Community perspective survey summary on current treatments and need for treatments at point of platinum resistance (PROC)

The Ovacome survey collected survey responses from 145 members of the Ovacome community in the UK between 19th December 2025 and 16th December 2026. The survey was called 'Have your say on availability of a treatment for patients with platinum resistance'.

Many potential respondents would have been undergoing treatment and choosing family time at that stage of disease. Therefore, a response rate of 145 people over a short period of time represents a decent sample size. The total number of members of Ovacome (i.e. those who are registered as members who are also affected by ovarian cancer) is 5,600 people. However, many people access our services anonymously and are not members. The survey was promoted to our members and others who access our services. Therefore, this was less likely to be a self-selecting group of people who often engage in research and more likely to include responses from people who feel less able to self-advocate. We made it possible to access the survey by offering calls with our support team and interpreters or translators.

We have removed responses where they contained identifiable information but kept in all the answers where this could be removed and the intended meaning retained.

As survey responses have been included exactly as submitted by respondents, they may contain spelling or grammatical errors.

In this survey, at this time, we were consulting with a group of people who are generally unfamiliar with the possible availability of treatment at point of Platinum resistance. For a small number of respondents there was confusion around terminology – e.g.; using the term PARPs when referring to other forms of treatment. We have not corrected this but would like it noted.

The feedback gathered from our community has focused mainly on the:

- Day to day and long-term side effects of chemotherapy – the severity of the side effects.
- The views expressed by members of our community as to the availability of treatments for ovarian cancer at the later stages of disease, specifically platinum resistance.
- Their opinions as to availability of treatments at point of platinum resistance (specifically relating to mirvetuximab/Elahere).

The NICE committee identified the following specific areas where further evidence would be helpful in their decision making:

- The impact of chemotherapy on people's quality of life. This is included below.
- The impact of mirvetuximab on people's quality of life. This is included below.
- Any reasons why the trial of mirvetuximab (MIRASOL) may not capture the quality of life of people having mirvetuximab and chemotherapy. We did not ask this question.

Because mirvetuximab has not been widely available to this community of people, there are few people who are able to make a comparison between the side effects of mirvetuximab and Chemotherapy. However, feedback from our community alongside this survey is that the frequency of treatment (i.e. once every 3 weeks for mirvetuximab versus often weekly for chemotherapy) is favourable at this stage of the disease and that the side effect profile is favourable too given that chemotherapy is so incredibly debilitating for so many. We received one comment noting negative side effects of mirvetuximab, but the rest of the responses noted fewer side effects and, where there were side effects, they were better tolerated than chemotherapy. This is especially important at this stage of disease because people understand that they probably have limited time and want to make the best of it with family and friends. Likewise, for those who did not have the possibility of treatment at the point of platinum resistance (i.e. family members who had a relative die of ovarian cancer prior to mirvetuximab availability through trial or compassionate access) were also able to respond.

Survey results in italics, narrative explanation in normal text.

Participant breakdown

Survey participants were able to select more than one answer because it is possible to be a relative of someone diagnosed and also the patient diagnosed themselves or a healthcare professional and also a relative of someone diagnosed with the disease. Some respondents were reflecting on different stages of treatment. For completeness we have supplied all anonymised data in a spreadsheet alongside this narrative report.

Tell us who you are (please select all that apply)

Answered: 145 Skipped: 0

I am having chemotherapy for ovarian cancer	*26.21%*
I am a healthcare professional working with ovarian cancer patients	*3.45%*
Other (please specify): (See below for list)	*7.59%*
I have been diagnosed with ovarian cancer	*66.90%*
I have platinum-resistant ovarian cancer	*26.90%*
I have taken mirvetuximab soravtansine (Elahere)	*4.14%*
I am a family member or friend of someone with ovarian cancer	*11.03%*

If other, please specify:

I will soon, be having chemotherapy for ovarian cancer, soon, but not yet.

My sister died from ovarian cancer

I am BRCA1 positive

Brother of Sister who died from Ovarian Cancer in 2010

I had ovarian cancer and am in remission

Having Immunotherapy

3 weekly Avastin infusion paid for due to NICE delay (approved and free in Scotland)

My mum passed away in 2024 from ovarian cancer, this being found at end stage 3

Diagnosed with a borderline ovarian tumour in 2025

Diagnosed with ovarian cancer Jan 2015

I have had chemotherapy

Presently on Olaparib, in remission.

My wife recently passed away from Ovarian Cancer at the age of 46.

The side effects of chemotherapy.

Please tell us about the side effects of chemotherapy with regard to your mobility (was it easy to walk around or move?) 94 responses

No bad effect from chemotherapy *21.28%*

Some effect from chemotherapy *43.62%*

A significant effect from chemotherapy *35.11%*

How people answer this can depend on how much support they have in place. Mobility issues most commonly relate to chemotherapy induced peripheral neuropathy and fatigue. Both of these side effects can endure long after chemotherapy has finished and some people never recover, even partially, from these side effects. Over 78% of respondents noted some or a

significant effect on mobility. Please note that some people who have chemotherapy have side effects from the medication given to them to help them with the side effects of chemotherapy.

