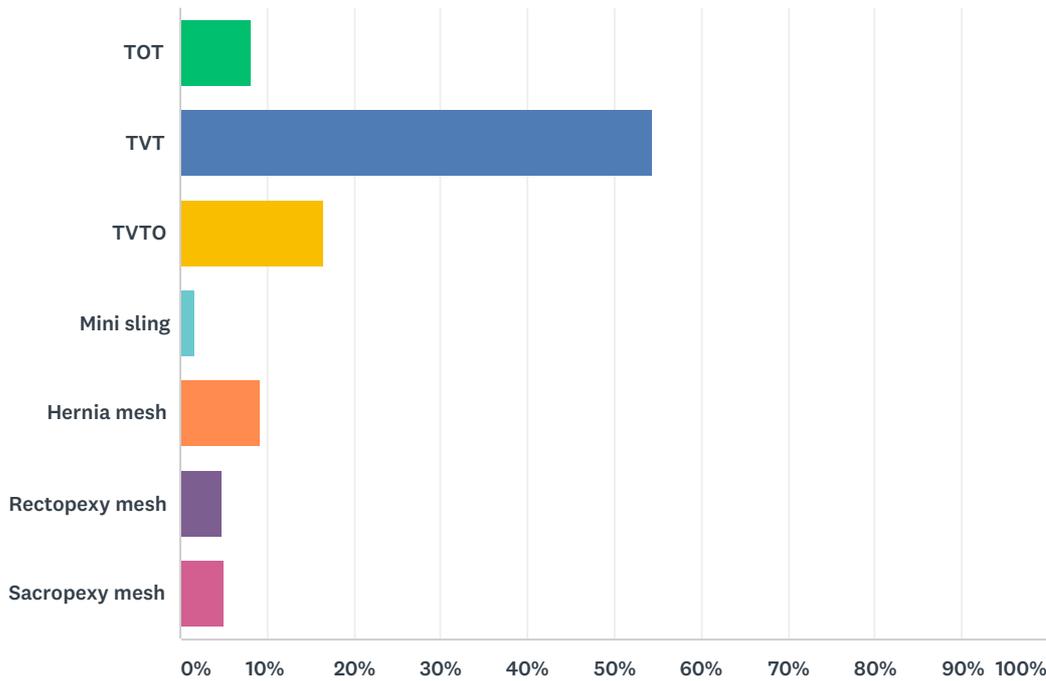


Q1 What type of mesh do you have?

Answered: 534 Skipped: 36



ANSWER CHOICES	RESPONSES
TOT	8.24% 44
TVT	54.49% 291
TVTO	16.48% 88
Mini sling	1.69% 9
Hernia mesh	9.18% 49
Rectopexy mesh	4.87% 26
Sacropexy mesh	5.06% 27
TOTAL	534

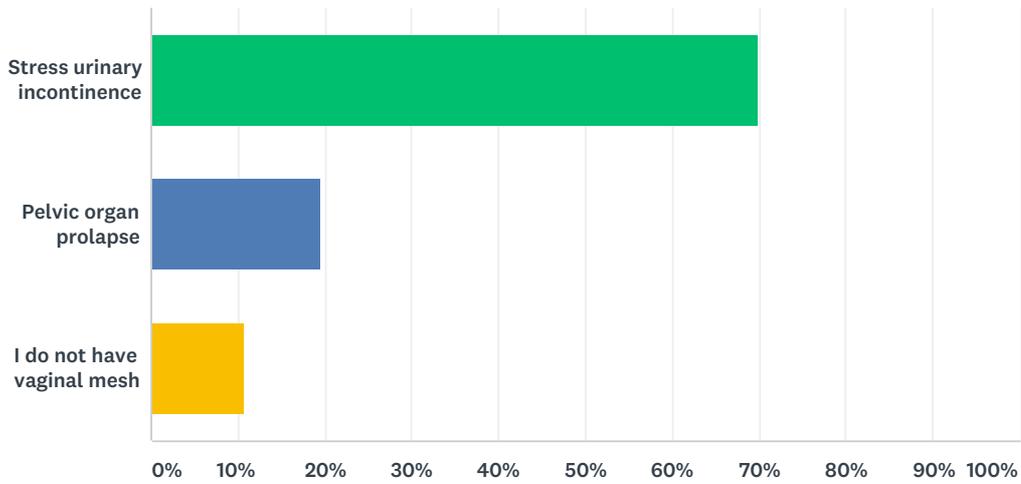
#	OTHER (PLEASE SPECIFY)	DATE
1	not sure/plastic	12/21/2017 8:29 AM
2	TVT + Pelvic floor repair 2008. TVTO + Posterior repair + Posterior prolift 2009	12/20/2017 9:33 PM
3	Not sure	12/20/2017 9:51 AM
4	Monach,by ams	12/20/2017 9:30 AM
5	not sure	12/20/2017 8:06 AM
6	And other mesh	12/20/2017 7:52 AM
7	And TVT	12/20/2017 7:40 AM
8	Prolift Vaginal	12/20/2017 3:57 AM
9	Tvt	12/20/2017 12:31 AM
10	And mini sling	12/20/2017 12:21 AM
11	Abdominal Sacrocolpopexy	12/16/2017 9:53 PM
12	Used in LVMR!!!	12/15/2017 8:15 PM

13	I HAD a TVT, but have had it removed	12/15/2017 12:39 AM
14	promesh in 2004 and prolift mesh in 2012	12/14/2017 11:28 PM
15	Gore tex duomesh	12/14/2017 11:12 PM
16	Don't know	12/14/2017 11:10 PM
17	Unsure what one I had awaiting my notes	12/14/2017 11:06 PM
18	+ TOT + rectocele mesh	12/14/2017 9:59 PM
19	Mesh inlay	12/14/2017 9:44 PM
20	And TVTO	12/14/2017 6:26 PM
21	Now removed	12/14/2017 5:43 PM
22	Tfs	12/14/2017 1:01 PM
23	Have 2 types waiting to find out other	12/14/2017 12:45 PM
24	Posterior and anterior prolift mesh implants	12/14/2017 10:58 AM
25	Rectopexy mesh, vaginal wall and tvt	12/14/2017 10:52 AM
26	Total prolift, and additional mesh attaching womb to spine.	12/14/2017 10:42 AM
27	Rectopexy aswell	12/14/2017 10:29 AM
28	Tot as well	12/14/2017 10:27 AM
29	gynae mesh	12/14/2017 10:17 AM
30	Rectopexy & Sacropexy	12/14/2017 9:48 AM
31	Mesh kit for prolapsed bladder	12/14/2017 8:29 AM
32	Abdominal	12/14/2017 8:03 AM
33	2 TVT and hernia mesh	12/14/2017 7:38 AM
34	Hernia	12/14/2017 6:48 AM
35	TVT, Rectopexy and Sacroplexy	12/14/2017 6:09 AM
36	Pop	12/14/2017 4:09 AM
37	and hernia mesh	12/14/2017 2:45 AM
38	Inguinal hernia mesh too (2005), TOT 2013	12/14/2017 1:46 AM
39	And Tvt. Two mesh	12/14/2017 1:27 AM
40	Rectocele & cystocele	12/14/2017 1:19 AM
41	Gynecare Ethicon	12/14/2017 12:51 AM
42	Waiting for medical notes	12/14/2017 12:30 AM
43	Awaiting confirmation of other type of mesh	12/14/2017 12:09 AM
44	Mesh has been removed	12/13/2017 11:58 PM
45	AMS Elevate anterior and apical prolapse mesh	12/13/2017 11:56 PM
46	Infracoccygeal hysteropexy	12/13/2017 11:51 PM
47	2 ops. One for stress incontinance, one for prolapse	12/13/2017 11:49 PM
48	Sacral Colpopexy and Posterior	12/13/2017 11:34 PM
49	Hysteropexy	12/13/2017 11:32 PM
50	hysteropexy	12/13/2017 11:30 PM
51	I don't know. Was told it was TVT but found out last week it can't be because of the way it was put in	12/13/2017 11:24 PM
52	Ventral sacrocolporectopexy and hysteropexy	12/13/2017 11:16 PM
53	And rectopexy mesh	12/13/2017 8:38 PM
54	TOT, Hernia and Cystocele and Rectocele repairs	12/13/2017 8:26 PM
55	And tvt	12/13/2017 8:25 PM

56	Cystocele repair	12/13/2017 8:01 PM
57	Plus mesh for bowl prolapse	12/13/2017 7:56 PM
58	Don't know	12/13/2017 7:49 PM
59	TVT also	12/13/2017 7:49 PM
60	Tvt now removed	12/13/2017 7:43 PM
61	And rectopexy and sacropexy	12/13/2017 7:17 PM
62	And sacrohysteropexy	12/13/2017 7:16 PM
63	2 x TOT & 1 x TVT	12/13/2017 7:12 PM
64	Plus a SPARC sling was put over the tvt0	12/13/2017 7:09 PM
65	I stop	12/13/2017 7:08 PM
66	Not sure	12/13/2017 6:57 PM
67	Sacrocolpopexy	12/13/2017 5:26 PM
68	Total prolift and additional mesh sewn to back of womb and attached to spine. And Essure	12/13/2017 3:10 PM
69	And Hernia	12/13/2017 2:00 PM
70	Two TVTO's one for stress incontinence and one for prolapse	12/13/2017 2:00 PM
71	Also have TVT	12/13/2017 1:54 PM
72	2 tvt 2 Hernia	12/13/2017 1:33 PM
73	Still awaiting medical records.	12/13/2017 1:31 PM
74	Biological + AMS Elevate	12/13/2017 1:21 PM
75	No, this site made me decide not to have the operation	12/13/2017 1:19 PM
76	Was told tape have been unable to clarify at the moment	12/13/2017 1:17 PM

Q2 If you have vaginal mesh, what is it for?

