

Hernia repair

Public engagement survey appendix

The Scottish Health Technologies Group (SHTG) conducted a 5-week public engagement exercise using a survey to gather patient and public views and experiences of hernia repair in Scotland. This document presents the complete list of responses received from the 68 people who completed the survey. A report summarising the responses is available on [our website](#). All responses are anonymised. Not all respondents commented on all of the survey questions.

Question: how did having a hernia affect your life? (65 responses)

ID	Comment	Hernia type
Abdominal hernia		
31	I was unable to effectively look after my children or do normal day to day activities	Abdominal
42	It was unsightly, sore and caused issues in daily living.	Abdominal
67	Bulging in abdominal left quadrant. Likely to enlarge and cause intestinal constriction.	Abdominal
68	I have no life to speak of. It has made me a recluse.	Abdominal
36	Pain at times and an unsightly bulge	Abdominal
Epigastric hernia		
6	My breasts were separated and were under my armpits. I had a large lump in between my breast and was in constant pain.	Epigastric
11	The hernia was uncomfortable and very visible. Clothes didn't fit, I felt very conscious of it, affected my social life and general confidence.	Epigastric
Femoral hernia		
35	Strangulated hernia so it became painful very quickly. [Emergency repair]	Femoral
Groin hernia		
2	Nothing really.	Groin

9	It didn't	Groin
12	Still affecting my walking, sitting even just standing. The pain is excruciating. It makes me feel sick every time I get shooting pain in my groin & down my leg.	Groin
18	Very uncomfortable and sometimes painful and can be so sore that I miss work.	Groin
51	Intense pain	Groin
53	Couldn't lift anything, problems with bending, pain in the groin.	Groin
69	<p>I had to be careful about how I moved, carried, sat, slept, walked, basically it affected my full capacity to work properly or to full capacity so to self-preserve as hernia care before and after was non-existent in my region but I suspect other regions too as those seem to get media attention – I cannot be the only one in my region male or female, other health groupings seem to be allowed to be visible and group. I think my region practised ‘watchful waiting’ and I know recently according to whistle-blowers my region may have deliberately dropped people off lists so to treat ‘new’ patients. I was definitely dropped off my list.</p> <p>My present job has given me reasonable adjustments but my previous job used my injury to bully me out and because NHS and leaflets did not give me information or the words I needed I could not defend myself – hernia pain and injury is invisible to others and a stigma to women and I think embarrassing for men to admit to – I found no proper information on tear injuries before or after operation and even using the word hernia the information I find are incomplete – I found online a ‘guru’ male who did leg cycle moves but probably not researched. I had a feeling of low health and energy my body was probably tired of fighting each day, the blanket of pain continuous but I found ways to lift, slow down, use escalators – before my injury I ran upstairs and enjoyed it and went to the gym but just for light exercise not to put muscle or weight lift and not long sessions, this stopped immediately and have not gone back a) lack of money, b) fear of tearing. Any chance of a relationship disappeared. It affected my sleep having to sleep on my back though my preferred was front even after the surgery for the next few years, it is only very recently I can sleep on my front and move my leg the way I want and not get woken by the niggling pain or ache. I was not told where to get help, what to do, how to conduct myself even after operation even after enquiring when I could no longer cope and my mental health was failing badly.</p> <p>The lump would reduce on lying down and sleeping and I wear tights so that helped, I did not stretch outwards and kept upright and on</p>	Groin

	<p>sitting though I felt like being very unladylike socially its not good to readjust yourself though men seem to do this openly! A fear of ice, falling, reduced ability to climb, problems with urination due to pressure, gave up nice shoes, a backpack instead of a handbag.</p> <p>The hernia, the waiting, the 'recovery' has ruined my life, took a parent with good opportunities away from their children the youngest especially and financial and I was and am a single parent. The hernia was not due to smoking or weightlifting or overweight, it was an accident that should have brought more not less care to me. The loss to my parents and my friends when they became ill was heart-wrenching, I'll never get that back.</p>	
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Incisional hernia

7	It was uncomfortable and caused great pain at times	Incisional
8	Uncomfortable	Incisional
10	It was very sore, sometimes debilitating and a constant worry because of the possibility of strangulation and it becoming bigger so surgery to repair it seemed the obvious solution.	Incisional
25	It still does, it hurts when I catch it or lay on it, it's on my side, I have to wear a belt or I have a big bulge	Incisional
30	It has affected my mobility (ability to bend over, twist etc). It affected my health anxiety greatly. Pain levels left me almost unable to walk	Incisional
34	This box isn't big enough to describe the living hell I've been living for the past 6 and years, been looked at like a freak 😳💔😢	Incisional
54	It has destroyed any kind of a normal life , it was caused by missed diagnosis of a burst appendix so this box isn't big enough for my feelings on this	Incisional
62	Trying to live with one eventually becomes impossible as it grows. The pain, nausea, bowel and digestion issues make any kind of life difficult.	Incisional

Inguinal hernia

3	Painful but not too bad, nothing protruding.	Inguinal
4	Pain, discomfort,	Inguinal
5	Mainly discomfort if standing or sitting for long periods. Also some concern about complications (strangulation etc.). But no major impact.	Inguinal
15	Very significant impairment of freedom and function. Forced to use a support belt in order to function. At times significant pain.	Inguinal
16	It causes some minor discomfort	Inguinal
23	Aunt said it caused some discomfort	Inguinal
24	Pain in tummy	Inguinal
26	Mild ache and bulge	Inguinal

28	I had to give up my business, my exercise, my lifestyle. Once I was 'repaired' with mesh, things only got worse. I have not worked for five years now. My sex life is a shadow of it's former self. I wish I had never had mesh implanted.	Inguinal
43	Pain at first which eased before surgery	Inguinal
44	Not at all	Inguinal
45	It caused mild pain during exercise and discomfort at times	Inguinal
47	It got really big and hurt a lot to where I couldn't bend over or perform my job very well.	Inguinal
48	I have pain daily take painkillers. Have to take how I move about as it goes into painful spasms. I have another hernia at the site of the original hernia which is 2cm long. Waiting to get this fixed	Inguinal
50	I was no longer able to carry on my business as a furniture retailer.	Inguinal
55	Pain after the operation and went to see the doctor after 1 month for a check up, was told that the pain would go away. It didn't and phoned the doctor weeks later and told that he had retired. Cannot lift anything heavy and have pain most days.	Inguinal
56	<p>It didn't effect me as badly as the mesh has.</p> <p>The inguinal hernia I had was small, a bit of pain when lifting etc which was a daily part of me job.</p> <p>Having the hernia slowed down my ability a bit.</p> <p>Having the hernia was a uncomfortable at times, and painful.</p> <p>If mesh is the cure to this then please stop using it.</p> <p>It has ruined my life more than the hernia!!!!</p>	Inguinal
59	Inguinal not a lot for a few years but increasing got stuck so had to have repaired in case it became incarcerated or strangulated	Inguinal
60	Having a hernia meant I wasn't able to play soccer, gym etc.	Inguinal

66	<p>My daughter has loss of mobility mostly due to extreme tiredness and pain, she has now had to change her car to an automatic, has a mobility scooter and an electric scooter and occasionally a wheelchair. Despite moving house to a ground floor and reducing her hours at work she finds life a great deal more difficult and stressful, she went in for this operation in good health and came out in a wheelchair.</p> <p>One year after the operation she and her husband went to London to have the mesh removed by Dr David Knott at great cost for travel, hotel and the operation itself, it was found that the mesh had moved and attached itself to other organs, which it does regularly, the damage was done during that year, causing autoimmune and foreign body symptoms resulting in an inability to sit or stand for long periods of time as this causes pain and extreme tiredness and requiring rest periods which is not possible at work where she has to work through it and go to bed on her return.</p>	Inguinal
40	Annoying with slight pain after a long day.	Inguinal
61	Having a hernia was very painful and left me unable to carry out my full duties at work. I found it hard to walk and move around and I couldn't stand up straight because of the pain. I couldn't lift anything, even milk cartons, without it causing extreme pain.	Inguinal
Mixed hernias		
14	Partly blocked my bowel and made having sex too painful also caused further surgery tvt [<i>transvaginal tape</i>] mesh 2 x	Mixed
52	I have been medically retired at 54 can't walk unaided, and can't get intimate with my wife	Mixed
Other hernia		
29	The hernia was increasingly sliding out and causing pain.	Other
49	It has caused extreme pain, I can't work since 2007. It was undiagnosed till it got really big due to its rarity. It's caused me to have a sluggish bowel and now severe gluten intolerance and difficult to manage bowel habits. I had a big operation they used mesh and I awoke in agony to then be overdosed with morphine and then they gave me less pain relief than I'd previously been on. It was an agonising few months. I can't take part in any sports or even long walks. I get daily pain from the mesh repair and it immediately affected my bowel. I can't lift my grandkids up so I miss out on babysitting and playing with them. It's affected every aspect of my life with episodes of deep depression to being "ok" also affected my self confidence and my sex life with my husband too.	Other
70	It restricts movement and restricts what I can do. Have to be careful bending and cannot lift heavy items.	Other

Umbilical hernia		
1	It was unsightly and worrying but not painful. I consulted my GP who recommended surgery to pre-empt problems if condition was not checked.	Umbilical
19	Initially restricted some forms of exercise and awareness on manual handling techniques when lifting objects of differing weights and size.	Umbilical
20	1/ Clothes didn't fit and I felt very self conscious, I had to wait so long for the op it was huge 2/ Limited the activities I could do exercise-wise and what I could lift	Umbilical
22	severe pain at times	Umbilical
32	Surgery with mesh to repair muscles and hernias has disabled me	Umbilical
37	Pain, kept getting 'stuck' very noticeable through clothing, made loud noises	Umbilical
38	It didn't. It got stuck twice but wasn't life threatening at all. I would have rather suffered that than having mesh in.	Umbilical
39	Pain, bowel problems.	Umbilical
46	It changed my life and made me realise most hernias are caused by malnutrition. I have changed my lifestyle and reversed my hernia with plant based wholefoods	Umbilical
63	Couldn't walk for long, constant throbbing and bloated abdomen	Umbilical
64	Pain and discomfort. Trouble eating	Umbilical
Unknown hernia		
17	I am in a lot of pain. I now take loperamide morning and night just to be able to function	Unknown
41	I wasn't even aware of it, urologist came across it during surgery	Unknown
65	Weakness in lower left quadrant. Caused probably by my tram flap reconstruction surgery in 1999.	Unknown
Blank response		
13	The mesh was explanted for complications: chronic pain, testicular pain, infection, perforation into the bladder or bowel, adhesions to the bowel [<i>pathologist who examined explanted mesh</i>]	-

Question: please tell us about your experience of having a hernia repair (63 responses)

ID	Comment	Hernia type
Abdominal hernia		
31	Having the actual operation was fine it was not till about a few months later that I started getting extreme pain my hernia was operated on in 2013. The doctor used mesh to repair my hernia and I was not told it had been used until after it was done.	Abdominal
42	Surgical mesh was used and I didn't know much about it however would have agreed to anything to help the pain. After surgery my bladder wouldn't work properly for 2 weeks, initially having a catheter in for relief.	Abdominal
67	Hernia repaired without mesh in 2002. Hernia recurred a year later and was repaired with a different surgeon in 2003.	Abdominal
68	9 hernia repair surgeries with multiples totalling over 11, 3 hernias now, and 4 pieces of infected mesh still inside abdomen that nothing can be done.	Abdominal
36	My hernia was large, polypropylene mesh was inserted	Abdominal
Epigastric hernia		
6	I wish I had known prior to my operation the real affects of having mesh. I was only aware that it may get infected and would need to be removed. I had 4 x 6cm of mesh. I was in pain 4 weeks after my surgery and my surgeon told me to chin up. I hid my pain for 6 months as I was ashamed.	Epigastric
11	I was told by NHS hospital initially that repair was classed as "cosmetic" and until it posed a serious health the wait would be long. My family, knowing how upset I was getting, supported me by seeking private care before it got serious. I googled a lot about the problems ie twisted bowel, gut, infection and life threatening issues if it strangulated (which the NHS hospital said) and didn't want to wait till that point. Besides the hernia was increasing and I was in pain. Seeing the private surgeon, told me there was no other option at all just mesh repair. If I didn't have it done soon I would get the above complications and strangulation can be fatal. Signed there and then. He assured me no issues with mesh, very safe. Within 6 weeks I felt a lump after surgery. Told it was scaring. Within 9 months the hernia had returned. Saw the surgeon who implanted it privately and was advised there was nothing he could do. The surgery was too complex.	Epigastric
Femoral hernia		