The following are just some of the 65 written responses:

- *I am writing this on behalf of my mother- the effects were awful. Terrible nausea, severe weakness, hardly able to get out of bed some days*
- *Have peripheral neuropathy in my feet which affects my mobility. I also get short of breath on exertion, particularly going up hill. I do not have the energy to carry out activities as I used to do prior to being diagnosed*
- *Neuropathy, leading to treatment being discontinued*
- *I was tired/exhausted for years and years afterwards, so tired that walking around shops I would pass out. I needed 12 hours sleep per day even 10 years afterwards.*
- *Extreme fatigue from one set in particular Neuropathy*
- *I developed an allergy to carboplatin whilst having my second course of chemo in 2022. My cancer returned this year and I developed another allergic reaction to carboplatin during round 3 and despite the desensitising process, was unable to tolerate the carboplatin during round 4. It has been decided that I will not be rechallenged with any platinum-based drugs. I am going to try and get through the last 2 rounds of paclitaxel but am struggling to cope with the side effects.*
- *My mother had her 1st dose of carboplatin/paclitaxel and a few days later was in ICU fighting for her life with neutropenic sepsis. Fortunately she survived but spent 2 months as an inpatient. Before chemotherapy she was performance status 0, looking after 4 grandchildren and fully independent. After that first dose of chemotherapy she is now dependent in most ADLs, is housebound and totally a changed person. She has continued on chemotherapy at lower doses or altered regiment (now one weekly paclitaxel).*
- *Chemo left me out of breath. I couldn't walk upstairs & could only walk very short distances. I also suffered from neuropathy*
- *I am massively fatigued and deconditioned after chemo. I cannot walk for more than 1minute (timed) without getting breathless with an elevated heart rate up to 130. I have to crawl up the stairs.*
- *I don't have much energy and walk slowly. I feel vulnerable and don't like going out by myself.*
- *I cannot stand for long periods of time or walk long distances anymore. This restricts the activities I can do with my grandchildren, a great sadness for me personally.*
- *My chemo caused large blisters on my toes. My chemo treatment was postponed because the nurses viewed this as an open wound. Additionally, I had to reduce my daily walking routine- to let the current blisters heal, & prevent further blisters occurring.*

- *Unable to drive or walk very far as a side effect for approx. half of time between treatments*
- *Painful feet and legs when walking.*
- *Neuropathy in my feet for 5 years now.*
- *Steroid side effects: terrible bone/joint pain - only managed 10/18 Avastin Brain fog*
- *Wiped out in first week so could only manage very short walks*
- *I had 6 cycles of Carboplatin and Paclitaxel, The pain in my legs was so painful it left me bedbound for several days after each treatment.*
- *Initially apart from fatigue I was mobile but I now have substantial nerve damage and have great difficulties walking - this damage is thought to be treatment related*
- *I have Neuropathy as a result of treatment and use a stick now.*

Please tell us about any side effects of chemotherapy with regard to self care (did it affect your ability to look after yourself)? 94 responses

No bad effect from chemotherapy	*38.30%*
Some effect from chemotherapy	*37.23%*
A significant effect from chemotherapy	*24.47%*

Responses often noted the need to have carers or family members to support them with basic tasks. For some, the side effects of chemotherapy mean that they give up work or have to bring in carers. Even when family members are providing significant levels of personal care this had an impact on the whole family dynamic, on relationships and on finances.

Responses included:

- *It did have an effect on my mother looking after herself I was with her 24/7 to help her even get out of bed etc*
- *Needed help with showering, drying etc. Not able to stand for long periods of time to cook meals and the like*
- *Lack of energy and inclination to cook*
- *I could not walk far. It affected my muscles and my energy levels. I was very weak*
- *Tiredness sometimes means that my husband needs to do things that I would otherwise have done myself*
- *So tired/exhausted that my husband had to do everything for me, cooking, shopping etc, I spent such a lot of time sleeping, 12 hours at night plus several hours in the daytime.*
- *I remained fully independent, and capable of all normal activities of daily living, and able to play golf and take a weekly dance fit class.*

- *Complete loss of taste for first 10 days after chemo. Constipation/diarrhoea for first 10 days. Severe pain in legs and feet making it difficult to walk during days 4-8. Pain in back and chest. Nausea for first week. Severe fatigue for at least first 10 days.*
- *Difficult to shower due to breathlessness and ability to safely stand long enough to shower*
- *Difficult to put socks and inderwear on. Also difficult to fasten buttons.*
- *It's been hard to live a normal life*
- *From my 3rd cycle to my last I did not have the energy ir strength do anything, it was made worse bybthe fact I live alone.*
- *Fatigue made everything tiring & needing rest/recovery, especially when haemoglobin low.*
- *For some days after treatment I was grateful to not live alone. This includes having to have injections, not being able to cook or not wanting to prepare food, no energy to do housework or look after pets. I can't imagine how people living alone cope.*
- *My husband has to do everything for a few days after my chemo*
- *She now requires assistance with showering, and due to the peripheral neuropathy from chemotherapy is unsteady on her feet too, unable to walk up stairs and needing support walking on the straight.*
- *Couldn't do my housework I had to have someone come in to do the basics.Couldn't lift my legs to get in the bath.*
- *Yes I need my wife to prepare all my meals, drinks, take me to appointments, do all the housework and help me manage my medications and pain relief. She runs baths for me and massages my legs when I can tolerate it.*
- *Not able to continue my cottage cleaning business without significant help or walk my dog or take as much exercise*
- *I have to use a seat for a shower and mist days can only strip wash, sometimes with help.*
- *Sickness and diaherra along with malaise made looking after themselves impossible*
- *Joint aches particularly low back pain limit walking and bending to the floor for foot care. I need to regularly see a podiatrist for nail cutting as chemo has made the nails thick and mishappen*
- *It meant I needed a lot of help from my husband.*
- *Had to break up jobs into small sections, rather than performing the whole ftom start to finish.*
- *It was difficult to find joy in life. I still went through the motions, but with limited enjoyment.*
- *Fatigue meant that I had to sleep for several hours a day and I felt guilty that I could not do much at all. I could not work*
- *Shaking useless hands Twitching in legs Nump feet*

