

My Life, My Experience

Capturing Lived Experience of Complication
Following Transvaginal Mesh Surgery

What We Heard from
Scotland's Women



ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

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1. Context

The Short Life Working Group on Transvaginal Mesh Complications¹, in collaboration with the Transvaginal Mesh Oversight Group (Healthcare Improvement Scotland)² identified the necessity to engage with women who have experienced complications following transvaginal mesh surgery.

The purpose was to build on previous engagement and reports with an aim to explore the effects of surgery and determine the type of impact it had on the lives of the women concerned.

The Health and Social Care Alliance Scotland (the ALLIANCE) was invited to undertake this independent engagement work to give a voice to those with lived experience. The experiences shared

in this report will apprise future care and support options.

The ALLIANCE is a third sector strategic intermediary and has experience of engaging with people who have lived experience in policy and practice development across health and social care in Scotland.

This engagement work builds upon the ALLIANCE's experience of engagement through the independent inquiry into mental health services in Tayside. The same principles of effective engagement, sensitivity towards participants, respecting confidentiality and standard of report were employed during this process.

2. Scope and Principles

The scope of this consultation covered women who have had or are experiencing complications following Transvaginal Mesh surgery.

Appreciating the sensitivity around this engagement exercise the following were principles applied:

- To be open and transparent
- To include and involve people with lived experience of complications following Transvaginal Mesh surgery

- To be truly independent
- To include a public call for evidence to ensure everyone concerned had the opportunity to participate and have their voice heard

The ALLIANCE co-created the design of this engagement work with the TVMO Patient Resource Subgroup and people who have experience of transvaginal mesh surgery.

¹<https://www2.gov.scot/About/Review/Transvaginal-Mesh-Implants>

²http://www.healthcareimprovementscotland.org/our_work/technologies_and_medicines/programme_resources/transvaginal_mesh_implants.aspx

3. Engagement Process

The ALLIANCE team was led by experienced facilitators, with clinical backgrounds. They ensured that the conditions were conducive for participants to feel supported and able to share their experiences.

To maximise engagement opportunities, within the timeframe, the ALLIANCE adopted a variety of engagement methods. These took cognisance of Scotland’s urban and rural geography while offering a menu of options to support and facilitate participation:

- One to one interviews
- On-line survey
- Pop-Up cafes

The **one to one interviews** were available for those who felt more comfortable sharing their experiences in private. These were either

conducted in person during the “Pop-Up Cafes”, in the person’s own home or over the telephone. The co-produced core questions informed the interview process and facilitated open discussion.

The **on-line survey** was conducted over a four-week period. This enabled the widest possible inclusion of experiences from across Scotland. The survey consisted of the core inquiry questions forming the basis of the one to one interviews and was designed to also allow free text.

The **Pop-Up Cafes** were held in five locations across Scotland - Aberdeen, Dumfries, Edinburgh, Glasgow and Inverness. Spanning over morning, afternoon and evening, the cafes took account of participants’ commitments. All venues were out with either a hospital or social care environment and consideration was taken to ensure they were accessible, welcoming and comfortable.

Pop-Up Cafes



4. Communication and reach

To raise awareness of this consultation and to support reach and maximise participation, a variety of methods were used. These included:

- Social Media i.e. Twitter and Facebook
- Contact with healthcare professional networks
- Information on the ALLIANCE website
- Direct contact with The ALLIANCE's membership and networks
- Approaching existing lived experience representative groups
- Direct contact with all MSP's
- Direct contact with HSCP Chief Officers
- Direct contact with Chief Officers of NHS Boards

Taking an appreciative inquiry approach

An appreciative enquiry approach³ was adopted when engaging with participants. Seven core questions were developed, and these formed the basis of all interviews and the on-line survey. This ensured consistency during all engagement opportunities and enabled the identification of common themes when collating the data

gathered. These themes then informed the content of this report.

Questions asked:

- 1) Can you tell us what procedure you had performed, and when and why this was done?
- 2) Do you feel you were adequately informed about the detail of the treatment and potential outcomes?
- 3) What complications have you experienced?
- 4) How long after your surgery did the complications occur?
- 5) Can you please tell us how these complications have impacted on your life?
- 6) How is this being managed? Have you received treatment or is it being self-managed?
- 7) What would be a good outcome for you moving forward?
- 8) Is there anything else you would like to tell us?

