

## Health, Social Care and Sport Committee

# Complex Mesh Surgical Service – Summary of evidence

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# 1. Introduction

As a follow-up to the Health, Social Care and Sport Committee's scrutiny of the [Transvaginal Mesh Removal \(Cost Reimbursement\) \(Scotland\) Bill](#), the Committee agreed to review how the Complex Mesh Surgical Service supports women in Scotland who have experience of transvaginal mesh.

The Committee issued a call for views asking about women's experiences of the [Complex Mesh Surgical Service \(CMSS\), hosted by NHS Greater Glasgow and Clyde](#), responses to which will be used to inform its formal scrutiny. 75 women responded to the call for views, which was open between 10 February and 24 March 2023.

The purpose of this [call for views](#) was expressly to gain an understanding of individuals' experiences with the Complex Mesh Surgical Service (CMSS), the support it provides and decision-making regarding mesh removal or other treatments. The survey contained questions about the following areas:

1. Symptoms
2. Referral and access to the service and treatment options
3. Mesh removal surgery
4. Support following surgery
5. Issues and more information

In the call for views, many women recounted the negative experiences they have had since having TVM fitted, both in terms of the physical and mental impact. Some recounted the lack of support received from NHS services over many years.

## Summary of main issues

The overall conclusion from the open text responses to the survey is of a service that does not yet have a clear identity, clear referral pathways nor a full range of treatment and support options for the women referred to it.

Women have difficulty communicating with the CMSS and communication about options, shared care arrangements and appointments. Advice about non-surgical issues, such as pain management and ongoing severe health issues, appears to be hard to access for many women who are in contact with the service.

It is not clear how well-developed shared decision-making is in relation to the service and treatment options. It is clear however, that many of the responses come from women who have suffered life-changing symptoms for many years and whose trust in the many medical professionals they have encountered is all but completely depleted. This long-term, negative experience will, unsurprisingly, colour their views of the current service.

## 2. Summary of quantitative responses

This section summarises the responses for the multiple choice questions in the survey, where women were asked for yes/no answers, or where only a short response was required, such as how they were referred into the service.

Some questions only received a very few responses and have not been tabulated in this section because they would not be representative. However, where a mix of multiple choice and follow-up, open-ended questions were used, the narrative responses have been analysed under the qualitative themes in the later sections.

The call for views asked 33 questions, a mix of multiple choice and open text.

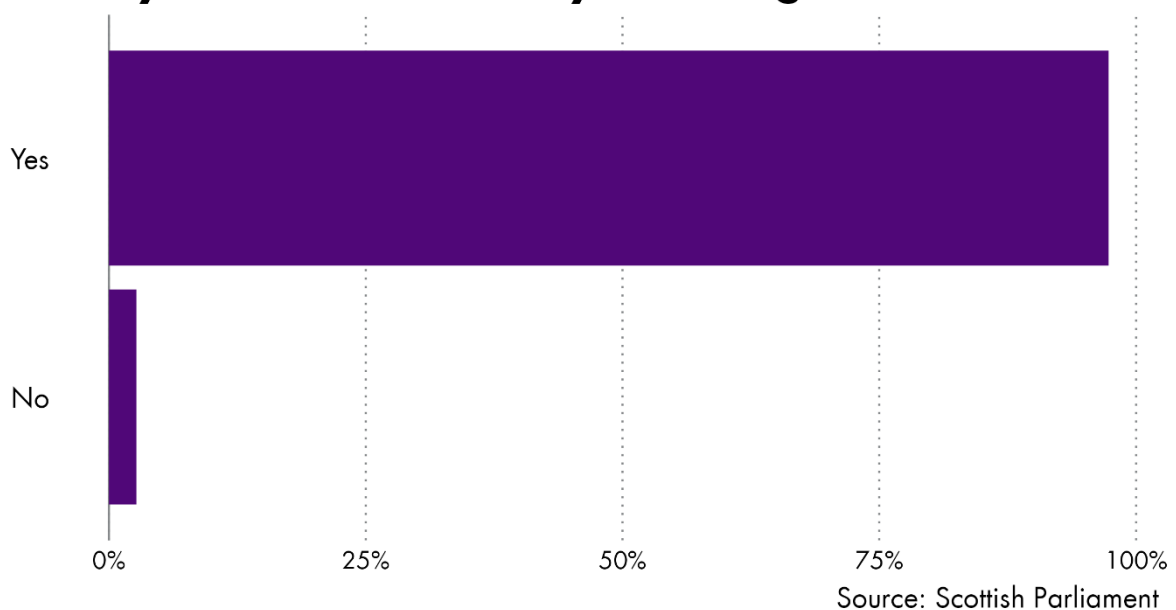
The charts below illustrate some of the responses, where at least 50 (66%) women answered.

