

## IP Survey IP1724\_2

This report was generated on 14/04/25. Overall 51 respondents completed this questionnaire. The report has been filtered to show the responses for 'All Respondents'. A total of 51 cases fall into this category.

The following charts are restricted to the top 12 codes. Lists are restricted to the most recent 100 rows. I

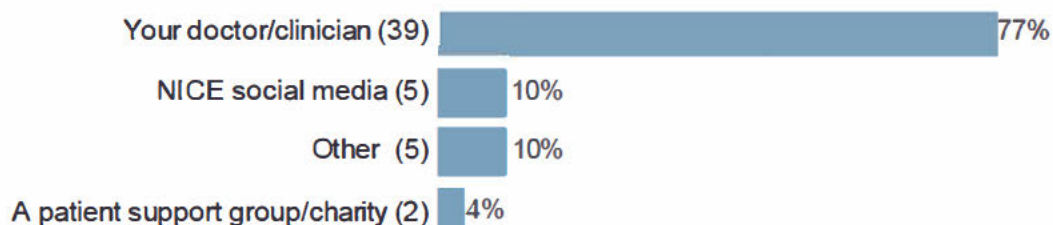
I have read the information above which explains the purpose of the project and how any information I provide will be used



I consent (agree) to NICE using the information I have given in the ways described above



How did you hear about this survey?



If other, please specify

Direct email from The Clinical Effectiveness Team PP: [REDACTED]

By email

I did not know about the survey until it was emailed to me.

direct contact from NICE via email

Researched it myself as alternative to surgery

Are you (the person completing the questionnaire)



## Your age

75	68	81	57	77	58	57	85	55	55	60	71	73	78	75	56
51	69	59	83	68	75	54	85	55	73	80	80	75	72	69	46
65	83	66	71	66	68	84	74	60	61	80	69	73	64	78	94
45	75														

## In years

4	7	7	0	8
5	5	0	14	0
10	0	0	14	15
13	1 year			

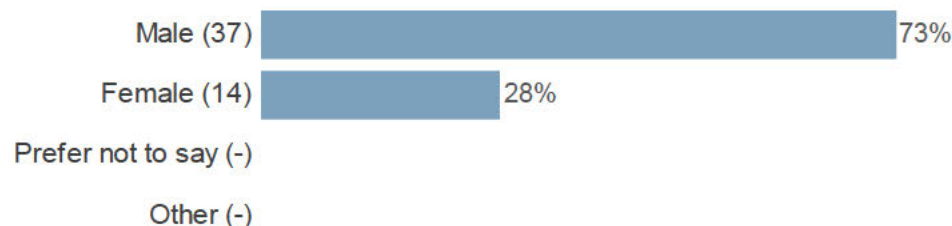
## In months

3	7	9	16	2
22	8	7	11	10
14	6	4 months	11	2
19	10	8	3	17
53	8	One month ago	7	1
2	6	4	1 month	
6 months	7	5	3	

## in weeks

1	4	2	6
3	2	2	6
0	1	1	0
2			

## To which gender identity do you most identify?



## What other treatment options did you consider, and why did you choose this one?

Surgery. My age, the thought of having a permanent stoms, and activities caring for an adult son with learning disability. I had read about this non surgical option on the internet. Even though my Oncologist was not enthusiastic, my local surgeon got me n touch with the Professor at [REDACTED], only 40 miles away from my home. He assured that based on the size/stage of my cancer, complete cure was very likely with the treatment, in his opinion.



## What other treatment options did you consider, and why did you choose this one?

Surgery was the other curative option I was offered but it would require a stoma which would have not been reversible. I chose the trial as treatment as it meant that I would not have to have a stoma at this point and surgery could be offered as at a later date still as a curative option if the treatment did not work and the disease had not upstaged.

It was initially recommended that I had invasive surgery and the section of bowel removed resulting in a stoma bag. I was referred immediately to attend hospital to learn more about how to live with and manage a stoma. The thought of this was quite distressing when only 55 years old. I then heard about Papillon as an alternative treatment and decided to investigate further. I was referred to [REDACTED] and met [REDACTED] to discuss the suitability of the treatment. It was offered as an alternative and I decided to proceed as the risks were minimal and the procedure had a promising outcome. The advantages being no major surgery and associated risk and no stoma bag. If it wasn't successful there was the option of a stoma later. The risk of some rectal bleeding was explained but this all seemed manageable and acceptable. The treatment was immediate and had no affect on my day to day activities. I actually went on holiday immediately following the second session of brachytherapy. I have had regular followups locally and reviews with [REDACTED] and no issues.

I considered several treatment options, including External Beam Radiation and Chemotherapy. The goal was to shrink the tumor and achieve a clinical complete response, which would help preserve the organ. While I achieved a near-complete response, I chose contact X-ray brachytherapy (Papillon) to avoid major surgery and to further work towards a clinical complete response, ultimately aiming for a better quality of life and to avoid a major surgery.

I had 25 sessions of beam radiotherapy and a course of Chemo tablets. The tumour had almost disappeared but started to show signs of growth after a year. Options were surgery and temporary stoma bag or contact radiotherapy. The professor treating me at the Christie was content with me trying contact radiotherapy. its been almost 2 years and so far the tumour has continued to heal with no sign of recurrence. The reason I chose this course of treatment was because the success rate was very high. and the number of sessions is low and over a relatively short period of time..