³Appreciative Inquiry is a change management approach that focuses on identifying what is working well, analyzing why it is working well and then doing more of it.

5. My Life, My Experiences

The ALLIANCE team engaged with 46 women from across Scotland who all shared their experience of living with complications following transvaginal mesh surgery, and the impact these complications have had on their lives. Without exception, the participants reported the impact as being moderate to negative and for many extremely debilitating.

Whilst the impact of complications experienced have been themed, there was an overlap between thematic areas with many impacting on more than one aspect of each participant and their family's lives.

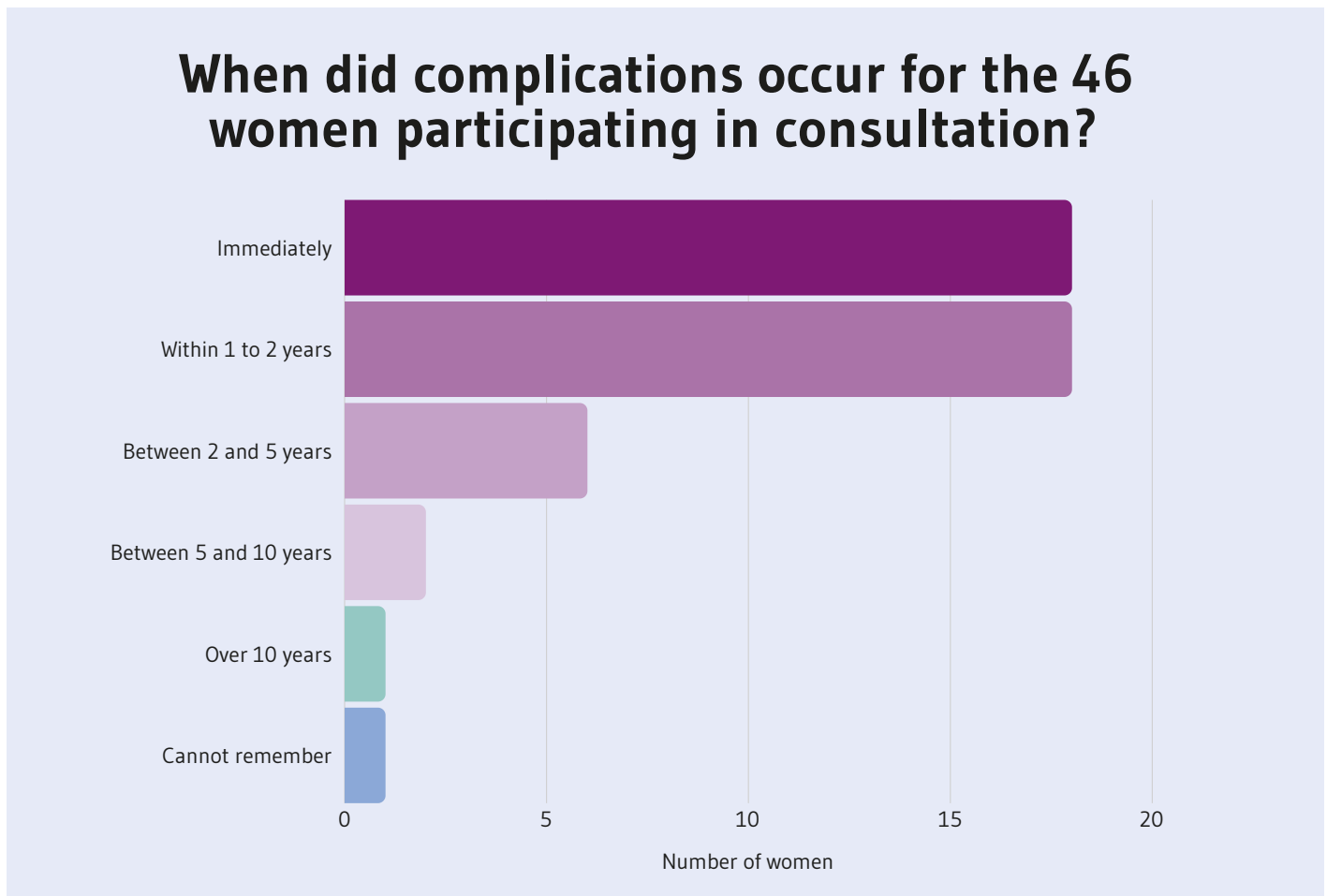
This could be likened to a spectrum of effects ranging from a pebble being thrown into a pond to a tsunami or life changing event. The overarching themes that emerged were:

