

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 gastroenterologists (n=9, 64.29%), followed by general practitioners (n=5, 35.71%).

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 6 participants (42.86%) that travelled for less than 30 minutes, 4 participants (28.57%) that travelled between 30 and 60 minutes, 2 participants (14.28%) that travelled for more than 60 minutes.

Ease of getting medical appointments

Participants were asked in the online questionnaire how easy it was to get appointments with their main treatment provider.

There were 3 participants (21.43%) found it not very easy, 2 participants (14.29%) that found it somewhat easy, 6 participants (42.86%) that found it quite easy, and 3 participants (21.43%) that found it very easy to get an appointment with their main treatment provider.

Access to healthcare professionals

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

Almost all participants had access to a gastroenterologist (n=8, 57.14%), and more than half had access to a Hepatologist (n=8, 57.14%). There were 12 participants (85.71%) that had a general practitioner (GP) and 5 participants (35.71%) that had a hepatology nurse.

There were 6 participants (42.86%) that had access to a pharmacist, and 3 participants (21.43%) treated by a dietitian/nutritionist.

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 8 participants (57.14%) that indicated that they had been treated with respect throughout their experience, and 5 participants (35.71%) that were treated with respect with the exception of one or two occasions. There was one participant (7.14%) that felt they had not been treated respectfully at all.

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=7, 53.85%). The majority of participants were not asked if they wanted to be treated as a public or private patient (n=8, 61.54%), however, they were asked if they had private health insurance (n=10, 76.92%).

Throughout their treatment, there was 1 participant (7.69%) that was treated as a private patient, 7 participants (53.85%) were mostly treated as a public patient, and there were 2 participants (15.38%) that were equally treated as a private and public patient.

Throughout their treatment, there were 2 participants (15.38%) that were treated mostly in the private hospital system, 10 participants (76.92%) were mostly treated in the public system, and there was 1 participant (7.69%) that was 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 cancel healthcare appointments because they were unable to afford them. Almost all the participants never or rarely had to delay or cancel appointments due to affordability (n = 9, 69.23%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=9, 69.23%).

The third question was about the affordability of basic essentials such as food, housing and power. There were 9 participants (69.23%) that never or rarely had trouble paying for essentials, and 4 participants (30.77%) that sometimes found it difficult, and 0 participants (0.00%) 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 3 participants (23.08%) 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 (Table 5.8, Figure 5.9).

The most common amount was between \$1 and \$150 (N=5, 38.46%). There were 2 participants (15.38%) that did not spend anything, and the same number that spent more than \$100 per month.

Burden of cost

As a follow up question, for participants that 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 4 participants (30.77%), somewhat significant for 1 participants (7.69%), and slightly or not at all significant for 8 participants (61.54%).

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 3 participants (23.08%) had not changed since diagnosis, and 0 participants (0.00%) were retired or did not have a job. There was 1 participant (7.69%) had to quit their job, 5 participants (38.46%) reduced the number of hours they worked, and 2 participants (15.38%) that accessed their superannuation early. There were 2

participants (15.38%) that took leave from work without pay, and 3 participants (23.08%) 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 3 participants (23.08%), 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=6, 46.15%). There was 1 participant (7.69%) whose partner reduced the numbers of hours they worked, and 1 partner (7.69%) that quit their job. The partners of no partners of participants (0.00%) that took leave without pay, and there was 1 partner (7.69%) that took leave with pay.

Reduced income due to condition

Almost a third of the participants (n=4, 30.77%) 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.

There were 4 participants (30.77%) with a reduced monthly income, and 9 participants (69.23%) with no reduced income.

Summary of treatments and management

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

The majority of participants had drug treatments (n=13, 92.86%), and 7 participants (50.00%) that used allied health. Participants used complementary therapy (n=5, 35.71%), made lifestyle changes (n=8, 57.14%). There was 1 participant (7.14%) that had no treatment, 1 participant (7.14%) that had a liver transplant.

Summary of drug treatments

Participants completed a series of questions about drug therapies, including, quality of life, effectiveness of treatment, and side effects. .

The majority of participants had drug treatments (n=13, 92.86%). The most common types of drug treatments were Pegylated interferon alpha (Pegasys, Peg-Intron), (n=11, 78.57%), Entecavir (Baraclude) n=4,28.57%) and, Ribavirin (Ibavyr) (n=4,28.57%).

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

On average, quality of life from Pegylated interferon alpha (Pegasys, Peg-Intron) was in the 'life was distressing' range (median=2.00, IQR=1.00), and was found to be ineffective (median=1.00, IQR=3.00).

Allied health

The most common allied health service used was psychology (n=4, 28.57%), followed by dietary (n=3, 21.43%), and social work (n=2, 14.29%). There were 1 participant (7.14%) that saw a physiotherapist, 1 participant (7.14%) that saw a podiatrist. No participants had speech therapy or occupational therapy.

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.

Most participants used at made at least one lifestyle change (n=8, 57.14%).

The most common lifestyle change used was diet changes (n=7, 50.00%), followed by reducing or quitting alcohol (n=6, 42.86%), and exercise (n=4, 28.57%).

On average, quality of life from diet changes was in the 'life was average' range (median=4.00, IQR=2.00), and was found to be moderately (median=3.00, IQR=1.50).

On average, quality of life from reducing or quitting alcohol was in the 'life was average' range (median=4.00, IQR=1.50), and was found to be very effective (median=5.00, IQR=0.75).

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=5, 35.71%)

The most common complementary therapy used was, massage therapy (n=4, 28.57%), followed by mindfulness or relaxation (n=4, 28.57%), and supplements (n=3, 21.43%).

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 8 participants (57.14%) that had discussions about clinical trials, 3 participants (21.43%) had brought up the topic with their doctor, and the doctor of 5 participants (35.71%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=6, 42.86%).

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 (7.14%) that had taken part in a clinical trial, 10 participants (71.43%) that would like to take part in a clinical trial if there was a suitable one, and 3 participants, that have not participated in a clinical trial and do not want to (21.43%).

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 those that do not interfere with life (50.00%), and they described

mild side effects using a specific example (50.00%). Other themes included those that can be managed with self-medication or self-management (8.33%), and those that resolve in short time (8.33%).

When a specific side effect was described, the most common responses were headaches (16.67%), and skin itch or rash (16.67%). Other themes included aches and pain (8.33%), emotional or mental impact (8.33%), gastrointestinal distress (8.33%), lightheadedness or being dizzy (8.33%), nausea or loss of appetite (8.33%), heavy periods and low blood iron (8.33%), and low immunity (8.33%).

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 those that impact everyday life or ability to conduct activities of daily living (16.67%), described using a specific example (16.67%), and that the treatment is worse than condition (16.67%). Other themes included those that are life threatening or result in hospitalisation (8.33%), those that cause long-term damage to their body (8.33%), those that requires medical intervention (8.33%), and those that impact their everyday life by being bed ridden (8.33%).

When a specific side effect was described, the examples were aches and pain (8.33%), and emotional and mental impact (8.33%), fatigue and lethargy (8.33%), and allergic reaction (8.33%).

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 according to the advice of their specialist or as long as prescribed (58.33%), needing to see test results/no evidence or reduction of disease (33.33%), and adhering to treatment as long as side effects are tolerable (16.67%).

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 physical signs and symptoms disappear/reduce side effects (25.00%), needing to see evidence of stable disease or no disease progression (16.67%), and needing to see a specific symptom reduction (8.33%).

When a specific side effect or symptom was described, they were aches and pain (16.67%), cognitive difficulties (8.33%), fatigue and lethargy (8.33 %), and night sweats (8.33%).

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/return to normal life (33.33%), and have a positive impact on their mental health (25.00%). Other themes included lead to a reduction in symptoms and side effects (8.33%), less medical interventions, doctor visits, or hospitalisation (8.33%), and a longer life (8.33%).

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 healthcare professional considered to be the main provider of care were hepatologists (n=9, 64.28%), followed by general practitioners (n=5, 35.71%).

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 6 participants (42.86%) that travelled for less than 30 minutes, 4 participants (28.57%) that travelled between 30 and 60 minutes, 2 participants (14.28%) that travelled for more than 60 minutes.

Ease of getting medical appointments

Participants were asked in the online questionnaire how easy it was to get appointments with their main treatment provider.

There were 3 participants (21.43%) found it not very easy, 2 participants (14.29%) that found it somewhat easy, 6 participants (42.86%) that found it quite easy, and 3 participants (21.43%) that found it very easy to get an appointment with their main treatment provider.

Table 5.1: Time to travel to main provider of treatment

Main provider of treatment	Number (n=14)	Percent
Less than 15 minutes	1	7.14
Between 15 and 30 minutes	5	35.71
Between 30 and 60 minutes	4	28.57
Between 60 and 90 minutes	1	7.14
More than 90 minutes	1	7.14
NA	2	14.29

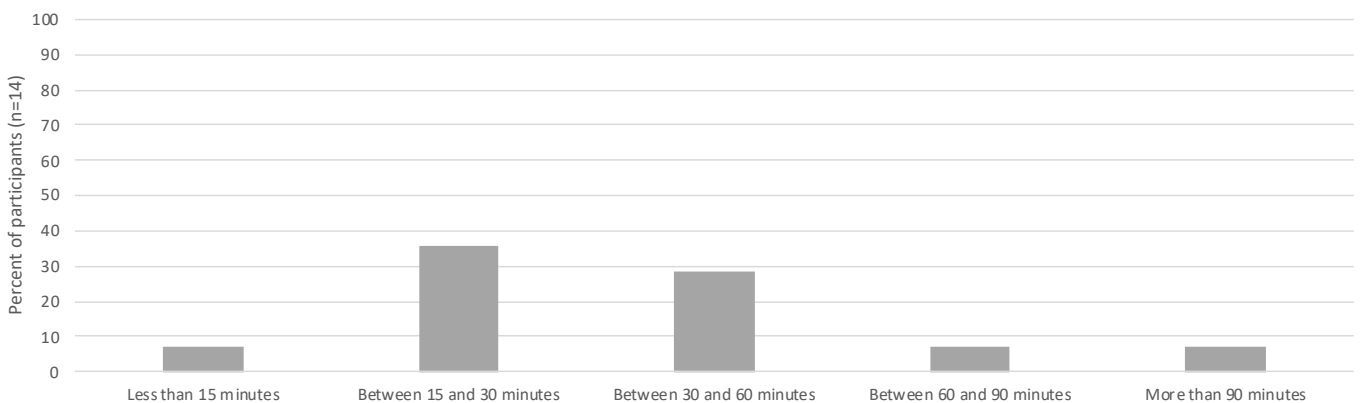


Figure 5.1: Time to travel to main provider of treatment

Table 5.2: Ease of getting medical appointments

Ease of getting medical appointments	Number (n=14)	Percent
Not very easy	3	21.43
Somewhat easy	2	14.29
Quite easy	6	42.86
Very easy	3	21.43

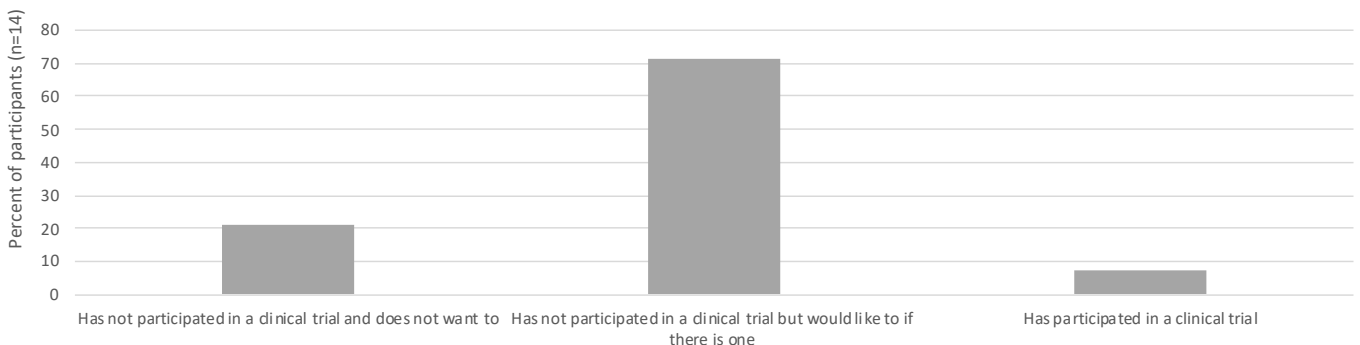


Figure 5.2: Ease of getting medical appointments

Access to healthcare professionals

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

Almost all participants had access to a gastroenterologist (n=8, 57.14%), and more than half had access to a Hepatologist (n=8, 57.14%). There were

12 participants (85.71%) that had a general practitioner (GP) and 5 participants (35.71%) that had a hepatology nurse.

