

Section 5

Treatment

Section 5: Experience of treatment

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 examples (55.00%), and side effects that do not interfere with life (35.00%). This was followed by side effects that can be managed with self-medication or self-management (25.00 %), and side effects that resolve quickly (5.00%).

When a specific side effect was described, the most common responses were rash, dry skin or itchy skin (30.00%), aches and pains (20.00%), and nausea, vomiting or loss of appetite (15.00 %). Other side effects included headaches (10.00%), indigestion (5.00%), lightheaded or dizzy (5.00%), bleeding (5.00%), bloating (5.00%), dry lips (5.00%), and thrush (5.00%).

Description of severe side effects

In the structured interview, participants were asked how they would describe the term 'severe side effects'. The most common description of severe side effects were those that impact everyday life or ability to conduct activities of daily living (40.00%), and described using a specific example (30.00%). Other descriptions of side effects included those that are life threatening or result in hospitalisation (15.00%), side effects that impact their everyday life by being bed ridden (15.00%), side effects that are worse than condition (10.00%), side effects that cause long-term damage to their body (5.00%), side effects that require medical intervention (5.00%), and side effects that cause them to stop taking the treatment (5%).

When a specific side effect was described, the most common examples were allergic reaction (10.00%), and skin blistering or skin eruptions (10.00%). Other side effects included arthritis (5.00%), blood clots (5.00%), fever (5.00%), loss of vision (5.00%), painful urination (5.00%), and tremors (5.00%).

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime.

The most common responses were adhering to treatment for a specific amount of time (55.00%), adhering to treatment according to the advice of their specialist or as long as prescribed (50.00%), and adhering to treatment as long as side effects are tolerable (30.00 %). Other themes included adhering to treatment as long as treatment is working (20.00%), needing to see test results/no evidence or reduction of disease (5.00%), and never giving up on any treatment (5.00%).

When participants stated a specific amount of time to adhere to a treatment, the most common amount of time was two to three months (20.00%), and six to twelve months (15.00%). This was followed by one month (10.00 %), and two to three weeks (5.00%).

What needs to change to feel like treatment is working

Participants were asked to describe what needs to change to feel like treatment is effective. The most common responses were needing to see physical signs and symptoms disappear or reduced side effects (85.00%), and needing to see a specific symptom reduction (35.00%). Other themes included needing to see improvements in general wellbeing or quality of life (10.00%), and needing to see evidence of stable disease or no disease progression (5.00%).

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 examples (55.00%), and side effects that do not interfere with life (35.00%). This was followed by side effects that can be managed with self-medication or self-management (25.00 %), and side effects that resolve quickly (5.00%).

When a specific side effect was described, the most common responses were rash, dry skin or itchy skin (30.00%), aches and pains (20.00%), and nausea, vomiting or loss of appetite (15.00 %). Other side effects included headaches (10.00%), indigestion (5.00%), lightheaded or dizzy (5.00%), bleeding (5.00%), bloating (5.00%), dry lips (5.00%), and thrush (5.00%).

Participant provides a specific side effect as an example

Yeah, like a little bit of itch. Yes, yes. Stuff that you could easily cope with might be a bit annoying, but yes, yeah.

Participant 019_2023AUHIS

Mild side effects I describe as occasional headaches, very very faint disorientation, slight skin rash, cold flu symptoms for a few days. Pain at the injection site for a few days afterwards though. Those sorts of things. The occasional headache, that that sort of stuff. I yeah, I don't know how, I haven't actually experienced many. I wouldn't know what to describe with with mild side effects other than those.

Participant 012_2023AUHIS

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

How would I describe the term mild side effects? Yeah, I guess side effects that don't majorly impact on your life.

Participant 001_2023AUHIS

Mild side effects for me would just be anything that I noticed and is inconvenient, but I can still get on with my day. I can still function normally.

Participant 010_2023AUHIS

Basically he's he he can like still go and do his go to school and and do his things. It doesn't impact too much on his daily life.

Participant 009_2023AUHIS

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

So mild side effects I would kind of refer to as probably something like thrush and you can just use Caniston and you know sort it out you can, you can sort out the side effect.

Participant 017_2023AUHIS

Well, I've only had the dry lips. Mine was just mild. Just Vaseline on the lips and just live with it.

Participant 013_2023AUHIS

Table 5.1: Description of mild side effects

Description of mild side effects	All participants	
	n=20	%
Participant provides a specific side effect as an example	11	55.00
Participant describes mild side effects as those that do not interfere with daily life	7	35.00
Participant describes mild side effects as those that can be self-managed	5	25.00
Participant describes mild side effects as those that resolve quickly	1	5.00