### Symptoms and primary care support

#### Have you been affected by transvaginal mesh?

- 73 of the 75 women had been affected by transvaginal mesh (TVM)

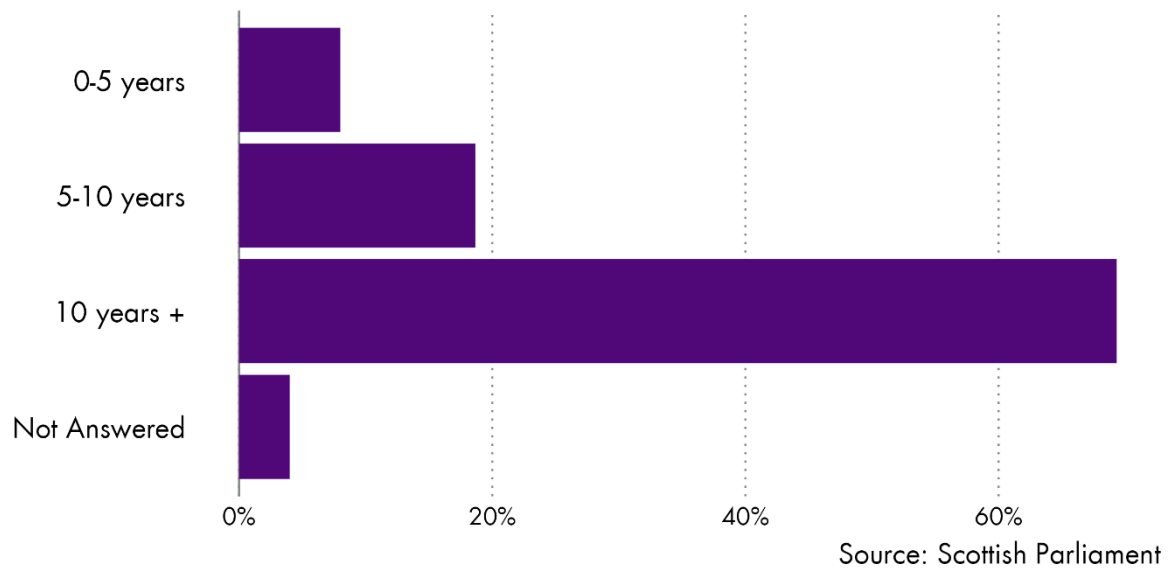
#### Have you been affected by transvaginal mesh?



#### How long have you had symptoms you believe were associated with (TV) Mesh?

- 52 (69%) have been affected for more than 10 years, 14 for 5-10 years and 6 for 0-5 years