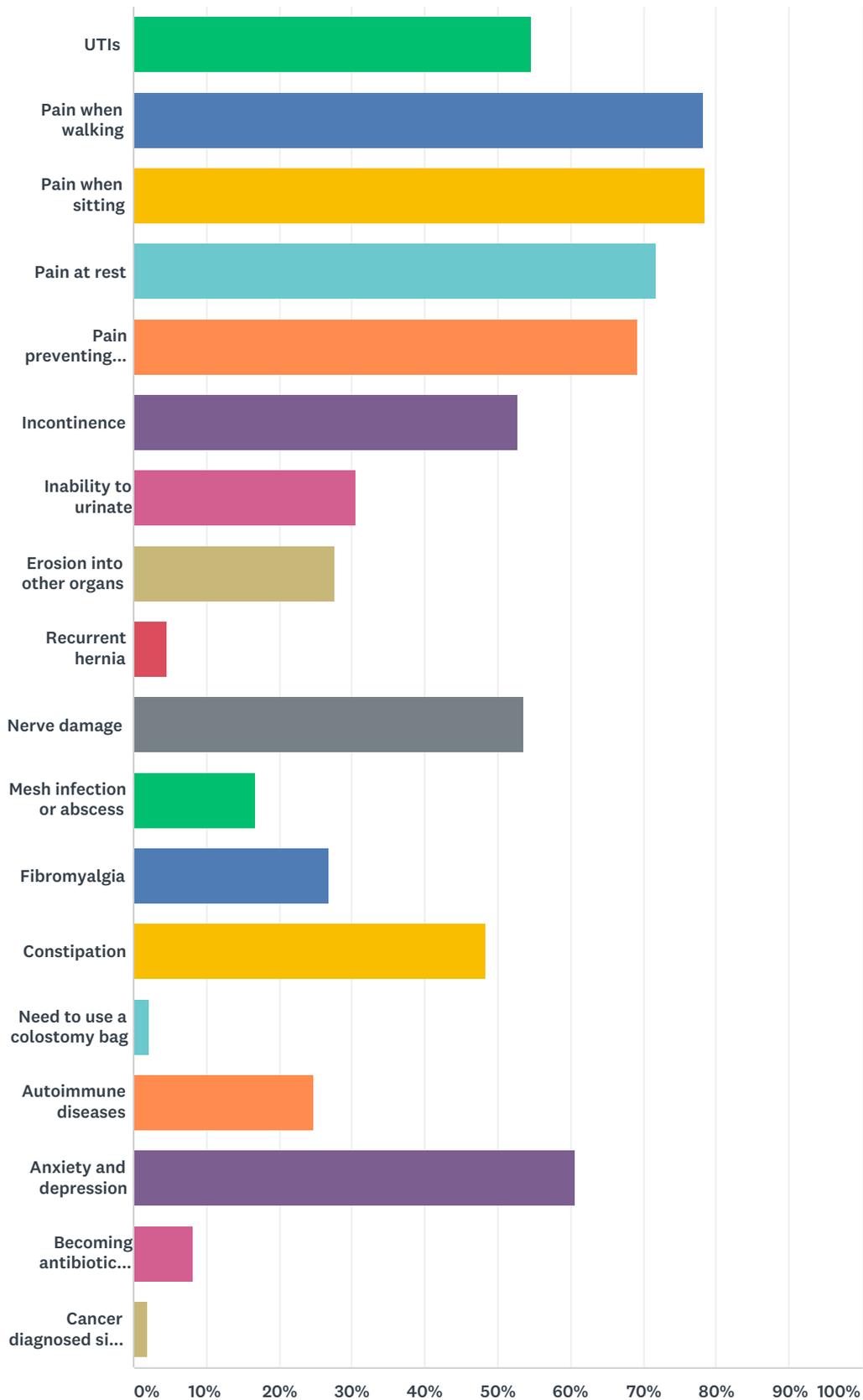
Answered: 555 Skipped: 15



ANSWER CHOICES	RESPONSES	
Stress urinary incontinence	69.91%	388
Pelvic organ prolapse	19.46%	108
I do not have vaginal mesh	10.63%	59
TOTAL		555

Q3 What type of complications have you experienced since your mesh operation?

Answered: 560 Skipped: 10



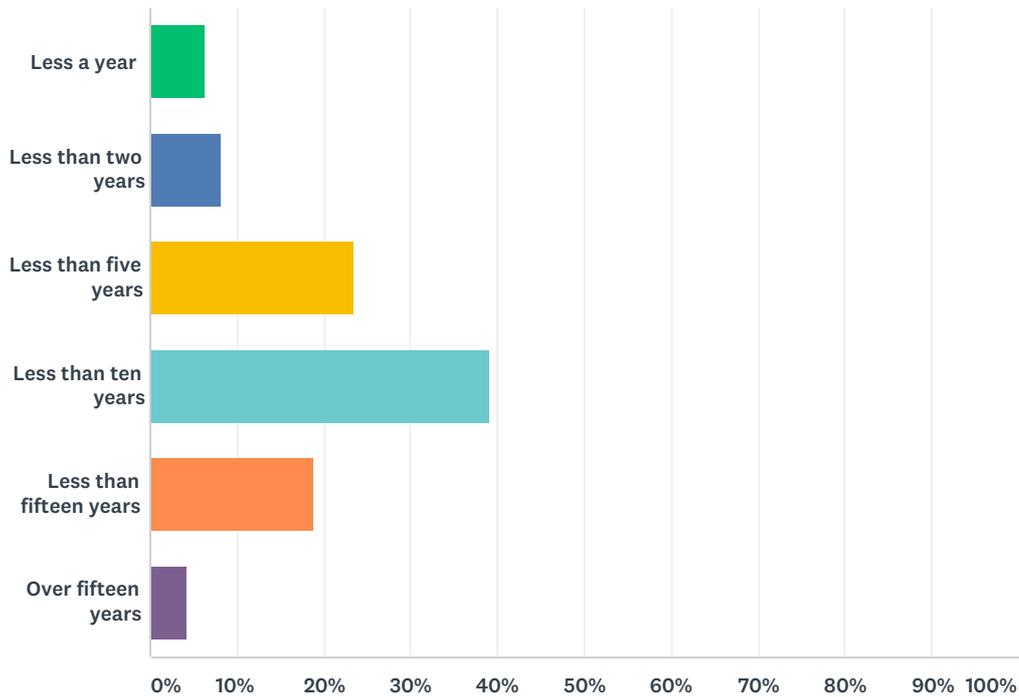
UTIs	54.64%	306
Pain when walking	78.21%	438
Pain when sitting	78.39%	439
Pain at rest	71.79%	402
Pain preventing intercourse	69.29%	388
Incontinence	52.68%	295
Inability to urinate	30.54%	171
Erosion into other organs	27.68%	155
Recurrent hernia	4.64%	26
Nerve damage	53.57%	300
Mesh infection or abscess	16.79%	94
Fibromyalgia	26.79%	150
Constipation	48.39%	271
Need to use a colostomy bag	2.14%	12
Autoimmune diseases	24.64%	138
Anxiety and depression	60.71%	340
Becoming antibiotic resistant	8.21%	46
Cancer diagnosed since mesh implanted	1.96%	11
Total Respondents: 560		

