

# Groin hernia repair

Public engagement survey feedback report

November 2019

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# Contents

- Introduction..... 2
- Summary of responses..... 2
- Survey responses..... 6
  - Experiences and views of groin hernia repair (42 responses) ..... 6
  - How having a groin hernia affected patient’s lives (38 responses) ..... 10
  - Impact of hernia repair surgery on patients, family and quality of life (42 responses) ..... 12
  - Benefits expected from hernia repair surgery and complications that caused concern (36 responses) ..... 14
  - Chronic pain (>3 months): experience and impact (37 responses) ..... 16
  - General comments (32 responses) ..... 17

# Introduction

To enhance the [SHTG review of primary inguinal \(groin\) hernia repair using surgical mesh](#), we conducted a 5-week public engagement exercise to gather patient and public views and experiences of groin hernia repair in Scotland. In this engagement exercise people were asked:

- about their experience of groin hernia repair and whether mesh was used
- how having a groin hernia affected their life
- how having surgery to repair a groin hernia had affected them, their family and their quality of life
- what benefits they expected from groin hernia repair and whether there were any complications they were concerned about
- whether they experienced chronic pain (lasting 3 months or longer) after having groin hernia repair surgery and, if so, how that pain affected them, and
- if there was anything else SHTG should consider when developing advice on groin hernia repair for NHSScotland (general comments).

This document presents all the relevant comments received\*, along with a summary of the key findings and themes extracted from the survey responses. All comments have been anonymised.

The comments received were considered by the SHTG Committee when formulating advice for NHSScotland on the use of surgical mesh for the repair of primary inguinal hernias in adult men. It should be noted that the results of this survey should be interpreted with caution, and not viewed in isolation, for the following reasons:

- respondents were self-selecting and may therefore represent a bias sample
- the respondents may not be representative of all patients who have undergone groin hernia repair in Scotland, and
- responses were received from 42 people which is a small sample compared with the approximately 5,000 groin repair surgeries in Scotland each year.

## Summary of responses

During the engagement exercise, 51 survey responses were received from a range of stakeholders:

- Forty patients or members of the public (including one GP who was also a patient).

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\* Comments that were provided by women (particularly those that made no mention of hernia), submitted on behalf of children, or related to other types of hernia were excluded from this report.

- Three people responding on behalf of a partner, family member or friend.
- Seven healthcare staff/volunteers.
- Two responses on behalf of an organisation.

Nine responses were excluded from this report because they related to women or transvaginal mesh (n=5), children (n=1), patients with other types of hernia (n=2), or people who did not have any experience of hernia repair or surgical mesh (n=1). This left 42 sets of comments<sup>†</sup> that are discussed in the sections below.

Twenty-one respondents specifically mentioned surgery to repair an inguinal or groin hernia. One response was from an individual who had a hernia repaired using a non-mesh technique (Desarda). Twelve respondents mentioned having a hernia repair but did not specify the type of hernia.

### Experiences of groin hernia repair

Sixteen survey respondents described positive experiences of groin hernia repair and ten reported having a negative experience. The remaining 16 responses did not indicate a positive or negative experience of groin hernia repair. For example:

- *"I had a groin hernia repair ....in February 2019. Surgical mesh was used ..... The use of surgical mesh was fully explained to me by the surgeon prior to my operation. I was up and about 1 hour after my operation, pain free. The following day I walked over two miles with no problems at all, and had fully recovered within two weeks."* Respondent #7810, groin hernia
- *"I had a groin hernia repair using surgical mesh approx. 15 years ago and have had no problems whatsoever."* Respondent #6846, groin hernia
- *"I had an inguinal hernia repaired with mesh in 2007, had chronic pain from the outset which has worsened and become debilitating over the years. I suffer from seemingly associated problems in and around the area including dysejaculation, rashes, bouts of epididymitis, painful bowel movements and severe pain spasms. I am in no doubt that nerve damage has been done."* Respondent #1531, inguinal hernia
- *"My right side was repaired with mesh for an inguinal hernia, I've been in great pain from day one that no pain medication takes away. Also since the operation I've started with lots of other problems like coughing, skin problems, constipation, foggy brain, leg spasm, irregular bmp and high blood pressure plus can hardly walk. Before this I used to be a personal fitness trainer."* Respondent #9465, inguinal hernia

### Having a groin hernia

Thirty-eight people responded to the question about how having a groin hernia affected their lives. From these comments it is clear that some people were describing the effects of hernia repair instead. Six people reported their hernia had no impact on daily life. Other respondents

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<sup>†</sup> As the survey used in the engagement exercise did not require respondents to state their gender, it is possible that some of the comments retained are from women who had transvaginal mesh for pelvic organ prolapse.

who appeared to be talking about their hernia rather than surgery, identified the following ways that having a groin hernia affected their lives:

- Modifying activities at work, losing their job, being unable to work or changing job.
- Difficulty exercising, including walking, cycling and weight lifting.
- Pain and/or a swelling in the groin.
- Restrictions on daily activities and lifting heavy objects.
- Reduced mental health, including elevated levels of worry.