## How long have you had symptoms you believe were associated with (TV) Mesh?



## Referral to CMSS

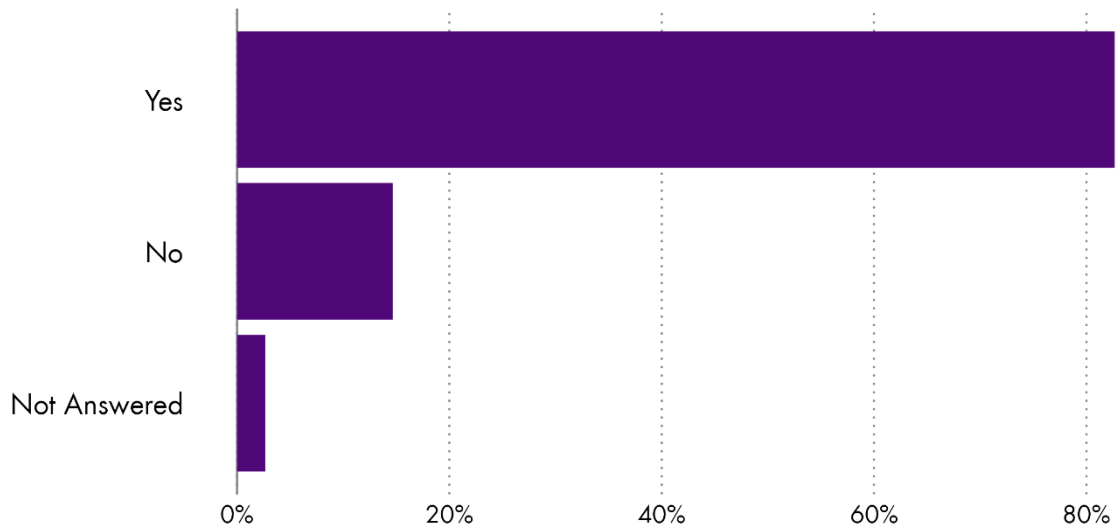
### Have you been referred to the Complex Mesh Surgical Service (CMSS) in Glasgow?

- 62 of the women had been referred to the CMSS, 11 had not and 2 didn't answer

### If not, have you requested a referral to the Complex Mesh Surgical Service in Glasgow, or would like to be referred?

- 6 answered 'yes', and 6 answered 'no'

## Have you been referred to the Complex Mesh Surgical Service (CMSS) in Glasgow?



Source: Scottish Parliament

### When were you referred to the service? (open-text)

- Most women have been referred since 2020, however, a number state their engagement with the service dates from 2013 - 2016

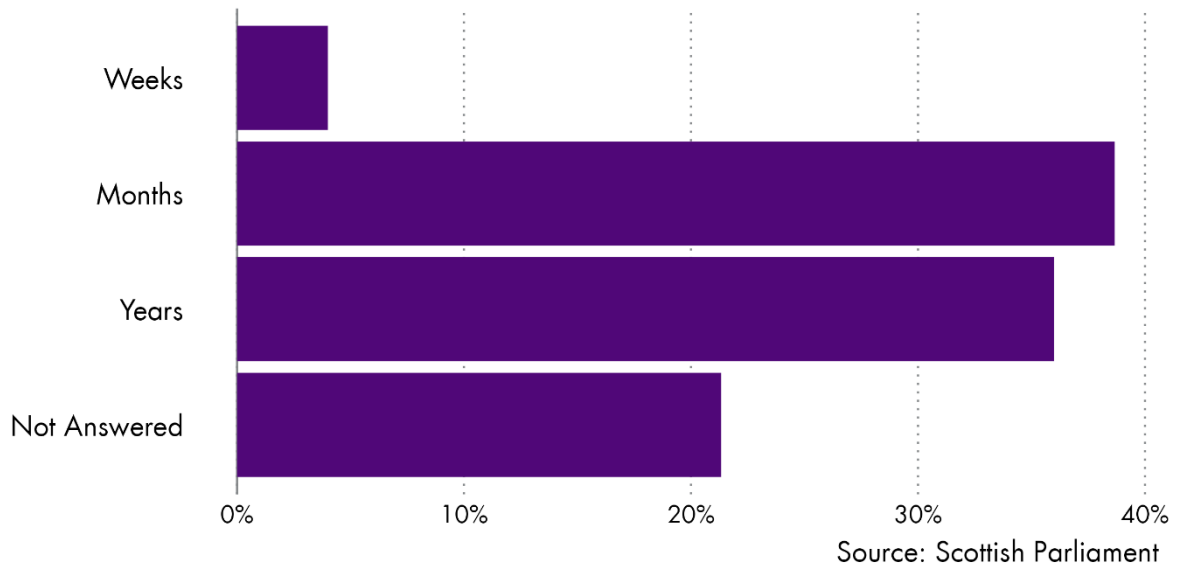
### Who referred you to the service? (open text)

