

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 haematologists (n=26,76.47 %), followed by general practitioners (GPs) (n=4, 11.76%).

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 (20.69%) that travelled for less than 15 minutes, 12 participants (41.38%) that travelled between 15 and 30 minutes, 6 participants (20.69%) that travelled between 30 and 60 minutes, 1 participants (3.45%) that travelled between 60 and 90 minutes, and 4 participants (13.79%) that travelled more than 90 minutes.

Access to healthcare professionals

All participants had access to a haematologist (n=36, 100.00%), and almost a third had a medical oncologist (n=11, 30.56%), and a radiation oncologist (n=11, 30.56%).

Almost all participants had access to a general practitioner (GP) (n=34, 94.44%), and more than half had access to a chemotherapy nurse (n=21, 58.33%) There were 16 participants (44.44%) that had a registered nurse and 12 participants (33.33%) that had a nurse care coordinator.

Participants noted allied health professionals that treated them for blood cancer, most commonly physiotherapists (n=14, 38.89%), dieticians, counselling or psychological support, and social workers.

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 22 participants (75.86%) that indicated that they had been treated with respect throughout their experience, and 7 participants (24.14%) that were treated with respect with the exception of one or two occasions.

Health care system

The majority of participants had private health insurance (n=23, 67.65%). The majority of participants were asked if they wanted to be treated as a public or private patient (n=20, 58.82%), and they were asked if they had private health insurance (n=27, 79.41%).

Throughout their treatment, there were 5 participants (14.71%) that were treated as a private patient, 21 participants (61.76%) were mostly treated as a public patient, and there were 6 participants (17.65%) that were equally treated as a private and public patient.

Throughout their treatment, there were 3 participants (8.82%) that were treated mostly in the private hospital system, 27 participants (79.41%) were mostly treated in the public system, and there were 4 participants (11.76%) 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 cancel healthcare appointments because they were unable to afford them. All participants never or rarely had to delay or cancel appointments due to affordability (n = 34, 100.00%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=33, 97.06%).

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 between \$51 to 100 (n=4, 11.76%), followed by between \$101 to 250 (n=7, 20.59%). There were 2 participants (5.88%), that spent \$501 to 1000 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 8 participants (23.53%), somewhat significant for 6 participants (17.65%), and slightly or not at all significant for 20 participants (58.82%).

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 (8.82%) had not changed since diagnosis, and 7 participants (20.59%) were retired or did not have a job. There were 11 participants (32.35%) had to quit their job, 7 participants (20.59%) reduced the number of hours they worked, and 6 participants (17.65%) accessed their superannuation early. There were 9 participants (26.47%) that took leave from work without pay, and 6 participants (17.65%) 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 their employment status due to their condition. Participants were able to choose multiple changes to employment.

Work status for 3 participants (8.82%) had not changed since diagnosis, and 7 participants (20.59%) were retired or did not have a job. There were 11 participants (32.35%) had to quit their job, 7 participants (20.59%) reduced the number of hours they worked, and 6 participants (17.65%) accessed their superannuation early. There were 9 participants (26.47%) that took leave from work without pay, and 6 participants (17.65%) 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 8 participants (23.53%), 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=3, 8.82%). There were 6 participants (17.65%)

whose partners reduced the numbers of hours they worked, and 3 partners, (8.82%) that quit their job. The partners of 9 participants (26.47%) took leave without pay, and there were 4 partners (11.76%) that took leave with pay.

Reduced income due to condition

Half of the participants (n=17, 50.00%) indicated in the online questionnaire that they had a reduced family income due to their condition.

Estimated reduction monthly income

Most commonly, participants were not sure about the amount their monthly income was reduced by (n=7, 20.59%), or monthly income was reduced by between \$101 to 250 per month (n=7, 20.59%).

Burden of reduced income

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

For 6 of these participants (25.00%), the burden of this reduced income was extremely or moderately significant, for 7 participants (29.17%) the burden was somewhat significant, and for 11 participants (45.83%) the burden was slightly or not all significant.

Summary of 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.

The most common types of treatments were stem cell transplants, (n=25, 71.43%), radiotherapy (n=13,37.14%), maintenance chemotherapy (n=10,28.57%), CAR T-cell therapy (n=8, 22.86%), Lenalidomide and dexamethasone (n=7, 20.00%), Zoledronic acid (n=7, 20.00%), CyBorD (Cyclophosphamide, bortezomib, dexamethasone) (n=6, 17.14%), R-CHOP (rituximab cyclophosphamide, doxorubicin, vincristine and prednisolone) (n=5, 14.29%), and Blood and platelet transfusions (n=5, 14.29%).

Participants reported having CVAD plus Imatinib: (Imatinib, Vincristine, Doxorubicin, Dexamethasone , Cytarabine, Methotrexate, and Cyclophosphamide) (n=2), or were not sure of the type (n=2) as induction therapy.

Participants reported having ALL06: Vincristine, Doxorubicin, Dexamethasone, Cytarabine, Pegaspargase, Mercaptopurine, Methotrexate, Cyclophosphamide, and Thioguanine (n=1), or were not sure of the type (n=2) as consolidation therapy.

Participants reported having Lenalidomide (n=7), CALGB: Prednisone, Vincristine, Mercaptopurine and Methotrexate (n=1) or were not sure of the type (n=2) as maintenance therapy.

Allied health

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

Most participants used at least one type of allied health service (n=22, 64.71%), and on average used 1 service (median=1.00, IQR=2.00).

The most common allied health service used was physiotherapy (n=14, 41.18%), followed by dietary (n=11, 32.35%), and psychology/counselling (n=7, 20.59%). There were 7 participants (20.59%) that saw a social worker, 4 participants (11.76%) that saw a podiatrist, and 2 participants (5.88%) that saw an occupational therapist.

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=29, 85.29%), and on average made 2 changes (median=2.00, IQR=2.00).

The most common lifestyle change was exercise (n=22, 64.71%), followed by diet changes (n=17, 50.00%), and reducing or cutting out alcohol (n=17, 50.00%).

Complementary therapies

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

Most participants used at made at least one complementary therapy (n=17, 50.00%), and on average used 0.5 therapies (median=0.50, IQR=2.00).

The most common complementary therapy used was Mindfulness or relaxation techniques (n=12, 35.29%), followed by Massage therapy (n=8, 23.53%), and Supplements (n=7, 20.59%).

Clinical trials discussions

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

There was a total of 17 participants (50%) that had discussions about clinical trials, 5 participants (14.71%) had brought up the topic with their doctor, and the doctor of 12 participants (35.29%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=17, 50.00%).

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 were 7 participants (20.59%) that had taken part in a clinical trial, 24 participants (70.59%) 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 (8.82%).

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 (69.70%), those that do not interfere with life(30.30%), and those that can be managed with self-medication or self-management (9.09%).

When a specific side effect was described, the most common responses were aches and pain in general (18.18%), and fatigue or lethargy (18.18%). Other themes included gastrointestinal distress (15.15%), headaches (15.15%), nausea or loss of appetite (12.12%), and neuropathy (9.09%).

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 (78.79%), and those that requires medical intervention (30.30%). Other themes included those that impact everyday life or ability to conduct activities of daily living (15.15%), and those that impact their everyday life by being bed ridden (9.09%).

When a specific side effect was described, the most common examples were nausea or loss of appetite (30.30%), aches and pain in general (24.24%), and fatigue or lethargy (15.15 %). Other themes included gastrointestinal distress (12.12%), emotional or mental impact (9.09%), impact on sleep (9.09%), neuropathy (9.09%), and swelling from fluid build up including lymphoedema (9.09%).

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 (75.76%), and never giving up on any treatment (39.39%). Other themes included adhering to treatment as long as side effects are tolerable (12.12%), needing to see test results/no evidence or reduction of disease (12.12%), adhering to treatment as long as treatment is working (9.09%), and adhering to treatment for a specific amount of time (9.09%).

When participants stated a specific amount of time to adhere to a treatment, the amount of time specified was one month (3.03%), six to twelve months (3.03%), and six to twelve months (3.03 %).

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 evidence of stable disease or no disease progression (39.39%), and needing to see physical signs and symptoms disappear or reduced side effects (33.33%). Other themes included needing to see a specific symptom reduction (27.27%), and needing to see a return to day-to-day functionality (15.15%).

When a specific side effect or symptom was described, the most common examples were aches and pain in general (12.12%), and fatigue or lethargy (12.12%).

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 (42.42%), and that it would have a positive impact on their mental health (24.24%). Other themes included allowing them to do more exercise (18.18%), allowing them to return to work (12.12%), and allowing them to engage more with social activities and family life (12.12%).

Main provider 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 haematologists (n=26, 76.47%), followed by general practitioners (GPs) (n=4, 11.76%).

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 (20.69%) that travelled for less than 15 minutes, 12 participants (41.38%) that travelled between 15 and 30 minutes, 6 participants (20.69%) that travelled between 30 and 60 minutes, 1 participant (3.45%) that travelled between 60 and 90 minutes, and 4 participants (13.79%) that travelled more than 90 minutes.

Table 5.1: Main provider of treatment

Main provider of treatment	Number (n=34)	Percent
Haematologist	26	76.47
General practitioner (GP)	4	11.76
Oncologist	2	5.88
Other	2	5.88

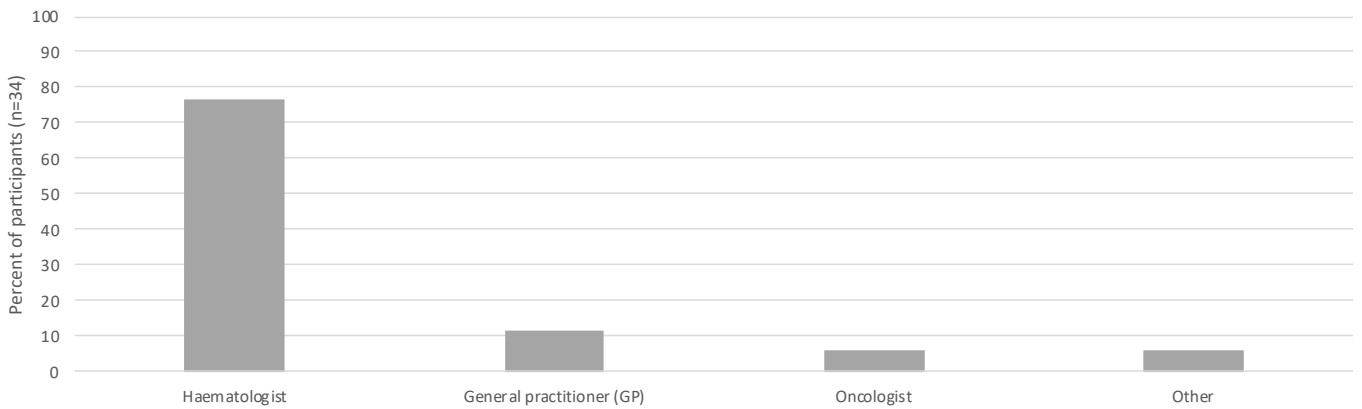


Figure 5.1: Main provider of treatment

Table 5.2: Time to travel to main provider of treatment

Time to travel to main provider of treatment	Number (n=29)	Percent
Less than 15 minutes	6	20.69
Between 15 and 30 minutes	12	41.38
Between 30 and 60 minutes	6	20.69
Between 60 and 90 minutes	1	3.45
More than 90 minutes	4	13.79

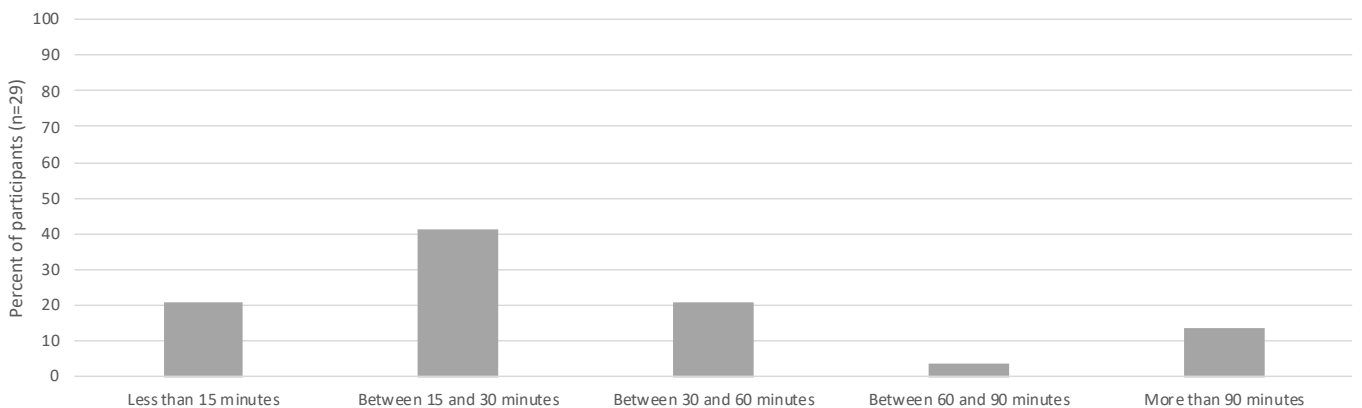


Figure 5.2: Time to travel to main provider of treatment

Access to healthcare professionals

All participants had access to a haematologist (n=36, 100.00%), and almost a third had a medical oncologist (n=11, 30.56%), and a radiation oncologist (n=11, 30.56%).

Almost all participants had access to a general practitioner (GP) (n=34, 94.44%), and more than half had access to a chemotherapy nurse (n=21, 58.33%) There were 16 participants (44.44%) that had a

registered nurse and 12 participants (33.33%) that had a nurse care coordinator.

Participants noted allied health professionals that treated them for blood cancer, most commonly physiotherapists (n=14, 38.89%), dieticians, counselling or psychological support, and social workers.

Table 5.3: Access to healthcare professionals

Healthcare professional	Number (n=36)	Percent
Haematologist	36	100.00
Medical Oncologist	11	30.56
Radiation Oncologist	11	30.56
Cardiologist	2	5.56
Respiratory Physician	1	2.78
Surgeon	1	2.78
General Practitioner (GP)	34	94.44
Chemotherapy nurse	21	58.33
Registered Nurse	16	44.44
Nurse Care Coordinator	12	33.33
Haematology nurse	6	16.67
Community nurse	5	13.89
Physiotherapist	14	38.89
Dietician	11	30.56
Counselling or psychological support	11	30.56
Social worker	7	19.44
Pharmacist	6	16.67
Cancer care coordinator, discharge planner or key worker	4	11.11
Occupational therapist	4	11.11
Exercise Physiologist	2	5.56
Chiropractor	1	2.78
Weight loss specialist	1	2.78

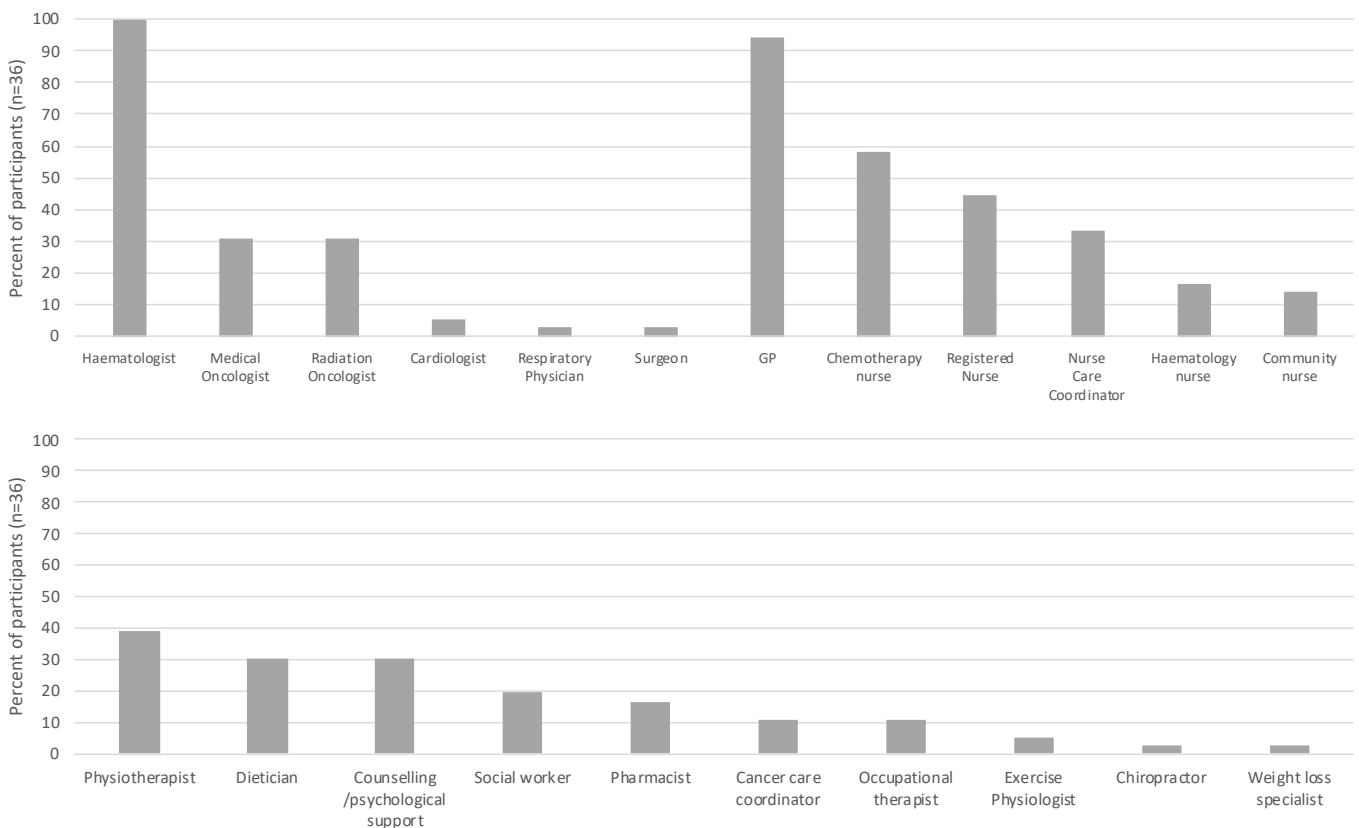


Figure 5.3: Access to healthcare professionals

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 22 participants (75.86%) that indicated that they had been treated with respect throughout their experience, and 7 participants (24.14%) that were treated with respect with the exception of one or two occasions.