The alternative was surgery and a colostomy due to the position of the tumour in the rectum. As a fit, sporty, active and otherwise healthy individual I wanted to avoid this life changing option.

Low anterior resection which did not suit my lifestyle

Full bowel removal. I chose brachytherapy because full bowel removal was too extreme and I did not want a bag.

Had radiotherapy and recommended by Christies

Was told this may prevent me from having a bag

I was horrified that I may have had to have a stoma bag for life. My vanity sought out other options as I did not want to be, in my mind to be lumbered with this procedure everyday. At this time I would have had to had an operation that did not involve key hole surgery which was another consideration. Fortunately my surgeons assistant mentioned the Papillon treatment via the Opera trial at the [REDACTED] Centre. I chose to pursue this and was introduced to [REDACTED] who put me forward for the trial and oversaw my treatment through to sign off.

Rectal removal and stoma for life. I chose this one in hope I could carry on a normal life.

Reccomend

removal of bowel section. Do nothing. Didn't want a stoma or invasive surgery at my age.

Referred by consultant at Stepping Hill Hospital after previously attending Christie Hospital for treatment.

Recommended by surgeon

Already had surgery, chemo and radiotherapy

To avoid a stoma at all costs

It was offered following my reluctance to have an operation

I was offered surgery, but opted for radiotherapy and chemotherapy and the papillon treatment



What other treatment options did you consider, and why did you choose this one?

Surgery. To avoid surgery and permanent colostomy if possible

Surgery

I was initially informed that I would require surgery following chemoradiation and chemotherapy. However, after a near complete response my surgeon referred me to [REDACTED] for consideration of Papillon.

Stoma but I was not strong enough to undertake the surgery

I followed the medical advice

Tumour was not suitable for TEM-too bulky. Recommended papillon treatment after close discussion with professional staff in the hospital and my family as an alternative option.

Chemo/radiotherapy or surgery. This treatment recommended by my consultant and seemed to be best suited to me. Although I am 74 I don't feel it and am quite fit and active.

Went through 1) Rectal Polyp removal by surgery It was then offered to do External radiotherapy. however because the cancer was at a very early stage it was decided to go for Papillon

None

I have had radiotherapy and chemotherapy

I was offered non reversible surgery with a stoma and didn't want to have life changing surgery if there were other options available

I'd already had radiotherapy and chemotherapy which were initially succesful but the tumor returned within a few months. Papillon seemed the only alternative to major surgery which would have resulted in the need for a permanent stoma, which I was keen to avoid.

None

Only surgery was offered - I wanted a non- surgical option

Bowel removal(stoma,). Micro surgery?

None. Due to existing health condition unable to have surgery

I had previously undergone external beam radiotherapy with chemotherapy the year before, which proved effective but my oncologist brought my attention to the 'Papillon' treatment as a 'belt and braces' type treatment. Having only just completed the 'Papillon' treatment recently (on 17 March 2025) it is far too early to say whther it has worked - but I will answer Yes to the following question on the assumption it will be!

TACE & Radiotherapy. Did not want surgery. Papillon direct contact on tumour. Possibility of complete response curation elimination of cancer.

Best option

It was the best option to avoid major surgery

I was only offered a stoma bag and didn't want this. It was only when I asked for another solution that I was offered this treatment

I considered all the available treatments offered to me. I went ahead with chemotherapy and Radiotherapy, but could not bring myself to have life changing bowel surgery with a permanent stoma.

This is the only one I considered and I am stoma averse

Operation, but decided this suited me better

I choose this one as it saved me having a massive operation and was very grateful to get this treatment

Surgery. Less invasive and organ preservation

I had had chemo therapy and radiotherapy to treat bowel cancer. After this treatment I was offered n operation which I refused as it would mean me having a stoma. After this I was offered the Papillon treatment by [REDACTED] at [REDACTED] Hospital.



## Did the procedure work?



If **somewhat** or **no**, please provide further details along with information about whether symptoms later reoccurred.

Prof [REDACTED] said the tumour had gone, but cancer had spread to lymph nodes and I was bleeding again so had to have operation to remove everything.

Still under post treatment surveillance

Too early to assess

Although initially the treatment was considered successful, a recurrence of my tumour was found after six months.

Symptoms reocured after 11 months operation now required to remove the bowel and rectum

I am not at the end of my review process

Still ongoing

Still on active treatment

## Did you have any side-effects following your procedure?



If **yes**, please provide further details along with information about whether symptoms later reoccurred.

I experienced common side effects, such as minor fatigue and changes in bowel habits, including diarrhea, urgency, and more frequent trips to the toilet on some days.

Small residual nodule removed by TEM in February 2014

Some pain and aching in the treatment area

I have had to control my bowel movements as I am susceptible to cold mornings. For example I can move my bowels first thing in the morning satisfactorily but when going outside into a cold atmosphere I can suddenly have the urge to move them again. I find I have to respond to this immediately to avoid an accident! I have learnt to control this situation which I believe is something to do with the natural production of stool softening by my body not corresponding with the bowel movement process. My sex life is impaired. I have full desire and interest but I cannot respond immediately. I find having to plan and not just respond immediately is embarrassing. As a relatively young guy going through this procedure I would definitely make future recipients of this treatment aware.

Spotting of blood and very tender.

Soreness around the site for several weeks. Very unpredictable bowel movements but the above were also present after earlier chemo and radiotherapy and surgery a few months before.

Change in bowel habits

If **yes**, please provide further details along with information about whether symptoms later reoccurred.