- 18 of the 62 women referred had been referred by their GP, the remainder were referred by consultants from different specialties: urogynaecology, colorectal, obstetrics/gynaecology, urology

### How long did you have to wait for an appointment with the CMSS since referral?

- 3 women had waited weeks, 29 had waited a number of months and 27 had waited years

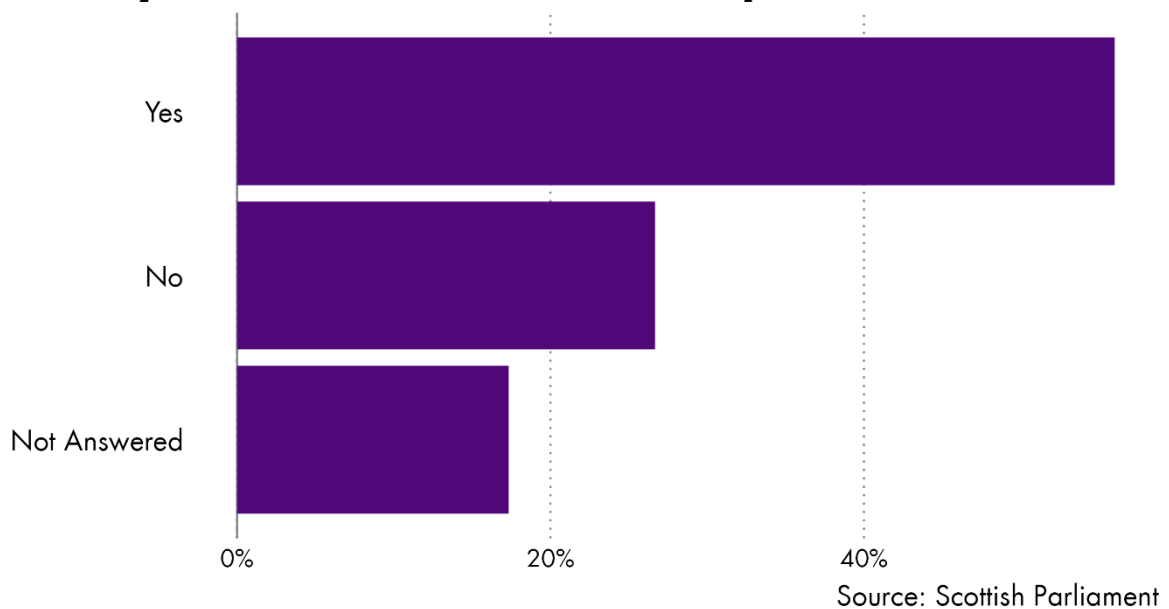
## How long did you have to wait for an appointment with the CMSS since referral?



## Have you seen a member of the specialist team?

- All women (62) referred to the service answered this question. 42 have seen a member of the team, 20 say they have not.

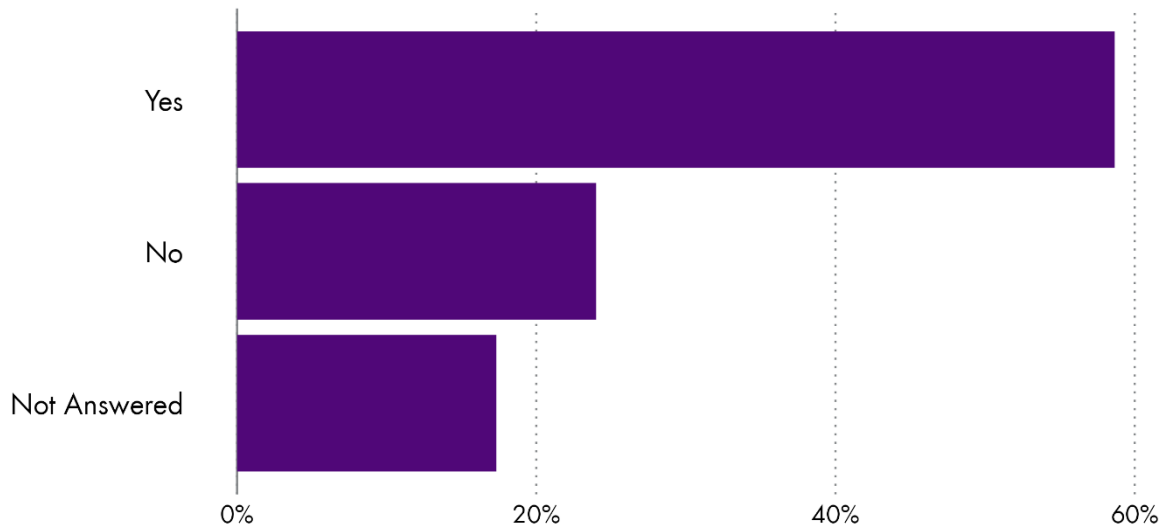
## Have you seen a member of the specialist team?