35	Nightmare. In 2019 March I had a strangulated femoral hernia. The surgeon done open surgery and placed a mesh plug and a mesh layer over it. Six weeks later I was in terrible pain and ultrasound found another hernia on the edge of the mesh -inguinal hernia. Open surgery again but couldn't find the hernia so more stitches over the first hernia and another layer of mesh on top of the first. At the time I didn't know what mesh was and the chronic health issues post implantation because of foreign plastic in the body	Femoral
Groin hernia		
2	Yes it was used.	Groin
9	X2 10cm x 15cm mesh inserted laparoscopically. Operation went well not told of any problems during surgery. I never healed properly and have went physically down hill since operation. Later found absorbatacks clop/ foreign objects left less than a mm from my femoral vein and nerve	Groin
12	I have had 2 surgeries & 3 pieces of mesh to try & repair but it is still not mended.	Groin
18	I got the repair done back in 1999 and I'm sure it was the surgical mesh that was used	Groin
51	Mesh was used in the repair. Its use and implications were not discussed with me. I was merely informed after surgery that mesh had been used	Groin
53	I don't think my repair has been successful as I still get spasms of pain in the groin area.	Groin
69	On waking I felt the surgery was in the wrong place, they told me all patients feel like that, my discharged form said I had had an inguinal hernia, I was not told about the mesh or told of aftercare except given tablets and forced to walk though I could not put my foot down, my child had to get a wheelchair to the taxi for me with me trying to tell her how to operate it. I was later to be proved right.	Groin
Incisional hernia		
7	Mesh was used	Incisional
8	Hernia repaired ok but parts of the edges of the mesh dig into me.	Incisional
10	<p>My surgeon apologised profusely for leaving me with an incisional hernia after surgery to remove gallstones and insisted that mesh was the best solution to prevent recurrence.</p> <p>I was in agony when I came round (on a morphine drip) and extremely bruised and swollen, 7 weeks afterwards I felt something tear and burning, searing pain across the repair area and further along my abdomen, I have had stabbing pains ever since, often it feels like there's a knife sticking in my side, I can't function and my</p>	Incisional

	<p>core has also been seriously affected because I also need surgery now to correct severe diastasis recti (separated abdominal muscles) which is a condition that I never had previous to hernia repair surgery.</p> <p>My repair was in 2016 and I am currently on an NHS list for removal (after a nightmare of a journey to get to this point) which is out of my area .</p> <p>I am not currently being supported by my gp in fact it feels like he is discriminating against me by withholding pain medication and being extremely rude and unhelpful.</p> <p>My children and my relationship with my partner have been very badly affected as has my mental health and mobility.</p> <p>My life has been ruined and I have been in near constant pain for nearly 6 years, every day is a struggle, a struggle to carry on.</p>	
25	Surgical mesh was used, it was an awful op, I got infection after, eight years on, it's failed! I was never told the dangers of mesh, or even showed the mesh!	Incisional
34	<p>First repair I wasn't aware mesh was used I was in pain from the start but was told its just the mesh protruding 😬</p> <p>I began to experience severe pain in my lower back then had to be taken by ambulance to hospital several times the Hernia came back they were not sure what to do so referred to new consultant who did the next repair More mesh after he spent hours removing it from my bowels that was what was causing my pain, the second lot of parietex mesh was put in laparoscopically which wasn't the right thing to do this also wrapped around my bowels which caused me so much pain and nearly killed me again. I'm currently left with a giant Hernia that is very difficult to fix 😬 all because they missed my burst appendix waited 2 days before I got sepsis and then had to rush me into theatre.</p>	Incisional
54	The first lot of mesh was a problem straight away I wasn't informed of mesh being used but as I was experiencing lots of discomfort the surgeon said oh just the mesh protruding 😬 still unaware of mesh problems at this point my pain increased till surgery was required to remove mesh that gad wrapped around my bowels but MORE mesh was put in laparoscopically this eventually wrapped around my bowels also 😬 7 years of hell had major surgery reactions of bowels still left with Giant Hernia .	Incisional

62	My life has forever been changed in a negative way. I live in constant pain and the Ethicon Physio mesh has been falling apart within 2 years of it being placed. I have regular bouts of bloating so severe it's painful and at any time I can get hit with stabbing pain that will bring me to a stop.	Incisional
Inguinal hernia		
3	Fine for 10 years apart from getting C.F.S. after 10 years terrible pain. Took too much persuading of GP's and surgeon to get help. One gp said what is mesh. It took 6 ops to finally remove it, whereas it should have only taken 2 if I had been listened to. Mesh was Johnson and Johnson.	Inguinal
4	Destroyed my life. Had 2 meshes, one TAPP, one TEP. Both eroded into me. 4 operations to try and remove the 2 meshes.	Inguinal
5	I had my operation in 2007. Repair was made using open surgery and surgical mesh was used. Recovery was slow with vastly reduced mobility for 2-3 weeks. For at least 6-8 weeks there felt like an internal tension or tightness on the side of the repair between the ribs and the groin. This tension and pain (feeling similar to a stitch) recurred fairly regularly for about one year after the surgery and did not appear to be triggered by anything specific. After about one year, most of the pain eased and stopped bothering me, although the slight tension and feeling that 'something is in there' occasionally returns. There has also been permanent, localised post-operative sensory loss in the skin around my groin and upper thigh.	Inguinal
15	I found my carers in Scotland only raised the option of mesh repair despite my reservations of the emerging evidence of long term complications including 'meshoma' inflammatory masses.. They were unaware of the evidence for the Desarda method that I eventually opted for. I needed to travel to Germany and pay privately for this.	Inguinal
16	11x13cm Prolene to fix a small reducible hernia. Not told of any possible complications other than usual from any surgery. Not told there was another option	Inguinal
23	I advised my aunt the hernia was due to malnutrition and showed her a link on the FDA website. Her diet was high in refined carbs and low in fibre causing straining, weak tissue, small stools and other problems. She reversed her hernia with a hernia belt and proper nutrition that excluded highly processed foods and animal products that has zero fibre	Inguinal
24	Hernia has returned. Permanent painful and hot spot on tummy. Mesh was used to repair first hernia	Inguinal

26	<p>I had two Bard 3D Max meshes put in each groin. A symptomless hernia was falsely diagnosed on one side. The other side actually had one.</p> <p>Previously an active, sporty 32 year old with a good job, and after just getting my first home, the hernia mesh left me unable to:</p> <ul style="list-style-type: none"> Stand up fully straight (I was hunched) Walk without pain or at a normal speed Sit without pain Lie down or sleep without pain Cook Clean Travel to or sit in an office Bend to pick things up <p>I had to move back in with my parents so they could care for me. I had to have two major mesh removal surgeries, each with a week in hospital and six month recovery. The second one was urgent because the mesh was eroding into my bowel.</p>	Inguinal
28	<p>Covidien Mesh was used on my inguinal hernia repair. I now suffer from more pain than pre operation. My surgeon says “sometimes that’s the risk”...he never said that pre-op.</p> <p>I advise anyone who’ll listen to investigate mesh fully. If I’d been fully informed, I wouldn’t have had mesh.</p>	Inguinal
43	Mesh used. General anaesthetic. Healing took twice as long as expected.	Inguinal
44	Hernia kept extruding for about a month. Surgery was performed. I believe mesh was installed. (about 15 years ago)	Inguinal
45	Surgical mesh was used to repair hernia. I initially felt an improvement within the first month, but I started to feel increased pain in the area and stiffness in my hip, back. This would improve slightly with complete rest but always returned when I became mobile. I suffered auto-immune problems causing other symptoms and problems.	Inguinal

47	My was knotted and they had to cut me open and yes hernia mesh was used and since I had the hernia mesh I have had a harder time bending over to bus tables and to perform other task.	Inguinal
48	Surgical mesh was used for my hernia repair. After the operation I got stabbing pain a like a pair of scissors stabbing me within. I thought the surgeon had left something inside me. On my return to the clinic I was informed that the procedure went well and I could not be in the pain that I was telling him. I did not know anything about mesh repair.	Inguinal
50	My hernia was repaired in 2007 at [...] using mesh. After a couple of weeks recovery I was still unable to walk without extreme pain. I received injections into the wound which stopped the pain for 24 hours. The pain continued to be excruciating and I was put on Amitriptylene, it was about six weeks before I was nearly normal but continued to have breath taking spontaneous pain and still do.	Inguinal
55	Yes surgical mesh was used. I was not informed about pain later on or I would not have had the operation. I think I should have been informed the first time I was at the doctors.	Inguinal
56	<p>At no time was I warned of the danger of mesh. I was told it was the “gold standard”. Quick op home and in 2 weeks I'll be better than brand new. Wow!!!!</p> <p>7 years of torturous hell. The pain is unbelievable. Nothing, NOTHING takes it away. Nerve damage, muscular damage. Creased and folded mesh, which I have recently found out is called a “Meshoma”.</p> <p>My life before mesh was a breeze in comparison to this!!!!!!</p> <p>If I was a dog, or a cat, or a horse, they'd have put me down a loooong time ago!!!!</p> <p>Animals get treated better.</p> <p>The resistance from Surgeons, Doctors, from medical professionals to be heard and listened to as to how the mesh feels in my body, as to how it's making me feel. What it's doing inside my body, as to what has been done to rectify it.</p> <p>The achievement resulted in more pain, more loss, of MY life.</p> <p>I am complaining as a PERSON NOT a customer.</p>	Inguinal

	<p>5 further revision surgeries.</p> <p>The loss of sex life.</p> <p>The lost of bodily parts.</p> <p>The loss of everything I was ever pre mesh, all gone!!!</p> <p>The tax, the cost, the suffering, all paid for by ME!</p> <p>I pay the TRUE cost of mesh.</p> <p>All who suffer mesh implants wrong doing suffer this cost.</p> <p>If given the choice I would have preferred to be given a nutrias repair, if that had failed, and only IF, then I may have thought about mesh, but now KNOWING the truth of mesh, I'll never ever have another piece of it implanted in me ever!!!!</p>	
59	<p>4 hours in hospital. Found out later mesh was used. Not told how it would be repaired and thought hernia op was a simple procedure and just thought consultant surgeon was experienced. Found out from notes that consultant surgeon 'assisted' with op.</p>	Inguinal
60	<p>Surgical Mesh was used. Operation was defined as a success.</p> <p>Unable to work for 6 months after op. After 4 years, still unable to sit upright in an office chair.</p>	Inguinal
66	<p>Inguinal Mesh used in operation in [...], after complaining she was given a further appointment including a private visit to [...] where the Doctor offered to cut the nerves re pain, she was given an apology from the Doctor who operated and told nothing further could be done and referred to the pain clinic. The pain clinic was a distressing visit and only after a further complaint was she referred to pain management which although attending classes is of little use. Doctors are reluctant to admit responsibility in case of Court cases and to be unaware of the damage this operation can do especially to women and there are no Doctors in Scotland who can successfully remove the Mesh despite a Doctor from USA offering to teach them.</p>	Inguinal
40	<p>The operation was a success they told me. I had mesh inserted but I didn't know this at the time.</p>	Inguinal
61	<p>Yes, surgical mesh was used to repair my hernia. Firstly, I wasn't told by the surgeon, in any detail, what the hernia mesh was or how the recovery would effect me. The surgeon didn't disclose any of the</p>	Inguinal

	<p>possible complications or side effects of the hernia mesh. I had never even heard of hernia mesh before actually having it inserted into my body.</p> <p>After the surgery I was told to rest for up to 6 weeks before being able to go about life almost as normal. But life never became normal again!</p> <p>Having the hernia mesh destroyed my life as I knew it. It's aged me about 30 years in physicality, not to mention the excruciating pain I've had to deal with on an almost daily basis. Even going to the toilet leaves me in excruciating pain and getting showered and dressed has become a slow and painful process.</p>	
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Mixed hernias		
14	I had no symptoms when told I needed a hernia repair. Soon after the hernia operation I have suffered with pain, constipation, bowel blockage, unable to have sex. I'm on the waiting list to have one of my hernia meshes removed and my bowel repaired by 2 surgeons. When recovered I hope to have my 2 tvts [<i>transvaginal tape</i>] removed .	Mixed