#	IF YOU ARE ANTIBIOTIC RESISTANT, PLEASE TELL US HOW MANY ANTIBIOTICS STILL WORK FOR YOU BY PUTTING THE NUMBER 1, 2, 3, 4 OR 5+ BELOW.	DATE
1	1	12/20/2017 8:53 PM
2	One	12/20/2017 10:26 AM
3	3	12/20/2017 9:30 AM
4	It is starting to become apparent I am doctors words yesterday	12/20/2017 7:21 AM
5	1	12/20/2017 1:21 AM
6	None so far	12/19/2017 11:55 PM
7	2	12/19/2017 11:15 PM
8	1	12/19/2017 10:54 PM
9	4	12/19/2017 10:36 PM
10	1	12/19/2017 10:31 PM
11	Not sure	12/15/2017 1:04 PM
12	1	12/15/2017 8:37 AM
13	2	12/15/2017 12:41 AM
14	3	12/15/2017 12:34 AM
15	Get chronic pain in abdomen	12/14/2017 11:14 PM
16	2	12/14/2017 10:18 PM
17	I can't take any penicillin!	12/14/2017 9:25 PM
18	1	12/14/2017 7:58 PM
19	2	12/14/2017 7:33 PM
20	2	12/14/2017 4:02 PM

21	I'm resistant to one for UTI cannot recall name.	12/14/2017 2:54 PM
22	1	12/14/2017 2:39 PM
23	1	12/14/2017 1:12 PM
24	2	12/14/2017 11:44 AM
25	2	12/14/2017 10:49 AM
26	2	12/14/2017 10:16 AM
27	don't know	12/14/2017 8:22 AM
28	1	12/14/2017 6:03 AM
29	Ileostomy Bag	12/14/2017 2:45 AM
30	5 don't work	12/14/2017 1:51 AM
31	Infertility, bowel and urge incontinence, sepsis, premature births linked to the inflammation in my body, all children have serious allergies (no family history) and one child has white matter brain damage as a result of his prematurity	12/14/2017 1:46 AM
32	3	12/14/2017 12:42 AM
33	0	12/14/2017 12:30 AM
34	1	12/13/2017 11:47 PM
35	2	12/13/2017 11:45 PM
36	Cutting through vaginal wall	12/13/2017 11:24 PM
37	2	12/13/2017 7:36 PM
38	4	12/13/2017 7:33 PM
39	Mesh ErosionForeign Body Reaction, Inflammation, which led to hip joint damage and hip surgeries as well.	12/13/2017 7:24 PM
40	2	12/13/2017 7:19 PM
41	2	12/13/2017 7:01 PM
42	1 + iv antibiotics	12/13/2017 7:00 PM
43	1	12/13/2017 6:58 PM
44	1	12/13/2017 6:54 PM
45	don't know	12/13/2017 4:02 PM
46	2	12/13/2017 1:18 PM
47	2	12/13/2017 1:16 PM

Q4 How long is it since you had your mesh implant?

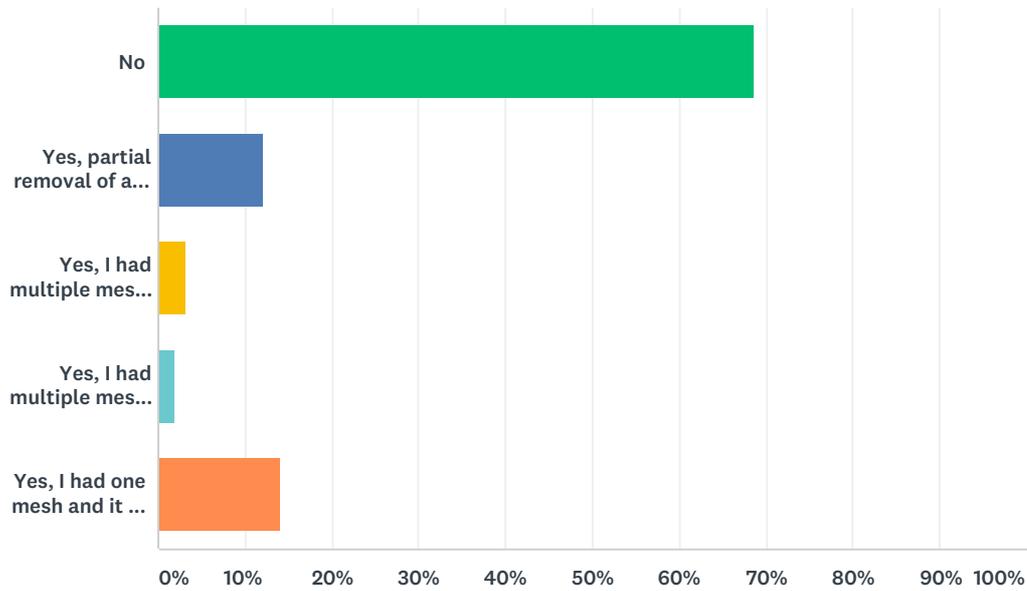
Answered: 564 Skipped: 6



ANSWER CHOICES	RESPONSES	
Less a year	6.21%	35
Less than two years	8.16%	46
Less than five years	23.40%	132
Less than ten years	39.18%	221
Less than fifteen years	18.79%	106
Over fifteen years	4.26%	24
TOTAL		564

Q5 Have you had mesh removal surgery?

Answered: 559 Skipped: 11



ANSWER CHOICES	RESPONSES
No	68.69% 384
Yes, partial removal of a single mesh	12.16% 68
Yes, I had multiple mesh implants and one or more was fully removed but I still have one or more inside me.	3.22% 18
Yes, I had multiple mesh implants and they have all been removed.	1.97% 11
Yes, I had one mesh and it was fully removed	13.95% 78
TOTAL	559

#	IF YOU HAVE HAD MESH REMOVAL, WHAT EFFECT HAS IT HAD ON YOUR SYMPTOMS?	DATE
1	I am new to removal list	12/21/2017 2:30 PM
2	Pain due to nerve damage.	12/20/2017 9:51 PM
3	Removed only a couple of weeks after being put in place due to necrotic infection.	12/20/2017 9:27 PM
4	It has made it worse, I have chronic pain and on multiple painkillers	12/20/2017 5:44 PM
5	A partial removal before full removal. Still have grown pain scar damage Incontience has returned as it xpected	12/20/2017 5:16 PM
6	No intercourse Scar tissue discomfort Depression	12/20/2017 4:41 PM
7	Symptoms the same	12/20/2017 1:55 PM
8	Most of them went but I have some ongoing nerve damage. I also had a rare benign tumour on my outer labia that gives pain despite removal.	12/20/2017 11:16 AM
9	I had the tape stretched...no difference though.	12/20/2017 11:08 AM
10	Not sure it's all removed.	12/20/2017 10:25 AM
11	Had trimmed because of erosion	12/20/2017 10:15 AM
12	Incontinence, nerve damage, removal of vagina due to damage	12/20/2017 9:30 AM
13	None all the same	12/20/2017 9:08 AM