Table 5.4: Respect shown

Respect shown	Number (n=29)	Percent
Yes	22	75.86
Yes, with the exception of one or two occasions	7	24.14
No	0	0.00

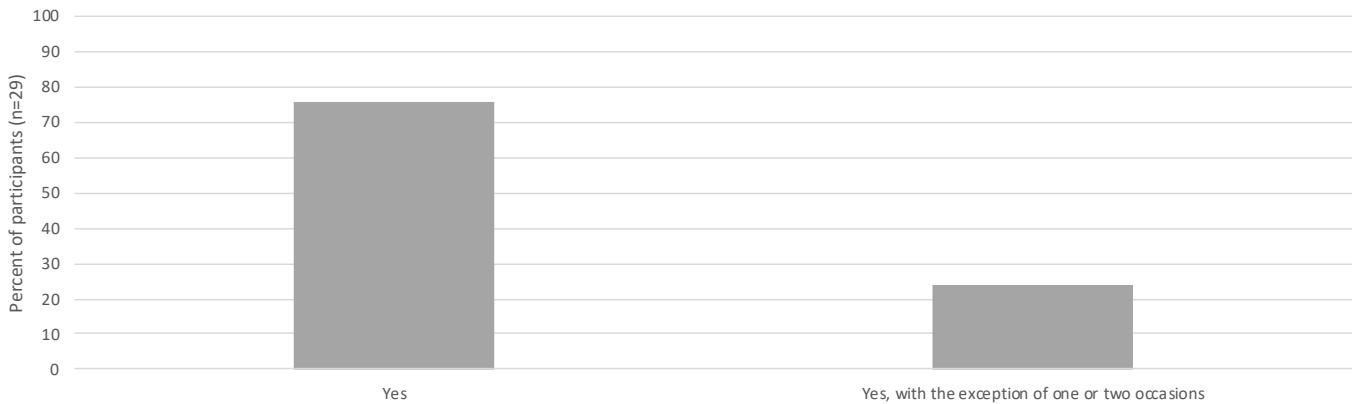


Figure 5.4: Respect shown

Health care system

The majority of participants had private health insurance (n=23, 67.65%). The majority of participants were asked if they wanted to be treated as a public or private patient (n=20, 58.82%), and they were asked if they had private health insurance (n=27, 79.41%).

Throughout their treatment, there were 5 participants (14.71%) that were treated as a private patient, 21 participants (61.76%) were mostly treated as a public

patient, and there were 6 participants (17.65%) that were equally treated as a private and public patient.

Throughout their treatment, there were 3 participants (8.82%) that were treated mostly in the private hospital system, 27 participants (79.41%) were mostly treated in the public system, and there were 4 participants (11.76%) that were equally treated in the private and public systems.

Table 5.5: Health care system

Health care system	Response	Number (n=34)	Percent
Private health insurance	No	11	32.35
	Yes	23	67.65
Asked whether you want to be treated as a public or private patient	No	14	41.18
	Yes	20	58.82
Asked whether you had private health insurance	No	7	20.59
	Yes	27	79.41
Throughout your treatment in hospital, have you most been treated as a public or a private patient	Equally as a public and private patient	6	17.65
	Private patient	5	14.71
	Public patient	21	61.76
	Not sure	2	5.88
Which hospital system have you primarily been treated in	Both public and private	4	11.76
	Private	3	8.82
	Public patient	27	79.41
	Not sure	0	0.00

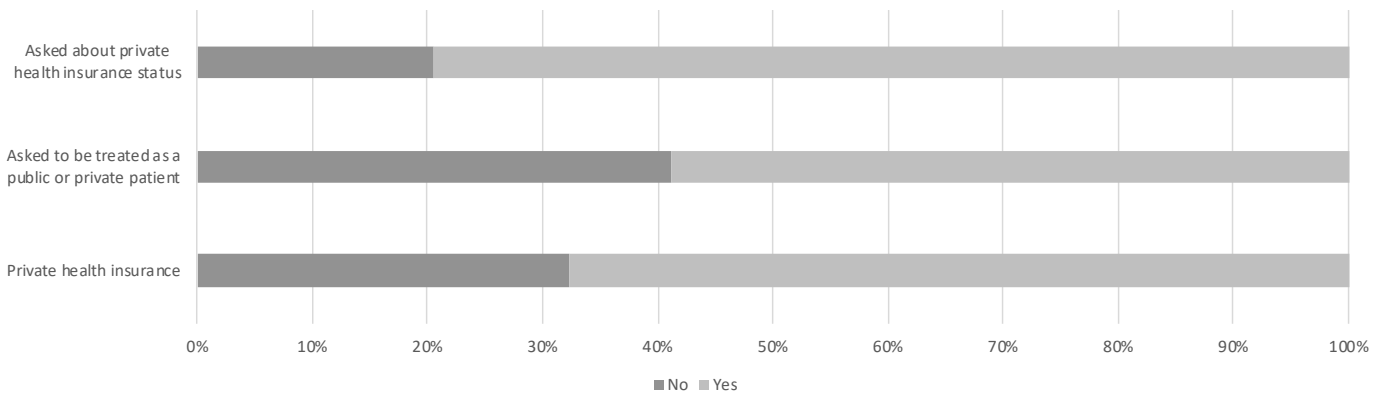


Figure 5.5: Health insurance

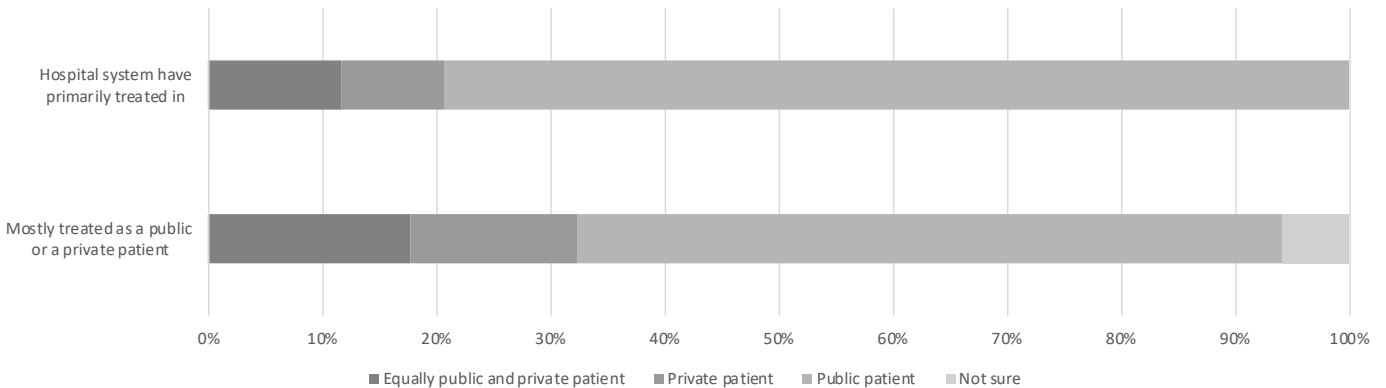


Figure 5.6: Hospital system

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 cancel healthcare appointments because they were unable to afford them. All participants never or rarely had to delay or cancel appointments due to affordability (n = 34, 100.00%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=33, 97.06%).

The third question was about the affordability of basic essentials such as food, housing and power. There were 26 participants (76.47%) that never or rarely had trouble paying for essentials, and 6 participants (17.65%) that sometimes found it difficult, and 2 participants (5.88%) 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 4 participants (11.76%) that paid for additional carers due to their condition.

Table 5.6: Affordability of healthcare

Affordability of healthcare	Response	Number (n=34)	Percent
Delay or cancel healthcare appointments due to affordability	Never	29	85.29
	Rarely	5	14.71
	Sometimes	0	0.00
	Often	0	0.00
	Very often	0	0.00
Did not fill prescriptions due to cost	Never	29	85.29
	Rarely	4	11.76
	Sometimes	1	2.94
	Often	0	0.00
	Very often	0	0.00
Difficult to pay for basic essentials	Never	23	67.65
	Rarely	3	8.82
	Sometimes	6	17.65
	Often	0	0.00
	Very often	2	5.88
Pay for additional carers for self or family	Yes	4	11.76
	No	30	88.24

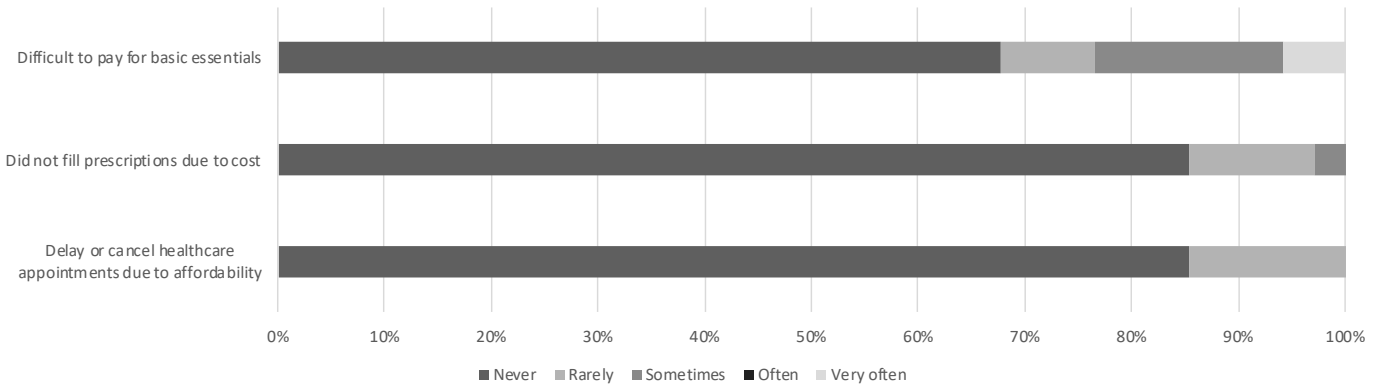


Figure 5.7: Affordability of healthcare

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 between \$51 to 100 (n=4, 11.76%), followed by between \$101 to 250 (n=7, 20.59%). There were 2 participants (5.88%), that spent \$501 to 1000 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 8 participants (23.53%), somewhat significant for 6 participants (17.65%), and slightly or not at all significant for 20 participants (58.82%).

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

Estimated monthly out of pocket expenses	Number (n=34)	Percent
0	2	5.88
\$1 to 50	4	11.76
\$51 to 100	4	11.76
\$101 to 250	7	20.59
\$251 to 500	5	14.71
\$501 to 1000	2	5.88
\$1001 or more	3	8.82
Not sure/not specified	7	20.59

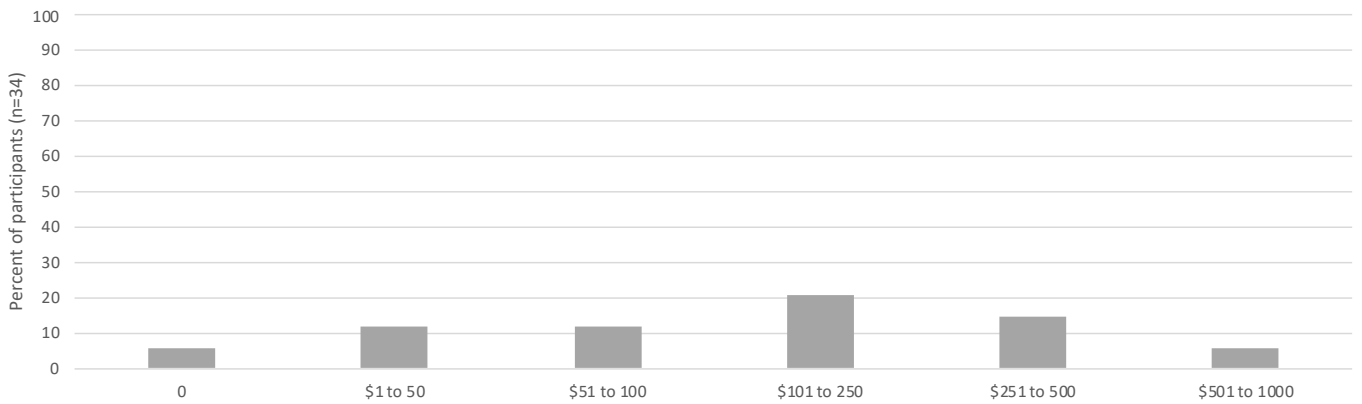


Figure 5.8: Estimated monthly out of pocket expenses due to condition

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

Burden of out of pocket expenses	Number (n=34)	Percent
Extremely significant	7	20.59
Moderately significant	1	2.94
Somewhat significant	6	17.65
Slightly significant	10	29.41
Not at all significant	10	29.41

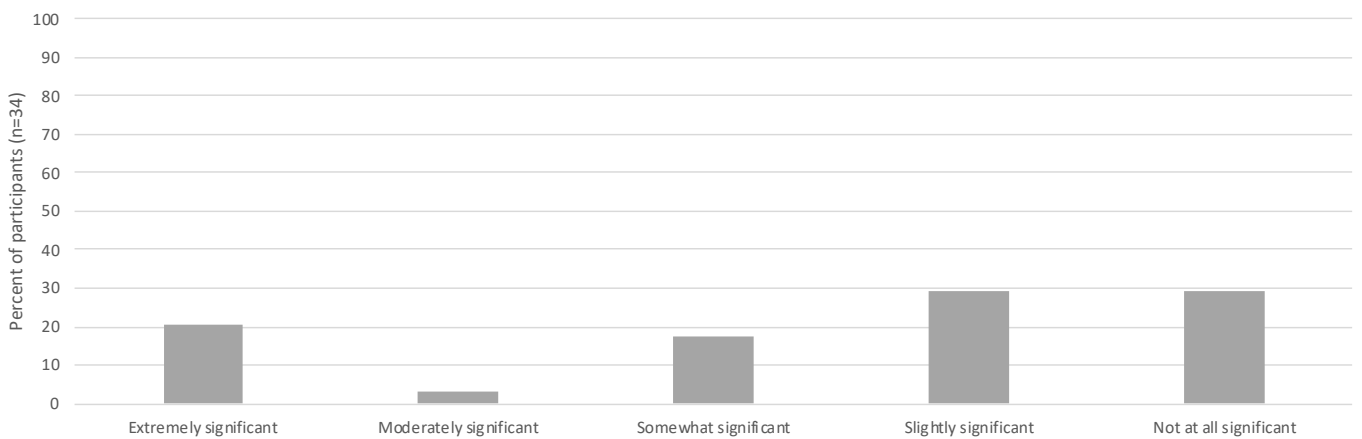


Figure 5.9: Burden of out-of-pocket expenses due to condition

Changes to employment status

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 (8.82%) had not changed since diagnosis, and 7 participants (20.59%) were retired or did not have a job. There were 11 participants (32.35%) had to quit their job, 7 participants (20.59%) reduced the number of hours they worked, and 6 participants (17.65%) accessed their superannuation early. There were 9 participants (26.47%) that took leave from work without pay, and 6 participants (17.65%) 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 8 participants (23.53%), 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=3, 8.82%). There were 6 participants (17.65%) whose partners reduced the numbers of hours they worked, and 3 partners, (8.82%) that quit their job. The partners of 9 participants (26.47%) took leave without pay, and there were 4 partners (11.76%) that took leave with pay.