There were 6 participants (42.86%) that had access to a pharmacist, and 3 participants (21.43%) treated by a dietitian/nutritionist.

Table 5.3: Access to healthcare professionals

Healthcare professional	Number (n=14)	Percent
Gastroenterologist	8	57.14
Hepatologist	8	57.14
Surgeon	2	14.29
General Practitioner (GP)	12	85.71
Hepatology nurse	5	35.71
Pharmacist	6	42.86
Dietitian/nutritionist	3	21.43
Exercise physiologist	2	14.29
Psychologist	2	14.29
Counsellor	1	7.14
Osteopath	1	7.14
Social worker	1	7.14

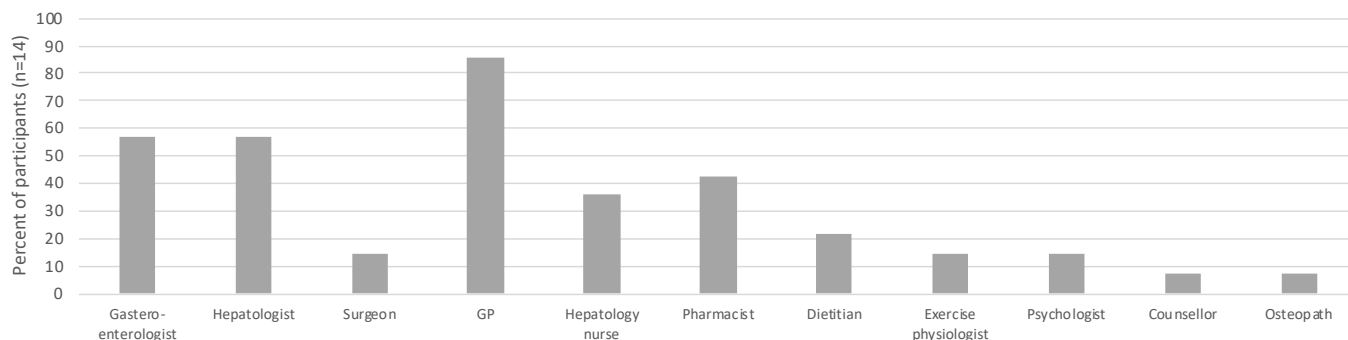


Figure 5.3: Access to healthcare professionals

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 8 participants (57.14%) that indicated that they had been treated with respect throughout their experience, and 5 participants (35.71%) that were treated with respect with the exception of one or two occasions. There was one participant (7.14%) that felt they had not been treated respectfully at all.

Table 5.5: Respect shown

Respect shown	Number (n=14)	Percent
Respect shown	8	57.14
Respect shown, with the exception of one or two occasions	5	35.71
Respect not shown	1	7.14

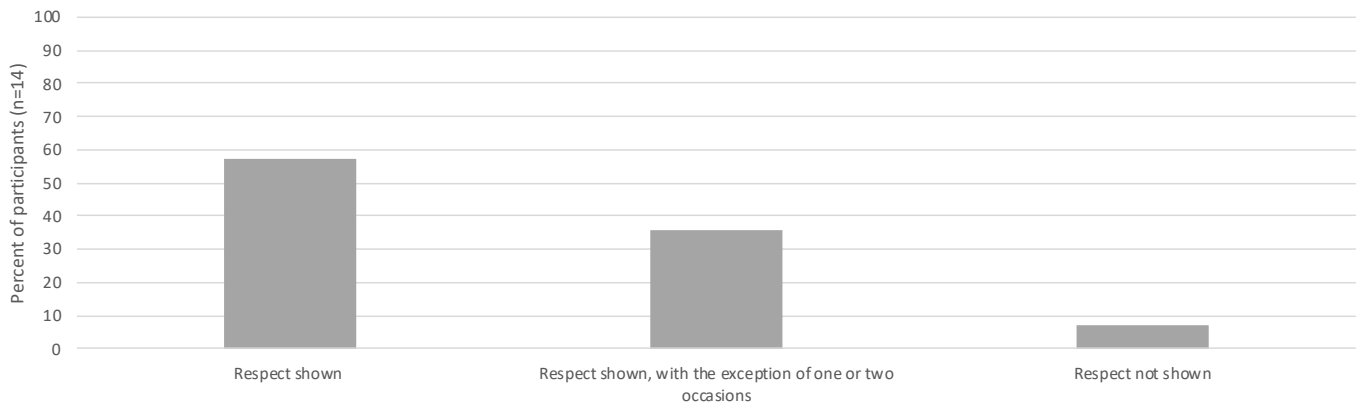


Figure 5.5: Respect shown

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.

Half of the participants had private health insurance (n=7, 53.85%). The majority of participants were not asked if they wanted to be treated as a public or private patient (n=8, 61.54%), however, they were asked if they had private health insurance (n=10, 76.92%).

Throughout their treatment, there was 1 participant (7.69%) that was treated as a private patient, 7 participants (53.85%) were mostly treated as a public patient, and there were 2 participants (15.38%) that were equally treated as a private and public patient.

Throughout their treatment, there were 2 participants (15.38%) that were treated mostly in the private hospital system, 10 participants (76.92%) were mostly treated in the public system, and there was 1 participant (7.69%) that was equally treated in the private and public systems.

Table 5.6: Health care system

Health care services	Response	Number (n=13)	Percent
Private health insurance	No	6	46.15
	Yes	7	53.85
Asked whether you want to be treated as a public or private patient	No	8	61.54
	Yes	5	38.46
Asked whether you had private health insurance	No	3	23.08
	Yes	10	76.92
Throughout your treatment in hospital, have you most been treated as a public or a private patient	Equally as a public and private patient	2	15.38
	Private patient	1	7.69
	Public patient	7	53.85
	Not sure	3	23.08
Which hospital system have you primarily been treated in	Both public and private	1	7.69
	Private	2	15.38
	Public patient	10	76.92

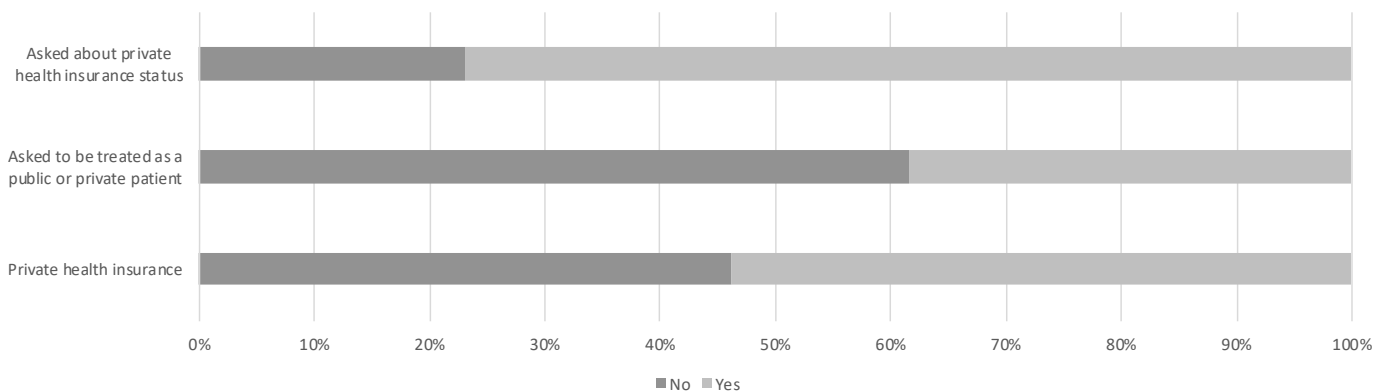


Figure 5.6: Health insurance

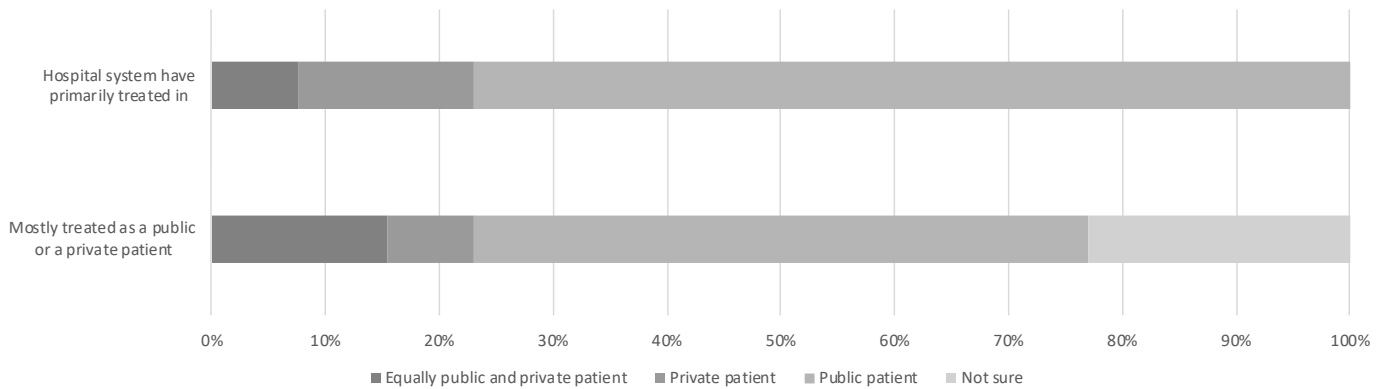


Figure 5.7: Hospital system

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 cancel healthcare appointments because they were unable to afford them. Almost all the participants never or rarely had to delay or cancel appointments due to affordability (n = 9, 69.23%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=9, 69.23%).

The third question was about the affordability of basic essentials such as such as food, housing and power. There were 9 participants (69.23%) that never or rarely had trouble paying for essentials, and 4 participants (30.77%) that sometimes found it difficult, and 0 participants (0.00%) 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 3 participants (23.08%) that paid for additional carers due to their condition.

Table 5.7: Affordability of healthcare

Health services and insurance	Response	Number (n=13)	Percent
Delay or cancel healthcare appointments due to affordability	Never	8	61.54
	Rarely	1	7.69
	Sometimes	3	23.08
	Often	0	0.00
	Very often	1	7.69
Did not fill prescriptions due to cost	Never	8	61.54
	Rarely	1	7.69
	Sometimes	3	23.08
	Often	0	0.00
	Very often	1	7.69
Difficult to pay for basic essentials	Never	8	61.54
	Rarely	1	7.69
	Sometimes	4	30.77
	Often	0	0.00
	Very often	0	0.00
Pay for additional carers for self or family	Yes	3	23.08
	No	10	76.92

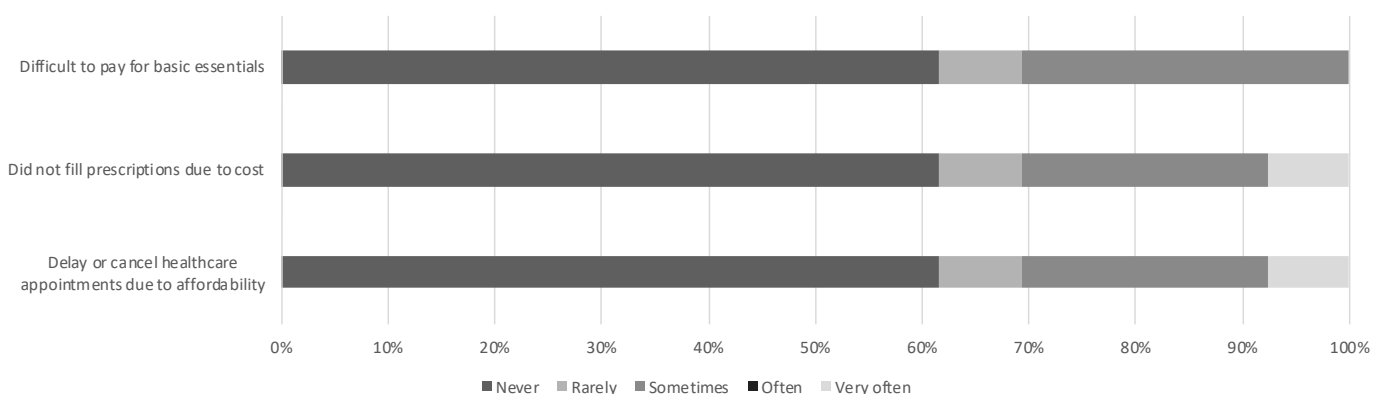


Figure 5.8: Affordability of healthcare

Cost of condition

In the online questionnaire, participants estimated the amount they spend per month due to their condition, including doctors' fees, transport, carers, health insurance gaps and complementary therapies. Where the response was given in a dollar amount, it is listed below (Table 5.8, Figure 5.9).