Other hernia		
29	Bard 11.4cm compofix mesh was placed laparoscopically, inside the peritoneum, using barbaric protacs. The mesh did not cover the hole as apparently my pelvic bone got in the surgeon's way. Absorbable stitches were also placed from the open side to close the hole.	Other
49	It was 15cm x 20cm of Covidien Parietex Composite Mesh with over 40 Protacks to affix it. These protacks can cause cancer and the mesh has been recalled. I have my medical notes and photos of an X-ray which shows the protacks.	Other
70	I have had two hernia repairs and mesh was used both times. The first repair was carried out during an operation to replace a colostomy for a permanent ileostomy. The second operation was a repair to the existing hernia in that area.	Other

Umbilical hernia		
1	Surgical mesh was inserted. I can feel it and can feel that it has moved/gathered somewhat under the belly button. I don't recall any discussion about mesh other than an explanation of how it would help the existing problem. Surgery seemed straightforward.	Umbilical
19	Surgical mesh was used to repair my hernia , the initial surgery and recovery was within reasonable expectation ,with clear guidelines and instructions of care during recovery .	Umbilical

	Manageable pain was experienced with little or no painkillers used.	
20	<p>Yes a mesh was used.</p> <p>If the surgeon hadn't waited so long to do the op I wouldn't have had internal complications (can't remember the medical term but some tubes had fused to other bits that weren't where they should have been due to the hernia) and this caused a 3 month work absence instead of the expected 2 weeks.</p> <p>The anaesthetist was outstanding, explained what was going to happen in detail and made it much less stressful.</p> <p>The surgery itself went very well and the aftercare instructions were excellent, I followed them to the letter. It seemed that the hernia had returned despite all that but it wasn't the case. When I was told the mesh had held I had to stop the surgeon leaving to explain why I had a big hernia-like bulge (after effects of surgery apparently).</p> <p>So surgery itself: excellent, but surgeon communication could definitely be improved.</p>	Umbilical
32	Surgical (phasix) mesh was used between muscle layers and caused FBR. The FBR led to disability, loss of job, etc.	Umbilical
37	Surgical mesh was used in a keyhole day procedure. Significant pain afterwards which never fully went away. Went to out-of-hours one day not long after surgery (3 weeks approx) as unable to stand fully upright, got misdiagnosed with gastritis and given omeprazole. Pain eventually died down but has remained since, and in past 6 months has increased dramatically.	Umbilical
38	<p>My self and husband were told I was receiving pig skin with dissolvable stitches. Took me a bit of getting use to. Was told this was gold standard. No complications within 3 weeks I would be back to normal. Only risk of a bleed as usual with any surgery.</p> <p>I woke up in agony. Was in tacchiochardi [<i>tachycardia</i>] which we now know was because my body was rejecting the mesh but no one done anything about it. I looked 9 months pregnant and still do to this day. The pain never went away. I was told 3 months. 6 no. A year to 18 months when I asked for a second opinion. My surgeon told me couldn't be due to the mesh. Which I had only found out the week previous that I had mesh. I never agreed to that. I'd have looked it up. I researched pig skin. My hernia when found was 1cm.</p>	Umbilical

	<p>Rule of thumb is 5cm overlap. Why have I got 15cms? There was no hernia present on the day of surgery. My 3rd opinion surgeon confirmed this and said mesh should never have been used. I have too many allergies. Plasters being one. Why wasn't this investigated before someone was allowed to put this horrendous plastic inside my body? Why did the surgeon go ahead when my hernia had corrected itself?</p> <p>I now have no life. Lost my job. Can't do weight lifting or go to the gym. I'm now registered disabled. No mobility and loads of weight gain because I struggle to move. I lost my life because of constant pain. Not to mention how tight this feels in my abdomen. I have been diagnosed with FND. Fibromyalgia and other illnesses linked to mesh complications. I take allergies to normal stuff now. React to medications I never did before. I have been told my body is constantly fighting and rejecting the mesh. Imagine a dinner plate stuck inside your stomach well that's how it feels. I can't put my own shoes or socks on. Can't bend over get in or out a bath anymore. We're having adaptions done in our home to get a shower put in. I am 37 and I have lost my life. I was just married to my husband when this was put in. He said he married a wife but became a carer. Our marriage and life is strained because of this. I was my 3 disabled sons carers and now my husband cared for all 4 of us. Covidien paritex mesh was used in my operation. It has been withdrawn and people have sued as the manufacturers were aware but yet they still continue to use this rubbish. I also have protacks in that hold it in place that have shot through my muscle wall and send electric shocks through me. One is attached to my bowel and one close to my heart. The surgeon who is going to remove this says this is a big removal operation and risky. But he is concerned about the protacks as they carry a cancer warning and should never be used in humans. I may need a double stoma for the rest of my life after this. I may need abdomen reconstruction. I may not make it off the operating table but I am desperate. No life is better than the life I am living now. I can't do it anymore. The surgeon who done this to me took my life.</p>	
39	Surgical mesh was used. Rejected as foreign body... unable to remove surgically. Did not consent to mesh. Now have many auto immune type problems	Umbilical
46	Used a support from Amazon and proper nutrition WFPB	Umbilical

63	Surgical mesh was used to repair both of my hernias. To be honest, after my hernias were repaired, I began to suffer pain/discomfort/stretching/nerve type pains. Even now, over 5 years on, I am still in pain. It hurts when I turn or bend - a pulling sensation, and lots of nerve type pains, similar to electric shocks. I have been back to the hospital, but all they do is take a CT scan and tell me the mesh hasn't moved. Well it may not have moved, but it IS causing me problems.	Umbilical
64	I had the prolene mesh system put in Jan 2020. The surgery and 6 week post op seamed to go well. 3 hernias were repaired.	Umbilical
Unknown hernia		
17	Surgical mesh was used. All went to plan in 2010/11 however it has been back and worse since 2017	Unknown
41	I didn't know when they were revising my urostomy that I had a hernia. First I knew about it was waking up in HDU with an urologist telling me about it and also telling me that he used surgical mesh. When I challenged him I was told that it was ok as he had used 'the good mesh'	Unknown
65	1st repair did not utilize mesh (2002). 2nd repair the surgeon inserted mesh without my knowledge or permission.	Unknown
Blank response		
13	I am a pathologist. I examined over 500 specimens of explanted mesh, from hernias and pelvic devices.	-
57	My experience thus far has been a terrible one. Paritex ProGrip polypropylene mesh was used	-

Question: what impact has having surgery to repair your hernia had on you, your family and your quality of life? (65 responses)

ID	Comment	Hernia type
Abdominal hernia		
31	It has been one of the worst things to ever happen to me. I have extreme pain at times and cannot move I am doubled up in 2. I am bed bound for days and I am sick because the pain is so bad. I cannot look after my 3 children when this happens or go to work so it has emotionally and financially hit me and my family. I also cannot perform certain daily task because the mesh pulls on my organs. I also cannot exercise because of the pain I am in when I do it.	Abdominal

42	The pain is excruciating when moving or bending. I can't do housework or be in a semi bent position for any period of time without being so sore and crying. My family have to support me in doing tasks and watch me in pain afterwards. I can't pack shopping in the shop as the pain is excruciating with bending to pack it.	Abdominal
67	Hernia mesh became infected in 2020. I've had 3 surgeries since July, 2020 to address abscesses, carbuncles, furuncles. Adhesions, descending colon perforation with faecal discharge into abdominal cavities.	Abdominal
68	Absolutely no quality of life. Better off not being here anymore, sometimes I wish that were true!!!	Abdominal
36	My life has been destroyed, I'm constantly feeling sharp nips inside my stomach, if I move a particular way. I can't laugh like I used to, it causes pain. Can't eat full dinners, I've discomfort. There's a hot feeling in and around the mesh area at times. I have complete numbness on touching my tummy as nerves were damaged during surgery but the pain I experienced inside is overwhelming. I've been referred to a pain clinic as the surgeon said they would not be going back in to remove the mesh, it would be impossible to do so. On a CT scan my mesh does not look very good, whatever that means. I've been left in a horrible situation and feel my body has basically been butchered.	Abdominal
Epigastric hernia		
6	It hurts to breathe, it hurts to do cleaning/ gardening. Tying my shoes hurts. I am unable to exercise including yoga. Sex hurts. I am now in a situation where I am not sure I will be able to have a child. I also need to self fund the removal operation.	Epigastric
11	Over time I have become quite ill with various issues. The hernia is back bigger than ever. I am in constant pain with it. I have got joint pain, weight gain (due to inactivity because of the restrictions of the hernia, dry eye, hiatus hernia, constant heartburn, diastasis recti, mystery illnesses my GP doesn't seem to know. Been for various scans and tests.... nothing conclusive comes back. I have to wear support wear to hold the hernia which is uncomfortable in itself. Waiting to see an NHS surgeon now for over a year. Been told I have to lose weight and will probably have to have full abdominal reconstruction. I have lost my job, lost my marriage, lost my self esteem and confidence. Now supported by the benefit system when I should be able to work.	Epigastric
Femoral hernia		

35	<p>My life hasn't been the same since. Been in terrible pain, I have permanent nerve damage in the genital area, I have been ill constantly with infections, my arthritis has got worse, suffer with constant digging pain in my groin. The mesh has gone rock solid and feels like a wooden ruler with a knot on one the end. My family have had to take me into hospital and look after me. Mesh has fired up my immune system. I am constantly tired and because of pain starting to feel depressed. I never suffered with colds, never had the flu and done a lot more physical things before Mesh . Now things have really gone down hill.</p>	Femoral
Groin hernia		
2	Recovering from surgery was worst part. I didn't have pain before but was quite sore for 2 weeks.	Groin
9	I no longer have a good quality of life. Left with chronic pain and less mobility. Had to give up my career and cannot care for my 2 young children. This has ruined my life as I knew it. I had to give up exercise too.	Groin
12	My life is constant pain making me miserable. My Partner & I have split up after 20 years as He couldn't cope with my moods any more.	Groin
18	The repair made a difference as I was able to do my job without any more pain.	Groin
51	I still get pain. I am constantly aware of the repair.	Groin
53	At the time of having the repair (1982) it gave me relief for a few years but gradually the pain returned. In 1985 I was on sick leave from work as I couldn't work due to pain in the groin, which caused hardship to my family at the time.	Groin
69	<p>I had been told to avoid lifting for 6 or 8 weeks I gave it 10 as I felt low in health and energy I felt nothing had changed, I tried to do hoovering on the 10th week and I felt something was wrong, I went back on the list and was given 'stitches over' the first operation area to strengthen what they had done before. I had the idea everything I had was dissolvable, what I thought might be a patch or stitching might have been dissolvable or cotton such was the poor information. The low energy feeling did not go and the burning and tearing and ripping and 'cheese grater or raw skin' took over. Such is the poor information on after surgery that reading about 'meshoma' and 'coatings' possible cancers and further failures has created a lot of fear, and the NHS and GPs not giving proper information creates fear, and those who create information have totally ignored patients no matter male or female that are known to be expected to suffer. I do not look disabled and have to explain to people which reduces my right to privacy, to see</p>	Groin

	others suffering 5/6/7 years is no exaggeration, not told of types or given choices.	
Incisional hernia		
7	Since the time the surgery took place I've been in constant pain , nerve damage and the feeling of something is tugging my insides, I can hardly walk sit or stand, I live most of my life laying down, my husband has to help me in every matter	Incisional
8	The mesh can just catch me at any time and be uncomfortable.	Incisional
10	<p>I have no quality of life anymore, I am in constant pain and my core (stomach muscles are) held together with super firm control wear otherwise I cannot stand up, I look 9 months pregnant and cannot stand unaided because of pain and a lack of balance.</p> <p>My youngest son was 7 when I had the mesh repair and he has been affected very badly by the whole experience he mourns for the mum he lost who can no longer cycle, play, walk with or even read to him (I have ongoing chronic inflammatory response to the mesh which even affects my eyesight!) and he has worsened anxiety because of the whole situation and also because of how badly I have been (and continue to be by a certain gp) treated .My relationship has been at breaking point for some time because of the mesh and the constant pain I am suffering with, intimacy is no longer an option because of the pain leaving us both cross and upset and lonely, I will be very surprised if he stays with me much longer because he is now my carer not my lover. I am depressed and have also lost touch with friends and some family because I am stuck in a seemingly endless cycle of pain.</p>	Incisional
25	I have aches and pains all over, I get depressed because of all the pain I get, I can't have it repaired again, I was told this, I have a huge lump on my side! And have to wear a belt, my working life is done, I used to be a care worker, it's all I know, I'm in constant chronic pain all over my body, diagnosed with fibromyalgia plus other health problems	Incisional
34	Devastating I have NO LIFE 😢💔 my family have all suffered too its caused so much physical and mental pain 💔 after researching the Mesh I'm outraged that they are putting this crap into people without full explanation the lack of human testing using us a guinea pigs my mesh was banned in America for years but they used it on me TWICE then left me to rot saying I don't have a hernia??? Just my abdomen is like a saggy pair of knickers yet CT SCANS says different the hole was 9cm and its 17cm with my entire bowels in my abdomen 😢💔 HOW WOULD YOU FEEL ?	Incisional
54	I've nearly died a few times so my family are upset and angry that I have been left to rot and disabled and no definite hope I have no	Incisional

