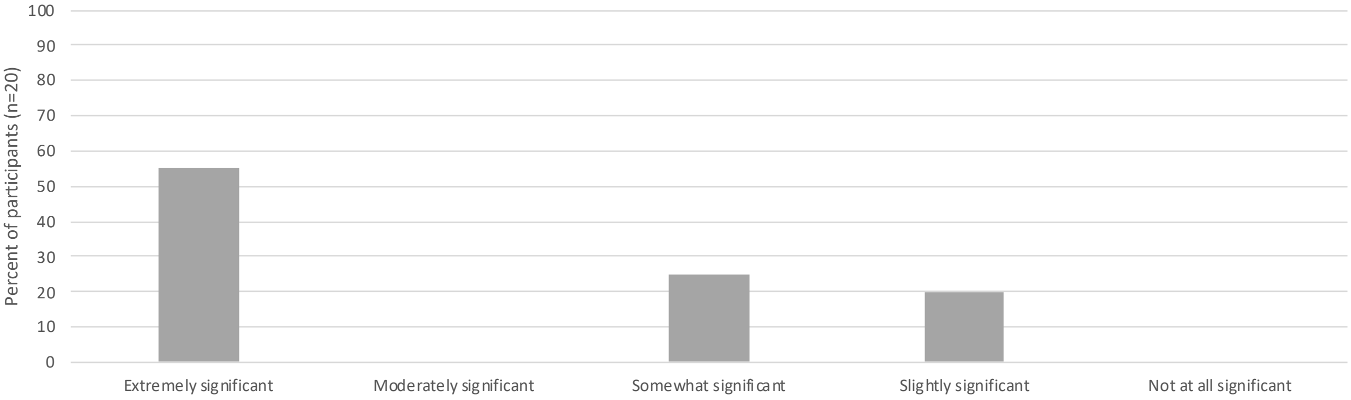

Figure 5.13: Burden of reduced income

Treatments overview

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

There were 17 participants (34.00%) that had surgical treatments, 40 participants (80.00%) that had drug treatments and 28 participants (56.00%) that used allied health services. The majority of participants had made lifestyle changes (n=42, 84%), and approximately a third used complementary therapies (n=42) (n=15, 35.71%).

Table 5.13: Treatments overview

Treatments overview	Number (n=50)	Percent
No surgery or medications	9	18.00
Surgery	17	34.00
Drug treatments	40	80.00
Allied health	28	56.00
Complementary therapies (n=42)	15	35.71
Lifestyle Changes	42	84.00

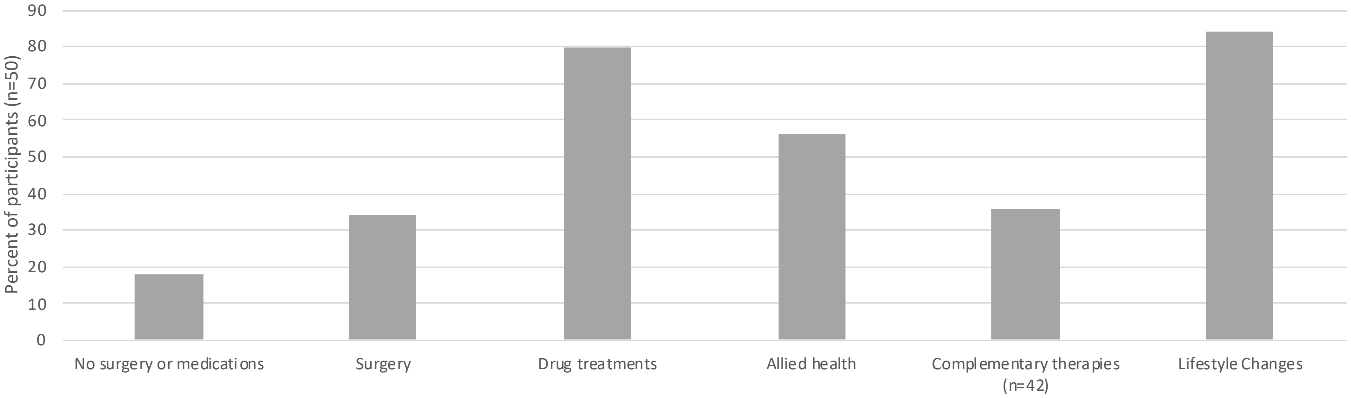

Figure 5.14: Treatments overview

Surgical treatments

Participants completed a series of questions about surgery, including type of surgery, quality of life, effectiveness of surgery, and side effects.
Details of quality of life and effectiveness are given for surgical interventions in 5 or more participants.

There were 6 participants (12.00%) that had coronary angioplasty, percutaneous coronary intervention or stents, 5 participants (10.00%) that had pacemaker or an implantable cardiac defibrillator (ICD) and 4 participants (8.00%) that had surgery for pacemaker or implantable cardioverter defibrillator. Other surgical interventions included Bypass surgery (n=2, 4.00%), and Heart valve surgery (n=1, 2.00%).

On average, quality of life from coronary angioplasty, percutaneous coronary intervention or stents was in the 'life was good' range (median=5.00, IQR = 2.25), and was found to be very effective (median=5.00 , IQR=0.00).

On average, quality of life from pacemaker or an implantable cardiac defibrillator (ICD) was in the 'life was average' range (median=4.00, IQR=1.00), and was found to be effective (median=4.00 , IQR=1.00).

Table 5.14 Summary of surgeries

Surgical treatments	Number (n=50)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Coronary angioplasty, percutaneous coronary intervention or stents	6	12.00	5.00	2.25	5.00	0.00
Pacemaker or an implantable cardiac defibrillator (ICD)	5	10.00	4.00	1.00	4.00	1.00
Surgery for pacemaker or implantable cardioverter defibrillator	4	8.00	NA	NA	NA	NA
Bypass surgery	2	4.00	NA	NA	NA	NA
Heart valve surgery	1	2.00	NA	NA	NA	NA

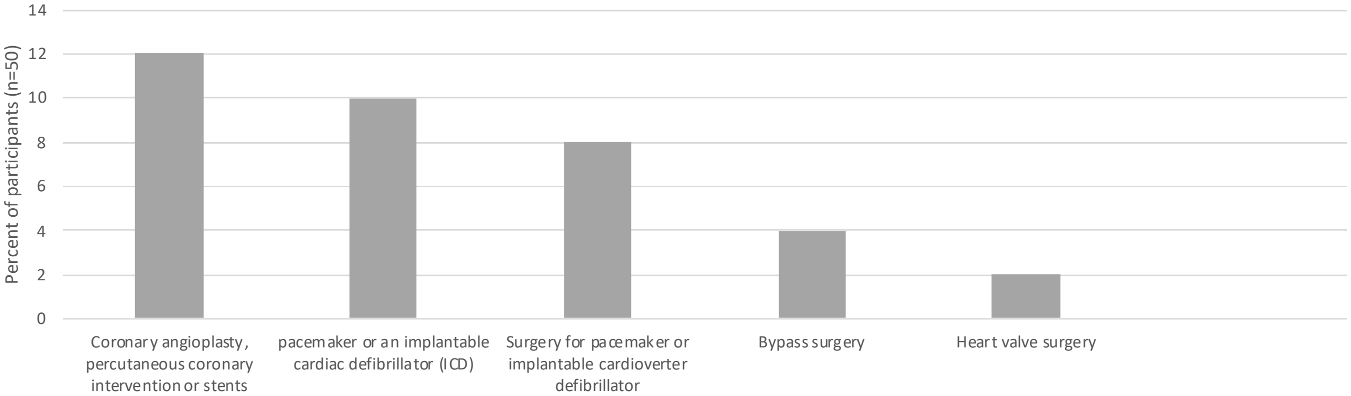

Figure 5.15: Summary of surgeries

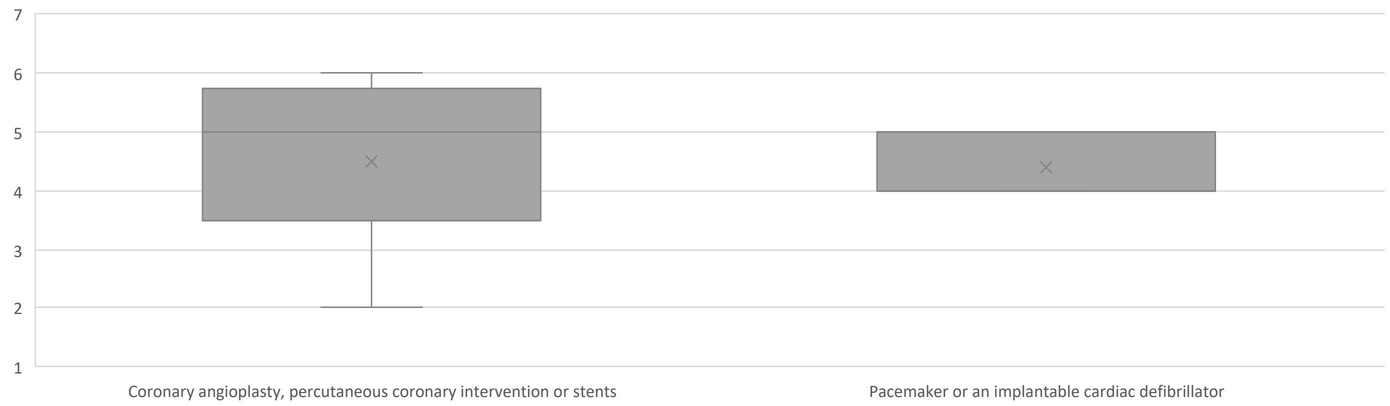

Figure 5.16: Quality of life from surgery

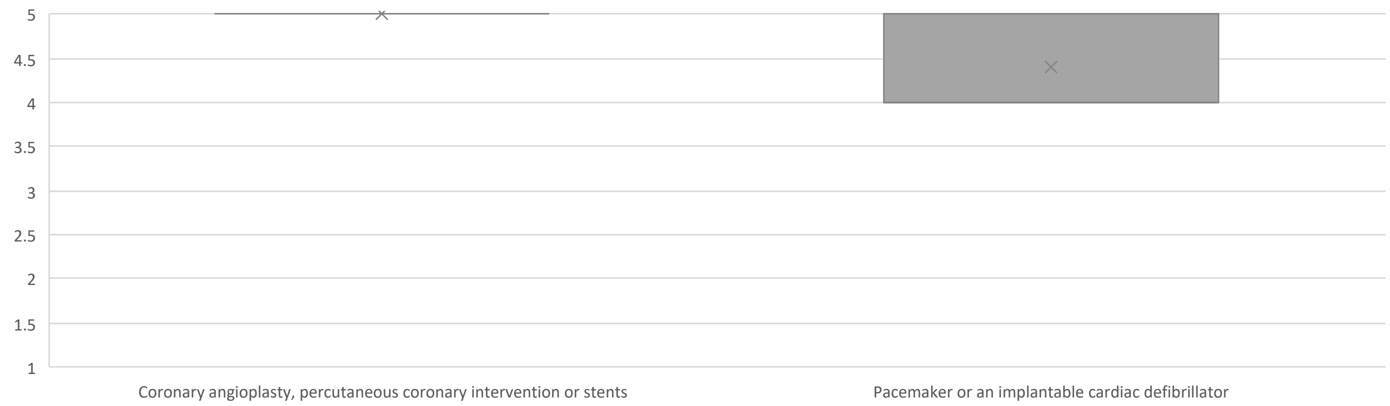

Figure 5.17: Effectiveness of surgery

Summary of drug treatments

In the online questionnaire, participants answered a series of questions about their treatment, including treatment given, quality of life from treatment, side effects from treatment and how effective they thought the treatment was. Details of quality of life and effectiveness are given for surgical interventions in 5 or more participants.

There were 23 participants (46.00%) that had antiplatelets, 18 participants (36.00%) that had beta blockers and 18 participants (36.00%) that had statins. Participants also took ACE inhibitors (n=10, 20%), ARBs (n=8, 16%), diurectics (n=6, 12%), cholesterol absorption inhibitors (n=5, 10.00%), calcium channel blockers (n=3, 6.00%), ARNIs (n=2, 4.00%), sinus node inhibitors (n=2, 4.00%), and glycosides (n=2, 4.00%).

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.

On average, quality of life from antiplatelets was in the 'life was average' range (median=4.00, IQR = 1.00), and was found to be effective (median=4.00 , IQR=0.50).

On average, quality of life from beta blockers was in the 'life was average to good' range (median=4.50, IQR=2.75), and was found to be effective (median=4.50 , IQR=1.00).

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

On average, quality of life from ACE inhibitors was in the 'life was average' range (median=4.00, IQR=1.50), and was found to be effective (median=4.00 , IQR=0.75).

On average, quality of life from ARBs e.g. candesartan, losartan, valsartan was in the 'life was average' range (median=4.00, IQR=2.25), and was found to be moderately effective to effective (median=3.50 , IQR=2.25).

On average, quality of life from anticoagulants was in the 'life was good to very good' range (median=5.50, IQR=3.25), and was found to be effective (median=4.00 , IQR=0.50).

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

On average, quality of life from cholesterol absorption inhibitors was in the 'life was average' range (median=5.00, IQR=0.00), and was found to be effective (median=4.00 , IQR=0.00).