The most common amount was between \$1 and \$150 (N=5, 38.46%). There were 2 participants (15.38%) that did not spend anything, and the same number that spent more than \$100 per month.

Burden of cost

As a follow up question, for participants that 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 4 participants (30.77%), somewhat significant for 1 participants (7.69%), and slightly or not at all significant for 8 participants (61.54%).

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

Estimated monthly out of pocket expenses	Number (n=13)	Percent
\$0	2	15.38
\$1 to \$150	5	38.46
>\$1000	2	15.38
Not sure/Not applicable	4	30.77

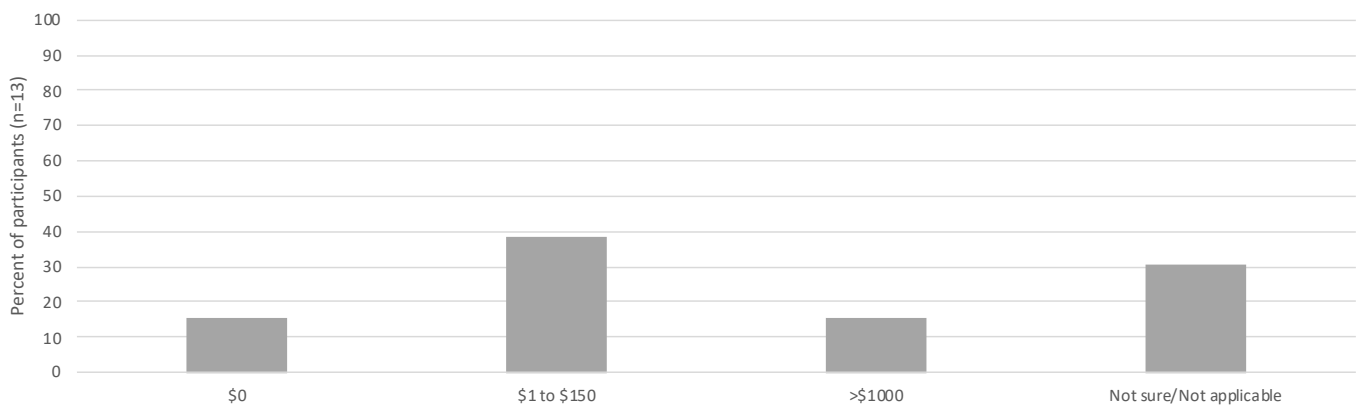


Figure 5.9: Estimated monthly out of pocket expenses due to condition

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

Burden of out of pocket expenses	Number (n=13)	Percent
Extremely significant	3	23.08
Moderately significant	1	7.69
Somewhat significant	1	7.69
Slightly significant	3	23.08
Not at all significant	5	38.46

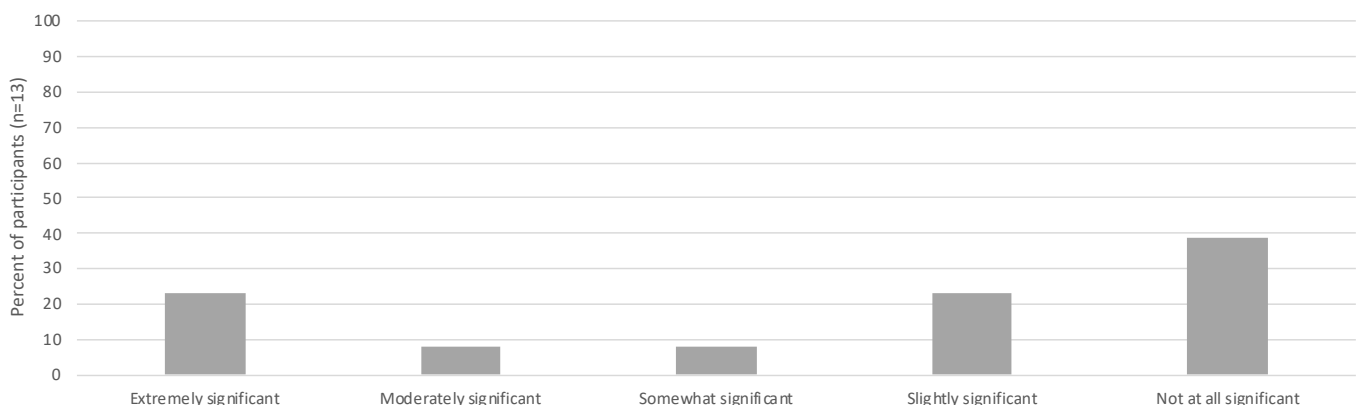


Figure 5.10: Burden of out-of-pocket expenses due to condition

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 3 participants (23.08%) had not changed since diagnosis, and 0 participants (0.00%) were retired or did not have a job. There was 1 participant (7.69%) had to quit their job, 5 participants (38.46%) reduced the number of hours they worked, and 2 participants (15.38%) that accessed their superannuation early. There were 2 participants (15.38%) that took leave from work without pay, and 3 participants (23.08%) that took leave from work with pay.

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 3 participants (23.08%), 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=6, 46.15%). There was 1 participant (7.69%) whose partner reduced the numbers of hours they worked, and 1 partner (7.69%) that quit their job. The partners of no partners of participants (0.00%) that took leave without pay, and there was 1 partner (7.69%) that took leave with pay.

Changes to carer/partner employment status

Table 5.10: Changes to employment status

Changes in work status due to condition	Number (n=13)	Percent
Work status has not changed	3	23.08
Retired or did not have a job	0	0.00
Had to quit job	1	7.69
Reduced number of hours worked	5	38.46
Leave from work without pay	2	15.38
Leave from work with pay	3	23.08
Accessed Superannuation early due to condition	2	15.38

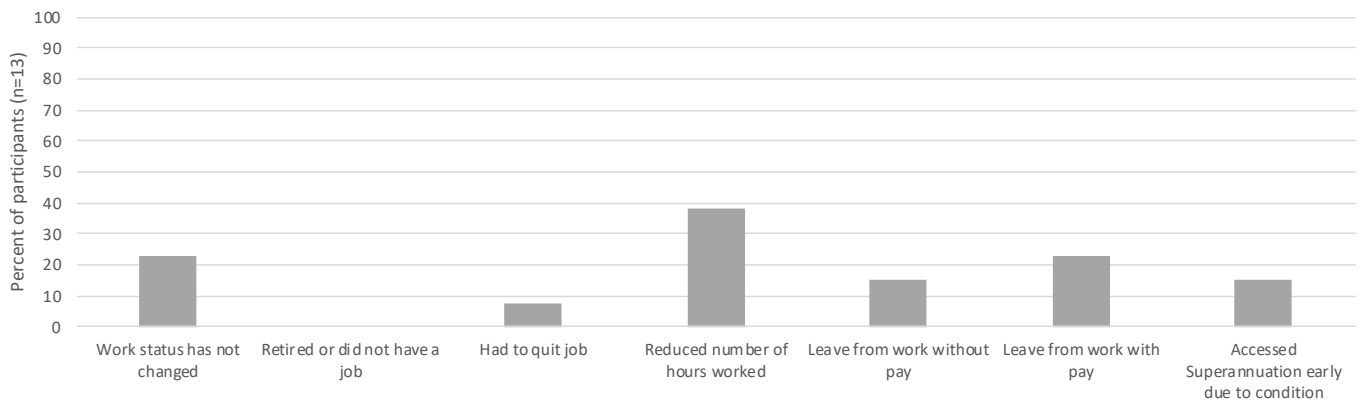


Figure 5.11: Changes to employment status

Table 5.11: Changes to care/partner employment status

Changes in partner or main carer work status due to condition	Number (n=13)	Percent
Does not have a partner/main carer	3	23.08
Work status has not changed	6	46.15
Retired or did not have a job	1	7.69
Had to quit job	1	7.69
Reduced number of hours worked	1	7.69
Leave from work without pay	0	0.00
Leave from work with pay	1	7.69

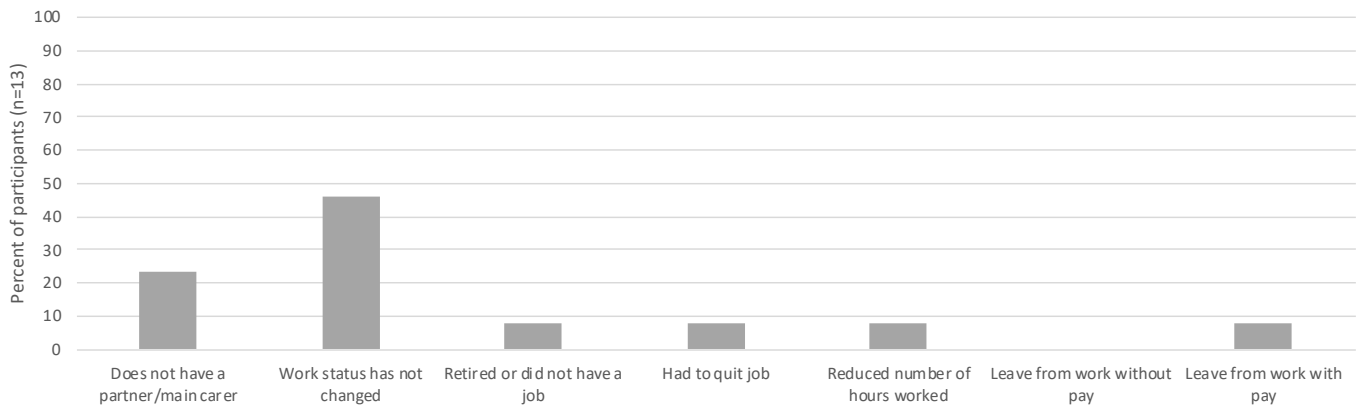


Figure 5.12: Changes to care/partner employment status

Reduced income due to condition

Almost a third of the participants (n=4, 30.77%) indicated in the online questionnaire that they had a reduced family income due to their condition.

As a follow up question, participants were asked if their family or household income had reduced due to their condition.

Estimated reduction monthly income

There were 4 participants (30.77%) with a reduced monthly income, and 9 participants (69.23%) with no reduced income.

Table 5.12: Monthly loss of income

Monthly loss of income	Number (n=13)	Percent
Income not reduced	9	69.23
Income reduced	4	30.77



Figure 5.13: Monthly loss of income

Summary of treatments and management

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

allied health. Participants used complementary therapy (n=5, 35.71%), made lifestyle changes (n=8, 57.14%). There was 1 participant (7.14%) that had no treatment, 1 participant (7.14%) that had a liver transplant.