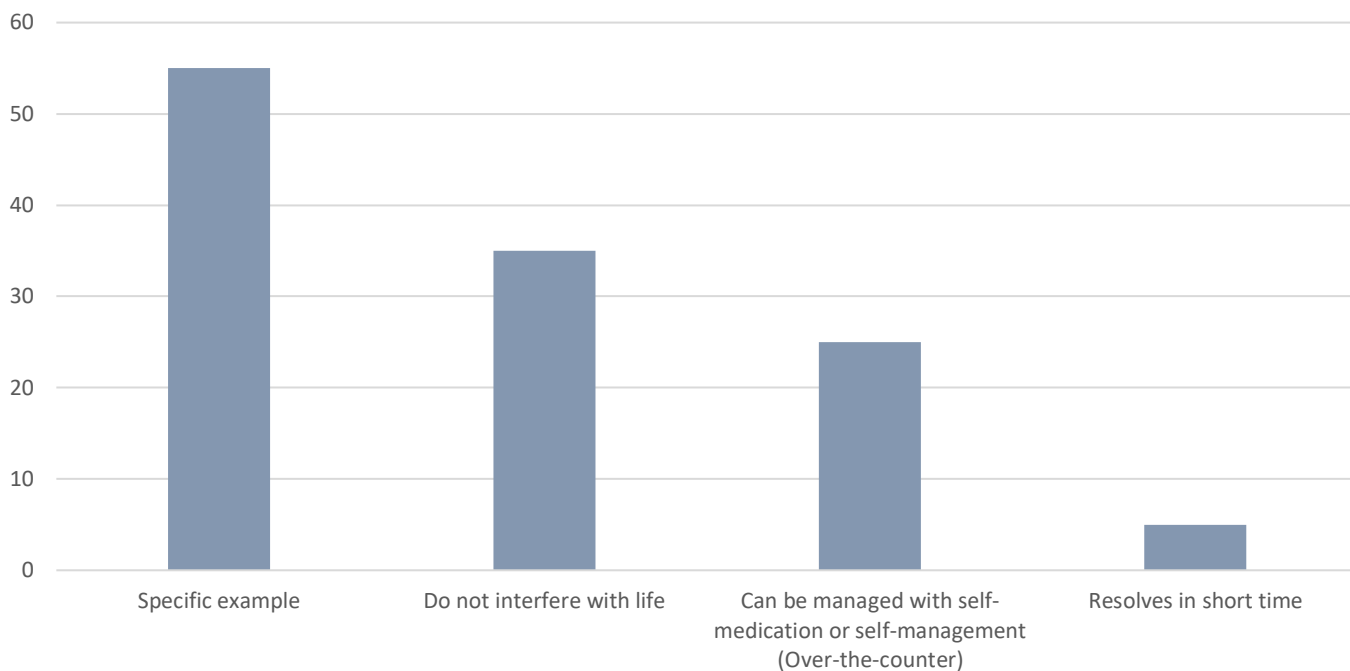


Figure 5.1: Description of mild side effects

Table 5.2: Description of mild side effects (Specific side effects)

Description of mild side effects (specific example)	All participants	
	n=20	%
Participant describes mild side effects giving the specific example of rash, dry skin or itchy skin	6	30.00
Participant describes mild side effects giving the specific example of aches/pain (general)	4	20.00
Participant describes mild side effects giving the specific example of nausea, vomiting or loss of appetite	3	15.00
Participant describes mild side effects giving the specific example of headaches	2	10.00
Participant describes mild side effects giving the specific example of indigestion	1	5.00
Participant describes mild side effects giving the specific example of lightheaded and/or dizzy	1	5.00
Participant describes mild side effects giving the specific example of bleeding	1	5.00
Participant describes mild side effects giving the specific example of bloating	1	5.00
Participant describes mild side effects giving the specific example of dry lips	1	5.00
Participant describes mild side effects giving the specific example of thrush	1	5.00

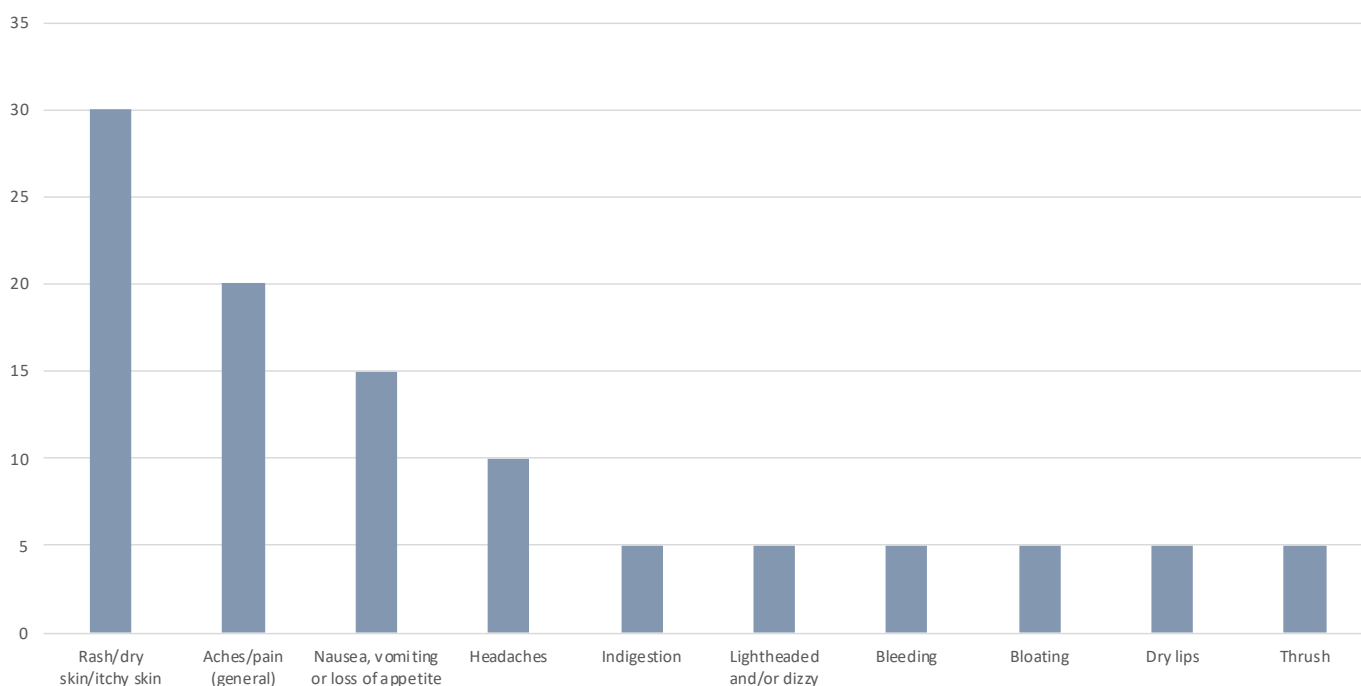


Figure 5.2: Description of mild side effects (Specific side effects)

Description of severe side effects

In the structured interview, participants were asked how they would describe the term 'severe side effects'. The most common description of severe side effects were those that impact everyday life or ability to conduct activities of daily living (40.00%), and described using a specific example (30.00%). Other descriptions of side effects included those that are life threatening or result in hospitalisation (15.00%), side effects that impact their everyday life by being bed ridden (15.00%), side effects that are worse than condition (10.00%), side effects that cause long-term damage to their body (5.00%), side effects that require medical intervention (5.00%), and side effects that cause them to stop taking the treatment (5%).

When a specific side effect was described, the most common examples were allergic reaction (10.00%), and skin blistering or skin eruptions (10.00%). Other side effects included arthritis (5.00%), blood clots (5.00%), fever (5.00%), loss of vision (5.00%), painful urination (5.00%), and tremors (5.00%).

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

Would be the ones that impact severely on your quality of life, but being able to function from day-to-day.

Participant 001_2023AUHIS

I'd say severe is when it's actually impacting what you're what you're able to do. So when it when it has an impact on your functioning.

Participant 007_2023AUHIS

Daily life severe is when he can't go to school or he can't do his daily activities.

Participant 009_2023AUHIS

Participant provides a specific side effect as an example

Bleeding, body aches, pain, shake, fever. I describe it as lack of ability, lack of being able to function on during your day-to-day life and any capacity. Loss of vision, blistering bump, blood clots, those sorts.