## Have you discussed your symptoms and treatment options with the team?

- All women (62) referred to the service answered this question. 44 had discussed treatment options with someone associated with the team, 18 had not.

## Have you discussed your symptoms and treatment options with the team?



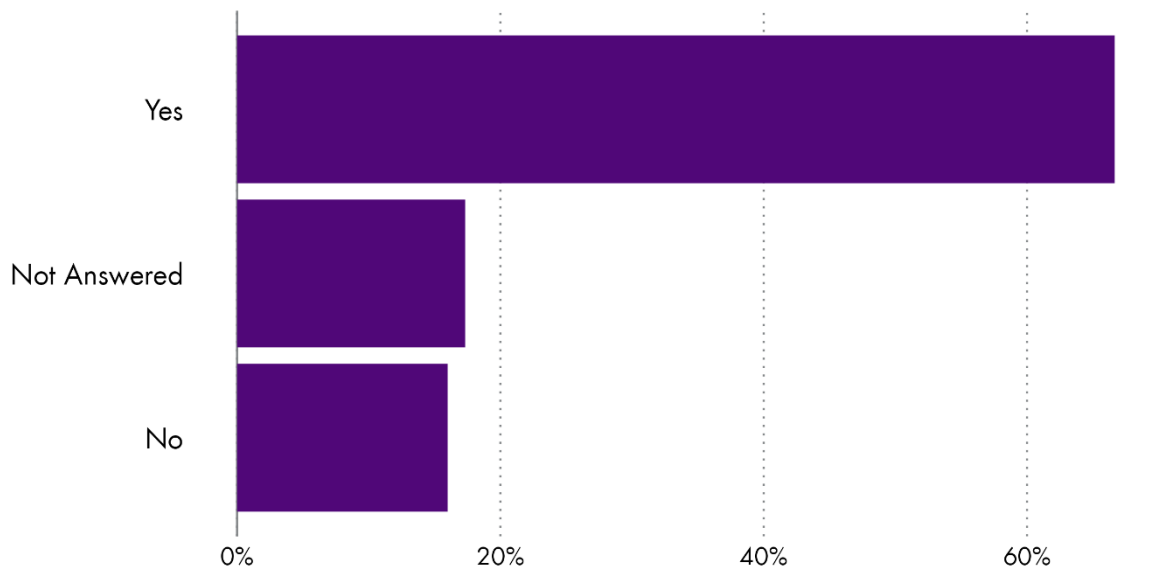
Source: Scottish Parliament

## Surgery

### Did you decide to have mesh removal surgery? (yes/no)

- 50 of the 62 women had decided to have surgery or had gone on to have surgery, 12 had not.

### Did you decide to have mesh removal surgery?



Source: Scottish Parliament

If yes, where did you decide to have mesh removal surgery.

- 30 women did not answer this question, suggesting the phrasing of the question may not have been clear enough. However, 6 had surgery at the CMSS, 11 had gone to Bristol, 21 to the US.
- Those who chose 'Other' (as well as some who made a selection above) were either waiting for surgery, had surgery at the Queen Elizabeth University Hospital, where the CMSS is based (3), the Southern General Maternity Hospital, or that it had been performed in the US by Dr Veronikis or in Bristol, at Spire.