The majority of participants had drug treatments (n=13, 92.86%), and 7 participants (50.00%) that used

Table 5.13: Summary of treatments and management

Treatments overview	Number (n=14)	Percent
Drug treatments	13	92.86
Liver transplant	1	7.14
Allied health	7	50.00
Complementary therapy	5	35.71
Lifestyle changes	8	57.14
Clinical trials	1	7.14
No treatment	1	7.14

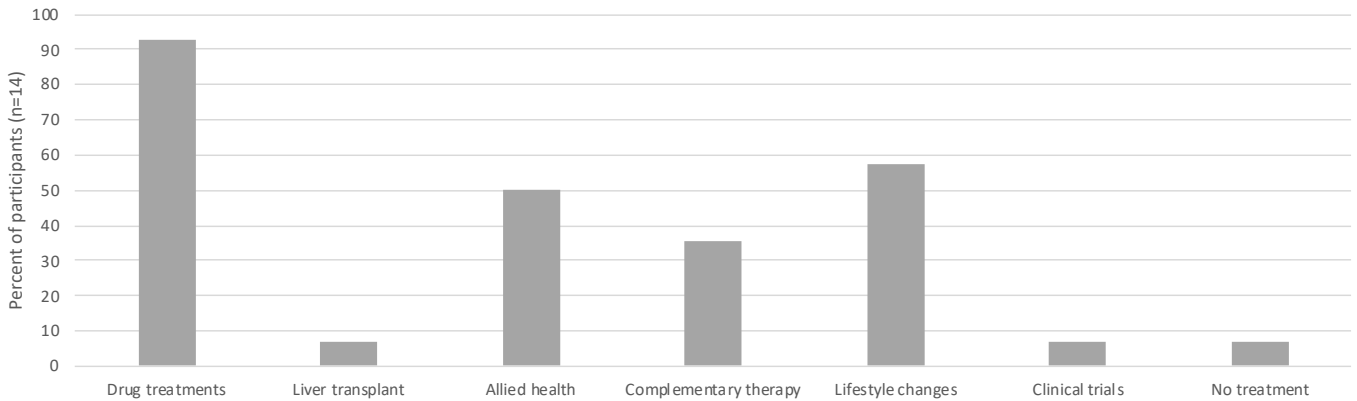


Figure 5.14: Summary of treatments and management

Summary of drug treatments

Participants completed a series of questions about drug therapies, including, quality of life, effectiveness of treatment, and side effects. .

The majority of participants had drug treatments (n=13, 92.86%). The most common types of drug treatments were Pegylated interferon alpha (Pegasys, Peg-Intron), (n=11, 78.57%), Entecavir (Baraclude) n=4,28.57%) and, Ribavirin (Ibavyr) (n=4,28.57%).

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

On average, quality of life from Pegylated interferon alpha (Pegasys, Peg-Intron) was in the 'life was distressing' range (median=2.00, IQR=1.00), and was found to be ineffective (median=1.00 , IQR=3.00).

Table 5.14: Overview of treatments reported

Drug treatments	Number (n=xx)	Percent
Pegylated interferon alpha (Pegasys, Peg-Intron)	11	78.57
Entecavir (Baraclude)	4	28.57
Ribavirin (Ibavyr)	4	28.57
Tenofovir (Viread)	4	28.57
Glecaprevir/pibrentasvir (Maviret)	1	7.14
Sofosbuvir/ Velpatasvir (Epclusa)	1	7.14

Table 5.15: Side effects from treatments

Pegylated interferon alpha (Pegasys, Peg-Intron)	Number (n=11)	Percent	Ribavirin (Ibavyr)	Number (n=4)	Percent	Tenofovir (Viread)	Number (n=4)	Percent	Entecavir (Baraclude)	Number (n=4)	Percent
Muscle or joint pain	10	90.91	Fatigue/weakness/lack of energy	4	100.00	Confusion/feeling light headed	2	50.00	Diarrhoea	1	25.00
Mood changes (such as depression/anxiety/irritability)	8	72.73	Irritation of eye or eye lid	2	50.00	Headache	1	25.00	Fatigue/weakness/lack of energy	1	25.00
Hair loss	7	63.64	Allergic reaction	1	25.00	No side effects	3	75.00	No side effects	2	50.00
Changes in eyesight	6	54.55	Sore joints	1	25.00						
Sleep problems (insomnia)	6	54.55	Brain-fog	1	25.00						
Confusion/feeling light headed	5	45.45	Anxiety	1	25.00						
Nausea	5	45.45	Breathing problems	1	25.00						
Allergic reaction	3	27.27	Cough	1	25.00						
Easy bruising or bleeding	1	9.09	Hair loss	1	25.00						
Lack of energy	1	9.09	Low blood count	1	25.00						
Weight loss	1	9.09									

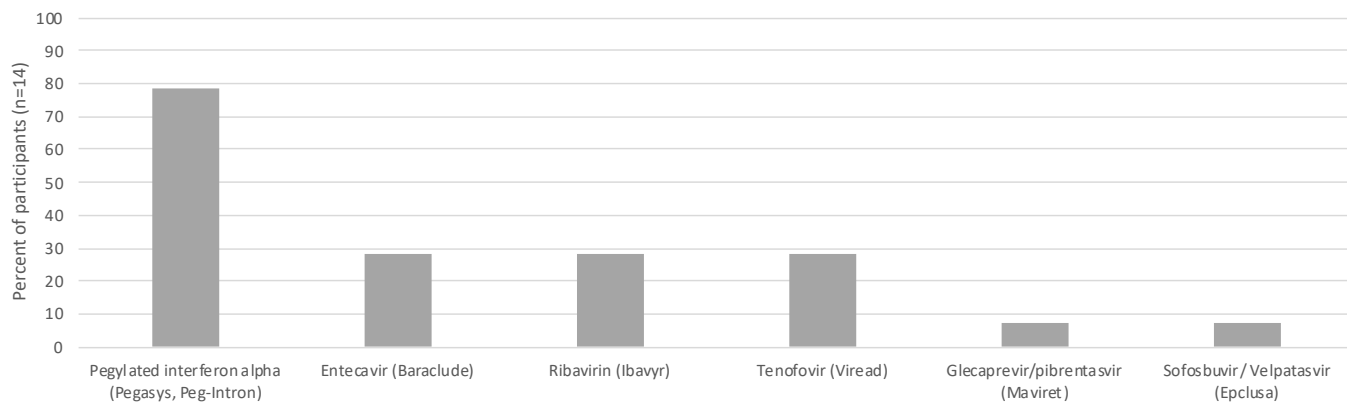


Figure 5.15: Overview of treatments reported

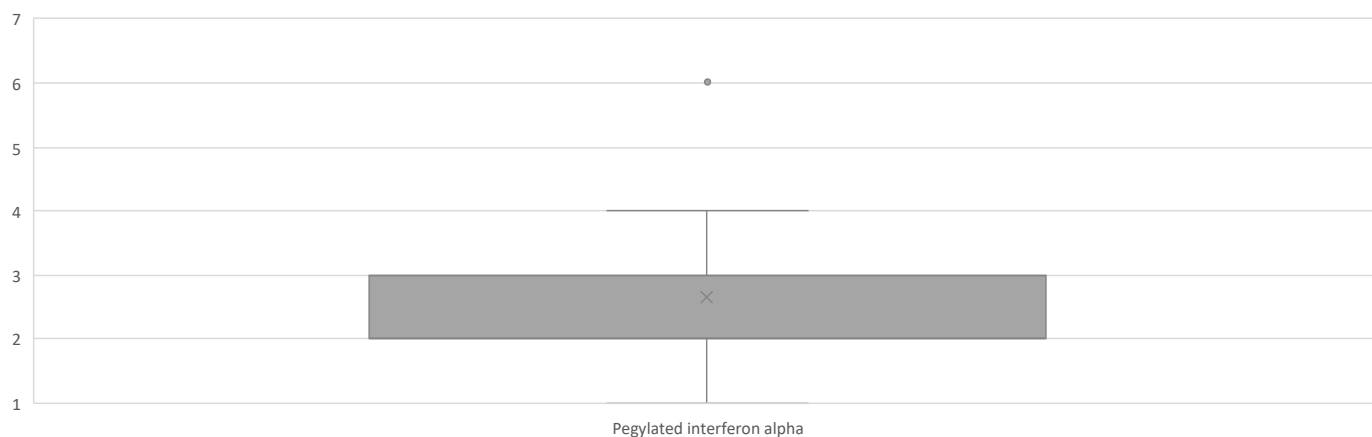


Figure 5.16: Quality of life from drug treatments (where complete data was available)



Figure 5.17: Effectiveness of drug treatments (where complete data was available)

Allied health

The most common allied health service used was psychology (n=4, 28.57%), followed by dietary (n=3, 21.43%), and social work (n=2, 14.29%). There were 1 participant (7.14%) that saw a physiotherapist , 1

participant (7.14%) that saw a podiatrist. No participants had speech therapy or occupational therapy.

Table 5.16: Allied health

Allied health	Number (n=14)	Percent
Psychologist	4	28.57
Dietician	3	21.43
Social worker	2	14.29
Physiotherapist	1	7.14
Podiatrist	1	7.14
Speech pathologist or speech therapist	0	0.00
Occupational therapy	0	0.00

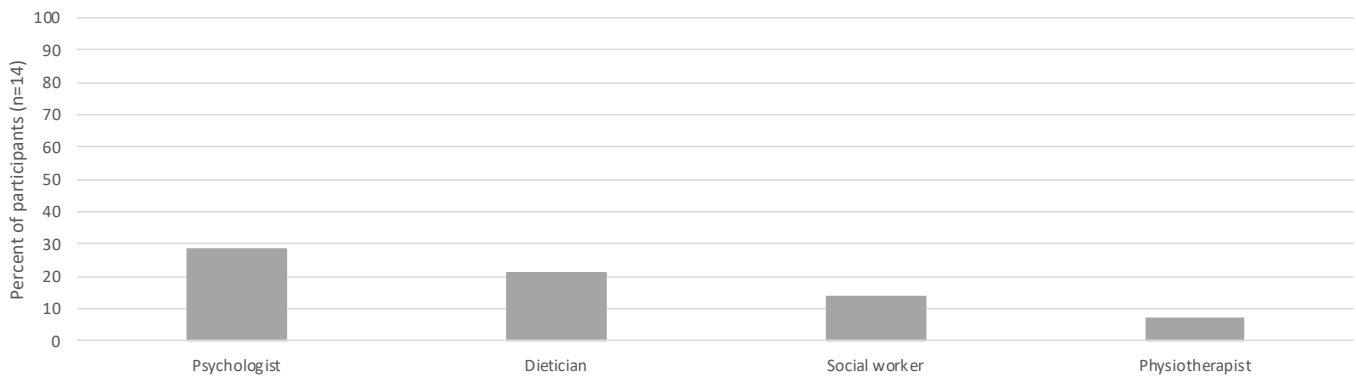


Figure 5.18: Allied health

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.

Most participants used at made at least one lifestyle change (n=8, 57.14%).

The most common lifestyle change used was diet changes (n=7, 50.00%), followed by reducing or quitting alcohol (n=6, 42.86%), and exercise (n=4, 28.57%).

On average, quality of life from diet changes was in the 'life was average' range (median=4.00, IQR=2.00), and was found to be moderately (median=3.00, IQR=1.50).

On average, quality of life from reducing or quitting alcohol was in the 'life was average' range (median=4.00, IQR=1.50), and was found to be very effective (median=5.00, IQR=0.75).

