

Hernia repair

Public engagement survey: feedback report

Background

The Scottish Health Technologies Group (SHTG) conducted a survey to gather the views and experiences of patients and the public on hernia repair in Scotland. The survey ran for 5 weeks and was carried out in addition to SHTG's review of the published literature on surgical mesh for the elective repair of primary and incisional hernias. The findings of the survey informed SHTG's Recommendation on the use of mesh for hernia repair.

The online survey was distributed and promoted through the Healthcare Improvement Scotland (HIS) website and networks, social media platforms, patient organisations, NHS health boards, and Scottish Government contacts. Assistance was offered to anyone requesting support to take part in the survey, for example, completing it over the telephone with a contact at HIS or submitting a postal survey.

This report summarises the key findings and themes identified following analysis of the survey responses. All the comments received in response to the survey are available in the [appendix published alongside this report](#). The comments have been anonymised.

A [similar summary report](#) is available for a previous public engagement exercise on inguinal hernia repair in men in 2019.

About the survey participants

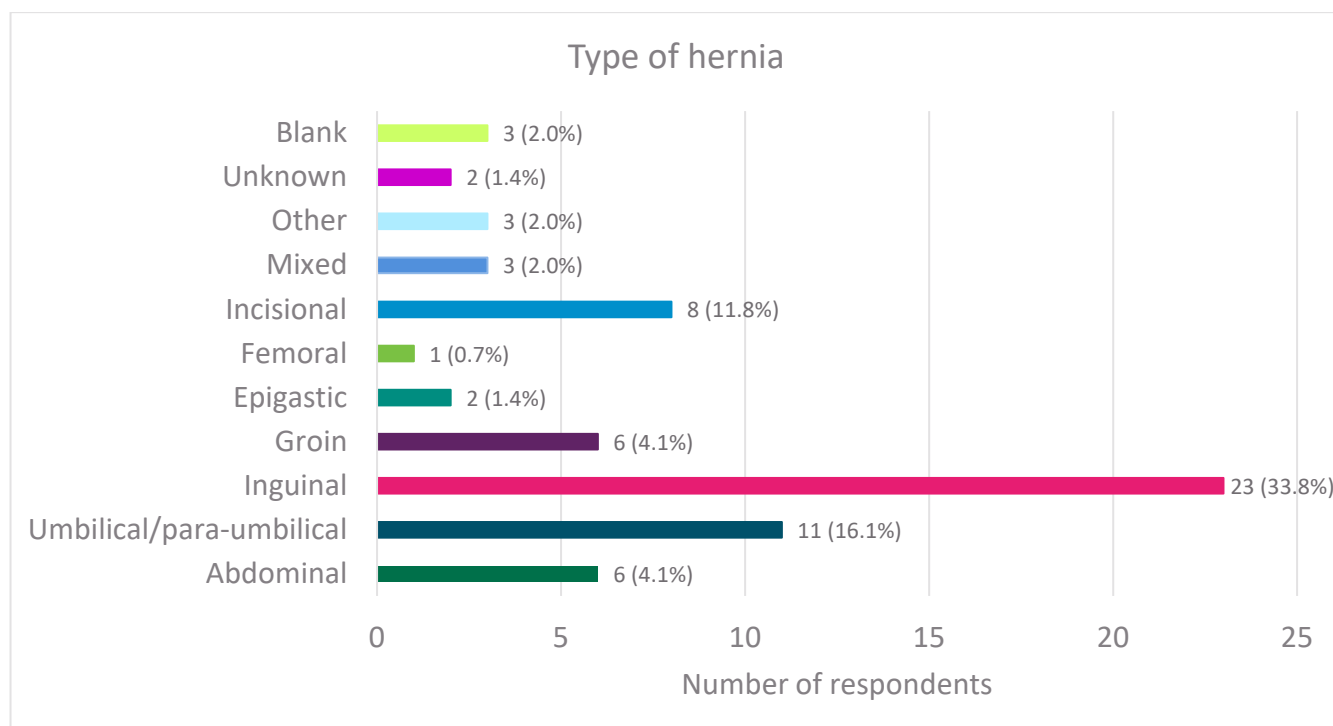
Sixty-eight responses were received from a range of stakeholders:

- sixty-one patients or members of the public
- two people responding on behalf of a partner, family member or friend
- two healthcare staff/volunteers
- two responses on behalf of an organisation (Sling the Mesh; Deaf Scotland), and
- one other (mother of someone who had a negative mesh experience).