- Impact on physical health
- Impact on mental health
- Impact on relationships
- Impact on finances
- Impact on confidence in Healthcare systems

6. Complications Experienced

The majority of women who participated in this consultation process experienced symptoms / complications immediately or within the first year following surgery. Of these 35 women, 18 stated their complications were evident immediately.

Of the remainder, 18 women experienced complications within 2 years, 6 within 5 years, 2 within 10 years, 1 over 10 and 1 who was unclear of the time scale.



This overall aim of this report was to capture the impact of living with complications following transvaginal mesh surgery. For all the women who contributed, this has been significant and for many life changing.

"I have lost and mourn the person I was and absolutely loathe the person I have become. If it wasn't for my husband, children and grandchildren I would absolutely without a doubt have taken my own life by now."

"My physical, emotional and mental health has been impacted. I can't go out and I feel stuck inside."

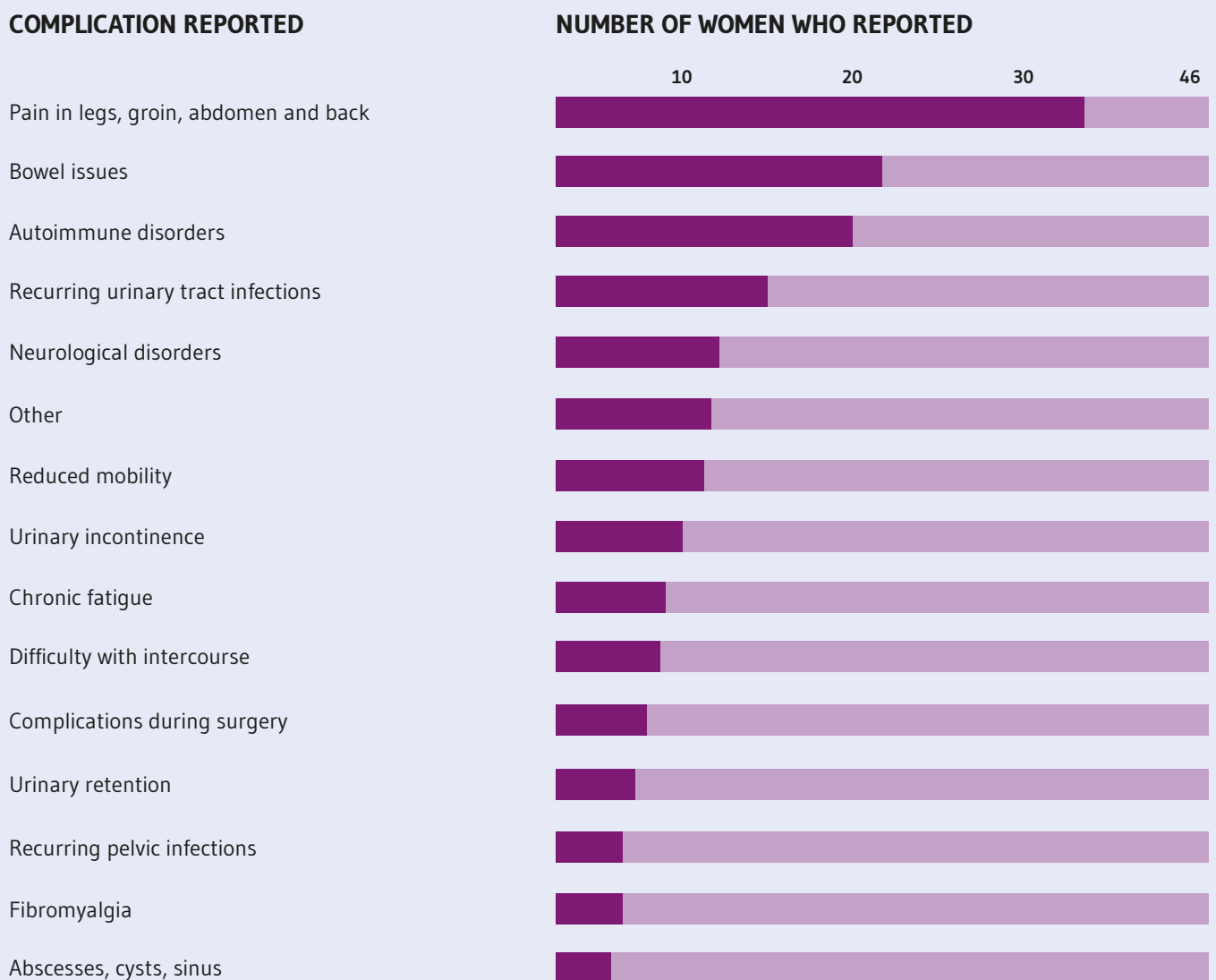
"It's like having a cancer in a way – it's hard having a foreign body in you that you just want out."