14	It took 4 removals...2 cutbacks.. a removal which was NOT removed!! Then a complete removal. Am not incontinent as had colposuspension now. Starting to sleep more now...my hair has stopped falling out. People have said I am starting to look better now as looked so ill before. Still have a lot of nerve pain in legs and stomach where scarring is and mesh had to be lasered off everywhere inside me..Bladder and pelvic floor had to be repaired as mesh was eroding both.	12/20/2017 7:51 AM
15	Had partial removal twice and mesh is again through my bladder. Last removal left me with a hole in my bladder leaking urine for 5 days. Never been so ill and in pain before.	12/20/2017 7:40 AM
16	Partial removal somore pain extending to hips and down both legs. Unable to sit or walk for long periods of time. Unable to drive. Unable to be intimate	12/20/2017 7:25 AM
17	Improved for a number of years but now recurring problems and removal of remaining tvt due 2018	12/20/2017 7:10 AM
18	Same. Pain can not urinate. Tired all the time don't want to go anywhere anymore	12/20/2017 1:21 AM
19	Chronic pelvic pain, chronic nerve damage, obturator nerve damage right leg. Just been fitted with Neuro Nerve Stimulator for pelvic pain	12/20/2017 12:35 AM
20	Still have a lot of pain but it is different. I had a lot of damage from the mesh	12/20/2017 12:21 AM
21	some have got better, some have got worse. Now fully incontinent and also have large hernia..two more operations at least to go.	12/19/2017 11:46 PM
22	Not really removal but "snipped " as it was poking out abdominal wall (not thru the skin just a lump)	12/19/2017 11:43 PM
23	Damaged bladder, rebuilt urethra painful intercourse	12/19/2017 11:34 PM
24	Incontinent	12/19/2017 11:26 PM
25	It's a long road healing, and while things will never be the same sexually, I can walk and bend a bit easier since the sling's been cut.	12/19/2017 11:22 PM
26	Burning across tummy , burning down right leg, sex life completely gone. Low energy levels, not feeling like a human being	12/19/2017 11:19 PM
27	I'm having removal I. January 2018	12/19/2017 11:17 PM
28	Unable to remove anchors as was losing too much blood during surgery. They are too deeply embedded. Symptoms have changed. Now have vaginal vault prolapse. Had bladder prolapse also - attempted to stitch up using on tissue but have difficulty emptying/stress incontinence. Nerve damage remains in legs. Mobility can be bad. Pelvic spasms.	12/19/2017 11:16 PM
29	Made worse	12/19/2017 11:04 PM
30	Even though they have been removed, they had broken down and eroded badly. There were particles that couldn't be and will never be safely removed	12/19/2017 11:01 PM
31	It helped at first but now have vaginal pain again and blood in urine.	12/19/2017 11:01 PM
32	Still get pelvic pain and original symptoms are back	12/19/2017 10:51 PM
33	Systemic symptoms improved immediately, including severe fatigue, brain fog, heart and eye spasms, but pain and scar tissue from multiple surgeries has increased substantially.	12/19/2017 10:50 PM
34	Alleviated extreme allodynia and other nerve disturbance by approximately 40%. Surgery left me with a persistent re-filling seroma, so left with me with different pain systems. Saw no effect on defunct and widespread sensory nerve function.	12/19/2017 10:45 PM
35	Reduction of pain. UTI worse.	12/19/2017 10:41 PM
36	Too early to say as only just had surgery	12/19/2017 10:36 PM
37	I can now sit down without being in agony. I can walk further but I am totally incontinent again. I still have pain in joints but pain is not as severe. I still can't sleep and my stomach still bloats. I am happier that it has been removed.	12/19/2017 10:31 PM
38	Yes I've had partial removal. Not any real reduction of pain, but it's difficult to say because I'm now on better pain relief, and have acupuncture. Combined, these intervention has reduced my pain to tolerable level. However, numerous times each day, I still get sharp stabbing pains in front and back passage, vagina,coccyx and thighs. The pain I experienced walking, is muc better due to my purchasing a mobility scooter.	12/17/2017 12:31 AM
39	Waiting for removal	12/16/2017 8:19 PM
40	More nerve pain	12/15/2017 11:53 PM

41	Still have symptoms waiting for Examination under GA with camera, to see if rest can be removed. Now involved with bowel risk colosomy..	12/15/2017 8:15 PM
42	The chronic pain is much less. I still have other complications but I am able to cope better without the mesh.	12/15/2017 9:34 AM
43	4 Surgery's to remove Mesh and more surgery Rectocele bowel surgery.	12/15/2017 8:34 AM
44	Symptoms have changed, I have a different pain, prolapse has returned and can't have intercourse due to nerve damage and scar tissue	12/15/2017 8:04 AM
45	Some relief, but damage already done.	12/15/2017 3:48 AM
46	The problems I had with foreign body response have gradually been getting better. However, I still suffer from pain and have since been diagnosed with Interstitial Cystitis and painful bladder syndrome and fibromyalgia.	12/15/2017 12:39 AM
47	None,still left with nerve damage,chronic lower back pain	12/14/2017 10:27 PM
48	Only removed 9 days ago, so too soon to comment.	12/14/2017 9:59 PM
49	Still too early to make a definitive decision	12/14/2017 9:43 PM
50	3 partial removals then full removal	12/14/2017 9:29 PM
51	Most symptoms have gone. Now have a prolapse and still have chronic groin and leg pain	12/14/2017 9:17 PM
52	For the first two years I was almost pain free Incontinence really bad tho 2 yrs on i'm In pain again with remainder mesh mainly in and just above my vagina , burning , sizzling popping feelings	12/14/2017 9:09 PM
53	Slowly mesh pain improved, but left with SUI, pudendal nerve damage and susceptibility to UTIs.	12/14/2017 8:45 PM
54	3 weeks after removal my pains have gone. Too early to mention about intercourse	12/14/2017 8:31 PM
55	I have had 3 removal surgeries so far one more to come, I am a bit better as I used to collapse all the time with agonising abdominal pain that has stopped however I am still in chronic pain, with severe leg pain, pelvic pain, urethral pain, , neurological pain etc perhaps full removal will help although I've been told it could also increase!	12/14/2017 8:09 PM
56	I have had 2 operations for mesh erosion (mesh coming through the vaginal wall) and awaiting another possible operation as I now have mesh just under the skin next to my urethra entrance. The pain disappeared when the mesh was removed.	12/14/2017 7:09 PM
57	Still have some	12/14/2017 6:40 PM
58	Pain and movement now much better. Still some nerve damage	12/14/2017 5:43 PM
59	Still early days as I needed a total of 4 operations - last one August	12/14/2017 4:55 PM
60	Less painful but still suffer from infections and still no sex life and still have difficulty walking and suffer depression and pain	12/14/2017 4:02 PM
61	Not much difference	12/14/2017 1:01 PM
62	Had op to fix erosion and she did partial removal , now waiting on appointment for full removal	12/14/2017 12:57 PM
63	Having had partial removal my symptoms continue	12/14/2017 12:17 PM
64	More operations urethral reconstructure Bladder problems extremely incontinent no feeling of needing to go	12/14/2017 11:47 AM
65	still get pains in top of legs incontinence twice as bad	12/14/2017 11:44 AM
66	Since the partial removal I have experience a further erosion into the vagina and my symptoms have deteriorated and struggle to sit and walk	12/14/2017 11:24 AM
67	Also had partial removal op which increased symptoms and felt very unwell. I am 15 days post op full removal and doing well. Still in recovery so too early to say but so far so good.	12/14/2017 10:52 AM
68	Symptoms are worse due to nerve damage	12/14/2017 10:36 AM
69	i still got the same pain as before expect the mesh has gone so theres no knife like pain in my stomach has gone	12/14/2017 10:17 AM
70	Good Improvement and lessening of pain. Psoriasis has disappeared	12/14/2017 10:04 AM
71	Incontinence resumed	12/14/2017 9:58 AM

72	My pain has decreased and I feel better in myself. I find driving and being a car passenger is very painful during, and after, very painful. Housework hurts if I do more than waving a duster about. I can't food shop or walk my dogs on the lead. Intercourse is painful.	12/14/2017 9:50 AM
73	Mostly relieved	12/14/2017 9:29 AM
74	I had mess trim while having a coil removed which I was not aware this happened	12/14/2017 9:27 AM
75	My symptoms have improved slightly pain by about 40%	12/14/2017 8:29 AM
76	All pain gone , just left with non existent immune system .	12/14/2017 8:01 AM
77	Part of first TVT removal due to erosion made things worse	12/14/2017 7:38 AM
78	The biggest difference is no more uti's. I still have chronic pain and I always will. Still living on painkillers and I still cannot have intercourse, walk very far or live a normal life. This is my new normal.	12/14/2017 7:34 AM
79	Now able to work full time and enjoy a new kind of normal.	12/14/2017 7:10 AM
80	It's given me piece of mind that the bit they removed isn't breaking up inside me	12/14/2017 6:52 AM
81	All symptoms are gone	12/14/2017 6:17 AM
82	They are worse than before but I was warned this could happen plus mesh pieces needed to come out	12/14/2017 6:09 AM
83	I've had a partial and full removal. I am still in pain, ongoing problems with autoimmune diseases esp Lupus. My body is fighting constantly and the infections are still happening .	12/14/2017 6:03 AM
84	Not sure def had 2 meshes one partial possible fully removed.	12/14/2017 3:27 AM
85	Not so much pain ,still get uti's and bowl problems	12/14/2017 3:16 AM
86	Just 3 weeks post TOT removal, all my pain symptoms has gone, despite being told it was caused by permanent nerve damage! Hernia mesh yet to be removed.	12/14/2017 1:46 AM
87	I have been left with permanent chronic pelvic nerve damage.	12/14/2017 12:48 AM
88	Only 5 weeks post op but uti free and pain free and no burning sensation Still have back ache on walking	12/14/2017 12:42 AM
89	Incontinance got worse, pain in back worse.	12/14/2017 12:19 AM
90	Partial removal on five occasions and still eroding which I feel is causing a auto immune disease pain,swelling,hair loss,teeth hurt,chronic back ache leg numbness the list goes on	12/14/2017 12:09 AM
91	I had 3 removal operations in total. First one 6 weeks after imput. 2nd after found eroded into bladder. Mesh removed. 3rd after rogue piece eroded into vagina. Mentally and emotionally scarred, difficulty in urinating since removal	12/14/2017 12:04 AM
92	Only had it two,weeks ago, still in pain from the surgery.	12/13/2017 11:52 PM
93	Two bladder stone removals. Have a third stone now. Mesh gone into bladder	12/13/2017 11:49 PM
94	Can stand and walk slowly now but still pain but not as much after removed, still unable to have sex	12/13/2017 11:45 PM