Three responses were excluded from this report because they related to pelvic organ prolapse (two responses) or a hiatus hernia (one response). One of the included responses was from a pathologist with experience of examining samples of mesh removed from patients with a hernia repair or other pelvic surgery.

The most common type of hernia experienced by survey respondents was an inguinal hernia (33.8%, n=23), followed by umbilical or para-umbilical hernias (16.1%, n=11), and incisional hernias (11.8%, n=8) (*Figure 1*). This reflects the epidemiological evidence reported in the SHTG Recommendation. Other hernias consisted of a Spigelian hernia, a lumbar hernia, and a parastomal hernia.

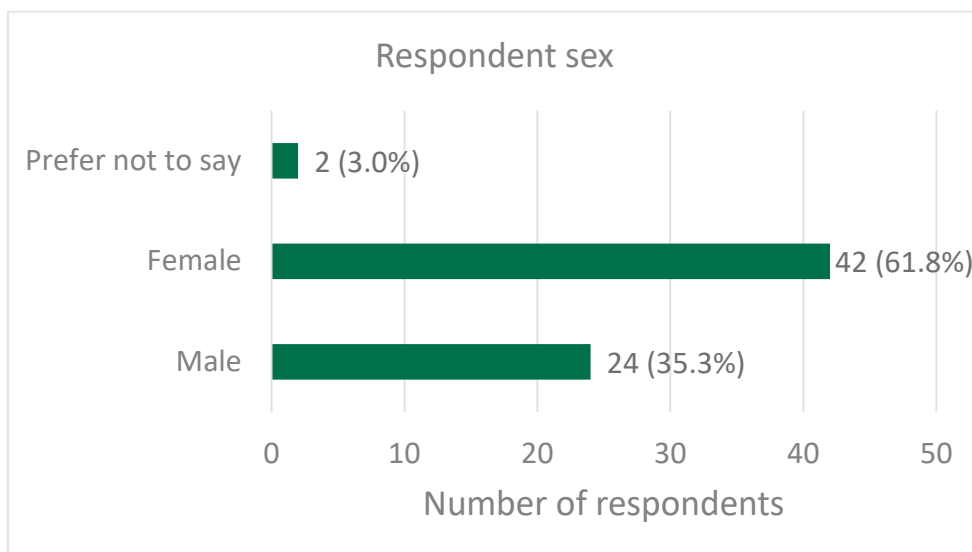
Figure 1: Type of hernia experienced by survey respondents



The majority of respondents were female (61.8%, n=42, *Figure 2*), which is at odds with the predominance of inguinal hernia repairs in the general population as this is a hernia that occurs more commonly in men. Sixty-four respondents (97.0%) stated they did not consider

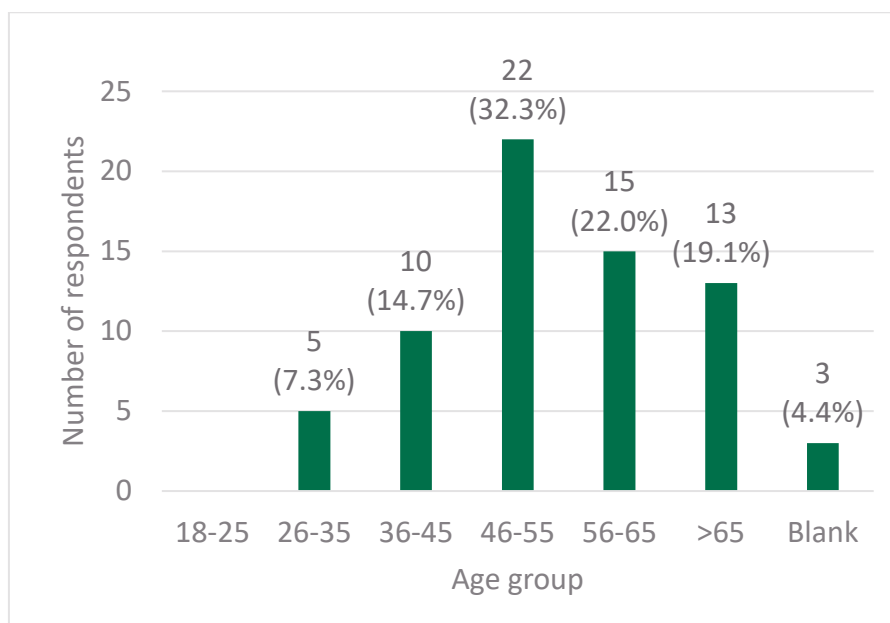
themselves a trans person, two people (3.0%) preferred not to say, and two did not reply to this question.