- *Unable to do the things I usually did so could no longer work. Devastating effect on my mental health*
- *I needed a private care service to come and help me with personal care in the first few days after chemo. I was unsteady on my feet and nauseous. I did not expect side effects to be that serious.*
- *Unable to prepare or cook food due to fatigue, pain and feeling unwell. Struggling to maintain healthy weight. Unable to shop independently due to feeling unwell, pain and fatigue and immunosuppression.*
- *Joint stiffness in my hands make it difficult to cook, shop, and wash*

Please tell us about any side effects of chemotherapy with regard to you doing the things that are important to you. We mean everyday things like time with friends and family, work, study or leisure activities. 93 answers

A significant effect from chemotherapy	*48.39%*
No bad effect from chemotherapy	*6.45%*
Some effect from chemotherapy	*45.16%*

Just 6.45% reported no bad effect on their everyday lives from Chemotherapy. For some people this has been a sustained change – beyond the duration of treatment. This is often reported to us at Ovacome as the reason why people choose to stop treatment when they become platinum resistant; the inability to continue life and maintain important relationships and a degree of connection to important things means that the negatives associated with the side effects of chemotherapy come to outweigh the positives of continuing treatment. The isolation reported by many people on chemotherapy is often particularly affecting.

- *It had a significant effect on. Apart from hospital visits my mother was not well enough to go out during chemo*
- *I am no longer able to participate in sports as I used to. Have had to give up my badminton sessions with husband and friends. I am no longer able to participate in gym sessions. I don't eat out very often due to taste changes. I don't have the energy to enjoy shopping so have had to resort to online purchases*
- *Less interest in friends and activities I would normally participate in*
- *Normal life is on hold with chemo. I didn't go out much and I couldn't work, exercise or socialize.*
- *I did not feel like being sociable or doing the things I enjoy when I am in pain. I suffered from stomach issues, bloating, pain, mouth ulcers, acid reflux, & mucositis.*

- *I couldn't work but took early retirement, too tired to enjoy physical activities, eg dancing, swimming, walking and hiking. It took 10 years before I became stronger and able to cope with everything.*
- *I can't make any arrangements to see friends/family for at least 10 days after chemo. I then have to be very careful the week before chemo not to get tired in order to make sure that my neutraphils are high enough to have the treatment.*
- *Any cycle of chemotherapy brings a cycle of fatigue and lack of focus. The following week after treatment is the worst for concentration and fatigue but regular mild exercise helps. It is a matter of being aware of management strategies. However, the burden can be significant and prolonged.*
- *Difficult to socialise with friends and family. Had to give up work. Unable to pursue leisure activities*
- *Self isolate due to lowered immune system. Breathless, joint/bone pain, facial rash*
- *Too sick most of the time to do things*
- *The effects were in the 10 days after each cycle. Fatigue has been a lasting symptom.*
- *Had to cancel a range of social activities and less frequent exercise because of fatigue*
- *For the frontline and second line Chemo I was not able to work at all. I struggled to socialize for some of the time as for 2 weeks did not feel well enough. Your life literally goes on hold while you have treatment.*
- *I became quite isolated*
- *I used to love walking but now it is a struggle.*
- *Become housebound for a few days , quality of life very low*
- *She is unable to leave the house again due to unsteadiness on her feet, likely from peripheral neuropathy but also reconditioning having been so ill from the first round of chemotherapy. Therefore any social interaction has to be people visiting her, not the other way round.*
- *Friends came to visit me I couldn't go out to meet them I felt isolated as all I did was sit on the settee as was exhausted all the time*
- *I can't concentrate or focus on things so my hobbies have dropped. I don't get out much as I'm too exhausted and it's really hard to plan as I don't know how I'll feel until the last of the 3 week cycle. Then it's time for appointments and chemo again .*
- *Excessive tiredness, lack of sleep little exercise which seriously affects the mental health journey too*
- *I hardly see anyone anymore.*
- *No energy to do anything, sickness and feeling unwell along with exhaustion*
- *No longer able to work due to pain which has a significant financial impact and has resulted in loss of confidence and of self. Socialising has reduced because of pain*