Slight bleeding, but this soon passed .

Proctitis, incontinence after treatment

Irregular bowel movements

Minor symptoms of passing blood (small amounts) when having my bowels open. I also had some mild discomfort whilst sitting down. This was also a symptom I had prior to being diagnosed with rectal cancer.

I was sore for about two weeks and then all was well

Irregular bowel function

Very small temporary discharge of blood after treatment. This quickly cleared up in a couple of weeks

Bladder issues worsened but not impossible to cope with. Drinking plenty and following recommendations on the website

For a few months after the last session no side effects at all. 5 months later, starting to feel discomfort in the area of the scar, especially after defecating. That is still the case.

My bowel movements are now very sudden and considerably more frequent

Bowel movements more loose / frequent than before

Again, I have to say that I've perhaps been given this survey to complete somewhat prematurely. I only finished the treatment some 2/3 weeks ago. For what it's worth, my symptoms aren't too bad (so far). I tend to have to take more craps than I did before - usually 2, sometimes 3 a day. I can't say I'm feeling any pain or discomfort though. Immediately following the procedure, I was full of gas/wind, which was inconvenient for the rest of the day, but I don't think that is what your question is aimed towards. So far, things aren't going too badly.

Discomfort, pain and erratic bowel function

Stiff hip

Mucus in stool and urgent need to open bowels.

## How long did it take you to recover from the procedure?

Virtually a painless outpatient procedure, I drove home unaccompanied soon after each of the 3 procedures. I was fully functioning within a few days.

I continued to work during the three sessions of internal radiotherapy and recovered from the concurrent chemotherapy/radiotherapy within two to three months of completion.

Less than a day although I did have Radio and chemotherapy to reduce the risk of any secondary cancers. Recovery from this did take sometime but no worse than expected for this treatment. I did pass small amounts of blood and mucus during the first couple of years but this was minimal and normally as a result of harder stools/ constipation. It rarely lasted more than one or two bowel movements. I don't eat special diet other than trying to eat healthily and now have no issues.

I am now three months post-treatment, and the symptoms are beginning to stabilize.

I had no side effects and therefore no recovery time

There really wasn't a notable recovery period. I had 4 fractions of Papillon brachiotherapy in total. In each instance I was back on the tennis court the NEXT day. I had to be careful about when I ate because I had diarrhoea, but that was easily controllable with Imodium. In each instance it took approx 3 or 4 days for my system to settle. There was no bleeding apart from after the 1st treatment but that lasted 2 hours at the most.

Approx 18 months

A couple of weeks

A few weeks



## How long did it take you to recover from the procedure?

Can't really remember, a week or so after each treatment

I have had no side affects other than the above which I assume I will have to live with. I live an active life playing golf three times a week an enjoying everything I did before the procedure aside from the sex. Fortunately I have a brilliant partner and we manage. I have actually stated many times that I feel like a fraud when cancer is mentioned, as compared to what some people go through I have never been laid up by this procedure. I chose to work all through my treatment so that I could see any change to my lifestyle. I am coming up to my fifth year clear now and although I never tempted fate by ringing the bell I am confident that this part of my life is behind me. I would recommend this treatment and the brilliant care of the [REDACTED] team.

2 weeks

No time at all

a good nights sleep.Next day

No real identifiable recovery required.

Since the treatment I have had an ileostomy

Several months but not sure if that was just the Papillon or surgery etc ..

I had no real side effects at all , recovery was minimal

Can't say there were any noticeable side effects other than above

Around a week or so .

No time at all as well tolerated

General fatigue for a period

I recovered quickley from the procedure. I was prescribed some antibiotics by my Oncologist which helped to alleviate the symptoms.

2 weeks

Ongoing

Very short amount of time

Immediately as no treatment localised. It is early days at the moment but apart from tiredness I feel really good

Overall quickly, few weeks, but as said just 5 months later getting some recurrent side effects

No recovery issues just tiredness

Just tired but also due to travelling for procedure

I am still recovering

Not including the above which is still ongoing, recovery was instant

Immediately - no side-effects of any significance.

2/3 hours

Less than an hour for each of the 3 treatments

Over night.

N/A

See above. Too early to give any sensible reply

Instant recovery

Couple of hours

No recovery needed rode my 1300cc motorcycle All the time I was in treatment

Almost immediately. It was amazing and I was delighted

I recovered immediately after every treatment and no discomfort or side - effects.

Still recovering



## How long did it take you to recover from the procedure?

1 hour

On going

There was no need for recovery as had no operation and walked straight out of hospital

Ongoing - only one month after treatment

I made a good recovery immediately.

## How did the procedure positively affect your condition and/or your quality of life? Please consider things such as:

- Your physical symptoms
- Your ability to perform daily activities
- Your quality of life, lifestyle and/or social life
- Your state of mind, emotional health and/or wellbeing
- The effect on family, friends and others

It was painless, not disabling, and I was fully functional soon after each procedure. I felt well, apart from a few weeks of bleeding from the resolving cancer site. My mental state remained good. Family and friends were supportive and not adversely affected.

I cannot thank the Team enough for giving me the opportunity of the Trial. If I had not had this done my life would have been very different living with a permanent stoma at a 'young' age. The impact from the cancer diagnosis and treatment has left no lasting physical symptoms and my quality of life is excellent. I live a full and healthy life and it has not had any impact on me being able to enjoy a normal life. Initially emotional health and well being is impacted as you have been given a cancer diagnosis but the intense follow up was very reassuring although coming to the end of follow up is slightly daunting but only from a 'diagnosed cancer' perspective. In some ways it feels like it never happened as I am so well and I know family feel the same.