Table 5.17: Lifestyle changes

Lifestyle changes	Number (n=14)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Diet	7	50.00	4.00	2.00	3.00	1.50
Reduce or quit alcohol	6	42.86	4.00	1.50	5.00	0.75
Exercise	4	28.57	NA	NA	NA	NA
Quit smoking	2	14.29	NA	NA	NA	NA

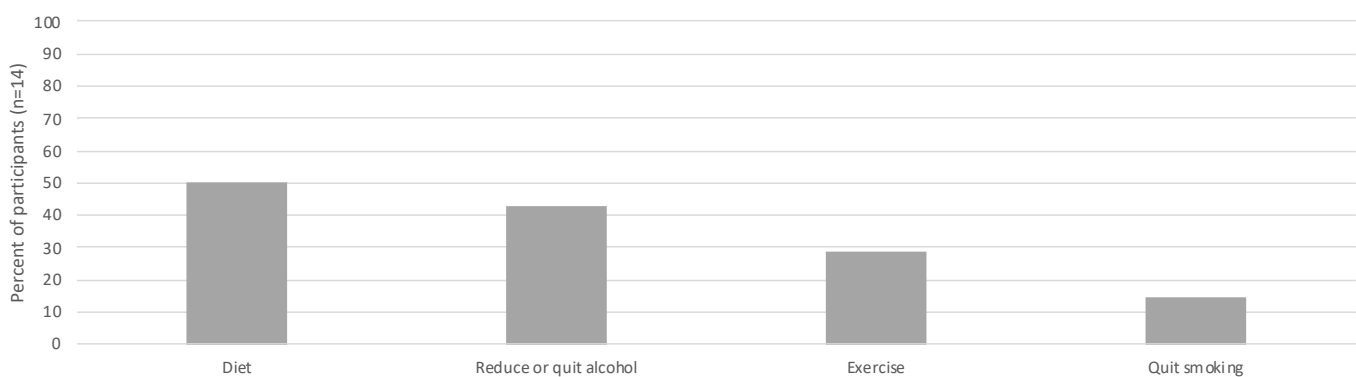


Figure 5.19: Lifestyle changes

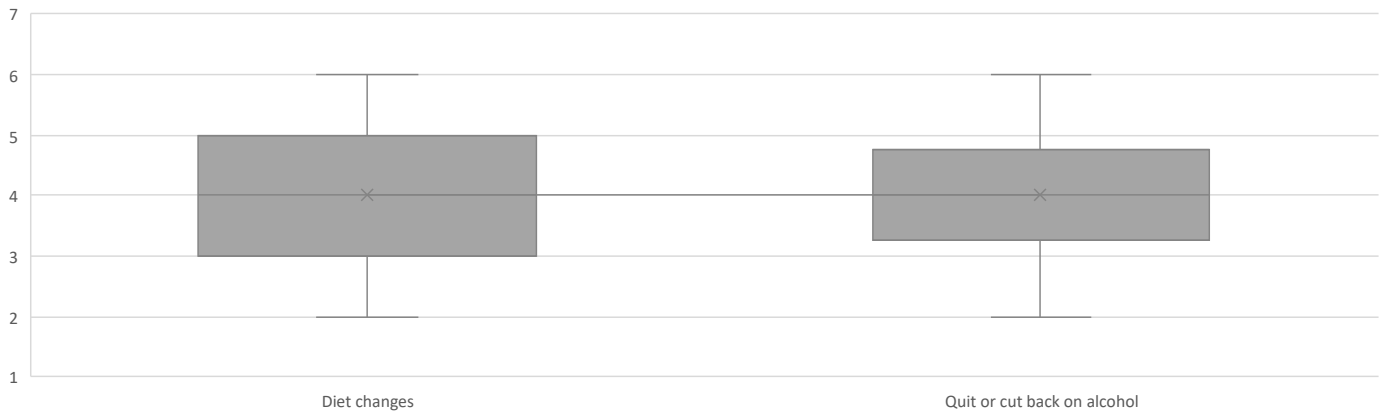


Figure 5.20: Quality of life from lifestyle changes

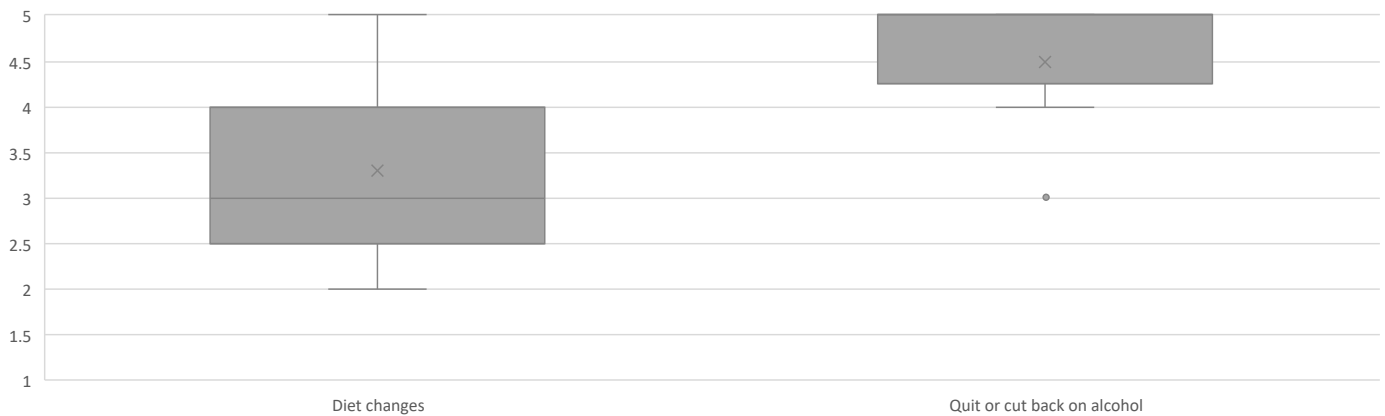


Figure 5.21: Effectiveness from lifestyle changes

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.

The most common complementary therapy used was , massage therapy (n=4, 28.57%), followed by mindfulness or relaxation (n=4, 28.57%), and supplements (n=3, 21.43%).

Approximately a third of participants used at least one complementary therapy (n=5, 35.71%)

Table 5.18: Complementary therapies

Complementary therapies	Number (n=14)	Percent
Massage therapy	4	28.57
Mindfulness or relaxation techniques	4	28.57
Acupuncture	3	21.43
Supplements	1	7.14
Naturopath	1	7.14
Homeopathy	0	0.00

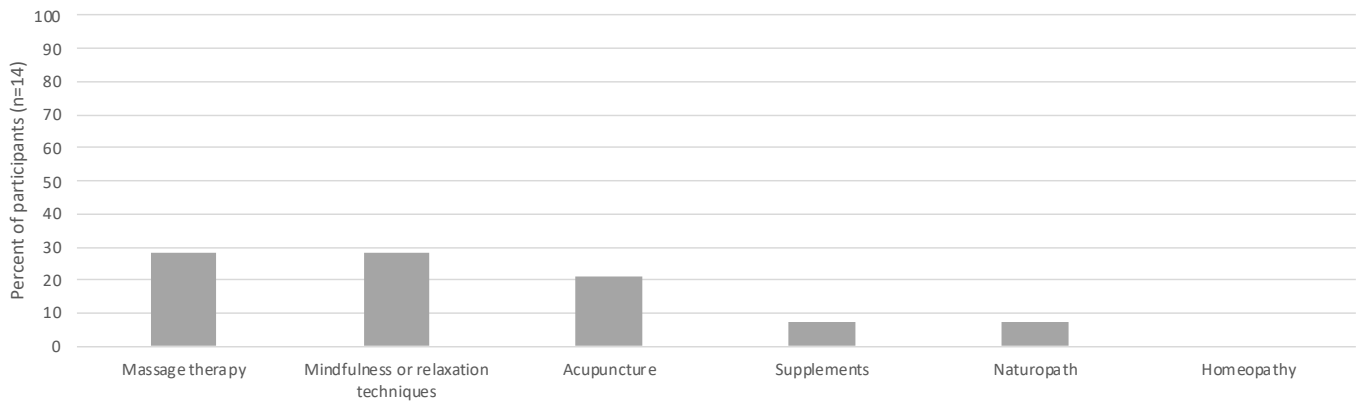


Figure 5.22: Complementary therapies

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 8 participants (57.14%) that had discussions about clinical trials, 3 participants (21.43%) had brought up the topic with their doctor, and the doctor of 5 participants (35.71%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=6, 42.86%).

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 (7.14%) that had taken part in a clinical trial, 10 participants (71.43%) that would like to take part in a clinical trial if there was a suitable one, and 3 participants, that have not participated in a clinical trial and do not want to (21.43%).

Table 5.19: Clinical trial discussions

Clinical trial discussions	Number (n=14)	Percent
Participant brought up the topic of clinical trials doctor for discussion	3	21.43
Doctor brought up the topic of clinical trials for discussion	5	35.71
Participant has ever spoken to me about clinical trials	6	42.86

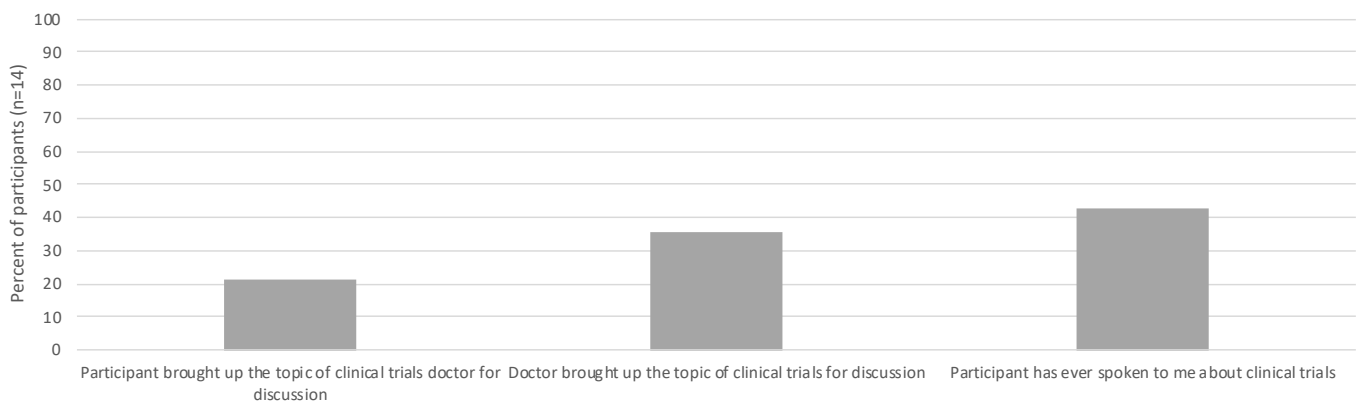


Figure 5.23: Clinical trial discussions

Table 5.20: Clinical trial participation

Clinical trial participation	Number (n=14)	Percent
Has not participated in a clinical trial and does not want to	3	21.43
Has not participated in a clinical trial but would like to if there is one	10	71.43
Has participated in a clinical trial	1	7.14

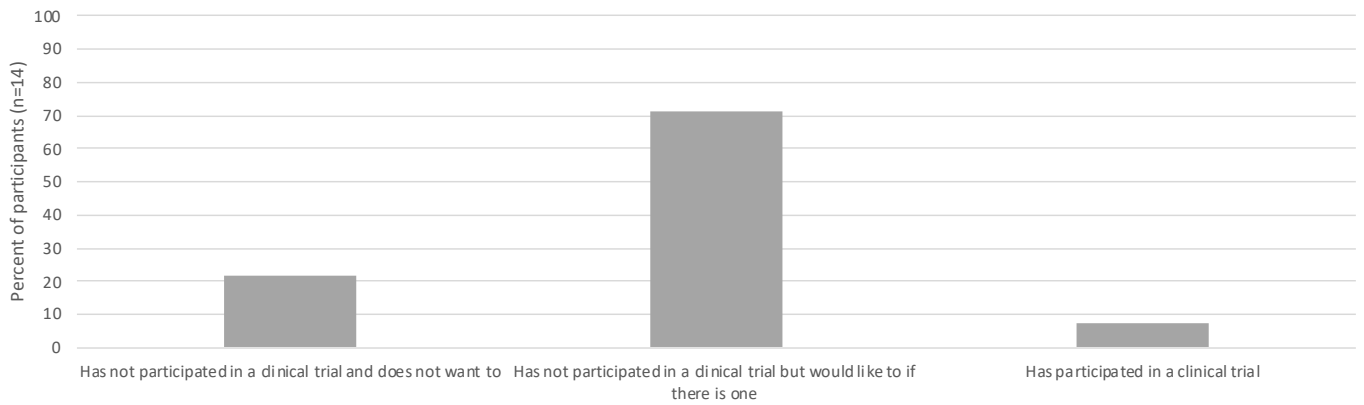


Figure 5.24: Clinical trial participation

Description of mild side effects

In the structured interview, participants were asked how they would describe the term 'mild side effects'. The most common descriptions of mild side effects were those that do not interfere with life (50.00%), and they described mild side effects using a specific example (50.00%). Other themes included those that can be managed with self-medication or self-management (8.33%), and those that resolve in short time (8.33%).

When a specific side effect was described, the most common responses were headaches (16.67%), and skin itch or rash (16.67%). Other themes included aches and pain (8.33%), emotional or mental impact (8.33%), gastrointestinal distress (8.33%), lightheadedness or being dizzy (8.33%), nausea or loss of appetite (8.33%), heavy periods and low blood iron (8.33%), and low immunity (8.33%).