- *Could not undertake my job as a Radiographer due to lack of energy. Likewise, could not perform ususal hobbies (Hill walking, swimming).*
- *Due to immune system being compromised, afraid to go out and mix. Hair loss… horrific. Unpleasant and ugly … did not want to be seen by others*
- *I can't look after my grand daughter for the day (I used to) and she has to go for an extra day in nursery. I can't do my job and I took ill health retirement- I was a headteacher and CEO due to brain fog. Getting bathed showered takes longer - need to rest before getting dressed. When my haemoglobin plummets I am exhausted by simple tasks eg putting on socks. Back ache pain means cooking is difficult - use a perching chair when I can but standing by job is difficult. I need more rest which means less time being with family and fruends.*
- *I was to tired to meet with friends. Family had to make short visits and if they were unwell then had to stay away due to my immunity being low.*
- *leg pain on day 3/4 , sort of fluey feeling day 5 , normal by day 6*
- *I struggled to concentrate and remember things. Even reading was very difficult as I could not understand what I was reading after a few lines. I could not carry on studying for the same reasons. It took me two years to go back to a more decent cognitive level*
- *The first week after chemo was always "written off". After seven days, I was able to slowly pick up things again. I suffered mentally as my house was untidy and I did not get help*
- *I only worked part time during chemo. I chose to reduce contact with friends and family due to the infection risk*
- *During my first round of chemotherapy I took 5 months off sick from work. I have a full time job where focus and concentration is imperative for me to work safely. I did return to full time work for 16months but am currently off sick again whilst on chemotherapy.*
- *Need to stay in bed due to lack of energy. Unable to socialise indoors due to infection risk Trouble with eating due to mouth ulcers, cold sores, pain on eating and digestion issues. Unable to eat many favourite foods due to gas production and bowel problems Have to use specific skin products due to skin sensitivity.*
- *Due to reduced immunity I was unable to mix with family and friends for the whole course. Thus caused significant mental issues on top of the anxiety of the disease itself*
- *Folliculitis was unbearably painful and the prescribed antibiotics further reduced my immune system so I had to shield for significant periods of time between chemo cycles. Very isolating experience.*
- *Needing to isolate due to compromised immune system means not seeing friends or joining in a wealth of Christmas activities such as attending carol concerts or even shopping*

- *I could not work at all and general activities were much restricted at various points in my chemo cycle dependant on energy levels and the need to minimise exposure to potential germs due to compromised immune system.*

Please tell us about any pain or discomfort you experienced as a result of chemotherapy. 91 answers

No bad effect from chemotherapy	*14.29%*
Some effect from chemotherapy	*48.35%*
A significant effect from chemotherapy	*37.36%*

86% of people experienced pain or discomfort as a result of the chemotherapy. The reports range from bone, joints, arms and legs to bowel pain. Some people reported significant pain that has continued and for some it was controllable with medication and eased when treatment ceased. Discomfort was rarely mentioned – pain is a more accurate description of the severity. The full set of answers has been included in the accompanying spreadsheet. Here we have included quotes for context.

- *My effects were primarily after the first session and they were horrify . Subsequent treatments gave me fatigue, loss of appetite and abdominal pain and constipation.*
- *Lots of discomfort, and some pain from the following - stomach issues such as bloating, diarrhea, constipation, & mouth ulcers, acid reflux, & mucositis, squashed torso pain, breast to shoulder stabbing pain, & squashed when lying on either side, kidney pain.*
- *Quite severe pain from first set of chemo GI issues also*
- *I suffered from vertigo and fatigue. I felt a loss of control and very depressed. I also developed mouth sores.*
- *Hated the pain*
- *Pain in neck , back , arms , feet . Have to take Omeprazole and painkillers*
- *Joint pain during chemo. I've just got pleral effusion because of my low immune system which is agony.*
- *Back ache - and belly ache managed with paracetamol and sometimes Oramorph.walking and standing are the worst. Must be able to sit down regular. Cooking is problematic-standing at the job. Chopping ingredients etc.*
- *I had severe pain in my feet from peripheral neuropathy which was unbearable despite pain relief My chemo had ti be reduced I still have to take pain relief two years later*
- *Bone pain during week 1 of each round of chemotherapy. Aching knees which continued for approx 6 months following the initial six rounds of chemotherapy.*

- *Need to take Paracetamol and Ibruptofen four times a day. Abdominal pain wakes me up at night.*
- *Some neuropathy which increased over time. I developed superficial thrombophlebitis which was extremely painful in my left hand/wrist.*

Please tell us about any anxiety or depression you experienced as a result of chemotherapy. 94 responses

No bad effect from chemotherapy	*15.96%*
Some effect from chemotherapy	*57.45%*
A significant effect from chemotherapy	*26.60%*

There was a high % of people reporting anxiety or depression as a result of chemotherapy. For some this related to the side effects of the treatment (e.g. becoming more isolated due to poor mobility/peripheral neuropathy or chemo related fatigue). However, for some the anxiety or depression is due to fears about lack of treatment options at point of platinum resistance. Within many people in our community there is a fear of becoming platinum resistant because there are so few (or no) options at that point. This is an important aspect of our submission – it cannot be overstated how important it is for those diagnosed with ovarian cancer to see that treatments are becoming available at later stages of the disease. Platinum resistance is a key term that we identify on our support line that is more likely to lead to callers expressing suicidal ideation and this is reportedly due to the lack of options at that stage and the fear of undergoing chemotherapy again.