"I feel this has taken 10 – 20 years off my life and that doesn't feel good. My kids could do with their Mum a bit longer."

Impact on Physical Health

All the women involved in this consultation have experienced more than one symptom which they regard as being mesh related. With some women experiencing 2 or 3 symptoms and others as many as 18 symptoms, the impact on lives has been varied and multifaceted.

TVM Consultation Which complications were reported?



35 of 46 women described **pain** as the most common complication



Pain was the most common complication and was described by 35 of the participants. Descriptions ranged from chronic to severe and debilitating. Abdominal and groin pain was the most reported followed by back, hips and legs.

"I am in constant pain, ranging from period pain to labour pains."

"I can put up with the pains in my legs but not my pelvic area. That's unbearable."

"Then it all went pear shaped – stabbing pains in my hips, shooting pains in my sacrum, right hip and legs."

"I am never without pain."

"Burning sensation, it feels like an infection."

"My pain gradually got worse, I have shooting pains down my legs, my right is worse."

This obviously impacted on women's **mobility**. 11 women reported having trouble in walking, this ranged from some now only able to walk short distances to others who have to rely on walking aids. In severe cases women reported being housebound and requiring the use of a wheelchair when outdoors.

"I live in constant pain and have to walk with a stick for support."

"I used to do 10K's, now I have to ration my steps. I am unable to cycle now due to pain."

"It's ruined my life, I used to dance at the weekends, I was in a dancing group. I loved walking but I can't do that anymore, I'm now housebound."

"I retired early from my nursing career, I'm in constant pain and now walk with crutches and have to take medication."

"I can only walk a few yards with the aid of crutches and use a rollator in the house. I need a bath lift and grab rail, often I can't walk and have to use a wheelchair."

Pain has also made physical relationships either extremely difficult or no longer possible for many of the participants. 10 women spoke about the excruciating pain experienced when attempting intimacy and the impact this has had on their relationships.

"I haven't been able to have intercourse since my surgery; I feel my husband is deprived."

"Sex is just not possible, there's no intimacy anymore."

"Painful intercourse, I've not had intercourse for nine years."

Recurring **urinary tract infections** were reported by 14 women, 2 of which developed sepsis as result of this. Women described the necessity for hospital admissions for IV antibiotics and repeated courses of oral antibiotics. This has caused some to query the long-term effects of such a regime on their immune system. 6 participants have trouble passing urine and experience episodes of **urinary retention** which requires them to self-catheterise. One woman has had to endure this for 5 years post-surgery.

"The prospect of self-catheterising for the rest of my life terrifies me – I plan my day around going to the toilet and having a clean place to attend to my catheter."

21 women had TVM surgery as a result of **urinary incontinence**, of these, 10 continued to have this following surgery.

"Surgery has made no difference; I still need to wear pads."

Chronic fatigue was specifically reported by 9 of the participants and referred to by others. This has impacted on every aspect of their lives. Their ability to work, ability to socialise and maintain relationships, ability to exercise, ability to travel, ability to look after their homes and ability to continue with hobbies and interests have been affected. Women spoke about having to pace themselves and plan any activities very carefully.

"After being here today I will have to go home and rest for the remainder of the day."

"I am desperate to work but some days I can't even get out of bed. I rarely leave the house now."

Neuropathic symptoms were the third highest complication reported (after pain and urinary incontinence). 11 women described loss of sensation, tingling, limb weakness and "twitchy legs."