Figure 2: Survey respondent sex



Responses were received from patients in all age groups, except people aged 18–25 (Figure 3), reflecting that the incidence of most hernias increases with age.

Figure 3: Age distribution of survey respondents



Almost half the survey respondents stated they had no religion or beliefs (48.5%, n=33) and 38.2% (n=26) stated they were Christian. No survey participants identified as Buddhist, Hindu, Jewish, Muslim, or Sikh.

Forty-seven people (69.1%) responding to the survey considered themselves to have a disability or health condition.

Owing to a flaw in the survey design for the question on ethnic group, we were unable to interpret the data from respondents on this characteristic.

Summary of responses

Question: how did having a hernia affect your life?

Sixty-five people (95.6%) responded to this question. Based on the comments received it was clear that some people were describing the effects of hernia repair, not the effects of the hernia itself. These responses were considered under the subsequent question on hernia repair. Six people (9.2%) reported that their hernia had no impact on daily life. Other respondents identified the following ways that having a hernia affected them:

- mild or intense pain and discomfort on a daily basis
- reduced ability to engage in everyday activities, including exercising and going to work
- concerns about the appearance of the hernia that affected confidence and self-esteem
- anxiety or worry about the hernia and the possibility of it becoming strangulated
- mobility issues, including limited ability to lift heavy objects, and
- altered bowel function.

The selection of quotes below illustrate the impact of living with a hernia:

- 'The hernia was uncomfortable and very visible. Clothes didn't fit, I felt very conscious of it, affected my social life and general confidence.' *Female respondent, age 46–55, epigastric hernia*
- 'Couldn't lift anything, problems with bending, pain in the groin.' *Male respondent, age 56–65, groin hernia*
- '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.' *Female respondent, age 46–55, incisional hernia*
- '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.' *Male respondent, age 46–55, inguinal hernia*

Question: please tell us about your experience of having a hernia repair

Three survey respondents (4.4%) described positive experiences of hernia repair and 30 (44.1%) reported having a negative experience. Twenty-nine people (42.6%) gave a neutral response or provided experiences that were both positive and negative. Four people (5.9%) who had non-mesh (suture) repairs or treated their hernia using dietary changes and support belts, reported neutral experiences. Negative experiences described by survey participants include chronic pain, a lack of information about mesh prior to surgery, and foreign body reactions.

- '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. Manageable pain was experienced with little or no painkillers used.' *Male respondent, unknown age, umbilical hernia*
- 'Surgical mesh was used for my hernia repair. After the operation I got stabbing pain 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.' *Female respondent, age >65, inguinal hernia*
- '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 approximately) 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.' *Female respondent, age 26–37, umbilical hernia*
- '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.' *Male respondent, age >65, inguinal hernia*
- '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.' *Female respondent, age >65, inguinal hernia*

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

Sixty-five respondents (95.6%) described a variety of positive and negative effects of hernia repair surgery. Themes identified in these responses include:

- severe chronic pain affecting all aspects of life, including quality of life, social life, child rearing, and employment
- inability to perform tasks of daily living such as washing, housework, shopping, and driving
- effects on mental health including depression, anxiety, anger, stress, suicidal ideation, and low self-esteem
- impact on family and partners who become long-term carers
- breakdown or strain on intimate relationships due to increased need for care and reduced sex life
- reduced mobility, including an inability to bend or sit and being unable to exercise
- postoperative complications or development of illnesses after surgery, and
- sensory changes in the area of the hernia repair due to nerve damage.