Table 5.9: Changes to employment status

Changes in work status due to condition	Number (n=34)	Percent
Work status has not changed	3	8.82
Retired or did not have a job	7	20.59
Had to quit job	11	32.35
Reduced number of hours worked	7	20.59
Leave from work without pay	9	26.47
Leave from work with pay	6	17.65
Accessed Superannuation early due to condition	6	17.65

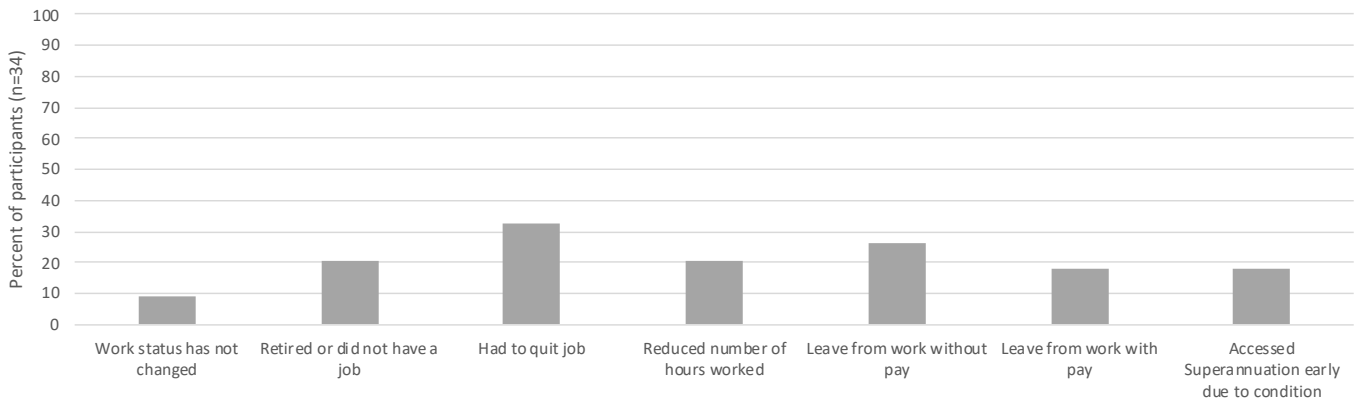


Figure 5.10: Changes to employment status

Table 5.10: Changes to care/partner employment status

Changes in partner or main carer work status due to condition	Number (n=34)	Percent
Does not have a partner/main carer	8	23.53
Work status has not changed	3	8.82
Retired or did not have a job	8	23.53
Had to quit job	3	8.82
Reduced number of hours worked	6	17.65
Leave from work without pay	9	26.47
Leave from work with pay	4	11.76

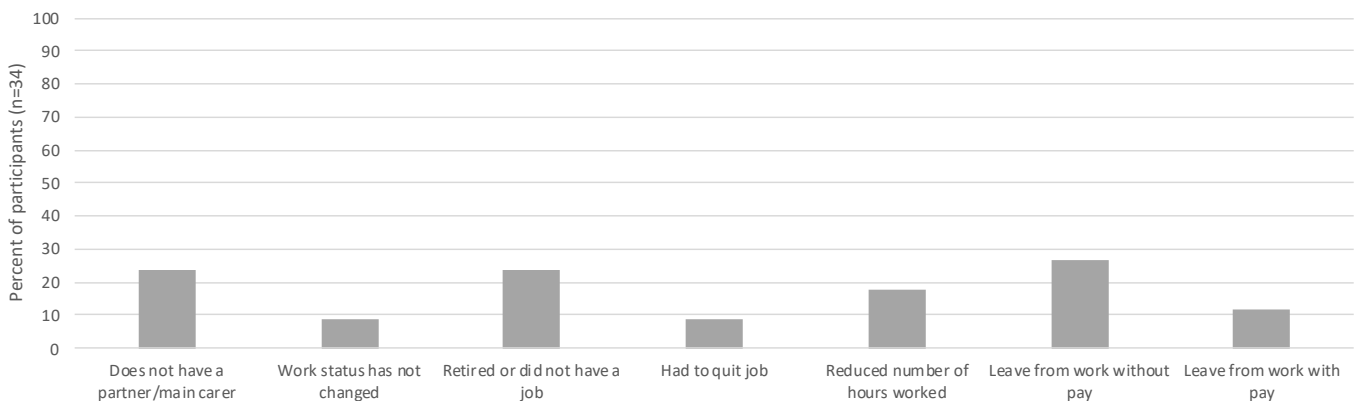


Figure 5.11: Changes to care/partner employment status

Reduced income due to condition

Half of the participants (n=17, 50.00%) indicated in the online questionnaire that they had a reduced family income due to their condition.

Estimated reduction monthly income

Most commonly, participants were not sure about the amount their monthly income was reduced by (n=7, 20.59%), or monthly income was reduced by between \$101 to 250 per month (n=7, 20.59%).

Burden of reduced income

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

For 6 of these participants (25.00%), the burden of this reduced income was extremely or moderately significant, for 7 participants (29.17%) the burden was somewhat significant, and for 11 participants (45.83%) the burden was slightly or not all significant.

Table 5.11: Estimated monthly loss of income

Estimated monthly loss of income	Number (n=34)	Percent
\$0	10	29.41
\$1000 to 2499	5	14.71
\$2500 to 4999	4	11.76
\$5000 to 9999	2	5.88
\$10000 or more	6	17.65
Not sure/not specified	7	20.59

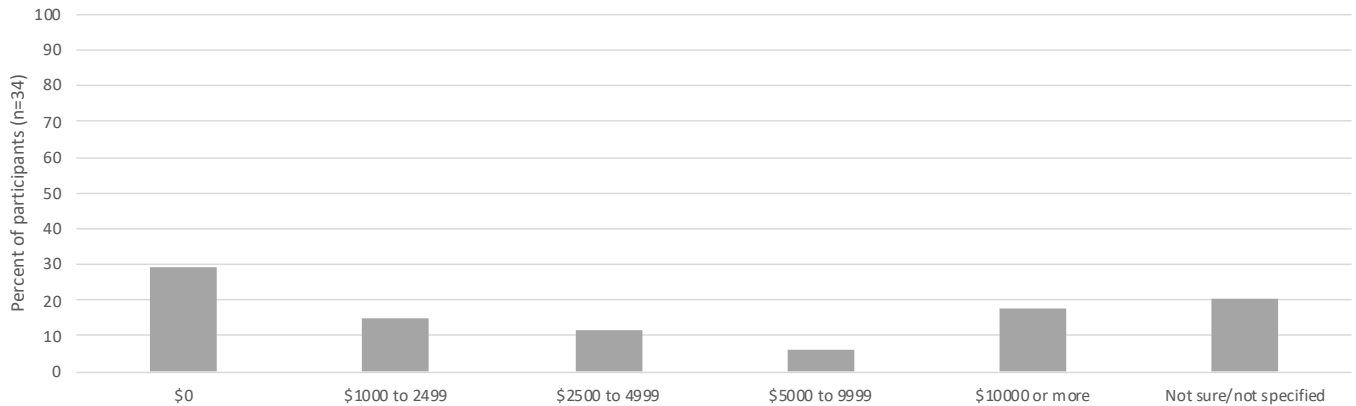


Figure 5.12: Estimated monthly loss of income

Table 5.12: Burden of reduced income

Burden of reduced monthly income	Number (n=24)	Percent
Extremely significant	8	33.33
Moderately significant	3	12.50
Somewhat significant	7	29.17
Slightly significant	5	20.83
Not at all significant	1	4.17

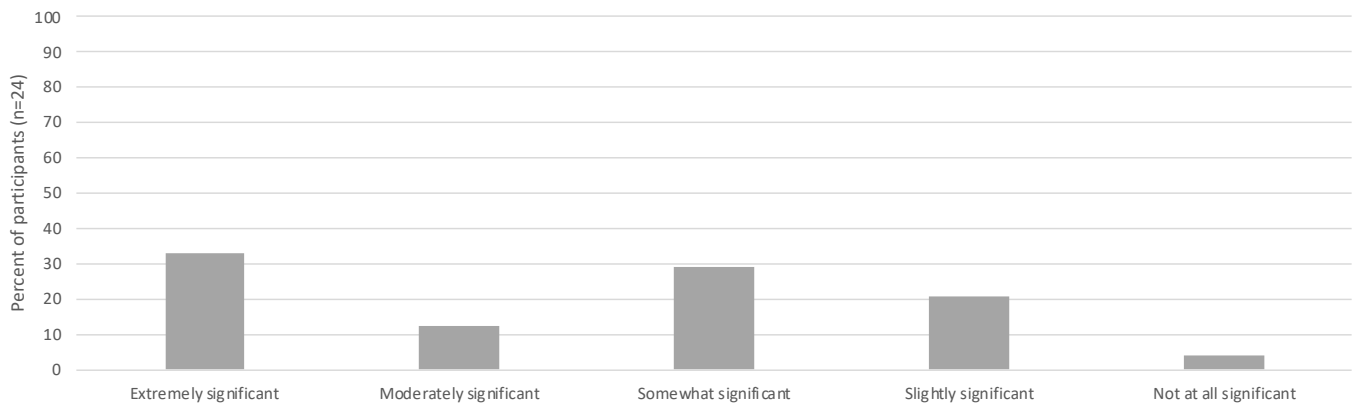


Figure 5.13: Burden of reduced income

Summary of 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.

The most common types of treatments were stem cell transplants, (n=25, 71.43%), radiotherapy (n=13,37.14%), maintenance chemotherapy (n=10,28.57%), CAR T-cell therapy (n=8, 22.86%), Lenalidomide and dexamethasone (n=7, 20.00%), Zoledronic acid (n=7, 20.00%), CyBorD (Cyclophosphamide, bortezomib, dexamethasone) (n=6, 17.14%), R-CHOP (rituximab cyclophosphamide,

doxorubicin, vincristine and prednisolone) (n=5, 14.29%), and Blood and platelet transfusions (n=5, 14.29%).

Participants reported having CVAD plus Imatinib: (Imatinib, Vincristine, Doxorubicin, Dexamethasone , Cytarabine, Methotrexate, and Cyclophosphamide) (n=2), or were not sure of the type (n=2) as induction therapy.

Participants reported having ALL06: Vincristine, Doxorubicin, Dexamethasone, Cytarabine, Pegaspargase, Mercaptopurine, Methotrexate, Cyclophosphamide, and Thioguanine (n=1), or were not sure of the type (n=2) as consolidation therapy.

Participants reported having Lenalidomide (n=7), CALGB: Prednisone, Vincristine, Mercaptopurine and Methotrexate (n=1) or were not sure of the type (n=2) as maintenance therapy.

Quality of life and effectiveness was calculated for treatments where 5 or more participants had the treatment. Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Values are calculated where there was adequate data available. 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 Stem cell transplants was in the 'life was distressing' range (median=2.00, IQR=2.00), and was found to be very effective (median=5.00 , IQR=0.75).

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

On average, quality of life from Maintenance chemotherapy was in the 'life was average' range (median=4.00, IQR=2.00), and was found to be very effective (median=5.00 , IQR=0.50).

On average, quality of life from Car-T therapy was in the 'life was a little distressing' range (median=3.00, IQR=0.75), and was found to be very effective (median=5.00 , IQR=0.25).

On average, quality of life from Lenalidomide and dexamethasone was in the 'life was a little distressing' range (median=4.00, IQR=2.00), and was found to be somewhat to moderately effective (median=2.50 , IQR=2.25).

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

On average, quality of life from CyBorD was in the 'life was average' range (median=4.00, IQR=0.75), and was found to be effective to very effective (median=4.50 , IQR=1.75).

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

On average, quality of life from blood and platelet transfusions was in the 'life was a little distressing' range (median=3.00, IQR=2.00), and was found to be very effective (median=5.00 , IQR=1.00).

Table 5.13: Overview of treatments

Drug treatments	Number (n=35)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Stem cells	25	71.43	2.00	2.00	5.00	0.75
Radiotherapy	13	37.14	4.00	2.00	5.00	1.00
Maintenance chemotherapy	10	28.57	4.00	2.00	5.00	0.50
Car-T therapy	8	22.86	3.00	0.75	5.00	0.25
Lenalidomide and dexamethasone	7	20.00	4.00	2.00	2.50	2.25
Zoledronic acid	7	20.00	5.00	1.00	4.00	1.00
CyBorD	6	17.14	4.00	0.75	4.50	1.75
R-CHOP	5	14.29	3.00	1.00	3.00	3.00
Blood and platelet transfusions	5	14.29	3.00	2.00	5.00	1.00
Induction chemotherapy	4	11.43	NA	NA	NA	NA
Corticosteroids	4	11.43	NA	NA	NA	NA
Antibiotics	4	11.43	NA	NA	NA	NA
ICE	3	8.57	NA	NA	NA	NA
Consolidation	2	5.71	NA	NA	NA	NA
Hyper-CVAD	2	5.71	NA	NA	NA	NA
DVd	2	5.71	NA	NA	NA	NA
Kd (Carfilzomib and dexamethasone)	2	5.71	NA	NA	NA	NA
MPB (Melphalan, prednisolone, bortezomib)	2	5.71	NA	NA	NA	NA
Pomalidomide and dexamethasone	2	5.71	NA	NA	NA	NA
Pamidronate	2	5.71	NA	NA	NA	NA
Chemotherapy for recurrence	1	2.86	NA	NA	NA	NA
DA-R-EPOCH	1	2.86	NA	NA	NA	NA
KCd	1	2.86	NA	NA	NA	NA
Sd (Selinexor and dexamethasone)	1	2.86	NA	NA	NA	NA
Methotrexate	1	2.86	NA	NA	NA	NA
Daratumumab	1	2.86	NA	NA	NA	NA
Immunoglobulin infusions	1	2.86	NA	NA	NA	NA