The selection of responses below illustrate the impact on patients of living with a groin hernia:

- *“Unable to lift weight except small. Very uncomfortable when the hernia popped out.”* Respondent #6846, groin hernia
- *“I was in pain from the hernia before surgery, but ok at rest. I had difficulty at work so had to have rests and couldn’t do overtime.”* Respondent #7180, inguinal hernia
- *“Painful sitting in certain positions for long. Originally thought it was a muscular issue.”* Respondent #1580, inguinal hernia
- *“It didn’t really. I had a sudden swelling in my left groin, panicked, and dashed down to A&E, they advised me it was a hernia, got me an appointment with the consultant [...], had the op within about 3 weeks.”* Respondent #2612, groin hernia
- *“I discovered the hernia while having a shower. There was no pain or discomfort associated with it, but I was aware that I needed to be more careful to avoid a strangulated hernia.”* Respondent #1278, unspecified hernia

### Hernia repair surgery

Respondents (n=42) described a variety of both positive and negative experiences of groin hernia repair surgery. Themes identified in these responses include:

- a return to normal daily life, including work and hobbies, or significant improvements in these activities
- continued restriction on activities of daily life, work and exercise
- development of chronic pain or a substantial reduction in pain
- an inability to have sex
- negative effects on mental health, and
- both negative and positive effects on quality of life.

The following quotes illustrate the range of responses received on hernia repair surgery:

- *“I’ve not seen friends in months as I cannot drive, hardly walk, put on weight, getting depressed and caused other problems due to no sex life.”* Respondent #9465, inguinal hernia

- *"It has had a severe impact on my quality of life, my mobility is affected, my mental health from living in constant pain, I can't sit or stand for long periods or walk far so don't go out much. I am no longer able to work so our family income is severely affected and I am no longer able to have sex."* Respondent #1531, inguinal hernia
- *"Now everything is fine and I can lift weights and at 67 years of age count myself as reasonably fit."* Respondent #6846, groin hernia
- *"I am fine now, so apart from the scar and a slow recovery after operation side effects, I think the surgery has been a success....."* Respondent #7180, inguinal hernia

## Benefits and complications

Twenty-nine people identified one or more benefits they expected to gain from having groin hernia surgery. These included a return to 'normal' life, being pain-free, and no longer having the hernia, swelling or symptoms.

Sixteen people noted one or more complications they were concerned about. Unlike the benefits of hernia repair surgery, most complications were only cited by one or two respondents. Complications of concern included testicular atrophy, anaesthetic risks, any surgical complication, use of surgical mesh, infection, hernia recurrence, chronic pain and nerve damage.

## Chronic pain (>3 months)

Thirteen people reported experiencing chronic pain lasting more than 3 months after hernia surgery. Of these patients four had pain lasting more than 12 months. Twenty-four people had not experienced chronic pain, including eight people with minimal or no pain even on the day of the operation. Three people reported their post-operative pain passed within 2 weeks which aligned with what their surgeon had advised them to expect.

Below are a selection of survey responses on chronic pain following hernia repair surgery:

- *"...the pain is 24/7 and I do not have my life back to a bit of normality yet, I can not only see the mesh but I feel it scrunching up where it was implanted.....pain is horrible."* Respondent #7614, inguinal hernia
- *"Hardly any pain from groin but did suffer severe bruising and swelling from the active bladder."* Respondent #2639, inguinal hernia
- *"I experienced no pain even on the day of the operation. I walked out of the ward unaided one hour after my operation and went home after two hours."* Respondent #7810, groin hernia

## General comments

Thirty-two people submitted general comments that could be grouped into five categories: avoid using mesh for hernia repair surgery; importance of informed patient consent for mesh-based procedures; clear communication and shared decision-making on hernia repair; clarity on treatment options available; describing mesh procedures and potential post-surgery outcomes.

# Survey responses

## Experiences and views of groin hernia repair (42 responses)

ID	Comment
6673	Keyhole surgery left me with 3 scars and in a lot of pain and discomfort.
0638	Surgical is almost a routine in repair of inguinal hernia in adult men. [Healthcare Staff]
5954	Woke up after exploratory operation. Was told I had a hernia and mesh was in place, within weeks I was crippled with lower back pain.
6196	Yes surgical mesh was used in my hernia repair.
7614	Yes mesh was used on me to repair a "direct" inguinal hernia.
2639	I had the surgical mesh used on myself for a left side inguinal hernia repair, in 2000. Haven't had any problems with it since. My only problem was that the surgeon when stitching me back up, had gone through the femoral artery!! Was in hospital for an extra 2 days, he came round and apologised for it. That was it, chuffed he admitted he made a mistake and no problems since. P.S. no I didn't sue him or the hospital nor did I seek compo [compensation] 😊👍
4260	Surgical mesh used to repair my partner's hernia (suspected cause of hernia was appendectomy surgery several years earlier).
9465	My right side was repaired with mesh for an inguinal hernia, I've been in great pain from day one that no pain medication takes away. Also since operation I've started with lots of other problems like coughing, skin problems, constipation, foggy brain, leg spasm, irregular bmp and high blood pressure plus can hardly walk. Before this I used to be a personal fitness trainer.
1531	I had inguinal hernia repaired with mesh in 2007, had chronic pain from the outset which has worsened and become debilitating over the years, I suffer from seemingly associated problems in and around the area including dysejaculation, rashes, bouts of epididymitis, painful bowel movements and severe pain spasms. I am in no doubt that nerve damage has been done.
7161	Fairly clear process, good pre assessment. Clear guidelines and explanation before, during and after. 5 inch incision followed with mesh repair.
0750	Left inguinal hernia repair using mesh in 2015. In excruciating pain as soon as I woke from surgery... what was supposed to be a day case turned into 3 nights in hospital. Was left in pain & sent home. Gradually recovered although left with constant niggle deep in groin. The pain got gradually worse [...] so I returned to implanting surgeon who stated nothing wrong & packed me off to pain management where I was expected to do exercises to manage the pain. I don't want to manage it I want the mesh removed & the pain to stop! This poison is causing all sorts of other symptoms including exacerbating my arthritis in my back, horrible nerve pain both sciatic & pudendal which in turn is painful when I sit & painful when I stand.... so can't win. I'm currently waiting for mesh removal via a surgeon in Manchester (I live in Liverpool) as there is no way the original implanting surgeon is