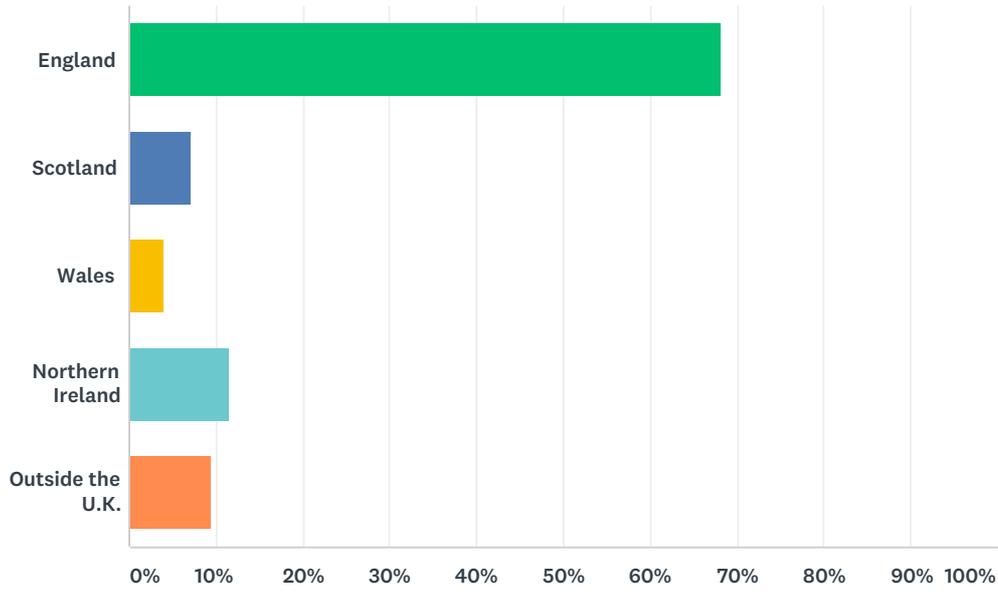
95	<p>Sorry its a long story. I had vaginal mesh (TOT) implanted in February 2006 in order to fix a prolapse of my urethra causing stress urinary incontinence. Since then I have lived with chronic, inflammation and pain. In January 2007 I had Surgery to trim a "hefty" scar in my vagina. This did not cure my pain. I had further surgery to remove a portion of the mesh on my right side in August 2007. This did not cure my pain. I was prescribed various painkillers and anti epilepsy drugs, which impaired me cognitively. So in order to function at work, I had to balance taking pain medication against being able to function in a responsible job managing a team of professional staff and an administrator. This job involved advising on employment law, undertaking complex investigations (some involving safeguarding allegations) advocacy at disciplinary hearings, and Councillor level appeals against dismissal, TUPE transfers, large organizational restructures, training development and delivery. In April 2008 I left my job to go traveling for a year in the hope my body would heal, as working at this level full time, managing a team was not sustainable in the long term with the medication I took and the level of pain I had to cope with. Whilst traveling I experienced significant pain and returned to the UK in April 2009 and had further surgery to remove more mesh. This improved but did not cure my pain and in December 2009 I had more surgery. From 2010 my quality of life improved, in that I had less flare ups and decreased pain. However, I never worked full time again in order to manage my pain and balance my quality of life. Then in Autumn 2015 I had chemotherapy for breast cancer. This caused an instant early menopause, resulting in my symptoms of pain and inflammation flaring up again to the levels they were in 2006 as follows: - - Stabbing skewer pain into pubic bone in several places. - Feeling of knife stuck through pubic bone, through vagina and out through knicker line. - Burning, red, heat, swelling, pain inflammation on right side. - Feeling like knicker elastic is too tight on right side. - Pain across right side - groin, vagina, top of leg - Pain if any pressure from my bowels when constipated (mesh has caused voiding difficulties and I use suppositories most days) - Moving, sitting, walking causes pain. - Feeling like a painful pressure point (size of finger tip) pressing inside vagina at 7 'o' clock – like broken glass the size of a marble. - Driving or traveling by car causes pain. -Vaginal bleeding. - Inside top of vagina excruciatingly sore on both sides. - Strange sensations in my big and second toes of my right foot and at times a loss of feeling in my big and second toes. Once pain is triggered it can last days or weeks. A GP referred me to one of the new regional NHS centers for mesh injured women and I had further surgery to remove more mesh on 16th October 2017. Vaginal mesh is designed so that your body heals through the mesh. The feeling of cracked glass in my vagina has improved to a blunter pain however; overall my symptoms are still significant. I also have some new symptoms: a dull ache, which radiates from my vagina around the top of my leg under my bum. I also have a dull ache, which goes down the back of my thigh into the back of my knee. I have a dull sensation on my left hand side of my knicker-line at the front of my groin, which I didn't have before. Last week I started getting a new worrying symptom - the feeling of pressure building in my vagina, then cramp type feeling going down back of leg into back of knee and loss of feeling in my big and second toe and ball of foot. Also cramp feeling down outside of thigh. Very painful. Also my buttocks become very painful. I paid for a private massage to relieve pain and tension in buttocks. Extremely painful but after a few days I noticed some improvement and also loss of weight, so I think massage helped with fluid retention. The consultant who did the removal this year explained that he had to go in quite deep to get the mesh (it had been there 11 years). I was also told there was a risk of nerve damage caused by removal. I am getting more and more anxious that since this last partial removal my symptoms haven't significantly improved and I've got new ones.</p>	12/13/2017 11:33 PM
96	After a year it had gone through my vaginal wall and had become twist so the surgeon snipped some off.	12/13/2017 11:33 PM
97	Not much. And more partial removals. And nerve damage	12/13/2017 11:32 PM
98	Some of my symptoms have gone but I am still left with pain amd nerve damage	12/13/2017 8:25 PM
99	Couldn't remove all. It's left me in severe pain and unable to walk sometimes. When I can walk it's not far. Life is ruined.	12/13/2017 8:22 PM
100	I am so grateful to be where i am now and not where I was. I felt wretched on a daily basis, nights were horrendous and it felt like being in labour on a nightly basis. Although I still have to do daily rectal irrigation as due to nerve damage (had a rectal resection, STARR procedure as I couldn't defacate) feel that I am able to defecate better since the mesh has been removed. My mobility has improved but I have to work on this on a daily basis and the leg pain is not as intense and less frequent, I still have the constant vibration internally which I experience when resting. My urinary incontinence has improved significantly. Had the mesh not been removed I feel I would not be writing this now. I was slowly dying.	12/13/2017 8:20 PM
101	I had mesh trimmed as it eroded into my vagina, very little control over urine flow, urgency much worse, frequency is now a big issue sometimes not even leaving the bathroom before having to go again, sometimes can't pass urine and bladder seems to spasm and stop flow before empty. Now also prolapse of bladder and vagina. Now have to wear pads constantly.	12/13/2017 8:12 PM
102	But think it is beginning to cut through	12/13/2017 7:56 PM