Much of this was stated earlier. Physical symptoms other than occasional bleeding and passing mucus have been minimal once I recovered from the Radio/ Chemo therapy. There has been no impact on my daily activities and no impact at all on my quality of life. As stated before I went on holiday immediately after the treatment flying transatlantic without issue. It greatly benefitted my state of mind not having a stoma to remind me. I had no worries at work or socially. Whilst recovering from Cancer and the thought of recurrence was a worry as the original diagnosis was very much unexpected the treatment and caring team at [REDACTED] helped considerably. The treatment resulted in no external signs or need any change to my lifestyle other than avoiding foods that led to constipation. Initially it was of concern to my family but they had confidence in the treatment through me and through talking to [REDACTED] and attending his annual support meeting.

The procedure positively impacted both my condition and quality of life. I achieved a clinical response, which allowed me to avoid major surgery. It also enabled me to return to work and resume my social life more quickly. Moreover, it had a positive effect on my state of mind, knowing that if I hadn't received a complete response, I still had another option to try before considering major surgery. My bowel functions are gradually returning to normal three months after contact therapy, and the post-treatment symptoms are stabilizing. I am now on a watch-and-wait monitoring plan and have a bright outlook for the future.

I continued to walk 4 miles every day during treatment with no impact I continued to undertake all activities I could do before I was diagnosed with cancer My quality of life and social life is the same as before cancer diagnosis I was very positive about this treatment and did not suffer any emotional or health issues The only impact on my family was having someone to drive me back home after the sessions.



How did the procedure positively affect your condition and/or your quality of life?  
Please consider things such as:

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Papillon is a game changer in the treatment of early stage rectal cancer. From a patient perspective it is such a simple and quick procedure and I was able to continue my life after each fraction without interruption. No impact on daily activities, lifestyle, holidays or social life, for which I am eternally grateful. Emotionally it was a worrying time of course... as any cancer diagnosis would be, but I had tremendous confidence in the treatment, which helped me and my husband remain positive throughout

My quality of life and lifestyle returned

It had a big impact as I could not countenance bowel removal and all the ramifications. Brachytherapy allowed me to continue my normal lifestyle and travel commitments. Once you have had a cancer diagnosis there is always a concern that it will return which effects your personal and family emotional health and this brachytherapy gave us hope of a less extreme treatment for a cure.

After my first visit too see [REDACTED] I always felt confident that I had made the right decision to go ahead with this procedure. It did not affect any of the things stated above and I carried on with life as normal.

It was very positive, my family were relieved it was working. Travelling to [REDACTED] from Suffolk was a long way, luckily my husband could drive me. They were all caring at [REDACTED] I felt very well looked after under [REDACTED]. I was also going for scans etc under mr Ali Malik at Ipswich hospital, they did a colonoscopy and spent ages scraping the tumour, very painful, which [REDACTED] said they should not have done. So that was confusing. After that, [REDACTED] said I had to have the operation to give me a bag as it had spread. It would have been fantastic if it had worked, I felt grateful for the trial.

As my tumour was detected having failed the stool sample test sent out to me on my sixtieth birthday, I was totally unaware of any issues other than wrongly assuming the bit of blood I occasionally witnessed on bowel movement was due to piles. So the positives of this procedure for me have been the early detection (I implore all guys my age to take complete the test). I continue to enjoy life. I am reassured in my own mind of my health. I am more health conscious. Throughout my treatment I stayed positive bearing in mind I had never had anything majorly wrong with me at this point. This was encouraged by [REDACTED] whom I wholly trusted and had great rapport with. The effect on my family and friends has obviously been a massive positive relief.

It is very early days, you asked previously if it has worked, I answered yes but as yet we don't know. I am hoping that it gives me all of the above. A better quality of life. Better state of mind and able to get day to day activities including work back to normal as much as possible.

No problem

had no negative effect what-so-ever. Mind, body, soul and physical wellbeing boosted.

This procedure did not affect my quality of life. I was previously on 3 monthly watch and wait and this has carried on. I have been clear since this treatment so far. I am just relieved after each review if I am still clear.

I had a 10cm tumor chemo/radiotherapy reduced to 3cm that is when I got papilon treatment which got rid of the rest, I won't pretend it is a comfortable treatment but it worked thankyou to all the staff



How did the procedure positively affect your condition and/or your quality of life?  
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It was such an amazing treatment after being simply offered radical surgery with colostomy bag at the outset. None of the above was necessary. I had three monthly obs and endoscopies and one further surgery to remove a benign polyp in same region but no further sign of any cancer. For my age then and now it was so important to stay positive and mentally having the option for Papillon was wonderful. The staff and team at [REDACTED] were marvellous - headed by [REDACTED] was extremely reassuring and listened as well as being very accurate with his procedures and predictions and very honest. He had set up a "buddy" scheme at age unit so we could all talk about what to expect which was extremely helpful. It also helped my husband and children to get all the information as it happened which reassured everyone. The clinical team were extremely kind and thoughtful as it is a very undignified position to be in as a patient and they made it as comfortable as they were able

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The procedure was to allow me to avoid a stoma, it was offered only at the end of all other treatment options. This Treatment gave me and my family hope, that there were further options for a cure. I had no real side effects, nothing compared to the other treatments I had.