	getting anywhere near me... I've never felt so ill since I had that mesh repair. I've already lost 3 years of my life due to chronic pain.....
1580	<p>[...] In 2017 there was considerable media reporting of problems with vaginal mesh repairs. I had been diagnosed with an inguinal hernia, and on the day, prior to mesh surgery, I asked the surgeon if this mesh problem was known as an issue for hernia surgery. The young surgeon said he was not aware of any.</p> <p>Two years later I was experiencing pain in the area of the hernia repair. In [...] 2019 my GP referred me to a consultant [...] I was referred and subsequently had a (painful) CT scan in April. I finally received confirmation in July that my new groin pain was due to diverticulitis. I have been told I will receive a further CT scan in spring 2020.</p> <p>Prior to the CT scan, my consultant advised that mesh problems were rare and usually surfaced soon after surgery. Although my case has not turned out to be mesh related, it was sufficiently worrying to make me wonder if the delay in advising the result of the 2019 CT scan was due to some kind of mesh related "cover up".</p>
1427	In mid-2005 I was diagnosed with a groin hernia and listed for routine surgery. In late 2015 the hernia became strangulated and I had emergency surgery (using surgical mesh) to repair the hernia.
5187	<p>Many patients who have had a mesh groin repair often return and state that they wish that they hadn't had the operation as it feels much worse than before the operation. They often seem to return with additional symptoms and possible recurrence.</p> <p><i>[Healthcare Staff]</i></p>
8400	Had inguinal hernia mesh fitted using mesh. I had an anaphylactic shock on the operating table. 6 months after my blood counts were incorrect, low platelets and iron deficiency. I have now been diagnosed with bone lymphoma and told my low platelets mean I can't have the mesh removed.
6563	Excellent! Yes, surgical mesh was used. I had to wait some months for the operation [...]. My experience could hardly have been better. The surgeon explained the options very clearly so I made the choice of a surgical mesh operation. The written guidance was very useful both in preparing me for the operation and in guiding me on what to do/not do afterwards. When I arrived, the surgeon and nurses explained what was to happen in a very helpful way. Although I was given painkillers, the pain was not sufficient for me to want to take them. I had slight discomfort and exercised as suggested but the inconvenience only lasted for a few days. I have had no trouble whatever since.
9894	After doctors confirmation I had a hernia I was examined by a consultant who indicated I had a double hernia [...]. After discussion with him and others I requested a laparoscopic procedure with mesh implant. The operation took place in early November [...] but due to the extent of the hernias my surgeon decided to complete the procedure with open surgery. My recovery period was a little longer than expected, but was without any issues and I was back golfing within two months. All has been fine since then.
7985	I had a surgical mesh implant to repair a groin hernia circa 15 years ago: the operation was successful and was told by the consultant that rather than go around the nerves he cut through them to minimise the pain during the healing process. I have had no real problems since.