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

Something that was a minor inconvenience. Slight diarrhea, something like that, not something that would keep you in the house, right?
Participant 007_2023AUHDV

Participant provides a specific side effect as an example

Minor side effects may be purely some physical discomfort, such as headache and dizziness. Those are so scary, if they hit it, that is, for example, it may

already affect the normal? Do things, that is, those in daily life, such as possible. Get up, even if it is already affected, well, if it is serious, you may not be able to fall into bed at all. Participant 008_2023AUHDV

Well, you know, like I said, I had a I had a sort of dull headache and I didn't feel the need to take anything. And then one night I had a more severe headache. But I just took two Panadol and I was fine and increased my water. So I drank a lot of water and I didn't have any severe.
Participant 010_2023AUHDV

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

So like you know you break out and I don't know you're a rash or something and that's like you you know for sure that that's come from the medication and it's not just you know some you know an allergic reaction or something else.
Participant 011_2023AUHDV

Participant describes mild side effects as those that resolve in a short time

I would say mild side effects would be as a result of, you know, taking this drugs and it's upset something. Maybe there's some changes in your system which as a result of a reaction to the drugs which you've taken and this is just temporary which will go away.
Participant 006_2023AUHDV

Table 5.21: Description of mild side effects

Description of mild side effects	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes mild side effects as those that do not interfere with daily life	6	50.00	1	16.67	5	83.33	3	37.50	3	75.00	3	50.00	3	50.00	1	100.00	5	45.45	1	100.00	5	45.45
Participant provides a specific side effect as an example	6	50.00	4	66.67	2	33.33	3	37.50	3	75.00	4	66.67	2	33.33	1	100.00	5	45.45	1	100.00	5	45.45
Participants reports not experiencing any mild side effects	2	16.67	2	33.33	0	0.00	2	25.00	0	0.00	1	16.67	1	16.67	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes mild side effects as those that can be self-managed	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes mild side effects as those that resolve in a short time	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09

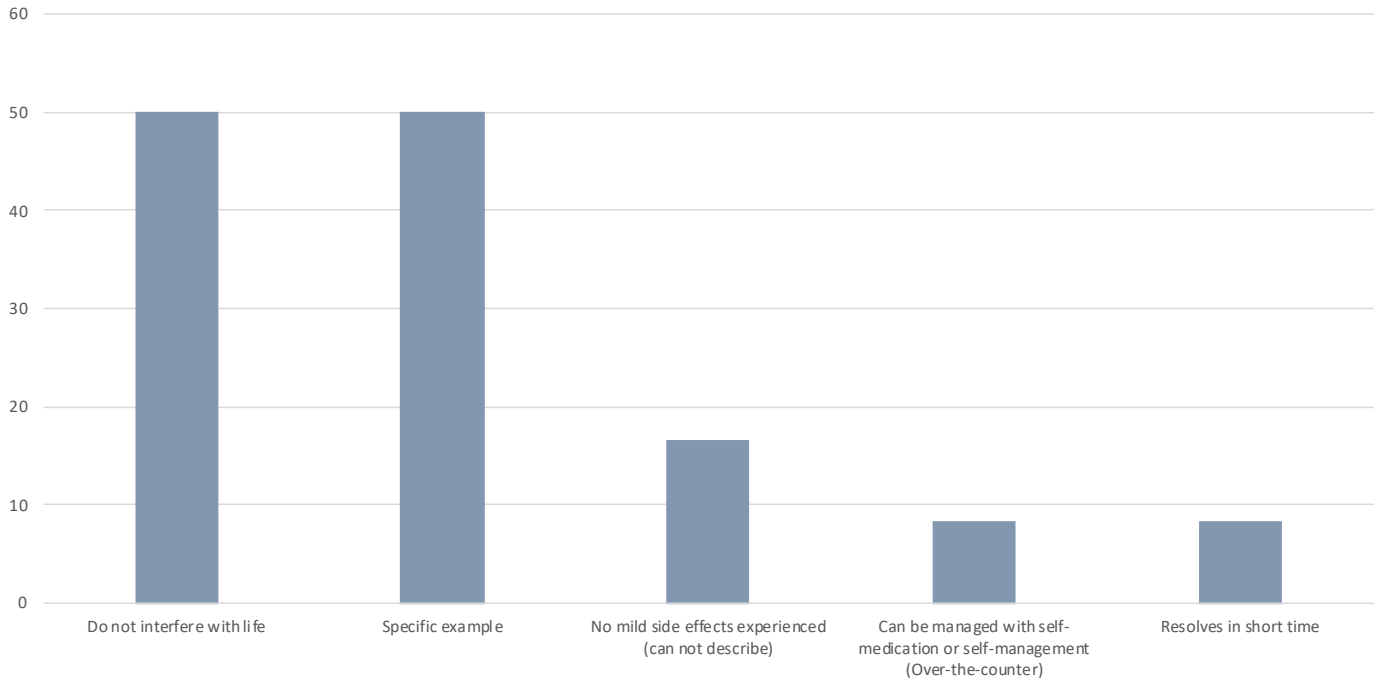


Figure 5.25: Description of mild side effects

Table 5.22: Description of mild side effects – subgroup variations

Description of mild side effects	Reported less frequently		Reported more frequently	
	Female Aged 18 to 44	Male Aged 18 to 44 University	Male Aged 45 and older	Female Aged 45 and older Trade or high school
Participant describes mild side effects as those that do not interfere with daily life				
Participant provides a specific side effect as an example				

Table 5.23: Description of mild side effects (Specific side effects)

Description of mild side effects (Specific side effects)	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes mild side effects giving the specific example of headaches	2	16.67	2	33.33	0	0.00	0	0.00	2	50.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes mild side effects giving the specific example of a skin itch or rash	2	16.67	0	0.00	2	33.33	2	25.00	0	0.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes mild side effects giving the specific example of aches/pain (general)	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes mild side effects giving the specific example of emotion/mental impact	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes mild side effects giving the specific example of gastrointestinal distress	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Participant describes mild side effects giving the specific example of lightheaded and/or dizzy	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes mild side effects giving the specific example of nausea or loss of appetite	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes mild side effects giving the specific example of having a heavy period or low blood iron	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes mild side effects giving the specific example low immunity	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09

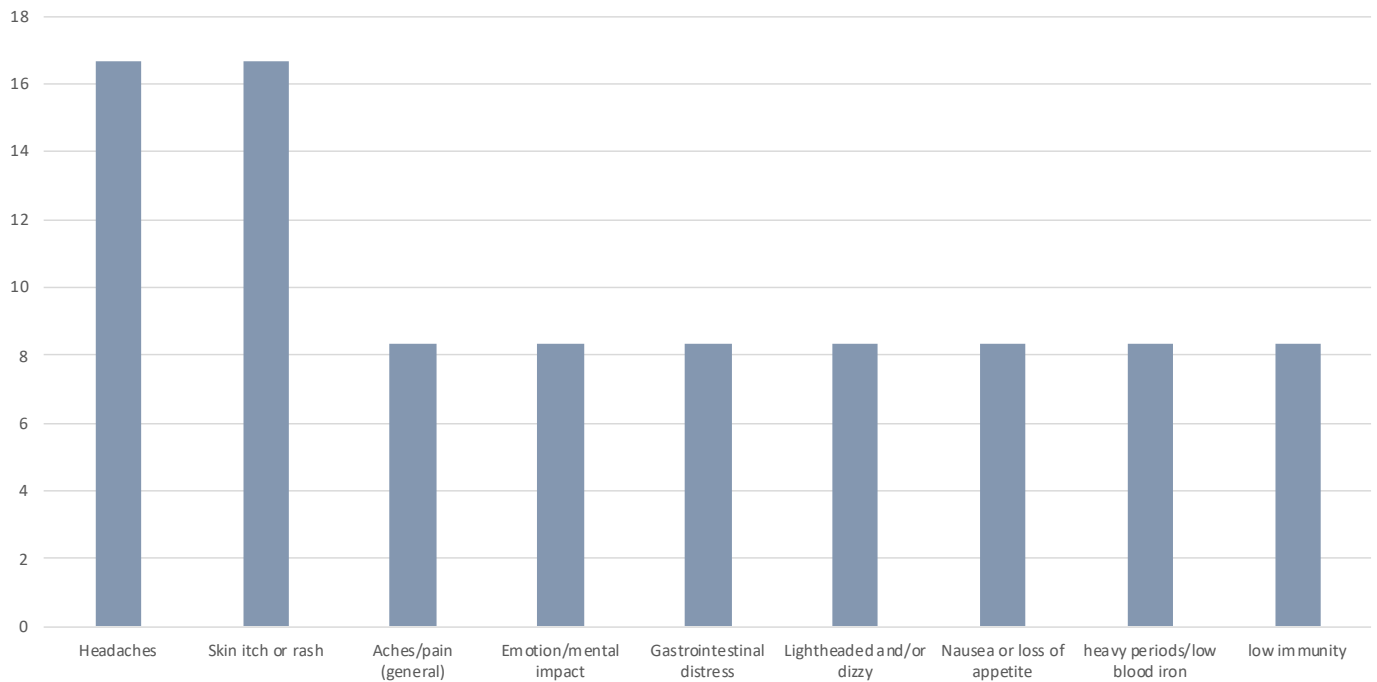


Figure 5.26: Description of mild side effects (Specific side effects)

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 those that impact everyday life or ability to conduct activities of daily living (16.67%), described using a specific example (16.67%), and that the treatment is worse than condition (16.67%). Other themes included those that are life threatening or result in hospitalisation (8.33%), those that cause long-term damage to their body (8.33%), those that requires medical intervention (8.33%), and those that impact their everyday life by being bed ridden (8.33%).

When a specific side effect was described, the examples were aches and pain (8.33%), and emotional and mental impact (8.33%), fatigue and lethargy (8.33%), and allergic reaction (8.33%).

Participant describes severe side effects as when treatment is worse than the condition

*Severe side effects of medication would be something that makes it even worse.
Participant 004_2023AUHDV*

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

*Worst case scenario, allergy and an ambulance.
Participant 007_2023AUHDV*

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

Participant describes those that cause long-term damage to their body

*So yeah, where it's where it's, it's having a negative and again fairly like noticeable, measurable and immediate or long term impact on your quality of life. So it's, you know, it's it's it's having a negative impact. That's in terms of your mental health, in terms of pain and discomfort, in terms of the potential to cause other medical problems, that's what I'd call severe side effects.
Participant 011_2023AUHDV*

Table 5.24: Description of severe side effects

Description of severe side effects	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participants reported not experiencing any severe side effects	3	25.00	3	50.00	0	0.00	2	25.00	1	25.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	2	16.67	0	0.00	2	33.33	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant provides a specific side effect as an example	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes severe side effects as when treatment is worse than the condition	2	16.67	1	16.67	1	16.67	2	25.00	0	0.00	0	0.00	2	33.33	0	0.00	2	18.18	0	0.00	2	18.18
Participant describes severe side effects as those that are life threatening or result in hospitalisation	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Participant describes severe side effects as those that cause long-term damage to their body	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant identifies severe side effects as requiring medical intervention	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant identifies severe side effects as impacting their everyday life by being bed ridden	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Other description/No response	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09