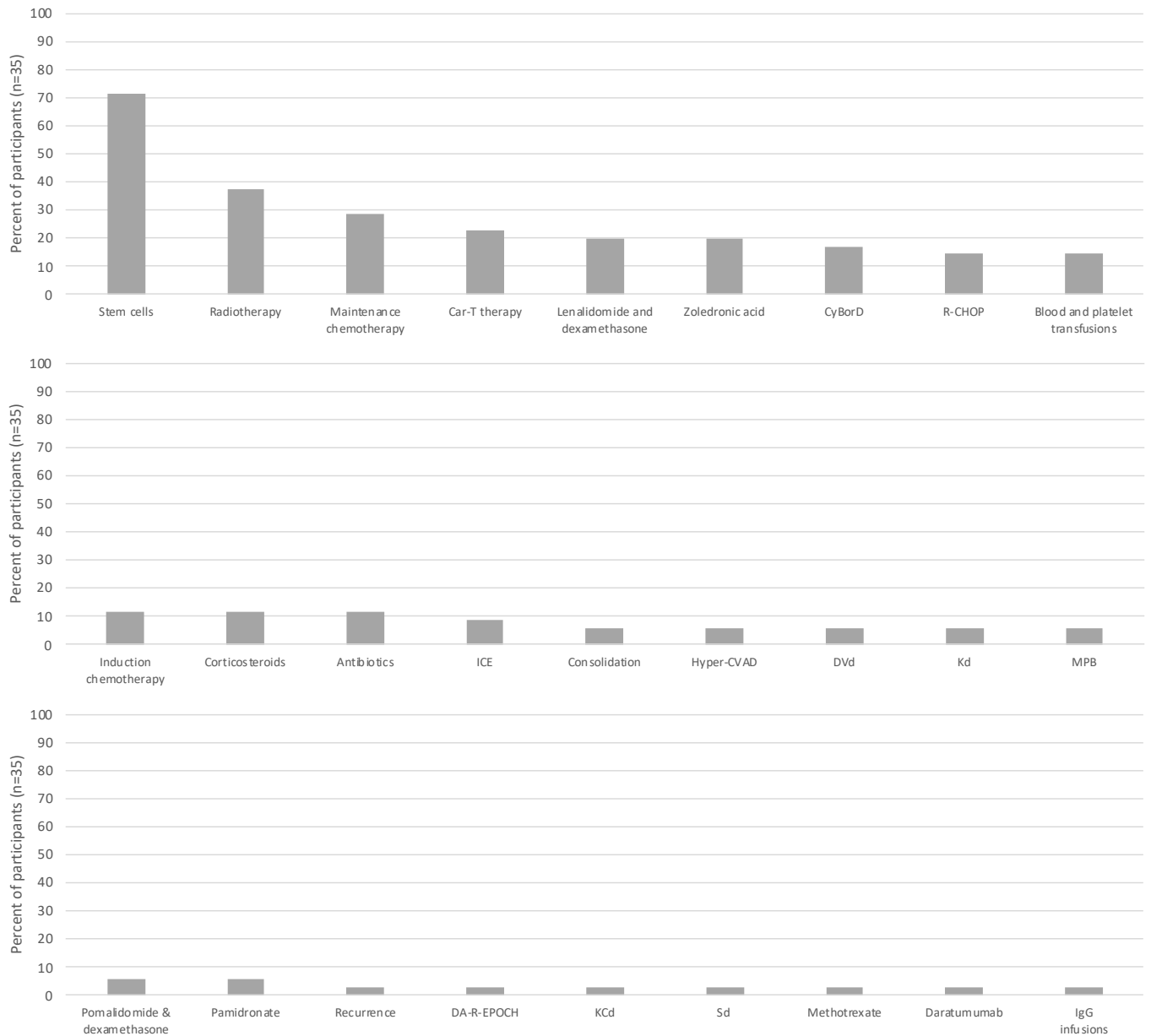


Figure 5.14: Overview of treatments

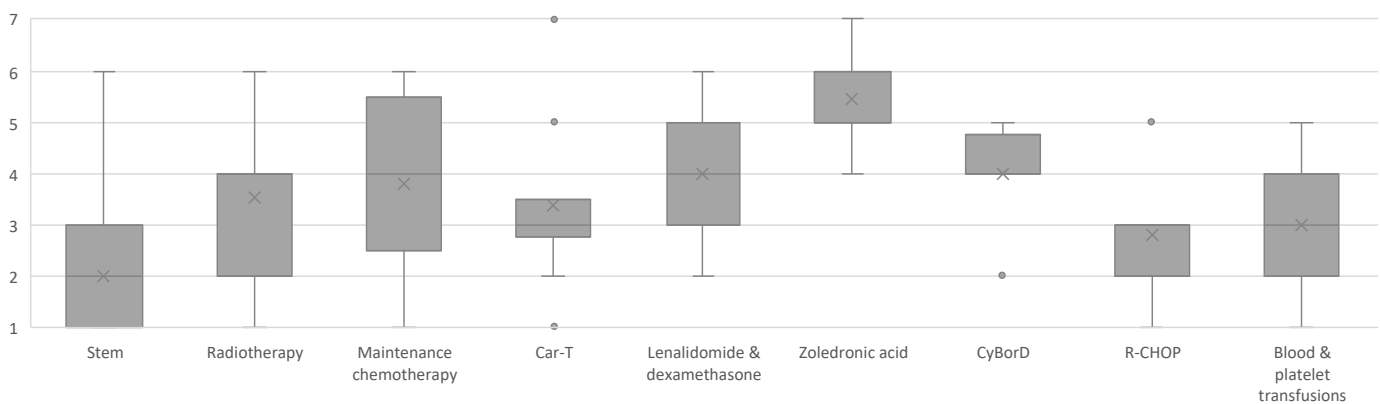


Figure 5.15: Quality of life from drug treatments

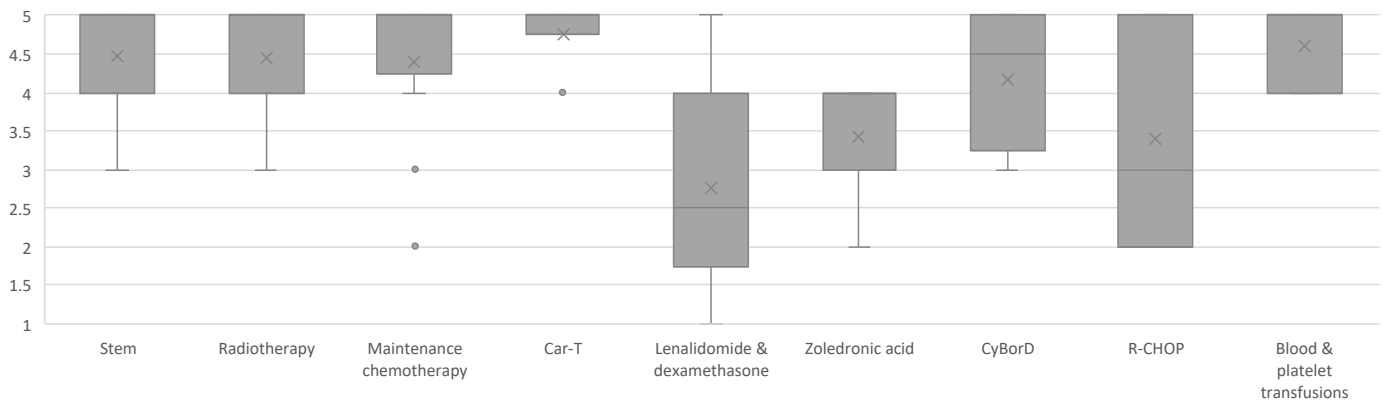


Figure 5.16: Effectiveness of drug treatments

Table 5.14: Detailed summary of drug treatments taken by 5 or more participants

Treatment details	Stem cells		Radiotherapy		Maintenance chemotherapy			
	n=25	%	n=13	%	N=10	%		
Median quality of life	2.00		4.00		4			
IQR quality of life	2.00		2.00		2			
Median effectiveness	5.00		5.00		5			
IQR effectiveness	0.75		1		0.5			
2020 to 2023	10	40.00	5	38.46	7	70.00		
2015 to 2020	11	44.00	3	23.08	0	0.00		
before 2015	3	12.00	4	30.77	1	10.00		
Not specified	1	4.00	1	7.69	2	20.00		
Treatment finished as planned or not needed any more	18	72.00	10	76.92	1	10.00		
Stopped due to side effects	0	0.00	1	7.69	0	0.00		
Taking as prescribed	2	8.00	0	0.00	6	60.00		
Stopped as it was not working	0	0.00	0	0.00	1	10.00		
Not specified	0	0.00	2	15.38	1	10.00		
Side effects								
No side effects	2	8.00	No side effects	5	38.46	Feeling tired and weak	8	80.00
Feeling tired and weak	17	68.00	Fatigue	4	30.77	Diarrhoea or constipation	7	70.00
Diarrhoea or constipation	16	64.00	Nausea and vomiting	3	23.08	Trouble sleeping	7	70.00
Difficulty eating and drinking	15	60.00	Discomfort when swallowing	2	15.38	Increased risk of infection (drop in white blood cells)	6	60.00
Increased risk of infection (drop in white blood cells)	14	56.00	Hair loss	2	15.38	Nerve damage (peripheral neuropathy)	5	50.00
Weight loss	11	44.00	Loss of appetite and weight loss	2	15.38	Chemo brain	3	30.00
Nausea and or vomiting	10	40.00	Skin problems (red irritated swollen blistered sunburned tanned)	2	15.38	Loss of appetite	3	30.00
Breathlessness and looking pale (anemia)	8	32.00	Diarrhoea	1	7.69	Skin: dry skin, rash or itchiness	3	30.00
Joint and muscle aches	8	32.00	Fertility issues	1	7.69	Stomach upsets	3	30.00
Sore mouth and ulcers	6	24.00	Mouth pain or ulcers	1	7.69	Breathlessness and looking pale (drop in red blood cells)	2	20.00
Bruising, bleeding gums or nose bleeds (drop in platelets)	4	16.00	Sexual issues	1	7.69	Changes in taste and smell	2	20.00
Diarrhoea	4	16.00	Sore mouth	1	7.69	Hair loss or thinning	2	20.00
Frequent infections	4	16.00	Stiff joints and muscles	1	7.69	Mood swings and behaviour changes	2	20.00
Tiredness and lack of energy (fatigue)	4	16.00	Swollen limbs	1	7.69	Nausea and or vomiting	2	20.00
Bleeding and bruising more easily	3	12.00	Taste and smell changes	1	7.69	Sore mouth and ulcers	2	20.00
Dizziness or feeling light headed	3	12.00	Tiredness and lack of energy (fatigue)	1	7.69	Weakness, numbness and pain from nerve damage, usually in the hands and feet	2	20.00
Mouth pain or ulcers	3	12.00				General swelling/build up of fluid	1	10.00
Nausea and vomiting	3	12.00				Joint and muscle aches	1	10.00
Headache Irregular heartbeat	2	8.00				Nausea and or vomiting	1	10.00
Short of breath	2	8.00				Weight gain	1	10.00

Treatment details	Car-T Therapy		Lenalidomide and dexamethasone		Zoledronic acid	
	n=8	%	n=7	%	N=7	%
Median quality of life	3		4		5	
IQR quality of life	0.75		2		1	
Median effectiveness	5		2.5		4	
IQR effectiveness	0.25		2.25		1	
2020 to 2023	8	100.00	4	57.14	3	42.86
2015 to 2020	0	0.00	1	14.29	2	28.57
before 2015	0	0.00	1	14.29		0.00
Not specified	0	0.00	1	14.29	2	28.57
Treatment finished as planned or not needed any more	7	87.50	2	28.57	4	57.14
Stopped due to side effects	0	0.00	1	14.29	0	0.00
Taking as prescribed	1	12.50	2	28.57	1	14.29
Stopped as it was not working	0	0.00	2	28.57	1	14.29
Not specified	0	0.00	0	0.00	2	28.57
Side effects						
No side effects	4	50.00	5	71.43	4	57.14
Increased risk of infection (drop in white blood cells)	7	87.50	5	71.43	4	57.14
Fever	3	37.50	5	71.43	1	14.29
Blood pressure changes	2	25.00	4	57.14	1	14.29
Confusion/disorientated	1	12.50	3	42.86		0.00
Dizziness	1	12.50	2	28.57		0.00
Headaches	1	12.50	2	28.57		0.00
Speech changes	1	12.50	1	14.29		0.00
			1	14.29		0.00
			1	14.29		0.00
			1	14.29		0.00
			1	14.29		0.00
			1	14.29		0.00
			1	14.29		0.00
			1	14.29		0.00

Treatment details	CyBorD		R-CHOP		Blood and platelet transfusions	
	n=6	%	n=5	%	n=5	%
Median quality of life	4		3		3	
IQR quality of life	0.75		1		2	
Median effectiveness	4.5		3		5	
IQR effectiveness	1.75		3		1	
2020 to 2023	2	33.33	2	40.00	0	0.00
2015 to 2020	2	33.33	2	40.00	0	0.00
before 2015	0	0.00	1	20.00	0	0.00
Not specified	2	33.33	0	0.00	5	100.00
Treatment finished as planned or not needed any more	4	66.67	4	80.00	0	0.00
Stopped due to side effects	0	0.00	0	0.00	0	0.00
Taking as prescribed	1	16.67	0	0.00	0	0.00
Stopped as it was not working	1	16.67	1	20.00	0	0.00
Not specified	0	0.00	0	0.00	5	100.00
Side effects						
No side effects	1	16.67	5	100.00	1	20.00
Trouble sleeping	4	66.67	5	100.00	3	60.00
Dizziness or feeling light-headed	2	33.33	5	100.00	2	40.00
Feeling tired and weak	2	33.33	5	100.00	1	20.00
Mood swings and behaviour changes	2	33.33	4	80.00	1	20.00
Weight gain	2	33.33	4	80.00		
Breathlessness and looking pale (drop in red blood cells)	1	16.67	3	60.00		
Diarrhoea or constipation	1	16.67	3	60.00		
General swelling/build up of fluid	1	16.67	3	60.00		
Nausea and or vomiting	1	16.67	2	40.00		
Nerve damage (peripheral neuropathy)	1	16.67	2	40.00		
Skin: dry skin, rash or itchiness	1	16.67	1	20.00		
Stomach upsets	1	16.67				

Allied health

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

Most participants used at least one type of allied health service (n=22, 64.71%), and on average used 1 service (median=1.00, IQR=2.00).

The most common allied health service used was physiotherapy (n=14, 41.18%), followed by dietary (n=11, 32.35%), and psychology/counselling (n=7,

20.59%). There were 7 participants (20.59%) that saw a social worker, 4 participants (11.76%) that saw a podiatrist, and 2 participants (5.88%) that saw an occupational therapist.

On average, quality of life from physiotherapy was in the 'life was good' range (median=5.00, IQR = 1.00), and was found to be effective (median=4.00, IQR = 1.75).

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

On average, quality of life from psychology/counselling was in the 'life was a little distressing' range (median=3.00, IQR=1.00), and was found to be somewhat effect (median=2.00, IQR=1.00).

Table 5.15: Allied health

Allied health	Number (n=34)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Physiotherapy	14	41.18	5.00	1.00	4.00	1.75
Dietician	11	32.35	4.00	2.50	4.00	1.00
Psychology/counselling	7	20.59	3.00	1.00	2.00	1.00
Social work	7	20.59	3.00	1.00	4.00	1.00
Podiatry	4	11.76	NA	NA	NA	NA
Occupational therapy	2	5.88	NA	NA	NA	NA
Speech therapy	0	0.00	NA	NA	NA	NA

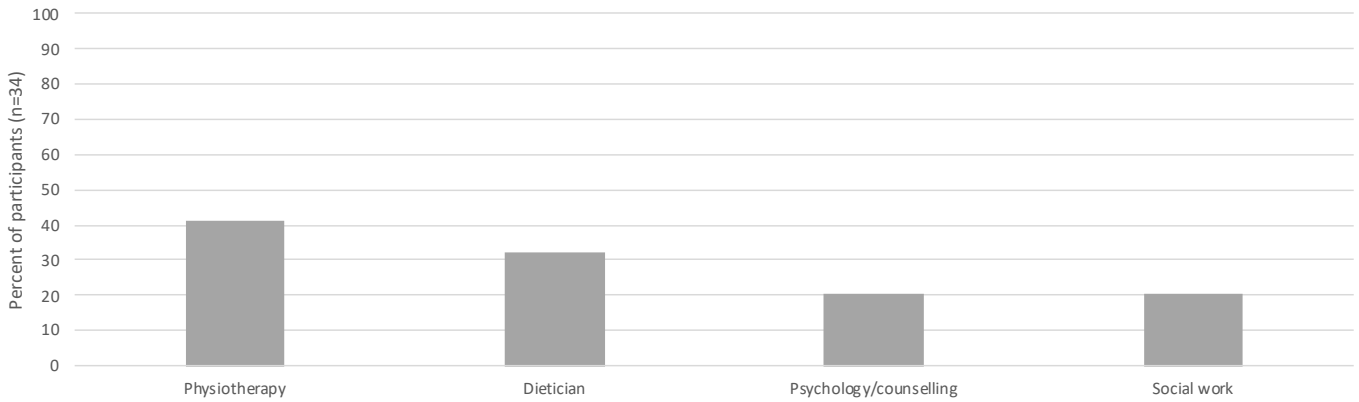


Figure 5.17: Allied health

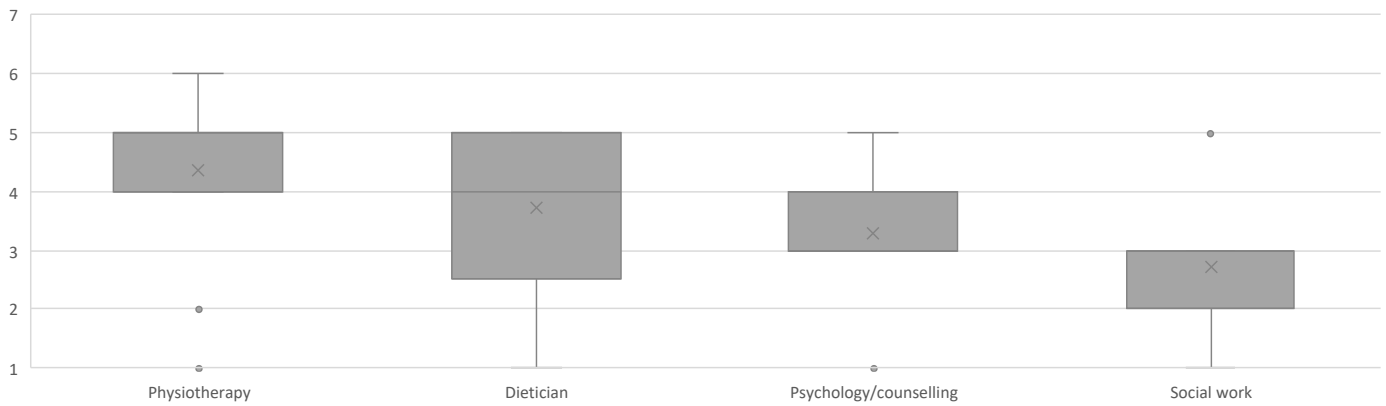


Figure 5.18: Quality of life from allied health

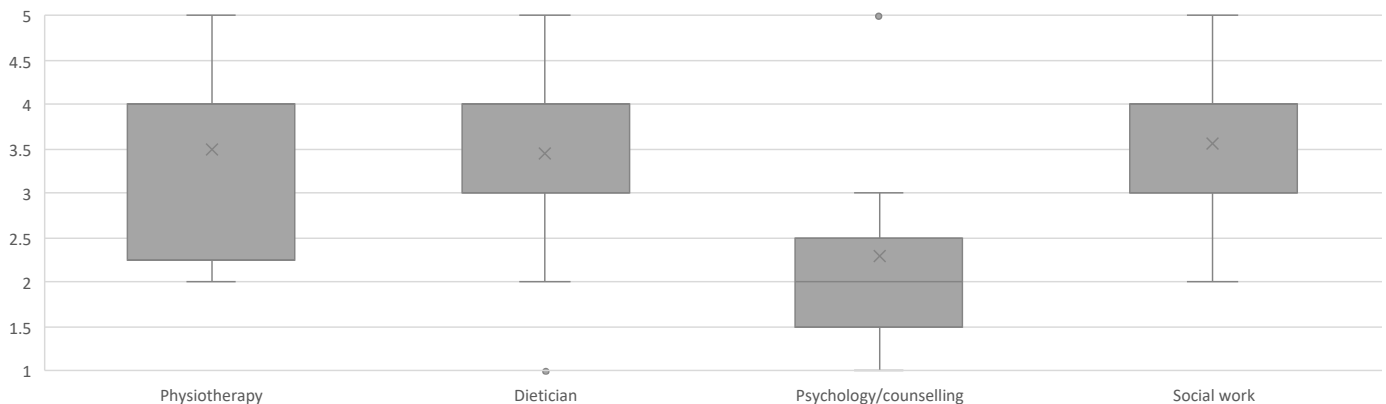


Figure 5.19: Effectiveness of allied health

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.

Most participants used at made at least one lifestyle change (n=29, 85.29%), and on average made 2 changes (median=2.00, IQR=2.00).

The most common lifestyle change was exercise (n=22, 64.71%), followed by diet changes (n=17, 50.00%), and reducing or cutting out alcohol (n=17, 50.00%).

On average, quality of life from exercise was in the 'life was good' range (median=5.00, IQR=3.00), and was found to be very effective (median=5.00, IQR=2.00).

On average, quality of life from reducing or cutting out alcohol was in the 'life was average' range (median=4.00, IQR=3.00), and was found to be effective (median=4.00, IQR=2.00).

Table 5.16: Lifestyle changes

Lifestyle changes	Number (n=34)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Exercise	22	64.71	5.00	3.00	5.00	2.00
Diet changes	17	50.00	3.00	3.00	4.00	1.00
Reduce or cut out alcohol	17	50.00	4.00	3.00	4.00	2.00
Reduce or quit smoking	4	11.76	NA	NA	NA	NA

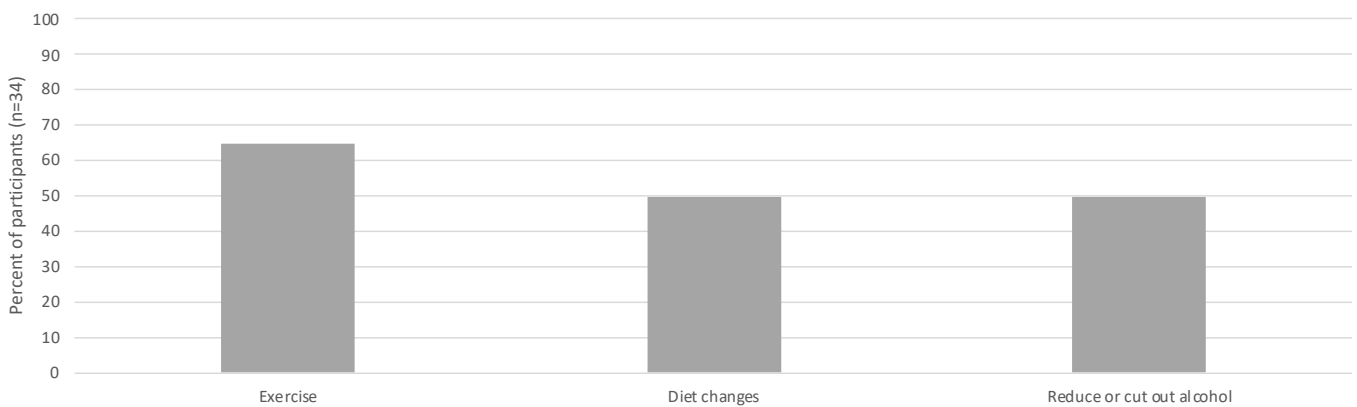


Figure 5.20: Lifestyle changes

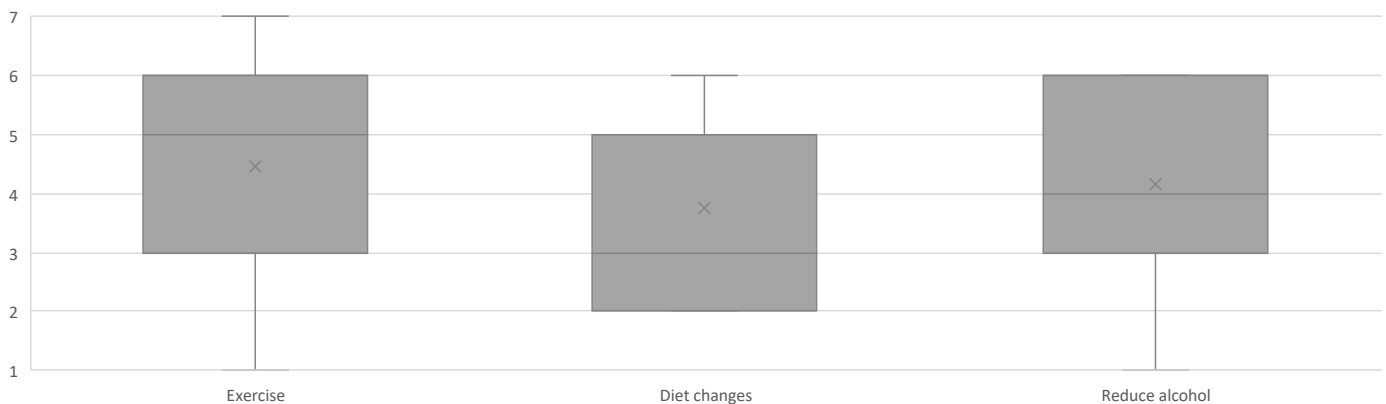


Figure 5.21: Quality of life from lifestyle changes



Figure 5.22: Effectiveness from lifestyle changes

Complementary therapies

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

Half of the participants used at made at least one complementary therapy (n=17, 50.00%), and on average used 0.5 therapies (median=0.50, IQR=2.00).