- *Inevitably chemotherapy makes one anxious. Waiting for results between sessions or waiting to hear about a new treatment starting is without doubt one of the hardest things to endure*
- *After the chemotherapy had finished, I had a few occurrences of feeling panicky and anxious about things that were unrelated to my cancer. I had never experienced anything like this before, so believe it is definitely related to my diagnosis.*
- *Low mood which I guess would be like depression. These horrible feelings came out of the blue. I found it took a long time to return to a normal mindset & overcome the feeling of being totally lost. I still have to work hard to stop my mind going down that path again.*
- *Going to hospital caused severe anxiety because my son had died of cancer a few years earlier and I was his carer.*
- *Anxiety around recurrences and life span Very poor outcomes in UK limitations on treatments Fears about the impact on my young children Hard to stay positive*

- *I am terrified that I will lose the use of my legs and fear behind immobile. When I'm well I spend a lot of time outside, particularly working on my allotment.*
- *Too anxious to go out for several days each cycle*
- *Very depressed and anxious.*
- *Anxiety and worry about what treatment maybe available*
- *Terrible anxiety, loss of confidence and self esteem, huge weight gain*
- *I had to go on antidepressants and therapy.*
- *Chemotherapy is a difficult treatment to navigate, and although I suffered from some anxiety followibg treatment my mental health improved.*
- *Felt very low the first week after chemo*
- *Lack of confidence self esteem with hair loss poor had a wig and still do and helps*
- *The effects of chemotherapy really did did depress me I tnought Id bever get through it.*
- *Some depression especially with a come down from the steroids you have to take. But the main anxieties stem from being ill with a serious condition and managing all the appointments, scans (have major scanxiety) tests and navigating the struggling entity that is the nhs*
- *I am worried about the future and get upset when I think about it.*
- *It's a double edged sword : I feel extremely low after chemo but the fear that I cannot continue with it due to my being highly reactive (have been to lots of things throughout my life) is terrifying. I will cope with the low mood to gain the benefit of course The fear always is: if not this drug , then what is available next to me ?*
- *Following the turbulent recovery from neutropenic sepsis after 1st chemo (carboplatin/paclitaxal) there is ongoing anxiety and depression that the same will happen again. Also constant worry that there will be no further options if mirvetuximab is not approved on the nhs - she would be eligible given her folate receptor status. Mirvetuximab could really be a life saver for her but only if approved on the nhs.*
- *As some lines of treatment have not worked well I feel anxious about my future.*
- *Loss of worth loss of confidence reduced social activities makes me low in mood*
- *Feeling very unwell tired and aches makes you depressed as you can't go out and see friends*
- *For me, this was the most significant impact.*
- *Mentally I suffer from anxiety from stage 3 HGSOC as I am platinum resistance.*
- *Felt low when I felt weak Found loosing my hair very difficukt*
- *Major anxiety depression*
- *Suicidal*
- *I was anxious because of the side effects and the restrictions I experienced.*
- *In the days I felt fatigued and nauseous I thought it was awful, and wondered if the treatment was worth feeling bad*

- *I felt alone and scared.*
- *Yo-yo moods due to steroids*
- *Extremely anxious when starting treatment and whilst this did subside I was always anxious about getting infection, doing the 'right' thing, any side effects related to fatigue as you constantly second guess whether you will have enough energy to do something and, if you do, what the impact on you will be if you do choose to go out or do something. Brain fog was also very depressing at times, feeling like you couldn't think straight or function properly and I definitely could not drive more than a very short distance which made me feel quite isolated at times and really impacted my independence. Again, this affects your mental health.*
- *The anxiety around my long term survival*

If you have taken mirvetuximab soravtansine (Elahere) and have platinum resistant ovarian cancer we really want to hear about your experience with this treatment. Please leave your contact details or anything you would like to share below.

- *I had no significant side effects from Elahere. I travelled from Glasgow to London for the treatment and was able to do this every 3 weeks.*
- *Have had three cycles of mirvetuximab so far. 1st cycle severe side effects, including abdominal pain, muscular pain and neuropathy especially in hands. 2nd cycle reduced by 20%. Severity of side effects less but neuropathy still there. 3rd cycle reduced to 70% but neuropathy still there. Continued with mirvetuximab treatment as "good, partial response to treatment" noted on CT scan following 3rd treatment. Ca125 reduced x 10 following treatment.*
- *Haven't yet Gemcarbo seems to be working If gemcarbo stops I will be put on elehere as I've been tested and show positive for what I need to take Elehere*
- *I had my third cycle this week. Still waiting for actual ca 125 numbers but oncologist away at moment. Before the 2nd cycle my numbers had dropped by 2/3rds down over 1000 which is staggering. Whether this is a one off I don't know yet. Side effects - eye issues but these are being carefully managed. Low magnesium seems to have caused a few issues but again currently being sorted.*
- *No not taken it but i would like to be given the opportunity to be considered even having 5 lines of chemotherapy - its not fair that we are always left out especially when platinum resistant, it shouldn't matter the number of lines you've had of chemotherapy as long as you are fit enough to have the drug*

If you have platinum resistant ovarian cancer please share your experiences below.