**Were you able to proceed with treatment from your preferred provider? (y/n)**

- 13 women said they were, 28 said they were not.

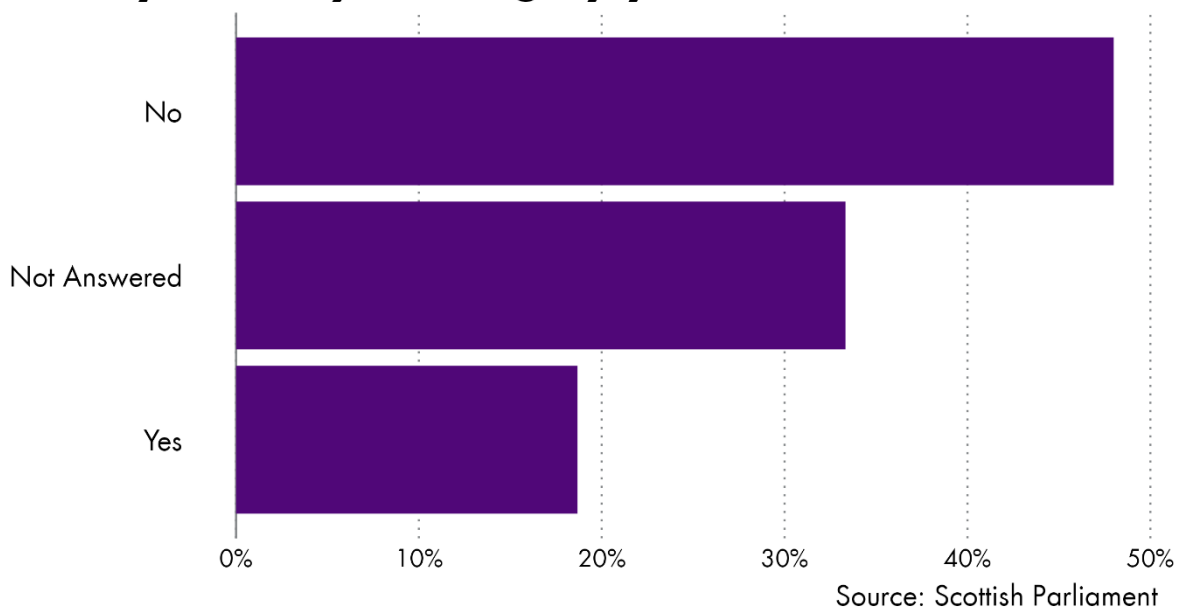
**Were you supported to make travel and accommodation plans for your chosen provider? (y/n)**

- 7 said that they were supported in this, 32 said they were not.

**Have you had surgery yet? (y/n)**

- 50 women answered this question. 14 had already had surgery, 36 had not.

**Have you had your surgery yet?**



**. Do you feel your surgery has been successful? (y/n)**

- Only 12 women answered this question, 9 of whom felt it had been successful, 3 did not.

**Do you feel you need further care and support? (y/n)**



- 13 women answered this question, 11 of these feel that they do need further care and support, 2 did not.

## **Support following surgery**

### **How long did you have to wait for your post-operative assessment?**

(weeks, months, years)

- 8 women responded to this: 4 had waited weeks/months, 4 say they had waited years

### **Have you seen the CMSS in relation to any follow-up care? (y/n)**

- 14 women responded to this question: 3 said yes they had, 11 said they had not

## **3. Summary of qualitative responses to all questions**

### **i. Issues affecting women prior to referral**

#### **Theme 1: (lack of) support for and knowledge of mesh issues in primary care**

Responses were mixed regarding support for symptoms and referral in primary care. Many women have been well supported by their GPs over many years in both managing symptoms and liaising with secondary care specialist services:

“My GP has been very supportive, helpful, understanding and empathetic and doesn’t patronise me.”