7810	I had a groin hernia repair carried out in February 2019. Surgical mesh was used in this procedure. The use of surgical mesh was fully explained to me by the surgeon prior to my operation. I was up and about 1 hour after my operation, pain free. The following day I walked over two miles with no problems at all, and had fully recovered within two weeks.
2612	Double hernia - given the option of 4 months between the ops or both at once. Chose the latter. Surgical mesh in both. Had rumbling pain for about 10 days, went to the GP and she said this was normal. Now, 6 years ago and all is perfect.
8927	[...] right inguinal hernia repair with bard 3dmax mesh implanted. I was told after the surgery was complete that I had 3 hernias. A direct inguinal, an indirect inguinal, and a femoral hernia. Surgery was done laparoscopic. I had pain from the first day of surgery. I had several genitofemoral nerve blocks done that made it worse. I did pelvic floor rehabilitation. Which helped but didn't last. I had a revision surgery [...] that removed a lot of adhesions. I was still in pain so [...] almost one year from mesh implant my surgeon told me she took out the mesh 90%. I was still in pain and did pelvic floor therapy again which helped a little bit. But not enough. I also had urinary retention after third surgery and use catheters now. I finally went to new surgeon and [...] he performed two surgeries. He went in with incision to try and fix something in inguinal canal and then laparoscopic to check mesh. I was told the previous surgeon only got about 1/3 of mesh out and he took out another 1/3. I am still recovering but still have urinary retention. I can't tell if it helped yet because I am still in pain.
6846	I had a groin hernia repair using surgical mesh approx. 15 years ago and have had no problems whatsoever.
5374	I am a surgeon who does hernia repair and I strongly believe that mesh is important in achieving a strong durable repair. [Healthcare Staff]
5033	Yes.
2653	I use non-absorbable mesh in the repair of inguinal and abdominal wall hernias and have done so for the last 25 years. The recurrence rates for most repairs using sutures are significantly higher and the associated complications for mesh within the abdominal wall are no different. [Healthcare Staff]
8240	Surgical mesh was used in my operation.
7180	I had an inguinal hernia open repair ten years ago. I was on a randomised clinical trial of a mesh.
1278	I have checked the paperwork and it states that mesh was used to repair a hernia on my left side, but I am not certain. The incision was a few inches long. The procedure was undertaken as a day patient [...].
7545	Local anaesthetic. Not keyhole. Mesh was used. Procedure was simple and painless. The nurse was very clever at sussing out my interests and distracting me. It was all over before I could get a story I was telling her about my dog finished, so she never heard the end. I guess she'll have to live with that.
5436	I had bilateral hernia repair with the mesh done laparoscopically 5 years ago. It was a complete success in short and long term. I got back to work as a GP in 2 weeks and have had no recurrence or problems since.

5068	I had a bilateral inguinal hernia repair done 2016, using Desarda (mesh free) technique. No issues since.
5461	I had a double inguinal hernia repair done in the year 2000. The [meshes] were called kugel patch.... both rolled up inside of me in the year 2003. Dr tried to repair but could not. Another doctor put another mesh on the left side underneath the kugel patch. I have never felt pain like that in my life. I lost my job of 32 years working as an electrician as no one would employ me being on opioids. I was on opioids for 16 years. This year I had the right side mesh removed. Biopsy said nerves were caught up in the mesh. My life was taken from me because of this mesh. I was called a malingerer a bludger and told to get myself a job. I think mentally wise was worse than the pain.
8531	Day case herniorraphy with mesh for inguinal hernia.
0253	I had an inguinal hernia repaired in 2006 [...] in London. I had mesh inserted but not sure on what type.
2666	Yes, mesh was used. It was a straightforward procedure.
3721	I had hernia surgery in 2017 with surgical mesh used. I am only in 20s and never thought at my age you can get a hernia.
1699	<p>I first noticed the hernia during a round of golf and booked a GP appointment for an examination which confirmed it and referred me to my local hospital where, several weeks later, I was given an appointment to see the relevant consultant and was given an initial check prior to the operation by the hospital.</p> <p>After the elapsed period in which I was supposed to have been dealt with I was contacted by the hospital and asked if I was prepared to go elsewhere in several weeks time for the operation with the proviso that, should anything go wrong during or after the operation it would have to be dealt with by the hospital which carried out the operation. I asked about having it done privately and was contacted 10 minutes later by the secretary of the surgeon at my local hospital and offered a date 5 days later which I accepted.</p> <p>The operation was carried out efficiently and painlessly, using a mesh, in the morning and I was able to walk out of the hospital that afternoon with no complications or problems during the recovery phase.</p>
4843	Mesh was used and had a good experience.
9875	It was fine, good care.
6946	Yes, it was used. All good.
7486	Mesh was used and my life was a misery. Pain was terrible, had to give up job because of it.
4874	No problems with it.

## How having a groin hernia affected patient's lives (38 responses)

ID	Comment
6673	It was hard to exercise and do the normal things in my work.
5954	Constant pain.
6196	It didn't really only until it got to large I had to stop cycling and doing downhill mountain biking.
7614	I struggle to walk for more than 15 minutes which is horrible when you have grandchildren that need your help. Not to mention the pain.
2639	It crippled me from the day it happened. I was a gravedigger for 17 years, so that job got the heave ho!
4260	Severe pain & movement restriction.
9465	I cannot now drive, hardly walk, cannot have sex, cannot work.
1531	I was a furniture retailer before the operation and hoped to get back to normal after the operation, not the case, ultimately I could no longer continue in that business. I have struggled with the physicality of several other jobs and recently been unable to work and receive a PIP payment. I am no longer able to have sex with my wife so it has put a strain on our relationship and my mental health.
7161	Achy groin, mindful of pain, always aware of not doing certain tasks.
0750	I couldn't walk far at all.... constant toothache feeling in groin.
1580	Painful sitting in certain positions for long. Originally thought it was a muscular issue.
1427	It was often painful to move and meant that my groin area felt tender. My left side testicle has retracted as a result of the hernia repair so it sits further up within my groin area. This doesn't cause any pain or discomfort.
5187	Patients with mesh repairs that come back for an additional scan often state that their quality of life has reduced considerably. They regret getting the operation. Please bear in mind that I am sure that there are many patients who undergo successful mesh repairs and obviously don't return to me for a scan, so I am unaware of their experiences. [Healthcare Staff]
8400	It has stopped me working.
6563	Slightly. I was more careful to avoid strenuous exercise or sudden movements.
9894	Other than a swelling in the lower abdomen I had no issues or discomfort. I chose to have the operation on my terms as I have private health insurance.
7985	Regular pain preventing me to do certain daily tasks at home and in business.
7810	I had no problems after my operation and I would have returned to work within two weeks if I had not retired a few months before. I played golf within four weeks of the operation with no discomfort or side effects.
2612	It didn't really. I had a sudden swelling in my left groin, panicked, and dashed down to A&E, they advised me it was a hernia got me an appointment with the consultant [...], had the operation within about 3 weeks.