103	Still in as much pain as before but incontinence came back much worse than before	12/13/2017 7:56 PM
104	Overactive small bladder constant infections blood in urine still unable to have sex as it eroded through my vagina wall 3 times	12/13/2017 7:43 PM
105	I had a partial trim in 2016 and my pain has got worse	12/13/2017 7:39 PM
106	Partial removal then full removal 3 years later. Broke through again in two places.	12/13/2017 7:38 PM
107	Had a partial removal of only 3 cm, then 8 weeks later had full Removal Of further 25 cm. Most symptoms greatly improved.	12/13/2017 7:33 PM
108	Worsening pelvic pain Recurrent UTI symptoms Loss of libido Dyapaurenia	12/13/2017 7:27 PM
109	Has reduced frequency of urine and got rid of vaginal pain ...	12/13/2017 7:25 PM
110	Traveled across the country to go to reputable doctor that had experience removing fully. Difficult, but best thing I did. Immediate relief from stabbing pain in groin. However, I did still suffer hip joint damage and needed hip surgeries. Doing much better now then before mesh removal, back to working full time, walking, and doing most activities again. But still not as good as before I had mesh put IN.	12/13/2017 7:24 PM
111	None	12/13/2017 7:23 PM
112	I have had most on my TVT removed by Miss Elneil. I am having the rest removed in January as well as the sacrohysteropexy mesh. Symptoms improved - no Sui, no infection and less pain	12/13/2017 7:16 PM
113	Still incontinent, nerve damage and still eroded Mesh needs removing. 4 operations so far and at least another 2 to come.	12/13/2017 7:12 PM
114	Actually had partial removal of 2 different mesh	12/13/2017 7:09 PM
115	There may be some still in. I no longer have the feeling of glass stuck inside my vagina (it had gone through vagina wall and eroded everywhere). I still have UTI's and been on daily antibiotics for few years . I still have vaginal and bladder stabs, spasms and pain, I still have pain walking, sitting, standing, bending. I have exhaustion still. I had treatment for PTSD and anxiety caused by mesh which has improved since mesh out. still have weakness in legs, pains around body, hip pain, abdominal pain. I had urethra repair as mesh in it so this sharp pain much milder without mesh.	12/13/2017 7:08 PM
116	50% reduction on pain	12/13/2017 7:05 PM
117	I had the mesh removed after 48 hours - immediate reaction leading to sepsis, cellulitis and kidney failure. All the above are since the removal.	12/13/2017 7:03 PM
118	I've had multiple operations to remove 1 mesh. I no longer have the cheese wire pain. And restriction of weeing has been resolved but am now incont	12/13/2017 7:01 PM
119	Nerve pain not changed. No glass or burning inside vagina. Tingly itchy tummy and inside left leg since centre removed	12/13/2017 6:58 PM
120	Since centre removed very itchy tummy like tingly and inside my left leg	12/13/2017 6:54 PM
121	I can walk again now, but only about two miles max before it is too painful, was in a wheelchair for five months before removal. Incontinence back worse than before.	12/13/2017 6:54 PM
122	Awaiting mesh removal surgery	12/13/2017 6:53 PM
123	I hope it has all been removed have asked dr if the anchors were removed aswell or just the mesh	12/13/2017 6:49 PM
124	It took three operations to remove my mesh. Fewer utis, less pain, but pain is not entirely gone. Still no sex life.	12/13/2017 6:49 PM
125	Worse,awaiting full removal	12/13/2017 6:45 PM
126	Pain I see different now. Skin is clearer, cheesewire pain gone, brain fog gone. UTIs are less. Now live with permanent nerve damage and constant pain and lack of energy, depression, unable to sit for too long or stand any length of time. Went on to have hysterectomy and ovarian cysts removed. Ovary ruptured and was removed then final,ovary had cysts and needed removed. Left with major scar tissue which causes intense pain and don't have quality of life.	12/13/2017 6:45 PM
127	My symptoms are nerve damage self catheter infections I've had 13 operations	12/13/2017 6:28 PM
128	More pain than before.	12/13/2017 5:11 PM
129	They took out as much as possible, symptoms didnt go until after they then removed my bladder, full hysterectomy and I was fine for 3 months until the pain returned to be told that there is still mesh in there somewhere	12/13/2017 4:33 PM

130	Only change is I am no longer incontinence, but that's because I have had a Burch colospension .	12/13/2017 3:02 PM
131	I am fully back to normal. No side effects apart from occasional pain, especially on palpation. No problems with sexual intercourse.	12/13/2017 2:46 PM
132	Surgery for complete removal of sacrocolpopexy January 19	12/13/2017 1:54 PM
133	I had a partial removal within the first nine weeks after my first surgery for implantation of original mesh. Then I had full removal 16 months later. Since removal, I get UTI's every time I have sex with my husband, and I get horrible pain like a UTI after intercourse from inflammation. I am more incontinent that I was when I went in for surgery in the first place. My groin nerve pain is still there; my core and fitness are weaker because of all the surgeries and recovery and having to stop weight training, etc. I couldn't get off the sofa because of the reaction of intolerance and fatigue with mesh in me, and now that has all gone, so that's good.	12/13/2017 1:37 PM
134	Stopped an erosion through my vagina but think 2 tvt done the same.	12/13/2017 1:33 PM
135	I have poor mobility and left very incontinent..	12/13/2017 1:28 PM
136	Had it trimmed once as it was produding through vaginal wall now protruding again ten yrs later	12/13/2017 1:22 PM
137	Biological mesh had balled up, once removed and new mesh inserted most symptoms gone.	12/13/2017 1:21 PM
138	It has only been three months since my mesh removal so I am still recovering from major open surgery. I currently have sharp hip pain and a lot of scar tissue. It hurts just as much to sit, but it is MUCH easier to walk and stand up straight, and the deep grinding pain has gone.	12/13/2017 1:20 PM

Q6 Which country are you from?

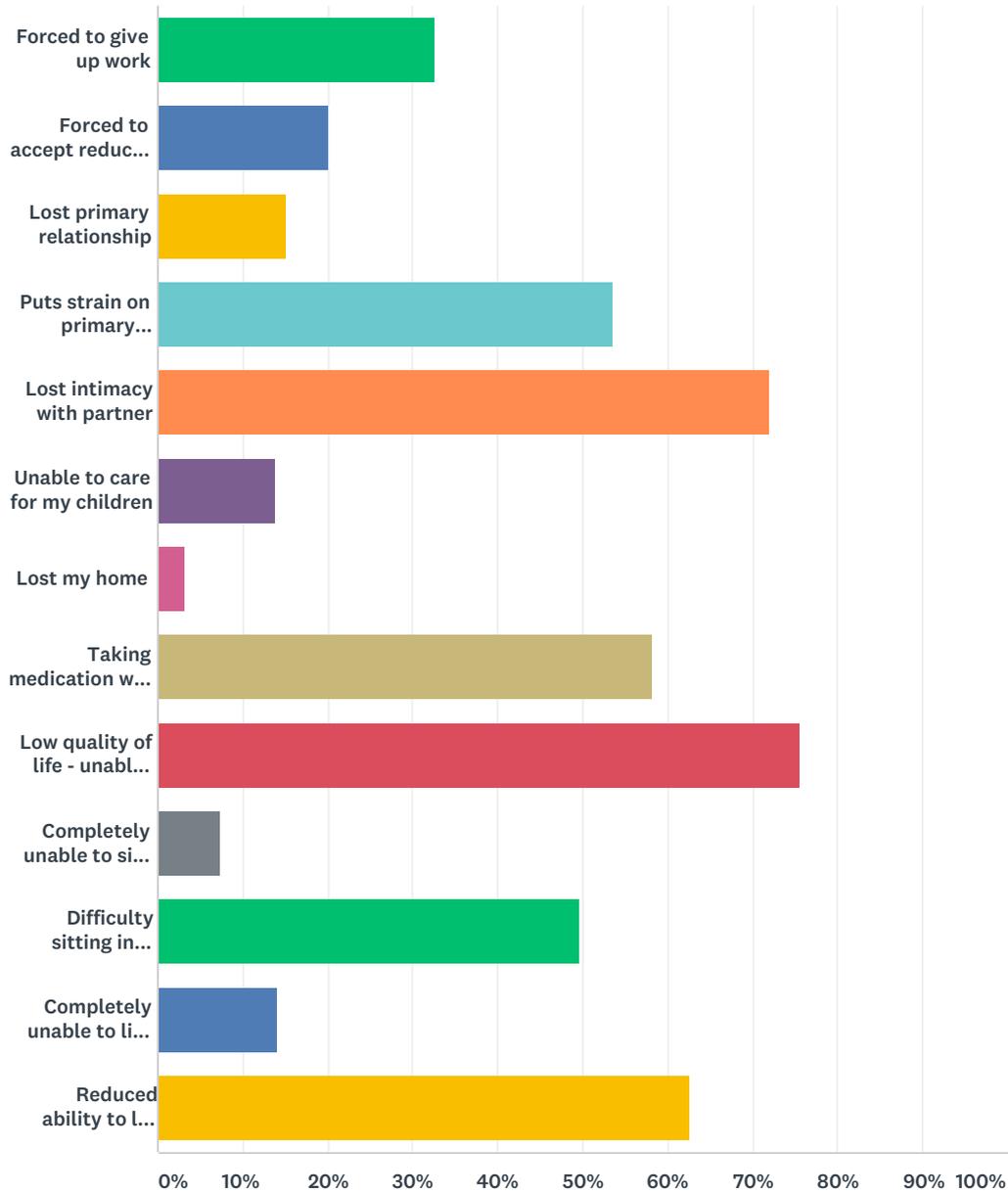
Answered: 568 Skipped: 2



ANSWER CHOICES	RESPONSES	
England	68.13%	387
Scotland	7.04%	40
Wales	4.05%	23
Northern Ireland	11.44%	65
Outside the U.K.	9.33%	53
TOTAL		568

Q7 How have mesh complications affected your life?