- *I am BRCA negative and HRD inconclusive. This limits my treatment options. To then find that I was platinum resistant was another blow. I am currently waiting for a start date for Doxorubicin which I will have for 6 cycles so come June/July of 2026 I will be in limbo in terms of treatment options. The chance of Mirvetuximab would take away some of the pressures of the unknown*
- *First became platinum resistant to Carboplatin approx 2 and a half years ago. Had Paclitaxel on its own which was successful but from January to June 2025 was only partially successful. Was put on Caelyx on its own which was only partially successful. There does not seem to be any other drugs left for me to try. The disease is in my immune system , ie lymph nodes and spleen and although the oncology team are keen to keep the disease in the immune system there is nothing left for me to try.*
- *I am frustrated and angry that there are very limited treatment options for platinum resistance ovarian cancer.*
- *NED never achieved throughout chemotherapy treatments. Platinum resistance followed 3rd regime. Mirvetuximab offered and accepted on compassionate access.*
- *I have had 5 rounds of different chemotherapies over 5 years with only short amounts of remission.*
- *Carboplatin stoppped working during the third cycle I have 3 times recuring ovarian cancer. My experience has always been good over the 8 years that I have had ancer, but I know that my options are now significantly reduced, so other non- platinum treatment options would be welcome.*
- *Am waiting to find out if I am platinum resistant*
- *I had further treatment and this has helped but I'm very scared that my future options are so limited*
- *I think elahere should be available in UK I've never had it I've had carboplatin pictaxil which gave me severe allergic reaction I've had parp inhibitors they were great tablets to take at home for my stage 4 my tumors shrank but after a yr my body got immune to them!*
- *I have had PARPi which made me anaemic requiring blood transfusions fatigue and gave me a PE but my cancer returned, I was started on Carbo and Calix which gave me dreadful side effects and I only had a partial response. This is demoralising. I was hoping I could use Elehere but to hear it is not available to me is devastating.*
- *Treatment options are limited, access to new treatments are not available if you have had more than 3 lots of chemo, the Outlook is bleak*

- *Living with platinum-resistant disease and seeing limited responses comes with intense emotional distress and constant fear.*
- *Feel disheartened as original platinum therapy appears to have become in effective. Further anxiety and stress about where I go from here and is it worth it? .*
- *Being platinum resistant is very frightening and worrying that the options we have are very limited. We need urgently to find treatments that may make a difference to our outcome and have an impact on our mental health too*
- *I have just been told that my cancer is platinum resistant. Another option would be wonderful for me.*

Please share your views on the importance of new treatments for platinum resistant ovarian cancer.

There were 79 answers recorded and we have included some below.

- *Gosh. If my numbers get right down then this Elahere should be allowed on the NHS. Nothing else has worked for me as dramatically as this drug. I have had to travel to London to get this drug, stay in hotels at mighty costs while routine tests carried out which can be very tiring. New drugs give hope, just need a maintenance drug that stops the cancer coming back. Need more miracles*
- *New treatments are vital for ovarian cancer patients with this horrific disease Women have limited treatment options with low response rates and short survival times There is a high unmet need for target therapies. New drugs are vital to provide clinically meaningful improvements without compromising the patient's daily quality of life This is urgent*
- *I was a fit and healthy woman enjoying an active and fulfilling life before starting on this terrifying journey. To know that there is a drug available to women in other countries but not available here in the UK is morally wrong. Of course there are always cost restraints*
- *but for women who probably have no other options available to them, this has to be considered an imperative. We should not have to come with a begging bowl, this affects our whole life.*
- *As above, there are no drugs left for me to try or any trials that Iam able to go on because I have had 6 lines of chemotherapy and many trials are restricted to patients who have had 4 lines of treatment only. It is devastating as I've done my best to keep myself fit and optimistic for the last 8 years and would keep on taking chemotherapy to keep my cancer in check if there were drugs available . New treatments and trials are vital to managing this cancer and it's the most horrible feeling to think I may have run out of options.*
- *I feel its important to try new treatments which may reduce cancer growth and extend life expectancy. I don't believe that age or stage of cancer should factor in decision. The*

possibility for extending a life and improving quality of life is important. Careful management of side effects is essential.