8927	I never knew I had a hernia originally it was found during my physical. It never bothered me before. Now I have constant pain. My right testicle hurts whenever it travels up inguinal canal. Also my groin on right side hurts and my thigh is numb from 3rd surgery. I have anxiety and depression and one of my doctors says I have PTSD from the surgeries. I should never have had it fixed with mesh. I even asked first surgeon before she did it because I was seeing commercials on TV she told me oh don't worry that is a different mesh and it's for women only you have hernia and it won't be an issue for you. What a lie that was.
6846	Unable to lift weight except small. Very uncomfortable when the hernia popped out.
8240	At the time as a relatively young man, quite a lot. It stopped or prevented me from taking part in hobbies/activities as I was in constant pain and discomfort.
7180	I was in pain from the hernia before surgery, but ok at rest. I had difficulty at work so had to have rests and couldn't do overtime.
1278	I discovered the hernia while having a shower. There was no pain or discomfort associated with it, but I was aware that I needed to be more careful to avoid a strangulated hernia. I went to the GP and was referred [...]. The time from discovery to repair was just a few weeks, as far as I recall.
7545	Before diagnosis, worried it might be sinister. After diagnosis, always worried it might strangulate. Had to be very careful with anything heavy. Restricted nearly everything.
5436	It was nuisance for 15 years, but I never had time to go for surgery as a GP.
5068	Yes, worry about strangulation, difficulty in doing sports and exercise. [non-mesh repair]
5461	I went to the doctor for a slight pain who said I will fix the left side also. The pain wasn't bad he said that it would get worse. If having the little pain that I had I would have been happy to stay like that.
8531	Yes. Lots of pain, some very severe.
0253	Prior to the surgery it didn't really affect my life style much. Some days there was little discomfort but not really something that bothered me. If I lifted heavy things or excessive situations then it would pop out more but I would just push it back (what I was led to believe).
2666	It did before I got the surgery, was off work for weeks.
3721	It was not sore to start with and got worse. I put off going to see doctor which in hindsight was not a good idea as I was in a lot of pain until I got it fixed.
1699	I suffered very little with the hernia and, as a keen golfer, I was hoping to have the surgery over the winter period so that I was able to resume playing by the following Spring, one of the reasons I decided to have it done privately. Apart from avoiding any heavy lifting it did not cause any major problems.
4843	Pain like I have never experienced. Was off work until operation was horrible.
9875	Didn't really, only a couple days of pain after operation.
6946	Very little.
7486	Lost job as a lorry driver and was in and out of hospital for months.

4874	Nothing.
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## Impact of hernia repair surgery on patients, family and quality of life (42 responses)

ID	Comment
6673	None at the moment as I had constipated for 8 days after the operation.
5954	Not able to run or walk fast. Always in pain.
6196	After my surgery up until 7 months I was fine just the normal recovery then pain kicked in pain I could manage but as time went on the pain has got worse. I no longer work full weeks. I find it hard to have an intimate relationship with anyone cause of the pain and other side effects.
7614	I was told at least 5 times I had a femoral hernia by my own doctor, 2 upper G.I. surgeons, ultrasound scans, x-rays. I consented to a femoral repair yet I woke up to find I had a "direct" inguinal hernia repair (this shocked me and still does) with mesh.....I still have pain and cannot walk far, my doctor was in as much shock as me as NO "direct hernia" was ever found on ultrasound, so I have just gone through more tests to be told yes you still have a femoral hernia and need it repairing ASAP.....
2639	Helped me get back to work in a different profession. Now 18 years A&E ambulance service.
4260	He has had periodic moderate to severe discomfort since the surgery 3 years ago. It has affected his ability to undertake exercise.
9465	I've not seen friends in months as I cannot drive, hardly walk, put on weight, getting depressed and caused other problems due to no sex life.
1531	It has had a severe impact on my quality of life, my mobility is affected, my mental health from living in constant pain, I can't sit or stand for long periods or walk far so don't go out much. I am no longer able to work so our family income is severely affected and I am no longer able to have sex.
7161	Improved level of movement, reduction in pain although cannot ache in a different way.
0750	My life & my health have been horrendous I can't live with this constant pain.
1580	Was told after surgery the hernia was larger than anticipated. General improvement in lifestyle until after a year or so started suffering pain in the hernia region.
1427	It has made a significant difference to my life. 14 years on I have had very few issues. Mainly a little numbness on occasion where I was operated and some minor discomfort probably on 2 or 3 occasions throughout the whole 14 years.
5187	I have terrible pain and no quality of life.
6563	Absolutely none. I have returned to living life as I did before, with no awareness of any problem in that area.
9894	None.
7985	A much better quality of life.