Table 5.15: Drug treatments overview

Drug treatments	Number (n=50)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Antiplatelets	23	46.00	4.00	1.00	4.00	0.50
Beta blockers	18	36.00	4.50	2.75	4.50	1.00
Statins	18	36.00	4.00	1.00	4.00	1.00
ACE inhibitors	10	20.00	4.00	1.50	4.00	0.75
ARBs e.g. candesartan, losartan, valsartan	8	16.00	4.00	2.25	3.50	2.25
Anticoagulants	8	16.00	5.50	3.25	4.00	0.50
Diurectics	6	12.00	4.00	1.50	4.00	0.75
Cholesterol absorption inhibitors	5	10.00	5.00	0.00	4.00	0.00
Calcium channel blockers	3	6.00	NA	NA	NA	NA
Angiotensin receptor-neprilysin inhibitors (ARNIs)	2	4.00	NA	NA	NA	NA
Sinus node inhibitors (ivabradine)	2	4.00	NA	NA	NA	NA
Glycosides	2	4.00	NA	NA	NA	NA

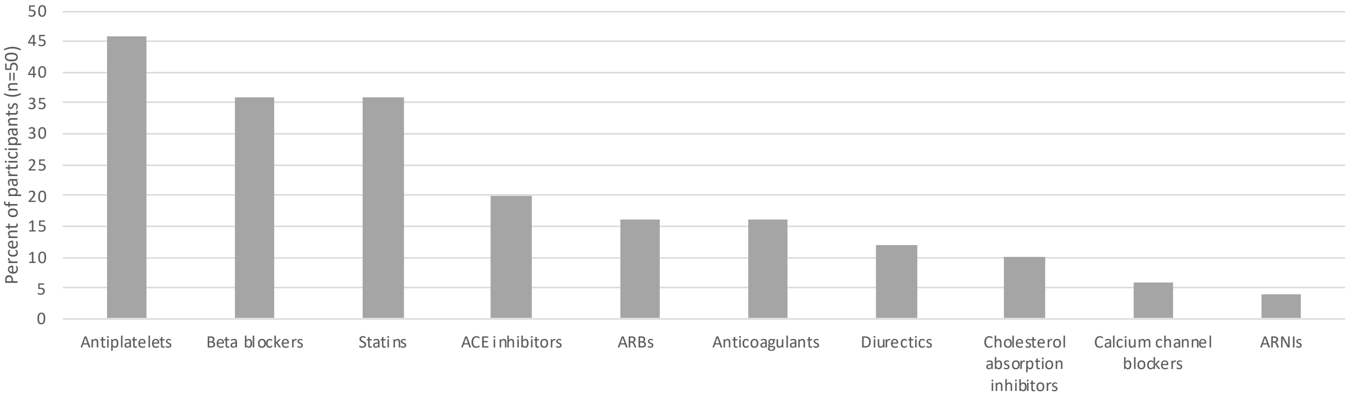

Figure 5.18: Drug treatments overview

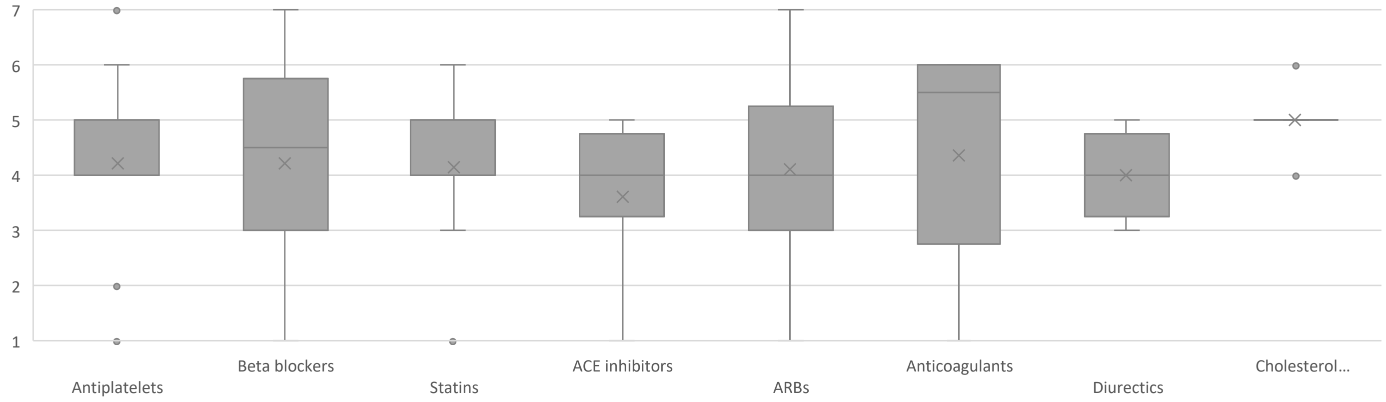

Figure 5.19: Quality of life from drug treatments (where complete data was available)

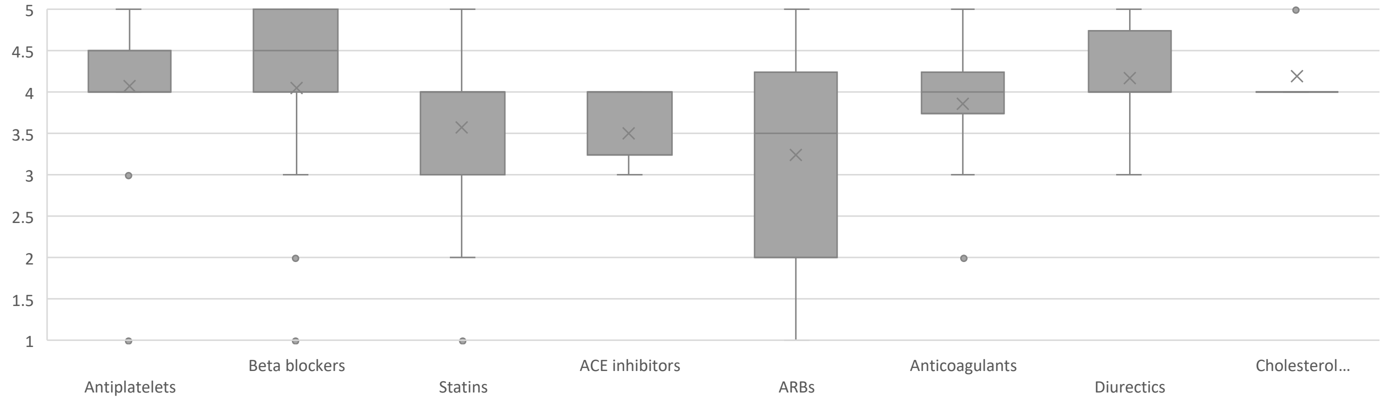

Figure 5.20: Effectiveness of drug treatments (where complete data was available)

Allied health

The most common allied health service used was seeing a dietician (n=14, 28.00%), followed by physiotherapy (n=13, 26.00%), and psychology or counselling (n=12, 24.00%). There were 9 participants (18.00%) that had occupational therapy, 9 participants (18.00%) that had speech therapy, and 5 participants (10.00%) that saw a social worker.

On average, quality of life from seeing a dietician was in the 'life was average' range (median=4.00, IQR = 2.75), and was found to be effective (median=4.00, IQR = 1.00).

On average, quality of life from physiotherapy 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=3.00).

On average, quality of life from psychology or counselling was in the 'life was distressing' range (median=2.00, IQR=2.25), and was found to be moderately effective (median=3.00, IQR=2.00).

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

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

Table 5.16: Allied health

Allied health	Number (n=50)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Dietician	14	28.00	4.00	2.75	4.00	1.00
Physiotherapy	13	26.00	3.00	3.00	4.00	3.00
Psychology/counselling	12	24.00	2.00	2.25	3.00	2.00
Occupational therapy	9	18.00	4.00	3.00	4.00	1.00
Speech therapy	9	18.00	3.00	2.00	4.00	2.00
Social work	5	10.00	4.00	1.00	4.00	4.00
Podiatry	4	8.00	NA	NA	NA	NA

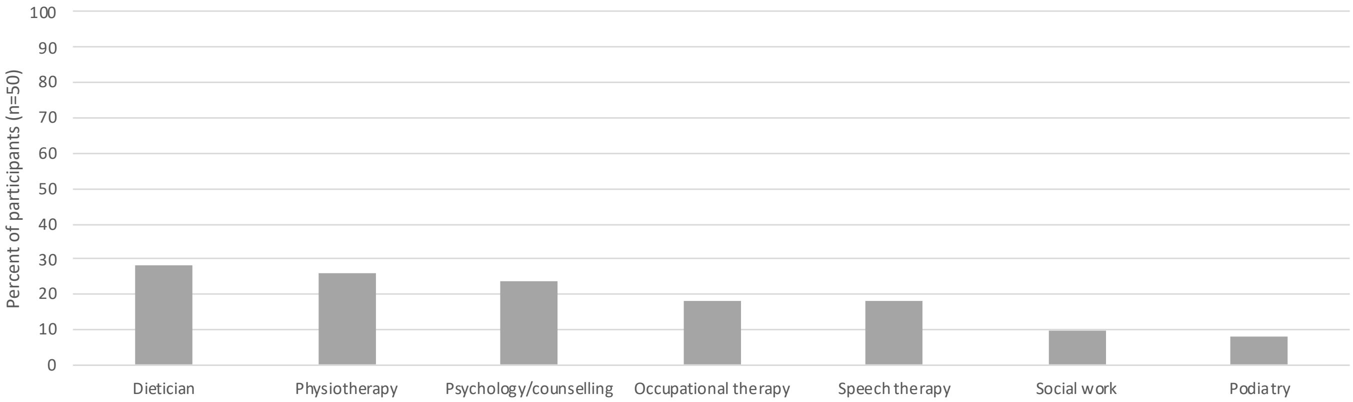

Figure 5.21: Allied health

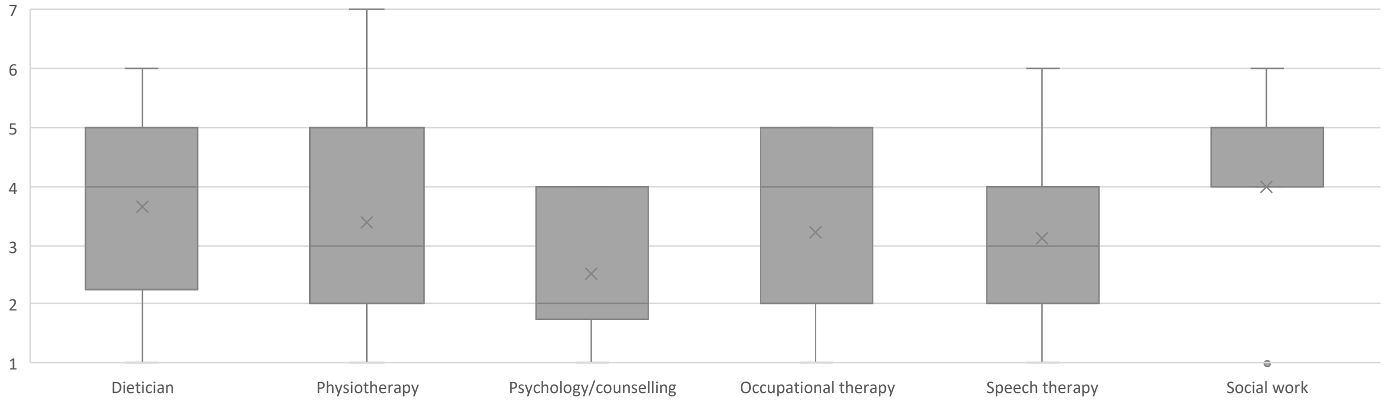

Figure 5.22: Quality of life from allied health

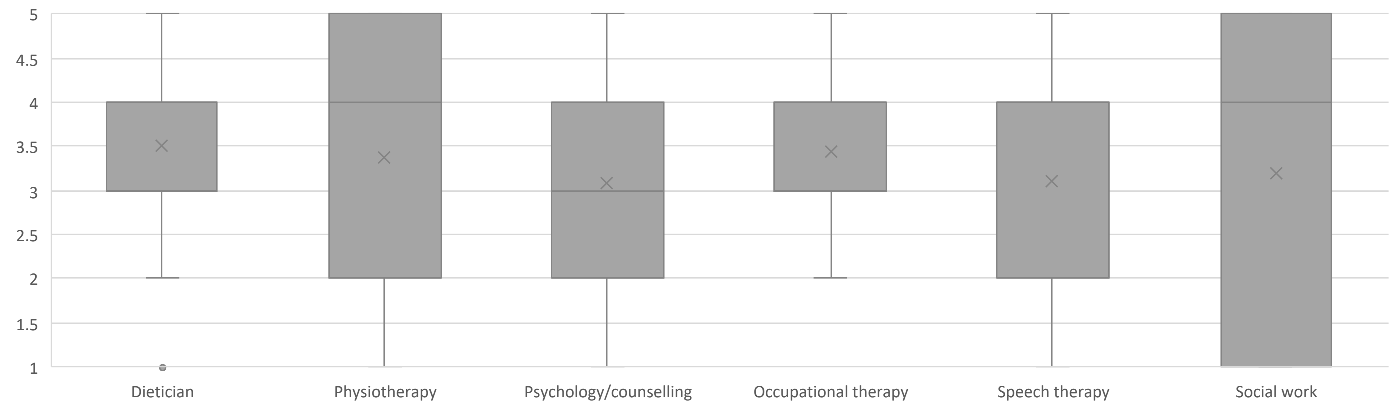

Figure 5.23: Effectiveness of allied health

Lifestyle changes

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

The majority of participants used at made at least one lifestyle change (n=42, 84.00%), and on average made 2 changes (median=2.00, IQR=1.75).

The most common lifestyle changes used were diet changes (n=29, 58.00%), and exercise (n=29, 58.00%), followed by and Quitting or cutting back on alcohol (n=19, 38.00%), and Quitting or cutting back on smoking (n=10, 20.00%).

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 effective (median=4.00, IQR=2.00).

On average, quality of life from exercise was in the 'life was good' range (median=5.00, IQR=2.00), and was found to be effective (median=4.00, IQR=1.00).

On average, quality of life from quitting or cutting back on alcohol was in the 'life was good' range (median=5.00, IQR=2.00), and was found to be effective (median=4.00, IQR=2.00).

On average, quality of life from quitting or cutting back on smoking was in the 'life was average' range (median=4.00, IQR=2.00), and was found to be effective (median=4.00, IQR=1.00).

Table 5.17: Lifestyle changes

Lifestyle changes	Number (n=50)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Diet changes	29	58.00	4.00	2.00	4.00	2.00
Exercise	29	58.00	5.00	2.00	4.00	1.00
Quitting or cutting back on alcohol	19	38.00	5.00	2.00	4.00	2.00
Quitting or cutting back on smoking	10	20.00	4.00	2.00	4.00	1.00