- *My only option now is eithea trial based on similar science to Elahare or Caeylxwhicg is older science and not tailored to ovarian . I strongly feel there should be other newer treatments available As a result of being platinum resistant, I haven't had any treatment for several months and subsequently have suffered two strokes which has been very difficult my consultant is certain the activecancer is to blame. If I had had another option back in August*
- *Ovarian cancer gives little hope. Most women have recurrences and there have been little or no new treatments in the last ten years. We don't deserve this lack of choice or lack of hope. There is so much research on resistance exercise for aptosis, polyphenols and nutrition, gut health and repurposed medicines but oncologists often seem ignorant or loathe to discuss alternatives leaving us isolated and desperate. It's just not good enough. We are the staple of society. We carry children, we multi task, we care for everyone else, often to the detriment of ourselves, we live with huge stress and elevated cortisol and our immune systems get a battering. It's no wonder they can't fight off this silent and viscous killer cancer. We need more research and we need more hope for better outcomes.*
- *I believe there is a need for more treatment options or for platinum resistant ovarian cancer.*
- *Treatments for platinum resistant ovarian cancer are vitally important to a whole swathe of the female population who are unfortunate to be in this situation. The thought that there may be nomore treatment available to me is a very scary one that will determine how long I can live with advanced cancer.*
- *When diagnosed with cancer there is both a physical and psychological effect. Knowing that the disease is incurable, but treatable means that every available treatment is precious. Each one allows for the hope of longer survival. Perhaps one treatment may last for 12 months and another for 6 months... that's 18 months of life! Knowing that there are a finite number of treatments available means that every treatment that is not suitable, or is denied, reduces the life you have left. It's like fighting a battle against an army that will ultimately overwhelm you. Each treatment is an arrow in your quiver with which you can hold back the advancing hordes. When a treatment is denied, it's like somebody takes an arrow from your quiver and snaps it in half. Now the battle will be lost more quickly.*
- *The physical effect is obvious - I will die sooner and the psychological effect is devastating - my hope is taken away.*
- *Without new treatments for platinum resistant ovarian cancer affected patients are looking at a very short remaining lifespan, and hoping that palliative care will make the end of life not too awful. The mechanisms of death from progressive ovarian cancer are not easy ones to bear or to watch.*
- *So important to someone like myself who can no longer be treated with a platinum based drug.*
- *They are very important to me.*

- *New treatments for platinum resistant ovarian cancer give hope to women who have run out of chemotherapy options. Alternative option was to be placed on palliative care.*
- *I cannot stress enough the importance of a new therapy. It will give hope of remission and more time with family.*
- *I'm on second line treatment. I'm platinum sensitive and feel that I've used up two of four possible available treatment. I know that eventually I'll become platinum resistant. I'm HSOC stage 4, HRD+ and BRCA -, therefore the treatments available to me are few. It is vital that new treatments are developed specially for those that are platinum sensitive or resistant.*
- *Need them desperately*
- *I have had five lines of chemo and a mid way scan showed an incomplete response in my current line of chemo. I am worried about being platinum resistant as there seem to be very few treatment options so it seems a pity to not allow Mirvetuxemab*
- *Think it needs to be pushed for . Breast cancer gets lots of publicity ovarian cancer is a silent killer*
- *It's so very important that women are given the best chance to survive this disease the recurrence rates in ovarian cancer are common, research is so important in helping to combat this disease the frigtening thing is more younger women are being diagnosed with Ovarian Cancer theses trial drugs can be a last ditch hope for many women, they should not be denied it if its available.*
- *There are not enough treatments and ovarian cancer is seriously lacking in experts and specialists outside of major cities. To read in your medical notes written by your oncologistthat after 1 recurrence your treatment options are now 'limited and not indefinite' is heart breaking. There appears to be no tailored approach just a set of criteria set previously that dictates what you can and can't have. For example when you ask if secondary surgery is possible or can you have radiotherapy, you are just told no. Without the options of new treatments it feels as though there's no hope and you are just waiting for the inevitable.*
- *There is so little available; I find it difficult to accept that my life is not cost effective when there are no real alternatives*
- *It is so important that everyone is given the chance to live life to the full. As much as they can. If the medical science exists to help women in this dreadful situation, they should be able to access it . It is inhumane to suggest otherwise*
- *These women have a terrible prognosis. As an NHS consultant myself in a different speciality I have now seen the reality of being on the other side of the NHS as a patients relative. And it is brutal - being at the mercy of guidelines and postcode prescribing. Mirvetuximab is a treatment now available over a lot of Europe and the US, we are significantly behind them and this drug could be a lifeline for many women. Please consider the data carefully, which is very positive for improved side effects and survival compared to standard chemo.*

- *Our lives have worth. I have teenage children going through exams. I feel well and am active and yet I have platinum resistant OC. I have much to give and not having access to treatment that can extend my life is cruel. Not just to me but my family. This is a killer and without these treatments we are being discarded. There are no effective long term treatments currently, only chemotherapy with its side effects. There are so many options for breast cancer, why is ovarian cancer to receiving the same funding.*
  My cancer is stage 4 and treatment now is limited, it would mean the world to me and my family if new treatments were available..
- *The treatment for ovarian cancer is hard but always feels worth it if it gives more time with loved ones. I feel all advances which give women more time should be considered worthwhile*
- *I've been told I am out of options and my cancer is growing. Having new treatment would give me hope and more time with my young son. I was 33 at diagnosis because gp wouldn't listen to me whii ohch meant I was diagnosed after it had spread everywhere and at the moment it looks like I won't make 40.*
- *Vital for this to be available*
- *It is vitally important given the late stages we are often diagnosed at. Anyone's cancer can become platinum resistant over time and treatment options should be available to us. Until more effort is made in diagnosing women earlier then funding and research must be put into giving the current cohort of people with ovarian cancer the best chance of a quality of life*
- *MOC affects a lot of women under 40, so the other half of our life is lived with this lingering fear of recurrence and lack of effective chemotherapy*
- *These new and expanding treatments are what keep us going between episodes of treatment, when we become useful contributors to society again, we still lack years behind other cancers such as breast cancer do not pull one of our rugs away! This could provide hope for a lot of patients whose treatment options are limited*
- *Every cancer victim deserves hope and each individual responds differently to treatment. People should not be denied new treatments because of where they live, that's not equality. I myself am a survivor on my 34th year thanks to surgery and modern day medicine. We should be moving forward not restricting these treatments to patients.*
- *It is so hard to balance hope with the reality of limited options and efficacy. Platinum resistant patients need optimism and hope. At the moment there is only emotional overwhelm and fear. It is crucial to expand options to improve outcomes for patients with platinum-resistant disease!*
- *New treatments are absolutely vital for those of us living with platinum-resistant ovarian cancer. Once the standard options stop working, every new therapy means more time, more stability, and a better quality of life. It's not just about treatment — it's about hope, control, and being able to keep living your life. Research really does make a difference!*
- *I felt so lucky to be able to access the full range of treatments. I think that I would struggle emotionally if I thought that my options were limited because of a resistance to the usual*