The most common complementary therapy used was Mindfulness or relaxation techniques (n=12, 35.29%), followed by Massage therapy (n=8, 23.53%), and Supplements (n=7, 20.59%).

On average, quality of life from Mindfulness or relaxation techniques was in the 'life was average to good' range (median=4.50, IQR=3.25), and was found

to be moderately effective to effective (median=3.50, IQR=2.25).

On average, quality of life from Massage therapy was in the 'life was average to good' range (median=4.50, IQR=1.75), and was found to be effective (median=4.00, IQR=0.25).

On average, quality of life from Massage therapy was in the 'life was average to good' range (median=4.50, IQR=1.75), and was found to be effective (median=4.00, IQR=0.25).

On average, quality of life from Acupuncture was in the 'life was average to good' range (median=4.50, IQR=1.00), and was found to be somewhat effective (median=2.00, IQR=1.50).

Table 5.17: Complementary therapies

Complementary therapies	Number (n=34)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Mindfulness or relaxation techniques	12	35.29	4.50	3.25	3.50	2.25
Massage therapy	8	23.53	4.50	1.75	4.00	0.25
Supplements	7	20.59	4.00	2.00	4.00	1.50
Acupuncture	6	17.65	4.50	1.00	2.00	0.75
Naturopathy	3	8.82	NA	NA	NA	NA
Homeopathy	0	0.00	NA	NA	NA	NA

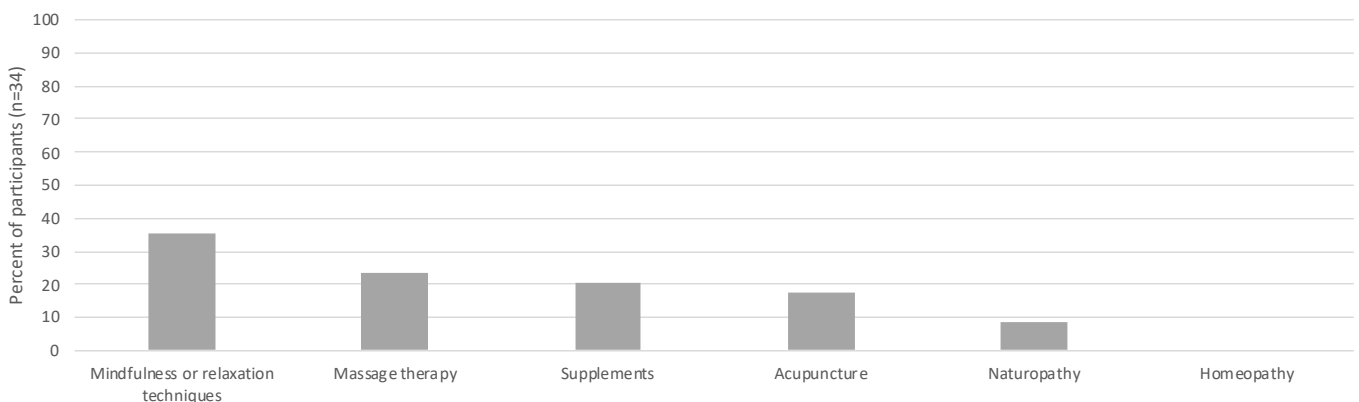


Figure 5.23: Complementary therapies

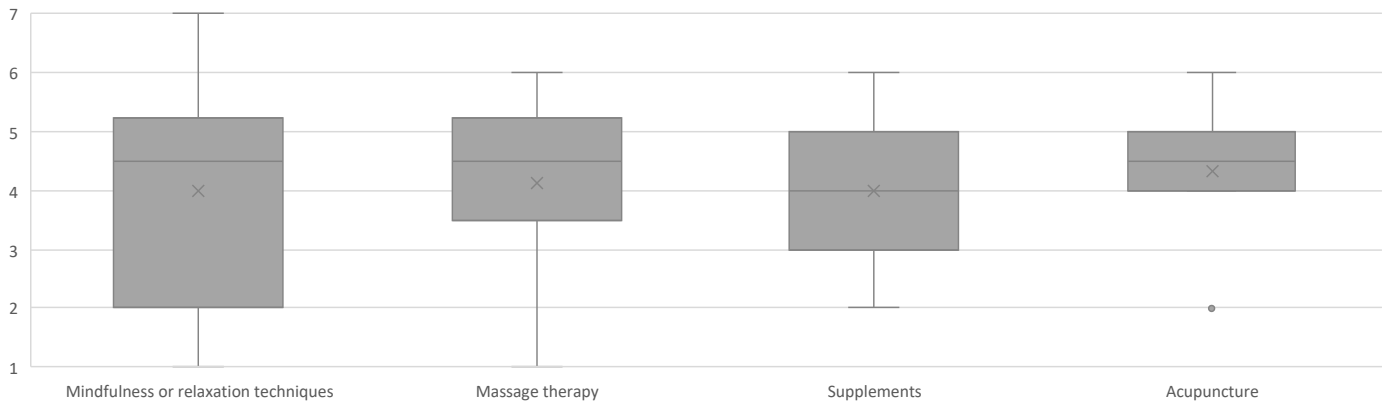


Figure 5.24: Quality of life from complementary therapies

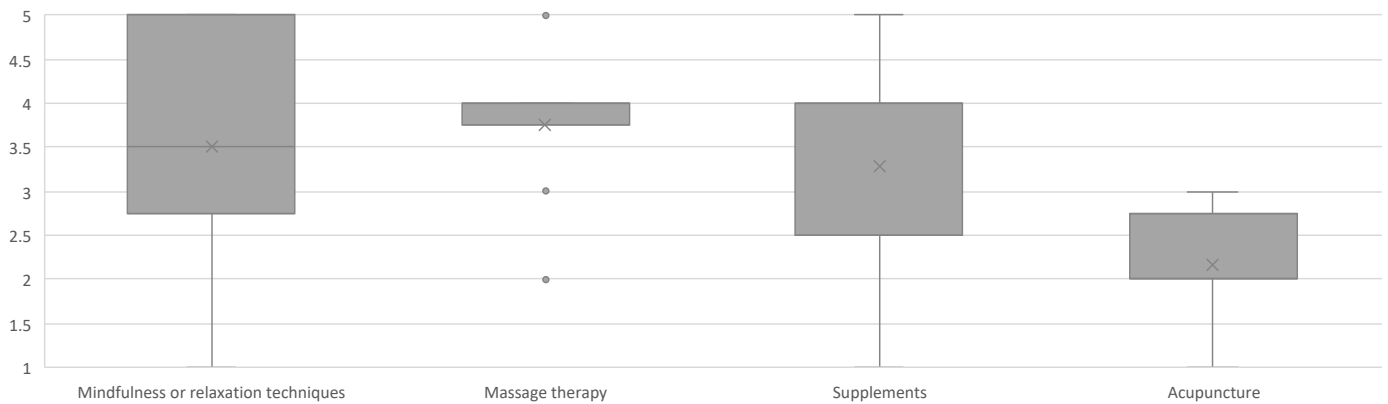


Figure 5.25: Effectiveness of complementary therapies

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 17 participants (50%) that had discussions about clinical trials, 5 participants (14.71%) had brought up the topic with their doctor, and the doctor of 12 participants (35.29%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=17, 50.00%).

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 were 7 participants (20.59%) that had taken part in a clinical trial, 24 participants (70.59%) 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 (8.82%).

Table 5.18: Clinical trial discussions

Clinical trial discussions	Number (n=34)	Percent
Participant brought up the topic of clinical trials doctor for discussion	5	14.71
Doctor brought up the topic of clinical trials for discussion	12	35.29
Participant has ever spoken about clinical trials	17	50.00

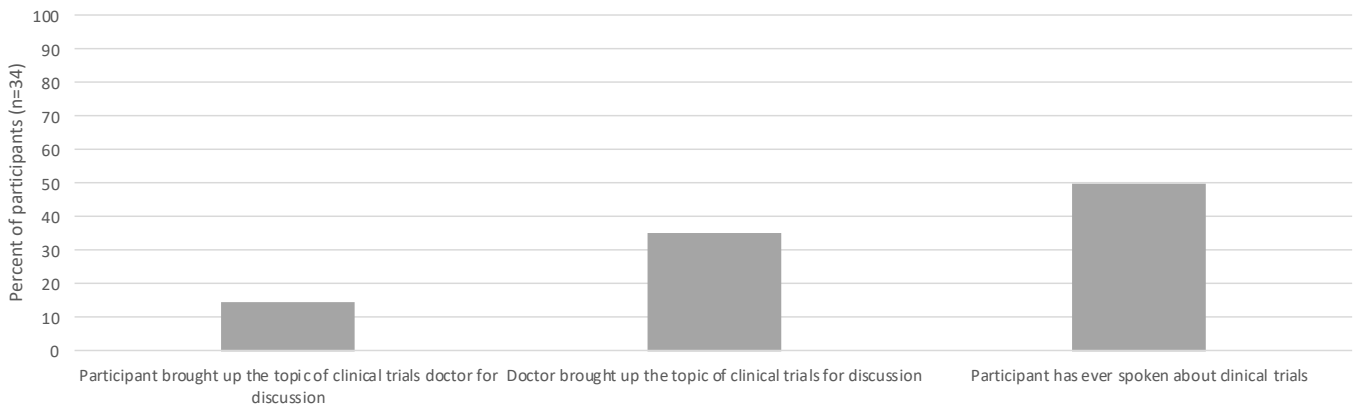


Figure 5.26: Clinical trial discussions

Table 5.19: Clinical trial participation

Clinical trial participation	Number (n=34)	Percent
Has not participated in a clinical trial and does not want to	3	8.82
Has not participated in a clinical trial but would like to if there is one	24	70.59
Has participated in a clinical trial	7	20.59

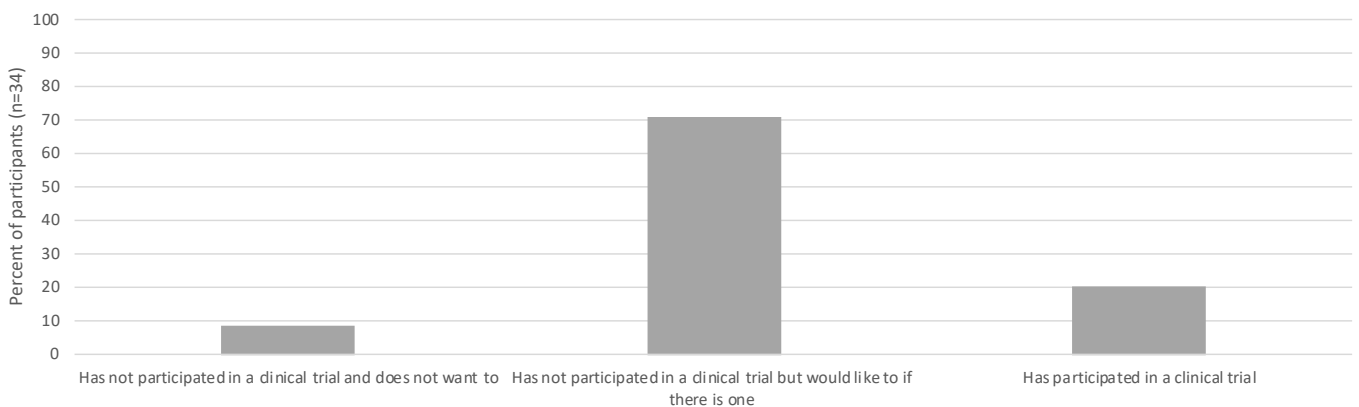


Figure 5.27: Clinical trial participation

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 described using a specific example (69.70%), those that do not interfere with life (30.30%), and those that can be managed with self-medication or self-management (9.09%).

When a specific side effect was described, the most common responses were aches and pain in general (18.18%), and fatigue or lethargy (18.18%). Other themes included gastrointestinal distress (15.15%), headaches (15.15%), nausea or loss of appetite (12.12%), and neuropathy (9.09%).

Participant provides a specific side effect as an example

Mild were neuropathy in both hands. I guess when we we got the recipe right, I could cope with a certain

amount of diarrhea, yeah. Basically, after the first lot of chemo, I became quite, you know, I managed it.
2023AUCRT

No, just I didn't really have any side effects apart from the the loss of hair. I didn't hardly notice, you know? All of a sudden it was gone. But my hair, my facial hair and my hair and my head didn't. None of that fell out. It just didn't grow. But my body hair all fell out, like on my arms, my legs, my body, everything at all, at all disappeared.
010_2023AUCRT

Just feeling a bit off, like, you know, like you just don't feel well, like you get headaches and yeah, like you. That's hard to describe. Like you're just, you're just not right. You know, there's something wrong. And yeah, you just don't feel sparky and you don't feel like eating.
011_2023AUCRT

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

Well, to me, a mild side effects would be what I've got with my tongue or my hips, where they're annoying and they hurt a little bit, but you can live with them and not really, they're not changing my life. Like I'm still like, it's not stopping me eating or drinking certain things, or my hip pain isn't stopping me from exercising or doing things I need to do.
006_2023AUCRT

Inconvenient or uncomfortable, like dexamethasone keeps me awake on Wednesday night, so I'll get two or three hours of sleep on a Wednesday night. But it's just, it's irritating and it's just that's a mild side effect, something that really is a first world problem. I don't sleep well.
019_2023AUCRT

Ohh, wow. Mild side effects is kind of something that's slightly irritating, but you get on with it.
016_2023AUCRT

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

Something I could easily cope with and wouldn't really need medication unless it was really unbearable.
002_2023AUCRT

Well, I've described the mild side effect would be something that's quite easily to control. In terms of a side effect, it's something that's you know, that's there and it's quite easy to control. Which as an example it could be, it could be constipation, but you know, it might be it might last for it might only last, it might only last for a couple of days, or maybe three days to the maximum, probably 2 days, but where a severe side effect would be, the would be lasting longer.
023_2023AUCRT

Table 5.20: Description of mild side effects

Description of mild side effects	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7	%	n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant provides a specific side effect as an example	23	69.70	5	71.43	8	80.00	10	62.50	18	69.23	5	71.43	11	73.33	12	66.67
Participant describes mild side effects as those that do not interfere with daily life	10	30.30	2	28.57	2	20.00	6	37.50	7	26.92	3	42.86	5	33.33	5	27.78
Participant describes mild side effects as those that can be self-managed	3	9.09	1	14.29	1	10.00	1	6.25	3	11.54	0	0.00	2	13.33	1	5.56

Description of mild side effects	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant provides a specific side effect as an example	23	69.70	15	78.95	8	57.14	11	78.57	12	63.16	12	85.71	11	57.89
Participant describes mild side effects as those that do not interfere with daily life	10	30.30	5	26.32	5	35.71	1	7.14	9	47.37	2	14.29	8	42.11
Participant describes mild side effects as those that can be self-managed	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	1	7.14	2	10.53