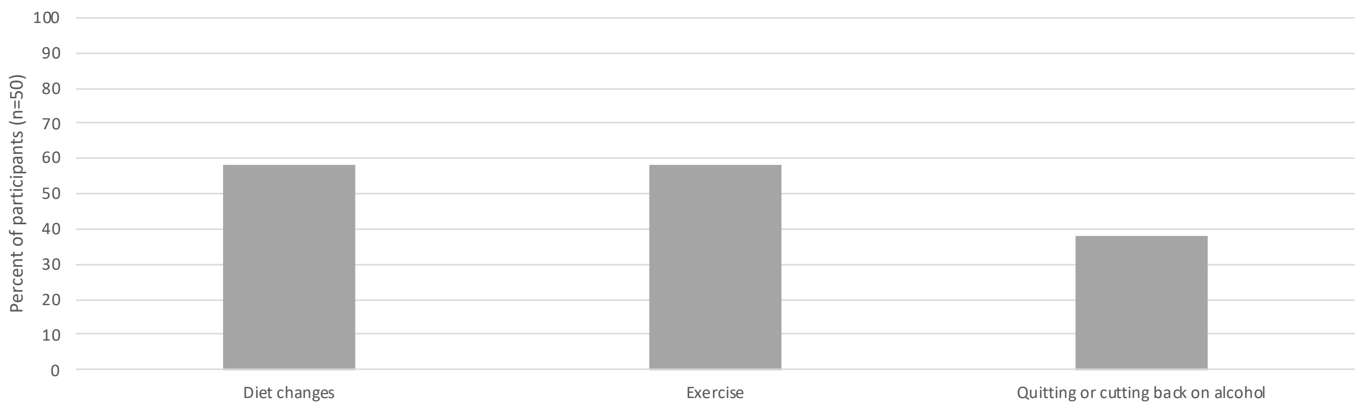

Figure 5.24: Lifestyle changes

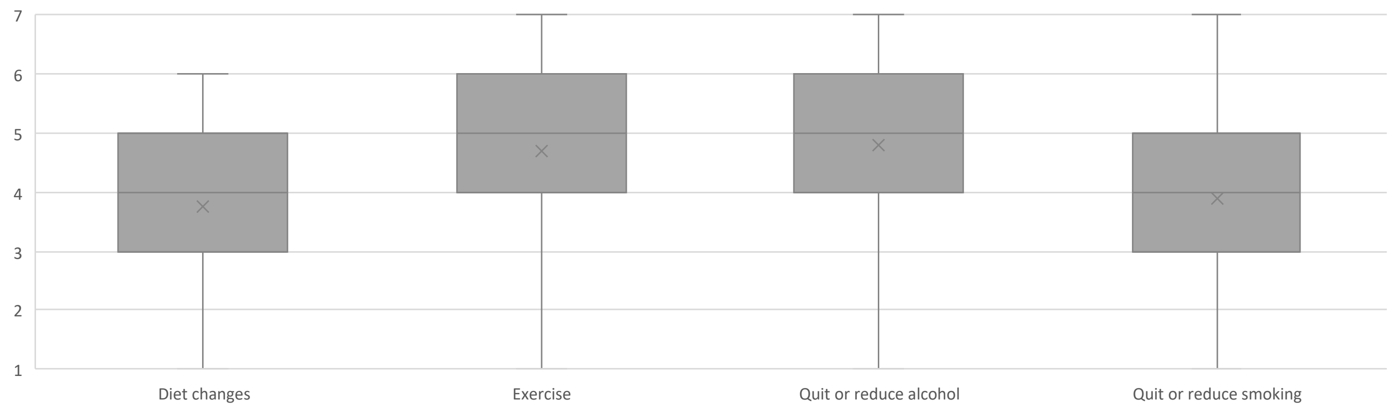

Figure 5.25: Quality of life from lifestyle changes

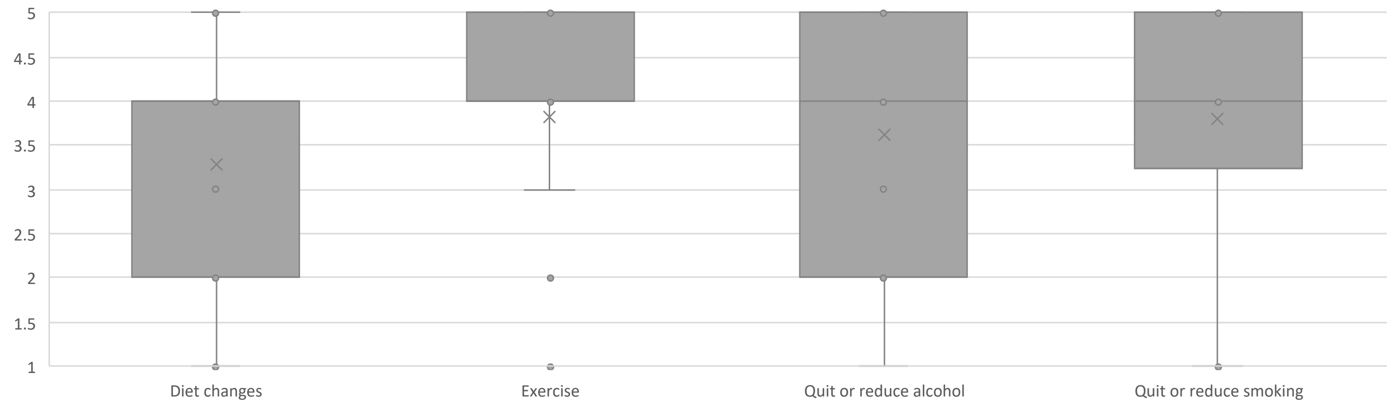

Figure 5.26: Effectiveness from lifestyle changes

Complementary therapies

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

Approximately a third of participants used at least one complementary therapy (n=15, 35.71%). The most common complementary therapy used was Mindfulness or relaxation techniques (n=11, 26.19%), followed by Massage therapy (n=7, 16.67%), Supplements (n=6, 14.29%), and acupuncture (n=5, 11.90%)

On average, quality of life from mindfulness or relaxation techniques was in the 'life was good' range (median=5.00, IQR=2.00), and was found to be effective (median=4.00, IQR=1.50).

On average, quality of life from massage therapy was in the 'life was distressing' range (median=2.00, IQR=2.50), and was found to be moderately effective (median=3.00, IQR=2.50).

On average, quality of life from supplements was in the 'life was average to good' range (median=4.50, IQR=2.50), and was found to be moderately effective to effective (median=3.50, IQR=1.00).

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

Table 5.18: Complementary therapies

Complementary therapies	Number (n=42)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Mindfulness or relaxation techniques	11	26.19	5.00	2.00	4.00	1.50
Massage therapy	7	16.67	2.00	2.50	3.00	2.50
Supplements	6	14.29	4.50	2.50	3.50	1.00
Acupuncture	5	11.90	3.00	2.00	3.00	2.00
Naturopathy	2	4.76	NA	NA	NA	NA
Homeopathy	1	2.38	NA	NA	NA	NA

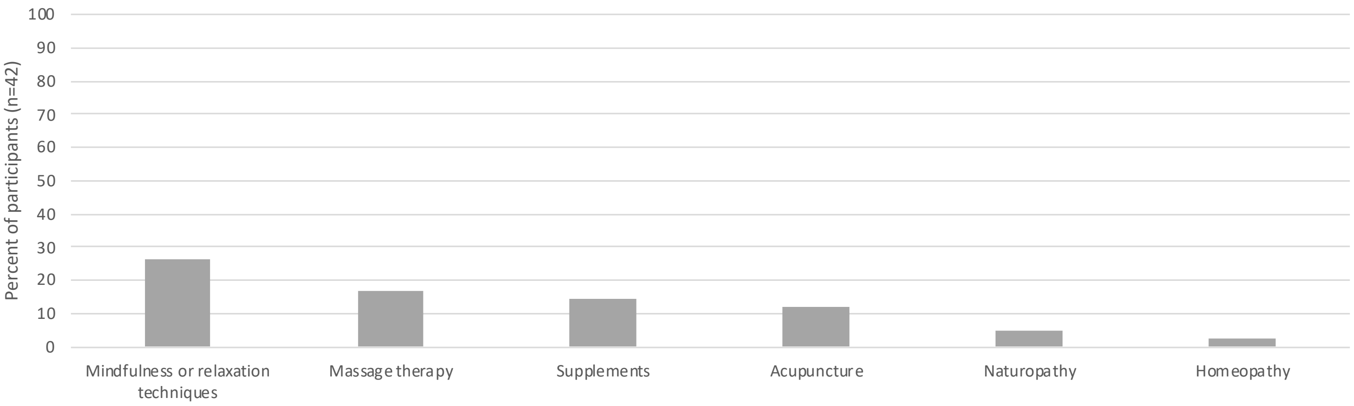

Figure 5.27: Complementary therapies

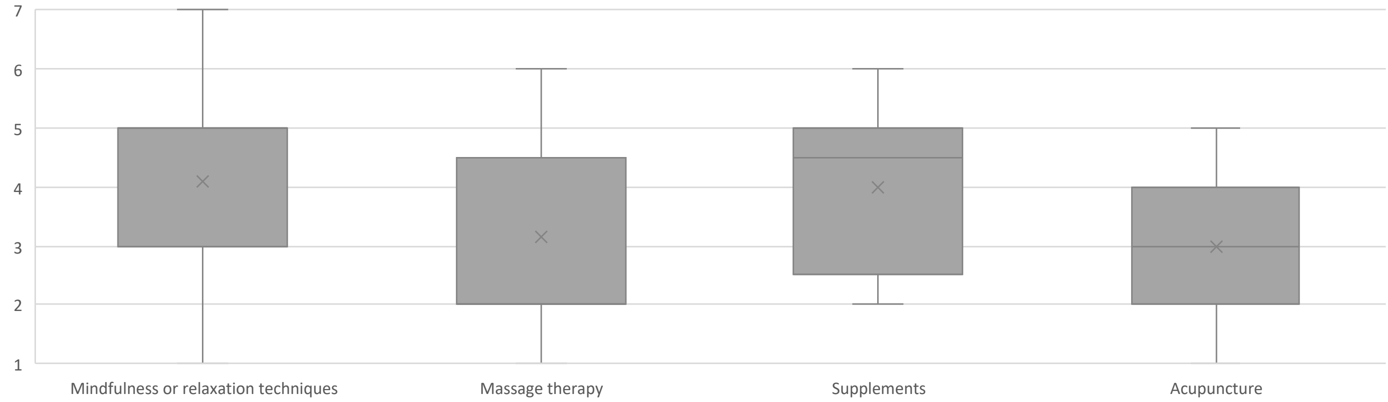

Figure 5.28: Quality of life from complementary therapies

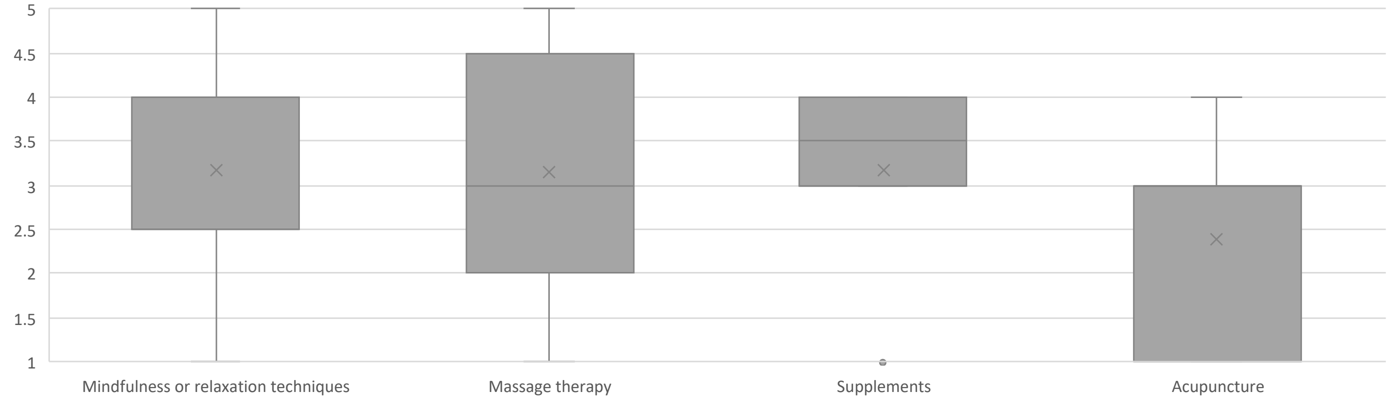

Figure 5.29: Effectiveness of complementary therapies

Clinical trials

Clinical trials discussions

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

There was a total of 4 participants (8%) that had discussions about clinical trials, 3 participants (6.00%) had brought up the topic with their doctor, and the doctor of 1 participant (2.00%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=46, 92.00%).

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 was 1 participant (2.00%) that had taken part in a clinical trial, 36 participants (72.00%) that would like to take part in a clinical trial if there was a suitable one, and 13 participants, that have not participated in a clinical trial and do not want to (26.00%).

Table 5.19: Clinical trial discussions

Clinical trial discussions	Number (n=50)	Percent
Participant brought up the topic of clinical trials doctor for discussion	3	6.00
Doctor brought up the topic of clinical trials for discussion	1	2.00
Participant has never spoken about clinical trials	46	92.00

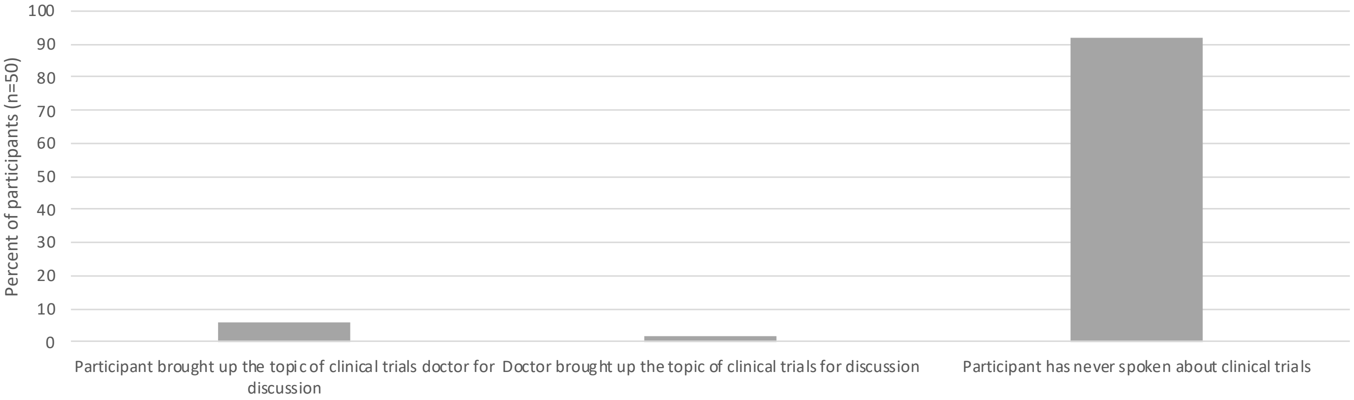

Figure 5.30: Clinical trial discussions

Table 5.20: Clinical trial participation

Clinical trial participation	Number (n=50)	Percent
Has not participated in a clinical trial and does not want to	13	26.00
Has not participated in a clinical trial but would like to if there is one	36	72.00
Has participated in a clinical trial	1	2.00

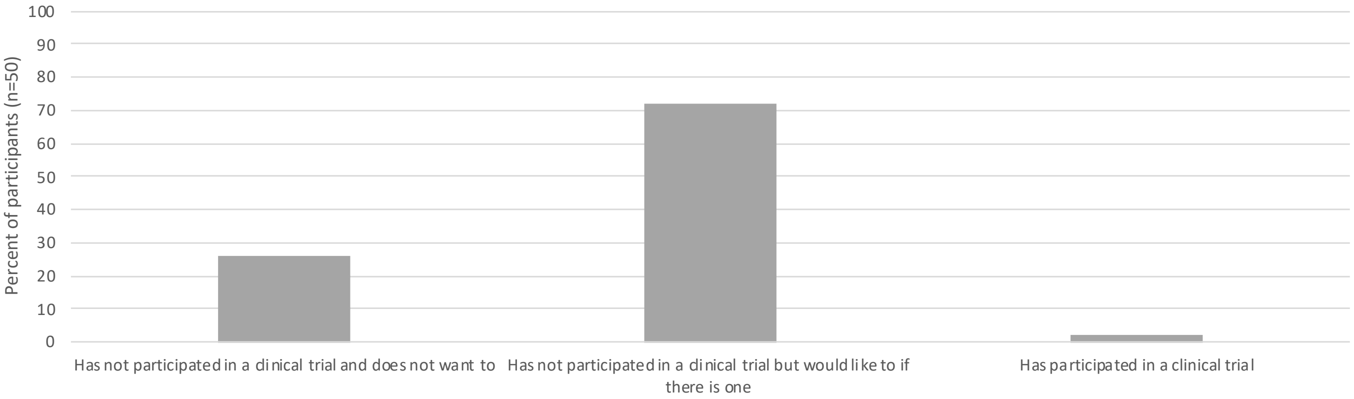

Figure 5.31: Clinical trial participation

Treatment and management following lipoprotein a test

Lipoprotein a testing

In the online questionnaire, participants noted if they had a Lipoprotein a test. There were 24 participants (43.64%) that had a Lipoprotein a test.

Lipoprotein a test results

As a follow up question, participants were asked if they knew the result of their Lipoprotein a test. There were 9 participants (16.36%) that did not know their result, 9 participants (16.36%) that knew result and gave a numerical value, and 6 participants (10.91%) that were not sure of exact result but that it was high.

