

IP survey IP964

This report was generated on 22/08/22. Overall 14 respondents completed this questionnaire. The report has been filtered to show the responses for 'All Respondents'.

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

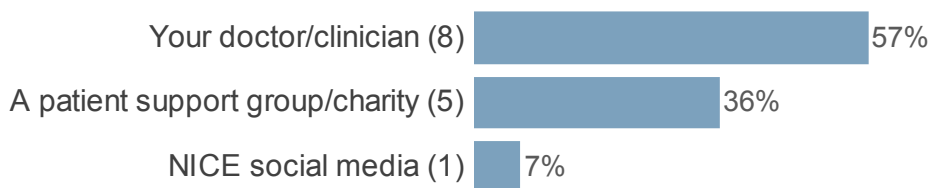
I have read the information above which explains the purpose of the project and how any information I provide will be used



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



How did you hear about this survey?



Other (please sepcify)

- _____
Email
- _____
E mail
- _____
Phone call
- _____
Got a phone call asking if I would be interested in filling it in
- _____
telephone call from hospital

Are you (the person completing the questionnaire):



Your age (in years)

Count	Sum	Mean	Sample Standard Deviation	Minimum	Maximum	Range
14	867	61.93	7.89	48	76	28

How long ago did you have the procedure?

November 2018	5 years come October	Nov 2020
1st April 2019	One year ago	Aug 2020
July 21 2020	QS	About 6 months ago so I was 58

In years

Count	Sum	Mean	Sample Standard Deviation	Minimum	Maximum	Range
3	6	2	1.00	1	3	2

In months (OR In months)

Count	Sum	Mean	Sample Standard Deviation	Minimum	Maximum	Range
7	119	17	10.77	6	33	27

In months (OR In weeks)

Count	Sum	Mean	Sample Standard Deviation	Minimum	Maximum	Range
0	-	-	-	-	-	-

To which gender identity do you most identify?



Did the procedure work?



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

Worked for over a year then a reoccurrence

Did you have any side-effects following your procedure?



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

Extreme weakness and fatigue

No spleen = antibiotics for life Stoma permanent

Usual post surgery grumbles!Numbness rt thigh, parastomal hernia,

very sick from anaesthetic, very emotional, tiredness - took about week to get over

Sepsis, had to be opened up through same scar after 7 days. Lots of fatigue

nausea, sickness, fatigue, some bladder incontinence, weight and muscle loss, emotional, lack of confidence

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

About 3 months

3 months

6-8 weeks

6 months

About six weeks, to be able to walk around an do little things but around six months to feel able to achieve more daily tasks

6 months

A couple of month

2 months, complicated by second round of debilitating chemo

Difficult to say as having chemo at same time and now having side effects from Olaparib. I was in intensive care fir 5 days and in general ward for 5 days. At home, I was so week and exhausted fir 6 weeks I could not get the energy to get out of my nightdress but did get out the bed all day. I. Had someone to prepare all my meals. I could not even speak to my friends. Just no energy.

The procedure was followed by 6 cycles of intense chemo and I was also fitted with a stoma as the cancer had spread to my bowel. In all it took approximately 18 months to recover from surgery and chemo

5 days

In hospital 3 weeks but took about 4 months, then started chemo

About 3 months, I had a small hole in the mid line incision which wouldn't heal, it leaked fluid which was difficult to keep covered but eventually it healed on its own

still recovering from operation and follow up chemotherapy

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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

Eliminated some symptoms like acetes, swollen legs and abdominal bloating Very pleased generally to have had it done and get through without any immediate side effects

I was leading a fairly normal life prior to op but with severe side effects from 3 sessions of chemotherapy given to shrink tumour to enable op to go ahead. Recovered from op well.

It was life-saving for me and life-changing for both me, my husband and family. I still have 'what if it comes back' moments but mostly I have 'Thank God, chemotherapy and the skills of my Surgeon and Oncologist' days. Three years on, from a cancer point of view, I do more and enjoy life with my grandchildren, two of whom I didn't think I'd live to see.

It seemed to take a long time to positively effect my life . Eventually within about 8 weeks I was able to go out and about and appeared to walk out with a good step not in any stomach pain like before . I got more and more faster and with positive spring in my step . I didn't start lifting until the 6 weeks were up and then took it very slowly

It made me feel less anxious about the diagnosis and feel like this will improve my quality of life, with ongoing chemotherapy I still get fatigued but this has made me feel more positive.

Extreme fatigue very weak. Emotionally very low.