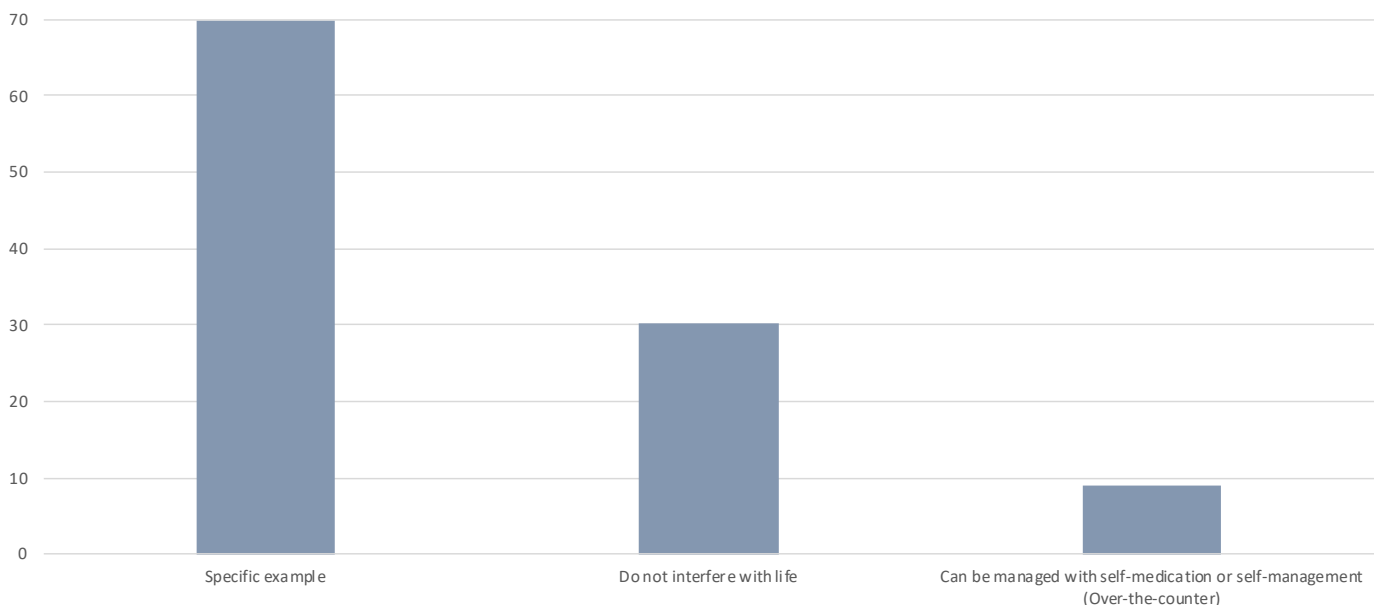


Figure 5.28: Description of mild side effects

Table 5.21: 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	Aged 65 or older Higher status	Diffuse Large B-Cell Lymphoma Mid to low status
Participant describes mild side effects as those that do not interfere with daily life	Diffuse Large B-Cell Lymphoma Regional or remote Mid to low status	CAR T-Cell therapy Metropolitan Higher status

Table 5.22: Description of mild side effects (Specific side effects)

Description of mild side effects (Specific side effects)	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7	%	n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes mild side effects giving the specific example of aches/pain (general)	6	18.18	3	42.86	1	10.00	2	12.50	6	23.08	0	0.00	3	20.00	3	16.67
Participant describes mild side effects giving the specific example of fatigue/lethargy	6	18.18	1	14.29	2	20.00	3	18.75	5	19.23	1	14.29	3	20.00	3	16.67
Participant describes mild side effects giving the specific example of gastrointestinal distress	5	15.15	0	0.00	2	20.00	3	18.75	3	11.54	2	28.57	4	26.67	1	5.56
Participant describes mild side effects giving the specific example of headaches	5	15.15	1	14.29	3	30.00	1	6.25	4	15.38	1	14.29	3	20.00	2	11.11
Participant describes mild side effects giving the specific example of nausea or loss of appetite	4	12.12	0	0.00	3	30.00	1	6.25	3	11.54	1	14.29	2	13.33	2	11.11
Participant describes mild side effects giving the specific example of neuropathy	3	9.09	1	14.29	1	10.00	1	6.25	2	7.69	1	14.29	2	13.33	1	5.56

Description of mild side effects (Specific side effects)	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes mild side effects giving the specific example of aches/pain (general)	6	18.18	6	31.58	0	0.00	4	28.57	2	10.53	4	28.57	2	10.53
Participant describes mild side effects giving the specific example of fatigue/lethargy	6	18.18	3	15.79	3	21.43	3	21.43	3	15.79	3	21.43	3	15.79
Participant describes mild side effects giving the specific example of gastrointestinal distress	5	15.15	1	5.26	4	28.57	2	14.29	3	15.79	2	14.29	3	15.79
Participant describes mild side effects giving the specific example of headaches	5	15.15	5	26.32	0	0.00	2	14.29	3	15.79	2	14.29	3	15.79
Participant describes mild side effects giving the specific example of nausea or loss of appetite	4	12.12	4	21.05	0	0.00	3	21.43	1	5.26	4	28.57	0	0.00
Participant describes mild side effects giving the specific example of neuropathy	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	1	7.14	2	10.53

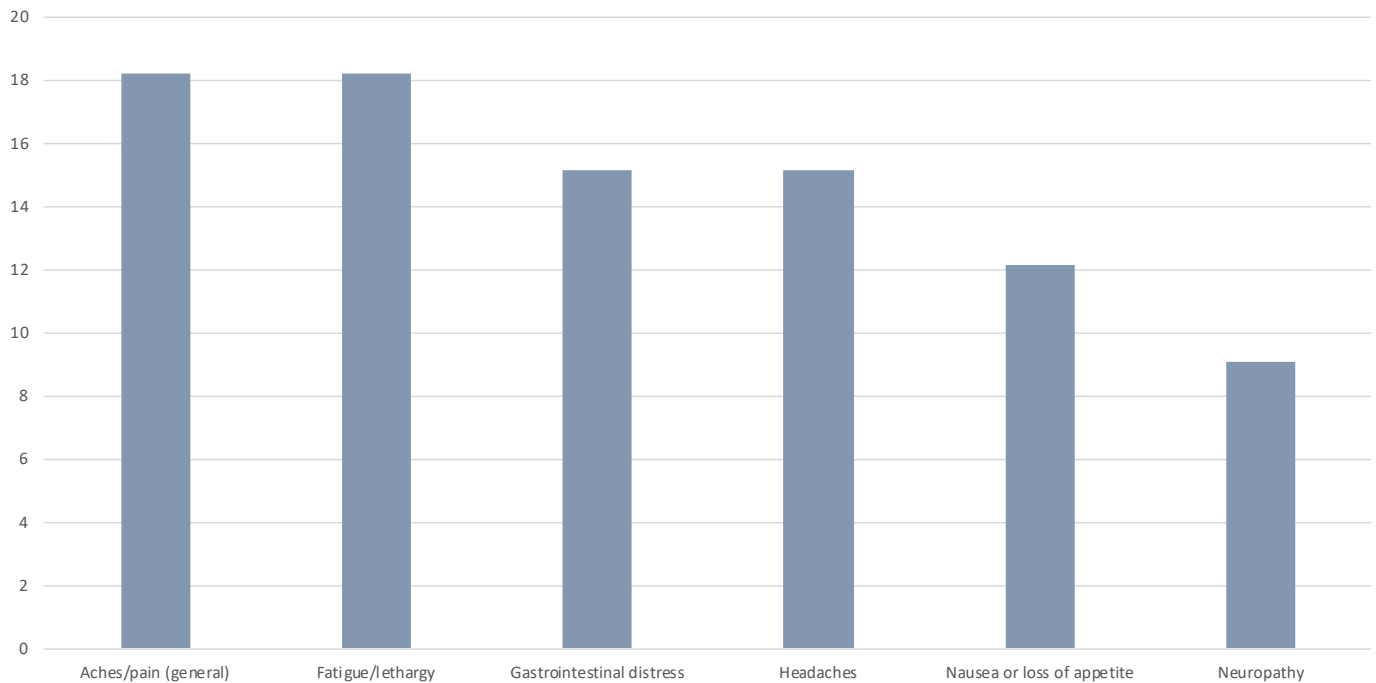


Figure 5.29: Description of mild side effects (Specific side effects)

Table 5.23: 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)	CAR T-Cell therapy Aged 65 or older	B-cell acute lymphoblastic leukaemia (ALL) Aged 25 to 64 Regional or remote Mid to low status
Participant describes mild side effects giving the specific example of gastrointestinal distress	B-cell acute lymphoblastic leukaemia (ALL)	CAR T-Cell therapy Female Aged 65 or older
Participant describes mild side effects giving the specific example of headaches	Aged 65 or older	Diffuse Large B-Cell Lymphoma Aged 25 to 64
Participant describes mild side effects giving the specific example of nausea or loss of appetite	B-cell acute lymphoblastic leukaemia (ALL) Aged 65 or older Higher status	Diffuse Large B-Cell Lymphoma Mid to low status

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 (78.79%), and those that requires medical intervention (30.30%). Other themes included those that impact everyday life or ability to conduct activities of daily living (15.15%), and those that impact their everyday life by being bed ridden (9.09%).

When a specific side effect was described, the most common examples were nausea or loss of appetite (30.30%), aches and pain in general (24.24%), and fatigue or lethargy (15.15 %). Other themes included gastrointestinal distress (12.12%), emotional or mental impact (9.09%), impact on sleep (9.09%), neuropathy (9.09%), and swelling from fluid build up including lymphoedema (9.09%).

Participant provides a specific side effect as an example

Just like excruciating pain or severe sickness. Probably like an eight or a nine on the pain scale. To the point where you have to call like press the emergency button or something.

005_2023AUCRT

Well, to me the severe one would have been the the mucositis and the the pain of that because I couldn't couldn't eat and I couldn't even, it hurt even just to swallow water and that was so and that was even with the medication, so and they had to give me medication that was strong enough to make you feel really dopey and everything. So that was pretty severe.

006_2023AUCRT

That was when I had that last thing when I had the transplant. It was just describe it horrible. Yeah. You just you're just so sick. You wanna you just don't want to be there. You sort of you open your eyes and think 'not another day of this' and you try and sleep and you can't you're just sick and then when you do you yeah. It's just it's hard to describe how to, you know, when you haven't been through it to when you go through it. Yeah, it's just really, really bad it.

011_2023AUCRT

Participant identifies severe side effects as requiring medical intervention

I was lucky that I didn't have that really bad mucositis that a lot of people get. I think that was because of the treatment that they were giving me. One really bad side effect that shouldn't be bad, was constipation in the last three rounds. It was terrible. I also was left with fissures once they did the colonoscopy, because of the bleeding, so I actually felt like I had glass cutting me every time I went to the toilet. That was pretty horrific, that was one of the worst things actually, in the last round. The swelling of my legs probably went down after a couple of weeks. The folliculitis kept coming back, but they kept putting me on antibiotics for that. I think I did have quite a few fevers and had to go into hospital and go on the drip. 004_2023AUCRT

The only the only severe one I've had was the blood clot last year and and that was resolved in the day I went in. My doctor, my GP found it straight away sent me into he she'd already they'd already he'd already booked up to me get all these scans and then he sent me straight to hospital.

018_2023AUCRT

Severe side effects would be unable to eat food, I suppose, without excruciating pain in my stomach. So some of the foods I realized that they weren't good for me to eat at the particular time. So I was. I had to return to hospital for morphine. I couldn't physically cope with the pain anymore. Another one was the other one, I can't remember at the moment. No, that's probably, that's probably the worst one.

024_2023AUCRT

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

Things that would prevent me from doing what I want to do or have a severe impact.

013_2023AUCRT

So with pain, you know, I can't do anything, you know, I mean, we're, yeah, a lot of people say 10 where it's not really ten level of 10 pain ... you know, I mean, reality is called five or six, you know what I mean? Yeah, so what I would get what I'm saying it gets to a severe side effect. Now we're talking about debilitation.

027_2023AUCRT

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

I think there's two for me, one is you can't get out of bed...but I'd say in the simplest answer, a severe side effect is just not being able to get out of bed.
016_2023AUCRT

Well, I had a severe when I was in acute care, and that was just as sick as you could imagine. Lying there feeling like you're inside to being eaten out, can't concentrate, completely fatigued, just just lying there in bed. Just passing time really.
022_2023AUCRT

Table 5.24: Description of severe side effects

Description of severe side effects	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7	%	n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant provides a specific side effect as an example	26	78.79	5	71.43	7	70.00	14	87.50	21	80.77	5	71.43	11	73.33	15	83.33
Participant identifies severe side effects as requiring medical intervention	10	30.30	4	57.14	4	40.00	2	12.50	8	30.77	2	28.57	7	46.67	3	16.67
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	5	15.15	0	0.00	0	0.00	5	31.25	5	19.23	0	0.00	2	13.33	3	16.67
Participant identifies severe side effects as impacting their everyday life by being bed ridden	3	9.09	1	14.29	0	0.00	2	12.50	3	11.54	0	0.00	1	6.67	2	11.11

Description of severe side effects	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant provides a specific side effect as an example	26	78.79	15	78.95	11	78.57	10	71.43	16	84.21	11	78.57	15	78.95
Participant identifies severe side effects as requiring medical intervention	10	30.30	7	36.84	3	21.43	4	28.57	6	31.58	3	21.43	7	36.84
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	5	15.15	1	5.26	4	28.57	1	7.14	4	21.05	2	14.29	3	15.79
Participant identifies severe side effects as impacting their everyday life by being bed ridden	3	9.09	3	15.79	0	0.00	1	7.14	2	10.53	0	0.00	3	15.79

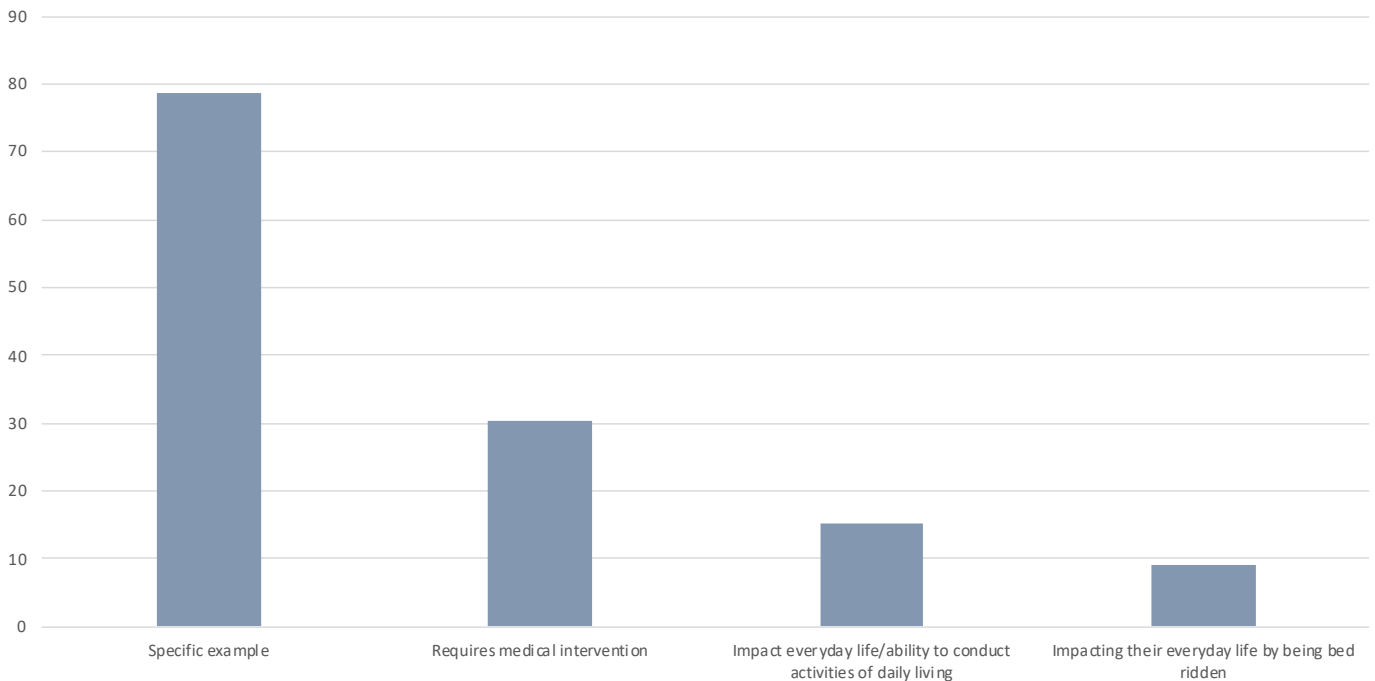


Figure 5.30: Description of severe side effects

Table 5.25: 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		
Participant identifies severe side effects as requiring medical intervention	Multiple Myeloma Male	B-cell acute lymphoblastic leukaemia (ALL) Female
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	B-cell acute lymphoblastic leukaemia (ALL) Diffuse Large B-Cell Lymphoma CAR T-Cell therapy	Multiple Myeloma Aged 65 or older

Table 5.26: Description of severe side effects (Specific example)

Description of severe side effects (Specific side effects)	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7	%	n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes severe side effects giving the specific example of nausea or loss of appetite	10	30.30	2	28.57	4	40.00	4	25.00	8	30.77	2	28.57	3	20.00	7	38.89
Participant describes severe side effects giving the specific example of aches/pain (general)	8	24.24	1	14.29	1	10.00	6	37.50	8	30.77	0	0.00	3	20.00	5	27.78
Participant describes severe side effects giving the specific example of fatigue/lethargy	5	15.15	1	14.29	1	10.00	3	18.75	4	15.38	1	14.29	1	6.67	4	22.22
Participant describes severe side effects giving the specific example of gastrointestinal distress	4	12.12	0	0.00	2	20.00	2	12.50	3	11.54	1	14.29	3	20.00	1	5.56
Participant describes severe side effects giving the specific example of emotion/mental impact	3	9.09	0	0.00	0	0.00	3	18.75	3	11.54	0	0.00	1	6.67	2	11.11
Participant describes severe side effects giving the specific example of impact on sleep	3	9.09	1	14.29	1	10.00	1	6.25	2	7.69	1	14.29	0	0.00	3	16.67
Participant describes severe side effects giving the specific example of neuropathy	3	9.09	0	0.00	1	10.00	2	12.50	1	3.85	2	28.57	1	6.67	2	11.11
Participant describes severe side effects giving the specific example of swelling from fluid build up (including lymphoedema)	3	9.09	1	14.29	1	10.00	1	6.25	3	11.54	0	0.00	1	6.67	2	11.11