7810	I have had no impact with my family life after the operation. I may be one of the lucky ones. Back doing everything I did before the operation.
2612	Nothing adverse.
8927	My life is miserable I can't concentrate at times. I sometimes have extreme anxiety. I'm always in pain. I am not sexually active because it hurts during an erection. I get some relief from exercise but it is no way to live.
6846	Now everything is fine and I can lift weights and at 67 years of age count myself as reasonably fit.
8240	Successful outcome. No more pain or discomfort when the wound had healed properly which had a positive effect on my quality of health and well-being.
7180	I am fine now, so apart from the scar and a slow recovery after operation side effects, I think the surgery has been a success. I am interested in this survey and have been thinking about it because of recent publicity on Victoria Derbyshire TV and Sling the Mesh campaign. That is how I found out about the survey, but feel I should have been contacted as I am only one of 600 worldwide who was on the trial, and TV was pointing out there should have been a register kept of patients for future reference.
1278	Difficult to measure the impact of having the repair. I would consider that my quality of life as completely normal now. If I had not had a repair, then I am convinced that my quality of life would be very much reduced. It would not have got better by itself, only worse.
7545	Perfect repair. Allowed me to keep fit and function as husband, grandfather, uncle etc. Also enabled me to function in the community. I play keyboard in a band, often for dementia support groups. That involved humphing gear around. I would have had to stop that, but for the repair. Now I can do everything.
5436	100% improvement.
5068	Great, massive improvement, especially as I am mesh free. [non-mesh repair]
5461	I don't know how my family put up with me I was suicidal for 16 years nearly. Never had the guts to do anything. We were lucky that we owned our house. I could not work I was bed down for the first two years till they put me on opioids. Everything was an effort. If we went out to dinner I'd be standing behind my chair because I couldn't sit. I stayed home as often as I could. Lost our friends. We didn't get asked to go out anymore. I lost my life.
8531	Brilliant. Day case. Few days recovery. No further symptoms.
0253	After the surgery I was out of action for 6 weeks (the recommended time I was told). I was told not to lift or strain myself at all to which I did. The 8th week I was in serious pain where it felt when I walked there was stabbing sharp pain in my groin and when I returned to A&E I had a check-up and was sent for a ultrasound, I was told it was where the scar tissue had attached to the nerves. I was told that nothing could be done and that I should rest more and it would go away eventually. It did after another 3 weeks but I was in serious pain. I still have pain and discomfort to this day, if I am active then the next day I have discomfort, after intercourse, fishing and certain other movements. I have an inguinal hernia on the left side which I have not had repaired because of the first experience.
2666	I got my life back.

3721	Couldn't do much for 2 weeks after surgery but fine after that. I'm just really careful now with everything I do and probably not as active with keeping fit as I used to be.
1699	Very little apart from the recovery phase, I was well looked after at home as my wife is a retired Consultant Gynaecologist used to dealing with operations in that area of the human anatomy.
4843	Live alone so nothing on family. Was off work as above.
9875	None.
6946	Very little.
7486	My wife is now the main income source for the house. My quality of life is slowly improving but I'm a shadow of what I could do before.
4874	None.

## Benefits expected from hernia repair surgery and complications that caused concern (36 responses)

ID	Comment
5954	Didn't know or consent to hernia mesh.
6196	I was told nothing only next morning I was told I had mesh implanted and I would be staying in hospital longer than normal for some reason I don't know of. I thought after surgery I would be back cycling but I couldn't do that after surgery.
7614	I expected to at least be pain free but now I am left with a horrible mesh where it shouldn't be and still needing the original femoral hernia repaired.....Now I fear allowing this surgery to go ahead as I have lost faith in my local hospital.
2639	It was going to get me back on my feet again and be able to work and provide for my family again!
9465	I expected to have a little pain once in a while after operation as it is expected but was told nothing of any side effects except that there may be odd complications. My surgeon said I could lose a testicle or one could shrink, I could become infertile. He did not explain any other complications.
1531	I expected that it was going to be a routine common operation with little or no complications and I would be back to normal in a couple of weeks.
7161	New job meant I needed to be fit for lifting etc., which before operation I was struggling to do.
0750	I fully expected to be back to 100% once repair had been completed - instead I'm left miserable & in horrible pain.
1580	Expected a routine procedure, which it was. Spoke (as mentioned above) to surgeon re mesh issues, but was reassured.
1427	I expected to return to normal living and little or no discomfort. The main concerns for me were around the anaesthetic and the potential risks were described in detail.
5187	Most patients state that they thought that all their symptoms would go and that they would be pain free.