Table 5.21: Lipoprotein a testing

Had a lipoprotein a/Lpa test	n=55	%
No	31	56.36
Yes	24	43.64

Figure 5.32: Lipoprotein a testing

Table 5.22: Lipoprotein a test results

Lipoprotein a/ Lp(a) level or result known	n=55	Percent
Not known	9	16.36
Knew result and gave a numerical value	9	16.36
Not sure of exact result but it was high	6	10.91

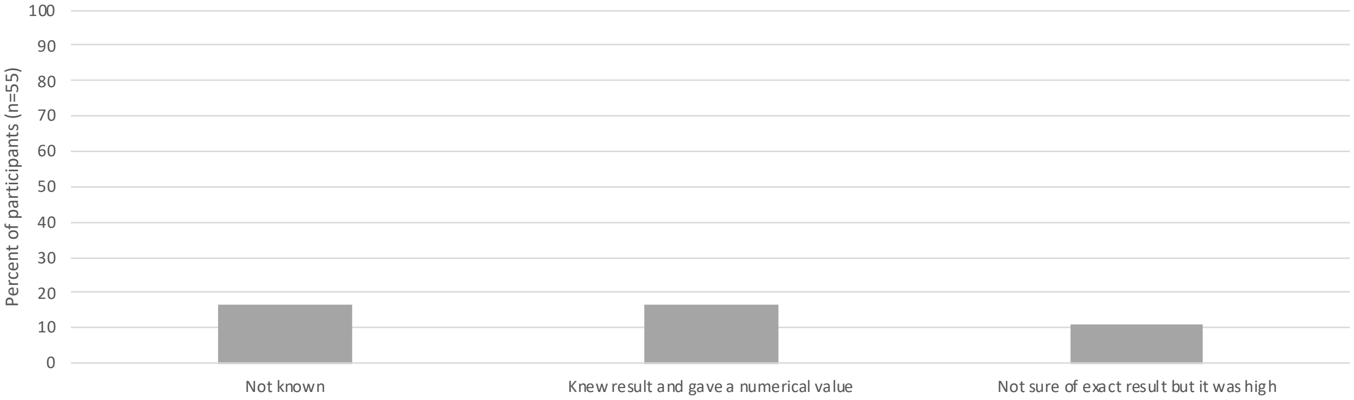

Figure 5.33: Lipoprotein a test results

Changes in treatment and management following Lipoprotein a testing

Participants noted in the online questionnaire any changes their doctor made to the treatment or management of their condition following lipoprotein a testing.

Most commonly, changes were made to medication (n=10, 41.67%), followed by recommendations for diet and lifestyle changes (n=6, 25.00%). There were 5 participants (20.83%) that were had additional monitoring, and 2 participants (8.33%), that had no made changes to treatment or management.

Table 5.23: Changes in treatment and management following Lipoprotein a testing

Types of changes to treatment or management following Lipoprotein a/ Lp(a) test	Number (n=24)	Percent
Medication changes	10	41.67
Diet and life style changes	6	25.00
Monitoring	5	20.83
No changes	2	8.33
Not clear	2	8.33

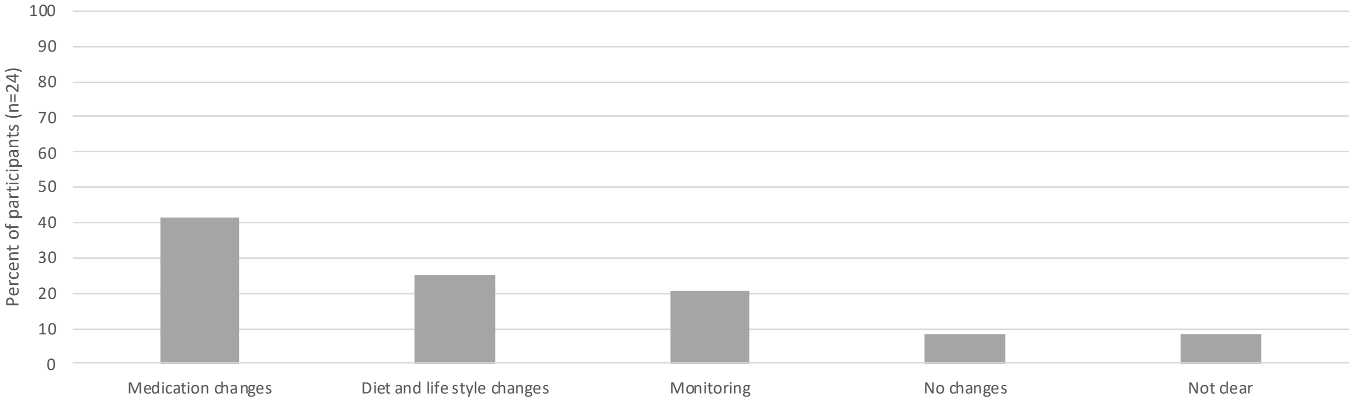

Figure 5.34: Changes in treatment and management following Lipoprotein a testing

Participant-made changes following lipoprotein a/Lp(a) results

In the online questionnaire, participants noted the changes that they had made following getting their lipoprotein a/Lp(a) results.

The majority of participants made diet changes (n=18, 75.00%), and half the participants (50.00%) tried to exercise more. There were 8 participants (33.33%) that tried to drink less alcohol, and 8 participants (33.33%) that tried to lose weight. Other changes included tried to give up smoking (20.83%), became more careful about taking medicatins (16.67%) and became more caredful about making and attending medical appointments (12.50%). There were 2 participants (12.50%) that made no changes following thier lipoprotein a test result.

After getting Lipoprotein a/Lp(a) results, activities to learn more about it

Participants noted the activities they had done to learn more about lipoprotein a.

More than half of the participants looked for information about it (n=13, 54.17%), and a third asked their doctor about it (n=8, 33.33%). There were 3 participants (12.50%) that joined a heart management program, and 3 participants (12.50%) that joined a patient group. There were 9 participants (37.50%) that did not do anything to find out more about Lp(a).

Did other members of family have a Lipoprotein a /Lp(a) test because of test result

Participants were asked if family members had a lipoprotein a /Lp(a) test because of test result. There were 6 participants (25.00%) that noted other family members had this test due to their result.

Table 5.24: Participant-made changes following lipoprotein a/Lp(a) results

Participant changes following lipoprotein a/Lp(a) results	Number (n=24)	Percent
Diet changes	18	75.00
Tried to exercise more	12	50.00
Tried to drink less alcohol	8	33.33
Tried to lose weight	8	33.33
Tried to give up smoking	5	20.83
Became more careful about taking medications	4	16.67
No changes	3	12.50
Became more careful about making and attending medical appointments	3	12.50

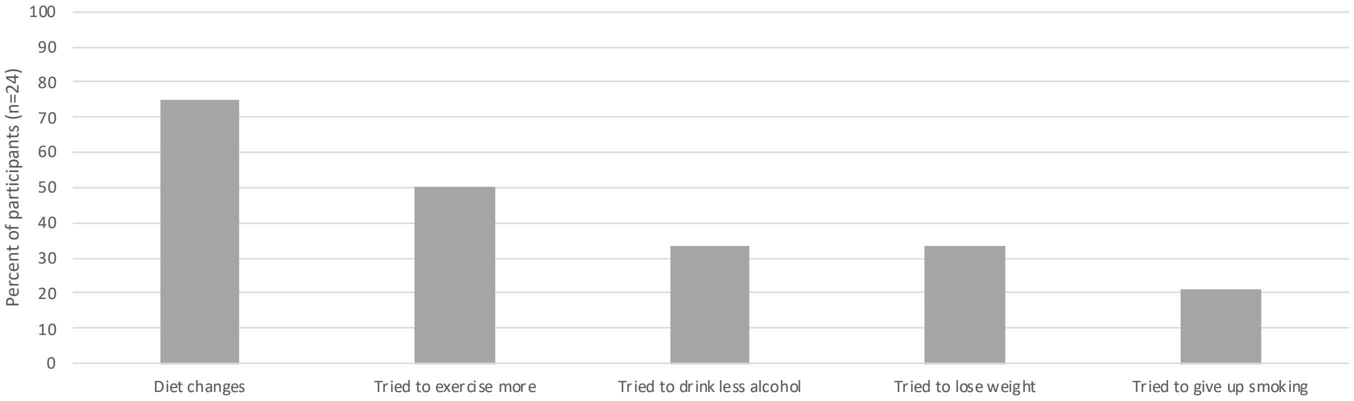

Figure 5.35: Participant-made changes following lipoprotein a/Lp(a) results

Table 5.25: After getting Lipoprotein a/Lp(a) results, activities to learn more about it

After getting Lipoprotein a/Lp(a) results, activities to learn more about it	n=24	Percent
Looking for information about it	13	54.17
Did not do anything to find out more about Lp(a)	9	37.50
Asking a doctor about it	8	33.33
Joining a heart management program	3	12.50
Joining a patient group	3	12.50

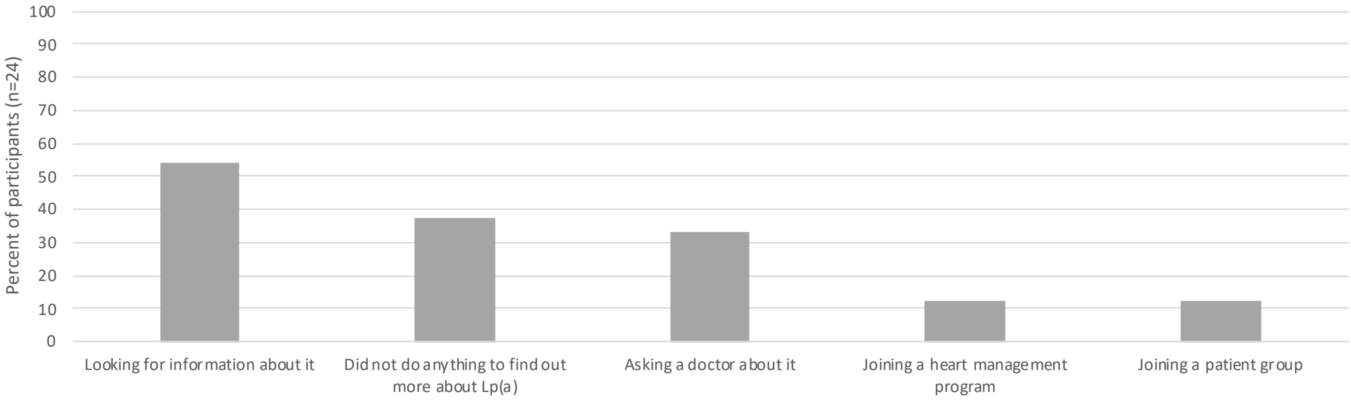

Figure 5.36: After getting Lipoprotein a/Lp(a) results, activities to learn more about it

Table 5.26: Did other members of family have a Lipoprotein a /Lp(a) test because of test result

Did other members of family have a Lipoprotein a /Lp(a) test because of test result	n=24	Percent
No	16	66.67
Yes	6	25.00
Not sure	2	8.33

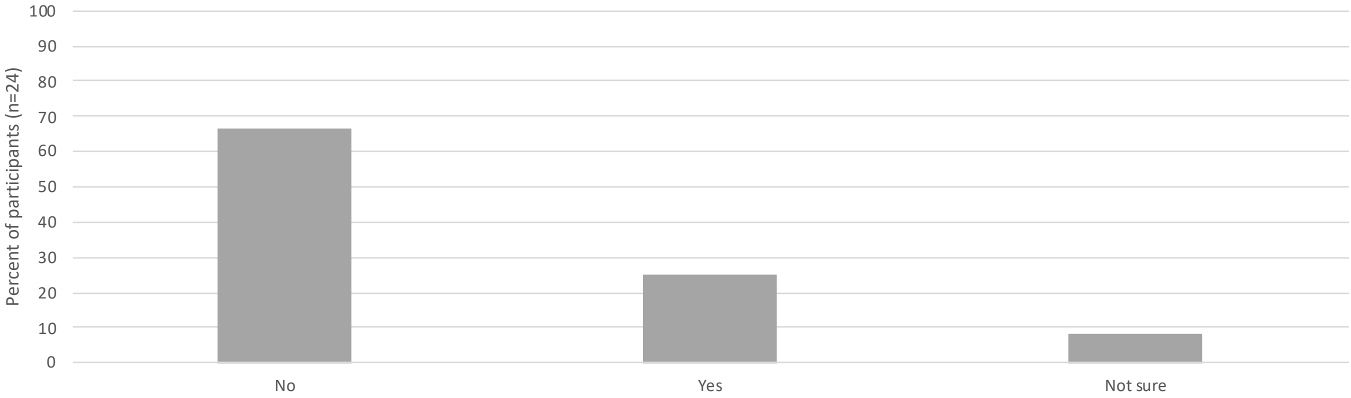

Figure 5.37: Did other members of family have a Lipoprotein a /Lp(a) test because of test result

Description of mild side effects

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 described using a specific example (57.45%), and those that do not interfere with life (36.17%). Other themes included side effects that have a short duration (10.64%), and that they had only experienced or only described severe side effects (8.51%).

When a specific side effect was described, the most common side effects were aches and pain (23.40%), fatigue/lethargy (23.40%), headaches (6.38%), and nausea, vomiting,or loss of appetite (6.38%).

Participant provides a specific side effect as an example

I guess the mild side effect would be something like maybe a bit of back pain or some cramping bit of fatigue as well, maybe just feeling a little bit foggy headed, things like that. But I think a severe side effect would be something, you know, like we're cramping, that's so severe you can't walk properly, or you've got maybe breathing difficulties, things like that. Or maybe you're that fatigued that you can't get out of bed. That's the way I describe it. Participant 011_2023AUHBV

The mild side effect that I have is if I try and exercise to a certain level or if I have a big day with lots of stuff in it, the next day I'm wiped out with regard to tiredness.
Participant 015_2023AUHBV

Maybe a slight inconvenience to your life would be a mild. Side effect, maybe a little bit sick, maybe a little bit of a light headache, maybe a little bit of a lack of energy, that kind of thing.
Participant 020_2023AUHBV

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

Something that you could just suck it up and live with, I suppose.
Participant 014_2023AUHBV

Well, I think that would be something you could easily cope with if you knew it was a side effect.
Participant 016_2023AUHBV

All all depends sort of what what the side effects are, and I think that if it's at a level that that isn't. Stopping you doing things. You're not throwing up, you haven't got diarrhea. You haven't got stomach pains or nausea or feeling unwell from the medication then that's that's the sort of things that that that level that would make me. Yeah, not want to take medication.
Participant 017_2023AUHBV

Participant describes mild side effects as those that have a short duration

A mild side effect is an ongoing and ever-present-- I can't think of any other way to describe it other than a lack of clarity in thinking. It's a cloudy thought process for me all the time. It's not impaired but I have to really concentrate when I'm going through some thinking. It's a cloud. I'm sure obviously that's a result of the stroke. It's not an impairment but it's a constant brain fatigue.
Participant 045_2023AUHBV

Yes, easy. Yeah, easy to cope with. Can deal with it. You can kind of just accept it and tell yourself that it's really gonna be over soon, whatever the side effect is.
Participant 029_2023AUHBV

Just feeling a little bit off. Maybe having a headache for a couple of days and a little bit of nausea. Symptoms that will pass.
Participant 049_2023AUHBV

Participant describes having only experienced or only describes severe side effects

I don't really have mild. I just have major side effects.
Participant 042_2023AUHBV

My cardiologist put me onto super strength statins afterwards, 8 milligrams. And my body stopped working. It just it was so painful. I could not get off the couch.
Participant 005_2023AUHBV

Table 5.27: Description of mild side effects

Description of mild side effects	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant provides a specific side effect as an example	27	57.45	9	50.00	18	62.07	6	66.67	9	52.94	12	57.14	15	55.56	12	60.00
Participant describes mild side effects as those that do not interfere with daily life	17	36.17	8	44.44	9	31.03	**5**	**55.56**	6	35.29	6	28.57	**7**	**25.93**	**10**	**50.00**
Participant describes mild side effects as those that have a short duration	5	10.64	2	11.11	3	10.34	**0**	**0.00**	**4**	**23.53**	1	4.76	2	7.41	3	15.00
Participant describes having only experienced or only describes severe side effects	4	8.51	1	5.56	3	10.34	0	0.00	2	11.76	2	9.52	4	14.81	0	0.00