Participant 012_2023AUHIS

And I guess the severe one is the depression. But obviously I know what it is, I know what it feels like. I can pretty much handle it until it goes away.

Participant 014_2023AUHIS

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

Side effect might be a rash, OK, or vomiting. Have severe side effects, might be losing consciousness or you know.

Participant 002_2023AUHIS

So for me, a severe side effect would be, you know, obviously allergic reactions, bleeding in the stomach or severe constipation, impacted bowels, things that would affect you from living your normal day-to-day life. Participant 005_2023AUHIS

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

Severe would probably be something where I'm in a bit more pain where I maybe need to lay down and get a heat pack out and put it on the area or I have an intense migraine. To the point where I need to turn off the lights and put myself to sleep and I can't really do much.

Participant 010_2023AUHIS

The healing process from surgery is quite hard I it I didn't heal properly from the first scar tissue removal, so I spent probably. Over six weeks in bed, not being able to walk properly, trying to let it heal. But again, I live on my own so the healing process is quite frustrating.

Participant 018_2023AUHIS

Table 5.3: Description of severe side effects

Description of severe side effects	All participants	
	n=20	%
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	8	40.00
Participant provides a specific side effect as an example	6	30.00
Participant describes severe side effects as those that are life threatening or result in hospitalisation	3	15.00
Participant identifies severe side effects as impacting their everyday life by being bed ridden	3	15.00
Participant describes severe side effects as those that are worse than condition	2	10.00
Participant describes severe side effects as those that cause long-term damage to their body	1	5.00
Participants reported not experiencing any severe side effects	1	5.00
Participant identifies severe side effects as requiring medical intervention	1	5.00
Participant describes severe side effects as those that cause them to stop taking the treatment	1	5.00

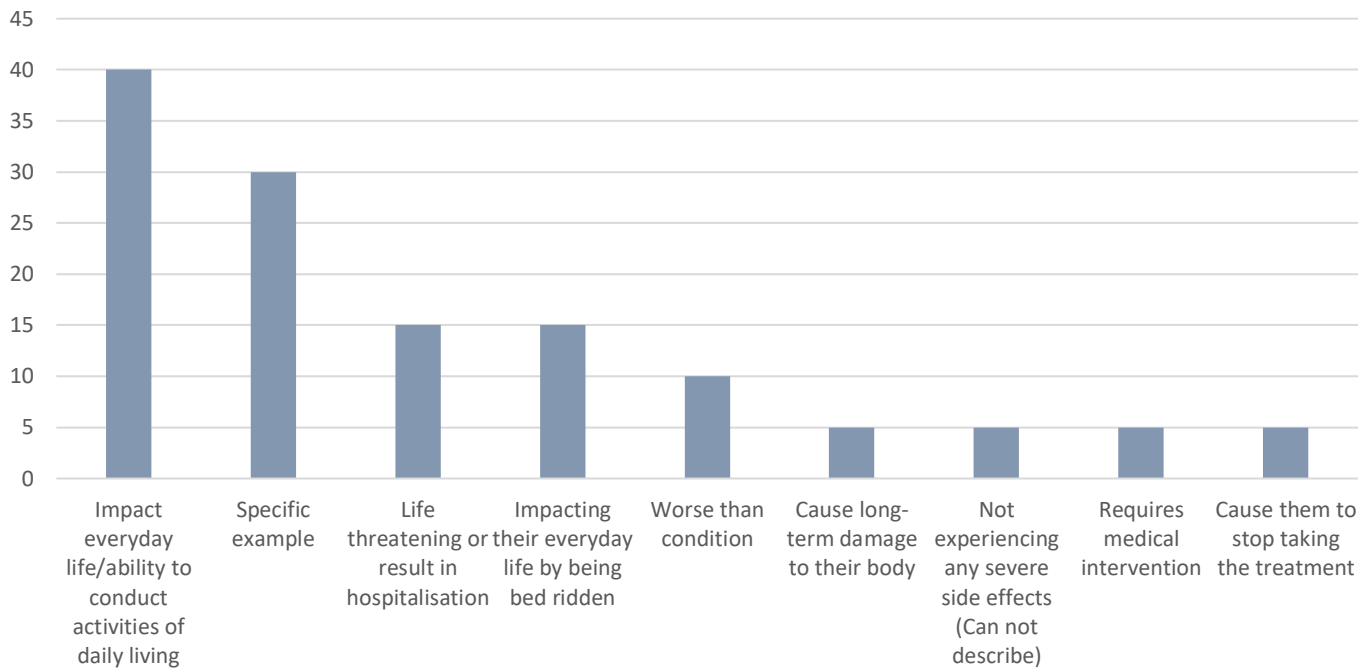


Figure 5.3: Description of severe side effects

Table 5.4: Description of severe side effects (Specific example)

Description of severe side effects (specific examples)	All participants	
	n=20	%
Participant describes severe side effects giving the specific example of allergic reaction	2	10.00
Participant describes severe side effects giving the specific example of skin blistering or skin eruptions	2	10.00
Participant describes severe side effects giving the specific example of arthritis	1	5.00
Participant describes severe side effects giving the specific example of blood clots	1	5.00
Participant describes severe side effects giving the specific example of fever	1	5.00
Participant describes severe side effects giving the specific example of loss of vision	1	5.00
Participant describes severe side effects giving the specific example of painful urination	1	5.00
Participant describes severe side effects giving the specific example of tremors	1	5.00