- *front line treatments. Every cancer patient deserves the best treatment available, including new options which have been shown to work.*
- *It's essential, vital ., not just for the physical improvements but for the mental and emotional improvements. It is beyond measure. All cancer patients sore praying for something/ anything that at least gives them hope let alone reduces the horrendous bad effects/ times.*
- *My hope is that ADCs are the new treatment for ovarian cancer. It would be amazing not to have to go through standard chemo and so avoid the terrible mental and physical side effects.*
- *There seems limited options if you are Brac and HRD negative. This drug has brought hope of a longer life well lived.*
- *My oncologist has said I will be put forward for trials after this live if treatment. I am very keen for this of course.*
- *I believe that elahare should be available for platinum resistant patients. Every time I look on N.I.C.E website for drugs like avastin etc it seems like every drug is available for Braca patients or if you have have a mutation or be first line. What about patients whom have had more than 5 lines of chemotherapy no braca gene or mutations it seems we are left out to graze as so to speak - don't our lives matter?? It is very important to us to have some hope its difficult enough living with this disease, as stated it shoudn't matter how many lines of chemotherapy we've had as long as we are well enough to have elahere*
- *Awareness is still low for ovarian cancer and hence most women are diagnosed at a late stage, including myself, so it's crucial that new treatments are available which bring hope to patients and their families. Due to the high recurrence rate associated with ovarian cancer more options need to be available to manage the disease, especially as each patients cancer if different.*
- *Far too many women are dying from lack of options for treatment , we need more and urgently*
- *Very important they might keep me alive*
- *I have only had chemo once but I know in the future i will probably develop resistance I feel it's very important ti have new treatments available so I can have some hope for my future ti try and give myself longer with my husband and family i so want ti see my little grandson grow up*
- *I live in hope that there will be new treatments, if not for me, then for other women in the future. New treatments are critical. This is an awful disease and there need to be options.*
- *We desperately need new alternative treatments which are available to us in other countries. It adds to our mental health burden knowing we get worse care than most other countries.*
- *There are limited options for the treatment of ovarian cancer particularly for platinum resistant patients*
- *For me , I worry that due to being allergic to taxol without elahere as an option if I'm platinum resistant my treatment options are more limited. The side effects from what I*

- *have read and heard about from those who have it are more tolerable than chemotherapy. I want to be around for as long as I can, only new treatments can help.*
- *Currently experiencing first recurrence, I need to know there are other treatments available to me, now and in the future.*
- *It is expected that many of us will become platinum resistant at some point during our treatment. For some people this is very early on when they are feeling fit, well and enjoying a good quality of life. These people should have options available to them and*
- *Invariably most high grade advanced ovarian cancer patients become platinum resistant. Surely those patients deserve the right to have the best evidence-based treatments to deliver the best possible outcomes. Treatkent choices for OC patients in the UK are few, why can't women with ovarian cancer have access to the best? We, the UK are sixth from the bottom in Europe for ovarian cancer survival. Why can't women we not be at the top?*
- *With a disease like this all you have us hope that new treatments will come along. Refusing this new drug for patients takes away this hope and the chance of extended family life which should not be underestimated*
- *I was diagnosed relatively young at age 46, unlike many other patients who tend to be much older - I want to know how much is being down to prolong the lives of younger patients like myself as it feels that there are few options available after first line chemo. I.e., just waiting to die*
- *It is vitally important that new treatments are researched, developed, trialled and AVAILABLE in the UK - all countries equally. We lag behind so many other countries in the world with our treatment for advanced and recurrent OC, especially that which is platinum resistant. Any of us could reach that point at any time during treatment and there has to be other options.*
- *It is vitally important that Elahere becomes available for all those affected to be able to take and give more quality of life and life extension. It is available in other areas of the world and should not be disallowed here*
- *Any new treatment that gives women more options to treat this disease has got to be a great, if not lifesaving event. Once you become resistant to the drugs designed to save you your options become more limited - to have a new drug come on to the scene for me is great news as I am on my second recurrence and know that options are starting to limit. Please keep the research and the drugs and the funding for women like me and women in the future.*