Description of mild side effects	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant provides a specific side effect as an example	27	57.45	16	61.54	11	52.38	14	58.33	13	56.52	**11**	**73.33**	16	50.00	**17**	**68.00**	**10**	**45.45**
Participant describes mild side effects as those that do not interfere with daily life	17	36.17	**14**	**53.85**	**3**	**14.29**	10	41.67	7	30.43	**7**	**46.67**	10	31.25	10	40.00	7	31.82
Participant describes mild side effects as those that have a short duration	5	10.64	4	15.38	1	4.76	3	12.50	2	8.70	3	20.00	2	6.25	3	12.00	2	9.09
Participant describes having only experienced or only describes severe side effects	4	8.51	2	7.69	2	9.52	1	4.17	3	13.04	1	6.67	3	9.38	1	4.00	3	13.64

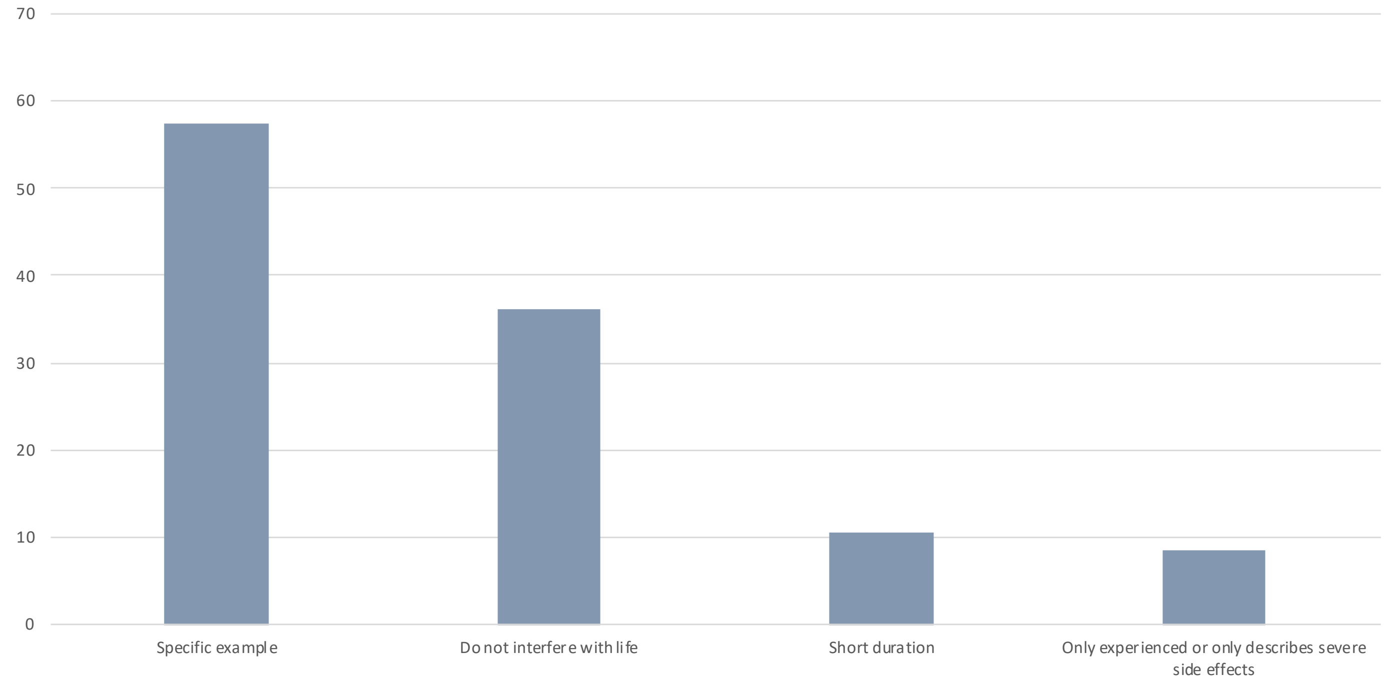

Figure 5.38: Description of mild side effects

Table 5.28: Description of mild side effects – subgroup variations

Description of mild side effects	Reported less frequently	Reported more frequently
Participant provides a specific side effect as an example	Higher socioeconomic status	Regional or remote Mid to low socioeconomic status
Participant describes mild side effects as those that do not interfere with daily life	0 to 5 other conditions Male	High cholesterol under 50 years of age 6 to 11 other conditions Female Regional or remote
Participant describes mild side effects as those that have a short duration	High cholesterol under 50 years of age	Blood vessel conditions

Table 5.29: Description of mild side effects (Specific side effects)

Description of mild side effects (Specific side effects)	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes mild side effects giving the specific example of aches/pain (general)	11	23.40	5	27.78	6	20.69	3	33.33	3	17.65	5	23.81	7	25.93	4	20.00
Participant describes mild side effects giving the specific example of fatigue/lethargy	11	23.40	4	22.22	7	24.14	**4**	**44.44**	3	17.65	4	19.05	7	25.93	4	20.00
Participant describes mild side effects giving the specific example of headaches	3	6.38	0	0.00	3	10.34	**2**	**22.22**	1	5.88	0	0.00	1	3.70	2	10.00
Participant describes mild side effects giving the specific example of nausea, vomiting, or loss of appetite	3	6.38	1	5.56	2	6.90	1	11.11	1	5.88	1	4.76	1	3.70	2	10.00

Description of mild side effects (Specific side effects)	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes mild side effects giving the specific example of aches/pain (general)	11	23.40	7	26.92	4	19.05	7	29.17	4	17.39	**6**	**40.00**	5	15.63	**9**	**36.00**	**2**	**9.09**
Participant describes mild side effects giving the specific example of fatigue/lethargy	11	23.40	7	26.92	4	19.05	5	20.83	6	26.09	4	26.67	7	21.88	6	24.00	5	22.73
Participant describes mild side effects giving the specific example of headaches	3	6.38	2	7.69	1	4.76	2	8.33	1	4.35	2	13.33	1	3.13	2	8.00	1	4.55
Participant describes mild side effects giving the specific example of nausea, vomiting, or loss of appetite	3	6.38	1	3.85	2	9.52	2	8.33	1	4.35	2	13.33	1	3.13	2	8.00	1	4.55

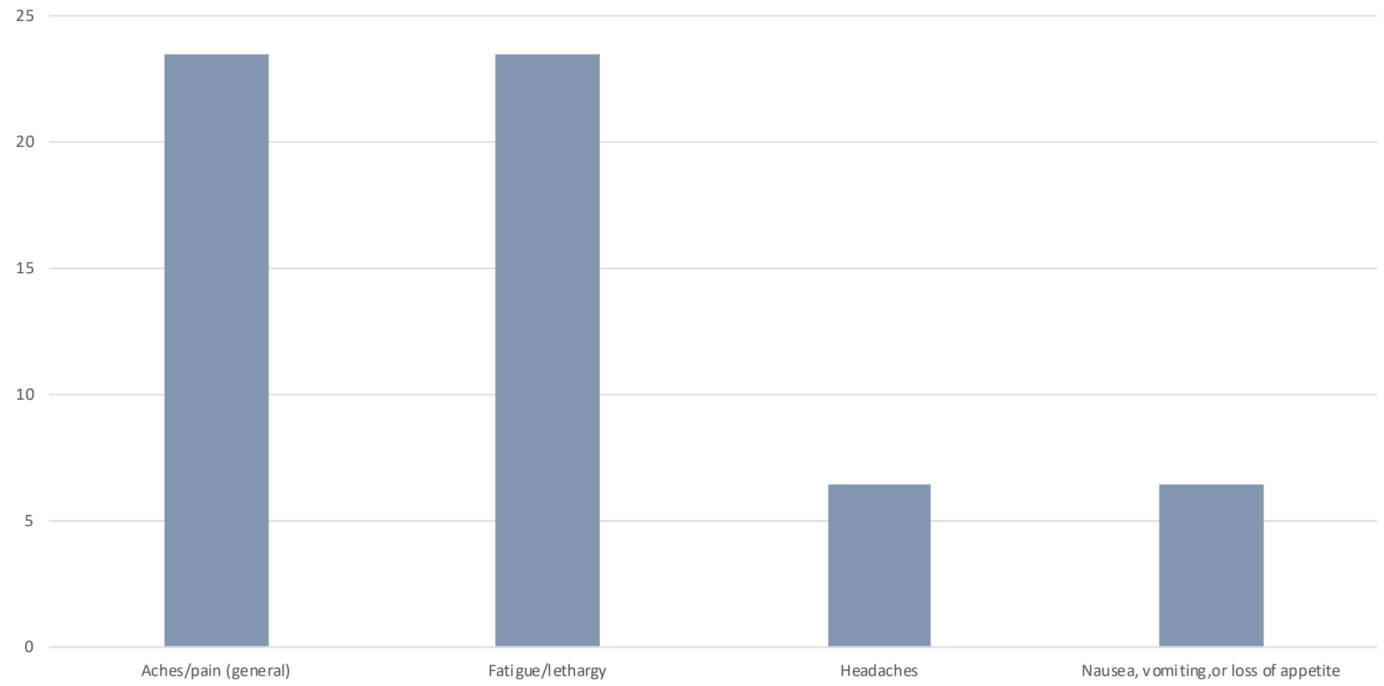

Figure 5.39: Description of mild side effects (Specific side effects)

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

Description of mild side effects (Specific side effects)	Reported less frequently	Reported more frequently
Participant describes mild side effects giving the specific example of aches/pain (general)	Higher socioeconomic status	Regional or remote Mid to low socioeconomic status
Participant describes mild side effects giving the specific example of fatigue/lethargy	-	High cholesterol under 50 years of age
Participant describes mild side effects giving the specific example ofheadaches	-	High cholesterol under 50 years of age

Description of severe side effects

In the structured interview, participants were asked how they would describe the term ‘severe side effects’. The most common description of severe side effects were described using a specific example (57.45%), and those that impact everyday life or ability to conduct activities of daily living (34.04%). Other themes included those that are life threatening or result in hospitalisation (6.38%), those that cause long-term damage to their body (6.38%), those that requires medical intervention (6.38%), and those that cause a need to change or stop using medication (6.38%).

When a specific side effect was described, the most common examples were aches and pain (21.28%), cognitive difficulties, including brain fog and difficulty communicating (14.89%), the emotional or mental impact (10.64%). Other side effects included fatigue or lethargy (10.64%), nausea, vomiting,or loss of appetite (6.38%), reduced mobility or loss of independence (6.38%), and shortness of breath (6.38%).

Participant provides a specific side effect as an example

I guess the mild side effect would be something like maybe a bit of back pain or some cramping bit of fatigue as well, maybe just feeling a little bit foggy headed, things like that. But I think a severe side effect would be something, you know, like we're cramping, that's so severe you can't walk properly, or you've got maybe breathing difficulties, things like that. Or maybe you're that fatigued that you can't get out of bed. That's the way I describe it.
Participant 011_2023AUHBV

Severe, severe would obviously be like I was saying with the, you know, I suppose the extreme vomiting, you know, the the extreme pain. Yeah, the full disorientation is not knowing where you are, how you are, why you are. Yeah.
Participant 018_2023AUHBV

There's severe nausea, and a general feeling of feeling fairly unwell, migraines, that sort of thing.
Participant 043_2023AUHBV

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

So severe side effects would mean that you couldn't go about your daily living, or your daily living would be severely impacted.
Participant 014_2023AUHBV

Severe heart effect. Yeah, well, I'd say this is the side effect is that I've got beta blockers, so I can't push myself as much as I want to quickly as I'd like to. I'm just thinking about sports performance.
Participant 015_2023AUHBV

Think things that that that stop you carrying out the normal. Daily routines, just looking after the house, shopping like say, meeting, meeting with friends, coffee. I'm retired, but you know, if you're a working person, being able to manage work, those sorts of things.
Participant 017_2023AUHBV

Fatigue is definitely a severe side effect for me. It changes everything. I can feel fine one minute and 15 minutes later I'll be on the couch and not being able to move. It greatly affects. I have two teenage children who still need lots of help and assistance. It definitely greatly affects their lives as well.
Participant 047_2023AUHBV

One which really prevents you from doing what you want to do.
Participant 048_2023AUHBV

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

A severe side effect is when I'm wanting to go to hospital. So something that's causing me extreme pain. Yeah, really a lot of discomfort. Yeah, a lot of distress.
Participant 021_2023AUHBV

Uh, mild side effects when I have, well, when I have, uh, sort of mild side effects, which is angina to me. Um. I kept it reasonably well because I know my, I know the routine I'm, I'm sort of I try the spray I use. If it doesn't work after twice I'll call an ambulance, you know. So that's how I deal with that. Basically I use my spray, I give it 5 minutes and if it hasn't said I'll give another spray and if hasn't worked after 10 minutes I'll be in an ambulance.
Participant 025_2023AUHBV

Participant describes severe side effects as those that cause long-term damage to their body

Well, to me, a severe side effect is now that I can't is the fact that I can't be medicated for something else Like to me that's very, like that's very detrimental to well, it's ruining my life. Honestly, I can't work as much as I would like. I am very not happy, like mentally because I can't be medicated and everyone else seems just seems to get this magical medication that fix them and I'm just not allowed to have a yeah, I'll call that a serious thing, but it doesn't hurt me other than for the rest of my life, just not physically.
Participant 007_2023AUHBV

So, so for me, like the fainting or long term health repercussions, anything that puts you in danger physically thank you.
Participant 020_2023AUHBV

Participant describes severe side effects as those that cause a need to change or stop using medication

If I had a severe side effect, I think I'd like a reaction and I would probably try another medication. I think I did have a bad side effect of one of the medications that I was originally on. I don't remember what it was called to be honest and I swapped it. Now this so much better than the other one that I was taking, but I don't remember what it was called.
Participant 016_2023AUHBV

Something that majorly impacts you and would can make you consider stopping the medication
Participant 019_2023AUHBV

Table 5.31: Description of severe side effects

Description of severe side effects	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant provides a specific side effect as an example	27	57.45	7	38.89	20	68.97	5	55.56	12	70.59	10	47.62	16	59.26	11	55.00
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	16	34.04	8	44.44	8	27.59	3	33.33	6	35.29	7	33.33	8	29.63	8	40.00
Participant describes severe side effects as those that are life threatening or result in hospitalisation	3	6.38	2	11.11	1	3.45	1	11.11	0	0.00	2	9.52	2	7.41	1	5.00
Participant describes severe side effects as those that cause long-term damage to their body	3	6.38	2	11.11	1	3.45	3	33.33	0	0.00	0	0.00	2	7.41	1	5.00
Participant identifies severe side effects as requiring medical intervention	3	6.38	1	5.56	2	6.90	0	0.00	1	5.88	2	9.52	1	3.70	2	10.00
Participant describes severe side effects as those that cause a need to change or stop using medication	3	6.38	2	11.11	1	3.45	1	11.11	0	0.00	2	9.52	2	7.41	1	5.00