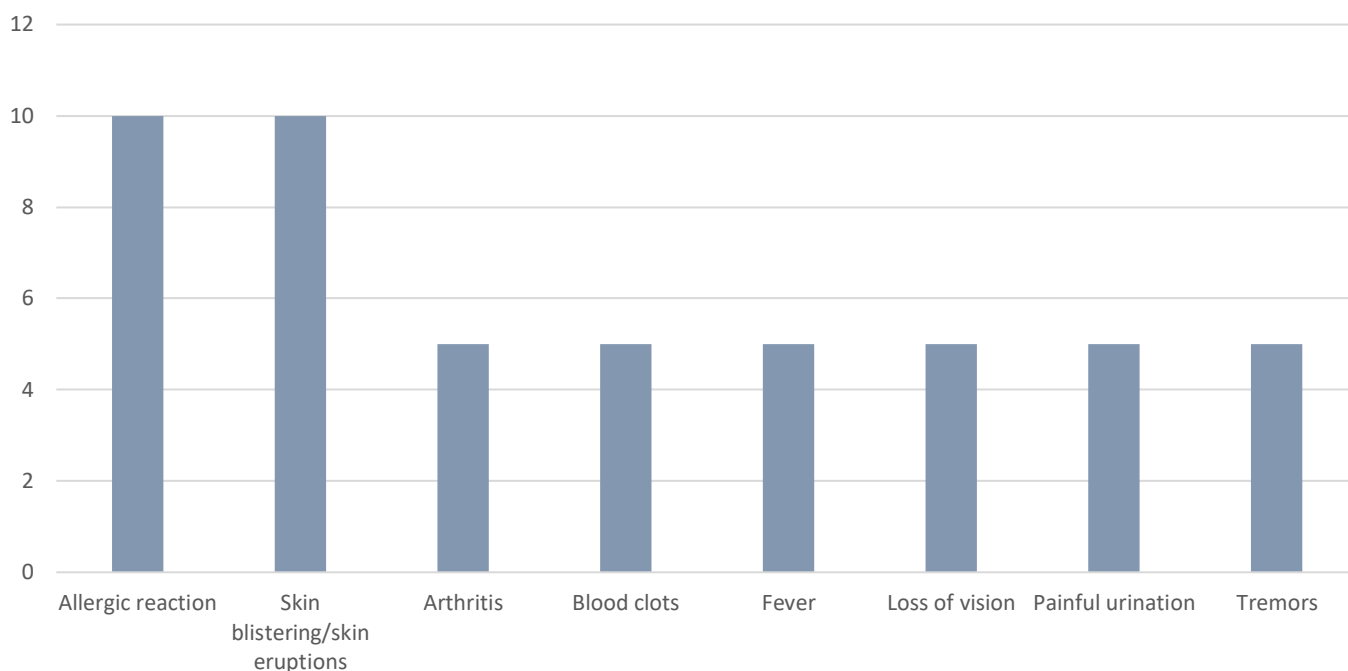


Figure 5.4: Description of severe side effects (Specific example)

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime.

The most common responses were adhering to treatment for a specific amount of time (55.00%), adhering to treatment according to the advice of their specialist or as long as prescribed (50.00%), and adhering to treatment as long as side effects are tolerable (30.00%). Other themes included adhering to treatment as long as treatment is working (20.00%), needing to see test results/no evidence or reduction of disease (5.00%), and never giving up on any treatment (5.00%).

When participants stated a specific amount of time to adhere to a treatment, the most common amount of time was two to three months (20.00%), and six to twelve months (15.00%). This was followed by one month (10.00%), and two to three weeks (5.00%).

Participant describes adhering to treatment for a specific amount of time

PARTICIPANT: *Depends on the treatment. Like antibiotics, I'll give I'll give no more than than two to three weeks, because any longer than that and I find I start getting gut problems regardless. Steroids, I'll go the full course. Humira. The biologics like Humira. The first time I was on Humira I gave it 8 weeks. The second time, but they wanted to try it*

again. After my second pregnancy, I gave it three months before I just threw the town and said I can't deal with it anymore. It it really depends on on the drug, on the side effects.

Participant 012_2023AUHIS

I guess my rule for any medication is 3 months and if it's not working then it's probably not going to work. But yeah, this is my first lot of actual meds that I've tried.

Participant 014_2023AUHIS

About a month.

Participant 004_2023AUHIS

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

OK, so I've always gone. So with any of the medications I've taken to HS, I've always gone with the recommend recommendation of of my specialists and my, my, my GP or my dermatologist. So if they've said to me I need to give it three months, then I would give it three months. If they said to me I've got to give it six months, I would give it six months.

Participant 001_2023AUHIS

I mean, I finished the course typically, but then yeah, if I go back to the doctors and I told them I finished it and nothing's changed and. Yeah, I mean I I'm open noise trying something new.

Participant 003_2023AUHIS

I'd have to be recommended by the what the doctor. Would say the doctor might. Well, the doctor told us that he thought that he needed to have, I don't know, minimum of three months on unbroken stint on the Humira. We had a very rocky start last year because he's at an age where he had to have all the whole his vaccinations. And as it turns out, we ended up. And you have to go off the medication in order to have the vaccinations. So we ended up missing out on a couple of vaccinations that we've got to do in a month or two time.

Participant 009_2023AUHIS

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

It depends if the side effects were outweighing the attempts. So if if there were significant side effects then it would be a lot. The time scale would be a lot reduced than if there were no side effects. So like the an example I'll give you is the antibiotics. They were inefficient, they cost a lot of money, but I stuck with it for a year to prove a point. To meet criteria to to get to the next level of treatment, you know, start with the wrong Accutane visit for a year. Obviously this is not working, but what's next?

Participant 002_2023AUHIS

I will usually I follow the the prescribed course unless unless I think I've had a big reaction to it, in which case I'll reach out to the prescriber and say this is what's going on. Can I stop this or should I be stopping this?

Participant 007_2023AUHIS

Oh, you've just reminded me. Oh my goodness, sorry, I have had another another treatment. I've had this cream that they gave me. This is that you've just prompted my my thoughts on that. Everything else I've stuck with it for as long as the doctor has has recommended. And then if they've decided it's not working and that I should come off it, then I'll come off it. But I was given cream that had to be made-up at a compounding pharmacy, which is commonly and it peels your skin, Oh my gosh, what's it called? Recorsic cold, recorsic cold cream and. It's topical and it's supposed to pale your skin. I don't know. Anyway, I'm sorry, I am allergic to that and I stopped using it

after the second or third time that I used it because I got a quite a bad rash and the dermatologist has continually tried to get me to go back. Onto using it and I've completely sitting on he's like why don't you you know put half Sauberlene like break it down don't use it and I'm yeah so I gave up on that one pretty quickly and because it it was just my skin was just not very very happy with that so sorry that. That's the tenth option that I've been the 10th.

Participant 017_2023AUHIS

It depends on what it does. If it has no effects and and it's causing side effects, there's no point in staying on it. Yeah, you know they put me on doxycycline at one point. And the reflux was so out of control. I slept on a kitchen chair because I couldn't lie down and I felt like here and I felt like I couldn't breathe. Yeah, so. And I was supposed to be on that for three months. And after one month I literally just stopped taking it. I rang them and said, and I'd rather, I'd rather put up with the disease than what I'm doing because it was the reflux was just horrible.