	quality of life I was an Artist self employed I can't get my life back nothing can repair my loss of my passion and creativity my time with my grandchildren they are upset that I look this way like a freak 	
62	Huge impact, not only are there many things that I used to do and now cannot but even the simple act of getting through the grocery store is a challenge.	Incisional
Inguinal hernia		
3	Ruined my life and now it's out left with other effects and pain. Pretty much disabled but can't get help or financial help. Ruined my life!	Inguinal
4	Changed my Life beyond repair. Took me a couple of years to finally find a surgeon that believed me when I said the meshes were causing me so much pain. I live with chronic pain, every hour of every day. I used to be fit, active, could run, hike. Now days am unable to get out of bed with pain.	Inguinal
5	The first year was affected by the pain. I started to regret having the surgery especially after a friend had telescopic surgery and appeared to make a much faster recovery. After the first year, it bothered me less. Long-term it did not really prevent me exercising or being active. The sensory loss in the skin can give strange sensations if that area is touched, and being so close to my genitals means there has sometimes been an impact on my sex life and intimacy.	Inguinal
15	It was nothing less than transformative. The restrictions were gone and normal health and function returned. Now some years on, the hernia is just a fading memory.	Inguinal
16	I'm now disabled and it's caused my pelvic organs to collapse	Inguinal
23	No surgery was necessary and the hernia self healed	Inguinal
24	Not a lot apart from pain	Inguinal
26	I still can't sit in chairs. My parents are 68 now and it's had a horrendous impact on them. I suffer badly with PTSD. I tried to move in with my boyfriend last year but the challenges of caring for me were too great and we broke up. I have been granted PIP. I never thought all this would happen to me and I was never told 28cm pf plastic would be put in me. I feel violated and so angry because the original hernia was nothing compared to the mesh damage. The pain and disability from the mesh is 50 times that of my original minor issue.	Inguinal
28	No job. No sex life. No exercise. Depression. No comeback. Depressing doesn't scratch the surface.	Inguinal
43	No problems	Inguinal
44	I was able to continue as normal.	Inguinal

45	<p>It has ruined my life. Caused my immeasurable and constant pain. Financial implications are severe, I can't work full time, can't walk or stand for long, I paid for a private removal of the mesh. My family have suffered and continue to do so. I worry for the future, I have developed other health problems now as a result, mental health issues, side affects of medication. My life has changed and this has had a stressful affect on family who have tried to support me. I had to use a wheelchair for a long time and now still need a mobility scooter. I was so fit and healthy before the operation and it has devastating my life.</p>	Inguinal
47	My qualify of life to perform busing jobs and to clean my house	Inguinal
48	I suffer from pain also it affects me mentally as I keep thinking about this foreign body inside me. My husband has lost patience with me as he is fed up with me talking about me feeling let down by doctors. I now face with the dilemma of surgery and the consultant tells me that they are going to use mesh. I was very upset so I wrote a letter to my GP who telephoned me back and said he would contact the hospital to say that I wanted my repair to be stitched.	Inguinal
50	I was unable to continue my job after 30 years, I have not been able to have a normal sex life since. I need help from my family to get everyday things done. My mobility is severely affected.	Inguinal
55	My quality of life is worse after I had the mesh put in. I am annoyed that NO one said anything about the mesh and how it could affect me. I cannot lift anything heavier than a small bag of potatoes which I find very annoying.	Inguinal
56	<p>I have lost everything. My 90+hours working a week. My band. My life. My ability to drive. My ability to walk run , stand sit. To be with others intimately. The disgust I see in peoples faces looking when I walk up the road fills me with utter shame. I'm begging for life, constantly being kicked by a mesh, by doctors and surgeons unwilling to accept the truth of mesh.</p>	Inguinal
59	Fine for about 18 months then started to have health & bowel problems. Was fit and healthy up till then. Eventually had to give up my part time job which I enjoyed doing in my retirement. Lots of tests all negative. Developed SIBO [<i>small intestinal bacterial overgrowth</i>] but still do not know underlying cause. Severe effect socially and how does one show and prove that since Mesh put in my quality of life plummeted	Inguinal

60	Unable to play soccer, run or go to the gym anymore. Unable to drive long distance in car. Unable to lift any heavy.	Inguinal
66	My daughter went into hospital healthy apart from the Hernia and came out in a wheelchair her life altered, this has caused a great deal of worry for her immediate and wider family and friends, visits and outings have to be curtailed due to her pain and exhaustion. All house work and cooking is now done by her husband and son reducing her work life balance as work is her main occupation being unable to cope with much else.	Inguinal
40	The mesh repair is the worst thing that has happened to me in my lifetime. This mesh implant has impacted in everything I do. Pain, mobility, stress, sex life, enjoyment, social life, work life and of course sleep.	Inguinal
61	I eventually lost a job that I loved because I wasn't fit to return to work. My family have had to witness me, not only in more pain than I could ever have imagined, but also with severe depression and anxiety since my hernia operation. They have had to witness the side effects of many different medications that I've been prescribed to deal with the pain, some of these left me "spaced out" and asleep for many hours during the day while some had me running to the bathroom to vomit. I haven't been able to physically run around with my kids for many years now. I have been left unemployable and not even entitled to relevant benefits as my disability "doesn't count", despite being in receipt of Industrial Injury Benefits as I'm classed as 25% disabled in their report.	Inguinal
Mixed hernia		
14	Loss of sex life with husband has been so heart breaking. I am unable to pass a bowel movement without the use of daily strong medication called sodium pico sulphate. I have bleeding from my anus and vagina and some days the pain is unbearable. I had to give up my business due to pain and discomfort.	Mixed
52	Can no longer do all the things I took for granted like walk unaided, shower myself and clean myself when I go to the toilet	Mixed
Other hernia		
29	I have been in pain ever since the procedure in February 2020. The hernia recurred, after two months, as soon as the stitches degraded enough. The mesh never covered the hole and was removed laparoscopically, by a different surgeon, in November 2020. Part of my bowels had begun to adhere to the mesh and the adhesions had to be cleared too.	Other

	<p>However, only 22 of the 28 protacs were removed and the remaining 6 protacs are still causing pain. I have been wearing loose waistbands for over a year as pressure on the protacs causes pain.</p> <p>The impact of the hernia repair with mesh surgery has been major, in a negative way, on my life. I rarely leave my house.</p>	
49	See above and it terrified my husband when he saw how much pain I was in straight after the operation and as the tears have gone on as well.	Other
70	This has impacted on my quality of life as I am unable to do things I could do before i.e. play golf, bowls, gardening and walking. This also has an impact on my flow from my ileostomy as I have to wear a support belt restricting the flow and this can result in leakages from the ileostomy. I have also experienced pain from my hernia repair and have spasms and also nerve pain. This is ongoing.	Other
Umbilical hernia		
1	Improved - dealt with previous concern.	Umbilical
19	It created minimal restriction, I am always aware that I have had the operation especially if I occasional attempt to step outside my comfort zone of activity and it's just a case of disciplining myself to step back. There are some restrictions that I have to observe but not a huge impact on daily life.	Umbilical
20	Removed a pain/ache source, significantly improved my silhouette and therefore my self image.	Umbilical
22	none yet	Umbilical
32	I lost my job due to disability caused from reaction to mesh. I have become unable to take care of children independently and suffer from many lingering symptoms including Sever nausea, chronic fatigue and pain.	Umbilical
37	Had to cut down on recreational activities previously enjoyed (Parkour, aerial arts, pole fitness) due to being in pain for days afterwards in this area. Daily analgesia.	Umbilical
38	As above we have no quality of life. I am disabled. I need care. I am 37 and can't even dress myself. At least when I did have hernia it only bothered me twice in my life. So why have repair that I never needed as it had repaired itself with the work I done at the gym. Also that took my life. My family are sick of seeing me sick and in pain. I've lost friends as no one understands. I have no life. I'd rather be dead than be like this anymore. I only have surgery to try and help but I will never be me. The me I was before. This has affected me mentally.	Umbilical
39	Massively affected health, mobility and quality of life	Umbilical

63	I feel like it has ruined my quality of life. I feel that I can never get back to "normal" i.e. to how I was before I had the hernias. It is not very nice for my husband either, as I don't want to go out to places in case I get the pains. I can't walk for long, and don't feel like I can go on holiday. When the pains are really bad, I panic and think something bad is going to happen. I also get worried that the mesh is attaching to organs in my body. I cannot press on my belly button, and I cannot sleep on my tummy. I cannot even get into a bath, as I can't bend down that far without bad pain.	Umbilical
64	Since the surgery, I've been in constant pain. I can't wear Jeans or anything tight. I can barely touch my abdomen without pain. Sitting up right, bending, crouching anything that puts pressure on my stomach hurts. It's has effected all parts of my live, my job, playing with my kids.... it's all painful. My stomach looks distorted, there's a bulge above my belly button. I'm exhausted and have headaches all the time.	Umbilical
Unknown hernia		
17	In the early years it made a massive difference, I no longer had the pain and I could enjoy life again	Unknown
41	The hernia repair has had a devastating effect on me. A few days after my surgery my surgeon said he hadn't used mesh, my urologist (different cons) said no mesh was used as it wasn't in my notes from the surgery and that I wouldn't be a good candidate for surgical mesh due to my autoimmune disease and the amount of scarring in my body. It took 6 months to prove that they had used mesh, surgeon was surprised at the evidence although did confirm that he does use the words 'I used the good mesh' The pain has been terrible, I had to give up work 6 months after my surgery, I get terrible pain at my stoma and shooting pains down my leg. I've lost my wage, some of my friends, my social life and my husband is now my carer.	Unknown
65	Years of mysterious health problems in my abdomen area. Had 3 major surgery procedures since July 2020 because of infections, perforated small intestine and descending colon.	Unknown
Blank responses		
13	After reviewing medical histories the impact on patients' life ranged from none to severe limitations in abilities due to chronic pain.	-
57	It has stopped me working, affected my wellbeing every day. Has affected my mother as I'm living with her.	-

Question: when deciding to have surgery to repair your hernia, what benefits did you expect the surgery to have? Were there any complications you were concerned about? (63 responses)

ID	Comment	Hernia type
Abdominal hernia		
31	I have had a groin hernia repair before when I was at 22, and have never had any problems with it, but that was not a mesh repair. I expected the same from this repair for it just to be closed over without any complications. They said it would be keyhole surgery but it wasn't. I thought it would be closed over and you would not be able to see anything and I would be pain free, but I still have a big gap in my stomach and the pain is extreme.	Abdominal
42	I expected to be pain free with a minimal scar, not the thick one I have. I don't remember any great discussions around mesh being used therefore little concerns.	Abdominal
67	Relieve pain and protrusion in abdominal area.	Abdominal
68	None in the beginning because you have faith and trust in your surgeon and the products they use	Abdominal
36	I was not concerned, I was glad the bulge would be fixed and I'd be free from the pain that hernias bring.	Abdominal
Epigastric hernia		
6	I knew the lump was going to go and there was a high % that my pain would go or reduce. I was concerned about the use of mesh as I had seen the articles about vaginal mesh complications. I was advised it was not the same thing.	Epigastric
11	The full repair of the surgery. Nothing to the level I have experienced. If I was told that this was a side effect. I doubt I would have agreed. I was told the only complications are what can happen after any surgery, infection, bruising etc. No one mentioned the mesh can rot, move, decompose, crumple, poison you from the inside, rejection.	Epigastric
Femoral hernia		
35	I had a life threatening hernia so I had to get it repaired. Wish they hadn't put plastic mesh in me .	Femoral
Groin hernia		
2	I had the surgery to stop complications later on.	Groin