Initial diagnosis stage 3/4C prior to surgery, down graded to 3c following tests on tumours after surgery. Gave me piece of mind that all visible signs of cancer had been removed (chemo followed) Life hasn't really been the same since but at the time new the de-bulking hysterectomy and definitely saved my life.

I felt I recovered fairly quickly after such extensive surgery. I was physically fit before the op. For me , after initially being felt not to be suitable for second surgery, this was very important as I wanted the best chance to survive so a massive impact on my mental health that surgeon agreed to proceed. I also asked for opinion from a prof in London, well known for her expertise in ultra radical surgery and she agreed this could be done at my local expert centre. My family and friends were very glad I was given this option . My surgeon was able to completely " cytoreduce" my cancer.

No physical symptoms apart from fatigue and UTI. Emotionally ok. I had all surgery done by keyhole as I have Ehlers Danlos and I came through with no EDS symptoms which was a miracle.

The procedure saved my life. At first I couldn't do basic tasks explained below but over time I started to regain my independence but not at the point at where I was pre the procedure but enough to get on with my life.

came home and couldn't do much at the time, slowed down. 3 months later, doing housework and I know the op saved my life really

The pain associated with being unable to move my bowel stopped at the cost of having a permanent ileostomy.

Well as it was completely successful due to my surgeon I was very happy right from the moment I woke up after my surgery so my quality of life was instantly much better! My emotional state of mind improved tremendously which in turn meant my children and siblings worries were very much improved too. I haven't seen my surgeon, and wish I could say thank you to him.

It eliminated the pain I was in. It has hopefully prolonged my life.

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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

Difficult to say as following chemotherapy has left me very fatigued and less able to do many tasks but that may also be to do with cancer in parts of the body other than the primary site.

As above recovered from op well but more chemotherapy caused severe side effects again which impacted on my recovery.

My physical abilities are limited by my severe Rheumatoid Arthritis so this is a difficult question to answer.

All I remember is life was hard it was a good job I had my husband looking after me , tbh I never expected to do much I was warned I wouldn't be able to so I didn't have big expectations. I was never in the mood for friends of a lot of visitors found them to be to much effort . My emotional health was very low I'd say due to a very low state of mind .

I felt useless after the procedure as couldn't do to much and felt I was putting on my family, but I have a strong family and friend network who encouraged me to take one day at a time. Didn't do too much socially but now feel able to do this

Fatigue and low mood

I am very self conscious about my stoma. I am a weaker person, become tired easier and am not the person I was. That said I try to enjoy life and time with my family and have a positive out look on life. I am still a glass half full type of woman. My family support me and cover for me on my low times.

I recovered quickly so I think the only negative issues were my numb thigh and a few initial bladder issues. I needed help with ADL's for a few weeks after surgery.

See above

I was totally dependent on a full time carer to help with food preparation, housekeeping, financials, shopping, showering, getting ready and transportation to hospital and GP appointments. hing and I wanted my independence back it was a tricky situation to manage because they were there when I needed then most but it came a time when I needed to do stuff myself did manage this through. State of mind - mixed emotions coming to terms with cancer, experiencing of chemo and the creation of the stoma. I had great support from the family but at the same time they were experiencing and having to come to terms with the diagnosis and the management of the stoma. This took a particular toll on my husband and daughter (who was pregnant at the time with our 1st grandson). We openly talked about recovery and had honest and open conversations with the lead consultants (the surgeon and chemo lead) which helped us all understand the recover plan the importance of being positive but it also give my husband and daughter to ask their questions. At times I felt overwhelmed and smothered by the carers who were trying their best but wanted to do everything but as I was recovering I wanted my independence back so we had to compromise and agreed no lifting, shower on my own but leave bathroom door unlocked etc I regained some independence but help was always on hand. I was a very active person jogging, walking, cycling I had to pair back some of these activities due the procedure but found other ways to enjoy outdoor activities like buying an electric bike, planning shorter walks.

felt very anxious, felt very low, maybe that was the shock of the operation and knowing how poorly i had been

Living with an ileostomy, fatigue, change to foods I was able to eat.

There are very few negatives, I had a bit of an issue with my mid line scar healing as a hole about 1cm wouldn't heal as it leaked for a couple of months, eventually it healed on its own once it stopped leaking fluid. I never worried about any change in my lifestyle as I knew it was temporary and the alternative wasn't an option!