Participant 005_2023AUHIS

Participant describes adhering to treatment as long as treatment is working

So it's kind of like a hypothetical. I'd give it three months. In a bizarro universe, if if I did accept adalimumab or Humira, which is the one drug on label, I'd give it three months. Even if a dermatologist tells me, you know, you should give it seven or ten months or two to four years or whatever, that's three months. But that'd be a fair enough time. If it's not working, it's not working.

Participant 008_2023AUHIS

I think it's hard to say if this is the first time I've been given like long term medication to take for the disease, but I'm only supposed to be on it for about 6 to 8 months. I'm at months to and I'm not seeing too much of a change, but I think like I don't want to give up. I don't know what it would take for me to give up on the medication. But I'd say if it didn't work after a year, I'd probably stop taking it because there's just no point.

Participant 010_2023AUHIS

Table 5.5: Adherence to treatment

Adherence to treatment	All participants	
	n=20	%
Participant describes adhering to treatment for a specific amount of time	11	55.00
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	10	50.00
Participant describes adhering to treatment as long as side effects are tolerable	6	30.00
Participant describes adhering to treatment as long as treatment is working	4	20.00
Participant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	1	5.00
Participant describes not giving up on any treatment	1	5.00

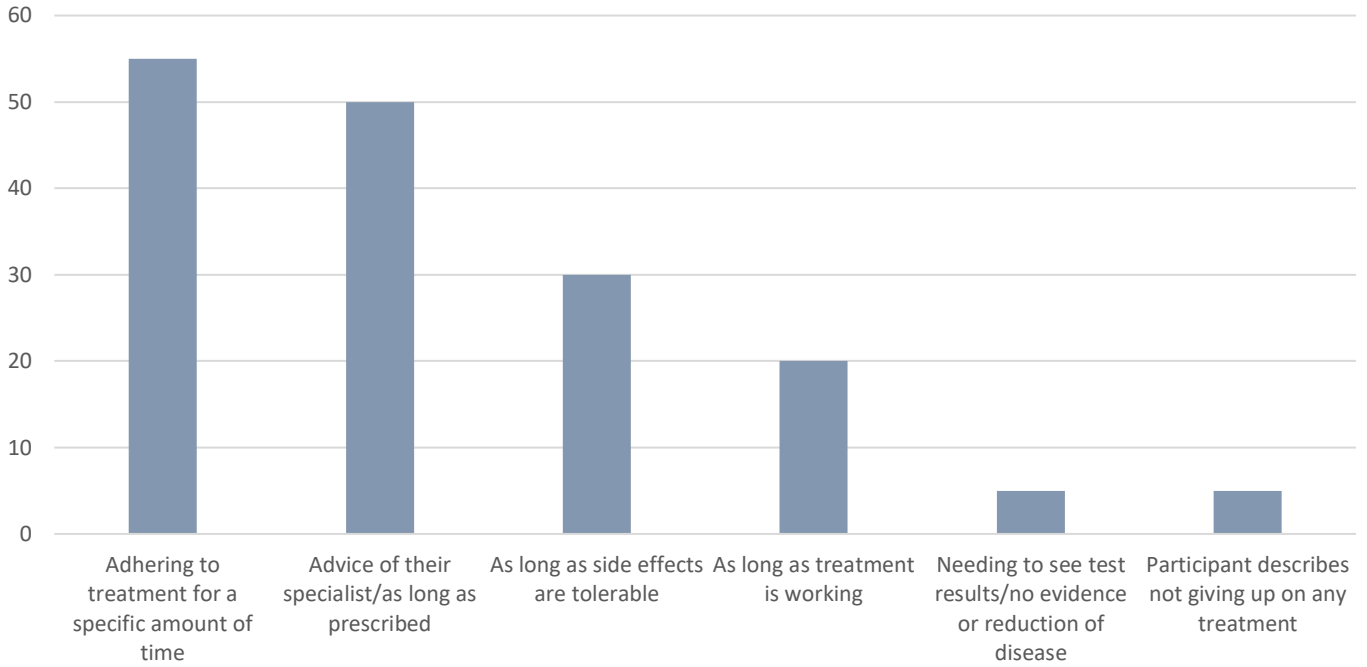


Figure 5.5: Adherence to treatment

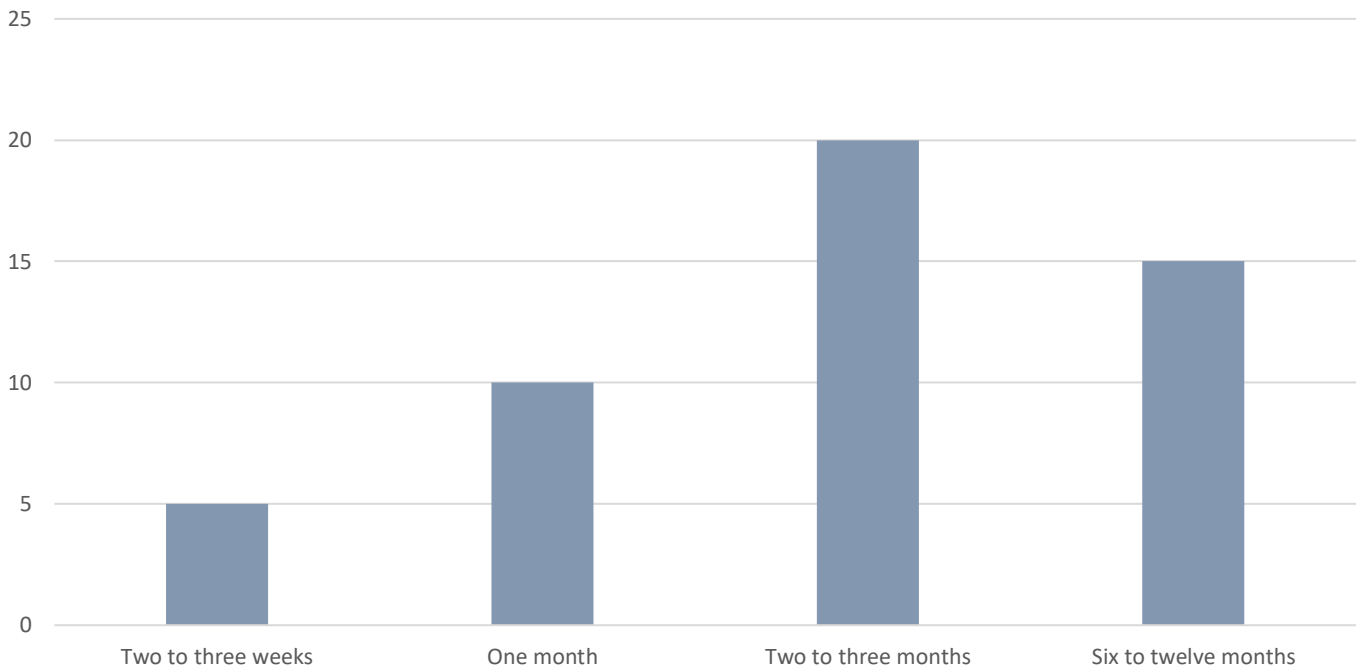


Figure 5.6: Adherence to treatment (Time to adhere to treatment)

What needs to change to feel like treatment is working

Participants were asked to describe what needs to change to feel like treatment is effective. The most common responses were needing to see physical signs and symptoms disappear or reduced side effects (85.00%), and needing to see a specific symptom reduction (35.00%). Other themes included needing to see improvements in general wellbeing or quality of life (10.00%), and needing to see evidence of stable disease or no disease progression (5.00%).