Description of severe side effects (Specific side effects)	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes severe side effects giving the specific example of nausea or loss of appetite	10	30.30	7	36.84	3	21.43	5	35.71	5	26.32	4	28.57	6	31.58
Participant describes severe side effects giving the specific example of aches/pain (general)	8	24.24	4	21.05	4	28.57	5	35.71	3	15.79	6	42.86	2	10.53
Participant describes severe side effects giving the specific example of fatigue/lethargy	5	15.15	5	26.32	0	0.00	4	28.57	1	5.26	4	28.57	1	5.26
Participant describes severe side effects giving the specific example of gastrointestinal distress	4	12.12	1	5.26	3	21.43	0	0.00	4	21.05	0	0.00	4	21.05
Participant describes severe side effects giving the specific example of emotion/mental impact	3	9.09	1	5.26	2	14.29	0	0.00	3	15.79	0	0.00	3	15.79
Participant describes severe side effects giving the specific example of impact on sleep	3	9.09	2	10.53	1	7.14	3	21.43	0	0.00	2	14.29	1	5.26
Participant describes severe side effects giving the specific example of neuropathy	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	2	14.29	1	5.26
Participant describes severe side effects giving the specific example of swelling from fluid build up (including lymphoedema)	3	9.09	3	15.79	0	0.00	2	14.29	1	5.26	2	14.29	1	5.26

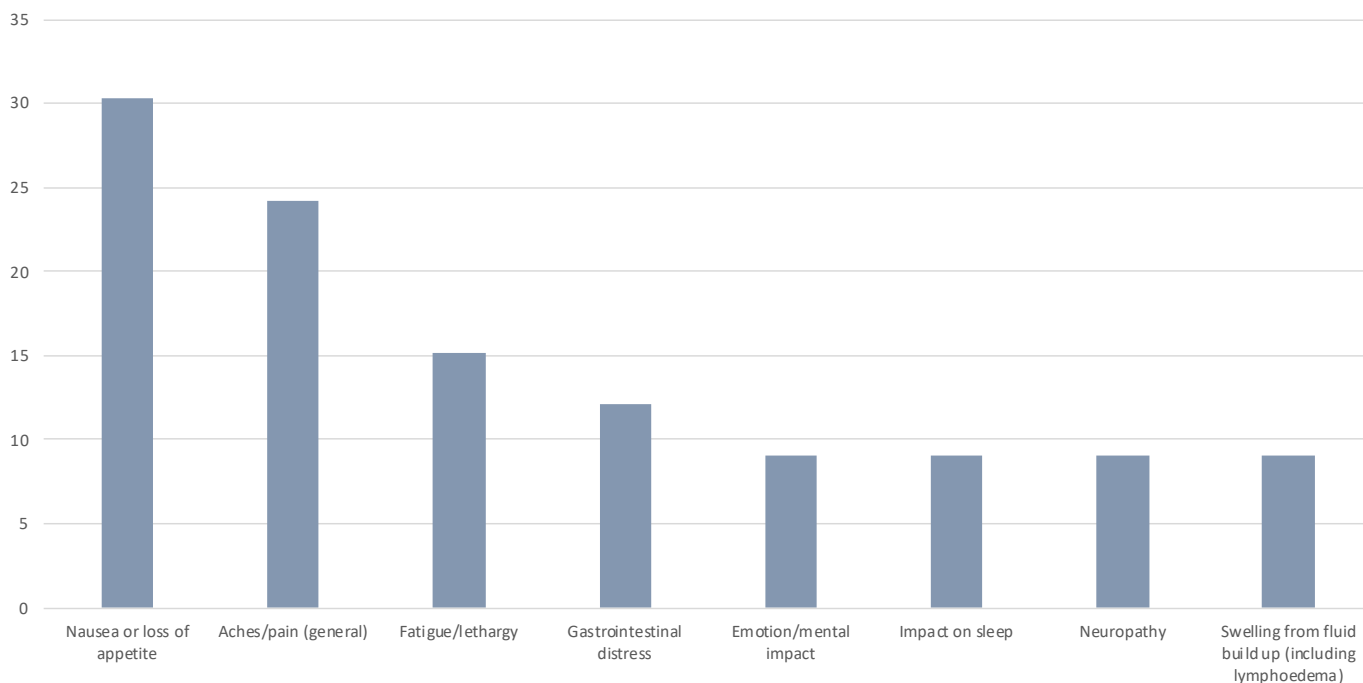


Figure 5.31: Description of severe side effects (Specific example)

Table 5.27: Description of severe side effects (Specific side effects)– subgroup variations

Description of severe side effects (Specific side effects)	Reported less frequently		Reported more frequently	
	Female	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Higher status	Multiple Myeloma Regional or remote Mid to low status	Aged 25 to 64 Regional or remote Mid to low status
Participant describes severe side effects giving the specific example of nausea or loss of appetite	-	-	-	-
Participant describes severe side effects giving the specific example of aches/pain (general)	-	-	-	-
Participant describes severe side effects giving the specific example of fatigue/lethargy	-	-	-	-
Participant describes severe side effects giving the specific example of gastrointestinal distress	-	B-cell acute lymphoblastic leukaemia (ALL) Regional or remote Mid to low status	-	-
Participant describes severe side effects giving the specific example of impact on sleep	-	-	-	Regional or remote
Participant describes severe side effects giving the specific example of neuropathy	-	-	-	CAR T-Cell therapy

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 (75.76%), and never giving up on any treatment (39.39%). Other themes included adhering to treatment as long as side effects are tolerable (12.12%), needing to see test results/no evidence or reduction of disease (12.12%), adhering to treatment as long as treatment is working (9.09%), and adhering to treatment for a specific amount of time (9.09%).

When participants stated a specific amount of time to adhere to a treatment, the amount of time specified was one month (3.03%), six to twelve months (3.03%), and six to twelve months (3.03 %).

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

Oh, I don't give up on it unless the doctor tells me to.
002_2023AUCRT

Probably until. Until the doctor says, I mean there's there's really the only times I've had to well with well when I had the rash the creams on the tablet work. So I did. They worked pretty quickly with the ton thing. They tried a few different ones but at that stage I was I was probably going every week anyway to see them. So within a waste nothing had happened. They'd say okay, we'll we'll give it another week or. Now let's try something different. So, well, we're pretty well guided by what they said. I have a lot of faith in the in the whole medical team, so.
006_2023AUCRT

I've been on the same treatment and as I said before, whatever the doctors and specialists recommend, they're the experts. So I'll do it. 013_2023AUCRT

Participant describes not giving up on any treatment

In my experience, I was on this protocol and they assured me if I stuck on the protocol, it was the best result I could possibly get. So I just stayed the whole distance on the medications for those three years or so. I didn't stop it on any medications at all.
024_2023AUCRT

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

No, I've never given up. I've. I've taken it for as long as I've been under orders too but I have discussed the impact on me with the people treating me you know, I reported the, you know, the rash and I guess it could be regarded as a joint decision.
014_2023AUCRT

Difficult question, I don't know. I think the specialist would tell me but I would say I haven't been thinking about it. But I would say if I get a treatment like my friend in in LOCATION and start having rashes, start having fever, start having problems with breathing or things like that, I don't want to go through them if they have too much serious and side effects.
017_2023AUCRT

I've only given up on one, which was thalidomide, because it was exacerbating the nerve damage in my legs and they swapped to a different one, which was for the nerves in my feet, but it wasn't working well. And after three months we swapped that to amitriptyline.
022_2023AUCRT

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

It's been usually around about in between 3 to six months. I suppose probably minimum of three months is probably the best way. The Thalidomide, we started that in October and we finished in January and the Lantimidomide, we started that in the May and we pulled out in the September. So that's a rough one, yeah but that was visually on my blood counts. So that was placed here on the doctor's sort of indicator if like it's not working. These are the counts and they've gone up to this sort of thing.
019_2023AUCRT

Participant describes adhering to treatment as long as treatment is working

The first one, we did it for about 3 months and then it wasn't affecting...in fact it was not improving, in fact it was spiking so, that's when the hematologist you said, look, it's not working, let's let's move to another medication.
031_2023AUCRT

Wow, depending on what doctors are telling me. Yeah, they they they as as it started with that you know chemotherapy, they explained to me that they started with that baseline the very first, you know medication. Then they monitored, then I said Okay, this one was not really affective. We are adding something stronger, then again something stronger and then they said they have exhausted all all options and nothing it's working. So that's why they had to go away from therapy to CAR-T and and even as I speak you know to you I, I have no, I have no words to express my gratitude that that did have a chance to have that treatment you know, literally to to save my life and for long. So I'm just you know so grateful I know there is new treatment and and and so on and

that that I have been you know qualified you know for this one. So and that's why I so willingly participate in absolutely every clinical trial for whenever I was approached I said yes, you know for we have to support that medical advancement and because I know how was close call for me.

034_2023AUCRT

Participant describes adhering to treatment for a specific amount of time

I'd probably give something maybe about four weeks, three or four weeks.

001_2023AUCRT

Table 5.28: Adherence to treatment

Adherence to treatment	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7	%	n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	25	75.76	6	85.71	8	80.00	11	68.75	19	73.08	6	85.71	12	80.00	13	72.22
Participant describes not giving up on any treatment	13	39.39	4	57.14	5	50.00	4	25.00	9	34.62	4	57.14	5	33.33	8	44.44
Participant describes adhering to treatment as long as side effects are tolerable	4	12.12	0	0.00	0	0.00	4	25.00	4	15.38	0	0.00	0	0.00	4	22.22
Participant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	4	12.12	2	28.57	0	0.00	2	12.50	4	15.38	0	0.00	3	20.00	1	5.56
Participant describes adhering to treatment as long as treatment is working	3	9.09	0	0.00	2	20.00	1	6.25	2	7.69	1	14.29	1	6.67	2	11.11
Participant describes adhering to treatment for a specific amount of time	3	9.09	1	14.29	0	0.00	2	12.50	3	11.54	0	0.00	1	6.67	2	11.11

Adherence to treatment	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	25	75.76	14	73.68	11	78.57	10	71.43	15	78.95	9	64.29	16	84.21
Participant describes not giving up on any treatment	13	39.39	8	42.11	5	35.71	6	42.86	7	36.84	6	42.86	7	36.84
Participant describes adhering to treatment as long as side effects are tolerable	4	12.12	2	10.53	2	14.29	3	21.43	1	5.26	2	14.29	2	10.53
Participant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	4	12.12	3	15.79	1	7.14	0	0.00	4	21.05	1	7.14	3	15.79
Participant describes adhering to treatment as long as treatment is working	3	9.09	2	10.53	1	7.14	1	7.14	2	10.53	1	7.14	2	10.53
Participant describes adhering to treatment for a specific amount of time	3	9.09	3	15.79	0	0.00	1	7.14	2	10.53	2	14.29	1	5.26

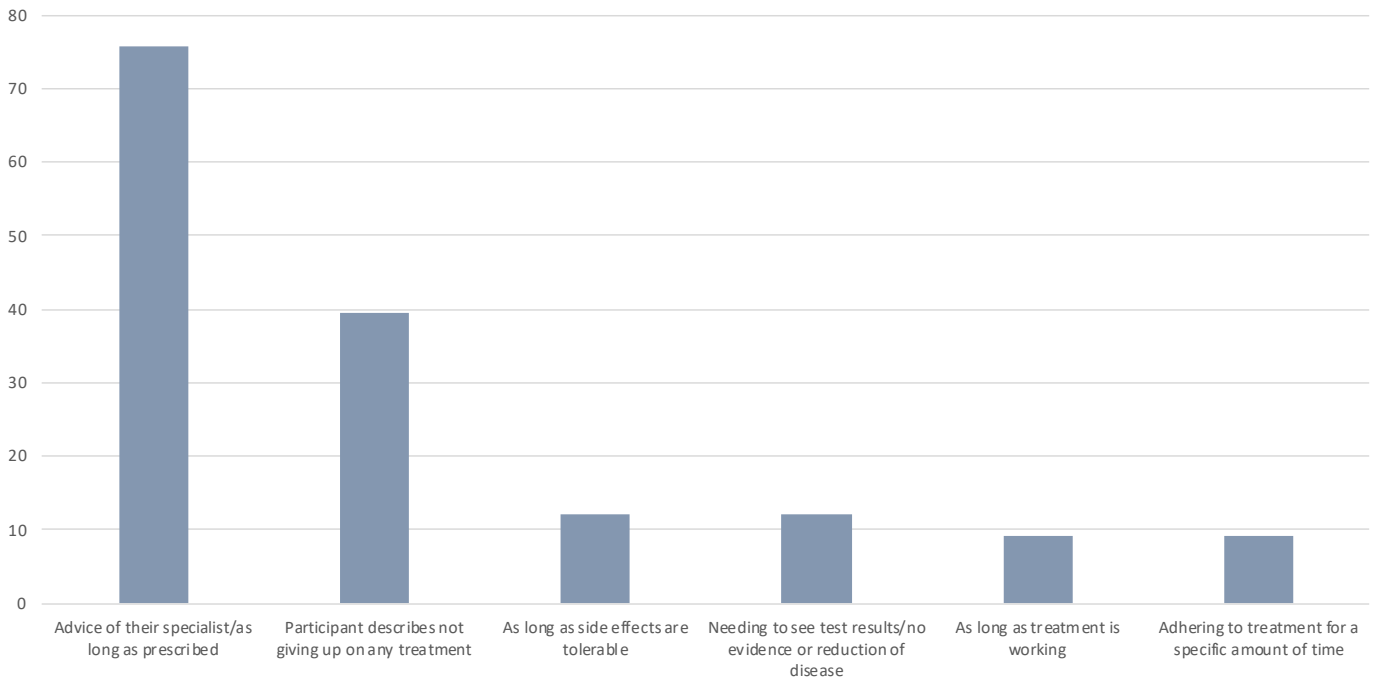


Figure 5.32: Adherence to treatment

Table 5.29 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	Mid to low status	-
Participant describes not giving up on any treatment	Multiple Myeloma	B-cell acute lymphoblastic leukaemia (ALL) Diffuse Large B-Cell Lymphoma CAR T-Cell therapy
Participant describes adhering to treatment as long as side effects are tolerable	B-cell acute lymphoblastic leukaemia (ALL) Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Female	Multiple Myeloma Male
Participant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Regional or remote	B-cell acute lymphoblastic leukaemia (ALL)
Participant describes adhering to treatment as long as treatment is working	-	Diffuse Large B-Cell Lymphoma

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 evidence of stable disease or no disease progression (39.39%), and needing to see physical signs and symptoms disappear or reduced side effects (33.33%). Other themes included needing to see a specific symptom reduction (27.27%), and needing to see a return to day-to-day functionality (15.15%).

When a specific side effect or symptom was described, the most common examples were aches and pain in general (12.12%), and fatigue or lethargy (12.12%).

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

The thing that really made me think it was working was the blood tests, the markers, how active myeloma was. If what he thought was working, if he thought it was working, I thought it was working.
014_2023AUCRT

So far, just the blood biochemistry. I'm just relying on the monthly or weekly blood tests that we are receiving and my especially way of looking at the numbers. So the specialists in the state, for example, recommended having a PET scan after two years of treatment. He was recommending having a PET scan, having a new bone marrow and staging your cancer again for the second time and all of these things.
017_2023AUCRT

I don't know if it's working or not. I just wait for the blood tests and I asked them, so what's the paraprotein level? And she, she will tell me what it is. And she's even given me chance to show how where the various treatments have been extremely fantastic. So she's got a full graph from when I started to where I am now, you know. And so and so she's very clear about that.
018_2023AUCRT

I suppose I measure everything on my count. So I just, I measure a couple of things in my blood counts and if they're going down, I feel great. If they're going the other way, I get determined, yeah, and go from there.
019_2023AUCRT

Participants reported needing to see all physical signs and symptoms disappear

Obviously, you need to see an improvement in yourself, but even so, if I can't see an improvement and the doctors are telling me that there's only been an improvement in my blood or whatever, then that's enough for me.
002_2023AUCRT

Yeah, I suppose a reduction in side effects and generally that you feel that there is all of a sudden, it might be a doctor saying your levels have gone from here to there, your functions gone from here to there. So I suppose again that feedback from a medical professional or you can feel it yourself that you do generally feel better.
026_2023AUCRT

Participant describes needing to see a reduction in a specific symptom

Yes. One of the ones I knew really helped me was the mouth ulcers. I was really grateful because I still had ulcers, and I still had swelling, but I still get that now, it seems to be an ongoing thing that I'm left with. I knew that that mouthwash helped enormously.
004_2023AUCRT

I think for me there's two things. I have this host disease of my gut. So for me it's a sense that I don't have to plan where the toilet is before I go out. So you know, that's kind of a bit of a gauge for me, but also my emotional well-being. All of those things that I take can make you feel really tired and worn out and cranky. So the other one is my emotional well-being.