Answered: 539 Skipped: 31

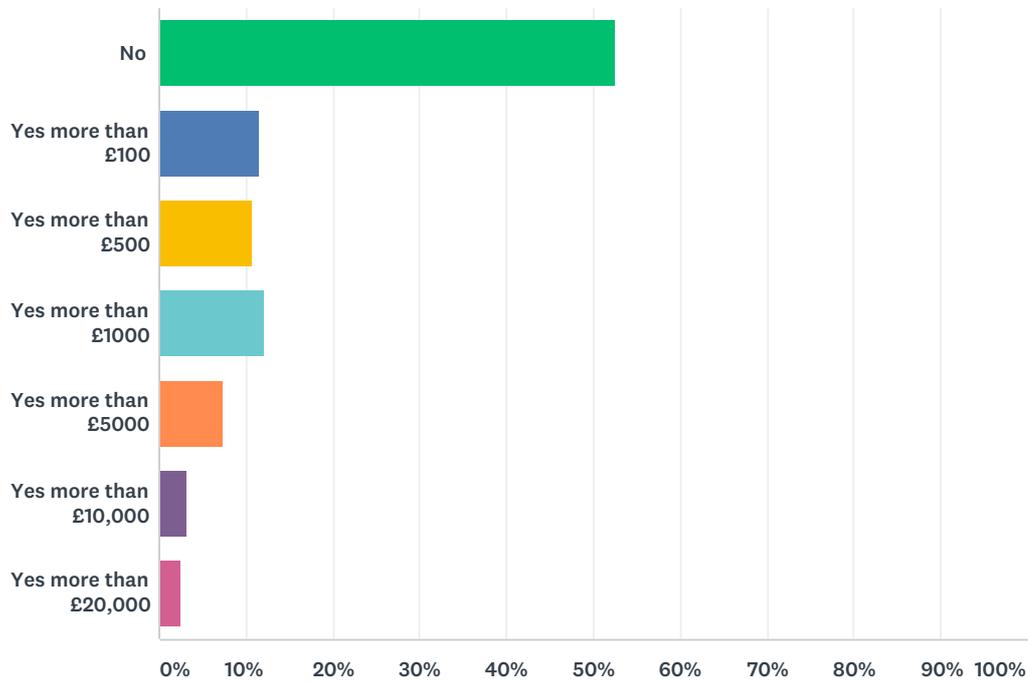


ANSWER CHOICES	RESPONSES	
Forced to give up work	32.65%	176
Forced to accept reduced working hours	20.04%	108
Lost primary relationship	15.03%	81
Puts strain on primary relationship	53.62%	289
Lost intimacy with partner	71.99%	388
Unable to care for my children	13.73%	74
Lost my home	3.15%	17
Taking medication with side effects on physical and mental health	58.26%	314
Low quality of life - unable to enjoy socialising or hobbies	75.51%	407

Completely unable to sit in vehicles or on public transport	7.42%	40
Difficulty sitting in vehicles or on public transport	49.54%	267
Completely unable to lift food shopping, cook or clean	14.10%	76
Reduced ability to lift food shopping, cook or clean	62.52%	337
Total Respondents: 539		

Q8 Have you spent any of your own money on healthcare for mesh problems?

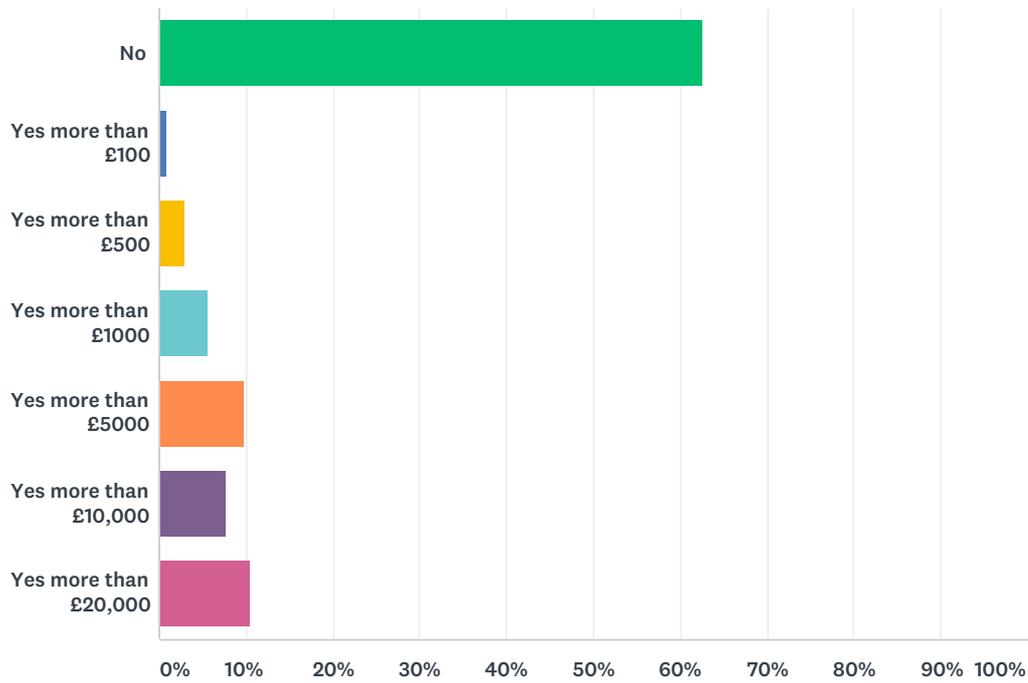
Answered: 560 Skipped: 10



ANSWER CHOICES	RESPONSES	
No	52.50%	294
Yes more than £100	11.61%	65
Yes more than £500	10.71%	60
Yes more than £1000	12.14%	68
Yes more than £5000	7.32%	41
Yes more than £10,000	3.21%	18
Yes more than £20,000	2.50%	14
TOTAL		560

Q9 Are you able to estimate how much NHS money has been spent treating your mesh problems?

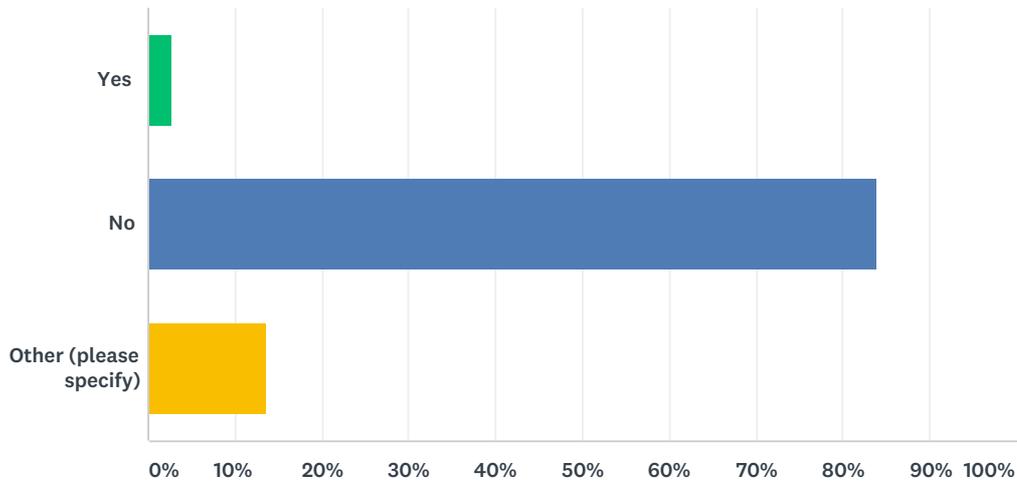
Answered: 556 Skipped: 14



ANSWER CHOICES	RESPONSES	
No	62.59%	348
Yes more than £100	0.90%	5
Yes more than £500	2.88%	16
Yes more than £1000	5.58%	31
Yes more than £5000	9.89%	55
Yes more than £10,000	7.73%	43
Yes more than £20,000	10.43%	58
TOTAL		556

Q10 Did your implanting surgeon warn you of the risks of mesh?