9	I was concerned about the side effects of mesh and when I voiced my concerns I was told it had been used for the last 30 years with no problems" gold standard" was the exact phrase used.	Groin
12	I was hoping to be pain free at least. I wasn't told about any complications that might occur. Only the risk of General Anaesthetic.	Groin
18	To get back to a normal working life. I had no complications at all.	Groin
51	Beyond knowing that I needed surgery for a "trapped hernia" (as put to me), no other discussion took place	Groin
53	I was advised by the surgeon to have surgery as I was in constant chronic pain which he advised having the repair would relieve all the pain. I was not advised of any complications that could arise from the surgery.	Groin
69	I expected to get better, no pain, get back to work, my degree, my life choices, set my children up – none of that happened and what has has been too slow. I did not get told of pain and complications even when I started asking questions then complaining, a nurse friend of mine two years after my surgery offered that something must be wrong. I was at a very vulnerable state by then, cheese grated every minute of every day for three years after mesh, to cheese grated on moving with ripping and contractions, I was told in 2017 that 'mesh is meant to crumple and in an ideal world would be taken out'! I had to self-seek my own physiotherapy by crying down an NHS call referral card! 2015 to 2017 my leg had seized badly the contractions would seize movement altogether, 2018 fewer seizures with physiotherapy and though pain daily not continuous and feelings of being Taser'ed – imagine sunny day you feel for the first time maybe the pain has gone and you walk and enjoy looking at the river then the first taser' – it affects your mental health – I still fear ice and slipping and stairs, I still have a numbness and an ache that is like getting stitches out and sometimes a 1cm tube like feeling and sometimes a pricking rather than a prickling and now and again a painful ouch with what maybe the "crumpled " mesh and I still have to concentrate on every step I take to lift as I can trip even on smallest of inclines but that last bit improves as I walk a lot and try to keep on the move as even days off will set me back.	Groin
Incisional hernia		
7	I presumed hernia would be repaired and that would be it	Incisional
8	I assumed a complete repair and pain free living.	Incisional

	I expected the incision (hernia) to be repaired and for the swelling to go down leaving me able to get on with my life as normal after about 6 weeks. I was concerned about the pain and it felt like mesh sticking into me but my surgeon wanted to rule out all other possibilities first thus giving me the run around before fobbing me off to pain management who thankfully asked for an ultrasound to show that the mesh was still fine which it clearly wasn't. The sonographer wrote as little as possible about what he had found and advised me not to go private which I found odd.	Incisional
10	I thought I would be ok, I wasn't told of the dangers of mesh! My life is just pain now, I expected to get on with life as I was before I had mesh implanted in me!	Incisional
25	I totally trusted them to fix it not knowing anything about mesh or even that they would be using it! After several attempts and nearly dying from bowel complications and obstruction from the mesh I refused more mesh in my last operation to free my bowels.	Incisional
34	I was hopeful to have a normal waste and try and get my life back, I was concerned about dying on the table but knew I couldn't continue as I was and my body was shutting down	Incisional
54	I was aware of the issues surrounding the transvaginal mesh problems but we're led to believe that the replacement is better and safe	Incisional
62		Incisional
Inguinal hernia		
3	Not explained to me.	Inguinal
4	To fix hernia and get my life back.	Inguinal
5	I felt that the repair was the best course of action to prevent complications like strangulation and the mesh would reinforce this repair and integrate into my natural connective tissue. No real implications (or complications) were discussed by the consultant or medical staff prior to surgery.	Inguinal
15	The surgeon [...] had extensive experience, and excellent long term follow-up to prove good results and few complications. I have a lot of allergies, including reactions to plastic (for example peri-oral irritation even from drinking from a plastic bottle). I did not want to have a synthetic compound left in situ in the wound.	Inguinal
16	To be free from the discomfort I had. I had no concerns at the time	Inguinal
23	She was concerned about the disabling effects caused by implants and risks of surgical procedures	Inguinal

24	Pain would be gone	Inguinal
26	I thought I would get better! I wasn't warned about chronic pain or nerve injury.	Inguinal
28	I expected to be able to work, rock climb, cycle...have my old life back. I was told complications were 'very, very rare'. I was not concerned about anything.	Inguinal
43	It was to take the swelling and discomfort away. I didn't think about complications before surgery.	Inguinal
44	Surgery was clearly necessary. No complications.	Inguinal
45	I was informed that it was a simple operation and expected it to allow me to return to the gym to exercise.	Inguinal
47	Just the mesh and...	Inguinal
48	I expected to be able to move freely after convalescent. Not have to worry of the complication of strangulation of the hernia. I trusted the consultant to do the best for me [not to save money] to do the repair.	Inguinal
50	I was told at the time it was the modern way, the gold standard and that I would be back to normal in a couple of weeks.	Inguinal
55	I expected to have a full recovery and a normal life with no pain. Was not informed about any complications that could happen.	Inguinal
56	I was told that the hernia would be "stronger than it is now" it'll stop more hernia appearing and it's a quick surgery. I wasn't informed that there was major complications like I am suffering. I want informed of what the mesh is, what it's made from. I was only made aware of general surgical issues like infection moderate pain for a couple days and the 2 weeks back to work. So no there wasn't anything I was concerned about as it was sold as a "gold standard" op. A sales pitch!	Inguinal
59	Just thought that surgery would prevent hernia slipping down. Only concerned about usual things associated with anaesthesia	Inguinal
60	No concerns of complications. Generally, I don't heal quickly so I was thinking it will take a few weeks longer to be back playing soccer than other people. But I knew after one week, things weren't going well. I was only able to walk 50 meters a day.	Inguinal
66	No longer having the pain of the Hernia complications were unknown and not discussed.	Inguinal
40	Expected the hernia to be fixed.	Inguinal

	I expected that the surgery would eventually take the pain of the hernia away, that I'd have to have to rest for a few weeks and then I'd slowly be able to get back to doing my normal daily tasks both at work and at home. I wasn't concerned about complications because I wasn't informed of any major concerns	Inguinal
Mixed hernia		
14	I had no symptoms so had no benefits only complications!	Mixed
52	I was told mesh was gold standard, so didn't feel the need to challenge a doctor who is supposed to be on your side	Mixed
Other hernia		
29	I was expecting to be pain and hernia free and back to normal self a few weeks after surgery, but none of that has happened. I was concerned about mesh next to the bowel but trusted in the wisdom of a colorectal surgeon. I should have listened to myself instead.	Other
49	I specifically asked if mesh would be used and that I don't want mesh. I was assured that this was the only way they could fix my hernia due to its size and that this was a new mesh and not at all like Tvt [<i>transvaginal tape</i>] mesh. It was completely safe they said and that it had a special coating so it could not adhere to my organs. I expected to get my life back, be able to go for walks at more than a slow pace, be able to do housework, play with grandkids and care for them. To be able to sleep and to take a part time job on. To be pain free!	Other
70	I expected the hernia to reduce in size and give me back some quality of life but this has not happened as it is just the same size as it was before surgery. I have had five operations in this area, two colostomy operations, one ileostomy and two hernia. The surgeons won't go back in to repair again as the previous operations have caused weakness in this area.	Other
Umbilical hernia		

19	I was confident in the team carrying out the surgery after consultation. Complication arose in the recovery room. I personally was happy with managing my pain without painkillers but was advised to take an intravenous painkiller (tramadol) after some encouragement I accepted the advice given. Within a minute of being administered tramadol I experienced an anaphylactic shock reaction, I immediately asked for assistance and I personally injected myself with my own adrenalin epipen, I was attended to and cared for but during the reaction, the surgery wounds began to bleed heavily, the bleeding was stopped and I carried on with the normal recovery. This was the only complication experienced.	Umbilical
20	Benefit of removing the hernia! Complications - because of my weight apparently I was higher risk for the anaesthetic.	Umbilical
22	type of anaesthetic, local or general, general might make my dementia worse	Umbilical
32	Fully functioning core. I was concerned with synthetic materials and complications from surgery.	Umbilical
37	Was told extremely low risk of complications and also that it would stop hernia becoming strangulated which would have been a medical emergency	Umbilical
38	I was told I had to have surgery. I wasn't given a choice. I trusted surgeon I never thought they would lie and put people in harms way. I was told it wouldn't get stuck again although it had never got stuck again for months. I was told I still needed surgery who am I to argue with an expert. He told me it could become trapped and I could die. I was scared. (Since found out it was only ever 1cm of fatty tissue that had closed before the day of surgery). He told me this was the best option and I would never have any issues. So I was never given an option. I trusted what I was being told and scared so I agreed given what I was told. He said the only complication was bleeding as with all operations that was all. 3 weeks I'd be back at the gym.	Umbilical
39	Alleviate symptoms and pain.	Umbilical
63	I expected the hernias to be stitched up and then I would be well and fit again. I had previously had my appendix out, and never had any problems with that.	Umbilical

64	I was concerned about rejection, inflammation, mesh entanglement, pain.... I decided to have the surgery because I felt like it was my only option and I didn't want to get strangled Intestines. I was told this was the only option by the dr. even after asking about others. I expected to have less pain and hernias repaired.	Umbilical
Unknown hernia		
17	No complications that I am aware of. I was due to have it done again in 2019 but it was postponed and of course covid took over	Unknown
41	As above, I didn't know I was getting a hernia repair.	Unknown
65	To get all the mesh removed which was impossible bc [<i>because</i>] it's embedded after being in place for 17 years.	Unknown
Blank responses		
13	<p>The issues with patient counselling by the surgeons are:</p> <ol style="list-style-type: none"> 1. Surgeons earn their living doing surgeries 2. Most surgeons cannot offer pure tissue repairs, only mesh 3. Surgeons are measure results by recurrence and many totally forget that the final measure is patient satisfaction, not anatomical correction 4. Published literature has a large volume of intentionally or unintentionally biased publications. For example, complication rates are reported after short follow up of 2-3 years while long term studies showed that only 50% of complications present within 4 years after mesh implantation. The remaining 50% accumulate over additional 10-15 years. Therefore, short studies, which predominate in published literature underestimate rates by 50% or more. 	-
57	I expected the pain in my groin to be less after surgery. It is now worse than ever. I was reassured by the surgeon that there wouldn't be complications	-

Question: did you experience chronic pain (lasting 3 months or longer) after having hernia repair surgery? And if so, how did this pain affect you and your life? (62 responses)

ID	Comment	Hernia type
Abdominal hernia		
31	Yes I have had extreme pain from the surgical mesh where I have been bed bound, and not been able to look after my 3 children or go to work.	Abdominal
42	I have had chronic pain for 8 years and affects my life daily.	Abdominal
67	No, not for several years	Abdominal
68	Pain is still ongoing and its been 11 years of this bullshit....	Abdominal
Epigastric hernia		
6	I have been in pain since the operation in 2018. The pain has destroyed my life. I cannot do any exercises and I have gained weight. It's affecting my personal life with my fiancée. I am not sure if I can have a child. I am always tired. Getting on planes hurt as it makes the area swell up. I cannot wear a bra or the clothes that I want to as I have a huge lump where the operation is. I am constantly feeling like I am wearing a tight belt around my upper abdomen.	Epigastric
11	I had my repair done 9 yrs ago and have been in constant pain since. Nothing relieves it. Due to the pain I was unable to do my work.	Epigastric
Femoral hernia		
35	Had pain since it was put in .I have a constant hard lump digging into my leg, pubic bone, tummy and pelvis. Everyday I get pain and stinging. Every night I get woken up because of the mesh digging into me. I get trapped nerves in my pelvis from the mesh and I have fallen downstairs twice. My leg doesn't always communicate with my brain. My permanent damaged nerve means I am numb down below and I can't feel myself go to toilet .	Femoral
Groin hernia		
2	No	Groin

9	At this stage after opp I thought I was still recovering I never got better the pain just got worse and continues to do so over 4 years later. I am now under pain management for chronic pain and mobility is limited. This has had a very bad affect on my daily life.	Groin
12	Yes after 4 months the pain & Hernia was back. After 12 months I went back for more surgery. To repair again.	Groin
18	No	Groin
51	Yes. Constant awareness, tenderness at the site of the surgery	Groin
53	Yes, 3 years after surgery chronic pain which resulted in me being on long term sickness benefit and unfortunately I had to leave that employment as it was too much heavy lifting which I could not do.	Groin
69	<p>2011 - 2012 – 2019</p> <p>I kept a pain diary just a couple of times a year just to see if I improved and try to find reason and where pain was. 2011 – the long wait, radiology and the web agreed but consultants argued and deeper politics was said by whistle-blowers to be going on, I was only a patient no information no pre-care no consent.</p> <p>2012 –operation – mesh - high pain constant burning ripping tearing ‘cheese grater’ felt low in energy and health and hoped to get better but depression and fear – I had to keep working with the fear I would fail 2014 – high pain constant but of different types of prickling pricking burning ripping ‘Cheese grater’ confused suicidal fear no reasons no help, when I asked questions no answer came, I have to hide the pain as no-one sees and I can’t explain and those medical have not and will not tell me 2015 – high pain but intermittent with other pains contractions tasered 1cm of tube?</p> <p>Numbness,</p> <p>pricking prickling feeling ‘dressed sharp pain on moving wrong way feel as if lump might push out and a round hardness and of lifting shopping thus a back pack is not going away felt low in energy and health and thinking this might be too long for me, fear depression, when I asked questions the GP gets told to reassure me and send me away, bus journeys I just want to sit the way I need to but would not be socially correct, I want to rub and massage the pain away 2016 -2017 – pain high when it happens and every day and for long periods but I get first snippet of what it could feel like not to have pain but the</p>	Groin