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The procedure itself was fairly straightforward and I was happy to be told it had gone well. I understand that I will need to be monitored for some time in the future and this has given me confidence that everything is being done to ensure that I will one day be able to say that have recovered from the illness.

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The procedure did not affect my quality of life, I could still do daily activities my social life was also not affected, my state of mind was fine also there was no impact on family and friends.

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Able to continue working albeit with challenges due to side effects. No need to adjust to a colostomy  
Positive as potentially avoided surgery and a stoma

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The Papillon procedure meant that I avoided major surgery at that time. I was able to return to work and other aspects of my life, albeit only temporarily. However, being rather a risk averse person I was worried about the chances of the tumour recurring from the outset.

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The procedure itself was uncomfortable but I was very distressed with the two journeys to Liverpool from Devon

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Positive state of mind & effect on family

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The physical symptoms are minimal. I can still carry on pretty much as normal although slightly reduced walks. My quality of life is excellent and I'm keeping up with my social life whilst trying not to overdo anything. I've always had a positive outlook on life. My family and friends have been with me all through and are delighted at how well the treatment has gone

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Positivity and better outlook on the future

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Overall positively because it was less intrusive than external radiotherapy and affecting much less my quality of life

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Reduced tumour by 80%

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The bloated feeling and stomach ache considerably reduced. To be informed that the tumour had gone was amazing. I was given the treatment when a small tumour was seen a year after receiving radiotherapy and chemotherapy

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I would say there were no negative affects. I felt very positive that the treatment was targeted precisely at my tumour

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I was able to avoid life changing surgery with a permanent stoma, which had both physical as well as emotional benefits

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How did the procedure positively affect your condition and/or your quality of life?  
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Given my abhorrence to the idea of having a stoma, the fact that I was able to avoid it (at least so far) due to this treatment has had a major positive psychological effect on my life. Physically, I would say I've made a complete recovery from both the original cancer and subsequent treatment.

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Having it done made me feel that I had made a good choice

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Option 1/2/3 no effect Option 4/5. Vast relief

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Due to completing treatment 2 days ago, I am unable at this time to say how this will impact on my life/etc going forward. As this tumour has now gone, hopefully this will have a positive impact on my life going forward.

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I need to once more state that I am far too early into the treatment to give a comprehensive response. I don't think the procedure has so far made any serious impact on my life. When you weigh in the balance that we're talking about rectal cancer and having a treatment such as this, which is aimed at reducing the chances of recurrence, moaning about spending a bit more time on the toilet - hopefully in just these early stages - is not worth worrying about. I tend to keep mornings free because this is a 'bowel active' time for me, but again it isn't so problematic. I don't think this particular procedure has caused me any additional stress in terms of mind, emotional health and well being. Having been through the mill with rectal cancer and now awaiting an unknown outcome is the main thing.

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The procedure was an alternative to having a life changing operation that would have left me with a Stoma bag and health deteriorating affects both physically and mentally.

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Positively effected both.

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It had a positive effect on everything

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Did not affect me at all quality of life was good. My family were more concerned than I was. I had fath in the team providing the treatment

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It was extremely positive. I didn't have any side effects. I was able to continue in a manual occupation. I was able to continue my life as before without having to cope with the problems of a colostomy and stoma bag. My emotional health and well-being would have been adversely affected by surgery which I was able to avoid. My wife and family were delighted at my recovery and 15 yrs later I am still able to live a normal life

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It was a life saver for me. I was able to carry on with all my sporting interests and social life. I was mentally drained from the thought having life changing bowl surgery, it consumed my every thought. The treatment gave me back my dignity and has enabled me and my family to enjoy our time together. Having life changing bowl surgery was just not an option for me, as I am not a live at all costs type of fella. Having the Papillon treatment has given me and my family a wonderful, and full active life.

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There is no major curtailment of movement

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Still ongoing

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Not at all

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It was amazing what it prevented me going through .i was told if I had to have the operation it would be 9 -12 months recovery time so this was a complete game changer mentally and physically 100% positive.I would 200% recommend it

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No physical symptoms prior to treatment so no change. Had a positive impact on mental health which has led to positive impact on family and friends.

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How did the procedure positively affect your condition and/or your quality of life?  
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After the procedure I made a very good recovery and was able to perform all the activities I had previously enjoyed. The papillon treatment enabled me to have a very good quality of life and I could still go skiing and swimming which I enjoy. My family and friends were amazed at how well I had recovered and the treatment had no adverse effect on my state of mind. I had no after effects at all and could go back to eating and drinking as I had done before the cancer.

How did the procedure negatively affect your condition and/or your quality of life?  
Please consider things such as:

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It did not negatively affect me in any way.

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The only negative effects were during the actual treatment with side effects of tiredness, pain and soreness which impacted my daily activities at the time but following recovery there are no lasting negative impacts on my quality of life, daily activities, family or social life.

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There was little to no effect. The radio and chemo therapy was quite stressful feeling very tired to the end of the session. The effect of the Papillon treatment being minimal other than occasional bleeding and passing of Mucus. Whilst there was concern when this occurred fearing the worst in that cancer had returned. There was no real impact in any other area other than perhaps needing the loo a little more often. Otherwise there have been no real negative impacts. Any that were there have diminished with time.

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I was aware that there would be post-therapy symptoms, but these were easily managed and were far preferable to undergoing major surgery. The treatment did not have any negative effects. I understood that some time would be needed to recover, so there was no negative impact overall.