Vaginal and pelvic **infections** and the development of **abscesses** were also reported.

Issues with **bowel control** were also commonly reported. 10 women described living with reduced bowel control resulting in an urgency and in some cases incontinence. These women described how their bowel was damaged either during surgery or after when the mesh became embedded into their bowel wall.

Autoimmune disorders featured heavily when women were sharing their experiences. A significant increase in susceptibility to infection i.e. flu's and colds, mumps, alopecia, shingles and recurring cysts was reported. Two women have been diagnosed with hidradenitis suppurativa and one with Sjogren's Syndrome, both rare disorders. These women feel strongly that this has been related to them having a mesh implant.

Fibromyalgia also featured; this was reported by 5 participants. They described debilitating pain and a heavy reliance on analgesia.

Less common complications reported included developing an intolerance to lactose and/or other food allergies, dental issues, deterioration of eyesight and reduced renal function.

Impact on Mental Health

All of the women with whom we spoke indicated that mesh has taken over their lives.

Many women reported experiencing suicidal ideation, some at times having clear intent to complete suicide. Depression, anxiety, low self-esteem, and loss of self-worth were prominently featured in both on-line surveys and during interviews. It was reported that long waiting times for mental health assessment and services have exacerbated symptoms and saw some women entering what was described as a “downward spiral”. For some, it was indicated that anti-depressants eased symptoms.

“I feel so useless, if they hadn’t put new fences on the Erskine Bridge I would have jumped.”

“This has had a huge impact on my mental health. My marriage ended and I contemplated suicide.”

“I have had two mental health admissions due to anxiety and depression because of the constant pain taking its toll.”

“I don’t go out much due to my pain. I feel isolated, anxious and depressed.”

“I’m grieving for the person I used to be and for the future I will no longer have. I know my mesh can’t be removed so I am trying to come to terms with that.”

Women spoke openly about mounting frustration, being fearful of the future, feelings of helplessness, increasing anger and for many, grief for the life they once had. Many explained that this was exacerbated by a feeling of not being listened to or being taken seriously when seeking medical advice.

Most women made the connection between their symptoms and their mesh immediately post-surgery or as soon as they presented. For others, the connection was not made until later when they heard other women describe their experiences. One woman described this as being a “light bulb moment”. After years of not knowing what was causing her symptoms, she felt she finally knew what was wrong with her.

For many women, not knowing the cause of what they described as life changing symptoms caused great distress, fear and anxiety.

“I felt patronised, judged and dismissed by the Doctors. I’ve had to let go of my old self; I can’t do the things I used to do. I have to grieve for the loss of my job and my finances. My husband feels quite overwhelmed when I’m down.”

“I am not as active as I once was. I was depressed for a while before it was admitted that it was mesh causing the pain.”

Impact on Relationships

By participating in this consultation, women shared some very personal and sensitive information. For many, particularly during the face to face interviews, this proved to be a very emotional experience. This was mostly evident when they shared what impact their surgery and associated complications has had on their relationships with others.

Women spoke about their inability to play with or hug their grandchildren and being unable to have normal mother - daughter relationships where they could go shopping or on holiday together.

Many women spoke of friendships ending because of having to cancel arrangements due to being unwell and their friends gradually withdrawing. This added to feelings of isolation. For women with urinary incontinence and bowel issues, socialising was described as being increasingly difficult, and for some, non-existent.

For those now requiring assistance with personal hygiene and grooming or with domestic chores, family members have had to adopt a caring role. This impacted the dynamics of relationships and adding to a feeling of helplessness and vulnerability.

"I can't play with my grandchildren, I can't travel, I can't plan anything. I now need mental health support."

"I know I am not going to be the mother I want to be for my boys, I can't do the things other mothers my age do. I can't play with them, I can't go for exciting holidays, some days I can hardly get off the couch. As for being the wife I want to be, I can just forget about that."

For many of the women who shared their experiences, their inability to have an intimate relationship with their partners has had a momentous impact on their lives. Severe pain, recurring infections, and chronic fatigue have all taken their toll and have resulted in years of celibacy. This reported loss of intimacy has resulted in women experiencing guilt and feeling a great void in their lives. Four women who were interviewed described this as a major factor in the breakdown of their marriages.