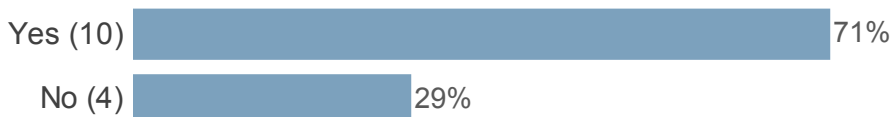
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I became initially totally dependant on my partner for everyday tasks. I became very emotional and anxious about things which I would not normally be too concerned about. I was unable to socialise for a long time. The operation included an ileostomy so this has affected my diet, eating and drinking habits. Also, it has obvious implications for going to the toilet with me having to be extra prepared for all eventualities when I go out. I have a lowered immune system due to spleen removal so have to be careful when meeting other people. I have had to take ill health retirement as I will not be physically or mentally able to continue my role at work (headteacher).

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



If yes, please provide further details.

Chemotherapy 9 rounds paclotaxyl and carboplatin, 9 rounds carboplatin and calyx, 18 weekly sessions of paclotaxyl. Also 18 sessions of bevacizamab.

Chemotherapy then Avastln.

Removal of nephrostomy, removal of stent, adrenalectomy to remove cancerous tumour

I was still receiving chemotherapy

Chemotherapy

I went in for a stoma reversal but cancer had returned so procedure was aborted.

Chemotherapy six cycles

Not sure about the next steps - tablet keeping cancer at bay - might need chemo.

Full course of chemo Then taking daily niraparib for 3 years(I still have 1 year of niraparib to take)

Chemotherapy. Ongoing chemo medication as a treatment management plan in case of recurrence. Life-long antibiotics for spleen removal.

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



If yes, what might you tell them?

Be prepared to do very little for 3 months, be careful to avoid picking up infections as much as possible, give your body time to recover, exercise gently and build up slowly, tell people around you how you are, focus on recovery.

The problem for me was having to have aggressive chemotherapy before and after the op. All the problems I have had have been due to the chemotherapy not the procedure, from which I recovered incredibly well with no difficulties apart from being told not to work in the garden after a few days back at home when I wanted to! I felt well. The effects of the chemo are still with me.

I was told I had Grade 4 metastatic cancer that had spread quite significantly and the prognosis was bleak. I was initially told it was 'inoperable, untreatable and incurable. However, following Chemo, I had my surgery and haven't looked back. I would 100% recommend this surgery.

If you can get through the three months not expecting anything wonderful to happen to will get through it and it will improve your life .

It is a big operation but all concerned in this were amazing and done an excellent job

Be prepared for a slow recovery. Depending on how long the operation took.

I would recommend the de-bulking surgery, my cancer is low grade ovarian so physical removal of the disease will have a better outcome than chemo.

I asked my surgeon if I could speak with a similar patient prior to my op. This was exceptionally helpful. I am reflecting on this to answer this question...I would absolutely recommend this, provided the surgeon was very experienced . I think an older, frailer person may have difficulty after this level of surgery.

Keyhole was miraculous.

Trust your surgeon and NHS make sure you have support on hand and openly talk about sent you sent through people are eager to know but it also helps yourself to come to terms with the procedure, process and after care

definitely - i was stage 4, i didn't realise how poorly i was, it can save your life

Its radical and longer to recover but i felt it was better to have all traces removed for better chance of recovery.

I would tell them that it won't be easy and they may have to be brave but it's well worth it! And the alternative isn't an option!

Expect to be incapacitated for a long time. Expect to have good days and bad days, and feel emotional for no particular reason! Write down any concerns or questions as they come to you - no matter how small they seem - to discuss with your consultant. Remember that this surgery will have prolonged your life, no matter how bad it may make you feel at the time. Plan some future activities to have something to aim for and look forward to.

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.

Loss of interest in sexual activity

N/A

Too weak to ever work again.

The stoma and parastomal hernia have been troublesome. Having said that I am back to swimming and spinning classes after chemo effects allowed this. I have just had another ct scan which is clear. I have the most brilliant GP, surgeon and oncologist. I have worked as a NHS senior nurse for most of my working life. I am very grateful for the care I have received and pray this awful disease does not return.

I think I've covered all the areas where my life has been impacted by the procedure

info was overwhelming at the time but made to feel safe and reassured by the hospital and staff.

I had to have a stoma which is a shame but because I had complete faith in my surgeon I knew it was unavoidable so have accepted it and am coping with it well. It has changed my life slightly but again, my surgeon saved my life so it's a small price to pay.