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

- '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.' *Female respondent, age 36–45, abdominal hernia*
- '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.' *Female respondent, age 46–55, inguinal hernia*
- '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.' *Male respondent, age >65, inguinal hernia*
- '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 able to have a child. I also need to self fund the removal operation.' *Female respondent, age 26–35, epigastric hernia*
- 'The mesh repair is the worst thing that has happened to me in my lifetime. This mesh implant has impacted on everything I do. Pain, mobility, stress, sex life, enjoyment, social life, work life and of course sleep.' *Male respondent, age 36–45, inguinal hernia*

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?

Forty-six people (67.6%) identified one or more benefits they expected to gain from having hernia surgery. These included a return to 'normal' life, being pain-free, preventing future complications such as strangulation, and no longer having the hernia, swelling or symptoms.

Nineteen people (27.9%) noted one or more complications of concern to them. The most common concerns expressed among this group of respondents related to the use of mesh and general anaesthesia. Other complications mentioned by respondents included any surgical complication, chronic pain, dying during surgery, having mesh placed near the bowel, bleeding, and mesh rejection or inflammation.

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

Forty-seven people (69.1%) reported experiencing chronic pain lasting more than 3 months, and in 25 patients (53.2%) for several years, after hernia surgery. Thirteen people (19.1%) had not experienced chronic pain. Below are a selection of survey responses on chronic pain following hernia repair surgery.

- 'I have had chronic pain for 8 years and it affects my life daily.' *Female respondent, age 46–55, abdominal hernia*
- 'I've 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.' *Female respondent, age 56–65, incisional hernia*
- '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.' *Male respondent, age 46–55, inguinal hernia*
- 'Yes... 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.' *Female respondent, age 26–35, umbilical hernia*

Question: did your doctor discuss alternative methods of managing your hernia?

Eighty-five percent (n=58) of respondents said they could not remember having a discussion with their clinician about alternative methods of hernia management. Only four people (6.1%) responded that they had discussed treatment options with their doctor.

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

Thirty-one respondents (45.6%) stated they received information about hernia repair and/or surgical mesh prior to their procedure. Twenty-nine people (42.6%) stated they had received no information or very limited information. Two respondents (2.9%) were unable to recall how much information they received.

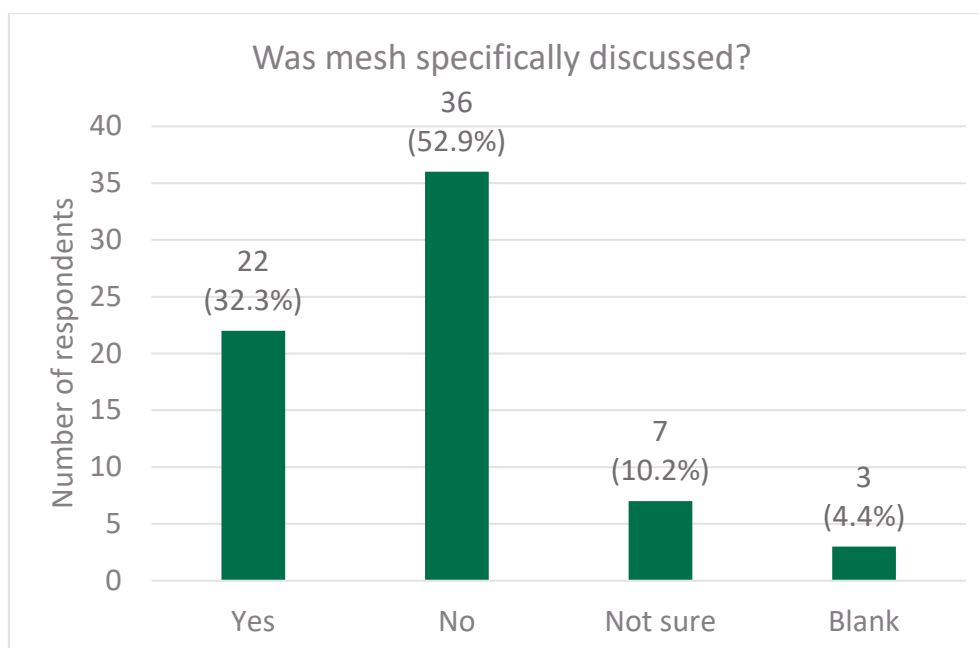
Patients who received information, either verbally or in the form of leaflets, said the information covered some or all of the following:

- mesh-based hernia repair was a safe, routine operation
- use of mesh to repair hernias was the gold standard
- repairing a hernia using mesh would prevent the hernia recurring and relieve symptoms
- there was a very low risk of complications from hernia repair using mesh
- potential complications of hernia repair surgery included bleeding, infection, and chronic pain
- standard information about anaesthesia risks and common surgical complications
- the mesh used to repair hernias was not the same as that used for pelvic organ prolapse [this is incorrect] and patients should not believe the 'scare stories' about mesh
- there is no alternative to mesh-based repair of hernias
- patients should rest and avoid lifting heavy objects for a period after surgery, and
- recovery time would be approximately 2 weeks, 3 weeks, 4 weeks, or 6 weeks.

Question: was the use of surgical mesh for hernia repair specifically discussed with you prior to the procedure?

Over half (52.9%, n=36) of the respondents did not remember discussing the use of mesh in their hernia repair, 32.3% (n=22) did discuss mesh prior to surgery, and 10.2% (n=7) were unsure whether mesh had been discussed or not (*Figure 4*).

Figure 4: Mesh discussion with clinicians



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

Sixty-one people (89.7%) responded to this question. Thirty-six (59.0%) had a follow-up appointment with their surgical team, 19 (31.1%) did not have any follow-up appointments, and six people (9.8%) were unclear or could not remember whether they had any follow-up appointments. Of the people who did have a follow-up appointment, 19 (52.7%) did not find these appointments helpful, five (13.9%) found the appointment useful, and 12 (33.3%) responses were unclear as to whether the respondent had found their appointment useful or not.

- 'Yes, very helpful to put mind at ease and draw a line under it.' Male respondent, age 46–55, groin hernia
- '[...] 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.' Male respondent, age >65, inguinal hernia
- 'Yes. My surgeon said pain post operation was a factor. He was completely useless at understanding me and my pain.' Male respondent, age 46–55, inguinal hernia
- '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.' Male respondent, age 56–65, other (parastomal) hernia
- 'Yes I did and said about the pain I was in and told it would calm down.' Female respondent, age 46–55, incisional hernia

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

Fifty-seven people (83.8%) submitted general comments that are summarised below:

- do not use mesh for hernia repair
- people should be offered alternatives to mesh repair and training needs to be provided so that more surgeons in Scotland can offer non-mesh repairs
- improved informed consent is needed for mesh-based procedures, including providing more information about the mesh being used and potential long-term complications, such as chronic pain
- surgeon training needs to be provided to support removal of mesh in patients who experience long-term complications
- clinicians need to acknowledge long-term complications and chronic pain in some patients after mesh-based hernia repair, and
- provide patient information in accessible formats, including British Sign Language.

Limitations

This summary report (alongside the full survey responses) was considered by the SHTG Council when formulating SHTG's Recommendation for NHSScotland on the use of surgical mesh for hernia repair. The Council were informed of the following limitations of the public engagement exercise:

- respondents were self-selecting and may therefore represent a biased sample
- the respondents are not considered representative of all patients who have undergone hernia repair in Scotland, and
- responses were received from 68 people, which is a small sample compared with approximately 6,500 hernia repair surgeries in Scotland each year.

Despite these limitations, the lived experiences of survey respondents are valuable for adding depth and colour to our understanding of the Scottish public's experiences of hernia repair and mesh. In particular, lived experiences help us to understand what it is like for people who have had a negative experience of hernia repair using mesh. Complications from hernia mesh may not be common, but insight into the experiences of those who do have a negative experience is highly valued.

Acknowledgements

SHTG would like to take the opportunity to thank everyone who responded to this engagement exercise. We would also like to thank everyone who assisted with promoting and disseminating the survey across Scotland.

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