"My last relationship ceased due to me being unable to have any intimacy."

"My marriage ended, and I contemplated suicide. I lost all my confidence and didn't want to go out."

"What kind of wife am I if I can't have intercourse with my husband? I feel I have let him down."

For one woman in particular her inability to have intercourse with her husband had a life changing effect.

"I didn't want a physical relationship with my husband, so I pushed him away. He was convinced this was because I was having an affair. He took his own life. This has had a huge impact on me and my daughters."

Impact on Finances

Reducing working hours or giving up paid employment is unfortunately common for people living with a long term condition. This has proved also to be the case for women experiencing complications following transvaginal mesh surgery. Women spoke about the challenges they faced living on a reduced income. For some this meant a significant change in lifestyle and, for some, it resulted in significant debt.

Accessing benefits proved to be challenging for those who had to do this. A reported lack of understanding from the Department of Work and Pensions (DWP) regarding why they were no longer able to work caused delays and an increase in financial pressure.

"I am financially devastated, I've lost my house, my full-time job and I can no longer get credit. I have had to drop my hours at work, and this just adds to my financial burden."

"I have had a horrendous experience dealing with DWP with regards to benefits. I was made to feel useless and had to jump through hoops to access what I was entitled to."

"Living with complications of mesh usually doesn't warrant benefits. People are being left in poverty because of this and then unable to work."

"We have now used up all our savings as my husband had to sell his business to become my carer."

"My parents died, and I have had to use my inheritance to survive. I don't know what I would have done if I hadn't had that."

"I have lost in excess of £80,000 in earnings over the last 8 years."

The costs incurred in attending frequent hospital appointments were reported as challenging for some. This was particularly the case for women living in rural areas when an overnight stay was required.

Some women explained that their dissatisfaction with the response or service led them to seek self funded trans-labial scanning. While these women felt this money was well-spent, they still felt frustrated that they had to do this to get the answers they needed.

"I have spent £3000 trying to address the pain."

Impact on Confidence in the Healthcare Systems

For the majority of participants, their reported experiences when interacting with healthcare professionals were not positive, and according to many, were detrimental to their treatment and recovery. With long delays to review and treatment, lack of continuity in care and feelings of not being taken seriously, many women expressed dissatisfaction in their care. Although there had been some participants who complimented their GP they were very much in the minority.

Of the 46 women who shared their experience, 36 reported being given very minimal information about the procedure beforehand. They informed us they underwent the procedure with extremely limited knowledge of what the surgery entailed and what the potential risks were. Of the remainder, 8 women said they had been given

some detail about the procedure but not of the potential risks or complications. The remaining 2 women were unable to recall what information they had been given beforehand.

Prior to surgery the women had confidence in their surgeon and were relieved to be undergoing surgery and hopefully seeing an end to their presenting condition. Many were aware this was a relatively new procedure but with it being described as being the “gold standard” they felt positive and saw no need to seek further information.

All the women who shared their experiences, said without exception, had they known what they know now, they would have not gone ahead with the procedure, or would certainly have proceeded with caution.

7. Moving Forward – Key Messages from Women

During the consultation process, women participating were asked to consider what would be a good outcome for them moving forward.

What was reported was a strong desire that they do not want anyone else to go through what they or their families have experienced and a sincere hope that lessons would be learned, and access to services improved.

While sharing their experiences was visibly difficult and, for some, quite traumatic, they felt it was an important thing to do and were appreciative of being given the opportunity to do so.

“It’s too late for me, but if we can avoid other women being left disabled, then I’m all for that.”

While each woman’s experiences were unique to them, there were recurring themes and recommendations based on their personal experiences’:

- Full removal of mesh for those who still wished it.
- Permanent ban on transvaginal mesh implants in Scotland.
- Recognition of the impact mesh has had on their lives.
- Clear and coordinated care pathways with easy to access to services.
- Awareness of mesh related complications amongst all healthcare professionals.
- To have a choice of surgeon and treatment centre.
- Clear information on treatment options.
- Improved communication between primary and secondary care.
- Recognition of their disabilities and access to support services/resources as appropriate to their needs.
- Easy access to advice and financial support from DWP.

- To be symptom free and able to return to normal life.