Description of severe side effects	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant provides a specific side effect as an example	27	57.45	14	53.85	13	61.90	10	41.67	17	73.91	11	73.33	16	50.00	16	64.00	11	50.00
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	16	34.04	12	46.15	4	19.05	7	29.17	9	39.13	7	46.67	9	28.13	7	28.00	9	40.91
Participant describes severe side effects as those that are life threatening or result in hospitalisation	3	6.38	1	3.85	2	9.52	3	12.50	0	0.00	2	13.33	1	3.13	2	8.00	1	4.55
Participant describes severe side effects as those that cause long-term damage to their body	3	6.38	2	7.69	1	4.76	3	12.50	0	0.00	2	13.33	1	3.13	2	8.00	1	4.55
Participant identifies severe side effects as requiring medical intervention	3	6.38	3	11.54	0	0.00	3	12.50	0	0.00	0	0.00	3	9.38	1	4.00	2	9.09
Participant describes severe side effects as those that cause a need to change or stop using medication	3	6.38	3	11.54	0	0.00	2	8.33	1	4.35	1	6.67	2	6.25	1	4.00	2	9.09

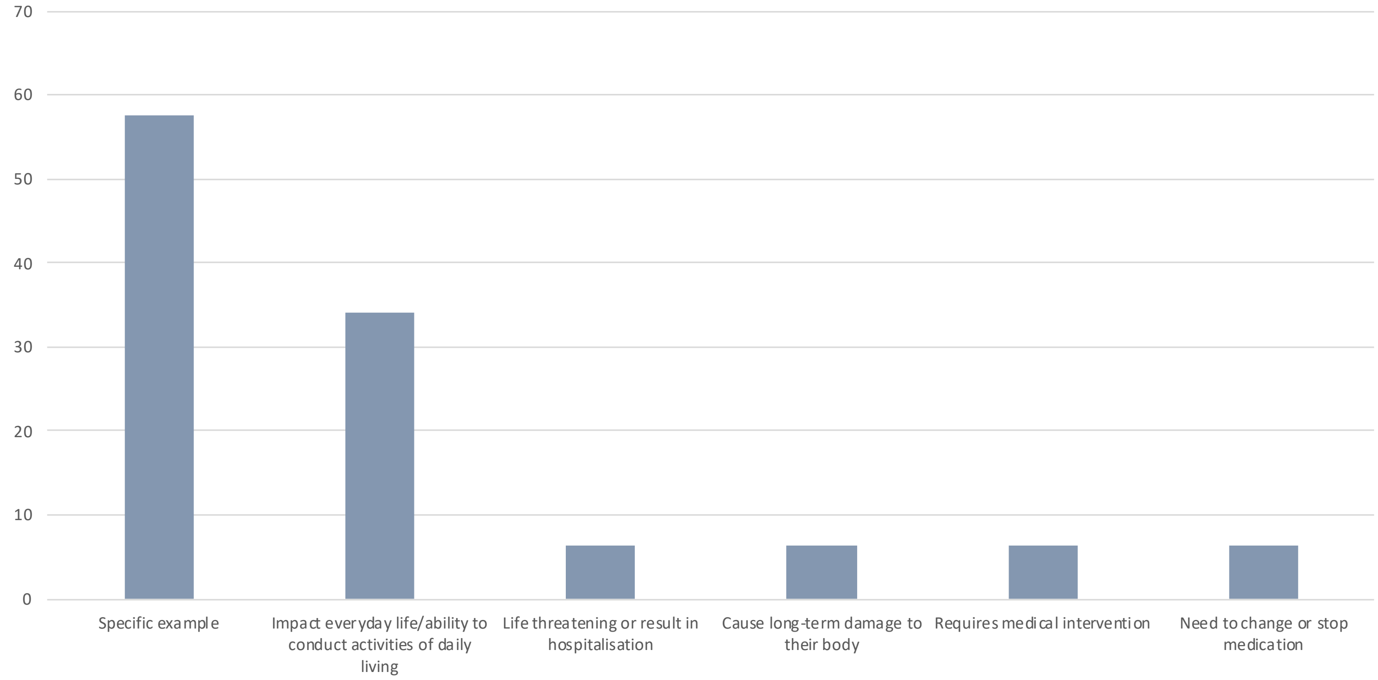

Figure 5.40: Description of severe side effects

Table 5.32: Description of severe side effects – subgroup variations

Description of severe side effects	Reported less frequently	Reported more frequently
Participant provides a specific side effect as an example	Had LP(a) test Aged 25 to 44	Did not had LP(a) test Blood vessel conditions Aged 45 and older Regional or remote
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	Male	Had LP(a) test Female Regional or remote
Participant describes severe side effects as those that cause long-term damage to their body	-	High cholesterol under 50 years of age

Table 5.33: Description of severe side effects (Specific example)

Description of severe side effects (Specific side effects)	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes severe side effects giving the specific example of aches/pain (general)	10	21.28	3	16.67	7	24.14	2	22.22	2	11.76	6	28.57	5	18.52	5	25.00
Participant describes severe side effects giving the specific example of cognitive difficulties (including brain fog, difficulty communicating)	7	14.89	1	5.56	6	20.69	0	0.00	5	29.41	2	9.52	2	7.41	5	25.00
Participant describes severe side effects giving the specific example of emotion/mental impact	5	10.64	2	11.11	3	10.34	2	22.22	2	11.76	1	4.76	3	11.11	2	10.00
Participant describes severe side effects giving the specific example of fatigue/lethargy	5	10.64	0	0.00	5	17.24	0	0.00	3	17.65	2	9.52	3	11.11	2	10.00
Participant describes severe side effects giving the specific example of nausea, vomiting, or loss of appetite	3	6.38	2	11.11	1	3.45	0	0.00	2	11.76	1	4.76	2	7.41	1	5.00
Participant describes severe side effects giving the specific example of reduced mobility/independence	3	6.38	0	0.00	3	10.34	0	0.00	2	11.76	1	4.76	1	3.70	2	10.00
Participant describes severe side effects giving the specific example of shortness of breath	3	6.38	0	0.00	3	10.34	0	0.00	1	5.88	2	9.52	1	3.70	2	10.00

Description of severe side effects (Specific side effects)	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes severe side effects giving the specific example of aches/pain (general)	10	21.28	7	26.92	3	14.29	5	20.83	5	21.74	3	20.00	7	21.88	7	28.00	3	13.64
Participant describes severe side effects giving the specific example of cognitive difficulties (including brain fog, difficulty communicating)	7	14.89	4	15.38	3	14.29	3	12.50	4	17.39	2	13.33	5	15.63	5	20.00	2	9.09
Participant describes severe side effects giving the specific example of emotion/mental impact	5	10.64	3	11.54	2	9.52	3	12.50	2	8.70	5	33.33	0	0.00	4	16.00	1	4.55
Participant describes severe side effects giving the specific example of fatigue/lethargy	5	10.64	3	11.54	2	9.52	1	4.17	4	17.39	3	20.00	2	6.25	2	8.00	3	13.64
Participant describes severe side effects giving the specific example of nausea, vomiting, or loss of appetite	3	6.38	0	0.00	3	14.29	1	4.17	2	8.70	1	6.67	2	6.25	1	4.00	2	9.09
Participant describes severe side effects giving the specific example of reduced mobility/independence	3	6.38	1	3.85	2	9.52	2	8.33	1	4.35	0	0.00	3	9.38	2	8.00	1	4.55
Participant describes severe side effects giving the specific example of shortness of breath	3	6.38	3	11.54	0	0.00	1	4.17	2	8.70	1	6.67	2	6.25	1	4.00	2	9.09

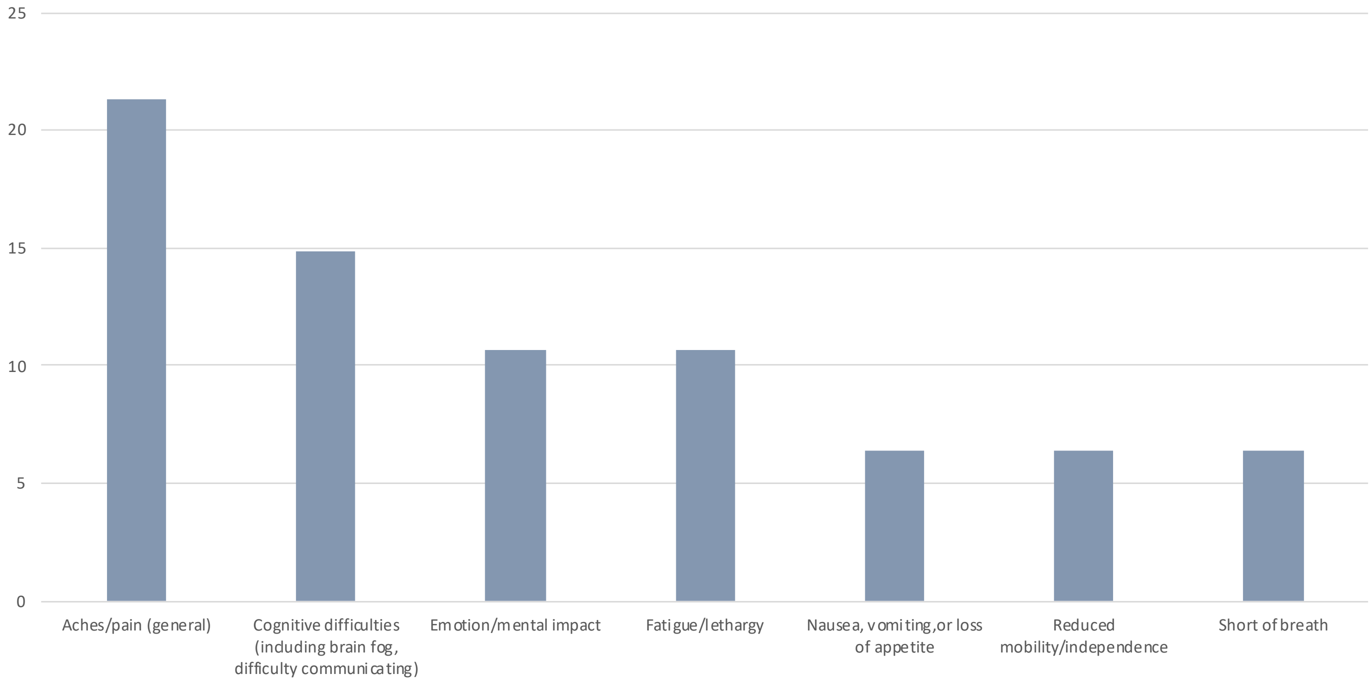

Figure 5.41: Description of severe side effects (Specific example)

Table 5.34: Description of severe side effects (Specific side effects)– subgroup variations

Description of severe side effects (Specific side effects)	Reported less frequently	Reported more frequently
Participant describes severe side effects giving the specific example of aches/pain (general)	-	-
Participant describes severe side effects giving the specific example of cognitive difficulties (including brain fog, difficulty communicating)	High cholesterol under 50 years of age	Blood vessel conditions 6 to 11 other conditions
Participant describes severe side effects giving the specific example of emotion/mental impact	Metropolitan	High cholesterol under 50 years of age Regional or remote
Participant describes severe side effects giving the specific example of fatigue/lethargy	Had LP(a) test High cholesterol under 50 years of age	-

Adherence to treatment

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 for a specific amount of time (46.81%), adhering to treatment according to the advice of their specialist or as long as prescribed (27.66%), and adhering to treatment as long as side effects are tolerable (25.53 %). Other themes included never giving up on any treatment (21.28%), and adhering to treatment as long as treatment is working (21.28%).

When participants stated a specific amount of time to adhere to a treatment, the most common amount of time was two to three months (14.89%), and six to twelve months (8.51%).

Participant describes adhering to treatment for a specific amount of time

If you feel that it's not working, I'd give it a good six months.
Participant 021_2023AUHBV

About one year, yeah.
Participant 026_2023AUHBV

I haven't had any that causing me adverse side effects so far, so I've never given up on a medication, but I would say probably a month. Participant 039_2023AUHBV

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

Well, with all of the medications that I've been prescribed, I've just stuck with it. I've just stuck with it until the doctor's. Basically, you know, I decided to change the dose and luckily I've had no trouble with side effects. I haven't actually had to stop anything due to that, but I'm sure that if I did get a side effect, I'd probably stop it and go back to the doctor and and say hang on and you please look at this for me.
Participant 011_2023AUHBV

But hypothetically, you know, because it. Yeah, because it works, it's hard to say. But if I tried something and it wasn't working, I would probably default to the doctor. So I would say to the doctor, how long should I try this? How long should I continue before you can conclusively say, look, no, that's not working, so yeah, so I would. Because they're the ones that are going to have the information on how like every medication is going to have a different time frame. So whether it be working, yes. Yeah.
Participant 019_2023AUHBV

Like doctor said to me it will go with the over the life because so my family background so I need to be very strict about my medications or my diet or exercise.
Participant 027_2023AUHBV

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

Oh, you need to give it a good six weeks, I suppose. Sometimes after a week, I've felt like coming off something, but you need to give it a longer go, so probably six weeks. Just to see whether-- the thing that I battle mostly with the medications is the time. Like, you know, it's like you hit a brick wall at some stages with it, and so I need to see whether I can get over that before, and then if that doesn't go away, just affects my family life too much. Participant 030_2023AUHBV

Well, with the first medication change, I just couldn't get out of bed. After I started taking it, my blood pressure went through the floor, so I tried it for about two days, I think, before the doctor told me to stop it, when I rang him. So no, that wasn't any lack of trying, that was because it was dangerous. In other words, I wanted more evidence, so I gave that a few days, and then I thought, … And otherwise, I don't change anything else. Yeah, I go on it, and stay on it. The rest of them. Participant 032_2023AUHBV

It depends what the side effects are. Generally I will speak to the doctor if I don't think it's working or I'll make the tough choice to come off it and then I'll ring them and tell them why I've done what I've done or organise an appointment sooner rather than later. Generally if a specialist does put me on a medication, I will say, "Okay, let's reconvene in three weeks." I think three weeks is a good number of weeks to see if the medication's working, you can expect a few rough days in that three weeks, but there's lots of factors involved. It could be the stroke, it could be fatigue, it could be the drug, you just don't know. I'm also very lucky there my cardiologist and I speak weekly. I don't even wait the three weeks. If I'm having side effects straight away, he'll just be like, "I'm glad you've come off it."
Participant 050_2023AUHBV

Participant describes not giving up on any treatment

I’ve never give it up and I’ve never changed the management system.
Participant 004_2023AUHBV

PARTICIPANT: Well, I have not experienced that. INTERVIEWER: Fair enough.
PARTICIPANT: I’ve been on the same medication now for 15 years.
INTERVIEWER: There you go. Pretty sure it’s working, huh? PARTICIPANT: It it seems to be yes, it has just increased my cholesterol medication because I’ve heard that people with coronary heart disease there’s a new benchmark and he said. He wants me to be a little bit lower than I am at, I think. It’s cholesterol is about 3.5, a bit less so OK, good.
Participant 005_2023AUHBV

PARTICIPANT: I don’t think I’ve ever given up on anything. I don’t think I’ve gone back and said anything about any medication. I just took it and just moved on.
Participant 037_2023AUHBV

Participant describes adhering to treatment as long as treatment is working

That would depend on the way it works in a way. If I had an infection and I was taking an antibiotic and it wasn’t working within three days then I would want to go back to the doctor and say, “That antibiotic’s not working.” If it’s a headache tablet, well, you’re going to know within an hour if it’s working. Then I’d give up on it in an hour. If it’s something for blood pressure, I don’t know long I would try, I don’t know. It was till the doct”r told’me it wasn't working. It would’depend on what it was.
Participant 041_2023AUHBV