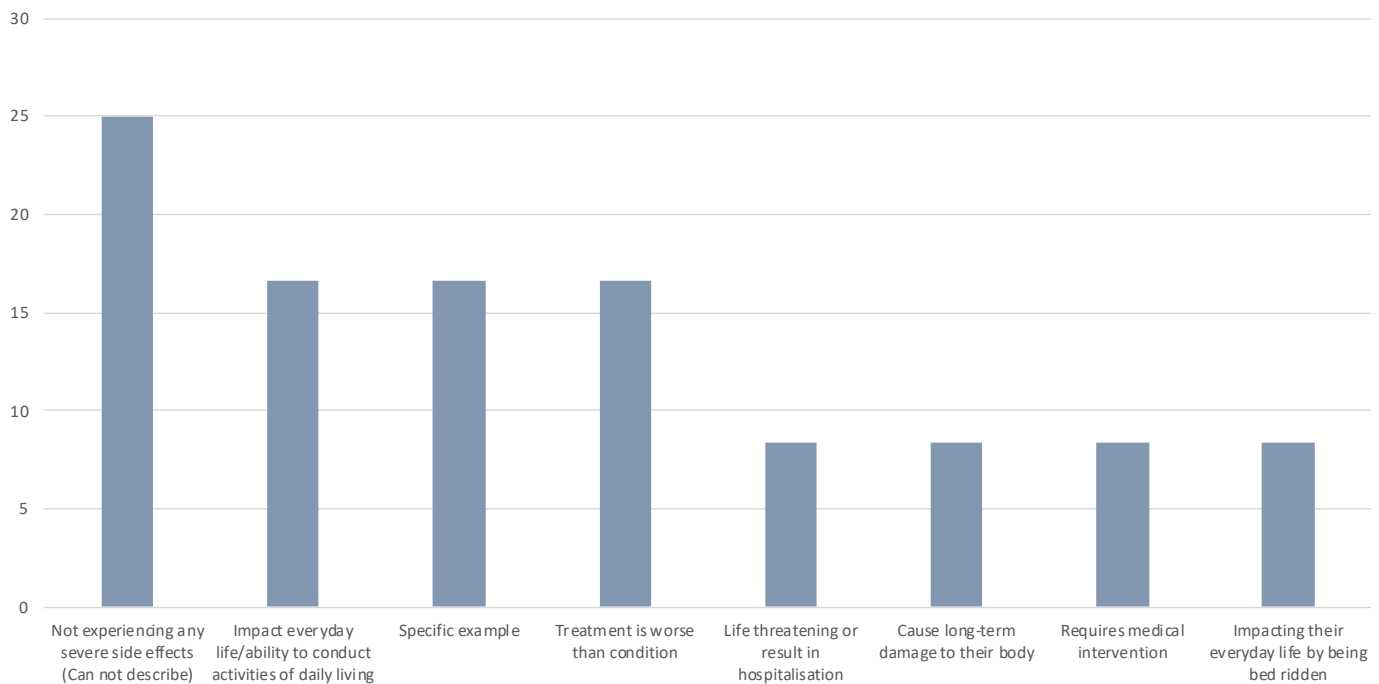


Figure 5.27: Description of severe side effects

Table 5.25: Description of severe side effects (Specific example)

Description of severe side effects (Specific side effects)	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes severe side effects giving the specific example of aches/pain (general)	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes severe side effects giving the specific example of emotion/mental impact	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes severe side effects giving the specific example of fatigue/lethargy	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes severe side effects giving the specific example of allergic reaction	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00

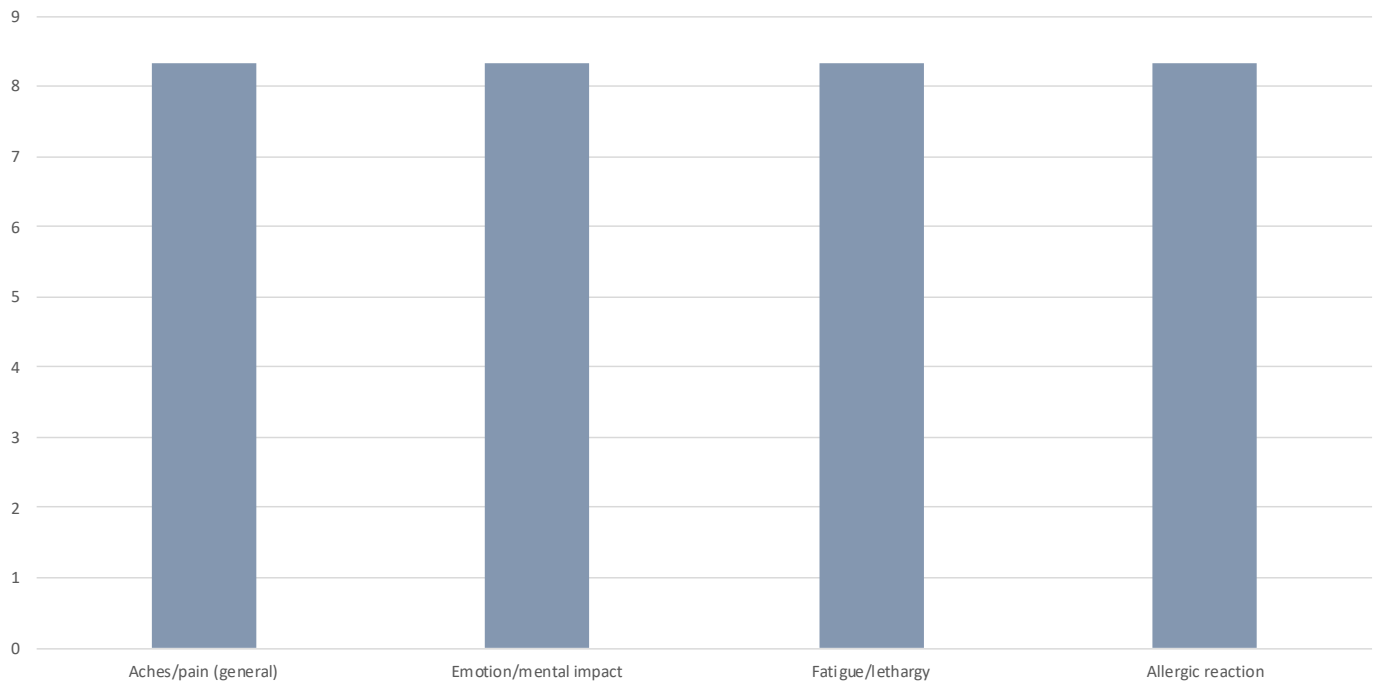


Figure 5.28: Description of severe side effects (Specific example)

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 according to the advice of their specialist or as long as prescribed (58.33%), needing to see test results/no evidence or reduction of disease (33.33%), and adhering to treatment as long as side effects are tolerable (16.67%).

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

Well, if there's any new treatment, so I'll stick to it till my doctor says I have to stop it. So it's just based on my doctor.

Participant 006_2023AUHDV

Participant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment

I think what helps is the regular blood tests of monitoring the levels of what is happening with my body.

Participant 004_2023AUHDV

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

Well, I'm not that kind of person. If I get a if I get a a treatment and I'm told to take it from the beginning to the end, I take it until it's finished. I never, I never stop unless unless it's giving me a severe side effect which really makes me ill, then I take it till it's finished.

Participant 010_2023AUHDV

Table 5.26: Adherence to treatment

Adherence to treatment	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	7	58.33	3	50.00	4	66.67	4	50.00	3	75.00	3	50.00	4	66.67	1	100.00	6	54.55	1	100.00	6	54.55
Participant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	4	33.33	2	33.33	2	33.33	2	25.00	2	50.00	1	16.67	3	50.00	1	100.00	3	27.27	1	100.00	3	27.27
Participant describes adhering to treatment as long as side effects are tolerable	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	2	33.33	0	0.00	0	0.00	2	18.18	0	0.00	2	18.18
Participant is unable to answer because they have not had treatment and/or cannot answer hypothetical question	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Other/No response	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09

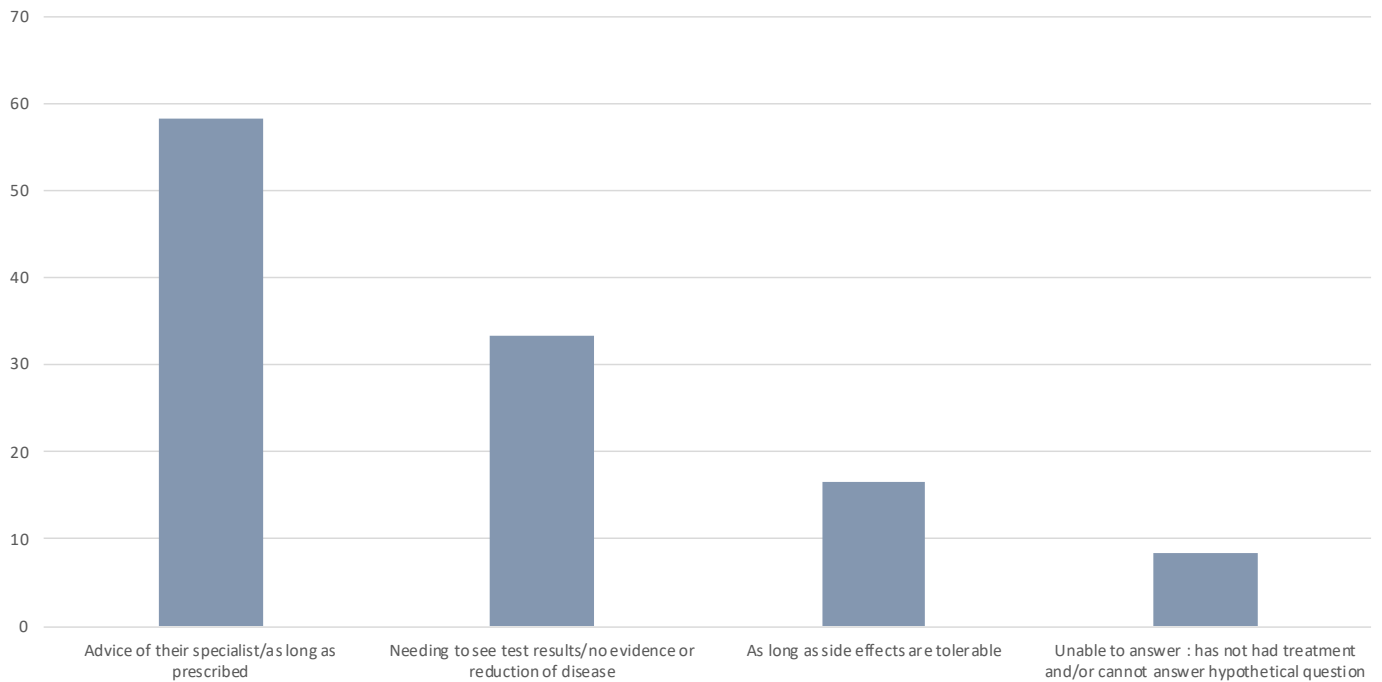


Figure 5.29: Adherence to treatment

Table 5.27: Adherence to treatment – subgroup variations

Adherence to treatment	Reported less frequently	Reported more frequently
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	-	Aged 45 and older
Participant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	Trade or high school	Aged 45 and older University

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 physical signs and symptoms disappear/reduce side effects (25.00%), needing to see evidence of stable disease or no disease progression (16.67%), and needing to see a specific symptom reduction (8.33%).

When a specific side effect or symptom was described, they were aches and pain (16.67%), cognitive difficulties (8.33%), fatigue and lethargy (8.33%), and night sweats (8.33%).

Participants reported needing to see all physical signs and symptoms disappear

Well, I, I have, I have to experience a reduction in pains and a reduction in the symptoms that counts for me. If this is if this has been experienced when I take a part time medication, then I know that for sure it's it's working for me.
Participant 006_2023AUHDV

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

As long as my mark is the same, I'm happy because long ago we came to realization my markers aren't going to improve, so as long as they're holding, I'm quite happy... so once they start to drop, that's when I'll start to get in a bit of a panic with doctors.
Participant 007_2023AUHDV

I think you just need to see some level of results and sometimes I think the blood test results are just a stronger indication of how I'm feeling day-to-day to attribute that. So I think the monitoring of the actual condition and knowing that, you know, when you do do my blood test, you are looking for viral load, you're looking for all the other impacts.
Participant 004_2023AUHDV

Table 5.28: What needs to change to feel like treatment is working

What needs to change to feel like treatment is working	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participants reported needing to see all physical signs and symptoms disappear	3	25.00	1	16.67	2	33.33	2	25.00	1	25.00	2	33.33	1	16.67	0	0.00	3	27.27	0	0.00	3	27.27
Participants reported needing to experience evidence of stable disease/no disease progression	2	16.67	1	16.67	1	16.67	1	12.50	1	25.00	0	0.00	2	33.33	1	100.00	1	9.09	1	100.00	1	9.09
Participant describes needing to see a reduction in a specific symptom	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes not having had any treatments that worked	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Other\No response	5	41.67	4	66.67	1	16.67	4	50.00	1	25.00	3	50.00	2	33.33	0	0.00	5	45.45	0	0.00	5	45.45