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

Well, I think it's difficult to group any particular medication and it's affecting side effects on its own. I think as a whole, the fact that I'm back at work now and living a what I would call a 80% normal life means that it's worked, I think. But it's been the combination of everything...You're at a new normal.
022_2023AUCRT

Just that I'm sort of apart from the treatment I operate daily, as I would if I didn't have cancer, more or less. Apart from the mild side effects, but I can, you know, I can stay up all day and not have to rest and go out and do things and not get fatigued like a lot of people do. Yeah, like be out really late. Like, as an example, I went to the Women's World Cup and we didn't get home till 1:30 in the morning. So I was still like, didn't get tired, whereas other people would.
032_2023AUCRT

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

What needs to change to feel like treatment is working	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7	%	n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Participants reported needing to experience evidence of stable disease/no disease progression	13	39.39	3	42.86	4	40.00	6	37.50	9	34.62	4	57.14	4	26.67	9	50.00
Participants reported needing to see all physical signs and symptoms disappear	11	33.33	4	57.14	5	50.00	2	12.50	6	23.08	5	71.43	7	46.67	4	22.22
Participant describes needing to see a reduction in a specific symptom	9	27.27	2	28.57	0	0.00	7	43.75	8	30.77	1	14.29	4	26.67	5	27.78
Participants reported needing to experience a return to day-to-day functionality	5	15.15	0	0.00	1	10.00	4	25.00	5	19.23	0	0.00	1	6.67	4	22.22

What needs to change to feel like treatment is working	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Participants reported needing to experience evidence of stable disease/no disease progression	13	39.39	8	42.11	5	35.71	7	50.00	6	31.58	7	50.00	6	31.58
Participants reported needing to see all physical signs and symptoms disappear	11	33.33	7	36.84	4	28.57	3	21.43	8	42.11	3	21.43	8	42.11
Participant describes needing to see a reduction in a specific symptom	9	27.27	3	15.79	6	42.86	1	7.14	8	42.11	2	14.29	7	36.84
Participants reported needing to experience a return to day-to-day functionality	5	15.15	3	15.79	2	14.29	3	21.43	2	10.53	3	21.43	2	10.53

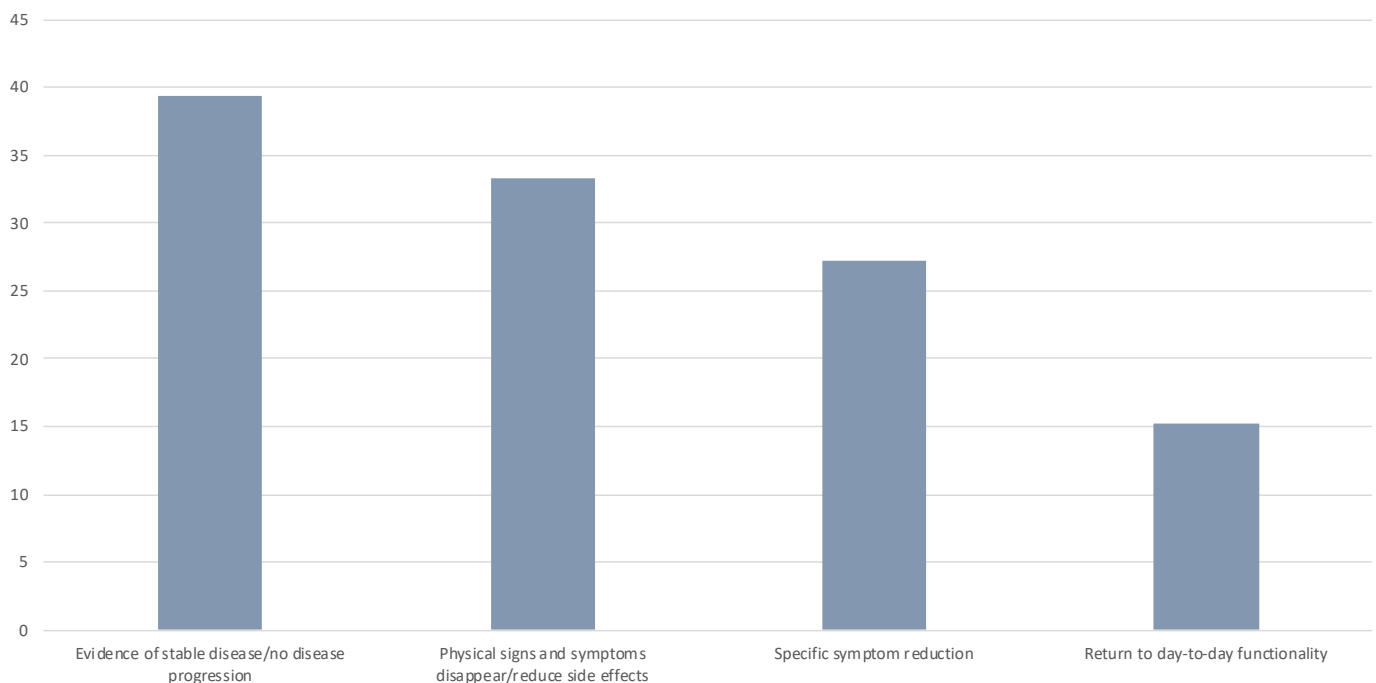


Figure 5.33: What needs to change to feel like treatment is working

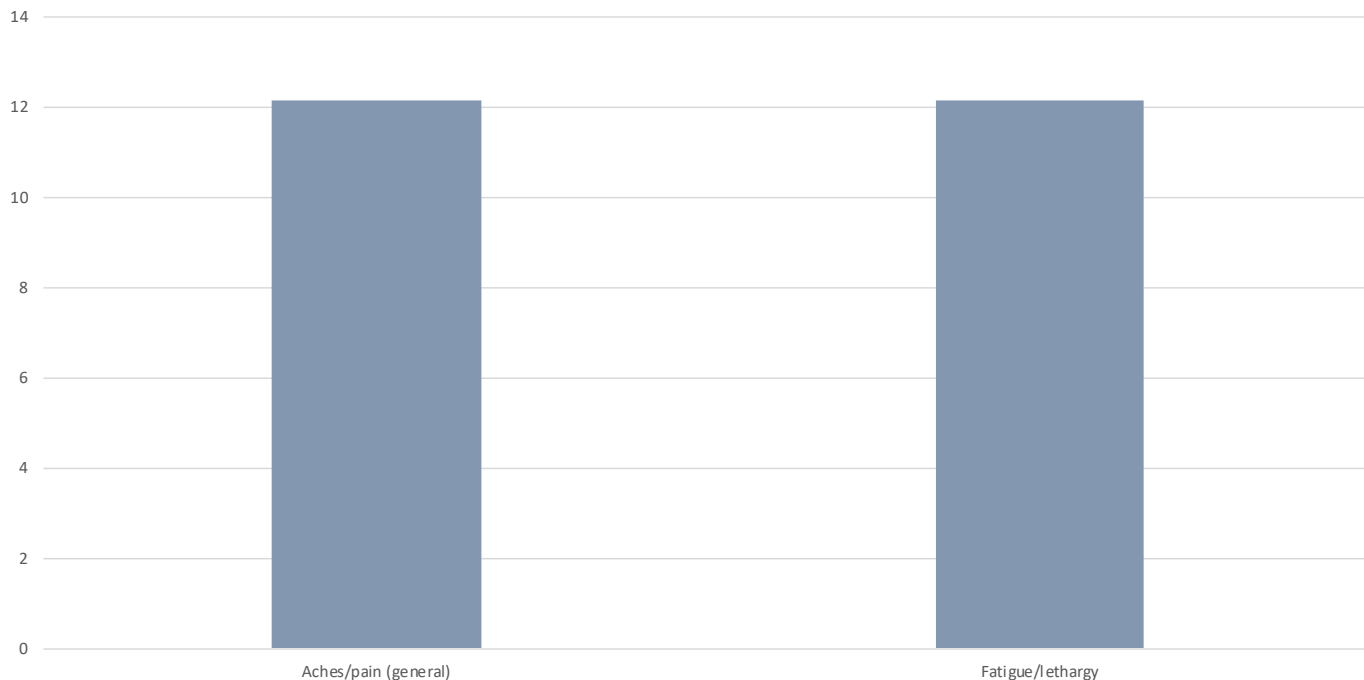


Figure 5.34: What needs to change to feel like treatment is working (specific symptoms)

Table 5.31: What needs to change to feel like treatment is working – subgroup variations

What needs to change to feel like treatment is working	Reported less frequently	Reported more frequently
Participants reported needing to experience evidence of stable disease/no disease progression	Female	CAR T-Cell therapy Male Regional or remote Mid to low status
Participants reported needing to see all physical signs and symptoms disappear	Multiple Myeloma No CAR T-Cell therapy Male Regional or remote Mid to low status	B-cell acute lymphoblastic leukaemia (ALL) Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Female
Participant describes needing to see a reduction in a specific symptom	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy Aged 25 to 64 Regional or remote Mid to low status	Multiple Myeloma Aged 65 or older Metropolitan
Participants reported needing to experience a return to day-to-day functionality	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy	

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 (42.42%), and that it would have a positive impact on their mental health (24.24%). Other themes included allowing them to do more exercise (18.18%), allowing them to return to work (12.12%), and allowing them to engage more with social activities and family life (12.12%).

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

Well, when I was really sick, I couldn't do anything. Like basically all I did was sit in a chair, or lay in a bed. That's all I did. And slowly over the it's taken like a couple of years, like I can get out and do a bit of

garden now and do a few things. I still can't do what I used to do. 011_2023AUCRT

If you can feel well and get on with some of your activities, it certainly makes you feel like you're living a bit more of a normal life. Yes. Yeah. So it is quite important manage side effects. 021_2023AUCRT

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

I don't know whether there would be any change, but just mentally, there's that change. 002_2023AUCRT

I guess it'd just give me a bit of hope, keep planning for the future. Yes, like there's a light at the end of the tunnel, I guess.

005_2023AUCRT

I think your question was about how how does it affect my life and I think it just, I just felt better when when things were, I felt happier I guess, although I wasn't, I wasn't unhappy. Once I got off the steroids I was not not unhappy but the I actually I the I did take thalidomide in conjunction with Prednisolone. So I was pleased to get off the thalidomide because of the rash and I was pleased to get off the off the Prednisolone because of the its impact on my body and putting on weight.

014_2023AUCRT

If it wasn't working I'd it'd be a constant mental battle to feel update that you feel it's spiraling downwards and and that's probably because I live with an incurable condition. So I if it's going backwards as much as I try and maintain a positive outlook in life, you know, occasionally, well it does. It catches up on you and you think you get a bit despondent if it's going the right direction it would give me hope and excitement and and it'd be you know it may give you or may give me a reprieve from having it constantly in the back of your mind every minute of every day. You know you all cancer patients are the same and that you know we all get about laughing, get on with it. But it's just there in the back that you know that 1% or half percent in the back of your head, Be nice to be able to remove that one or half a percent in the back of your head. What you're saying, you know, it's tick, tick, tick, tick sort of thing, that's all.

019_2023AUCRT

Participant describes that if treatment worked for them, it would allow them to do more exercise

I'm not sure I know the answer to that either. I haven't let this stop me. I took up bowls because the surgeon said you can't play golf for six months. Last time I played golf was in January this year and I found myself disoriented and with a total lack of energy to be able to play the other ten holes.

008_2023AUCRT

PARTICIPANT: It'd make me happier that I can get out into the Bush. Yes, yeah, yeah. And I mean, part of bush walking and engaging in nature is, of course maintaining mental health, as NAME just said.

I guess my major hobby would be severely limited if if the treatment wasn't working.

013_2023AUCRT

Participant describes that if treatment worked for them, it would allow them to return to work

Oh well, I think if my life would be able to look a lot more like it did before I became unwell, you know, I'd have a bit of stamina to be able to, you know, do to finish things. You know, instead of working on something for an hour or two, I'd be able to, you know, do it all day. I'd be going back to work. I'd be, you know, thinking more. I'd be feeling more confident about going back to work. Yeah, they're the main two, I think. I mean, I try and do all the things that I used to do and I've got a really strong list of things that I've achieved but it's yeah, it's about stamina to do them and you know, not needing a day to recover or a week to recover cuz you've done one of them.

016_2023AUCRT

The only other thing I suppose, treatment that I'd like is because I still get, I still get tired quite a bit and I get a bit foggy in the brain. So yeah, I wouldn't mind a bit more energy and alertness, I suppose. Yeah, yeah, very nice. That would be good and that would make it. Easier for me because as yet I haven't gone back to work. I'll probably will need to soon and it'll be just part time. So I suppose if I could if there could be some treatment for the for the sort of the the brain fog and that that would that would make it easier to go back to work I guess.

006_2023AUCRT

Participant describes that if treatment worked for them, it would allow them to engage more with social activities and family life

The best thing for me was been able to get out of an isolated room in the hospital, so I needed my neutrophils to increase to a level where it was safe for me to to go out into sort of public spaces and things like that, so. Just take me away from the isolated room. That was my main goal at the start of the treatment.

024_2023AUCRT

Oh, I mean, we go for walks along the beach with family a lot and more socializing. If we go to a cinema or something, we always pick a session where there's hardly anyone there. So we can do that, so we can eat out picking where we sit, preferably outside. If you didn't have the treatment, I think you just wouldn't do anything. You know I'd just be sitting on the couch.

035_2023AUCRT

Table 5.32: What it would mean if treatment worked

What it would mean if treatment worked	All participants		B-cell acute lymphoblastic leukaemia (ALL)		Diffuse Large B-Cell Lymphoma		Multiple Myeloma		No CAR T-Cell therapy		CAR T-Cell therapy		Female		Male	
	n=33	%	n=7	%	n=10	%	n=16	%	n=26	%	n=7	%	n=15	%	n=18	%
Allowing them to do everyday activities/return to normal life	14	42.42	2	28.57	4	40.00	8	50.00	12	46.15	2	28.57	7	46.67	7	38.89
A positive impact on their mental health	8	24.24	1	14.29	1	10.00	6	37.50	8	30.77	0	0.00	3	20.00	5	27.78
Allowing them to do more exercise	6	18.18	0	0.00	1	10.00	5	31.25	3	11.54	3	42.86	2	13.33	4	22.22
Allowing them to return to work	4	12.12	2	28.57	1	10.00	1	6.25	3	11.54	1	14.29	4	26.67	0	0.00
Allowing them to engage more with social activities and family life	4	12.12	2	28.57	0	0.00	2	12.50	3	11.54	1	14.29	0	0.00	4	22.22

What it would mean if treatment worked	All participants		Aged 25 to 64		Aged 65 or older		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=33	%	n=19	%	n=14	%	n=14	%	n=19	%	n=14	%	n=19	%
Allowing them to do everyday activities/return to normal life	14	42.42	8	42.11	6	42.86	5	35.71	9	47.37	5	35.71	9	47.37
A positive impact on their mental health	8	24.24	4	21.05	4	28.57	2	14.29	6	31.58	3	21.43	5	26.32
Allowing them to do more exercise	6	18.18	0	0.00	6	42.86	2	14.29	4	21.05	1	7.14	5	26.32
Allowing them to return to work	4	12.12	2	10.53	2	14.29	0	0.00	4	21.05	0	0.00	4	21.05
Allowing them to engage more with social activities and family life	4	12.12	2	10.53	2	14.29	2	14.29	2	10.53	2	14.29	2	10.53

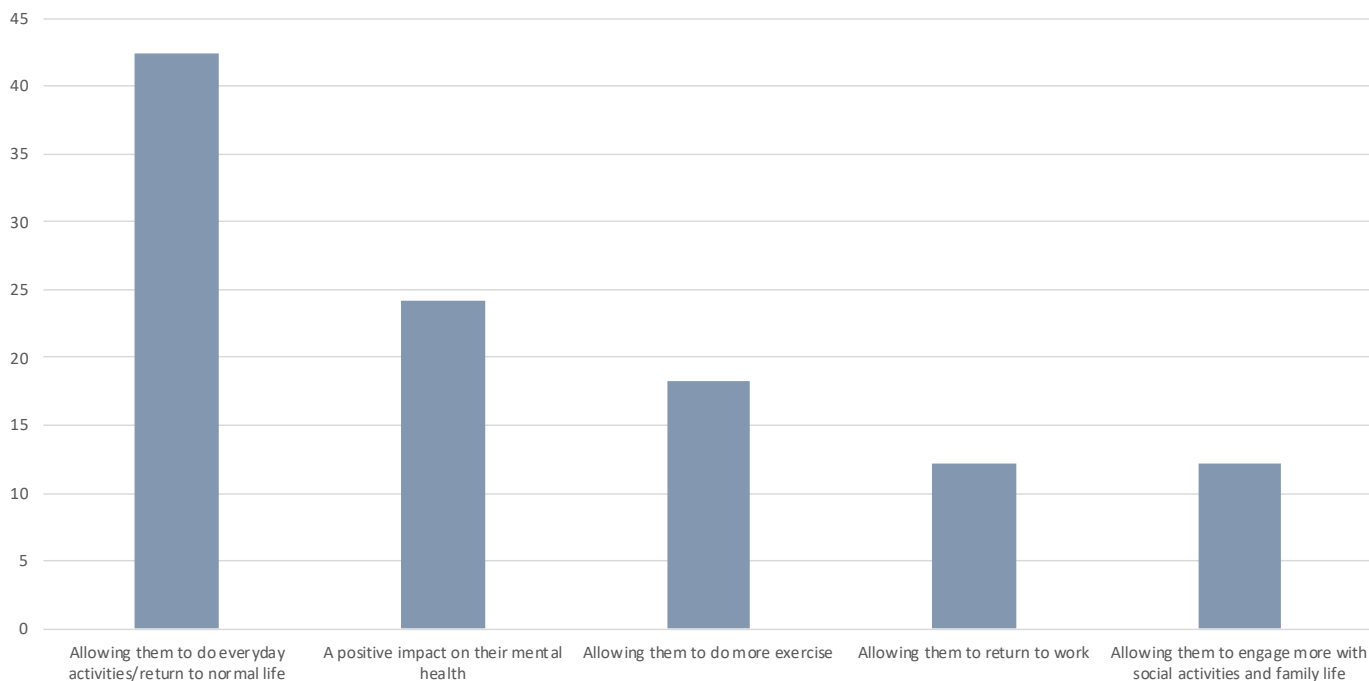


Figure 5.35: What it would mean if treatment worked

Table 5.33: 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	B-cell acute lymphoblastic leukaemia (ALL) CAR T-Cell therapy	-
A positive impact on their mental health	Diffuse Large B-Cell Lymphoma CAR T-Cell therapy	Multiple Myeloma
Allowing them to do more exercise	B-cell acute lymphoblastic leukaemia (ALL) Aged 25 to 64 Mid to low status	Multiple Myeloma CAR T-Cell therapy Aged 65 or older
Allowing them to return to work	Male Regional or remote Mid to low status	B-cell acute lymphoblastic leukaemia (ALL) Female
Allowing them to engage more with social activities and family life	Diffuse Large B-Cell Lymphoma Female	B-cell acute lymphoblastic leukaemia (ALL) Male