There was never any real treatment. The medications were a range of medicines. Basically blood thinners, a few other things. I haven’t given up on any of the original medications. I don’t feel that I’m qualified to do that. Why would I if they’re working for me? I’m still on the original medication that I was taking. I realized the life-saving benefit of blood thinners. I had no side-effects from the medication so I’ve been very lucky.
Participant 045_2023AUHBV

I haven’t been offered massive amounts of different treatments. I am willing to try anything and to stick with things to be able to get a better quality of life.
Participant 047_2023AUHBV

Table 5.35: Adherence to treatment

Adherence to treatment	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes adhering to treatment for a specific amount of time [	22	46.81	10	55.56	12	41.38	8	88.89	6	35.29	8	38.10	12	44.44	10	50.00
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	13	27.66	5	27.78	8	27.59	1	11.11	7	41.18	5	23.81	7	25.93	6	30.00
Participant describes adhering to treatment as long as side effects are tolerable	12	25.53	4	22.22	8	27.59	4	44.44	5	29.41	3	14.29	7	25.93	5	25.00
Participant describes not giving up on any treatment	10	21.28	4	22.22	6	20.69	0	0.00	6	35.29	4	19.05	7	25.93	3	15.00
Participant describes adhering to treatment as long as treatment is working	10	21.28	2	11.11	8	27.59	1	11.11	6	35.29	3	14.29	5	18.52	5	25.00

Adherence to treatment	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes adhering to treatment for a specific amount of time	22	46.81	12	46.15	10	47.62	13	54.17	9	39.13	8	53.33	14	43.75	13	52.00	9	40.91
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	13	27.66	9	34.62	4	19.05	6	25.00	7	30.43	6	40.00	7	21.88	8	32.00	5	22.73
Participant describes adhering to treatment as long as side effects are tolerable	12	25.53	8	30.77	4	19.05	4	16.67	8	34.78	4	26.67	8	25.00	8	32.00	4	18.18
Participant describes not giving up on any treatment	10	21.28	4	15.38	6	28.57	2	8.33	8	34.78	2	13.33	8	25.00	5	20.00	5	22.73
Participant describes adhering to treatment as long as treatment is working	10	21.28	7	26.92	3	14.29	4	16.67	6	26.09	4	26.67	6	18.75	6	24.00	4	18.18

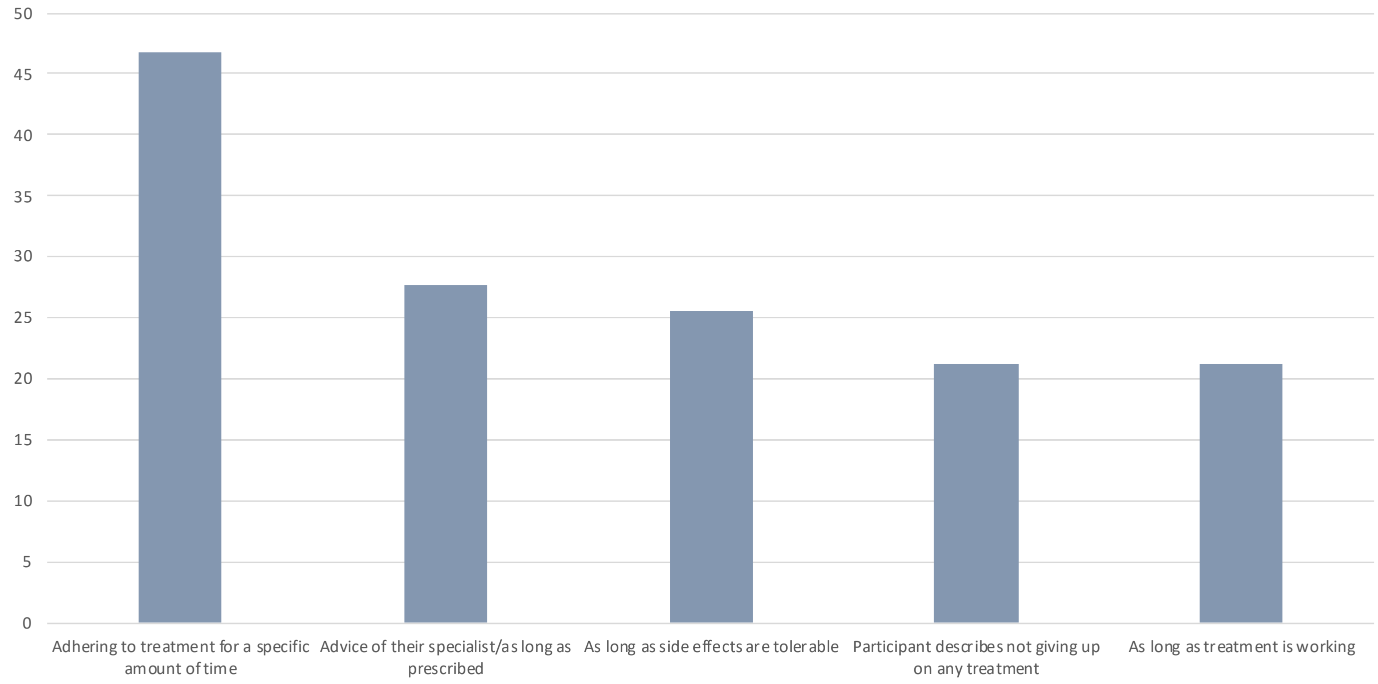

Figure 5.42: Adherence to treatment

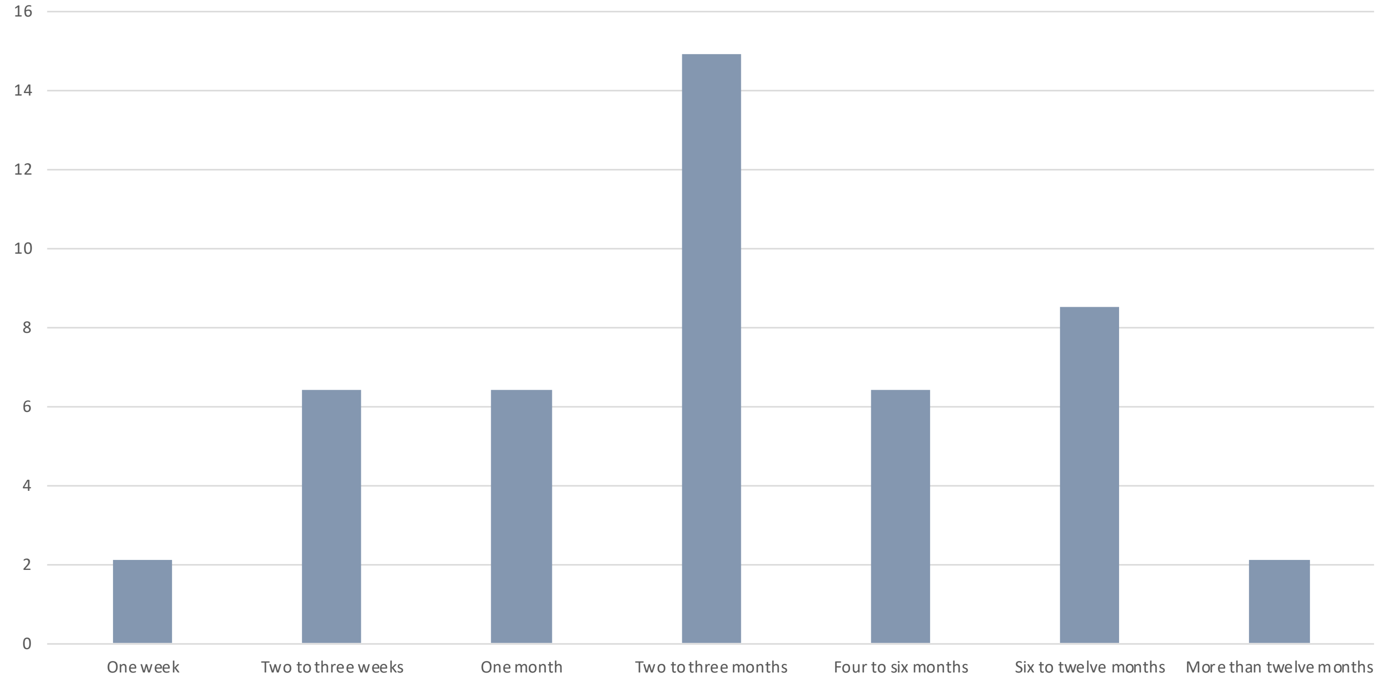

Figure 5.43: Adherence to treatment (Time to adhere to treatment)

Table 5.36: Adherence to treatment – subgroup variations

Adherence to treatment	Reported less frequently	Reported more frequently
Participant describes adhering to treatment for a specific amount of time	Blood vessel conditions	High cholesterol under 50 years of age
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	High cholesterol under 50 years of age	Blood vessel conditions Regional or remote
Participant describes adhering to treatment as long as side effects are tolerable	Heart conditions	High cholesterol under 50 years of age
Participant describes not giving up on any treatment	High cholesterol under 50 years of age Aged 25 to 44	Blood vessel conditions Aged 45 and older
Participant describes adhering to treatment as long as treatment is working	Had LP(a) test High cholesterol under 50 years of age	Blood vessel conditions

What needs to change to feel like treatment is working

Participants were asked to describe what needs to change to feel like treatment is effective. The most common responses were needing to see a specific symptom reduction (44.68%), and needing to see physical signs and symptoms disappear or reduce side effects (27.66%). Other themes included needing to see test results (14.89%), needing to see a return to day-to-day functionality (12.77%), and needing to have a balance between benefits and potential side effects (8.51%).

When a specific side effect or symptom was described, the most common examples were fatigue or lethargy (17.02%), heart rate or regular heart beat (8.51%), aches or pain (6.38 %), and the emotional, or mental impact (6.38%).

Participant describes needing to see a reduction in a specific symptom

I would want, I would need to feel like my heart. My heart rate would have to be lowered and not as sort of heavily pulsating throughout my upper body, which sort of turns into more. It's like a throbbing pain. My blood pressure would have to stabilize when I'm standing and not be consistently low, feeling like I can walk in a straight line and not something dizzy off, off kilter. Yeah, all those symptoms would have to be improved.
Participant 019_2023AUHBV

I think physically I need to feel an uptake in energy. So not being as tired, which is, you know, one of the things I deal with now is, is is being tired. I can't help the heart the way it is. Yeah. It's just an uptake in energy, you know, just a little bit, a little bit more upbeat, I guess.
Participant 028_2023AUHBV

What needs to improve. Whatever symptoms that I'm being medicated for, that has to improve, so if it's hypertension, then that has to improve over time, and I do give it four to six weeks before I see results. What else? The AF, obviously, the medication I wanted to see results immediately, but that took time. Whatever symptoms I'm being medicated for, they have to improve, and I do give it time.
Participant 034_2023AUHBV

The primary treatment for me was psychological treatment and that was repetition. When I was in rehab, I would sit down with my rehab provider and I would try and read. To enhance my memory, I would repeat, repeat, repeat, repeat. I've now realized that true repetition, that that's how the brain makes these synaptic connections. If I learned anything in my rehab, it is that I can control my brain and train my brain to improve memory.
Participant 045_2023AUHBV

Participants reported needing to see all physical signs and symptoms disappear

So a reduction in. Symptoms, but or at the AT, you know, a reduction in the numbers.
Participant 003_2023AUHBV

The side effects, I think, and for it to actually do something to alleviate the symptoms.
Participant 008_2023AUHBV

Whatever symptoms I had, improve.
Participant 041_2023AUHBV

Participant describes needing to see test results to know that a treatment is working

Yeah, I think it's looking at my blood tests is the important thing for me. Um, just checking my cholesterol levels and making sure that they're at Target or trying to get down to Target. So that would be an indicator of that. The medication's working.
Participant 011_2023AUHBV

The fact that when I have my, you know regular blood tests and my cholesterol is where it should be and that's all good. And so I keep my GP keeps a track on that. I'm just about to have a test this week to make sure that the so when all those markers are OK then it makes me feel OK.
Participant 013_2023AUHBV

Well, the results obviously from for me it was the cholesterol results. If they had worked, if they'd moved, especially with the diet, I might have been tempted to stick with it a little bit longer:
Participant 020_2023AUHBV

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

Right. I I understand that it's not all medication makes you feel better. I have some treatment for osteoporosis which on a day-to-day level doesn't affect me or or improve my health. What it does is in *the long term it stops degeneration of of the bones. So I think like like that with with the heart, the sort of things that I would hope to see is that I would be able to do more exercise. I wouldn't get out of breath so quickly, or my heart rate wouldn't go up so quickly*

Participant 017_2023AUHBV

Visible improvement in my daily activity and the way I feel mentally and physically.

Participant 049_2023AUHBV

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

In my case, it would be like to see the blood results. So if I start to see the data that literally there's at least at first there's something that's would be coming down and and there's like a trend, you know, yeah, it it might take six months, yeah, six months or a year to kind of see the trend. And I and I could, I guess I would, yeah. So that that gives me more food. So I might even go back and have to kind of give it. Yeah, even six months to see what the data would come in at. Yeah, I mean I might get a blood test after three months just to see if it's making a difference because that would that would spur me to continue that spur me on motivate me to keep going. Yeah. And then I guess, yeah, I guess I'm sorry and I guess kind of your question, I would be assessing in a sense like myself reported. You know what? I'm perceived side effects or if my quality of life from day-to-day was suffering in a way. If you know, I would definitely be keeping like a a bit of a mental tab and like a bit of a sort of a checking with myself just to just to try to notice if there are small differences. Like maybe I'm experiencing like pain in my joints or something like that, or mental fogginess or whatever or something with this. That just seems OK. And then trying to see if it's connected to this, this, if it is a drug therapy or what have you. Yeah. So maybe I would keep a little journal kind of thing and just kind of weigh that up as well. Cuz I know that's gonna be a factor in my decision making this stay on or not.