“Initially unaware my problems were caused by mesh implant but once recognised I was referred swiftly and been given full support from my GP”

Other responses were less positive or qualified:

“Unfortunately it was a long number of years before it was recognised that my problems were related to mesh. However as soon as it was they have been better”

“GP’s have no idea what symptoms of mesh damage are and do not have the time to listen”

The lack of awareness among GPs of mesh and the issues it could cause was a common recurring theme. Some women felt that they were ‘educating’ their GPs, others said that they had suffered for years before appropriate referrals were made. The extreme manifestation of this lack of knowledge in primary care was that women said that they weren’t believed or felt dismissed:

“They have done their best but i don't think they have much knowledge in the complications that are associated with Mesh and i feel GPs should have more training or at least information regarding associated ailments that come with Mesh such as autoimmune issues, fatigue uti's etc.”

“Dismissed by GP. Told I possibly have fibromyalgia. Been crying in the surgery begging for help. Eventually sent for a gynaecologist appointment. I obtained a copy of my medical report. The GP actually said in her letter she was "just referring me as I wasn't believing anything" the GP said.”

“GP simply says he has never heard of mesh even when I would mention it every time I contacted my GP and even after the baroness First Do No Harm report, he simply advised me that was just for those effected in England. There are 7 that I know of effected by vaginal mesh in my GP practice alone so this attitude deeply concerns me!”

“It took 2 years before a GP believed me and actually listened to what symptoms/chronic pain I have been enduring and still am enduring since day 1 of having a Mesh implant (TVT)”

## **Theme 2: Barriers in accessing the CMSS**

From the responses (9 responses) where further detail on barriers was provided, it appears that the experiences pre-date the full establishment of the CMSS. Some responses suggest there has been such a service since 2015. However, the web page states that the service was established in response to the recommendations in the [Cumberlege report](#) ‘First Do No Harm’, published in 2020.

The women describe waiting, being referred and re referred and being seen by local specialists or not being listened to. If women aren't believed in primary or secondary care locally, they will find it hard to get a referral to the CMSS.

## **Theme 3: Experiences of referral and access to the CMSS**

### **Long waits and poor communication**

Women had the opportunity to write anything else about accessing the CMSS. 60 of the women elaborated on their experiences.

For some, while the wait had been quite long, they had accessed the service:

“It took me more than 3 years to convince my consultant that several of the symptoms I had been experiencing since 2013 are due to the mesh. It was then 13 months from the date he referred me to the CMSS until I had my first appointment, which was in September 2021. At the end of that appointment, a follow up appointment was arranged for July 2022”

Around half (28) of the women mention the very long waits, either from referral, or between appointments, waiting for scans etc.:

“I first attended Glasgow in 2019 then had to wait till December 2022 for my next appointment”

“Fought for over 4yrs to get 1st referral to Glasgow then wanted a second opinion which I waited again months for referral to Edinburgh where surgery was then scheduled for 2021 ..then that was cancelled and was then advised by surgeon she wasn't allowed to operate in Edinburgh so had to be referred back to Glasgow and still waiting to be seen as of yet ..I am wanting surgery out with Glasgow and Edinburgh now as no faith or trust in any of the teams there”

“most of my appointments had been cancelled I waited nearly 2 years in between appointments”

Communication issues also emerged as another theme in the responses to this question, with women finding it hard to contact someone in the service or in their own health board to answer questions or to provide support, especially if they are seeking treatment outwith the service. Women also reported that communications from the service are inconsistent:

“No contacts for service. No email address, no telephone no, no liaison person”

“I have attended the Glasgow Mesh clinic but am still waiting to hear back from them regarding the way forward.  
I was given a choice of 3 options at the clinic, but these were to be considered and confirmed by their mdt. One of the 3 options was “to do nothing” but that really isn't an option at all is it?”

Despite the focus of the question on accessing the service, this was the first opportunity women had in providing narrative about their experiences more generally, and many took this opportunity to describe their journey more fully.