	[Healthcare Staff]
8400	I was told it was a routine operation and would be OK in 6 weeks.
6563	The benefits expected were to return to how things had been before I tore my hernia. They have been realised. Naturally, I was concerned about complications but the surgeon's explanation reassured me how minimal they were.
9894	Expected to remove the swellings - this was done. I had concerns about the mesh but these were alleviated after discussion with the surgeon.
7985	To be pain free: there were no complications.
7810	I had an unsightly lump in my groin area that was giving me some discomfort so was looking to have the lump repaired to give me some relief. As with any operation the surgeon explained a few scenarios that could happen but I was happy to proceed.
2612	Consultant advised me that many people just ignored it, but it could lead to problems. Had the operations on her advice and have been okay ever since.
8927	I thought it was normal common surgery I was told have it while you are young by surgeon. I expected they would fix it and I would be ok. Even told by first surgeon she never had a case with any issues. I was initially concerned about mesh because I saw commercials on TV but was told right away by surgeon not to worry that mesh was only affecting women.
6846	Improved health generally and no more discomfort. Not concerned about any complications.
8240	Pure and simple to repair my hernia and get back to normal. At the time no complications or concerns as I was under the impression it was a straight forward operation up until concerns were raised about the use of mesh and possible problems resulting from this material.
7180	I had to have the surgery as my inguinal hernia was often painful but I wasn't so worried about the lump. I knew the wound could get infected and painful and the lump could come back, but I didn't realise I could get an infected seroma which I had. It wasn't mentioned in the trial document, I've just checked.
1278	The benefits and complications were explained to me before the surgery. I expected the problem to be repaired to allow normal physical activity to be possible. It was explained that the area below the repair may become numb. To a certain extent this is the case, but from time-to-time I experience mild shooting pain. I put this down to a trapped nerve. It is not a problem and it does not happen very often.
7545	Hoped for an effective repair. Was advised before the op it might not work and could recur, but you're always told that and the surgeon seemed confident. I was unaware of any possible mesh issue.
5436	I asked my GP for laparoscopic referral in order to return to work more quickly and asked for both sides to be done in one session.
5068	I wanted to be back to my old self. By using Desarda technique I was confident in being free of mesh complications but I did have a little concern about infection and spermatic cord damage, which proved baseless. [non-mesh repair]

5461	Doctor told me how good he was. Was not concerned at all. When I went back to him. It was like I gone back to see doctor Jekyll. He was a complete mongrel.
8531	Reduce pain. Eliminate hernia. Main concern was risk of long term pain.
0253	The benefits I was led to believe that it would be a quick repair and recovery and that it wouldn't pain if I sneezed anymore. Complications with the meds after surgery making me constipated which didn't help situation. Also the nerve issue and the fact that I still have huge discomfort and some days have a lot of pain.
2666	I hoped I could get back to normal and I did.
3721	To take away the pain and let me get back to my normal life. I was worried it wouldn't work and what support I would get after surgery.
1699	Apart from removing the problem of the hernia, none.
4843	Worried if it didn't work that my sick pay at work would run out so needed it to work.
9875	Would get back to normal.
6946	Get back to normal. Worried when I could ride my bike again.
7486	I thought it was a straightforward operation, I never thought it would impact my life so much.
4874	Repair it.

### Chronic pain (>3 months): experience and impact (37 responses)

ID	Comment
5954	Had to have injections into back for pain.
6196	7 months after surgery pain started and have it daily for last 5 years.
7614	YES.....the pain is 24/7 and I do not have my life back to a bit of normality yet, I can not only see the mesh but I feel it scrunching up where it was implanted.....pain is horrible.
2639	Hardly any pain from groin but did suffer severe bruising and swelling from the active bladder.
4260	Yes, see above.
9465	Yes, constant pain in groin area, no sex life, unable to hardly walk, unable to bend over, not pick things up and not able to work or sleep. It's now been 5 months since operation and surgeon team keep coming up with different results. No one seems to know what's going on.
1531	Yes. From the outset I have suffered chronic pain, required strong addictive painkillers of various types over the years with an associated depression surrounding the constant pain which is gradually grinding me down.
7161	No, just mild ache now and then.
0750	Yes... see previous comments.
1580	No. Minimal pain after procedure (though might have been less if area had been shaved).
1427	No.
5187	No.
8400	Yes since Jan 2018 and have no life.
6563	Absolutely not. See above.

9894	No pain. Just a little initial discomfort and a day or so of bowel issues!
7985	Did not experience chronic pain after surgery.
7810	I experienced no pain even on the day of the operation. I walked out of the ward unaided one hour after my operation and went home after two hours.
2612	No - just about 10 days. It was bad.... but the GP said it was normal. Now, I don't even know the surgical nets are there.
8927	For over 1 1/2 years I have been in pain. Exercising and physical therapy help. I have no idea where my life is going I am sad at times and fine at times but the pain always reminds me of a decision I will regret the rest of my life.
6846	No pain at all.
8240	No.
7180	No.
1278	Immediately after surgery I had acute pain when I walked forward. I was able to walk sideways, so could get about the house. My GP gave me some pain-killers and the pain subsided after a couple of weeks.
7545	No. No significant post-op pain.
5436	No pain or problems in 5 years.
5068	No, pain free after two weeks. [non-mesh repair]
5461	I had the operations in 2003. I am still in chronic pain. Affect me before I went to bed at night I used to do it on the floor I'll pray to God that I wouldn't wake up the next morning. I must have done this hundreds of times. Death to me is probably my only time I will be out of pain. It is not a little pain that I have.
8531	No.
0253	Yes the pain was dreadful and yes 13 years later I still have pain after certain days. I stopped certain activities and also cut back on others. You learn to live with the pain and some circumstances you just need to bite the bullet and carry one.
2666	No.
3721	Was bad for a month after but faded, I had an issue with my wound being infected but it cleared up after I was given antibiotics.
1699	None experienced.
4843	It was sore for 6 months but got back to work and normal life after 2 months but took the full 6 months for pain to totally go.
9875	No.
6946	No.
7486	Yes.
4874	No.