Participant 001_2023AUHBV

Table 5.37: What needs to change to feel like treatment is working

What needs to change to feel like treatment is working	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Participant describes needing to see a reduction in a specific symptom	21	44.68	9	50.00	11	37.93	4	44.44	7	41.18	9	42.86	11	40.74	9	45.00
Participants reported needing to see all physical signs and symptoms disappear	13	27.66	**1**	**5.56**	**12**	**41.38**	**1**	**11.11**	**7**	**41.18**	5	23.81	5	18.52	**8**	**40.00**
Participant describes needing to see test results to know that a treatment is working	7	14.89	3	16.67	4	13.79	**3**	**33.33**	1	5.88	3	14.29	3	11.11	4	20.00
Participants reported needing to experience a return to day-to-day functionality	6	12.77	**5**	**27.78**	1	3.45	1	11.11	2	11.76	3	14.29	4	14.81	2	10.00
Participant describes needing to have a balance between benefits and potential side effects	4	8.51	3	16.67	1	3.45	**4**	**44.44**	0	0.00	0	0.00	1	3.70	3	15.00

What needs to change to feel like treatment is working	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Participant describes needing to see a reduction in a specific symptom	21	44.68	13	50.00	**7**	**33.33**	12	50.00	8	34.78	6	40.00	14	43.75	11	44.00	9	40.91
Participants reported needing to see all physical signs and symptoms disappear	13	27.66	**10**	**38.46**	**3**	**14.29**	**3**	**12.50**	**10**	**43.48**	5	33.33	8	25.00	8	32.00	5	22.73
Participant describes needing to see test results to know that a treatment is working	7	14.89	3	11.54	4	19.05	**6**	**25.00**	**1**	**4.35**	3	20.00	4	12.50	4	16.00	3	13.64
Participants reported needing to experience a return to day-to-day functionality	6	12.77	3	11.54	3	14.29	5	20.83	1	4.35	1	6.67	5	15.63	4	16.00	2	9.09
Participant describes needing to have a balance between benefits and potential side effects	4	8.51	1	3.85	3	14.29	4	16.67	0	0.00	1	6.67	3	9.38	1	4.00	3	13.64

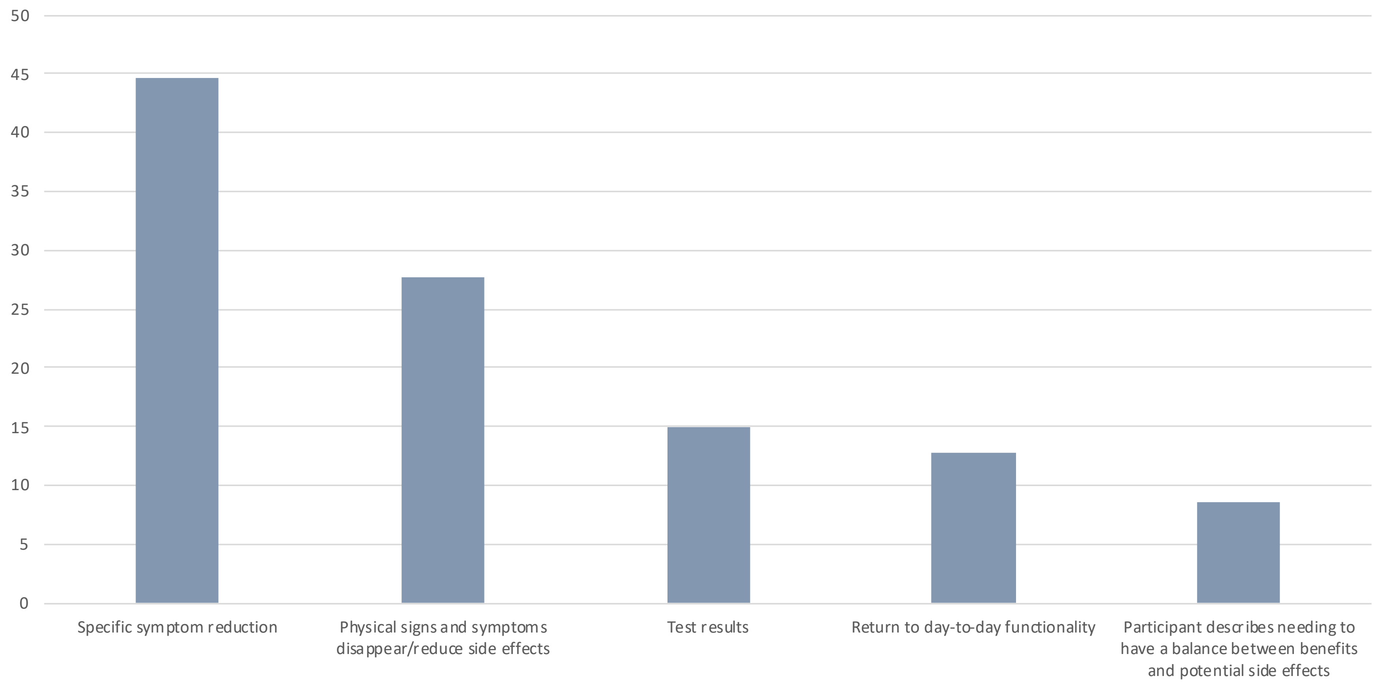

Figure 5.44: What needs to change to feel like treatment is working

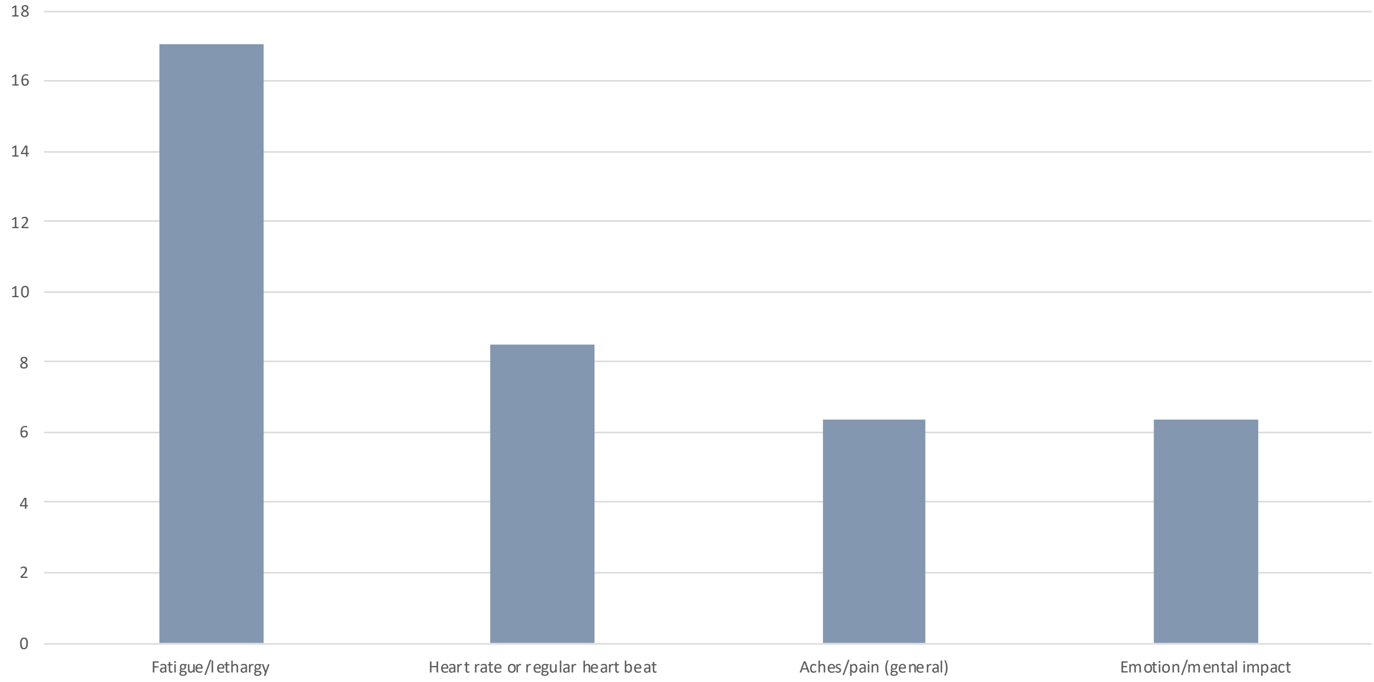

Figure 5.45: What needs to change to feel like treatment is working (Specific symptoms)

Table 5.38: What needs to change to feel like treatment is working – subgroup variations

What needs to change to feel like treatment is working	Reported less frequently	Reported more frequently
Participant describes needing to see a reduction in a specific symptom	Male	-
Participants reported needing to see all physical signs and symptoms disappear	Had LP(a) test High cholesterol under 50 years of age Male Aged 25 to 44	Did not had LP(a) test Blood vessel conditions 6 to 11 other conditions Female Aged 45 and older
Participant describes needing to see test results to know that a treatment is working	Aged 45 and older	High cholesterol under 50 years of age Aged 25 to 44
Participants reported needing to experience a return to day-to-day functionality	-	Had LP(a) test
Participant describes needing to have a balance between benefits and potential side effects	-	High cholesterol under 50 years of age

What it would mean if treatment worked

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 responses were that it would allow them to do everyday activities or return to normal life (17.02%), and it would lead to a reduction in symptoms or side effects (14.89%). This was followed by it would have positive impact on their mental health (12.77 %), and allow them to engage more with social activities and family life (8.51%).

Allowing them to do everyday activities/return to normal life

Oh, it'd mean a lot of things. I can do more, be more independent.
Participant 044_2023AUHBV

Probably concentrate more and be able to get out and do activities.
Participant 049_2023AUHBV

Maybe I could use my left arm more often and carry things, at the moment, it's a pretty useless arm to be honest.
Participant 039_2023AUHBV

I would have been a lot more freer. I have more freedom. Now my pain is out of control. I really can't do much now. That was one of my big goals.
Participant 042_2023AUHBV

Leading to a reduction in symptoms/side effects

I think just have more, more energy to do things. For example, with the housework I'm only able to do sort of one or two small rooms at a time, and then I feel exhausted, and that's partly because. I can feel, you know, that I'm breathing more heavily and I'm getting that pressed and it it's like I've been running, it's that sort of tiredness. And so if the medication was working, then it would mean I would be able to do more of that and I would be able to walk further because I like walking and you know, I I would like to be able to walk for an hour at a time and that sort of thing. So they're the sort of things that I would like, like to be able to do, and I like swimming, but I can only do it for a short, a short time, you know, And aerobics, aerobics class of 45 minutes is sort of the maximum I can do, and I'd like to be able to do something like that and have a bit of energy. Left at the end.
Participant 017_2023AUHBV

The primary treatment for me was psychological treatment and that was repetition. When I was in rehab, I would sit down with my rehab provider and I would try and read. To enhance my memory, I would repeat, repeat, repeat, repeat. I've now realized that true repetition, that that's how the brain makes these synaptic connections. If I learned anything in my rehab, it is that I can control my brain and train my brain to improve memory.
Participant 045_2023AUHBV

Well, yes, it has completely removed my migraines. It means that my quality of life is probably better than it was before I had my stroke because I did not get recurrent, debilitating migraines.
Participant 046_2023AUHBV

A positive impact on their mental health

Probably wouldn't change too much in my day-to-day life, but it would remove the stress of the condition.
Participant 020_2023AUHBV

Allowing them to engage more with social activities and family life

Yeah, look, it would mean the world. Like, I've got three kids, so one of them's 18 soon. The others are quite young, so being able to do a lot more physical activity with those, those ones would be really good. So you know, I've started walking with my daughter. She's only seven, but she's already, I swear, a lot more fitter than what I am, you know. But just being able to do things with that, with the family, just means the world.
Participant 028_2023AUHBV

Table 5.39: What it would mean if treatment worked

What it would mean if treatment worked	All participants		Had LP(a) test		Did not had LP(a) test		High cholesterol under 50 years of age		Blood vessel conditions		Heart conditions		0 to 5 other conditions		6 to 11 other conditions	
	n=47	%	n=18	%	n=29	%	n=9	%	n=17	%	n=21	%	n=27	%	n=20	%
Allowing them to do everyday activities/return to normal life	8	17.02	5	27.78	3	10.34	1	11.11	4	23.53	3	14.29	5	18.52	3	15.00
Leading to a reduction in symptoms/side effects	7	14.89	4	22.22	3	10.34	2	22.22	4	23.53	1	4.76	2	7.41	5	25.00
A positive impact on their mental health	6	12.77	4	22.22	2	6.90	2	22.22	1	5.88	3	14.29	3	11.11	3	15.00
Allowing them to engage more with social activities and family life	4	8.51	3	16.67	1	3.45	1	11.11	0	0.00	3	14.29	2	7.41	2	10.00

What it would mean if treatment worked	All participants		Female		Male		Aged 25 to 44		Aged 45 and older		Regional or remote		Metropolitan		Mid to low socioeconomic status		Higher socioeconomic status	
	n=47	%	n=26	%	n=21	%	n=24	%	n=23	%	n=15	%	n=32	%	n=25	%	n=22	%
Allowing them to do everyday activities/return to normal life	8	17.02	4	15.38	4	19.05	4	16.67	4	17.39	3	20.00	5	15.63	6	24.00	2	9.09
Leading to a reduction in symptoms/side effects	7	14.89	6	23.08	1	4.76	4	16.67	3	13.04	3	20.00	4	12.50	5	20.00	2	9.09
A positive impact on their mental health	6	12.77	5	19.23	1	4.76	4	16.67	2	8.70	3	20.00	3	9.38	5	20.00	1	4.55
Allowing them to engage more with social activities and family life	4	8.51	2	7.69	2	9.52	3	12.50	1	4.35	2	13.33	2	6.25	3	12.00	1	4.55

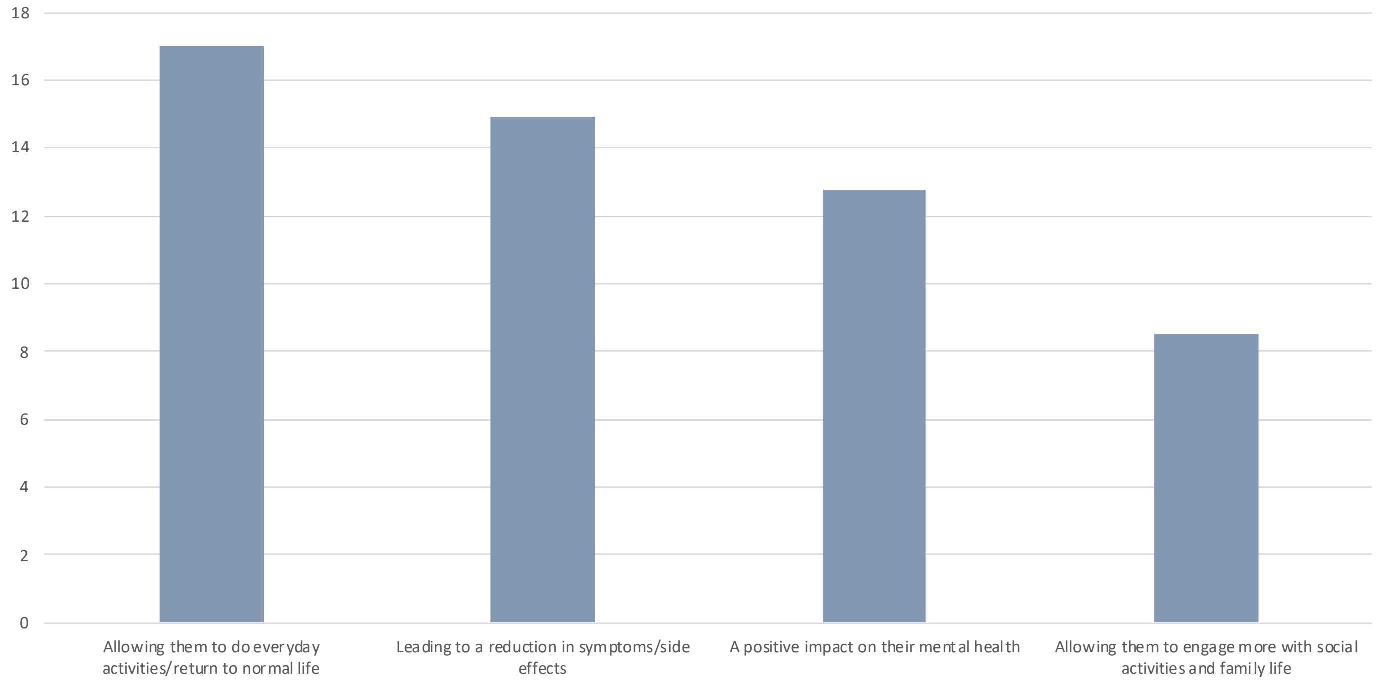

Figure 5.46: What it would mean if treatment worked

Table 5.40: What it would mean if treatment worked – subgroup variations

What it would mean if treatment worked	Reported less frequently	Reported more frequently
Allowing them to do everyday activities/return to normal life	-	Had LP(a) test
Leading to a reduction in symptoms/side effects	Heart conditions Male	6 to 11 other conditions