	<p>taser'ing is the punishment, the pains are lots of different pains instead of the one long pain merging all pains, most pain is of groin, my leg is seizing, I'm losing ability, in desperation I call physiotherapy they help, I ask questions, I complain, I keep complaining 2018 – intermittent pains which are sore enough to swear at in groin and of mesh and of leg, I don't carry much, the lump still hurts if I accidentally lean on it i.e. dishwashing, I still have to concentrate on each step, people do not see this, I feel my core going and my balance is very poor the physiotherapy gives me different moves, I am seeing other regions seem to have more information and am told I am a percentage of patients expected to suffer, I am very angry 2019 – I still have numbness, ache on touch, sudden round pains, feeling 'dressed' "crumpled lump"? , trying to pick self-up, this year since the exercises are taking hold seem better, the last two months seem best but still try not to think back or I get emotional at what I have lost, I say no a lot more at work, reduced hours and reasonable adjustments at work, and I 'pace' I use tiptoe technique to get my core strength back, In an ideal world there should have been a lot of help in the beginning, I fear if I do have a failure, I do not trust the NHS or GPs, and I have an unwanted piece / pieces of polypropylene in me. Since then the Sturrock Report and the Cumberledge Report has come out. We are the 'other mesh scandal'.</p>	
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Incisional hernia

7	Yes I 14 years after surgery now , I'm in so much pain every day, I was given pain killers but I had suicidal thoughts while on them so to frightened to take anything now	Incisional
8	No. Minor pain and discomfort	Incisional
10	Yes the chronic pain after hernia repair surgery with mesh has got progressively worse with time affecting every aspect of mine and my family's lives.	Incisional
25	Iv had chronic pain ever since, over eight years! My life has had to alter work wise, and I cannot lift anything heavy, I can't sleep properly either because of pain and discomfort	Incisional

34	Yes I was in constant pain to the point I was admitted several times to hospital but sent home with morphine with NO ANSWERS I can't describe just how bad this pain is its taken away my soul to the point where I didn't want to live like this , if I were a dog or a cat they would just put me to sleep 💔😊	Incisional
54	I was in constant pain had to be blue lighted a few times but they could never find out what was causing it until surgery when the realised it was wrapped around my bowels this was a 6 year period The whole thing has left me with ptsd I constantly think about it and worry I'm going to die but I need to live to make people aware NOT TO HAVE MESH	Incisional
62	I have never had a day without pain since implantation. I once used to be able to work 50 hours a week in manufacturing. Now, at the age of 57, I cannot repetitively lift anything over 10 lbs, twist, bend, stand, sit or walk. Simply rolling over in bed can cause scar tissue or an adhesion to fire up. Often times it takes days for it to settle and I have a hard time just breathing.	Incisional
Inguinal hernia		
3	Initially no pain however after 10 years I had disabling pain. The mesh was infected and damaging my bladder.	Inguinal
4	I experience chronic pain for 24 hours a day. It is debilitating, and soul destroying.	Inguinal
5	Yes, I believe the pain during the first year after surgery was chronic pain. It had some impact on my ability to exercise, and it did give me reason to regret having the repair. I did not seek medical care for it, as I believed that it was just part of the recovery process. Eventually it eased and my life mostly returned to normal.	Inguinal
15	remarkable quick recovery with mobilising from the same evening. Gradually reducing pain over next month then petered out. At the 4 month stage I over strained the area and had a temp recurrence of discomfort - but since then nothing.	Inguinal
16	Problems started after another procedure disturbed the mesh. Now had 5 years of hell	Inguinal
23	She has zero pain, large easy to pass stools and all is well	Inguinal
24	Yes. It makes me feel sick and can double me over in pain.	Inguinal

26	Yes. It has had a good go at ruining it. And I am very positive and lucky to have funds to try everything from nerve block injections to multi disciplinary pain programmes. But one you have nerve damage from mesh it is nigh on impossible to reverse - I know this from talking to sufferers all over the world.	Inguinal
28	Yes. Pain every single day since my surgery. Pain killers work, sometimes, but I don't take powerful drugs as I fear addiction. My life, as it was pre-op, no longer exists.	Inguinal
43	Mild pain. Wound was infected and I had a Sedona but it settled after a few months	Inguinal
44	Initial discomfort during healing only	Inguinal
45	Yes, I have a good pain threshold but this was unbearable at times, there was nothing anyone could do to help me, it was very stressful for family and friends. I was taking a lot of painkillers and meds to help me sleep which caused me other problems, it was very difficult for everyone. There was very little advice or help from NHS, no answers or explanation. I felt like I was just being fobbed off constantly with no real diagnosis. I was off work for a year and a half, unable still to go back full time. Unable to walk, sit or stand for long, chronic fatigue.	Inguinal
47	No not at the time.	Inguinal
48	Initially the pain was excruciating then it eased a bit. In December 2017 I had a bad chest infection. I was coughing quite a lot and had trouble breathing. I was left with most excruciating pain in the site of my hernia, I went to the doctor and she referred me back to the hospital but it was ages before I was seen. I'm not sure of the dates,	Inguinal
50	Yes. It has been extremely difficult living with sometime constant chronic pain. I've had numerous treatments some that have exacerbated things, bad side effects from some painkillers. It has changed my outlook I'm no longer happy and suffer from depression. This has also affected my family.	Inguinal
55	I have had the operation 4 years now and it is just as bad as day 1. I cannot lift heavy things as I use to do.	Inguinal

56	I experienced the worst pain ever after waking up from surgery. It was horrific. The pain has only gotten worse over time. This pain still affects my life everyday to where I'm considering dying. Everyday this pain destroys me. Physically, and mentally.	Inguinal
59	Intermittent pain depending on how bowels are. Affected my ability to make arrangements ahead of time eg optician, hair dentist appts.	Inguinal
60	I still have chronic pain after 4 years. The first few months after the op, I was suffering from a lot of anxiety and depression. Lucky I came through this, but it has always worried me what could have happened in those few months if not for the support of my family.	Inguinal
66	3 years later my daughter is still in pain and the management of this takes all the joy from her life, outings have to be fitted around energy levels and uses her electric scooter when possible which is not always appropriate and not at work.	Inguinal
40	8 years later and after mesh removal I'm still in pain. See answer above to see how it affects me.	Inguinal
61	Yes I did experience chronic pain and still to this day suffer chronic pain due to the hernia mesh repair. I have had many many trips to my GP for painkillers (all of which I couldn't continue taking because of side effects), anti depressants and eventually sleeping pills. I've been referred to various other doctors for "muscle" and various other problems that were thought to be the cause of my chronic pain but it has always come right back to the hernia mesh	Inguinal
Mixed hernia		
14	Yes pain from day one in 2006 and still have complications and pain	Mixed
52	Yes straight away was in chronic pain and years later is getting worse	Mixed
Other hernia		
29	Yes, I suffered excruciating pain immediately after surgery. This pain took months to subside. There is also pain from remaining protacs when they are pressed.	Other

49	Yes I had the hernia op in 2015 and still have daily pain. All explained above. I also have a lot of paresthesia in my limbs since the mesh and fatigue as well as the pain. I've been hospitalised after the mesh as my back contorted so painfully and hospital said nothing they could do as I had mesh and would have to learn to live with the pain.	Other
70	Yes I did and had to get medication for nerve pain. I still experience pain from the hernia but not as severe.	Other
Umbilical hernia		
1	No	Umbilical
19	No chronic pain experienced. I do have a slight dull discomfort on my left side which has always been there . It feels like somthing is there and pulling .	Umbilical
20	No	Umbilical
32	Yes. After 1.5 years I still suffer from chronic pain and eventration of the lower abdomen.	Umbilical
37	Yes, as above. Had to cut down on recreational activities previously enjoyed (Parkour, aerial arts, pole fitness) due to being in pain for days afterwards in this area. Daily analgesia which I also had to take during a subsequent pregnancy.	Umbilical
38	I have suffered chronic pain since day 1. We contacted the surgeon several times my GP included and he denied it was the repair. But I was fine before. He said 3 weeks recovery, 3 months, 6 months a year. 18 months. 5 years later i sit here in the same pain but worse as I lost the life I once had and weight gain due to no mobility. I was going to take my life as no one knew what was wrong with me until we found out I had mesh in my abdomen. It affects me everyday. I can't think straight as the meds make my head cloudy. I can't do this life anymore. I can't cope with it. I wasn't told these complications yet in the USA and Canada, Australia, New Zealand and Ireland they are being taken seriously. I'm sick of being fobbed off.	Umbilical
39	Yes, and even after 20+ years still suffering. Loss of independence /chronic pain	Umbilical
63	Yes, chronic pain on and off for over 5 years now. I would have the mesh removed if I could afford it.	Umbilical
64	yes as stated in the answer above. I have constant chronic pain every day that affects my home live, my job, my children, love life	Umbilical
Unknown hernia		

17	I only experienced pain for a few weeks after the surgery. However when it came back the pain is so bad . It affects me in that I can't go out , I can't lift my grandchildren nor can I play with them. I can't lift heavy pots or pans	Unknown
41	My life has been decimated by mesh surgery in November 17. The pain has been truly awful, I've had chronic pain for a long time but this new pain tops it all. My working life has been destroyed, I've been relying on savings to get by, I've had to buy an accessible home and I don't qualify for benefits. I truly wished I had died in my surgery	Unknown
65	Yes, and 2 subsequent surges still has not resolved the pain, bowel, and diarrhoea issues	Unknown
Blank responses		
13	I've examined specimens of patients who had chronic pain. The degree of discomfort was sufficient to justify excision surgery.	-
57	There was pain post surgery that continuously got worse with each year. I'm not working, can't exercise, sex life greatly impacted	-

Question: what information (if any) was given to you about hernia repair and surgical mesh? (62 responses)

ID	Comment	Hernia type
Abdominal hernia		
31	None I did not know until I woke up that the doctor had used mesh.	Abdominal
42	Limited memory as this was so long ago.	Abdominal
67	None	Abdominal
68	Nothing really, after, just to rest and not lift or do a lot of stress related things to your stomach	Abdominal
36	Basically told mesh would be used to help the hernia from happening again as the mesh strengthens the stomach wall muscles. No mention of long term complications that I'm suffering today	Abdominal
Epigastric hernia		
6	That the mesh was not the same mesh used in the vaginal mesh scandal (it is).	Epigastric

11	I purposely asked if there were any options and was told definitely not... just mesh. No information was given to me regards the mesh and was told 2 weeks after surgery I should be fine.	Epigastric
Femoral hernia		
35	None. Just told I could get infections, blood clots, pain and inflammation from surgery.	Femoral
Groin hernia		
2	It was the only way to go.	Groin
9	I was told there was no other type of repair possible and surgical mesh was excellent and without problems.	Groin
12	None	Groin
18	All the necessary information was given to me	Groin
51	None	Groin
53	I was assured that having the surgery would relieve all the symptoms.	Groin
69	None the first op and not after it either, the second op the GP seemed embarrassed and firmly told me 'you are discharged', I was confused.	Groin
Incisional hernia		
7	I wasn't told I would be having mesh	Incisional
8	Very little	Incisional
10	I was told that I wouldn't even know it was there, I didn't know that incisional hernias were common and my surgeon said I was just one of the unlucky ones and he couldn't understand it! (at first). I wasn't told hardly anything about it.	Incisional
25	Not a lot!	Incisional
34	NONE	Incisional
54	Nothing	Incisional
62	Not a whole lot of discussion about mesh occurred before the repair. When it involves the entire core muscle group if there's not enough of you it's the standard option.	Incisional
Inguinal hernia		
3	None	Inguinal
4	None. No one told me the mesh may be rejected by me. That it would erode into me, That i would not be believed by doctors that mesh doesn't cause pain. I was told that every time I visited a& e	Inguinal
5	I had one appointment with the consultant prior to surgery. I was only informed that my surgery would involve mesh that would be used to reinforce the repair. No other information was given.	Inguinal