Participants reported needing to see all physical signs and symptoms disappear

The condition you can improve the the the number of boils, the size of the boil, the you know quality of life because the boils are not you know there.

Participant 002_2023AUHIS

Pain reduction #1 increase mobility, better mental health, better mental alertness. It's arthritis etc etc.

Participant 008_2023AUHIS

Yeah. So with the disease. It it is quite painful the the lumps and bumps that I get on my chest. So I'd say a reduction in pain as well as physically how it looks. It's a very ugly disease. I will say it looks, you know, it's gross. There's lumps and bumps and puffs. So I would say another one would be physically if I can see that the disease is. Going away and it's calming down and I don't have as many bumps on my chest and they're not bursting open. And I can see that the skin is healing and it's not as red and inflamed.

Participant 010_2023AUHIS

Participant describes needing to see a reduction in a specific symptom

The timing of the flare, so say does it come and go in a couple of days? Does it linger for three weeks before it hovers up and down and then nothing and sits there for another couple of weeks just burning and doing nothing and? You know, are those symptoms managed? Are they better? Are they? They might come and go in a week, but it never actually burst and it actually went, you know, I need some solid evidence of change and I haven't received that yet.

Participant 015_2023AUHIS

The physical appearance of the lesions and the reduction in the number of them and the size of them and. Yeah, So that makes me think that it's working. Although they do. So they do burst, but they do scar quite badly and they eventually go down. But I think if I'm not getting any new ones, then I feel like it's working. If I'm getting new ones because quite often they come in groups, I don't, you know, sometimes I'll get one under each bar. Under one, under each bust, one of my groin, one of my butt, all at the same time. Not getting any, then I feel like it's working.

Participant 017_2023AUHIS

Yeah, a reduction in side effects may be a difference in in what you're seeing in terms of the nodules and things like that or not flaring as often.

Participant 019_2023AUHIS

Table 5.6: What needs to change to feel like treatment is working

What needs to change to feel like treatment is working	All participants	
	n=20	%
Participants reported needing to see all physical signs and symptoms disappear	17	85.00
Participant describes needing to see a reduction in a specific symptom	7	35.00
Participants reported needing to experience an improvement in general wellbeing (quality of life)	2	10.00
Participants reported needing to experience evidence of stable disease/no disease progression	1	5.00