## General comments (32 responses)

ID	Comment
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5954	Try get it repaired without mesh. I have developed a hernia in my stomach from surgery. No way mesh been put in.
6196	Give proper consent and explain clearly the pros and cons of mesh. Explain it is never tested on humans not even the new mesh.
7614	I'm in the south west of England, all I ask is honesty and a clear explanation of what will be put in your body I was never told it would be mesh repair.
2639	Can't think of anything just now.
4260	Mesh inserts can be felt at times & my partner does not feel like they were a good option for repair.
9465	Make sure doctors and surgeons tell people all options they can have about the surgery also make surgeons tell all complications to patients as I'd been explained very little plus lied to about what was available to me.
1531	Offer an alternative to implanting polypropylene mesh.
0750	Yes... train your surgeons to carry out hernia repairs without using mesh... like they did in the days before polypropylene mesh... the stuff they use in carpets. No wonder we're all a mess.
1580	Consider if current mesh is optimal method. Could any other "tube" be used to contain and supporting the intestines? And of course, the patients should have full written information on the latest advice in clear language.
1427	Alerting patients to potential factors to consider such as impact on testicle which I hadn't considered or been informed about.
5187	Make the patients aware that their symptoms may be worse post-operatively and to really consider if they really need an operation. I am aware that when I scan patients and discover a hernia, the vast majority of patients seem to want an operation even if they are pain free with, with a reducible bowel free hernia. I think it should be emphasised that they may well feel worse post operation. [Healthcare Staff]
8400	Do not use mesh.
6563	Not that I can think of. It was a great tribute to the NHS and the service it gives to its patients.
9894	Reassure patients that the mesh used is different from that used for female vaginal mesh repair.
7985	No further comment.
7810	Prior to having a hernia operation you should be as fit as possible to help with your recovery. Fitness is a great healer.
2612	Maybe give a handout/leaflet when you are discharged.
8927	I don't honestly know if mesh affects everyone, but I know it affected me. I am a thin person and one thing my first surgeon told me is that I don't have a lot of fat that's why it hurts me more. I don't know if that is true but if it is I would say mesh should not be used on thin men. I also have read inguinal hernia repairs with mesh have higher pain rates in men. Maybe they shouldn't use mesh in men for inguinal hernia repairs especially for thin men. I don't know about anyone else but it's made my life miserable.

2653	Recurrence rates. Chronic groin pain. Return to normal activities. Standard of the operation/surgical expertise.
8240	Raising awareness and understanding of this particular operation.
7180	I did not receive the results of the clinical trial I was on. I thought I should have. Some years later I googled the mesh manufacturer. It seems the share price of the company was most important depending on interim results of the trial. Eventually I saw the trial results five years later as a friend was able to access the British Journal of Surgery. So I was a statistic in that I was one in twelve out of 600 who got an infected seroma. But as the Victoria Derbyshire programme pointed out, maybe I should have been worried about infected mesh long term, and I think my follow-up and long term checks was lacking.
1278	I would recommend that the repair is done as soon as possible after discovery.
5436	In my experience it is safe and well worth doing. I should have asked for an operation 15 years previously and looked after my own health as a GP!
5068	Train your surgeons in doing Desarda technique. [non-mesh repair]
5461	If something goes wrong. Doctors have to be a bit more understanding. I was sent from psychiatrist to psychiatrist. They were all trying to tell me it was in my head. Maybe they should learn how to repair hernias the old way. The doctor that removed my mesh everyone said the way that he sewed me up is stronger than having a mesh put in.
8531	Day case. Shouldice repair?
0253	I didn't have keyhole surgery but I'm guessing that is the way forward now. Better products or way of strengthening wall.
3721	I wasn't given a choice about having mesh or not. I'm not sure if I had been given a choice what I would of done. You rely on the doctor to do what is best.
1699	If I had not paid for the private treatment I would have imposed a financial burden on the NHS, I thought it was unfair that half the cost of having it done privately was paid to the hospital who ought to have done the operation weeks earlier. I understand that private treatment involves extra staff having to be provided by the hospital on the day of the operation, but in cases where the patient is relieving the pressure on the system should they have to pay such a high sum?
4843	To be clear that it is a serious operation and you need to be prepared for all eventualities.
9875	Make sure your GP knows you had the operation.
7486	Tell people about how bad mesh is!

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or email [contactpublicinvolvement.his@nhs.net](mailto:contactpublicinvolvement.his@nhs.net)

Healthcare Improvement Scotland  
Scottish Health Technologies Group

Edinburgh Office  
Gyle Square  
1 South Gyle Crescent  
Edinburgh  
EH12 9EB

0131 623 4300

Glasgow Office  
Delta House  
50 West Nile Street  
Glasgow  
G1 2NP

0141 225 6999

[www.healthcareimprovementscotland.org](http://www.healthcareimprovementscotland.org)