15	It was recommended by the surgeon - who indeed suggested also doing the other side as a prophylactic move (that side now years on has no problem). I asked for alternatives and sought another opinion. There was a possibility of trying an absorbable mesh (pig skin-derived) but leaving non-absorbable sutures. So people were conscientious and helpful but were not attuned to possible problems with the mesh, or alternatives to it.	Inguinal
16	None	Inguinal
24	Not a lot. Told hernia could return.	Inguinal
26	Very little except pushed towards having both sides done at same time. Was told woman generally prefer open surgery because they want to wear bikinis?! I said please just do whatever is medically best for me.	Inguinal
28	None.	Inguinal
43	Just that it would be open and not laparoscopic	Inguinal
44	None	Inguinal
45	I signed the forms and they say there is a slight but very minimal risk of pain after, I was never given the correct info telling me I could end up having to use a wheelchair, that the pain could be severe and debilitating with life changing consequences, I feel deceived by the NHS, no one gave me any appropriate information.	Inguinal
47	All of the risk involved with it	Inguinal
48	Just the usual ie they could rupture an organ when doing the surgery. I could take a reaction to the anaesthetic which could result in death.	Inguinal
50	Mesh was the new Gold Standard, it was as if you'd be stupid not to opt for it.	Inguinal
55	Not a lot, it was just a lets get on with it. I went private as the waiting list was so long.	Inguinal
56	None.	Inguinal
59	None only that he'd done thousands of these repair. No info about plastic mesh	Inguinal
60	It's a routine operation and will take 4 weeks to completely recover. You will be back to work after one week.	Inguinal
66	None the leaflet given mentioned that a few cases might cause life long pain.	Inguinal
40	None	Inguinal
61	None!	Inguinal
Mixed hernias		
14	None	Mixed

52	Was told its a simple operation and will be back doing all the things I loved doing after 6 weeks	Mixed
Other hernia		
29	I was told the hernia would be repaired using mesh and that mesh was wonderful. Also told not to believe the scare stories and that a laparoscopic repair was best way forward for a Spigelian hernia repair.	Other
70	Just informed surgical mesh was used. Did not receive any other information that I am aware of.	Other
Umbilical hernia		
1	Not much by way of discussion. I was just told that was what the operation involved.	Umbilical
19	I was given a leaflet on care after surgery.	Umbilical
20	That they were going to use it	Umbilical
22	none	Umbilical
32	That it was the gold standard and that it was biologic mesh not synthetic	Umbilical
37	Not much at all, just that it was a simple procedure and very safe.	Umbilical
38	That it would be pig skin with dissolvable stitches. I would be better within 3 weeks and back to weight lifting. It was gold standard. The only risk was bleeding like any other operation. No other risks were told to me there fore I never made an informed choice. Also I wasn't given a choice. I wasn't fitted with pig skin or dissolvable stitches. It was Covidien paritex composit mesh and polypropylene stitches.	Umbilical
39	None	Umbilical
46	My doctor encouraged me to eat plant based wholefoods instead because mesh is harmful	Umbilical
63	I wasn't really given any info about mesh. The consultant said he could repair the hernia, but that I might suffer more pain. I didn't really understand why, as when I had my appendix out, after a few months, I never experienced any problems.	Umbilical
64	I was told the name of the mesh and Infection risk	Umbilical
Unknown hernia		
17	Only that a mesh square would be stitched across the opening to keep everything in place	Unknown
41	Absolutely none. As above surgeon changed his story several days after my surgery and said he hadn't used mesh. It took me 6 months to prove it	Unknown

65	None except he told me after the surgery that mesh had been implanted.	Unknown
Blank responses		
57	I was told it was totally safe with a very low risk of complication	-

Question: did you have a follow-up appointment with your surgical team after the hernia repair? If so, did you find this appointment helpful? (61 responses)

ID	Comment	Hernia type
Abdominal hernia		
31	None	Abdominal
42	Yes, basic discussion. Concern about the size (depth) of the scar and underlying pain. Told to expect this.	Abdominal
67	Yes. Yes.	Abdominal
68	I don't remember but once again at that time no one knew what was going to happen with the mesh	Abdominal
36	No I was continuously returning due to infection in the wound and for several years later. Then informed it would be almost impossible to remove the mesh, I have been left with an empty sac inside my abdomen also, this was seen on CT. For months after my surgery I had a calcified mass inside my tummy.	Abdominal
Epigastric hernia		
6	The appointment was awful. He told me to have a glass of Prosecco and chin up when I said I was in too much pain to work.	Epigastric
11	One... and no. When I found out a few years after surgery following a visit to family in the States, I requested my notes. Found out I had a Johnson and Johnson ethicon mesh which was discontinued after my operation as unsafe for human implantation.	Epigastric
Femoral hernia		
35	The surgeon refuses to remove the mesh even though he knows it is causing health issues. He is frightened that it will cause more damage removing it even though it's only been a couple of years, since the operation and its already causing problems. Ultrasound can't even see through two layers of mesh	Femoral

Groin hernia		
2	Yes, very helpful to put mind at ease and draw a line under it.	Groin
9	Yes I did 3 months after repair I was told my pain was due to me still healing. I was discharged by consultant at this point.	Groin
12	Yes I said I was still in the same pain but was told it was just phantom pain	Groin
18	Yes & yes	Groin
51	None offered	Groin
53	No.	Groin
69	No, not even when I later asked about the pain.	Groin
Incisional hernia		
7	Yes I did and said about the pain I was in and told it would calm down	Incisional
8	No	Incisional
10	I had to chase this up as an appointment should have been made but wasn't.	Incisional
25	Yes, I was in pain at the time so cannot remember much about it to be fair	Incisional
34	Yes and no not helpful	Incisional
54	Yes but because it didn't work there was no alternative discussed	Incisional
62	Several but in my case not really because I was in the midst of still recovering from the previous surgery. My pain was coming from everything so it was impossible to realise that most of the pain was coming from what the mesh was doing inside of me.	Incisional
Inguinal hernia		
3	Can't remember	Inguinal
4	Only to check on wound etc.	Inguinal
5	No. I had one appointment with the nurse at my GP to remove the stitches. No other post-operative consultation occurred.	Inguinal
15	[...] who did the Desarda's for me followed me appropriately, and then did a 1-year survey to check on any pain or complications etc	Inguinal
16	A check up a few weeks later. Was asked if I felt I'm and if discomfort had gone which it had. Discharged at that point	Inguinal
24	No follow up	Inguinal
26	I did. It was not helpful. The surgeon offered me a free private operation to try and correct the damage, which made me feel very suspicious.	Inguinal
28	Yes. Mr surgeon said pain post operation was a factor. He was completely useless at understanding me and my pain.	Inguinal
43	Yes. It was needed to review seroma and I was on a trial	Inguinal

44	No follow up.	Inguinal
45	I only had a follow up because I demanded and fought to see them. It was very upsetting as they could tell me nothing. The surgeon was not an expert on hernia repair but a general surgeon, he did refer me eventually to an expert, but this took far too long and I continued to be in unmanageable pain.	Inguinal
47	Yes	Inguinal
48	I had a follow up appointment I did not find it helpful as I felt that no one listened to me	Inguinal
50	Yes that was when I was injected in the wound site which gave 24 hours pain relief.	Inguinal
55	No I told the doctor I was in pain and he said it would go away which was a load off bull.	Inguinal
56	Yes, due to issues with non stop pain, it hasn't yet been resolved. 7+years!!!!!!	Inguinal
59	Just routine follow up	Inguinal
60	After care was very poor. Consultant would refuse to see me and when he did, it would be for 1 minute. I also went to two private consultants after the operation and they were also no use. They knew exactly what the problem was but they wouldn't say. You could see it on their faces.	Inguinal
66	No the follow up was in reply to a complaint, the Doctor apologised and stated he could not help other referring her on to other departments.	Inguinal
40	No follow up appointment.	Inguinal
61	No I did not have a follow appointment with my surgical team. I did have numerous appointments with different consultants to complain about the pain I was still suffering but was told it was in my head and that the hernia mesh was not the cause of the pain I was suffering. I was told I had a detached muscle in my public bone by the consultant that lead my operation, and then I was added to a 4 year waiting list.	Inguinal
Mixed hernias		
14	No	Mixed
52	No, but had an appointment with several surgeons to see about mesh removal, none would do the operation due to further complications	Mixed
Other hernia		

29	I had a number of consultations with the hernia surgeon. He refuses to consider that my pain is caused by protacs, was not convinced that the hernia had recurred until an ultrasound was performed to prove the recurrence. He gave conflicting versions of mesh being in the right place but pelvic bone got in the way. X Rays showing protacs and pictures of the mesh prove the mesh was placed ineffectively and should never have been placed at all. This all should have been obvious to the surgeon, at the consultation stage, but he went ahead anyway.	Other
49	Yes but only at my request and my consultant said vehemently that the pain was nothing to do with the use of mesh.	Other
70	Yes I had a follow up appointment but it was unhelpful. I was told it was unnecessary to operate again even though it had not reduced in size as far as they were concerned the operation had been a success but my own doctor disagreed.	Other
Umbilical hernia		
1	I don't remember one.	Umbilical
19	No, I did have a follow up with the local nurse for wound management.	Umbilical
20	Yes, see above	Umbilical
22	waiting two + years for appointment	Umbilical
37	No, nothing.	Umbilical
38	No we had to push a follow up appointment and didn't see him till 18 months later. My GP kept referring me back she was shocked.	Umbilical
39	Yes ... not helpful	Umbilical
63	Yes, I had a follow-up appt. I told the consultant about the continued pain, but he just said that it was side effects of the operation.	Umbilical
64	no, due to Covid 19	Umbilical
Unknown hernia		
17	Not that I remember	Unknown

41	Follow up appointment when I proved he had used mesh seemed positive. He was utterly shocked that it wasn't in the operation notes. He promised faithfully to remove it but in the removal surgery in January 2020, he had a look and said it was too complex to do so he didn't try but he did unstuck the mesh from my ureter. I got no apology or anything. I'm now discharged from his 'care'. My urologist (not my recent surgeon) of 19 years was found to be a paedophile and was sacked and has now been erased from the medical register. I have not been referred to any other urologist, I really feel abandoned.	Unknown
65	Can't remember. Probably did. No problems began until several years post-surgery.	Unknown
Blank responses		
57	I did have follow ups but was told it has healed and that the surgery was a success. That the pain I'm feeling will improve after 6 months or so	-

Question: is there anything else we should consider when developing recommendations on hernia repair in NHSScotland? (57 responses)

ID	Comments	Hernia type
Abdominal hernia		
31	Individual case to make sure it is really needed or are there other forms of treatment	Abdominal
42	All those in receipt of it should be given the chance to have the mesh checked and option for removal.	Abdominal
67	Hernia mesh—all brands—should be banned permanently.	Abdominal
68	Make sure that the surgeon the hospital home ever it may be knows that the product that you are going to be using is absolutely under strict regulation qualifies to be used for this type of procedure	Abdominal
36	No mesh should be used as its life changing for many people.	Abdominal
Epigastric hernia		
6	There has to be more awareness and accountability for the affect it can have on the body. My post surgery symptoms are not recorded and not considered to be an issue. It's just in my head.	Epigastric
11	Making surgeons and Doctors aware of this	Epigastric