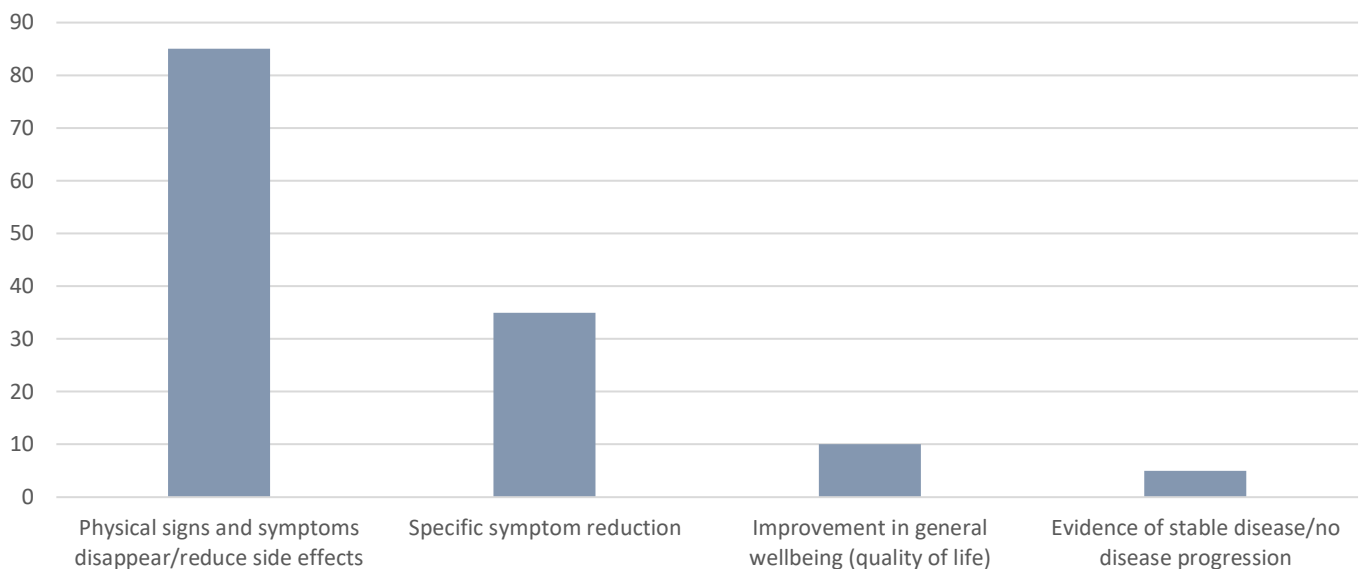


Figure 5.7: What needs to change to feel like treatment is working

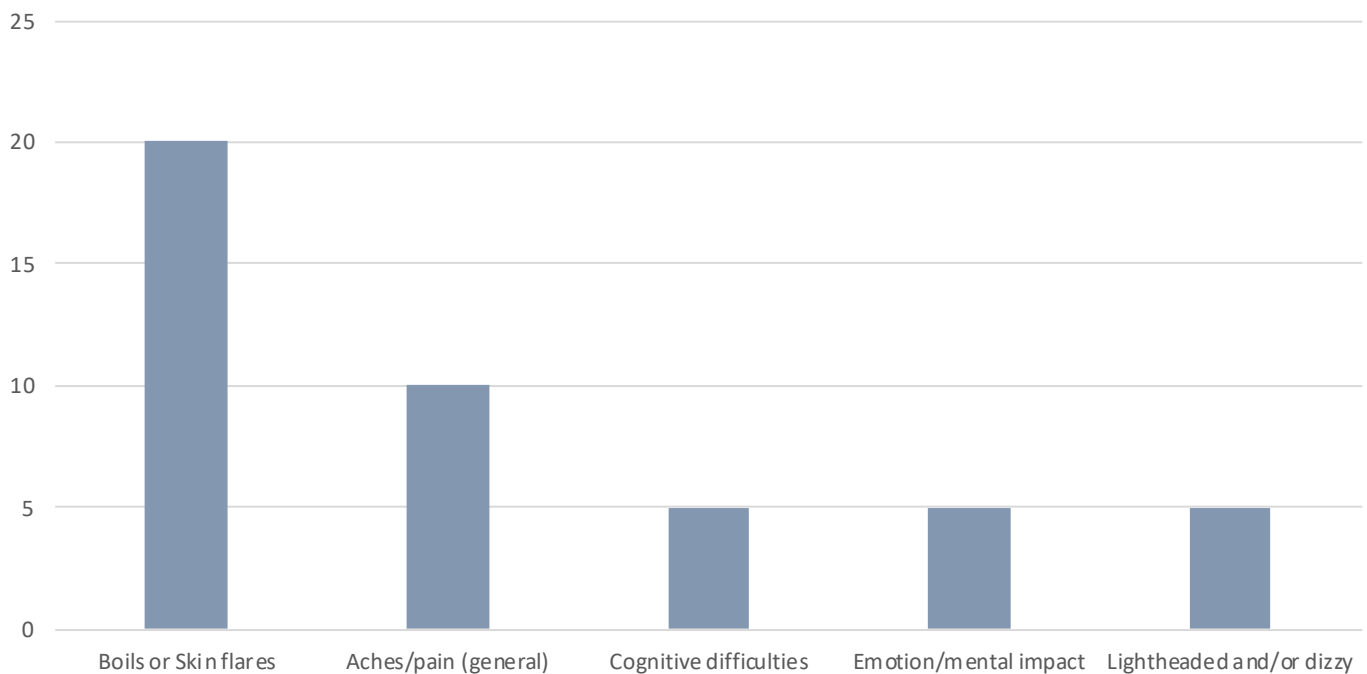


Figure 5.8: What needs to change to feel like treatment is working

What it would mean if treatment worked

As a follow up question, participants were asked what it would mean to them if the treatment worked in the way they described. The most common responses were that it would allow them to do everyday activities/return to normal life (50.00%), and allow them to engage more with social activities and family life (25.00%). Other themes included allow them to return to work (20.00%), less worried about appearance/self image (20.00%), have a positive impact on their mental health (15.00%), lead to a reduction in symptoms/side effects (15.00%), allow them to do domestic tasks (10.00%), and allow them to do more exercise (10.00%).

Allowing them to do everyday activities/return to normal life

Life. It would be life changing. I have to. I often say to my husband, I would just love to have one day of my life. Just one day. Like between now and death where I don't feel pain 24/7 so that would mean everything. To be able to live without the disease, it would probably one of the biggest breakthroughs I think for me. Like if I have to live with this disease for the rest of my life and I'm assuming I do one of the biggest things that could. Could change my life. Is GP's understanding what the disease is?
Participant 005_2023AUHIS

Well, I doubt that I would ever be able to wear a bikini, but maybe so. I do keep myself covered over very much. Like I don't wear shorts that are any shorter than my knees. My swimmers are all longer than my knees. I feel like, you know. If I was young and single and and or even if I was just single and trying to get into the dating scene, that would be a massive issue for me. Fortunately, I'm married and have a very understanding husband who doesn't care about them and but it's a self confident you know, it's definitely a self esteem because you just, I just don't want people. Seeing them, so you know I think and I did have to have some time off work during that 2021. And having to explain to. My male boss, who is a young guy, I I was very fortunate working in the hospital. My one of the female managers said, look, just tell him that you don't have to tell him what you've got. I was telling that you've got an auto inflammatory disease and that you're going to need some time off work because I did need some time off work. There was a lot of times I just couldn't wear underwear. And so I literally couldn't. I wasn't going to go to work without any underwear on, and I was on painkillers. And so to be able to just go through life without having to worry about that, if I do have now any, I now work from home four days a week, which is great, and I'm in the clinic one day a week, but. I if I do have any, I've got to make sure that I'm. I've got pads on them to make sure that they don't burst all over my clothes while I'm out, but just having not to worry about that would be amazing, yeah.

Participant 017_2023AUHIS

Allowing them to engage more with social activities and family life

I'd be able to go for walks again and be able to actually play with my kids properly clean the house. Stack the dishwasher. I can't even stack the bloody dishwasher at the moment. Be able to go horse riding again and and do the activities and and go back to competition. So like, I haven't been able to do that since I had the really bad flair in 2019. That's just gone from spot to spot to spot.

Participant 012_2023AUHIS

I just can't even explain, really. That's the saddest question, I think. You know, I often feel like when, you know, when I get a flare, I think, [UNINTELLIGIBLE], I don't think I got a flare in the last four weeks. What have I been doing with my time? I just sit there and think I'm not living my life every day to my fullest as I can. I often when I'm fine, I'm so exhausted by my previous six weeks or 8 weeks that I just want to sit without feeling pain. But I'm not motivated to go and

start. Yeah, I can do roller coaster now I'm gonna go back to doing cartwheels. I'm just. I'm just wallowing in a piece of satisfaction for free. Paying free. I can lie down properly. I can put my own clothes on. I don't smell myself. You know but as sure enough as soon as I get a flare again I I think you know what the ... it's been so long. I should have gone for a run and you totally could have joined a Tennis Club. What are you know and and so just having the ability to some certainty, I'd really enjoy that. I think you know it's only around May that I get upset so I'm going to do everything up until that point and then I'm just going to prepare. I have no idea what a trigger is for me. I can't avoid things. I don't understand it at all.