The desire to be listened to and have the impact mesh has had on their lives acknowledged was a prominent message throughout. Women felt that their feelings of helplessness, isolation and frustration could perhaps have been reduced, even avoided, if they had been supported as they would have wished and felt they deserved. Women detailed how they adapted their lives and self managed their symptoms. They spoke about their constant use of analgesia, using complementary therapies and holistic medicine, accessing private healthcare, how they managed their incontinence, communicating with other women in similar circumstances and their reliance on family and friends for practical and emotional support.

The women felt that their journey would have been less traumatic had they been listened to in the beginning and the connection made between their symptoms and their mesh. The request that there be clear care pathways and a range of options available was also frequently made, with some women emphasising the importance of people with lived experience being involved in what these might look like.

Holistic, person centred care with women being involved in all decisions regarding their care featured in many responses. An end to Multi-Disciplinary Team meetings, where the woman concerned was not present or involved, was seen as a must.

The time lapse from first appointment to referral to a specialist and then to treatment was, for most women, extremely long. This resulted in a perceived delay in any potential treatment and an increased impact from complications.

Given the high number of women who reported experiencing pain, it is suggested that access to Pain Clinics and specialists in this area would be beneficial. This would be particularly beneficial to those women who are deemed unsuitable for mesh removal.

8. Conclusion

Given the complexities of the complications and the far-reaching impact on women's lives, designing and implementing person centred care pathways and resources is not a simple process. Additionally, because of the loss of trust and confidence some women have in the medical profession, huge consideration must be given to approaching the development of pathways in a sensitive and all-inclusive manner.

Involving and listening to people with lived experience adds value to service design and should be integral in the development of care pathways for women with complications following TVM surgery.

The establishment of a Stakeholder Engagement Group would be beneficial; this could inform future agenda and consider different mechanisms as to how women can be supported to achieve optimum health and wellbeing.

The establishment of support groups at local levels and the setting up of a more formal national group could be beneficial. There is notable evidence⁴ of the benefits of membership of such condition specific groups and organisations.

Care pathways must involve the third sector and DWP. By adopting a "more than medicine" approach, the non-clinical impact of complications can be explored and better addressed.

As well as informing future care, this could help rebuild the trust that has been eroded over recent years. The feeling of being listened to, of a making a positive contribution and being regarded as experts in living with complications and their impact could be extremely beneficial to the women involved. It will also add value to the process and outputs.

As mentioned previously in this report, living with complications following surgery has impacted negatively on many women's mental health. Though no participants specifically mentioned accessing or receiving psychological support as being a want, many said following their interview that they found participating in this consultation to be cathartic. They openly thanked the facilitators for giving them the opportunity to share their experiences and reflect on how these had impacted on their lives. This indicated to us that having the opportunity to do this earlier in their journey could perhaps have been beneficial to some. Having support to adjust to disabilities, deal with changes in relationships, status and lifestyles and the management of anxiety and depression could possibly lead to improved outcomes for women affected by mesh. This could be a range of interventions including Community Link Workers and Clinical Psychology.

The strong desire to return to "normal" and live a life without pain and disability may not be an option for some of the women affected by TVM surgery. For these women, the ability to access services and support specific to their needs and wishes is key.

In summary the ALLIANCE suggests further consideration of the following:

- Setting up of a Stakeholder Participation Group to consider and inform the future agenda;
- Consideration to be given to different mechanisms as to how women can be supported to achieve optimum health and well being;
- Person centred approaches to be put in place and evident involving a range of allied health professionals and others such as community link workers-and/ or psychological services where necessary and appropriate.

⁴<http://peersforprogress.org/learn-about-peer-support/science-behind-peer-support/>

9. Acknowledgement

The ALLIANCE would like to thank the women who participated in this consultation process. By sharing their experiences, they divulged personal and sensitive information. This was not easy for some, particularly for those speaking for the first time to people outside their close family and friends. Their strong desire to contribute towards an improvement in services for women both now and in the future was a driving force and their reason for participating.

10. For More Information

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11. About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations.

The ALLIANCE works with its 2,700 plus members towards the vision of:

A Scotland where people who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens with support and services that put them at the centre.

The ALLIANCE does this through three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services
- Support transformational change, towards approaches that are preventative and that work with individual and community assets, supporting human rights, self-management, co-production and independent living
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.



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