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I had no negative impacts on any of these categories.

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The Papillon treatment did not affect me or my family negatively in any way, physically or mentally. It was an entirely positive experience with only the brief and minor inconvenience of diarrhoea immediately after each fraction.

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I was prescribed loperamide to control my bowel functions which gave me confidence to live a full life.

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The procedure did not negatively effect any of these.

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I put this in last comment. It was a time of hope, no negativity. The capcetabine and radiotherapy made me feel a bit tired and sick .

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Physically as stated previously my sex life is impaired. I have to monitor my bowel movements carefully. Daily activities - unaffected Quality of life - unaffected Wellbeing, emotions -unaffected Family and friends - unaffected

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I found it quite uncomfortable during procedures which made me quite anxious. Physically I was limited in day to day activities due to the soreness and was extra worry for family as I had to travel a distance to Hull for the treatment.

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How did the procedure negatively affect your condition and/or your quality of life?  
Please consider things such as:

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- The effect on family, friends and others

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None

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absolutely nothing negative to report.

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It didn't have any negative affects on my quality of life beyond what was there originally.

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After a few weeks the procedure itself was forgotten but the lack of certainty of bowel movements lasted almost 3 years but I did have constant scopes, biopsies and tests throughout that period which the Professor actually asked grit them to reduce as the biopsies were causing bleeding. I then had a course of sucralfate (?) enemas which seemed to calm thing down. I could perform daily activities very quickly but had to have access to toilets if venturing out in a dog walk or theatre visit or train journey etc.. I got used to stopping regularly "just in case" It is very difficult to identify whether one needs the loo or if it's just a feeling so that was quite limiting and embarrassing for a while but then I got used to it and it improved over time. It was useful having a Cancer Key fob from Macmillan for when I needed access to a loo for the disabled if there was a long queue so that I didn't have to get anxious about having an a accident. I was understandably emotionally stressed having been told of my cancer but and have found sleeping very difficult since then but I have since had a knee replacement and am awaiting a hip replacement so these factors do certainly add to the problems I have sleeping. My initial Cancer diagnosis was badly actioned as I had waited almost 2 years for a referral after reporting bleeding and was told it was probably haemorrhoids but then after a local anaesthetic procedure to remove a polyp the surgeon couldn't do it after 45 mins of trying and then two months later I had surgery under general anaesthetic just after Christmas and the ward was chaotic and ten days later I returned to have what I thought were stitches removed when I was immediately told , without any preamble that I had cancer and would need a radical ablation and told how to use a colostomy bag. All within 10 mins! Quite a shock! I asked if I could have a week to think things over and got a second opinion re the Radio and Chemo route and was advised that this was a viable option especially with the Papillon at [REDACTED]. I had two of those treatments after my 5 weeks of 5 days chemo and radiotherapy at [REDACTED]. Family were and still are very supportive but I'm not sure that any of them really realised how out of control one felt in the bowel movement area for up to three years post op. Very difficult to retrain yourself as to holding things in or mistaking when you need the loo or just a twinge. I had to start reintroducing various foods which I'd once loved but could no longer tolerate as they either gave me tummy ache, wind or just went straight through my system. I've now learnt which I can manage and have reintroduced quite a few but some absolutely not since my treatments.

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There were no negatives

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I don't feel it has negatively affected me at all

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I had no negative experience with the treatment.

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Adjustments needed re bowel dysfunction, these may not persist or be as severe in time

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Not applicable

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The procedure itself did not negatively affect me physically. All effects experienced were mild and resolved with time and treatment. However, from an emotional perspective things were more difficult I think. Due to the larger size of my original tumour I was informed that my risk of recurrence was higher than that quoted in the Papillon literature provided to me prior to treatment starting. The 20% risk of recurrence approximated in my case weighed heavily on me over time, making it a stressful transition back to post treatment life. It also worried me that the patient information leaflet mentioned Papillon treatment bring an option for patients unsuitable for surgery (of which I was not).

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None

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How did the procedure negatively affect your condition and/or your quality of life?  
Please consider things such as:

- Your physical symptoms
- Your ability to perform daily activities
- Your quality of life, lifestyle and/or social life
- Your state of mind, emotional health and/or wellbeing
- The effect on family, friends and others

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All seems well at the present. Still recovering from previous medical procedures with resultant long lasting fatigue and tiredness.

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The procedure has had no negative effects at all

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No negative effects

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Not that much except for the current side-effects I described before

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N/A

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No negatives at all. The staff and treatment were exemplary. How can there be negatives if it's saved my life 😊

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I now need to ensure that I empty my bowels first thing in the morning before engaging in any activity or travel

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There is still some ongoing issues with frequency and loose bowel movements, but this could also be attributed to the previous external beam radiation that I had before, which in fact caused a lot more discomfort / symptoms at the time.

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No negative effects.

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Not at all

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No negative effects whatsoever

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I can't say that the procedure negatively impacted my condition/life. The only downside was the travelling as I am 81 with COPD and on antidepressants. I had to rely on my daughter to take time off work to come with us

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I think I've already answered this in my reply to the previous question. On the whole, for me, I don't think the 'Papillon' treatment has had any significant negative effects.

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It enhanced my state of mind . I had no after symptoms that affected me and my wellbeing. It also put my partner and my family's mind at rest as it had been a very worrying time for all.