Answered: 569 Skipped: 1



ANSWER CHOICES	RESPONSES	
Yes	2.64%	15
No	83.83%	477
Other (please specify)	13.53%	77
TOTAL		569

#	OTHER (PLEASE SPECIFY)	DATE
1	Gave me a pamphlet but told me it's a precaution due to the nasty mesh but that mines was tape AND NOT MESH	12/22/2017 8:45 AM
2	Warned me of mesh failure, erosion, infection but not fecal inontinence.	12/20/2017 9:33 PM
3	Told a small percentage of woman have pain issues.	12/20/2017 1:55 PM
4	Les than 2 per cent chanceof pelvic painor problems with intercourse.	12/20/2017 10:01 AM
5	Told me not to worry gave me leaflets about it and I was left feeling it carried some risks but nowt I need overly worried about	12/20/2017 9:11 AM
6	Leaflet which didn,t mention loss of intimacy. Asked if I was still sexually active to which I said yes. Did not understand why.	12/20/2017 8:12 AM
7	He didn't go through them in detail it was very much the gold standard treatment, he did give a couple of leaflets that describe possible erosion but this can easily be rectified, no list of complications in 2006	12/20/2017 7:10 AM
8	Not really	12/20/2017 2:24 AM
9	Can't remember	12/20/2017 1:57 AM
10	This was brushed over as the partial hysterectomy took more time to explain	12/20/2017 12:49 AM
11	Not really	12/19/2017 11:57 PM
12	The term erosion was mentioned but not explained. I was told it was very rare. The mesh was referred to as a tape.	12/19/2017 11:46 PM
13	Asked if I'd seen papers recently I said no he said good as all media hype anyway	12/19/2017 11:39 PM
14	She gave me a leaflet	12/19/2017 11:33 PM
15	The only thing I was told was that it would only last 10 years! No other risks!!	12/19/2017 11:16 PM
16	Not fully	12/19/2017 11:14 PM

17	Vaguely, said occasionally there were some problems and had to warn as protocol but was usually successful.	12/19/2017 11:03 PM
18	Risks during operation but not long term risks, erosion, etc	12/19/2017 10:56 PM
19	Partially	12/19/2017 10:45 PM
20	Only some risks, and percentages weren't accurate.	12/19/2017 10:37 PM
21	I believe that he said that I might need it redoing after 10 years	12/19/2017 10:32 PM
22	I was just told once in cannot be removed.its taken two years to obtain facts such as attached to sacrum. Now cannot obtain information...	12/15/2017 8:15 PM
23	Just before I went down to surgery, no time to digest it and investigate it	12/15/2017 7:13 PM
24	Did mention there could be certain risks	12/14/2017 11:14 PM
25	I was never told I would have all these lasting symptoms plus be rushed back into hospital a week after surgery with bowel problems and a year later with next hanging down making me bleed	12/14/2017 11:06 PM
26	Only risk of bleeding	12/14/2017 10:27 PM
27	bleeding,infection, anaesthetic risks	12/14/2017 10:18 PM
28	Not all risks, only of vaginal wall erosion not organ erosion!	12/14/2017 9:59 PM
29	It was 12 years ago. Can't remember but certainly didn't expect part of it to come out itself.	12/14/2017 9:44 PM
30	Of erosion only	12/14/2017 9:37 PM
31	Only usual operation complications and erosion but was told that would be easily fixed	12/14/2017 9:17 PM
32	Did warn of vaginal erosion which could be resealed	12/14/2017 8:31 PM
33	I was given a leaflet but erosion wasn't explained and it was said complications are extremely rare so I don't need to worry about that!	12/14/2017 8:09 PM
34	Kind of not to the degree of what I have since read	12/14/2017 4:35 PM
35	I was told rhe mesh could invade my vagina but ir was unlikely ro happen	12/14/2017 2:54 PM
36	I didn't even know they did it until after doing my hysterectomy	12/14/2017 12:45 PM
37	not sure was warned of operating problems as with all operations but do not remember being told of mesh compklications oinly how much better things would be after several operations	12/14/2017 11:44 AM
38	Warned of risks of hernia operation, not specifically with mesh itself	12/14/2017 10:50 AM
39	yes but this was the only solution I was ever offered	12/14/2017 10:50 AM
40	thats all i was tol it would keep prolaps up my have to have trim but at least no prolaps landed having six surgerys	12/14/2017 10:17 AM
41	Not all	12/14/2017 10:13 AM
42	Some but not all	12/14/2017 9:53 AM
43	Some of them	12/14/2017 9:48 AM
44	He gave pamphlet with possible side effects but said not to worry it's not the bad mesh just tape. We perform these simple ops every day and nothing to worry about. These forms are just a precautionary due to today's culture . You will be fine	12/14/2017 9:09 AM
45	Some but we're said as very low risk	12/14/2017 7:32 AM
46	Some - ie its fairly new and no long term studies on how long it will last. No mention of failings, erosion, pain	12/14/2017 6:50 AM
47	Only general surgical risks and a slight chance of erosion	12/14/2017 6:46 AM
48	warned posible erosion and it did not work would be a larger apperation to correct , nothing else	12/14/2017 3:30 AM
49	Didn't tell me mesh was being used I didn't find out until the 2nd mesh. I wasn't told about 3rd mesh for hernia until afterwards.	12/14/2017 2:45 AM
50	I didn't know i had Mesh, I was told a tape that lasted 10yrs approx, it Dissolvled, As i asked him,did he have to remove it ,when its effects stopped and it needed redoing/ He Never told it was a New procedure, or I was a Guinea Pig ,as they had No long term data, as it had No trials or testing/ He also told me(i said i didn't want a blind procedure) that It was Only procedure that cld help my problem, as I had Strong Pelvic Floor Muscles	12/14/2017 2:38 AM

51	They said if eroded it so easy to fix and benefits outweigh risks.was never told of all I am learning.was assured intimacy would never be affected .it is currently beginning to be	12/14/2017 1:29 AM
52	Yes but not sufficiently explained or how long these would last or the severity	12/14/2017 12:42 AM
53	Not sufficiently. Put in writing after agreement but at consultations was assured the risks were low and he had carried out hundreds of the ops.	12/14/2017 12:04 AM
54	Down played the risks	12/13/2017 11:51 PM
55	Went private 2 ops then NHS for tests, mri X-ray, ops for stone removals	12/13/2017 11:49 PM
56	The only problems he explained would be that I may need to self catheterise for up to a month after the op and I would be taught how to do so before I left hospital. That may bladder may be slightly damaged - but if so they would put a catheter in whilst my bladder healed. I wasn't warned of any permanent irreversible damage.	12/13/2017 11:33 PM
57	Just less than 1% chance it will not work	12/13/2017 11:32 PM
58	He did but he wasn't specific and he rushed over it as an aside right before I signed consent	12/13/2017 11:24 PM
59	My TVT was cancelled by surgeon	12/13/2017 11:16 PM
60	Not in enough detail. Only 1% of nerve damage	12/13/2017 8:18 PM
61	To an extent, he was very pro mesh and made me aware that Scotland were anti mesh. He said that this was a positive step for myself and future health	12/13/2017 8:01 PM
62	He promoted the op, said there were no risks , would save time in future if done with the prolapse repair. I had no urine leakage prior to this. He made me incontinent!!	12/13/2017 7:56 PM
63	Can't remember	12/13/2017 7:23 PM
64	Definitely not the first, he said he did for 2nd & 3rd but I do not recollect this.	12/13/2017 7:12 PM
65	Was told it was a SUPER simple surgery. Only told of the usual warnings of every surgery ☺	12/13/2017 7:09 PM
66	I don't remember clearly, but I do remember the word erosion being used!	12/13/2017 7:01 PM
67	No she didn't I signed them on way into theatre	12/13/2017 6:49 PM
68	Only some of the risks and not how severe they would be	12/13/2017 5:04 PM
69	I was told it was very unusual for it to erode, nobody told me about pain loss of my bladder etc	12/13/2017 4:33 PM
70	Told me it was permanent on the way into theatre! Only 1% possible complications mentioned.	12/13/2017 4:01 PM
71	Yes, but said this is the new mesh so nothing to worry about	12/13/2017 1:54 PM
72	I was the one who brought up concerns and she said they were all not applicable to me because 1. She was the best surgeon in the UK, lectured around the world on Mesh and repairs everyone else's mistakes and if she did it there would be no problems; and 2. I had no risk factors and all problems with mesh are either surgeon error or the fact that a patient has other issues such as being overweight, which I wasn't (my BMI was only 18.5 as I was training for a half marathon and was a runner), and I wasn't in menopause and she said any problems could be easily fixed. I have that bit in writing. She said there was only a slight risk of erosion, that is all she told me. She said erosion was easily fixed. She explained it as a little piece of tape so she downplayed every single risk there was. I'm so frustrated with myself that I let her talk me into this surgery. She also told me that the mesh was the best surgery even though she told me about the other two. She really only told me about the other two flippantly...as if they were stupid choices. :(12/13/2017 1:37 PM
73	pls note i had op done in uk but now live in Malta where i have no one qualified to help me	12/13/2017 1:22 PM
74	Some	12/13/2017 1:22 PM
75	mentioned may be able feel it but not how bad it would be. Also said he could remove in this circumstance now he can't remove	12/13/2017 1:21 PM
76	Only the 10% success rate, and the potential for it to protrude into the vagina that's treated by trimming	12/13/2017 1:20 PM
77	No, I didn't go ahead with the op, but had been given the impression it was low risk	12/13/2017 1:19 PM