	Ban mesh full stop. It's a foreign piece of plastic mesh that goes rigid then breaks up, due to the body rejecting it and what's to get rid of it. You fire up the immune system all the time then many nasty diseases turn up. Thousands of patients are suffering and their doctors are refusing to put the reason for suffering as mesh. I myself have proof that the doctors will not write down - mesh caused this. Go on social media and thousands of victims of mesh are gathering. Mesh companies in America and Australia are being sued. The NHS need to get back to securing bodies without plastic mesh. Mesh is just a quick and easy hole filler and sod the consequences.	Femoral
Groin hernia		
9	Candidates should be given an alternative to mesh ie sutures. They should be fully informed of complications and the real figures of people who have complications.	Groin
12	Show peoples views	Groin
69	<p>According to all leaflets unless the NHS took them while I was asleep as well I am not going 'to feel pain in my testicles' and waiting for that is not going to help! I am female.</p> <p>Hernia information is incomplete, consent is incomplete, differing reasons for pain is missed, exercises in different ways to help different needs before and after surgery is incomplete, females are missing, female body pains are missing, what to tell employers or DWP or GPs is missing, contractions of mesh are dangerous to driving, timescales of 2 weeks are misleading, where are the pathways after. I do not underestimate the pains the media reported POP mesh women and the hidden rectal mesh men have suffered, for hernia suffers their pain is a window into their pain and I can only call that inhumane and cruel, and it is cruel to leave hernia patients with no or half information.</p> <p>I note BHS have only just taken on their first female. Foreseeability goes way back. I feel failed and let down and for the men who have suffered it must be difficult to have to pretend.</p> <p>I feel if the hernias were treated and followed up promptly a lot of people could have been saved pain, certainly my career and I would have had the ability to stand and speak up. I feel surgeons etc don't listen to patients, I feel mesh pain is different to surgical damage pain, people ought to listen to the reasons for pain and where and to get immediate pathways for that, mental health should be top when pain is suffered, pain should not have to fit a call centres 'criteria', follow up is a disgrace and on all who are supposed to monitor or record or inform, and for females a total total disgrace. I hope I sound angry because in real life I have learnt to accept</p>	Groin

	failure at my most vulnerable and each turn shook my head more. Please make real change. I am just one person but I heard of two more near me as females and one man so there must be more. It made it worse having no voice, no recognitions, you could not fit into healthcare, so no 'next'. The Patients rights Act 2011 does not serve my type of patient need, it became an NHS rights Act. I now have help through another process to process the delayed PTSD I suffered.	
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Incisional hernia

7	Don't recommend mesh!	Incisional
10	Yes that a non mesh hernia repair if possible is always the best way of avoiding hernia mesh complications!!!! I wish that I had been given a choice.	Incisional
25	Don't do it! Mesh ruins your life!!	Incisional
34	DONT USE MESH FULL STOP	Incisional
54	DONT USE MESH	Incisional
62	More testing needs to be done prior to it's use. How many lives are going to be destroyed before they stop allowing medical device companies use the general public as their guinea pigs.	Incisional

Inguinal hernia

3	Please stop using it, the risks are too high.	Inguinal
15	I urge you to examine the use of the Desarda technique.	Inguinal
16	Don't operate unless it's necessary and don't use mesh unless no other option	Inguinal
23	Plant based wholefoods especially complex carbs and high fibre as these build strong tissue and aid the GI tract. Exclude highly processed foods and all animal products as these are known to cause hernias	Inguinal
24	Don't allow mesh usage it's not good for surgical use.	Inguinal
26	Look at the Shouldice Clinic in Canada, and hernia mesh regulations in Australia. Mesh is still used but only in 1-2% of cases. I suspect natural tissue repairs are the better option even if they may fail as the pain and disability of mesh is avoided. Evidence also shows the Shouldice technique can have lower levels of hernia recurrence than mesh - the evidence on mesh as the gold standard is outdated and yet we cling to it. And please check for a tendency to allergies before putting mesh or permanent stitches in anyone. Thank you.	Inguinal
28	Go mesh free! Look at mesh free training - it exists!	Inguinal
43	A standard information sheet pre op discussing options and reasons why because there is so much to google and often not appropriate. Please note I did a similar but different survey 2 years ago for you. Is this still valid?	Inguinal
44	Information leaflet would have been useful	Inguinal

	Give honest Information on consequences Train surgeons to be experts in repair without mesh, In reality very few surgeons can do non mesh repair. Only operate if there are no other options. Research everyone long term having hernia repair and find out who is more likely to have issues of on going health problems or foreign body reaction - which I have had. Test people for foreign body reaction to mesh before operation.	Inguinal
45	I do not think mesh should be used in the body. I did not know about it if I had known this was being used and knew about the horror stories I now know about I would not have allowed them to use it on me	Inguinal
48	Why describe a procedure as Gold Standard? That's a sales technique! I just wanted to know I was going to be ok, I didn't want to be super human. Now I'm disabled.	Inguinal
50	The person's should be informed that it may not work and could give you a lot of pain.	Inguinal
55	Patients should be made aware that mesh for hernia is the same Nah for vaginal implants. Vaginas Implants are now being found to fail. Hernia mesh will be next. You are implanting a ticking time bomb that destroys life's. I know it has destroyed mine. To think that if I had on older style repair like a Shouldice, or McVey technique, the Manchester groin technique. These techniques are the true way of repair. Any patient who's mesh has failed will say this, for we would rather deal with the chance of recurrence than the torture of this!!! Why would you put something into someone if you don't know how to get it out??	Inguinal
56	Mesh should not be used. It's plastic. Surgeons need to be trained in the tried and tested repairs for inguinal hernia eg Desarda, Shouldice etc. Just because mesh method is cheap, less time in hospital no reason to put polypropylene in the human body. Surgeons and hospitals should receive no commission for using specific products.	Inguinal
59	I had another Inguinal Hernia on the other leg. I went to Germany for the repair, which was a non-mesh repair using the shouldice repair method. No issues what so ever.This type of repair should be offered to all patients.	Inguinal
60		Inguinal

	The Doctors need expert tuition on both using and removing the Mesh, they should always give allergy tests to make sure patients will not suffer foreign body symptoms with the Mesh and also be trained in Hernia without Mesh a skill no longer in general use and more suited to women whose anatomy does not suit the use of Mesh.	
66		Inguinal
40	Non mesh repair must be offered.	Inguinal
61	More tests need to be conducted to see if people can cope with this foreign body inside them. More choice and much more information needs to be given to the patient before deciding to use hernia mesh repair.	Inguinal
Mixed hernias		
14	Ban mesh inside the body.	Mixed
52	Be truthful to patients before, during and after the operation	Mixed
Other hernia		
	You need to start taking hernia repair seriously by investing in training surgeons in natural tissue repair. Mesh is not a quick fix for the patient who goes on to suffer pain and complications.	
29	I gave no idea if I will ever be right again because mesh has been pushed down every one's throats and no other options are given.	Other
49	Yes please include hernias of all types for all genders and ages as yet again I feel Excluded even though I've directly been in touch with SHTG and have been an active petitioner for Hernia Mesh awareness. I've met with Nicola Sturgeon twice.	Other
70	A fuller explanation on how the mesh is supposed to reduce and hold in the hernia as it has not had that effect for me. I have a lot of mesh in that area and I am no better off than I was before the procedure.	Other
Umbilical hernia		
19	More information on what the mesh is and its lifespan and what effects to be aware of in the future .	Umbilical
20	Deal with them as soon as possible to minimise the operation time and reduce the chance of complications arising	Umbilical
22	complications on people with dementia	Umbilical
37	Stop lying. Stop hiding things. I'd heard about the mesh scandals but didn't think it would ever apply in reality or during abdominal mesh, as seemed it was mainly with TVT mesh. Stop gas lighting patients who query mesh as a possibility for new, ongoing chronic pain. Be honest, like the GMC and NMC requires you to be. Start acting with integrity.	Umbilical

	Please don't use this. Don't ruin anyone else's lives. Give people choices. Not just mesh. I didn't need this operation. Make it stricter please. I beg you. I nearly ended my life until I found a surgeon who is going to remove it all. He is shocked at my situation. Please don't put anyone else through my suffering. Make sure the operation about to be carried out is necessary as I never needed it. This is medical negligence. I'm not interested in suing I just want to get me and my life back. If I die trying then so be it. The past 5 years have been cruel to live. If I was a dog I'd have been put down.	
38		Umbilical
39	Clear explanation of poss side effects	Umbilical
46	Everyone should be warned about malnutrition and hernia risk as per the US FDA website	Umbilical
63	I cannot understand why mesh is used. I know people who had hernia repairs years ago, and they were repaired by stitching and no mesh was involved. I also have a friend who had 2 hernias several years apart. The first one was repaired by stitching, and he has never had a problem with it; the second was by mesh, and he is in constant pain with it, and has had several infections in his belly button.	Umbilical
64	No mesh is the only opinion. It has ruined my life.	Umbilical
Unknown hernia		
17	Yes please. When it fails and the hernia returns please treat it as an emergency and repair as soon as possible	Unknown
41	Mesh in all forms needs to be banned. If there is any risk of mesh being used then the patient needs to be properly consented. If mesh is used and is found to cause complications then full removal should be offered and if the surgeon is not capable of doing the surgery then a referral must be made to a surgeon who can truly help. Patients cannot be abandoned like I have been.	Unknown
65	Mesh files not belong in people. It's dangerous, toxic, and impossible to remove entirely	Unknown
Blank responses		
13	<p>Based on published literature and my experience, primary inguinal repairs should be without mesh. Mesh could be indicated after hernia recurrence repaired by pure tissue techniques. The problem is that tissue repairs need good technique while the new generation of surgeons has been raised to believe that mesh is the gold standard and they have no skills in pure tissue repair.</p> <p>Some incisional /ventral and umbilical hernias cannot be repaired without mesh. My view is that these should be repaired via open techniques, not laparoscopically as laparoscopic techniques carry risks of bowel involvement long term</p>	-

	<p>Accessible Information: we would like to ensure those affected by deafness, particularly those requiring information in British Sign Language and others requiring accessible formats such as easy read are able to understand problems, solutions and choices regarding this and associated matters.</p> <p>Inclusive Communication: we would like to ensure there are resources and adequate systems to ensure good communication and language support is in place for individuals and carers dealing with this and related issues.</p> <p>Context: Completing the form, I am unaware of any specific cases regarding this particular issue that relate to barriers and issues for those affected by deafness. However with over a million Scot's directly affected by deafness it is likely that some people will have encountered issues of access and participation due to lack of adequate information, support and ancillary service support offering a range of communication and language access support services. The provision of BSL/English interpretation can be erratic at best, very limited offering of electronic notetaking or use of digital tools to support hearing access: loops, microphones, captions/subtitles etc.</p>	
33	Hernia mesh should not be put into the human body. It should be sutures only	-
57		-
71	<p>On behalf of Sling The Mesh I am concerned at the lack of fully informed consent given to patients on the risks of using mesh to repair hernia. I am also concerned at the lack of alternative options by surgeons skilled in regularly performing alternative native tissue repairs. It is a skill being lost among the younger surgeon community and this needs urgently addressing.</p> <p>I see members of the group – male and female – having their pain and complications dismissed and their concerns being ignored or told there is nothing anyone can do to help them so they have to live with the pain. This is not an acceptable state of affairs, especially as none of our members were warned of long term chronic pain, erosion sand foreign body reactions as a risk.</p> <p>I hope you have taken into consideration the published work of Robert Bendavid and Vladimir Iakovlev who have done much to investigate the long-term complications of polypropylene hernia mesh implants and degradation once implanted.</p> <p>https://pubmed.ncbi.nlm.nih.gov/26315946/ https://link.springer.com/article/10.1007/s10029-019-02002-x https://pubmed.ncbi.nlm.nih.gov/26597872/ https://www.researchgate.net/publication/283472994_Pain_after_Hernia_</p>	-

Surgery_Must_Be_Avoided_and_Hopefully_Treated
<https://www.researchgate.net/profile/Robert-Bendavid>
<https://www.legalscoops.com/pathologist-explains-mesh-complications-in-jj-pelvic-mesh-trial/>

Additional Comments: There are no databases to capture hernia mesh complications so of course everyone thinks hernia mesh is safe / low risk in the same way everyone thought vagina mesh was safe / low risk for the same reasons. Also a lot of the outcome logging measures are based on efficacy. So if a hernia is fixed the operation is deemed a success - nobody logs if it has caused new onset of pain, infection.

For some men mesh has sliced their spermatic cord and for some caused sexual dysfunction

Surgeons deny mesh has caused the problem so details will not be locked in HES data either and actually most people in pain stay going round in circles in the primary care sector so their data won't be captured in relation to hernia mesh complications HES either.

It's not mandatory for clinicians to report adverse events to the MHRA so hernia mesh complications will be lost from that system of data capture too

There's not a full set of NICE guidelines for hernia mesh and when I have queried this via Parliamentary questions I've been told not all healthcare treatments have a nice guideline and that hernia mesh is well established. I was also advised that hernia mesh use is based on the European and World Hernia Society guidelines. However these are written by a community that is incredibly pro mesh and has conflicts of interest, which is like marking your own exam papers!

The fact there's not a full set of NICE guidelines for such a widespread operation is remiss to put it mildly.

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