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Did not effect negativly

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Was all positive

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Did not affect me in any way. Just carried on as usual

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No negative effects at all!!

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Papillon had NO negative effect on my life whatsoever.

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No major negative effects

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Still ongoing

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Only positive all the way nothing negative whatsoever

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Negative was needing to travel to Liverpool (4.5 hours from home) and leaving children at home.

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The procedure had no negative effects at all .



Did you require anymore treatment, including procedures or surgery after this procedure?



If **yes**, please provide further details.

I undergo CT and MRI scans every 6 months as well as 6 monthly sigmoidoscopy to check if all is well.

5 weeks (25 doses) low level chemo adjacent(?) conventional pelvic radiotherapy as a precaution. Again had no significant impact on my quality of life, other than diarrhoea which was easily addressed with Imodium

I had a minor regrowth 8mm which has been removed by the TEMS surgical procedure with a reported clear margin. My consultant has advised that there is no visible cancer remaining

I had to have my anus and bowel removed and a permanent stoma

Pelvic radiotherapy

Endoscopy

external beam radiotherapy/chemotherapy

I had to have a ileostomy and stoma bag fitted as cancers was found on a pet scan

Endoscopies and CT Scans and MRI Scans and blood tests three monthly at the Leicester Hospitals and sucralfate enemas at the hospital then a further surgery to remove another polyp near the original site three years post treatment which proved to be benign. Now on Bowel Cancer Screening programme.

CT and MRI scans are scheduled for the next 2 years I believe. Regular blood tests are also called for and regular updates from a Colorectal nurse as well

It's a don't know as still under surveillance

I underwent APR surgery approximately 7 months after completing Papillon treatment.

Sigmoidoscopy to monitor the effects

Hernia may require further operation in the future

External beam radiotherapy

External beam radiotherapy for five days

The tumour has been removed but I need to be monitored over the next 1-2 years with endoscopy and MRI

External beam radiotherapy/ chemotherapy

3 monthly CT scans locally

I need to have an MRI scan every 3 months for the next two years.

A 5 week course of radiotherapy external beam.

Radiotherapy at shrewsbury

Removal of residual tumour

TEM Surgery in 2018 as the tumour had shrunk. I am 8 years into my recovery from colorectal T3/4 cancer

Follow up

Would you recommend this procedure to another patient with your condition?

Yes (51)  100%

No (-)

If **yes**, what might you tell them?

It is a very effective alternative to surgery, provided it is not advanced. Get a second opinion from the experts in the procedure after consulting the Oncologist.

I have had a positive experience and now am able to live a full and healthy life without the lasting impact of a stoma for life.

Mine was a positive story and I am now cured with no side effects or very importantly the need for a stoma. Whilst the stoma service is excellent the thought of this as a woman and the potential need to dress differently etc was quite worrying and stressful. I would tell them that it now has no effect at all on my life or lifestyle. I can go on holiday, sunbathe, swim and dress as before as there are no external reminders.

It is an effective treatment that can help achieve a complete response, increase the chances of organ preservation, and allow you to maintain a good quality of life.

I would recommend this treatment 100%. It is quick, just a little discomfort for a few minutes of the procedure, no side effects, the course of treatment is short and the success rate is high. You can avoid life changing operations and the need for stoma bags resulting in long term care. The only reason more people don't opt for this treatment is that it is not publicised in any NHS or McMillan literature. It is a shame that so many patients and doctors do not know about this procedure. I am sure many patients would take this course of treatment if they knew about it. I would tell patients to go for it!


That Papillon is the future of treatment for early stage rectal cancer. It really is a game changer. That they would be able to continue their life as normal throughout the treatment phases. There is nothing to be afraid of during the procedure. It does not feel invasive and is not painful. And importantly, past research has demonstrated an unmatched and incredibly high success rate for the Papillon treatment

Having Papillon treatment could enable them to avoid the indignity of having a stoma.

You have nothing to lose by having the treatment as in the event that it is not successful you can still proceed with bowel removal. The brachytherapy will at least prolong your normal lifestyle perhaps indefinitely.

In my case it has been highly successful and would recommend this treatment to anyone who is offered it.

If it works, life won't change after.

If you don't want to wear a bag for life seriously consider this procedure. Go onto the  website and watch the Papillon video. Trust the staff who are fantastic. Stay positive, if the Professor says it can be done you're in great hands.

If it gives you chance to be cured and resume some normality it's definitely worth it.

Its painless and can be quite funny

Procedure is a little uncomfortable but not painful. Doesn't take long, Treated like royalty.

If normal radiotherapy fails this is well worth trying. A life line for me as my consultant and I did not want surgery due to other health concerns.

It's not comfortable but very worthwhile



If **yes**, what might you tell them?

There is definitely life after Papillon and although quite painful it is a very short time actually having the procedure. A very close friend of mine had to have tys radical ablation and he had almost two years of recovery time before he could even walk very far and had to sell his business as he was so fatigued. He is still here but the cancer has come back elsewhere so not always the best result for radical treatment sadly.

Please ask for all options, and effectively ask for this, if it is not offered, they do a fantastic job!

As an alternative to an operation possibly requiring a stoma it is well worth going through this procedure

That there was nothing to fear as the treatment was slightly uncomfortable but painless.

All the above re pros and cons

Preferable to surgery

Although this treatment was not successful for me, I believe for some people it is. Looking back on my experience, at the point of achieving a near complete response to treatment I would have preferred a conversation with my surgeon to discuss the option of surgery versus referral for Papillon consideration.