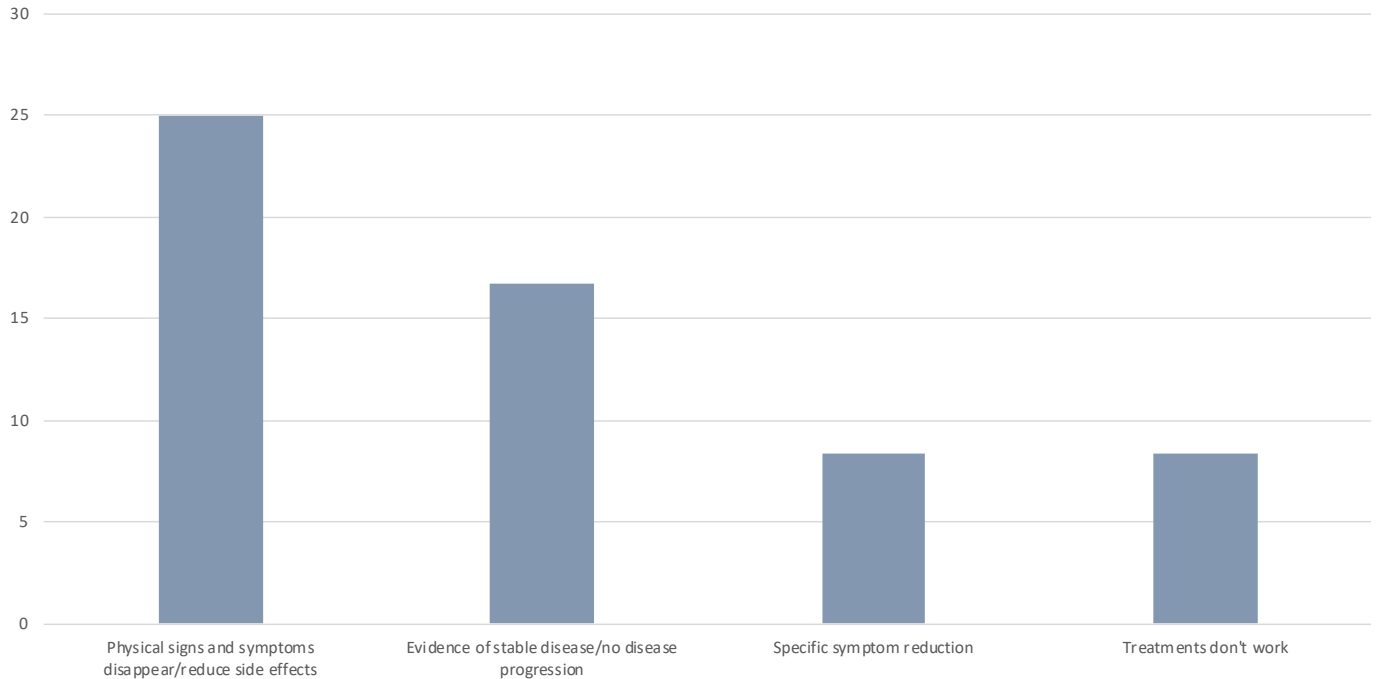


Figure 5.30: What needs to change to feel like treatment is working

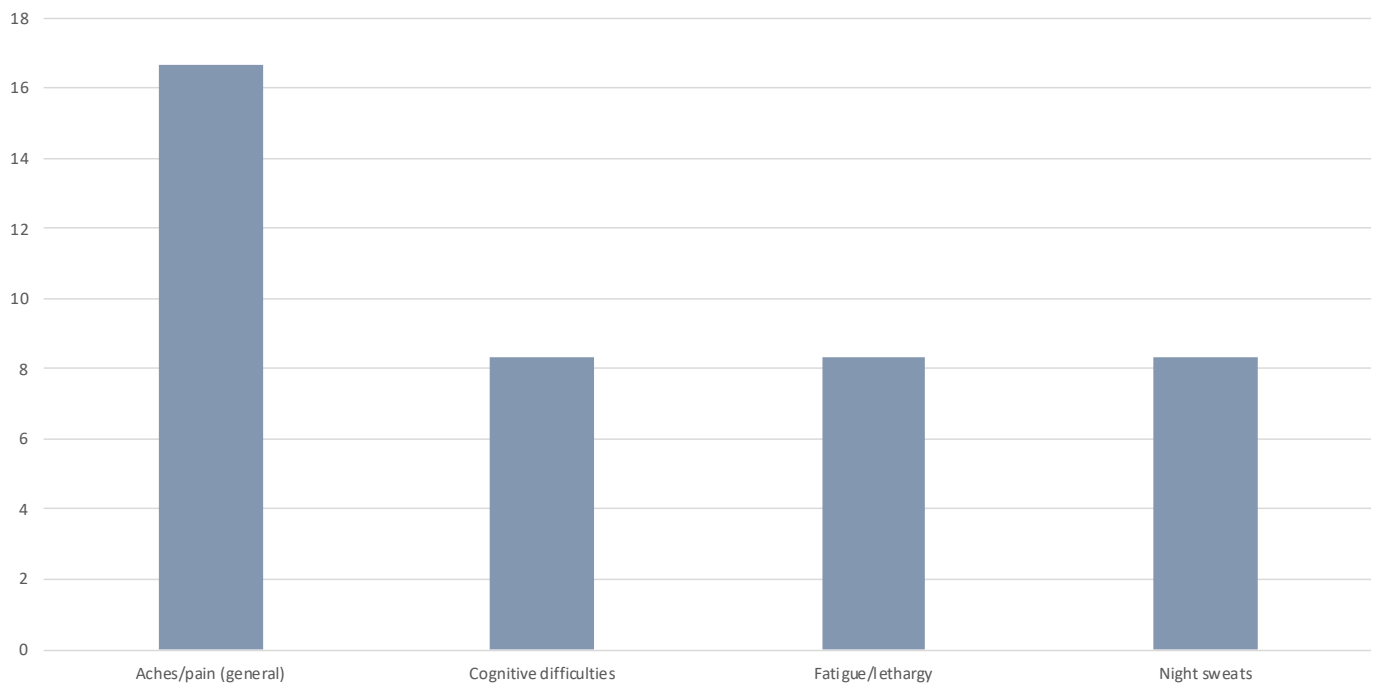


Figure 5.31: What needs to change to feel like treatment is working – specific symptoms

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/return to normal life (33.33%), and have a positive impact on their mental health (25.00%). Other themes included lead to a reduction in symptoms and side effects (8.33%), less medical interventions, doctor visits, or hospitalisation (8.33%), and a longer life (8.33%).

Participant describes that if treatment worked, it would allow them to do everyday activities/return to normal life

Rest me, I would actually feel alive again and I would feel invincible and I would also feel that I have actually broken out of the virus and and then that I could actually go ahead and do whatever I want to do.
Participant 009_2023AUHDV

It's going to give me more energy. I won't have Brian Fog, I won't have aching limbs. I won't have night sweats. I'm, you know, I'm going to be a much more productive member of society and to my family.
Participant 011_2023AUHDV

Participant describes that if treatment worked, it would have a positive impact on their mental health

Well, it's it to be a very beautiful, you know, after experience for me to realize that the medication or drugs given is working because I know I'll be able to chat freely they the psychological stress that comes with, you know, having to bear in mind of this is quite heavy ... every space in my thinking and everything. So I think to bring about a good a high degree of enough relief to me.

Participant 006_2023AUHDV

Participant describes that condition has not had an impact on their life

I've been fortunate in that I've I've maintained my energy levels, I'm still social. I get out and about, I can do things.

Participant 007_2023AUHDV

Table 5.29: What needit would mean if treatment worked

What it would mean if treatment worked	All participants		Female		Male		Aged 18 to 44		Aged 45 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=12	%	n=6	%	n=6	%	n=8	%	n=4	%	n=6	%	n=6	%	n=1	%	n=11	%	n=1	%	n=11	%
Participant describes that if treatment worked, it would allow them to do everyday activities/return to normal life	4	33.33	2	33.33	2	33.33	3	37.50	1	25.00	3	50.00	1	16.67	0	0.00	4	36.36	0	0.00	4	36.36
Participant describes that if treatment worked, it would have a positive impact on their mental health	3	25.00	0	0.00	3	50.00	2	25.00	1	25.00	1	16.67	2	33.33	0	0.00	3	27.27	0	0.00	3	27.27
Participant describes that if treatment worked, it would lead to a reduction in symptoms/side effects	1	8.33	1	16.67	0	0.00	0	0.00	1	25.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes that if treatment worked, it would lead to less medical interventions/doctor visits/hospitalisation	1	8.33	1	16.67	0	0.00	1	12.50	0	0.00	0	0.00	1	16.67	0	0.00	1	9.09	0	0.00	1	9.09
Participant describes that condition has not had an impact on their life	1	8.33	0	0.00	1	16.67	0	0.00	1	25.00	0	0.00	1	16.67	1	100.00	0	0.00	1	100.00	0	0.00
Participant describes that if treatment worked, it would allow them to live longer	1	8.33	0	0.00	1	16.67	1	12.50	0	0.00	1	16.67	0	0.00	0	0.00	1	9.09	0	0.00	1	9.09
Other\No response	4	33.33	3	50.00	1	16.67	3	37.50	1	25.00	2	33.33	2	33.33	0	0.00	4	36.36	0	0.00	4	36.36

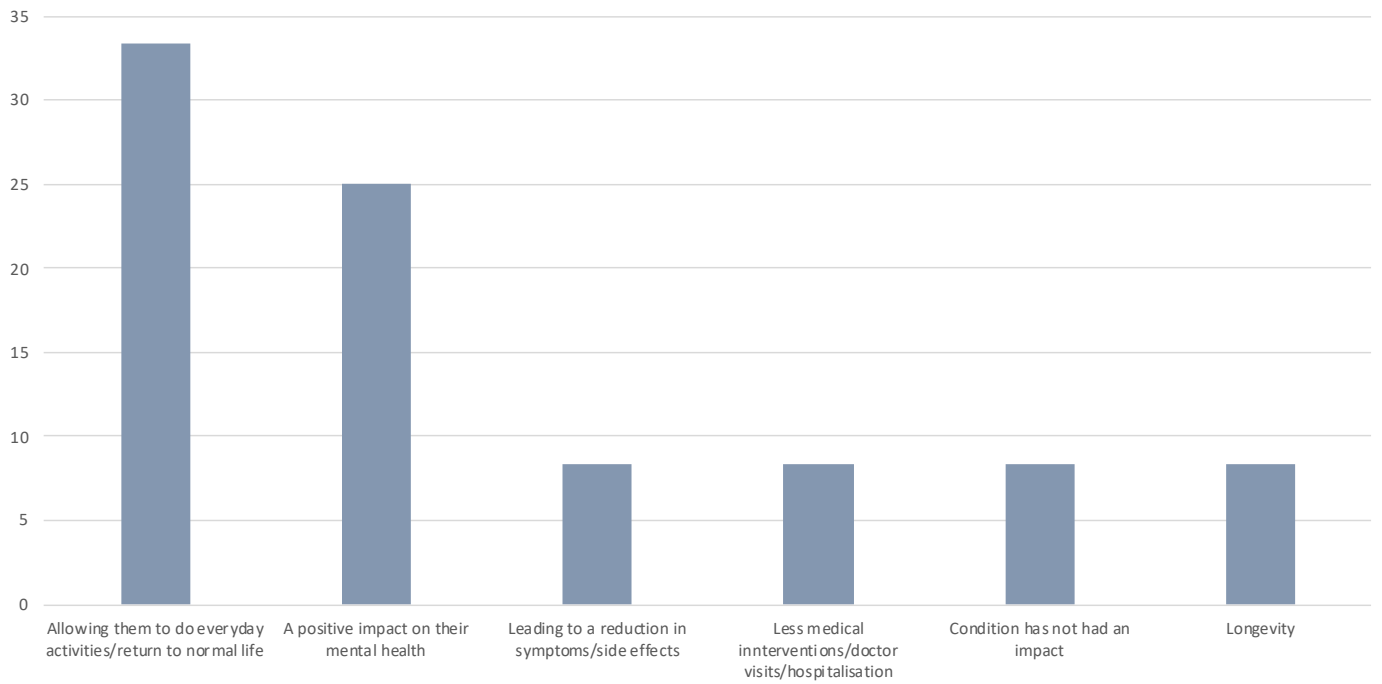


Figure 5.32: What need it would mean if treatment worked

What it would mean if treatment worked	Reported less frequently	Reported more frequently
Participant describes that if treatment worked, it would allow them to do everyday activities/return to normal life	University	Trade or high school