Participant 015_2023AUHIS

Allowing them to return to work

It would mean so much better. Like I I could go out and get an actual job which I can lift up my arms to reach something. Participant 004_2023AUHIS

Less worried about appearance/self image

If there was something I could take easily that wasn't going to have any other effects on my health that were detrimental in any way, and it just helped with my HS, it would help my life a lot. And what would you be able to do? What would you be, you know, like I would have the security to be able to go to the beach or go swimming or wear a dress because you have to wear underwear. Just, just normal things like that that I can't do and, you know, feel more confident myself if you were being intimate with somebody. I know mine isn't very bad because nobody in my life has ever noticed. So I guess that's, you know, even in a relationship for three years, no one, no one noticed. So I guess that's something. Other people have it worse than me, but I am aware of it and it's just a conversation you don't want to have to have with somebody. Because it's not like it's an STD, but you just can't help but you lean that way, can you really, if you were uninformed. So yeah, it's always in the back of my head. So yeah, something like that would just make my life a lot easier. Participant 006_2023AUHIS

I mean because like. My disease is only at stage two, which is kind of middle ground. I'm still quite active, so I feel like it's not so much physical things that I wouldn't be able to do. But if the treatment worked and it cleared up my disease, then I would be able to wear nice clothes. I would feel more confident going to the beach and wearing a bikini. I think, yeah, just kind of more of like a confidence thing because it's a very shameful. Disease. Like, I don't want to show my body. I don't want to wear nice clothes because I, you

know, I don't want people to see what I've got on my skin. So I think for me it would just be like gaining confidence and feeling pretty again to wear the things that I want to wear.
Participant 010_2023AUHIS

It would mean a lot if it worked, but it affects everything. I struggle. Having intimate partners. Because of my scars, I had somebody ask what they were once. Yeah, when? I didn't think they were noticeable. It's getting to the point where I can't even wear, you know, kind of like short his shorts to the beach. They're traveling further down my thigh.

The constant concern that people can smell them. You're right with it. I can't even tell people what I have because they Google it and see horrific images.
Participant 018_2023AUHIS

A positive impact on their mental health
I would. I'd be working. I would be able to afford dental care. I could improve my mental health, my mental outlook. I could reconnect with my family. I could basically, in inverted commas, get a life. Yeah, I'm just hiding away from the world at the moment. That's what my life is.
Participant 008_2023AUHIS

Table 5.7: What it would mean if treatment worked

What it would mean if treatment worked	All participants	
	n=20	%
Participant describes that it would allow them to do everyday activities or normal life	10	50.00
Participant describes that it would allow them to engage more with social activities and family life	5	25.00
Participant describes that it would allow them to return to work	4	20.00
Participant describes that it would allow them to be less worried about appearance or self image	4	20.00
A positive impact on their mental health	3	15.00
Leading to a reduction in symptoms or side effects	3	15.00
Participant describes that it would allow them to do domestic tasks	2	10.00
Participant describes that it would allow them to do more exercise	2	10.00
Participant describes that it would allow them to live without pain	2	10.00
Participant describes that it would allow them to sleep	1	5.00
Participant describes that it would allow them to have intimate relationships	1	5.00
Participant describes that it would allow them to have fewer doctor visits	1	5.00

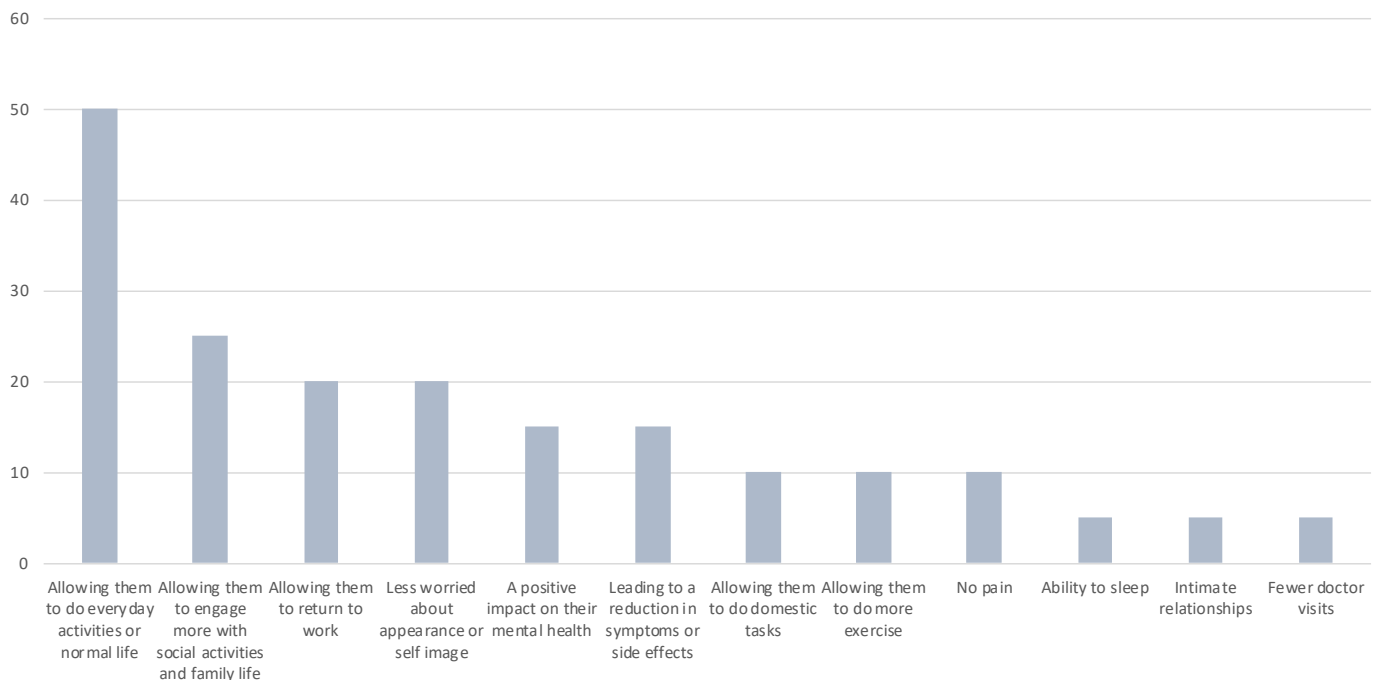


Figure 5.9: What it would mean if treatment worked

What it would mean if treatment worked

As a follow up question, participants were asked what it would mean to them if the treatment worked in the way they described. The most common responses were that it would allow them to do everyday activities/return to normal life (50.00%), and allow them to engage more with social activities and family life (25.00%). Other themes included allow them to return to work (20.00%), less worried about appearance/self image (20.00%), have a positive impact on their mental health (15.00%), lead to a reduction in symptoms/side effects (15.00%), allow them to do domestic tasks (10.00%), and allow them to do more exercise (10.00%).