I would recommend the treatment but not the journey.

Follow the medical advice

Be bold and resolute. Trust recommendations from your professional advisors. Nothing to fear from this procedure.

I've already said to people if you are offered this amazing treatment go for it 100%

It is a fairly new treatment which could prevent surgery

The whole experience, from the procedure itself to the support I got from [REDACTED] and the staff, has been outstanding. Can only advise to evaluate this procedure to reduce the impact of discovering to have a cancer put already on a person's life and the one of his/her family

It's a short intense treatment and has reduced my requirement to have a permanent stoma bag

Why wouldn't you. It can save your life. Compared to radiotherapy and chemotherapy which I managed well this procedure was easy. I was given full details throughout by the amazing staff and despite its evasive nature I was always treated with respect and dignity

Yes it's uncomfortable and not very pleasant but the staff are so understanding and helpful and the duration is very short. It is well worth the minor inconvenience and I cannot understand why it isn't more widely available

This is a major advancement in the treatment of rectal tumours that can preserve your quality of life

That, in my experience at least, the treatment was painless, the side-effects minimal and to date appears to have been successful.

Positive, well worth considering

It is relatively painless and gives you a chance of recovery without the need for surgery

It works. It's a little uncomfortable but not painful. Doesn't take long. You are treated like royalty. Go for it.

That after 3 procedures, the treatment worked as the tumour has now gone

Again, I need to qualify my answer here. Firstly by saying that I am only in the early stages of post treatment and I cannot say what side effects or other issues may arise in the future. Secondly, I entered this treatment having been fortunate enough to have had no visual signs of the tumour. It was put to me by my oncologist (and also by the team at [REDACTED]) that the 'Papillon' treatment would help to 'mop up' any trace of cancer cells, which were otherwise not visible (or appearing on MRI scans) and further that it would reduce my chances of a recurrence (by a significant margin). This is what I would tell another patient - that he/she would have nothing to lose, that any short term effects would be outweighed by the long term benefits.



If **yes**, what might you tell them?

I would make them aware that there is an alternative to having a very complex and life changing operation. Unfortunately I wasn't given this alternative freely as I asked if there were any other options and only because I asked I was informed of Direct Contact performed by [REDACTED]. I would therefore urge any patient to ask for this option and to be referred for this treatment.

Incredible miraculous technique

It's very uncomfortable but worth it

It is the best option if it fails there is always surgery

I know that it may not be the same for everyone but in my experience it was the best decision I ever made and I have no regrets whatsoever

I would tell them that it can be the difference between life and death. For many patients facing the prospect of a stoma life can be daunting and in my case not worth living.

You set up, hospital

I would tell them to go for this treatment 100% as it saves you a massive operation and you can carry on and live a normal life

It has had a limited impact on daily living with positive results in terms of cancer

Since the pappillon I have lived to a n old age, I am now 94 and have had a very good quality of life. I would highly recommend this treatment to anybody considering it. They will not regret it .

If the procedure had an impact on any other areas of your life that are not covered by the questions above please tell us about them here.

N/A

N/A.

Not at all. I must add that the positive attitude to dealing with this at [REDACTED] with [REDACTED] and his team have helped considerably particularly in the early years. They were all particularly caring even to the ease of making appointments and attitude of every one involved

The procedure did not have any impact on any other areas of my life.

I just feel frustration that more NHS money has not been dedicated to contact radiotherapy. The equipment and support facilities required is relatively inexpensive when compared to expensive Beam therapy machines, Avoiding patients being hospitalised must ease the NHS burden

Nothing to add. An entirely positive experience for which I will be eternally grateful

Not applicable

None whatsoever

Just thankful for the chance and being part of the trial. Meeting [REDACTED] and team. I meet a roomful of people it had worked for, definitely should be on offer to all.

Having gone through this procedure successfully I have definitely moved on from the bloke syndrome of not seeking out advice when I have any health issues. I have had every injection/scan/scope offered to me. I will talk openly to anybody about any issues or treatment I have had. This is is down to the fantastic treatment/ consultancy received by me at [REDACTED] and the Papillon team at [REDACTED] in Liverpool.

Considering everything I was going through I felt lucky to be given the option and am very grateful to Hull hospital for their care from start to finish.

No

As a result I am now in remission. Gives a sense of invincibility. My world is a happier place.

It has just extended my life expentency as I could not have surgery.

I would like to think that the outcome is successful and I can look forward to a relatively good life moving forward

If the procedure had an impact on any other areas of your life that are not covered by the questions above please tell us about them here.

Not applicable3

Nil else to add.

I don't know the long term effects yet. But I am hopeful that it gives me longer to lead a normal life

None

NONE

N/A

None, but I would like to point out how dissatisfied I was with the Welsh Health Authority to approve cross border (England) funding, causing a significant delay and possible increased risk to my prognosis until I wrote to my MP and got a review of my case. It was emotional very distressing during this waiting period and I believe those making decisions should be accountable for not adhering to NICE principles of patient choice.

None

I can't think of anything else.

None

The Papillon procedure has enabled me to help others, with two of my friends having had the treatment and both are doing fabulously well 3 years down the line

None

Only complete relief and joy to have got the treatment from the absolute brilliant [REDACTED] and his amazing staff who go out of there way to make you feel comfortable and relaxed.All in all I cannot praise the procedure,the PROFESSOR and his staff in [REDACTED] clinic highly enough

N/A