What becomes clear is that treatment with surgery is neither straightforward nor always successful, and sometimes only partial removal is or has been done, leaving women with ongoing issues such as pain, incontinence, and poor mental health:

“I have had mesh removal, it initially helped with urine infections, but they came back almost daily after several months, I still have a rectal mesh not removed and parts of vaginal mesh”

“I've been told the whole mesh thing has been over reported in the press. Also I feel unsupported by the medical profession at mesh clinic they put the fear of death into me by describing what might happen if I have mesh removed. They have told me if I have removal it could cause more damage.”

“I do feel the main focus for everyone including professionals & government is on removal. It needs to be recognised many of us may have to live with mesh for the rest of our lives”

## **ii. Issues affecting women engaging with the service**

As noted above, many of the women have been engaging with services for a number of years, seeking to navigate their way to the right treatment with varying levels of support. Their descriptions of their experience suggest that the specialist service has evolved over a number of years, rather than being established at a set point. Experiences vary according to when and how they have first encountered the service, but what appears to be universal is a long period of waiting for an initial appointment, and subsequently long waits between appointments.

### **Theme 1: Treatment and management options (non-surgical)**

Twelve women wrote about their experiences with the team. One commented on the positive input and support from the psychologist working in the service, others are awaiting scans, and some have been advised of the risks of surgery and have decided not to go ahead. However, the care offered to these women appears to be limited, with some being advised to 'self-care', and some waiting to find out about treatments that will help with ongoing symptoms, surgery having been ruled out.

### **Theme 2: Supported decision-making (surgery)**

Women were asked how they felt supported in the decision-making process. Views were mixed, with some feeling supported by CMSS in their decision-making, with time being given to weigh up different options. A number of women had undertaken their own research to help their decision-making:

“The consultants at QEUH were very informative. As a former nurse myself, medically retired due to mesh, I was fairly knowledgeable and had also researched online.”

“Supported extremely well by Dr Wael Agur who has been an outstanding doctor and surgeon to me”

But for others, a lack of faith and trust in the service to carry out surgery was clear in their responses:

“I wasn't supported at all I asked how many successful full removals was carried out in Glasgow mesh centre & my question got twisted to me about how many were performed in America/ Bristol”

“Poorly so far. Information is everything and although the 2 consultants I saw claim to be experts in mesh removal and told me they have done “lots” of removals of my type of mesh, pinning them down on factual accurate numbers and outcomes proved impossible while at the clinic.”

Others felt that once they expressed a wish to be treated outwith the CMSS, they were dismissed:

“No support, no contact after I had made my choice known”

“Whilst exactly what is involved in complete surgical removal of my TVTO was fully outlined to me by one of the consultants at the CMSS, I felt that once I had made my wishes known that I wanted to be referred to Dr Veronikis, they couldn't wait to get rid of me.”

### **Theme 3: Treatment involving surgical removal or partial removal**

Only small numbers of women answered open text questions about mesh surgery (14), but they did go into some detail about their particular experiences.

Most of the responses describe the complexity of their individual situation: of partial removal, of mesh becoming embedded in muscle, scar tissue, nerve damage, difficulties in complete removal, and the ongoing problems despite surgery. They do not describe being well-supported post-operatively by the service, regardless of where surgery was carried out.

## **4. Ongoing issues affecting women and conclusions**

The majority of the women (61/67 out of 75) who responded to the survey chose to answer the final, general questions.

These responses reiterate issues raised in their previous answers. They describe a service that:

- has no streamlined, consistent referral pathway, and where there is considerable variation between health boards,
- has continuity issues where problems can start in primary care, because of a lack of knowledge or understanding, and where problems can arise in secondary care with lack of knowledge regarding the referral process,
- does not communicate well and is hard to contact,
- has very long waiting times and poor communication between appointments,
- can provide excellent care, but only in exceptional circumstances, and
- places a focus on removal surgery at the expense of treatment for those for whom surgery is either:
  - not indicated,
  - hasn't been successful or

- who have ongoing disabling pain and severe health issues despite surgeries.

“As a former nurse I’m really disappointed that this much heralded service has not even lived up to what were already low expectations.”

**Anne Jepson, Senior Researcher, SPICe Research**

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